

Heart Network Heart Matters

WWW.CHILDRENSHEARTNETWORK.ORG

SUMMER 2017



Tim and Tracey Wispinski with their daughter Hailey.

WINE GALA WRAP UP:

More than \$46,000 raised

BY SAMANTHA AITKEN

n Friday, May 5th the Children's Heart Network held its 15th Annual Wine Gala Dinner at the Diamond Ballroom in Vancouver. Over 160 guests enjoyed gorgeous city views, a fabulous dinner with wine pairings, and both live and silent auctions. It was CHN's premiere fundraising event of the year.

The evening started with a glass of Evolve Effervescence and canapés while guests admired the view and perused the silent auction items. This room was buzzing! Guests sat down to enjoy dinner prepared by executive chef Matthew

Kamieniecki while our emcee for the evening, local actor and heart dad John Emmett Tracy, entertained us with both his wit and heartfelt reflections.

We were enlightened as heart parents Tim and Tracey Wispinski shared their story of their heart journey with their daughter Hailey. They spoke of how the Children's

Heart Network has supported them along the way. They attended the Family Camp in Squamish in 2016 and were involved in the making of CHN's new awareness video (which you can see at www.childrensheartnework.org). The highlight of the evening however, was hearing from their daughter, Hailey Wispinski. Hailey eloquently shared with us her heart journey as well as her experiences with CHN and her fun times at Camp Zajac with other heart kids. So well-spoken and no doubt soon to be a regular presenter!

Sending more heart kids to camp was one of CHN's goals this year, and thanks to the energy of our auctioneer, Jody Vance, and the generosity of our guests, we collected donations totaling more than \$8,000 to benefit our kids heading to Camp Zajac this summer.

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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.

Heart Matters

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/ChildrensHeartNetwork

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.



COFFEE GROUPS NEAR YOU

These groups meet monthly; come and meet other heart parents while enjoying treats on CHN. For more information please contact:

ABBOTSFORD – Rachel Gammon

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YOUNG ADULT HEART NETWORK COFFEE GROUP

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

Lauren Fougner | lfougner@uvic.ca

THANK YOU

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



The Province of BC

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!

CHN BOARD

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SAMANTHA AITKEN – Provincial coordinator

PATTY RIPPEL - Administrative assistant

KRISTI COLDWELL – Lower Mainland Hearts of Gold vouth coordinator

KRISTA MOLIA – Vancouver Island Hearts of Gold youth coordinator



Everything at the Gala sparkled so brightly, the guests were forced to wear shades.

The evening culminated with the Glasses On/Glasses Off game and the winner took home a brand new iPad donated by Telus. In total, we raised over \$46,000! Children's Heart Network families will benefit greatly thanks to the generous support of all our attendees, supportive corporate sponsors, and auction donators. Thank you to all of our guests, donators, and the following major sponsors:

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- Dean Alexander
- The Pediatric Cardiology Associates
- Dr Brian Sinclair
- Riverrock Casino Resort
- Air Canada
- Burrowing Owl Winery
- Colby Red wine
- Chateau Ste. Michelle Winery
- Evolve Cellars
- Jane and Pete Morgan
- A & B Party Rentals
- Mark Corra
- Cindy Thaler
- Daniel's Le Chocolate Belge

Next year's gala is already booked: mark your calendar for Friday, May 4th, 2018!





Cody: A story of determination

BY ELENA HALFPENNY

ody was born on July 29, 1999. A couple of hours after his arrival, the nurse came in and told us that he was looking a little "dusky" and she was going to take him for the doctor to check out.

"There might be something wrong with his heart," we were told. Within 12 hours Cody and I were ambulanced to BC Children's Hospital with Corey, his dad, following behind. He was admitted to PICU where we met with Dr Duncan, who did an ECG, ECHO, and so on, then gave us the news that Cody had transposition of the great arteries. He explained that he would be taking our baby to the catheterization lab to place a hole in his heart to allow him to survive while he waited for surgery. This was a success and after a few days we were allowed to take Cody home to grow in preparation for his first big surgery.

On August 26, 1999 Cody was operated on by Dr Sett at BCCH. After a grueling 14 hours, we were told surgery was a success and we were allowed to see him. He was home just a couple weeks later.

