



Keeping the Beat

Fall & Winter 2020

Offering information, resources and emotional support to families dealing with congenital heart disease.

In this Issue

“Strolling to the Stollery” Fun Run



Thank you from the bottom of our hearts to everyone who participated in the Stroll to the Stollery event. So many participants got together to share being active with friends and family to raise funds for this great cause. The messages of support and encouragement including pictures posted over the weekend were truly heart warming.

You walked, ran and biked 4,544.65 kilometres. That equates to 15.3 trips to the Stollery Hospital! Together we raised \$12,842 to support families with children with Congenital Heart Disease.

While we all were winners over the weekend, prizes have been awarded for the following accomplishments:

Individual:

Longest total distance for:

- Running: Sara Bond with 31.73 kilometres
 - Biking: Caitlyn Adams with 213.22 kilometres
 - Walking: Ferrell Beleshko - with 32.01 kilometres
- Most individual minutes tracked walking, running and biking:
Vittorio Borelli with a total time of nine hours and 32 minutes



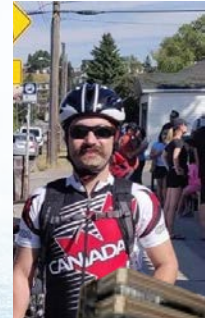
Team:

Longest combined distance for:

- Running: Team Xander Hesketh with 29.88 kilometres
 - Biking: The Moustache Men with 429.98 kilometres
 - Walking: Hadley's Hero Heart Team with 311.34-kilometres
- All three activities combined:
Hadley's Hero Heart Team with 563.08-kilometres

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For a complete Participant list see inside on page 4



Here's what's coming up with

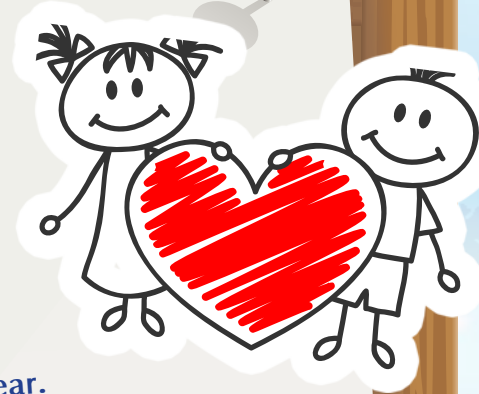
HEART BEATS

Heart Beats Siblings Group

My name is Janelle Wiebe and I, along with co-leaders Ashley, Marcella and Sophia, are so excited to announce the start of the Heart Beats Siblings Group. The four of us are fun and supportive community for heart children and are passionate about creating a community like as Offbeats has done for heart children.

For the remainder of 2020, the siblings group and Offbeats will have joint activities while we all get to know one another. The two groups will split off and have separate events in the new year. If you have any questions, please do not hesitate to contact me at janellewiebe@hotmail.com.

-Janelle, Ashley, Marcella and Sophia



Guys' Night & Ladies' Night on Zoom!

That warm weather is getting harder to come by for those outdoor meet-ups. So perhaps you feel like socializing with old friends or maybe want to meet someone new in your Heart Community.

Please watch for email updates on when the next meetings are, and come "out" for a good time. Tell your husbands, tell your wives, that they've got the kids for the night, so you can enjoy an evening to relax and have some fun on Zoom!

If you are interested in hosting a Virtual Guys' or Ladies' Night or even have new ideas on hosting an event, please email info@heartbeats.ca for more information.

Heart Beats Virtual Board Meetings

Your Heart Beats Board are still meeting virtually via Zoom. We however cannot wait until it's safe to gather again in person and see all our fellow heart families



Year End Message

FROM THE BOARD OF DIRECTORS

2020 was a challenging year for many charities, and Heart Beats was no exception. With the Covid-19 pandemic running rampant, our events and fundraisers looked very different. Our board meetings and Offbeats events took place via Zoom. Our Mom and Dad's Night were also held virtually and we had to cancel our Family Camp Out in September.

Our fundraisers had to be adapted. The CP Hockey Tournament scheduled to take place in early April was forced to cancel, however the team managed to raise over \$14,000 by selling Heart Beats teddy bears, hosting a virtual auction and soliciting donations and that amount was matched by CP Rail. We are so grateful for CP's continued support of Heart Beats.

In April, we were informed that the Shaw Birdies for Kids program which matches donations raised between February and August, was cancelled until 2021. Still, Shaw committed a \$1 Million Dollar pool for matching that would be shared among the many participating charities.

At our June 25 board meeting, it became evident that the pandemic was not going away anytime soon and that we would have to either cancel the 2020 Fun Run (our biggest fundraiser of the year) or adapt it somehow. Donna Iverson, our new run manager, came up with a plan to host a virtual run weekend with a goal of seeing how many times participants, as a group, could make it from the Alberta Children's Hospital in Calgary to the Stollery in Edmonton. Two hundred and thirty-eight people participated in the Virtual Fun Run and we were able to raise \$12,800.00 in donations.

