



Keeping The Beat

Heart Beats - Children's Society of Calgary

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

Camp Del Corazon ... Healing Heart Scars

Every Labor Day weekend, for the past nine years, on a little island 26 miles off the coast of Los Angeles, children from around the world living

with congenital heart disease get to forget for a few days that they are unlike anyone else. Indeed, for those few days, they are like everyone else.

Shannon, Camp Del Corazon's medical director and pediatric cardiologist at the UCLA Medical Centre in Los Angeles.



Campers and counselor at Camp Del Corazon enjoying an afternoon of water sports.

Camp Del Corazon is a residential camp program designed specifically for young people, aged seven through 17 living with CHD.

"It is about teaching children with heart disease that they are not alone, and that strength derives from overcoming obstacles," says Dr. Kevin

Founded in 1995 and largely the brainchild of Lisa Knight, electrophysiology nurse at UCLA, Camp Del Corazon hosted 49 campers that first year. Now, three times that amount of volunteers alone are required to facilitate the volume of Camp Del Corazon participants.

Speaking to her inspiration, co-founder and executive director Lisa

(Continued on page 2)

Inside this issue:

Camp Del Corazon ... Healing Heart Scars	2
Oloff at Camp Del Corazon	2
AGM Honours Heart Beats' Contributors	3 + 4
Jilli's Quilt	4
Global Acid Gas Chili Cook-off	5
Looking for Volunteers	
Building Bridges to Tomorrow Heart Conference in Winnipeg	5
Family Event Planned for June	6
Heart Beats Membership Renewal Form	6
Mom & Tots	7
Off Beats	7
Your Feedback	7

Local Transplant Recipient Receives Life Giving Gift ... Twice

by Oloff Dreyer

My name is Oloff Dreyer, I am fifteen years old and I received a heart transplant in March 2001. My family and I live in Coch-

rane, Alberta, just west of Calgary.

I was very fortunate to be able to attend Camp Del Corazon at Catalina Island just off the west coast of

California in August 2003. Any child that has a heart defect or that has had a transplant can attend the camp, and it's free! I was

(Continued on page 2)

Camp Del Corazon ... Healing Heart Scars

(Continued from page 1)

says, "I realized that what we were doing (at UCLA) was making a difference ... but there was a whole other side of their life that we were missing.

"A lot of that had to do with not the scars on their chest, but the scars on their heart. So, we started this camp for children, so that they could have a special place to go to and be with other children like them."

Campers are divided by age groups: eighth grade and above and seventh grade and below. This year, the teen camp will host about 150 campers August 30th through September 3rd, and the junior camp will host about 150 campers September 3rd through September 7th.

"I do more in those ten days for congeni-

tal heart disease than the rest of the year ... by leaps and bounds," says Dr. Shannon.

"I couldn't be a pediatric cardiologist at this point and not run the camp," he says, "Because I think the camp does every bit as much for me to reach my goal of helping children as my being a doctor does."

He's not alone in his conviction. About 150 volunteers take time off from their commitments to play with, teach, and serve the kids at Camp Del Corazon. At all times, three to five pediatric cardiologists and about 20

nurses are on site. As well, a medi-evac boat and helicopter are always on standby.

"We could run a small emergency unit from our infirmary," beams Lisa.



The team comprising the growing force behind Camp Del Corazon - which includes Lisa's husband and the camp's CEO, Glenn Knight, (they were married at Camp Del Corazon) - are committed to making this opportunity available to "anyone who would benefit from it," says Dr. Shannon. The camp is free to anyone who wants to attend, although personal travel arrangements for campers traveling in from away are the responsibility of the participant.

Camp Del Corazon has a fabulous website offering excellent information, donor and registration forms and celebrations of campers who have been there.

Surf to:

www.campdelcorazon.org

Oloff at Camp Del Corazon

(Continued from page 1)

very fortunate to be sponsored by the Children's Heart Society of Edmonton, who helped cover some of my travel expenses.

After arriving at the airport in Los Angeles we went to our hotel and had supper. The next day, we took a taxi to the harbor and boarded a ferry to Catalina Island. On the boat ride over to the Island we saw whales and dolphins!

At camp we stayed in cabins with 8 beds each. I met children living with CHD from all over North and South America. The food was excellent and included a lot of fresh fruit and vegetables.

Activities at camp included canoeing, wall climbing, archery, water sports, team sports and so many other activities that were a blast. It was really interesting and exciting to do activities with other children that have

experienced heart problems similar to mine.

It was an overall wonderful experience that I will cherish for a long, long time. The friends I made at camp will be friends forever.

Many people were involved in making this trip happen for me, and I truly thank everyone who played a part.

