

♥♥ Heart Matters ♥♥

The Newsletter of the Children's Heart Network
"Working together in British Columbia...
to enhance through education and support,
the lives of children, youth and families, who
are living with congenital and acquired heart disease"



**CHILDREN'S
HEART
NETWORK**

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Heart Matters

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Heart Matters October 2012 Edition

Growing Up with Heart Disease Conference 2012

On the weekend of Sept. 22/23 over 250 family members and health professionals from Manitoba to the Yukon attended the "Step by Step, Hand in Hand" conference held at British Columbia Children's Hospital (BCCH), hosted by the Children's Heart Network. There were 20 different presentations for heart parents and health care professionals, and 8 presentations for heart youth with a varying number of topics on both structural and electrical cardiac conditions. Some examples of these sessions were a surgical update by Dr. Sanjiv Gandhi focussed on the "Growth of the Cardiac Program at BCCH" as well as "Living with a Cardiac Rhythm Disorder: Treatment Options for Inherited Arrhythmia Conditions" by Dr. Michal J. Kantoach from the University of Alberta. Dr. Hoskings gave an update on "New Catheter Interventions", parents had an opportunity to learn and discuss "How to Navigate the School System" and "How to Foster Effective Coping and Resilience in your Child", as well as "How to Transition to the Adult World of Cardiology." There were many more fantastic and informative sessions, one of the most popular being "Behind Closed Doors: A Guided Tour of the Cardiac Operating Room" with some of the lead BCCH operating room nursing staff.



Our Amazing Conference Committee!

The Hearts of Gold Youth Group gave a presentation that earned a standing ovation entitled, "YEY! Youth Empowering Youth". Their humour, insight and tenacity were appreciated by a packed auditorium.



Eddie – The Youngest
Conference Participant

The keynote speaker, Mr. Simon Keith, who grew up in Victoria, BC, wound up two amazing days with his "Moments of Truth" presentation. Keith holds the distinction of being the first athlete in the world to play a professional sport after undergoing a heart transplant. Keith was just 21 when, in July of 1986, he received the heart of a 17

Continued on Page 2



Tracy, Mary, Dr. Leblanc & Dr. Patterson
having some fun at the photo booth

year old boy who died while playing soccer. Keith, a world class soccer player prior to the operation, was determined to return to his "normal life." Keith was drafted number one overall into the Major Indoor Soccer League just three years after his surgery. Now one of the longest-living organ transplant recipients in the world and most notable professional soccer players of his time, Keith travels the world captivating audiences with his "Moments of Truth" speech while daring people to live. In 2011, he founded the Simon Keith Foundation, an organization dedicated to increasing organ awareness and education on behalf of transplant patients. Keith uses proceeds from his speaking engagements to provide athletic training for other transplant recipients who choose to return to an active and healthy lifestyle.

We are grateful to the Conference Committee, our speakers, our financial sponsors and all of our invaluable volunteers; we truly couldn't have made this conference such a success without you!

Hearts of Gold Youth Group Event



HOG group and the party bus

The equation is simple: 29 youth+Dr.Sanatani acting+1 HUGE limo bus= a fun filled two day conference for families, youth, and professionals! The Growing Up With Heart Disease conference this past September brought together youth living with heart disease, some who had recently been diagnosed as well as some seasoned heart patients. The conference also gave siblings of heart patients the chance to participate, alongside their brother or sister, in educational sessions

aimed at empowerment in health care. Thanks to an entertaining skit (with Dr.Sanatani as the lead actor) the youth learned how to work collaboratively with their healthcare team and make the most of their medical appointments. Dr. Auld engaged the youth in an interactive session aimed at learning how the heart functions. As chocolate bars were the prizes for correct answers to skill testing questions, the youth were highly attentive students. Sunday's session focused on being proud of ones self, while embracing and loving who you are, heart condition and all! Most importantly, the weekend provided the youth with the opportunity to reconnect and establish new relationships; relationships founded on the unspoken bond that only a fellow heart patient can understand. These youth shared stories and compared notes about what life is not was like living with a heart condition, including discussing past surgeries and life at school.



HOG group dining at the Keg



Sydney, Zenani and Jillian
on the "OR" tour

The highlight of the weekend was the evening Hearts of Gold Youth Group event. Twenty nine youth boarded a party bus from PhatCat Limo Services. Complete with wall to wall granite, 6000 LED lights, and eleven TV's, the bus was rocking all the way to Granville Island where we had dinner at the Keg and enjoyed "TheatreSports" at the Improv Centre. The teens came away from the conference with a real sense of belonging and a strong sense of camaraderie emerged. There were 29 tired youth and one exhausted youth coordinator by the end of the weekend but so many fantastic memories!

