Interviewer:

All right. So my first question, before we get to introductions, we generally like to call this type of heart condition an anomalous aortic origin of a coronary artery or AAOCA. We just were wondering, is that what you guys also call it or is there anything else that you refer to it as?

Participant 4023:

That's what I call it.

Participant 2032:

I just call it a congenital heart defect. I can't say all those words, I forget all those words.

Participant 4023:

Yeah, the kids are usually the ones that say it, I turn to them and they'll say the whole thing. I'm like, "Yep, that."

Participant 2032:

"That, that thing."

Participant 4023:

Mm-hmm (affirmative).

Interviewer:

All right, so thank you for clarifying that. So if we can just jump into introductions really quick, everyone could go around and say your first name, your age and a hobby that you have or just something that you enjoy doing, something that brings you joy. I'll put this in the chat too.

Participant 4023:

I guess I can start. My name is (beep) and I am 42 years old. I have two of my kids who have this issue. I guess I don't really have a hobby, I guess they're my hobby. Everything I do is around them, so they take up all my time.

Interviewer:

Yeah.

Participant 2032:

I'm stuck on thinking about a hobby.

Interviewer:

Or anything you just like in general. I also have a hard time with these icebreaker questions, so completely understand.

Participant 2032:

I know, I know. My name's (beep), I just turned 60 and had a big blowout party for myself. I threw a party for 84 people and it was great. I live on Plum Island, Massachusetts and there was a musical festival that was happening all throughout the whole island and so people came to my house and they went to the different musical venues throughout the island and it was just a blast, it was a wonderful party. So that's just an interesting little thing about me and my son is 15.

Interviewer:

Thanks so much for sharing, (beep).

Participant 2032:

Yeah.

Interviewer:

(Beep), can you hear us? Would you like to introduce yourself?

Participant 1015:

My name is (beep) and I have a 16 year old that went for a sports physical and had a heart murmur and it was found that he had a congenital heart defect. And a hobby, he's a football player. All my kids are in something, so I'm a busy sports mom.

Interviewer:

Got you. Awesome. Thanks so much everyone, for sharing. For the second part of your introduction, can you tell us a little bit about your children, their ages and anything about them that you'd like to share?

Participant 4023:

Sure. Let's see, my daughter is going to be 12 on Friday and she's in a bunch, she's in dance, she's in this Mexican dance that we call... It's Baile Folklorico. So I kept her on that and she seems to be doing fine with that. And then we just maybe have under a year in jujitsu, so she's doing jujitsu now and that's where I'm at now, I had to go drop her off for that. She's active, she's a lot better than my son. My son now is 17 years old and we found out about this issue also with a physical.

Participant 4023:

Just the annual physicals he was having and the doctor heard what she thought was a small murmur maybe and didn't want to make a big deal but said, "You know what? Let's just take it to a cardiologist, just to see," and that's how he found his issue. But he's my worst one because I can't have him in any kind of sports or anything like that. He's in orchestra as well, so is my daughter but he's in orchestra and that's what he's been with and stayed in. But he really doesn't do a lot of the physical activities, his heart basically... He has a lot more, I guess effects of that than my daughter does. So yeah, it's tough.

Interviewer:

Thank you so much for sharing, (beep). (Beep)... Oh, (beep).

Participant 1015:

Again, my only child that has this problem, has this issue, is a 16 year old. He has been active in sports and football his entire life, from the age of about five. He's never had any issues, we went to have our physical every year. We went for our physical this year and that issue was discovered. He was still allowed to play football, so he is still playing football, starting running back on varsity.

Interviewer:

Wow.

Participant 1015:

And he's doing really well, not having any complications. So they will run some tests at the end of football season, to see if everything still looks the same pretty much. And he's number three of six, so we have four boys and two girls. No, four girls and two boys. And so that's it and three are in college, three are home and we're busy.

Interviewer:

Thanks so much, (beep). (Beep), would you like to share anything?

Participant 2032:

Sure. My son is 15, he's a sophomore in high school. He's adopted and unfortunately, it's a closed adoption, so we don't have any biological information. And also, unfortunately, how we found out about this was quite traumatic. It was a warm, hot day and he passed out at a football practice. So we're like, "Oh, all right, just have some water, lay down, you're dehydrated," so forth. And then he passed out again at school, they were walking around the school, some assembly or something and he passed out again and the nurse was there and she was able to see him and say, "This is not just passing out, something's wrong." So they took him to the hospital and that was our introduction to all of this and so we went and we're in Boston, so it was Boston Children's Hospital.

Participant 2032:

And they said, "Well, his cardiac rhythms are fine now," his EKG had been abnormal at the local hospital but when we went to Boston, it was fine. And they said, "Okay, go home. Everything's okay but come back in a couple of days for a stress test and an echocardiogram because we're a children's hospital and we want to be thorough," and blah, blah, blah. So we did that, so we went back to get the stress test and the echo and the echo shows that his heart is all malformed and we're like, "What the fuck?" Excuse my language. Oh, I forgot, this is being recorded too, great. Don't identify me.

Interviewer:

You can use profanity, there's nothing wrong with that.

Participant 2032:

But that was such a shock, here we are thinking he passed out, maybe something's going on. The next thing is, he has this AAOCA thing and he needs surgery. It was mind-blowing, it really threw us for a big loop. I don't know, do you want to know more?

Interviewer:

Oh yeah, please feel free to go. I have another question but if you weren't done, please continue.

Participant 2032:

So he had open heart surgery and I thought they were just going to move one artery to the other place in his heart. That was the thing, is there were two arteries coming out of the same place, instead of one there and one there type of thing. And so they didn't, they had to cut the artery and cut part of the heart to make the blood flow. It was just ghastly, it just was ghastly. I'd never been through something myself as a parent as horrible as that, I was a mess but he did fine, he did great. It's been three years now since he had his surgery and he's doing great but I worry because we get checkup every six months and now, I think it's every year because he's been doing so well but I worry because he's asymptomatic and so how do you manage that?

