



Keeping the Beat

Spring 2020

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

In this Issue

HEART MONTH Pool Event



On February 8, we had the Heart Month Pool Party at Vecova Recreation Centre. Over 35 attendees participated in an hour of swimming followed by an hour in a party room where families were able to socialize while enjoying light snacks and informal games. Thank you to everyone who participated and came out to connect with other heart families!

- Heart Beats Pool Event..... 1
- Heart Beats Virtual AGM..... 1
- Upcoming Events 2
- Talk with the Docs: Meet Dr. Mah..... 3
- Bringing Disney to Evanna... 4
- Your Support in Action..... 7
- Donating to Heart Beats..... 7
- Spotlight on donation: Eagles Ladies Auxiliary 7
- Welcome to the Party!: CHD, Covid-19 & Me. 8
- Subscribe to “Keeping the Beat”..... 5
- Pediatric emergency beds centralized within Calgary Zone during COVID-19 response..... 9
- Heart Beats and Social Media 9
- Camp Del Corazon 9
- Emma’s Journey..... 10
- Heart Beats Update..... 12
- WCCHN Update..... 14
- Welcome to Holland: Part 2..... 15
- CHD Proclamation..... 16



VIRTUAL AGM

For the first time in the history of Heart Beats, the Annual General Meeting was held via Zoom.

The virtual meeting worked out very well, with all the directors and visitors able to participate. This technology will be utilized going forward as an alternate way to hold meetings virtually when circumstances prevent in person gatherings.



Here's what's coming up with

HEART BEATS

Heart Beats has planned two major events this fall. Due to the current COVID-19 pandemic, one or both, of these events may not take place. We therefore ask you to save the dates and keep on the lookout for upcoming emails with registration updates. To register for email updates, please reach out to us at info@heartbeats.ca.

Heart Beats Annual Family Camp

The Heart Beats' Annual Family Camp is held at Camp Evergreen (located south of Sundre). The dates for the camp has been tentatively booked for September 11-13. Families with a Heart child that is being seen at the Alberta Children's Hospital or at Quarry Park in Calgary are eligible to attend. Some of the activities offered at Camp Evergreen include canoeing, rock climbing, archery, ziplining, trail rides and a chance to connect with other Heart Families.



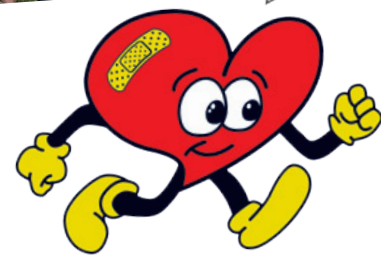
Heart Beats Annual Fun Run

The 11th Annual Family Fun Run is scheduled for Sunday, October 18th at Eau Claire Market beginning at 9:00 a.m. This is Heart Beat's biggest fundraiser of the year and we ask that you help us make it the best run yet by promoting it to your friends, colleagues and on your social media.



If you are planning to collect donations for Heart Beats with your participation in the Family Fun Run, we invite you to encourage your donors to increase the impact of their donation by donating to Heart Beats before September 1st through Shaw Birdies for Kids presented by AltaLink (BFK) at shawcharityclassic.com/donate/ heartbeats. Donations made through through BFK incur no administration fee and are matched up to 50%.

We would like to welcome our new Run Manager, Donna Iverson, to the Fun Run. Please feel free to contact her at run@heartbeats.ca with any questions about the Run. We ask that you please check your emails for registration timelines.



Talk with the Docs: Meet Dr Mah

Dr. Kandice Mah

So often we know only the cardiologist our child visits at the Cardiology Clinic, but each of the cardiologists has an area of expertise which contributes to the overall care they provide to patients at the Cardiology Clinic. In the past issues of "Keeping the Beat", we have featured Dr. Frank Dicke, Dr. David Patton, Dr. Deborah Fruitman, Dr. Robin Clegg, Dr. Joyce Harder, Dr. Kimberley Myers and Dr. Michael Giuffre. Please join us in welcoming Dr Kandice Mah to Cardiology clinic at ACH. Here's a small interview with her.

1. Tell us about where you grew up? What was your home life like? Do you have any siblings?

I grew up in Ontario, north of Toronto. I have two older brothers who I look up to a lot, so my childhood was full of tackle football with our stuffed animals and me trying to keep up with them.

2. Please tell us about what you do in your personal time? Hobbies?

I enjoy spending time outdoors and going for hikes, making Calgary an ideal place to live.

3. Please tell about your back ground professionally (Where did you attend school and where have your worked previously)and how did you ended up at ACH?

I went to school in Ontario and Alberta, and I worked in Alberta, Saskatchewan and Ontario prior to coming to Calgary. My main focus in cardiology has been cardiac imaging with a sub-specialty in 3D echocardiography which is used for surgical planning.

4. What inspired you to become a pediatric cardiologist?

I had the combination of everything that excited me about medicine – complex physiology, which at times required quick thinking, and the chance to build long-term relationships with the patients and their families.

5. Are there any particular heart conditions that you have a special interest in?

I don't have a particular heart condition that I specialize in. I focus more on anatomical cardiac lesions from a research perspective as my subspecialty is 3D echocardiography.

6. What is the best/ most rewarding part of your job?

I am inspired daily by the resilience of the kids and the unconditional love of their families. Even in their worst moments, each child teaches you life long lessons on perseverance, the importance of laughter and how to care for your family.

7. What is the challenging elements of your job?

Wishing that you could do more. Medicine has come a long way, but there are definitely days that I wish I could help more, either medically or otherwise.

