



Keeping the Beat

Winter 2010

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

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Congenital Heart Defect Awareness Week

February 7-14, 2010

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

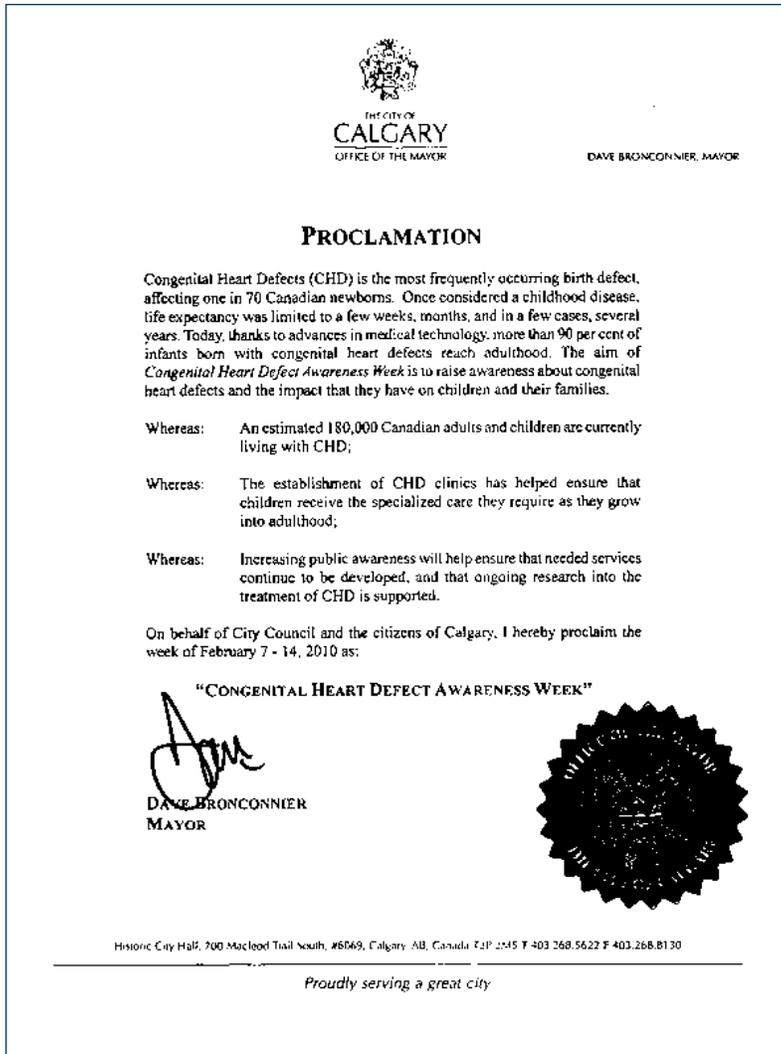
- Send an e-card to those in your address book, letting them know about CHD (see below for instructions on how to send a Heart Beats e-card).
- Provide information to your child’s teacher or school about Congenital Heart Defect Awareness Week.
- Create a dialogue about Congenital Heart Defect Awareness 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 below) to meet local families dealing with CHD.

Thank you for participating in this important campaign!



Heart Beats
Supporting Children with Heart Disease

Congenital Heart Defect Awareness Week Proclamation



Send an E-card and Show Your 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 the e-card:

- Visit the Heart Beats website at www.heartbeats.ca
- Click on the e-card link on the right-hand side of the page
- Be prepared with the e-mail addresses you wish to send to
- Select which message you want to accompany your e-card

Annual Family Event

Please join us in kicking off this year's Congenital Heart Defect Awareness Week by attending the Annual Family Event on Saturday, February 6, 2010 at 3:30 p.m. This year, the event will be held at the Southland Leisure Centre located at 2000 Southland Dr. S.W. in Calgary. There will be plenty of fun activities for the whole family to participate in, and food and beverages will 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 \$25 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. Heart Beats has a fund available to assist with the cost of the Annual Event; if cost is a concern, 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, please let us know if you will be attending the event by contacting Patty Wiebe by e-mail at pattyw@heartbeats.ca or by phone at 403-256-7423.

We look forward to seeing you there!

Heart Beats Continues its Tradition of Christmas Hampers



For many families, the added medical expenses of having a heart child in the family can make things difficult at this time of year. For Christmas 2009, three families received Christmas hampers from Heart Beats, helping to make their holiday a little brighter. As an 'elf' who has been delivering Christmas Hampers for several years, it is always gratifying to see Heart Beats' family support in action!

