Interviewer: Also being mindful that everyone's here sharing information that's sensitive, so please don't share what you hear here outside of the group. What is said in the group stays in the group. Everyone, for the most part, has their camera on. So, free to turn it on, turn it off as you feel comfortable. I believe that's it. Anything you'd like to add before we begin? All right. So, in the chat, I've posted some intro questions. If you can't see the chat, just let me know and I will say them out loud when you want to speak. So, whoever wants to start, just briefly answer these questions in the chat. I will ask more detailed information about your journey as we go through the conversation, so don't feel obligated to share everything right now. These are just intros. So, whoever would like to start, go ahead.

Participant 2020: I'll start.

Interviewer: Thank you. Go ahead.

Participant 2020: [censored 00:03:07] I am 34. Something I like to do is run and workout and exercise. I have three kids. They're two almost three, five almost six, and my oldest daughter... three girls, my oldest daughter just turned eight. I'm going to make sure I got everything here. Okay. So, my middle child has Anomalous Right Coronary Artery. She was just diagnosed in April. We have seen a few specialists and is now scheduled to have surgery in November. How this affects me? It's like a rollercoaster, I feel like. Everything has happened so quickly. Sometimes... I just said to my husband the other day, sometimes I feel like I'm watching somebody else's life seeing just things pop up in her medical records. So, I try to take things day-by-day, but it's a little hard sometimes. That's all I got right now.

Participant 3008: I'll go next. This is Alvin. My camera's off, because I'm walking my wife's dog. My wife is going to actually... Give me one second and I'll turn the camera on, as well. Can you guys see me? [inaudible 00:03:00] Okay. My name is [censored 00:03:05]. My wife is [censored 00:03:07]. I am... My age... I'm 47. Sweetie, you want me to give them your age or your going to do that?

Participant 3004: Sure. I'm 51.

Participant 3008: Hobbies... I coach and I like to refinish furniture in my spare time here. We have two children. [censored 00:03:46] two boys. [censored 00:03:47] is 21, [censored 00:03:50] just turned 20. They're both in college at [inaudible 00:03:56] and they both play basketball. [censored 00:04:03] was diagnosed with Anomalous Right when he was 14, maybe 15.

Participant 3004: 14.

Participant 3008: Yeah. What was the next question? How it affected us?

Interviewer: Yes. How would you describe in two to three words how you've been affected?

Participant 3008: How we've been affected... I mean, it definitely caught us off guard. At that point, when he was diagnosed, there wasn't even as much information as it is right now. We kind of... I wasn't there when the diagnosis came out. My wife was with him and the nurse pretty much told him he had to stop everything he's doing because he could just drop dead or whatever, right? So, that kind of freaked him out. So, it was a lot of trying to calm him down, but as we did our own research, we had a better understanding of it and the risks involved. My son... Like I said, both of them played Division I basketball. So, they're extremely active. To take that away because of this, that would've probably hurt him more. So, [censored 00:05:41], you want to add anything? Because that's really all I have.

Participant 3004: No. I mean, the original diagnosis, like my husband said, caught us off guard and it was just... we thought it was a death sentence at that point. Again, we did the research, we spoke to his doctor, then we were referred to Dr. Brothers to get a better understanding. If we had any questions or concerns, she was there to help. Again, we just thought it was a death sentence and it didn't turn out to be that thankfully so.

Participant 3008: I would disagree with the death sentence, though.

Participant 3004: I mean, he didn't understand because in layman's terms was an Anomalous Right Coronary Artery. Then, at 14 years old hearing that, they haven't a clue. So, it scared him more so...

Participant 3008: You mean for him?

Participant 3004: For him, yeah. At that point, he wasn't allowed to do any sports and at that time he was football, basketball. He was running track. So, it was just a number of things that he was doing and just to cease it until more information came out or we did the research, it bothered him.

Interviewer: Thank you. I'll ask more details as we move along. Who would like to go next?

Participant 3002: I can go next. My name is [censored 00:07:34]. I'm 54 years old. I have two children. One is age... two boys. One is age 18, just graduated from high school. Then, my younger son, he is the one who was diagnosed with Anomalous origin of the right coronary artery. He was diagnosed about two and a half years ago, I think. He's almost 17 now. He's 16, about to be 17 in a few weeks. I think he was... just like the [censored 00:08:08] son, I think around 14 or 15. He found out by a fluke. It was just a series of... It was because of an unrelated thing that led one appointment to the other to the diagnosis. There were no symptoms that would have ever led us to bring him to a cardiologist. He was a very active athlete at the time, performing very well and not feeling anything.

Participant 3002: So, when we got the diagnosis, it was very confusing because here was a condition associated with such... associated with fatality... I guess, at one point had been associated... and here is this young man, this child, who's completely healthy for all appearances. So, it took a long time to even process that there was something of a grave nature. As we did our research, though, my husband and I realized it was grave only because a lot of the research... the more recent the information, the less grave the condition seemed to appear. The older the information you read, the more it seemed like a very grave condition. We were very fortunate that we encountered both the cardiologist, then Dr. Brothers who took a very modern approach. [censored 00:10:08] thankfully not told to stop any of his athletic activities, which, if he had been asked at the time, would have been very devastating.

Participant 3002: He, I think, was in shock at first. He just had a hard time processing. He kept asking these, "So, what exactly is wrong with me?" After a few explanations and diagrams and all that, he just kind of came to accept it. I think the fact that it was diagnosed when it was by a doctor who considered surgery... didn't advocate open heart surgery, that made it a lot easier to accept and a lot easier to live with because at first blush, you're like, "Oh my gosh, open heart surgery." It's very scary, but like I said, I think we're fortunate that our diagnosis was recent and all of the information that we had was very well developed.

Participant 3002: So, how does it affect my son and our family now? It's just something that you live with. You take precautions and just as my son says, "I'm just built different." That's our story.

Interviewer: Thank you [censored 00:11:46]. Who would like to go next?

Participant 1013: I can go. My name is [censored 00:11:52]. I am 38. I like to just spend time with family. I don't have a lot of free time with two little kids for hobbies. I have a three and a half year old daughter and a son [censored 00:12:07] that has the Anomalous Right Coronary Artery. He is three and a half weeks old. He was diagnosed at one day old in NICU. So, I haven't been sitting with this information for very long. So, I'm still in the throws of this rollercoaster like a lot of you all said and going through some of the same feelings that you guys were talking about. It feels like the end of the world, then maybe it isn't, but it still sort of feels like the end of the world sometimes, too. Just trying to process it.

