



Keeping The Beat

Heart Beats Children's Society of Calgary

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

20th Anniversary Celebrations a Success

On Sunday February 11th, approximately 70 people gathered at the new Alberta Children's Hospital to celebrate the 20th anniversary of the Heart Beats Children's Society of Calgary.

The celebrations included valentine crafts for the young children, tours of the new cardiology clinic and cake for all. It was a day to connect with families who may have gone through similar

experiences. It was also a day for families with older heart children to reminisce.

Two special guests were present at the celebrations, the founders of the Heart Beats Children's Society of Calgary, Anne Lockwood and Pam Francis. Pam and Anne served cake and were honoured by the current Heart Beats executive for creating this lasting legacy.

Photo Below: The 20th Anniversary Celebration took place during Congenital Heart Defect Awareness Week. Seventeen "heart children" were present, ranging in age from two months to young adult. Back Row L to R: Matthew, Kassandra, Emily, Carly, Alysha, Matthew, Courtney, Vittorio and Sam Front Row L to R: Joshua held by Mardi, Isabelle, Mathias, Ryan, Emily and Kirsten held by Jillian

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The Birth of Heart Beats

by Nikki Ballendine

Twenty-one years ago two long time friends, Anne Lockwood and Pam Francis, were each expecting their first babies. It was a wonderful time full of expectations, hopes and dreams. That is until they received the news that both of their children had Congenital Heart Disease (CHD) and they would have to take their babies to Toronto for heart surgery.

While in Toronto, Anne and Pam connected with a parent support group through the hospital that provided the families with valuable resources, information and support. It was a small life line in the midst of chaos. Sadly, once they returned to Calgary the ladies discovered there was no such support available to them here in Calgary. This set the wheels in motion and with the help of Amanda Reid, who was the cardiac nurse at the Alberta Children's Hospital, Anne and Pam founded Heart Beats Children's Society of Calgary in 1987. Twenty years later Heart Beats is still going strong and continues to build a lasting legacy supporting families with CHD!

The goal of Heart Beats remains

unchanged over the last 20 years - to provide information, resources and emotional support to families dealing with congenital heart disease. The approach of Heart Beats has changed a little over the years though. Pam commented that the biggest change has been access to the Internet. She reflects, "The Internet has changed the dynamics of the group as far as how information gets passed



Anne Lockwood (left) and Pam Francis (right), co-founders of Heart Beats Children's Society of Calgary

along and who can access that information." What's encouraging to Pam, though, is that Heart Beats continues to provide a hands-on, face-to-face approach in supporting families dealing with CHD. Talking to another parent whose child has been through a similar procedure as your child and seeing the older child being a 'normal kid' provides hope, understanding and support that cannot be acquired in any other way.

Most parents who deal with CHD will agree that the experience of having a sick child, surgery, medications and other complications will change your life. Having a heart baby is so difficult and affects the whole family. But as Pam said, "something good always comes out of it. There is always a silver lining." Both Pam and Anne said their favourite memory of 20 years of Heart Beats is the wonderful families they have related with because of CHD. They were thrilled to re-connect with so many of these families at the 20th Anniversary Party at the new Alberta Children's Hospital on February 11, 2007.

When the crisis of surgery and recovery is over, when your child is growing well and just being a 'normal kid', many parents feel the need for something to 'sink their teeth into'. The parents currently involved with Heart Beats have found this to be a satisfying way to give back to others and share their experiences. Through Heart-to-Heart parents meet monthly to share their experiences and knowledge with others. Off Beats is an opportunity for teenagers living with CHD to meet once a month during the school year to share, connect and have some fun. This newsletter, 'Keeping the Beat', comes out four times a year and our website, www.heartbeats.ca is updated regularly.

We invite you to come share your knowledge and talents with Heart Beats!

- Nikki Ballendine is the mother of two. Her first child, Emily, now 3, was born with a coarctation of the aorta, multiple ventricular septal defects and an atrial septic defect. ♥



Keeping The Beat By E-Mail

In our efforts to be good stewards of the donations made to Heart Beats, and to make use of the benefits technology can provide, we invite you to receive *Keeping the Beat* by e-mail rather than "snail" mail. Please send us an e-mail at info@heartbeats.ca advising us of your e-mail address, and you will receive future issues of *Keeping the Beat* by e-mail. Thank you for assisting us in this way which will reduce printing and postage costs, and allow us to use these funds to assist heart families in other ways.

