



# Keeping The Beat

Heart Beats Children's Society of Calgary

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

## Mayor Bronconnier declares Valentine's Day Congenital Heart Defect Awareness Day in Calgary

Since 1999, Calgarians have been encouraged by the mayor to interrupt their bon-bon eating and flower-sniffing on Valentine's Day to consider the thousands of children and families living with CHD in the Calgary area.

And this year is no different.

"On behalf of city council and the citizens of Calgary, I hereby proclaim February 14, 2006, Congenital Heart Defect Awareness Day," announces Mayor Dave Bronconnier.

In petitioning the mayor to issue this proclamation, the Heart Beats Children's Society of Calgary joins

hundreds of institutions around the world in celebrating the millions of children and their families living with the number one, single most common birth defect.

To join with others in honouring your children and their community of support, head downtown for a live reading of the proclamation by Deputy Mayor Andre Chabot at noon, sharp, on February 14th. The event, which will include a media presence, happens outside Council Chambers, in the municipal building atrium, next to the historic city hall, at 700 Macleod Trail South, just off 9th Avenue.

*Dave Bronconnier*  
Mayor



THE CITY OF  
**CALGARY**  
OFFICE OF THE MAYOR



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## Annual General Meeting

### Tuesday, April 4, 2006

7:00 p.m.  
at Sugo Caffe Italia  
1214 9th Avenue S.E.  
phone 263-1115 for directions

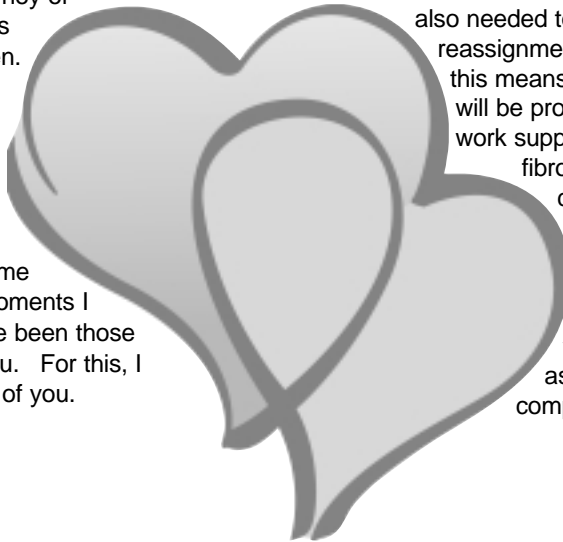
Everyone is welcome and encouraged to attend – whether or not you've participated in any Heart Beats activities before!

# A Sad Goodbye to Two Dear Friends

## Dear Families:

*It is with a very heavy heart that I advise you that I am no longer the social worker for the Cardiology Clinic at the Alberta Children's Hospital.*

The four years that I spent in the clinic provided me with many learning opportunities and new challenges. Along the way, I made new friends, met some incredible families and was inspired by so many success stories. I have been privileged to share a small piece of the journey of so many families and their children. You came to mean a great deal to me. In my eighteen years as a social worker at this hospital, some of the richest moments I have spent have been those I shared with you. For this, I thank each one of you.



The good news for the cardiorespiratory division at the hospital (which includes: perinatal, cardiology and respiratory) is that we have been fortunate to receive increased social work time. This enabled the hospital to hire another social worker. Because of increases to the time in some clinical areas, we also needed to make some reassignments. In the end, this means for me that I will be providing social work support to cystic fibrosis and asthma clinics. While I have been the social worker for cystic fibrosis for ten years now, asthma is completely new to

me and will require new learning and new challenges.

I am thrilled that I will be able to continue with the Off Beats youth group through to the end of June 2006.

In the future, please feel free to contact social worker Laura Thurber-Larsen at 943-7778. Laura will be providing social work coverage for the cardiology and respiratory clinics.

Once again, I wish all the best to each of you. If you happen to see me in the halls of the hospital, please stop and let me know how things are going for your family.

