CHILDREN'S HEART NETWORK of BC Society

Heart Matters

WWW.CHILDRENSHEARTNETWORK.ORG WINTER 2023

Ada's Story

BY SONIA MILBRADT

Ada's story begins before she was born—her heart defect was detected at the 20-week anatomy scan. The scan happened on a Friday afternoon and I received a call on Monday from the Burnaby Maternity Clinic, where the pregnancy was being followed, to come in to discuss the results. The doctor must have been very busy, because I was given the news very quickly and frankly that the scan showed that half of her heart hadn't formed. He pointed out how all four chambers were supposed to be the same size and highlighted how the right ventricle was not formed. He said he would refer me to the BC Children's Hospital (BCCH) and we would find more out after a fetal echocardiogra.

What followed was an agonizing week while my husband and I waited for our appointment at BCCH. The day arrived, and it was a whirlwind. We had the fetal echocardiogram, then met with the amazing cardiology nurse and cardiologist who talked us through the diagnosis, then met with the genetics team, then met with a doctor from Maternal Fetal Medicine.

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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.

IN THIS ISSUE

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.

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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.

ABBOTSFORD – Rupe Brah
rupe3395@gmail.com

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veronicav0603@gmail.com

RICHMOND – Kate Walker
kwalker@childrensheartnetwork.org

VANCOUVER – Samantha Aitken
saitken@childrensheartnetwork.org

VICTORIA – Teri Godin
terigodin@gmail.com

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.

CHN BOARD

TRACEY CARPENTER – President

KERRY HARDING – Vice-president

JEFF MERCER – Treasurer

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JOELLY SEGAL – Member at large

LESLIE RAFFIN – Member at large

STEPHANIE ISAAC – Member at large

The CHN board of directors would like to thank Heidi Scorgie (five years) and Sabrina Robertson (six years) for their generous commitment and hours of volunteer work as board members. We will miss you!

CHN STAFF

SAMANTHA AITKEN – Provincial coordinator

PATTY RIPPEL – Administrative assistant

KRISTI COLDWELL – Lower Mainland Hearts of Gold youth coordinator

MEGAN MADSEN – Vancouver Island Hearts of Gold youth coordinator

Ada's Story, continued from page 1

We were told that Ada had tricuspid stenosis (diagnosed as functionally tricuspid atresia after birth), which means the valve between the right atrium and ventricle was too small and there wasn't enough blood flow on that side of the heart during development. This resulted in a hypoplastic right ventricle, meaning an underdeveloped right ventricle. She also has a large ventricular septal defect. This is good in her case, because it means oxygenated blood and deoxygenated blood can mix and get to the stronger left ventricle, as her heart acts like only a single pump.

Knowing the diagnosis before birth was both a blessing and a burden. Ada was our first child, and we didn't know how eager to be and how much to prepare, despite the assurances of the cardiology nurses and cardiologists we saw in the next months. The phrase "knowing but not knowing" kept coming up, because we knew about Ada's congenital heart defect (CHD), but we didn't know exactly what she would need or how the interventions would go until she was born. It was very hard to be excited, because we didn't want to get too attached for fear of the worst-case scenario. Luckily, medical advances in the field of cardiac surgery in the past 40 years have meant that children born with this defect can live into adulthood.

Ada made her appearance into the world via an emergency C-section on September 8, 2019, at 4:00 am, when progress stalled after many hours of active labour. She was whisked away to the cardiac intensive care unit (CICU) for tests as planned quickly after birth with my husband right by her side while I went to recovery. I did get a cheeky detour to the CICU to see her before they brought me to my own room on the maternity side. I was given one of the smaller rooms since Ada was in her own big room in the gorgeous Teck Acute Care Centre. I am so thankful that we have such a lovely facility in Vancouver for such a challenging time. It was very hard listening to all the moms bonding with their children and hearing the cries of the babies while I was alone in my room on the maternity side. I was able to arrange it so that I spent most of the time over with Ada and my husband in the CICU, only being wheeled back every four hours for the required checkup and to take my pain medication. That way I was able to begin my breastfeeding journey with Ada as well, which she did well at despite the ballet of tubes and wires we had to do with the CICU nurse every time.

