



Kai's Story

BY SANDY BARLOW

Kai was born on Friday the 13th, and despite the superstitions, I had always considered 13 to be my favourite number. He was born by urgent Caesarean section, as he was past his due date and a non-stress test showed that he was not coping well anymore. For the first few hours after birth he was managing life well, but soon his breathing became more and more laboured. His first days were rough, as he was on CPAP (continuous positive airway pressure with a mask) and teetering on needing intubation and a full respirator support, which would mean that he would have had to be transferred to either Victoria or Vancouver. All the tests, ultrasounds, etc. during pregnancy were normal, so doctors were a bit puzzled as to why he was struggling. In those first few days, we got a glimpse of the red-headed fighter as he improved, requiring less and less support, and after about a week we were sent home with our boy. No one could say for sure why he had struggled, but since he recovered without any interventions beyond CPAP, it was felt that he had “transient

tachypnea” (self-limited fast breathing after birth).

Our first months at home were relatively uneventful, and he was growing and smiling. His breathing continued to be off; he would sweat when he nursed and was a poor sleeper. He tricked many a doctor, as despite this, he was gaining weight and hitting growth milestones. We were reassured that he was just “healing” from whatever it was that had slowed him down at birth. As December approached, his breathing and eating struggles were worsening, and a heart murmur was heard. Kai was quickly seen by his now-regular pediatrician, Dr. Cox, and an X-ray showed that he was in serious heart failure. A few days before Kai's first Christmas, we met Dr. Sinclair for the first time at Victoria General Hospital. Kai was diagnosed with a severely dysplastic mitral valve, so he had severe stenosis and regurgitation. His left atrium had enlarged significantly to try to accommodate, and his lungs were taking the brunt of the extra pressure from blood not being

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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

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

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SIGN UP TO GET CONNECTED

If you have a child growing up with heart disease please email us at chn@childrensheartnetwork.org so that we can add you to our mailing list to receive invitations to all our fun events!

THANK YOU

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



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



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able to get from the lungs to his body properly. We were told that he would have to have surgery fairly soon, and he was put on a few medications, including Lasix (a diuretic/water pill). Almost overnight, he lost several pounds of retained fluid weight, and it was clear that our boy was not “growing well,” as he then fell off the growth curve. Mitral valve disease in babies is a tricky thing. If they can in any way possible, they will try to repair mitral valves, especially when they are still infants (even if only buying a few more years before replacement to allow babies to grow more). Replacement is tough, as tissue valves just do not last well or for very long in the mitral position in kids, and mechanical valves often do not fit properly in babies and then come with the required blood thinners of warfarin and aspirin. Early in the new year, the team at BC Children's Hospital met, and we were told that while they would try if at all possible to repair, Kai most likely would need a mechanical valve. This was very tough news for us, and so many questions and concerns. There are not a lot of babies who get mechanical valves. What we could find online was a lot of anxiety about warfarin, and the medical literature was not helpful or reassuring. Dr. Sinclair did connect us with a few families who had walked the mechanical valve journey, but only one had done so as an infant. Those early phone calls to other moms were most supportive and reassuring. Kai had his surgery in early February (yes, heart month), and unfortunately, Dr. Gandhi's only option was to place a mechanical valve.

Kai's first post-op year was not the smoothest. Warfarin is a finicky drug at the best of times, as diet, illness, and growth can all affect how it works, and it is even more challenging in a baby who is not even eating solids yet. We were well supported by both Dr. Sinclair and Dr. Halparin (BCCH hematologist) and the echo technologists, but our most important medical supports have been the nurses involved in Kai's care, including Anne (Victoria General Peds) and Deborah (Nanaimo Hospital Peds). Jane Braun, who was Kai's thrombosis nurse at BC Children's Hospital, helped in so many ways, from sorting through big highs and lows in INR readings, troubleshooting our home INR monitor (which is a positive game changer for anyone on warfarin), and advocating for Kai on so many occasions. We were sad to have to say goodbye to her when she retired last year. Kai unfortunately had two blood clots on his mechanical valve in his first post-op year that required

him to be air-lifted back to BCCH for clot busters (tPA) in the ICU. The first time he was really sick; both leaflets of his mechanical valve were clotted and getting worse with every hour that passed. We were lucky that the medications worked and he did not need emergency heart surgery, but those 24 hours had taken a toll on both him and us. He was then put on a higher anti-coagulation regime, and that came with its own set of challenges and anxieties. Soon, though, in what seemed like the blink of an eye, he was three years old, and life had settled enough to consider sending him to preschool or daycare.

