



Alexandra's Story

BY ANDREEA AND CAM APPELS

After spending 41 of the first 60 days of her life in the hospital, our two-month-old daughter Alexandra had open-heart surgery on May 18, 2022.

Alexandra was born on March 15, 2022, at 38 weeks, through a planned Caesarean section.

I was considered to have a high-risk pregnancy due to complications I had with my son, who was delivered after an emergency Caesarean section at 36 weeks, but the nine months of carrying Alexandra went well. All signs were pointing to a healthy baby

and a smooth delivery.

But since it was considered a high-risk pregnancy, I had ultrasounds at 21, 28, and 34 weeks, which all returned normal scans.

I recall the last one when the ultrasound tech showed me her heart and said, "It's a healthy heart. Look at the four chambers!"

But all these reassurances came crashing down shortly after Alexandra was born.

The delivery went well, but she was admitted immediately from the operating room to the neonatal

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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.

 @ChildrensHeartNetwork
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COFFEE GROUPS NEAR YOU

Our coffee groups are normally held in person; however, due to COVID, we are now hosting virtual get-togethers. Email Sam at saitken@childrensheartnetwork.org for more information.

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rupe3395@gmail.com

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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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KRISTA MOLIA – Vancouver Island Heart Beats coordinator

MEGAN MADSEN – Vancouver Island Hearts of Gold youth coordinator

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intensive care unit (NICU) because her oxygen levels were not high enough and needed monitoring.

This was not easy on us, but we were assured by the doctors and the team that she was perfectly healthy otherwise.

Little did we know that this was an early indication of her heart condition.

After a short stay in the NICU, we were able to start spending time with our new baby girl. After we had been at home for a week, however, when she was nine days old, everything changed.

After a walk and a feed, I put her on my chest as she fell asleep. It was then I noticed she was taking fast, shallow breaths. I was immediately overwhelmed with the feeling that something was not right. I opened her sleeper and watched as she was drawing inward under the ribs with every breath she took.

After observing her for an hour, my husband and I called our family doctor, who told us to go to the clinic. He then suggested we take her to Royal Columbian Hospital (RCH), where she was born.

We spent six hours in the emergency room while doctors ran blood tests, a chest X-ray, and an ECG, which came back with normal results.

Despite this, the pediatrician had a feeling something was off and did not feel comfortable sending us home. Alexandra was admitted to the pediatric ward and given antibiotics, and she went through countless tests over the next two days. They all came back negative, but her breathing never improved.

A few days later, the pediatrician heard a slight heart murmur during his assessment.

He called the pediatric cardiologist, Dr. Amanda Barlow, and they performed an echocardiogram to further examine Alexandra's heart.

We then found out the devastating news that Alexandra was born with a ventricular septal defect (VSD), a hole between the wall of the two ventricles. Due to its size, Alexandra would require open-heart surgery by the time she was six months old.

We were in shock, and our hearts sank. My husband and I had a hard time wrapping our head around the idea of our small baby undergoing open-heart surgery. Her future seemed uncertain.

Within a couple days, Alexandra's health took a turn for the worse, and the effects of the VSD became apparent. She was not feeding well, and her jaundice worsened, so she required light therapy treatment. She was losing weight when she should have been gaining it. She was extremely tired and was no longer able to feed on her own, which resulted in her needing a feeding tube.

She struggled more to breathe, so they started her on medications to help relieve the extra fluid in her lungs

caused by the VSD. We spent the next two weeks at RCH while the team monitored her and adjusted her medication so she could begin gaining weight and breathing more easily.

After 16 days, she was finally at a comfortable level, and we were able to take her home.

The following few weeks at home came with many challenges. We had weekly appointments with cardiology and her pediatrician. She was gravity fed through a tube every three to four hours; however, she was not tolerating these feeds and was vomiting frequently. It was hard for us to leave the house, as we had to keep her healthy.

She required frequent tube feeds, and she did not tolerate the car seat. One afternoon, on the way home from a doctor's appointment, Alexandra screamed and screamed. She was clearly distressed, so we pulled the car over and got her out of the car seat. She went pale and limp and almost passed out.

We were home for three weeks when she took another drastic turn at six weeks old.

She was pale, irritable, crying constantly, and inconsolable. She went from being okay to struggling for every breath.

