Interviewer:

And just a couple other, I guess, housekeeping type items. I think everybody has had a chance, looks like, to either have their name on here or change their name. Please feel free, you don't have to have your last name on there, if you're not comfortable with that. Feel free to add whatever name you prefer to go by for this session. We will do our best to end on time. I was telling (beep) a moment ago that the sessions usually last about an hour and a half. It's about 05:12 Central Time. So, we'll still try to finish right around 06:30, and I'll try to do my best for us to end on time. So, if at any point in the conversation, you all are saying something, or I have to cut you off at some point, or something like that, it's not because I don't want to hear what you have to say, but if we get into a time crunch, then I might have to just move us forward at different points in the session.

Interviewer:

If you all are comfortable with it, it looks like most of you are. And if you're able to, if you don't mind using your camera so that we can all see each other while we're talking, that's just helpful for us to have a face to the name. And you don't have to stay on mute. If you have a crazy dog in the background, like I do, and it starts barking, obviously, feel free to go on mute, but please feel free to just stay off mute. And again, if something comes up and if somebody says something and you want to share something, just feel free to jump in and share. So, I think that is about it. Before we get started, does anybody have any questions for me?

Interviewer:

All right. Okay, I see. Is it (beep) saying that you're more of a Teams person, not too good with Zoom? "Audio seems disabled, how do I connect?" Sorry, just seeing that chat, (beep). There should be a way for you to check your microphone settings. If you're on a computer, and let's see, that's all video settings. Oh, yeah, if you're on the computer, at the bottom left, you'll see a microphone that allows you to mute and unmute yourself, okay? And so, I'm guessing that you're probably un-muted. On the microphone, there's a little arrow, and I think you can click on that arrow, and let's see here, that allows you to test speaker and microphone, might be a good option. Not me, it says, "Exclamation." Not sure what that means. Hmm. Okay, sure. Yeah, if you want to join back again, (beep), feel free. No, yeah. Sorry, that you're having trouble. All right, if anybody on the call is a Zoom expert, feel free to jump in. All right, well, hopefully (beep) will be able to join. (beep), did you want to --

Interviewer 2:

I would say, also, if anyone is having audio problems through their computer, you're also welcome to dial in with your phone. And you can be on the computer with the video, but speaking through your phones, that's another way to connect to audio.

Interviewer:

Okay, that's a great suggestion. If (beep)'s not able to fix her audio problems, maybe we can suggest that to her. All right.

Interviewer 2:

I'll send her a chat message.

Interviewer:

Okay, thanks. Cool. Well, just to get started then, I guess before I actually have each of you go around and introduce yourself, I just had a quick question, which is that we, internally, refer to this condition as AAOCA, but, I'm just curious, is that also what you all call it, and, if not, how do you refer to this condition yourself? Within your family or talking to other people outside of your family?

Participant 1008:

Within our family, I mean, from the very first moment it was introduced to us, it was referred to as AAOCA. So, within the family, we're all on the same page when we talk about it that way.

Interviewer:

Okay, do you refer to it a different way when you talk to people outside of your family?

Participant 1008:

Yeah. I mean, just very basically, well, I just generalize and say, "Well, she had a congenital defect with her heart." Or, if somebody asked for more information, which nobody really ever does, then I might get into a little bit more information about coronary artery, or something like that, but we usually just say it's very high level and very generalized.

Interviewer:

Got you. Thank you. What about others?

Participant 2010:

It wasn't called that when my son was diagnosed 21 years ago. So, it was just called an anomalous coronary artery, and that's how we refer to it.

Participant 2001:

For us as well.

Interviewer:

Anomalous coronary artery?

Participant 2010:

Mm-hmm (affirmative).

Interviewer:

Okay.

Participant 2010:

He has one on the right and the left, so they found them years apart. So, just that right, or left.

Interviewer:

Okay. Anybody --

Participant 1008:

That was 20-something years ago?

Participant 2010:

Yes. He'll be 21 in a month, and it was found when he was six months old. He's one of the first that's had the corrective surgery for it in the country.

Interviewer:

Cool. Well, we'll be coming back to that. Anybody else referred to it differently? I guess, other in ways --

Participant 2006:

Sorry, what was the question? I had to join back again.

Interviewer:

I'm glad that you're here and that your mic and audio is working. The question was, I guess, just before we even introduce ourselves, I was wondering, internally, we refer to this condition as AAOCA, but I was curious if, is that how you all refer to it as well? Or, do you have a different name for it, I guess?

Participant 2006:

Yeah. So, we absolutely call it, exactly, AAOCA. And also, because my kid was way older when it got detected, so just went into the science behind it. So, the immediate family definitely refers it that way. But, I think I heard (beep) say that people outside of family, if they want to know, I mean, we may just leave it as basic as, he's got some plumbing issue with his heart, things like that.

Interviewer:

Mm-hmm (affirmative). Got you, thank you.

Participant 2006:

So, very generic. I mean, nobody ever questions beyond that, they're very sensitive, right? People don't want to be incorrect, or inappropriate and stuff like that. So nobody's ever asked us more than that.

Interviewer:

Mm-hmm (affirmative).

Participant 2006:

Honestly.

Interviewer:

Okay, awesome. Well, I want to go ahead and have you all introduce yourselves, and I'm going to put in the chat, actually, just a few points, so you don't have to remember everything, maybe to make it easier to introduce yourself. But, you can see ... Let me see. Oh, well, not yet. There you go. So, your first name, age, a hobby, or just something that brings you joy in your life, number of children, if you have more than one, and the age of your child, or children, and then in two or three sentences, maybe introduce your child with AAOCA. And then, finally, in two to three words, how would you describe what being affected by this condition is like? So, would anybody like to volunteer to go first? (beep) Sorry, I saw (beep)'s hand go up, if you want to start, (beep).

Participant 2010:

Okay. Hi, my name's (beep). You want my age or my son's age?

Interviewer:

Both please.

Participant 2010:

So, my son's name is (beep), and he will be 21 next month. I'm over the age of 40, that's all you're going to get. Something that brings me joy? We have a house down the Cape. I enjoy Cape Cod. We live in Boston, so I enjoy going to the beach and being with my family down there. We have three children. My oldest is 22, (beep) is 21, and I have a daughter who's 18. And my son, (beep), is a sophomore at University of South Sewanee, where he actually plays football. He's extremely athletic. He's 6' 4", and he is completely and 100% normal since his two surgeries. So, he's a great kid. He's an Economics major, and his hope is to be on Wall Street someday. And affected by this, we think of it as the cross that we had to bear when he was a child, but we had really great doctors and they were able to correct his plumbing, and we pretty much treated him like any other child.

Participant 2010:

We never treated him any more special. We never made him feel different than any other child, and we allowed him to participate in all activities that he was cleared to participate with. And it was as if he was just like our other two children who have perfect normal hearts. We never dwelled on it, and we never talked a lot about it, and we never made him feel like he was different. And we made sure in school that all of his teachers, and coaches, and everything were aware of his condition, but we never made him feel like he had to stand out, or that he was any different. So, he's grown up just like everybody else. He knows he has a scar. He's 21 now. He's actually having a tattoo put around his scar as a cross that he bears and he's proud of it. And he shares with anybody that asks about his experience of what he has. He's actually paid it forward with some younger kids at the hospital.

