



Blessings in Disguise: My Life Journey with Congenital Heart Disease

22-YEAR-OLD CREDITS KANSAS CITY PHYSICIANS WITH HELPING HER MANAGE THE CONDITION AND LEAD A NORMAL LIFE, INCLUDING PURSUING A CAREER IN JOURNALISM AND COMMUNICATIONS

By Madeline Mapes

When my parents went to Saint Luke's Hospital in Kansas City, Mo., January 21, 1999, they were expecting a life-changing event; the birth of their first and only child. What they didn't expect was their little girl would be born with congenital heart disease.

My life with congenital heart disease has been one full of fear and love. Fear of potential surgeries if needed, and not knowing if I would suddenly have issues with my heart, but always loved and supported by family, friends and the wonderful doctors at Children's Mercy Hospital who have taken care of me for 22 going on 23 years.

About an hour after my birth, I was taken for a bath, as all babies go through after birth. My parents waited for over an hour and still hadn't seen their baby girl. They asked the nurses where I was and didn't get an immediate answer. Not too long later, a doctor came in and informed my parents there was something wrong with me, but they hadn't figured out what.

I was a blue baby and was clearly not oxygenating properly. A while later the doctor came back and said I was in critical condition and had been taken to the NICU. The doctors said the issue was either with my heart or my lungs. My mom described it as, "Our whole world fell apart."

Doctors from Children's Mercy came to Saint Luke's and discovered the source of my smurf-like look was due to my heart. I was officially diagnosed with congenital



Madeline during a 2015 trip to Washington, D.C., as a youth ambassador lobbying Congress for support of Tourette Syndrome research and education.

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heart disease and scheduled for emergency surgery. At 11 days old, Gary Lofland, MD, performed an arterial switch on me. This procedure had been around for roughly 30 years and had been proven more effective than other methods of arterial correction at the time. Dr. Lofland also closed a gap between two of my chambers, which was one of the reasons why I was fine for a few hours after my birth. This was the first blessing in disguise: **I got the opportunity to live my life because of the trained professionals at both Saint Luke's Hospital and Children's Mercy Hospital.**

My parents didn't get to take me home until about a month after my birth. It wasn't until after I had turned 22 years old did my mom reveal to me that when my parents first took me home, they would constantly check on me throughout the night, worried that they would get up the next morning and their little girl would no longer be with them. The rest of my life has been filled with annual cardiology visits, physical limitations and the occasional fear that something bad could happen, and I would need surgery or worse.

GROWING UP

I would say I am one of the lucky ones. I have had, knock on wood, very few issues with my heart. I had one balloon procedure when I was 9 years old aside from my initial surgery. I have fantastic doctors and nurses who have reassured me and my parents since day one, and have patiently sat



(Above left) Madeline with her mother participating in a walk for Tourette Syndrome. (Above right) Madeline, left, back to camera, while a student at Excelsior Springs High School, presents her school project on the need for greater community support of Tourette Syndrome.

through all my questions. I was, and still am, the kid who did research and asked questions that most kids my age wouldn't think to ask about their own health.

Stephen Kaine, MD, at Children's Mercy Hospital, has been my cardiologist since I was probably around 10 years old. Before him was Edward Hulse, MD. Both always took the time to listen to my parents and my concerns or questions. They explained things in layman's terms so we understood what they were talking about (although, after 22 years of visiting with a cardiologist, I think I am fluent in cardiology).

That is probably the best thing Dr. Hulse and Dr. Kaine could have done for my family and me; taking the time to answer all of our questions, addressing our concerns and not making us feel like they were rushing to get to the next patient. I have never once felt like my doctors and nurses at Children's Mercy Hospital didn't have time for me, even as I got older and closer to aging out of the hospital.

For about nine years, I was a semi-healthy kid who got to play sports and play with her friends. Granted, I wasn't very

good at keeping up with the other kids athletically due to the repercussions of my surgery, including a heart murmur and low stamina, but I am an oddly optimistic person despite what I went through as a baby, and later being diagnosed with Tourette Syndrome at the age of 10. There is the second blessing in disguise: **I see the bright side in everything, even in life-changing health diagnoses. Maybe it is those doctors constantly reassuring us. They must have rubbed off on me.**

Around the time I was about to turn 9, I was struggling more than usual to keep up when playing sports and found it harder to recover from physically strenuous activities. Concerned, my parents reached out to my cardiologist, who recommended my parents bring me in as soon as they could.

