



Jacob's surgery.

Jacob's story

BY SARA SUNDHOLM

Our son Jacob is four-years-old and just started preschool. He is a precocious boy who loves to ham it up for the camera and doesn't shy away from all the boy things that make my mama heart skip a beat.

When I look back on his heart journey, the single hardest day of my life was when Jacob had his surgery on January 21, 2014 at just 11 days old.

Jacob was born one month early, in our bathroom, completely unattended as he arrived quickly. We were sent to the hospital overnight so nurses could keep an eye on his blood sugar levels.

The next morning, we were sent home with a clean bill of health except that his bilirubin levels were a little high. For the next five days, our midwife came every day to check on them. On the sixth day, we were admitted to hospital overnight for phototherapy because his levels got too high.

While we were there, the nurses checked his oxygen levels, which were low. At first, they thought it was the monitor

and tried a few others. Every few hours, they came in with warm towels and tried to get a higher reading.

The next morning, the resident pediatrician was discharging us when the nurse-on-duty mentioned Jacob's oxygen levels were quite low and suggested a checkup with the on-call pediatrician. He listened to Jacob's heart and said there was a murmur. The cardiology team from BC Children's Hospital just happened to be there that day conducting a rural clinic.

The on-call pediatrician spoke with Dr Human and his team and asked him to do an echo and ECG. After the tests were done, we were asked to sit down and given the difficult news that Jacob was born with a rare congenital heart defect: Supracardiac Total Anomalous Pulmonary Venous Connection (TAPVC).

We were flown out that day to BC Children's and prepped for his open-heart surgery, which was scheduled to happen in four days.

Time stood still, and there was a lot of

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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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Tel: 604 521-3037 | 1 877 833-1773
chn@childrensheartnetwork.org

 /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
mellymartz@outlook.com

KAMLOOPS – Miranda Brown
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KELOWNA – Karla Allan
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VICTORIA – Teri Godin
terigodin@gmail.com



The CHN would like to thank the CKNW Orphans Fund for their generous support of our Heartbeats and Hearts of Gold camp programs.

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 so that we can add you to our mailing list to receive invitations to all our fun events!

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- KRISTI COLDWELL – Lower Mainland Hearts of Gold youth coordinator
- KRISTA MOLIA – Vancouver Island Hearts of Gold youth coordinator



Heart Warrior – all healed.

emotion in the room. Back at home, we had a four year-old and a 10 month-old, from whom I had never been apart.

The flight team came to get us at 4:00pm. I said goodbye to my family and off Jacob and I went.

We arrived at Children's and were brought to the pediatric intensive care unit (PICU) for the night. I slept in a cot beside his bed. I was completely overwhelmed and in a state of shock. The next morning, he was deemed stable enough and we were moved up to the unit to prepare for surgery.

We were blessed to have Dr. Campbell and his team repair Jacob's heart. The surgery took eight hours, but it went very well with no hiccups.

One hour after it ended, we were allowed to go in and see him in the PICU. My husband stayed with Jacob while I went to the pumping room.

On my way back into the PICU, I heard monitors going off and saw nurses and doctors running towards Jacob's bed.

The scene plays over again and again, in slow-motion, in my head: I began screaming out to my husband, "What's going on!!!?" while he just stood there in disbelief. We were ushered into the consultation room and told that Jacob's heart had gone into hypertension and stopped.

Thankfully, he was resuscitated and stabilized without cardiac and respiratory support.

Jacob spent a week in the PICU as he wasn't doing well with breathing on his own and they couldn't extubate him. Finally, the breathing tube was removed and we were moved up to the unit.

Discharge was planned for January 31. On the 30th at bedtime, I was rocking Jacob to sleep when, all of a sudden, the monitor started beeping and our nurse rushed in and

took him from me. His heart rate spiked at 302 BPM. He was having an episode of supra ventricular tachycardia.

It took three hours and some miracle medicine to break the cycle and get his heart rate down to normal.

