



Keeping the Beat

Winter 2011

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

In this issue



Congenital Heart Defect Awareness Week . . .	1
Send an E-card and Show You Care	1
Annual Family Event at Shakers Fun Centre . .	2
Under Construction – Heart Beats to Launch New Website	2
Offbeats	2
Heart Beats Holds its 1st Family Fun Run . . .	3
Your Support in Action	4
First-ever congenital heart surgery trial identifies procedure that improves babies' survival in first year	5
Cardiology Clinic News	6
Heart to Heart	6
Heart Beats Continues its Tradition of Christmas Hampers	6
Talk with the Docs – Dr. Ivan Rebeyka	7
Who are we?	7
CHD and Me – Talking With Adults With CHD	8
Safeguarding Study Safeguarding Survival: Parenting Children & Adolescents with Complex CHD	9
Summer Camps for Kids with CHD.	10
Community Updates.	11
Parent Resources.	12
Advice From Our Parent Experts – You!. . . .	12

Congenital Heart Defect Awareness Week

February 7-14, 2011

Congenital heart disease is the most common birth defect worldwide, affecting 1 in every 100 births. Without treatment, one third of children born with a heart defect will die before their first birthday (statistics taken from www.childrensheartlink.org). Despite that staggering statistic, many people remain unaware of the severity of this disease and its lifelong impact on survivors. Congenital Heart Defect Awareness Week is an international campaign designed to increase public awareness of Congenital Heart Defects. In Calgary, Mayor Nenshi has proclaimed February 7-14th to be Congenital Heart Defects Awareness Week.

You can play a vital role in helping to raise awareness by doing the following:

- Send an e-card to those in your address book, letting them know about CHD (see below for instructions on how to send a Heart Beats e-card).
- Provide information to your child's teacher or school about Congenital Heart Defect Awareness Week.
- Create a dialogue about Congenital Heart Defect Awareness Week with friends and coworkers.
- Donate to Heart Beats so we can continue to educate and advocate for those with CHD.
- Come to a Heart to Heart meeting to support other families dealing with CHD.
- Get involved with the Heart Beats Executive and become part of a core group making a difference to those living with CHD.
- Attend our Annual Family Event (details on page 2) to meet local families dealing with CHD.

Thank you for participating in this important campaign!

Send an E-card and Show You Care

Heart Beats has developed an e-card to celebrate Congenital Heart Defect Awareness Week. We encourage you to send this e-card to family, friends and others in your address book to let them know more about CHD.

You may wish to send this e-card in lieu of a valentine to show that this holiday can be an opportunity to give more than chocolates and flowers. It can be a way to truly help heal broken hearts.

To send an e-card, visit the Heart Beats website at www.heartbeats.ca and follow the onscreen instructions. Be prepared with the e-mail addresses you wish to send the card to.



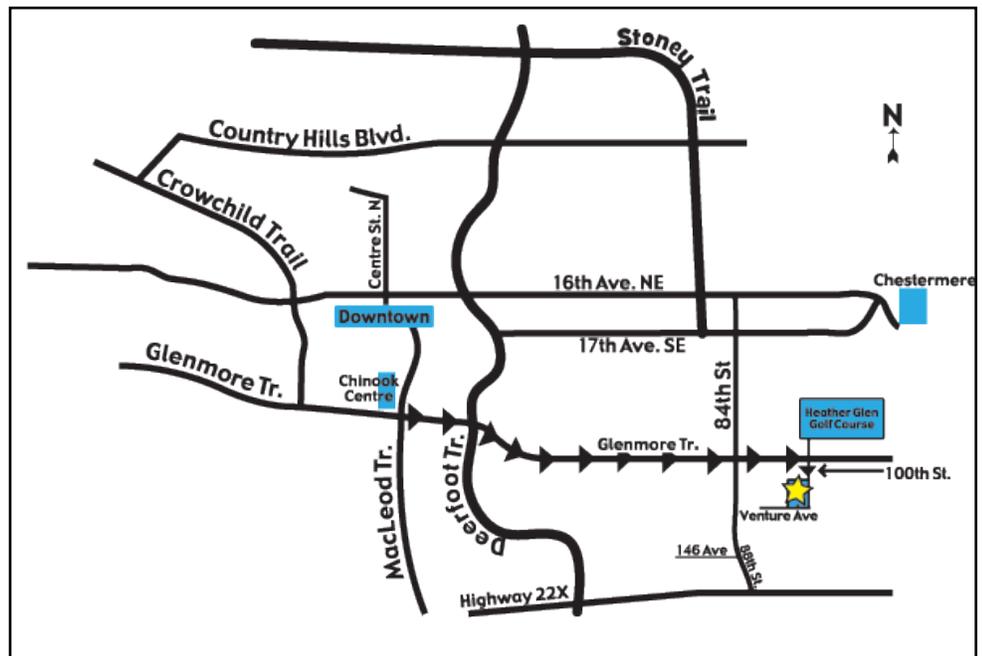
Heart Beats
Supporting Children with Heart Disease

Annual Family Event at Shakers Fun Centre

Please join us in celebrating Congenital Heart Defect Awareness Week by attending the Annual Family Event on Saturday, February 12, 2011 at 6 pm. This year, the event will be held at Shakers Fun Centre located in Southeast Calgary (please see the map for directions). There will be plenty of fun activities for the whole family to participate in, including a climbing wall, laser tag, an indoor playground, and a large variety of arcade games. (Your admission will include a \$5 Player Card for the arcade games. If you choose to play more that will be at your own expense.) A full dinner will also be provided.

