



Carmen, Dalena, Mallory, and Kevin Gosnell

## Living with long QT syndrome

BY CARMEN GOSNELL

Our world came crashing down in March 2006. My niece had an odd episode with her heart and, unsure which side of the family it came from, we all got tested for long QT syndrome. Long QT syndrome (LQTS) is a rare inherited heart condition that causes irregular heartbeats. This can lead to palpitations, fainting, and sudden death due to ventricular fibrillation. After many months of anxiety waiting for our results to come back we got a call to come in to the doctor's office. My heart sank hearing that my two daughters (ages 2 and almost 4) and I tested positive for

long QT. My first feeling was sadness and then that quickly turned to disbelief. Looking back we determined that there had been four sudden "heart attacks" in our extended family and now 17 of us have tested positive for LQTS.

During my first two pregnancies I had experienced tachycardia; at one point my heart rate reached 211 beats per minute and I was hospitalized. I had heart ablation done, still not knowing I had long QT. It wasn't until 3 years later that we were diagnosed. Both of my girls, Mallory and Dalena, tested positive but my son was

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### Volunteers needed

Our families enjoy the spring, summer, fall, and winter gatherings that the 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)

### CHN STAFF

SAMANTHA AITKEN –  
Provincial Coordinator

DANIELLE SEGUR –  
Administrative Assistant

KRISTI COLDWELL – Lower  
Mainland HOG Youth Coordinator

KRISTA MOLIA – Vancouver Island  
HOG Youth Coordinator

### Heart Matters

5151 Canada Way, Burnaby, BC V5E 3N1

Tel: 604 521-3037 | 1 877 833-1773

[chn@childrensheartnetwork.org](mailto:chn@childrensheartnetwork.org)



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.

negative. We were all put on beta blocker medications, which slow down the heart and help to prevent irregular heartbeats. The girls began to see Dr Sanatani regularly, whenever he came to our area with the outpatient clinics. At the time, we lived in a remote community outside Terrace, BC with no access to an ambulance. Thus, if we needed one it was quite scary.

We relocated to Vancouver a few years later and if I thought being so far away from an ambulance if we needed one was scary, I soon found out how wrong I was. Living in the city and dropping my kids off at school was even scarier. I always had the fear of something happening and that I wouldn't be close enough.

Sure enough, when Dalena was in grade one, I got the frightening phone call from the school. All I could hear was "Is this Carmen? We have Dalena here in the office and we are waiting for the ambulance to arrive." It was a good thing I was very close by to her school.



Dalena at the Aquarium

I had been on my way to Children's Hospital for an appointment with my son. I could not drive fast enough and I just wanted everyone out of my way. I parked my van, ran into the school as the ambulance was still driving down the street. I could see my baby girl sitting with the principal, she was clammy, very pale and could still not talk. The paramedics came in and did an ECG right away and loaded her in the ambulance. Along the way they did another ECG and that one was still abnormal. Dalena had been sitting in class and all of sudden she had chest pain and couldn't talk. She tried to put her hand up to tell her teacher, but nothing would come out. Her teacher could tell something was wrong and immediately got the principal. To this day I am so grateful that my daughter was in good hands. The school handled things very well.

At the hospital we were seen by a doctor that I wasn't familiar with. I felt scared and very numb and it felt like all I could hear was a snowy TV. I recall them talking to me about a pacemaker or going another route and implanting a Reveal device. It was decided that a Reveal device would be implanted and it would be a simple procedure. They told me it would be simple, but in the back of my mind I was terrified. A Reveal is a device about the size and shape of a rectangular cigarette lighter. It monitors your heart's rate and rhythm and sends the results to the Heart Centre at BC Children's.

