Interviewer:

... that as a no. Okay, great. Just even before we start with you all introducing yourselves, I guess my first question is that in this project thus far, you know, we and, I guess, providers and people clinically, the way that they refer to this type of heart condition is as anomalous aortic origin of a coronary artery, the acronym being AAOCA. I guess, before we get started, I just wanted to ask you all: Is that what you all call it? Or how do you refer to this condition?

Participant 1001:

The same. My daughter got very proficient in using the acronym, and she knows what it stands for, and we also say, "AAOCA" and "ALCA," which is the anomalous left coronary artery, because that is where she had her defect.

Interviewer:

Okay. Cool. [crosstalk 00:01:06]

Participant 1002:

So, my case, instead of the left, it's the right coronary artery for my son, anomalous right coronary artery, so he has abnormal origin of the RCA.

Interviewer:

Okay.

Participant 1002:

Yeah.

Participant 2003:

I actually have it in my notes, because it's such a long name, but hers is anomalous right coronary from the left sinus of Valsalva. But I just say, "Anomalous right coronary." That's what I do.

Interviewer:

That's how you refer to it?

Participant 2003:

Yeah. I mean, in passing, just congenital heart defect. I really don't get too specific with anyone because --

Interviewer:

Okay. Have you-

Participant 2003:

they don't know what it is, other than the doctors.

Participant 2004:

We've been similar to what (beep) is saying, simply because a lot of people, even some of the medical practitioners, have no idea of what we're talking about. So, we've kept it simple, anomalous right coronary artery.

Interviewer:

That's how you refer to it with other people?

Participant 2004:

Right.

Interviewer:

Anomalous right coronary artery?

Participant 2004:

Correct.

Interviewer:

Okay. Got you. Awesome, thank you all so much. (beep), how do you all refer to it?

Participant 1006:

Pretty much, I don't really get into it either because nobody really knows what I'm talking about. So it's pretty much the same thing, just keep it simple.

Interviewer:

Yeah. How do you all talk about it even at home, just among your close family members?

Participant 1006:

Just his heart condition, that's really all we say about it.

Interviewer:

Okay. Got you. Cool.

Participant 2003:

Congenital heart defect, that's kind of how we keep ...

Participant 1006:

Yeah.

Interviewer:

Okay, awesome. Thank you all.

Participant 1002:

To be honest with you, in my case, I wouldn't even let my son know about it. I don't want him to feel like he has something. He does know a little bit, some heart condition he keeps asking and I say, "Everything is fine with you," just we don't want to ... We usually don't talk much in front of him either because I just don't want him to feel that something is wrong with him. It's not like something is wrong, but I don't want him to feel that way, so I usually don't talk. That's the reason I actually came outside, because he's at home and I didn't want him to know all these discussions or hear all these discussions. I just keep it a little bit private, away from him.

Interviewer:

I see. Thank you for sharing that. I think it's probably helpful at this point, and I'd like to follow up on that with you, (beep), but before doing so, it's probably helpful for everybody to introduce themselves at this point. I actually have a very short list of things that I would like you to share as you introduce yourselves, and I'll put it in the chat here. Is everybody able to see? Let me see. Let's see if this works. Can everybody see that in the chat?

Participant 2004:

Yeah.

Interviewer:

There doesn't have to be any particular order here, but share your first name, age, just a hobby that you have or something that brings you joy. If you all can see this, I don't need to read it all out, but would someone like to start?

Participant 2004:

Sure, might as well. I'm (beep). I'm from Ohio. I'm 50-something, that's why I do backpacking, things like that. When you hear me talk, when I'm talking about my 17-year-old high school senior, who is now eight months post-surgery.

Interviewer:

Seventeen-year-old high school senior, is that right?

Participant 2004:

Correct, sir.

Interviewer:

Okay. And then in two to three words, (beep), how would you describe what being affected by this condition is like for you and or your son?

Participant 2004:

At this point, we're in the relief stage, but we're dealing with a lot of unknowns going forward because there isn't a lot of data. In his case, he was asymptomatic with this, it was discovered incidentally after being treated for something else, Wolff-Parkinson-White.

Participant 2003:

My brother had that.

Participant 2004:

When you hear us talking about this, you aren't going to hear -- the negative effects were emotional and that things were not done well at times. We actually switched cardiologists, sought second opinions because things weren't done, the emotional need was not well-addressed at one place. We needed distrust, even though with the original cardiologist had the proper technical diagnosis, their interactions were not good, but ultimately, frankly, it was a good thing because it forced us to dig deeper and we ended up at a very good facility. Actually, two of them, some of you were talking about were -- two of them we were dealing with at the same time and it was in the midst of COVID. But we're on the relief stage, eight months past surgery, things are going very, very well. For him, it's different because he was an asymptomatic case that chose to be treated, rather than being limited.

Interviewer:

Okay. Thank you so much, (beep), for sharing that. Would someone like to introduce themselves next?

Participant 1002:

Yeah, I can go next.

Interviewer:

Thank you, (beep). Can you see the chat?

Participant 1002:

I'm sorry?

Interviewer:

Can you see the chat, what's in the chat for introductions?

Participant 1002:

Yes.

Interviewer:

Okay great.

Participant 1002:

Yes, I can. My name is (beep) and I'm 44 years old. I'm a singer as well, so I sing a lot. And then I have two children. And then my first one is 15 years old and my second one is the person who actually has this condition, and he's turning 11 this year. Actually, this is very interesting. When he was born, we actually found out as soon as he was born because he was -- I mean, within just less than 24-hour timeframe, he actually got affected with pulmonary hypertension. We had to take him to the tertiary level hospital, and then that is when we found out that he actually has, I mean, after a few days, before he was discharged, we were told that he has an abnormal heart condition. I was definitely devastated when I came to know about it. We really didn't understand. We don't even know what it is exactly, but the doctor who actually treated him was really, really good doctor. He gave us a lot of courage and comfort.

