Resource Summary Report

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Barth Syndrome Foundation

RRID:SCR_010556
Type: Tool

Proper Citation

Barth Syndrome Foundation (RRID:SCR_010556)

Resource Information

URL: http://www.barthsyndrome.org/english/view.asp?x=1

Proper Citation: Barth Syndrome Foundation (RRID:SCR_010556)

Description: The Barth Syndrome Foundation, together with our affiliates, is a community of families, physicians, scientists, donors and volunteers around the world. As our mission statement says, we are dedicated to saving lives through education, advances in treatment, and finding a cure for Barth syndrome - a sometimes fatal, oftentimes debilitating genetic disease. Our work includes: * Raising awareness among physicians, scientists, and the general public; * Supporting relevant research through an international grant research program; * Providing a caring and educational community for affected families; and * Hosting a unique information resource. Working together we are making a difference in the lives of children and their families. One day there will be a cure; we hope you will help us make that day come sooner. We are the only world-wide volunteer organization dedicated to saving lives through education, advances in treatment and pursuit of a cure for Barth syndrome (BTHS). We started in 2000, after the first international conference held in Baltimore, MD (USA) where families from around the world met to discuss BTHS. As a result, we made a unanimous decision to work together to find a cure for this multi-system disorder. Our Foundation strives to accelerate progress through collaboration between families and scientists. We encourage family participation in research. Also, we provide several ways to keep up-to-date about advances in science and medicine. Our principal education event is our biennial international scientific, medical and family conference, which brings together the largest number of individuals interested in Barth syndrome. Our Family Services team is continually developing new informational resources in response to the needs of families, individuals, and professionals working with those affected by Barth syndrome.

Abbreviations: BSF

Resource Type: institution

Resource Name: Barth Syndrome Foundation

Resource ID: SCR_010556

Alternate IDs: Crossref funder ID: 100002651, nlx_35906, grid.427791.e

Alternate URLs: https://ror.org/00p5z3m34

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Ratings and Alerts

No rating or validation information has been found for Barth Syndrome Foundation.

No alerts have been found for Barth Syndrome Foundation.

Data and Source Information

Source: SciCrunch Registry

Usage and Citation Metrics

We found 1 mentions in open access literature.

Listed below are recent publications. The full list is available at dkNET .

Dinca AA, et al. (2018) Identification of novel mitochondrial localization signals in human Tafazzin, the cause of the inherited cardiomyopathic disorder Barth syndrome. Journal of molecular and cellular cardiology, 114, 83.