The plan was that Dalena would keep



Mallory on her way to basketball

the device in for 3 years and if she had more episodes we would look at other options. She did have another episode of some sort, but we're not sure what exactly it was as the battery was dead in the remote control to activate her Reveal device. I learned very quickly to change the battery every month (more often than required) just to be on the safe side. When Dalena has a new teacher or caregiver I have to teach them how to use her device in case of any episodes. This means holding the remote over her device and pressing the button until the green arrow comes on. Many people are scared of having to use it and I don't blame them! Having to carry a purse around with something so critical (the remote) at the age of 9 isn't normal, but is our "new normal." Give a 9-year-old girl the responsibility of carrying a purse everywhere and it will eventually get left in the mall washroom, which can be very frightening.

Managing the medications for all four of us (my son has other health issues) can be very challenging. I was always worried that I would make an error in giving medication to Dalena. I accidentally did give her Mallory's medication one night. I love the advantage of having our medication "blister packed" now. When having to administer medication between the four of us, it makes life a tiny bit more simple.

The girls are now 11 and 9 years old and both are doing well. I'm glad to say that



*Out here we raise spirits.*

## Camp for heart kids at Zajac Ranch

If you live in the Southern Interior region of BC and would like to come to camp we could cover your transportation costs to get to camp – flights and bus travel sponsored by "Cops for Kids." Camp dates are as follows:

*Hearts of Gold* (ages 13 to 18)

May 16 – 19, 2014

*HeartBeats* (ages 8 to 12)

July 8 – 12, 2014

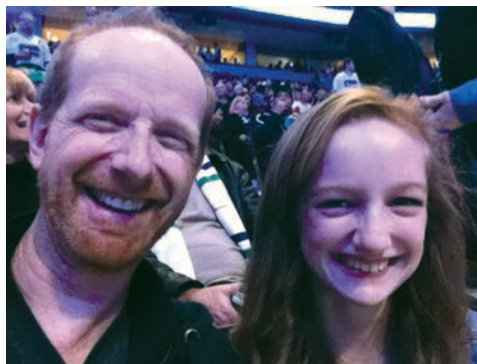
For more information  
email Samantha Aitken at  
saitken@childrensheartnetwork.org



my eldest daughter, Mallory, hasn't had any episodes but I worry constantly as she is very athletic. She has had the most difficulties with the beta blockers (weight gain and severe headaches) so she has had to change her meds a few times. We think we have found the right one for now. I was initially very nervous to allow them to play soccer but after the okay from cardiology they have been enjoying a fairly active life; Mallory is playing basketball as well.

Seven years ago I was in denial – I didn't think that this diagnosis would have a drastic impact on our lives. Today I'm thankful for the beta blockers and for my close proximity to our cardiologists. Dalena has cardiology check-ups every 6 months and Mallory and I go annually.

I am always making the people in our lives aware of the symptoms: chest pain, shortness of breath, dizziness, fainting and sudden cardiac arrest; however, I really try to focus on being positive! I am so happy to have connected with the CHN, thank you for allowing me to share a tiny piece of our life. ■



Jay and Sophia at a Canucks game

A Canucks experience thanks to



On October 30th we were fortunate enough send one of our heart kids, Sophia Draper and her dad Jay, to see the Canucks play the Detroit Red Wings thanks to a fabulous non-profit organization called Kids Up Front. Kids Up Front is a charitable organization that provides access to arts, culture, sports, and recreation for kids who otherwise would not have the opportunity. Generous folks donate their tickets to KUF who then distribute the tickets to child-serving partner agencies, of which the CHN is now a partner. Jay and Sophia had a memorable evening sitting right beside the Canucks bench!

### Thank you to Kids Up Front! Got spare tickets?

Whether it's a game, a concert or any event, you'll be creating a smile, a laugh, an experience. Contact [info@kidsupfrontvancouver.com](mailto:info@kidsupfrontvancouver.com).



## Heart heroes

### Rhys Isaac's gift

The Children's Heart Network would like to give a heart-felt thank you to an amazing young man. Rhys Isaac had his 6th birthday at the Extreme Air Trampoline Park on November 24, 2013. Instead of bringing him gifts, he asked his friends and family to make donations to CHN in memory of his cousin Mila. Rhys and Mila are pictured here at a family barbeque in the summer of 2012. He raised an incredible \$485!

