Critical Congenital Heart Disease Webinar
June 2015

Presenters: Michele Coleman, Gretchen Whitehurst, and Annamarie Saarinen

Please direct all comments/questions pertaining to this webinar to Thalia Wood at Thalia.wood@aphl.org or 240-485-2701.

Thalia Wood: I think this is going to be an excellent call to get some parent perspectives on CCHD. Amy Gaviglio, if you're on the phone, go ahead and unmute yourself and get us rolling here.

Amy Gaviglio: Okay, can you hear me?

Thalia Wood: I can thank you.

Amy Gaviglio: All right. I will echo what Thalia just said. Thank you all very much for joining us on this Friday for the CCHD Technical Assistance webinar. I, too, am very excited to present today's topic and speakers. We have put together, I think, a wonderful panel of parent advocates who will share with us their experiences with pulse oximetry screening. I think I'm going to start by introducing each of the 3 speakers now and then we can save questions to the end. At that time, we very much encourage you to ask questions of our speakers about advice on education of parents, thoughts on long term follow-up and support needs after a diagnosis, or suggestions for improving the process from screening to diagnosis. With that, our first speaker today is Michele Coleman. Michele is the Chief of Staff at Vornado Realty Trust in Washington DC and she is a wife of 8 years and mother of 2 rambunctious boys. Do they make other kinds of boys? Davis, age 5, and Dylan age 2 1/2. She became an advocate for critical congenital heart disease when her youngest son Dylan was born with 3 of them. As you will hear during her talk his heart is now fully repaired and he is considered heart healthy. However, if it was not for the pulse oximetry screen, he would likely, literally may not have lived.

Our second speaker is Gretchen Whitehurst. Gretchen became a heart mom 7 years ago when her son, Cooper, was born. Since that time, she has been advocating for critical heart disease awareness and funding at the national level at Washington DC, along with lobbying at the state capitals in both Wisconsin and Colorado for mandatory pulse ox testing. She currently resides in Centennial, Colorado with her husband and 3 children.

Our third and final speaker is Annamarie Saarinen. Annamarie is a Humphrey college fellow and co-founder of the Newborn Foundation Coalition, which is focused on leveraging health technologies to improve policies, access and outcomes for their youngest patients. Annamarie founded 1in100 as an online parent community for families facing critical heart disease while spearheading the federal effort to add congenital heart defects to the recommended uniform screening panel in the United States. The Newborn Foundation is currently engaged with the government of China on the BORN Project which is piloting neonatal mobile phone pulse oximetry screening for 52,000 newborns for early detection of sepsis, pneumonia and asymptomatic heart defects in low resource settings. I think Annamarie likes to end with the fact that she is actually also a mother of 3 children, including a daughter, Eve, who was diagnosed with critical congenital heart disease as a newborn. So with that, I will turn it over to Michele to start her presentation.

Michele Coleman: All right, great. Can everyone hear me?

Thalia Wood: Yes, thank you Michele. Just tell me when you want me to move the slide. Thank you.

Michele Coleman: Okay. Thanks. Thanks so much for the introduction. Like you heard my name is Michele Coleman and I'm a mother of 2, full-time worker, a wife, busy like all of us. I run the local chapter of Mended Little Hearts here in Washington DC and consider myself at a core level to be a CHD advocate always. It's this thread that runs through my life since Dylan was born back in December. I was told the other day that I had 20 minutes to talk, which normally my spiel is 3 to 5 so I'm excited to give the long version.

Quickly, Dylan was diagnosed at 13 weeks with congenital scoliosis. He has what's called a hemivertebrae. We knew something was going wrong with the spine. We were followed very, very closely at Children's National Medical Center. I had all my sonograms there. We actually had a fetal echocardiogram performed there and he checked out fine. He was doing fine. The spinal cord was not tethered and we were cleared to deliver at the hospital of our choice with no interventions. We were of course thrilled that what started early to be something stressful sort of worked out and was going to be fine. I actually live in Washington, DC but my obstetrician is obstinate and he said, "No, absolutely, you have to come to Holy Cross in Silver Spring and deliver here. That's where I have privileges and I want to deliver this baby and I'll see you there." So we acquiesced and we went to Silver Spring, had an unremarkable delivery. We actually had a neonatologist at the birth, which is unusual at that hospital. She was present and lots of people checked him out especially because, you know, making sure that what we saw in utero was good when he came out. He was doing fine, eating, sleeping, not blue, not sweaty, he presented no signs while we were in the hospital.

Our last day I was discharged and we were waiting for his discharge. The pediatrician on call came in that morning, it was just whoever was on call there, and they came in and said, "Uh, something is going on with Dylan and we want you to wait here in the hospital and get a echocardiogram." We were like what's going on and they said, "He had an abnormal pulse ox and it means we need to look at his heart." We said, "All right," and they said, "Don't worry, it's probably nothing. It's probably him just regulating and babies do this but let's just be safe." It was a Saturday. No one was there to do one. Perform the test or read the echo so we actually waited 7 hours until somebody finished their rounds in Virginia to come to Maryland to do the echo. I had a really nice day. Everything was fine. My husband actually left because our other son needed to be picked up. He came in, did the echo, and they said, "He's got 3 congenital heart defects and he has to go to the NICU immediately to be put on prostaglandin and then he will have heart surgery as soon as possible." You can only imagine what, in that instant, in that moment, when that doctor said that to me, everything changed for me. I was alone with [inaudible 00:07:10] and this diagnosis. Very scary.

