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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CHILDREN'S HEART NETWORK

The Church Family Story

Our story begins at the end of August 2009 when our then 13 year old son Justin was at Children's Hospital for an unrelated appointment. The doctor wanted to start Justin on medication but first needed a baseline electrocardiogram (ECG) to check Justin's heart. This visit to the doctor's office changed the course of our lives forever. The next day I received a phone call from the doctor telling me that Justin's ECG was abnormal and that was all he knew. He told me he would walk the report down to a colleague in the Heart Clinic and get back to me. Within two days we were on our way back to the hospital, but this time to the Heart Clinic, and we had no idea why.

"Justin, Madilyn & Brayden"

At the hospital Justin had another ECG and an echocardiogram then we met with Dr. Tipple, Pediatric Cardiologist and her nurse Mandy. We were in no way prepared for the news she was about to tell us. She told us Justin has a heart condition called Hypertrophic Cardiomyopathy (HCM).

My husband Brian, our then 9 year old son Brayden and 6 year old daughter Madilyn were all at the appointment. After hours of talking at the clinic we understood that this was usually a hereditary heart condition and it was important for the rest of the family to have ECG's and echocardiograms.

The day Brayden and Madilyn had their appointments Brian and I were still numb from the weeks before. When we were called into see Dr. Tipple I felt something was horribly wrong. Sadly, my instincts were right. She told us that Madilyn's heart was normal but Brayden also has Hypertrophic Cardiomyopathy. This brought even more grief and sadness to our family. The diagnosis now appeared hereditary so it was urgent for Brian and I to have our tests done right away. At this time we were also referred to the Genetics Department to have genetic testing done.

Our tests showed my heart to be normal but there was something not quite right with Brian's reporting but we had no definitive diagnosis. In October 2009, Brian fainted and 911 had to be called. He was taken to Mission Hospital then transferred to Abbotsford Hospital. There the doctor confirmed Brian's diagnosis of HCM and he

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Church Family

was then admitted to St. Paul's hospital in Vancouver for an ICD/pacemaker to be put in. Soon after, we received the results of our genetic testing confirming that Brian, Justin and Brayden all have the same genetic defect causing their HCM. Madilyn tested negative for the gene, which was the only good news we had heard for sometime. Because Brian had been diagnosed with HCM prior to our genetic testing the doctor felt it was not necessary for me to be tested.

Before Justin's diagnosis he was a very active boy who enjoyed all sports but soccer was his game. Justin was playing competitive soccer on a gold level team and was waiting for the chance to one day play professional soccer but HCM and competitive sports do not go well together. Justin had to quit playing competitive soccer and really monitor his activity level. Brayden was also an active boy who enjoyed sports and was also playing recreational soccer at the time of his diagnosis but after recalling events that had happened the previous year when he had to stop and sit during physical activity because he was having trouble catching his breath, Brayden decided to quit soccer too.

Shortly after Justin and Brayden were diagnosed we were referred to the Children's Heart Network (CHN). Our first event was at the Apple Barn where we met Nancy Fraser and several other heart families. Nancy gave me the biggest hug and let me know that the CHN family was here for all of us. We enjoyed several more events but our trip to Critter Cove in the spring of 2010 was a significant turning point for me and my family. Finally at this point, I was ready to embrace the support that was shown to me and my family, and it was a great feeling. It was very therapeutic to talk to other families who experience the challenges we face everyday. We all have very unique situations but I began to realize that the more I talked about my family the better I felt about our situation.

After two years of adjusting to our diagnosis we are all doing much better. Though there are challenges for everyone the boys have done amazingly well. We go to the Heart Clinic every six months for follow-up ECGs, echocardiograms and stress tests. Thankfully, since September 2009 there has been no health changes. Hypertrophic Cardiomyopathy is never far from my thoughts but it no longer consumes them. You get out of life what you put into it and the people you share that with makes all the difference in the world and for that we are very grateful to everyone involved with our family.

What the Children's Heart Network means to Justin:

"The CHN has been a great asset to our family, but really me. There are awesome events like camping. The camp is a great way to make friends who are just like you. I appreciate what the CHN has done for me and I encourage other kids to join and go to events. You will have a blast!" Thank you CHN.