Participant 2032:

And he's cleared for sports, he doesn't want to do it. And originally, he was really into football and I said, "Oh, you're going to go for the high school team?" And he was like, "No," and I said, "Why?" He says, "Well, I'm really afraid," and I said, "Oh because of the impact on the chest?" And he said, "No," he said, "I'm afraid of the trainer or the coach really pushing. I heard they really push you really, really hard beyond your limits or to test your limits. I'm afraid that something bad would happen to me." And it broke my heart, it just broke my heart. So he's a very athletic kid and I don't think he's experiencing the full range of athletics that he could have. Okay, I'm all done now.

Interviewer:

Thank you so much for sharing and again, anyone feel free to jump in but I did have a quick follow-up for everyone. How did everyone else's children feel about sports and physical activity in general? Anything around exercise or being restricted with exercise?

Participant 1015:

I know...

Participant 4023:

So my son... Go ahead.

Participant 1015:

I know for my son, it was pretty devastating when we got the diagnosis because he is a naturally athletic young man, where he has college scouts and everything already calling us and looking at him for college ball. And the thought that he wouldn't be able to play was almost breathtaking for him and for us because we could see the devastation on him and the frustration on him, just at the thought of, everything he's ever known or done turning around. So it was rough, we were allowed to still train during the summer, so we still went to camps and things like that but I think the moment when the doctor called me when we were at a camp in Florida and he says, "I need you to make sure they have an AD..."

Participant 2032:

AED, AED.

Participant 1015:

It started hitting home. And so it just was a long, emotional... It took us about three months I think and it was just a long, emotional time, just trying to navigate through encouraging him, while we're really worried and things like that.

Participant 4023:

I know that my... Well, my daughter, they haven't took her off of anything, they said, "Just keep on doing what she's doing. She knows her limits, if she starts having pain or pressure," to stop. And my daughter's really aware of that and I think overly aware, so she's always constantly, "Mom, I think I feel something," or any little thing. And I tell her, "You know your body, you know how far you can take it." And my son, he likes to run, he used to always be running and doing stuff like that at track but then when we got this diagnosed, everything just stopped. And sometimes, he forgets and does it and then I guess he feels overwhelmed or something or he just has no confidence and he just looks... His face, you can just see it, he looks worried.

Participant 4023:

He just worries, he doesn't want to do it, so then he'll just sit. And I always tell him, "Well, at least, you have to go walking," and I have to push him, he doesn't want to do it. And now that he's older, I feel like I have to push him even more because I'm like, "You can't do this, you have to keep working your heart out. You can't just sit there." But I think he just keeps it in but I can see that he worries a lot about it and he's just stopped everything. Everything's, "Oh, well, I can't do that. What if something happens?" That's the first thing he tells me. I'm like, "Don't think that way." But the bad thing is, we worry about our kids like this and we're always around them, to try to make sure that they're safe. So when they're at school, these people at school, they don't know. These nurses, these teachers, they don't know. Not everyone knows about this type of diagnosis and they just don't know how to treat it, they don't know how to look out for that.

Participant 4023:

So I feel like every time I'm registering them, I'm constantly telling... "Who's the nurse?" Or, "Let me talk to the PE teacher, let me do this." And they do, they push the kids so far and that's how I found out my son had this, because the coach was pushing him to run so many laps in under so many minutes. If not, he was going to flunk him, so there we were, "Here, go push, push, do it, you need to do it," and he was stressing. And I always thought, he's so young, why is he having such a hard time? And then we go to this physical and then we find this out and we're like, "Oh my God, this is why."

Interviewer:

Right.

Participant 4023:

It's stressful on my part.

Interviewer:

Thanks, everyone for sharing, that's really important to hear. And I want to circle back to so many different things but one thing I wanted to go back to is that diagnosis moment and what were some thoughts going through your head, emotions, reactions? How did that feel?

Participant 2032:

I have a question, (beep). It's AAOCA?

Interviewer:

Some people call it AAOCA.

Participant 2032:

AAOCA, okay. So is that precise? Does my son have the precise thing as (beep)’s and (beep)’s son?

Interviewer:

I'm not personally a clinician and probably not the best person to speak on that. I don't know, (beep), if you want to jump in and say anything.

Interviewer 2:

Of course, so we don't know the specifics of each group, so we have different coordinators in each center, so we don't know what is exact disease of each of the child’s but you are here in the group because the diagnosis is in the same group. They all have AAOCA, which is the anomaly of the coronaries coming from the wrong side.

Participant 2032:

Right.

Interviewer 2:

So even if it's different for each other, it might be different degrees or characteristics but in general, they are all diagnosed with the same and that's why you are all in the same group.

Participant 2032:

Okay. Thank you.

Interviewer 2:

I hope that answers your question.

Participant 2032:

Mm-hmm (affirmative). It just seems to be so rare and so particular. We went for a PET scan over at a neighboring hospital because they had the newest PET machine and they were all excited that my son was there because they had never seen anybody like this. And one of the doctors, the head of Cardiology, I couldn't believe this, I was so upset, I was upset, she comes over and she's like, "This is so exciting." She said, "We've never had a child like this or a person like this. This is one for the record books. It's not like we can just go to a book and look up how to treat him. We're just going by the seat of our pants." I was like, "Are you kidding me? This is not what a mother wants to hear."

Interviewer 2:

No, thank you for saying that and one of the reasons why we put together people from different hospitals is exactly that. The condition is so rare and so uncommon that it's difficult to create a group with the same diagnosis in the same hospital. So we've had to go to other centers, so we can find parents with similar characteristics in the diagnosis of their children. But yeah, you're totally right and thank you for sharing that, that's exactly the information we're looking for future improvement.

Participant 2032:

Yeah and there were at least 12 cardiologists in the room while my son is running on the treadmill, all hooked up and then the chief of Cardiology comes over and says this to me and in front of my son, my son's right there. It was not a good scene.

Interviewer:

Yeah, I have a follow-up question but really quickly, I just want to say hi to (beep). (Beep), can you hear us?

Participant 3006:

Hi. Yes, I can hear you guys. I just had my camera on... I just got in a little late from work and I'm just finishing up my dinner, so that's why I have my camera off but I am listening and I will join in the conversation.

Interviewer:

Oh, great. Yeah, feel free to turn your camera on or off, we're just glad to have you. I just really quickly want to make sure that you had the chance to sign a form agreeing to participate, right?

Participant 3006:

Yeah, I did. It went back to Dr. Brothers and Antonia over at CHOP.

