



Joanna and baby Natalie. "When I told my family I was pregnant, they were shocked, scared, worried, and happy."

Motherhood:

The dream I never dared to dream

BY JOANNA BARKER

For as long as I can remember, motherhood was not in the cards for me. Sitting on the examination table, as a young girl, I recall a doctor recommend to my mother that I have my tubes tied at 16. At the time, I didn't understand what "tubes tied" meant, but I understood what their concerns were about: pregnancy. Pregnancy meant death, something we all wanted to avoid.

I was born with a complex heart condition called hypoplastic right heart syndrome. Essentially, the right side of my heart was not working. The right ventricle did not pump, a pulmonary valve was missing; I had two holes in my heart and underdeveloped lungs. Doctors have said it is one of the most complex of complex heart diseases.

At 10 days old, I underwent my first heart surgery. At 1 year, my second open heart surgery. The mortality rate was 40%. At 6 years old I underwent another open heart surgery. It was a major palliative repair. At 8 years old, because I was increasingly cyanotic, the cardiac team at BC Children's Hospital planned for another cardiac surgery and

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Volunteers needed

Our families enjoy the spring, summer, fall, and winter gatherings that 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.

THE VIEWS EXPRESSED IN THIS NEWSLETTER ARE THOSE OF THE AUTHORS, AND NOT NECESSARILY THOSE OF THE BOARD OF THE CHILDREN'S HEART NETWORK. THE BEST SOURCES OF MEDICAL INFORMATION ARE YOUR CHILD'S PHYSICIAN AND THE HEALTH CARE PROFESSIONALS WHO PROVIDE CARE FOR YOUR CHILD.

Heart Matters

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/ChildrensHeartNetwork



COFFEE GROUPS—THERE'S PROBABLY ONE IN YOUR NEIGHBOURHOOD

These groups meet monthly; come and meet other heart parents while enjoying treats on CHN. For more information please contact:

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YOUNG ADULT HEART NETWORK COFFEE GROUP

We have a group for young adults living with heart disease. For more information please contact:

[Lauren Fougner](#) | lfougner@uvic.ca

THANK YOU TO OUR GENEROUS DONORS

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



The Province of BC



The CKNW Orphans Fund

ARE YOU A MEMBER OF A HEART FAMILY?

If you have a child growing up with heart disease please email us at chn@childrensheartnetwork.org so that we can add you to our mailing list to receive invitations to all our fun events!

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implanted a Blalock-Taussig shunt. The doctors' overall plan was to extend my life with cardiac interventions and then proceed with a heart and lung transplant. When I was 17 years old, my health took a turn for the worse; I was in congestive heart failure. Yet, the advancements in research enabled me to have a complete repair of my heart, instead of a having a heart and lung transplant.

From then on, at my cardiology visits, whenever I was asked about whether I was thinking of planning a family, I immediately said I was not interested—I never asked any questions about it, and I figured everything was status quo.

It wasn't until I was 30 years old, living in Toronto, when I learned that the status quo had changed. At a yearly check-up with my doctor, I said, "I can't have children because of my heart." He stopped and looked at me. "Yes, you can," he said.

I was stunned. I thought my heart could not withstand the increased blood flow from pregnancy. He explained that after the final repair, my heart had better blood flow. But most importantly, what had really changed was in the last 20 years, clinical studies and research had shown that women with various complex heart diseases could manage pregnancy.

I became pregnant at 36 years old. I kept it a secret from my family until I was 20 weeks pregnant. I didn't want to worry them unnecessarily. When I finally told them, they were shocked, scared, worried, and happy. I think they were also relieved to know I wasn't letting myself go with all my weight gain!

My pregnancy was just like any other, though mine carried a few more doctor appointments and tests. My obstetricians and cardiologists worked together managing the pregnancy. They meet every week to discuss the cardiac obstetric patients.

