



Zachary's Heart Journey

BY SABRINA ROBERTSON

We had feelings of anticipation and excitement about being pregnant, the same ones many first-time parents have. So we were worried when we went for our first ultrasound and heard there was an abnormality with our child's heart. He was diagnosed, in utero, with Tetralogy of Fallot, and everything changed from there.

We never thought we would know so much about a human heart.

Our baby was born by scheduled Caesarean section at 38 and a half weeks, weighing six pounds, seven ounces. He was quiet and a little gray in colour.

We were lucky. Zachary was a good baby. He wasn't fussy and he

was meeting certain milestones even though he was smaller for his age.

At three months old, Zach had a Tet spell at home. A few days later, after a scheduled appointment with Cardiology, we were admitted to hospital for observation. Three days later, on my husband's first Father's Day, we got a call from BC Children's Hospital. They were waiting for one of us to sign consent for our son to go in for his first heart surgery. Overnight, his oxygen levels had plunged. Zachary's first surgery provided a BT shunt to help improve the blood flow into his lungs.

At nine months old, when he was a little bigger and stronger, Zachary had an open-heart surgery to repair

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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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COFFEE GROUPS NEAR YOU

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

For more information please contact:

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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 Orphans' Fund for their generous support of our Heartbeats and Hearts of Gold camp programs.



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the hole between his left and right ventricle and shave some of the thickened muscle in his right ventricle.

After that, the plan was that we would see Cardiology on a yearly basis for regular checkups and again for a pulmonary valve replacement in his teenage years.

However, when Zach was five years old, we noticed that he had started to slow down and he wasn't quite his usual self. This led us back to Cardiology for an unscheduled visit. We learned from his echo that the outlet from the right ventricle had become obstructed again, making blood pressure in it too high.

Zach needed a second patch repair and another open-heart surgery. Then, at our eight weeks post-op visit, our cardiologist gave us the devastating news that, for a second time, the procedure had failed, and we were back to square one.

After much discussion, the cardiac team decided to place a stent within the obstruction. This would buy some time until Zach's pulmonary valve replacement. He was eight years old.

Fast-forward and now Zach is 14 years old. In the past year, we have been on an emotional roller coaster, preparing for his next surgery, a valve replacement.

After multiple stress tests and a cardiac MRI, plus a lot of back and forth with Cardiology and the interventionist team, we learned Zach was not an ideal candidate for the less invasive catheter-based procedure. This would have placed a stent-mounted valve through a vein in the groin. It

would have been very complex, given the way Zach's heart sits, the mechanical situation of his existing stent, and the space in his right ventricle.

Instead, we were presented with the option of doing a third open-heart repair in which the existing hardware inside his heart would be cleaned up, the patch would be replaced, and a homograft valve would be placed. This would make him a more suitable candidate in the future for a valve replacement, using the less invasive catheter-based procedure, should he need one.

And now we wait.

While the pressure in Zach's right ventricle is higher than normal, it is still in a safe zone.

There is hesitation in doing the valve replacement for a 14-year-old boy who is expected to go through a growth spurt. Mainly, there is a chance that Zach's body could view this valve as something to be turned to bone and calcify it, rendering this next surgery a failure too. So the cardiac team will continue monitoring him to see when he should proceed with that valve replacement, possibly in the next year or two.

And so, this is the incredible journey of our heart warrior.

We wouldn't be here able to share our story if it wasn't for the support of CHN. Zach was five years old when we first joined. I would go to some of the monthly coffee meetings and talk with other parents. As a family, we started going to fun events at the water slides, the Vancouver



