



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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The Heart of Christmas!



On a sunny Saturday morning just before Christmas over 300 Heart Network folks got together to celebrate the season at The Metrotown Hilton Hotel. There was lots of time for parents to chat over coffee while the kids were entertained by the award winning children's performer "Dustin the Purple Pirate!" Dustin's passion for performance and his gift with children really shined through as he engaged so many of our heart kids, both young and old. They smiled, giggled and yearned to be one of his lucky volunteers. Thank you Dustin for making our event so special!

We all enjoyed a fabulous buffet brunch topped off with many gorgeous home-made treats donated by our families and then the magic happened....as we sang "Jingle Bells" we were surprised by a visit from the legendary, white-bearded man and his wife, Mrs. Claus. All of our heart kids must have made the "nice" list as they presented each one with a perfectly chosen gift (which wouldn't have been possible without the tireless efforts of the Chilliwack Heart Mamas



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For more information or to book a party/event please contact Dustin at www.purplepirate.com

Heart Matters

Coffee Group - they did all the shopping and wrapping!) Another fun part of the event was watching so many happy faces being entertained by the face-painters, balloon animal makers and the fantastic caricature artist!



The Homan Family

The creative kids enjoyed making crafts and decorating gingerbread men (with the help of our Hearts of Gold youth and Houston's grandma, Kathy Maxwell.) Many lucky winners got to take home raffle prizes that were generously donated by so many of our CHN members.

We are so grateful for all the volunteers, bakers, raffle donators and entertainers. This special event would never be possible without the generosity of all of our Children's Heart Network supporters.



Houston & Grandma



The Martz Family



Ben - our helper at the check in desk



A big heart-felt thank you to:

The Purple Pirate
Dustin Anderson

Lisa Nicole Brown
Bob and Dee McLennan
Crayola
Dr. Potts
Deanne Lane-Smith Photography
The Metrotown Hilton
McDonalds
The Chilliwack Heart Mamas Coffee Group
Global Container Terminals
Chantelle Bisschop
Melissa Martz
Stillwood Conference Centre

Samantha Palmer
The Hoskins Family
The Church Family
Lori Homan
Sara Lessing
Ivette Varga
Nina Grimshaw
BCAA
Annie White
John Scholtens
O'Hares Gastro Pub
phoTobin Photography
Cary Van Ieperen - "Corycatures"
Arthur Murray School of Dance
A Star Art Parlour

The Taylor Family
The Crocker Family
Midland Appliance
Joelly Segal
The Roaming Dragon
Food Truck
Rustic Soap Company
Tecia Beulens
Rich-Tek Industries
Thriftys Foods
Milestones Park Royal
Save On Foods
Safeway
Mary Kay

Thanks

“Keepin the Beat” by Bill Coon

Let me begin by saying that it is both an honor and a privilege to be sharing my story with the Canadian public. For my first heart donor was an infant born in Ontario, Canada. My name is Bill Coon. I am a two-time heart transplant recipient, first-time kidney transplant recipient, an author, a son, and a man who is forever, eternally grateful to two complete strangers.

I was born with a congenital birth defect (Hypoplastic Left Heart Syndrome) on April 24, 1989, in Barrington, Illinois, USA. In laymen’s terms, it meant that the left side of my heart was severely underdeveloped. It also meant I would require a heart transplant and my life expectancy clock of twenty-one days had just begun ticking.

I came into this world not breathing. I had a heart attack seconds before I was born. Before I had even seen the light of day, I was in severe pain. I had stabilized, but not for long. The doctors knew I was deathly ill, and the next day I was placed into a helicopter and flown directly to a pediatric hospital in Chicago, Illinois, USA.

It was that very pediatric hospital where the “King of Hearts” practiced. His name was Dr. Idris. He was a German Pediatric Cardiac Surgeon who had spent the last sixteen years of his life experimenting on puppies and kittens, perfecting his technique at heart transplantation. He had the steadiest of hands, and they were going to have to remain steady, for the baby that just arrived on the roof of his hospital was in dire need of his expertise.

Days went by. My parents watched me grow sicker with every passing hour. They witnessed families come and go, many of them with tears running down their faces, for a great deal of babies in the NICU nursery did not survive. My parents developed friendships with these couples. Several of them offered their child’s heart to me as their parting gift. None of the hearts were ever a match.

My Mom could not stay by my hospital bed every night. Instead, she would leave me a wind-up music box that she knew I loved. She had a motherly intuition that told her I enjoyed the music, even though in my first twenty-one days on this Earth I never once opened my eyes, nor did I ever smile. My Mom would instruct the nurses to play the music for me as I slept—she wanted to comfort me even when she was not around.