Her pediatrician, Dr. McGuffin, told us to come to his office right away. Alexandra's heart and respiration rates were high, and she did not look well. He made the decision to call an ambulance, which transported us to RCH. We spent a few hours in trauma as they stabilized her, placed her on oxygen to help her breathe, and increased her heart medications. Then, an infant transport team took us to BC Children's Hospital (BCCH).

We were admitted to BCCH, where we would spend the next four weeks with Alexandra.

Alexandra's VSD case was a little bit of a mystery and not a textbook one. She had fevers and still struggled to breathe, so they did many tests to rule out infection and any other possible underlying conditions.

The doctors placed her on a feeding pump, but she was still not tolerating her feeds. Her heart was working at 150% all the time, and she was always burning energy. She was slowly gaining weight, but not nearly as fast as she should have been.

The doctors moved her feeding tube from her stomach to her small intestine to help prevent vomiting and aspiration. Lung specialists and respiratory therapists assessed her daily.

After having two more episodes like the one she had in the car, she was assessed by neurology, but everything seemed to be focused on her heart. She was in congestive heart failure.

After 11 days of treating and observing Alexandra, Dr. Barlow, the cardiology team, and the surgeon decided that it was in her best interest to move up her surgery date to

the following week. They did not want to wait, as she was not thriving. She was struggling.

The next week went by very slowly, and the anticipation of the surgery made us very anxious. We were provided with many resources, and the surgery was discussed in detail. We were told that a VSD was the most common of all heart defects and the repair was straightforward, but we weren't feeling reassured. We were told that some babies can tolerate a VSD until they are six months or older. I did not understand why this wasn't the case for Alexandra.

Dr. Campbell performed Alexandra's heart surgery on May 18, when she was two months old. She recovered quite quickly, and we were able to take her home five days after. Her feeding tube came out one week later, and as the following weeks went by, our worries began to fade.

Although she endured a difficult start to life, Alexandra is a happy, healthy baby who is hitting her height and weight milestones. She is now six months old, loves to smile and giggle, and is almost crawling. She has shown us that even though she is small, she is mighty, and her heart defect has not set her back one bit. We will be forever grateful to Dr. Campbell, the cardiologists, all her doctors and nurses, and the volunteers and staff at BCCH and RCH.

We can't even begin to explain the emotions and pain we felt through the entire process. Not being able to connect with someone who has gone through a similar experience felt lonely. It was during the diagnosis that Dr. Barlow provided us with information on congenital heart defects and included a brochure with information for the Children's Heart Network (CHN). Cam reached out to

CHN and was able to speak with another heart parent. It was very helpful and gave us hope that everything would be okay. It helped to be able to communicate with someone who had been through a similar situation and completely understood how we were feeling. We found comfort in the resources they provided and the stories they shared. CHN has created a great support program for heart parents and heart kids. We are now members, and we will continue to support CHN, as they are crucial in helping families get through very difficult times.

This August, we hosted a celebration for Alexandra and a fundraiser for CHN. We were grateful to raise a little over \$1,500. Cam and I matched the amount and donated \$3,000 to help support CHN. We would like to thank CHN for its support and commend it for all the work it does in the children's heart community.

Alexandra is a special little girl. She is our rainbow baby. We had several names that we were debating between, but Alexandra is very meaningful to us, and we kept coming back to it.

In November 2020, we unexpectedly lost one of our best friends, whose name was Alexander (Alex). The day after Alexandra was born, we had a special moment when we knew what we would name her.

Alexandra was sleeping with her mouth open, and she looked exactly like her uncle Alex when he would sleep. It was a sign that we had to name her after him. The strength, resilience, and fight she showed during and after her procedure are a true testament of the name, and he would have been so proud of her. ♥



Mirella's Heart Journey

BY MIRELLA CERVO

My name is Mirella Cervo, and I was born on September 14, 2011, in Abbotsford, BC, at Abbotsford Regional Hospital.

When I was born, my mother was advised by the pediatrician who helped deliver me that there was a subtle noise on my heart known as a heart murmur. The doctors monitored my heart regularly over the next few years.

When I was two years old, my condition was reassessed by the team at BC Children's Hospital, and they recommended that I get an echocardiogram when I was four years old.

On January 2017, I was diagnosed with an atrial septal defect with partial anomalous pulmonary venous return. Open-heart surgery was recommended by the hospital team to correct both defects.

Dr. Duncan and the pre-admission clinic arranged for my surgery on May 11, 2017, at 8:00 am. My surgeon was Dr. Gandhi. My mom and dad brought me to pre-op and said, "See you soon!" My surgery was successful and took only one and a half hours. Dr. Gandhi mentioned that he corrected the issue with my veins and closed the hole in my heart, putting a patch of my own skin over the hole. The murmur was gone. (Yay!)

