



## My Heart Journey

BY GREG WALLACE

**T**his August, I will celebrate the 62nd anniversary of the open-heart surgery that repaired the atrial septal defect (ASD) in my heart.

There have been many advances in the way these are treated, but I hope that by hearing, first-hand, the story of my early struggles to survive and adapt, and then also my successes, a young family or teenager experiencing life-altering heart surgery now will get some inspiration. Or maybe it will nudge someone else to speak of their experiences.

My name is Greg "Spike" Wallace, and I was born in 1958 in Kamloops. I am now retired, and I reached many

life goals with the support of family and friends.

When I was born, the doctors and my parents suspected a serious health problem. According to my mother's notes, I cried all the time and only doubled my birth weight at one year of age. By the time I was two, I still weighed only 20 pounds.

Finally, a cardiac doctor at the University of British Columbia diagnosed the ASD.

Open-heart surgery for children was quite a new procedure at Vancouver General Hospital. (BC Children's Hospital did not exist yet.) On August 24, 1960, Drs. Philip

*continued on page 3*




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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](mailto: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

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

### **ABBOTSFORD – Rupe Brah**

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### **VANCOUVER – Samantha Aitken**

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### **VICTORIA – Teri Godin**

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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](mailto:chn@childrensheartnetwork.org) so that we can add you to our mailing list to receive invitations to all our fun events!

## THANK YOU

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



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



## CHN BOARD

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**KRISTI COLDWELL** – Lower Mainland Hearts of Gold youth coordinator

**KRISTA MOLIA** – Vancouver Island Heart Beats coordinator

**JADE PALM** – Vancouver Island Hearts of Gold youth coordinator

## My Heart Journey, continued from page 1

Ashmore and Dennis Vince, along with their operating crew, performed one on me. I was two years old. They split my breast bone and connected my heart to a heart-lung machine, which, in 1960, was the size of a small car. My heart was stopped for 35 minutes. Dr. Ashmore repaired the opening in the septum, and it took 26 stitches to close the chest incision.

There were no GoFundMe pages back then, and my parents had to pay for the ICU nurses and the blood to prime the heart-lung machine. I was sent home after four weeks without any support groups or advice. We were basically on our own!

Unfortunately, checkups in the years that followed were not positive, and the doctors worried about the quality of life I would have. By the time I was seven, I was still only 39 pounds and quite frail. For exercise, they suggested I could get a large dog and take him for a walk.

I had many friends at school, but I had a tough time until my best friend introduced me to the junior high football program. I started as the water boy, but by the time I graduated from senior high school, I was an accomplished equipment technician.

This allowed me to do a two-year stint with a junior

football program in Utah. I then got accepted into an athletic therapy program at Sheridan College in Oakville, Ontario.

In the off seasons, I became an accomplished chef. After graduation, I got my first trainer job with the Victoria Cougars of the WHL. Two seasons later, I joined the Kamloops Blazers. For 28 seasons, I held different positions. My teams won three Memorial Cups, and I was fortunate to travel to Japan and Switzerland with Hockey Canada.

In 2018, I was humbled by an induction into the Kamloops Sports Hall of Fame.

Nowadays, I am enjoying retirement. I spent many years volunteering at a ranch managed by a local family. I have worked at Save-On-Foods and our local Dolson's Source for Sports store. In some capacity, I would like to become involved with the BC Women's Hospital and help it care for and support heart patients and their families.

I think Dr. Ashmore would be very pleased with the path I took in life, and I am forever grateful for his skill so many years ago. I really have had a great journey so far. My life would never have been possible without the support of my family and so many close friends. ♥





# Meet Leslie Raffin, Cardiology Nurse Clinician and CHN Board Member

BY LESLIE RAFFIN

**M**y name is Leslie, and I've been working in cardiology for 22 years. I have spent 15 of those at the Children's Heart Centre.

Thank you for taking the time to get to know me. I have always loved children and am grateful for my position at the Children's Heart Centre.

My talented coworkers and I are justifiably proud of our knowledge and the level of care we provide even as we always challenge ourselves to do better.

In the old Children's Hospital on 3G, I worked in the infamous "Room 9" and was a charge nurse. I also did my pediatric advanced life support and intensive care unit (ICU) step-down courses and covered a lot in ICU. Before working at Children's Hospital, I worked at Shaughnessy Hospital as a float nurse and in the areas of emergency and eyes, ears, nose, and throat.

