

Loving Life...



Romer began playing T-ball at age 5. "[Softball] was a perfect sport because I could stop at the bases and stand in the field, yet it was active enough to be fun."

...With 5 Congenital Heart Defects

30-year-old Stephanie Romer talked one-on-one with *Heartbeat* contributor Jamie Friedlander about working with her cardiologist and taking care of her physical and emotional health.



"In 1988 my parents were faced with three options: waiting for a heart transplant, letting me die or having me undergo a brand new surgery with no proof that it would work. My incredibly brave parents chose the new surgery: the Fontan."

Editor's note: This interview has been minimally edited for brevity.

Jamie Friedlander: What type of congenital heart defect do you have?

Stephanie Romer: I have five of them.

Hypoplastic left heart syndrome, transposition of the great vessels, atrial septal defect, ventricular septal defect and severe mitral stenosis. I had four surgeries before I was 3 years old, including the now-famous Fontan procedure.

JF: How did you find ways to play on your strengths as a child?

SR: My mother was amazing at maintaining a busy and active schedule for us. She made sure we were always staying active. Due to my heart condition, I couldn't play every sport, but I still exercised the strengths I had, which were running fast and racing my friends, playing softball, singing in the church and school choir, dancing, cheer-leading, and while at home, I created my own exercise routine I made myself do every single night. I was very strict with myself and always have been.

As I grew into an early adolescent and teenager, I thrived on building and pushing myself physically. I was constantly hearing I couldn't do this and shouldn't do that, so I made it a personal mission to do everything I was told I couldn't do. I have accomplished it all, within reason. Be careful what you tell your child they "can't" and "shouldn't" do because I have found that kids either want to prove people wrong, or they internalize these feelings and become depressed. I struggled with both.

JF: What can parents do to help empower their children to become healthy, emotionally strong adults?

SR: I think emotional strength depends on physical strength. My greatest weakness is my [inability] to have the physical stamina that everyone else has. I had a hard time simply keeping up with the busy life of a growing child. It's also hard to physically keep up sometimes as an adult.

I think parents can build self-esteem in their child with a CHD by giving him or her a small physical challenge that they can achieve. Much of our lives are wrapped around who we are physically, and, CHD or not, a person's physical health is at the root of how good or bad you feel emotionally and mentally.

If I could offer advice to parents of a child with CHD, I would say to allow your child to show you their limits. Your child will show you, not necessarily tell you, when they are tired. If your child says they can do more, try to let them. If they do too much and get sick, they will learn not to do it next time.

You don't want to hinder them from discovering what could be their biggest accomplishment — something that they may remember for the rest of their lives. This happened to me when I was 8 years old. I didn't care what anyone said, I was going to compete in the jump-roping contest like every other kid in the first and second grades, even though my doctor and my mom said no. I not only jump roped, I won the Jump-A-Thon contest in a gymnasium full of 50 heart-healthy kids.

You want your child to say, "I can because I tried, and look what I can do now." It's not about winning or being the best; it's about being able to say that in the end, I tried. They will carry that feeling into every single thing they do, and they will hold on to those accomplishments for the rest of their lives.

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— Stephanie Romer

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Gear Up for CHD Awareness Week 2016

Mended Little Hearts has two big virtual fundraisers on the horizon, just in time for February, aka Hearth Month: the self-directed “Roar ‘N Run” race, and the “Rock Your Scar” Instagram contest. Both campaigns take place during CHD Awareness Week, Feb. 7-14.

Siobhan Pawelczyk, of MLH of Western New York, co-chair of Roar ‘N Run 2016, wants to see an enormous national turnout for the Roar ‘N Run event this year, with MLH chapters and children’s schools getting involved.

“Anyone of any physical ability, from the smallest child to the oldest adult can do this,” says Pawelczyk. Pre-registration is not required. Participants have the week to complete any distance, at their own pace. “We’re looking for the success of ALS,” says Pawelczyk, referring to the “ice bucket challenge” that went viral in 2014.

Rock Your Scar, the photo contest where kids get creative in showing off their (literal and metaphorical) CHD scars, runs throughout January, and judging occurs at the beginning of CHD week. “It’s a great way to show people that our kids are leading full lives and that they’re not just a statistic,” says Julie Rowbotham, lead coordinator, MLH of Philadelphia. For more information, go to mendedlittlehearts.org/news.shtml.

— Maria Carter



Online contests, such as the Rock Your Scar Instagram campaign, increase awareness about CHD. Tyler Hanson, above, participated in last year’s contest.

JF: How important is your relationship with your pediatric cardiologist?

SR: You must keep consistent appointments with your cardiologist to stay on top of your health. Growing up, my cardiologist was my best friend, and I think it’s important to make sure kids who are growing up with a CHD have one consistent cardiologist that they truly love to see. I absolutely loved going to see my cardiologist because I knew he wouldn’t hurt me and just wanted to check on me, order tests, adjust medications and talk about my life and what I was doing.

The cardiologist has a big influence on a child’s self-esteem and overall physical and mental health. This is approximately a 22-year relationship, so it is absolutely critical to build a strong, positive relationship with him or her.

JF: What makes you want to stay involved with CHD community?

SR: I just started meeting so many people [with CHD]. Then Facebook came out and I became friends with hundreds of CHDers. Sometimes I wouldn’t leave my room for days so that I could personally get to know each of these adult patients. I was trying to figure out how much we’re alike and how much we’re different.

I like staying involved in the community because I don’t feel that enough people are speaking out about serious topics. There just are not enough people speaking about it, so I’ve always been that person since I was a little girl.

JF: What are some things that make you optimistic about the CHD landscape today?

SR: The medical advancements are absolutely mind-blowing. Every single one of us is so different physically that I cannot even imagine how hard it is for these doctors to figure out what is wrong with us. The 3-D heart printing is awesome because they can print out [a model of] our individual heart and then figure out how to do surgery. 🎸