



Kita's Heart Journey

BY SARA STENABAUGH

It's interesting what the mind remembers after a traumatic event. Mine holds on to a hallway with walls covered in ceramic tiles.

Every morning I walked down that hallway, leaving the maternity ward to visit my daughter in the

Pediatric Intensive Care Unit (PICU) at BC Children's Hospital.

She was only a few days old and struggling for her life.

At night, I would shuffle back down that hallway to the maternity ward, completely exhausted.

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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.

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Heart Matters is 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.

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COFFEE GROUPS NEAR YOU

These groups meet monthly; come and meet other heart parents while enjoying treats on CHN.

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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!

THANK YOU

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



CHN would like to thank the CKNW Kids' Fund for their generous support of our Heart Beats and Hearts of Gold camp programs.



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Sometimes, I would stop to read the tiles. Most of them were birth tiles, celebrating all the babies born just a few steps away. Others were memorial plaques for all the infants who sadly didn't make it.

I remember staring at the tiles the night before my daughter's heart surgery and weeping, worried about which tile her name would go on.

It's a girl!

We found out early on that we were having a girl. My husband and I were thrilled, since we already had a rambunctious boy.

My pregnancy was fairly by the book. I had nausea and heartburn and felt tired all of the time. It was my second pregnancy, so I felt reassured when all my tests and ultrasounds came back normal.

I went into labour two weeks early and delivered her at Royal Columbian Hospital in New Westminster. As soon as she was born, the nurses noticed that she was blue and wasn't crying. They gave her oxygen, but she struggled to breathe every time they took off the mask.

The doctor was worried something might be wrong with her heart or lungs and transferred us to BC Children's Hospital. She went first, while I waited for the second ambulance.

By the time we got to the PICU, the doctors had finished all of their tests. Dr. Shreya Moodley, our pediatric cardiologist, sat us down and told us that our daughter had transposition of the great arteries (TGA) and would need surgery soon.

TGA is a rare heart defect where the two main arteries are reversed. It means blood can't oxygenate properly. Without oxygen-rich blood, the body can't survive.

In that moment, everything became a blur, and there was panic. While the doctors explained what would need to happen in the next few days, my head kept spinning with questions: *Why? Why her? Why us? What did I do wrong?*

The next morning, our daughter underwent a balloon atrial septum, a temporary procedure to help her blood mix until they could perform heart surgery.

She was less than a day old.

New arrival

We met Dr. Sanjiv Gandhi, a pediatric heart surgeon, soon after we were admitted into the hospital. A stoic but kind physician, Dr. Gandhi is a straight shooter and told us exactly what we were facing. Our daughter was very sick, and her surgery would be complex.

At the time, her heart was the size of a walnut, and her arteries were like pin heads. Her arteries were also fragile, so the surgery had to be precise.

The night before the surgery, we spent hours reading and singing to our daughter. We rubbed her hands and wrapped her in warm blankets. I held her as often as I was able. I had to be careful not to tangle all the wires attached to her little body.

While we helped bathe her before surgery, the nurse mentioned that it was a good time to name her. My husband and I had been stuck between two names before her birth and had decided to wait until she was born to decide which one suited her best.

Looking down at her, only one name stood out: Kita.

Kita can mean *new arrival* or "I have arrived" in Japanese. We thought it was a perfect name for a little girl who was about to get a second chance at life.

When the surgical team came to get her, I felt a rush



Kita shortly after surgery.



Fun times at the park with brother Jett.

of emotions that is difficult to explain. I was terrified that something would go wrong. I was terrified that she wasn't strong enough to handle the surgery. I was scared that I wouldn't see her again.

I paced back and forth within the hospital, making sure to avoid that long, winding hallway of tiles.

The road to recovery

As soon as I saw Dr. Gandhi walk through the door, I felt an enormous weight lift. Kita's surgery had gone well, and she was expected to fully recover.

