

# KEEPING THE BEAT

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

## SPRING 2023 In this issue

Heart Month Party	2
Donations	3
Upcoming Events	4
Heart Run	5
Boost up Compitition	6
Boost up Compitition	7
Neuropsychology	8
Celebrity/Garden	9
lokos	10



After a two-year pause, the Heart Beats Holiday Party was back and was better than ever!



We are thrilled to share the excitement and success of Heart Beats' most recent event, the Heart Party, held on February 11, 2023. It was an unforgettable gathering filled with joy, crafts, games, and sensational music that had our hearts dancing! The event was beautifully decorated with vibrant colors, heart-shaped decorations, and

captivating visuals, setting the stage for an extraordinary celebration.

Craft stations were a major hit at the Heart Party, offering guests of all ages the opportunity to unleash their creativity. The craftsmanship and imagination on display were truly remarkable. There was also the amazing DJ Dan from Big DEEZ DJ Services who had everyone on their feet and grooving to the rhythm



Heart Beats' Heart Party was a resounding success, leaving all attendees with hearts full of joy and cherished memories. We extend our deepest gratitude to everyone who contributed to this fantastic event, including the dedicated volunteers, sponsors, and our wonderful community. Stay tuned for more heartwarming events and initiatives from Heart Beats, as we continue to spread love and make a difference in the lives of others.



#### DONINGONS: YOUR SUPPORT IN LIGITON

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.



#### WAYS TO DONATE 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. Direct to Heart Beats

If you wish to make your donation by mail, please send it 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 To make an e-transfer please email to treasurer@heartbeats.ca for details. Be sure to provide an email address and mailing address to receive your donation receipt.

2. Online Donations through Canada Helps

Please go to <a href="https://www.canadahelps.org/en/charities/id/62663">https://www.canadahelps.org/en/charities/id/62663</a> and choose "Donate Now" or "Donate Monthy".

A receipt with be provided at the completion of your transaction.

3. 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

SKIPTHEDEPOT RECYCLING & FUNDRAISING

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

https://app.skipthedepot.com/heartbeats



Have your donation to Heart Beats matched up to 50% DONATE



## UPCOMING EVENTS









SUMMER CAMP 2023 DATES

Session 1: August 17th - 21st

Session 2: August 21st - 25th

Session 1: August 25th - 29th

For information on how to apply for camp, visit <a href="https://www.campdelcorazon.org">www.campdelcorazon.org</a>. Registration is open and spaces are limited.



Saturday June 10, 2023











This year we are returning to Confederation Park for a 5km run and 3km walk at 10:00 am. Please note that this is a fun event and is not timed.

We are also excited to host a free kids fun event at 11:00, to be held by the Community Centre. Although this is a free event, please remember to register to ensure every child receives their gift.

The package pick-up for all events is at Rosemont Community Centre from 8:00 am to 10:00 am, on the morning of the event.

#### Registration Fees:

Children ages 3 and under are free Children ages 4 to 12 are \$15 For all other participants registration is \$40.

#### Awards:

All registrants will be entered into a draw for some amazing door prizes. Fundraising prizes:

Top 3 individual fundraisers

Top 3 team fundraisers

To register visit the Heart Beats website or click on the heart below.









The second annual WCCHN BoostUp Pitch Competition was a phenomenal event and a huge success. From the submitted applications, 6 finalists were selected to pitch for a chance to win in one of 3 prize categories. Awarded live that evening, over \$28,500 in funding will be distributed to help support important heart projects. Three prize categories included the Audience Favorite, Judge's Choice, and Alumni's Pick, as well as a \$500 Pay-it-Forward Raffle for the audience.

