

REALTIME FILE

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>> URSULA PHOENIX WEIR, MPH: Hello, I'm Ursula Phoenix Weir, Deputy associate director for communication science with CDC's national center on birth defects and developmental disabilities. Happy valentine's day and welcome to our Facebook live, a heart to heart chat, living with a heart defect. Before we begin, I would like to set some ground rules for the next half hour. Participants should type their questions into the comment section. And if we can't answer your question live, we'll try to post a written response later. If participants have trouble posting questions, please feel free to e-mail us at NCBDDInquiry@CDC.gov and we'll respond by e-mail following the event. As a reminder, CDC cannot provide personal or individual medical advice. And lastly, the purpose of today is to foster dialogue and share information about congenital heart defects.

So today we have several guests with us to discuss congenital heart defects for congenital heart defects awareness week, which runs from February 7th through today the 14th. So I'm going to turn it over to our panel now and allow them to introduce themselves.

>> DR. MATT OSTER: Hi, I'm Dr. Matt Oster, a pediatric cardiologist at Sibley Heart Center at Children's Healthcare of Atlanta. I also work with the CDC on a variety of projects related to congenital heart defects.

>> KEN WOODHOUSE: My name is Ken Woodhouse, I'm a 37 year-old from Chicago, Illinois. I've undergone two open heart surgeries for my heart defects which are

collectively referred to as Tetralogy of Fallot.

>> MARISSA MENDOZA: My name is Marissa Mendoza, I am a 22 year-old from New Jersey and I underwent through three open heart surgeries for my six heart defects all before the age of two. I now work as a cardiac nurse.

>> Alright, so we are going to go ahead and get started with our conversation. We'll start with Dr. Oster who is going to tell us about heart defects in general, and then we'll hear from our panelists, Ken and Marissa who will share their stories on living with heart defects. At the end, we will open it up to your questions. So, Dr. Oster, starting with you, can you explain exactly what a congenital heart defect is?

>> DR. MATT OSTER: Certainly. So, congenital heart defects are problems present at birth with the formation and structure of the heart and how it works. As a result, the heart can't pump blood or oxygen to all the tissues sometimes. This could be, you know, problems with holes in the heart, or problems with the valves, or problems with how the vessels are formed in the heart. Or, any combination of that. And so, there are many options to treat these heart defects once people have them.

>> Alright, so, How many people are living with heart defects?

>> DR. MATT OSTER: Well, heart defects are the most common birth defect. We estimate about a million children living with heart defects and about 1.4 million adults in the United States. CDC is working with a variety of partners around the country right now to get a better estimate on the numbers of people living with heart defects and perhaps more importantly what are the issues addressing them as they grow older.

>> I see. How do you treat heart defects?

>> DR. MATT OSTER: Yeah, so, It's a spectrum. Right? Some heart defects are minor and might need just some medicine or possibly no treatment at all. Some are more severe and can require surgeries or interventions or multiple surgeries or interventions.

>> So, After an individual has surgery, are they cured?

>> DR. MATT OSTER: In most cases, no. While a surgery can help to get the blood flowing in the right direction or allow the heart to pump blood and oxygen to the rest of the body, over time there can be issues that arise. So it's important for people who, especially those who have had interventions for heart defects, to keep following up regularly with a cardiologist where they can look for problems with how the heart is functioning, with the heart rhythm, with any problems with the intervention that they had over time.

>> All right. So Dr. Oster what advice would you give people with heart defects so they can take control of their individual health?

>> DR. MATT OSTER: That's a great question. There are few things I like to tell people with heart defects. So, first and most importantly: Know your defect. Know what your condition is, know what surgeries and medications you've had. Know your story. Know everything about your heart defect. And if you're a parent, make sure your child as they grow older knows everything about that. Secondly, just like people who aren't born with a heart defect-- It's important to take care of your heart. Leading a healthy lifestyle. Which means appropriate diet of course, but also trying to do as much exercise as is recommended for your heart condition. So we suggest to people with heart defects: Talk with your doctor and find out what sort of exercises can they do. Do they have any limitations or can they do what other normal kids can do? And then finally, most importantly, also is stay in care. Or if you're out of care, come back to care. As I said, there can be problems long term. So even though a person is feeling great and doing well and that's our goal and we love that, we want to be monitoring them so that if problems arise we can treat them before they really start to affect a person's life.

>> I see. Well Dr. Oster thank you for sharing your knowledge on heart defects. We have Ken and Marissa here who are going to share their individual experiences on living with congenital heart defects. So Ken, I'm going to get started with you and our questions. Can you tell us about your heart defect and how it's affected your life up until now?

