



Keeping the Beat

Spring / Summer

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

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Heart Month Event

A great big thank you to the Tao of Peace Martial Arts Studio for donating their beautiful space and putting on an amazing show for our Heart Month event on February 24th. Also another big thank you to the Tim Hortons in Bowness who donated half of our beverages and Timbits as well. Families were treated to an exciting martial arts demonstration. The children were then divided into groups and taught some martial arts skills. The parents had a great time chatting and connecting and the kids had fun burning off some energy!



Lake Day at Midnapore Lake

Thanks to all of the families who braved the cold to attend the Heart Beats Skate and Sled Day on February 3rd. It was great to meet some new heart families and catch up with some old ones. Hope to see you all again at a future event!



What's been happening in the world of HEART BEATS

Mom's Night Out

On April 9th we met up at the Cheesecake Cafe and had a great evening of conversation and desserts. A perfect "Mom's Night Out!"



Hey there heart families!

It's the Offbeats here. Just wanted to let you all know what we have been up to this year.

This year has been a super fun one! In October we kicked off the year with a trip to Laser Quest where we had a blast duking it out under black light then finished off the night with board games and snacks. Our next event was our annual Christmas Party where we all made gingerbread houses and exchanged gifts in a white elephant gift exchange. In February we got cozy at Fire Escape where we escaped the cold and painted some pottery. On April 14th we met at Vittorio's house and had a fun evening of playing games and eating Vittorio's yummy cookies!"

On June 2nd (weather permitting) we are planning on going Go-Karting and Mini Golfing! In September we are looking forward to the Heart Beats Family Camp at Camp Evergreen.

If your child is in junior or senior high, we would love to have them join our group. For more info on Offbeats feel free to contact us at offbeats@heartbeats.ca. We're looking forward to seeing you all at our future events!

-Your Offbeats Leadership Team (Courtney, Meghan, Vittorio, & Sam)



Dad's Night Out

On March 26th Dad's Night Out was at The Rec Room. Great conversation and good food were had by all the many dads who attended. Watch your email for details of our next get-together.



SAVE the DATE

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

The 9th Annual Family Fun Run will take place on Sunday, October 14, 2018 at 9:00 am. As in past years, the race will commence at Eau Claire Market and follow the running paths along the Bow River. There will be a 10k, 5k, and 1k children's race with prizes and medals in each category.

All proceeds raised will go directly to helping children born with congenital heart defects and their families.

For more information, please contact our run manager 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



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.

Other fun events are coming up too like Summer Lake Day, and Heart to Heart Parent and Tot so keep an eye on your email.



Heart Beats' annual Family Camp is coming up on September 7th- 9th, 2018 at Camp Evergreen (located near Sundre). The weekend includes:

- Two nights' accommodation in a heated cabin or lodge;
- Meals (snack Friday night, all Saturday meals, breakfast & lunch on Sunday); and
- Awesome activities including canoeing, ziplining, archery, trail rides, climbing wall, ropes course, Frisbee Golf, WillsonBall, horse-drawn wagon rides, etc.

Heart Beats subsidizes the cost of our Family Camp so we can offer all of this to our heart families for the reduced fee of:

- \$50 per adult (ages 18 and older)
- \$25 per child/youth (ages 5-17)
- \$0 per child ages 4 and younger.

If you wish to bring your own trailer, your camp fee will be reduced by \$50.

To register, email Keremy Dry at RSVP@heartbeats.ca. Our Family Camp is very popular, so we encourage you to register early to ensure you don't miss out!

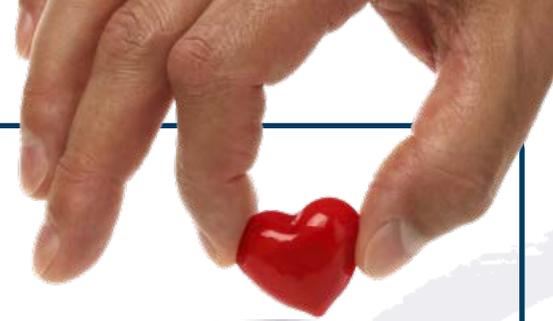
Your spot will not be confirmed until your payment has been received.



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)

