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### A Cause for Life

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# A Cause for **Life**



Kelly Wittich '00 knew nothing about congenital heart defects until her daughter was born with one. She now wants to raise awareness regarding this most common and deadly of all birth defects.

## **Story by Kelly (Piepenbrink) Wittich '00**

My pregnancy with our first child was uneventful, a fact acknowledged by my OB during a check in my 38th week when he joked that my entire prenatal history could fit on a half-sheet of paper. I breathed a sigh of relief.

Knowing friends and family members who had suffered miscarriages and pregnancy loss, I was so thankful to be full term. A few days later, our beautiful daughter, Allison, was born — perfect and seemingly healthy. She had a heart murmur, but we were told that many babies have murmurs that just disappear in time. Another sigh of relief. We went home a day and a half later in a haze of bliss, exhaustion and absolute adoration for our baby girl.

When Allison was four days old, our pediatrician checked her out. Since the murmur was prominent, she said she'd feel better if we got a quick echocardiogram. She scheduled a cardiology appointment for the very next day, just to be safe; hopefully it was nothing. At the time, I still believed that could be true.

That hope vanished at the cardiologist's office. That's where my husband, Chris, and I learned that Allison was born with a congenital heart defect (CHD), a malformation of the heart or the large blood vessels near the heart that occurs soon after conception. In Allison's case, a stiff valve on the right side of her heart had caused her heart muscle to thicken and the pressures in her heart to dangerously increase. We were sent immediately to the children's hospital and admitted to a cardiac ICU for monitoring. Allison was stable, but her defect was critical. If not treated, her heart could suddenly become overworked and stop beating, and she would die.

Though I had extensive prenatal care and hold two advanced degrees in health-related fields, I knew nothing about CHD before our child's diagnosis. Why did I not know about the most common and deadly birth defect in the U.S. that impacts almost one percent of children until we were in that one percent?



Told her daughter had “a high risk for mortality,” Kelly Wittich rarely left the hospital as doctors struggled to save her baby's life. Through the Children's Heart Foundation, Wittich helps raise awareness about CHD.

Likewise, most among our extended family and friends only learned about CHD because of Allison. Perhaps this unawareness is because CHDs, for the most part, are invisible. Other than the “zipper scar” on her tiny chest, you would never guess what Allison has been through. Unfortunately, this lack of public awareness means that research to prevent and treat congenital heart defects is grossly underfunded compared with how many it impacts. Among the many facts I have learned since Allison’s diagnosis:

- Nearly one in 100 children is born with CHD. Each year approximately 40,000 babies are born in the United States with a congenital heart defect, making CHD the most common birth defect.
- CHDs are also the most common cause of infant death due to birth defects.
- 25 percent of children born with CHD will require an invasive intervention such as open-heart surgery or a cardiac catheterization to survive (for Allison, these were both in her first month of life).
- People with CHD face lifelong health problems, such as difficulty with growth and eating, developmental delays and sudden cardiac arrest or stroke. According to the Congenital Heart Public Health Consortium, approximately two to three million individuals in the U.S. are thought to be living with CHD. (Because there is no U.S. system to track CHD beyond early childhood, more precise estimates are not available.)

The condition may be even more widespread than is currently known. Each year, an estimated 100 to 200 newborn deaths are caused by unrecognized heart disease. While examining Allison’s heart, a cardiology fellow told us that they believed that some sudden infant death syndrome cases were undiagnosed CHD.



Kate Szcudlo '00 shares an ice cream cone with daughter Mira, who endured three open-heart surgeries to correct a CHD. Kate says she would trade places with her child “in a healthy heartbeat.”

At eight days old, our tiny, less than 8-pound baby girl had a catheter placed in a vein in her leg and traced up to her heart to open up one of her valves. Waiting for that procedure to be completed was traumatic and terrifying. But it was nothing compared with the anxiety we faced when she developed an infection and complications less than a week later. Infected clots on the tissue-paper-thin valves in Allison’s tiny newborn heart led her to an emergency resuscitation and open-heart surgery at 19 days old.

