

♥♥ 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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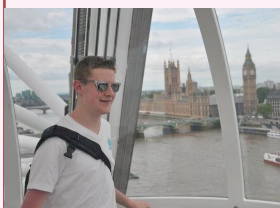
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"Transition from BCCH to St. Paul's" – An Interview with Two of our Hearts of Gold Teens



My name is Corey Zinger and I went to Children's Hospital from 1992 to 2011 and spent the first months of my life in the ICU and room 3G. This was before the renovations were done and it was a really child friendly place to be. I have a univentricular heart defect, a pacemaker, and I had a stroke on my right side before the age of 1. Now I am almost 20 and I am taking business at Kwantlen Polytechnic University. I am also a volunteer with Young Life. In my spare time I like to take photos, travel, walk through downtown and Stanley Park as well as spend time with my friends.

My name is Jillian Wiebe. I have been a heart patient at BCCH since I was born. I am now 18 and BCCH has been a huge part of my life. I was born with a congenital heart defect called HLHS, or hypoplastic left heart syndrome which means a series of things were wrong with my heart. The biggest part of my defect was that my left ventricle did not form properly. Without a left ventricle there is no way for the heart to pump oxygenated blood to the rest of the body. Our bodies need oxygenated blood to survive. I did survive thanks to the knowledge and skills of my cardiologist, Dr. Human and my surgeon Dr. Leblanc.



I had a series of three open heart surgeries by the time I was 3. I have had other surgeries during my life. I had my appendix out and I had surgery for a broken ankle! I have also had a number of heart catheterizations which help the doctors to check my heart and take internal pressure measurements to make sure things are going well. I am pretty healthy considering how things started out. I have had really great check-ups for many years.

This January I had my first visit to St. Paul's and the Pacific Adult Congenital Heart clinic as I am now too old to be followed at BCCH. I am lucky as Dr. Human, my cardiologist, is working with patients at the PACH clinic so he will continue to follow my progress for a few more years. Going to St. Paul's was different but not scary at all. I had some of the same tests as I had at BCCH, just in a different building. I went in for

my chest x-ray and they were so speedy I was done in minutes!

I haven't let having a heart condition slow me down or change my life too much. I graduated from high school in June 2011 and have spent the past year working full-time as a nanny. I have my driver's license and I use the "kid" car which I share with my sister. I plan to take some college courses in another year or two after I work for a bit longer. I am interested in taking the Early Childhood Education program at Kwantlen.

1.) How did you feel when you found out you would be starting the transition from BC Children's to St. Paul's?

Corey: *I found out that I'd be making the transition from BCCH to St. Paul's when I was in my last year of high school but never moved over till the beginning of this year, 2012. I was nervous, excited and scared all at the same time, but I had the time to prepare myself so it wasn't so sudden.*

Jillian: *When I found out that I would be going to St. Paul's for checkups once a year I was actually kind of excited.*

2.) What was your biggest worry about the transition?

Corey: *My biggest worry about going to St. Paul's was that I'd have a bigger responsibility to keep my doctor informed when I wasn't feeling right. I also worried that as I was 19 (an adult) I wouldn't have my parents to explain things to me in case I wasn't paying attention.*

Jillian: *I really did worry much about the transition as I knew it was going to be a much bigger more mature hospital than BCCH.*

3.) What were you looking forward to most about the transition?

Corey: *I was looking forward to being in a new environment with adults and no children as at BCCH I always felt older than everyone else. At St. Paul's I feel young again.*

Jillian: *I was looking forward to seeing the hospital and I was glad that I would be seeing Dr. Human when I went for checkups.*

4.) What are the differences between the 2 hospitals?

Corey: *The big difference I see so far is the responsibility patients have with their own health. Another difference is that St. Paul's PACH clinic is a leading heart clinic in Canada, whereas BCCH treats children with all conditions, not just cardiac conditions.*

Jillian: *The two things I have noticed are that the cafeteria is really different and the elevators are slower.*

5.) What are the similarities with the 2 hospitals?

Corey: *Some doctors work out of both hospitals (such as Dr. Human) and the doctors in both have great personable skills!*

Jillian: *I haven't noticed anything truly similar yet.*

6.) What do you miss most about Children's?