Interviewer:

Thank you for sharing that. And I meant to also add actually in the chat. So, when was (beep) diagnosed with AAOCA?

Participant 2010:

He was diagnosed about seven months old. So, back in ... 20 -- 20-21, right after he was born. He had his first surgery about six weeks after his first initial diagnosis. And he had a second surgery for, he has both the left and a right anomalous coronary artery. His second surgery was when he was in first grade. And then, he's had a couple of catheterizations since then. Just for more checking, to make sure everything's working. Not because anything beyond.

Interviewer:

Got it. Okay, thank you. (beep), you were going to introduce yourself before.

Participant 2001:

Yeah, sure. I'm (beep). I'm 48, my son is 17, and I have a daughter who's 19, and a daughter who's 9, and I forgot what the second thing was. Oh, something that makes me happy. My kids row, my son who had the surgery is a big rower, so I like going to their regattas. I also like the Cape, so I'm just going to jump in there. That's one of my favorite places, but we live a little farther away. We live in New York, so it's not quite as easy to get up there. And (beep) was diagnosed as a newborn. He was premature, and then had a VSD also. So, they did an echo, found his right coronary, and then waited on it. At the time, the recommendation was not to do anything. And then, he became symptomatic when he was around 12, 13, 12, and then they decided to do the surgery, and it turned out that he had the left as well. So they ended up doing both sides.

Participant 2001:

And another thing I think we have in common, (beep), is he's 6' 6" and 220 pounds now, rowing at national tournaments and regattas and things and just healthy as can be. We restricted him from sports for the first 12 years. He played rec soccer and things like that, but his sister is very athletic, and he never did any of the things she did. So, I felt badly about that, but after his surgery, he's done everything, and he's been very good. What was the next part? I'm forgetting, I'm sorry.

Interviewer:

No, it's no problem. So, in two to three sentences, introduce your child with AAOCA, which you've done. And two to three words, how would you describe, as a parent, what being affected by this condition is like for you?

Participant 2001:

I think anxious. I had a lot of anxiety about it. I can't really even think of any other words. I just was very anxious about it, worried that something was going to happen. So, I don't know.

Interviewer:

Thank you for sharing, (beep). Would someone like to go next?

Participant 1008:

I can go next.

Interviewer:

Thank you.

Participant 1008:

Hi, I'm (beep), I'm 55, as of quite recently. My daughter, (beep), will be 21 in a couple of months. Hobby or something that brings me joy, I'm a man of many hobbies, but I suppose the one that I'll pick right now is that I am a home coffee roaster. I've been roasting my own coffee at my house for a couple of decades. I have two children, including (beep), (beep) the older sister (beep) is 23 years old and has just recently gotten her first job here in the Austin area, her first professional job after graduating school. Two to three sentences briefly introduce your child with AAOCA. So, (beep) was diagnosed with AAOCA fairly early 2019, I believe. She is a, (beep), very much a charge forward and go getter person. So, when she was diagnosed with AAOCA, it didn't really faze her at all.

Participant 1008:

And she was presented with the opportunity to either, don't do anything about it and live a limited life, or have the surgery and live a full life. And she didn't bat an eye, and she immediately said, "I'm having the surgery." And now, I'm going to use more than two to three words for the last part of the answer to (beep).

Interviewer:

Sure, that's okay.

Participant 1008:

This is in the midst -- (beep) has also been struggling for the last four years or so with anorexia nervosa. And so, at the time that she received her AAOCA diagnosis, she was in a really bad place with her anorexia. And so, the two to three words that apply for questions after (beep), are mild interruption. Because, compared to her anorexia, the issue with her heart was no big deal. Initially, we were very confident in medical practitioners and in the science. And so, that was a very easy decision relative to everything that was going on with her anorexia.

Interviewer:

Mm-hmm (affirmative).

Participant 1008:

Mild interruption.

Interviewer:

Mm-hmm (affirmative). Thank you. All right, who would like to go next? Oh, we couldn't hear you there (beep).

Participant 2006:

Yeah, I could be next, yeah. Hi.

Interviewer:

Thank you.

Participant 2006:

So, yeah, my name is (beep), and my son's (beep). So, my age, I don't know why you need that, but I'm 44, and my son is going to be 16 soon. So, both are boys, I have one other kid, he's going to be 13 soon. So, yeah, one's in middle school, and (beep) is in high school. Hobbies that bring you joy ... Well, I'm going to choose, of course, quite a few, but right now it's gardening. It's just that time of the year. So, yeah, major gardener. Lately, I do a lot of veggies, a lot of flowers, whatever. If more than one child/ children ... Okay, that's that. Introduce your child. Okay, so our case was, I think, very different from most others that I've heard so far, in the way the condition presented itself. So, we knew nothing of this condition until (beep) was 11, almost 12.

Participant 2006:

And very athletic, was doing his soccer stuff, was doing his track and field. And this is towards end of the sixth grade. He was 11, almost turning 12. I get a call from his PE teacher that he's collapsed on the field and that they're giving him CPR. So, that's how it presented itself. So, that was the first cardiac arrest. We live in Seattle. He was immediately taken to Seattle Children's, and there he had a couple of -- Well, he survived eight cardiac arrests subsequently. So, how did it affect me? So, there's a lot of PTSD and all that stuff as well. We know things like code blue, it's part of our vocabulary, even though shouldn't be. And so, the way it happened is when he actually went into cardiac arrest on the field, again, we'd not seen that. He was intubated and all that stuff.

Participant 2006:

We learned subsequently that the intubation caused injury in his trachea. His trachea and his esophagus fused, so he actually couldn't breathe and he had to be on trach for six months. So, one of his conditions that he was born with, which was presented that way, one which was an accidental occurrence, and this manifolded the situation many times. So, AAOCA for him hits only the left coronary artery, it was repaired in Seattle. When he came out of surgery, they couldn't extravasate him. And that's when they did a couple of other tests, and they realized that his trachea and esophagus were fusing. They tried to do a corrective surgery on that. That was not a success. He went into a cardiac arrest after that, that actually ruptured his first surgery effective, and things were just getting bad to worse.

Participant 2006:

So, in the interim, he was on ECMO, he was on life support. So, things were very, very dismal at that point in time. Thankfully, after the trach. And honestly, it happened so fast, but we were in the hospital for six, seven months stretch in Seattle. And as this is panning out ... After the trach, of course, things stabilized. We learned that this rupture and the valve, it needed a little bit more, what is it? Care, or whatever, so we consulted other doctors, and we had some company-related benefits, we could do consultations and stuff like that. We figured out Boston would be the place to go.

Participant 2006:

So, we went to Boston Children's for his second surgery. So, the second surgery is what fixed his thing. And things progressively has gotten better for his trachea injury, which was a seven inches fusion. We went for a slight tracheoplasty, that happened in Cincinnati. So, things were really, really bad for us. From a very healthy, normal kid to just progressively being in that state on life support and stuff. So, yeah, seven months in Seattle Children's, a month in Cincinnati,

Participant 2006:

Another month in Boston, and we will be going for an annual soon in Boston, so that's where we continue to do our care. The trachea part has fully come undone, and, of course, this is also absolutely now things that we don't necessarily discuss. He is leading a very healthy, normal life at this point in time. This incident is about three years back. He's not necessarily picked up sports the way he would before, but that's also because he's in high school. He's getting into 11th grade, is very focused on his academics at this point in time, doing very good at school. I remember one of the moms said that he wishes -- his kid wishes to go to Wall Street. My son wants to go there as well. He was a Wish kid, so he actually went. We went to Wall Street for his wish.