Interviewer:

Awesome, that's great. And also, we're audio recording this conversation, are you comfortable with that?

Participant 3006:

Sure.

Interviewer:

Okay, great. Yeah, if you could just go ahead and introduce yourself to the group, maybe your name, your age and introduce your children.

Participant 3006:

Sure. My name's (beep), I'm 51. I have three children. My son, (beep), is the one... He'll be 18 very soon, he's 17 now. He's the one who's diagnosed with the cardiac anomaly. We came on it accidentally when my son started, I think it was freshman year of high school. He was in a new school and he kept on saying and he even texted me from school one day, that he felt like his heart was racing and it sounded to me like... He's not a super anxious kid but it sounded to me like that could have been what it was, he was in a new school and meeting a lot of new people and it was a small STEM school, so really a different environment than what he was used to.

Participant 3006:

So we thought it was that. And then he had stayed home sick from school one day and he reported the same thing. I was at work but he had reported that he was feeling like his heart was racing. And on that day, he had had... I don't know if it was a cough or allergy symptoms and he had taken some kind of medication that he doesn't take frequently. So I attributed it to that and I'm a nurse, nurses are the worst patients, you ignore things until it's really evident something is not right. And actually, I said, "Let me just run it by my pediatrician. It doesn't seem like it's anything but let's just talk to her." So I did talk to the pediatrician and she examined him and she felt that nothing was wrong. And she said, "Well, since you're bringing this up, that this is not the first time you're concerned, let's just send him, just standard... Yeah, send him out. He can go to see a cardiologist and they'll just do a general workup and find out what's going on."

Participant 3006:

So when we went to the cardiologist, she did find that he was having heart palpitations and she found it to be that that was related to a completely different issue that has resolved since then, it was a completely benign issue. But because she did the full workup and she did the echo, she was like, "Well, we found this and that's what's causing his symptoms and it's really nothing." But she's like, "We also found something else that's really concerning." So at that point, she's our local cardiologist, we had a friend whose son had a medical condition that seemed to be something higher than what you would treat with your normal regular practitioners. So she had advised me, "You want to go to CHOP for this. It sounds like it's a little more complicated than the run-of-the-mill stuff here." And that's what we did, that's how we found Dr. Brothers. So yeah, she did verify that he had this condition.

Interviewer:

Yeah. And this question's open for everyone but can you tell me a little bit more about the moment of diagnosis, what that was like? What thoughts were going through your head at that moment?

Participant 3006:

I can speak for myself, when we first got the diagnosis from our local cardiologist, who was a pediatric cardiologist, she was a little bit of an alarmist. She made me really very, very concerned. She was like, "You're going to want to sit down. This is really big news here, I need to talk to you about this," and she made it sound like it was really something that was potentially very, very serious. And yeah, she scared me, she scared the crap out of me and she's always... We've disconnected from that practice, just because I don't feel a need to have two practitioners following this and Dr. Brothers is definitely the more experienced. She had come across this a few times before, our local person but Dr. Brothers, this is what she does. So we certainly felt a higher level of expertise was available to us at CHOP and that we could have confidence in the decisions that we made based on what Dr. Brothers was recommending for us.

Participant 3006:

I think that something's that's always been a little bit concerning to me, is that Dr. Brothers, she allows him to do a lot more than the local practice would have allowed. The local practice didn't want him to ever run, jump, sneeze or anything, she was really conservative about, he really can't do these things. And Dr. Brothers, she allows a lot more. She wouldn't allow him to play competitive sports or anything or any heavy weight lifting or anything extremely cardiovascular but she allows a lot more. So it took me a while to feel comfortable with that, to really trust that decision and feel like he's safe doing these things. And it wasn't until we started to go for really involved testing, where I could see they're getting his heart up to 200 beats a minute and he's just fine, he can do this. It took me a long time to feel comfortable.

Interviewer 2:

The continued interruptions, it seems like we're getting new people joining. Just to make sure, before we continue, (beep), did you get a chance to sign a consent form?

Participant 3006:

Yep, I signed the consent. It went back to (beep) at CHOP.

Interviewer 2:

Perfect and then sorry to be asking this, we just have to before we continue. (Beep), just saying if we have to interrupt a little bit, just before I let (beep) continue, just to make sure you consented as well.

Participant 2031:

Yeah.

Interviewer 2:

Yes.

Participant 2031:

Yes. Yes, I filled out the forms.

Interviewer 2:

Okay.

Participant 2031:

Yeah. Sorry, I'm late.

Interviewer 2:

I'm so sorry and I'm sorry for the rest, for the interruptions. I'll let (beep) continue with the questions and I'll let you introduce yourselves as well.

Interviewer:

Yeah, no worries. We're just so glad that everyone can join, we're just really happy to have you here. (Beep), would you like to introduce yourself to the group? Maybe your name, a hobby you have and maybe introduce your children.

Participant 2031:

Sure, (beep). Hobby, apparently ordering from Amazon, judging by the packages in the background. Kids, I have three of them. Ages, oh God, let's see, 16, 14 and 12 and the middle one is the one with the condition.

Interviewer:

All right. Just for context, we were talking about different people's diagnosis experiences. People were sharing, does anyone else want to jump in and talk about what that diagnosis experience was like for them and their family?

Participant 4023:

Well, for me, it's very emotional and still, even till right now. Nervous, then what she told me was confusing because it's like, they tell you this is what they have but basically, even giving you all the medical stuff, at the end, it's like, "Well, we really don't know what's going to happen, we're just going to see what we can do." So they gave you it like that because they've never seen it before, so they're just, "Let's see where it goes." And that's how I feel even now, it's like, "Okay, yeah, let her do what she can," but I'm thinking, let her do what she can until she falls out? It just makes me feel very uncomfortable, I don't know what to do. You can't really read a lot about it online either because it tells you so many different things and you're like, well, I don't know if my kid has all this stuff but I know she has this. And I understand because it's a rare condition, so what can we do, just wait and see? I don't know.

Participant 2032:

It's like, the plan is, there's no plan.

Participant 4023:

Yeah. So it's, yeah, stressful.

Participant 2032:

Has everybody had surgery or no? No.

Participant 4023:

Mine has not.

Participant 2031:

We just... Oh, I'm sorry. I was going to say, we just found out in the last couple months, so we're very new and no surgery, I've been very confused.

