

CHILDREN'S Heart Network Heart Network

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FALL 2015



Matt, Christine, and Dakota with their fishing hosts Jay and Emily.

Critter Cove: Smiling for 4 days straight

BY MATT STEFFICH

n a Sunday night in April we received a call from Kerry, a volunteer with the Children's Heart Network, informing us that we were invited to an all-expense paid trip to a fishing lodge called Critter Cove. At first it sounded like a telemarketing scam, but the more she spoke the more I realize it was the real deal. Our name had been passed along because our son Dakota had gone through heart surgery several years before at BC Children's Hospital.

Although the description of the adventure sounded great, it could not describe what we actually experienced this June. Critter Cove fishing lodge is located in Nootka Sound. The setting is spectacular. Ten families had been invited, all of whom had had children who had experienced some type of heart episode from significant to severe. Although none of us had ever met, we were connected by our children. From the minute we stepped off



Traditional salmon barbeque.

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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

The newsletter of the Children's Heart Network, which works to educate, support, and enhance the lives of children, youth, and families living with congenital heart disease.



COFFEE GROUPS

These groups meet monthly, come and meet other heart parents while enjoying treats on us! For more information please contact:

VANCOUVER – Samantha Aitken saitken@childrensheartnetwork.org

BURNABY/COQUITLAM - Sarah Kertcher sarah.kertcher@outlook.com

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VICTORIA – Teri Godin | terigodin@gmail.com

NANAIMO - Andrea Van Rossum andrea.vanrossum@gmail.com

KAMLOOPS - Miranda Brown cmazn2003@yahoo.ca

We would like to get a **KELOWNA** Coffee group up and running! Please email Sam at saitken@ childrensheartnetwork.org if you are interested in attending one.



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

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!

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

HELPFUL WEBSITES

heartbeats.ca

Supporting Children with Heart Disease

chdquilt.org

The Congenital Heart Defect Awarenees Project

westerncanadianheartnetwork.ca

Western Canadian Children's Heart Network

achaheart.org

Adult Congenital Heart Association

cchaforlife.org

Canadian Congenital Heart Alliance

CHN STAFF

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KRISTA MOLIA – Vancouver Island Hearts of Gold youth coordinator

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(Above) Ten families and all their hosts on the Critter Cove docks.

the bus and onto the shuttle boats to the lodge, we, and most importantly, the kids, were simply spoiled rotten!

The food was relentless and awesome. The accommodation was spartan and perfect. We were assigned to a boat with two of the sweetest people, Captain Jay and Emily. It seemed like Jay knew every inch of Nootka Sound. When I asked him if he thought we would catch any fish, he smiled and said "yes." We caught six.

We had a fantastic salmon barbeque on the beach at the head of Friendly Cove, a historic former Native village and were treated to Zodiac rides from the RCMP, department of fisheries, and the Coast Guard. When a photographer came by and offered to take our photo and said "smile," I replied, "I haven't been able to stop since I got here!"

The final evening each child was given a framed eagle feather as a memento. The night was capped off with fireworks. The owners of Critter Cove and all the volunteers that take families out fishing have been doing this for 15 years for the simple and altruistic reasons of giving back to the community. They understand that what they are doing for the kids will give them a lifetime of memories. It would be impossible to thank them enough for what they gave our children and families. I have done many things in my lifetime, but it will be hard to rival the experience of those 4 days in June.

(Top left) Storytime on the dock. (Bottom left) Riding with the RCMP.



Above: Judah at 14 months. Top right: Judah in the ICU. Bottom right: Nurse Jan Rooks holding Judah, along with mom Kristen, dad Mike, and brother Liam.

HEART STORY

Judah makes his own rules

BY KRISTIN AVIS

t wasn't until our routine ultrasound that I realized something was going on with our baby's heart. After a more detailed ultrasound in Victoria (we live in Nanaimo) we were quickly referred to Dr Sinclair who is the paediatric cardiologist for the island. Dr Sinclair scanned me and the baby and had the unenviable task of leading my husband Mike and I to a private room to deliver the news of a difficult diagnosis to two hopeful parents.

