



# Keeping the Beat

Winter 2008

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, 2008

Since 2000, Heart Beats has helped raise public awareness of Congenital Heart Defects (CHDs) in Calgary by obtaining mayoral proclamations. For the first seven years, the proclamation designated one day as Congenital Heart Defect Awareness Day; appropriately, the day chosen was February 14th. Last year, Calgary joined many other communities around the world in proclaiming February 7-14 Congenital Heart Defect Awareness Week. This year, Mayor David Bronconnier has proclaimed February 7-14, 2008 as Congenital Heart Defect Awareness Week in Calgary.

Why do we need a Congenital Heart Defect Awareness Week? CHD is the most frequently occurring birth defect, affecting 1 in 70 Canadian newborns. It is the leading cause of birth-defect related deaths worldwide. Despite its being so common, many people are unaware of or misinformed about CHD, confusing it with adult, lifestyle-acquired cardiovascular disease. CHDs develop in a child prior to birth, whereas adult, lifestyle-acquired cardiovascular disease develops later in life, as a result of lifestyle factors such as an unhealthy diet and little or no exercise.

Approximately 180,000 adults and children in Canada are currently living with CHD. Medical advances have reduced the mortality rate of babies born with CHD, and so more adults are living with CHD than ever before. While this is obviously welcome progress, it has resulted in a growing need for research and treatment for adults with CHD. The estimated 130,000 Canadian adults currently living with CHD have no program of care equal to that provided for people with lifestyle-acquired heart disease. (Statistics are from the Canadian Congenital Heart Alliance website, [www.cchaforlife.org](http://www.cchaforlife.org))

### How can you help during this week?

- Send an e-card to those in your address book, letting them know about CHD (see page 2 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.
- Open up a conversation about Congenital Heart Defect Awareness Week with someone new.
- 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 Celebration to meet other families dealing with CHD.



**Heart Beats**  
Supporting Children with Heart Disease

# Congenital Heart Week Proclamation

Congenital Heart Defects (CHD) is the leading cause of infant mortality and affects one out of every 100 babies born.

Of these, 60 per cent develop critical and life-threatening lesions that need repair in the first year of life. Prior to 1945 the mortality rate for this group was 90 per cent, with the remaining 10 per cent dying before 21 years of age. Today, thanks to advances in medical technology, more than 75 per cent of infants born with congenital heart defects reach adulthood. The aim of Congenital Heart Defect Awareness Week is to raise awareness about congenital heart defects and the impact that they have on children and their families.

**Whereas:** An estimated 180,000 Canadians have CHD of which, approximately 8,000 reside in the Calgary area;

**Whereas:** The establishment of CHD clinics has helped ensure that children receive the specialized care they require as they grow into adulthood;

**Whereas:** Increasing public awareness will help ensure that needed services continue to be developed, and that ongoing research into the treatment of CHD is supported.

On behalf of City Council and the citizens of Calgary, I hereby proclaim the week of February 7 - 14, 2008 as:

***“Congenital Heart Defect Awareness Week”***

Dave Bronconnier, Mayor



## Join us on February 9th for Our Annual Family Celebration

To celebrate Congenital Heart Defect Awareness Week, Heart Beats is holding its Annual Family Event on Saturday, February 9th, 2008 at the Calgary Winter Club Bowling Lanes. We invite you to join us for a fun time of bowling followed by pizza and sundaes! We will also have activities for little ones too young to bowl.

Tickets for the event are \$10 per adult and \$5 per child (children too young to bowl may attend for free), but we do not want the cost to keep anyone away who would like to attend. Heart Beats has a fund available to assist with the cost of attending our Annual Event; if the cost is a concern we would be happy to sponsor your attendance (confidentially, of course).

Due to space restrictions for bowling, this event is limited to children living with CHD and their immediate family members. To register, contact Patty Wiebe by e-mail at [pattyw@heartbeats.ca](mailto:pattyw@heartbeats.ca) or by phone at 256-7423. Advance payment will be required to reserve your spot. Register early to avoid disappointment.