Soon after, she was moved to a different ward, where the nurses watched over her and taught us how to care for her and clean her surgical dressing.

For the first time, we were able to change her diapers, give her sponge baths, and pick her up without help. Every four hours, I would pump my breast milk and bottle feed her so that we could measure how much she was eating.

Each day, she drank a bit more and got a bit stronger. As her health improved, the nurses slowly removed the wires and monitors that she no longer needed.

When the time came to take Kita home, we hugged the nurses and doctors who had spent countless hours caring for her. They had become family and our pillars of strength.

We wrapped Kita up in her new fluffy pink blanket and made our way through the long hallway towards the parking lot.

I didn't look at the walls. I just held her close and kept walking forward.

Finding community

During the first few weeks at home with Kita, I was both ecstatic and scared. We had both been through so much, and while the well-wishes from friends and family kept pouring in, I still felt alone.

Through the BC Children's Hospital, we were connected to the Children's Heart Network, a non-profit organization offering support, information, and education to families who are living with congenital heart disease.

The CHN community welcomed us with open arms. We met families with similar stories. They offered their support and knowledge. We grieved together, picked each other up, and celebrated in all our children's successes.

The organization has also given us skills and training we needed to keep our kids safe, including CPR training and a virtual session on what to do during the COVID-19 pandemic.

We formed friendships and a sense of community through CHN's social events, including the Santa Claus breakfast, wine gala, and meet-ups.

Today, our lives are a far cry from a year ago. Each day is filled with dripping sippy cups, scattered Cheerios, and sleepless nights.

Our little Kita is now a thriving 17-month-old, who is a force to be reckoned with. She is loud and stubborn and has an insatiable appetite for chocolate.

She is perfect in every way. ♥





Kailen's Heart Story

BY KAILEN HARDING

Hil My name is Kailen. I am 13. I was born with transposition of the great arteries. I had my first surgery at two days old, and my second full open-heart surgery at two weeks old. Recently, I got a pacemaker.

I live a fairly active life, and I am able to participate in basically everything. I take medication once a day, at night.

My family and I have been a part of the Children's Heart Network ever since I can remember. We've been to many CHN events, from the Christmas party to Critter Cove.

I am a typical active and lazy teenager who enjoys playing video games, making YouTube videos (@KailenRH), and playing hockey.

I have been playing hockey forever, and for the last four seasons, I've been playing goalie. This September, I started to feel more tired during high-exertion periods, so I had to wear a heart monitor for 24 hours during hockey season.

The doctors also had me do a stress test earlier than scheduled. At first, they weren't sure about the results, so they asked for another stress test. After the second one, they realized I probably should get a pacemaker. When the doctors told me this, I was a little scared and unsure, but they explained it more, and it made perfect sense.

They said there was a lot of scar tissue on my heart, which meant not all the signals were getting through. The pacemaker would help with this and would listen to both sides of my heart. If one side wasn't getting the signal, the pacemaker would step in.

I was scheduled to have my pacemaker put in at the beginning of April. But they were able to bump me up to an earlier slot because they had cancelled all elective surgeries due to COVID-19. My surgery had to do with the heart, so they wanted me to come in earlier. I was glad. Going to

the BC Children's Hospital (BCCH) wasn't much different during COVID-19, except only one parent was allowed in the pre-op room until after the surgery.

The surgery went as planned. They decided during the surgery to put the pacemaker in my abdomen. When I went to my room after surgery, it was nice and spacious. The television was in the perfect spot, and the bed was very comfortable. I also received a DM video on Instagram from Jacob Markström, the Vancouver Canucks goalie, wishing me a good recovery. That was epic!

I recommend the freezies and ice cream that you can get from the ward's kitchen. My back was kind of sore after the surgery, but after some time, it got better. We stayed one night in the hospital and then I was able to come home.

In my first week of being home, I watched a lot of TV. It kind of hurt to talk, sneeze, yawn, and laugh, but it got a lot better over time.