That same year around the beginning of December we were at BCCH for a routine follow up when Dr Duncan informed us that Cody had developed aortic stenosis. "He needs another surgery," he said, "but we can't do it here." A short time later we were on our way to San Francisco to be operated on by world-renowned surgeon Dr Hanley. We had to leave our oldest son, Tyler, who was 2 at the time, at home with family. Dr Hanley was able to fix the stenosis and within a few days we were sent home.

Our nurse at the time at BCCH, Mandy, thought it would be best if we come for one more check-up at BCCH before the Christmas holidays started. Boy, are we glad we did. During Cody's echo on Christmas Eve 1999, they found a huge, life-threatening ventricular aneurism. We were told we had to make our way back to San Francisco. Of course, being Christmas Eve there were no flights available. Luckily, we had a private company with a jet and pilots who were available to fly us right back.

On December 28, 1999 Cody had his third open-heart surgery and the aneurism was patched. He left the operation room on a left ventricular assist device (LVAD), which in those days were massive and took up the whole room. He was successfully weaned off and again we were sent home.

Life was normal until May 2001 when Dr Duncan told us that Cody's aortic valve was failing and he needed it replaced, again it would be best to have it done in San



Cody has been through a lot, but is thriving now, due to his hard work and determination.

Francisco. So off we went for a short 1-week trip and came home with a mechanical valve.

Life was good, Cody was a happy normal kid. He loved hanging out with his friends, playing video games, skate boarding, wakeboarding, and everything else teenage boys enjoy. We only had to go to BCCH once a year for check-ups and had no problems for 11 years—until March 2013. It was time to replace Cody's valve, which he had grown out of.

I was very nervous about this surgery, maybe a premonition, I don't know. March 19, 2013 Cody went into BCCH to have his valve replaced by Dr Gandhi. Around 10 hours later Dr Gandhi came and told us it was a very difficult surgery but a success. We would be able to see him shortly. We sat and waited. And waited.

Finally, I said to Cody's dad, "something's wrong, it shouldn't take this long." Sure enough Dr Duncan came into the room and said Cody had gone into cardiac arrest on his way to ICU and was rushed back into the OR. After a few more grueling hours Dr Gandhi came out and told us that he was okay, but his heart was not. He was placed on an LVAD in hopes that in the next few days his heart would recover on its own.

The next 8 days were the most horrible days that our family has ever been through. Dr Gandhi was able to wean him from the LVAD and things were ok for a few hours, when suddenly he went into ventricular tachycardia. The ICU was turned into a mini operating room and they attempted to put Cody back on the LVAD but in the process, he had a massive stroke. Over the next few days he was cardioverted numerous times due to arrhythmias. It was decided he could not be listed for transplant due to the stroke so a portable LVAD was implanted. He had a massive, week-long gastrointestinal bleed and we were



Cody's brother Tyler, his dad Corey, Cody, and his mom Elena.

called into the hospital numerous times when they thought he wasn't going to make it.

When all the paralytics were weaned off we were able to see the extensive damage the stoke had caused. Cody could not talk, see, swallow, or move his left side. Neurology came and told us he wouldn't recover. This was awful. Words cannot express how truly horrible it was. Over the next couple months, we worked hard with Cody, trying to teach him how to swallow (which is not an easy thing to do,) show him flash cards, stretch his limbs, make him stand, make him walk, and so on.

After 3 months in ICU we were transferred to Sunnyhill where he had 6 month of intense physio, speech, school, and OT. In October of 2013 he had recovered enough to be listed for transplant. We were discharged from Sunnyhill in December of 2013 and we went home to continue our therapies and wait for a heart. During this time, Cody worked hard to get better. The stroke had severely damaged his left hand so he was fairly dependent on the people around him for help. But he could talk, walk, and eat, and managed to adapt his hand to play video games. It was the LVAD he hated. He had to have 24/7 care in case of emergencies, always had to be hooked up to a power source, and we made numerous trips to the ER for cardioversion when he was in ventricular tachycardia. Life was not good for

him. He didn't see his friends, couldn't go to school, and felt like a wait for a new heart was taking forever.

After waiting for 2 years and 8 months for a heart at BCCH, our family made the gut-wrenching decision to pull his care from there and move to adult care at St. Paul's Hospital. This was not an easy decision to make and there were many talks and consults before we decided to do this. Cody was listed with the adult program and less than 2 weeks later he was blessed with his hero heart. The surgery was 14 hours and we were told it was the longest transplant St. Paul's has ever done, as well as one of the most difficult. Seventeen days later Cody was home.

