



Keeping The Beat

Heart Beats - Children's Society of Calgary

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

Heart Beats Celebrates 20 Years of Service

We have a lot to celebrate! Two decades ago, a compassionate group of parents founded the Heart Beats Children's Society of Calgary, and 2007 marks our 20th anniversary. Two decades of care, support, service, generosity and gratitude offered entirely by a collective of volunteers is worth taking note of!

Join us!

Sunday, February 11th

2- 4 pm

**new Alberta Children's Hospital
fourth floor, conference room 2**

This family-friendly event will include activities for children, cake and beverages. You'll also have an opportunity to tour the Cardiology Clinic at the new Alberta Children's Hospital.

On this day, we also mark the ninth time Calgary's mayor has made an official proclamation calling attention to families living with congenital heart defects in the region, and the professionals who serve them. This year, Mayor Bronconnier has extended Congenital Heart Defect Awareness Day to an entire commemorative week. In this

(Continued on page 2)



At the reading of the 2006 Mayoral Proclamation in the city hall atrium, Alderman Andre Chabot added a personal note, revealing that his own mother, years after her own children were grown, was diagnosed with a CHD, that, later in life, needed, and received, repair.

l to r: Andre Chabot, Patty Wiebe, Isabelle Wiebe, Laura Thurber-Larsen, Norma Becker, Heidi Smethurst, Cindy Bablitz

It takes a lot to maintain the vitality of a grass roots organization like Heart Beats!

Over the years, the needs of the community we serve, and from whom we solicit our support, has changed, and our small executive team is beginning to consider what Heart Beats' long term legacy might look like. We need your involvement!

Heart Beats activities often fly under the radar, and you might not immediately assume that you have something to offer, or a reason to connect. In this issue of Keeping The Beat, be sure to check out the many invitations for your participation.

Heart to Heart

Heart to Heart is a new group for parents of children with congenital heart defects (CHD). Beginning in January 2007, we will meet once a month for coffee, etc. and a chat about parenting children with CHD.

Heart to Heart is open to parents of children of all ages, whether they are infants, toddlers, elementary age, or teenagers.

Parents with children at home are welcome to bring them.

Come to meet other parents, to ask questions about caring for and raising children with CHD, to share your knowledge and experience, and to enjoy some coffee and goodies.

Check out page 5, inside, for details on meeting dates and location.

(Continued on page 7)

Official Proclamation



Congenital Heart Defects (CHD) is the leading cause of infant mortality and affects one out of every 100 babies born. Of these, 60 percent 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 percent, with the remaining 10 percent dying before 21 years of age. Today, thanks to advances in medical technology, more than 75 percent 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 200,000 Canadians have CHD of which, approximately 10,000 reside in Calgary;

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, 2007 as:

Congenital Heart Defect Awareness Week

Dave Bronconnier

Mayor

Your Support in Action

Each year, one of the ways Heart Beats puts your donations into action is by sponsoring a few families from our community with gifts and groceries at Christmas. For many families, an unfortunate side effect of dealing with a child living with a congenital heart defect can be the financial burden inherent in either additional care costs or in missed income as parents tend to their child's needs.

"You all have made this Christmas a bit easier for us," says one grateful mom.

This year, Heart Beats confidentially sponsored three families, offering support to five parents and five children.

"I can only imagine the delight of a child opening an unexpected, but most

wished for, Christmas gift; or the relief of a parent knowing there would be some packages under the tree and a Christmas dinner to enjoy, but the image has warmed my heart and comforted my spirit," says Heidi Smethurst, one of Heart Beats' long standing volunteers and executive team member.

Say another family, "Thank you for making our Christmas so very memorable and special, as this was our first year together as a family at home."

Your ongoing financial support helps us help other families like you, living with CHD, and appreciating the support Heart Beats offers through a tough time.



(Continued from page 1)

Heart Beats Celebrates

proclamation, we join thousands of communities in Canada, the United States and around the world likewise advocating for awareness about CHD.

If you have a child with a congenital heart defect, you are encouraged and welcome to attend – whether or not you have attended any previous activities or been in touch with Heart Beats before. We look forward to meeting new families, as well as re-connecting with families who have been associated with Heart Beats and/or attended Heart Beats events over the past 20 years.

