



# Keeping the Beat

Fall 2011

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

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## Heart to Heart at Lake Midnapore

Once again, Heart to Heart in July was held at beautiful Lake Midnapore in SE Calgary. Eight families attended this year, and while the adults conversed, the children played in the water, built sand castles and played beach volleyball. What a pleasant way to share experiences with new families and catch up with the “regulars”! We look forward to many more opportunities to get together in the future. Be sure to continue reading *Keeping the Beat* for upcoming family events.



## 2nd Annual Heart Beats Family Fun Run

Heart Beats will be hosting its 2nd Annual Heart Beats Family Fun Run on Saturday, October 15, 2011. The race will begin at Eau Claire Market and follow 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. Entry fees will be refunded to runners who collect over \$300 in donation/pledges. If you would like a donation/pledge form, please email us at [info@heartbeats.ca](mailto:info@heartbeats.ca) and we will send one to you.

Please see the back page of this newsletter for more information, or contact Cindy at [cindyc@heartbeats.ca](mailto:cindyc@heartbeats.ca). Look for sign-up information at [www.heartbeats.ca](http://www.heartbeats.ca) or at [www.runningroom.com](http://www.runningroom.com).



## 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:

- **September:** Monday, September 12th at 10 am at the home of Cindy Castillo, 83 Auburn Glen Heights SE.
- **October:** Friday, October 14th at 10 am at the home of Patty Wiebe, 43 Midvalley Crescent SE.
- **November:** Tuesday, November 8th at 10 am at the home of Lynn Nakoneshny, 187 Willowmere Close, Chestermere.
- **December:** In December we invite the whole family to our Annual Christmas Party on Sunday, December 4th at 1:30 pm at the home of Colin & Patty Wiebe, 43 Midvalley Crescent SE. If you are able to attend, please RSVP to Patty at [pattyw@heartbeats.ca](mailto:pattyw@heartbeats.ca) by November 27th.

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](mailto:pattyw@heartbeats.ca) or by phone at 403-256-7423.

## Keeping the Beat by e-mail

Never miss an issue! Subscribe to our newsletter today by sending an email to [info@heartbeats.ca](mailto:info@heartbeats.ca) advising us of your name and e-mail address, and you will receive our electronic version of "Keeping the Beat". Your email subscription will enable us to reduce printing and postage costs, so that we may use these funds to assist heart families in other ways. Alternatively, you may download a full-colour version of Keeping the Beat from our website at [www.heartbeats.ca](http://www.heartbeats.ca).

Note: E-mail addresses will be used only to distribute *Keeping the Beat* newsletter and notices of Heart Beats events; e-mail addresses will **not** be given to any third party.



# The Canadian Congenital Heart Alliance – we're here for you!

In 2004, a group of adult congenital heart defect (CHD) patients attended a meeting at the Toronto General Hospital where we learned that the clinic, the largest and most prestigious in the world, was at risk of being closed due to lack of funding. The doctors and nurses there encouraged us to band together to advocate for ourselves because they said they couldn't do it alone. Until that evening none of us had a clue that our care was in jeopardy. Like most patients, none of us knew anyone else with a heart defect and besides our appointments and surgeries, didn't have much to do with the hospital. It was a real wake-up call!

Later that month four of us formed the Canadian Congenital Heart Alliance (CCHA), a registered non-profit organization made up of patients, their families and friends, and the medical community, to support and advocate on behalf of Canadians with CHD. While collecting information and statistics to create a brochure and website I learned that thanks to outstanding pediatric care there are now far more adult "survivors" than there are children (130,000 adults vs. 50,000 kids) and yet the medical system hasn't kept pace. While it was known that more and more children were surviving past 18 years of age, not much was done to prepare for what has been referred to as a "tsunami" of survivors. In the 1960s only about 20% of children survived to age 18 and now it is 98%. In fact there are more Canadians with CHD than there are with multiple sclerosis, HIV/AIDS, Parkinson's disease, cerebral palsy, or cystic fibrosis, and yet hardly anyone knows about it, and the funding just isn't there.

There are numerous children's support groups across the country (mostly raising money for pediatric hospitals) and several local adult groups but CCHA is the only national organization representing both children and adults with CHD. Our thinking is that although the medical system is divided into pediatric and adult care, CHD lasts a lifetime; while CHD patients can be repaired with surgeries, they are never fixed.

