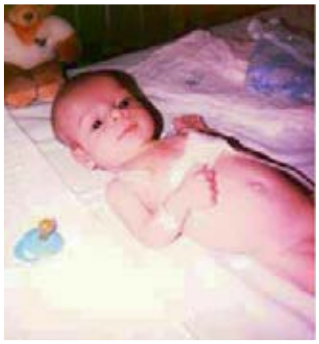
CHD & Me Talking With Adults With CHD

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 Matthew Moreira

"A Modified Life"

I was born on November 2nd 1984, with brown eyes, brown hair, and powerful lungs. Born into an already big Portuguese family I was the new talk of the town. I was given a clean bill of health and was sent home with my very beautiful, but very new first time mother. Four weeks went by when I suddenly began to show weird symptoms no one had ever seen before. I would scream and cry out of the blue, heavy breathing was becoming more and more usual, and feeding was becoming a hassle. After trying to figure it out – blaming it on itchy clothes, etc., my mother took me to the family doctor and that is when my life would change forever.



My mother recalls that I was breathing heavily and rapidly, moaning and groaning along with crying and screaming that could be heard for miles, it seemed. The family doctor immediately said "Get your son to Sick Kids Hospital ASAP". Once there, I was rushed into a room and was surrounded by nurses and doctors. Within the hour the doctors told my parents that I had a rare heart abnormality called tricuspid atresia. As the doctor explained further, my parents couldn't help but wonder if I would even live past that night. The doctor told my parents that I needed emergency surgery immediately, After my parents agreed, I had a 9-hour surgery performed by Dr. Williams and Dr. Coles. I had survived my first of three surgeries and was doing just fine. The doctors' informed my parents that, to their amazement, during surgery they found a small hole where my forth chamber should have been. This hole had kept me alive up until that point. The doctors then made an adjustment to this hole. I spent my first Christmas in the ICU, where my mother spent endless hours by my side while my father went to work, worrying constantly about his first-born son. A few days had passed after my first surgery when an echo revealed that the pulmonary banding was too tight and the hole they had widened was too large. Later that night I was back in surgery and by morning I was back in ICU. For the next nine months I lived at Sick Kids. My mother would pretty much become a nurse by the time those hard nine months were over. Finally I was sent home, finally I could start to live my life, and all the way to age 3 I did. I went on many outings that every child goes on: Toronto's Centre Island, birthday parties, and always causing trouble and giving my parents a few early gray hairs. At a routine checkup the doctors informed my parents that it was now time for what they called a "modified Fontan" surgery.

I remember the day of the surgery, and walking into the pre-surgery rooms that looked like a huge indoor playground with paintings on the walls of animals and cartoon characters. Nurses dressed up as clowns as they made balloons and handed out toys. I, along with many other congenital patients, was rather comfortable! This a congenital patient's life from day one: hospitals, doctors, nurses, appointments, ECG's, echo's, stress tests, Holter monitors - it all becomes the norm to the point where, heck, you could probably perform all the test yourself and even make your own diagnosis!

A congenital heart disease child's life is a different life. From day one our cardiologist reminds us time and time again how we must live our lives. They tell us we cannot do this and cannot do that, how they rather us go to a salad bar instead of McDonalds, how we should drink water and not Coca Cola. A brisk walk is better than playing a game of football, and when playing any sport to take many breaks. Well I say that is all great advice, and it is great that we were reminded on a regular basis. But, I say that every patient should at least try everything once. I always joined school sports, played street hockey, rode my bike, skate boarded (not very well mind you), went on school trips. As I got older I got into cars, went out with friends, and did pretty much anything they could do. The only thing I never tried was a cigarette. I tried alcohol in my early 20's and realized that I wasn't really missing that much.

Sadly not every congenital patient has the same opportunities as me; some do not even see their 20th birthday, or even their 2nd. There have been many amazing advancements in the congenital heart disease world that are making our life spans decades longer, but some do not have the chance to make it to those stages and even some of those who do really struggle.

I am now 28 years old. I had my last heart surgery at the age of 3, but the past few years have been rough. At 25 I developed Warm Auto Immune Hemolytic Anemia (WAIHA) which has resulted in having my spleen removed, and just this June I spent four weeks in Toronto General Hospital fighting off two blood clots in my right atrium and a few others in my lungs due to a heavy relapse that sent my CBC from 153 to 77 in two weeks. I have been on prednisone and Imuran for about a year and at the moment I am receiving Rituximab infusion in hopes that this will cure my relapsing WAIHA. In February 2011, I had brain surgery from a brain abscess that was again most likely caused by my heart disease. Since the surgery I have developed epilepsy and have a seizure every two to four months. I can no longer work due to all these complications. I take about 20 pills in total every day, one of which is Metoprolol to control my arrhythmias. I have even changed my diet; I am finally picking salad over fries and water over Coke. There is even talk of future heart surgery as my cardiologist tells me that my right atrium is 8cm and that this may become a bigger issue as time goes on. But, a positive mind is a positive body, and anything is possible. I am living proof. No matter how dark the path may look I am confident I will get passed all this. I have faith in God and myself that one day I will look back at this and smile and thank God for being blessed for everything I have experienced and accomplished in my life, and that I can move forward knowing that heart disease to me is not a death sentence but a "modified" way of life. With encouragement from family, friends, other congenital patients, and most importantly my mother, I will continue to push through everything that is sent my way.

I would like to remind everyone that a congenital disease is a disease that not only affects the child but the entire family. Everyone is affected since day one of the child's life in dealing with the disease, but they are often forgotten in all the chaos. So please remember the child's family. Finally, to my fellow "Cardiac Kids" young and old, always remember your mother! There is no greater love in the world than a mother's love for her children and for all they experience with us - the ups and downs, the tears and the smiles. So remember, honour your appointments, take your medication, and live a healthy, happy fulfilled life.

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