

**Minutes of the
BARTH SYNDROME FOUNDATION
BOARD OF DIRECTORS**
April 4-5, 2009

The Board of Directors of The Barth Syndrome Foundation, Inc. (BSF) held the Board's annual meeting on April 4-5, 2009 in Greenwich, CT.

Members in Attendance

Stephen B. McCurdy (Steve)	Board Member, Chairman
Randy Buddemeyer	Board Member, Treasurer
Katherine R. McCurdy (Kate)	Board Member
Susan S. Osnos (Suze)	Board Member
Marcus E. Sernel (Marc)	Board Member
Susan V. Wilkins (Sue)	Board Member

Members Attending by Teleconference

Valerie Bowen (Shelley)	Board Member, President
Stephen Kugelmann	Board Member
Linda Stundis, Executive Director	Board Member, <i>ex officio</i>

Members Not in Attendance

Michaela Damin	Board Member
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Board Staff

Lynda Sedefian	Executive Assistant
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Invited Attendees:

Matthew J. Toth, PhD	Science Director
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David Ashenfarb, CPA, Schall & Ashenfarb, Certified Public Accounts was an invited guest who joined the meeting via teleconference to disclose BSF's 2008 Audited Financial Statements and Form 990.

The meeting was called to order by the Chairman on Saturday, April 4, 2009 at 9:30 AM EST.

Agenda Items

1. 2008 Audit Report and 990
2. Welcome Marc Sernel
3. Approval of Minutes
4. *Ex-Officio* Discussion
5. Kirkland Retention Letter
6. National Health Council
7. LPL Non-Corporate Resolution
8. Approval of 2009 Budget
9. 2009 Financial Statements
10. 2009 Goals & Objectives

11. 2009 Fundraising Plan
12. Re-Election of Board Members
13. Record Retention Policy
14. BRR Update
15. BSF of Canada Update (Licensing Agreement)
16. SMAB/Science Updates

2008 Audit Report

David Ashenfarb, CPA, partner in the firm of Schall & Ashenfarb, has delivered a clean audit of BSF's 2008 financial statements. David reviewed all of the financial statements and the contents of the 2008 audit in detail with the members of the Board, who were satisfied with the financial statements and pleased with the findings of BSF's auditor.

Following a discussion and upon Motion duly made and Seconded, it was:

VOTED: That the Board of Directors accept the 2008 Audited Financial Statements 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 2008 Auditor's Report and IRS Form 990.

Per a Board consensus, it was recommended that going forward the Audited Financial Statement/990 should include a disclosure note regarding the impact of the biennial conference.

Welcome Marc Sernel

The Board welcomed Marc Sernel and expressed its appreciation for his willingness to devote his time and resources to BSF. Marc in turn thanked the Board for this opportunity and stated that he looks forward to working with the Board to bring the Foundation to the next level. Marc was elected to the Board of Directors on February 7, 2009, and will serve a three-year term, ending April 2012.

Minutes

The Board has tabled the approval of the January and February 2009 minutes pending approval at the Board's July 2009 meeting.*

Ex Officio Members

After a lengthy discussion regarding the role of an *ex officio* officer, Steve McCurdy proposed that an *ex officio* is a non-voting member of the Board, a committee, or other body by virtue of his/her right or virtue of the office held; and who is appointed by the Board of Directors.

Steve McCurdy proposed that the Executive Director (Linda Stundis) be appointed to the Board as an *ex officio* non-voting member.

*Items placed on upcoming Board Meeting agenda

VOTED: That the Board of Directors accept and ratify the decision to appoint the Executive Director (Linda Stundis) as an *ex officio* officer of the Board of Directors.

Per a Board consensus, BSF's By-Laws will be amended to reflect the role of the Executive Director serving on the Board as a non-voting ex officio member.

Kirkland Retention Letter

Steve McCurdy submitted a proposed retention letter to the Board outlining the terms of representation of Kirkland & Ellis LLP, who has agreed to represent BSF on a pro bono basis for legal counsel in connection with its general legal matters. Marc Sernel clarified that although he is a partner at Kirkland & Ellis LLP, his participation on the Board precluded him from personally providing legal advice and that other lawyers from the firm would be relied upon.

Following a discussion, and upon Motion duly made and Seconded, it was:

VOTED: That the Board of Directors accept and ratify Kirkland & Ellis LLP as legal counsel to BSF on a pro bono basis for general matters, subject to finalization of the details of a formal retention agreement.

