



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 Highlights *by Cindy Bablitz*

Last spring, May 28-29, 2005, the fifth Growing Up With Heart Disease conference was held at the Chan Centre for Family Health Education in Vancouver, B.C.

Although almost a year has passed since the conference, (and life has gotten in the way of my best intentions to share some of the invaluable information and insight brought to light during the conference) so much of the experience of attending a heart conference is timeless, and worth sharing even at this late date.

Growing Up With Heart Disease is touted as a collaborative conference – jointly organized every two years by the Cardiac Sciences Program of the B.C. Children's

Hospital and the Children's Heart Network – for families and professionals by families and professionals of children living with congenital heart defects. 2005's offering included specialists in pediatric cardiac surgery and transplantation, research, feeding, sexual health issues and diagnostics.

By far, the conference highlights were the two keynote speakers. Ying Gu, RN, BScN, head nurse in the Cardiac Intensive Care Unit at Shanghai, China's Children's Hospital of Fudan University offered up a sometimes heart wrenching story of reasons to be grateful to live where we do. Mark Black was billed simply as "speaker, teacher and runner" but in fact he is a heart/lung transplant survivor ... and marathoner ... who has such an incredibly refreshing perspective on life, I'm confident no one leaves the same after hearing Mark speak. I sure didn't.

The theme for 2005's Growing Up With Heart Disease Conference was "Celebrating the Young at Heart." True to theme, Saturday afternoon saw us engaged in a Jeopardy-esque game of "So Smart it Hurts: Pick a Stupid Answer and Get a Stupid Question" created and hosted by the Hearts of Gold Youth Group.

Participants chose from categories as "Broken Record", "Things That Make Me Cringe" and "Silly Questions, Dumb Answers", for

answers like, "Don't fight for space with my stethoscope", (Question: "What is a group of medical students vying for a listen to my heart?") and "If you wear that top your scar will show", (Question: "What is something obvious that people say when I wear a low cut top?").

This group of young people offered a glimpse of lighthearted perspective on what it's like to be a young adult living with CHD.

Said one, "Our life is just like your life ... but it's cooler!"

And, indeed, they shared their dreams for the future which sounded a lot like the dreams of young people without CHD: to become an archeologist, a chef, a scriptwriter, an actress, a 3D video game designer ... They giggled about buying an orange grad dress and bragged about their 3.8 GPA and lit up talking about riding dirt bikes for the past 11 years.

This is the second Congenital Heart Defect Conference I've had the privilege of attending ... and I can't say it strongly enough: no matter what point you are at in the CHD spectrum, attending one of these conferences is so powerful. I strongly encourage you to consider finding a way to attend the next conference, which I would expect to be happening about this time next year.

Watch the next issue of Keeping The Beat for features on keynote speakers Ying Gu and Mark Black.

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A Long View of Support

By Tracey Contrada

At my career planning session last year with my manager Dan Sottile, Vice-President of Long View Systems, an IT solutions provider, I was asked what my interests outside of work were. My initial response was "not many", as I was struggling to maintain that precarious balance between work and life, having just returned to the corporate world after a 9-month maternity leave.

Working 4 days a week, having a 16-month old with congenital heart disease, a husband and a home to manage seemed to be all consuming at the time. I then realized that my life embraced so much more - my friendships, my beliefs and my passions, especially Heart Beats. When this was discovered, Dan immediately responded with asking how Long View could help support me. He stated that as a company Long View needed to do what it could to help me be successful with my life, not just in my career, and that obviously includes helping Heart Beats.

Long View selected the Heart Beats Children's Society of Calgary as the charity to support at its annual Long View golf tournament held at the Glencoe Club last July. The tournament attracted 144 Long View employees, valued clients and manufacturing partners who together raised over \$2,200, and our CEO Don Bialik matched it dollar for dollar for a total of just under \$4,500!

After the tournament, Dan thanked the audience, announced the amount raised and gave a passionate speech describing the Heart Beats mission and why it was the selected charity. He then stated how important it was that Long View not just talk about supporting its employees but actually demonstrate its commitment to them.

Words cannot describe how proud I was at that very moment to work for this company.

Long View is an organization built on four core pillars: Integrity, Competence, Value and Fun. I'd like suggest to Don, Dan and the team at Long View that they need to add a fifth pillar – Heart.