8. Do you have any words of wisdom for your patients and their parents?

Not particularly, but I do want to say thank you. Thank you for always motivating me to be a better physician and for giving me the opportunity to be a part of your child's care.



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.



Bringing Disney to EVANNA



As completely entitled as it sounds, I always kept it in the back of my mind that perhaps a trip to Disney would be in the cards for our family the moment we got Evanna's diagnosis and that major open heart surgeries would mark her life. I'm a planner, and so while our entry into parenthood would also throw us into the CHD world, "going to Disney" just subconsciously became a life event that would go along with it. But despite reading every "heart journey" I could get my hands on and scouring the internet for "heart mom blogs" when I was pregnant and feeling like I knew what we were in for – nothing would prepare me and my husband for what would actually unfold.

Evanna's original open heart surgery took place when she was just 5 months old in October 2014 at the Stollery Children's Hospital. Surgery went relatively well, but troubles began to arise when it came to

extubate her, and we gained another diagnosis called "tracheobronchomalacia". After 2 more additional open heart surgeries and a multitude of other procedures, we finally consented to a tracheostomy in March 2015, however a string of hospital acquired infections would keep us in ICU through the rest of that spring and summer and not graduate to the floor at the Alberta Children's Hospital until August 2015. After resolving a few more medical issues, lots of preparation and intense trach training, we finally got to take Evanna home on day 400 on November 9, 2015. While not necessarily a priority at the time, internally I was hopeful that this was our first giant step towards a "wish trip to Disney", and we just had to work on getting Evanna stronger and healthier to make the journey possible.

While Evanna's health did indeed improve and she became more medically stable, her oxygen needs of 4L wouldn't budge,

and it was somewhat of a logistical nightmare on day-to-day basis and knew that it would be really difficult to manage a trip far from our home (...such as Disney) on that level of support. Through personal research and networking, I became aware of a particular surgeon in the USA who was very proficient in Evanna's very unique and rare heart defect, and when it was confirmed that our surgical team at the Stollery didn't feel like there was more they could offer — with the help of our incredible cardiologist Dr. Fruitman, we began to pursue the huge undertaking of getting a surgical opinion of Dr. Frank Hanley at LPCH Stanford in California, followed by the daunting task of gaining Out-of-Country funding approval from Alberta Health. While this process officially began in September 2016, we would not see the operating room in California for the first time until August 2018. Throughout the whole process, the idea of "Disney" was definitely put on the back burner, but also remained a bit of a potential sweet, sweet reward that laid ahead.

The "California heart surgeries" were 2 part — with the first part of the pulmonary reconstruction

taking place on August 15, 2018. While the post recovery was a little bumpy (but nothing we weren't somewhat already accustomed to), we saw fantastic postop results with getting her down to 1-2L of oxygen (the lowest we've ever been able to get too), and took steps to secure a surgery date for the 2nd surgery and hopefully gain a "full repair".

After a fantastic winter and early spring that saw a surge of development, we ventured back down to California Easter weekend 2019, and Evanna had her 6th open heart surgery 5 days before her 5th birthday on April 24th. Dr. Hanley came out of the operating room at 1am (his full repair surgeries are known for taking 12-20 hours) declaring surgery a success, to which my husband and I let out a collected breath of relief while expressing our gratitude. With finally achieving a "full repair", we hoped this would help us wean Evanna off of oxygen, the ventilator, and lead to decannulation (taking the trach out). We were medically transported back to ACH in Calgary at the end of May and discharge home shortly after.

However, not long after discharge (June), we saw a massive decline in Evanna's



health that lead to back-to-back ICU admissions. Initially it was thought that maybe she had pneumonia (at least that was kind of the hope), but a quick lung scan revealed no pulmonary blood flow to her left lung, and Evanna was rushed up to the Stollery in Edmonton for an emergency cardiac cath. Unfortunately the cath confirmed what the lung perfusion scan showed, and they weren't able to re-establish blood flow during the procedure. These images were quickly sent back down to Dr. Hanley in California for his opinion, but much to our dismay, he felt that due to how quickly blood flow was lost to her left lung, that another invasive open heart surgery would garner the exact same results, and that unfortunately with how the "full repair" changed blood flow and pressures within her heart, it also wasn't possible to undo the "full repair", and the whole situation has now put Evanna into permanent and irreversible heart failure. In the weeks and months following this news, the Stollery surgical team met to discuss if there was any other options we could explore. However, after much deliberation

and consultation with the transplant team, it too was decided that for both anatomical reasons and Evanna's extensive surgical history, she was a very poor transplant candidate (with at minimum a lung transplant — at most a double lung/heart transplant), and would very unlikely survive the transplant postop recovery.

While we thankfully were able to bring Evanna home, we quickly found her respiratory support has needed to be greatly increased. Immediately we had to put her back on the ventilator full time, and her oxygen requirements also went back to 4L with that "baseline" changing and increasing on almost a monthly basis (currently sitting at 8-9L). I don't know exactly when it hit me, but it was during this time that it dawned on me that if we can barely get Evanna across the city to her medical appointments, traveling to California or Florida was going to be literally next to impossible, and the idea of a "wish trip" was completely dashed.

When I came to this realization, I conveyed this tidbit of information in an online update, and implied we may look into

different Make-A-Wish options in the coming months. At the beginning of November, I received a message from a Calgary mother named Laura that had been following Evanna's medical journey online for several years — in which it stated that she had recently become in contact with Canadian blogger Jillian Harris, and was wondering if we would potentially be interested in the idea of hosting a little party here in Calgary and essentially try to "bring Disney to Evanna" due to Evanna's poor health and no longer capable of traveling. I still remember my heart skipping a beat upon seeing "Jillian Harris's" name in the body of that message (been following Jillian since her days on the Bachelor and Bachelorette) and that my first reaction and response was "wait — Jillian Harris knows about us?!" Laura laughed and responded "yes, Jillian knows who you are", followed by more messages to determine our comfort level and what we would actually like to see happen and take place.