Participant 2006:

And what else? So, I think that's about the child. Describe how it affected us. Well, seven months in the hospital, of course, I had to quit work, and lucky enough to do so, because my husband could manage to do work there. He was actually sleeping in the hospital, working from there. So, we tried to do all of the best we could, and, right now, does it have a lingering effect? I think most of the thing, the anxiety that I had, the PTSD that I had, I think most of that kind of improved, of course, with the child improving, everything falls in place. But, there's still somewhat of PTSD. I still can't see a movie where there's a hospital scene. I would walk out. And what else? Yeah, I think that's pretty much it. And since the condition was detected later in life, we are very technical about how we explain this and having a 5% chance of survival to now coming out of it, that's a success story. So, we are happy about the outcome, and we openly share about it if anybody wants to talk about it. Thank you.

Interviewer:

Thank you. Thank you so much for sharing that. Who would like to go next?

Participant 2012:

I can go next. Hi, I am (beep), I am 45. My son is now 11. I also have a daughter that is 14. Something that we like to do is travel together as a family. I'm also in the Boston area, and we're heading to the Cape next week. So, (beep) was diagnosed in November 2019. He was playing soccer and had shortness of breath. I didn't think much of it; I just thought he was winded, but his dad really pushed it. He was coaching him, so he saw him more. So, we went to the pediatrician. They recommended that we see a cardiologist. They did the echo and found that his right coronary artery was coming from the wrong place. He had surgery six weeks later.

Participant 2012:

It was the hardest decision we've ever made in our lives, but he was a big sports player, a huge athlete and he knew from day one that he wanted the surgery. Everything went very well. He's back in all the sports, living a really active life. I think the biggest way that it's affected us is, we're very grateful that we found it when we did, but we're also very anxious. We worry about it every day, even though it never went well. And they tell us he's healthy. It's still something that's always in the back of our minds. So, that's hard, but he doesn't seem to worry about it, and so that's good.

Interviewer:

Thank you so much. And you said -- Oh, sorry. Really quick to follow up.

Interviewer:

You said (beep) is 11 now, is that right? He was diagnosed in 2019.

Participant 2001:

He was diagnosed at 10. He's 11 now.

Interviewer:

At 10. Okay. Thank you.

Participant 4002:

I guess I'll go last. My name's (beep), I'm 40. My son (beep), he's 12. He'll be 13 in August. We are very new to this diagnosis. Last month, it was basically an incidental finding. He had no symptoms; he was feeling lightheaded from sitting up, from sitting to standing. His pediatrician just thought that it would be good to see a cardiologist. And given the diagnosis, I don't think that's related to the diagnosis. He's a typical 12-year-old boy. No symptoms, very active. Our plan was for him to start competitive sports this summer.

Participant 4002:

As of now, he's been clear. The last appointment, his stress test and everything came back great. Next month, we're going to have his stress MRI, which is going to give us a little more information, but the cardiologist seems to think that he's okay. He's being cleared to pursue competitive sports this summer. I'm a registered nurse in the medical center. My expertise is not biology, at all. So, I'm an anxious person to begin with, and this diagnosis, it's made me even more anxious. I have two other children. (beep) is the oldest. I have two girls, one is 11, and one is a six year old.

Participant 4002:

How has this affected our family? Well, we're very new. After this diagnosis, at this point, he's asymptomatic. Nothing really has changed at this point, but, well, I guess the only thing that's changed is that I'm more anxious than usual. I'm always thinking about what could go wrong, and he's the typical 12 year old. Like I said, he wants to be a surgeon when he grows up. He swims, he plays basketball, he skateboards. This point, there's no limitations to any of these activities. We love traveling; we just had our first vacation since COVID. We went to Oregon. So, we had a great time, and now we're just waiting for next month to find out more information.

Interviewer:

Thank you so much for sharing that. So, thank you all for introducing yourselves and your children. I really appreciate everything that you shared. I did want to start off by having you all talk a little bit just about the moment when you first heard about this diagnosis. And I know that many of you have different experiences with that and how that happened and how the diagnosis came about. But I am still curious nonetheless about what it was like for you when you first heard that your child was diagnosed, that your child had AAOCA, and what it was like, sort of, receiving that diagnosis for you. And please, whoever would like to jump in, feel free.

Participant 4002:

I want to start because I guess we're newly diagnosed and the first cardiologist that we saw that diagnosed (beep), it was very scary, very shocking. And she basically told me, "This is the sort of thing that kills athletes when they're 20 years old; they just drop dead." And I feel like it was very scary. We switched. I did my research, and I found out that Texas Children's has an amazing program, and we switched. It was hard, you know, just the first -- I'm trying to find out: What are we going to do? He said, "Well, if you don't hear back from us in two weeks about doing the MRI or the CTM, then call us." And that was when I realized I needed to see a new cardiologist, because you cannot tell me that this is the sort of thing that kills 20-year-old athletes, and then expect me to sit back and do nothing.

Interviewer:

What did they tell you about? I mean, so, obviously this cardiologist, the first person who sort of revealed this diagnosis to you said, "This is the kind of thing that kills athletes," but, I mean, what did they tell you about AAOCA? Have you heard of that condition? What is it, what did you learn about it?

Participant 4002:

He printed a diagram, and he showed me. My son has the right coronary artery going into the left side, and he told me it is very rare, but it's the less, I guess, serious kind. But he said that we needed that CT before we knew more about it.

Interviewer:

And that was it.

Participant 4002:

That was it. They said, "We're going to try to schedule a CT. If you don't hear back from us in two weeks, you can call us." But, obviously, I didn't wait two weeks. I just found a different place.

Interviewer:

And so that was your next step, (beep)?

Participant 4002:

Yes. I got online. Like I said, I'm in the medical center, probably the biggest medical center in the world. So I did my research and tried to find a cardiologist that specialized in that condition and read a lot of papers, a lot of clinical studies, and found that Texas Children's has data. It's been following patients for about 20 years with that condition, and Texas Children’s has a very informative page on their website about how they treat it and everything that entitles that condition. Yes.

Interviewer:

And so then you set up an appointment with them, is that correct?

Participant 4002:

Then I called and asked if I need a referral from my pediatrician. They said, "No." And then that's how we got here.

Interviewer:

When you first received that diagnosis, what would you say went through your mind?

Participant 4002:

I was scared to death. I was like, "Okay, I'm not going to let him do anything from this point on," because you cannot tell a parent, "This is the kind of thing that kills healthy 20 year olds," and not expect you to panic and want to protect your child.

Interviewer:

Thank you. Others have similar or different experiences?

Participant 2012:

I have a very similar experience.