Corey: *I miss all the people that have helped me get through all my extended stays at Children's. I also miss the giant tree in the lobby where I spent a good part of my childhood playing around when I wasn't well enough to go outdoors.*

Jillian: *I miss seeing some nurses that my parents and I know from when I was little.*

7.) What things were/weren't done to prepare you for this transition?

Corey: *I wish I could have had a tour of St. Paul's before my first check up as I did get lost for a minute or two on my first day.*

Jillian: *They told me at my last appointment at BCCH that I would be going to St. Paul's for the next appointment and that my file would be updated and sent over. I was fine with that.*

8.) Is there anything that you wish you had known before you made the switch?

Corey: *I wish I had known the amount of responsibility I'd be undertaking, so that I could use my last few visits at BCCH as a trial run for what I'd face at St. Paul's.*

Jillian: *Nothing really, I am just glad I was told ahead of time.*

9.) Do you feel you have more responsibility for your care now that you are in an adult hospital?

Corey: *Yes, there is more responsibility but I feel that through my childhood I have learned what I needed to in order to*

be prepared. At BCCH my responsibility was to let my parents know that my heart was racing or that I had a fever then they would let my doctor know and he would give me the appropriate care. I didn't have to worry about all the medical terms. Now I am more aware of all the terms and I know when I need to see the doctor.

Jillian: Yes I would say that I have more responsibility for my care and I feel more grown up. When I was at BCCH I was the oldest person in the waiting room.

10.) What would you tell someone who was worried about making the transition from BC Children's to St. Paul's?

Corey: "Don't worry, it will all come to you in time. If you aren't certain about things, ask your parents or your doctor. Don't be afraid to ask any question at all. Your new doctors will be able to answer them!"

Jillian: "I would tell them that it is a much different hospital than what we are used to but you will feel comfortable as there are lots of people your age. You won't be the oldest person in the waiting room anymore! If you are worried, find someone to talk to."

The CHN encourages youth and families to discuss readiness for or questions about transition with the BCCH Heart Centre staff. Preparation for the switch from pediatric care to adult care may look different for each youth or family, depending on individual and family needs. The Heart Centre nurse clinicians, the outreach staff who visit BC communities, the physicians, and child life specialists are all aware of the concerns that youth may experience as they prepare to leave BCCH for the "adult world." All of these health care providers are prepared to help with youth transitions.

Ideally, discussions and skill building around changes in responsibilities, developing one's support network, learning self-advocacy and understanding your own health condition should take place from middle-school age until the transition occurs. However, conversations about these issues are welcome at any time! There is staff to support ongoing learning in the adult centres too, you just need to ask.

In addition, your families and caregivers can answer a lot of questions, or help you to find answers, if you are thinking about transition to adult care. Remember that the relationships you build through the Hearts of Gold youth support network can be friends and supporters for life.

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.

Children's Heart Network Staff:
Samantha Aitken – Provincial Coordinator
Brie Barron – HOG Youth Coordinator
Krista Molia – VIHOG Youth Coordinator
Working together to help children with who are living with congenital and acquired heart disease.

- 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

To make a tax deductible donation, please contact the Children's Heart Network Registered Charity
Tax Number:
BN139462394
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The “Harding Heart Day Walk”

“February, 14th has come to mean something very different for our family. We found out on February 14th, 2006 at our 18 week ultrasound that our second child would be born with a Congenital Heart Defect (Transposition of the Great Arteries.) After he was born he had open heart surgery at two weeks old. He is now a very feisty five year old who reminds us constantly of how blessed we are” Kerry Harding

The Children’s Heart Network and the Harding Family hosted the 3rd Annual “Heart Day Walk” at Cates Park in North Vancouver on Feb 12, 2012. It was a small community event to which heart families and friends were invited to come out for a short walk to bring awareness to being healthy and active.

The weather co-operated and over 50 people came out to enjoy this event and more than \$481 was raised!

February 7-14 was also Congenital Heart Disease Awareness Week!