National Health Council Standards of Excellence

Steve McCurdy reported that the National Health Council (NHC) has adopted a new standard (**Standard 9**), which reads as follows:

Organizations engaged in corporate relationships must have a written board-approved policy that: a) enumerates the criteria for evaluating corporate relationships; b) requires a written agreement with the corporation prior to entering the relationship; c) mandates the disclosure of financial support received as a result of the corporate relationship; d) requires compliance with its corporate relations policy by divisions, chapters or affiliates of the organization; and e) mandates the development of written operating procedures for the review and approval of corporate relationships and ongoing evaluation of such relationships.

It was suggested that the task of developing a new written policy be assigned to Linda Stundis, Steve McCurdy and Marc Sernel, who will begin the process of developing such a policy, as well as a statement regarding implementation and adherence. They will report back to the Board at its November 2009 meeting. The NHC has afforded a 1-year timeline to adhere to this standard.*

Steve McCurdy also reported that BSF is not currently in compliance with **Standard 15**, which reads as follows:

Organizations with three or more paid staff have a written statement of personnel policies, reviewed periodically (at least every three years) by legal counsel to ensure compliance with applicable state and federal law and reviewed annually by the chief staff executive or other authorized senior staff person to assure appropriate personnel practices.

*Items placed on upcoming Board Meeting agenda

Linda Stundis will develop a written statement of personnel policies and will report back to the Board at its November 2009 meeting.*

In addition, Linda Stundis and staff will develop implementation and adherence plans for all BSF policies, and will report back to the Board at its November 2009 meeting. *

LPL Non-Corporate Resolution

After a brief discussion, BSF hereby authorizes LPL to take direction from the following officers to buy, sell, assign and endorse for transfer, certificates representing stocks, bonds or other securities now registered or hereafter registered in the name of the Barth Syndrome Foundation. Said resolution authorizes

- **Chairman** – Stephen McCurdy
- **Executive Director** – Linda Stundis
- **Treasurer** – Randy Buddemeyer

to act on behalf of BSF in this regard.

The Board will revisit authorization limits given by corporate resolution to manage transactions on behalf of BSF and this issue will be discussed at the Board's July 2009 meeting.*

Per a Board consensus, the BSF's By-Laws will be amended to reflect the aforementioned Non-Corporate Resolution.

2009 Operating Budget

Linda Stundis, together with Ellen Bruno, BSF's bookkeeper who joined this portion of the meeting via teleconference, provided an overview of BSF's proposed 2009 operating budget and 1st Q financials.

After a lengthy discussion, Steve McCurdy and Randy Buddemeyer requested that Linda and Ellen provide a strategic variance report (2008 vs. 2009) which will be reviewed by the Board prior to approving the 2009 operating budget.*

2009 Financial Statements

Linda Stundis submitted preliminary 1st quarter financial statements, which reflect the following:

Total Current Assets	\$2,291,729.52
Total Current Liabilities	\$ 228,170.10
Total Fund Balance	\$2,063,559.42
Total Liabilities & Fund Balance	\$2,291,729.52

*Items placed on upcoming Board Meeting agenda

2009 Goals & Objectives

Linda Stundis submitted the 2009 goals and objectives of the Executive Director, President, Science Director and Executive Assistant, which were reviewed by the Board.

Following a lengthy discussion during Executive Session, Steve McCurdy requested that each staff member submit a revised outline of their 2009 goals and objectives to the Board incorporating the following:

Executive Director Priorities:

1. Fundraising (Priority)
2. Administration – ongoing
3. 2010 Conference Planning – Overall Plan (3rd quarter)
4. BRR – address challenges (Priority)
5. Develop strategic plan which will elevate BSF to next level (4th quarter) and include:
 - a. BSI/affiliate license
 - b. Future leadership of organization (Board, inc. succession plan, staff, scientific support, and the SMAB)

Executive Director Secondary Priorities:

1. Cultivate and make better use of volunteers
2. Attend both outreach events in 2009

Executive Leadership Role:

Elevate level of teamwork and progress among President, Science Director, Executive Assistant and Executive Director.

President Priorities:

1. Family Support – ongoing
2. Planning of 2010 Conference (Family Session and Clinics) (3rd & 4th quarters)
3. Develop programs to build better relationships with genetic clinical labs (w/ Matt's involvement)
4. Organization of Outreach events (2nd quarter)
5. Focus on developing materials:
 - a. Cardiology document (top priority)
 - b. Grand Rounds (minimum of 4 presentations) (3rd & 4th quarters)
6. Involvement with BRR – collecting medical releases to obtain complete dataset (top priority), data entry following Hippa compliance, and increasing level of family involvement in BRR.

