

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

- 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