All the best,

*Gaye Hopkins*

## Patty Knox Heads South

If you've been to the Cardiology Clinic at the Alberta Children's Hospital in the past six or seven years, chances are you've been helped by nurse clinician Patty Knox. Many of us, over the years, have indeed come to call Patty, friend. So it is with a heavy heart that we said goodbye to Patty, who left the clinic after her final shift on August 11, 2005.

"It wasn't an easy decision to leave, but it was the right decision for our family," she explains.

Patty, her husband Pat and their two children Kelsey and Kie, left Calgary to move to southern California to be closer to Patty's mom and her father, who is aging with Alzheimer's disease.

"It just breaks my heart," says Patty.

"He is very confused and doesn't say much of anything that makes sense anymore. My mom is so good with him. I am so thankful to be here close to my family, and to do all I can to support my mom."

Moving a family south of the border brought with it a unique set of challenges – from packing, nail biting while the moving truck was a week late in arriving, re-establishing a sense of home in a new house, coordinating mountains of immigration paperwork and, it turns out, having to reaffirm one's ability to drive!

"I guess they think Canadians don't

know how to drive!" says Patty.

"I am off to take my driving test. I feel like I am 16 again!"

Although we will miss Patty very much, we caregivers and moms appreciate in a heartfelt way her decision to move where her family needs her, and we at Heart Beats wish Patty the very best of all good things in this new phase of her life.

*Watch the next issue of Keeping The Beat for our feature on Norma Becker, the new nurse clinician working with Kelly Webber at the ACH Cardiology Clinic.*

# Heart Beats Families Advise Western Canadian Children's Heart Network

Over the past several months, the Western Canadian Children's Heart Network (WCCHN) has been working with a Family Advisory Committee in developing a family's section of the Network's website, [www.westernchildrensheartnetwork.ca](http://www.westernchildrensheartnetwork.ca).

In Calgary, Heart Beats' own Heidi Smethurst and Tracey Contrada serve as the family liaison members for the WCCHN. Heidi brings to this position not only her own experience as a mother of a child living with CHD, but years of service with the Heart Beats executive as well as previous experience as volunteer with the Alberta Children's Hospital's Family Liaison Council. Tracey, a new and enthusiastic addition to the Heart Beats executive, is mother to a child living with an extremely rare form of congenital heart disease. (Tracey has recently been elected as the Fundraising Director for the Heart Beats Children's Society of Calgary.)

The WCCHN is an initiative which began in the year 2000 to better link the expertise between professionals and caregivers in the four western Canadian

provinces. Last year, Denise Clark, RN, MN, WCCHN Coordinator, began in earnest to solicit the support and input of the families served by WCCHN's efforts. The development of the family's portion of the website stands as an important hallmark of her team's efforts.

"There are two portions of our families' section we would like to draw your attention to," says Diana Locher, WCCHN's administrative assistant.

"These include the Q&A section, as well as the portion dedicated to "Family Stories". To date, we have collected and posted several questions along with incredible family stories," Diana says.

The WCCHN continues inviting your submissions in the form of either questions for the Q&A column or your own family experiences.

"We are always looking for more information – questions and experiences – to share with others via our website," explains Diana.

In other WCCHN news, coordinator Denise Clarke commenced her one-year

maternity leave on October 14, 2005. The WCCHN is pleased to announce that Sharon Chow will be assuming Denise's role, effective November 2005.

"Sharon comes to us from the Health Quality Council of Saskatoon," explains Denise.

Sharon has vast pediatric clinical experience, along with several years experience with the Saskatchewan Registered Nurses Association and the College of Nursing at the University of Saskatchewan.

"Please join us in welcoming Sharon to her new role!" Denise encourages.

*You may contact the WCCHN by surfing to their website, [www.westernchildrensheartnetwork.ca](http://www.westernchildrensheartnetwork.ca) or by e-mailing coordinator Sharon Chow at [sharonchow@cha.ab.ca](mailto:sharonchow@cha.ab.ca), or administrative assistant Diana Locher at [dianalocher@cha.ab.ca](mailto:dianalocher@cha.ab.ca). Or, send a general e-mail to [wcchn@cha.ab.ca](mailto:wcchn@cha.ab.ca) or phone (780) 407-1519.*

## Adventure Zone Family Event

by *Patty Wiebe*

This year's annual Heart Beats family event will be hosted at Adventure Zone on Sunday, March 12, 2006, from 4:30 – 7:30 p.m. The entire facility will be closed to the public, for the exclusive enjoyment of our families and friends for this event!