A typical day of recovering from surgery in COVID-19 isolation looks like this: I wake up, play video games, do online school, exercise, eat dinner with my family, and hang out.

After one week of being at home, we went for a check-up. During this appointment, they checked if my pacemaker was working by putting a magnet on top of it and then making my heart rate go up and down. It felt odd, like someone was controlling my heart.

After six weeks, I was able to do everything I could do before the surgery. At my next follow-up appointment, I will be doing a stress test, an ECG, an ECHO, and the pacemaker check.

I am glad that I got the surgery when I did, and I am looking forward to returning to sports.

I started going to Hearts of Gold (HOG) events this

year, including laser tag and the Old Spaghetti Factory, and ice skating followed by Red Robin. At these events, I enjoyed the group of people, and it was fun to do the activities.

Since COVID-19, we have been meeting on Zoom, and that has also been a fun experience. During our Zoom meetings, we had a talent show and did camp stuff like making s'mores and candy bracelets. I like being a part of

this group, because they are cool to hang out with and they all have similar stories.

It wasn't that big of a deal to get a pacemaker. I recommend cream soda Slurpees after appointments at BCCH and freezies after your surgery.

I would like to send a special thanks to the doctors and nurses who worked with me at BCCH. I hope everyone is staying safe and healthy during COVID-19. ♥

My Time with Hearts of Gold

BY JORDAN ALEXANDER LANDRY-GIBSON

My name is Jordan, and I'm writing because the Children's Heart Network asked me to describe my experience with the Hearts of Gold (HOG) program.

I was born with a heart condition called Tetralogy of Fallot, and I have had three open-heart surgeries and a stent replacement.

I live in Kelowna, and in 2017, I joined the HOG program and went to my first event. It was the annual camp trip at Zajac Ranch for Children in Mission.

When I arrived, I was pretty scared to spend three days with complete strangers. But as soon as I stepped out of my car, I was greeted with such positivity and kindness that I knew it wasn't going to be so bad.

After our parents left, we all headed to our cabins, where we would live for the next three days. We did all sorts of fun stuff, like archery and rock climbing. There was a high-ropes obstacle course. We had a talent show by the fireplace, and so much more.

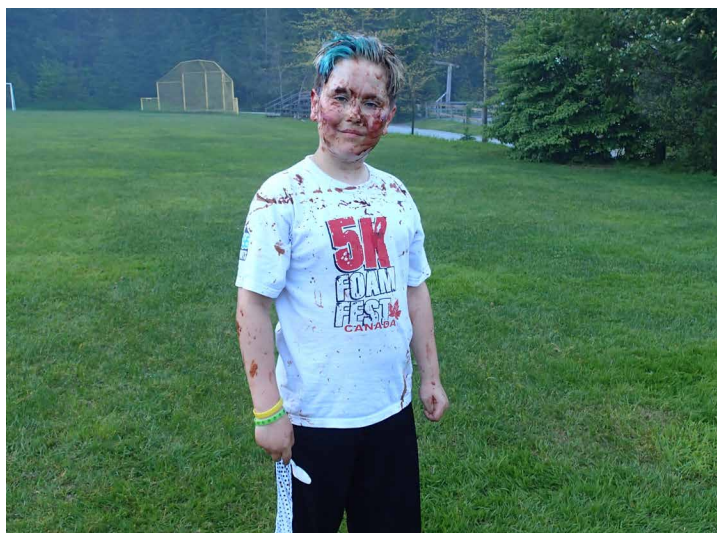
On the third day, we all went to the field and did a lot of activities with water and had water gun fights. One of our camp leaders, Kristy, came up with the amazing idea of having a pudding fight, which would go on to be a tradition for years to come

I recently had my third open-heart surgery and stayed at the Ronald McDonald House in Vancouver. I was really bummed out that I had to go for another surgery, but there was a silver lining because I got to go to a HOG event that wasn't camp. It was so much fun to paint porcelain figurines with my friends. As I waited for my surgery, I got a lovely surprise when Kristy came over with a signed card from all of my friends at HOG, encouraging me to stay strong and telling me they would see me at camp.