This event is open to **all families of children and teens with a CHD**. Even if you have not participated in any other Heart Beats' activities, we encourage you to come to the Family Event this year. It's a great opportunity to meet and/or reconnect with other families of children with CHD.

A contribution of \$5 per family member (or \$20 per family, whichever amount is less) is requested to help cover the cost of this event. However, we do not want the cost to keep away anyone who would like to attend. If cost



is a concern, Heart Beats has a fund available to assist with the cost of the Annual Event. We would be happy to sponsor your attendance (confidentially, of course!). When you RSVP, please let Patty know you would like to access this fund.

To help us plan accordingly, send an e-mail confirming your attendance to Patty Wiebe at pattyw@heartbeats.ca AND mail your cheque to Heart Beats, Box 30233, Chinook Postal Outlet, Calgary, Alberta, T2H 2V9 no later than January 27, 2011.



Under Construction – Heart Beats to Launch New Website

Over the past few months we have been hard at work updating the Heart Beats' Website. We have changed the look so that it is consistent with the new brochure and our other communication materials. The content now better reflects the organization that we have become. Keep your eyes open as we hope to have the new Website up and running in the near future. If you have any links or resources you would like to see on the Website, you may contact Karen Perl-Pollard at karenperl_pollard@hotmail.com and she will see if it can be included. A special thank you to Leesa Iverson who provided her Web design services free of charge for this project. As well, thank you to Ferrell Beleshko, from Terra Software Corporation, for hosting the Website for Heart Beats.

Offbeats

We have had a great season so far with Offbeats. In September, we met at the hospital and had a drumming session with the Alberta Children's Hospital music therapist. In October, we went to Build-A-Bear and designed teddy bears for the Cardiology patients who are admitted at ACH. In December, we had a jam session in the main space of the hospital. The music therapist led us in some creative music.

We look forward to more fun activities in the new year, including celebrating Heart Month in February with heart shaped pizzas, a "Rock Band" night, and going to the Fire Escape.

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

Heart Beats Holds its 1st Family Fun Run

On Saturday, October 16th, over 270 walkers and runners from Calgary and beyond braved the cold to take part in Heart Beats very first ever Family Fun Run. The race, which began at Eau Claire Market, featured a 10K run, a 5K walk or run and a 1K kids run and the turn out exceeded all expectations. \$17,000 was raised to help families dealing with congenital heart defects in our community. A big thank you to the participants, event organizers, volunteers, and sponsors for making this event such a success. We look forward to the next Family Fun Run, which will take place on Saturday, October 15, 2011. Look for details in our next issues of Keeping the Beat.



Below is a letter that Lucas, a young child in the Heart Beats community, sent out to his friends and family. Lucas raised \$1000 in pledges for Heart Beats. Way to go, Lucas!

Hi! My name is Lucas and I am 9 years old. I am going to run the Heart Beats Family Run on Oct. 16th in Calgary. I was born in 2001 with 3 serious heart problems but amazing doctors and surgeons in Edmonton and Calgary saved me. Thanks to their work, I now swim, ski, climb etc... I am supposed to walk the 1K, but I would like to try the 5K run with

my Mom and big sister. Click on this link and enter my name (Lucas Neander in the Find an athlete box in the upper left corner) you can make a donation on my behalf. You will be encouraging me and contributing to a great cause. There is no minimum, even \$5 would be great; my objective is \$100. All the money goes to Heart Beats, the association of parents with kids like me. Heart Beats is the bridge between families and the hospital and they help everybody a lot. A huge thanks from a Heart Kid!



Lucas Neander, Age 9, born with coarctation of the aorta, aortic stenosis and bicuspid valve. With his family at the Heart Beats Family Run/Walk

Your Support in Action

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

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

We appreciate and acknowledge the donations received from the following individuals and organizations from September through December, 2010:

Tom Alford	Jean Pierre Chevallier	Keith S. Gill	Nanette Miller	Courtney Slama
Michelle Amlin	Ruby Choi	Anja Gray	Courtney Morin	Elmer Stang
Micheal Anderson	Annette M Christensen	Melanie P Hagel	Martin Mudryk	JoAnne St.Onge
Megan Arneson	Heather R Christensen	Bryan Har	Tamara Mutemwa	Ali Taher
Seline Badel-Wong	Isabelle IC Cloez	Shauna & Rob Harms	Mag Neander	Sharon Tebb
Cam Baldwin	Jeff Coles	Terri Hayman	Charlotte C Neander	Tannis Teskey
Greg Beatson	Eric Compton	Marlo Hertling	Clara M Neander	Ostyn Th��r��se
Norma Becker	Tracey D Contrada	Krista Hoffert	Sheryl Newton	Daniel Therrien
Nicole & JF Belanger	Sonja Cornelissen-Botha	Sheena Howdle	Jeanette & Brent Nielsen	Jillian Thornton
Joe Bennett	Carol Cowie	Andrea L Hudson	Rebecca Niven	Greg Toews
Stan/Nancy Bernbaum	David Cracknell	Faith A Hughes	Carissa Notland	Jakob Tornqvist
Rene Bertrand	Jody Crowe	Deb Hymers	Patricia Olson	Franca Torriero
Laurence Bezu	Susan A Dai	Sajan Jairath	Ryan Olson	Lloyd & Colleen Trentham
Don & Marni E. Bold	Carmelo Daprocida	Cecile Jaster	Katherine Paget	Mark & Jacqueline Trentham
Monica Bishop	Cathy Daprocida	Greg Kanashiro	Eugene Pelletier	Lisa Trotta
Joan Boehm	Nick Daprocida	Amanda Kennedy	Florence & Michael Perl	Wendy Van Doren
Steffen Botha	Christine De Bruyn	Laura D Kirkhope	Rostaing Pierre	Mary Van fraassen
Alan & Louise Bourne	Anna DeCarlo	Moira Klein Swormink	Vincent Piperni	Maria Vetter
Angus Bradford	Denise Decoste	Marion Kwasnecha	Barbara Potzauf	Reg Vickers
Betty Bradford	Helen Dickson	Alain Al Lechiguero	Andrew Powers	Jevins Waddell
Jim & Lucy Brietzke	Tanya Dmytryshyn	Sandra Lemay	Barry Pratt	Scott Walters
Mike Brietzke	Patti B Dolan	Nathalie Levesque	Christine Riley	Nicole Wasylenko
Linda Brinks	Craig & Ramzie Donaghy	Phil Lindsay	Delphine Ringot	Pete Watkins
Laree Brummund	Allan & Michele Donsky	Shannon Lindsay	Aileen Rios	Florence Weber
Marilou Brummund	Corie Doyle	Sarah Lluberas	Jane L Roberts	Carmen Williams
Paul Buccini	Doug & Lynn Dry	Brad & Erin Luijkx	Suzanne Saba	Harry Williamson
Lucette Bucknor	Keremy A Dry	Tracy MacKenzie	Jennifer L. Sadler	Bruce & Ruth Wold
Heidi Bundschoks	Joy Epperly	Jennifer Madriaga	Lyyette Sanderson	Meghan Zvaigzne
Lindsay Burchill	Rachel Evans	Heather McCollister	Cathy Sangregorio	Ancora Developments Inc.
Rob & Kara Bustin	Doug Fearn	Valerie M McKinney	Ian C. Schofield	Cadillac Fairview – Encor Place
Bob Cameron	Simon Fletcher	Eli McKitrick	Emily Schultz	D & M Developments
Ken H Cha	Andrew & Barb Frere	Joanne Mclay	Gord Shmyrko	McCormick Canada
Jennie & Nick Cherniwchan	Patricia Fox	Kim McNeil	Wale Shobo	Paget Holdings Inc.
A Chevallier & R Neander	Jean-Pierre Gauthier	Lori & Hermes Michelini	Annie Simard	WCCHN

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.)

First-ever congenital heart surgery trial identifies procedure that improves babies' survival in first year

By Matet Nebres (Preprinted with permission from Hospital News, July 2010 edition).

In the first and largest study of its kind, doctors compared two routine surgical procedures used to treat infants with a severe form of congenital heart disease. They found that one procedure resulted in higher survival rates than the other in the baby's first year. The study is published in the May 26 advance online edition of the *New England Journal of Medicine*.

The randomized, multi-centre surgical trial was conducted by the Pediatric Heart Network (PHN), a National Institutes of Health sponsored consortium of eight North American institutions. The Hospital for Sick Children (SickKids) is the only Canadian member of the PHN and was the only Canadian centre out of 15 to participate in this study. The study evaluated 555 operations performed on babies born with Hypoplastic Left Heart Syndrome (HLHS).

HLHS is a complex heart defect where the left side of the heart does not form. It is the most common severe congenital heart defect, accounting for 3.8 per cent of all congenital heart defects. Children with HLHS typically undergo at least three major heart surgeries to establish a reliable flow of blood from the heart to the body, while ultimately directing blood to the lungs, without the direct assistance of the heart. The Norwood procedure, usually performed right after birth, is the most difficult to perform and has the highest risk of death.

"The risk of death during the first year, after this procedure is 29 per cent, which is why it is so important for us to find better ways to treat these babies," says Dr. Brian McCrindle, SickKids' principal investigator for the study, Staff Cardiologist and Senior Scientist in Child Health Evaluative Sciences and Professor in the Department of Paediatrics at the University of Toronto. "Being able to follow such a large group of patients should make a significant impact on how we will be able to care for children with HLHS in the future."