DONATION

Donations received from January to April 2018

Thank You

Anton & Sandra EWANISHIN
in memory of Florence Winters

Ashley EXALL & Paige HAGEL

Cathy HOWARTH

Johan LOEWEN

Caterina SHOLTER

in honour of Vittorio Borrelli

Fraternal Order of Eagles – Calgary
Fraternal Order of Eagles – Aerie 2098

Watson Family Foundation
at the Calgary Foundation

Suzana PETRUNIC
through United Way of Greater Toronto

anonymous
through United Way of Central Alberta

anonymous
through United Way of New Brunswick

anonymous
through Benevity

Heart Beats and Social Media Find us on Facebook...and Twitter



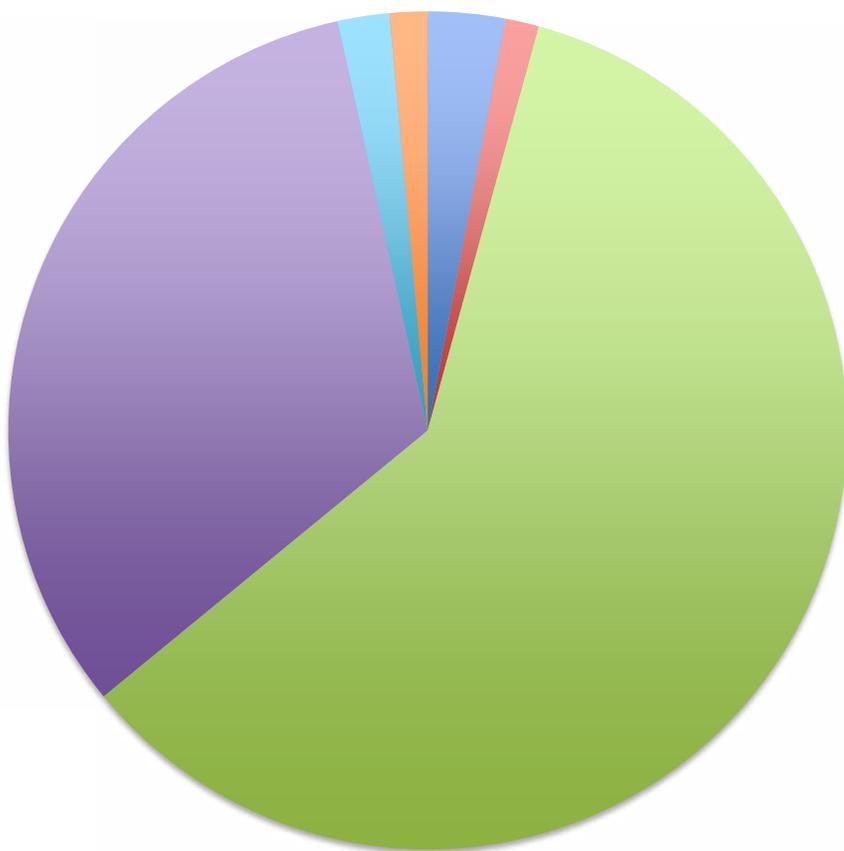
Staying in touch with other heart families and joining in fascinating conversations has never been easier! Our Facebook group is always growing, so stay in the loop by searching Heart Beats from your Facebook page or click on the link at our website to become a part of this expanding group.



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.



Wonder where Heart Beats' donations go?



- Administration
- Advocacy and Education
- Direct Financial Assistance
- Programs
- Alberta Children's Hospital Cardiology Clinic
- Marketing

Spotlight on Donation from Ashley Exall

My sister Lauren was born with severe CHD when I was 3 years old. We have spent a lot of time in the hospital and over the years Heart Beats has made a real difference in our lives and in the lives of other CHD families. We love Heart Beats events where we can meet other families who have gone through the same things we have. We really wanted to give back, so in 2015 my friend Paige Hagel and I started raising money for Heart Beats. We ran lemonade stands, held garage sales and did bottle drives. At the end of more than two years of fundraising, we finally presented the money to Heart Beats. We had collected more than \$2,600! What a great feeling to know that we have made a difference for Heart Beats families.



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In Memory of Isabella Grace Sophia Bonan



Erin Elizabeth Bonan



A Heart Story

When I was 4 months pregnant on January 8th, 2017, my husband and I discovered our baby girl had a heart defect. That particular day is ingrained in my brain forever, and I will never forget it. At 5 months pregnant on February 8th, 2017 our baby girl Isabella Grace Sophia (we named her) was diagnosed with Truncus Arteriosis Type 2, VSD, (a hole in her heart), and stenotic ventricles. My husband and I were shocked, upset, angry, devastated, and heart broken. It felt like our fairytale life had come crashing down around us.

Once Isabella had her heart diagnosis, we had to have ultrasounds, alternating with echocardiograms once a week at the EFW Radiology department in Calgary. We met with many different doctors who specialize in babies with heart defects-High risk OB-GYNs, cardiologists, geneticists, neonatologists, and surgeons. On April 26, 2017, I was admitted to the Foothills Medical Centre Hospital on unit 41A. Isabella's heart started to go into failure and I

needed to be placed on a medication called Digoxin, to help pump her heart better. I have never been on a heart medication personally before, so the doctors needed to monitor my symptoms and assess if I had side effects from the medication. The doctors also had to determine if the medication was improving Isabella's heart function. I did not mind taking the medication, as long as it was helping my baby girl Bella. I stayed in the hospital for 3 days and endured many tests. This included blood tests, baby heart monitoring with a fetal doppler, a fetal Non-Stress Test-NST, an amniocentesis, and monitoring of the new medication Digoxin. Isabella's heart had a good response to the medication. It helped her heart pump more efficiently, for her body to grow bigger, and to help keep her inside me longer.