If you've never been to Adventure Zone, you're in for a pleasant surprise, as Adventure Zone has activities for all ages! Youngsters will enjoy the Toddler Zone Playscape and the Play Zone Treehouse with jungle gyms and interactive play centres – including an indoor sandbox and a painting studio! Older kids – and even teens – will have a blast with the two-storey inflatable slide, the climbing wall, arcade games, and glow-in-the-dark mini golf!

And, adults not busy reviving their own childhood creative energies are welcome to sit back and visit, while Adventure Zone party coaches keep our children entertained.

Tickets for the event are \$5 per child, (no charge for children under one year) to a maximum of \$10 per family. Your admission fee includes participation in all activities and pizza and pop for the children. We grown ups can purchase food and beverages from the Adventure Café.

Don't miss out on this great opportunity to fellowship with families like you, affected by and living with CHD!

Reserve your spot today by surfing to [www.heartbeats.ca](http://www.heartbeats.ca). Click on Annual Family Event and follow the steps. Or, RSVP to Olana Thomson at [olana.thomson@shaw.ca](mailto:olana.thomson@shaw.ca) or 203-2633. Advance payment will be required before February 22nd, and, until that time, registrations will be limited to children living with CHD and their immediate family. (If the expense is a burden, Heart Beats will happily, confidentially, sponsor your attendance). After the 22nd, we will gladly accept registration for your

extended family and friends, at a cost of \$5 per child, up to maximum occupancy. All registrations must be confirmed with payment by February 27th.

Consider yourself encouraged and welcome to attend this event – whether or not you have attended any previous activities or been in touch with Heart Beats before! These occasions are unique opportunities to meet other families living with CHD, and to connect with a dynamic network of support and information. Don't be shy!

**We look forward to seeing you at Adventure Zone:**

**#128 - 6008 Macleod Trail SW**  
(In the big purple building across from Chinook Centre. Entrance is on the east side of the building.)  
**Sunday, March 12, 2006**  
**4:30 – 7:30 pm.**

Adventure Zone asks that children wear socks. Adventure Zone is also a peanut-free environment.

# Colourful Blessings for Heart Kids

by Anna Lipp

Of all the places in the world to be born with a congenital heart defect, you couldn't pick much better than Alberta, Canada. We have access to some of the world's finest surgeons, health care teams and facilities and, unlike our neighbors south of the border, most of our health care costs are funded by provincial and federal health care programs. Still, being a parent of a child with a CHD often requires funding certain extraordinary costs out of pocket ... and, for some families, this can mean there is little left over for extras.

Enter the Rainbow Society of Alberta



The Society isn't your typical wish-granting organization.

"We are unique in that we help chronically ill children – not just those who are terminally ill," says Heather Zerveld, Special Events Coordinator with the Society.

"In fact, 98 per cent of the wishes we have fulfilled come from chronically ill children."

Since 1986, the Rainbow Society has granted 569 wishes! Some examples include a custom set of skis, a hot tub – and meeting Shania Twain!

"We do set some boundaries as to what can be wished for, such as only one wish can include travel," explains Heather.

(Children "wishing" to the Rainbow Society are requested to include a short list of more than one wish from which the Society can select, and try to coordinate.)

"However," Heather adds, "We do try and fulfill the wish that best suits your child."

Every wish 'granted' by the Rainbow Society has a one year window.

"If your child isn't feeling well right now, you can wait a few months before we fulfill the wish," Heather assures.

The Society operates in a very honouring way in protecting the privacy and confidentiality of the families they aim to serve.

"We do not solicit wishes or accept anonymous referrals," explains Heather.

The Rainbow Society accepts referrals from your child's doctor, a friend or a parent. Once a referral is made, an application is completed, which includes a letter from your child's doctor detailing the diagnosis and prognosis, along with three of your child's wishes. Members of the Society confidentially review all applications, and then contact families to arrange a face-to-face meeting. Successful applications are approved by a board of directors who also select the 'winning' wish.

