

CHD and Me - Talking With Adults With CHD



A concern that "heart parents" often have is how our children will do in the future. Will they be able to lead productive adult lives? Will their heart defects prevent them from doing activities or jobs that they want to do? In this edition, we feature the story of Angela Akerman.

Angela completed the 30k MS Bike-a-Thon in just over an hour.

Hi, my name is Angela. I was born in 1968 in Truro, Nova Scotia. I was put up for adoption and when I was taken to the hospital at 4 months for a routine check-up, it was determined that I had an extreme heart condition. I was put into a foster home with instructions that the family could keep me until I died, as the doctors had given me a year to live at that point. I, of course, was way too young to understand what that meant and my foster mom let me do pretty much anything I wanted to in the way of activities. I found out later that she had kept notes; at one point I had found an entry saying "Angela came home blue in the face from playing". I went to the Children's Hospital in Halifax – Izaak Walton Killam – now known as the IWK Health Center, every 6 months for check-ups and always enjoyed my visits. I have many things wrong with my heart, a few would be a large hole between the left and right ventricle, my heart is enlarged and turned slightly, VSD and I also had no pulmonary valve. These are a few of about 13 things that ran amuck in my heart.

I fortunately managed to outlive the doctor's prediction and thrived. My foster mother, in allowing me to do pretty much any physical activity, actually ended up saving my life as it strengthened my heart and allowed me live fairly normally as a child. Now I cannot sustain lengthy physical activity as I lose the ability to get air and my muscles cease to work very well. If I stop and let myself catch my breath I can continue. This of course ended up getting me heckled as a child because no one understood that I had an issue and they only saw that I didn't have to do the hard things in gym class and they were not happy. Sometimes our disease does make us easy to pick-on and get bullied but strength of character always wins in the end.

My first open heart surgery was at age 13 in 1980. I went in to get a patch put on the hole between the ventricles and a pulmonary valve. Unfortunately, I developed endocarditis, which is an infection in the heart, and ended up in ICU and back in the operating room. Because of the infection, the second surgery was to remove the valve and patch, sanitize them and put them back. Unfortunately, because I so weak they could only replace the patch. All in all, I was in the hospital for a month.

I then went home and continued my life. I finished high school and decided that I wanted to work with horses and went to college for that and went to Ontario. When I hit 21, I was no longer a ward of the county and was therefore not covered by

Medicare. I really lapsed in any form of doctor visits let alone specialists and went for close to 10 years without having anyone looking after my health in relation to my heart. I moved to BC in 1996 and everything was going well for a while, but in the summer of 2002 I started feeling lethargic and didn't have much energy for much of anything, so I decided to go to my doctor and get a referral. I got referred to the Pacific Adult Congenital Heart Clinic at St. Paul's Hospital. They sent me to the BC Children's Hospital for a MRI... I ended up stuck in that thing for close to 1 and ½ hours because they were getting such good pictures they didn't want to stop! After the MRI, the doctor that supervised it took me in and told me that I needed surgery fast, as I was overdue by about 5 years in having a pulmonary valve put in and the patch repaired.

The surgery was scheduled for June of 2003. I, of course, got an infection (starting to see a pattern here?) and ended up staying in the hospital for 2 weeks. I got home and healed really well and went back to work and continued on with my life.

On New Year's Day in 2006, I all of sudden had an episode where my heart beat really, really fast. It scared me silly and off to the hospital I went in Langley. I ended up having to stay in overnight because they figured at one point my heart had been going at a rate of 225 beats per minute, and no way were they letting me leave. I got cardioverted (which is a procedure where they give you an anesthetic which is quick acting and then they track the rhythm of your heart and then stop your heart and shock it to a regular beat) and got put on medication for slowing my heart down. This happened about 10 times between the years of 2006 to 2011. There was never any reason for it to happen or warning signs - it just happened. I could be laying down talking, I could be out walking, it was honestly quite scary, for someone who was as active as I was. I was a bit deterred in allowing myself to do activities. I managed to get through it by never giving up and simply continued on with what I could do and deal with the episodes when they happened, whether it was at work, home or out with a friend.

In the summer of 2011, I was given a procedure called an ablation, which is a wire that is put up your femoral artery to the heart. The wire has a laser on the end and it allows the doctor to burn off scar tissue as well as close the opening that allowed the electrical impulse to go to the wrong receiver. Since this procedure, so far, everything has gone fairly normal and I hope it continues to go that way.

The reason I share my story is to say to parents - let your children, if possible, live normally and enjoy their time, and just because a doctor gives you a timeline doesn't mean it is set in stone. Persevere, love, live life and never give up. I am 43 and have enjoyed most activities that everyone else has done: biking, hiking, camping, kayaking, canoeing, snowboarding, dancing, riding horses etc. Nothing is beyond your abilities if you don't let them be.