



Keeping the Beat

Spring/Summer 2010

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

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Congenital Heart Defect Awareness Week Celebrations Annual Family Event

Heart Beats kicked off Congenital Heart Defect Awareness Week on February 6th by hosting a party at the Southland Leisure Centre. Over forty people attended the event which featured activities for every age group. While the adults and older kids played a spirited game of floor hockey, the younger children amused themselves with a variety of activities like bowling, skipping, basketball and some imaginative combinations thereof. For those looking for more creative pursuits, a crafts table was set up and our talented young ones came up with some beautiful artwork in the form of valentines, bookmarks and picture frames. Afterwards, the crowd gathered together to enjoy some heart-shaped pizzas and other delicious treats. Before leaving, each “heart kid” received a beautiful heart shaped balloon in addition to a goodie bag, which was given to all the children in attendance. Thank you to Heart Beats for hosting another enjoyable event.

If you have not yet had the opportunity to attend one of our family events, we encourage you to attend this occasion next year.

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“Heart Kids” holding their special balloons



Heart Beats
Supporting Children with Heart Disease

Congenital Heart Defect Awareness Week Celebrations

CHD Awareness Week in the News

On February 15th, CTV ran a news segment about the Pacemaker Clinic at the Alberta Children's Hospital. Prior to the clinic opening, children requiring pacemakers had to have their check-ups at adult facilities. The piece featured 6 year old Mathias Pollard having his regular check-up with Dr. Fruitman. Way to go, Mathias!



Floor Hockey Championships!

2nd Annual Heart to Heart Easter Egg Hunt

We enjoyed hosting this fun-filled occasion at our acreage on March 28, 2010. It was a sunny day and all 23 participants enjoyed an Egg Hunt with a view! The event began with a delicious lunch of barbecued farmer's sausage, hot dogs and a healthy mix of bell peppers. Then the hunt was on, with children and their parents searching the acreage for brightly coloured eggs. All the kids did well with collecting and locating eggs, even the eggs that were hidden in real nests with spotted shells. Back in the house and away from the wind, the children indulged in their chocolate treasures. Later, many of the children partook in colouring spring time pages and decorating hard boiled eggs in the Playhouse. They also enjoyed playing on the trampoline and swing set while their parents benefited from a good heart-to-heart talk. The event wrapped up with a live performance by Mathias Pollard and his sister Veronika. Even the strong Chinook winds could not blow the smiles off the children's faces after the fun they all had. I want to thank my mother, Joanna Mangan, for helping with the crafts table and to our oldest daughter Aurora for helping with the event.



Nathan and Kirsten hunt for Easter eggs



Michelle and Paul Aris, Parents of Owen Aris – Coartation Repair on March 6th 2008.

The Aris family looks forward to again hosting this fun filled event that celebrates the strength of our families, Easter and the start of new life! We hope you all enjoy the wonders that Spring brings and that you and yours will be able to join us next year.

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 having extended hospitalization.
- "Heart & Soul: Your Guide to Living with Heart Disease" information binders (distributed through the Cardiology Clinic).
- Supplemental equipment and toys 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 2010:

Nazan Alp

Tracey Contrada, in honour of Ava Contrada

Mike & Donna Gerlinsky, in memory of Brittany Gerlinsky

Donald Nakoneshny, in honour of Joshua Nakoneshny

Kelly Perkins

Miranda Waterhouse

The Watson Family Foundation at The Calgary Foundation

United Way of Calgary, Donor Choice program*

Anonymous, in honour of Mathias Pollard

Anonymous

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.)

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.

- **May** – Monday, May 17, 2010 at 10 am at the home of Lynn Nakoneshny, 187 Willowmere Close, Chestermere
- **June** – Wednesday, June 16, 2010 at 10 am at the home of Michelle Aris, 281130, Township Road 230, just outside the east city limits.
- **July** – Sunday, July 11, 2010 at 1:30 pm at Lake Midnapore. The entire family is encouraged to come! If you are able to attend, please contact Patty Wiebe at 403-256-7423 or pattyw@heartbeats.ca as she must provide your name to Lake Midnapore staff so you can be admitted.
- **September** – Tuesday, September 14, 2010 at 10:00 am at the home of Karen Perl-Pollard at 324 Norseman Road NW, Calgary.

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

Keeping the Beat by e-mail

Never miss an issue! Subscribe to our newsletter today by sending an email to 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.

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.



Talk with the Docs – Dr. Michael Giuffre

So often we know only the cardiologist our child visits at the Cardiology Clinic, but each of the cardiologists has an area of expertise which contributes to the overall care they provide to patients at the Cardiology Clinic. In the past issues of “Keeping the Beat”, we have featured Dr. Frank Dicke, Dr. David Patton, Dr. Deborah Fruitman, Dr. Robin Clegg, Dr. Joyce Harder and Dr. Kimberley Myers. In this issue, we are pleased to introduce Dr. Michael Giuffre.

How long have you been in Pediatric Cardiology? Has that time always been in Calgary?

My enlightenment in Pediatric Cardiology began with fellowship training at Hospital for Sick Children in Toronto in 1987, after I had completed my pediatric fellowship in Calgary and Australia. I spent 2 years in Toronto and then went to Houston Texas to do a year of subspecialty training in the field of pacemakers and electrophysiology, which is the diagnosis and treatment of arrhythmias of the heart. This was at Baylor University at the Texas children’s Hospital. I came back to Calgary in 1990 and joined Dr. J. Harder and Dr. B. Sommerville, working at the Associate Clinic and the old Alberta Children’s Hospital. Dr Sommerville soon retired and our small clinical service was then joined by firstly Dr. D. Patton. Now we are a group of 7 pediatric cardiologists, with many subspecialized in their individual training. I have been privileged to work in Calgary throughout my career, involved in research and teaching medical students, graduate students, residents and fellows throughout my years, and have been recently given the title of Clinical Professor of Cardiac Sciences and Pediatrics.

What is the biggest reward about being a Pediatric Cardiologist?

