



Barth Syndrome
Foundation

BOARD OF DIRECTORS ROLES AND RESPONSIBILITIES

Adopted 2015

Reviewed and Approved - April 24, 2019

BOARD OF DIRECTORS

OVERVIEW OF THE RESPONSIBILITY OF BOARD MEMBERS

The board of the Barth Syndrome Foundation (BSF) is responsible for overseeing the mission and purpose of the organization. Its duties include participation in strategic planning and making policy decisions, then securing the financing of them and the monitoring of their execution. Members must be willing to attend the requisite meetings, follow through on commitments, and participate fully in the decision-making process. The board also presents the organization's image to the community and solicits its support in achieving BSF's goals.

GENERAL RESPONSIBILITIES

PLANNING

- Approves BSF's mission, vision and reviews the organization's management performance in achieving it. Management is defined as the Chair, the Board of Directors, and the Executive Director/CEO.
- Annually assesses the ever-changing environment of the sector in which BSF functions and approves the organization's strategies in relation to it.
- Reviews and approves the Association's programs, plans, and directions.

ORGANIZATION

- Work with the Executive Director/CEO to create a strategic direction for the organization and to set short- and long-term goals.
- Assure that management continuity is properly provided.
- Approve appropriate compensation and benefit policies and practices.
- Identify candidates and determine the eligibility of candidates for the

nomination of officers and directors to sustain proper leadership, succession, and development of the Board.

- Review and approve reports as deemed appropriate.
- Actively participate at the Board meetings and on Board Committee assignments.
- Support sponsoring donor and community support building events as designated by the Board.
- Financially support the organization through the annual individual gift and or fundraising campaign.
- Identify potential funding sources and serve as an Ambassador in securing organizational funding.
- Annually evaluate the performance of the Executive Director/CEO and determine any bonus awards or increases in salary.
- Review the performance of the Board of Directors and take steps (including recommendation for its composition, organization, and responsibilities) to improve its performance.

OPERATIONS

- Review the results achieved by management as compared to the organization's mission, program plans, and the Alliance Strategic Plan as well as in comparison with those of similar organizations.
- Ascertain the financial structure of the organization is adequate for its current needs and the implementation of the organization's Strategic Plan by approving the annual budget.
- Provide candid and constructive criticism, advice and comments to the Chair, other members of the Board of Directors, and the Executive Director/CEO.
- Approve major actions of the organization, such as capital expenditures on all projects over authorized limits or major changes in programs, services, office location, etc.
- Review financial results for the organization and ensuring, through the oversight of the audit committee, that reports are accurate and in accordance with accepted accounting principles.
- Ensure the organization is in compliance with sector specific Standards of Excellence, to include organizational cultural competency, maintaining the highest standard of fiduciary duty and responsibility to the organization.

AUDIT

- Assure that the Board of Directors and its committees are adequately and currently informed through reports and other methods of the state of the organization.
- Assure that published reports properly reflect operating results and the financial condition of the organization.
- Conclude that management has established appropriate policies practices and procedures to define and identify conflicts of interest throughout the Association and is diligently overseeing the enforcement of established policies.
- Approve independent auditors.
- Review compliance with relevant material law affecting the organization.

DIRECTOR POSITION DESCRIPTION

The role of each Director is to serve a three-year term by leading, advising, and supporting the activities of BSF. Each Director participates by:

- Attending all board meetings, prepared to further the success of BSF and to support the organization's mission statement and goals.
- Monitoring and mentoring committees of the board as assigned and on an as needed basis providing advice, encouragement, and voice for the committee to the board.
- Identifying and nominating candidates to the Board for vacant board positions.
- Accepting special assignments designated by the Chair.
- Remaining current on the activities of the organization by following its publications (includes electronic, print and virtual), issues, and interests.
- Remaining current on issues affecting the nonprofit sector as it relates to the mission of the organization, its members or community at large.
- Informing the Board and staying proactive in helping position BSF to support its members or to enhance its funding sources.
- Acting as a role model, change agent, and professional exemplar.

TIME COMMITMENT

- Three-year term (up to three consecutive terms)
- Biennial BSF International Conference – summer of each even year
- Two face-to-face board meetings each year generally held in late fall and late spring of each year
- At least two teleconferences each year

- Ad-hoc leadership assignments as required in executing the mission of the organization

REQUIREMENTS OF CANDIDATES

- The Barth Syndrome Foundation seeks a diverse group of professionals, government and foundation executives, public health and healthcare providers, and business executives and/or community leaders, who will bring access and influence to the organization. Each Director is expected to use his/her access and influence to support the growth and development of the organization.
- Each Director is expected to maintain relationships with contributors or prospects who may lead to potentially advantageous relationships for the organization.
- Candidates must have a commitment to quality health in its broadest sense to make a difference in the lives of the people within our community. They must also be committed to supporting the organization in making its Board of Directors representative and inclusive of the entire community, including people of varied ethnicity, gender, gender identity, sexual orientation, and physical abilities.
- Candidates must have innate leadership, management and interpersonal skills, patience and good humor, and must be able to participate in and sustain collaborative group efforts.