Participant 1002:

And then I ended up going to so many different doctors for second opinion, third opinion, I even went to Duke. I mean, initially, he was born with bicuspid valve vessel, but the bicuspid actually got fixed by itself. There is no resuscitation or it is actually not a problem anymore. But then again, with this one, lately, when we have shown him in Austin, one of the doctors, he really did not indicate a serious problem or he did not indicate something is majorly wrong or something, so we still have a little bit of doubt there, but then I know for sure there is definitely anomalous artery for him, but again, we don't know what is in store for his own future. There are definitely lots and lots of unknown. He's definitely asymptomatic. He's a very, very active kid, to be honest with you, very, very cute and very active kid, so I don't even know if he actually has to go with the surgery at this point because no doctor is suggesting us to move forward with getting surgery since he's not showing any symptoms.

Participant 1002:

Also, we don't even know if it is actually safe for him to open the heart when he's still growing. That is where we are at this point. We are hoping that everything will be fine, but then we are monitoring this condition very, very closely, every year almost and then seeing how he's actually progressing and how his heart is also progressing. That's where we are at, but I went to almost half a dozen doctors to actually get some kind of a positive, not saying -- hoping that in case one doctor will say, "No, your child's heart is really good." Hopefully, I will hear that in some time in future. I'm expecting some kind of a miracle to happen, but we'll see how it goes.

Interviewer:

Thank you, (beep), for sharing that. Just for context, (beep), you said your son was 17. How long ago was he diagnosed?

Participant 2004:

The original WPW was --

Participant 1002:

My son was diagnosed as soon as he was born.

Interviewer:

Okay, thank you. And then, thank you, (beep), but sorry, for (beep), your son was diagnosed at what age?

Participant 2004:

I want to say the WPW was 13, and while treating that, they noted he had an anomalous coronary artery, right. They didn't know the significance of it. At the point, the discussion was that it was most likely benign because most are. He was in the process of additional testing to try to join the military, and at that point, we ran some additional tests and things went, obviously, very poorly. To be honest with you, by the time he was done, he had both the right and the left surgically repaired. But again, from the anomalous coronary arteries, he had no symptoms. He was running well, it was just a matter, we now had enough test data in front of us that said the [inaudible 00:11:08] was a significant danger in his case, and he made the decision, he was old enough to make the surgery rather than be restricted to sitting in a chair.

Interviewer:

Okay, thank you. Who would like to go next?

Participant 2003:

I'll go.

Interviewer:

Okay, thanks.

Participant 2003:

Sorry, (beep). (beep) 43. I run marathons, run. My daughter was diagnosed with it. She was born with heart murmurs. When we were discharged, the doctor found heart murmurs, and she went into Children's probably two weeks after she was born and they ran tests and found out that she had the anomalous of the right coronary. She is now 12. She has been going to Children's probably every two years, where they do testing, and we are at the point where they did further testing this year, deciding whether she should have surgery or not. I would say we're always walking on eggshells because there's not enough information. I always tell the doctors --It's like, I asked the doctor actually this time, who's very nice, "Is this a choice we have or is this... Do doctors do perform surgery or not?" And he's like, "Well, there are doctors that believe surgery should happen."

Participant 2003:

And I'm like, "Well, is this like a flipping of a coin situation?" I think that's what's difficult for me, for us as parents, is knowing that she has this and she's an active soccer player, hockey player. If we don't do anything, are we the parents that should be responsible for that because we didn't do anything knowing that there was a solution, even though of very high risk? And then, if something did happen in the surgery, so you're kind of like -- It's emotional. You don't know whether to do anything or not do anything.

Participant 2004:

Yes.

Participant 2003:

There's no data because it's so rare. That's where we are.

Participant 1002:

Yeah, (beep), thanks for that. That's exactly how I would state it as well. It's like, my son, he loves to play baseball, basketball, and all, but then I don't know ... I mean, I don't want anything to happen to him, but then when I actually spoke to Duke, they said, "The chance of getting him surgery and then getting the heart fixed is very rare. You just have to leave him like that and then let the age take the course or let the time take the course." I don't know if that is a right answer or not, but I'm like, "Should I get him surgery? Should I get his heart fixed?" But the doctor says there is no fix to the heart. But then I don't want to restrict my son from any physical activity either. But then if I let him play, then what is actually going to happen? Because the stress or the strain of the heart can cause something else that we don't want to. This is a real catch-22. I'm like, "I don't know." I mean, we know he's sitting on the pawn, but then how do you get that fixed?

Participant 1002:

It's a real pain actually to -- It's not like they're abnormal, they're very healthy kids. They're very active kids. It's not like they're dull or anything like that, and that is what makes me more and more scary. It's like, I want him to be active like that. I don't want trouble. I don't want anything to happen to him, but then I don't know what is in store, what is unknown that we have to be watching for. So that's a very tough situation, to be honest.

Interviewer:

Thanks for sharing that, (beep). And thank you, (beep), for introducing yourself and your daughter. One of the things you shared, (beep), was that you feel like you're always walking on eggshells. Can you say a little bit more about that and what you mean by that?

Participant 2003:

Well, I think it's like, my daughter is a sports fanatic. She is high energy all the time and she is not restricted according to the doctors, which is comforting, but it also ... You hear about these kids on the soccer field that drop and it's some sort of congenital heart thing. And it's like, that could be my child, and I knew -- It wasn't a case where I didn't know she had anything. I do my best and trust that it will be okay and know that she needs to be active for her mental health and she just is that kid. But it's in the back of my head, the worry that we didn't do enough. And should we have gotten more opinions? Also, just the frustration in terms of statistics. It's not like there's so much out there that this is so common, you'd be like, "Okay."

Participant 2003:

Like Wolff-Parkinson-White now, it's like when my brother had the surgery 40 years ago, it was very rare, but now it's like a routine surgery to fix Wolff-Parkinson-White, no problem. We're in the midst of not knowing that statistically, and as a parent, to not have numbers or some sort of how many people were asymptomatic and had the surgery and are fine? That kind of data, for me, would be helpful, I guess, but there's just not any of it. (beep) it's not eggshells, it's just worry. You don't want to have a guilty regret that you were not proactive in saying ... My mother was proactive with the surgery. She was going to go down to Texas to have the surgery, even though we lived in Boston, because she just knew, but at the time, it wasn't. So, I'm wondering, am I in the same position and not advocating enough or something? I guess that's what it is, eggshell, worry. It's really worry.

