



Keeping the Beat

Spring/Summer 2011

Offering information, resources and emotional support to families dealing with congenital heart disease.

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Family Event at Shakers Fun Center

In recognition of Congenital Heart Defect Awareness week, Heart Beats held its annual family event at Shakers Fun Centre on February 12th. Children of all ages (including some middle-agers!) enjoyed an evening of arcade games, rock climbing and laser tag. A full meal was served, and everyone had a wonderful time catching up with old friends and making some new acquaintances. As the evening came to a close, the children and teenagers cashed in their gaming tickets for some souvenirs of the day. Thank you to all of the attendees for helping to make this an enjoyable evening for all. We look forward to seeing everyone again next February as we once again celebrate Congenital Heart Defect Awareness Week.



Heart to Heart Easter Egg Hunt

This year's annual Easter Egg Hunt had an eggcellent turn out! We had twelve children participate in the festivities. The fun included a bouncy castle, egg decorating, Easter coloring and a race to Chocolate Heaven, the egg hunt!



Despite the blizzard many families made the drive to the Indus hall, which just goes to show that you can't keep these resilient families, and even tougher kids, down.

We would like to extend a big thank you to our generous sponsors who make events like this happen. Thank you to Patty Wiebe for helping to coordinate the event, Joanna

Mangan for donating and running the crafts table, and Paul and Aurora Aris for setting up and cleaning up the hall.

Michelle and Paul Aris, Parents of Owen Aris – Coartation Repair on March 6th 2008. Heart Beats would like to thank the Aris family for the hard work they put into organizing this event.

Being an Overprotective Parent May Have Adverse Effects

By Jen Beleshko

Information adapted from Science Daily (Sep. 18, 2010)

As parents of children with congenital heart disease, we may at times wonder if we will ever stop worrying about them. We accompany them to their appointments, are by their side during surgeries and are responsible for administering their medications. As our children grow and become more independent, we may worry about not being able to observe how they are doing during the school day. Will the teacher be able to recognize a heart-related problem? Will our child be able to monitor him/herself and take breaks when needed? Adolescence can compound our worries as we wonder how they are coping with peer pressure; will they engage in risky behaviour and endanger their health? As they move on to adulthood, we may wonder if they are taking care of themselves, keeping their appointments, taking their medication, etc. While these concerns may be normal, for some parents it can become overwhelming and can result in being overprotective.

According to a study conducted by Dr. Lephuong Ong from Orion Health Services in Vancouver, and colleagues from University Health Network and York University in Toronto, levels of parental protection are likely to be higher in children with congenital heart disease compared with healthy children. What impact does parental overprotection have as the child moves into adulthood? Dr. Ong's research has shown that adults with CDH are more likely to suffer heart-focused anxiety if their parents were overprotective. Parental overprotection, which is defined as intrusion, excessive contact, infantilization and prevention of independent behaviour, is directly related to heart-focused anxiety in adults with congenital heart disease. The study results show that levels of anxiety rise as levels of parental overprotection increases. Disease severity is also linked to higher anxiety levels.

The study suggests encouraging greater independence for adolescents and adults with congenital heart disease to improve their psychosocial adjustment. The authors conclude: "Adults with congenital heart disease, who report their parents as being overprotective, might have learned to form negative interpretations of their symptoms and use maladaptive coping behaviors, like avoidance and fearful responding, when experiencing cardiac symptoms or when faced with situations that trigger cardiac-related sensations. Clinicians could consider providing recommended activity guidelines for parents and their children to reduce limitations on activities that are deemed medically appropriate, to encourage independence among adolescents and young adults with congenital heart defects."

Dr. Ong's work is published online in Springer's *International Journal of Behavioral Medicine*.

On Being 'Part Cow'

By Jeffrey Moore

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I am part cow.

No, I'm not talking about my genetic code or an unhealthy steak diet. I mean that I have a living active piece of cow completely incorporated into my anatomy that will probably add 40 years to my life.

This summer I had open heart surgery. For you nursing and biology students: I had a pulmonary valve replacement with 29mm perimount bioprosthetic heart valve and a tricuspid valve annuloplasty. For everyone else: the doctors cut me open, inserted a piece of cow into my heart, and closed me up again. O.K., it isn't that simple, but it sounds cooler that way. I play it down because I'm not sure I can do justice to the incredibly complex and difficult procedure that preemptively saved my life.

I was born with congenital heart disease, which basically means that my heart was screwed up and I would have died if it wasn't for the quick thinking and steady knife of several courageous surgeons. The main problem was that my pulmonary valve, which works as a kind of flood gate for blood leaving my heart, was malformed and stuck closed, blocking the flow. The doctors created a bypass around the valve in one surgery and removed it completely in a second.

Since then I have lived without a pulmonary valve and my heart has had to work extra hard to move blood properly. In the past, according to my doctor, people with my condition rarely lived past their mid-thirties because the heart grew so large from all the extra pumping that it failed. The solution is to insert an artificial or bioprosthetic valve where mine should be. This allows my heart to return to normal size and function.