We were so lucky to have connected with other local heart families through the Children's Heart Network when Kai had just turned one year old. My only regret was that I wished that we had connected sooner, right when Kai was diagnosed. To meet and see so many heart families who are thriving despite so many major diagnoses, big surgeries, and many obstacles has been an anchor to our lives. I joke that few people would know that our kids have heart conditions when they meet our crew at Starbucks, the pumpkin patch, the Vancouver Aquarium, etc. Such active, wildly wonderful kids just being kids. This year we had the opportunity to attend the Island Heart Families Camp, and it was so wonderful to meet even more Island families. What a gift CHN is!

Over the past few years, we have watched Kai grow, explore, and live every moment to the fullest (including starting school this year). Many of our worries about him not being able to participate in activities like other kids due to his heart and warfarin have faded away. Sure, things like contact hockey or football will not be a part of his life due to his increased bleeding risk, but few other activities are off the table. Letting him run, play, climb, ride his bike, and be an active boy has allowed him to develop his spatial abilities to balance, know his body, and reduce his risks of falling and getting hurt. We have a saying around our home of “no bubble wrap needed.” Kai faces a few more open-heart surgeries as he grows out of his mechanical valves, but we know that we are in good hands at BCCH and the travelling outreach programs here on the Island (it is so nice to see Dr. Sinclair closer to home when he comes up to Nanaimo Regional General Hospital) and that Kai and our family are supported by the Children's Heart Network and the families that makes it a thriving organization. ♥



Self-Care Circle

BY SAMANTHA AITKEN

On Thursday, September 19, we held our second Self-Care Circle evening for heart parents in the Vancouver area. This was a one-night retreat led by our facilitator, Veronica Harris, a registered clinical counsellor.

Board member Joelly Segal hosted us in her warm, welcoming home, and the evening was well attended with a total of 20 heart moms.

The evening's focus was "to nurture your own well-being. A night just for you, a time and space for you to find ease and comfort," while connecting with other heart moms.

By far, the most powerful part of the evening was the beginning. We each took the time to share a bit about our own family's personal heart journey.

For some moms, this was the first time they had ever shared their story and what they are going through with other people outside their immediate family.

For others, whose children are older, it was an opportunity to share how their child is doing now, as they are further down the heart journey path.

No one understands better than someone who has experienced similar challenges. There was empathy, love, and compassion in the room.

Veronica invited us to take a few minutes to "check in, to breathe, to relax, and to look a little deeper into what makes us us. When we can connect to our truths, to our values, to what is important in our lives, it can provide us with what makes life so meaningful to us. Doing this can also ease the everyday stress and reconnect us with what is truly important."

Another exercise focused on connecting with who we are, looking at our circle of life. We considered many factors: health, spirituality, community, career, finances, family, friends, fun and recreation, and our physical environment.

We rated how much each of these aspects was a part of our lives and whether we wanted to change those weightings. Did we want more or less of each of these things in our lives? This was a helpful tool in creating self-care goals for ourselves and moving toward the parts of our lives that are more important to us.

We talked about stress and anxiety and how we know when we are experiencing those feelings and how we can manage them. Noticing how our body feels can give us clues into feeling our emotions. How can we label those emotions, and what thoughts are running through our head when we are feeling stressed and anxious? What is the story you are telling yourself? Veronica suggested writing out this story as a way to help see where there might



be inconsistencies, assumptions, or any other means we might have taken to move away from our discomfort. She explained how important it is to recognize what is happening; to allow the experience to be there, just as it is; to investigate with curiosity and care; and to nurture ourselves with self-compassion.

We also talked about journalling and how it can be a powerful tool for connecting to our emotions. It can be flexible: a couple of sentences, a few words, a poem, doodles, or illustrations. It can often be a struggle to connect with others in our lives. Journalling can be helpful. We can get down on paper some of the complex thoughts and uncomfortable feelings or experiences that feel overwhelming. This can then help us validate the feelings and experiences and strengthen our awareness and can lead to stronger emotional resiliency. And we all need more of that!

