



# Keeping the Beat

Spring / Summer 2019

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

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## HEART BEATS Family Camp 2019

Heart Beats’ annual Family Camp is coming up on September 6-8, 2019 at Camp Evergreen (located south of Sundre).

Families with a Heart child that is being seen at the Alberta Children’s Hospital or at Quarry Park in Calgary are eligible to attend. Since the camp is so popular we can include only immediate family members.

Some of the activities offered at Camp Evergreen include canoeing, rock climbing, archery, zip lining, trail rides and a chance to connect with other Heart Families.

Heart Beats subsidizes the cost of the camp so we can offer two nights in a heated cabin, room in the lodge, or trailer parking, all meals (from Friday snack through Sunday lunch) and the amazing activities for 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)**

**\*\* Age of attendee is at the time of the Camp Weekend \*\***

If you wish to bring your trailer, your camp fee will be reduced by \$50. To register, email Keremy Dry at [RSVP@heartbeats.ca](mailto:RSVP@heartbeats.ca) . Emails will be responded to within 7 days. Please include the following information in your RSVP email:

Number of immediate family members wanting to attend

Each family member’s name and age at the time of camp (<17 years of age, indicate adult)

Any allergies and/or dietary requirements for each family member, if applicable

Preference: cabin, lodge or trailer parking

Any accessibility accommodations (the activities centre and dining room are accessible as well as some of the cabins).

Registration will open on June 15, 2019 and close when the camp is full. The monthly Heart Beats email will be updated as we reach capacity.

Our family camp is very popular so we encourage you to register early; you do not want to miss out! Your spot will not be confirmed until your payment has been received.

Heart Beats is thrilled to now be a participating charity in Shaw Birdies for Kids presented by AltaLink (BFK). As such, your camp registration fees will be matched by BFK up to 50%.



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

## Outdoor Party

On Saturday, February 23, nine kids and their brave parents/caregivers ignored freezing temperatures to attend the Heart Month Outdoor Party at Lake Bonavista. Kids ranged in age from toddlers to teens, and tons of fun were had by all! There was lots of skating, conversations around the fire pit, and warming up with hot chocolate and treats. Thanks to everyone who attended!



Offbeats have been growing in number and having several fun get togethers over the past few months. In December we had a Holiday Party which included playing games, decorating gingerbread houses, and a "white elephant" gift exchange.

In February we celebrated CHD Awareness Week by making individual terrariums at PLANT in Inglewood. A HUGE thank you to owner Kyle Chow who donated all the materials for the terrariums, and employee Brooke Cupelli who set up the event and donated her time to teach the class.

In April the Offbeats group had a fun evening playing glow-in-the dark mini-golf and arcade games and eating pizza at Monster Mini Golf.

In June we had a great time at Cobb's Adventure Park which included Archery Tag and petting baby kangaroos! We also said "good bye" to Isabelle, Korynn and Maddie who have "graduated" from Offbeats (but may return as leaders!)

Offbeats is for junior high and senior high aged youth with CHD's and is led by Offbeats alumni. To receive information about Offbeats events, email [offbeats@heartbeats.ca](mailto:offbeats@heartbeats.ca) to be included in the Offbeats email communications.



# 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](mailto:info@heartbeats.ca).

SAVE  
the  
DATE

## Annual Family Fun Run

Our 10th Annual Family Fun Run will be taking place on Sunday, October 20th at Eau Claire Market beginning at 9:00 a.m. This is Heart Beat's biggest fundraiser of the year and we ask that you help us make it the best run yet by promoting it to your friends, colleagues and on your social media.

If you are planning to collect donations for Heart Beats with your participation in the Family Fun Run, we invite you to encourage your donors to increase the impact of their donation by donating to Heart Beats before September 1st through Shaw Birdies for Kids presented by AltaLink (BFK) at [shawcharityclassic.com/donate/heartbeats](http://shawcharityclassic.com/donate/heartbeats). Donations made through the Running Room have a 6% administration fee deducted, and donations made through CanadaHelps.org have a 4% administration fee deducted, but donations made through BFK incur no administration fee and are matched up to 50%.

