



Keeping the Beat

Fall 2009

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

In this issue



First in Canada: baby has heart procedure while inside her mother's womb and is now doing fine. 1

Your Support in Action 2

New Product May Reduce Scar Tissue 3

Heart to Heart 3

Donations in Memory of Kevin Moore Making a Difference. 3

CHD and Me – Talking With Adults With CHD 4

Research Advisory Group – Parent Participation. 5

Offbeats 5

Western Canadian Children's Heart Network (WCCHN) Update 6

Cardiology Clinic News 7

Community Updates. 7

Parent Resources. 8

First in Canada: baby has heart procedure while inside her mother's womb and is now doing fine

Reprinted with permission from the Hospital for Sick Kids in Toronto originally reported on May 8, 2009

(Toronto) – In a Canadian first, doctors at The Hospital for Sick Children (SickKids) and Mount Sinai Hospital successfully performed a lifesaving heart intervention on a baby in utero. A team of doctors, including Dr. Edgar Jaeggi, Head of the Fetal Cardiac Program at SickKids, Dr. Greg Ryan, Head of the Fetal Medicine Unit at Mount Sinai and Dr. Lee Benson, Director of the Cardiac Diagnostic and Interventional Unit at SickKids, expanded the baby's aortic valve using a balloon catheter inserted through the mother's abdomen while the baby was still in her womb to reverse the baby's heart failure before birth. This allowed the baby to remain safely in utero for a crucial extra month.

"The fetal intervention was minimally invasive for the mother and lifesaving for the baby," says Ryan. "Our ability to repair the aortic valve at 31 weeks gestation allowed the fetus to grow and thrive for four more weeks in the mother's uterus, resulting in a bigger, healthier baby at birth with decreased likelihood of additional health risks. Had the baby been delivered at 31 weeks, the heart's left ventricle could not have been saved. The collaboration of expertise between SickKids and Mount Sinai saved this infant's life."

Thirty weeks into her pregnancy, Vicki McKenzie, a mother of two from the Ottawa area, had an ultrasound indicating her baby, Océane, had a heart condition called Critical Aortic Stenosis, meaning there was severe narrowing of the main outlet valve of the left ventricle. She was immediately referred to Toronto, where doctors at SickKids and Mount Sinai offered her an experimental procedure.



Vicki McKenzie and her daughter who had life saving surgery in utero.

The procedure is called Balloon Dilation of Critical Aortic Stenosis in the Fetus. Under continuous ultrasound guidance, doctors inserted a needle into the left ventricle of the baby's heart through McKenzie's abdomen; a guide wire was passed through the narrowed valve so the special balloon would open the valve leading to the baby's aorta. In theory it was simple, but in reality it was an innovative and risky procedure. It has been tried in only a few centres worldwide; this was the first successful such procedure in Canada.

"It can only be offered to a few babies in utero who are detected at the correct stage and when their aorta hasn't yet narrowed too much. This baby came to us at just the right time," says Jaeggi.

Untreated, the condition would inevitably lead to a lifelong condition called Hypoplastic Left Heart Syndrome (HLHS). Children with HLHS typically need to undergo at least three major heart surgeries.

(continued on page 2)



First in Canada: (continued from page 1)

Most children would not be expected to live a normal lifespan; the 10-year survival rate is only 65 per cent. This experimental intervention aims to repair the heart early, allowing it to recover its normal function to avoid risky surgeries after birth and hopefully lead to a longer and better quality of life.

McKenzie, who was prepared for anything, agreed to the intervention. Océane stayed in her mother's womb for a full month following the procedure, until the team determined that she could be safely delivered on April 15.

Doctors anticipated that as soon as she was born, the baby would need to undergo another procedure to further open her aortic valve. Within an hour of her birth at Mount Sinai, Océane was stabilized and transported by Mount Sinai's neonatal team to the Cardiac Diagnostic & Interventional Unit at SickKids, where she underwent another procedure. A third procedure followed a few weeks later.

"They have saved my daughter's life. Having access to the expertise at these two hospitals was a comfort. I could confidently have my baby at Mount Sinai and know that she would immediately receive the urgent care she needed across the street at SickKids," says McKenzie.

