



Keeping the Beat

Fall 2018

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

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HEART BEATS



FAMILYCAMP



2018

On the weekend of September 7-10, the Heart Beats community came together at Camp Evergreen in Sundre, Alberta. The weekend was filled with some amazing activities, campfire songs and a glow-in-the-dark Pac-Man adventure put on by some of the heart dads. The weather was perfect, the accommodations were warm and cozy and the meals and snacks were delicious. The attendance this year was 114 including several new campers who everyone enjoyed meeting and getting to know. Heart Beats extends a big thank you to the Calgary Children's Foundation and CP Rail for their generous support of our Family Camp.



Photo Credit: Ramsey Kunkel



What's been happening in the world of **HEART BEATS**

Heart Beats Day at the Lake

On Sunday, July 15th, ten families gathered at Midnapore Lake for Heart Beats' annual Lake Day. The young heart kids and their siblings enjoyed playing together in the sand and water, and their parents enjoyed visiting with one another. For two families it was their first time attending a Heart Beats event and we so enjoyed meeting and getting to know them.

Heart Beats events are great opportunities to connect with other heart families who understand the CHD journey, and they often lead to life-long friendships among parents and heart kids. All children and youth with CHDs, and their families, are welcome to attend any of our family events!



Meet the Heart Beats Board Members

The Board of Directors are volunteers from various backgrounds who became involved with Heart Beats through personal (or professional) experiences with congenital heart defects. Most board members are parents of children in the heart community with a variety of different congenital heart defects and ranging in age from babies to adults; this allows for Heart Beats' initiatives to support families and children right from initial diagnosis to the time they are ready to transition to the adult clinic.

We are always looking for new volunteers to help carry out the many Heart Beats initiatives. If you would like to give back and help create more opportunities and programs to support heart families, please email info@heartbeats.ca for more information.



Upcoming Events

Dates and times are subject to change, so please check your email for monthly updates. If you would like to receive information about upcoming events, please email our Communications Director at info@heartbeats.ca.

Annual Family Fun Run

Heart Beats will be holding its 9th Annual Family Fun Run on Sunday, October 14th. As in prior years, the race will begin at Eau Claire Market and follow the running paths along the Bow River. There will be a 10km Run, a 5km Run or Walk, and a 1km Children's Race. You can sign up by clicking FAMILY FUN RUN on our website at www.heartbeats.ca or at www.runningroom.com. Don't miss this opportunity to take part in our biggest fundraiser of the year! Form a team and collect sponsors! There are prizes for the top fundraisers. All funds raised go directly to helping families with congenital heart disease in Calgary and Southern Alberta. For more information about the race or to volunteer on race day, please contact our run coordinator, Jorge Castillo, at run@heartbeats.ca

REGISTER NOW FOR THE RUN

Please visit www.runningroom.com to register

Once arriving on the page use the search bar located on the top right hand corner to search Heart beats and select run



Offbeats is for junior high and senior high aged youth with CHDs. Led by Offbeats alumni Vittorio, Meghan, Sam and Daniel, Offbeats organizes fun activities throughout the school year. If you are interested in joining in on the fun, email offbeats@heartbeats.ca to receive notices about upcoming events!



Moms' Night Out & Dads' Night Out

Moms' & Dads' Night Out meet several times throughout the year. Whether your heart child is an infant, teen or adult, we welcome you to visit and chat with other moms and dads about parenting kids with CHD or just to take a break with people that understand. Grandparents are welcome too! An appetizer or dessert and a non-alcoholic beverage is covered by Heart Beats. The group will meet on various dates and locations around Calgary, so please check your monthly email for upcoming events.

Christmas Party



Make memories and meet Santa! Heart Beats will be hosting its annual Christmas Party on November 24th, 2018 between 1:00 p.m. and 3:30 p.m. The event will take place at the Silver Springs Community Centre located at 5720 Silver Ridge Drive NW and will feature crafts, refreshments and special visit from Santa who will be distributing presents to all children under 17. If you would like to attend, please RSVP to RSVP@heartbeats.ca no later than November 10th. Please include the names of each person attending, the ages of the children in your family and a gift idea in the \$20 range for each child under 12 (teens will receive a gift card).

HO HO HO

HOPE TO SEE YOU THERE!

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.



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.

Mail

Heart Beats Children's Society of Calgary
Box 30233, Chinook Postal Outlet
Calgary, AB T2H 2V9

E-transfer

to our Heart Beats Treasurer at
pattyw@heartbeats.ca (remember to include your mailing address to receive the receipt).

Credit Card

through CanadaHelps.org
(a link can be found on our website at www.heartbeats.ca)

Donations received from May through August 2018

Thank You

Scott Bissell
Philip Churton
In Memory Of Marilyn Kay Murphy
Ron Davison
Maxwell Degroat
Denny Deren
Dave Evans
Daniela Gandarillas
In Memory Of Isabella Bonan
Phil Hodge
Cathy Howarth

Jeremy Joly
In Memory Of Callen Spooner
Katherine Leigh-Smith
Jeff Malinowski
In Memory Of Marilyn Kay Murphy
Kay Price
In Honour Of Aliyah Badrudin
Daniel Rossiter
Fred Rumak
Marcel Savoie
Heidi Smethurst

ATCO Structures & Logistics
Calgary Children's Foundation
Rainer EXALL
through the Benevity Community Impact Fund
Clayton HAYES
through the Benevity Community Impact Fund
Brad HEIDT
through United Way of Calgary
Suzana Petronic
through United Way of Greater Toronto

SPOTLIGHT ON DONATION

Yahoo!