We were kept for another six days and given training on how to check his heart and what to do if he had another episode

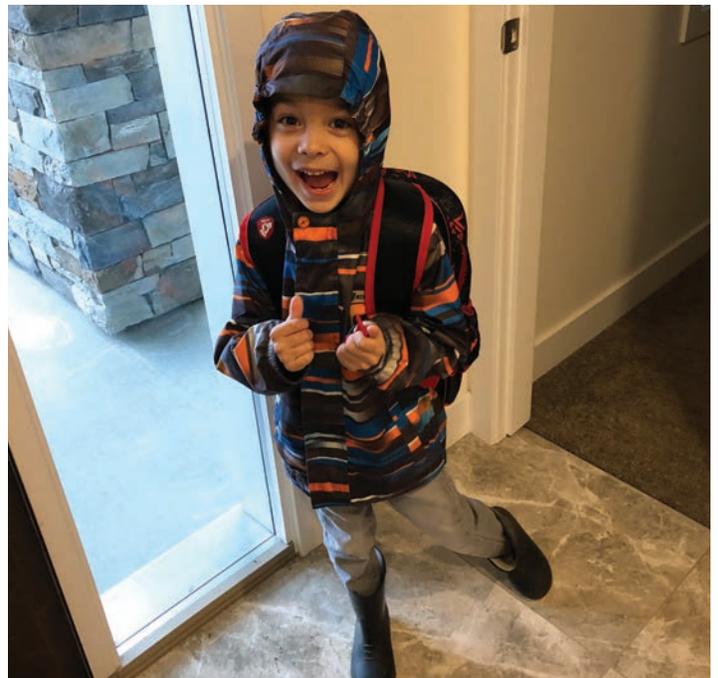
On February 6, we got to go home. It was a bittersweet moment. It was scary to leave the safety of the hospital, but I was glad to be able to try and start our "normal" life.

In the fall of 2014, a few other local heart moms I'd met through Facebook decided to get together and start having coffee. What started out as a humble group turned into a Children's Heart Network monthly coffee support group. We welcomed any new families that were going through what we all had experienced.

It was invaluable to have this group. It helped me get beyond the overwhelming crush of knowing my child was incredibly fragile.

Over the years, we have also had a few family gatherings as well. It has been such a support for Jacob too, knowing he's not the only one who was born with a broken heart that needed surgery. He is comforted, knowing other children have "love line" scars just like he does, and it helps him be proud to rock them!

We will always be grateful for every single person at BC Children's who had a hand in saving our son's life. Without them, he wouldn't be here today. 🍓



Jacob heading back to school.

Audrey's bike

BY ERIC CYTRYNBAUM

We found out we were having twins during a week-13 ultrasound. At a week-19 ultrasound, we found out that the girls were in the same amniotic sac, which made for a precarious pregnancy, and Baby A (aka Audrey) was diagnosed with a CHD. Over the next few weeks, follow-up ultrasounds revealed that she had a rare condition called Right Isomerism - her internal organs had somehow developed with roughly mirror-image right sides instead of the usual left-right arrangement. This meant a more symmetric looking heart with several anomalies (AVSD, double-outlet right ventricle, pulmonary atresia, two symmetric SVCs) and no spleen (a left-side organ). The prognosis was not encouraging, with a 15% chance of surviving to the age of five and the best case scenario being a series of surgeries (BT shunt, Glenn, Fontan) to reconstruct a single-loop circulatory system around her two-chambered heart. Long term, we watch for valve leakage and ultimately congestive heart failure. But not for a few decades.

We're now almost two and half years past Audrey's third and final scheduled surgery. The girls will be six in a few months. We've been extremely lucky. Aside from twice-daily meds, surgical scars, and an annual visit to the BC Children's Heart Centre, there are few signs that Audrey is different from her friends at school. When the kids take off at full speed across the soccer field, or we hit a hill on a hike at Lighthouse park, her heart can't keep up and she has to take a break. We talk about her special heart and how she can call for a break whenever she needs one and how important exercise is to keep her heart strong. But she struggles with understanding why she gets left behind and sometimes asks why the other kids don't want to play with her.