Participant 2012:

(\*internet cut out\*) At Boston Children's, I got in touch with her. She was amazing, and got us in right away for a CT scan, and sat down with us, and walked us through everything, telling us all about it, and we just -- Thank God, I went to her.

Interviewer:

And how are you? Sorry, you froze for a minute there for me. I think my internet connection was unstable for a moment. But how did you feel when you first heard that diagnosis?

Participant 2012:

Terrified and helpless. I was trying to do the research on my own, and there's very little out there right now. It was just the scariest thing that anyone's ever said to me and that I couldn't find any information on it, and they were asking me to wait four weeks, and then my poor son was terrified also. So, it was really scary.

Interviewer:

When you say your son was terrified also, can you say a little bit more about what that? Was --?

Participant 2012:

He was worrying that he was going to have a heart attack every day.

Interviewer:

And so, what did you -- How did you navigate that? I mean, how did you navigate that as a parent?

Participant 2012:

I just kept telling him he'd be fine. They did restrict sports. So, I said, "As long as you don't do sports and don't run around, you'll be okay." And it helped a ton once we finally met with the cardiologist at Children's. She totally reassured him and said, "You're not going to have a heart attack." And it just helped 100% once he met with that team.

Interviewer:

And because the cardiologist or surgeon there said, "You're not going to have heart attack." What else, if anything, was reassuring about that visit for either you or your son?

Participant 2012:

Well, for both of us, it was reassuring just not having to worry every single day. He was also really upset that he couldn't play sports because that was his life. He played three different sports, and he was always on the go. So, that was tough, but I think that's what made him decide. He said from day one, "I want the surgery," and we ended up having the surgery just six weeks after diagnosis.

Interviewer:

Okay. And we'll get to that in just a moment, but I want to let other people share about their experience with the diagnosis, whether it was similar or different.

Participant 2010:

I had a completely different experience. So, my son was over 20 years ago, he was a baby. He was having some difficulty breathing. We used to describe him as a 75-year-old man in a six-month-old body. To roll over, he would breathe heavily. He was always pale, just really looked like my grandmother who had angina, and his lips turned blue one day, and the doctor said, "This is enough. We're going to see the cardiologist." So, we went in not thinking anything. He was at 30 pounds, six months old. So, he was completely thriving. We had a seven-and-a-half-hour echocardiogram because, when they started the echo, they could not find his right coronary artery anywhere, and they had about eight people in the room.

Participant 2010:

They literally sent us to lunch, and I'm a young mother. I have no idea. I think this was just normal, right? This is the Boston Children's. This is the kind of experience you get. Well, come to find out he had an anomalous right coronary artery. It is a very atypical one. It's only about a quarter of the size of a full right coronary artery. So, it's very tiny, and it was embedded in the aortic muscle wall, so it wasn't even flowing at all. They just described it to us; they didn't really have a name at that time. They just literally drew an entire picture of our heart. The cardiologist was not alarming, said, "This is unusual, and we have to do more tests." We went right to catheterization. We didn't go to CT at the time. Not sure that -- And within a few weeks -- The cath happened about a week later, and he had surgery like three weeks after that because his right coronary was so small and it was 90-plus percent blocked, meaning it didn't really have any blood flowing through it.

Participant 2010:

So, we felt it was blocked enough that they needed to do surgery. It wasn't a discussion. It was: We're going to do surgery. I happen to work for a big, huge health system here in Boston too. So, it was helpful to be surrounded by physicians who kind of helped me understand. So, the complexities of what was going on, it wasn't any of the congenital heart defects that you would find typically when you Google. It was very rare at the time. I think he was one of the very few children that have ever had the surgery. And then the second, his left one, he just never seemed to get 100% better growing up, and he would describe when he would run or be active that he felt like he had a truck sitting on his chest, very simple, like an angina.

Participant 2010:

He would turn really ashen gray, and he had severe tachycardia. We went through years of testing, and testing, and testing to try to see what was wrong, or if there was something different. And he had a cardiac arrest in an MRI machine because they did a stress echo. He was too little to run on the treadmill, so they had to do a dobutamine stress echo. And he had a cardiac arrest in there. At the time, they were able to take a picture and see that his left coronary artery was embedded in his left ventricle wall. So, because he was having symptoms at such a young age, they took his case to Texas Children, and Philadelphia, and a whole bunch of other places and had cardiologists at the time take a look at it. His left is more like a bridge, like a myocardial bridge.

Participant 2010:

And at the time, most people weren't having surgeries for it. It was something that you just lived with, but because of what happened in the MRI machine, and because he was having such severe angina pain, it was spelled across the country that they probably should go in and correct it so that he could live a normal life. Then, within the month of post -- second surgery, he never had one cardiac symptom again. So, for 20 years, and they cleared him, he was completely healed enough to play football as soon as he was in third grade and the doctor said, "You've had two years of healing; you can play football". He's been playing football, basketball, and whatever since then.

Interviewer:

And so you said surgery wasn't really presented as an option to you. Is that right?

Participant 2010:

It wasn't. Yeah. At the very first surgery, there was not enough blood flow. His right coronary didn't grow long enough to even sustain through. It wasn't an option for him not to have surgery. It was within a matter of weeks that he was on the operating table. The second one, it was a discussion. They decided to go out and get some multiple opinions across the country on what to do. He was held from Phys Ed and sports during that time period. And he didn't want to live like that. Even at that age, if the surgery was an option, we wanted him to be able to have surgery, he could go back and live a normal life.

Participant 2010:

I don't think my husband and I thought twice about it after having the first surgery. It wasn't really even a discussion in our household. If they came back and said they were willing to do it, then we were going to do it. It wasn't a discussion.

Interviewer:

Thank you. Anybody else like to share about their experience or their child's experience with the diagnosis?

Participant 2006:

So for us, getting the diagnosis was a relief in some sense. So, my sixth grader leaves for school in a school bus, and I'm supposed to pick him up because he's staying back for his track, and the call I get is, "Your son has collapsed, and he does not have a pulse." I cannot forget those words. "He does not have a pulse." And I'm like, "What are you talking about?” Right? The whole thing that happened after, we are in the hospital, he is already on ECMO. He's had eight other cardiac arrests, so his heart has stopped eight more times till we ever got a diagnosis. Those 10 days, or that 12 days, was hell. Everything from whether it's an auto-immune disease that has filled his lungs with all of this to -- Anything and everything under the sun was considered.

Participant 2006:

And nobody had an answer. We went through all kinds of transfusions. Everything was going on. And honestly, at this point, two weeks out, we didn't know what we didn't know. The doctors didn't know what they didn't know. So the day we moved from the ICU to the cardiac ICU, we knew there was a path. We knew that they had at least found out a root cause. It was very -- Honestly, at this point, with everything going on, we didn't know what to expect, but there was a sense of relief that they found out what it is. And yes, then the doctors came that, yes, it's going to be a surgery, an open-heart surgery. That in itself is a big, big, big news. I've heard people, and anybody in our support group who referred to incidents, like before the incident or after the incident.