A great big Stampede thank you to Animus Capital Partners and J. Vair Anderson Jewellers!

On July 6, 2018, Brett Stevenson and Mathew August, Managing Directors of Animus Capital Partners, threw their 2nd annual Stampede Kick-Off Party and raised money for Heart Beats at the event. Brett's cousin, Lauren Exall, was born with a congenital heart defect and her family are active in the Heart Beats community. Thanks to Annette Toro of J. Vair Anderson Jewellers and her generous donation of an Omega Speedmaster Moon Watch and a lady's necklace to be auctioned at the event, \$6,250 was raised! This money will assist Heart Beats in providing financial support for families traveling to Edmonton for heart procedures, scholarships for kids to attend a specialized heart camp in California, and programs which give heart families opportunities to connect with other families who are dealing with similar circumstances.

This is not the first time that Animus Capital Partners has supported Heart Beats. They have also been sponsors of the annual Heart Beats Family Run. Thank you from the bottom of our hearts!



Spotlight on Donation: CP HAS HEART

On June 12th, CP Rail held their inaugural Supplier Golf Tournament at the Elbow Springs Golf Club and selected Heart Beats to be the recipient of funds raised through the tournament. Heart Beats members volunteered at the tournament, and Bernadette Foulonneau shared her family's story of having a child with CHD and how Heart Beats has been a support for them. (See page 6 to read her story.) At the end of the evening, Heart Beats' Executive were overwhelmed to be presented with a cheque for \$100,000!

"CP and its community of supply partners are honored to make this donation to Heart Beats Children's Society of Calgary," said Chad Rolstad, CP's Assistant Vice-President of Procurement. "Having worked with Heart Beats in the past, we really felt strongly they were the perfect charitable partner for this tournament. Through the generosity of the golfers and our supply partners, we are extremely proud to have helped raise \$100,000 for this great cause."

Through its CP Has Heart community investment program, CP is committed to improving the heart health of men, women and children across North America. Whenever possible, CP includes a charitable partner for many of their corporate sponsorships and events. Since 2014, CP has committed over \$12 million to heart health research, equipment and care through the CP Has Heart program.



Thank You

CP

The Following Speech was presented by Bernadette Foulonneau at the CP Rail golf tournament.



“I can’t even imagine.”

Those are the words I heard and hear so often when people hear about my daughter Marie.

When I was 19 weeks along with my second daughter we found out she had hypoplastic left heart syndrome or HLHS. She only had half a heart as the left side of her heart had not grown and would not be able to deliver oxygen rich blood to her body. My world came crashing down when the doctor walked in the room and said those words. She was surprised I knew what they meant – I told her I was a nurse at the Children’s hospital in cardiology. The only cases I really knew had fatal outcomes. I felt my baby had been given a terminal diagnosis before she could take her first breath. My husband and I were completely devastated.

Our happy life felt like it

was falling apart.

I couldn’t imagine living in the hospital with my newborn then handing her over to a surgeon, instead of cuddling at home.

I imagined the endless procedures.

I imagined the painful needle pokes.

I imagined her pain.

I imagined her suffering.

I imagined her cries.

Thinking about all of this – broke me.

Almost immediately after this terrifying diagnosis we were put in contact with Heart Beats. We were warmly welcomed and put in contact with families who had a child or teenager with HLHS. We were given such hope when we saw how kids with heart defects were able to live, grow, play and thrive with their families. To witness firsthand the miracles these families were going through gave

us hope and strength to get us through a very stressful pregnancy where so much was unknown. We were able to reach out and talk to other parents and develop friendships, during Moms’ and Dads’ Nights Out. It was a lifesaver for us. Heart Beats opened a door to so much love and support.

We had to relocate to Edmonton for Marie’s birth, where all the surgeons, specialists and facilities are. We planned with our doctors to be there about two weeks before she was due. My husband, daughter and I traveled to Edmonton and stayed at the Ronald McDonald house during this time. Heart Beats provided us with gift cards for gas, groceries and Tim Hortons (for when we needed a break from the hospital). It was such a help to have these gift cards and helped put us at ease for our journey. It helped us be 100% focused on the health issues and less on money issues which are really the last things you want to think about in these difficult situations.

Marie Eloise was born on April 1st 2015 at 07:15 in the morning. She was born ten days early and caught us somewhat off guard with her slightly early arrival. We guessed she didn’t want to miss out on April Fools. She spent the first few days of her life in the NICU unit at the Stollery, where we spent as much

time as humanly possible with her. We wanted to create as many memories as possible. When she was just five days old she had her first open heart surgery out of the three required to “fix” her heart. When she came back from the OR that day we nearly lost her in front of our eyes.

What followed were several weeks of recovery in hospital, then mercifully recovery at home. We knew we were so incredibly lucky. We felt so blessed to have this beautiful little miracle. She woke up every day smiling and laughing despite so many challenges. She was a delight.