Our next seven weeks were filled with ventilators, an external heart/lung machine (ECMO), dialysis, heavy antibiotics, central lines, blood thinners, bleeds, clots and feeding tubes. It was weeks before we could even hold her — and then, it was a production of carefully arranging her lines to avoid disrupting one of the life-sustaining pieces of equipment. They said she was at “high risk for mortality.” It was a long time before we even allowed ourselves to believe we would ever get to take her home again. I hardly ever went home during that hospital stay, but when I did, I could barely look at her room, clothes, toys and crib — not knowing if she would ever get to use them again. I’ve since read studies that discuss post-traumatic stress disorder in children and families with CHD, likening the lack of control and extreme stress to individuals living in a war zone. I still can see those moments in painful detail like they were yesterday.

As horrible as it was, it could have been worse. A dear friend lost her 23-day-old baby girl to CHD. She died while my friend was desperately performing CPR on a fresh chest incision — all the while praying that she

wasn't hurting her little girl, but trying so hard to keep her alive. Another friend, whose son developed complications after the same two surgeries as my daughter, spent the better part of a year in the hospital, watching her son on life support as they waited for a heart transplant. He lost one lower arm and a few fingers on the other hand to blood clots and experienced a host of other problems. These are just a few of the grim realities of CHD, and why more research is needed to prevent complications and save kids' lives.

### Tomorrow's miracles

Months later, when things were relatively stable — and by stable, I mean waiting for Allison's next open-heart surgery at 5 months old, giving her daily medications and injections, and feeding her through a tube in her nose — I came across the [Children's Heart Foundation](#) (CHF). CHF was founded in Illinois in 1996 by another "heart mom," Betsy Peterson, who lost her son Sam to a CHD.

Since its inception 20 years ago, the CHF has been dedicated to funding the most promising research to advance the diagnosis, prevention and treatment of CHD. Connecting with others who are also desperate for answers that may improve the long-term outcome and life expectancy of our kids, I found the CHF was the perfect place to channel my desire to *do something* to help. I joined the board of the foundation's Illinois Chapter, started a team for the Chicago Congenital Heart Walk and started raising funds and raising awareness among anyone who would listen.

Last year, on a committee for the Children's Heart Foundation's Red Tie Ball, I ran into Shweta (Taswala) Stuart '00. I remembered Shweta from classes we took together at IWU's Center for Natural Sciences. I discovered that she, too, is a heart mom: Shweta's son, Noah, had a problem with development of one of the valves on the right side of his heart. Consequently, that side of his heart had not grown properly and was unable to pump blood to the lungs to get oxygen.

A pediatrician, Shweta remembers being nervous about starting a family, always fearing the worst. Still, nothing could have prepared her for her 20-week ultrasound, when she was told, "There is something wrong with your baby's heart." She learned that Noah would need at least three open-heart surgeries. Even if everything went as planned, she was told his heart would never function like a healthy heart.

She and her husband, Michael, had so many questions and so few answers. Prior to Noah's birth, they met with a cardiovascular surgeon, who underscored the importance of ongoing research in helping improve practice and outcomes. Shweta vividly recalls his words. "He looked at us simply and said, 'We don't know what the future holds.'" The good news, he told her and Michael, was that patients like Noah are surviving longer than they have in the past, even into adulthood. "We are constantly learning," the cardiologist continued. "We are constantly improving and refining our practices to generate better outcomes."

Shweta had a glimmer of hope that their family could have a fairly normal life. They survived some very dark moments and significant complications during Noah's recovery, but he is now a vibrant, active and happy 7-year-old who is finishing up first grade. He loves his family (including his little brother), enjoys rooting for Chicago sports teams and is playing baseball this spring.



Kelly and her former biology classmate Shweta Stuart '00 reunite at a CHF fundraiser.

Shweta and Michael began volunteering for the Children's Heart Foundation because they "were immediately drawn to an organization solely committed to funding CHD research." As she came to grips with her son's diagnosis and long-term potential, Shweta couldn't help but wonder: Why didn't his valve form properly? Why couldn't it be fixed in utero to allow his heart to develop normally? How can complications of the many procedures and surgeries these kids face be reduced? Why are some children more likely to develop neurodevelopmental delays and how can we prevent them?