Participant 2006:

But our incident duration was very, very long. Diagnosis or the surgery considers -- That's that incident. For us, it was a sense of relief or a sense of taking a breath, doing something. Of course, experience, we were hopeful. We didn't see signs because the doctors were worried. They didn't know what they didn't know, so all our discussions was, "We're trying, we're looking" and at this point, we were already two weeks in the hospital. So, when we got the diagnosis, honestly, it was a sense of relief. And from that point on, his medication and everything came down. They started to take him out for the ECMO so that they could prep him up for the surgery. In the meantime, we were all stationed at the hospital. But me and my husband, we were doing all this research. There was a great library that we had access to. And we started looking up what this thing was, what AAOCA was and all of that. And then we got into these conversations.

Participant 2006:

The doctors had started to have some more clarity. And then, I think about four weeks into the hospital -- So, two weeks we didn't know, and then about another week or so, just prep him and stuff like that for the surgery. And then we had the searching, but then I mentioned before, they couldn't extubate him. That's when they found out that it just got multiplied by other stuff. It was like, he had those fusions that happened -- He was, that surgery, another ... So, anyways, we went to the hospital for seven months, but that was a turning point in some sense that we kind of knew what we were dealing with and at least realizing that this is the root cause and then working towards a resolution.

Interviewer:

Yeah. Thanks. Thank you for sharing that.

Participant 2001:

I think we had a very different experience with (beep), because he was in the NICU and he was sort of sicker from other things. And when they said, "Well he's got this thing," it was kind of like, "He's got a VSD, and he's got this other thing, but we don't -- Certainly not a problem right now. We're going to follow it. We're going to watch it." And we were sort of overwhelmed with all the other things going on with him, so being told that was sort of like secondary, and I'm a doctor, and so doing the research and things, I felt sort of responsible for deciding the path to take and things. But at the time, that time, to echo what's already been said, they really said, they diagnosed the right and they said, "We don't think he'll ever need this unless he has symptoms, unless something changes. We'll just keep following and see if he has these symptoms."

Interviewer:

When you said -- When you say, "We don't think he'll need this," what do you mean by that?

Participant 2001:

Oh, the surgery? Sorry. So, when they said, you know, "Sometimes people will have surgery for this, particularly if it's the left side," they automatically go to surgery to do the right side. "If they have symptoms, we'll go to surgery." I can't remember if they knew that right away. We kind of went everywhere. We went to CHOP, we went to Columbia, we went up to Boston, sort of trying to figure out, navigating "Do we want to have the surgery or not?" because we were basically told, "You don't have to have it until you have the symptoms," but it's the initial telling us was sort of, "Okay, he's got this thing, watch it, but don't worry about it."

Interviewer:

And can you help me understand? So, you went to all these different places when you were trying to figure out whether or not to have, for your son to have surgery or not. Why do that? Maybe it sounds like a silly question, but how is that helping you, to go to those different places? What information --?

Participant 2001:

Probably helps me more than him. I always recommend for my patients to get a second opinion and having access to all these great ... Basically, CHOP has had a big study going on there with Dr. Brothers and then Columbia is right here. We're in New York, and we ended up at Boston, which I'm thrilled that we did because they were, like, phenomenal. And I think it's probably treating my anxiety more because I felt very responsible for making the decision of whether he's going to have the surgery or not. My husband is non-medical. We never told (beep) about it at all.

Participant 2001:

He actually brought up after he did one of these sessions, "I didn't even know what was going on. I just kind of showed up at the hospital," and I kind of thought, "Okay, well, did I make a mistake there?" But he never knew about it. And I felt like we needed all these opinions to decide that we weren't going to do it, mostly to alleviate, I think, my guilt if he had one of these terrible outcomes, like a cardiac arrest. I don't know what I would've done if I knew he had this and had that happened to him.

Interviewer:

And you said that you didn't really talk with him much about it. You didn't talk with him about the diagnosis or just about the whole surgery option piece?

Participant 2001:

We didn't talk to him too much about ... I mean, he clearly knew because we were going to a lot of different places and seeing people. We didn't talk to him about what exactly the problem was but said, "If you have chest pain, if you have trouble breathing, let us know." His teachers knew, sort of, what his PE teacher knew. In terms of making the decision for the surgery, I can't actually remember if -- At that point he was symptomatic, and once he was symptomatic, to me, he had to have a surgery. And then I think he sort of said, "Yeah, I'll have the surgery," so ... It's hard to believe that some of these aspects, and I don't know if you guys have the same experience, you feel like you'll never forget any of these little things that happen, then all of a sudden you start trying to look back. I can't remember what I told them, who I talked to. It all just seems like it happened. I don't know.

Interviewer:

Thanks for sharing that. (beep), did you want to talk?

Participant 1008:

Yeah. I mean, so, I introduced a little bit (beep) was dealing with anorexia at the time that she received her AAOCA diagnosis. As a result of the anorexia, she was not in a position to actually do anything about her heart because she was already -- She was too weak. Her heart was already struggling just from the anorexia. So, when they notified us, first of all, the way they found out about it, it was really kind of funny.

Participant 1008:

She had gone in for a routine checkup, and the person did an MRI and said, "Well, there's part of your heart that we can't find," which is a funny way to tell a person something about their heart. "We just can't find part of it." And then when -- did whatever tests that they knew to do then, and that's the point where they found out that she had this condition. We educated ourselves on it to the extent of, "Well, once we're -- Once (beep) is strong enough to be in a position to do anything about this, well then, what will we do?" And that's where I told you, (beep) really didn't bat an eyelash about it. She just said, I'm just going to have the surgery.

Participant 1008:

She's not the sort of person who is going to accept gracefully being told, "Well, you're going to have to live a life of not getting your heart rate up. And you have a limited life, right?" So, she said, "I'm having the surgery," and her mother and I just were kind of interested, involved bystanders, basically. She's an adult and could make that decision on her own. And she did so, and we fully supported her.

Participant 1008:

We went in for all of her appointments with her, but it wasn't really until probably over a year later that she was actually strong enough to go ahead with surgery. The reaction when we found out about it, it was... She had a suicide attempt because of the anorexia, and some self-esteem issues, and such. And so the whole family's reaction was, "Well, of course she's going to have something with her heart now." It was almost -- In a way, it was almost funny. It was just one more thing to deal with. But then that's about it. She's had nothing but support from her friends, and family, and loved ones.

Interviewer:

Yep. Thank you for sharing that.

Participant 1008:

I should say there was no panic or anything like that. Nobody ever freaked out about it. The folks at the hospital here in Austin handled her wonderfully and handled the family wonderfully. And we've all been very calm about it the whole time. It was almost funny from the start.

Interviewer:

What does it mean that they handled this well, the hospital?

Participant 1008:

Just educating us and helping us understand that maybe there's not a world of information and research out there about AAOCA, but it's also not a mystery. Right? Dr. Mery was very experienced with this condition and was an expert in the country on it. And just set us at ease rather quickly that (beep) was in the right place at the right time and that everything was going to be okay.

Interviewer:

I'm curious, did they offer guidance on surgery, whether that was something that she should choose to do or not, or was it more like offered as you can do this or not do it?

Participant 1008:

Well, I don't know that they ever guided -- Well, I mean, they didn't literally guide, but whether you want to admit it or not, you are providing guidance. When you say you can either lead a limited life, or you could have this surgery. Maybe in the next breath, you're going to say, "I'm not trying to give you any guidance," but, to us, that was guidance. (beep) is not going to live the rest of her life being overly mindful of her heart rate, and her physical activity, and such.

