



Keeping the Beat

Spring 2021 *Offering information, resources and emotional support to families dealing with congenital heart disease*

In this Issue

CHD Awareness Week



Congenital Heart Defect Awareness Week runs annually from February 7-14. Heart Beats normally holds an in-person event during this week but because of pandemic restrictions, a virtual challenge was held instead. We posted a random act of kindness every day that week to help bring awareness to this special week.

The Heart Families that completed all 8 challenges and who posted photos on social media would win a prize. We congratulate Carrie Glowach and Anastasia Burgess for completing the challenge and thank everyone else who participated in this event.

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Here's whats coming up with

HEART BEATS

Save the Date: August 20-22, 2021

Family Fun Run – Stroll to the Stollery is back! This year we will feature a 5K run, a 3K walk and a 1K kids run. We are still in the planning stages and will fill you in on all the details soon. If you would like an email when registration is open, please contact us at info@heartbeats.ca and you will be added to our email list.

“Strolling to the Stollery”
Fun Run



UPDATE

Offbeats and the new sibling group celebrated the winter holidays over Zoom. The group decorated ginger bread houses and played games. The party also had a few guests come to celebrate with the new generation. Maddie, Isabelle and Korynn, former Offbeats members, joined the festivities again this year.

In February Offbeats had a pottery painting night which is shown in the photo attached and it was super fun.

In March, we had a games night and had a new member join the group which was great.

On April 10th we will be doing a cookie baking class that we will be facilitating. The key ingredients will be dropped off at the members homes along with the recipe. If anyone is interested in joining they can email us at offbeats@heartbeats.ca.



WEAR RED CANADA



CANADA LIT RED
in support of
CHD AWARENESS



Wear Red Canada is an annual event on February 13 to raise awareness to support women with heart disease. Normally there are events held throughout the country but due to COVID-19 it was held virtually. This allowed people to “go” to other provinces’ events. The events were very informative on how heart disease differs in women and men. Guests at the events also had an opportunity to ask the doctors presenting questions. To learn more about Wear Red Canada go to <https://cwahc.ottawaheart.ca/how-get-involved/wear-red-campaign>

Buildings all over Canada were lit red during CHD week starting from Vancouver’s BC Place to High Level Bridge in Edmonton that were lit on February 7. In our home city, Calgary, the Calgary Tower was lit red on February 9. In London, Ontario a few buildings in the city were lit red from February 12 to 14, these buildings were London City Hall, JA Taylor Building, Canada Life building and RBC Place Convention Centre. The CN Tower in Toronto was lit red on February 14 along with Niagara Falls.



SUBSCRIBE TO “KEEPING THE BEAT”

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The Heart transplant journey of Vittorio Borelli



It was clear when he was 16 that he needed a new heart. Vittorio was not happy about having to have a heart transplant but it was the only option, so at 16 he was assessed for the transplant list. He was “healthy” at the time and was put on the bottom of the list.

When Vittorio turned 18, he was still feeling pretty good, so his parents decided to go on their 25th wedding anniversary in Italy. Twelve hours after they left for Italy, Vittorio ended being in the hospital due to bad arrhythmias. He spent two weeks in the hospital and was moved up the transplant list.

Vittorio got a heart within four weeks of moving up the list. He received a call one night saying that they had a heart for him and the plane was waiting for him at the airport to take him to Edmonton.

Vittorio response to the news, “No, I’m good. My parents aren’t here, I’ll take the next one.” His parents were still on their trip and weren’t going to be home until the following Saturday. His doctor told him that there might not be a next one and that he should take this heart.

Vittorio called his parents and they told him that he would have to make the decision for himself because he was an adult. His decision was to take the heart.

After that everything moved quickly. The ambulance was already in his driveway to take him to the airport where a medical plane was waiting for him. His friends that lived in the community

came to send Vittorio off with hugs as he made his way to the ambulance.

Vittorio wanted his sister to come with him but the only way that could happen is if they were weighed with their luggage to see if they were under the weight limit for the small medical plane. They just made it. And within two and a half hours Vittorio was at the hospital prepping for the transplant.