AGM Honours Heart Beats' Contributors

by Jeannine Oliphant

For the past five years, it has been a passion and a privilege of mine to be in service to the Heart Beats Children's Society of Calgary, after my daughter Alysha was born with hypoplastic left heart syndrome in May 1997. As we concluded the 2003/04 business year at the end of March, and Heart Beats' 17th year of operations, I reflect on the good work of all you who give yourselves in service to our children.

Thank You

Specifically, I'd like to acknowledge Gail MacKean, Patty Wiebe, Sylvia Falk, Patty Knox, Heidi Smethurst, Kathleen Hambley, Cindy Bablitz, Michele & Andrew Maurette, Angie Enslow, Gaye Hopkins and Lori Moch. It is truly a pleasure to volunteer with all of you. It is because of your energy and dedication that this organization continues to live and breathe. On behalf of so many children and their families living with CHD who are impacted in so many important ways, directly and indirectly, by you who serve, thank you!

May I also take a moment to offer another heartfelt thank you to Robin and Ken Purnell, who for years served important roles producing this newsletter and setting up and operating our website. Last summer, Ken and Robin moved forward into celebrating other wonderful gifts in their lives - including a new grandchild!

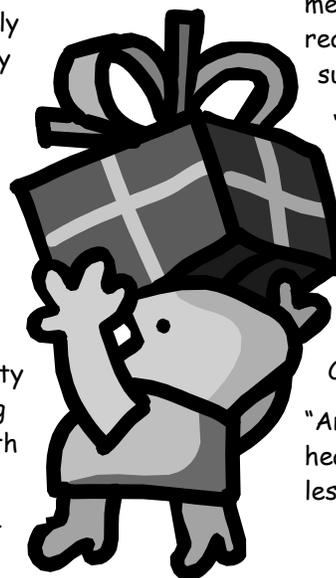
Also, thank you to Bev Moore and Denise Nimmo who tirelessly served on the Heart Beats executive for many years. Your dedication to our children and our organization is remembered and appreciated.

Family Support

Since its inception February 5, 1987, the Heart Beats mandate has been to provide families of children born with CHD information, resources, and emotional support. Our activities this past year continue reflecting our commitment to this mandate.

Through the Cardiology Clinic, we continue providing pillows to those children who are going for heart surgery for the first time. (These pillows were made for us, for this purpose, by the Progress Club of Calgary.) At Christmas, Heart Beats put together 'hampers' of food and gifts for three families of kids with special hearts - all of whom gratefully received our support during a difficult financial time. This year, we also made arrangements for a family awaiting a transplant to have a pager; we purchased a used apartment-sized washer and dryer for a family who was having to take their oxygen-dependant child with CHD out to a laundromat; and we paid an outstanding medical bill. These gifts have, to the families who received them, profoundly impacted quality of life and are one way Heart Beats serves, by helping to reduce a certain amount of financial stress in the face of the more weighty stress of caring for children with CHD.

Although Heart



Beats did not do any big fundraisers this year, we continue receiving generous and ongoing financial support from First Energy and the Calgary Foundation - The Watson Family Fund. Also, your annual membership fees of \$15 support the ongoing service work of Heart Beats and many families and friends of children with congenital heart defects are further moved to offer additional charitable gifts throughout the year to Heart Beats. It all adds up and it all goes, 100 per cent, in service to our children with CHD.

Activity Groups

Mom & Tots is gaining some momentum with new parents of babies born with congenital heart defects joining the group. In 2003/04, the group did only meet a couple of times, but monthly meeting dates have been appointed for the next full year.

Off Beats continues being an important support group for teens and tweens, and Heart Beats is pleased to fund some of their activities. A core group of kids consistently attends meetings. They have developed some really nice friendships and are very supportive of each other.

"Without Heart Beats' funding support, I know some of our kids wouldn't be able to be as faithful to the group as they are," says Patty Knox, founder of Off Beats and clinical resource nurse at the Alberta Children's Hospital Cardiology Clinic.

"And this group is so important to our heart kids as they enter their adolescent years ... we all are so grateful

(Continued on page 4)

Jilli's Quilt

On the wall in the hallway that runs behind the reception desk in the Cardiology Clinic at the Alberta Children's Hospital is mounted a quilt. If your child has undergone heart surgery, you'll recognize the patches of the quilt, for they are, singly, the pillow slipcovers gifted to children as comfort and support for their upcoming journey, on behalf of the Heart



Beats Children's Society of Calgary.

"This quilt was created in celebration of Jillian's life," says Jilli's mom, Lori Moch.

"It's a testament to the power of people," Lori adds.

