



Keeping The Beat

Heart Beats - Children's Society of Calgary

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

Growing Up With Heart Disease Conference Upcoming



The fifth Growing Up With Heart Disease Conference in Vancouver, BC, will take place this year on May

28th and 29th at the Chan Centre for Family Health Education on the site of BC's Children's Hospital. This is a collaborative conference for families and professionals by families and professionals offering exciting and informative plenary and concurrent sessions on a wide range of issues related to living with congenital heart disease.

"If you are a parent or caregiver of a child born with CHD, attending a heart conference is something you should definitely try to manage at some point," says Cindy Bablitz, editor of Keeping The Beat and mom to Noah, 5, who was born with a ventricular septal defect (VSD).

"Even though Noah's condition required surgical repair very early in his life, and even though our lives are no longer affected on a daily basis by his CHD, I still found attending the Building Bridges heart conference last May in Winnipeg to be very worthwhile," she adds.

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Annual Family Event Upcoming

Heart Beats' annual celebration of the family is quickly approaching — and selling out.

"Tickets are already more than two thirds sold," says Jeannine Oliphant, Heart Beats chair.

Tickets, including an early supper, are \$10 per adult and \$5 per child, to a maximum of \$30 per family. To reserve your spot, contact Jeannine at 289-4329 and arrange your advanced payment. Please don't let a tight budget stand in your way of taking advantage of this opportunity to meet and fellowship with other families living with CHD! Heart Beats has a limited amount of funding to confidentially sponsor your attendance.

- Calgary Winter Club Bowling Lanes
- 4611 14th Street N.W. (right beside the District Three Police Station)
- Saturday, February 26th, 2005
- 3:00—6:30 p.m.



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Mayor Declares Valentine's Day Congenital Heart Day

One of the ways the Heart Beats Children's Society of Calgary serves the community of children and adults born with CHD and their families is by lobbying institutions and governments on your behalf. And, one of the ways we lobby to raise awareness about CHD is by cooperating with local, national and international organizations in petitioning government officials to officially declare one day each year, February 14, Congenital Heart Day. 2005 marks the sixth year in a row Valentine's Day has been proclaimed CHD Day in Calgary.

This year, Mayor Bronconnier joins hundreds of organizations and politicians in Canada, the United States, Australia,

France, Germany, India, Ireland and the United Arab Emirates in commemorating February 14th as a day to celebrate the lives of millions of children around the world who live with, and sadly, who have died from, congenital heart defects (CHDs).

CHD is considered the most common birth defect, and is the leading cause of birth-defect-related deaths worldwide. Many people don't realize that congenital heart defects are far more prevalent than any other birth defect, including spina bifida, Down Syndrome and hearing loss.

Yet, a relatively small amount of funding is currently available for parent and patient educational

services, research and support.

About 10,000 Calgarians live with congenital heart defects.

"By sharing our experiences and information with our elected officials and the media, we hope to raise public awareness about a condition little understood by most people not personally affected," says Gail McKean, executive board member of the Heart Beats Children's Society of Calgary.

"It is our sincere hope that our efforts to educate the public will result in additional funding for support and educational services, scientific research and improved quality of care for children and adults living with CHD."

Official Proclamation

The aim of Congenital Heart Day is to raise awareness about congenital heart defects and the impact that they have on children and their families.

One percent of all babies are born with congenital heart disease. Of these, 60 per cent develop crucial 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 disease reach adulthood.



THE CITY OF
CALGARY

- Whereas: There are an estimated 100,000 adults in Canada living with congenital heart disease;
- Whereas: The establishment of congenital heart disease 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 congenital heart defects is supported.

On behalf of City Council and the citizens of Calgary, I hereby proclaim February 14, 2005:
"CONGENITAL HEART DAY"

Dave Bronconnier
Mayor

Growing Up With Heart Disease Conference Upcoming

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In addition to sessions of particular interest to family members and professionals, organizers of this year's Growing Up With Heart Disease conference will again be offering a series of sessions of particular interest to youth and young adults living with congenital heart disease.