That was 6 months ago, and today Cody is thriving. He continues with his therapies, he is running, jumping, swimming, and hanging out with the Hearts of Gold teen group. He will be returning to school in February and will graduate in 2018. One year behind schedule but for all he was been through we think this is pretty amazing!

These last 4 years have been very stressful emotionally, physically, and mentally on our family but we have made it through and have grown stronger and closer because of it. We are so proud of Cody's brother Tyler because at 14, he grew into the role of caregiver to his brother and grew up faster than he should have had to. And we are so proud of Cody for his hard work, motivation, determination, and never giving up.

Supporting Mila's Fund on two wheels

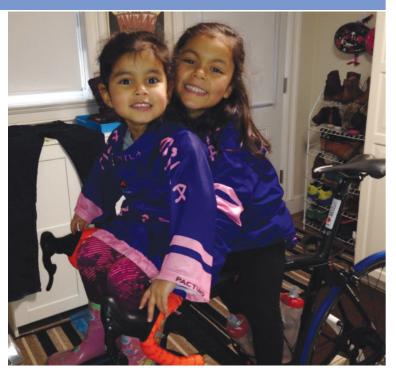
BY LISA AND DUSTIN DICKOUT

ach year the Children's Heart Network organizes two summer camps, one for children ages 8 to 12 and one for teens ages 13 to 19.

The intent of Mila's Fund is to provide funding to ensure that all heart kids throughout BC, regardless of family income or where they reside, have the opportunity to attend summer camp with the Children's Heart Network. While Mila was alive, she was too young to attend the CHN camps, but we were grateful that these amazing opportunities existed. Camp provides the chance, for a few days, to set aside the daily struggles that often come with living with heart disease. It creates an annual experience for heart kids to connect with peers and to form friendships with others who face similar challenges. It is within this safe environment that they can gain independence, explore the outdoors and be active, while still having their medical needs met.

We believe that the gift of summer camp is just one of the many ways that we can help other heart families to embrace life. We feel certain that Mila would be proud to be part of the efforts to help make summer camp available to all heart kids living in BC.

The Tour of Sufferlandria has been completed, and it was quite an adventure. Around Stage 5 of the ride, I questioned



Mila's Fund is all about ensuring kids with CHD get to go to camp. Pictured here are her little sisters Kala and Asha.

my sanity and wondered what I had committed myself to. Nonetheless, I had a lot of fun and I always feel very close to Mila when doing things like the Tour. We would like to thank you for your generous support of our family and for Mila's Fund. In the last two weeks we have raised over \$2600. It truly means a lot and we are most grateful.

We know that there are many great causes to support. Thank you for supporting this one in Mila's memory.

Hold the date for the 2017 Growing Up With Heart Disease Conference – "Journeys"

November 4th and 5th, 2017 9:00 am – 4:00 pm at the Chan Centre for Family Health Education, Vancouver

This is a unique conference that brings heart families, heart professionals, and others together in order to empower heart children and their families through their physical and emotional health and provide knowledge in advances in cardiac care and support for heart children.

This year's conference includes a wide variety of session, including special sessions for teens with CHD. A children's program with licensed childcare is also offered for a fee.

The full conference program and registration will be available in early September. Information regarding registration will be posted on the Children's Heart Network website at **www.childrensheartnetwork.org**.

Jonathan: Beating all the odds

BY SUSAN KONYU

Jonathan's journey started early. I was 22 weeks pregnant when a very wise technician from our local hospital spotted something unusual and referred us to BC Children's Hospital for further testing. We were trying to be realistic, this was routine, but when we were met by a team of people, we knew something was up. After all the testing, we were taken into a counselling office where the diagnoses was given of our much awaited son. We were told he has something called hyperplastic right ventricle, pulmonary atresia, VSD, tricuspid atresia, and ASD. The only real thing we heard was three open-heart surgeries before the age of 3, with the first one being within 24 hours of birth. The drive home was very quiet.

We had no idea what the future held, and back in 1999 the internet was not as full of information overload as it is today in 2017. We read some terrible stats on life expectancy on this type of heart condition that set us into panic mode. We had a few more team meetings and tests throughout the pregnancy, and felt much reassurance that as a training hospital BC Children's was the cutting edge on new procedures, techniques, and the latest information.