"Thankfully," Shweta acknowledges, "there are a countless number of researchers out there trying to answer these questions and more." Yet those researchers need funding to continue to support their missions and find the answers that our families are craving.

Allison's heart defect has reconnected me with two more heart moms from my graduating class at IWU. At their son Blake's two-week, well-baby checkup, Jordyn (Frelk) Pins '00 and her husband, Jeff '01, found out their baby was in heart failure, with a heart rate of 280 beats per minute. Since then, Blake has faced urgent hospitalizations, complications and medications to help keep his heart rhythm in check. "The worst part is that I would have never known," admits Jordyn. "Thank God he had a doctor's appointment." Jordyn feels grateful for organizations that raise awareness and money that provides critical research. "We are extremely lucky that Blake's heart is doing great, but CHDs are a leading cause of infant death," she states.

Kate (Walker) Szczudlo '00 also has a young daughter, Mira, who survived three open-heart surgeries due to an underdeveloped right side of her heart. After Mira's third surgery, Kate lugged around a 25-pound oxygen tank, balancing 16 daily doses of medication and weekly cardiology appointments. "It's a Catch 22, where I want everyone to know how I feel, but I never want one more parent to know what this feels like," Kate states. Like many heart parents, she would trade places with her child in a "healthy heartbeat" but Kate also knows she has to be strong and brave for Mira, and sing "Let It Go" from the movie *Frozen* "for the 600th time to distract her as nurses fumble with an IV stick."



Jordyn Pins '00 and sons Blake and Charlie enjoy a family outing.

We all realize we are among the lucky ones. My daughter, now three and a half years old, is home — chattering up a storm; learning to read, write and ride a tricycle; swimming, dancing and playing t-ball; and, of course, fighting with her little brother over toys. Yet we also know that there are still battles to face, along with the reality that there is so much still unknown about how to treat CHDs. Chris and I are starting to plan Allison's third open-heart surgery — the last planned surgery in a course of three that both Noah and Mira have completed. I am haunted by the reality that this surgery is far from a cure — there are inevitable liver and kidney complications that come from the altered physiology. Experts don't know exactly why the altered pressures cause damage to the organs, and they certainly don't know how to prevent it.

The Children's Heart Foundation is trying to fill that knowledge gap. Someday, our children will face complications that don't currently have a treatment.

Well-intentioned people tell me that things will be fine because medical science is advancing so quickly. But that is only true if there is adequate funding to support research. I want them to find the answers that Allison, Noah, Blake, Mira and countless others need to survive and thrive well into adulthood. I want our kids to be able to have kids and grandkids — and right now that is far from a certainty. Volunteering for CHF is my best chance to make those answers a reality. CHF has funded over \$8 million in promising

research studies since its inception 20 years ago. There are chapters and Congenital Heart Walks across the country to raise money to advance knowledge in this area.

It's hard to put into words how it felt to reconnect with former classmates Shweta, Jordyn and Kate. (Because one in 100 babies are born with CHD, it's likely even more parents in our class or others we knew at IWU are heart parents like us.) It saddens me that we share what we do, but I am grateful for them, who truly understand how close we came to losing our children and the preciousness of every milestone and healthy day. For Shweta and me, it's also incredibly hopeful to be able to make a difference in our children's future through our work with the Children's Heart Foundation. Putting all we learned at Illinois Wesleyan and in life to the best possible use, we are funding the miracles of tomorrow.

**About the author:** *Kelly Wittich '00 holds master's degrees in physical therapy and public health and manages a not-for-profit health benefits plan for the General Board of Pension and Health Benefits of the United Methodist Church, which provides comprehensive health and wellness services to over 8,000 clergy and lay workers. She previously practiced as a hospital-based physical therapist at the University of Illinois Medical Center. She leverages her hospital and health benefits expertise both on a personal level in fighting her daughter's CHD and as a PR/marketing chair on the board of the Illinois Chapter of the Children's Heart Foundation. She lives in Lake Zurich, Ill., with her husband and two children.*