

HEART MATTERS



Kai's Heart Journey

By Dr. Sandy Barlow

Kai was what was considered a “late” diagnosis. His heart defect was not detected in prenatal scans. He spent his first few weeks in the NICU due to struggles with breathing but no one was able to give us an answer as to why he struggled at birth. The next few months he continued to breath irregularly and had frequent checks with our GP but we were told that likely he was “recovering” from whatever happened at birth. At 6 months, and as a heart murmur was very noticeable, we were seen by our now cherished pediatrician Dr. Cox. Kai looked ok, but what we couldn't see was that his body was struggling. A call was made to make an appointment with the only pediatric cardiologist on the island at the time, Dr. Sinclair.

I remember awaiting the X-ray results, knowing deep down this was the start of a long journey. Dr. Cox received a call from the radiologist, who asked if Kai was “the sickest kid in the hospital.” His lungs were filled with fluid, and he was in severe heart failure. We met with Dr. Sinclair the next day. With the department largely closed for Christmas, Dr. Sinclair performed Kai's first echocardiogram himself. The diagnosis was a severely dysplastic mitral valve. Kai's heart had been working overtime to compensate, but it was failing to do so.

Dr. Sinclair explained that Kai would need multiple surgeries. He hoped that a repair would be possible, but because it was so severely malformed, a replacement might be necessary, something he hoped to avoid at such a young age. It was overwhelming to learn that our seemingly healthy baby was critically ill. After starting medication, including a diuretic, Kai lost several pounds of fluid almost overnight, transforming from a chubby baby into an underweight infant. For the first time, his appearance reflected the struggle his heart had been fighting all along.

It was at that first cardiology appointment that we were given a brochure for the Children's Heart Network (CHN). While I appreciated the gesture, I didn't think we needed a support group. I tucked the brochure away and turned instead to medical journals and textbooks, hoping to find reassurance. What I found were the phrases “high morbidity and mortality”, clinical terms for a high risk of illness, disability, and death. The comfort I was searching for simply wasn't there.

continued on page 5

IN THIS ISSUE

KAI'S HEART JOURNEY

WHAT'S HAPPENING

SEEING STRENGTH IN SCARS

AN EVENING FOR EVERY HEART

THANK YOU TRIPLE CROWN!

HEARTS OF GOLD AND FAMILY CAMPS

WHAT'S HAPPENING

Coffee Groups Near You

If you would like to organize a coffee group for heart parents in your community, please contact Sam Aitken at saitken@childrensheartnetwork.org and we can get you set up with a coffee card for drinks and treats!

- ABBOTSFORD - Rupe Brah - rupe3395@gmail.com
- CHILLIWACK - Jenna Winterhoff - jennawinterhoff@gmail.com
- SURREY/LANGLEY - Ashlee Forero - ashlee.gugins@hotmail.com
- MAPLE RIDGE - Meghan Fabbi - safabbi@gmail.com
- NANAIMO - Sandy Barlow - sandygbarlow@gmail.com
- SUNSHINE COAST - Courtney Carolei - courtneycarolei@gmail.com
- VANCOUVER - Samantha Aitken - saitken@childrensheartnetwork.org

Hearts of Gold – Lower Mainland and Victoria

Hearts of Gold is a community for teens aged 13–18 who have congenital heart conditions. The group meets monthly for fun and engaging activities, including hockey games, ceramic painting, dinner and a movie, skating, bowling, Playland visits, and an annual trip to Camp Zajac.

If you are a heart teen or a parent of one and would like more information about joining a Hearts of Gold group, please contact the appropriate coordinator:

- Lower Mainland: Emily Deimling – chnheartsofgold@gmail.com
- Victoria/Island: Shae Mellors – viheartsofgold@gmail.com



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

This guide was developed by heart families and heart professionals for new heart families. [Read more here](#), or check it out on our website: childrensheartnetwork.org.

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ABOUT

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.

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.

CONTACT US

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Have you heard of MyBooklet?

MyBooklet BC is A FREE online tool that families and people with disabilities can use to create a beautiful and personalized information booklet for a loved one, a care-giver, a teacher or for themselves.

