



CHN's generous guests enjoyed food and wine pairings, great entertainment, and lively auctions.

## CHN Wine Gala Dinner sets new fundraising record

BY SAM AITKEN



Air Canada pilot Darren Nadeau presents two airline tickets to lucky draw winner Dr Lynn Schouls.

**O**n Friday, May 1 the Children's Heart Network held its 13th Annual Wine Gala Dinner at the Diamond Ballroom in Vancouver. The 185 guests enjoyed gorgeous city views, a fabulous dinner with wine pairings, live music, and both live and silent auctions. It's CHN's premiere fundraising event of the year.

The evening started with a glass of bubbly and canapés while listening to the acoustic duo of Chrystal Leigh and Jimmy Thow, known as Sons of Daughters. This room was buzzing with their addictive melodies and amazing harmonies. Guests sat down to enjoy dinner prepared by executive chef Matthew Kamieniecki while looking out over the twinkling lights

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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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Tel: 604 521-3037 | 1 877 833-1773  
chn@childrensheartnetwork.org



/ChildrensHeartNetwork



## COFFEE GROUPS

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

**VANCOUVER** – **Samantha Aitken**

saitken@childrensheartnetwork.org

**BURNABY/COQUITLAM** – **Sarah Kertcher**

sarah.kertcher@outlook.com

**RICHMOND** – **Kate Walker**

kwalker@childrensheartnetwork.org

**ABBOTSFORD** – **Rachel Gammon**

footballmama02@hotmail.com

**MAPLE RIDGE/TRI-CITIES** – **Mandy Taylor**

caleb02@telus.net

**CHILLIWACK** – **Melissa Martz**

melmartz@shaw.ca

**LANGLEY** – **Tecia Beulens**

tbeulens@telus.net

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

**NANAIMO** – **Andrea Van Rossum**

andrea.vanrossum@gmail.com

**KAMLOOPS** – **Miranda Brown**

cmazn2003@yahoo.ca

We would like to get a **KELOWNA** Coffee group up and running! Please email Sam at [saitken@childrensheartnetwork.org](mailto:saitken@childrensheartnetwork.org) if you are interested in attending one.



## 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

## ARE YOU A MEMBER OF A HEART FAMILY?

If you have a child growing up with heart disease please email us at [chn@childrensheartnetwork.org](mailto:chn@childrensheartnetwork.org) so that we can add you to our mailing list to receive invitations to all our fun events!

## 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**



## TRAINED RESOURCE PARENTS OFFER ONE-ON-ONE SUPPORT

If your child or someone you know has been diagnosed with a congenital heart condition, the Children's Heart Network is here to help. If you'd like to connect with another heart parent, we have a province-wide network of resource parents trained to support other parents. Resource parents are in communities all over British Columbia and are available to listen and offer support and information through phone calls, e-mails, or in person. Talking to another parent who's been there can make a world of difference. Please contact our coordinator Sam Aitken if you would like to connect with a resource parent.

*Heart Matters* newsletter is created by Sam Aitken, Jay Draper, Leigh Striegler (Scout Creative), and the contributors named on each story.

## 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

## CHN BOARD

**TRACEY CARPENTER** – Vice president

**STEPHANIE ISAAC** – Member at large

**BARBARA JOHNSTON** – Member at large

**MANDY JOHNSON** – President

**SARAH KERTCHER** – Member at large

**JEFF MERCER** – Treasurer

**BINDY SWEETT** – Member at large

**KATE WALKER** – Member at large

**BARB WILLSON** – Secretary





Each unique heart painted by CHN kids was inset into custom-designed tiles, decorated, and finally fired by internationally renowned BC artist Sid Dickens.



Our creative heart kids making the tiles at an art workshop.

of downtown Vancouver. Our emcee for the evening was local actor and heart dad John Emmett Tracy, who was tremendously witty and kept the crowd well entertained.

We were enlightened as teenager Samantha Armstrong shared stories of her heart journey, as well as telling us about what the Children's Heart Network, and especially the Hearts of Gold teen group and Camp Zajac, has meant to her.