Dr. Gandhi and the cardiac team took diligent care of me, checking every hour to see how I was doing. I was sleeping most of the time. I stayed overnight in my own private room (my dad slept in my room on the couch). In the morning, Dr. Gandhi told me and my dad that after a few tests (easy peasy ones) I could go home in the afternoon...and I did! It was nice to go home so soon. My mom and grandma came to visit me in the morning, and my dad told them the good news. The hospital was kind and gave me a quilt to take home with me and said it would keep me warm while I was recuperating. I guess it did, as I got better very quickly!

I was sent home with a detailed package of instructions showing how to take care of the wound and to help with my recuperation. Happily, within eight weeks of my surgery, I was back at my daycare and enjoying summer camps with my friends.

I was told to avoid contact sports and any other activities that put a lot of stress on my heart, so I took it easy. Ever since then, I've been able to do and play whatever I want, like T-ball, soccer, competitive swimming, and softball!

I had to return a few times each year for follow-ups and tests, but that was no big deal. Now I'm almost 11, and I only have to go back once every two years for a checkup.

The Children's Heart Network was a big support for my family when I was diagnosed with my condition. CHN



connected my parents with other families who had been through a similar journey as us. I have also been able to meet other heart warriors like me by attending the events organized by CHN, like the Cultus Lake Waterpark, Pumpkin Patch, and Christmas Breakfast with Santa.

I want to thank BC Children's Hospital, CHN, all the members of the cardiac department, and the volunteers that helped me and my parents get through the operation and all of the follow-up appointments. ♥

Hearts of Gold Camp at Zajac Ranch

After two years of cancellations due to COVID-19, our Hearts of Gold (HOG) youth group was thrilled to get back to camp this summer! Zajac Ranch is outside of Mission, BC, and hosted our group of 30 teens and coordinators over the July long weekend. The weather cooperated, and the food was great, the highlight being s'mores made over the campfire. Some of the favourite activities were the Skynet (think trampolining in the air), the high ropes course, swimming in the pool, hanging out in the hot tub, making tie-dye shirts, playing Ping-Pong, the outdoor "pudding fight," and the special graduation dinner and slideshow for the teens turning 19. Next year the HOG group will be heading back to Zajac Ranch over the May long weekend.



Quotes from some of our campers:

"My experiences at Zajac Ranch with my Hearts of Gold friends have always been jam-packed balls of fun. Even in the pouring rain years ago we managed to have a good time together. At camp I built a sense of community and lifelong friends!" —Hailey

"I really enjoyed being at camp with everyone in HOG and spending time in person. My favourite part was the talent show and seeing everyone stepping out of their comfort zone to perform." —Hibiki

"My favourite activity at camp was the aggressive Ping-Pong games and when the ball went flying everywhere, because it was chaotic, fun, and silly. When I was there, it was very nice, because I never felt left out, and everyone was very including. It would be awesome to be able to go again next year since I enjoyed myself a ton." —Dani

If you are between 13 and 18 years old, are a heart warrior, and would like to join in on the HOG monthly events and camp, please feel free to email one of our coordinators:

Lower Mainland

Kristi Coldwell at chnheartsofgold@gmail.com

Vancouver Island

Megan Madsen at viheartsofgold@gmail.com ♥

CHN Family Camps

This summer, we hosted two family camps. The first was at Camp Thunderbird in Sooke, BC, in June, for our Vancouver Island families, and the second was at Camp Stillwood near Cultus Lake in late September, for our Lower Mainland families. Each camp hosted 12–14 families and included many of these fun activities: kayaking, archery, ropes course, rock climbing, bubble soccer, nine-square ball, laser tag, and arts and crafts. New friendships and heart connections were made, oodles of marshmallows were roasted, and many fond memories were crafted. A huge heartfelt thank you to our hosts and helpers, Kristin Avis and Stephanie Vink at Camp Thunderbird and Sabrina Robertson and Heidi Scorgie at Camp Stillwood.

Here is a sonnet written by heart mom Doreen Queen-McIntyre. "Stillwood Sonnet" is a Shakespearean sonnet (iambic pentameter) in the style of Shakespeare's prologue to *Romeo and Juliet*, Act 1, Scene 1.