With a little help from Jillian, the Fairmont Palliser graciously agreed to host the event, but it was felt this "princess



Bringing Disney to EVANNA

party” could wait until after the busy holiday season. Calgary based Princess Parties by Mimi kindly offered to supply as many princesses as we’d like, and so we requested a few characters from Evanna’s favourite movies (while also inviting Spiderman to join them for the benefit of baby brother Bennett). Pretty quickly, local event planner Saaraa of Blush & Co Events (whom has worked with Jillian Harris in the past) was asked to oversee the execution of the event, and Saaraa and her team seriously took the whole idea to the next level. Many local vendors were approached over the course of several weeks, and many immediately offered up both their time, services and resources to bring this Princess Tea Party to life. When it came to choose whom to actually invite to this grand tea party, I quickly decided that this event would also serve as a great opportunity to honour the many amazing homecare nurses who have worked in our home over the years, and even extended an invitation to our incredible cardiologist Dr. Fruitman and Nurse Patty too. All these individuals have been intimately involved in Evanna’s care over the years, and truly the individuals my husband Nick and I wanted to celebrate Evanna with.

January 17th arrived, and we were transported to a magical ice

castle in downtown Calgary. The room was adorned with pastel balloons (Little Chic Parties) and white floral arrangements (Amborella Floral). Large glass tables and clear chairs were set up in the middle of the room adorned with some of the most gorgeous glassware and cutlery (Modern Luxe Rentals), and the most delicious looking desserts were displayed over on the far side of the hall (Sugar Shimmer). Each guest was presented a personalized gift boxes that contained keepsake mugs (PrairiePressed) that featured a row of hand drawn flowers that represents the 6 open heart surgeries Evanna has had (4 Alberta Roses and 2 California poppies) and an “Evanna” candle made by Milk Jar Candles that was for sale through the month of February – where all proceeds were donated to the Heart Beats Children’s Society.

We enjoyed the most delicious offerings that is accustomed at High Tea, and overall enjoyed a moment of lavish attention that has created some incredibly beautiful memories for our little family. This event has since been highlighted on both the news and



Jillian Harris’s blog that has helped shed a little light and awareness on congenital heart defects and the impact they can have on patients and their families.

While we remain devastated and heartbroken about Evanna’s recent health decline, prognosis and so emotionally & mentally exhausted from a turbulent “heart journey” spanning these past 6 years – we also continue to be grateful and in awe of the generous community of support that surrounds us, and this incredible city we live in.

Complete List of Vendors: Jennie Guenard Photography, Blush & Co Events, Fairmont Palliser, Jillian Harris, Princess Parties by Mimi, Milk Jar Candle Co, Mountain Grove Studio, Holly Loves Paper, Custom Laser Works, Adorn Calgary, YNOT Digital, Modern Luxe Rental, PrairiePressed, Little Chic Parties, Amborella Floral, Make Me Blush Gifts, Black and White Bake Shop & Sugar Shimmer



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) Donate through Shaw Birdies for Kids

Heart Beats is pleased to be a participating charity in Shaw Birdies for Kids presented by AltaLink (BFK). All donations made through BFK will be matched up to 50% making your donation go even further. To donate through September 1, 2020, please go to <https://shawcharityclassic.com/donate/heartbeats>

2) 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.

3) 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

4) E-Transfer

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

5) 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

Thank You

Donations received from November 2019 ~ March 2020

Cathy Howarth

John Quinn

Happy new year to Heart Beats Calgary from Aodhán QUINN and family

Kierra Irvine

On behalf of Riley's 2nd Birthday

Trevor Pollock

Thank you for successful surgery Dr. Ross and ongoing monitoring Dr. Dickie

Lenore Anderson

Steve Lamb

Clayton Hayes

Jefferey Keep

In honour of Wilson Glowach
(for family fun run)

Zaldivar Patascil

Wendy Yu

Appreciation for care for son with CHD

Saunduson

Floyd McCormick

Anonymous

In honour of Victoria Neira

Edith Mack

Orian Bambrough

Aliyah's Amigos

Anonymous

Canadian Pacific Railway Company
CP Healthy Eating Challenge Week 1 Group Winners 'The Number Crunchers' decided their prize \$ should be donated to your amazing cause!

United Way Moncton

ATB Financial

ATCO

EPIC Campaign

Total Cardiology

Calgary Shaw Charity Classic Foundation



Spotlight on Donation:

Fraternal Order of the Eagles Ladies Auxiliary

Fraternal Order of the Eagles Ladies Auxiliary 70th Anniversary Banquet \$500.00 donation. Special thanks should be given to Jeremy and Jamie Stinson for their continued support of our organization.

Welcome to the Party! CHD, Covid-19, and Me

Lia Louiser

Global Pandemic you say?! That just means it is another Tuesday for me Karen!

I've been prepping for this day for the last eight years give or take. No, not by building a bomb shelter, (although that's not a half bad idea at this point), but because I have a Medically Complex and Fragile child.