Here is a letter of appreciation from a young recipient of a Christmas Hamper.

To Everyone at Heart Beats,

Thank you so much! I love the wii! You guys are so nice. I'm shocked and amazed that you would go out on a busy shopping season to get a stranger a wii. I hope you had a good Christmas! I did, I got lots of stuff from my wish list! I didn't have a wii on my list, but I still got it! I have wanted a wii since it came out. I hope you got what you wanted too. The wii is important to me because I can exercise without getting my heart rate up, like baseball, and I don't have to run from home base to first, to second, to third and back. It is really fun!

Sincerely yours,

Eric, age 10.

Thank you to all our donors for your generous support!

Heidi Smethurst is a mother of four. Her third child, Ryan (10) was born with Transposition of the Great Arteries and a Ventricular Septal Defect.

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.



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 and toys for the Alberta Children's Hospital Cardiology Clinic

We appreciate and acknowledge the donations received from the following individuals and organizations from October through December, 2009:

Jasmin Craig & Michelle Robertson in honour of Ava Contrada

Cathy Howarth in honour of Ryan Howarth

John Croft in honour of Dr. Joyce Harder

Andrew & Cindy Seibel

United Way of Calgary, Donor Choice 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 Sponsors Family Suite in Ronald McDonald House® Northern Alberta

Ronald McDonald House® Northern Alberta is a compassionate, safe and affordable home away from home for out-of-town families whose children are receiving treatment at Edmonton hospitals. The purpose of Ronald McDonald House® Northern Alberta is to keep families together and provide a supportive environment while the family member is being treated for their illness.

Most pediatric heart surgeries in Alberta are performed at the Stollery Children's Hospital in Edmonton. Because of this, many families living in Calgary need to travel and stay in Edmonton for the duration of treatment and recovery. Ronald McDonald House® Northern Alberta is there for families to stay for as long as they need. Families can face staggering costs associated with travel, accommodation, and lost wages during the illness of a child, and Ronald McDonald House® Northern Alberta has helped many Calgarians offset these costs significantly.

This is why Heart Beats Children's Society of Calgary decided to sponsor a room in the newly expanded Ronald McDonald House® Northern Alberta. "The Ronald McDonald House has provided so

much support to heart families traveling to Edmonton," says Heidi Smethurst, a Director with Heart Beats, "We had funds that were raised with a legacy project in mind, and the expansion of the Ronald McDonald House in Edmonton was perfect for these funds. We are pleased that our contribution will help to support more families."

"We are thrilled to partner with an organization that is also committed to helping families," says Larry Mathieson, Executive Director at Ronald McDonald House® Northern Alberta. "The family suite Heart Beats has generously sponsored will help provide a warm, safe, and comforting place for a family to stay while receiving care at a local Edmonton hospital. We are very grateful to Heart Beats for their generous contribution."

On November 20th, some of the directors of Heart Beats met with the executive team from the Ronald McDonald House Southern Alberta for the cheque presentation. This was followed by a tour of the facility.



Photo: (left to right) Jeannine Oliphant, Heidi Smethurst, Larry Mathieson (Executive Director-Ronald McDonald House Northern Alberta), Patty Wiebe, Karen Perl-Pollard, Cindy Castillo with her daughter Alexa, Marla Cohen (Director of Development – Ronald McDonald House Southern Alberta) and Jen Beleshko.

CHD and Me – Talking With Adults With CHD

My name is Jeni Busta, and I am a 24-year-old living with Hypoplastic Left Heart Syndrome, which means the left side of my heart is underdeveloped. In other words, I was born with only half a heart!

I have had two open-heart surgeries: the first at one day old, and the second at 17 months old. I have a pacemaker, which was implanted when I was 3 years old because my high and low heart rates were ranging from 300 to 18 beats per minute (bpm). I was one of the first children to receive a pacemaker. I have had four minor surgeries to replace the pacemaker's battery. I have also had numerous heart catheterizations growing up, including two radiofrequency catheterization ablations. Due to having open-heart surgeries at such a young age, I have minor scoliosis, which comes with a lot of back pain. I also have rib-cage problems which sometimes indirectly put more pressure on the heart. Plus, I have slight mental issues where I still have trouble distinguishing left from right quickly, and I am slightly absentminded in terms of where I leave my purse, keys, cell phone, etc... pretty much anything small and expensive! I would probably lose my head if it were not attached! Although all of these conditions make life more challenging for me than for the average person, I feel that everything happens for a reason and that I can use what some think as a tragedy to give hope to others.

