



Hunter with Dr. Campbell after his second surgery (left) and recovering with mom, Andrea

## Hunter's Heart Journey

BY ANDREA JACOBS

**H**unter Anthony Schadow (Jacobs) was born, two weeks earlier than expected, on September 29, 2004. We had a healthy birth and were so proud to bring another boy into this world.

The next day, I had him in his sleeper, ready to take him home. A nurse came in to check on us, looked at Hunter and said, "he looks a little blue. I'm just going to take him to check his oxygen level." The next thing we knew, he was in an incubator, attached to an IV and being sent to B.C. Children's Hospital.

When we arrived at the intensive care unit, we met with cardiologist Dr. Human, who explained to us that Hunter had congenital heart disease: Tetralogy of Fallot with pulmonary atresia and a genetic disorder called Di-George Syndrome, Q22.

At just three days old, Hunter had his first surgery with Dr. LeBlanc, who inserted a BT Shunt that would help his heart along until he was ready for open-heart surgery. We were able to take Hunter home with medication. I learned to change Hunter's dressings and give him

daily injections while his dad distracted him.

Due to his weakened immune system, we were back at BCCH with RSV and pneumonia often. At six months old, Hunter's first Easter was spent in the ICU at Children's. We stayed in the hospital, in isolation, until he was strong enough for open-heart surgery. He was so lucky to have family come visit and was never alone.

Hunter's first open-heart surgery, on May 5, 2005 with Dr. Campbell, lasted six hours, a little longer than predicted. He now had a conduit and a patch for the hole in his heart. We were out of the hospital in just five days and Hunter was ready for the world. They told us that he would need another surgery in about five years. Year after year, we would come to the Heart Center and I would anxiously wait to see if the time had come for him to have surgery. Luckily, we did not get that news until he was 12 years old!

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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](mailto: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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Tel: 604 521-3037 | 1 877 833-1773  
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/ChildrensHeartNetwork



## COFFEE GROUPS NEAR YOU

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

**ABBOTSFORD** – [Rachel Gammon](#)  
footballmama02@hotmail.com

**CHILLIWACK** – [Melissa Martz](#)  
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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

CHN would like to thank The Province of BC for its continued support of CHN through its Community Gaming Grants program.



**The Province of BC**

## SIGN UP TO GET CONNECTED

If you have a child growing up with heart disease please email us at [chn@childrensheartnetwork.org](mailto: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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Hunter in ICU after first surgery

Prior to Hunter's second open-heart surgery, he got sick and contracted a staph infection, which meant weeks in the hospital. The nurses will never forget him; you see, Hunter was named the trickster in preschool for his smart behaviour. One day, his nurse was just a little late giving him his meds. When she came in and apologized, Hunter said: "Nope, that's not okay. You're fired!" He laughed hysterically when she was taken aback.

Hunter's second open-heart surgery was on July 5, 2017, and we were so lucky to have Dr. Campbell again. This time it was just five hours, but it did not go without complications. During the angioplasty when they were enlarging the stent to allow for more flow, it ruptured and caused a tear in Hunter's left ventricle. A graft was used to cover the tear. He had a large hole in his heart repaired, and he was on bypass for 115 minutes. Dr. Campbell removed a calcified conduit from his heart and replaced it with a healthy conduit, making Hunter an organ donor recipient.

It was hard to see him in ICU with a breathing mask and multiple IVs. When he woke up, the first thing he said was, "Am I done?" We all said: "YES!" The nurse told him that he could sleep now and Hunter rolled over and said "good-night."

During this hospital stay, I started a Facebook page called Hunter's Heart Journey. I posted updates and family and friends sent photos and inspiring words to help him through his day. Most inspiring were the messages from kids and youth workers at the Tsawwassen First Nation youth center.