Note: E-mail addresses will only be used for distribution of Keeping The Beat or notice of Heart Beats events and will not be given to any third party.

Share Your Story

Do you have a story to tell? Do you want to share your experiences of dealing with Congenital Heart Disease? You may submit your story to the Newsletter Coordinator at karenp@heartbeats.ca Your story may provide the support that someone else needs. We are not alone and we have shared many experiences. Let's support each other.

Share Your Talents and Knowledge

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

However, we cannot do it without you.

Please join us. You may contact any of the executive or join us at our next meeting in September.

2007 Growing Up With Heart Disease Conference

By Heidi Smethurst

On May 12 and 13, 2007 families and professionals gathered at the Child & Family Research Institute on the B.C. Children's Hospital site for the sixth biennial Growing Up With Heart Disease Conference. The collaborative conference proved to be a weekend filled with hope, reassurance, empowerment, encouragement and inspiration. Each day featured one-hour sessions on different issues related to the experience and care of children and youth with congenital heart disease. Some of the highlights included presentations on:

- **The Evolution of Cardiac Surgery**
Doctors Jacques LeBlanc and Martin Hosking spoke about cutting edge techniques that are being used to reduce the risks associated with open heart surgery. 'Hybrid surgical solutions' are being used for both maintenance and repair. They also spoke to the innovations in neonatal cardiac surgery and the possible incorporation of robotic surgery in the future.

- **Heart and Brain Connection**
Pediatric Neurologist, Dr. Stephen Miller

discussed bedside brain monitoring that can be used to understand brain development and injury. This will directly improve the outcomes for high-risk newborns.

- **Building Self-Esteem in Your Child**
Dr. Barbara Rosen, Pediatric Medical Psychologist, discussed self-esteem issues. She illustrated how parents and caregivers can help our children strive to reach their potential and also develop resiliency skills to meet the challenges of chronic illness.

- **'Heart of Gold' - Youth Presentation**
These articulate, creative and energetic youth provided an informative and lively session - as experts living and growing up with congenital heart disease. A younger panel of kids answered questions that we, as parents, would like to ask our kids, but due to age and stage, are unable to get the answers to. Their candour and enthusiasm made me realize how often we underestimate the strength and resiliency of our heart kids.

- **Adults Living With CHD**
A panel of adults, whose journey with

congenital heart disease stretches back over 40 years, closed the circle with their experience on how to live life to its fullest.

- **Bring MELLOW Into Your Life**
Dr. Martin Collins inspired us all to incorporate MELLOW (Mind, Exercise, Love, Laughter, Optimal Nutrition, and Wonder) to achieve a high level of personal and professional performance.

The conference was very informative, entertaining and enjoyable. The organizers ensured that everyone felt welcome and comfortable. A daycare was available for families with young children, and we were well fed and watered!

The next family conference is tentatively scheduled for Spring 2008 in Winnipeg. The next B.C. conference is scheduled for Spring 2009.

- Heidi Smethurst is a mother of four. Her third child, Ryan (8), had his open heart surgery for TGA/VSD done at the B.C. Children's Hospital. ♥

Your Support in Action

by Patty Wiebe

Your donations to the Heart Beats Children's Society of Calgary provide information, resources and support to families dealing with congenital heart defects. Your donations have provided:

- 'Heart and Soul: Your Guide to Living With Heart Disease' information binders to families (distributed through the Cardiology Clinic).
- Financial assistance to families having difficulties meeting expenses related to their child's heart defect.
- Toys and supplemental equipment for the Alberta Children's Hospital Cardiology Clinic. (See page 4 for details regarding the latest purchase.)

We appreciate and acknowledge the donations received from the following individuals and organizations from January through May 2007:

- Jasmin Craig & Michelle Robertson, in honour of Ava Contrada's 3rd birthday

- Donna & Michael Gerlinsky
- Isabelle Wiebe's Kindergarten classmates - Matthew, Michaela, Jordan, Zachary, Jillian, Meghan, Ellen and Michael, and neighbours - Jaden, Mackenzie and Zack, in honour of Isabelle's 6th birthday.
- United Way of Calgary, Donor Choice program
- The Watson Family Foundation at The Calgary Foundation.

