



Keeping the Beat

Fall 2010

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

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Heart to Heart at Lake Midnapore

On July 11th, *Heart to Heart* was held at Lake Midnapore in SE Calgary. Six “heart kids” along with their parents and siblings braved some serious storm clouds to attend an afternoon at the beach. To everyone’s delight, the sun peaked through just in time and the children were able to enjoy the sun, sand and surf. Refreshments were provided, as well as some wonderful water toys which were enthusiastically played with and enjoyed by both young and old. “It’s always so encouraging to spend time with other families with whom we share a common bond”, expressed one parent in attendance. If you have not yet had an opportunity to attend a *Heart to Heart* gathering, we encourage you to tap into this enjoyable and supportive resource. Upcoming times and locations are listed in this newsletter.



Families enjoying themselves at Lake Midnapore



Heart Beats
Supporting Children with Heart Disease

The Heart of a Family – Our Journey with CHD

In January of 2007, my husband and I were surprised and delighted to find out we were expecting our first child. However, our excitement turned to anguish when, at our 18 week routine ultrasound, the technician had difficulty seeing all four chambers of our baby's heart. I will never forget the look on the technician's face as she stared at the screen – it was obvious to us that something was wrong. She left the room and, moments later, two senior technicians entered and took turns looking at our baby's heart. After what seemed like forever, our worst fears were realized; our baby would be born with at least two heart defects. This was the moment our heart journey began.

One week later we were called in for a prenatal echocardiogram at the Foothills Hospital. After outlining the complexities of our baby's heart, a perinatologist informed us that we could terminate the pregnancy within the next two weeks. We decided that this was not an option for us – we would at least give our baby a chance at life. The following days were very difficult for us and many tears were shed. Just when we thought things were hopeless, we got a phone call from Dr. Harder at the Alberta Children's Hospital. She had examined the echocardiogram and wanted to meet with us. For the first time we were given straightforward answers to our questions. Dr. Harder drew us a picture of the baby's heart defects, which included transposition of the great arteries, an absent left ventricle, and dextrocardia (the heart being on the right side, instead of the left). Our options were clearly defined for us; compassionate care which means no intervention and allowing nature to take its course, a heart transplant (if one was available), or a series of three palliative surgeries which would reroute his circulation to alleviate the burden on the one pumping chamber. Suddenly, we had options, and even a glimmer of hope! No longer feeling helpless, we immediately opted for surgical intervention and Dr. Harder got the ball rolling right away. We will always be grateful to her for the empathy that she showed us that day.

The months leading up to the birth were filled with appointments, multiple echocardiograms, and a birth plan that would require traveling to Edmonton to deliver the baby. Our baby boy was born that fall, full term, weighing in at an impressive 8 lbs, 10 oz. We named him Roman, a family



Seeing our baby for the first time. He was intubated, on an IV, and hooked up to machines, but I was still a proud new mom.

name on my husband's side, because it was the strongest name we could think of. He was immediately transferred to the Stollery Children's Hospital in Edmonton for surgical assessment. Perhaps one of the greatest disappointments of my life is that I was not able to hold my baby before he was whisked away by the transport team.

The next day I was finally able to see him. He was intubated, being fed through an IV, and hooked up to so many different machines that beeped and buzzed. As new parents it was hard to see our brand new baby in such a state. But over the course of the next few days he began to improve – so much so that it was determined he would skip the first surgery (called the Norwood). We were overjoyed! Roman was soon transported to the NICU at the Foothills in Calgary to work on weight gain, and after three weeks of hospitalization, we were finally able to take our son home – on one condition. We would have to learn how to insert and remove his nasogastric (NG) tube. Because he was still too weak to nurse or drink from a bottle, my expressed breast milk was delivered through an NG tube going through his nose into his stomach. My husband and I took a crash course on inserting and removing the tube, a nerve-racking job when our test subject was our three week old son! Somehow we did it, and we were thrilled to finally bring our baby home.

Within months, however, it was clear that he was not doing well. His oxygen saturation was hovering in the 60's (normal being

100) so he was put on oxygen. A homecare company came by and supplied us with portable tanks, an oxygen converter and yards of tubing. This was only a band-aid solution and, when his sats plummeted to the 50's while on 1 litre oxygen, his first surgery was quickly booked. Back to Edmonton we went where our fragile infant underwent open heart surgery. During our stay we met many other families from all over Alberta and other parts of western Canada who had travelled to Edmonton for their children's surgeries. We counted our blessings that my husband's parents lived in Edmonton and were able to put us up. Roman breezed through the Glenn Procedure, which was performed by the very talented Dr. Ross, and he was home within a week. In the months that followed, Roman began to thrive. He was off the NG tube and was growing by leaps and bounds.