Two years after she born with pulmonary artresia and tetralogy of fallot, a group of women from Lori's Mommy Day at the St. Andrew's United Church volunteered to stitch panels of the teddy bear squares in support of an upcoming Heart Beats fundraiser. Rose Soares, maternity nurse at the Rockyview Hospital, coordinated the stitching to bring the squares together into a finished quilt.

"Originally the quilt was intended to be an auction item for our dinner dance and silent auction," says Lori.

"In the end, we had so many items donated for the event that we decided to honour all the love and hard work that went into the quilt by having it permanently mounted on display for everyone to enjoy in the Cardiol-

ogy Clinic rather than risk it being too undervalued at auction."

For the Moch family, cardiology check ups - which, for the past four years, have been nothing but good news - carry an additional blessing every time they pass the quilt and remember the unconditional goodness and generosity of strangers who, in gentle compassion, became a part of the Moch's circle of support early in Jilli's life.

By the time Jilli was five years old, her heart function deteriorated in efficiency such that she required a pulmonary artery transplant. At some point in the future, as Jilli grows, it is expected she will require further surgeries. For now, Jilli, together with her mom and dad, (dad Darcy is the chairman of the Alberta Hospital Foundation board of directors) and her siblings Christopher and Erin, live with the ironic blessing that is congenital heart disease. The very best in people rises to the surface, and flows out in service to the world, in the community of a child born in need.

Heart Beats' Annual General Meeting

(Continued from page 3)

for the endorsement of Heart Beats!"

Off-Beats has been very busy this year, with their activities including hot dog roasts, pumpkin carving, cookie decorating, bowling, games nights and movie nights.

Heart Month

Mayor Bronconnier again declared February 14th Congenital Heart Day in Calgary. This year we invited the

community of our children with CHD, through a special invitation mailing distributed to the Heart Beats mailing list, as well as members of the media, to a 'Proclamation Launch' at the City of Calgary Municipal Building. Off Beats member 16-year-old Jared Harrill read the Mayor's Proclamation and Colin Wiebe spoke about congenital heart defects and what it's like to be a parent of a child with a special heart. Our event made the evening news on both CFCN and A-Channel!

Heart Month was also commemorated with a Heart Beats sponsored night at the Calgary Science Centre open to children with CHD and their families.

If you would like more information about how you can support the work of Heart Beats, or to find out more about upcoming activities, contact anyone featured on the back page of this newsletter.

Global Acid Gas Chili Cook-Off Looking for Volunteers

Proceeds Support ACH Cardiology Clinic

The third annual Global Acid Gas Chili Cook-Off is scheduled for Friday, June 18, and organizers are looking for volunteers to support this important fundraiser supporting the Alberta Children's Hospital Cardiology Clinic.

Last year, the second annual Global Acid Gas Chili Cook-Off raised almost \$35,000 and, this year, organizers are aiming to raise \$40,000.

"This event is a blast," says Ralph Maybaum, president of the Global Acid Gas Chili Cook-off Foundation Of Alberta.

"Teams do whatever they can to persuade the judges in an intense competition to determine who has the magic recipe, the best costumes and the best team spirit."

The event invites teams of four, with a \$1,500 entrance fee, to be creative in cooking, theming and scheming.

"Anyone caught *openly* bribing the judges will be required to eat 24 chili peppers," warns Ralph.

Last year's event, held at the upper level parking lot of Palliser Square Parkade and broadcast live on A-Channel's Big Breakfast, attracted some 1,500 members of the public,

who for \$5 sampled the chili offerings of 20 teams.

This year's event will feature emcee Ron Barge, whom many of us remember as "Buckshot".

This year, organizers are looking for volunteers:

- ♥ Physically fit persons for lifting, moving, setting up and tearing down equipment for Thursday, June 17 and/or for Saturday, June 19
- ♥ Pickup trucks and drivers for Thursday, Friday and Saturday

On event day, June 18:

- ♥ Runners to work with the corporate teams
- ♥ Cleaners
- ♥ Entrance booth volunteers
- ♥ Ticket sellers for 50/50 draws, raffles and beer sales
- ♥ Volunteers to assist with prize organization and disbursement
- ♥ Stage set up

Funds raised in the 2004 Global Acid Gas Chili Cook-Off will be used to purchase a treadmill stress test system for the Cardiology Clinic at the ACH.

"Currently, cardiologists have limited



access to the treadmill stress testing system because the system belongs to the Pulmonary Function Lab," says a spokesperson for the Alberta Children's Hospital Foundation.

"A new treadmill stress testing system at the new Alberta Children's Hospital would help ensure efficient practices in testing the physical activity of cardiac patients."