There are two common ways to perform the Norwood procedure. The classic procedure is referred to as Norwood using a modified Blalock-Taussig shunt (MBTS). MBTS is a part of the procedure that involves placement of a connecting tube from the aorta (which directs blood to the body) to the pulmonary artery that supplies blood to the lungs. The alternate procedure is called Norwood using right ventricle-to-pulmonary artery shunt (RVPAS). RVPAS establishes blood flow to the lungs by connecting the right ventricle directly to the pulmonary artery.

With MBTS, 64 per cent of the babies survived in their first year without a transplant, while the remaining babies either required a transplant or did not survive. Seventy-four per cent of the RVPAS babies survived to the age of one without a transplant. However, RVPAS was also found to be associated with a higher rate of unintended cardiovascular interventions and complications.

"We must be cautious in interpreting these results and refrain from labeling one procedure as the better option," says Dr. Seema Mital, Staff Transplant Cardiologist and Associate Scientist at SickKids and Associate Professor in the Department of Paediatrics at the University of Toronto. "Our early results indicate increased survival associated with RVPAS, but also suggest that this benefit may not continue past the first year of life. We are still studying how these procedures impact survival and complication rates beyond one year."

The research also showed that patient care provided by a comprehensive interdisciplinary clinical team had an impact on results. The centres with the most experienced clinical teams had the best outcomes regardless of which operation was performed.

Doctors at SickKids' Labatt Family Heart Centre are currently developing an alternative to the Norwood procedure that avoids the initial surgery. Instead the procedure is performed using less invasive means in the catheterization laboratory.

The study was supported by the National Heart, Lung and Blood Institute and SickKids Foundation.

Matet Nebres is Manager, Media Relations at The Hospital for Sick Children.

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 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. We look forward to seeing you on:

- **January** – Monday, January 17th at 10 am at the home of Lynn Nakoneshny, 187 Willowmere Close, Chestermere.
- **February** – Tuesday, February 22nd at 10 am at the home of Patty Wiebe, 43 Midvalley Crescent SE.
- **March** – Monday, March 21st at 10 am at the home of Cindy Castillo, 83 Auburn Glen Hts SE.
- **April** – Sunday, April 17th at 1:30 pm – We invite the whole family to our Annual Easter Egg Hunt at the acreage of Michelle and Paul Aris at 281130, Township Road 230, just outside the east city limits. For more detailed directions, contact Patty Wiebe.

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.

Cardiology Clinic News

The Cardiology Clinic will no longer be providing toys in the waiting room. We encourage parents to bring their own toys from home to amuse their child while waiting for their appointment.

Heart to Heart Christmas Party



Once again Patty and Colin Wiebe hosted the Heart Beats Christmas party at their home in Midnapore. The event took place on Sunday, December 5 and was enjoyed by all. There were 18 children and 18 adults in attendance. Guests enjoyed an abundance of food and drink and great conversation. Children were invited to decorate their own Christmas ornaments and each child received a special gift from under the Christmas tree. Thank-you to Heart Beats for providing the gifts and crafts and to the Wiebes for being such gracious hosts!

Heart Beats Continues its Tradition of Christmas Hampers

Christmas arrived early for four heart families this year. As part of our ongoing support of families, Heart Beats provided Christmas gifts and goodies for eleven children and their parents. A big thank you, once again, to Lori Moch, and her daughters, Jillian and Erin. These Christmas elves, along with others, have worked for the last ten years to make sure heart kids wake up to something under

the tree! Thank you to Patty Knox for your "behind the scenes" help. I could not do it without all of your assistance! Wishing all of our heart families a merry Christmas.

Heidi Smethurst is a mother of four. Her third child, Ryan, was born with Transposition of the Great Arteries and a Ventricular Septal Defect.

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*.

Talk with the Docs – Dr. Ivan Rebeyka

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

"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 continue my series by featuring Dr. Ivan Rebeyka."

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

I grew up in Saskatoon with 1 older brother and 1 older sister. Spent my youth playing sports and wanted to be a pro football player.

What made you want to become a pediatric cardiac surgeon?

I spent time in Alabama with a famous pediatric heart surgeon as a medical student who influenced my choice in careers.

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

I started my career in Toronto at The Hospital for Sick Children in 1989 but decided to move back out West primarily for family reasons.

Do you remember how it felt the first time you performed surgery alone?

Yes, the mother told me she was putting her baby in my hands.

After performing as many surgeries as you have, do you ever get nervous?

Of course. All surgeons get nervous about difficult cases.

How much time do you dedicate to research, and is there something specific you are working on now?

I try to spend about 20% of my time in research looking at various ways to make heart surgery safer and more successful.

How has cardiac surgery changed since you first started and how much do you think it will change in the next ten years?

Too many ways to list, but certainly the overall risk of surgery has fallen dramatically.

What do you consider to be the greatest advancement in cardiac surgery to date?

It's hard to say, but repairing a baby's heart and giving them a full life has to be considered a pretty great achievement.

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

I get to travel a lot in association with surgical meetings and try to sneak in a round of golf whenever possible.

How do you deal with patient loss? Is there a specific thing you do in order to cope with it?

The only way to cope is to assure yourself that you have done everything possible and as carefully as if the patient was a family member.

By Cindy Castillo

Who are we?