Heart Day Walk with Baby Balloons

Lower Mainland CHN Easter Egg Hunt

On Saturday, Mar. 31st over 30 families trekked to Queens Park in New Westminster for our Annual Easter Egg hunt. The weather man had cooperated and the Easter bunny had hidden colored eggs all over the park! The children had to collect one in every colour and then they could trade them in for a goody bag. One of our Hearts of Gold teens, Bradley Hoskins, was in charge of ensuring the little ones had accomplished the task and he handed out all the treats. We had

“Egg & Spoon” races for all ages which delighted the little ones (thank goodness they were hard-boiled!) While the kids played on the fantastic playground, the adults enjoyed a cup of coffee and a snack while connecting with other heart parents. A good time was had by all!

Thank you to Queens Landing Starbucks for the coffee and hot chocolate!

“Helen at the finish line”



“Bradley handing out treat bags”

Dates at a Glance

June 24 – Scotiabank Challenge Half Marathon and 5 km Walk/Run in Stanley Park

Come and join the CHN families, collect pledges from friends and family in support of the CHN and have a great time while walking or running 5km!

August 25 – Cultus Lake Waterslides Picnic

Save the date, more info to come via email invitation!

Sept 22/23 – CHN Conference

Growing up with Heart Disease: “Step by step, Hand in hand”

Chan Centre for Family Health Education (at BC Children’s Hospital)



**CHILDREN’S HEART
NETWORK**

10th Annual Wine Gala Dinner

On May 10th we held the 10th Annual Wine Gala dinner at a brand new venue called The Vancouver Urban Winery in the historic "Railtown" district of Vancouver. The building was stunning, it had a 15 foot antique door, large wine vats along one side of the room and a huge wall of oak wine barrels down the other side. We had over 150 guests for a 5 course dinner with wine pairings from La Vieux Pin and La Stella Wineries and with dessert we enjoyed an exquisite 7 year old "late bottle vintage" La Quinta do Noval port donated by long-time CHN supporter Cindy Thaler. The dinner, executed by the owners of "Two Chefs & A Table," featured local BC foods and was absolutely divine. Once again, our MC and auctioneer Richard Brodeur, well-known Canucks alumnus, was very entertaining and he helped us raise over \$29,000.



The Vancouver Urban Winery



Dawn and Mandy

the owners of "Two Chefs & A Table," featured local BC foods and was absolutely divine. Once again, our MC and auctioneer Richard Brodeur, well-known Canucks alumnus, was very entertaining and he helped us raise over \$29,000.

We would like to express our gratitude to our heart parent speakers, Don and Lee Schwartz, as well as all those that attended, donated and supported the CHN as a corporate sponsor. It was a magical evening that will help us to continue supporting our BC families that are bringing up children with heart disease.

Corporate Sponsors:

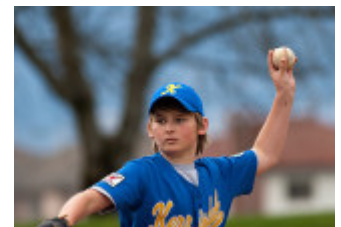
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"A Birthday Boy with Heart!"

Over twenty good friends got together at Quilchena Park on a sunny Sunday afternoon in May in honour of Will Hick's 12th birthday. They played football, soccer and British bulldog and then enjoyed pizza, cake and popsicles on the grass. This year, Will decided not to receive gifts but rather to collect donations from friends and family on behalf of the Children's Heart Network. He has a good friend, Danielle Aitken, who had heart surgery when she was a baby and who is involved with the CHN. Will raised \$620 which will more than cover the cost of sending two heart kids to Camp Zajac this summer for a memorable lifetime experience. This incredible "heart-felt" act of generosity is only one small example of Will's thoughtfulness.

Will playing ball



Will's Party Boys

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Thank you Will!



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"Follow CHN on Facebook and to check the web site for conference updates."