"The intervention recovered Océane's ventricular function completely. It is operating at a normal level now. We hope this successful collaboration opens the door to giving other babies a healthier start in life," says Jaeggi.

The Mitchell Goldhar Cardiac Diagnostic & Interventional Unit at SickKids enables Canada's largest paediatric interventional catheterization program to develop innovations in minimally invasive alternatives to open-heart surgery. The unit, opened in 2007, combines the latest technology to diagnose and treat children with congenital heart disease using minimally invasive procedures that can reduce or eliminate the need for open-heart surgery.

The Fetal Medicine Program and Perinatal Program at Mount Sinai Hospital are among the largest in North America, and receive referrals from all across Canada for a wide range of fetal problems needing complex interventions.

About SickKids

The Hospital for Sick Children (SickKids), affiliated with the University of Toronto, is Canada's most research-intensive hospital and the largest centre dedicated to improving children's health in the country. As innovators in child health, SickKids improves the health of children by integrating care, research and teaching. Our mission is to provide the best in complex and specialized care by creating scientific and clinical advancements, sharing our knowledge and expertise and championing the development of an accessible, comprehensive and sustainable child health system. For more information, please visit www.sickkids.ca. SickKids is committed to healthier children for a better world.

About Mount Sinai Hospital

Mount Sinai Hospital is an internationally recognized, 472-bed acute care academic health sciences centre affiliated with the University of Toronto. It is known for excellence in the provision of compassionate patient care, innovative education, and leading-edge research. Mount Sinai's Centres of Excellence include the Lawrence and Frances Centre for Women's and Infants' Health; Christopher Sharp Centre for Surgery and Oncology; Acute and Chronic Medicine; Laboratory Medicine and Infection Control, and the Samuel Lunenfeld Research Institute. For more information about Mount Sinai Hospital, please visit us online at www.mountsinai.on.ca.

Your Support in Action

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

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

- Supplemental equipment and toys for the Alberta Children's Hospital Cardiology Clinic

We appreciate and acknowledge the donations received from the following individuals and organizations from May through September 2009:

- Ferrell & Jen Beleshko
- Government of Alberta Community Spirit Donation Grant
- Long View Systems Corporation
- Grade 6 Students of Grant MacEwan School
- 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.)

New Product May Reduce Scar Tissue

Adhesions, or scar tissue, occur after virtually all open-heart surgical procedures. These adhesions can result in the heart becoming attached to the sternum and other surrounding tissue surfaces, which can increase the duration and risk of secondary surgical procedures.

On July 10, 2008, Health Canada issued a Class IV Licence with conditions to SyntheMed, Inc. for the REPEL-CV (Bioresorbable Adhesion Barrier). REPEL-CV is a synthetic film that is placed over the surface of the heart at the conclusion of open-heart surgery and acts as a temporary barrier to separate opposing surfaces from interconnecting, thus reducing the extent and severity of adhesions. This product is bioresorbable, meaning that over time it degrades and absorbs into the body.

Clinical safety and efficacy of the REPEL-CV device were determined through four clinical studies. Results for the intent-to-treat population

showed a statistically significant reduction in the mean, patient-specific percentage of study-defined surface area with severe adhesions. There were also no statistically significant differences in adverse events or serious adverse events between the REPEL-CV-treated group and the non-treatment control group.

Based on the Health Canada review of data on quality, safety, and effectiveness, Health Canada considers that the benefit/risk profile of REPEL-CV is favourable for use as a surgical adjuvant to reduce the incidence, severity, and extent of post-operative adhesion formation in patients under 21 years of age undergoing cardiac surgery and for whom subsequent staged procedures are planned.

Jen Beleshko is mom to Roman, born in 2007 with Dextrocardia, Double Outlet Right Ventricle, Single Right Ventricle and Transposition of the Great Arteries.

Heart to Heart

Heart to Heart is a support group 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. Those with children at home are welcome to bring them along. For our weekend dates, we enjoy having the whole family attend. We vary our meeting days, times and locations from month to month to try to include as many parents and families as possible.

Heart to Heart in October will be on Friday, October 16th at 10 am at the home of Patty Wiebe at 43 Midvalley Crescent SE.