Stillwood Sonnet

Two teams—they match in dignity
In fair Camp Stillwood where we lay our scene.
New laser grudge—laid down for unity
Midst grass and trees near Cultus Lake serene.
We gathered here to play in fall sunshine;
Nine square, ropes course and archery above;
Relax, chit chat then paint your heart wind chime:
Reminders of heart-strength and family love.
Forth from the fire—heart warriors arise;
From pain and strain to new courageous life.
Each day they wake with peace and hopeful eyes;
To bravely walk our world away from strife.
Big heart, warm smile, we're present. We attend.
We've learned, like hearts, teams help people mend.

—Doreen Queen-McIntyre (heart mom) ♥

Camp Stillwood



Arts and crafts.



Arts and crafts.



Bubble soccer.



Group photo.



Nine-square ball.



Paul and his work of heart.

Camp Thunderbird



Grayson and Mikayla on the rocks.



Grayson solo kayaking.



Vink Family mastering archery.



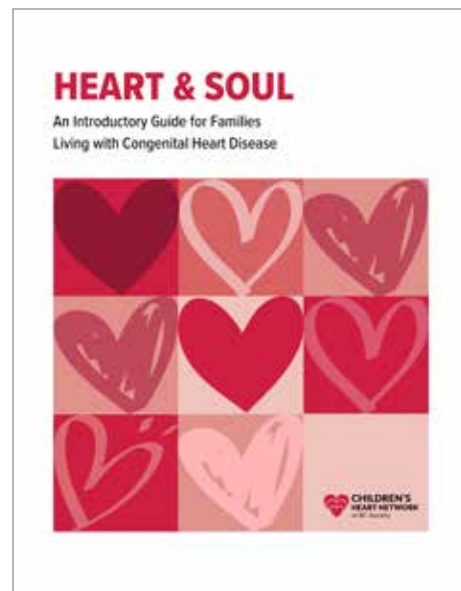
Top Bunk – Grayson and Caitlyn.

Heart & Soul: An Introductory Guide for Families Living with Congenital Heart Disease

After years of research, collaboration, and hard work from many volunteers, we are so very excited to share the online version of our revised *Heart & Soul* guide. This guide was developed by heart families and medical professionals for new heart families, but it will also benefit many that are still on their heart journey.

Please feel free to share with friends, family, co-workers, and anyone that has recently become part of the children's heart community.

View the online version of the *Heart & Soul* guide at www.childrensheartnetwork.org/heart-soul. ♥



Have a Heartiversary Coming Up? Let Us Help You Celebrate!

Dear heart families,

Is your heart kid celebrating a heartiversary or a birthday soon? CHN has partnered with Dee de los Santos, a fellow heart mom, to sponsor her Heart Box project and provide heart boxes for CHN members.

A heart box is a care package sent to children living with CHD who are celebrating a heartiversary or a birthday. In the box, there are items to help celebrate the special day, including balloons, decor, and some surprise gifts for your heart warrior.

If your child will be celebrating a heartiversary or a birthday soon, please fill out the form at <https://forms.gle/zPbSTpYJgTLrGhkb9>.

—Dee and Winston ♥



We Need You!

How can you help support CHN so that we can continue to provide programs, events, education, and camps for our BC heart families? Join our fundraising committee!

Here are the details:

- Meet once per month via Zoom with a team leader and other heart parent volunteers to discuss fundraising opportunities.
- Help put our fundraising initiatives into action.

- Support our annual Wine Gala & Dinner by rounding up donations by emailing, phoning, or meeting with businesses and contacts that could be potential donors. Easy to do on the weekends or evenings from home!

You don't have to live in Vancouver! If you can offer up some of your free time to support CHN, please contact board member and fundraising committee leader Sabrina Robertson at sabrinarobertson2@gmail.com. ♥

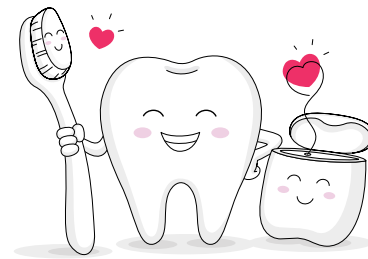
Dental Care for Children with Heart Disease

Children with congenital heart disease (CHD) are at risk of developing an uncommon but life-threatening heart infection called bacterial endocarditis from bad teeth or gums. We all have germs in our mouths. When teeth have cavities or gums are infected, germs can get into the bloodstream and travel to the heart lining or valves, causing a serious infection. Taking care of your child's teeth helps prevent endocarditis and keeps your child's heart healthy. There are a few factors unique to children with CHD that put them at greater risk of tooth decay:

- Medications in liquid form are usually sweetened with sugar. Since children with CHD may have to take medications for a long time, the sugars can collect on the teeth and add to tooth decay.
- Some cardiac medicines such as Lasix can decrease saliva, leading to a buildup of plaque on your child's teeth, causing tooth decay.
- Some children with congenital heart disease can have weak tooth enamel, leading to increased tooth decay.

