

## MINUTES

Barth Syndrome Foundation, Inc.  
Board of Directors Meeting – Research Grant Review  
March 13, 2021

### **Members in Attendance:**

Kate McCurdy	Board Member, Chair
Emily Milligan	Board Member <i>ex officio</i> , Executive Director
Kevin Woodward	Board Member, Treasurer
Jamie Baffa	Board Member, Acting Secretary
Florence Mannes	Board Member
Michelle Florez	Board Member
Peter van Loo	Board Member
Nina Russell, MD	Board Member
Matthew Blumenthal	Board Member
Brandi Dague	Board Member
B.J. Develle	Board Member
Megan Branagh	Board Member

### **Invited Guests**

Shelley Bowen	Director of Family Services, BSF
Erik Lontok	Director of Research, BSF
Brett Smith	Operations & Communications Lead, BSF
Susan Hone	Barth Syndrome Foundation of Canada
Chris Hope	Barth Syndrome Foundation of Canada
Lynn Elwood	Barth Syndrome Foundation of Canada
Michaela Damin	Barth Syndrome UK
Cheryl Parish	Barth Syndrome UK
Geoff Parish	Barth Syndrome UK

### **Members NOT in Attendance:**

David Axelrod, MD	Board Member
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## AGENDA

The meeting, held via Zoom, was called to order by Kate McCurdy on Saturday, March 13 at 12 p.m. ET.

1. Opening Remarks

- a. Kate McCurdy welcome participants and noted that this meeting included members of the Board of Directors, BSF staff, and representatives from our international affiliates.
  - b. International affiliates participate in this meeting as they help fund research and so they can review the grant proposals under consideration.
  - c. Kate expressed gratitude that the grant proposals BSF received this year are in alignment with the foundation’s strategic plan
- 2. Research Priorities Review
  - a. Erik Lontok reviewed the three areas of research that are a priority for BSF and summarized what each means
    - i. Natural History
    - ii. Drug Development / Disease Management
    - iii. Discovery Research
  - b. In addition, Erik shared a summary of the Scientific and Medical Advisory Board’s (SMAB) role, which includes
    - i. Advising on research grants
    - ii. Planning the SciMed conference
    - iii. Members of the SMAB will also join others in an arrhythmia working group to advise on research in this area
    - iv. Members of the SMAB will also join others in a natural history working group to advise BSF as it prepares to launch its natural history study
  - c. Before reviewing individual research proposals, Erik noted that the SMAB has reviewed all submitted proposals and brings a recommendation to the board regarding whether or not BSF should fund the proposal. Erik will present the research proposals in order of support, beginning with the proposals with the highest level of support among the SMAB.
    - i. During the review, Erik committed to sharing his own view of each proposal, noting where he may have a slightly different view from the SMAB
- 3. All thirteen of the submitted applications were presented by Erik Lontok, Director of Research, along with the recommendations of the BSF Scientific and Medical Advisory Board (SMAB) as well as his own perspectives.
- 4. The Board voted to **APPROVE FUNDING** for the following four research grant proposals:
  - a. APPLICATION #1: Studying TAZ genetic interactions and mutational landscape in human cells (Jason Moffat / \$50,000)
  - b. APPLICATION #2: Activating Pyruvate Dehydrogenase Complex to improve Barth syndrome cardiac function (Charles McCall / \$100,000)
  - c. APPLICATION #3: “What is Barth Tired?” (Stacey Reynolds / \$50,000)
  - d. APPLICATION #4: Cardiolipin synthesis and remodeling regulate mitochondrial metabolic plasticity and signaling function (Mauro Corrado / \$50,000)
- 5. Funding discussions
  - a. The board then turned to the question of funding the approved proposals

- b. Barth Syndrome UK and Barth Syndrome Canada offered to jointly fund \$50,000 in research pending formal votes by both organizations the week of March 15; they will confirm this and let Emily know of the details as soon as possible
  - c. Florence Mannes offered her support for the arrhythmia working group that will emerge as the result of one of the applications not funded at this time
  - d. The Board APPROVED to use the following funding sources for the four research grant proposals that were funded:
    - i. **Application #1 (Jason Moffat) – \$50,000 funded by Barth Syndrome UK and Barth Syndrome Canada**
    - ii. **Application #2 (Charles McCall) – \$100,000 funded by the McCurdy Therapy Development Fund**
    - iii. **Application #3 (Stacey Reynolds) – \$50,000 funded by the McCurdy Therapy Development Fund**
    - iv. **Application #4 (Mauro Corrado) – \$50,000 funded by the SciMed Fund**
6. Thanks
- a. The Board of Directors expressed their appreciation to Dr. Michael Schlame and to all the members of the SMAB who served as grant reviewers, as well as the other experts who served as external reviewers. Additionally, the Board expressed its appreciation to Dr. Erik Lontok for his oversight of the 2021 research grant process on behalf of BSF.
7. Adjournment
- a. Kate McCurdy adjourned the meeting at 2:00 p.m. ET with no other business pending

Respectfully submitted,

Jamie Baffa – Secretary