Today, Roman is a typical 2½ year old and is truly the "heart" of our family. He has helped us realize what is truly important – embracing life! He attends a Spanish dayhome three days per week, and is busy exploring his world with wide-eyed enthusiasm. This fall, Roman is in line for another heart surgery which will complete his new circulation (the Fontan). Somehow, the thought of turning over our seemingly healthy child for surgery seems harder this time than it did when he was a struggling infant. We hope and pray that this surgery will go well and tide him over to adulthood when other treatments, perhaps through stem cells or other medical advances, will allow him to lead a long and normal life.



The Beleshko Family today. Jen, Ferrell and little Roman.

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. *Heart to Heart* dates and times for September through December are:

- **September:** Tuesday, September 14, 2010 at 10 am at the home of Karen Perl-Pollard, 324 Norseman Road NW, Calgary.
- **October:** Wednesday, October 13, 2010 at 10 am at the home of Lynn Nakoneshny, 187 Willowmere Close, Chestermere.
- **November:** Tuesday, November 16, 2010 at 9:30 am at the home of Michelle Aris, 281130, Township road 230, just outside the east city limits.
- **December:** In December we invite the whole family to our Annual Christmas Party on Sunday, December 5 at 1:30 pm at the home of Patty and Colin Wiebe, 43 Midvalley Crescent SE. If you are able to attend, please RSVP to Patty by November 28 by email at pattyw@heartbeats.ca or by phone at 403-256-7423.

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

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

Your Support in Action

Donations made to Heart Beats Children's Society of Calgary are used to provide information, resources and support to families 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:

- Jean Bauer and family
- Marie-Rose Bussiere
- Children's Hospital Aid Society
- Verna Crossen
- Government of Alberta Community Spirit Program
- Candace Henderson
- Nexen Inc.
- Telus Employee Charitable Giving Program

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 Beats Thanks CHAS

We thank the Children's Hospital Aid Society (CHAS) for selecting Heart Beats to be a recipient of funds raised from the raffle at their 28th Annual Charity Golf Classic held on August 4, 2010. Heart Beats plans to use this money to set up a scholarship fund to assist young people with CHD from Calgary and the surrounding area to attend Camp del Corazon in California or Zajac Ranch in BC. Watch for more details about this scholarship fund in the next issue of "Keeping the Beat".

Cardiology Clinic News

Sherry Soltys has joined the Cardiology Clinic team as a part-time Social Worker. She is in the office on Mondays, Wednesdays, and Fridays and can be reached at (403) 955-2786. She is available to assist families with resource questions/concerns and provide ongoing counselling support. Sherry brings over 13 years experience as a Social Worker across the continuum of health care and is excited to be returning to work with children and families. Please feel free to contact her at any time.

The clinic is also pleased to introduce a new Echo Supervisor, Dal Disler. Dal began his career as a neonatal intensive care nurse, but soon became interested in ultrasound and eventually became intrigued by echocardiography. As the supervisor at the FMC echo lab, he has specialized in the both adult and pediatric echo for over 20 years. Prior to his move to the Alberta Children's Hospital, he was the regional Education Coordinator, looking after education for staff development, ultrasound students, and cardiology fellows. Dal can be reached by phone at (403) 955-2794 or by email at dal.disler@albertahealthservices.ca.



Paul Cardall – Living for Eden

By Jen Beleshko. Photos and quotes courtesy of Paul Cardall.

On June 9th, 2010, a man reached the summit of Mount Olympus, one of the highest peaks in Wasatch Mountain State Park, Utah. Together with his friends and family, he climbed more than 6.5 miles to pay tribute to his younger brother who was killed in a tragic accident exactly one year ago. He also took the time to reflect on the untimely passing of another young man, a man he never had the opportunity to meet. At the peak of the mountain he found a mailbox containing a visitors' log. On it he entered two names: Brian Cardall, December 7, 1976 to June 9, 2009; and Paul Cardall, April 24, 1973, still living.

Nine months before his climb, the same man was so weak that he spent most of his days sitting in a chair hooked up to an oxygen tank. Living with end-stage heart failure, he prayed for the strength to carry on for the sake of his beloved wife Lynnette and little girl, Eden.

Paul Cardall was born with complex congenital heart defects including a large ASD, L-Transposed AO, Single Ventricle, Single A-V Valve, and Pulmonary Atresia. In his first hours of life, he received the Potts shunt. At 13 years, he developed endocarditis and a walnut size blister of staff was removed from his Potts shunt. A year later, surgeons performed the Fontan procedure on Paul. He soon developed a serious condition called protein losing enteropathy (PLE). By age 37, Paul was living with severe heart failure and was put onto the heart transplant list.