With these funds as well as other donations from Atco, Tech Resources, Watson Foundation and other generous donors, we were able to continue supporting families throughout the year. The Ronald McDonald House in Edmonton was temporarily closed in the spring, and Heart Beats stepped up cover the cost of accommodations for families traveling for their children's heart surgeries. We continued to fund our prenatal, cath, surgery, and antenatal packages to children at various stages of their heart journey. Heart Beats also created a temporary fund to support struggling families facing job losses by providing them with emergency funds and reimbursing the cost of their children's medication and equipment such as CoaguStrips and Pulse-ox monitors. This December, we provided Christmas Hamper to families in need.

In late summer, we mourned the loss of Evanna Irvine, a precious heart warrior who will be forever in our hearts. Our deepest condolences go out to the Irvine family who will always be a cherished part of the Heart Beats community.

It's hard to predict what 2021 will look like, but we remain hopeful that a vaccine will develop and bring about a sense of normalcy to the world. We have heard this so many times this year, but we really are all in this together.

Wishing everyone peace, joy and good health this holiday season.

SUBSCRIBE TO "KEEPING THE BEAT"

If you would like to receive Keeping the Beat directly to your inbox, please email us at info@heartbeats.ca. Alternatively, you may pick up a printed edition at the Cardiology Clinic or download a copy from our website at www.Heartbeats.ca. Note: E-mail addresses will be used only to distribute Keeping the Beat newsletter and notices of Heart Beats events; e-mail addresses will not be given to any third party.



"Strolling to the Stollery"

Virtual Fun Run Participants



Connect by Heart

Adam Spooner
Maddie Spooner
Melissa Spooner
Norah Spooner

Eltons Rockets

Rachel Jacques
Cory Jerace
Jill Jerace
Sammy Jerace
Denise McLaren
Katie Mizzau-McNinch

Girlfriends with Tight Ends

Crystal Armstrong
Tara Ernst

Hadley's Hero Hear Team

Caitlyn Adams
Dale Beadle
Hadley Belisle
Milan Belisle
Waylon Belisle
Darla Blackmore
Darla's son Blackmore
Karen Blakmer-Thompson
Fiona Duffy
Maverick Duffy
Tadgh Duffy
Dallas Duncan
Janet Dunn
Sean Dunn
Denise Dunn-Reker
Kyles Elliott
Calvin Fitch
Carma Fitch
Brielle Gamache
Kahl Gamache
Shantel Gamache
Steven Gamache
Athena Jeffries

Athena's kid #1 Jeffries
Athena's kids #2 Jeffries
Athena's kid #3 Jeffries
Athena's kid #4 Jeffries

Ryan Jeffries
Ashley Koszman
Dane Michelle
Shara Orr
Shars's husband Orr
Donita Orsten
Wade Orsten
Megan Pompu
Adalyn Reker
Emma Reker
Evan Reker
Mylie Reker
Sean Reker
Nikole Sharpe
Thomas Skelton
Ken Thompson
Sue Wagner
Peyton

Heart of a Lion

Mark Foster
Ashleigh Grundy
Dion Mahadeo
J'nai Mahadeo
Shinell

Hope Holly Lincoln

Leah Abday
Trevor Brophy
Amy Koslowski
Sam Osmond

Lauren's Angels

Natasha Bartwicki
Stuart Bartwicki
Lisa Becker
Clint Brennan
Cole Brennan
Georgia Brennan
Kayla Brennan
Cathy Courage
Greg Courage
Jackson Courage
Julie Courage
Quinton Courage
Claudia DaCosta

Georgie DaCosta
Paulo DaCosta
Rio DaCosta
Charlene Dorey
Ashely Exall
Brooklyn Exall
Cole Exall
Holy Exall
Kristen Exall
Lauren Exall
Nilah Exall
Peter Exall
Rainer Exall
Tara Exall
Greg Girard
Keaton Girard
Mikayla Girard
Jane Hagel
Mark Hagel
Paige Hagel
Edward Hergott
Emma Hergott
Mark Hergott
Donna Iverson
Kim Iverson
Daniel Kennedy
Yalda-Rosa Khaje
Alexandra Kipp
Danica Kipp
David Kipp
Helena Kipp
Charlene Lazruk
Gary Leach
Benda Liddle
Jani Long
Riley Long
Mariannna Makkai
Karen Marshall
Kristen Marshall
Myley Marshall
Maryam MKhani
Daniel Ogden
Gabrielle Ogden
Madeline Ogden
Peter Ogden
Brianna Olson
Heidi Olson
Jason Olson