Participant 1013: We are so at the beginning of this just... Do we live in an area with good enough care? Are they specialist enough? Should I be looking for jobs somewhere else where like insurance is going to cover something better? Is this going to be on a network? Is this going to change the whole trajectory of our lives? He doesn't know anything, yet, obviously. He's like a minute old. So, how much do we tell him at what point? How much do we restrict him? We have to sit with this for a while because he's just so tiny. Just looking at this teeny tiny little baby and thinking like, "Do you have an increased risk of SIDS?" We can't do anything for a while and it's scary. So, just trying to sit with all that and process it and make sure that we're...

Participant 1013: I just feel like a chicken with my head cut off because our doctor's like, "He's little, we can't really do anything. He probably won't drop dead at some point. So, just come back in ten years and we'll do a scan." I'm just like... Okay, I just have to hope for the best for a decade. So, just getting second opinions and all that. It feels all encompassing right now. We hope that will dissipate with time.

Interviewer: Thank you for sharing [censored 00:14:01]. Who would like to go next?

Speaker 7: I can go next. My name is [censored 00:14:10]. Similar to a couple of you, I like to run. I just got back from a run. I have two children, twin girls, age 17. [censored 00:14:26] which was born a second later than her sister [censored 00:14:29], she was diagnosed with anomalous in the right coronary artery last August. She was on the operating table November 10. So, she is through her recovery and her story is a success. She feels better than she has in a long time. What brought us...

Interviewer: [censored 00:14:57] can you still hear us? You're frozen. All right. I think while we wait for [censored 00:15:22], would you like to jump in?

Participant 2023: Yeah, of course. My name's [censored 00:15:28]. I'm 44 years old. Hobbies... pretty much watching my kids' sports events because I have no time for anything else except to drive them there. I have two children, two boys. I have a 15 year old and a 14 year old. My 14 year old is the one who has an Anomalous Coronary Right Artery. Our story resembles pieces of every single story that has been told so far. Everybody who has spoken, there's a piece that resonated with me. He was diagnosed four years ago and he had zero symptoms. It was completely by accident. They were doing a scan for something else and it just popped up. So, it was a complete smack in the face, if you will.

Participant 2023: Actually, what they were scanning for was not even a worry. It was kind of just a, "Let's just cross this T and dot this I and walk out of here." As a matter of fact, my kid was in there like, "Mom, I need you to hurry up. I'm going to be late for practice," type of thing. It was discovered and things moved very quickly and I felt every word that a couple of parents said that this is new where you feel like your head is spinning and all of a sudden, one day my life was okay and the next, you're worried about your kid's health and everything and what is going to happen.

Participant 2023: We obviously had to face the decision of whether to have surgery or not, but his life is sports just like you guys talked about. Life is sports for my children. So, I couldn't fathom taking that away from him. Although, it sounds like he was young because he was ten, he's a real mature old soul. So, we involved him in that decision even at that time. I'm glad I did. To be honest, he's taught me a lot about how to handle this. Fast forward to today, I think we handled it really well.

Participant 2023: He's a super competitive athlete in hockey, which of all the sports is one of the more aggressive high intensity, all of that. How we handle that is everybody in our family and his coaches and around him is all trained in CPR, is aware of the situation, he has his own personal AED that travels with him for sporting events. To be honest, I think we've finally, although it seems like some of you have a long road ahead of you, you finally get to a point where it is just part of your life. I guess, you make it happen. He is okay with it and he has been successful dealing with it. So, that's where we're at now.

Interviewer: All right. Thank you all for sharing. If we get [censored 00:18:34] back in, may have her just continue and finish introducing herself. For the purposes of time, I'll move us along. So, you all started sharing about the diagnosis experience and I just wanted to get... to ask a few more details about that. So, whatever you didn't get a chance to share, would like to add more details, just tell us about when you first heard or when your child was first diagnosed. What was it like receiving the diagnosis in that moment? What did you feel? Those kinds of things, whoever would like to start.

Participant 2020: I can start again if that's okay. So, my daughter started having symptoms when she was four. We took her to the cardiologist and they tried to do... her EKG looked okay. They tried to do an echocardiogram, but she completely lost it and refused to let us do the echo. So, they tried to do a holter, but the holter wasn't turned on correctly so she wore it for 14 days with absolutely zero results, which was horrible for her. Then, we just decided because it was so stressful for her to let her just chill for a little bit and we just monitored her symptoms still not knowing there was anything going on until she continued to have them and her heart rate would be all over the place. She kept saying, "My heart hurts," or when she was really little, she would say, "My pumper's beeping really fast." Just her way of describing how she was feeling, which to me that seems very unusual for a four year old.

Participant 2020: In April, when we took her in, the cardiologist we had seen the year before was like, "It's fine. She's going to... We're not going to find anything. It's fine. She just can feel her heart." Then, when she gave me the results, she almost seemed caught off guard herself and not confident in the diagnosis... not confident in the diagnosis, but confident in her presentation of the diagnosis. Which, for a mom who was told it's nothing and then to be told something, was awful because I don't think she even knew really what she was talking about and was very nonchalant about it. She gave us minimal information. Told us, "You can research it, but don't because you'll find all this stuff about cardiac arrest and it'll scare you and you don't need to be scared."

Participant 2020: So, of course, we went through the gamete of tests and the Cts and the everything. Again, she just continued the whole time to be very nonchalant. When I had asked for information to be able to present my daughter's school... she was in preschool at the time, with information, she had told me, "You don't have to tell anybody about this." That was a huge red flag for me because I felt like people should know because if she passes out, they should know that she has a heart condition and she's not passing out from low sugar or whatever.

Participant 2020: So, we then got two second opinions. One was another person up in St. Louis, another person at a different hospital in St. Louis. Similar answers, but a little bit more proactive. Then, we ended up getting a referral to Boston, who was... the doctors there were so much more knowledgeable and I felt like listened. Everyone chalked [censored 00:22:17]'s symptoms up to nothing, which was incredibly frustrating because my child continuously, even after being poked and prodded and tested and had all these tests done, is still reporting symptoms something's wrong. So, I felt like finally Boston listened and really, really took everything into account where some of our local doctors did not. So, that was just kind of our experience and that's why we have a lot of frustration and confusion and why this process was so long.