We have been focusing a lot of our energies on adult CHD because that's where the crisis is. After age 18 the standard of care largely evaporates; that's not to say it isn't very good, but there just isn't enough of it. There are too few centres in Canada with specially trained cardiologists and surgeons, and little incentive for young cardiologists to specialize. There are very few "soft services" available, like social workers and psychologists to deal with the psycho-social issues which plague patients who have struggled all of their lives with a life-threatening illness.

We would like to have more parents involved because they have a vested interest in their child's care and have the energy to help.

## What we've done so far

### Funding for an adult CHD research project

With a small executive committee and an advisory board we have accomplished several landmark events: we were finally successful in getting Heart & Stroke Ontario to provide, for the very first time, \$100,000 for an adult CHD research project. We have made a couple of strong allies there who are trying to help us though CHD is still not part of their mandate and may never be.

### The Beat Retreat Camp

For the past two years we have run an adult weekend camp called the Beat Retreat. It provides adult patients the rare opportunity to get together to share stories, support, and the chance to have fun canoeing, rock wall climbing, playing volleyball, doing arts and crafts, and much more. For many, it's the first time they've been away to camp. In the future we hope to run a kid's camp because there is only one in all of Canada for kids with devices or who have had a heart transplant.

### Website and online forum

We have a great website with lots of information including recent statistics, as well as an online forum/chat room for CHD parents, kids and adults to share information.

### Awareness DVD

Last summer we created an awareness film called "Born with a Broken Heart" – you can see it on our website or on YouTube. So far it has over 1,800 views!

### Attendance at CCS

For the past three years we have set up our booth at the Canadian Cardiovascular Society meeting to help make regular cardiologists more aware of CHD and the need for specialized care for their patients. We will be attending again this fall in Vancouver.

### Education days, service clubs, and more

We have participated in pediatric family education days, talking to parents and kids, and we have spoken at several Rotary and Lion's clubs in Ontario, Quebec, and NS. We have also spoken to hundreds of cardiologists at regional meetings and have tried to get our brochure available in every centre. There is so much more we can do, but we're limited by funds, people power, and energy. Many of our members are struggling with major health issues.

### Life, dental, and travel insurance without a medical

For most of us, getting life insurance was out of the question. Some patients manage to get coverage through work, but many are out of luck. CCHA is the only organization to offer life, dental, and travel insurance to patients with no medical. For contact information, visit the website and click on "Resource Centre".

### Chapters

We have Ontario and Maritime chapters and possibly a chapter starting up in BC. Unfortunately, our Alberta chapter was discontinued but we're hoping to get another one going in the future. We're hoping more people take the initiative to set up chapters in their community and to fundraise so we can expand our programs and help more people.

If you would like to learn more about CCHA please visit our website at [www.cchaforlife.org](http://www.cchaforlife.org) and if you'd like to get involved please email me at [communications@cchaforlife.org](mailto:communications@cchaforlife.org).

*Shelagh Ross*

*Vice-president and CHD patient*

## Offbeats

While we are sad to see Kelly Webber leave the group, we are very excited to welcome Julie Westlund, the new Cardiology Clinic nurse, to Offbeats. Julie already has lots of excitement and energy for Offbeats and she hasn't even met the great group of youth yet!!!

Offbeats will kick off again at the end of September and run monthly until May. We plan to enjoy some of our usual favourite activities but welcome any new ideas the group might have for this year.

For more information, contact Laura Thurber-Larsen, at [Laura.Thurber-Larsen@albertahealthservices.ca](mailto:Laura.Thurber-Larsen@albertahealthservices.ca)

## Cardiology Clinic News

The clinic is in the process of evaluating a new echo system called "Ventri Point" which has the ability to rapidly and easily provide right ventricular function including shape and volume.

A Family Heart Transplant Camp is planned for September 23-25, 2011 at Camp Warwa. Please contact Kelly Webber for more information (403) 955-7316.

