



Briana has endured multiple procedures, but today is a witty, fun-loving girl.

Briana's heart journey

BY IONA DE FRESNES-LEMAY

Briana came into this world with a bang. I delivered her within 30 minutes of arriving at the hospital, and we were ecstatic. She was perfect.

However, what was soon to follow would forever change our lives. Briana wouldn't nurse, she didn't cry, and we remained at our local hospital for 5 days trying to get her to feed. They discharged me and were in the process of discharging Briana when she went into an apnea and stopped breathing for 20 seconds. This actually saved her. If I had taken her home she would have died, because Briana was in heart failure. Her lungs were full of

fluids, and she could barely stay conscious.

She was transferred to BC Children's Hospital, where we were met by a cardiologist who informed us that they were going to perform an echocardiogram. That night Dr Human came to us and informed me that Briana had a rare complex heart condition called truncus arteriosus with an interrupted aortic arch. He explained that they see one about every 2 years. She was in major heart failure and that if they did not operate first thing in the morning, she would not make it. My mind went blank. We were horrified and overwhelmed.

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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.

The newsletter of the Children's Heart Network, which works to educate, support, and enhance the lives of children, youth, and families living with congenital heart disease.

Heart Matters

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



ChildrensHeartNetwork

Briana's Heart Journey

I just needed her to live and fight, and we would deal with everything else after.

August 2, 2006 was the day that Briana was reborn. She went through a 12-hour operation performed by cardiac surgeon Dr Jacques Leblanc, and Dr Human was there as they preformed a relatively new procedure called the Rastelli procedure to reconstruct her heart by separating the aorta, and using arteries from her arms to connect to a bovine valve, to make her a pulmonary conduit that would lead to her lungs. In turn, they stretched her aortic arch to repair the coarctation blocking her aorta.

Briana was brought to the ICU for recovery. It killed me that I had to leave her at night as there was no place to sleep. We stayed at Heather House at the old Shaughnessy Hospital. I rushed in to see her and was told that Briana had started to fail, and they did not know why, and they had to re-open her chest right in the ICU and found a huge blood clot had formed under her heart. I felt like I had died all over again.

The next days, which turned into weeks, were a blur. All I did was stay beside her in the ICU and pray she would make it. She was in an induced coma to help her heal. She spent about 3 weeks in this state with her little heart beating beneath a plastic window, as they did not want to close the breastbone until the swelling, caused by the lung and heart failure, went down. Her little body was so swollen, I was mentally and physically sick just watching her go through this recovery period, so many supports and medicines. And all the while not even

able to hold or comfort her.

I tried not to leave her side. Finally we took a quick trip, home to Chilliwack, and we got a call not long after arriving. She had woken up.

We raced back to Vancouver. Arriving in the ICU, I saw my baby's crib surrounded by nurses and doctors. I deked in and got close to her, saw this withering baby taking in all the excitement of so many people around her. She looked at me as I spoke to her, started to turn away, and then did a double-take and stared right at me. She knew I was her mommy, I knew she recognized me. I knew then that it was going to be okay, and that we would make it through whatever obstacles she had to endure, because this resilient little girl is a true miracle.

And there were many obstacles. She had slow weight gain, and she was only able to eat at night when she was relaxed. She was constantly sweating because bottle feeding was so much exertion for her. She had a feeding tube in her nose for 6 months. Her limbs were constantly cold. We stayed on the cardiology ward for 2 months, until September 26, 2006.

Now we were to start a new journey: going home. I was so scared, I just wanted to stay there. But with the great help from the team of nurses, who showed me how to care and feed Briana with a kangaroo pump, we gained the confidence to go home.