Paul began to write about his physical and emotional condition as he awaited a lifesaving heart transplant. His blog, which he aptly named "Living for Eden", quickly attracted



Paul's daughter Eden being lifted up by his wife Lynnette so she could feel the beat of his new heart.

readers from all over the world as they followed Paul on his amazing journey. Paul used his story to draw attention to hurdles that face adults, children and their families as they live with congenital heart defects. Soon the blog that Paul started as a means to come to terms with his own condition became a source of wisdom, strength and inspiration to all who read it.

Meanwhile, Paul's condition continued to worsen. A family meeting was called where plans were discussed for the worst case scenario; that a donor would not be found in time. Paul blogged about his feelings surrounding the future of his family. *"It's been a tough week. My body is tired. And I'll admit that I've been depressed at times and full of anxiety. Why do I feel so empty? I have every reason to live and love."*

Just when the family was at its most vulnerable, the inconceivable happened; his little brother Brian, who had no previous medical issues, was killed when he was tasered by a police officer during an isolated manic episode. As the family mourned this shocking loss, Paul received another life changing phone call: a donor had been found.

The family later learned that the donor heart belonged to a young man who had taken his own life. The irony was not lost on Paul. He wrote, *"Here I was waiting for a new heart, which requires someone to die, my whole family praying for my survival, and another member of our family dies. Could life be any more ironic? Where could I find understanding and peace? How can any of us find answers to life's most challenging moments with such tragedy? Devastated and heartbroken our family understood the sacrifice, heartache and pain my donor's family would feel losing their son, brother, father, and friend."*

Paul received his heart in September of 2009. The surgery went well and he spent only two weeks in the hospital. Almost immediately, Paul began to feel better physically than he ever remembered. He could feel the blood returning to his fingertips, and his PLE quickly cleared up. He felt invigorated. As Paul recovered in the hospital, he gazed into the distance at Mount Olympus. He made a pact with himself – he will do something he has never even dared to imagine. He will climb that mountain in honour of the two lives that ended far too soon; that of his beloved brother on the first anniversary of his passing, and for the young man whose heart now beats within him.



Hugging his daughter at his first performance after receiving his new heart.

Paul's wife, Lynnette, reflects over the complex emotions of the past year: *"The lows this year have been awful, but the highs have been exquisite. The outcome of Paul's transplant has exceeded all our expectations and to be next to him as he experiences a second chance at life with a newness of adventure has been exhilarating. The love and support we have felt from so many was overwhelming and so sweet. We have crossed paths with forever friends who have shaped our lives for the better."*

Today, Paul Cardall is a busy man. Aside from keeping up with his active daughter, he continues his work of raising awareness of CHD. He is an award-winning recording artist, and last February, just months after receiving his new heart, Paul performed at a benefit concert to raise funds for families affected by CHD (to learn more about Paul's amazing career as a pianist, you can visit his website at <http://www.paulcardall.com>.) Paul is also planning a book tour this fall, during the first anniversary of his heart transplant. The book, entitled "Before my Heart Stops", will chronicle his journey with congenital heart disease. In addition, he and his family recently founded The Paul Cardall Family Foundation, a non-profit entity whose purpose is to assist families affected by congenital disorders by means of private donations and scholarship funds, and to spread public awareness through various events such as concerts and conferences. He continues to share his experiences and inspire others through his blog, *Living for Eden* (www.livingforeden.com).

Heart Beats Sponsors a Room at the Ronald McDonald House

As many "heart kids" and their families can attest to, the Ronald McDonald House® Northern Alberta offers a compassionate, safe and affordable home away from home for Calgary families whose children are receiving treatment at the Stollery Hospital in Edmonton. Heart Beats recently committed funds to aid in the expansion of the facility and a wall plaque has been placed outside one of the family rooms in honour of that commitment.

We encourage all of our readers who visit the Ronald McDonald House in Edmonton to check it out!



Offbeats

After a break for the summer, Offbeats is starting up again this fall. We look forward to another season of fun activities including bowling, decorating the clinic for Christmas, Wii game night and pizza parties! The goals of Offbeats are FUN, FRIENDS, AND FOOD. So if you are between the ages of 10 and 17, have a heart condition and like making new friends, please contact Kelly Webber in the cardiology nursing office at (403) 955-7316.

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.



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*.



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 of “Keeping the Beat”, we feature the story of Sheila Dolan.