Participant 2004:

(beep) is absolutely on it, the way I felt, and I can't tell you how many nights up in tears and reading medical journals not in my field, and they're overwhelmingly dominated by people or children who were symptomatic with negative outcomes, and it so was really, really difficult to the point that at one point I was driving ... one of my other children was driving to Arizona, 2,000 miles away for college. I'm in the car watching the surgery on YouTube making myself sick because I wanted to know more what was going on. The first group of doctors we dealt with at [inaudible 00:18:33] Hospital were, once we had the additional data from the CT scans and everything else, were out of the blue very adamant about surgery. Shocking and emotionally, it was not well done, and again, I will say they were technically correct, but their approach became a block and a barrier to getting treatment.

Participant 2004:

The second set of doctors which referred us to somebody else, even though they were imperfect and they said they don't deal with as much, they knew of it, helped us much better emotionally to get to a decent decision and presented things as options. And then the last part, she just nailed it, that there is no good data or easily ... Good data as for the short-term outcomes and then also data as for the long-term outcomes because right now, I'm sitting with my other son, sitting 20 feet away from me, who is eight months from surgery preparing for a half marathon. He's on the good end, but I tell you, every race he runs, I sit there and I chock up. It's not easy, but I'm not going to stop him. It's his decision at this point. The other ladies are being quiet. Please jump in.

Interviewer:

No, thank you for sharing that, (beep). I want to give (beep), whichever one of you would like to go first.

Participant 1001:

I guess I'll go. My name is (beep), and I am 46. Actually, I won't say that I like to bake, but I have to bake because my daughter also has celiac, and so I learnt how to gluten-free bake and cook since she was four, she's 12 now. That's sort of a hobby, an unintentional hobby. Things that bring me joy are just spending time with my family. I have two children. One is 26, he's married and out of the house, and my daughter is 12. I don't want to alarm people, it sounds like you all have not gone through a sudden cardiac event, but my daughter has a left coronary. Hers is anomalous left and I know that there's a difference between anomalous right and anomalous left coronary. We did not know that she had it when she was 11, so two Thanksgivings ago. It was right before Thanksgiving of 2019, she was running in PE and she collapsed. She had a heart attack and the nurse...

Participant 1001:

They didn't know that she was having a heart attack. We of course, found that out. They didn't know what was going on. She collapsed, she fainted. She kind of came to. She threw up. They immediately called the EMTs and then they called me and my husband. As I got to the school, the ambulance was about to leave with her and I got in the ambulance. They rushed her over to Dell Children's here in Austin and ran a lot of emergency tests. They had to intubate her and sedate her almost immediately because she was failing and they didn't know what was going ... They knew that her heart was having a problem. The more common things of what they were suspecting was maybe she had gotten a virus. Just a nasal congestion, nasal virus can get to the heart, and penetrate the heart and cause problems. That's more common, of course, than AAOCA. They're asking all sorts of questions, "Has she been sick? If she really hadn't been."

Participant 1001:

The following day, so she was heavily monitored overnight while the doctors were trying to figure out what test they wanted to run on her. My husband and I are, of course, there at the hospital. At the time, thankfully, COVID was not a thing, and so there weren't any restrictions and we had family and friends coming to help support us, visit us, taking turns. We were obviously in the cardiac intensive care unit, so there's only four people at a time allowed, so they were coming and going, but helping us with what they could and praying over her. The doctors told me very bluntly that they were worried because they didn't know what it was. She was on an enormous amount of ... I'm forgetting what makes your heartbeat really fast. I think adrenaline. I can't think of the name of it. Anyway, she was on a really high dosage of that just to keep her heart beating. And because her heart rate was so fast, the CT scan was inconclusive at first, so they couldn't really tell what was going on with the CT scan. Then they went through and they did an angio, where they went up and through her thigh, her groin, and then up looking at her heart.

Participant 1001:

Then they found that there was some sort of narrowing on her left coronary. With that information, they decided they were going to do another CT, specifically very much trying to look at that left coronary. And they were going to try to ease back on the medication so that her heart rate would slow down. Every time she left for a test, I mean, it was a group of people, a group of doctors, nurses, everything going with her. She was very unsteady, just moving her, reclining her, her blood pressure would drop. The three words I will say right now is traumatic and terrifying, but also supported. We did feel very supported. They found that it was the left coronary originating out of the right side of the aorta. And, [beep], my daughter, [beep], she started to -- Her heart rate started to calm down a little bit, so they thought, "Okay, if she's doing better, it's very high risk to go into surgery when you're that tenuous. When you're that sick, it's really, very high risk," is what our cardiologist told us and our cardiac surgeon told us.

Participant 1001:

They wanted to give her a little bit of time, and by a little bit, it would just be a couple of days for her body to calm down because her body seemed to start calming down after the heart attack. When she had had the heart attack at school, her lungs ... and then when she got rushed to the hospital and was declining, her lungs were filling with fluid, so she had a really bad case of pulmonary edema. Her lungs were in trouble also, so they were wanting to just get her a little more stable before taking her into surgery. She went in on a Wednesday, they found out everything, what she had on Thursday. And then Friday, they actually woke her back up and extubated her, and said, "We're just going to keep her really calm till about Monday and just watch her," obviously in the hospital. She was still very sick, it's not like we could go home or anything and that they were just wanting to schedule the surgery for a Monday or a Tuesday and hope that her body would just continue to be more relaxed and calm, but she had other plans.

Participant 1001:

She was extubated at about, I want to say about 5:00 P.M. on Friday, and by 11:00 P.M., she was re-intubated. That was a really scary few hours. Her heart started failing terribly, and it was stopping, and they were restarting her heart, and they were gathering the surgical team together. At 7:00 A.M. on Saturday, she went in for surgery and it was about 10 hours. The cardiology team and the surgeon, the head surgeon told us that -- He really couldn't even give us a percent, like, "She has this much percent of success." He said because she was very, very sick that she could die on the operating table. That was really hard to hear. But she came through it. After that, she came through that, she did pretty well, but then she started to accumulate a lot of fluid around her heart, so they had to -- They'd already taken out her chest tube, or the drainage tube, and so they had to reinsert that, which was a drag, because that thing, unfortunately, it's extremely uncomfortable. I don't know what it's like, but from what she's told me and just being with her the whole time, you can't even breathe. It just feels like she can't even take a whole breath.

