



Dr Derek Human and Mandy Johnson with Houston.

## Houston's journey

BY CARLY CROCKER

No parent is ever prepared to hear the words, "Your baby is on a tremendous amount of support and may not make it." During that time of uncertainty, unable to hold our baby, all we could do was wait minute by minute, hour by hour at his side and love him. We prayed continuously that our son would never give up the fight. Now, nearly 6 years later, I can share the story of our courageous son, Houston, and how the Children's Heart Network has impacted our family.

Our life-altering journey began during a routine ultrasound at 5 months

pregnancy. Doctors discovered that our unborn baby had a congenital heart defect and several other significant health issues. After weeks of close monitoring and several surgical procedures to remove the fast-pooling fluid surrounding his heart and lungs, it was decided that the best chance of survival was treatment outside the womb. With a team of nearly two dozen medical staff on hand, Houston was delivered by emergency cesarean section 2 ½-months premature. My husband Mark and I had one quick look at our son before he was rushed off by BC Children's Hospital specialists for life-saving treatment.

—continued on page 3

### IN THIS ISSUE

Houston's journey .....	1
Coffee groups .....	2
Critter Cove .....	4
Hearts of Gold .....	6
The story of me, Jillian Wiebe .....	7
Events.....	8
Obesity, exercise, and the heart .....	10
Meet Leslie Raffin .....	11
Scotia Bank Half Marathon .....	12

### 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.

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.

### Heart Matters

5151 Canada Way, Burnaby, BC V5E 3N1  
Tel: 604 521-3037 | 1 877 833-1773  
chn@childrensheartnetwork.org



ChildrensHeartNetwork



## COFFEE GROUPS

These groups meet monthly, come and meet other heart parents while enjoying treats on us! For more information please contact:

**VANCOUVER** – [Samantha Aitken](#)  
saitken@childrensheartnetwork.org

**BURNABY/COQUITLAM** – [Sarah Kertcher](#)  
sarah.kertcher@outlook.com

**RICHMOND** – [Kate Walker](#)  
kwalker@childrensheartnetwork.org

**ABBOTSFORD** – [Rachel Gammon](#)  
footballmama02@hotmail.com

**MAPLE RIDGE/TRI-CITIES** – [Amy Watkins](#)  
amylouwatkins@hotmail.com

**CHILLIWACK** – [Melissa Martz](#)  
melmartz@shaw.ca

**VICTORIA** – [Teri Godin](#) | terigodin@gmail.com

**NANAIMO** – [Andrea Van Rossum](#)  
andrea.vanrossum@gmail.com



## YOUNG ADULT HEART NETWORK COFFEE GROUPS

We have two groups for young adults living with heart disease. For more information please contact:

**VANCOUVER** – [Corey Zinger](#) | zinger92@telus.net  
**VICTORIA** – [Lauren Fougner](#) | lfougner@uvic.ca

## Thank you to our generous donors

CHN would like to thank the following organizations for their support and generous gifts over the past six months:

**Cops for Kids**  
**The CKNW Orphans Fund**



## HELPFUL WEBSITES

[heartbeats.ca](#)

Supporting Children with Heart Disease

[chdquilt.org](#)

The Congenital Heart Defect Awareness Project

[westerncanadianheartnetwork.ca](#)

Western Canadian Children's Heart Network

[achaheart.org](#)

Adult Congenital Heart Association

[cchaforlife.org](#)

Canadian Congenital Heart Alliance

## ARE YOU A MEMBER OF A HEART FAMILY?

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!

## CHN STAFF

**SAMANTHA AITKEN** – Provincial coordinator  
**DANIELLE SEGUR** – Administrative assistant  
**KRISTI COLDWELL** – Lower Mainland Hearts of Gold youth coordinator  
**KRISTA MOLIA** – Vancouver Island Hearts of Gold youth coordinator

## CHN BOARD

**TRACEY CARPENTER** – Member at large  
**STEPHANIE ISAAC** – Member at large  
**BARBARA JOHNSTON** – Member at large  
**MANDY JOHNSON** – President  
**SARAH KERTCHER** – Member at large  
**JEFF MERCER** – Treasurer  
**BINDY SWEETT** – Member at large  
**KATE WALKER** – Member at large  
**BARB WILLSON** – Secretary



In the days and weeks that followed, Houston underwent major surgery and fought infections that many times nearly took his life. Our little warrior was fighting battles of great magnitude. After an excruciating 30 days in the Neonatal Intensive Care Unit, we were finally able to hold our baby in our arms for the first time—a moment that will forever be imprinted in our hearts. Where there is love there are miracles, and on day 97, thanks to mega-love and care, Mark and I were given the words that every NICU parent longs to hear: “You can take your baby home.” *Finally*, our family of four—at that time—would be together under one roof.