Participant 2032:

Participant 1015, has your son had surgery?

Participant 1015:

I'm sorry, repeat that.

Participant 2032:

Has your child had surgery?

Participant 1015:

No. No, he did... They thought that depending on how his tests come, that he would. They would have to first do a... We're so new to this, this literally has been within the last four or five months. I think they said a stent to open up the vessel I guess and that would've been the first thing and they ended up... When he did his last test, they just didn't have a definitive answer. They're like, "We can't say he'll have a problem. We can't say he won't have a problem. The fact is that he's gone all these years playing these intense sports with high impact and contact and things like that and has never had an issue, then he may never have an issue."

Participant 2032:

Right.

Participant 1015:

They asked to bring him back in six months and they're going to run a whole slew of tests again on him, to see if there's any changes or anything like that and then we will wait I guess.

Participant 2032:

Yeah, similarly...

Participant 4023:

Did they...

Participant 2032:

Go ahead, Participant 4023.

Participant 4023:

I'm sorry. Did they check the siblings? Because I know, my son, they checked him and he had that and we were going for checkups and all that and my cardiologist said, "It may run in the family, it may be in the family." So that's how they checked my daughter and then she ended up that she had it too. So I'm just wondering if any of y'all's other kids have been checked or have they said anything like that? "Let's check the siblings, to see if it's in their..."

Participant 1015:

They didn't check any of my other children, his was found because of a heart murmur and so none of them have ever had that and he's always... Over the years, they've said, "Oh, he has a slight heart murmur but it's okay..." As a potential problem but now, over recent years because so many athletes or high school boys are starting to die and things like that from unknown heart conditions, when he went this year, because he is a varsity player and because it is such impact with his position, they decided, well, let's get you cleared completely and that's how we got sent out to the cardiologist.

Participant 2031:

I actually asked that question and they said that no, it's not hereditary and that the other kids didn't need to be checked, so now I'm confused and worried.

Participant 3006:

Dr. Brothers did tell us that it could be connected to the other kids too, so we did have them checked and they don't have it, only my middle child has it but they were all checked.

Participant 2032:

I don't think they know, personally.

Participant 4023:

Right.

Participant 2032:

I think this whole thing is, they're trying but they're shooting in the dark for a lot of it. With my son, they're like, "Well, come back every six months and we'll see how he does." "Is he going to need surgery again?" "We don't know." "Well, is he going to need medication?" "We don't know." That's always the answer, it's, "We don't know, we don't know." Which is hard, it's hard to live with that. So my son did have surgery. Our whole thing, like I was sharing before was, it was all emergency type of stuff, it was horrible. If you want, I'll tell you again. No, I'm kidding.

Participant 2031:

Sorry to hear that. Sorry I was late.

Participant 2032:

No, it's okay. It was diagnosed and then he had to have open heart surgery to fix it right away, so it was just, blegh.

Participant 2031:

Well, I don't know how much detail you got into but I guess hers, the way that it's wrapped around is the better way, so that it didn't need surgery right away and it was more the wait and see. We found it because she was having chest pains. She's played sports like soccer her whole life and run and the coach has always yelled at her for getting winded. And her chest pains were getting worse and they were happening when she wasn't running, so we took her in for something else. We took her in for that but then this just happened to... We weren't looking for this at all, obviously and then it just, "Oh, by the way, you're fine with whatever... You have this thing but the other thing's fine." So I don't know where we go from here, they just said every six months just... "We'll check every six months and see if there's any change." But she is having symptoms but they're not severe.

Interviewer:

(Beep), I know you mentioned that with your situation, it wasn't really a choice but for everyone else, was surgery presented as an option or were you pushed one way or the other? Or how is that decision-making process?

Participant 2031:

Surgery was an option for us and the doctor was very nice and honest and said if it were him, he would probably do it but that the other doctors that he consulted with didn't feel that way and that it was a 50/50 split. And so basically, they don't know and in that case, that they would just reassess it and that they would never make a decision without the parents' input and he implied that it was really up to us, which I'm not very comfortable with. But there wasn't really any answer but it was presented to us.

Participant 4023:

Not to me, they said, "Let's just see how it goes." So we're getting checked out annually now. It used to be every six months, now it's annual.

Participant 3006:

My son actually, he went for his testing and then we met with Dr. Brothers at CHOP but I guess apparently, there's a few doctors who weigh in their decisions on which way it should go. And ahead of meeting my son, they had decided that he would likely need surgery and they felt that if he was a kid who's an athletic kid, he would most definitely need surgery but if he wasn't and he's not, that he would hold off, that they would advise against it. But they also did tell me that they were not unanimous in their decision, that they were a straight-up split. Some people on the team thought he should have the surgery, even though he's not an extremely athletic kid. He does have restrictions, where he shouldn't weight lift, he can't do timed tests, he can't play competitive sports. But he can do the things that he... He doesn't feel limited because he can do the things that he enjoys doing, like bike riding, swimming, stuff like that has always been more his thing.

Participant 3006:

So yeah, we feel confident in the decision because his testing so far has really aligned with that decision not to have surgery. He's not symptomatic of any hypoxia or anything at all, regardless of how high they can get his heart rate up in the testing. So we do feel that we should hold off and not have surgery at this time. But I do have a big concern that, my son is 17, he'll be 18 in December and at some point, we will have to transition to another doctor. Dr. Brothers is a cardiologist, pediatric specialized, so we'll have to transition to another provider and I don't have any level of confidence that that person is not going to recommend surgery the day we walk in the door. So that is on my mind, with him aging out of this program potentially at some point. And Dr. Brothers did generously offer to keep him through college, so it's not something that's going to happen right away but I'm not exactly sure how I'm going to find the next provider, if they'll recommend completely differently because there doesn't seem to be a clear answer here, as to which way this should have gone.

Interviewer:

I do have a quick follow-up question? Do you think one day when that comes, if he has another provider and they had a different recommendation, would that influence your decision, given that they would still talk through that with you?