Even though hearing Judah's diagnosis for the first time was one of the most difficult moments of my life, I was truly impressed by the way Dr Sinclair was professional but also very sensitive and caring in the way he delivered the news. He told us our baby had a small right ventricle, double-inlet left ventricle, and a very small aorta. He explained that we would have to relocate to Vancouver 3 weeks before the baby's due date and give birth at BC Women's Hospital. We learned that the baby would have open heart surgery within the first week of life, another surgery around 6 months of

age, and another around 3 or 4 years of age. Our heads were spinning. It was difficult news to comprehend.

We relocated to Easter Seals House in Vancouver on May 22, 2014 with our 2-year-old son Liam in tow to await the birth of our son. We were incredibly blessed to have also been under the care of Jan Rooks, who was a nurse clinician at Children's Hospital. Jan met with us to tour us around the hospital, and show us pictures of other babies in the ICU who had similar surgeries to help to prepare us for what was to

Judah was born on June 17, 2014. As they placed him on my chest for the first time I knew that he was big and strong and he was going to be okay. It was very difficult to hand him over to the nurses to take him to the ICU. I was happy Mike got to go be with Judah even though my heart was aching to be with him too. I was so happy my family was able to bring our son Liam in to be with me as I recovered and waited to see Judah in the ICU.

The evening after Judah was born and the following day was a blur of activity. We found out that Judah would only be 36 hours old when he went in for his surgery. I felt incredibly tired and overwhelmed as we met with cardiac surgeon Dr Gandhi, who tried to explain Judah's full diagnosis of "hypoplastic right ventricle, double inlet left ventricle, hypoplastic arch, transposition of the great arteries, ventral septal defect and patent ductus arteriosus." To be totally honest, I'm still not sure what it all means! That whole day was like a weird dream as we met with different doctors in the ICU and watched Judah go through all of his preoperative testing. Jan

was with us the whole time re-explaining everything to us, encouraging us, and keeping us smiling.

The day of Judah's Norwood operation was the longest day of my life. The surgery was scheduled to be 5 to 7 hours long. Dr Gandhi would be repairing Judah's aorta with donor material, and inserting a BT shunt to help with blood flow to the lungs. Nineand-a-half hours after we watched our tiny baby wheeled out for surgery, the beeper they had given us



Daddy and baby Judah.

finally went off and Dr Gandhi and Jan Rooks met with us in the ICU waiting room. Dr Gandhi told us that the surgery went okay. The repair of the aorta had gone really well and he explained to us the difficulty he had inserting the shunt, which he was able to successfully insert on the third attempt. Dr Gandhi told us that the next 24 to 48 hours were critical for Judah. Jan stayed with us until we were able to go and see Judah in the ICU. Jan told us to try to look past all the equipment that Judah would have on him and to really see our baby under there.

It was scary walking into the ICU to see Judah for the first time after his surgery. His sternum was still open due to swelling from the surgery and it seemed as though there were tubes coming out from everywhere. Thanks to Jan, we felt really prepared for what we saw and it wasn't as traumatic as it could have been. I sat next to my baby and found his tiny hand underneath all of his tubes and held it. We kissed just about every spot of skin that was free of equipment and both talked and sang softly to our sweet little baby as he recovered.

Judah did incredibly well over the next couple of days and

48 hours after his surgery Dr Gandhi was ready to close his sternum. They performed the surgery right in the ICU. Judah's body started showing signs of stress after the procedure. Judah wasn't producing enough urine which meant that his kidneys weren't functioning properly. Dr Gandhi explained to us that if that Judah didn't produce a certain amount of urine in a certain amount time that they would have to operate on him again and open him back up. I never thought I would ever pray so hard for someone to pee in my entire life! It felt like it was the last second in double overtime when Judah finally peed enough to show the doctors that everything

was functioning well. We were ecstatic. Two days later Judah graduated to upstairs.

The nurses in 3M taught us how to care for Judah. We were thankful that Iudah was our second child because there was a lot to learn and we were glad we already knew how to change diapers! The nurses really empowered us to feel confident in our abilities to feed Judah with a feeding tube at home, monitor his O2 saturations, and care for his incision. They also taught us about what is normal for Judah and what signs to look for

if something was to go wrong. Judah was doing so well that we were discharged from the hospital only 6 days after his Norwood operation.