Sending more heart kids to camp is one of CHN's goals this year, and thanks to the energy of our auctioneer Robb Lucy and the generosity of our guests, we collected donations totaling more than \$13,000 that will benefit our kids heading to Camp Zajac this summer. The evening culminated with the exciting live auction item Fire in the Kitchen—a dinner for eight in the successful bidder's home prepared and served by Vancouver's Finest—a team from the Vancouver

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## CHN NOW ACCEPTS DONATIONS OF SHARES

The Children's Heart Network is pleased to announce that it can now accept donations of shares of publically traded companies. Donating shares provides a significant tax deduction and capital gains exemption for the donor, while at the same time benefiting a worthy cause. We would like to thank Mr. Mark Corra for the first share donation to CHN of 5,000 B2Gold shares. Talk to your financial advisor for more information, and to see if donating shares is an option for you.



The Sid Dickens heart tiles were a hot silent auction item, helping to raise thousands of dollars to support heart kids.

Fire Department, and finally a draw for two tickets anywhere in North America, Hawaii, Mexico, or the Caribbean donated by Air Canada.

In total, we raised \$52,000, which makes it our most successful year ever. Children's Heart Network families will benefit greatly thanks to the generous support of all our attendees, supportive corporate sponsors, and auction donators. Thank you to all of our guests, donators, and the following major sponsors:

- The Sorin Group
- The Pediatric Cardiology Associates
- Dr Brian Sinclair
- Air Canada
- Colby Red wine
- Chateau Ste. Michelle Winery
- Trialto Wines
- Cindy Thaler

Next year's gala is already booked: mark your calendar for April 29, 2016! 🍷

## What's Up? Upcoming CHN Events

### Grind for Kids Day

(Lower Mainland)

Sunday July 26th, 11:00 a.m.–12:30 p.m.

Join BC Children's Hospital cardiology team members Dr Gandhi and Dr Sanatani on a climb up the Grind and collect sponsorship from friends and family to support BC Children's Hospital or ride the gondola up to cheer them on as they arrive at the top. Visit

[www.bcchf.ca/events/event-calendar/cp-has-heart-grind-for-kids-day/](http://www.bcchf.ca/events/event-calendar/cp-has-heart-grind-for-kids-day/) for more information and to register.

### Butchart Gardens

(Victoria)

Friday August 7th, 4–6 p.m.

Come and celebrate the summer season with light snacks and carousel rides at the Butchart Gardens and more while meeting other heart families. Please bring a dessert to share. All Island families are welcome!

**WHERE:** Butchart Gardens, 800 Benvenuto Ave., Brentwood Bay  
See [www.butchartgardens.com](http://www.butchartgardens.com) for more

information. Please RSVP by July 25 (as we need to mail tickets) with the number of people in your family and children's ages to Krista Molia at [viheartsofgold@gmail.com](mailto:viheartsofgold@gmail.com)

### Nanaimo Barbeque

Sunday August 16, 3–7 p.m.

Come and celebrate the summer season while connecting with heart families at our summer BBQ! Hosted by one of our heart families. Entrée and beverages provided by the CHN, please bring a side dish to share!

**WHERE:** Tara & Jack's home at 760 Craig Road, Ladysmith

Please RSVP with the number of people to Andrea Van Rossum at [andrea.vanrossum@gmail.com](mailto:andrea.vanrossum@gmail.com)

### Cultus Lake Waterslides

(Lower Mainland)

Sunday August 23, 10 a.m.–4 p.m.

**WHERE:** The Cultus Lake Water Slides at 4150 Columbia Valley Hwy., Cultus Lake  
For more information: [www.cultus.com](http://www.cultus.com)



Come and celebrate the summer while meeting other heart families!

Please RSVP with the number of people in your family to [saitken@childrensheartnetwork.org](mailto:saitken@childrensheartnetwork.org)

### CHN Annual Christmas Breakfast

(Lower Mainland)

Saturday November 28

Enjoy a complimentary breakfast, family fun, a silent auction, and Mr & Mrs Claus at the Metrotown Hilton Hotel in Burnaby. More details to come!

### CHN Wine Gala Dinner

(Lower Mainland)

Friday April 29, 2016

Mark your calendar and be sure to attend next year's Gala!





Hearts of Gold is a program for cardiac youth aged 13 to 19 to meet, learn, and have fun with other youth growing up with heart disease. [www.childrensheartnetwork.org/what-we-do/hearts-of-gold](http://www.childrensheartnetwork.org/what-we-do/hearts-of-gold)

## HEARTS OF GOLD

# Zajac Ranch: Give it a try!

BY ROBBIE THOMPSON, Double heart transplant recipient

Things went well at Zajac Ranch when I was there in May—in fact, even better than I expected! The camp's defining aspects were the beautiful environment combined with a stellar and enthusiastic staff. There were plenty of activities to participate in, most of which ran very smoothly.

