

HAPPY HEART WEEK

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Henry, age 11

Greetings!

Thank you for your thoughtful consideration in sponsoring Happy Heart Week 2024! As a reminder, our family hosts an annual awareness and fundraising event in honor of our second son, Henry. Henry has an ultra-rare, life-threatening, progressive genetic disorder called Barth syndrome. All proceeds from Happy Heart Week go directly to the Barth Syndrome Foundation to support the life-saving work they are doing. This year, during the week of May 6th, we will be hosting the 12th Annual Happy Heart Week and we would love your support.

While we are not hosting an in-person party (the Happy Heart Party will be next year, 2025 to celebrate Henry's 13th birthday), Happy Heart Week in its traditional form will occur. We have several different sponsorship opportunities, and all sponsors will have varying levels of acknowledgement throughout the event week. Great for both businesses and families. Please see the attached sheet for details.

Happy Heart Week has become a much loved and anticipated event not only within our local community, but all over the U.S. It would be our honor to have your support in this special week! Pivotal and exciting things are happening within the Barth syndrome community this year, and we are looking forward to sharing it all with our network next month. Barth syndrome is an ultra-rare and under-diagnosed disease (Henry is 1 of 300 living in the world) with no treatment or cure (although it is our mission to find one). Therefore, we do not have the luxury to wait for someone else to fund the critical research necessary to save lives. Please join us in this mission!

Happy Heart Week Facts:

Our email campaign goes out to nearly 600 households, and had a 66% opening rate in 2023.

The Happy Heart Campaigns have accrued approximately 500 donors over 12 years.

945 HAPPY shirts have been purchased over the last 3 years.

Happy Heart Week has sent \$871,000 to the Barth Syndrome Foundation. We have plans to cross the million dollar mark during our event this year.

Please let us know if you have any questions. Thank you so very much for your time and consideration. We would love to have you on our team this year!

With happy and hopeful hearts,

John and Meg Branagh

Happy Heart Walk started 12 years ago in honor of our second son, Henry. He was born with an ultra-rare, life-threatening, mitochondrial disease called Barth syndrome. He spent his first few years of life very sick with heart failure, and his future was unknown. In an effort to bring awareness around this rare disease that we had never heard of, we hosted the first ever Happy Heart Walk. While the details of this event have shifted over the years, the purpose has remained the same - to bring our community together for the greater good of others, specifically those affected by Barth syndrome. Each year, Happy Heart has grown exponentially both in the number of people involved and the dollars raised—hundreds of people have learned about Barth syndrome, and \$871,000 has been sent directly to the Barth Syndrome Foundation, the only organization in the world dedicated to finding a treatment or cure for this deadly disease, of which there is currently NONE.

*All proceeds from Happy Heart Week benefit Barth Syndrome Foundation (501c3) and are tax deductible.

BARTH SYNDROME FOUNDATION

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Barth syndrome is a genetic, multi-symptom disorder affecting primarily males. Cardinal characteristics include cardiomyopathy, neutropenia (low white blood cells), muscle weakness, exercise intolerance, extreme fatigue, and growth delay. Historically, boys died of heart failure or infection by three years of age, but with improved diagnosis and appropriate medical treatment, the survival rate and future of these individuals is much brighter.

"The cruelest irony about Barth Syndrome is how deceptively healthy those who have it may appear. A casual observer would never appreciate them to have such a devastating illness."

~Peter Barth, MD, PhD