We got through the first surgery, (BT shunt) but were shaken by such a beginning to ours son's life. Very quickly we became nurses looking for signs of distress. I bought a stethoscope to be prepared. He had trouble feeding, as he was only 4 lb. 10 oz. at birth, and too weak to nurse, so he had to be fed by an NG tube through his nose. It was crucial he "bulk up" for his next open heart at 8 months. I pumped around the clock as I felt it was the one gift I could truly give him. Quickly our house became a hospital with tubes, syringes, and kangaroo pumps; he would reflux 20 or 30 times a day, so it was a challenge. Occasionally the tubes would come out of his nose as he became more active and off we go for a 45 minute drive each way to the hospital to get it put back in under X-ray.

At 8 months old, he was showing signs of distress and it was decided it was time for surgery number two, called the bidirectional Glenn procedure. This one was longer, more complicated, and hard on our hearts because we had the joy of getting to know him for the past 8 months vs. the first surgery where we had only known him for less than 24 hours. Up at the crack of dawn, nothing to eat or drink, and off we went to the hospital before 6 a.m. I gowned up and carried him into the OR and laid him down on the table with 6 or 7 hospital staff watching me; I was watching them back, hoping they had a miracle touch for my baby.



Jonathan has had over 15 surgeries.

Once I walked through the doors I cried from every pore I had. This was tough.

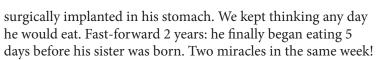
After recovery, I was called into the ICU and noticed more than a few people around his bedside. It appeared he had lost oxygen and had a mini stroke. He was diagnosed with cerebral palsy, hemiplegia, affecting his left arm and left leg. Again, we were in the dark: what did this mean? Sometimes, Google is not your best friend.

As time went on, the tube feeds were getting harder to deal with as he was getting more active and pulling them out. We faced a difficult decision and had the tube

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Jonathan: Beating all the odds —continued from page 7





As my husband continued to work to support us, I was at Children's Hospital Tuesdays, Wednesdays, and Thursdays very week for a year with a standing appointment for physio, cardiologist, feeding team, pediatrician, etc. It kept me busy.

By age 3, it was time for the big one, the 5 to 6-hour Fontan surgery. This was the surgery that would alter his life and sustain him into adulthood. We were told not to sit in the waiting room. They gave us a pager and we walked the Sea Wall and stopped at a local church, lit a candle, and said our prayers. As we pulled into the hospital parking lot, the pager went off: done!

Since that time, Jonathan has had over 15 other surgeries, some minor, some more about his CP, where they lengthened his heel cord and hamstrings, which put him in a leg cast to his hip and wheelchair for 2 months in grade 1. He has come through everything with amazing results and continues to beat all the odds.

Now in high school, he is thriving. He has a part time job, good grades, friends, and he just got his N for driving and drives with a spinner knob on his steering wheel to accommodate his one good arm. He is finishing grade 11 this year with full academic credits to graduate, and has been accepted into college a year early for his heavy duty mechanic course.

We are blessed to have two amazing children, a daughter who is kind, smart, and excels in sports and understands the challenges her brother has faced. We are immensely proud of both of them.

Never did I allow myself to foresee the future as Jon was so fragile. I used to think his life might be about chess and other





Jonathan recently completed a 4-day hiking trip in the mountains — unimaginable a few short years ago.

quiet activities. I used to sit in the parking lot at preschool in case something went wrong with his heart. Recently he joined a class called Outdoor Pursuits, which is about active living and outdoor education. I thought perfect (in a way...). Now, I am waiting to pick him up from his school trip after hiking for 4 days in the snow, with an elevation of 2093 m while carrying a 40-lb. pack on his back--go figure. Life is a gift and I am eternally grateful he has had the opportunity to live life large.

MEET THE CARDIOLOGIST:

Dr Shreya Moodley

Where did you grow up?

I was born in the beautiful coastal city of Durban, South Africa and grew up in an exciting time as the country transitioned from apartheid to democracy during my childhood and teenage years. During my first decades I also spent some time living in the United Kingdom and Canada. Once I reached my university years I returned to Canada, met my husband, and now call another beautiful coastal city, Vancouver, my home.

What made you want to be a pediatric cardiologist?