We stayed at Easter Seals House for a week to be close to the hospital before we got the okay to head home. There were a few bumps in the road that week as we continued on our steep learning curve of caring for Judah. We were able to head home to Nanaimo after our week at Easter Seals House. We both felt Judah was healthy enough to be at home and that the nurses had given us the knowledge and the ability to care for him.

We spent the next few months busy with appointments and learning what it is like to be a heart patient family living on Vancouver Island. Sometimes we see Dr Sinclair in Victoria or at the heart clinics in Nanaimo. We have been so impressed at how everyone on Judah's team stays in communication. We have our nurse clinicians Deb in Nanaimo, Anne in Victoria, and Rosella at Children's Hospital. All three of them have worked together to keep Judah's team organized and have surrounded us with unbelievable support that has

helped our confidence as Judah's parents and helped Judah to thrive at home.

Judah had his second open heart surgery, the Glenn, at 4 months of age. It was even harder for us to hand over Judah to the nurses for his second surgery. Thankfully, Judah's surgery went very well. It was approximately 5 hours long with no complications. It was a lot less scary visiting him in the ICU this time as he didn't have a ventilator and his sternum was closed completely. Judah looked peaceful as he recovered in the ICU.

Judah was discharged from the hospital only 4 days after his surgery. Once again, we stayed in Vancouver for another week before getting the okay to head home to Nanaimo. After Judah's Glenn, he developed something called chylothorax, which was an injury to his lymphatic system. To heal this injury, Judah had to have a non-fat formula called Monogen for 6 weeks. Judah and I had worked so hard at breastfeeding and getting him off the feeding tube that this was really upsetting news for me. It took patience and work, but fortunately our Judah is very resilient and took the Monogen formula like a champ and was amazingly able to resume breastfeeding after 6 weeks.

Judah is now 14 months old and full of life. He is walking and talking and determined to do everything he can to keep up with his big brother Liam. I feel our family is now living the life we originally dreamed about when we first found out I was pregnant with Judah. People are often surprised to find out that Judah has a heart condition because he doesn't seem to ever stop moving and will greet them with this huge smile and contagious laugh. We have been enjoying what is called the interphase period until his next surgery, the Fontan, which is scheduled for when he will be about 3 or 4 years old. We still see Dr Sinclair every 3 to 6 months but the number of appointments have dropped significantly. Our next big appointment will be heading to Children's sometime this fall for a heart cath to remove some unwanted blood vessels growing around his aorta.



Judah in the ICU.

I know Judah has come a long way because the favourite bath toys in our house are now Judah's old feeding tube supplies. There have been a lot of life-defining moments for me as Judah's mother throughout his journey. I know Judah will carry his heart condition with him for the rest of his life, but I do not believe it will define who he will become. Doctors have discussed what limitations he might face in life, but I can already tell from Judah's young life and demonstrated resilience that he is going to make his own rules and create his own unique path to live his life.



WCCHN Update

The Western Canadian Children's Heart Network was established to link expertise between the five Pediatric Cardiac Centres and improve inter-provincial cooperation and partnership. The WCCHN spans more than 4 million square kilometers and serves a population of over 11 million. Pediatric Cardiac Surgical services are regionalized at two of the Network's five centres, BC Children's Hospital in Vancouver and Stollery Children's Hospital in Edmonton. The core function of the Network is to coordinate and integrate care for Pediatric Cardiac Patients across the Western Canadian provinces. The

Network encourages cooperation in education and clinical practice, supports research efforts, and advocates for the continual improvement of pediatric cardiac care services across the four western provinces. Collaboration among the WCCHN partners ensures that pediatric cardiac patients in Western Canada have access to the highest standard of pediatric cardiac care.

www.westerncanadianchildrensheartnetwork.ca

Vancouver Island: Summer report and fall preview

BY KRISTA MOLIA

earts of Gold on Vancouver Island enjoyed two summer events this year. We started by going to All Fun Recreation to play mini golf and to hit some balls in the batting cages. In August we teamed up with Power To Be for some ocean kayaking. We braved the windy elements, paddled by many seals, and made it back to shore smiling. We had two new youth just us that day and it was great to see our group grow. In September, right around press time, we're planning to go horseback riding.