### REGISTER NOW FOR THE RUN

Please visit [www.runningroom.com](http://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



## Heart Beats

Heart Beats is a purely volunteer-run organization by parents whose own children have congenital heart defects, and we are always looking for other people to join us in giving back to this community we have all been personally touched by. We meet four times a year as a board but also have one-off opportunities for you to volunteer as well, whether it be hosting a mom or dad's night or a parent & tot playdate. We invite you to reach out us by emailing us at [info@heartbeats.ca](mailto:info@heartbeats.ca). We also welcome ideas for future events or initiatives.

## 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.

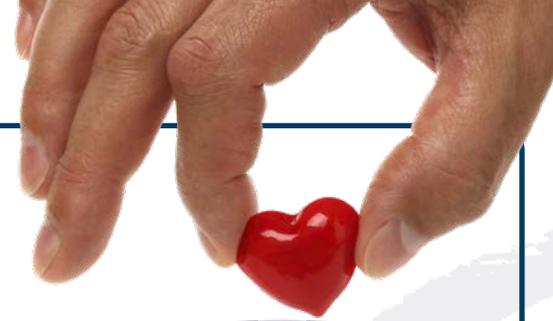


Other fun events are coming up too like Summer Lake Day, and Heart to Heart Parent and Tot so keep an eye on your email.

# 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  
[treasurer@heartbeats.ca](mailto:treasurer@heartbeats.ca) (remember to include your mailing address to receive the receipt).

### Credit Card

through [CanadaHelps.org](http://CanadaHelps.org)  
(a link can be found on our website at [www.heartbeats.ca](http://www.heartbeats.ca))

## Donations received from November 2018 to May 2019

Thank You

Leah Abday  
Debbie Barnes  
*In Memory Of Frieda Steg*  
Brett Cole  
Laurent Foulonneau  
Josephine Frangou  
Cathy Howarth  
Chelsey Leidl  
Annabella Loewen  
Jeremiah Loewen  
Mathias Loewen  
Edith Mack  
Scott Malachy  
Andrea Morrow  
Todd & Jeannine Oliphant  
*In Memory Of Alysha Oliphant*  
Kimberly Roberge

Muyo & Selzeta Sehic  
*In Honour Of Xander Hesketh*  
Kim Twohig  
*In Honour Of Finn Twohig*  
Melanie Wilson  
Anonymous  
*In Honour Of Jeriah Bear*  
ATB Financial  
Atco Epic – Pipelines & Liquids  
Beerguys Craft Club  
Mode Fitness Inc.  
Rocky Mountain Charitable Giving Fund  
Watson Family Foundation Fund  
At Calgary Foundation  
Kelly Hewson & Gordon Salahor  
*Through Benefaction*  
Anonymous  
*Through The Benevity Impact Fund*

Anonymous  
*Through The Paypal Giving Fund*  
Craig Heskety  
*Through Shaw Birdies For Kids*  
Litwiniuk & Company  
*Through Shaw Birdies For Kids*  
Anonymous  
*Through United Way Of GM & SENB*  
Jessica Cole  
*through United Way of Calgary, Donor Choice Program*  
Thomas Mccarthy  
*Through United Way Of Greater Toronto*  
Karen Perl-Pollard---  
*through United Way of Calgary, Donor Choice Program*



# A Great Fundraising Opportunity

Through Shaw Birdies for Kids presented by AltaLink

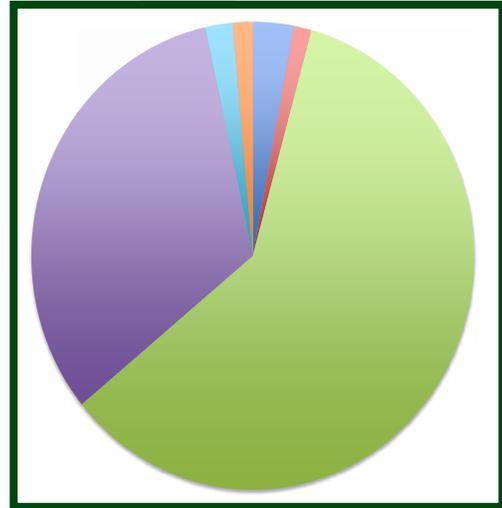


Heart Beats is thrilled to be partnering with Shaw Birdies for Kids presented by AltaLink (BFK). BFK is a non-profit program run under the Calgary Shaw Charity Classic Foundation which supports local charities. [For any non-golfers, the Shaw Charity Classic is a PGA Tour Champions event being held in Calgary August 28 – September 1, 2019.]