Tips to help you care for your child's teeth and heart:

- Ensure your child has two dental checkups per year, starting as soon as your baby has teeth.
- For babies, begin cleaning teeth twice a day as soon as they appear. Use a soft baby toothbrush or small piece of soft cloth.
- Do not settle your baby to sleep with a bottle of milk or juice in their mouth. Milk, juice, and formula all contain sugar, which can cause tooth decay when allowed to sit in the mouth.
- Limit sugary fluids in sippy cups throughout the day.
- For toddlers and older children, brush teeth at least twice a day. Floss teeth once a day.



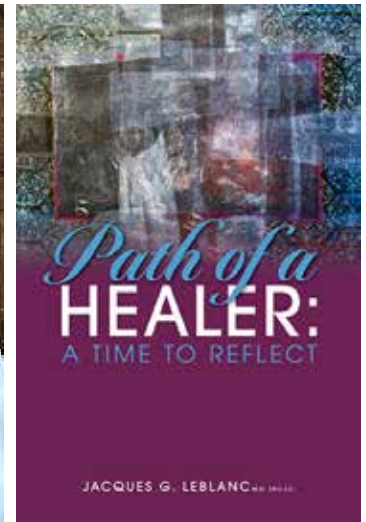
- Help young children up to eight years of age with teeth brushing to ensure that they have cleaned all tooth surfaces adequately.
- Give medicines before brushing your child's teeth.
- Use a tiny amount of fluoride toothpaste to brush your child's teeth. Fluoride helps teeth develop a hard outer shell that is more resistant to decay. Don't let your child eat the toothpaste, since too much fluoride can be harmful.
- Choose healthy foods—good nutrition promotes a healthy body, healthy teeth, and resistance to disease.
- For children with braces, check with your cardiologist to find out whether antibiotics are needed for placement or adjustment of braces.
- Ensure your child wears a mouthguard for contact sports.
- Children with certain heart problems have a higher risk of endocarditis and should take antibiotics before dental procedures (these preventive antibiotics are called antibiotic prophylaxis). If you are not sure if your child needs antibiotic prophylaxis, check with your cardiologist.
- Children needing heart surgery should have a dental checkup and any required dental work before the surgery.

For more tips on caring for your child's teeth, talk to your dentist and dental hygienist. ♥

A Good Read

P*ath of a Healer: A Time to Reflect* is a memoir by pediatric cardiac surgeon Dr. Jacques LeBlanc. It examines and pays homage to a father-son relationship, faith, friendship, mentorship, rural Quebec, and the mysteries of open-heart surgery. It also explores the concept of spiritual life on earth. The author writes of love and loss and speaks about facing death without trying to cure it.

Dr. Jacques LeBlanc was the director of the cardiac sciences program at BC Children's Hospital. He led and fostered the expansion and development of cardiovascular services for 17 years. The book will appeal to readers of memoir and non-fiction who are intrigued by the topics of medicine, healing, spirituality, family relationships, and family history. ♥



Get the Live 5-2-1-0 App

Supporting health behaviour change in children can be challenging. Even when you work together with families to set healthy lifestyle goals during appointments, it can be difficult to keep patients motivated in between visits.

The Live 5-2-1-0 app¹ is designed to motivate children ages 8–12 to adopt healthy behaviours related to nutrition, screen time, and physical activity through simple, customized goal setting and fun weekly challenges. Children receive positive messaging when they log activities in the app and earn tokens when they complete goals. Tokens can be spent at the Reward Bank—a collection of family-based activities, excursions, and items chosen and provided by the family (e.g., play a new board game, choose a dress-up theme for dinner, or go to the movies).

Over the past two years, families and health care providers have provided valuable feedback to improve the functionality of the Live 5-2-1-0 app. An upgraded version has been built, offering exciting new features and more customizability so that families can adapt the app to their needs and preferences.