This event is open to all families of children with CHD, whether or not you have attended any previous activities with Heart Beats. This is a great opportunity to meet and/or reconnect with other families of children with CHD. We look forward to having you join us:

Saturday, February 9th, 2008  
4:00 – 7:00 pm  
Calgary Winter Club Bowling Lanes  
4611 – 14th Street NW

## Send an E-card and Show You Care

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

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

To send the e-card:

- Visit the Heart Beats website at [www.heartbeats.ca](http://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

Thank you for helping to inform others about Congenital Heart Disease!

# Heart Beats Unveils New Logo

In 2007, Heart Beats celebrated its 20th anniversary! This was a time to reflect on the legacy of this group and also to re-evaluate where we are going. As a part of this process, we decided to update Heart Beats' look. (After all, not much stays in style for 20 years...)



**Heart Beats**  
Supporting Children with Heart Disease

You will be noticing some changes over the next little while. First is the new logo, which was kindly designed for us free of charge by Brad Hendricks of Saw Communications. We are very grateful for his willingness to donate his time and talent to Heart Beats.

The logo depicts four hands coming together to form a heart, illustrating the community of support that Heart Beats provides for families dealing with CHD. The four hands also represent the four chambers of the heart, circulating blue blood to the lungs and red blood to the body. You will notice that this heart is asymmetrical—or imperfect—because the children we support have special hearts that are unlike others. We also chose to add the tag-line, "Supporting Children with Heart Disease" so people will immediately know our purpose.

You may have also noticed that this newsletter looks different from the last one you received. We have updated the look of the newsletter so that new readers can more clearly identify it as a publication from Heart Beats.

In the coming months we also plan to update the look of the website and our information brochure. If you have any questions or comments regarding our new look, please contact the Newsletter Coordinator at [karenp@heartbeats.ca](mailto:karenp@heartbeats.ca).

# Heart to Heart

Heart to Heart is a 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, school-aged children are welcome as well. We vary our meeting days, times, and locations from month to month to try to include as many parents and families as possible.

At our Christmas Party in December we celebrated the season with seven heart children ranging in age from one to eleven, and their families. It was an enjoyable time of indulging in Christmas goodies, doing crafts, sharing our "heart" experiences, and getting to know one another better. Thank you to Heart Beats for providing gifts for the children!



*Heart to Heart Christmas Party Pictured left to right: back row: Lindsay, Sierra holding Saige, Kathleen front row: Isabelle, Nathan, Mathias, Janelle holding Joshua*

## Upcoming Heart to Heart Meetings

- Friday, January 18th at 10:00 am at the home of Patty Wiebe, 43 Midvalley Crescent SE.
- Tuesday, February 19th at 10:00 am at the home of Lynn Nakoneshny, 187 Willowmere Close in Chestermere
- Sunday, March 16th at 2:00 pm at the home of Patty Wiebe, 43 Midvalley Crescent SE.
- Friday, April 18th at 10:00 am at the home of Patty Wiebe, 43 Midvalley Crescent SE.

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](mailto:pattyw@heartbeats.ca) or by phone at 256-7423.



# Heart Beats Executive Member Shares Her Story

BY KRISTINA PRUSINA

*Natalia Malnar joined the Heart Beats executive in September 2007 after learning about the group from a friend. Natalia is an adult with Congenital Heart Disease (CHD) who has kindly chosen to share her story with us.*

Natalia Malnar knows the process to a healthy life is a hard battle; she was born with a rare heart disease. Her parents remember the courage it took to face the heartache the whole family went through.

Natalia was born with Ebstein Pulmonary Syndrome, which is, "the congenital absence of the pulmonary valve, with displacement of the pulmonary annulus to the pulmonary bifurcation." As if those obstacles were not enough, Natalia was also born with skeletal muscle abnormalities of the forearm and jaw. Natalia doesn't remember the early years when she was in the hospital all the time. Her mother, Theresa, still remembers the details vividly.

In 1981, Theresa was two weeks overdue and she was admitted to the hospital to induce labour. When she was hooked up to a drip to induce labour Theresa recalls, "the baby immediately started kicking and moving around and the machines started to go crazy." Theresa was concerned that something was wrong with the baby. When the baby was delivered Theresa heard no cries, and "as a mother you know something's not right." Her instincts were correct, for at that moment Natalia turned blue and the doctor tried to revive her. Theresa recalls the horrifying moment when she heard the doctor say, "We're going to lose her." Those words "echo in my mind 'til this day." Theresa still finds her daughter's medical conditions hard to believe. She had had a good pregnancy and there were no indications of complications, even ultrasounds showed no evidence of heart problems. Natalia was in the hospital for approximately one

month after birth. After she was released from the NICU she had to come into the hospital every week for check-ups for the first few years of her life.

