

MINUTES
Barth Syndrome Foundation, Inc.
Board of Directors Meeting
March 29, 2025

Members in Attendance:

BJ Develle	Board Member
Emily Milligan	Board Member <i>ex officio</i> , Executive Director
Jamie Baffa	Board Member, Vice Chair
Kate McCurdy	Board Member, Chair
Megan Branagh	Board Member
Peter van Loo	Board Member
Jonathan Stokes	Board Member
Mark Greene	Board Member
Michelle Florez	Board Member
Nina Russell, MD	Board Member

Invited Guests

Lindsay Marjoram, PhD	Director of Research, BSF
Mindong Ren, PhD	Grant Review Representative, BSF SMAB
Melissa Huang, PhD	Research Associate, BSF
Michaela Damin	Barth Syndrome UK
Ralph Easterbrook	Barth Syndrome UK
Susan Hone	Barth Syndrome Foundation of Canada
Christiane Hope	Barth Syndrome Foundation of Canada
Marilyn Pridgen	Barth Syndrome Foundation of Canada

Members in Not Attendance:

Brandi Dague	Board Member
Miriam Greenberg (recused)	Board Member

The meeting, held via Zoom, was called to order by Kate McCurdy on Saturday, March 29 at 12:03 p.m. ET.

1. Welcome
 - a. Kate McCurdy welcomed the Board and our affiliates to the meeting

- b. Kate noted that BSF's grant program is particularly important with recent scientific research funding cutbacks to ensure continuity of pipeline of possible new therapy targets

2. Grant Review Representative Introduction

- a. Mindong Ren, a member of BSF's Scientific and Medical Advisory Board introduced himself as this year's Grant Review Representative
- b. Mindong added that two of this cycle's highest scoring grants were very promising in the area of therapeutic development

3. 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) structural and noted that while 3 structural grants were received last year, zero were received this year
- b. BSF received 13 grant applications for this cycle. Applicants were diverse, with first-time applicants, people who have applied previously, young investigators, and individuals who contacted BSF prior to submission. 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 proposals as scored by the SMAB post-grant review and opened the floor to ask if others had any additional grants they would like to discuss.
- 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. Kate noted that the affiliate contributions this year were as follows: Barth France for up to \$100,000 USD, Barth Syndrome UK for \$10,000, Barth Syndrome Foundation Canada for \$15,000, and Barth Italia for 25,000 Euros. Affiliates will confirm which grants they would like their funds to support post-meeting.
 - 1. *Michaela of Barth Syndrome UK noted that they were in the process of lining up new insurance for their foundation and that wire transfers to the United States were currently challenging.*
 - ii. After discussion from the Board, it was felt that the top 3 grants were candidates for funding. The fourth grant, by Dr. Yoonjeong Lim, was still to preliminary to warrant funding this year.
 - iii. Mindong suggested that we could fund the Blomen grant fully at \$100,000 and at \$80,000 each for the Conway and Moffat grants. Lindsay agreed with suggested funding levels, with the understanding that there may be slight changes to the scope of work the Conway and Moffat grants. Lindsay will follow up with each applicant to discuss.
 - iv. **APPROVED:** BSF to fund the following four BSF research grant proposals:

1. *In vivo POC of an ABHD18-targeted ASO in TAZ knock-out mice* (Vincent Blomen, PhD at Scenic Biotech/ \$100,000)
 - *Lindsay suggested that this grant should be funded by the Therapy Restricted fund; the Board did not vote on this suggestion.*
2. *Role of p53 Pathway in Barth Syndrome* (Simon Conway, PhD, FAHA at Indiana University / \$80,000)
3. *Evaluation of ABHD18 as a target to correct TFAZZIN mutant phenotypes* (Jason Moffat, PhD at the The Hospital for Sick Children/ \$80,000*) *Up to \$10,000 would be paid fee-for-service directly to a medicinal chemist consultant to assess the candidate drug and guide revision of the research strategy. Contingent upon original SMAB reviewer approval post-consultant discussion, a grant of \$70,000 would be made to Dr. Moffat's lab.
 - *Lindsay suggested that this grant should be funded by the Therapy Restricted fund; the Board did not vote on this suggestion.*

4. Adjournment

- a. Kate McCurdy adjourned the grants portion of the meeting at 2:43 p.m. ET

Respectfully submitted,

Melissa Huang – BSF Research Associate