

Rethinking Food Allergies

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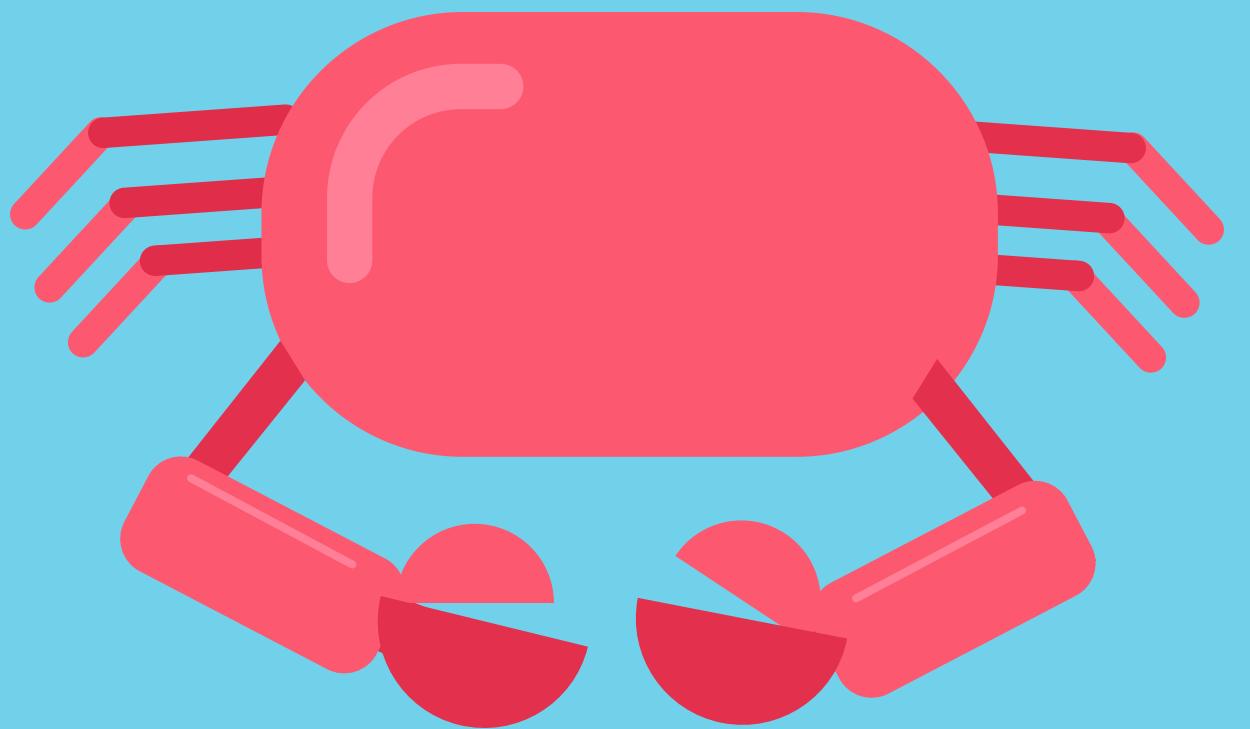


Artefact Group

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Why Food Allergies?



The presence of food allergies cannot be understated. 1 in 13 children in the United States, or roughly 2 in each classroom, are allergic to one or more food allergens [1]. Seemingly harmless foods that the rest of us take for granted can symbolize life or death for these children. With food allergies on the rise and nearly 90 percent of reactions caused by the top 8 food allergens, we have seen a shift in society's accommodations, with the prohibiting of sharing foods and/or the banning of peanuts and tree nuts in various schools [1].

There is no cure for food allergies, which makes living with this medical condition all the more serious. The physical symptoms of an allergy reaction are undoubtedly painful for the child to endure and for the parent to watch. Yet, through a series of research activities, we learned that both the children and parents' feelings surrounding food allergies extended far beyond the physical—they were deep-rooted in that of trust, isolation, fear, and awareness. With this in mind, we see the greatest opportunity to design a solution that eases the emotional and psychological impact of living with food allergies. By focusing on these areas, the physical strains of food allergies will consequently be lessened as well. We hope to provide support in navigating the all-encompassing experience from diagnosis to acceptance.

Why Preteens?



Studies have shown that 50 percent of deaths from severe allergic reactions occur in teens [1]. Transitioning from parents' constant vigilance to basking in greater independence and social livelihood makes teens the most susceptible to engaging in risky eating. Therefore, we aim to focus our efforts on properly educating the preteen population, ages 9-12, before they enter the complexities of teenagehood. Our hope is that they can transition into a more empowered role and make sound decisions when it comes to navigating their food allergies.

Note: Throughout this report, any mention of 'parents' are inclusive of 'guardians' as well.

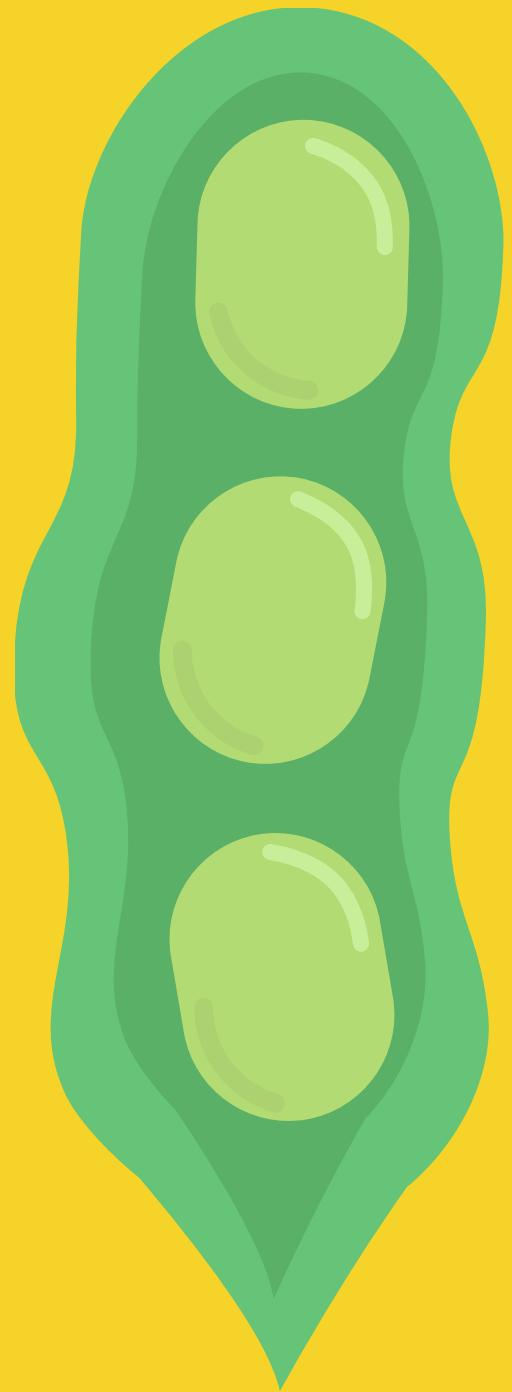
Challenge Statement

We strive to *support* preteens to
independently manage their food allergies

Research Questions

1. How do food allergies affect *interpersonal relationships* in both the *child* and *guardians' lives*?

2. How do children and parents *prevent, react to, and manage* food allergies?



Literature Review

We explored various types of sources to inform our knowledge around food allergies before beginning our primary research and going out into the field. We acquired this background information from magazine and newspaper articles, blog posts, nonprofit websites, and research papers. At its essence, food allergies are a health problem.

Therefore, we knew we had to understand, at a medical level, why food allergies exist and how the body's immune system is affected. We learned staggering statistics about the severity of food allergies in our current state, and from there, we delved further out, into the social and psychological implications of food allergies. Our extensive review led us to realize how complex food allergies can be for not only the child, but for all the relationships intertwined in the child's life.

- • **What is a food allergy?**

Food allergies are separated into two categories of reaction. The first is IgE-mediated food allergies, which have a rapid onset that causes epidermal reactions as well as anaphylaxis shock. The second is non IgE-mediated allergies, which can cause a latent reaction hours or days after ingesting the food [2]. Food allergies happen when the body's immune system believes the food someone has just eaten is an invader. The body, to mediate the attack produces histamines, which is a compound that your body releases when you are injured. Antibodies then swarm to the histamines to attack the foreign attacker, causing anaphylaxis shock. [3].

- • **Food allergies are on the rise**

Since 2016, there has been a 104% increase per 10,000 children in the diagnosis for at-risk anaphylaxis reactions. This means that an average of two children per school classroom have a food allergy. In relation to these staggering statistics, Peanut and tree nut allergies tripled over the course of 11 years and visits to the Emergency Room for Kids with food allergies have spiked 150% [4]. 30 years ago Eosinophilic Esophagitis, or EoE, a chronic allergic inflammatory disease, didn't exist. Today there has been a dramatic increase in the diagnosis of this EoE in children [5]. In 2004 it was stated that 1 in 10,000 children were diagnosed with EoE, today it is 1 in 1,000 [6]. Our research shows the dramatic increase and prevalence of food allergies are specifically to children.

- • **Teenagers are the highest risk demographic for reactions**

While death from anaphylaxis is rare, studies show the highest risk for death is in the teenage years. The reasoning comes from a greater increase in risk-taking behavior, including eating foods that the children are allergic to as well as not carrying an auto-injector around while being in uncontrolled environments [11].

- • **Reactions to allergies are not just physical**

1 in 3 children with a food allergy have reported being bullied as a result of their food allergy [8]. One study showed that children living with a peanut allergy had greater anxiety and an overall lower quality of life than children who were diagnosed with Type 1 Diabetes. Families must deal with life-altering changes when diagnosed with food allergies. Another study revealed an increase in marital tensions due to a pediatric food allergy diagnosis [9]. Mothers are seemingly more affected by their child's diagnosis, though the whole family experiences a lower quality of life if one of their kin is diagnosed [10].

- • **Auto-injectors are causing havoc**

The tools necessary for saving lives during anaphylaxis are causing issues and crisis amongst the food allergy community. In 2015, the Auvi-Q, a more compact version of the EpiPen that relays verbal instructions during anaphylaxis, had a major recall. The FDA stated that "the [Auvi-Q] has been found to potentially have inaccurate dosage delivery, which may include failure to deliver the drug," [7]. After two years off the market, the Auvi-Q returned and its manufacturer gave away free auto-injectors, promising a more reliable device. This recall occurred amidst the wake of the EpiPen crisis that is currently happening. EpiPen production is officially in a "critical stage" and is on the FDA drug shortage list. What some are calling a "constitutional crisis," means price surges for families in need of auto-injectors accompanied by feelings of panic surrounding the fear of not being able to get critical medication.



Research Methods

- • Expert Interviews
- • Semi-Structured Interviews
- • Diary Study
- • Relationship Circle Exercise

Expert Interviews

Our goal in recruiting experts was to seek out information about the allergy community at a scientific and local level. We needed professional knowledge when it came to something as complex as food allergies, as well as their perspective on the child/parent relationship. Additionally, we tried to understand what treating these allergies was like from a technical standpoint, using that information to further add to our secondary research. From a community perspective, we wanted to gather insights about the importance of community support around food allergies and how food allergies are managed.

Procedure

For each expert we recruited, we created a set of questions [see appendix] tailored to their specific specialty and conducted a semi-structured interview. Interviews were either done in-person or over the phone, each lasting about an hour long.

Expert One

Lisa Rutter

Lisa Rutter is the founder and leader of Facebook's 'No Nuts' community where parents around the world come together to discuss, host events, and offer advice on child food allergies. The community is structured with local 'No Nuts' chapters throughout the US, UK, and Australia.

Lisa herself has a child with peanut and tree nut allergies. She was inspired to create the group without having much success speaking with doctors and specialists about her son's condition.

Expert Two

Dr. Stephen Tilles

Dr. Stephen Tilles is a Board Certified doctor with specialization in Internal Medicine, Allergy, and Immunology. He received his medical degree from the University of California San Diego School of Medicine in 1990 and completed his undergrad at Harvard University. He currently serves as Physician Partner at the Northwest Asthma and Allergy Center, Executive Director of ASTHMA Inc., and Executive Committee member of the Seattle Food Allergy Consortium. He has authored more than 60 peer-review publications, and has served as Principal Investigator for more than 100 clinical trials related to treatments for asthma, rhinitis, urticaria, and food allergies.

Dr. Tilles is a valuable source of knowledge and input for our topic of food allergies. He sees up to 20 patients on a daily basis, and although trained to treat both pediatric and adult patients, his practice has now become primarily pediatric-driven with 75 percent of his patients being children. We knew we could acquire more specific, factual insights from someone of his experienced nature.

Expert Three

Devra Shiba

Devra Shiba is the Senior Manager of Nutrition Services at Sodexo, a food catering company for major businesses and universities worldwide. Devra oversees facilities in 13 states for regulatory compliance, education, training, and professional growth. As a registered dietitian, she keeps her skills sharp by working in a clinic whenever she can.

As Devra is in a management position for a major catering company, part of her responsibility is to educate her team on how to deal with daily dietary needs and restrictions in a regulated way. She works with communities to make sure schools and environments are equipped to deal with food allergies, and often comes in direct contact with parents of preteens to educate them on what her team is doing to keep the children safe.

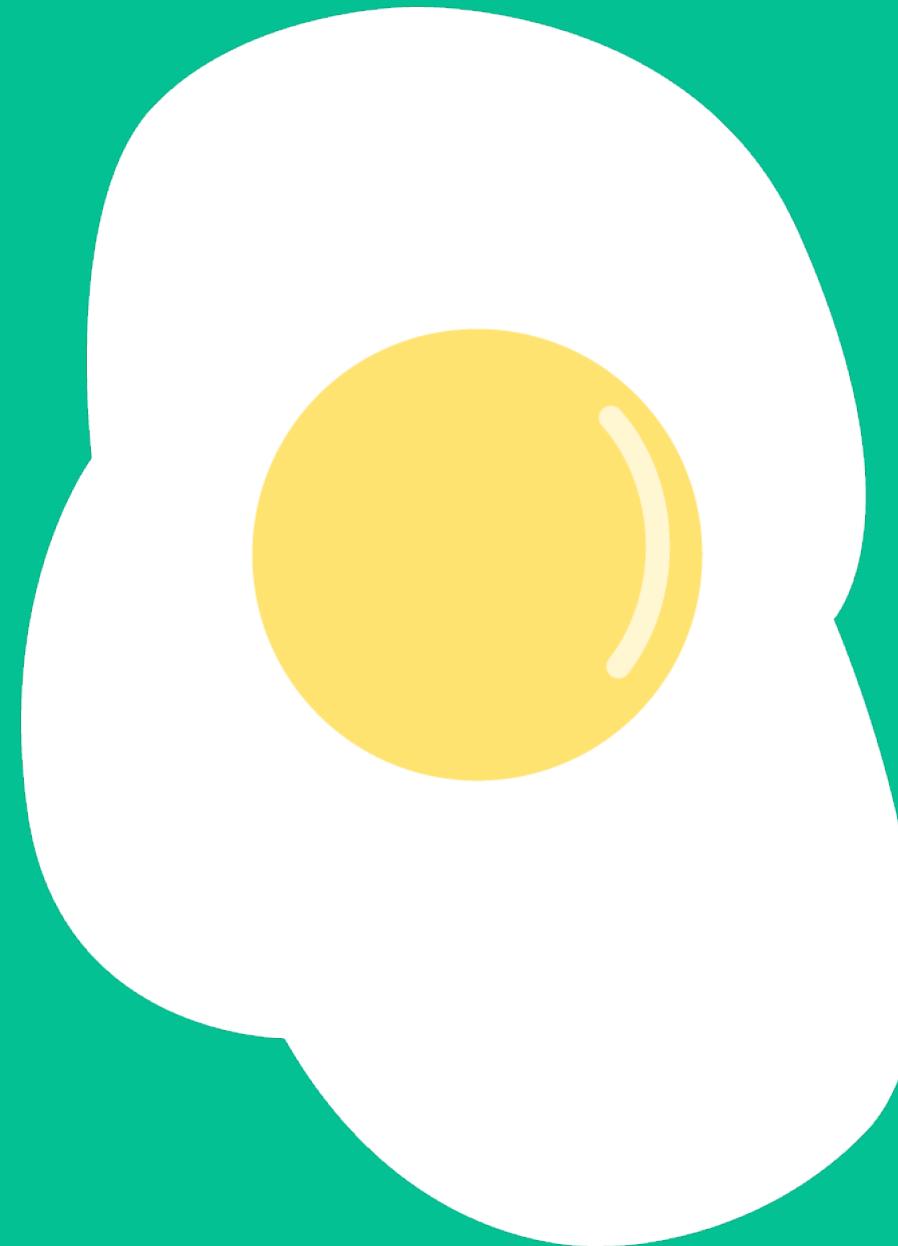
With schools often being a stressful environment for parents and children in regards to food allergies, speaking to Devra about her work and management of food services helped to confirm and add additional context to our original assumptions.

Expert Four

Dr. Geetu Deogun

Geetu Deogun is a pediatric-trained allergist who has been practicing for over 10 years. She went to medical school at the University of Nebraska and completed her residency and fellowship at Rush University Medical Center.

Geetu engages with 15-20 patients a day. She believes that empathetic listening and patient education is key to maintaining a healthy relationship with families. She has dealt with a wide range of food allergies with her patients and is well known in the Cary, North Carolina community for her expertise and approach to allergy treatments.



Recruitment

We reached out to a number of experts who had experience working with children, as well as past HCDE groups that designed for similar topic areas and demographics. These individuals gave us insights and resources to help us understand how to work with sensitive populations.

Once we had a solid grasp on how to proceed, we chose to recruit by:

- • Leveraging social media and public Slack groups
- • Reaching out to food allergy support groups
- • Using the UW community
- • Directly emailing SeaFAC members, a group of professionals with expertise in childhood allergies
- • Designing posters with pull-off tabs to place in libraries and community centers

This strategy created a “snowball effect”, continuously leading us to new experts and families. While this ended up being a large part of how we were able to get our remaining participants, we also relied heavily on continuously re-posting on social media and hanging posters around our community.

Primary Participants

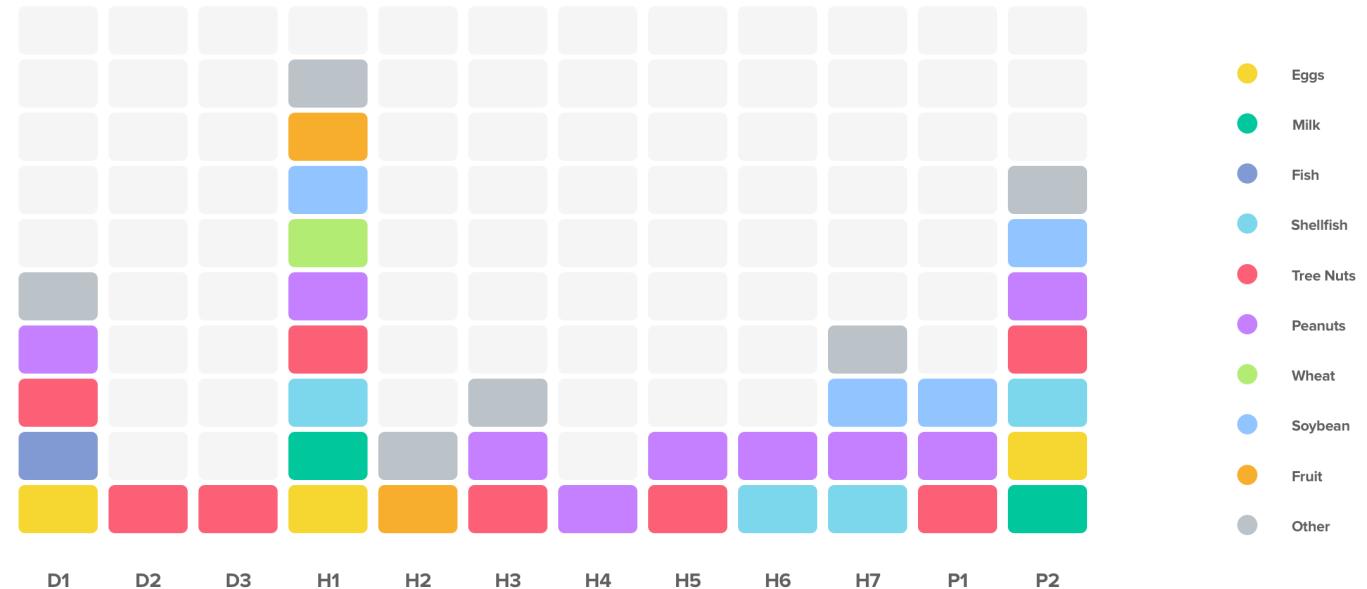
ads. We aimed for preteen children (ages 9-12) with one or more food allergies. We specifically chose to recruit in dyads so as to better understand and gain empathy for both parties when it came to food allergies. We believe the partnership between the two are essential in managing a preteen's food allergies.

Other stakeholders

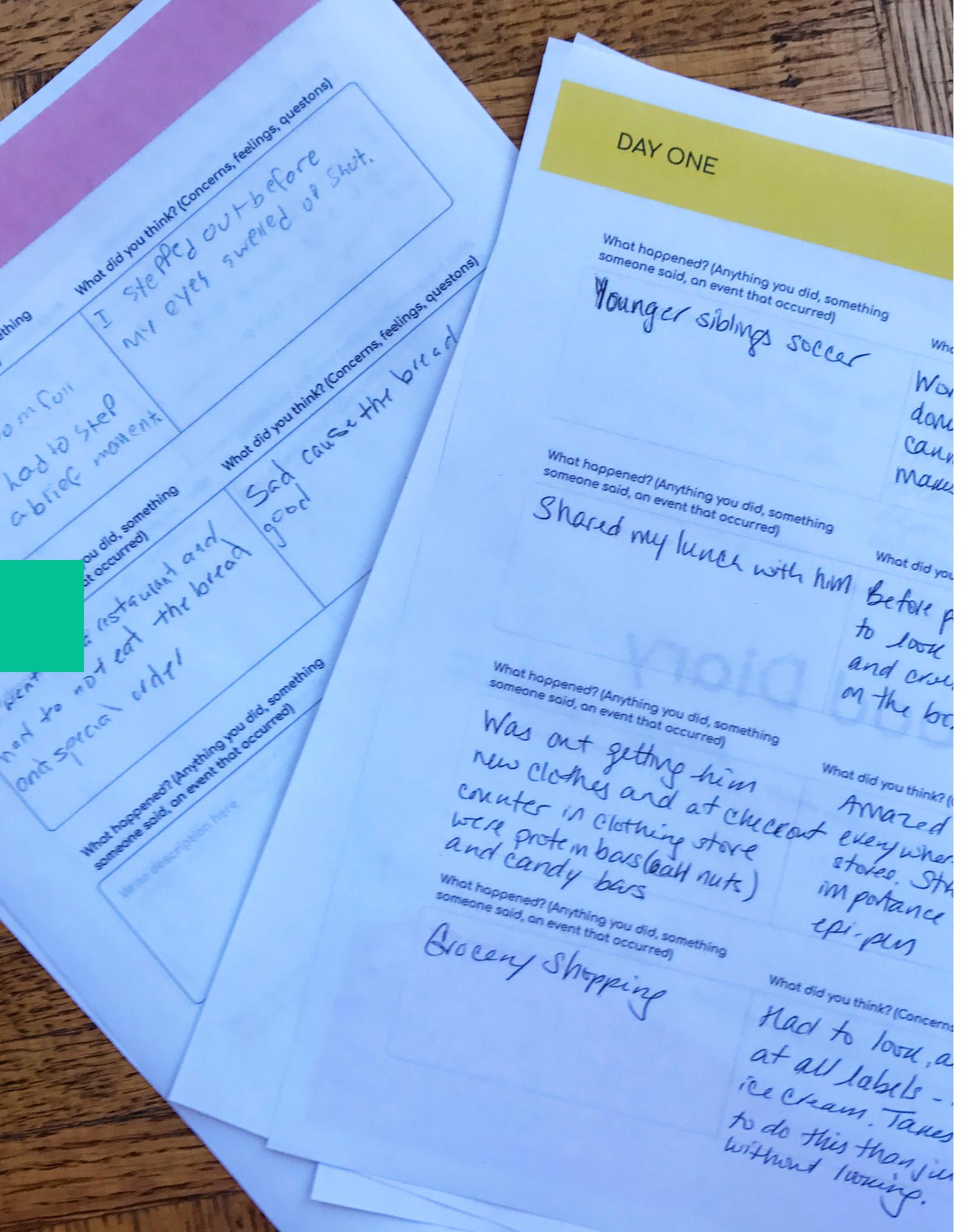
We also talked to family members of children with food allergies, allergists, nutritionists, and experts with extensive knowledge of our topic.

**For the privacy of the parents, children, and experts that we interviewed, we have omitted their names below and are instead using an abbreviated format.*

Allergy Breakdown Amongst Participants



Diary Study



The diary study was a week-long journal that we had our parent-child dyads fill out (see Appendix for template). We chose to conduct the diary study with three remote participants. The goal for the Diary Study was to learn about our participant's thoughts and feelings toward food, as well as to recognize situations in which food allergies were brought up during their day. Data ranged from experiences in schools, grocery stores, restaurants, even with other people in and outside of their community. This information helped us to uncover opportunities for easing stress involved with food allergies.

Procedure

After recruiting our participants, we sent over email instructions with the diary template attached. We asked our parent-child dyads to fill out the packet over a 7-day period. To ensure our participants were completing the diary as intended, we asked them to send their entries after the first day. Each day, participants recorded different occasions when something happened that was relevant to their child's food allergy (i.e. anything the participant did, something someone may have said, or an event that has occurred). Additionally, participants recorded their moods, concerns, and thoughts in relation to these events. We followed up with a 30-minute debrief call, in which we delved deeper into their entries. It was an opportunity for us to further identify and refine questions that we wanted to address in later research methods.

Semi-Structured Interviews

After studying literature on food allergies and talking to four experts from relevant fields, we sought to gain deeper insight into the daily lives of preteens and their parents. Our primary research consisted of semi-structured interviews with parent-child dyads. We conducted these interviews in-home to add context to our research, or in-person via pre-agreed locations. By asking both parents and preteens about their lives managing allergies, we were able to gain a more holistic understanding of their interpersonal relationships as well as their relationships with their food allergies.

Our screener survey was used as a recruiting method for the majority of our participants. Participants within the Seattle area were recruited as semi-structured interviews, whereas participants outside the Seattle area were asked to participate in our diary study. In the survey, participants were asked the age of their preteen, allergies their preteen had, location, and email address.

Procedure

We conducted 12 semi-structured interview sessions that ranged from 45-75 minutes with dyads that met our criteria. We built rapport with the preteens by starting them off with a drawing exercise while asking the parent questions about their experiences dealing with their preteen's allergy. Partway through the interview, we switched back to the preteen and asked them questions about their daily experiences and followed up with our relationship circle exercise. We welcomed interjections from the preteen at any point throughout the interview in order to create an environment where both the parent and preteen felt heard.

Questions focused on home, school, and social life, as well as family and community relationships. We also brushed on policy-related issues in regards to allergies, especially if the guardian felt compelled to bring it up. For in-home interviews, we ended our interview by asking to see a tour of the participant's kitchen—this helped us to better understand their unique organizational methods. We also conducted semi-structured phone interviews as a reflection method for diary studies and for remote dyads using the same script from in-home interviews.





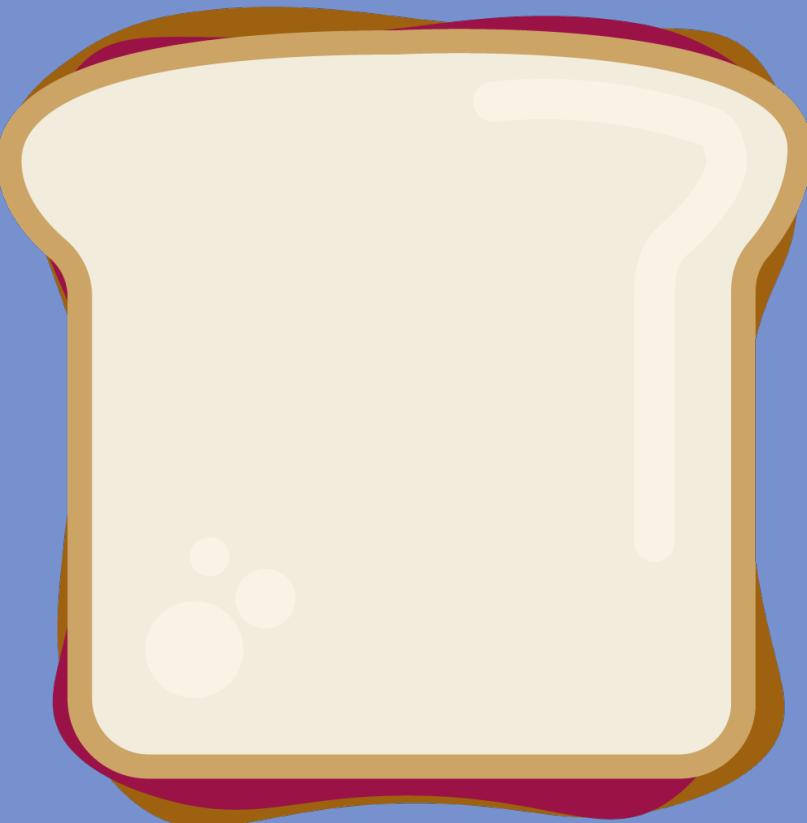
Relationship Circle

The Relationship Circle is a research method we used to see how preteens view their relationships with people in their immediate and extended community. We presented our participants with a mat. The center circle said 'me' and rings moved outwards to the edge of the mat (see Appendix). We presented our participants with cards that represented people we believed might be part of the preteen's life and asked them to place whichever cards they saw best fit on the mat. The closer the people were to the center, the more comfortable the child felt to the person. We asked them to repeat this activity by placing people accordingly when it came to the child's food allergies. We asked our participants to think aloud while completing the activity, asking them why they placed the people where they did, as well as why the two versions of the mat did or did not differ from each other. We documented the artifacts by taking pictures of the final layouts and taking notes throughout the activity.

Competitive Assessment

We conducted a competitive analysis of eight products in the food allergy space. Each application used a different form to address the needs of people experiencing food allergies. They comprised of portable food testers, wearables, and Oral Immunotherapy. Most of the products we analyzed were designed to prevent an allergic reaction from occurring, whereas only a few were response-based solutions. This might be due to the impact they could have on policy or insurance-related issues that inevitably come up with reactionary solutions, which require greater time and money on medical research backing. The EpiPen, which uses autoinjector technology, remains the dominator in the reactionary space.

We evaluated each product using the criteria of credibility, price, and physical design. Our assessment led us to think about these products as future opportunity areas to explore. We saw some overall themes during our analysis of the products. First was the importance of creating a seemingly simple and easy-to-use design. Because food allergy reactions are high-stakes, the less steps a user can take to achieve results or navigate the situation, the higher adoption and success rates will be. An important feature we noticed that was lacking in these products was an educational component, particularly if the product was targeted towards children.



Product Assessment



Aibi

Uses a three-fold system consisting of a wearable, mobile alert system, and EpiPen. Each layer can work independently from each other if something were to go wrong.



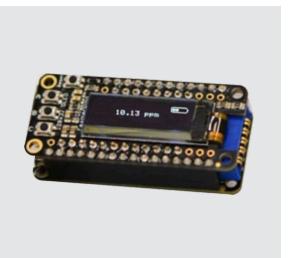
Ally

A food testing device that allows people to test their meals for lactose.



Nima

Portable sensor device that detects if a certain food contains gluten or peanut within minutes.



iEat

Uses small samples to test for a wide variety of common food allergens.



AllerGuarder

Bluetooth-connected wristband for children that alerts their parents or people within a 50-foot radius via mobile app. AllerGuarder relies on the public to also download the app, and requires users to invite people into their "circle" when the child is around new adults.



Intrommune

Toothpaste with pharmaceutical ingredients that target the mouth to retain the immune system.



Allergy Amulet

Portable food allergen and ingredient detection device.



Auvi-Q

Cheaper and more compact alternative to the EpiPen, Auvi-Q uses voice instruction to guide users through the entire epinephrine injection.

Trust

Theme One

Insight One

Trust between the parent and teacher is reliant on the teacher's proven understanding of how to deal with food allergies.

Outside of home, children spend the greatest amount of time at school. Parents often look to teachers to take on the role of 'secondary guardian'. Because the nature of food at school revolves around situations such as lunch, class parties, and the sharing of snacks between peers, the risk of allergy attacks increases. Unforeseen circumstances in this uncontrolled environment causes parents to worry. If parents set up preventative measures with teachers at the start of the school year, and teachers prove their loyalty and understanding over time, only then can reassurance take form.



"The main thing that makes me feel like he's safe at school is actually his teacher. So the teacher he gets every year, I meet with [her] beforehand. The teacher he has this year has food allergies herself so she is really, really good. She's amazing. We lucked out this year. The one last year, she didn't have personal experience with food allergies, but she did take it seriously."

– Phone Interview 4, Parent

"The teachers didn't talk to me. The communication was not adequate so we switched schools. I eventually heard about the peanut butter incident through [my son] and then his teacher was like, 'Oh yeah, that's what happened.'"

– Home Interview 5, Parent

Insight Two

Trust in the school system is compromised when regulations surrounding allergy education are inconsistent.

National guidelines exist around food allergies in school systems, however, every school district differs from one another—even in the same state. We found most schools did have some guidelines in place but they were not necessarily being followed by school staff, students, or parents. These inconsistencies proved frustrating, as parents who had children with allergies believed their child to be in a safe space, only to be reminded by one-off incidents that protocols were not being enforced. When failures like this happen even once, trust from the parents becomes harder to earn back.



"The school does not fully understand the impact of inclusivity or the impact of food allergies. I wish schools were universally better. I wish they didn't use food-based incentives at all. I wish there were laws on how things were regulated on food. I wish there were more specific laws for schools."

— Diary Study 2, Parent

"I was kind of wondering what I was reacting to. Because I go to a nut-free school, I can't be reacting to nuts. I was a little confused."

— Phone Interview 1, Child

Insight Three

Parental trust is dependent on the child's ability to take control of their environment.

As much as parents can teach their children about food allergies and how to protect themselves, children are still children. As our demographic comes close to entering their teen years, they become susceptible to peer pressure and food urges. Parental fear is derived from a distrust in the child's ability to be emotionally responsible with their food decisions. From the parents we talked to, some children knew they couldn't eat something, yet they still choose to consume it. This caused parents to remain fearful of their child's food intake. The feeling was only relieved once the child proved their understanding of the severity of their food condition.



"I don't feel that school is safe for her because she just had an incident two weeks ago. We would give her Benadryl and it's right there at school in her file with the EpiPen. The nurse said, 'No, I can't.' It wasn't that she couldn't, it was [the nurse's] judgment and it was annoying to me. She didn't want to deal with her. It's a very alarming situation. I really feel like this school has a liability concern instead of what's practical."

— Home Interview 6, Parent

"We never allow anything in the house that she is allergic to. Every once in a while, my husband and I will bring in something. She always finds some chocolates so sometimes we will put them somewhere high. But she said 'that doesn't mean I can't reach them.'

— Diary Study 2, Parent

"Oh yeah, we trust him. He can sense if he doesn't want to eat. I just trust his instincts."

— Home Interview 7, Parent

"I'm most nervous that she will want to rebel and eat things. I think that already came through in the peanut candy incident. She knew, but the fact that she ate the candy and being with her peers pressured her do that."

— Home Interview 6, Parent

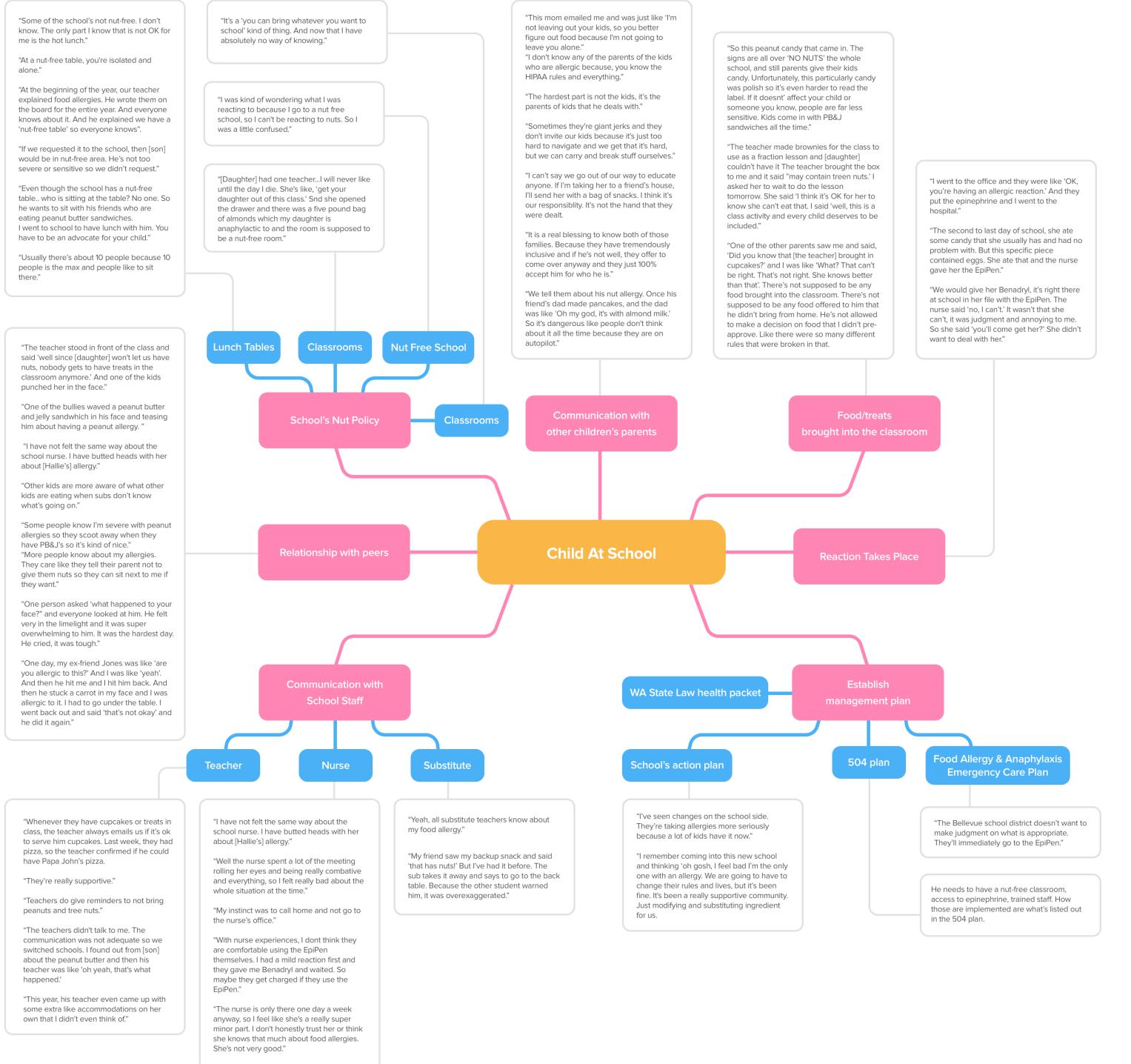
"Sometimes, I see a lot of wrappers here and there. He was sneaking, eating something he was not supposed to."

— Home Interview 2, Parent

Food Allergy Discrepancies in School Systems

As many as 18% of children with food allergies have had a reaction from accidentally eating food allergens while at school.

– Center for Disease Control and Prevention



Theme Two

Isolation

Insight Four

Children feel isolated with their food allergy because their natural curiosity to try new things is severely restricted, relative to their social circle.

When it comes to a child's social circle, many interactions are based on experiencing things with their peers for the first time. Whether it is trying new foods, playing new games, or watching a new movie, there is a natural curiosity in children to absorb new experiences and discuss them with their friends. When that part of their life is limited, such as the case with food allergies, children feel most isolated.



"I feel sad about it a lot. Like when my sister's eating [foods I can't have] in front of me."

– Home Interview 6, Child

"My friends always have something that I can't always have. Almost always. They use it against me sometimes like they might eat it so I can't be around them."

– Diary 2, Child

Insight Five

Because food is a central aspect for social activity, there is a cultural stigma when one cannot participate.

In so many different cultures, the breaking of bread is a core part of social interactions. It's often the norm to center social gatherings around food and to offer a share of one's food in the presence of others. Because the nature of food is a communal contribution or personal offering, it is considered rude to decline and could create a cultural stigma around that parent/child.



"Because more people know about my allergies. They care to tell their parent not to give me nuts so they can sit next to me if they want." –

– Home Interview 8

"I asked her to wait to do the lesson tomorrow and I would make the brownies. And the teacher said, 'Well, I think it's okay for her to know she can't eat that,' and I said, 'This is a class activity and every child deserves to be included.'

– Diary Study 2, Parent

"Usually, I have to bring my own food. Almost every birthday party."

– Phone Interview 1, Child

Insight Six

Parents feel their child is isolated when others do not consider the higher threshold of needs.

Parents want their kids to be treated with the same level of attention and care as their peers without food allergies. It is especially difficult for parents to hear that their child was excluded from activities in the classroom or social setting.

