CHILDREN'S HEART NETWORK of BC Society

SUMMER 2024

HEART MATTERS

Hearts of Gold Go to Camp!

By Edward Chow

Hi everyone, my name is Edward Chow.

I have been with the Hearts of Gold (HOG) youth program for about 5 or 6 years now and I am very happy to have them in my life, because without them, I would be living in a very lonely world right now.

A little bit about me starting with my congenital heart condition, which is called an Atrial Septal Defect (ASD). An ASD is a defect in which a hole forms in between the upper atrium chambers of the heart. This caused my oxygen-rich blood and my oxygen-poor blood to flow to the wrong chambers and resulted in me becoming sick quite often. If this defect had not been repaired, I would likely have died before reaching adulthood. Luckily for me, I was able to get heart surgery when I was old enough, and the surgeons were able to seal the hole in my heart.

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WHAT'S HAPPENING

Cultus Lake Waterpark for Heart Families

Are you ready for some fun in the sun while connecting with other Heart Families?

The CHN invites all members to our annual event at the Cultus Lake Waterslides on August 24 from 10am-3pm.

Check your emails for the RSVP link!

Coffee Groups Near You

If you would like to organize a coffee group for heart parents in your community, please contact Sam Aitken at saitken@childrensheartnetwork.org and we can get you set up with a coffee card for drinks and treats!

ABBOTSFORD – Rupe Brah - rupe3395@gmail.com

CHILLIWACK – Jenna Winterhoff - jennawinterhoff@gmail.com

LANGLEY – Meghan Fabbi - meghan.fabbi@gmail.com

NANAIMO – Sandy Barlow - sandygbarlow@gmail.com

VANCOUVER – Samantha Aitken - saitken@childrensheartnetwork.org

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SHAE MELLORS – Vancouver Island Hearts of Gold youth coordinator

ABOUT

Heart Matters is 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.

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.

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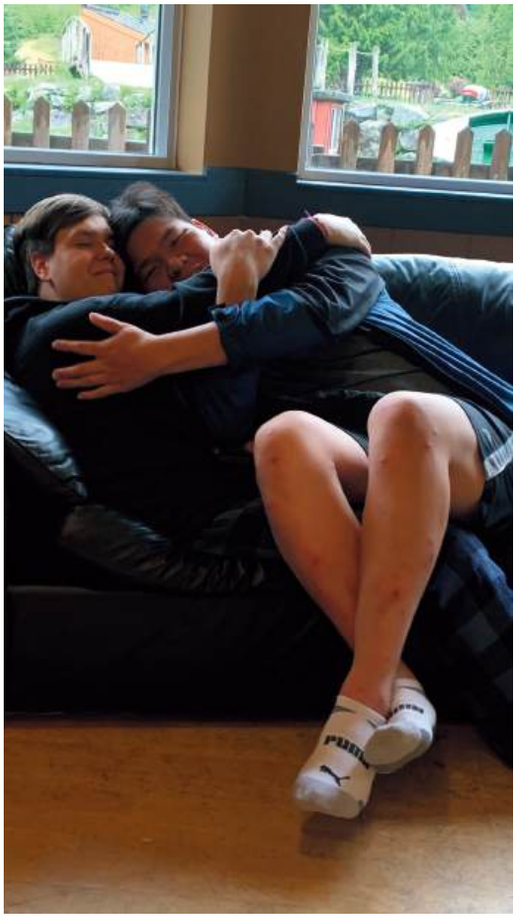
Joining HOG has allowed me to participate in numerous activities and events as well as to connect with others who have experienced similar life circumstances as I have. The activities and events I participated in so far have ranged from activities like going to the PNE, Go-Karting, formal dinners, sporting events, etc. While these activities are very fun and enjoyable, making friends is what makes being with HOG most meaningful. As congenital heart defects are relatively rare, it feels rewarding to finally connect with others who have gone through similar experiences.



HOG camp happens every year over the May long weekend. The years that I have gone camp has always taken place at Zajac Ranch in Mission, BC. At camp, there are many activities to do such as archery and swimming. There are also other activities that test your limits such as the high ropes course. However, the activities are not the only things that make camp special. Campers come from all over BC. Our lower mainland group joins up with the Vancouver Island group and we have some teens that come from the Okanagan and sometimes Northern BC. This makes camp even more fun as there are always new people to make friends with.