## Your Support in Action

Donations made to Heart Beats Children's Society of Calgary are used to provide information, resources and support to families dealing 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
- Expansion of the Ronald McDonald House in Edmonton, Alberta

We appreciate and acknowledge the donations received from the following individuals and organizations from May through August 2011:

- Cathy Howarth
- Government of Alberta Community Spirit Grant
- Mike Power through the Telus Dollars for Doers programme
- Telus Charitable Giving programme
- Raimount Energy Inc.
- Wolsey Structural Engineering Ltd.

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](http://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.)

## Important research for Fontan, Protein Losing Enteropathy (PLE), and Plastic Bronchitis (PB) Patients

The Fontan palliation is the final planned surgery in the repair of a single ventricle-type of heart defect. Despite the best efforts of those who care for patients who have had this surgery, a small number of patients develop poorly understood and difficult to treat complications including Protein Losing Enteropathy (PLE) and Plastic Bronchitis (PB).

We do not know exactly how or why PLE and PB occur. We believe that many factors may lead to PLE and PB and that the causes may vary some from one patient to the next. The key to treating these difficult but rare conditions will be to learn as much about them as we can from as many different patients as possible. We will try to find things that patients with these conditions have in common and determine what may be the most important areas for future research and for the development of new treatments. The University of Michigan C.S. Mott Children's Hospital Congenital Heart Center is committed to developing new treatments for some of our most challenging problems. We have therefore made learning more about PLE and PB a priority for our program. Our goal is to identify causes and potential treatments to improve the lives of our patients.

**If you have had a Fontan (even if you haven't had PLE or PB), please take a few minutes to fill out our anonymous survey. The information you provide will help to lead us toward a cure. Please visit our website at <http://www.mottchildren.org/congenital/research/FontanFacepage.html>**

# 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 Bill Coon.**

Let me begin by saying that it is both an honor and a privilege to be sharing my story with the Canadian public, because my first heart donor was an infant born in Ontario, Canada. My name is Bill Coon. I am a two-time heart transplant recipient, first-time kidney transplant recipient, an author, a son, and a man who is forever, eternally grateful to two complete strangers.

I was born with a congenital birth defect (Hypoplastic Left Heart Syndrome) on April 24, 1989, in Barrington, Illinois, USA. In laymen’s terms, it meant that the left side of my heart was severely underdeveloped. It also meant I would require a heart transplant and my life expectancy clock of twenty-one days had just begun ticking.

I came into this world not breathing. I had a heart attack seconds before I was born. Before I had even seen the light of day, I was in severe pain. I had stabilized, but not for long. The doctors knew I was deathly ill, and the next day I was placed into a helicopter and flown directly to a pediatric hospital in Chicago, Illinois, USA.

It was that very pediatric hospital where the “King of Hearts” practiced. His name was Dr. Idris. He was a German Pediatric Cardiac Surgeon who had spent the last sixteen years of his life experimenting on puppies and kittens, perfecting his technique at heart transplantation. He had the steadiest of hands, and they were going to have to remain steady, for the baby that just arrived on the roof of his hospital was in dire need of his expertise.

Days went by. My parents watched me grow sicker with every passing hour. They witnessed families come and go, many of them with tears running down their faces, for a great deal of babies in the NICU nursery did not survive.

My parents developed friendships with these couples. Several of them offered their child’s heart to me as their parting gift. None of the hearts were ever a match.

My Mom could not stay by my hospital bed every night. Instead, she would leave me a wind-up music box that she knew I loved. She had a motherly intuition that told her I enjoyed the music, even though in my first twenty-one days on this Earth I never once opened my eyes, nor did I ever smile. My Mom would instruct the nurses to play the music for me as I slept—she wanted to comfort me even when she was not around.

On May 15, 1989, my life expectancy clock had reached its final hours. It had been twenty-one days. The doctors were going to pull the plug because on the twenty-second day my other organs would begin to fail. Nobody wanted me to experience any more pain. I have been told that death was in the air that day. I had hit rock bottom, but something was different. The energy of the doctors had changed. They were awkwardly upbeat given the upsetting circumstances. At 4:15 PM, my parents were pulled aside and informed that Canada had just joined UNOS (The United Network for Organ Sharing) and that a matching heart in Ontario, Canada had just been located. “All we can do now is pray for good weather and clear skies,” my parents were told. With that, a helicopter and a Learjet embarked on a journey to Canada to save my life.