So what can a parent do to help a kid that can't always keep up? Open communication about her challenges is certainly important. Teaching her to self advocate is also big. But I also want her to have a place where she CAN keep up. Enter biking...

The girls started on balance bikes when they were about two and half. By four and half, they were riding "big girl" bikes with hand brakes. I started taking them on the trails in the Pacific Spirit Park and they loved it. Mostly flat ones to start but occasionally slight hills which slowed Audrey down. About this time, a friend got an electric bike for commuting and I started to think that maybe an electric bike was the answer.

When I first walked in to Grin Technologies and explained my plan, the guy at the front desk asked me if I seriously thought it was a good idea to put a five year old on an electric bike. Three trips to Grin, a few more to my local bike shop and a lot of fiddling later, Audrey's bike is up and running. For the first couple rides, while I was still



Audrey hits the road!

figuring out the settings, I'm pretty sure the motor was just ten pounds of dead weight holding her back but she was so excited to be riding with it that I could barely tell. With a torque sensor in the bottom bracket, the entire system can be hands free meaning Audrey can focus on riding. The on-board computer can tell how much power Audrey is pumping into the bike and directs the motor to supplement according to a preprogrammed setting. She just gets on and rides.

I also wanted this setup to be as reversible as possible, so in about five minutes, I can switch out the motored wheel for a regular wheel and strip most of the wires and hardware. That way, she can take the bike to the neighbourhood park and I don't have to worry about \$1000+ of high tech gear disappearing. When we go trail riding, I can quickly switch back to motorized.

If you're thinking of doing something similar, I can offer some thoughts. First, the price tag is not small but with Grin's conversion kits it's easy to move the setup from bike to bike as she grows. And given the low power requirements, these motors will last a long time. So think of it as a long-term investment. The biggest challenge for me still is remaining convinced that the motor is going to help in the way I envision it - giving her breaks when she needs then rather than replacing exercise. It's still not clear as we've only been out with it a handful of times. Grin was very helpful with some of the technical aspects and my local bike shop had to fill in others. Then I had to do a bunch of fiddling to put it all together. Feel free to contact me for technical advice.

Finally, some thank you's are in order. First, to the incredibly dedicated doctors, nurses, and other staff at BC Children's Hospital, in the Heart Clinic, the NICU, the PICU, and 3M, without whom I wouldn't even be talking about taking Audrey biking and who took great care of all of us. And thanks to Grin Technologies and Kissing Crows Cyclery for helping set Audrey up with a great bike. 🍓



Emily, Dr. Gandhi and Dr. Hosking.

The Triple Crown

BY SHAUN CARPENTER

Children admitted to the Heart and Specialty Medical Unit at BC Children's Hospital undergo extended hospital stays while awaiting surgery and recovery from cardiac and other serious medical conditions. Prolonged stays put tremendous pressure on the entire family as they often must put their lives on hold during this time, and since many of the families come to the Heart and Specialty Medical Unit from other parts of the province, they are not in their own family homes.

The Triple Crown for Heart Association is a not-for-profit society dedicated to supporting the care of pediatric patients and their families. Through the annual Triple Crown for Heart road biking event, where cyclists challenge all three North Shore Mountains in one day, our goal is to raise funds to support projects aimed to improve patient care and hospital experiences for the four hundred plus children who are treated annually at the BC Children's Hospital Heart Unit. The donation amount to support our heart kids getting to camp in 2019 is \$10,000.

The Triple Crown for Heart road riding event has gained popularity, having grown from just 13 participants for the inaugural ride in 2009 to approximately 200 in recent years. Cyclists at all levels are increasingly drawn to the fun and camaraderie of the event in a safe and supported environment that would not otherwise be available.

The event also serves to promote fitness by giving cyclists the impetus to train for the North Shore's most challenging day on two wheels.