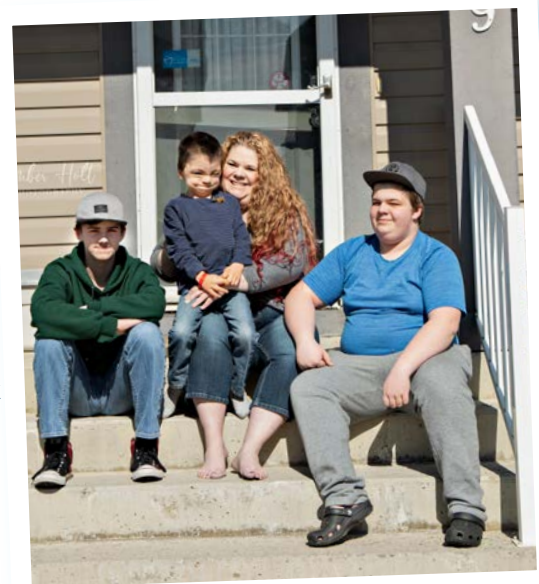
For how many of us does it feel like life as we already know it to a certain degree? The gross majority of CHD Parents have spent weeks, months, and years doing one form of isolation or another. How many times have we tried to explain to non-CHD parents why they can't come over if they, or their kids, have "just a cold"? Or people rolling their eyes when they don't think you are looking? The exhaustion, the frustration, the missing of too many life events to count. Living a life in isolation (both physically and mentally), is simply part of who we are as Heart Parents. It's really just part of the whole package that no one even bothered to ask us if we wanted to sign up for. These past weeks we've been subjected to people telling us that they "know how we feel" or scrolling past parents that have kids that are, heaven forbid, "BORED"?! Of course then you also get the flip side of the Parents that are enraged that they cannot take their desperate kids to a playground! Oh the inhumanity, (I jest)! Lately though? I find it is just better for my own mental health to take a step away from Social Media when I see too much of this and enjoy my bubble of solitude and isolation.

What I do find though is, in this world full of uncertainty and fear right now, is to focus on the little things in life I am thankful for. For me over here, we're already three weeks into our isolation and you know what? It's been a pretty wonderful existence thus far...what?! Again, it's the little things. It's the getting to (finally) know my neighbours. It's the zero need to rush here and there. It's the 'I can do it later' and mean it. It's the extra snuggles, the staying up late or having a nap (if you're one of the lucky ones). It's the massive hearts of those that have offered help and have dropped off supplies. We are most certainly not alone in this and our community, our village(s), have done nothing but grow. Accept help when it is offered!

Am I scared? Hell ya I am. Terrified actually. As many of you, I've watched my CHD son go through too many pneumonias to count and have seen first hand what happens when the virus overtakes the lungs. I have already seen him go from needing a 'sniff' of oxygen, to 10L in under 20 mins. From all that I have been told and have seen, this newest virus can be even more devastating than our already dreaded Influenzas and our RSVs. My medically complex son has many other diagnoses aside from his CHDs and already has scarring in his lungs due to the permanent damage that pneumonias can leave. He has always been 'palliative', even from before he was born. I have also been told that I need to plan for the very worst case scenario if we contract this COVID-19. Even his strongest medical team members do not think he would or will survive this.

One of the things I have found helpful, even more so at our scariest times, is to force myself to think of one positive thing that has happened that day. Writing it down even solidifies it more for me. For those of us that journal, it can be incredibly cathartic at a time like this. We can get so caught up in the 'what ifs' and the 'unknown futures' that it will bring us to a stop. The fear can slowly eat at you, the dread, the uncertainties. Now, more than ever it is important to practice self-care. I know, some of you are laughing and that's ok! Self-care doesn't have to mean hours of massage (although I'd sign up in an instant), or days away at a spa (ha!)...it just means, do yourself a favour and do a mental check-in. It doesn't even have to be at the end of the day on those harder days. Find out what works for you! It can be from the moment of waking and through your entire day, if that is what you feel you need. I am finding it incredibly helpful to have one or two or ten (medical momma) friends that I can send a quick text to. We are certainly not alone in this, it is a big world out there. Take those moments to breathe, to focus on the here and now. Find some music that makes an instant dance party happen! Fill the house with an 'obstacle' course or build those couch blanket forts. Try not to focus on all of the can-nots but take generous advantage of all of the cans. The house cleaning can wait an hour or 24 to be tidied. The pressure to do therapies and homeschooling is there, yes, but also realize that we all have limits that we need to work within without burning ourselves out (further).

Now is a great time for making memories and to just live each day as it comes.



CALGARY – As Alberta Health Services (AHS) proactively plans for the anticipated surge in demand for acute care and emergency department (ED) spaces, AHS is converting the nine beds currently reserved for pediatric ED patients at South Health Campus (SHC) into adult ED spaces, effective immediately.

Dedicated pediatric ED beds and pediatrician-provided emergency services for any child under 18 years of age will now be offered at the Alberta Children’s Hospital (ACH) only.

Please note that all emergency departments in the Calgary Zone continue to accept both adult and pediatric patients. This change reduces the number of ED beds specifically allotted for pediatric patients, where children are provided care exclusively through a pediatrician. This change is only temporary and pediatric ED services will resume at SHC when the COVID-19 pandemic ends.

Families with pediatric family members requiring non-emergency medical care continue to be encouraged to call their family physician. To speak to a nurse and receive telephone advice and health information, families can also contact Health Link 24/7, by dialing 811.

All patients with potentially life-threatening conditions should immediately phone 911.

Alberta Health Services is the provincial health authority responsible for planning and delivering health supports and services for more than four million adults and children living in Alberta. Its mission is to provide a patient-focused, quality health system that is accessible and sustainable for all Albertans.



Heart Beats and Social Media

Find us on Facebook..and Instagram



Staying in touch with other heart families and joining in fascinating conversations has never been easier! Our Facebook group is always growing, so stay in the loop by searching Heart Beats from your Facebook page or click on the link at our website to become a part of this expanding group.



