



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 Series: A Focus On Adolescence

by Cindy Bablitz

As parents of children born with congenital heart defects, we perhaps have come to surprise ourselves with the depth and breadth of our medical knowledge as pertains to the heart

organ. As parents of children moving through the adolescent years, our challenges compound as we continue dealing with medical realities while our children are dealing with a growing awareness of and interaction with, a life of increasing opportunity and accountability.

cardiology clinic nurse clinician Patty Knox discussed the ways a peer-centered cardiac youth group — like Off Beats — can support self confidence, esteem and self-image for teenagers living with the unique life experiences inherent in being born with a CHD.



At the Building Bridges to Tomorrow conference held last May in Winnipeg, several presenters discussed the phenomena of helping children transition out of their childhood, through adolescence and into adulthood. Alberta Children's Hospital's own

"Adolescence is a time when people are really trying to develop who they are, and what they're about," says Patty.

"And," she says, "Some kids are really open about their CHD, saying, 'this sucks!' while other kids think, 'God forbid anyone should find out there's

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An Executive Decision

We've made an executive decision. It's a risky move, and we who comprise the executive of Heart Beats are not in unanimous agreement with this decision. And, you who comprise the community we serve will need to buy into the idea, literally, in order to make this decision work, and to sustain the life of Heart

Beats for the long run.

We've decided to eliminate membership fees. Instead, we hereby offer a standing invitation for you to support Heart Beats with your charitable givings.

Let us explain the history that led to — and the implications of making — this decision.

Every year, beginning in March, we devote space in Keeping The Beat to membership renewal. Since our founding year in 1987, the numbers of new and renewed memberships annually have fluctuated up and down, but this year, we've only heard from about a dozen of you. At the

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You Are Invited to Another Family Event!

by Patty Wiebe

Fellowship opportunities for families of children living with CHD continue being a popular request! We last met on Saturday, August 21st, with five families, (including ten children) meeting at Midnapore Lake. While rain altered our plans, (we all ended up bundling our things together and relocating to our home) it did not dampen our spirits! The children, ranging in age from one to ten, had a lot of fun together, and we parents capitalized on the opportunity to get to know each other better and to share experiences and insights.

Our next family outing is planned for Saturday, November 6, from 3:00 to 5:00 p.m. Whether or not you've ever taken part in a Heart Beats activity in the past, you are welcome — and encouraged — to attend! There is so much wisdom, insight and perspective to be gained in fellowship with others who live with the day-to-day reality of congenital heart disease!

On November 6th, we'll be meeting at Mountain View Bowl, located at #11, 3919 Richmond Road S.W. (This is by the Glamorgan Bakery, at 137th Street and Richmond Road.) Bowling will cost \$3.50 per person, per game,

plus shoe rental. If we have a group of more than 20, shoe rental will be free.

We are not permitted to bring food into Mountain View Bowl, so for those who are available and interested in continuing the fun with supper, we'll follow up bowling with McDonald's (or wherever people decide).

Please contact Patty Wiebe at 256-7423 or pattywiebe@shaw.ca or Michele Maurette at 251-2446 or mmaurette@shaw.ca by October 30th, so we can ensure we have enough lanes reserved for everyone.

Youth Advisory Panel Recruiting Youth Members

The Alberta Children's Services Youth Advisory Panel (YAP) is a group



of youth who are selected from across Alberta to provide feedback on proposed recommendations and findings, comment on current initiatives, and

propose improvements or new ideas to enhance the quality of services to youth. YAP's key role is to ensure a solid, youth perspective on all work done by the Youth Secretariat.

The Youth Advisory Panel is currently recruiting new members. Of particular interest are youth, between 16 to 21 years of age, who are familiar with:

- Youth leadership
- The Aboriginal community
- Child protection services
- The youth justice system

- The rural perspective
- Youth with disabilities

This is a unique opportunity to work with others from around the province, and ensure the voice of Alberta's young people is heard in a meaningful and relevant way on issues that impact their lives. If you are interested in joining the panel, visit www.child.gov.ab.ca/whowere/youth/pdf/recruitment.pdf for a recruitment package. October 15th is the published deadline for applications.

Surgery Number Three A Big Success

Sam recently went through his third surgery in Edmonton (on June 21st) and now, at the age of 13, considers himself a pro at this stuff.