Participant 1001:

Anyway, so she had to have that reinserted. We finally got to go home Thanksgiving Day, so we were there for about three weeks. We were in the hospital till about three weeks. Went home Thanksgiving Day. She was still very weak. She was tired a lot, and a lot of that though had to do with the fact that she'd had a heart attack and her heart was just not well. She did need to recover from that and her body needed to recover from that. She lost 10 pounds in the hospital, just in those few -- 10 pounds in a growing 11-year-old is a lot to lose in a week. But she lost in three weeks, so she lost about 10 pounds. She was weak, but she recovered, but something didn't seem right. Her heart would thump very hard. She would get moments where she would just start to feel like it was beating too hard, fluttering too much. We had an MRI done, a cardiac MRI, actually, it's called a stress cardiac MRI, something like that, to test to see how her heart reacted to being elevated. They medically elevated her heart rate, and we also had a CT scan, the cardiac CT scan, and treadmill stress test.

Participant 1001:

What they concluded after that was that there was still a narrowing of her left coronary because they didn't move it. What they did was they unroofed it because it was traveling through the cardiac muscle. And they unroofed it, meaning they just dislodged it, made the opening bigger where it was coming out. But unfortunately, it was passing between the aorta and the pulmonary artery, so it was still being pinched, and so there was a little bit of a thin area that was still there. That was still causing her problems. Her cardiology team decided that it would be in her best interest to go ahead and have another open-heart surgery and this time translocate the artery. So they had to cut it and move it and in addition, they wanted to implant an abdominal ICD, which is the ... What is it? The internal cardioverter defibrillator. She has an ICD, which is a little more than the pacemaker, because it'll actually shock you if it needs to. It doesn't pace her, so she's not paced.

Participant 1001:

It's there. It just monitors her. It's nice knowing that it's there, but it's like a double-edges sword. It's nice that it's there because we feel comforted in that if she were to have another sudden cardiac event where her heart would fail, then it would shock her heart back. But the negative about it is that she has it and she has to be ... Sorry, my phone dropped. At PE, she wears a guard around it under her shirt, so that in case a ball hits it ... There's a lot of uncertainty about the ICD. And then sometimes she feels it and pokes her in the ribs and it's uncomfortable. She has her scars and she's almost a teenager. She's 12 now. So she's a little self-conscious about it, but at this point, she's doing really well. After the second surgery, she had a CT scan and another treadmill test, and those look really good, so we're in a good place right now. That's it. Sorry for the long story.

Interviewer:

No, that's okay. Thank you, (beep), for sharing all of that. Really appreciate it. And then, I guess, before we move on, (beep), can you introduce yourself?

Participant 1006:

My name's (beep). I'm 21. I had my son and his twin sister when I was 16. I found out about my son's heart condition when he was three weeks old. Being so young and getting that information was a very hard pill to swallow, knowing that there's really nothing I can do about it. He is five. He's a very active five-year-old. He's all over the place. You wouldn't think that anything was wrong with him. If you didn't know, you just wouldn't know. Going to the cardiologist, we go to Dell, and right now, he doesn't have any restrictions or anything that would make you think that he had anything wrong, but of course, as being his mom, I'm very ... If I see that he's getting super tired or anything like that, I'm like, "Okay, you can sit down. You just need to sit." He doesn't understand, obviously. It's hard to explain to his school and things like that like, "If you see him get tired or overworked, just please sit him down, let him cool off, let him just chill."

Participant 1006:

About two years ago, he was complaining that his chest was hurting, and he was three at the time, so he doesn't really know what that means, he just knows something is hurting. His daycare called me, I was across town, and they told me that, "His chest was hurting him" that, "he wanted to go to sleep." He had ended up falling asleep holding his chest, and so they called 911. I got there, by the time that I guess everyone got there, everything looked normal and seemed normal, but ever since then, I've always been very skeptical about it because I'm just like, "He's three." Well, he was three, he doesn't know. It's the same thing that (beep) said, it's walking on eggshells. You never know how to explain it. You don't know what to say or what to do.

Participant 1006:

My son hasn't really had very much testing. They wanted to wait until he was about six or seven to start doing the testing. But of course, still day-to-day basis, it's something that you want to watch, you're always watching. It's a blessing and a curse. It's a blessing that you know, but at the same time, it's a curse because it's just very stressful, because you're always like, "What if this happens? What if he gets sick?" Then you're worried, if he's sleeping all the time, is he still breathing? There's just all these different emotions you feel with it, but right now, it's just day by day, go through the motion and hope for the best.

Interviewer:

You said, "There are so many different emotions that you feel with it." What are some of the emotions that you feel, being a parent of somebody with this heart condition?

Participant 1006:

It's very stressful. There's times where I blame myself because I'm like, "I gave him life, so what did I do wrong?" That makes it hard because I carried him. He has it, but his twin sister doesn't have it. It's very emotional, it's always wondering. Whenever you don't really get the answers you want from the doctors, sometimes it's anger or frustration because you want answers and you want to ... You go and try and Google it to get more information because you can't really get any information from the doctors and there's nothing really there either because nobody knows about it. As my son's getting older and wants to do more sports, I don't really want ... I want to let him do it, but then the other side of me is like, "I don't want him to do it," because I don't want to get a call saying, "Your child's on the way to the hospital because this happened." I don't know. You want to hold him back, but at the same time, you don't, because you don't want him to feel like he's different. It's just very emotional.

Interviewer:

Thank you so much for sharing that. What about others in terms of the emotions that you all feel throughout this? Are they similar to what (beep) shared, different?

Participant 2003:

I'd say it's similar. I like how you put it. It's like you want them to play sports and be "normal," but as you send them out on the field, you're bracing with each hockey start, with each soccer start that there won't be a cardiac event, as they say, because I'd always ... The last time I went, I said ... "Well what... (beep)," before, I used to say, "If you're tired, is that a symptom?" And the doctor's like, "No. It's pain in the chest." The problem with this is it's not a slow thing, like okay, this happened. It's like bam, and there's no warning for it, like (beep) experienced with her daughter. It's not like I missed the signs a few days before. You know what I mean? And that's the worry. It's like there are no signs, it's an instant kind of event.

Participant 2004:

You have guilt no matter what --

Participant 2003:

Yes.

