



Keeping the Beat

Winter 2009

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, 2009

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, smoking, or lack of exercise. (Statistics are from the Canadian Congenital Heart Alliance website, www.cchaforlife.org) Calgary joins many communities around the world in proclaiming February 7-14 as Congenital Heart Defect Awareness Week.

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 Defect Awareness Week Proclamation



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
- Click on the e-card link on the right-hand side of the page.
- Be prepared with the e-mail addresses you wish to send to.
- Select which message you want to accompany your e-card.

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

Annual Family Event – Free Family Movie Matinee

We invite you to kick off Congenital Heart Defect Awareness Week by joining us for our Annual Family Event on Saturday, February 7th, 2009. This year we are having a **Family Movie Matinee** at the Cardel Theatre. In addition to the movie, snacks and beverages will also be provided.

There is no fee for this event and it is open to all families of children and teens with a CHD. Even if you have not participated in any other Heart Beats' activities, we

encourage you to come to the Family Movie Matinee. 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 7th, 2009
1:00 pm
Cardel Theatre
6010 - 12th Street SE.

Cardel does not charge for the use of the theatre, but asks groups who use it to please bring non-perishable food items to support local charities.

To help us plan, please let us know you will be attending the Family Movie Matinee by contacting Patty Wiebe by e-mail at pattyw@heartbeats.ca or by phone at 403-256-7423.

Antibiotic Coverage Prior to Dental Procedures for Children with Congenital Heart Disease

by Colin Wiebe, DDS and Joyce Harder, MD.

Infective endocarditis (IE) is an uncommon but life-threatening infection. When the heart or its blood vessels are malformed or surgically altered the blood flow can become more turbulent. This turbulence can damage the lining of the heart (endothelium) and allow platelets and fibrin from the blood to adhere in a “vegetation”. Bacteria that get into the bloodstream via bleeding in the mouth can colonize the vegetation and cause an infection in the heart (often in a valve). Despite advances in diagnosis, antimicrobial therapy, surgical techniques and management of complications, patients with IE still have a high incidence of serious illness and death. One of the methods doctors have used to prevent this from occurring is to prescribe preventative, or “prophylactic”, antibiotics, for a patient to use prior to dental procedures.

It has been found that routine antibiotics prior to dental treatment are not drastically reducing the incidence of IE in many types of heart problems. It is calculated that the likelihood of a person with congenital heart disease developing IE is 1 in 475,000 dental visits, and that even if the patient had taken an antibiotic the infection may not have been prevented. The risk of a patient dying due to an anaphylactic reaction to penicillin is 11 in 475,000. This has resulted in a change of medical guidelines.

The American Heart Association (AHA) has been publishing antibiotic regimens (prophylactic antibiotics) for dental procedures to prevent IE since 1955. The most recent guidelines were published in 2007 and they greatly reduced the types of heart conditions recommended to receive antibiotics prior to dental procedures. The reasons for these reductions include:

- 1) IE is much more likely to result from frequent exposure to random bacteremias associated with daily activities such as chewing food and flossing than from bacteremia caused by a dental procedure.
- 2) Prophylactic antibiotics may prevent an exceedingly small number of cases, if any, in people undergoing dental procedures.
- 3) The risk of an allergic or other serious reaction to the antibiotic exceeds the benefit from prophylactic antibiotic therapy in all but the most high-risk heart conditions.
- 4) Maintaining optimal oral health and hygiene may reduce the incidence of bacteremia from daily activities and is more important than antibiotic prophylaxis for dental procedures to prevent IE.
- 5) The vast majority of IE patients have not had a dental visit in the 2 weeks prior to onset of IE.

Congenital heart disease (CHD) conditions with the highest risk of adverse outcomes from IE include:

- Palliative shunts.
- Repaired defects in the first 6 months after surgery.
- Repaired residual defects adjacent to a prosthetic patch as this inhibits endothelialization.
- Heart transplants where valve problems develop.

