

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 Toby Marchegiano.

Imagine being in elementary school and not having to go outside for recess in the winter and not having to participate in gym class... pretty cool right? Well, it was for me, but a lot of baggage came along with that.

I was born on March 15th, 1979 as a normal baby. Well, that is what everyone thought. I was home no longer than 7 weeks. I wouldn't eat much at all and was a little blue. After a visit to the Doctors, I was sent straight – not even going home to pack a bag – to Sick Kids Hospital and remained there for a couple of months. The doctors found out that I had congenital heart problems, and if that label wasn't bad enough they added “complex” congenital heart disease. My diagnoses included DORV, complete AV septal defect, and a hypoplastic right ventricle, among others.

I grew up as a normal kid playing with my friends, going out and being a pain to parents. But with all that freedom came many surgeries to keep me going, until I was ready and the technology was ready for me to have a Fontan Procedure.

It was at this point when things changed big time for me. The Fontan went very well and they replaced my mitral valve with a mechanical one at the same time. One of the major side effects to the Fontan, which was never mentioned to me or to my parents, was “arrhythmia”. I had my surgery in December, 1997 and the following May got really sick. I thought it was the flu, I felt weak and tired, not normal for me. My cardiologist told me to go straight to Toronto General Hospital and right into the Peter Munk clinic and skip going to emergency. I was brought in by wheel chair and flat lined. I stayed in the hospital for a few days for the doctors to figure out what to do with me. After being there two days, I was laying in the hospital bed at about 2am and felt my heart slow down big time and I pushed the button for the nurse before I flat lined again. The feeling was so weird; it just felt like I blacked out for a while. When I woke up, I had doctors all around me with the paddles to my chest. Unfortunately for the nurse beside me, I was

sick all over her. They had called my parents and told them to get to the hospital ASAP, but wouldn't tell them what happened. I can't imagine how they felt. I was in the hospital for two months, and was put on a load of medications, which I still take to this day.

During this stay, I got a pacemaker which failed the following October of 2008. So I now had a pacemaker for my slow heart rate of 35bpm and arrhythmia medication for my fast heart rate of 220bpm. After being sent home I was good for about a year. When the first pacemaker failed, I just felt my heart go so slow and could barely stand and had to sit. I was rushed to emergency and spent a few days there and got a new pacemaker. This happened three more times, always with a new pacemaker. Then finally, I actually wore a pacemaker battery out. I recently had a scheduled replacement this year – so far so good.

Today, my quality of life is good and I have really no restrictions other than to do things within my own limits. I own a graphic design business and an arcade business with my husband. I have no complaints! Three years ago I started, along with other very helpful volunteers, the first congenital cardiac camp for adults. The program is run by Canadian Congenital Heart Alliance “CCHA” and is now going on its 4th year. It's an amazing experience for congenital patients who never had the chance to go to camp as a kid. We do all kinds of things like rock wall climbing, canoeing, low ropes, archery, and other games. The best part is just sitting around the camp fire and sharing stories. We have created such a strong bond because we just “know how it is”. We all have different issues but in the end we all feel alike. The camp is run every September for a weekend and is called “The Beat Retreat”. For more about the camp please visit www.cchaforlife.org.

I truly feel for my parents Nora & Gary, my husband Andrew and my sister Heather. They have gone through so much in the past 32 years that most people would ever imagine going through in their entire life. They are truly the best people ever! I have an amazing best friend Sheila who stuck with me and stood at the school doors and watched me sit inside by myself.

Are you an adult with CHD? If so, we want to hear from you! Please submit your story to jenb@heartbeats.ca and share your experiences with our readers.

Western Canadian Children's Heart Network Update

The WCCHN Website is getting a facelift! Work is underway to renovate the WCCHN website, making it more comprehensive and reader friendly. The new site will have:

- Improved layout and graphics
- Improved navigation throughout the site
- Search feature to help users find information quickly
- Photos and bios for clinicians at each of the WCCHN Centers
- More success stories – some with video
- Streamlined links for patients and families – and much more!

Watch for the new site to be launched in late December 2011!

www.westernchildrensheartnetwork.ca

Long-term outcomes in children undergoing cardiac surgery with and without acute kidney injury

Dr. Catherine Morgan in the Pediatric Nephrology Department at the Stollery Children's Hospital is conducting a study looking at kidney injury following cardiac surgery.

“Children admitted to intensive care, including after open-heart surgery, can experience injury to their kidneys. Although we know that kidney injury during intensive care stay affects how children do in hospital, we know very little about how it might affect their health long term. We think that kidney injury during intensive care might be a risk factor for chronic kidney disease and related conditions like high blood pressure. We are doing a study to see if this is true”.

If you or your child was admitted to intensive care between January 1, 2005 and January 1, 2010 and were 18 years of age or younger at the time, you/he/she may be eligible to participate in this study.

If you would like more information about this study, please contact:

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