



Khol after second surgery

Heart Story

Khol is my superhero

BY MELISSA MARTZ

When my husband and I decided to have a baby we never dreamed that our first born would have a congenital heart defect. When I went for my routine ultrasound, the technician showed my husband and I our baby, pointing out the feet, the hands, and the heartbeat. She printed off the sonogram pictures for us and I couldn't wait to show the family. I never had a clue something was wrong.

The next day I received a call from a doctor whom I didn't really know, my regular doctor being on holidays. The doctor tried to explain that they noticed that the baby's heart was on the wrong side of the body, called dextrocardia. He said some babies can live normal lives with this, while others will have more heart defects. I would have to go to BC Women's Hospital for a fetal echo and more investigation.

I was in shock, in total disbelief. I was supposed to be leaving within a couple hours for a weekend away with my sister, so I called and told her I was not up to going because something was wrong with the baby—and then the tears started. I wasn't sure how to get hold of my husband because he had just started a new job, but after some time my mom got hold of him and he promptly left work to come home. My mom then called the doctor back to ask more questions because I was in shock and didn't understand what was going on.

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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

I cried and cried, but held on to the hope that my baby would be okay. Over the next while I prayed and did Internet research. The next week they scheduled a fetal echo at BC Women's Hospital in Vancouver. At the appointment the cardiologists studied the echo for what felt like forever, and it's no wonder, as our baby had a very complex heart: dextrocardia, double outlet right ventricle, VSD, and ASD. They weren't able to tell how well his pulmonary artery and surrounding vessels had formed. They gave us the option of terminating the pregnancy, but that wasn't a choice for us. Then they explained a three-stage surgical "palliative" procedure that the baby would need.

After that I had fetal echoes monthly so the cardiologists were able to develop a plan: a BT shunt operation at birth, a Glenn shunt at 4 to 8 months, and a Fontan between 2 to 3 years. All of this information was shocking and difficult to deal with at times, but we have a great support system that helped us through the difficult times. We found out we were having a boy, which really helped us get excited for the birth and helped us prepare for our son. We decided to name him Khol Wally Martz.

The cardiologists decided I needed to move closer to BC Children's when I was 37 weeks pregnant, so I moved to the Easter Seals House. I was supposed to be induced December 8, which didn't happen because there were no ICU beds available. It kept being delayed due to a lack of ICU beds, with the hospital considering transferring me to Alberta and Seattle—but still, no beds. They finally found a bed for Khol at Legacy Emmanuel Hospital in Portland, Oregon. What a shock! I was devastated at first.

We had our passports rushed out to us by a family member, we quickly packed a small bag, and that evening we were transferred to Portland via ambulance and airplane.



Khol the fighter takes a break.

Now not only was I away from my family and support system, but I had no idea about this hospital and its staff. But after we arrived, I felt better right away—it's a gorgeous hospital with incredible staff. Some of our family drove out to be with us the following day. The evening of December 12 I was induced and by 2:13 the next day Khol was born. He was so precious, my husband and I just couldn't stop looking at him! I was able to hold him for a few minutes before they took him to get assessed, with my husband accompanying him.

The next few days we spent staring at him and being by his side. We were able to hold him with the help of the nurses. His official diagnosis is dextrocardia, pulmonary atresia, single ventricle, levo-transposition of the great arteries, double outlet ventricle, and a severely narrowed and deformed left pulmonary artery.

At 3 days old on Khol had his BT shunt operation. What an emotional day! It was hard to see him with all the tubes, drains, and wires, but we were prepared and thankful he was alive. The next morning they were able to extubate him, and the doctors and nurses were all surprised at how well he was doing. Three days later we were able to come back to Canada, staying at BC Children's until December 23.

The Glenn surgery would be May 28, 2010. I prayed and prayed, putting my trust in God; I kept telling myself that God couldn't take him away from us after such a short time. Some days I felt at peace about it and other days I felt like a ball of nerves!