In 1987, Natalia required open-heart surgery in Edmonton. Doctors could not believe this rare case existed so close to home, and requested that Natalia be their study subject. Natalia's parents decided to allow Natalia to be the subject of their study, in hope that it would help other children and families. After watching the doctors examine her baby, however, Theresa decided she was no longer comfortable with Natalia being a research subject. "I found it extremely hard when I saw the poking and prodding, I didn't want it anymore. She was a human being and it seemed so impersonal to them (the doctors). I said they could use her information but not touch her anymore."

The surgery was required to repair a Ventricular Septal Defect (VSD), to resection the sub-aortic ridge and relieve obstruction with a right ventricular outflow patch. Natalia also required a pulmonary valve. Instead of using a mechanical valve, doctors decided to use a bovine valve. Natalia also had a pacemaker implanted for Acquired Complete Heart Block. In Complete Heart Block, the heart's electrical signal doesn't pass from the atria to the ventricles.

Although Natalia had a wonderful surgeon, the procedure was long and nerve-racking for her parents. Doctors had estimated it would take three hours for the surgery, based on all the x-rays taken when she was born. During surgery Natalia's surgeon discovered more problems than the x-rays had shown, resulting in seven hours of surgery. The additional stress on Natalia's heart caused her to have a heart attack. Natalia's chest was open for so long her heart swelled and the doctors could not



Natalia Malnar

close her chest around it. She stayed in ICU with her chest wired and covered until the swelling finally went down enough that her sternum could safely be closed.

The crucial hours after surgery were difficult for Natalia's family. Anton and Theresa were given a beeper and went to rest for a few hours. At two a.m. the beeper went off. "That was the first time in my life that I had fear like that," said Theresa. Luckily for Natalia and her parents, the beeper had gone off accidentally, and when Anton and Theresa arrived at the hospital the doctor informed them that Natalia had made it. Theresa recalls the doctor saying, "Your child made it. The sheer strength of this girl and her will to survive pulled her through this. She's a very strong girl and she wants to live and fight against this."

Right after surgery Natalia's lung collapsed. Theresa had to lightly pound on Natalia's back to make sure fluid and phlegm wouldn't accumulate. A nerve hit during surgery caused temporary paralysis on the left side of Natalia's body. Natalia went through a rehabilitation process and after a few weeks began to get her full movement back.

(continued on page 5)

(continued from page 4)

The recovery process was a difficult six months for Natalia, who lost weight and some hair as well. According to doctors, this was due to the medications she was taking and the physical stress of the whole experience on Natalia's body.

In 1995, Natalia and Theresa were watching TV when one of the leads that connected Natalia's pacemaker to her heart fell out. Natalia had gotten up to change the channel when she fell onto the floor. Natalia recalls that moment saying, "It felt like I was dreaming. I could hear her (Theresa) but couldn't talk." Because of the backup system in the pacemaker, Natalia survived.

Theresa rushed Natalia to the emergency department at the hospital where it was determined that she would need another surgery. The doctors did a "resection right ventricular outflow muscle bundle and placement No. 23 Carpentier Edwards pulmonary valve." Natalia went into cardiac arrest and had to be resuscitated with shock paddles. She had a mini relapse in ICU and stayed in for a couple of weeks. After being released, Natalia had to go in for a check-up every three months for doctors to check her pacemaker and heart rate and make sure everything was working smoothly. Natalia had minor surgery to replace her children's pacemaker with an adult one in 1996.

In 2001 Natalia started on Nifedipine because it "might defer the need for aortic valve replacement in individuals with chronic aortic insufficiency." She took Nifedipine for six years, until her doctor suggested it was no longer needed. Natalia was already a veteran of surgical procedures when she went in for surgery in 2003 to get the battery in her pacemaker changed. It was a minor procedure and she was in and out of hospital quickly.

Today, Natalia is preparing for another surgery. Her body has grown since her pulmonary valve was replaced; the valve has stretched and started to rip and there is minor leakage. She will have another open-heart surgery in the next few years to repair or replace old patches she has outgrown.