One way I think my pregnancy differed from the norm was the amount of the unsolicited comments I received from medical staff, family, friends, and coworkers. At my 12-week echocardiogram, the technician told me,

"I would never do it!"—meaning have a baby if she had CHD. I lay there wondering if I was making a huge mistake. She sees patients every day, I thought, maybe she knows something I don't. I decided to listen to the words of my brilliant and competent cardiologist, Dr Grewal. I cannot count the number of times people who weren't health care workers told me to have a C-section. "It will be easier on your heart," they thought. I explained that a natural delivery is actually safer for my heart and a C-section had increased medical risks. The majority of people remained unconvinced. People often commented on the condition of the baby, believing she would have a heart problem, be a born small, be born premature—funny no one ever guessed she'd be born gorgeous.

The PACH Clinic did an echo, ECG, and check-up for each term of pregnancy, along with a prenatal ultrasound to look for any signs of CHD in the baby. The rest of the care was through the obstetrician's office.

I was to deliver at St. Paul's Hospital, which is where I did the fetal monitoring. It started at 28 weeks (normally they do it at 32 weeks for heart patients), but my oxygen levels were low and my heart rate was steadily climbing to 130 bpm. My heart rate is naturally high, at around 120 bpm, but as one nurse said, we don't want it higher than the baby's heart rate!

Five days before due date, I was admitted for an induction. My blood pressure was high and I was really ready to have the baby. I experienced extreme fatigue throughout the pregnancy, but the last few weeks were even more exhausting. In the end, my water broke just when they started the induction. They then stopped the induction, and I progressed naturally. I had an early epidural so my heart rate would stay lower during the contractions. After 12 hours of labour, a gorgeous baby girl was born, 8.3 pounds. She was healthy and beautiful; I was elated.

Motherhood is a dream come true, except it was never my dream, I never thought I could dream it, which makes it even sweeter! 🍓

CHN accepts donations of shares

The Pacific Children's Heart Network (the full name of CHN) accepts donations of shares of publically traded companies. Donating shares provides a significant tax deduction and capital gains exemption for the donor, while at the same time benefiting a worthy cause. Talk to your financial advisor for more information, and to see if donating shares is an option for you.



Hailey Wispinski, July 2016, left and leaning on the rail under the letter B for Bank at the mixed medical camp #1 (Children's Heart Network, hematology, gastrointestinal) July 4th – 8th, 2016.

Zajac Ranch: Experience of a lifetime

BY HAILEY WISPINSKI

When I was first told about Zajac Ranch it was 2013. I was 9 years and I was terrified to go away all by myself to camp. The thought of spending four whole nights away from home was stomach churning. I wanted to go to camp, but I was simply too afraid. My mom tried to explain the truly amazing things that go on at Camp Zajac, but I just shut her down, I was not ready. Time passed and I hadn't really thought about it, but then all of a sudden it was registration time for camp and I was now 10 years old. My mom approached me again with the idea of going to camp, and man, am I glad I registered. I have been to going to Camp Zajac during the Heart Network Week for the last 3 years. I am now 12, and I am still impressed at how much fun I have and how safe all the counsellors make me feel.

When you arrive you're greeted by a cowboy on his horse. After you park, you go to the OK Corral, where the nurses talk to your parents and find out about your medical needs. The nurses are really nice and accommodating and they make you feel very safe and take good care of you. Then

you go into one of three cabins. You get to your assigned bed, and get your sleeping bag set up, and then your parent leaves. The counsellors introduce you to some of the other campers and we play some games while the other campers are arriving. We always have a great cook who makes all of our meals. During the week we go horseback riding, canoeing, kayaking, swim in the lake and the pool, climb the high ropes, and even have a chance to sleep one night in a tepee if you want. We have flush toilets and a warm building to sleep in, but we spend almost all day outside. We have campfires and sing songs, we play games and also have some quiet time every day. Each day is so action-packed, you go to bed very tired after experiencing many fun activities.

I really enjoy Camp Zajac because even though I have many medical conditions I feel normal with all the other campers. Although camp is just a week you make friends that last a lifetime. If you are thinking about going, just trust me—you will have the time of your life. 🍓



Physical activity in children with CHD across British Columbia

BY CHRISTINE VOSS AND PAIGE DEAN

Everyone knows that physical activity is good for their health. Children and teens should spend at least 1 hour per day in moderate-to-vigorous intensity activities. This advice is also true for the vast majority of children who have congenital heart disease (CHD).