On May 27 we got up bright and early and checked him in for surgery. What a terrible feeling to hand your baby to the nurse for surgery! Khol was smiling and laughing at the nurse as they walked down the hall. Hours later, at around 1 p.m., I called the ICU to see if Khol was there, but not yet. Finally, around 2 p.m. a friend who had her daughter in ICU came and told me Khol was there. Then the surgeon, Dr Campbell, came in a few minutes later to tell us how it all went. He said it went pretty well, but since Khol's heart is on the right side the surgery was a bit more complicated. Also Khol's pulmonary arteries were very small and Dr Campbell did extensive repairs by attaching cow tissue to these areas. Once again our baby was hooked up to many machines, tubes and wires, but he was a fighter and he was able to go home 6 days later.

Over the next couple years Khol developed quite normally; he crawled at around 9 months and started walking at around 14 months old. As he started to walk and then run we noticed that living with a lower oxygen level was affecting him and he had to pace himself. Khol became a big brother in August of 2010.

When he was around 2 1/2 years old we started to notice more bluing around his lips and darkness under his eyes, and the cardiac team confirmed that his oxygen level was getting



Khol after his third surgery.

At home Khol is a very happy boy – he loves life. He has two younger brothers and a puppy that he loves a bunch.

too low and it was time for the next step—the Fontan surgery!

The Fontan surgery was booked for August 17, 2011. Once again we put all our trust in Dr Campbell and the surgical team, and prayed for another miracle. The surgery took around 5 hours and when we saw him, Dr Campbell confirmed that all went well.

Khol's recovery was a bumpy one, with lots of pain and lots of fluid in his lung. Khol ended up having his chest tubes in for almost 3 weeks due to excessive drainage. It was so discouraging; every day I would wake up and watch for less fluid in his drains, and I felt like it was never going to stop! Khol started to hate the nurses, hate anyone that entered his room. He hated his tubes being stripped, and his vitals being taken. He would scream and fight with the staff, he wouldn't sleep. I had to ask the staff not to disturb him and that I personally would do his vitals and stripping. Once he was up to it we took him out of his room in his wheelchair as much as possible. We walked laps around that hospital, so grateful we had nice weather! Finally on September 3 we were discharged, but had to check back in a couple days to make sure his lungs stayed dry. Once home Khol started to get back to himself and started to smile again, eat again, and gain weight back.

Since then Khol has not had any further surgeries. At some point he may need a pacemaker, but currently we are just monitoring him. We go regularly to BCCH, but at our last appointment was cleared for a full year! Khol is now 6 years old, and in kindergarten. He is currently doing his second year of kindergarten; he has shown some developmental delays. He has also been diagnosed with low muscle tone and some sensory processing difficulties. Khol has a teacher's aide at school that assists him a couple hours a day.

At home Khol is a very happy boy—he loves life. He has two younger brothers and a puppy that he loves a bunch. He loves to be outside, be with his friends, play Minecraft, and do Lego. He plays hockey in a non-competitive league and is in jiu-jitsu. He is not very athletic, but still enjoys being in these sports. We took him and his brothers to Disneyland in October and it was a fabulous trip! He is an amazing child.

We have lots of hopes and dreams for Khol; we pray for him daily and we try to live life to the fullest. We have no idea how long he will be with us; we pray that it is a long time. Everything we have been through has been worth every second. 🇺🇸



Khol and family at Disneyland.

Jan Rooks: A friend to us all

May 9, 1959 to October 14, 2014

BY BARBARA JOHNSTON

On October 14, Jan Rooks, beloved nurse clinician in the Children's Heart Centre, died in an avalanche while trekking in Nepal. Heart families, colleagues, friends, and family were devastated by the news.

A celebration of Jan's life was held on December 6 at the CFRI Chan Centre at BC Children's Hospital. Friends, family, heart families, and colleagues came together to celebrate Jan's amazing life and share our many wonderful memories of Jan through stories, tributes, music, and a beautiful slide show. The service touchingly reflected Jan's love of people, children, nursing, adventure, and her great musical talent. Jan's husband, Grant Tomlinson gave a poignant tribute to his beloved wife, and we were so moved by his openness and willingness to share his love for Jan with us all.

As a nurse, Jan helped many heart families through their darkest hours and seemed to instinctively know just what we needed. At the Heart Centre, she was always there to explain complex information, celebrate the milestones, and remember small but important personal details about our children and families. I have learned from her colleagues, friends, and family that she had that same compassion and gave that same support to everyone she knew.