CHN arranged for me to be flown to and from Vancouver Island and the Mainland (Camp Zajac is near Mission). Staff from the Children's Heart Network ensured that I was able to get to the airport on time while I was going back, and the bus trips were pretty smooth.

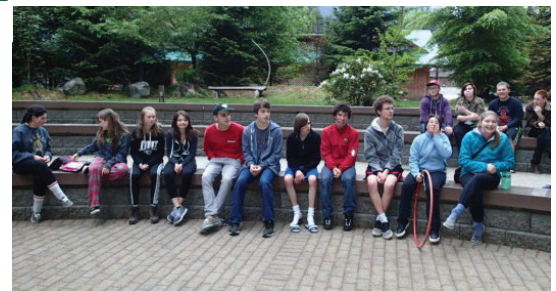
The counselors were extremely kind and competent, happily interacting with the campers, ensuring we were safe and giving us plenty to do. I even got to play guitar with one of the counselors, which was awesome! The food was good in addition with being free.

There were no issues in terms of health problems. Medications were well managed and any concerns were dealt with.

Some of the activities included your camp standards like archery and horseback riding, with a game of rather intense capture the flag. We also got to do a little bit of kayaking! There was also water games (Zao), an Amazing Race, we watched a movie, and on the last day we had got to go in the pool, which was pretty radical.

If you're like me and have trouble with certain activities (I can't do high ropes for example) then that's perfectly okay. Participation is encouraged, but if you can't do something you're just fine to sit on the side and watch, or perhaps read a book. Nonetheless I'd highly recommend that new campers give everything a try at least once or twice!

Zajac Ranch itself along with the staff was great. I'd encourage anybody to give the program a try! 🍓



## MORE ABOUT CAMPS FOR KIDS

CHN, in partnership with Zajac Ranch, offers two summer camps each year: one for teens over the May long weekend and one for children (ages 8 to 12) in early July.

Camp provides dozens of fun activities available, and the camps are safe and medically supervised by a cardiology nurse. Every year kids come back from camp with new confidence and new friends. CHN is very proud that we can offer these wonderful opportunities to kids thanks to Mila's Fund, the CKNW Orphans Fund, and our generous donors.

For more information: [www.childrensheartnetwork.org](http://www.childrensheartnetwork.org)



## BOARD PROFILE

# Jeff Mercer – Treasurer

**My family** My wife, Darlene, and I have a son, Matt who is 22 years old and attending SFU, in their Software Systems Program. He is studying computer programming and has already worked for EA Games as a co-op student.

**My work and education background** After graduating in accounting BCIT I obtained my professional designation in 1984 as a management accountant, which is now called “CPA, CMA” or chartered professional accountant.

I began my accounting career in 1981 with Westbay Instruments Ltd., eventually becoming the controller for 3 years. I joined Paradigm Environmental Technologies in 2003. After 10 challenging and interesting years, I left in 2014 and am now working as director, Finance and Administration for Lance Bissett Ltd.

**Activities I enjoy** What I most enjoy is family time. Hiking, walking, bowling, or even catching up on our family’s favourite TV shows in the evening as we all decompress from busy days. In the summer I enjoy getting in the odd round of golf, and have rededicated myself to personal fitness, visiting the local rec centre as often as possible.

**A little-known fact about me** I feel a certain discomfort peering down from heights greater than 6 feet.

**What I hope to bring to the Board** I hope that my financial management and leadership skills will complement the Board’s experience and help to facilitate the important work being done by CHN. I believe that CHN can grow and provide even more services and support for children with heart disease and their families. 🍷

## HEART HEROES

# Hannah and Teah

BY SAM AITKEN

A few months ago I received an email from two students in grade 7 attending Vancouver Talmud Torah School (VTT.) Hannah Casseres and Teah Bakonyi contacted me as they had chosen The Children’s Heart Network as the charity they would like to support for their school project. In Grade 7, students become B’nei Mitzvah and learn about their responsibilities to the community and the world around them. The culmination of their Tikkun Olam learning happens with the Mitzvah of Valuing Philanthropy (MVP) program. During this teen philanthropy program the students learn in a hands-on way what it means to become a caring and responsible adult.

