



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**

Kaylie – Big on Heart & Soul!

Story by Chantelle Bisschop

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**CHILDREN'S HEART
NETWORK**

When Kaylie was 8 months old she was sick and didn't seem to be getting better. She was very tired, a little blue and seemed to be fighting to breathe. I took her to our local walk in clinic to get checked out. The doctor asked if she had a heart murmur and I said that I wasn't aware of one. He scheduled us to see a pediatrician in Chilliwack, where we lived. The appointment was for the end of the week but I got a call a few days later to come in right away. Kaylie and I met with Dr. Ebesh. He listened to her heart and told me that he was going to send us to BC Children's Hospital for further testing. I asked some questions about what he had heard; I really didn't understand what we were facing. He told me that I should go home and treat her like a normal child. He also mentioned that I shouldn't do research on the internet as the information might not be relevant to Kaylie's situation.



"Kaylie goes for her heart cath"

A few days passed, it was June/09, and I got a call that Dr. Sanitani was going to be in New Westminster and could we meet him there instead of driving all the way into BCCH? At that point I really didn't think anything was wrong with my daughter and I was relieved not to have to drive all the way into Vancouver. Tyler (Kaylie's dad), Kaylie, and I arrived at the hospital in New West and we started the process. During the ECG, Dr. Sanatani came in and shut the door. I knew something was wrong. He delivered the news that Kaylie had a heart condition called Tetralogy of Fallot as well as Pulmonary Atresia (when the pulmonary valve doesn't form properly.) He explained that she needed to have open heart surgery before her first birthday. I was in shock. We had just sold our townhouse and purchased a new house that very day. What should have been an exciting day had changed so quickly. I couldn't believe Kaylie needed open heart



surgery. I kept thinking....What did I do? What happened? Why me? Why Kaylie? Why?

We learned later that Kaylie didn't have tetralogy but that her heart was missing almost the entire pulmonary artery. The surgeon would use a pulmonary artery from a cow and attach it to Kaylie's heart. I will never forget the phone call I got about a month and a half later. I was in the parking lot of McDonalds in Abbotsford when Christine at BCCH called to say that we had a surgery date in two weeks. The following week Kaylie, myself and her two grandmothers went to the hospital for her pre-admission appointment. We met with Dr. Leblanc (the surgeon) and we all fell into a peaceful place. He really reassured us and we knew that our princess was going to be ok in his hands.



"Chantelle, Riley, Tyler & Kaylie"

The day came; it was July 27th/09. We arrived at BCCH early in the morning. Kaylie went in to surgery at 8:30am and came out at 2:30pm. The nurses said she was a fighter and that she did very well! After a few days in ICU we were transferred up to 3M, the cardiac recovery ward. Kaylie had a rough time. She was dehydrated and had a few other complications but she fought through everything and we got to go home on August 5th /09. On May 11/10 Kaylie became a big sister to her brother Riley who is a healthy baby boy!

Eighteen months after her surgery, in January/11, we went for a check-up at the Heart Centre. Dr. Sanitani told us that her upper pulmonary artery wasn't growing and he wanted to do a heart cath (cardiac catheterization.)

Kaylie would be anesthetized while they would insert a catheter into her heart so that they could investigate and get a better assessment of the problem. We would have to stay overnight in the hospital. Kaylie went under anaesthetic for the cath. The surgeon came back quite quickly and I knew that something was wrong. He said that the pulmonary artery that they had put in during her first surgery needed to be replaced. He sent us home but said they would do the surgery quite soon.

On March 2/11 we learned that Dr. Leblanc had retired and that Dr. Campbell would be doing Kaylie's next surgery. He wanted to replace the cow artery with a larger human pulmonary artery. It was scheduled for March 22/11 and Kaylie did really well! I couldn't believe how quickly we left ICU (less than 24 hours) and I was thrilled with the new area of 3M which is designated for cardiac patients. In addition, some of the new protocols (the ventilator was removed before she was transferred from the OR to ICU, smaller chest tubes and new medications) led to Kaylie recovering more quickly than she did from her first surgery. It took some time to find the right pain management strategies for Kaylie but Dr. Campbell did a fabulous job of making her comfortable. I was so impressed with the facilities and the amazing cardiac nurses. I felt so supported and I really hope that as CHN families we can all support each other.

Kaylie will likely need 3 or 4 more surgeries as she grows to replace the artery with one that is larger.