Ada was stable and didn't need any interventions on the day of her birth. On day two, she had a catheter procedure, called an atrial septostomy. This involved running a tube through her veins with a little balloon on the end that was then blown up in her heart to widen the small hole she had between her atria. This allowed better mixing of the deoxygenated and oxygenated blood in the upper chambers of her heart. She was sent back to her room in the CICU with an adorable diaper hat to keep her warm.

We were very lucky to be discharged on day four, with plans for many more doctor appointments and needing her weight checked by our GP every two days. She struggled staying awake with feedings, so we supplemented with formula or pumped milk after every nursing session. We were then in the waiting game to see when her first intervention would be, but they suspected it would be a pulmonary artery (PA) band at a few weeks old due to her high oxygen saturations levels, which meant that there was most likely too much pressure to her lungs.

At two and a half weeks old, Ada had another catheter procedure for diagnostic purposes and to open the hole between her atria a bit more, as it was "floppy." She was inconsolable before the procedure as she wasn't allowed to eat anything, which was really hard to deny a newborn (especially when we kept getting pushed to later in the day due to emergent patients). Finally, she was brought into the cath lab. We were told afterwards that there was a brief arrythmia during the procedure but that they got it under control without incident. She stayed overnight in the CICU for observation, but we were discharged the next day.

A few days later, we had another round of scans and a pre-surgery consultation. This is when we were able to speak to her surgeon, Dr. Gandhi. We were so impressed with his professionalism, knowledge, and confidence, and we knew Ada was in good hands.

On Wednesday, October 2, 2019, at three weeks old, Ada had her first open-heart surgery for a PA band to reduce the pressure on her lungs. When Ada was taken away from us in the surgical waiting area by a nurse, she said, "Let's make a warrior out of you," and it really hit me how amazing the entire specialty of pediatric cardiology is and also how incredibly resilient and strong Ada is. Placing a PA band is both a scientific procedure and an art form to get the tightness just right, and Dr. Gandhi did an amazing job and completed her surgery in about two hours.

Ada's little body had a hard time adjusting to the new pressures her first night in the CICU after her surgery, and I remember a team of people swooping in and lights turning on at 2:00 am while I was in the middle of pumping. Ada's breathing rate was dropping to very low levels, and they couldn't figure out if she was "snowed under" because of all the pain meds or if it was her heart. They ended up deciding to intervene, and she was put back on some oxygen. After a couple scans, they determined that her heart was struggling to adjust to the new physiology, so to help her manage this, they started giving her some drugs (dopamine and milrinone) that helped her heart beat stronger. She was also placed on a mini hot air bed that helped with her body temperature. She started to feel a lot better the next day, and I remember Dr. Gandhi calling in for rounds even though it was his day off, which is when we knew how much he cared.

The next few days were a waiting game in the CICU while they tried to wean her off her medicines and kept chasing a seemingly elusive blood pressure. Five days after her surgery, we were moved up to the ward. Two days after that, after scans, tests, and wound care/CHD teaching from the nurse practitioner, we were able to go home!

Everything was able to be "normal" for a few months as we settled into a routine and waited out the months until we knew she would need her next open-heart surgery. Ada grew into a happy and goofy little baby who loved independent play and being silly. We even got to go the 2019 CHN Christmas party when she was three months old. It was so great seeing so many families and children who were in similar situations to our own. We were also able to travel to Calgary to visit family for Christmas, where she got to meet her cousin for the first time.

March 2020 rolled around with Ada's half birthday (six months old). We had a celebration at a local community centre where we were able to introduce her to a lot of friends who hadn't met her yet. The following weekend, the world shut down, and COVID-19 lockdown began.