With COVID-19 going around this year, camp was cancelled. I was really sad I couldn't go and see everyone after the surgery. Our leaders thought of that and sent us each a little package, with instructions to wait until camp week before opening it

When that arrived, they set up a Zoom call, and we had a virtual camp. It was a lot of fun to see everyone after surgery and catch up. We did a talent show, and inside the little package they sent, there was a mini s'mores kit, which was a lot of fun to make

Even though camp was cancelled, we still had fun. I'm so lucky to be a part of this community. They are so nice and welcoming. It was truly a life-changing experience to be with HOG. Thank you, HOG! I can't wait to see you all next year. ♥





Let's Talk about Fear

BY VERONICA HARRIS

I would like to talk about fear, and I would suggest that, in these exceptional times, you should talk about fear too. Right now, many of us are struggling with the uncertainty of what life looks like for us in the present and what it means for our future selves as well. Faced with this uncertainty, fear can take hold. What is unknown, unexpected, or not understood is unsettling to most of us in our society. We have built our lives around us to ensure that we are confronted with as little uncertainty as possible, lending us a sense of control. However, the uncertainty has always been there. For families of heart children, you may be familiar with uncertainty and fear, cautiously welcoming some level of uncertainty into your lives with resolve. As difficult as those experiences may be, they are learning experiences to understand how you and your family manage when faced with adversity.

I would like to comfort you by saying, *we were made for this*. Our survival as human beings has been built on uncertainty. We have evolved and adapted in tremendously uncertain environments. Now is the time for us to connect with our innate capabilities for resilience and adaptability. To do so, we need to address our fears, acknowledge them, speak them out loud, and connect with the support of loved ones.

Here are some tips for addressing fear:

- Addressing fear in the present moment: What are you feeling most fearful of **right now**?
- What is the **feeling** of fear? Label it: terrified, fearful, numbing, petrified, panicked, alarmed?
- Notice where you **feel** it in your body. What does that emotion **feel** like? Tightness, heat, tension, prickly, numbing?
- How do you know you are in fear? What does your **behaviour** look like? We either become mobilized (fight or flight) or petrified (freeze).
- What does that **fear** mean for you or your family, your community?

It can be helpful to also have these conversations with your children. Remain curious and compassionate, providing that safe space without feeling the need to rescue your child from their discomfort. This is how they can also build the resilience to address their fears as they enter adulthood.

An important part of this practice of addressing fear is to write these things down or—even better—to talk to someone about it. Give yourself the mental space to **unpack your fear**, as scary as that might be. **Acknowledge** and **accept** the fear you feel so that you can move more intentionally through your life now, without fear being in the driver's seat. In turn, you might notice you have a greater tolerance for stressful situations, and even an increased sense of ease and confidence when faced with uncertain times. This will also result in reduced tension and stress within the family, as well as building strengthened connections within your community, and nurturing feelings of support and care. ♥



Is My Child or Adolescent Feeling Stressed about COVID-19?

Learn how children and adolescents express stress through their thoughts, feelings, and behaviours. Find some strategies for how you can help your child.

BY SICKKIDS STAFF

Stress is a normal response to everyday experiences that we perceive as difficult or challenging. Children and adolescents often experience stress when faced with uncertainty or disruptions in their everyday routine.

During difficult or challenging experiences such as COVID-19, you may have noticed changes in your child or adolescent's behaviour, which can be difficult to understand and address as a parent. It is important to know you are not alone. Difficult and challenging experiences can be very stressful for everyone. Children and adolescents often sense when their parents are feeling worried or stressed, which can increase their own feelings of stress and uncertainty. As a parent, expressing your emotions gives your child or adolescent permission to do the same. It also lets

your child or adolescent know that the range of emotions they may be experiencing is OK.

Children and adolescents often express stress through their thoughts, feelings, and behaviours.