Visit Our Heart Matters Website at: childrensheartnetwork.org



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Maxx's Journey



Our journey began when I found out I was pregnant on Mother's Day. What should have been a joyous time turned into an emotional roller coaster ride. I had a very difficult pregnancy. I had hyperemesis gravidarum (extreme nausea, vomiting, and dehydration) which required IV treatments and many medications. At our 18 week ultrasound my husband and I were devastated to discover our son, Maxx, had common congenital heart defects (an atrialventricular septal defect and a ventricular septal defect) both associated with Down Syndrome. An amniocentesis confirmed the diagnosis. We were devastated and I broke down in the waiting room. I don't remember now if it was the pain of knowing my son had Down Syndrome or if it was the fact he would require heart surgery.



Maxx had three heart surgeries in the first year of his life. On April 29th/09, at 3 months old, Maxx had a pulmonary band placed on his artery. We were told that the success rate of this operation was about 90% and that once Maxx was bigger he would need an additional operation to complete the full repair to his heart. The day before the surgery they had Maxx come in for an echo to determine if they were to go ahead with the surgery or whether to wait for him to get bigger (as the size of the right side of his heart was not quite as big as they would like it.) Our cardiologist's opinion was that we should proceed.

During the operation the surgeon noticed that the anatomy of Maxx's heart was quite unique. They described parts of his heart as having a snake-like formation and the right side of his heart was smaller than the left.

After the operation, Maxx was in the ICU longer than expected. The doctors didn't know why he was one of the few that did not tolerate the PA banding procedure, which was supposed to be standard. Maxx had gone into renal failure and had to remain on the ventilator for a great portion of his recovery time. His oxygen levels were low; he would desaturate and he had constant unexplained fevers. The nurses found it very hard to find his veins to insert lines to take blood and to give medications. He still has scarring from these procedures (they told us this was common for children with Down Syndrome.) After a week in ICU he was taken off the ventilator and moved up to the 3M cardiac recovery ward. However, once there his health deteriorated. He had shortness of breath and seemed very agitated. They immediately moved him back to the ICU where they determined that the pulmonary band needed to be removed as there was increased blood flow to the lungs. He was quickly put back on the ventilator and the band was removed during his 2nd surgery.

Unfortunately, Maxx's health did not improve. Doctors were preparing us for the worst. Initially it was thought Maxx should be put on a bypass machine so that he could get bigger before they could look at performing his 3rd surgery, a complete heart repair. Another option was to send Maxx to Edmonton Heart Centre for a heart transplant. Doctors in Edmonton reviewed his echo and determined that the right side of his heart was indeed large enough to perform the complete heart repair at BC Children's and thought it should be done asap. The surgery took 5 hours, it was difficult, but the surgeon was happy with the outcome. Maxx was ventilated for a long time to give his body a chance to heal.

Finally, on June 8, although Maxx remained on oxygen the ventilator was removed and on June 10

we moved back up to 3M. There were 3 hurdles that Maxx had to overcome in order to be well enough to be sent home. He had to be able to breathe on his own, be able to feed, and he had to gain weight. By June 20 he had accomplished these 3 goals so he was released from BC Children's.

The first night home from the hospital was difficult. At one point Maxx stopped breathing for a few seconds and was unresponsive. I quickly called the on-call cardiologist and he told me that if he had another episode to return to the hospital. Luckily we didn't have to.

For a long time we had weekly appointments with our cardiologist and pediatrician in Vancouver to ensure Maxx was gaining weight and recovering from his ordeal. During the summer something changed. Maxx would cry out in pain, arch his back, and eventually stopped eating. I didn't realize Maxx was having feeding problems and nor did the doctors as he was gaining weight. I told the doctors that Maxx would vomit significant amounts and was reminded that it always looks like a lot more than you think. I felt it was too much so I began measuring and it was about half his feed. He was prescribed ranitidine for acid reflux but it didn't help. I took him to a feeding team at Surrey Memorial Hospital where they conducted a test which was inconclusive. Then he started to vomit stomach acid so we went back to BCCH emergency. A chest x-ray showed that he had water in his lungs so they admitted him back into 3M. He had an upper GI exam and a feeding test which showed he had severe acid reflux and he was aspirating into his lungs. After about 10 days we went home with him on oxygen and a feeding tube. His lungs were fragile from being on the ventilator for so long during his surgeries. Maxx tolerates his feeds better if they are thickened with Simply Thick and as of Oct 2009 he has been off the feeding tube. He stayed on oxygen until May 2010.