In the end, being apart of the HOG youth program is an amazing experience because there are always many new things to do with HOG and it is great to connect with other teens that are also living with heart disease.

Heart Hero Award - Presented at our 20th Gala

In honour of the 20th Anniversary Gala, the CHN is pleased to announce the launch of the Heart Hero Award. This is meant to celebrate those who've made a profound impact in the lives of children living with congenital heart disease (CHD), who are engaged in research to further the development of CHD treatments and care or who have helped to further the mission of the Children's Heart Network (CHN).

Nominations were made by active members of the CHN, board members and staff as well as doctors, nurses, and other healthcare professionals at BCCH who work with the CHN.

This year the award was presented by heart teen Kailen Harding and his mom, Kerry Harding, a long standing CHN Board Member and our current Vice-President.

They were honoured to present the first Heart Hero Award to **Dr. Derek Human** for his outstanding contributions to the field of pediatric cardiology and his integral role in many CHN family's journeys through the challenges of (CHD).

"Dr. Human's unwavering commitment to his patients has been nothing short of remarkable. From the moment I was assigned to him on July 5, 2006, the day I was born, Dr. Human has consistently gone above and beyond to provide compassionate care and support."

-Kailen

"Dr. Human has dedicated his career to improving the quality of care and engaging the clinicians in the Province-wide Partnership Program for Pediatric Cardiology, which he founded nearly 30 years ago at BCCH. This program has enhanced the quality and accessibility of cardiac care for children, serving more than 800 patients and their families annually in 11 different locations around the province. Dr. Human has also been a leader and a mentor in the Division of Cardiology at BCCH, where he served as the Head for many years, and a Clinical Professor at the University of British Columbia. Dr. Human currently continues to support BCCH as the Medical Director for Quality and Safety. Over the years he has been a generous supporter of the Children's Heart Network, hosting and participating in many events, conferences and galas, including the Growing Up With Heart Disease Conferences."

-Kerry

"Dr. Human embodies the qualities of a truly outstanding physician. His dedication, empathy, and expertise have made an impact on our lives. We are profoundly grateful for the exceptional care he provided us. His legacy of compassion and excellence deserves to be celebrated. Dr. Human is an outstanding cardiologist who has made a lasting impact on the lives of many children and families."

-Kailen

Congratulations and Thank You, Dr. Human!

Meet Dr. Saketh Saravu: BCCH Pediatric Cardiologist

How and why did you become a Cardiologist?
After completing Pediatric training in India, I pursued higher training in pediatric intensive care in the United Kingdom. I was impressed by the complex care needed to treat children with heart disease and focused my training towards becoming a cardiologist. I was referred to BC Children's Hospital (BCCH) from a mentor in the UK and advised to undergo the 3-year core cardiology training at the University of British Columbia. Here I gained skills to become a competent cardiologist. Having found electrical disease of the heart most challenging and rewarding to deal with I pursued specialized training in adult Electrophysiology (EP) in London, Ontario (Western University) and then finished my training in adult congenital and pediatric EP at Boston Children's Hospital (Harvard University). I currently practice at BCCH as a pediatric cardiologist and interventional electrophysiologist. I also practice at St. Paul's Hospital as an adult congenital cardiologist and interventional electrophysiologist.

Who influenced you to go into medicine and where did you study? Do you have a mentor?
My uncle influenced me to go into medicine. He is a physician in rural India and runs a research institute which has over the years conducted groundbreaking research in the treatment of tropical and neglected diseases such as filariasis. His dedication and passion to work inspired me and I wanted to lead a life where I am excited to go to work everyday and the fruits of this work help people around me.

I have been lucky to have great mentors along my journey. Dr. Orhan Uzun in the UK guided me towards Vancouver, BC and Dr. Shu Sanatani in Vancouver guided me towards becoming a competent EP. Without their support this journey would not have been possible.

Tell us about any specialties you have within your department? Are you doing any research?
Electrophysiology is the specialty I work in. It deals with the treatment of electrical disorders in the heart; more specifically performing interventions such as ablations and implantations of cardiac defibrillators and pacemakers. The EP research team is currently working on gene induced arrhythmias, scores for evaluation of arrhythmias and is part of many national and international registries for arrhythmias in children.