Heart Beats is on Instagram Staying on top of community news and upcoming events has never been easier.

CAMP DEL CORAZON



CAMP DEL CORAZON WILL CONTINUE ITS MISSION TO MAKE A DIFFERENCE IN THE LIVES OF CHILDREN AND YOUNG ADULTS WITH HEART DISEASE. AT THIS TIME WE ARE STILL PLANNING ON OUR CURRENTLY SCHEDULED CAMP SESSIONS IN AUGUST.

We will keep you up-to-date as we approach our decision-making with loving caution. The safety of our extended camp family is always our priority.

Camp del Corazon is located on Catalina Island in California and provides a summer camp experience for children ages 7-17 offering opportunities for growth, education and support for children and youth living with heart disease. The camp is free to attend, and Heart Beats has a scholarship that will onset the travel costs to any youth wanting to attend. Please reach out to us at info@heartbeats.ca to learn more about this scholarship.

2020 Summer Camp Sessions

- Session 0: August 23-27
- Session 1: August 27-31
- Session 2: August 31-September 4
- Session 3: September 4-8

Visit campdelcorazon.org to register.

EMMA'S JOURNEY

By Janine and Mike Kirk



In June, 2016 we were having a regular ultrasound, but it seemed to be taking longer. The technician left the room. We looked at each other and knew something was wrong. When the technician returned, she said we need some more pictures. Over the next 15mins/lifetime we could see she was focused on Lucas's heart. We then went to another room where we were told us they believe Lucas has a coarctation of the aorta (COA) They explained everything to us and worst case scenario Lucas would have to be flown to the Stollery Children's Hospital in Edmonton for heart surgery once born.

Lucas was born August 16th, 2016 at the Foothills Hospital in Calgary by c-section as he decided he wasn't ready to meet us yet. Rushed into the NICU where he would spend less than 48hrs, Lucas was fine and able to go home! Mom took 5 more days due to high blood pressure that went away as soon as we were all home. Three months of tears and worrying for nothing.

Friday November 16th, 2018 Emma was born! Again, at Foothills by c-section. Everything went great and we were all home 48hrs later.

The following Monday, the home nurse came by to check on Emma and Mom. Everything looked good but Emma's jaundice level was right on the line and we needed to go for

a follow up check-up the next day.

On the Tuesday, we had our appointment booked for 1pm at the North Hill Community Health Centre. That morning Janine didn't feel like Emma was interested in feeding and was very sleepy. At the appointment the nurse said the jaundice had gone down and was not an issue. Janine let the nurse know she felt Emma was off today as she was completing her checkup of Emma. The nurse agreed that she didn't like what she was seeing and wanted us to take Emma to the Children's Hospital right away. It was 5 minutes away. The nurse called ahead and let them know we were coming.

When we arrived, we were taken in right away. The doctor and nurses would check Emma out for the next 3 hrs. What they didn't like was that Emma's blood pressures were lower in her legs than arms. It should be the other way around. Emma also didn't feed or really wake up over that time. At 6 pm the cardiologist came down to take an echo of Emma's heart. 30 mins later we were told the same thing we had heard back in 2016... Emma had a COA which would have to be fixed right away, plus a large VSD (a hole between the two chambers in her heart). She was slowly dying. The doctor had tears in his eyes as he explained what would happen next. Emma was taken to the PICU where she would spend the night.

On Wednesday morning, Emma was flown to Stollery Children's Hospital in Edmonton. We ran home and packed for 2 weeks. We tried to explain to Lucas (2yrs old) that we had to go, Emma was sick, but he could come as soon as we were settled in Edmonton. It was a very quiet drive filled with all kinds of

emotions. It almost seemed unreal as if it was just a bad dream. When we arrived in the NICU Emma had already made her presence known with her high pitch cry. It was late and we had all these questions hoping to be answered right away but it had to wait till the following day.

Thursday, we met with the doctors and surgeon during morning rounds. Emma was responding well to the medications to help her heart, and they would try the following week for Surgery - we didn't want to hear that. It was so hard to look at Emma hooked up to all those monitors and IV's. Then one of the doctors came back 20 mins later to say they were going to schedule Emma in the tomorrow morning! They would fix the COA but didn't think they could fix the VSD at the same time due to the location of the hole. Later that afternoon, the surgeon let us know he would just be fixing the COA and put a band around the aorta to help with the pressure between the two chambers. The VSD would have to be fixed once Emma was a little bigger and stronger.

That Friday, when Emma was 7 days old, we watched our newborn being rolled away from us into surgery. It was the saddest, scariest, most helplessness feeling we have ever felt. We had been positive and held it together up to that moment. It was easy as all the nurses, doctors, and surgeons had all the answers, and everything to them was so routine. Just another day at work for these miracle workers! The next 3hrs felt like a lifetime - then we saw Emma get rolled into the NICU and the surgeon and his team coming down the hallway. Everything went great and we would be able to see her shortly. We were on cloud 9.

Saturday was tough. Emma had so many tubes, IV's, and cables coming out of her that we couldn't even pick her up. She didn't look like herself due to all the swelling, and then when she cried nothing came out... that high pitch cry was muted from the breathing tube... it was the hardest thing to watch. It was a rough day.

Sunday was a different story! The breathing tube was out, and others followed the rest of the day. Janine even got to hold Emma again and feed her just a little.