Maxx, Cheryl and Tom

Despite Maxx's challenges he has proven to be an active baby with a resilient personality! He is definitely a fighter and a charmer. His smile alone can melt anyone's heart. No child should have to go through what Maxx went through and that is why he inspires me and I hope inspires other moms as well.

In April 2011, recognizing a need for family support in our community, I founded the Langley Down Syndrome Resource Group. The Langley Advance newspaper has helped promote the group and we received a great response from an article featuring Maxx. My duties as the Volunteer Parent Networking Coordinator are to:

- Research topics, organize speakers and provide updates to our head office.
- Advocate for families and connect them to services.
- Create and present funding proposals to sponsors to assist families with respite, childcare and medical costs not covered by the Provincial and Federal Government.

For more information on the Lower Mainland Down Syndrome Society please contact:

Phone (604) 591-2722 Fax (604) 591-2730
Email info@lmdss.com Website www.lmdss.com

"The CHN would like to give heart-felt thanks to both The CKNW Orphans Fund and to Camp Zajac for supporting us with grants that allowed us to send over 40 kids to camp this year!"

The Gala!

On Thursday, March 3rd we hosted our 9th Annual Wine Gala dinner at Le Bistro Chez Michel in North Vancouver. Guests enjoyed a fabulous evening of fine wines and a five course dinner served up by restaurant owner Philippe Segur and his team. The festivities began with a warm welcome from MC Richard Brodeur, entertainer and former Canucks goalie, and ended with an amazing live auction which included a "Work of Art" painted by a group of young heart kids. Thanks to heart mom Kerry Harding, this talented group of heart



"CHN staff and board members Carmen, Sam, Dawn and Bindy"

artists created a beautiful painting that was the highlight of the evening's auction and fetched a whopping \$2500! We would also like to send out a huge "Thank You" to Gabby and Chris Torrens, for sharing a touching video of their heart journey with son Hudson and another big "Thank You" to Jennifer Schneider for sharing her story of their daughter Hannah's special heart journey.



"A work of Heart Art"

We are grateful to all our CHN donators and supporters as we were able to raise over \$42,000 to support families that have children growing up with heart disease!! Watch for the date of our next Wine Gala dinner in early 2012.



"Philippe Segur and Richard Brodeur"

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 some time, talent and expertise that you are willing to share, please contact Sam Aitken at saitken@childrensheartnetwork.org



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.

Call Us Today Toll Free: 1-877-833-1773

Camp Zajac with the Hearts of Gold

Camp Zajac for many is a magical place where young adults get the chance to be kids. The adolescent years are a time of busy schedules, lots of school work, responsibilities and commitments. A long weekend at Zajac gives this group the opportunity to leave all that at home and come to have fun. There is no cell phone reception at Zajac (a welcomed relief for some) so everyone has lots of time to visit, play games and plot pranks! We had a wonderful weekend at Zajac this past May long weekend and look forward to the next chance we all get to be together.

By Brie Barron, HOG Coordinator



Here are some quotes from our HOG campers this year:

"Camp is a place where all worries die and you can just relax and be yourself. The most fun thing to do here was the arts and crafts and just hanging out with friends. Oh and having fires was pretty awesome. This place is amazing!" ~Callahan

"Camp is and was very fun and it was awesome to see all my friends again because I don't get to see them very often as I live so far away from them." ~Chad H.

"I appreciate Zajac letting us come here. The best thing was everything! Loved it! Zajac is awesome. P.S. I own at poker" ~Justin

"I love this camp. I love the climbing wall. I love walking in the forest." ~Montana

"It was fun. I liked the activities. People were nice, food was great, lots of fun. Can't wait for next year" ~Chris B.

"20 cups of tea, 17 sore stomachs from laughing, 10 sticky fingers from marshmallows and countless memories made. I always have an amazing time at Zajac! The campers are always enthusiastic and supportive and the counselors are incredible. The food is great, the activities are fun and the company is fantastic. I can't wait until next year!" ~Anna D.

"Why camp is awesome every year? Umm... well, obviously because of us awesome campers right? Yah! But what makes camp special to me is the leaders and the volunteers! They are always energetic, happy and fun-loving! I swear I just grew abs because I laughed so much! Camp is always including and exciting. I love camp and you can tell that the people who stay and hangout with us never act like they are bored. Camp Zajac with Hearts of Gold is totally the best camp I have been to! Thanks so much for the awesome memories and smiles!" ~Zenani

"I always have such a great time here at Zajac. The best part about this weekend were the campfires and the petting zoo. The volunteers made it a much better weekend. Hope to see everyone next year." Jillian W.

