



# Keeping the Beat

Fall 2022

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

## In this Issue

# HEART BEATS FAMILYCAMP 2022



On the beautiful weekend of September 11th, after a two-year pause, some of our Heart Beats families attended Camp Evergreen. The official dedicated weekend of activities for Heart Beats started back in 2016. A BIG THANK YOU to The Calgary Children's foundation for the sponsorship of our Heart Beats Camp this year. There was a total of 22 families that attended. Yet again, the staff at Camp Evergreen took care of us with providing amazing meals and opportunities for trail rides, a petting zoo, archery, Wilsonball, canoeing and Bazooka ball, just to name a few. At the end of the day children and families enjoyed the board games in the lodge, having a hot chocolate or tea while connecting with other families, making memories and a favourite... PacMan. The children and adults had a blast again playing PacMan after the Yodel'nHum at The Fort fire circle; it was a night to remember! Watch for information for the 2023 camp next year, as the camp was full within the first day of opening up registration. Looking forward to seeing many of you at other Heart Beats events. Thanks to Ramsey Kunkel/Lilian Au who brought a drone to take the amazing group picture.

- Heart Beats Camp 2022 ..... 1
- Heart Beats Camp Photos ..... 2
- CP has Heart ..... 2
- Heart Garden Dedication ..... 3
- WCCHN Update ..... 6
- Donating to Heart Beats ..... 7
- Subscribe to "Keeping the Beat" ..... 7
- Camp Del Corazon ..... 8
- Adjustable Heart Valves Grow with Kids ..... 9
- Birthdays ..... 10
- Back to School ..... 10
- Special Events ..... 10
- Kristy Wolf Project ..... 11
- OffBeats Update ..... 11
- Jokes: Holiday Edition ..... 12



# HEART BEATS FAMILYCAMP Photos



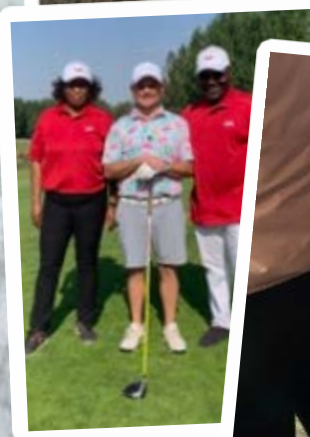
# CP has heart: September 7

CP has Heart and lots of it! On September 7th they held their suppliers golf tournament at Elbow Springs with all of the money raised going to Heart Beats.

It was a decently beautiful day, with the rain holding off. The Heart Beats crew set up on Hole #5 to run the Wheel of Fortune, which gave golfers a fun extra game, and also ran a 50/50 which raised \$2800 (\$1400 of which went to Heart Beats).

Dinner gave an opportunity for a family to tell about their experience with Heart Beats and this year featured Xander Hesketh and his dad Jon. During the dinner it was announced that the charitable donation this year to Heart Beats would be One Hundred and Ten Thousand Dollars!!!

Thank you so much to CP Rail and the tournament organizers and attendees. This donation will make such a difference in the lives of the families of the Heart Beats community. Also a big thanks to the Heart Beats volunteers that made it such a fun day!



**CP**  
HAS HEART

*Thank You*

# Heart Beats

## Memorial Heart Garden

**O**n August 27th the Heart Beats community got together to officially open the Heart Memorial Garden located within the Botanical Gardens of Silver Springs.

The garden and the get together are intended to be a tribute to both current Heart Heroes and to those that we have lost. The garden was beautiful and in full bloom. The amazing volunteers at the Botanical Gardens are always working their magic to ensure everything is as majestic as it can be.

The opening was hosted by heart hero Jaqui Esler and the ribbon was cut by two other heroes, Dr. Fruitman and Dr. Harder. There was also an appearance by our Honorable Mayor Jyoti Gondek who gave a speech. Then to take advantage of the everyone being together, we moved to the field area where there was games, food, and an ice cream truck, balloon animals and a performance by Heart Hero Leon on the drums.