If you wish to contribute to the support of families of children with congenital heart defects, you may mail your donation to:

Heart Beats Children's Society of Calgary
Box 30233, Chinook Postal Outlet
Calgary, AB T2H 2V9

We are also finalizing arrangements for donations to be received online at www.heartbeats.ca where you will be

able to make secure donations by credit card. We anticipate this will be operational by mid-June 2007.



Cardiology Clinic News

Heart Beats Donation Enhances Patient Experience

If your child has recently been to the Alberta Children's Hospital Cardiology Clinic for an ECG or an echocardiogram, you have likely seen the new "lava lamps" in action. In response to a request by the Cardiology Clinic, Heart Beats donated three Calming Devices. These Calming Devices project images onto the wall or ceiling, much like a kaleidoscope. The images help keep patients' attention during ECGs and echocardiograms allowing for a more relaxed experience resulting in more effective tests. Dr. Joyce Harder expressed her appreciation to Heart Beats in the following letter.

"We are very excited with the recent installation of the 'lava lamps' in the ECG room and in the two echo rooms. For those of you who have not seen this modern technology, it is the projection of multiple lights and shapes on the wall in ever changing colors and patterns. They are absolutely fascinating to watch, even for an adult. For the little babies and the smaller

toddlers, this is just ideal as it manages to keep their attention during the time that the ECG or the echo is performed. It doesn't work for everybody, but it certainly helps with the quality of the studies. This was not a small expenditure, and it is not easy to have the Calgary Health Region pay for such luxuries! We are very grateful for the ongoing support of Heart Beats as we try to provide the best quality care possible for kids with heart problems."

*Yours sincerely,
Joyce Harder, M.D., F.R.C.P (C)
Division Head
Pediatric Cardiologist*

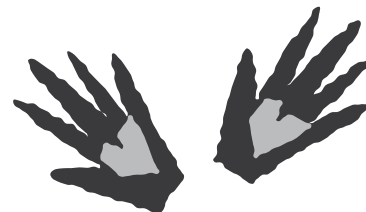
Welcome Back!

Sandy Taylor, our Echocardiogram Technician, has returned after her maternity leave. Sandy has spent the past year with her baby boy, Brandon. Welcome Back, Sandy.

Pacemaker Clinic to Come to the Alberta Children's Hospital

Currently, children with pacemakers go to the Foothills Hospital for their routine check-ups and adjustments. In the fall of 2007, the Pacemaker Clinic will begin monthly clinics at the Alberta Children's Hospital. This will enable the children to be seen in a more comfortable, child-centred environment.

In the Fall of 2008, the Cardiology Clinic will welcome a new Cardiologist. She is currently completing her Fellowship with a special interest in heart rhythms. Upon her arrival at the Cardiology Clinic, she will coordinate the monthly pacemaker clinic. Stay tuned to future issues of *Keeping the Beat* for more information about this new addition to the Cardiology Clinic. ♥



Western Canadian Children's Heart Network

The Western Canadian Children's Heart Network (WCCHN) is a network of pediatric cardiac care providers from the four western provinces - British Columbia, Alberta, Saskatchewan, and Manitoba. The Network'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. They also advocate for high quality pediatric cardiac care throughout the four western provinces.

The WCCHN distributed a Family Satisfaction Survey in 2005 to 590 parents whose child had a cardiac

procedure done in one of the two surgical centres of the WCCHN (BC Children's in Vancouver or Stollery Children's in Edmonton). The purpose of this study was to assess the family satisfaction with the care provided before, during and after a pediatric cardiac procedure, to identify areas for improvement, and to evaluate how effective family supports are within the WCCHN. A summary of the results of this survey is now available at www.westernchildrensheartnetwork.ca.

In response to input from families about their experience with the Pre-Admission Clinic at the Stollery Children's Hospital, the WCCHN

produced a DVD that informs parents and children of the Pre-Admission Clinic process. Heart Beats contributed to the cost of producing this DVD.