No matter how hard we tried, Briana would not gain weight. We tripled her calories, she ate a can of Enfalac to a



HEART PARENT 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

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

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



CHN STAFF

SAMANTHA AITKEN – Provincial coordinator
DANIELLE SEGUR – Administrative assistant
KRISTI COLDWELL – Lower Mainland HOG youth coordinator
KRISTA MOLIA – Vancouver Island HOG youth coordinator

CHN BOARD

TRACEY CARPENTER, STEPHANIE ISAAC, BARBARA JOHNSTON, MANDY JOHNSON, SARAH KERCHER, BINDY SWEETT, KATE WALKER, BARB WILSON

YOUNG ADULT HEART NETWORK COFFEE GROUPS

We are pleased to announce our two new 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



Briana has endured more than most people will endure in their entire lives. She has come a long way, to become the smart, witty, and fun-loving little girl that she is today. She is a true heart warrior!

litre of water a day. We made monthly visits back for check-ups, she endured so many different procedures: angiograms, and catheterizations to find out why she was failing to thrive. They did a dye-test and we were told that Briana needed an operation to get blood flow to her brain because she had blockages in her carotoid arteries. But before this could be repaired she needed to put on weight because they would not do this operation on a 10-pound baby. It took forever to get her to 12 pounds. Finally at 2-½ years old we could wait no longer.

If I thought I had gone through hell, nothing could prepare me for what was to come. In order to fix the carotoids, they would need to stop all blood flow for 21 minutes. They repaired her carotids, but while preparing to repair her heart, her aorta was cut, and she almost bled to death. They had no choice but to put her under for an additional 21 minutes to make this repair, then they did the open-heart surgery to replace the conduit to the lungs. In total Briana was flat-lined for 42 minutes. [Editor's note: the child's circulation is maintained on the bypass (or hear-lung) machine while the heart is stopped.]

When the surgeon and cardiologist came out of the operating room, they were totally spent after a long day of fight-

ing to save Briana's life. They came up to her, while she was still unconscious, and remarked while rubbing her foot, "You gave us a run for our money today."

When we go to the hospital, they wheel Briana's file in on a cart—it's four huge volumes on what she has endured in her short life. She has struggled all her life to catch up. She has had delays with feeding, was slow to sit up, slow to walk, slow to speak, and had to go through procedure after procedure to keep her heart and body healthy.

In addition to all this, she had an eye operation at 9 months. She also has third-stage kidney damage. She has many scars all over her chest and abdomen, she has had hernia surgery, and many dental operations to protect her teeth. She has hypertonia, loose joints, and has always struggled with fine motor skills.

Briana has always had feeding issues—she has a 5-minute window where she is hungry, then nothing. She has a hard time to swallowing food like meat or bread--as a baby she would just hold food in her cheeks, or spit it out, which she still does.

It's a daily struggle of ups and downs as she is sensitive to much of her surrounding, and must learn to live with the struggle of being a child with a life-threatening disease. I'm constantly worried for her: Is she is going to fall behind? Is she eating enough at school? Will she get hurt?

Then instead of crying, "why me," or "why us?" I think, "I got dealt these cards, so play them." And play we have. In her 7 years Briana has been to Disneyland twice. The last time we drove our RV to Las Vegas, then to the California coast, where she found \$960 floating in the water while beach combing. She has gone to a Justin Bieber concert, where she was given a front-row, centre seat where Bieber high-fived her throughout the show. She has also sat in the Stanley Cup; she

has met Scotty Bowman; along with Steve Nash and Mashiah Vaughn she has helped raise \$10 000; through the Children's Wish Foundation she has visited Disneyland, Universal Studios, Sea World, the San Diego Zoo, and the Grand Canyon.

We try to give her the world because she deserves it. She has endured more than most people will endure in their entire lives. Briana has come a long way, to become the smart, witty, and fun-loving little girl that she is today. She is a true heart warrior!

Thank you to everyone who has been there for us: the amazing doctors and nurses at the Children's Heart Clinic at BCCH, the Children's Heart Network, Variety Club, and the Children's Wish Foundation. You have all been there to support us every step of the way. Without you, I don't know where we would be today. I fear, and worry every day, what the future holds for Briana, as we wait for the cardiac surgeries she will require throughout her life. But, like always, we will persevere, because that's what we do. ■



Meet the new CHN Board Members

At the Children's Heart Network AGM on February 6, 2014, four new board members were elected to join the CHN Board. Tracey Carpenter, Stephanie Isaac, Barbara Johnston, and Barb Willson will join long-time board members Mandy Johnston, Bindy Sweett, Kate Walker, and Sarah Kercher. Here is a bit of information about your new Board members.