What made Jan truly stand out was how she made everyone around her feel. After seeing Jan, I always felt better and more positive—and I know now that she had this effect on everyone. I was amazed at her ability to calm an upset 2-year-old, brighten a mom's day, or start a meaningful conversation with a teenager. Her love of life and positive energy were infectious, and children and adults alike loved her.

Jan was a bright light, and she is sadly missed. It is hard to accept that she is gone, but how very lucky we all are to have known her. 🇨🇦

Barbara Johnston is a heart mom and member of the CHN board.



**“I’ve learned that people
will forget what you said,
forget what you did, but
people will never forget how
you made them feel.”**

—Maya Angelou

DONATIONS MAY BE MADE TO A MEMORIAL FUND IN JAN'S NAME AT WWW.BCCHF.CA/JANROOKS.

Summits of Hope flies flag for Jan Rooks at Everest Base Camp

BY JENNIFER SCHNEIDER

We were very saddened to hear about the news of the tragic passing of Jan Rooks in the avalanche in Nepal. Being well connected in the heart community, we know first-hand the positive impact Jan had on countless heart families. When I listen to heart families speak of their journeys, they often speak of the special caregivers who were there for them during their most vulnerable moments. The ones who eased the pain, explained a procedure, held a hand, or who simply made the heavy burden lighter. Jan has been fondly spoken of by nearly all the heart families I know and described as such a person. Simply an angel.

Ironically, when we heard the sad news, our dear friend and neighbour was busy packing for his trek to Nepal. Russ Barstow, co-founder of Summits of Hope (www.summitsofhope.com), was getting ready to embark on another climb, guiding a group of dedicated fundraisers to climb Everest Base Camp in order to raise money for BC Children's Hospital. Russ has been climbing mountains since 1999 and has raised close to \$3 million to date for the hospital, leading groups on various climbs, similar to the one Jan and Grant were on together.

Our family was at Russ's house the night before he was leaving. Mountain climbing equipment, backpacks, and food were all laid out on the living room floor as he packed to leave the next morning. The week prior, we had heard the news of the devastating avalanche in Nepal and I immediately contacted Russ's wife to make sure they were aware of the story. Of course Russ was well in tuned. At that time, I had no idea Jan would be one of the victims.



Russ explained that each climber carries messages up the mountain for the people who inspired them to fund-raise. These messages are put on to flags (flags of hope) that are flown at the summit when they reach it. We talked about Jan and asked if he would do us the honour of carrying up a message for Jan. Of course he would.

My daughter began drawing a picture for Jan. Together we wrote our message: "For Jan Rooks, and all the heart angels she touched. May you climb mountains in heaven."

Russ took the message up the mountain and flew it on a flag of hope when they reached the summit. That morning, I got a text from him with him holding the picture with Everest in the backdrop and the beautiful words saying "Delivered Hannah's message today."

When Russ came home safely, he brought back a replica of the flag. This was presented to Jan's husband Grant while this story was explained at the beautiful memorial held at BC Children's Hospital on December 7, 2014.

There are no words to describe the incredible loss the heart community and BCCH has experienced in losing Jan. She was an amazing person with an adventurous spirit, with a special gift to heal heart families and help them along in their journeys. Although Jan was never able to finish her last climb, her flag of hope flies high at Everest, and in some respects, I feel Russ was able to finish the climb for her. What a wonderful tribute to who she was.

Dear Jan, may you climb mountains in heaven indeed. ❤️

Upcoming Events

Congenital Heart Disease Awareness Week

February 7 to 14 is Congenital Heart Disease Awareness Week, so watch for ways you can increase awareness in your workplace or community!

Harding Heart Day Walk

Saturday, February 14 at 10:30 a.m. at Cates Park in North Vancouver. CHN and the Harding family will be hosting the 6th annual Heart Day Walk at Cates Park. 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

Saturday, February 14 from 10:30 a.m. to 1:00 p.m. at Mill Lake Park, Abbotsford, Shelter #4 off Bevan Avenue (red park). Receive a gift and tax receipt with your charitable registration. Registration cost: \$25, under 10: free. Hot chocolate and snacks!