One Friday in early April, Ada had a breath-holding/cyanotic spell, and we called an ambulance to take her to BCCH. Since it was so early in the pandemic, it was a very strange experience, because a lot of policies were changing by the day and/or were not well established. My husband had to wait in the car in the parking lot while I was in the ER triage room since only one parent was allowed in. They decided to keep Ada overnight for observation and so they could do a series of tests the next day. She was also swabbed for the major respiratory viruses (including COVID-19) and thankfully came back negative for all of those. We saw Dr. Gandhi and Ada's cardiologist, Dr. Sanatani, and they decided based on her scans and her lower blood oxygen levels they would move up her surgery by a month to the following Monday.

Just shy of her seven-month birthday, Ada went in for her second open-heart surgery—the Glenn—at 7:45 am on Monday, April 6, 2020. Even though this was our second time doing it in less than a year, and knowing how skilled Dr. Gandhi is, it was still very hard to hand her over. We ended up watching a movie on my husband's phone in the room we were waiting in (no coffee shops or family spaces to hang out in due to COVID-19), because we couldn't focus on anything else. At 10:30 am we got the word that she was through surgery. We were able to see her in the CICU an hour later. It was so hard seeing her with all of the wires and tubes again. We were moved to the ward the next day and then able to go home a couple days later. It was hard being in the CICU and ward so early in the pandemic, because everything was really shut down and we were basically stuck in the room with nowhere else to go, but the staff were really lovely and we were so lucky to have such a short stay as well.

Since her Glenn surgery, Ada has grown into a creative, smart, chatty, silly three-year-old who loves playing and attends daycare full-time. She has done swim lessons and soccer lessons and loved them both. She's a feisty toddler who loves books, colouring, and everything Mickey and Minnie related. We have been able to enjoy life with her without worrying for a while, other than when she gets sick. She became an amazing big sister in December 2021 and is the sweetest little helper. We know that the Fontan surgery is looming over us for when she is around four years old, but until then we enjoy every day with her, and it's easy to forget she has a "special heart." ♥

Hearts of Gold Holiday Cruise

BY KRISTI COLDWELL, CHILD LIFE SPECIALIST AND HEARTS OF GOLD COORDINATOR

This past December our Lower Mainland Hearts of Gold group came together to celebrate the holiday season by enjoying a Christmas carol dinner cruise! After a two-year hiatus due to the pandemic, our Hearts of Gold teens were excited to enjoy this beloved tradition once again. The three-and-a-half-hour cruise saw the group take to the water, where everyone enjoyed a triple-entree buffet dinner, Christmas carolling, and dancing, complete with a DJ. Between all the excitement the teens managed to find some time to engage in the much-anticipated gift exchange. After everyone danced the night away, the boat docked with more than a few tired teens! It was a great evening and a perfect way to get into the holiday spirit. ♥

Did You Know?

Do You Wear Contact Lenses?

If so, every time you order, you can donate to the Children's Heart Network. At MyLens.ca, their core values are built around giving back to their employees, customers, and communities. From the very beginning, the owners decided they would donate a portion of each sale to organizations that are close to their hearts due to personal life experiences. They proudly donate 5% of each sale to the Canadian Mental Health Association or the Children's Heart Network. (When you place your order, you can choose which charity you would like to support.)

https://www.mylens.ca/

The Heart of the Matter

The Heart of the Matter is the first comprehensive documentary on congenital heart disease (CHD) ever produced for television. Written and produced by TMK Productions, Inc., in collaboration with The Children's Heart Foundation, the program examines all aspects of CHD, the most common birth defect in the world. Hosted by Golden Globe–nominated actor Chris O'Donnell, *The Heart of the Matter* premiered on WTTW Chicago on May 6, 2012. Did you know that Backstreet Boys member Brian Littrell is a CHD survivor? He is featured in the documentary and tells his story (38 minutes in).

https://www.youtube.com/watch?v=TMX9zv64O04 ♥

CHN Celebrates the Holidays!