Start counting... we're roughly 8 out of every 1,000 people (or 1 out of every 125, if you want a number you can get your head around.) We represent both genders and we are all ages. A million of us are adults, and about 800,000 of us are children.

We've made it through surgeries, hospital stays, infections, endocarditis (infection of the heart), pacemakers, and heaven know what else. We've given gallons of blood, one vial at a time. We've fought back against tremendous odds. We've been so sick that we've scared the world's best doctors witless... and then amazed them even more when we've fought back.

We've celebrated our victories and we've mourned our losses. We know that most of those who came before us died, including

14 of the first 70 to have the Blalock-Taussig Shunt. We know that most of us shouldn't even be here and so we live every moment as if it is our last – because it could be.

We're Cardiac Kids and Heart Warriors. We have an amazing inner strength, but we are terribly fragile at the same time. We refer to our parents as Heart Dad and Heart Mom, and we use those titles as Badges of Honor. Why? Because they DESERVE them! They were the first ones to discover that a heart defect doesn't just break one heart, it breaks three.

We work, we play, we pay our taxes and we live our lives. We're in your community, in your church, in your school, in your office, and quite possibly in your home. We

move a little slower, do some things a little differently, but we usually get along without causing a fuss.

We are people living with Congenital Heart Defects.

Written by Steve Catoe, known to many as the "Funky Heart". Steve passed away on November 28, 2010, at the age 44, from complications due to his congenital heart defects. He will be missed by many in the CHD community, including those who followed his blog, Adventures of a Funky Heart (featured in the Fall, 2009 edition 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, we feature the story of Brad Johnson.



I was born in Camrose, Alberta in 1963. My birth was ordinary as far as births go, but that is where “ordinary” ended and “complicated” began. I was born with a congenital hole in my heart, which closed on its own without medical assistance. However, when doing so, it created a complete heart block that left me with a slow heart beat (bradycardia.) I thought that it was pretty interesting, growing up, that I had a medical condition that started with my first name!

Over the next 3 ½ years, I would make many journeys to the University of Alberta Hospital with recurring bouts of pneumonia and bronchitis. Regardless of my health issues, we moved multiple times a year because of my father’s job. It never mattered where in Alberta we lived, we always knew where the nearest hospital was located, even when we moved as far away as Drumheller.

In 1969, we moved to Calgary where I spent the next seven years under the care of Dr. Robert Sommerville. Until I received my first pacemaker, the first eight years of life were a struggle. I battled epileptic-like fainting spells due to having a slow heart rate of 35 bpm and I was exhausted all the time and had trouble remembering things. I took a medication called Phenobarbital to help combat this issue. In 1972, through the surgical skills of Dr. George Miller, I was one of the first children in Canada to receive a pacemaker. The pacemaker was battery powered and had a life

span of two years. A year later, at the ripe old age of 10, I became interested in art through an art club while attending my elementary school, Lee Roi Daniels in the Fairview district of Calgary, which started me onto a lifetime of developing my artistic abilities.

In June of 1974, I received my second pacemaker at the Holy Cross Hospital, and became the youngest Canadian to have a nuclear pacemaker implanted. This pacemaker had a life expectancy of 21 years, which gave me hope of being able to live quite awhile without having to return for new pacemaker implantations every two years. I attended a Pacemaker Club at the Holy Cross Hospital started by Jane Beauman, the head ECG technician back then. With an avid interest in dinosaurs, I was equally happy with the Medtronic Pacemaker Representative for giving me a very realistic pre-historic dinosaur model kit. At least being a kid, there were some perks I suppose! Articles were written about me in the old *Albertan Newspaper*, the *Calgary Herald* and a *Central Albertan* paper about my being the youngest Canadian to get a nuclear pacemaker. A downside from obtaining the nuclear pacemaker came in the form of a letter my parents received from an anonymous individual from Rocky Mountain House. In response to an article in the *Calgary Herald*, they stated that since the taxpayers were picking up the tab for this \$4800 pacemaker operation, “wasn’t birth control possible?” This individual thought it would have been better had I never been born in the first place, so “they” wouldn’t be paying for my operation! I guess some people couldn’t understand what reality was like for a child like me, unless they had a child themselves who been through this. I wouldn’t have wished that upon them, no matter how ignorant and insensitive their comment was. Other downsides of having a nuclear pacemaker were not being able to go near microwave ovens, otherwise the pacemaker would be disrupted, and travel. If I wanted to go to the U.S., or anywhere overseas for that matter, I would have to obtain export/import permits for the transport of Nuclear Material from the Atomic Energy Control Board of Canada, and the Nuclear Regulatory Commission of Washington D.C.

Over the next several years I lived quite well without any real health issues except for periodic fainting spells, which could not be adequately explained at that time. In grade 7, in Fort McMurray, I played on a basketball team and we even won the playoffs. I was able to finish High School and go on to

attend Red Deer College in 1983. However, two years later while staying with my folks in Camrose, I had a major blackout. I was home with my Mom and was waiting for a friend to come over. When I saw their car pull up, I stood up, took two steps... and the next thing I remember was Mom sitting over me crying and (thankfully) me not remembering hitting the floor! My heart, broken as it was, really went out to my mom for the many times over the years that she worried about my health and drove me to hospitals – far too many times for me to even remember. After my big blackout episode, my doctor in Camrose sent me to the Royal Alexandra Hospital in Edmonton. There it was determined that the cause of my blackouts and previous fainting spells were due to the fact that the leads of my pacemaker were corroding. It was decided without delay that I should get a new pacemaker to rectify this issue. I heartily (no pun intended) agreed, given that it was not very comforting to know now that I had defective leads in my body.