Tracey Carpenter joined CHN when her daughter Avery was diagnosed with ALCAPA in 2009. Avery has had two open heart surgeries, her ALCA-PA repair immediately after diagnosis, and her mitral valve repair two years later. The Carpenters have two daughters Chloe and Avery and reside in Port Moody. Tracey has a bachelor of commerce degree from the University of Calgary and also studied at the University of Strathclyde in Glasgow, Scotland. She has worked for her family business in industrial sales for her entire career. Tracey was thrilled to be a part of the organizing committee for the CHN "Growing Up with Heart Disease Conference" in 2012 and she has trained as a family resource parent for the CHN.

"I am very thankful for the support that we have received from the CHN and its members throughout our journey. Knowing that you are not alone in this sometimes surreal experience of being a heart parent has been a tremendous comfort and I am so honoured to be able to help other families through their journeys. As a new board member I look forward to collaborating with our more experienced board members and helping to carry the CHN and its membership forward. Even though all of our stories are unique we find common threads that join us together and help to make us stronger when we know we are not alone."



Stephanie Isaac is a new CHN board member. She grew up in Victoria and trained and worked as a social worker in Victoria and in the UK before moving to Vancouver with her husband, Charlie, and their three children, Chloë, Rhys, and Drew.

Stephanie first became involved with CHN as a volunteer in 2010. Her niece Mila was a heart child, who, sadly, passed away in August, 2012. Stephanie's sister and brother-in-law started Mila's Fund to "enable heart kids living throughout BC to enjoy the experience of camp."

Thank you to our major sponsors



WE ACKNOWLEDGE THE FINANCIAL SUPPORT OF
THE CKNW ORPHANS' FUND AND THE PROVINCE
OF BRITISH COLUMBIA.



Barbara Johnston is a writer, editor, and instructor living in Port Moody with her husband Jay and two girls, Sophia and Anna. Barb has been connected with the Children's Heart Network since 1998, shortly after the birth of her first daughter Sophia, who was born with a complex congenital heart condition. Today, Sophia is a healthy teenager who attends almost every Hearts of Gold Youth program monthly events and looks forward to attending CHN's summer camp every year.

Having specialized in working with educational and health care organizations and publishers, Barb is excited to use her experience to help Children's Heart Network with its communications strategies. Barb has previously served on the CHN conference planning committee and has taken the resource parent training to support families.

As a new board member, Barb is looking forward giving back to an organization that has done so much for her family. "I have always been so very grateful for the great support our family has received from the Children's Heart Network. From the conferences, the unforgettable weekend at Critter Cove, to the amazing Hearts of Gold program, these experiences have all made the journey a whole lot easier."



Barb Willson is a new member of the CHN board and has taken on the role of secretary. She is a registered nurse who has spent 17 years working with heart kids and families. Barb is one of the founders of the Hearts of Gold Youth Program. While she no longer works in heart care, she continues to have a desire to support heart kids and families. "My niece has grown up with a heart condition and as an aunt I'm so grateful for the support she has received along her journey."

Barb lives in Vancouver with her husband Gordon. "I look forward to volunteering on the Board so that every heart child and family has access to peer and family support." ■

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

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

Camp at Zajac Ranch, 2014

BY SOPHIA DRAPER



Camp with Hearts of Gold (CHN's group for heart kids aged 13 to 19) is a lot of fun every year, and this year was no different. We got to camp at around 4 p.m. on Friday, which gave us just enough time to meet everyone and get settled in before dinner. After dinner (the food at camp is always really good) we went outside and tie-dyed the t-shirts that we had brought—which also caused us to dye our hands. We got the t-shirts back just before we left, and everyone's looked great!

On our first full day, we were divided up into two groups for activities. The first group did high ropes, while the second group did low ropes, which were both really fun. After lunch, we had geocaching, followed by archery. Finally, after dinner we had the talent show and campfire. There were a lot of really great performances, including an original song and "I Will Always Love You"!

