



Keeping the Beat

Summer 2009

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

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Congenital Heart Defect Awareness Week Celebrations

Annual Family Celebration Fun for Everyone

Over fifty people kicked off Congenital Heart Defect Awareness Week in February by attending the Heart Beats Family Movie Matinee at Cardel Theatre. “Heart kids”, ranging in age from babies to adult, and their families enjoyed watching “Madagascar 2” and episodes of the “Flintstones”, as well as doing crafts, and eating heart-shaped pizza and other goodies. There was a mix of long-term and new Heart Beats families, and it was a great opportunity to connect with old friends and to also make new ones.

Thank you to Cardel Homes for the use of the Theatre, and to Heart Beats for providing the crafts, food, beverages and goodie bags for all the children.



2009 Congenital Heart Week celebration. Pictured left to right back row: Cassandra, Roman, Carly front row: Nathan, Mathias, Saige, Emily, Kirsten, Isabelle, Noah and Ryan



Making new connections and celebrating with old friends.

CHD Awareness Week in the News

Patty Knox and Cindy Castillo appeared on the Global Television morning news on February 9, 2009 as representatives of Heart Beats to provide viewers with more information about CHD Awareness Week. They were a great team and they provided a balanced view from both the clinic and a parent. In addition, Heart Beats had several public service announcements appearing in the February issues of community newsletters within Calgary. Thank you to everyone who sent out e-cards from the Heart Beats Website for helping to create awareness about congenital heart disease.



Heart Beats
Supporting Children with Heart Disease

Family Centred Care in Context 2009 Conference

The Family Centred Care Conference is scheduled for May 24-26 at the Shaw Conference Centre in Edmonton. This conference is for families, professionals, policy makers and researchers.

There is a discounted rate for parents. For more information visit www.fcc-conference.ca/registration.htm. The hotel block at the Westin expired on April 27, 2009 but there may still be some rooms available.

A complete conference program is available at www.fcc-conference.ca/program.htm. The following is a general outline of the events for the three days.

Sunday May 24

- | | |
|-------------------|--|
| 3:30 pm – 5:30 pm | Panel presentation – Moving Forward Together: Family and Youth Perspectives on Family Centred Care |
| 5:30 pm – 8:00 pm | Conference registration (registration also available Monday) |
| 6:00 pm – 8:00 pm | Welcome reception |

Monday May 25

- | | |
|-------------------|---|
| 7:30 am – 8:30 am | Registration and continental breakfast |
| 8:30 am – 4:15 pm | Conference sessions |
| 4:30 pm – 8:30 pm | Stollery Children's Hospital tour/reception |

Tuesday May 26

- | | |
|-------------------|--|
| 8:15 am – 9:15 am | Continental breakfast and poster viewing |
| 9:15 am – 3:45 pm | Conference sessions |

A representative from Heart Beats will be attending. Please see the next issue of *Keeping the Beat* for a summary of the conference.

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

Your Support in Action

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

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

We appreciate and acknowledge the donations received from the following individuals and organizations from January through April 2009:

- Ferrell & Jen Beleshko
- Patricia Floc'h-Anderson – in honour of Loic Floc'h-Anderson
- Michael & Donna Gerlinsky – in memory of Brittany Gerlinsky
- Douglas & Donna Longson
- Olusesan & Adewumi Olorunfemi
- Melanie Tornqvist – in honour of Ava Tornqvist
- Anonymous – in honour of Ava Tornqvist
- United Way of Calgary, Donor Choice program*
- The Watson Family Foundation at The Calgary Foundation

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.)

Portable Music and Heart Devices

A recent news report had mentioned concerns regarding portable music players and heart devices. Since my son, Mathias, is pacemaker dependent, this immediately grabbed my attention. I e-mailed the Cardiology Clinic to get more details and see how this may relate to my son. The doctors were amazing with a quick, informative and reassuring response. For those of you who also have children with heart devices, here is a summary of the research.

Headphones (ear buds)

A research paper (that has not been reviewed or published yet) was presented by Dr. Maisel at the American Heart Association meeting in November.

The research indicated that headphones could possibly cause interference with some pacemakers/defibrillators but only if they are held close to the device. The headphone's magnetic effect falls off quickly as it is moved away from the device.