A new partnership beginning in 2018:

In addition to raising funds to support projects that improve patient care and hospital experiences, the Triple Crown for Heart has partnered with the Children's Heart Network (CHN), a provincial, non-profit organization offering support, information, and education to families, children, and youth dealing with congenital or acquired heart disease. Each year the CHN organizes summer camp for families living with congenital or acquired heart disease and is geared toward providing opportunities for children and youth to participate in a wide range of physical and social activities to have fun and connect with others who have faced similar challenges. A portion of the TCH fundraising efforts is now being directed toward the CHN to support bringing children and youth to camp!

Public awareness for the event has also grown as it benefits from Global Television media coverage. Our 10th annual road biking event is poised to yet again set records for both attendance and fundraising on Saturday July 20th, 2019. Join us in building on the success of this event! 🍷

A Huge “heart-felt” thank you to Colliers International in Victoria



Colliers International in Victoria has been hosting the Annual Colliers International Charity Golf Tournament for 30 years. During this time, it has supported over 20 different charities and this year, we were absolutely thrilled at the Children’s Heart Network to hear we were chosen to be its beneficiary.

The tournament was held on June 21st at the picturesque Cordoba Bay Golf Course. It was sold out with over 145 golfers in attendance. Volunteers and dinner guests enjoyed a beautiful day, a fabulous auction and a presentation by two local heart moms, Kristin Avis and Andrea Van Rossum.

Kristin has a 4-year-old boy named Judah and Andrea has a 5-year-old boy named Reid. Both were born with complex heart conditions and both have endured multiple open-heart surgeries.

These two families were able to connect through the Children’s Heart Network and have supported each other through the difficult times that come with having a child growing up with congenital heart disease.

We were enlightened as they spoke of the challenges as well as the fun times they have shared through many CHN programs and events such as going to the Pumpkin Patch, the Christmas party at Butchart Gardens, CPR courses and the recent Family Camp held at Camp Pioneer in Sooke.

Thank you Kristin and Andrea for sharing your heart journey with everyone at the tournament.

Along with the support of their clients, vendors, attendees and volunteers, Colliers has donated over \$950,000 to local charities in the past 30 years. Colliers International recognizes the value and support the Children’s Heart Network provides to families in BC and chose us this year as their gold tournament charity!

We are thrilled to report the tournament raised over \$52,000 in support of the Children’s Heart Network! This massive donation will allow us to increase our programs offered for families all over Vancouver Island and BC.

We are so grateful to everyone involved for the amazing support. Thank you Colliers International Victoria, Andrea and Kristin, all the attendees, sponsors, donors and volunteers! 🍷



Andrea Van Rossum, Samantha Aitken, Kristin Avis and Tracey Carpenter attending the Colliers Gold Tournament

Nutrition Bites

WITH RHN HEIDI SEIDMAN | OCTOBER 2108

It's THAT time of year again...

As you settle into a fall routine, remember that starting your kids' day with a healthy, nutritious breakfast will go a long way.

It is the most important meal of the day. However, don't forget the role a healthy lunch plays in maintaining your child's energy and keeping him/her focused.

Packing lunchboxes can be a collaborative effort! Involving your child in the process of packing healthy lunches will ensure s/he's eating nutritious foods they enjoy.

Here are a few tips and tricks for making nutrient-dense lunches and delicious after-school snacks.

ELIMINATE THE WHITE STUFF:

Eating white, refined, packaged and over-processed sugars and flours leads to sugar spikes and crashes, which can seriously affect one's energy and ability to focus at school

Over-processed foods rob vital nutrients from a child's growing body. Over time, these foods can lead to cravings, behavior challenges and inflammatory diseases.

Try switching to whole grains instead. These complex carbs will keep a child's blood sugar balanced and provide your body with vital nutrients.

EAT YOUR RAINBOW:

Encouraging your kids to eat a variety of colorful, whole foods daily will almost certainly ensure they're getting their daily vitamin and mineral needs.

- Strawberries, sweet potatoes, yellow peppers, broccoli, blueberries, and grapes are all great choices.

INCLUDE ESSENTIAL FATTY ACIDS:

Providing your kids with heart healthy EFAs in the form of Omega 3s help with proper brain and nervous system functioning, and is especially beneficial to your heart.