Cases of IE caused by oral bacteria are likely due to routine daily activities and not occasional dental treatment. That being said, prophylactic antibiotics are still recommended for the highest-risk congenital heart conditions prior to dental treatment. The need for prophylactic antibiotics will be determined by the cardiologist. If antibiotic coverage is required then it should be used for all dental treatment that results in bleeding of the gums, e.g., for a dental cleaning but not for replacement of an orthodontic wire.

In terms of dentistry and the prevention of IE, the most important factor is prevention of dental disease including gingivitis and periodontal disease. Excellent daily brushing and flossing are required and should be done by or supervised by a parent until age eight years or longer if their dentist notes poor oral hygiene. The greatest risk period for people with CHD is early adulthood when they take over their own care, with less parental supervision, so they must have a well-established oral hygiene regimen before that time.

Reference

Prevention of Infective Endocarditis. *Circulation* 2007 Oct 9;116(15):1736-1754

Colin Wiebe is a periodontist and the father of two. His youngest daughter, Isabelle (7) was born with Hypoplastic Left Heart Syndrome. Dr. Joyce Harder is a cardiologist at the ACH Cardiology Clinic.



Deciding Where to Give

The heart, above all organs in the body, it is the one we most associate with life. Not just with life but with emotions like love, sorrow, and joy. So when a baby is diagnosed with a congenital heart defect, it is no wonder people come forward to help. They give emotional support when we need a shoulder to cry on, practical support when we need things like sibling care, spiritual support when things look bleak, and in some cases people give monetary support not only to the people affected with CHD but also to organizations that do important research, provide the excellent cardiology medical care we have and provide more comfortable medical environments for our children.

Where should people direct donations to provide for our children? Probably the first association that comes to mind is the Heart and Stroke Foundation. The Heart and Stroke Foundation provides some excellent information on CHDs; the *Heart & Soul: Your Guide to Living with Heart Disease* manual was funded by the Foundation. Their website contains a very detailed list of what they do with donations. Categories start with donations under \$10.00 and go up all the way to what they would do with a \$50,000 donation. Of the eleven categories on the website, only one mentions CHDs.

The \$25 category says that that level of donation would provide three *Heart & Soul: Your Guide to Living with Heart Disease* manuals for parents and children born with a CHD. The only other category that may be pertinent to CHD would be Automated External Defibrillators for public venues. What is not mentioned in the donations part of the website, however, is that they do fund some research for CHD. For instance, Dr Lori West does research in the area of infant heart transplants at the Stollery Children's Hospital; she is funded by the Heart and Stroke Foundation. So although the website emphasizes the prevention of heart disease and stroke later in life, it turns out that they do more funding for CHD than they publicize.

Donations can be made to the Alberta Children's Hospital Foundation; an accompanying letter stating that the donor specifically wants the donation to go towards Cardiology will ensure that the donation is directed to that department. This can also be done at the Stollery Children's Hospital in Edmonton. These donations may be used for equipment or resources that the department needs (such as new echo machines) or they may be used to fund research.

Donations can also be made to the Heart Beats Children's Society. Heart Beats uses donations to provide: financial assistance to families having difficulty 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 (the Heart and Stroke Foundation provided for the initial development of this resource and Heart Beats provides funds for the ongoing distribution); and supplemental equipment and toys for the Alberta Children's Hospital Cardiology Clinic.

When making your decision to donate, you need to set your priorities. Decide if you want your funds to go to information, research, equipment or to families. Then contact the foundations directly to see if your funds can be designated for congenital heart defects or for the cardiology department. If your funds can be directed, ask what your donation would potentially fund so you can be assured that this matches with your priorities.

Cindy Castillo is the mother of two daughters. Her youngest, Alexa (15 months), was born with Hypoplastic Left Heart Syndrome.

Study Update Ready or Not: Parenting Adolescents with Congenital Heart Disease. We are pleased to report that 10 families have been recruited and interviewed and we are now looking for 5 more families.

Ready or Not: Parenting Adolescents with CONGENITAL HEART DISEASE

- 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

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.