What the Children's Heart Network means to Brayden:

"The Children's Heart Network is lots of fun a great place to meet new friends. I have made some really cool friends. The CHN has a lot of great events like Zajac Ranch that I can go to. All the other events are really fun!" Thank you CHN.

Written by Tammy Church

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To make a tax deductible donation, please contact the **Children's Heart Network**

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CRITTER COVE 2011

For 10 years now, Cameron and Kathy Forbes have been supporting CHN in a very unique way. Every June they invite 10 heart families to come up to their "one of a kind" floating fishing village in Nootka Sound for 4 days and 3 nights of all-inclusive fishing, fun and new life experiences.

He organizes many friends to volunteer their time and their boats to take our families out fishing, a local First Nations family puts on a Salmon BBQ on the beach and the Coast Guard come to take the kids out on their zodiac!

We are so very grateful for the generosity the Forbes family has shown to all of our heart families! The connections and friendships made amongst heart families over these many treasured trips are priceless. In addition to providing our families with this wonderful opportunity, Cameron Forbes and his family have just finished holding their 2nd Annual Fishing Derby which raises funds in support of the CHN.
Thank you, Thank you, Thank you from all of us at the CHN!!

Nick, Juliana & Annie

The following was written by Annie White (a heart mom) upon her return from Critter Cove with her heart daughter, Juliana and her son, Nick....

What did we know about Critter Cove – Nothing.

What did we expect from Critter Cove – Something?!?

What did we get from Critter Cove – Plenty!

Welcoming – the smile of the bus driver, the flotilla of guide boats picking us up and showing us around, the volunteers who provided food and hugs, and our hosts whose hearts are open.

Relaxation – the distance from the hustle and bustle of daily life, chatting dock side with new friends, sharing a cup of coffee with one family, a meal with another and a beer with our guides.

Excitement – reeling in a fish from dock side for the first time, seeing the open ocean, smelling open pit bbq salmon and hauling the BIG one on board with the help of a seasoned guide.

Understanding –sharing your family's story, finding someone else has been there too, knowing that even if they haven't been there exactly they understand the heart ache of a parent with a sick child or an ailing partner.

Acceptance – the almost instant connection on a 'coronary' level: loud kids, rainy days, boredom, sadness, quiet time, and big group activities.

Lasting friendships – wanting to be a part of these families' lives not only for this weekend but days, weeks and hopefully years to come.

Thank you *to Cam and Kathy Forbes for giving us this gift.*

Thank you *to the Gold River residents and businesses, and friends for contributing.*

Thank you *to our guides for graciously trolling around and hoping, with and, for us to land at least one fish.*

Thank you *to the Vargas, Church, Perrit, McConachie, Palmer, Hawkins, Bylsma, Armstrong Families.*

Written by: Annie White

My Weekend at Critter Cove by Juliana White

As you feel the wind in your face and smell the ocean you turn the corner and there it is ... Critter Cove. All the cabins and docks lined up! It's pretty amazing in every way that every single person that is working is a volunteer.

Juliana with a catch!

There is a place called the lodge where we did most of our eating and there is a little store attached where you can buy weights, snacks and other fishing stuff.

Each family is paired up with a guide and that guide will take you fishing out on the ocean in their boats. As you are on their boats, they let down their reels and you troll for a bit but as soon as you feel a bite or the rod is zipping around - you reel in – its hard and it hurts. If it's a big fish, it is all worth it – because you get the fish at the end of the day and you can bring it home.

One of the days you get taken to a First Nation man's house, his name is Ray Williams. It's pretty cool because they catch the salmon, they roast it over a fire on the beach and it tastes amazing. The Coast Guard gives you Zodiac rides and those are just down-right fun and they do go super fast. Then the Coast Guard gives you a fishing license that usually cost money but they give it for free!

I enjoyed Critter Cove a lot and I think all the families did very much too. Through the time we were there we made some friends and I think most of the kids are now better fishers. It made it even more enjoyable because there were people there that had some of the same issues and some totally different, but we all just want our hearts to be better. Some of ours are fixed and some not yet, and some never will be - but we all enjoyed our time together at Critter Cove.