Overall, our experience was really positive. Sam had two male nurses during his stay: one in PICU and one on the ward and Sam really liked this. His PICU nurse actually went out during his break and bought Sam a slurpee — which Sam was able to have a

few sips of less than 12 hours post-op. Kind of amazing, eh!

Anyway, I just wanted to extend our heartfelt thanks to Heart Beats for their support over this stressful period. Oh! And thanks of course to the wonderful folks at the Cardiology Clinic as well! Yes, yes, I know I can be a bit trying at times! So, I guess I should also extend a (very) belated apology for my stress-induced periods

of delirium. Sam may have breezed through the surgery, but the anticipatory stress just about did me in!

Thank you! THANK YOU!

Gail MacKean, Bill, Ellen and Sam Brunton

P.S. Sam really loved his Playstation Spiderman game, a gift from Heart Beats. He managed to while away many hours playing the thing during his recovery!

Building Bridges Series: A Focus on Adolescence

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anything wrong with me, or that I had surgery, or that I have to take medication!"

Patty offered encouragement and a voice of experience for conference participants wishing to support their teenagers by developing a youth peer support group, "by and for the kids themselves".

"As adult facilitators, we provide the venue, we develop the framework within which we see the group can best sustain its vitality and we support relationship building by enabling consistent gatherings," says Patty.

"Beyond that, we allow a natural development of peer support by allowing the kids to talk, or not, amongst themselves about whatever topics naturally arise among them."

This concept of enabling self-reliance was reinforced at the conference by Dr. Dylan Taylor, cardiologist and clinical professor of medicine at the University of Alberta.

Dr. Taylor, who was instrumental in developing the Adult Congenital Heart Disease program in Edmonton and who was a founding member of the Canadian Adult Congenital Heart Disease Network says, "Far fewer adults living with CHD are seen in adult CHD clinics than are babies born with, and surviving, CHD."

"Therefore," he adds, "Clearly, patients transitioning from pediatric cardiology clinics into the adult care system are falling between the cracks."

"A transition plan is critical in order to avoid 'crisis transition'."

Characterizing the difference between managing the care of children living with congenital heart defects versus managing the care of adolescents and adults living with CHD, Dr. Taylor noted that kids hate needles, seek independence, want to hold your hand, don't want to take medications, need reminders and need practice while adults ... well, hate needles, seek independence, want a hand to hold, don't want to take medications, need reminders and need practice.

"Therefore," he surmised, "Growth from childhood through adolescence and into adulthood means dealing with the same medical and psychosocial realities while increasing one's independence, taking on new responsibilities and exploring new options."

Supporting your child beyond the scope of pediatric health care means acknowledging certain realities:

- Change is certain
- Managing change helps us all cope
- CHD care is a continuum
- Risk is certain
- The onus is on the patient to manage a successful transition out of pediatric care for successful ongoing care throughout adulthood.

In terms of successfully transitioning medical care of CHD through to adulthood, one conference participant stressed the importance of maintaining your own medical diary.

"Your child's medical file may be up to your knees," said the participant,

"And your child's adult care team will look to you for continuity of history and treatment. Having your own historical record highlighting surgeries, medications and other relevant information may save your child's life."

Other parents and caregivers in attendance concurred, several mentioning their own versions of the 'medical diary', including a 'little black book' and even a laminated business-card-sized medical thumbnail including contact information.

Whether by grand design or by happy coincidence, the real value of attending a heart conference, like Building Bridges to Tomorrow, was evidenced in the collaborative nature of participants sharing their experiences during and between presentations which complemented and expanded on themes relevant — and unique — to caregivers living with the myriad of issues arising from the reality of CHD.

Two full days of presentations were videotaped, and conference planners intend to make these videotapes — complete with the presenters' Power Point productions — available for borrowing. To check on the progress of the Building Bridges videotape series, surf to www.vchc.ca, click on Family Support and then select Announcements.

An Executive Decision

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same time, more of you are asking to be added to the newsletter mailing list and the number of copies we're distributing per issue through the mail and from the clinic is increasing.

The cost to produce and distribute KTB runs around \$1,800 per year.

Heart Beats membership fees, at \$15 per year per family, has generated, in the past, fluctuating annual cash flow ranging from about \$600 to \$1,200. This money, along with charitable donations from a variety of sources, is used in a variety of ways — all which directly impact children and their families living with CHD.