On Sunday, we started the with rock climbing, then moved on to the petting zoo and horseback riding. Later that day, we did arts and crafts, and then played Jeopardy, which was really fun—even though my team lost. After our last dinner at camp, we finally got to swim in the indoor pool and hot tub when we had a pool party, which was a lot of fun. For our last activity of the night, we watched *Bridge to Terabithia* and ate snacks.

On our last morning, everybody was tired and very sad to leave their friends, so it was a pretty quiet morning. After everybody had eaten breakfast and packed up, it was time to get on the bus. But first, everybody had to take lots of photos with their friends, all the counselors, and a group photo!

We're all grateful to Megan Crane, a nurse from Children's Hospital who spent the whole weekend with us, Lauren Fougner, a Hearts of Gold alumni who helped Megan, and all the counselors at Zajac. Thanks also to CHN and Zajac Ranch for putting this together for us. I had a great weekend with my friends, and I can't wait for next year! ■

CHN would like to acknowledge and thank the CKNW Orphan's Fund for their support through grants that allow us to send our heart kids to camp.

Hearts of Gold camp is a long-weekend full of fun and sometimes challenging activities, but the best part is the friendships that are made.



MEET THE NURSE CLINICIAN

Stella Cockett:

Nurse Clinician, Cardiology Partnership Program

Where did you grow up?

I was born in England and came to Canada when I was 6 years old. I've lived in Vancouver ever since, and I love it here.

What made you want to be a cardiology nurse?

I never thought I would become a nurse. Years ago, I spent a weekend at our family cabin on Salt Spring Island studying for final exams with my friend. I was majoring in organic chemistry and she was studying nursing. I realized that her textbooks were far more interesting than

mine, and the next thing that I did was enroll in nursing school. After working one year with adult patients, I came to BC Children's for a tour and ended up walking out with a job – on the cardiology ward. And the rest is history.

What do you like about working at BC Children's Hospital?

I love that everyone who works here loves being with children and their families. The atmosphere is one of true caring.

Tell us about any specialties you have within cardiology.

For the last 14 years I've worked with the traveling Cardiology Partnership Program. Twice monthly I jump on a plane with one of the cardiologists and one of the echo techs and we travel to one of nine locations around BC (and one in the Yukon) where we set up a temporary clinic in the local hospital and see outpatients with congenital cardiac defects or rhythm disturbances or questions about their hearts. We travel to Kamloops, Kelowna, Penticton, Vernon, Trail, Williams Lake, Prince George, Fort Saint John, Terrace and Whitehorse.

It is a great job and a great program. I love our patients, and it's wonderful to be able to see them with their families in their own communities. The cardiology team has a lot of fun traveling too. Sometimes the team stays on for the weekend to sightsee or ski. One of my favourite locations is Whitehorse, where we travel to once yearly in June and experience almost (but not quite) 24 hours daylight.

Did you have a mentor?

One thing about working in this field is that the learning never stops. There are so many advances in cardiology and in



child/family care, and I'm fortunate to work with a team that continually strives for excellence. I learn daily from everyone.

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

I enjoy traveling (not just with the clinics), singing in a choir, practicing holistic health, and hiking. This year my husband and I are returning to Nepal with our good friends (nurse) Jan Rooks and her husband to trek for a month in the Himalayas. We can't wait!



FOR CHILDREN

Out here we rise 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:

HeartBeats (ages 8 to 12)
July 8 – 12, 2014

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

HELPFUL WEBSITES

heartbeats.ca – Supporting Children with Heart Disease

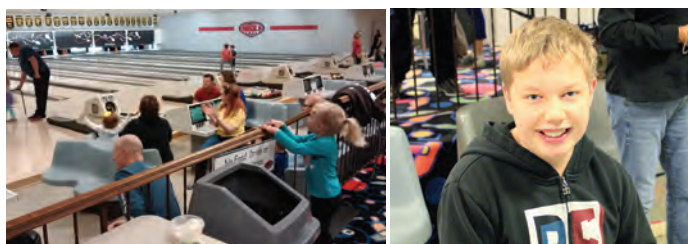
chdquilt.org – The Congenital Heart Defect Awarenees Project

