



Keeping The Beat

Heart Beats - Children's Society of Calgary

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

Building Bridges to Tomorrow Series

by Cindy Bablitz

On May 15 and 16, in Winnipeg, Manitoba, the Variety Children's Heart Centre in conjunction with the Circle

of Hearts Family Support Network hosted a collaborative conference for families and professionals in the care community of children born with congenital heart disease. Calgary's own Dr. Joyce Harder and Patty Knox were featured presenters at the conference — as were Dr. Ivan Rebeyka, Dr. Dylan Taylor and Dr. David Ross, all from the University of Alberta Hospital in Edmonton.

This was the first pediatric heart conference hosted in Winnipeg and it marked a definitive turning point for the centre which, although founded in 1958, may be most known for a 12

month period beginning in February 1994.

"During those twelve months, 75 patients were treated at the centre, and 12 died," explained Dr. Reeni Soni, section head of pediatric cardiology at Winnipeg Children's Hospital since September 2000.

In February 1995, the pediatric cardiology program in Winnipeg was shut down, and what became the longest and most expensive medical inquest in Canadian history — \$14 million — was launched by judge Murray Sinclair.

"Out of that inquest, numerous system-wide recommendations were made to improve patient treatment, family support and "whistle blowing" legislation," explained Dr. Soni.

Today, the Variety Children's Heart

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At the end of the Building Bridges to Tomorrow conference, a "hearty" group of children living with CHD paraded into the room carrying dozens of helium-filled red heart-shaped balloons.

Hot Fun in the Summer Sun

by Patty Wiebe

On Saturday, June 26, five Heart Beats families met at the Southland Leisure Centre for fun in the waves and the water-slides. The group in-

cluded new families and "veterans". A number of other families would have joined us, but, due to surgery or early summer vacation plans, were unable to attend. Still,

feedback about a family outing at Southland Leisure Centre was very positive, and we will plan another outing there in the future.

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Building Bridges to Tomorrow Series

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Centre is a contributing member of the Western Canadian Children's Health Network (WCCHN) — one cooperative program which is a by-product of the unfortunate period in Winnipeg's heart centre history.

The WCCHN provides a vehicle for



ACH's Patty Knox offers a presentation on building a cardiac youth group at the Building Bridges conference.

members of the professional care team of children living with congenital heart disease to be in weekly teleconferencing consultation with other pediatric cardiology professionals in Canada.

"The WCCHN is the first program in Canadian history that spans provincial boundaries in cooperation and collaboration, creating transparency in health care service providing as well as important education opportunities," says Dr. Soni.

Fourteen conference sessions over two days featured a diverse range of presenters covering a diverse range of information — from the newest advances being made in pediatric cardiovascular and transplant surgery, to helping siblings of children with CHD cope.

In his closing remarks, Social Worker Garry Robinson said, "For many years we were known for many negative reasons, but in the past few years we've been turning a corner. I believe this weekend we completed that U-turn."

Several presenters honoured Dr. Walter Lillehei who, on March 26, 1954,

conducted the world's first cardiovascular surgery, employing an innovative technique called "cross-circulation". Dr. Lillehei's patient, ten year old Gregory Gliddon, survived his open heart surgery with the help of his father's circulation system, a milking machine and beer hose tubing!

And, from these archaic and humble beginnings, one presenter speculated mankind may one day eliminate congenital heart defects altogether, employing the use of tiny robots to enter fetal bodies to fix nature's accidents — in utero.

The Building Bridges to Tomorrow conference truly celebrated the sentiment shared in a poignant moment on Sunday afternoon by Garry Robinson.

"It is my belief that people who are brought together in care and compassion for children born with sick hearts create stronger bonds."

In coming issues, watch for the Building Bridges series, which will highlight important and interesting information from the Building Bridges to Tomorrow: Growing Up With Heart Disease conference.

Hot Fun in the Summer Sun

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Our next family get together is planned for Saturday, August 21 at Midnapore Lake. We will meet at 3:00pm for fun in the lake, playgrounds and tennis courts. We will also enjoy a potluck barbecue and picnic. If the weather foils our plans to be at the lake, we will meet at the home of Colin and Patty Wiebe who

live in Midnapore.

This event is open to ALL families of "heart" children — and newcomers are especially welcome!



Please let us know by August 14 if you plan to join us, so that we can have your name on the list for entrance into Midnapore Lake. You may contact either Patty Wiebe at 256-7423 or pattywiebe@shaw.ca or Michele Maurette at 251-2446 or mmaurette@shaw.ca.