Then we can communicate more easily with the other important people in our lives and gain insight into our own path.

The evening wasn't long enough. We enjoyed wine, coffee, tea, and treats, but most importantly, we left feeling more supported and connected to others walking down similar paths.

CHN hopes to host more Self-Care Circle evenings in the near future in both Victoria and the Lower Mainland. A huge heartfelt thank you to Joelly Segal for opening her home to us and to all the moms that took the time away from their families to make this evening such a success! ♥

Triple Crown for Heart 2019

BY SHAUN CARPENTER

The Triple Crown for Heart began in 2008 with a few employees from BC Children's Hospital and their friends asking themselves if it would be possible to summit all three North Shore mountains on a bike in one day. They conceived a route that is meant to look like a heartbeat on an EKG monitor, covering a distance of 75 km and over 2,000 m of elevation. To put it in perspective, this gruelling ride has the same elevation gain as Vancouver to Whistler! Well, the answer to their question was yes . . . it could be done, and it could also turn into something much bigger. The ride grew in volunteers, ridership, sponsorship, and notoriety every year, and this summer we celebrated the 10-year anniversary!

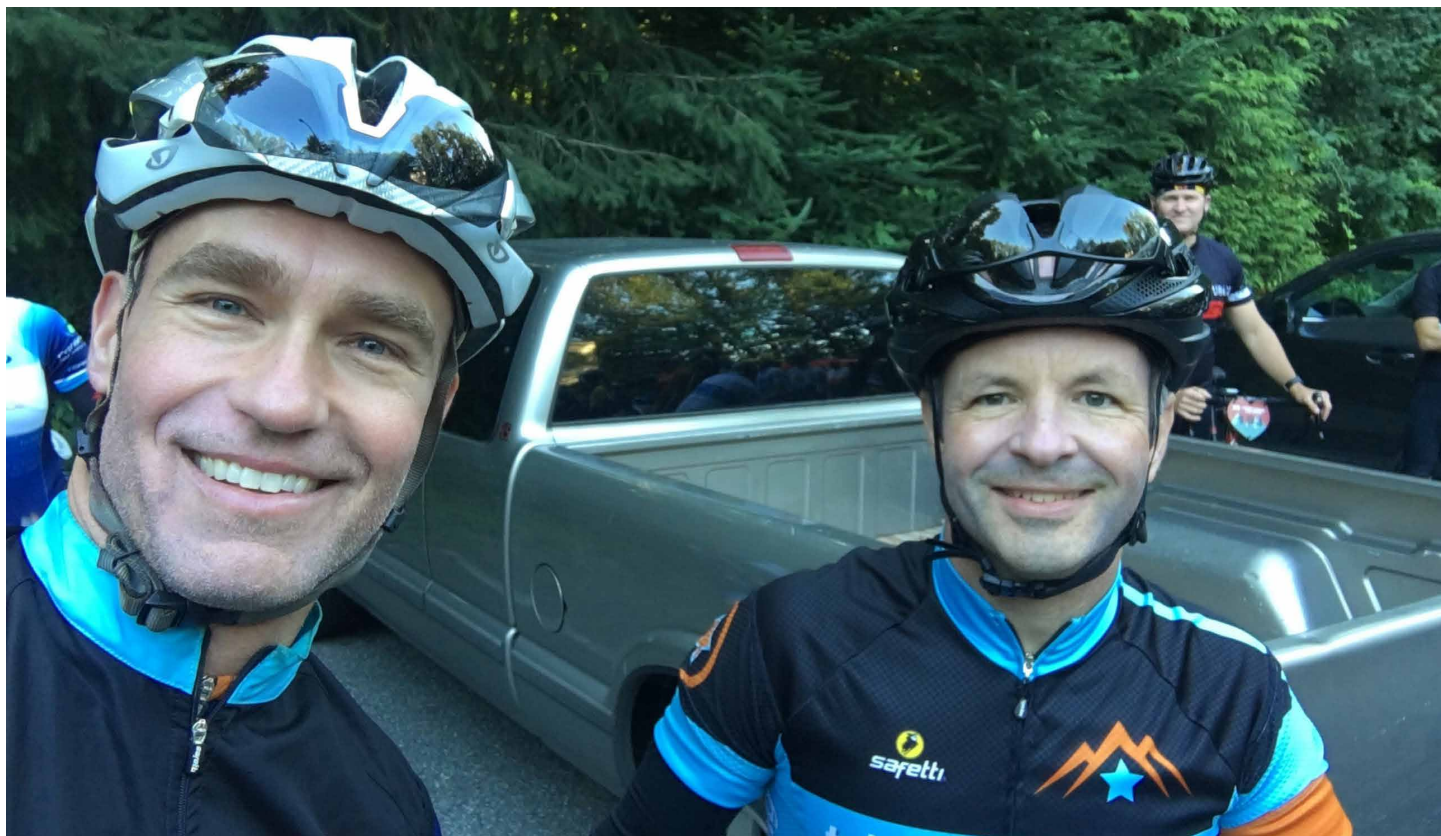
On ride day this year, the weather couldn't have been better, which probably contributed to the over 200 participants who showed up for our 8 am start at the base of Mount Seymour. Tackling the elevation is never easy, but it sure was made more enjoyable whenever I saw a smiling face or heard cheering from our amazing volunteers or the family members who were out on the course. We even had some European tourists near the Capilano Suspension Bridge who were yelling support as if we were riding in the Tour de France. Unlike two years ago when riders were wrapped in emergency blankets at the top of Mount