“When he was younger, he would avoid other kids. After one allergic reaction, it scarred him and that affected his ability to be.”
– Home Interview 4, Parent

“The school does not fully understand the impact of inclusivity or the impact of food allergies. If there are cupcakes or something and my child can't eat it, she has to be away from it, and for a long time I felt like it bothered me more than it bothered her.”
– Diary Study 2, Parent

“Her teacher did not have a food allergy but still went above and beyond.”
– Home Interview 6, Parent

“I was embarrassed. I feel like people were listening to that conversation with my mom and my coach.”
– Home Interview 6, Parent

Insight Seven

The isolating nature of food allergies is the foundation of a tight knit community.

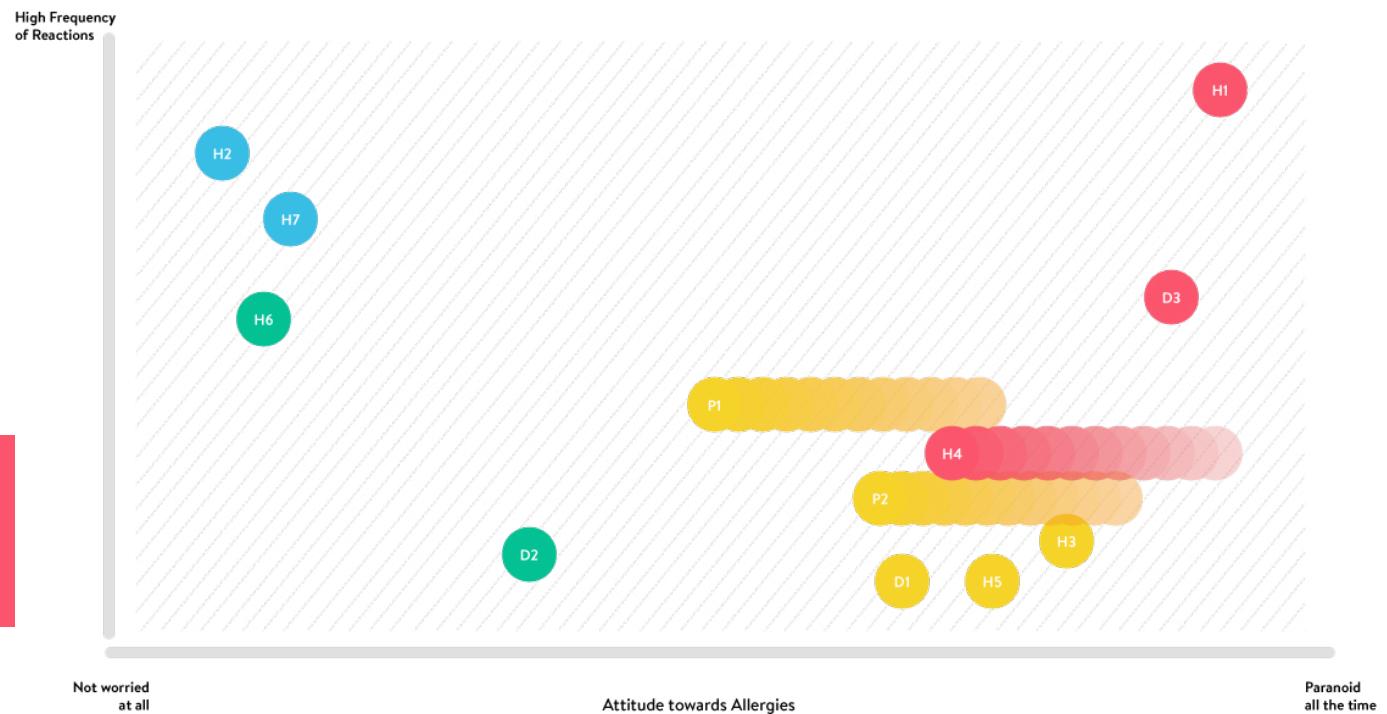
Communities such as Facebook Groups or child friend groups are often formed on the basis of isolation. There is a mutual understanding in these communities that other people ‘just don’t get it like we do.’ The life and death nature of food allergies creates a mutual discussion point that parents often feel is underappreciated and disregarded.

“I have people in the Michigan area that are really good friends and spent a lot of time together. It's inspiring to me knowing I made lifelong friendships.”
– Expert Interview 1

“So this mom emailed me and was like, ‘I'm not leaving out your kid so you better figure out food because I'm not going to leave you alone until I find it,’ and this was because she has food allergies too [and understood].”
– Home Interview 1, Child

“For a little while, I was labeled the food allergy mom. It was fine, but it was kind of negative because everyone wanted me to fight their battles. I had to separate myself in certain situations because it was affecting myself and my son. I'll give advice instead of going [out and fighting their battles] on behalf of them.”
– Expert Interview 1

Personality Spectrum



Not worried
at all

Attitude towards Allergies

Paranoid
all the time

Severe Allergic Reaction
Anaphylaxis shock, airborne reactions,
or allergic reactions that send preteen
to the hospital

Moderate to Severe Allergic Reactions
Reactions that range from a rare, full
Anaphylaxis Shock to the more normalized
moderate level Anaphylaxis.

**Shows from semi-structured interview
reflection on how mood has changed
as age has increased

Moderate Allergic Reactions
Have only had reactions that do not need
epinephrine intervention, but may use other
medicinal medication like Benadryl.

Mild Allergic Reaction
Reaction that rarely needs medical
interventions (i.e. skin reactions such as hives)

Theme Three

Awareness

Insight Eight

The high variability in food allergies causes society to be jaded by the word 'allergy.'

Between our 12 participants there was a variance of over 12 different food allergies. Reactions also ranged from severe, full-blown anaphylaxis, to skin and gastrointestinal reactions. It is because of the varying degrees of severity, and the rise in both food sensitivities and allergies, that society finds it hard to define 'food allergies' as a real problem. With the diagnostic tests that are used now, experts can't even define severity. In addition parents have expressed concerns and questions as to what their child may be allergic to. These limitations cause people outside the allergen community, who understand even less than the people within the community, to think of the word "allergy" as a catch-all for food issues. This, mixed with the varying degree of allergic reactions, makes the outside community view allergies as mild disruption and even an inconvenience in their lives.



"You would think it would be the kids that are the worst about food allergies, but it's really the other parents."

—Home Interview 1, Parent

"It's hard to know what he is actually allergic to."

— Home Interview 2, Parent

"People don't get it, or find it inconvenient until they have to deal with something similar."

— Phone Interview 1, Parent

Insight Nine

There is a consensus amongst the food allergy community that unknown environmental triggers have caused an increase in food allergies.

There has been a 106% increase in the diagnosis of children at risk for anaphylaxis in the United States since 2016. Doctors have seen a 2.5% increase in doctor's visits related to food allergies since 2006. A new allergy, Eosinophilic esophagitis (EoE), a food allergic swallowing disorder that didn't even exist in 2009, has made a 1200% increase in the past year. These statistics are not just facts, they are sirens. Both doctors and parents agree that unknown environmental triggers are the cause of many food allergies in western culture. We can see this through the famous Israeli peanut study and doctor's views on the Hygiene Theory, that environment is a big contributor to the Western prevalence of food allergies.

We found this same thread of truth within our own data when talking with the dyads. P2, who has a soy and fruit allergy that causes skin reactions, went to Taiwan for a summer and his "skin never looked better". Once he came back to the US, his problems came back. P1 is a child who struggles with EoE. His parents said "kids are the canaries in the coalmine," meaning they are telling us we are doing something wrong in our process of manufacturing foods and eating.



"Kids are the canaries in the coal mine. They are the sirens telling us something is not right with our food or environment."

— Home Interview 1, Parent

"In Asia, they tend to boil their peanuts and [in the United States], we roast them. There isn't a genetic explanation for this, it's the way they are prepared."

— Expert Interview 2,

Journey Map

Meet Jimmy.

Meet Jimmy, an 11 year old boy from Seattle, Washington. Jimmy was eating a peanut butter jelly sandwich for lunch with his parents when he suddenly started to experience tingliness and itchiness in his mouth. His mom immediately rushed him to the doctors after.



Theme Four

Fear

Insight Ten

Heightened anxiety stems from the trauma experienced during a past allergic reaction.

It is a scary moment for parents when their child goes through an allergic reaction. Allergic reactions range from minor hives to difficulty breathing. There are certain elements parents cannot control such as the school environment and hidden food ingredients in packaging. The traumatic experiences of going through an allergic reaction can remain present in parents' minds. The loss of control and predictability drives fear.

• • •

"As the child becomes more independent, they start making their own decisions. They don't want to be different, their risk increases."

– Expert Interview 3

"My daughter had a severe reaction and I had to get off of Facebook for a month because I would get anxiety from reading other people's stories."

– Diary Study 2, Parent

"It's scary to send her to school knowing a hug or high-five can be deadly."

– Phone Interview 1, Parent

"I don't want the symptoms to be so bad. I don't want to feel like I'm going to die if I eat eggs."

– Phone Interview 1, Child

Insight Eleven

Parents assume the worst about their child's condition due to limitations and ambiguities of diagnostic testing.

Once children are diagnosed with food allergies, parents tend to sensationalize their child's condition. Currently, diagnostic testing methods are unreliable and lack reassurance that the treatment will do more good than harm. Skin prick testing, for example, requires a small drop of liquid food extract in the skin. Moments later, redness may appear, showing an allergic reaction to that food. These red spots are then measured by a ruler and based on that measurement, treatment is defined.

Food allergy testing is time-consuming and can give false-positives. The anxiety surrounding these food allergies takes an emotional toll on parents and children, leading them to believe that taking on a more restrictive approach and avoiding all foods in a category is better.



"There are problems with testing. There needs to be better diagnosis because we never really know from testing."

– Expert Interview 2

"The problem with testing is they have to have a reaction during testing."

– Expert Interview 3

"Testing is annoying. It's itchy and I can't do anything."

– Home Interview 2, Child

"It took 92 days to diagnose him and he was screaming in pain every night."

– Home Interview 1, Parent

Insight Twelve

Distraction is a commonly-applied coping mechanism for children experiencing allergy attacks, either during or after.

When children experience an allergic reaction, they take epinephrine or generic medication and wait it out until symptoms lessen. In the meantime, they might be in pain, experience anxiety, stomach aches, and restlessness. The only thing children can do is to shift their attention to something else. Some distraction methods our participants said they used were watching and playing video games, reading books, or applying ice packs to the pained area. Distractions keep the children's mind occupied from the pain.



"And then we're starting to do meditation techniques. Like, let's breathe deeply. Or if it's really bad, he asked me to play a video game in front of him, or if I can read him a book, so that it distracts them."

– Home Interview 1, Parent

"We use ice packs all the time."

– Home Interview 4, Child

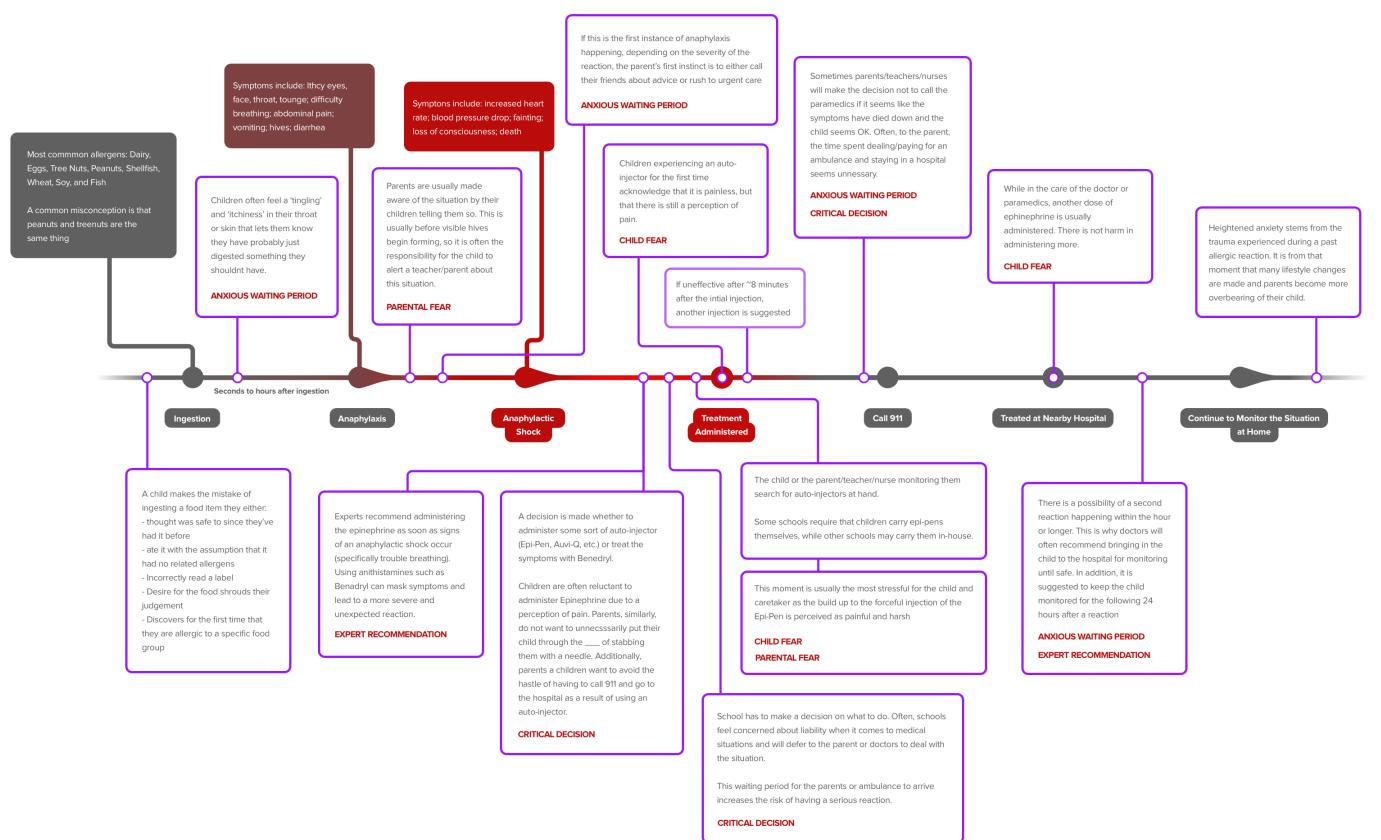
"Distraction during reactions is critical"

– Home Interview 1, Parent

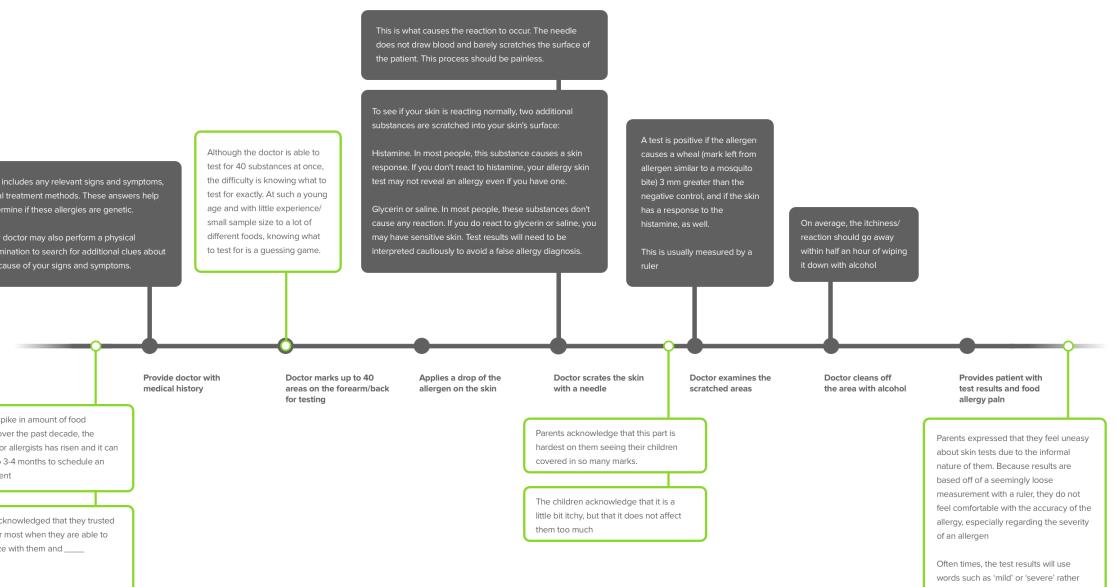
"If I start getting really, really sweaty, and then it starts itching and I can't take my mind off of it, then I get an ice pack. And if I still can't get my mind off of it, I tell my mom. This happens like one or two times a month."

– Home Interview 2, Child

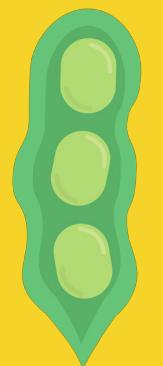
Allergic Reaction Model



Skin Test Timeline



Design Principles



• • Inclusion

For many cultures, food is intertwined with social interactions. Our design should allow the user to feel comfortable, safe, and integrated with their social circle.

• • Assurance

Food allergies can be a life or death situation, which leaves parents and children highly fearful. We hope to provide a solution that the user can trust and depend on, in any situation, to ease this fear.

• • Engaging

Our research uncovered the importance of proving trust, building communities, and alleviating anxiety through action. Our solution should bring children and parents, as well as the outside community, into the conversation in an unobtrusive way.

• • Reliability

The science and terminology behind food allergies is complex and often misunderstood. Additionally, the variability of education, precautionary, and reactionary methods creates confusion around how to properly deal with food allergies. Our design solution should provide users with proper and up-to-date education.

Design Opportunities

Better educate people on how to properly deal with a reaction while it's taking place

When a child experiences an allergy attack, a flux of emotions can instigate "fight-or-flight" or leave one frozen in time. Preparation is one thing, but how you act when an allergy attack takes place is something different. With the possibility of multiple people being present and thereby responsible for assisting during a reaction, we see an opportunity in creating an inclusive teaching curriculum for school systems and abroad. We also see a huge opportunity for side-by-side assistance education while an allergy attack is taking place, as this is when logic is easily superseded by emotional uncertainties.

Build on support of the local community to ease the mourning process for families

The most difficult process for families learning about their child's diagnosis is always the beginning. The complete shift in lifestyle leads families through a mourning process, often feeling isolated, lost, and overwhelmed. They have to also learn how to cope and manage a high-stakes situation for the long-term.

Make the process of determining which foods are safe to consume easier to understand

Whether it is checking labels at grocery stores or asking chefs at restaurants about menu items, it is time-consuming and inconvenient for families to know exactly what is safe to eat. Even the most routine purchases require label-checking, as some companies change out ingredients without notice or indication. Some parents go as far as contacting food manufacturers to find out if specific factory lines are clear of allergens.

Create a more informed diagnostic experience for children and their parents

Currently, the two mainstream diagnostic tests are the skin prick test and blood test. Both are considered unreliable, as about 50-60% of testings yield "false positive" results. For the skin test, the only symptom a child needs to have is a raised bump with redness around the pricks. Sometimes, children test "allergic" to the food, but have no symptoms when that food is consumed. If this is the case, allergists will proceed to the "food challenge" test—the child eats small portions of foods to see if an allergic reaction develops. This form of painful testing is deemed cruel for a child to endure by both parents and doctors alike. Blood tests are no better. They test for the presence of IgE antibodies (these trigger food allergy symptoms) to specific foods, however, they are unable to predict the actual severity of an allergy. The test reveals only the likelihood that there is an allergy. The lack of a definite diagnostic test leaves the food allergy community confused and unsure of what to expect and make of their results.

Alleviate the concern of making mistakes when dealing with a reaction in the moment

Parents and children voiced concerns over being able to make the 'right' decision amidst the panic of an allergic reaction. Whether it was making sure that an EpiPen is being used correctly, the necessity of administering epinephrine over benadryl, or a general fear of needles, we believe there is potential in alleviating this uncertainty in the heat of the moment.

Build trust between the parent and school through established expectations

Year after year, parents have to establish trust with teachers as parents leave their loved ones under the teacher's supervision. This is important because not all schools follow the national guidelines for food allergies. Developing a trusting parent-teacher relationship mitigates parental anxiety.

Design for control in an uncontrolled environment

One of the most anxiety-inducing problems parents face when dealing with their preteen's food allergies is letting go and allowing their children to partake in events in uncontrolled environments. By designing to allow for a perceived perception of control, we could ease anxiety and isolation for both parents and children.

Appendix

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Expert Interviews

Expert Interview Report – Lisa Rutter

No Nuts Moms Group

Profile

Lisa Rutter is the leader and founder of the online ‘No Nuts’ community where parents and guardians around the nation come together to discuss, host events, and offer advice regarding child food allergies. The community is structured where there are local No Nuts chapters throughout the US, UK, and Australia. Each has a leader and corresponding group on facebook where members can start discussions with other local moms and arrange events for their kids in the area.

Lisa herself has a child with tree nuts and peanut allergies. She was inspired to create the group without having much success speaking with doctors and specialists about her son’s condition. Lisa is a great source of knowledge having spoken to and been a vocal member of the community.

Observations & Insights

Being the ‘Food Allergy Person’ can be isolating

- For a little while I was labeled the food allergy mom.. it was fine, but it was kind of negative because everyone wanted me to fight their battles. But I had to separate myself in certain situations because it was affecting myself and my son, so I'll give advice instead of going on behalf of them.

The bond from the community extends further than medical advice

- I want to connect families and continue doing the events.. now that my children are getting older. I was about doing playdates but now I am interested in play dates and I'd like to pass the responsibilities down. There's also life long bonds of raising awareness for the community.
- I didn't have friends or family there so now I was a stay at home mom, and didn't have friends or family around so I joined mommy groups to get out of the house and interact with other adults.

The issue is not talked about enough

- A lot of people leave the office and just go on with their days, but when he said this, it really got to me. I don't get why parents don't look into this further. This is important, we are changing our lifestyle immediately.

Treatments involving feeding cause anxiety

- Need to look into the **patch** but there's an age limit for that. I'm not into the whole IT thing, but maybe down the road. I would like to see a treatment where I don't have to feed him. I have anxiety over it. I am looking for something like the patch.

Communication between parents

- I'm in contact with the parent when my kid is with them since he does not have a phone. When I talk to parents, they send me a picture of the label and they will ask me "can Evan have this?" And I'll look into it and say yes or no. I'll talk to them about the EpiPen.

People go to relatable communities first

- I used to always go to the Facebook groups for questions.. a lot of people go directly to groups for advice "how do you handle this situation?"

Facebook as a free and extensive community has been invaluable

- When I first started we used [meetup.com](https://www.meetup.com) but that wasn't doing anything plus you had to pay for it. Then I moved to Facebook and that's when it really took off and we connected with other food allergy groups.

Expert Interview Guide– Lisa Rutter
No Nuts Moms Group

Participant Profile:

- Lisa Rutter
- Founder & Support Group Leader
- No Nuts Mom Group

Relevant Information:

- <http://www.yummymummyclub.ca/blogs/alexandria-durrell-irritated-by-allergies/20140630/an-interview-with-lisa-rutter-of-no-nuts>
- Founder and Leader of online ‘No-Nuts’ Community
 - Holds different ‘chapters’ in multiple states
 - Facilitates in-person meetings/events
 - Has a child with severe food allergies

Key Research Questions:

- Get a better understanding of what benefits the ‘No Nuts’ community has in dealing with child food allergies

Interview Script:

1. Personal Introduction

- a. Thank you for offering to participate today. My name is Derrick, and this is Vijay. We’re both currently graduate students at the University of Washington studying design and we’re looking into child food allergies and how they’re currently dealt with. My job today is to spark conversation about your role as a leader within the ‘No Nuts’ community and get an understanding of how you deal with child food allergies yourself. I also want to make it clear that there are no right or wrong answers, so we’d encourage you to be as candid with your feedback as possible. This conversation should take about 45 minutes, but please let us know if you need to take a break at any time.
- b. *Ask for permission to record conversation* <start recording>

2. Interviewee Introduction

- a. Can you tell me a little bit about yourself and your experience with child food allergies?
 - i. Can you tell us a little background about yourself?
 1. Summarize yourself
 2. Where did your inspiration come from for creating your ‘peanut-free’ playground and the Non Nuts group
 - ii. What is your experience with child food allergies
 1. How old is your child and what is he/she allergic to?

3. No Nuts Group Introduction

- a. What is the No Nuts Group and how does it operate?
 - i. Number of people involved
 - ii. The role of other people
 - iii. Meeting logistics
 - 1. Times
 - 2. Talking points
 - 3. Etc.
- b. Effects of this group?
 - i. Visible impact
 - 1. What change has been made
 - a. Entire allergy community
 - i. Positive or negative?
 - b. Personal relationship with your child
 - i. Positive or negative?
 - ii. Goals for this group
 - 1. Current impact
 - 2. Future impact
 - a. What do you hope the future of dealing with food allergies looks like?
 - b. What problems you don't foresee being solved?

4. No Nuts Group Conversation Content

- a. What are some pain points that parents bring up about their children's allergies?
- b. What are some current trends that you are hearing from your community groups about how people deal with allergies
- c. How do you feel about the community and your child's ability to independently take the right steps to dealing with food allergies
 - i. What are the conversations you have with him to help educate him on food allergies?
- d. You mentioned how 'dealing with food celebrations at school' is especially hard. How have you combatted this issue, or wish to see changed about this?

5. Wrap Up

- a. That's all we wanted to talk about and we can't thank you enough for taking the time to talk to us.
- b. Are there any other local moms you might be able to connect us with to discuss this further?
- c. Do you have any questions for us? Anything that you might be curious about. We want to make this as transparent as possible.

<stop recording>

Expert Interview Notes – Lisa Rutter
No Nuts Moms Group

10 year old allergic to peanut and tree nuts. Diagnosed when 3. At 2, suspected it early on, and the pediatricians weren't up on food allergies so it was dismissed until they re-located and spoke to a new pediatrician. They went to an allergist, and that's when everything changed. Suspects possible other allergies like lagoons but not 100% yet.

There were no play groups for kids with food allergies, so I started one and it took off from there then other people from other states/countries asked me to help start groups and I help them by giving them flyers, cards and groups and we have just one big group. We have a big nonutsmom group and we are very connected. I am also a leader in a couple other groups in Michigan. One big community where we are connected together.

From Cincinnati, but her husband works in the automotive industry. She has two boys, 17 months apart, her oldest son was having most reactions and he would always have bad reactions. The top pediatrician there, was recommended, was very old school and didn't know what he was talking about food allergies. Told us to give him Benadryl and put him to bed. When we came back to Michigan and he got properly diagnosed - read more online and I took it upon myself. Our allergist said to me, **he can die from this**, and that's what opened my eyes.

-Traveled a lot. Pediatrician was one of the top - people recommended they go to him. He was old school, and she didn't think he knew what he was talking about before moving to Michigan. "I may have needed to hear that to dive into it myself." She meets so many people like that.. Where either they don't want to know, or doctors aren't being straightforward with how serious this can be. For some people, it doesn't affect them at all. They walk through it blindly.. It may not be a bad thing, but I don't get it.

A lot of people leave the office and just go on with their days, but when he said this, it really got to me. I don't get why parents don't look into this further. This is important, we are changing our lifestyle immediately.

How did No Nuts start?

I didn't have friends or family there so now I was a stay at home mom, and didn't have friends or family around so I joined mommy groups to get out of the house and interact with other adults. When we moved back to Michigan I had kids and our groups are different. I joined mom groups in Michigan and I was uncomfortable and not confident. It was uncomfortable for me to ask other parents "please don't eat peanut butter around my 3 year old." I wish there was another way for me to meet other food allergic families, then my child could meet other children who share this.

We originally had the Michigan group, and I had 3 leaders help since its the largest and most active group. After that, it was Orange County, California. Then all these local groups popped up. They will all have individual leaders and can have co-leaders. Its their group, im there to help them set it up and help out any where. We have a national group which is our online forum. We have 7/8 admins in that group. We have ladies who volunteer and enjoy doing that.

When I first started we used [meetup.com](https://www.meetup.com) but that wasn't doing anything plus you had to pay for it. Then I moved to facebook and that's when it really took off and we connected with other food allergy groups.

What goes on within the groups

We are not a traditional support group. We are strictly an online forum where people can connect with other members for playdates inside or outside of the home. We do mom nights and outings, easter, and halloween events. But we do not have traditional support groups meetings.

Halloween and Easter

Had the first one at my house, and we were so much smaller. But now we have to rent out a field. We get a grant through FACT(?) so they pay for everything. My husband does the easter bunny for us. Prior to that, everyone had to chip in. We are so much bigger so we can get grants. We are going to have halloween carnival. They will have pumpkin painting. We don't do ANY food at all so its more inclusive for the kids.

50-100 people show up. If it's a mom night outing it's a lot smaller. Mom's outing can be anywhere between 4-10 people in a restaurant. That's just the moms.

Changes/Impact

To see families connect, I have people in Michigan area that are really good friends and spent a lot of time together is inspiring to me knowing I made lifelong friendships.

It's come a long way since my son has been diagnosed, I can't speak for every school but my school does food free celebrations and occasionally they do things with food but they work with us so it's nice to see schools come a long way with that.

National guidelines came out, and that's when our school was trying to structure what they were doing. Not all schools were like that.

Lisa talks to the school, and her son has a 504 plan and she has to go through the plan and talks to the school districts and she's on the allergy committee.

For a little while I was labeled the food allergy mom.. it was fine, but it was kind of negative because everyone wanted me to fight their battles. But I had to separate myself in certain situations because it was affecting myself and my son, so I'll give advice instead of going on behalf of them.

My son and I have a great relationship with the school and I was worried about that before. I didn't want our reputation to come off as bad. We didn't have negative from any one but we stepped away from that.

I want to connect families and continue doing the events.. now that my children are getting older. I was about doing playdates but now I am interested in play dates and I'd like to pass the responsibilities down. There's also life long bonds of raising awareness for the community.

Need to look into the **patch** but there's an age limit for that. I'm not into the whole IT thing, but maybe down the road. I would like to see a treatment where I don't have to feed him. I have anxiety over it. I am looking for something like the patch.

I have to sit him down and talk to him about things..but right now he is good at reading labels. He does sleepovers, we don't let anything hold him back so he's an active kid. But when it comes to kissing girls eventually we are going to have to talk about that.

I'm in contact with the parent when my kid is with them since he does not have a phone. When I talk to parents, they send me a picture of the label and they will ask me "can Evan have this?" And I'll look into it and say yes or no. I'll talk to them about the EpiPen. It's been pretty good and manageable so far.

I used to always go to the Facebook groups for questions.. a lot of people go directly to groups for advice "how do you handle this situation?"

The best Allergist in Michigan that everyone swears by, takes an HOUR waiting in the wait room. So I don't mind going to another allergist.

When they first get diagnosed they want to meet within a month to make sure parents are doing what they are supposed to do. My son goes every year.

Expert Interview Report – Stephen A. Tilles, MD

Northwest Allergy & Asthma Center

Profile

Dr. Stephen Tilles is a Board-Certified doctor with specialization in Internal Medicine and Allergy and Immunology. He received his medical degree from the University of California San Diego School of Medicine in 1990 and completed his undergrad at Harvard University. He currently serves as Physician Partner at the Northwest Asthma and Allergy Center, Clinical Associate Professor of Medicine at the University of Washington, Executive Director of ASTHMA Inc., and Executive Committee member of the Seattle Food Allergy Consortium. He has authored more than 60 peer-review publications, and has served as Principal Investigator for more than 100 clinical trials related to treatments for asthma, rhinitis, urticaria, and food allergies.

Dr. Tilles is a valuable source of knowledge and input for our topic on food allergies. He sees up to 20 patients on a daily basis and although trained to treat both pediatric and adult patients, his practice has now become primarily pediatric-driven with 75% of his patients being children. We knew we could acquire more specialized, factual insights from someone of his experienced nature.

Observations & Insights

Food allergy visits have increased.

- Visits to Dr. Tilles's office (Northwest Allergy & Asthma Center) have dramatically increased from ~4,000 in 2006 → 12,000 in 2017, a two-and-a-half fold increase.

The increase in food allergies may be attributed to the 'Hygiene Hypothesis.'

- The allergic immune system is always there but genetically, there are people who are predisposed to developing allergies. This can be dependent on environmental influences or epigenetics, when happens environmentally that change your genes so it gets expressed the rest of your life. Once it is expressed, it becomes a part of you.

The death rate from a peanut allergy is about 100 fold less than accidents.

- Food allergies can create anxiety that can affect a family's quality of life. This is actually an inconvenience and fear that comes with thinking that they are stuck in their way.

Fear of using the EpiPen is irrational.

- Earlier administration is much safer. The EpiPen has never hurt anybody because it uses a natural hormone. Delaying the EpiPen until there's obvious symptoms increases risk.

Hysteria is a big problem.

- Hysteria can create more psychopathology. There's a fine line between taking it really seriously but at the same time being careful not to create unnecessary anxiety.

Preteen children are at the age when we can address behavior modification right before they become high risk.

- Empower them to take responsibility and be part of an action plan rather than relying on somebody else to do it like 'helicopter parents'.. It's better if they've bought into it and it just becomes part of their life. This is the age when they come in annually and start having more serious talks with their allergist, like making sure they know where and how to use their EpiPen.

The Auvi-Q is a competitor to the EpiPen.

- Slimmer, more compact, and better fitted for boy's back pockets. Offers the same dosage of epinephrine as the EpiPen. Patients don't have to pay anything, insurance companies pay \$1,700.

There needs to be better and more accurate diagnostics.

- Skin and blood testing are the two most common forms of diagnostics that doctors use. However, both are limited and you never really know whether somebody is allergic based on their testing (could come out as positive due to eczema).The process can be traumatic for patients as they are required by the FDA to show a food allergy reaction when participating in first clinical studies. Then, to be approved for the study, they must show an improvement over time through continuous unsafe testing.

At age 5, over 80% lower likelihood of peanut allergy if you've been eating it.

- Not exposing peanuts to children early is the worst thing you can do. In Israel, they have a teething snack called bomba which uses a peanut protein. The same sect in London had allergies to peanuts but the kids in Israel didn't. The study showed that exposure to peanuts at an early age was effective. However, there aren't enough studies to prove the same for other types of foods though.

Severe reactions can impact a child psychologically.

- Dr. Tilles was called to treat a friend's kid who suffered from a severe reaction at a potluck. After the incident, he lost a lot of weight and became anxious all the time. He eventually had to see a psychologist.

Expert Interview Guide – Stephen A. Tilles, MD
Northwest Allergy & Asthma Center

Interview date: Wednesday, April 25, 1:00 PM

Attending team members: Kelly Hwu, moderator & Derrick Ho, notetaker

Interviewee: Stephen A. Tilles, MD | Northwest Allergy & Asthma Center

Dr. Stephen Tilles is a Board-Certified doctor with specialization in Internal Medicine and Allergy and Immunology. He received his medical degree from the University of California San Diego School of Medicine in 1990 and completed his undergrad at Harvard University. He currently serves as Physician Partner at the Northwest Asthma and Allergy Center, Clinical Associate Professor of Medicine at the University of Washington, Executive Director of ASTHMA Inc., and an Executive Committee member of the Seattle Food Allergy Consortium. He has authored more than 60 peer-review publications, and has served as Principal Investigator for more than 100 clinical trials related to treatments for asthma, rhinitis, urticaria, and food allergies.

With such an extensive experience over a long period time, Dr. Tilles will be a valuable source of knowledge and input for our topic. Talking to experts like him who are on the frontline will better inform our research questions for when we talk to parents/guardians, children, school staff, etc.

Interview Guide

A. Introduction

- Thank him for agreeing to the interview and taking time out of his day to chat with us
- Introduce Kelly and Derrick, well as our team and capstone project
- Explain why we chose to interview him and what we want to get out of it
- Ask for permission to record audio

"Our target demographic is pretty specific. We are looking at preteens between the ages of 9-12 who have food allergies. Children at this age are more likely to participate in risky eating. They aren't being watched as diligently by their parents and are put in social situations where they are tempted to eat. Studies have also shown that 50% of deaths from severe allergic reactions occur in teens. By targeting these kids on the cusp of entering teenagehood, we feel we can make an impact on properly educating them and curbing their habits so they can transition into a more independent role when it comes to their food consumption."

B. Warm up

1. As an allergist, what does a day in the life look like for you?
2. How many of your patients come in for food allergies?
 - a. Are any of them children?
 - b. What's their age range?

3. If you could break it down percentage-wise, how many patients would you consider have mild vs. moderate vs. severe food allergies?
4. Are there any common misconceptions that parents or children have about food allergies?

C. In practice

1. What is your relationship with parents who bring in their kids with food allergies?
 - a. How do you build rapport with them?
2. What are the biggest pain points parents bring up when dealing with their child's allergies?
 - a. Or conversely, any pain points children bring up?
 - b. Do you see a common theme surrounding the occurrence of these problems?
 - c. What do you recommend to alleviate these so-called challenges?
3. What is being done now that is successful for parents and kids with food allergies?
4. Have you dealt with any parents or children who have been psychologically impacted by a food allergy?
 - a. What is being done about this?
5. For kids in the preteen phase, what do you think are the best resources for them when it comes to managing their food allergies?
6. What are pieces of advice you would share for when we deal with this population of kids, ages 9-12?
 - a. What is being done about this?

D. Looking ahead

1. Are there any points of interests for you personally related to food allergies that you wish could be addressed on a larger scope?
2. How do you feel about current tactics for preventing food allergies in children, such as introducing small doses of peanuts? (Can refer to study in which kids who were introduced to peanuts when young had up to an 80% lower risk of developing peanut allergies than those who were not)
3. Studies have shown that food allergies have tripled in the last 20-30 years. What are your thoughts on this dramatic increase?
4. What do you hope to see in the near future that could help in the food allergy space?

E. Conclusion

- Let him know that was all the questions we had. Ask if there's anything else he'd like to add or expand on.
- Thank him again for his time

Expert Interview Notes – Stephen A. Tilles, MD

Northwest Allergy & Asthma Center

Day in the life:

- Day I'm seeing patients
 - Get up, excursive, 4am, 7:30 in to work
 - Turn on computer, emails, boot up EMR, say hello
 - First patients by 8am
 - 8 - 10 patients in a half day (3-4 are new)
 - 4 patient rooms per doctor, and 2 medical assistants
 - 10 major diagnoses that we deal with
 - Most cases are similar and so it's easier to deal with

Do most people come in for food allergies?

- EMR in 2005
- 2006 pulled all data for office visits
- Growing and a lot more office visits
- Trained to see adult patients
- Internist or pediatrician
- Both pediatric and adult training
- Usually, parent certification will dictate your practice
- 75% of patients are pediatric
- Peanut allergy has grown from once a week to 5 times a week
- Hygiene hypothesis

Allergic immune system is always there

- Environmental influences
 - Change your genes
- As western culture got more affluent → people became more clean
 - Less exposure to 'dirty' things
 - Doesn't explain it all, but a big part of it
 - Something about our bodies that are primed to maintain the allergy

Types of peanuts that we expose our kids to is roasted peanuts

- Asia is not prevalent
 - tend to be boiled, rather than roasted

There is no genetic explanation, it's the way that the peanuts are prepared

clinicaltrials.gov

- Search for peanut
- Search for tree nut
 - Big difference, tree nuts are understudied and under appreciated

9-12 - about 50% of the patients

- Epidemic started before they were born

- Most people get it early

Hard to determine severe vs. moderate

- Extremely rare to have a death
- Equal number come from patients without a severe reaction before
- Have to be careful, because they do such a good job of avoiding it that they don't know the severity of it themselves

Common misconceptions

- YES
- Not as much as being unrecognized as it once was
- Sometimes the anxiety and the quality of life impairment is a lot more than it needs to be
- Death rate is about 100 fold less than accidents
- Inconvenience and fear of staying safe
- Misconception is that fear of the needle...etc. are irrational
- Earlier administration is much safer and never will hurt someone, even a child
- Not every reaction needs it, but EX
 - Allergic reaction that's not that bad → Benadryl → keep EPI on hand
 - Need to administer immediately
 - Not giving it is more dangerous
 - Completely irrational
 - Need to call 911!!! Don't just do Benadryl
- Deaths from peanut, is because there's a delay in EPI for more than 45 minutes
 - There's a way to ensure that it doesn't happen

Are there cases where parents use EPI when not needed

- Pretty rare, but can happen
- The fear that is preached will result in scaring people into using it more often
- Is there a history?
- Doctors don't want to take chances
- Really challenging role to play as a doctor

How do you navigate the relationships between parents and children

- Make sure that they are serious about the avoidance
- Convince them that they are willing to use the EPI
- They don't necessarily need to be afraid. They can live a normal life
- TEACH THEM the difference between peanuts in the air vs. peanuts being eaten
- Accidental ingestions are the ones we worry about
- Comforted knowing the statistics of fatalities
 - LET'S PREVENT BAD REACTIONS
- Hysteria is overdone and creates more psychopathology than is needed
- Take it really seriously, but don't want to create unnecessary anxiety

Have you dealt with any psychologically-impacted patients?