Heart to Heart in November will be on Tuesday, November 10th at 10:30 am at the home of Michelle Aris at 281130 Township Road 230, just east of the Calgary city limits. For more detailed directions, contact Patty Wiebe.

In December we will have our annual Christmas party on Sunday, December 6th at 1:30 pm. If you are able to attend, please RSVP to Patty by November 27th by e-mail at pattyw@heartbeats.ca or by phone at 403-256-7423.

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

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

Donations in Memory of Kevin Moore Making a Difference

With the funds donated last fall in memory of Kevin Moore (Refer to the Fall 2008 issue of *Keeping the Beat*), Heart Beats has purchased six esophageal pacing wires for the Cardiology Clinic. The pacing wires are used for therapeutic intervention and diagnostic treatment of certain heart rhythms. The wires are smaller than a feeding tube and are inserted down the esophagus to get behind the heart. These leads are minimally invasive, require no anesthesia and eliminate the need to cardiovert or "shock" the heart to correct dangerous heart rhythms. They are excellent for neonates and very safe. Dr. Robin Clegg has found them to be extremely useful for cardiology patients.

Keeping the Beat by e-mail

In our efforts to be good stewards of the donations made to Heart Beats, and to make use of the benefits technology can provide, we invite you to receive *Keeping the Beat* by e-mail rather than "snail mail". Please send us an e-mail at info@heartbeats.ca advising us of your e-mail address, and you will receive future issues of *Keeping the Beat* by e-mail. Thank you for helping us to reduce printing and postage costs and allowing us to use these funds to assist heart families in other ways.

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



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? This year I had the privilege of meeting Jacqui Esler, owner of a ceramic painting company called Fire Escape. Jacqui was born with CHD and is now living a very successful life as a business owner. She is truly an inspiration. Here is her story:

I am 39 years old and will be turning 40 this December!

I was born in Owen Sound, Ontario, with Ventricular Septal Defect. The right side of my heart wasn't working at all and I had a stenosis of the pulmonary valve. In 1969 there were few kids with my condition in Canada and I was number 11 out of 13 kids to live through my type of heart surgery. My first surgery was in 1975 at Sick Children's Hospital in Toronto. She may not want to be reminded, but Dr. Harder was a student at the time, and she and I met at “Sick Kids” when I was doing some tests before my surgery.

I grew up in Winnipeg. It was very cold in the winter so I had purple lips and fingers most of the time. I was always the slowest kid in gym class. That was hard, but I never had great ambitions to be the next “Super Jock”....that was probably a good thing.

During my first surgery, I remember being in the hospital for quite a long time. My stay was about four to five weeks. My family was stretched out all over the country. My dad was in Winnipeg working, my sister was staying with relatives in Ontario and my mom was with me in the adjoining “nurses' quarters” where parents would stay for a prolonged time while their kids were in hospital. According to my mom, this was quite a lonely place. The building where the parents would stay was not part of the main hospital building. It was connected by a dark corridor. I wish I could tell you more about this but my mom has passed away and I don't know much more about her experience.

My memories of hospital stays were pretty good. Being I was kind of a statistic at the time, I was lucky to be on the front cover of the *Toronto Star*. Comedian Danny Kaye

was giving a large donation to the heart department at Sick Children's and so they wanted a heart patient to be there with him for a photo op. I guess I was at the right place at the right time. I also have memories of the play room and visiting other patients with my mom. She would push me in my wheel chair down the hall and we would always visit this family who had a son who was in a coma. I still don't remember why Daniel was in a coma, but I do remember when we left his room, after visiting with his mom and dad, that my mom would tell me that I had a problem that could be fixed, and how lucky I was.

I don't feel like I have any limitations. I did have my second surgery in 2000 at the Mayo Clinic in Rochester, Minnesota. This is where my pulmonary valve was replaced with a porcine (pig) valve. The Mayo Clinic is an amazing place. I was very lucky to have had the opportunity to go there. My cardiologist, Dr. Nanette Alvarez, had been sending my reports to a cardiologist there after my follow-up in my high school years. So when it came for my second surgery, it seemed natural to go there. This time I was in the hospital for only one week. My surgeon used the same incision as my first one, so I am quite lucky to not have too many zippers down my chest. I was given a porcine valve as opposed to an artificial one because I was heading into my “child-bearing” years, and an artificial valve requires the use of drugs.