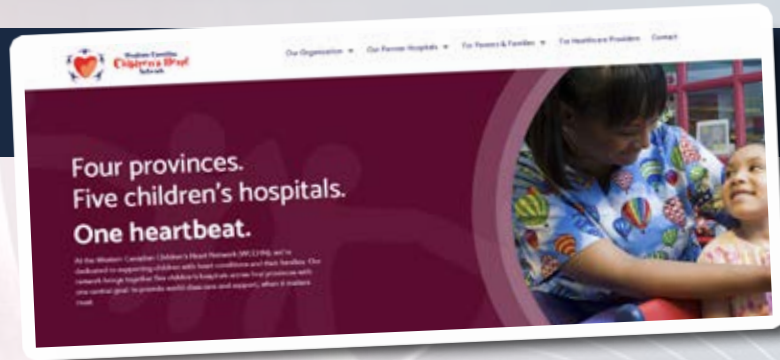
Special thanks to the Rogue Group for sponsoring the Garden, Jennifer Robin for the music, everyone who attended and all the volunteers that made the day possible.







## WCCHN Update



### WCCHN's New Website

Did you know that WCCHN's or Western Canadian Children's Heart Network has a brand new website? They're feeling pretty proud of how it's come together, and that many heart families were active participants in the development of its website and the messages of assurance it sends.

It is a great resources for information, so make sure to check it out to see the updates or to see it for the first time.

[www.wcchn.ca](http://www.wcchn.ca)

Also make sure to check out their YouTube channel!

### Get excited for Heart Week 2023 because WCCHN's BoostUp is back!

WCCHN's BoostUp Pitch Competition is designed to give good ideas a leg up. Innovators and change-makers across Western Canada are invited to ideate and pitch for funding. Give your project a boost by building, testing, and validating your plan. Let WCCHN help fund the mission.



This is a great event to watch and learn about what kind of innovative ideas are happening in our local Heart Community.

Live virtual event on February 9th 2023, 19:00 – 20:30

To learn more, apply to pitch, or register to watch please visit:

[TinyUrl.com/BoostUp23](https://TinyUrl.com/BoostUp23)

## TAG US ON YOUR SOCIAL MEDIA POSTS

We want to see more of our families and heart warriors on our social media so we can re-share what fun and adventures you have all been up to. Please use the hash tag **#heartbeatsyc** so we can find your posts.



Fall 2022

# Your Support in Action

Donations made to Heart Beats Children's Society of Calgary are used to provide information, resources and support to families living with congenital heart defects in Southern Alberta. The following is just a few ways your donations have helped:

- Financial assistance to families traveling to Edmonton for their child's heart surgery through our "Helping Hand Fund".
- Supplemental equipment for the Alberta Children's Hospital Cardiology Clinic.
- Items of encouragement for children undergoing extended hospitalization.
- Camp Scholarships for children with congenital heart disease.



## Donating to Heart Beats

If you wish to contribute to the support of families of children with congenital heart defects, you may do so in the following ways:

### 1) Online Donation through Canada Helps

Please go to <https://www.canadahelps.org/en/charities/id/62663> and choose "Donate Now" or "Donate Monthly". A receipt will be provided at the completion of your transaction.

### 2) Direct Mail to Heart Beats

If you wish to make your donation by mail, please send them to the address below. We will send you a receipt if your contribution is over \$20.00.

**Heart Beats Children Society, Box 30233, Chinook Postal Outlet Calgary, AB. T2H 2V9**

### 3) E-Transfer

Email to [treasurer@heartbeats.ca](mailto:treasurer@heartbeats.ca) for details. Be sure to provide an email address and mailing address to receive your donation receipt.

### 4) Make a directed donation through the United Way

(either one-time or through payroll deduction):

To make a payroll donation - fill out the United Way Payroll Donation Application Form, In Section 3, entitled: How I Would Like to Help the Community, check the "Other" box and indicate an amount to: "Heart Beats Children's Society of Calgary".

Please include our Charitable Registration Number: 88907 6261 RR0001

## Donations received from July - November 2022

**Anonymous**

*On behalf of Ferrel Beleshko*

**Cathy Howarth**

**Khizar Rattu**

*On behalf of Hajra Hayat*

**Dave Tadros**

**Kendra Massie**

**Michael Chai**

**Barry Walters**

**Shibanee Verma**

**Angela Ottenhof**

*On behalf of Hope and Lincoln*

**Michelle Mcleay**

**Cathy Howarth**

**Runze Xie**

*On behalf of Hope and Lincoln*

**Jeannine Oliphant**

**Mustang Randall**

**Trevor Pollock**

*Thank You*



**SKIP THE DEPOT**  
RECYCLING & FUNDRAISING

Heart Beats has a recycling program through Skip the Depot where your returns will go directly to Heart Beats! Please use the following link to get set up.