*Natalia Malnar today.*

Although the Malnars had support from family and friends, Theresa says a lot of her comfort and support came from the Ronald McDonald House in Edmonton. She and Anton stayed there during both surgeries that Natalia had in Edmonton. It was great to meet other families going through the same thing or worse. "It was a comforting place," said Theresa. "They make it like a home. Everyone there is incredible." Natalia's family was assigned a social worker as soon as they found out about Natalia's condition. "They were there to take care of everything, bookings and stuff. It was a comfort. It really helps you through everything. Help is out there, don't be afraid to ask."

Natalia is currently working in the accounting department at Marks Work Warehouse and has nearly completed her requirements towards her Certified General Accountant (CGA) designation. Despite everything that has happened, Natalia doesn't let things hold her back. "I believe it's important for people to stay positive," says Natalia. "You need to continue with life and do your thing." Natalia still has some physical issues as a result of her condition, her body has to work extra hard to do some things and she sweats a lot. That doesn't stop her from doing the things she wants and helping others.

*Kristina Prusina is a newly graduated journalism student from SAIT.*

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

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. The Network's goals are to share clinical knowledge and expertise to improve care for children with heart disease, and to provide support for these children and their families. They also advocate for high quality pediatric cardiac care throughout the four western provinces.

On November 20th, representatives from Winnipeg, Saskatoon, Regina, Edmonton, Calgary and Vancouver dialled in for a teleconference meeting. Each city discussed their family support groups and exchanged ideas on making their groups more visible and accessible to heart families. Ongoing discussion regarding out of province expenses related to hospital visits resulted in a request that families share their personal experiences. If you have any opinions or stories, please e-mail, in confidence, to Diana Locher ([DianaLocher@cha.ab.ca](mailto:DianaLocher@cha.ab.ca)). In addition, feedback on the website, [www.westernchildrensheartnetwork.ca](http://www.westernchildrensheartnetwork.ca) would be much appreciated, as we attempt to serve heart families across western Canada. Please consider using the website as a tool to prepare for upcoming surgery or doctor visits, as well as general information on subjects relating to congenital heart disease.

*Heidi Smethurst is a mother of four. Her third child, Ryan (8) was born with Transposition of the Greater Arteries and a Ventricular Septal Defect.*

# Cardiology Clinic *News*

## Kelly Webber on Parental Leave

Kelly and her husband Tim are now the proud parents of a little girl named Samantha Dawn Webber. Samantha was born early at 33 weeks on September 23. Kelly and Tim were surprised and pleased to learn on September 24 that they would be the proud adoptive parents. "We went through all the emotions of 9 months in 10 hours," said Kelly with a smile in her voice.

Being a preemie, Samantha weighed only 4 pounds 12 ounces when she was born in Cold Lake. She was taken to the Grey Nuns Hospital in Edmonton where she received the special care she needed to grow stronger. Kelly and Tim spent seventeen days in Edmonton with Samantha and found the care to be fantastic. Samantha has been doing well ever since she was discharged and as of November 20th she was weighing in at a healthy 7 pounds. Kelly misses the gang at Off Beats and looks forward to seeing everyone when she returns sometime in the summer.

## Karen Stosky Joins the Cardiology Clinic Team

Karen Stosky brings over 27 years of nursing experience to her new role as Cardiology Clinic Nurse at the Alberta Children's Hospital. Karen has been at the ACH for the past fifteen years where she has worked on N Cluster, in the Emergency Department and at Health Link.

Karen was interested in joining the Cardiology Team because of her past experience in the Respiratory Clinic and working with cardiology patients in N Cluster. She is enjoying the staff, patients and doctors in the clinic. She is also enjoying the learning curve—understanding the diagnoses of the various cardiac kids and the different surgeries associated with these conditions. Karen will be a part of the Cardiology Clinic team until October 2008. Welcome Karen!

## New Echo Machines Have Arrived!

New echo machines arrived in the Echocardiograph Lab on November 28, 2007. The new machines replace models which were 8-10 years old. These new machines will provide brighter, clearer and more precise images, resulting in better measurements.

## Off Beats

Off Beats is a fun, activity-based group for youth aged 12-17, offering peer-to-peer support and friendship.