However, having children has not been easy for my husband, JD, and me. I have had two miscarriages and one tubal pregnancy. I have been to specialists about genetics and heart-related issues. Every one of them stated that my heart condition was not a reason for my inability to stay pregnant. I have a very loving and supportive husband. JD and I both decided that having children may not be in our cards. We are very blessed with other gifts in our life. Both of our siblings have kids. We also have a busy little business, two dogs and a cat that keep us running around the clock.

In 2006, I started a new chapter in my life. I was at work one busy Christmas day and noticed my heart suddenly starting to beat very fast. I had experienced small palpitations in the past, but not ones that would run-on for a long period of time. I remember not



wanting to tell JD because we had a busy day ahead of us, so I just kept going. That night I went to bed thinking by morning the fast heart beats would be gone. Well, they weren't. I woke up with them pounding in my chest. I finally told JD and he drove me to the Foothills ER. Then he drove to work. We were short-staffed that day and he had to be there. I told him to go!!! What I didn't know was that I was in atrial fibrillation and needed a cardioversion. “A what?” I asked the ER doctor at the time. “A cardioversion,” he told me. This is when they bring out the paddles... yes, like the ones you see on “ER” and all those hospital TV shows. But they first sedate you so you don't remember anything about the “electric shock” you are about to receive. I remember talking to JD on the phone, while lying in my emergency hospital bed, telling him that they were going to give me a shock! He couldn't quite grasp this idea either. Well, I got through the first cardioversion no problem and I felt great afterwards.

Little did I know that experience was to be the first of six cardioversions over two years. I noticed that there was a pattern starting. When I would overwork during stressful times like Christmas or other times I need to work extra long hours, I, like anyone, would put extra stress on my body, heart, etc. After my second miscarriage in 2005, I was given a sedation drug that made my heart go too slow. When I came out of the OR and made my way into the recovery room, I had a buzz of nurses around me because my heart was not beating as fast as it should have been. That's when I happened to meet Dr. Exner.

(continued on page 5)

CHD and Me (continued from page 4)

He was on call at the time and he was called over to check on me. It was then that Dr. Exner became part of my growing pool of medical professional friends. Over the next couple of years and many cardioversions later, it was he, along with Dr. Alvarez, who recommended I receive a pacemaker to help me with my irregular heart beats. However, Dr. Exner wanted me to wait for a special pacemaker which was being invented and wasn't available until 2008. I was one of the lucky candidates last year to receive an MRI friendly pacemaker and am part of a study to help bring this pacemaker to the masses.

Just as an aside, my sister-in-law has a similar heart condition and is in the same study. She had her pacemaker installed in May of last year – mine was installed in June. We both went in for our “installation” and we both came out with two incisions, not just one. The left side (where your heart is) up near your clavicle is the side of choice to install a pacemaker. However, it just so happens that both of our anatomies are a little screwed up and the surgeon (in both of our cases) was not able to insert the leads in the proper placements on the left side, so he installed the pacemakers on our right sides. So we each have a large incision down the middle of our chests and two incisions near each clavicle, one on each side. I guess my chance of wearing a two-piece bathing suit is no longer.

I laugh at it because, if I didn't have these scars to talk about, I wouldn't be here today. I am a very lucky person. I have a great team of doctors looking after me and a great supportive network of friends and family. I have never been self-conscious of my scars, but just aware of them. I know when people are looking at them. They might not always ask, but they may look. I wear v-neck blouses all the time; I never hide them. I was even more aware of my scars when the pacemaker came along, these are a pair of cuties! I sometimes smile in the mirror when I get into the shower. My life has been a journey and my scars tell the story I am so lucky to be able to tell.

I enjoy a regular life, like anyone else does. I run, bike, play sports and have an active job. I am lucky I can do all those things. Never once do I look at myself as a heart patient first. I'm just Jacqui. I just keep going. If there is any advice I can give anyone, it is, don't use your condition as a crutch. Keep in contact with health professionals who are there to help you. Always have a positive attitude you will make friends quicker that way and keep them longer.