>> KEN: Absolutely. So, I was born in 1981 with a condition known as Tetralogy of Fallot which is four separate defects to the heart. I had my first open heart surgery at the age of 8 months old, which they called a complete repair. I went about my life and had annual checkups as a youngster. My parents were very insistent and very good about making sure I went to those check-ups. But with the exception of football, I had no restrictions. I was told to live an active life, be healthy. So, I always loved the outdoors, loved being active and was always a fan of cycling, and as I grew up became more active with cycling and did some long-distance rides. And then kind of forgot that I was a heart patient. Never really actively thought about it. After high school I went off to college and stopped going for annual checkups. I thought I was fixed, I thought I was cured. Never really gave it much thought after that. Fast forward about ten years in the fall of 2011, I was out on my bike for a ride one day after work, which is very common for me. But I didn't end up going home after that ride.

I fell off my bike, had a concussion, was taken by ambulance to the E.R., which I don't remember to this day. Fortunately because I ride with an emergency medical bracelet that mentions my heart defect, the doctors and first responders were able to schedule some followup tests that fortunately longer term revealed an aneurysm in my pulmonary artery, which is the artery that brings blood from the heart to the lungs. And it was suddenly very clear to me and I was reminded that I'm not fixed, that I'm not cured, and that I would require intervention in the not too distant future and life-long care. A couple years later, In January of 2014 I did have my second open heart surgery to repair that aneurysm and they also replaced my pulmonary valve which had been leaking since I was born. And, I've been very fortunate. Just over 100 days post-op, I ran a 5K, I

clocked my personal best time, and I've been fortunate to be able to stay active. I'm back to cycling, I'm back to running, and I'm excited to be here and share awareness.

>> Terrific. Well, thank you. What advice would you give other individuals that are living with a heart defect?

>> KEN: The best advice I can give is to not follow my example when I was younger. Don't fall out of care. And, like Dr. Oster said If you find yourself out of care, do everything you can to come back into care. And to parents with children who have congenital heart defects, talk to them about their defect, educate them, and talk to them and to their doctors about what the appropriate transition plan is as they get older and grow into adulthood.

>> Wonderful. Thank you. Marissa, similar questions. So, can you tell us about your heart defect and how it's affected your life up until now.

>> MARISSA: Of course. So, When I was born in 1996, my parents didn't know I had a heart condition. It wasn't until a few hours after my birth when I remained this dark, dusky bluish-reddish color that they realized something was wrong. So, I was quickly rushed to a nearby heart and lung specialty hospital where I eventually underwent three open-heart surgeries for my six complex congenital heart defects. Collectively, the surgeries were known as the Fontan Procedure. So, I'm a single ventricle Fontan. Single ventricle meaning: Most people have two ventricles in their heart. And those ventricles—one pumps blood to the body and one pumps blood to the lungs. So instead of that two chamber system, I only have one on the bottom. I grew up and did not let my heart defects define me. Despite my cardiology appointments, my echoes, EKGs, I wore halter monitors, I didn't let it stop me. And, while I was growing up, I enjoyed playing sports with a lot of my friends, mainly soccer. And, My grandfather, he actually played soccer in the Olympics and the World Cup. So, I intended to be like him. I wanted to go to college and play soccer. And then, After college I was just going to play soccer. That was my original plan. And then I realized I was getting short of breath and I couldn't keep up with all of my friends while I was playing. So because of that I underwent my first exercise stress test around the age of 11 where I was told I could no longer play strenuous sports such as soccer. So, That was really the very first time I felt like I had a heart condition. And it was as I learned growing up the first setback of many. It was partially a good thing because it let me learn how to get through that and move on with life despite these obstacles.

So following that restriction, I joined my school's show choir and chorus and also began taking piano lessons. Music is something I still love today. For college, I went to school to be a nurse. I just graduated in May. During school, though, I had the amazing opportunity to work at the same heart and lung specialty hospital where I underwent my three open heart surgeries. What is even more special is my nurse manager was actually one of my nurses during my multiple hospitalizations when I was an infant. And that experience in itself is something that I can't even put into words. It was so amazing

for me to be able to work with her. Right now I am working at a different hospital as a cardiac nurse, but in the future I hope to get back into the congenital heart defect side of things.

>> Wonderful. Thank you, Well Congratulations on your graduation.

>> MARISSA: Thank you.

>> You're welcome. What other advice would you give other individuals that are living with a heart defect?