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

We appreciate and acknowledge the donations received from the following individuals and organizations from October to December 2008.

- Myrna & Barry Bennett - in memory of Kevin Moore

- Marilyn & Robert Burke - in memory of Kevin Moore
- Claudette & Marty Chisholm
- Cathy, Steve, Chelsea, Brad & Bryana Hale - in memory of Kevin Moore
- Sherry & Ian Harrill - in memory of Kevin Moore
- Alan & Ella Heffren
- Dale & Rosalin Heffren
- Quintin Heffren
- Rob & Susan Hiebert - in memory of Kevin Moore
- Gail MacKean – in memory of Kevin Moore
- Loretta Taylor – in memory of Kevin Moore
- Petro-Canada Alumni Association
- United Way of Calgary, Donor Choice program
- Janelle Wiebe
- The Calgary Hitmen for including Heart Beats as one of the recipients of teddy bears collected at the "Teddy-Bear Toss".

Please note: In the last issue of *Keeping the Beat* we acknowledged that donations were received January through May 2008. This should have read that we acknowledged donations from June through September 2008. We apologize for this error.

If you wish to contribute to the support of families of children with congenital heart defects, you may mail your donation to:

Heart Beats Children's Society of Calgary
Box 30233, Chinook Postal Outlet
Calgary, AB T2H 2V9

You may also donate online at www.heartbeats.ca where you can make secure donations by credit card to **Heart Beats** through CanadaHelps.org.

*(If you donate to Heart Beats through the United Way, please let us know so we can acknowledge you as the United Way does not provide us with the names of the donors.)

Heart Families Support the Alberta Children's Hospital Foundation's 6th Annual Radiothon November 5-7

The "Country 105 and Q107 Caring for Kids Radiothon" was broadcast live from the Alberta Children's Hospital November 5-7, 2008.

Several members of the Heart Beats community shared their stories including: Karen Perl-Pollard and Mathias; Cindy Castillo and Alexa; John & Tracey Contrada and Ava; Russ & Lynn Nakoneshny and Joshua; and Colin & Patty Wiebe and Isabelle.

In total, the Radiothon raised \$1.9 million for the Alberta Children's Hospital. Thank you all for sharing your stories and thank you to all the generous donors!

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

Heart Beats Continues its Tradition of Christmas Hampers

For many families the added medical expenses of having a heart child in the family can make things difficult at Christmas time. This year three families received Christmas hampers from Heart Beats, making their holiday a little brighter. Six adults and five children received a variety of gifts from Heart Beats, who did their very best to make holiday wishes come true. As an "elf" who has been delivering Christmas Hampers for several years, it is always gratifying to see Heart Beats' family support in action! Thank you to all our donors for your generous support.

Heidi Smethurst is a mother of four. Her third child, Ryan (9) was born with Transposition of the Great Arteries and a Ventricular Septal Defect.

Offbeats

Offbeats is a fun, activity-based group for youth aged 12-17, offering peer-to-peer support and friendship. We meet monthly during the school year.

We encourage any patients of the Cardiology Clinic aged 12 to 17 to join us!

Offbeats met in October and welcomed Kelly Webber back to the group. We met at ACH for a bit of Wii fun and discussed ideas for the upcoming year. We hope to partake in another Flames game, go bowling, have an in-house pizza party and tap into our creative side at Fire Escape. In December we have signed up to volunteer our time at Operation Christmas Child and two lucky participants will win some Flames tickets. We will also celebrate Congenital Heart Defect Week with our annual heart-shaped pizzas at Boston Pizza!

For more information, contact Laura Thurber-Larsen at 403-955-7888 or Laura.Thurber-Larsen@CalgaryHealthRegion.ca

Heart to Heart

Heart to Heart is open to all parents of children born with congenital heart defects (CHDs). 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



Families getting to know one another at the Heart Beats Christmas party.

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.