On May 16, 2017, my husband, mom and I had to relocate to Edmonton in order for the radiologists and cardiologists to closely monitor Isabella's heart before her birth. Isabella had to be born in Edmonton as that is where the pediatric cardiac surgeons who would perform Isabella's open-heart surgery are located. We moved into the Ronald McDonald House the next day and

were very grateful, blessed and thankful to live there. Everyone took wonderful care of us.

I had to have daily ultrasounds and echoes done in Edmonton, so that the cardiologists could closely monitor Isabella's heart once we were there. One week later the cardiologists Dr. Hornberger and Dr. McBrien did not feel that



it was safe to keep Isabella inside me any longer. I was scheduled to deliver Isabella on Thursday May 25, 2017 via C-section at the Stollery Children's Hospital/University of the Alberta Hospital. Dr. McBrien did not feel it was safe to deliver Isabella at the Royal Alexandria Hospital where most babies are delivered. The Stollery is not setup to take care of mothers post-partum, so I would have to be admitted to the Royal Alexandria Hospital and transferred in an ambulance

to the Stollery, and back again to the Royal Alex after I gave birth. Mike and I did not have much time now to prepare to be parents. We also had little time to fatten Isabella up before birth, so I ate as much healthy foods as possible. I wanted Isabella to weigh as much as she could so she had a better chance at survival. The doctors were also thinking that Isabella may need a heart transplant, as they were still not sure if her surgery would be successful. This news, and meetings with the heart transplant team terrified Mike and I completely. We prayed to God that Isabella's heart could be fixed surgically, as we really did not want her to have a heart transplant.

Isabella Grace Sophia was born on May 25, 2017 at 08:01, weighing 5 pounds 1/2 an ounce, and 17 inches long via C-section. A team of 20 doctors and nurses were waiting for her in another procedural room. The doctors were worried that Isabella's health would decline rapidly following birth and that she would have to be placed on a heart lung machine known as ECHMO. Isabella screamed and cried for the first time after she was born. My husband and I were overcome with emotion by hearing her first cry. Isabella had the most beautiful cry



in the world that we had ever heard before. Shortly after birth, Isabella stopped breathing and had to be intubated with a breathing tube. Once she was assessed, IVs and an arterial line were started on her by the doctors and then she was sent to the NICU. I was wheeled into the NICU so that I could meet and take pictures of my new baby girl for the first time. Seeing Isabella for the first time felt very dream-like and magical. I immediately bonded with my beautiful, precious daughter, and she was everything I imagined her to be. Her face looked a lot like her daddy, but I thought she had my hair, arms, hands, fingers, legs, feet and toes. I instantly fell deeply in love with my baby girl.

When Isabella was only five days old, on May 30, 2017, she had her open-heart surgery. That was one of the worst days of my life. It was very stressful, heartbreaking, and devastating sending my newborn baby girl for surgery. Mike, my mom and I cried a lot that day once the doctors took Isabella to the operating room. We did not know if she was going to survive the surgery. After about five hours of waiting, Dr. Freed came out of the operating room to give us the good news, Isabella had survived her surgery. Dr. Freed was able to repair all of Isabella's heart defects. Her surgery went better than expected.

Isabella was moved to the PCICU (pediatric cardiac intensive care unit) after surgery. This is the unit where babies and children go after surgery to recover. The first complication after surgery for Isabella was that her kidneys had shut down and were not producing much urine. She had to be put on PD catheter dialysis, and her abdomen was filled with fluid, and emptied every hour. Isabella had her ups and downs in the PCICU. It seemed like every two days she would be very ill. It felt like we were on a rollercoaster with our baby girl. We experienced a range of emotions every day, from happy to sad, and scared to nervous. We were always anticipating her future and wondering what would happen next. The next complication for Isabella in the PCICU was her lactate level-a blood gas was climbing high every day. This meant her heart was swelling and it needed more room to expand in her chest. Isabella had to have the skin of her incision opened for eight days, and her chest incision opened, and reopened for 10 days. This was a long time for a baby to have her chest open, as it could have led to an infection. Once Isabella was finally stable on June 13, 2017 she was sent back to the NICU after being in the PCICU for 15 days.

Isabella had a difficult transition back to the NICU,

as it took her two whole days to recover and get used to the new doctors and nurses. There was a lot of noise in the NICU, with babies crying, monitors beeping, and nurses talking. Her nurse Hannah built her a tent with a blanket over her crib bed, gave her spa days with lotion and lip balm, and played her monkey music box. This helped to keep Isabella calm, relaxed, and sleeping.