From 2007 to 2012, I helped one of our cardiologists who was working in clinical research to guide treatment for Marfan syndrome, a connective tissue disease.

I always wanted to be a nurse or a doctor. My mom is a retired maternity nurse, and I remember reading about medical procedures when I was a young girl. My dad, a television news station anchor, had a rare condition called Gaucher disease, which forced him to spend weeks and months in hospital.

I grew up with a passion for helping the sick and hurting through watching my dad's health care journey. I was always surrounded by home nurses and spent lots of time in hospitals. I have always felt right at home in a hospital.

I am also very interested in health care delivery in other countries, such as Guatemala, Tanzania, and Brazil, where the stories range from heartbreaking to inspiring.

In Brazil, for example, children scheduled for cardiac surgery are divided into those who can afford the cost of an analgesic sedative called Precedex and those who can't. However, doctors and nurses there try to level out the socioeconomic differences by giving half doses to both groups. It may not seem ethical, but it's a choice we don't have to consider here in Canada.

There are so many reasons to appreciate work in other countries. There is the immediacy in some places of being able to treat a disease as well as the satisfaction of teaching others who are eager to learn.

There are also some very deeply frustrating aspects to nursing in other countries, such as worrying about sick patients we were unable to see and wondering about the effectiveness of short-term, one-off care. Some patients wait

hours or even days to be seen.

I always thought I would be part of Doctors Without Borders or some other similar organization that travels to remote places.

But, life happened! I married and had children. Ryan is now 35 years old, and John is 25 years old. I also had a few medical hiccups involving burn surgery and spinal fusions. And then, I was diagnosed with MS. Each time something happened, I took a bit of time off and regrouped.

This seems to be my motto in life: regroup, reassess, restart, relearn...and appreciate the process.

I would never again choose to be in a body cast with a toddler to care for, but I certainly learned more about myself during the process. I remember starting my degree at Capilano University, getting there by HandyDART during my second spinal fusion.

Hard times can be used to do all the quiet work in our lives. I deliberately reward myself with some small treat after I undergo any medical procedure. Well, sometimes it's a big treat, such as a Cirque du Soleil ticket!

In my spare time, I love to play the French horn in a local band, kayak, and garden. All four of us also love to cook and have friends and family over for board games. ♥



# Continued Support for BC Heart Kids and Families

## Telus Community Ambassadors—Fraser Valley Club

BY BARB WILLSON

**T**hank you to the Telus Community Ambassadors—Fraser Valley Club for once again supporting BC heart kids and families with their generous donation of \$2,510.00. Their donation will enable two youth to attend CHN's Hearts of Gold youth camp and two children to attend the HeartBeats camp.

The Children's Heart Network relies on the generosity of caring supporters. We want to acknowledge the dedication and fundraising efforts of the Telus Community Ambassadors—Fraser Valley Club during this particularly challenging time of the pandemic. ♥

## The Rotary Club of Vancouver

BY HEGE BOLTHOF HOEGLER

**T**he Rotary Club of Vancouver has made generous donations to specific programs at the Children's Heart Network over the last few years.

In 2020, the Rotary Club gave \$4,900 to fund the Hearts of Gold (HOG) monthly care packages and youth meetings. In 2021, the Rotary donated \$2,500 to the HOG online spring camp, and this year, they contributed \$2,500 to support the Zajac Ranch summer camps.

The Rotary Club of Vancouver recognizes how important it is for heart kids to connect with others who understand their struggle and to mitigate anxiety and depression by preventing feelings of being different or alone. They also acknowledge the value of creating friendships with peers and are very happy to be able to contribute to such a worthy cause.

In May, heart parent Hege Bolthof Hoegler spoke to Rotary Club of Vancouver members to share her personal story and to talk about the different kinds of support offered by CHN.

Hoegler is seen here with Dr. Rene Abi-Rached, who has been her contact person and has represented CHN within the Rotary Club's committees. Also in the photo is Rotary Club president-elect Kendall Jessiman.

CHN would like to thank the Rotary Club for their continued generosity. We truly appreciate their support. ♥



Linda Jackson, Telus Community Ambassadors—Fraser Valley Club treasurer; Tracey Carpenter, CHN board president; and Sandra Keayes, Telus Community Ambassadors—Fraser Valley Club president.



Dr. Rene Abi-Rached, Hege Bolthof Hoegler, and Kendall Jessiman.