In response to stress, children and adolescents may show:

- Increased irritability and/or moodiness
- Less interest in activities that they enjoy
- Appetite changes
- Feelings of sadness and/or fear
- Worry and/or fear of leaving the home
- Increased complaining about completing school-work or chores

- Physical symptoms of anxiety, such as headaches, nausea, and fatigue
- Increased aggression towards siblings and/or other members of the family
- Outward expression of emotions more frequently, such as crying
- Increased rebellion—for example, not complying with requests to complete a chore

Young children and school-age children

Young children and school-age children often express stress through their emotions and behaviours. You may notice a regression in your child's reaction to everyday experiences; for example, they may be more easily frustrated when faced with minor obstacles. This is a normal response to stressful situations.

You may also notice your young child or school-aged child:

- Incorporating COVID-19 themes into play—for example, a grandparent going to the hospital because they are sick with a virus.
- Incorporating themes of death and dying into play or conversation due to overhearing the topic on TV or in adult conversations.
- Developing new or regressive behaviours, such as thumb sucking, reliance on comforting objects, and bedwetting.
- Expressing fear of separation from you or other caregivers; for example, if you are going to the grocery store, your child may not want you to leave.
- Having difficulty falling asleep and/or staying asleep in their own bed.
- Engaging in magical thinking—for example, expressing that they have caused a loved one to become ill with COVID-19 by being mean to their loved one.

Adolescents

Adolescents tend to keep their thoughts and feelings inside when they are feeling stressed. Over time, keeping these negative thoughts and feelings inside can increase their stress and negatively impact how well your adolescent functions.

You may notice your adolescent:

- Withdrawing from friends and family members
- Pushing their boundaries—for example, staying up past their set bedtime, neglecting typical responsibilities, or engaging in risky behaviours
- Directing their frustration at their parents or siblings rather than the situation itself
- Appearing tense
- Spending more time on their electronic devices

- Neglecting personal hygiene
- Becoming overly reliant on their parents or caregivers, or appearing indecisive when completing everyday tasks

How parents can help

- Schedules may look different because children and adolescents are not in school, and parents are working from home. However, maintaining a daily routine reduces uncertainty and allows children and adolescents to maintain a sense of normalcy.
- Set up virtual play dates or other virtual opportunities for your child or adolescent to socialize with their friends.
- Limit access to news, social media, and sources of COVID-19-related information, both for yourself and your family. For adolescents, encourage them to take breaks from the internet and social media.
- Avoid discussions about money and employment in front of children and adolescents, as this can be a source of anxiety.
- Be accessible and ready to listen if your child or adolescent wants to share their thoughts and feelings about COVID-19. Oftentimes, children and adolescents may be looking for validation and reassurance that their feelings are OK.
- Schedule time to play a board game, watch a movie, or enjoy an activity together as a family.
- Engage your child or adolescent in effective strategies for managing stress—for example, mindfulness, deep breathing, or distraction.
- Schedule time each day to play or spend quality time with your child or adolescent. Children learn through playing and often use play to express themselves. Adolescents often learn through social experiences.
- Parents need to remember to take care of themselves! As a parent, it is easy to prioritize your family's needs instead of your own. When you are feeling worried or overwhelmed, this can increase your child's or adolescent's stress. There are many skills or strategies you can try to manage your own stress. For example, taking a break, using relaxation and mindfulness apps, journalling, calling a friend, and taking a shower are all ways to reset and feel more empowered to continue supporting yourself and your family. ♥

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How to Stay Active during the COVID-19 Pandemic

BY ASTRID DE SOUZA, “THE EXERCISE GIRL”

It has definitely been an interesting few weeks. I’m sure that you, like many, have gone through a wealth of emotions during this uncertain time. Are you or your kids feeling frustrated from having to be inside so much? I’m sure there are a lot of questions about when things will return to “normal.”