President Leadership Role:

Build on teamwork, transparency, cooperation with Executive Director, staff and Board.

2009 Fundraising Plan

Linda Stundis reported that per the Board's direction given at the January 2009 meeting, she is in the process of creating a plan which will result in revenue of \$600,000 in 2009. Each Board member indicated the amount they intended to raise in 2009, and Steve McCurdy then asked Linda to prepare a plan which incorporates the board commitments as well as her fundraising plans.

*Items placed on upcoming Board Meeting agenda

Record Retention Policy

The approval of the Record Retention policy amendment and adherence plan was tabled until the Board's November 2009 meeting, when all BSF policies and adherence plans will be discussed.*

Re-Election of Board Members

The Board of Directors thanked Shelley Bowen, Steve Kugelmann, and Suze Osnos for their dedicated services on the Board. Following a discussion, and upon Motion duly made and Seconded, it was:

VOTED: That the Board of Directors re-elect Valerie (Shelley) Bowen as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2012.

VOTED: That the Board of Directors re-elect Stephen Kugelmann as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2012.

VOTED: That the Board of Directors re-elect Susan Osnos as a member of the Board of Directors for an additional 3-year term. Said term will run thru April 2012.

Note: Each board member mentioned above abstained from voting on the re-election of their seat to the Board.

Per a Board consensus, the By-Laws will be amended to reflect that the minimum number of Board members will be increased from three to eight members, in compliance with the National Health Council's Standards of Excellence.

Barth Syndrome Medical Database & BioRepository Update

Linda Stundis reported that on March 20, 2009 she met with Carolyn Spencer, MD, Barry Byrne, MD, PhD, Melissa Maisenbacher (geneticist), and Dan Estrada (grant administrator), via teleconference to discuss Year 4 program budget and objectives.

The current challenges facing the BRR are:

1. It is not clear what progress is being made scientifically,
2. Currently we have limited amounts of information for each subject registered and this information is self-reported data only,
3. There has been a perpetual delay gathering and entering medical data,
4. The BSF Board and staff have limited knowledge on how/where samples are being stored and accessed.

*Items placed on upcoming Board Meeting agenda

The goals and priorities proposed for Year 4 are:

1. Register all newly identified subjects in a timely manner
2. Ensure that the correct mutation for each subject is obtained and entered
3. Ensure up to date and ongoing medical as well as self-reported data entry for existing and new registry participants
4. BSF and UofF promote registry and actively recruit families/patients for ongoing involvement in the registry

After a lengthy discussion, the Board authorized Shelley Bowen to work with Melissa Maisenbacher to begin obtaining consents from each family registered in the BRR in order to obtain complete dataset, to undergo HIPPA training, and to provide data entry assistance.

The Board then agreed upon the following BSF planning and follow-up:

1. Shelley will work w/ Melissa and families to obtain new consents, undergo HIPPA training, and begin assisting with data entry.
2. Linda is scheduled to meet with Audrey Gordon (Progeria ED/President) to obtain information on Progeria's database & biorepository (including cost).
3. Kate, Shelley and Linda will speak with Richard Kelley for his input/recommendations.
4. Following a conversation with Richard Kelley, Linda will meet with Carolyn Spencer to discuss ongoing concerns.
5. Shelley will send Linda her benchmarking material.
6. Creation of a detailed plan of action to resolve issue and concerns by the end of 2009.

Linda recommended that before the Year 4 payment is made, she request of U of F that the Year 4 payment be split into two payments: ½ spring 2009 and ½ following receipt of a year-end report (March 2010).

BSF of CA Update (Licensing)

Linda Stundis reported that Lynn Elwood (President, BSF CA) has obtained legal counsel to review the BSF affiliate licensing agreement, and today has submitted their recommended changes to the agreement. Steve, Marc and Linda will meet via teleconference to discuss the issue and Linda will report back to Lynn.

Following the resolution of the Canada licensing issue, Linda will work with Jeannette Thorpe regarding South Africa's non-license status.

SMAB/Science Updates

2009—SMAB+ meeting

Matt Toth, PhD reported that the 2009—SMAB+ meeting at the AMC in Amsterdam has been tentatively scheduled for June 20-21, 2009. Confirmed attendees to date are Richard Kelley, Michael Schlame, Gerald Cox, Peter Barth, Ronald Wanders, Iris Gonzalez, Matt Toth and Kate McCurdy. Following Matt's report, Board members expressed concerns regarding the topic/agenda for the meeting, and the roles and expectations of attendees.