At midnight, my transplant was performed. I was the eighth infant heart transplant to be performed in the USA and the fourth in the Midwest. After the procedure, my entire body was so swollen that I supposedly did not look like myself. I looked like a different baby. My Mom watched me in my cradle that night. She wound the music box and it began playing the sounds that I had fallen asleep to the first three weeks of my life. That was when I turned my head towards the music. It was May 16, 1989, the day I opened my eyes for the first time.



From that day on, I lived a wonderful, healthy, normal life. I was just as rambunctious and playful like any other child. Truthfully, the only limitations that I ever had were those that I put on myself. For years, I refused to attend any pool parties or take my shirt off in locker rooms because I was embarrassed of my surgical scars. I feared everyone would ask questions and once they received the answers, they would treat me differently. It wasn’t until my junior year in high school that I finally overcame my body image issues and told my friends, Jen and Jo, I had a heart transplant. In my mind, junior year is when I finally came into myself. I had matured mentally and I was finally comfortable with “me.” It was junior year when I understood that my transplant was a blessing and not something to be embarrassed of.

In the fall of 2008, I began studying advertising and communications at Columbia College Chicago. I excelled in my classes and I eventually obtained an internship at one of the top radio stations in the Chicago market.

*(Continued on page 6)*

## CHD and Me – Talking With Adults With CHD

(continued from page 5)

I loved every moment of it. My life seemed to be on autopilot. Everything was going my way. I learned that if you put forth the effort, you eventually reap the benefits. However, as they say, “All good things must come to an end,” my autopilot feature shut off just as the school year ended.

On June 8, 2009, I was rushed to my community hospital after I looked down and found that everything below my knee was swollen. Upon arriving to the emergency room, the doctor evaluated me, took a chest X-ray, and returned to my room with a solemn look on his face. He turned to my parents, and in a sad, but assertive way said, “Your son is in heart failure.”

A pocket of fluid had enveloped my heart. The water retention had gotten so severe that my heart was no longer strong enough to pump the fluid through my body, thus causing the build-up in my legs. I had developed Transplant Vasculopathy, a rare phenomenon in which a transplanted heart deteriorates rapidly in a short period of time. My kidneys were also failing. Due to a lifetime of taking anti-rejection medications (immunosuppressant), my kidneys happened to simultaneously crash alongside my heart.

The ensuing four months featured a misdiagnosis, countless procedures, and three separate hospitalizations. The final hospitalization was the longest—I spent 70 days in the CCU fighting the clock as I awaited a second chance at life.

Fortunately, due to the selflessness of one family, my life was saved for a second time on October 21, 2009. That day, I received my second heart transplant. The kidney was transplanted the following day. To provide you with an idea of how quickly my life turned around, I was discharged from the hospital on November 2, 2009. On December 28, 2009, I moved into a studio apartment in Chicago.

Something I did not mention was that at the onset of my illness, I began to keep a journal. Initially, the purpose of the journal was for my own, personal therapeutic use. Eventually, after two weeks of writing, I realized that if I were to survive I could potentially be an inspiration to

others to do the same. I also hoped to serve as a support system to anyone battling any kind of illness. I am proud to say that on September 13, 2010, I published all my journal entries (along with some short stories) in the form of a book entitled, *Swim: A Memoir of Survival*. In just under a year, the book has sold internationally and it has been adopted and praised by both readers and charities battling cancer, organ failure, congenital birth defects, Crohn’s Disease, and a plethora of other illnesses.

I am currently writing my next novel, *The Perfect Cloud*, public speaking, promoting organ donor awareness, and fulfilling my dream of aiding readers (via e-mail) who need someone to talk to when they are ill.

If you would like more information about *Swim* or myself, please feel free to visit my website at [www.billcoonbooks.com](http://www.billcoonbooks.com)

## 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](mailto:jenb@heartbeats.ca)

## Information about Organ Donation

Adapted from the Southern Alberta Organ and Tissue Donation Program

### Did You Know...

- One organ and tissue donor can save up to 8 lives and enhance as many as 75 more
- There are nearly 400 Albertans on the waiting list for an organ donation
- There is a greater chance you will require an organ transplant than there is of becoming an organ donor.