Houston's congenital heart defect (tetralogy of Fallot) and intricate little system were caused by a complex genetic disorder called Noonan syndrome. This created a very weak and fragile immunity. While preparing for his upcoming heart and bowel surgeries our home transformed into an instant “bubble” necessary for Houston's survival. We were isolated from most of our family and friends and before we knew it our home shifted into a mini medical centre. Mark and I became the experts, working around the clock managing our son's care all while balancing the needs of a healthy and vibrant 3-year-old daughter. Threading feeding tubes down his nose, priming and connecting the feeding machines, changing ostomy bags, and drawing up medications were just a few of the many things we were willing to do have our son home. At 3 months of age there was very little information to help and guide us with Houston's needs, he was by no means your typical baby. As we nurtured and

protected our family we slowly came to realize how overwhelming and financially draining this new normal had become.

It was during this vulnerable period in our family's life where the support of the Children's Heart Network came to the rescue. During one of Houston's routine cardiac appointments I came across a CHN newsletter inviting families to join a local parent support group. This coffee group provided me with the much-needed opportunity to socialize with other moms in a casual environment where I could talk about my son and listen to other success stories. Even though most of our medical journeys with our heart children were different, empathy and understanding was the common thread that linked us all.

At 18 months of age Houston underwent a successful open-heart surgery, which was the turning point in his health. For the first time in nearly 2 years, Houston was able to live outside of the bubble, which meant our family was finally able to start enjoying outings altogether. The CHN welcomed us with many opportunities. The Christmas party, Easter egg hunt, pumpkin patch, and Cultus Lake Waterslides are all events our family looks forward to attending annually. What has always stood out about CHN is its focus on family and not just on the heart kids. The importance of these organized events is that it encourages the families to leave the safety of their home and join the fun with a supportive

community. In addition, with the cost of these events being covered, it takes away any financial stress allowing families to simply enjoy their day. For our oldest daughter Olivia, the CHN community has given her the opportunity to meet other heart children and their siblings. This has certainly strengthened her empathy and compassion toward others.

Whether putting on a concert with his trombone, sporting his Michael Buble outfit, his spiked hair and microphone in hand, Houston's gentle and loving spirit and infectious squeal, lights up any room. With 13 major surgeries and procedures under his belt, Houston has proved countless times that he is our hero. His ability to overcome daily obstacles—from his vision and hearing impairments and speech delay—amazes everyone he meets. He inspires many people with his unique gift to keep on smiling no matter the hardship he faces.

“Helping to bring hope to heart families” is the root of the Children's Heart Network. Mark and I would like to spread hope to all those families starting their journey. With a second open-heart surgery needed in his future, we are fortunate to have an amazing community within CHN that we know will empower, support, and spread hope to Houston and our family alongside our journey!

I'd like to share with you a few lines from one of Houston's favourite Buble songs—a song that we sing together everyday. It's called “Close your eyes.” ■



*Close your eyes  
Let me tell you all the reasons why  
You're never gonna have to cry.  
Because you're one of a kind.  
Here's to you  
You're the one that always pulls us  
through  
You always do what you gotta do  
Because you're one of a kind  
Thank god you're mine.*



# Critter Cove weekend:

## Fishing, fun, and new friends

BY LEANNE SHUPARSKI



Desiree, Leanne, Sam and their guide Jay.



The big catch!

Thanks to the generous support of the Children's Heart Network, my daughter Desiree and I were able to attend the Critter Cove Kids weekend, which took place June 26 to 30, 2014.

Desiree was born with tetralogy of Fallot. She has underwent two heart surgeries, the first at 6 months old to repair a hole and another at age 4 to remove muscle from her heart. Her scar did not heal well after the second surgery, forming a keloid scar which is quite noticeable, but thankfully she doesn't fret about it.