Growing up for me was extremely hard. Throughout my life, I had to face many difficult heart procedures and surgeries.

Because of being hospitalized, going to doctors' appointments, and undergoing surgeries, I missed a lot of school. There were a lot of cruel children there who would always make fun of me because I was small and delicate, and because I could never do any of the strenuous activities that most normal kids could do. Very frequently, I would come home from school crying in my mother's arms. Being reminded that God was always there for me no matter what was the only true thing that kept me strong. I always knew He never left my side. Despite the ridicule from some of my peers, my family and faith in God helped me to overcome the emotional and physical pain I had endured. Even though I was young, I experienced a lot, and that made me realize that God put me on this earth for a reason.

One of the ways I coped with the pain was getting involved with Camp Del Corazon or "Heart Camp". At the age of eight, my cardiologist mentioned to my mom and me that a camp was being planned for children with heart disease. The first time I went to Heart Camp was also my first time being away from home. I was a little scared, but mostly excited. Each summer we spent 5 days on Catalina Island. Going to Heart Camp was a huge turning point in my life. I got to know many children with all different types of heart disease. I have a certain bond with these people from Heart Camp that I do not have with anyone else, simply because we understand one another's rare life challenges. We are all so much alike in so many ways,



because we face a lot of the same obstacles at a young age. We all have scars on our chests, several medications to take, doctor appointments to attend, and heart surgeries to go through. I thank God for granting me this life-changing experience that will always be a part of me.

The only downfall of the camp is that some of the friends I became so close to have passed away. One of my best friends, Daviana, unexpectedly passed away nine years ago. Losing her was a devastating experience that taught me to be stronger. It reminded me once again that every moment God grants me to remain on this earth is precious. I realized I had not shown the ones I love how much they really mean to me until I lost Daviana. I now cherish each and every loved one and I need to continually show how much I love them because we never know when our lives will be taken away.

The transition from pediatric to adult care was something I was concerned about, since I would be the first HLHS patient at UCLA to transfer into adult cardiology. Honestly though, my doctors made the switch as easy as possible. For months beforehand, they were at work making sure my paperwork was ready and that the technical aspects were already taken care of. When I visited the doctors for a check-up, my pediatric physicians would talk to me about more adult issues like pregnancy and other womanly issues. Therefore, when I physically transferred over to adult cardiology, it was less of a leap and more like a normal step.



Jeni with her father (Paul), husband (Nick) and brother (Jon) at the finish line!

(continued on page 6)

CHD and Me *(continued from page 5)*

What I remember most from that visit is one diagnosis where my adult cardiologist disagreed with my pediatric cardiologist. Growing up, I was told that I could not do any strenuous physical activity, since it would just be too hard on my heart. During my first adult visit, I told my doctor that I was feeling tired all the time. He thought it was because I wasn't getting enough strenuous exercise! Since this was so close to our wedding day, my husband bought me a pink bicycle so we could ride bikes together. This has helped both my physical strength and my self-esteem because it has taught me to safely push my limits and to not let my heart problem stop me from doing what I want to do. To emphasize this point, in November, 2009 my husband, one of my older brothers, my father and I completed a 28-mile charity bike

ride that benefited the heart camp I attended growing up. It was definitely a challenge, since 15 miles into it I wanted to stop! But as I was getting tired, I kept thinking about all of the heart families who were told by their doctors that their child was not going to make it, and I used that anger and the fact that I wanted to prove those doctors wrong as fuel to keep me going.

Today, my heart is stable and my life seems normal. I cannot work though, as every time I try to hold down a job, the energy required is far more than I can handle. However, I enjoy not working, since it allows me time to reach out to heart families and to do things like write this article! I also spend a lot of time with family, which to me is one of the most important things I can do. Although

my heart condition has made life quite a challenge (there's an understatement!), I've learned to appreciate every breath God gives me. This has given me the understanding that no matter what I do, I want to do it for the glory of God. I've learned to not think of my heart condition as a problem, but as a true blessing from Him. This in turn, has given me the desire to live every single day as if it were my last.

If anyone would like to contact me, please do not hesitate to reach me. I love talking to heart families and would love to hear from you! My email is bustasgirl25@usa.com, and I am on Facebook (search "Jeni Busta") and MySpace (but I check my Facebook much more often than MySpace).