Donations made to Heart Beats through BFK will not only be processed by BFK without charging any administrative fees, but BFK will also match the donations up to 50%! So this is a great opportunity to increase the impact of donations to Heart Beats!

However, this opportunity ends September 1, 2019! So contact your family members, friends, employers, etc. and encourage them to donate to Heart Beats through BFK today! To donate, go to <https://shawcharityclassic.com/donate/heartbeats>.

# Wonder where Heart Beats' donations go?



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

# Spotlight on Donation from ATB Financial

ATB Financial sets aside money for donations and sponsorship for organizations where ATB team members volunteer. ATB Customer Service Representative, Harvinder Singh Anand, nominated Heart Beats to receive funds in appreciation for how Heart Beats has supported his wife, son, Prabhnoor, and many kids like Prabhnoor.

*Thank you Harvinder,*  
and **ATB Financial!**



## 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](mailto: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](http://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.



# Spotlight on Donation

The South Slope 4H Club is a multi-club consisting of twenty-six members and five cleavers. This year the club was responsible for raising and selling a donor steer at the annual Newell District 4H beef show and sale held on May 27 in Brooks Alberta. Each year the club responsible for the donor steer chooses charities they would like the money raised to go to. This year the South Slope 4H beef club chose Heart Beats as one of three charities. The steer was donated and raised by Janzen Ranches and the feed was donated by Trouw Nutrition.

At the sale the steer, named Orion, was bought ten times!! The last buyer then donated the beef to the local food bank. South Slope members, leaders and parents were overwhelmed by the support and generosity of the community.

It was truly a very emotional evening for all involved. Orion raised \$36,623.00 that night!! South Slope is excited to present Heart Beats with a donation from their steer.

A heartfelt "thank-you" to Megan and Shannon Andrews and the South Slope 4H Club for your support!



## Asher's Lemonade Stand

Asher is a 4 year old Heart Warrior - at seven weeks old he had open heart surgery.

This past year he started asking me what the scar on his chest meant. I think his preschool friends started asking him about it when they noticed it at swimming lessons. Kids are curious, and I was expecting the day to come that questions about his surgery would be asked. Now we talk about it all the time, and he calls his scar his warrior stripe.

He is confident with his body because he knows that scars are beautiful and to be worn with pride!!!

On May 26th, Asher decided to have his first lemonade stand to raise awareness and money for (his words) "heart babies like he was". He was so proud and successful that he wants to continue having lemonade stands all summer long! At the end of the summer he is going to donate all of his lemonade money to Heart Beats to help families in need - just like the help we had.



Asher's Mom



## Wish Granted: Hunter Brown

On November 17, 2018 our heart warrior's wish was granted by the Children's Wish Foundation. We got approved back in 2017 and after glancing through the projected wishes, we decided that if Hunter could communicate, he would wish for an all-weather swim spa! It took a few months and back and forth to get everything in place, however on the morning of November 17 we got to watch as this 12ft swim spa was craned right into our backyard! We also had the pleasure of having the Calgary Fire Department fill the pool and as the Children's Wish Foundation promised, we had a very special visitor: Spider-Man swung by!

Since having the swim spa, Hunter has had increased stamina and his tone has changed too. Hunter has always been in some type of aquatic therapy and we really wanted to keep up with the benefits of this therapy for him. Some benefits include continued rehabilitation, relaxing muscles, enhanced range of motion, increased stamina and agility and even provides excellent resistance to build muscle and core strength. We absolutely love our swim spa and are so grateful Hunter's wish was granted! It's been truly a life changing experience for our whole family and Hunter's GRIT team.