Dates at a Glance

Oct. 23/11

Fall Fun Day at the Pumpkin Patch for Okanagan Families
Mcmillan Farms
RSVP to saitken@childrensheartnetwork.org

Nov. 26/11

The Annual CHN Christmas Party for Lower Mainland Families
Mark the date – Email invitation to follow!
Metrotown Hilton Hotel

Nov. 26/11

The Annual CHN Christmas Party for Victoria Families
"Christmas in Hawaii" at The Commonwealth Pool

For more information on these events
Email saitken@childrensheartnetwork.org
Phone toll free 1-877-833-1773

"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!"

Heart Beats Events

A Great Day at the Cultus Lake Water Slides

Pirate Playground

On a gorgeous sunny Sunday in August over 250 members of the Children's Heart Network joined together for a fabulous day of excitement, thrills and fun. A couple of the kids comments overheard were "Wow, I think I have landed in Disneyland for the Day" and "I can't believe this...is this a dream or is this really happening?" The highlights were the Pirates Cove interactive water playground for all ages, the Valley of Fear and the Colossal Canyon – 700 feet of twists and turns that the whole family can enjoy together while sitting in a big round tube! Many old "heart friends" had the opportunity to re-connect and some fabulous new relationships were formed!

Kayley on the slide!

Camp Zajac

Calvin ready to climb...

This year we were able to send almost 40 kids to Camp Zajac for many days and nights of fun while connecting with other Heart friends. They enjoyed all the fantastic things to do at the ranch.....swimming, horse-riding, climbing, games and more! We are so very fortunate to be able to offer this opportunity to our CHN children. We wouldn't have been able to make this happen without the support of the following organizations: Zajac Ranch for Children, The CKNW Orphan's Fund, Cops for Kids and Boston Pizza.

Thank you so much!

Chris, Joey, Calvin & their counsellor

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

variety the children's charity

BC CHILDREN'S HOSPITAL An agency of the Provincial Health Services Authority

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.

What's Up!

Welcome!!

This past June Nancy & Jamie Fraser welcomed their new baby daughter Abigail into the world. Big sister Hayley is very excited! Baby Abi has had a hard few months.....a surgery in her first few days followed by a recent trip to Edmonton due to further complications. We are all sending our good wishes and prayers so that Abigail can come home soon.

Christmas Party Donations

If you would like to make a donation to the raffle draw or if you would like to contribute some treats for dessert please email Samantha Aitken at saitken@childrensheartnetwork.org

Thank you!!

Our newsletter would not be possible without the many hours of volunteer work that John Sikorski from JonCom Design (604.726.5037) provides for us. We are so grateful, Thank you John!

Thank you!!

Our gratitude goes out to Joey Dachwitz, a heart teen from Kelowna, for presenting a Thank You on our behalf to the Cops For Kids Foundation in appreciation of the generous donation they made this year. The fantastic donation covered the cost of travel for kids coming from the Okanagan area to Camp Zajac! Joey made the presentation as a large group of "cops" rode into town on their motorcycles upon completion of a big ride that helped raise awareness of the organization

Did you know?

There are a number of Foundations that grant wishes for children that have life-threatening medical conditions? The children can be referred by health professionals at BCCH or by their families. There is specific criteria that must be met. For more information you can go to the following websites:

Children's Wish Foundation
www.childrenswish.ca

Make-A-Wish Foundation
www.makeawish.ca

"Carmen's Corner" - Carmen Carriere interviews Jan Rooks, Cardiology Nurse Clinician

Jan Rooks

1) Where did you grow up?

I grew up in Toronto, but as a child I also spent a year in North Bay and four years in Sudbury. I did my first degree (in music) at the University of Toronto.

2) Were there any childhood influences that made you want to become a nurse?

Unlike many nurses, I didn't know any nurses when I was growing up. But my best friend's older sister went into nursing and I remembered that when I made my career change to nursing when I was in my early 30's.

3) How did you become interested in pediatric cardiac nursing?

When I was about 30 and living in Fort St John, I met a family with a son who was then about 8, and he had been born with Transposition of the Great Arteries. He was doing great. In the next few years, I changed my career. During my clinical practicums I had the opportunity to work on 3G at BCCH (the cardiology dept at that time.) That experience, combined with the personal connection to a family who had a child with CHD, caused me to fall in love with paediatric cardiology.