In 1960, my family moved to Calgary from the east. I was seven years old. A new doctor detected a heart murmur and referred me to a cardiologist who, after many tests and a catheterization, determined that I had a hole between the upper chambers of my heart. It is commonly known as an atrial septal defect or ASD. ASD is a *defect* in the *septum* between the heart’s two upper chambers (*atria*). The septum is a wall that separates the heart’s left and right sides. Septal defects are sometimes called a “hole” in the heart. Everyone is born with an opening between the upper heart chambers. It’s a normal opening that exists in the baby before it is born that allows blood to detour away from the lungs before birth. After birth, the opening is no longer needed and usually closes or becomes very small within several weeks or months. Sometimes this opening is larger than normal and doesn’t close after birth. As many as one in five healthy adults still have a small leftover opening in the wall between the atria.

In the olden days, the medical profession did not react as they do now, and it was recommended that if I was not having any symptoms related to the problem, it would be better to wait until my teens when the heart would have grown to its full size. Over the next few years, I was referred to the cardiologist for follow ups at various stages in my life, but had no symptoms to indicate that the condition had changed.

In 1998, I was diagnosed with breast cancer. I was more fortunate than most with my treatment. Apart from some mild nausea and fatigue, the side effects were minimal. However, during the course of treatment, I began to have episodes of atrial fibrillation where my heart raced, I had difficulty breathing and any movement made both symptoms worse. I had several trips to emergency to have my heart put back into

a normal rhythm – initially it corrected itself on its own, but as time went on, each episode seemed more severe and required cardioversion to correct the problem. Under light anesthesia, I received an electrical shock through paddles or patches on my chest. The shock stops the heart’s electrical activity for a split second. When the heart’s electrical activity resumes, the rhythm may be normal.

My family doctor suggested that the episodes were very likely caused by the hearts reaction to chemotherapy. He referred me to a new cardiologist. After a very thorough exam and more testing, it was determined that the hole was a significant size and that the right side of the heart was twice the size of the left, caused by improper blood flow.

He advised that a new procedure was being used at the University of Edmonton Hospital to close ASDs. It involved having an umbrella-like device inserted in the hole to stop the blood from flowing back, but the best part of it was that it could be done without invasive surgery. A catheter is inserted in the groin and guided to the heart. The device is fed through the catheter and placed in the heart and can be done in day surgery. Needless to say, this procedure sounded much less threatening than having my chest opened.

My cardiologist made arrangements for me to be assessed for the procedure. I went to Edmonton for a transesophageal echocardiogram which is a probe containing an ultrasound tip that is passed into the esophagus. It provides an evaluation of the heart on a larger scale and can be recorded. I was advised that I was a candidate for the procedure. Within a few weeks, a booking was arranged and I returned to Edmonton with high hopes, only to be disappointed. After waiting for results for what seemed like forever, the surgeon advised that the hole was too large to hold the device in place. It was not a solution for me!

The bouts of atrial fibrillation continued and seemed like they were getting more intense. I will not pretend that the combination of treatment for cancer and the problems with my heart did not affect me emotionally and

mentally. Because the episodes seemed to start for no reason, my fear of never knowing when it would occur again was very stressful and I did seek some professional help. However, the support I received from my family and friends was what helped me more than anything. I think that they had more faith in me than I had in myself.

It became very clear that my only alternative to deal with the problem was to have surgery. My cardiologist referred me to the surgeon and, in 2003, I had surgery to close the ASD and to repair the tricuspid valve that was leaking slightly, but not enough to warrant surgery on its own. I have to say that recovery was not as painful as I expected it to be and I did not have any reason for pain medication.

I have been told that there is never a 100% guarantee that the atrial fibrillation will not happen again – there are many who go through their lives with flutters and do not even know they are experiencing them. I have had two episodes since the surgery, but they may have been self-inflicted. What I have learned is that I cannot lift things that are too heavy for me and to ‘give in’ when I am fatigued. Otherwise, I lead a very normal life.

My follow-up has been semi annual visits and now annual visits to the cardiologist at the Adult Congenital Heart Defect Clinic. I cannot describe how appreciative I am for the care I have received from the doctor and his staff. I know that at some point the follow-up will end and while that will be a good sign for me, it will be like giving up my ‘blankie’.

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

Talk with the Docs – Dr. David Ross

In our previous issues, we have had the privilege of learning more about the Cardiologists at the Alberta Children's Hospital. We have featured Dr. Frank Dicke, Dr. David Patton, Dr. Deborah Fruitman, Dr. Robin Clegg, Dr. Joyce Harder, Dr. Kim Myers and most recently, Dr. Michael Giuffre. In this edition, we are pleased to feature Dr. David Ross, one of the three Pediatric Cardiac Surgeons at the Stollery Children's Hospital in Edmonton. This is the first of three interviews by Cindy Castillo.