Hunter's Mom



## Heart Beats and Social Media

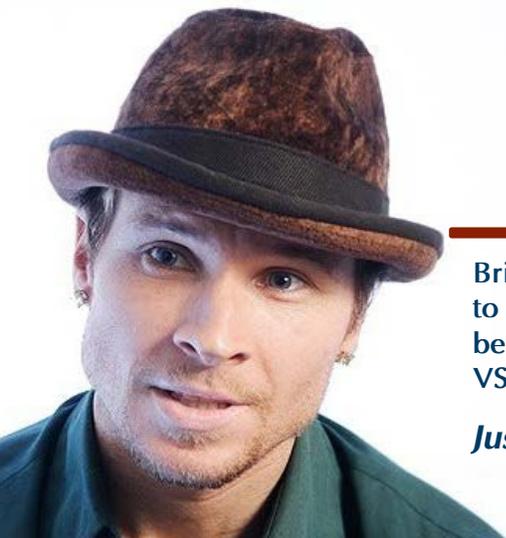
Find us on Facebook... and Twitter...and Instagram



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



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



## CHD Celebrity: Brian Littrell

Brian was in the hospital for two months, where he was clinically supposed to die. He had bacterial infection called bacterial endocarditis. At 18 he then became a Backstreet Boy, then at 23 he required open heart surgery to repair the VSD.

*Just shows that CHD didn't hold him back.*

# CAMP DEL CORAZON

Camp del Corazon is an organization that provides a medically supervised, residential summer camp for children ages 7-17 who are living with heart disease. Located on Catalina Island, 22 miles off the California coastline, the camp has served approximately 300 children each year since 1995. The camp offers an opportunity for heart kids to be 'normal', to forget their ailments, and to connect with others who have had similar experiences and scars. Camp del Corazon offers the camp free of charge; the only cost for campers is transportation to and from the camp.

Last year a record eight young people from Calgary attended – four repeat campers and four first-time campers. For all it was a great experience:

*The camp was awesome. I really enjoyed meeting new friends and all the great activities. A funny thing happened to me when snorkeling; I tripped over a sea turtle and we both got a big shock! It was super cool. My favourite part of camp was having a party on the last day with all my new friends.* Kahlan (age 8, first time camper)

*Very fun! Definitely worth going to. Thank you to all in Calgary, California and beyond that make this camp happen!* Quinn (age 11, repeat camper)

*Highlights of the camp for me were:*

*Beating a lot of records (best only camper kayak team, fastest crossing of "pipe dreams" with Mathias, fastest crossing of "postman's walk")*

*"Wake and Win" morning hike*

*Raising the Canadian flag twice along with the US flag*

*Being able to go with a friend (Mathias)*

*Loic (age 15, first time camper)*

*When I am at Camp del Corazon I'm at my happiest. I forget about the struggles I am going through with my heart. I just get to be a normal kid having the time of my life!*

*Maddie (age 17, repeat camper)*



This camp was one of the best experiences of my summer, and I will remember this until at least next year. I was rarely bored as there were activities almost the whole time and almost all the activities were new and interesting. Some of my favorite activities were snorkeling, high ropes, and lunch. At first, I didn't think there would be very good food (I thought it would be ok but not that good) but the food was always very good. There were a good number of Canadians there and we even got to raise the flag in the mornings. Overall, it was a very good trip and I would definitely like to go again.

*Mathias (age 14, first time camper)*





*Camp Del Corazon was a really fun experience for me for the past four summers. I really enjoyed all the activities I was able to do there, and I liked meeting other campers and going back to see the friends I had made over the four years I attended.* Isabelle (age 17, repeat camper)

*Going to camp Del Corazon for four years was one of the most fun things I have ever done. The counselors, nurses and staff are all so supportive and fun. I wish this wasn't my last year. I hope that anyone who wants to go to the camp gets to!* Korynn (age 17, repeat camper)

*Thanks Heart Beats for the opportunity to attend this camp. It was so amazing, and I met a lot of new friends from all over North America. This was the best camp I have ever attended, and I want to go back and do it again next year. There were so many fun activities like snorkeling, sea kayaking, high ropes, yoga and climbing wall! I'm looking forward to next year's camp and meeting up with all my new friends once again!* Max (age 14, first time camper)

The 2019 Camp Session Dates are August 22-26, August 26-30, and August 30-September 3. For information on how to apply for camp, visit [www.campdelcorazon.org](http://www.campdelcorazon.org). Registration is open and spaces are limited.

Heart Beats has a scholarship fund that will cover the plane fare for first-time campers and provide subsidies for repeat campers. For more information, contact [info@heartbeats.ca](mailto:info@heartbeats.ca).