Artificial Hearts and Ventricular Assist Devices

With the high survival rate of children born with hypoplastic left heart syndrome (HLHS) and other serious heart conditions where there is only one ventricle functioning, one wonders what the long-term outcome will be for these children later in life. Can a single-ventricle heart feed the body its blood supply for the eight decades that is considered a normal life span these days? The back-up plan has always been a heart transplant, but there is a shortage of donor organs.

A synthetic replacement for the heart remains one of the long sought-after goals of modern medicine. Dr. Willem Kolff, who died earlier this year at age 97, spent a good portion of his life working on the design of an artificial heart which culminated in the Jarvic 7 model. To date, the artificial heart has not delivered long-term results or a high quality of life for its recipients. The Biomedical firm Carmat announced in October, 2008 that its fully implantable artificial heart will be ready for clinical trials in 2011 and could be used as an alternative to heart transplants by 2013. The prototype uses electronic sensors and is made from chemically treated animal tissues called "biomaterials". Another U.S. team is working on a similar project called the MagScrew Total Artificial Heart. With continued developments in prosthetics engineering, computing technology, electronics, batteries and fuel cells, a practical artificial heart may one day become a reality.

Closer to home, the Stollery Children's Hospital team successfully implanted a temporary Berlin Heart in a 15-year-old girl in 2006. This was supposed to be used only until a donor heart was found, but in the meantime, the girl's own heart recovered during its 146-day "rest break".

Making the news lately is a ventricular assist device (VAD) that replaces the function of the left ventricle in pumping blood to the body. It is the fifth generation of the DeBakey Heart developed by Dr. Michael DeBakey in the 1990s. Doctors in Germany implanted the "world's smallest artificial heart pump" into a 50-year-old woman. This VAD weighs 92 grams and is made of plastic and titanium. It is implanted adjacent to the ailing heart and allows for external monitoring and adjustment.

As a parent of a child with HLHS, I follow with interest the development of ventricular assist devices. It is interesting to follow the history of the scientific/medical developments in the areas of cardiac care that affect our children.

Colin Wiebe is the father of Isabelle, age 8, born with Hypoplastic Left Heart Syndrome.

Save the date!

On Sunday, October 17, 2010, Heart Beats will be holding its first ever Family Fun Run/Walk to raise awareness and money for Congenital Heart Defects. The run is being sponsored by the Running Room. So put on your running shoes now and start training! Watch for further details in upcoming newsletters.

Western Canadian Children's Heart Network (WCCHN) Update

Submitted by Angela Krizan, RN, BN, WCCHN Coordinator

My name is Angela Krizan, and I am grateful for this opportunity to introduce myself to you as the new Coordinator for the Western Canadian Children's Heart Network.

For the past 12 years, I have been a registered nurse and have worked at the Alberta Children's Hospital since 1998. The majority of my experience is in the area of Pediatric Intensive Care and Pediatric Critical Care Transport. In 2007, I decided to work as an Organ Donor Coordinator and took a 2-year break while remaining as a casual nurse in the PICU. My passion has always been pediatrics, so I returned to the Children's Hospital and was a Supervisor for the PICU until I accepted my new position.

I grew up in the Southern Alberta farming community of Taber. I moved to Calgary to attend university and have stayed here since. Most of my family lives in Calgary now, with the exception of my older sister who still lives in Taber with her family. My older brother lives in Calgary with his wife and their 20-month-old twins. I absolutely love to spoil my nieces and nephews.

I am really looking forward to continuing the momentum the WCCHN has and to keep building on the strong foundation that has been established. I attended the most recent Family Advisory Committee meeting and loved the welcoming spirit I received. The depth and breadth of the support to families and children on this journey is amazing.

I look forward to supporting your groups.

My primary office will be located in Calgary at the Alberta Children's Hospital; and I will spend one week per month in the WCCHN office in Edmonton. I welcome phone calls, questions, and feedback you may have for me. Thank you again for providing me with this opportunity to introduce myself in your newsletter. I look forward to meeting more of you along the way!