THE SELECTION PROCESS

- Candidates will be interviewed by the Chairman of the Board and will be approved by governing body (the board). Directors will be nominated by board members to the entire board with criteria to support the nomination of the prospective board member.
- The process will be open and unbiased with equal opportunity for any qualified candidate to serve as a director provided there is a vacancy in the board for which the governing body is seeking a replacement.

OPPORTUNITY

This is an exceptional opportunity to foster the growth and development of a nonprofit organization devoted to improving the lives of members within our community and to promote standards of governance capacity to assist within the nonprofit sector and rare disease sub-sector in fulfilling a meaningful mission.



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STATEMENT OF COVENANT FOR BSF BOARD MEMBERS

1. **I am morally responsible** for the health and well-being of this organization. As a member of the board, I have pledged myself to help realize the mission, which is: *"Saving lives through education, advances in treatments and pursuit of a cure."*
2. **I am fiscally responsible**, with the other board members, for this organization. It is my duty to know what our budget is, to be active in planning that budget, and planning the fundraising to meet that budget.
3. **I am legally responsible**, along with other board members, for this organization.
 - a. I am responsible to know and approve all policies and programs, and to oversee the implementation of policies and programs.
 - b. I will attend all board meetings unless circumstances beyond my control prevent my attendance, and I will be available for home consultation.
 - c. I will read materials sent to me in advance of the board meetings.
 - d. I understand that if I am absent without excuse from regularly scheduled board meetings I will be asked to resign from the board.
 - e. I know that if I neglect my duties or if I act in bad faith, it may be possible for me to be held personally liable in suits brought by a private person, a business, a governmental entity, or even the organization itself. However, I understand that I am not responsible for the day-to-day operations of the organization as these are the responsibility of the chief executive.
 - f. My one direct management responsibility, along with other members of the board, is the selection and supervision of the chief executive.
4. **I will give** what is for me a significant donation. I may give this as a one-time donation each year, or I may pledge to give to BSF several times during the year.

5. **I will work to raise money for BSF**, in whatever ways are best suited for me. These may include individual solicitation, helping with special events, writing mail appeals and the like. There is no set amount of money that I must raise because I am making a good-faith agreement to do my best and bring in as much money as I can.
6. **I will act with the care and loyalty** required of board members and put the interests of the organization first. I will observe the organization's conflict-of-interest policy in letter and spirit, taking care to disclose publicly any conflicts that arise in the course of my business or the organization's, and to recuse myself from decisions that create or appear to create a conflict of interest for me.
7. **I promise to preserve the investment of time and money** made over years by all the donors and volunteers who created this organization and brought it to this point. Every board member is making a statement of faith to carry out the above agreements to the best of our ability, each in our own way, with knowledge, approval, and support of all.

In its turn, BSF is responsible to me in a number of ways:

1. **I will be sent**, without request, regular financial reports that allow me to review BSF's financial position.
2. **I can call** on the paid staff to discuss program and policy, goals, and objectives.
3. **Board members and staff will respond** in a straightforward and thorough fashion to any questions I have that I feel are necessary to carry out my fiscal, legal, or moral responsibilities to this organization.
4. **Directors & Officers liability insurance** will be provided.

Board Member (Please print name)

Signature

Date

For board term beginning _____ and ending _____



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CHAIRMAN OF THE BOARD

POSITION SUMMARY

The board chair is the senior volunteer leader of the Barth Syndrome Foundation (BSF) and presides at all meetings of the board, the executive committee, and other meetings as required.

KEY RESPONSIBILITIES

POLICY AND PLANNING: Works with the chief executive and the board to establish the guiding principles, policies, and mission for the organization — for example, by initiating a regular review of the organization’s strategic plan and mission to keep them fresh and relevant, and by establishing metrics to measure success.

BUDGET AND FINANCES: Works with the appropriate board members to oversee the budget of the organization and assumes ultimate responsibility for the integrity of its finances — for example, by overseeing independent outside audits and, as appropriate, internal audits as well.

BOARD MEETINGS: Leads and facilitates board meetings by making sure that the agenda is closely followed, every board member has the opportunity to participate in discussions, and the board uses proper decision-making procedures.

BOARD COMMITTEES: Serves as an ad hoc member of all board committees and works to structure a committee system that contributes to the board’s overall effectiveness.