# “Teens Talk Transition” Workshops at ACH

“Teens Talk Transition” workshops are offered at the Alberta Children’s Hospital. The free workshops are held on four consecutive Saturday mornings, and are designed to help youth (ages 14-18) learn to manage their chronic health condition and prepare to transition to adult care. The sessions are peer-led and teach teens skills on balancing priorities, goal setting, creating action plans, communicating effectively with their healthcare team, and developing problem-solving skills. A workshop for parents is also offered simultaneously to assist parents in helping their teens develop medical management and self-advocacy skills.

17-year-old CHD teens Maddie and Isabelle, and their mothers Leah and Patty, attended the workshops last fall. All found them to be very informative and beneficial. The workshops addressed relevant topics and provided a number of helpful resources.

*Isabelle says, “The ‘Teens Talk Transition’ workshop helped me feel ready for my transition into adult health care. They had a lot of resources and activities to describe how adult health care is different from child health care and they explained a lot of the differences to us so that we could feel ready for the transition. Another thing I found helpful was guidance in how to describe my medical condition to others including medical people, employers etc.”*

*Patty says, “I think my biggest take-away from the Adult workshop was recognizing how I need to step back and hand control over to Isabelle for her medical care ... that my role isn’t so much looking after Isabelle anymore but rather helping her become equipped to look after her medical condition and needs.”*

Patty also appreciated the many resources that she became aware of through the workshop. A particularly helpful resource is the “Transition” section of the Family & Community Resource Centre website at <http://fcrc.albertahealthservices.ca/transition>.

Maddie found the Teen Workshop so helpful, she decided to “pay it forward” by becoming a peer leader for the Winter Session of the “Teens Talk Transition” workshop. For more information or to register for a workshop, contact Deb Thul at 403-955-7252 or [Deborah.Thul@albertahealthservices.ca](mailto:Deborah.Thul@albertahealthservices.ca).



## Teens Talk Transition: A Mom’s Awakening by Leah Hofer

I used to believe that after so many years of playing “Supermom” in the life of someone with medical challenges, I was equipped to face anything head-on. Then I looked at the calendar and realized my little girl was turning 18 years old. The sudden knowing that my only sense of control during uncontrollable circumstances would soon be taken away and given to my daughter was the stuff that made me start to crumble. It also alerted me to how my coping skills, although somewhat effective in survival during the toughest days, lacked solid foundation and might be somewhat of an illusion. Yes, I’m talking about the perceived sense of power and control that comes with being a parent and making all the decisions about what is best. Desperate to stop myself from passing on my issues to my kid, I called our amazing nurse, Patty Knox, for advice. That’s when I heard about Teens Talk Transition. It’s a four week program at ACH where teens can get information and guidance from other teens about navigating the adult medical world. Brilliant! As I was in such denial that I would one day allow my daughter to be in charge of her own life, I had not done any work to prepare her. Even more brilliant was the parent group that met down the hall to talk about “parenty” stuff. What a relief to know that I wasn’t the only parent struggling to let go! What a safe environment to admit that I was terrified to let my amazingly capable daughter be an adult! We set goals each week and stumbled together through the new world of empowering our kids. We heard reassuring stories from survivors of this transition that normalized our own processes. That was the big message for me -- transition is a process, not an overnight event. We are now well into life in the adult world and I am happy to report that we not only survived; we kinda rocked it! Although my daughter manages the day to day medical tasks, the big stuff is still shared with her Dad and I by her side. Her new doctors have been compassionate and inclusive while recognizing that our daughter is the real superhero of this story and is as braver and wiser about her health than anyone else in her life.

If you have any concerns about letting your teens take full charge of their health care, or if you have any concerns about their ability to do so, I highly recommend this program. If you have no concerns, still sign up and get all the great information and advice so that you and your teen can have every advantage moving forward. Two of my daughter’s friends were transitioning so we all signed up together. We have been supports for each other over the years and now we are informed supporters! I am so grateful to our friends and to all the wonderful people involved in the program. Just so you know, my daughter loved it so much she came back to be a facilitator. Maybe she can do something to help your teen.



# Cardiology Clinic Update

## Alberta Children's Hospital



We are pleased to announce that a new Cardiologist will be joining us in July! Dr. Kandice Mah comes to us by way of Toronto, Edmonton and Saskatoon. She brings with her a wealth of experience and has a keen interest in echocardiography.