Interviewer:

Thanks for sharing that. I would love to hear from others a little bit more about this issue of choosing whether or not for your child to have surgery. And I know that people have different experiences around this. A couple of you didn't really have the choice. One of you is still, I think, in the process of kind of getting all the information needed to make the choice, and then two or three of you actually did, as parents, help make that choice for your child. And I'm curious about that. And can you all just talk a little bit about what helps you come to the determination for your child to have surgery or not to have surgery, in this with AAOCA? What were the most important sort of factors, I guess, in that decision-making process?

Participant 2006:

I think, for us, the decision was easy. Like I said, it was the small beacon of hope that we had identified the cause. The kid had already gone through eight cardiac arrests, which was a record. We didn't want to keep, I mean, that hopefully nobody has to go through this, right? I remember the nurses are all telling us he's here for a reason. I've heard things like, "I've never seen anybody go through this many." "God is there," and, "He's here for a reason," all of that stuff, right? So, you think -- Spirit, you start whenever the conversation gets to that, something in the physical surrounding is not right. So when we've identified that this was this, and they said surgery is a way to mend this we were like, yes, when? When can we get it done? The day we were told (beep) he was still on ECMO.

Participant 2006:

He had been on ECMO for so long because he'd had so many cardiac arrests, so they wanted the heart to take a rest, and then gradually they weaned him out. And that took up, I think, about another 10, 20 days, because he was on all these drugs and medications. They had to kind of get him physically in a position to be able to get the surgery. So I think once we learned it was all about getting him medically ready for the surgery and how long that took. And I'm thinking that was about 10 days since we learned that, because he was very weak at this point, after having had eight cardiac arrests.

Participant 2006:

So yeah, we went to do the surgery after that. So it wasn't a decision. It was just our way of yes, now we will be gradually coming out of it. Things got complicated, like I said, after that, right, all these other things. But then it was that he's more in the right direction for us in some sense.

Participant 4002:

Can I ask a question to the group?

Interviewer:

Yes. Yes. Please.

Participant 4002:

How many people were dealing with right versus left, because I think that was a really big difference in the advice they were giving us. When we were making our decisions or when we were looking at it, where they're saying left go straight to surgery. Right? We never heard don't get your heart rate up. We kind of just heard watch things. So I'm just curious how many people had right versus left, if anyone does want to share.

Participant 2010:

We had both sides.

Participant 4002:

And you knew from the start you had both sides?

Participant 2010:

We only knew about the right from the start, but his was blocked at 90%. So they went and it was only a quarter. So there wasn't a discussion, but when it came to the left, because it was an unusual left one, there was debate. But it was interesting. I heard you guys on talk about having to go to different places like Boston Children's, our cardiologist’s team actually took all of his information and test results and everything and sent it all over the country. I never had to go travel around to get multiple opinions. They did it for us, which I found out just so fascinating when you were on talking about having to sort of go from place to place. So I guess I feel fortunate for the team that we had, that they did it for me the second time around.

Participant 2006:

We actually use the services called Good Doctors, which actually lets you get in touch with the doctors all across, and honestly since my son was at about seven months in the hospital at the time that we left, the doctors were also in, at the point where they didn't know there was traveling. It had become complicated with his trachea and things like that. So they, they always encouraged us to take another opinion and that's fine. We would always ask the parents to be happy with the decision that they make because it's a very huge decision. We all know that. And we used that Good Doctors as a service, I don't know if you guys are aware of that. And that's how we connected with Texas and Boston. And the reason for choosing Boston over Texas was only because there're friends and family there. So we just wanted to be sure because we were flying in from Seattle.

Participant 1008:

(beep) was right coronary artery, and right from the very start they were talking to her about... they very quickly said risk for sudden heart failure, immediately to her.

Participant 4002:

Really?

Participant 4002:

I kind of feel like when we talk about making decisions about this, that would have been nice to hear because I think I would have had less guilt about deciding to have the surgery. We waited 12 years. And with me thinking like I'm going to have him have this surgery and something will happen to him. And then why did we have the surgery if they were telling us everything would be fine? And anyway, thank you for telling me that. I'm glad that you had the information there.

Participant 1008:

Well, and then they framed to her as risk of sudden heart failure, if you get your heart rate up too high. Right? Don't do that. (beep)

Participant 2012:

That's also right. And they said the same thing, they said, you can not have the surgery, but you need to kind of be a couch potato.

Interviewer:

(beep) And you were saying earlier, when you were introducing yourself, you were saying that that decision of getting surgery or not getting surgery was one of the hardest decisions of your life. Can you say a little bit about that decision-making process for you and what that looked like for you all?

Participant 2012:

Yeah, sure. So by far the hardest decision I've ever had to make, having your 10 year old son go into open heart surgery, it's just terrifying. And I kept saying to myself, well, maybe we can just have him be kind of a potato. And my husband just looked at me and said (beep) for 10 years he's been playing sports and on the go and running around, he won't lead a happy life. And so there was lots of, especially beyond that, I mean, one of the cardiologists you've mentioned, well maybe if you could have a defibrillator with you at all times, are we really talking about having carrying a defibrillator around, what kind of quality of life is this? And we're going to be waiting for the minute that it's going to happen. We're going to go watch a soccer game now, is he going to drop? And we couldn't live like that.

Interviewer:

So when you chose to have the surgery, was there anything that a doctor told you or a surgeon told you, cause you said you were also nervous about your child, your ten-year-old, having open heart surgery. Was there anything that helped you kind of cope with that or negotiate that?

Participant 2012:

Yeah, so we met with the surgeon, just my husband and I, for like a good hour, one day. And he walked us through the whole surgery and answered all our questions. I mean, that was huge. And then that same day, we also met with his cardiologist without him. And so we were able to ask a ton of questions and that just played a huge role in it. And they were both really reassuring. His cardiologist at Children's, Boston, had also sent his records to Philadelphia. So, the same thing, we didn't have to go down to Philadelphia and they agreed that the surgery was the best for him.

Interviewer:

What were some of the questions that you had (beep), that you wanted answered?

Participant 2012:

So my biggest fear was what's the risk of death while he's on the table. And then things like risk of infection, recovery. I mean, I had pages and pages. I can't really think of it all right now, but there's just so many things, like what's his quality of life going to be like after? I think the main thing was just him getting through the surgery though.

Interviewer:

(beep) you've come off mute. Did you want to add something?

Participant 4002:

I wanted to say (beep)’s the right coronary origin, it's going to the left. But as of now, they said they don't, they don't anticipate him needing surgery because he's asymptomatic. Like I said, they're waiting to do the MRI, stress MRI, to confirm what they think will be the course of treatment. But they don't seem to be too concerned at this point, based on the test results that we had so far. But I was told that the right coronary origin one is, is not as serious as the one on the left and that, unless it's symptomatic, they don't really consider surgery.

Participant 2010:

Any of your kids who were, have had surgery, are you guys on, are they on medication? My son he's been on both beta and beta blockers and channel blockers, his whole life. I just was curious if any of your kids are?

Participant 1008:

As a result of the surgery or just general?