Please join us for the following upcoming events: In October we will brave Victoria's brand new glow in the dark mini-golf and in November we will tap into our creative side for Paint your own Ceramics. Our annual Christmas feast at a restaurant voted for by our group will be the wind-up for the year, always a super fun evening!



Hearts of Gold teens kayaking with Power to Be.

Lower Mainland: Pirates, circus, and ... deep-fried Oreos? BY KRISTI COLDWELL



The pirates of False Creek.

It has been a very eventful summer for the Lower Mainland Hearts of Gold youth program! We kicked off the summer with our June event, a pirate-themed boat cruise from Granville Island around False Creek, where we enjoyed an improv-style experience of being a pirate for a couple hours, complete with personalized pirate names and costumes.

Our adventures continued with our July event of circus school and dinner at Old Spaghetti Factory. It was a great opportunity to learn how to juggle, perform tricks on the trampoline and hang upside-down on the aerial silks. Everyone was very hungry and ready for a pasta feast following the afternoon learning circus tricks!

We wrapped up summer with a trip to the Fair at the PNE. The cheesecake on a stick, deep-fried Oreos, and cotton candy supplied the fuel to watch the Superdogs, take in the superhero exhibit, and end the evening with an outdoor concert performance by Christina Perri and Colby Calliat.

It was a great summer for Hearts of Gold and great to see a few new faces join the group–welcome!

For more information

If your child is between the ages of 13 and 18, email chn@childrensheartnetwork.org for more information and to add your name to our email list to receive information about monthly events. **childrensheartnetwork.org/what-we-do/hearts-of-gold**

What you need to know about infective endocarditis

BY ALYSSA POWER

Alyssa Power is a Pediatric Resident at Alberta Children's Hospital

What is infective endocarditis?

Infective endocarditis is the term used when there is an infection of the endocardium (the inner lining of the heart). Small clumps of infected material called vegetations form near or on a heart valve. They are made up of bacteria, small blood clots, and proteins.

Endocarditis can affect the heart by causing heart failure (where the heart has trouble pumping blood around the body) and arrhythmias (abnormal electricity of the heart). In addition, pieces of the vegetation can break off and travel to other parts of the body. These pieces can get stuck in small blood vessels and block off blood flow to other organs, causing damage away from the heart.

Infective endocarditis is a very serious infection that is life threatening if not treated. Thankfully, endocarditis is a rare diagnosis in children. However, some children with a congenital heart disease are at increased risk of developing infective endocarditis.

What causes infective endocarditis?

Endocarditis is usually caused by bacteria. Most bacteria that enter the blood are killed by our body's immune system. However, bacteria sometimes survive and travel through the blood to the heart. When the lining of the heart (the endothelium) is damaged because of turbulent blood flow from heart problems, the body reacts by forming a blood clot in that area. Bacteria in the blood can attach to this blood clot, creating an infected vegetation. Once attached, the bacteria are further covered with small blood clots and proteins, escaping the body's immune system.

What are the symptoms of infective endocarditis?

Endocarditis usually causes an unexplained fever lasting for 5 to 7 days or longer. It can also cause fatigue, decreased appetite, muscle and joint pain, and a general feeling of weakness. It can be difficult for you to know if your child has infective endocarditis because these symptoms are like those of the flu! You should contact your child's pediatrician or the cardiology team if your child has some of these symptoms and they do not go away.

These warning symptoms should prompt a visit to the emergency room:

• Symptoms of heart failure such as rapid breathing, breathlessness, difficulty with exercise or, in infants and young children, difficulty feeding, pallor and profuse perspiration.

- Signs of kidney damage, such as red or brown urine.
- Signs of a stroke, such as trouble speaking, trouble swallowing, weakness or paralysis on one side of the body.

How is endocarditis diagnosed and treated?

If your child's doctor believes that your child may have endocarditis, several tests will be done, including:

- Multiple blood cultures (to check for bacteria in the blood). Finding the specific bacteria that is causing endocarditis is important to help the medical team select the best therapy.
- An echocardiogram. This ultrasound of the heart will help to visualize any vegetations or changes to the heart valves, and will evaluate heart function.