The app now includes a special dashboard for health care providers, offering a quick glimpse of the patient's progress at follow-up visits. The patient's progress report can be viewed on their device to see a summary of:

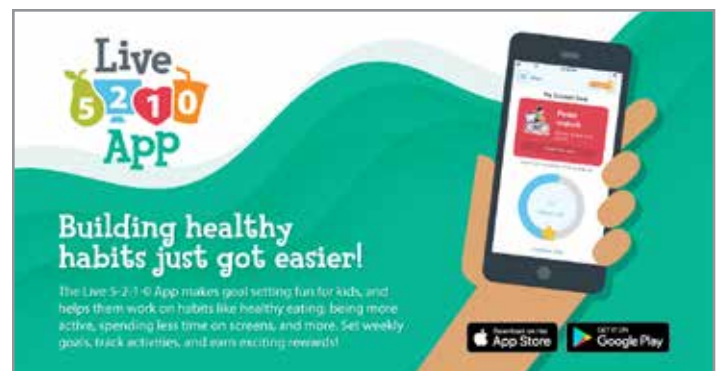
- Changes in the child's daily health behaviours and willingness to change over time (collected through the app's built-in assessment, repeated every 90 days).

- Total number of goals completed by the child over time.
- A complete history of the goals a child has set.
- Self-reported reasons why goals were changed or incomplete.

Version 1.2 also includes a new category of activities where children can work on habits outside of the Live 5-2-1-0 message—like sleep, mindfulness, and self-compassion.

Try the app today with pediatric patients and families! Parents can download it for free from Google Play or the App Store. ♥

Reprinted with permission from www.bcchr.ca/news/introducing-live-5-2-1-0-app.



1 <https://live5210.ca/resourceContainers/live-5-2-1-0-app-how-it-works>

What's Happening?

Lower Mainland Breakfast with Santa

Saturday, December 3, at the Delta Hotels Burnaby Conference Centre. A pancake breakfast, crafts, cookie decorating, and a visit with Santa and Mrs. Claus! To RSVP, watch for the invitation coming soon to your inbox!

Island Holiday Celebration

Saturday, December 3, or Sunday, December 4, at The Butchart Gardens. Ride the carousel, have cookies and hot chocolate with other heart families, and explore the incredible light display! To RSVP, watch for the invitation coming soon to your inbox!

19th Annual Children's Heart Network Wine Gala & Dinner

Friday, April 28, at the Terminal City Club in Vancouver. A four-course dinner with wine pairings and the best auction in town! Mark your calendars! Invitations will be sent out in early January. ♥



Did You Know?

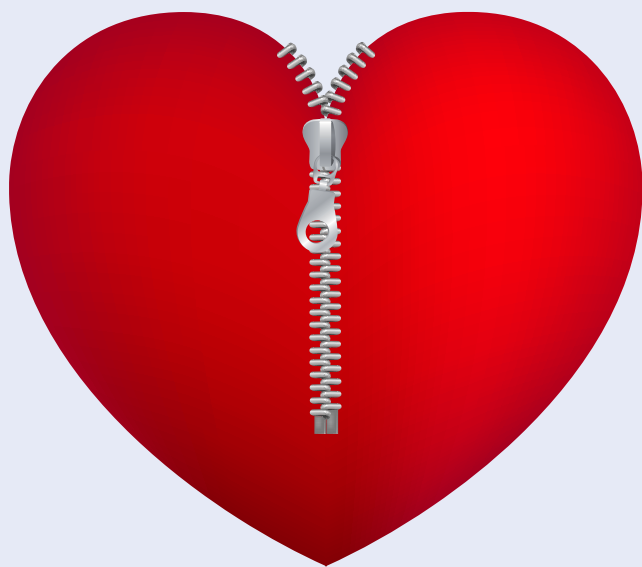
Zipper Sisters: Women with CHD

This is an exclusive group for women born with congenital heart defects. Their focus is those who were diagnosed at birth or in early life and received treatment or surgery in childhood—in other words, little girls who grew up with CHD!

They don't accept heart moms or those with acquired heart disease. You must be 18 years old to become a member. Join and follow them on Instagram or Facebook:

Instagram: [@zipper_sisters](https://www.instagram.com/zipper_sisters)

Facebook: www.facebook.com/groups/womenwithchd ♥





**CHILDREN'S
Heart Network**

WOULD BE HONOURED BY
YOUR PRESENCE AT THE
19TH ANNUAL



FRIDAY APRIL 28
6 O'CLOCK PM

TERMINAL CITY CLUB
837 WEST HASTINGS