Participant 3006:

I'm really stuck there, that's a question that I've had. I really do feel... And we research providers and I feel like we just got very lucky landing on Dr. Brothers because she's an authority. I think that there's very few people in the country, as pediatric providers, that I would trust their opinion more or that I feel like has more information to inform their decisions than she does. I do think she's an expert and I plan to research that for an adult provider as well and find somebody who really has a lot of experience in dealing with this. And it may even be somebody that Dr. Brothers recommends to us but I do not know if I will have that level... It took me a long time to trust that Dr. Brothers decision or recommendation here, that's where we should be and we should follow that path. So I don't know, if we were to switch to somebody else and they have a totally different opinion, I'm not sure how we'll handle that.

Participant 2032:

One of the things that's been really helpful and has boosted my confidence in the providers has been when they've done a consortium thing. Excuse me, the dog's barking. I'm in Boston Children's Hospital and because this is such an unusual case, they have, I wouldn't call it rounds but they get together with Philadelphia and Texas and whatever and they talk about these cases and maybe that's how this research study came to be, I don't know. But they talk about it and they talk about the cases and it's very reassuring to me. Our cardiologist at Children's is like, "Yeah, don't worry, (beep)’s name is on the docket every month, (beep)." And I was like, "Okay, that makes me feel better," because I trust him but I also like to know that he's running it by all these other people around the country.

Participant 3006:

It was presented to us in a very similar way at CHOP, that they had told us that (beep)'s case was discussed with, I believe it was Texas and Boston and he was a straight up the middle divide they had told us. And it wasn't Dr. Brothers who told us this, it was a radiologist who did some testing for (beep). He said to me, he's like, "This is not a clear cut case at all. If you had gone to Boston, they wouldn't have done it and if you had gone to Texas, they would have but you're here and we're straight up the middle, we're not sure which way it's going to go."

Participant 2032:

Wow.

Participant 3006:

So it was a coin toss, total coin toss with my kid. He didn't fall in either side clearly, it was straight-up coin toss.

Participant 2032:

Yeah. Well, I mean the consortium thing also in terms of when you move on to another doctor, if somehow they can tie into that or some way to get that information.

Participant 3006:

Right.

Interviewer:

Several of you have mentioned building that trust and confidence, are there any other factors that influence building that trust or influencing how you feel, how confident you feel with your providers?

Participant 2031:

I'm trying to think but I can't think of any... We're fairly new, we've only seen him maybe three or four times, so I haven't thought if I should trust him or not, I just do. So I don't know.

Participant 3006:

We just got lucky coming upon CHOP. I said I'm a nurse and at the time, I worked in Robert Wood Johnson Hospital and the medical director there, who I reported to, was a cardiologist. So when I got (beep)'s test results, obviously I was pretty alarmed and I went to him to show him the test results and he told me, he's like, "You're not going to go here, you're going to go to CHOP and I'm going to research who you should go to. I'm going to make some phone calls and I'll let you know." And at the same time, we had a family member whose son had been in CHOP for, I believe it was some kind of brain surgery. So I knew that they had had a real success story with something that was very complicated, so we already had CHOP on our radar as where we would go to.

Participant 3006:

So once my medical director came up with that name, it actually matched the name that a friend of ours had researched through her own doctor at CHOP. It matched, they were both recommending the same person who would be the expert for us to go to. So we felt pretty confident at that point, that we weren't going to get a better opinion, we weren't going to find somebody who was really more capable of making an informed decision. So we were pretty confident that going to CHOP was the right choice for us.

Participant 2032:

Where do you live, (beep)?

Participant 2031:

We're in Boston, so we went to MGH and to me, that's the best hospital in the world.

Participant 2032:

You need to go... I shouldn't say this but you might want to try Children's.

Participant 2031:

Well, are they all connected?

Participant 2032:

No. No.

Participant 2031:

Oh, they're all next to each other, so I figured they were...

Participant 2032:

I know. The reason why I say that is... Well, we went to Children's. We're in Boston, so we went to Boston Children's Hospital and one of the big reasons for us is they deal with children. Were you here when I talked about the PET scan that we did at a neighboring hospital? Well, it's a story but any case, when we went to Brigham and Women's, which is, again, a great hospital and so forth, they're not used to dealing with children. I think when you go to a children's hospital, they specialize in children's cardiology, which is different than just regular cardiology. And not only do they specialize in it, they see it over and over and over and over and over and over again. You know what I mean?

Participant 2031:

Yeah, I agree. I don't know, we went to the pediatric unit, so I have confidence they see kids at my option.

Participant 2032:

Oh, good. Then if you're happy there, then that's great.

Participant 2031:

My mom was a nurse there for 40 years, so if I went anywhere else, she'd probably kill me anyway.

Participant 2032:

Yeah, yeah.

Interviewer:

Yeah. Just as a quick reminder, everyone's coming from very, very unique experiences and we're all at different stages of the journey. So really, we're just here to hear about each of your stories, what resonates with each other and what even might be different. Thank you again everyone, for sharing. I'm going to jump onto the next question. I really want to hear about your clinical experiences with nurses, with doctors. So could you tell us a little bit about, since diagnosis, what have your clinical experiences been like and how do you feel about those experiences?

Participant 2031:

Do you mean about the doctors or pediatricians we see or the ones that do the testing or everything?

Interviewer:

Sure, everything. Whatever comes to mind first.

Participant 2031:

Oh, we had one nurse that left an impression on us. I'm awful with the names of things, I think it was a CAT scan. She had to have a dye injected into her, so that they could measure her heart before and after and the nurse who came to do the procedure questioned the doctor's orders and told us that we shouldn't have the procedure. And we were very upset by that because he said, "Well, you're injecting your daughter with radiation and why would you give her radiation? You shouldn't be doing that. You should do a different test." And we were like, "I'm sorry, what? I understand that you're concerned for us but the doctor ordered this test for a reason and we're going to do it."

Participant 2031:

And I actually had my mom in the waiting room, so I brought her in and talked to her and I said, "Am I poisoning my daughter with radiation?" And she said, "No, it's the same thing as an X-ray, it's not any higher dosage, it's fine." But he really scared us and left an impression, like, oh boy and maybe we should have gone to Children's to do the procedures, so they didn't scare us but it was odd but we like the doctor.

Participant 4023:

My experience has been the best at Texas Children's here in Houston, they're awesome. They baby my kids like crazy.