<https://app.skipthedepot.com/heartbeats>



## 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 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.



# Camp del Corazon 2022 Written by Jen Beleshko

Five Calgarian teens attended Camp del Corazon this summer for the first time. The camp is located on beautiful Catalina Island in Southern California and is run exclusively for youth with CHD.

The Calgary group, headed by Offbeats leader Vittorio Borelli and included two parent chaperones (Cindy Castillo and me), caught an early flight to California on August 17th. Sleepy but excited, we checked into our hotel and grabbed some lunch at Chipotle, just one of the restaurants that the teens wanted to try during the trip. We then drove to Pasadena and attended a live taping of America's Got Talent. It was very exciting!

*Photo: from left: Lucas, Jacob, Cindy, Sophia, Vittorio, Roman at America's Got Talent*



The following morning, after a big breakfast, we arrived at the departure port where our vehicle was greeted by staff members. The teens found out what groups they were in and turned in their medications and paperwork. After a quick round of covid tests, (all negative, thank goodness) we said our goodbyes and the kids boarded the ferry to Catalina Island.

Once at camp, the youth met their counsellors and got settled into their respective cabins. Over the course of the next 5 days, the Campers took part in a variety of amazing activities including kayaking, rock climbing, snorkeling and ziplining. Amid beautiful surroundings, the campers got to know one another, and friends were made. A dance party on the last day wrapped up a wonderful stay at Camp del Corazon.

The campers were greeted the following morning by Vittorio holding a box of fresh Krispy Kreme donuts! The teens spent the rest of the afternoon and evening recounting their adventures while we explored the boardwalk at Long Beach and browsed the shops for souvenirs.

*Photo: From left: Sitara, Sophia, Jacob, Lucas and Roman: all happy campers!*

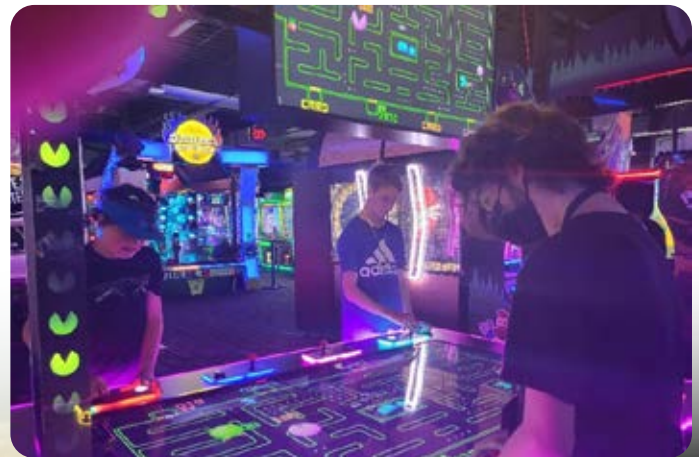
The next morning it was time to pack up and get ready to go home. Our flight home was delayed, and so we spent the afternoon exploring Hollywood before heading to the airport and catching the flight back to Calgary.

*Photo: Jacob, Roman and Lucas playing videogames in Hollywood.*

A HUGE thank you goes out to Heart Beats for covering the cost of the airfare and vehicle rental and to Vittorio who went out of his way to make sure that all the teens had the best time.

*I loved Camp del Corazon, it was a great experience for people like me who were born with a heart condition. Everyone there was so nice and the counselors were a lot of fun. I made so many friends with people in my cabin and also people not in my cabin. My favorite part was the rock wall, it was awesome. I would love to go back again next year!" – Sitara*

*"One of my favorite memories from Camp is making new friends and all the fun I had with them! I would love to go back if I can. It was a fantastically fun experience. My hope for generations to come is that they love the camp as much as I did." – Jacob*



*I thought the camp was great. I was able to kayak and snorkel for the first time in my life and I met a lot of new people. Hopefully I can go again next year and maybe return as a counselor when I'm an adult." - Roman*

*"Camp del Corazon was a great experience that gave me the opportunity to make friends that I am still in touch with. The activities were super fun and the counselors were all very nice. I loved that I got to meet other kids with struggles similar to mine!" - Alexa*



## CAMP DEL CORAZON

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

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. Camp activities include a climbing wall, adventure games, waterfront activities (i.e. swimming, kayaking), archery, court games, and "boom ball". 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.