Endocarditis requires an admission to the hospital and treatment with a prolonged course of intravenous antibiotics (medications that destroy bacteria given through a vein). Your child may need 6 or more weeks of antibiotics to get rid of the infection.

Some children require surgery if the infection is not improving or if the endocarditis has seriously damaged a heart valve. Surgery can involve removing vegetations or replacing the diseased heart valve.

What can you do to decrease your child's risk?

Though the risk of your child developing infective endocarditis is low, it is important to know how to prevent it, because it can be a very serious infection. It is better to prevent infective endocarditis than to treat it.

There are some medical procedures that increase the risk of bacteria entering the blood, including certain dental procedures (involving the teeth). Your cardiologist will tell you whether your child needs an antibiotic before these procedures to prevent infective endocarditis (also known as prophylactic antibiotics). Your dentist will want to know whether your child needs antibiotics.

The American Heart Association published new guidelines about infective endocarditis in 2007. These guidelines emphasized that most cases of infective endocarditis are not caused by surgical procedures. Instead, we know that bacteria from our mouth can enter our blood every time we chew on food or brush and floss our teeth. That is why proper dental care is so important!

Good dental hygiene can even start before your child's first tooth appears! Gently running a damp (and clean) washcloth over a baby's gums every day can help to remove harmful bacteria. From when your child's first tooth appears until the age of 2 years, you can brush their teeth without toothpaste

using an infant toothbrush. You should avoid putting your child to sleep with a bottle-the sugars in milk and juice will remain on a baby's teeth for hours and can destroy the enamel, sometimes even resulting in cavities!

Many children as young as 2 or 3 should be able to spit while brushing, and can start to use a pea-sized amount of toothpaste, under supervision. You should choose toothpaste that contains fluoride, since regular contact with fluoride strengthens teeth. Brushing twice a day and daily flossing will help keep your child's mouth healthy. Flossing can start as soon as your baby has two teeth that touch.

In addition to developing good oral health habits at home, don't forget to schedule regular visits with your child's dentist! Reducing the amount of bad bacteria that stay in your child's mouth helps decrease the chance that they will develop infective endocarditis.

Conclusion

In summary, infective endocarditis is a rare but very serious infection of the heart. It presents with symptoms that are hard to distinguish from the flu. Endocarditis requires an

admission to the hospital and treatment with 6 or more weeks of intravenous antibiotics.

Knowing how to prevent infective endocarditis is crucial. Good oral hygiene and regular visits with your child's dentist are the most important things you can do! Finally, your cardiology team will tell you if your child needs antibiotics before dental procedures.

Resources and further Information

- Prevention of Infective Endocarditis: Guidelines from the American Heart Association. Circulation. 2007. Available from: http://circ.ahajournals.org/content/116/15/1736.long
- About Kids Health: Trusted Answers from the Hospital for Sick Children. Infective Endocarditis. 2010. Available from: www.aboutkidshealth.ca/En/HealthAZ/
- Conditions and Diseases/Heart and Blood Vessel Disorders/ Pages/Infective-Endocarditis-IE.aspx
- Kids Health. Keeping Your Child's Teeth Healthy. 2012.
 Available from: http://kidshealth.org/parent/general/teeth/healthy.html



Right: Asha celebrating her birthday at 4Cats Art Studio. Inset: Her sister Mila.



HEART HEROES

Asha's birthday wish

In April 2015, Asha celebrated her fourth birthday at 4Cats Art Studio in the Dunbar area of Vancouver. Ten of her friends attended and they made magical polymer clay fairies and pirates. All of the guests worked on their own sculpture mounted onto a painted canvas. In lieu of gifts Asha requested that her friends bring two toonies to be donated to the Children's Heart Network in memory of her beloved big sister, Mila. Many of Asha's friends were extra generous and she raised \$100 for Mila's Fund.

Mila was a heart child, who sadly, passed away in August 2012 at the age of four-and-a-half. She too was a budding artist who loved to take art classes and celebrate birthdays at 4Cats Dunbar.