Interviewer:

(Beep), can you say more about-

Participant 2032:

Same with Boston. Boston's been great every time we go, they even have... The whole hospital I think but in particular, the Cardiology, even just the waiting rooms are just very kid friendly. They're also like, "Do you want a cup of coffee?" This is just for a routine visit too. They're like, "If you want to go down and go get something to eat and then come back up," or, "Oh, we'll show you where the next appointment is. Come on, follow me." They'll get up from their chair and take us where the next appointment is. They've just been great.

Participant 2031:

How old is your... Is it son? How old is your son?

Participant 2032:

My son (beep)'s 15.

Participant 2031:

15. Okay, yeah, my daughter's 14.

Participant 2032:

Yeah.

Participant 3006:

We've been really impressed with CHOP too. Whenever we go in there, we have a sense that the people who are managing his care that particular day are really well informed on his case. They seem to really have a lot of relevant information and always super friendly and quick to put you at ease, everyone. The first time we were there, the person who directs the whole program with the exercise testing, he came over and he introduced himself to us and gave us his business card and encouraged us to reach out if we had any questions after. Sometimes you don't know what to ask until something will occur to you a while later. But he came over to us and made sure that we knew how to contact him if something was to come up outside of an appointment, which we appreciated that.

Interviewer:

Yeah. Could everyone say a little more about what makes these experiences good? And what are some specific things that people do that make those experiences good?

Participant 4023:

I like that they cater to the kids, they just make them feel... If they're scared, they're around, they do things for them. They even have someone who's dedicated to that I guess, that's all they do all day, they'll go and they'll sit with your child and they'll talk to them, explain to them what's going to happen. Even if it's a MRI or whatnot that they're doing, that they are basically like, "Let me hold your hand through this, so that you don't stress out, so that you're not freaking out." And they'll talk to them, they'll even have a little iPad thing and then they're sitting there like, "What do you want to watch?" Or, "Do you know how to play this game?" So they're making them feel better while they're doing all this other stuff to them on the other side. So I like that because my kids are real nervous. Probably get it from me but yeah, that's the best. I hope I never have to change.

Participant 2031:

Our doctors are really good at explaining things too, now that you say that. They overexplained and they talked to her.

Participant 4023:

Right.

Participant 2031:

They talked to me too but they talked to her and that meant a lot to her because she felt like an adult and involved and 14 year old girls, they don't want their mom anymore anyway. But they really overexplain things and I really appreciated that.

Participant 2032:

I think they engage the kids, it's really getting them involved, like you said, (beep). It's engaging them in what's going on. I just think the compassion that's shown to the parents and to the kids is just really incredible and the empathy. It's not even done in words so much, it's just done in actions and even little mannerisms. Even walking from the waiting room to the doctor's office, whether it's a little joke or it's whatever but it's conveyed that it's like, we know you, we care about you and it's going to be okay.

Participant 3006:

I appreciate that and I've called the office so many times with very minor things, even COVID related, should he get a vaccine? Should he participate in a certain activity? I always, every single time, get a call back from the physician and it could be the most basic of questions, like I just need a note for something to excuse him from school for the day. Every single time, I get a call directly from Dr. Brothers, which I appreciate, it shows that they go the extra mile to me. And I also appreciate that we've been going there for a while and it seems like every time we go, people know things about my son, besides that he has a disease. They know he plays the bass and he's in the orchestra and he's applying to colleges, they know that about him. And I appreciate that they've gotten to know him a little bit more than what they're seeing on an MRI, that goes a long way.

Interviewer:

As a follow-up question, is there anything that you would like to change about your experiences looking back or anything that could be changed to be improved?

Participant 2031:

Can you find an answer?

Participant 2032:

Yes.

Participant 2031:

Yeah. I think there was one...

Participant 3006:

I think if I had a better sense... We've been going through this for a while and I still don't feel like I have a real solid grasp on, when does this condition that's been benign and we're watching it at this point... What are we actually looking for that changes, that makes us to decide that surgery's necessary? And I know at one point they had said if he's having shortness of breath or loses consciousness with exercise, that they would certainly do the surgery. And then a couple of weeks later, my son fainted in gym class. So we were like, oh, I guess we're going in for surgery and then they did all this testing and they were like, "Well, no, it wasn't related to that, it was another issue." But I don't feel that I've ever really felt that I know what it is that is going to precipitate that decision and I wish I knew a little bit more.

Participant 4023:

Same, I like that they're basically just holding our hands through this whole process, they don't know, we don't know, let's just figure it out, I guess together. I'm guessing that's what they're thinking.

Interviewer:

Or I guess another question I have is, as a parent, what do you think is most challenging part of living with or being affected by this condition?

Participant 2031:

I'm trying not to scare her too much. She does know everything but I definitely say it in a positive way and not scare her into making it worse emotionally.

Participant 4023:

I think it's hard because they get online and they look. My kids, they're online and if they have a question and I don't answer it quite as what they want I guess or I'm being not specific I guess, they'll go online and they'll look and say, "Oh my God, this is it, what?" And they want to find out more and they want to find out more and like I say, it's hard to find online but you can read about a lot of things and it opens their eyes and they get scared and they don't know I guess exactly what. That's scary.

Participant 2032:

I'm on other extreme, I want to scare the poop out of my son. I really do because about a month ago, I caught him vaping. Vaping. Vaping. I'm going to say it again, vaping. I'm like, "Are you crazy? Are you crazy?" I'm like, "Do you know you have a heart condition?" I couldn't believe it, I could not believe it. I'm like, "You got to be nuts." And then he's like, "No," the whole thing, "It wasn't mine, I was holding it for somebody." I was like, "Do you think I just fell off the turnip truck? Seriously, it's yours, it was in your pocket. It fell out when you got up." "No, I know, I only did it once," the whole thing. So it's dealing with a teenage boy growing up. This is confidential, right?

Interviewer:

Yes.

Participant 2032:

All of what we're talking about here?

Interviewer:

Yes.

Participant 2032:

And then two weeks ago, it was discovered that a friend of his was smoking weed. So of course, we had to have that conversation. I said, "Did you smoke weed?" And he goes, "Yes, I did." I said, "Oh my God." I said, "You didn't even do an edible or something, you smoked it?" I'm like, "What is wrong with you? Do you not know that you have a heart condition and how this is affected by this?" So we had the whole weed talk and all of that but having a heart condition comes into this. So I don't want to scare him to pieces, you know what I mean? But I totally want to dope slap him and be like, "What the hell?"