Payton Olson
Brian Purdy
Emma Purdy
Kate Purdy
Andrew Reed
Nicole Reed
Ethan Roesler
Greg Roesler
Josh Roesler
Luke Roesler
Ronda Roesler
Alyssa Ross
Shane Ross
Damon Rossiter
Daniel Rossiter
Dave Rossiter
Patricia Rossiter
Roxanne Rossiter
Melanie Rowan
Bonnie Rush
Nicole Rush
Peter Sargious
James Sargious
Paula Sargious
Aaron Short
Kyra Stevenson
Maire Stevenson
Richard Stevenson
Kathryn Taylor

Super G's

Jeff Bickell
Regan Bickell
Ben Glowach
Carrie Glowach
Max Glowach
Wilson Glowach
Bernie Raven
Susan Raven
Susan Raven
Corrinne Stillings
Jeff Stillings
Sheri Tobin

Team Organizer

Bob's your uncle
Meg



The Moustache Men

Brent Boghean
Vittorio Borelli
Austin Traboulay

The Hearts Of Cochrane

Maddie Beynon
Darryl Cordell

Tracked under Nadia

Leo Monaghan
William Monaghan

Xander Hesketh

Catherine Hesketh
Craig Hesketh
Mary Catherine Hesketh
Matt Hesketh
Patricia Hesketh
Ronin Hesketh
Tom Hesketh
Ronald Mar
Heather Rombough
Jon

Individuals

Julie B
Jessi Badrudin
Karam Badrudin
Megan Bambrough
Dana Beck
Ferrell Beleshko
Jen Beleshko
Roman Beleshko
Sara Bond
Karen Crofton (Quinn)
Jayden Curilla
Regsn Dahmer
Shrenui Dave
Mat Davis
Brian BeBruin
Koen Duineveld
Adrienne Duffield
Barry Duffield
Jax Duffield
Quin Duffield
Dave Dupuis
Madison Dupuis
Jacqui Esler
JD Esler
Megan Hagel
Susan Harbridge

Kayley Jalali
Millan Kenna
Ballie Koszman
Michelle Kotlewski
Ryan McDowell
Nadia Monaghan
Yannick Monaghan
Ulo Ng
Chelsea O'Leary
Bren-Ann Poelzer
John Quinn
Ni R
Ashley Reist
Daniel Reist
Bunny Rossiter
Laura Sawler
Sean Soucy
Heather Starseed
Sandra Strang
Erin Trophy
Kelly Webber
Cassidy Wyntjes
Morgan Wyntjes

Thank You



Your Support in Action

Donations made to Heart Beats Children's Society of Calgary are used to provide information, resources and support to families living with congenital heart defects in Southern Alberta. The following is just a few ways your donations have helped:

- Financial assistance to families traveling to Edmonton for their child's heart surgery through our "Helping Hand Fund";
- Supplemental equipment for the Alberta Children's Hospital Cardiology Clinic;
- Items of encouragement for children undergoing extended hospitalization;
- Camp Scholarships for children with congenital heart disease.

Donating to Heart Beats

If you wish to contribute to the support of families of children with congenital heart defects, you may do so in the following ways:

1) Online Donation through Canada Helps

Please go to <https://www.canadahelps.org/en/charities/id/62663> and choose "Donate Now" or "Donate Monthly". A receipt will be provided at the completion of your transaction.

2) Direct Mail to Heart Beats

If you wish to make your donation by mail, please send them to the address below. We will send you a receipt if your contribution is over \$20.00.

Heart Beats Children Society, Box 30233, Chinook Postal Outlet Calgary, AB. T2H 2V9

3) E-Transfer

Email to treasurer@heartbeats.ca for details. Be sure to provide an email address and mailing address to receive your donation receipt.

4) Make a directed donation through the United Way

(either one-time or through payroll deduction):

To make a payroll donation - fill out the United Way Payroll Donation Application Form, In Section 3, entitled: How I Would Like to Help the Community Check the "Other" box and indicate an amount to: "Heart Beats Children's Society of Calgary".

Please include our Charitable Registration Number: 88907 6261 RR0001



Donations received from May ~ October 2020

ATCO
Canada Children's Aid Foundation
Charity Aid Foundation
Donations made through Canada Helps

In Memory of Evanna Irvine
Paypal
Snowblush Berry
Teck Resources

Thank You



SKIP THE DEPOT
RECYCLING & FUNDRAISING

Heart Beats now has a recycling program through Skip the Depot where your returns will go directly to Heart Beats!

Please use the following link to get set up.

<https://app.skipthdepot.com/heartbeats>

SPOTLIGHT ON TEAM XANDER

Team Xander Hesketh came together to help give back to an amazing organization! We will be forever grateful for all of the support we've received from Heart Beats, as our son Xander has Hypoplastic Left Heart Syndrome and has travelled to Edmonton for 3 open-heart surgeries.



TAG US ON YOUR SOCIAL MEDIA POSTS

We want to see more of our families and heart warriors on our social media so we can re-share what fun and adventures you have all been up to, please use the hash tag [#heartbeatsyyc](#) so we can find your posts.