We are also very pleased to welcome Kim Dingle (LPN) to our Cardiology team. Kim comes to us with 17 years of experience, most recently in the Sensory Clinic (ENT & Plastics) here at ACH. Kim is married with 2 beautiful children and loves to camp! Currently Kim's primary role is to support clinic flow and rooming of patients. This is a new role for our clinic and so far it has been a very welcomed addition. We anticipate that the LPN role will grow and expand over time to help meet the ever growing needs of our clinic.

In keeping with ACH's "Commitment to Comfort" initiative, Heart Beats has generously donated 2 new iPads to our clinic to assist with distraction during clinic visits and testing. These iPads will be used, along with other distraction toys, on an as needed basis. At this time the iPads will not be able to be reserved for your child's appointment.

As many of you may already know, our renovations are complete! This project was a long time coming, but we are very happy with the additional space we gained and thankful for the generous donation from CP that allowed this to happen.

The month of February was an excellent time to raise awareness of CHD. Aside from Valentine's Day, February was Heart Month and the week of February 7-14 is Congenital Heart Defect Awareness Week. CHD Awareness Week is an annual awareness effort to help educate the public about congenital heart defects. Participants include individuals, local support groups, national and local organizations and congenital cardiology centers around the world. Calgary mayor Naheed Nenshi has issued a proclamation acknowledging February 7-14, 2019 as Congenital Heart Defect Awareness Week.



### PROCLAMATION

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

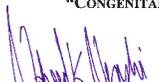
Whereas: More than 50 percent of all children born with CHD will require at least one invasive surgery in their lifetime;

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

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

On behalf of City Council and the citizens of Calgary, I hereby proclaim the week of February 7-14, 2019 as:

**"CONGENITAL HEART DISEASE AWARENESS WEEK"**

  
NAHEED K. NENSHI  
MAYOR



Spring & Summer



# PARENTING A CHILD: WHOSE SECOND HOME IS THE HOSPITAL

Article written by Kathryn Sneed at [www.singingthroughtherain.net](http://www.singingthroughtherain.net)

When I dreamed about becoming a mom, I never once asked myself the question, “What if my child was chronically ill?”

When we think about becoming parents we think in terms of healthy and whole. We hear, “We don’t care what gender the baby is as long as he or she is healthy.” But what if the baby isn’t healthy? What if your child had to spend more time inside hospitals and doctor’s offices than at home?

Nothing can prepare you for parenting a child who is medically complex and whose second home is the hospital. It is the one thing I have struggled with for the entire four years of my daughter’s life and I never imagined that this would change the way I parent, but it has and it did.

## HOW HOSPITAL LIFE AFFECTS PARENTING

### 1. EXHAUSTION

People talk about exhaustion when you’re a new mom. That “baby-cries-all-night-long-and-I-just-need-to-sleep” exhaustion. But for parents of a chronically ill child, this exhaustion never gets better and it is compounded by stress, worry, and fear.

I stress about my parenting, the way I parent, and if I am doing it right. I worry about the medical decisions I made, the ones I am making, and the ones I will have to make in the future. I fear for my daughter, wondering if she will be safe, wondering if she will ever have a “normal” life.

Exhaustion can make or break you as a person. If you’re a parent you know exactly what I mean. For my family, exhaustion is our constant whether we are in or out of the hospital. It is very hard to be the parent your child needs when you are exhausted. Your guard is down, you’re less likely to be firm and consistent, and it’s easy to resort to irritability or anger.

### 2. EMPATHY

Most parents feel empathy for their child when they go through hard things. It’s hard to watch your child go through something painful. It’s hard to hold your child down for a medical procedure knowing that it’s for their own good. It’s hard not to take your child’s feelings and feel them as your own.

While I would do anything to take my daughter’s pain as my own, the hardest part of empathy when your second home is the hospital is the urge to spoil her and give her whatever she wants because of it. It can be easy to resort to bribing or buying things to make her happy or make her feel better. It can also be easy to make excuses for bad behavior. While I feel bad and empathize with what she’s going through, it is still my job to parent her, not spoil her and let her do whatever she wants.

## COMING TO TERMS WITH PARENTING A MEDICALLY COMPLEX CHILD

While the “mommy wars” wage on and other moms worry about breastfeeding vs. bottle feeding, natural birth vs. medicated birth, regular snacks vs. organic snacks, and spanking vs. time-outs, my greatest parenting worry is how can I give my daughter the best quality of life right now and in the future?

