

MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

March 30, 2024

Members in Attendance:

Brandi Dague	Board Member
BJ Develle	Board Member
Emily Milligan	Board Member <i>ex officio</i> , Executive Director
Florence Mannes	Board Member
Jamie Baffa	Board Member, Secretary
Kate McCurdy	Board Member, Chair
Megan Branagh	Board Member
Miriam Greenberg, PhD	Board Member
Peter van Loo	Board Member
Jonathan Stokes	Board Member
Mark Greene	Board Member
Michelle Florez	Board Member

Invited Guests

Lindsay Marjoam, PhD	Director of Research, BSF
Melissa Huang, PhD	Research Associate, BSF
Natalie Cohn	Controller, BSF
Daniela Toniolo, PhD	Barth Italia
Michaela Damin	Barth Syndrome UK
Susan Hone	Barth Syndrome Foundation of Canada
Christiane Hope	Barth Syndrome Foundation of Canada
Marilyn Pridgeon	Barth Syndrome Foundation of Canada

Members in Not Attendance:

Andrew Buddemeyer	Board Member
Nina Russell, MD	Board Member

The meeting, held via Zoom, was called to order by Kate McCurdy on Saturday, March 30 at 12:08 p.m. ET.

1. Welcome
 - a. Kate McCurdy welcomed everyone to the meeting (including representatives from our affiliates) and reminded the board that due to budget considerations the foundation has had to scale back the budget to \$200,000 to fund research grants this cycle
 - b. The BSF Grant Research Program remains a vital part of our scientific and medical initiatives, however, as it is critical to continue to support and

advance both basic scientific understanding of our disease as well as to encourage the pipeline of new potential clinical treatment ideas

- c. Depending on affiliate contributions, there may be a possibility the budget could slightly increase

2. Review of Grant Proposals

- a. Lindsay Marjoram shared an overview of the four major buckets of research areas the proposals BSF received this funding cycle fell into: 1) systemic, 2) cell/tissue, 3) biochemical, and 4) atomic/structural
- b. BSF received 12 grant applications for this cycle and each application has been evaluated by the SMAB and an external reviewer based on 1) the importance and impact to Barth syndrome, 2) feasibility of the proposed work, and 3) prospects for long-term funding
- c. Lindsay reviewed the research grant proposals, with emphasis on the top four scored proposals
- d. Kate then moved that the board discuss and vote on the grant proposals, incorporating the recommendations of the SMAB and Director of Research
 - i. Emily Milligan noted that Barth Italia has budgeted \$25,000 to support the grant cycle this year, which Dr. Daniela Toniolo confirmed
 - ii. Florence Mannes shared that Barth France may be able to fund \$50,000 to support one of the grant proposals
 - iii. Susan Hone shared that Barth Syndrome Canada has budgeted \$15,000 to support one of the grant proposals
 - iv. Michaela Damin shared that Barth Trust does not have additional funds to support the research grant program in 2024, and instead allocated their funds to support travel for the Bristol Clinic team to the 2024 Conference
 - v. Miriam Greenberg noted that, in order to be able to support more meritorious projects, BSF could choose to fund some grants at a level less than the full requested budget
 - vi. **APPROVED:** BSF to fund the following four BSF research grant proposals:
 - 1. *Cardiac and Skeletal Muscle Myofilament Activators for the Treatment of Barth syndrome* (Leonardo Ferreira, PhD at Duke University / \$99,519)
 - 2. *Mechanism of Cardiolipin Remodeling by Tafazzin* (David Stokes, PhD at New York University / \$75,000)
 - 3. *Structural analysis of a pathogenic protein-lipin complex in BTHS* (Patrick van der Wel, PhD at the University of Groningen/ \$75,000)

4. *Investigating the molecular basis for the impaired mitochondrial dynamics in Barth syndrome* (Halil Aydin, PhD at University of Colorado Boulder / \$40,000)

vii. Affiliates agreed to review internally which grants they would like to support and inform BSF

e. Melissa Huang shared an overview of the Iris L. Gonzalez Prize program and Human TFAZZIN variants database

f. Melissa reviewed the 2 Iris L. Gonzalez Prize proposals that were received

g. Kate then moved that the board discuss and vote on the prize proposals, incorporating the recommendations of the review committee and BSF research team

i. **APPROVED:** BSF to award the Iris L. Gonzalez Prize to:

1. *From genotype to phenotype: Comprehensive bioinformatic analyses of the Tafazzin Human Variants Database* (Irma Markesina, MS at University of Rijeka / \$10,000)

ii. **APPROVED:** BSF to fund runner-up proposal at reduced amount to be used to attend the 2024 Conference.

1. *Barth Syndrome Foundation Human TFAZZIN Variant Database 2.0: Classification of the pathogenicity of the more than 30,000 possible TFAZZIN single nucleotide variants* (Brendan Floyd, MD, PhD at Stanford University / \$2,000)

h. In addition to the grant proposals submitted in this BSF grant cycle, Lindsay reviewed the opportunity for BSF to co-fund a fellowship for Anshu Kumari at the University of Maryland, Baltimore in partnership with the American Heart Association (AHA)

i. Lindsay noted that while the grant was well written and funded by the AHA, several considerations (i.e., use of knockdown mouse model) may preclude BSF from providing funding this year.

j. **APPROVED:** In lieu of funding the proposal, BSF will offer a poster stipend of \$1000 and registration waiver for Anshu Kumari's AHA-BSF fellowship at the University of Maryland, Baltimore

3. Adjournment

a. Kate McCurdy adjourned the meeting at 2:17

p.m. ET Respectfully submitted,

Jamie Baffa – Secretary