Participant 2020: We had started to get to this, I guess, accepting like, "Okay, we're just going to get an AED and we're going to just watch everything." I felt like I was living with a ticking time bomb because she had the high risk features of everything was narrowed and it was in her aorta and it's squished between her arteries. Then, people were like, "Don't worry about it. It's fine. She's fine. Nothing will probably happen." Which, is not what you want to hear as a parent. So, that's where we are. Now, I'm trying to wrap my head around surgery, which is also really hard. I think it's kind of a no win situation in that. Because everybody's ideas of what to do, the treatment modes are so different, I don't think I ever will feel 100% on anything, if that makes sense to you guys. That's all I got.

Interviewer: I saw a lot of reactions and before I let other people jump in with their reactions and their diagnosis experience, I wanted to ask [censored 00:24:02] what could've been different or better about that diagnosis experience?

Participant 2020: I don't know that answer. I wish, at least, my first doctor was not so... one, I understand this is a rare diagnosis. So, it's probably not something they know quite a lot about. She probably even had to go and research it herself. When I asked, "Is this something you guys see?" "Well, kind of." That was just the response, which is also frightening to hear as a parent. I would've almost rather her been very frank with me versus beating around the bush around stuff and being honest about... everybody kept saying, "Surgery is higher risk than this or lower risk than this," but no one could give me numbers. No one could tell me on a continuum what that looks like.

Participant 2020: It was just this very open ended blob of information that we then had to... Again, I heard everybody talking about researching. I think I read every single article ever written on this diagnosis probably 100 times trying to wrap my head around it to make the right decision because I felt like the people who maybe should know didn't or just didn't a great job of explaining it to us. So, I guess... I don't know, more education, more straight delivery like, "This is what's going on," and not, "Well, maybe this and maybe that." I don't even know if that's a possibility with this diagnosis right now.

Interviewer: Thank you. Feel free to jump in, anyone.

Participant 3008: I'll go next. So, I think... Like I said, when we got [censored 00:26:00] diagnosis, it wasn't for anything that he was feeling. He didn't have any symptoms, but he's extremely self motivated and overdoes things. When he works out, he thinks he can do more and really doesn't need to do it. So, my personal diagnosis was he strained his shoulder blade, pretty much, underneath of it... something. So, we told his pediatrician and she recommended that he go and get his heart checked. That's when they found it. Like I said, that was almost like seven years ago and I wasn't there. My wife called me and told me. They were both in a panic because again, the nurse that diagnosed him said, "You can't play sports anymore." That was like... To him, that was the end of the world.

Participant 3008: So, I started looking up articles and what I found was that they didn't have a lot of information and because they didn't have a lot of information, a lot of the decisions are made based upon the anomalous left percentages. So, "Okay, cool, you got an anomalous right. So, we're going to treat you like you have anomalous left even though we don't know exactly what the anomalous right entails." So, when we first went to the cardiologist, we went to Nova, Virginia. We met with her, they did his tests. His tests have always been fine. He just went Monday to CHOP and did a stress test and he got whatever... I know he beat his score from last time which was over 300 on that bike. So, he doesn't have any symptoms, right?

Participant 3008: So, when we met with the cardiologist, she was telling us that they recommend surgery and I asked her point blank, I was like, "Why?" I was like, "You know just as much as I know." She kind of sat back and she said, "Well, you're right. We don't know." I said, "You can't promise me that..." because I watched the un-roofing and I was like, "No, I can't see that happening." I told her... Again, this is seven years ago. I said, "If you all can't guarantee that he's going to be fixed, then why should I do it when the chances are slim to none that something's going to happen to him as long as he stays in the shape that he's in?"

Participant 3008: So, at that point, what they did... I don't know if you all have the documentations from Dr. Brothers... about seven years ago, they had some case studies. He was actually one of those case studies in making that determination that they can continue to play sports. Dr. Brothers did tell us it's also based on where in the country he was diagnosed. She said if he was diagnosed on the West coast at this point in time back then, we would've had no choice but to get surgery. So, he was involved in the decision. He'll tell you today if you talk to him that he'll probably get the surgery when he's a little older. Anything that we've seen someone with an Anomalous Right having some type of issues, just from what I've seen, they're normally like over 50 years old or something like that. So, in his mind, he's saying, "Maybe down the line I'll get it."

Participant 3008: Right now as a parent, I understand what [censored 00:30:14] is saying like you don't know if you're ever going to get to that point because even when we go to his games, me and his mother sit on the edge of the seat like something's going to happen. Even though we're just watching, we watch everything. We watch all of his movements and that's because even from that initial diagnosis, just hearing that, that's still in the back of our mind. We go through times... It's been a while, so we've been dealing with this. We've been taking our annual trip up to CHOP so they can get his numbers and all that good stuff. We don't really think about it, honestly, until we see him playing or he's got to go to the doctor. Every time it goes so far, everything's fine. That was our decision, conversation. My wife might've thought differently here and there. Like I said, if there are no guarantees, then why? That's my spiel.

Interviewer: Thank you. Also saw more reactions, so whoever wants to jump in.

Participant 3002: I can jump in here. So, the original question like how did we feel in the moment of diagnosis of finding out about it... Our experience, like I said, we fell upon it. It was during a regular well exam where the PA felt something funny. Turns out it was an arrhythmia. That's what we thought we were going to go check out. Turns out it was... The arrhythmia had nothing to do with the ARCA.

Participant 3002: Anyway, in our experience, the doctor that we went to was... I can't remember who it was, was talking about the lack up information. The doctor we went to was a wealth of information, a lot of information. I felt like a student in a course in medical school about the heart. It was... God bless them for spending so much time with us and really trying to make sure we understood, but he was very technically, very detailed. This is... absorbing it, understanding it, was so difficult. It's to the doctor's credit that he gave so much information. I think that's probably better than lack of information, but it is overwhelming. I was trying to process. I'm like, "So, what does this have to do with the arrhythmia," which was the original reason we came into the office. He's like, "Nothing at all, probably." So, I walked out of that office with my son and trying to explain to my husband what this was, what was happening. I was just like, "I don't really know. All I know is, we're lucky that it's the right. That's all I can really tell you that I fully understood."