For Elizabeth, it’s never going to be “just one” hospital stay. For her, it will most likely be a lifetime of hospital stays. Knowing that breaks my heart, but it has also made me stop and think about how I parent her and what I can do to be the parent she needs.

## HOW TO PARENT A CHILD WHOSE SECOND HOME IS THE HOSPITAL

### 1. CONSISTENCY.

In order to help with all the unknowns in your child’s life, consistency is key. Trying to be consistent whether you’re at home or the hospital will help your child know and understand (for the most part) what to expect. For us, that means trying to keep bedtimes the same as much as possible, and having the same rules and expectations as at home.

This will not always be easy. Bedtime in a hospital can be difficult due to nurses coming in and out, or the distraction of machines beeping and your child missing their own bed. A possible solution to this is to keep the same bedtime but lay down in the bed with your child until they fall asleep.

Having a rule that your child will not hit or spit at you may be fine until your child is in the hospital and is tired and angry. But you can keep consistency by telling them you understand why they are upset and that it’s okay to be angry, they just do not need to take their anger out on you. If your child receives consequences (time-out, toy taken away, etc.) for this at home, then they should receive the same or similar consequences at the hospital. This sets the expectation that your child will not get away with bad behaviors no matter where they are.



## 2. EMPATHY.

While I mentioned above that empathy can affect parenting a child whose second home is the hospital, I also believe it can be a helpful tool for parenting a child with complex medical conditions. In order to understand what my daughter goes through, I must try and put myself in her place.

I've had many doctors and nurses ask me, "How would you feel if...?" This helps me think about it from a different perspective. If my daughter needs to meet a certain calorie goal, but she's not feeling good, do I push her? Not usually, because I know that when I am sick or not feeling well I don't feel like eating either.

Empathy has helped me to understand how she feels, which in turn gives me direction in how I parent her. It has also helped give me the words to explain things to her and how to know what is age appropriate to tell her and what is not.

## 3. PERSPECTIVE

Sometimes we as special needs parents are private. We know that people don't always understand what we go through so we close ourselves off. But what we don't realize is that sometimes an outside perspective can be the key to helping us get through a tough situation.

You've heard the phrase, "It takes a village," and while I don't believe that using a village to help raise your child in every single aspect is wise, I do believe that for special needs parents, sometimes it takes a village to help get your child to where they need to be.

Your village may be doctors, nurses, family members, or a few close friends who can offer advice from an outside perspective. While there have been many unhelpful "tips" I've received from people trying to be helpful, there have been many more things said that have changed my mind and perspective on how I raise my daughter.

## 4. ACCEPTANCE

One of the things I've had to learn over and over again is acceptance. I've had to learn to accept many of my daughter's medical diagnoses. Some were harder to accept than others. But what I've realized is that it's hard to move forward without acceptance. Not being willing or able to accept your current situation or child's diagnosis is what holds us back from reaching our and our child's full potential.

Read that last sentence again. It may be hard to hear it now, but looking back acceptance and moving forward has been the key that has unlocked much great potential in myself and my daughter. Our kids are watching us. They see how we react and they see how we deal with things. What will they see you do?

## 5. NORMALIZATION

Once we have learned to accept our child's situation and diagnosis, then we can move on to normalizing it for the child. This is one I've been learning lately and am really having a tough time with. I keep asking why we would want to normalize medical procedures, hospitalizations, and doctor's appointments?

But I've realized that this IS her normal. Her genetic diagnoses aren't going away, and neither will the doctor's appointments and hospital stays. If I don't accept this as normal, then neither will she. Helping my daughter understand that this is her normal and that's okay will help her grow up accepting her situation and help her advocate for herself better.

## 6. SELF-CARE

In order to parent a child with medically complex needs, you must take time for yourself and care for yourself. I've learned that if I don't take care of me then I can't take care of her. Self-care may look like different things to different people. For me, it means counseling, anti-depressants, chiropractor care, and respite care for my kids. Sometimes it means taking turns watching the kids with my husband so we can sleep in or nap. Whatever it is, whether it's big or small, find what's right for you.