You can go ahead to the next slide.

There's a picture, this is this little drawing. I don't know if you guys can see it. This is the drawing that they gave to me, that he walked into the room and gave to me. He drew where his 3 defects were. He wrote them out for me. He has like a little textbook; he made a copy of it and gave it to me. Then that's the other picture of Dylan in the NICU where they gave him the prostaglandin to keep his ductus open in order to get him stable enough to get the surgery.

You can go to the next slide.

This is just us waiting for surgery. We actually waited 7 days. Day 2 we got diagnosis so we made it until day 7 to get his surgery. He seemed stable enough. We just hung out and held him as much as possible.

Next slide.

This picture, this is my favorite picture. This is actually a picture that was freehand drawn by our surgeon, Dr. [Progna Sinha 00:08:14] at Children's and it shows exactly what he did. It shows his opening [inaudible 00:08:21] and for me that's good to know. I love this picture. I look at it all the time and it just reminds me that on the inside he's got his repair and they and this in his room and I just think it's such a cool drawing. I'm going to stop here. You can go actually to the other slide. This is us in the hospital. We stayed. We had a tough recovery, stayed in there through Christmas. He finally figured out how to eat. Next slide. We were released on New Year's Eve, which was amazing. Next slide. Came home and he's done really well ever since then. As you can see he is a wild man.

I'm going to stop right here and talk about pulse ox specifically as it related to our whole, you can just go back. We live in DC. At that time DC was not testing for pulse ox. They may have voluntarily been doing it. It was definitely not as much as it is now, even before the legislation that hopefully will be signed by the mayor very soon, yeah! So if I had delivered in DC, we have been told that because of the CCHD, even though he wasn't presenting with anything, he would have gone home and then within 48 to 72 hours died of congestive heart failure with no interventions. Even if there were interventions, there was no profusion to the stomach and so the amount of food that we were giving him would have begun to cause something I think called NEC. He would have been compromised and would not be this wild man that he is today.

We were really, really lucky that I landed in Silver Spring, that I had this OB that he was a pain that he said you have to come here. I count everyday my stars that Holy Cross was a pilot program for pulse ox. That they have worked with Dr. Martin at the Heart Institute. That they have just been forerunners in fetal maternal health and that we were really, really lucky to live in an area that I was able to have this care. Since Maryland has legislated pulse ox testing, Dylan was not the first baby to ever be caught by pulse ox in Maryland but he was the first baby since legislation had been passed. That sort of vaulted me into the place with Children's National and the Heart Institute which is why I sort of have become an advocate because I was sought out because of his status. I'm thankful that I have because it's really been great for me and empowering.

The other thing I want to say is that the on call physician that day, I credit her with a lot of the credit. How much of it is my inference on what she did and I actually spoke to her after we were discharged. I found her information and called her and thanked her for the work she did. I let her know that keeping us in the hospital for that extra look, saved his life. She was really pleased to hear that. She said that the pulse ox testing is new and the protocol was in its infancy then and making sure that all the pediatricians that were coming in, who are making those decisions, really know what they're doing. From what she told me, she was glad that she made that decision but she was sort of on the fence. She said, "Yeah, the numbers, it was 100 in the upper extremities and between 82 and 84 in the lower. It was moving around." She really thought maybe something's going on and she didn't hear anything in the heart and she said, "Let's just be safe. I would rather be safe than sorry." I really do credit her with making the call to make us stay because it wasn't convenient. She called friends of hers, I don't really know how it works, but she called somebody that she works with in her practice to come up and do the echo. She had to the get the right cardiologist to make sure that he knew what he was looking at and could read it correctly. There's just so many things that had to fall into place so I do credit her with literally saving his life by making that call to get the echo and then to get us into the places that we needed to.

We can go to the next slide.

Fast forward he's recovered. Everything's good. He's at home. I started thinking this is how it happened, this is how mothers get causes, how families get causes, and I started leading the local chapter of the Mended Little Hearts in DC. We provide support to parents and caregivers of children with congenital heart defects specifically at Children's National Medical Center. But then if anybody else calls we always talk to them. We make care bags, take them up there so that everybody who has a surgery will get a care bag that has an information binder on what to expect in surgery, recovery, going home, going forward. Little gifts for the kids, toiletries for the parents. For me this bag was a safety net, a lifeline. Because I thought I was being discharged. I checked myself out of the hospital and I drove myself to Children's National to meet him there. Didn't go home, nothing, I had nothing. It was great for me to have this [inaudible 00:13:56] to hold on to. Specifically a book that said all the other ABC alphabet of CHD. To know that I wasn't alone. So that's what I've been doing, that's what I do. My kids are like, oh you're going to go help the babies. We do that.

Next slide.

Dylan has been featured in several articles and blogs because of the pulse ox and because in the ramp up to get DC to pass pulse ox and then directly after he was released APA [inaudible 00:14:28] actually did a story on him. They did a story in the Washington Post, American Heart Association has pushed our story out to other media outlets to try and just get the word out about pulse ox.

Next page. The next slide, yeah.

Dylan was honored at the American Heart Association heart ball. In 2014, as a face of heart, this was ramping up to getting pulse ox passed in DC. They literally had just, Governor McAuliffe had signed the bill in Virginia, I think, two days before the heart ball. That was great. I got to stand up on stage and announce that. I didn't really do anything with that. These are things just to try to get the word out to talk about pulse ox advocacy.