Rhys would like the contributions to go to something that "would make Mila really happy." Thank you Rhys, we are grateful for your thoughtfulness!



Rhys with his cousin Mila

# Dental care for children with heart disease

Children with congenital heart disease are at risk of developing an uncommon but life-threatening heart infection called *bacterial endocarditis* from bad teeth or gums. We all have germs in our mouths. When teeth have cavities or gums are infected, germs can get into the bloodstream and travel to the heart lining or valves, causing a serious infection. Taking care of your child's teeth helps prevent endocarditis and keeps your child's heart healthy.

There are a few factors unique to children with CHD that put them at greater risk of tooth decay:

- Medications in liquid form are usually sweetened with sugar. Since children with CHD may have to take medications for a long time, the sugars can collect on the teeth and add to tooth decay.
- Some cardiac medicines such as Lasix can decrease saliva, leading to a build-up of plaque on your child's teeth, causing tooth decay.
- Some children with congenital heart disease can have weak tooth enamel leading to increased tooth decay.

## Tips to help you care for your child's teeth and heart

- Ensure your child has two dental checkups per year, starting as soon as your baby has teeth.
- For babies, begin cleaning teeth twice a day as soon as they appear. Use a soft baby toothbrush or small piece of soft cloth.
- Do not settle your baby to sleep with a bottle of milk or juice in his or her mouth. Milk, juice, and formula all contain sugar, which can cause tooth decay when allowed to sit in the mouth.
- Limit sugary fluids in sippy cups throughout the day.
- For toddlers and older children, brush teeth at least twice a day. Floss teeth once a day.
- Help young children up to 8 years of age with tooth brushing to ensure that they have cleaned all tooth surfaces adequately.
- Give medicines before brushing your child's teeth.
- Use a tiny amount of fluoride toothpaste to brush your child's teeth. Fluoride helps teeth develop a hard outer shell that is more resistant to decay. Don't let your child eat the toothpaste, since too much fluoride can be harmful.
- Choose healthy foods – good nutrition promotes a healthy body, healthy teeth, and resistance to disease.
- For children with braces, check with your cardiologist to find out whether antibiotics are needed for placement or adjustment of braces.
- Ensure your child wears a mouth guard for contact sports.
- Children with certain heart problems have a higher risk of endocarditis and should take antibiotics before dental procedures (these preventive antibiotics are called *antibiotic prophylaxis*). If you are not sure if your child needs antibiotic prophylaxis, check with your cardiologist.
- Children needing heart surgery should have a dental checkup and any required dental work before the surgery.

For more tips on caring for your child's teeth, talk to your dentist and dental hygienist. ■

## BC Children's to launch new heart transplant program

BC children who need a life-saving heart transplant will soon be able to receive the procedure at BC Children's Hospital. BC Children's has received approval from the Provincial Health Services Authority to establish the program.

Until now, most children who needed a heart transplant or ventricular assist device therapy (or both) needed to travel out-of-province to either Stollery Children's Hospital in Edmonton, or, on rare occasions, to the Hospital for Sick Children in Toronto. This new program will enable BC families to access this very specialized service closer to home.

The new program will operate as one of two transplant sites within the Western Canadian Children's Heart Network, a network of children's hospital and health centres from Manitoba through to BC that collaborate to provide access to pediatric cardiac care and surgery.

Since 2010, BC Children's has added new medical personnel, introduced a number of practice changes, and made financial investments that are continuously improving the already strong cardiac surgery program. In addition the Pediatric Intensive Care Unit has been using the Berlin heart as a stepping stone to heart transplant and ventricular assist devices. These artificial hearts have already saved many children's lives and are continuing to do so.