On May 15, 1989, my life expectancy clock had reached its final hours. It had been twenty-one days. The doctors were going to pull the plug because on the twenty-second day my other organs would begin to fail. Nobody wanted me to experience any more pain. I have been told that death was in the air that day. I had hit rock bottom, but something was different. The energy of the doctors had changed. They were awkwardly upbeat given the upsetting circumstances. At 4:15 PM, my parents were pulled aside and informed that Canada had just joined UNOS (The United Network for Organ Sharing) and that a matching heart in Ontario, Canada had just been located. “All we can do now is pray for good weather and clear skies,” my parents were told. With that, a helicopter and a Learjet embarked on a journey to Canada to save my life.

At midnight, my transplant was performed. I was the eighth infant heart transplant to be performed in the USA and the fourth in the Midwest. After the procedure, my entire body was so swollen that I supposedly did not look like myself. I looked like a different baby. My Mom watched me in my cradle that night. She wound the music box and it began playing the sounds that I had fallen asleep to the first three weeks of my life. That was when I turned my head towards the music. It was May 16, 1989, the day I opened my eyes for the first time.





From that day on, I lived a wonderful, healthy, normal life. I was just as rambunctious and playful like any other child. Truthfully, the only limitations that I ever had were those that I put on myself. For years, I refused to attend any pool parties or take my shirt off in locker rooms because I was embarrassed of my surgical scars. I feared everyone would ask questions and once they received the answers, they would treat me differently. It wasn't until my junior year in high school that I finally overcame my body image issues and told my friends, Jen and Jo, I had a heart transplant. In my mind, junior year is when I finally came into myself. I had matured mentally and I was finally comfortable with "me." It was junior year when I understood that my transplant was a blessing and not something to be embarrassed of.

In the fall of 2008, I began studying advertising and communications at Columbia College Chicago. I excelled in my classes and I eventually obtained an internship at one of the top radio station's in the Chicago market. I loved every moment of it. My life seemed to be on autopilot. Everything was going my way. I learned that if you put forth the effort, you eventually reap the benefits. However, as they say, "All good things must come to an end," my autopilot feature shut off just as the school year ended.

On June 8, 2009, I was rushed to my community hospital after I looked down and found that everything below my knee was swollen. Upon arriving to the emergency room, the doctor evaluated me, took a chest X-ray, and returned to my room with a solemn look on his face. He turned to my parents, and in a sad, but assertive way said, "Your son is in heart failure."

A pocket of fluid had enveloped my heart. The water retention had gotten so severe that my heart was no longer strong enough to pump the fluid through my body, thus causing the buildup in my legs. I had developed Transplant Vasculopathy, a rare phenomenon in which a transplanted heart deteriorates rapidly in a short period of time. My kidneys were also failing. Due to a lifetime of taking anti-rejection medications (immunosuppressant), my kidneys happened to simultaneously crash alongside my heart.

The ensuing four months featured a misdiagnosis, countless procedures, and three separate hospitalizations. The final hospitalization was the longest—I spent 70 days in the CCU fighting the clock as I awaited a second chance at life.

Fortunately, due to the selflessness of one family, my life was saved for a second time on October 21, 2009. That day, I received my second heart transplant. The kidney was transplanted the following day.

To provide you with an idea of how quickly my life turned around, I was discharged from the hospital on November 2, 2009. On December 28, 2009, I moved into a studio apartment in Chicago.

Something I did not mention was that at the onset of my illness, I began to keep a journal. Initially, the purpose of the journal was for my own, personal therapeutic use. Eventually, after two weeks of writing, I realized that if I were to survive I could potentially be an inspiration to others to do the same. I also hoped to serve as a support system to anyone battling any kind of illness. I am proud to say that on September 13, 2010, I published all of my journal entries (along with some short stories) in the form of a book entitled, *Swim: A Memoir of Survival*. In just under a year, the book has sold internationally and it has been adopted and praised by both readers and charities battling cancer, organ failure, congenital birth defects, Crohn's Disease, and a plethora of other illnesses.

I am currently writing my next novel, *The Perfect Cloud*, public speaking, promoting organ donor awareness, and fulfilling my dream of aiding readers (via e-mail) who need someone to talk to when they are ill.

If you would like more information about *Swim* or myself, please feel free to visit my website at www.billcoonbooks.com

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Volunteers Needed

Volunteers Needed – Join the Conference Planning Committee! We are in need of people to help us plan the next Heart Matters Conference which will be Oct. 21 & 22, 2012. We just meet once per month and you can be part of a very fun and exciting event for the whole family.