We contribute about \$5,000 annually directly to families in need where the realities of CHD are placing a financial burden. Sometimes this burden is the cost of a child's needed medication where there isn't access to health plan coverage. Sometimes, this burden is the costs associated with traveling to, and staying in, Edmonton for a child's open heart surgery. In the past, Heart Beats has even offered compassionate financial assistance for the funeral costs of a

child who sadly did not survive CHD. Always our support is incredibly discreet and, we trust, discriminately used for its intended purpose by families who truly need it.

Also, Heart Beats provides funding support so that, through Off Beats, our teens and tweens can connect with peers experiencing the similar life issues of adolescence and living with CHD, at little or no cost.

And, in the past, Heart Beats has funded equipment and improvements to the ACH Cardiology Clinic.

The bottom line is that membership fees do not cover the costs of operating Heart Beats. And, more than the financial implications, diminishing membership participation impacts our ongoing vitality.

You might be wondering then, why eliminate membership fees altogether? It's because, while your feedback indicates you appreciate Heart Beats' grass roots service to the community of children born with CHD, by and large, you're not buying into the idea of paying to be a member. At least this year you're not.

So we want to change your terms of

reference in relationship to Heart Beats. We want you to think voluntary charitable giving instead of expected membership fee.

"Opportunity" instead of "obligation".

We invite you to think of Heart Beats at Christmas time, when many families find themselves more in need than at other times of the year.

Maybe think of Heart Beats every year on your child's birthday, or on a surgery anniversary. Maybe you'll think of encouraging your employer to add Heart Beats to its philanthropic list of supported charities.

We need to hear from you. This move is a trial run, and it won't work without your compassionate cooperation. In almost 18 years, we haven't operated without membership fees and, no doubt about it, we won't be around in another 18 years to continue our quiet, but vital, work without you.

You may e-mail your comments to cindy.bablitz@telusplanet.net, or mail them, and your donation, to Box 30233 Chinook Postal Outlet, Calgary, T2H 2V9. All donations to Heart Beats are tax deductible and will be acknowledged with a tax receipt.

Acid Gas Cook-Off Raises Funds for Cardiology Clinic

In the May/June issue of *Keeping The Beat*, we invited you to enjoy a fun day volunteering with the Third Annual Global Acid Gas Chili Cook-Off, which raises funds that are donated to the Cardiology Clinic at the Alberta Children's Hospital. This year, the event, held June 18, raised more than \$30,000 — all of which was directed to the Cardiology Clinic in support of the purchase of a new treadmill stress testing system. (Currently, cardiologists and their patients have limited access to a treadmill stress testing

system located in the Pulmonary Function Lab at ACH.)

Money raised in the cook-off comes from team entrance fees, (corporate teams pay \$1,500 to participate) gate entrance fees, (\$5 per attendee) and beverage and ticket sales. All the chili left over at the end of the day went to the Mustard Seed.

"The event was such a fantastic success, plans

are already underway for a June 17, 2005 chili cook-off to again raise more money for the children using the ACH Cardiology Clinic," says

Ralph Maybaum, president of the Global Acid Gas Chili Cook-Off Foundation of Alberta.

For more information on the Global Acid Gas Chili Cook-Off, or to find out how you can help, contact Ralph Maybaum at 681-2670.



Off Beats

September saw the beginning of another year of fellowship for our Off Beats group. Patty Knox, who, together with Gaye Hopkins has been facilitating the group since its inception — and who stands as a cardiac youth group guru since speaking on the subject at the Building Bridges to Tomorrow heart conference in Winnipeg in May — is taking a year off from leadership of Off Beats to serve the growing demands of her own family and to free up some time for some continuing education herself ... which, we hear, includes guitar lessons! Rock on Patty!

Off Beats welcomed a few new young people at their meeting in September.

"We met at the Children's and made pizzas and played Cranium," says ACH cardiology clinic nurse clinician Kelly Webber, who is stepping into a leadership role aside Gaye Hopkins for Off Beats this year.

"Everyone had fun catching up with old friends after the summer, and we were so pleased to welcome some new friends into the group," she adds.

On October 22, Off Beats will meet at Frank Sissons for a night of bowling and snacks.

For more information about Off Beats, contact Kelly Webber in the Cardiology Clinic at 943-7316.

Mom & Tots

We continue enjoying meeting new families who are joining us for our monthly get togethers. In the past six months we have met five new families! We encourage anyone who is interested in meeting other heart children and parents to give us a call.