During the year, students select a



Teah and Hannah chose CHN as their charity to learn about and support.

mitzvah (commandment) of meaning to them, and then research, interview, and select an agency that delivers on that mitzvah. Hannah and Teah selected the CHN. They then presented the mission and needs of the CHN to their classmates. As a group, the whole class

raised funds in many different ways. Some of the different initiatives were bake sales, babysitting, a 5 km run, and organizing birthday parties. Hannah and Teah enjoyed making cake pops for the bake sale and babysitting the most!

The students subsequently worked together to assess the needs and, as a class, decided how to allocate to every agency from their pool of funds. The year culminates in a Ceremony of Giving, as representatives from the chosen agencies come to VTT to receive their grants from the students. I had the pleasure of being at that ceremony and am so very proud of the incredible job they did with their presentation to the class. I was thrilled to accept a cheque on behalf of the CHN for \$810! A huge heart-felt thank you to Teah and Hannah for the amazing job they did and to the whole grade 7 class for selecting to support our heart families! 🍷





Annual cardiology check-ups became routine from Sam and her family.



Sam and her friend Daniella.



Sam and some of her friends from Hearts of Gold at the PNE.

## Sam's Heart Story

BY SAM ARMSTRONG

**A**lmost 17 years ago when I was born I was diagnosed with a congenital heart defect called Ebstein's anomaly with atrial-septal defect; the leaflets of my tricuspid valve were displaced downward and didn't close properly, making my right atria huge and my right ventricle "atrialised" and very small as well as having a hole in the septum between the atria.

Before I was born everything seemed fine, so my family was unprepared to get the devastating news. I seemed fine when I was born, but a test of my oxygen saturation showed only 40%, and I soon started having blue colouring. The doctors told my parents that I had a low chance of surviving the day, but if I pulled through they would perform emergency surgery on my second day of life. My family was all told to say goodbye – possibly forever – and allow me to rest.

I didn't just live the day; I showed signs of improvement, so they put off the surgery for another day. I was still staying strong so the surgery got put off even further and further so I'd be in the best shape when the day finally came. The surgery was put off for 9 years!

My family and I had gotten comfortable in our routine of annual cardiology check-ups and when we were told, "It's time," our whole world was once again flipped upside down. The challenge I faced being a 9-year-old was that I was very much aware that something was very wrong, but I had very little understanding of what was happening. I went through a three-part surgery where my tricuspid valve was turned into

a "monocusp valve," my superior vena cava was shunted onto the pulmonary trunk, and the hole between my atria was patched. The surgery was a huge success! My oxygen saturation (which had been 40% to 60% my whole life) was now at 90% to 100%. I was supposed to have a 2 week in-hospital recovery, but I was sent home 4 days later!

Since the surgery I've been stronger than ever before. Right away I began to grow taller and gain weight. Now, though I still have to pace myself, I can be active and exercise regularly without taxing my heart. It's thanks to the doctors at BC Children's Hospital that I'm alive, well, and strong, and my family and I are so extremely grateful!

After my surgery I began to feel scared and insecure about my scar, until the Children's Heart Network sent me to camp when I was 11. There I met kids with the same scar as me; we shared stories, told jokes, and had fun together. I grew close with the kids from CHN and when I turned 13 and joined Hearts of Gold, we grew even closer.

The people I've met through CHN are more than my friends—we're a family. We lift each other up and we share the same struggles from our defects, all while going on exciting activities together like the water slides, bowling, CPR courses, and much more.

CHN has not only given me an outlet to adventure with some awesome people, it has shifted my perspective on my condition and empowered me to stay strong in the face of adversity, love myself despite my differences, and has truly made me into the person I am today. 🍷

# Transitioning to Adult Care: Strategies to Help Your Child Prepare

ALYSSA POWER, *Pediatric Resident, Alberta Children's Hospital*

For families of children with congenital heart disease, the transfer from pediatric to adult health care marks a true rite of passage. While there is always some excitement about the prospect of new beginnings, many families tell me that it can also be hard to say goodbye to the pediatric care team that they have become comfortable with. The pediatric system provides family-centered care, and the move to the adult health-care system can certainly be challenging. The good news is that there is a great deal that you and the health care team can do to help prepare your child for a smooth transition.

As a parent or caregiver, you are your child's best advocate and can ensure that your child is equipped with the necessary tools to make wise choices that will affect their life-long health. There are many steps you can take to foster autonomy and independence, and make sure that your child is prepared for this big period of change. You can help your child to develop the strong communication skills that are vital to maximize success as a patient navigating the adult health system.