The decision to become an organ and/or tissue donor differs from person to person. To many, donation represents a way to give life to others, while some may not be at ease with the idea. It is truly a personal choice and is often based upon a person’s individual values, beliefs and comfort levels.

For those who have made the decision to donate, signing the back of their Alberta Health Care card is an important step. However, it is imperative to discuss your wishes with family members because the next-of-kin will need to sign a consent form that can overrule a signed health card. Since timing is crucial when it comes to organ and/or tissue donation, family members may feel better about dealing with the issue of donation if they know what the wishes of the patient are in advance.

More information about organ donation in Alberta can be found at [www.calgaryhealthregion.ca/hope](http://www.calgaryhealthregion.ca/hope).

# Community Updates

## Finding Our Niche

By Susan van Asselt

Over the years, my husband and I have read the stories of families and kids dealing with the impact of having Congenital Heart Defects (CHD). We have been inspired by those stories and reading them has allowed our family to move away from a bubble of isolation that develops because of living in a small community to being part of something larger and knowing that we are not alone in living with CHD and learning from it as well.

Our daughter, Nadia, blessed us with her presence on September 24, 1994. She was born with a congenital heart defect called Ebstein's Anomaly. This is a rare defect that, in Nadia's case, became apparent right at birth when she had a blue tinge to her skin. We were fortunate enough to be referred to Calgary where we met Dr. Harder and all of the wonderful people at the Alberta Children's Hospital. They were able to answer all of our questions in a caring and practical, no nonsense manner, and we could go home to Rossland, BC feeling safe and secure and knowing we could live a fairly normal life. Nadia has had three tricuspid valve replacements spaced over her 16 years. The latest valve replacement took place in Edmonton on May 9, 2011. Nadia's team in Calgary has been rounded out by the equally supportive team at the Stollery Children's Hospital where she has had two of her three surgeries, headed by Dr. Rebeyka.

Rossland is a small community in the Interior of British Columbia. It is home to some of the best powder skiing you will ever find. Walk down the streets of Rossland in winter or summer and you will invariably hear about the epic powder day people had or the great mountain bike ride they just did with friends. This all did not come so easily to Nadia. Skiing made Nadia cold; backpacking with other families was met with definite difficulties for Nadia. She tried mountain biking for a couple of summers and then soccer, which worked until she was about

11 when they switched to a larger playing field which involved too much cardio for her. Throughout the years, she took some dance classes and then the year Nadia was 12, an angel came to town in the form of Renee Salsiccioli.

Renee was trained by and has taught at the Royal Winnipeg Ballet School. She and her husband decided to return to their hometown to raise their daughter. Renee and Nadia click. Renee instils discipline, structure and respect for dance and Nadia has been inspired by this challenge. They have worked together to create a program that pushes Nadia to be an elite dancer while respecting the limitations she has. Renee expects a lot from her dancers. Nadia loves this. She rises to it over and over again. Nadia loves the therapeutic aspect of the program and says, "Dance is a way I can express myself. I can show people the different side of me without having to speak or write it down. I believe that everyone can speak the language of dance so you can get through to more people. When I turn on the music and start to dance, I forget all the bad things in the world and focus on the moment and the music. I'll know that I'll be ok when I can dance. I love to dance; it means the world to me and it gives me the power to survive through the good and bad. Dance motivates me to inspire other people to follow their dreams!" She and her dance troupe perform locally and as far away as Kamloops. She has found her niche.

From the day that Nadia was born, we started learning about a different world. It was a world where not everything happened "by the book" and developmental milestones were not going to be met in the same way. We also had to come face to face with death and realized that we all can die at any time. We learned to live in the present, to do everything we can now because there might be a time when we will not be able to. We have learned not to take life too seriously and at the same time, make every minute count. When someone says, "I can't", I think about Nadia and say, there is no such thing as can't. There is only, "let's figure out a way. Let's find out how, if that is your passion." We have learned to dwell in possibility.

When Nadia sets foot on the stage, she inspires all of us to do that; to dwell in possibility; to find a way to make all of our dreams be realized. Whatever we realistically set our minds to, we can accomplish. This is Nadia's legacy. And, we are so grateful to witness this over and over again. While the journey has not always been easy, it has been a profound one.