For more info please contact Julie Bard at BCHearts@cchaforlife.org or secure.eventsonline.ca/events/congenital_heart_warriors_walk/

CHN Easter Egg Hunt for Island families

Goldstream Provincial Park – Day Use Area

Sunday, March 29 from 3 to 5 pm

Please RSVP to Krista at viheartsofgold@gmail.com

CHN Bowling Event for Lower Mainland families

CHN Bowling Event for Lower Mainland families

Saturday, February 28 at The Zone Bowling in Coquitlam,

e-mail invitation to come! For more information email

saitken@childrensheartnetwork.org

The 13th Annual CHN Wine Gala Dinner

Friday, May 1 at the Diamond Ballroom at 8th and Granville in Vancouver. Don't miss this fabulous event, as we do sell out! Tickets are \$150 (early bird until February 28) and then \$175 per person. Includes a five-course dinner with wine pairings. 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

Hearts of Gold Youth Camp (ages 13 to 18)

May 15 to 18 at Zajac Ranch. An invitation to camp will be sent soon. For more information e-mail Kristi Coldwell at chnheartsofgold@gmail.com

Heartbeats Camp (ages 8 to 12)

July 6 to 19 at Zajac Ranch. An invitation will be e-mailed soon. For more information contact Samantha Aitken at saitken@childrensheartnetwork.org.



Jeff Mercer (right) and family.

Network news

Welcome to **Jeff Mercer**, our newest board member and CHN Treasurer. Farewell wishes to **Danielle Segur** for the fabulous contribution she made over the past few years as the CHN Administrative Assistant. We will miss her greatly and wish her all the best in her new job. Welcome to **Patty Rippel**, our new Administrative Assistant. Patty is a heart mom, a CHN resource parent, and a long-time member of CHN. We are thrilled to have Patty join our team! Watch for her profile in the next issue of *Heart Matters*.



Patty Rippel (second from left) and family.

CHILDREN'S HEART NETWORK CONFERENCE 2015 • APRIL 11 – 12, 2015 (SATURDAY – SUNDAY)

GROWING UP WITH HEART DISEASE: CELEBRATING LIFE

CHAN CENTRE FOR FAMILY HEALTH EDUCATION (AT BC CHILDREN'S HOSPITAL), 950 WEST 28TH AVE., VANCOUVER, BC
THE CHILDREN'S HEART NETWORK IS PLEASED TO ANNOUNCE THE EIGHTH GROWING UP WITH HEART DISEASE CONFERENCE,
AN EVENT THAT THIS YEAR IS ABOUT CELEBRATING LIFE

This Children's Heart Network event is a collaborative conference by and for families and healthcare professionals. It is an opportunity to learn from the experts—physicians, nurses, psychologists, researchers, fellow parents, and other heart kids—connect with parents to share your stories and support each other, and it's an occasion to celebrate life.

This special conference will be dedicated to cardiac nurse clinician, Jan Rooks. We will be celebrating her life and the many lives she touched at BC Children's Hospital.

HIGHLIGHTS:

- Families and healthcare professionals sharing and learning from each other's experiences of caring for children and youth with congenital, acquired, and electrical heart disease.
- Fun programs for children and youth.
- Plenary speakers, concurrent sessions, and workshops on:
 - Common pediatric issues for children and youth with CHD,
 - Current research and innovations in pediatric cardiac surgery,
 - Research on mindfulness and hypnosis to build coping and comfort,
 - Strategies for supporting children with heart disease to help build resilience,
 - A panel discussion on heart health and physical activity,
 - A parent panel on dealing with discharge from the hospital to home, and
 - A special presentation by youth from the Hearts of Gold Youth Program.

Healthcare professionals, parents, youth, and children of all ages are welcome. Online registration will be "live" soon at the same time as the launch of the Children Heart Network's new website. Watch for updates coming soon.

FEES:

Adult: \$75

Healthcare professional: \$150

Youth: \$35

Student: \$75

Child: \$50

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.



THANK YOU TO OUR GENEROUS SPONSORS



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HEART & STROKE FOUNDATION

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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](#)
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MAPLE RIDGE/TRI-CITIES – [Mandy Taylor](#)
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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 so that we can add you to our mailing list to receive invitations to all our fun events!