It was a very natural combination of passion for my work and compassion for my patients that drew me to pediatrics. Pediatric medicine resonated with me; it fulfilled my desire to make my life's work helping others, with a patient population that really stole my heart. Children are honest, intrinsically happy, and remarkably curious about the world. They are resilient and positive and remind me of all the little joys in life. There is a lot of fun in caring for children - they laugh at my jokes and ask the best questions. My interest in cardiology came during my residency training. Cardiology satisfied my intellectual craving for complicated physiology and interesting disease processes. I found the patient population diverse, the evolving technology exciting, and the medical and surgical management promising. I enjoy getting to know my patients and their families over the years and watching them grow. This long-term relationship is a unique privilege. Pediatric cardiology is a challenging but very rewarding career.



Dr Moodley enjoys some time with her daughter Kaavya.



What do you like about working at BCCH?

BC Children's Hospital is a wonderful place to work because there is a shared passion and dedication when it comes to caring for sick children. The teams that I work with work hard and support each other. People take their roles seriously but also know how to have a bit of fun. Some of my best friendships blossomed at this hospital.

Do you have any specialties within cardiology?

My area of expertise is echocardiography. In particular I perform fetal echocardiograms, diagnosing congenital heart disease during pregnancy. This provides information to families to help them make decisions regarding pregnancy and postnatal care. It also prepares the medical team to allow them to provide optimal management to the newborn with heart disease.

Can you tell us about your mentors?

There have been many influential people who have inspired or supported me through my journey to becoming a pediatric cardiologist. From a spiritual teacher who taught me at a young age the joy of "selfless service," to my grandparents and parents who lived that message, to my husband who always encourages me. I am constantly learning from those around me, including my patients.

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

I have two young children – a 2 1/2 year old daughter and a 9 month old son. Hearing my kids squeal in delight as they splash around with their water table while I soak in some sunshine is my current description of a pretty fun day. Otherwise, I love travelling; learning about different cultures, and trying new foods. I am also told I am a good cook and baker. I love experimenting with flavours and presentation.

Do you have any hobbies?

I enjoy being creative and for many years I would draw, paint, and write poetry. My daughter, Kaavya, whose name means poetry, loves art, which has given me a good excuse to bring out my easel!

HEARTS OF GOLD



Camp is a great bonding experience, and a time to connect with one another away from life's everday distractions.

My Hearts of Gold and Camp Zajac experience

BY MINA SHAHSAVAR

or a long time I was in search of a group of people who understood the ins and outs of growing up sick, more specifically, growing up with congenital heart disease. I wanted people in my life that understood all of the fears and challenges that come with it, as well as the many trials and triumphs that we face over the years.

It was not until my fantastic nurse on the cardiac ward at BC Children's Hospital connected me with this lovely network that I really found my place. The Children's Heart Network Hearts of Gold youth group is such a special place to have a home, a second family of sorts. Our fearless leader Kristi is awe-inspiring in her own journey through CHD, really encouraging and pushing us to reach our full potential despite the health-related obstacles that we all cope with. Each month we get together and enjoy a special outing doing something fun, from bowling to boat cruising and everything in between.

Camp is a special annual event that is put on by the Children's Heart Network for us Hearts of Gold kids to spend an entire long weekend together out at the Zajac Ranch in Mission, enjoying various thrilling experiences together as a group. It really is the perfect place for us to go because the incredible people there, including BCCH's own Megan Crane, have made it so that just about anyone can participate in the activities, regardless of each individual's physical ability level. Camp is a great bonding experience, and a time to connect with one another away from life's everyday distractions.

My hope for this community is that it continues to grow in people and in value. I would love for those who are not sure if this is the right fit for them to just try it, you will be surprised at how quickly connections are made. I felt like I was alone in this journey for so long, and now I have friends for life that get me in a way that very few others do.

For those of us who have been a part of this group for some time now, I hope we always remember how very lucky we are to have a place like this, not everyone does. Please join us in making lasting memories with a diverse group of people that all share in the same struggle, you will not look back!



Daniela, Sophia, Mina, and Samantha.

Thanks to our many donors for making the camp experience possible for so many kids. If you would like to help send a heart kid to camp, donate now at www.childrensheartnetwork.org.



BY DRS SUSAN O'GORMAN AND GILLIAN MURPHY

ith summer coming it's important that people who have had transplants remember to stay hydrated and protect their skin from sun exposure. Below is a clip of an article reinforcing the importance of using sunscreen if on immunosuppression.

