

# Barth Syndrome Foundation Fundraising Toolkit Overview



Barth Syndrome  
Foundation

## 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 tax-exempt 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  
[lynda.sedefian@barthsyndrome.org](mailto:lynda.sedefian@barthsyndrome.org)

*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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## Planning Your Event

### Step 1: Contact BSF

#### Why this is important:

The sooner you get in touch with us, the better we will be able to assist you as you begin planning your event! We can answer questions, provide materials, connect you with someone who has organized an event before, and help publicize your event. Also, it helps for us to know if you are collaborating, or co-hosting this event, with another organization, as they may require additional documentation.

Please complete our Fundraising Information Form to notify us about your event:

<http://www.barthysyndrome.org/english/View.asp?x=1565&id=862>

Once you fill out this form, we'll reach out to you to offer our assistance.

### Step 2: Plan Your Event

1. **Choose your event.** Decide which type is best for you, based on your resources, timeframe and fundraising goals. Look through the suggestions offered on page 9 of this toolkit or come up with an idea of your own.
2. **We encourage you to organize an event committee.** Choose your committee members wisely. You may need a:
  - Bookkeeper to document all income and expenses
  - Volunteer chairperson to recruit and organize volunteers for the day of your event
  - Publicity chairperson who will contact radio and TV stations
  - Printing chairperson to have brochures, signs, T-shirts, etc. printed
  - Sponsorship chairperson to recruit sponsors, to get auction items donated, to follow up with confirmation letters, etc. You'll need someone in this position who can network and who isn't afraid to ASK.

**Why form an event committee?** Events can take a lot of effort. By forming a committee, or team, you can share the work of planning, coordinating, and executing your event. By making these decisions early, you help give everyone involved an idea of what you expect from their participation.

**Who should you ask to join the event committee?** We suggest gathering a group of family and friends whom you can trust and depend on. Ideally you should try and organize your committee with real "go-getters." This is also a great opportunity to involve those family members and friends who always ask, "What can I do to help?"

3. **Create a timeline.** Once you have determined who will be on your event committee, organize a kick-off meeting to set a date, create a timeline and delegate tasks. Try to think of everything that needs to be done to make this event happen. You may need as long as 10-12 months to plan your event.

4. **Reserve a location.** Consider the space you will need, activities that will be held, the weather, and anything else that could restrict the venue of your event. Begin gathering supplies and reserving any vendors you need as well.
5. **Obtain necessary and appropriate licenses, permits, and insurance.** For your protection and peace of mind, we encourage you to obtain event insurance appropriate for the size and nature of the event. Event insurance can protect you against loss due to cancellation or postponement, and against financial liability that could arise from your event. Event insurance is required by many venues. Here are some resources to assist with obtaining event insurance:

<a href="http://www.nasep.org/insurance-apply-now.jsp">www.nasep.org/insurance-apply-now.jsp</a>	<a href="http://www.insureaparty.com">www.insureaparty.com</a>
<a href="http://www.privateeventinsurance.com">www.privateeventinsurance.com</a>	<a href="http://www.csicoverage.com">www.csicoverage.com</a>

**We recommend that alcohol not be served** unless it is believed to be necessary to the success of the event. If alcohol will be served, you are responsible for obtaining insurance, permits and licenses that may be required by your state. Check with the venue about policies for hosting events where alcoholic beverages will be served.

**Depending on your state, if you are selling products or conducting certain types of events**, such as a raffle, bingo, or games of chance, you might need to obtain an appropriate permit or sales tax license. The National Association of State Charity Officials provides a directory of state agencies responsible for regulating such activities: [www.nasconet.org/agencies](http://www.nasconet.org/agencies).

**It is important to know that** bingo, raffles, sweepstakes and other gaming activities are **not** considered charitable activities under federal, and most state, laws. Therefore, fees paid to participate in gaming fundraisers are not tax deductible. There are also federal reporting requirements concerning gaming fundraisers. See IRS Publication 3079: [www.irs.gov/pub/irs-pdf/p3079.pdf](http://www.irs.gov/pub/irs-pdf/p3079.pdf).

6. **Recruit sponsors.** Ask corporations, restaurants, local vendors, individuals, and anyone else you can think of. Ask for in-kind (goods and services) as well as monetary donations.
7. **Enlist volunteers** for the day of the event from local high schools, your neighborhood, area youth groups, churches, etc.

### Step 3: Publicize Your Event

When you organize a fundraising event, you have a unique opportunity to garner media attention. The effective use of free media opportunities gives you the chance to raise awareness about Barth syndrome within your community and to call attention to the importance of raising funds for research.

For information about how to contact various media outlets and tips for talking about Barth syndrome and BSF, please refer to the **Media Relations Toolkit**.

The BSF logo may be used on marketing and event materials only with permission from BSF. In order to use the logo, please fill out the **Third-Party Fundraiser Agreement** and return it to us. Once we receive

this document, digital versions of the logo will be emailed to you.

Please refer to the **Fundraising Policies** to insure compliance with the BSF policies on promotion and publicity.

## **Step 4: Collect Donations**

In order to insure that all donations are tax deductible to the donor to the fullest extent permitted by law, all checks and credit card donations should be made payable to Barth Syndrome Foundation. In order to maximize the donations to BSF, we ask the organizer to work to the best of their abilities to find in-kind donations to cover the costs of the event or fundraising activity or to commit to cover these expenses themselves.