- Eggs (yolk and all), chia, flax seeds and hemp hearts are all great choices, as are dark, leafy greens.

EATING IN SEASON:

While eating a variety of whole foods every day is important to one's overall health, it's also vital to keep it as local and seasonal as possible, whenever you can. Buying food that hasn't had far to travel from farm to table (literally), ensures that you're getting all the necessary nutrients of that food.

ENERGY BALLS:

Eating healthy, nutrient-dense meals goes a long way toward keeping your family healthy. However, we all need a bit of a boost from time to time. These energy balls have a hint of sweetness and are loaded with goodness the whole family will love. For school lunches, be sure to use sunflower seed butter. I love them with rich, creamy and raw peanut butter. Keep them in the freezer to grab and go as you need them!



Heidi Seidman is a Registered Holistic Nutritionist whose main focus is helping families eat healthier. Heidi believes that every sprouting body begins with proper nourishment for growth and development.
heidi@seidman.com • www.heidiseidman.com

Energy Balls (GF) Fan Favorite!!

Loaded with nutrients and flavor, these energy balls will keep your kids satisfied for hours. Use peanut butter for a great after-school snack or at home.

INGREDIENTS:

- 1 1/2 cups lightly crushed, gluten free, crispy rice cereal
- 2/3 cup organic peanut butter
- 1/4 cup honey
- 3/4 cup shredded coconut flakes
- 1/4 cup hemp hearts
- 3/4 cup mini chocolate chips

DIRECTIONS:

Add the rice crispies to a bowl, crush lightly with bottom of a glass.

Add remaining ingredients and stir together. Chill about an hour. Then form into balls. Freezes well.

INSANELY DELICIOUS!!!

Max and Matthew

BY SAMANTHA AITKEN

A few months ago I received an email from two students in grade 7 attending Vancouver Talmud Torah School (VTT). Max Finkleman and Matthew Armstrong contacted me as they had chosen The Children's Heart Network as the charity they would like to support for their school project. Matthew was born with Tetralogy of Fallot, a complex heart condition and Max has a brother, Leo, with the same condition. In Grade 7, students become B'nei Mitzvah and learn about their responsibilities to the community and the world around them. The culmination of their Tikkun Olam learning happens with the Mitzvah of Valuing Philanthropy (MVP) program. During this teen philanthropy program the students learn in a hands-on way what it means to become a caring and responsible adult.

During the year, students will select a mitzvah (commandment) of meaning to them, and then research, interview and select an agency that delivers on that mitzvah. Max and Matthew selected the CHN. They then presented the mission and needs of the CHN to their classmates. As a group, the whole class raised funds in many different ways. Some of the different initiatives were bake sales, babysitting, a 5KM run and organizing birthday parties.

The students subsequently worked together to assess the needs and, as a class, decided how to allocate to every agency from their pool of funds. The year culminates in a Ceremony of Giving, as representatives from the chosen agencies come to VTT to receive their grants from the students. I had the pleasure of being at that ceremony and am so very proud of the incredible job they did with their presentation to the class. I was thrilled to accept a cheque on behalf of the CHN for \$930! A huge heart-felt thank you to Max and Matthew for the amazing job they did and to the whole grade 7 class for selecting to support our heart families! 🍀



Samantha attending the Ceremony of Giving with Max & Matthew.