Members of Heart Beats were involved in two of the pitches for this years finalist. It was an amazing evening of generating energy, changing the conversation, and growing good things for our heart community

#### AUDIENCE FAVOURITE

#### VIRTUAL HEART CONNECTION: FONTAN FAMILY CAMP



The Virtual Heart Connection is a virtual heart camp that began during the pandemic to connect children who have a single ventricle and a Fontan operation. Through several successful virtual camps in 2020-2022, they helped these children to build a community of peers with similar heart conditions so they could learn from each other and feel less isolated. Dr. George Slim and his team proposed to expand their virtual camp into an in-person Fontan Family camp, free for both children with Fontan heart surgery and their families to attend on an annual basis.

Project Team Members:

- Dr Christopher Spence & Dr George Slim (Pediatric Cardiology Residents, Stollery Children's Hospital, University of Alberta)
- Dr Manisha Bhardia (General Pediatrics Resident, Stollery Children's Hospital, University of Alberta)
- Lucy Harris (Medical Student, University of Alberta)
- Jody Gingrich (transition nurse, Alberta Health Services)
- Dr Edythe Tham & Dr Carolina Escudero (Pediatric Cardiologists, Stollery Children's Hospital), supervisors

Our Team has acquired the support of the following organizations:

- Heart Beats Children's Society
- Canadian Congenital Heart Alliance (CCHA)
- Children's Heart network of BC Society



# JUDGE'S CHOICE AWARD MODIFIED FAT BREASTMILK: A FAMILY CENTRED STRATEGY FOR CHYLOTHORAX

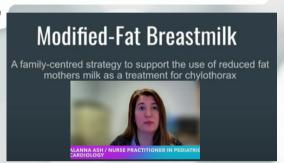
Chylothorax is a condition in which fat-rich lymphatic fluid called chyle accumulates within the chest from the digestive system. This postoperative complication prolongs a patient's length of hospital stay due to longer drainage times before the chest tube can be removed. The first step in treatment of chylothorax is changing to a lower fat diet. Alanna Ash and her team of Registered Dieticians propose to reduce the fat content in breastmilk via centrifuge to allow breastfed infants with a diagnosis of chylothorax to continue to receive their mother's milk. Project Team Members:

Stollery Children's Hospital: (Edmonton, AB)

- Pediatric Cardiology (4C): Alanna Ash NP, Stephanie Lavoie RD, Dr. Luke Eckersley MD
- PCICU: Dr. Lindsay Ryerson MD & Brittney Bernard RD
- NICU: Dr. Dalal Abdelgadir MD & Jennifer Flowers RD

Alberta Children's Hospital: (Calgary, AB)

- Dr. Ravneet Sekhon MD & Roxanne Chabun RD
   Jim Pattison Children's Hospital: (Saskatoon, SK)
  - Dr. Charissa Pockett MD & Kellie Frey RD



#### ALUMNI'S PICK

#### DIGITAL STORYTELLING WORKSHOP: STORIES OF YOUNG ADULTS WITH CHD



A digital story is a 2-to-4-minute movie created with images and video clips, voiceover narration, and music to help individuals create authentic digital stories that enhance resilience. They create an opportunity to meet, make meaningful connections with peers who have similar experiences and create a resource for other patients and families to benefit from in the future. Kristy Wolfe and her team proposed to lead a digital storytelling workshop for six young adults with congenital heart disease.

Project Team Members:

- Kristy Wolfe CHD Parent & Digital Storytelling Facilitator
- Kristina McGuire CHD Parent, Nurse, Patient Researcher
- Vittorio Borrelli Community Leader, Adult with lived experience







## New projects for 2023 include:

1.Parent Workshops – How does your child's heart disease affect their neurodevelopment from fetus to adolescence?

We want to hear from you! See the survey link below.

2. Social Skills Development group sessions – watch for more to come on this!

#### Alberta Children's Hospital

# CARDIAC NEURODEVELOPMENT PROGRAM

We have expanded our program to include assessment of neurodevelopmental outcomes in children living with complex CHD.

We are delivering this care at regular follow-up visits with your Cardiology team.

•We are screening for cognitive, learning, emotional, behavior, and social developmental concerns, supporting children from ages 6-18 years.