And, the new system would benefit other children as well. More and more, oncology patients are using the treadmill stress test as cancer treatments often result in a damaged or weakened heart. As well, the Juvenile Amputee Clinic will use the treadmill to assess the gait of their amputee patients.

"We hope that, together with your help, we can again make the 2004 Cook-off a blow-out success," says Ralph.

On May 14 and 15, the Variety Children's Heart Centre together with the Circle of Hearts are hosting Manitoba's first heart conference.

Building Bridges To Tomorrow ... Growing Up With Heart Disease
is designed cooperatively *by* families and professionals,
***for* families and professionals.**

Watch upcoming issues of Keeping The Beat for articles featuring the conference.

For more information, phone Audree at (204) 787-2412,

or surf to www.vchc.ca,

If you are interested in volunteering, or if you have any further questions about the event, please contact Judith Churchill at 803-7767

or by e-mail at judith_churchill@murphyoilcorp.com.



Another Family Event Planned for June

Everyone is invited to a family gathering at the Southland Leisure Centre, (on Southland Drive, just west of 14th Street SW) on Saturday, June 26, 2004 beginning at 4:00 pm. This is an opportunity to meet - or renew acquaintance with - other families of children born with congenital heart defects for fun, food and friendship. Whether your "heart child" is 2 weeks old or 20 years old, we would love to have you join us!

Southland Leisure Centre features a wave pool, a diving tank, a hot tub, a separate warm and shallow infant pool, and three waterslides appropriate for kids as young as two years old on up to the daredevils among you! We'll have free reign of their patio, just off the pool deck, and you're invited to bring along your own picnic supper. They also have a concession if you wish to purchase food.

Southland is offering us a group rate of \$3.25 per person, to a maximum charge of \$19.00 per family. Children under 2 are free. They offer life jackets for rent at a cost of \$1.75,

and you are also welcome to bring your own flotation devices.

To confirm your attendance and purchase your admission passes, please contact either:

- ♥ Patty Wiebe at 256-7423 or e-mail pattywiebe@shaw.ca
- ♥ Michele Maurette at 251-2446 or mmaurette@shaw.ca

You must purchase your admission passes before June 10 ... Southland requires an attendance count so they can have the appropriate number of lifeguards present.

We look forward to seeing you there!

It's Time To Renew Your Heart Beats Membership!

Parents Names (first and last)

Street Address

City, Province, Postal Code

Phone

Work / Cell Phone

E-mail

Child's Name and Birthdate (day/month/year)

Description / Name of Congenital Heart Defect

Siblings and Birthdates (day/month/year)

- I have included my \$15 membership fee
- Please just add me to the Keeping The Beat mailing list
- I am enclosing an additional donation of _____

Charitable registration number: 88907 6261 RR0001

The Alberta Freedom of Information and Protection of Privacy Act legislates your confidentiality. From time to time, Heart Beats receives requests from parents who wish to be connected with other families dealing with similar heart defects. If you do not wish your name to be included on our parent referral list, please check this box.

If you do want your name included on the Heart Beats parent referral list, please sign here.

signature

Please cut out this form and mail to:
Heart Beats Children's Society of Calgary
Box 30233, Chinook Postal Outlet
Calgary, AB T2H 2V9

Mom & Tots

Momentum is gaining for the Mom & Tots group, with monthly gatherings being scheduled and attended by a growing group of moms and tots!

A small group gathered on March 25 at Patty Wiebe's home and, on April 22, a larger group gathered at Michele Maurette's home.

"We are having a great time, and are welcoming a few new faces," says Michele.

"In April, we had six moms and eight children in attendance ... five of them under 15 months old! And, the girls outnumbered the boys six to two!"



Michele adds, "The group is starting to grow and we're looking forward to getting together on a more regular basis — the kids are excited about future activities outside!"

Upcoming activities include:

- ♥ A gathering at the zoo, May 31, 10 am
- ♥ A visit to Heritage Park, June 28, 10:30 am
- ♥ Butterfield Acres, July 26, 10:30 am

"And we're always looking for moms interested in hosting future get togethers for Mom & Tots," says organizer Angie Enslow.

She adds, "We have dates selected for monthly Mom & Tots gatherings through to the end of the year, and if you'd like to volunteer ideas or support of any kind, call me!"

Once the group gets a phone list together, Patty Wiebe has offered reminder phone calls to interested moms.

Heart Beats Mom & Tots is an informal group offering opportunities for families with young children to connect with other families sharing the common experience of living with congenital heart defects. For more information about upcoming activities, contact Angie Enslow at 251-3989, Michele Maurette at 251-2446 or Patty Wiebe at 256-7423.