- *Are you tired of constantly repeating your "story" to doctors, teachers, therapists, friends and family?*
- *Do you wish all your important information was in one document?*
- *Do you wish you could share more than just the medical and diagnostic facts?*

If you answered yes to any of these questions, you'll want YOUR OWN myBooklet now!

It's as easy as 1-2-3

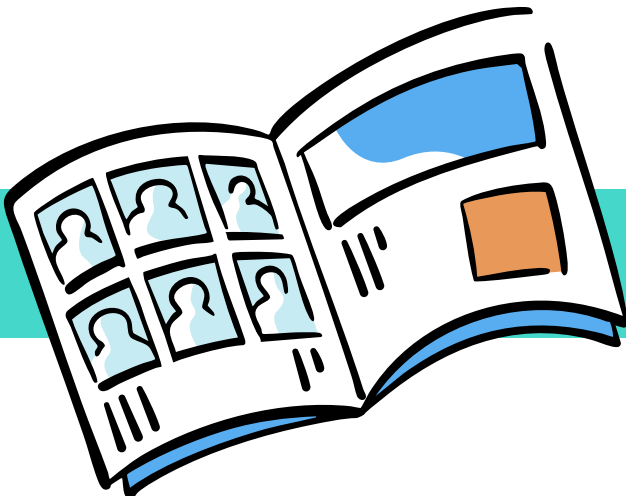
1. *Create a FREE user account.*
2. *Fill in the information.*
3. *Print and share YOUR OWN myBooklet!*

myBooklet BC was directly inspired by Julia, a vibrant and funny girl with complex health challenges. Julia has many gifts and strengths. She also has a very active life in her community.

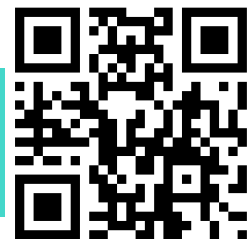
The Family Support Institute of BC (FSI) collaborated with Julia's family to turn Julia's booklet into a FREE online tool. Julia's family donated their booklet idea to FSI in order for all families to have access to this tool from anywhere in the province. Our goal is to help, support and inspire families and people with disabilities in BC to create a person-centered plan using myBooklet BC.

Julia's booklets are always about celebrating her skills and abilities and creating opportunities for her to lead a full and meaningful life in her community.

myBooklet BC creates opportunities for every person with disabilities in BC to have a rich life with active participation in the community, a strong sense of contribution and a social life free from isolation!



VISIT:
mybookletbc.com



Kai's Story (cont'd from page one)

By Dr. Sandy Barlow



Things moved quickly as plans were made for Kai's surgery. Nathan and I struggled to imagine what lay ahead. I could understand the medical details, but I couldn't picture what life after surgery would look like for Kai or for us. Every article and study seemed to lead back to the same phrase: "high morbidity and mortality." Those words shaped every vision I had of our future.

Kai made it through surgery, but there was no chance of repair, and he needed a mechanical heart valve, the least preferred option for his heart defect. Within weeks, we were home managing post-operative care and navigating life with a baby on heavy blood thinners, warfarin and aspirin, meant to prevent clotting on his valve.

A few months later, Kai woke unwell, and what began that morning became the longest day of our lives. We went to our local emergency department, but he deteriorated quickly and was airlifted to BC Children's Hospital (BCCH).

His mechanical valve had clotted, and the clot was progressing. He was in a critical state and not a candidate for surgery; the only option was clot-busting medication with significant risks. A hematologist simply said, "you know the risks" as I sat beside his ICU bed holding my breath. Kai survived, and weeks later we were home again, this time carrying even more uncertainty and fear.

I realized I needed different support and reached out to the CHN resource mom. I emailed her our story and received a simple reply: "I am so glad that you reached out." Andrea, a mother to a heart child named Reid, introduced us to other heart families. It was the piece I had been missing, the "what does the future hold" part.

We met at Starbucks, where the kids played and laughed, and seeing them brought a sense of hope I hadn't felt before.