Sadly, his parents couldn’t make it back for the transplant but Vittorio had family in Edmonton that met him and his sister at the hospital.

The transplant took over ten hours. The surgeons had to reverse his previous fontan surgeries and then after that do the transplant.

By the time Vittorio woke up it was a few days later and his mom was by his side. The first thing he noticed when he woke up was it was so easy to breathe. He had never experienced a deep breath like he did after his transplant.

Vittorio expressed that the worst part of the experience had nothing to do with the actual surgery. The worst part was when he had leaking lymph fluid that caused him to have to stay in the hospital an extra two weeks.

Vittorio felt like a new human. He had never had fully oxygenated blood so being able to breathe was easier, he felt sharper and his thoughts were clearer. Most importantly he didn’t feel like a sick kid anymore.

Vittorio Borelli’s story is remarkable and inspiring. At the age of 18 Vittorio had a heart transplant, when most kids his age were freaking out about what to do after high school. Before his transplant his diagnosis was Tetralogy of Fallot and Coarctation of the Aorta. Like many heart kids he had his first surgeries at a young age. When he was a kid the Fontan procedure which at the time was in two parts. He had the first part done at one and a half. The second part was done a year later. After that he was healthy kid.

At six years old Vittorio’s heart started going into funny arrhythmias. It wasn’t until he was nine that his doctor decided he needed a pace maker. With his first pace maker he was told it would last five to seven years. Vittorio’s lasted nine months. Vittorio went through five pace makers by the time he was 17.

“They kept putting pace makers in me to control my rhythm issues,” Vittorio said.

Talk with the Docs: Meet Dr. Jonker

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 this issue, we will talk with Dr. De Villiers Jonker

Dr. Jonker attained his Bachelor of Medicine and Surgery degree and his Master of Medicine in Cardiothoracic Surgery at the University of the Free State in South Africa. He then completed a five year cardiothoracic surgery residency program at the Universitas Academic Hospital in South Africa. From 2011 to 2013, he joined Dr. Ivan Rebeyka (Head of Congenital Cardiac Surgery at that time) at the Mazankowski Alberta Institute in Edmonton for subspecialty training in both Adult Cardiac Surgery and Congenital Cardiac Surgery. Dr Jonker obtained his Royal College of Physicians and Surgeons of Canada Cardiac Surgery Board Certification in 2013.

Before joining the Division of Cardiac Surgery at the Mazankowski Alberta Heart Institute in 2019, Dr. Jonker practiced at the Netcare Sunninghill Hospital and Maboneng Heart and Lung Institute in South Africa for five years. He was co-founder of the Maboneng Heart and Lung Institute and started a dedicated pediatric Cardiac Transplant Program and the first Pediatric Ventricular Assist Device Program in South Africa.



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

I grew up in a regular home in Potchefstroom, South Africa. We are a loving family of 6. My parents are still relatively healthy and siblings still work and live in amazing South Africa.

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

I love spending time with my family and friends. Seeing how my children grow up and learn new life skills provides a great deal of gratitude. I love the outdoors and participate in Snowboarding, running and cycling.

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

My medical school and residency were completed at the University of the Free State in South Africa. I was inspired to come to Edmonton for adult and pediatric cardiac surgery fellowships from 2011 – 2013. For 5 years after that I had a successful practice in Johannesburg, South Africa, before being recruited back to Stollery.

4. What inspired you to your role?

I wanted to be a cardiac surgeon before I even wanted to be a doctor and got inspired learning of Christiaan Barnard and the first heart transplant. Since qualifying as a cardiac surgeon, my main inspiration has been Dr. Ivan Rebeyka from the Stollery.

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

I love all of cardiac surgery but if I have to choose, dealing with complex left ventricular outflow tract obstruction, neonatal cardiac surgery and the Ross procedure, probably have the edge.

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

Having a good outcome and experiencing how the anatomy and physiology comes together in a perfect repair. Being part of a competent and passionate team. Being trusted by parents to take care of their absolute dearest.

7. What is the challenging elements of your job?

Knowing that no matter how well we do and how hard we try, there are limitations to care that is out of our hands. Dealing with complications of a given procedure.