The WCCHN is currently looking into the issue of the costs incurred by families to travel to Edmonton or Vancouver for heart surgery, and the availability or, more often, lack of government assistance for these costs. The WCCHN wants to hear from families about the costs they have incurred for travel for heart surgery. Please contact Sharon Chow, WCCHN Coordinator, by phone (780) 407-1522 or e-mail wcchn@cha.ab.ca. ♥

Off Beats

Off Beats is a fun, activity-based group for youth aged 12-17, offering peer-to-peer support and friendship.

Off Beats has had a great year! We started the year by saying good-bye to the old hospital site and at our next meeting we toured the new Alberta Children's Hospital. We have enjoyed fun activities such as bowling, pizza parties and even enjoyed watching a Calgary Flames game in the Mega box at the Saddledome.

Christmas brought a competitive gingerbread house building competition:

Kelly and the boys versus Laura and the girls. Both gingerbread houses turned out great and were proudly displayed in the Cardiology Clinic and Unit 2 at the Alberta Children's Hospital.

Last month we painted pottery at Fire Escape. We have some very artistic kids in the group and their pottery looks great!

June is our final meeting before we break for the summer. We will be meeting at the Alberta Children's Hospital on Tuesday June 5th for a wind up party and to say goodbye to some dear friends. Tiffany and Vittorio, who have been members of

Off Beats since it began, will be leaving us as they are turning 18. We wish them well, but will miss their positive energy and constant chatter that they bring to the group every month.

Off Beats will resume in September. We invite all youth between the ages of 12 and 17, living with congenital heart defects, to join us. For more information, please call Kelly Webber at 955-7316 or Laura Thurber-Larsen at 955-7888.

We wish everyone a safe and fun summer.♥

Heart Beats & CarePages Partner to Benefit Heart Families

Heart Beats is pleased to offer CarePages to the Heart Beats community. CarePages are free, private, personalized Web pages available to patients and families that help you stay in touch while dealing with a healthcare issue.

The service allows you control over communication and provides an easy way for friends and loved ones to respond with messages of support. You can share updates, photos and contact information when the time is right for you. Friends and loved ones can then visit your CarePage to be kept up-to-date and to provide you with emotional support.

CarePages let patients and families:

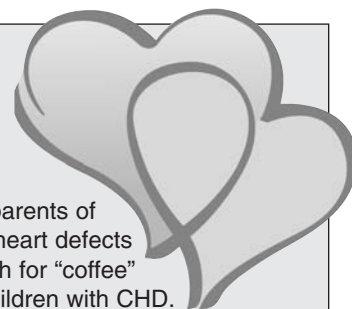
- Update everyone at the same time without repeated phone calls or emails
- Create a web page that is private and not open to the general public
- Create web pages that they can update themselves
- Receive messages of support from family and friends

CarePages are fully secure, password protected and comply with all patient privacy regulations.

For the next two months, CarePages will donate \$10 per active CarePage which is created through Heart Beats' CarePage website at www.carepages.com/heartbeats. Should you require help in setting up a CarePage, please contact support@carepages.com or by calling 1-888-852-5521, Monday through Friday from 8 a.m. to 6 p.m., Central time.

To create or access CarePages, visit www.carepages.com/heartbeats or visit www.heartbeats.ca and click on the CarePages icon.♥

Heart to Heart



Heart to Heart is a group for parents of children born with congenital heart defects (CHD). We meet once a month for "coffee" and a chat about parenting children with CHD. Heart to Heart is open to parents of children of all ages - from infants to teenagers. Parents with children at home are welcome to bring them.

Come join us to meet other parents, to ask questions about caring for and raising children with CHD, and to share your knowledge and experience with others.

In June we are meeting at the home of Jennifer Keane MacKinnon on Tuesday, June 19th at 10 a.m. at 233 Midridge Crescent SE.

In July we are meeting at Midnapore Lake on Wednesday, July 25th at 10 a.m. Please note that if you are able to come, contact Patty Wiebe at pattyw@heartbeats.ca or 256-7423 as she must provide your name to the Lake Staff so you can be admitted.