With this information, what precautions should our children with heart devices take? It is still okay for our kids to use headphones, but keep them in the ears. When the headphones are not in use you should store them at least 6 inches from the device. If your device is located under the collar bone / chest area – put them in your bag or your pant pockets. If the device in the abdomen, maybe store them in your backpack. Tell your child if they are ever feeling funny while using headphones to move them away from their device.

(Please note that all speakers have magnets. The larger the speakers, the larger the magnets and the magnetic field. When going to concerts, it is not advisable for people with pacemakers/ defibrillators to stand near the large speakers.)

Digital Music Players (such as iPods)

Dr. Robin Clegg was one of the authors of a research study from the Labatt Family Heart Centre, The Hospital for Sick Children and the University of Toronto which tested

digital music players to see if they caused interference with pacemakers/ defibrillators. The study concluded that digital music players only interfere with device telemetry (when you are in the pacemaker clinic having your device programmed/adjusted/interrogated). So do not bring your digital music player to your appointment at the pacemaker clinic.

No interference is found with standard usage but it is still advised to keep digital music players 6 inches away from the device.

In summary, it is okay to let the music play! (Just keep the ear phones and player a good distance away...)

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.

Dr. Robin Clegg is a cardiologist at the ACH Cardiology Clinic.

Ronald McDonald House:

Northern Alberta – Expansion and Grand Re-opening

Many of our Heart Beats families have stayed or will stay at the Ronald McDonald House: Northern Alberta. In the past 5 years alone, over 2700 families have stayed at this facility and 28 per cent of these families come from the Calgary area. Forty per cent of these stays were due to cardiac diagnosis and treatment.

With only 16 bedrooms and increasing demand the Ronald McDonald House: Northern Alberta was forced to turn away over 150 families each year. As a result, Ronald McDonald House undertook an expansion that increased their living space as well as added additional bedrooms so that a total of 30 bedrooms are now available to families. On March 24, 2009 the newly expanded facility celebrated a grand re-opening showcasing the expansion and renovation.

Only half of the rooms in this expansion have been sponsored. Heart Beats is considering sponsorship of one of these rooms and has struck a sub-committee with past members to investigate this possible legacy project. We will keep you informed regarding the progress of this sub-committee.

In the meantime, should you wish to contribute to the expansion of Ronald McDonald House: Northern Alberta please contact them at (780) 439-5437.

The Children's Wish Foundation of Canada Provides Wishes and Hope for Heart Families

Imagine the difference a wish can make.

At The Children's Wish Foundation of Canada, they not only imagine it, they see the difference wishes make to children and their families every day. Since its inception 25 years ago, the Foundation has seen that difference over 14,500 times. In this past year alone, almost 950 wishes have been granted.

Once a child is deemed eligible, they are asked a simple but important question; in the wide realm of possibilities, what would bring them the greatest joy? Whatever the wish, The Children's Wish Foundation is committed to using its talents, time, energy and resources to ensure that each and every child realizes their dream. The Foundation has never denied an eligible child their wish, despite having had to deliver some of the most complex wishes imaginable.

The Children's Wish Foundation of Canada provides children with a variety of illnesses the opportunity to realize their most heartfelt wish. The work they do is about dignity, about dreams come true and about quality of life. It is about precious moments

spent enjoying the special magic of a wish fulfilled. It's about allowing families a break from the day to day trials of tests, treatments, and hospital stays and most importantly it's about smiles on the faces of very special children. Krista is just one of these children.

Eight year old Krista was diagnosed with congenital heart disease at just 2 weeks of age. She was in and out of hospitals and had already undergone three open heart surgeries in seven short years. While waiting for her third surgery, a good friend of their family referred Krista to the Children's Wish Foundation. She was quickly approved and the wheels were set in motion for Krista's Disney Cruise wish! The trip started with 4 magical days in Disney World, where her and her family got to explore all the rides and many attractions. Then they boarded the Disney Wonder cruise ship where they were treated like royalty as Krista got her "Princess Makeover." Krista's whole family got to share in the excitement of her wish trip, and it is an experience that they will never forget. A year after her Disney

wish trip, Krista led the Children's Wish Foundation's "Walk for Wishes –Wishmaker Parade" as the official parade marshal. The 3 mile walk happens in various cities all over the country to raise money to grant more wishes to children like Krista.