Please RSVP to Patty Wiebe by e-mail at pattywiebe@shaw.ca or phone 256-7423 by February 6 please.

We wish you'll come.

Chinese Cardiac Nurse Specialist Speaks at Conference

by Cindy Bablitz

I am grateful.

My first child was born with a potentially fatal heart defect. This past December 10th marks the seventh anniversary of his life-saving surgery.

We live in a part of the world where information, surgical and medical intervention and family support are abundant. What good fortune was our birthright.

At the Growing Up With Heart Disease Conference in Vancouver in May, 2005, keynote speaker Ying Gu reminded all in attendance how very fortunate indeed we are to be parents in Canada.

Ying Gu is the head nurse of the Cardiac Intensive Care Unit of the Children's Hospital of Fudan University, in Shanghai, China. She is a role model and mentor at one of China's most prestigious medical training facilities, and an integral member of the partnership between the BC Children's Hospital and Fudan University.

In her pausing English, in a room riveted on Ying's humble and slight stature, this ambassador shared her sometimes heart-wrenching experience being a cardiac care nurse in a country far removed from the high tech, advantaged western world many of us take for granted. Ying told of her personal experiences as an agent for change in a country where family-centered care is not yet embraced, sharing feedback from a group of 14

mothers and fathers of children born with CHD she interviewed.

"There is no public research on the parents' experience of caring for a child with CHD in China," explains Ying, whose documented interviews may represent a first step on this progressive path.

In China, where legislation enforces a one-child rule, mothers who give birth to a daughter are already socially compromised, as sons are preferred.

When a child comes to be diagnosed with a congenital heart defect, the stigma of birthing a defective child can bring fear and dishonour to a mother ... and if that child is a daughter, the shame on the family can create social obstacles almost insurmountable.

"It is like someone took away all of my thinking, and my brain is empty," said Xing's mum.

"I cannot think about it, so I work and work and work and hope I can escape it."

Little is yet understood about congenital defects in the population at large in China.

Ying explains, "Some parents feel guilty that they caused the CHD."

The cost to repair what western pediatric cardiac surgeons today consider "routine", a Ventricular Septal Defect repair, including a seven-day hospital stay, can cost a family the Canadian equivalent of \$4-5,000 ... with typical monthly in-

comes ranging from \$156 - \$1,563. The financial burden, in a country with no universal health care benefits, can strap an extended family for years – and the cost of repairing a daughter born with CHD is often perceived as not worth it. Adding to the cultural bias against treatment for CHD is that parents are given a second chance from the one-child policy.

Ying explained that mothers will often experience pressure from their in-laws to alleviate the heavy financial toll of heart surgery by letting their first, sick child die, and to try for a second, healthy baby.

"I wish I could take my child to the doctor sooner, but to collect a big amount of money is like to ask me to fly to the moon," grieved one father.

"There is a knot in my child's life and everything will be ok if it is untied."

Xiu's mum



(Continued on page 4)

Chinese Cardiac Nurse Specialist Speaks at Conference

(Continued from page 3)

Even when a family is able to muster the courage and fortitude to pursue diagnosis and treatment for congenital heart defects – something profoundly difficult especially for rural families – so little regard is given to family-centered care, (as so little is understood about its importance) that parents often suffer needless additional worry once their child is taken into the medical system. Unlike our experience in North America, and in most westernized nations, parents in China are not coddled with explanations and information about the medical process and care of their child.

“In China, there is no 24-hour parental visitation allowed in the CCU because there is no support for the evidence-based value of bedside parenting attendance”

Said one parent Ying interviewed, “It seems like a game; if my child is lucky enough, we win the game.”

And another, “I’m not sure if my child needs the operation.”

It’s not that surgical and medical staff in China are dispassionate about their care, for of course, they are

devoted professionals giving their life’s work to the children they serve, rather, that care and attention to the patient is considered paramount. And, staffing, time and other resources often don’t allow for attention to be extended beyond the critical care needs of the child. At the Children’s Hospital of Fudan University where Ying works, for example, the Cardiac Intensive Care Unit is outfitted with eight beds, 12 nurses and three intensivists. And that staffing isn’t per shift – that’s total. Twelve nurses must divide their time for the care of eight pediatric heart patients, 24 hours a day, 365 days a year.