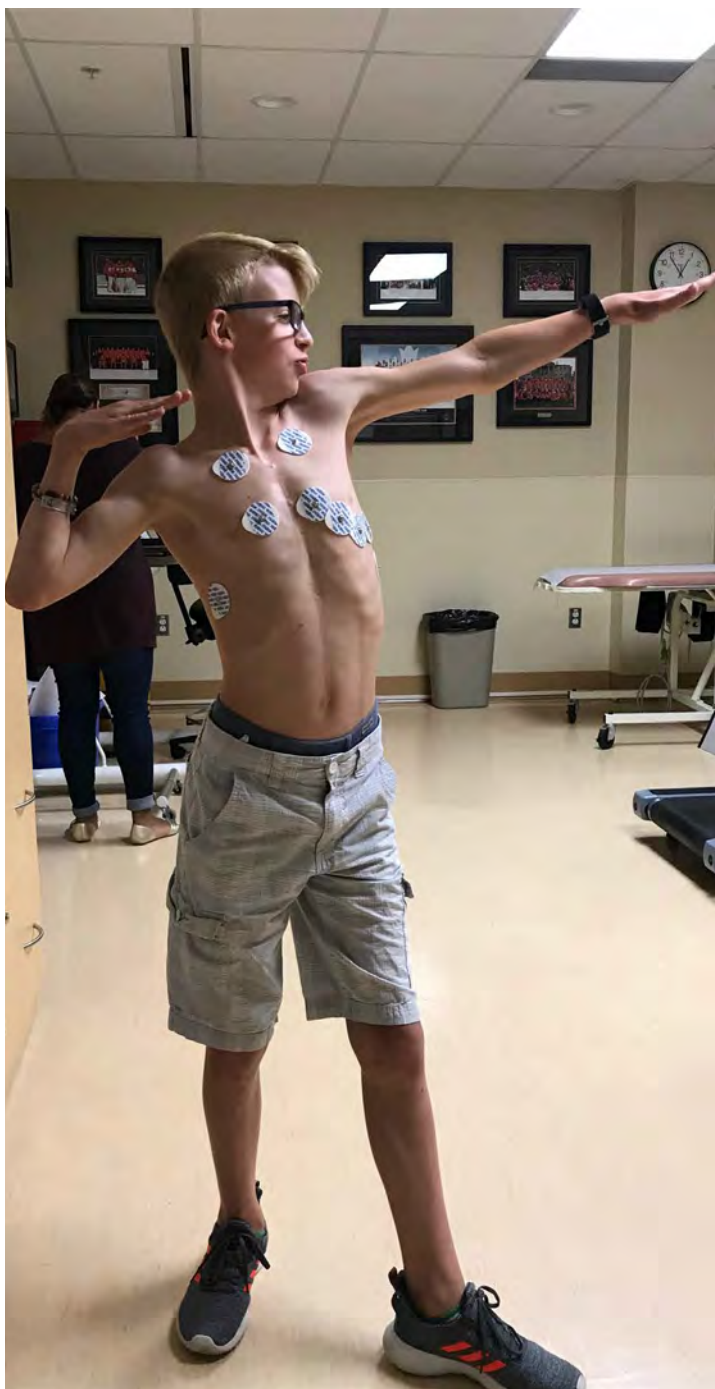
Aquarium, and the pumpkin patch, and having breakfast with Santa. We were fortunate to attend the fishing adventure at Critter Cove in Nootka Sound. I've been on the committee for the biannual Growing up with Heart Disease conference. I'm a resource parent and now sit on the CHN board as a member at large.

As Zach got older, we encouraged him to go to Camp Zajac for Heart Beats so he could be with and relate to kids his age that have gone through comparable procedures.

Zach has now graduated to the Hearts of Gold teen group, and in the past year, he joined some of their monthly outings. He has now been to Camp Zajac for two years, and this year, he attended his first HOG camp over the May long weekend.

Thanks to CHN, our family also had the pleasure of hosting the first family camp last September in the Fraser Valley at Camp Stillwood. We had a fun weekend, getting to know each other through crafts, games, rope walks, zip-lining, archery, and rock-wall climbing.

Through opportunities like this, CHN brings complete strangers together, quickly turning them into friends and extended family. It is a place for kids to be kids and to have a sense of normal, away from hospitals and tests. It lets parents give their child a full camp experience, knowing they are in good hands. It connects people who didn't go to med school and shouldn't have to know all this heart jargon, but who understand each other because of their similar paths. ♥





HOGs on the Ranch

BY ZOË GILLIARD

My name is Zoë Gilliard. I'm 16 years old and a member of Hearts of Gold. I was lucky enough to be able to go to Zajac Ranch over the May long weekend.