Participant 3002: So, it took a few days just to let the information wash over. The doctor had written notes for us and drawn diagrams. So, it was just going back and trying to understand it. Then, of course, going to the internet. Which, again, I feel very fortunate that this was two and half, three years ago because there was... Well, I guess like [censored 00:34:14] explained, there had been young people my son's age who had lived this who showed that you can live with it and be fine. My son is trying to process this and he said, "Okay, all I need to know is can I still run?" Fortunately, our doctor very well educated on this matter said, "Yeah. Until you meet Dr. Brothers and she tells you otherwise, keep doing everything that you're doing."

Participant 3002: So, by the time we met Dr. Brothers, she's very good at condensing the information and conveying it in a way that someone who never went to medical school who didn't even do all that well in biology could understand. Having her watering down the information and distilling it and really presenting it on a, "What you need to know and what your particulars are," I think helped reassure me and my son and certainly the rest of the family. The one advice that she did give, she said, "Make sure he stays hydrated because if he faints for any reason, even if it has nothing to do with his heart, in the current climate, it will be very difficult for me to advocate for nonintervention." So, he's drinking water all the time. He's taking the [inaudible 00:35:56] tablets, the electrolytes that help retain water. It is a rollercoaster.

Participant 3002: There is a worse case scenario and the worst case scenario is devastating, but you really have to pull through it to figure out that a lot of... if you're not symptomatic, then you probably don't have to worry about the worse case scenario. So, that was our experience.

Interviewer: Thank you. [censored 00:36:32], I believe you wanted to go next.

Participant 1013: Yeah. I just wanted to echo a lot of what everyone was saying. [censored 00:36:41] maybe is like a Midwest thing because I feel very similar to you. My doctor... [censored 00:36:48] doctor, he's nice and he seems to know a lot, but I'm an East Coast scientist in the Midwest right now and I just feel like everyone here sugarcoats stuff and I don't need that and I don't want that. I understand what you're saying. I don't want you to freak me out. I get it. I get how scary it is and stuff, but I just want you to be honest about what the limitations of your knowledge are. So, I was just a little bit frustrated with that.

Participant 1013: We found out so early because we've just been in hell with this whole pregnancy this whole time. We've just had a bunch of things. So, they saw something a little bit abnormal on the ultrasound. So, we were just waiting for the other screw to drop this whole time. So, they said... the genetic counselor said there's like a 4% chance it's like a genetic anomaly and a 3% chance it's a heart thing. So, we had to wait. That was when I was 12 weeks pregnant. Then, when I was 20 weeks pregnant, we got an echo. Everything looked okay then. They were like, "It's totally fine. It's going to be great. When he's born, we'll just look again." Then, he was already in the NICU for something else, then that came. I was trying to recover from an emergency c-section and this guy's telling me all this stuff. It was just terrible. It was just really terrible. Just the way it went down.

Participant 1013: We found out really early. So, it wasn't like terribly surprised. I knew this was a possibility. Not this specific thing because no one knows about this until it happens. I mean, even a lot of doctors. Then, just what everyone else is saying, too. It kind of feels a little bit up to us whether we want to do the surgery. That is a crazy burden on our shoulder. It's just like, "Well, [inaudible 00:38:40] probably fine." Probably? How probably? No one knows. This is probably underdiagnosed because some people go through [inaudible 00:38:49] so maybe it's not as bad. You just don't know. So, it just feels like... then, they're like, "If you go see a surgeon that does a lot of these surgeries, they're probably going to want to do the surgery." So, it's like, are you making that decision before you get that decision, sort of type of thing.

Participant 1013: It just feels really heavy. You're just trying to do your best and we're all just reading all of the things and we're all becoming heart experts and trying to explain to your families and other caretakers and stuff. My husband bought like a 3D model of the heart and he's like showing his parents. He's like, "Do you see the coronary artery here?" It's just a whole weird thing now. So, yeah. I just totally understand what all of you are saying. I feel the same way.

Participant 2023: Our diagnosis experience, like I said before, he didn't have any symptoms. So, it kind of came out of nowhere. We live in Massachusetts, so we're lucky we have access to really good healthcare, but we live in the Western part of the state. So, the first initial diagnosis was out here in the Western part of the state and the doctor who first found it... I was thankful, knew his limitations of knowledge, but knew enough to give us enough information and was able to get us into Boston Children's extremely quickly and in with Dr. Newburger who is one of the premier doctors working on this and has a great amount of knowledge on it and a great bedside manner and able to explain it in really a fantastic way.

Participant 2023: For feedback, as far as the diagnosis process... as far as the process explaining it to adults... Me, I thought it was phenomenal. I thought the open-mindedness and the collaboration and all of that was great and my biggest fear was that when we decided not to have surgery that there would be some sort of pushback or I don't know... judgment or something and there wasn't. I was thankful for that.

Participant 2023: I don't want to say a criticism, but maybe an area of improvement for my son because of his age at the time, which was 10, so it's old enough to understand some, but not old enough to understand a lot... Then, he was also in the position where they kind of put him back out into the world and said, "Okay, you're going to go back out and play your sports, but you need to be very self-aware and aware of your body." Tell that to a 10 year old boy and say, "Okay, well..." He's playing sports at a very high level like the [inaudible 00:41:41] are saying, right? Like extremely high levels, right? You know. "You can be out of breath and you can push yourself to the extreme levels, but hold on. Wait a minute. If you get a little bit dizzy or your chest hurts a little bit..." That's very hard for a child to know their limits. They're clearly learning their body, then their body is then going to change for the next year every minute, it seems.

Participant 2023: So, I guess my feedback would be it would've been... He didn't even know the right questions to ask. People were certainly patient and gave him all the opportunity in the world to ask questions, but the poor kid didn't even know what to ask and he didn't even know what information he was missing. I wish as a parent I was better at being able to help him even know what questions to tell him to ask, but I didn't either. That part felt a little bit lost to us. It felt like we waited through that alone trying to navigate that and I wish there had been more resources for that.

Interviewer: [inaudible 00:42:54]. So, to use that to segue into something many of y'all already started talking about which was what happened after the diagnosis and the conversations that were had with different medical providers and decisions that had to be made. Can anyone start just talking about those next visits and how that decision making process came about?