"Building on our past success, this year's conference will showcase topics that highlight the multidimensional aspects of congenital heart disease," says conference planner Colleen Corder of the Children's Heart Network in BC.

Guest speakers will share their experience and expertise on a wide variety of topics relevant to living with congenital heart disease, including:

- advances in cardiac surgery
- cardiac transplantation
- cardiac research

- understanding diagnostic tests and procedures
- feeding issues
- traveling out of province for care
- optimizing the health of your child
- CHD and puberty, pregnancy and menopause
- transition to adult care

Keynote speaker, Ying Gu, head nurse in the CICU, Children's Hospital of Fudan University, Shanghai, China, will

be presenting on *Caring for Children with CHD in China: Understanding the Family's Perspective*.

The conference will also include a session, *Behind Closed Doors*, an opportunity to tour the operating room.

Conference registration will begin in March. For more information, contact Colleen Corder at the Children's Heart Network office at 1-250-598-2524, or by e-mail at

chn@childrensheartnetwork.org

Growing Up With Heart Disease Conference 2005
Celebrating The Young At Heart
Is presented collaboratively by:



Children's Hospital
Cardiac Sciences Program



**Children's
Heart
Network**

New Act Leaves Some Without Financial Support

Family Support for Children with Disabilities (FSCD) — historically known by an ever changing variety of names, (including *Handicapped Children's Services*, *Services for Children With Special Needs* and *Resources for Children With Disabilities*) — has recently made a newest change that will significantly impact some families caring for children with CHD.

"Previously, every child with a heart defect that had to travel to Edmonton for surgery would have been able to access services and financial support through the program currently known as Family Support for Children with Disabilities," says Gaye Hopkins, social worker at the Alberta Children's Hospital.

"Now, the key consideration determining eligibility for financial support from FSCD is whether the child can be labeled "disabled" according to the newly legislated definition," she adds.

This bears significant ramifications for families of children living with CHD who used to be able to rely on FSCD services and financial assistance — particularly when care required a trip to Edmonton's Stollery Children's Hospital.

The problem is, for Albertan families not living within commuting distance of Stollery, the costs associated with the medical necessity of traveling to and staying in Edmonton now bear an additional financial implication into an already highly stressful situation.

Although the new Family Support for Children with Disabilities Act does offer a broad range of improvements in service and funding access for children who qualify, the same Act is inadvertently leaving some families of children with CHD out in the cold. Under the new legislation, families of children with CHD fall somewhere between the cracks — and the practical reality is financial discrimination for patients and their caregivers who must travel versus those who don't have to in order to access the same non-elective surgical health care in Alberta.

Since the new legislation went into effect in August 2004, families of

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The Western Canadian Children's Heart Network

The Western Canadian Children's Heart Network (WCCHN) was created in the year 2000 to better link expertise between the five pediatric cardiac care centres in Manitoba, Saskatchewan, Alberta and British Columbia. The five equal partners in the network include the BC Children's Hospital in Vancouver, the Stollery Children's Hospital in Edmonton, the Alberta Children's Hospital in Calgary, the Royal University Hospital in Saskatoon and the Winnipeg Children's Hospital.



"The WCCHN is committed to supporting patients and their families with information and resources about children's heart disease and care," says Denise Clarke, WCCHN coordinator.

The aim of the network is to work collaboratively with children's heart care providers in sharing knowledge, research and work practices to improve care for CHD-affected children and their families.

"Our goal is to provide care and services for the whole family," adds Denise.

"We are now working with patients and families from all centers to help us develop our website and educational materials," says Denise.

The WCCHN is actively recruiting your input for the development of

their website. If you have a request for information you'd like to see featured on a western Canadian website dedicated to the cooperative improvement of care for your child, contact Denise Clarke, RN, MN at deniseclarke@cha.ab.ca, or (780) 407-1522.

"We are very excited about our network," says Denise, "And we look forward to hearing from you if you have any questions or would like to provide us with some feedback."

This opportunity for collaboration and cooperation from a grass roots level up to the most senior medical and administrative levels is unprecedented, and heralds an era of important progress for the community of CHD stakeholders. Don't miss out on your opportunity to be involved in this progressive movement.