CHN STAFF

SAMANTHA AITKEN – Provincial coordinator

PATTY RIPPEL – Administrative assistant

KRISTI COLDWELL – Lower Mainland Hearts of Gold youth coordinator

KRISTA MOLIA – Vancouver Island Hearts of Gold youth coordinator

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Heart veteran joins dragon boat team

BY JACK PALMER

I have always liked being on the water in canoes or kayaks, and I was constantly looking for a place to get on the water, but with a group or team. During last year's Transplant Trot, the Gift of Life dragon boating team had a booth set up with a couple of its members. I went over and talked to them and got some information as I wasn't sure if it was something I really wanted to pursue. As it turned out the entire team was made up of adults who all have a personal connection to organ donation; most members are recipients but some are donor families. Dragon boats are 40' long and fit a team of 22. It's a much more popular sport than I thought as teams from around the world compete each year; Vancouver's Rio Tinto Alcan Festival attracts over 100,000 people.

Later that week I decided to give it a try. I had never paddled a dragon boat before, and I just hoped that my experience canoeing would help me adapt. My first day I got a quick intro from the coach just before getting on the water, he explained to me, "Get rid of any techniques you have used to paddle before, especially canoe." Not quite what I expected, and it turned out that he was right.

The team is made up of adults; I am the youngest by about 10 years. When I first met everyone they were all incredibly welcoming and supportive, even when I would mess up and soak people in front of me; thankfully the support and friendliness have continued to this day. We train weekly and compete in regularly, but the main purpose behind the team to promote organ donation.

My favourite part about being part of this team is the comradery and hearing people's stories. I paddle alongside many fellow recipients with different types of transplants, each with an amazing story. One time an adult was asking me many questions about my transplant; it turns out that he recently received his transplant and considered me a veteran because I have lived with mine for far longer! The most incredible experience I have had so far was paddling alongside mothers who shared their stories about their kids who were organ donors. This was a very special connection to make and an eye-opening experience. Hearing different organ donation stories helps me put my own experience into perspective.

I think what makes the Gift of Life team special isn't just the fact that our team is made up of people touched by organ donation, it's that we are a team of people touched by organ donation, paddling for a cause. 🇨🇦



Jack Palmer is the youngest member of the Gift of Life dragon boat team.

The Hearts of Gold Christmas Party this year was a repeat from last year as the teens had so much fun! A Boat Cruise Dinner and Dance with 22 youth attending. The highlights were the buffet dinner and the dancing. The entire group had a ball!

Hearts of Gold participants Daniela, Susie, Sophia, and Sam.



Developmental delays and children with congenital heart disease

BY ALYSSA POWER, PEDIATRIC RESIDENT, ALBERTA CHILDREN'S HOSPITAL

Some children with congenital heart disease are at risk of having problems with development, most commonly in the form of learning disorders and problems with attention and behaviour. Most children with CHD who experience developmental difficulties *don't* have severe disabilities. Since early testing and intervention or educational services will help maximize your child's potential, it is useful for you to know how to identify problems early.

What is developmental delay?

Babies, infants, and children follow a pattern of so-called "normal development," with specific motor, language, and social milestones set for various ages. However, normal development can vary widely from child to child. Just like physical growth, skill development often occurs in sudden bursts rather than a slow, steady progression.

A developmental delay occurs when a child has not met an expected developmental milestone by the age at which most children have met this milestone. Such delays can be in the physical (fine motor or gross motor skills), cognitive (intellectual abilities and learning), communication (speech and language), and social or emotional domains of development. There are many resources available to help guide you if you are concerned that your infant is not meeting their developmental milestones, or if your school-aged child seems to be having trouble learning, paying attention, or making friends. If you are ever worried then it is best to raise your concerns with your child's family doctor, pediatrician, or cardiologist.

Why are children with heart disease at increased risk for developmental problems?

We do not yet understand all the reasons why children with CHD are at greater risk for learning disorders, attention deficit hyperactivity disorder (ADHD), and other developmental difficulties. However, we continue to learn more each year. Some likely contributors include the effects of being on a heart/lung bypass machine during open heart surgery, lower oxygen levels, and prolonged stays in the intensive care unit and in the hospital. In some children, premature birth and a genetic abnormality or syndrome may play a role. be having trouble learning, paying attention, or making friends. If you are ever worried then it is best to raise your concerns with your child's family doctor, pediatrician, or cardiologist.

What should we watch out for

Not every child with CHD will have problems with their development or challenges in school, but it is important that they be closely observed during infancy, preschool, and school years to promote early detection and intervention. Your child's doctors will regularly ask questions to gauge your child's development and ensure that they are reaching their milestones appropriately.