Helping your child understand their cardiac condition is vital to empowering them. In conjunction with their pediatrician and cardiologist, you can help them to acquire developmentally-appropriate information about their heart. The better you understand your child's heart condition, the better your child will understand it. Together, you can start a journal including the name(s) of your child's heart condition and other health problems, a list of medications and dosages, past surgeries and catheterization procedures (including the date on which they occurred), and relevant notes from cardiology appointments and hospitalizations.

At eighteen, your child will become uniquely responsible for making decisions regarding their health, ideally working jointly with you and the healthcare team. Preparing for the transition to adult care should start much earlier. The guidelines below were inspired by the Transition Resources for Patients and Families website created by the Children's Hospital of Philadelphia (the link for this excellent resource is provided at the end). The age brackets are just general guidelines – you know your child best. Ultimately, the transition process that should be individualized to your child's unique personality traits and developmental capabilities.

**AGES 4 TO 6:** You can start to explain your child's heart condition to them using simple words and descriptions they can understand. Ask your child's pediatrician or cardiologist

for advice on how to give your child information in a developmentally-appropriate way. You can start to teach your child to pay attention to the way their body feels. Review with your child the warning symptoms that mean that they might be getting sick (such as shortness of breath) and who they should tell (you or other trusted adults such as caregivers, relatives, teachers). You can also begin teaching your child about his medications, using a simple explanation of why they need it.

**AGES 7 TO 10:** Start to explain your child's heart condition to them in an increasingly detailed and complex way as they grow older and mature. Your child might also be ready to start having more responsibility for taking their medication (with your continued supervision of course!). Using an alarm clock or a chart might help. Praise for remembering to take their medication builds up their self-esteem and reinforces the importance of becoming self-reliant for their health needs.

It is important that your child becomes comfortable around health care professionals and eager to share information about their wishes and concerns. Before each appointment, you can ask if your child has any questions and encourage your child to bring them up during the appointment. Try to encourage your child to answer more of the questions that their doctor asks, then adding in any corrections or clarifications yourself. By beginning the process of engaging your child in health care discussions, you are allowing your child to become comfortable discussing their cardiac condition and gain confidence in talking to nurses and physicians.

**AGES 11 TO 13:** Your child can practice talking about their medical condition with others, such as the school nurse, coaches, and peers. As your child demonstrates increasing responsibility, they can become the main person responsible for remembering to take their medications (always telling you when they do so, so that you can watch them take their medicine or remind them when they forget). You can work with your child to make a wallet-sized emergency card listing their medical condition(s), allergies, medications, and emergency contact information.

**AGES 14 TO 17:** At this stage, the importance of life-long follow-up with cardiology should be stressed. Continue to make sure that you teen understands their cardiac and other

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# Growing Up with Heart Disease: Celebrating Life

CHN's Conference, April 11 and 12, 2015

BY JEN BELESHKO

*Jen Beleshko is director of communications at Heart Beats Children's Society of Calgary. A version of this article first appeared in their newsletter; they have kindly given us permission to reprint it here.*

This amazing conference in Vancouver was dedicated to Jan Rooks, cardiology nurse clinician and chair of the Growing Up with Heart Disease conferences for 2012 and 2015. Jan passed away tragically last fall following a blizzard and avalanche in Nepal's Himalayas where she had travelled with her husband Grant and two friends. Grant attended the opening of the conference and provided a photo album so that her friends could see parts of her life outside the hospital spent with her loving family and friends. Here are my notes from some of the sessions I attended.

## Saturday Keynote: Mindfulness and Hypnosis to Build Coping and Comfort

*Presentation by Leora Kuttner, PhD, clinical psychologist internationally recognized for her work in pediatric pain management.*

Dr Kuttner gave a fascinating presentation on how to help children cope with stress and pain through two self-regulation techniques: mindfulness and hypnosis. She first dispelled what most associate hypnosis with—mind control and its use for entertainment. She explained that hypnosis is one of the oldest therapeutic interventions; it does not mean holding a person under control, but rather enhancing one's own self-control. She explained how hypnosis can eliminate fear by allowing a child's attention to be drawn away from needles and other painful procedures, by focusing on breathing—for example, blowing bubbles or hugging a teddy bear—in order to cope. Dr Kuttner then spoke about stress, and how children imitate us and our reactions to stress. She advocates calming responses and acting in a way that encourages mindfulness to thus put the brakes on stress. She defined mindfulness as being in the moment with awareness of thought. It is focusing on the here and now, accessing your brain, and focusing on breathing. We can greatly reduce our stress reaction through mindfulness. In conclusion, a video of a teen who suffered from migraines was able to find relief by turning her attention inward to her breathing and then visualizing a panel of pain switches connected to the nerves throughout her body and being able to switch them off the one by one. Through the use of self-hypnosis and breathing, the teen no longer suffers from frequent migraines and is often able to stop them when she senses the first signs of a migraine coming up.