Hunter has grown out of 'Thomas the Tank Engine,' but he still has a whole collection of trains that he will keep forever. Every year, we go visit 'Thomas and Friends' at the Squamish Heritage Railway. We are a bigger family now, with step

dad Joe, Tyler, and younger siblings Dayton and Maddie. Hunter's favorite thing to do is travel. He loves planes, trains, ferries or just going for a drive. His dream is to go to Disneyland to visit Cars. We are going to make that a reality this September.

He loves sleepovers at his Dad's place, visiting with Fozzy the cat, watching movies and doing magic tricks. Hunter participates in a TEENS program with Reach and is making new friends in the Delta community. We live on Tsawwassen lands and so Hunter enjoys attending programs with some of his friends, family and Jen, his youth worker, at the Tsawwassen First Nation preteen center.

As Hunter got older, he was diagnosed with a Mild Intellectual Disability. I wanted to surround him with as much support as possible, including Reach and many behavioural and life skills resources. We participate in CHN functions including the Christmas party and Cultus Lake Waterpark trip. A few years ago, we were able to attend Critter Cove with other heart families and now Hunter is almost ready to join the Hearts of Gold program.

We wanted to give back to other heart families in honour of all that the CHN does for us. For the last four years we have organized 'Hunter's Heart Breakfast,' which raises \$1,000 a year for CHN. Hunter just loves family and community gatherings and he is what brings us all together!

The journey we are on with Hunter is not easy. It does not define who he is as a person. In fact, it is a gentle reminder of how much he is loved. What is important in this world is bringing family and friends together. We take the stress, anxiety and worries he has one day at a time. Hunter's siblings know him very well. They support him, and consider his feelings in everything we do. Hunter came to us for a reason, and we are ever so grateful! Hunter is my hero – our hero. 🍓



Hunter and the Tsawwassen First Nation Youth Centre

# Christmas party in the Bulkley Valley

BY JAYMIE PRAUGHT

The CHN is so excited to announce that we have helped support a group of heart families to get connected in the Bulkley Valley. The Bulkley Valley is located in the northwest Central Interior of BC, near Smithers. We were thrilled to get the below letter from our new CHN families up North:

“On behalf of all of the families who attended the first ever Children’s Heart Network holiday party in the Bulkley Valley, I want to extend our thanks and gratitude for sponsoring this event! Though it was the first ever CHN event held in our area, I hope it won’t be the last and that we can continue to bring our local heart families together with your help. The party was held at B&T Sleigh Rides in Telkwa. Thanks to B&T, we were able to split the sleigh ride into two smaller rides so that everyone got to have a turn on the sleigh. In between sleigh rides, we had a great time visiting and roasting hot dogs and marshmallows around the campfire, playing in the snow and even trying out the child sized zip line. Thanks also to Bulkley Valley Wholesale who kindly donated most of the food for our party. It was wonderful to spend time with both old and new heart family friends, and I hope our network here in the Bulkley Valley will continue to grow and thrive. As you know, having the support of other families in similar situations means a lot. Thank you to Children’s Heart Network for bringing heart families together across BC!”



Sleigh ride fun!

## Did you know ...

One of the world’s pioneer leading cardiologists, who worked in the early 1900s, was a Canadian named Maude Abbott?



**Maude Elizabeth Seymour Abbott** (March 18, 1869 – September 2, 1940) was a Canadian physician. She was one of the country’s first female medical graduates and became a world-famous expert on congenital heart disease.

Despite being one of the first women to obtain a Bachelor’s degree from McGill University, Abbott was declined admission to its medical school because of her gender.

She persevered, and four years later, received a medical degree from Bishop’s University. She was the only woman in the class and graduated at the top of it.

In her practice, Dr. Abbott steadily broke down barriers faced by women in medicine and became an international authority on cardiac disease.

In 1897, she opened an independent clinic dedicated to treating women and children. It was here that she also did much first-hand research in pathology. She was especially concerned with the nature of heart disease and defects in newborn babies.

In 1905, she was invited to write the chapter on ‘Congenital Heart Disease’ for Dr. Osler’s *System of Modern Medicine*.