And so, four weeks before my return to Goshen College for my sophomore year, I found myself at the Cleveland Clinic facing the knife. I don't remember much about the first day or so after surgery because I was seriously tripped out on pain medication. (Having your chest cut open isn't exactly a painless surgery. In the following weeks sneezing, coughing, and even laughing hurt.)

What amazed me was how quickly I recovered. I only spent five days in the hospital and felt awesome after just two months. Sure, the twelve-inch scars down my chest ruin my chance to be America's next hot model, but then again, that isn't much of a loss. I can run, play, and laugh because of miracles both this summer and almost 20 years ago.



Ultimately I have to acknowledge God's hand in my story. I would be a fool to explain it any other way after seeing what happened and witnessing the multitude of people who prayed for me. Before surgery, I had a wonderful feeling of peace that I can only attribute to the work of God.

Perhaps it would due to end by thanking the cow for sacrificing its valve to fill the void in my heart. To you, Clover, wherever you are in the world of bovine, I offer my modest thanks.

Keeping the Beat by e-mail

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Granting a Wish for a Heart Child

Growing up with a CHD can often mean surgeries, procedures, medication and a lifetime of appointments. In some cases, it can also mean periods of extended hospitalization. In recognition of these and other challenges facing these children and their families, *Children's Wish Foundation* and *Make-A-Wish* have granted the wishes of some of these brave children. These wishes have included anything from a family vacation to meeting a favorite celebrity. Any Canadian child between the ages of 3 and 17, regardless of economic background, who has been diagnosed with a life-threatening illness qualifies for a wish. This includes children who have had complex cardiac surgery.

Below is the story of Eric, who had his wish granted by Children's Wish Foundation.

Eric was a typical young boy, liked to ride his bike, play soccer, do all the things boys like to do. That all changed in the spring of 2008 while we were out walking and Eric collapsed. After seeing our doctor and having a few tests, we were told to take him immediately to the Children's Hospital where he spent two weeks starting in Intensive Care. His diagnosis wasn't what a parent wants to hear.

Eric has Prolonged QT Syndrome and Pulmonary Hypertension – both are life threatening and progressive illnesses and very rare in children. That was the day life as we knew it changed.

As we were trying to come to terms with this, we were approached by Children's Wish Foundation February 2009 who had been contacted by Laura (social worker for the Cardiology Department at the Children's Hospital) and asked "If Eric had one wish, what would it be?"



After numerous suggestions he decided he would like to go to London, England and see the HMS Belfast, the ship his late grandpa had served on as a gunner in the Korean War. His wish was granted and the Children's Wish Foundation began to work their magic. Everything that goes into planning a trip and then some was accomplished in a short space of time...for 5 people! They booked the hotel, flights, transport to and from Heathrow Airport, travel passes for the week in London, a personal tour of the HMS Belfast as well as several other tours. They dealt with organizing Eric's oxygen for the week as well as copious amounts of paperwork for passports and medical information. (i.e. Letters from doctors and insurance).

So! On September 14th 2009, we boarded the plane and began Eric's trip of a lifetime! For that one week we had normalcy back in our lives and spent a wonderful seven days just being a family enjoying each other and the gift given to us by an exceptional group of caring, hardworking, compassionate people that make up the Children's Wish Foundation.

Written by Nikki Meyer (Eric's mom) and Jean Cooke (Eric's grandma)

For more information on referring a child, please contact the following:

The Children's Wish Foundation of Canada
Alberta & N.W.T. Chapter
271 – 339 50 Avenue SE,
Calgary, AB T2G 2B3
Tel: 403-265-9039
Fax: 403-265-1704
Email: ab@childrenswish.ca

Make-A-Wish® Southern Alberta Canada
Bay #4, 2308-24 Street SW
Calgary, Alberta, T2T 5H8
Toll free number: 1-866-502-3666
Local number: 403-228-3666
Fax: 403-246-0946
General email: salbertachapter@makeawish.ca

Offbeats

Offbeats has had a great winter of activities. In February, we celebrated Congenital Heart Defect Awareness Week with heart shaped pizzas at Boston Pizza. March was bowling, where one member doubled their score from last year – way to go! In April, the group set out to "rescue their creativity" at Fire Escape, one of the favourite activities of the year.

Offbeats will wrap up for this school year in May. In addition to refreshments, activities will include doing some drumming with the one of the music therapists. Anyone who came to Fire Escape will get their finished product at that time. Offbeats will resume again in September.

If you are between 10 and 17 years old, have a heart condition and would like to join in on the fun, please contact the cardiology nursing office at (403) 955-7316.