I have taken this opportunity to slow down and to make the best of this unique situation. I have tried to be really good to my body by doing something active every day, which has also been good for my mental health.

What are you and your family doing to try to stay active during this time? Public health guidelines recognize the importance of exercise during this time. We just need to take the necessary precautions.

Here are some ideas to be active that may work for your family:

- Could you start your day with a kid-friendly mindful meditation? https://youtu.be/Bk_qU7l-fcU
- How about some yoga? Cosmic Kids Yoga was suggested to me by a little seven-year-old I know! <https://youtu.be/xlg052EKMTk>

- Have you heard of The Body Coach TV? Maybe try it as a family. <https://youtu.be/Rz0go1pTda8>
- What about movement breaks? After every hour of sitting, can everyone get up and do 10 jumping jacks? Five star jumps? Hold a 20-second plank? Try the 5 Minute Move Kids Workout! <https://youtu.be/d3LPrhI0v-w>
- How about a family activity after school/work? A walk? Family bike ride? Scootering? Skateboarding? All of these things can be done at a safe distance from other people.
- Many school grounds are still open. The playgrounds may be closed, but there is lots of open space for different activities. Can you take out an old badminton set? Fly a kite? Kick a soccer ball around? The possibilities are endless!

Go outside, be creative, and have some fun! Remember to stay home if you have any symptoms, physically distance yourself from others when you are outside (stay two metres apart), and wash your hands when you come home.. ♥



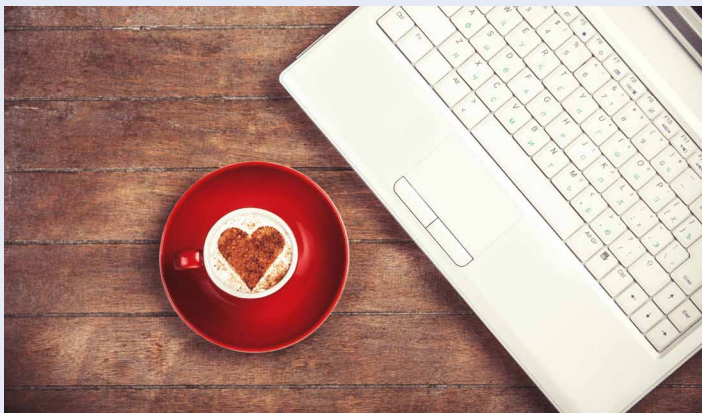
What's Happening?

Heart Mamas and Papas Virtual Coffee Nights via Zoom

We have had great success with our heart parent virtual get-togethers since COVID-19 hit. Wonderful to have both mom and dad attend in some families. Watch for emails inviting you to join!

Online Silent Auction

As we had to cancel the Wine Gala and Dinner and we had collected so many fabulous donations, we will be hosting an online silent auction in September. Watch for an email with a link to bid on many exciting items!



Did You Know?

BC Family Residence Program

Families from outside Metro Vancouver with a child who requires care at BC Children's Hospital may be eligible for travel and accommodation assistance during their child's medical stay.

To learn more, visit <http://www.bcfamilyresidence.gov.bc.ca/>. ❤

CHN Camps

Vancouver Island Weekend Family Camp

WHEN: Postponed until further notice; hopefully September

WHERE: Camp Thunderbird in Sooke

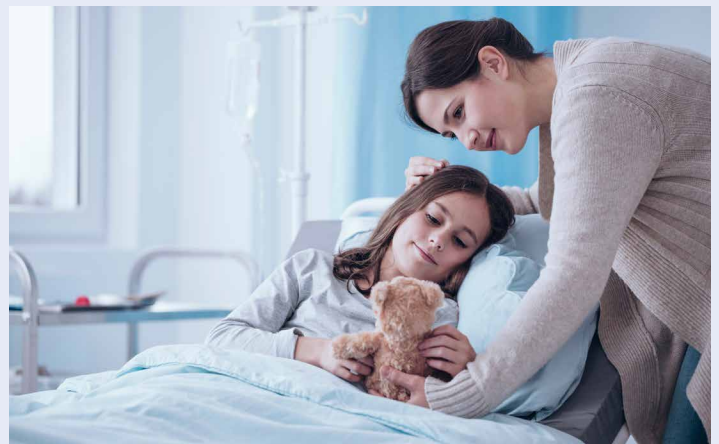
This camp is for Island heart families who have children ages 4 and up. A fun weekend of archery, rock climbing, crafts, campfires, and more while connecting with other heart families. Spaces are limited; priority will be given to families that haven't attended in the past. For more information, please email Samantha Aitken at saitken@childrensheartnetwork.org.