Participant 2004:

... that's the phrase I was ... If I deny him doing something, I'm guilty. If I let him do something, I'm guilty. One other thing's, again, my son's 17, is already in anatomy class as college level when all this happened. We haven't talked about my impression of the kid's emotional things. I have a kid who's extremely able to divorce the emotion versus decision process way more than the average adult on one side, but the flip side is just last week, he finally asked me and came to see the CT scans and all the stuff like that. The kid who knows anatomy, knows the heart, everything else, wouldn't even look at his own scans. He was in a bit of denial too, on that end.

Participant 2003:

Wow.

Participant 2004:

I'm very grateful to hear this from you guys, because if you sat down and talked to my wife and I, the way it's been that last year, it's been insane. COVID's made it much more interesting.

Participant 2003:

I think what (beep) said too earlier was that when you try to Google this, it's like I would need a medical MD to understand what the heck. They're all documents that are for doctors. There's nothing in my speak that I can understand and relate to. I think (beep) mentioned it too. Some of it's just symptomatic people, but to read these medical journals is really difficult to try to figure out. The lack of information for parents, for me and for my husband, has been really hard.

Participant 2004:

Can I add on to that because we're in a different stage than most of you guys? The next part is having lack of information as to the follow-up, and that seems to be because we're post-surgery and it depends on which doctor I talk to, which hospital, defining what follow-up is. Is follow-up once a year, you just see a doctor, you call one every two years? Do they want a cardiologist? Because again, my kid's on to something else, very athletic and doing well, now we're more worried about him being limited by the lack of knowledge going forward. But again, there's the guilt, should we let him? It's outside my hands for now.

Participant 1001:

I think that our situation is unique. Like (beep), we're post-surgery, for those that are not and that are just weighing the options, I would think that that is an extraordinarily difficult thing to do. I didn't have the option. It was made for us with my daughter's heart attack. Really, the statistic, the cardiologist told us that the statistic is actually one in a million. You hear that phrase, "You're one in a million." It is actually one in a million that they were able to revive her from her heart attack, that she survived her heart attack. She really was one-in-a-million statistic to have survived it. The EMTs actually shocked her heart out on the field. They had driven the ambulance out on to the field, and it was an extraordinarily difficult time, but the decision was made for us. I think as for where we are now is because she has sustained damage to her heart, her heart does not function at 100%, like someone else's. You learn things as you go on. Our cardiologist said that, "No heart pumps at 100%," meaning it doesn't evacuate 100% of your blood from the chamber exchange. Everybody is at around 55 to 60%. That's supposed to be normal.

Participant 1001:

My daughter's just under that. My daughter's heart function is a little under that because she did lose some heart muscle that they did not revive. They were hopeful that it would come back, and it didn't, but it doesn't seem to cause her a lot of problems. She does have quite a few PVCs, which are the premature ventricular contraction. She feels those and "Everybody gets those," is what our cardiologist tells us. People that don't have heart issues get those. We don't normally feel them. If you feel them, sometimes they feel like flutters. She gets a lot of them, and she feels them all the time that she gets them.

Participant 1001:

She's always constantly aware of her heart, and so whenever she feels something, she tells me then it's like, "Okay, what is it?" We talked to the cardiologist, and the tests look okay. They say that it's because of some of the heart muscle that died. And because there's not a lot of data, I don't know what it looks like for later on when she's 20, 30, 40, 50 years old and she's had her artery translocated. We asked if there was any data on how those people are doing, "How are those people doing that had a translocated artery?" And they said, "We don't know. We don't have that data, but we think it will be fine, but that's about it." I never felt like I blamed them for not knowing though. What they don't know, they just don't know. I think we're very fortunate, we have a wonderful group here where we are. Her primary cardiologist is fantastic. Her cardiologist now that we have, because she has the ICD, is fantastic. Her surgeons were amazing, brilliant people, and I'm just thankful for all of them.

Participant 1001:

For us, follow-up looks like twice a year now, so every six months. Before her second surgery, it was every month, we were seeing them every month, every six weeks. After the second surgery, now we're at a every six months, we're going to see them. I don't know how long it's going to last, so I would imagine that at some point, it will be once a year. Her (beep) cardiologist said that, "Eventually, it would probably be once a year, but it would probably be once a year for her whole life," is what she told us. Her ICD, when the battery runs out, should probably be at about 10 years when she'll start beeping. They'll assess whether or not they need to replace it or if maybe she'll be in a place where she doesn't have to have it replaced, and that would be good too, if it can be taken out. But we don't know. We don't know about that yet.

Interviewer:

Thanks for sharing that. I did want to follow up on, many of you have talked about there just being so many unknowns moving forward. (beep) mentioned that and just so many unknowns and searching, asking questions at the doctors, searching, not getting answers to those questions, then going to Google and searching on Google and oftentimes, maybe there not being the data or answers that you want online. I guess I'm curious, what is it that you all are wanting to know? What are your questions that for which you're not finding answers? Maybe there's a lot of stuff, but I'm just curious, what are the answers that you're searching for?

Participant 2003:

I think it's case statistics. How many cases of this are there? How many cases have opted for surgery or have not opted for surgery? Again, it could be because it's so rare and it could be that the doctors just don't know. The doctors have all been great, but it's just, it's almost frustrating. How can this not be available, because there have been surgeries for these things? I don't know.

Participant 1002:

What I would like to know is whoever has opted for the surgery and whoever had surgery, what is the whole process like? How are they doing right now? Did they get better with that or do they still have that risk that they will usually have without the surgery? How did the quality of life get impacted? Did it improve for good? I think that is one thing that I would like to know as well. It's so frustrating to know that there is no data to actually validate all those things, but then I think it's really helpful to have some. Even if there is not enough data, but it is one or two patients or a few patients, 100 or 50 ... I don't know. Even in single digits, but it will be really helpful to understand how those patients are doing once the surgery has been done. And then the second thing is these days we have a lot of technology with robotics and everything, so is there any progress in the medical field with respect of treating such anomalies, other than the conventional surgery? Is there any other surgery advancement that has happened in the medical field that will probably have more success rate and have less impact on the patient? I think that is also another thing that I would like to know.