When he declared her work “the best thing he had ever read on the subject,” the article established her place as a respected

voice in the field.

She had outlined a new classification system for congenital heart disease and significantly improved the understanding of the heart’s anatomy. These put in place the foundation for modern heart surgery.

In 1943, Diego Rivera included her in his painting of a mural for the National Institute of Cardiology of Mexico City. She was the only Canadian, and the only woman depicted in the work.



Have you seen the movie “Something the Lord Made?”

*Something the Lord Made* is a 2004 film about the African-American cardiac pioneer Vivien Thomas and his complex and volatile partnership with white surgeon Alfred Blalock, the world-famous “Blue Baby doctor” who pioneered modern heart surgery. The film traces the two men’s work including their move in 1943 from Vanderbilt to Johns Hopkins, an institution where the only African-American employees are janitors and where Thomas must enter by the back door. Together, they open the field of heart surgery by tackling the congenital heart defect tetralogy of Fallot, also known as Blue Baby Syndrome.

You can find the movie on iTunes.

BY EMILY SAGE COTEY

**F**ive of our Children's Heart Network kids, who have never been to Disneyland, enjoyed the experience of a lifetime this past October, thanks to Dreams Take Flight.

The night before their trip, they enjoyed a wonderful dinner where they got to know all the other kids and volunteers. Then, they started early with a wake-up call the next day at 3:30am, with take-off from YVR at 5am.

Dressed in new Disney clothes and backpacks, the group with kids all between the ages of 6 and 12 landed in Los Angeles and were shuttled to Disneyland for an incredible day of rides, shows, VIP tours, meals and treats.

It was a long day, but one never to be forgotten!

The CHN would like to send a heartfelt thank you to Dreams Take Fight, especially all the volunteers that made this special day happen for our heart kids.

Dreams Take Flight is a registered and national non-profit charity dedicated to providing the trip-of-a-lifetime to medically, mentally, physically, socially or emotionally-challenged children.

Backed by their most significant sponsor, Air Canada, as well as other national and local organizations and businesses, Dreams Take Flight raises money to make dream trips a reality for children in Vancouver, Edmonton, Calgary, Winnipeg, Toronto, Montreal, Ottawa and Halifax.

Dreams Take Flight Vancouver has been taking deserving children with special needs from British Columbia to Disneyland since 1993. Now, in its 25th year, the goal is to take another 125 children to Disneyland for a day on **October 16th, 2018**. Funding will be raised through corporate and private donations, charity golf tournaments and our annual Gala for Dreams.

What does the trip mean? In the words of Johanna Kendall, mom of one of the lucky heart warriors who got to experience this amazing day:

"Dylan had a blast on this trip!"

"Initially, it was all about the treats, but then came what he deemed to be his favourite ride: 'Indiana Jones!' When Dylan got home, he was thrilled to show off all of his cool new toys and clothes to his family. He also enjoyed telling his teacher and his classmates all about this adventure. Before the trip, no one believed what he was about to do. 'Disneyland in one day? You're making that up!'

"He showed them the evidence when he returned to school and they thought it was pretty darn cool! As a parent, even seeing all these rules being broken—Ice cream for breakfast? No sleep for 24 hours?"—I was thrilled that Dylan could take this trip of a lifetime. I am grateful for the CHN and the Dreams Take Flight event for taking him on this adventure! Thank you!"

**M**y name is Emily and I would like to thank "Dreams Take Flight" and also the B.C. Children's Heart Network for making my dream come true.

This is my story of an amazing trip to Disneyland.

In the summer, my Mom Erin asked me if I would like to go to Disneyland. I said yes. She said we would be going with "Dreams Take Flight." I didn't know what that was then, so I thought about it. The next morning I told her that I wanted to go and she told Samantha that I would love to go.

A month later, on Monday, October 17th, after lunch and a good morning at my school, my mom came and picked me up. While everyone else was outside having recess, I went home to get changed out of my uniform and into my other clothes. Then my grandfather picked us up and drove us to the airport.