Western Canadian Children's Heart Network (WCCHN) Update

Submitted by Angela Krizan, RN, BN, WCCHN Coordinator

It has been just over 10 years since the Western Canadian Children's Heart Network was established! It's hard to believe that a decade has gone by. The WCCHN is the largest geographical clinical network in the world spanning over 4 million square kilometres. The WCCHN has always been committed to bringing world-class pediatric cardiac care to the patients and families of Western Canada. The advances in practice and growth in the Network over the past 10 years is incredible. With that in mind the WCCHN Steering Committee and Clinical Operations Committee alone met in Banff, Alberta early in April to discuss and plan the future directives for the Network. You could call it a bit of spring cleaning for the Network; an opportunity to look at what we have developed over the years, what the current needs are in Western Canada, and what we as a Network can do to build and improve on our programs. A summary of the retreat outcomes will be available on the WCCHN Website.

Heart to Heart

Heart to Heart is open to all parents of children born with congenital heart defects (CHD). Whether your "heart child" is an infant, a teenager, or somewhere in between, we welcome you. We meet once a month to visit and chat about parenting children with CHD. We vary our meeting days, times and locations from month to month to try to include as many parents and families as possible. Those with children at home are welcome to bring them along. For our weekend dates, we enjoy having the whole family attend. Upcoming *Heart to Heart* dates are:

- **May** – Friday, May 13th at 10 am at the home of Karen Perl-Pollard, 324 Norseman Road NW.
- **June** – Friday, June 10th at 10 am at the home of Lynn Nakoneshny, 187 Willowmere Close, Chestermere
- **July** – Sunday, July 10th at 1:30 pm at Lake Midnapore. The entire family is encouraged to come! If you are able to attend, please RSVP to Patty at pattyw@heartbeats.ca as she must provide your name to Lake Midnapore staff so you can be admitted.
- **September** – Monday, September 12th at 10 am at the home of Cindy Castillo, 83 Auburn Glen Heights SE.

We invite you to join us to meet other parents, to ask questions about caring for and raising children with CHD, and to share your knowledge and experience with others.

For more information, feel free to contact Patty Wiebe by e-mail at pattyw@heartbeats.ca or by phone at 403-256-7423.

Your Support in Action

Donations made to Heart Beats Children's Society of Calgary are used to provide information, resources and support to families living with congenital heart defects. Your donations have provided:

- Financial assistance to families having difficulties meeting expenses relating to their child's heart defect.
- Items of encouragement for children undergoing extended hospitalization.
- "Heart & Soul: Your Guide to Living with Heart Disease" information binders (distributed through the Cardiology Clinic).
- Supplemental equipment for the Alberta Children's Hospital Cardiology Clinic

We appreciate and acknowledge the donations received from the following individuals and organizations from January through April, 2011:

Norma Becker
Donna & Michael Gerlinsky in memory of Brittany Gerlinsky
Sherry Harrill through the United Way of Calgary Donor Choice program
Cathy Howarth
Barry Pratt
Ayisha Raja-Qadri
Telus
The Watson Family Foundation at The Calgary Foundation
anonymous in honour of Kirsten

If you wish to contribute to the support of families of children with congenital heart defects, you may mail your donation to:

Heart Beats Children's Society of Calgary
Box 30233, Chinook Postal Outlet
Calgary, AB T2H 2V9

You may also donate online at www.heartbeats.ca where you can make secure donations by credit card to Heart Beats through CanadaHelps.org.

*(If you donate to *Heart Beats* through the United Way, please let us know so we can acknowledge you as the United Way does not provide us with the names of the donors.)

Talk with the Docs – Dr. Quiñonez

In our previous issues, we have had the privilege of learning more about the Cardiologists at the Alberta Children's Hospital. We have featured Dr. Frank Dicke, Dr. David Patton, Dr. Deborah Fruitman, Dr. Robin Clegg, Dr. Joyce Harder, Dr. Kim Myers and Dr. Michael Giuffre. In our Fall 2010 newsletter, we began the first of a three part series featuring the Pediatric Heart Surgeons at the Stollery Children's Hospital by interviewing Dr. David Ross and Dr. Ivan Rebeyka. In this edition, we are pleased to feature Dr. Luis Quiñonez.

"When my daughter, Alexa, was in Edmonton after she was born, I spent many hours sitting by her bed as she slept peacefully. Every time her surgeon, Dr. Rebeyka, came around the corner I would leap up and wait for him to tell me something disastrous, which he never did. He once commented that I always looked like I was going to cry when I saw him, and I probably did. But it wasn't completely because of Alexa's condition; it was also because I respected him so much and knew that, literally, Alexa's life had been in this man's hands. I felt a great awe and even intimidation towards the cardiac surgeons. So I decided that I wanted to know them on a more human level and I imagine that other parents feel the same. It is my privilege to interview the three pediatric surgeons, and I conclude my series by featuring Dr. Quiñonez"

Where did you grow up? What was your home life like? How many siblings do you have?

I spent my youth in a number of places: El Salvador, United States, Mexico, and Canada. Political circumstances in El Salvador eventually brought us to Canada as refugees. Eventually, we became Canadian citizens and established roots in this country.

My home life was great. I have the good fortune of having wonderful and supportive parents, who always encouraged, and expected, my sister, brother and I to get a higher education.

Did you always want to be a pediatric cardiology surgeon? How did you end up in this career?