The new program is expected to provide about three transplants per year. ■



# Shelagh Ross: Congenital heart disease pioneer

I was born 51 years ago in Toronto, the youngest in a family of four kids. The first clue that something was wrong was that I didn't have the strength to nurse, and I had blue spells. I was diagnosed in that first year with tetralogy of Fallot, one of the most common congenital heart defects, made up of four related defects. I was also born with two sets of bowels and intestines and at first that was my biggest problem because I wasn't able to properly absorb food and gain weight, but that was fixed with surgery early on and that part of me has been okay ever since.

At age two I had the Blalock-Taussig shunt as palliative surgery to help increase blood flow to the lungs (they took a major artery from my right arm and used it to re-route the

considered very risky, with about an 80% mortality rate. The surgeons were Drs Mustard and Trussler. Dr Mustard would make me run up and down the stairs at the hospital before listening to my heart with a stethoscope (before the days of treadmills and stress echos) and to me he looked exactly like the wizard in the *Wizard of Oz*.

I stayed at Sick Kids for about two months to recover and basically, besides the needles and being away from home, I enjoyed being treated like someone who just had something very special happen to them.

Life after surgery was a whole new world for me. I roared around on my bike, played tennis, became a ski instructor at 16, and in grade 13 won the Toronto schools tennis finals.



From left: At age 4; with her dog; speaking at ToF conference in France in 2013.



blood). It was all they could do at the time and the hope was that I'd live long enough to survive open heart surgery when I was older and stronger. My parents were told I would likely have stunted growth and perhaps they were right. I'm "short" at 5'7" compared to my 5'10" sisters and 6'4" brother!

I was sick a lot with infections and I remember often being cold and tired. I still have a hard time staying warm, and often wonder why I live in Ontario and not somewhere sunny and warm! I'm told I used to squat a lot, which apparently kids with my heart defect do to cut off circulation to the legs and divert the blood to the heart. I also used to get terrible headaches. But I think I was fairly oblivious to my problems, and like most kids I just wanted to keep up with my siblings. I think I can probably thank them for growing up "normal" because they certainly didn't coddle me.

In 1970, at age 8, I underwent nine hours of open heart surgery at Toronto's Sick Kids Hospital. In 1970 it was still

I had lots of friends and did all the things normal kids do, including things I shouldn't have done. I knew I had a heart condition but I felt normal. In addition to things heart-related, I have scoliosis, migraines, and am very allergic to peanuts; even though I'm very careful and carry an EpiPen, the peanut allergy has always been the main reason for visits to the hospital ER.

From age 18 to 33 I saw a cardiologist every year, and every year he said, "Things are great!" I'd been told I wouldn't be able to have kids but when I was about 19 the cardiologist said, "I don't see why not." I know now that no one really knew if it was safe or not; they just didn't know. I got pregnant at age 28 and despite not having any heart-related care besides an ultrasound on the baby's heart, everything went smoothly and I felt really healthy and energetic. After my son, Graham, was born I thought I was fine but in retrospect I think I was unusually tired and

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Shelagh and her family celebrating her 50th birthday

during those first few years I really struggled with fatigue and migraines. For several years we tried to have another baby but had no luck. I think it was actually a blessing because my health was great—until I was 33.

I woke up early one Victoria Day weekend in May with my heart pounding so hard my husband thought there was an earthquake. My son was 4. The big lilac tree outside the front door was in full bloom, along with the lily of the valley, and I was so sad to be leaving in an ambulance. I was diagnosed with ventricular tachycardia, a life-threatening heart arrhythmia. After three hours of constant pounding I was put under anesthetic and my heart was shocked back into rhythm. I woke up feeling like I'd been hit by a truck, but I was basically feeling normal again. For three weeks I underwent tests at the Toronto General Hospital, and became a patient for the first time at the adult congenital clinic—a clinic I didn't know existed! My pulmonary valve was leaky and my heart had become so enlarged that I would need a pulmonary valve replacement. This was in 1994, pre-Internet, and I knew very little about my heart condition. The lead-up to surgery was pretty scary for me and it was compounded by having to be suddenly away from my family. I was in the hospital for three weeks having tests and my husband and son would come to visit me and invariably my son's clothes would all be on backwards. My little son would get up on my bed, eat my lunch(!), then fall asleep.