One hour every day may seem a lot at first, because most people still think that physical activity means you have to play competitive sports or do an intense workout in the gym. Getting sweaty and muddy on the soccer field certainly counts toward your daily goal, but so do things like dance, skateboarding, walking from place to place, taking the stairs instead of the elevator, and so on.

Many of our colleagues who work with children who have CHD say that they are less active than their friends or siblings who do not have this condition, but we don't believe that this is really true. We have heard some great stories of children with CHD who are sports aficionados; one family told us about a fun family challenge where they clock kilometres to run to Disneyland.

Over 100 children and teens with CHD or cardiac transplants recently took part in a Children's Heart Centre research project led by Dr Kevin Harris, where children

received a small device to measure their activity for a week. We were really excited to learn that these children and teens were just as active as Canadian children of the same age without a heart condition. It also really didn't seem to matter for their activity levels what type of CHD they had. But not all children in our study achieved the recommended 60 minutes of activity per day.

Everybody has their own reasons for why they are active or inactive. Some just haven't found an activity that they enjoy, or they are too busy with sitting at a computer doing homework. Some might live in areas with few opportunities to be active, because not all communities have sidewalks and parks nearby. Of course some families might also feel unsure about what activities they can do safely, so they end up doing very little or none at all.

We are currently hoping to learn more from children with heart conditions and their parents/guardians about their physical activity and what things help or hinder them to be more active. If you would like to learn more or get involved in the Children's Heart Centre physical activity research, please get in touch with our team by contacting christine.voss@ubc.ca.

Critter Cove: An out-of-this-world experience

BY KARLA ALLAN



Heart families and all the amazing volunteers.



Words cannot express our family's gratitude to the Children's Heart Network for sending us on a fishing trip to Critter Cove in beautiful Nootka Sound. We are absolutely blessed to have experienced this with other heart kids and their families.

As we were coming from Kelowna, we had a bit of a drive and didn't want to miss the early morning ferry ride. So we decided to leave a day early, and stayed the night at a hotel in North Vancouver. We met the group at the ferry terminal and headed off to Nanaimo. After the ferry ride and many hours on the bus (thank you Wilsons), we arrived at Cougar Creek late that afternoon. In the pouring rain, we were picked up by boat and brought to our floating resort for 2 days and 3 nights of unforgettable memories and fun.

We were treated like royalty the moment we arrived at Critter Cove. Each child received his or her own fishing rod, tackle box, and toque. Oceans and Fisheries Coast Guard gave all the children fishing licenses and t-shirts. Immediately the kids were fishing off of the docks with their families. We were introduced to Val and Don, our guides for the weekend. Then we all gathered and shared in an amazing dinner together while we slowly got to know one another, made fishing arrangements for the next morning, and connected over discussions about our heart kids.

Karla Allan and family on the right, with their volunteer guides Val and Don.



The next day we headed out fishing. We trolled along neat little islands, eagerly watching the fishing monitor on the boat. The girls enjoyed a friendly game of snakes and ladders while the guys were watching the rods off the boat. We stopped to check in at Val and Don's friends cabin (also volunteers) just across from the resort in this little bay. About 50 feet away from their place we saw a black bear with her cub; it was the cutest thing to see. That afternoon the Canada Coast Guard vessel came to Critter Cove. Members of Oceans and Fisheries then transported a couple of families at a time via their Zodiac to tour the *M. Charles M.B.* vessel. Once each family had their tour some Canada Coast Guard members demonstrated a rescue from their Zodiac for all to see. Later the children played cards, made crafts, and decorated the dining room with red and white balloons and streamers for Canada Day.

Sunday July 3rd, a birthday celebration for this family, we were picked up by boat and taken to historic Friendly Cove. The children spent the afternoon running around and playing on the beach. They collected driftwood and rocks and shells and watched the waves come crashing in. We wandered about the island and toured the church, the grave sites, and the lighthouse. The rescue aircraft even made an appearance hovering above us and landing on the beach. The guys came out and took photos with some of the group and handed out stickers and posters for the kids. What a great day!