Next slide.

It sounds like Gretchen, I probably met Gretchen. This is Congenital Heart Advocacy Day where I think 300 parents from across the country came together in DC this past February and amassed on to the Capitol, talked to all of our legislators. Told them how important it is to keep funding in the budget for congenital heart disease. How we need to CDC to be able to have money to collect data so when we collect these numbers we really know how to analyze them and put them to work for these babies. I think it was really powerful. It was great to see. We were able to walk in to Senator's and Representative's [inaudible 00:16:07] offices, have audiences and be able to share our stories and put a face to CHD which I think is what we all do as mothers and as advocates. All 3 presenters, that's what we do, we try to put a face on CHD everyday.

The next slide is Dylan and me at the DC counsel subcommittee hearing for pulse ox testing where we testified. Dylan just tried to grab the microphone the whole time and drink the water from the pitcher on the table. So that's us and then the big group there, most of these women, and there are some dads, some doctors in there, Lisa [Holm 00:16:51] is in there, Dr. Martin in the yellow tie, he's head of the Heart Institute. These are other advocates, members of Mended Little Hearts who came and told their story. Not pictured here but a very important story that was told that day was a woman who coincidentally also delivered at Silver Spring who's baby passed away and her defect was undetected and it could have been detected through pulse ox. She could have lived. I think it was important for us to both be there and for me to tell my story and to have Dylan there and for Olivia to be there and tell her story because while it's not a face we all want to see or we all see, she's extremely brave to tell her story. I think it really does illustrate how important pulse ox is and how important it is to constantly be spreading the word, telling people and being able to get the message out there.

The next two slides are just [inaudible 00:17:54] slides of my children. Dylan's little one and then the last slide, that's just all of us. I know that we're going to have a question and answer. As I was thinking about this and thinking about my experiences with pulse ox and what I knew about pulse ox, my experience in a hospital was, I'm a very type A, knowledge monger, I think that I am medically minded. I had no info no pulse ox before I delivered. Even after they brought Dylan to me, they brought him back from the test. The only thing that I sort of remember is that he was gone for a long time that morning and I was a little freaked out that he was gone so long. I did ask specifically where is Dylan? Why are you not bringing him back to me? I'm nursing, he's not supposed to be away from me, I wanted him back. They said, "Oh, we're just doing some tests." Even at any point during my stay, and so I waited that 6 hours, 7 hours, no one talked to me about pulse ox. They didn't tell me what was going on. They didn't tell me what could be wrong, why he was really coming. It probably was to keep me from being hysterical which in retrospect was probably a good idea because then I would have had 7 hours to freak out and go and [inaudible 00:19:16] and just totally spiral down into a bad place.

In retrospect it was good, but I do think that we can do a better job of getting the information about pulse ox out. I personally think it should be talked about well in advance of any delivery, any trip to the hospital when you're in labor. Because if anyone's had a baby, you know that you're not really paying attention to anything. There may be like a lull after you have your epidural and before you start pushing, but you're not really focused on that. There's people in and out, there's monitors, you're not able to process the information you're being given. You're certainly not able to process any information after the baby comes out. I barely remember telling them he's had a hearing test, got a hepatitis B shot and all that. I barely remember that and I probably had that for my first son. Giving the information in the Ob's office, talking about it on a hospital floor, talking about it at birth classes, those are the kind of places that I think that pulse ox has a place to talk about. Not to scare people but in my daily life, I urge everybody I know, every pregnant woman I see, not to be a fear monger but just to say, "Look, you should make sure that your baby gets a pulse ox test at the hospital." Even if they live in a state that is mandatorily testing, I say just ask. Make sure they got the pulse ox and I'd ask what the results are. Because then you know that it happens.

Not saying that things are going to slip through the cracks because things are in place for a reason and hospitals do their job. But for me, I want to know. I think that getting this information into the hands of publishers for baby books, What to Expect When You're Expecting, you know if there is a way to get the information out to new mothers. They have those baby apps that tell your baby is an avocado, or it's a pear, it should come up and tell you, "Hey, these are the tests you're going to get when you get to the hospital." Those are the kinds of the moms that are paying attention before the baby comes and I think those are good opportunities to get the information about pulse ox out. Then as far as the information coming to parents when they're getting pulse ox tests in the hospital, I obviously have no idea how to dictate policy or what would be allowable but if there was a positive pulse ox test that required further testing I think education is needed. Because while they don't want to freak the mother out on what could happen, I think not knowing, in retrospect, feels insulting because I'm an adult and I can handle it. It can be presented in such a way that I am able to handle the information and if not their information to have, it's my information to have because it's my child and I should be able to process it any way I can. Would I have been more prepared for what Dr. Callahan told me when he walked in the room? I don't know. But I at least would have had something. Because I really had no idea what was going to happen or what that really, really meant. I'm pretty sure they didn't even tell me that it was a pulse ox test because I am a crazy Googler and I would have definitely been looking it up and I had just a lovely day in the hospital hanging out with Dylan. So that's it!

Thalia Wood: Thank you so much Michele. Yeah, thank you so much. We have a couple of comments but we'll save those until the end because in the interest of time we are going to go ahead and move ahead to Gretchen. Gretchen if you want to start. Just do star 7 on your phone and you can take the next few slides.