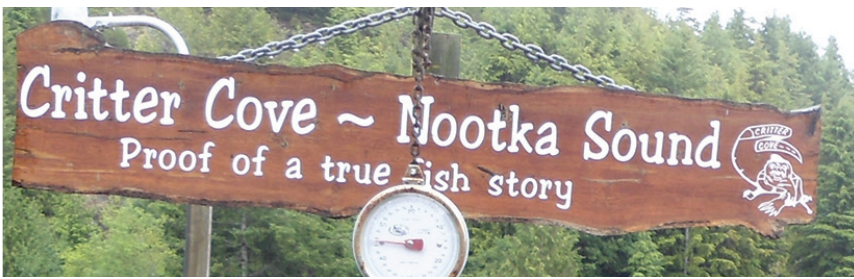
Until going to camp, Desiree, age 8, had never met another child living with heart a condition. I was so happy that she met Avery, age 7, and her sister and became instant friends. I felt so comfortable meeting this group of families who all seemed to possess an unspoken empathy, kindness, and appreciation for each day and new experience, especially when dealing with a child/children with health difficulties.

The older kids bonded right away, at the back of the bus. During the long ride we all kept busy watching movies, stopping at Tim Hortons for a donut and beverage, and staying patient and optimistic after the charter bus stalled on the steeper sections of the logging road on the way to camp.

We were then chartered by boat to Critter Cove Resort where the kids received their own fishing rods and fishing gear, including a nice warm toque, t-shirt, and fishing licenses. Shrimp appies were served to us on the wharf before dinner as the kids tested out their new rods.

Desiree and I joined our guides, Jay and Emily, early the next morning. We were lucky: the fish were biting and Desiree pulled in her first salmon with a little help from Sam. Thanks to our knowledgeable hosts, we learned how to differentiate between chinook and sockeye (by the spotted tail) and farmed or wild salmon (by the absence of the upper back fin), and how to clean and debone a salmon. We caught 8 salmon the





Lucas Woodbeck caught the largest fish.



Desiree with one of the many fish caught over the weekend.

first day as a group for a total of 10 that weekend. Six of which we took home—by bus, ferry, truck, taxi, and plane in a huge cooler complimentary of Critter Cove.

The camp cooks were amazing, serving up fabulous meals buffet-style throughout the weekend, including appies and dessert as well as coffee, tea, and hot chocolate for a quick warm-up. All meals were served in the warm and quaint cookhouse. The wonderful side dishes and yummy Rice Krispie squares perfectly complimented the salmon picnic at Friendly Cove.

In the evenings, the children took part in fun activities like sharing stories about gummy bears as their main characters and a participating in the annual fishing derby. We were dazzled by an illuminated hula hoop performance and a beautiful fireworks display on our last evening at Critter Cove.

Special thanks to Jessica, the Forbes family, Noemi and family, Nina, and Racquel. ■

## The Smith/Woodbeck family on their Critter Cove trip

BY LUCAS WOODBECK, AGE 7

This summer I got to catch fish and I got to go in a boat. I caught the biggest fish in our family, it was more than 7 lbs! We got to sleep in a cabin with my family.

I really liked Harvey and Shannon. They took us in their boat and showed me how to catch the big fish. My dad showed me how to fish too.

I liked the food. I loved driving the fast boat. I had fun on the bus with all the families.

I liked Critter Cove!

BY ETHAN SMITH, AGE 14

The Heart Network Critter Cove trip was a great experience. On the trip I had the chance to go out on an amazing ocean fishing boat and go salmon fishing which was a lot of fun. We even were able to keep all the fish we had caught.

During the trip I was able to make a few new friends. We went fishing off the docks and hung out.

The food was really good too—my favourite meal was the halibut.

On the last day of the trip I was able to drive the Fisheries and Oceans boat. That was really exciting, especially since the boat was a Zodiac with twin 300s powering it!

We had a great time together as a family. Thank you.

BY MAYA SMITH, AGE 16

There are so many reasons that I liked Critter Cove. First, it's a wonderful experience to get to go ocean fishing! Second, the people you get to meet are amazing—all the kids, the heart families, the guides, and all of the volunteers.

There was never a dull moment on the trip. We were either fishing, playing fun activities, or just hanging out with our new friends.