As I write this we just finished some wonderful Nootka Sound salmon steaks for dinner. Although our family only caught one spring salmon, I'd have been happy catching nothing. This was the most amazing experience and the people we met and shared it with was more than we could have imagined. To top it off, we had one of the most amazing firework displays on our last night! According to the kids this was their favourite part of their trip, along with meeting all their new friends.



Above left: Adabelle and Josephine touring the Coast Guard ship; right: Jaedyn loving her hot chocolate; bottom: the Torrens family kids (Hayden, Hailey and Hudson).

It was a very sad day getting ready to leave and say goodbye to the many wonderful people involved in one of the most memorable and spectacular experiences to be had. Most of us were tired, but still grinning from ear to ear reflecting this amazing experience and the special connections we made with other heart families. It is wonderful to know we are not alone in our journey as we bring up these special heart kids.

Thank you to everyone involved—from the bottom of our hearts. We are so grateful to the many volunteers and supporters of CHN, our fishing guides Val and Don, whom we will never forget, and most importantly, to the Forbes family for hosting us all. 🍓

Meet Anna Murray, cardiac nurse clinician

Where did you grow up?

I was born at Saint Paul's Hospital. I grew up in Vancouver, four doors down from Dr Duncan, now a cardiologist at the Heart Centre. I didn't know him at the time but I'm sure I must have sold him Girl Guide cookies at least once!

What made you want to be a pediatric nurse?

I have always loved being around kids, but I wasn't sure if that would be enough to make me a good pediatric nurse. My first pediatric nursing experience was during a student placement on 3F at BC Children's. Taking care of those sick babies and children scared me silly, but it also inspired and energized me in a way that no other nursing specialty had before. I came back to BC Children's the following year for a placement on 3M and I fell in love. I knew instantly that pediatric cardiology was for me. I took a job on 3M as soon as I finished nursing school and have never looked back! The courage and resiliency of the heart kids and their families was incredible to witness, and to this day I consider it the most incredible honour imaginable to be a part of their journey.

What are your main responsibilities?

As a cardiac nurse clinician, my main role is to provide education and support to children and families living with congenital heart disease and/or arrhythmias out in the community. I see patients when they come in for their clinic visits, and I am available to families by phone and email between their appointments. I follow patients from when they are first diagnosed, which is often before they are even born, until they graduate from our program in their late teens. One of my favourite things is meeting up with families year after year and seeing their tiny, fragile babies grow into amazing, resilient, energetic little people. It is just so cool.

What do you like about working at BCCH?

I love that everyone at our hospital has the same goal, regardless of our different jobs. We are all here to provide the very best care and support we can to kids and their families. It never ceases to amaze me how much people truly care about their patients, and the lengths they will go to provide what is needed at every step along the way. I play on a great team!

Can you tell us about a memorable work experience?

One of my favourite experiences so far has been helping to organize the CHN Conference in 2012. It was so much fun, and it was a great demonstration of how close our heart community is. BC Children's staff and CHN families joined forces to create a program that was educational, inspiring and lots of fun for everyone involved. I wasn't able to do as much for the most recent conference because my own babies were so little, but I am really looking forward to preparing for the next conference.



Brian and Anna Murray with their twins Oliver and Nathaniel.

Do you have any specialties within nursing?

I work in the Fetal Heart Program, supporting and educating families expecting babies with congenital heart defects. I also provide home monitoring support for our most fragile infants, many of whom I first meet through the Fetal Heart Program.

Did you have a mentor?

I had the most incredible mentor imaginable, Jan Rooks. When I first came down to the clinic from 3M in 2011, Jan took me under her wing and taught me more than I ever imagined possible about congenital heart disease and what life is like for families living with a cardiac diagnosis. Jan had a calm and compassionate manner and an energy that made her loved by families and hospital staff alike. I can only hope that some of her nature rubbed off on me, because she was one fine cardiac nurse, not to mention a true friend.

Can you tell us about your family?

I have 3-year-old twin boys named Oliver and Nathaniel with my husband Brian. I also have a naughty but adorable little black and white cat called Memphis.

Outside work, what do you like to do for fun?