Gretchen Whitehurst: Wonderful. Can you hear me all right?

Thalia Wood: Yes we can hear you fine, thank you.

Gretchen Whitehurst: Perfect. Like she said, my name is Gretchen Whitehurst and I'm going to tell you after listening to Michele's story, our stories are so incredibly similar and our experiences. In 2007, my husband and I found out that we were pregnant with our second child and we were absolutely ecstatic. We were so excited to have our family grow and at the beginning of our pregnancy everything was wonderful. I just enjoyed every minute of it. We went in for our 20 week ultrasound, just the routine ultrasound, and we were in there and after having our first child I noticed that the ultrasound tech spent a little bit extra time looking at the heart. Of course they aren't able to tell you what's going on. They need to send it off to somebody to read and everything else but I knew something just wasn't quite right. I walked out of there and I looked at my husband and I had said, "You know I feel like something just isn't right with this. Something isn't vibing well with me." We went home and we didn't hear for a couple of days and then the day before Thanksgiving, I got a call at work. I was a teacher at the time and I got a call and the nurse said, "I'm just relaying the results of your ultrasound and we just found out that your son does not have 4 chambers in his heart." Well of course I had no idea what this meant but I said, "Well is it possible that I could get another ultrasound quickly?" She said, "Well, because of the Thanksgiving weekend and everything else we're going to have to wait until next week." My doctor was out of town and after hearing that of course, just like Michele, I went online and of course I got incredibly scared. I ran out of the room, luckily I didn't have any kids in my room at the time. I ran out of the room crying and I was just hysterical because all of a sudden you hear the words that your child is imperfect and you get so worried. Luckily my doctor found out the results and called in and I said, "You know what, it's probably just a bad picture. Let's redo an ultrasound on Monday. No worries. Let's see what happens." On Monday we went in for an ultrasound and a doctor was present at the time and they said, "Yes, they have 4 chambers. Everything is fine, everything looks wonderful. Just enjoy the rest of your pregnancy." And so we did.

Then in April of 2008 I went into labor and we went to our local hospital. At the time I was living in Reedsburg, Wisconsin, which is a town of about 9,000 people in a rural setting. Everything looked fine with the pregnancy, labor was going well and then all of a sudden his heart rate absolutely dropped. It went from being in the 140s down into the 30s. Just like with my first son, we went in for an emergency C-section and when Cooper was born, he was born completely blue. He was motionless, he was not breathing at all and he just had a faint heart rate. When he got his first Apgar scores he had a 1. We were absolutely terrified. We thought we'd lost him. The first few minutes of his life we watched absolutely helplessly as a doctor and a nurse performed CPR on him and at that moment I was just trying to wrap my mind around what would happen if I had to walk out of that hospital without my son.

Luckily after a few minutes, all of a sudden we heard him cry and to us that was the most beautiful heart sound we had ever heard. We were so excited. He started breathing on his own, he started to pink up, he started moving around like crazy. In our eyes he looked perfect. He was our son, we were so happy we could take him back to our room, we could cuddle him, nurse him that night, just look at him in amazement at everything that he had already been through in his short, short life. After a while, the next morning, after we had spent all night with him and everything else the nurse came in and just told us, "You know we always do routine newborn screening and so we're just going to take your son. Just for a little while and it's a perfect time for you guys to get a little bit of rest because you didn't rest much last night." We said, "Okay, that sounds good." She took him off into the nursery to do the newborn screening and my husband and I just rested. All of a sudden, out of nowhere, I spring up from my bed and I looked at my husband and I told him, "You need to run down there. Something is not right." Mother's intuition, whatever it is, I just knew something wasn't right with him. He literally ran down the hallway to the nursery and when he got there he not only saw the nurse but multiple doctors as well. What they told us at the time was they said, she had heard in the news about this thing called this pulse ox test and she learned a little bit about it. The nurse decided that day it would be a good baby just to try it out on. When she did it she got some abnormal results. Not only was the oxygenation, the saturation, all those, not only were they low, but there was a huge discrepancy between his upper and lower extremities. At that time she called in the on call doc who came in and he did another pulse ox test on him and found that the results again were abnormal. So he brought in another doc. One from his house and he came in as well and they started doing some further testing. After feeling his femoral pulses and looking at his color, because in his upper body he was nice and bright pink and in his lower body he started to be kind of a dusky color. They checked his femoral pulses and they could not find any. With all of these things they said, "You know, we have never had this in our hospital before. But after looking through some of our medical books we think that he has a coarctation of the aorta. We cannot do an echo here. We don't have the personnel so we're going to have to send him to a children's hospital in Madison, Wisconsin."

At one day old, I had to stay in the hospital because of my C-section and I had to kiss my son goodbye and him and my husband went by ambulance ride, when he was a day old, to Madison where they had the specialists in order to go ahead and do the further testing. When he was down there, after doing the echocardiogram, they found that yes, he not only had a coarctation of the aorta, it was a near interruption so much that if the aorta was connected at all, he said literally the red blood cells were going one at a time because it was that thin. They also found that his left ventricle was only doing about 30% of what it should, that he had mitral valve issues and that he also has a bicuspid aortic valve along with a septal defect.