Cypress to generate some warmth, this year's sunshine made the BBQ a fantastic social afternoon to cap off a terrific ride and a huge personal accomplishment for many of the first timers who came out.

We ended up breaking every record this year in both ridership numbers and fundraising, and the donations continue to flow in. Our stretch goal was \$30,000, and total donations nearly hit the \$40,000 mark. With our partnership with the BC Children's Hospital Foundation as well as the Children's Heart Network, all the money raised goes to sending heart families to camp and to support initiatives within the Heart Centre and Critical Care Unit of the BC Children's Hospital. Thank you to all who make the event so amazing this year and every year since its inception.

Mark your calendars for our 2020 event, which will be on Saturday, July 18. If you aren't a cyclist, you can still support by volunteering or even just showing up to cheer the riders on. ♥

The Children's Heart Network would like to extend a huge "heartfelt" thank you to the Triple Crown for Heart for the fabulous donation, which will support many of our children's, youth, and family camps!



Heart dad Shaun Carpenter and friend Lance Richardson

The Importance of Rest and Play for Managing Stress and Creating Balance and Connection

BY VERONICA HARRIS

This time of year, transitioning back to school can be downright crazy for a lot of families. We shift from summer, where we spend a bit more time having fun, connecting with friends and family, and spending more time outside, to a full-tilt schedule of school and afterschool activities, personal obligations, and work. Structure and routine are great, and for the most part people and families thrive with some level of structure and routine in their lives, but when stressful moments arise in our lives, we depend on our routine to distract us from whatever that stressful issue is. We find ourselves as parents scrambling for the mental and emotional capacity to deal with the stressful issue and realize we are already functioning at capacity; we have no tolerance left for coping in distress. This is where rest and play come in.

What are rest and play?

Rest is truly a time to do nothing. It's a blank spot in your timetable to stop, reflect, and just be with you. It is also a time to sleep; it's true we need sleep. Rest can be a 10-minute break to sit outside at work, or it can be a few minutes to sit on the couch at home without turning on the TV, checking your phone, or going on the computer. It can be a short nap, just to recline and close your eyes.

Play is to do something just for the fun and enjoyment of it, with no goal or expected outcome. When we are in play, it opens us to being present, and it invites us to experience joy. For everyone play will look different; it might be reflected in your hobbies and interests or the relationships you have in your life. Play can be activities you do on your own, but it is also great when we can do them with other

people in our lives. When we share in play, we strengthen connections with our kids and partners, in turn deepening our bonds as a family.

Why are rest and play important?

Rest and play provide us the opportunity to clear our heads, process emotional experiences, and sort our thoughts. Although we might not be directly focused on the processing and sorting of thoughts, quite often it happens indirectly. Play inherently makes way for creativity and innovation, strengthening our ability to problem solve and navigate difficult decisions. Including more play in our lives also encourages us to be present and experience positive emotions like joy and amusement, which in turn helps to balance our lives when we are going through difficult times. During rest and sleep, our brain is able to process with less influence from the cognitive functions that are active throughout the day, also giving that cognitive part of our brain a break. When we get sufficient rest and sleep, we also increase our emotional resiliency, giving us a greater capacity to cope under stressful situations.