My favourite part of the day is seeing patients. The research and teaching are rewarding too, but fade in comparison to seeing the families and the children we care for. I enjoy the relationships I have fostered with both the children and their parents or caregivers. Over time the feelings run deep and go beyond the heart anatomy, medications, procedures

or surgeries. Watching the young grow and blossom under the care of their parents, family, teachers, and medical supports is truly the reward. Seeing challenges managed and conquered, often ones that have been difficult, has been the reward. An addition reward for me seeing patients at ACH, is to be back in the community, as I have an office, near Chinook Center, at the Providence Children’s Center. It is so great to have a full community facility that includes ECG, Holter, Treadmill and Echo. This has allowed me to pursue my “patient care focus and interest” as I can now see patients in my community office 4 days a week, which I really love. It has been a transition for me to go back to the community as my first 10years of practice was at the Associate Clinic followed by almost 10 years exclusively at the old ACH hospital, but I have really enjoyed this transition. I still continue to have my ACH clinic once a week on average.

For those of us, who haven’t met you, how would you describe yourself? How would we recognize you in clinic?

I like to think that I am part of the “team” of caregivers that make a difference in the lives we are privileged to touch. I love to hold the babies, interact with the toddlers and have some positive impact on the older children. I feel like I have time for those who come to see me and that when they do, they get my full attention. I consider myself friendly and easy to talk to, able to express compassion, caring and respect to my patients, their families and also my colleagues. I guess you would now recognize me as one of the “oldies” in the clinics, as the hair is gaining the gray, the waist is not as slim and even the walk may be slowing...ha! Hopefully you’d still see my smile and a calm demeanor.

Do you have any special interests in the area of Pediatric Cardiology that you would like to share?

When I started out my interest was in rhythm disorders, but really, early on in my practice, with few of us covering all of southern Alberta, one had to learn to be good at

everything. Now, I would say my special interest is in seeing patients everyday that I work. I still do the research, but on my own time. I enjoy the teaching, but my favourite or special interest is the “patient”. Even if they are well and just needing a check, it holds my interest. I also enjoy the advances in pediatric cardiology, in MRI, in EP and pacemakers/ defibrillators, in heart failure and transplant medicine, and in echocardiography. It has been great having new colleagues join our clinics with additional expertise and training.

As a Pediatric Cardiologist, you manage and care for some kids with complex hearts. Any advice that you can give to parents of these kids regarding their everyday care/daily activities?

The care of a child with a chronic problem is often life-long with moments of turmoil and trauma. Complex heart problems are really one form of chronic disease and the impact is not only on the affected child but on siblings and parents. One’s efforts, as a caregiver, can be “all consuming”. Parents become an integral team member, driving a health care system that is far from perfect. My advice is perhaps simple in nature but full of intricacy and impact. The advice for the parents or caregivers, is taking the time for oneself, starting with recognizing the stress and strain of having a child with heart disease, not only to its impact on you and your inner being or peace you may once have had inside, but also the impact on all the other “significant” people in your life. Time is needed for “self”, for the siblings, and for the marriage. Your spousal relationship is at great risk, as most, in fact 75% of parents don’t stay married. It’s nasty statistic that needs early intervention and constant attention if it is to be avoided. It is easy to be trapped into a self imposed “critical care role”, whereby the parent or parents provide 24 hour care and vigilance, even when this is not required. Remembering the importance of the others in your life, taking the time for one-on-one interactions, having a date with your significant other is really my best advice. Trying to keep your life as “normal” and intact as possible takes a concerted effort.

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Talk with the Docs

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Treatment and management of complex heart defects has come a long way in the last 25 years, where do you see possible advancements in the future for these complex hearts?

I really like what I see for the future. The bioengineering has been amazing in recent years. More and more interventions without surgery and more minimally invasive surgery. Improved imaging without radiation exposure is exciting. Advances in complex surgery procedures with less repeat surgery required. The field of adult congenital heart disease is now well established for ongoing health care issues. Advanced fetal diagnosis and intervention continues. Molecular genetics is answering many past unknowns.

When you are not busy doing Cardiology “stuff”, what do you like to do?

I seem to keep busy, that is for sure. I enjoy my family and spending time together. I like to contribute to meeting my childrens' needs, but too often do not contribute enough. I have been involved in medical administration, as past president of physician groups that have included the ACH medical staff association, Calgary Medical Society, and CAPA (Calgary and Area Medical Staff Association). I am currently on the Board of Directors of the Alberta Medical Association and have been on the board for over 5 years. I am also on the Board of Directors for Unicef Canada, and am on the Patrons Council for Unicef Alberta. I am involved in medical biotechnology and medical informatics, as a consultant and/or board member for several small private companies in Canada. For fun I enjoy racquet sports and try to participate in these sports 3 or 4 times a week to stay healthy. I also really like watching my kids do their sports and activities.

Thanks for asking me to participate in your newsletter. I remember the origins of *Heart Beats*, the evolution of the supports, the ongoing fund raising and many of past and current contributors that make this such a success. Keep up the great work.

Interview by Lynn Nakoneshny. Lynn's son Joshua, age 3, is a patient of Dr. Giuffre.

Cardiology Clinic News

Change in Social Workers

Laura Thurber-Larsen is no longer the Clinic's social worker. We thank Laura for her commitment to Cardiology over the past four years. Our new social worker is Amra Lusic. Amra will work 3 days a week in Cardiology; Wednesdays thru Fridays. Her office number is (403) 955-2210.

Baby News

Trish, our echo technician, had a beautiful baby boy named Colin Kurt Dansereau. Both Mom and baby are doing well. Congratulations, Trish!

Offbeats

Offbeats met on December 1, 2009 to decorate the Cardiology Clinic – they did a beautiful job! That night, we also had our Annual Gingerbread House Competition. Two teams battled it out and the final result produced two very nice gingerbread houses that helped to decorate the clinic. We celebrated Congenital Heart Defect Awareness Week with our annual heart-shaped pizzas at Boston Pizza on February 10, 2010. Thank you to Boston Pizza for making us these special pizzas. Back by popular demand, March 30, 2010 was an evening filled with loud music with Rock Band again. An added bonus for this evening and at members' special request, we also feasted on ice cream sundaes! We will participate in our annual pottery making in April and wrap up the year with a gathering at the Alberta Children's Hospital in May.