As anyone who has sat by their baby’s bedside in the NICU or PICU can guess, perhaps one of the most heart-wrenching quotes Ying shared came from a father who obviously did not understand that babies are kept unconscious with medication immediately following open heart surgery.

“I felt my spirit was outside my body. We got up 15, 16 times in one night just to stand outside CCU to hear if she was crying.”

Ying explains, “In China, there is no 24-hour parental visitation allowed in the CCU because there is no support for the evidence-based value of bedside parenting attendance.”



One hundred and fifty thousand new cases of CHD are diagnosed per year in China, and pediatric cardiovascular surgeries are increasing at a rate of 10 – 20 per cent per year.

“But staffing isn’t keeping pace,” says Ying.

Cooperative ventures like the one between the Children’s Hospital of Fudan University and the BC Children’s Hospital are improving education and access. As parents of children born with CHD, we can empathize with our brothers and sisters across the globe, and hope that families in China one day enjoy the full privileges of family-centered care we enjoy here.

“Treatment will cost a lot of money, but I can earn more,” says Hui’s mum, adding, “This child will only be in this world once, and since I gave her life, I must be responsible for her ... even if I have to sell my blood.”

2007 Growing Up With Heart Disease Conference

Coming To Vancouver in May

The Sixth Biennial Growing Up With Heart Disease Conference will take place on **May 12 and 13, 2007** at the BC Research Institute for Children's and Women's Health on the site of BC Children's Hospital in Vancouver, BC. This is a collaborative conference for families and professionals by families and professionals and offers exciting and informative sessions on issues related to living with congenital heart disease.

This year's conference will showcase topics that highlight the multidimensional aspects of congenital heart disease. Guest speakers will share their experience and expertise on a wide variety of topics relevant to living with congenital heart disease including advances in fetal cardiac surgery, interventional catheter - valve implantations, cardiac research, understanding diagnostic tests and procedures, medical error reporting, ad-

vocacy, coping strategies, and pain management.

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

Youth with heart disease and their siblings 13 – 19 years of age are invited to participate in the conferences Youth Forum. This active and growing component of the conference is packed full of fun.

Qualified early childcare educators and assistants will provide care for children from infants to 5 years and a Children's Program for children 6-13 years. The child care centre is located at the adjacent GF Strong Building. Lunches and snacks will be provided. Infants in arms are welcome during the conference.

Co-chairs for this event are Colleen Corder, Provincial Coordinator of the Children's Heart Network and Mary Spencer, Clinical Nurse Specialist at the BC Children's Hospital. Registration can be completed online, at www.childrensheartnetwork.org/conferences.asp

or by contacting **Colleen Corder** at 1-877-833-1773, or by email: chn@childrensheartnetwork.org

Heart Beats highly recommends this excellent conference! Contact us if you have questions about how we may support your attendance.



Vancouver is a safe and cosmopolitan city nestled between the Pacific Ocean and the hovering peaks of the Coastal Mountains. The Growing Up With Heart Disease: Together We Can! conference is held on the site of the Children's and Women's Health Centre, minutes from beautiful downtown Vancouver and 20 minutes from the airport. For a detailed listing of accommodations and attractions in the conference area contact Tourism British Columbia at 1-800-663-6000.

Western Canadian Children's Heart Network

On behalf of the Heart Beats Children's Society of Calgary, and all the families we serve, Tracey Contrada and Heidi Smethurst volunteer as liaisons with the Western Canadian Children's Heart Network, a network of professionals and families in Manitoba, Saskatchewan, Alberta and British Columbia.

During the course of 2006 the WCCHN Family Advisory Committee's initiatives included the investigation of federal and provincial support options for out-of-province care for families. This initiative is currently ongoing and results and information will be updated on the WCCHN website (www.westernchildrensheartnetwork.com) under Resources and Links - Financial Support.

"In our research, we discovered that most families are not aware of what support they can access," says Tracey, adding, "Families should make sure they check the WCCHN site regularly."

(Continued on page 6)

Heart Beats Introduces Care Pages

Heart Beats is thrilled to be offering a new, free service to families living with CHD!

"CarePages are a proven way to help healthcare providers deliver better care for patients and their families and friends by supporting their emotional and spiritual needs," says Sara Freire of TLContact Inc., makers of CarePages.