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

I respect any family that comes through these doors and allow us to provide comprehensive cardiac care for their most loved ones

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 Nov. 20th, 2020 - Feb. 2021

Canadahelps

Nevada Maier -100 rides in 100 days

United Way Charities Aid Foundation

In memory of Evanna Irvine

Shaw Charity

Anonymous

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>



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.



Spring 2021

SPOTLIGHT ON DONATION

Written by Nevada Maier

My name Nevada Maier and I'm 15 years old. I'm a two-time open heart surgery survivor! I was born with shone syndrome. I'm currently monitoring my moderate mitral valve stenosis and upper ascending aorta aneurysm.

In the beginning of COVID-19, I was in lockdown in Scotland for 14 weeks. I could barely leave my house; it was looking like the whole world was falling apart. Then my mum decided it was a good time for us to move to Calgary to be closer to family.

Last June we made the trek across the pond and began a new life here. This meant a new city, home, school and most importantly a new team of doctors.

During all my hospital stays, treatments, exams, scans and procedures, I was also diagnosed with spina bifida occulta and factor 7 blood deficiency.

I've never been the sporty type, mostly due to CHD, my easily exhausted state, and the strict rule of no contact sports. So my mum decided a bike would be a great way to stay fit. She then told me of Canadian winters lasting months on end, so an indoor bike was the best choice. Enter the Peloton into my life.

I started to attend Strathcona Tweedsmuir school in the fall and through them I started my community service project. Again COVID-19 got in the way of going out into the community. This was the beginning of my idea to ride my Peloton for a local charity and give back anyway I could. Doing some online research with my mum, we stumbled across Heart Beats Children's Society of Calgary and thought it was the perfect fit for me.

My challenge was to do 100 rides in 100 days; the most continuous exercise I'd ever undertaken.

I knew it was going to be a challenge but I also understood the challenges families face with CHD. My goal was to raise \$5000 through a Go Fund Me page and with the generous support of donors, I passed this goal halfway through the rides. I'm almost at the finish line!

The best part of this journey has been meeting other CHD warriors and their families on Instagram. and connecting with them from all around the globe. I've read so many inspiring comments and stories about other survivors and their struggles. It gives me hope and pushes me to keep going. This journey has also taught me about my own CHD and the actual medical terminology. Before I would just say I have a heart problem, but now I'm more aware of my own CHD.

I've learned that I'm more than my CHD and if I have the will I'll find a way! I'm stronger than I thought I was back in December and I look forward with a positive mindset to my future and living with CHD.

I want to say a huge thank you to my mum for being with me throughout all my medical needs and also, for every ride, helping me document it all. She's a true inspiration for me and I love her so much. And a huge thanks for all the generous people that donated, it truly means the world to me.

Stay strong, stay safe, stay vigilant.



Transition Stories



Questions and Answers with mother (Leah) and daughter (Maddie)

What were your biggest fears with the transition into adult care?

Maddie: I had two big fears about adult care. My first fear about transition was that I wouldn't be able to handle everything. It's such a huge responsibility and I didn't think I was ready to take full control. Before my transition I did order my prescriptions, take the lead on checking and monitoring INR and other various responsibilities. In the end this fear was pointless. My other fear was about my doctors. That they wouldn't be as lovely as my pediatric doctors. My new doctor, Dr. Keir, is amazing, kind and overall a cool human being that is also a fantastic doctor. I also have Dr. Clegg as my other specialist in adult care. I had her a bit before I was transitioned into adult care so it was wonderful to have still be on my medical team in the adult world.



Leah: One of my biggest fears around my daughter's transition was being shut out. I heard that as soon as kids went into adult care, the parents were in the waiting room without exception. I was worried that my daughter would be on her own and if there was difficult news to hear, she wouldn't have anyone to lean on. It might sound dramatic, but after some of the appointments we had prior to her transition, it was more than concerning. I was also worried that she would think she had to deal with everything on her own; not just the appointments for tests and consults, but also the emotional parts as well.

How did your/child's transition go?