Participant 2020: I'll jump in again. When we got the diagnosis, the doctor had ordered all the tests and you get the basic information from the echo, then the CT is the test, right? You're hoping that it's a path or a course that is least resistance or it's not going to cause as many issues. Then, of course you get the one that has all the issues. So, I think the hardest part for us is that the first two doctors didn't take her symptoms seriously and I felt like... again, if this wasn't related, then why would she be having these symptoms and continue to tell us after all these tests if it wasn't related? That was super frustrating because I felt like no one listened to us or no one listened to her.

Participant 2020: So, we went through all the tests. She even, at five, did the stress test. She was very angry about it, but she got up there and ran her little heart out on the treadmill. Of course, she was so tiny that everything was falling off and we didn't really get a good reading. So, again, it was frustrating that we put her through this test and it didn't work as well as they wanted to. Then, they kind of just chopped it up, "Well, it was good enough." It was like we didn't get all the information that we were supposed to get. So, that was very frustrating.

Participant 2020: Then, after that whole ordeal, when we went to see the other specialist or the cardiologist, his information was, "I think we should wait and see, but she shouldn't do competitive sports. She should do this without having a surgery." At her age, she's not necessarily doing competitive sports, but is starting to jump into that area. So, now that's terrifying. So, then we're left with, we had one doctor that says, "No surgery. We'll see what her activities look like when she's 10." Or we have a doctor who's saying, "You don't need to do anything now, but when she gets to 8 or 10, she shouldn't do anything without having surgery." Then, we went to Boston and they're like, "No, she needs surgery." So, that also was just very... I can't remember who said it. I think [censored 00:45:46] said it felt like we were left with this very, very difficult decision.

Participant 2020: Finally, at Boston, they took her symptoms seriously which then I think helped us say, "This kiddo's going to keep having these problems." In fact, our symptoms are almost evolving into other things. It's allowing us to feel a little bit better about that decision, but also a lot of it's just, "Well, we'll wait and see." And left with a lot of unknowns. That's hard. Very, very hard. We've been trying to advocate for her as much as we can and trying to do the best that we can, but not even sure if we're doing the right thing.

Interviewer: So, [censored 00:46:33], what if anything would you change about your medical journey so far?

Participant 2020: I don't know. I think... I wish that... You have these textbook ideas. The medical world I think has this textbook. If it meets this criteria, then this. If it meets this criteria, then this. I don't think it's quite that simple. I think... I don't know. We just go lumped into a box that I don't think she quite fit into. She had all these very high risk elements and symptoms, but we were told to wait and see, which is... everything else we were reading was telling us... was going against it. So, it was a huge conflict for us. So, I think just some better explanation on that.

Participant 2020: I understand that she's young and she doesn't necessarily push herself to the degree as some of your older kiddos who do in competitive sports, but she does do sports and she does bob around the house. You can't tell a five year old to sit still. So, even when she's running in the house or dancing around the house, it's terrifying because that's when most of her symptoms occur, not even when she's playing her sports. So, I think it's just better direction, better information. I know that's what part of this is about, is just better information because what's out there, I felt like was contradictory to what my doctors where telling me and I felt like all I had was to listen to these doctors that were telling me things that just didn't mesh right, if that makes sense.

Interviewer: Thank you. Whoever would like to jump in, go ahead.

Participant 3002: I can go next. So, remind me again... the question was, "How did we feel about the decision making process with the medical attention, with the doctors that we've seen?" Is that the question?

Interviewer: Yeah, after diagnosis, what happened? What were those visits like? What conversations were had?

Participant 3002: Okay. Well, the diagnosis was with Dr. Brothers at CHOP and it was very matter of fact. I really liked her decision matrix. She explained well... this is her perspective. She said there are doctors around the country who have a different perspective, but this is why she feels... and enumerated why she feels that surgery is not the solution here. One of the biggest factors was he was asymptomatic plus other factors that she showed me on the ultrasound and all that. So, I was very relieved because one of the...

Participant 3002: After the initial... I don't want to call it diagnosis... After the cardiologist that we had gone to who sent us to Dr. Brothers told us that this is what it might be, what it might end up being, there was that shock that we talked about earlier, trying to process. So, a few... I don't know... days or weeks into the processing, it occurred to me that this isn't something that just developed. This is something that has been there. He's 15 now. This has been there since he was in the womb. This isn't anything new. We don't have to react to something that's happening. So, my common sense or my thinking was sort of like, "Well, if it ain't broke, why should we fix it?" He's never been symptomatic. He's never complained of anything with his heart. Again, it has been there all the time, we're just discovering it now. It's sort of like with the sunrise. It's not that the sun hasn't been there. It's been there the whole time, you're just seeing it in the morning. It doesn't actually change any of it's properties.

Participant 3002: So, I was very... I had an intuitive agreement with Dr. Brothers when she said... when she recommended nonintervention and just monitoring. What made it even more reassuring was when we went back to our cardiologist, who my son also sees every six months, who had initially told us that this is what he suspects the diagnosis may lead to, and he's a lot more... He told us had this been diagnosed earlier in his life, he may very well have told my son to stop competing, but because of what we have learned in the last few years, there's no reason for that. So, when I told him Dr. Brothers recommended against surgery, and he concurred. He was more of a... He admitted that he's a... He takes a more interventionist approach and he's like, "As a dad, I heard this. I might tell my children to stop competing." Just because that's his personal disposition, not his medical opinion. Even he said, "Well, if that's what she says, I trust her completely. Based on everything we're seeing, that makes a lot of sense."

Participant 3002: So, it was very reassuring to have those two voices... I think they know each other professionally... to be in agreement and that helps tremendously. I mean, you're talking to one very educated person in their field and they agree with another very educated person in their field and it reinforces your intuitive sort of, "Why should I fix something that's never been a problem?" That is... I guess we're the lucky ones because there was not much confusion or controversy in our story and our process. So, unity... unified message helps.

Interviewer: Thank you. Who would like to jump in?

Participant 3008: I can go. I'll go next. My wife has to log off. She's getting ready to leave the office. I guess, like I said, from the beginning we were lucky enough that the cardiologist that we were sent to in Virginia was aware of the diagnosis. She knew enough about it. She knew Dr. Brothers and recommended we go see her. Dr. Brothers told us we had to come see her, at that point, after she got all of his test results. She just wanted to see him and put him through some more tests at that point. So, we kind of knew at that point that [censored 00:54:34] was being... he was being used to actually gather some information. I don't want to say they were kind of like surprised when he kind of like fell into their lap, but I think they were.