A few months later, Kai's valve clotted again. This time it was only on one side and was caught at a routine cardiology appointment. Still, we were back on a helicopter to BCCH, returning to the ICU and the same treatments. This time, though, my phone was filled with messages of support from our CHN community. Once home, we began attending more CHN events, including coffee nights. As Kai grew, he joined the other heart kids in running and playing, simply being children. Watching them outdoors was especially healing—on the surface, just happy kids laughing, with no visible sign of the medical challenges beneath. We welcomed new families, supported each other through surgeries, procedures, complications, and milestones, and grieved together when some of our heart warriors were lost.

Over the past few years, CHN has supported our family through events, Camp Zajac, and a growing community of heart families. Kai has loved camp, where he can be a kid alongside others who understand his journey, with medical support close by. He will soon join the Hearts of Gold program as he transitions into his teen years.

This past winter, as Kai prepared for another surgery, our CHN community rallied around us with support, cards, and encouragement. At pre-op, he was even given a personalized heart box from CHN. We received many check-ins and messages, and Sam herself reached out several times. People also checked in on Hilo, recognizing that siblings are often overlooked. Kai even had a visit from a heart friend in Vancouver who shares the same condition and understands his journey in a way few others can. We have been supported in ways that medicine alone cannot provide.

Kai has come so far since those early days of uncertainty. He is now a passionate soccer goalkeeper, something that makes us hold our breath even more, given he's on blood thinners. He plans to join Air Cadets at 12 and already mentors other children navigating medical challenges. He is an advocate (including media appearances), a fundraiser, and an ambassador for the BC Children's Hospital Foundation, supporting initiatives across British Columbia. Through his efforts, he has raised over \$8,000 for children's causes.

His 2026 Triple Crown for Heart fundraiser is currently open:



[Donate Today](#)

Seeing Strength in Scars

Body Image and Heart Surgery

By Dawn McKellar, BA, CCLS

A heart scar tells a powerful story—one of courage, healing, and resilience. One of our former Hearts of Gold teens describes it like this: *“I would describe the story of my scar to a new person as exactly what it is, saying that I was born with a congenital heart condition and this scar is from a surgery I had when I was a kid,”* ~ Kailen. For children and youth with congenital heart disease (CHD), a surgical scar is often a lasting reminder of hospital stays, procedures, and moments that may have felt overwhelming. Even after the body has healed, the scar remains. It can bring up a mix of emotions over time, from pride to uncertainty, especially as children grow and become more aware of how they look and how others might see them.

Body image refers to how we think and feel about our bodies. It’s shaped not only by what we see in the mirror, but also by our experiences and the reactions of others. Research shows that body image begins developing early in childhood and becomes especially important during adolescence, when peer relationships, social comparison, and physical changes all intensify. For youth with visible differences, such as surgical scars, this stage can feel more complex. Some may feel self-conscious or worry about standing out, particularly in settings like school, sports, or social activities. As another former Hearts of Gold youth shared, *“When I was younger I hated my scar showing. As I got older, I looked at my scar and said, no—I should be proud of my scar, as it shows who I am, and I am not afraid to tell my story.”* ~ Jillian

Studies in paediatric psychology suggest that how young people interpret their experiences plays a key role in their emotional well-being. Adolescents who practice self-kindness and balanced self-reflection tend to report healthier body image and greater confidence.



Kailen, mentioned earlier, reflects this gradual shift: *“I felt that not one experience made me more comfortable but rather over a duration of time, going to the gym and working out helped me feel more confident in my scar—proving to myself that my scars are only a small part of me and my story. I slowly changed from being uncomfortable seeing my scar, to being proud and confident every time I see my scar now.”*

His experience highlights the importance of **cognitive reframing** — learning to see something in a new way. Instead of focusing on a scar as something that makes them different, young people can begin to view it as evidence of what their body has been through— and overcome.

A scar, from a medical perspective, is simply the body’s natural way of healing after surgery or injury. But psychologically, it can take longer for that meaning to shift. Research with individuals living with chronic health conditions shows that when young people are supported in viewing their medical experiences as sources of strength rather than limitation, they often develop stronger self-esteem and better emotional adjustment. Over time, many begin to see their scars not as flaws, but as symbols of survival, skilled medical care, and the support they received from family and healthcare teams.