I was scheduled for surgery in November (six months away) but they advanced the date and in July I had surgery for a pulmonary pig valve replacement. I stayed in the hospital for all of five days, and was at my sister's wedding two weeks later. About six weeks after surgery I resumed my regular activities, including tennis, bike riding, walking with my dog, and working.

Despite everything I feel very healthy and generally live a pretty ordinary life. I have a BA in English from the University of Toronto and have travelled a lot (including hitch-hiking across Canada, walking down and up the

## Find out more about the Canadian Congenital Heart Alliance

If you would like to learn more about Canadian Congenital Heart Alliance, visit their web site at [www.cchaforlife.org](http://www.cchaforlife.org). Membership is free.

If you'd like to get involved, e-mail Shelagh Ross at [communications@cchaforlife.org](mailto:communications@cchaforlife.org).

**THE CANADIAN CONGENITAL HEART ALLIANCE  
NOW HAS A BC CHAPTER. FOR MORE INFORMATION  
ABOUT THE BC CHAPTER, CONTACT JULIE BARD AT  
[BCHEARTS@CCHAforLIFE.ORG](mailto:BCHEARTS@CCHAforLIFE.ORG).**

Grand Canyon, and backpacking through South America).

I work in publishing, my son is now 23 and about to graduate from university, and I generally can do most things I want to do. I have my parents, and particularly my mom, to thank for all the care she gave me through those years — and rewarding my hospital visits with an Eskimo pie from the vending machine! She's 84 and she still worries about me. If I'm lucky I will live long enough to have another surgery to replace the pulmonary valve because at some point it will wear out. I know that I'm actually old for a CHD patient (though I know two people with the same heart condition who are in their 70s!) and of course I worry about the future. I try to manage stress and stay fit by walking and biking, and working from home allows me to manage my own time.

In 2004, I and three other patients started the Canadian Congenital Heart Alliance ([www.cchaforlife.org](http://www.cchaforlife.org)), a registered non-profit, to support and advocate for Canadians with congenital heart disease. We have been working as volunteers to educate patients and the public that congenital heart defects lasts a lifetime: they can be repaired but are never fixed. About half of all patients will require follow-up surgeries, medications, or devices like pacemakers and implantable defibrillators. Back in the 1960s when I was a kid only about 20% of us survived; now it is around 95% thanks to incredible medical advancements! As a result, there are now more adults with CHD than kids (about 100,000 adults vs. 80,000 kids in Canada). The problem is that the healthcare system hasn't kept pace and there are too few cardiologists specially trained in adult CHD, too few hospital beds, too long wait times for surgery, no social workers, and basically no support system in place to help patients. The Canadian Congenital Heart Alliance has worked closely with both adult and pediatric medical professionals and patients across Canada to raise awareness of congenital heart disease and the need for lifelong expert care. With 95% of children with heart defects living to adulthood and well beyond, and we are working to ensure that the care and support is there for them every step of the way. ■



## HEART MAMA/PAPA COFFEE GROUPS

These groups meet monthly, come and meet other heart parents while enjoying treats provided by 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

**LANGLEY/ABBOTSFORD** – Tecia Beulens  
tbeulens@telus.net

**MAPLE RIDGE/TRI-CITIES** – Amy Watkins  
amylouwatkins@hotmail.com

**CHILLIWACK** – Chantelle Bisschop  
bissch18@telus.net

**VICTORIA** – Teri Godin | terigodin@gmail.com

**NANAIMO** – Andrea Van Rossum  
andrea.vanrossum@gmail.com



## YOUNG ADULT HEART NETWORK COFFEE GROUPS

We are thrilled to announce our two new groups for graduates of the HOG program or any young adults living with heart disease. For more information please contact:

**VANCOUVER** – Corey Zinger | zinger92@telus.net

**VICTORIA** – Lauren Fougner | lfougner@uvic.ca



WE ACKNOWLEDGE THE  
FINANCIAL SUPPORT OF  
THE PROVINCE OF  
BRITISH COLUMBIA.