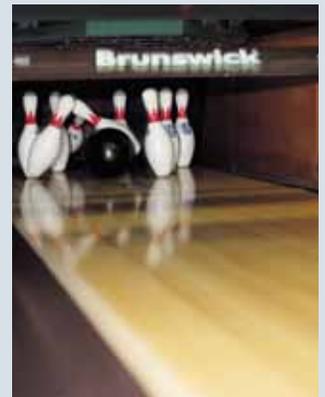
Jacqui Esler, Subject #412 – Pacemaker Recipient

Offbeats

Offbeats is a fun, activity-based group for youth aged 10-17, offering peer-to-peer support and friendship. We are kicking off a new year in the fall, and will meet every second month for fun activities.

As part of our wrap-up for last year we hosted a “meet-and-greet” at the Alberta Children's Hospital and sent out invitations to some new potential members. We have changed the age range for members from 12-17 years of age to 10-17 years of age. A number of kids and parents came to the ‘meet-and-greet’ to learn more about Offbeats and what we do. Sept 29, 2009, is our first meeting for this year and we are going to have a “Rock Band” good time here at the Alberta Children's Hospital. On October 27, 2009, we are hosting our annual bowling night.

Offbeats is always looking to welcome new members. If you would like to learn more about Offbeats, please call Laura Thurber-Larsen at 403-955-7778 or Kelly Webber at 403-955-7316. We hope to see you there.



Research Advisory Group – Parent Participation

Dr. Gwen Rempel (Assistant Professor, Faculty of Nursing, University of Alberta) conducts research with parents of children and teens with complex congenital heart disease (CHD) to figure out what moms and dads need as they parent their child who is growing up with health challenges. To help advance this work, Dr. Rempel's team is building a research advisory group to provide input into developing and conducting the next research study. The topic of this study is **Shifting Our Focus from Survival to Quality of Life** and will explore what parents can do to achieve the best outcomes for their children, themselves, and their families.

We're looking for two parents of children and teens born with complex CHD to join this advisory group to offer their valuable insights, knowledge, and experience. The group will also include researchers, practitioners, and policy makers. They will meet three times per year in Edmonton (teleconference will be provided for out of town members).

- Are you a parent of a pre-school or school aged child with HLHS?
- Are you a parent of a teen with complex congenital heart disease?
- Would you like to advise a researcher who is learning more about parenting children/teens born with CHD?

To learn more about this unique opportunity and/or to express your interest in joining the advisory group, please contact:

Sandy MacPhail RN MN, Project Coordinator
(780) 492-9047 • sandra.macphail@nurs.ualberta.ca

Western Canadian Children's Heart Network (WCCHN) Update

Submitted by: Sharon Chow, RN, MN, WCCHN Coordinator

1. What is the WCCHN?

The Western Canadian Children's Heart Network (WCCHN) is a network of pediatric cardiac care providers from the four western provinces: British Columbia, Alberta, Saskatchewan, and Manitoba. As a group, we are committed to delivering world-class pediatric cardiac care throughout Western Canada. Our goal is to share clinical knowledge and expertise amongst the pediatric cardiology divisions throughout Western Canada to improve care for children with heart disease, and to provide support for these children and their families.

The centres that make up the WCCHN are:

- Provincial Health Services Authority (Vancouver) – BC Children's Hospital: Pediatric Cardiology and Pediatric Cardiac Surgery Departments
- Alberta Health Services (Edmonton) – Stollery Children's Hospital: Pediatric Cardiology and Pediatric Cardiac Surgery Departments
- Alberta Health Services (Calgary) – Alberta Children's Hospital: Pediatric Cardiology Department
- Saskatoon Health Region (Saskatoon) – Royal University Hospital: Pediatric Cardiology Department
- Winnipeg Regional Health Authority (Winnipeg) – Winnipeg Children's Hospital: Pediatric Cardiology Department

2. What pediatric cardiac services are available and where?

Pediatric cardiac services vary across the centres. Although not all hospitals can offer the same type of procedures, the goal of the Network is to ensure accessibility to these services for all children. To do this, various referral processes have been put into place to ensure access for all.