Lower Mainland Weekend Family Camp

WHEN: TBD; hopefully September 25–27

WHERE: Camp Stillwood near Cultus Lake

This camp is for Lower Mainland and Okanagan heart families who have children ages 4 and up. A fun weekend of archery, crafts, rock climbing, campfires, and more while connecting with other heart families. For more information, please email Samantha Aitken at saitken@childrensheartnetwork.org. ❤



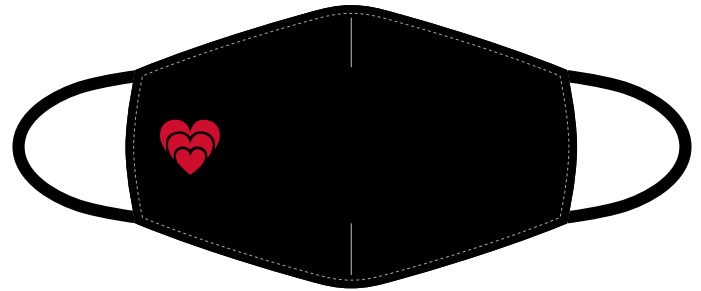
Face Masks Available for Purchase from CHN Website

CHN has ordered face masks that are available to our members at a discounted rate.

There are two sizes available, one for adults and teens, and one for kids under 12. The cost for both sizes is \$6.00. Prices are subsidized by CHN and include free shipping anywhere in BC.

CHN would like to thank Greengrass Productions Inc. and Tribe Solutions for their generous assistance with sourcing top-quality masks.

Please visit our website to purchase: <https://www.childrensheartnetwork.org/masks/>. ♥



18th Annual Wine Gala and Dinner

Sadly, due to COVID-19, we had to cancel the 18th Annual Wine Gala and Dinner, which was planned for late April. Thanks to the incredible hard work of our event coordinator, Hege Bolthof Hoegler, we are auctioning off the amazing array of donated items online. We held the first stage of the online auction in June. A heartfelt **thank you** to all those who supported the Children's Heart Network during the first phase of our online auction. We are grateful to all those who donated or bid on items, and those who donated to our "Send a Kid to Camp" program. With your support, we raised over \$39,000! Watch for an email about the second phase of the auction in September.

A heartfelt **thank you** to all of our sponsors:

- Wine Sponsors:** Country Vines Winery, Dean Alexander, The View Winery & Vineyard, Wild Goose Vineyards
- Gold Sponsors:** Hayward Sheppard Barristers & Solicitors, Pediatric Cardiology Associates, Dr. Brian Sinclair
- Bronze Sponsors:** Air Canada, Daniel Le Chocolat Belge, Medtronic of Canada
- Associate Sponsors:** Eye Station Optical, TD Bank (Todd Laycraft), The Drinks List (Tim Wispinski)
- Regular Sponsors:** Advanced Storage Centres, BC Ferries, Critter Cove, Forbidden Vancouver Walking Tours, Harbour Air Seaplanes, Hera Studios Inc., Olive + Piper, Oceania Cruises, Pacific Coastal Airlines, Porsche Club of America, Porsche Club of America: Canada West Region, Royal Roland, Sam's Original Art

In addition, we would like to thank and recognize The Rotary Club of Vancouver as an **Annual Donor**. ♥