Contact Information:

Angela Krizan, RN, BN

WCCHN Coordinator

Phone: (780) 407-1519

E-mail: wcchn@albertahealthservices.ca

Website: www.westernchildrensheartnetwork.ca

Reflections on the Family-Centred Care Conference

In May of 2009, I had the privilege of attending the second annual provincial conference on Family-Centred Care. The theme of the symposium was "Beyond the Intersection: Family-Centred Approaches across Sectors". Delegates from various health sectors including doctors, policy makers and researchers came together with families to find a common understanding surrounding family-centred care. The goal of the conference was to find ways to adapt the concept of family-centered care into the healthcare system to better serve children and their families.

The two-day conference featured keynote speakers addressing family centeredness and leadership, strengthening family resilience, family-centred service and finding solutions through peace. Some of the break-out sessions included empowering families, children and youth, family-centred care in the NICU, meeting the transition challenge, the power of family-to-family connections, laughter being the language of love and parents' perspectives on goals and goal-setting.

The emphasis on family participation was paramount throughout the conference sessions. I thoroughly enjoyed a presentation by Dr. Peter Rosenbaum entitled "Family-Centred Service: What Is It, and Why

Should I Care?" Dr. Rosenbaum, a Professor of Paediatrics and Canada Research Chair in Childhood Disability, offered an understandable conceptual framework of family-centred service and discussed whether or not these principles are put into practice. Dr. Froma Walsh is a professor at the University of Chicago and a leading authority on family resilience. Her presentation, "Building Family Resilience", detailed the need to build families' resources and explained how to strengthen supportive bonds and find blessings amidst suffering and loss. She outlined the experience potential for positive personal, relational and spiritual growth through collaborative efforts. I found her to be a warm and engaging inspirational presenter.

In all, it was a very worthwhile and interesting conference. We should all feel encouraged that our health professionals are striving toward family-centred care, thus benefitting our children and youth.

The presentations featured at the convention are available for viewing online at www.fcc-conference.ca/program.htm.

Heidi Smethurst is a director with Heart Beats and is a member of the Western Canadian Children's Heart Network (WCCHN) Family Advisory Committee.

Her son Ryan, age 10, was born with Transposition of the Great Arteries and a Ventricular Septal Defect.

Heidi Smethurst obtained two very interesting books at the Family-Centred Care conference entitled "The Bounce Back Book—Laying the Foundation for Resiliency in your Infant and Toddler" and "The Bounce Back Book—Building Resiliency Skills in Your Preschooler". These fun and upbeat books outline the importance of developing a close attachment with your infant early on to lay the foundation for developing resiliency. The books explain how resiliency can be cultivated through play, problem-solving, self-confidence and good communication with your child. Both books are colourful and beautifully illustrated and include a variety of age-appropriate activities. Because children with congenital heart defects will face a unique set of challenges from infancy onward, their ability to "bounce back" from health issues and other adversities is something we should strive to cultivate in them, and in ourselves. These books are an excellent resource for achieving these goals.

Both books are available for \$3.00 each and can be ordered directly from the Alberta Mental Health Board website at www.amhb.ab.ca/Publications/publications/bouncebackbook

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.

January: Tuesday, January 19th at 10:00 a.m. at the home of Lynn Nakoneshny, 187 Willowmere Close, Chestermere.

February: Thursday, February 25th at 10:00 a.m. at the home of Tara Exall, 5812 Dalridge Hill NW, Calgary.

March: We invite the whole family to an Easter Egg Hunt at the acreage of Michelle Aris on Sunday, March 28th at 1:00 p.m. Her home is at 281130, Township Road 230, just outside the east city limits. For more detailed directions, contact Patty Wiebe at 403-256-7423.

April: Thursday, April 22nd at 10:00 a.m. at the home of Patty Wiebe, 43 Midvalley Crescent SE, Calgary.

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

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

OffBeats

OffBeats met on September 29th at the Alberta Children’s Hospital and had a “Rock Band” good time. Oh, the talent...drums, guitars, even singing! October 27th was a fun night out bowling. We have more enjoyable activities planned for 2010.

OffBeats is always looking for and welcoming new members. Anyone who is aged 10-17 and involved with the Cardiology Clinic can learn more about OffBeats by contacting Laura Thurber-Larsen at 403-955-7778 or laura.thurber-larsen@albertahealthservices.ca.

Ready or Not Study Analysis Update

We are currently “swimming” in the data and hope to have more findings available for the next newsletter.

As analysis continues we plan to provide study updates. If you would like to find out more about Gwen Rempel’s **Extraordinary Parenting** research program please check our website www.nursing.ualberta.ca/rempe. An interview with Gwen Rempel will appear in our next edition of Keeping the Beat.