Maddie: My transition was great. It was unexpected due to the fact I was transitioned a bit early. I really love my new nurse and doctor. They allow my parents to come to my appointments with me. The only difference with having my parents in my appointments in adult care is that I make all the final decisions. My parents did struggle with that at first when I had a few treatment options and choose a different path than they would have. The way I had imagined transition in my head was far more scary than it actually is.

Leah: My daughter's transition was surprising. Clearly we knew she would turn 18 and we would need to say goodbye to the amazing medical team we had relied on for so long. But months before her 18th birthday, the appointments for the PLC came in and she was in adult care. The good news for us was that I was still welcome in appointments. I mostly stay quiet, but I also got to weigh in on a pretty significant decision. Of course my daughter went with the opposite of what I thought was best!



What is one piece of advice that you'd give to someone/parent about to transition to adult care?

Maddie: Don't worry would be my advice. Adult care is going to happen no matter what and there is no point of worrying about it. I spent too much time wondering and worrying if I could even take care of my medical needs on my own and it was pointless. I was clearly ready for adult care and the responsibility of taking care of my health but I was too busy worrying to realize that I was ready.

Leah: My advice to you? Start early and help them to learn all the aspects of managing their own care. If there is another parent you know going through this, consider partnering and supporting each other.

Isabelle

I transitioned into adult health care in the spring of 2019. Throughout this process I met many new healthcare providers and began visiting multiple different hospitals for all of my appointments. While this was all confusing, visiting the transition clinic was a helpful first step during these changes. The leaders at the clinic helped me understand what I could expect in adult healthcare and what I needed to know about my own health and experience as a heart patient in order to work with my new doctors as they studied my medical history and decided how they could provide the best care for me. Overall I have had a very good experience in adult care. I have a good understanding of my health because my health care providers speak to me more directly than those at the Children's Hospital could due to my age. I appreciate the way they keep me involved in my health and the decisions being made around it.



SIMPLE CONGENITAL HEART DISEASE

Periodic heart checks should occur. General cardiologists can usually oversee care. One visit to an adult CHD program to verify diagnosis and health status is recommended. Adult CHD care is usually not needed unless new problems arise.

Unrepaired Conditions:

- Isolated small atrial septal defect (ASD)
- Isolated small ventricular septal defect (VSD)
- Mild pulmonic stenosis
- Isolated dextrocardia, no other heart problems

Repaired Conditions:

- Patent ductus arteriosus (PDA)
- Secundum atrial septal defect (ASD)
- Isolated ventricular septal defect (VSD)

Repaired or Unrepaired Conditions:

- Isolated aortic valve disease
- Isolated mitral valve disease
- Isolated patent foramen ovale (PFO)

MODERATELY COMPLEX CONGENITAL HEART DISEASE

These patients should be seen every two years or more frequently at an adult congenital heart program.

Repaired or unrepaired conditions:

- Anomalous left coronary artery from pulmonary artery (ALCAPA)
- Anomalous pulmonary venous drainage (partial or total)
- Atrioventricular (AV) canal/septal defects (partial or complete)
- Ostium primum or sinus venosus ASD
- Coarctation of the aorta
- Ebstein anomaly
- Inundibular right ventricular outflow obstruction (moderate or severe)
- Pulmonary valve regurgitation (moderate or severe)
- Pulmonic valve stenosis (moderate or severe)
- Sinus of Valsalva fistula/aneurysm
- Subvalvar or supravalvar aortic stenosis
- Tetralogy of Fallot
- Ventricular septal defect (VSD) with any valve problems and/or obstructions

HIGHLY COMPLEX CONGENITAL HEART DISEASE

These patients should be seen every year or more frequently at an adult congenital heart program.