*Items placed on upcoming Board Meeting agenda

Targeted Scientific Expenditure Program

Matt Toth provided a report on the status of the tafazzin knockdown mouse line: The remaining commitment to the TaconicArtemis contract is \$41,375. Drs. Barry Byrne and Arnie Strauss/Zaza Khuchua have agreed to receive and analyze this line, although it was suggested that we should also establish a relationship with an independent distributor, which could be Taconic or JAX. This will cost approximately \$2,000 per year. Mouse distribution to the labs is expected to occur in late April 2009.

Board members asked that Matt notify the Board once the line has been genotyped, and that prior to sending lines to Drs. Byrne, Strauss/Khuchua, he send a letter to each outlining BSF's expectations (publishing articles, sharing data). It was requested that he copy Kate and Linda on this letter, as well as notify them when a line is ready to be sent to Jackson Laboratory, and which independent distributor was engaged.

Barth Syndrome Research

Matt Toth reported on Dr. Mindong Ren's success in winning funding from the NIH for a major study to identify genetic modifiers for Barth syndrome. This NIH funding opportunity was clearly enabled by earlier seed grants from BSF. This work has been highlighted as critically important to gain a deeper understanding of why our boys' experience with Barth syndrome differs so markedly... and should help us devise better treatments in the future.

Application for R13 grant to support BSF Conferences and SMAB meetings

Matt Toth reported that he is in the process of preparing to submit to the NIH an application for an R13 grant to support BSF conferences and scientific meetings and the first draft of a 3-year proposal has been submitted to Richard Kelley for input. It was requested that this draft as well as future revisions be sent to Kate and Linda.

Other Science Updates

Board members expressed concern about the 2008 Research Grant Program results and asked Matt to write an annual research report for 2008 and going forward, and work to ensure wider distribution/PR of the grant program information beginning in 2009. It was also suggested that Matt create multiple up-to-date mailing lists prior to the April newsletter mailing (May 11, 2009). Lynda Sedefian will maintain these lists on an ongoing basis.

Other Issues (not identified on the agenda as distributed)

Role of Corporate Secretary

During the discussion of *ex-officio* board members, a discussion ensued regarding the official role of Corporate Secretary. It was proposed that going forward the Secretary be an elected board member, and that Marc Sernel be duly elected to serve as Corporate Secretary, subject to any conditions or approval that might be needed from his law firm.

*Items placed on upcoming Board Meeting agenda

VOTED: That the Board of Directors accept and ratify the decision to elect Marc Sernel to serve in the role as Corporate Secretary.

Per a Board consensus, BBSF's By-Laws will be amended to reflect the role and responsibilities of Corporate Secretary.

Executive Committee

Steve McCurdy proposed that the BSF Executive Committee be comprised of the officers of the organization, as well as board liaisons to family services and science/medicine. The Executive Committee role is to act on behalf of the Board as necessary during the interim times between board meetings, or when a Board quorum cannot be obtained.

After a discussion, it was proposed that the Executive Committee be comprised of the following elected officers by virtue of the office held; officially:

- **Executive Director** - Linda Stundis, *ex officio*
- **Chairman** - Stephen McCurdy
- **Treasurer** - Randy Buddemeyer
- **Corporate Secretary** - Marc Sernel
- **Board liaison representing Families** - Shelley Bowen
- **Board liaison representing Science/Medicine** - Kate McCurdy

VOTED: That the Board of Directors accept and ratify the decision to revise the composition of the Executive Committee and elect/appoint the aforementioned officers to serve on the Executive Committee, and establish that the minimum number of officers who must be present at an Executive Committee meeting to form a quorum is 2/3 of the voting officers (i.e., 4).

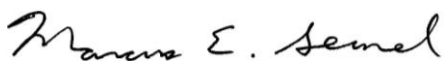
Kate McCurdy reported that she is willing to accept the role of serving on the Executive Committee as a liaison representing Science/Medicine until such time as a new officer can be identified.

Per a Board consensus, BSF's By-Laws will be amended to reflect the role, responsibility and roster of officers who will comprise the Executive Committee.

Adjournment

The meeting was adjourned on Sunday, April 5, 2009 at 2:30 PM EST.

Respectfully submitted,



Marcus E. Sernel
Corporate Secretary

*Items placed on upcoming Board Meeting agenda