Heart to Heart Christmas Party

On December 6th, 2009, Heart to Heart had its annual Christmas party at the home of Colin and Patty Wiebe. Five families attended the party and a good time was had by all. While the adults socialized, the children took part in making handmade ornaments to take home with them. Food and drink were abundant, and the children each received a wrapped gift from Santa. The real star of the show may have been Peanut, the Wiebes’ dog, who provided hours of entertainment for the younger kids. Thank you to Heart Beats for providing the crafts and gifts for the children, and to the Wiebe family for hosting this event!



Back row: Janelle, Matthew, Grace; Middle row: Kirsten, Sophia, Nolan; Front row: Isabelle, Alexa, Roman

Safeguarding Study

Safeguarding Survival: Parenting Children & Adolescents with Complex CHD

- ♥ Does your child have hypoplastic left heart syndrome?
- ♥ Did your teen have heart surgery during the first month of life?
- ♥ Has your teen had more than one heart operation?

If yes to any of the above, please call or e-mail me:

Sandy MacPhail RN MN
Project Coordinator
Phone (780) 492-9047
E-Mail sandra.macphail@nurs.ualberta.ca

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

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

***Walk on Water* by Michael Ruhlman (published by Penguin Books)**

Not everyone wants to know the story that this book tells. But for those who do, it is a very interesting read.

In 2000, Michael Ruhlman heard of renowned pediatric heart surgeon Dr. Roger Mee. Dr. Mee works at the Cleveland Clinic in Cleveland, Ohio, and is one of the best heart surgeons not only in the United States, but worldwide. Ruhlman was so intrigued with Dr. Mee that in 2001 he convinced the entire staff at the Cleveland clinic to let him shadow their every move for one whole year. Ruhlman writes about Dr. Mee, and about his assistants, pediatric nurses, neonatal nurses and about another well-known heart surgeon, Dr. Jonathan Drummond-Webb. He writes about their cases, mistakes that are made and politics they must confront.

I cried throughout the entire first chapter. I then toughened up and only cried a few more times during the rest of the book. It takes you to the other side, the side we often don't understand or don't even want to know about. It shows the human side of surgeons, the human side of their assistants, the dedication involved in treating our children, and unfortunately, the hard choices that sometimes have to be made and the errors that sometimes happen.

The book is called *Walk on Water* because it is said that when a surgeon becomes really good, they are gods—they “walk on water”. But this book also shows us that they are, in fact, human. They have families who are so often ignored, and have feelings that they usually hide. After reading the book, I was googling one of the patients described and I was shocked and saddened to find out that in 2004, Dr. Drummond-Webb took his own life. This further shows that these surgeons are not in fact “walking on water”. They are only human, and happen to be very good at what they do.

Cindy Castillo is the mother of two daughters. Her youngest, Alexa (age 2), was born with hypoplastic left heart syndrome.

ADVICE FROM OUR PARENT EXPERTS – YOU!

Lifelong medical care is required for most congenital heart defects. As parents, what responsibilities have you (or will you) encourage your child to take for their own medical care, and at what age?

My mom has tried to make sure I eat healthy meals but in my teen years I basically took over my own health. I was transferred to the adult clinic and they suggested I no longer need to bring my mom to appointments.

I am pretty committed to walking stairs at school and not using the escalators, and in winter I ski and do winter sports like tobogganing.

I leave my pills out where I see them so I see them every morning to take them. No one checks on me about that. Other than that, I try to stay active, even though sometimes it really is hit and miss. I don't do much intentional exercise (like working out, jogging, etc.) but try to stay active with recreational and casual activities with friends, such as floor hockey, basketball, Frisbee, and stuff like that.

Daniel Falk is 21 years old and was born with a single ventricle and pulmonary stenosis. Daniel had a modified Fontan at the age of 2 ½.

Mathias has a pacemaker. When we go to the pacemaker clinic for an adjustment, there are times when it is momentarily disabled. He immediately feels ill. We have told him to make note of this feeling—and if he ever feels that way when he is not at the pacemaker clinic to let mommy and daddy know. He is five and a half, so I think that this is an appropriate way to get him familiar with observing what his body is doing and how it feels.

Karen Perl-Pollard is the mother of two. Her son, Mathias (5 years) was born with Tetralogy of Fallot, Atrial Septal Defect (ASD), Patent Ductus Arteriosus (PDA) and now has a pacemaker for acquired heart block.