Meet volunteer Leigh Striegler

Leigh Striegler has been designing CHN's Heart Matters since 2010. If you were a member before then you likely noticed a sudden improvement in the attractiveness of that issue! Leigh has been an independent designer since 1992, operating her company Olive Design from 1997-2013 and now Scout Creative for the past 2 years. In 2005 she became a certified fitness instructor, and began a double professional life doing both. CHN has benefitted from both sides of Leigh's business—she has donated fitness classes to help our fundraising activities, designed all conference materials for our 2012 Growing Up With Heart Disease Conference, and designs each issue of Heart Matters. Learn more about this dedicated volunteer below.

What profession might you have pursued, if not a designerfitness instructor?

Well there's still time—so don't count me out just yet. I like shaking things up so I'm sure there's still a few more occupations that I'll fill by the time I'm through. But journalism/reporter is the career that I would have chosen had I been accepted into the Ryerson Journalism program back in 1987. All applicants already had bachelor's or master's degrees, so it wasn't in the cards for me. I had 2 years of journalism from Langara College and was looking to do the full program but ended up apprenticing for a graphic design studio for a summer and a new career option was found.

Which talent would you most like to have?

A singer. I'm musical but my singing voice—not so great.

What do you consider your greatest achievement?

Probably creating my own work-life so that I'm able to travel and work at the same time. In particular, spending the better part of 5 years living and working remotely from Maui while learning how to surf.

Who are your heroes?

In my immediate life, I'd say my sister. Her son Nathan was diagnosed with autism at age 2 and she's persistent in finding alternative treatments to get him better. Sourcing behavioural therapists, nutrition experts, changing his diet and sourcing medical experts across North America to get him the help he needs. She's an inspiration.

What is your idea of perfect happiness?

Balance. Equal parts work life, active lifestyle, and friends and family. Throw in a little getaway in there with all parts and life is perfect.

What is your greatest fear?

It used to be a fear of water but I think I've overcome that with learning how to dive (with sharks) and also having been beat up many times when I was learning to surf.

What is the trait you most deplore in yourself?

Procrastination. Maybe that's why I keep so busy. As they say, if you want something done, give it to a busy person.

What characteristics do your favorite people share?

Humour. Sense of adventure. Wanderlust. Empathy.

Which living person do you most admire?

Well there are many people and for different reasons. I'm currently loving Ethel Kennedy. Her life story and perseverance fascinate me. A guilty pleasure of mine is also watching Bear Grylls. I love his survivalist instinct. Confronting your fears, etc.

What is your favorite activity?

Anything outdoors. Teaching fitness at 6 a.m. and seeing the sun come up every day is one of my favourite moments of the day.

On what occasion do you lie?

Well I do follow the motto that honesty is the best policy but there are occasions where I will tell a white lie to spare someone's feelings.

Where would you most like to live?

In a perfect world—a few months in Vancouver, a month on Maui, and the summers in Europe (south of France and Italy). I better buy a lottery ticket.

What do you most value in your friends?

Honesty, integrity and humour.

Who are your favorite writers?

John Irving, Philip Roth, Philipa Gregory, Dave Eggers.

What is your greatest regret?

Not moving to New York City instead of Toronto as a young person. Who knows where I'd be today had I started out there.

What is your motto?

That which doesn't break you, will certainly make you stronger and the glass is always half full.

What is your most marked characteristic?

I don't sweat the small stuff. And my ability to have a laugh. I see the humour in most things.



Above: Sam and her sister at Euro Disney. Inset: Sam and family preparing to get in the limo enroute to YVR and then on to Paris.

Wishes can be granted

BY ANDY KALLSTROM

Andy Kallstrom is a communications specialist at Children's Wish

ike many heart kids, Samantha Armstrong's medical life started early. She was diagnosed with Ebstein's anomaly within a day of her birth. Doctors told her parents, Deborah and Richard, that babies with the most serious cases of Ebstein's don't survive, so they feared the worst.

Fortunately, Sam did survive, and thrive. When Sam was 12, another Children's Heart Network family that she had met at the Critter Cove referred her to the Children's Wish Foundation of Canada.