Repaired or unrepaired conditions:

- Congenitally corrected transposition of the great arteries (ccTGA or L-TGA)
- Double outlet ventricle
- Mitral atresia
- Pulmonary atresia (all forms)
- Pulmonary arterial hypertension
- Shone syndrome
- Single ventricle - all forms (i.e. double-inlet ventricle, HLHS, HRHS, common/primitive ventricle)
- Transposition of the great arteries (d-TGA)
- Tricuspid atresia
- Truncus arteriosus/hemitruncus
- Other abnormalities of AV connections (i.e., criss-cross heart, isomerism, heterotaxy syndromes)

All patients who have undergone any of the following procedures

- Arterial switch procedure
- Any conduit(s), valved or nonvalved
- Double-switch procedure
- Fontan procedure
- Mustard procedure
- Norwood procedure
- Rastelli procedure
- Senning procedure

All patients with Eisenmenger syndrome

All patients who are cyanotic ("blue")



Information on COVID-19 and CHD

CANADIAN CONGENITAL HEART ALLIANCE

Since last March when the World Health Organization declared COVID-19 a global pandemic the world has changed. We are all dealing with emotions such as fear and anxiety due to the uncertainty around the future with COVID-19.

Along with the chaos that we have felt there has been a ton of misinformation about COVID-19. Add on the stress of living with CHD and their increased risk of serious complications from COVID-19.

The Canadian Congenital Heart Alliance has created a CHD and COVID-19 tips infographic. The infographic was developed with the help of other Canadian heart organizations to support people living with congenital heart disease by providing information on how to manage their health and how to stay safe during the pandemic.

The information below has been prepared for adults and children along with their families living with CHD and is based on information provided by Pacific Adult Congenital Heart clinic and other CHD partners. Please note that this is an evolving public health situation the following information may change over time.

All persons living with CHD and their family members need to take precautions while they are isolating during the pandemic?

Please follow the advice of public health officials (and keep up to date as this may change throughout the pandemic):

- Stay at home
- Wash your hands regularly with soap and water
- Don't touch your face with your hands
- Cough or sneeze into the crease of your elbow
- Keep a social distance of two meters (6 feet) from other people when shopping, out for a walk, etc.

TIPS FOR PEOPLE LIVING WITH CONGENITAL HEART DISEASE TO MANAGE YOUR HEALTH DURING THE COVID-19 PANDEMIC

We are still learning how COVID-19 affects people. Some children and adults living with congenital heart disease (CHD) may be at higher risk for more severe symptoms and complications due to COVID-19, specifically those living with the following conditions¹:

- Complex defects
 - e.g. single ventricle, cyanotic heart defects and double-outlet ventricle
- Significant valvular disease (e.g. severely leaky valve)
- Low oxygen levels or being blue (chronic cyanosis)
- Heart failure or reduced heart strength (cardiomyopathy)
- High blood pressure in the lungs (pulmonary hypertension)
- Other health conditions
 - e.g. chronic kidney disease, diabetes, or chronic lung disease
- Heart transplantation or recent heart surgery
- Heart rhythm problems (arrhythmias)

¹Tan W, Aboulhoss J. Int J Cardiol. March 2020.

Visit our partner websites for more information and support

We are still learning how COVID-19 affects people. Some children and adults living with congenital heart disease (CHD) may be at higher risk for more severe symptoms and complications due to COVID-19. We have prepared some tips for managing your health during this challenging time:



Continue medications

Continue all regular medications unless your doctor tells you otherwise. Keep your medication supply current and ask if your pharmacy offers home delivery.



Ask about virtual care

If an upcoming appointment, test or surgery can be safely postponed, your doctor will confirm that with you. For care that is deemed necessary, ask your health team about the safest way to do so, be it in person, or via phone or video.



Stay connected and supported

Stay connected with family and friends for support. Join an online community like [Heart & Stroke](#), [Braveheart Support Society](#) or [Fondation En Coeur](#) to find support from people in similar health situations.



Contact your health team

If any symptoms of your condition worsen, or if new symptoms develop, contact your health team to discuss. If you develop COVID-19 symptoms, immediately self isolate and then contact your health team to discuss.



Practice distancing and hygiene

Follow the guidelines from the [Public Health Agency of Canada](#) and your public health authority to reduce your risk of contracting COVID-19.



An emergency is always an emergency

Dial 9-1-1 immediately if you become blue or breathless, or are experiencing signs of heart attack or stroke.