What gets in the way of rest and play?

So why do we keep ourselves from rest and play? For everyone it might look a little different, but for a lot of us we value productivity. Being a productive person means getting things done; when we get things done we see that as an achievement. We lead busy lives, in part because we value those achievements, so to make time for rest and play would mean we would need to value our own well-being. Sometimes slowing down is worth more than finishing a task, and to play would mean we could allow ourselves to experience joy.

Making space for rest and play, if it isn't easy to fit into your schedule, needs to be intentional. It needs to be looking at your day and making time to play, even if it is just 10 or 20 minutes, taking a rest at work or in your car because you are having a hard time focusing and find yourself questioning how you are going to get through the rest of the day. Even taking a few moments to do nothing is a great place to start when it comes to rest throughout the day. Start to make a list of things you like to do for fun, ask the rest of your family to do the same, and see if anything overlaps—these are the things you can do to play together. ♥





Speaking From the Heart

Fostering optimal physical activity experiences
in children with congenital heart disease



PURPOSE

We examined how children with CHD and their parents **THINK** and **FEEL** about physical activity and how this impacts their physical activity **PARTICIPATION**



STUDY METHODS

WHO



16 Children
9-12 years old
moderate-to-severe CHDs
and their parents

WHERE



BC Children's Hospital
Children's Heart Centre

WHAT



Interviews

FINDINGS

1. Children were active for fun, skill and confidence building, and for health and well-being



Kids with CHD said they engage in physical activity

- ♥ because it was fun
- ♥ to spend time with friends
- ♥ to improve overall health and well-being
- ♥ to work on building movement skills and confidence

2. Kids and their parents experienced complex emotions in relation to physical activity



Children with CHD...

- ♥ felt proud when they mastered a movement and could play with older peers
- ♥ sometimes felt **embarrassment, shame, and envy** when they were not able to keep up with their peers

Parents...

- ♥ felt proud when their kids were having fun, putting in effort, challenging themselves, and improving their skills
- ♥ sometimes were **fearful** and/or **anxious** as they worry about their kids' heart condition and its impact on their activity involvement

3. Kids learned to self-regulate during physical activity to ensure safe and continued participation



Kids talked about the importance of pacing themselves to manage CHD-related symptoms

- ♥ sometimes during physical activity, kids felt tired, dizzy, and were breathing heavily. During these times, they listened to what their bodies were telling them and adjusted the type and intensity of their activities so that they could continue to participate



How did parents assist in their kids' self-regulation practice?

- ♥ parents tried to hide their concerns so as to not deter their kids from participating in physical activity
- ♥ parents also helped their kids learn how to self-regulate during physical activity
- ♥ physical activity leaders (e.g. sport coaches, PE teachers) were made aware of the kids' heart condition and ensured that they let the children take breaks when needed



Show support by encouraging kids to...

- ♥ be active for fun
- ♥ focus on effort
- ♥ work on skill building and teamwork
- ♥ get involved in accessible activities where they can play within their abilities and thrive



Interested in research? Visit us at www.bcchr.ca/childrens-heart-centre-research
Or send us an email at Cardioresearch@bcchr.ca

The above poster is based on work done by Dr. Harris's research team. It was created by Mimi Kuan and Erica Bennett. ♥

Vancouver Island Hearts of Gold

BY MEGAN MADSEN

I feel thankful to be invited back into the Children's Heart Network community. Three years ago, I had the pleasure of covering Krista Molia's maternity leave with the Vancouver Island Hearts of Gold (VIHOG) youth group. Since that time, I have become a mom myself.

I am excited to be back, and I most look forward to getting to know the VIHOG youth and their families.

Outside of the CHN, I currently work with children

and families who have fetal alcohol spectrum disorders or similar neurological conditions.

My free time is spent with my husband and our energetic toddler.

I want to say a big thank you to Krista for all her hard work over the years and how she has shaped our youth group.