Participant 2004:

You guys are on the same thing that we went through in making decision process and to fill in a little more detail without getting specifics, my son's aunt is actually a chief nursing officer for a large hospital down south and a former cardiologist, cardiac nurse. She hadn't heard of this. Finding, when we were getting desperate, getting to the near of making the decision, we were saved by a text to her and she texted her friend who turned out to be chief nursing officer at another one of the hospitals that does this regularly. As we found out, in the U.S., there were really only about three hospitals that do this on a fairly regular basis. One of them in Texas had some documentation, which was decent, had some of the data, but I had to dig as to how many asymptomatic versus the other one, versus symptomatic patients. It wasn't clearly laid out. The hospital that we actually chose, and again, it was with COVID and availability, was on the East Coast.

Participant 2004:

Again, at that point, we had a nice conversation like this with the surgeon after they'd read the file. He told us how many cases he had done and, very clear, the outcomes of each and what the complications were. And in that, we were reassured by the odds, especially. We are walking in with a very healthy boy other than this one item and our son is also, right now, a part of a study being run in Toronto, where their tracking his performance going forward. I can't say we're the forerunners, but we're in the first couple of groups of people that are being tracked. Again, it's hard to say, I mean, one of the hospitals we rejected, at the same time too, they had a write-up here with a young girl. The East Coast came and it was... I'm glad I rejected this hospital. Again, I don't know her case specifics, but they had this whole newspaper article. Her recovery time was double what my son's was and I think it had very much to do with the techniques that were being used.

Participant 2004:

We had a surgeon who, a 17-year-old normally works on pediatric patients, very, very small patients, so the techniques in our case, that could be another factor, the techniques that are being used. I would have liked to have known a little more beforehand. Pardon me as my computer's trying to update something, but had my wife and I not spent endless hours, sleepless hours reading medical journals that we barely understood, we're engineers, I don't know how we'd have gotten through it. At least we kind of knew what questions to ask and we had at least one decent doctor advocating for us that got us to the right people, who then were very compassionate and took the time to explain it to us. It was tough.

Interviewer:

Thanks for sharing that, (beep). What would you say were the most important factors for you and your wife in that decision-making process?

Participant 2004:

To be honest with you, when we get... it felt like we're being treated honestly. But again, (beep), my son because the first group of doctors, while technically correct, were pushing very hard the surgery and as it turned out, our son had, we thought, three features going in that could kill him. When they were done with the surgery, he had five features on both left and right, all that were potentially lethal. So, when we became comfortable with the doctor, and the surgeon, and the statistics, and what he explained, the possible outcomes the surgery would be like, and also, he talked about patients he knew of, several patients he can't say names, but he would say, "Patients that he had to support. I've had a couple of collegiate-level athletes, a couple major level people that had done things that were pro athletes that had had the surgery successfully." He also said he had a few patients that did not fare so well and he told us what their outcomes were.

Participant 2004:

I think it was one out of, he'd done the surgery nearly a hundred times. That was reassuring compared to... frankly, we had with our original person we were talking to, we could never get a straight answer, how many times he'd done the surgery. It was a low number, I found out later on. So that's the kind of data we were looking for. In the midst of that too, also trying to read. You guys know the same thing too, if you start reading case studies and you read a lot of negative outcomes, it was very hard to find the good outcomes or find the outcomes that weren't a 55-year-old farmer compared to a pediatric case. It was a different thing.

Participant 1001:

I think one of the things that I am frustrated about is that we didn't know. She had physical every year since she was born. She had all her baby check-ups and then every year, when it was time for a yearly, we go to yearly check-ups, they listen to your heart, your pediatrician, they don't do any other... they don't do a quick EKG or a quick echocardiogram. They would have considered that, I'm sure, unnecessary, but that's frustrating because they would have found it in my daughter, potentially, and then we wouldn't have had to go through a heart attack and almost dying. And then I hear your stories and I think, well now that you know, now you have to struggle with what do you do? And that would be frustrating, but I think it's better to know, I would think. I would have loved to have known what my daughter had before this thing happened to her. There is not enough that is being done to check for heart anomalies in children, I think, because they go undiagnosed.

Participant 1001:

I have heard stories, the kid that was playing on the soccer field and collapsed. I'm thinking, wow, that's awful, never thinking in a million years that would be my child, and then it was. And that it's like, why do we not... Is it because the insurance company wouldn't want to pay for it? I would have paid for it, if I had known that I needed to get her heart checked better than what it was, than just the actually little thing they do every year and just listening to the heart with a stethoscope. Nothing against her pediatricians either because her pediatrician was awesome, but it's not common to do more than just that because I realize that what our kids have isn't necessarily common, but kids have it.

Participant 1001:

I think one of the things that the cardiology nurses were telling me when we were there at the hospital and she had a heart attack was that one in a 100 or something kids has... not AAOCA, but they have some form of heart issue when they're born and that's a lot. So, they should be checking more. That's what frustrates me is that we didn't know. Now, looking back, there is some awareness of it and there are groups that try to make people aware of it, but even if you were, if I had attended a talk of, "You should get your child checked for something." if I had asked my pediatrician, they probably would have said, "Well, there's no reason to do that."

Participant 2004:

I got mixed answers for you on that and I don't mean to... What started the ball roll with us is our son had a... they came in for all the football team and for $70 test, they were get an EKG and get a quick scan of everybody has hearts, ultrasound. That's when they caught the WPW. Had the technician looked harder, the one coronary artery wasn't visible on the normal spot, so it should have been a flag. That wasn't caught, then we were dealing with years of... The WPW was dealt with, but again, we were at a major hospital and they... I'm kind of being apologetic to the doctors, but in our case, they didn't fully comprehend significance of his case because they were seeing it was a right coronary artery, but his right coronary artery ended up having multiple lethal features, was the phrase that they were using with me. I have mixed feelings. It was a $70 test that got us down this road, started everything going off, but boy, I wish we could have moved up things a couple of years sooner.

Participant 1006:

I can definitely agree with (beep) too. I wouldn't have known had I not taken my son to the hospital when he was three weeks old and I had only taken him because we were trying different formulas and he was constipated. At 16, I didn't know that and they just did an EKG and I got a call several days later that was like, "Your child's EKG is abnormal." They did a cardiologist visit and they did an ultrasound and confirmed it, but as he's gotten older, it's gotten harder to see because whenever they found it, he was so little, but it's very frustrating because I think about it all the time. Had I not taken him in, would I even know or would I know when he dropped on a sports field or doing whatever it is?