# Children's Heart Network's 18th Annual Wine Gala and Dinner

BY HEGE BOLTHOF HOEGLER

After two years without a wine gala, we were very excited to be able to hold one this year. The fabulous event took place at the Terminal City Club in downtown Vancouver. Guests came from Victoria, Whistler, and all over the Lower Mainland to celebrate and support the Children's Heart Network.

Attendees were welcomed with live piano, bubbly, and hors d'oeuvres. The room quickly filled up with people perusing and bidding on the more than 200 silent auction items. It was a challenging year to solicit donations, and we are extremely thankful for all the companies and individuals that donated to make this auction special.

Once it was time to take our seats, our beloved emcee John Emmet Tracy acknowledged the four Indigenous territories we were on, welcomed the guests with his witty humour, and started off with some fun stories from his latest acting gig on the TV show *Yellowstone*. It was clear he had some fans in the audience.

However, it was the Vasquez family that really stole

everyone's heart that night. Charles and his daughter Carlee told their heroic story of Carlee's struggles with heart disease, the many other challenges that often come with having a heart condition, and the loss of their wife and mom to cancer. There were many wet eyes in the room, and Charles and Carlee received a heartfelt standing ovation at the end.

Guests were then served a baby spinach, almond, and strawberry salad to start, paired with The Hatch 2019 Gobsnacked Cyclops Love white wine donated by Jason Parkes Customs and Crown & Thieves Winery. For the entrée, guests had a choice between braised beef short rib, roasted ling cod, or quinoa vegetable galette. The 2018 Cabernet Franc was donated by Country Vines Winery. For dessert, a delicious salted caramel chocolate ganache cake was served with Quevedo Tawny Port donated by The Drinks List. Together with The View Winery, they also donated the welcome bubbly, a 2018 Pearls Traditional Brut.



After the silent auction closed, our incredible auctioneer Fred Lee took to the stage. With his oozing energy, he captured the room and in no time raised a whopping \$26,300 for CHN's Send a Kid to Camp program. Lee then went on to the five live auction items, which also were a huge success. As a bonus, John Emmet Tracy had managed to secure a very special *Yellowstone* merchandise collection that is not available to the public. The set arrived the evening before, and some devoted fans were eyeing it with excitement. It even included a replica of the vest Kevin Costner wore in the show.

It was then time for the "Rings on/off" game. Participants purchased a glowing heart ring that could be turned on or off. A coin was flipped for each round, and those who selected the same choice as indicated by the coin by turning their rings on or off got to remain in the game. The winner would go home with a \$1,000 gift certificate from Burrowing Owl Estate Winery that is redeemable in its restaurant, for its guest house, or to purchase wine. As the only child present in the room, Carlee had bought a ring and excitedly played the game. When she and one other contestant were left to battle for the prize, there was a growing anticipation among the audience. Incredibly enough, and to everyone's delight, Carlee did win the last round, and her grandmother accepted the gift card with her.

Finally, before some short thank you speeches, we enjoyed the raffle of the night. Anyone that had purchased numbered wine corks was entered in the draw for two tickets to anywhere Air Canada flies in North America, including Mexico, Hawaii, and the Caribbean. Captain Darren Nadeau was happy to present the tickets on Air Canada's behalf.

**After all expenses were paid, the total amount raised at the gala came to just over \$98,000.**

This amount will keep the Children's Heart Network pumping for yet another year. CHN serves about 1,000 families in BC and will continue to do so to the best of its ability, thanks to all the wonderful prizes generously donated to the gala, and all the guests who came with their wallets open to enjoy this festive and fun evening. We are so grateful for the continuous support from many of our heart families every year.

A heartfelt thank you to all the volunteers that helped set up the venue during the day and those who helped with the many tasks on a busy evening. Thank you to Glen Spence who stepped in at the last minute to take photos, and to Carolyn Willson Rendle for helping with the staging of the auction tables. Thank you to Amy Willson for creating the beautiful catalogue cover. Thank you to Sophie's Flower Pedals for creating and donating the





beautiful centrepieces and to United Floral Inc. and Carly Crocker for donating the flowers. Also, thank you to Daniel Chocolates for the delicious chocolate hearts decorating every plate in the room. They truly made the tables look festive!