Thanks to our guides we learned a tremendous amount about ocean fishing. We spent so much time with our guides that they felt just like a part of our family! It was really hard to say goodbye to them.

We made memories on this trip that I know my family and I will never forget. ■



Justin at work.

## From camp to career

BY JUSTIN CHURCH

I was 13 years old when I was diagnosed with hypertrophic cardiomyopathy. It felt like a carpet had been ripped from beneath my feet. All that was left was a feeling of loss for the care-free life I had once lived only moments before the diagnosis. However, the life I have made for myself now is life I have to deal with and I am going to make the most of it! I made a decision to turn the negatives of having a heart condition into positives and to never let this bring me down. As it turns out this diagnosis has had some positive effects on me, both mental and physical.

Being part of the Hearts of Gold group has had many positive effects on my life—the greatest one being able to attend camp at Zajac Ranch. My first experience was the summer of 2010. After a week at camp I came home and told my parents, “I’m going to be a camp counsellor one day.” Attending camp regularly now for several years has really brought out my true colors. I have grown as an individual and learned to accept my heart condition for what it is and always make it better. I also know I want to make others feel the same way.

I have always had a passion to work with children but growing up with my own health problems has made me realize that I really want to work with children with medical conditions. My passion for working with and helping children and my many experiences at Zajac Ranch led me to take the Leadership In Training Program at the Ranch. I’ve taken this week-long training program for two summers now. The LIT program is four structured days of learning how to be a camp counsellor. We cover many different areas like learning how to lead group activities, how to deal with a variety of problems and assess them effectively and efficiently, how to find the best in every situation and make it better—even if only for a moment. I have even learned to make lemonade in the back

kitchen! My experiences through camp and the LIT program have led me to make a decision to attend Riverside College to take the Community Support Worker/Educational Assistant certificate course to further my education working with children. Next June, with my college certificate in hand, I hope to work as a camp counsellor at Zajac Ranch. My goal is to one day be a camp director.

I am blessed with the opportunity to experience all of these things and it wouldn’t be done without the love and support of our family and friends! ■

## SUPPORTERS

### Thanks, Cops for Kids

The CHN would like to thank Cops For Kids for their financial support in getting some of our heart teens to Camp Zajac this summer.

Cops for Kids foundation is committed to assisting children that are in medical, physical, or traumatic crisis. They have many events throughout the year, but their signature event is the Cops for Kids Ride. This gruelling 10-day ride occurs each year over some very challenging terrain. Riders are driven by their commitment to children in the southern interior region of British Columbia and are devoted to making a difference in their lives!

One of our heart teens from Kamloops, Chad Hellingman, presented a thank you card on behalf of the CHN as the riders came through town! ■





---

# The story of me

BY JILLIAN WIEBE

---



Me at Camp Zajac.

I was born on my due date, November 17, 1993, after a pretty normal pregnancy (according to my mum). Everything seemed fine until the next morning when the doctors detected an abnormal sound in my heart. This sound led them to send my parents and I, now 12 hours old, to BC Children's Hospital in Vancouver.

Before leaving my local hospital I had an ECG and a chest X-ray. Upon arrival at BCCH my parents had a lengthy interview with Dr Derek Human, who was to become my cardiologist for all of my life. He sent me right in for an echocardiogram. It was following that very first echocardiogram that I was diagnosed with hypoplastic left heart syndrome.

I had my first open-heart surgery on November 19, 1993. That surgery was the Norwood procedure. Dr Leblanc, my surgeon, told my parents my heart was the size of a walnut! My parents were also told that I would probably be in the hospital for at least a month, and after a month had gone by they wouldn't really

know how long I would have to stay! Imagine their surprise when after 6 days in ICU and another 4 days in Room 9 (as the cardiac ward was called at the time), the now-retired Dr Patterson told my mum they were running out of reasons to keep me in in the hospital! I was discharged about 11 days after my first surgery. My parents and my sisters quickly adjusted to life as a family of five, with many doctor's appointments thrown in for good measure!

I had my second open-heart surgery, the bidirectional Glenn, in April 1994 when I was 5 months old and weighed all of 12 pounds. Mum says I was the happiest little person ever and handled all the poking and prodding involved with a smile! Although my immediate post-op time was a little tricky, I was able to return home again in less than 2 weeks.