Mom & Tots

Heart Beats' Mom & Tots group continues gathering regularly, with new faces showing up monthly! This is good news for the life of this group, and for the moms and their children who find support among a group of new friends who share the common bond of congenital heart defects.

May, June and July gatherings at the zoo, Heritage Park and Butterfield Acres were each attended by a good group of moms and their young children.

"Our gathering for June was shaping up to be a good-sized group but our plans became thwarted by

illness and injury — including vomiting and falling out of a bunk bed, as I recall!" laments Patty Wiebe.

(We hope you feel better!)

Mom & Tots have scheduled a family barbecue at Lake Chapparel for Saturday, August 28 at 11:00 a.m. To confirm your attendance, please call Angie Enslow at 251-3989. A get together is also scheduled for September 20, although what and where is yet to be confirmed. If you have an idea, or would like to host a group of moms and tots at your home, call Angie. For more information about upcoming activities, contact either Angie or Patty Wiebe at 256-7423.

It's Time To Renew Your Heart Beats Membership!

Parents Names (first and last)

Street Address

City, Province, Postal Code

Phone

Work / Cell Phone

E-mail

Child's Name and Birthdate (day/month/year)

Description / Name of Congenital Heart Defect

Siblings and Birthdates (day/month/year)

- I have included my \$15 membership fee
- Please just add me to the Keeping The Beat mailing list
- I am enclosing an additional donation of _____

Charitable registration number: 88907 6261 RR0001

The Alberta Freedom of Information and Protection of Privacy Act legislates your confidentiality. From time to time, Heart Beats receives requests from parents who wish to be connected with other families dealing with similar heart defects. If you do not wish your name to be included on our parent referral list, please check this box.

If you do want your name included on the Heart Beats parent referral list, please sign here.

signature

Please cut out this form and mail to:
Heart Beats Children's Society of Calgary
Box 30233, Chinook Postal Outlet
Calgary, AB T2H 2V9

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
Librarian VACANT
Website Administrator Michele & Andrew Maurette
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
Patty Knox (Off Beats) 943-7316
Angie Enslow (Mom & Tots) 251-3989

Off Beats

The Off Beats group met for the last time before summer on May 12, at the UofC Campus Cove where they played video and computer games and billiards. The Cove was closed specially for the Off Beats group, who had a great time! A planned family barbecue in June conflicted with year end finals and school activities and unfortunately had to be canceled.

"We'll have to remember to schedule our June event earlier next year, before school obligations get in the way of our fun!" laughs Patty Knox.

Off Beats is on a summer hiatus, with plans to reconvene in September.

For more information about Off Beats, or, to learn how you can lend your support, phone Patty at 943-7316.

Beat The Drum Slowly

an editorial by cindy bablitz

In a bit of karmic irony, my two-legged tornado, the child without CHD, fell against a metal railing and split his head open days after I lamented in this column that my second son needs me less than did my first one. Finally! My little independent spirit needed me! What joy! What bliss! Not.

As I swung around the corner to the screams of two young boys, taking in the blood covered face of one and the panic covered face of the other, I knew in an instant I was a darn fool to think that facing a major medical emergency somehow elevated the communion between a mother and her child. My lion-hearted conviction to advocate for my child's care — and my compassion for his pain — was as fierce in service to my son needing a few stitches as during the days of my first son's open heart surgery. (What

do you mean my son has to wait to see a doctor?! How much longer do you expect him to suffer and bleed?!)

And then, with one boy's scar still red and swollen, my careful son, the one *with* CHD, had the unfortunate timing of finding himself in the arc of a swinging baseball bat. Off we returned to the Children's Hospital with a lip split neatly in two, as though it had been carefully snipped with a scissor. Again, a hapless triage nurse had to deal with the disgust of a mother who, yes, it's true, didn't care if there were children having respiratory problems, but demanded to know just how much longer was her suffering child expected to wait?!

I am still new at this mothering gig. Apparently. A more seasoned veteran would never have looked the gift horse of a healthy child in the mouth.

So again I am reminded to choose my words wisely. To be sparing with them, even. It was foolish of me to tempt fate with the selfish murmurings of a caregiver wishing to be needed to give care.

To be a mother is to be given one of life's greatest gifts. I have learned, to be a mother of a child with compromised health is a gift all unto its own. And now, I appreciate that to be a mother of a healthy child is to be no less needed, no less significant, no less a gift.

Lord, let me remember these lessons I reluctantly learn.