- Each event participant writes a check payable to Barth Syndrome Foundation or donates online at [www.barthsyndrome.org](http://www.barthsyndrome.org).
- The event organizer records the value of any goods and/or services received by each participant, and sends this information, along with all collected checks, to BSF.
- Each participant receives a tax receipt from BSF for the tax-deductible portion of their payment, which is the amount of the payment above and beyond the value of any goods or services received in exchange for the donation. (For example: a gala participant writes a check for \$100 to BSF and the value of the dinner is \$40; then the donor receives a letter acknowledging their \$60 tax deductible contribution.)
- Event organizer pays for all expenses through sponsorships and in-kind donations that they have collected.

## **Step 5: Expenses**

To the best of their ability, each fundraising event host should strive to find in-kind donors who will cover the cost associated with the event or activity. BSF will have no financial responsibility for fundraising expenses unless the organizer contacts BSF in advance and obtains written approval prior to incurring any expenses.

BSF will only consider covering expenses for an event following a full review of event plans, budgets, and Board approval. Please contact Executive Director, Lindsay Groff for further details.

### **PLEASE NOTE**

- In order for donors to receive a tax receipt from BSF they must make a payment by check or credit card directly to Barth Syndrome Foundation. BSF CANNOT issue a tax receipt for payments made to the event organizer or any other organization. That means that if you accept cash or in-kind donations, they must still be fully documented including donors name, address, donation description, value, and date. This must be clearly communicated to event participants.

- In the absence of prior BSF Board approval, all bills and expenses are the responsibility of the event organizer. BSF CANNOT, under any circumstances, reimburse event organizers for any expenses without prior Board approval.

**What to do with cash donations.** If you receive cash donations, please go to your local bank and get a bank check (issued to BSF), or a money order for the total cash amount. Then, mail it to BSF.

Please refer to the **Fundraising Policies** in order to insure that all funds are handled in compliance with the IRS and BSF policies.

## Step 6: Submit Donations and Reports

Within 15 days after your event:

- Send all checks to the lockbox:

**Barth Syndrome Foundation**  
**PO Box 582**  
**Gretna, NE 68028**

- Email the following to [lindsay.groff@barthsyndrome.org](mailto:lindsay.groff@barthsyndrome.org)
  - An Excel spreadsheet containing the following information:
    - Contact information of event attendees, donors, and sponsors, including any individual or corporations who made in-kind (i.e., non-cash) contributions.
    - The type and amount of all donations or sponsorships, whether cash or in-kind.
    - A description and estimated fair market value of any goods and/or services received by each donor. (e.g. if you are conducting an auction we must know the fair-market value and auctioned price of each item purchased, so that we can provide accurate tax receipts).

At your earliest convenience, please email or mail us the following:

- A brief summary of your event, including anything notable that happened, and any lessons learned so that we can share this knowledge with future event organizers.
- A final sample of marketing materials, tickets, invitations, checklists, programs, or anything else we can use as a model to help future fundraisers.
- Pictures! We'd love to showcase your successful fundraiser in our newsletter, website, at the conference, and beyond, so please send any pictures you'd like to share, especially group pictures.

## Step 7: Send Thank You Notes

We believe it is important to acknowledge the generosity of all donors in a timely manner. We will send a tax receipt to all donors who make payments directly to BSF. Donors should receive their tax receipt within 2 to 3 weeks of the date that BSF receives the donation, depending on the time of year and the volume of donors.

In addition, we encourage you to send a personal “thank you” note to all donors, event participants, sponsors, and volunteers, as your note will have more personal meaning. In your note, you may want to include a sentence that states, “Keep an eye out for your official tax receipt in the mail from BSF.”



## Ideas for Fundraising Events

### Dinner & Party Events

Birthday party  
Casual at-home approach  
Children's party  
Gourmet food & wine  
Masked ball  
Seasonal parties  
Themed parties  
Valentine dance

### Sporting Events

Bike-a-thon  
Bowling  
Golf tournament  
Motorcycles  
Poker  
Runs & walks  
Swim-a-thon

### Other Ideas

Art exhibit  
Ask retailers for daily percentage of sales  
Bagel or donut sales  
Bingo  
Book sale  
Car wash  
Chocolate festival  
Dance-a-thon  
Fashion show  
Garage sale  
Holiday bazaar  
Ice cream social  
Movie night  
Pizza sale  
Raffle  
Sidewalk sale  
Sporting events parties (Super Bowl, etc.)  
Teen dance  
Treasure hunt  
Yard sale

Bar-b-que  
Black & white ball  
Celebrities  
Dessert  
Halloween party  
Restaurant tasting menu  
Spaghetti supper  
Unique locations  
Wine & cheese reception

Bowl-a-thon  
Golf  
Monopoly  
Pet parades  
Rides  
Stroll-a-thons  
Tennis tournament

Auction  
Benefit concert  
Block party  
Candy bar sale  
Carnival  
Craft fair  
Disco night  
Flower arranging  
Garden tour  
House sale  
Loose change collections  
Pay to dress down at work  
Prize drawing  
Services for sale  
Soup sale  
Talent competition  
Toy fair  
Wine tasting