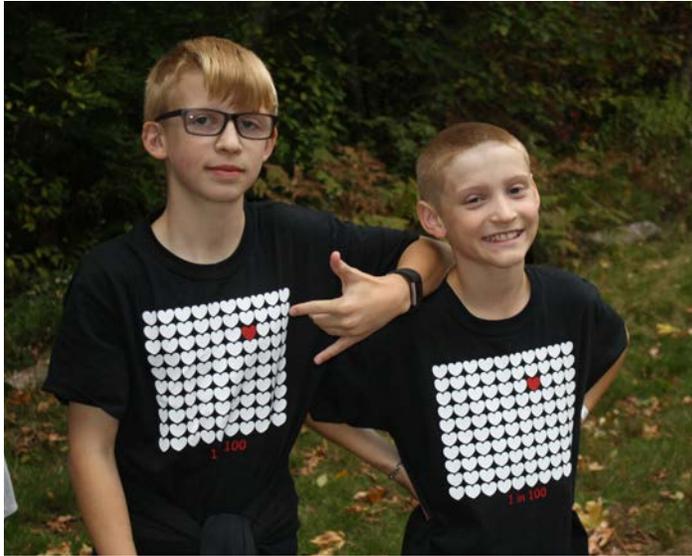
Lower Mainland pumpkin patch event

On October 13th the CHN hosted the 9th Annual Fall Pumpkin Harvest at Taves Apple Barn in Abbotsford. We had over 140 guests! Heart Kids and their families enjoyed connecting with others, while participating in some of the many activities on the farm. Trampoline jumping, hay riding and finding their way through the corn maze were just some of the fun options for the children to enjoy. Heart kids and their siblings were able to pick out a pumpkin to take home! The weather was outstanding and no one was in a hurry to leave the beautiful location. A huge thank you to Starbucks, Tim Hortons and heart mom, Monika Qually, for supporting our event with coffee, hot chocolate, Timbits, cookies and more! 🍀

Kids having fun at the annual pumpkin patch event.

FAMILY CAMP:

Weekend making memories and new heart friends



Ziplining, campfires and S'mores, Sloan creating her string art heart and new friends.

FACTSHEET FOR SCHOOLS

Below is a link to a fact sheet that you can print and complete for your child's teachers.
Please follow these guidelines when filling in your child's school factsheet.

- Include a passport picture of your child.
- Fill in your child's name in the relevant spaces.
- Signs to be aware of: This is to highlight the general signs teachers and schools should be looking out for with any child who has congenital heart disease. You know your child best—let the teacher know which of these is commonplace with your child and what is not normal.
- Your child's consultant cardiologist will be happy to help you with this. A good idea is to bring the factsheet to your next appointment so you can write down all the relevant information.
- Every child with congenital heart disease has different care requirements. Even children with the same heart condition will require individual information. Examples as below for the sections:

Meds & Side Effects: e.g., Warfarin can cause bruising

Exercise: Ask your child's doctor what exercise your child can do

Other Notes: Upcoming surgery / equipment needed / feeding issues and anything else that may be relevant for your child

Include the best way to contact you in an emergency. It is important to update the factsheet as your child's condition or requirements change. Your child's teacher and school need to know the nature of your child's heart condition and any implications it will have in school.

To download: www.childrensheartnetwork.org/factsheet-for-schools

The influenza "flu" vaccine and children with congenital heart disease

Children with congenital heart disease are at an increased risk of developing complications from influenza, so it is especially important for them to receive the flu vaccine.

Influenza or "the flu" is a respiratory illness caused by influenza viruses.

It typically comes on abruptly and is accompanied by high fever, chills, muscle aches and pains, weakness, coughing, headache and sometimes, a sore throat and runny nose. Children can also get nausea and diarrhea. It can last for between four to five days and vary from mild to severe. One common complication is viral or bacterial pneumonia. The virus is very contagious, which means that it can be passed onto others very easily.

The Centre for Disease Control states that everyone over the age of six months should get the flu vaccine. The flu vaccine is the first and best way to prevent getting the flu and passing it on to others. It is recommended to receive the flu vaccine before the end of October.

Flu vaccines cause antibodies to develop in the body about two weeks after vaccination. These antibodies provide protection against infection with the viruses that are in the vaccine. A flu vaccine protects against the flu viruses that research indicates will

be most common during the upcoming season. The 2018-2019 vaccine has been updated from last season's vaccine to better match circulating viruses.

Flu vaccines have a good safety record. Hundreds of millions of people have safely received the flu vaccine over the last several decades. They cannot give you the flu. The vaccines either contain inactivated viruses, meaning the viruses are no longer infectious, or a particle designed to look like a flu virus to your immune system.

Parents and caregivers of children with congenital heart disease should be vaccinated as well.