By Kristi Coldwell – Vancouver HOG Coordinator

"I really, really enjoyed the conference, learned lots, and it has prompted me to be more involved and proactive in my son's care. I would also like to mention that both my children had an absolutely awesome time with their groups and they are still talking about it with everyone at home. It was an overall AWESOME weekend!"
Monica Donnelly – Heart Parent

"...how much we enjoyed coming over to the conference... absolutely one of the best we have attended as far as the mix of careproviders, parents, youth and children. The exchanges of information were heartfelt (excuse pun) and eloquent and we felt we really needed the update as far as rhythm disorder."

Anne Carrelli – Cardiac RN from Vancouver Island

"What an amazing 2 days for everyone!"
Angela Krizan – Western Canadian Children's Heart Network (WCCHN)

*Natasha Feuchuk – CN Miracle Match Champion Child *

Natasha Feuchuk is a bright, vibrant 15-year-old girl who likes swimming, hip hop, skating and has a flair for the dramatic arts. But the vivacious young woman hasn't always been able to enjoy life to the fullest. At six days old Natasha was diagnosed with truncus arteriosus type II, a rare and complex defect of the heart. At 10 weeks old Natasha had her first heart surgery – a repair that would last for nine years. When Natasha was in Grade 3 she started to tire easily, and was having chest pains. Although she was healthy, the exhaustion and pain were signs that she had outgrown her heart repair, and needed surgery to put in a larger conduit and valve.



The prospect of heart surgery was daunting for Natasha, who had no memory of the surgery she underwent as an infant. Fortunately, she had a helpful resource in Mandy, her clinical nurse at BC Children's Hospital. Mandy explained what would happen during surgery and gave Natasha a "Heart and Soul" binder that described the procedure and what to expect. This gave her confidence and reassured her. "The knowledge I gained helped me understand exactly what was going to happen during my surgery," says Natasha. "I no longer felt afraid." To further build her comfort level, Natasha and her family toured the Pediatric Intensive Care Unit (PICU) and cardiac ward. On July 4, 2006 a very nervous Natasha was scheduled for the second open heart surgery of her young life. The surgery took over seven hours and was a success. After two days in the PICU and another four days in the cardiac ward, Natasha was allowed to go home. Natasha's recovery included a difficult rehab process, which she undertook with the help of the talented physiotherapists at BC Children's Hospital. "I really did not like the oxygen tubes in my nose, so I had to do breathing exercises to make sure my lungs did not fill up with fluid," she says. "The physiotherapists tried to make the breathing exercises fun. At first I could barely do the exercises – gradually with practice I got better."

The physiotherapists weren't the only ones helping during recovery, which went smoothly. Throughout the entire process Natasha was supported by her loving family including her parents Danny and Tessa Feuchuk and her two older brothers Erik and Errol.

Although she will likely need another surgery when she's in her mid-20s, Natasha is happy and healthy today and able to reflect on the challenges that she has faced, and those faced by other children with heart disease.

"We and our parents, go through a lifetime of challenges," she says. "It is therefore a blessing to know that because of advanced research and modern technology, children's lives are not only spared but they are given a chance for longer lifetimes."

Every year, about 265 children in BC and the Yukon are born with heart disease. BC Children's Hospital's cardiac team performs about 360 heart surgeries on children a year, including roughly 230 open heart surgeries, more than half of which are performed on children under a year old.

(re-printed with the permission of The Vancouver Sun, photo by Brian Hawkes)

This summer, Natasha was delighted to be the CN Miracle Match Ambassador and to participate in the CN Miracle Match program, which raised \$1.8 million for the children of British Columbia. CN Miracle Match is a national charitable initiative designed to rally communities across Canada behind a very worthy cause – supporting pediatric care. Each year, prior to the CN Canadian Women's Open, CN and Golf Canada select a new foundation to be the official charity and beneficiary of the CN Miracle Match program. This year, BC Children's Hospital was the lucky recipient!

**Thanks to Cameron Forbes and his family, who operate the Critter Cove Fishing Lodge, 10 of our heart families were able to have the experience of a lifetime this past July.*

*Here is a little summary from the Lessing Family**



Helen & Family with their fishing hosts Jay & Emily

All the families that went with us to Critter Cove this year came back with great memories, new friends and an abundance of delicious fish! Each heart family was matched with a "fishing host," a couple or family that has volunteered their time and their boat for three days. Our hosts, Jay and Emily, were so wonderful right from the first moment. We were told "this trip is for you, so whatever you want to do, we will do it! We can go fishing at the crack of dawn or we can go a little later. We can fish all day or just float in the sun!"

Having someone donate their time, put in so much effort, afford us so much attention (and with such thoughtfulness) was something we will never forget. A "Thank You" was just not enough for what we were given that weekend.