After four months of enjoying life at home with several hospital appointments, the time came to plan for the second surgery. For this we made another trip to Edmonton for a cardiac catheter to ensure she was ready for the surgery. For this trip to Edmonton we were not able to secure a room at the Ronald McDonald house and Heart Beats was able to help us with the cost of the hotel. Not having to stress about our accommodation was such an enormous gift and helped us again to fully focus on helping our daughter recover from her cardiac procedure.

Marie had her second open heart surgery on September 2nd 2015 - she was 5 months old. We were prepared for the worst but

the surgery went well and she recovered quickly. So fast that before we knew it we were driving back home with our daughter.

Unfortunately after the second surgery Marie developed a condition called a chylothorax, where lymph fluid filled the space around her lung. This is a known complication from the heart surgeries. She was admitted emergently to the pediatric ICU after only 15 days at home - she stayed in the ICU at the Alberta Children's hospital and then the Stollery in Edmonton for three months total. During those long months we were visited by several of our friends from Heart Beats. They would often drop by with coffee or other lovely treats and would chat and keep up our spirits. Those visits helped us pull through some dark times.

It's not always easy to speak during these difficult moments. You don't always have the strength to explain what's happening or to relive what happened during the day. Therefore it is definitely important to talk with other heart families that have gone through similar situations.

Marie eventually recovered enough to return home and to continue her journey. Last year she became a big sister

- to her great delight.

Early this year she had her third surgery in Edmonton. This surgery, called the Fontan, completed the reconfiguration of her blood circulation. The surgery went well but there were



still a few complications. We still managed to find the strength to go through all of them and to bring her home where she belongs. Today she's finally off oxygen, fully recovered from the surgery and playing lots with her two sisters.

Whether it's their Christmas parties, Family Camp or Mom and Dad Nights Out, Heart Beats provides us with such an amazing place to share our experiences, without fear of judgment. It allows us to be vulnerable but also to draw strength. We are able to share strategies to keep our little ones healthy

and happy.

Last September at the Heart Beats Family Camp our three daughters were able to enjoy some quality time together and also with new friends they made through Heart Beats. It was

wonderful to be able to see all of the heart kids and their sibling playing together and just being "normal kids". We were able to connect with other families who were in a similar situation - there was no need for explanations; Heart Beats families simply understood because of our shared experience. It was liberating, comforting and empowering.

This is the most important thing about Heart Beats. We are all free to just be ourselves, be free to play, to discuss and share - without judgment, without horrifying or scaring people

around us. No need to filter the information or to explain medical terminologies. All parents want is to be understood - heart parents are no different. Parents of medically fragile children need a safe place as so much of our experience is rooted in trauma; having a safe place is critical to being able to support our own kids. This is why having a supportive community around you is so crucial.

Heart Beats has taught us to acknowledge the people in our community, and give. Give our time and energy to help encourage those around us who might be dealing with their child's hardships. Give our support to friends in need. Give our love to a struggling parent or child.

Heart Beats helped put our broken hearts back together - and gave us strength.

Many people I meet tell me they can't imagine having a child as ill as Marie - but I can't imagine my life without her.

Importantly - I can't imagine our daughter's heart journey without the love, kindness, support of Heart Beats.

Thank you everyone. Thank you Heart Beats.



Thank you to the Foulonneau's for sharing your Heart Beats Journey

Do you know about the Family Room at the Stollery Hospital?

It offers a quiet environment with a place to relax, take care of personal business and learn more about childhood diseases and conditions and community resources. The Family Room is dedicated to helping families find the information and resources they need to understand their child's medical conditions and take part in their care.

Resources and services offered at the Family Room include:

- books, newspapers and magazines
- pamphlets and websites about diseases and conditions
- community support services and local events and information
- a phone for making local calls
- computers with Internet access.
(Wi-Fi access for families and children who are inpatients at the Stollery)
- small play area for children
- a fish tank
- photocopier and fax machine
- comfortable sitting area with couches & chairs in which to relax & recharge
- Meals that Mend Frozen Edition



The mission of the Family Room is to support families before, during and after their hospital experience by building capacity in families, health professionals and hospital staff for informed, collaborative decision-making and care of the pediatric patient.

WHERE CAN YOU FIND IT??? Room 4H2.02, Walter Mackenzie Centre

Heart Beats and Social Media

Find us on Facebook... and Twitter



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.



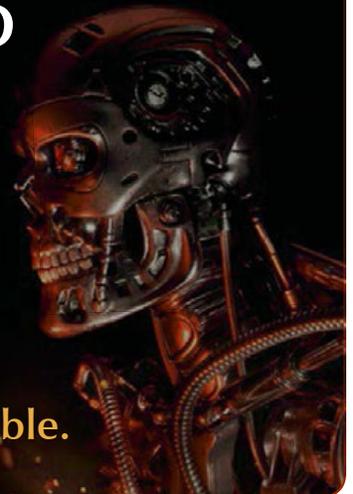
Heart Beats is on Twitter! Staying on top of community news and upcoming events has never been easier. Simply follow our tweets at: twitter.com/HeartBeatsChild.



Spotlight on Celebrity CHD Arnold Schwarzenegger

Look at everything he has achieved, he recently just had his pulmonary valve replaced via Catheter. He also has had open heart surgery years ago on his bicuspid aortic valve.

