



Keeping The Beat

Heart Beats - Children's Society of Calgary

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

Just a Spoonful of Sugar Helps the Medicine Go Down



Mary Poppins was no dummy. She knew, "Just a spoonful of sugar helps the medicine go down."

Some 70 years after the magical nanny first appeared in children's literature, caregivers are still struggling to get the medicine down — but today, there's more help.

FLAVORx is a new offering in Canadian pharmacies. Like its name suggests, FLAVORx is a formula that improves the taste of bitter and un-

pleasant-tasting medicines. On request, pharmacists can make children's prescription and over-the-counter medications in liquid, powder and pill form more palatable — without affecting the stability or effectiveness of the drug — for about \$3.00 per prescription.

Some medications commonly pre-

scribed to patients living with some types of congenital heart defects can be made more pleasant tasting with the addition of a FLAVORx additive, including, for example, dygoxin, anti-hypertensive medications and anti-arrhythmic medications.

(Continued on page 4)

Conference Attracts Heart Families

Plans are well underway for the fifth Growing Up With Heart Disease Conference hosted by our colleagues at the BC Children's Hospital and their family support organization, the Children's Heart Network.

The conference, subtitled, *Celebrating The Young At Heart*, is scheduled for May 28th and 29th, in Vancouver BC.

"The aim of this conference is to provide education about growing up with heart disease and to continue fostering effective relationships between children, youth, their families and health care providers," says conference organizer and program coordinator for the Children's Heart Network, Colleen Corder.

Registration began in March, and interested participants can now register online. (Surf to www.childrensheartnetwork.org and follow easy to access links direct from the home page.)

Youth aged 13-19 can attend the conference for free. Fees for adults are \$75 per person, or \$125 per family of two adults. Registration fees include continental breakfasts and lunches on both days, as well as a reception on Saturday afternoon.

(Continued on page 4)

Inside this issue:

First Birthday Gifts Pay It Forward	2+3
Helping Hands Help Heart Beats	2
Hot Chili Fundraises For ACH Cardiology Clinic	2+3
Conference Attracts Heart Families	4
Just a Spoonful of Sugar Helps the Medicine Go Down	4
Mom & Tots	5
Off Beats	5
AGM Reminder	5

First Birthday Gifts ...



On March 21, little Ava Contrada turned one year old, much to the celebration of a grateful community of family and friends.

"When we look back at the past year we are overcome with emotion," says Ava's mom Tracey Contrada.

Ava was born with left ventricular non-compaction, several ventricular septal defects and blood clots. Later, she was also diagnosed with kidney reflux and acid reflux.

"To be able to celebrate Ava's first birthday is such a privilege!" says Tracey.

"We feel Ava has been blessed by so many gifts over her short lifespan, that the best way we could honour her first birthday was to find a way to give back to the community that has been so supportive to us." So, Tracey and her husband John invited well over a

(Continued on page 3)

One of the surprising joys of having a child born with less than "perfect" health is finding yourself exposed to the remarkable ways good people have of making a difference.

Here are three stories of ordinary people making an extraordinary effort to reach out in support of our heart kids.

Helping Hands Help Heart Beats

The helping hands in Mrs. Cussigh's first grade class at St. Benedict Elementary School in SW Calgary helped bring a tree — and a fundraising drive — to life.

"As part of (the Separate School Board's) Community of Caring program, the students in my class worked for coins they would then bring to school to be donated to charity," says Johanna Cussigh.

"When they brought coins in, the students would tell me what they did to earn them, and I would write

this on a cutout hand, which we would then stick as leaves on our 'helping hand' tree," Johanna explains.

As the tree blossomed in leaves, more money was raised for one of St. Benedict's 2005 Lenten project's chosen charities, the Heart Beats Children's Society of Calgary.

Three other classrooms joined in the fundraising effort, collecting coins and recycling bottles to generate \$409 for Heart Beats.

The Community of Caring program is a dedicated effort to create a generation of children who value kindness, charity and a commitment to their community.

The funds raised by the students of St. Benedict Elementary will directly support families who find they need assistance to help deal with some of the extraordinary costs of caring with a child living with congenital heart defects and acquired heart diseases.



Hot Chili Fundraises ...

Ralph Maybaum — dad to nine-year-old Austin, who was diagnosed with transposition of the great arteries requiring emergency surgery in his first days of life — is one of those inspired people who said, 'I can help with that', and

turned an ordinary bowl of chili into big cash for our heart kids.

Last year, the third annual Global Acid Gas Chili Cook-Off raised \$40,100 in a single day.