Santa and Paige

## VANCOUVER ISLAND HEARTBEATS CHRISTMAS PARTY

The Heartbeats families on Vancouver Island gathered at the infamous Butchart Gardens on December 7th in Brentwood Bay for this year's Christmas party. Families came from as far as Nanaimo, Cobble Hill, and Duncan. A private party room was set up with crafts, endless food, and plenty of space for families to mingle. A highlight for many children was taking several rides on the Rose Carousel. Santa was also able to make it to the party and give the children a North Pole welcome and treat. Families reconnecting and new families connecting during and following the party as they strolled through the frosty gardens was a pleasure to witness.

## HELPFUL WEBSITES

[www.heartbeats.ca](http://www.heartbeats.ca) – Supporting Children with Heart Disease

[www.chdquilt.org](http://www.chdquilt.org) – The Congenital Heart Defect Awareness Project – Passionately promoting CHD awareness, one stitch at a time.

[www.westerncanadianheartnetwork.ca](http://www.westerncanadianheartnetwork.ca) – Western Canadian Children's Heart Network

[www.achaheart.org](http://www.achaheart.org) – Adult Congenital Heart Association

[www.cchaforlife.org](http://www.cchaforlife.org) – Canadian Congenital Heart Alliance





Adrien and Santa



Hudson, Hayley, and Hayden



Kim and Philippe



Avery



Hawi, Beza, and Mesky

## Lower Mainland CHN Christmas party

On December 7th we hosted the 20th annual CHN Christmas Party, and what a success it was! Over 250 members of CHN celebrated the holidays with a fabulous brunch at the Metrotown Hilton Hotel. The festivities started with a live show performed by Bertolt the Magnificent, who had both children and parents giggling endlessly. We decorated gingerbread men, and made candy cane reindeer and holiday ornament at the craft tables. Some had their caricatures drawn, some had airbrush tattoos and some had their faces painted. The highlight of the event was when we heard the sleigh bells and both Mr and Mrs Claus arrived to have photos with all the children!

We would like to send out a heart-felt thank you to the Metrotown Hilton, to Bob and Dee McLennan, and to all the volunteers who helped make this event so special. Happy New Year! ■



## BRING ON THE FOOD!

The Vancouver Island Hearts of Gold (VIHOG) teens enjoyed their annual Christmas Dinner on December 19th. White Spot was the voted favourite restaurant this year and proved to be a good choice. From milkshakes, appys, mains and a few who had room for dessert (or a second burger!) we were stuffed by the end of the evening. The group looks forward to future events this year such as a hockey game, ceramics painting, and definitely camp in May!





# MOVIES, AERIAL CLIMBING, AND A BOAT CRUISE

HEARTS OF GOLD LOWER MAINLAND

BY KRISTI COLDWELL

**T**his fall and winter has been an eventful time for Vancouver Hearts of Gold! These past few months the group had a night out at the movies, spent the day in Maple Ridge at Wildplay climbing through an aerial obstacle course, and concluded the year with an evening boat cruise around the downtown harbour. The December boat cruise event was a chance for the group to get together to celebrate the holiday season complete with a four-course dinner, carolling, and dancing. Twenty-two youth participated in this fun evening and everyone danced and sang the night away!

This past year also marked the transition of some long-time Hearts of Gold members with a few of our youth turning 19 and entering the world of adult care and subsequently graduating from the group. Although the group is not quite the same without these teens we have had many new members join, ensuring the atmosphere of support, connection, and commonality that makes Hearts of Gold so special continues. If you are a heart teen between the ages of 12 and 18 and you'd like to come and join us for an event please e-mail at [kristicoldwell@gmail.com](mailto:kristicoldwell@gmail.com). ■



**TOP:** Jack, Chad, Brayden, Andrew, Eric, Tasha, Kat

**CENTRE:** Sophia, Sydney, Justin

**BOTTOM:** Jules, Eric, Tasha, Calvin, Francesca, Kristi, Susie, Patrick and Chloe

# UPCOMING EVENTS

February 7 to 14 is Congenital Heart Disease Awareness Week!