Thanks Arnie for showing us what's possible.



MEDICAL BINDER APP

In 2017, the 22q Foundation Australia & NZ began development of a 22q patient coordination web portal and App. The App allows families and patients with 22q to co-ordinate and have access to their our own records, reports and care via an online digital portal.

Did you know this App can also be utilized for all types of Medical children including Heart Kids?

The App will allow families and patients to have all their records, appointments, treatments centres, physicians or therapists list, medication list and assessment reminders with them wherever they are without carrying large binders.

The App allows the user to :

Set up a personal profile for yourself and your loved ones

Tick off the assessment checklist and receive annual reminders for the recommended assessments due each year (The Assessment Checklist was formulated and published in the Practical Guidelines for Managing Patients with 22q11.2 Deletion Syndrome.) This is not mandatory if not required

Create a list of emergency contacts

Create a list of medications with dosage and reminder (it also allows you to keep a history of your medications)

Set up a list of care, medical and treatment centres including physicians , therapists or anyone who works with you or your 22q person and includes Google Maps

Store a list of your immunization records

Create a list of appointments, meetings, events etc... and be reminded via notifications

Create a list of symptoms and allergies including treatment, severity and the ability to upload photos, reports and files

Create a list of surgeries, treatments and helpful information

Send the personal medical profile including reports or files directly from the portal and App to any person via email

Join the 22q community directory and connect with people near you (optional)

Join the 22q Registry and be a part of research (optional) (Privacy Policy Applies)



This is an example of the medical report that can be emailed to yourself or anyone you wish to send it to....



Medical profile for Charlotte KAMPER generated on 08/18/2018 12:32 AM

Name: Charlotte KAMPER
Age: 19
DOB: 01/09/1999
Gender: Female

Address: 2507 Lagoon Road
Phone: 404502561
Email: mmkamper@westnet.com.au
Key Information: CRN: 2805851847 TFN 389431062 Diagnosed with 22q11.2 Deletion Syndrome 10th May 2004 - Dr Patricia McViegh Documents attached

Name	Phone	Email	Relationship
Megan Fookes	0418452940	director@fabry.com.au	Friend
Mark Kamper	0438265106	Kamperadventures@westnet.com.au	Father
Marla Kamper	0404302561	mmkamper@westnet.com.au	Mother

Name	Dosage	Frequency	Reason
Fluoxetine	3	Daily	Anxiety & OCD
Eutroxig	50	Daily	Thyroid

Medication Notes
 Eutroxig: 75 MG Tuesday and Thursday

Physician Name	Contact Number	Specialities	Location
Stacey Callen	02 6330 0984	Disability Employment	Verto
Dr Roshan Aamee	63325055	NP	George Street Medical Centre
David Fitzsimons	0298450000	Speech Language Pathologists	Westmead Childrens Hospital
Dr Linda Campbell	0423977064	Clinical Psychologist	The Find Lab
Dr Michae	63325355	hearing	George Street Medical Centre
Jessica Kennelly	02 6393 0500	hearing	Australian Hearing

Physician Notes
 Stacey Callen : Casey

Jessica Kennelly: assisted devices connect to tv , to computer, phone , camps for hearing impairments

Description	Date
A combined injection for diphtheria, tetanus, whooping cough (pertussis)	03/05/2013
HPV (human papillomavirus) (2 doses)	03/05/2013
pneumococcal	09/01/2004
diphtheria, tetanus, whooping cough (pertussis), polio	02/25/0007
diphtheria, tetanus, whooping cough (pertussis)	03/01/2001
measles, mumps, rubella, chickenpox (varicella)	03/01/2001
Haemophilus influenzae type b (Hib)	09/01/2000
measles, mumps, rubella	09/01/2000
Oral drops for rotavirus	11/03/1999
pneumococcal	11/03/1999
A combined injection for diphtheria, tetanus, whooping cough (pertussis), hepatitis B, polio, Hib (Haemophilus influenzae type b)	11/03/1999
An injection for hepatitis B	09/01/1999

Immunisation Record Notes

Symptoms and Allergies	Reaction	Severity
Small Left Superior Vena Carvia Draining into Coronary Sinus		mild
Hypercholesterolaemia		mild
Laryngeal web (anterior)	If this separation does not occur and a web of tissue is left across the laryngeal inlet it is called a laryngeal web or glottic web	moderate
Learning disabilities (math concept, reading comprehension)		moderate
Obsessive compulsive disorder		moderate
Social immaturity		moderate
Hypothyroidism	Too little thyroid hormone. Symptoms include weight gain, constipation, dry skin, and sensitivity to the cold. Also called underactive thyroid.	moderate
Narrow external ear canals	In most cases, blockage of the ear canal with wax is a harmless event.	moderate
Scoliosis		moderate

Medical profile for Charlotte KAMPER generated on 08/18/2018 12:32 AM

Symptom or Allergen	Reaction	Severity
Impulsiveness		moderate
Mild conductive hearing loss	Conductive hearing loss usually involves a reduction in sound level, or the ability to hear faint sounds.	moderate
Narrow external ear canals	In most cases, blockage of the ear canal with wax is a harmless event.	moderate
Frequent otitis media	Otitis media is an infection or inflammation of the middle ear.	moderate
Overfolded helix	The helix is the curled ridge made of cartilage on the outer edge of the ear	moderate
Overt, submucous or occult submucous cleft palate	The condition described as submucous cleft palate is when the palate appears to be structurally intact, but there are bony and/or muscular abnormalities underlying the skin's surface	mild