Lower Mainland

This year's event was such a fun, festive day! We had over 250 heart family members join us at the Delta Hotels Burnaby Conference Centre to celebrate the holidays. The decorations were gorgeous, and a very entertaining show was put on by Norden the Magician. Families got dressed up, enjoyed a fabulous brunch, and then took part in face painting, balloon animals, Christmas crafts, assessing the dozens of raffle prizes, and cookie decorating. The highlight for the little ones was undoubtedly the arrival of Mr. and Mrs. Claus, who spent time chatting with children, with everyone providing big smiles for our amazing photographer, heart mom Christina Amy Morris. We would like to thank our team of volunteers and the following sponsors, without whom this event would not be possible: Delta Hotels by Marriott, Fratelli Bakery, Daniel Chocolates, and all the families and businesses that donated to the raffle.

Crocker family.

Londyn and Thalia.

Santa and Mrs. Claus.

Okanagan

After many years, we are finally back to hosting events in the Okanagan area. Long-time heart mom Deb Dachwitz and her volunteers got together to plan a wonderful breakfast with Santa on December 10 at the Coast Capri Hotel in Kelowna. Families came from far and wide to join in the fun, and some took advantage of the "Take the elevator home" special room rate offered by the hotel and made a weekend out of it. After a plentiful buffet breakfast, some crafts, and cookie decorating, a very special guest arrived! Heart parents made new connections and children made new friends, leading the way to many more fun Okanagan CHN events. If you live in the Okanagan and have an idea for a spring or summer CHN event, please email us!

Santa and Ashton.

Hailey and Santa.

Hailey decorating cookies.

Vancouver Island

After two years of not having our in-person holiday parties, we were thrilled to host our events again! On December 4, families from Vancouver Island's HeartBeats group met at The Butchart Gardens in the Carousel Room to share in some festive fun. The children rode the gorgeous vintage merry-go-round while moms and dads were able to sip hot chocolate, chat, and connect with other heart parents. Many thanks to Megan Madsen, our Hearts of Gold youth group coordinator, for hosting and making it so special. ♥

Panagrot family.

The Butchart Gardens.

Kai.

Kai and Hilo.

Jayme.

CHN's Year in Review

The year started with us still in the thick of the pandemic, which meant restrictions and life modifications for many of us, but especially for those that are more vulnerable. Thankfully we were able to alter the structure of many of our programs to continue to support our BC heart families.

Our Lower Mainland and Vancouver Island Hearts of Gold youth groups both hosted virtual get-togethers instead of in-person events. We mailed a package to teens that included group crafts like birdhouse building, making memory boards, soapstone carving, ornament painting, and building gingerbread houses. Facilitated by our child life specialist, Kristi Coldwell, these fun online gatherings using Zoom allowed the teens to see their heart friends, chat, laugh, and connect all year long while doing a fun activity. The kit with the bingo boards was one of the highlights. (Who knew online bingo could be so fun!?) For some of our youth, receiving this package filled with treats, crafts, and games, and taking part in the event was the highlight of their month.

Our HeartBeats events for families and children 12 and under started back up in the spring as we hosted an outdoor picnic at Rocky Point Park in Maple Ridge. Finally families could meet safely outside and make new heart connections while on the swings, climbing the play structures, and enjoying a treat from the famous ice cream shop. The summer event was back on at Cultus Lake Waterpark and was attended by over 250 people. Families drove from far and wide (even the Okanagan and the Sunshine Coast), and some boarded the CHN bus from Vancouver Island to join us for the day.

We also hosted a virtual mindfulness-based stress reduction course for heart parents, CPR training for parents and caregivers, and a resource parent training workshop. We were able to send over 40 heart kids to camp, and we hosted two family camp weekends, one for the Lower Mainland and one for our Island families.