It’s important to recognize that acceptance doesn’t happen all at once. Children and teens may feel proud of their scar one day and unsure the next. Both reactions are normal. Positive body image in this context doesn’t mean loving every part of the experience—it means understanding that their worth is not defined by appearance. Strength and vulnerability can exist side by side.

Families and caregivers play an important role in shaping how children understand their scars. Research and clinical experience both highlight that open, supportive conversations can make a meaningful difference. When adults talk about scars in a calm, matter-of-fact, and even positive way, children are more likely to adopt that same perspective. Encouraging children to ask questions, express feelings, and share their story helps build confidence over time. Opportunities to connect with peers who have had similar experiences can also reduce feelings of isolation and reinforce a sense of belonging. As Jillian shared, *“My friends helped me feel confident in my body as I was growing up. My friends and family helped me feel proud of who I am.”*

Seeing Strength in Scars (cont.)

By Dawn McKellar, BA, CCLS

As children grow into adolescence and adulthood, many describe a gradual shift in how they view their scar. What may have once felt like something to hide can become something meaningful—a visible reminder of resilience. Some even describe their scar as evidence: evidence of survival, of the body’s ability to heal, and of a life made possible through care and perseverance.

For children and youth living with CHD, the journey toward positive body image is ongoing. With support, understanding, and space to explore their feelings, they can come to see their scars not as something that takes away from who they are, but as part of a much larger story.

A story of strength.

How to Support Your Child When They Want to Talk About Their Scar

When your child comes to you to talk about their scar, try not to feel worried or unsure — this is a positive sign that they feel ready to have the conversation. Meet them where they are, and let their questions and feelings guide the discussion.

As you talk, gently help reframe what the scar represents. Instead of something to hide, a heart scar can be seen as:

- A symbol of bravery - ‘you went through something incredibly hard’
- Proof of healing - ‘Look how hard your body worked to recover and grow even stronger than it was before’
- A unique story - ‘everyone’s heart story is unique just like your scars, let’s talk about your story’

Resources from the KidsHealth website (www.kidshealth.org) suggest that open conversations and normalizing differences can help children build self-esteem and feel more comfortable in their own bodies. When talking about scars, here are some helpful points to keep in mind:

- Use positive language
- Invite your child to share their story
- Encourage creative expression as a way to understand their scars
- Encourage connection with peers - giving the opportunities to share their stories with those with similar experiences

A note on withdrawal: if your child begins to pull away from activities they once enjoyed (such as swimming), avoids social situations, or shows ongoing distress related to their scars, congenital heart condition, or body image, it may be helpful to seek additional support from a counsellor or psychologist. Speak with your child’s cardiology team to explore available support options.



FINDING SUPPORT IN BC

1. Family Support Institute of BC – We connect families of persons with disabilities with resources available to them; just select your criteria and get started. BC’s first user-friendly, searchable database of disability related supports, services and community activities.
www.findsupportbc.com

2. Find A Support Worker – A province-wide job board that helps people with disabilities find support staff.



How it works:

1. Create an account
2. Post a job
3. Explore profiles and message job seekers
4. Conduct interviews, check references, and hire support staff

www.supportworkercentral.ca

@supportworkercentral

An Evening For Every Heart – Our 22nd Annual Gala Dinner



We were thrilled to host our Gala at a beautiful new venue this year, **The Arras Ballroom** in Vancouver. This modern and elegantly designed space, featuring multiple levels and a lovely outdoor patio, provided the perfect setting for an unforgettable evening.

Guests were welcomed with beautiful grand piano music by **Susan Gillmore**, delicious passed canapés, and glasses of Prosecco generously donated by **Everything Wine**.

Our emcee for the evening, heart dad and actor **John Emmet Tracy**, greeted guests with his trademark wit and humour while sharing a glimpse into his family's own heart journey.

Throughout the evening, guests enjoyed an exceptional selection of wines provided by our wine sponsor, **Sage Hayward Vineyards**, paired perfectly with a delicious three-course dinner.