The services offered throughout the WCCHN centres are:

- Pediatric Cardiology Care: All centres.
- Pediatric Cardiac Surgery: BC Children's Hospital (Vancouver) & Stollery Children's Hospital (Edmonton).
- Pediatric Cardiac Catheterization: All centres.

- Pediatric Electrophysiological Studies and Radio Frequency Ablation: BC Children's Hospital (Vancouver), Stollery Children's Hospital (Edmonton), Alberta Children's Hospital (Calgary) and Winnipeg Children's Hospital (Winnipeg). Children in Saskatchewan who require this service are referred for it.

3. Does the WCCHN involve families?

Families are critical members of the WCCHN. The WCCHN has established a Family Advisory Committee (FAC) which consists of ten representatives: two from each of the pediatric cardiac family support groups.

In May 2009, the WCCHN FAC met in Edmonton in conjunction with the Family Centered Care Conference. Here are a few things that would be worth talking to your local representatives about:

A. Canadian Family Advisory Network (CFAN):

Sue Robbins, Chair of CFAN, met with the WCCHN FAC. We learned that CFAN was formed in 2002 to link family advisory groups involved with pediatric care across Canada. Invitation to all was given to learn more through their website: http://www.caphc.org/partnerships_cfan.html and to join CFAN – membership is free!!

B. Stollery Children's Hospital's plan for a Family Advisory Committee:

Laurene Black of the Stollery Children's Hospital shared with the WCCHN FAC the Stollery's plans to create a Family Advisory Committee for the hospital.

C. Neurodevelopmental Outcomes of Children After Open Heart Surgery (by Dr. Charlene Robertson):

Dr. Robertson provided the group with an overview of what the research is showing about neurodevelopmental development of children who have had open heart surgery. Copies of the research articles and her presentation are available through the family representatives.

D. Behaviour & Learning Issues In School:

Warning Signs, Prevention, Interventions, and Advocating for Your Child (by Dr. Robin Adkins): Dr. Adkins followed Dr. Robertson's talk with some practical tips related to behaviour and learning issues for these children. A copy of her presentation has been made available through the family representatives.

E. Extraordinary Parenting Research (by Sandy McPhail and Dr. Gwen Rempel):

Sandy and Gwen shared some preliminary results of their research in the field of pediatric cardiology. In addition, family representatives were made aware of the numerous research opportunities in pediatric cardiology.

F. Pre-surgery checklist: The group also provided the content to develop a checklist for parents so that they can prepare to leave their home to accompany their child to another city for surgery.

G. Ronald McDonald House Tour: The WCCHN FAC had the opportunity to tour the newly expanded and reopened Ronald McDonald House. With over 42,000 square feet and 30 rooms, families now have an improved place to stay as their child receives care from the Stollery Children's Hospital. For more information, see their website at: www.rmhedmonton.ca.

4. How do I contact the WCCHN?

Website:

www.westernchildrensheartnetwork.ca

Phone: (780) 407-1519

E-mail: wcchn@albertahealthservices.ca

5. The Family Advisory Committee:



The WCCHN Family Advisory Committee 2009

(Taken in the front door way of the Ronald McDonald House Northern Alberta – Edmonton).

Back: Craig Moroz (Edmonton), Sharon Chow (WCCHN Coordinator), Charlene Stuart (Winnipeg), Shannon Trickett (Winnipeg), Jessica Palmer (Vancouver), Sandi Hildebrand (Saskatoon)

Front: Heidi Smethurst (Calgary), Kate Walker (Vancouver), Lynne Telfer (Saskatoon)

Missing: Diane Barilko (Edmonton), Tracey Contrada (Calgary) Photographer: Diana Arbuckle – WCCHN Admin Asst.

Cardiology Clinic *News*

Correction

In the last issue of Keeping the Beat, we published an incorrect name for Dr. Fruitman's baby girl. Her correct name is Kimberley. We sincerely apologize for this error.

Returning Doctors

Dr. Fruitman and Dr. Clegg are back from their maternity leaves.

New Doctor to Join the Clinic in October

Dr. Kim Myers will be starting in October. We will introduce you to Dr. Myers in the Talk with the Docs section of the next issue of *Keeping the Beat*.