>> MARISSA: So, what I would always say is Don't let your congenital heart defect define you. I never did. Of course you need to go to your doctor's appointment and continue with follow-up care, and listen to what your cardiologist recommends for you. But don't let your congenital heart defect be all that you are. That's not who you are as an individual. So, I tell that to everyone. Just be you and then you can have the heart defect on the side really. As I mentioned earlier, I fell into Broadway shows and chorus and show choir after I was restricted from sports. And, my favorite Broadway show, Dear Evan Hanson has a quote that I live by every day. And it's "All you got to do is just believe you can be who you want to be." And Every morning I wake up and follow that quote until the second that I go to bed and I start over fresh the next morning. If I had let my heart condition define me, I wouldn't be anywhere close to where I am today, including right here talking to everyone about congenital heart defects.

>> Thank you for sharing your stories. Your stories highlight the importance of staying in care to keep your heart healthy. So, we'll now take some questions from the audience. Again, if we can't answer your question live, we'll try to post a written response later. All right. So we have been receiving questions during our conversation through the Facebook Live feed. And I'm going to go to the feed right now and see what has come in during our conversation. Okay. The first question is for Dr. Oster. Let's see. I would like to get a, let's see here. Should adults with heart defects be evaluated later in life even if they have no symptoms and feel healthy? Dr. Oster.

>> DR. MATT OSTER: Yes, so, as I mentioned before it's great that we're seeing many children now grow up to be adults to live great lives, especially with more severe heart defects. That didn't happen many years ago. We want to keep that going. We want to encourage them to have a very long, productive life, but problems can arise. Problems can arise when you least expect it. Whether it's falling off a bike. Whether it's, you know, many women come back into care when they all of a sudden get pregnant and start having problems. Yes, we do want to see people coming back to care. I had a family last week where a kid came in for an evaluation for a heart murmur and he was fine, but the mom had a scar on her chest. And, she thought she was fixed. But, she had had two surgeries as a kid. Fortunately, we were able to get her back into care. We want people to—especially if you've had an intervention as a child, if you were born with a heart problem, Make sure you have seen a cardiologist recently.

>> Okay. Next question for Ken and Marissa, alright, what do you do when someone asks about your scar. Ken, we'll start with you.

>> KEN: Sure. So, That has changed quite a bit since I was younger. When I was younger I was very self-conscious about my scar. I never wanted to take my shirt off at a pool. I also have heard plenty of stories where I was afraid of band-aids in general. So, I wanted to hide it. I didn't want to think about it. But in the last few years since I fell back into care, I have become an advocate. And, uh, I'm very open about it and If someone asks me about it, I will tell them as much or as little as they want. And, Usually it's more than they want to know, but I use it as a chance to share information, because as Dr. Oster was saying there are a lot of folks who fall out of care and think that they are fixed. I was one of them. I try to use that as a teaching moment.

>> Okay. Marissa?

>> MARISSA: My answer is very similar to that, to be honest. When I was younger, I was embarrassed and self-conscious about my scar. So for gym class, I didn't like getting changed in front of all of my classmates. For pool parties, I would try not to swim in the pool, even though I used to love swimming. And, then one day it kind of clicked for me, I guess. It wasn't a sign of weakness, but instead a sign of strength and empowerment. And now I will go on and on for as long as anyone is willing to listen about my scar just because that's how you raise awareness and you tell your story to other people that want to learn.

>> All right. Thank you. Okay. So it looks like our next question is for Dr. Oster again. And this individual is asking what mental health challenges are often encountered by people with heart defects?

>> DR. MATT OSTER: Yes. So, We think of congenital heart defects as just affecting the heart.

But part of the reason why we think of this as a life-long condition and want to make sure people are getting back into care is over time we have realized that a defect that might affect structurally just the heart have implications on the rest of the body: other organs, including the brain. And, with that we can see—you know, starting in childhood problems either with, behavioral problems, developmental problems, problems in school that can also manifest as children get older into adolescence and adulthood into mental health issues or PTSD or other things. Uh, and, you know, It's a spectrum. Different people are affected different ways. But we think it's important to recognize that people with heart defects are at a higher risk of having mental health problems so that we can identify those, address them, and again with the whole goal of allowing them to manage any mental health issues they have so they can have as normal and as healthy a life as they can.

Do any of you have any experiences that you want to share?