Krista is just one of the thousands of children whose lives have been touched by the magic of a wish in the Foundation's 25 year history. Since 1984, the Foundation has built its reputation and identity on the unparalleled dedication of its staff, volunteers and donors who share a heartfelt passion to lift the spirits of children with life threatening illnesses by making their wishes come true. Through these efforts, the Foundation has established itself as one of the most recognizable children's charities in Canada and the premiere wish-granting organization.

To refer a child, explore how to get involved or to simply learn more, please visit their website at www.childrenswish.ca or call 1(800) 267-9474.

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.

Ready or Not: Parenting Adolescents with CONGENITAL HEART DISEASE Recruiting Update:

We are pleased to report that since the last *Keeping the Beat* newsletter 2 more families have come into the study.... We now have 12 families and would like to reach our goal of 15 families. We continue to welcome families into the 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!

Dr. Gwen Rempel, Faculty of Nursing, University of Alberta, is conducting a study with parents and adolescents to learn more about parenting teens (13-17 years) with CHD. She would love to talk to moms, dads and teens (interviewing each one on his or her own on two occasions) and needs to have at least one willing parent along with their teen from each participating family.

For more information about this study, please contact:

Sandy MacPhail RN MN, Project Coordinator

Phone (780) 492-9047

E-Mail sandra.macphail@nurs.ualberta.ca

Ready or Not Analysis Update

Here's what we are finding in the **Ready or Not** interviews we have done so far:

To date, one of the key findings in the analysis is that parents, teens and pediatric cardiologists are often not on the same page regarding efforts to promote and facilitate the teens' growing independence concerning their chronic health issues. The teens seem to be the most open to taking on more self-care responsibilities but many lack basic knowledge about their condition, medications, and need for follow-up. Among the parents, there is less evidence of their readiness to facilitate their teen's transition to independently managing their health condition. So far, few parents or teens report a collaborative process for transition to adult care between the teen, parents and practitioners. Ecomap data reveals that most parents include the teen's pediatric cardiologist as a key member of their support network while fewer teens include their cardiac specialist as a key support.

As analysis continues we plan to provide study updates. To find out more about Gwen Rempel's **Extraordinary Parenting** research program please check our website www.nursing.ualberta.ca/rempe1

Heart to Heart Easter Egg Hunt

On April 5th, 2009, we hosted an Easter egg hunt and hot dog roast for Heart to Heart at our family Acreage near Indus Alberta. Fun was had by all the children despite the cool conditions. All the eggs were found in record time and then giggles filled the air as the children jumped on the trampoline. Every one enjoyed chatting over lunch. After eating some healthy food, the children cracked open their brightly coloured plastic eggs to reveal their long awaited chocolaty goodness, jelly beans and gummy bunnies.



Hunting for Easter Eggs

Our son, Owen Aris, and our whole family want to thank everyone who braved the weather to come out and celebrate this season of new life with us. We enjoyed your company and all the children's smiles brought on by this event.

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.



Found one!

Offbeats

Offbeats is a fun, activity-based group for youth aged 12-17, offering peer-to-peer support and friendship. This year Offbeats has been meeting every two months for fun activities. In October the group played Wii at the Alberta Children's Hospital. The group volunteered at Operation Christmas Child in December and a pair of Calgary Flames tickets were given to a lucky winner. In February we celebrated Congenital Heart Week by sharing heart shaped pizza at Boston Pizza. We flexed our creative muscles by painting pottery at the Fire Escape in April. In May we will have our annual wrap up party.

Offbeats is always looking for and welcoming 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. Offbeats will kick off a new year in the fall. Hope to see you there.

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. 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 June will be on Monday, June 8th at 10 am at the home of Patty Wiebe at 43 Midvalley Crescent SE.

Heart to Heart in July will be on Sunday, July 5th at 1:30 pm at Lake Midnapore. The entire family is encouraged to come! If you .

are able to attend, please contact Patty Wiebe at 403-256-7423 or pattyw@heartbeats.ca as she must provide your name to Lake Midnapore staff so you can be admitted.