BOARD DEVELOPMENT: Oversees efforts to build and maintain a strong board by setting goals and expectations for the board, cultivating leadership among individual board members, and working with the nominating committee to make board development a priority.

BOARD RECRUITMENT AND ORIENTATION: Establish a process to ensure succession of the board and work with the committee members who are designated to this task in an effort to identify and recruit new board members who bring important skills and knowledge to the board.

BOARD EVALUATION: Works to make sure the board has opportunities to reflect regularly on how well it is meeting its responsibilities to the organization — in part by overseeing a board self-assessment on a biennial basis (odd years).

STAFF OVERSIGHT, COMPENSATION, AND EVALUATION: Oversees the hiring, evaluation, and compensation of the chief executive; and works to develop a succession plan for the chief executive's position — for example, by making sure that other staff members have the capabilities they need to lead the organization.

FUNDRAISING: Guides the work of the board to secure funds for the organization by overseeing the development of fundraising policies, encouraging and supporting the fundraising efforts of the development committee and individual board members, soliciting contributions from board members and selected outside contributors, and setting an example by contributing his or her own funds to the organization.

PUBLIC RELATIONS AND COMMUNICATIONS: Speaks for the board in the event of a controversy or crisis; oversees the development of communications policies; and works to promote the work of the organization in conversations, speeches, interviews, and other day-to-day activities.

SELECTION PROCESS

- Appointed by the board after proper approval/election processes of the board have been executed

REPORTS TO:

- The BSF Board of Directors

QUALIFICATIONS

- A commitment to BSF and its values; an understanding of BSF's objectives, organization, and services; and the responsibilities and relationship of paid staff and volunteers
- Knowledge of and influence in the community
- Ability to understand concepts and articulate ideas
- Proven record of leadership within the Board of Directors



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TREASURER CHIEF FINANCIAL OFFICER

POSITION SUMMARY

The treasurer/CFO, jointly with the board chair and finance committee chair upon such time that this committee has been established if other than the treasurer/CFO, ensures that current records are maintained reflecting the financial condition of the Barth Syndrome Foundation (BSF). These records will include cash, outstanding advances, investments, accounts receivable and other assets, accounts payable, and fund balances (net assets).

KEY RESPONSIBILITIES

- Control all BSF funds.
- Participate in the preparation of the budget.
- Once established, serve as the chair of the finance committee.
- Ensure that accurate books and records on financial condition are maintained.
- Ensure that the assets are protected and invested according to organization policy.
- Ensure that BSF complies with organization and statutory reporting requirements.
- Ensure that comprehensive financial reports to the board are prepared in a timely and accurate manner.
- Ensure that the complete records of the organization are available to the individual or individuals preparing the annual financial statements.
- Perform all duties incident to the office of the treasurer.

REPORTING

- The treasurer/CFO reports to the board chair and to the board

SUPPORT

- The treasurer/CFO is supported by a financial oversight committee

TIME COMMITMENT

- As required to accomplish major duties

QUALIFICATIONS

- A commitment to BSF and its values; an understanding of BSF's principles, mission, goals, objectives, organization, and services
- An understanding of needs for BSF services, as well as the financial and human resources
- An understanding of the record keeping, accounting systems, and financial reports
- An ability to work with the controller, accountant or bookkeeper, and auditors as necessary

LEADERSHIP DEVELOPMENT OPPORTUNITIES

- The treasurer is expected to attend and participate in training courses, conferences, and seminars as appropriate, to ensure adequate knowledge about sector-wide standards and implications, and to remain abreast of legal and ethical implications that would affect the mission of BSF.



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SECRETARY

POSITION SUMMARY

To ensure that actions of the board are documented.

KEY RESPONSIBILITIES

- Certify and maintain a centralized repository of records including but not limited to:
 - An original or a copy of the bylaws as amended or otherwise altered by the board of directors to date.
 - A recording of minutes of all meetings of the directors and meetings of committees.
 - Minutes shall record time and place of meeting, whether regular or special, how called, how notice was given, the names of those present or represented at the meeting, and the proceedings thereof.
- Ensure that all notices are duly given in accordance with the provisions of the bylaws or as required by law.
- Be custodian of the records and of the seal of the organization and affix the seal, as authorized by law or the provisions of the bylaws, to duly executed documents of the organization.
- In general, perform all duties incident to the office of the secretary and such other duties as may be required by law, by the articles of incorporation, or by the bylaws, or which may be assigned to him or her from time to time by the board.
- Ensure that legal documents are available for public inspection
- Promote the organization's accountability and standards through transparent leadership and reporting practices
- Ensure that minutes of the board are available in a timely manner for board inspection and approval and post the approved minutes to the BSF website