Please email saitken@childrensheartnetwork.org





What's Up

Mark the Dates!

March 31st: Lower Mainland Easter Egg Hunt at Queens Park in New Westminster

May 10th: The 10th Annual Wine Gala dinner will be held at The Vancouver Urban Winery

June 24th : The Scotiabank Challenge 5KM run/walk and half marathon

July 3-7th: Heartbeats go to Camp Zajac (ages 8-12)

July 12-15th: Hearts of Gold go to Camp Zajac (ages 13-18)

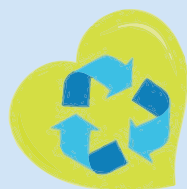
Fishing For Hearts

Jim & Mavis Decker, Cam Forbes and the winning fish!

This past August, Critter Cove Fishing Lodge held their annual fishing derby in support of the Children's Heart Network and they raised a whopping \$3200! These funds will help us send our heart kids to Camp Zajac this summer. We are so grateful to Cameron Forbes and his family as well as all the volunteers that help Cam support our heart families.... they have been doing this for 10 years now.



Thank you Critter Cove!

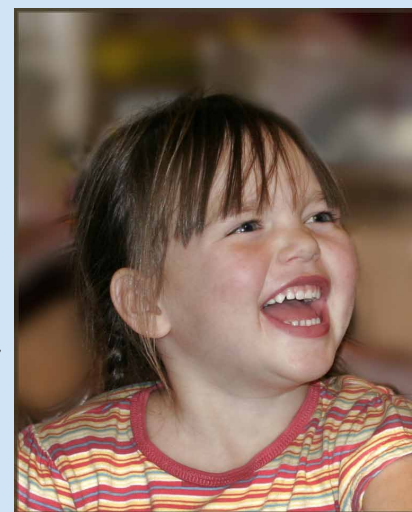


Recycling with Heart

With Layna Lawes...



*Layna Lawes was born in 2007 with Tricuspid Stenosis and a VSD. In March of 2008, at 6 months old, she had surgery to make the necessary repairs to her heart and ended up having a pacemaker implanted. Layna is a bubbly 4 year old with an older sister and brother, she loves to go ice skating but does get tired sometimes. The Lawes family lives in Princeton BC and owns the Bridge Street Car Wash. Tanya Lawes noticed that lots of bottles and cans were getting thrown in the garbage so she put a special recycling box out with a sign that tells their customers that all the proceeds will go to the CHN. This year, they collected \$294 and then the Lawes family topped up the donation to \$500. **Thank you so much!***



"Hearts of Gold" – our youth group for heart teens from 13-18 years old

The Hearts of Gold (HOG) group took the summer off but we were back in action this fall. In September, we braved the forest and had an amazing adventure at Wildplay in Maple Ridge. Our fearless group members jumped, swung, walked and wobbled through an obstacle course between 6 and 60 feet above ground. We conquered several challenges which included tightropes, missing plank bridges and swinging logs. We soared on ziplines, climbed on cargo nets and ascended tree ladders! It was a beautiful day and everyone worked as a team, encouraging and coaching each other on how to get through the next obstacle.

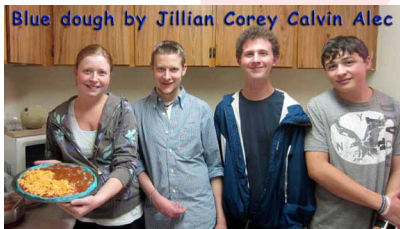


October wouldn't be October without a pumpkin carving night. We gathered at my house and started designing individual pizzas. Being Halloween, we had green, blue and orange dough! Then we gutted our pumpkins (trying not to have too many gut fights) and carved away. The pumpkins

looked wonderful illuminated on the deck! Everyone did a great job with their designs and we sure had some unique pumpkins.

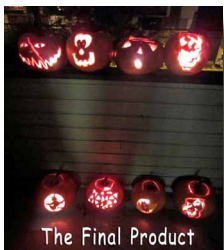


November was a great opportunity for some of the HOG members to give back. It was the CHN Christmas party and we needed a bit of help running the craft tables. We had some very kind youth volunteers and they did a great job helping me get the crafts organized and then they ran the craft tables on the day of the party. Thank you for all of your help!



December called for some Christmas fun. We bundled up for the cold weather and spent the evening at Van

Dusen Gardens for the Festival of Lights. The display was beautiful. We walked around the grounds with hot chocolate and enjoyed the light shows that are synced to music, a different one every half hour. We finished the evening with a gift exchange so we all went home with a little surprise!