This year, the trip started on Friday. The Vancouver Island HOGs boarded the bus at the Tsawwassen Ferry Terminal while the rest of us met up with it in Burnaby. Some of our HOG friends who live further east met us at the ranch.

I'm part of the Lower Mainland HOGs, and we get to do all kinds of amazing things throughout the year: Go Kart racing, the Christmas carol cruise around the Inner Harbour, Playland and the PNE, kayaking . . . you name it, and HOG does it!

But Zajac Ranch really is the highlight of our year, and you could feel the excitement building the minute you stepped onto the bus.

When we arrived, we got organized quickly. We gave all our meds to Meghan, who dishes them out like a sergeant major throughout our stay. Then, we set up our bunks and relaxed until dinner time. There was a lot of catching up to do because we only get to see some campers, who come from outside of the Lower Mainland, once a year.

We ate all our meals in the dining hall, where we sat six to a table with our friends. After dinner on Friday, the campfire brought all of us together at the amphitheatre, where we made s'mores and told memorable stories.

On Saturday, I woke up at 6 am, ready to go! Unfortunately wake-up time was not until 8 am, so early risers like me have to pass the time quietly until breakfast. Thankfully, by 7:30 am, everybody got hungry and the cabin was considerably louder. At 8:30 am, with morning meds taken, everybody rushed to the dining hall

for breakfast. Afterward, Cole, Kristi, and Meghan led assigned groups, making sure we were all grouped with our friends for the day's activities.

This was my second time at Zajac with HOG and my fourth in total, as I got to go twice before with Heart Beats when I was younger. The trips with Heart Beats run from Monday to Friday, so they are a little longer than the four-day HOG trips. However, the younger groups are larger in size and they are mixed medical camps with more than just heart kids, meaning there is less time for each activity. The smaller HOG-only group stays for less time, but we get to chill for longer on each of the cool activities.

The all-time favourite activity is the Skynet. It's like a trampoline with two levels in the trees. If you are scared of heights, you can go on the lower level. There's no judging because lots of people stay on the bottom level. Sometimes, we just sat and relaxed in the tree in the Skynet. Other times, we cranked up the energy and played games like dodgeball. Other popular activities include the high ropes, horse riding, archery, and swimming. The great thing is you can try all of them.

After two activities, it was lunch time and everybody was ready to eat! Then, it was quiet time. Some took naps while others just relaxed. Break time was followed by two more activities in our groups. At 4 pm, we all gathered to swim in the indoor swimming pool. We all complained that the water was cold, but soon got warm. Plus, there was a hot tub, which helped.

After two happy hours in the pool, we went for dinner and exchanged stories with friends about how the day went. The second night there was no fire at the amphitheatre, but there were lots of fun activities such as singing contests and games with the camp leaders.

All through camp, Devon directed an ongoing reenactment of *The Lion King* and assigned us roles, which we enthusiastically adopted. Once again, I was proudly “hired” as Pumbaa, the warthog. I took my role very seriously and knew all Pumbaa’s lines. I was happy that Devon didn’t “fire” me from my role.

Sunday ran like Saturday. We got to try more great activities with our groups. The highlight, however, was the big event of the afternoon: THE PUDDING FIGHT!

Dressed in our bathing suits, some of us sitting in wheelchairs covered in many layers of plastic, we covered each other in chocolate pudding, shaving cream, and lots and lots of water. This fight is always a scream and by far the most fun part of camp! We chased each other around with hoses, water guns, and buckets. We zipped along the

slide downs. It all ended with a shower before heading, once again, to the pool.

After Sunday dinner, it was time for the talent show. The leaders did a great job of encouraging us to participate. I had a lot of fun, listening to everyone sing, act, and make us laugh. My favourite part of the evening was when we all stood on stage as one big group and sang “Girl on Fire”! It felt like we were one big family. We rounded off our last night together with Movie Night, watching *Ralph Breaks the Internet*.

Our final morning fell on Victoria Day Monday. We packed and cleaned the cabins after breakfast. We said some of our goodbyes at the bus and some of them later.

It was another brilliant long weekend at Zajac. Thank you, Children’s Heart Network! ♥



After the famous pudding fight!