Heart to Heart in August will be on Wednesday, August 12th at 10:00 am at Lake Midnapore. Again, if you are able to attend, please contact Patty Wiebe at 403-256-7423 or pattyw@heartbeats.ca as she must provide your name to Lake Midnapore staff so you can be admitted.

Heart to Heart in September will be on Friday, September 11th at 10:00 at the home of Patty Wiebe at 43 Midvalley Crescent SE.

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

Talk with the Docs – Dr. Joyce Harder

So often we only know the Cardiologist our child visits at the Cardiology Clinic, but each of the Cardiologists has their own area of expertise that contributes to their overall care provided to patients at the Cardiology Clinic. We want to introduce you to each of the Cardiologists at the Cardiology Clinic. In past issues of Keeping the Beat we have featured Dr. Frank Dicke, Dr. David Patton, Dr. Deborah Fruitman and Dr. Robin Clegg. In this issue we feature Dr. Joyce Harder.

Within a few moments of meeting Dr. Joyce Harder it is easy to understand why the parents of her patients speak so highly of her. A slender, fit woman with a warm, friendly handshake and deeply intelligent eyes, Dr. Harder exudes an air of calm powerful enough to steady many a worried parent. Alberta's families of children with CHD have been blessed with her excellent care for more than 30 years.

Currently a Pediatric Cardiologist with Alberta Children's Hospital and Clinical Associate Professor in the Departments of Pediatrics, Cardiac Sciences and Medicine at the University of Calgary, Dr. Harder began her career when fewer women entered the field of medicine. There were only 12 women in her graduating class of 120. Dr. Harder was initially drawn to the practice of surgery, but, she says, "It was difficult for women to do surgery. It was even more difficult to have two surgeons in the family, and I'm married to an orthoped! I decided against surgery, I think that was a good decision now. I really liked cardiology. Cardiology walks between medicine and surgery.... Pediatric cardiology and cardiac surgery have a very symbiotic relationship. The surgeons rely on us for accurate pre-op diagnosis, and we rely on them for superb surgery."

Before 1990, ACH did not have a department of cardiology. In the 1980s and up to the 1990s, Calgary's few pediatric cardiologists practiced independently, outside the hospital. Pediatric cardiology remained entirely community-based until 1985, when Dr. Harder began a once-per-week clinic at ACH for the more-complex patients (about eight per week). When the cardiology clinic was added in 1990,

Dr. Harder moved into ACH to become head of the new Division of Pediatric Cardiology, a position she held for 18 years and from which she stepped away last year. During those years, the cardiology clinic grew to a staff of 24, including six cardiologists, each with their own area of specialization. ACH's cardiology clinic now treats 5000 patients per year.

Dr. Harder enjoys the collaborative nature of the practice of cardiology. "Pediatric cardiology is a really complex specialty, we do so much of it together in the sense that we discuss it, we work on the difficult cases together, and that works so well." When asked what is the secret to her famously comforting bedside manner, Dr. Harder is thoughtful. She believes that being female has helped her in that regard, because many people are more comfortable asking questions of a woman, and Dr. Harder believes in the benefit of simply listening. "I think the answer is not speaking, personally," she says. "This is a hard experience for people to get through and so if you have a bit of time to listen to them, that says a whole lot."

Dr. Harder points out that the development of pediatric heart surgery has occurred entirely within her lifetime, and has gone from being a very high-risk procedure to one which now has a mortality rate of under one percent. She credits the "perseverance and optimism" of early pediatric cardiologists such as Richard Rowe and Bob Freedom for the success of the field. And, she says, "The people we really, really have to remember are the surgeons who battled through the first stages." One of these surgeons was Dr. Bill Mustard, who was the first pediatric heart surgeon in Canada.

Dr. Harder recognizes that, to an outsider, the world of cardiology looks like an intense one in which to live, a world which has both a highly technical and a deeply emotional side. She considers the opportunity to help and to share the tragedies and triumphs of families to be a privilege.