Allergy Notes
 Hypercholesterolaemia: Diagnosed May 2004

Preferred Care Centres	Name	Address	Contact Number
Verto		227 Howick St, Bathurst NSW, Australia	02 6330 0984
Ochre Medical Centre		1470 Panorama Avenue, Bathurst, NSW, 2795, Australia	(02) 6331 9444
Macquarie Park Medical Centre		2 Technology Place, Macquarie Park, New South Wales, 2109, Australia	(02) 9812 3966
Australian Hearing		122 Kite St, Orange, NSW, 2800, Australia	(02) 6393 0500
The Find Lab		The Boulevard, Durimbah, New South Wales, Australia	0423977064
Westmead Childrens Hospital		170 Hawkesbury Road, Westmead, New South Wales, Australia	0298450000
Bathurst Base Hospital		361 Howick Street, Bathurst, New South Wales, Australia	0263305311
George Street Medical Centre		115 George Street, Bathurst, New South Wales, Australia	63325355

Preferred Care Centre Notes
 Ochre Medical Centre: Dr Ross Wilson

It's time to thank some of the most important people, our cardiac clinic nurses at Alberta Children's Hospital.

We rely on them so much and can't thank them enough for everything they do for our kids. In case you haven't met them all, here's a little interview with each of them.



Patty Knox



What made you want to become a nurse?

When I was a little girl I always dreamed of being a waitress. I couldn't wait to happily take orders, deliver delicious food and if all went well I would be gifted with a fine tip. Obviously, the need to serve people started at a very young age, but unfortunately the gifting of money thing never really panned out! In all seriousness, becoming a nurse really did come from an innate desire to help, care for & comfort others. Nursing was a natural fit to fulfill that desire. My love of children & family lead me into Pediatric nursing & I have never regretted it.

How did you end up working in the Cardiology Clinic at ACH?

Prior to working in the Cardiology Clinic I was working as a staff nurse in the PICU at ACH. Although I loved my job, I was also ready for a change. As luck would have it, there was a posting for a temporary nurse clinician position in the Cardiology clinic. The current nurse had adopted a baby and would take a year off to enjoy her new bundle of joy. Fortunately for me I was the successful candidate! The following year challenged me in many ways, especially my knowledge & understanding of heart disease, but I loved it. Again, fortunately for me, the nurse I had replaced decided not to come back and I was the successful candidate for the second time for the permanent position. Eighteen plus years later and I am still doing what I feel I was meant to do.

What/Where would we find you in your personal time outside of the Clinic?

Probably at the gym or in a row, spin or yoga class. I love to be physically active and to try new things that challenge me physically (hopefully not embarrassing myself while doing it)! You might also find me with my nose in book, trying out a new recipe or just hanging out with my beautiful family.

Advice and Tips for parents of your patients (or patients themselves)?

1. First and foremost to "trust your gut" if you feel something is wrong you are probably right
2. No question is a silly question
3. Knowledge is power but avoid "internet overload" stick to reputable websites
4. This is one of my favorite quotes:

"Just as man cannot live without dreams, he cannot live without hope. If dreams reflect the past, hope summons the future." Elie Wiesel

Kelly Webber



What made you want to become a nurse?

I was born with a type of congenital heart disease called Tetralogy of Fallot. Back when I was a child surgery for this particular condition took place later in life (I was 10) than it is now. Whenever I needed to be admitted to the hospital it was always at an adult based hospital on the cardiac ward. So there I was a little kid admitted with seniors as my roommates and my parents weren't allowed to stay the night.

It was the nurses who would comfort me and entertain me. They would let me play nurse and help them however I could and they would sneak me treats after hours. I always looked up to them and couldn't wait till I could be a nurse and hopefully comfort kids when they were scared and sick.

How did you end up working in the Cardiology Clinic at ACH?

When I graduated from Nursing I immediately got a job as a casual nurse at ACH. I mainly worked on N Cluster (now known as Unit 2) and eventually got a position on that unit. The patient population admitted to N Cluster included cardiac patients. One day there was a casual position available in Cardiology, which Patty interviewed me for. Eventually I ended up getting a position in Cardiology and went casual on the unit.

What/Where would we find you in your personal time outside of the Clinic?

When not at work you will usually find me driving my daughter to one of her activities. When I have free time I love to go for bike rides, hiking or meeting up with friends for dinner or games night. Once a month a group of us girls get together to try new activities. This year we tried ax throwing, glass blowing and bungee workouts.

Advice and Tips for parents of your patients (or patients themselves)?

My advice is to both parents and the youth. This comes more from my experience as a congenital heart patient then as a nurse. It is human nature for parents to worry about and want to protect their child, especially if they have some form of CHD. The youth will want to try new things, perhaps take up a new sport, activity or hobby, but they might be too scared thinking it isn't safe for them to do. Never assume. Call the cardiologist. Have a conversation and see what, if any, limitations there are. Never limit yourself!

Norma Becker



What made you want to become a nurse?