As a not for profit organization, the Rainbow Society depends on the generosity of others to help fulfill wishes. All donations stay local, used in the granting of wishes of Albertan children.

*For more information, or to make a donation, please contact the Rainbow Society at [rainbowsociety@shaw.ca](mailto:rainbowsociety@shaw.ca), or (403) 252-3891, or by mail at P.O. Box 1153, Station M Calgary, AB T2P 2K9.*



**Don't Forget!**  
**Annual General Meeting**  
Tuesday, April 4, 2006  
7:00 p.m.

Sugo Caffe Italia  
1214 9th Avenue S.E.  
phone 263-1115 for  
directions

Everyone is welcome and encouraged to attend – whether or not you've participated in any Heart Beats activities before!

# Off Beats

In the words of Robert Munsch, 'Well, that teenager grew. He grew and he grew and he grew!'

Seems the teens in Off Beats are doing what teenagers do – they're growing up! And the number of participants in Off Beats activities is dwindling! If you're a teen or tween looking to connect with other kids who've 'been there, done that', contact Off Beats coordinator Kelly Webber at 943-7316 or [Kelly.Webber@CalgaryHealthRegion.ca](mailto:Kelly.Webber@CalgaryHealthRegion.ca).

Gaye Hopkins remains involved with Off Beats, and will do so until June, even though her 'official' responsibilities have her serving another area in the Children's Hospital.

In September, Off Beats met for a mini-golf tournament – and weren't rained out or snowed out ... which is something to say for autumn in Calgary! In October, a group gathered for games and snacks. Unfortunately, after that, a couple of planned activities had to be cancelled due to a lack of participants. In January, Off Beats went bowling.

"Some mastered the ten-pin bowling better than others," grins Kelly.

On Wednesday, February 8, Off Beats will be going for pizza at Boston Pizza, and in March, the group will enjoy a swanky night at the Saddledome, enjoying a Flames game in the Rhett

Warrener box. For more information on these events, call Kelly at 943-7316, or e-mail [Kelly.Webber@CalgaryHealthRegion.ca](mailto:Kelly.Webber@CalgaryHealthRegion.ca).

Looking for a way to play a bit of hookie from school? Talk to your parents about attending the Congenital Heart Defect Awareness Day proclamation launch on Tuesday, February 14th, at noon, in the atrium of the municipal building beside the historic City Hall at 700 Macleod Trail South, right off 9th Avenue! Media will also be invited to this event, and you may have an opportunity to speak "live, on-air" as a "typical" teen living with CHD!

# Mom & Tots

The Mom & Tots group continues being an important group of fellowship and support for families of young children living with CHD. New moms and tots are always welcome to participate, or to simply call for support or information! The next planned activities are

historic city hall, at 700 Macleod Trail south, right off 9th Avenue.) Media will be invited to this event as well.

Later on in the day, Mom & Tots, (and siblings and dads!) are invited to break bread together at a Boston Pizza

location to be announced ... well, technically, we'll be breaking heart-shaped pizzas together! For meeting time and location, contact Angie Enslow at 251-3989, or [zoe1st@telus.net](mailto:zoe1st@telus.net).

On December 11, 2005, the Mom & Tots group met at the home of Colin and Patty Wiebe for the second annual Mom & Tots Christmas party. There were eight heart children present ranging in age from 4 months to 6 years,

along with their siblings and parents.

"It was great to get together and celebrate the season with people who have become special friends," says host Patty Wiebe.

"We really enjoyed this extra time to get to know some new families who have

just recently started attending Mom & Tots activities."

"Also, thank you to Heart Beats for providing gifts for the children," Patty adds.

For more information on the Mom & Tots group, or on upcoming events, surf to [www.heartbeats.ca](http://www.heartbeats.ca), and click on Mom & Tots under Upcoming Events, or, contact Angie Enslow at 251-3989 or Patty Wiebe at 256-7423.