## 7. GRACE

Last, but not least, give yourself some grace! None of us are perfect parents. We will make mistakes. But learning from our mistakes, giving ourselves some grace, and moving toward the future is what our children need us to do. You must find what works for you. It's not going to be what everyone else does. Even the tips in this article might not work, but once you find ways to give yourself grace, you will find the parenting success you seek.

## WHAT ABOUT YOU?

I get it. Parenting a medically complex child is HARD work. There's nothing like having to choose between difficult medical decisions and trying to find the one that will help your child the most and there's nothing like having your second home as the hospital. But if no one has told you yet today, you're a great mom, you're a fantastic dad, and you're doing a great job!

# 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](mailto:newsletter@heartbeats.ca) for inclusion in our next newsletter.

Lucas Neander is graduating from High School this year. This is a miracle on so many levels! Lucas turned 18 in May and is also graduating from pediatric care which is a challenging transition. *Thank you, Heart Beats, for ALL your support over the years!*



Isabelle Wiebe turned 18 in May and graduates from Centennial High School in June. In the Fall, she will be attending Columbia Bible College in Abbotsford



It's been a year of transition for Maddie Bosgra. Starting with the graduation from Camp del Corazon in August to the transition to adult care at the Peter Lougheed Centre in the fall, Maddie has said her goodbyes to the many people who cared for her throughout her childhood. Now graduating from high school, Maddie is excited to launch into her post-secondary life at Mount Royal University, majoring in Public Relations with a minor in Creative Writing. Maddie hopes to spend part of her career in the corporate sector, but plans to dedicate much of her career to the non-profit world, giving voice to vulnerable populations. For now, Maddie is happy to continue her volunteer positions with ACH's CAYAC and Teens Talk Transitions Program. Maddie promises that one day she will also volunteer with Offbeats so she can be the kind of mentor and friend that she has encountered as a youth. No wonder Maddie was a Great Kid Award recipient and Youth of Distinction finalist! Our eternal thanks to the village that helped raise our daughter!



Aurora celebrated her 2nd Zipper day on May 26th. She and her family cook every year for the families staying at Ronald McDonald House in Calgary to celebrate everything she has overcome



# BIRTHDAYS

John celebrated his 9th birthday on March 17. John has just celebrated his 8th open heart surgery anniversary. He's happy and doing well. Huge success this year is that John gets to see Cardio only every 12 months!! Grateful for stability and continued health.



Rukia & Orihime celebrated their birthday February 11



Marie celebrated her 4th birthday on April 1st. She became a big sister again to a little sister Lucia on March 14th.



Riley Winstanley celebrated her 4th birthday on June 3rd

Aurora turned 2 on April 15. She only just started walking and loves going on walks with her big sister Zara (as pictured)



# 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



# Family Fun Run

**Sunday, Oct. 20, 2019**  
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 insurance reasons). Please contact Jorge at [run@heartbeats.ca](mailto: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.)

## ENTRY FEE

- Early Bird (until June 30) - \$35
- Regular Fee (July 1 - Sept 15) - \$40
- Late Fee (Sept 16 - Oct 17) - \$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](http://www.heartbeats.ca)

## RACE PACKAGE PICK-UP

Friday, October 18th: 12:00pm to 7:00pm

Saturday, October 19th: 10:00am to 3:00pm

## PLEDGES AND DONATIONS

Donations can be made by clicking "Donate Now" at [www.heartbeats.ca](http://www.heartbeats.ca).

Donations and pledges can also be made at [www.runningroom.com](http://www.runningroom.com) or at race package pick-up/race day.



**Prabhnoor**  
7 years old



**Bentlee**  
8 years old



## In Memory of Callen

Prabhnoor was born with Ebstein's Anomaly. He likes programming, playing with robots and travelling to new places.

Callen was born with hypoplastic left heart syndrome and underwent 5 open heart surgeries in his short life. He loved all superheroes and pickles.

Bentlee was born with double inlet left ventricle, congenitally corrected transposition of the great arteries and pulmonary stenosis.

Callen passed away just after his fourth birthday while awaiting a heart transplant. He is missed by his friends and family and all those whose lives he touched.

She has had 5 heart catheterizations and 2 open heart surgeries! She is an active girl who loves cheerleading, and has recently found a new love of baseball.



Register online at [www.heartbeats.ca](http://www.heartbeats.ca)