Growing up I always pictured myself as a nurse because of the influence of my own hospital experience as a very young child, with frequent asthma episodes. In the 'old days' we didn't have puffers, so I was treated with lots of mists and masks and placed in tents, for days and days. There was no 'family centered care', so my family could only visit during the afternoons. I mostly remember the kind and caring nurses who looked after me, and a particular few that still have a special place in my heart. I also had two aunts who were nurses, and I thought their careers sounded interesting. In junior high, I discovered my love for children, and from then onwards, I knew I wanted to work with this population somehow.

How did you end up working in the Cardiology Clinic at ACH?

After graduating from nursing in New Brunswick, I moved across country with some nursing friends, and worked at the children's hospital in Vancouver, in the cardiac ward. I worked at BCCH for many years in the in-patient unit, and then the out-patient clinic, before moving to Alberta. I started at ACH in 2005, working part time in the clinic, soon after with a young family of two daughters. I love Pediatric Cardiology, and the many amazing families I have had the pleasure of working with, over the years, through 'thick and thin'.

What/Where would we find you in your personal time outside of clinic?

As an older mom, I've been lucky to do some fun travelling before our kids arrived. So these days, we spend most of our spare time doing typical family things, hanging out in Calgary or visiting Central Alberta with extended family.

Advice and Tips for parents of your patients/or patients themselves?

For parents: believe that you know your child best. Despite all the various professionals involved, you are often the best advocate and the most important member of the team. Enjoy your children, and treat them as normal in every way possible. For young people – lots of fun experiences and challenges in life to face, and sometimes it's difficult to know who you can chat to or ask questions. Always know we are on your team, we are always open to any question or information you want to chat about. To parents and youth: Nurses are a great place to start, with any questions or concerns, we are always open to meeting with you, or chatting on the phone, and can connect with your Cardiologist readily as needed.

*See you again
soon in the clinic!*

Kiitos! Grazie!

Obrigado!

Bedankt!

Díky!

Danke!

Tack!

Thank
you!

Dzięk!

Tak!

Merci!

Gracias!

Novus



WCCHN Update



Home Center Survey

Our Nursing Coordinators committee have created a "Home Site Survey" that is set to be distributed within the month.

The overall objectives and goals of the survey is to understand if the care received at the referral centres (Winnipeg, Saskatoon and Calgary) meets the expectations and needs of the family. The survey helps us to understand how the family feels about the care they receive from initial assessment and diagnosis to treatment and follow up at the referral centres.

We hope to also assess pre-operative teaching and provision of appropriate supports from allied health care professionals (financial resource help, psychosocial help etc). Furthermore we hope to assess if the education and support materials were helpful to the families. Another important factor that the survey evaluates is the financial stressors and barriers that families endure.

The surveys are sent to all patients every three months who are referred for surgical or catheterization intervention or diagnostic procedure. Surveys are sent to patients that were referred to either Edmonton Stollery Children's Hospital or to Vancouver BC Children's Hospital, however it also includes Edmonton and Vancouver patients whom refer to their own surgical centres.

Family Advisory Committee

The Family Advisory Committee has provided the Western Canadian Children's Heart Network with valuable feedback regarding the website. The Network ran analytics on the website to understand areas of improvement and what resources that are most frequently accessed and those not utilized. The WCCHN is working with the Family Advisory Group to create a compendium of family resources for the WCCHN websites so that families and clinicians can expect high quality pediatric cardiology resources stored on our site in a layout that is well organized and easy to find. Stay tuned for a new improved website!

Negotiation for decreased hotel rates

The Network is connecting with preferred local hotels to obtain the best rates in all western Canadian cities. If you have a suggestion for a hotel that you would like us to contact for potential rates, please let us know at wcchn@ahs.ca.

Annual Report for 2016/17 and 2017/18

The Western Canadian Children's Heart Network has experienced some delays with the 2016/17 Annual Report. Therefore the Network has decided to publish both 2016/17 and 2017/18 together, and anticipates a release date of September 2018.

American College of Cardiology's (ACC)

Improving Pediatric and Adult Congenital Treatments Registry (IMPACT).

The WCCHN has purchased ACC IMPACT and will be able to implement this exciting database and registry for the Stollery Children's Hospital within the next 3 months. We will purchase and implement the same database and registry for the British Columbia Children's Hospital within 6 months. All other centres in western Canada did not have the volume of patients to necessitate the purchase at this time.

The IMPACT registry is an important quality assurance/quality improvement initiative as it allows us to measure variability in the performance and outcomes of both diagnostic and interventional cardiac catheterization procedures. The ACC IMPACT database will allow the Stollery Children's Hospital and British Columbia Children's Hospital to collect data for diagnostic catheterization procedures. The IMPACT Registry provides the necessary benchmarking tools for quality improvement activities for cardiac catheterization procedures in Congenital Heart Disease. Our two Western Canadian sites will be benchmarked to numerous sites throughout the United States, helping us to learn and make improvements as necessary. The National Cardiovascular Data Registry (NCDR) is the ACC's suite of cardiovascular data registries helping to measure and improve quality care.

New Database for Western Canadian Children's Heart Network – the WCCHN v2

Currently, the Western Canadian Children's Heart Network is working on preparing the WCCHN version 2 for physicians, nurses, and staff to utilize. With a new exciting Connect Care program starting in Alberta, the Network is working to understand the implications of Connect Care and how it may impact the production of the WCCHN v2.