For my daughter Helen, it was her first chance to experience being on a boat on the ocean and it was my husband's first time ever fishing in Canada. We had such great accommodations and food; it was truly an experience that we will cherish forever. Helen enjoyed every minute of her time. The highlights were meeting the other heart kids, fishing off the dock and playing games. Her days could have been full even before we take into consideration all the great group activities that were planned. The only thing she would change is how long she stayed, I'm pretty sure she was prepared to live there forever! Being offered an experience like this is something that makes you feel really blessed.

Another comment on the Heart Conference (From page 2)

"First of all Sophia, Dexter and I wanted to THANK YOU so much for having us at the Heart Conference. To say it was beyond our expectations is an understatement. The two days were so very informative and affirming, that this journey we are on, is shared by so many. It was also fantastic to meet and hear the amazing speakers, so many from the medical profession - how human and refreshingly connecting it was. We are still discussing last weekend - which in our household is rather rare considering all the balls we juggle at the present moment. So, to all of those and especially you Jan (Rooks), for organizing and facilitating this conference, a heartfelt hug and thank you!"

Sar and Dexter Quaw – Heart Parents

Introducing.....Our New "Hearts of Gold" Coordinator

My name is Kristi and I am a recent graduate of the University of Victoria's Child and Youth Care degree program. This past winter I completed my Child Life internship at BCCH and Surrey Memorial Hospital and had a great time doing it!

I enjoy taking my two little dogs for walks (I have been known to dress up my dogs for Halloween) I like going to the beach and I love spending time at Granville Island.

I feel very fortunate to be taking over this position from Brie and I am looking forward to meeting each of you!

By Kristi Coldwell



Kristi and her buddies!

Mark the Dates

CPR Course for Heart Parents – Nov. 24/12 10am to 2pm (lunch provided) at Matsqui Recreation Center 3106 Clearbrook Road, Abbotsford. Please RSVP by Nov. 20th to:
pacificchildrensheartnetwork@gmail.com

CHN Christmas Pool Party for Island families - Sunday, Dec. 2nd at the Commonwealth Pool, more info to come

CHN "Breakfast with Santa" Christmas Party for Lower Mainland families - Saturday, Dec. 1st at the Metrotown Hilton Hotel - more information to come.

The 10th Annual Wine Gala Dinner – Wednesday, May 1st/2013 at The Vancouver Urban Winery

What's Up?

♥ CONGRATULATIONS!

Vancouver "Hearts of Gold" coordinator Brie Barron and Taylor Swanson are the proud parents of baby girl "Audrey Elise", born 8 lbs 7 ounces on September 12/12.



Baby Audrey

♥ EXCITING NEWS FOR NEW MOMS!

The CHN was able to provide the funding for two brand new breast pump machines which are now available for use on the cardiology ward, 3M.

♥ CPR COURSES

The recent CPR was so well attended that the CHN will be hosting one in Abbotsford (see above.) We hope to host another session in Vancouver shortly. Please let us know if you are keen for us to hold a CPR session in your area (including the Okanagan and Vancouver Island.) Meet some other heart parents while learning some valuable life saving skills.

♥ HOW CAN YOU HELP?

We are looking for volunteers with the Christmas party for the following things:

- Greeting people at the registration table
- Selling raffle tickets
- Bringing baked goods or treats for dessert
- Can you help us find a Children's Entertainer (such as a magician etc?)

CHN Annual General Meeting – We invite all CHN members to join us on Thurs. Nov 15th at 7pm in Room 3D16 at BC Children's Hospital. Our guest speakers will be Dr. Curran Warf, Pediatrician and Head of the Division of Adolescent Health and Medicine at BCCH, and Sabrina Gill, Nurse Clinician with the Youth Health Program. Together they will facilitate a discussion on bullying, focussing on the experiences of children growing up with chronic health issues.

Heart Matters

is produced by the Children's Heart Network
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Hearts of Gold Teens Hit Camp Zajac

HIGHLIGHT #1: This year the Hearts of Gold (HOG) camp was in July, whereas in past years it has been in May. This meant that we had the opportunity to experience some nice summer weather! We saw the sunshine every day, applied lots of sunscreen and drank lots of water. Having the nice weather makes the outdoor activities so much fun.

The first morning, the group was up bright and early to partake in the POLAR BEAR swim! The sun hadn't warmed the water yet so many found it quite chilly jumping into the lake first thing in the morning. The screams of the youth as they jumped from the dock and faces of some of them as they emerged from the water after their plunge was priceless. The brave jumpers had many cheerleaders standing on the side encouraging them and snapping pictures as they jumped.