My wife reminded me once, regarding operating on children, that their parents are "handing over to you their most precious thing in life". These words have stayed with me and reminded me of why I became a doctor. I did not think about becoming a pediatric cardiac surgeon until the latter part of my training. I have been a peripatetic surgeon, going through general surgery, thoracic surgery and adult cardiac surgery. Nevertheless, I ended up choosing the specialty that challenged and fulfilled me the most.

When and where did you begin your career? How did you end up in Edmonton?

After having spent 3 years in the US doing advanced fellowships at the Mayo Clinic and Cleveland Clinic, I had the opportunity to come back to Edmonton and train for an additional year at the Stollery. I knew Drs. Rebeyka and Ross from my residency days, and they were gracious enough to accept me into their program. It was an exciting time, because the heart failure program was starting up. After one year I was offered a position as an Associate Surgeon with their group and I stayed on.

I know you did your Fellowship with Dr Rebeyka. How long was your Fellowship and what did it involve?

It takes about 10 years of training, after medical school, to become a pediatric cardiac surgeon. The last few years are called fellowships. The training, of necessity, is long and hard, with long hours of work and study. I did my fellowships in the US and Canada.

Why did you decide to work with children and not adults?

Many people may not know that congenital surgeons operate on both children and adults with congenital heart disease. Each group poses different sets of challenges. Both groups require significant forethought and planning prior to an operation. Children's operations require precision and significant attention to detail. Adult congenital operations are difficult because patients often have had multiple previous interventions. Both groups are very interesting to me.

What is the most difficult thing for you in your career so far?

Technology is so advanced that we are able to make children live through and survive very complex conditions. However, this comes with a significant intellectual, emotional and financial burden to the child, family and society. One of the most difficult things is knowing when to stop and when to say "enough".

What do you find most rewarding?

It fills me with great satisfaction to be able to come out of the operating room and tell a child's parents that everything is OK and that their child is doing well. It feels as if I have lifted the world off their shoulders and I am glad I can do this for them.

When you are not at work, where are you? What do you like to do?

When I am not at work, I am at home with my wife and our dog and cat. We have no "human" children yet. We enjoy going to the mountains and hiking, when able. We are lucky to live in such a beautiful part of the world.

What are some of your future goals as a pediatric surgeon?

I would like to bring to pediatric cardiac surgery the principles and practice of aviation safety. The use of checklists to enhance safety is one example. Another example is the use of simulators, which have long been used in the training of pilots.

Obviously you are involved in a very stressful career. How do you deal with stress?

I like to read the biographies of great individuals in history. Knowing and understanding how they overcame tribulations helps me deal with the stresses encountered in life and work. However, spending time with my wife, Morgan, and being able to share with her my successes and failures, is the greatest joy and stress-relief in my life.

By Cindy Castillo

2nd Annual *Heart Beats* Family Fun Run



Heart Beats is pleased to announce preparations are underway for the 2nd Annual Heart Beats Family Fun Run which will take place on Saturday, October 15, 2011 at Eau Claire Market on the running paths along the Bow River. Once again there will be a 10km Run, a 5km Run or Walk and a 1km Children's Race. This year we have made several format improvements including chip timed 10km and 5km races and prizes for the winners of each race.

If you would like more information or if you would like to volunteer for this event, please contact Cindy at cindyc@heartbeats.ca. Look for sign-up information at www.heartbeats.ca or at www.runningroom.com.

We hope to see you there!

Heart Beats 25th Anniversary Event

To commemorate 25 years of helping children and families in our community, Heart Beats is planning a celebration and fundraising gala on February 11, 2012 at the Calgary Italian Club. You will not want to miss this exciting event that will feature Brenda Finley as the MC and will offer live entertainment from the Heebejeebees, a full course dinner, contests, prizes and much more! If you would like more information or would like to contribute your time, expertise or fundraising ideas for this event, please contact Sylvia Falk at (403) 241-3026 or email her at sylviaf@heartbeats.ca. Meanwhile, plan to join us on February 11th, 2012.



Zajac Ranch Heart Camp



Zajac Ranch, located in beautiful Mission, British Columbia, is now accepting applications for this year's camps. The heart camp will run from Tuesday, July 5th to Saturday, July 9th. If you are between the ages of 7 and 17, have a CHD and enjoy activities such as horseback riding, canoeing, basketball, hiking, arts & crafts or drama (just to name a few!), please speak with Patty Knox at the ACH Cardiology Clinic. Heart Beats has funds available to assist with the cost for the camp. But hurry, applications must be submitted no later than May 24, 2011. For more information, please visit the website at www.zajacranch.com.