- Family friend
 - Dad is chiropractor
 - Nicest people in the world
- Kid has peanut allergy and asthma

- Didn't take it
 - At least have it around
- Called Tilles
 - Kid at potluck at church and accidentally ate peanut
 - Coughing in the BG
 - Hives all over
 - GIVE THE EPIPEN RIGHT NOW
 - Convinced the mom and drove over there
- They finally got it, but its hard
- Test you as a physician, can't expect everyone to be the same

Resources or tools given

- Patent information literature
- Organization called FARE Food allergy research and E—
 - Also fund research
 - Lots of resources such as internet based, mailing list, patient registry

Focus on preteens, what are some pieces of advice when dealing with this population

- Transition from grade school to more independence (solo wandering)
- Hormonally, things are starting to change
- The last chance before they are at a high risk chance times
- Behavioral modification
- When they come in, they start asking
 - Oh where is your episode pen 'WELL WHERE IS IT?'
 - State law now where the parents think its ok for them to carry it ok, then the school HAS to be ok with
 - EMPOWER THEM TO TAKE RESPONSIBILITY
 - Epi pen is very important
- Overlake
 - Required all students to carry their own stuff
 - Proactive
 - And not reliant on helicopter parents
 - Focused on the kids
 - They are adults
- That age is huge
 - Boys especially are stubborn about it
 - They need to already buy in and have it be a part of their lives

Is there a stigma attached with EPI

- Not as much as before (my age)
- Not as odd or acceptable to ostracize people
 - Things have changed enough
- Way more common, but still natural for developing preteens to FEEL DIFFERENT and cause stress on them
 - Whether or not its conscious or not. Not necessarily bullying, but just knowing
- Competitor of EPI is the obvue Auvi-q (LOOK INTO IT)
 - Boys don't really have an inconspicuous place to place it
 - A lot smaller and portable

- AUVI-Q
 - Pharmacoeconomics
 - No competition
 - Just price them however they want
 - Competitor just priced it the same
 - Why not just be cheaper
 - We're better!!
 - Wars between the two
 - 3 years ago, the FDA closed down their factory because of dosing issues
 - The parent company
 - KALEO took over and then since got it back on the market
 - The same product was 40 retail years ago. It's all about the profit \$\$
 - Auvi Q guarantees that the patients won't have to pay a dime
 - They cage 1700 to insurance company, not to the patients though...
 - Better for boys, and preteens since it's easier to carry
- Prescribe both to kids
 - Just came out with a baby size

Points of interest that you wish could be addressed on a larger scale

- Couple things
 - It would be great to have a treatment
 - Better diagnostics
 - Skin testing/blood testing are both limited
 - never really know based off testing
 - Oral challenges
 - Traumatic if they're wrong
 - 'Barbaric'
 - In the real world
 - A lot of times the primary doctor ???
 - Positive test doesn't mean you have a food allergy
 - 15% outgrow it...
 - Knowing when that happens would be great
 - Right now, skin testing every year....
 - Better part of the day
 - More efficient way to know how to diagnose

How do you feel about current tactics about small dosages

- LEAP Study in London
 - Changed the whole thinking on what to do
 - Before: avoid it all
 - Study showed that at age 5, there was an 80% lower if you've been eating it already
 - Peanut is not so much controversial
 - Unsure how early to introduce it
 - Studies take years and are hard things to answer

Not exposing to it early

Someone made the observation how certain countries have no food allergies

- The difference was that in Israel that they use this teething snack that has peanuts in it

- Peanuts are only part of it
 - 9-12, there are no eating guidelines

That kid

- Ended up losing a lot of weight
- Became anxious all the time
- Wouldn't eat anything
- Had to go see a psychologist
- When they were on it ??? They were eating peanuts, pecans...
 - several of them ended up in psychologist

What's worse, being treated or not treated

Hope to see in the near future that could help in this space

- Biased toward innovation for treatment
- Two products likely to be approved
- Hope to see that
- Targeting a biological part
- Most of those patients also have asthma or nasal allergies
- Link between asthma and food allergies (>50%)

New thing coming out that should treat asthma and peanut allergies

Hopefully we get all that solved

10 years from now, I hope there's a more cost effective way to turn it off

FARE WEBSITE

AGE appropriate information

Expert Interview Report – Geetu Deogun, MD

Allergy Partners of Raleigh

Profile

Geetu is a pediatric trained allergist who has been practicing for over 10 years. She went to medical school at the University of Nebraska and completed her residency and fellowship at Rush University Medical Center.

Her commitment is to enhance the quality of life for both children and adults by diagnosis and treatment of asthma, food and environmental allergies and immune disease. She believes that empathetic listening and patient education is key to this goal. She engages with fifteen to twenty patients a day. Geetu has been exposed to a variety of food allergies and is well known in the Cary, North Carolina community for her empathetic approach to patients.

Observations & Insights

Patients don't know it's possible to outgrowing food allergies

- Many people who have food allergies are not aware that they can go away over time, and its important for caretakers to remain hopeful in the process of outgrowing their food allergy

Patients avoid neighboring food groups they are allergic to when they shouldn't

- Those who are allergic to peanuts and almonds tend to avoid ALL tree nuts since they assume they may fall under the same family. People don't realize they should try eating neighboring food groups to grow the tolerance

Empathy and showing care to patients and their parents are key to earning their trust

- Geetu treats the parents of children as patients too (in addition to the children with food allergies). She does this to educate the parent as much. In order for parents to really trust Geetu's advice, she has to earn their trust through empathy and showing care

School policies and food packaging are two large pain points

- Two huge pain points include: School policies on treating students who have allergies are not consistent and in addition to reading and checking food packaging

As children grow, the risk of death from a reaction increases

- As children grow up, their risks for a reaction increases since they become more independent and make their own decisions. The risk of death from shock is the highest in their teenage years since there are social norms/pressures of not 'being different.' They are less careful and have a god complex

Kids with food allergies feel isolated and bullied

- There aren't many resources for kids with food allergies. Isolation and bullying is known as one of the biggest problems and there are many other negative connotations

Children who consume foods early in their diet are more likely to avoid food allergies

- Children who adopt a diet where they consume foods (like peanuts) as early as 5-6 months are more likely to avoid allergic reactions (from an Israeli Peanut study)

Expert Interview Guide – Geetu Deogun, MD
Allergy Partners of Raleigh

Used same interview guide as Stephen A. Tilles, MD (pg. _____)

Expert Interview Notes – Geetu Deogun, MD
Allergy Partners of Raleigh

As an allergist, what does a day in the life look like for you?

- I see 15-20 patients a day on a busy day and see food allergies, environmental allergies, venom, eczema, asthma, immune deficiency. Most are food allergies, a lot of pediatric food allergies, an even break between the categories. I am pediatric trained.

How many of your patients come in for food allergies? Are any of them children?

- Just about all of them are for food allergies. Adults, 50% and kids 50%

If you could break it down percentage-wise, how many patients would you consider have mild vs. moderate vs. severe food allergies?

- There's no such a things as a mild food allergy, either you are allergic or you are not. Some might have just eczema and not anaphylaxis but shocks are serious.

Are there any common misconceptions that parents or children have about food allergies?

- Not understanding properly food allergies can go away, if someone has a food allergy at age at 3, check often, dependent on skin test . If you are allergic to peanuts and almonds-- they are then avoiding all tree nuts, that's not necessarily the best thing. They should avoid the thing, but try to eat neighboring food groups to help have tolerances grow

What is your relationship with parents who bring in their kids with food allergies? How do you build rapport with them?

- It comes with experience. I usually treat the parent as the patient, and they have to trust you, understand you. They need to see the data as to why they are doing what they are doing. It's important to speak to the parent and educate the parent as much as they can. Some parents will trust you right away, others will trust you later, but trust comes with time. It's essential that we show that you care and empathy. Parents respond well if you can show that this is something we've seen before. Also, hope is so important and showing them this is what we could do to prevent or maybe allow the child to outgrow this food allergy.

What are the biggest pain points parents bring up when dealing with their child's allergies?

- Schools and school policies are not consistent with how they treat allergy patients. Travelling is hard, and airlines have gotten better. Also packaging is a problem, i.e. this might contain nuts and they can't have that. Some of these things aren't moderated, they may just be saying this from a legal standpoint.

Are there any pain points children bring up?

- As the child becomes more independent -- they are making their own decisions, they don't want to be different, so their risk increases. There has been a ton of research at UNC -- for food allergies like oral immunotherapy to teach bodies to slowly tolerate these foods. There are also tools and apps like App Allergy Eats which has mixed reviews, free, restaurants in the zip code area, parents review

What do you recommend to alleviate these so-called challenges?

- Don't sit next to people that eat foods they are allergic to and try to find support groups. It's tough, there's not much else we can do. Also pediatricians do the testing and then that's it-- they don't tell them to see an allergist

Have you dealt with any parents or children who have been psychologically impacted by a food allergy?

- It's not very common but yes -- anorexia, agoraphobic, they only want to eat inside, psychiatric involvement.

What is being done about this?

- Seek mental health help, she will talk to them about the low risk if you are being cautious.

For kids in the preteen phase, what do you think are the best resources for them when it comes to managing their food allergies?

- There aren't that many resources for the kid themselves. I don't know if there is a teenager food allergy, facebook group.

What are pieces of advice you would share for when we deal with this population of kids, ages 9-12?

- The risk of death from shock is the highest in teenage years, yet teenagers don't want to be different. They have this god complex, less careful, they ignore issues. Above age 12 is a really interesting age group.

Studies have shown that food allergies have tripled in the last 20-30 years. What are your thoughts on this dramatic increase?

- Look up Israeli peanut study -- proven what happened, they took this population and followed them and their development of peanut allergy-- took that same population in England -- same genetic makeup-- one adopted more Western dietary habits -- over a generation the israeli children did not have much risk, but the England population went up a frightening increase
- The kids in Israeli have popular snacks -- they eat peanut puffs, starting when they gnaw on food. Western countries don't eat any peanut until 2 years old-- after one generation it has increased.
- As soon as they are 5-6 months old, they eat it all, unless there is a known risk factor.

What do you hope to see in the near future that could help in the food allergy space?

- We have been waiting for a patch for food allergies to come out, and FDA approved immunotherapy stuff to come out. That's how we can change the disease process.
- ***Isolation as one of the biggest problems make a facebook group or chat group for these kids -- Negative connotations and bullying that happens

Expert Interview Report – Devra Shiba

Senior Manager of Nutrition, Sodexo

Profile

Devra Shiba is the Senior Manager of Nutrition Services at Sodexo, a food catering company for major businesses and universities worldwide. Devra oversees facilities in 13 states for regulatory compliance, education, training, and professional growth. As a registered dietitian, she keeps her skills sharp by working in a clinic whenever she can.

As Devra is in a management position for a major catering company, it is part of her responsibility to educate her team on how to deal with the daily dietary needs and restrictions that they may come in contact with in a regulatory and safe way. She works within communities to make sure schools and environments are equipped to deal with food allergies and often comes in direct contact with parents of preteens to educate them on what her team is doing to keep their children safe.

With schools often being a stressful environment for parents and children with food allergies to deal with, we believed speaking to Devra about her work and management of food services would be an insightful interview that would inform our design process and decisions.

Observations & Insights

There are misconceptions about food allergies across the board.

- The difference between preferences and a life threatening allergy is big and important to understand when dealing with food services.

“This one time isn’t going to affect me”

- The misconception, especially with preteens and teenagers due to peer influence, that engaging in risky eating and eating something one time won’t have severe repercussions.

This is a community effort

- Sodexo doesn’t work directly with doctors, rather with the community and families to make sure they are treating their child’s allergies with the right amount of attention.

Parental fear for their child increases with age

- When children grow older and parents lose more control over what their kid is doing and eating, fear and anxiety grows

Education for stakeholders involved in the allergy is crucial

- “One-to-one contact with a dietitian and nutritionist to make sure not only the child but the family understands what the allergy involves so you're teaching them the signs and symptoms of reactions. ”

Empower preteens to use their voice

- Kids oftentimes don't want to be different and therefore they don't speak up about their allergies, leading to adverse reactions to foods. Empowering preteens to use their voice and ask for what they need is one key to successfully managing allergies.

Food Management technology tools in schools

- Oftentimes food services at schools, if they are managed by a larger company, have technology based systems that allow chefs to pull up allergens for specific children.

Psychological problems don't just affect the children

- “We see parents sitting on the sides of the cafeteria nervous about their child eating in a big environment. ” It can affect the whole family.

Peripheral involvement is key

People can be successful at managing food allergies as long as the people around them are educated and are aware of what an allergy is.

Expert Interview Guide – Devra Shiba
Senior Manager of Nutrition, Sodexo

Interview date: Monday, April 30th, 10:00 am, 12 pm CT

Attending team members: Whitney, moderator & Kelly, notetaker

Interviewee: Devra Shiba, Nutritionist

Interview Guide

A. Introduction

- Thank Devra for agreeing to the interview and taking time out of her day to chat with us
- Introduce myself and Kelly, well as our team and capstone project
- Explain why we chose to interview her and what we want to get out of it
- Ask for permission to record audio

"Our target demographic is pretty specific. We are looking at preteens between the ages of 9-12 who have food allergies. Children at this age are more likely to participate in risky eating. They aren't being watched as diligently by their parents and are put in social situations where they are tempted to eat.

Studies have also shown that 50% of deaths from severe allergic reactions occur in teens. By targeting these kids on the cusp of entering teenagehood, we feel we can make an impact on properly educating them and curbing their habits so they can transition into a more independent role when it comes to their food consumption."

B. Warm up

1. How many people come in with food allergies?
 - a. Are any of them children?
 - b. What's their age range?
2. If you could break it down percentage-wise, how many people do you see have mild vs. moderate vs. severe food allergies?
3. Do you ever have an instance when you are the one to find the allergy in the patient? And what are tactics or tools that you use to help you pinpoint that?
4. Are there any common misconceptions that parents or children have about food allergies and nutrition?

C. In practice

1. What is your relationship with parents who bring in their kids with food allergies?
 - a. How do you build rapport with them?
2. Do you work with just the family, or are you part of a connected system of doctors?
3. What are the biggest pain points when dealing with eating and food allergies?
 - a. Do these pain points get more challenging with younger children?
 - b. Are there any pain points children bring up to you?

- c. Do you see a common theme surrounding the occurrence of these problems?
 - d. What do you recommend to alleviate these so-called challenges?
4. What is being done now that is successful for parents and kids with food allergies in your specific field?
 5. What are common tools (either using tech or not) you use to help families or yourself deal with food allergies?
 6. Have you dealt with any parents or children who have been psychologically impacted by a food allergy?
 - a. How do you help them deal with these issues?
 7. For kids in the preteen phase, what do you think are the best resources for them when it comes to managing their food allergies and their nutrition?
 8. What are pieces of advice you would share for when we deal with this population of kids, ages 9-12?

D. Looking ahead

1. Are there any points of interests for you personally related to food allergies and nutrition that you wish could be addressed on a larger scope?
2. How do you feel about current tactics for managing food allergies?
3. Studies have shown that food allergies have tripled in the last 20-30 years. What are your thoughts on this dramatic increase?
4. What do you hope to see in the near future that could help in the food allergy space?

E. Conclusion

- Let her know that was all the questions we had. Ask if there's anything else she'd like to add or expand on.
- Thank her again for her time.

Expert Interview Notes – Devra Shiba
Senior Manager of Nutrition, Sodexo

As a nutritionist, what does a day in the life look like for you?

I'm in a position where I oversee facilities in 13 states for regulatory compliance, education, training, and professional growth. I do clinical when I can just to keep myself involved and make sure I don't lose my clinical skills. So pretty much my day varies. Friday is a big day for a conference call and catching up with my team. Today, I did auditing to make sure my team is doing what they need to for regulations, and their clinical expertise is maintained.

How many people come in with food allergies?

I am not in a clinic, I'm in a management role. But our company is global and I'm senior. I take care of that population. I've done some things on the school level as well as the university level. A lot of specifics that deal with allergies in our company. It's high on our radar. That is one focus on mine, to see do we have allergies and are we addressing their needs?

Being able to define whether it's a true allergy or a preference. People have these misconceptions bc they read so much online and speaking with preteens not only have the input from their parents but now there is the peer influence. They need to deal with "I want to be cool and I want to be part of the group" the thought process is going on. Depends on how much their parents have instilled..if it's something that's going to cause death or harm. The importance of watching their diet. Whether it's an allergy or with diabetes, there's that group that really doesn't allow it to...

Are there any common misconceptions that parents or children have about food allergies and nutrition?

That one time isn't going to hurt...or in some cases not only ingesting but something the particles can transfer in the air and affect somebody. But I think that's one of the biggest misconceptions...one time isn't going to affect me.

Do you work with just the family, or are you part of a connected system of doctors?

We don't work directly all the time with doctors. If I'm working in a community, I'll make sure my team does connect with the physician or if it's a school setting, working with preteens on the university level just making sure there is a valid diagnosis of an allergy and the school is equipped to treat an allergic reaction if they're at that level.

When you're talking about preteens a lot of that is parents fear lead into that, that once the kids get to that level it's out of their control they're more on their own. They're going out with friends, there's going to be food everywhere.

One-to-one contact with a dietitian and nutritionist to make sure not only the child but the family understands what the allergy involves so you're teaching them the signs and symptoms of reactions.

Specifically how to read labels, the clearer the labels are, the easier it will be to interpret by just knowing what is your allergy.

Not going out to eat, kids are going to hang out after school, 7-11, just go out with their friends, recognizing there could be a concern in the preteen area. You may get kids that won't speak up if they are with a group of kids and start asking questions at your local fast food place. That's a huge part of the education...is being able to really instill that importance.

Northwestern..I was there with peer groups...specifically this age group...one of the little boys said "can i speak to a manager" and he told him "i have an allergy" and the one thing our company has is a special chef and section and so this boy was taught to go tell somebody and they walked him through the whole process. They had him speak to a chef so when he comes in every day he specifically has to meet his needs so he doesn't feel excluded. Big one is peanuts, wheat, gluten. Teaching them to make sure they work with somebody at that level.

At a preteen level, they're just in grade school and making sure the nurse is aware of allergies, whoever runs the food management in the system is aware of food allergies so they can assist, it's when they go out on their own is when education needs to be enforced.

What are common tools (either using tech or not) you use to help families or yourself deal with food allergies?

Within our company yes. I can speak from that. If a school system is managed by a management company whether that's our or another, we all have technology-based systems that can pull up that information and tell you all the allergens in the food. I know we have specific ones that we can go in and it's on your smartphone that you can look and see if something is allergen-free or not.

A lot of places are not necessarily with apps or online but they have that in a holder or a book. More chain restaurants...they're very tuned into that but that local fast food place and independent place may or may not have that information. They may have to go to the [bathroom] to look at the label.

Have you dealt with any parents or children who have been psychologically impacted by a food allergy?

Go to a psychiatrist. I had some parents that would sit in the lunchroom or sit on the sidelines during the entire camp program. All you can do is support them. Your child has basically had a reaction so you're going to be fearful. You've got schools that have peanut-free zones.

For kids in the preteen phase, what do you think are the best resources for them when it comes to managing their food allergies and their nutrition?

Brainpop - it's an animated website that discusses different health issues for kids. It's good for adults too. Go under Health.

What are pieces of advice you would share for when we deal with this population of kids, ages 9-12?

You've got to make them..it's okay to be different. You're different from one another. Finding some way to keep it cool. It's okay to watch your diet. For some, you have a minor allergy. For others, it's life threatening. Using tools like brainpop where they can find an entertaining way to learn about that. It's your body, it's your life.

Having knowledge and we're looking at the group that gets information at their fingertips. Easy ways to find that information and increasing awareness. I know in some states like in Illinois i am a certified AllerTrain - it's an added expertise. It's a short course [allerten?] The more you know, you're never going to be 100% correct when you go into a restaurant. My brother-in-law is gluten-free. We went out for asian food. The person there said our wontons are gluten-free because nobody said they were. So you're never going to get 100% compliance.

It'd be cool to have a tool in your neighborhood where you get support. It'd be cool to develop a coalition of independent restaurants in your area and support some kind of knowledge base for when people are going to hang out there. Kids don't want their peers to think there's something different so a confidentiality agreement. You can put it on a website...neighborhood app? In our area, we have a neighborhood app. It includes all these neighborhood apps, it's another source to post allergy-free restaurants where they're not using peanut oil to cook.

[not sure which question led to this comment]

[There's a lot of different reasons. Immunization...increased awareness?]

Current tactics - how do you feel?

No i don't think anything is missing - i think so much of it you know peripheral involvement. It's just a need to educate and to make sure the information is out there...some kind of training or awareness.

Or if it's camp problem, the parent and child will meet with the chef and go over the menu to make sure there is something every day when they go to eat that they can pick up.

It's collaboration, there's also...a lot going on behind the scenes. If there are true allergies going on, you have to make sure you're set up. Won't be contaminated by other food, separate cutting boards, knives, if somebody is allergic to shrimp and shrimp is on the menu and you're also making french fries, or gluten free where you are toasting your toast, you want to give an allergy-free environment. You have to in preparation of foods be able to ensure you are doing it right. You say you'll have this but what's going on behind the scenes?

AllerTrain - allergy training that others can go through, lots of resources, link to school nutrition association

- ✓ Screener Survey
- ✓ In-Person Interview Cover Page
- ✓ Interview Guide
- ✓ Consent Form
- ✓ Participatory Design Mat
- ✓ Participatory Cards
- ✓ P1 Notes
- ✓ P1 Design Exercise
- ✓ P1 PD
- ✓ P2 Notes
- ✓ P2 Design Exercise
- ✓ P2 PD
- ✓ P3 Notes
- ✓ P3 Design Exercise
- ✓ P3 PD
- ✓ P4 Notes
- ✓ P4 Design Exercise
- ✓ P4 PD
- ✓ P5 Notes
- ✓ P5 Design Exercise
- P5 PD
- ✓ P6 Notes
- ✓ P6 Design Exercise
- ✓ P6 PD
- ✓ P7 Notes
- ✓ P7 Design Exercise
- ✓ P7 PD

Screener Survey

Food Allergy Survey

We are graduate students at the University of Washington looking for participants to take part in a research study on how preteens manage their food allergy. Activities can range from interviews, diary studies, an interactive exercise and a focus group. Please contact Vijay Farmah at Vfarmah@uw.edu for any questions or concerns.

*Required

Do you have a child between the ages of 9-12 with a food allergy? *

- Yes
 No

Please select the food(s) that your child is allergic to: *

- Fruits
 Milk
 Eggs
 Wheat
 Peanut
 Tree Nuts
 Soy
 Shellfish
 Fish
 Other:

Are you based in the Seattle area? *

- Yes
 No

If no, please list your location:

Your answer

Please provide your email address: *

Your answer

Phone Number (optional):

Your answer

Thank you. We will follow up within 2 days if you meet our criteria.

SUBMIT

Never submit passwords through Google Forms.

Consent Form

What We Are Studying

We are investigating the relationship between pre-teen children and their food allergies. This is part of a research project conducted by graduate students from the Human-Computer Interaction + Design program at the University of Washington. We hope to design a better way for pre-teen children to manage their food allergies in a safe, effective, and trustworthy manner.

What You Will Do

During the study, I will be answering questions asked by the moderator. Although the questions will be asked in the format of an interview, we see this as more of a conversation. Please remember you do not need to answer any questions if you do not want to.

Risks and Benefits

I permit the other members of the research team to take notes, photos, and video throughout the process. I understand that these will remain confidential and will be used solely for purposes only related to this project. I understand that the students will not use me and/or my child's name in any reports, and that my private matters will be kept safe and not shared.

Our Commitment to You

I understand that participation in this study is voluntary and I agree to immediately raise any concerns or areas of discomfort during the session with the moderator.

I understand that the research team will not identify me and/or my child by name in any reports using information obtained from this interview, and that my confidentiality in this study will remain secure.

For your participation and thanks, you will be given a \$20 Amazon gift card.

Your Options

If you have any questions about this project or how your information may be used, please raise them now. You may also contact the faculty supervisor, Vijay Farmah, at vkfarmah@uw.edu or (919) 740-7622.

By signing below, you indicate that you have read and understand the information on this form, and agree to proceed with the study.

DATE

NAME

SIGNATURE

Interview Script

Hi! Thanks for agreeing to talk to us today. I'm [*insert name*] and these are my teammates [*insert name & insert name & insert name*] who will be taking notes and obtaining artifacts from our discussion today.

Today we will be asking both of you questions about your lives, living with and caring for food allergies. Our goal of this interview is to understand more about your day-to-day lives when dealing with a food allergy, your highs and your lows and to gain a better understanding of the opportunities surrounding this medical issue.

Your participation is solicited, but voluntary, so you both may skip questions or stop at any time. Do you have any questions at this time?

[*wait for answer*]

We also would like to record this session. All recordings will be used only for research purposes, and the recording file and anything you say on it will stay confidential amongst our research team. Is this okay with you?

[*wait for agreeance or denial*]

Alright, let's get started...

For children

How long have you had your food allergy?

Do you know what a food allergy is?

How do you feel about having a food allergy?

Do you carry an EpiPen?

- How often do you say you actually have it on you?
- When you go out with friends do you bring it?

- Do you ever engage in "risky" eating?

- Do you know what a reaction to an allergy feels like?

- Have you ever had a severe reaction?

- if you have did that change anything in the way you live day-to-day?
- If you have had an allergic reaction, do you have a certain protocol, besides using your EpiPen that you follow?

- How does your allergy affect your life?

- Does your food allergy ever affect your mood?

- Does your food allergy affect your relationships with friends and family/ social life?

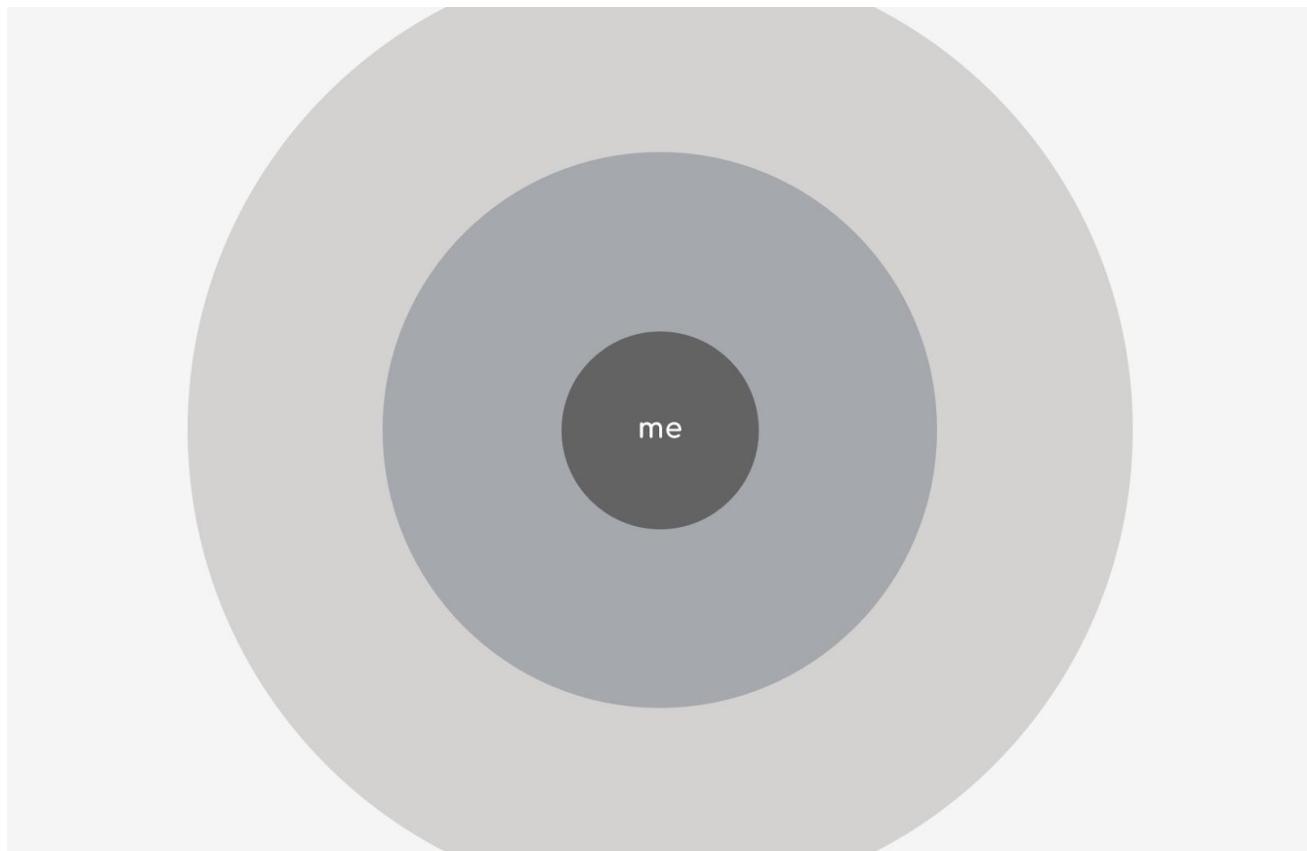
- How do you currently manage your food allergies?

- What goes into your food management decisions?
 - What makes or pressures you to participate in risky eating?
 - What makes you say no?
- What is a typical weekday like?
- What types of tools do you use?
- What goes on through your head when you have a reaction?
- Is there anything you want to know more about in terms of your food allergy?
- Is there anything that would make living with your allergy easier on you or your family?
- If you could make something to help you with your food allergy what would it be?
 - Do you hang out and eat with your friends independently of parental supervision?
 - How do you cope with eating out without your parents?
 - Do you trust the establishment?
 - Do you feel more comfortable eating with your family around or do you have no feelings?

For parents

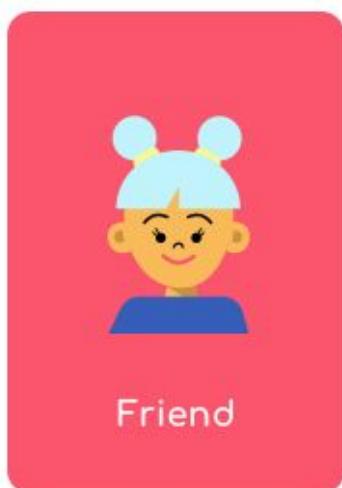
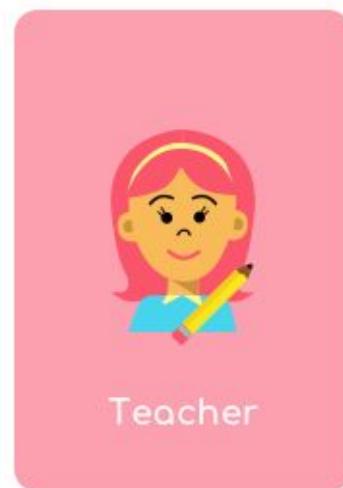
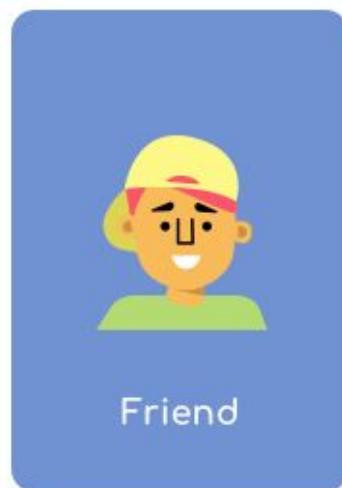
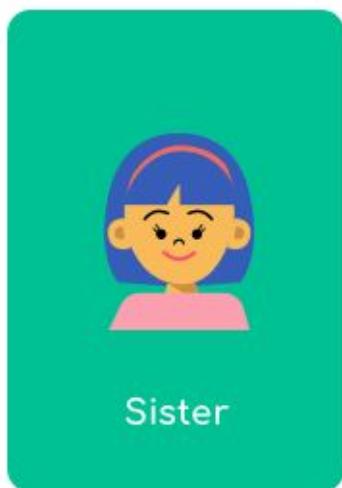
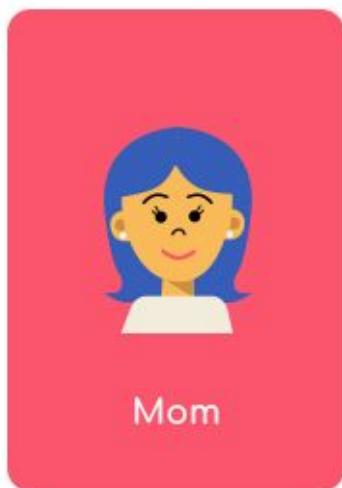
- What are your feelings towards your child's allergy?
- What do you like or dislike about those tools?
- What goes on through their heads when they have a reaction?
- What goes on their parents minds when their children are out of sight?
- How do parents handle meal prepping or grocery shopping?
- What's the biggest pain point for managing food allergies?
 - What could help address that? Or What would make it easier on you and/or your child?
- What are you currently doing to making it easier?
- Have you noticed any big changes in your child psychologically?

Participatory Design Activity Board



(Will be in tabloid, landscape format)

Participatory Design Stakeholder Card Set





Doctor



Uncle



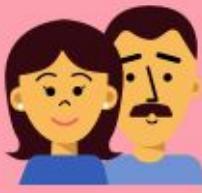
Aunt



Grandma



Grandpa



Friend's Parents

H1 Interview Notes

In-Home

H1-M: Take certain chemicals that are in packaging for foods, flips a switch for kids and their white blood cells treat food as if they were diseases and it's classified as a food allergy disease.

The problem with this is traditional allergy testing does not work for EOE. You have to do the elimination diet. And for reactions for this, it can be eczema but the number one is pain. So it took 92 days to diagnose him and he was screaming in pain every night. No pain meds touch it because it's your nervous system to not your regular system....like nerve pain, nerve pain which is harder to treat. So like I said, there's been a 1,200% increase in this in just a year and the disease did not exist 10 years ago.

Or at least enough been diagnosed. That's one of the ways that they figure out whether or not you got it is...[ESNO fields?] are white blood cells...they scope you and if you're reacting at the time they'll find a really high count in your esophagus. You can also get something called the [EOG?], which is basically gastro....it happens in your gastric system too. So for P2-C when they tested him the first time normal. ENSFL is for people who don't have any food allergies is under 10 his was 178.

WJ: And it's just happening now?

H1-M: Yeah, well there's there's some hypothesis that maybe existed previously within the food system, but they're not sure. There was a Michigan State study where...and this is where the some of the packaging comes into play....

H1-D: Basically this researcher got approved for additional funding. I think it was from NIH...she's been doing laboratory testing where she exposes...I can't remember if it's white mice or rats...to exposure to BHA which is a compound news thing micro amounts in foods as a preservative so it's in such small amounts it's now been thought to trigger responses. But when she exposed her laboratory animals to it, some of them developed food allergies.

And a lot of the chemicals and stuff like this that they think are the causes that are with epigenetic effect have been banned in Europe for a decade. A

WJ: Okay P2-C, how old are you?

H1-C: Nine.

WJ: Nine? Okay, what grade does that make you?

H1-C: Third.

WJ: Third, how do you like it?

P1-C: There's a stealer in my school...more than one.

P1-M: They don't have locks in their locker oh no take about sometimes

WJ: I remember third grade those were my golden years.

It's been the exact opposite. Because it's been hard...

P1-M: You can tell them why...it's ok

P1-C: I don't really know....

P1-M: You want to talk about how you missed a lot of school lately because of the food allergies and how it makes you feel? You could do that if you want.

P1-C: I missed the end of school today because I didn't feel well.

P1-M: So he's missed part of 30 at the past 45 days because the allergies have been so systemic...because the kind of food allergies he has, we have to do through elimination diet. Sometimes he gets stuff that...he is allergic to.

And with EOE, the white blood cell responses for the food allergies, they can take a few days to get out of a system too.

WJ: So when talking about the elimination diet like what were the things then that you found that triggered?

Well, in most cases if you have EOE...and we're trying to figure it out...they take you off the top eight, you know, soy, wheat, eggs, dairy, tree nuts, peanuts, fish and shellfish. We did that to him and at first it got better but then he started screaming in pain again...and then he was doing that for another month. And we were at our wits end because it's very hard when someone you love is screaming in pain. They're little and you can't really help them.

So in a normal situation, the top eight or take it back and every two weeks you add something back. But it was clear that we were missing something. So Mike and I just finally decided that we were not...they kept trying to give us steroids and stuff which we just don't want to put them on massive doses because there are no longitudinal studies on the effects of that so we pulled him back to about five foods.

About five or six...like rice and chicken very bland very basic and we started adding food back so we discovered that he for sure...we're not done. This usually takes two years which stinks. The [MID?] thing we're missing is citrus. Everything with lemon and citrus fiber, which is a lot, is one of his triggers.

[P1-D mentions pea protein in the background]

P1-C: I was having pizza sauce and you can also use it for spaghetti and I had every day...

P1-M: and he was allergic to it, so we had to pull him back to figure it out.

P1-C: I was screaming every day.

P1-M: Do you know all your allergies? Do you want to tell them?

P1-C: I can remember four of them. Wheat, dairy, eggs, soy. Wait five. Lemon, pea, rosemary, shellfish, fish. More actually I can't remember.

P2-M: We have to keep a list because...our daughter, she's in there....she's 14 so she's out, too old for you. But she is also allergic to like seven [P2-C says in the background "almonds") and anaphylactic to almonds. Luckily he's at least not anaphylactic to anything.

WJ: So he has his reaction...is strictly like eczema and pain

P1-D: His food reactions are primarily esophageal but he has had some...

P1-M: Well the eczema too and then he's gotten hives only with peas which we have to go back to the allergist because with EOE that doesn't normally isn't one of the side effects so we're not sure why that happened. That was pretty recent. But for the esophageal, you get reflux from it, your stomach acid shoots up because the food tends to get stuck in the throat. So for EOE with people in sometimes with him...he feels like food is stuck in his esophagus when he has a reaction. His stomach hurts. He gets more eczema too and reflux.

P1-D: Eczema is the canary in the coal mine. I misspoke. By the way, it is TVHQ...which is the...i looked it up...cheryl rockwell...[inaudible]

WJ: And then you said his reaction can last days, and there's nothing really that can help in terms of..?

P1-D: Actually distraction, like with a lot of pain issues.

P1-M: Well, we're teaching him meditation because there's not medicine that helps with the pain and his is part of his life, so we have to...

The best thing is avoidance, but with some of these like soy. It's hard.

Eating out's just become almost impossible.

Although we have found a couple places so that's kind of exciting. So that's kind of exciting

P1-D: And we have used steroids, steroid medicine on his eczema, which is part of our reluctance for...the additional oral on top of that. And also we didn't want to just treat the symptoms, we want to figure out the cause.

P1-M: So avoidance, Benadryl, daily Flonase (side note: this is an over the counter allergy nasal spray) just during the highest season for outside. sees outsize allergies to outsource stuff. And that's it. Yeah, in terms of the pain there's nothing that can be done.

WJ: Can you tell me from like a parent standpoint what it's like to be a parent of I guess children with food allergies?

P1-M: The hardest part is not the kids, it's the parents of kids that he deals with. And there's a lot of education that goes with being a parent and the exclusion because of parents, not because of the kids.

So when Wren start...she's our daughter who's 14 with anaphylactic allergy. She was in a class with two other kids with nut allergies that were anaphylactic which ended up being a great gift because they had their own little support network.

And one of the P2-Ms came in and taught me everything and I've tried to pass that on. They have, you know, the Arthur book series, they have a book about being he's got peanut allergies, if you don't know, and then they have a video for it, too. So they showed it to the kids and what ended up happening is the kids went "oh, well we want to protect you." And so parents would be like "I don't want to deal with" and they'd be like "No, no, P2-M, you can't do this" when they wanted to bring something in with nuts or whatever...the kids were the ones who were leading the parents' way.

So sometimes parents are really, really great about it and we tell P2-C to focus on those people. But yeah, sometimes they're giant jerks and they don't invite our kids because it's just too hard to navigate and we get that it's hard, but we can carry and break stuff ourselves. So I would say, having to educate people is and deal with that component of, not even the physical part of it sometimes, but the emotional part of it. Especially as they start becoming teens and preteens because there's so many parties and stuff and you have to navigate differently. You just do.

P1-D: There's a line from the movie Food, Inc. A farmer was talking to a Pakistani farmer...he said Americans fear nothing except inconvenience. I think that is what it really comes down to. People want to help or understand until it becomes inconvenient time and it's like whatever...and then it's like well, not whatever...and for example I'm not allergic to poison ivy. I'm part of the 5% of the population that's not. You don't want me to come over your house with a handful poison ivy. Highly inconvenient. It would also be a health hazard.

P1-M: The other thing is that I don't think a lot of people really believe that food allergies are a real disability and it's definitely an invisible one. And so we've had like, we went to a restaurant once and the cook was like, 'this is such a first world problem. It doesn't even exist' kind of things. So really, it's a constant effort.

P1-D: It's a roll of the dice if we eat out.

P1-M: We think about food all the time. All the time. It would be nice to not have to...the people that have the luxury of not having to are really lucky and they have no idea.

WJ: You talked about um school being a problem. Can you dive deeper into that?

P1-M: His school's been better. There was a learning curve and they think that the teachers that he had overall have been good. Wren had one who was terrible though. I'm just gonna share this...

Wren had one teacher...I will never like until the day I die. One of the subs who I befriended because I go in and talk to the subs when I have that because they have food allergies, right? That's what we do. And she's like, get your daughter out of this class. And I said, Why, and she opened the drawer and there was a five pound bag of almonds which my daughter is anaphylactic to and the room is supposed to be a nut free room. And then she took me over to where they have seated reading and there were nuts all on the couch and I was like 'oh my god this is not okay' so you know...they call it East Coast Mama which is my bitchy side.