Participant 1006:

It is very frustrating not knowing the unknowns, but it's definitely a blessing to know, so that, yes, there's not really much you can do to prevent something if it happens, but if it does happen, at least you can tell a doctor, "Hey, this is what he has" and they have a better insight of okay, maybe that's what caused it. I think it's just more data with it or more statistics and case things would make it easier to understand because a lot of people don't understand. I'm his mom and I don't understand, so it's just kind of definitely a catch-22, you have it on a double-edged sword, really.

Interviewer:

Thanks for sharing that, (beep). You talked earlier about all the different emotions that you feel as a parent of a child with this condition and, (beep), you talked, when you were first introducing yourself and your son, about wanting there to be more support emotionally or emotional support for the emotional side of this, I think is what you said. Can you all say a little bit more about that and potentially, what do you all think that doctors could do to offer more, I guess, emotional support for having a child with this condition?

Participant 1006:

I think for me, when I found out, like I said, I was only 16 and it was very vague. It was like, "Your son has this. This is what it is and that's it." There was no explanation behind it. There was just nothing behind it. There was no emotion behind it. Really even still to this day, there's really no emotion behind it. It's just like, "He's fine, he has no restriction." Okay. Well, he might not have any restriction, but you can help me understand this a little better, ease my mind a little bit more. Just help me understand what I'm dealing with, so that if something does happen, then I'm aware of it.

Participant 1006:

But it's not the doctor's fault because a lot of them don't understand either. They don't really know about it, but I think, for me, it was just not being so insensitive about it because that's how I really felt. It was very insensitive. Being his mom, it's going to hurt regardless, so I think it's just a matter of just putting aside the doctor face when you're explaining it and helping that person to understand it, then be a little bit more sensitive about it.

Participant 2003:

I think it's the delivery. When (beep) was born, three weeks later... I have four, she's my first and in the office after the first ultrasound, they were like, "Okay, so we're probably going to do open-heart surgery when she's six. We'll see you in a couple of years." I'm like, "What does that mean? You can't find any information on this and now we're having open-heart surgery, what?" It was almost very clinical and hear I am with my first child, who now has open-heart surgery. It's like "They'll be fine. Kids are young, they'll cut open a thing, she'll be back to school in six week" I'm like, "What the hell is..." It's like... I can’t... I mean (beep) went through it. I can't imagine seeing your child going through all of that and to just have a bomb drop like that on you is overwhelming and it can't be so clinical when it's -- there's some guidance, like (beep) said. Your child won't have restrictions or if you feel the child feels chest pains, that's a warning sign, but nothing was told, that was the first time I heard about that, was this year, it's chest pains.

Participant 2003:

Meanwhile, (beep) each time my child was sweating or over heated, I was like, "It's an event. I think it's an event." I only heard now, that it's chest pain, not necessarily over exertion, headaches, she would be dizzy and I would say, "It's definitely the heart." Maybe more guidance in terms of what are we supposed to look out for, if anything, because we wait these periods between scans and those two years or a year is like a countdown and you're waiting like, is this the year that they're going to have more information? Is this the year they're going to have a medical new advance that will... It's like you're waiting, it's a clock ticking down for information or something for you to have.

Interviewer:

Thanks for sharing that. Anybody else?

Interviewer:

Okay. I also wanted to ask you all about... A couple of you have mentioned just how difficult it is to talk about this with other people because nobody knows what it is, nobody's heard or it and also even talking about it with your own kids. (beep), you were sharing earlier about how you're going outside because you didn't want to talk about it in front of your child. Can you all talk a little bit more about that, what it's like? Either talking to your own children about this, talking to other people about this, other doctors, et cetera.

Participant 1002:

Yes. I did let my first son know about his condition, but the problem is, like someone was saying, nobody will understand what exactly this is all about. I tried talking to my in-laws, but then they never understood the situation. Nobody even realizes what is the magnitude, so the only thing I do at this point is I would honestly not disclose this issue with anybody, not discuss with anyone. It's just within the family, within me, my husband and my first son. My second one, we wouldn't even let him know anything. When he goes to the doctor, when doctor does some ultrasound on him, that is when we just try to calm him down saying that, "It's just a regular check-up on the heart, even we do get those check-ups." That's the extent of the conversation we usually have with him.

Participant 1002:

But the way how I try to manage this his condition is I will always have my eyes on him, when he is getting exerted or exhaustion is happening or when he's sweating too much. I don't try to restrict him too much, but then I let him be what he wants to be, but then always having my eyes on him wherever he is. Somehow, people don't understand and when they don't understand they can't empathize or sympathize with you and you can't even blame them at that point. My in-laws probably taught me a lesson there, is not to discuss this with anyone who does not understand the situation because if I try to do that and if they don't understand and if they don't even empathize or express any kind of emotion, then it hurts me further. I don't want to be in that situation. Then I thought, I'm his mother, it's my job, it's my responsibility, so let me handle it myself, whatever comes in the way, God is there. That's how I confide.

Participant 1006:

I can't really talk to my son about it right now because he's not going to understand, but as he gets older, I'm going to let him know about it, but I'm also going to express to him that he's not different and he's just as capable as everybody else. He just has to be a little bit more careful than somebody that doesn't have that issue.

Participant 2003:

I let my daughter know about it. Just she knows, she's always known. I always wanted her to know in case she would be able to tell someone who came on the scene if she was coherent what was going on, and my parents, my immediate family. My husband's parents know about it, but I wanted her to know and I just say, "You're unique. You have a really rare thing. Your heart's unique, that's it. You have no restrictions and that's it." But like (beep) said, I don't know how she really takes it. I don't know how they internalize all that because it's a lot. It's a lot of exams and stuff like that, so I don't... She's a tough nut to crack. I'm not sure how she really processes it, but she seems okay for now.

Participant 2004:

Even when he was recovering before this, even now that we're on the different page than many of you guys, I still have this GPS tracker on his phone and it's not because I don't trust him, it's because still at times I still get panicked and I openly admit that if I know he's out jogging, doing something else, I will cruise around and I will hide or I can watch him because I cannot get rid of the feeling. It ain't easy, that's for sure, but wish you guys the best on that. You guys solve that one, let me know how it works.