AGM Your Opportunity to Get Involved, Get Informed

The Heart Beats Children's Society of Calgary will hold its 2005 Annual General Meeting on April 20, 7:00 p.m. at the home of Gail McKean, 122 Discovery Ridge Way S.W. Whether or not you've been involved with Heart Beats formally or informally, you are invited to attend! This is a great opportunity to learn more about the ins and outs of our mission and mandate. Also, if you are interested in discovering if there is a volunteer fit for you with Heart Beats, the AGM offers an informal, no-obligation opportunity to ask questions.

The following positions will be elected at the AGM.

CHAIRPERSON

- Oversees operations of society
- Organizes and prepares agenda for executive meetings

SECRETARY

- Records and distributes minutes of the meetings

TREASURER

- Balances monthly statements
- Ensures cheque requisitions and receipts are in order
- Sends out tax receipts
- Completes yearly taxes

ACH FAMILY LIAISON COUNCIL REP

- Attends monthly meetings
- Liaises with ACH in a consulting capacity regarding the hospital

care needs of CHD children and their families

FUNDRAISER CO-ORDINATOR

- Oversees fundraising events and generates fundraising activity ideas

NEWSLETTER EDITOR

- Produces Keeping The Beat four times per year
- Recruits contributors and facilitates writing assignments

WEBSITE MANAGER

- Monitors and manages the website

BOARD OF DIRECTORS

- Remains informed of and adheres to the Bylaws of Society
- Remains informed of and generates new business, activities and policies

Mom & Tots

Mom & Tots met on January 31st for a casual visit at the Devonian Gardens.

"There were only two of us moms with our three girls, but we did enjoy chatting about our daughters' upcoming cardiology appointments," says Patty Wiebe.

"The girls had a great time playing in the indoor play area and watching the gigantic koi in the many water pools."

For a safe and relaxing indoor venue suitable for play and relaxation year round, the Devonian Gardens is a great spot to check out!



The next planned get together for Mom & Tots is a Valentine's party at the home of Angie Enslow in celebration of Congenital Heart Day. For details, contact PattyWiebe@shaw.ca or 256-7423, or Angie Enslow at 251-3989.

Off Beats

Off Beats greeted a snowy new year with a gathering to see the movie *Are We There Yet?* at the Chinook Theatre.

"It was a funny and upbeat movie," says Kelly Webber, nurse clinician at the ACH cardiology clinic and Off Beats facilitator.

"We had six teens join us and, like movie critics, their feedback varied."

On Wednesday, February 23rd, thanks to the generous folks at Morrison Homes, Off Beats will be going to a Calgary Hitman hockey game!

"If you're interested in joining us, we need to hear from you by February 14th," says Kelly.

Call the clinic at 943-7316 for more details.

In March, Off Beats is planning an informal gathering to play games, eat pizza and decorate some spring ornaments for one of the ACH inpatient areas.

Off Beats is a group for youth aged 12–17 years living with CHD. For more information on upcoming events, or on how you can encourage this important peer-to-peer support group, contact Kelly Webber, Patty Knox or Gaye Hopkins at 943-7316.

New Act Leaves Some Without Financial Support

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children with CHD are only eligible for assistance if their child meets the criteria of "a chronic developmental physical, sensory, mental or neurological condition or impairment but does not include a condition for which the primary need is for medical care or health services to treat or manage the condition, unless it is a chronic condition that significantly limits a child's ability to function in normal living."

This definition excludes many Albertan children with CHD who do require the life-sustaining surgery only of-

fered in Edmonton, but who, once repaired, are not expected to be functionally limited in the future. Even some children whose CHD will require a lifetime of ongoing medical attention may not necessarily be deemed significantly limited in their ability to function in normal living.

For sure, there were all good intentions behind the new FSCD Act and, for sure, many families will benefit. However, many families of children with CHD will not.

This is an important issue requiring your input.