Participant 3008: He went to CHOP to get tested. He went to children's hospital in Washington DC, did more tests. Then, out back to Virginia again. So, we were constantly running, but in my mind, the thought of surgery was still that wasn't going to happen. Again, just like [censored 00:55:22] just said, there... he's had it his whole life. I've literally watched this kid go play a football game, then go to a track meet, and nothing. So, again, like she said, if it's not broke, why fix it? Because they had no guarantees, again, we just said, "Okay, fine. We'll go through the tests." In our mind, we were helping like, "Okay, this is going to help someone else because someone else is going to be told the same thing and that's not necessarily true that they have to have this or that."

Participant 3008: Like I said, we've been going every year. It's routine. We kind of remind him. Then, his mind kind of thinks about it just because of that initial diagnosis and what that particular nurse told him is still in his head, but it's something that we're kind of... it is what it is. This is what we deal with and that's pretty much it. I mean, we've come to... this is a part of what we have to do. So, his coaches know, his trainers, everybody... they know when he has to go get checked out. There's no problem there. They just want some documentation for their own records and we'll keep going until we don't see Dr. Brothers anymore, but I will that us being that close to Philadelphia and her being one of the top researchers... that was a blessing. So, that definitely helped. I don't know if I answered the question, but I think so.

Interviewer: No, thank you, thank you, thank you.

Participant 3008: Okay.

Interviewer: Who would like to go next?

Participant 1013: I guess I can go. I haven't really had gotten to... had to... I don't even know... make any decisions, yet. He's just so small. Basically, our decisions are not do we believe the doctor, but should we accept that. Should we look for second opinions? We are in the process of doing that now and I'm just trying to figure out where to go for that because we really just don't have very much information right now. It just feels like this is just this thing that is hanging over us like every year we'll get an echo and see if anything's worse, reassess, reassess every year, see if he has more symptoms, see if... or any symptoms. It's just scary right now because obviously he doesn't play any sports because he's just a baby, but I'm just like, "He's crying so much. Is that not normal?" Everything is just through the lens of this now.

Participant 1013: Is him crying so much... he's like really out of sorts... is that a kin to like if he was running really hard when he was older? Is that a lot on his heart? I don't know. Does anyone know? You can probably hear him screaming right now. It's like inconsolable. So, just all that. Every day is like, "Are we doing enough? Is there anything we can do? What should we be doing?" So, that's really all. We haven't had too many decisions yet, but just thinking about the possibilities just every day... I don't know... five, ten years until we can future this out more.

Interviewer: Thank you, Sarah. Just a follow up question... outside of the doctors, have there been... What other medical staff or personnel have you been in contact with or given as a resource, if any?

Participant 1013: Well, the doctor here, he's seen a few people with this, but... I don't know. Maybe I'm being unfair because it's so high stakes for us, but I wasn't like thrilled with the way he was talking about it. I was just like, "How much do you know about this?" He was speaking just... he's fairly well informed about it, I guess, and he's seen a couple, but this is not like a thing that they do a lot. So, I wanted to find someone there. So, I just reached out to CHOP recently... So, Dr. Brothers, like you guys are all talking about... So, CHOP and Boston... So, I got into a Facebook group, I did research, and tried to find like who knows a lot about this. I did my PhD at Penn, so I feel like I have some people still there ties to CHOP. I did a training grant there and I have family closer to there, so I went with that. So, reached out to her team and will be following up with that soon.

Participant 1013: All we have is an echo from a one day old baby. So, hopefully she can see something there. Then, help deciding when we should get a CT. He's so little and they're just like, "I don't know how well it's going to do us right now and you'd have to anesthetize him and his tiny little heart and stuff." When should I do that? I just have to sit here and wait until. So, if I can have a second opinion on that. So, that's really it. They didn't tell us to do anything else. He felt like he knew enough. We needed second opinions, though. That's like where we're at with that.

Interviewer: Thank you, [censored 01:01:24].

Participant 2023: Sorry. So, after diagnosis appointments, first was to decide of surgery kind of immediately. It seemed like, to me, that decision was immediate. We made that pretty quickly and was confident in that. Then, once that was behind us, then it seems like the protocol was more like [censored 01:01:51] was describing where annually he goes for a pretty intense stress test. Then, as long as that continues to pass with flying colors, then he kind of goes back out into his regular routine.

Participant 2023: I will say, I really related to how [censored 01:02:09] described it because it's almost like it's out of sight, out of mind for him a little bit. I mean, until that appointment. I will tell you, every year it catches me off guard. After that test is done and whatever time period is in between that test being done, the doctor coming in to discuss the results, that look on his face catches me off guard every single year because it's like all of sudden, it hits him like out of nowhere like, "Oh, shit..." Oh, sorry. "This doctor is going to come in here and tell me I can't play hockey again, right?" Even though he knows he did well on the running or treadmill, whatever it is.

Participant 2023: I did want to just mention something to [censored 01:02:56] because I can't imagine you guys listening to the rest of us that have been living with this information longer than you guys and have kids that are older and can give us back feedback that is a little bit more older than... I mean, [censored 01:03:09] I know your child is four or five you said, but not old enough... like a teenager. I just wanted to say I sympathize with you guys. When you guys are talking, it might sound like we all are handling this and have a handle on it, but every time you guys talk, I resonate with you completely because that is exactly how I felt when I was there at that time period.

Participant 2023: Especially, [censored 01:03:37] you were saying the next 18 years and that's what it felt like, right? When you get that news, it's like all of a sudden. It's not like I'm making a decision for today or I'm making a decision for the next year. It's like, "I'm making a decision for this baby..." No matter what age they are, they're your baby.. "For the next however many years of their life." So, I just wanted to mention to you guys because... I don't know. If I was in your shoes, I might be intimidated with everyone else handling it a little bit further down the line, but I just wanted to compliment you guys because you're doing amazing and you're right on track.

Interviewer: Thank you, [censored 01:04:21] for those kind words. I've heard all of you talk about the challenges that come, right, with your family, for your child. So, I wanted to also ask what supports have really helped you, have helped your child, have helped your family cope throughout this journey?