Fall & Winter 2020





STOLLERY HOSPITAL

Tips & Tricks

Written by Candice Kalyn (Mom to Cecily- Heart Transplant Warrior)

The journey of CHD is many things: amazing, scary, hard, roller coaster, beautiful and at time feels like your life has been flipped upside down. And now you find yourself in a new city and a new hospital. I know some of you reading this already seamlessly transition between hospitals without hesitation. Your car is already programmed to the fourth floor Mazankowski parkade, which elevators are the quickest to get to 4C Cardiac Unit or Pre-Admission Clinic. Unlike Alberta Children's Hospital, the Stollery is a children's hospital within a hospital. Well, actually, three hospitals. The University of Alberta Hospital, the Stollery Children's Hospital and the Mazankowski Heart institute. So it's easy to get a bit turned around but it's basically one big circle and units that run in alphabetical order in case you ever get lost.

On the ground floor, you have two cafeterias one that opens and closes early and has healthier options and one that closes late and has greasier option. There is also gift shops and during non COVID-19 days, the halls were filled with home based businesses. Everything from Epicure to Tupperware, shoes and clothes. Oh and the most important a coffee shop that serves Starbucks coffee and lattes. The elevators that are notoriously slow and filled with all kinds of people impatiently waiting to get off and on. And why doesn't anyone wait for you to get off before they walk in? I've always found that so strange.

Luckily, the hospitals are located next to Old Strathcona and its Main Street, Whyte Avenue (whyte or whyte ave if you speak Edmontonian). Whyte is notoriously Edmonton's main arts and entertainment district with plenty of restaurants for all kinds of cravings. And I would be amiss if I didn't mention Sugar Bowl, Remedy Cafe and my personal favourite Dadeo's if you find yourself venturing out of the hospital walls and onto the nearby streets. There's also Sherlock Holmes, Earls, Wendy's/Tim Hortons (suitable for quick trips), Second Cup and Starbucks right across the street. You can hop onto the LRT and get to Southgate Centre, a great mall to browse through or to get some essentials you forgot to pack.

Ronald McDonald house can help you find a place to stay if they don't have room available and offer support like meals or gift cards. Several hotels across the city offer special Stollery rates for medical families. And Campus Towers across the street offer a clean and affordable place to stay for longer admissions.

If you're social media savvy, you can join several Stollery focused Facebook groups a powerful resource for all things Stollery and an enormous support system.

Of course COVID-19 has changed a few things, only one parent allowed at a time, when you're first admitted your little one will get a COVID-19 test and you can't leave the room until the test comes back negative further parents rooms and fridges are closed. The nurses can help you get everything you need.

So if you find yourself on your way up to Edmonton, know that you'll be well taken care of. Family centered care is standard and you'll find help and support at any turn. And always, you have your heart army at your fingertips. We are always here and ready to help.

Stay strong, stay safe, stay vigilant.



Living Life and Thriving with CHD

Hi!

My name is Lauren and I'm 33 years old. I was born with Tricuspid Atresia, severely Hypoplastic Right Ventricle, and large VSD. I wasn't diagnosed until I was 10 weeks old and in severe heart failure. I've had two open heart surgeries, multiple heart cath, and one cardiac ablation so far in my life. My second and, last planned open heart surgery called the Fontan, was on Nov. 21, 1989. This November will mark my 31 year anniversary. That is a huge milestone for me! My last intervention, as of right now, was a cardiac ablation this past February 2020, which despite a bumpy recovery start, I have been arrhythmia free since March. I know the cardiac ablation isn't a permanent fix for my arrhythmias, but I hope I can get a few years of no or few arrhythmia episodes before they need to be addressed again.

I was also born with an eye muscle disease. I've had three eye muscle surgeries and I've worn glasses since I was nine months old. I also have scoliosis with mild hip dysplasia; which, luckily I have not had to have surgery to correct. I'm only on two heart medications.

I've lived a pretty "normal" life for the most part (whatever normal is). I've been happily married for almost nine years now. I'm a homeowner and I'm currently a homemaker which I love. I have a BA in Psychology. I've been part of the CHD community for over 13 years; further, I'm a huge CHD advocate. A few things I enjoy doing: bargain hunting, listening to music, bowling, organizing and making people smile and laugh.

Living with CHD isn't always easy, but we can live very full happy lives despite whatever challenges we face... I sure do! There is hope! I'm so grateful for my life and all the blessings in it. Hugs & blessings to all!