The formal program began with welcoming remarks from our Board President, **Tracey Carpenter**, followed by a touching video featuring many of our incredible heart kids expressing their gratitude to our sponsors. Guests then heard from heart mom **Dr. Sandy Barlow** and her son **Kai**, who shared their family's heart journey and spoke about the support they have received from the Children's Heart Network over the years. One of the evening's highlights was hearing Kai talk about his experiences at **Camp Zajac** and the many lifelong friendships he has formed there.

We were also honoured to present our **Heart Hero Award** to **Dr. Brian Sinclair**, Vancouver Island's dedicated pediatric cardiologist. For decades, Dr. Sinclair has supported CHN families with extraordinary compassion, empathy, and unwavering commitment, consistently going above and beyond for his patients and their families. As Dr. Sinclair was unable to attend the Gala in person, he sent a special video message recorded from one of his favourite fishing spots. In his heartfelt remarks, he shared the story of his journey into pediatric cardiology, reflecting on the experiences and mentors that inspired his career. He also expressed his deep gratitude for receiving the award and spoke movingly about the privilege and fulfillment he has found in caring for children and families living with heart disease throughout his remarkable career.



Dr. Sandy Barlow with her sons Kai and Hilo

Following dinner, our incredible auctioneer, **Fred Lee**, energized the room and inspired remarkable generosity from our guests. In a matter of minutes, he raised an astounding **\$48,500** for our "Send Kids to Camp" initiative and helped generate an additional **\$20,000** through our live auction.



John and Alia Tracy

The excitement continued with our popular **Cork Draw**. Guests who had purchased numbered wine corks were entered to win two Air Canada tickets to anywhere Air Canada flies within North America, including Mexico, Hawaii, and the Caribbean. On behalf of Air Canada, **Captain Darren Nadeau** was delighted to present the prize to our lucky winner.



The amazing Fred Lee

To cap off the evening, guests enjoyed professional black-and-white portraits to take home as keepsakes before hitting the dance floor and celebrating late into the night.

Thanks to the extraordinary generosity of our sponsors, donors, volunteers, and guests, the Gala raised **just over \$109,000 net of expenses**.

These funds will help keep the Children's Heart Network pumping strong for another year. CHN serves approximately **1,000 families across British Columbia**, providing support, connection, education, and programs for children and youth living with congenital and acquired heart conditions.

We are deeply grateful to everyone who donated prizes, sponsored the event, volunteered their time, attended the Gala, and supported our mission. A special thank you goes to the many heart families who continue to stand beside CHN year after year. Your generosity, commitment, and belief in our work make all the difference.



Kai, Captain Darren Nadeau and the winner of the Air Canada tickets, Patty Rippel

Thank you to all of our Sponsors this year!

Gold: BC Children's Hospital Pediatric Cardiology Group | Dr. Sinclair and Dr. Young | Hayward Sheppard Barristers & Solicitors | Explore World | Raven Excavation | Westmont Construction | Harken Towing | Dolce Amore

Silver: TD Bank | Tennis Goat 100

Bronze: Notion CPA | Regent Security Services

Heart Heroes/In Kind Sponsors: MEM Services | Dang Good Booths | Mei Mei Florists | Prospec Production Services | Big Heart Baker

Nurses Table: Michael Judge and the Cooney Family

Wine Sponsors: Sage Hayward Vineyards | Tim Wispinski | Everything Wine

Decor Sponsor: Social Ingredients

Print Sponsor: Third Eye Productions

Photography: Nathalie de los Santos

The CHN would like to extend our gratitude to our dedicated Gala Coordinators, Serena and Tatiana Mawani, whose incredible teamwork and commitment made this event such a success. We are also deeply thankful to Dee de los Santos our Production Manager, and to Deepti Advani, Tushar Biware and Zahra Ladha for their outstanding leadership managing our auction.

A special thank you goes to our RBC volunteers and to all of the helpers who generously contributed their time and energy throughout the day and evening. Your hard work, enthusiasm, and support were instrumental in making the Gala a memorable and successful event. We sincerely appreciate each and every one of you. Together, we are creating brighter futures for children and families living with heart disease.



With Heartfelt Thanks to Triple Crown for Heart



The Children's Heart Network (CHN) extends our sincere thanks to the Triple Crown for Heart organizing committee, riders, volunteers, and donors for their continued commitment to heart families across British Columbia.