Before my little guys came along I enjoyed playing field hockey, hiking, baking, and making handmade cards. These days I watch Paw Patrol, play with trains, do laundry and ask, "Who needs to go pee?" about a thousand times a day! I still manage to do some baking, but my field hockey career is on hold for now. With a full-time job at the Heart Centre and two little guys to run after at home my days are pretty full, but I wouldn't have it any other way. 🍓

Loving the campfires at CHN's first Family Camp

BY TRACEY CARPENTER



Being completely unplugged from technology was a treat, and made connecting with other heart families easier.

game of camp-wide hide-and-seek where the families formed groups and had to find the counsellors, who were hiding around the camp and in the woods, by listening for their whistles. The evening ended as you would hope an evening at camp would: with a fun-packed campfire ("campfires I love campfires, highya!") including songs, stories, and of course a marshmallow roast. On the Sunday, there was a waffle breakfast more activities, including a scavenger hunt.

One highlight was the fact we were completely unplugged from our technologically dominated world—it was such a

In late September this year, 13 heart families attended our first ever, much-anticipated CHN Family Camp. Hosting a family camp has been a goal for of the CHN Board for a number of years, and we were thrilled to finally be able to offer this experience thanks to new donations from many generous sponsors over the past year.

Leading up to the weekend we were sent directions to Camp Summit near Squamish, packing lists as well as an itinerary for the weekend, but none of us really knew what to expect.

We drove up to the camp to see our CHN flag at the gate on the Friday night and were met in the driveway by a group of counsellors who checked us in and helped carry all of our gear to our individual family tents and cabins. Then we congregated in the main hall for same late-night snacks, a camp orientation, and some group games to break the ice. It was great to reconnect with some familiar faces and to meet some families for the first time. Families were all given a bag with camp T-shirts for all the kids, a new CHN water bottle, and most importantly, flashlights to make our way back to our bunks.

After a bit of a chilly night the breakfast bell rang and we made our way back to the main hall. We met more of the camp counsellors and learned what a day at Camp Summit looks like. We participated in activities such as the high-ropes course, archery, mountain biking, geocaching, hikes, and arts and crafts like tie dying. It was exciting to see so many kids and parents conquering the high-ropes course and learning to trust their spotters, belayers, the structure, and most importantly, themselves. Archery was also a very popular activity where people could really see themselves improve with patience and persistence. There were two rounds of activities and then we convened in the main hall for lunch, which was followed by more activities and some free time. Later Saturday night we enjoyed dinner together followed by a fun



great experience for the families to really be present at camp, which is not something we do very often.

We had a videography company come out to capture some moments of our time at camp and interview some of our families about what CHN means to them. One family talked about how they had had a challenging week with uncertainty but knowing that the CHN Family Camp was coming up on the weekend gave them something to look forward to all week. Another parent talked about how safe she feels at Children's Heart Network events because she knows other parents will not bring their children if they have colds or other illnesses because all heart parents understand the risks. We can't wait to see the video and share it with you this spring.

While the games and activities were amazing, the highlight was really the connections that were made between parents, the children and the siblings. All heart family stories are unique but we all have many similarities too, and often only another heart family can say, "I understand, we've experienced that too."

I'd like to send a big shout-out to the amazing staff at Camp Summit. It was apparent from the moment we arrived that they all absolutely love their job and have so much fun doing what they do. All the tasty meals were served family style with one person from each table being assigned "hopper" duties and collecting all the food for their tables. The camp kitchen did a fantastic job being aware of food allergies and was very accommodating to people with celiac as well as nut and dairy allergies.

We hope to raise enough money to offer this camp again

next year so even more families can have the opportunity to experience this fun-filled family event. If you would like to donate to CHN to help offer camp experiences for children with congenital heart disease and their families, please visit CHN's website at childrensheartnetwork.org and click on our Donate button. 🍎



It's almost flu season...

Flu (influenza) vaccines are free for individuals at high risk of serious illness from influenza. This includes children with heart conditions and their immediate family.

What is influenza?