Thank you Long View for your generosity, from me, my family and everyone who is touched by Heart Beats.

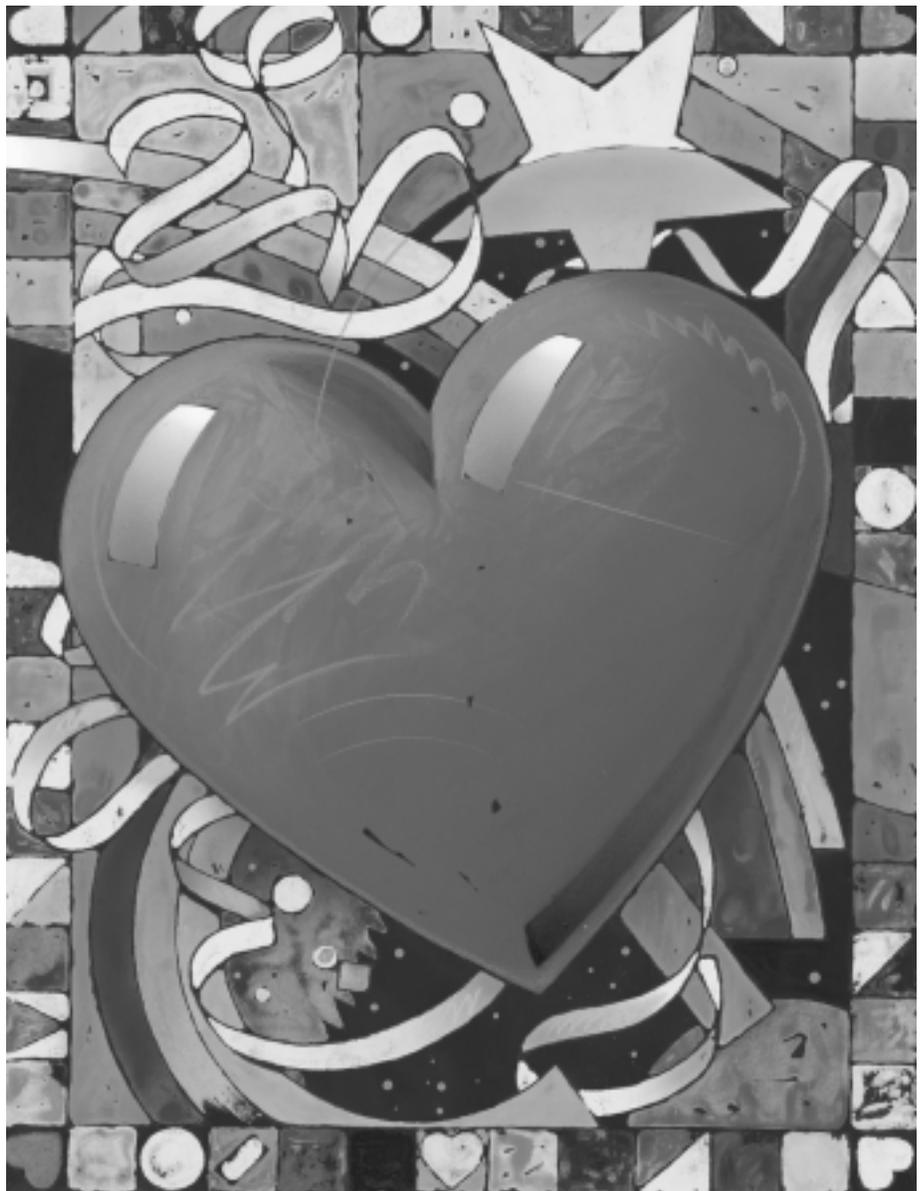
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Welcome Two New Faces to ACH Cardiology Clinic

Laura Thurber-Larsen

They say that all things happen for a reason. And for Laura Thurber-Larsen, filling in at the Cardiology Clinic for a colleague who was recovering at home after a bike accident, gave her a glimpse of where her career was headed.