This past month we went "cosmic bowling" and had a pizza dinner at the bowling alley. It was fun, but it sure is hard to bowl well when you are playing 10 pin! The bowling balls are SO heavy. We had a great time laughing at ourselves as we got gutterball after gutterball! Some of our HOG kids however, could be budding Olympians, as they scored many strikes and spares. Very impressive!

Coming up soon, we have planned a snowshoeing adventure and a day of geocaching (scavenger hunt with GPS's). This Spring promises new adventures and with camp in the near future, there is lots to look forward to.

This is going to be an exciting year as we have a lot of heart kids who will be turning 13 and they can now join the HOG group. We are really excited to have some new group members! If you are 13 to 18 (or are close to turning 13) please e-mail me (**Brie Barron**) at chnheartsofgold@gmail.com and I can add you to the e-mail list so you can learn about all our great events!

Are you interested in training the next generation of doctors? The UBC Faculty of Medicine Southern Medical Program (SMP) is recruiting Volunteer Patients to help train its inaugural class of medical students.

On March 20th and 22nd, 2012, the 1st year medical students in Kelowna will be learning how to recognize cardiovascular conditions in children. To facilitate this, the SMP is recruiting Volunteer Patients to help the students become great physicians.

Students, supervised by a mentoring doctor, will learn:

- how to perform a cardiovascular exam (listening for heart sounds and pulses only; no ECG, X-rays or invasive procedures)
- how to communicate with children and their families
- how to recognize audible cardiovascular conditions in children.

Each 1 hour session is held at the Clinical Academic Campus beside Kelowna General Hospital between the hours of 3:00 pm – 5:30 pm. Volunteer Patients receive a \$20 reimbursement to help offset any travel or parking related costs.

If your child is interested in participating, please contact Diane Oorebeek, Standardized and Volunteer Patient Recruiter, at 250-980-1329 or smp.volunteer@ubc.ca.

Heart Mamas Coffee Groups

If you are interested in connecting with some other heart moms & dads please let us know. Coffee, Tea and treats provided by the CHN.

Richmond – Jennifer Schneider: jenniferpschneider@telus.net

Vancouver/Burnaby – Samantha Aitken: saitken@childrensheartnetwork.org

Kamloops – Melanie Kopytko: mkopytko@shaw.ca

Langley – Tacia Beulens: tbeulens@telus.net

Victoria – Teri Godin: terigodin@gmail.com

Chilliwack – Chantelle Bisschop: bissch18@telus.net

*Would you like to share your child's heart journey?
Please email them to: saitken@childrensheartnetwork.org*

BCCH Updates

Did you know that BCCH has a tollfree number within BC?

1-888-300-3088

BC Family Residence Program

Families from outside Metro Vancouver (even Chilliwack) now have increased access to travel and accommodation support if their child or infant needs medical care at BC Children's Hospital. A provincial government initiative, this program began on April 1, 2010. The accommodation component of the program will be administered by Variety – The Children's Charity of British Columbia, on behalf of PHSA and the Ministry of Health Services. The Province will also provide annual funding to Hope Air and the Shriners of British Columbia and Yukon to support their existing medical travel programs for British Columbians. To learn more about the program, visit www.BCfamilyresidence.gov.bc.ca.



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Christmas in Hawaii



The Vancouver Island Heartbeat families celebrated the Christmas Season with a twist this year - "Christmas in Hawaii". Families joined in on a family swim followed by a pizza party, Christmas crafts and of course a visit from Santa.

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

CHN Staff:
Samantha Aitken – Provincial Coordinator
Nancy Fraser – Programs Coordinator
Brie Barron – HOG Youth Coordinator
Krista Molia – VIHOG Youth Coordinator



You are cordially invited to the..

10th Annual Wine Gala on
Thursday May 10th, 2012
Guaranteed to be the best event yet!
Vancouver Urban Winery
Vancouver's newest and most contemporary venue nestled in the heart of historic Railtown at
55 Dunlevy Ave., Vancouver.

Cocktails and Canapés - 6pm
Dinner by local acclaimed chef, Karl Gregg - 7pm
MC and Auctioneer - Legendary Canucks Alumnus Richard Brodeur
Tickets - \$150 per person or \$1,200 per table of eight included is a 5 course dinner with accompanying wines included.



THE CHILDREN'S HEART NETWORK'S

10th Annual Wine Gala

THURSDAY MAY 10TH, 2012

THE VANCOUVER URBAN WINERY
55 DUNLEVY AVE
VANCOUVER, BC

For additional information contact Samantha at saitken@childrensheartnetwork.org



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