Participant 2010:

As a result of the surgery, he’s on both.

Participant 2012:

(beep) takes a baby aspirin every day since the surgery.

Participant 2010:

No one else's kids? That's the one thing that I questioned is this use of medication. He still has. He's unable to control. Like his heart rate is just always tachycardic even after the two surgeries. So I have struggled with him having to take these heavy meds since...

Participant 1008:

(beep) was only on the surgery or other meds that one would have to have after major surgery, like pain relief and such. But other than that... No.

Participant 2006:

Yeah. For us also, from being on life support and that kind of medication to zero medication right now, we are really blessed. No medication after surgery. He's doing just fine.

Participant 2010:

Wow. I need to question why he's still on medicine.

Participant 1008:

Well, everybody's different, right? Questioning it is appropriate, but just because one child wasn't on medicine, doesn't mean none of them should be. Anyway...

Interviewer:

And I was going to ask (beep). So your child is asymptomatic, the doctor has said that he's not restricted from any playing any sports or anything. How are you feeling just currently? I know there's still testing that needs to be done, but how are you feeling at this point in your journey with this?

Participant 4002:

I do feel better after going to Texas Children's, given how they explain everything. That doesn't take away the anxiety and fear, I think. I'll probably feel better after stress MRI, just to make sure there's no obstruction or anything like that. I feel like I have better support at this point. I have the team, there's an interdisciplinary team that I feel, treats the whole spectrum of the diagnosis, not just one thing, but that doesn't take away from the anxiety of worrying every day. I try not to stress my child. He seems to be okay, he doesn't seem to be fearful, maybe, cause he's asymptomatic, I don't know, but he's ready to play competitive sports. And I'm just going to trust the team of doctors and, of course, keeping a close eye on him at all times.

Interviewer:

And so (beep), you also used the word anxiety earlier and I think maybe another person or two talked about feeling anxious at different points in this journey. Was all that anxiety before surgery or do you all... I think everybody else on this call other than (beep), their children have had surgery. So is this something that you all feel even after surgery happens or is life just back to normal? What's the experience for you all as parents like, post-surgery?

Participant 4002:

Well, to that point, my son was at rowing nationals in Florida and he had finished a race and I'm watching him through the binoculars and I see him do that, and I lost it. I lost it. My husband was like... And I get even emotional just talking about it and I thought, oh my God, this is going to happen. And my husband's like, "It's been five, four years." He's had every test. They've done everything. They keep telling us everything's fine and I still feel... He comes home and says, "Oh, I had something here when I was running." And I still feel that sense when he says it, like, oh my God, something's wrong. And it takes a lot for me to try to be normal. Do you know what I mean? So that he doesn't think something's going on. So yeah. I still have anxiety. I don't think my husband has as much as I do, and I'm not sure if that's just his personality or I don't know, but yeah.

Interviewer:

Thanks for sharing that. Do others feel similarly to (beep) or different?

Participant 2001:

I feel very similarly. He'll come home and say, I had a big heartbeat today and I try to play it off as, it's okay. But it scares me so much more than I would have just a regular kid that hasn't had a heart issue. I'm constantly emailing his cardiologist and she does reassure me, but I don't think it'll ever stop.

Participant 2010:

Mine's been 20 years. So we came to terms with it. It was a reason why we founded so young in him, and there was two of them and we found them, did not have an incident on a soccer field, which after the fact we were told would have been probably something he would have probably had cardiac arrest given it. And I just hand it up to God and say, we've done what we can. He's got to live a normal life and hope... I want him to be happy. It would have hurt me more if something had happened to him and he was sitting on the couch and we didn't let him live his life and didn't do the surgery because we were scared, than to do the surgery and let him live his life. I worry as a parent, he's 21 now, drinking and I don't want him to vape or do any of that stuff.

Participant 2010:

I worked really hard to get you healthy back then, don't screw it up now with doing something stupid. So it's more that. And so I think that's what I worry about. You were given the gift of life, please don't screw it up by doing all these other influences, other things that they're influenced to. (beep) she has a 17 year old, so you probably will have the same conversation going to college. You have to be careful. You have a gift, you have to protect this gift. So stay away from all the bad influences. But yeah, I think we came to terms with it a long time ago. We did what we could and everything... If something happens, it happens, but I cannot live my life going to bed every night, living like that. I have two other children. I will be dead before he will. So we had to let it go, but it took time and it took meditation and a bunch of other things to let go of it.

Participant 1008:

We had hoped in (beep)'s case that having gone through the heart surgery would be the swift, pardon my French, the swift kick in the ass she would need to finally push past her anorexia. If you're going to go through all that trouble to have somebody stop your heart, crack your chest open, do all this work on you, then don't screw it up by then letting the anorexia stand in your way. But we knew that once she had basically recovered from the surgery, that it was back to the business of trying to deal with the anorexia and thankfully she's, well, unfortunately it did not end up being the kick in the butt that she needed. However, she found some other kick in the butt and is doing well with her anorexia now and is living a pretty, well, a quite normal life. You never really recover from anorexia, but she's handling it, she's managing it instead of it managing her.

Interviewer:

And just wanted to follow up on one thing. (beep), you were saying that you still, to this day, email your cardiologists, every week, I guess you said-

Participant 2001:

Every week.

Interviewer:

What are you emailing your cardiologist about? What questions do you still have that feel unanswered to you?

Participant 2001:

Just anytime he has a symptom, so I'll email her with the symptom. I described exactly what he tells me, and then I'll say, "Do I need to worry about this?" And she usually says, “No”. I can't ignore it because I could have ignored, I wanted to ignore it when he had the initial symptom and it was my husband that pushed it. So now I'm afraid if I ignore anything, I'm going to miss something.

Participant 4002:

I was going to say, anything from my headache to pain in his leg, I'm like, "Oh my gosh, is this... Can this be related to this condition?" So I just have to bring myself to the knowledge and be like, "Okay, just relax. It's not nothing to do with that." But yes, every little thing scares me.

Participant 2006:

Yeah. We are three years out of surgery now, but still we email, I would say, if there is a symptom and we don't know or it hasn't happened before, just like (beep) mentioned. We would reach out to the cardiologist and ask if this is related to his cardiac issue. Yeah. And the answer mostly is no and we would want it that way, but yeah, we'd ask.

Interviewer:

Is there, I know that we're out of time, I guess my last question is, is there anything, in thinking about your all's journey with this being affected by this condition, having a child with this condition, is there anything that, I guess, was missing? Is there anything, thinking back on it, that that could have helped or any kind of support that wasn't there that you wished had been there to help either you or your child through this journey with AAOCA?

Participant 2006:

Yeah. I would start off by saying that I don't know how we missed till about, he was almost 12. How did we miss it? That comes to me as the biggest surprise. What if those eight cardiac arrests had a different outcome? I can't think about it. How come we missed for so long? I don't know, we've had normal checkups. And he's a kid who's never even... Not one of those kids who falls sick or has the flu symptoms, none of those, none of those and suddenly you're presented with this. So I don't know. And considering it's AOLC, so it's the left one and we are aware that the right one doesn't get detected as easily, the left one not as much, but then the way it presented to us, just so, so different.

