

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 Brad Johnson.



I was born in Camrose, Alberta in 1963. My birth was ordinary as far as births go, but that is where “ordinary” ended and “complicated” began. I was born with a congenital hole in my heart, which closed on its own without medical assistance. However, when doing so, it created a complete heart block that left me with a slow heart beat (bradycardia.) I thought that it was pretty interesting, growing up, that I had a medical condition that started with my first name!

Over the next 3 ½ years, I would make many journeys to the University of Alberta Hospital with recurring bouts of pneumonia and bronchitis. Regardless of my health issues, we moved multiple times a year because of my father’s job. It never mattered where in Alberta we lived, we always knew where the nearest hospital was located, even when we moved as far away as Drumheller.

In 1969, we moved to Calgary where I spent the next seven years under the care of Dr. Robert Sommerville. Until I received my first pacemaker, the first eight years of life were a struggle. I battled epileptic-like fainting spells due to having a slow heart rate of 35 bpm and I was exhausted all the time and had trouble remembering things. I took a medication called Phenobarbital to help combat this issue. In 1972, through the surgical skills of Dr. George Miller, I was one of the first children in Canada to receive a pacemaker. The pacemaker was battery powered and had a life

span of two years. A year later, at the ripe old age of 10, I became interested in art through an art club while attending my elementary school, Lee Roi Daniels in the Fairview district of Calgary, which started me onto a lifetime of developing my artistic abilities.

In June of 1974, I received my second pacemaker at the Holy Cross Hospital, and became the youngest Canadian to have a nuclear pacemaker implanted. This pacemaker had a life expectancy of 21 years, which gave me hope of being able to live quite awhile without having to return for new pacemaker implantations every two years. I attended a Pacemaker Club at the Holy Cross Hospital started by Jane Beauman, the head ECG technician back then. With an avid interest in dinosaurs, I was equally happy with the Medtronic Pacemaker Representative for giving me a very realistic pre-historic dinosaur model kit. At least being a kid, there were some perks I suppose! Articles were written about me in the old Albertan Newspaper, the Calgary Herald and a Central Albertan paper about my being the youngest Canadian to get a nuclear pacemaker. A downside from obtaining the nuclear pacemaker came in the form of a letter my parents received from an anonymous individual from Rocky Mountain House. In response to an article in the Calgary Herald, they stated that since the taxpayers were picking up the tab for this \$4800 pacemaker operation, “wasn’t birth control possible?” This individual thought it would have been better had I never been born in the first place, so “they” wouldn’t be paying for my operation! I guess some people couldn’t understand what reality was like for a child like me, unless they had a child themselves who been through this. I wouldn’t have wished that upon them, no matter how ignorant and insensitive their comment was. Other downsides of having a nuclear pacemaker were not being able to go near microwave ovens, otherwise the pacemaker would be disrupted, and travel. If I wanted to go to the U.S., or anywhere overseas for that matter, I would have to obtain export/import permits for the transport of Nuclear Material from the Atomic Energy Control Board of Canada, and the Nuclear Regulatory Commission of Washington D.C.

Over the next several years I lived quite well without any real health issues except for periodic fainting spells, which could not be adequately explained at that time. In grade 7, in Fort McMurray, I played on a basketball team and we even won the playoffs. I was able to finish High School and go on to

attend Red Deer College in 1983. However, two years later while staying with my folks in Camrose, I had a major blackout. I was home with my Mom and was waiting for a friend to come over. When I saw their car pull up, I stood up, took two steps... and the next thing I remember was Mom sitting over me crying and (thankfully) me not remembering hitting the floor! My heart, broken as it was, really went out to my mom for the many times over the years that she worried about my health and drove me to hospitals – far too many times for me to even remember. After my big blackout episode, my doctor in Camrose sent me to the Royal Alexandra Hospital in Edmonton. There it was determined that the cause of my blackouts and previous fainting spells were due to the fact that the leads of my pacemaker were corroding. It was decided without delay that I should get a new pacemaker to rectify this issue. I heartily (no pun intended) agreed, given that it was not very comforting to know now that I had defective leads in my body.