Back row, L to R: Janelle holding Emily, Grace  
Middle row, L to R: Kaden, Teagan holding Korey, Morgan holding Landen, Isabelle holding Nathan, Matthew, Noah  
Front row, L to R: Mathias, Elijah, Tristan

scheduled for February 14th, to coincide with the annual Congenital Heart Defect Awareness Day officially declared in the city of Calgary by Mayor Bronconnier. All are welcome to attend the official reading of the proclamation by Deputy Mayor Andre Chabot at noon, in the atrium of the municipal building. (The municipal building is located next to the



Morgan, left and Korey, right, together with their moms, enjoyed a crisp day of hay wagon rides and pumpkin hunting at Butterfield Acres on October 22, 2005.

"We also wish to send a special blessing of support and gratitude to one member of our Mom & Tots group who recently received a life saving heart transplant," says Angie Enslow.

# 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.**

Chairperson	Jeannine Oliphant
Secretary	Patty Wiebe
Treasurer	Sylvia Falk
Nurse Liaison	Norma Becker
Fundraising Coordinator	Tracey Contrada
Communications Director	Cindy Bablitz
Additional Directors	Heidi Smethurst Olana Thompson

**You may contact us! [www.heartbeats.ca](http://www.heartbeats.ca)**  
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Jeannine Oliphant (chairperson) 289-4329  
Kelly Webber (Off Beats) 943-7316  
Angie Enslow (Mom & Tots) 251-3989

You can be added to the mailing list to have *Keeping the Beat* delivered direct to your door – or you can have your name removed! If you're interested in receiving this newsletter electronically, in PDF format, direct to your e-mail Inbox – or with an e-mail announcement linking you to the newest issue of *Keeping The Beat* located at [www.heartbeats.ca](http://www.heartbeats.ca), let us know!

E-mail [PattyWiebe@shaw.ca](mailto:PattyWiebe@shaw.ca) and let us know:

- You wish to be added to our snail mail list (at no charge!) or
- You wish to receive your newsletter electronically, in PDF format, by e-mail or
- 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*

On a warm Saturday morning last summer, my good friend and her family flew to Minnesota to attend the funeral of her father. He'd passed suddenly, catching pneumonia after breaking his hip. Sunday morning, in the pew beside us, the aging mother of a long time congregant dropped her hymnal and appeared to be having a stroke. Monday evening, we attended the memorial service for a 34-year-old man...the son of dear friends. On Tuesday, I had tea with a friend of mine who had just been told she needed a recall mammogram. Wednesday morning, I dialed another friend to see if she and the girls were ready for our zoo play date. My call interrupted an emergency in progress. Her one-year-old daughter just had her finger tip cut off. When I got to the house a few moments later, I joined two paramedics and two neighbors in the blade-by-blade of grass search for the fingertip.

Just over an hour later, with three of us still searching, and a small pile of cherry pits attesting to our diminishing hopes, I

found the wee fingertip, and it was rushed to the Children's Hospital. Regrettably, the tip...alas, the finger... was deemed by the orthopedic surgeon too small to functionally reattach.

My mammogramming friend – who recently lost her father to cancer – made her recall appointment and rejoiced to hear that her breast tissue is simply fibrous, not cancerous.

We continue grieving with our friends who mourn the loss of their addicted son. For twenty years he struggled in a life foreign to his parents and in his passing we all experienced the paradox of regret and relief.

The stroke turned out to be a seizure, and mum, discharged from hospital after five hours, is fine.

And, we console our American friend and her family, who mourn the untimely death of her dad, yet still contemplate

that perhaps this passing was a merciful escape from the slow ravages of his Alzheimer's.

I've said it before, I'll say it again - I'll say it a thousand times. Having a child born with CHD is a mixed bag of blessings and pain, each, I think, in equal measure.

Knowing CHD means knowing the fragility of life, and this knowing breeds both compassion and perspective. We know, its a risky business, this living. We know, it could always be worse. We know, one single moment matters. We know the value of now. We know, sometimes one more... or one less... word can mean the world.



Five times in seven days last summer, I, the wordsmith, hadn't known a single right word to say. But, thanks to that I've sat at a PICU bedside, I know that a silent, listening ear will never be the wrong thing.