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Happy Heart Walk for Henry Raises Awareness of Rare Disorder

Submitted by Molly Devinger



Friends and family gathered for the third annual event. Photos Provided

Branagh, "but today with improved diagnosis and management, hopefully Henry's survival rate will be much brighter. The Foundation has been extremely helpful to us since Henry's diagnosis. And since Barth syndrome is so rare, we feel that it is even more important that we do all that we can do to help the Foundation."

Last year's Happy Heart Walk helped to raise more than \$10,000 for the Foundation. This year's walk raised over \$15,000. Local sponsors included Whole Foods, Diablo Foods, Costco, Susie Cakes, Bakesale Betty, Peet's Coffee, Be Real Foods, Chow, Family Style Photography and Chickfila.

"The past two and a half years have been quite a journey, definitely the most trying time in our lives, but also a time of feeling very loved and supported by our family, friends, and community," said Branagh. "Without this support group, I'm not sure how our family would be surviving! Community is very important to us, as is Henry, so putting together some kind of event bringing these two together has been heavy on my heart."

Branagh says Henry is doing well right now. He still takes several medications daily and has a couple hours of therapy per week. She says her family is excited to see what this year has coming with the research for treatment and eventually a cure for Barth syndrome. "This is something Henry will battle with daily for the rest of his life and to think that our community is directly affecting the advancements in Barth syndrome is quite a feeling."

For more information about Barth syndrome and the Barth Syndrome Foundation, visit www.barthsyndrome.org. For additional information, visit www.HappyHeartWalk.com.

Approximately 275 people took to the pavement at Lafayette Reservoir Feb. 28 as part of the third annual Happy Heart Walk for Henry, established by Megan and John Branagh to support the Barth Syndrome Foundation and to help find a cure for their 2-and-a-half-year-old son Henry, who is fighting a lifelong battle with the rare genetic disorder.

Barth syndrome primarily affects males, with fewer than 500 cases reported worldwide; many more cases probably exist but are undiagnosed, according to the Foundation. The cardinal characteristics of this multi-system disorder include cardiomyopathy, neutropenia (low white blood cells that can make one prone to infection), muscle weakness, exercise intolerance, growth delay, and energy deficiency.

"Historically, boys died of heart failure or infection before three years of age," said Megan



Grady, John, Henry and Megan Branagh during the Happy Heart Walk for Henry at Lafayette Reservoir.

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