Participant 2020: [censored 01:04:49] I think you had mentioned you joined the Facebook group. I don't know how many of you guys are on this, but there is this group for Anomalous Coronary Artery and it has been awesome. People... That's where I actually got our surgeon's name. We were told about Boston having an excellent second opinion program, but I had... Dr. Brother's name comes up all the time. Dr. [inaudible 01:05:17]'s name comes up. These names, these specialists in this... It's nice because it's people who... parents who are dealing with this, patients... adult patients that are dealing with this that have been dealing with this for years or five seconds. Even though, sometimes I feel like I've been dealing with it for five seconds, I can even jump in and be like, "Hey, it's okay." It allows people who have already been there, done that help the newbies. Even as a newbie, I feel like you can kind of jump in. That has been tremendous.

Participant 2020: Obviously, just family and friends. Because, we have to go to Boston and be up there for so long, our family and friends have rallied around us in helping us raise funds and prepare and take care of our other kids while we're going to be gone. We're so blessed that we have that... that we have that.

Participant 1013: So, I can go next. Yeah, that Facebook group has really helped me because there's not a lot of people in the world that know if it. So, it's really great to see everyone's perspectives. Like you said, just from different perspectives like people that are older that just got the news, people that have had the news. Just really super helpful and sweet. So, that's amazing. Obviously, my husband is great. Our family is, too. Some friends that I've told... I don't know if you guys feel like this, but you're the parent and now you feel like you have to be this warrior and like you have to advocate and you need to reach out and you're just like, "When I lived in Philadelphia, is there anyone that's still..." I'm in a completely different field, but is there anyone there that would know anyone? It feels like you've changed focus and you don't want to be the crazy person that's just always having this in the back of my mind.

Participant 1013: I've told some friends. They're nice. I think people sometimes don't know what to say and I get kind of annoyed with people. Again, I don't want to be pessimistic about it by any means, but I just kind of get annoyed when people look for like the silver lining. They're like, "Oh, that's great. At least you know now." And I'm like, "Yeah, [inaudible 01:07:44]." They don't know what to say. They're trying to be nice. So, I'm intolerant, I guess. Our families are great, but we live really far. We're living in the Midwest right now just because of work. My husband's family's on the West coast, my family is on the East coast. We're like as far away as you can get. We really don't have very many... We have like one friend here, basically. We haven't been here that long and might not be here that much longer. So, we're just kind of nomadic. So, that's tough. All of our support is far away, but they're great.

Participant 3008: I can go, I guess. So, luckily, we've had my parents, my wife's parents... were and still are extremely supportive. We're lucky to still have them here. We pretty much told who needed to know, but eventually... [censored 01:09:07] will tell you, once he gets to know you, he'll tell you what he has. He just got a tattoo on his forearm of a heart. His mother was pissed off because she's not a fan of the tattoos, but he claimed he had to get it for his own mental, I guess. It's kind of like we just took it... We've been dealing with it for quite a while. So, it's like a part of every day... It's just a part of him. It's a part of what we deal with. Now, we still... that thought it still in the back of your mind, but we kind of just learned to deal with it, I guess.

Participant 3008: As far as like people, we didn't really go to a lot of people because no one really... as far as like anyone that actually knew what he had, the diagnosis, we didn't have anyone to really talk to at that point outside of just the doctors and whatever we found online. So, when they brought this up, I told them when we were up there Monday, last Monday... I told Dr. Brothers, I said, "Yeah, I'll do it. I'd love to talk to someone." Especially like [censored 01:10:42]. I know it's crazy because we've been there. Honestly, some of those thoughts, they don't go away. Trust me, you'll still... [censored 01:10:52] is 20 right... we will watch his moves sometimes. I know that I do and I know his mother is just... yeah. We watch how he reacts when he's working out in games. We're watching his body language more than actually watching the game sometimes when he's out there because it's still in the back of your mind.

Participant 3008: It is what it is, like I said. It's just what we do. It's how we deal with it. Like I said, I'll keep screaming Dr. Brother's name because she does... she makes it easy to understand. I'll tell you, when we first met her, I kind of talked to her the same way I did to the cardiologist down here. I was like, "You can't tell me that surgery is going to work or whatever. You can't guarantee me that. I think his heart is fine," that's what I told her. I said, "I think his heart is fine, for real. He's got a super heart." She said, "Well, other than the anomaly." It's just what we deal with every day. It's a part of our life. So, we take the good with the bad.

Participant 3008: He deals with it now. I will say, as far as my son, he doesn't drink, he doesn't smoke or anything. Part of that, I kind of put in his head when as he was growing... 16, 17, I was like, "Look, dude. You know you can't drink or do anything." I put it in there. I don't know if that's the case, but I was still strongly speaking against it, but I put that in his head early like, "If you do anything, you going to have a problem." So, he's a health nut. Drinks water all day, he works out. Like I said, he plays basketball. So, he has to work out. Watches what he eats... He's taken that approach like, "The healthier that I am," then the better it'll be for him as he continues to play or whatever else he does in the future. That's my story.

Participant 2023: Can I just add on to that because I think I agree, [censored 01:13:32]. It doesn't go away. I think the difference for me is when it first happened, I felt like my own heart was going to explode every time I thought of it and every time I watched my son, right? I thought my own heart was going to explode because I was that worried. It doesn't go away, but that doesn't happen anymore. My own heart doesn't... my own heart rate doesn't go up anymore. You can watch it now and it's just a part of life. Do I still watch? Yeah. I'm probably going to watch my kids until I'm gone just to make sure. So, it's more like that. It's more of the... At least for me, the difference is more of the you're not anxious about the watching. You're still going to watch, but you're not as anxious about it... at least for me. I don't know if that describes your experience.

Interviewer: [censored 01:14:18], what has helped you and your family?

Participant 2023: I'm a single mom of two boys. I do have my parents close by and they are helpful in a lot of ways, but they have a lot of their own things to deal with. So, I didn't necessarily want to burden them with this. I also am very independent about wanting to make my own decisions and I was very confident in wanting to make the decision myself... meaning with the help of the medical professionals and all of that and with [censored 01:15:01], my son. So, we're just a really tight knit little three and very grounded in faith. So, I don't want to say we didn't have any support because we certainly do, but when it came to the specific subject, we dealt with it ourselves first before sharing with the world. That's a personal decision, I guess. I'm not recommending that to everyone because it wouldn't work for everyone.