For years after leaving Calgary, I had not seen a cardiologist for any of my heart issues, as it was not impressed upon me that I needed to be followed by a cardiologist on a regular basis. In March of 2007, I saw my family doctor in Sherwood Park because of issues with chest pains and edema in my lower legs. He diagnosed me with Congestive Heart Failure, and later in July, while at a scheduled pacemaker examination, it was noted that a period of Ventricular Tachycardia had taken place. From December, 2007 to February, 2008, I had a series of tests at the cardiology department of the University of Alberta Hospital to determine why, with just having a diagnosis of bradycardia, was I then having these V-Tach episodes? After my first test, questions and eyebrows were already being raised, such as: did I have open heart surgery performed on me as a baby? After all of the tests were done, and archived doctor’s notes were found in the University Hospital dating back to 1964-66, another congenital heart issue was discovered – one of which I knew nothing about! I also had Congenitally Corrected Transposition of the Greater Arteries of the heart. In simpler terms, my lower right heart chamber was and is doing the work that the left side of the heart should be doing, and vice-a-versa. The blood that should be going to the lungs wasn’t, and was instead being diverted to the rest of my body. This is also where I discovered that I had moderate pulmonary hypertension. All along I had naively thought that it was difficulties to do with mild asthma that I’d also had since

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childhood. It had been determined by the doctors back in the 60's that corrective surgery would be too stressful on my system and therefore was not done. My folks remember being told that since corrective surgery could not be done in my case, that it would be best to just take me home, love me and hope for the best. They were never told exactly what my heart defects were. Thankfully, with the vital addition of the pacemaker at age 9, my parents were told that I would live a relatively normal life through to the age of 35. Well, I have beaten those odds thus far as I will be turning 48 in January of 2011.

I have had a few more pacemakers implanted over the years, and now with these new issues in my life, my cardiologist, Dr. Isabelle Vonder-Muhll, determined with her team that the best course of action for me was to get a heart transplant. Since I am in my late forties, corrective surgery is no longer possible, even with the advanced surgical knowledge and technologies that exist today. So until the opportunity arises for me to get a heart transplant, it was decided as a precaution to prevent sudden cardiac death, that my seventh pacemaker, which was implanted in June of 2008 by Dr. Ivan Rebeyka, would be an Artificially Implanted Cardioverter Defibrillator pacemaker, or AICD. I've attended the Cardiac Rehabilitation Program at the Glenrose Rehabilitation Hospital and I now visit the YMCA regularly to help reduce my weight so that I can eventually be listed for a heart transplant.

Because of my multiple heart issues, I am unable to work and I am on AISH. Aside from dealing with my heart issues, I spend a good portion of my time on the four most important areas in my life. First, spending time with my significant other, April, who is celebrating seven years of being a double transplant recipient of a kidney/pancreas on November 20th. April has been a great support and mentor throughout my recent experiences, and a wonderful teacher as to what to expect for a transplant in the future for myself. Secondly, maintaining a positive relationship with my children, who are all wonderfully supportive. With my eldest getting married next year, I would really like to be around much longer to enjoy any future grand-kids. Thirdly, a continual development of my being a scratchboard artist and seeking ways of making my particular niche of art better known. Lastly, my most recent project which I hope to see an eventual benefit for all adults who have Congenital Heart Defects.

Since February of 2010, I have been working with a few others, in conjunction with the Canadian Congenital Heart Alliance to establish (which we now have) the Alberta Chapter of the Canadian Congenital Heart Alliance. This project was borne from my inquiries to Dr. Isabelle Vonder-Muhll as to how I could get involved in a support network for adults with CHD. I was informed that there was only a support network in the Province of Alberta for those under the age of 18, but not

for anyone beyond that age. Dr. Vonder-Muhll got me in contact with John MacEachern, the founder of the CCHA, about setting up an Alberta Chapter. We have 5-8 people actively in attendance at our meetings, and our hopes are to raise funds for CHD research and education of the public about the real need of supporting individuals with CHD, who are now in greater numbers living into their adulthoods, just like myself. I have yet to be in contact with someone who has my particular heart problem, but that is the beauty of what our group is trying to accomplish, and I remain positive that I will meet someone through our efforts with our own Alberta Chapter.

Share Your Story

We invite you to share with us your experience with congenital heart disease. We would like to hear from parents, as well as children, teens and adults who themselves have a CHD. Your story may provide the encouragement and support someone else needs. For assistance in preparing your story, or to submit your story, contact the Newsletter Coordinator at jenb@heartbeats.ca

Safeguarding Study

Safeguarding Survival: Parenting Children & Adolescents with Complex CHD

- ♥ Are you a parent of a child with HLHS?
- ♥ Are you a parent of a teen who had heart surgery during the first month of life?

If yes, we would like to talk with you!

Dr. Gwen Rempel, Faculty of Nursing, University of Alberta, is conducting a study with parents of children and teens born with complex CHD. The study involves completing questionnaires that we will mail to you. We will also be interviewing as many moms and dads as we can (interviewing each one on his or her own). Interviews will be in person or by telephone.

For more information about this study, please contact:

Louisa Fricker: (780) 492-6279 E-Mail safeguarding@ualberta.ca

Study Update!

We have received questionnaires from 18 parents of children with HLHS and 3 parents of teens with CHD to date, and are looking for more families to participate. Interviews with families will begin in the new year.