When we were in the air, I asked my Mom how long we would be away. She told me two days and gave me more details. We would be at our hotel room in Vancouver for the rest of the day until dinner, which would be at the Pacific Gateway Hotel.

I asked her if we could go to the pool and she said yes. My friend Dylan (from CHN) came down with his Dad. Dylan and I had the time of our lives on the waterslide!

Then my Mom said it was time to go back up and get ready for bed. At 3am in the morning, she woke me up. I didn't want to get up so I just went back under the covers. She said, "I guess you don't want to go to Disneyland!"

I got up, put my clothes on and we went downstairs to the lobby, where we saw my friend Dylan. We all got in the same taxi.

We went to an Air Canada airplane hangar that had no plane in it, just Star Wars dudes and other people. Then, we got our special "Dreams Take Flight" clothes and ran for the bus. The bus took us to the airport. There were other "Dreams Take Flight" groups on the plane, but no other people, not even my Mom! The plane took us to California. I even got to see the Hollywood sign from the air! All the kids on the plane got Dairy Queen Dilly Bars even though it was six o'clock in the morning.

When we got to Disneyland, we had to go through security, which took forever. But we finally got through and headed for the train that took us to the park. We were amazed with what we saw. We saw lots of rides that we could go on. The scariest one was Space Mountain. I went on that ride and I was so scared, I closed my eyes and covered my ears. The best ride was "It's A Small World After All."

At the end of the day, we got to buy things from the stores and I got a Minnie Mouse stuffy, pen and Disneyland magnet. Then we went back on the train, back on the bus and got to the airport. On the plane ride back to Vancouver, we fell asleep. When we got back to the hangar, our parents were waiting for us behind the tables. We also got "Dreams Take Flight" medals and they were so cool!

Thank you for reading my story. 🍷



# What you need to know about infective endocarditis

BY ALYSSA POWER, PEDIATRIC RESIDENT, ALBERTA CHILDREN'S HOSPITAL

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## 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.about-kidshealth.ca/En/HealthAZ/](http://www.about-kidshealth.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>



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This memorable evening will be attended by over 180 guests who will enjoy hors d'oeuvres with bubbly and a four course dinner with wine pairings at \$175 per ticket. The Children's Heart Network is a provincial non-profit organization that, through education and support, works to enhance the lives of children, youth and families affected by congenital or acquired heart disease. Heart disease is one of the most common birth defects in BC, affecting 1 in every 100 babies. This year in British Columbia another 500 families will receive the news that their child has a heart defect. The CHN was founded in 1983 and is dedicated to supporting families through a range of programs and services which assist them in their lifelong journey with heart disease.



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**VILLA AMATO BALLROOM**

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Please take advantage of the complimentary valet parking.

# Growing Up with Heart Disease – Journeys – CHN’s conference Nov 5 & 6, 2017

BY CONNIE ENS, CARDIOLOGY NURSE CLINICIAN

The ninth ‘Growing Up with Heart Disease’ conference (link to conference guide) was held on November 5 and 6, 2017 at the Child & Family Research Institute at B.C. Children’s Hospital. The Children’s Heart Network and the Children’s Heart Centre at B.C. Children’s Hospital jointly organizes this biennial event. Almost 200 heart parents, youth, children and heart professionals participated in this year’s conference to make it a wonderful success.

*“This is my first time at the conference. Really appreciate such an opportunity to gather together.”*

*“Chance to chat and learn from so many families. High quality presentations. Great food!”*

*“That once again this conference is a source of inspiration and belief in the staff and families.”*

*“I really appreciate feeling like I am and we are part of a community.”*

*“Food was great. I loved the blend of parents, patients, and health practitioners.”*

Many thanks to all the volunteers and sponsors who made this conference possible. And many thanks to the those who travelled from other provinces to participate.