Laura is the new social worker for the Cardiology Clinic and the Respiratory Home Care Clinic at the Alberta Children's Hospital replacing Gaye Hopkins. Laura started working at the ACH on a casual basis in November 2004 based out of the emergency department. At the time, she also covered a number of different clinics on a casual basis at the ACH and the Foothills Hospital. In January 2005, Laura started a temporary position in the Asthma and Respiratory Home Care clinics.

After cardiorespiratory received additional social work time, a new position was created to cover Cardiology and the Respiratory Home Care Clinic. "I applied for the position as I had been

working in the Respiratory Home Care Clinic and had covered the Cardiology Clinic when Gaye unfortunately had a bike accident and was off work due to an injury," says Laura.

"I was absolutely thrilled when I was offered the position and accepted the offer with much excitement and a bit of nervousness. I came into this position with no knowledge of congenital heart defects but I am learning something new every day and I'm enjoying this new challenge," she adds.

Laura brings to her new position 16 years of social work experience. She has a Bachelor of Social Work degree from the University of Victoria and worked primarily with adolescents and their families in a variety of different settings and roles including in-home counseling, crisis intervention and managing a mental health adolescent treatment centre before coming to the ACH. "The families I have met so far amaze me with their show of strength and

courage in dealing with everything that goes along with having a sick child," says Laura. "My hope in this position is that I can support families to build on the skills and strength that they already have."

"My definition of what a social worker does is very broad - I am available to every family in the clinic and my job is really defined by the family's needs." Some specific examples include advocating, resourcing, and offering financial and emotional support depending on the family's needs.

Laura is married and has two children - a four-year-old daughter and a two-year-old son. She and her husband, who is also in the field, facilitate marriage preparation courses for the United Church. Laura lives with her family on the same piece of land she grew up on southeast of the city.

Norma Becker

After a few years working on a general pediatric unit and special care nursery in Red Deer, Norma Becker is back working in her area of expertise - pediatric cardiology - as the new nurse clinician at the Alberta Children's Hospital Cardiology Clinic.

"I am excited and thrilled to be back in the world of little hearts again!" says Norma. "I have always felt a special place in my heart for these children, and am looking forward to my new role here, serving these families of Southern Alberta."

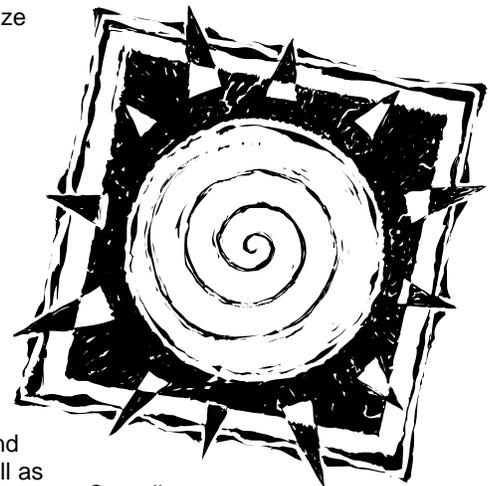
Norma started at the ACH last October after a 13 year career as a nurse clinician in the Cardiac Sciences program at British Columbia's Children's Hospital (BCCH) in Vancouver. She has worked both at the bedside and in the clinic setting, contributed to various educational materials, has been a member of the conference planning committee for the Growing Up With

Heart Disease collaborative conferences and participated in nursing research while at BCCH.

Since her first days as a bedside nurse in pediatric cardiology, Norma has seen many advances and improvements in the medical and surgical care children receive as well as the struggles and challenges families face every day when their children receive a new diagnosis or changes in their condition.

"It is my hope to be the best advocate and offer my support and be a source of education and resources for the families, not only when in times of crisis but on a regular basis when questions and concerns arise," says Norma.

As Norma settles into her new home at ACH, she looks forward to some program development in the nurse's role in areas such as youth transition to adult care. As a member of the Western



Canadian Children's Heart Network, Norma is able to connect with her nursing peers at other pediatric cardiac centres, who work together to develop standards of nursing care for children with heart disease across the West.

"This is an exciting time to be a health care professional in pediatric cardiology," says Norma. "The children and families are the most important part of the nurse's role, with the goal of ensuring their needs are met, in areas such as education and support. I also look forward to working closely with the Heart Beats Children's Society of Calgary."