On December 7th, seven families braved the heavy snowfall and treacherous road conditions to attend the annual Heart to Heart Christmas party hosted by Colin and Patty Wiebe. They enjoyed Christmas goodies, crafts, playing, and visiting with one another. Thank you to Heart Beats for providing gifts for the children.

Heart to Heart in January will be on Monday, January 12th at 10 am at the home of Patty Wiebe at 47 Midvalley Crescent SE.

Heart to Heart in February will be on Wednesday, February 11th at 10:00 at the home of Lynn Nakoneshny at 187 Willowmere Close in Chestermere.

Heart to Heart in March will be on Tuesday, March 10th at 10:00 at the home of Lynn Nakoneshny at 187 Willowmere Close in Chestermere.

In April, we invite you to come for an Easter Egg Hunt at the acreage of Michelle Aris on Sunday, April 5th at 10:00 am. Her home is at 281130 Township Road 230, just outside the east city limits. For more detailed directions, contact Patty Wiebe.

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

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

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!

Advice From Our Parent Experts – You!

Celebrating Congenital Heart Week

Last year we celebrated Congenital Heart Week by providing all the children in Mathias pre-school class with heart-shaped balloons and a card that said, "Happy Valentine's Day from Karen, Ron, and Mathias. In addition to Valentine's Day, February 7-14 is Congenital Heart Week in Calgary. This is important to our family because Mathias was born with a heart condition called Tetralogy of Fallot. He has had two open-heart surgeries and is now doing fine – which is certainly a reason to celebrate! If you are interested in learning more about Congenital Heart Disease you may visit tchin.org or heartbeats.ca" We had lots of positive feedback from the other families and Mathias loved giving the gifts to his friends!

Karen Perl-Pollard is the mother of two. Her oldest child, Mathias (4) was born with Tetralogy of Fallot, Atrial Septal Defect (ASD), Patent Ductus Arteriosus (PDA) and now has a Pacemaker for acquired Heart Block.

For the first few years we celebrated Congenital Heart Defect Awareness Day--then Week--with other heart families at either a Mom & Tots party or the Heart Beats Family Event. Last year we expanded our acknowledgement of CHD Awareness Week to include extended family and friends by sending them e-cards from the Heart Beats website. The e-cards were well received!

Patty Wiebe is the mother of two. Her youngest child, Isabelle (7) was born with Hypoplastic Left Heart Syndrome.

Website Review

Website: <http://www.cachnet.org>

The Canadian Adult Congenital Heart (CACH) Network was founded in October 1991, and was created to pool the knowledge and experience of congenital heart disease professionals in Canada, to help strengthen their skills and knowledge of the discipline, and to create a community of individuals committed to caring for adults with congenital heart disease and for their families. As a result of improved diagnosis and interventions over the last two decades, more and more adults are living with CHD. While these adult patients are role models and offer hope for those of us with children with CHD, they are also forging into somewhat uncharted territory. The CACH Network aims to meet the needs of this rapidly expanding group of adults.

Some facts about congenital heart defects in Canada (www.cachnet.org)

- CHD is the most common birth defect, affecting 1 in 70 Canadian newborns
- Historically, the focus of CHD care was confined to newborns and children whose life expectancy was limited to weeks, months, and in a few cases, several years
- The amazing progress over the past 50 years in diagnosis, surgery, and other interventions has vastly improved survival
- Presently, an estimated 130,000 adults who live with CHD in Canada have no program of care equivalent to that provided for children with CHD or people with "lifestyle-acquired" heart disease
- We have a wide variety of heart defects, each type requiring different levels of intervention and monitoring
- Adult patients have far fewer resources than children, and they must wait as much as 33 times longer for surgical intervention than patients with acquired heart disease
- At least half of adult patients face the prospect of complications, re-operation, and premature/sudden death

- The numbers are growing--now more than 50% of CHD patients are adults

At first glance, their website is easy to read and the links are easy to navigate (and all of the links really do work). The home page contains a "What's New" section for both professionals and patients. There is also a heading called "The Beat" which is the network's newsletter and includes up-to-date articles. For instance, did you know that some patients no longer have to take antibiotics before dental work? Past issues of "The Beat" are archived and are easily accessible on the website. To make your life even easier, you may sign up for news updates sent directly to your email address.