On the 26th day of her hospitalization, June 20th, 2017, Isabella had an echo done on her heart. The doctors gave us the horrible news - Isabella's ventricles had not remodeled themselves as expected. Her ventricles had formed EFE, a heart complication after surgery. Isabella's doctor, Dr. Chloe Joint, explained that EFE or Endocardial fibroelastosis is a rare heart disorder which can affect babies or children after heart surgery that can occur anytime up to two years of age. It usually happens as a reaction to stress and can have different forms from mild to severe. EFE is like an orange peel or scar tissue forming around the ventricles of the heart. Poor Isabella's ventricles had developed a severe case of EFE and there was no surgical intervention possible to correct it. I cried instantly once I heard the news. How could this be possible? Why Isabella? She had fought so

hard, and been through so much, and now we could not save her anymore. My husband and I did not expect this at all. We had tried to stay positive and optimistic as always. We had two days to prepare to say our goodbyes to our baby girl. We had to make difficult decisions that we were not prepared to decide upon. We had Isabella baptized by our United Church Minister Denise. My husband and I took turns holding Isabella every two hours for her last two days. We got to give Bella her first bath, wash her hair, and dress her in her pink onesies. We had professional pictures taken of us with Isabella as a family. This was one of the most difficult times I had ever been through in my life. I kept praying to God to let us have another miracle and make Isabella's heart better. I would do anything for my daughter, even give up my own life so she could survive. The worst part was that I knew in my heart what was about to happen. I felt very out of control, and powerless. There was absolutely nothing I could do to save my daughter now but continue to pray.

Isabella passed away in my arms on June 22, 2017,



after only 28 days of life. Dr. Chloe Joint, our social worker Theresa, and the nurses were very kind and supportive to us at this time. They made us a memory box for Isabella with her name on it, a shadow box of her hands and feet, and gave me a heart necklace. We will always remember Isabella for how strong, tough, and a true heart warrior she was. She was my beautiful, pretty, and gorgeous baby girl. She was a sassy drama queen, and a Miss Attitude kinda girl. Isabella hated being cold, and she loved watching the nurses with her one eye spying on them when they were not looking.

A lesson to be learned from Isabella is to never give up and keep fighting, until you have no energy left. She came into our lives for a reason. She showed us how to love each other deeper,

live life to the fullest, and not to take a second of life for granted. Be kind to others and treat others like you would want to be treated. Try not to worry about the small things in life. I am blessed, grateful, and thankful that I got to meet my daughter, and to spend every day of her life with her.

The advice I would give to other heart families would be to always ask a lot of questions. No question is unimportant, it is always helpful and beneficial. If you have concerns you should voice them with the staff immediately. Keep a journal and pen with you in the hospital at all times. You can write down anything that you think is important for example questions, and anything that happened to your baby that particular day. Always take pictures of your baby every single day.

When you are pregnant and have an echo done tape record the sound of your baby's heartbeat.

For coping with the loss of my baby girl Isabella, I have been going for counselling with EAP, and with the Children's Hospital in Calgary, my social worker Megan. I have framed her pictures in special picture frames, started to create her scrapbook, and I am writing her story into a book. I create art projects where I paint pink wooden hearts or make pink jewelry boxes. I have a Mason jar painted with Isabella's name on it with pink and white hearts. I write my thoughts and feelings about my daughter and place them in the jar. I had a pink Build-A-Bear created and I dress it up in Isabella's onesies, bows, and heart necklace. I have also made bracelets with Isabella's names on them,

and I wear different ones each day.

My husband and I would like to take this time to thank Heart Beats, Ronald McDonald House, the Stollery Children's Hospital in Edmonton, and all the doctors and nurses who helped us through our heart journey with our daughter Isabella. We could not have gone through this experience without your knowledge and expertise. We are very grateful and blessed that each and every one of you helped and supported us in this very difficult time.



SHAUN WHITE WINS ANOTHER GOLD MEDAL!

To all the heart families out there, maybe it was described to you that your CHD child would be able to participate in some sports but probably wouldn't be an Olympian. For those that don't know, Shaun White (skateboarder and snowboarder) is now a three-time Olympic gold medalist who has CHD and is 31 years old. He was born with Tetralogy of Fallot and has had three open-heart surgeries. Shaun is a huge inspiration to his fellow heart warriors and gives them the hope that they can all strive to be whoever they want to be, no matter how imperfect their heart is. Among both girls and boys, TOF occurs in roughly five out of every 10,000 babies. While CHD Olympians may be rare, stories like Shaun's help us realize that anything is possible.

Source: <https://www.clickondetroit.com/health/shaun-white-shares-childhood-battle-with-heart-defects>



Former Heart Beats Chairperson Passes Away

It is with great sadness that we have lost a special member of our Heart Beats family, Monica Croft. Monica was very involved and was our chairperson for several years in the late nineties and early two thousands. Her son Sam was born with a complex congenital heart defect and underwent the BT shunt and Fontan very early in life. Her husband John has also been an involved Heart Beats member. Sam now supports Offbeats as one of the leaders. Monica contributed to our Heart Beats family through sharing her gifts of compassion, her intelligence and quest for education to support us, as well as her talent for working with children. As our chairperson she led and supported one of our major fundraising galas and was instrumental in organizing children's Christmas parties and family events at Heritage Park. She was a true friend to us; someone we connected to on a deeper level. She was able to share with the greatest of empathy as we moved through our own journeys together. Although her own illness contributed to her decision to resign from her chairperson position with Heart Beats, she remained and will always remain as an integral spirit in our family. She will be deeply missed but her strong legacy will forever be with us. - Denise Nimmo

Obituary of *Monica Croft*

Former Heart Beats Chairperson

Monica, beloved wife of John Croft of Calgary, passed away peacefully on Monday, March 19, 2018 after a 20 year courageous and inspirational disagreement with Adenoid Cystic Carcinoma (ACC).