Offbeats is always looking for and welcoming new members. If any youth aged 10-17 are involved with the Cardiology Clinic and are interested in learning more about Offbeats, they can contact Kelly Webber at 403-955-7858 or by email at kelly.webber@albertahealthservices.ca

Calling All Transplant Families!

As many of you are now aware, Dr. Coe has resigned his position as Transplant Cardiologist with the Stollery Children's Hospital effective May 1st, 2010. A celebration of his dedication to our families, in the form of a carnival, will be held (at a date and location to be confirmed) in either May or June here in Calgary. We welcome all families to come together to represent and celebrate Dr. Coe's incredible body of work.

If you would be interested in attending/volunteering/performing and/or contributing to the cost of the event, please email: coekids@hotmail.com.

Monetary contributions for the event can be sent directly to:
Melanie Cantius
21 Cranwell Court S.E.
Calgary AB T3M 0B7
Any proceeds will be donated to *Heart Beats*.

The “Flying Tomato” Wins Olympic Gold!

Shaun White was perhaps one of the most recognizable athletes at the Vancouver 2010 Olympic games. With his shock of red hair, broad smile and incredible snowboarding skills, the “Flying Tomato”, as he is often nicknamed, easily won gold for his spectacular halfpipe performance.

A remarkable aspect of Shaun’s life occurred even before he strapped on his first pair of skis at the age of 4. Shaun was born with a congenital heart defect called tetralogy of Fallot. This condition refers to a combination of four abnormalities: 1) a ventricular septal defect (a hole between the ventricles) and 2) obstruction of blood flow from the right ventricle to the lungs (pulmonary stenosis) are the most important. Sometimes the pulmonary valve isn’t just narrowed but is completely obstructed (pulmonary atresia). Also, 3) the aorta (major artery from the heart to the body) lies directly over the ventricular septal defect and 4) the right ventricle develops hypertrophy (thickened muscle).

Tetralogy of Fallot is treated with two kinds of surgery. One provides temporary improvement by a shunt to give more blood flow to the lungs. The other is a complete repair of the two most important abnormalities that make up tetralogy of Fallot. Patients might have one or both surgeries in their lifetime (source: American Heart Association). In Shaun’s case, he underwent both open-heart surgeries in his first year of life.

In addition to being a talented athlete, Shaun finds time to give back. He supports Target House, a residence for families and patients receiving long-term treatment at



Photo: Brian Howell (reproduced with permission)

St. Jude Children’s Research Hospital. There he designed and funded the Shaun White Great Room, a place for patients to hang out and meet new friends. Shaun also supports Make A Wish Foundation and Heartgift, an organization that performs life saving heart surgeries on children in developing countries. Perhaps his greatest contribution could be the inspiration he gives kids everywhere, including “heart kids”, to dream big and go for the gold!

Jen Beleshko is mom to Roman, age 2, dextrocardia, double outlet right ventricle (DORV), single right ventricle and transposition of the great arteries.

Heart Beats Unveils Its New Brochure

Heart Beats is pleased to introduce its new brochure featuring the latest information about Heart Beats. You may obtain a copy during your next visit to the Cardiology Clinic. A special thank you goes out to Karen Perl-Pollard and Paul Warren for donating their time and talents to the design of this pamphlet.

Children's Researchers Investigate the Genetics of Congenital Heart Disease

Written by Melissa Jeltsen, Children's Hospital Boston, on December 30, 2009 (reprinted with permission)

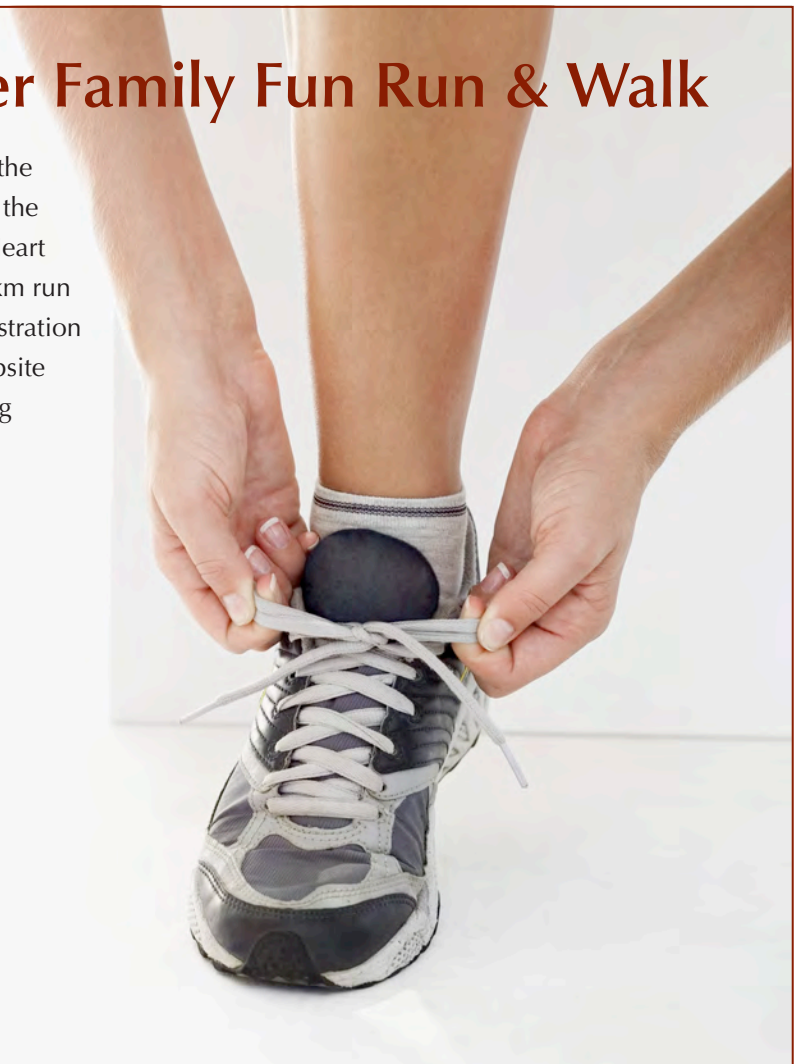
It's a sad fact that congenital heart disease, the most common group of birth defects, affects 35,000 to 40,000 U.S. infants born annually. Currently, most congenital heart defects have no known cause.