After a few standard tests, including an EKG, an echocardiogram and a stress test, Dr. Hulse found scar tissue had built up in one of my arteries, forcing the left side of my heart to work harder than the right. He scheduled me for a balloon to remove the scar tissue as soon as we could get in. The

third blessing: **My doctors, yet again, gave me the opportunity to live my life without further complication.**

ADVOCACY WORK

I continued with my annual cardiology check-ups. And I had recently started a new medication for my Tourette Syndrome, which had grown significantly worse (I normally don't take medication for it unless I have no other option to alleviate my symptoms).

During this time, I also became involved in advocacy work for people with Tourette. In 2015, as a youth ambassador from Missouri, I was among a group that spent a day meeting with members of Congress to gain support for increased education and research for Tourette. I have also done presentations to high school and college classes.

While in Washington D.C. I met a young man, a year younger than me, who also had the same form of congenital heart disease as myself and Tourette Syndrome. What were the odds? Our families have been through eerily similar experiences.

He is from the Chicago area, and we still stay in touch through social media.

A frightening incident occurred during my senior year of high school. I had come down with a nasty case of the flu at the time. I was approaching the 24-hour mark of breaking my fever from the flu so I could go back to school the next day. I was having dinner with my family, when I was suddenly hit with a terrible stomach ache. I left the table and passed out. My dad found me convulsing on the floor for about 10 seconds. I had not been prone to seizures. We feared a cardiac-related cause.

After a short time at our community hospital in Excelsior Springs, I was transported to Children's Mercy Hospital. The next day, after monitoring my heart and a few tests, Dr. Kaine came in and delivered the news that my episode had nothing to do with my heart. It was a fast response considering how busy Children's Mercy is. That was the fourth blessing in disguise: **A speedy response helped relieve our stress by ruling out atrial fibrillation and any**

other potential issue with my heart. It was one less thing for us to worry about.

While I stayed at the hospital for four days, the doctors were never able to determine why I passed out and had the seizure. But the Ward Family Heart Center's cardiology team alleviated the stress of worrying about the health of my heart. Since then, I have only had to go to my annual check-ups.

GRADUATING COLLEGE

This spring, I was at the point where I was graduating college and aging out of Children's Mercy Hospital. At my cardiology appointment, my cardiologist found some narrowing in my aorta artery, which makes physical activity more difficult with my already stunted arteries. Concerned about the narrowing, Dr. Kaine said he would like to keep me at Children's Mercy for another year because of the narrowing, and because of COVID-19, many cardiologists in the area were not seeing patients in person unless an emergency. Where

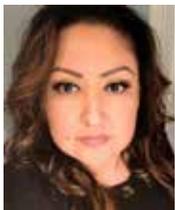
are we? The fifth blessing? They just keep coming: **Dr. Kaine could have easily said, "You are out of school and have aged out of our system. You need to find an adult cardiologist." Instead, he kept me because he knew it would be in my best interest, considering my circumstances.**

I have had few struggles with my heart condition. I can firmly say that if I had different experiences with my doctors, I would not be where I am today. It is these little blessings, and the ones not noted above, that have made my life as a congenital heart disease patient easier, and for that I am thankful. 🙏

Madeline Mapes is a May 2021 graduate of Northwest Missouri State University with a degree in multimedia journalism and was assistant editor of the school newspaper. She is now employed as communications manager with Alpha Gamma Rho Fraternity in Kansas City, Mo.

Madeline contributed her writing skills with the profile of KCMS 2021 honoree Andrew Schlachter, MD, in this issue of Kansas City Medicine.

Joins KCMS Foundation Staff



Rocío Melchor has joined the KCMS Foundation as program manager. Overseeing the Wy Jo Care and Metro Care programs,

Rocío brings 14 years' experience helping underserved populations as a referral coordinator, practice administrative manager, and supervisor at three safety-net clinics and federally qualified health centers. 🙏

Graduate School at Stowers Institute Granted Accreditation

The Graduate School of the Stowers Institute for Medical Research has received institutional accreditation from the Higher Learning Commission, an accrediting agency recognized by the U.S. Department of Education and the Council for Higher Education Accreditation.

"Receiving this accreditation is an important milestone for our school," said Betty M. Drees, MD, president of the Graduate School. "Our graduate program provides a distinct experience to

predoctoral researchers who are interested in pursuing a Ph.D. in biology."

Housed on the campus of the Stowers Institute for Medical Research, the Graduate School currently has 40 predoctoral researchers enrolled and 23 Ph.D. graduates. 🙏