She will be lovingly held forever in the hearts of her husband John and son Samuel Croft; her parents, Irwin and Irene Endicott; her sister Rosalind and nephew Mitchell Topolinsky; her special cousin Jodie Endicott, and her numerous aunts, cousins, and in-laws. Monica was born and grew up in Estevan, Saskatchewan. After moving from Radville, Saskatchewan to Calgary, Monica graduated from Sir Winston Churchill High School. She earned a Bachelor of Education degree in Mathematics from the University of Calgary, and taught with The Calgary Board of Education.

As an elementary teacher she championed the uniqueness in every child and saw the reluctant learner as an opportunity to instill joy and wonder in creative expression and knowledge. Her passion for teaching and mathematics was obvious from her early teaching days at West Dover, and continued through her time at Edgemont, and the Hillhurst GATE program. There she defined what gifted education should be and stressed the importance of making sure each day counted for these students that left their community schools to come to GATE. As one student, that she taught over 20 years ago, put it in a recent letter "thank you for being phenomenal, Mrs. Croft. Thank you for teaching me how to see it, and how to be it".

In 1986 she wed John, someone she had admired from a safe distance in high school. In 1990, Monica and John welcomed Sam into their world. Together they faced the particular challenges that come with having a child born with a congenital heart defect. These circumstances propelled Monica to lead a full and meaningful life, drawing to her the people and situations that helped her expand as an advocate for cardiac children. Monica was Chairperson for Heart Beats Children's Society for many years and had to reluctantly resign to deal with her advancing cancer prognosis. After numerous surgeries and radiation therapies including a complete left lung pneumonectomy in 2002, she decided to also step away from teaching and focus on surviving her prognosis. Against all odds she set a goal to live to see Sam graduate from grade 6. Then revised her goal to grade 9, grade 12, and then to see Sam earn his engineering degree. All this time pushing her medical team, at the Tom Baker and Foothills hospitals, to do one more surgery or radiation treatment to try and extend her wonderful life. Monica was a strong patient advocate for ACC and through her grace, determination, and ability to connect with patients and ACC professionals she helped establish the ACC Patient Support Network. She also reached out to patients with terminal ACC and was a mentor and friend to them until their final days.

Throughout all of her challenges with cancer she found refuge at her family cabin in Windermere, BC. The cabin was known as her healing place for the past 20 years with her cabin friends supporting her there. In 2002, thinking she only had one summer left to live, the family decided that we needed to learn to sail. This started another passion with many sailing trips in the Gulf Islands and the British Virgin Islands. Monica's love for skiing continued throughout her life from Sunshine, to Panorama, to Fernie, where she managed to ski every year until 2015. Monica loved life and did not want to leave any sooner than she had to, and lived the last 15 years knowing each year was precious. She had a large network of friends and supporters in Calgary that did everything they could to make her days a bit easier. She found wonder and amazement in the simple things in life and was always planning for a future adventure. She formed deep and meaningful friendships and had great compassion and empathy for others. She will be greatly missed by all that knew her. Go, little lung go!

Special thanks to her long time and best friend Lisa who was incredible in supporting Monica and family for these past 20 years. The family would also like to thank Dr. McFadden and Dr. Lau for their heroic efforts over the years, Dr. Kuzyk Monica's long time family physician, and Dr. Murphy and nurses Rachel and Jennifer of the Palliative Care team. A heartfelt thank you also goes to the Rosedale Hospice doctors and nurses who helped guide Monica to a peaceful place.

Interment for Monica will be held in Windermere BC this spring and a Celebration of Life will be held in Calgary at a later date. Condolences may be forwarded through www.mcinnisandholloway.com. In lieu of flowers, donations in memory of Monica Croft may be made to support Adenoid Cystic Cancer research at the University of Calgary. Cheques should be made payable to "University of Calgary", with "Adenoid Cystic Cancer Research" in the memo line, and mailed to: Fund Development Office, Health Science Centre G302, Cumming School of Medicine, University of Calgary, 3330 Hospital Drive N.W. Calgary, Alberta, T2N 4N1. Donations by credit card may be made by contacting the Fund Development office at 403-220-4266.

In living memory of Monica Croft a tree will be planted at Fish Creek Provincial Park.

- Published in The Calgary Herald



Monica Croft 1959-2018

New PCICU at the Stollery

Wonder what the new PCICU looks like in Edmonton?