Can you imagine riding your bike up 3 mountains in one day? Seymour, Grouse and then Seymour again? Some of our Heart Centre cardiologists, surgeons and healthcare professionals are doing this in support of our kids! The funds raised go to many different initiatives that support the BCCH Heart Community including our CHN Camps.

The Triple Crown for Heart donates the money raised to both the Children's Heart Network and BC Children's Hospital Foundation. **Recently they presented a cheque for an incredible \$33,000 to the Children's Heart Network!** These funds will help support our children's, teen, and family camps, where families affected by congenital heart defects can connect, share experiences, and build lasting relationships. These programs create spaces where children and teens feel understood, and where families are reminded they are not alone.

The success of Triple Crown for Heart is the result of months of thoughtful planning and dedication by the organizing committee. Their hard work behind the scenes ensures the ride is not only well run and safe, but also welcoming and meaningful for everyone involved. We are deeply grateful for the time, care, and energy they give year after year in support of our community.

Volunteers play a vital role in bringing this event to life, from supporting riders along the route to cheering them on at the finish line. We warmly encourage members of the CHN and the congenital heart community to consider volunteering and being part of this inspiring day.

To everyone involved, thank you! Your generosity and dedication continue to strengthen our heart family community across BC and make these vital programs possible.

This year's ride will take place on July 18, 2026, **if you would like to volunteer** please email Marie Campbell at triplecrownforheart@gmail.com

[Donate today:](#)





Hearts of Gold at Camp Zajac

By Emily Deimling

This May our teen group, Hearts of Gold, met up for the annual Heart of Gold camp at Zajac Ranch in Mission for a weekend of packed fun and meeting new like-minded teens! This year, we had 21 teenagers attend between ages 13 to 19 years old.

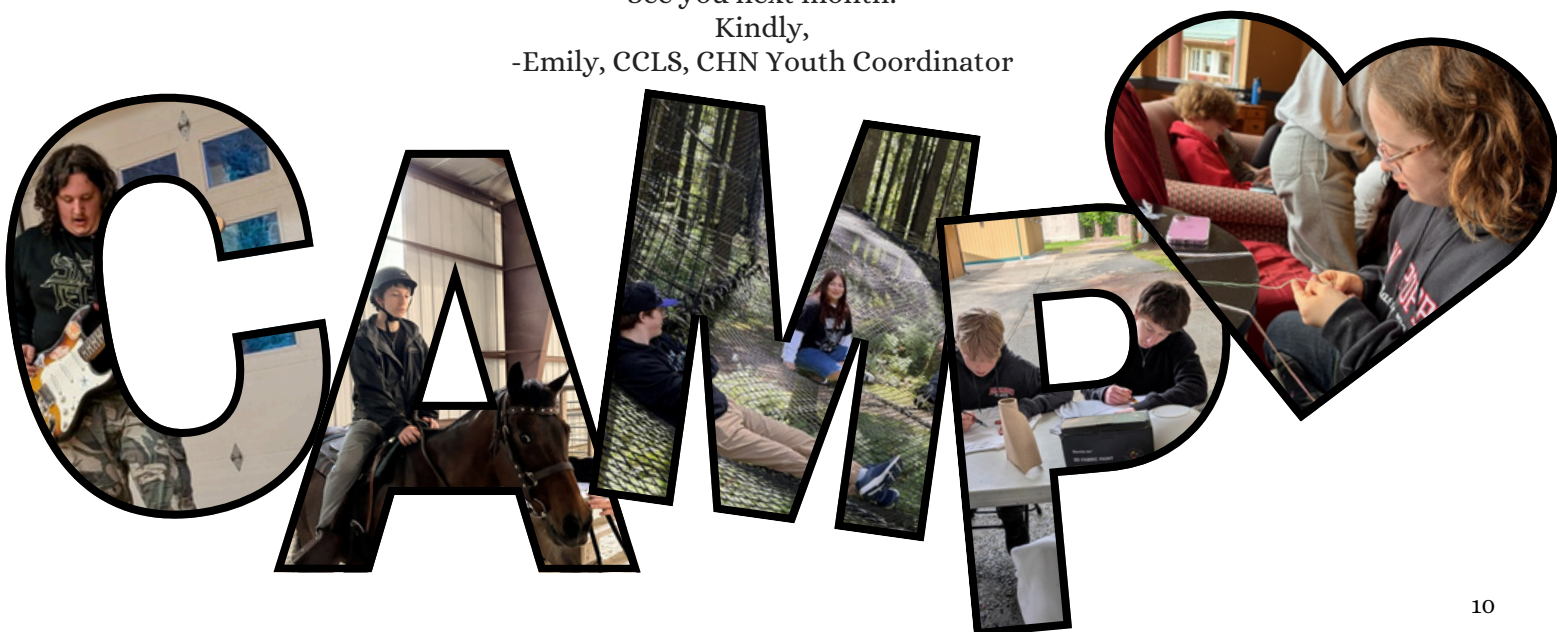
In past years, the rain has taken ahold of the weekend, but this year, we saw the SUN. This allowed for an Epic annual pudding fight, fun high ropes adventures, and even horse back riding for the first time in years!!