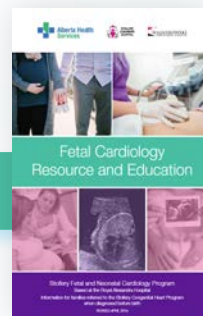
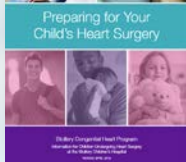
My CHD story was in the Keeping the Beat Spring/Summer 2012 edition which I was honored to be in and share my story. For anyone interested in following my CHD journey my CHD Instagram name is @lauren_b_hopeful heart and CHD Facebook group is called "Lauren B- Adult CHDer/Fontaner with Tricuspid Atresia, HRHS"



Updates on the Heart Beats Website

Heart families, we are happy to announce we have some new valuable information from Alberta Health Services on our website. Please see our publications link on our website and scroll to the bottom of the page to see the below three booklets online for you to view or reference any time. www.heartbeats.ca

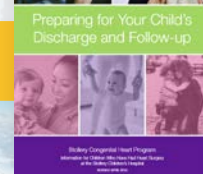
1. Fetal Cardiology- Resources & Education



2. Preparing your Child for Heart Surgery



3. Preparing for your Child's Discharge & Follow Up





Ronald McDonald House Charities® Alberta

Ronald McDonald House Charities® Alberta is a home-away-from-home for families who must travel for their sick or injured child's vital medical treatment. Over 65 per cent of Canadian families live outside of a city centre with a children's hospital.

Our four Houses in Calgary, Edmonton, Red Deer and Medicine Hat offer a total of 79 private family suites, as well as communal kitchens, living areas, indoor and outdoor play spaces, nursing rooms, laundry facilities, parking, and Wifi. In Calgary, Red Deer, and Medicine Hat, our Houses are just steps away from the hospital. In Edmonton, there is a free shuttle service that provides rides for families to and from the hospital, seven days a week.

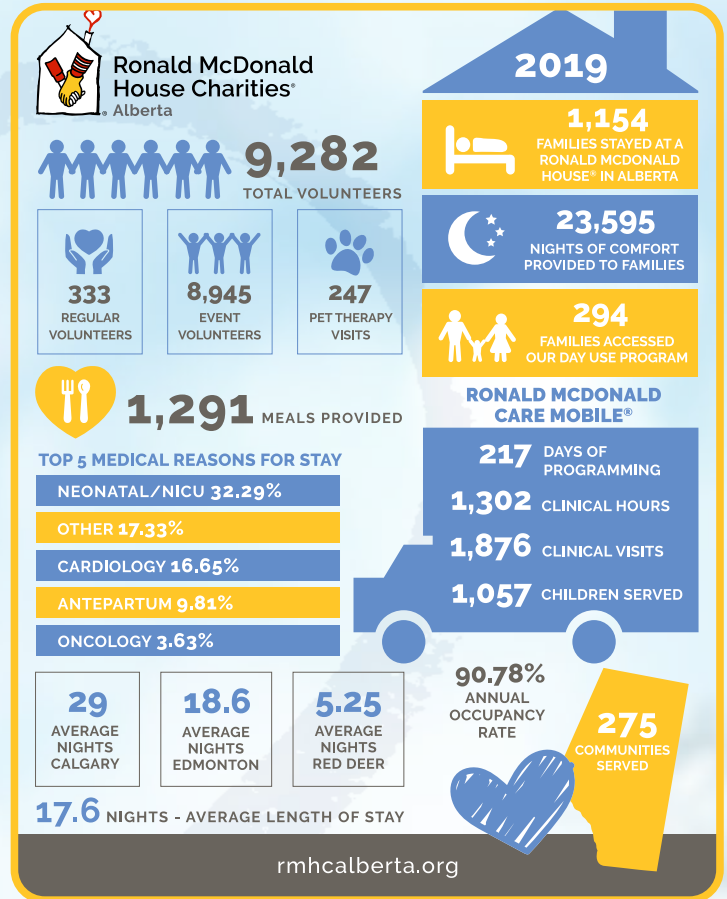
Volunteer bakers and meal groups keep our families well-fed and nourished. Volunteers provide recreational programming for families, as well as services such as massage, haircuts, and yoga. When families arrive, they are gifted a homemade quilt made lovingly by dedicated volunteers in the community that will forever be a cherished keepsake. Each House has a Magic Room, where kids can choose a toy to mark special occasions including birthdays, treatment milestones, or the best news of all – when they get to go home!

Our Day Use program enables families who are at the hospital for day treatment to access many of the amenities offered at the Ronald McDonald House, such as a warm meal or cup of coffee, shower, laundry, or just a place to rest and recharge.

RMHC Alberta alleviates the financial, emotional, and physical burdens placed on families who must leave home for the specialized care their child needs. When a child is sick, the whole family is sick. RMHC Alberta understands that and supports the whole family throughout their medical journey.

In 2019, RMHC Alberta served over 1,200 families from 275 communities, providing a total of 23,595 nights of comfort and saving them a total of \$6.5 million.