But the long and short of it is we got it so she had to remove the nuts...but then she stood in front of the class and said 'well since Wren won't let us have nuts, nobody gets to have treats in the classroom anymore.'

And one of the kids punched her in the face because that made her 'Yeah, Ben was then removed from that class and put in another one because we threw holy hell for it.'

So there's that. That's an extreme we've never faced anything that bad again but that exists. And then on the other end of stuff, we have an incredibly helpful team with him.

P1-C: There's one more thing. Remember when Joe stuck a carrot in my face and

P1-M: You can share that in a minute...

He has an IEP and individualized education plan because kids with EOE, because the effects are much longer than even your normal big reaction, tend to miss a lot more school. So the school has been magnificent at providing a tutor for him so that he hasn't fallen behind at all and that we're really grateful for. And though his teacher now really didn't understand, she's really

really tried to...and his class has eight kids with food allergies in it and that wasn't planned. So I think that shows habits growing.

And you know school's a mixed bag. I mean, some people understand, some don't. I think I've seen a real progression in educating of the teachers themselves, which is good. And most of schools have at least have part-time nurses and they're very well-versed on Epipens and all that too so that's also positive. But then you get a sprinkle of...the other woman.

WJ: P1-C, what was the story you were going to tell us?

P1-C: So one day, my ex friend Jones was like are you allergic to this? And I was like, yeah. And then he hit me and I hit him back. And then he stucked a carrot in my face and I was allergic to it. And I said I was allergic to it. I had to go under the table and I went back out and said 'that's not okay' and then he did it again.

P1-D: He defended himself appropriately.

P1-C: And the school was not okay with it. He had stay in the office.

P1-M: He got in-school suspension.

P1-C: For five or three days.

P1-M: It was a week. So there is some school bullying. This goes really fast about fixing it. I mean, there's zero tolerance for it.

P2-D: It's gotten a lot better since our daughter was his age.

P2-M: I think there's much bigger understanding. But there's still a long way to go in terms of guidelines for how to make this easier for the kids to understand and for the teachers even. And I don't think a lot of people truly understand until either someone they love has allergies or they themselves have it, which is pretty true for a lot of things right?

WJ: So in terms of doctors who who's like the main do see how often do you see an allergist versus like a nutritionist?

P1-M: So P1-C has only had food allergies and been diagnosed with EOE for about seven months so he was in the hospital 23 times with allergies last year. Yeah before we got it under control. So we didn't really have a typical answer for you. We're still figuring out stuff, we've taken a couple months off of doctors because he was just so sick and tired of going to the doctor. But but figuring out EOE, your gastroenterologist actually works really closely with a food allergy specialist. They work hand in hand to make sure that the kids are okay who have allergies in this way.

P1-D: The GI specialist, at least with ours, he will say just outright 'you need to check with your allergist about this'

P1-M: And they communicate very closely even though one's at Childrens and one's at Kaiser.

WJ: So you said that elimination diet was one of the methods that you took. Are there any other methods or ways you go about cautioning or staying preventing this.

P1-D: We have to do a lot of cooking.

P1-M: We cook vegan now which I honestly never thought I'd say my life.

P1-D: We don't cook vegan.

P1-M: We do plus chicken. When we bake and stuff, we use egg replacers instead of eggs. We don't use butter anymore because [faux butter?] has pea protein. So like we do a lot more Google searches like we figured out how to make butter with apple um with coconut vinegar, and rice milk which was crazy. You just set it on the counter for 25 minutes, it becomes buttery.

P1-C: something about chicken nuggets

P1-M: If you want to know for sure. So we cook ahead a lot. Like we do cooking on Sundays for the week. It just makes it easier. We work too.

P1-D: We freeze a lot.

P1-M: So we make huge [inaudible] of chicken nuggets. Which is coconut aminos, tapioca flour, potato flour,

WJ: Are these your favorite? [to P2-C]

P1-C: Yes.

P1-D: What did you say the chicken nuggets were? [to P2-M]

P1-M: They're organic chicken, potato and tapioca flour, coconut aminos, which I didn't know existed before he got diagnosed, and canola oil. Luckily, he's not allergic to coconut, so there's coconut aminos which takes like soy sauce. And coconut vinegar, which allows us to make a lot of things so that we can bake. Like the butter.

P1-D: Because of default, non soy vegan butter are made with pea protein.

P1-M: One thing we've really had to work on too is label reading because that's something you have to do. And another thing that we do too is call companies now and ask how they clean lines and stuff. If there's something that's made in a facility with. With our daughter anaphylactic to tree nuts, if it's made in a facility with tree nuts, we just don't get it. But with a lot of EOE kids, if it's made in a facility. It's okay. But we still call the companies and we've even changed all of our shampoos, you know, in case anything gets in his face. I changed all my makeup. Finding a toothpaste. Oh my gosh. You have no idea how hard it was...because he can't eat mint either. So no mint, no citrus, no soy, good luck. It took weeks to find one. And the last time we went to the dentist, he's like, I don't know what to do. So we're actually working with our dentist to try to figure out a way to safely clean his teeth there. He's not allergic to corn but for people with corn, almost all medication use corn as a way to preserve them. So there are a lot of issues that people don't think about.

P1-D: [The suspensions....inaudible]

P1-M: And like he can't use a multivitamin because all of them have citrus in it.

P1-D: Citrus is also used for bread or wash for cleaning vegetables.

P1-M: Yeah that's the really interesting thing. We thought he was allergic to a bunch of vegetables but by researching, because we live on Google now, we found that most of the fruits and vegetables at Safeway and Fred Meyer and everything have a citrus-lemon spray on them. That spray they spray has not just water, it's got lemon juice in it.

So if you have a child with allergies or you're a person with allergies, you're a detective too.

So you say you use Google a lot like what what have you how do you find recipes and like how do you find all this stuff do you have like certain websites that you go to? Are their communities?

P1-M: There are really good Facebook community. There are no EOE support groups in the Washington area. I actually went to a social worker because he qualifies with EOE because he has so many food allergies. She could not find one either so I found two on Facebook and they have like 3-5,000 people so it's quite a few people. I actually find the adult one to be far more helpful because they can tell me what's working for them and how they feel in a way that the parents who were having...you know. With our daughter, we already knew how to navigate allergies and in some way a lot of people just starting out are just completely overwhelmed by this. We were in an advantage that we had some background in it, but the Facebook groups have been invaluable. It's completely where I have found recipe websites like the minimalist Baker. a lot of her stuff is really easy to modify to the EOE stuff. So that's one of our go-to's. And then bythecost.com. And then we have all these...

P1-D: We just have to do a lot of substituting.

WJ: You said that going out to eat was basically a gamble.

P1-M: Well, we find good places and when we do we share with everybody on Facebook in the groups that we can. But we have a rule that we're agree on which is when in doubt or they don't seem to know what they're doing, walk away because we've made, we've had bad reactions. Wren's had one anaphylactic episode and it was because the manager of the place was good, the cook was good, but the waiter blew it off. So you're dealing with a lot.

Now the best place I've ever seen is Mod Pizza, which you wouldn't think. Their allergy website, you should look at it, because it should be a model for everyone, which is modpizza.com/allergen.

They actually list everything in their facility. And there's a chart and it shows you where the allergen is for the top eight, and then they have a different code for anything they source out of their store. And if there's a possibility of cross contamination for that too. Which is amazing! It's very hard to get. I've never seen. Yeah, it's really great. And we've been to three and two of the places. One of the managers had celiac's who was working there so he totally got it. And then one was vegan. So he's like, Oh, yeah, totally.

P1-M: He can eat bacon and chicken for meats. He just can't eat nuts...protein..you know

So we don't eat out a lot, because it's just too risky. We went to Disneyland because they're known for their allergy practices. If you don't know this, there's a blog from them. I can't remember. It's mouse allergy or Disney allergy or whatever. You should look for it. What I would say about that is, they're very fastidious about cooking at the park, but it doesn't mean it's good. It's very super duper bland.

P1-M: Yeah, when you're in the elimination diet, they tell you 'oh don't worry about all the other things, just focus on the 8. And you have one that's not the 8. Then, you know, it stinks, right? So FARE. That's where I that that's where I found out you all were doing this stuff. The food allergy research and education. They put out a list once a year of the top 20 best restaurants to go to if you have allergies which is very good. And then there are a bunch of blogs that do it. And I'm starting a column on the Maven, which is a blog that Disney sponsors for food allergy parents. Yeah so I start there, and we're talking tomorrow.

I talked about this enough. And you know, both of us have just become better cooks than we ever thought we'd be. Like he makes really good bread which is a challenge without butter and eggs.

With Wren, how was like the first time around like what was that..

P1-M: I laugh at nuts.

P1-D: Because it's a super serious reaction. There's still a ton of options. She just needs to read everything, needed me to fastidious but it is doable. There are, you know, depending on your level of sensitivity, but you can do it and you can still have lots of things. Plus, there are some people who are allergic to tree nuts who aren't allergic to peanuts because they're legumes...trying to explain that to a group full of people.

P1-M: The big, big challenge that P2-C's had and what's made it so much harder when they had the EOE type allergies, as opposed to the other kind, is we could do a test and tell what she was allergic to. We're having to take two years to figure his out. It's a lot harder on him than any of us.

I mean, when we were in it, it was like, Oh, this is really hard, and we have to educate people, but it's been a lot harder for P2-C than it was for navigating the first one. I'm thankful though for having had that and I was just diagnosed with food allergies three years ago for the first time.

WJ: Oh, wow. What are you allergic to?

P1-M: Do you know about latex allergies and food? So some foods because of nature have latex in them to protect them from animals eating them until they're ripe, like bananas and avocado, stuff like that. So you have a latex allergy like to a Band-aid, you also can't eat these foods until they're ripe. So that [] was my worst one.

So we have like a gajillion EpiPens, which you know, there's a shortage but not in our house. So there's a huge long thing about this. They've under-produced, it's a critical stage and FARE put out a press release about it today. Canada covered it last week because the situation in Canada is far worse than here. When there was that whole debacle about raising the rates and the prices for it, they quit making some of the ingredients to make it. So now FARE I think reported over 400 people have reported to them in the past month and they have not able to renew their prescriptions which is a big deal. So

A lot of people are doing that [referring to what P2-D said about epinephrine..[couldn't hear him]. It's really become a sort of civil rights issue because people who don't have insurance or don't have a lot of money can't afford these anymore, right? I mean, the prices went from being like a \$10 copay to \$450 for some people in a year.

P1-D: Two years ago, when it really started up in MIT Technology had a article and...it costs \$30 to make a do-it yourself EpiPen, here's the proof MIT Technology.

WJ: So can you discuss a little bit how like you have gone about educating your children on their food allergies. Like getting them ready, through the preteen to teen.

P1-M: There's a lot. We've done a ton. He goes to the store and reads the labels. Because they need to know how to do that.

P1-C: I checked my bubblegum toothpaste once and it had citrus in it.

P1-M: Right sometimes you know, you miss something. Labels are this big and it's hard.

When Wren was nine we started making her ask for allergy menus and to talk to the chefs and stuff when we do go out because we want them to be empowered so that when, which is now happening with her like her friends want to go out to eat. And you feel totally comfortable with her maneuvering it herself. So we did that, we read them the books like the [inaudible] He has nut allergies and stuff and there's one EOE book that just came out it's pretty bad. But at least there's one. We donated copies of the books to the school library. We've, at different times, gone and talked to people.

I've actually gone into like six or seven people's home to help them organize their kitchens because someone taught me so I want to pass it on.

Today I wanted him to listen to me when I talked to the Hilton about not helping my food allergies, because I want him to hear that I'm not afraid to say I need this and I have the right for this and if you don't do it then you can do better. So we try to model for them. And sometimes you get mad. And we show it. We're not gonna pretend we're not. And they know all about the Americans with Disabilities Act and section 504. And when he's in really bad pain, he's allowed to say a bad word.

P1-D: He hardly ever does it.

P1-M: Yeah, he saves it. I mean what and we say to them over and over again 'yes, this stinks.' We totally acknowledge this stinks, but this is what you were given. So let's look at the people who help. Like, we really do a lot of redirection because it's easy. I think we [inaudible] for him and nothing. And then suddenly he can't eat everything he loves, right? It's a loss. And there's a mourning process for the kids, especially when they get these later, that they go through. He really struggled with it for a long time. And we let him have that mourning. And then we said, okay, now you have to live with us. So you don't have to be miserable. Like today, you told him about a woman who had he always had kids and she's really happy. And so we tried to give them examples of that too, like Debra Messing, if you don't know, the actress. She has like 35 food allergies. So when we see that, we show them. You're not alone. And I found another EOE P1-M who lives about an hour from here. So she and I talk and every now and then she'll show me a picture of her son and he's a little older. He's 12, just so they can see that there's a face besides their face. Oh, it's been a lot of tears. It hasn't been easy. It's been really, really hard for P1-C. The pain thing...it's been horrific I wouldn't wish it on anybody. With having the allergies that just had this kind of reaction which is different than the other. It's, um. It's It's horrible. Yeah,

I hate seeing him suffer and I hate the exclusion portion of this too. It makes me really mad because it is not necessary at all.

P1-D: The hardest distinction between P1-C's condition versus his sister's is lack of a quick definable scratch test. There are sometimes false positive, but very rarely false negatives. It's more of a trial and error.

But there you have, you know, some sort of roadmap in front of

And trying to explain that once you have...we try to reintroduce foods. Part of the elimination diet is the reintroduction of foods and it takes a certain amount of time to work into the system. So you may find the first couple and then all the sudden...build up in your system.

P1-M: And I will say there was a point where we were at each other's throats. We realized that we were just guessing all the time with every bite he took which was not good for either of us. So we had to reframe how we did stuff too because we were like, Oh my gosh, what if it was this? What if it was this? What if it was this? and you can't know 100%. It stinks!

But we stopped doing that because it wasn't good for him. It wasn't good for us. And now we're doing a more regimented approach to it, where we don't...because at first his gastroenterologist wanted us to do a few at a time, but then don't know which of it it is, So it takes a minute.

P1-D: And there are sometimes we wind up making like 3 different meals, like every night

P1-M: Okay, so I make it during the week and he usually does the weekend. So there's like one thing and then I [sent her at all around?] Okay, one thing. But yeah, we have four different meals a night. I mean, that's just the way it has to be. Yeah, and we have three different cabinets. We have to. There's just not enough. So we have three cabinets. So that's how we roll.

VF: You mentioned a mourning process? Can you tell me more about that?

P1-M: Sure, so if you lose a person or you lose a friend or anything big or the ability to walk or whatever. There's a mourning process where you go from just having life be what you expected to be doing something completely different. The same is true if you have a lot of food allergies too.

P1-D: There's a socialization aspect of food in our society. A large part of the interactions that we have, it has to do with the, you know, the breaking of bread. Breaking of bread is considered cross cultural to be a huge deal in sharing meals. To refuse that in some cultures is considered a great insult (P1-M: and here too some) I mean, if someone offers to cook you food when your kid is sick and you tell them all your allergies, there are some people who get really angry.

P1-M: So Mike had cancer, he's fine now. But there was a family who asked to cook. And I said, I just can't take what you've made. Thank you so much, went to want to make. I didn't know she had already made it. But Wren's anaphylactic to nuts which I already had on the thing, just please don't bring it. She screamed at me. It was horrible. And I was like, Look, this is not helping. I just cannot with you right now, but that's a great point.

P1-D: It comes down to a lot of times people want to help, how they won't be [inconvenienced?] how they perceive is the best way to help and that's very much a judgment on individuals who are going through pain. But that's also been beneficial to us, I think as a family and it's made us closer. Well, it's also taught empathy to our kids, because when someone's hurting now, they don't offer them stuff. They ask 'what do you need?' And to P1-C's credit, he's been very understand of other kids with other issues and has pointed out where things could be worse for him.

P1-M: And if someone's like, wow, you can't eat anything, he's like, 'Yeah, but I'm healthier than you.'

But there's a morning. And one thing I want to say about that is because you don't get to have cake the way you had it before. For me for my allergies, stopping wanting to have the exact same food and trying to replace that all the time and accepting that there are new tastes that I can like was a huge thing for me. And he's gotten to the point now...a year, the whole thing, he got diagnosed about seven months ago but it's been a year since it started. I think he forgets a little bit now but that's good because now he can appreciate the new foods for what they are. I didn't know how good some foods tasted. I mean, I don't eat dairy anymore either because it just made me feel gross. So not eating these foods...I don't feel sick every day. Same for him. Right? But I think for a lot of food allergy people, letting go of the wants and the trying to replace because it's like they're vegan food, right? Why are you trying to get vegan food that tastes like chicken meat? I just don't understand. No, you don't want to eat chicken meat. fine if that's what you want. I'm not trying to, you know, hate on anybody. I just think it's been a lot easier for P1-C to see 'Oh, this is different, but I kind of like it' and the same for me.

P1-D: We're also really lucky to live where we live. I mean, we have a lot of options living in Seattle. And even 10 years ago, there are a lot of options that have come out...partially as result trying to eat healthier...

P1-M: But yeah an important part. Hella expensive. So for a lot of families. I think they can't.

P1-D: So they do use the steroids or the [EOE?] support groups online. Facebook has a fair number of EOE support. But yeah, I think, I think we're extremely privileged to live where we do to have the funds to have the option to, you know, you buy a big thing of flour and it's like this big and that's \$4 bucks. You buy King Arthur flour

P1-M: it's a huge social justice issue. And I am absolutely positive that you're going to read more and more about this as years go on. If you're having a 1200% increase in EOE and 3 and 400% in some of the allergies for nuts and stuff, there's no way this can be ignored forever. But like Mike already said these kids especially are the canaries in the coal mine. Something is not right in our food. It's no longer what it used to be. And people are getting sick from it so much

P1-D: But he tells him to recognize that tells that a 1200% increase is still a very small percentage of the population. So it's easy to march. It's like when the thing came out from World Health Organization about bacon being a card type on carcinogen, know, like it raises the percentage of your risk for cancer by I forget exactly what the percentage was. But that's still only if you sit down and do the math raises your percentage of cancer for 5-6%. So yeah, we're still talking a small percentage of the population, but that makes them less [inaudible]

WJ: P1-C, do you want to answer some questions?

So you kind of talked about it already but how do you feel about having your allergies?

P1-C: I kind of like the food better. It kind of tastes better to me. I just don't know what to say pretty much but the only thing I miss really is cheese because I don't really get to have pizza cheese anymore and I liked pizza.

P1-M: You can tell her how you feel, like when some of your friends talk about food a lot.

P1-C: it makes me feel sad but I try to think they're way less healthier than I am.

P1-D: it's a coping mechanism. And he tried the Gaya cheese but it has pea protein and he had a major reaction

P1-M: There are some nut-based ones but while she's here until she goes to college.

WJ: How does your food allergy affect your mood?

P1-C: Sometimes I don't know. But sometimes I wish I didn't have allergies...like go out to eat. We used to go out to eat more but we go out to eat way less.

P1-M: What about when you had a big reaction when we were out the other day?

P1-C: I felt stressed out. I kind of wish I never had this. I wish it didn't exist.

WJ: What happened with the reaction?

P1-M: Well, we tried to go to Portland and stay at a hotel for the first time since all the diagnosis were in place so it's learning curve.

P1-C: I was so itchy...my eyes.

P1-M: yeah we think that we managed the food okay that some of the environmental allergies really got bad for him.

P1-D: It was a smell of [comments]. Yes. Comment the place reeked of [comet]. So we're not sure if that was a chemical sensitivity reaction. Or if it was simply an allergic reaction. Or it was simply the different pollen types in one geographic location...

WJ: How does your food allergy change what you do with your friends? Or does it?

P1-C: Usually sometimes I have to bring my own food. almost every birthday party. but one her P1-M had allergies so she bought potato chips.

P1-M: Yeah, so this mom emailed me and was just like I'm not leaving out your kids so you better figure out food because I'm not going to leave you alone till I find it cuz she has food allergies too. So I was like, you're not gonna believe this, but Lay's potato chips only has 3 ingredients so they're safe and so she brought little bags of Lays for everybody in the classroom. So he wouldn't be left out which was awesome of her. So yes, it's potatoes, vegetable oil and salt. So one of the other things we do is try to look for stuff with four ingredients or less. If we don't know what it is, he doesn't eat it.

WJ: P1-C, what does your typical week day look like, school day?

P1-M: one other thing..the way that food allergies change is there are some days that he can't go to stuff. He's missed a lot of karate and stuff with his friends because he just doesn't feel well while we're doing the elimination diet and that's definitely something that didn't happen before the food allergies. And the amount of school he's messed.

P1-C: First we have math. Then we have snack then I go to recess and run or play DND.

P1-M: What do you do if your stomach's bothering you?

I speed bump when I play running games and ..[something about video games?]

WJ: Can you describe what an allergic reaction maybe feels like?

P1-M: You can use the language we want to use to

P1-C: Fuck.

P1-M: See? he's so cute and little and yet...bam.

P1-D: Describe, does it burn?

P1-C: It burns, it stings, it's itchy, it hurts...a lot.

P1-D: Do you feel like you're losing control when it happens?

P1-C: Sometimes. Most of the time actually.

WJ: So when he has a reaction, what are your like immediate next steps?

P1-M: Well first we panic. I mean I'd like to say we're cooler but we're not. Then we assess his skin to see if there are hives or anything. So if he has hives, then we definitely give him Benadryl. Then if it's the burning and stomach pain we get him ice. He eats ice, it can numb it a little bit.

I just read from an EOE group that drinking aloe juice when there's a reaction can help a lot too. But then if you're EOE and you don't know your allergies, it's a risk. You can make it a lot worse.

If it's his skin and not just his stomach or if he's having both then he'll take a shower to rinse off and we make sure he showers every night. So, at least the outdoor allergens get off of him because sometimes when he has a food allergy, it's all of that too. But it can calm him down, just to be in the water too.

And then we're starting to do meditation techniques. Like, let's breathe deeply. Or if it's really bad, he asked me to play a video game in front of him, or if I can read him a book, so that it distracts them. So distraction is really critical too.

WJ: Do you guys use any, like apps like of any sorts to help with this? Or is it just mostly Google and Facebook groups?

P1-M: Let me tell you, so I don't know of any that would really help. So there's a huge opening there for that. If you find them, share with me. Yeah, there's not a lot. And there's definitely parents who are desperate for this stuff. And like I said, I can't just do that. Now I feel like we have a pretty good educated view on this. And I see other parents just not knowing where to start. I can't, I mean we've been doing the food allergy thing with kids for 13 years. So it's been part of our, you know, our journey lexicon for a really long time.

P1-D: Yeah. No, I mean, I think mature that make you just made me think maybe Dan Harris has something to do with a book called 10% happier. That's not meditation. But he might have an app you would not surprise. Yeah, there's not one for food specific for kids that I'm aware of for kids.

But maybe there should even just be one that explains what it is. I mean, I mentioned a book too which is good, right? Yeah, in EOE there's 1 book. And like I said, it's increasing and there's definitely a dearth of information. The problem is that there are people who just don't understand that the reaction is. I think one kid has asked him how he feels when it happens ever.

WJ: How many? How many of your friends know about?

P1-C: All of them.

P1-M: Okay. Well, let's talk about that. Because they should hear that. So P2-C sometimes when he has a big food reaction, he gets an eczema mask on his face and it's very pronounced. You want to tell them how that was?

P1-C: Horrible. I had to go and walk around in a washcloth one day? and one person asked 'what happened to your face?' and everyone looked at me and i was embarrassed.

P1-M: Yeah. And then he was on the playground and people kept coming up and they were well-intended but he felt very in the limelight. And it was super overwhelming to him. And it was the hardest day. He cried, it was tough.

WJ: There must be a fine line between like, obviously meeting care and then wanting to be left alone and, like, yeah

P1-M: We've suggested he just be open.

WJ: Can we do one more exercise with you?

So we have this mat and we have these cards that have just like different people on them and starting from that you, we would like you to like lay out where, how, like close you are with them in terms of relationships. Does that make sense?

Yeah. And they ended up having a baby who has not allergies to Wow. So they have switched to it. And it's funny because every holiday that email from us inside saying, so where do you go for the recipe? I'm like, okay, go here. They're great.

WJ: So can you tell me about your closest friends in the circle?

P1-C: So four..one of them's Ben and he has ADHD so sometimes he can forget stuff and it was kind of hard for him when he had this up. I heard it when a new he did something but he's couldn't remember...some story about Ben..not relevant. He's super kind to me and

I have two super close friends.

One of my first friends was my friend Theo. I met Kai in preschool. They are my best friends. Sometimes my friend Theo brags.

P1-M: They're wonderful support.

P1-C: He's super kind to me. His P2-M and sister went off dairy and his P2-M mentioned [a milk?] that Wren can't have and me but we haven't tried..

P1-M: They always keep an eye out for him. Always. And we carpool to karate.

P1-C: And Kai has a wheat allergy.

P1-M: It is a real blessing to know both of those families. Because they have tremendously inclusive and if he's not well they offer to come over anyway and they just 100% accept him for who he is.

P1-C: When I was first in the hospital, every one one all my friends wanted to come over so bad. And they missed me a lot.

What about your aunt and uncle? Can you tell me more about them?

P1-C: I'd say why Aunt Becky is right there because she had wheats when she was allergic to it. She tried to have it but mom did not let her because it is our house and our house, our decisions.

P1-M: My sister was diagnosed with Celiacs when she was 13 and my mother who has mental health issues decided they were just gonna ignore it and they made her eat wheat even though it made her sick constantly and she has massive health problems because of it. I don't want them to have the message that it's okay and we want her to know we love her enough that we want to help too.

P1-C: So my coach isn't really my coach. It's actually my karate teacher.

P1-M: but we love them.

P1-C: They're super kind. My favorite, the ones that are most kind to me are Miss Allison and Mr. Matt. We get like kind cards if they think we're doing well and most of mine were from Mr. Matt and my sister's were from Miss Allison.

P1-M: We've been there 10 years wow so Allison was 16 when we started she's 26 and now. They're very kind whenever he has reaction they email or call us.

You have you are you really close with your sister it looks like she's yes yeah. Can you tell me more about your relationship with her?

She doesn't like when I hug her. And when I was young, she was really cuddly and I didn't like it, and now its flipped, right?

P1-M: Tell them about stuff you do together like Comic-con.

P1-C: We like Comic-con, and one of the things that Wren and I both like is rocks. Definitely not pokemon. We both say potato as a catchphrase.

P1-M: They play a lot of games together too when he had the worst time she would play games with him and read to him and stuff too. They're actually really close. They're five years apart but they're really well four and three quarters.

Do you see the nurse a lot?

Yes, I used to. but not that much anymore.

P1-M: What about Judy at school the nurse?

P1-D: There's one nurse at Kaiser who...he can move in. I love this guy is so awesome. Well, I don't care. I love him. He's magnificent with children. Absolutely. He makes it fun when it you know you just don't think it's gonna be so he was a gift Judy's had a harder time understanding EOE

And is she the school nurse?

yeah

P1-D: Also P1-C, you were seeing her a lot of times when you were feeling sick.

P1-M: She does care about the kids an awful lot

P1-C: But she used to she give EpiPens when they work

P1-M: She doesn't do that anymore

But does she not understand the difference in his allergy?

P1-M: She's starting to and she's trying to because he's the first EOE kid and there are a lot of allergy kids. There's a learning curve you know with anything and this is nowhere...I think with allergies you know you're allergic to x, y, and z and here we go this is well we're trying to figure it out and then she was like 'well, why don't you know?'

Because this former food allergies just isn't in a nice box, it just isn't and so we're figuring out now as we go, so as hard as it is for you to understand, it's way worse for him and us.

P1-C: Like this is not what they say just makes me question, question, question, question, question, question, question about 5 times about 50 times

And does this circle change at all in terms of, like, who you trust when you have a reaction or when you're dealing with things? Or is this, is this how you feel all the time?

P1-C: How I feel the time.

P1-M: Can I ask a question? (to P2-C) Why didn't you include the doctors in there at all?

P1-C: As in the nurses are the doctors...

P1-M: Huh..interesting.

P1-C: Some of them are...the person that you said you wanted to move in with him.

P1-M: Yeah, he can move in with us. All right. That's interesting. I guess the nurses do spend more time with you, actually. That's very fascinating to me.

The doctor at Children's is very compassionate, for sure. And our allergist is...we've been working with him since Wren was one or two. Yeah, I like him because he's very direct but not everybody loves that...he's like you're being stupid, so don't do that, which I love, but that's not everyone's cup of tea. We've been with him for 13 years. I love him. Yeah, he's gonna retire soon. I don't know what we're gonna do. When you find a doctor that works, it's amazing. The first doctor we had at Children's did not follow up with stuff and pediatrician who is also like an angel son from heaven, her name is Edelweiss. That's her first name, her last name is Clap. She's amazing. She called Childrens. She got to switch to someone who she knew was a little more specialized in EOE and he's much better fit for us. Yeah, I think a lot of people don't know to like where they're on this journey that if a doctor doesn't work for you, it's OK To ask for another one. With food allergies and allergist, there aren't necessarily though a lot of choices, especially I think if you're in more rural areas, but we do have choices here so it's nice.

WJ: And then you look and you mentioned that your you have your kitchen organized a certain way. Would we be able to see that?

P1-D: And my daughter's only safe...only peanut butter that she feel safe with just believe it or not.

[START AUDIO AT 1:11 FOR CABINET TOUR]

WJ: You said that you went in and organized somebody else's kitchen. Did you do it in this type of fashion?

P1-M: I've done it a lot. Yeah I mean like the most recent one I did is, we have someone in Buy Nothing who said on Buy Nothing 'does anyone know how to navigate nut allergies? we just found out our kid has it. can someone come over and help me?' he was two at the time and all the nut stuff was beside the nut-free stuff and was like 'OK, if you're gonna have nuts, if that's the choice that you make, then you should put it up where you know your son can never reach it. And so I talked to her about what cross contamination was and she didn't know and so we put this up higher that he couldn't climb on the shelf and get, and his was in a separate area

P1-D: Make sure you get your coffee so it's not pre-ground because a lot of the grinding facilities also roast nuts there.

P1-M: Like that tea bags have soy in them. I mean it's never ending man. We've talked about like doing or writing maybe like an EOE guide or something. There's so much and we're super active in the Facebook groups because I just want to save people any amount of time that we can because this is a lot. My friend in DC just introduced me to a friend who had her twins who were three just got diagnosed with EOE, both of them so today she's like 'WHAT DO YOU MEAN SOY ISN'T [inaudible] and I'm like 'okay here's where you need to go to shop. This is what you can look for' and you know.

VF: So would you say you spend...you said it's a lot of time, what would you say the biggest most time goes to for you?

P1-D: A lot of times finding stuff in the grocery store.

P1-M: I mean because who would have known that tea bags have soy in them? And that I learned from my hairdresser who has a food allergy. She's the one who told me about gum too. That month I told you we went back and we could not figure out what was going on, it never occurred to me to look at the gum. my friend. I FORGOT THE GUM! So being detectives. And constant vigilance.

P1-D: and really accepting that you're...as hard as it is, you have to accept it every now and then you're going to screw up. Yeah, or that a company is going to change their packaging...like, we thought Rice Krispies from Trader Joes were safer and they were for a long time and they added soy.

P1-M: So you have always read every single time. And I will say this because this was a good moment for me. Wren came in the kitchen the other day and said 'thank you for being the kind of parents who do this with us and who don't have nuts around me all the time.' It's worth it.

P1-D: You will have those moments where you're standing in the grocery store and you're trying to find something and you're like going through each label and you're going 'me just want to break down.'

P1-M: I have cried in the grocery store but I've helped people at the grocery store too. I remember one person who was like 'what are these coconut aminos? thank you!'

I guess my final question is like, what would you hope is like the biggest change for the future in terms of...

P1-M: some sort of treatment that is not potentially long-term damaging for their bodies. Something other than steroids that mask it. Anything. Apparently the genome they found specifically for EOE is one that's very responsive to treatments for other diseases. So the National Institutes of Health just [inaudible] that 5 million to the clinic and...Cincinnati yeah to to try and find treatments.

P1-D: It was Cincinnati or Cleveland.

P1-M: It was Cincinnati.

VF: Could I ask one last question, you talk about spending a lot of time at the grocery store. Do you ever find yourself talking to any grocery store employees and asking if there's product and are they helpful with that?

P1-M: Oh, yeah. So Safeway has a way you can request food be carried in their stores and you've done it at Trader Joes too. So the Safeway over on the corner now carries gluten-free chicken that we can eat still and Wren can eat still because we were [crossed to it?] And the funny thing is, is the checkout person's kid was just diagnosed with EOE and so I've helped them. Because you never know...

P1-C: You've help a lot of people who just get diagnosed with EOE

P1-M: Yeah I try and so to say...you've talked to the Trader Joe's people a lot because it's near his work too...and Frey Meyer.

P1-D: You just have to accept that you can't do it all. I guess my biggest wish would be that they could just, they could zero in on potential epigenetic causes. So that other kids won't wind up with this.

P1-M: And if we're getting real big about it, maybe our government can focus on the food issues and the chemical issues that other countries are focusing on.

P1-D: I mean, that's to me, that's also a huge social justice issue. Which we shouldn't be subsidizing massive amounts of industrialized produced food when there are people who are so poor that they can't afford fresh fruits and vegetables. Where you spend your time and where you spend your money is what you value and right now, what we have is a system that does not value people's health, it values people's profit.

H1 Warm-Up Exercise

[insert photo here]

Design Exercise: Imagine a genie granted you one wish to magically help you manage your food allergies (except getting rid of them). Draw, or explain in the box below what your wish would be.

I would like to
have ~~it~~ easier to make
Food the Food that my
mom and dad make.

H1 Participatory Design

[insert photo here]



H2 Interview Notes

Library

K: How do you feel about his food allergy, ok you're rolling your eyes, haha

M: It's hard especially since he has soy allergy that's how we grow up, with everything soy sauce all this oriental food, I totally had to change my cooking style and start researching and read labels carefully

K: when did you find out he had this food allergy

M: when he was four.

K: when he was four, ok

M: ummmm, it's just a lot of this makes life a little difficult, he knew, but he has a hard time controlling himself. You can help him at home, change the cooking style and try to help him boost his immune style so he can fight it himself, but when he's at school or something, it's out of control, which he knows, the peer pressures, what other kids are doing, he's not a life threatening type, school is separate, this small type of allergy you have to control yourself otherwise it will show on your skin, the rash and with eczema. So that is something I can do.. Change my cooking style and help him manage his allergy, otherwise it's just on him.

K: umm, how have you sort of educated him-- to -- you know when he's not at home -- how have you educated him?

M: well it's what they tell you to just get him used to it, right? So internalize it, not eating too much, having healthy foods, he knew he's not supposed to eat, when we go to the doctor he tells him, he tells everybody, but sometimes I see a lot of wrapper, here, there, you know he was sneaking, eating, something he was not supposed to, you know, he knew.

K:oh, interesting ok, so are his reactions--

M: So are his reactions he is notorious rashes, but now it's more contained when he's older, you know he used to have all rashes, all the time, and we didn't know until four years old. We tried to ask the family history to figure out who had something not being identified. someone told me that they had apple whatever..... and we were suspicious and that's why what we went to the doctor for.

But after that he told everyone that it was real and he can't have soy. So when he went out from the family, we told our other to be careful, to not give the kids, you know.. But now that he's older, it's hard. He's still eating something.. Between peers, sneaking, uuuhhh

K: So it sounds like he isn't too scared of the foods he's allergic to, because he will still eat them
M: he's not, sometimes he will say "I tried this and I was fine." The problem is he doesn't see rashes now, but you see his skin conditions getting worse sometimes for me it's between, either it's from eczema itself and it can crack or just directly from the "i don't see rashes," but it's definitely soy-- you see he itches. Mystery between what caused those itches. But he's not like peanuts where you need an EpiPen where he's choking or could die, so he would just like, sneaking things, but at home I just try not to, you know. But he's old enough to know what to do or with a skin condition, he put lotions

C: (to his participatory design) I just drew stuff that could be substitutes

K: do you want to go through it" So, is this you

C: yeah that's me

K: and what's this

C: umm that's just like a table and I'm imagining things that I could eat as a substitute, you know, sooo

K: Ok, so you wrote.. This is chocolate?

C: yeah

K: You can't eat chocolate

C: like some I can, but

K: so what foods are you allergic to?

C: Soy, Wheat, Kiwi, Cherry, Beet? Apple, raspberry and Pear

K: Did you recently find out you were allergic to kiwi?

M: yeah last year, we found out through blood testing, but you know they don't all show you different things, some that have a mild, is not really strong and others are more severe

K: oh like, mild moderate severe

M: and some I never saw, but now when I eat apple, it itches. I used to be able to eat those, but,

K: It's like a food, there's a certain word for it

M: yeah, you just don't feel comfortable. But I don't have that sensation before. But like a cherry, I cannot have it. I cannot have peach either. And there's some food that when I eat, now I have the same reaction too.

K: Interesting

M: So that's what I said about the different study and I'm not used to having that, we did not have a pollen allergy at all. And we tried to go out for some time in this environment, but eventually, because of that.

K: Ok, so, why don't you talk me through this, so you, I see a table, is this, this is chocolate,

C: which doesn't have so so I can eat it. There's tofu made of coconut and something else, and then there's soy sauce, which I mean just doesn't have soy, but I mean you can call it "something sauce"

K: what kind of substitute do you eat then if you --

M: I just eat salt, buy all different types of sea salt, with the different minerals in the salt

K: ok, and then what does this say?

C: tofu made out of coconut and something else

K: ok, and then, what are you thinking here

C: umm, what foods can be used as substitutes

K: ok, cool, so you're thinking of, you want foods that taste the same, but they just don't have those ingredient in them, cool thanks for doing that

K: umm, so, lets see, I guess I can ask him some questions.. And then come back to you (to mom) so Calvin, how old are you?

C: I'm 11.

K: How do you liek school?

C: umm I don't really like it, it's boring

K: do any of your friends at school know about your food allergies?

C:yes, everyone knows

K: how did they know?

C: umm well when I go to their house, I'll tell them I can't have something and then I'll just pass on it

K: Ok, how do you feel about sharing that information with other people.

C: I really don't care

K: Ok! Good! Have you ever had any reactions at school?

C: umm, well most of my reactions are not very severe, I don't think any of them are but sometimes I'll itch a lot during school.

K: Do you do anything when these reactions come up?

C: umm I Itch,

K: do you have any creams

C: No, I don't think so, not at school

M: we use a cream the doctor prescribes, we have a prescribed one just for the eczema not for the full allergies itches.

K": ok, so it sounds like you sort of let the reaction slowly go away. Can you remember a time you had a more severe reaction or is it usually just --

C: usually just pretty mild.

K: how often do you get them

C: umm at least like 1-3 times a week

K: oh wow, even if you avoid the foods that week

M: yeah because of the eczema, it's all combined

C: yeah

M: so now that he's older we don't see rashes like when he was a baby, but he still itches.

K: I see, umm have you ever talked to his doctor about it, I know that some people grow out of their food allergies

M: yeah, I haven't gone back to check since the last time, for the blood testing they can only test the five of them

K: do you remember what the five of them were?

M: I remember we tested some fruits, that's why we know all about the fruit. Sometimes He itches and I wondered if it was because he didn't like it and was using it as an excuse. It's weird we actually tried bean sprout and organic bean sprout and they all had itches. IT's kind of weird, I try organic if I'm sensing. It's not very clear. Last time we tested wheat, fruits with a pit and peas. So we have kiwi and apple that's what we found out last year. IT's tricky, And after we got the results we stopped eating wheat for three months. That's his favorite so, his skin is actually getting better but I'm not sure if it's because of weather, because that could be a factor. We were in Taiwan this summer and his skin was sooo nice, soft and moist. And when he came back we go to the doctor and the doctor had nothing to tell us, nice normal after a few months later, its too dry, it doesn't matter how much cream you put on. So that's almost three years ago.

K: did he grow up here?

M: yeah... we've never seen his skin like a baby before.. So it's hard to tell if this one is from the eczema itself or from the food allergies because I don't see rashes, he just itches. He might feel something bad like

K: so do you ever eat out as a family, does he ever go out to eat?

M: yeah, we can only eat Thai food, sometimes we can still go try to get other noodles, not much, but most of our meal is all based on the rice. Rice cracker.. No soy, haha,

C: pasta

M: pasta sometimes has, I've tried to reduce the wheat because it's been bad, but he can still have a little bit of the wheat.. You know that's his favorite, bread.. I tried to just replace with rice flour, but he just

C: doesn't taste the same --

M: doesn't even eat it

K: so it sounds like you care alot about the taste, huh?

C: yes, or texture

M: you're spoiled -- kisses him

K: what are some of your favorite foods to eat

C: I really like bread, and more bread .. and some bread and bread.. And pickles\

M: We have tried all these rice products, the problem is they now all have this wheat in them, just after we found out there was wheat in processed food.

K: So what about your grocery shopping experience, what is that?