Leora Kuttner (left), clinical psychologist, was the keynote speaker on Saturday. She presented on Mindfulness and Hypnosis to Build Coping and Comfort. Gwen Rempel (right), is an associate professor, Faculty of Health Disciplines, Athabasca University and a former BCCH clinical nurse in cardiology. Her keynote on Sunday was "There is Much More to a Child than Their Heart."

## Transitioning from Pediatric to Adult Care: A look at ON TRAC and other Transition Initiatives

*Presentation by Mary Paone, MSN, CNS, RN, nursing lead for the ON TRAC Transition Initiative and Dr Brian Sinclair, cardiologist and pediatrician at BC Children's Hospital.*

The ON TRAC transition initiative was developed to help teens with chronic health conditions plan, prepare, and transfer from pediatric care to adult care. While it's never too early to educate your child about their condition and promote autonomy, the transition timeline should begin at around age 12 to 13. The ON TRAC program was designed for the BC health system and contains valuable information for all youth and their parents who are preparing for transition. Smart phone apps are also available for download and can help to organize and coordinate appointments, list conditions and medications, and contain important phone numbers. To access this program which includes readiness quizzes and checklists, visit [www.ontracbc.ca](http://www.ontracbc.ca).

The goal of transition is to avoid being one of the 50% of cardiac patients who are lost to follow-up after leaving pediatric care. The presentation focused on the importance of having a structured, long-term health management team in place prior to transitioning, which includes having a



(Left) Mary Paone presenting “Transition from Pediatric to Adult Care: A look at ON TRAC and Other Transition Initiatives” at CHN’s Growing Up with Heart Disease Conference. (Right) Dr Derek Human emceed the conference with characteristic wit and compassion.

family physician by the age of 14. This primary physician will become the central point of the young adult’s care and will follow your child long after graduating from pediatric care. While the cardiologist follows the heart function, the family physician helps with all other health matters and can counsel on diet and exercise, stress and anxiety, drugs and alcohol, and sex and contraception.

### Exercise: The “Techy” Stuff!

*Presentation by Astrid De Souza, MSc, exercise physiologist at the Cardiology Clinic.*

This session discussed the importance of physical exercise for everyone, especially heart patients. Youth were asked for their thoughts about exercise including gym class and team sports. Some comments included not being able to keep up, being nervous about how their chest felt, getting out of breath, and feeling dizzy. One adult with a heart condition said that they played rugby and cricket as a teen growing up but chose positions that included the least amount of running. Astrid recommended keeping a log to see if there is a pattern of chest pain or dizziness during different activities and to share it with their cardiologist.

Astrid addressed the question of when it’s okay to push yourself and when you should stop. An exercise test at the cardiology lab measures your heart response to activity and is done on a treadmill. A mouth piece that you blow into monitors how much oxygen you are using and measures your endurance.

Like brushing our teeth, exercise is not an option. It is recommended to get 60 to 90 minutes of physical activity per day. She encouraged everyone to try new things to find what you like to do as not all exercise needs to be hard. Consider being active with your friends to make it more fun. The heart is a muscle that will get stronger with time.

Activity trackers and various gadgets were reviewed. While most are beneficial, it is always advised to read the inserts as some trackers are not suitable for people with heart conditions.

### Panel: Long-term Heart Health, Prevention and Exercise—Beyond just CHD

*Panel discussion by Astrid De Souza, MSc, exercise physiologist at the Cardiology Clinic, Dr Brian Sinclair, cardiologist and pediatrician, and two young adults: Alyssa Ramanzin and Jordan Marcia, who both put a high priority on physical activity to manage their heart conditions.*

Jordan Marcia received a heart transplant at the age of four. He said he grew up not feeling like he fit in because he was not able to run as fast or as far as his peers. He decided to hit the gym and now works out 6 days a week and today is a certified personal trainer. He considers himself a good motivator and pushes his friends and family members to push themselves and try new activities.