Caring for a child with a congenital heart defect can be challenging and stressful. Being in hospital, going through surgery, or caring for special needs at home can be very wearing. During these times the concern and support of family and friends is so appreciated, yet it can also add to your already heavy load when you are inundated with phone calls and e-mails from them. CarePages provides a free, private avenue for you and your loved ones to stay in touch and keep updated on your child's progress. Using easy, step-by-step online instructions and a Member Name you create, you invite family and friends to your individualized, private CarePage and they select a password that's unique to them. It's a secure service.

If you've experienced a stay at the Stollery Children's Hospital in Edmonton in recent years, you may already be familiar with CarePages, as this is a service that Stollery has offered for years.

"Adding CarePages to heartbeats.ca is an important step forward in responding to the changing needs of our community," says Cindy Bablitz, Heart Beats' Communications Director.

Patty Wiebe, co-chairperson and secretary with Heart Beats adds, "Our daughter Isabelle has had three open heart surgeries. In preparation for her third surgery, we received infor-

mation from the Stollery Children's Hospital about CarePages."

Using CarePages, you can post updates and upload digital pictures and your family and friends can, if they choose, post notes back to you.

"I am far from being computer savvy, but I found it easy to set up and use," says Patty.

"We also found it to be very supportive to us, as we were able to "tell the story" only once, rather than repeat it over and over to individual people. Also, it was so encouraging to read the messages from people while we were in the hospital with Isabelle."

"And," Patty adds, "Many of our family members and friends said they



thought it was great because they were able to find out how things were going without feeling like they were pestering us with phone calls or e-mails."

CarePages is currently being installed as a service on www.heartbeats.ca and should be operational by February.

"Having been through surgeries with Isabelle both with and without CarePages, I highly recommend using them to keep in touch with caring family and friends," says Patty.

(Continued from page 5)

WCCHN

A Family Centered Care Conference will be held in Calgary April 29 - May 1, 2007. The purpose of the conference is to bring parents, professionals, policy makers, and researchers together to develop a common understanding of family centered care and how it can be adapted within a variety of settings. This common understanding will contribute to more consistent and collaborative approaches to care, ultimately improving the experience and outcomes for children and youth. This goal is aligned with interest in health regions to adopt a more family centered approach, as well as with the family centered focus of the new Family Support for Children with Disabilities Act. For more information or to register, please visit:

<http://www.sacyhn.ca/pages/fccbackground.html>

The WCCHN'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. We also advocate for high quality pediatric cardiac care throughout the four western provinces.

Off Beats

We have had a good fall with Off Beats, welcoming everyone back in September with our last gathering at the "old" Children's hospital. We welcomed Laura Thurber-Larsen to our group. She is the new social worker taking over from Gaye Hopkins for the Cardiology Clinic and will join Kelly in planning group activities.

In October we had an excellent tour of the new Alberta Children's Hospital site. ICU and ER charge nurses took us behind the scenes for an interesting perspective on places we've been ...

Last June we enjoyed a year end gathering at Fire Escape. We said good bye to our good friend Jared, who has transitioned into adult care. We also said good bye to Gaye Hopkins who has worked and played with us in Off Beats for years.

"We miss them both and wish them well," says Kelly Webber, Cardiology Clinic nurse and Off Beats co-coordinator.

In November we went bowling. Again this year the competition was fierce! In two teams of four we played three games.

In December we made gingerbread houses for the Cardiology clinic and Unit 2. Kelly joined the boys, Vittorio, Sam and Kyle, while the girls Laura, Ginelle and Melanie tried to outdo the boys in their decorating techniques.

"But the boys would not be outdone!" laughs Kelly, "And took their job very seriously. In the end, two great houses were decorated and lots of laughs were had."

The new year is going to bring lots of fun events. In February we will celebrate congenital heart month with a pizza party, and we hope to once again take in a Flames game!

Off Beats is a peer group for teens and tweens living with congenital heart defects. For more information about upcoming activities, or to find out how you can help, contact Kelly at 943-7316 or Kelly.Webber@CalgaryHealthRegion.ca or Laura Thurber-Larsen at 943-7778 or Laura.Thurber-Larsen@CalgaryHealthRegion.ca.

Heart to Heart

Heart to Heart is an opportunity for parents of children of all ages to come together and share their experience of living with CHD.