"One thing that I love about Children's Wish is that anyone can refer a child," says Lindsay Barnett, wish coordinator at Children's Wish. "Sam is a great example, because she wasn't referred for her wish by a doctor or nurse, but by another wish family who heard her story and thought she would meet our criteria."

Lindsay adds that heart families tend not to be referred for wishes at the same rate as other eligible children, like oncology kids. "It may be because a lot of heart families don't know that they may be eligible to receive a wish from us, but our criteria are fairly simple: Canadian children aged 3 to 17 who have

faced a high-risk life threatening illness can apply to have their wish granted, so many heart kids certainly do qualify. Not every heart condition meets these criteria, but many do."

Sam's diagnosis did meet the criteria, and on Christmas Eve Sam received a call from Children's Wish letting her know her wish would be granted. According to Deborah, "Sam was overjoyed. She was completely ecstatic for weeks afterward."

Next Sam had to make the decision of what to wish for. It wasn't a difficult choice to make: she had always wanted to go to Paris, and she loved all things Disney. So she chose to take her mom, dad and two siblings on a family trip to Paris, where they were able to visit Euro Disney. They also checked out the Paris Catacombs, Notre Dame, and the Louvre. "It was truly life changing. We were so happy on the trip and we were so happy to have the opportunity to see and do so many amazing things. It allowed us and Sam to see that something good could come out of something so terrible," says Deborah. Even now, years later, Sam still considers herself very fortunate to have received such a wonderful gift.

Refer a child—including your own

If you know any child—including your own—who you believe meets the criteria, please get in touch with Lindsay at Children's Wish, who will look into granting their most heartfelt wish. Lindsay can be reached at 778 383-1416 or Lindsay.Barnett@childrenswish.ca.

MEET MEGAN CRANE

Megan is a cardiology nurse who also takes our heart teens to camp every year.

Where did you grow up?

I grew up in Surrey, BC.

Can you describe your job?

My job consists of giving out medicine, taking vital signs, listening to parents and patients concerns, advocating for them to the doctors, teaching about what they need to know in order to go home, supporting patients and families through difficult times, laughing and crying with families. Some of the perks are cuddling babies, playing with the older kids, and meeting amazingly strong patients and parents, and getting to be part of their lives briefly.



Megan and Tigger.

What made you want to be a pediatric nurse?

I always knew I wanted to work with children, so in my mind that meant either becoming a teacher or a nurse. As I couldn't see how I'd be able to teach a class of 30 students I chose nursing. Best decision ever.

Can you tell us about a recent memorable experience?

My most recent memorable experience is becoming a member of "The Secret Ninja Club." One of my 6 year old patients had formed this club, and in order for me to become a member I needed to do something sneaky on each of my night shifts. The first morning he woke up to his toenails painted, and the second morning he had 2 temporary tattoos on his hands.

Tell us about any specialties you have within cardiology/nursing.

As a nurse cardiology and respiratory are my specialties. In the past few years I have been working more on the medical side of 3M than the cardiac side, and am often in charge of the nurses on 3M on my night shifts.

Did you have a mentor?

I don't think I have just one mentor. At work it would have to be our 2 charge nurses, and Therese (now retired). In life it would have to be my Grandma.

Outside work, what do you like to do for fun and what are you good at besides being a nurse?

When I'm not working I never sit still. In the winter I am a volunteer ski patroller at Mount Seymour, this summer I learned how to kiteboard, and all year round I take trampoline lessons. I love skiing, trampoline, travelling, kayaking, and now kiteboarding. I also do some woodcarving, and currently am carving a totem pole.



DID YOU KNOW?

You can have your car valet parked for free at BC Children's Hospital. Pull up outside the ER and look for the Free Valet Parking sign – same price as regular parking.

SAVE THE DATE

OUR ANNUAL CHRISTMAS PARTIES

LOWER MAINLAND – Breakfast with Santa will be held on Saturday, Nov. 28th at the Metrotown Hilton hotel. More details will be emailed out shortly.

VICTORIA – Holiday Season at Butchart Gardens on Sunday, Dec. 6th from 2 to 4pm. Come and enjoy the famous carousel, snacks and the stunning lights. More details will be emailed out shortly.

NANAIMO AND KAMLOOPS - to be announced!