### 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 the newsletter coordinator at [jenb@heartbeats.ca](mailto:jenb@heartbeats.ca)*

# The “Beach” at the Stollery Children’s Hospital

By Dianne Tuterra, Child Life Team Leader, Child Life Department

A hospital stay can be a challenging and unfamiliar experience for children and their families. The Child Life Department at the Stollery Children’s Hospital helps children and families adjust to and understand hospitalization, illness and treatment. They do that in many ways but most importantly they try to promote normalization for children, and what’s most normal for children? Play, of course!

The “Beach” is a pre-school/school-age playroom located on the 4C walkway at the Stollery Children’s Hospital. It is safe place for children to come to get away from their room and do what comes naturally for them. A place to play, socialize with other children and spend time with family members.

Child Life Specialists use arts and crafts, music, games, socio-dramatic play, medical play, cooking and many other experiences to normalize the environment and provide opportunities for socialization, exploration and the expression of feelings.

Through involvement on the “Beach” children are creating positive experiences and memories of their hospitalization. It is a place that focuses on the strengths of the child while promoting optimal development. It is a place to make choices, be in control of their world and have fun.

The “Beach” is also the place where special events are celebrated, special guests come to visit and family lunches or events are held.

The “Beach” is open daily and playroom activities are planned each day to address the developmental needs of the specific patients in the hospital.

Often when children leave the hospital and they are asked about their time there they will say, “I got to go to the Beach”.



# 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 two such grandparents.**

Love isn't a feeling; it's something you do. Love is action. Love rolls up its sleeves and wades into messes it did not make.

This is how we, the grandparents to be, encouraged our son, Ferrell, and daughter in law, Jen, to seek advanced professional medical advice concerning the indicated heart defects of their unborn child.

Despondent with initial negative advice, they refused to abort. Ferrell was able to gain medical insight from his mother, Lorraine, a retired RN, who had worked at the University Hospital in Edmonton. She sat side by side her son and daughter-in-law during a collaborative meeting of physicians from Edmonton and Calgary that took place one month after the initial diagnosis. Jen was then put under the prenatal care of Dr. Billy Wong, and was required to commute to Edmonton every month for monitoring of the pregnancy and development of the fetus. During the last month, Ferrell and Jen followed medical protocol and came to live in our home in Edmonton since the birth would be at the Royal Alexandra Hospital in Edmonton.

Our grandson, Roman Beleshko, was born on October 9, 2007 and was soon after transported to the Stollery Children's Hospital, Neonatal Unit. Before he was taken to the Stollery, we saw our grandson Roman, in the incubator. It was a promising and relieving observation. Hours later, we visited Roman at the Neonatal Unit where we were required to wear mask and gown. He responded to our touches and voices. After many more visits, Roman was discharged and transferred to the Calgary Foothills NICU by medical air transport. Roman was well on his way to becoming a frequent air flyer.

A few weeks later, he was discharged from the Calgary Foothills to be home with his parents. Jen and Ferrell exhibited tremendous

inner strength, commitment and dedication in providing all of the post-op care. They had very little help and experience in nasogastric gavage feeding, but somehow rose to the occasion so they could bring their baby home.

Within months, they were back in Edmonton for Roman's first open heart surgery by Dr. David Ross (a very compassionate and talented surgeon) because Roman's oxygen sats were down to below 60. He had blue aura around his mouth and fingertips even when on continuous O2. The surgery was successful, and we visited Roman every day that he was admitted. Roman was discharged within a week, and completely bounced back within a month.

In the fall of 2010, at age 3, a second surgery was required, called the Fontan procedure. Winter was upon us and precautions were needed to avoid contact with anyone with colds and flu virus. Our home was prepared for their arrival and we requested anyone with colds to stay away. They arrived a few days before the scheduled November 30th surgery to have all pre-op tests taken. The surgery was cancelled due to lack of beds. They returned to Calgary and were asked to return to Edmonton in two weeks, surgery rescheduled for December 10th. No Pre-op work was required as it was recently done. After several hours in surgery, Dr. David Ross came out to give the parents the good news that all went well, which was a relief to all of us. After spending one day in the PICU and two days in the ICE room, he was transferred to the standard ward where we were allowed to bring him gifts, go to the playroom with Roman and wheel him around. He responded remarkably with good spirits and a fine sense of humour. A few days post recovery, the Doctors visiting Roman noticed his toy dinosaurs perched on the edge of his bed. They asked him, "What does your dinosaur eat?" Roman looked with intent at the physicians and replied, "Doctors!" The room erupted with heart filled laughter. Great medicine!

