Barth Syndrome Foundation Fundraising Toolkit Policies



Introduction

Thank you for your interest in raising funds to support the Barth Syndrome Foundation (BSF). Our success depends on the initiative of supporters like you. Each dollar that you raise will help BSF accelerate the development of possible treatments as well as provide vital information to Barth syndrome patients and their families. We are grateful for your desire to help and look forward to working with you to bring closer the day when people will no longer suffer from this disorder.

Whether you've hosted fundraising events in the past or are new to fundraising, this Fundraising Toolkit is designed to help you effectively raise money and awareness for BSF. We ask that you carefully review this document as it contains important guidelines to follow when raising money on behalf of BSF.

BSF has the extraordinary privilege of being recognized by the Internal Revenue Service (IRS) as a taxexempt charitable organization; this tax exempt status is crucial for our ability to carry out our mission. In order to preserve this status, it is essential that you comply with the various IRS regulations regarding nonprofit fundraising activities.

We are here to help make your event as easy and successful as possible. If you have any questions, or if there is anything we can do to support your efforts, please don't hesitate to contact us.

Community Fundraiser Contact: Lynda Sedefian, BSF Executive Assistant <u>lynda.sedefian@barthsyndrome.org</u>

BSF would like to thank the following organizations who generously contributed materials to this fundraising kit: The Friedreich's Ataxia Research Alliance (FARA), Parent Project Muscular Dystrophy (PPMD), Chordoma Foundation

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Fundraising Policies

A "Third-Party Event" is defined as any fundraising activity conducted by a group or individual that is not employed by BSF, where BSF has no fiduciary responsibility and little or no staff involvement in its execution. These policies pertain to all events or activities benefiting BSF that are organized and executed by third parties.

Organizer Responsibilities

- All expenses are the responsibility of the event organizer. BSF is not responsible for any
 expenses incurred for a third-party fundraising activity, and will not advance funds or reimburse
 expenses unless approved in advance by the Board of Directors. We recommend finding event
 sponsors or charging a registration fee to help cover expenses. You may not purchase goods or
 services under BSF's name, and BSF sales tax-exemption (on purchases) cannot be extended to
 any third-party event or fundraising effort.
- The event organizer is responsible for the planning and execution of the event including safety precautions and adherence to applicable laws. As the beneficiary of a fundraising event, BSF does not accept or assume any liability associated with the event including but not limited to any injuries sustained by event volunteers or participants during the event. The event organizer will indemnify, defend, and hold harmless BSF, its directors, officers, and employees from any and all claims that may arise out of or relate to such event.
- The event organizer is responsible for obtaining all applicable permits or licenses, including but not limited to alcohol, solicitation, and sales tax licenses.

Promotion & Publicity

- All third party events must be publicized and conducted in a manner that makes it clear that BSF is the beneficiary, not the sponsor or host of the event.
- Promotional materials must clearly state that the event is raising funds that will benefit BSF (e.g. "proceeds benefit Barth Syndrome Foundation").
- Event names may not incorporate the name of BSF, as in "The BSF Walk-a-thon." BSF's name may be used in a second clause identifying the relationship of the event with the Foundation, such as "John Doe Walk-a-thon, benefitting BSF."
- All event materials that include BSF's logo, including, but not limited to, advertising, press releases, posters, flyers, t-shirts, and public service announcements, must be reviewed and approved prior to distribution.

Financial Policies

- The event organizer may not keep any portion of the proceeds (beyond real expenses) as profit or compensation for organizing the event.
- The event organizer may not set up a temporary bank account in BSF's name, as this is illegal.
- Donors must be informed that the tax deductible amount of a donation is only the amount that is over and above the value of any goods or services received in exchange for the donation. For example, if a participant pays \$200 to participate in a golf outing, and the value of the outing is \$50, the donation amount is \$150. If a donor pays less than the value of an item then they will not receive a tax deduction.
- If goods are sold to raise money as part of a fundraising event it must be made clear to the event participants what percentage of the sale price benefits BSF.

Third Party Agreement

This Agreement is entered into between the Barth Syndrome Foundation ("BSF") and the event organizer ("Organizer").

Clearly Print First and Last Name

Organizer plans to conduct a fundraising event for the purpose of generating money to support the mission and work of BSF. BSF gratefully acknowledges Organizer' efforts and agrees to use the donation in its charitable work.

Organizer agrees that it has read and will comply with BSF's policies related to third-party fundraising, incorporated herein by reference. Organizer acknowledges that it is not an agent of BSF and BSF has played no part in the organization, promotion, or execution of its fundraising event and has no control over it. Consequently, Organizer agrees that it will fully indemnify, defend and hold harmless BSF, its directors and employees from any and all claims that may arise out of or relate to such event, regardless of who might make such a claim.

Event Organizer - printed name

Event Organizer's signature

Date