4) Where did you study to become a nurse?

Langara College for my diploma and then I finished my nursing degree at UVic while I was working.

5) Where did you begin your career?

I started at St Paul's on a medical ward, with some additional shifts on orthopaedics and the HIV unit. It was fascinating and a great learning experience, but in 1997 when I heard they were hiring at Children's on 3G, I applied and was really pleased to get hired.

6) Your job is multi-faceted. Could you tell us what your job entails?

As a nurse clinician in the Heart Centre I teach and support families who have a child with congenital heart disease. I see them at the time of diagnosis, before and after surgery, and for ongoing follow-up. The information that the family needs is different through the stages of this process and I try to provide the answers and support for whatever they are going through.

7) What are the biggest challenges you face in your work?

Just not enough time! There are families every day in the clinic and in the hospital that I just don't get to see and I wish I had time to see all of them.

8) What would you like to see developed at BCCH to help heart kids and their families?

I'd love to see more resources available in terms of allied health -- dietician, physiotherapist, psychologist, social worker, etc. -- particularly for the outpatients where this support is currently lacking. The subject of serious abnormal heart rhythms is expanding in knowledge and treatment, and I'd like to be part of that expert subspecialty. As your readers may know, we have a vision of offering heart transplants and the support needed when a child is waiting for transplant, and I'm excited about BCCH Cardiology expanding into this area.

9) What do you like best about working with heart kids and their families?

I love learning from the families. I consider it a real privilege to be connected with them at a time of such stress (like a new diagnosis of a heart problem, or going through surgery) and for parents to share their emotions and fears with me, and for me to be able to help them cope better with these stresses, is very special. The path that parents follow and the strengths that emerge really attest to the power of the human spirit.

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10) What advice could you give to new families about how to prepare for a clinic visit to the heart centre?

Bring a support person, someone that can also hear the information being given and can help you go over it afterwards. Feel free to ask about what you don't know -- there are no dumb questions! Know that the vast majority of children with a heart problem do well -- even if they need surgery -- and will participate in life like kids without heart conditions.

11) What do you do with your time when you are not at BCCH?

My music is still very important to me. I play classical piano and do a few concerts every year; I'm just getting ready to do a recording of music by Bach and Shostakovich. My husband and I also have a real passion for hiking in the mountains, and our vacations have taken us to the Himalayas, the Swiss Alps, and of course our fantastic Rockies.

***Happy 10th Birthday Ava ***

With an Alice in Wonderland theme, seven girls got together on a Saturday afternoon in July to celebrate Ava Lougheed's 10th birthday.

First a climb through the Rabbit Hole and then the "Drink Me" potion to ensure the girls all fit into the party room. A sunny deck with Hearts playing cards hung from the rafters. They enjoyed playing croquet on the lawn, sipping tea from china cups and eating heart shaped scones and strawberry tarts.

The March Hare even showed up – Late!

Ava decided this year to not receive gifts and asked her friends (and family) to donate instead to the Children's Heart Network. One of Ava's good friends had had open heart surgery last year to correct a congenital heart defect: ASD (atrial septal defect).

Thank you Ava – your donation of over $100 will help provide support for children and families within the Children's' Heart Network!

CHN Community Partnership Program

The Children's Heart Network would like to thank the following organizations and businesses for their support and generous gifts:
The Province of British Columbia – we acknowledge the financial assistance of the Province of British Columbia.
CKNW Orphan's Fund – Camp Grants to enable us to send 40+ Heart kids to Camp Zajac.
Zajac Ranch Camp for Kids – for their sponsorship in sending heart kids to Camp Zajac.
Critter Cove Marina – for funds donated from their Annual Fishing Derby and for sponsoring 10 families.

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CKNW Orphans' FUND

"HELP US BRING HOPE TO HEART FAMILIES"

It is now easier than ever to give a gift to the CHN. Donate online at www.CanadaHelps.org or go to www.childrensheartnetwork.org and click on the "Canada Helps" icon on the homepage. Please consider making a scheduled monthly donation on this secured site that will issue you tax receipts for every donation over $20. ***Thank you so much!***