Visit our partner websites for more information and support



10 Spring 2021

Poster created by



In Partnership with



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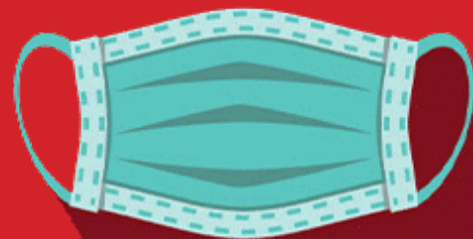
Who is at risk of getting COVID-19 infections?

- Most patients with CHD will have the same risk as the general population
- Patients with more complex heart conditions may have more complications if they get a COVID-19 infection. These are patients with:
 - Complex defects including but not limited to
 - single ventricle (including Fontan) or one heart pump
 - double-outlet ventricle
- Congenitally Corrected Transposition of the Great Arteries (CCTGA)
- Transposition of the Great Arteries who have had a Mustard or Senning surgical procedure
- Individuals who have a right ventricle to pulmonary artery conduit (RV to PA conduits)
- High blood pressure in the lungs (e.g. Pulmonary hypertension or Eisenmenger syndrome)
- Cyanotic heart disease (low oxygen saturations or being blue)
- Significant valvular disease (e.g. severely leaky valve)
- Significant arrhythmia (heart rhythm conditions) associated with CHD
- Heart failure or reduced heart strength associated with CHD
- Heart transplantation or recent heart surgery
- Heritable Aortopathies (for example, Marfan's Syndrome, Loeys Dietz Syndrome, Familial Thoracic Aortic Aneurysms) with significant heart valve and/or lung issues
- Those who have CHD and other health conditions such as diabetes, severe kidney failure, lung disease, a compromised immune system (including immunosuppression or active/recent cancer treatment)

If you have a CHD that is at higher risk for complications as described:

- Stay at home, except to attend necessary medical appointments
- Request that someone else do the shopping or shop online or do home delivery
- **Consider pharmacy home delivery for your prescriptions**

MASK REQUIRED



Questions about CHD and Covid-19

As governments begin to talk about lifting restrictions and gradual reopening of the economy many of you have questions and requests for information related to the COVID 19 pandemic and the impact on those living with congenital heart disease (CHD).

If you think you might have COVID-19?

If you are feeling unwell or have any of the following symptoms: fever, cough and or difficulty breathing, and feel that your symptoms are significant, please seek out medical attention either through your primary care provider or an urgent primary care centre. If you have mild symptoms, have traveled outside of Canada within the last 14 days, or have been in contact with a person with probable or confirmed COVID-19, we urge you to self-isolate, monitor for symptoms and call 811 or contact your Primary care provider or an urgent primary care centre for more information if required.

Should individuals with CHD go to work?

- Individuals at high risk of complications from COVID-19 (as described above), and who work in a public setting (health care, service industries) should contact the PACH clinic to review their restrictions and we will support a letter for the workplace should you meet criteria for being at high risk of complications.
- Individuals with CHD who are not at high risk of complications from COVID-19 (as described above) are subject to the same recommendations as the general population and must follow workplace, government and public health recommendations.

Should patients get INR levels checked to monitor their warfarin?

- For patients who require regular blood sampling for warfarin monitoring, please continue to get this done.
- We request that you make an appointment at the lab (versus dropping in) and maintain the 6 feet or 2 metre social distance with others in lineups and waiting rooms.


What if I am pregnant?

If you are currently pregnant, your follow-up will be assessed and you will be contacted by your CHD healthcare team about your appointment.

What if I have an upcoming clinic appointment/follow up scheduled?

- Since March, most provincial health authorities moved all hospitals to Outbreak Response Phase 2. This means hospitals will undertake only urgent and emergency procedures/surgeries and will postpone all non-urgent scheduled procedures/surgeries. This is to keep you, the staff and communities safe.
- Most paediatric and adults CHD clinics are converting many patient clinic visits to telephone appointments and cancelling testing. If you have an appointment booked in upcoming months, they will contact. Some patients who will require cardiac testing and in-person cardiology appointments – they will contact you to let you know if you are one of those patients
- If you had a cardiac surgery or a procedure that was cancelled due to the COVID-19 pandemic, your clinic will contact you to arrange rescheduling.





A letter to the mom who's child was just diagnosed: it's okay to grieve.