But researchers at Children's Hospital Boston and Brigham and Women's Hospital hope to change that. They were recently awarded a large, 6-year grant from the National Heart, Lung, and Blood Institute (NHLBI) to probe the genetic causes of congenital heart disease. The \$4.19 million grant is part of the Pediatric Cardiac Genomics Consortium (PCGC), which seeks to identify genetic and epigenetic causes of human congenital heart disease and to ultimately find preventive strategies, targets for treatment, and better diagnostic and prognostic information for families.

Although a few genetic causes of congenital heart disease are already known, the researchers hope to zero in on novel, undiscovered genes. Because gene discovery research requires a high number of patient samples, a collaborative consortium such as the PCGC will aid research by allowing scientists to share patient samples, data and technology.

Heart Beats First Ever Family Fun Run & Walk

On Saturday, October 16, 2010 (please note the date change) Heart Beats, along with our sponsor the Running Room will be holding our First Annual Heart Beats Family Fun Run or Walk. There will be a 5 km run or walk, a 10 km run and a 1 km Kid's Race. Registration is now available through the Running Room's website (www.runningroom.com). So put on your running shoes and start training!



CHD & Me – Talking With Adults With CHD

A concern that “heart parents” often have is how our children will do in the future. Will they be able to lead productive adult lives? Will their heart defects prevent them from doing activities or jobs that they want to do? In this edition, we feature the compelling story of Shirley Peeters, an active woman with a positive attitude who is living life to its fullest.

As I begin my story, I ask that you remember the limited medical technology that was available during that time. The capacity to correct congenital heart defects was still in its ground breaking stage, and my generation was the ‘Trail Blazers’ for the new generation. As with all the surgeries that are preformed and perfected, we learn from one another. To this day, I am amazed by what can be done, what our bodies can endure and that we not only survive but thrive.

I was born in 1958 in a small town in Southern Alberta. I had an enjoyable, traditional upbringing in a close family unit which included my parents and four siblings. My heart condition was obvious right at birth so there was never a mystery or a surprise for either my parents or myself. I was born with a double aortic arch with the aortas coarctating until just before the branch off to the kidneys. Basically, my aorta splits in two after it leaves the heart, the two small branches join behind the heart and just before the kidneys my aorta becomes normal in size. The narrowed aortas combined do not equal half the size of a normal aorta. All of my blood flow was directed to my head with the arms and legs receiving a minimal flow. As a child the only pulse that could be located on me was at my left carotid. My parents were given minimal hope that I would make it through infancy let alone grade school. Every year was the same prognosis, and every year as we made our silent trek back from Edmonton to Southern Alberta my mom would say “Shirley Ann, there is always hope and Baby Jesus”, and that was that. Since surgery was not an option, the hope was that if I made it to 15 years of age, maybe technology would have advanced enough to give me a chance for a future.



In my garden with Taylor and Tucker

Looking back, I would say the biggest challenge for me was from Grade 1 right through adolescence. As a child, my physical capabilities were limited; I could not run, I could not even climb up a slide. I could only swim a few strokes before my face was as red as a tomato. I tried skating and skiing but I had about 30 to 60 seconds of activity that I could do before I would have to stop due to fatigue. The strongest feeling or memory I have in relation to my condition is of the cold and the noise; cold feet, cold legs, cold hands and arms up to my elbows. I was always so cold and there was never any quiet as I was always aware of the constant rushing of the blood flow in my head. My heart beat sounded like an ocean tide.

In school, I would take notes during my classes, come home at lunch time, read over all my notes from the morning then go back to school for the afternoon. After school, I would read over my afternoon and morning notes have supper and an hour before my bedtime I would go over the notes once more. In the morning I would get up an hour earlier to go over my notes one more time. I just couldn't seem to remember. I also had a visual problem which I still have today to a small degree, which includes somewhat of a double vision which my brain has learned to compensate for.

At the age of 15, I had a left subclavian steal caused by the excessive blood flow (a brain hemorrhage caused by the pressure in the blood vessels in the brain being so high that the blood oozes through the vessel walls). The solution to relieve the pressure in my head and create additional blood flow to my extremities was to have my first surgery, one of the first artificial ascending and descending aortic bypass (otherwise known as a conduit). The recovery time was slow and had many complications. The surgery was 12 hours long, and I had a brain hemorrhage, pneumonia and was in kidney and liver distress. Then when I was taken off the pain medication, I had developed an addiction to morphine and codeine. I clearly remember Dr. Sommerville coming in to see me in ICU and telling me that I had to go off the pain medication because it was becoming too difficult to read what my body needed. He said that it would not be fun for a while, but my body would make its own drugs and I would be fine. I believed him. He was right, it wasn't fun for a while; but he was also correct in saying that our bodies are our own pharmacy. To this day, I can handle a lot of pain before I take anything for it.

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CHD and Me *(continued from page 8)*

I was left with short term memory loss, constant moderate to severe headaches as my body had to learn to function with a new blood flow system. Plus at 15, I had not finished growing. Ironically, at that time my horror of horrors was that I had a scar that was raised at least 12mm (due to keloid) in height and seemed to go on forever. So if anyone is self conscious about their scar, believe it or not there will be a day when you don't even notice it. Really! I kid you not.