The WCCHN database contains diagnostic, cardiac intervention and outcomes information on all pediatric congenital heart patients followed at one of the WCCHN centres. The database has a robust referral module and surgical bookings module allowing tracking of intervention referral patterns and wait times.

The WCCHN database needs to be updated for technical reasons. We will survey clinician's stakeholders to ensure that we are creating a product that is useful for them.

Connect Care is a software that is created by Epic and brought by Alberta Health Services to link all EMR's and databases within Alberta



Heart Story: Lucas Watamanuk

Written by Melissa and Chris Watamanuk



On April 24, 2017 at 26.4 weeks pregnant my water spontaneously ruptured. After a completely uneventful pregnancy where I had followed all of the rules I suddenly found myself being rushed by ambulance from hospital to hospital surrounded by doctors who were discussing the possibility of a premature birth.

We managed to keep Lucas inside for another week but on May 2, 2017 he decided it was time to join us.

The Foothills team took good care of us and miraculously made Lucas's arrival seem quite calm. We were even able to delay his cord clamping and spend a few minutes together before Lucas (with Dad in tow) headed to the NICU.

After 3 days in the NICU our tough little "27-weeker" was doing quite well. He was breathing room air on his CPAP machine and we had settled into the routine of NICU life. We could do this. Babies were born early all the time we told ourselves. Then our world crashed.

The NICU team had heard a heart murmur and an echocardiogram had been performed to check it out. We soon found ourselves in the family room with the Director of Neonatology and a Cardiologist from the Alberta Children's Hospital. We were told that Lucas had Severe Aortic Valve Stenosis and without intervention his heart would soon fail.

Typically a cath surgeon would perform a balloon dilation using the femoral artery to tear open the

valve. However, no surgeon in North America had done this on a baby as small as Lucas. We needed to buy time and put some weight on Lucas who was just 1100 grams at the time. It was decided he would be given Prostaglandin to keep his PDA open, therefore relieving pressure on Lucas's heart. The downside of the medication was that it causes apneas and our son would likely stop breathing on his own. A few short hours later we were being woken up to watch our new baby be put on a ventilator.

All of this had happened during the first 72 hours of Lucas's life which is considered the critical window for a premie. Doctors and nurses like to minimize sound and touch during this time to reduce the risk of brain bleeds. Our son was currently surrounded by doctors and bright lights. Our son was fighting for his life in so many ways we had lost count.

Days passed and we couldn't get weight on Lucas. We transferred to ACH for 24 hours before it was decided we needed to get to a surgeon who could perform his balloon procedure. Dr. Lee Benson at Sick Kids Hospital in Toronto had successfully performed this balloon on a baby of 1500 grams. Before funding had even been approved by the government ACH had chartered a jet and had us on our way.

Another week passed and still we couldn't get weight on Lucas. He continued to have bradycardias and apneas and his heart function was declining. On May 19th we wheeled Lucas and his incubator down to the cath lab and left him in the surgical team's hands. The minute he went through those doors I fell apart. I couldn't imagine a life without Lucas and the risks were so incredibly high. The procedure was so risky Dr. Benson would have to use the carotid artery to get in and out as quickly as possible. This meant that if he did make it out of surgery there was still a huge risk of brain damage.

After hours of waiting and trying to stay calm, Dr. Benson and his resident found us in the Ronald Mc-

Donald House room in the hospital. They brought us into the hallway and after what felt like another couple hours they told us everything had gone extremely well. My knees nearly buckled and I nearly hugged Dr. Benson, who didn't appear to be much of a hugger.

Following another week in recovery we flew back home to the Alberta Children's Hospital. For the next several months we worked to teach Lucas how to take milk from a bottle and to breathe on his own.

After 94 days in 4 NICU hospitals, including the trip to Sick Kids, we were finally able to take Lucas home free of all equipment and weighing over 8 lbs.

We know the cath procedure was just a knock at the door in terms of fixing Lucas's heart. We are continuing to follow up with our cardiologist and we hold our breath at each and every one of these appointments.



This heart journey is a new world to us and we are constantly educating ourselves on Lucas's condition. We are continuing to try to get Lucas further along so that the options for his heart improve but in the mean-time we are truly enjoying each moment we spend with our little hero. Lucas has taught us so much about love and strength that we can hardly remember what life was like before his arrival, just one year ago.



COMMUNITY UPDATES

**America's
got Talent**

In August, Isabelle Wiebe had a wish granted by the Children's Wish Foundation. She and her family were flown to Hollywood to attend the August 14th live quarterfinal show of America's Got Talent and the August 15th results show. The AGT team made her feel like a VIP! She had opportunities to chat and take photos with each of the acts, she met last year's winner – Darci Lynne, she met the host, Tyra Banks, and the judges – Simon Cowell, Heidi Klum, Mel B and Howie Mandel, and she even got her picture taken with the judges' desk during one of the commercial breaks. The Children's Wish Foundation and AGT created a very memorable experience for Isabelle and her family!



Sam McGuire-After multiple postponements, he finally had his Fontan on June 28th, came home after 3 weeks and is doing great! He turned 5 on August 23 and will be starting Kindergarten in September. He is the silliest, sweetest boy and he couldn't be any happier!