Dear Mama,

I know it has been a long and tough road and yet you are only at the beginning. There has been sleepless nights, never ending days, endless google searches, and too many tears. Ever since the first thought of there being something "different" about your child, you have not been at peace. You have wondered what, why, and how. You have blamed yourself for not remembering your prenatal vitamin everyday, or for that one time you caved and ate unpasteurized cheese during your pregnancy. You have scolded yourself for not recognizing what was going on sooner, or not pushing the doctors to look harder. And then all at once you have quickly forced yourself into acceptance and bravery. You know your husband does not understand half of the medical terms being tossed around, and your mother is beside herself with worry for your child so you have to be there to support them. Speaking of your child, how can you show them anything but bravery and acceptance? This is their life after all and they are so young and innocent. This diagnosis changes things, possibly everything. You have to keep it all together, the dishes, laundry, making meals, signing field trip forms, blood tests, specialist appointments, the list only gets longer. You make all the calls, telling family and friends the same information over and over, always answering "I'm fine" if they ask how you are handling things.

But Mama, you are not fine and that's okay. You are allowed to feel the roller coaster of emotions this diagnosis came with. You are allowed to be angry and blame the universe if that gets you through the day. You are allowed to be afraid for every single worst case scenario that could come your way. You are allowed to laugh at things that are completely inappropriate at the time. You are allowed to eat every piece of chocolate you can get your hands on. You are allowed to ugly cry into a pillow. Your life just changed in a big way too. And tomorrow or two weeks from now you will get up and continue on with the bravery and acceptance because you are a great mom. But until then feel all the feelings, let yourself go through the healing process. It's okay to grieve.

Sincerely,

A mama who's been there.

By Melissa Gagy @ happinessblind.com

happinessblind.com/2019/12/05/a-letter-to-the-mom-whos-child-just-received-a-diagnosis/

Maria's Heart Book

When Maria Bergman was 5 years old, she underwent heart surgery in Edmonton. Maria's parents had a difficult time finding a book that was age appropriate to help her overcome her fear of her surgery. To help Maria cope with her feelings, her mother, a Child Psychologist, suggested that Maria write her own book about the experience. The result is a book written from the point of view of a 5-year-old. It is beautifully illustrated and would be appropriate for any child under 10 years of age who is about to undergo heart surgery. The book is available for purchase on Amazon.



Spotlight on Celebrity CHD

Did you know that Miley Cyrus suffers from Tachycardia? It's a condition where the heart beats >100 times per minute. It is generally said that when the tachycardia is being observed without any underlying reason then the person should consult their physician.



CAMP DEL CORAZON

A non-profit organization providing year-round opportunities for children with heart disease

Camp del Corazon is a non-profit corporation that provides a medically supervised residential summer camp for children ages 7-17 who are living with heart disease. Located on Catalina Island, 22 miles off the California coastline, Camp del Corazon has served approximately 300 children each year since 1995.

The cost of the Camp is free to attend. Heart Beats has a fund that will cover the cost of airfare for all eligible first-time campers and offset the airfare cost for repeat campers. Please reach out to us at info@heartbeats.ca to learn more.

Registration is now open for in-person or virtual camp.
Sign up at www.campdelcorazon.org/camp

CAMP DEL CORAZON



Spring 2021

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.



Rukia and Orihime 11 birthday's on February 11 and also their little heart healthy little sister who turned 8 on February 8 and as always amazed and surprised that all their birthdays are in heart week.



Heart Warrior Aurora is turning 4 in April. Her mom can't believe how time flies. She happily attends Renfrew preschool and is loving life.



Jokes from Dal

our trusty Pediatric Echocardiography Instructor

- What do you call a snail on a ship?
A Snailor.
- Why do monkeys play golf?
To practice their swing.
- What do you call a bear with no teeth?
A gummy bear.



Heart Beats
Children's Society of Calgary

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- Vice-Chairperson** Tara Exall
- Treasurer** Golden Bhatia
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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.



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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 in Canada. 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 cardiac 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 February 7-14, 2021 as:

“CONGENITAL HEART DISEASE AWARENESS WEEK”

NAHEED K. NENSHI
MAYOR