"The monies raised (from

2004's event) will purchase a treadmill stress test system for the Cardiology Clinic," says Bonnie Lee B. Morris, of the Alberta Children's Hospital Foundation.

(Continued on page 3)

... Pay It Forward

(Continued from page 2)

hundred of Ava's closest family and friends to a series of three birthday parties. ("Did I mention John is Italian?") With the invitations was included this note, along with Heart Beats' address and Mission Statement:

"The only gift we wish to receive is your presence, but if you so choose, Ava would certainly appreciate a donation to: Heart Beats - Children's Society of Calgary."

Says Tracey, "At each of the parties we explained how we have been encouraged and impacted by Heart Beats, and what you mean to the Contrada Family."

"Unfortunately," says Tracey, "While family and friends try to be empathetic, they cannot truly understand what you go through as parents of a child with CHD. Connecting with

families in the Heart Beats community has provided us with a much needed cushion of support!"

She adds, "The Mom & Tots group has been fantastic! The support offered, and advice given has enabled us to understand and effectively deal with Ava's challenges — especially around feeding!"

After her birth, Ava left the hospital with a feeding tube — as well as 11 different medications and two daily shots of enoxaparin. It took nine months before Ava's progress was sufficient to remove the feeding tube and stop the enoxaparin shots. Today, all of her VSDs have closed and only one tiny blood clot remains.

To say John and Tracey are grateful for Ava's life is an understatement.

"We have been given incredible support from Dr. Dickie, Patty Knox and Kelly Webber at the ACH Cardiology

Clinic," says Tracey.

"And," she adds, "Each month we look forward to connecting with our newfound friends at Mom & Tots — our first year with our daughter has been profoundly impacted by Heart Beats and we are so grateful!"

The Contrada's family and friends have been more than generous responding to Ava's mom and dad's appeal for support to Heart Beats. So far, they have donated over \$1,200!

"We would encourage anyone when asked by family and friends, 'What can we do?' to request support for Heart Beats," says Tracey.

"It is a wonderful feeling to know exactly where your raised funds go — to support the family next to you dealing with congenital heart disease."

"Thank you Heart Beats, from the bottom of our hearts."

... For ACH Cardiology Clinic

(Continued from page 2)

Currently, only 7-8 pediatric heart patients have access to treadmill stress testing at the ACH each week. The new system will give access to double that number.

This June 17th will mark the fourth annual event and, says Ralph Maybaum, founder and president of the Global Acid Gas Chili Cook-Off Foundation, "This year, we plan and believe we can be even more of a success."

Funds from the 2005 event will purchase cutting edge software to work in conjunction with magnetic resonance imagery (MRI) technology.

"This is a very important new technological advance in the field of cardiology," says Dr. Joyce Harder, pediatric

cardiologist at the Alberta Children's Hospital, "As it allows us to have beautiful visualization of the heart, in motion, non-invasively."

The supporting intricate — and expensive — cardiac MRI software will facilitate the evaluation of different valves, narrowing across a valve, and the leakiness occurring with each heart beat, Dr. Harder explains.

Generous donations from the Global Acid Gas Chili Cook-Off Foundation support our children having access to the newest quality technology in pediatric cardiology at the ACH Cardiol-

ogy Clinic.

This year's Cook-Off will be held at Eau Claire, behind the Barley Mill, and volunteers are currently being recruited.

"Volunteers get a t-shirt, some food and beverages, (chili perhaps?) and a great time for a great cause!" says volunteer coordinator Brandy Petch.

To volunteer, contact Brandy at bpetch@flint-energy.com or 218-7152.

For more information on the 2005 Global Acid Gas Chili Cook-Off, contact Ralph at 681-2670, or e-mail rmaybaum@accutech-eng.org.



Conference Attracts Heart Families

(Continued from page 1)

Also, childcare is being offered by qualified early childcare educators and assistants for children from infants to 12 years. A charge of \$60 per child covers all conference hours, over both days, and includes lunch and snacks. Space is limited, and prefer-



ence will be given to out-of-town registrants and children less than six years of age.

"I would recommend this conference to others," said one participant in attendance at the 2003 Growing Up With Heart Disease Conference.

"I believe it is important for families, patients and health professionals to get together. It facilitates communication and learning. Plus, families and

professionals gain a better appreciation and understanding of one another."

For more information, check out www.childrensheartnetwork.org for an excellent online resource about the conference. If you have any further questions, e-mail Colleen Corder at chn@childrensheartnetwork.org, or phone 1-250-598-2524.