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

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

I grew up in Goderich, Ontario, a small town 2.5 hours west of Toronto, on Lake Huron. I have one sister and two brothers. It was a terrific time growing up in a town of 6,500, very rural area so lots of outdoor activities.

Where did you go to school?

I attended the University of Toronto for undergraduate and medical school. I interned and did one year of anesthesia at McGill in Montreal. I worked as a GP in a small northern Ontario town for 2 years (Fort Frances). I did general surgery, cardiovascular and thoracic surgery training at Dalhousie University, Halifax, followed by a one year fellowship at the Hospital for Sick Children in Toronto and one year in the UK at the Royal Brompton National Heart Hospital in London.

What made you want to become a pediatric cardiac surgeon?

While doing anesthesia at McGill, I saw Dr. Dobell performing pediatric cardiac surgery on small children as well as a 20 year old he had operated on as a newborn. I thought that was pretty neat. At Dalhousie, I had the opportunity to work with Dr. David Murphy, also an impressive pediatric cardiac surgeon, and again found the care of children to be very challenging, and rewarding.

How did it feel the time you performed your first surgery?

I can't really remember – you train for so long (in my case 15 years following high school, 9 years after medical school) and do so much that it is anticlimactic. In addition, I probably did over 100 cases completely independently in London during my fellowship.

How did you end up in Edmonton?

I am good friends with Dr. Ivan Rebeyka, the other pediatric cardiac surgeon already here. The program here was rapidly expanding due to consolidation of the Winnipeg and Saskatoon programs and needed assistance. We often discussed problem cases with each other prior to my moving here, so working together seemed natural.

I have heard again and again from famous, well-loved performers that they still get nervous when they go on stage. Is that the same for surgeons?

I don't think I am famous and not sure about well-loved. I don't think nervous is the right word. We never consider any operation boring or routine and some are certainly more challenging than others. So I wouldn't say we get nervous before an operation, more a state of heightened anticipation.

What is the most difficult thing about being a pediatric surgeon? What is the most rewarding?

The most difficult part of course is dealing with those children and patients that, despite our best efforts, we are unable to help. That is not nearly as many as there used to be even just 10 or 15 years ago, but they still exist and it is difficult.

The most rewarding is seeing how well some of the children do, particularly those that have a really difficult problem and do much better than anyone expects. Some with very complex problems requiring artificial heart support and

transplantation are with us in hospital a long time and it is a lot of fun to see them come back to visit once they are home.

The other very rewarding part of the job is that as a team we are very close and many of my best friends are colleagues with whom I work. We do things together outside of the hospital including back country overnight ski trips, fishing, etc. This year we are taking a team of eight back to work in China for a couple of weeks; we did this two years ago and it was a great experience.

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

I have a group of friends with whom I go either canoe tripping or high elevation trekking pretty much every year since medical school. This year we just came back from ten days of trekking in the Bolivian Andes. My wife Rachel, kids (twin 20 year olds), and I have always enjoyed travelling as a family and particularly like skiing together in Jasper. I have a light airplane and enjoy day trips in it into the foothills, often adding in some fly fishing or scrambling in the mountains west of Calgary. Finally, Rachel and I own a small farm/orchard in the Annapolis valley in Nova Scotia and spend several weeks a year there working on clearing the old orchard. Not quite sure what we will do with it, but it is an area with a growing wine industry so perhaps one day it will be in grapes.

Your job obviously comes with a lot of stress, expectations, and unfortunately sometimes losses. That must be hard on you. How do you deal with all of that?

Having one's own family is very important, as is the support of the people with whom you work. We really try to work as a team so that decisions on children's care are taken as a group – that way our patients benefit from having had a number of people's opinions. If unfortunate results do occur then at least we know that we did our best. We also participate in a group that compares our results to 43 other North American centres – again if we have an unfortunate outcome then we can at least assure ourselves that our overall results are equal, or in many cases superior to our peers. We cannot promise that we will save every child – what we can promise is that any child will have as good, or better, chance of success here in Edmonton as he or she would anywhere else in the world.

University of Maryland School Of Medicine Awarded Grant to Develop Tiny Heart Pumps for Children

Grant funds preclinical tests on devices for infants and children with congenital heart defects

The University of Maryland School of Medicine in Baltimore has been awarded a contract from the National Heart, Lung, and Blood Institute (NHLBI), part of the National Institutes of Health, to begin preclinical testing of new, lifesaving devices to help children born with congenital heart defects or those who develop heart failure.