For years after leaving Calgary, I had not seen a cardiologist for any of my heart issues, as it was not impressed upon me that I needed to be followed by a cardiologist on a regular basis. In March of 2007, I saw my family doctor in Sherwood Park because of issues with chest pains and edema in my lower legs. He diagnosed me with Congestive Heart Failure, and later in July, while at a scheduled pacemaker examination, it was noted that a period of Ventricular Tachycardia had taken place. From December, 2007 to February, 2008, I had a series of tests at the cardiology department of the University of Alberta Hospital to determine why, with just having a diagnosis of bradycardia, was I then having these V-Tach episodes? After my first test, questions and eyebrows were already being raised, such as: did I have open heart surgery performed on me as a baby? After all of the tests were done, and archived doctor’s notes were found in the University Hospital dating back to 1964-66, another congenital heart issue was discovered – one of which I knew nothing about! I also had Congenitally Corrected Transposition of the Greater Arteries of the heart. In simpler terms, my lower right heart chamber was and is doing the work that the left side of the heart should be doing, and vice-a-versa. The blood that should be going to the lungs wasn’t, and was instead being diverted to the rest of my body. This is also where I discovered that I had moderate pulmonary hypertension. All along I had naively thought that it was difficulties to do with mild asthma that I’d also had since

(continued on page 9)

childhood. It had been determined by the doctors back in the 60's that corrective surgery would be too stressful on my system and therefore was not done. My folks remember being told that since corrective surgery could not be done in my case, that it would be best to just take me home, love me and hope for the best. They were never told exactly what my heart defects were. Thankfully, with the vital addition of the pacemaker at age 9, my parents were told that I would live a relatively normal life through to the age of 35. Well, I have beaten those odds thus far as I will be turning 48 in January of 2011.

I have had a few more pacemakers implanted over the years, and now with these new issues in my life, my cardiologist, Dr. Isabelle Vonder-Muhll, determined with her team that the best course of action for me was to get a heart transplant. Since I am in my late forties, corrective surgery is no longer possible, even with the advanced surgical knowledge and technologies that exist today. So until the opportunity arises for me to get a heart transplant, it was decided as a precaution to prevent sudden cardiac death, that my seventh pacemaker, which was implanted in June of 2008 by Dr. Ivan Rebeyka, would be an Artificially Implanted Cardioverter Defibrillator pacemaker, or AICD. I've attended the Cardiac Rehabilitation Program at the Glenrose Rehabilitation Hospital and I now visit the YMCA regularly to help reduce my weight so that I can eventually be listed for a heart transplant.

Because of my multiple heart issues, I am unable to work and I am on AISH. Aside from dealing with my heart issues, I spend a good portion of my time on the four most important areas in my life. First, spending time with my significant other, April, who is celebrating seven years of being a double transplant recipient of a kidney/pancreas on November 20th. April has been a great support and mentor throughout my recent experiences, and a wonderful teacher as to what to expect for a transplant in the future for myself. Secondly, maintaining a positive relationship with my children, who are all wonderfully supportive. With my eldest getting married next year, I would really like to be around much longer to enjoy any future grand-kids. Thirdly, a continual development of my being a scratchboard artist and seeking ways of making my particular niche of art better known. Lastly, my most recent project which I hope to see an eventual benefit for all adults who have Congenital Heart Defects.

Since February of 2010, I have been working with a few others, in conjunction with the Canadian Congenital Heart Alliance to establish (which we now have) the Alberta Chapter of the Canadian Congenital Heart Alliance. This project was borne from my inquiries to Dr. Isabelle Vonder-Muhll as to how I could get involved in a support network for adults with CHD. I was informed that there was only a support network in the Province of Alberta for those under the age of 18, but not

for anyone beyond that age. Dr. Vonder-Muhll got me in contact with John MacEachern, the founder of the CCHA, about setting up an Alberta Chapter. We have 5-8 people actively in attendance at our meetings, and our hopes are to raise funds for CHD research and education of the public about the real need of supporting individuals with CHD, who are now in greater numbers living into their adulthoods, just like myself. I have yet to be in contact with someone who has my particular heart problem, but that is the beauty of what our group is trying to accomplish, and I remain positive that I will meet someone through our efforts with our own Alberta Chapter.

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

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:

Louisa Fricker: (780) 492-6279 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 new year.



Summer Camps for Kids with CHD



Summer camps are usually associated with memories of great fun, new experiences, and special friendships. However, some parents of children with CHDs may be concerned about sending their heart child to a regular camp. Fortunately, there are camps available which are specifically tailored for children with CHDs and the issues that may arise from their conditions. These include Camp del Corazon in California and Zajac Ranch in British Columbia.