- Influenza, often called the flu, is an infection of the nose, throat and lungs caused by the influenza virus. A person with influenza is at risk of other infections, including viral or bacterial pneumonia (infection of the lungs). In Canada, it is estimated that up to 7,000 people a year die from influenza and its complications.

What is the influenza vaccine?

- The influenza vaccine protects against viruses that cause influenza. The vaccine does not protect against other viruses or bacteria that cause colds or stomach

illness. The vaccine is approved by Health Canada.

- It is best to get vaccinated by the end of November to give your body enough time—about two weeks—to build immunity before the influenza season starts, which usually occurs from November to April.

Did you know?

- Immunization has saved more lives in Canada in the last 50 years than any other health measure.

Contact your local community health unit or your family physician to get your flu shot today!

Information from: www.bchealthguide.org

Some interesting and helpful blogs and websites for heart families



- ★ theheartmoms.com
- ★ thriving.childrenshospital.org/experience-journal-growing-congenital-heart-disease
- ★ cardiackids.wordpress.com
- ★ lensofmotherhood.blogspot.ca/?wref=bif
- ★ healthline.com/health/heart-disease/best-blogs-of-the-year
- ★ blog.heartandstroke.ca/2015/10/fitness-trackers-help-teens-with-heart-disease
- ★ www.bcchildrens.ca/our-services/support-services/transition-to-adult-care
- ★ huffingtonpost.com/mia-carella/i-am-a-heart-mom-what-its_b_9322004.html
- ★ childrensheartfoundation.org/about-chf/fact-sheets
- ★ themighty.com/2016/03/6-things-you-may-not-know-about-moms-of-kids-with-congenital-heart-defects
- ★ blog.wholehearts.org/?p=32



What's Happening?

The 2nd Annual CHN Pub Night Fundraiser

WHEN: Saturday, Nov. 5 at 6:00pm

WHERE: Manchester Pub & Eatery at 1941 West Broadway, Vancouver
To order tickets please go to <https://chnpubnight.benefittickets.com> or email Sam at saitken@childrensheartnetwork.org

Lower Mainland Christmas Party

WHEN: Saturday, Nov. 26

WHERE: The Metrotown Hilton Hotel

Save the date for the Lower Mainland CHN Christmas Party, a fabulous breakfast with Santa! If you would like to attend or to make a donation to the silent auction, please contact Sam at saitken@childrensheartnetwork.org

For more information on all events, please contact Sam at saitken@childrensheartnetwork.org

EVENTS ROUNDUP

A great day at the Cultus Lake Water Slides

On a slightly sunny Sunday in August over 250 members of the Children's Heart Network joined together for a fabulous day of water, thrills, and fun. Our group had a large area right next to the Pirates Cove water playground. The weather wasn't the best—it could have been hotter—but that meant the lineups were short and our families got to have many more rides on the slides. Some of the highlights were 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! Lunch was served in the build-your-own burger bar—a huge hit. It was wonderful to see so many families come from afar to join us (Victoria, Kelowna, and Kamloops.) Many old heart friends had the opportunity to reconnect, and some fabulous new relationships were formed.

Hearts of Gold Vancouver summer events

Hearts of Gold had an extremely busy season full of fun and unique adventures. The group kicked off the summer with our June event at Playland, where everyone enjoyed some pretty crazy rides and tasty food. The excitement continued in July with a day spent kayaking on the water in Cates Park. Hearts of Gold was fortunate to work closely with the community group Power to Be that helps facilitate adaptive outdoor recreation activities. Working in conjunction with Power to Be guides, the group enjoyed time on the water where we observed jellyfish and seals. Following lunch the group went on a short but memorable nature walk where the teens all had a chance to stand in a massive hallow tree. Summer concluded in August with a dinner out at a Moxies Restaurant prior to taking in a BC Lions game. It was a close and eventful game that left the crowd on the edge of their seats. We had a great turnout and it was a fun way to wrap up the summer season! 🍷



Cultus kids pose between rides (above); Pearce waving our new CHN flag at Cultus Lake (middle); and Bridget, Susie, Daniela, Kristi, Sarah, J.J., Kyle, Francesca, Andrew and Ryan at the PNE (bottom).