Additionally, it offers an opportunity for parents to send their child to camp with peace of mind knowing it is staffed by medically trained volunteers including nurses and cardiologists. Camp del Corazon offers the camping program free-of charge. The only cost for campers is transportation to and from the camp. Heart Beats has a scholarship fund that will cover the plane fare for first-time campers and provide subsidies for repeat campers.

For information on how to apply for camp, visit [www.campdelcorazon.org](http://www.campdelcorazon.org). Registration is open and spaces are limited. For information on the Heart Beats camp scholarship fund, please contact us at [info@heartbeats.ca](mailto:info@heartbeats.ca)



# Adjustable Heart Valves Grow with Kids Hearts

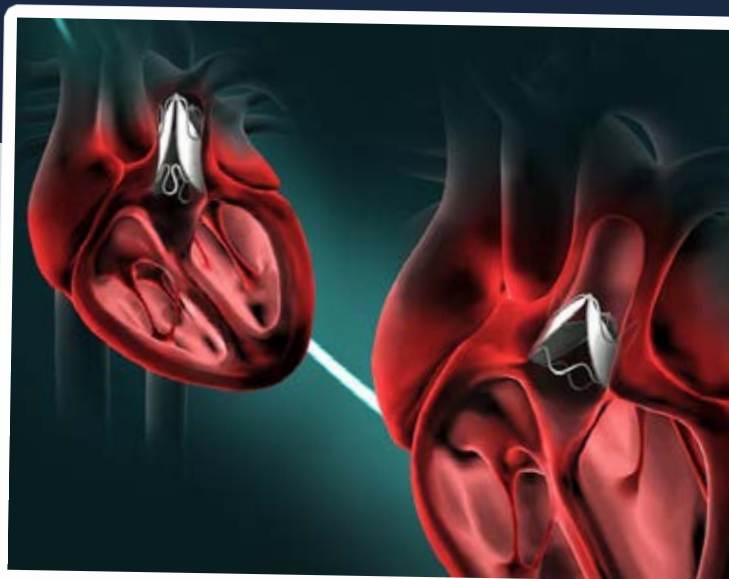
A variety of congenital cardiac abnormalities require the placement of prosthetic heart valves in very young children. As the hearts grow, the valves have to be replaced through repeated surgeries.

A team of researchers from Harvard and Boston Children's Hospital have now developed an artificial valve that can be expanded, via a minimally invasive transcatheter procedure, to compensate for the growing lumen within which it sits. Such adjustment procedures are a lot easier on the patients and considerably cheaper to perform.

While existing prosthetic heart valves usually have three leaflets, this valve relies on two leaflets, similar to how venous valves operate in our legs. Since they are designed to adapt to expanding and contracting vessel size, the same approach works well for pediatric valves. "Veins carry approximately 70 percent of our blood volume, and their dimensions can change dramatically depending on body position," said Sophie Hofferberth, MD, a leader of the research, in a Boston Children's Hospital press release. "We mimicked the geometric profile of the human venous valve to design a bileaflet heart valve of programmed dimensions that is adaptable to growth without loss of one-way flow control."

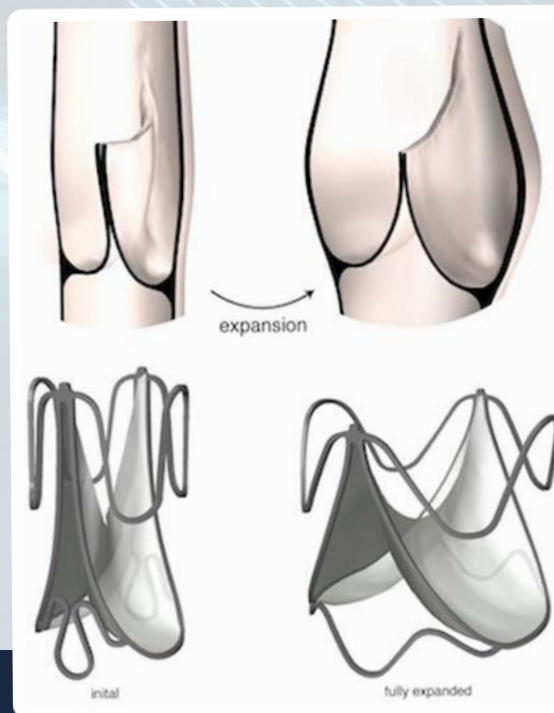
The device has already been tried in sheep who were implanted with the new valve and allowed to grow, and the valve performed as expected, correctly functioning through the cardiac cycle to open and close blood flow access while being able to be repeatedly adjusted throughout the study.