Alyssa Ramanzin was a very active child and preteen who loved doing sports until she had a frightening experience at an amusement park. After coming off of a ride, she experienced tachycardia (rapid heart rate). She was diagnosed with Wolff-Parkinson-White syndrome, a disorder of the electrical system of the heart. From that point forward, she could no longer keep up with her team due to her many subsequent tachycardic episodes, and she fell behind in her sport. At age 16, she had an ablation performed to restore a normal heart rhythm. Today, as a young adult, Alyssa is healthy and makes physical exercise and healthy eating a priority.

The panel discussed the benefits and risks of structured sports. The obvious benefits are endurance, strength, socialization, and self-esteem. Young children tend to go at their own pace and do well, but as they grow up, team performance expectations and competition increases. This is where risk factors increase for those with lower cardiac output and the impact and injury to those on blood thinners, prosthetic valves, and pacemakers. While those with simple heart lesions that are fully repaired can normally “go for it,” those with more complex lesions should focus on sports with moderate aerobic/low intensity strength activities. Your child’s cardiologist can let you know what sports are suitable for them.

### Keynote: There is Much More to Your Child than Their Heart

*Presentation by Gwen Rempel, PhD, Faculty of Health Disciplines, Athabasca University and a Circle of Security registered parent educator.*

Gwen Rempel gave a wonderful talk about the stresses of parenting a child with complex heart disease. She has spent several years researching, interviewing, and writing about



children with hypoplastic left heart syndrome and their parents. Her research findings reveal that there is very little support for parents raising children with complex heart disease. They must live through traumatic experiences, face an uncertain future with their child, experience significant financial burden, and navigate a complex health care system that is not prepared for their needs. Many struggle to prepare their children for surgery—what, when and how much to tell them—and they are further traumatized by their child's stress reactions. The realities that these parents must face throughout the life of their child have major impact on them. In fact, a study has shown that 37% of these parents scored similarly to those being treated for post-traumatic stress disorder and anxiety.

Children too face tremendous stress. They often have regulatory challenges (sleep, feeding, sensory, and behavior) that require intervention. Unfortunately many miss valuable linkages with early intervention and community support because of hospitalization and necessary surgeries. They experience stress reactions, especially when returning for subsequent surgeries and procedures, possibly related to trauma from previous life-saving interventions. The school system is not prepared for these children and many do not adequately monitor and support developmental and learning challenges in kids with CHD.

There is a direct correlation with how parents cope with stress and how their child will cope with stress. Regular assessments of how parents and children's emotional states are needed. Parents need to let the medical staff take care of the child's physical needs and be there an emotional level for their child to build security for them—to be their safe haven.

Gwen talked about the Circle of Security, which is a relationship-based early intervention program designed to

enhance attachment security between parents and children. The illustration shows how parents can attend to their child's needs. Also see [circleofsecurity.net](http://circleofsecurity.net) for more information. Gwen's concluded with suggesting that parents let the medical staff worry about tubes being pulled out and focus their energy on being there for your child emotionally. "Be there for your child—don't just do something, but stand there and pay attention—your child is trying to tell you something."

### Cardiac Surgery: Looking Forward, Looking Back

*Presentation by Dr Andrew Campbell, cardiac surgeon.*

This talk looked back to the earliest interventions and forward to what innovations are on the horizon in cardiac surgery (he focussed on the "looking forward" part). Throughout the history of cardiac surgery, the following is true: every advance takes time and every innovation costs lives.

#### Some recent advancements include:

- The portable extracorporeal membrane oxygenation (ECMO) machine, which can now be transported to a patient who is then transported to the hospital for treatment. The newest ECMO now deliver better oxygenation and more efficient pumps.
- Assessing neurodevelopment in children. Ten years ago, there was no method of assessing neurodevelopment in children with CHD. Now, there are consistent and ongoing studies using brain imagery. While the belief has always been that neurodevelopmental problems stemmed from surgeries, bypass, ECMO, etc., studies are now leaning toward restricted blood flow in the prenatal period. White matter lesions, perhaps indicating tiny strokes, were indicated during prenatal development which is believed to be responsible for learning disabilities.
- Ventricular assist devices (VADs) are used for keeping patients alive while awaiting a heart transplant, to let the heart recover so a transplant is unnecessary or to support people who will never be a candidate for a transplant. These VADs can allow a patient to go home and resume a life outside of a hospital; however, clots and stroke remain the Achilles heel of these devices.