Participant 2006:

In some sense that I wish I was in the other shoe. Surgery in and of itself and the condition in and of itself is difficult, but to see that... And the question of about anxiety, when eight times over, you have your son not have a pulse, it takes a while to come out of that kind of a PTSD. So yeah. I just wish I knew. I wish we had caught it earlier and he didn't have to go through so many ups and downs before we came to where we are right now.

Interviewer:

Thank you. What about others? Are there types of support that you wish had been available or anything that you wish had been available that wasn't available to you through this journey?

Participant 2010:

I wish, 20 years ago there was not a whole lot around it, so my question kept being, what does this mean long-term for him? This idea of, he's been on medication and I think he's been on medication because that's what they thought they needed to do back then. I just wish there was more information. There wasn't. There wasn't even parents to talk to even in the hospital, on the cardiac floor, nobody on the floor, everybody had similar issues and my son was always the one that was an issue that no one else had. So there was never anybody to share experiences with. So that's what I wish, had someone to talk to back then.

Interviewer:

Has anybody now, I guess 20 years later, I'm imagining there's more information about this. Has anybody been able to answer any of your questions about sort of like long-term health?

Participant 2010:

No. They keep saying they don't know enough about it. They really just started fixing it, I think, maybe 20 plus years ago. I said, what happens when he's older? What happens with his lipids and other things? How is this going to affect his two coronaries? Will he ever have to have surgery again? Or are they going to stay open or are they going to... Because his are slightly different. And does this, having this very teeny right coronary artery going to affect him as he gets older? So far, it's like, "He's feeling okay. He's doing okay."

Participant 2001:

And I think, I would say to (beep)'s point, when he said, sometimes they're guiding you without really guiding you. I guess I feel like that would have been helpful for us to make the decision because I feel to some extent, and it's not to anyone's fault, again, ours was 17 years ago and (beep) 20 years ago. They really didn't know anything. Nobody knew anything to say, you should do this surgery. So they really weren't guiding us in any direction and then it really left you in a position where you're going to make a decision based on nothing to put your kid through the surgery, and that was really hard. I wish, at some point once he had the symptom, it like, okay, well, he's having a symptom, now I recommend having this surgery and it made it, I don't know if it's easier to do it, but to (beep)'s point, maybe the surgeons or the way they're presenting it or the way someone's presenting it, is going guide you, I think, which way you're going to go and it's subtle, but it's there.

Participant 2010:

Yeah.

Interviewer:

Thanks for sharing that. (beep), is there anything that you wish, maybe, in addition to what you were just mentioning that had been different or types of support that you wish you had had early on that wasn't there?

Participant 2001:

Well, I have to say, I think people's experience at Boston was really... I found the experience at Boston to be very different from the experience at CHOP in Columbia. I found it to be very (beep) focused, very patient focused, making things a lot easier for the family to figure out and to... It didn't seem as overwhelming when they said, "Okay, we're going to do this surgery, but we're going to set it all up. We're going to do a..." When we went to other places, it was like, show up here and then five hours later show up here, and then you just didn't feel like you could do the surgery. So I think having that support system of taking care of all the different parts of the situation, so the surgeon and the cardiologist, and then someone who's organizing it, like they have at Boston, was really, really helpful. So that would be my... And I think they're doing that now, I just don't think they were doing it 17 years ago.

Interviewer:

What was that doing for you to have Boston set things up like that and support you in that way?

Participant 2001:

I guess it just, it made me feel like there was a process. When I was driving it on my own, I felt like, okay, is everyone just doing this because I'm pushing them to do this? Or once people were acting in concert and sort of supporting the decision that was made, it felt like, okay, this is the right direction to be going. And right or wrong, I guess that was just, again, a subtle sort of support that you get and pushes you toward a decision.

Participant 2010:

I think it reduces your anxiety. My son has surgeries at Children's and (beep)'s right, I guess I took it for granted, not recognizing what others went through at other places, but the fact, they literally, they just did everything, they guided you. It was like having your own concierge.

Participant 2001:

Yes. Yeah.

Participant 2010:

You didn't have to think twice about it. They called, everything was set up. It allowed me to focus on my son and sort of absorb and process what was going to happen, versus having to worry about the day-to-day details. Even from, you valet park and then everybody works for you. And it was like having your own personal VIP concierge. I didn't appreciate until I heard all of your stories. Even doing the second opinions, they got me six opinions and I never had to leave the state of Massachusetts. It was great. I am grateful and humbled by that.

Interviewer:

Well, I know we're eight minutes over our allotted time. So I guess the last thing is, is there anything that we haven't discussed today that you all would like to talk about? Anything that we haven't or you haven't already talked about that you feel like is important to share?

Participant 1008:

One of the things that we still wonder in our family is should (beep)'s older sister get checked for the condition as well.

Participant 2001:

That's a great point.

Participant 1008:

And I think that would be nice to have, is as a routine, standardized part of the communication protocol with anybody who's dealing with AAOCA, is how should all other family members deal with it too? Should mom and dad go get checked? Should older sister get checked? etc, etc. Considering that it took (beep) 18 years to finally find out. It would've been nice to just set people at ease immediately and go, no, you don't need to or yes you need to, or what have you, instead of leaving us wondering.

Participant 2006:

We had a younger son checked as well with all that was going on, there was no way we weren't doing an echocardiogram for him.

Participant 2010:

I had both my children checked, but they did say that there is no link. They don't understand if there's a genetic link. That would be really a nice piece of information to know long-term for families. Is there a genetic link?

Participant 1008:

That's why I say, standardize on it. Just have that as a checklist of things that you talked to the family about.

Participant 2010:

Yeah.

Interviewer:

Thanks for adding that. Anything else from anyone? Anything we haven't talked about, that's important to talk about?

Participant 2010:

No. I'm grateful to have met all of you. I felt so alone for so long around here, it's nice to, not that we're all going through it, but...

Participant 1008:

When do we get to meet at the Cape?

Participant 2010:

Anytime you want. When you're down, let me know. (beep), you're coming next week, so just let me know.

Participant 2006:

I'm also going to be in Boston, my son's checkup is on the 12th of July. So yeah, we're all heading to the Cape.

Participant 1008:

Don't come to Austin, it's hot as hell here. So yeah, we'll meet at the Cape.

Interviewer:

It's crazy.

Participant 2010:

I've always wanted to go to Austin, it sounds like a cool town, a cool city.

Participant 1008:

It is, but not at this time of year, it's too hot.

Interviewer:

Come in March. It's a good time. February.

Participant 1008:

Yes.

Interviewer:

Well, I just want to say thank you again, all of you for being on this call this evening. It's so helpful and meaningful for us to, to hear about your stories and experiences. So can't tell you how much I appreciate it. And I think the coordinators who have been talking about this project with you, will be in touch with you about gift cards or compensation, I guess, for participating in this. But yeah. And if you have any questions moving forward, they are the person to reach out to. But again, thank you so much. Really appreciate your all's time.

Participant 2010:

Thank you.

Participant 2006:

All right.

Participant 1008:

Thank you and good luck to all of you.

Participant 4002:

Thank you very much.

Participant 1008:

Nice to talk to all of you. Thank you very much.

Participant 2006:

Goodbye.

Interviewer:

Bye everybody.