We were privileged to share our home with them for both of Roman's surgical procedures. Benefits were gained during these stressed



times; we saw Roman from learning to crawl, to walk and then lots of talking. When Roman had his second surgery we babysat his cat "Brewster", who would daily, usually at 4 pm., sit at the front living room window in expectation of Roman coming home. When Roman was released from the Stollery and entered our home, Brewster rolled over in excitement, and Roman joyfully rubbed Brewster's tummy: friendship confirmed. These were times of concern, worry, prayer and sharing for which we are most grateful for the Doctors, Nurses and support staff providing excellent service to our little grandson.

Our precious Roman is a fighter; he recovered from the surgeries quickly, and today he is very active, growing, full of imagination and is advancing with his verbal skills, word recognition and child computer skills. His newest joy is going fishing with his Dad and his uncle Jeremy at local lakes and ponds around Calgary.

*Written by Harry & Lorraine Beleshko, grandparents to Roman, age 3, born with complex congenital heart defects.*

## 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](mailto: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!

## BOOK REVIEW

### **Every Second Counts: The Race to Transplant the First Human Heart – by Donald McRae**

We all remember, or at least have heard about, the great race of the 1960's – the race to be the first country to send a man to the moon. At the same time, another race was going on, one that most of us are unfamiliar with. It was the race between four cardiologists to be the first to transplant a human heart. This book tells that story and tells it well.

If you Google who transplanted the first human heart, the answer that comes up is South African Dr. Christiaan Barnard, and indeed it was. A little known fact, however, is that three other doctors, Dr. Norman Shumway, Dr. Adrian Kantrowitz, and Dr. Richard Lower, all in three separate cities in the United States, had all been doing extensive research and experiments with transplantation even longer than Dr. Barnard had, but had only practiced with canines rather than people. In fact, Dr Barnard had observed and studied Dr Lower's work.

It could be said that Dr Barnard's success at being the first had to do with luck, as

he happened to have the right patients at the right time, with politics, as the lawful definition of when a heart could be extracted from a body differed in South Africa and the USA, or it could be said that he was the first one brave enough to actually try it.

This book tells the story of all four cardiologists and the unfortunate politics and competition that inevitably enter in, even when dealing with people's lives.

*Cindy Castillo is the mother of two daughters. Her youngest, Alexa (age 3), was born with hypoplastic left heart syndrome.*

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## Advice From Our Parent Experts – You!

### What physical activities does your heart child enjoy?

Daniel loves soccer, swimming, fishing and skiing. He also lifts weights and does chin ups! I guess it helps if you don't weigh too much and only have one chin! He finally got it I think this year when he started eating healthier, lost weight and got fit. I wish it would rub off on me!!!

*Sylvia is Mom to Daniel, age 22, born with a single ventricle and pulmonary stenosis.*

Kimberly enjoys karate, biking, scootering, playing in the backyard pool for hours on end, and playing at the park especially on the swing.

*Wayne is Dad to Kimberly, age 9, born with Tetralogy of Fallot with absent pulmonary valve.*

Lucas loves riding his bike and after spending two years on a run bike he transitioned to a regular bike without ever using training wheels.

He also loves to play basketball and did play on a soccer team this year. He just started playing golf and loves it.

*Aaron is Dad to Lucas, age 4, born with Ebstein's Anomaly and had a Heart Transplant in May 2007.*

Reese likes to go for walks with her dogs, swimming and going to a park.

*Keremy and Scott are Parents to Reese, age 18 months old, born with VSD and ASD*

Jillian has been involved with dancing, soccer, running club, softball, basketball, volleyball, wakeboarding, skiing, swimming and snorkelling. The only thing that she can't do is scuba diving – doctor's orders.