To find out more about staying at our Houses across the province, visit our website at www.rmhcalberta.org



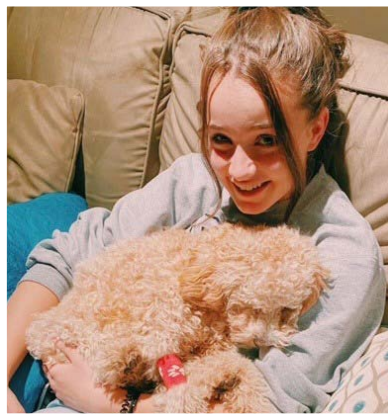
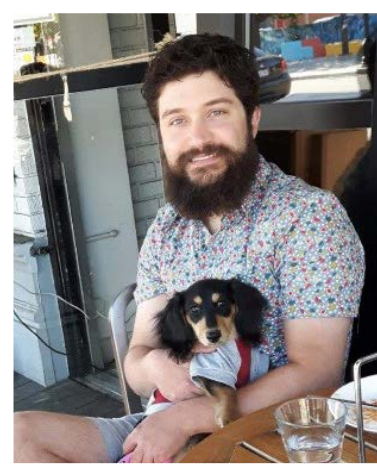


VITTORIO BORRELLI

Hello. My name is Vittorio Borrelli and I was born with Tetralogy of Fallot. Before my third birthday, I had had three heart surgeries and at the age of 18 I received a heart transplant. In 1989, my family became involved with Heart Beats Society and over the years we have made some incredible memories along lifelong connections. I joined Offbeats at 11.

Offbeats was a great experience for me where I met some of my best friends; which I am still very close with today. In 2016, I was given the opportunity to become a leader for Offbeats which was a great honor that gave me a chance to give back to a group that was important to me as a youth. The past four years have been such a great experience getting to know our youth group members and seeing them grow.

In 2013 I became a Journeyman machinist and I am working in the aviation industry. Recently, I have also taken part in Patient Centered Research through the University of Calgary as a patient advisor. In my free time, I like to keep active by rock climbing, practicing yoga, snowboarding and other various forms of exercise. When I'm not being active I like to spend lots of time in the kitchen or socializing with friends and family. It really brings me joy to share my kitchen creations with others.



ASHLEY EXALL

My name is Ashley Exall. I am 15 years old and I'm in grade 10 at William Aberhart High School. I love martial arts and I'm working on my black belt which I hope to earn in 2021. I have been involved with Heart Beats for just over 12 years. My sister Lauren was born with CHD in 2008 and my family has been a part of Heart Beats Society ever since. I have always loved attending the Heart Beats Society events and gatherings, but I felt a little left out as a sibling of a heart kid. That's why I was super excited when I heard about the possibility of a sibling group starting up. I can't wait to get started helping out with the group.

JANELLE WIEBE

Hello! My name is Janelle Wiebe. My family has been involved with Heart Beats for almost 20 years. My younger sister Isabelle was born with Hypoplastic Left Heart Syndrome and is now in her second year of college. Isabelle thoroughly enjoyed her time in the Offbeats group and is still good friends with a couple girls she met through the group. I was an Offbeats leader for one year which allowed me to see first-hand how beneficial it was for children born with heart defects to connect with other children and leaders with similar medical experiences. I am very excited to be a part of the new siblings group which has yet to be named. I'm passionate about working to create the same fun and supportive environment for siblings of children born with heart defects, just like myself.

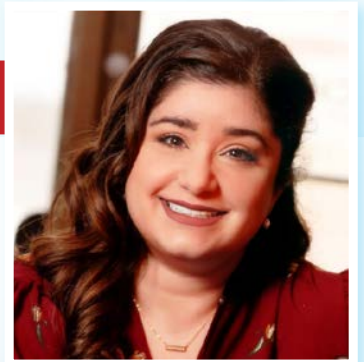
I am working on an undergraduate degree in math and astrophysics at the University of Calgary with the goal of becoming a cryptographer. I am also on the University of Calgary cross country and track and field teams, so I am often found running or cycling in my free time. I enjoy crocheting mittens, listening to audiobooks and as well spending time with friends and family. My favorite food is Vittorio's chocolate chip cookies - if you've had them at one of the previous Offbeats events, I'm sure you agree!



MARCELLA BORRELLI

Hey my name is Marcella Borrelli and I'm Vittorio's older sister. Our Family has been involved with Heart Beats Children's Society since 1989. Vittorio was born with Tetralogy of Fallot, and over the years endured many surgeries and procedures which inevitably lead to him receiving a Heart Transplant in 2007. When Offbeats started Vittorio joined the group, over the years I have been able to see the long-term effects that this youth group has had on him as well as the lifetime friendships that he has developed. During my teenage years, I often felt a little left out because he was able to do so much with Offbeats and wished there was also a sibling's group. When Vittorio mentioned that Heartbeats was going to start up a sibling's group this year, I was so elated and could not wait to create the same experiences for the siblings.

Since 2011 I have been working as an architectural technologist here in Calgary specializing in residential design. In my free time I enjoy cooking and baking for friends and family, reading and listening to audiobook as well as indulging in my love for live music by attending many local shows(pre-COVID-19).