I hope to preserve our special spirit and continue to provide opportunities for heart youth to connect and have fun! ♥

Upcoming Events

SEPTEMBER: A trip to Flying Squirrel Trampoline Park

OCTOBER: A fall-themed event, possibly a visit to the Saanichton Corn Maze or a gathering at Galey Farms

NOVEMBER: Painting pottery at FiredUp! ceramics studio

DECEMBER: Dinner out at Japanese Village

For more information about VIHOG events in Victoria, please contact Megan at viheartsofgold@gmail.com.



Camp Stillwood September 2019

BY JULIANE KHADRA

We were all very excited when we got the email to let us know that our family had been one of the lucky ones selected to attend the Lower Mainland CHN Family Camp. When we arrived at Camp Stillwood, we were greeted by a familiar face, one of the heart moms and a CHN board member, Sabrina Robertson. She had everything ready for us, which made checking in to our cabin smooth and easy. Our fun had just begun! The camp was very clean, and the food was amazing; kids and adults alike loved it. Our days were filled with fun activities for everyone: archery, rock climbing, arts and crafts, low and high ropes courses, games rooms, and campfires.

It was heartwarming to see my heart kid bond with other heart kids. They were encouraging each other and cheering each other on as they accomplished new challenges. They shared laughs, made new friends, and even showed each other their surgery scars.

It was such an incredible experience for our family to meet other heart families. We realized that although we come from different places and backgrounds, we all have



similar stories that involve struggles and pain as we travel the journey of bringing up children with heart disease. It is valuable to our family to know that we aren't alone.

We left the camp knowing we had made new friends and new heart family connections. Thank you to CHN for

this amazing opportunity. Thank you to Sabrina Robertson for hosting us and for making this trip a stress-free experience—you really went the extra mile for all of us. We were pampered and treated like royalty; it was an experience we will never forget! ♥



9 Ways to Support Your Child's Creativity

BY MARGARITA TARTAKOVSKY, MS, ASSOCIATE EDITOR, *PSYCH CENTRAL*

Kids are natural innovators with powerful imaginations. And creativity offers a bounty of intellectual, emotional, and even health benefits.

One study found that kids' imaginations helped them cope better with pain.¹ Creativity also helps kids be more confident, develop social skills, and learn better. Below, three experts share how parents can encourage their kids' creativity.

1. Designate a space for creating.

Carving out a space where your child can be creative is important, said Pam Allyn, executive director of LitWorld and LitLife and the author of many books, including *Your Child's Writing Life: How to Inspire Confidence, Creativity, and Skill at Every Age*.

But this doesn't mean having a fancy playroom. It could be a tiny corner with a sack of Legos or a box of your old clothes for playing dress-up, she said. Allyn has seen creativity flourish in the most cramped spaces, including the slums of Kenya. The key is for your child to feel like they have power over their space, she said.

¹ <https://www.futurity.org/imagination-helps-kids-cope-with-pain/>

2. Keep it simple.

Just like you don't need to create an elaborate play area, you don't need the latest and greatest toys either. Child educational psychologist Charlotte Reznick, PhD,² suggested keeping simple games and activities. For instance, she plays Legos with her child clients. But instead of following instructions, the kids let the wheels of their imagination spin and build what they want.

3. Allow for "free time."

It's also important to give your child unstructured time, Allyn said. Spend a few hours at home without activities scheduled, so your child can just putter around and play, she said.

4. Help your kids activate their senses.

Expose your kids to the world so they can use all of their senses, according to Reznick, who's also an associate clinical professor of psychology at UCLA and author of *The*

² <https://www.imageryforkids.com/>

*Power of Your Child's Imagination: How to Transform Stress and Anxiety into Joy and Success.*³

Again, this doesn't mean costly or complicated trips. Take them to the library, the museum, and outdoors, she said. Ask them to imagine what travelling to faraway places, such as the African safari, might be like, Reznick said. What animals would they encounter? What would the safari look like? What would it smell like? What noises would the animals make?

5. Discuss creativity.

Ask your kids when they come up with their best ideas or have their most creative moments, Allyn said. If it's in the car while getting to soccer practice, honour that by keeping a notebook, iPad, or even a tape recorder handy, she said.

6. Cultivate creative critical thinking.

As your kids get older, ask them how they approach certain problems and how they might do things differently, Reznick said. Have your kids brainstorm their ideas on paper or use mind-mapping,⁴ she said.