The Off Beats group is having a great time. Our participation has been a bit low so far this year but there has been no shortage of fun. Strikes and spares were had by all while bowling at Frank Sisson's Silver Dollar and the Cardiology clinic and Unit 2 proudly displayed the gingerbread houses made at our 2nd Annual Gingerbread House competition. On January 8, 2008 the group was invited for supper and a Calgary Flames game at the Saddledome. Go Flames Go!!!

Some very exciting news is that Kelly adopted a beautiful baby girl. Although we will miss Kelly while she is off enjoying spending time with her daughter, we wish them the best. We want to welcome Norma, one of the other Cardiology Clinic nurses, to the group. Welcome Norma!

We have some exciting plans for the rest of the year and hope more people will come enjoy the fun, friendship, and laughs. For more information, please call Laura Thurber-Larsen at 955-7888.

## 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](mailto:info@heartbeats.ca) advising us of your e-mail address to receive future issues of Keeping the Beat by e-mail. Thank you for helping us to reduce printing and postage costs, so that we may use these funds to assist heart families in other ways!

Note: E-mail addresses will be used only to distribute Keeping the Beat newsletter and notices of Heart Beats events and 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 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 experiencing extended hospitalization.
- "Heart & Soul: Your Guide to Living with Heart Disease" information binders (distributed through the Cardiology Clinic).
- Toys and supplemental equipment 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 2007:

The guests of Irene Endicott's Birthday "Casino Night" (see page 8):	Anne Lenstra
Marg Bohonos	David Morihira
Roberta Bremner	Al Neish
Auriana Burns	George Ongyerth
Marisa Croft	Marie Rhodes
John Croft	Adele Thomson
Dianna Dryden	Daniel Topolinsky
Deryl Duncan	Jan Walton
Louise Easch	Mike Westby
Lisa Graham-Hill	Kari Imperato in honour of Ava Contrada
Gloria Heisler	Petro-Canada and the Calgary Hitmen for including Heart Beats as one of the recipients of the teddy bears collected at the "Teddy-Bear Toss".
Harvey Hull	
Al Huzar	
Liz Huzar	
Dwaine Korsbrek	
Dolores Kowalchuk	
Sig Larson	

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](http://www.heartbeats.ca) where you can make secure donations by credit card.

# Heart Beats Continues its Tradition of Christmas Hampers

This year three families received Christmas hampers from Heart Beats, making their holiday a little brighter. In total, eight children had presents under the tree and moms and dads had some "extras" to make Christmas day a little more special. As an 'elf' that delivered hampers, it was very gratifying to see Heart Beats' family-support in action! The wide-eyed look and huge grin of the kids was priceless, and in essence, captured the spirit of Christmas. A very special thank you to fellow elves, Lori and Erin Moch, and Natalia Malnar, who braced the shopping crowds and full parking lots, and shopped, wrapped and delivered Christmas cheer!

*'Heidi Smethurst is a mother of four. Her third child, Ryan (8) was born with Transposition of the Greater Arteries and a Ventricular Septal Defect.*

# Heart Beats and CarePages Partner to Benefit Heart Families

Heart Beats is pleased to offer CarePages to the Heart Beats community. CarePages are free, private, personalized Web pages available to patients and families to help you stay in touch while dealing with a healthcare issue. The service allows you to control communication and provides an easy way for friends and loved ones to receive updates and respond with messages of support. CarePages are fully secure, password-protected and comply with all patient privacy regulations.

To create or access CarePages, visit [www.carepages.com/heartbeats](http://www.carepages.com/heartbeats) or visit [www.heartbeats.ca](http://www.heartbeats.ca) and click on the CarePages icon.



# Directing Donations Creatively

Members of the Heart Beats community have been finding creative ways to raise awareness and money for Heart Beats and the ACH Cardiology Clinic.

In October 2007, Monica Croft, a former chairperson of Heart Beats, organized a "Surprise Casino Night" in honour of the 70th birthday of her mother, Irene Endicott. Guests were invited to play blackjack, poker, roulette and horse racing; proceeds from the purchase of casino chips were donated to a local charity of Irene's choice. In May 1990, Irene's first grandson, Sam Croft, was born with Tricuspid Atresia. Having witnessed first hand the challenges faced by families of children with heart defects and the importance of ongoing support, she selected Heart Beats as the recipient of the casino proceeds.