In contrast to the first surgery, the second surgery had absolutely no complications. It was performed in Houston, Texas when I was 33 years old. Day one was my surgery date and on day six I was traveling down to Galveston to feast on shrimps and scallops, albeit sore and swollen, but nonetheless I was there. The surgery replaced 90% of the original conduit and was needed due to growth issues. At the time, it was one of the largest 'cutting' surgeries done in Houston. I was cut from the sternum to the kidneys and filleted along the way. I now have a conduit that attaches at the base of the aorta and to just before the aorta branches off to the kidneys. A small portion of the original conduit of 1974 was left intact. As my aorta separates almost immediately at the base, there was not much to choose from as to where to sew on a new conduit given the fact I already had an existing conduit with its complexities. This time, I took no pain medication after day three post-op. I would sooner choose pain then risking another addiction.

The extent of my congenital defect and its rarity were the reasons why I went to Houston as referred by my Calgary doctors. Houston had the most experience in dealing with this type of congenital condition at the time. To give credit where credit is due, I had fabulous doctors in Houston and they in turn were very clear to give credit to the Doctors in Calgary, namely Dr. Miller, Dr. Goldstein and Dr. Sommerville; not only did they give me my original bypass in 1974 but at that time, they were 11 years ahead of their time in grafting an artificial aortic conduit that was both ascending and descending.

Today, my life is great. I am semi-retired and the owner of a small home based business constructing custom leaded stained glass windows. In my life, I have been fortunate

enough to travel around the globe. I maintain a healthy and active lifestyle which includes trips to the gym approximately four times a week. I love the Extreme Biking and Pump-it Up classes. I like to mix it up a bit and take in a Kick Boxing and Bike n Buff class. I am stronger now than I have ever been and can keep up with the rest of the cyclists in my class, most of whom are younger than me. Gardening is another joy that I actively participate in. The home that I currently reside in has 27 mature trees on a large pie shaped lot with south exposure. This is an excellent canvas for the garden which I have been able to create and enjoy so much. I am very fortunate to share all of this with my Partner, a special furry best friend named Taylor (my dog) and one fat black cat named Kitty. I have a simple lifestyle and try to live my life with no regrets. I have a strong belief in the Almighty and if He is going to send something my way, then I just have to go through it knowing that He will be with me all the way. It is just the way it is, it is how we learn.

For all of the teenagers out there that may be reading this article, I have a very tender place in my heart for you in this timeframe of your life. Teenage years can be challenging and awkward no matter if you have a heart condition or not. From my experience, having a heart condition is different in the sense that we grow up with knowing more about the heart than the majority and we know the realities of a heart pumping or not. Somehow, we learn to accept and live with that knowledge from a very young age. Soon if not already, you will graduate from Pediatrics to Adult care; the transition should not be a big hurdle. You are nearly ready to make your own decisions and we are so fortunate to have the doctors that we have who guide us along the way. They will recognize your transition as well and I can tell you honestly, you will be well looked after in the Adult care. They are an amazing group of dedicated and compassionate people. Being an adult can be just as much fun as being a teenager. If you make healthy life choices, the rewards can be sweet. Eat right, live right and always remember 'Hope' and 'Believe'. Without a doubt, I do Believe, and have learned that Hope is found in all the goodness around us.

For parents who are reading this article, it

is just as important for you to 'Hope' and 'Believe'. We just never know what is in store for us. The odds may look pretty bad at times and they may very well be that way, but you just cannot give up. My parents' biggest gift to me was that they 'normalized' my condition at a very early age. I did not get out of any punishments or chores. And when I came home crying on my first day of school because I felt so different from my classmates, Mom's response was "Shirley Ann, everyone has something to go through in life and there is always someone worse off than yourself", and that was that. I was treated no different than my siblings, except when I took ill, the silent worry was obvious and my chores were what I physically could do (shoe shining and ironing)! That normalizing that my parents instilled in me, without a doubt had a profound impact overall on me in living with a CHD and greatly contributed in successfully dealing with my first surgery at the age of 15. Giving up was not an option. Every day, Mom or Dad would say, "Well, Shirley Ann, another day in the hospital means one day closer to going home", and I believed that. When I mentioned to my Mom that I would be contributing to this Newsletter, I asked her if she had something to say. Her reply was this, "Yes, take one day at a time and take it as it comes", once again holding true to form and normalizing CHD. In 1962, my Mother asked the surgeons and cardiologists why they couldn't just sew up a sleeve and attach it to my aorta so that blood flow would happen to the rest of my body. Little did she know at the time, but she was predicting my future.

In closing, I'd like to share a story with you. It was told to me by a lady that I would often share a room with when I frequented the Holy Cross hospital as a patient. She was very ill and frail and was in constant pain, yet always seemed to be happy. Her words have never left me. She said, "If you take all your sorrows, troubles, aches and pains, put them in a bag and put your bag in a row with everyone else's and then had to choose a bag to carry, you'll choose your own bag, you won't choose another because their bag may be filled with a lot more grief than your own. You already know what you have and can live with. So take your bag and just don't make it any heavier, it's your bag to deal with".

Community Updates

Joshua Nakoneshny



Joshua, age 3, post-Fontan

Joshua had his third and final scheduled surgery, the Fontan, on September 18, 2010. The surgery lasted 4 hours and was performed by Dr. Ross at Stollery Children's Hospital in Edmonton. Joshua did well through his surgery and all went as expected. He was immediately transferred to the PICU where he remained for 3 days before being moved to Unit 4C. His post op course seemed to be going smoothly, and we were to be discharged just 8 days post op. On the scheduled day of discharge, a routine discharge x-ray was taken and it was discovered that Joshua had a condition known as Pneumothorax. This is where an air pocket forms between the lung and the chest wall. This sometimes occurs when a drain tube is removed from the pleural space and the child takes a breath during that time. We ended up staying in the hospital overnight for oxygen therapy and had a repeat x-ray the next day to see if the condition had decreased in size - it had, and we were discharged home.