Just a Spoonful of Sugar Helps the Medicine Go Down

(Continued from page 1)

"The product is founded on the concept that medication, no matter how effective, won't work unless it is actually consumed by the patient it is intended to help," says Dianne Gammache, pharmacist at Calgary's Rocky Ridge Co-op. (Dianne, a long time Heart Beats member is also mom to five year old Kassandra, who was diagnosed at birth with transposition of the great vessels, which was repaired at six days old.)

The idea for FLAVORx was born in 1992 to Maryland native Kenny Kramm, whose daughter Hadley, a premature newborn, developed cerebral palsy and a seizure disorder. Four times a day, she was required to take Phenobarbital and, often, she'd spit out, or throw up, the bitter tasting medicine, leaving her parents unsure how much medication she was actually absorbing. When it wasn't enough, Hadley would suffer seizures. "We were ending up in the emergency room on a weekly basis," Kenny recalls.

So, Kenny, a pharmacy technician, and his pharmacist father began fiddling with flavorings to make Hadley's medicine more palatable.

"We all know," says Dianne, "That compliance is one of the most important factors of any medication regime ... anything that can help children be more cooperative in taking their medicine is a good thing!"

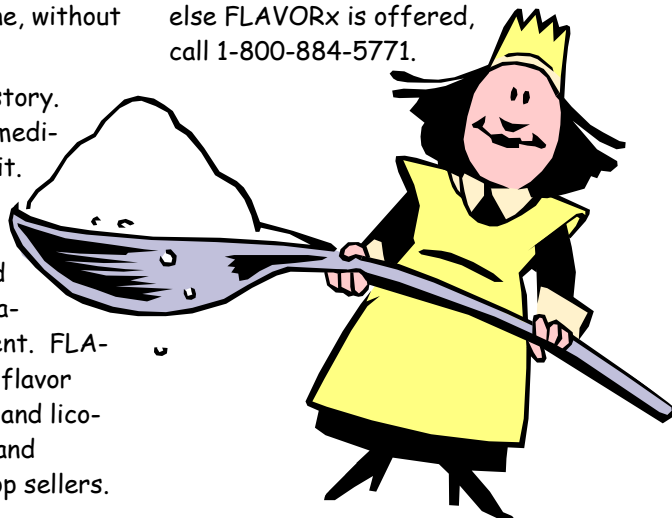
Research studies show that children create psychological and physiological barriers to taking unpleasant medicine ... which can lead not only to lengthy ailments or complicated or compromised conditions, but to drug resistance. Studies also show that, with children, medication regime compliance averages around 50 per cent. Eventually Kenny and his father created a tutti-frutti concoction comprised of harmless additives that sweetened Hadley's medicine, without diluting the drug.

The rest, as they say, is history. Hadley hasn't had another medications-related hospital visit. And, FLAVORx has become a multi-million dollar business, now being offered in more than 20,000 pharmacies throughout the continent. FLAVORx offers more than 40 flavor choices. Banana, root beer and licorice are popular choices — and bubblegum and grape are top sellers.

Pediatric patients using FLAVORx-enhanced medications are also given a colouring chart which actively engages — and rewards — children for being compliant. Children bring their successfully-completed compliance chart back to the pharmacy where they receive a prize. Then, pharmacists submit the chart to FLAVORx to be entered in a drawing for a cash prize.

Hadley's mom Shelley says, "It's nice to know that out of Hadley's complicated little life, so many other children's lives will be improved."

In Calgary, FLAVORx is offered at all Calgary Co-op Pharmacy outlets. For more information, or to find where else FLAVORx is offered, call 1-800-884-5771.



Mom & Tots

by patty wiebe

Angie Enslow and her daughter, Morgan, hosted a party for Mom & Tots on February 14 to celebrate Congenital Heart Day. Five heart children, ranging in age from 10 months to five years, were present with their siblings and friends, and it truly was an occasion for we moms to celebrate how well our heart children are doing.

In March we met at Coffee & S'Cream where our children had a good time playing under the supervision of their hot-chocolate-and-fancy-coffee-sipping moms.

We always enjoy having new parents and heart children join us!

When I first became involved with Mom & Tots, I appreciated the opportunity to meet other families of children with congenital heart defects who understood, in a way that even caring family and close friends could not, about having a child in the hospital, going through heart surgery, and dealing with medications and feeding tubes. I have learned so much from other moms and I have been so encouraged seeing other children who have already been through what our own child is dealing with or about to go through.