"It's interesting," she says, "it took me a long time to understand how my job is different. It came to me when a friend from church took her family to the Philippines and they

built houses and they had a wonderful time, including their kids, and I said, 'Well what made you do it?'. They went from village to village and they helped people however they could, that is, sweeping out their houses or putting on a new roof, or whatever, and they couldn't wait to go back again. And I had to think about that a lot and I realized that their jobs are different, they don't get the same feedback that we get every day. Every day we have people thanking us for the work we do, we have feedback that we actually made a difference in someone's life.... It's an unusual job and it has a lot of meaning. It's a real privilege."

Although she was one of Canada's first female pediatric cardiologists, Dr. Harder doesn't see her accomplishments as particularly extraordinary. "I was given a set of skills that I always felt I had to use, so I don't view it as anything outstanding. Just like Dr. Rebeyka, who is a superb surgeon, or Dr. Ross, both of them are superb surgeons, they take it for granted that that's the skill set they were given and that it's their responsibility, to use it to the best to help people... We do what we were meant to do."

Looking to the future, Dr. Harder sees exciting developments in the field of transplantation, which, she says, is "just, just beginning". With the mortality rate for all heart repairs now under one per cent, studies are being undertaken to learn what are the long-term effects of open-heart surgery on children, and to learn how to moderate potential effects such as learning disabilities. Another area of exploration is the potential for treating some forms of congenital heart disease in-utero.

When asked what advice she would give to someone just starting out in the field, Dr. Harder doesn't hesitate. "I think the important thing is to follow your dreams. Look at your own skill set and decide where it fits the best, but follow your dreams. Don't let anybody tell you there are no jobs or there's no need for this or that, just do what you want to do and eventually it will work out well."

Jennifer Keane Mackinnon, mother of Kathleen (12) and Lindsay (7) who were both born with Atrial Septal Defects.

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:

The Parent's Guide to Children's Congenital Heart Defects

When I was first told that our daughter had a heart defect and would need at least one surgery, after the initial shock dissipated, my mind was flooded with questions. It is difficult to know where to find answers. I found a great book that answered, and continues to answer, many of these questions. The book is called, *The Parent's Guide to Children's Congenital Heart Defects*, and was written by Gerri Freid Kramer and Shari Maurer. Both authors are mothers to children with CHD who decided to write the book when they could not find many resources about CHD.

The book is very well organized and laid out. It starts with the diagnosis stage, continues through things like day-to-day living, surgery, life in the hospital and finally ends with a section for older kids. There is also a glossary, a resource section and a list of books that may also be useful. Throughout each section there are people's stories which include parents, grandparents, and even the children affected with CHD. Also, there is advice from parents throughout, so that the book also has a personal touch, rather than being too technical.

The book is easy to follow and understand, yet it is very factual as thirty-three doctors made contributions. Instead of just text, the book is made up of questions and answers, and it is explained in terms that the average person can understand. This is great because even if the answer to the question does not pertain to everyone's specific case, at least parents know what questions they can ask their child's cardiologist. In the section where specific defects are described, every diagnosis, as well as being described, is shown in a picture of a heart, which also includes a picture of a normal heart so the difference can be seen clearly.

This book is great for any stage of CHD and is informative to all, no matter how simple or complex the defect. I would highly recommend it!

This book is available at the Alberta Children's Hospital lending library, at the Calgary public library and is available to order through most book stores.

Cindy Castillo is the mother of two daughters. Her youngest, Alexa (18 months), was born with Hypoplastic Left Heart Syndrome.

Advice From Our Parent Experts – You!

Many of our heart children have limitations such as cardio functioning, gross motor skills, fine motor skills and some cognitive. How do you decide whether to give a gentle push or be content with where they are at?

From our experience, Daniel is a quieter less active person but he always loved skiing and tobogganing and swimming. He paced himself naturally and he just did not do a lot of sports that were intense except he did play basketball for one year in high school. It did tax him though. He was not so hardy right after the Fontan and he did get cold quite easily so we bought him extra protective gear. He managed to hike and keep up bike riding and in general did a lot more than we ever thought he would. But, he determined how much he could do and we just let him. We did encourage him to hang tough when he got tired but never tried to push him. Remember, those were the early years when cardiologists still said "don't over tax his heart and wear it out early on". That was the thinking back 20 years ago. Boy, we have come a long way...