Fridays, January 12, February 9, March 9
at 10:00 am

at the home of Patty Wiebe
43 Midvalley Crescent SE

For more information, contact Patty Wiebe at 256-7423 or pattywiebe@shaw.ca

If you would like to attend "Heart to Heart" but are unable to attend on Friday mornings, please contact Patty to discuss alternate days that would work for you.

Mom & Tots

Mom & Tots will celebrate our fifth annual Heart Day get together:

February 14, 6:00 pm at
Boston Pizza, 130th Ave.

"This will be a family affair and we look forward to seeing everyone!" says Angie Enslow.

In March, we'll gather:

Saturday, March 17, 11:00 am
Calgary Zoo, north entrance, by the C-Train

For more information about Mom & Tots, and upcoming activities, contact Angie Enslow at 251-3989 or zoe1st@telus.net.



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.

Co-Chairperson	Jeannine Oliphant 289-4329
Co-Chairperson and Secretary	Patty Wiebe 256-7423
Treasurer	Sylvia Falk
Fundraising Director	Tracey Contrada
Communications Director	Cindy Bablitz 201-4889 cindy.bablitz@telusplanet.net
Nurse Liaison	Patty Knox (yup, she's back!)
Additional Directors	Heidi Smethurst Olana Thomson
.....	
Off Beats Coordinators	Kelly Webber Kelly.Webber@CalgaryHealthRegion.ca Laura Thurber-Larsen
Mom & Tots Coordinator	Angie Enslow 251-3989
Heart to Heart Coordinator	Patty Wiebe pattywiebe@shaw.ca

Box 30233 Chinook Postal Outlet Calgary, AB T2H 2V9

Volunteers Urgently Needed

In 2007, Heart Beats celebrates 20 years of service, support, community and compassion. We can only guess how many children and their families have accessed information, financial and emotional support and encouragement by the dozens of volunteers that have kept Heart Beats beating through two decades.

A very small roster of active volunteers is currently looking forward to envision our role as advocates and service providers through the next decade. We have dreams of a legacy project.

However, the bottom line is that we cannot do it without you.

Simply producing this newsletter is a time-intensive process feeling increasingly burdensome to this multi-tasking editor!

Please come forward with your offer of help. If Heart Beats is to celebrate the anniversary of another decade, it is critical that more volunteers get involved. We know there is a need for the services and support we generate. We've appreciated the heartfelt gratitude of those families we've helped. And we know that time is a limited resource, for all of us.

Still.

We welcome your input.

Beat The Drum Slowly

an editorial by cindy bablitz

One day I was crying.

"One thing I can tell about you mommy is that whenever someone is sad, your spirit is spread and it helps them; and that you're very caring."

My heart babe, now seven, sat beside me and comforted me.

"And without you there wouldn't be a world. There wouldn't be a creature, there wouldn't be a house, there wouldn't be an egg, or a tree. Without you, there wouldn't even be a solar system, or stars; just a black, blank sky. Just blank everywhere. This is something you don't even know about yourself."

I found his outpouring of compassionate insight so compelling we went to the computer and wrote down his precise words immediately.

A few weeks later, Deepak Chopra was in town, and I went to listen. In the eloquent, studied way he has of

delivering information, Deepak listed the names of renowned theologians, philosophers, scientists, all world leaders in their specialties, who have gathered recently to discuss the nature of God. Arising out of this forum, (which, as you can imagine generated more questions than answers) grew a list of five characteristics that all present agreed comprised universally agreeable attributes of God.

The fifth has to do with the "observer influence". Deepak explained the way our human observation of divine mystery affects outcome.

"If you weren't here, there would be no Universe," Deepak said.

When my first son was born with a heart defect, I sent out a letter to all of our family, friends and acquaintances inviting them to pray, meditate, hope for his healing.

"We believe the hole in Noah's heart was held open by God as a special chamber to be filled early in his life consciously and purposefully with love and strength and energy to be held in reserve for all of his life," I wrote.

As I sat and listened to one of the world's best known and widely respected leaders in the field of mind/body medicine articulate in eloquent, scientific terms what my son had articulated in spontaneous, compassionate terms earlier in the month, I knew in an instant that our innocent appeal seven years ago had borne fruit.

From the time our heart babe began uttering his first words, he's been stopping us cold with insight and wisdom that transcends his age, and we are grateful observers.