Thank you to our gold sponsors this year, AP Capital, Dr. Sinclair and Dr. Young from Victoria, Hayward Sheppard, Pediatric Cardiology Associates from BC Children's Hospital, and Raven Excavation. Medtronic of Canada and TD Bank supported us with a bronze sponsorship, and the associate sponsors for 2022 were Canadian

Forest Products, G&F Financial Group, the Rotary Club of Steveston, Sid Dickens, and Tim Wispinski/The Drinks List.

Hege Bolthof Hoegler has been the events coordinator for the last four years and was a gala volunteer before that. She is now stepping down and passing on the baton. She would like to thank CHN and the board for giving her this unique opportunity. It has been both a fun and stressful adventure to fundraise during a pandemic, and she now looks forward to participating as a guest next year and taking it all in from a new perspective. ♥

## We would like to thank our sponsors:

### Wine sponsors

Country Vines Winery

Dean Alexander

Jason Parkes Customs

The View Winery & Vineyard



### Gold sponsors

AP Capital

Dr. Sinclair and Dr. Young

Hayward Sheppard

Pediatric Cardiology Associates

Raven Excavation



### Bronze sponsors

Medtronic of Canada

TD Canada Trust



### Associate sponsors

Canadian Forest Products Ltd.

G&F Financial Group

Rotary Club of Steveston

Sid Dickens

Tim Wispinski/The Drinks List





# HeartBeats Event at Rocky Point Park in Port Moody

On Sunday, June 19, CHN had our first in-person event in over two and a half years! How fun to get together and play with our heart friends and to chat with other parents as we enjoyed Rocky Point's famous ice cream. It was a tad chilly, but lots of fun was had by all. Watch for the invitation to our next event at the Cultus Lake Waterpark in August. ♥



Maddox.



CHN flag.



Van Koughnett family.

# Checking Your Gauge

BY JENNIFER SIRAN, AUTHOR OF *WHEN YOUR WORLD STOPS: FINDING HOPE IN YOUR CHILD'S MEDICAL JOURNEY*

**“Y**our son’s heart is doing great! No changes. We will see you in a year.”

Have you ever felt unsettled with good news? It’s an odd side effect of chronic illness and one that has caught me off guard on more than one occasion. My son was born with congenital heart disease 11 years ago. In 11 years, we have NEVER gone a year between appointments, and as soon as his doctor shared the great news this spring, I immediately requested an appointment sooner. I panicked.

## Emotions are tricky.

Emotions are unpredictable on this journey. Just when you think you are able to handle the twists and turns that come with the journey with congenital heart disease, anything can pivot you back into feelings of fear, anxiety, and depression—even GOOD news! If this resonates, you are not alone.

The past two years have been a challenge to our world, and my heart has continually gone out to families just starting the journey with a child with medical differences. For our family, the connection with other families and their stories has been an encouragement and great support for us. I am thankful for excellent communities of support, like the Children’s Heart Network and others, that give space for us to be with those who understand, who “get” why good news unsettled me.

But what if you aren’t an extrovert like me who dives into community? What if talking to medical professionals makes your mouth dry and causes your brain to shut down, leaving you with unspoken questions and deep frustration? What if the grief is hitting so hard that trying to share your heart with anyone breaks open a dam of emotion so large and powerful, and you don’t want to drown anyone?

## Looking for your team.

The solitude of COVID gave me time to ponder this need, and out of that came a book. It is a compilation of short chapters, collected over a decade, with feedback from other families, to serve as a sort of lighthouse in the storm. There are days that we lack the strength to interact with other people. The format of a book allows us to enter into the deeper emotions of our world when we are ready to do so, giving us a place where we can control the narrative.

The best support comes from those who understand the journey, who have felt bitter disappointment and are willing to name that feeling without guilt or shame. It is seen with the shared excitement of “My kid is peeing!”



which other families may not get the importance of. It’s the odd medical humour that one acquires as a means of survival when the constant beeping of machines threatens to drive you to madness.

## Look out, driver!

The reality is that we can face many challenges. Having grown up in Manitoba, I experienced flat, straight, mile-grid roads. I saw what was coming from miles away, from every side. Having lived in BC more recently for a time, I never really knew where the road would take me. Would it turn right or left? Would it go up or down? Was I driving to mountains or lakes? For most, having a child with congenital heart disease is like navigating mountain roads. You don’t always know what’s coming, or what is around the bend. Things can change quickly, or they can be more repetitious, like countless weaves through the mountains.

As parents, we are the navigators of our family. We are the drivers of the vehicles, through this unknown, and our attentiveness and care are extremely important for the safety of all whom we carry with us, our families. How are you doing today? Are you getting the support you need?