>> MARISSA: So I know, for me, throughout school I've done research and I've seen that there are studies published on children and adults with congenital heart defects having higher instances of anxiety, depression, and PTSD. So, for me what comes into play is if I'm in a stressful situation, I'll start getting chest pain and maybe some shortness of breath. I will feel like my heart is racing fast or I might feel a little dizzy or light headed. And in my mind I'm wondering is this all just because I'm a little stressed right now or is something wrong with my heart? So that just makes it ten times worse. So for people like us, I feel like that can lead to emergency room visits and just the unknown, the fear of the unknown with that. And for me I have ended up in the emergency room for different situations like that. So, it's really important to understand that illnesses such as those are really common in people like us with congenital heart defects.

>> All right. Thank you.

>> KEN: I think there is one more thing I would add to that if I could. One of the challenges for a lot of folks with congenital heart defects is you can go through very long periods of feeling perfectly normal and healthy. So, when I got back into care and was getting ready for my second open heart surgery, I felt completely asymptomatic. I didn't feel short of breath, I didn't feel ill. So, It becomes a mental minefield for "Why me?" Why do I have to go through this? I feel okay, I was just out biking or I was just out running, why do I have to go on for this major surgery? So it's this thought of, you know, this isn't real and then it's kind of dealing with the mental aspect of accepting and owning the fact that it is real and it is something that you need to take care of.

>> Great. Thank you. Okay. Ken and Marissa again, this question is from let's see, the National Birth Defects Prevention Network. And they're asking do either of you experience any mental health issues as a result of living with a heart defect? Ken?

>> KEN: That's a really good question, but I don't think that I do other than what I just spoke about, feeling apprehensive to accept ownership of not being fixed, and knowing that even at the moment I feel perfectly fine and the last checkup I had, the prognosis was fantastic. But that can change any moment. And like Dr. Oster said earlier, sometimes there are things bubbling under the surface. It's important to just keep it monitored because unfortunately the reality is that could change at any moment.

>> MARISSA: And for me in a way I'm very lucky that my surgeries were performed before I turned two years old, so I don't remember any of that. And in the past few years I've had minor things such as a cardiac catheterization or just little things like that. So fortunately I don't feel I deal with the PTSD aspects of living with congenital heart defects. What comes into play for me like I mentioned previously is knowing that I have a heart condition and then feeling symptoms of chest pain or shortness of breath. I'm wondering is something wrong with my heart? Should I go to my cardiologist? Or is this normal? Do normal people experience this too? Not that we're not normal, but do

people without the congenital heart defect experience it, too?

>> Alright, thank you. Okay, now this next question is for Dr. Oster again. And this viewer is from Spain. And they're asking any prevalence data of neurological complications due to congenital heart defects?

>> DR. MATT OSTER: Yes, there actually is a lot of data about that. In fact, you know, in children, it's recommended especially those who have more severe defects, who require surgery during infancy, that they get monitored for that. So, actually, in our center, certain kids even before a year of age will undergo some pretty intensive neurodevelopmental testing to make sure they're on the right track. And kids when they're older and going into school age you know, will do other testing, as well to make sure they're getting any services they need, do they need special education services or even have minor learning disabilities that aren't recognized. And again, this is a lifespan approach. This goes across into the lifespan. Everyone is different. It's important to be aware of that. But there are some data that as, you know, adults with heart defects age that they can have some of the neurological issues that affect the elderly, but at an earlier time. So, an earlier onset. So, it's important just to be aware of these. And if someone has a heart defect has concerns, just to get checked out.

>> Okay, great. All right. So this next question is for Ken, Marissa, and Dr. Oster. And it's from Samantha Erin. And she would like to know what do you want people to know about adults living with CHD?

>> MARISSA: So that's for me the big thing that I try to tell everyone is that it's not just our heart. We were born with these heart conditions, these congenital heart defects, but it doesn't only impact our hearts. We can have different issues in our liver, as we mentioned mental health problems, neurocognitive issues. The list is endless. And I always try to share that with everyone, just because if somebody is having trouble walking up a flight of stairs, they might not understand why. Sure, their lungs might not be able to work at the same capacity as someone else. Or for me personally, my heart condition can lead to liver issues. So I try to steer clear of alcohol and people my age they don't really understand that. So that's what I try to explain to everyone. It's not just my heart. It's my whole entire person that is impacted by these congenital heart defects.

>> KEN: Yeah. One thing I would add to that is there is no universal answer. There are so many different defects and every single patient is different, even within an individual defect. So there's been times when I've met other patients with Tetralogy of Fallot and they hear my story and want to know why they don't have the same outcome. They say I get winded walking up a flight of stairs, why? And it goes back to what we were talking about earlier just the need for personalized care. Because no two stories are the same. So, just because I'm incredibly fortunate to have my story, unfortunately that's not true for everyone. Other people have far more success with their stories than I've had. It's all individual. So, Just because you have a similar diagnosis or you have a

CHD or multiple CHDs, there's not a one size fits all answer. So it's important to get that specialized care, absolutely.