M: you know it's good, because there we don't, that's why we have to cook more at home instead, we tried to get him to try to cook at home-- try something simple because his eating style is much different than his older brother, his brother grew up more asian cultured food , but if I had simple then he can eat korean seaweed, rice, protein which I see as vegetable and carb. Something simple like american kids -- but you know like fruits, vegetables, pickle. Some of these things I can buy, I can't tell you what he can eat, depends on brand, so I read label, like hot dog buns. Some of them he can have others he cannot because they use soy oil in there. Or other bread have soy oil or some chocolate, like Theo chocolate he can't eat it, because some some of the products substitute sunflower and it's the same thing as soy. So I read everything. He knows how to read. It's good we teach him how to read the nutrition label on the package. I teach him when he's little, when he learned how to read, I taught him why he can't have it

K: So you make separate meals for him?

M: I tired but now it's so hard, we all eat with him, everything does not have soy, when his brother comes home sometimes we eat out because it's easier for everybody to get what they want. Because he used to eat more oriental, but it just doesn't taste the same, you know. And you know it's food less processed as possible

K: So C, how do you feel about your food allergies

C: yeah I really think about it because it's just something I have and it's just something like the daily norm, it doesn't really disturb me

K: so you don't really think about it too much?

M: he have other sever things to think about

K: what are the other more severe things to think about?

C: what are the other severe things to think about umm, what do you think I'm thinking about -- what --

M: we just found out he had has ADHD, everything haha, so energy now is coming a mess

K: um ok so do you ever eat food at school from the cafeteria or do you ever eat food from a friends house?

C: oh yes, of course

M: yes, one or two time you had to buy lunch from school

C: yes because you were sick

M: yes, what did you choose?

C: there was only one choice

M: pizza?

C: No! Pizza is terrible, there was this BBQ chicken hamburger thing, it was nasty so I threw it out

K: so how do you know that food doesn't have soy in it

C: Well I don't know, that's the thing, that's why I don't get it.

K: But you said you did get it

C: But I don't usually get it. I got it like once or twice

M: I always pack lunch. One thing from the school -- if you plan on having your kids eat long-term their lunch, you fill out a form, but he has allergies, so I don't know what they would prepare, I think separate from kids that don't have the allergy, I don't know how they do that, so I just prepare the food at home

K: So you didn't fill out the form

M: no I didn't, since he only ate it one or two times instead of packing lunches father just gave him money. Sometimes he's mad, I will just buy lunch and then we owe money and we had to pay because kids have an account. But the other reason is that he eats really slow, so he never finishes his school lunch. What I used to do, kids just throw away all their lunches so when he gets home after school , he's so hungry, because everything got thrown away, so he doesn't have anything. So, that's why I said no, everything if you're hungry, anytime even after school you have something to eat.

When he goes to kids house the adults will say, oh this doesn't have soy in it , he can eat it. But now recently, we have a neighbor who likes to be with the kids and then we just make sure it doesn't have any soy in it,

K: so if he goes to a friends house do you let him control the situation? Do you trust him or do you let the parents know.

M: I let the parents know, but because there is so many things going on, I want to make sure the other parent is ok and they can call or anything um anytime my friends help me drive him, I pack everything with him, just everything, make sure I don't anyone an extra burden for them to look for something he can eat and sometimes kids aren't hungry. They are only hungry when we pick

them up so Idk, i do it but I educate him he knows everything, the problem is he has attention deficit, and he's on his own, that's his own life.

K: You talked about teaching him when he was younger to read labels and other ways you educated him, can you talk about that further?

M: like you can check check out a book that tells them what happens, you can have them watch a movie. They will. And he knows what happens. He itches. He experiences. Some people have to fall 100 times to learn.

PD Exercise -- not all transcribed

I'm not close to my doctor at all

My relationship with the nurse is fine

-- if something happened someone from school will call me

For allergies the school has never called - -the school will separate peanut allergies from his.

And I know some schools are nut free

Actually at his school he's allowed to share food,

C: actually it's a sharing table technically

M: yeah, but some schools aren't allowed to share any food. So they don't have the sharing table and maybe they don't want school to go to waste - so you just put it on the table and other kids can take it, I know other schools will have kids sit at separate tables who has al the tree or whatever allergy table and some classrooms the teacher at the school the teacher don't want to eat snack in classroom they can eat in the hallroom in a proper area it's just every school is different.

K: alright, let's see, how often do you see your doctor

C: once a year, but we see a pediatrician

K so you see a pediatrician

M: not an allergist

M: last year we did, we went to a childrens specialist for the skin problem so his allergy is just controlled form food is just not eating it-- it's not too serious so we only go when we need input--idk in the future what will affect him and if he will have new allergies. Recently idk but we got claritin because we had the pollen symptoms and then we would try to see and when he had it once or twice he said he was feeling better, not sneezing, not coughing, no watery eyes. So if something you can take care of once or twice instead of seeing a doctor we do. If it is something severe we could call the nurse before the doctor, we would call nurse

K: I see

M: otherwise ER

K has he been to the ER

M: once for something else

K : Alrighty, so you are close with you mom, dad and brother?

C: for food allergies otherwise my other brother would be closer- -I would tell him but he's in California right now

K so you have your friends here, friends parents so lets see you teacher is closer to you than the nurse

C: I see the teacher everyday-- I would tell the teacher before the nurse

K: do your teachers know about your food allergies

C: yes

K: do they all know

C: yes I only have one, well two, two teachers

K: grandma, and doctor and two nurses

C: yeah

K: and uncle do they live around here

C: nope-- if they are on the outside part that means they live somewhere else

K: and you trust your friends with your food allergy

C: yes

K and your friends parents all know too?

C: yes, most of them, they probably all know

M: well he actually tells them that "I have this I cannot eat this"

K: when you meet new people do you tell them about your food allergy

C: when I meet someone new like a stranger on the street?

K: not a stranger on the street, but maybe a new friend at school

C: if they would become my friend I would tell them. But not first thing. But like after a while

K: what do your friends think about your food allergy

C: I don't think they really care-- it's just something I have to them

K: did you say your other friends have food allergies?

C: umm no, but some of them will be like lactose intolerant or whatever

K: Ok umm let's see do we have any other Q's do you have any other specific stories from Calivins past of something that stood out in your mind or change how you thought about changing your habits around his food allergies?

M: mmm. I think I told you about his rashes all over over his body, here, here, all over his body and neck and now he doesn't get those, and again now it's all concentrated on his joints. So I don't see hsi rashes now like I used to he sneak out and eat chocolate abr but because he is

older he's stronger so maybe he doesn't show the symptom that's why he itches but doesn't see the rashes so we don't know if it's from eczema or from food. But that's why he's sneaking out. He came home the other day and was like " mom I don't think I have an allergy to kiwi, and I was liek what happened and he was like I tried it today"

K: you sound pretty brave C

C: It's just kiwi is fine

K: thinking about your food allergies -- 1-10

C: 3 or 4

M: like itching?

C: yeah like it's just irritating but it doesn't hurt, no

K: so it seems to not bother enough that it still makes you want to sneak the food and not eat it..

Do you feel like you listen to your mom when it comes to advice about eating with your food allergies

C: no.. possibly, sometimes, I'll just say sometimes.. Idk

K: u said right now the concentration of the allergies is on the joints -- I noticed some rashes on the joints -- is that from the eczema

M: it's because all his friends eat candy, chocolate bars, wrappers, are always in his pocket so idk where they are from. The other day I think he did, he asked for some meat with soy sauce, but at night he was so itchy he had to go get an ice pack.

K: so it sounds like it itches alot but its still worth it

C: yeah it's worth it

M: I was working and I didn't know he eat it. Until that night he was like "ahhh I'm so itchy"

C: I asked you

M: actually no, I'm checking 24 hours and he's always like mom, my hands look at this. He actually sometimes puts medicine on himself.

K: has he ever tried to hide his reactions from you?

M: umm not hiding but like I told you, he know that this happened before he has a skin problem caused by the food, he know that the food causes the itch, he knows even before. But still daring.

D: any other methods you use

M: ice pack is the thing we most use, we use them all the time and the blanket is all bloody because you know, because he itches and he's bleeding, but know it's less and only certain-- that's a skin problem -- when material is made from different fabric and cuts him -- he cannot wear it because it is so uncomfortable

K: is there anything else you want to tell us about your food allergies

C: mmm, not about my food allergies no, do you want to share something (to mom?)

M: no like I said it's a very important time to consider A lot of mystery that I don't really know about. I didn't test until last year...There's so many things that we don't really know about and get tested as they come up but its really hard to know. But he has so many problems every time its hard to figure out the suspect. He kept complaining and I just thought he didn't want to eat the vegetables and that's why I got him tested. LAst year, I requested I asked if we could do the blood test and that's when we found out about the other 5. The other doctor doesn't think the blood test is accurate, it's better to do the skin test, that's when he gets the reaction. The other one shows the small amount

K: is there a reason he only got tested for the small amount

M: because it's rashes, everywhere , the whole body since he was born

K: C, how do you feel about your mom explaining the rashes and the bleeding

C: mmm I mostly don't remember

M: look at the pictures

C: It sounds like what she's been saying over the years

M: yeah but he Hadn't had seafood for 4 years. Because his family, some relative has problem, so we were suspect, seafood not good, pineapple not good, so what am I going to cook?? lets just do the test to find out but again the test center there are so many things I don't know where to start. I only tell them the things that I heard from family history and his auntie cannot eat tomato and pineapple, but again if something irritates her she never finds out what kind.

K: oh so she just continues to

M: yeah so that's why I keep asking to see

K: so there is some sort of genetic link?

M: maybe yeah, when we found out, we were like he has that, but I don't know, there will be, but if nothing happened to them or in the family they won't get tested.

D: so it sounds like with testing you go in and tell them what you want to be tested for.

C: I really don't like the blood test

D: why don't you like the blood test?

C: because they stick a needle in you, I don't like needles, but the skin test they do it on your back and it doesn't hurt. I think it just tickles to me.

____ some stuff

M: you will wait a little bit and it will get swollen and they will measure how big that area got and what kind of foods he reacts to.

K: so do you think you will test him in the next couple years to see?

M: yeah I think we need to try to figure out whether the problem is I don't know which one to test for because each one is only 20. So you are supposed to do 20 every year. Umm so that's why I

waited until last year, because if it's not like a peanut where you might die and cannot swallow or cannot breathe umm

K: has it ever affected like his throat

M: no mostly it's just his skin.

K You get a reaction. What do you do, what's the process?

C: I grab an ice pack and tell my mom

K: ok so you know to start with an ice pack, you do it yourself?

C: yeah if it's really bothering me, otherwise if it is just some chocolate and not really bothering me, I will just ignore it.

K: what would make it really bother you?

C: umm if I start getting really really sweaty and then it starts itching and I can't take my mind off of it then I get an Icepack and if I still can't get my mind off of it I tell my mom

K: how often does it happen where you can't get your mind off of it?

C: like two time, actually just like one time a month, it doesn't happen very often.

M: are you eating something that I did not know. Actually this time last year, the doctor prescribed some stronger steroid cream, I tried not to eat those , that's why I didn't go to the specialist or the skin specialist and I used the itch cream, cortisone to prevent it. Well just when you are itching, I don't know what causes it, the food, what you eat, so I just make sure you don't scratch otherwise your blanket will have blood all over it

K: do you sometimes scratch without realizing it?

C: mostly in my sleep otherwise I realize I'm scratching, if I'm awake

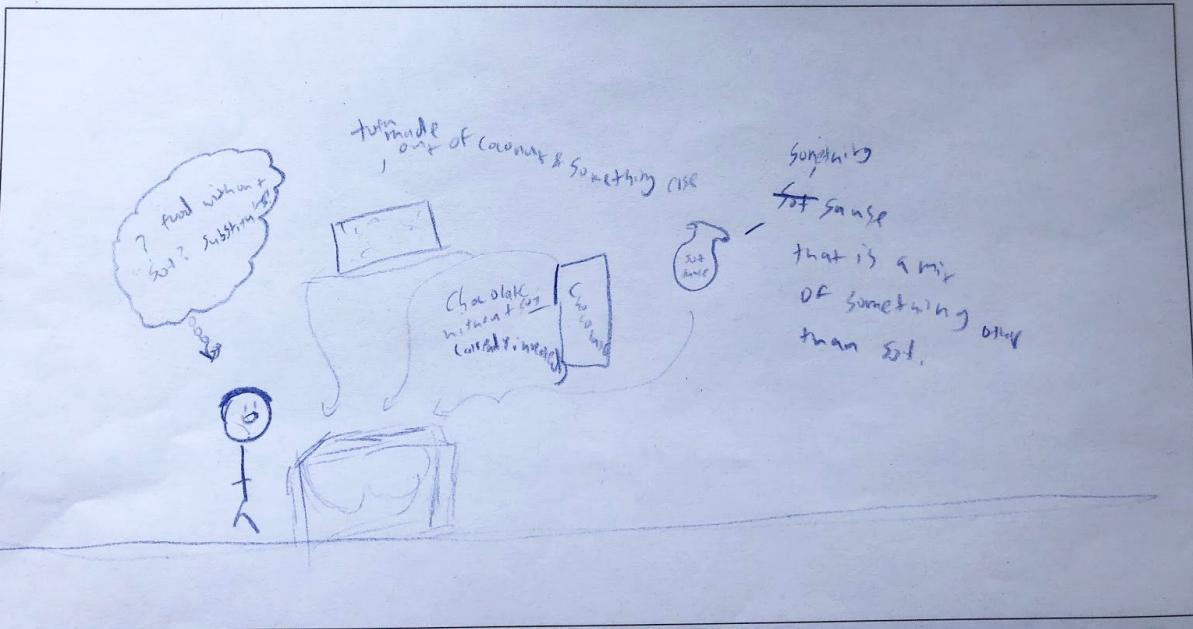
K: so let's say you're sleeping and you don't realize you are scratching and you wake up and you see some blood spots

C: I don't notice the blood spots, my mom is the one that notices, I don't .. and I'm like oh wow ok ... but it's because it doesn't really happen anymore.. They are just like there.

K+D: ok that was really good information, thank you for sharing and thank you for joining us and being so open with us

H2 Warm-Up Exercise

Design Exercise: Imagine a genie granted you one wish to magically help you manage your food allergies (except getting rid of them). Draw, or explain in the box below what your wish would be.



H2 Participatory Design

[insert photo here]



H3 Interview Notes

Starbucks

[VF giving instructions on participatory design exercise, building rapport with mom]

Can you tell me more about what you can't eat right now?

H3-C: I can't have peanuts, tree nuts, sesame, or chickpeas.

And what do you what do you like to eat?

H3-C: I like to eat many foods that I can't have but there's not a specific favorite.

P2-M: What's some of the things you don't really have?

What are some foods that you can't have that you really love?

H3-C: Brownies.

Brownies? Brownies are delicious. I love brownies. I love casing my brownies down with milk. So how old are you?

H3-C: I'm 10

What grade are you in?

H3-C: 4th. I'm about to go to 5th.

Wow. 5th grade is my favorite year. There's a lot of field trips in 5th grade. Did you go on many field trips yet?

H3-C: I'm about to next week.

Really? Where you going?

H3-C: It's for Native Americans, but I don't know, it's like a museum.

It's a museum? I like museums. How far is the museum, do you know?

H3-C: 30 minutes maybe.

What's your favorite class?

H3-C: My favorite class is math.

Math? What do you like about math?

H3-C: What I like about math is multiplication.

Multiplication? What's 2 times 2?

H3-C: 4.

Nice. OK, so how do you feel about your food allergies?

H3-C: I feel kind of unique and different because I can't have most foods.

Can you tell me more about different, how do you feel different?

H3-C: Some people can do stuff that I can't like going to certain restaurant, like I have limits to like what I can eat and it's hard to like get new food that you don't know.

So when you go to a restaurant, what do you do?

H3-C: We..i don't know.

H3-M: He only has about 4 or 5 safe restaurants and we've already pre-checked them before we go, pretty well, and we're already familiar when we go, and then we remind the servers over there. We never go anywhere new is really what I think you're saying.

Is there anywhere new that you'd like to go to?

H3-C: Um not really. I like the ones that I have right now.

Which ones do you go to right now?

H3-C: Red Robin and Chipotle and McDonalds..and some others.

Which one's your favorite?

H3-C: Red Robin.

Why is Red Robin your favorite?

H3-C: Because I like their steak fries and magic cheese.

So Red Robin, they have a big menu, right? There's a lot of options there. And then he said, McDonald's and Chipotle and there's a couple others. That's a pretty good option. There's some good choices.

Do you go to school? Do you eat at the school or take food from home?

H3-C: I take food from home to be safe.

What do you usually take from home?

H3-C: I take a GoGurt, some cheese puffs, dessert, [mom says sandwich] and drink and that's like all.

Where do you sit when you go eat at school?

H3-C: We have a special nut-free table that I have and I sit at.

How many people are at that table?

H3-C: Usually there's about 10 people because 10 people is the max and people like to sit there.

Do you usually know the people that you sit with?

H3-C: Yeah I know my my entire class.

How many are in your entire class?

H3-C: 26, including the teacher.

What's your teacher's name?

H3-C: Ms. Gray.

How's Ms. Gray?

H3-C: Ms. Gray just recovered from a surgery so she's kind of feeling [inaudible] probably

Did you have a substitute teacher for a while?

H3-C: Yeah, 2 months.

Did the substitute teacher know about your food allergy?

H3-C: Yeah, all substitute teachers know.

And Ms. Gray also? Does she know about your food allergy?

H3-C: Yeah.

Did you say the school's not nut-free?

H3-C: Some of it.

Some of the school is and some of it's not? What parts are and what parts aren't? It's okay. You can answer it.

H3-C: I don't know. The only part I know that is not okay for me is the hot lunch.

So you said you know all your classmates. Do all your classmates know you as well? Do they know about your food allergy?

H3-C: Yes.

Can you tell me more about that?

H3-C: So like at the beginning of the year, our teacher explained the food allergies and all the allergies, he wrote them on the board for the entire year. And everyone knows about it. And he explained we have a nut free table so everyone knows.

How does that make you feel?

H3-C: It makes me feel better.

How so?

H3-C: Because more people know about my allergies. They care like tell their parent not to give them nuts so they can sit next to me if they want.

That makes you feel better?

H3-C: Yeah.

Can you tell me what a typical day looks like for you?

H3-C: I don't know.

That's OK. Have you ever had a reaction before?

H3-C: Once, right?

P2-M: His big reaction, he was 15 months old.

Was that the only reaction you've had?

H3-C: I think so.

H3-M: The only major one.

Have you ever had minor ones or thought that you may have had something, or was there any moments like 'Mom', you know, were there any moments where you were not so sure?

H3-M: Remember, like at the butterfly thing at the zoo. Like times like that is what he's talking about.

H3-C: Twice at school, one at the zoo because of the butterflies. And that's...

Can you tell me more about those times, what happened? And

H3-C: Well, one of the school ones was I was at battle of the books. We were making our team and we were sitting at a table and everyone like around me had nuts except for my team so I didn't feel that good so I had to go home early from school.

So kids around you had nuts and you didn't feel good?

H3-C: Yeah and like...it just made me feel uncomfortable so I had to go out of school early at like two o'clock or something like that.

Did those kids around you know about your allergy?

H3-C: Yeah.

And they had nuts around you?

H3-C: No, they were from different classes, but the people from my class knew about it. So they weren't sitting near me.

So you said you didn't feel well. How did you feel and what did you do about that?

H3-C: When we got back in the class, well before we got back into class I wiped down my hands and where I was sitting so I would feel a little more comfortable. And when I got back to class I asked my teacher if I could call my parents and then I went out of school early.

So you said you wiped your hands. How did you know to wipe your hands?

H3-C: I just have wipes in my lunchbox just for like wiping stuff down and hands and so..

How did you know to wipe your hands? In that moment, 'You're like Okay, I need to wipe my hands.'

H3-C: Just to make sure because like people could have touched the table with nuts. So I just wanted to make sure that I was okay.

Did anyone teach you that?

H3-C: Yes, my mom.

What else did your mom teach you?

H3-C: How to, like, check labels on stuff.

How do you check labels?

H3-C: You look on the box for labels and see what the ingredients are.

Is there anything else? Have you ever gone out to eat before? And then..that's ok.

Do you know what an EpiPen is?

H3-C: Yes.

What's an EpiPen?

H3-C: An epipen is something that insert medicine into you without having to drink it, or without having it in your mouth at all.

VF: Do you have an EpiPen? Do you have it on you right now? So Mom has it?

H3-C: Yeah.

VF: When you go to school, do you carry an EpiPen?

H3-C: No, there's just an EpiPen in the office and in my classroom so like if I'm at lunch and I have a reaction I just run into an office with an EpiPen or if I have it in class I can go over and use the EpiPen there

VF: So you know where the EpiPens are. Do you know how to use an EpiPen?

H3-C: Yes.

VF: How do you use an EpiPen?

H3-C: You put it next to your leg and then you...well we have this thing that pop teeth...he talks about it so i know what the instructions are.

VF: So what does the instructions say, do you know?

H3-C: Not by memory. You just have to hold it by your leg for 3 or 5 seconds, it's like really quick.

WJ: It speaks out loud?

H3-M: Yeah, are you guys familiar with that one? It's the Auvi-Q. It talks to you when you take the cap...

[H3-M takes out Auvi-Q, taking photos]

H3-M: At school though they have EpiPens because the teachers aren't familiar with these [referring to Auvi-Q]

VF: Do you prefer EpiPens or Auvi-Q's?

H3-M: I prefer these.

VF: Why?

H3-M: For one, it talks to you. And in the moment when you're freaking out and stressed, a lot of people accidentally do the other pin upside-down, or in their hand or whatever. And this one I think is just a lot easier for everybody all around. Also, I don't like the company that makes EpiPens.

VF: Why not?

H3-M: I don't know if you've heard in the news, but major price gauging and now there's this big shortage going on and stuff and the CEO is [audible] for Congress for price gauging. I mean it was this whole big thing, so in general I don't like them but you know they supply EpiPens so...

VF: You threw up the air-quotes. Can you tell me a little bit more about that?

H3-M: I just think it's a shady company.

VF; What are your thoughts on EpiPens?

H3-C: I feel like the EpiPens are kind of like a basic one of the Auvi-Q. Yeah it's like a lower, a lower quality of like the Auvi-Q. The Auvi-Q is better because it can stop you freaking out and the class freaking out. They'll stop when they hear the voice because the voice is very loud. That's why we can't do it in here.

VF: So you said the Auvi-Q stops you from freaking out? Is that what you just said?

H3-C: Yeah like it sounds like everybody's freaking. Listen to instructions.

Well like if it's like far to the school year, they know that that person needs to do that so when they hear the voice, they'll stop doing it because the person needs to concentrate to not have a major reaction.

VF: Is there anything you want to know more about in terms of your food allergy?

H3-C: Umm not really.

VF: Is there anything that would make having a food allergy easier for you?

H3-C: Make it search company become food allergy friendly would be better.

VF: How would you want it to be more food allergy friendly?

H3-C: Like not take nuts or tree nuts into the facility and mix it with the ingredients. Make me feel safer.

So how do you feel now?

H3-C: I feel a little bit not good about like every company.

Which companies do you not feel so good about?

H3-C: No..but I do know one that is good. Enjoy Life.

VF: What makes them good?

H3-C: They are food allergy free and that's kind of what their name is. Enjoy Life, or something like that. It's a good company and its name fits into it. It's a good company.

H3-M: And they make chocolate chips.

H3-C: Yes, I love their cookies. I wish they made brownies.

VF: If you could make something that would help with your food allergy, what would it be?

H3-C: It would something that alerts me that there are something that could make me react around me.

[VF giving instructions for participatory design exercise, P4-C doing activity and talking through his board]

I would place Ms. grey really close, even to mom and dad.

[talking about soccer]

Soccer coach knew about his food allergies, placed him next to his twin brothers.
Doesn't remember his school nurse.

I remember you got scary reaction almost the reaction that school when the students reading that's around here and you use the wipes to wash your hands and then you

Because I have this allergy necklace on that says my name, my allergy, and my mom and dad's phone number so I know their phone numbers.

Is that a cat on the necklace?

Yeah.

Where did you get that necklace?

My mom ordered it online. My old one was breaking, it was getting really loud.

[VF looks at necklace]

VF: Do you like your necklace?

H3-C: Yes.

VF: How often do you wear it?

H3-C: I wear it as long as I can find it.

Do you ever lose it?

H3-C: Sometimes I do. Either I lose it in my room, playroom, etc.

P4-C: I try to wear it every day so that I'm more safe. Because I don't really know my parent's phone number by heart so I kind of need this so I can make it correct. So I know that I'm calling them.

When do you take it off?

H3-C: When i go to sleep and I put it on when I get ready for school and brush my teeth.

When you had a scary moment in class with students surrounding you with peanuts, you said you washed your hands and called home?

H3-C: I wiped my hands and then I wiped the table around me just to make sure no one put [inaudible] on the table and then that's what makes it feel safer until I get back to class so I can call home

Does your school nurse know about your food allergy?

H3-C: I think so. I think everyone in the office knows.

But your instinct was to call home and not to go to the nurse's office?

H3-C: Yeah.

Where would you put the nurse in the circle?

H3-C: Right between these two [points].

If you had a reaction, what would you do?

H3-C: I would use the Epipen, I would call mom and dad immediately, and that's like what I would do.

WJ: Do you have a cell phone?

H3-C: Yeah.

H3-M: His teacher lets the kids use phones in classrooms so that's what he used that day.

[switch to mom]

VF: Can you tell me what it's like to be a parent of a child with food allergies?

H3-M: It's hard at first, I'm totally used to it now. But you see the new moms because I run that group...there's a lot of panic at first. You have to strip everything out of your house and everything that might be unsafe. But now it's just the usual thing. I mean we have to do special precautions with the school, special precautions when we travel, special stuff with...he doesn't really go to friend's houses very often. We have to do special things even for birthday parties.

VF: Can you dig deeper on a little of everything you said? You said it was difficult at first and then it got easier? What was difficult and what made it easier?

H3-M: Well it's difficult at first because you cry and you freak out because your life changed. And I think some people get more information than others, help from their doctors, so forth, and like where to start. Luckily I had a pretty good doctor that helped us learn how to adapt and stuff. I think the only thing that made it better honestly was just time. It's been 9 years now.

VF: How did the doctor make it better?

H3-M: He gave us a specific plan. If this happens, then do this. We actually have a written plan that I still carry because like I said in the heat of the moment or whatever, you need to know and sometimes you can't really think straight so we still carry all that with us so I think having that is really important. He always backs us up with schools, if we have issues with that. He also is really good about...he trusts...mother's intuition...we feel or know what's happening.

VF: Can you tell me more about your plan? And where exactly is it?

H3-M: Do you want to see it? [brings out from purse] School has it too.

VF: And you keep this in your purse?

H3-M: Yeah, I usually keep it folded up. I took it out to make sure I had it with me today.

VF: So you said you made copies of this. And the school has one as well. And you also mentioned the doctor helps your school, something about issues at school. Can you tell

me more about anything you face at school and how the doctor may have intervened or helped support you?

H3-M: So we had to set up a 504 plan, a legal plan to keep kids safe. So every school I guess, handles it differently, but they basically handed us a template and said 'here, sign it'. I said 'that's not how a 504 works' so we had these back and forth meetings where they tried to put as few accommodations as possible and I'm trying to put what he needs to be safe. The doctor, he wrote a note, describing the major things that he needs. He needs to have a nut-free classroom, he needs to have access to epinephrine, he needs to have trained staff. So those are the 3 main things, and how then how those are implemented are what's listed out in the 504 plan.

How do you feel now when he goes to school?

H3-M: Well the nurse spent a lot of the meeting rolling her eyes and being really combative and everything so I felt really bad about the whole situation at the time. And now I think it's better because I don't know, I just kept arguing, and not really arguing but pointing out, you know, legally we need to do this, this, and this. You just have to keep repeating yourself, I guess. I don't know. Eventually I got through to them and we managed to make a plan. The main thing that makes me feel like he's safe at school is actually his teacher. So the teacher he gets every year, I meet with them beforehand every year. The nurse is only there one day a week anyway, so I feel like she's a really super minor part. I don't honestly trust her or think she knows that much about food allergies. She's not very good. So it's almost entirely the teacher.

VF: And you mentioned that you meet with that every time you have a conversation at the beginning of the area. Can you tell me about that conversation? What are some of the discussion points?

H3-M: Well, we go through the 504 and then we talk about anything that may have come up the year before like issues or whatever so that we can hopefully not have that happen again. And then, you know, when you're talking to somebody, it's pretty easy to tell whether or not they get it you know? The teacher he has this year has food allergies herself so she is really, really good. She's amazing. So we lucked out this year. The one last year, she didn't have personal experience with it but she did take it seriously. So we had a couple of slip-ups like she brought in cupcakes for some reason at the end of the year, stuff like that.

But this year, we're good. This year, his teacher even came up with some extra like accommodations on her own that I didn't even think of. She actually just has him move his whole desk so that we don't have to clean it all out. And then I was like, Oh, that's a good idea. That was all her, so she's really good.

VF: Can you tell me about what happened last year when he bought it, what was going on?

H3-M: We had been pretty good all year mostly. But at the end of the year, the last day of school, was it the day before? OK. I was even there, because she saw me and talked to me in the morning and I was there for an assembly or whatever. And one of the other parents saw me and said, 'Did you know that so-and-so brought in cupcakes?' and I was like 'What? That can't be right. That's not right. She knows better than that'. And I go over there to get him at the end of the day and she comes out and offers me a cupcake like she gave to the rest of the class. And I was just like, 'Uhhhhh you don't get it? Just kind of like everything goes out the door at the end of the year. I don't know. There's not supposed to be any food brought into the classroom. There's not supposed to be any food offered to him that he didn't bring from home. He's not allowed to make a decision on food that I didn't pre-approve. Like there were so many different rules that were broken in that. So it's just like 'I don't understand'. So that's one of the things we talked about this year.

What was that conversation like? What ended up happening?

H3-M: He did eat a cupcake because she told him it was safe. He was fine luckily. We've talked about it a million times how he shouldn't accept food from somebody even if they say it's safe. But when she puts a...you know...you were what, nine, she puts a beautiful, decorated cupcake in front of a kid and everybody else in the class has one and it's glittery and fun and everything like he doesn't want to say no, right? I think he's better about it now because there was another incident this year where a substitute did something with jelly beans and he did decline it. This year, he did.

H3-C: I had to because it could have blueberries or peach or pink or strawberry. Only one person in the class got the good flavor. About like 90% of the class got throw up. And they chewed it so it's going to stay in their mouth for most of the day...like they bit into it and the stuff stick on their teeth so they can taste it for a very long time.

H3-M: Yeah, I guess maybe that was easier to pass.

VF: Can you tell me about how you said there's a lesson learned. how do you educate [P4-C] on food allergies and you mentioned he doesn't go to friends' houses often. Can you tell me about that? and educating him?

H3-M: Friends usually come to our house. Specific friends that we've talked to and know very well and the parents know how to use EpiPens so he can go to, but there's maybe one right now where we're living. We meet at parks and other places usually. As far as educating him, we pretty much started as soon as he was old enough to talk, so like 2. We started off by saying 'you know, those can make us really sick'. You say like how sick or how serious it was but demonstrate reading labels or whatever it was just all the time, showing him that we're always gonna read a label, stuff like that. Mostly, that's almost entirely modeling like he always sees us always take the EpiPen even if we're just going down the street, you know, just...

And then he comes along when I meet with the teacher and the nurse. We have trainers at home for the Epis and Auvis and him and his brothers use those quite a bit.

Every once in a while, he'll do it at the restaurant where he'll bring it up and talk to the server, but usually he does not feel comfortable doing that. So he looks at me to talk to the server or whoever it is.

Whenever he does start talking to the waiter or waitress about his food allergy, how do you feel about that?

H3-M: I usually say 'Go ahead, you can do it. I know you can do it.' And I try to encourage him to, but if he's really not feeling it, then I do it because it needs to be done, but I try to encourage him to do it of course. He speaks up pretty well for himself at school now, which he didn't always.

H3-C: Well because you're not there.

H3-M: I feel like your teacher this year treats you more like an equal, more respectfully than when he was younger so he feels more part of the adult group so he can talk to people that way.

VF: Compared to a couple of years ago, how do you feel about going into this and he's 10...middle school is right around the corner. What are your thoughts on middle school coming up, in terms of [age range?] and friend group?

H3-M: I would like to homeschool him for middle school. No..middle school is.

VF: Can you tell me about the community at school? Are there any other parents?

H3-M: Yeah, Ethan. Yeah, he's got one or two in his class. I can tell you that almost every single classroom at his school has a sign out front that says 'dairy or nuts or whatever' so I know it's an everyday classroom just about but there is no kind of group or community or they don't do anything to recognize it or...I don't know any the parents and the other classrooms because, you know the HIPAA rules and everything so it's not like...I don't know anybody else, only Ethan because he's your friend. They can't just publicize like a list or anything like who's in it like out people.

VF: What are your thoughts on No Nuts Mom group? What has your experience been?

H3-M: It's pretty good event. I've been with them a really long time which is, I kind of just fell into it, leading the Washington group. I think mainly because I was like one of the first to be in the Washington group, but what's helpful is people sharing information about like, because the labeling laws are pretty bad. I don't know if you guys are familiar with that. But like the

company's...the labeling...they don't have to label a lot of stuff. Like if something's on shared lines with nuts or whatever, they don't have to put that. So there's major flaws in the labeling law. So what happens is we will share, like, Oh, I contacted such and such company, here's the email I got. They'll put it up so everybody can see the information. So sharing that is super valuable. I save a lot of like emails and stuff to my phone so when I'm shopping or grocery shopping, I can pull that up and read policies, aren't

We also share, you know, things about like reactions and stuff that we've experienced, you know, just kind of not really because we try not to give medical advice, but for like moral support, you know, because a lot of people don't get it, you know, but every immigrant gets it. And then the local group. restaurants, doctors, you know who has a good doctor in Bellevue or whatever. There aren't too many local events, but like planning the FARE walk, we do the walk

VF: Why no events?

H3-M: It's a pretty I mean it's a few hundred people and it's spread across the state. We've tried to do a couple of get togethers but it's been pretty small because it's really spread out.

VF: What are other tools that you have in your back pocket or anything else that you use to manage the food allergy control it somehow?

H3-M: I'm not sure. There is an app I use especially like when we're traveling so I wouldn't be familiar with, you know, local restaurants or whatever. It was called Allergy Eats where people rate like restaurants and stuff. I have some cookbooks, yes, and sites that have, you know, like allergy friendly recipes and stuff although I've pretty good at substituting stuff already by now.

VF: How does the app work?

H3-M: I think it sees where you're at, like we traveled to the Oregon coast recently to see like, what's around and then we'll have stars, you know, like like, Oh, we had a good experience here. I'm allergic to nuts and wheat or whatever they're allergic to. It didn't work very well for us on that trip because there weren't very many readings but I think if you're in a busier like if you're in Portland, we would have had a lot more luck. So it's not big enough to be really helpful all the time. But sometimes we have found if you...like when we went over to swim a while back we found some through the app that way.

VF: Is there anything you wish you could change about the state of food allergies right now?

H3-M: Sort of a cure? I think the main problem is that people just don't take it seriously you know, or they say things like survival of the fittest, which I'm sorry is beyond cruel you know? Like that's the kind of comments we get. People just see it as how they affect themselves. Like my kid can't bring in cupcakes for their birthday for school or whatever. They just don't, they

don't see that, you know, we're talking life or death like this is for real. You know, it's literally his life.

VF: It almost sounds like the teachers who have that experience with food allergies have empathy or have experience whereas other people may not know. I have one last question. What is your kitchen like?

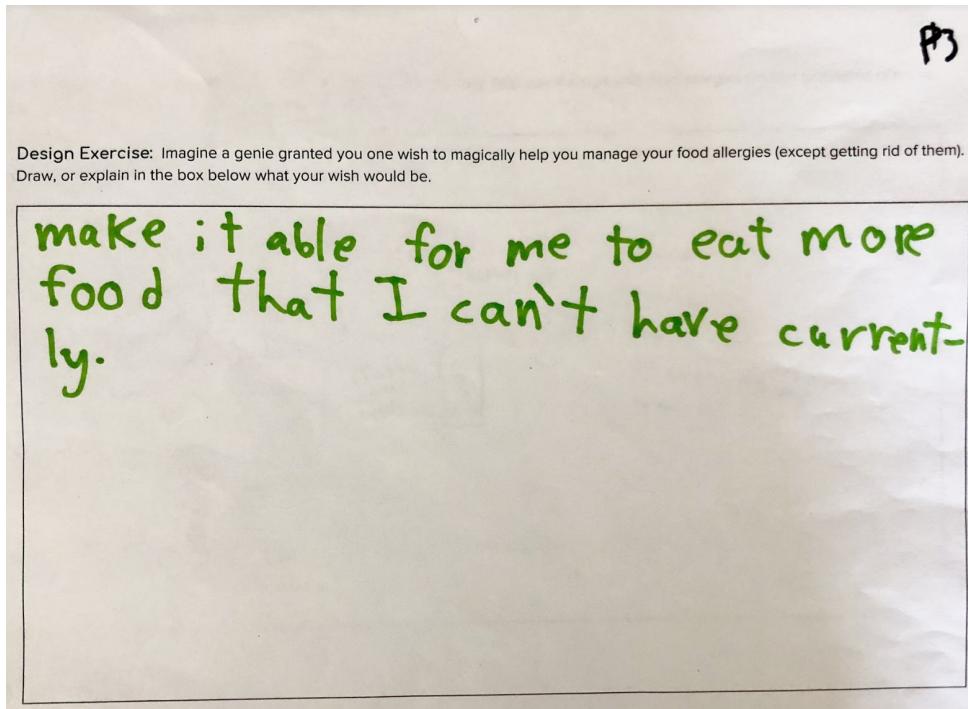
H3-M: My kitchen? Small and annoying. No, it's nut free. We want Jack to have a safe space at all. Not all families do that. They label things like with a happy face sticker or whatever, but I want him to be safe at home with everything. So it's all nut free.

Does that mean like when your family goes out to eat you all eat nut free or allergy free?

H3-M: Um...yes. definitely when he's with us. When he's not with us, we still do because especially for my husband and I, it's actually kind of repulsive now at this point to eat like a Reese's. It actually turns me off like and I used to love Reese's right but I'm actually, like, oh, that could literally kill someone. I'm not eating that, you know. Like I still say no nuts on my salad or whatever. It wasn't always like that. Only in the last few years. Before that I would actually eat like candy or whatever with nuts when I wasn't with him. But as time went on, now I'm just like I don't even want to go near it. Then I'll feel like I have to shower you know, just like brush your teeth, wash your hands, forget it, not worth it...

H3 Warm-Up Exercise

[insert photo here]



Design Exercise: Imagine a genie granted you one wish to magically help you manage your food allergies (except getting rid of them). Draw, or explain in the box below what your wish would be.

make itable for me to eat more
food that I can't have currently.

H3 Participatory Design

[insert photo here]



H4 Interview Notes

In-Home

H4-D 0:06

When he was around 3 or 4 he ate banana bread from Starbucks and then he threw up in the car. We didn't know why at first then we found out he was having an allergic reaction the first time we remember.

Kelly 0:37

Do you think that was the first time he was exposed to nuts?

H4-D 1:03

He had not been exposed until later. That was the time when doctors said hey don't explore this until later.

Kelly 1:18

Studies are saying that was all wrong

Kelly 1:25

So he's allergic to peanuts and tree nut? How are things going right now?

H4-D 1:38

Yeah. I got him tested and we wanted him to also check out needle therapy and the immunization process. My wife went through that. It ended up not working, towards the end it was the highest seeds or something.

Kelly 2:10

You can't take it anymore?

H4-M 3:20

I felt like I was drowning. The doctors said the desensitization would have to involve all the things individually.

H4-D 4:28

We were considering therapy because he is sensitive with that stuff. So we aren't sure.

Kelly 5:02

So it's like introducing it in small doses?

H4-D 5:11

Yeah, he could have potentially a really bad reaction to multiple things which can have a multiplier affect that makes us nervous.

Kelly 5:12

Kai how do you feel about that?

H4-C 5:16

I'm a little nervous. Mom- your story didn't really help. You would be being at the doctors office for a long time after it happens, doctors will monitor you. Minor allergic reactions don't sit well with me.

Kelly 5:36

Its like we have to see you in pain to see how it processes?

H4-D 5:38

They kind of push it until, yeah it's a process for sure. It's supposed to dull out the reaction. He's in a controlled environment, but when he's older he'll be in a less controlled environment so hopefully he'll be more responsible when he's in those environments.

Kelly 5:44

Have you done much education for him when parents aren't around?

H4-D 5:54

Yeah he's doing projects and he did research on that book so he learned a lot about them. so I think immunotherapy

H4-C 6:55

Should I make this realistic?

Kelly 7:18

you can make it whatever you want. It's just, it's your wish, you know. Yeah,

H4-D 8:00

I think we are messing with the experiment. You can do what you want.

H4-D 8:24

anyway, so that's an education we thought the book would be like the best thing but like if he gets older you know he's like you know you just an uncontrolled environment or also we talked about like like drinking if he's older like okay if you ever get drunk and you're not sure what you are doing like something and you pass out like that's really dangerous you know so there's talking about how you know not being in control.

Kelly 9:05

How long does immunotherapy last?