Over the next few days things were improving, and Emma was flown back to Calgary on Wednesday. Just 5 days after surgery. Emma would then spend the next 2 weeks in the NICU at the ACH in Calgary, trying to get her feeding and weight up, and off the pain medication. Emma was finally released and home in time for Christmas! We will never forget the excitement Lucas had when we brought Emma home! He knew how big of a moment that was for everyone. The hard part was we knew we had to do it all over again in the New Year.

The following months were spent with countless checkups at the Children's. We had very few visitors and didn't go anywhere as we didn't want to take the chance of Emma getting sick as we waited for the next surgery. We just concentrated on Emma getting stronger.

On Tuesday, February 19th, 2019 Emma was at her checkup. Her weight was not really improving anymore, her stats were starting to slip, and we let the team know if there was an opening in Edmonton, we could be there in 3hrs. Our Cardiologist agreed it was time to get Emma back up to Edmonton for the 2nd Surgery. A few days later we heard back that Edmonton agreed and now it was just a waiting game. The following Monday afternoon,

we received the call we had been waiting for, but we had to be in Edmonton the following morning at 8am. We scrambled to get ready and left at 3am for our next journey at the Stollery.

That Tuesday, Emma went through 5hrs pre-admission examination. Echo, EKG, X-Ray, Blood work. She was a trooper through it all and was ready for surgery the next day.

It was Wednesday, and Emma was scheduled for open heart surgery that morning. We were all ready to go when the Stollery called to say Emma was pushed back to later that afternoon. We started to worry that Emma had missed her chance. We arrived that afternoon and Emma was all ready to go. Janine held Emma on the bed as we were heading up to surgery. That is when the porter's phone rang. We stopped in the hallway and he passed me the phone. There was another baby that needed the miracle workers more today... we were crushed but knew Emma was healthy enough to wait and prayed for the little baby going up.

On Thursday, we waited by the phone to see what was next. The Stollery called and said they could get Emma in on Friday. This time Emma went into surgery just as planned. Again, we waited. It was even harder this time as Emma had become our Emma over the last 3 months. This time they were doing open heart surgery to patch the hole in her heart and remove the band they had placed last time. After 3 hrs, Emma was out. The surgery had gone great and Emma was recovering in the PCICU.

Over the next few days, Emma improved and was moved out of the PCICU on Sunday. By Tuesday, Emma had shed the 13 tubes, IV's and wires she had after surgery. On Wednesday Emma was discharged to our disbelief. We had her back-

home smiling in her swing just 5 days after open heart surgery. Emma hasn't looked back since. She has recovered amazingly well and is now a happy little 15-month-old troublemaker, her high pitch cry is now a high pitch squeal of excitement.

The one thing we always tell people is how amazing everyone was during all of this! Everyone involved showed so much care and compassion for Emma and us. They truly are miracle workers at these two hospitals.

We also knew that after everything we saw, we needed to try and give back. Emma's journey was very smooth. But what we saw and learned over all our time spent in the two NICU's, checkups, and walking the hallways of the hospitals, is that not all families have such an easy ride. A lot of families must face and deal with much more difficult situations and complications.

We wanted to find a way that others could help and at the same time create a special memory for someone. We wanted to give back through Heart Beats who showed up that very first morning Emma flew to Edmonton. They comforted us, gave us guidance, and even had gift cards for our drive to Edmonton. My wife Janine is an amazing artist and has teamed up with Heart Beats to give back 50% of all proceeds from any special PORTRAITURE custom artwork order. For more information or to see examples of her portraits, please visit www.snowblushberry.com and click on the shop tab and visit [portraiture](http://www.portraiture.com).

Heart Beats Update

After many years of serving on the board of Heart Beats, it is with hearts full of gratitude that we say goodbye to Sylvia Falk, Heidi Smethurst and Patty Wiebe. These remarkable women have been the backbone of Heart Beats for decades and have created initiatives, achieved outstanding fundraising goals and have never ceased to advocate on behalf of our children. Perhaps their biggest contribution has been the moral support, hope and guidance they have given to new parents trying to navigate the realities of raising a child with CHD. Although they are resigning from the board, we look forward to seeing them again at future events. Below are some parting thoughts from these amazing women.



Sylvia

I can clearly remember the first time I attended a Heart Beats event. Our Daniel was six weeks old and I read about Heart Beats in the waiting room at the NICU of Foothills Hospital. We had 3 children all under the age of 2.5 and in those days, information was scant. I went to the library and found a tiny paragraph about a single ventricle diagnosis in a medical book. I was desperate for information. It was through Heart Beats that I met lifelong friends, and the first meeting I attended hosted a surgeon from Edmonton discussing transplantation in neonates followed by a video.

Soon afterwards, I was offered the position of secretary. This led to almost every position at Heart Beats including chairperson for several years. During this time, we hosted a banquet which was our first official fundraiser. It was a huge success, held at the Italian Club and included a silent auction (a novelty at that time). We were able to lobby the Calgary Caucus when NICU beds were cut back at the Stollery Hospital with favourable results and we continued to fund necessary medical equipment. Public awareness was our mandate and at that time there was no internet or Facebook so it was very important that people knew CHD was not the same as acquired heart disease and so we made this a priority. Fundraising also became a huge priority as we saw many families struggling with CHD.

After 31 years with HB, I am now retired, we have 3 grandchildren and my 90 year-old elderly father living with us. I work part time and find myself babysitting with great enthusiasm. I will always remain a Heart Beats supporter and will no doubt see you at the annual Fun Run and the Children's party during CHD Awareness Week. The children are a huge joy to see grow up and while we have had many sadnesses in losing beloved children with CHD, we have made bonds that are life long. Our Daniel is married, has a little boy who is so special, and we rejoice that in spite of his health setbacks, there continues to be developments and new technology that we can benefit from.

