

Kenny Knox - "My journey with heart disease has been a blessing and has taught me so much!"

My heart journey began when I was diagnosed at 8 weeks old with a congenital heart defect (CHD) known as coarctation of the aorta (CoA). I was born in 1981, with my identical twin brother, our parents first born children.

At around 8 weeks I became ill and the local hospital referred me to Nationwide Children's Hospital in Columbus. Enter Dr. Jo Cranean into my life. Dr. Cranean diagnosed me with CoA, put me on a prescription plan, and advised that a surgery to repair the CoA would be needed in the next 5-7 years. She also advised that it was very common



for patients with CoA to develop aortic stenosis, which I did develop later down the road. Dr. Cranean was a very special doctor whom I would see up until my teens. She and the entire NCH staff were absolutely amazing to both me and my family.

## (Kenny and his niece Daphne at Myrtle Beach – July 2014)

I would continue to visit NCH annually for check-ups. The two and half hour drive and festivities associated with the annual event became a journey in itself. My parents always did a great job of making the trip fun and something to look forward to.

I had my first heart surgery at the age of 7. My pre-op tests, surgery, ICU stay, post-op hospital stay, and recovery are of no account in comparison to coming home to a welcoming family and a brand new Gibson electric guitar that my parents bought for me as a reward for surgery! My twin brother got drums and we began immediately upsetting the neighbors.

I recovered very well and continued with the annual checkups. Dr. Cranean was correct and I developed aortic stenosis shortly after my surgery. Prior to becoming symptomatic, my doctors decided to perform a double valve replacement surgery, the Ross Procedure, to replace my leaky aortic valve. I had my second heart surgery between my freshman and sophomore years in high school.

My journey from 8 weeks old until roughly 21 years of age was characterized mainly by visits to NCH, typical heart patient tests, and a few hospital stays. Overall, a very positive experience – mainly due to my parents' love and support! From age 21 until now (32), I've been seeing an adult cardiologist and know a third surgery is right around the corner. My journey with heart disease has been a blessing and has taught me so much! I haven't always embraced having heart disease but a wakeup call in 2010 opened my eyes and reshaped how I approach my life with my blessing – heart disease.

For me, the most important part of this journey is giving back. My parents, my siblings, my extended family, my doctors, and NCH have all done an amazing job for me and I value the opportunity to be able to give back to others who are in a similar journey of their own. I'm hopeful that my experiences can have a positive impact on others.

If you've had a similar experience, or would just like to talk to Kenny about living with heart disease, his contact information is listed below!