In Room Couch
And Parent Bed

We weren't too excited to hear that our daughter needed to return to the Stollery for her fourth heart surgery this winter. But we could at least look forward to the new cardiac ICU! It is a beautiful new unit: Bright, cheerful, modern and with vastly improved comfort and privacy. With individual rooms and (reasonably) comfy parent beds, it is similar to the ACH PICU but extra sparkly and new. There are a few things that could have been designed better (e.g., why do the IV pumps and monitors have to share the same space?). The space overall, however, has been well-designed to try to allow families to be together, with extra attention paid to those that spend extended periods of time in the PCICU. There is a well-stocked kitchen with coffee, snacks, frozen meals and a play-place for siblings. For us though, the most important improvement was the space to be at your child's bedside but be out of the way of the medical team when needed. We have had some difficult and stressful times in the old unit and there was so little space that it always felt like parents were in the way when stressful things were happening. In the new unit there was plenty of room to back away, to let them do the work they needed to do but also be there with your child. I hope we don't have to return any time soon, but if we do I am so happy that it would be to such an improved new unit. - Marie-Claire Shanahan

Thank you to Marie-Claire Shanahan, Bernadette Foulonneau & Cindy Guardado for sharing their photos.



New PCICU Waiting Room



New PCICU Waiting Room Fish Tank



New PCICU



New PCICU Room



Kitchen



In room
massage chair



New PCICU



Family Lounge

Meet the Surgeon: Dr Freed

Where did you grow up? What was your home life like? How many siblings do you have?

I was born in Killam, Alberta, I then lived there for two years before living all over the world as my father was a minister. We lived in other places in Canada such as Moose Jaw, Winnipeg, Regina as well as also living abroad for 6 years.

My home life was remarkable, as a child I liked to get into things and break them apart and try and put them back together, this drove my father crazy. I am also the baby of the family with one older brother and sister.

What made you want to become a pediatric cardiac surgeon?

This is a true story, when I was 12 years old I read an article about baby Fae, she is the only human to receive a baboon heart. The transplant was performed by Dr Leonard Bailey in California. This article really resonated with me and I said "This is what I want to be when I grow up"

Where did you go to school and train previously? What led you to Edmonton?

I did my pre-med degree at Andrews University in America then my medical degree at the University of Alberta. I then went to Manitoba to complete cardiac surgical training and to gain my PhD in Physiology. I then proceeded abroad to train further in my area of interest in transplants in the United Kingdom at Papworth Hospital located just outside of Cambridge. After this I came back to Winnipeg to perform cardiac surgeries and then decided to move to Edmonton as it's a main hub for transplants (not just hearts) and then decided to retrain in pediatric cardiac surgery.

Do you remember how it felt the first time you performed open heart surgery alone on a child?

As I've come from the adult heart surgery world I felt very comfortable and confident in performing open heart surgery on children. I certainly know and feel the weight of families entrusting their children's hearts in my hands and do my absolute best for each and every patient and their family.

Do you ever get nervous going in to operate? Are there some cases compared to others that get you more nervous, if so why?

Yes, some surgeries have higher stakes than others as they have less "bale out strategies" (back up plans if things don't go according to plan). For those types of surgeries where we only have one chance they can be very nerve-wracking.

Is there any specific research you are working on right now?

Yes, my team and I actually work on organ preservation for transplantation. My goal is to increase the number and quality of organs available for transplants. We work on improving the methods to preserve the organs better.

What are your interests outside of the medical world? When you are not at work, where are you? What do you like to do?

Well I spend time also on the company (Tevosol) to do with my research I mentioned above. When I'm not at the hospital or there I like to spend my time outside. I like to do a range of things like back country camping, hiking or skiing, really anything I can do outside with my three sons in nature and the great outdoors.

How do you deal with the loss of a patient?

This is a really hard one as being a surgeon we have a direct impact on our patients and their families but sometimes not everything goes accordingly to plan. I am really involved with my patients' families and try to help them understand the process and procedures to try and ensure they can understand what has happened as we grieve together.

We as the medical team along with the family have been working very hard for their child, we also take losing a patient as a personal loss/failure. We grieve and work through it together as a team but being outdoors in the beauty of nature with my boys also helps me through these hard times.

What would you say is the best thing about being a pediatric cardiac surgeon?

I can't say one as there are multiple things, it's amazing being able to make a difference in a child's life. These children with congenital heart disease did not do anything to cause their conditions, it's not their fault so being able to improve their quality of life and live with less restrictions is very gratifying to see as surgeon.

Are there any parting words of wisdom you'd like to share with the parents of your patients?

We as surgeons try to relay what a heart operation actually consists of and describing in detail what's going to happen during surgery can be very overwhelming for parents, they are all words until you actually are going through the process. We are trying to mentally prepare parents for what's to come including unexpected outcomes and possible long haul stays, so being as mentally prepared as possible.