H4-D 9:24

I think it's more frequent earlier and then I think you get almost kind of once you get a monthly rhythm you have to maintain over time and catches like also like hey, I'm good. You know it's like keep exposing your body

H4-D 9:43

so I guess for you How is it

Kelly 9:46

How is it being a parent of a kid who has food allergies?

H4-D 9:58

It's a little nerve racking, you know, it's like you know, we worry about whatever these places but he's he's been really responsible about his food allergy.. he's even responsible in the house like if he's eating something before here

H4-D 10:13

He ate so much candy that he threw up.

H4-D 10:34

So I think the big thing is just like you know it's just you know you worry about like he can die from reaction right so obviously it's a really serious thing that we were concerned about so you know but you can also potentially have something really bad happened from being treated as well as immunotherapy can be a little dangerous too. Also the doctors idk about the doctors because they are like oh its safe, but they say we don't have time to that yet so they have not looked at the statistics yet so they will be biased in the treatment and whether or not we want to do that.

H4-D 12:21

He ends up ordering or familiar things in the menu.

Kelly 12:28

like when he first went to the restaurant and he ordered so and so dish. How did that process happen? Like, how did you find out what the ingredients are?

H4-D 12:42

Kai does not like Tai food. It becomes much more understood but early on we were very worried about eating out when he was younger.

Kelly 13:49

Would you say that has prevented you from going out to eat now?

H4-D 13:54

No places have food allergy menus and things like that, we would a request like we'll make sure that we ask the chef because sometimes you got the wings that don't just say, Oh, yeah, no, there's no, there should be no, next will be fine. Well, no, we need to talk to the chef. So you take people's feedback at face value, you can find yourself, you know, in scary situation. For them It's like, they may not be trained on those things. So it's like training around that food allergies. Seems a little relaxed in restaurants.

H4-D 14:39

buffets are really really dangerous due to contamination..Private foods and people use oils.

H4-D 14:58

It just doesn't take much for him to get a reaction. He is very sensitive to smell.

Kelly 15:16

Does he have a reaction when he smells it?

H4-d 15:20

No allergies is adjetating it just brings back memories

H4-D 15:39

not supposed to be like that. But it's like, but he definitely had it

Kelly 15:54

So you guys don't have in the house?

H4-D 16:01

We have to be very contentious. So no. We did have almonds before.

H4-D 16:24

He needs to learn to be around it. He's in the bubble right now. We're coming hard but he needs to learn.

H4-D 16:39

Oh, he's writing stuff down okay.

Kelly 17:05

Can you talk about when he goes to a friend's house? And how do these friends parents know? Do friends know?

H4-D 17:18

yeah so he brings his epipen and we tell them about their nut allergy. Once his dad made

pancakes, and he's like omg it's with almond milk.. so it's So it's dangerous like people just don't think about it all the time because they are on autopilot. He had not have a reaction for a while now.

Kelly 18:03

So in the book. You said that he had a reaction. The last one was like May 2017

H4-D 18:08

Yeah. About a year ago.

Kelly 18:12

So ever since then no serious reaction

H4-D 18:19

No no serious reaction. If he has any swollen in the throat or tongue it can be really concerning because his breathing.

Kelly 19:16

now it's great to see that you're feeling so diligent about it because my brother has a food allergy and he's allergic to tree nuts but all men is the one thing that he can eat. Which is kind of weird. But my parents were like, very, like he was pretty much like paranoid about like peanuts and all that stuff. And we always ask around, but like he never uses epi pen, even when he had serious like, panting and, like, like, my parents are just like, it's okay like Benadryl? Yeah, yeah, the doctor say like Benadryl is like, not for that. You should stick the epi pen in like the earlier the better, right?

H4-D 19:54

Which is, what we're still working. I mean, you read the story. He's never had to stick the epipen in himself before.

Kelly 20:13

Can, can you talk about how you feel about the epipen.

H4-C 20:19

Well, I'm not a big fan of needles. I went well. Okay, maybe I might run away from when but I'm getting I'm getting better about it Shots...shots. Um, they're not that bad. I don't know why I am so afraid of the epi pen because it doesn't hurt but in my mind is still needles. So I know that is necessary that I need to do it if I'm going to want to live through a reaction but then again in my mindset, I still think that It's gonna hurt and forget its pretty much close to painless law so I get I usually get a little dramatic.

Kelly 21:16

Haha at least you recognize it

Kelly 21:19

So at school to your friends know about your allergy?

H4-C 21:26

yes..yeah pretty much anyone a god knows for sure and other people just they bring treats his whole and I need to ask them or investigate the food to make sure I can eat it.

Kelly 21:44

yeah in your book you talk about how people can treat people differently and how like there's the allergy free table and can started talking about that?

H4-C 22:00

So the allergy free table was at my elementary school where the Teachers wanted to keep all nuts instead of having reactions having a chance of reaction occurring at lunch every day they wanted to have a peanut Free table or just enough free table where people could people with allergies could go to the table and bring it was one to two friends that did not have any nuts in their lunch so it was an interesting experience cuz when people have it felt like we're being singled out and that was interesting experience.

Kelly 23:15

So what about now at your school? Do they still have that?

H4-C 23:19

Okay, um, so I haven't really had that situation for a while and people are just careful with when they have food and try to go to another table and I say no just be careful in should be okay. And so it's not as bad before because before I'd be like, I like to switch to a different table. I would like I said, with like the epi pen, I'd be a little melodramatic. I'd be a little too serious.

Kelly 24:37

Finishing that up. Um. Can you guys talk about your food shopping experiences like how do you go searching for foods, sort of your process around that

H4-M 25:18

If I want to shop I have to take the time to check the ingredients although it's something that should be safe. Yeah, but prepared foods, we don't really purchase.. but a lot of the places say might contain milk as in that's really nice. But he's not allergic to a lot of the main things.. he's allergic to cashews and nuts. It doesn't always have the word nut in it. I've seen I've seen products that didn't say it didn't have nuts but had macadamia or Brazilian nuts. So we have to read it and we learned from mistakes especially if ingredients are super long.

Kelly 27:05

Earlier you mentioned that you let him shop by himself. Does that happen often?

H4-D 27:12

Not really, in one of the first time he'll go in with his bike and get a bunch of candy and he got sick.

H4-C 27:24

The day before I didn't eat much because I wasn't feeling good and I had like major vertigo. So I feel like that was part of the reason.

H4-D 27:39

It's not often shopping by himself, but he knows how to read food labels well. So it's not super concerning. I'm more concerned about him making healthy purchases. He's really careful about labels here. He's way more responsible.

Kelly 28:11

Kai you mentioned earlier that sometimes you're you feel like you were being melodramatic about your allergies Do you feel like that's changed?

H4-C 28:22

I'm still a little paranoid but not as much as I was when I was a lot younger especially like car rides when I see baby wipes and I say like hey can you put those on. Being in assemblies in my old school people would bring food in like almonds or nuts because they are easy to put in your bag as a good source of protein and lots of people had them so I'm a little less melodramatic. I got used to the fact that people bring nuts to school because I when I was younger, I wouldn't imagine people bringing nuts into the school where other people have allergies and can cause a reaction, but I just learned to accept that and just be cautious around it

Kelly 29:53

How do you feel overall about your food allergy?

H4-C 30:07

Well, I just accepted it as part of my life. My life would definitely go a lot different if it wasn't there, but I guess it just keeps you on your toes. And other than the fact that, you know, you have life situations because of it..I guess its is just nice to be kept on your toes.

Kelly 30:49

Do you think it's changed the way you see things differently from your friends?

H4-C 30:59

Not really Now maybe when I was a little younger when people had nuts I would tend to stay away from them because you know I can have an allergic reaction that's something I

believe I had a reaction in kindergarten or before first grade and its something I don't want to go

through again and it was an experience that was scarring for me. So that affected my life. Like oh you have nuts, I used to be somewhat biased, but now I don't judge people if they carry nuts around. I judge them by their character.

Kelly 31:55

Yeah, sounds like you've matured as you've gotten older.

Kelly 32:05

So we don't have much time I see that it's 640. So I guess we can move on to the interactive activity we'd like you to do. It's really simple. We just want to sort of get an understanding of relationships when it comes to it. So you can sort of pause on here your warm up assignment. (Says instructions)

Kelly 34:41

So I guess Um, can you talk more about how obviously Kais getting older? He's Are you 13? Or 14? Okay. So he's sort of he's becoming a teenager, right? How are you guys navigating that as parents

H4-D 35:26

I think at this point for us is 1) are we gonna do immunotherapy? The older you get he is in less controlled environment. Even the school he goes to is conscious of these things. He's in a very controlled environment right now and as a teenager he'll be in a less controlled environment. That's why immunotherapy is a big decision that we want to knock out because it has potential to make it so that all of his allergies are not life threatening so it's a big deal. We also want to be active in new projects that help other people. So multiple projects we are thinking of doing. We usually do 1 or 2 projects a summer.

Kelly 36:22

What are what are some of the projects that you're thinking

H4-D 36:28

A couple of them.. one is getting exposed to legislation a bit. Potentially putting a nonprofit that works with restaurants. We talked about an app that were considering making that helps people with food allergies. Nothing super serious but they're just things like what is very practical with technology. So I own a software consultancy so I have a technology background and so there's like practical solutions that makes things easier for people.

Kelly 37:37

Do you use any like apps right now?

H4-D 37:43

they don't really do what we want for the most part, like people can find you, or things that record your allergy.

Like a profile that's not helpful. He's not going to be by himself. The scenario doesn't seem helpful.

Kelly 38:25

If you had to choose one thing that you would want that would help. What would that thing be?

H4-D 38:32

So I'll just tell you because I don't know if it's legal actually. Like the big thing..the biggest challenge we have is do they have an epipen all the time. and kids just don't have it. So some people have their kid who has a fanny pack and they take it off. You know, so, and then also, even if you had, like clothing had like an epi pens or something. So, so I think like for us the technology side of things that we talked about building is just the basic app that will just tell you, you can say I need an epipen. We have one and we'll just come to your location. And so that's a really simple application. But it takes time for an ambulance to show up in a small window of time that needs that and there are people with allergies around you. They have amber alerts but they don't have an allergic reaction?

So anyways so that's the application we are looking at.

Kelly 40:32

Kai are you done with your exercise? Can you talk us through why you put these people?

H4-C 40:50

Okay I am so sorry mom. So I put my dad closest cuz he's the one who's most firm with me around my allergies and he's very serious about my allergies, more serious than me. And he's very supportive very attentive always make sure that we have an epipen in our hands you sometimes you don't and that's a problem but and of course they work together..Okay, so, um, Mom, you always do your best to make sure that the food in the house is safe to eat. You're on the line is because the pasta incident. My friends are really supportive and they're really careful around me and I really appreciate that they do that. And again, it looks like I'm being a little biased here. well um just your grandparents in general are ..they they're not your parents so they get to love love you as much as they can. And just

Be able to be able to have as much fun as possible with you and

Um especially with um they're not as careful with nut allergies already so that's why they are farther out and ones farther in because she I guess she stood up for me because we were at a Pancake House canola oil? Does it taste better? It's a little bit healthier. Teachers are really supportive

Kelly:

Do they know about your nut allergy?

H4-C 44:41

most that I tell, um, we have home teachers where you go to go to home room for 15 minutes before school after break.

They're really supportive.

H4-C 45:02

They're really nice about it..doctors. Um, they're always there for you, but I never really know they always like check up on me like, in emergency rooms always helpful. I never really felt like that there were part of my life will have all the priests on Monday they were the people who I didn't find that out but after that it seemed like mostly my people I to depend on are family friends, immediately family and those are the people I depend on the most. Lianna, um lets move on to the next one.

Kelly 46:56

Then you wrote down nurse. Um,

H4-C 47:00

I just found them written down. Nurses usually have epipens, with nurse experiences I dont think they are comfortable using the epi pen themselves. I had a mild reaction first and they give me Benadryl and wait. So maybe they get charged if they use the epipen.

H4-D 47:40

The doctor did say something about educating them on using the pen right away.

Kelly 48:33

Moving on, Coach

H4-C 48:40

Well, it was in the pile. So I decided to use it. It wasn't um, they aren't exactly the world. They're kind of like teachers, except I see him once, like a year so they're not a big part of my allergy. They're polite about it. They're just they're really understanding..they're really open about this. Like okay you can't have nuts so you can't have this.. and Okay, I'll get some thing else next time.

Kelly 49:46

Are you up front about your allergy? Or would you tell people when it comes up?

H4-C 49:55

I bring it up when I need to.

Unknown 50:11

So my first idea would be working to yeah, this just shows how like I'm very educated news area but pass a law just in the Seattle area at first, all restaurants should have clarion or Allegra or

some medication that stops or slows down an reaction at its early stages...restaurants alongside. Second idea. I was thinking of something similar to a like something similar to having pumps for people in the arms for people who have..no diabetes. There you go. Okay, pumped that people with diabetes for people that.. it would be like a needle injecting how they would get insulin without any or to little pain. My 3rd idea, another law, it's annoying having to read the first half of the ingredients, then get to the bottom where it says process like making facility that may have nuts that's annoying...cuz some people like oh just dairy meat okay..I feel like of course there's still the chancel I understand why this wouldn't be the most practical solution

but maybe try get rid of processed in a facility or get rid of shared equipment with peanuts or something. I know that there's probably not a chance that it's going to be hard to get rid of the "may contain" and like that whole side..I wanted I would want it to be more control if possible..with the washing equipment or

Kelly 54:44

that's great. I think those are very practical solutions..honestly

Whitney 54:55

as parents, do you have anything that you like see missing. That you like or it could be anything that like that you wish you had in order to make your lives easier with dealing with it.

H4-D 55:29

If The backup epipen — new stuff stick something and you can tell if it contains allergies. We would love if they had a cure for allergies. The big thing is what are the new techniques to prevent, especially in uncontrolled environments or even if there is AR — is really interesting — the phone knows his allergies if he holds a product in his hand — is it easy for him to see that he can eat this.

In Japan — for kids snacks — it has a clear mark that it does not contain shellfish or shrimp or nuts with a nut— more visual as opposed to the US you have to read every single letter. —nice to have product regulations at least for kids.

UPC code would be nice. It would be interesting too if there were any products— if you include this in the food — it could protects, like a dose of epinephrine.. if you mix this in your food it could prevent things from happening in the mouth rather than the stomach. We find things we don't know when traveling internationally. Not going to lie we usually take the risk — start on the lips then he bites it, then waits and then he eats it — usually have a reaction in the first two steps — our own method the preventing specially

H4-D 1:00:00

Tell us what you guys are planning on working on because we're actually curious. We're doing food allergy initiatives in the area.

Kelly 1:00:18

Yeah. General we're sort of just we really don't know what we're designing it could be anything. It could be it's going to be technology related or don't know bits like experience like product, an app like anything. I think right now we've sort of been taught to not think of like what to design yet but just be open minded and just like taken all of these all these data points and then use that to better inform later on. Yeah. So right now it's like we have like just huge boards filled with our data that were coding down into categories. Yeah, we're in the process of like coming up with insights are doing some Thai Grammy and through connecting the dots. So I don't have like a clear answer for you as to like what we're going to do with. Happy to like in the future we can keep you updated. Yeah, you can come to her final.

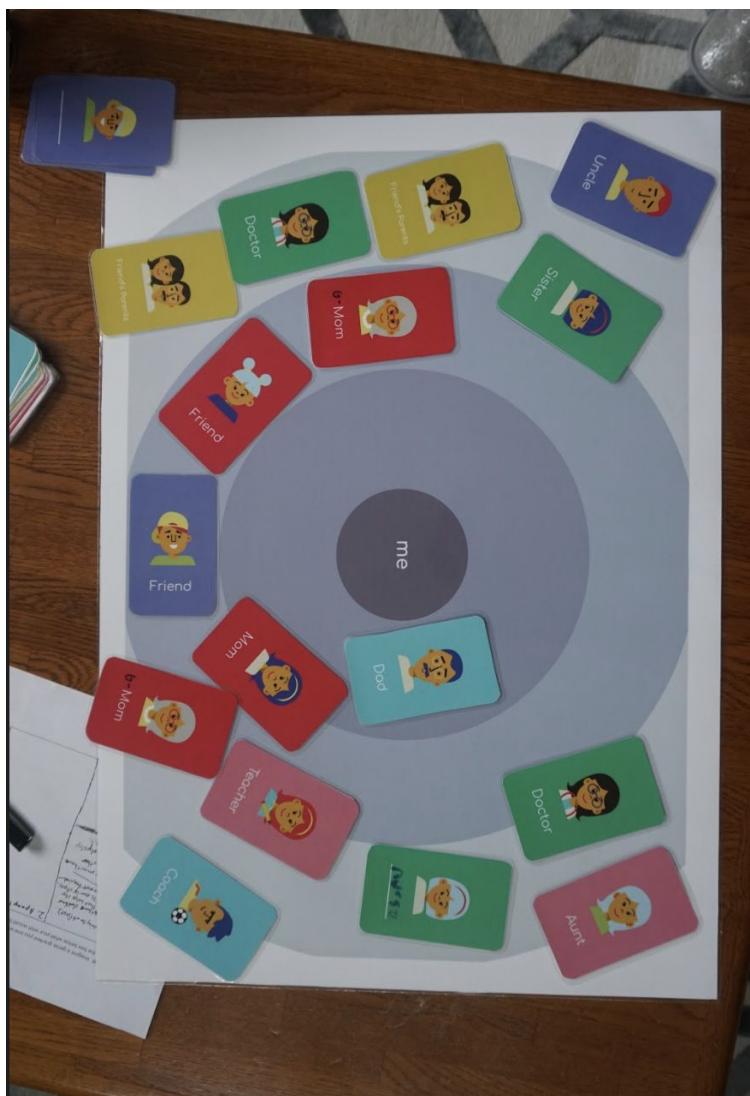
H4 Warm-Up Exercise

[insert photo here]

Design Exercise: Imagine a genie granted you one wish to magically help you manage your food allergies (except get Draw, or explain in the box below what your wish would be.

1.	Law (in washing ton at first) - All restaurants must have Claritin or some other medication that helps stop allergic reactions at its early stages. x It will be recommended -- not required to have - All restaurants must have Claritin, Benedryl, or other medications that help stop or slow allergic reactions at its early steps. It will be recommended	2. A pump that looks like a water bottle
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H4 Participatory Design



H5 Interview Notes

Starbucks

Derrick 0:52

As a mom who deals with food allergies, what's it like

H5-P 1:10

it's gotten better because Nathan is at an age where he can read food labels and understands his food allergy which makes it easier for me.

Derrick 1:36

Can you talk about the process of kind of

H5-P 1:38

funny it's gotten easier as he's gotten older. Although he was actually starting in kindergarten, I was really, really nervous about him being in school. And even though the school. And even though the school has a nut free table.. who is sitting at the table, no one. So he wants to sit with his friends who are eating peanut butter sandwiches. I went to school to have lunch with him and you have to be an advocate for your child. He took responsibility to talk to other people and I was actually really surprised that he did. I don't know if that was him being nervous about it or what not.

Derrick 2:44

So this what you came up with, you know, no nut school? No, not

H5-C 2:56

they're not allowed to allow nuts.

Derrick 3:10

How do you imagine that coming true? Remember magic can be evolved or anything.

H5-P 3:31

We typically don't have peanuts in the house. Once I had peanuts and I washed my hands really well. And he told me about it.

Derrick 3:48

so he knew that there was nuts involved.

Derrick 3:55

How would you get rid of nuts at your school?

H5-P 4:14

There are bullies at old school and one of the bullies waved a peanut butter and jelly sandwich in his face and teasing him about having a peanut allergy. He's the same age. I was just I don't know. My friends were nice and they told the teachers but the teacher didn't do anything.

Derrick 5:28

so you said your friends help you out. And they told the teachers or how did they so they know about your food allergy and they're like, they knew that this guy. My friends were friends with him too.

Derrick 6:26

So you said the teacher didn't help you out. What did the teacher say to you?

H5-C 7:05

So they just sent them to the office for half an hour.

Derrick 7:08

You still see her or you don't feel as old school? Right? So you did you see him around afterwards?

H5-C 7:47

I feel like it just picks on the kids and it made things even worse. That was in 4th grade.

Derrick 7:55

the kids nicer there? Hopefully.

Derrick 8:24

So what prompted you to pick the school

H5-P 8:37

If someone waved a sandwich infant of his face, it would be disrespectful but not scary for him if you have an allergen waving in your face. The teachers didn't talk to me the communication was not adequate so we switched schools. For me to hear things through Nathan, I eventually heard it from him but he's frustrated and his behavior angered towards me or family or is frustrated or can't communicate that. So there was a lot of stuff happening. I found out from Nathan peanut butter and then his teacher was like 'oh yeah that's what happened.'

H5-C 11:56

Next time I need to be sitting at a nut free table, but there was only one person there.

H5-P 12:02

In a nut-free table you're isolated and alone. I understand but if parents don't have food allergy they are like "why can't my child have a pb&j sandwich" it's real and they won't understand until

they go through it. Do something about the peanut table!

Derrick 12:09

What is your when you talk to other parents here how do you communicate and get your point across? Is there anything specifically that you

H5-P 12:21

We have to make sure we have the epipen at school boys and girls club? And there are parents that have been good too. Parents are becoming more aware of it. But yeah, I mean, just making sure people are trained on the epipen and avoid tree nuts and reading the nutrition label.

Derrick 13:22

I mean, do they understand the severity of it? Or how do you really get across?

H5-P 14:30

I don't know. How do I?

H5-C 14:41

If the parents don't know very much, if they ask if I want a snack I'll tell them I can't have peanuts or Brazil nuts and they let me double check the labels to make sure it's okay but at my boys and girls club they know about my allergy. Sometimes they give out candy that a kid might have peanuts or eggs or something and they'll say oh he can't have this or he'll explode.

H5-P 14:57

Oh I've never heard that before!

Derrick 15:02

Yeah, so do you like going to the boys and girls club? Do you have a personal issue?

H5-P 15:42

When they have new staff I double check periodically and demo and ask if they want me to train them. They told me and I trust that that they know how to use the epipen. I talked to Christina. She's really good about it. Well, I mean, she. Yeah, yeah.

Derrick 16:20

Have you ever gone and train them on how to use the epipen?

H5-P 16:35

Maybe.

H5-C 16:43

You told her

Derrick 17:10

So how about how do you educating the severity to Nathan?

H5-P 17:56

We talked about it a lot and what can happen, and doctors talked about it. He had one reaction when we went to grandma's. Corn country and brought back desserts and he felt sick. You put it in your mouth and spat it out right away. And didn't have anaphylactic. I had the epipen and didn't know what to do. Grandma didn't know what to do. The doctors didn't know either. They they're like, She's like, Well, you could monitor him. Or you could bring them in, but there's gonna monitor. Yeah, yeah. So we just didn't read the labels. We weren't paying attention.

Derrick 19:48

Can you walk me through the timeline of the reaction?

H5-C 19:51

I swallowed it and it tasted fine, then my throat started feeling really really weird. Then I was crying because I was feeling sick and scared. My stomach felt weird and I was nauseous and I threw up. 15 minutes then we looked at the box and was like oh god there's peanuts. Then we got the epipen gave him benadryl. Then I paged the doctor asking what I should do. In the first minute my throat started getting weird. Within the time period of 15 minutes I was asleep from when this happened. My throat just really really hurt, I didn't feel anything in my stomach, my throat was the only thing hurting. I feel the same thing when I have soy milk. It doesn't hurt but it doesn't feel good.

H5-P 20:00

We are upset with grandma -- we had to talk to grandma -- grandma knows it's serious- but she doesn't really think. Grandma is living in the age where no one is allergic to peanuts

Derrick 23:56

Why do you think we have allergies?

H5-P 24:01

I mean, I think we have allergies because of the environment. I think there are more endocrine disorders because of all the plastics. Idk what it is.. maybe it's the dirt.. I am reading different things -- maybe everything is too clean -- maybe it's the processed foods or the environment. I don't know.

Derrick 24:43

And then I guess there's a lot of things, a lot of things like there's no high schools. Now. There's, I guess there's some laws and regulations. There's some but it's not super significant. if you had a wish on how things could change or be dealt with what would it be?

H5-P 25:08

Me personally would have loved to have a better handle on the diagnosis. Theres numbers to how we reacted -- but that doesn't tell us how he is actually going to react. Is it compounding? I don't feel like I have good answers on that. Then there is also introducing peanut allergen over time to build immunity towards that. I don't know how far along that is yet. I don't know if I want to put him through that or if it will help. If there was something we could do when he doesn't allergies that would be great.

Derrick 25:14

Do you want to tell us what you want changed in the diagnosis?

H5-P 25:21

When I first gave him when he was 1 years old -- I gave him a kashi cracker with peanut butter he started reacting right away with hives it was just.. I noticed it right away (shakes her head) I was home alone with him. I -- started to panic, I didn't know what was going on so I put him in a bathtub and asked a friend to run out to the store to grab benadryl. She went out and gave it to him -- then it was better. I then went to pediatrician then they tested him. And the epipen and benadryl we had to carry it around. Then went to Allergist because I wanted to and had a little asthma. Then the doctor diagnosed him with asthma -- been to the ER for that and he's growing out of it They did the testing on his arm-- that's when we found out he was also allergic to Brazil nuts and then after a while when he went to his friends house, he started sneezing with watery eyes. I got him tested and he was allergic to cats. He couldn't have any sleepovers or barely any playdates Get him ready with benadryl before seeing people. I just really feel bad for my son.

H5-C 31:40

The smell makes me feel weird because, like, they have people buy peanuts and stuff at a game and people are sometimes right near me and I can smell it and I have to like walk around it.

H5-P 31:45

It's nice because on airplanes they won't allow nuts now. And when we want to buy something nutrition label, although I guess

H5-P 33:34

IT would be kind of cool if there was something that could read the nutrition label that could tell the allergens for us. But we could read it ourselves. Trader Joe's is not really good. They are okay. They have Brazil nuts.

Derrick 34:15

Tell me more about the shopping experience

H5-P 34:19

Grocery experience - he can eat things that may be made in a facility -- I didn't know if I could do it at first -- so she tried it and so far it has been ok. If it's not in it but was made in a facility has been ok -- made me branch out and make my own things which is good -- like homemade trail mix -- eat almonds and cashews. If it doesn't have peanuts in it but still made in the factory then it's okay.

H5-C 34:27

At the school that I go to now -- they are really good about the nuts -- I'm not allergic to almonds. So on how to make a peanut butter sandwich at school -- but they switched it to almond butter

H5-P 34:37

I remember coming into this new school with only one with an allergy -- that oh gosh I feel bad I'm the only one -- we are going to have to change their rules and lives-- but it's been fine. It's been a really supportive community. Just modifying and substituting ingredient for us. They are good at modifying for his safety or parents saying what can Nathan have -- molly sends out that Nathan has an allergy. Nathan is really good at double checking as a parent's mom gave him peanuts in a bar by accident and she still texted her and felt ok as it was respectful and good.

Derrick 38:34

So do you tell your friends about your food allergy? Do they know?

H5-C 38:52

In the bullying unit he told everyone what happened -- they didn't believe him at first but when he told them during that unit they got it -- didn't believe the severity. They were still asking questions, like really? Are you?

H5-P 39:25

It would be nice to have a reminder that the EpiPen is going to expire. I check them. And also yeah an expiration date. When I bought Benadryl at bartels I didn't know it was expiring in like 3 months. So I brought it back.

Derrick 40:09

So you've talked a bit about using the epipen and Benadryl. Did you have to use it yet?

H5-P 40:13

I didn't have to use it yet.

H5-C 40:17

I am comfortable using Benadryl. If it's going to save my life then yeah I understand. I'm scared of needles.

Derrick 41:00

but you have taught him how to use the epipen?

H5-P&C 41:07

Yes I have. We used a tennis ball because I wanted him to hear the really loud noise. It's stronger than you think. And I wanted to tell him to go straight in. Becky, one of his teachers in pre-school, there were two twins who had severe food allergies younger than him, and she was so nervous, she didn't put it straight in and it didn't work so I remember I wanted Nathan to know this is how you do it. You go straight in. They needed stitches because they put it in wrong. So that's what prompted me.

Derrick 44:00

Explains interactive activity

H5-C 44:14

Some of my friends know about it but don't know what to do

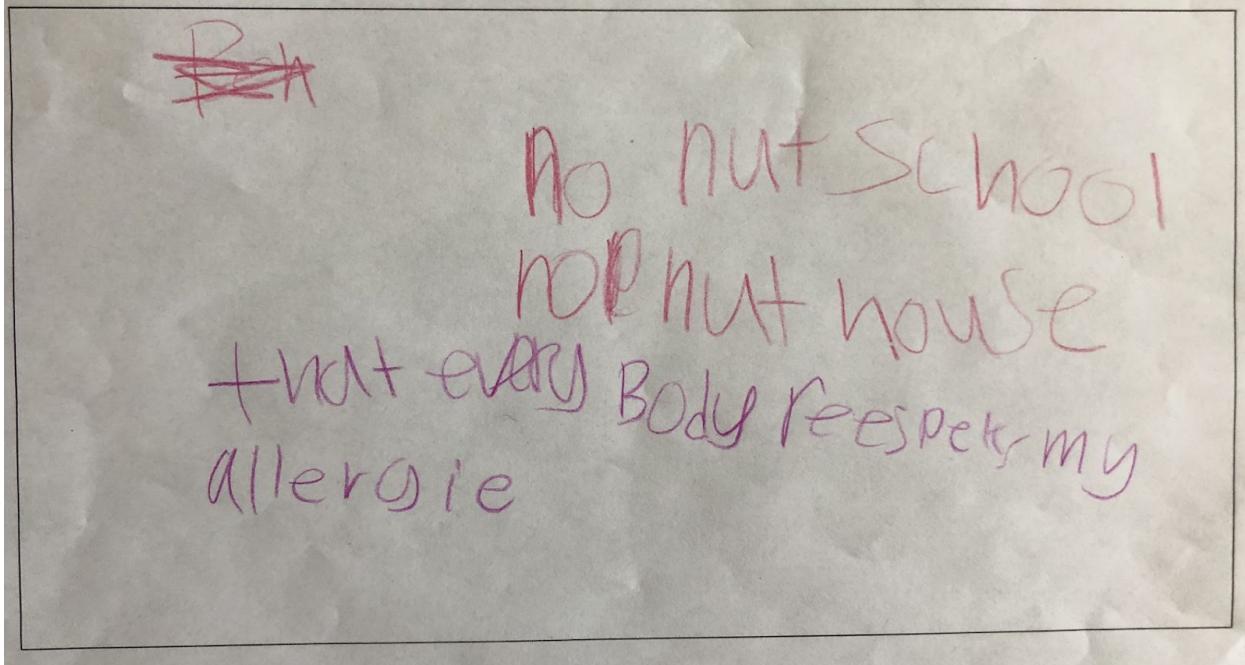
H5-P 45:32

Nathan is visiting his aunt and flying by himself. I just need to call her and remind her about the food allergy. I also let the airline know. They all ask about food allergies. My question is do they read it? I will have an epipen and Benadryl with him while he travels.

H5 Warm-Up Exercise

P3

Design Exercise: Imagine a genie granted you one wish to magically help you manage your food allergies (except getting rid of them). Draw, or explain in the box below what your wish would be.



H5 Participatory Design



H6 Interview Notes

Starbucks

H6 - 9 years old

i think there's always this constant fear it's essentially constant fear bc i don't have control of her environment bc she's school aged. it's easier if you have a baby or toddler bc you control everything in their lives. she has a mind of her own. i would say constant fear and worry in the back of my mind. being realistic, you have to let them go and have faith in the systems and the things that are in place. the school's management protocols in place and that i've taught her well enough to be careful, but we're still working on the latter one.

when you talk about school management, what are her regulations?

if you have serious food allergies that are life threatening in public school you automailyd get a formal plan. the plan includes the prescription by your doctor as to what the school is supposed to do and truthfully there aren't parents notes. so the doctor ...i don't have input..the doctor said epipen for anaphylaxis. i had actually tried to put in an intermediate measure if she gets hives i want to get benadryl not an epipen. the bellevue school district don't want to make judgment on what is appropriate, they'll write that down but they'll immediately go to epipen for danger the reason is having the epipen doesn't harm you their liability is not increased if they just automatically go to that.

is the plan in place 504? it is

did that ease your worries for going to school?

the plan itself yes knowing that teachers are aware and the epees are located at school. but no i don't feel that school is safe for her because she just had an incident 2 weeks ago. there are so many other places where things can fail in fourth grade a classmate could bring a peanut and offer it to you. you don't have full control of that peer environment. the other thing is schools in bellevue don't have full time nurses...they share...either 2 or 3....they are assigned to each. the day she had her incident, there happened to be a nurse there. if not, she has to go to office staff trying to deal with your child. it's those 2 things.

how often does she allergy reactions?

because for food, with the amount of control that we exert over her diet, it's not that often. we're about a year apart. once a year.

at 6 months. i was nursing her and she got a huge red ring around her ring and we were like what's that? i had a craving for peanut butter and jelly sandwich..

it's even interesting in light of the current studies go on..you should expose infants to peanuts. if i were following that consciously it didn't work.

what was that like for you when you realize she first had an allergy?

at the beginning i think because kids do grow out of allergies i thought it's not that big a deal. just take out all the peanut butter products in our house. so i wasn't super concerned..i didn't have much knowledge. i couldn't even predict..i was hopeful she would grow out of it. the ring around the ring...there were 5 things. they were egg, dairy, shellfish, and peanut

she is now only allergic to peanuts.

and once you eat solid food, you find out how strangest you have to be.

so what are your main changes to your daily life?

first of all, .

my sister gets to eat cheese and bread. there's a lot of family turmoil it's not the hand her sister was dealt. so we don't restrict her from eating those things.

managing family conflict about it...that currently is something they're aware of. reading labels and being incredibly vigilant...it's really way out of routine. going into a birthday party or out to eat. otherwise we have a really good system in the household. where you buy the same products and what she's going to have for lunch. managing restaurants and parties, it's READING and not necessarily trusting what everybody thinks is in it. scaling back. and holding back. it's not a big deal. we have done a lot of bringing your own food if we're...in a restaurant we grill the servers what they're serving. bring your food is a big thing in her life.

how does your community been receptive to her allergies?

they're very enlightened in bellevue. they're trained by the school who does want to keep kids safe and avoid liability. there are occasionally people who are not that sensitive to it. and but they're very few. it's unfortunate if it happens. so this peanut candy that came in. it's all over no nuts in the whole school. and still parents still give her kids this candy and unfortunately this particularly candy was polish. it's even harder to read the label. if it doesn't' affect your child to someone you know, people are far less sensitive. kids come in with peanut butter and jelly sandwiches all the time.

you can have peanuts in the lunchroom. i didn't get any last year and they banned..when i told her someone had peanuts she just said you have to wash your hands after you're done.

so you're saying she bends the rules..

when you say ppl are trained in the schools...how do you know of these rules?

they're usually the beginning of the year, you'll be sent paperwork and it says we don't have peanuts or tree nut products. the 504 plan, the nurse will touch base with each family. i'd say there's a general communication and more specific. teachers do give reminders to not bring peanuts and tree nuts..it's one of those things if you're not thinking about it...

You're talking about educating Arden on her food allergy, how to deal with it now that she's older?

well for us it's very clear. what do i say to you about things you eat? only eat things that you brought. but protecting yourself?

only you can protect yourself. what i've been trying to say to her is your parents and teachers can only do so much. you are the only one for the rest of her life who puts the food into her mouth so she's the one that has to be responsible for it. at this age, when she's taught to use an epipen i would say up through now it's us managing her and her food. but we're trying to get her to be the one that says 'what's in this?' so the peanut candy thing 2 weeks ago she said does it have peanuts? her friend said i don't think so. so she ate it. that brought up the more specific instruction you have to look at the label yourself. if somebody offered her a banana, she can probably make that judgement, but not for processed foods.

when we're talking about label reading, when it says may contain..do you stay away? we have not stayed away from that. we have thought well maybe it's too conservative. i'm starting to..think about that a little bit more. there's another layer of judgment on that. if it's a granola bar and it doesn't have peanut in it but it says may be processed a facility..i'm probably going to stay away from that. i do an evaluation..what are the chances...how many peanuts are in it? if it's something ...maybe popcorn will say that..i might say ok on the popcorn. because..i don't know this...a place the processes popcorn and chips if it's different from the granola..i'm starting to rethink all that and maybe we'll just stay away from that.maybe a popsicle will say that...you're like...what? how? if it's a peanut in a popsicle

we were supposed to get popsicles she didn't let me have it..

what's your family protocol when arden has a reaction?
her common reactions symptoms are she'll be very itchy or a hive or throw up, vomit if it's a peanut. we try to take care of the hie and itchiness through zyrtec or benadryl. we've only had to give her the epipen once. if you do that, you have to call 911. my husband administered it.

she was basically screaming my throat is closing. she was pretty much yelling...crying..becoming hysterical about it.

timeline wise?

the ambulance will give ...we gave her one injection. the ambulance give another dose. they stabilized her throat closing on the way. that was all very quick. we noted they came within 5

minutes. it was very very quick. got her to the hospital, within about 2 hours she was stable and resting. it's super taxing on her system, she's like drained. that was probably when she was 7.

what was the reaction from?

that was from oyster..the intern thing about that is she had never tested positive for oysters and she had been eating oysters. it's about subsequent exposure..not having a positive allergy test...the peanut we know about. well what else could you be allergic to that we don't know about? so to finish eh timeline..you need to rest for 24 hours. but it's a 24 hour to prevent rebound.

we were going to go on the plane tonight so we had to stay. we didn't end up staying...so then like she stayed away from oysters for 2 more years and then she tested negative.

so what was the testing experience like for you and your family?

she has had mostly skin prick tests each year. we want dot have it once a year and uses been doing it once a year through the age of 8. and then, we didn't actually do it the year bc her doctor said she probably isn't going to grow out of peanut. there's a highly more sensitive test of peanut that breaks down the component of peanut but here's 4 of them if your' a person who's allergic to some of the components you are likely to grow out of peanut allergy if...if you're allergic to that...it's a blood test.

did you trust the system? did you find your doctors helpful?

i think so, i think the allergist we have seen is really good in this area. the only i think just not trusting the system doesn't have to do with the medical car. it's knowing you might develop a new allergy bc your body is hypersensitive to oysters.

what is your biggest pain point when dealing with the dynamics of having a child with food allergies?

i think it's definitely food prepared by other people. i feel pretty confident about labels i don't know anyone who's had labeled one way and turned out not to be true. but most of her situation and friends will be like 'i asked if they had cashews' and it did. it's food that wasn't prepared by you.

do you ever go through a process of education her friends' parents about her allergy?

i think everyone knows arden has food allergies and it's mostly when an event that comes up a birthday party or a girl scout meeting and they all take turns bringing snacks. in our immediate circle, yes everybody knows. we don't...i can't say we go out of our way to educate anyone. we just say...let's say i'm taking her to a friend's house. bag of snacks. i bring with a i put it on us rather than anyone else. i think it's our responsibility. it's not the hand that they were dealt.

what are you most nervous about as arden gets older?

that she will want to rebel and want to eat things. i think that already came through in the peanut candy incident because i mean she knows but the fact that she ate the candy man..being with her peers...wanting to have some freedom that you have to read every label and grill every server.

controlling the urge to have something..i want shrimp and oyster.

so she's not..she doesn't test positive for gluten or dairy right now but we keep her off of it because her skin itches...eczema it's because she has a sensitivity than an allergy. it does make a difference for her if she restricts her diet.

she'll just got have constant desires for...

are you in 4th grade?

yes

how do you like your school..don't like it bc my last school was better because there were nicer people.

the gifted school...those classes have a lot of behavioral issues. it turns out this is a constant..it's not just her class. i had to talk to her principal..in these classes..diff skills..

computer programmer

they're two of my best friends at this school and there's 2 other friends at the other school. at my school are ava and anya and anya broke her arm...

do they know about your food allergies..yes...

i never have any of their food

never went to their house

there's my friend alien and christina at my other school. not a lot bc i dont see them a lot.

when you go to someone's house? you keep your epipen with me. sometimes..so that's a problem. because at school it's there. when she's going places...i have one right now but we are trying to make it her responsibility to carry it with her. but other parents will ask 'oh do you have an epipen you want to leave with us?'

how do you feel about your epipen?

it's ok. it doesn't hurt that much.

would you feel comfortable using it?

i practice with a trainer. the auvi-q is scary because the voice is creepy. i heard it at the doctor's office. we have both. because the auvi q is cheaper. they had a recall it wasn't working when it wasn't supposed to..right now they're paying what your insurance doesn't pay you basically get fit for free..until they recoup their presentation.

how do you feel about food allergies?

sad because i don't get to eat anything good.

mom: i would disagree

i miss foods that i used to eat...bread and cheese...and cake and stuff like that.

do you use substitutions?

gluten-free bread is terrible...dairy-free cheese is really bad...tastes really bad

i think as a result of having these food allergies her diet is much healthier than most kids. she eats a lot of fruit, good quality meat, eggs, she eats far less processed food than kids her age. and that makes her mad.

i feel sad about it a lot. when my sister's eating it in front of me.

no, it doesn't change what i do with friends. yeah i feel comfortable...

i and then i asked her if it has peanuts and she said i don't think so. they have to be absolutely sure and you have to check the label yourself and she didn't have the label. i ate part of it. and

it was itchy and it tickled.

i knew right away it was wrong..i told my teacher. she sent me downstairs to the office. they took my blood pressure...they called my friend that gave me it...and then she went back upstairs and we went home.

did you get any medicine?

no but that was the issue i alluded. at this the we don't know what's in it. other than her throat being itchy she wasn't having a breathing problem. when the school called me. we would give her benadryl it's right there at school in her file with the epipen. the nurse said no i can't. it wasn't that she can't, it was judgment it was annoying to me. so eh said you'll come get her? she didn't want to deal with her...it's a very alarming situation i think the school is very i really feel like this school is a liability concern instead of what's practical. and when i talked to a nurse at a different school they had undergone a training if we're going to have to do something we're going to..

and the nurse didn't give her the epipen or the benadryl?

so if the topic is hanging allergies, the schools don't want to manage it.

does that add to your fear or ...any type of emotion you might have about her allergy?
i can't say it does...i'm resigned to the fact that it's our problem. i manage it when i'm with her
and "ts why it's all super important when she's not with me or husband. when she's in high
school she has Benadryl with her i don't know..it feels like oh we'll have to take it into our own
hands. that's been my approach from day one.

do you have a phone?