Gratitude - Attitude - Altitude

By Heather Heywood, Resource Liaison, Family Caregiver Centre

Caring for a child with CHD can be a challenge at times to stay positive. I'd like to show you how I use these three great words - gratitude, attitude and altitude - to keep my negative thoughts in check.

Gratitude is all about being thankful for what we have. Writer Candy Paul says, "Abundance is not how much I own but how much I appreciate." It's important for me to remember that thankfulness is a choice. Being thankful for something in life increases my peace of mind. I recall a time when I was very angry about the death of a loved one. I was full of rage and all kinds of questions about "why?" What helped me through this tough time was realizing I could simply be thankful for the fact that I would now have a better understanding for and empathy with others who experience similar losses.

Attitude is about the feelings we have regarding the details and circumstances of our life. Our attitude can have a lot to do with our emotional health. Researcher Walt Schafer describes emotional wellness habits as ones that include:

- awareness regarding one's feelings or emotions at any given time;
- the ability to maintain a somewhat even emotional state by way of reasonable emotional responses to life events;
- the ability to keep relative control over emotional states;
- and the ability to experience a prevalence of positive over negative feeling states.

I feel that I am taking care of my emotional well-being whenever I acknowledge my feelings and emotions while working to maintain a somewhat even-tempered state. I also know that I need to strive to develop my attitude of gratitude and other positive thoughts and feelings in order to move to a place where they dominate my thinking and

help me achieve a greater level of emotional wellness.

Altitude deals with how high or low our mood is. Like most people, I prefer emotional highs over emotional lows or depression. Researchers Rude, Valdez, Odom and Ebrahimi report, "It is a well established fact that depressed individuals tend to focus their attention on unhappy and unflattering information to interpret ambiguous information negatively and to hold persistent pessimistic beliefs." With this in mind, I think it is important to consider whether or not my negative beliefs are lowering my emotional altitude. I ask myself am I thinking about and begrudging what I don't have, rather than appreciating what I do have? Am I seeing only what's wrong with me, rather than acknowledging my positive attributes? If so, recognizing that I have the power to stop these negative thoughts and replace them with more positive

thoughts may be helpful in raising my emotional altitude. One good strategy for accomplishing this is to keep a gratitude journal where we document each day the people, situations and things we are thankful for. Developing an attitude of gratitude can help us move to a higher emotional altitude where positive emotions and feelings can dominate our lives.

In conclusion, my gratitude stems from my attitude and my attitude determines my altitude. What I like about all this is the fact that I have it within myself to embrace an attitude of gratitude, which can propel me upwards. And I've also discovered that a grateful heart is a content heart.

-Used with permission from the Calgary Family Caregiver Centre.



Off Beats

Keeping busy is what it's all about when you're a tween or teen and Off Beats is a great way to expend some of that positive energy. At special events and activities throughout the year, this peer group for youth aged 12-17 years living with CHD, lets you connect with other kids who've been there, done that.

In February the group went to Boston Pizza to celebrate Congenital Heart Day. Ten youth turned out to enjoy delicious pizza and great conversation. In March Off Beats was treated to a Flames Game. In true Flames spirit, defenseman Rhett Warrener donated his box called "Warrener's Corner" to us, says Kelly Webber, host. There were plenty of opportunities to cheer in the high scoring match between the Flames and Colorado.

In April, Off Beats had a pizza party and games night at the hospital. If you haven't participated in an Off Beats adventure yet this year, come out and enjoy the last meeting before summer slated for the last Wednesday in May. If anyone is interested in finding out more about Off Beats please call Kelly Webber at 943-7316 or e-mail at kelly.webber@calgaryhealthregion.ca

Mom & Tots

The Mom & Tots group offers support, information and fellowship to families of young children living with CHD. New moms and tots are always welcome to participate in a number of events throughout the year or can simply call for support or information.

On Valentine's Day - proclaimed Heart Day by Mayor Bronconnier, the Mom & Tots Group met at Boston Pizza for its 5th Annual Heart Shaped Pizza party.

"February 14th has been a very important day for all of our 'Heart Families' and we are very lucky to be able to share this day together!" says host Angie Enslow. From every heart-shaped pizza ordered by customers throughout the day, \$1 was donated to the Heart & Stroke Foundation.