People who undergo organ transplants are living longer than ever, with some 250,000 patients alive in the US as of 2011. With improved survival, however, the increased risk of skin cancer in transplant patients has become ever more apparent. Transplant patients are given drugs to suppress their immune system so that it will not attack the donated organ as a foreign invader; the drugs enable the body to accept the organ. Unfortunately, immune-suppressed people, including recipients of all major solid organs (heart, lung, kidney, pancreas, liver), have a much higher risk of skin cancers than people in the general population.

Squamous cell carcinoma, the second most common skin cancer, is the most frequent problem, occurring 65 to 250 times more often in transplant patients, but melanoma also occurs 6 to 8 times more frequently. Kaposi's sarcoma, basal cell carcinoma (the most common skin cancer), and Merkel cell carcinoma (a virulent but normally very rare skin cancer) are also more common in transplant patients.

Though UV exposure is an important skin cancer risk factor for transplant patients, it can be readily reduced. Following a transplant, patients must be exceptionally diligent about using sun protection. First and foremost, they need to seek the shade and avoid sun exposure when the sun is most intense, between 10 a.m. and 4 p.m. in temperate zones. This is true even on cloudy days, since UV rays pass through clouds. If sun exposure is unavoidable, they should wear bright- or darkcolored, tightly woven or knit opaque clothing. Ideally, this should include long-sleeved shirts, long pants, a broadbrimmed hat, and wide-lensed wraparound UV-blocking sunglasses to cover as much skin as possible. For greater assurance, they can seek specially designed UV-protective clothes that display an ultraviolet protection factor (UPF) label, indicating their level of sun protection; clothes with a UPF of 50 or higher are needed for transplant patients.

What's Happening?

Cultus Lake Water Slides Picnic

A fabulous day of fun in the sun with hundreds of other CHN members. A great way to connect with BC heart families! Due to tight times financially we won't be hosting the barbeque this year so, please pack a picnic lunch.

When: 19 August, from 10 am **Where:** Cultus Lake Waterpark

RSVP: saitken@childrensheartnetwork.org. Please ensure your membership is up to date.



Growing Up with Heart Disease

The Children's Heart Network is pleased to present Journeys, the ninth Growing Up with Heart Disease conference. This is a collaborative conference by and for families and health care professionals. It's an opportunity to learn from the experts—physicians, nurses, psychologists, researchers, fellow parents, and other heart kids—and connect, share, support each other.

When: 4 – 5 November 2017

Where: Chan Centre for Family Health Education

(at BC Children's Hospital)

More info: chnconference@childrensheartnetwork.org,

call 1 877 833-1773 or see next page.

Renew your membership & consider a donation

This is the perfect time of year to renew your CHN membership (\$25 per family per year) and to consider making a tax-deductible donation to CHN. www.canadahelps.org/en/charities/childrens-heart-network/#donate_now

Thank you to our generous donors









GROWING UP WITH HEART DISEASE

JOURNEYS

November 4-5, 2017

A collaborative conference by professionals and families for professionals and families

Chan Centre for Family Health Education (at BC Children's Hospital) 950 West 28th Ave., Vancouver, BC

he Children's Heart Network is pleased to announce the ninth Growing Up with Heart Disease conference. This is a collaborative conference by and for families and health care professionals. It's an opportunity to learn from the experts—physicians, nurses, psychologists, researchers, fellow parents, and other heart kids—and connect, share, support each other.

Parent and Health Care Professional Program

Plenary speakers, concurrent sessions, and workshops on:

- Current research and innovations in pediatric cardiac care
- Strategies for supporting children with heart disease
- Heart health and physical activity
- Dealing with issue like hospital discharge, school, and nutrition...and don't miss the conference favorite: a special presentation by youth from the Hearts of Gold Youth Program!

Children's Program

The Children's Program will be available for infants (6 months or older) and children up to age 12. (Babies under 6 months can attend the conference sessions with a parent.) The program welcomes children with heart disease and their siblings. Qualified early childhood educators will care for and have a variety of fun age-appropriate art and activities for the kids. You will be able to relax and enjoy the conference while your kids play and have lots of fun!

Hearts of Gold Youth Program

The Youth Program welcomes all youth with heart disease and their siblings aged 13-19 years. The Hearts of Gold Program caters to the needs and interests of youth and provides a forum for expressing their ideas related to living with heart disease.

Watch for online registration coming soon!
Health care professionals, parents, youth, and children of all ages are welcome.