Community Updates

Roman Beleshko



In November of 2010, we received a phone call from the Stollery Children's Hospital in Edmonton booking in our 3-year old son, Roman, for his second heart surgery, the Fontan. We were given the date of November 30th along with a warning that if anyone in our household had so much as a runny nose the surgery would be postponed. The following weeks were spent trying to organize work schedules and keeping away from germs. The day before the scheduled surgery, we spent the day at the Stollery doing the usual pre-op tests, including blood work, an echocardiogram, an x-ray and meeting with the various medical professionals that would be contributing to the surgery. Just as we were about to meet with our surgeon, we were informed that the operation was cancelled and we would have to return in two weeks. Although we knew that cancellations were common, the emotional toll was great as not only did we already give notice to work and daycare, but we had all psyched ourselves up for the surgery. The staff at the Stollery was very supportive and repeatedly apologized, even though it was beyond their control. There were simply no available beds. We were given a new date of December 14th, but ended up being bumped up to December 10th. Thankfully, we did not have to repeat the pre-op appointments.

The surgery was a go, and I accompanied Roman into the surgical room for his anesthetic. Unlike his previous experiences, it was much harder to put him under. He panicked and struggled underneath the gas mask and this was very traumatic to both Roman and I. He had nightmares about it for several weeks after, often refusing to close his eyes despite being very tired.

Like most parents waiting for their child to come out of surgery, we sat nervously staring at that fish tank trying to keep positive. After several hours, Dr. Ross found us and gave us the good news that the operation was over and that everything went beautifully. We could feel the stress of the past months melt away. As our son was wheeled into the PICU, we got the thumbs up from everyone. Soon we were able to see our little guy, who was very discombobulated and uncomfortable. We were prepared for the sight of our son hooked up to machines with drainage tubes coming out of chest, but we didn't expect that he would be awake and alert. Many of these patients are now extubated almost immediately after surgery which has drastically reduced recovery times. Roman was aware and not liking where he was, in fact he was trying to roll over and get out of bed! The nurses had to strap his hands down until he calmed. Thankfully, he spent only one night in PICU before going to the ICE room on the ward where he was weaned off the morphine and could watch TV and begin to eat real food. He remained in the ICE room for two days before going into a standard ward, simply because there were no available beds. We were glad to finally be moved to a regular room where there was less noise, more privacy, and where a parent can finally sleep horizontally instead of in a chair.

Administering Roman's oral meds turned out to be the hardest parts of his stay. Since he had so little control over the other parts of his body which were being frequently poked and prodded, he felt the only control he had was what went into his mouth. And so he would spit out or throw up all of the meds and it would sometimes take me two hours to convince him to eat a tablespoon of pudding with the meds mixed in. Then we would repeat the whole ordeal several hours

later. It was exhausting for both of us. To add to his gloom, Roman also lost two of his favorite stuffed toys that were accidentally put into the laundry when his sheets were being changed. The laundry is picked up by a third party company who are rarely able to recover lost items. One of his favorite nurses kindly bought him a stuffed parrot, which he loves, but he still misses his two favorite "buddies" that were his constant companions since infancy.

On day 4, Roman was finally able to walk around, and from then on he began to recover very quickly. He would spend several hours a day playing with his dad at The Beach, a wonderful play area for recovering children. He also kept busy entertaining his grandparents who live in Edmonton and visited Roman every day. I was so grateful to have my in-laws close by and for all of their support and encouragement. Before long, the drainage tubes were removed, and after a final echo, Roman was discharged just one week post-surgery. In all, we could not have asked for a better outcome. Roman has had no complications whatsoever post-surgery other than some emotional ups and downs.

Today, our little guy is stable and doing well. In April, he held us to our promise of a trip to Disneyland where he had the time of his life. This summer, we have enrolled him in soccer and he will be attending a week long "dino camp" for budding paleontologists. Our gratitude goes out to the amazing staff at the Stollery, especially Dr. David Ross, whose surgical talents and compassion for his little patients is boundless.

Jen Beleshko is mom to Roman, age 3, born with dextrocardia, DORV, and a single right ventricle.

We want to hear what is happening with your CHD child and family! Whether it is an update on their treatment, or a special accomplishment in school, music or sports, please let us know so we can share it with the rest of the Heart Beats Community. Send your update to jenb@heartbeats.ca

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 Shelagh Ross.



I was born 48 years ago in Toronto, the youngest in a family of four kids. The first clue that something was wrong was that I didn't have the strength to nurse, and I had “blue spells”. I was diagnosed in that first year with tetralogy of fallot, one of the most common congenital heart defects, made up of four related defects. I was also born with two sets of bowels and intestines and at first that was my biggest problem because I wasn't able to properly digest food and gain weight, but that was fixed with surgery early on and that part of me has been ok since.

At age two I had the Blalock-Taussig shunt as palliative surgery to help increase blood flow to the lungs (they took a major artery from my right arm and used it to re-route the blood. To this day I don't have a detectable pulse in my right arm). It was all they could do at the time and the hope was that I'd live long enough to survive open heart surgery when I was older and stronger. My parents were told I would likely have stunted growth and perhaps they were right. I'm “short” at 5'7” compared to my 5'10” sisters and 6'4” brother!