Heart Matters

is produced by the Children's Heart Network
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memberships, or make a tax deductible donation, please contact the CHN.
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"Dreamnight at the Aquarium"



*"Ethan, his brother
Spencer and Dad Chris"*

On May 8th the CHN was lucky enough to be invited to a very special evening hosted by the Vancouver Aquarium called "Dream Night." Over 50 of our CHN families were able to attend and it truly was a magical night. Ice cream for all, a very special gift bag for all the children, and this year there was entertainment by "Bobs and Lolo" who provided a fantastic musical adventure! So many fun characters walking around: Fin from the Canucks, Bob from the Whitecaps and the BC Lions



"Mattias and Marcus"

So many shows to watch: the dolphins, seals and whales. Our friend Ethan insisted on dressing as a shark for the special event and he had a great night! Thank you to the Vancouver Aquarium for treating our CHN kids and their families to this very special night.

Heartbeats Art Workshop

On Saturday, Feb. 25th one of our "heart" moms, Kerry Harding, hosted a fabulous painting workshop for 15 of our CHN kids at Crofton House School. The children had a great time creating a unique canvas painting to take home with them and then they all contributed to a large work of art to be auctioned at the Wine Gala dinner. The piece was called "Mapping Your Heart." The children were inspired by American Pop Artist, Jim Dine. This brightly coloured gorgeous artwork was a collaborative collection of individual marks by each child. The winning bidder was one of our corporate sponsors, Trotter & Morton. They will proudly hang it in their office!



"Kerry and her artists!"



"Hailey working on her masterpiece"

What's Up?

♥ CONGRATULATIONS!

Vancouver Island Hearts of Gold coordinator Krista Molia and her husband, Sipili, welcomed their second baby girl, Kale'a on April 12th.

♥ FAREWELL!

Past CHN Programs Coordinator Nancy Fraser, and her husband Jamie, have moved to Edmonton with their two daughters, Hayley and Abigail. We will miss you greatly and send wishes for a transition!

♥ Job Posting - Want to work for the CHN? Stay tuned for more information on some exciting opportunities that will be posted soon!

Gabrielle's Heart to Heart Doula

By Amanda Seguin

I was a week past my due date and I went into the hospital for an ultrasound that changed my life. After having several ultrasounds with no problem, this scan detected an abnormality in my baby's heart.

"Probably just a small hole," said the obstetrician. "It'll close as she grows and it's probably nothing to worry about. But I'll get the cardiologist to look at it, just in case."

A couple days later, the cardiologist, Dr. Brian Sinclair, did a long ultrasound on my belly and found that the diagnosis was far less optimistic than first thought.

My unborn baby was diagnosed with Tetralogy of Fallot. Four days later, at Victoria General Hospital, I gave birth to a beautiful baby girl. She was blue upon emerging but after a small poof of oxygen, she was right as rain and no one could tell the difference.

My husband and I breathed a sigh of relief. Maybe this heart diagnoses wasn't going to be so bad after all?

At a four week check up, Gabrielle's oxygen saturation levels were all over the map, going as low as 40% and as high as 90%. They booked her in for an emergency heart surgery at Vancouver Children's Hospital a couple days later.

Gabrielle's surgery was not without complications. The day after the BT shunt surgery was complete, we were transferred out of ICU and up to the ward. Then Gabrielle crashed. Her vitals plummeted and we took a quick ride back down to the ICU where she was hooked up to a breathing machine and pumped full of drugs to stabilize her. It was several days where she slowly weaned herself off the drugs and machines.

Five weeks after heart surgery, and three weeks out of the hospital we had another emergency surgery for an inguinal hernia. Back in the hospital, our stay was much shorter this time.

Gabrielle had her full Tetralogy Repair in November 2011 and the surgery went smoothly. The recovery was a little slow and the medical team were cautious because of her history, but her colour and temperament has improved by one hundred fold. It's like we have our little girl back, but the 'pink-deluxe-super-energizer-bunny' version.

Our little girl is now nearly 18 months old and thriving. She will have subsequent heart surgeries to replace the pulmonary conduit throughout her life but we hope to have a couple more years before another medical intervention.

After our baby was healed from her surgery, I took a course to become a certified Doula through DONA International. I have been practising as a Doula since December and find the work extremely gratifying. I found having a baby with a heart defect so entirely different than watching these new Mamas with their healthy babies and I thought, someone should offer specialized Doula services for Moms who are expecting a heart baby.

I am offering my Doula services to expectant Moms of heart babies at no cost. The change in expectations, the medical terminology, the interventions necessary for a baby with compromised health is so utterly different than a baby who has no cardiac issues. I am willing to assist in births at Victoria General Hospital or BC Children's Hospital.