Participant 2032:

And so I struggle with that, I don't know what to do. He won't go out for football, he won't go out for team sport because of the whole, they're going to push me too hard and I'm afraid he'll do a pick-up game of football or a pick-up game of basketball, so that's good. But the whole thing about being a teenager and experimenting is going to be the death of me because like I said, I want to-

Participant 2031:

I did scare her and I did do the same thing. I did tell her, I was like, "Well, you know you can't smoke and drink because you'll die," I did do that.

Participant 2032:

That's what I said, "If you do this, you are going to die."

Participant 2031:

But her friends are really good. Her friends actually... When I remind her quite often not to do those things, she says, "Don't worry, every friend I have knows I have a heart condition and they tell me all the time that I can't do it."

Participant 2032:

Right, right, I know. So I sat down with him while we're having this discussion about weed and, "How come your friend, (beep), didn't smoke when he was there?" And he said, "Oh, well, (beep) told him, 'No, thanks, I'm all set.'" I said, "You can't say that, you don't know those words? You can't say that?" So I said, "Well, you need to come up with your own line, your own thing that you're going to say when someone says, 'Oh here, you want a hit of this?'" So a week later, he comes back to me and he says, "I got a line, Ma. I got a line." I said, "Oh, what is it?" He goes, "My line is, 'No thanks, I got a heart condition.'" I was like, "That's great." And I said, "And if they want proof, you can open up your shirt and show them the scars." And he goes, "And I'm not lying." I said, "Duh, no, you're not lying. You really do have a heart condition and you never should have smoked anything in the first place." Yeah, we're having fun over here.

Interviewer 2:

No, no, that's great. You raise a very good point, that's one of our questions actually. For those who have other kids and for those who have other teenagers for example, do you think that you treat them differently because of the condition in these specific things? For example, the smoking or the drinking, that's something that parents deal with with teenagers, do you think it's different because of the condition?

Participant 2032:

Oh yeah, definitely. Definitely. I am on his case about it. Like I said, when I found out that he smoked weed, I hit the roof. I was just like... It didn't mean that I was going to ground him forever but I was like... We had another sit down talk about his condition and I think that's hard because he's asymptomatic and so life is fine. If he didn't have this huge scar down the front of his body, he wouldn't even know that he had a heart condition. It's not like he gets winded, he doesn't have heart palpitations, he doesn't have chest pain, he doesn't pass out. What's the problem? I can take a couple of hits off a joint. So it's hard, it's very, very difficult for him and for me.

Participant 2031:

I would agree, I think I treat them differently. I try not to but I do.

Participant 2032:

Yeah, yeah.

Participant 2031:

Every time she has an appointment, she's like, "Mom, I had my blood drawn," or, "Mom, I had an MRI, I had this, I think you need to buy me a shirt from Lululemon." She definitely milks it and I do because she has a heart condition, I want to make her happy.

Participant 2032:

That's so funny, I'm laughing, thinking, oh, that's so funny thinking about you and then I'm thinking, (beep), you do the same thing. We always go out to lunch or out to dinner and then we go to the Champion outlet.

Participant 4023:

Yeah, that's what we did too. "Oh, let's go for lunch," or brunch or whatnot and oh, they need to go shopping. What a coincidence. Okay, fine.

Participant 2032:

Yeah, yeah. Well, I'd buy him all the Champion things in the world if it would make this go away.

Participant 4023:

Very true.

Interviewer:

(Beep), is it similar for your children or different?

Participant 3006:

I find my son doesn't share his condition with a lot of people, so he ends up doing things sometimes that I certainly would have advised against. So recently, his friends went to the Six Flags Great Adventure here and he went on rides that I felt he shouldn't have gone on because he's got a heart condition. But he doesn't really share that with many people and he really downplays a lot. The only reason anybody knows that he has a heart condition is because he had to wear a heart monitor for a couple of weeks when he was first diagnosed and he wore it in school and sometimes it used to make beeping sounds. So a teacher actually asked about it because they thought that he had some kind of device, he could be cheating on a test or something.

Participant 3006:

And the teacher asked him about it in the class and he said it, "It's a heart monitor, I have a heart condition," that's the only reason anybody at all, even his closest friends, know about it. So I think that he does sometimes do things that I would've advised against, just based on... He doesn't really share that part of his life with anybody, so he just does what everybody does. As a family, I do find though that I will limit what we do now, things that we used to enjoy doing on vacation and stuff. The kids used to like to go zip lining at this place that we go on vacation. I don't go there anymore because I don't want to put us in a position where the two kids can do it but (beep) can't. So I'd rather just find something, an alternate thing that we can all enjoy together. And I don't even think the kids, the other kids, are even aware of it. I think they just think we do different things now than we used to. But yeah, it's complicated.

Participant 2032:

Yeah. I think with the older kids... Well, I don't know, I'll just speak for myself, that (beep) is 15 and whereas when he was younger, he would more readily express his feelings about things. Now that he's 15, we've got a little bit of the wall coming up and he's not going to say, "Mom, gee, I'm really nervous," or, "I'm really afraid." He's not going to express those feelings to me. So if he has something seriously wrong with him, he'll tell me but other than that, he's not going to say. He's not going to voluntarily tell me how he's feeling, except, "Fine, fine. I'm fine."

Interviewer:

(Beep), can you say a little more about maybe before he turned 15? Did he talk to you more about how he was feeling and what he was feeling?

Participant 2032:

Yeah. You mean physically or emotionally?

Interviewer:

Yeah, both.

Participant 2032:

Yeah, he was much more expressive. Now, we sometimes can have conversations and go back and forth and talk more about more than just fine. But when he was younger, yeah, there'd be much more dialogue about what was going on, what was going on with his body, in terms of, "Oh, I ran today," or, "We played kickball today and it was awesome," and blah, blah, blah, blah, blah and just his emotional life was much more apparent and talked about. Like, "I really didn't like that kid," and that type of stuff. Again, he'll have conversations with me if I initiate them and if it's at the right time, which is usually in the car.

Participant 3006:

I was going to say that, in the car.

Participant 2032:

Yeah, in the car, yeah.