Colin and Patty Wiebe learned about "Two-Fives" birthday parties that friends in their community were having. For

these parties, guests make a birthday card for the birthday child and enclose two \$5 bills. The birthday child uses one \$5 bill towards the purchase of a gift, and donates the second \$5 to a charity. Colin and Patty thought the idea sounded great and mentioned it to their two daughters, who were game to have a "Two-Fives" birthday. For her 6th birthday their daughter Isabelle, who was born with Hypoplastic Left Heart Syndrome, told her guests about Heart Beats and why she chose it as her charity to receive the donation portion of her birthday money. This was so well received that even guests who were unable to attend the party gave a card to Isabelle with the donation for Heart Beats.

Tracey Contrada's daughter, Ava, was born with Left Ventricular Non Compaction. The Contradas have a large, caring circle of relatives and friends. Overwhelmed with their generosity, Tracey has encouraged them to make donations

to Heart Beats in lieu of birthday and Christmas gifts, in honour of Ava. Tracey has also told her employer, Long View Systems, about Heart Beats; as a result, Long View Systems chose Heart Beats to be one of the recipients of funds raised at their annual client appreciation golf tournament.

Todd Oliphant's daughter Alysha, was born with Hypoplastic Left Heart Syndrome. This past spring, Todd organized Unified Valve's annual golf tournament. As the coordinator of this event, he chose the ACH Cardiology Clinic to be the recipient of funds raised from the golf tournament.

Perhaps these examples give you ideas of ways to raise awareness of CHD within your circles of family, friends, co-workers, etc. and also ways to help raise support for children with CHD and their families. We would love to hear how you choose to do so!



*Irene Endicott and 'Neil Diamond'.*



*Monica Croft, a former chairperson of Heart Beats, organized a "Surprise Casino Night" in honour of the 70th birthday of her mother, Irene Endicott. Proceeds were donated to Heart Beats.*



*Isabelle Wiebe's Two-Fives Birthday Party.*



# 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! For the next issue of *Keeping the Beat* please submit your tips on preparing for surgery. You may submit these to the Newsletter Coordinator at [karenp@heartbeats.ca](mailto:karenp@heartbeats.ca)

## Advice From Our Parent Experts – You! Dealing With Medications

I was pretty lucky with Alysha. Of course, liquid meds were always easy when she had the feeding tube. After the feeding tube was removed she would up-chuck any form of liquid medicine she needed to take. It was an absolute gong-show trying to get it in her. The only thing we lucked out with was mixing it with a bit of juice, chocolate milk or pudding, but that was always a hit and miss thing. She knew what was going on. Finally we just asked if we could get the meds in a pill form and see how she would do. From that day on life was easier, she would just chew 'em up. It would always turn my tummy, but she was fine with it.

*– Jeannine Oliphant, mother of Alysha (10 years old) who was born with Hypoplastic Left Heart Syndrome.*

Even though dealing with a feeding tube for the first year was difficult, it was an easy way to administer medication. When the tube came out, having to give meds to a very squirmy and wiggly child required some different tactics. After several “misses”, I finally clued into squirting the meds into the cheek area (not down the throat as that caused gagging on a few occasions). I would crush the pills and mix them with chocolate milk to make them taste better, and then squirt into the cheek area. Now that Ava is 3 years old, she understands that she needs to take the meds and we put the pills into her food on her first bite.

*– Tracey Contrada, mother of Ava (3 years old) who was born with Left Ventricular Non-Compaction.*

When I gave Daniel his meds, when he was littler, I used a syringe and squirted his pills crushed in a bit of juice/water into his mouth. Later he took all the vile meds like a little soldier. Hmmm...I know some people hide them in a spoonful of peanut butter or jam.

*– Sylvia Falk, mother of Daniel (19 years old) who was born with Pulmonary Stenosis and a Single Ventricle.*

# Website Review

**The Congenital Heart Information Network**  
<http://tchin.org>

The Congenital Heart Information Network was launched in 1996 as an international non-profit group, based in the US. This group provides information and support services to families of children with heart disease and the professionals who work with them.

This group is one of the driving forces behind Congenital Heart Defect Awareness Week throughout the US, Canada and the rest of the world.