The "Polar Bear Swim"

HIGHLIGHT #2: Our group was able to do a few new activities this year as we were there in the summer months, kayaking and swimming. The lake was nice and calm and everyone did a great job of keeping their kayaks from tipping... until the games started! We played a game called "PIANO KEYS." We lined the kayaks up in a row facing the same way so that they essentially looked like piano keys. Then one person would climb out of their kayak, walk to the tip of it and walk, run, crawl or in some cases fall from one kayak to the next. The goal was to get from one end to the other and back to your own kayak without falling. The challenge was that kayaks are very tippy so when you step on the bow of the boat it can sink and move as you try to move on to the next kayak. This was a very entertaining afternoon indeed!



The group playing "Piano Keys"

HIGHLIGHT #3: Another highlight this year was the beautiful indoor pool, as it was just recently constructed. Everyone had a great time at the pool party! We played volleyball, did aqua aerobics with pool noodles (a sight to see) and had dance parties. The facility is gorgeous as the pool is surrounded by rocks and a great waterfall. We had a fantastic time and can't wait to re-connect with all our heart friends next year!



"Pool Party!!!"

To make a tax deductible donation, please contact the Children's Heart Network
Registered Charity Tax Number: BN139462394 RR0001

Keep Our Kids Safe - AEDs in Schools

At the recent "Growing up with Heart Disease" Conference at BC Children's Hospital in Vancouver, there was a lot of interest from both heart families and physicians in getting AED's (automated external defibrillators) into schools. However, equipping schools with AED's is not as simple as hanging a case on the wall! It requires planning, funding, staff training, maintenance and the support of families. The good news is that some school districts have moved ahead and have been installing AED's. Coquitlam, Belcarra, many Catholic schools and a few secondary schools in B.C. have recently accomplished this. One of the B.C. Heart and Stroke foundations mandates is to help get AEDs into community centres across the province. These are stories of success. However, many of us would love to see every school in the province equipped with an AED.

This article highlights that AEDs do save lives: <http://www.vancouversun.com/health/Child+saved+lifeguards+highlights+need+more+AEDs/6767640/story.html> I encourage all families to educate themselves as to where AED's are currently available in their communities, such as community centres, arenas, schools and so on.

I believe that as a group of concerned parents we can help make change happen more quickly. I would like to begin by compiling a list of schools/school districts that have AEDs available. If you have this information or can help by acquiring it, please send your feedback to Sandy Hoshizki at sandiaporter@yahoo.com and we will collate the results. In addition, if you have successfully placed an AED in your school, we would like to hear your story. If you would like to be involved, please let me know. Let's spread the word about the importance of AED's in keeping our children safe at school and in the community.

Submitted by Sandy Hoshizaki

Summer Fun at the Waterslides

On a gorgeous and "hot" August day, about 300 members of the Children's Heart Network joined together at the Cultus Lake Waterpark for an incredible day of fun in the sun with all their heart friends. We were thrilled to have a number of families come all the way from Vancouver Island to join us as well as some families from the Okanagan area. We are so thankful to the Gizeh Shriners for providing the bus to transport our island friends from the ferry terminal all the way to Chilliwack and back. The highlight for the little ones was the Pirates Cove interactive playground (which had grown in size from last year) and for the big kids it was the "Colossal Canyon." It was great to see many of the Hearts of Gold teens reconnecting as they had just come back from a great time together at Camp Zajac and so many parents building relationships both old and new. Hope to see everyone there again next year!



Fun at the Pirate Park

Children's Heart Network Staff:

Samantha Aitken – Provincial Coordinator

Kristi Coldwell – HOG Youth Coordinator

Krista Molia – VIHOG Youth Coordinator

Working together to help children who are living with congenital and acquired heart disease.

BCCH Partners in Care (PiC) is always looking for family members to participate in providing feedback to the hospital. If you are interested in providing feedback and suggestions for the Heart program, please contact:
Carmen Carriere at 604-946-5494 or carmike28@hotmail.com.



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Employment Insurance for Parents with Sick Children

In August 2012, Prime Minister Steven Harper announced that the federal government intends to follow through with its 2011 election promise which will allow parents of seriously ill children to collect EI for a longer period of time. He said "we understand the vital role that a parent plays in helping a child back to health."

Currently, a parent or guardian can collect up to 6 weeks of "compassionate care benefits" through the employment insurance program for a child with a life threatening illness. The new benefit would extend this support for up to 35 weeks. As with the current benefit, a signed medical certificate from the child's doctor or specialist is required. This is such great news and will be of huge value to many of our heart families as parents could take more time off from work to help care for their child when needed.

Special Acknowledgment



We would like to send a heart-felt thank you to all those that made such generous donations to the Children's Heart Network in memory of Mila Dickout. We are so grateful for your support!

- Volunteers Needed -

Our families enjoy the spring, summer, fall and winter gatherings that the CHN sponsors. We are always looking for volunteers, so if you have sometime, talent and expertise that you are willing to share, please contact Sam Aitken at: saitken@childrensheartnetwork.org



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