Camp Del Corazon is a non-profit organization that provides no cost, year round experiential opportunities for children faced with the challenges of growing up and living with heart disease. This includes three five-day summer camps for children ages 7-17 which are staffed by volunteer counsellors, nurses and physicians. The camp is located at Catalina Island, California which is approximately 22 miles off the west coast of Los Angeles in a natural island setting. Activities include horseback riding, canoeing, kayaking, paddleboats, swimming, archery, hiking, basketball, softball, volleyball, soccer, high and low ropes courses, climbing wall, drama, arts/crafts, adventure and team building and many more.

This camp is free of charge for any child age 7-17 with heart disease or a history of heart disease. The only cost for campers is for their transportation to and from the camp.

Each camp session has three to six pediatric cardiologists and physicians as well as 15 to 19 nurses whose role is to oversee the medication intake of the children as well as monitor the children's well being at all times while ensuring everyone is having fun.

Camp Dates for 2011 are:

Session 1: August 25 – August 29, 2011

Session 2: August 29 – September 2, 2011

Session 3: September 2 – September 6, 2011

Children are registered on a first come first serve basis. Applications start in April.

For more information please see www.campdelcorazon.info as they have a very detailed website with FAQ regarding accreditation, safeguards, child medical insurance, and documentation requirements for camp.

Zajac Ranch is located in Mission, British Columbia and is also for children ages 7-17. This camp is not exclusive to heart kids, but is for all children with serious and chronic illnesses and disabilities. Each camp session throughout the summer hosts kids with different needs, including one week for children with CHD. At the time of this printing they do not have their camp schedule for 2011 available yet (last year, Gastro Intestinal/Blood disorder & Heart Network was held from July 6-10). Activities at camp include swimming, fishing, canoeing, kayaking, volleyball, archery, rope courses, climbing wall, baseball, basketball, bocce ball, horseback riding, scenic walking trails (wheelchair accessible), orienteering, arts/crafts, drama, music and gardening.

There is a fee for this camp of approximately \$545 in addition to travel expenses to get there and back. This camp has a 24 hour medical facility equipped to handle immediate needs as well as a first rate medical team to watch over every child. There is also a hospital 25 minutes away. For more information visit their website at www.zajacranch.com.

Heart Beats is working towards setting up a scholarship fund to assist children and youth who want to attend these camps. While a fund is not yet in place, Heart Beats may be able to provide some financial assistance if someone from the Heart Beats community would like to attend one of these camps. If you are interested in this, contact us at info@heartbeats.ca.

Community Updates

The day that the calendar changed from December 31, 2009 to January 1, 2010, I started getting tense. It's amazing how we can be so affected by calendars and dates. Why the sudden tension? 2010 was a surgery year. We had known since she was one month old that our daughter Alexa would need her third open heart surgery, the Fontan, sometime in the year she turned three. So here we were and the wait began.

In May we were given a date for her heart catheter to check to see if her pressures were right to be able to have the Fontan. We got ready for that as best we could. The day we were going to leave for Edmonton we got a call cancelling the procedure. It was rebooked for one week later. It was very frustrating as we were already prepared both in being packed etc to being emotionally prepared for what Alexa would have to go through. But we knew that a cancellation invariably means that another Heart Child needed something more urgently than our child, and so I tried not to get down and simply said a small prayer for that child and that family.

Alexa had her catheter on May 15 and everything went well. She was discharged from the hospital the same day and we went home the next.

Then we began our wait for the surgery. For me, waiting is one of the most difficult parts. The unknown. It is a time when faith and patience is tested. I decided we would assume the surgery was going to take place in September or October and try to enjoy our summer.

On August 4 a call came from the Stollery. I expected that they were going to give us a date for surgery two weeks from then. What I was told shocked me! There was a space for surgery on August 6. We would have to leave for Edmonton that night, go to pre-op clinic the next day and she would have surgery the day after that. I would also have to take her to the dentist that day, since she hadn't been yet. I was told we could think about it and let them know within the next hour or so. I immediately called my husband and we both agreed to go with it. For the next few hours I was like a tornado getting everything ready. I found a dentist that would check Alexa's teeth that afternoon; I called my parents and asked them to take care of our other daughter; I called the Ronald McDonald House and was relieved they had space. Finally, we were off.



Alexa (left) with her sister Sophia

Her surgery went very well and her surgeon, Dr Rebeyka, was very pleased with how the Fontan turned out. After three days in the PICU she was transferred to the Ward. She did well and kept her nurses entertained. After two weeks she was discharged from the hospital. She had lost weight and seemed weak, but her heart was functioning fine so we thought she just needed to recuperate a bit longer at home to be back to her regular self.