Between the second surgery at 5 months of age and age 3, I had many check-ups with Dr Human. I tended to grow and develop a little slower than other babies of the same age. Dr Human told us that as a heart child I needed to use my calorie intake to have good cardiac output and whatever was left over was used for growing.

At age 3 I was ready for my third and final open-heart surgery, the fenestrated Fontan. Shortly after my third birthday I was back in BCCH with Dr Leblanc once again performing my surgery. I had an uneventful recovery and was soon home with my sisters.

My life seemed to take off after that surgery. I grew and grew and grew, I rode my tricycle as fast as I could. I went to preschool and I was just a little girl with a big scar!

I've had many visits to BCCH over the years. I had my appendix out when I was 14 and then when I was 15 I fell off my bicycle, broke my ankle, and had to have surgery. Those surgeries were pretty uneventful after going through three open-heart surgeries in 3 years.

At 18 I graduated to the PACH (Pacific Adult Congenital Heart) program at St. Paul's Hospital in Vancouver. I am very fortunate that Dr Human continues to follow many of his high-risk cardiac babies as they grow into adulthood, so I continue to see him once a year.

My life has been pretty amazing. I can't change what is, I just accept and do and live life to the fullest in the most normal way possible. ■



Me at age 3.



# EVENTS

## Grind for Kids:

### Thanks Drs Sanatani & Gandhi!

On August 29 two BC Children's cardiology specialists, Dr Sanatani and Dr Gandhi, climbed the Grouse Grind with some of their heart kids. It was a gorgeous sunny day and fabulous to see these amazing kids and parents accomplish something so challenging together!

They did it as part of Grind for Kids, a fundraiser that runs until the end of Grind season in October, 2014. Grind for Kids is in its fifth year, and over that time nearly \$600,000 has been raised for BC Children's Hospital Foundation. People sign up and ask friends, family, and co-workers to pledge to donate \$1 or more for every grind they do.

To register, and for more information, visit [www.bcchf.ca/events/event-calendar/grind-for-kids](http://www.bcchf.ca/events/event-calendar/grind-for-kids)

Thanks Drs Gandhi and Sanatani—talk about putting your heart into it!



Liam and Dr Gandhi both did the Grind for Kids.



Cultus Lake Waterpark picnic on August 24. The Berg family – Halle, Dominic, Aiden, Camille, and Blaise.

## Summer fun with CHN

The past season our families enjoyed a lot of fun activities while meeting and reconnecting with other heart families. If you would like to get on our email list to receive invitations to these great events, please email [saitken@childrensheartnetwork.org](mailto:saitken@childrensheartnetwork.org).



The Gormley family

## Fall Pumpkin Harvest

On October 4th CHN hosted the 6th Annual Fall Pumpkin Harvest at the Apple Barn in Abbotsford. Over 120 heart kids and their families enjoyed connecting with others, while participating in some of the many activities on the farm.

Trampoline jumping, hay riding, and finding their way through the corn maze were just some of the fun options for the children to enjoy. Heart kids and their siblings were able to pick out a pumpkin to take home! Thank you to Starbucks and Superstore for supporting our event with coffee, hot chocolate, cookies and more!





Nanaimo heart families at McNabb's Corn Maze.

## Nanaimo heart families celebrate the fall season at McNabb's Corn Maze

On Sunday October 5 five heart families and a few grandparents spent the day at McNabb's Corn Maze. A hayride, a trip through the corn maze, a hot dog roast, and a pumpkin to take home was part of the Pumpkin Patch event. The kids (and adults!) all had a blast.

Thanks to donations from Costco Nanaimo, Superstore, and Tim Horton's South Gate for donations of food and refreshments for the families.

Various events, such as the Pumpkin Patch, are planned throughout the year for the heart kids and their entire families. This is a great opportunity for our families to meet, have fun, connect, and support each other.

We welcome all heart families from the North Island area (Parkville North) to join us for upcoming events. Contact [andrea.vanrossum@gmail.com](mailto:andrea.vanrossum@gmail.com) to be placed on our contact list.

## HEART TEENS

# Vancouver Island update

BY KRISTA MOLIA

Over this splendid summer the Hearts of Gold group on Vancouver Island enjoyed time on the water. In July, Power to Be hosted an afternoon kayak trip where we explored many hidden bays of sandy beaches along the coastal waters of the western side of Victoria. Then in September we were delighted to enjoy a 4-hour whale-watching trip where we viewed sea lions, mince whale, and orca whales, including a new baby orca born 10 days earlier.