In a younger child, pay attention to their acquisition of fine motor, gross motor, social, and language skills. Your child's doctor can let you know what to watch for, or you can use the Centers for Disease Control and Prevention website (URL below) for information on the average age that children reach various developmental milestones. If your child is older, then you can watch for learning problems (difficulty with reading, writing, math, or language) and trouble with social interactions. Look out for changes in your child's behaviour, as attention issues or impulsive behaviour are more common in children with congenital heart disease. Though many behavioural changes are simply a normal part of growing up, some can be a sign of ADHD or can be the first clue to a learning disorder.

Teachers are a valuable resource as they can identify concerns in school that may not be readily apparent at home. Be sure to ask your child's teacher if they have any concerns about your child's language skills, academic performance, learning ability, or attention and concentration.

Keep your child's pediatrician informed about anything that you are concerned about, as they can start the process for a formal evaluation. For a school-aged child, this may take the form of a more objective psychosocial and cognitive assessment.

How can we help promote normal development and support a child having difficulty?

Certain games and activities that we play with children naturally promote healthy cognitive development. For example, you can use sing-a-longs to promote memory and word identification, identify opportunities during the day to practice counting, shapes and colors to promote language development, regularly read to your child (even as a baby) to support social and language development, and ask lots of "why" questions during the

day to help your child problem solve and think critically about their environment.

You can also play a range of games with your child to promote problem solving and creativity, from building with blocks to engaging your older child in board games and puzzles. There are myriad ways to encourage cognitive and even physical development in children. If your child is having trouble in a specific area, then your pediatrician may suggest specific techniques to target that specific domain of difficulty. At the school level, it is helpful for some children with learning or attention difficulties to have an IPP (individualized program plan), focusing on their needs and strengths. Finally, your pediatrician can also be an excellent resource in coordinating community resources to help support your child.

Children require continued support and understanding from their family. If any developmental difficulties are present, emphasize to your child that all children are unique and face different challenges and everyone has certain things that they may find difficult. Continually remind your child that a challenge with learning or paying attention doesn't reflect on their self-worth. 🍷

Resources and further information

- California Heart Connection. Developmental Delays, Learning Difficulties/Disabilities and Behavioral Issues in Children with Congenital Heart Disease. 2013. Available from http://caheartconnection.homestead.com/files/Developmental_issues_and_CHD_2013.pdf [accessed 20 Dec 2014].
- Developmental Milestones. Centers for Disease Control and Prevention. Available from www.cdc.gov/ncbddd/actearly/milestones/ [accessed 22 Dec 2014].
- Sara Peronto. 10 Ways to Promote Your Child's Cognitive Development. Friendship Circle. Available from www.friendshipcircle.org/blog/2014/06/09/10-ways-to-promote-your-childs-cognitive-development/ [accessed 20 Dec 2014].



CHILD AND FAMILY RESEARCH INSTITUTE BC CHILDREN'S HOSPITAL VANCOUVER, BC

This collaborative conference Growing Up with Heart Disease: *Celebrating Life* will be a wonderful opportunity for families and healthcare professionals to share and learn from each other's experiences of caring for children and youth with congenital, acquired, and electrical heart disease.

HIGHLIGHTS:

- A children's program and child care
- A program for teens
- Workshops on the latest in pediatric cardiology and supporting our children

For information about the conference and to register, please visit
www.childrensheartnetwork.org

If you have any other questions please email or call
chn@childrensheartnetwork.org / 1-877-833-1773



CHILDREN'S
Heart Network



♥ YOU ARE CORDIALLY INVITED TO ♥



The 13th Annual **Children's Heart Network** **WINE GALA DINNER**

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

Arrive at 6 pm 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 1st, 2015

TIME

Beginning at 6:00pm

PLACE

The Diamond Ballroom

1495 West 8th Avenue, Vancouver

Vancouver's newest & most contemporary location

Tickets purchased prior to February 28th **EARLY BIRD** Price \$150
(\$75 Tax receipt will be issued per ticket)

March 1st ticket price increases to \$175
(tax receipt of \$87.50 will be issued per ticket)

To purchase tickets, please email Samantha
at saitken@childrensheartnetwork.org