-yes, it's only for emergency...

she's in places where people know...pretty much there ..for instance.. her girl scout troop is
planning on going to wolf...

essentially rather than hanging the allergies i manage the environment she's in.

do you ever feel restricted?

-no

[asked her question about sister eating peanuts in front of her]

i would love to have a sensor...it's peanut specific..there could be a sensor to detect peanut
dust or whole peanuts...and that if she's unsure...puts it towards the sensor and it tells ...i wish
it were through her phone or app...

[participatory design exercise]

this is one specific teacher...

cecilia...that's the spanish teacher...

my grandmother accidentally fed me the oyster

i have a lot of aunts and uncles..the don't live close by but they are aware

[she gives a description of her food allergy]

something to make food taste good...something to make food that tastes good that isn't an
allergy because the bread doesn't taste good

we're on cruise control with food purchasing...pretty much very little processed foods. my mom
threatens to not take her food shopping anymore bc i want everything i can't eat.

she can read labels.she's read kai's book.

i don't participate in communities online.

i probably have benefitted from forums that other ppl have populated.

what keeps you from not participating?

i think i spent a lot of time in the beginning of her food allergy...i feel like a lot of things we've implemented so far are fine. i haven't looked for anything else. we know other ppl in our immediate community who sympathize. we know what we're doing with this.

do you have any words of wisdom where you were when she first had a food allergy versus now?

I think probably i think i should have reached out at what point to more people in the community bc i did so much research myself but actually connecting others in the beginning would have been

i think it's fear of the unknown bc since we've gotten all the reactions i think that since we've had had this range of reactions we've already been through that before ever having to give her the epipen that was much worse. but now remain calm. so i think it's just not knowing.

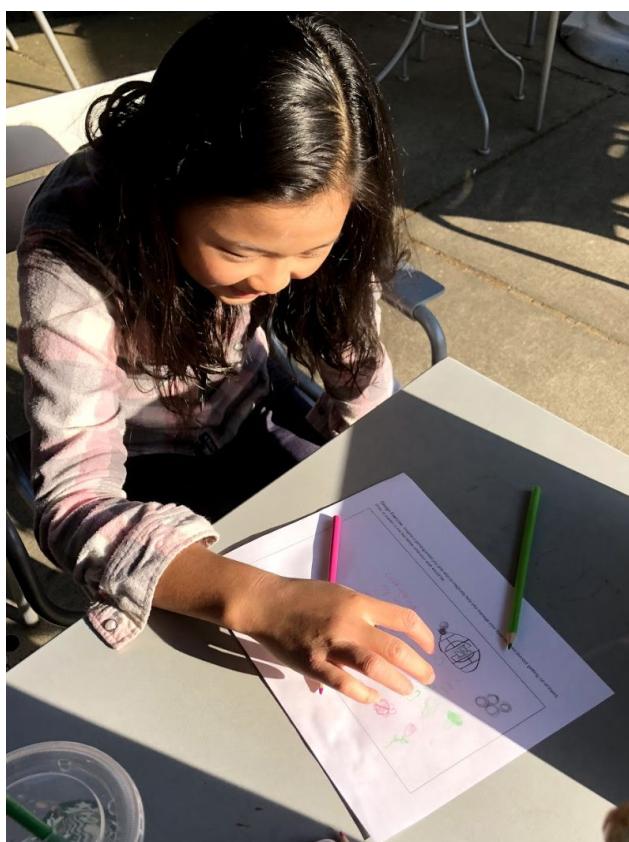
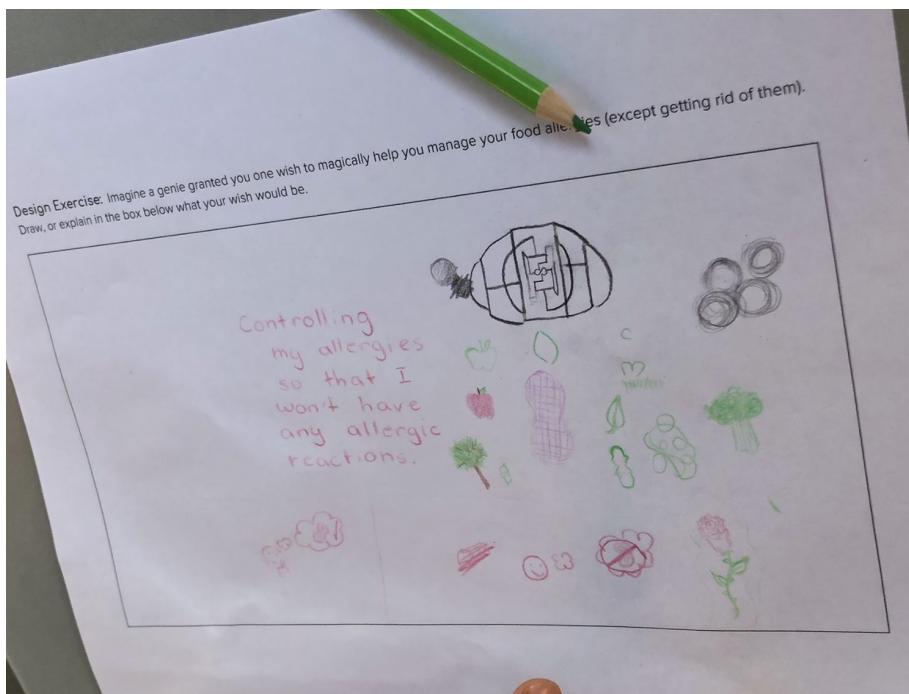
so no i don't trust her. right now i don't think she's at a place at 9 years old can do it.

when do you see yourself knowing you have to let her..gain her independence?

my hope is it's tomorrow..i think watching my older child in middle school it's not too far away. i think she might be fine if i'm not complete there.

H6 Warm-Up Exercise

[insert photo here]



H6 Participatory Design



H7 Interview Notes

In-Home

I am allergic to severely allergic to peanuts, pistachios, and cashews. but i avoid all nuts to be sure. i also have cat and dog allergies.

so as parents...summary of experience so far?

-grocery store, finding out about it

reading labels about it, going to the bakery (he wants a cookie, look at it, free samples, oh wait make sure there's no nuts, going to restaurants, if there's peanuts...he's also allergic to shellfish shrimp and crab is bad but he can eat clams..throws up and his lips gets really big

going out to eat, being careful that dishes don't have. the worry i have is cross-contamination. we were in italy last year and we got gelato and he got chocolate. within half hour, he was feeling sick and threw up. we thought chocolate had peanuts or used the same scoop. so luckily we didn't have to use the epipen? he threw up, still breathing, we were supposed to use it (we were afraid to go to the hospital)

we experienced before so we knew...in this case we knew he would be okay. if he eats a whole peanut we'd have to use it.

can you talk about fear or unknown and how you go around dealing with that?

-avoid restraints that we know...five guys..the obvious places

-our awareness level goes up if we go thai or vietnamese..we got to make sure..he's not severe enough...he can be in the same room.

-kids who lick their hands, touch the handles so i use my jacket sleeve

changes to daily lives?

-definitely reading labels, asking wherever we go to restaurants like the noodle place do they use shellfish as a base or chicken stock, we do ask questions more

-so you ask the waiter, what do you say to the waiter?"does it contain shellfish or shrimp, what's this made out of?" they just answer

-we assume the soup is based on chicken, one time he confused noodle with shellfish and immediately difficulty breathing, as soon as he found out allergic reaction we asked waiter..., from them we decided not to take any chances

-we gradually learned, at the beginning didn't think it was severe, it was a learning process, i made a lot of mistakes, i would take him to cafe and for playmate and someone offered him a cookie we took it back home. it was a peanut butter snickerdoodle but he took just a small bite and started vomiting like crazy

-even if it's a tiny thing, i have to ask

-how did you first learn, diagnostics process?

-he had eczema, his face was always red, so we got tested at 9 months, we found he got all these allergies including milk, the formula powder we were giving him was based on milk so we switched to soy, so we switched to soy, so from then on...

-diagnostics process?

-9 months was a blood draw and ran the report. we had a listing of everything he was allergic to. after a year, he got the skin test. 3 years ago, recommended by allergist, we went to seattle children's. the skin testing seems kind of cruel bc he gets really itchy.

-P7-C - i was fascinated by how it reacted. peanut was really big. pistachio was just as big. it was really itchy. i just went with the flow.

-mom: it's not just one or two. it's a variety.

what's the diff between skin test and blood test for you two? how do you feel?

-i thought blood test was more reliable. esp for nut allergy. with blood test you can tell if you outgrow. the higher the number, you won't outgrow.

[cruelness topic - was taking photos so didn't capture notes on this]

we were referred by his pediatrician because he had severe allergy reaction so he recommended him to go to specialist so that's where we found the allergist. we started carrying an epipen ever since we found out his high allergy to allergies.

-P7-C - dr. tran's pretty helpful. i keep asking him about nettle, it's an herb a natural remedy for allergies. she'll answer me in a very descriptive and understandable way.

-mom: she's really knowledgeable, i believe she has her own allergies so she can really relate to the patient. she doesn't force us to be on prescription medication and i tend to go in a holistic way i don't want to be on drugs or inhaler all the steroids. so she's really open and flexible so that's why we like her.

mom: some doctors want you to be on a special filter for your house, better breathing on home. because allergies are everywhere. we don't need to commit to all this that the doctor recommends.

dad: she stresses what's important and what's not. one time when i didn't use epipen when he consumed the cookie she said that's when you need to use the epipen. so she does emphasize to not be afraid of using the epipen because she's afraid more brain damage...

P7-C: i think the pigpen is a lifesaver. the kids to there who have used it...i think that's a really great tool to use.

dad: we've never had to administer it.

P7-C: I just redid instructions.

mom: Kai brown's book really helped him understand. even for me stabbing your child, it's scary. after reading his book, it's important to administer rather than wait.

P7-C: i never knew you have to do a lot of thing. but you have to take off the cap.

learning?

P7-C: multiple sources and just learning...accidentally consuming allergies.

[talked about drawing]

-alarm or gut feeling whenever...if i'm car a chocolate chip peanut butter cookie. it will warn me that there's meant butter. just some..another one was a phone app you take a picture of the serial picture of the peanut butter and highlighters the allergy

P7-C: i learned how to read by multiple sources, kai's book, i just read, if there's some weird stuff you can't pronounce i always keep my eyes peeled for peanuts . i don't really worry about the may contain nuts...

P7-C is in 5th grade,

lunch time

P7-C_tend to be careful with peanut butter eaters. i try to be careful on where i sit, seating chart. i have two friends with peanut allergies so we kind of sit in a triangle. my teacher put us in one area where kids can't eat peanut butter. but she didn't separate the kids that are allergic to peanut butter and those who aren't. she's careful.

mom: if we request to school, then you would be in nut free area. he's not too severe or sensitive so we didn't request.

not nut-free school but has a nut-free table.

he knows what to avoid and so i figured he will be ok. they can't share or trade food. he'll only be eating his.

P7-C: teacher put us in a seating chart. all the allergy kids on one side of the table. and puts random kids on other side. most of peanut butter people are away from us.

it used to be sit where you want..

hudson got for halloween party in 4th grade, as a goodie bag we got pretzel sticks. i didn't eat mine. he ate his. there was cross contamination in his bag but nobody else did and he said i'm not feeling well so he went home but it was an allergic reaction. that scratchy throat feeling. it's just a regular day, we don't talk about food allergies.

mom: whenever they have cupcakes or treats in class, the teacher always emails us if it's ok to serve him cupcakes. last week, you guys had pizza, so the teacher confirmed if he could have papa john's pizza.

P7-C: it was domino's first, then papa john's. papa john's i think they make gluten free?

mom: school nurse, a lot of time. they have medication and his epipen at school. had to fill the school district form, get that signed by dr. tran. from last year, before you could just submit one epic pen or just one benadryl. but they require the original form with the box. i don't know why it changed, but school district requires us to have the original epipen box because it has his label on that. it

dad: it shows the epipen was prescribed to you.

mom: over the years, i've seen changes in the school side. they're taking allergies more seriously because a lot of kids have now

P7-C: teacher is very aware of what i'm allergic to. like emailing my parents.

mom: one time i had a sub so sub gave you snack and your friend said it had nuts.

P7-C: it was my backup snack. my friend is a girl who also has food allergies. she said "that has nuts!" i've had this before. so the sub takes it away and says to go to the back table.

mom: kids are more aware and when you have a substitute.

emergency snack from home, i used to have a ziplock bag with fig bars and something valley bars, if i forget my container snack like fruit i just eat one of those from the ziplock bag, so it's a backup. mom makes it and he came home, and talked to me about it. P7-C: i was kind of mad.

other kids are more aware of what other kids are eating when subs don't know what's going on.

P7-C: i was kind of mad at kyla (she was being protective). and we ran out of nutrigrain bars and it was PE day. some people know i'm severe with peanut allergies so they scoot away when they pb&j so it's kind of nice.

prefer them to scoot away. i told him he doesn't need to go to another table.

mom: because the other student warned him, it was over exaggerated. it happened so i'm not going to bring the same bars again i don't want him to be uncomfortable.

kyla: she has eyes on other people than herself.

mom: oh yeah we trust him. he can sense if he doesn't want to eat, i just trust his instincts.

dad: over time, we just notice he doesn't want to eat certain things.

P7-C: comes in handy, i sense when food comes out at restaurants.

snickerdoodle was the first incident

gelato was tutabelllo

P7-C:pistachios...my friend and i ordered ice cream. are with pistachios, vanilla.. i think a lot of gelato has nuts, we weren't really aware of it. we didn't think to ask.

mom: we just have to look for puke bag because he just throw up. his first reaction is always throat, tingling, within 5 minutes he'll throw up.

P7-C: i don't feel good.

mom: we had an epipen but we didn't administer it.

P7-C: when i get itchy throat, i just know that if it's like that i kind of know i need to throw up. i try to be brave. sometimes i'm scared, sometimes i just know what's going to happen so we learned after he throws up he'll be ok.

mom: he refuses to go to the doctor;

P7-C: he doesn't want to get poked. get it out of my system. I don't want to get any shot.

[talking about participatory design activity]

-i would just my friend's parents, depending on which friend it is. like is it a friend who knows my allergy really well? or know that i'm allergic to stuff?

P7-C: i know my school nurse..been often but not for allergies.

mom: a lot of it is over email. i go to volunteer at school so i get to see the teachers more often. still it's a lot of communication over email.

mom: i think the cafeteria food are all allergy-free foods that they serve so not too worried about him buying lunch. he's been asking lunch from school, i'm not too worried about food allergies at school. it's more about environmental nowadays.

The cleaning agent they use he's sensitive. i don't know what they use. freshly cleaned...that's the more concerning over food allergies .that's good that they sterilize at end of day but he reacts to it.

P7-C: luckily i got a portable, classroom outside of the main building, maybe just 15 minutes at school. i'm in the main building very minimal. i just learn outside.

mom: i want to know the cause. why this food allergy...we weren't that sensitive before but what cause kids nowadays to be more allergic. it's environmental, GMO,...we don't know. but what's the cause?

it's more environmental..all the chemicals that we use.

mom: it's even hard to get an appointment with allergist. couple months. his birthday is in august. we always have to get authorization from the doctor for the school documents, so we always go in august for checkup, but we have to make appointment 4-5 months in advance.

a medication that you can eat, a sensor, i like app thing

 Diary Study Cover Page
 Diary Study Email Template
 Diary Study Template

 Diary Study P1 Packet Child
 Diary Study P1 Packet Mom
 Diary Study Debrief General Phone Guide
 Diary Study P1 Notes

 Diary Study P2 Packet Child
 Diary Study P2 Packet Mom
 Diary Study Debrief Phone Guide
 Diary Study P2 Notes

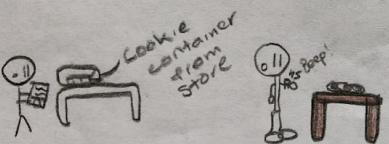
 Diary Study P3 Packet Child
 Diary Study P3 Packet Mom
 Diary Study P3 Debrief Phone Guide
Diary Study P3 Notes

H7 Warm-Up Exercise

[insert photo here]

P7

Design Exercise: Imagine a genie granted you one wish to magically help you manage your food allergies (except getting rid of them). Draw, or explain in the box below what your wish would be.



My wish would be ~~to eat~~ ✗
or some kind of alarm or feeling
when ~~a~~ a ingredient ~~is~~ that I
am allergic too is nearby
~~Or a ingredient list app that can~~
~~be used to scan the barcode~~
~~find describe the ingredients~~
with a ~~barcode~~

H7 Participatory Design

[insert photo here]





Diary Study

Diary Study Email Template

Hi _____,

Thank you for agreeing to participate in our diary study! We are graduate students at the University of Washington working on designing a better way for preteen children to manage their food allergies.

The diary study entails filling out a food diary packet (one for you and one for your son) for the duration of 7 consecutive days. We ask that you record any time during the course of the day when you have to think about food in relation to your child. These thoughts might come up when you are prepping meals, grocery shopping, or feeding your kids. Also record any specific tasks you do in relation to food allergies. The information collected from these diaries will really help us to uncover opportunities for easing stress involved with food allergies.

Attached is the diary packet for you to download and print two copies of. Plan to set aside approximately 10 minutes to complete a full day's entry. *Important: Once the first day is completed, please send me both you AND your son's diary entries.* This is just for us to make sure that both of you are capturing the most relevant information for what we are seeking.

As compensation for completing the study, you and your son will receive one \$20 Amazon gift card. Please let me know if you have any questions throughout the week. We appreciate your participation and candidness – you and your son's contribution will greatly inform our understanding of this space.

Best,

Kelly, Vijay, Derrick, and Whitney

Human-Computer Interaction + Design
Graduate Program, University of Washington
mhcid.washington.edu

Diary Study Template

<https://drive.google.com/open?id=13fuobBzm0YXmI6dNmVBr5M2DYMggx2Cw>

My Food Diary

DAY TWO

What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	
What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	
What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	
What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	

What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	

DAY ONE

What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	
What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	

What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	

DAY THREE

What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	

What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	

What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	

What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	

DAY FOUR

<p>What happened? (Anything you did, something someone said, on event that occurred)</p> <p>Write description here</p>	<p>What did you think? (Concerns, feelings, questions)</p>
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<p>What happened? (Anything you did, something someone said, an event that occurred)</p> <p>Write description here</p>	<p>What did you think? (Concerns, feelings, questions)</p>
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<p>What happened? (Anything you did, something someone said, an event that occurred)</p> <p>Write description here</p>	<p>What did you think? (Concerns, feelings, questions)</p>
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<p>What happened? (Anything you did, something someone said, an event that occurred)</p> <p>Write description here</p>	<p>What did you think? (Concerns, feelings, questions)</p>
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DAY FIVE

<p>What happened? (Anything you did, something someone said, an event that occurred)</p> <p>Write description here</p>	<p>What did you think? (Concerns, feelings, questions)</p>
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<p>What happened? (Anything you did, something someone said, an event that occurred)</p> <p>Write description here</p>	<p>What did you think? (Concerns, feelings, questions)</p>
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<p>What happened? (Anything you did, something someone said, an event that occurred)</p> <p>Write description here</p>	<p>What did you think? (Concerns, feelings, questions)</p>
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<p>What happened? (Anything you did, something someone said, an event that occurred)</p> <p>Write description here</p>	<p>What did you think? (Concerns, feelings, questions)</p>
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DAY SIX

<p>What happened? [Anything you did, something someone said, on event that occurred]</p> <p>Write description here</p>	<p>What did you think? [Concerns, feelings, questions]</p>
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What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
<p>Write description here</p>	

<p>What happened? (Anything you did, something someone said, an event that occurred)</p> <p>Write description here</p>	<p>What did you think? (Concerns, feelings, questions)</p>
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What happened? (Anything you did, something someone said, an event that occurred)	What did you think? (Concerns, feelings, questions)
Write description here	

DAY SEVEN

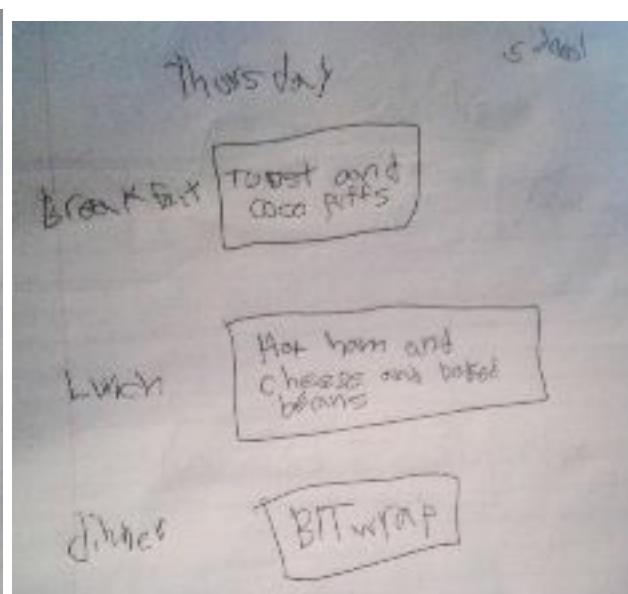
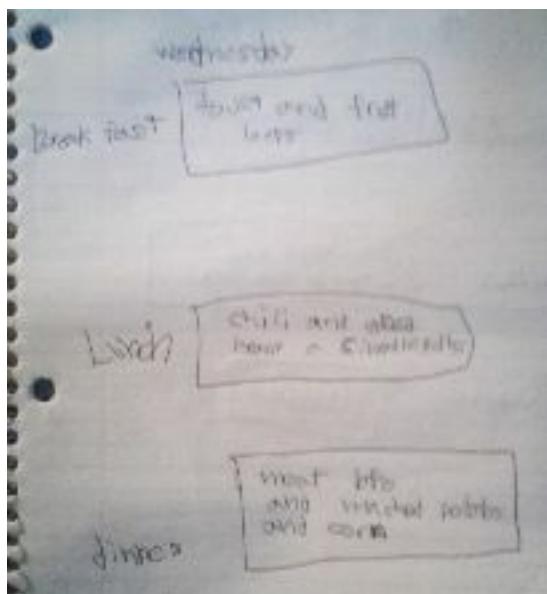
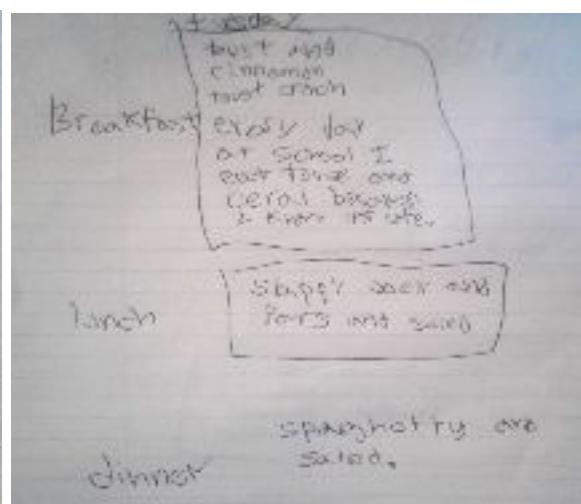
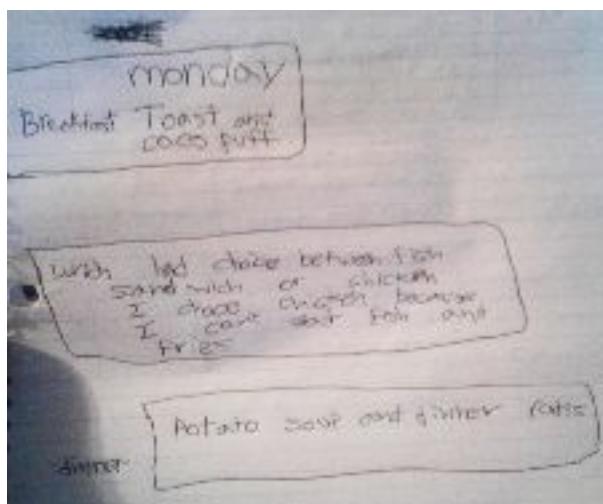
<p>What happened? (Anything you did, something someone said, an event that occurred)</p> <p>Write description here</p>	<p>What did you think? (Concerns, feelings, questions)</p>
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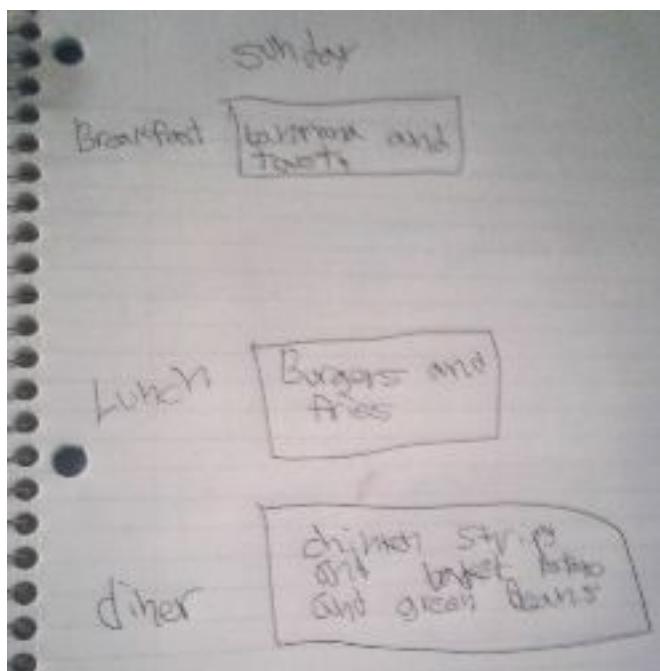
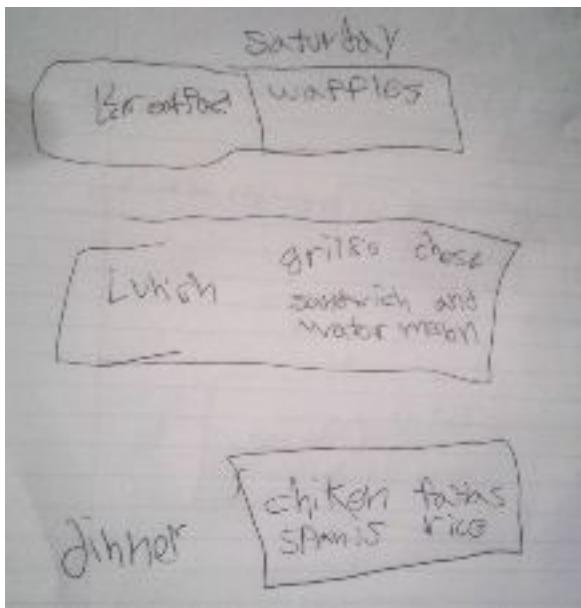
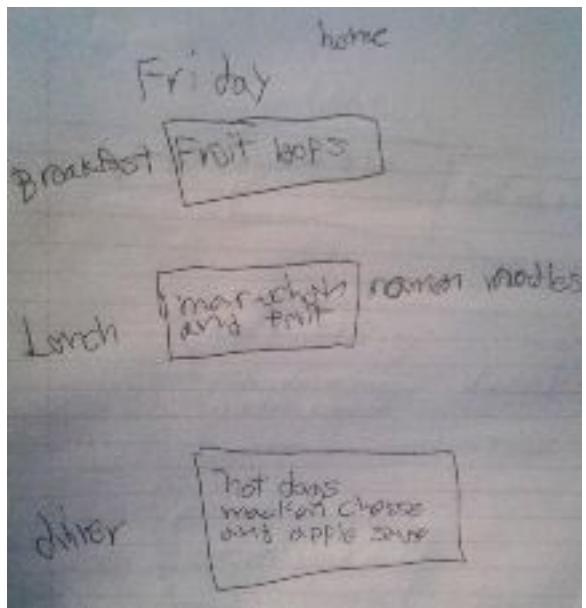
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<p>What happened? (Anything you did, something someone said, an event that occurred)</p> <p>Write description here</p>	<p>What do you think? (Concerns, feelings, questions)</p>
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<p>What happened? (Anything you did, something someone said, an event that occurred)</p> <p>Write description here</p>	<p>What did you think? (Concerns, feelings, questions)</p>
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D1 / Child's Entries





D1 / Mom's Entries

Monday

- bagel
- ham sandwich
- potato soup + dinner rolls
 - homemade potato soup, so I know it doesn't have certain allergens
 - made sure rolls were processed in a tree nut free factory. Checked two brands, one was safe

Tuesday

- eggs in a tortilla
- chicken noodle soup
- spaghetti and salad
 - Checked spaghetti sauce to make sure didn't contain any tree nuts

Wednesday

- toast
- mac & cheese
- french toast, mashed potatoes, eggs
 - no longer put eggs in sandwich because sauce in sandwich after finding out it contains egg whites.

Thursday

- bagel
- Chinese food (Beef/Chicken)
 - My favorite food I eat once in a while when Jordan is in school. There are too many sauces that contain nuts for it to be safe with Jordan
- BLT wrap
 - This is a very safe food to make w/ nuts or fish to worry about

Friday

toast

- ramen noodles + sandwich
maruchan or a safe brand

- nathan hot dogs
mac + cheese
apple sauce

pretty simple, besides making
sure brand of mac + cheese
was safe

Saturday

waffles

substituted apple sauce for
eggs, since Jordan can't have
egg unless baked in a cake
etc

- grilled cheese sandwiches
watermelon tomato soup

- chicken fajitas
spanish rice

homemade seasoning to
guarantee safety
most if not all
McCormick brands are
made in nut free facilities

Sunday

toast

cheburgers , fries

chicken strips, baked potato,
green beans

tyson brand was safe

D1 / Interview Guide

Hi [child's parent's name], this is [teammate] and [teammate] on the line. So glad we could set up a time to talk. Thank you so much for completing the diary study. For this call, we want to debrief with you to get a better understanding of your food choices and experiences around that, as well as clarify any notes we saw. Is [child's name] on the call? So we'll plan to talk to you for about 20 minutes and then move on to some questions for [child's name]. Does that sound good to you? Before we begin, would it be okay to record this conversation? It would be for note taking purposes only and will not be shared with anybody.

So to start off...

1. Do you do any meal planning in your household?
2. What is your shopping experience like?
3. Are there any [other] specific tasks you do in relation to food allergies?
4. How do you decide what to eat?
5. Was there anything out-of-the norm during the week you filled out the diary form? Like did [child] attend any events or maybe go to a friend's house to eat?
6. Ask specific questions about diary entries that need elaboration or want to dig into.
7. How does [child] food allergies affect you and your family?
8. How often does your family go out to eat?
 - a. How does [child] food allergies affect eating out?
8. Say [child] is invited to go to a friend's house to eat dinner or attend a sleepover. Is there any preparation involved with that? (walk us through the steps you would take)
9. Can you tell me about how you do your research on your child's food allergy?

D1 / Interview Notes

For mom

Do you do any meal planning in your household?

- Sometimes, it just depends. Sometimes I'll do the pre-planned crockpot meals. Like the frozen ones, we make ahead of time and put it in the crock pot. I do that every couple weeks and it's the same recipes

What is your shopping experience like?

- One thing i've noticed a lot...i shop a lot at walmart..they have that Great Value brand which is a cheaper brand...but a lot of the times it says "processed in a facility with nuts or tree nuts" so i always have to buy the more expensive brand because it's safe. Everything i buy whether it's from the box or [soft?] or anything, i have to look at the ingredients. If it's a top 8 allergen, it has to be labeled on there.

Are there any specific tasks you do in relation to food allergies?

- No

How do you decide what to eat?

- We can pretty much eat anything, it's just finding things at the store that don't have an allergen in it. Most people can just look at something and say 'oh that looks good'. But i have to look for every ingredient on everything.
- They're supposed to label, we never really have problems with that since i don't buy it if it can have cross-contamination. Like if it could be made in the same facility as tree nuts, then I don't buy it.

We noticed in your Wednesday post that you no longer use Worcester sauce after finding out it contains anchovies..

- That's something that i learned online because i joined this food allergen group (FB i just typed in food allergies...there's a lot of them..one is called no nuts mom group, food allergies mom, and they were talking about where there's things that have hidden ingredients and fish is one of them...worcester sauce has anchovies
- There is one that I stopped following because the moms were very extreme with it..they'd get mad if they saw a kid eating peanut butter and jelly sandwich.

How long did you use Worcester sauce before and when did you decide to not use it anymore?

- We got tested 3 weeks ago and the doctor said his allergens were still high that if it even had a little trace in it to not use it. He had to go to the hospital from eating french fries that had been on a pan that hadn't been washed after making peanut butter cookies and that's how we figured his allergens were bad.

On your Thursday post, you wrote that you ate Chinese food broccoli and chicken, your favorite food that you eat once in a while. Can you tell us more about that?

- I only ate that because he was in school. I don't take him to eat that anymore because last Mother's day in buffet he bit into something that had fish in it..after doing some research they use a lot of fish in their sauces and tree nuts and nuts..so it's not very safe to eat there
- No i don't eat out often when he's not in school. If i do, it's a place like that. his school is a no nut place so that helps.
- He does have a girl in his class who is allergic to nuts, it's not a big problem there because it's a no nuts school. in that group i know a lot of moms complain that their school is not nut free and so i'm grateful that ours is nut free. Each town we've lived in has been nut free.

Was there anything out-of-the norm for Jordan during the week you filled out the diary form? Like did he attend any events or maybe go to a friend's house to eat?

- No
- A typical day...he goes to school, he comes home, he goes out and plays with kids in the neighborhood or in our yard. He usually only eats home, home-cooked meals so that's not really a problem. He's joining football next month so we'll see how that goes.

How did you educate him on that?

- he knows he's been allergic the past 3 years. Just through the process of eating the food and knowing how it makes him feel. Knowing what's safe and not and the reaction he gets. He's pretty good about it, he'll tell people. His reaction is so extreme that he got scared and he knows not to eat that.
- When he eats fish, his mouth will automatically start burning and his throat and he starts coughing gets welts around his mouth.

How did you educate him?

- We've only had to use the EpiPen once and that was last month. That was both of our first experience with that. At school he's not allowed to carry it with him. The nurse has to. But he knows how it feels and when to tell adults.

Can you walk us through that experience?

- He went to a concert with some friends, like a band concert. His friend had given him some french fries and he got home and complained about this throat hurt and said it's kind of hard to breathe so i gave him benadryl and half an hour later he said it didn't help at all..so hard to breathe his throat felt tight. So i went ahead and gave him his EpiPen in the thigh. After that you have to go to the hospital to be observed. The nurse didn't know that so they tried to send me home. I was like no i called 911 and they said to come here so after i said that, they check all his vitals. Hey gave him a shot of steroids and sent us home with a prescription for steroids for 3 days.

How is Jordan's reaction to the EpiPen?

- I think at first he was trying not to tell me because he was scared of it because he doesn't like shots. But after i gave it to him he said it didn't even hurt. Even though it bled. It helped him immediately to breathe. Now he realizes in the future 'it didn't even hurt and it helped.'

How does Jordan's food allergies affect you and your family?

- Have 4 other kids so there's a lot of snacks that i don't buy. and i don't let him have fish in the house at all. Other than that..

How often do you go out to eat?

- Probably now only couple times a month, it's somewhere simple like fast food. Mcdonalds has certain fryers for their food like fish by itself. Fries are by itself. They're good with allergens
- Well he's sad he can't have chinese food. I guess you can ask him yourself..i don't think it affects him much anymore

Say Jordan is invited to go to a friend's house to eat dinner or attend a sleepover. Is there any preparation involved with that? (walk us through the steps you would take)

- He's actually been invited to only a couple birthday parties. Thankfully they each had pizza and i would just have to ask them where they got the pizza from so i can make sure it's one that's safe to eat. I call the number on the invitation, tell him about the allergy, ask where the pizza is from, they've usually been pretty nice...
- Sometimes i'll call the place and ask about nuts and cross-contamination. I know pizza hut's a safe one so we eat there. Luckily it's a small town so there's only a few choices. If it's homemade, i have to go through the trouble of finding out the name and stuff. I guess I make it easier on myself, i don't let him go to dinners at other people's houses, it's easier that way at least until he's older.

Do you have any thoughts for when he gets older?

- When he's older, he'll start carrying his EpiPen himself. Now i'm just doing the best i can to prepare him of his allergens and what questions to ask so he's prepared.

Could you tell me some of the ideas you might have to prepare him?

- When i go grocery shopping and he's with me i'll have him look at the ingredients as well, so i'm already teaching him that.

Son's interview

What's your favorite cereal?

- Cocoa puffs, but we ran out.

Best part of cocoa puffs?

- I like the taste.

What else do you like to eat?

- I like to eat pizza rolls.

How do you feel about your food allergies?

- They suck because i can't peanut butter or fish. [When you go to camp or go hiking you're allergic to some plants]...some plants. I don't know which ones. [mom says i've got them written down]

Why does it suck?

- Because sometimes well if you want to try new things you can't...well you can..but you can't try the things that my siblings have.

When you're in school, do you ever eat food from the cafeteria?

- Yeah...[then he said no]...i don't really eat from the cafeteria.

What do you usually eat?

- I eat stuff chicken strips sometimes, fries, or chili and crackers.

Where do you sit in the cafeteria?

- I sit at the [woodlawn] fence
- I sit with 2, yeah they know about my food allergies, one has allergic to all 3 animals [probably referring to chicken, beef, and pork?]
- No we don't share foods with each other
- Well once they offered and i said no. i said no because i don't like germs.

I heard you used the EpiPen one time. What was that like?

- It didn't hurt
- I thought that the epi pen was going to hurt but when i got the EpiPen it didn't really hurt or it felt really cold

How do your food allergies affect your life?

- One time..chicken. I accidentally got catfish so I had to go to the hospital. Hard to tell between chicken nuggets and fish. Can't tell the difference between stuff.
- Usually i don't go to the restaurant because that one time when i ate fish

Are you still afraid of your EpiPen?

- No. I think the EpiPen is weird. The [trainer] EpiPen is different from other EpiPens. The [trainer one] you hold it for 3 seconds and the [__] one you hold it for 10 seconds.

Do your friends at school know about your EpiPen?

- Well some of my friends

- Only some because i don't tell them. I told them i have food allergies and what im allergic to.

Are you comfortable telling them?

- I don't really care

D2 / Child's and Mom's Entries

[INSERT PDF OF DIARY ENTRIES]

https://drive.google.com/open?id=1rx-0FN3cxeyJMJPPpUI_3ID1ZA1HUW00

Date: Monday 4/30/18

Occassion:

Time: 7:30 am

What happened?

Husband purchased cookies that I had never heard of before for the kids' lunches at School. I double-checked the label to make sure it is safe. (He is good about it but sometimes we miss something)

Date: April 30th

Occassion:

Time:

What happened?
I ate Breakfast
Corndog, Kodiak cakes
Syrup, and Hot Coco
With Creamer, Last,
I ate a Pi wheel

8:32

before

I put my epi pen purse on ~~the~~ School.

Occassion:

Time:

Lunch at school
and had chicken,
apple sauce, yogurt, and
Cookie oreo.

~~12:05~~

12:05

Occassion:

Time:

What happened?
Dinner time!
Had a ~~hot~~ Bacon, lettuce, tomato
that my dad made
Made for me ~~on~~ on bread.
And my family. I put my epi pen purse in my

6:00

bag so I won't forget it.

Date: 5/1/18

Occassion: Breakfast

Time: 7:00 am

What happened? Smoothie: Fruit, milk, protein powder (nut free), + Vitamin C added. I made sure there were no mangoes in the frozen fruit blend. The pit to the mango is a cause to tree nuts.

Occassion: text w/ teacher
while at work

Time: 8:50 am

What happened? Received text from teacher asking if dum dum suckers are safe for Hallie, b/c she would like to use them as a reward for the class. I was not sure so I looked up the allergen info. on their website + then texted her back saying that they are safe for her.

Date: 5/1/18

Occassion: ~~Breakfast~~ Breakfast

Time: 7:00

What happened?

Smoothie!
It was really good,
But before lunch I
got really hungry.

Occassion: Cold lunch at School

Time: ~~12:05~~ 12:05

What happened?

Had my usual at lunch. Sandwich, chips, Cookies, Yogurt, Orange.
I get tired of it though. ALSO, today my friend had a granola bar with peanut butter. My other friend asked if he could have it. The friend that had the granola bar said no because it had peanut butter. Then my friend who wanted it said she could save it for me. Ugh I'm tired of this!!!