Interviewer:

Thanks for sharing that. Sorry, did somebody want to say something? I know that we only have a few minutes left and I wanted to pose another question and I'm curious. Maybe this had happened to you before, but if you were to meet somebody whose child has just had this diagnosis or just received the same diagnosis, what would you tell that parent? What advice would you give that parent?

Participant 1002:

I would say, be strong and always be prepared for the unknown. It's very unpredictable life because very... I think you probably become very close to the philosophy of the life and how unpredictable the life is. I think you start embracing those philosophies and spiritualties, but I would ask him to be very strong and courageous and then just be prepared.

Participant 1001:

I think getting a good support system is good. Like (beep) said, being strong and examining just how life, the rigidity of life. If you are a person of faith, I think you should hang on to that. We have a very big group of people at my, the parish that I attend, they all knew what she had and they were all very interested in knowing about it. They were all praying for her, of course, praying for us, praying for the doctors, praying for the best outcome. Unlike some of the experiences you all have had, there's a lot of people that know what my daughter has and they understand it to some extent. I took pictures for them because our cardiac surgeon drew pictures for us of this is what it looks like, this is what it's supposed to look like. This is where it's coming out, this is where it should come out. This is where they moved it, that sort of thing. We've done that. People are very curious, people want to understand it, so we talk to a lot of people about it, but I think if you have a good support system or if you can find a good support system, that would be good. If you find this out and need to go through it, that would be my advice.

Interviewer:

What do you mean when you say support system, (beep)?

Participant 1001:

Family and friends, close family and close friends. Her cardiology team said, "We also have therapists." They did encourage both my daughter, me, my husband, they encouraged all three of us to go to therapy, but we didn't. We were able to get through a lot of the emotions we were having just with talking through with our family, with our friends, with our faith community that we have. Our faith is very strong and there was a lot of prayer, a lot of time spent in prayer and that helped us through it. But like I said, that's not for everybody, but I would say that just having people walk with you through it is good. There's a lot of angst, there's so many emotions. I think all of us have said, "So many emotions." We got through this whole array of emotions, that's for sure, but maybe asking one of your cardiologists, your child's cardiologist what they think about maybe even getting a therapist for the parent. Again, we didn't do that, but that's what they told us, that that would be a good idea.

Participant 1006:

I would definitely say support system too just because if you don't have a support system, I'm sure it's very emotionally draining just because of all the unknowns, so I definitely agree with the support system.

Interviewer:

Thanks. (beep), what advice would you give to a parent just receiving this diagnosis?

Participant 2003:

I guess I would say you have to prepare for an unpredictable journey and you have to know you won't have all the answers because the doctors don't have all the answers. But I think, like everyone said, if you have family and friends that know about it, and they're on the journey with you, and they're caring for you, and they're hoping for you, and every time you take your child to the doctor, they're praying for the best outcome or a miraculous test result or they saw something they didn't see last time and it's just going to be a ride. It's going to be a day by day, appointment by appointment, should we, should we not? But your child still can live a life. She's 12, she's lived 12 years with this. She's healthy and alive and every day is a blessing. And maybe they wouldn't have found this had she not been born with something. There is a reason for everything, but just be strong. Be strong for your kid. You'll get through.

Participant 2004:

I guess from us again, our issue here has been so unique in not a good way. We were very isolated because of COVID. Matter of fact, our son here because he's awaiting testing was one of the first people in county to be identified with COVID, which made things even worse for us because we were shut off from even accessing the doctors for almost two months and he was firstly asymptomatic from it. Things I wish I had had in my hand as far as handed to me, as I've seen some algorithms or decision trees now. I think one of them was out of Texas and [inaudible 01:20:32], which explained their logic or when they recommend surgery, when they recommend observation. I've mostly had to find this by myself, but later on, the same document was presented to me when we got the second opinion. The thing that got us through it is that, one of the things is that I had a sister who was very handicap and an intensive medical case I grew up with, so I kind of learned that you are your only child's real advocate and I don't know if the average person can get through that. You have to.

Participant 2004:

And then I asked for second opinions and be very blunt with the doctors, how many times have you done this procedure? How many times have you seen this? Frankly, that's the one that made me trust the second doctor went to because he was very blunt about how few times he'd seen it and how little he knew about it, but he said he would make a few phone calls. He got me in touch with the right people and just being honest was what I needed and wanted most at that point, what my son needed. He was in most the conversations with us, but we also had a bunch of private conversations that helped us get better. That doctor is what I needed at that point and that's what I would [inaudible 01:21:53] any parent ought to get is a doctor who's honest and would tell you when they don't know what the answer is.

Interviewer:

Thanks for sharing that. I know we're five minutes over time, so I just want to ask, is there anything else that you all would like to share or talk about that we haven't already discussed so far today?

Participant 2003:

I wanted to say that this is really helpful speaking and listening to you all. I don't know any other parent that had this or has a child with this, so it's really therapeutic to hear you all and all your stories, so thank you.

Participant 1001:

Thank you, likewise, I feel the same. I'm glad for this opportunity as well.

Participant 1002:

Yeah. Same here. Thanks everyone. Thank you.

Interviewer:

If there's no other thing that you all feel like you'd like to share or other thing that you feel like we should talk about, we can stop there. I just want to thank all of you so much for being here taking your time in the evening and being a part of this and for sharing your stories. I just can't tell you how much we appreciate it.

Participant 2004:

Hey, Chris, I want for one thing and I'll throw this out there. Should anybody wish, because it seems like, just like (beep), we're one of the few people that are post-surgery, if you have any questions, you could have my permission to share my contact information. If somebody wanted to contact me directly and we could tell you what our experience was.

Participant 1001:

Me too.

Participant 2004:

I'm not a doctor, but I can tell you what we went through and like I said, you're probably one of the few people I know on this small who've been there, sleepless nights for weeks on end. All right, so that's open information now. You guys can contact me however you want.

Participant 2003:

That's so helpful.

Participant 1001:

Me too, if you need to reach out to me-

Participant 2003:

Thank you.

Participant 1001:

... they can share my information with you, that's fine.

Interviewer 2:

Thank you, guys. Well, Katy and I can... if that would be helpful, Katy and I can definitely facilitate that sharing. Katy and I will both follow up with you all.