The first day we were home was Friday, August 20. We were happy to be home, especially since it was our other daughter, Sophia's sixth birthday. She had been counting the days to the big day and we were all relieved that we were home for it. My parents came over and we were preparing to have cake and celebrate when suddenly Alexa sat down and began panting. Her skin turned a grayish blue. She said that her stomach hurt, and we all assumed it was her heart. We called 911 and she was rushed to the Children's Hospital. They immediately did an echocardiogram and an x-ray and saw that her heart was working fine. So they took blood and did a series of tests. We waited and waited and were finally told that her white blood count, which indicates infection, and her CRP levels, which indicate inflammation, were very high. Her chest tube sight looked a little off so they thought maybe it had become infected. They decided to do an ultrasound to see if there were any pus pockets underneath of it. What they found astonished us all. Her gall bladder was very inflamed. We later learned that this sometimes happens as a result of the stress of large surgeries. She was put on high doses of antibiotics through an IV. She stayed in the hospital for one week and fortunately the antibiotics succeeded in healing her

gall bladder and she didn't have to have it removed. So it was her stomach that hurt, as she said, and the blue spell was because she wasn't taking deep breaths because of the pain.

She came home from the hospital much more mature and much more knowledgeable about her heart. She announced that her high chair, which we were using for its height at the table, was for babies and she wasn't going to use it anymore. She also said that diapers were for babies and proceeded to use the toilet. She was very guarded about her chest for about a month and a half and whenever we went somewhere would ask if she would be safe. But slowly she healed and got her confidence back. She turned three on October 14 and is doing great.

Something I would have done differently is I would have arranged a dental appointment in advance since we knew her surgery was coming. You may not have the two weeks notice you are expecting! I would also have gone over her body parts with her more before the surgery. She knew them all before surgery but sometimes it didn't seem like she knew how to indicate exactly what hurt. I had also intended to bring along a picture of her looking at her best, but didn't have the time to get that together. There were times in the hospital when they were trying to get her diuretics dosages correct, that she looked way too thin or way too puffy. We showed doctors and nurses pictures of her from our camera to show them how she was supposed to look, but it would have been a lot better if we had an actual picture hanging above her bed.

We are not quite out of the woods yet as far as scheduled surgeries go. She will have to have another heart catheter as early as March, but at least the big one is over and she is happy being three!

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

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

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

Franklin Goes To The Hospital

By Paulette Bourgeois and Brenda Clark

When Franklin gets hit in the chest with a soccer ball, his shell cracks and he has to go to the hospital to have it mended. Everyone tells him how brave he is, but inside he feels very scared. He finally breaks down and confesses to his doctor that he is not brave; he is actually terrified inside. His doctor explains that being brave doesn't mean not being scared.

This is a great book for children going to the hospital, returning from the hospital and even for siblings so they understand a little of what their brother or sister will or has gone through. I read it to my daughter before her latest surgery, when she was two and a half and she enjoyed it but didn't make many comments. We read it again a couple of months later, after her surgery and she showed a lot of interest. She pointed at things Franklin was going through, like having numbing cream rubbed on his hands, and said "Just like me!" We have read it many times and I find it is a good way to get her to talk about what she went through and to ask any questions she may have. I have also read it with my other daughter, who is six, and was able to explain to her more easily what her sister experienced.

I would definitely recommend this book to families going through hospital stays.

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

Advice From Our Parent Experts – You!

What resources or support have you accessed that you have found beneficial in coping with your child's diagnosis?

I found our family doctor was a good source of support. He put us in touch with Lynn (Nakoneshny). Just talking with Lynn on the phone about Owen's diagnosis and all the medical language that I did not understand really helped alleviate my fears. Lynn was so supportive and sometimes no one knows better about what you are going through than another mom. That is why I feel the Heart Beats group and the regular Heart to Heart play dates are so important. We may not always get out to them, but I love knowing that all the other parents involved in that group are just a call or email away.

Michelle Dominique Aris, mom to Owen, age 2, with repaired coarctation (March 6, 2008), bicuspid valve and mitral stenosis.

Getting involved with Heart Beats and associating with other families affected by CHD has been a tremendous source of encouragement to our family. Being able to freely discuss surgeries, medications and other challenges with parents who have been there has been very therapeutic for me. I also find the nursing staff at the cardiology clinic to be outstanding. When Roman was first born, we would drop by the clinic to check his SATs whenever we were concerned, and we always felt welcome there. It certainly put our minds at ease to have such a caring team to talk with during stressful times.

Jen Beleshko, mom to Roman, Age 3, born with dextrocardia, DORV, single ventricle and pulmonary stenosis.

Heart Beats Children's Society of Calgary

Chairperson	Patty Wiebe pattyw@heartbeats.ca
Vice-Chairperson	Jeannine Oliphant jeannineo@heartbeats.ca
Secretary	Cindy Castillo cindyc@heartbeats.ca
Treasurer	Sylvia Falk sylviaf@heartbeats.ca
Newsletter Director	Jen Beleshko jenb@heartbeats.ca
Nurse Liaison	Patty Knox
Additional Directors:	Lynn Nakoneshny Heidi Smethurst
Communications Coordinator	Karen Perl-Pollard

mailing address:

Box 30233 Chinook Postal Outlet,
Calgary, AB T2H 2V9

website:

www.heartbeats.ca

e-mail address:

info@heartbeats.ca

phone:

403-289-4329 (Jeannine Oliphant)

Charitable registration number 88907 6261 RR 0001

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



– Ralph Waldo Emerson