I was an hour away in my hospital room and I'm just getting this all by phone. I had to call in a doctor and I said, "I have no idea what they're telling me." Because the only prior knowledge I had of this was through my kinesiology classes in college and there was very, very minimal. So I said, "You need to be able to describe what's happening because I don't understand what's wrong with his heart." He tried to describe it to me and just like Michele's, I said, "I love that you're trying to do that but I need to see what is wrong. How is his heart shaped differently than another? How is his functioning different than a normal healthy heart?" He sat down, drew out pictures for me and he said this is what's happening, this is what they will need to fix. I said okay but I need to get to my son right now. They said well we can't. I said, "I need to get to my son right now." So one day after I had him I walked out of, I got discharged. They said, "You can go and see him as long as you get hospital care while you're there."

So I walked into the Madison Hospital and at that time there was still part of me that was hoping that maybe it was an incorrect test result. Maybe that pulse ox, there was just a little bit of hope in me that something was wrong with the testing and that he was still a healthy baby. But after seeing the results from the echocardiogram and talking to the specialists I realized that it was much more severe, not only then the doctors in Reedsburg thought but also that I had in my mind. Again, they walked us through every step and what it would look like for surgery and things like that. But they said because of his complications it was too severe to do it at that Children's Hospital so at 2 days old, my son Cooper went on a second ambulance ride and went to a bigger children's hospital, the Children's Hospital in Milwaukee. There they were able to do his surgery. Just like Dylan's case, this is so similar, they kept the prostaglandin going so that his PDA would be open and they said, "What we want to do is wait and see if his left ventricle starts working. Because if it doesn't start working, we are going to have to do further surgeries and a different type of surgery. We also want him just to get stronger. The stronger he can be, the better. We have the medicine to keep him stable for now, but we want to see if he can get even stronger."

At 6 days old, they said, "It's time. We need to go ahead and do surgery." He had a phenomenal pediatric CT surgeon. His name is Dr. [Twuttle 00:33:09]. I just cannot even say enough good things about him. He was amazing. He walked us through every step. He walked us through what might happen, he walked us through what he thinks is going to happen, what it might look like, how long it might take. All of those things. He just put our mind at ease and the PA kept coming in and keeping us informed throughout the surgery, which I was so thankful for because otherwise your mind is just always trying to stay hopeful but in the back of your mind thinking worst case scenario. By having that communication, we were able to keep our mind at ease. After the surgery, Dr. Twuttle came in and he said, "Everything went perfectly. We could not have asked for a better surgery. We think everything is great." So they wheeled him back into the PICU for recovery and one thing that I was not prepared for is that his chest was still open at the time. I went in to see him for the first time and his chest was open and I saw his heart beating and I just broke down because, to me, it was not only the emotional part about seeing him in that condition, but knowing how amazing the medical staff was for working on something so small and helping him to become a healthy child again. To me, that was kind of the hardest part for me right there at that time emotionally, was trying to figure all of that out.

Then a day later he went in again to have his chest closed because everything was looking great and at 14 days old we were able to take him home and introduce him to the family and start our life together. I just can't say enough for that nurse as well because at the time, pulse ox wasn't in the news like it is now. Pulse ox wasn't in the newspapers, it wasn't on social media, it wasn't in any of those places and for her to just do it that day, saved our son's life. Because so many doctors along the way said had they not done that, he again, because of his defect and the PDA, would have looked like a completely healthy baby. We would have taken him home, cuddled him and because of our rural area, there is no way that we would have been able to get him into a hospital on time by the time we realized something was wrong and he would have not lived. For us, the pulse ox test saved our son's life. We have talked to the nurse since then and since my son Cooper was born, and because of the result they got, every single baby in that hospital, even before it was mandatory, has been tested with pulse ox just to make sure. Because they said, "Never in a million years would they have thought a child like that would have been born in their hospital, just because of the low amount of births. But then to know that that simple easy test saved our son's life. They said, "Why would we not do it on every child. We test for so many other things but why not a heart defect when it has such a big impact on their life?"

Since then, we have been meeting with cardiologists throughout the way and they have told us that is Cooper is absolutely phenomenal. It is growing with them. He is now 7 years old. He is growing like crazy, has just a couple of valve issues that will probably warrant for a couple more open heart surgeries but we're hoping that it is maybe 40 years down the line if we can. But we're just taking it year by year and appointment by appointment.

One of the hardest things that I think I have encountered, because our first child was a nice healthy child, with my heart baby is we never had anybody help us along the way. We never had a patient navigator help us through all of this. For us, it was all just being his advocate and having to step up to the plate and finding out information, finding out what he needs to do, where he needs to go, what kind of tests need to be done, what kind of restrictions he might have. All of that has been completely on our plate and I think that has been incredibly hard. So to just have people there or a patient navigator to be able to help families like this that have never been through it before and help them to navigate through the rest of the way. When you have a heart baby, their heart can be corrected but they'll always be a heart baby. There's always possibility for different types of issues to come up throughout their lives and it's nice to be able to have someone sit down with you and be able to help you through that and to figure out what steps you need to take, what things you need to be out there. Because I am part of some social media things and some other support groups but sometimes that can be scary because you see all kinds of different cases. Whereas if you could just look at your case, it kind of puts, again, kind of puts your mind at ease with that.