JESSE PETERSON

I'm Jesse Peterson, one of the original members of Offbeats and a leader since 2017. I am looking forward to returning as a leader for the 2020/2021 season. I was born with a congenital heart defect and have had three open heart surgeries. I have a Bachelor of Business Administration from Acadia University, and am working on earning the Chartered Professional Accountant designation while working as a financial analyst at AltaGas. In my spare time you can find me enjoying hobbies like rock climbing, hiking, snowboarding and of course, leading events for Offbeats.

Offbeats is near and dear to me because it was instrumental in providing me with a community of peers that I was able to connect with through our shared medical experiences. Through informal get-togethers and events such as watching hockey games and playing laser tag I was able to make a few life-long friends. Offbeats enriched my life by giving me a support network. I am thrilled to be carrying on the tradition so that a new generation of youth can benefit in the same way I did.

While this year's Offbeats activities will look a bit different from previous years in light of the COVID-19 pandemic, I am still committed towards helping organize fun and safe events for all of our members. I'm looking forward to catching up with our returning members as well as welcoming all new members who want to see what Offbeats is all about. **Hope to see you at our next event soon!**

Stollery: Fun Facts about the Surgeons.



Dr. Darren Freed

Role: Pediatric & Congenital Cardiac Surgeon

Fun Fact: Avid maker, tinkerer and inventor



Dr. De Villiers Jonker

Role: Pediatrics and Adult Congenital Thoracic surgeon

Fun facts: Sports fanatic, neat freak



COVID Q&A Series with BCCH Cardiology Team

1 Is my child immunocompromised due to their heart condition, and does this put them at increased risk for getting COVID-19?

The vast majority of babies and children with congenital heart defects (CHDs) are not immunocompromised and therefore are not at greater risk for contracting COVID-19. Some children with CHD have other associated syndromes or conditions, such as asplenia, that can affect their immune function, but this is not directly related to their cardiac condition. If your child has an immune disorder, it is best to ask your pediatrician for specific advice, as each child's situation will be unique.

2 I've read that people with underlying heart disease are at greater risk for severe illness. Does this hold true for kids with CHD? How about kids with heart rhythm issues?

The good news is that the evidence so far is that children with CHDs and/or heart rhythm issues who do contract COVID-19 do not fare any worse than their peers. In fact, COVID-19 causes much more mild illness than other better-known respiratory diseases (such as influenza) in the vast majority of children.

3 Are cardiac patients at greater risk for multisystem inflammatory syndrome (MIS) than other children? And is the consequence of MIS in children (MIS-C) more severe for kids with cardiac conditions?

No—we don't have any evidence that children with CHD or those with a history of Kawasaki Disease (KD) are at increased risk of MIS-C. In BC, we haven't had any cases of MIS-C to date.

MIS-C has been in the news recently after Dr. Henry spoke about the condition during the COVID-19 BC update on August 27. She described eight cases that have been reported and investigated since the beginning of the pandemic in BC. However, after extensive investigation, these children did not have evidence of recent COVID-19 infection nor of close contacts with COVID-19.

While MIS-C can result in serious illness, it is exceedingly rare. The recent reports of "suspect" cases did not have any link to COVID-19. The report of "suspect" cases in BC may sound alarming at first, but it speaks to how carefully the public health office in BC is monitoring the pandemic in our province. The signs and symptoms of MIS-C overlap with several other conditions, including Kawasaki Disease, and reporting any and all cases in this category of illnesses means that we are casting



as large a net as possible so that nothing flies under the radar. This approach allows the public health office to quickly identify any patterns of illness and adjust its guidance if necessary, while also contributing to the worldwide understanding of this rare condition.

4 How do I decide whether my child should return to school/daycare?

This is a question that is keeping parents across the country up at night. This anxiety is understandable, and it can be heightened for heart parents whose children have been through so much already and are still under the care of our cardiac team.

The vast majority of children who contract COVID-19 have very mild illness and recover at home. Other infectious illnesses that children are exposed to at school every year are more likely to result in severe illness than COVID-19. As such, most families are encouraged to send their children to school, as there are many important benefits to attending school, including education, physical activity, social interaction with peers, etc.

Some families may have particular circumstances where COVID-19 could be more serious for other family members (e.g., elderly grandparents living in the house, another family member who is immunocompromised). In these cases, the concern of children being exposed to COVID-19 at school and bringing it into the home must be considered and weighed against the benefits of attending school in person. Consulting with your GP or pediatrician may be worthwhile in these cases.

We are extremely fortunate in BC to have the world-class leadership of Dr. Henry and her team of public health experts to guide us through this pandemic. The cardiology team at BC Children's Hospital (BCCH) relies on this guidance to instruct how we do our day-to-day work in the hospital and how we counsel our heart families to navigate through this stressful time. We've included links to the BCCDC website and the BCCH website below, and recommend that you visit them for more information to guide your decisions.