On September 20th, we enjoyed a casual gathering at Patty Wiebe's home, and on October 29th, we plan to take in "Boo at the Zoo". The zoo is pre-selling a limited number of tickets per night for this event which runs Oct. 22—30, and we're told tickets will not be available at the gate. So, we're suggesting families (yup, dads and siblings are encouraged to

come join in on the fun!) contact the zoo directly (232-9300) to purchase your tickets.

(Tickets are \$8 per adult and \$6 per child. Season's Pass holders can deduct \$1 per ticket.) Then, contact Angie or Patty to let us know you're coming. We will meet at the north entrance at 5:50 p.m.

November 15th is also scheduled for a Mom & Tots gathering.

For more information on these and other Mom and Tots activities, contact either Angie Enslow at 251-3989 or Patty Wiebe at 256-7423.



Your Feedback

I have been reading your editorials [*Beat The Drum Slowly*] in Keeping The Beat and am always struck by your insight. I finally have decided to tell you how much I appreciate you sharing your thoughts and experiences. You have a talent for expressing what many of us feel and know in our hearts — thank you for the reminders.

As parents of children with special needs, (and I truly believe that *all* children have "special needs") and special gifts, we must use our own unique and special gifts to cope with — and enjoy! — the additional challenges and opportunities that are part of our family life.

God bless you and your family and thank you again for sharing.

Sincerely,

Jackie Schultz

Jackie and her husband Greg live in Calgary with their children Matthew, 10, Emily, 7 — whose supraventricular tachycardia is now well controlled with medication — and their yellow lab Lobo.

Heart Beats

Children's Society of Calgary

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

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We Need You!



There's a saying, you can lead a horse to water, but you can't make it drink. This year, in *Keeping The Beat*, we've been promoting the concept of membership in Heart Beats in a pretty intentional way. We've included your feedback extolling the virtues of Heart Beats, we've written articles highlighting the features and benefits of membership in Heart Beats and we've out and out asked you for your commitment to Heart Beats with membership renewal forms. Still, you're not drinking. So to speak. Check out the article *An Executive Decision* on the front page of this issue, and continued on page four. After 18 years of operating as a 'membership driven' organization, we're inviting you to reframe the way you think about Heart Beats. We're relying on you to help us continue serving our community of children born with congenital heart defects.

Beat The Drum Slowly

an editorial by cindy bablitz

I knew he was the one for me when I was fired from my first post-graduate job. Thoughtful man, he showed up with a consolation gift — a sweatshirt with the word "UNDERACHIEVER" emblazoned boldly above the defiant caricature of Bart Simpson.

He proposed a month later. I, unemployed and asset-less — but for a tin can of a car and my sparkling personality — thought his seemed like a decent offer and I took him up on it. This month we celebrated 13 years of wedded bliss, give or take a dose of bliss now and again.

We've endured a cross-continent move, family of origin crises, (on both sides) a car theft, a home invasion, a botched surgery, organ transplantation, medical malpractice litigation, his getting fired, (hal!) business ownership, business bankruptcy, homelessness, disease, more surgery ... all

before we started making babies.

We are now pregnant with our third. It took five ultrasounds — three by specialists — to observe the left ventricle of the heart.

Oh, how I long for the ignorant bliss of the 90s! Naively unaware that big hair was passé, my curly locks were free to be me. And, equally naively unaware of such a thing as now falls off the tip of my tongue with an acronym, I passed my first pregnancy blissfully oblivious of the CHD diagnosis awaiting us hours after the birth.

That gust of wind that swept through the city last Wednesday was me, exhaling, as the perinatologist assured me, "Now that's a pretty looking heart."

The early surgical renegades who dared venture into one of human anatomy's final frontiers — the sacred seat of a human's very soul —

defied common superstition and outraged their medical colleagues. Thank God they did. How many of our children would have been lost to us if it were not for the death-defying arrogance and bravado of those early surgical pioneers?

Still, I have to admit, there is a part of me — somewhere in the sacred seat of my soul — that longs not to know. Somewhere in me is a longing for innocence, yes, dare I utter it, even for ignorance. I wonder whether it was worth stopping my own heart for three weeks while the specialists sought to see the full function of my new babe's heart.

Had I known, 14 years ago, what lay ahead, I doubt I would have had the courage to say yes. And sometimes, a hearty resounding "yes" is precisely what our souls need to carry on.