7. Avoid managing.

"Children have an amazing innate ability to be creative when they play freely on their own, and unfortunately, the act of overparenting dampens or even wipes out that innate ability," according to Mike Lanza of [Playborhood.com](https://www.playborhood.com), author of the upcoming book *Playborhood: Turn Your Neighborhood into a Place for Play*. So it's important to figure out how to facilitate your child's creativity without managing it, he said.

³ <https://www.amazon.ca/dp/0399535071>

⁴ https://en.wikipedia.org/wiki/Mind_map

Lanza and his wife don't hover over their three boys as they play, and they also don't enroll them in many activities. Recently, Lanza's oldest son invented an intricate game of marbles with its own complex rules. (As Lanza said, he doesn't really understand it.) He's even adjusted the rules so that his younger brother can win once in a while, and the game continues.

Kids learn a lot by playing on their own. Lanza cited Jean Piaget's *The Moral Judgment of the Child*, where he discusses "how children develop moral sensibilities and reasoning through playing marbles on their own."

He also mentioned Alison Gopnik's *The Philosophical Baby*, which describes how babies' brains work. Gopnik asserts that babies are born experimental scientists that take in scrolls of information by trying things on their own and tweaking as they go. Being more hands off helps kids figure out how to problem solve and create in their own unique ways.

8. Help kids pursue their passions.

Pay attention to your child's interests, and make these materials and activities available to them. Lanza's oldest son is especially interested in geology, so Lanza buys him books on the topic, along with rock samples.

9. Take the time for your own creativity.

Since kids learn from watching their parents, be creative too, Reznick said. Join your child when they're drawing or building or colouring. One little girl wanted her parents to help her build an art jungle in the living room, she said. At first, Mom was hesitant. But this provided a great opportunity for the family to bond, and everyone had a fun time. ♥

"9 Ways to Support Your Child's Creativity" has been reprinted with permission from [PsychCentral.com](https://www.psychcentral.com).



Interview with Kirsten Bartels

Kirsten is a geneticist at BC Children's Hospital.

Where did you grow up?

I'm a BC girl all the way. I grew up in Coquitlam and have since lived in Victoria and Vancouver.

Where do you work?

I work at St. Paul's Hospital in Vancouver as the program coordinator and genetic counsellor for the BC Inherited Arrhythmia Program (BCIAP). The BCIAP provides state-of-the-art care to patients and families with a history of inherited arrhythmia (or inherited heart rhythm condition), an unexplained sudden cardiac arrest, or a family history of sudden unexpected death. Although I am located at St. Paul's Hospital, our program has three sites, including BC Children's Hospital in Vancouver and Royal Jubilee Hospital in Victoria.

What made you want to be a genetic counsellor?

I became fascinated by genetics and developmental biology during my undergraduate degree. In speaking with my genetics professor about career opportunities in this field, she mentioned genetic counselling as an interesting niche health care role that involved specializing in both medical genetics and psychosocial counselling. I was sold! The role of a genetic counsellor is not so niche anymore as we learn more and more about the importance of genetics in all parts of medicine. One day you might have a genetic counsellor in your family doctor's office!

What are your main responsibilities?

I work as part of a team alongside both adult and pediatric heart rhythm specialist cardiologists, cardiac nurses, and other genetic counsellors. Diagnosing someone with an inherited heart condition is like putting together the pieces of a puzzle, and it requires the expertise of the whole team. My role as a genetic counsellor involves helping patients and their families understand the complex genetic information related to their heart condition. This includes understanding the genetic cause of their condition, how the condition is inherited in their family, and the chance their children could be affected. I recommend appropriate genetic testing, if needed, to confirm a diagnosis or to guide management, as well as to aid in the interpretation of genetic testing results and to help facilitate family screening.

As program coordinator, I am responsible for ensuring the smooth running of our clinic at St. Paul's Hospital but



also the coordination of care across our three program sites. Since inherited heart rhythm conditions run in families, we are often coordinating care for a whole family, including parents and kids.

How does your job help heart families?

Receiving a diagnosis of an inherited heart condition not only changes the way you think about your own health, but also has implications for your family. Sometimes a new diagnosis can finally provide an explanation for generations of heart problems or a sudden death in a family. A new diagnosis can also mean that your children, parents, or siblings may have the condition as well. As genetic counsellors, we can help families better understand the genetic cause of their heart condition and provide supportive counselling to help them adapt to their diagnosis. We can serve as advocates and refer families to other available support services. We can also support them in communicating information about the condition in their family to other relatives who may be at risk and require screening.