What do you like about working at BCCH?
Helping and supporting the children and families we care for at BCCH is the best part of the our work. To cure rhythm disorders and provide relief for the patient and their families is such an amazing feeling. I truly feel fulfilled at the end of my days' work at BCCH. I also very much enjoy my work at St. Paul's Hospital where I treat adults with congenital heart disease. I feel like I am blessed to care for my patients as they go through the various stages of life.

Outside work, what do you like to do for fun? What are you good at besides being a pediatric cardiologist?
I am an avid physics enthusiast. I like reading about new developments in the world of particle and astrophysics. I also enjoy running in the beautiful neighborhoods of Vancouver, especially in the rain.

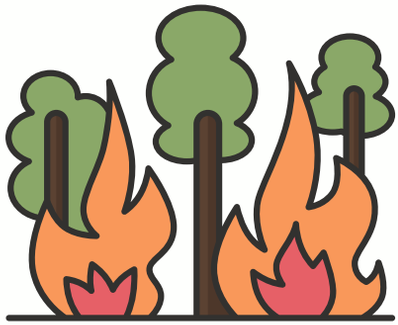
Tell us about your family. Do you have any pets?
My wife is a neonatologist at Surrey Memorial Hospital. Thus, there is a lot of medical chatter in the household. Our two daughters are well versed in tachycardia fast heartbeat) and bradycardia (slow heartbeat). They will often provide a diagnosis after looking at an ECG. We are presently pondering which breed of dog would be the best addition to our family.

Tips for wildfire smoke and children

Smoke from wildfires can trigger serious health issues for children, especially if they have chronic respiratory or heart conditions.

Children's lungs are especially sensitive to the harmful effects of air pollution. That's because they breathe faster than adults, which causes them to inhale a lot of pollution relative to their weight.

Use care when you take your young child outdoors, especially for physical activities. When children exercise, they breathe more heavily than normal. And they breathe more through their mouths than their noses. This allows pollution to be inhaled more deeply into the lungs where it can cause permanent damage.



- Check the air quality health index.
  - This index is often reported in the news. You can also go to: https://www.canada.ca/en/environment-climate-change/services/air-quality-health-index.html to find it.
- Go outside early in the morning in the summer and on days where smog may develop.
- On days when air is stagnant and temperatures reach over 32°C (90°F), smog levels usually peak in mid- to late afternoon.
- Stay away from areas with heavy traffic.

Canadian Pacific Kansas City Rail Charity Hockey Tournament Supports the CHN

CPKC and the 41st Charity Hockey Committee were so pleased to present a cheque for $82,238.16 to the Children's Heart Network of BC Society and the look on Samantha Aitken's face brought joy to all of us.

This is the largest amount the tournament has ever raised. A big thank you goes out to
all the participants, volunteers and of course our sponsors.

I would like to tell you a bit more about the history of the tournament. This was our 41st tournament however it was the first one held since the merger of Canadian Pacific and Kansas City Southern. It was very exciting to host the tournament here in the lower mainland. This year we had 21 teams, 17 mens and 4 mini womens, playing in different divisions, such as Open, Open Rec, 35 Open, 35 Rec, 45 Wreck and of course our Ladies division. Despite it being a charity tournament, there is always some really great hockey being played and everyone who attends has so much fun.
Each year the tournament is held in a different city and players come from across the country. We always choose a charity with "Heart" in mind, and I am so glad that I chose The Children's Heart Network.

It has not always been a charity tournament, in 2006 CP and the committee agreed to make it a fundraiser. CP would make a large donation to add to what is raised through the tournament and wanted to support a "heart" charity. Since then, the tournament has raised $388,208.16!

I would like to recognise the sponsors:
Title Sponsor - CPKC
Gold Sponsors - GIO Railway Corp., C.D.I Int., Brentwood Ent., Edmonton Railway Contracting, JayChris Indus-Rail Supply Inc., Rocky Mountaineer
Silver Sponsors - Veronneau Solutions, A&B Rails Service Ltd., Holland, Tri-City Industries Ltd., Vossloh, Blue Water Rail Services, M.A.C. Rail Contracting Ltd., Hatch, Herzog, Cando Rail Terminals
Bronze Sponsors - The Source for Sports, Steelworkers TC Local 1976, Aspen Crossing, Brandt, W.Mader Excavating and Trucking, Northern Plains Rail Services

Thank you so much CPKC and all of the players and sponsors involved!