Thunderbird Family Camp

BY MELISSA O'BRIEN

This was our first time at Camp Thunderbird and only our second time attending a Children's Heart Network event. What a great experience and invaluable opportunity to meet some other heart families. Coming from Comox, we've met very few heart families over the past nine years since my heart child was born. After our three-hour drive, we arrived at Camp Thunderbird, which is large but feels very much rustic and deep in the woods. We were greeted by an enthusiastic YMCA camp leader in addition to our CHN host Krista. Each of our three kids was given a collection of fun goodies that provided endless entertainment throughout the weekend. All five of us were given T-shirts. Immediately it felt like we were being welcomed into a supportive group that we'd been longing for—a group of parents and families like us, who in our experience to date, have been very few and far between. After settling into our cabin (full of six sets of bunks, a bathroom, and a shower), dinner followed and we had the chance to meet the other heart families in attendance. I found myself observing them at dinner, wondering what their experience has been, how they've managed the stress and triumphs, and how their other children have fared. It's definitely a different journey as a heart family and it was comforting to be in among people who understood, even if I didn't know them yet.

Over the course of the weekend, there were all sorts of activities, including archery, rock climbing, paddle boarding, canoeing, kayaking, and evening campfires. With all of our meals provided and schedules planned, there was a lot of room for family time in addition to time where we could engage with the other families. The evening campfires were incredibly entertaining with the camp leaders providing songs and improv skits that our kids are still singing and raving about even now that we're home. Being the introverts that we are, a weekend is a short amount of time for my husband and me to truly connect with others, but knowing from the start that we already had a very personal thing in common with each of the other families (our heart child), this gave way to meaningful conversations that might otherwise have taken longer to unfold. It was on the second evening that I met another heart mom that I really connected with. Although her son's diagnosis was much different than that of my son, our journeys had so many cross-overs (our child's life full of assessment, medication, other diagnoses being added to the mix, sibling dynamics, etc.). I found that I just wanted to keep talking with her. I could relate to her in ways that I can't with even my closest friends. Our conversations that evening and the next day were not long, but to know somebody else nearby who knows what it feels like in these shoes is the best thing that

I came away with from Camp Thunderbird. As for my kids, I don't think they thought too much about the emotional side of it all. They had so much fun experiencing new activities and living camp life that their biggest takeaway is their wish to return next year. Thank you, Children's Heart Network, for having given our family this very unique opportunity. ♥



Finding Resources to Support Child, Youth, and Family Mental Health

BY BRYN ASKWITH, PROGRAM MANAGER, BC CHILDREN'S KELTY MENTAL HEALTH RESOURCE CENTRE

Physical and mental health are closely connected and can very much influence one another. For parents and caregivers supporting children and youth with CHD, or children and youth living with CHD, it is understandable that both may experience more psychological and emotional challenges. Increased stress, anxiety, depression, sleep challenges, and little time for self-care can be a reality, all of which can impact overall mental health and well-being.

Helping children, youth, and families connect with

information and resources to promote mental health and wellness is important. BC Children's Kelty Mental Health Resource Centre provides mental health and substance use information and resources, help with mental health system navigation, and peer support to children, youth, and their families from across the province. We also provide these services to people of all ages with eating disorders or disordered eating concerns. All services are free of charge. You can reach the Kelty Centre by phone (1-800-665-1822), in person, or by email (keltycentre@cw.bc.ca). ♥



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How can we support you and your family?

Peer support

Wherever your family is in your mental health journey, you may want to talk to someone who has been through something similar. The Kelty Mental Health Resource Centre offers non-judgmental, compassionate peer support to families, caregivers, and youth. Parent and youth peer support workers with lived experience in mental health can discuss coping strategies, self-care, and helpful resources. Connect with a peer support worker 9:30 am–5 pm by phone (1-800-665-1822), in person, or by email (keltycentre@cw.bc.ca).

Online resources and tools

Through websites we offer online tools (e.g., apps, videos, toolkits, podcasts) and connect you to provincial mental health services.

- keltymentalhealth.ca – Contains evidence-based information created by trusted health experts at BC Children's Hospital to help parents and caregivers, schools, and health professionals support child and youth mental health and wellness.
- foundrybc.ca – Foundry offers young people ages 12–24 health and wellness resources, services, and supports—online and through integrated service centres in communities across BC.