The \$5.4 million, four-year grant is part of a broader \$23.6 million national research program among four facilities called Pumps for Kids, Infants, and Neonates (PumpKIN).

“The tiny devices that result from the PumpKIN research will make all the difference in the world for infants with these serious cardiac problems, particularly babies who have not responded to surgical or other measures to correct their heart defects,” says Bartley P. Griffith, M.D., the principal investigator for the Maryland arm of the project.

Dr. Griffith, professor of surgery at the University of Maryland School of Medicine and chief of cardiothoracic surgery at the University of Maryland Medical Center, has been working for several years with one of the other grantees in the pumpKIN project, Robert Jarvik, M.D., developer of the Jarvik heart pump for adults, to develop a child-sized pump.

The NHLBI launched the Pediatric Circulatory Support Program in 2004 by funding the development of five novel circulatory support devices for infants and young children with congenital and acquired cardiovascular disease. The PumpKIN program is the next phase of NHLBI support for the development and clinical realization of these devices. The program’s goal is to complete the needed

animal studies and other tests in artificial environments for the most promising devices in order to gain approval from the FDA to begin clinical testing.

The adult heart is about the size of a fist but a child’s heart is much smaller; in an infant, the heart is about the size of a large walnut. Devices in the PumpKIN program will provide circulatory support for newborns, older infants, and children less than 55 pounds who experience heart failure due to congenital and acquired cardiovascular disease. The devices must supply adequate blood flow to prevent organ damage while minimizing the risk of blood vessel damage, infection, breakdown of red blood cells, excessive bleeding, brain damage, and dangerous blood clots. The devices are intended to support circulation in pediatric patients for one to six months, be sufficiently small and reasonably portable, and be able to be routinely positioned and functioning in less than one hour, among other specifications.

The program will test ventricular assist devices (VADs) and advanced extracorporeal membrane oxygenator (ECMO) devices. The VADs in the PumpKIN program are very small rotary pumps which are implanted to provide circulatory support for extended periods of use. They work by drawing blood from the heart and pumping it to the body. ECMO devices circulate and supply oxygen to the blood, and are commonly used for patients who need both heart and lung support. For ECMO devices, tubes connecting the patient to the device are placed directly into large blood vessels near the base of the neck. Blood is drawn from the right side of the heart, pumped through the oxygenator,

and then returned to the body on the left side of the heart so the oxygen-rich blood can be delivered throughout the body.

“Circulatory support devices have been used in adults for years,” says E. Albert Reece, M.D., Ph.D., M.B.A., vice president for medical affairs at the University of Maryland and dean of the University of Maryland School of Medicine. “Design innovations in devices for adults have increased their reliability and effectiveness. Nevertheless, the miniaturization necessary for children presents enormous technical challenges that will require radical new designs. Dr. Griffith and his team have already demonstrated their ability to meet such challenges.”

Each year in the United States, nearly 1,800 infants die as a result of congenital heart defects and another 350 develop heart disease, which leads to heart failure for many. Approximately 60 infants and children under five years old who are placed on the heart transplant waiting list die each year before receiving one. Mechanically assisted circulatory support could be used to sustain these young patients as they seek to recover or wait to receive a heart transplant.

“For the first time that I am aware, this grant virtually guarantees the realization of a concept that we started literally with a sketch on a napkin,” says Dr. Griffith.

In addition to Drs. Griffith and Jarvik, the PumpKIN contractors include Harvey S. Borovetz, Ph.D., University of Pittsburgh, and Mark Gartner, Ph.D., Ension, Inc., Pittsburgh, Pa.

Reproduced with permission from the University of Maryland School of Medicine.

Heart Beats First Ever Walk & Run

Heart Beats will be holding its first ever Family Fun Run benefiting children and families coping with heart disease. The run will be held at Eau Claire Market on Saturday, October 16th. Please see the back cover of this newsletter for registration details.

Running & Walking Tips

- ♥ Be sure to consult with your physician before beginning any exercise regimen.
- ♥ Stretch before and after your run/ walk. This will improve your performance and help to prevent injury.
- ♥ Warm up before and cool down after your run/walk. This will allow your heart rate to gradually increase and decrease.
- ♥ If you haven't been active for awhile, use the run/walk technique – start with a two minute run/one minute walk. Gradually increase the run and decrease the walk as your conditioning improves.
- ♥ Maintain your level of hydration before, during and after your run/walk.
- ♥ Take time to recover between runs by incorporating rest days.
- ♥ Invest in a comfortable pair of walking shoes to avoid blisters.
- ♥ Pace yourself! You should be able to walk and talk at the same time.
- ♥ Find a running or walking buddy, or recruit a family member who will keep you motivated.