It has been a privilege to serve and work with a talented, energetic, amazing group of people. I am grateful for the opportunity that in spite of a life changing, difficult diagnosis for Daniel, there can be hope and support. We so appreciate Heart Beats role in our family.

Patty

I joined the Heart Beats Board of Directors when my "heart" daughter, Isabelle, was a year old. She will be turning 19 in May. Time flies! So much has happened in that time, with Isabelle and with Heart Beats!

Isabelle was born with critical aortic valve stenosis which resulted in her being treated for Hypoplastic Left Heart Syndrome. She has had four open heart surgeries: the Norwood at 11 days old, a bidirectional Glenn at 6 months old, a Fontan at age 4, and a native aortic valve reconstruction at age 12. Last year Isabelle transitioned to the adult cardiology clinic at the Peter Lougheed Centre. Isabelle has participated in school sports, travelled to 13 different countries on five different continents, graduated High School and moved away from home to attend college in BC.

When I first joined Heart Beats, our community was quite small. There were even discussions of whether Heart Beats should continue. I am so glad it has! Today our Heart Beats community includes so many more families, and we are able to provide emotional support and financial assistance to so many children with CHD and their families! When I first started, Heart Beats had Mom & Tots, Offbeats, and the February Family Event to celebrate CHD Awareness Week. Over the years more opportunities were added for families to connect ... Christmas party, Lake Day, Family Camp, Moms Night Out and Dads Night Out. And the Annual Fun Run which began in 2010 has had a significant impact in raising awareness of and funds for Heart Beats.

Shortly after I joined the Board, I was asked to submit a write-up for the "Meet the Executive" section of the Newsletter. In that article I identified three reasons why I wanted to become involved with Heart Beats:



- *I wanted to meet other parents of children with CHD who could understand our journey.*
- *I thought it would be beneficial for Isabelle to know other children with CHDs as she grew up.*
- *I wanted to connect with and assist other families of children with CHDs.*

It is so wonderful to look back and see how all three of these were met through my involvement with Heart Beats over the past 18 years.

I have met and developed meaningful friendships with other parents as we have journeyed together, shared information and helpful tips, celebrated successes and achievements, and at times mourned challenges and losses.

When Isabelle was young and we would attend Heart Beats events like Mom & Tots or the February Family Event, Isabelle would say, "I'm a Heart Beat"! When Isabelle was in junior high she started attending Offbeats and made two very special friends who are her age. In addition to Offbeats events, the three of them attended Camp del Corazon together for four summers, and still keep in regular contact.

Over the 18 years I have held the roles of Secretary, Vice-Chair, Chairperson and Treasurer of the Board of Directors. I have hosted Mom & Tots, Christmas parties, and Lake Days; I have helped plan February Family Events, and milestone Heart Beats' Anniversary celebrations; I have assisted with the Family Camp; and I have helped organize and facilitate the Annual Run. All of this provided me the opportunities to meet so many families, hear their stories, help meet needs, on occasion provide helpful advice, and facilitate opportunities for families to connect with one another.

Heart Beats has been a huge blessing to me and my family. It is with mixed emotions that I step down from the Board of Directors, but I leave knowing that Heart Beats is in good hands with a full Board of Directors who are very capable and passionate about making sure Heart Beats continues to provide information, resources, emotional support and financial assistance to families of children with CHDs for many years to come!

Heidi



Can it be that 20 years has gone by... I joined Heart Beats in September of 1999 when my "heart child" Ryan was 4 months old. We had just moved from White Rock, BC to Calgary. At our first cardiology appointment with Dr Harder and Patty Knox, they mentioned a parent support group called Heart Beats. The thought of having parents who had "walked in our shoes" was very appealing – a place to share, listen, and make new friends! My heart

child, Ryan, will be 21 on May 5th. He was born with a TGA and a VSD, and was repaired at one month old at BC Children's Hospital. Since then, he has had two stents for a stubborn PA at the Stollery. He transitioned to Peter Loughheed, and for the past two yearly appointments he has gone on his own, no longer needing his mom. Ryan is currently in his second year at Mount Royal University in Business. He plays hockey in a men's "beer league", intramural soccer, and keeps fit with gym and boxing workouts. He is enjoying the student life! Ryan attended Camp del Corazon, participated in the youth conference at BC Children's, and attended many of the Heart Beat parties throughout the years, along with his three siblings who also have fond memories of the events. As a director, I cherish the friendships I made with other moms who have shared the same journey. I am most proud of our run and how it has knit our community together, our contributions to the Ronald McDonald house in Edmonton, our care packages for families heading up to Edmonton and our Christmas hamper program! I will miss our meetings, the laughter (and tears) and the commitment of our executive board to lessen the stress of other heart families. Here's to another 20 years! Wishing the board continued enthusiasm, energy and vision as Heart Beats moves into this new decade

WCCHN Update: "Stronger Together"



THE WESTERN CANADIAN CHILDREN'S HEART NETWORK (WCCHN)

Stronger Together

Founded nearly 20 years ago, the WCCHN links expertise between the five pediatric cardiac centres in western Canada and has successfully established inter-provincial cooperation and partnership in the care of our patients. The WCCHN spans over 4-million square kilometers and serves a population base greater than 11 million. The WCCHN includes two pediatric cardiac surgical programs (British Columbia Children's Hospital in Vancouver and the Stollery Children's Hospital in Edmonton) and three referring centres (Alberta Children's Hospital in Calgary, Jim Pattison Children's Hospital in Saskatoon, and Children's Hospital – Health Sciences Centre in Winnipeg).