Children's Heart Network's 20th Annual Gala

What a night! The fabulous event took place at the Terminal City Club on April 26th. Guests came from Victoria, Whistler and all over the Lower Mainland to celebrate and support the Children's Heart Network.

The attendees were welcomed with live piano, a glass of rosé and hors d'oeuvres. The room quickly filled up with over 240 guests who perused and bid on the fantastic silent auction item.

Our beloved emcee, John Emmet Tracy, welcomed our guests with his witty humour and fun stories from his latest acting gig on the TV show, "Yellowstone." It was clear he had some fans in the audience!

Our wine sponsor for the evening, Sage Hayward Vineyards, provide a fabulous array of wines that were enjoyed alongside a 3-course dinner. We opened the evening with a video that chronicled the McBride Family's heart journey with their son William, which was then followed by our guest speaker, heart dad Craig Thiessen. He shared his family's heart journey with their son Zach. Zach was born with a very complex heart and has battled his way through multiple open-heart surgeries.

Shortly after dinner our incredible auctioneer, Fred Lee, took to the stage. With his oozing energy, he captured the room and, in no time, raised a whopping $43,000 to "Send a Kid to Camp." The Live auction was next, and bidders went wild for the unique items, one of which included tickets to the Wimbledon Final coming up this summer!

It was then time for the "Glasses On/Off Game." Participants purchased a glamorous pair of heart glasses and decided whether to put them on or take them off as we flipped a coin at the front of the room. We narrowed down the players to a handful and then the winner took home a $1,000 gift certificate from The Burrowing Owl Estate Winery & Guesthouse. A ton of fun and one of the highlights of the evening.

Finally, after some short thank you speeches, had the "cork draw." Guests that had purchased numbered wine corks were in the draw for two Air Canada tickets to anywhere they fly in North America including Mexico, Hawaii and the Caribbean. Captain Darren Nadeau was happy to present the tickets on Air Canada's behalf to our lucky winner. To top off the evening and to celebrate our 20th Anniversary we danced the rest of the night away!

After all expenses were paid, the total amount raised at the gala came to just over $126,000!

This amount will keep the Children's Heart Network pumping for yet another year. The CHN serves about 1,000 families in B.C. and will continue to do so to the best of its ability thanks to all the wonderful prizes generously donated to the gala, and all the guests who came with their wallets open to enjoy this festive and fun evening. We are so grateful for the continuous support from many of our heart families every year.

Thank you to all of our Sponsors this year!
Gold: APP Electric | BC Children's Hospital Pediatric Cardiology Group | Dr. Sinclair and Dr. Young | Explore India | Gatos Silver | Hayward Sheppard Barristers and Solicitors | Hub International | Raven Excavation
Silver: Tennis GOAT 100
Bronze: Boutique in the Creek | TD Bank
Wine Sponsors: Sage Hayward Vineyards | The Drinks List (Tim Wispinkski)
Decor Sponsors: Celebrate New Life | MeiMei Florist
Print Sponsor: Third Eye Productions
Gifting Sponsor: TESLA – Park Royal

We would like to thank the McBride family and the Thiessen family for sharing their Heart Journeys with us. We would like to recognize our auction team, captained by Tatiana Mawani and Philip Jaling as well as all the volunteers throughout the day and evening. Lastly, the CHN would like to extend a huge heart-felt "Thank You" to our hard-working, committed Gala coordinators who were an incredible team, Dee de los Santos and Serena Parbatani!

BC Children's Hospital to launch Cardiac Golden Hour Protocol for Eligible Newborns with Congenital Heart Disease (CHD)

Authors: Lisa Guo, Lana Tarik, Dr. Shreya Moodley, BC Children's Hospital

Introduction:
The BC Children's Hospital Cardiology Program is continually working to improve the lives of children living with CHD in our province. Part of the efforts involve a shift towards a more comprehensive and holistic approach to care. In addition to prioritizing the physical health of our patients, we hope to advocate for the emotional, mental, spiritual and neurodevelopmental health of our patients and families. We are working to understand what challenges exist that can impact these various components of health with a goal of creating a formal program to address these challenges and better support the overall wellbeing and quality of life of our patients and families.