Retirement of Dr. Ivan Rebeyka

written by Dr. Joyce Harder

Many of you will have heard from other parents or physicians that Dr. Ivan Rebeyka has decided to “retire”. We are sad to hear this news, but we are also happy that he is healthy and hopefully will enjoy many years of doing exactly what he chooses to do every day!

Dr. Rebeyka graduated from The University of Saskatchewan medical school, with Distinction, in 1979. He completed a one year rotating internship in Toronto, then returned to Saskatoon to complete a residency in General Surgery from 1980-1984. This was followed by a fellowship in Cardiovascular Surgery in Toronto from 1985-1987. His natural talent in pediatric CV surgery was recognized by the senior Pediatric CV surgeons, and he was encouraged to do a further fellowship in pediatric CV surgery, as well as a research fellowship in Richmond, Virginia. He was then asked to join the staff of the Department of Surgery at the U of T in 1989; for those of you who are counting, this was only 15 years of education after high school!

Dr. Rebeyka worked in Toronto as a pediatric heart surgeon until 1996, when he was invited to relocate to the University of Alberta. Moving from the U of T to the U of A was a hard sell initially, but he decided that the challenge and opportunity of building a new pediatric heart surgery program would be an adventure. As many of you will appreciate, he was the only pediatric CV surgeon for five years, until Dr. David Ross joined him in 2001. This meant that he was always on call, no matter where he was in the world. As a friend, I know that those were tough times for him.

Ivan married Darlene Elashuk in 1986, and together they have raised a daughter and a son. Darlene is an experienced and very accomplished cardiac nurse practitioner on the adult wards. She has been a wonderful partner for Ivan, one of the few who can keep him in line!

As physicians who have referred patients to Dr. Rebeyka, we have always appreciated his sensible approach to complex patient issues, and his availability to discuss clinical problems by telephone. His exceptional technical expertise has resulted in outstanding surgical results in the prairie provinces throughout his tenure. Despite being very busy with the clinical workload, he has also maintained a career in research, and has published almost 200 articles in the medical literature. Dr. Rebeyka has also been an invited speaker in many institutions, and has operated with other pediatric heart surgeons in many countries. His teaching skill, his self-discipline, and his very high expectations have all helped to develop an excellent surgical center in Edmonton, one which is always up to date with the latest knowledge and technical advances.

Many of us have been dreading the day that Dr. Rebeyka moves on, but he has worked very hard to develop the necessary wisdom and surgical skills in several younger CV surgeons. Dr. Al Aklabi, Dr. Freed, and Dr. Jonkers have all had the privilege of working and learning with Dr. Rebeyka, and I know that they will continue his legacy of providing high quality surgery and post op care for our children. We are all very grateful to Dr. Ivan Rebeyka for his years of service and dedication, and we wish him a Double Eagle in the next phase of his life.



COMMUNITY ANNOUNCEMENTS

What's new with your heart child and family? Send us your pictures, stories, updates and achievements (big or small) so we can acknowledge and share them with the community! Will your heart child be celebrating a birthday between May and August? Let us know so we can acknowledge their special day. Please email info@heartbeats.ca for inclusion in our next newsletter.

Xander turns 6 years old on November 11. He has really been loving kindergarten...with Mrs. Baba (his grandma!). He wants to be a firefighter when he grows up.



Wilson born with TGA and a large VSD will be 6 years old on November 6th and will have his 6 year open heart-anniversary on November 17th. He loves to ride his scooter, hang out with his big brother and is obsessed with dinosaurs. He also started kindergarten this year!



This little heart warrior turns a whole hand this year! She is healthy, happy and strong with a whole lot of personality! Happy 5 sweet Charlotte!



Alexa Castillo turned 13 on October 14! Alexa has critical aortic stenosis and is being treated with HLHS. She loves playing soccer, hanging out with her friends and playing with her dog.



Our little man is Thomas Monaghan, and he just turned 1 year old this past June.



Heart Beats

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Disclaimer: Any personal opinions/ comments expressed in this newsletter are not necessarily those of the Heart Beats Board of Directors. All submissions for the newsletter will be accepted; however, we reserve the right to publish in whole, in part or not at all. Remember, your best source of medical information is always your physician.

Jokes from Dal

our trusty Pediatric Echocardiography Instructor

What is the difference between a piano and a fish?

You can tune a piano but you cannot tune a fish (tunafish)

Why do bee's have sticky hair?

Because they use honey combs (honeycombs)

Why do fish live in salt water?

Because pepper makes them sneeze.



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Calling all heart parents to mentor new families

The Cardiology Clinic is looking for heart parents who would be willing to speak with new heart families. This would entail sharing your experiences to new families via email or over the phone along with answering their questions.

If you are interested in being a mentor heart parent, please call the Cardiology Clinic at 403-955-7316.