In July we were very excited to once again invite 10 families to participate in a four-day fishing trip at Critter Cove in Nootka Sound. This year marked the 20th anniversary of this magical trip that allows heart families to connect and support each other. The Forbes family, who own the Critter Cove Resort, have been inviting CHN families for 20 years. A large group of volunteers, coordinated by Critter Cove Resort, donate their time and funds for fuel to take our families out fishing on their boats. The entire weekend is filled with one-of-a-kind experiences!

After years of research, collaboration, and hard work from many volunteers, we were very excited to launch the revised and updated *Heart & Soul: An Introductory Guide for Families Living with Congenital Heart Disease.*[1] This guide is in a printed format, given to newly diagnosed families at the BC Children's Hospital, but also comes in an online version on our website. It was developed by heart families and medical professionals for new heart families but will also benefit many that are still on their heart journey.

Some of our fundraising events were held online, including the 50/50 draw and the Sid Dickens Memory Blocks Auction, but we were thrilled to host our wine gala in person in April at the Terminal City Club after not doing so for two years. And what an event it was! Emceed by

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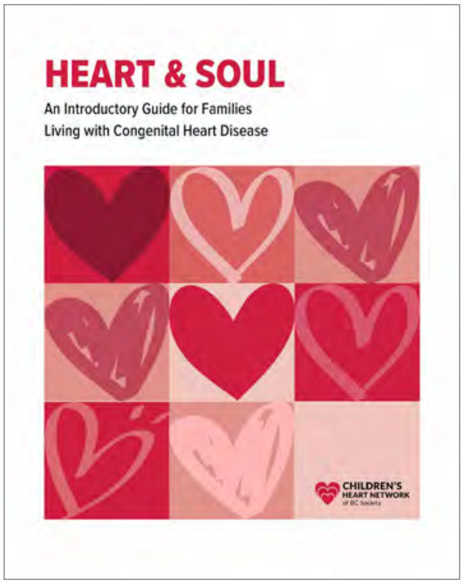
[1] https://www.childrensheartnetwork.org/heart-soul/

heart dad and *Yellowstone* actor John Emmet Tracy, with Fred Lee as his sidekick (what an incredible auctioneer!), we raised almost $100,000. In addition to our fundraising, we were fortunate to receive grants from the BC Gaming Commission, the CKNW Kids' Fund, and the Triple Crown for Heart.

The year ended with an exciting opportunity for us to send Samantha Aitken, our provincial coordinator, to a meeting in Toronto this past December, which was hosted by the Heart and Stroke Foundation of Canada. This important first roundtable was a strategic opportunity to help build a congenital heart disease (CHD) strategy, with the goal of ensuring that by 2030 people in Canada with CHD and their families will have equitable access to high-quality, personalized, and integrated health services and knowledge across their lifespan. The roundtable brought together people with lived experience of CHD with some of Canada's leading clinicians, researchers, and system leaders from across disciplines and the continuum of care. The strategy emerging from this meeting will support the advancement of provincial and regional CHD systems of care through national collaboration.

We would like to thank our many volunteers, donors, sponsors, and partners for their support, without which our activities and programs would not be possible. We are excited to continue to grow the membership of the Children's Heart Network in 2023. Wishing you all a very healthy and happy new year! ♥


HEART & SOUL

An Introductory Guide for Families
Living with Congenital Heart Disease

CHILDREN'S HEART NETWORK of BC Society

2023 Pediatric Cardiology Outreach Schedule

The BC Children's Hospital's community outreach program has been bringing cardiac care closer to home for pediatric cardiology patients since 1995. The outreach program provides specialized cardiac care by a multidisciplinary team from the Children's Heart Centre to children with a wide variety of conditions in their own community. Infants, children, and teens with a suspected non-acute cardiac condition and those with an established diagnosis of congenital heart disease requiring routine follow-up care are eligible for referral to the outreach program. In addition to the twice-weekly Fraser Health cardiology outreach clinics, our Heart Centre team is preparing to travel 28 times in 2023, and we are looking forward to partnering with families and health care professionals across BC and Yukon!