We are just so incredibly grateful for all the doctors that came in that didn't need to and went beyond to explain and sit down with us because if I didn't understand something I'm like, "Nope. We need to stop. We need to hold on. You need to show me what this looks like." They always had so much patience with me for that and I'm just so incredibly thankful for all the care because as you can see from these pictures he lives life to the fullest and he has taught us so much and has just completed our family. We just expect great things and we expect him to have a positive impact on the world and to live life and to have that impact on others. Because we want him to live that life of purpose, he has been going around with us and also lobbied in Wisconsin and in Colorado to help with pulse ox and it's neat because when we got in the car the other day and we came home, every day when I put my kids to bed I just ask them, what kind of impact did you have today? Give me an example. It can be a positive impact or a negative but I always ask them. I say, "What kind of impact did you have today and how did it make an impact? How do you think that made other's feel?" After we got done at the Colorado Capitol the other day, we got in the car and he looked at me and he said, "Today Mom, today I had a positive impact." I said, "Yeah, yeah you did," and he said, "I helped save babies." I'm like, "Yeah, you did." To me that's huge and to know that not only am I advocating for others and being able to spread the word but to know that he is doing that, even with his friends and things is talking about it, just raising that awareness is huge. That's the story of my Cooper.

Thalia Wood: Thank you so much and thank you for all those wonderful slides. He's a great kid it looks like. Those are wonderful photographs. In the interest of time we are going to go ahead and move right into Annamarie's presentation. So far, we don't have any real questions. We have a couple comments, mostly just thanking you for sharing your stories. One real quickly other comment was just, as we all know CCHD is just one screening. We also do hearing screening and the blood spot screening for metabolic disorders but since we're focused on CCHD that's kind of what our primary focus is for today's webinar. Annamarie, go ahead and take it away.

Annamarie Saarinen: Hi. Can you guys hear me okay?

Thalia Wood: Yes we can hear you fine, thank you.

Annamarie Saarinen: All right. Gosh, what a special treat to hear from two other moms today. My goodness. I want to know whoever your photographer is, you better send that information around to everyone on the listserv today because those pictures are amazing.

My story is actually funny when you start talking to other parents it's like wow, yeah, yeah, yeah. It's like so many similar things happen, I think, to those of us who weren't diagnosed prenatally. I think the journey is a little bit different for families that do know that they're having a heart baby ahead of time. But of course this screening is something a little bit different and it was meant always to try to detect the kids that aren't diagnosed while you're pregnant. I'll kind of do a little bit of the story and then a little bit of why the parent advocacy journey kind of took hold for us and what I think it's meant for so many other places in the country and now all around the world.

My slides are a little bit weird because they just transition so we'll just kind of blast through them. My third child was born in December of 2008 and we just had a very uneventful pregnancy and were really excited to welcome our third baby. I was a little bit of an older mom so I had a lot of extra tests and things along the way with Eve, including more than one level 2 ultrasound to really look at all the chambers of the heart and just see if there was function and inflow and outflow track and everything and of course everything looked great so we're just looking forward to welcoming her.

You can go ahead into the next slide.

We were actually kind of similar to Michele's story. We were ready to kind of pack up and go home. The rounding pediatrician had heard a murmur in Eve's case and hadn't thought much of it. She did mention it and said like, "Listen, it's just really common in babies. We don't really worry about it. We'll check it out at the 1 week well visit." So we weren't really worried about it either. She looked great, she was tiny and cute little pixie ears for Christmas and all that. We just kind of went on our merry way and then she stopped back in probably, I can't really remember if it was 4 hours later or 6 hours later, she said, "You know what, there's a tech here from the University of Minnesota." We were at a suburban hospital that didn't have an echo machine or an echo tech and they said, "There's someone here that evaluated another baby today and I think we'll maybe just take a look at Eve because, you know, I don't want you to have to go home and worry about it. It's piece of mind." We were much like Michele was mentioning, they kind of took her and we went in and watched the echo being done. I'd actually seen echocardiograms before because I've got a little bit of background in medical technology and so I couldn't understand it but I was following along and I was asking about it. They said no everything was great. She didn't say everything was great. I said I thought everything looked great which is, of course, an amateur’s perspective. The tech wouldn't say anything because of course they want a real doctor to read it. So we went back to our room and waited and within an hour we had a doctor standing in our doorway and saying, "We need to move your daughter right away to a NICU as she is in heart failure." Once we saw both the x-rays and a better explanation detailed of what they were seeing on the echo, we could really see what was going on and her mitral valve had a very significant defect that was basically allowing all the blood to splash between the upper and lower chambers and her heart was already 3 times the size it should have been at 2 1/2 days old. Her organs were being displaced into her stomach cavity and it was actually a pretty serious situation. We moved on from there, they led us to the next move.

At about a week old she started having SVT which is a very high heart rate and we had to quickly move her to the other side of the river in Minneapolis, which is where the PICU was at the time and that is also where the surgeon was. That was the day that they told us they didn't know if she would make it through the weekend and if she did, they'd probably have to put her on the transplant list. Things were very grim around day 7 but the good news was that thanks to an incredible team of doctors and our cardiologists and neonatologists working together she did make it over this very scary hump.

You can move on to the next slide.

We sort of regulated her care over the cocktail of kind of 9 different medications over the next 10 weeks or so to get her a little bit bigger and stronger to make the journey to Boston Children's Hospital where she underwent, actually she was one of the youngest baby ever to be ablated. Where they go in and burn the electrical pathway off to help her with her SVT problem and then 5 days later had her open heart surgery for her mitral valve. That was kind of the first of 4 months of our journey. Of course, there was no pulse oximetry screening at our hospital then, unlike the few little isolated places that at that time, in 2008, there was a few people who had just started hearing about it here and there and that's why Gretchen's story was so compelling because it's amazing that she had someone who thought to give that a try.