## HARDING HEART DAY WALK

**SATURDAY, FEBRUARY 15** at 10:30 a.m. – CHN and the Harding family will be hosting the 5th annual Heart Day Walk at Cates Park in North Vancouver. This is a small community event that invites heart families and friends to come out for a short walk to bring awareness of being healthy and active.

## CONGENITAL HEART WARRIORS WALK

**FEBRUARY 15** from 10 a.m. to 12:30 p.m. at Mill Lake Park, Abbotsford, Shelter #4 off Bevan Avenue (red park). Register in person at the registration table between 9 and 10 a.m. Cash or cheque only. Receive a gift and tax receipt with your charitable registration. Registration cost: Adults \$15, students \$10, under 10 free. Hot chocolate and snacks! For more info please contact Julie Bard at [BCHearts@cchaforlife.org](mailto:BCHearts@cchaforlife.org)

## CHN EASTER EGG HUNT FOR ISLAND FAMILIES

E-mail invitation to come!

## CHN EASTER EGG HUNT FOR LOWER MAINLAND FAMILIES

**SATURDAY, APRIL 5** at Queens Park in New Westminster, e-mail invitation to come!

## THE 12TH ANNUAL CHN WINE GALA DINNER

**FRIDAY, MAY 9** at a new venue, the Jewel Ballroom at 8th and Granville in Vancouver. Don't miss this fabulous event, as we do sell out! Tickets are \$150 and include a five-course dinner with wine pairings. An e-mail invitation will be sent out shortly. To get tickets or for more information about becoming a corporate sponsor please contact Samantha Aitken at [saitken@childrensheartnetwork.org](mailto:saitken@childrensheartnetwork.org).

## HEARTS OF GOLD YOUTH CAMP (AGES 13 TO 18)

**MAY 16 TO 19** at Zajac Ranch. An invitation to camp will be sent soon. For more information e-mail Kristi Coldwell at [chnheartsofgold@gmail.com](mailto:chnheartsofgold@gmail.com).

## HEARTBEATS CAMP (AGES 8 TO 12)

**JULY 8 TO 12** at Zajac Ranch. An invitation to register will be e-mailed soon. For more information contact Samantha Aitken at [saitken@childrensheartnetwork.org](mailto:saitken@childrensheartnetwork.org).

## NEWS FROM CHN

### WELCOME NEW BOARD MEMBERS

We would like to welcome our four new board members: Barb Willson, Barb Johnston, Tracey Carpenter, and Stephanie Isaac.

### CHN BOARD

Mandy Johnson – President  
Kate Walker – Vice-President  
Bindy Sweett – Secretary  
Sarah Kertcher, Jeff Cornell, Sam Birkenhead,  
Barb Willson, Barb Johnston, Tracey Carpenter, and  
Stephanie Isaac – Members at Large

### CONGRATULATIONS KRISTI COLDWELL

We would like to congratulate Kristi Coldwell, our Lower Mainland Hearts of Gold coordinator, on her new position. She is one of two child-life specialists in the new pediatric ER at Surrey Memorial Hospital, which opened in October 2013. Together they provide 7-day-a-week coverage from 2-10 p.m.