Participant 2023: Ironically, my son's hockey coach, [censored 01:15:37]'s hockey coach had a sister... this is just weird coincidence, small world stuff, who died of sudden cardiac arrest on the soccer field as a high school student at 16. It was not from an Anomalous Coronary Artery, but it was from a cardiac event and they had zero knowledge prior to it happening of any issue. It was just a freak incident. We're actually very close to his hockey coach. I went to high school with him. I knew about this when it happened when I was in high school, myself. So, believe it or not, he became... even though he's not my family, that was the hardest conversation to have because I have to go to the coach now and tell him because he's the one going to be on the ice with my son all the time and have to watch over him. I now have to tell him he has to watch over my son who he definitely cares about and he has lived this with his own sister before.

Participant 2023: So, I was actually more nervous about that conversation than to tell my own parents or extended family. It was a beautiful conversation and ended up being one of the biggest support systems that I could've had, believe it or not... someone who actually lost someone and had recovered family wise from it and just had a lot of nice supportive words and continued to be really close in our lives and really close to [censored 01:17:07] and that's been helpful.

Participant 2023: I will say, again, I know that some of this is trying to how to improve things for future patients and stuff, but what would've been helpful, I think, for [censored 01:17:23] to have had or in the future to have other patients similar to him to talk to. I also know that he would totally be willing in the future to talk to people who are younger than him or the same age as him or that are going to experience this. He's that type of kid, but also he's the type of kid who could use the advice of someone else or another athlete, things like that. Also that, as well.

Participant 3002: Just kind of want to chime in here because I've also found that coach... We didn't have a great... any specific support network that we felt we needed to rely on just because our cardiologist, Dr. Jacobson and Dr. Brothers were so great and found the situation so manageable. I do think that coaches, in our experience, are very supportive group even if they are completely ignorant of ARCA. Those people are the ones who are going to be closest to your child at the moment that something could go wrong because so many of these incidents have been at a high excursion, not all of them. I do find that coaches, regardless of their degree of knowledge, are a great source of support so to speak.

Participant 3002: I've also found that the precautions that the youth sports world takes make it so that you don't have to ask for special accommodations. There are AEDs in every high school, I think, in our state. So, I don't know if that's true in every state... If it's an indoor, it's probably during wrestling season, it's right there. There is a... for a lot of outdoor sports, there's a... not... an EMT trained trainer. In our town... I forget we're in a small town, so you can literally see the fire department from the high school soccer field or the middle school... the high school track. So, anyway, I find that the youth sports structure is actually very good source of support for these young athletes with this condition.

Interviewer: Thank you. So, we are two minutes away from time. Just wondering if, whoever's available can stay on for five more minutes? I have two really quick questions I'd like to ask. If you have to hop off at any point, please do so. So, some of you are closer to this than others, but what would you tell someone with a new diagnosis or who just received this diagnosis?

Participant 2020: I would say, educate yourself. I think somebody said it earlier that we've become like heart experts. I feel like I know all the inner workings of the heart now. So, educate yourself and get a second opinion. I was really hesitant to do it because I felt like it was disrespectful to my cardiologist's like knowledge and I felt really bad about it and I'm so glad that I did because I think we would be in a very different situation had I just taken her information and ran with it. So, I would say just for your piece of mind, get a second opinion because I think it helps you navigate it internally and you can hear other medical professional's opinions.

Participant 3008: I would agree, second opinion and do your research. Yeah. [censored 01:22:00] you said there's a Facebook page. I'm not on Facebook, but things like that definitely helps. Even what you all are doing now. I think this is definitely a step in the right direction for helping folks that are newly diagnosed... or their children are, rather.

Participant 3002: My... I'm sorry, [censored 01:22:43], were you finished or were you still... I echo get a second opinion from a medical professional, from a doctor, not your mother in law unless she's a doctor... not your mother's cousin. When I say second opinion from a doctor who understands the heart. The corollary to that, be very careful about listening to input and advice from other people. From what I understand, ARCA can affect different children very differently. Someone else's journey, someone else's effects are not necessarily right for your child. I know my mother in law when she heard this, she went overboard and it actually made it harder because she lived next door to a cardiologist. So, my point is, be careful about secondhand information. You live next door to a cardiologist, that doesn't make you a cardiologist.

Participant 3002: Friends who experience something similar or even the exact same thing, they mean well, but they do not know the heart the way a cardiologist or a heart expert does. So, Facebook... I'm not on Facebook, either, but my understanding is it can be a great resource. It can also be a viper pit and a very dangerous place. So, again, be very careful who you get that second opinion from and how you regard it.

Participant 2023: Yeah, I agree with your guy's advice. The only other thing I would add and maybe... it's definitely in addition to those two things first, but I just think the message should be changed to make sure it's clear that this diagnosis... kids with this diagnosis go on to be super successful in whatever they choose to do. Like [censored 01:25:16] is saying, not only... this diagnosis affects every kid different, but you know your kid best, too. I don't know. I just think that message should be loud and clear. I think sometimes in the medical world, diagnoses get tied with a certain feeling or a certain assumption about what that outcome will be. I think that overwhelmingly... this diagnosis is just another hurdle that the child needs to deal with just like any other one in life and there's going to be 75 million of them, but it is able to be dealt with and they're going to have a wonderful, beautiful, amazing life. Whatever they choose to accomplish or want to, they will.

Participant 2023: It's just a little challenge and it's just a different one than maybe you've heard of before, but I just wish that was like really loud and clear in your face right when you get that news.

Participant 1013: Yeah. I just want to thank all of you guys for your kind words and helpful information. I mean, I just got the news. So, I would agree with what you guys all said and I appreciate what you all said because that's me right now.

Interviewer: Lastly, what if anything did you want to talk about that we didn't ask about or mention today? Okay, sounds like we covered a lot of things. So, once again, thank you for your time and being so generous with sharing your stories. The program coordinators at each of your sites will be in touch with you. I think there's a survey they're going to send out. Then, they'll also get you the gift cards. I just wanted to, again, thank you. You were vulnerable and shared a lot of heavy things. So, I just encourage each and everyone of you to take some time to take care of yourself after this conversation in however way that looks for you. It was so wonderful to get to spend this hour and a half with you. If you have any questions or need anything, need any additional supports or resources, please reach out to your program coordinators. That's it. Happy Tuesday, everyone.

Participant 3008: All right, thank you.

Interviewer: Thank you all. Bye. [crosstalk 01:28:17]