#### What's on the horizon?

- Hybrid surgeries (cath/surgeries) for example a hybrid Norwood, which would avoid open heart and bypass and allow children to grow.
- Cardiac replacement remains the ultimate goal because while survival of cardiac transplantation remains good, immunosuppressants are not perfect. Rejection, infection, malignancy, and kidney disease all remain major concerns. A heart built from a patient's cells could solve the rejection problem. 🍷



At this year's Growing Up With Heart Disease conference, from left: Suzanna Mungall, Sophia Draper, Daniella Lester, and Sam Armstrong.

## Patty Rippel Administrative Assistant

In January this year I was very excited to start working for the Children's Heart Network. It's such a wonderful, important organization. A great way to start a new year.

My wonderful husband Ted and I have two sons, Kyle, 30, and Connor, our heart son, who is 22. Kyle is working in construction and Connor is going to university, going for his bachelor of business. Connor also works for my husband Ted, who owns his own successful renovation company.

Growing up, my family was in the hotel/pub business and from a very young age I learned the ins-and-outs of running a hotel so that one day I would be able to run one on my own. I attended school to take business/accounting, a necessity when learning to run a business. I was hired at an accounting firm—the same accounting firm I work at today.

My career path changed when my father passed away at only 48. I continued working in the accounting field until I left to have Kyle. As a young mom, I continued to work part-time at home doing bookkeeping for my mom's companies. After a few years, I went back to work at a different accounting firm, plus continued working from home, until I had Connor. I found myself working three part-time jobs around the boys' schedules: bookkeeper, photographer's photo lab technician, and a noon-hour supervisor for the school board. It was busy, but it worked, and I liked it. As the years passed and the boys grew, my three part-time jobs changed. I'm currently at the accounting firm that I had originally started at years ago. I still do the bookkeeping at home for my mom's company as well as my husband's, and am now so happy to be working for the Children's Heart Network.

Connor was born with a congenital heart defect called transposition of the great arteries and a VSD. That's when we were introduced to the amazing BC Children's Hospital. Ted and I joined the Hearts to Heart group that was started to



Ted, Connor, Patty and Kyle.

help parents with cardiac children by offering comfort and education. We found it a great help. I joined a Maple Ridge Children's Hospital committee for around 6 years that raised funds by putting on dances, hot dog sales, raffle sales, and so on, and we all took turns being on TV presenting our yearly donation cheque. It was fun and it gave us a chance to give back for all that Children's Hospital had done for our son. I also put together small photo albums of Connor's Children's Hospital story that were used to help families that were just starting their own cardiac journey.

Three years ago I helped start an event in Maple Ridge called Putting On the Glitz. It helps underprivileged high school graduates with donated formal attire so that they can celebrate this important milestone that they wouldn't normally attend due to the financial constraints. I enjoy it a lot.

I enjoy hiking with our dog Shasta, biking, and working on small projects. I also like to shop! I'm a summer person and I enjoy boating and spending time at our cottage with family and friends. I like to entertain but I also love my down time: watching Friday night movies with a big bowl of popcorn. 🍿

## TRANSITIONING TO ADULT CARE —continued from page 8

medical conditions. They should be able to both describe their disorder in detail and summarize it in a few short sentences. Your teen should know the names, doses and purpose of all their medications. Your child should be the main person responsible for taking their medications – continue to check on them periodically to ensure they are doing it correctly as they may make mistakes or forget. During medical appointments, your teen should do the majority of the talking. They will also spend part of the visit alone with their physician as they gain increasing maturity and independence. Your teen should be aware of whether or not endocarditis prophylaxis is required and which symptoms would warrant seeking emergency medical care.

Your child will become legally responsible for making healthcare decisions at eighteen, if they have the capacity to do so based on their developmental abilities. To prepare for this progression, your teen should begin making medical decisions alongside you and the healthcare team in order to learn how to make responsible choices. 🍿

For more information on how to help prepare your child to transition to adult care, here is a helpful link from the Children's Hospital of Philadelphia: April 2010. Transition to Adulthood – Resources for Patients and Families. Retrieved December 2013, from: [www.chop.edu/service/transition-to-adulthood/resources-for-patients-and-families.html](http://www.chop.edu/service/transition-to-adulthood/resources-for-patients-and-families.html).