Their website is divided into four main sections: Community, Resources, Links and more information about the Congenital Heart Information Network. The Community section focuses primarily on online support with a chat room and memorial garden. From my perspective, I prefer a more personal approach, but many people may really enjoy this online community.

Under the Resources section there is an area for book reviews which could be very useful to new parents just researching their child's condition. The wide variety of links can also help parents search for information. The resources for Congenital Heart Defect Awareness Week are generous with information, statistics and background information about Congenital Heart Disease.

I will keep this site book-marked, especially for the times that I need some background or statistics regarding CHD. But this site will not be my first go-to source as I have found a few more Canadian sites where information is more relevant to our situation. As well, I do prefer personal support to online support so I will continue to be involved locally.

*– Karen Perl-Pollard is the mother of Mathias (3) who was born with Tetralogy of Fallot, Atrial Septal Defect (ASD), Patent Ductus Arteriosus (PDA) and now has a pacemaker for acquired Heart Block.*



# Talk with the Docs – Dr. David Patton

So often we know only the cardiologist our child visits at the Cardiology Clinic, but each of the cardiologists has their own area of expertise that 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 our Fall 2007 issue we featured Dr. Frank Dicke. In this issue, we feature Dr. David Patton.

## 1.) How long have you been in cardiology?

Thanks for the opportunity of answering your questions today! I finished my training in Pediatric Cardiology in 1994.

## 2.) Have you always been in cardiology or have you worked in other areas of medicine? If so, what other areas and for how long? What do you bring from this other area to your work at the Cardiology Clinic?

I have also trained in Pediatric Intensive Care. In addition to cardiology, I worked in our ICU here at Alberta Children's Hospital from 1995 to 2003. As you know, the ICU is where the sickest children are cared for, so this allowed me to gain extra knowledge of how other body systems affect the heart, and has really helped in the care of our heart patients.

## 3.) How long have you been at the ACH?

I grew up in Calgary and was a pediatric resident at Alberta Children's Hospital in the late 1980s. After training in cardiology and ICU in Halifax and the United States, my family and I returned to Calgary in 1995 where I have been at Children's Hospital since.

## 4.) For those of us who haven't met you, how would you describe yourself? How would we recognize you in clinic?

I'd be the one who is a little taller than Dr. Harder and shorter than Dr. Dicke. I'm well-known for my ugly black shoes, but they are really comfortable!

## 5.) What is your favourite thing about working at the ACH?

I love working with kids and their families. Also, we have a really great group of people in our clinic—secretaries; ECG, echo, and MRI technologists; nurses; social workers; dieticians and physicians. It's a pleasure to work with all these dedicated individuals.

## 6.) I have heard that you have been doing some work with Cardiac MRI. Can you explain to me what this is?

Yes, in collaboration with Dr. Abou-Reslan here at Children's Hospital and Dr. Friedrich at Foothills Hospital, I have been doing clinical and research work in cardiac MRI (also known as CMR), which is a high-tech way of imaging the heart in patients of all ages, from newborn babies to adults with congenital heart problems. CMR images are useful in evaluating the structure and function of the heart, and are used to help decide how to best

treat heart problems.

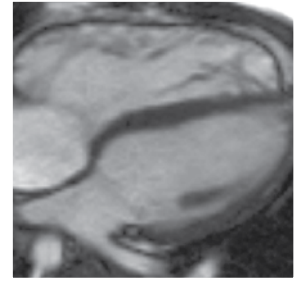
CMR is a non-invasive imaging technique (meaning no surgery or catheters are needed). It is used to create detailed images of the heart and its function. CMR studies are done on special MRI scanners that use radio waves, magnets, fast computers, and specialized software to produce moving and still pictures of the heart and blood vessels in two and three dimensions.

In a typical week, we perform 4-6 CMR exams on pediatric patients at ACH, and 6-8 on adults with "grown-up" congenital heart problems at the Stephenson CMR Centre at Foothills Hospital.

## 7.) What types of conditions are suitable for CMR?

CMR is extremely useful for evaluating complex types of congenital heart problems at all ages, especially after surgery, or for older patients when echocardiography is sometimes difficult.