For mental health challenges that may be a part of the journey for heart families, below are some additional resources that can help. These resources (all available at keltymentalhealth.ca) were featured in a CHN presentation in February 2019, Finding Resources to Support Child and Youth Mental Health. The presentation is available from the “Helpful Links” tab on CHN’s website.

Stress

- stresslr.ca – an online tool for kids ages 9–11 that provides a fun and engaging way for children to learn about stress, understand how they react to it, and develop healthy strategies to cope with stress in their daily lives.

Anxiety

- *Taming Worry Dragons*, a manual for children, parents, and other coaches – <https://keltymentalhealth.ca/twd>

- Breathr mindfulness app – <https://keltymentalhealth.ca/breathr>
- MindShift CBT app – <https://keltymentalhealth.ca/r/mindshift-cbt>
- Kelty's Recommended Resources: Anxiety – <https://keltymentalhealth.ca/collection/keltys-recommended-resources-anxiety-parentscaregivers>

Depression

- Hidden Depression in Children & Youth; Pinwheel Educational Webinar (video) – <http://mediasite.phsa.ca/Mediasite/Play/fcc12ff092d94a36a53093212a28713b1d>
- Kelty's Recommended Resources: Depression – <https://keltymentalhealth.ca/collection/keltys-recommended-resources-depression>

Sleep

- Healthy Living Toolkits for families – <https://keltymentalhealth.ca/toolkits>
- Kelty Podcast, *Where You Are*, Episode 4: “Healthy Sleep Habits for Kids” (coming August 2019) – <https://keltymentalhealth.ca/podcast>

ADHD

- Rolling with ADHD – <https://healthymindslearning.ca/rollingwith-adhd/>
- ADHD Education Day 2018 (video) – <http://mediasite.phsa.ca/Mediasite/Catalog/catalogs/adhdeducationday2018>

Self-care resources

- Self-Care Tips for Parents – https://keltymentalhealth.ca/sites/default/files/self-care_flyer_for_parents.pdf

Stay Connected with BC Children's Kelty Mental Health Resource Centre for the latest in mental health and substance use resources and information:

- Subscribe to our podcast, *Where You Are*, at <https://keltymentalhealth.ca/podcast>
- Follow our social media channels and sign up for our monthly e-newsletter

The 17th Annual Children's Heart Network Wine Gala

BY HEGE BOLTHOF HOEGLER

Over two hundred guests, all dressed to the nines, were welcomed with bubbly and hors d'œuvres to the Villa Amato Ballroom on the evening of April 26 for the annual CHN wine gala.

The hall was beautifully decorated, with dim lighting and music playing in the background. The tables were adorned with crisp linen, silverware, orchids, and hearts made of red glass.

Around the room, there were 220 auction prizes and packages, including hotel stays, weekend getaways, spa and photo sessions, wine, wine tastings, and fridges. Professional art pieces and ones created by heart parents were also on full display, along with tickets for different sporting events, plays, and performances.

Guests mingled and bid on all these donated prizes. Many lingered over the unique Sid Dickens memory blocks hand-painted by CHN kids and teens.

To officially start the evening, emcee John Emmet Tracy welcomed everyone and introduced the first course: a wonderful frutti di mare salad paired with Sippin' Pretty, a white wine from Country Vines Winery in Richmond.

This was followed by a West Coast surf and turf with delicious stuffed mushrooms, grilled peppers, and Orlando's Catering's signature puck potatoes.

In between courses, guests bid some more. Then, dinner ended with a strawberry gelato dessert from Mario's Gelati in the shape of a heart that was paired with Sandeman vintage port.

At the end of bidding for the silent auction, a team of 14 volunteers collected the paperwork and another group wrote up invoices for the winning bidders.

One of the most moving parts of the evening came when Sabrina and Zachary Robertson spoke of their struggles as a heart family. With photos rolling in the background, Zach reminisced about his time at Zajac Ranch. He talked about what it has meant to him to attend the heart camps and to meet other peers. Guests had tears in their eyes and the entire room gave Zach a standing ovation.