As parents of children with congenital heart defects, we are always asking questions and looking for answers. What will happen during surgery? Will my child have special restrictions placed on them? What does the future look like for my child? Under the "Patient" section of the CACH network website, there is a message board forum that you can post about anything related to congenital heart disease. You must create a new account before you log in, but once you've done that, you are connected to others with experience in CHD. As with anything you read on the Internet, caution is advised, and you should always consult your cardiologist with any questions you have or before making any changes to your health care regime.

And, finally, the all important "Resources" tab. This section is loaded with brochures and guides that are easy to print or save. There is also a resource archive base that is so easy to access and read.

This site was very useful! (So useful that's it's now bookmarked on my computer.) It's one of the easiest sites I've seen to navigate on. It's not only visually appealing, but it's simple, straight-forward and contains information that we all want to know. Check it out....www.cachnet.org.

Nikki Ballendine is the mother of two. Her eldest, Emily (5), was born with a Coarctation of the Aorta, multiple VSDs, and ASD.



Cardiology Clinic *News*

Norma Becker on Parental Leave

Norma and her husband Tom are now the proud parents of two daughters. Norma and Tom adopted their first daughter, Kira (now 3 ½ years old), from China in 2006. On September 7, 2008, Norma and Tom welcomed their second daughter, Aurora. They spent two weeks with her in China and arrived home in Calgary on September 20, 2008.

Aurora was adopted through the "Waiting Child Program", which is a program to adopt children from China who have minor or correctable special needs, with cleft lip and heart defects being common. With her background in pediatric nursing, Norma and Tom felt they could be a good fit for this program. When they applied, they did not know what special needs their new addition would have. Aurora, whose Chinese name means "rising sun in the morning", has a congenital heart defect. She has Tetralogy of Fallot, and at 2 ½ years old has not yet had surgery to repair it. She gets blue and tires very easily, but Norma and Tom have seen that she is happy, outgoing, strong-willed and wants to do a lot. She has also been getting stronger and stronger.

Aurora will be having an MRI in December and is scheduled for surgery on December 15, 2008. Norma, who has been working at the Cardiology Clinic for three years, acknowledges that there is a difference being on the other side. "Being a nurse helps a little bit... but it is different being a mom 24 hours a day, 7 days a week."

We wish Norma, Tom, Kira, and Aurora all the best with surgery in Edmonton and look forward to seeing their family at future Heart Beats events.

Angela Bernardo Joins the Cardiology Clinic Team

Angela Bernardo joined the Cardiology Clinic on October 14, 2008 on a one-year contract while Norma Becker is on parental leave. Angela has been nursing since 2000. For the past eight years Angela has worked at the Alberta Children's Hospital in ICU and adolescent medicine.

Angela is returning to nursing after a year-long parental leave with her new son, Talon. She has been enjoying the new experience and learning curve of working in a clinic. The most rewarding part of her new position has been getting to know all the families who come to the clinic. Angela will be a part of the Cardiology Clinic team until September 2009. Welcome Angela!



Kira, Tom, Aurora and Norma visiting the Great Wall of China.

Heart Heroes Bulletin Board Now On Display

Thank you to everyone who provided photos of your heart child in action! The Heart Heroes Bulletin Board is now on display in the Cardiology Clinic. It has already been a source of encouragement for new families, providing a positive point of view of the possibilities for life after treatment for CHD. This is not a static display. Please keep the photos coming in. We would love to add new photos of your heart child's accomplishments. Please include the following information with your photo: child's first name, age, the name of the heart defect repaired and a sentence or two to describe their favourite activities now. Please send them to: Nurse Clinician Patty Knox, by regular mail to Alberta Children's Hospital, Pediatric Cardiology, 2888 Shaganappi Trail NW, Calgary, AB T3B 6A8.

Heart Beats Children's Society of Calgary

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