This theme of this year’s conference was “Journeys” and the program was designed to inform and support many different aspects of a heart family’s journey. Once again, the Hearts of Gold youth panel presentation was a highlight. A wonderful blend of humour and thoughtful sharing from the heart youth really moved the audience.

*“Hearing from Hearts of Gold kids – very inspiring”.*

*“The teen groups are always a highlight! Enjoy their honesty and seeing their interactions with each other.”*

Keynote speaker Dr. Florencia Ricci travelled the furthest to participate in the conference. She is a developmental pediatrician from Alberta who recently relocated to Manitoba. Dr. Ricci’s talked about “the neurodevelopment journey: optimizing outcomes for children with cardiac conditions.”

She shared research highlighting the most common developmental issues for which heart children are at risk. These include mild cognitive delay, impairments in communication skills, clumsiness/motor delays, inattention or impulsive behaviour, impaired executive functioning (paying attention, initiating tasks and staying focused, organizing and planning, regulating emotions). She emphasized that while these impairments may be common, they are often of low severity and stated “the combined outcomes of developmental delay, academic difficulties, behavioural abnormalities represent the single



**Left top:** The WCCHN Board **Bottom left:** Dr. Human and some of the hard working conference committee **Right:** Dayna Kliachik, Tracey Carpenter, Dr. Sanatani and Samantha Aitken

most common morbidity affecting the quality of life of school-aged children with CHD.”

Dr. Ricci’s key message was the importance of following up to intervene early to support optimal development and quality of life. She indicated that the majority of children with CHD can grow to have fulfilling lives with intelligence and social skills in the normal range.

She shared a number of articles (see below) that heart parents have found useful as resources for sharing as needed with their children’s teachers.

“Presentation on neurodevelopment made me conscious about things that we can do to improve outcome for our child.”

A number of resources and on-line tools were also highlighted at the conference:

- [www.upopolis.com](http://www.upopolis.com) social support available to a hospitalized child
- [www.ontracbc.ca](http://www.ontracbc.ca) - transition tools available for youth
- [www.iheartchange.org](http://www.iheartchange.org) - resources to support youth and young adults with congenital heart conditions
- Link to presentations and article

*“I got something from every session I attended.”*

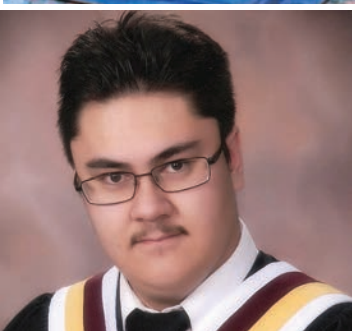
*“It felt good to meet with people who know what we are going through”.*

*“Thank you for organizing this conference. It is invaluable for parents”.*

Planning will be underway shortly for the next GUWHD conference in 2019. 🍷

# Liam's story by the numbers

BY JUDY TSUKIJIMA



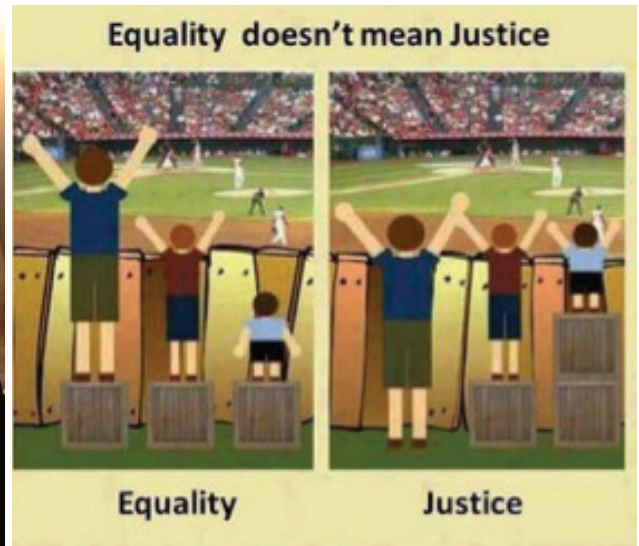
**Top:** transfer day, Liam and Dr Chan at VGH, Liam's 10th birthday and graduation day