We were able to go home in the end of April in 2009 and like everyone else, it was just the most glorious thing in the world to see your baby have color and to feed for the first time, to watch your child be able to actually feed for the first time, to actually take a bottle and be able to keep milk down. It's the most beautiful thing I think that's ever happened in my life, was just that transformation that happened right there.

Next one. Within probably a couple of months of being home we just decided that again, we didn't feel like we had these support systems. There just weren't any. We were doing our own research and finding our own way around, what doctors could do what and where and how and what were their outcome data and what could we do. We thought the best way to improve things was to connect parents who've had experiences before so they can share what they know. We just built a little organization called 1in100. It was mostly just an online, and still is, just a really active little Facebook community. I think there are 4300 families now or so on 1in100's Facebook page and I can't tell you what a true family and community that has been to our family and I think so many people have been able to help each other through just sharing their experiences and best practices and what to expect. It's just something that I continue to love to this day.

The next slide is a little bit about, mostly everybody knows here, the prenatal diagnosis tree and why we kind of move forward with advocating and why we started developing the idea of doing a pilot project in Minnesota in multiple hospitals. You can move along to the next one.

We launched a pilot in Minnesota that summer and Amy Gaviglio with the Minnesota Department of Health, she's on this call, was part of that. It ended up being 6 hospitals and all of [inaudible 00:49:04] 3 heart centers in Minnesota were involved. The State Department of Health, of course, was involved as well and we were the first, sort of, state to actually be actively engaged in a multi-center pilot study.

You can move on.

In October of that year I, [inaudible 00:49:25] Amy or someone else at the Department had asked me to come over to the Department of Health and talk a little bit about CCHD screening and what it was about and why we do it. What the data looked like right now. I did that and it turns out that it was someone that served on the State of [inaudible 00:49:40] that also served on the federal advisory committee that recommends things babies should be screened for. His recommendation was instead of waiting to get your data out of your pilot, you should probably just pursue this as a recommendation through the federal process and see where it goes.

You can move on from there.

That's what we actually did. 3 months later Dr. Rinaldo from the Mayo Clinic and I flew to Washington, DC to testify at this committee hearing for the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. He got the condition nominated and the committee unanimously accepted it into evidence review which is a very exhaustive and rigorous process of looking at all the literature, interviewing physicians, public health experts, to determine whether or not this meets the serious of tests that a public screening would need to meet to be included in the federal uniform screening panel.

You can move along.

Within 10 months actually, and there was testimony in the middle, there was a meeting in May and then one in September. That's the first time I actually met Olivia Easley, who you heard about earlier, who lost her daughter at 8 weeks old to undiagnosed TAPVR and she is a beautiful person, a compelling advocate, so happy to know her. The part of her story that I think really was even more ammunition then any of the rest of us could bring is that she is a physician. It was kind of like, listen if you don't understand what asymptomatic means, it means even a doctor in her own baby had difficulty seeing the signs and symptoms and recognizing that this is a child that had a serious heart problem. So what does that mean for the rest of us? Whether you're a mom or just a regular newborn nursery nurse, yeah instinct sometimes work, yeah, sometimes a sign or symptom is there but so often it's not and we just needed this extra tool to help make sure these kids weren't falling through the cracks.

I took Eve with me at this meeting when we launched the Newborn Foundation, the Newborn Coalition in Washington, DC, brought her to testify at that hearing where they did recommend to Secretary Sebelius at the time, that all 4 million newborns in the United States should be screened for critical congenital heart defects using pulse oximetry. She slept through the whole thing. But it was still fun to have her.

Okay, move along to the next one.

There's the picture. I just had to include it just because it's such a beautiful photo of Olivia and her mom. You can go ahead.

Then there was an implementation workgroup that was put together very shortly after that recommendation was made and there may be some familiar faces in that group. They're all familiar to me at this point but Dr. Martin is also in that picture from Children's National Medical Center and Dr. Kochilas, my daughter's cardiologist and many of the people who have long since, continued to be actually, amazing advocates for implementation of this screening state by state.

You can move ahead, please.

There was a little bit of a delay, for those of you don't remember kind of how this played out, it got to be April of the next year and the Secretary still hadn't sort of adopted or formalized the recommendation from her committee so she convened a small interagency coordinating group to sort of address some of the gaps and questions that were yet remaining. Then from there it just took a few more months.

You can move on to the next slide.

In September of 2011 that's when the formal adoption sort of came along. This was just another statistic that I wanted to throw in as of the point that we were still advocating to make sure this became a federal recommendation. The number of cases that were leaving and what the mortality rate was associated with that. As things moved along that summer, even before Secretary Sebelius actually put her pen to paper, New Jersey went ahead and signed the first bill, actual legislative language into law. Indiana just slightly before that had actually added CCHD screening into their omnibus budget bill so it was a little bit different way of passing it. But that baby you see in that picture, her mother, Cora, this is Cora, her mother Kristine McCormick remains to this day probably one of the most powerful advocates on the national level for newborn heart screening and she lost her daughter at 5 days old to an undiagnosed heart defect. She's in Indiana and was really responsible for getting that state up and running very quickly. Then Maryland, as you heard about earlier.

You can move ahead.

Thalia Wood: Just to let you know, we have about 5 slides left and we're running really close to the end here, Annamarie.