Clinical trials are expected to be conducted on the new valve fairly soon, as such capabilities would have a significant impact on hundreds of thousands of children.



## *Some additional details about the findings, according to Boston Children's:*

- *In multiple rounds of testing, valve prototypes were able to expand to accommodate growth and structural asymmetries within the heart. They remained fully functional across a range of dimensions, pressures, and flow rates.*
- *Because the valve can expand without requiring the frame and leaflet to stretch or enlarge, it is compatible with a range of off-the-shelf materials, the researchers say. The researchers successfully and safely expanded the device at multiple timepoints in a growing sheep model, using a balloon catheter.*
- *The researchers also observed that the bileaflet heart valve design encourages good blood flow through the valve. This could potentially reduce the risk for blood clots, a complication often seen with existing prosthetic valves. The team saw no evidence of blood clot formation in the growing sheep model over 10 weeks of observation, even without the use of blood-thinning medication typically given to prosthetic valve recipients.*



This article was courtesy of medgadget.com and the images come from the Boston Children's Hospital. The original article can be found here: <https://www.medgadget.com/2020/02/adjustable-heart-valves-grow-with-kids-hearts.html>

Will your child be celebrating a birthday between Nov-Feb.? 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.

# Happy Birthday

Alexa Castillo (critical aortic stenosis, HLHS) turned 15 on October 14!



Emmett Reist turned 3 on March 16

# BACK TO SCHOOL



Hunter First day at school

Emmett started preschool this past September and is loving it



## Special Events

On September 30 Emmett had his two year Heartiversary from his last heart surgery at Stanford in California



Hunter at Stamps game



Ryan Smethurst was engaged August 21. He is a heart kid (TGA /VSD). His fiance is a nurse at the Red Deer Regional Hospital . Ryan is finishing up his business degree at Mount Royal University, and will begin his CPA designation at KPMG in Calgary. They are getting married March 25 , 2023. Mom , Heidi and dad, David, are thrilled!

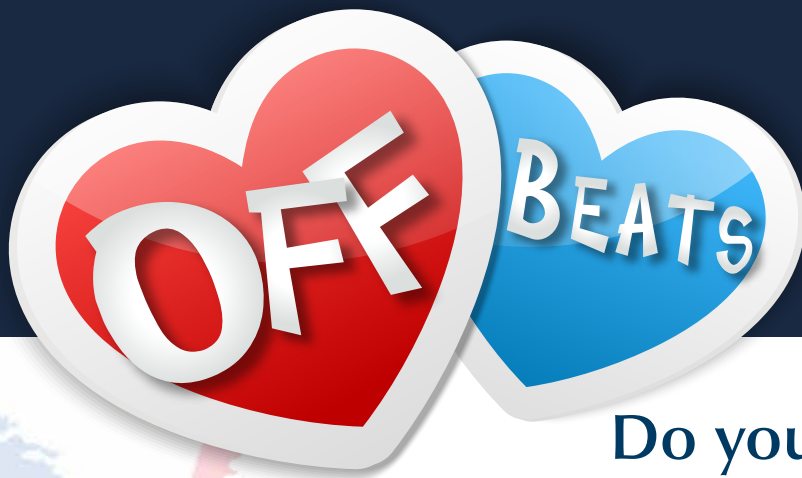


Wells Robert Blatchford will have his first birthday on March 9th, 2023. Sadly he was born sleeping March 9th, 2022. He passed in surgery (inutero at Toronto Sick Kids) to correct his 2nd CHD.

## Moms Night

What a lovely evening after almost three years! It was very nice to see new and old faces. Thank you, Heart Beats, for the complimentary appies and be vies and the opportunity to get out of the house with other Heart Moms.





# UPDATE

## Do you know about OffBeats?

Offbeats host events and get togethers, for junior and senior high-school aged youth with CHDs. These take place throughout the year and include activities such as neon bowling, laser tag, lake days etc. Here are some pictures of some recent OffBeats get togethers.