- 20-11-1997 The day Liam's Hypoplastic Right Ventricle was diagnosed in utero at B.C. Women's Hospital
- 21 Days between my first cervical cerclage followed by bedrest and my second cervical cerclage due to stitches "slipping" from the first cerclage, followed by admission to hospital until childbirth
- 8 Number of days before Liam's birth when the Infant Transport Team transported me by helicopter from Victoria General Hospital to Vancouver
- 20:24 Time of day that Liam was born on January 15, 1998
- 1135 Liam's weight in grams when he was born (2 ½ pounds)
- 3 The number of hours I had to wait to see Liam in the Special Care Nursery after he was born
- 12 Number of weeks Liam was born premature
- 48 Liam's oxygen saturation rate on February 4, 1998 before intubation and a ventilator with 60% oxygen
- 1.4 Liam's weight in kilograms when he had his Blalock-Tausig Shunt
- 1 The number of days after Liam's B-T Shunt when an abdominal catheter was inserted as his kidneys weren't working (chest tube, kidney dialysis tube and urinary catheter removed 4 days later)
- 10 Number of staples removed from Liam's B-T Shunt
- 55 Days old when Liam was transferred by helicopter from B.C. Children's Hospital to Victoria General Hospital
- 6 Number of weeks Liam spent in Victoria General Hospital's Special Care Nursery
- 99 Total number of consecutive days Liam spent in the preemie nurseries before coming home, weighing 4 pounds 15 ounces
- 2 and 1 The number of "steps forward" and then back during Liam's 99 days in hospital
- 1 and 2 Number of closed heart (B-T Shunt) and open heart surgeries Liam had before he was 2½ years old; Bi-directional Glenn Shunt at age 9 months and Fontan at 2 years 4 ½ months
- 14 Days in hospital Liam spent recovering from Fontan surgery
- 13 Number of years of public school including kindergarten, where Liam participated in whatever he felt like, including school swim club and cross-country team in elementary school
- 19 Liam's current age and number of birthdays he's had where I've been so proud of him and the young man he's become; he's recently transitioned from B.C. Children's Hospital Heart Centre to the St. Paul's PACH Clinic, but still wants me to come over on the ferry with him for his appointments. He's working part-time as a cashier in a local grocery store while attending Camosun College full-time in the Digital Media, Communications and Writing certificate program.
- ∞ The gratitude I have for the doctors, nurses, support staff and administrative staff at B.C. Children's Hospital, Victoria General Hospital, Saanich Peninsula Hospital and St. Paul's Hospital, as well as the Children's Heart Network, Hearts of Gold, HOG, VIHOG and CHN families I've met over the years for everything they've done to give this Mom the best son she could have hoped for 🍎

Connie Ens says she could write a book about the changes she has seen in cardiac surgery over the last 30 years. The veteran pediatric nurse at Children's Heart Centre talks about the care and progress she has witnessed, and what continues to inspire her work.



Basil the dog, Zoe, Thomas, Connie, Rebecca & Chase



Connie's favourite poster

### What remarkable changes have you seen over the last 30 years?

When I started in the pediatric intensive care unit (PICU), babies born with Hypoplastic Left Heart Syndrome did not have any options. The ones born with Transposition of the Great Arteries (TGA) were generally corrected with a surgery known as the mustard (the current surgery, the "switch" was just being introduced.) The Fontan was done when there were no other options and the child was very sick. The post-operative journey after the Fontan was very difficult and the survival rates were low.

Children were in the PICU for weeks and even months, and often on a ventilator for much of that time. ECMO (extracorporeal membrane oxygenation – similar to heart/lung bypass) was not even close to being an option at that time.

It is so very different now.

This does not, for a minute, minimize the stress for our families now.