During the following week at home, we noticed Joshua's face showing some puffiness. We kept an eye on him, knowing that we would be returning to the Albert Children's Hospital for a follow

up x-ray that Friday for the Pneumothorax. After the x-ray, we took Joshua to the Cardiology Clinic to have him checked over. Dr. Fruitman reviewed the x-ray, then came in to advise us that the Pneumothorax had resolved itself. However, Joshua now had a pleural effusion on his right side that was causing the puffiness (edema). His right pleural space was two thirds full of fluid and that meant that Joshua would have to be admitted. This was devastating news to hear, and we were very concerned about his new heart circulation. Fortunately, this was never in question and his heart function remained good. Dr. Ross, Joshua's heart surgeon from Edmonton, called our house later that day and spoke with my husband Russ. He wanted us to know that Joshua's effusion was common and urged us not to get too worried about it. He assured us that he was fully aware of Joshua's situation, and wanted to make sure that we were being looked after in Calgary. Wow, this made us feel a lot better! We have so much respect for Dr. Ross, taking the time out of his busy schedule to call and reassure us. The following day, Joshua was taken to the OR to have a drain tube placed through his rib cage into his pleural space to drain the fluid. The fluid was then tested and it was confirmed that Joshua had a condition known as Chylothorax. Chylothorax happens when a lymph node is nicked during open heart surgery and is very common given the close proximity of these nodes to the heart. It often heals itself during the first few days following surgery while the child does not eat by mouth. However, depending on the size of the nick and where it happens, once the child begins to eat, the fat in their diet can trigger this leak

to continue. The drainage tube helped drain off a lot of fluid, but by day 5 there was still a lot of fluid draining. It was then decided to put him a restriction of no fluid or food by mouth, he would have TPN. This was a bit of a challenge for a child who was almost 3 year old, but Joshua understood that in order for him to get out of the hospital he had to get better and therefore "follow the rules". We survived through this, and 7 days later the drainage stopped and he was able to start eating a low fat diet 2 days later. We were finally discharged home three weeks from the date of admission. This was a minor setback for Joshua, and thankfully short one. It was also a real learning experience for us as his parents as we go through this heart journey with Joshua.

Today Joshua is doing well. He attends preschool at Providence Children's Centre five mornings a week where he is getting help for his speech. He loves it and wants to be at school every day, including weekends. Joshua has made great strides in his speech and has made many new friends. He is very independent, active and energetic, loves playing outside, going to the park, reading books, watching any train go by anywhere, airplanes landing and taking off at the airport, the Zoo, running errands with Mom, going to the car wash with Dad and being a big brother to Jacob. Joshua's favourite television characters are The Wiggles, Thomas the Tank Engine, and Bob the Builder.

From a heart perspective, Joshua is stable with no more scheduled surgeries, just routine heart check-ups by his wonderful cardiologist, Dr. Giuffre. Our wish for Joshua is that he will just get to be a little boy for

awhile enjoying all things in life that a 3 year old should.

Lynn Nakoneshny is the mother of two young boys. Her oldest son, Joshua (3 years) was born with hypoplastic left heart syndrome.

Mathias Pollard



Mathias Pollard, Age 6

Mathias celebrated his sixth birthday with a six plus six party with his friends from his kindergarden class. His friends gave Mathias a card with six dollars in birthday money and six dollars for Mathias to donate to charity. Mathias chose to donate the money to the Alberta Children's Hospital, designated to cardiology.

Karen Perl-Pollard is the mother of two. Her son, Mathias (6 years) was born with Tetralogy of Fallot, Atrial Septal Defect (ASD), Patent Ductus Arteriosus (PDA) and now has a pacemaker for acquired heart block.

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 info@heartbeats.ca

Extraordinary Parenting: An Interview with Gwen Rempel

Gwen Rempel, RN PhD, is an Assistant Professor at the University of Alberta and has written extensively about her research into the parenting of children with life-threatening Congenital Heart Defects. Cindy Castillo recently had the opportunity to conduct an in-depth interview with Gwen Rempel to find out more about her research into what she refers to as “extraordinary parenting”.

Please tell us about your background.

In my third year of nursing school at the University of British Columbia (UBC) during my Pediatrics rotation, I did a “follow-through” with a family whose preschool son with Down’s syndrome required heart surgery. This was back in the day when children were hospitalized for their cardiac catheterizations. I went to the procedure with him, took care of him after the procedure, and had a wonderful time getting to know his family, especially his mom. I researched his heart condition; then did a home visit and taught his older school age siblings about the heart. I visited him and his family when he returned to the hospital for his surgery several months later. From that experience, I decided to do an independent study regarding pediatric cardiology in my fourth year of nursing. For my final project, I interviewed parents about their needs related to having a child with congenital heart disease and wrote a paper about their information needs, emotional needs, and physical needs.

Clearly, the ‘seed was sown’ as I worked in pediatric cardiology at BC Children’s Hospital from 1985-1995 as a staff nurse, assistant head nurse and head nurse of the pediatric cardiology ward. I then returned to UBC to do my Master’s degree and worked as a clinical nurse specialist for several years. I came to Edmonton in 1999 to do my PhD in nursing and joined the nursing faculty at the University of Alberta in 2006.

Can you give us a brief description of what you do and what you research?

I spend 75% of my time at the university doing research and 25% of my time teaching. Up until recently, my research has focused on two groups of families of preschool children with hypoplastic left heart syndrome (HLHS); the Norwood group and the Sano group. My focus reflects the early treatment era for HLHS in which the first operation for HLHS was the “classic Norwood” operation and the later treatment era when the Sano modification of the Norwood became the surgical treatment of choice at Stollery Children’s Hospital. Along with member of my research team, we interview mothers and fathers in person or by telephone to learn as much as we can about what it is like to parent a child who has received life-saving surgery for HLHS. I usually start with the question, “Can you think back to when you first found out that there might be something wrong with your child’s heart? Tell me about that time.” We talk about the challenges and rewards and about how their child’s heart problem has affected them as parents and the effect on the entire family. These recorded and transcribed interviews are my data for analysis and I work with my research team, including students, to systematically analyze the parents’ accounts by comparing data from the parents of one child, comparing all the father data with all the mother data as well as looking for different or similar themes between the Norwood and Sano groups.

What other research have you done?

Before coming to Edmonton, my research focused on parents who found out about their baby’s CHD during pregnancy. With my colleague Laurie Cender at BC Children’s Hospital we wrote the booklet for parents called “Knowing but not Knowing” that is still used in many fetal diagnosis programs.