CMR is also used in diagnosing and following many other types of heart problems including heart failure and inflammation, heart muscle and valve problems, coronary artery disease, damage after a heart attack, and heart tumours.



CMR image of the 4 chambers of the heart. The right ventricle (toward the top of the picture) is enlarged in this patient who has leakage of the pulmonary valve.

## 8.) How has CMR changed the patient experience? What are the advantages of this procedure?

CMR helps elaborate on results from other tests such as echocardiograms, and is often used to avoid the need for invasive procedures, tests that use radiation (such as CT scans), or contrast dyes that may be harmful to patients with allergies or kidney problems. Unlike CT scans or conventional chest X-rays, CMR doesn't use radiation, so CMR studies can be repeated over many years without the risk of radiation exposure.

CMR also provides information about the heart that is not available any other way. Using CMR we can look for scars or edema (swelling) in the heart, and precisely evaluate cardiac function and blood flow.

CMR has made a huge improvement in the management of complex heart

(continued on page 11)

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conditions, such as those patients with Hypoplastic Left Heart Syndrome or single ventricles. CMR now allows us to evaluate the heart anatomy and function before surgeries without needing more invasive testing, shortens time in hospital for tests, and provides extremely detailed information for our heart surgeons, Dr. Ross and Dr. Rebeyka, to help in planning for surgeries.

**9.) Are there even more innovations in this field to come? What can we expect to see in the next 5 years?**

In the next few years, CMR studies will become faster and provide even more information from one single test. We are currently working on new hardware for the MRI scanner, allowing us to image the whole heart in half the time it now takes. Techniques are being developed for looking at abnormal blood flow in the heart and assessing areas of low oxygen in heart tissue using CMR.

For those who are interested in more information about Cardiac MRI, see the following two websites:

Society for Cardiovascular Magnetic Resonance:  
[www.scmr.org](http://www.scmr.org)

Stephenson Cardiovascular MR Centre, Calgary:  
[www.cmrcentre.ucalgary.ca](http://www.cmrcentre.ucalgary.ca)

## Special Tribute to Fraser Lockwood

Fraser Lockwood, son of Heart Beats' co-founder Anne Lockwood and her husband Steve, passed away on September 29, 2007 at the age of 22.

Fraser was born with a mild Coarctation of the Aorta and both a VSD and ASD, which were corrected when he was ten months old. He also had a rare and difficult-to-diagnose syndrome which affected his growth and ability to walk and talk.

It did not, however, affect his ability to smile and laugh, which he did often. Fraser enjoyed being read to, and having someone close by. He loved people, especially his family and his caregiver Meli. He made those around him better people. His parents reflect: "Fraser made our friendships stronger, our love deeper, and because of him we learned to appreciate life all the more. Fraser was a shining example of strength and spirit and he is a genuine reminder that the parameters of what makes a human life exceptional are vast."



Fraser Lockwood

Anne wrote the following poem for Fraser a few years ago:

*no more tears  
after all these years  
We have been blessed  
for there can be joy  
that is born of sorrow*

*The light that shines  
within your heart  
is ever bright*

*no more tears  
do I wish for what could have been?  
do I dream of your life fulfilled?  
Yes—but you are our joy—  
our precious boy*

*a strength of spirit that  
knows no bounds  
perseverance  
patient and quiet*

*no more tears  
You embrace each day  
and accept the love of  
those who truly love you*

*That is your gift  
You've held a special  
place on this earth*

Anne shares, "Fraser was our angel—as our hearts heal we will come to see ever more clearly the gift he was to our family. He gave so much in his quiet, unassuming way."



## Heart Beats Children's Society of Calgary

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**Heart Beats**  
Supporting Children with Heart Disease

# Share Your Story

We invite you to share with us your experience with congenital heart disease. We would like to hear from parents, as well as children 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](mailto:karenp@heartbeats.ca)

## Heart Beats Children's Society of Calgary Annual General Meeting

We invite you to attend the Annual General Meeting of Heart Beats on

Tuesday, April 8th, 2008  
at 7:00 pm  
at the home of Patty Wiebe,  
43 Midvalley Crescent SE.

The meeting is open to all members of the Heart Beats community, whether or not you have ever attended any Heart Beats' activities. If you are interested in becoming involved with Heart Beats, or you just want to learn more about what we do, we encourage you to come to the AGM.