

**Minutes of the
BARTH SYNDROME FOUNDATION
BOARD OF DIRECTORS
March 30, 2008**

The Board of Directors of The Barth Syndrome Foundation, Inc. (BSF) met on Sunday, March 30, 2008, at an off-site location. All members of the Board of Directors were present, as follows:

Members in Attendance

Stephen B. McCurdy (Steve)	Chairman of the Board, Chief Financial Officer
Valerie "Shelley" Bowen	Board Member, President of BSF
Michaela Damin	Board Member
Stephen Kugelmann (Steve)	Board Member, Vice President, Awareness
Katherine R. McCurdy (Kate)	Board Member, Vice President, Science and Medicine
Susan S. Osnos (Suze)	Board Member
Susan V. Wilkins (Sue)	Board Member
Randy Buddemeyer	Board Member

Lynda Sedefian attended the meeting in the role of Secretary to the Board of Directors.

Steve McCurdy called the meeting to order.

Re-Election of Board Members

It was **PROPOSED** and **SECONDED** that the Board of Directors thank Katherine McCurdy for her dedicated service in her previous term on the BSF Board, and accept and ratify the Executive committee's recommendation to re-elect her as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2011.

RESOLVED, that the Board of Directors accept and ratify the Executive committee's recommendation to re-elect Katherine McCurdy as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2011.

It was **PROPOSED** and **SECONDED** that the Board of Directors thank Susan Wilkins for her dedicated service in her previous term on the BSF Board, and accept and ratify the Executive committee's recommendation to re-elect her as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2011.

RESOLVED, that the Board of Directors accept and ratify the Executive committee's recommendation to re-elect Susan Wilkins as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2011.

Open Issues:

Executive Director Search

Joseph McCormack of McCormack & Associates met with the Board of Directors, Matt Toth and Lynda Sedefian during BSF's off-site meeting to discuss the search for the position of Executive Director. A draft recruitment profile was distributed and reviewed at the meeting. A copy of the finalized Recruitment Plan is attached. Joe will begin the process of distributing the announcement for said position via direct mail, advertisement/web postings, targeted sources (e.g. medical associations/organizations; non-profits supporting medical/health issues and research; public & private health associations).

The Executive Director will have direct responsibility for the following programs: science and research, the BSF International Conference, communications, the bio-repository and registry, affiliate coordination, volunteer development and coordination, as well as day-to-day operations, administration, fund raising, finance, marketing and strategy. The successful candidate will work closely with the organization's President and co-founder, its eight-person Board, two paid full-time staff, volunteer program leaders and advisory boards and the heads of BSF's international affiliates. The President will continue to be liaison for the organization to families, and she will retain primary responsibility for BSF's family services and physician awareness programs. The Executive Director, along with the President/Founder, will report directly to the Board.

A timeline was created for the interview process, as follows:

- May 15, 2008: Teleconference with Joe McCormack and BSF's Search Committee (Steve McCurdy, Shelley Bowen, Susan Osnos) to review the top 8-10 candidates
- May 31-June 1, 2008: first round of face-to-face interviews with top 4-5 candidates (Joe McCormack; BSF Search Committee)
- June 5 or 6, 2008: second round of face-to-face interviews with top 2 candidates (BSF Search Committee, Available board members)
- June 28, 2008: final interviews of top two candidates (Full BSF Board, Affiliate Presidents, Matt Toth and Lynda Sedefian)

Search for Bookkeeper

As of March 31, 2008, Leonard Steinberg, LLC, has submitted his resignation from his position as bookkeeper for the Barth Syndrome Foundation and BSF has accepted it with regret and appreciation for his efforts on our behalf. Steve McCurdy is in the process of interviewing candidates for this position.

It was **PROPOSED** and **SECONDED** that the Board of Directors allow a budget of up to [Confidential] for Steve McCurdy to move forward with the search and hiring of the right candidate for the position of bookkeeper.

RESOLVED, that the Board of Directors accept and ratify the decision to allow a budget of up to [Confidential] for Steve McCurdy to move forward with the search and hiring of the right candidate for the position of bookkeeper.

2007 Financials

Steve McCurdy distributed BSF's 2007 Audited Financial Statement and 990, as submitted by Schall & Ashenfarb, Certified Public Accountants, LLC.

It was **PROPOSED** and **SECONDED** that the Board of Directors accept and ratify the 2007 Audited Financial Statement and 990, as submitted by Schall & Ashenfarb, Certified Public Accountants, LLC.