## Thank you to our generous donors

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

### PLATINUM HEART PARTNERS \$5000+

The Province of British Columbia  
CKNW Orphans Fund



### GOLD HEART PARTNERS \$1000+

Critter Cove Fishing Lodge  
The Forbes Family

### SILVER HEART PARTNERS \$500+

Dustin Dickout & Riding Friends

### BRONZE HEART PARTNERS \$100+

Telus Dollars for Doers  
Rhys Isaac  
Clearwater A & W  
Nina Grimshaw  
The Cassidy Family  
John Wilson  
Robert Hadden  
Eric Vipond





# How Reid made a Christmas video

*(secret weapon: big smiles)*

BY ANDREA VAN ROSSUM

Reid was born last February with hypoplastic right ventricle, pulmonary atresia, intact ventricular septum, and tricuspid atresia – a terrifying diagnosis for our family that turned into such a positive experience, thanks to his amazing team at the Heart Centre and the support of the Children’s Heart Network, that our family wanted to give back to BC Children’s Hospital in any way we could.

This led me to meeting with a BCCHF coordinator about formalizing a Nanaimo Communities for Kids committee, when she mentioned an exciting holiday fundraising opportunity with the Raymond James Foundation, CHEK TV, and Bobs & Lolo: a music video that raises money with every online view. Without hesitation we agreed to participate! Bobs & Lolo are from our hometown and our 3-year-old daughter, Alexa, is a big fan. We have almost daily living room dance parties to their DVD, usually ending in exhausted giggles. And what an exciting day for Reid to be a part of and meet other BCCH Island children during filming!

After a few days of Alexa teaching Reid some pretty impressive dance moves (and him just laughing and clapping at her), e-mails with the video coordinators on what to wear and basic expectations for the day, we were ready to head down to Victoria to CHEK studios and film “Jingle Jangle Holly Jolly Festive Time of Year.” We

arrived at the studio mid-day and met the other families involved and I had to smile at all of the smart phones out taking endless photos of kids dressed for winter singing and dancing under hot lights and in front of a green-screen. I think there were about 30 photos on my phone by the end of day! Reid was, by far, the youngest participant but Bobs, Lolo, and the whole crew

were quick to include him and make him feel just as special as the older kids, who all had a much stronger understanding of what was going on. He soaked up the coos, cuddles, and attention from everyone during and between takes and let us know he loved every minute of it with his big smiles.

We are so grateful for many things BC Children’s Hospital has given our family: the team in the Heart Centre who we love beyond words, the support of the Children’s Heart Network who have connected us with so many other heart families, opportunities like being a part of this super-fun music video, and for the platform to share our story. A huge THANK YOU to Bobs & Lolo, the Raymond James Foundation, and CHEK TV for the opportunity to participate in such a positive event and for the money donated to the best cause on earth – taking care of our kids! ■





♥ YOU ARE CORDIALLY INVITED TO ♥



# *The 12th Annual* **Children's Heart Network** **WINE GALA DINNER**

**THE EVENT THAT  
SELLS OUT EVERY YEAR!**

Arrive at 6pm for outstanding Hors d'oeuvres while enjoying a glass of bubbly and live piano! Then enjoy a 4 course dinner with wine pairings while perusing the Best Auction in Town. Please take advantage of the complimentary valet parking.



**Children's  
Heart Network**

**DATE**

Friday, May 9th, 2014

**TIME**

Beginning at 6:00pm

**PLACE**

*The Jewel Ballroom*

1495 West 8th Avenue, Vancouver

*Vancouver's newest & most contemporary location*

**TO PURCHASE TICKETS**

to The 12th Annual Childrens Heart Network Wine Gala Dinner  
contact Samantha at [saitken@childrensheartnetwork.org](mailto:saitken@childrensheartnetwork.org)

**FRIDAY, MAY 9TH**

at The Jewel Ballroom, Vancouver's newest and most contemporary location  
1495 West 8th Avenue, Vancouver  
Bubbly and hors d'Oeuvres – 6pm

**TICKETS**

\$150 per person or \$1,200 per table of eight (a portion of the ticket price will be issued as a tax receipt) Our event sells out every year!

**FOR ADDITIONAL INFORMATION**

contact Samantha at [saitken@childrensheartnetwork.org](mailto:saitken@childrensheartnetwork.org)