Isaac Tymchuk will be turning 4 on October 4th! He is excited to be starting pre-school in the fall, especially because he will get to ride a yellow school bus!



Evelyn is turning 5 on November 8



Kahlan's turns 9 on November 5th.



Roman is turning 11 on October 9th. His interests include competitive curling, traveling and spending time with his friends and cousins.



Prabhnor has his 9th birthday on November 26.

Wilson is celebrating his 4th birthday November 6th and 4 year open heart anniversary November 17th. Today he is a loud, quirky, funny little boy who won't stop talking. His heart is doing very well and has been cleared for another year by his cardiologist.



Grayson is turning 6 on October 10th



Chase is turning 4 on November 20th



Hunter turns 5 on November 14. It's crazy to think our journey into the medical world started 5 years ago. Our miracle baby is a warrior, he's defied all odds against him and continues to fight. He has the brightest strongest personality, the best sense of humor, he is very intelligent and blows the minds of all his doctors and GRIT team with his wit. Even on the toughest days he is known to crack a smile. He wants to please and he has the fiercest will. We are so excited to be able to celebrate this special milestone and look forward to celebrating many more!

Xander Hesketh aka Batman, turns four years old on November 11th





Icing Smiles

Icing Smiles is a nonprofit organization that provides custom celebration cakes and other treats to families impacted by the critical illness of a child. We understand that the simple things, like a birthday cake, are luxuries to a family battling illness. Our goal is to create a custom cake for the ill child, or their sibling, that provides a temporary escape from worry and creates a positive memory during a difficult time. We feel strongly that siblings are the unsung heroes in these families. They consistently put their own lives on hold and sacrifice the attention of their parents while their families are helping the medical child.

Memories have magical powers. Long after the cake is gone, the memories linger. Memories of the kindness of a stranger, of the art of the design, of the sweet smells of a special treat, of the smiles and laughs, of a normal childhood experience so often stolen from these children. These memories are why we say, "It is so much more than a cake."



For more information please visit their website at www.icingsmiles.ca



Heart Beats

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



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

HEART HEROES.



Capes for Heart Heros

In 2009, moms of children battling CHD wanted to empower their children throughout their CHD journey. They learned by wrapping their child in the simple idea of a superhero cape, their children felt invincible while visiting their cardiologists. In many cases, the children found comfort in their cape amidst a crowd of medical professionals, especially if they couldn't have the comfort of their parents' arms during some procedures.

They found the "superpower" their children gained through the cape is something that should be shared with all CHD children. Heart Heroes was created with the hope that all children will feel these superpowers – and that their parents will be comforted knowing that the arms that always protect them can momentarily be substituted with the superpowers of the Heart Hero cape.

To order your cape for your heart hero please visit the below website: heartheroes.org



Heart Beats
Supporting Children with Heart Disease



Family Fun Run

Sunday, October 14, 2018

10km Run • 5km Run/Walk • Kids Race

Aurora, 1 year old

Aurora was born with an Interrupted Aortic Arch type B, Ventricular Septal Defect and Bicuspid Aortic Valve along with 22q11 Deletion Syndrome. She loves to spend time with her older sister and doggy while giggling endlessly.



Marcelo, 1.5 years old

Marcelo was born with a Hypoplastic Aortic Branch, Hypoplastic Branch Pulmonary Arteries and Williams syndrome. He loves music and is always smiling.

We are always cheering Marcelo. We know that his heart may not be perfect but he is a strong boy and will overcome any obstacle!



Roman, 10 years old

Roman was born with Double Outlet Right Ventricle. He enjoys curling, Lego and riding his scooter.



Heart Beats

www.heartbeats.ca

Family Fun Run

Sunday, October 14, 2018

10km Run • 5km Run/Walk • Kids Race

RACE INFORMATION

All races will start in front of the Running Room at the Eau Claire Market in Calgary. The runs will follow the running paths along the Bow River.

NO DOGS PLEASE!

For more information, please contact Jorge at:
run@heartbeats.ca

START TIMES

- **10km Run** - 9:00 am
- **5km Run/Walk** - 9:05 am
- **1km Kids Race** - 10:00 am

(The Kids Race is for children 12 and under only. One adult can run with each child at no charge but the adult will not receive a t-shirt.)

ENTRY FEE

- **Early Bird (until June 30)** - \$35
- **Regular Fee (July 1 - Sept 15)** - \$40
- **Late Fee (Sept 16 - Oct 12)** - \$45
- **Package Pick-Up Day or Day of Race** - \$50
- **Children 12 and under** - \$15

REGISTRATION

Registration can be made online at www.heartbeats.ca

RACE PACKAGE PICK-UP

Friday, October 12th: 12:00pm to 7:00pm

Saturday, October 13th: 10:00am to 3:00pm

Eau Claire Running Room Unit #A01, 200 Barclay Parade SW

T-SHIRTS

We cannot guarantee a t-shirt for registration after September 15, 2018.

PLEDGES AND DONATIONS

Pledges and donations can be made online at www.runningroom.com through the "Sponsor an Athlete" or click on the "Donate Now" button on the Heart Beats website at www.heartbeats.ca. They will also be collected during race package pick-up or on race day.

Register online at
www.heartbeats.ca



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& Printing
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