Finally, it was time for Fred Lee of CBC and *The Province*, our spectacular auctioneer, to do his work. With enthusiasm, he rallied guests to donate a record amount of \$32,000 toward our annual heart camps for children, teens, and families.

Other live auction items included a luxury champagne adventure in Whistler, an evening at home with dinner prepared by a chef and guests chauffeured via limo, and a Porsche ride to Squamish with breakfast and a picnic lunch. In all, the live auction raised over \$11,000.

Everyone always loves playing the "glasses game" in what has become a beloved tradition at the wine gala. Participants buy sparkly, heart-shaped glasses and guess if the toss of a coin will deem it a round to keep them on or take them off. The lucky winner received a \$1,000 gift card to Burrowing Owl Estate Winery.

There was also a draw of numbered wine corks for two Air Canada tickets to anywhere in North America,



including Mexico, Hawaii, and the Caribbean. This year, karma came through when the winner also happened to be one of the most generous donors of the evening.

The total amount raised at the gala, minus all expenses, was an impressive \$86,610.

This will keep CHN pumping yet another year. It enables us to fill the summer and family camps, and also to work on renewing our educational material.

We serve 800 families in BC and will keep doing so thanks to everyone who supports the wine gala. We hope to see you next year. Please pencil into your calendars the night of Friday, April 24, 2020. ♥

A heartfelt thank you to our major sponsors:

The View Winery & Vineyards, Country Vines Winery, Pediatric Cardiology Associates, Dr. Brian Sinclair, Customplan Financial Advisors Inc., Hayward Sheppard – Barristers & Solicitors, Dean Alexander, Don Price, The Drinks List, TD Bank, Tom Lee Music, Cindy Thaler, Medtronic Canada, Air Canada



Auctioneer Fred Lee



Emcee John Emmet Tracy



Sabrina and Zachary Robertson

Heart Heroes: Cody Halfpenny

July 29, 1999 – January 15, 2018

The Cody Halfpenny Memorial Bursary was established in 2018. Each year, a graduate of the Abbotsford School District who has been affected in some way by organ donation will be awarded \$1,000 toward post-secondary studies. In 2018, the recipient was JJ Lane, one of Cody's best friends, who was deeply impacted by Cody. The 2019 recipient is Kris Malatinka.

Cody was born in July 1999 with severe heart defects. By the time he was two years old, he had gone through four open-heart surgeries. Despite this, he was the happiest, funniest kid you could meet. At age 13, he suffered a stroke during a cardiac surgery that badly damaged his heart. At age 16, he received a heart transplant. Life was finally looking up. Sadly, he passed away in 2018 at the age of 18 when his body rejected his hero heart.

Cody never let any of his heart defects or disabilities get him down. He remained positive and happy right up until the end. He enjoyed riding his ATV and his Sea-Doo and spending time at his cabin. He loved hanging out with his brother Tyler and his Hearts of Gold group. He was a role model to all those that knew him and he is missed every second of every day. ♥



What's Happening?

Vancouver Island Family Camp – June 6–8: Our second annual weekend for the entire family to connect with other heart families will be held at Camp Thunderbird in Sooke. If you missed the registration date for this year, make sure you are on our email list for next year!

Cultus Lake Waterpark Family Picnic – August 24: This year, we are organizing a bus to bring our Island families to Cultus Lake. It will pick up at Tsawwassen ferry terminal so families can come from Duke Point or Swartz Bay. For more information or to RSVP and get tickets, please contact Sam at saitken@childrensheartnetwork.org and ensure your CHN membership is up to date.

Self-Care Circle for Heart Moms: One evening in September (date to be determined), CHN will be hosting an evening in Vancouver. It will bring together about 10 to 15 heart mothers in a casual, intimate, and comfortable setting to share feelings, experiences, challenges, and successes in bringing up children with heart disease. The focus on self-care is a holistic one with an emphasis on emotional well-being. Veronica Harris, a registered clinical counsellor, will lead the evening. If you are interested and would like more information, please contact Sam at saitken@childrensheartnetwork.org.

Lower Mainland Family Camp – September 27–29: This year, we will be hosting about a dozen heart families at Camp Stillwood near Cultus Lake for a fabulous weekend of fun activities, good food, and new friendships. Watch for the email invitation shortly! ♥