But, what has changed is that the surgical experience happens so quickly. The children go home so fast that the families have very little time to process the rollercoaster that they have been on. There is so little time to prepare them as they are in hospital for such a short time and then go home exhausted and dazed. I am so very grateful to the Children's Heart Network for continuing to walk with our families as they slowly make sense of it all.

### Tell us about your work. What are your specific interests and responsibilities when it comes to cardiac care?

When I started at the Heart Centre, I was tasked with developing the program for CPAC or the Cardiac Preopera-

tive Assessment Clinic that serves the families of Western Canada.

I believe children intrinsically just want to be happy and to play. They live in the moment.

Heart surgery is a terrifying and difficult moment, so I need to ensure that this one moment in their lives does not define them negatively. This means ensuring the most important people in that child's life are ready. I try to understand the needs and fears of the parents, so that I can support their learning, emotional and social needs so they can best support their child. I now share this role with a wonderful colleague, Colleen Ring.

I later became involved with Dr. Sanatani and became the pediatric nurse clinician for the B.C. inherited arrhythmia program. Children are referred to us from around B.C. if there is a risk of them either having an inherited arrhythmia or developing one.

Cardiogenetics is fascinating. It's much like being a detective. The journey can be long and arduous. And since there is no cure, it can take a family a lifetime of learning to navigate the challenges of managing a diagnosis that carries with it the risk of sudden death.

I also took a position on a team that travels to B.C.'s Northern communities. Usually once a month, I travel with one of our cardiologists and a sonographer to staff three-day clinics for our cardiology families. The goal is to lessen the amount of travel, financial burden and disruption to their lives. I am privileged to work with and care for our amazingly resilient Northern families. Pretty much everything is harder up North. Access to the same care that we are graced with here in the Lower Mainland is not even

close to the same. Then, add in the multigenerational challenges faced by our Indigenous population.

When I am feeling overwhelmed by caring for these families, I think I cannot even begin to understand the depth of being one of these families.

### **Where did you grow up? And why did you become a pediatric nurse?**

I was born in Saskatoon, Saskatchewan, but moved to Vancouver when I was almost five.

I knew that I always wanted to be a mother. My childhood and youth were quite challenging, but, as I became an adult, it became apparent that caring and nurturing others was actually very healing.

That led me to nursing, and within a year, I was offered a position in the Pediatric Intensive Care Unit at B.C. Children's Hospital. This was in 1986 and I was 23 years old. PICU was my home until 2013 when I finally left to join the amazing team at the Children's Heart Centre.

### **Who has inspired or taught you? Did you have a mentor?**

Yes. Every person I have ever worked with. I have either learned some nugget of wisdom from those I respect or witnessed what to never do from those that I did not.

### **Tell us about your home life. Do you have pets or children?**

I have four absolutely amazing and completely individual children. They range from ages 19 to 23 currently and ALL still live at home. With the houses prices in Vancouver, we may all live together for a very long time.

I also have a wonderful English Springer named Basil that happily alternates between bedrooms at night. We met him six years ago on a field trip to the SPCA. Understandably, I do not go to the SPCA anymore.

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

I have been very lucky to have strong people in my life. By far, my biggest mentor has been my dad. He is always a phone call or text away.

### **Outside of work, what do you like to do for fun and what are you good at besides being a fantastic volunteer?**

Wow. Working full time and raising a busy family of four has taken most of all my time.

In my 20s, I travelled extensively until I got married at 31. I did finally start doing yoga about two years ago and am completely hooked. Any exercise where I can start lying down is a winner to me. I now go three to four times per week.