With this in mind, we are excited to announce a new practice called "Cardiac Golden Hour", that will be implemented at our hospital beginning this year for eligible newborns with a prenatal diagnosis of CHD and their mothers. This will be our first of many initiatives aimed at providing more comprehensive care. Through research, we know that babies with CHD may be at risk for poor bonding, neurodevelopmental challenges and troubles with feeding. Mothers of babies with CHD may also be at risk for mental health challenges with delivery of a baby with CHD known to be a particularly stressful time. Cardiac Golden Hour practice will be a great opportunity to address these challenges for baby and mother.

WHAT IS CARDIAC GOLDEN HOUR?

Golden Hour refers to the first hour after birth. Golden Hour protocol refers to a combination of well-established practices that support fetal to neonatal life transition and promote mother-baby bonding during this hour. This protocol is already standard practice for all healthy newborns delivered at BC Women's Hospital and has been implemented in the preterm population over the past few years. Now, we are looking to implement a special version of Golden Hour protocol for a subset of our newborns with CHD.

Cardiac Golden Hour protocol consists of 4 main components:

Delayed Cord Clamping
By delaying umbilical cord clamping following delivery, more time is allowed for iron rich blood to continue flowing from the placenta to the baby. This practice promotes healthy baby development and enhances the blood's capacity to transport oxygen.

Skin-to-Skin (Kangaroo Care)
Kangaroo care is a method of holding where your baby is placed skin-to-skin on the mother or caregiver's bare chest, wearing only a diaper. This skin-to-skin contact is the first step to encouraging breastfeeding.

This practice provides multiple benefits to the baby. It not only stabilizes heart rate, body temperature, and blood sugar, but also promotes early breastfeeding and longer periods of quiet sleep. Additionally, it reduces pain and stress during procedures, decreases the risk of infections by enhancing beneficial bacteria, and helps the baby feel safe and secure. Kangaroo care also has benefits for mothers: it can promote milk supply, decrease postpartum blood loss and pain, and foster feelings of bonding and attachment.

Early Breastfeeding Initiation
Human milk is the ideal food for all babies and is particularly beneficial for those with congenital heart disease. It supports a baby's development, provides essential proteins for brain growth, reduces the risk of infections, enhances feeding tolerance, and offers comforting nourishment.

Promoting Parent-Baby Togetherness
Parent-baby togetherness advocates for keeping parents and babies together. This component involves methods of maintaining closeness to facilitate parent-infant communication and attachment through skin-to-skin practice and/or scent cloth use.

Evidence suggests that mother-baby togetherness via skin-to-skin care results in improved attachment, communication, maternal self-confidence and stability, maternal emotional well-being, and less newborn crying. These benefits extend to partners and other involved caregivers.

GOLDEN HOUR FOCUS GROUP INSIGHT

From October - December 2023, we conducted discussion groups with mothers who recently delivered babies born with CHD here at BC Children's Hospital. When asked about their birthing experiences, many mothers reported common themes of physical isolation from baby immediately following birth, high stressors related to baby cardiac health, and gaps in knowledge regarding the types of services available to them. When introduced to the idea of Cardiac Golden Hour, there was unanimous support for the practice given that safe measures were put in place.

PATIENT SAFETY IS ALWAYS A TOP PRIORITY

Most neonates with CHD are clinically stable during the first hour of life.

The cardiology, NICU, CICU, and labour and delivery teams are working hard to ensure that we are able to provide Cardiac Golden Hour practice in a way that is beneficial, positive, and safe. We have conducted education and training sessions, as well as simulations with care teams to ensure that we are prepared and united for this practice.

Each mother-baby pair will have a pre-planned and patient-specific care plan in place to prepare for Golden Hour.

WHO IS ELIGIBLE FOR CARDIAC GOLDEN HOUR PRACTICE AT BC CHILDREN'S?

The fetal cardiology team at BC Women's Hospital oversees the triaging of all babies with a prenatal diagnosis of CHD for Golden Hour protocol eligibility.

Families that are eligible for Golden Hour are notified of this opportunity during a prenatal appointment, likely around the time of their scheduled CICU tour prior to delivery and will be given an information pamphlet to take home.