Send your concerns, comments and experiences to:

- Your MLA (surf to www.gov.ab.ca and click "Contact Your MLA")
- The Honorable Iris Evans
Minister of Health and Wellness
107 Legislature Building
10800–97th Avenue
Edmonton, AB T5K 2B6
fax (780) 415-0961
- The Honorable Heather Forsyth
Minister of Children's Services
424 Legislature Building
fax (780) 415-4859

Through Keeping The Beat, Heart Beats will continue updating you on the results of our ongoing and collective lobbying on this matter.

Heart Beats

Children's Society of Calgary

charitable registration no. 88907 6261 RR 0001
Providing information, resources and emotional support to
families dealing with congenital heart disease.

Chairperson Jeannine Oliphant
Secretary Patty Wiebe
Treasurer Sylvia Falk
Nurse Liaison Patty Knox
Newsletter Editor Cindy Bablitz
Additional Directors Gail MacKean
Heidi Smethurst

You may contact us!

Box 30233 Chinook Postal Outlet
Calgary, AB T2H 2V9
Cindy Bablitz (Editor) 201-4889
cindy.bablitz@telusplanet.net
Jeannine Oliphant (Chair) 289-4329
Kelly Webber (Off Beats) 943-7316
Angie Enslow (Mom & Tots) 251-3989

We Need You!



In this issue of *Keeping The Beat*, we've featured a number of opportunities for you to lend your voice in significant ways for the collective good of our children who live with CHD.

On page 3, check out an important announcement about the new Family Support for Children with Disabilities Act. You may or may not consider your child with CHD "disabled" ... regardless, this new legislation may impact your access to services and support. Don't be silent on this one.

On page 4, you are invited to offer input for an innovative new collaboration between CHD professionals and the community they serve. The WCCHN represents an unprecedented opportunity for non-hierarchical communication — and your experiences and feedback are critical to the success of this important opportunity.

Then, on page 4, you're invited to Heart Beats' Annual General Meeting.

You are the community we serve. Help us help you by speaking up.

Beat The Drum Slowly

an editorial by cindy bablitz

I'm having a baby tomorrow morning.

Two previous STAT caesarians have necessitated the scheduling of a third, and so, with a bit of a feeling of anticlimax, my last baby's birthday has been predetermined.

In less than 11 hours from now, I'll be in an OR in Foothills Hospital.

Unlike my typical Sunday morning routine which usually has me rushing into the shower at the last minute to be ready to leave for church so we'll be only a little bit late, this morning, I was up with enough time to bake a fresh batch of blueberry muffins, put a roast in the slow cooker, get a fresh loaf of bread going in the bread maker, make the beds, put laundry away and rearrange the boys' dressers.

All this with a vision of spending the remainder of the day in an idyllic embrace of the family that is now ... be-

fore it becomes the family that will be. My vision included a story time with my two boys cozied on my lap, some playtime on the floor, a heartily enjoyed dinner with specially appreciated maple glazed roasted root vegetables and a warm bedtime of family bonding during which we all reflected with contentment on the life we've treasured as a troupe of four and with excitement on the life we'll enjoy as a clan of five.

But first the boys needed a quick stop at the barber.

Before long, my panic-stricken, red-faced, vein-popping, drooling, shrieking two-year-old was in a wrestling match with a frantic barber most unfortunately lacking in chairside manner. With half of my terrorized child's head spiky with three-inch long tendrils and half chopped in uneven scissor-hacks, I didn't know whether to run interference and forfeit the

effort or to let the butcher, er, barber, finish what we'd started.

Later, the fistfuls of chocolate chocolate chip cookies enjoyed in the fireside room after church, combined with the fistfuls of secretly devoured candy from yesterday's birthday party loot bags sabotaged my cozy dinnertime image ... and then the day's accumulated lack of any substantive nutrition wreaked havoc with my idyllic bedtime dreams.

You'd think by now I'd have some grasp of our true human potential to predict outcomes. There's an entire branch of science dedicated to the folly: they call it chaos theory.

So it is. We breathe in, we breathe out. We hope for the best.

And I know it: for me, tomorrow morning, my best is a healthy baby, and a healthy mom.