RESOLVED, that the Board of Directors officially accept the 2007 Audited Financial Statement and 990, as submitted by Schall & Ashenfarb, Certified Public Accountants, LLC.

The Barth Syndrome Foundation will re-register its By-Laws with all thirteen (13) states where BSF solicits funds concurrently with the filing of its 2007 Auditor's Report and IRS Form 990.

Goal: *To encourage, guide and fund additional research to improve diagnosis and treatment and ultimately to develop a cure for Barth syndrome.*

Paula & Woody Varner Restricted Science & Medicine Fund

Susan Wilkins, daughter of Paula and Woody Varner, discussed with the Board various ways on how best to distribute the funds that have accrued in the Paula and Woody Varner Restricted Science & Medicine Fund.

It was **PROPOSED** and **SECONDED** that the Board of Directors accept and ratify Sue Wilkins's recommendations on the disbursement of restricted funds from the Paula & Woody Varner Fund, as follows:

1. The Barth Syndrome Foundation will initiate the formal process of acknowledging 'Pioneers in Science and Medicine' for Barth syndrome as part of its International Scientific, Medical & Family Conferences held every two years. Chosen candidates will be invited to attend BSF's Conference as a keynote speaker and will be presented with an award/stipend as a token of BSF's appreciation. It was agreed upon that BSF will allocate from the Paula & Woody Varner Fund the necessary funds to financially support these honoraria for a minimum of the next ten years, (which we expect will mean five international conferences).
2. BSF will also allocate from the The Paula and Woody Varner Restricted Science & Medicine Fund the necessary funds to financially support BSF's Scientific & Medical meetings which are held in the off-years of BSF's international conferences. It was agreed upon that said funding will be allocated for these scientific meetings over the next ten years, which will consist of five scientific meetings.
3. BSF will also allocate from The Paula and Woody Varner Restricted Science & Medicine Fund the necessary funds to financially support the recently submitted

research proposal by Michael Schoor, PhD, Scientific Project Management, TaconicArtemis Pharmaceuticals, for the generation and delivery of a genetically modified RNAi knock-down mouse model of Barth syndrome. The Barth Syndrome Foundation has allowed a budget of up to \$83,000.00 to fund said project. (Please refer to Science & Medicine / Research)

RESOLVED, that the Board of Directors officially accept and ratify Susan Wilkins's recommendations that BSF allocate the necessary funds from the Paula & Woody Varner Restricted Science & Medicine Fund to financially support the above projects/awards.

Science & Medicine / Research

Matt Toth, PhD, BSF's Science Director informed the Board of Directors that he has received a research proposal from Michael Schoor, PhD, Scientific Project Management, TaconicArtemis Pharmaceuticals, for the generation and delivery of a genetically modified RNAi knock-down mouse model of Barth syndrome. The Board of Directors discussed this proposal in great detail and it was unanimously agreed upon that said project should be funded with a budget of up to \$83,000 (though payments will be made only as certain milestones are reached).

It was **PROPOSED** and **SECONDED** that the Board of Directors accept and ratify Dr. Toth's recommendations to fund the research proposal submitted by Michael Schoor, PhD, Scientific Project Management, TaconicArtemis Pharmaceuticals, for the generation and delivery of a genetically modified RNAi knock-down mouse model of Barth syndrome. A budget of up to \$83,000.00 has been allowed.

RESOLVED, that the Board of Directors officially accept Dr. Toth's recommendations to fund the research proposal submitted by Michael Schoor, PhD, Scientific Project Management, TaconicArtemis Pharmaceuticals, for the generation and delivery of a genetically modified RNAi knock-down mouse model of Barth syndrome. A budget of up to \$83,000.00 has been allotted.

Acknowledgements

1. The Board would like to acknowledge that it is honored to have Katherine McCurdy and Susan Wilkins each accept re-nominations to the Board of Directors for an additional 3-year term and would also like to extend its sincere gratitude to both for their valuable commitment to this organization.
2. The Board would like to acknowledge and thank David C. Ashenfarb, CPA, and his team at Schall & Ashenfarb, LLC for the timely completion of BSF's 2007 Audit and preparation of its 2007 Federal Form 990 tax filing.
3. The Board would like to thank Susan Osnos for her generous hospitality of opening her home to the Board to hold the Board's off-site meeting.

The meeting was adjourned at 10:30 AM EST. The next scheduled Board of Directors meeting will be held via teleconference on Tuesday, July 8, 2008. The next scheduled Executive Committee meeting will be held on Tuesday, May 20, 2008 via teleconference.

Respectfully submitted,

Lynda M. Sedefian

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Secretary to the Board