In a recent parent education session with CHN, I spoke on the ripple effect of trauma on the whole family and the need for patience, care, and support for caregivers. As parents, we are already excellent at putting our needs last on the list of daily to-dos, and when our child is struggling, our needs get buried deeper down on the list. There is a sense of normalcy with ignoring our every need and focusing on our child; in fact, it sounds un-parent-like to do anything else! But what happens if we run out of gas?

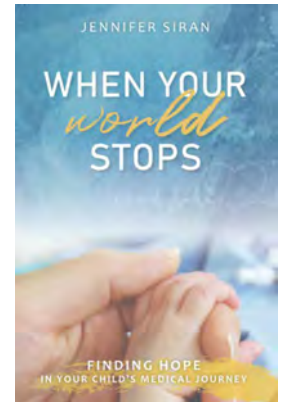
YOU are important too! Caregivers are important! When the life of the caregiver suffers, so does the care of the child. Take time for yourself today to take some deep breaths and chart your course. You got this. We are cheering you on! ♥

## Interested in finding out more?

When Your World Stops book:  
<https://www.amazon.ca/When-Your-World-Stops-Finding/dp/177762200X>

Parent education session:  
<https://www.childrensheartnetwork.org/parent-education-series/session-5/>

Personal website:  
[www.jennifersiran.com](http://www.jennifersiran.com)



# Lower Mainland Hearts of Gold Go Whale-Watching

BY COLE RENNER

The Lower Mainland Hearts of Gold (HOG) crew took to the high seas for a whale-watching adventure on April 24.

The trip got off to an interesting start as a grocery bag floating in the water got sucked up into the jet engine of the boat! After some careful and skillful manoeuvring by the captain, we were on our way.

The expedition went all the way to the Gulf Islands (which took no time at all with the speed and power of the vessel) where the HOGs were treated to seeing not one, not two, but three orcas swimming in the water! They lingered by the surface for over 45 minutes and were resting, which gave everyone an incredible opportunity for pictures. To see the beauty and size of the whales was a truly unforgettable experience! ♥



# What's Happening?

## Hearts of Gold Event at Playland

**Sunday, July 17, at Playland.** Lower Mainland Hearts of Gold (HOG) teens (ages 13–18 years old) will get together on July 17 at 11:00 am at the PNE grounds to enjoy an afternoon at Playland with their heart friends. If you are a heart teen and would like to join the HOG group, please contact Kristi Coldwell at [chnheartsofgold@gmail.com](mailto:chnheartsofgold@gmail.com) for more information..

## Hearts of Gold Camp (for youth ages 13–18)

**July 1–4 at Zajac Ranch in Mission.** We are excited to be hosting the Hearts of Gold (HOG) camp this year over the July long weekend (July 1–4) at Zajac Ranch in Mission. This camp is for our HOG youth groups that currently meet monthly. If your heart teen is interested in joining the monthly HOG group, please contact Samantha at [saitken@childrensheartnetwork.org](mailto:saitken@childrensheartnetwork.org).

## HeartBeats Camp (for children ages 8–12)

**July 5–9 at Zajac Ranch in Mission.** Our HeartBeats camp will be July 5–9 at Zajac Ranch in Mission. Our heart kids will join other children for the mixed medical camp, which will include horseback riding, canoeing, swimming, archery, crafts, and more! Watch for the invitation to camp (provided COVID allows).

## Cultus Lake Waterpark Event

**Sunday, August 21, at the Cultus Lake Waterpark.** Save the date for our super-fun summer get-together! It isn't confirmed yet, but we hope to host it on Sunday, August 21! Once confirmed we will send out an email invitation to all CHN members to come and join us.

## Lower Mainland Family Camp

**September 24–26 at Camp Stillwood near Cultus Lake.** Watch for an invitation to all our BC heart families (provided COVID allows). ♥



The Enterprise ride at Playland, at the Pacific National Exhibition in Vancouver. Photo by ThePointblank. Licensed under the Creative Commons Attribution-Share Alike 3.0 Unported licence. <https://creativecommons.org/licenses/by-sa/3.0/deed.en>



Panorama of the Cultus Lake Waterpark. Photo by The High Fin Sperm Whale. Licensed under the Creative Commons Attribution-Share Alike 3.0 Unported licence. <https://creativecommons.org/licenses/by-sa/3.0/deed.en>