Month	Locations
January	Penticton, Whitehorse, Prince George
February	Kelowna, Kamloops
March	Terrace, Cranbrook, Vernon
April	Prince George, Kamloops
May	Williams Lake, Penticton, Prince George
June	Kelowna, Whitehorse
July	Vernon, Terrace
August	Kamloops, Prince George
September	Trail, Fort St. John, Kelowna
October	Penticton, Prince George
November	Kamloops, Kelowna, Terrace
December	Vernon

Subject to change. ♥

Compounding Pharmacies

Compounding is a way for physicians and other health care professionals to order custom medications for their patients. Infants and toddlers often require compounding to convert medicine into liquid form. The compounding pharmacist combines the necessary ingredients into the form the doctor has ordered. At one time, nearly all prescriptions were compounded. With the advent of mass drug manufacturing in the 1950s and '60s, compounding rapidly declined. The pharmacist's role as a preparer of medications quickly changed to that of a dispenser of manufactured dosage forms, and most pharmacists were no longer trained to compound medications. However, the "one-size-fits-all" nature of many mass-produced medications meant that some patients' needs were not being met.

Fortunately, compounding has experienced a resurgence as modern technology and innovative techniques and research have allowed more pharmacists to customize medications to meet specific patient needs.

Trained compounding pharmacists can now personalize medicine for patients who need specific:

- Strengths
- Dosage forms
- Flavours
- Ingredients excluded from medications due to allergies or other sensitivities

In addition, you can compound Tylenol (no prescription required). Pharmacists require the current weight of the child. Do-it-yourself compounding at home (i.e., making your own solution) is not advised and can be dangerous.

Many of our heart children and their families require or find it helpful to compound medications (as prescribed by their doctors). To find a compounding pharmacy near you, visit https://acpcrx.org/find-a-pharmacy/. ♥

What's Happening?

February Is Heart Month!

To raise funds that will help us run the many programs that support heart families in BC, we will be having a 50/50 draw. The draw starts on **February 1** and runs until **February 24**. The winning ticket will be drawn at noon on **Saturday, February 25**, at West Coast Kids, at 4428 Main Street in Vancouver. The winner will be notified that day. Get your tickets, and use the link below to spread the word!

https://trellis.org/heart-month-5050-draw

Valentine's Chocolate Sale!

It's back! On **Monday, February 13**, we will be selling our famous Valentine's treats made by Daniel Chocolates in the lobby of the old BC Children's Hospital. Daniel Chocolates has a rich history of bringing chocolate tradition from Belgium to Canada. Their chocolates are made in Vancouver with more cocoa, much less sugar, and 100% natural ingredients. Filled with chewy caramel, velvety soft ganaches, and delightful truffles, their chocolates will leave a tasteful lasting impression you will remember with every bite! These Valentine's treats are both gorgeous and delicious, and all the profits will go to CHN.

Annual General Meeting

We invite all CHN members to join us for our annual general meeting on **Thursday, February 23, at 7:00 pm** at the old BC Children's Hospital, Room D210. Please RSVP to Sam at saitken@childrensheartnetwork.org.

Well-Being Night for Heart Parents

Wednesday, March 29, 7:00–9:00 pm

7:00–8:00 pm – Yoga class

8:00–9:00 pm – Tea and sweets; chat and connect with other heart parents

#290, 1275 Venables Street, Vancouver

Yoga mats are available. Wear comfortable clothing. There is no cost for CHN members, but please RSVP to Sam at saitken@childrensheartnetwork.org. ♥

CHILDREN'S HEART NETWORK
of BC Society

WOULD BE HONOURED BY
YOUR PRESENCE AT THE

19TH ANNUAL

FRIDAY APRIL 28
6 O'CLOCK PM

TERMINAL CITY CLUB
837 WEST HASTINGS