### Tentative OffBeats Save the Dates

February 11 2023 – In Person

April 22, 2023 – In Person

May 13, 2023 – Virtual

June 24, 2023 – In Person

Contact [offbeats@heartbeats.ca](mailto:offbeats@heartbeats.ca) for more information.



**K**risty Wolfe, parent of 10 year old heart warrior Kane Wolfe, is heading down to Miami to offer a parent perspective during the Pediatric Cardiac Intensive Care Society's Annual Meeting in December. Kristy is participating in three plenary panels around the following topics

*What is a Center of Excellence?*

*Regionalization of Care - is it Possible?*

*Can Internal & External Data Transparency Improve Outcomes?*

Kristy was hoping for parent perspectives on the pros and cons of having to travel to another pediatric hospital for surgical interventions. Feel free to contact her directly at [kristy.wolfe.photography@gmail.com](mailto:kristy.wolfe.photography@gmail.com)

Kristy is also presenting her own session: *The Importance of Telling and Sharing Your Story – Using Digital Storytelling to Foster Healing and Resilience*. To learn more about digital storytelling visit <https://kristywolfephotography.com/digital-storytelling/> or check out the digital story the Western Canadian Children's Heart Network co-created, *Imagine* <https://youtu.be/c5ykt8DYNfs>



## Heart Beats

Children's Society of Calgary

<b>Chairperson</b>	Uli Ng
<b>Vice-Chairperson</b>	Tara Exall
<b>Treasurer</b>	Golden Bhatia
<b>Secretary</b>	Jessi Badrudin
<b>Nurse Liaison</b>	Patty Knox
<b>Communications Director</b>	Jacqui Esler
<b>Run Director</b>	Donna Iverson
<b>Newsletter Coordinator</b>	Jon Hesketh
<b>Offbeats Leader</b>	Vittorio Borrelli
<b>Transition Liaison</b>	Cindy Castillo
<b>Fundraising Coordinator</b>	Jessi Badrudin

### Additional Directors

Brett Stevenson  
Katrina Randall

### Volunteer Ambassadors

Jen Beleshko, WCCHN Liaison  
Kathy Winstanley, Kids Up Front Coordinator  
Keremy Dry, Family Camp Coordinator  
Family Connections  
Peer Mentor Liaison, Kristina McGuire

### Mailing address:

Box 30233 Chinook Postal Outlet  
Calgary, AB T2H 2V9

**Website:** [www.heartbeats.ca](http://www.heartbeats.ca)

**E-mail address:** [info@heartbeats.ca](mailto:info@heartbeats.ca)

**Phone:** 587-432-8096 (Uli Ng)

Charitable registration number 88907 6261 RR 0001

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

## Celebrity Heart Corner

**T**he eldest Stallone sister, Sophia first underwent a successful heart surgery at just 2 months old, when doctors corrected a congenital malformation of a valve.

This wasn't the last time for Sylvester Stallone's now 26-year-old daughter, however. Sophia most recently underwent heart surgery in 2012.

Before the successful operation in 2012, Sophia told *Paris Match*, "Every day I think of my heart. I eat really healthy, and as I get more tired than normal, I have to be very careful when doing sports."



## HA HA! Holiday Edition.

What do fish sing during the holidays?

*Christmas corals!*

What do gingerbread men sleep on?

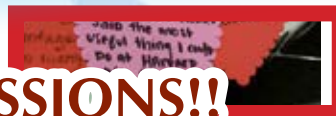
*Cookie sheets!*

Who was the snowman's favourite aunt?

*Aunt Arctica*

What's the first thing an elf learns in school?

*The ELFabet*



## WE WANT YOUR SUBMISSIONS!!

The Heart Beats newsletter is built around the strong Heart Beats community and the people in it. It is important to hear about the events and journeys of the all those in the community.

Should you have anything that you would like to contribute to the newsletter please submit it to [newsletter@heartbeats.ca](mailto:newsletter@heartbeats.ca)

*Examples of some types of submissions:*

*Heart Warrior Stories and Journeys*

*Transitioning Stories – Experiences of those transition from Pediatric to Adult cardiac care.*

*Grandparents Corner – Experiences from the viewpoint of a grandparent.*

*Community Announcements – Birthdays or special events*

*Heart Beats Events – Experiences from events such as Camp, Christmas Party etc.*



Fall 2022



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Dad of a Heart Child  
[www.immersiondesign.ca](http://www.immersiondesign.ca)