The first time a child is vaccinated, he or she requires two doses given one month apart as it may be the first time he or she has been exposed to the flu virus. The first dose sensitizes the immune system and the second dose causes the antibodies to develop.

Public health nurses and most physicians' offices offer vaccinations. BC Children's Hospital runs the first hospital-based immunization clinic. You and your family can receive flu immunizations on a drop-in basis at your convenience. 🍎

What's Happening?



Lower Mainland Breakfast with Santa

When: Saturday, Nov. 24th at 10:00am

Where: Delta Grand Villa Casino and Hotel, 4331 Dominion Street, Burnaby

To RSVP, please email saitken@childrensheartnetwork.org with the number of adults and children in your family (with children's ages) and ensure your CHN membership is up to date.

Vancouver Island Breakfast with Santa

When: Saturday, Dec. 1st at 10:00am

Where: Westin Bear Mountain, 1999 Country Club Way, Victoria

To RSVP, please email Krista at viheartsofgold@gmail.com with the number of adults and children in your family (with children's ages) and ensure your CHN membership is up to date.

Time to renew your CHN membership?

Go to www.canadahelps.org/en/charities/childrens-heart-network/#donate-now-pane and change the dropdown from "Donation" to "CHN Membership." It is \$25 per year per family. Thank you!

CHN Christmas chocolate sale with Daniel's Le Chocolate Belge: order gorgeous Belgian chocolates for friends, family and teachers! 30% of the proceeds will be donated back to the Children's heart Network! Pick up your order at the Breakfast with Santa or email Sam to arrange alternative pick up or for staff we can arrange delivery to BCCH.

Family Immunization Clinic:

This clinic provides all publicly-funded immunizations at no cost to patients at BC Children's and their friends and family visiting the hospital. This includes flu vaccinations. It is hoped that by making immunizations more accessible the number of people immunized will be increased. This is especially important in the more vulnerable children that BC Children's Hospital serves. It is a drop in clinic or by scheduled appointment and is located in the Ambulatory clinic building on the main floor.

You can access the CDC Immunization manual from their website and Appendix D has excellent resources for managing pain and children and parental anxiety during immunization familyImmunizationClinic@cw.bc.ca

Thank you to our generous donors



In addition to getting the flu vaccine, the spread of the flu can be stopped by:

- Washing your hands regularly
- Promptly disposing of used tissues in the waste basket or garbage
- Coughing and sneezing into your shirt sleeve rather than your hands
- Staying home when you are ill
- Keeping your hands away from your face
- Keeping common surface areas, such as doorknobs, light switches, and keyboards, clean and disinfected
- Eating healthy foods and staying physically active to keep your immune system strong 🍎

Amelia's heart journey

BY AMELIA TROTTIER

In early December 2014, I was diagnosed with pneumonia when I had just turned 12.

I was going to see the doctors every second day to treat this when they discovered I had a heart murmur. They sent me to the heart centre at B.C. Children's Hospital where there was a team of specialists lead by Dr. Elizabeth Sherwin.

They diagnosed that I had Hypertrophic Cardiomyopathy (HCM).

This is a condition where a portion of heart muscles becomes thickened. The result is the heart is less able to pump blood effectively. Symptoms vary from none to feeling tired, leg swelling, and shortness of breath. It may also result in chest pain or fainting.