I was sick a lot with infections and I remember often being cold and tired. I'm told I used to squat a lot, which apparently kids with my heart defect do to cut off circulation

to the legs and divert the blood to the heart. I also used to get terrible headaches and my dad would hold me to his chest with my legs tucked up under me. But I think I was fairly oblivious of my problems, and like most kids I just wanted to keep up with my siblings. I think I can probably thank them for growing up “normal” because they certainly didn't coddle me.

In 1970, at age 8, I underwent nine hours of open heart surgery at Sick Kids Hospital for what was called “a complete repair”. In 1970 it was still considered very risky, with about an 80% mortality rate. The surgeons were Drs. Mustard and Trussler. The only things I really remember about Dr. Mustard is that he used to make me run up and down the stairs at the hospital before listening to my heart with a stethoscope (before the days of treadmills and stress echos) and to me he looked exactly like the wizard in the Wizard of Oz.

It says in my chart that Dr. Mustard hoped he never had another patient like me because it was the most difficult surgery he'd ever performed. I stayed at Sick Kids for about two months to recover and basically, besides the needles and being away from home, I enjoyed being treated like someone who just had something very special happen to them. Everyone was extraordinarily nice.

Life after surgery was a whole new world for me. I roared around on my bike, played tennis, became a ski instructor at 16, and in grade 13 won the Toronto schools tennis finals. I had lots of friends and did all the things normal/bad kids do, including things I shouldn't have done. I knew I had a “heart condition” but I felt normal. In addition to things heart-related, I have scoliosis, migraines, and am very allergic to peanuts; even though I'm very careful and carry an EpiPen, the peanut allergy has always been the main reason for visits to the hospital ER.

From age 18 to 33 I saw a cardiologist every year and every year he said “Things are great!” I'd been told I wouldn't be able to have kids but when I was about 19 the cardiologist said “I don't see why not”. I know now that no one really knew if it was safe or not; they just didn't know. I got pregnant at age 28 and despite not having any heart-related care besides an

ultrasound on the baby's heart, everything went smoothly and I felt really healthy and energetic. After my son, Graham, was born I thought I was fine but in retrospect I think I was unusually tired and during those first few years really struggled with fatigue and migraines. For several years we tried to have another baby but had no luck. I think it was actually a blessing because my health was great...until I was 33.

I woke up early one Victoria Day weekend in May with my heart pounding so hard my husband literally thought there was an earthquake. My son was 4. The big lilac tree outside the front door was in full bloom, along with the lily of the valley, and I was so sad to be leaving in an ambulance. I was diagnosed with ventricular tachycardia, a life-threatening heart arrhythmia. After three hours of constant pounding I was put under anesthetic and my heart was shocked back into rhythm. I woke up feeling like I'd been hit by a truck, but I was basically feeling normal again. For three weeks I underwent tests at the Toronto General Hospital, and became a patient for the first time at the adult congenital clinic – a clinic I didn't know existed. My pulmonary valve was leaky and my heart had become so enlarged that I would need a pulmonary valve replacement. This was in 1994, pre-internet, and I basically knew very little about my heart condition besides being told not “to overdo it” – whatever that meant. The lead-up to surgery was pretty scary for me and it was compounded by having to be all of a sudden away from my family. I was in the hospital for three weeks having tests and my husband and son would come to visit me and invariably my son's clothes would all be on backwards. It's funny how something that would normally bother me didn't seem important at all! (I've pretty much maintained that perspective ever since).

I was scheduled for surgery in November (six months away) but my heart rate was so low that they advanced the date and in July I had surgery for a pulmonary pig valve replacement. I stayed in the hospital for all of five days, and was at my sister's wedding two weeks later (not the life of the party but

(continued on page 10)

I was there!). About six weeks after surgery I resumed my regular activities, including tennis, bike riding, walking with my dog, and working.

Despite everything I feel very healthy and generally live a pretty ordinary life. I have my B.A. in English from U of T, have travelled a lot (including hitch-hiking across Canada, walking down and up the Grand Canyon, and backpacking through South America). I work in publishing, my son is now 20 and at university, and I generally can do most things I want to do. I have my parents, and particularly my mom, to thank for all the care she gave me through those years – and rewarding my hospital visits with an Eskimo pie from the vending machine! She's 81 and she still worries about me. If I'm lucky I will live long enough to have another surgery to replace the pulmonary valve because at some point it will wear out. I know that I'm actually "old" for a CHD patient and of course I worry about the future and sometimes struggle with anxiety. I have to make an effort to manage stress otherwise I experience arrhythmias. I try to deal with it by walking and staying busy, and working from home, for the most part, allows me to manage my own time. Our second Border Collie named April, now 9, keeps me walking fast.