Interviewer:

Yeah, I just have a few more questions. I know we're about to run up on time but is there anything that you wish you had known at the beginning of your journey, looking back?

Participant 2031:

The lack of beginning. I guess one thing I do want to know is... So our doctor said that he didn't want to write her a note for gym and it reminded me because you were talking about the teachers in your son's school. The teachers have been... Some have been great, some have been really awful. The gym teacher especially was really awful and called her out in front of everybody and made a huge scene, which embarrassed her and forced her to go to the nurse. And the nurse called me and said, "There's no note in her file that says she has a heart condition, so she's lying and you're going to have to come pick her up because she won't go to gym class." And my mind was just blown, like what? But our doctor said he didn't want to write a note because he didn't want to feel like she had a limitation.

Participant 2031:

He didn't want her to be limited in what she could do, he wanted her to just proceed with life as usual and I wish I had pushed back on that and gotten a note and said, "Well, I know you want her to feel like life is usual but it's not and she's not going to run in class because she's scared." So maybe I'll call him and ask for that note. The nurse believed me after I explained everything to her and she was nice but that was after the drama of now, half the school knowing about her condition. Which is actually good when it comes to the peer pressure because they all tell her she can't smoke.

Interviewer 2:

(Beep), I have a follow-up question. If the doctor is saying that she should feel as if she was normal, if she didn't have the condition and she should exercise, where is the restriction coming from?

Participant 2031:

Well, he also said that she could just drop dead if she did exercise too much and had heart pains and she would have a heart attack and have to go to the ER. And so that was us saying, "Yeah, we're not really going to risk that."

Interviewer 2:

I get it, thank you. So yeah, sorry.

Participant 3006:

Our doctor's note, the limitations are very minimal, he can do stuff. In fact, I think since he was diagnosed, he does more than he used to. Not that he's a couch potato but he's a super academic kid and his focus is really, he's on his computer and behind his desk and reading books a lot. And he's in the state orchestra, so that takes up a lot of his time and it's not extremely physical. Since he's diagnosed, he's definitely more concerned about his health and he's taken up bike riding and he walks long distances, a couple miles, which he didn't used to do before. So I think that in a way, his testing has improved over time and his general cardiac health has improved over time.

Participant 3006:

In terms of gym, he does have a note that limits him but it's very minimal. It's, he can't lift weights, he can't lift anything extremely heavy and he can't participate in times tests. He needs to be able to just do things at his own pace and he's never really had anything more significant in terms of limitations. I almost sometimes wish that Dr. Brothers would be a bit more... She likes to give a lot of autonomy too and he's close to adulthood and she likes him to make his own decisions. But if he says, "Can I work out in a gym?" She'll say, "Yeah, you can but it should be a gym that is equipped with an AED, so that you could be resuscitated if something happened." To me, that's a hard no, if you're going to need to be resuscitated for something you're doing in the gym, then you shouldn't be doing that.

Participant 3006:

So I do wish that she'd pull the reins in on him a bit because she does tell him, "There's very few things you can't do. Maybe you shouldn't go skiing or rock climbing but you can do a lot of other things." And then he takes it as, I've had this my whole life and I've never had a heart attack, so I can just do whatever I've always done. And that's where it comes in, he's an adult now and his friends drive and he's at that age where they go and do things. And next thing you know, I'm finding out that he was on the rollercoasters at Six Flags and really, I don't think that that's a good idea. So I do wish that the medical staff was a little bit more clear in their directions for him, as to what he should be participating in and whatnot.

Participant 1015:

I think for me, with my son, one of the blessings in disguise was, his coach, his first year teaching, had a kid that had a similar condition. So when we started explaining it to him and he realized that he wasn't medically cleared yet, he took a personal interest in making sure he didn't overwork himself and he took the necessary breaks and things like that, to help us ease our worry while he's at practice and school. So it almost became like, okay, now you got a dad at school that's going to make sure you're not overdoing it. And like some of the other ones said, we had some of the similar issues as, "Hey, you can't smoke and you can't do this that some of the other people that you know are doing." Because I told my son, I said, "You'll die." I'm like, "Your heart may not be able to take what their heart can take." So it's been an up and down thing with it all.

Interviewer:

Thanks so much, everyone, for sharing. We're just at about time, so if you have to hop off, please feel free to do so. I just want to give space to ask if there's anything that you wanted to share or talk about that we didn't get to today.

Participant 2032:

I don't know if it's appropriate here but as I've shared, our situation was very immediate and urgent and led to surgery right away. And I would like to know if there's a way that it could have not happened that way and I don't know but I'd like to just pose that question. Is there a way that we could have known or the providers could have known, that it didn't have to be such an emergency?

Interviewer 2:

Not answering your question, (beep) but I can tell you that that's one of the questions that, our interest as researchers, we want to answer. That's an unanswered question in general. From other groups that we have talked to, other parents, other participants, including the providers, that's a question that has not been answered yet. And that specific thing, is there a way that we would be able to know or prevent it or do it in advance? Or even when it's not as urgent, is this something that we need to do or not?

Participant 2032:

Right because-

Interviewer 2:

So one of the hopes is to answer the question and if we do, we'll let you know.

Interviewer:

Yeah.

Participant 2032:

Yes, please because all that keeps going through my head and even now to this day, it just hits me in the gut, is that, what if we did not take him to the hospital that day? He would be a statistic, he would be one of those kids that dies on the football field, period. That's the reality and I think, isn't there a way, somehow... We could have missed this, we got to him in time, we, the collective we, got to him just in time, just in time. And that scares the bejesus out of me. We came that close and I would like that not to happen to somebody else.

Interviewer 2:

Of course and thank you for sharing that. That's really one of our main questions and not only ours, clearly yours too and other participants and parents as well.

Participant 2032:

Okay.

Interviewer:

Does anyone else want to share anything? And thank you so much for sharing that, (beep). All right, unless anyone wants to jump in at any point, I think that's all we have for today. Thank you everyone so much for joining us and for sharing your stories, it really means so much and we're really grateful and appreciative for your time, your vulnerability. The coordinator should be in touch with you with a quick follow-up email and I think that's all that I have for you. Thank you so much.

Participant 2032:

Great, thank you.

Participant 2031:

Thank you-