Thank you to CHN for providing us this opportunity for adventure but more importantly building supportive friendships with fellow teens!

## UPCOMING EVENTS

### Breakfast with Santa

Saturday, November 29, 2014

Metrotown Hilton Hotel, Burnaby

The Lower Mainland's CHN Breakfast with Santa is an annual tradition not to be missed! Watch for more details.

### CHN's AGM – Learn and connect

Thursday, January 29, 2015, 7pm

BC Children's Hospital, Vancouver

A chance to learn more about what CHN has been working on for members over the past 12 months and an opportunity to connect with other heart families while enjoying snacks and refreshments. We are also planning a special presentation at this year's AGM. More details coming soon.

### Growing up with heart disease conference

Saturday-Sunday, April 11-12, 2015

The Children's Heart Network is pleased to announce the date of the eighth Growing Up With Heart Disease conference: the weekend of April 11 to 12, 2015.

The conference is held at the Chan Centre at BC Children's Hospital in Vancouver, planned by families and professionals, and presented to families and professionals. Not only are there lots of great talks about many aspects of congenital heart conditions (from leading-edge technology to dealing with school issues to transitioning our teens to the adult world), there are opportunities to connect with other families and children on the same journey as you.

Adults and children of all ages are welcome. More details about the conference will be provided in the next *Heart Matters* newsletter. ■

# Obesity, exercise, and the heart

BY ASTRID DE SOUZA

Childhood obesity is a growing concern due to its increasing prevalence and its association with other illnesses and outcomes, including:

- Coronary artery disease
- High blood pressure
- Diabetes
- Premature death

In 2012, Dr Kevin Harris and his colleagues published an article about the health of the aorta in children who are overweight and obese. The aorta, the large artery that distributes blood to the body, has elastic properties that allow it to accommodate to changes in blood pressure as blood is transported in and out of the heart. Increased stiffness of the aorta changes the mechanics of blood flow and can negatively affect its proper functioning.

Previous studies have suggested that increased stiffness of the aorta may be the first sign of early cardiovascular disease. The goal of Dr Harris's study was to determine whether obese children had stiffer aortas than normal-weight children, to determine whether childhood obesity was associated with other changes in the heart, and whether it affected exercise capacity. He found that in the group of obese children, the aorta was stiffer, the heart was enlarged, and its function was impaired. His findings highlighted the importance of maintaining a healthy weight for heart health even in childhood and adolescence.

Exercise benefits the heart and plays an important role in the prevention of future cardiovascular disease. The findings from this study led us to ask the question, "Can exercise reverse some of the early changes to the heart that we see in these obese children?" We are currently doing a 12-week exercise program that looks at aortic stiffness in obese children before

and after the exercise program. Findings from this study may have important implications for the treatment of childhood obesity. We are currently looking for children who have structurally normal hearts but are overweight to take part in this study. If you know of a child who may benefit from this study, please contact me (See "for more information" below).

In other exercise research, we are currently doing a study looking at the activity habits of children with congenital heart disease (CHD). Previous studies have suggested that children with CHD are less active than their non-CHD peers. Despite their heart conditions, children with CHD need to exercise at least 60 minutes per day with suitable activity types guided by their cardiologist. Our study aims to look at the activity habits of these children and to see if an activity tracker (a little watch worn on the wrist) and specific exercise advice will help to motivate children to be more active. If you or your child may be interested in participating in this study, please contact me (See "for more information" below).

Dr Harris is an interventional pediatric cardiologist and director of the cardiac prevention clinic. He has developed a research program in vascular health and recently won the Canadian Cardiovascular Society Young Investigator Award in acknowledgement of his clinical research. He is the first pediatric cardiologist to win this national award. Dr Harris continues to lead several studies to better understand and improve the cardiovascular health of children with congenital and acquired heart conditions. ■

For more information, contact Astrid De Souza at 604 875-2120 or [adesouza2@cw.bc.ca](mailto:adesouza2@cw.bc.ca)

## Ronald McDonald House

### BC & Yukon opens new 73-bedroom facility



This summer, Ronald McDonald House BC & Yukon (RMH BC) reached a milestone seven years in the making by opening their brand new House on the grounds of BC Children's Hospital. Since opening its doors in July 2014, the new RMH BC has served over 150 families and will serve hundreds more in the year to come.