We hope that by setting good health/life skills as a family, Lucas will be able to maintain his routine, to get flu shots every year, eat/drink healthy food, exercise regularly. Also, we are trying to teach him to put words on his symptoms and to speak up quickly—not to wait to speak up for fear he might be seen as a not-tough-enough kind of guy. We are trying to show him and his sisters that being proactive is the best thing you can do for your health.

I was talking to some other parents in an H1N1-vaccine clinic five-hour line-up one Saturday. Their son is now 21 and living in B.C. Although he never had surgeries, he has a heart murmur severe enough that he was checked at the heart clinic all his childhood long. Now, he is an adult and refuses to get his flu shots. Those parents were very nervous.

I hope Lucas will never try to play the rough and tough guy. So far so good, he's always been very reasonable and we just hope that these skills/habits will stay with him. He's not a teenager yet though....

Anne-Claire Chevallier is Mom to Lucas Neander, age 8 ½, born with coarctation of the aorta, aortic stenosis and bicuspid valve.

We tried to get life insurance for both of our kids and were refused. They will have to get a very good education so that they will get good jobs with insurance packages for death or disability. We have enrolled them in private schools to make the commitment to education.

Nora Arnett is Mom to Veronica, age 17, born with Marfan Syndrome which affects the aortic root measurement; and Taylor, age 15, who has diabetes.

Although he is only 2, my son reminds me daily about taking his “meds” after breakfast. He likes the fact that he gets a gummie vitamin afterwards!

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

Talk with the Docs – Dr. Kimberley Myers

So often we know only the cardiologist our child visits at the Cardiology Clinic, but each of the cardiologists has an area of expertise which contributes to the overall care they provide to patients at the Cardiology Clinic. We want to introduce you to each of the cardiologists at the Cardiology Clinic. In the past issues of “Keeping the Beat”, we have featured Dr. Frank Dicke, Dr. David Patton, Dr. Deborah Fruitman, Dr. Robin Clegg and Dr. Joyce Harder. In this issue, we are pleased to introduce Dr. Kim Myers, who joined the Cardiology team in October, 2009.

First and foremost, welcome to Calgary! Where are you from, and where did you practice medicine prior to joining our Cardiology Clinic?

I am a true Canadian! I was born in northern Ontario, studied genetics in southern Ontario, medicine in British Columbia, pediatrics in Newfoundland, and cardiology in Alberta.

What is your impression of the Cardiology Clinic so far?

It is a wonderful team of people dedicated to the care of children with heart problems, and their families. I feel incredibly fortunate to be a part of it.

Share Your Story

We invite you to share your experience with congenital heart disease with us. We want to hear from parents, and from children and teenagers 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 karenp@heartbeats.ca



What made you decide to go into pediatric cardiology?

I was interested in the development of heart defects in children before I went into medicine. I was not sure if I wanted to do cardiac surgery or cardiology but I wanted to be involved in the ongoing care of children, so the decision was easy.

What do you consider to be the greatest challenge and greatest reward of treating children with congenital heart defects?

Simply achieving better survival for kids with severe heart problems was a challenge until the last decade or so but now we are focussing on improving the quality of life for these children.

The greatest reward is seeing kids with severe heart problems doing all the things that other kids do. These activities are often taken for granted but truly are of the greatest importance to our children and their families.

We understand that you are performing 3D echocardiograms. What can you tell us about these tests?

3D echocardiograms are a relatively new technology that allows us to look at the heart in three dimensions. It is proving to be an invaluable tool in understanding the pathology of some heart problems, and in planning surgery.

When you are not practicing medicine, what are your interests and hobbies?

As with many Calgarians, I love the mountains! I rock climb, hike and mountain bike. My free time is spent playing outside.

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

Cardiology Clinic News

In keeping with working to become a “centre for excellence” for imaging, Dr. Patton and Dr. Meyers are continuing on with cardiac MRIs. Dr. Fruitman and Dr. Meyers are also gearing up to perform 3D echos.

Here is some exciting news for patients with heart transplants: Patients will no longer have to travel to Edmonton for their heart biopsies, as our very own Dr. Dicke will now be performing heart biopsies right here at the Alberta Children’s Hospital.

The entire staff at the Cardiology Clinic would like to extend to you their warmest Christmas wishes and hopes for a happy and healthy New Year!

Heart Beats Children’s Society of Calgary

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