westerncanadianheartnetwork.ca – Western Canadian Children's Heart Network

achaheart.org – Adult Congenital Heart Association

cchaforlife.org – Canadian Congenital Heart Alliance

EVENT REPORTS



◀ First family event for Nanaimo heart families

The Nanaimo Heart Families came together for their first fun-filled family event on May 4. We enjoyed a Pizza and Bowling party at Brechin Lanes—it was a great opportunity for our families to meet, have fun, and connect with each other. The children ranged in age from 1 to 16 and completely embarrassed the adults with their superior bowling skills! Our first event was so successful that we are planning on another family event this summer. We wish to extend an invite to all families from the Island to join us for this next family event—stay tuned for details coming soon!

We hold Heart Parents Coffee Group meetings monthly. Come and Meet other heart parents while enjoying treats on us. For more information, please contact Andrea van Rossum at andrea.vanrossum@gmail.com or call 250 729-3855. ■

A first-ever bowling and pizza party connected heart families in Nanaimo in May. (Above) The Mack and Hawes families (lower right) Tyler Williams.

Heart Day Walk at Cates Park ▶

On Saturday, February 15 The Children's Heart Network and the Harding Family hosted the fifth annual Heart Day Walk held at Cates Park in North Vancouver, where about 100 people took part. This is a small community event that invites heart families and friends to come out for a short walk to bring awareness to being healthy and active. February 7-14, 2014 was also Congenital Heart Disease Awareness Week.

February 14th has come to mean something very different from Valentine's Day for the Harding family. They found out on February 14, 2006 at their 18 week ultrasound that their second child would be born with a congenital heart defect (transposition of the great arteries). After he was born he had open-heart surgery at 2 weeks old. He is now an active young boy. The Heart Day Walk has been a wonderful event that celebrates the journeys of these heart kids and their families. ■



Despite the cooler temperatures, about 100 people of all ages participated in the Heart Day Walk in North Vancouver.

EVENT REPORTS

Easter Egg Hunt draws kids to beautiful Queen's Park

On Sunday, April 6 about 130 heart kids and their families attended a fantastic Easter Egg Hunt at Queen's Park in New Westminster. Happy heart kids and their siblings scoured the park to find colourful Easter eggs hidden among the trees. Once they collected one of each colour they could trade them all in for a treat bag, which brought on a lot of smiles! Cookies, apples, hot chocolate, and coffee for the parents kept everyone warm while the kids climbed all over the playground and the moms and dads spent time connecting with other heart parents.

A huge thank you to Danielle Aitken, Tara McLenan, Breanna Chan, Sophia Draper and her friends Hannah Brown, Shauna Turner, and Nicole Ward for organizing the candy and hiding the eggs, and to Starbucks for providing the coffee and hot chocolate, helping make this event a big success. ■

Transplant kids at the Oval

Last December, transplant families joined together for a holiday celebration at the Olympic Oval in Richmond. Transplant children and their families enjoyed an afternoon of socializing, crafts, gingerbread house decorating, a magic show, basketball, and skating. A number of our heart transplant families enjoyed connecting and celebrating the gift of life with their children (above). To learn about the Children's Organ Transplant Society, a charity that supports BC families who have children waiting for an organ transplant or who have had one, visit www.childrensots.org. ■



Muskaan, Andrew, Addison, and Brynn.

Western Canadian Children's Heart Network Update

BY REENI SONI, MD, FRCPC
CHAIR, WCCHN STEERING COMMITTEE

WCCHN coordinator

Angela Krizan has resigned from her position as Western Canadian Children's Heart Network (WCCHN) coordinator to relocate to Qatar, where she will be a clinical educator in the Pediatric Intensive Care Unit at the Sidra Medical and Research Center. Over the last 4 years, Angela has been instrumental in the growth of the WCCHN. Recruitment is underway for a replacement WCCHN Coordinator.