A couple of events are planned for the next few months including an outing on Friday, May 26 to the Zoo starting at 11 a.m. and on Friday, June 30 to Lake Chaparral for the afternoon starting at noon. For the Lake Chaparral outing please bring a light lunch or snacks and your own life jackets.

For more information about the Mom & Tots group or planned events please call Angie Enslow at 251-3989 or 835-8605.

Heart Beats Annual Family Event

If you're a kid, can you think of anything better than your own private playground!

Well that's what 38 children experienced during this year's Annual Heart Beats Family Event at Adventure Zone.

"We rented the entire facility so the heart kids and their siblings and friends had free reign of the place - and it looked like everyone had a great time!" said Patty Wiebe, who together with Olana Thomson coordinated the event.

The children explored the treehouse with jungle gyms, had tons of fun in the inflatable jumping room and on the two-storey inflatable slide, practised their climbing skills on the climbing wall, and played arcade games and glow-in-the-dark mini-golf.

"They stayed 'charged up' with pizza and

pop," added Patty.

The annual event had a tremendous turnout with 14 families and 38 children, 17 of which were heart children, ranging in age from 7 months to 13 years old.

During the March 12th event, which ran from 4:30 p.m. to 7:30 p.m., Patty chatted with Sean, the Manager of Adventure Zone. He shared with Patty his staff's uncertainty about what activities to plan for the children because of their heart conditions. But, when the staff saw the kids running around FULL of energy, they asked Sean, "Are you sure they have heart problems?"

While the children played, the parents sat back and enjoyed their children having the time of their lives while having a chance to get to know one another in a fun, casual setting.



"It was great to see a number of new families come out," said Patty. "I enjoyed meeting everyone and hearing their 'heart' stories."

As always, the Heart Beats Annual Family Event is a fun way to meet other families living with CHD and to connect with a dynamic network of support and information.

Thanks to all for taking part in this year's adventure!

HEART BEATS

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.

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- You wish to receive notification – of the newsletter, and other current event updates – with a link to the website sent to your e-mail inbox

Beat the drum slowly

an editorial by Cindy Bablitz

Hi. My name is Cindy and I'm an eagleholic.

In early March, someone sent me a link to a nifty live "Eagle Cam" filming the comings and goings of a pair of bald eagles on B.C.'s Hornby Island. The pair had been observed for some 18 years returning to the same nest, when a neighbour decided to climb the 120 foot cedar tree, 18 feet in circumference at its base, to mount and camouflage a camera before the pair returned to mate and brood this spring.

For our homeschooling family, this seemed a unique, educational opportunity to observe wildlife from the comfort and convenience of home. Over the weeks, the compulsion to peek in on the brooding parents grew, and, as the expected hatching date drew near, I confess, my peeks grew more frequent ... perhaps even to the point of obsessively frequent. After the boys were tucked in bed, I spent more than a few hours mesmerized here behind this monitor growing ever more

awed at the untiring devotion and remarkable communication between these two bald eagles.

You fellow eagleholics – and, as literally millions of people eventually zoomed in, I'm willing to bet there are at least a few among you reading this – already know the outcome of the story. To our collective dismay, first one, then the other egg collapsed beneath the incubating parents as both eggs revealed themselves as undeveloped.

There are a number of theories on why the pair proved infertile this year. It may be that the pair, who have fledged some 15 offspring over the past 19 years, may be too old. It may be that the pair has been rendered infertile due to an accumulated amount of ingested toxins from a polluted diet. But I digress.

What took me quite by surprise was the extent to which I mourned with this pair of bald eagles. It's true: I cried. More than once. In the days after the demise

of the second egg, fellow eagleholics compiled lovely and moving homages set to music, featuring video and still clips of the previous 40 or so days in the life of these two parents who unwittingly connected millions of people all over the world in compassion and daily forum conversations.

My CHD babe, now gangly and almost seven years old, sat on my lap, watching me replay the haunting scene of the father eagle shuddering a cry over his now-empty nest, over and over again. He draped his arm over my shoulder and rubbed my cheek with his other hand, comforting me.

"Mommy, when I get to heaven, I'm going to find those baby eaglets who didn't hatch and I'm going to tell them, their parents were sad, and cried, when they died."

This month, I nod to you bereaved parents who have had to walk a road I'm breathless with gratitude I haven't had to turn down.