Thank you Dr. Freed to sharing your thoughts with your patients and families from Calgary. We hope to not require your services (too many times at least) but if we do we know you'll be in Edmonton to help us through. THANK YOU



Sibling Story: *My Sister is a Heart Kid*

*Interview with: Malcolm van Kampen Age: 11
Calgary, Alberta Canada*

Q. How many siblings do you have and how much older are you than your baby sister with the heart condition?

A. I have three sisters and I am nine years older than my baby sister. She is almost two years old.

Q. When did you come to understand that your sister had a heart problem? How would you describe it?

A. About a month after my baby sister was born, my mom told me. The name of the disease is Hypertrophic cardiomyopathy, which basically means that there is a layer of your heart that gets too thick, so it is cutting off blood from flowing. When she was 17 months old she had open heart surgery.

Q. How did having a baby sister with a heart condition affect you?

A. Having a sister with a heart condition really got me worried. I didn't know if she was going to be okay or not. Sometimes I would think about it late at night.

Q. Describe some supportive things that helped you get through the tough stuff.

A. When we were just about to go to Edmonton for Margot's surgery, we talked with an expert on this "stuff." My mom said she was a social worker and worked with heart kids. She told us what to expect and how to deal with anything. That made me feel more secure.

Q. What were the hardest parts for you?

A. The hardest stuff was just waiting while Margot was getting surgery done. It made me feel like I couldn't breathe.

Q. How do you feel this experience changed how you see the world?

A. I see the world as a better and less stressful place now that I know that Margot is going to be okay. I also think it's amazing how well people can help with heart conditions. It's pretty awesome.

Q. What is your baby sister like since she had the surgery?

A. My sister Margot is a little adventurous baby. She is very smart for a baby and gets along with everybody.

Q. How do you feel about her?

A. She is so strong and I am very proud of her. When we saw her after the surgery, she was smiling! That even made my grandpa cry!



Thank you for sharing with us, Malcolm!



Useful Heart Apps

Did you know there are cool apps out there to help understand your child's or your own heart condition better? These are just two of many heart apps that will enable you to learn more in a very user-friendly way.



Heartpedia

This app can help you understand the following conditions:



1. Tetralogy of Fallot
2. Atrial septal Defect
3. Ebstein's Anomaly
4. Interrupted Aortic Arch
5. Total Anomalous Venous Return
6. Truncus Arteriosus
7. Coarctation of the Aorta
8. Hypoplastic Left Heart Syndrome
9. Transposition of the Great Arteries
10. Ventricular Septal Defect
11. Patent Ductus Arteriosus
12. Atrioventricular Septal Defect

Discover each defect through the following interactions:

- Toggle between normal, defect and repair views
- View exterior and various interior heart planes / slices
- Pan, rotate and zoom
- Watch video animation with audio description of each defect and repair
- See labels of key heart structures
- Read a detailed description of the defect

HLHS Health Journal

The purpose of the HLHS Health Journal app is to help those living with HLHS. It has the capability to track any medical information and data associated with their condition. You can input oxygen saturation, heart rate, body weight, feeding, notes and media, and reminders. You are able to share the data by email, you can add contacts, and there is a resources tab that includes YouTube videos specific to HLHS. This app is a great way to keep all your HLHS information in one place.



Packing List for Hospital Stays in Edmonton

When you find out that you will be in-hospital for a certain period of time, it is always good to know what you will need to pack in your suitcase. Here is a list from experienced heart families to help you in those times of travel.

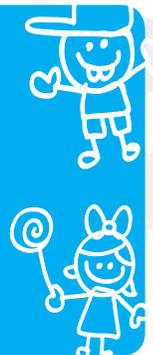
FOR PARENTS:

- Earplugs
- Eye mask
- Slippers/indoor shoes
- Books/activities
(like a deck of cards) while sitting bedside
- Headphones
- Your own blanket/pillow
- Chapstick
- Water bottle



FOR BABES:

- Sleepers with snaps down both legs
(good for tubes/lines)
- Socks (for keeping SAT probe on)
- Diaper shirts (in case IVs are in feet)
- Familiar sounds for kids (mobile, etc)
- Familiar soap/lotion for baths
- Blankets
- Bottles/soothers
- Activities for them to do in bed



Edmonton Daycare Options

Looking for daycare options while in Edmonton???

Heart Beats has done some of the ground work for you. Below is a list of facilities that do offer drop in childcare, pending availability. If you are looking for care, please call any of the below locations to enquire and mention you are from Heart Beats and looking for care of a sibling while at the Stollery Children's Hospital.