I am also an avid reader. I read at least one hour at bedtime no matter what time it is. Perspective is amazing. Between the families I have met over the years and the stories I have read, I am an extremely grateful person. No matter what challenges my own children are facing or I am experiencing, compared to the families I care for and the events occurring around the world, I am exceedingly blessed. 🍕

## *What's Happening?*

**February is "Heart Month" and Feb 7-14th is Congenital Heart Disease (CHD) Awareness week.**

### **How you can support the Children's Heart Network:**

1. Buy your Mario's Gelato heart shaped ice cream on a stick for \$3.00 each or \$30/box of ten starting February 1st at Mario's – 88 East 1st Avenue in Vancouver. Proceeds go to support the CHN! Spoil the kids? Have a birthday party coming up? The best Gelati in town!
2. CHN will be having the Annual Valentine's Day chocolate sale at **BCCH in the main lobby on Feb. 13th and 14th**. Come by to pick up top quality Belgian chocolates by Daniel le Chocolate Belge to give to your loved ones on this special day while supporting the CHN!
3. The **16th Annual Children's Heart Network Wine Gala** dinner will be on Friday, May 4th at Villa Amato Ballroom. We are thrilled to have Fred Lee (the man about town) as our auctioneer this year. Get your early bird tickets for \$150 per person and you will be attending one of the best Gala's in town. Enjoy an exquisite 4 course dinner with wine pairings and the best auction in town! To order tickets please go to: [www.chnevents.org](http://www.chnevents.org)  
To be a corporate sponsor or to donate to the silent auction please email Samantha at [saitken@childrensheartnetwork.org](mailto:saitken@childrensheartnetwork.org)
4. **Hearts of Gold Youth Camp** – Will be held May 18th to 21st at Camp Zajac – for heart teens between 13 and 18 years  
**HeartBeats Youth Camp** – Will be held July 2nd to 6th at Camp Zajac for children ages 8-12 years  
CHN will subsidize camp fees and transportation needs. The email invitations to camp will be sent out shortly. To get on the email list or for more information contact [saitken@childrensheartnetwork.org](mailto:saitken@childrensheartnetwork.org)

**Thank you to our generous donors**



## The CHN would like to send a “heartfelt” thank you to Cole Renner.

Cole has volunteered countless hours to the Hearts of Gold group in support of our teens ages 13 to 18 years old and he has become an integral part of the program. We are grateful to Cole for all his hard work and for volunteering his time!

### Tell us about where you grew up and where you work?

I grew up in Cloverdale until I was seven-years old. And then, I grew up on Vancouver Island in Nanaimo. I work for the Vancouver Canucks as a senior account executive.

### What made you want to volunteer with the CHN?

Funnily enough, it was the Hearts of Gold gang coming to a game that got everything rolling. Dealing with Kristi, the HOG coordinator, was great. Neither of us thought to plan for the new metal detectors at the building. I remember rushing to Gate 16 and working with security to get the kids permission to pass on the new security scans!

### What are your main responsibilities?

I provide support to Kristi in any way she needs. Whether it's making sure everyone is accounted for or helping to cut up food or simply being a “grown up” figure. And I use that term loosely! I do what I'm told!

### What excites you the most about working with the Hearts of Gold group?

By far, it's the connections I have formed with the teens. They have been really welcoming and are a blast to hang out with.

### What's been a really memorable experience?

Without question, I would say the pudding fight at Zajac. I took a spoonful of chocolate pudding directly in my open eye. That shot was courtesy of Ben. So, I wait... planning my revenge.

### Do you have a mentor?

I have been very lucky to have strong people in my life. By far, my biggest mentor has been my dad. He is always a phone call or text away.

### Outside of work, what do you like to do for fun and what are you good at besides being a fantastic volunteer?

I love spending time with good people and I pride myself on making time for them. I love to go back to the Island and spend time with friends and family, do fun things with my girlfriend or have a relaxing day or night at home. I love to play hockey, golf and tennis, but finding time for these has been a bit difficult.



The after effect of a pudding fight at Zajac Ranch

### Do you have any pets or children?

No kids, but I inherited a crested gecko named Alduin when my girlfriend moved in. He is pretty cool!

Cole Renner has been a Children's Heart Network volunteer since 2016. 🍓