Family educational webinars

The WCCHN is working to organize quarterly educational webinars for families and patients. More information will follow. We would love to hear from you! Topic suggestions for these educational sessions can be forwarded to our office: wcchn@albertahealthservices.ca.

Website: www.westernchildrensheartnetwork.ca

If you have family stories you would like to share on our website, or if you have an update to your story that is already posted on the website, please forward your story or updates to wcchn@albertahealthservices.ca. Be sure to include your child's name, diagnosis, and a picture(s) along with your story.

Research ideas

We are currently looking into research ideas from families, and potentially partnering researchers and families together to develop study protocols, etc. If you would like to submit research ideas/topics or are interested in working with researchers, please let us know: wcchn@albertahealthservices.ca

Canadian Congenital Heart Alliance (CCHA)

The CCHA, founded in 2004, is a nonprofit organization that supports all Canadians with congenital heart disease. They work closely with Canadian patients and medical professionals from pediatric and adult cardiology to bring awareness to and support Canadians—both children and adults—with CHD. The WCCHN and CCHA are working together to promote the enhancement of pediatric cardiac services across the lifespan. If you're interested in joining CCHA or would like more information, please visit their website: www.cchaforlife.org. ■

UPCOMING EVENTS

JUNE 22: FUN WALK IN STANLEY PARK

Come join our CHN Team for the Scotiabank Charity Challenge 5K on June 22. It's easy and fun!

In addition to the 5K, there's also a half marathon—Dr Shubyan Sanatani, BCCH cardiologist, is captain of a team running the half marathon, raising funds to benefit CHN (they had already raised over \$4000 for the CHN at the time of writing). So if you don't want to do the walk, why not come out for a nice Sunday morning and cheer for Dr Sanatani? Watch for him and his teammates in red bandanas. This is sure to be a fun event for all, so come out and have some fun at Stanley Park! To register for the walk: secure.eventsonline.ca/events/crs_vanhalf
For more information: Samantha Aitken, CHN Provincial Coordinator, 604 961-0380, toll free 1 877 833-1773.

AUGUST 24—CULTUS LAKE WATERSLIDES

Mark your calendars for an amazing day Cultus Lake Waterslide Park. This is such a fun day that families come from all over BC to attend. CHN members receive free admission and lunch. More details coming soon.

SEPTEMBER—LOWER MAINLAND FAMILY BOWLING EVENT

Come out for pizza and bowling while getting to know other heart families! Date and more details to come.



Artwork by Romero Britto, which was the inspiration for the art the kids created.



Ten children attended the art workshop to create a print that was auctioned off at the CHN Wine Gala.

Heartbeats art workshop

On Saturday, April 26th one of our heart moms, Kerry Harding, hosted a fabulous art workshop for 10 CHN kids at Crofton House School. The children had a great time creating a unique canvas

print to take home with them, then they all contributed to a large work of art that was auctioned at the Wine Gala dinner. The piece was called Pulling on Heart Strings. The children were inspired by Romero Britto, a Brazilian neo-pop artist, painter, serigrapher, and sculptor. He combines elements of cubism, pop art, and graffiti painting in his work. This brightly coloured, gorgeous print was a collaborative collection of individual marks by each child, and raised \$850 for the Children's Heart Network!



All the kids created a canvas print to take home as well.

Entering the adult world of health care

BY MARIT HAUGDAGL

Being transferred from children's (paediatric) to adult health care is part of becoming an adult and it brings along some challenges. This process is often called "transition." It can be compared with other changes, such as moving from primary to secondary school, or going through puberty.

You should have a personal plan for the transition period because, at its worst, a badly handled transition process can make you feel unsure of adult services, and less likely to go to your routine clinical appointments. Obviously, this might have effects on your health.

When does it start?

The timing of the transition depends on lots of things. There are many more reasons but here are just a few:

- Do you feel ready to move to adult care?
- Do your doctors feel you're ready to move to adult care?
- How severe is your heart defect?
- Are skilled health personnel available?