Sylvia Falk, mother of Daniel (20 years old) who was born with Pulmonary Stenosis and a single ventricle.

From as far back as I can remember I always remembered my parents pushing me. I would struggle with my coat or I would get tired when playing tag, but I always remember that they never helped

me do up my coat and they walked a bit slower so I could catch my breath when playing tag. And as bad as the coat part may sound, I eventually learned how to do up my coat and I didn't feel different about having to run slower in tag. We would often be at people's houses and other parents would give my parents the look of "help your poor child put on her shoes, she is struggling", but they always let me do it myself, just as they did my sister. And I think even as a child I knew I was different and I understood what my parents were trying to do. I only ever grew up in a world where I was taught to expect the same treatment as any other child my age and I should face the world with the same rule.

As I got older and attended school, a lot of things started to become more of a struggle for me to fit in. But I still felt and acted like I was any other child and I seemed to get the same response in return. To this day, if I didn't grow up with the same attitude my parents gave me, I don't think I would have half the independence or strength that I do today. Because of everything I have gone through, I needed that extra bit of strength and independence to overcome those extra obstacles I had above others. And I think it turned out to be the perfect remedy.

Natalia Malnar is an adult with CHD and a member of the Heart Beats executive. Natalia was born with Ebstein Pulmonary Syndrome and skeletal muscle abnormalities of the forearm and jaw.

Although our son is only 18 months old and hasn't yet displayed any limitations, it is our goal to create opportunities in which he can excel within his own parameters.

Jen Beleshko, Mom to Roman, DORV, single right ventricle, dextrocardia, TGA.

Cardiology Clinic *News*

Another New Cardiologist Joins the ACH Cardiology Clinic

Dr. Kim Meyers will be joining the Cardiology Clinic in October, 2009. She is completing her fellowship in Edmonton and then she will move to Calgary. Dr. Meyers will bring her expertise in echocardiography to the Cardiology Clinic.

Congratulations Dr. Fruitman and Dr. Clegg!

Dr. Deborah Fruitman welcomed a baby girl, Kimberley. Dr. Robin Clegg added to her family with the birth of baby girl, Harper.

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

Congratulations Lynn!

Heart Beats' former secretary Lynn Nakoneshny and her husband Russ celebrate the arrival of their second son, Jacob, born on April 22, 2009. Jacob joins big brother Joshua, who was born with Hypoplastic Left Heart Syndrome.

Aurora Becker Has Tetralogy of Fallot Repair

In the last issue of Keeping the Beat, we told you of Norma and Tom Becker's adoption of Aurora and that they were awaiting surgery for Aurora. Norma is currently on parental leave from her position as nurse clinician for the cardiology clinic. Since the last issue, Aurora had her surgery for Tetralogy of Fallot on February 19, and was discharged home February 26. Norma has provided us with the following update:

"She did very well, overall, only one night in ICU. Her chest tube drainage took a few extra days to stop, and that was the only real issue. She lost all her 'hard earned' weight by discharge, weighing even less than when we got her 5 months prior. So we are still trying to 'beef her up'. She is so happy and has so much more energy now, of course. She is really enjoying life, and we are so enjoying her! We are so grateful for everything and everyone who has touched her life, it is hard to imagine our lives without her already. She is truly our little sweetheart. She has been through so much in such a short time, she really is a trooper, and we are sooo proud of her! Even big sister Kira has been awesome.

Aurora turns 3 this month (May), and we are having a small but special celebration as she spends her first birthday with her new family. We are looking forward to getting out and meeting some new little friends who share her story at some future Heart Beats events!"

Pediatric Radio Frequency Ablation

Dr. Robin Clegg will be doing Calgary's first pediatric radio frequency ablation at the Foothills Hospital in May. For more information about this procedure, please see the next issue of Keeping the Beat.

Dr. Patton Rides for Cancer

Dr. David Patton will be riding in the 200km bike ride for Cancer in June. If you are interested in supporting him in this cause, you can donate at www.conquercancer.ca/goto.dpatton.

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 Nakoneshny 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

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