I am also starting to do research with adolescents with CHD and their parents and am collaborating with Dr. Andrew Mackie, pediatric cardiologist at Stollery Children’s Hospital with the goal of developing and testing interventions to help teens and their families successfully transition from pediatric cardiac care to adult cardiac care.

What is “Extraordinary Parenting”?

Extraordinary parenting encompasses all of the things that parents unquestioningly do to ensure that their child with life-threatening CHD can lead as normal a life as possible at home with his or her family. Children who undergo life saving treatment for their complex CHD receive high tech round-the-clock care in specialized children’s hospital settings. These children “beat the odds” and put our centres on the map. But it is the parents who safeguard this survival as they take over the complex care and monitoring when the child is discharged home. Although the intensive feeding, medication, oxygen regimens that characterize infancy for many babies with complex CHD ease up as the child progresses through the preschool years, parents continue to monitor their child’s physical and emotional health and face unique challenges at each transition in the child’s life; for example, starting preschool and then elementary school. What is extraordinary about this parenting is that it is done unquestioningly and with minimal support outside of the hospital setting. I have countless stories of parents having to figure out complex care requirements with minimal guidance and support. And they do not question why they have to do all the extra things; nor do they complain about lack of resources. These parents are so thrilled that their child survived that they savour each moment with their child, rearrange their life to accommodate the unique needs of their child and do what they feel every parent would do if in their situation.

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Extraordinary parenting

(continued from page 11)

What has your research shown regarding the neurodevelopmental effects of CHD on children and their families?

Although I have not conducted formal research regarding the neurodevelopment of children with congenital heart disease (CHD), I have analyzed my parent interview data which shows evidence of neurodevelopmental delays and deficits. As I proceed to my next study, the Safeguarding study, I will be interviewing parents of school age children with HLHS and intend to ask parents specific questions about their child's neurodevelopment and the services their child has received over the years. I will also be asking parents to complete questionnaires that could possibly give us some hints about any parenting practices that might contribute to optimal development.

One of the things that I wonder about concerning the long term developmental outcomes of children with CHD is whether there are things that parents could do during the preschool period that would enhance or optimize their child's outcomes. I am, however, sensitive about asking this question because how could we ever ask parents to do more than what they are already doing? There may, on the other hand, be resources that parents can access that would promote or enhance their child's development without being onerous for families. My ongoing analysis will continue to look at developmental issues and how to support early intervention.

Have you found any evidence to suggest that the attitude of the parents has any affect on the outcome of the development of the affected child?

I am constantly amazed by the resilience of parents that is fueled by positive attitudes and beliefs about their child's potential as well as their constant resourcefulness in advocating for and accessing care and interventions for their child.

The parents we have interviewed are often ones who have been able to access resources and/or learn the process of advocating for their child. One concern is that we have not heard from marginalized families and/or those who do not have the support of their family, community and health care team. As one father said, "Even with all the support we had from family and friends, we just barely made it under the wire." He expressed concern about families who did not have the resources his family was blessed with.

What advice can you give parents to ensure that their child with CHD reaches their full potential?

My advice would be to keep doing what you are doing! You know your child's complex needs so well. Listen to your gut, advocate for your child and above all, take care of yourself so that you can keep taking care of your child and the rest of your family.

I also might ask parents to consider accessing early intervention programs no matter how well they feel their child is doing developmentally. Get connected with your local Parent Link centre and follow-through with any developmental testing that is offered to your child. I will be the first to acknowledge that it is not easy for parents of young children with CHD to get involved with these activities when they are so busy providing for the physical care needs, numerous doctor's appointments and concerns about their child catching a cold when out with other children. If you are struggling with this balancing act, please talk with anyone and everyone about this including family, friends and health care providers. Find someone who will help you consider all your options and navigate the resources that are out there.

What resources are available to help parents deal and cope with developmental delays in their children with CHD?

There are community based resources – Parent Link Centers, Developmental screening programs and early intervention programs throughout the province.

<http://www.parentlinkalberta.ca/publish/default.htm>

<http://www.albertahealthservices.ca/services.asp?pid=service&rid=2367>

How can we access your articles?

My articles are published in academic journals available through university libraries. I am happy to send parents copies of my articles and eventually will have summaries of my findings on our Extraordinary Parenting web site.

If parents want to participate in your research, what can they do?

Contact me or Sandy MacPhail, the project coordinator for my research program.

Gwen Rempel
(780) 492 8167
gwen.rempel@ualberta.ca

Sandy MacPhail
(780) 492 9047
sandra.macphail@nurs.ualberta.ca

Safeguarding Study

Safeguarding Survival: Parenting Children & Adolescents with Complex CHD

♥ Are you a parent of a child with HLHS?

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

If yes, we would like to talk with you!

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

For more information about this study, please contact:

Sandy MacPhail RN MN, Project Coordinator

Phone (780) 492-9047 E-Mail sandra.macphail@nurs.ualberta.ca

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

Grown Up Congenital Heart Patients Association

www.guch.org.uk

This brilliant website out of the UK, nicknamed GUCH, is designed for the growing population of teens and adults born with congenital heart disease who, through advancements in cardiac surgeries, are surviving well into adulthood. The vast majority of these patients will require lifelong

cardiac care, and in addition to this, they face the usual adult issues and challenges, such as careers and families. Support groups like GUCH will no doubt continue to gain popularity as the need for information and support increases along with this population.

To call this website inclusive is an understatement! It contains an abundance of practical information about growing up with a CHD and making the sometimes difficult transition from pediatrics to adult care. The information includes lifestyle issues such as diet and exercise, emotional health, pregnancy, travel tips, tattoos, drugs and alcohol, medications, and advice for taking responsibility for one's own care. There is a special section for teenagers featuring links to a "just for teens" forum and a Facebook and MySpace group. The site also contains book reviews, links to medical journals, a newsletter and member's stories. There is also a series of links to other such organizations around the world.