Occassion: Dinner

Time: 5:45

What happened?

I ate chicken and beef casadea. My dad made it.
It was ~~sooooo~~ good.

Date: May 1st

Occassion: After School Snack

Time: 4:00

What happened?

I got myself a cookie.
It was good. It has
Chocolate and Marshmello
in it!

Date: 5/2/18

Occassion: Breakfast

Time: 6:30am

What happened?

I made the same smoothies as yesterday but added a banana! I told Halie to wait to brush her teeth so she could have another snack right before we leave for school b/c she got hungry yesterday.

Occassion: Dinner

Time: 5:30pm

What happened?

We had Nachos w/ beef + chicken. Halie likes a lot of sour cream. ☺ Quick + easy dinner b/c I worked all day + it was so warm out so we wanted to swim!

Date: May 2nd

Occasion: Breakfast

Time: 6:35 AM

What happened?

I had a barrie smoothie.
It has Vitamin C.
It is yummy!!!

Occasion: Snack

Time: 7:50 am

What happened?

I ate yogurt.
Good but a little
sour.

Occasion: Lunch

Time: 12:05

What happened?

Turkey, Cheese, and Crackers.
Yogurt, Orange, Cookies,
and Chips. One kid was eating a granola bar that ~~she~~
I ONLY LIKED the
Cookies and Orange

Date: May 2nd

Occassion: Dinner

Time: 5:30

What happened?

Nachos!!!
Chips, chicken, cheese, and sour cream. I enjoyed it. It
was very good.

Occassion: Snack

Time: 5:00

What happened?

I got oreos to munch on before my reading homework.

Date: May 3rd

Occassion: Breakfast

Time: 7:30 AM

What happened?

I had 2 floats
I had peanut butter and jelly toast. Yummy! Not very filling
✓ Peanut Butter though.
I've been craving Jif my whole life.

Occassion: Lunch

Time: 12:05 PM

What happened?

I had a half of a sandwich, a yogurt, cookies, orange,
apple sauce. I get so tired of this lunch.

Occassion: Dinner

Time: 6:00 PM

What happened?

Giantas with guacamole with peppers and tomatoes.
It was so good.

Date: 5/3/18

Occassion: Breakfast

Time: 7:30 am

What happened?
Toast on Whole Wheat bread That is from a nut-free facility. It had JIF Peanut Butter + Strawberry jelly. Hallie is only allergic to tree nuts + not peanuts. JIF is one of the few peanut butters that are safe for her. This often confuses people, "I thought she was allergic to nuts?" So I mostly tell people that shes allergic to all nuts. I don't want them to not believe me, or think peanuts are ok + feed them to her b/c most of them are
Occassion: processed in facilities w/ tree nuts and not safe
Time:

for her! So we only do JIF peanut butter and only
at home.

↳ she ended up making herself a
second piece

Occassion: Pack Made a sandwich
Time: 7:50am

What happened?
for school lunch

Turkey + cheese + mayo on whole wheat
bread from nut-free facility.

Date: 5/3/18

Occassion: Grocery Shopping @ Costco Time: 4:30 pm

The kids went w/ me. Of course they want the samples. I read the label on every sample to see if it is safe. They seemed to be doing all Mexican food samples and Hallie was able to have all of the ones she wanted. We ended up ~~buying~~ buying chicken flautas that they sampled & guacamole for dinner tonight. I check labels on everything, even if I've checked it before, because sometimes it changes & something that was once safe isn't any more! Hallie used to be allergic to coconut, but is not any more. She and I like coconut milk.

Occassion: ~~I bought some for a soup I want to make, for smoothies, & for cereal. This was at~~ Time: The label was a first for me: it said it is made in a facility that also processes tree nut products, but it had a whole paragraph explaining their cleaning process & testing for cross contamination in order to prevent cross contamination. It convinced me that they do a good job & I bought it!

Occassion: Field Trip Time: 9:30 am.

No food involved but I chaperoned, I met the bus at the destination. Hallie self-carries her epi-pens and she had forgotten them at school! I always keep 2 in my purse so it's a good thing I was there.

Date: 5/3/18

Occassion: Dinner

Time: ~~5:45~~ pm
6:00

What happened? Chicken fajitas & guacamole from Costco, labels read safe for her. Also cut up peppers, broccoli, & tomatoes. Water to drink!!

Occassion: Email

Time:

What happened? Today I emailed the volleyball club that Hallie is registered to attend today clinic w/ on Saturday. I wanted to know if there would be an adult there who is familiar w/ epi pens so I could leave her & not stay the whole time. They replied & said one of the coaches is a school ~~awkes~~ nurse & is comfortable w/ keeping an eye on Hallie. YAY!

Date: 5/4/18

Occassion: Breakfast

Time: 7:20 am

What happened? Smoothies again! W/ the new coconut milk,
I bought yesterday, protein, Vitamin C, berries,
banana, yogurt.

Occassion: Jog-a-thon @ school

Time: 10th

What happened?

Hallie was running, I volunteered. The
school gave apples + popcicles for snacks.
I checked the label on the bag of popcicles
+ they were safe for her! Not all popcicles are -
I was relieved I didn't have to run to the
grocery store!

Occassion: After School

Time: 3:30

What happened?

Strawberry lemonade (strawberry puree in
lemonade)

Date: 5/4/18

Occasion: Open house event
@ a spa/salon.

Time: 5:30 pm

What happened?

Hallie got her hair done + smelled essential oils. BUT they served cookies we had no way OF knowing if they were safe so she could not have one. I felt bad and she felt it WAS unfair. Also they were sampling lotions but none OF the employees knew the ingredients! So we stayed away from those too.

Occasion: Dinner

Time: 6:30pm

What happened?

Dad got Burger King.

Date: May 4th

Occassion: Breakfast

Time: 7:27

What happened?

I had a berry smoothie with yogurt and coconut milk.
~~Coconut~~ Coconut is safe for me now.

Occassion: Lunch

Time: 12:05

What happened?

I had a flourita w/ ~~cheese~~ guacamole, peppers w/ ranch,
yogurt, and orange, and chips.



Occassion: Open house at a Spa ~~place~~ Time: 5:30

What happened?

I could not have a cookie and my sister got one.
I was mad. !!

Date: May 4th

Occassion: Dinner

Time: ~~6:00~~ 6:15

What happened?

We had Burger King.

~~It was good!!!~~ I got a chicken sandwich and
onion rings w/ fry sauce.

Date: 5/5/18

Occasion: Breakfast

Time: 7:10 am

What happened?

1 Blueberry pancake
+ small bowl of oatmeal

Occasion: ^{her} Packed ^{lunch} ~~lunch~~

Time: 7:30 am

What happened?
Packed Hallie's lunch for volleyball camp. 1/2 turkey & cheese sandwich, sliced peppers + ranch dip, applesauce, an orange, chips, + yogurt.

Occasion: Volleyball Camp

Time: 8:30

What happened? Dropped Hallie off. Talked to the coach who is a nurse. She asked ~~me~~ about signs of a reaction specific to Hallie. She showed me snacks they had to share w/ all kids: water, apple juice, capri-sun, + applesauce. The applesauce had cinnamon added. It listed ingredients but did not mention anything about allergens. I assume they are safe.

Date: 5/5/18

Occasion: Snack

Time: 4pm

What happened? I gave my kids and the neighbor kids who were all playing out front some oreos to eat!!

Occasion: dinner

Time: 6:00pm

What happened? Mexican Quinoa Skillet w/ Avocado on top. It has black beans, seasonings, and a lot of veggies. Hallie loved it and had a second serving.

Occasion: dessert

Time: 8pm

What happened?

Brownies w/ a mix that is safe for Hallie w/ Vanilla ice cream that is safe!

Date: May 5th

Occasion: Breakfast

Time: 7:45

What happened?

I had a small pancake and oatmeal.
I liked the pancake but not the oatmeal.

Occasion: Volleyball Camp !!

Time: 8:30

What happened?

My mom had to talk to the coaches about my allergies.
It was kind of embarrassing.

Occasion: Lunch at camp.

Time: 12:00

What happened?

I ate my lunch which was Peppers w/ ranch, yogurt,
orange, and chips with my friends.

Date: May 6th

Occasion: Dinner

Time: 7:45

I had kinda w/ ~~an~~ avocado
and sour cream and salt.
It was very ~~yummy~~ yummy.

Occasion: Dessert

Time: 7:55

We had brownies w/ ice cream. I was sooooo
good.

Date: 5/18/18

Occassion: Breakfast

Time: 8:00am

Toast w/ peanut butter + strawberry jelly -
↓
(whole wheat) ↓
 (JIF)

She drank an Emergen-C and a hot coco
blc she woke w/ a sore throat.

Occassion: Snack

Time: 11am

After church she had a brownie from last night

Occassion: Church

Time: 9:30 am

They have ~~snacks~~ in kids' program. I always check what they are having. Today was rice crispy treats which are store bought + safe. Once I had her stay in church w/ us blc they were having cookies w/ macadamia nuts. The teacher said "well I can give her something different than the other kids" - heck not! 1st - Safety - over the eating nuts around her!?! 2nd - Inclusion - She always feels left out. Another time we literally left church. She used to be allergic to coconut + they made popcorn popped in coconut milk. Everyone around was eating it.

Date: 5/6/18

Occassion: movie

Time: 12:10 pm.

What happened? Hallie & I went to see Black Panther. She got a root-beer & Jr. Mints. She was too nervous to eat them so she held them in between her legs the entire movie. After the movie, she wanted them, but they had melted into 1 big blob.

Occassion: Lunch

Time: 3pm

What happened? When WL got home from the movie she had leftovers from dinner last night - the Quinoa dish w/ avocado.

Occassion: Dinner

Time: 6PM

What happened? Veggie soup - home made w/ spices. Yummy & Hallie liked it. Brownie for dessert.

Date: May 6th

Occassion: Breakfast

Time: 8:00

What happened?

I had peanut butter and jelly toast, with hot coco w/
It was good. coconut milk.

Occassion: Snack

Time: 10:50

What happened?

I had a brownie before I read.
It is a good snack.

Occassion: Movie

Time: 12:05

What happened?

I had popcorn and pop.
I was good.

Date: May 6th

Occasion: Lunch

I had ~~the~~ leftovers from dinner last night. It was
Very good.

Occasion: Dinner

I had a veggie soup. I Was SOOOOOOOO
Good!!!

Occasion: Dessert

I had a brownie w/ melted junior mints.
I Was Very good. Soon after I had some gummy
sharks.

D2 / Interview Guide

1. We noticed in your post on Monday, April 30th that your husband purchased cookies you have never heard of, and you double checked the label to make sure it's safe. You also mention how he's good about it but sometimes you miss something.. Could you tell me more about that?
2. You mentioned how you texted Hallie's teacher regarding dim sum, can you talk a bit more about your communication with the school/teachers/school nurses?
3. You mentioned brushing Hallie's teeth before having another snack, is there a particular reason for this related to the food allergy?
4. You also mentioned making a quick and easy dinner after working all day in one of your diary entries. Could you tell us about how you decide what to make on days that are busy for you? Versus days where you may have more time on your hands?
5. You mentioned how you just tell other people that Hallie's allergic to nuts since it's easier that way. Can you talk more about how you communicate with other people about what to do in certain situations? And what is the usual response?
6. You mention you read food labels on everything, even if you have already checked them before. Could you speak through that a bit more?
7. In that same post, you mention how Hallie was allergic to coconut but is not anymore. How did you know? What was that like?
8. In another post you mentioned watching a movie with Hallie where she was too nervous to eat the Junior Mints. Could you speak more about that? How often does that happen? In a later post she mentions eating junior mints with ice cream.

For daughter

Hi _____, so we saw your diary notes about the foods you ate during the week. They looked great! We're just going to ask you a couple questions about that.

1. So we noticed you have a purse for your epipen, can you tell us more about that?
 - a. Do you ever forget it?
2. You talked about how you weren't able to share a granola bar with your friend at school because it had peanut butter and said that 'you were tired of this :('. Does this happen often and can you talk about how you feel?
3. You talked about how you got tired of eating the same thing over and over, can you talk more about that?
4. You mentioned how it was a little embarrassing how your mom had to talk to your coach about your allergy? Can you talk more about that, do you get made fun of about it or what is the hardest part about it?

D2 / Interview Notes

We never allow anything in the house that Hallie is allergic to. Every once in a while my husband and I will bring in something. Hallie always finds some chocolates.. So sometimes we will put them somewhere high. But Hallie said that doesn't mean I can't reach them. Mom replied, well you know you shouldn't.

They check the labels on everything, even if we checked before because sometimes it changes. If the labels aren't clear (Bc by law they don't have to specify what else has been produced in the same facility). If the labels aren't clear, i'll check it on the website or call the company and find out myself.

We found out she was allergic at age 2, now she is 11. I've been dealing with it for a long time. When she was first diagnosed, the allergist was like, she was extremely allergic, she can stop breathing in as little as 10 seconds any moment.. Here's a packet of information - Bye! I have to teach myself and use websites to look at things.

I'm so scared so i'm super cautious and check labels and call companies so my daughter doesn't die.

So she used a lot of websites to look at things.. And i had a friend who has a son who also had a tree nut allergy so she helped me out.

I was scared so i was super cautious so i checked a lot of labels and called companies on the get-go.

School challenges - there is a facebook group, NoNutsMom group that was extremely helpful (it's where i found you). It was helpful because people would post articles. I think it's a manager on the facebook page who writes articles about writing 504 plans and whatnot. I don't know they just post information they come across.

Hallie had a severe reaction last november, so i had to go off that FB page for over a month. I would hear stories about other kids and their stories, and it would re-trigger my anxiety so i had to get off of it for a while.

She has 2 teachers right now, previous gardes has been one at a time. Each teacher has been awesome. Each teacher she has had was careful and cautious and has had good communication with her. They have not always been awesome at helping her feel included but they tried. I have not felt the same way about the school nurse. I have butted heads about her allergy. Each individual teacher has been great. A couple times a week i communicate with them.

Hallie: My teachers are nice.

Hallie: I'm used to getting fruit snacks and not having cupcakes or not having anything while everyone else is having anything. It started happening but now i'm used to it. They usually give me a fruit snack or a dum dum.

Emily- the school does not fully understand the impact of inclusivity or the impact of food allergies. If there is cupcakes or something and my child can't eat it, she has to be away from it, and for a long time i felt like it bothered me more than it bothered her. Over the last couple of years it seemed like it was getting to her now. They made brownies this year, the teacher did for the class to use as a fraction lesson and she couldn't have it. She brought the box to me to see where she got it and on the box it said "may contain tree nuts" i asked for her to wait to do the lesson tmw.. And the teacher said "well i think it's okay for her to know she can't eat that" and mom said "well this is a class activity and every child deserves to be included"

Hallie would say things like "oh one of our classmates brought cupcakes for her birthday and I couldn't have one." It's significant enough to tell me.

Hallie- Some of my friends know about my food allergies. I only talk about it if they have PB & J in front of me. But my whole class knows. And they are not nice about it. They will eat things that i can't have in my face. They will make comments and sometimes they say "oh it's Hallies fault." I'm used to it by now. I didn't like it. I came home upset.

Emily just lets people know Hallie is allergic to all nuts because she feels like if she goes into detail they will just get confused. If there is food involved she will ask what ingredients are in it. If she teaches people about the epi pen, i look into signs of anaphylactic and how to use EpiPens. I want everyone to know about her allergies because that will keep her safe. Sometimes Hallie will get tired of talking about it.

Hallie- I do not get tired of it. Sometimes maybe.

Emily- when allie was first diagnosed, when the doctor explained it, he said if he had the oil on his hand and wiped the table, and then Hallie touched the table, she could stop breathing in seconds. So i am very anxious about it.

At church, every sunday, i feel shut down a lot. They have snacks and the person that is in charge is like "yes i have a nephew with a nut allergy" so she comes in and asks anyway because she never comes in and assumes its okay. I always double check.

How do they educate grandma? I don't know if its just her and who she is, but she is absent minded about it. Since hallie's reaction in November, bc she was in the hospital and looked pretty bad so she was better about it. Grand dad is good about it, so she talks to him more when they go there and she hands him the EpiPen. When girls go to their grandparent's house, they have chocolate and walnuts and my parents will go out to their pantry and move it all to

the garage. I just don't trust her to take a hand full and eat them and then touch Hallie. I just don't trust them.

Hallie's epipen purse- I carry my hand sanitizer and epi pen in it. I got it at a store. I almost carry it all the time at school and other places. I forgot it once. I just started carrying it last year. Before i wore a lanyard.

It's her responsibility not the school but the school has one in their classroom and in the office.

I switched from the lanyard to the purse because the purse was easier to carry. She picked out the purse that she liked. It's blue.

I don't remember it hurting so bad, but i was having a reaction. Needles don't hurt me that much. It just hurts when they push it all the way in and they mash it in there.

I don't know if i would be able to to stick the epipen needle in myself. I don't know why.

Emily- that's why i want trained adults around me. Because i don't think she knows when to use it.

Hallie- i practice using it. I have a trainer one without a needle. We practiced with the needle that was expired on fruit.

One of my friends is allergic to peaches, she's not severe. (hallie whispers *mom make sure we don't have any peaches*)

I don't like wearing a purse everywhere. Sometimes i do, sometimes i don't. When I run i don't want it to move everywhere. My closer friends know what this is, but not everyone knows its an epi pen.

November allergic reaction experience- Emily- it's so crazy. We were at the hospital visiting my grandma, our whole family. We went to the cafeteria to eat dinner. Hallie ordered mac & cheese. The thought didn't even occur to me to check. And you know, you think mac and cheese is mac and cheese. It's her favorite food, or at least it was. We sat there, the 4 of us. She said the taste was really spicy, and we were yelling at her because we thought she was complaining (Because i do that a lot). I took a bite of her mac and cheese and it was very bland. So i went to the cafe to ask if there was nuts, and the cook said he doesn't know. He came out and said yes there are cashews in it. So i ran back to the table, and Hallie was crying. I grabbed hallie and the epipen, so i just took her to the ER. I knew there was actually cashew her worst allergen, so i immediately Epi'd her. The ER was packed full - and i went straight to the table and said i need help, my daughter is having a reaction. The lady said YOU HAVE TO WAIT IN LINE. The waiting room was packed full. I thought i would have to put her on the floor. And the security guard said come with me ma'am, and we went to the cubicle, i sat her on the chair, i

took the epipen out and then right when i was about to inject her a nurse came out and supervised as i injected her. The nurse then said she is breathing okay, do you want to take her home? And i said no, she needs to be checked out. They got a wristband on her and took her back to the room. Hallie was better for about 5 minutes. Then she got worse, her whole body turned red. She was breaking out in hives.. Like one big solid hive all over her body. I kept calling the nurse by hitting a button saying my daughter needs more epinephrine, we had to take the other nurse out of the room. At one point it was my dad and i in the room. So instead of waiting, then i ended up giving her my second epipen, but then she started vomiting. So i tried catching the vomit in the bag, then a nurse came in with a syringe and gave it to her while she was vomiting then she was improving minute by minute. Before the second epi, her eyes rolled back in her head. Her blood pressure dropped so low.

That was my first time using the epi pen.

Hallie- I was scared i was going to throw up and that's it. My stomach hurt, and that was it. I wanted to fall asleep, but mom said i fainted i didn't fall asleep.

We never had to use the epipen again. There was a hard reminder to be more careful. Being more careful is like, that situation, now i literally ask the server at the restaurant if they aren't sure about the pasta can i see the package. And not ordering things we aren't familiar with.

Hallie- if i go to the restaurant i didn't even know my mom talks to the waiters. I was just really hungry. They ordered appetizers. When we got there it was on the table. The waiters were great about it talking about what is safe for different allergens. We use new utensils, they had a whole protocol.

My sister got to eat a cookie and i couldn't. It wasn't fair because i wanted it to be equal. The cookies were just sitting out and there was no sign on whether it was safe or not. I got mad at my sister. My sister may have felt bad.

Hallie- my friends always have something that i can't always have. Almost always. I dont think they realize it because its like peanut butter jelly. They use it against me sometimes. Like they might eat it so i can't be around them.

There's this one friend who is not the greatest of friend. Middle school drama stuff. She said to Hallie before i'm not gonna bring PB&J, and then when she decides i'm mad at Hallie, she brings PB&J. It's like her way of saying, i'm not going to sit by you. Hallie doesn't really do anything about it, she just sits by herself. I'd like them to be nicer about it. It'd be nice for them not to do that stuff. I wish my food allergy is less severe. If i had a wish from a genie, it would be to have people be nicer about it. Just not talk about it maybe.

Emily- i wish everyone can understand the severity or significance of it. Like the life threatening conditions of it. People don't get it. If they did, people would be nicer and included more and be safer.

I'm very focused on Hallie. I have been vocal on Facebook really. It's hallies decision. Now I do speak up because it has helped people within my circle of friends. She said it was because of my post to email the coach. There are a couple more kids that are going to be more included and not excluded in a team activity. I wish schools were universally better. I wish they didn't use food-based incentives at all. I wish there were laws how things were regulated on food. I wish there were more specific laws for schools.

I felt better trained than the nurses when we were at the ER.

Volleyball camp- I was embarrassed. I feel like people were listening to that conversation with my mom and my coach. A lot of people were warming up, i dont think a lot of people figured it out. People were like, they had donuts there and were asking for donuts and if they did they would have to wash their hands afterwards.

Julie Brown - find her on Facebook. She does research for food allergies and is a big advocate. She does the ER for seattle children's. She is so big on training emergency personnel and families who use Epi first. She has some YouTube videos as well. Right now she is trying to make a video of kids with food allergies to enjoy and live life normally. So people are responding with pictures.

The school nurse thinks it's fine to lock the EpiPens in their office and that's not okay. And we have a fight about that. She's an RN. She should know.

EpiPen shortage, but we have so many that are good for a year so we are good. I want to go to UW.

D3 / Child's Entries

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DAY ONE

What happened? (Anything you did, something someone said, an event that occurred)

I wanted some of my mom's lunch.

What did you think? (Concerns, feelings, questions)

I had to find the box and check the contains/ingredients.

What happened? (Anything you did, something someone said, an event that occurred)

I wanted to have some crackers before dinner.

What did you think? (Concerns, feelings, questions)

I had to check the ingredients before I ate them.

DAY TWO

What happened? (Anything you did, something someone said, an event that occurred)

I was at church and my sister took out a snack and started to eat it but, it had nuts in it.

What did you think? (Concerns, feelings, questions)

I asked to put it away after I checked the ingredients.

DAY THREE

What happened? (Anything you did, something someone said, an event that occurred)

Write description here

I didn't have
to think about it.

What did you think? (Concerns, feelings, questions)

DAY FOUR

What happened? (Anything you did, something someone said, an event that occurred)

Write description here

I was in literacy class
and someone took out a
granola bar made out of
nuts.

What did you think? (Concerns, feelings, questions)

I had to step out of
class while they put the
granola bar away.

DAY FIVE

What happened? (Anything you did, something someone said, an event that occurred)

Write description here

I didn't have to
think about it.

What did you think? (Concerns, feelings, questions)

DAY SIX

What happened? (Anything you did, something someone said, an event that occurred)

Write description here

I sat down at my lunch table and someone was eating a nutella sandwich.

What did you think? (Concerns, feelings, questions)

I got up and walked out for a couple minutes.

DAY SEVEN

What happened? (Anything you did, something someone said, an event that occurred)

Write description here

I was in a room full of nuts and had to step outside for a brief moment.

What did you think? (Concerns, feelings, questions)

I stepped out before my eyes swelled up shut.

What happened? (Anything you did, something someone said, an event that occurred)

Write description here

I went to a restaurant and had to not eat the bread and special order!

What did you think? (Concerns, feelings, questions)

Sad cause the bread looked good

D3 / Mom's Entries

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DAY ONE

What happened? (Anything you did, something someone said, an event that occurred)

Younger siblings soccer

What did you think? (Concerns, feelings, questions)

Worried about someone buying donuts as often happens as he cannot eat them and it always makes him sad.

What happened? (Anything you did, something someone said, an event that occurred)

Shared my lunch with him

What did you think? (Concerns, feelings, questions)

Before permitting, he had to look through the ingredients and cross-contamination list on the box.

What happened? (Anything you did, something someone said, an event that occurred)

Was out getting him new clothes and at checkout counter in clothing store were protein bars (all nuts) and candy bars

What did you think? (Concerns, feelings, questions)

Amazed at how nuts are everywhere - even clothing stores. Spoke to him the importance of always having epi-pen

What happened? (Anything you did, something someone said, an event that occurred)

Grocery Shopping

What did you think? (Concerns, feelings, questions)

Had to look, as always, at all labels - especially ice cream. Takes a lot longer to do this than just shopping without looking.

DAY TWO

What happened? (Anything you did, something someone said, an event that occurred)

Found a snack one of my kid's friends had brought over and left here - Cashews!

What did you think? (Concerns, feelings, questions)

Checked to see if it was open - it was still sealed. Breathed easier then disposed of and washed surfaces and hands.

DAY THREE

What happened? (Anything you did, something someone said, an event that occurred)

~~Matt~~ Sent him to school and had to be certain he had his epipen.

What did you think? (Concerns, feelings, questions)

Hoping if he has a reaction that someone knows he carries an epi-pen.

DAY FOUR

What happened? (Anything you did, something someone said, an event that occurred)

Meal planned - considering his food allergy. Tried to be creative with ingredients I could use.

What did you think? (Concerns, feelings, questions)

What happened? (Anything you did, something someone said, an event that occurred)

Heard from my son that a friend at school forgot about his allergy & started eating nuts near him in class.

What did you think? (Concerns, feelings, questions)

Felt bad for my son for worrying about simply being able to breath. Felt sad for his friends who are also burdened with it by association.

What happened? (Anything you did, something someone said, an event that occurred)

What did you think? (Concerns, feelings, questions)

DAY FIVE

What happened? (Anything you did, something someone said, an event that occurred)

Received email from school concerned because my son asked to leave a room to take a walk b/c someone was eating nuts.

What did you think? (Concerns, feelings, questions)

Had to defend my child and his safety in school.

What happened? (Anything you did, something someone said, an event that occurred)

Teacher emailed again stating she did not realize the severity of his allergy. Included guidance in email.

What did you think? (Concerns, feelings, questions)

Wondered how this was possible. Frustrated.

DAY SIX

What happened? (Anything you did, something someone said, an event that occurred)

Received email from nurse asking us to add his allergy info to a 504 plan.

What did you think? (Concerns, feelings, questions)

Amazed this is considered a disability but willing to do anything to keep him safe.

What happened? (Anything you did, something someone said, an event that occurred)

Emailed guidance w/ request

What did you think? (Concerns, feelings, questions)

Feel bad about need to advocate for a teenage boy and make life tougher than it already is.

DAY SEVEN

What happened? (Anything you did, something someone said, an event that occurred)

Had to bake siblings' birthday cakes so he could eat them as he cannot eat food from bakeries.

What did you think? (Concerns, feelings, questions)

Wishing siblings could have cuter cakes but better to include me instead.

What happened? (Anything you did, something someone said, an event that occurred)

Went to restaurant and had to be very careful & intentional about food.

What did you think? (Concerns, feelings, questions)

Tedious & concerning even though we were told it was safe. Felt bad he couldn't eat the bread.

What happened? (Anything you did, something someone said, an event that occurred)

Was at event with nuts and he had to step outside because his eye was itchy.

What did you think? (Concerns, feelings, questions)

Went outside w him and felt bad he had to leave the event.

D3 / Interview Guide

1. Name/How old is he?
2. First thing I noticed was that he seems to be severely allergic to nuts. Can you tell me more about his testing process?
3. How many reactions has he had?
4. How has this affected your life as a mother of a child with allergies — I can feel your pain in terms of feeling bad for your child?
5. What's the hardest part for you?
6. What is your child's personality like surrounding his allergies?
7. Can you talk to me about your relationship with school? I noticed you had issues with his 504 and their understanding of his severity of his allergy?
8. What are your thoughts about him growing older with this — starting to gain more independence.
9. You made a comment about feeling bad for the other children who have to deal with his food allergy, can you tell me more about this and your feelings about the surrounding community that doesn't deal with allergies?

D3 / Interview Notes

Son is 13 years old.

One of the first things I noticed is that he seems to be severely allergic to nuts. Can you tell me more about his testing process?

- discovered it when he was 5 so he was born with it, he developed it
- all tree nuts, discovered when he started eating nutella and broke out in hives around his mouth

What would you say is the hardest part for you?

-I think when we're out and about. It's probably when we're, not even at restaurants because even though or he might 'are there nuts?' if there's no nuts doesn't necessarily mean they're safe to eat

What is his personality like surrounding his allergies?

- i think i probably project that onto him because i get sad for him
- went out to dinner for celebration, went to place so they could accomodate his eating but couldn't eat bread so we all ate and he didn't
- he's very understanding of it, hypervigilance, would rather be crying about everything in front of him rather than have a reaction.

Does his hypervigilance stem from anxiety or just him wanting to be responsible?

- definitely anxiety surrounding it

When was the last time he had a full blown reaction?

- a year ago we were in a room that had a plate of walnuts and his eyes were starting to close
- there was a time recently with walnuts but we noticed it together, gave him benadryl and walked out

Can you talk to me about your relationship with his school?

- he's in middle school now
- elementary school is much easier bc they say nut free classroom, but middle school not willing to do that, so much harder
- friend of him brought in a granola bar with nuts and pulled it out for snack while sitting next to him and son asked him to throw it away?
- socially it's challenging for him
- let the teacher know about his allergies but they can't declare a room to be nut-free

Had to resubmit 504?

-it wasn't in his 504 in elementary school because it was easy for me to write it in. so i didn't think to add it last year for 6th grade

-his teacher did email me to say 'hey, i'm bringing in treats for the class' but this year it was the first time, he left the class a couple times because he's not comfortable being in the classroom.

-I think she was looking for a way to bust him...i think she was looking for a reason to say you mom said you're not leaving the room' but he knows his body and if he wants a few minutes to breathe...

-my reaction was 'maybe we should add it to the 504'

What are your thoughts about him growing older with this allergy, starting to gain more independence?

-So he's very good about identifying what's safe and not safe, and good at abstaining if he's even unsure, better safe than sorry method.

-I'm concerned about long term especially in college. He's going to be away away. I have no control of any of his food

-Arming him with the tools that if he should ever have a severe reaction

You talked earlier about feeling bad for the other children who have to deal with his food allergies..

-i'm sorry that his allergy has to affect them but they don't have the freedom to eat what they want where they want so i do feel like that is putting a burden on them but at the same time, i'm not going to say don't worry about him

-sorry not sorry

Noted allergy causes conflict in the family?

-we've got 5, he's the second oldest. They're very understanding

-but there are times when his sisters want a granola bar or he will see them eating a granola bar even if they're eating on the porch

-he'll yell at them and say 'that's not safe, you can't eat that near me, i'm home'

-maybe they'll eat something when he's not home but throw the wrapper in the trash and he'll be very concerned that they ate it in the house

-it's really based off of his anxiety that that happens

How do you buffer that as a mother?

-i let his sisters keep nuts in the house if they're individually wrapped like granola bars or individual bags of cashews in a certain spot

-but they're not allowed to even open them unless they're away from the house, they can't eat or open it near him

How's your grocery experience like?

-It takes a long time

-found cross contamination with nuts even in rice

-i used to buy this one kind of rice and it was fine, sometimes label changes so it was baffling that companiesit's tedious. There's certain things to be cautious of brands..you can eat generic but not oreos...can eat hershey bars but mini ones are processed with nuts.

-it's so confusing

Do you ever use online communities as a source for information about what to buy?

-I do follow a facebook group, No nuts mom

-they post no nuts chocolate, only a few brands I buy that are truly no nuts? Usually can find a nut variety in a grocery store so i don't have to buy specialized food.

Also in diary, he seems pretty good about keeping his epipen on him?

-We have a whole lot of them and we really enforce that

-That's hard as a boy because he can't carry a purse and make it look normal

-So he has a couple things he uses. Baseball bag, or backpack, the school nurse has one. We have one in each of our cars. He has a little case, a handheld and he also has his belt. Almost like a running belt that you can stick your wallet but it actually sticks an EpiPen.

Is it specifically designed for EpiPen or lifehack?

-It was a lifehack for sure. Our friend whose son has diabetes uses it..it's a wide elastic that goes around his waist

What do you think he would say would be the hardest part of his experience dealing with food allergies?

-Just the restrictions, the hypervigilance he has to have all the time, everywhere he goes.

-I would just say just always being aware of everything he puts in his mouth

Does he have issues with friend relationships at school?

-no nothing to do with his allergies that affects his relationships

Phone Interview

P1 Interview Notes

9th grade, liking it a lot, Juanita in Kirkland
Biology, I like learning about cells. I like all my classes tbh
I don't know what I want to be though, def not a teacher

Peanuts, tree nuts, and soy. Not almonds
Basically, looks similar
If it's really hot outside, my body will think its a peanut
If you look at the ingredients in a lot of groups
Condensed soy protein in chicken...
Look at the back, and the ingredients involved
After 5 or 6 ingredients, it probably isn't of high quantity level to affect me
Soybean oil doesn't matter, since its only the protein that's left

Only time that it
2 years ago, I've never eaten a hot lunch
Nut free school
Second ingredient was soy protein
Went outside
Hives on her face

- Kind of weird, last time I've had a reaction was when
- 7 and then 13

Wondering, what am I reacting to exactly?

- Well its nut free
- Auvi Q doesn't hurt, it's cool

Felt like my face was all puffy,
Asked friend
Went to the office,
Ok, allergic reaction
Applied EPI
Went to hospital

It was my forehead. Felt like I got hit in the head. Went up to friends, what was that like

All friends know about food allergy
OMG are you OK. Yeah I'm ok..
They had no idea

Went to catholic school kindergarten to 8th grade which was Nut Free
School now is not nut free
Mostly bring school from home which is what I've been doing most of this year

Just because my mom was concerned and was skeptical
Used to making my own food at that point
A lot of time, I'll just buy store bought food but homemade food just tastes better tbh

Now, I still take food from home
Now that I have no way of knowing at all
Food at school looks kind of gross

Called up the place beforehand at volleyball problem

- Happy to accommodate
- Took in order and

Is that a typical scenario

- It's just what is

People don't comment on it.

Sometimes my mom, dad, and brother will get something and I'll eat pasta. But I don't mind since I love pasta.

Mom has epi pens in her purse
If for some reason I didn't
She's more careful than I am tbh
She reads through the ingredients again even though I've already done it
Kind of nice, not a big deal
I like it

One in my backpack, one in my purse
I've just always had it for most of my life

They're smaller
Someone else could do it
It's more user friendly
The Auvi Q tells you what to do

2 ways of testing allergies, both kind of weird
Blood test, I haven't done it for a few years

Very annoying since they're itchy

Anything to make living with your allergy easier?
Maybe sometimes there will be places that don't totally understand

- Their response is not confident

It may contain" label

A lot more people are becoming aware of it

My brother and dad would probably figure it out, but honestly they don't know much how to proceed with this stuff

Will eat nuts separately, at work or garage...

I know he cares because he was very convinced something that has nuts and was super serious about it

Other people seem to care a lot more about it than her

It's nice I can tell that people care about me

P2 Interview Notes

When i have a reaction, my stomach starts to hurt. It depends on what I eat. My tongue will get itchy. I'll know by the feeling in my stomach. I can't explain it. It's like a tight burning cramp. Not like a stomach ache, it's a tightness that also feels like it's burning.

Mom also has a food allergy that she grew up with, before I knew about my daughter's food allergies, I automatically assumed she had it because of my food allergy.

I took her to the ER when she broke out into hives when her cousin accidentally spilled milk on her, that's how we found out she was allergic to diary amongst other foods.

I skipped the long ingredients and read the bottom where it usually says: contains nuts and milk.

I felt my lips getting itchy, she gave me benadryl and i swashed my mouth out. I felt it getting worse so mom gave me the epipen, then it took the ambulance 5 minutes to get home. It kind of felt getting worse, then I got tired. When I got to the hospital we were there for like 4 hours and then felt fine and nauseous when I was there.

An epi-pen is a needle like a shot that gives me benadryl when I am having an allergic reaction. I know how to use it, but never used it before.

The nurse used the epipen on Shayna once and then the ambulance used the epipen once on the way to the hospital.

Last day of school, shayna ate a piece of candy that she usually always eats and she had a reaction. The school nurse had an epipen and administered it on her.

It was the same exact brand, same exact flavor, and same exact candy, but for some reason this one had eggs. It was a larger size. It was a laffy taffy. This one had egg whites for some reason. I am not sure if they changed the ingredients or what happened.

Every grocery trip involves looking at labels every single time. It also happens that we check the ingredients before we cook or eat before we get home.

When she has a reaction, everything else that's going on just stops and I go to her to check to see if she needs an epipen, benadryl, or what's going on. I bring in to action and ask her questions. I stay by her side, monitor her symptoms and figure out what course of action to take. She has a lot of panic because it's a scary thing.

I don't let any emotions come in play and they don't usually until things have calmed a little bit and I can reflect in the hospital.

Mommy I really thought I was going to die this time after this reaction. How would you feel if I died? When my daughter asked that it hit me harder this time than it ever has. I get angry that she has food allergies and it's a scary thing. It's scary to even send her to school knowing a hug or a high-five could potentially be deadly. There's a lot of emotions. Fear, anger, sadness, painfulness.. It's a lot.

I feel relieved after she has the epipen or when the EMT shows up. It's protocol, when you administer the epipen you have to call the EMT.

When I have a reaction, i'm aware of what's happening to my body, but i'm not aware of what's around me or how my feelings are. I just know i'm nervous, scared, and that's all... I'm nervous and scared. I feel like I was going to die because i couldn't really breath and that has never happened before. Usually I could breathe perfectly fine when i am slightly exposed. My stomach hurt more than it usually does. It made me scared.

School has been pretty good with her allergies as far as meeting with teachers and school administration beforehand. To get a feel for where they are at and their knowledge for food allergies and get an idea on what they will do when it's time to call into action.

Teachers have usually been great with making kids wash their hands and wipe down surface areas. They've been great with the lunch room by having a separate table for kids with food allergies.

This particular year, her teacher has food allergies herself. So me going into the classroom to do my rounds, hearing that the teacher having food allergies relieves me knowing that this woman has experienced everything we have. She knows exactly what to do if something goes wrong or something needs to be done. Her daughter is a school nurse so it's a relief knowing that she will be in the hands of someone who has gone through it and knows what needs to be done.

I feel comfortable with my food allergies around my teacher because she knows what to do. Two weeks ago when i had my reaction, she heard about it and calls me over and talks to me about what happened and how i'm feeling and she was good about it. She puts in the extra measures. All of her friends were concerned about her as well.

I feel the most trustworthy of the current teacher.

Her first year going into school, which was very fearful for me since it was the first time going out of the house. Her teacher did not have a food allergy but still went above and beyond. She let

shayna eat in the classroom or bring extra class or if she didn't feel comfortable eating in front of the other kids.

All my friends know about my food allergy, even though we are technically not supposed to, we still share food. My friend gave me a few strawberries today but no one gives me goldfish or Cheez-It's because they know i can't eat that.

My brother has teased me over the years threatening to put food near me. When he was at the 'brat' age, thinking it was funny, he didn't know better.

My friends son was kind of bullying her by throwing peanuts at her (Shayna was too young to remember it). We left after that.

My dad is worse with food allergies than my brother. He's not in top shape or form with knowing much about it. He brain washes her into thinking she can eat specific things. Like she's lactose intolerant rather than being allergic. He has given her things with skim milk or with the sauce which was one or two nights. My dad is not good at cooking so my step mom will cook dinner breakfast and stuff and she's really good at that stuff.

The epipen goes really quickly, you don't really feel it.

Mom- when you are getting the epipen you are so focused on the fact that it is going to make you better. So you know to tough it out. I don't prefer to use it but if it was to save my life of course I would use it.

In elementary school i can't carry an epipen around but there is one in the school nurse's office and in the classroom.

I take the school bus, and there is no epipen there but no one is allowed to eat food on the bus.

If I had a wish I don't want my food allergy completely gone because it would feel weird. I am so used to knowing what i can eat or what I can do. I would want them to not be so bad. I don't want the symptoms to be so bad. I don't want to feel like i am going to die if i eat eggs or something like that i guess.

My cheerleading friends is allergic to gluten and peanuts. There's a boy in my class and also actually there's a lot of people in my school who have food allergies.

Most of the people who have food allergies are boys and the boys seperate themselves from the girls so I don't really talk to them. My cheerleading friends, Becca, we're close and we will talk but we aren't best friends.

I'm used to my food allergy so it's not too difficult to control. It's like a part of me I guess. It's like saying, describe your fingers. You just know... you can't describe it because it became a part of

me. It became part of me when i learned how bad it could be and learn how to say no and tell people what you can or can't have. My mom would tell me how to handle it. I also taught myself since i knew it could be life threatening and i don't want to die.

My best friend took a 4 or 5 hour class on how to use an epipen just for me. I was so happy she did that. If something did happen she would know... even though i know.. She would also know in case I forgot how to do it.

I never take my own food when i go to my friends house. My friends parents are really good with my allergies. If I need something they will go to the store and buy it. If they don't have anything I can have.