*Lori is Mom to Jillian, age 17, born with Tetralogy of Fallot and Pulmonary Atresia*

Mathias does not really enjoy competitive sports. (I am not sure if this is due to personality, the fact that he is smaller than his peers, his heart condition or a combination of all of the above.) He really does enjoy swimming. When he was younger, he got cold easily so we went to VRRR (now Vecova) because they have a warm rehabilitation pool. Then, we got him a wet suit. Now that he is 7, his tolerance of the cold has improved greatly. He also really enjoys gymnastics and climbing, which I love because it is really helping to improve his core strength. He is starting to like running too. His first race was the Heart Beats 1k last year. This year we did the run for Ronald McDonald House, Rock the House 1K and are registered again for the Heart Beats run.

*Karen Perl-Pollard is Mom to Mathias, age 7, born with Tetralogy of Fallot, Atrial Septal Defect (ASD), Patent Ductus Arteriosus (PDA) and now has a pacemaker for acquired heart block.*

# Great Full Hearts – 25 years of Celebration



On February 11, 2012, Heart Beats Children's Society of Calgary will be celebrating 25 years of supporting children with heart disease and their families by hosting a fundraising gala at the Calgary Italian Club. This event will be emceed by radio and television personality Brenda Finley, and will feature live entertainment by the Heebiejeebees.

A five course Italian dinner will be served, and the evening will include dancing, raffles and fabulous door prizes. Tickets are \$100 each, and can be ordered by emailing Lori Moch at [mochingbrd@shaw.ca](mailto:mochingbrd@shaw.ca) (cheques only please). If you wish to volunteer or donate to this event, please contact Sylvia Falk at [sfalk@telusplanet.net](mailto:sfalk@telusplanet.net).

*A loving heart is the  
truest wisdom.*

– Charles Dickens



## Heart Beats Children's Society of Calgary

**Chairperson** Patty Wiebe  
[pattyw@heartbeats.ca](mailto:pattyw@heartbeats.ca)

**Vice-Chairperson** Jeannine Oliphant  
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**Secretary** Cindy Castillo

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*Disclaimer: Any personal opinions/comments expressed in this newsletter are not necessarily those of the Heart Beats Board of Directors. All submissions for the newsletter will be accepted, however we reserve the right to publish in whole, in part or not at all. Remember your best source of medical information is always your physician.*



**Heart Beats**  
Supporting Children with Heart Disease

# Heart Beats Children's Society

## 2<sup>ND</sup> ANNUAL



10 km Run, 5 km Run/Walk, 1 km Kids Run  
Saturday, October 15, 2011

Help Support Children with Heart Disease  
Register Online at



[www.runningroom.com](http://www.runningroom.com)

at any Running Room location

or

[www.heartbeats.ca](http://www.heartbeats.ca)

*Thank you for supporting children with  
Congenital Heart Disease and their  
families!*



**Heart Beats**

Supporting Children with Heart Disease



### RACE INFORMATION

Races will start at the Eau Claire market and will follow the running paths along the Bow River. The 10km and 5km races will be chip timed, and there will be prizes for the winners of each race.

### START TIMES

- 10 km Run: 9:00 am
- 5 km Run/Walk: 9:05 am
- 1 km Kids Run: 10:00 am

The Kids Run is for children 12 and under only. One adult can run with each child at no charge but the adult will not receive a T-shirt.

### ENTRY FEE

- Register before Aug. 15: \$35
- Register between Aug. 16 - Sept. 14: \$40
- Register after Sept. 15 - Race Day: \$45
- Children 12 years and under: \$10  
(for participation in any race)

### REGISTRATION

Registration can be made online at [www.runningroom.com](http://www.runningroom.com), at any Calgary Running Room location (cash or cheque only), or by mailing a cheque to:

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

### RACE PACKAGE PICK-UP

Eau Claire Running Room  
Unit #A01, 200 Barclay Parade SW

October 13, 2011: 4:00 pm - 7:30 pm

October 14, 2011: 12:00 pm - 7:30 pm

### T-SHIRTS

All participants will be given a free T-shirt. We cannot guarantee a shirt size if you register after Sept. 15<sup>th</sup>

### PLEDGES AND DONATIONS

Pledges will be collected during race package pick-up or on race day at a designated table. Entry fee will be returned for runners who collect over \$300 in donation/pledges. Donations can be made online at [www.runningroom.com](http://www.runningroom.com) or on our website at [www.heartbeats.ca](http://www.heartbeats.ca).