In August we are meeting at the home of Karen Perl-Pollard on Thursday, August 23rd at 10 a.m. at 69 Harvest Creek Close NE.

In September we are meeting at the home of Patty Wiebe on Friday, September 14th at 10 a.m. at 43 Midvalley Crescent SE.

We look forward to having you join us!

For more information, contact Patty Wiebe at pattyw@heartbeats.ca or 256-7423. ♥

Thank You for 'Keeping the Beat'

After almost four years of service to Heart Beats, Cindy Bablitz has stepped down as editor of our Newsletter, Keeping the Beat. We are grateful for the time, expertise, and passion she put into Keeping the Beat during her time as editor. We are pleased that she will continue to contribute "Beat the Drum Slowly".

Beat The Drum Slowly

By Cindy Bablitz

A terrible, horrible thing has happened. The data recovery specialists, whose efforts were mostly unsuccessful, called it a "spontaneous mainframe implosion." I woke up one morning and, without warning or circumstance, my relatively new PC just wouldn't boot up.

For many years, my computer has been the hub around which my day has begun and ended. A quick pop in in the morning to check e-mails. A last peek before bedtime to read any new contributions to my online discussion groups. I'll suspend comment on whether or not this learned attachment to virtual connections with people has been an entirely healthy trend. I do all my banking online. Six months ago I converted a two decade habit of paper DayTimers to an electronic Palm Pilot. My computer has become my electronic shoebox, with all of our family photos from the past year and a half stored in pixels mysteriously inside this little grey laptop -- while I completed all of the requisite photo editing digital photography now allows before printing en masse.

I am a writer by profession and passion, and I am still moved to cringing tears when I remember bits and pieces of the journaling, missives and random, unfinished digital scraps of story ideas that are now irretrievably lost.

A year and a half and hundreds and hundreds of hours of my effort were rendered nothing but indistinguishable ones and zeros like grains of sand scattered in a dune desert in an unprovoked, unpredictable, unpreventable instant.

I whiled away my horror by housecleaning. You'd be hard pressed to find a surface in my home that hasn't been scrubbed clean. With a toothbrush. Waiting for the data recovery specialists to perform their magic, I suspended my worst fears by keeping my hands, mind and heart occupied. Together with my husband I've built a fence. Together with

my three sons I've planted a vegetable garden, and pots of flowers. I've redesigned our kitchen, and ordered new cabinets. I've selected colour chips and painted samplings on the outside playhouse for an exterior freshening up later this spring or summer.

In brief, brief moments I began allowing myself to try on a bit of perspective. Yes we may have lost all our photos from our recent trip to Maui, but at least the children are here and healthy and we can travel again. Yes my entire e-mail program might be lost, but with it the hundreds of e-mails overflowing my Inbox and with them that low-grade feeling of never quite being free of an unfinished agenda.


Of course -- and this is a big Of Course - all of my lament could have been completely avoided. The spontaneous mainframe implosion could have been but a hiccup if at some point in the last year and a half I would have taken the time to learn how to do what matters most. Back up. It's all the rage. Everyone's doing it. As much as I am a savvy user of my software and of the world wide web, I am almost completely ignorant of my hardware and operating systems. If I would have taken the time

to learn the most important thing -- how to do a complete system back up -- my loss would have been greatly lessened. Instead my loss has been greatly lessened.

In the ironic way Life leads us, this idea of What Matters Most is emerging as the outcome that's sticking with me. Through a loss that's driven me to sobbing more than once, I am experiencing a vitality for this moment that may have been dulled a bit by my habit of virtually bracketing my days. By not doing what matters most, I am reconnecting with what matters most.

This is a recurring theme. When my first son was born with a potentially fatal heart defect, I learned through his congestive heart failure and surgery recovery that it isn't perfect health that matters most but Love and Life -- and both are imperfect. The archivist in me is horrified at the gap in my photographic record, but, in a painful epiphany, I understand it is not our memories but the fully present experience of this present moment that matters most.

- Cindy Bablitz is Heart Beats' former Communications Director and lives in Calgary with her husband and three sons. She can be reached at cindy.bablitz@telus.net.



Heart Beats Children's Society of Calgary

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