Perhaps the best resource on this site is the message boards. Its purpose is simple; to share experiences and offer support. There are currently 1,240 registered users and the boards are divided into three categories: General Discussion Groups, Teenage Forum and Non-heart Related Topics. New discussions often appear daily, and no password is required to read the posts.

GUCH's comprehensive website is easy to navigate and definitely worth checking out. I can easily recommend it for teens and young adults with CHD's, as well as their parents.

Jen Beleshko is mom to Roman, age 2, dextrocardia, double outlet right ventricle (DORV), single right ventricle and transposition of the great arteries.

Advice from Our Parents Experts – You!

What advice can you give parents who are traveling to Edmonton for their child's upcoming surgery?

In my experience, the things I found to make the time easier was to stay at the Ronald McDonald house (book as soon as you know the date as they do get full), and to make portion sized freezer meals to take and easy to eat snack foods.

Liza Maurette, mom to Emily

From our past experience of going to Edmonton with our daughter Kaley, I highly recommend staying at the Ronald McDonald House if there is room available. If there is no availability at the house then their recommendation is the Travelodge on the south side. I would not recommend this hotel to any family. It is very dirty and can be very noisy from people partying, not a place to be when you have a sick child.

We spent 2 1/2 months at the Ronald McDonald House and it has everything that you would have in your house. It is also a

5 minute drive or 20 minute walk from the hospital. It is very close to grocery and retail stores. The biggest thing was that the staff were very welcoming and generous. Also, I have met some very wonderful people from the house that will be my friends forever. They were the ones that kept everyday brighter for me while Kaley was critical in the PICU.

Vicki Biggar is mom to Kaley, age 2, Pulmonary Atresia and Trisomy 21.

Once we got on to the ward, we found it really nice to have two adults around. You think that time would be easier, but because there is not one-on-one care you really need an adult at the bedside at all times. So it is nice to have two adults so you can get a break, go for a walk or get something to eat. Ron had to go back to work at this time so my mom was able to come. It was really nice to have her there and she really felt that she was able to give us the support we needed in this role. We really enjoyed staying at the hotel across from the hospital.

Karen Perl-Pollard is mom to Mathias, age 6, born with Tetralogy of Fallot, Atrial Septal Defect (ASD), Patent Ductus Arteriosus (PDA) and now has a pacemaker for acquired heart block.

When our son had surgery at the Stollery Hospital, we were lucky enough to have had a social worker put in a call to the Ronald McDonald House for us from the Foothills Hospital. We also called there on our way up to Edmonton and were amazed when they could accommodate us. This doesn't always happen. The rooms are (or were at the time) \$7 a night and quite roomy and clean. Also, there was a nice women's group that brought by fresh baking every week, which was my only source of nutrition in those early (4-5 a.m.) runs to the hospital. The only thing that I was not aware of was that all Occupants' are assigned a special duty/chore which is listed on the wall. In the first few days when I was still in shock and sleep deprived, I felt guilty that we had not always been able to keep up with our chores. I soon came to realize that as long as you let the staff know



when you are unable to do an assigned chore, they can get someone else to complete it. Also, sometimes having those daily chores is a source of comfort and a link back to a familiar world called home.

We also found that the NICU had very close quarters, making it hard to have young visitors as you do not have a private room for them to walk around in or play in. There is a play room on the 4th floor and the staff and activities are wonderful there. Also, we found out during our stay that there is a community room that is for parents/families of children who are patients. It was a great place to just get away and use the phone or use the free internet service in a peaceful place. They always play calming music and have a big fish tank to unwind by. Make sure you ask your nurse where the family room is and ask the staff in there if you can set up a Care Page, its free and it will be your life line to all your family and support back home. In regards to an affordable, alternative place to stay, I heard that contacting the Grey Nuns or checking out the local Hostels was a good idea. They may not be the most luxurious accommodations, but when you are at the Hospital all day, all you really need is a place to rest your head. And remember, rest your

head as often as you can - your child may have surgery and will need a well rested parent to care for them when they get back at home.

Michelle and Paul Aris, Parents of Owen Aris – Coartation Repair on March 6th, 2008.

When our daughter was in Edmonton for her three surgeries, both my husband and I of course wanted to be with her on the surgery days. However, we soon learned that on the recovery days it was wise to do “split shifts” and take turns being with her so we could each get some rest and also spend some time with our other daughter. We were also very grateful for grandparents who took shifts as well. Although there is great nursing care, our experience was that the nurses had a lot on their plates so we always wanted to have one of us there with Isabelle to assist and also to make sure her needs were met.

We also found it very helpful to set up a CarePage to keep our family and friends updated on how Isabelle was doing. This saved us, and those around us, from having to repeat the same information over and over to concerned family members and friends. It allowed our family and friends to keep informed without worrying about bothering

us. It was also very encouraging to read their comments when we were in the hospital. A CarePage is easy to set up, and can be done so through www.carepages.com/heartbeats. There is also a link to it on the Heart Beats website at www.heartbeats.ca.”

Patty Wiebe, mother of Isabelle, age 9, born with Hypoplastic Left Heart Syndrome.

We found that purchasing a weekly parking pass saved us time and money. I also kept all of our receipts in an organizer (parking, gas, food, lodging) from the minute we left Calgary as we were able to claim some of these expenses on our taxes. The organizer was also great for jotting down notes and follow-up appointments, as well as storing phone numbers of friends and relatives.

Jen Beleshko is mom to Roman, age 2, dextrocardia, double outlet right ventricle (DORV), single right ventricle and transposition of the great arteries.

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



Heart Beats 25th Anniversary Event

Save the Date!

Heart Beats is pleased to announce that it will hold its 25th Anniversary Event on Saturday, February 11, 2012 at the Calgary Italian Club. This exciting social event is still in its planning stages, so mark your calendars now and look for details in upcoming editions of *Keeping the Beat*.



*"A loving heart is the truest wisdom
Every heart that has beat strong and
cheerfully has left a hopeful impulse
behind it in the world, and bettered the
tradition of mankind."*

– Charles Dickens



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Heart Beats
Supporting Children with Heart Disease