"What I love about Zajac? Everything! Everything was so much fun. In the last 3 days I there was not a dull moment. I made sooo many new friends, tried many new activities, played so many games and ate so much. The food was so good. That was my AWESOME weekend at Zajac!" ~Manmit B.

"I had the best time here. It is so much fun. I'm going to come here next year. My favourite activity was the horses, the low ropes, watching movies and the talent show. The food was the best food ever!! Hope to see all my friends next year." ~Taylor Z.

"Camp Zajac is the best place to relax. The best thing was learning how to play poker!" ~Justin S.

"Camp is awesome because it is the only Hearts of Gold event I get to do because I live so far away."

~Joey D.

"I had such a fun time at camp. The activities are always so much fun. My favourite things were the talent show and campfires. Everybody had really good energy and I had a really good time! The volunteers are amazing. They're such fun people and they made the weekend unforgettable. Hope to see everyone next year."

~Sydney W.

"I have the best time at camp no matter what we're doing. It's not only the activities that I enjoy, it's the people. Everyone is so welcoming and hilarious to be around. The counselors are just amazing people and so are all the kids that go to camp. I don't think I'll forget this camp, it was way too much fun!" ~Daley J.T.



"Zajac camp is a place where fun and dreams of fun and adventure come true. The people are warmhearted and nice. They accept everyone that walks through their gates and I was one of the many that walked through. It is truly awesome. They have everything to apply to every interest and you feel at home with homemade food and friends that are just like you. Zajac is very, very lucky!" ~Calvin C.

"After attending camp as a camper for the past 3 years I decided to volunteer! It was so much fun! It didn't even feel like I was working. All the Hearts of gold youth are very nice and friendly. The camp leaders at Zajac Ranch are also friendly and a lot of fun. Overall, I truly enjoyed volunteering at camp this year and I encourage anyone else to do the same!" ~Lauren

♥♥♥♥ Camp Zajac ♥♥♥♥

The Zajac Ranch Family Camp Program enables families to have a shared recreational experience while learning new skills and meeting others with similar life experiences. The next Family Camp will be a weekend in the Fall (Friday evening to Sunday afternoon.) It will give families the opportunity to try some of the activities at Zajac Ranch and to have a taste of a Zajac Summer Camp experience. To be eligible you must have a child aged 7 – 17 years with a medical condition. It's a great opportunity if you have not been to Zajac Ranch for Children before or if one of your children is considering a summer camp in 2012. Experience camp first as a family! Look for information at www.zajacranch.com following the summer for further information. Price is approximately \$200 for a family of four.



Ethan the
Easter Bunny

"Did you hear about the Easter Egg Hunt?"

On Sunday, April 17th about 130 heart kids and their families attended a fun-tastic Easter Egg Hunt at Queens Park in New Westminster. Thankfully, the rain held off while happy heart kids and their siblings scoured the park to find colourful Easter eggs which were hidden among the trees.

Cookies, muffins, hot chocolate and coffee kept everyone warm while the kids climbed all over the playground and the moms and dads spent time connecting with other heart parents.



Danielle and Chloe,
Heart Friends

A huge "Thank you" to the Talman family for organizing the candy and hiding the eggs, to Starbucks for providing the coffee and hot chocolate, to Thrifty Foods for providing the snacks and to all the parents that helped make this event a big success!

Heart Matters Spring 2011 Donor List

The Children's Heart Network would like to thank the following individuals, organizations and businesses for their support and generous gifts over the past 3 months

Platinum Heart (over \$5000)

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Dates at a Glance

June 26, 2011

Scotiabank Challenge 5KM/Half Marathon
Stanley Park
Run/walk and support the CHN!

July 5-9, 2011

Camp Zajac
HeartBeats group (ages 7-12)

July 30, 2011

Triple Crown for Heart
A ride to support BCCH Heart Unit on 3M
"Come Ride with Us!"
Volunteers and riders are welcome and needed for this 5 hour ride which starts in North Vancouver

and continues up to Mt. Seymour, Grouse Mountain and Cypress Mountain. Please see the website for ride details and information.
www.triplecrownforheart.ca

August 28, 2011

Cultus Lake Waterslides Picnic
RSVP to saitken@childrensheartnetwork.org
For more information on these events
Email saitken@childrensheartnetwork.org
Phone toll free 1-877-833-1773