•We offer recommendations for resources and supports; Full Neuropsychological assessments when indicated.

Parent Education Workshops: What do you want to learn more about? Please take a few moments to complete the survey here:

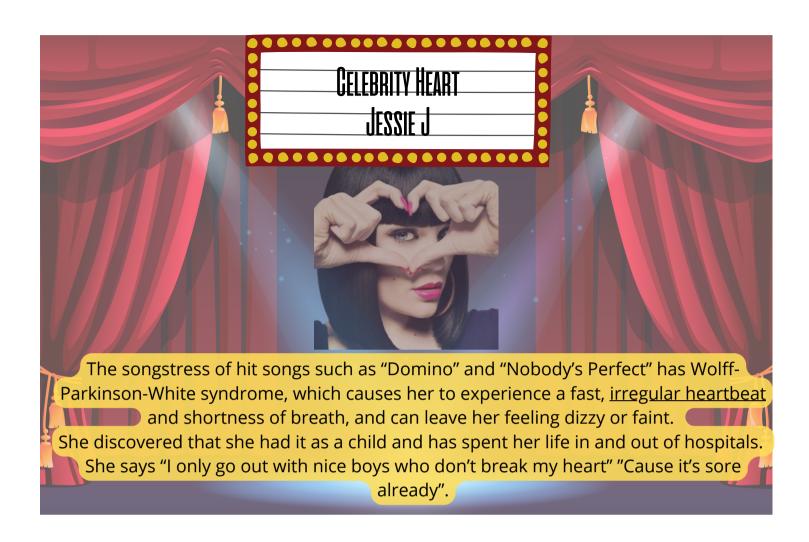
https://www.surveymonkey.com/r/Q5P3Z9Z

Or scan the QR code with your phone.

DR. MARSHA VASSERMAN, RPSYC, PHD, NEUROPSYCHOLOGY, ACH DR. KIMBERLEY MYERS, MD, PEDIATRIC CARDIOLOGIST, ACH NORMA BECKER, RN, NURSE CLINICIAN, CARDIOLOGY, ACH PHONE: 403-955-7316 EMAIL: NORMA.BECKER@AHS.CA









### 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

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, Parties etc.

#### HOW TO SUBSCRIBE TO "KEEPING THE BEAT"

If you would like to receive Keeping the Beat directly to your inbox, please email us at info@heartbeats.ca.

Alternatively, you may pick up a printed edition at the Cardiology Clinic or download a copy from our website at www.Heartbeats.ca. Note: E-mail addresses will be used only to distribute Keeping the Beat newsletter and notices of Heart Beats events; e-mail addresses will not be given to any third party.



In honor of the upcoming Heart Beats run, here are some running themed Dad jokes!

> 1.What do sprinters eat before a race? Nothing, they fast.....!

from a Why was the marathon runner put in jail?

Heart For resisting a rest....!

 $D\alpha d$  What do you call Cardi B on a treadmill? Cardi O.....!



## Heart Beats

Tara Exall

Vacant

Chairperson Iessi Badrudin Vice-Chairperson Golden Bhatia Treasurer Kim Iverson Secretary **Transition Liaison** lacqui Esler Governance Director Brett Stevenson Offbeats Liaison Vittorio Borelli Run Director Donna Iverson Nurse Liason Norma Becker Communications/events Chevenne DeWitt

Peer Mentor/IT Coordinator Kristina McGuire Kids up Front Kathy Winstanley

Camp, Moms/Dads nights Katrina Randall

Co-Treasurer **Robert Tromper** 

Newsletter Ion Hesketh

Website www.heartbeats.ca

Email address: info@heartbeats.ca

#### Mailing address:

WCCHN Liaison

Box 30233 Chinook Postal Outlet Calgary, AB T2H 2V9

Charitable registration number 88907 6261 RR 0001

Disclaimer: Any personal opinions / comments expressed in this newsletter are not necessarily those of Heart Beats 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.



