

California Family Raising Awareness and Funds for Barth Syndrome Foundation

Thanks to the Branaghs' efforts, they have raised over \$500,000 over the last decade to support BSF's research initiatives and other programs.



San Francisco, California May 12, 2022 ([Issuewire.com](https://www.issuewire.com)) - The Barth Syndrome Foundation, Inc. (BSF) is grateful to John and Megan Branagh, a San Francisco Bay Area family, who will be holding a week-long awareness and fundraising campaign (May 9-15, 2022) benefiting BSF. The campaign, Happy Heart Week (HHW), was started 10 years ago after their second son, Henry, was born with an ultra-rare and life-threatening genetic disorder called Barth syndrome that can significantly impair heart function. Thanks to the Branaghs' efforts, they have raised over \$500,000 over the last decade to support BSF's research initiatives and other programs.

2022 marks Henry's 10th birthday. Once again, John and Megan, family, friends, sponsors, and community supporters are celebrating him and his perseverance in the face of Barth syndrome, while honoring other individuals with Barth syndrome during this HHW campaign. "While tremendous strides have been made, we are not there yet. The community support and donations are critical in helping us get to the finish line," said Megan. They hope to raise more than \$150,000 with this year's special anniversary event.

For this special anniversary, the Branagh Family is hosting the 10th Anniversary Happy Heart Party at the JBL Ranch in Briones, CA. Guests will celebrate in person (outdoors), participate in a wine pull, dance, dining, auctions, and more.

Tickets are still available until sold out. Supporters can donate via **TEXT the word Barth to 366283** or visit the website happyheartweek.com to purchase tickets.

The Branaghs appreciate everyone's continued support and dedication to the cause. "Thank you for coming alongside us on this journey, cheering Henry on as he thrives and struggles, and making a difference in our lives and the lives of others affected by this difficult disease." ~ Megan Branagh

About Barth Syndrome Foundation (BSF)

Barth Syndrome Foundation (barthsyndrome.org) is the only global network of families, healthcare providers, and researchers solely driven by the mission to save lives through education advances in treatment and finding a cure for Barth syndrome. BSF has funded nearly \$6.1M USD since 2002 and catalyzed over \$32M in funding from other agencies to advance global scientific discoveries to end the suffering and loss of life from Barth syndrome. Additionally, BSF provides a lifeline to families and individuals living with Barth syndrome around the world, offering 24/7 individualized support, educational conferences, a robust patient registry, and collaborations with specialist healthcare providers to define standards of care, treatment, and rapid diagnosis.

What is Barth Syndrome?

Barth syndrome is a rare, life-threatening, genetic mitochondrial disorder primarily affecting boys. Affected individuals may suffer from heart failure, muscle weakness, and infection (caused by neutropenia). Additional characteristics of the syndrome commonly include growth delay, impaired lipid metabolism, fatigue, and cardiolipin deficiency. In some individuals affected by Barth syndrome, the symptoms can be very severe, sometimes resulting in heart transplants, potentially lethal infections, and even death.

To learn more about Barth syndrome and Barth Syndrome Foundation, please contact Shelley Bowen, O: 914-303-6323 Ext. 1 or email: shelley.bowen@barthsyndrome.org or visit barthsyndrome.org.

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Fast Facts About Barth Syndrome

- Barth syndrome is caused by a chromosomal mutation in the tafazzin gene.
- Because the genetic defect is on the X-chromosome, Barth syndrome overwhelmingly affects boys.
- Currently, there are no approved treatments and no cure for Barth syndrome.
- Most babies with Barth syndrome experience symptoms within their first year of life.
- A simple scratch or bug bite can lead to a life-threatening infection because the individual's body has a hard time-fighting infection.
- Extreme fatigue can result from activities most of us take for granted, including walking, writing, eating, and growing.
- Historically, children died before the age of 3, due to heart failure or infection, but with improved diagnosis and symptom management, the prognosis can be much brighter.



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