In 2004 I attended an information night at the Toronto General Hospital adult cardiology clinic. Dr. Gary Webb, the director at the time, told a group of us that we needed to advocate for our own health, because the doctors and nurses couldn't do it all. Following that meeting four of us formed the **Canadian Congenital Heart Alliance** (www.cchaforlife.org), a registered non-profit whose mission it is "To improve the quality of life and health outcomes for individuals with congenital heart defects by raising awareness, providing peer support and mentoring, and advancing research." Since 2004 one of the founding members died at age 40 of the same heart defect as mine, and a particularly dynamic executive member died following a heart transplant at age 34. Many others who help have had their own medical and psycho-social struggles. We have been working as volunteers

to try and educate patients and the public that congenital heart defects last a lifetime: they can be repaired but are never fixed. Most patients will require follow-up surgeries, medications, and/or devices like pacemakers and implantable defibrillators. When I was a kid I was told I was fixed, because back then they didn't know any better. Back then only 20% of us survived – now it is 98%! In fact, there are now more adults with CHD than kids (about 130,000 adults vs. 50,000 kids in Canada). The problem is that the healthcare system hasn't kept pace and there are too few cardiologists specially trained in adult CHD, too few hospital beds, too long wait times for surgery, no social workers, only one specially trained psychologist(!), and basically no support system in place to help patients. There are many more patients out there who are like I was; they aren't aware that they should be seen regularly by a specialist in adult CHD, often until it's too late.

It's been a real struggle for us to communicate this message to parents because to many of them age 18 seems forever away, but we know that it's important to lay the groundwork for life with CHD after age 18, when there will be a huge need for follow-up care. Though I'm doing well thanks to the outstanding medical care I've received all my life, many patients I know are unable to work, some are on disability, and many really struggle to get by. In my view, we owe them the same level of care as they received as children. I know we're not as cute, but we still have a lot to offer.

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

Three cheers for grandparents!

Our recently published article in a prestigious nursing journal, *Journal of Advanced Nursing*, highlights the key contribution that grandparents made in the families who participated in the Sano study. Thanks to the parents and grandparents who participated in this study!

AIM. This paper is a report of a study of the process of grandparent involvement with siblings of preschool children with hypoplastic left heart syndrome.

METHOD. Individual interviews were conducted in 2007 with 15 grandparents of six preschool children with complex congenital heart disease. The interviews were conducted in home settings or by telephone.

KEY FINDINGS. 'Stepping in as needed' and 'safeguarding relationships' were identified as two core categories related to grandparenting siblings of children with heart disease. Grandparents stepped into a parent role with toddler and preschool-aged siblings by attending to their daily care routines, recreational and play times, and relational needs while parents were occupied with their sick and hospitalized infants. Grandparents' concerted efforts to sustain parent-child and child-sibling relationships were also striking.

Reference: Ravindran, V., & Rempel, G. (2011). Grandparents and siblings of children with congenital heart disease. *Journal of Advanced Nursing*, 67(1), 169-175.

If you would like more information about the study findings, please contact us.

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Grandparents' Corner

A child with CHD affects not only the immediate family, but the extended family as well. As a grandparent, your experience is unique. Not only are you concerned about your grandchild's condition, but you worry how your own child is coping with the challenges of parenting a child with CHD. Here is the story of one such grandparent.



Being the fourth of five children in a southern Alberta farm family, I was well nested, but as often as not, I found myself having to fight for air and survival as well. It did not take many years to realize that life was not all bliss and comfort, but rather a place where self preservation was a definite requirement. I was a spontaneous, exuberant and curious child, and I often found life came with a slap in the face, as rules seemed to be more important to those around me than enthusiastic exploration. Puberty and young adulthood were no better, as I encountered the wily hunters of innocents with their surprise tactics and the attitudes towards females of my culturally male-dominant society.

Eventually, I married and had a lovely fair-haired boy and after 2 ½ years a beautiful girl. As I lay in my hospital bed after her delivery, I wondered how I would protect her and coach her from the same distasteful experiences I had lived and borne as a child and youth. I had wished for a boy, for in the male-ruled religious community I was born into, boys were obviously the winners in life and now I turned my face to the wall and wept for the future of this girl child.

The years passed with joy and confidence, then three ½ years ago, this lovely young woman was pregnant and I drove with her to

get an ultrasound. To my great alarm, when she emerged from the building, she was quiet and very solemn. "There may be a problem with the heart," she whispered sadly. My mother heart was stricken for my special daughter, but I stayed calm as I am wont to do and assured her that all would be done to help and if things could not be helped, we would weather the storm together, as we always had.

Her husband was informed and the proper doctors were consulted. It was determined that the child was a girl and that she had critical aortic stenosis which would most likely have to be treated as Hypoplastic Left Heart Syndrome. As the time of delivery grew near, Cindy and Jorge, who live in Calgary, were told she would have to deliver in Edmonton so the baby girl could be whisked immediately after her birth to the Stollery Children's Hospital for surgical intervention to save her life.

Because she would have to be in Edmonton well before her due date, we had to find a place for Cindy to stay in a city where she had never been before and was totally unfamiliar with. Vulnerable and afraid as she was, we both knew she would have to stay with someone supportive and loving if she was to carry out this heavy assignment. But, to our great advantage, I had a nephew working there while his wife attended U of A, and I knew they were faithful church goers! I contacted them, they asked of the congregation and a fine middle aged couple stepped forward with open arms and hearts to receive Cindy into their loving home until her confinement and delivery. Meanwhile, husband Jorge continued to work at his job in Calgary, traveling to Edmonton by bus on weekends while my own husband, John, and I cared for their then 3 year old daughter, Sophia, in Airdrie.