Off Beats

Off Beats continues to be an important group for teens and tweens living with CHD. Their casual camaraderie and common bond creates an empowering environment that translates into improved self confidence and esteem in the rest of their lives.

"On May 12, from 7-9 pm, we're meeting at the UofC Campus Cove for fun and games," says Patty Knox, founder of Off Beats and Clinical Resource Nurse at the Alberta Children's Hospital Cardiology Clinic.

"The owners of Campus Cove have a child who has spent a lot of time at ACH and, this month, they have chosen to donate time for Off Beats kids to come and play billiards and arcade games and stuff," says Patty.

The Cove will be closed to outside traffic during the Off Beats event.

It is this kind of generous support that keeps this important group alive.

"We are so grateful to the kids and their parents and others who make this group what it is!" beams Patty.

Tentative plans are in the works for an Off Beats family picnic in June, before a break for the summer months. For more information about this and other Off Beats events, or, to learn how you can lend your support, phone Patty at 943-7316.

Your Feedback

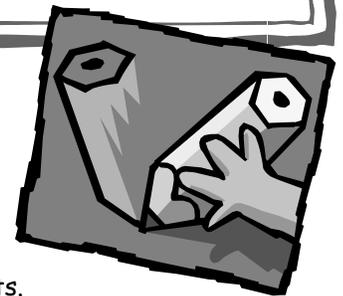
Thanks to one and all for the great job you continue doing on behalf of the families of Heart Beats.

We certainly don't mind a membership renewal fee — nothing in life is ever free!

You're doing a great job on the newsletter. Keep up the great work!

Sincerely,

Lavene and Les Morin



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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Secretary	Patty Wiebe
Treasurer	Sylvia Falk
Nurse Liaison	Patty Knox
Librarian	VACANT
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It's Time To Renew Your Heart Beats Membership!

On Page 6, there is a form and an invitation to donate \$15 in the name of renewing or joining the membership of Heart Beats. We encourage everyone who feels an ability to pay and a compassion for the empowering work of advocacy, access to information and financial and emotional support undertaken by Heart Beats on behalf of all children diagnosed with a congenital heart defect and their families, to support this work with your donation. You will be issued a charitable tax receipt. Here's the bottom line: No one who comes to us for services or support of a loved one affected by CHD will be denied. Our willingness as a collective of experienced parents, caregivers and professionals to offer ourselves in practical and compassionate service to you extends well beyond our attention to a membership list. Our desire is that the legacy of Heart Beats began some 17 years ago will live on as long as there are children born with congenital heart defects. Our hope is that Heart Beats will remain on your radar throughout the year as you consider your many opportunities to put your charitable offerings in service.

Beat The Drum Slowly

an editorial by cindy bablitz

I would like to speak about the child without CHD. My two legged tornado.

I was overjoyed, stunned even, when the nurse sent me home with him hours after he was born. No special care nursery. No bedside echocardiogram. No beckoning to meet with a "specialist".

I was downright giddy when my gp sent me away from our two-week checkup with a casual, 'see you in six months!'

Huh. No wonder moms were so sympathetic after the birth of my first boy. During those first six months, I naively carted my heart baby around, appointment to appointment, breast-pump, feeding tubes and medications in tow, with no clue how "easy" a healthy baby could be.

Easy schmeasy. My two legged tor-

nado has recently been upgraded to an apocalyptic event. Oh, I know I'll shock some of you when I admit, there are days I'd trade my flour-covered, sand-eating, lipstick-wearing 18-month-old for the docile lethargic child that was my heart baby before repair. I get to reminiscing over those long days my heart babe did little more than gurgle and wiggle, content in cuddling, dawn till dusk.

I am ashamed to say it, yet, there it is: I have to work harder at connecting with my healthy babe than I did with my sick babe. Perhaps it's simply a symptom of birth order. Perhaps it's that the tornado, the apocalypse, with all his unbounding energy, needs me less than did his big brother.

And there *is* something validating about being needed!

So I ask myself: Do I want the qual-

ity of my relationships to be measured in the extent to which I am, in some way, exalted by my status as provider? Yikes! How prehistoric!

I suppose it is a universal quest, the holy grail of humanity: to decipher meaning and connection independent of conditions. Perhaps I shall learn more about love from the one who demands less of it from me.

I do know for sure that congenital heart disease - the presence of it, the lack of it - has forever imprinted on my psyche a call to celebrate each moment ... yes, even the flour-covered, sand-gritted, lipstick-smearing moment.

More, may I ever celebrate each creator of those moments.

I love you boo.