Adapted from the Canadian Physiotherapy Association.



Heart Beats thanks the following sponsors for their generous contributions to the Heart Beat's First Annual Family Fun Run.

- ♥ Raimount Energy Inc.
- ♥ Running Room
- ♥ South Calgary Periodontal Group
- ♥ The Flyer Shop
- ♥ Threshold Performance Training

Safeguarding Study

Safeguarding Survival: Parenting Children & Adolescents with Complex CHD

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

If yes, we would like to talk with you!

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

For more information about this study, please contact:

Phone (780) 492-9047 E-Mail safeguarding@ualberta.ca

Study Update!

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



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

My Heart vs. The Real World; Children with Heart Disease, in Photographs and Interviews

By Max S. Gerber

Published by Cold Harbor Laboratory Press

Max Gerber is an editorial photographer whose work has appeared in such publications as Time, Newsweek, and the Wall Street Journal. He has photographed everyone from Bill Gates to Willie Nelson. He also happens to have CHD.

Max set out to capture the experience of growing up with congenital heart disease. As he explains in the book's Foreword, while he was growing up he had never met anyone his own age with a significant heart defect. He wanted to know if any other kids felt the way he once had; why he felt so old growing up, or why he was instinctively aware of his own mortality at age 8, or why everyone was intent on calling him brave (because "how can you be brave when you have no choice?"). His search for someone who had also grown up with these thoughts ended when he visited Camp del Corazon, a non-profit summer camp. Suddenly he was surrounded by 160 individuals who were facing the same issues and feelings he had faced as a child and teen, and he wanted to tell their stories.

Max's personal insight into growing up with CHD is reflected in this striking collection of photographs and interviews of young people with CHD. In their own words, these ten individuals capture the essence of what it is

like growing up with the surgeries, the scars and uncertain futures. At times, the parents also share their own unique perspective of raising children under these challenging circumstances. Each story is unique and captivating. The book concludes with Max's own candid story, and features those of his parents and siblings who have journeyed alongside him.

This book is poignant and inspirational, and I would recommend it to anyone who has, or knows of a person with congenital heart disease. It is honest, uncensored and at times tragic, and therefore may not be suitable for someone feeling emotionally vulnerable. The book can be purchased online at Amazon.ca.

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 Parent Experts – You!

How have you explained to your child their heart condition, and at what age did you do so?

We probably started explaining Mathias's heart condition just prior to his second heart surgery at two. We went to Scholar's Choice and got a foam model of a heart and that helped to explain. We did explain it in great detail. I am not sure how much he retained, but we did try to be open and complete with him. He still has a very serious murmur so we always tell him that most people's hearts go boom, boom but his goes boom, swish, swish, boom.

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

Our daughter, Isabelle, is nine now. At an early age we told her that she has a "special" heart, but did not go into a lot of detail. She has participated in Heart Beats activities since she was an infant and she knows we are involved with Heart Beats because of her. When she was younger she would refer to herself as a "heart beat". Throughout the years more detailed discussions about her heart condition have been in response to her questions such as if she will always have a scar and why she takes the medication she does. I expect this will be the approach we will continue to take with her -- to not avoid the topic, but to also not overwhelm her with more information than she is ready to take in.

Patty Wiebe, mother of Isabelle (9 years), born with Hypoplastic Left Heart Syndrome.

Joshua is 3 1/2 and too young to fully understand, but since he was about 2 we have repeatedly told him that he has a special heart. He sees his scars on his chest, belly and groin and knows that these were "owies" from the hospital. Joshua remembers being in the hospital and is somewhat apprehensive when we go there. When we drive by the Alberta Children's Hospital, he says "That's Joshie's hospital".

Joshua calls his chest scar a zipper because that is what we have named it. If asked, he will proudly show it and point to his special heart.

Because Joshua is on a blood thinner called Warfarin, we have told him, and he has learned, that he is not to hit his head. He reminds us of this almost daily.

(continued on page 11)

Advice from Our Parents Experts – You!

(continued from page 10)

Living a normal life and letting him do things other healthy kids would do is something we do every day, but we have taught him to be cautious as well.