As we all know, it can be hard to start something new or be new in a group for the first time. This year at camp we had many new faces joining us for the first time. I will never not be impressed by the bravery this takes, to choose to come to camp for the first time. But at the end of camp, I witness beginnings of life long friendships that have a special bond. Being able to talk to each other about their heart conditions, swim with no fear, and be ourselves are key factors in this camp.

The talent was a rockin', fears were conquered, and friendships made at camp this year, hopefully with anticipation for next month's events and the camp years to come!

Thank you to everyone and parents, for their dedication to getting the teens to camp this year. We could not do this without you, as a group of families to help make this successful.

See you next month!
Kindly,
-Emily, CCLS, CHN Youth Coordinator



Family Camp at Camp Kawkawa



This year, we hosted our annual Family Camp at Camp Kawkawa near Hope, BC, welcoming 19 families from the Lower Mainland, Vancouver Island, the Sunshine Coast, and the Okanagan. It was a wonderful weekend filled with fun, connection, and lasting memories.

The weekend kicked off Friday evening with a campfire, s'mores, and the chance to reconnect with old friends while welcoming new families into our heart community.

Saturday was packed with activities for all ages, including crafts, archery, face painting, human foosball, kayaking, swimming, and a very special visit from Wild Education. Their team introduced everyone to an incredible collection of animal ambassadors including a chinchilla, lizards, snakes, and a tortoise. They shared fascinating facts about each one and gave families the opportunity to interact with these amazing creatures.

One of the creative highlights of the weekend was making beautiful string heart art using nails, wood and colourful yarn. Each child left with a unique keepsake to remember the weekend.



While the activities were a great deal of fun, the true heart of Family Camp was the opportunity to connect with others who truly understand the journey of raising a child with congenital heart disease. The conversations, shared experiences, and friendships formed throughout the weekend were invaluable and reminded us all that no family has to walk this path alone.

A heartfelt thank you to Board Members Jackie Bonsal and Sonia Milbradt for hosting such an incredible weekend, and to Sanj Chetty for her outstanding organization and attention to every detail. Your dedication and hard work made this special weekend possible for so many families.

“This weekend was so incredible for our whole family! I'm always a bit nervous sharing about my daughter's past with CHD but it was so nice talking to other parents who went through similar journeys especially during COVID. Astraea had an absolute blast and is asking to go again and again! Thank you so much to the CHN and Kawkawa Camp!”

- Kailey Bertin



“Thank you so much for the invite to the family camp this year. Both kids had a great time! They didn't want to leave. There were so many outdoors activities we tried pickle ball and human foosball for the first time. Both were a highlight for the kids. The reptile guy and balloon/ face paint ladies smashed it out of the park! All the kids were talking about it with the biggest smiles on their faces. Even the adults got in on some of the face painting and holding the reptiles.”

- Mercedes Carrigan



What a wonderful weekend we had at camp! Thank you so much to everyone who helped make the camp possible!

- The Rietel Family ❤️