The core function of the Network is to coordinate and integrate care for pediatric cardiac patients across the four western provinces. The WCCHN promotes cooperation in education and clinical practice, supports research efforts, and advocates for the continual improvement of service delivery. Collaboration among Network sites ensures that our patients have the quickest and easiest access to the highest standard of care available.

The WCCHN welcomes a new Interim Board Chair

In May 2019, Dr. Charissa Pockett was appointed Interim Chair of the WCCHN's new Integrated Advisory Board. The WCCHN Integrated Advisory Board is designed to provide strategic guidance to the cross-province leadership and institutional members that form the Western Canadian Children's Heart Network. The Advisory Board helps to ensure that WCCHN initiatives remain true to the Network's mission, vision, and values. Membership is comprised of individuals from diverse backgrounds, including family representation, to provide the mix of expertise necessary for guiding the Network in their shared vision, priorities, and activity.

Dr. Charissa Pockett Credentials: MD, FRCPC

Title: Faculty, Division Head Pediatric Cardiology, Department of Pediatrics, University of Saskatchewan

Clinical interests: Diagnostic & interventional cardiac catheterization, single ventricle physiology, medical education

Originally from Manitoba, Dr. Pockett studied and completed medical school at the University of Calgary in 2005. She completed her Pediatric residency at the Alberta Children's Hospital in Calgary in 2009 which included 6 months of training at the Mater Children's Hospital in Brisbane Australia. She went on to train in Pediatric Cardiology at the Stollery Children's Hospital in Edmonton from 2009 to 2012. In July of 2012 Dr. Pockett joined the division of Pediatric Cardiology at the Royal University Hospital in Saskatoon. A one year leave of absence in 2014 allowed her to pursue advanced training in Pediatric Interventional Cardiology at the Rady Children's Hospital in San Diego, California. Since 2015 Dr. Pockett has been a full time Interventional Cardiologist at the Royal University Hospital, now the Jim Pattison Children's Hospital in Saskatoon. She became Division Head for Pediatric Cardiology in December 2017. She is a member of the CHAMPS research team at the University of Saskatchewan and is also currently studying the use of Robotic presence for remote murmur assessment. She became the interim Physician Lead at the Western Canadian Children's Heart Network in May 2019.

A Message from the WCCHN Program Manager

2019 has been a time of great renewal for the WCCHN. Not only has it been a chance to reset and recalibrate after 20 years of service, but also an invitation to re-imagine and recommit to the future that lies ahead. While the Network remains a large and productive group, the past twelve months have offered valuable opportunity to refresh strategy and approach. I have had the great privilege of working alongside some of our most senior leaders and administrators to drive our shared vision forward. Patients and families remain our first and highest priority. We commit to continuing to find new ways of keeping heart patients and their families at the center of all we do.

A handwritten signature in black ink that reads "Elina Williams".

Elina Williams RN, BSCN, PMP

Program Manager

Western Canadian Children's Heart Network

The WCCHN needs patient and family partners

If you or someone you know is passionate about patient and family advocacy, or if you have a story to share, the WCCHN invites you to get involved!

We are currently recruiting family advisors to our Equity of Resources platform. This group views equal access to services and resources as a domain of quality and safety. We believe that every patient's experience of the system should be the same from diagnosis to recovery regardless of where they live. And WCCHN is convinced that together, we can give rise to a louder voice from a larger platform.

For this opportunity or any other, email WCCHN@ahs.ca to learn more.

To learn more about the WCCHN and other resources available, check out our website at westernchildrensheartnetwork.ca





I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I'd planned.

I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger—the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay.

Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time. I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land.

I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends. Some of these fellow travelers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn't so bad.

I think that Holland is used to wayward travelers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land. Over the years, I've wondered what life would have been like if I'd landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest. And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift.

I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its tulips, windmills and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveler and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn't planned. Yet I am thankful, for this destination has been richer than I could have imagined!

Chairperson Jen Joly-Beleshko

Vice-Chairperson Tara Exall

Treasurer Golden Bhatia

Secretary Uli Ng

Nurse Liaison Patty Knox

Communications Director Catherine Hesketh

Newsletter Coordinator Hayley Beauregard

Additional Directors

Jacqui Esler
Cindy Castillo
Vittorio Borrelli

Volunteer Ambassadors

Elise Mitchell, WCCHN
Katrina Randall, Kids Up Front Coordinator
Keremy Dry, Family Camp Coordinator

Mailing address:

Box 30233 Chinook Postal Outlet
Calgary, AB T2H 2V9

Website: www.heartbeats.ca

E-mail address: info@heartbeats.ca

Phone: 403-616-8692 (Jen Beleshko)

Charitable registration number 88907 6261 RR 0001

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.



Design & Production:
Paul Warren, Immersion deSign Inc.
Dad of a Heart Child
www.immersiondesign.ca



Calgary

Naheed K. Nenshi, Mayor

PROCLAMATION

Congenital Heart Disease (CHD) is the most common of all birth defects occurring in about one in every 100 births. Heart defects are present at birth and affect the structure of the heart and how blood flows throughout the heart and body.

Whereas: More than 50 percent of all children born with CHD will require at least one invasive surgery in their lifetime;

Whereas: Survival of children with CHD has greatly improved thanks to advances in medical technology, but for some, CHD means lifelong care;

Whereas: With more patients reaching adulthood, continued efforts in fundraising and research is required to ensure access to ongoing care and support.

On behalf of City Council and the citizens of Calgary, I hereby proclaim the week of February 7-14, 2020 as:

“CONGENITAL HEART DISEASE AWARENESS WEEK”

NAHEED K. NENSHI
MAYOR