Ronald McDonald House BC is a home away from home for families who must travel to Vancouver for their child's life-saving medical treatment. At the house, financial burdens are eased and families can take comfort from a community of others who are facing similar situations. While the original facility on Angus Drive could serve 13

families each night, the new House will accommodate 73, and serve approximately 2,500 families each year.

The new, larger Ronald McDonald House BC has also allowed the organization to broaden the scope of families they serve, from mainly oncology to a number of diagnoses – from cardiac to respiratory to neonatal care.

Built to LEED Gold Standard, the new 73-bedroom RMH BC includes indoor and outdoor play areas, a fitness centre, a teen lounge, and many more innovative spaces built with family comfort in mind. For more information on staying at Ronald McDonald House BC, please visit [www.rmhbc.ca](http://www.rmhbc.ca). ■



# Meet Leslie Raffin, cardiology nurse

## Where did you grow up?

Pembroke, Ontario, a small town of 14,000 people.

## What made you want to be a pediatric cardiology nurse?

I always wanted to be a nurse from when I was a small child. My mom was a nurse. I graduated in 1985 and worked with adults in medical-surgical, spinal cord, EENT (eyes, ears, nose and throat) and emergency departments. The heart has always been interesting to me as it is the symbolic and mechanical centre of our bodies! I started working in the heart ward at Children's in 1998.

## What attracted you to work at Children's Hospital?

The kids! Children are vibrant, innocent, and fun. I love helping children get better and back to doing their activities, as well as working with their amazing families. The families have to deal with so much and they inspire me.

## Tell us about any specialties you have within cardiology.

I work with Marfan syndrome patients and do research in this area. Marfan syndrome is a connective tissue disease that can affect the heart, spine, eyes, and joints. Anyone who has

a curved spine or unusual chest bone or a specific eye problem where the lens has dislocated should ask about having an echocardiogram to look at the heart.

## Did you have a mentor?

Yes and still do. I choose mentors for many areas of my life because we never stop learning. I have mentors for work, for my music and for my own children!

## Outside work, what do you like to do for fun and what are you good at?

I have played French horn since grade 6 and play in a local concert band. We play about 10 concerts per year. I also enjoy cooking, growing vegetables and flowers, kayaking, and biking.

## Do you have any pets?

We have a little corgi-sheltie-shepherd. We got her from a shelter up north. She was living outside with her pups and keeping her pups healthy, but she was not doing well. Now though, she always has enough to eat!



## Triple Crown for Heart raises funds for heart kids

**O**n July 19, 165 riders tackled the challenging but fun road riding event Triple Crown for Heart to raise funds in support of cardiology patients comfort items for BC Children's Hospital!

Last year, they raised an astonishing \$23,000 tackling the infamous Triple Crown – Mount Seymour, Grouse Mountain, and Cypress Mountain – in one day. Now in its fifth year, the event continues to grow in both riders and funds raised.

Many heart parents, nurses, doctors, and other health care professionals got involved in the race both as participants and volunteers. Heart dad Shaun Carpenter was the top fundraiser, raising \$5,430, and pediatric cardiac surgeon Dr Gandhi participated and took second place for funds raised!

For more information please go to [www.triplecrownforheart.ca](http://www.triplecrownforheart.ca) and please think about getting involved in this fabulous event as either a volunteer or participant next summer. ■



Top fundraiser Shaun Carpenter and daughter Avery.



# The Scotiabank 5 km/Half Marathon Team



On Sunday, June 22nd our own cardiologist Dr Shu Sanatani and his team of runners tackled the half marathon in support of the CHN. He and many BCCH residents raised over \$5,000! A huge thank you to all those on the team as well as the families and board members who made fabulous posters and came out to cheer the team on.



## ANOTHER WAY TO DONATE TO CHN:

We are now part of the Charity Car Donation Program. If you have an old car that you would like to donate to the CHN go to [www.charitycarprogram.ca](http://www.charitycarprogram.ca). They will pick up your car, send you a tax receipt, and the Children's Heart Network will receive a donation!