What are you most excited about in working at the BCIAP?

I work with a wonderful team. One of the best! We have a true passion for providing the best care possible to those with inherited heart conditions.

Outside work, what do you like to do for fun?

I love getting outside for walks, runs, and hikes—even in the rain! And I have a toddler who keeps my husband and me very busy. Our weekends are filled with playgrounds and play dates. ♥

What's Happening?

Lower Mainland Breakfast with Santa

WHEN: Saturday, December 14, at 10:00 am

WHERE: Delta Grand Villa Casino and Hotel, 4331 Dominion Street, Burnaby, BC

TO RSVP: Please email Sam at saitken@childrensheartnetwork.org with the number of adults and children in your family and your children's ages, and ensure your CHN membership is up to date.

Vancouver Island Breakfast with Santa

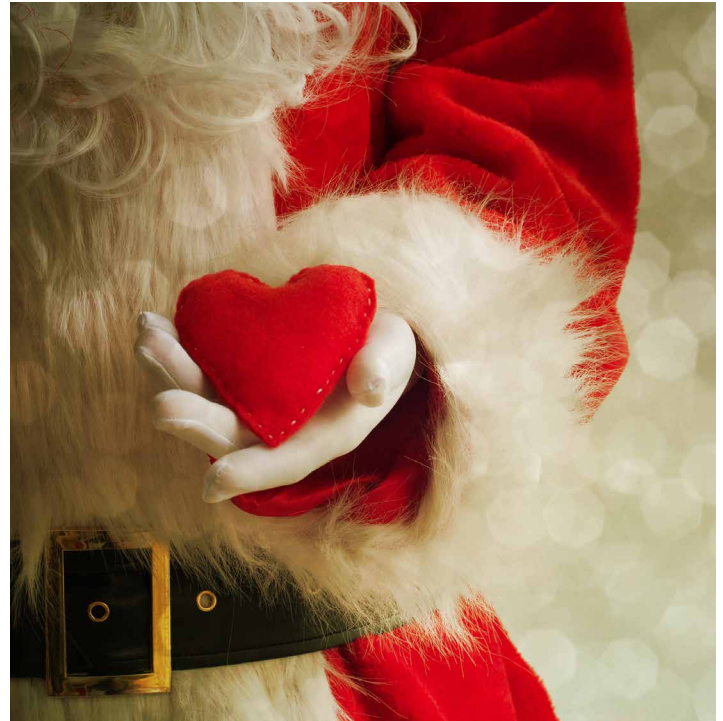
WHEN: Saturday, December 7, at 10:00 am

WHERE: Westin Bear Mountain Golf Resort & Spa, 1999 Country Club Way, Victoria, BC

TO RSVP: Please email Krista at viheartsofgold@gmail.com with the number of adults and children in your family and your children's ages, and ensure your CHN membership is up to date.

How to Renew Your CHN Membership

Go to <https://www.canadahelps.org/en/charities/childrens-heart-network>, scroll down to "Donate To This Charity Now," enter the amount of \$25, and change the dropdown from "CHN Donation" to "CHN Membership." It is \$25 per year per family. Thank you!



Save the Date! Wine Gala and Dinner

We are excited to announce that the 18th Annual Children's Heart Network Wine Gala and Dinner will be on Friday, April 24, 2020, at the Vancouver Terminal City Club. ♥

Did You Know?

Family Immunization Clinic

The Family Immunization Clinic provides publicly funded immunizations at no cost to patients at BC Children's Hospital and their friends and family visiting the hospital. This includes flu vaccinations. It is hoped that by making immunizations more accessible, the number of people immunized will increase. This is especially important in the more vulnerable children that BC Children's Hospital serves. The clinic is by drop in or scheduled appointment. It is located in the Ambulatory Care Building on the main floor.

You can access the BC Centre for Disease Control's *Immunization Manual* from their website. Appendix D has excellent resources for managing pain as well as child and parental anxiety during immunization.

familyimmunizationclinic@cw.bc.ca

Flu Clinics

If you don't live near BC Children's Hospital, you can find the nearest Flu Clinic by going to <https://immunizebc.ca/clinics/flu> and entering your postal code. ♥