COLLABORATION IS KEY

Practices like Cardiac Golden Hour are made possible through the support and collaboration between various individuals, care teams, and organizations. Additionally, patient and family engagement is fundamental for the development of these initiatives. The Children's Heart Network and heart community are our key partners for our program's work, and who we continue to look towards for support and guidance.

To learn more about Cardiac Golden Hour, scan the QR code for the Information Pamphlet.

CHN Island Family Camp at Camp Thunderbird

By: Megan Madsen

On the weekend of June 14-16, we had the privilege of attending Camp Thunderbird in Sooke, BC. This beautiful camp on Glintz Lake is surrounded by forests and mountains and provides a lovely retreat for people of all ages. We had the opportunity to participate in fun activities including archery, canoeing, rock climbing, crafts, camp fires and forest walks.

Everything was well organized with built in breaks between activities for families to have down time. The staff were kind, knowledgeable and accommodating. We also enjoyed delicious food in the dining hall. This weekend camp is a lot of fun for both kids and adults and an excellent opportunity for families with similar lived experience to connect. It was special to hear families interact, share their stories and encourage each other.

Triple Crown for Heart

The Triple Crown for Heart has supported both the Children's Heart Network of BC and BC Children's Hospital by raising over $25,000 every year. This past year they donated $15,000 to the CHN which was gratefully accepted by our Board President, Tracey Carpenter.

Founded by one of our Cardiac Nurses, the Triple Crown for Heart bike ride is coming up on Saturday, July 20th. The Triple Crown raises funds for the cardiac inpatient wards, the acute medical at BC Children's and Children's Heart Network in support of Camp Zajac.

This ride involves cycling all 3 North Shore mountains in 1 day - the funds raised support the Children's Heart Unit at BCCH and The Children's Heart Network of BC.

How can you support the riders? Come out to CHEER on the riders on the last climb up Cypress Mountain. Suggested time to be on the route up Cypress is 11:30am to 1:00pm.

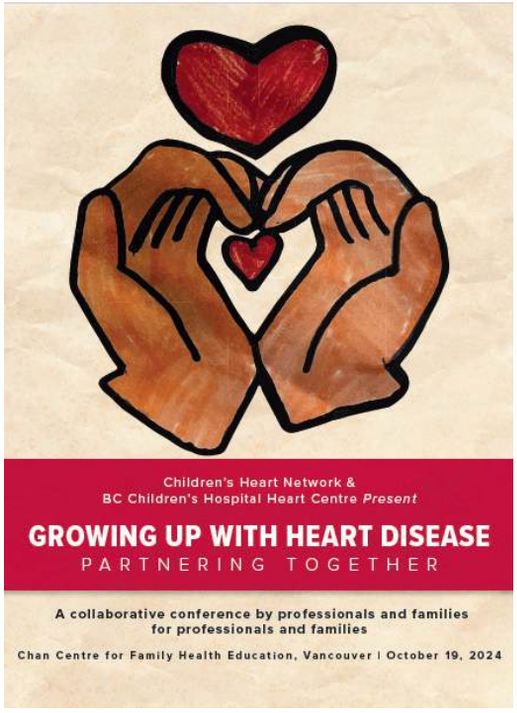
If you would like to sponsor a rider and donate to the cause please see link here for Shaun Carpenter (heart dad): https://donations.triplecrownforheart.ca/team_fundraising/fundraiser/220/

They are raising funds to support all of our BC Heart Families, lets help them up conquer that last hill!

GO Cardiology Team GO!

CHILDREN'S HEART NETWORK CONFERENCE 2024

Growing Up with Heart Disease: Partnering Together



Saturday, October 19, 2024
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 10th Growing Up with Heart Disease conference.

This is a collaborative conference by and for families and health care professionals. It's an opportunity to learn from the experts—physicians, nurses, psychologists, researchers, fellow parents, and other heart kids—and connect, share, support each other.

Parent and Health Care Professional Program
Plenary speakers, concurrent sessions, and workshops including:

- Opening Keynote with Dr. Derek Human
- Current research and innovations in pediatric cardiac care
- Strategies for supporting children with heart disease
- Coping and stress
- Transitional Care
- Dealing with issue like hospital discharge, school, and nutrition

...and don't miss the conference favourite:

A special presentation by youth from the Hearts of Gold Youth Program!

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

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