>> DR. MATT OSTER: I would say, I like how she used the term adults living with CHD. It's great that in this day and age we're talking about so many adults. And we are focusing on the adult as a whole, and CHD is one component of it as Marissa was talking about. We want adults living with CHD to get into care, stay in care, whatever works for you. My patients who have...could need annual visits, I try to anchor it to their birthday. So every year they have a birthday, they remember that's the day I'm coming. Some of them like to come around their heart-aversary, which is the term they use when they had their surgery. Whatever works for you, stay in care. And, they might say "But, I feel fine." Trust me, nothing makes me happier than having someone come in who I've taken care of for a while and I do nothing. I just say, "You're great, go have another wonderful year, I'll see you in a year." Because our goal here is to allow you to live as normal a life as possible. And there are many people thriving with CHD out there that you may not realize. There are people who are winning gold medals in the Olympics or people playing on national soccer teams or there are people-- you know, who are doctors and living normal lives who you wouldn't know until they took their shirt off and you see their scar. So, you know Thriving and living with CHD I think is a great thing that we're seeing these days.

>> Our questions are continuing to come in. And the next one appears to be for Dr. Oster again. It's from Theresa Bohannon and she would like to know: "Can you discuss how epidemiology can help move the field, especially when so many kids have various defects that make a large-scale study difficult? And she adds P.S., I love seeing single ventricle patients like Marissa. It gives her hope for her son.

>> DR. MATT OSTER: Excellent. That's an interesting question. It's important for us, for epidemiology, what does exactly that mean, It can mean different things for different people. For us, it really just means studying the health of a population. And now, as I mentioned, there are over 2.4 million people in the United States living with congenital heart defects. And we need to learn, especially as people are getting into adulthood more and more what are the issues that are affecting them. You know, we do -- I work with CDC on a variety of projects. We're trying to do a large survey to understand more about this and we're trying to capture as many people as possible because everyone is different. Everyone is going to have different issues. We want to use tools like this and studying the services people use so that our society can be better prepared to meet the needs of this population as they continue to grow.

>> Okay, great.

Thank you. Okay. So it looks like we have time for one more question. And let's see what we have. And this is for everyone. How can parents of a child with a heart defect help them stay as healthy as possible? Start with you Marissa.

>> MARISSA: So I think it's really important for parents to help their children learn about

their heart defect. Help them understand what they have, what this means for their future. And like Dr. Oster mentioned earlier, it's important for us along with everyone to just eat healthy, stay healthy, be active if you can, as long as you don't have those restrictions. So, from the parents, it's just important that they share with their child what they'll need to know while they're growing up, which is their diagnosis, their medications, and how they can take care of themselves as a whole.

>> KEN: And I think to add to that, once that base layer is established, allow the kid to be a kid. Once you know what is allowed, what is not allowed in terms of physical activity, let them do it. Let them be a kid. I've met a lot of folks who as adults feel like they were kept in this protective bubble out of genuine care from their parents, but unnecessarily. Now we're at a place where there is so much medical information out there and there is much knowledge, get that from your doctors, get that from your cardiologists and celebrate it. Focus on what you can do. You're a fantastic example. You had a restriction from competitive sports so you thrived in music. I think that's great and I would encourage all parents to focus on the positive as much as they can for their kids and for themselves.

>> DR. MATT OSTER: Wow, I'm not sure I have much to add. With Ken and Marissa-- Those were great answers. But yes, empowerment and encouragement I think are two big words and two big areas that parents can use with their children. First, empowering them to take control and recognize that you were born with this heart defect, but it doesn't define you. It's part of who you are, it's part of your whole person. But then encouragement: encourage them to get out into the world to work with their doctor to figure out what sort of activities are okay for them. We were talking earlier I had some families where the kid had a single ventricle and wanted to go on a roller coaster. Can they do that? They've got all these signs. Yeah, live your life. You can do that, you're healthy. You're doing great. So, everyone's different. Talk to your doctor and figure out what is right for you. But empowerment and encouragement I think, are two very important take-home messages for parents.

>> Wonderful. Thank you. Well, we're about out of time. I would like to thank Dr. Oster, Ken, and Marissa for joining us. Thank you to all of you who tuned in. We would also like to thank the Adult Congenital Heart Association for their support of this event. In closing, we want to highlight that ongoing cardiac care can help children and adults with a heart defect live as healthy as possible. For more information on heart defects, visit CDC.gov/heartdefects. Thank you for joining us.