Lynn Nakoneshny, mother of Joshua (3 years), born with Hypoplastic Left Heart Syndrome

Just like many other children in the Heart Beats support group, Kirsten has had several heart issues since birth. With that in mind we discussed these issues with Kirsten and her siblings since then. There was no one magic time to start explaining or talking about it with her. It has been part of all of our lives since she was born. As she is getting older, now 4 1/2 years old, we have started introducing more terminology as well as various signs and symptoms to her. Once children are able to speak and clarify their own physical feelings then it becomes so very important for them to be able to communicate that with parents and staff at the ACH. They are the little ones who can tell us adults when their health may be failing, lots of times sooner than we can. That being said we never hold her back physically. She is always the one to try new things and be adventurous. Her symptoms will let her know when to slow down. We do not focus on her heart and we try not to let it interfere with her everyday activities. These children are strong and bright but for us we chose not to introduce it at any one given time but rather all through her life. Any time she or her big brother had a question we would answer it honestly but yet not in great detail -- enough for them to understand, but not be scared. It is just part of our lives, and don't we all have something unique about us that makes us special?

Claudette & Marty Chisholm, parents of Kirsten (4 years), born with Di George's Syndrome, Tetralogy of Fallot and absent pulmonary valve.

We have always talked about Lucas' CHDs in our family and did not want to make it a big secret or anything to be ashamed or sorry for.

As soon as Lucas came back from Edmonton, I made a scrapbook of his first six months because it was important to us that he knew who to be thankful to later in life. In his book, he has his pictures with one of the nurses and one of the surgeons who took care of him. There are pictures of him in PICU that are quite dramatic and tough to look at but they've always been part of him. Kids are very visual so with his scrapbook, he can realize by himself how serious this was and what we owe doctors and nurses.

He often looks at his scrapbook and, back in Grade 1, he brought it to school and gave a presentation to his classmates about the importance of life. Last Spring, as we were going to Edmonton on a family trip, we stopped by the hospital to bring the nurses some flowers and luckily we "bumped" into Dr. Dyck. So nine years later, Lucas got his picture taken with his surgeon again. The first picture showed a very sick and weak baby and the new one shows a healthy, strong and smiling kid. We've always talked about the scars as Super Hero marks.

Lucas will challenge the 5K run in October for the Heart Beats Family Fun Run with me and his older sister (while dad and younger sister walk the 1-K). When he talks about his annual heart check-up, he always smiles because he thinks the EKG is the coolest thing when you are ticklish!

So we turn lots of little things into positives.

Anne-Claire Chevallier, mother of Lucas Neander (9 years), born with coarctation of the aorta, aortic stenosis and bicuspid valve.

Heart Beats Children's Society of Calgary

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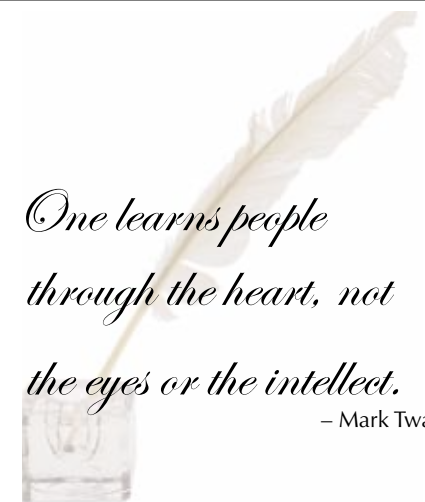
Disclaimer: Any personal opinions/comments expressed in this newsletter are not necessarily those of the Heart Beats Board of Directors. All submissions for the newsletter will be accepted, however we reserve the right to publish in whole, in part or not at all. Remember your best source of medical information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



Heart Beats
Supporting Children with Heart Disease

*One learns people
through the heart, not
the eyes or the intellect.*

– Mark Twain



Community Updates

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



Heart Beats

Supporting Children with Heart Disease

Family Fun Run

10 km Run, 5 km Run/Walk, 1 km Kids Run
Saturday, October 16, 2010



Help Support Children with Heart Disease
Register Online at



www.runningroom.com

at any Running Room location

or

www.heartbeats.ca

RACE INFORMATION

The races will start and finish at Eau Claire Market and go along the running paths next to the Bow River.

Start times:

- ♥ 10 km Run: 9:00 am
- ♥ 5 km Run/Walk: 9:05 am
- ♥ 1 km Kids Run: 10:30 am

RACE PACKAGE PICK-UP

Thursday October 14, 2010
4:00 pm - 6:00 pm

Friday October 15, 2010
12:00 pm - 6:00 pm

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

REGISTRATION

Registration can be done online at www.runningroom.com or www.heartbeats.ca or at any Running Room location.

T-SHIRTS

All participants will be given a free T-shirt. Register before September 20th to guarantee size.

Heart Beats provides information, resources and support for children born with congenital heart defects (CHD) and their families. CHD is the most common birth defect, affecting 1 in 100 Canadian newborns. Our website is www.heartbeats.ca.

If you cannot participate in the walk/run but would still like to support Heart Beats, you can donate at www.heartbeats.ca or www.runningroom.com.