Dr. Patton Rides for Cancer

Dr. Patton and his team of bike riders raised \$55,000 for cancer research and treatment. Dr. Patton stated that the weather was excellent, the crowds were amazing and the support was great. He is looking forward to the next ride in 2010. Anyone interested in finding out more about the ride or how they can donate can go to www.conquercancer.ca

3-Dimensional Echocardiograms

Dr. Fruitman and Dr. Myer will be doing 3-Dimensional Echocardiograms. This kind of echo provides more precise details of a heart's anatomy, especially of the valves. It is especially helpful in looking at the mitral valve. Doing a 3D echo will add only about 10-15 minutes to a heart study, however the post-processing done by the cardiologist can take about an hour. The process allows the cardiologist to crop the images so that they can look from above and below the valve. This type of imaging is extremely helpful to the surgeons.

Ready or Not: Parenting Adolescents with Congenital Heart Disease Research Update

Health Related Quality of Life (HRQOL) refers to one's physical, emotional, and social well-being. Unlike health status, which health care providers use to describe a person's problems related to their illness, HRQOL tells us about an individual's self perspective of their problems or limitations – their take on their health concerns.

Dr. Gwen Rempel at the University of Alberta conducts research in the field of parenting children and teens with CHD. In our **Ready or Not study**, we ask teens to complete a HRQOL questionnaire, and ask parents to also complete one about their teen, to get a fuller understanding of the influence of CHD on the teen's life. So far, we have conducted preliminary analysis of HRQOL scores from 11 teens, 9 mothers, and 6 fathers. We found that **mothers, fathers, and teens** scored similarly, meaning that parents and teens are usually on the same page in terms of the teen's quality of life. Further, the teens in this study reported higher scores on the physical health dimensions of the HRQOL than they did on psychosocial health dimensions. This may reflect the fact that many of the teens were functioning well physically with few limitations. Psychosocial health is composed of the emotional, social, and school functioning aspects of life.

The data from this small sample will serve as a pilot as we continue to explore HRQOL in the upcoming Safeguarding study which will begin recruiting in the fall of 2009. **We continue to welcome families into the Ready or Not study.**

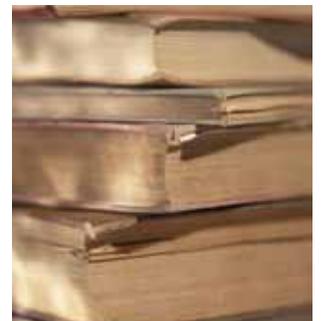
- Is your teenager 13-17 years of age?
- Has your teenager had more than one heart operation?

If yes, we would like to talk with you!

For more information about this study, please contact: Project Coordinator Sandy MacPhail RN MN
Phone (780) 492-9047 • E-Mail sandra.macphail@nurs.ualberta.ca

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



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

Parent Resources

In this section of the newsletter we invite you to share your expertise. As a parent of a child with heart disease, you have learned a lot! Share with us the books, websites and other resources you have found valuable on your journey. Whether your child is a baby, teen or somewhere in-between, we all have things that have made our days a little easier—so let's share these ideas with each other!

Website Review

Website: <http://tricuspid.wordpress.com/>
Blog Name: Adventures of a Funky Heart

Steve was born in the 1960s with a rare and complex Congenital Heart Defect (CHD) called Tricuspid Atresia. Now in his forties, Steve has been through three heart surgeries, outlived a pacemaker, battled bacterial endocarditis and is currently living with congestive heart failure...and he's doing well!

Steve's Blog, Adventures of a Funky Heart, has been growing by leaps and bounds since he first began sharing his experiences on the Web last summer. I find his blog to be very informative; he is up-to-date on all the latest medical research and also offers his readers a fascinating history lesson about the very first surgeries performed for CHDs. Steve recommends books, promotes upcoming events and has some very good links to other Websites. He also takes an active role in fundraising and is currently petitioning US Congress to create a national patient registry and to authorize more funding for CHD research. Beyond this, he gives great tips for both parenting a child with a heart defect and for growing up with one.