University Tender Loving Daycare (0-12yrs)
1124 76 Ave NW Edmonton T6G 0K1
1-780-756-6850

Strathcona Tender Loving Daycare (0-6yrs)
9932 81 Ave NW Edmonton T6E 1W6
1-780-756-0026

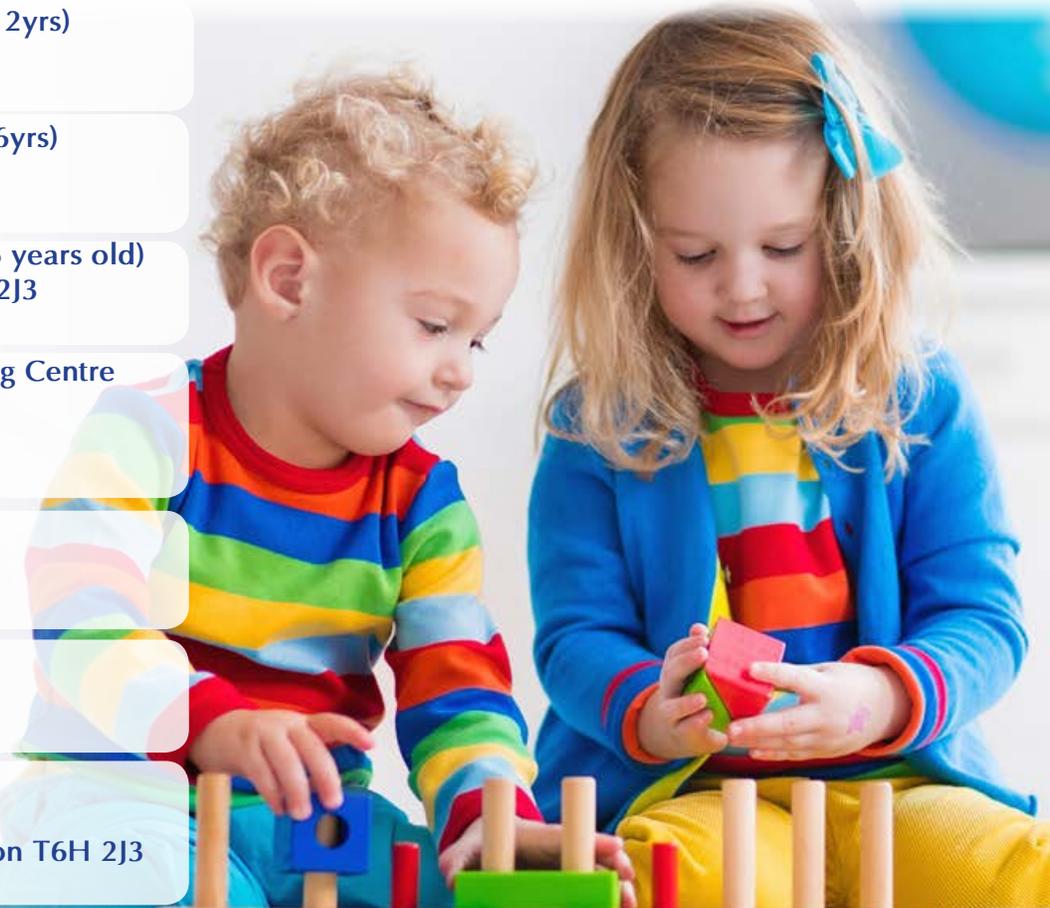
Hospital and Community Daycare (1-6 years old)
11403 University Ave Edmonton T6G 2J3
1-780-433-9663

University & Community Early Learning Centre
8720-118 Street Edmonton T6G 1T5
1-780-422-0070
www.uclc.ca

YMCA- Park Allen Childcare
6703 112st NW Edmonton T6H 3J9
1-780-437-1565

YMCA Mount Pleasant Childcare
10541 60A NW Edmonton T6H 1K4
1-780-437-4125

Tiny Town Daycare (2-6 years old)
203,10430, 61 ave NW
Allendale Professional Centre Edmonton T6H 2J3
1-780-463-4611



Please note: It is the responsibility of the parent to discuss directly with each individual childcare provider any and all details. We recommended every parent inspects whichever facilities they choose to care for their child. Heart Beats is not responsible in any way for care provided for children or any associated costs



COMMUNITY UPDATES

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 September and December? Let us know so we can acknowledge their special day. Please email newsletter@heartbeats.ca for inclusion in our next newsletter.

BIRTHDAYS



Callen Spooner celebrates his fourth birthday on May 26th.



Lucas Watamanuk's first birthday was on May 2nd.

Marie celebrated her third birthday on April 1st. She recently had her Fontan, on February 23rd.



Lauren turned 10 on May 9th.



Isabelle Wiebe turned 17 on May 11th. She enjoys Offbeats, especially when it includes Vittorio's cookies! She is looking forward to attending Camp del Corazon for her 4th time, this summer!



Atom is having his sixth birthday on Aug 20th. This is his second year surgery free and it is hard to believe he is such a strong and resilient little man after all the complications he's had. He loves going to kindergarten and is in the process of doing a 1500-piece puzzle, with a little help from us.



An eventful first year for Aliyah Jean with two open-heart surgeries under her belt. She is a curious, sweet and funny little girl, who will be turned one on May 10th. Happy birthday, Tiny Dancer!



Heart Beats

Children's Society of Calgary

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jenb@heartbeats.ca

Vice-Chairperson Uli Ng
info@heartbeats.ca

Treasurer Patty Wiebe
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Secretary Tara Exall
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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 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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