Annamarie Saarinen: Yep, I'm trying to go fast. You can cut me off if you need to.

Thalia Wood: Okay, thank you.

Annamarie Saarinen: This is where we were at in 2012 in terms of the CCHD screening map and Newborn Foundation, sort of, has been tracking this all along and is updating our map accordingly.

If you move on to the next slide, Thalia.

As we mentioned earlier, one of the biggest things about getting this screening, kind of, embraced is that both the clinical community and the public health community has been watching it work and so this another baby Dylan in New Jersey. He was actually detected on the very first day that New Jersey started implementing screening. There he is with the Governor of New Jersey in that photo which has been widely publicized. Then that's the time stamp that I just mentioned about Secretary Sebelius. That was actually the 1000 day journey so in a little less than 3 years when we first started to when it was formally added to the Routine Uniform Screening Panel.

You can move ahead please.

Then this was today, and anyone might chime in here to do any updates, but Colorado was the big news of the last couple weeks. There's just a couple of other states that I suspect in just in short order will be adding it statutorily to their panels in their state. We'll only end up with 1 or 2 stragglers. This has been my experience with parents, in terms of meeting them and watching them make for change. They have been integral in every single state in this country in advocating for pulse oximetry screening. They've helped develop the programs that are in the hospitals today, including how to explain the screening, which I know we talked about earlier. We can all do better and get it into the hands of parents earlier. Get it into their lines earlier, not just at the point of care, and how to remain vigilant for signs and symptoms too. That's been a important part from the very beginning because this test doesn't catch them all and we need to be clear with families so they don't have a false sense of security and pediatricians don't have a false sense of security that just because a baby's screened they absolutely don't have a problem.

Go ahead please.

Thalia Wood: That's the final one.

Annamarie Saarinen: That's it! Yeah! I made it to the end.

Thalia Wood: Thank you so much. Thank you to all of the parent presenters. Like it said, one of the comments was, "Thanks for sharing. It's not always easy for a parent to share this kind of information." If there are any other questions you can just type them into the chat box at this time or just star 7 and unmute to your phone and ask a question.

Amy Gaviglio: Yes, this is Amy. Can you hear me?

Thalia Wood: Yes.

Amy Gaviglio: Hi. I have a question and I think it was for Gretchen. You mentioned that your son was transferred and you were unable to go with him on that transfer so you were kind of getting the updates on what was going on secondhand. This sounds terrifying and frustrating but also a scenario that will likely not be uncommon, I'm imagining, with pulse oximetry screening. What recommendations do you have, maybe, to make this easier? Would it be good for programs to look at having a hotline that parents can call to help decipher information or something else you might have in mind?

Gretchen Whitehurst: Hi, can you hear me?

Amy Gaviglio: Yep.

Gretchen Whitehurst: Okay. This is Gretchen. It was incredibly hard. The thing that I was most scared about was just going to the internet and Googling it and things like that. There's so much out there and you know you just want to look at the unique case. The biggest thing I wanted to do throughout the whole process was get information from the hospital staff. What might be easier, in my mind, because I was still groggy from all the pain medications, going through a C-section and things like that, that your mind isn't always able to really picture what they're talking about just by talking over a phone or something like that. What I think would be best is if they could somehow relay the message to someone in staff at the hospital that the mother is at and then they could go and bring in pictures or bring in information and then they could sit down with them, face-to-face and be able to discuss it with them. That would be easier than me trying to go through the medical terminology and figure out what's important, what that means, things like that. Then I could just sit down with them and say, "Okay. Stop here for a sec, show me what that is that you're talking about. Or describe to me how that surgery would work or things like that." Then to be able to go through somebody who already knows that terminology and then can kind of talk to me as a layperson and be like, this is what's happening. Just make it easier to digest that way. To me that would have been a lot easier than me talking to my husband, who was talking to a surgeon. It's kind of like the telephone game when you're a little kid. Things start changing throughout that whole process and that's, for me, the biggest reason why I needed to get there. So I could get it firsthand from that surgeon. I don't know how it works with confidentiality or things like that but even if, and I know doctor's time is very precious, but if they could even talk to them face-to-face via a computer or whatever, so that they could show them things. Somehow to be able to talk to just a medical staff person either at your hospital or the one dealing with the case at the other one through technology. I think that would have been easier or better.

Amy Gaviglio: Okay. That's really helpful. Thank you so much.

Gretchen Whitehurst: Absolutely.

Thalia Wood: Okay. Do we have any other questions? We do have one more comment. Again, it was somebody that just said, "Thank you for such wonderful presentations, to all of you." Of course I wanted to echo and if there are any last minute questions, if not we'll go ahead and wrap this up for this month.

Well if you do have any questions, this is Thalia at APHL. Please don't hesitate to email me and I'll get back to the presenters. Thank you again to all the presenters. This was absolutely great and for sharing your stories and your photographs. We really appreciate it.

Amy, anything that you want to end with?

Amy Gaviglio: No, I would just echo exactly what you said. I think this was stellar. I'm very excited to take some of the comments made. I'm actually giving a webinar next week and I was changing my slides based on things that were being said today. I hope that you're willing to be contacted because I'm hoping to contact you for other ideas to make this better. Thank you very much for taking the time.

Thalia Wood: Yes, thank you everyone and we'll be seeing everybody back in a couple of months for another webinar.

Amy Gaviglio: Thank you.