The site couldn't be easier to navigate; in fact, he offers to e-mail you his updates directly, or he can be followed on Twitter. His older entries are easily accessed by scrolling down to the bottom of the page, and each entry includes "tags" that can be accessed for more information. His blog offers links to medical research, clinical trials and publications, as well as links to other bloggers, namely "Cardiac Kids" – parents with children who have CHDs, and "Heart Warriors" – adults living with CHD's. Best of all, his blog is updated almost daily with fresh, informative and sometimes very funny entries. I highly recommend this blog for any parent who wonders what the future might look like for our heart kids. He's got a great sense of humour and an even better attitude about living life with a congenital heart defect.

Jen Beleshko is mom to Roman, born in 2007 with Dextrocardia, Double Outlet Right Ventricle, Single Right Ventricle and Transposition of the Great Arteries.

Advice From Our Parent Experts – You!

Share an experience that stands out in your mind of someone providing you support. What was it? How did it make a difference? Did it inspire you in some way?

At my first Heart Beats meeting I met two babies who had just had their surgeries and were still on feeding tubes. Their mothers showed me how to continue on with life and how to deal with the encumbrances you might come back with. At this same meeting, a mom showed me photos from her son's surgery. They were difficult to see, but helped me to prepare for what I would be experiencing. It was amazing to see the contrast from those pictures to her happy son running around the room. That meeting helped me so much that I decided to volunteer with Heart Beats in the hope that I can provide that some kind of support to at least one other person.

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.

When I first had Owen taken from me at the postpartum floor of Foothills I was afraid and dismayed. I felt helpless trying to nurse my baby in the NICU and seeing his condition deteriorate but not knowing why, just knowing his feet should not be purple. All I can say is that Dr. Fruitman was a ray of light, and hope during those first few dark hours after Owen's birth. She not only took the time to delicately explain that Owen had a

Coartation of the Aorta but she drew me a little picture. I truly believe that it was her calm and kind attitude that helped my husband Paul and I to stay focused and positive heading into Owen's surgery. I was put into touch with another parent near my area named Lynn, and she put me at ease and helped to clarify the world of Cardiology. Those first few calls she made to me to ensure I was okay after Owen's return home from hospital meant so much more – than she'll ever know.

Michelle Dominique-Aris is the mother of Aurora (11 years), Adeline (3 years) and Owen (14 months). Owen was born with coartation of the aorta, bi-cuspid valve and mitral stenosis. At five days old, Owen had a coartation repair at the Stollery Children's Hospital in March 2008.

When we were first told that our son was to be born with a complex heart defect, we were given very little hope by the prenatal unit that was following us. We were told that if we made the decision to carry to term, the baby would most likely not survive. Just when we thought that all hope was gone, we received a phone call from Dr. Harder at the Alberta Children's Hospital. The prenatal echo had been sent to her and she asked if we could come in to see her the following day. We are so glad we did, because Dr. Harder gave us a whole new perspective on our baby's heart. She explained the test results to us in very simple terms, actually hand-drawing a diagram of what our baby's heart would look like. She described the staged surgeries that could be performed on our baby's heart, and best of all, the possibility that he could live a relatively normal life afterwards. We will be forever grateful to Dr. Harder for the encouragement, support and hope that she gave to us that day. We left her office completely elated, thrilled that there was some hope for our unborn child. Today, when we see our happy two-year-old running around and playing like any other child his age, we thank God for the compassionate support we received that day from Dr. Harder, and continue to receive today from Dr. Dicke and the entire Cardiology unit at ACH.

Jen Beleshko is mom to Roman, born in 2007 with Dextrocardia, Double Outlet Right Ventricle, Single Right Ventricle and Transposition of the Great Arteries.

Heart Beats Children's Society of Calgary

Chairperson	Patty Wiebe pattyw@heartbeats.ca
Vice-Chairperson	Jeannine Oliphant jeannineo@heartbeats.ca
Secretary	Cindy Castillo
Treasurer	Sylvia Falk
Communications Director	Karen Perl-Pollard karenp@heartbeats.ca
Newsletter Editor	Jennifer Keane Mackinnon jenniferk@heartbeats.ca
Fundraising Director	Tracey Contrada
Nurse Liaison	Patty Knox
Additional Directors:	Nikki Ballendine Lynn Nakoneskhy Natalia Malnar Heidi Smethurst

mailing address:

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

website:

www.heartbeats.ca

e-mail address:

info@heartbeats.ca

phone:

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.

