

MINUTES

Barth Syndrome Foundation, Inc.

Board of Directors Meeting

March 11, 2023

Members in Attendance:

Andrew Buddemeyer	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
Nina Russell, MD	Board Member
Peter van Loo	Board Member

Invited Guests

Erik Lontok, PhD	Director of Research, BSF
Melissa Huang, PhD	Clinical Research Coordinator, BSF
Daniela Toniolo, PhD	Barth Italia
Michaela Damin	Barth Syndrome UK
Lynn Elwood	Barth Syndrome Foundation of Canada
Susan Hone	Barth Syndrome Foundation of Canada
Chris Hope	Barth Syndrome Foundation of Canada

Members in Not Attendance:

Kevin Woodward	Board Member, Treasurer
Mark Greene	Board Member
Maryanne Chrisant, MD	Board Member
Michelle Florez	Board Member
Brandi Dague	Board Member

The meeting, held via Zoom, was called to order by Kate McCurdy on Saturday, March 11 at 12:10 p.m. ET.

1. Welcome
 - a. Kate McCurdy welcomed those to the meeting and reminded the board that the foundation has budgeted \$200,000 to fund research grants this cycle

- b. The board does not need to use the full amount and can also vote to exceed the budget based on the opportunities available

2. Review of Grant Proposals

- a. Erik Lontok shared an overview of the basic biology of BSF, what we know today, and the areas of research that the foundation is interested in funding
- b. BSF received 15 grant applications for this cycle and each application has been evaluated by the SMAB based on 1) the importance and impact to Barth syndrome, 2) feasibility of the proposed work, and 3) prospects for long-term funding
- c. Erik reviewed the research grant 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. Michaela Damin forecasted that the Barth Trust has a board meeting the following week, and they will not be able to make any funding commitments until after that meeting
 - ii. Emily Milligan noted that the BOD can take contingent votes pending additional fundings from affiliates
 - iii. Susan Hone shared that Barth Syndrome Canada has budgeted \$25,000 to support the research grant program in 2023
 - iv. Daniela Toniolo shared that Barth Italia is committing its resources to gene therapy and thus does not have additional funds to support the research grant program in 2023
 - v. **APPROVED:** BSF to fund the following four BSF research grant proposals:
 - 1. *Induced Pluripotent Stem Cells to Study Neutrophil Development in Barth Syndrome* (Riekelt Houtkooper, PhD at Amsterdam University Medical Centre / \$50,000)
 - 2. *Improving physical performance and cardiac function of Tafazzin deficient mice with nicotinamide riboside* (Taco Kuijpers, MD, PhD at Amsterdam University Medical Centre / \$49,854)
 - 3. *Optimizing Cardiac Energetics in Barth Syndrome* (John Ussher, PhD at the University of Alberta / \$100,000)
 - 4. *Elucidating Cardiolipin Immune Dysfunction in Barth Syndrome* (Kate Schroder, PhD at University of Queensland / \$50,000)
- e. Susan to confirm soon which proposal Barth Canada will support
- f. In addition to the grant proposals submitted in this BSF grant cycle, Erik reviewed the opportunity for BSF to fund a fellowship for Mack Reynolds at the University of Michigan in partnership with the American Heart Association (AHA)
- g. The proposal is to fund 25% of his fellowship (\$16,276.50)
- h. **APPROVED:** BSF to fund 25% (\$16,276.50) of Mack Reynold's fellowship at the University of Michigan in partnership with the AHA

- i. Kate proposed that two grant proposals (*Improving physical performance and cardiac function of Tafazzin deficient mice with nicotinamide riboside* and *Optimizing Cardiac Energetics in Barth Syndrome*) be funded through the Will McCurdy Fund for Advancement in Therapies for Barth Syndrome
- j. The two remaining grant proposals and the fellowship co-award with the AHA will be funded through the BSF general fund and Barth Syndrome Canada's contributions (or any funds that are offered soon by the Barth Trust in the UK for this purpose)
- k. **APPROVED:** *Improving physical performance and cardiac function of Tafazzin deficient mice with nicotinamide riboside* and *Optimizing Cardiac Energetics in Barth Syndrome*) to be funded through the Will McCurdy Fund for Advancement in Therapies for Barth Syndrome with remaining proposals funded through BSF general fund and Barth Syndrome Canada's contributions (or any funds that are offered soon by the Barth Trust in the UK for this purpose)

3. Adjournment

- a. Kate McCurdy adjourned the meeting at 2:17 p.m. ET

Respectfully submitted,

Jamie Baffa – Secretary