Because of Gabrielle's broken heart, I've learned that broken hearts sharing together can make them whole again.

*Amanda Seguin lives on the Southern Gulf Islands. She can be reached at amandaasabee@gmail.com
Her blog is <http://www.asabee.ca>*



Children's Heart Network Conference 2012

*Growing Up with Heart Disease: Step by Step, Hand in Hand
September 22 to 23, 2012*

I still remember vividly the first Children's Heart Network conference I attended over eight years ago. I was quite hesitant to come and arrived late, not at all sure what to expect. As I walked into the Chan Centre at BC Children's Hospital, I recall being greeted so warmly by both Children's Heart Network volunteers and some of the cardiology nurses I'd gotten to know well that I felt instantly at ease. I slipped into the back of the theatre to hear the first presenter and then during the first break, I reconnected with a nurse I'd gotten to know well, met a child psychologist who was about to present about school-age issues, and was thrilled to run into my daughter's first cardiologist who had recently retired and was very interested to know how my daughter was doing. Throughout the day, I met other parents who had been through similar experiences and understood what it meant to have logged many hours on the cardiology ward. I listened to their stories, learned from what they had been through, and had a chance to offer my own advice from things I had learned as a parent of a child with congenital heart disease. The sessions I attended were excellent but it was the people that I connected with that made that conference so memorable.

This year's conference theme, "Growing up with Heart Disease: Step by Step, Hand in Hand" will explore the many transitions of growing up with heart disease. All children go through many transitions through life—infant to toddler to preschooler to school-age children. With alarming speed, it seems they are suddenly entering the school system and adjusting to new grades every year and then making the transition to adulthood. These transitions can seem especially daunting when your child has heart disease and there are the added transitions of preparing for surgeries, transitioning within the hospital from ICU to the cardiology ward, and then from the hospital to home. Each transition can feel like a strange new world, but someone before us has been there before, and with the help of professionals, family, and friends we will find the path.

The conference will have sessions on the latest developments in pediatric cardiac care, physical activity and participation in sports, neurodevelopmental outcomes for children with congenital heart disease, and working with the health care and school systems. There will also be the Hearts of Gold teen panel, which is an opportunity for parents, cardiologists, pediatricians, nurses, and other professionals to hear first-hand from the teens what it's really like to grow up with heart disease. Their frank and humorous observations always make the Teen Panel a conference highlight.

If you've never been to a CHN Conference before, I hope you'll consider coming. Not only will the workshops be full of information, the chance to connect with other families and professionals is invaluable.

--Barbara Johnston

— Registration —

Online registration will be available in July. Please check the CHN web site <http://www.childrensheartnetwork.org/> or like us on Facebook at Children's Heart Network for updates. We'll also be sending out an e-mail to all CHN members in July to let you know when registration is open.

Programs for Children and Teens

In addition to the workshops, there will be a Children's Program and a Program for Teens.

Children's Program. During the conference, therapeutic child care with certified early childhood educators will be available for infants to children up to age five. There will also be a Children's Program available for children ages 6 to 8 and ages 9 to 12. The program welcomes all children with heart disease and their siblings but space is limited and preference will be given to families from outside the Lower Mainland.

Program for Teens: Hearts of Gold.

The conference committee welcomes all youth with heart disease and siblings ages 13 to 19 years to attend sessions that are specific to youth. The Hearts of Gold program is an opportunity for youth to share ideas, learn from experts, and have fun. They will enjoy a range of opportunities at the conference and in the city.

Heart Matters Winter 2012 Donor List

The CHN would like to thank the following individuals, organizations and businesses for their support and generous gifts over the past six months:

Platinum Heart Partners \$5000+

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CKNW Orphans Fund
Trotter & Morton
Crittter Cove Marina*

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River Rock Casino & Resort
Philippe Segur
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Vancouver Giants
Mission Hill Winery*



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The Best Place on Earth



CHN is looking for new board members. To attend our next meeting on June 21st/2012 6:30pm at the provincial office, please email chn@childrensheartnetwork.org for more information.