I have also seen how Mom & Tots is beneficial for my heart child, Isabelle, who is about to turn four. In the past few months she has started to ask questions, such as why does she have to take medications that her older sister does not, and why does she have a feeding tube in her nose in all her baby pictures? A few days ago she asked, "Mom, who else has a special heart like me?" It was so nice to be able to name a number of children that she knows through Mom & Tots and this satisfied her question.

Mom & Tots meets monthly, and upcoming gatherings include:

- Monday, April 18 at the Calgary Zoo
- Friday, June 3 at the Science Centre

For more information, contact Patty Wiebe, at 256-7423 or pattywiebe@shaw.ca or Angie Enslow at 251-3989.

Off Beats

"Off Beats has had a fun winter", says Kelly Webber, nurse clinician at the ACH Cardiology Clinic.

In February, Morrison Homes sponsored tickets so that six teens could join a few friends and family at a Hitman Game. At the game, Wendy's was sponsoring free burgers for everyone if the Hitmen scored a certain number of goals.


"At times, it seemed that we were cheering more for the chance to win a burger than for the Hitmen to win!" Kelly laughs.

On March 23, Off Beats hung out at the hospital for a pizza and games night.

"A game of Uno got very competitive," says Kelly, "But no one was a match for Jared and his 'lucky cards'."

On April 27th, plans are underway for a trip to Laser Quest, and in May, Off Beats will wrap up for the summer season with a wind up party that will include some mini golf.

Off Beats is a peer group for youth aged 12–17 years living with CHD. For more information on upcoming events, or on how you can encourage this important grass roots support group, contact Kelly Webber, Patty Knox or Gaye Hopkins at 943-7316.



Heart Beats AGM
April 20 7:00 p.m.
Call Gail 287-1712
for directions

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
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

Kelly Webber (Off Beats) 943-7316

Angie Enslow (Mom & Tots) 251-3989

www.heartbeats.ca

Long in production, we are so proud to introduce the new website featuring the Heart Beats Children's Society of Calgary. Check out www.heartbeats.ca for a complete listing of events, contact information, links and general information about Heart Beats specifically and congenital heart defects generally. We on the Heart Beats executive acknowledge that, since our humble beginnings in 1987, times have changed! So many of us, (but by no means all of us!) rely heavily on the internet for daily communication and periodic research. We hope you appreciate having an internet resource for your connection to Heart Beats, and we assure you, we shall nevertheless remain available, live, to all who reach for us for help. We welcome your feedback, which you may offer by e-mail to the editor, or by mail to our post office box!

Beat The Drum Slowly

an editorial by cindy bablitz

The first three days after my third son's birth were remarkably like the first three days of my first son's life — the one with the sick heart.

Like babe one, babe number three lost more of his birth weight than the hospital's math police allowed, and on the third day, I nursed with a calculator-wielding lactician lording over my shoulder. Like babe one, babe number three began showing blueness around his mouth and eyes. And like my first babe, my third babe found himself hustled into the special care nursery for a battery of tests, including blood work and, to my horror, an ecg and an echo.

"There is no cause for alarm, but we do hear a faint murmur," the neonatologist advised me at the end of an exhausting, poorly pain-managed day.

You know that camera trick cinematographers use where the central subject seems to swoop forward to-

ward the camera while the background simultaneously slides back? That was my picture of myself in the moments after the docs left me standing, dumbfounded, while they wheeled my babe away.

I thought, 'this can't be happening again. I can't deal with this again. This isn't fair.' I snotted it out in my room.

I walked into the special care nursery to an all-too-familiar scene: several doctors and more nurses hovering over my babe, in an isolette, with hands at him through every circular opening. I, in my robe and slippers, pulled up an all-too-familiar vinyl-covered armchair rocker and sat, and rocked, watching helplessly, girding my own resolve, remembering, 'we've been through this once before. We do know how to do this. We will deal with whatever we learn.'

A wise teacher once told me, "There

is no inherent meaning in anything. You attach meaning to circumstances and events based on your unique perspective, which is influenced by your personality, your life experiences and your attitude."

That night, I decided to change my mind from, 'this isn't fair' to, 'this is what it is.' After all, hadn't I already learned that living with CHD — and connecting with this community of such generosity, such courage — brings as much blessings as pain?

Before the week was out, my babe was wheeled back to my bedside with a clean bill of health. No explanation for the blueness, no explanation for his deteriorating lethargy in those first few days. No more murmur. No CHD.

Next Sunday, he shall join his two brothers and his devoted ma and pa — hardly any worse for the wear — around the baptismal font. We are grateful.