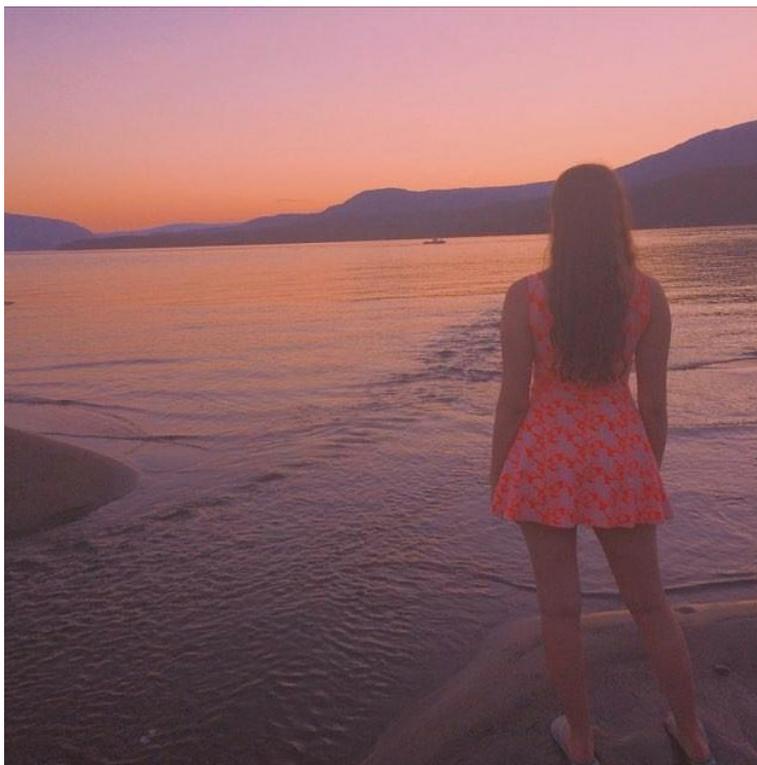
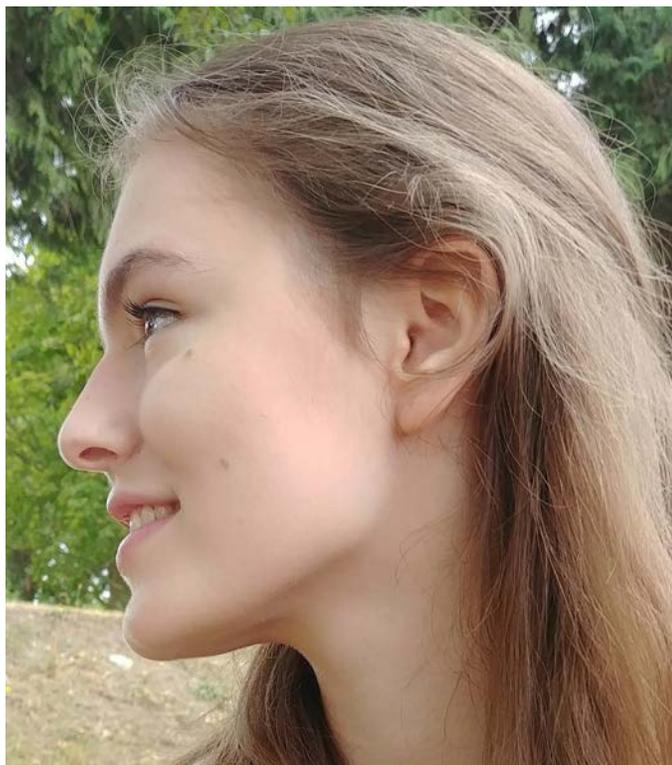
In my case, HCM was not allowing blood to circulate through my body properly, putting me at very high risk of having fainting spells and cardiac arrest.

Two days after the diagnosis, I had emergency open-heart surgery to clear some of the muscle that was blocking the passageways in my aorta. At the same time, they had to take care not to stress the rest of my heart.

They also implanted an implantable cardioverter-defibrillator (ICD) into my shoulder to help me from any future cardiac arrests. An ICD is a device that detects any life-threatening, rapid heartbeats known as arrhythmia. If this happens, the ICD quickly sends an electrical shock to the heart. The shock helps to regulate the rhythm back to normal and is called defibrillation.

While growing up, I was very sporty; I did as much physical activity as I could. I am very fortunate I did not have any cardiac arrests prior to my diagnosis. Although I am no longer able to do competitive sports and I had to leave that part of my life behind, I have found a new passion. I went into the arts.

Now, instead of sports, I am a film and television actor and model in the greater Vancouver area. I hope to branch out internationally when I turn 16 in November. Even though I do miss some of my sports, I am glad to have found an industry I enjoy and one in which I can truly shine in even with my heart disease. 🍷



Amelia enjoying her new found passion.