On October 14, 2007 the very sick and fragile, Alexa Lili was born and was duly transported to the ICU at the Stollery. And there my daughter lay alone at the Royal Alexandra, her husband having accompanied the child to the ICU, alone without even having been able to hold her baby daughter for a second, after having delivered her in haste without any time for medication. Now was the hour in which my mother-heart broke for the first time over my lovely daughter, for I had done a good job of being there for her always. Talking her through the tough spots of life while she attended university, worked at a job that threatened to

destroy her, and married and moved far away to Mexico for six years.

Some things cannot be undone, but they can be mended and reconsidered and built on for a better day. So from then on I have done whatever I could, to help wherever possible while the parents sat vigil and prayed beside a very sick child, and gave their precious daughter into hands of the miracle working doctors and to God. And given a great opportunity to serve, I stayed at the Ronald McDonald House in Edmonton to care for the 3 year old Sophia so she could have some family structure and so that her parents could feel more at ease in their duty to their invalid daughter, Alexa.

At the house we called The House of Joy and Pain I met so many, many other daughters and sons who had children in various stages of jeopardy and healing and gained more in compassion and reaching out than I could ever hope to do again in my lifetime. An unexpected gift, as we rejoiced and cried in turn as families came and went for the month we spent there, leaving with the bonus of a goodly number of "forever" friends that will remain in my heart always.

And now, 3 ½ years later, I have a bouquet of three girls to coach and encourage, no longer afraid of the hurt the world can bring, more often than not, to the female gender. For I have grown wise and informed and calm; able to nurture a joy within chaos that only suffering and experience can engender and teach us.

I do not know the outcome of our lives, or Alexa's life expectancy, but each day as I delight in her and her sister, Sophia, and my daughter, Lucinda – on the phone or in person, it is enough for that day to fill that caramel-soft and sweet spot that has grown in my heart because of them and I am content.

Submitted by Trudy Schmidt, Grandmother to Alexa, (age 3), who was born with critical aortic stenosis and hypoplastic left heart syndrome

Are you the grandparent to a child with CHD? If so, we would like to hear from you! Please submit your story to jenb@heartbeats.ca to share your unique perspective with our readers.

Parent Resources

In this section of the newsletter, we invite you to share your expertise. As a parent of a child with heart disease, you have learned a lot! Share with us the books, websites and other resources you have found valuable on your journey. Whether your child is a baby, teen or somewhere in-between, we all have things that have made our days a little easier—so let's share these ideas with each other!

Website Review

Cove Point Foundation – Congenital Heart Disease

Helen B. Taussig Children's Heart Center, Johns Hopkins University
www.pted.org

When I first learned that my baby would be born with a heart defect, one of the first things I did was research his diagnosis on the internet. Wading through an enormous amount of information can be very daunting, especially when all you want is reliable and straightforward answers. I was glad to come

across Cove Point Foundation's website because it had everything I was looking for; details of various forms of heart defects, tests and procedures, health concerns, nutrition, school issues, and much more. It was also one of the few sites that addressed one of my son's rarer heart anomalies (DORV). In total, the site provides information on 49 heart anomalies and related conditions, so it is very comprehensive. One of the features that I like the best is a nifty roll-over function that allows you to see your child's defect compared with a normal heart structure. There is also a section for adults with CHD that addresses health and lifestyle issues. I recommend this site to anyone looking for concise, easy to understand information about their child's heart defect. As my son gets older, I plan to use this site as a teaching tool to help him understand his own unique anatomy.

Jen Beleshko is mom to Roman, age 3, born with dextrocardia, DORV, and a single right ventricle.

Advice From Our Parent Experts – You!

Because a child's heart condition affects the entire family, how have you helped your other kids cope when your heart child required special attention?

Both our kids have heart issues, but when Grady was going through his surgery and subsequent recovery, Dawn-Marie would give Addison a vitamin or something when Grady was getting his medicine to make her feel like part of the process. Also, because of our unique situation, when we are going to appointments or getting procedures done for Grady we are able to explain to Addison about the similar things we had to do for her when she was in the same situation.

Danny Wolsey, Dad to Addison (age 3), born with an AVSD and Grady (age 11 months), born with a VSD and right ventricle tract obstruction.

Our daughter, Janelle, is only 20 months older than our heart child, Isabelle, so she was quite young also when Isabelle had her three surgeries at 11 days, 6 months and 4 years of age. We were extremely grateful for the help of extended family, especially grandparents, to look after Janelle and make her feel special while Colin and I had to be so focused on Isabelle. As well, as much as possible, Colin and I tried to make a point of spending time with Janelle when we weren't at the hospital with Isabelle.

Patty Wiebe, mother of Isabelle (age 10) born with Hypoplastic Left Heart Syndrome.

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Heart Beats
Supporting Children with Heart Disease

The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart.

– Helen Keller