There is often a difference of opinion between health care providers and parents about when young people should begin transition. Most experts recommend starting the process early, perhaps from the age of 11. You are gradually introduced to the idea of independent health care visits, which means spending time privately with the health professional, without your parents.

Saying goodbye

It's often quite difficult to say goodbye to paediatric health care – not just for you but for your parents and health care workers too – after all you have been in children's health care all your life! You may ask yourself a lot of questions about changing over. Do the people at the adult clinic know as much about my disease as they should? Will the care be as good as I am used to?

Be a heart expert

You've had your heart defect since you were born, and so you've probably been used to your parents taking care of you and your heart – particularly when you were younger. But as you become an adult it is important that you understand all about your heart defect, so that you can have a say when it comes to making decisions about your treatment and medication. Learning about how your heart defect affects your life can also help you become more independent.

Here are some questions you should know how to answer by the end of the transition period:

- Can you explain your condition in your own words?
- Who knows that you have a heart defect?
- What do other people think of you having this condition (friends, teachers, neighbours)?

- How would you tell a new boyfriend/girlfriend about your heart defect?

Teenager friendly

Some young people can feel a bit shy when it comes to talking to health professionals on their own. If you do, don't worry, it's very common. You might feel embarrassed or unsure how to ask questions or bring up topics. It is a good idea to prepare for visits by writing down any concerns or questions you may have so you don't forget to ask anything in your appointment. You could also ask if there are any health personnel available with expertise in adolescent health.

Give parents a break


Just like you, your parents also need a preparation period for transition. They need to get used to the idea that you are going to be seeing health care professionals without them. Often it's not easy for them to let go. Let them know that you still want to talk to them about your consultations and they shouldn't feel left out, but they also need to realise that being overprotective, or underprotective, could have a bad effect on your transition.

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Find information	Empower patients	Learn from one another	Share knowledge	Enhance debate
Personal experience	Link people	Find inspiration	Be active	Diagnosis and treatment methods
Doctors	Scientists	Patients	Families	Networking
Friends	Get advice	Research database	European community	Living with a heart defect
Latest research	Initiate dialogue	Get in touch	Diversity	Enjoy life

Corience is an independent European website on congenital heart defects for patients, parents, doctors, and scientists.

Visit our website. Enjoy it!
www.corience.org

 corience

12th Annual Wine Gala Dinner



(Left): Aaron McArthur and Hege Hoegler pull for the winning ticket. (Right): Fire in the Kitchen winner Ine Doorman (in the green)

BY SAMANTHA AITKEN

On May 9th we held the 12th Annual Wine Gala dinner at a brand new venue called The Jewel Ballroom. Just off 8th and Granville, this gorgeous room had a large patio and gorgeous views of the city's twinkling lights.

During cocktail hour, cardiology nurse Jan Rooks entertained us with her skills on the grand piano while over 160 guests enjoyed a glass of bubbly and "cutting edge" hors d'oeuvres. As the sun set we all sat down and were welcomed by emcee Aaron McArthur, heart dad and Global TV anchorman and reporter.

Guests enjoyed a four-course dinner with wine pairings from La Vieux Pin and La Stella Wineries and with dessert we enjoyed an exquisite 14-year-old "late bottle vintage" port donated by long-time CHN supporter Cindy Thaler. The dinner was absolutely divine. Some surprise guests arrived, a crew of Vancouver's Finest Firefighters, as our feature auction item was a "Fire in the Kitchen" Dinner – the winning bidder enjoys a very memorable evening, dinner for eight prepared and served by a team of Vancouver's Finest, a limo ride to and from for guests, and a case of Burrowing Owl wine! The end of the evening "Cork Draw" for two tickets with Air Canada was drawn by emcee Aaron McArthur and heart mom/volunteer Hege Hoegler, the lucky winner being heart mom Annie White.

Thank you to Aaron McArthur, who was very entertaining as emcee and helped us raise over \$38,000! We would like to express our gratitude our heart parent speaker, Carly Crocker as well as all those that attended, donated, and supported the CHN as a corporate sponsor. It was a magical evening that will help us to continue supporting our BC families who are bringing up children with heart disease. ■

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