

**bloom
syndrome**
association



Fundraising Toolkit

Version 2.0
Spring 2024

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This Fundraising Committee of the Bloom Syndrome Association (BSA) is here to help!

Thinking of hosting a fundraiser or otherwise have questions about how to support the Bloom Syndrome Association? Contact us to let us know and we're happy to support your efforts!

info@bloomsyndromeassociation.org

(802) 526-4959

BSA Website:

<https://www.bloomsyndromeassociation.org>

Donations:

<https://www.bloomsyndromeassociation.org/get-involved/donate>

1. Introduction

Thank you for your interest in fundraising on behalf of the Bloom Syndrome Association and the broader Bloom syndrome community! This toolkit is designed to help make your fundraising efforts a success. It likely will not answer all of your questions, so we encourage you to contact us as you are getting started.

How am I helping the Bloom syndrome community?

The BSA is an entirely volunteer-run organization, with the mission to connect, educate, and support the international Bloom syndrome community and stimulate research that leads to longer, healthier lives.

In order to implement its programs and activities, including the international patient & family conference, webinars, and its future goal of more actively supporting research into treatments for Bloom syndrome, it relies on donations from individuals. Your support and your efforts are critically important to helping the Bloom syndrome community.

Other ultra-rare disease groups have been able to achieve tremendous progress in short amounts of time, due to dedicated individuals in the community and successful fundraising. We want the Bloom syndrome community to be able to do the same. We must drive towards longer and healthier lives for Bloom syndrome individuals.

What does the BSA do with its donations?

The BSA develops strategic priorities it wants to address and outlines the funding needs associated with those efforts. For the 2023-2025 timeframe, some of the more costly activities will be:

- Hosting a 2024 international patient & family conference
- Collecting information on cancer treatment protocols
- Stimulating research and drug development efforts

For more information on the BSA and its programs, see:
www.bloomsyndromeassociation.org

2. Getting Started

Contact us: info@bloomsyndromeassociation.org

The first step in getting started is to let the Bloom Syndrome Association know! As described below, there are several things we can do to help, and it's useful for us to know so that we can help spread the word.

Fundraising 101

Many of us may have never done fundraising before, and it can seem daunting or intimidating to take on. Others who have not done fundraising before may think it's just a matter of asking for money, and hence can be easily done. Neither is right: fundraising is something that can be done by anyone, but it does take time and effort, and is primarily built on trusted relationships that need to be nurtured and maintained.

There are many resources online about fundraising and we can provide additional information as you begin your journey. For now, it's important to know the following¹:

- Most charitable donations come from individuals, either through direct donations, or supporting events or other fundraising activities.
- People give to people and organizations they care about. Generally speaking, if there is no relationship, there is no donation.
- People give money to make a change for good. They give because they are presented with an opportunity to achieve something and a vision of that achievement.
- It's not enough to communicate the need for more money—one must demonstrate a compelling reason.

It's not bad to start small and build on successes over time. Say you want to raise \$250 through a small bake sale - in addition to the funds, which are always welcomed, this also provides you with an opportunity to share information about Bloom syndrome, which may lead to individuals in your network caring more about future activities and ways to support.

¹ Taken from Global Genes' Finding Your Fundraising Strategy (https://globalgenes.org/wp-content/uploads/2016/06/Fundraising-Toolkit_spread_DIGITAL.pdf)

What we can provide

As the BSA, we are able to provide the following:

- This toolkit!
- Answers to any other questions you might have
- Publicity on the BSA Website and the BSA Facebook page
- Example wording and Bloom syndrome facts that can be used in your social media, email, or press outreach
- High-resolution files of the BSA logo
- If funds are made directly to the BSA (as opposed to being collected by you and handed over to the BSA in a lump sum), the BSA can provide:
 - A donation receipt for tax purposes
 - A thank you from the BSA
 - Updates on BSA activities through the BSA mailing list

What we are unable to provide

As the BSA, we are able to provide the following:

- Any dedicated staffing at an event or fundraiser
- Insurance or liability coverage for your event or activity
- Reimbursement for any expenses
- Details or contact information of existing BSA donors

More frequently asked questions are answered in the FAQ section of this toolkit. As always, contact info@bloomsyndromeassociation.org with any questions and a member of the Fundraising Committee will be in touch!

3. Planning

Once you've decided to hold an event or otherwise fundraise for the BSA, it's important to make a plan before asking for funds. Here are some steps that may be helpful to follow

- √ Get a group together to help you in your efforts. This could be just you and one other person, or a handful of people who have asked how they can help!
- √ Discuss different fundraising ideas (see suggestions below) or approach.
 - For example, do you want to hold an event, do you want to commit to a personal goal (e.g. running a marathon, or agreeing to be dunked in a tank if a certain goal is reached), or do you want to do more private, one-on-one outreach to your community to ask for support?
- √ Decide on which idea/approach to pursue, considering the size, interests, talents, goals, and time availability of everyone involved.
 - Think about whether you already have people in your group who have successfully fundraised.
 - Think about who in your group will be able to help spread the word.
 - Think about your audience for an event. Who do you want to attend, and what would interest them in coming? What do you imagine a reasonable donation would be, per person?
 - Once you've decided, let the BSA know, if you haven't already!
- √ Build out a budget for your event. Think about ways to increase revenues such as donations of supplies or sponsorship from local companies.
- √ Set a fundraising target to help your supporters know what you're aiming for.
 - Remember that it's more encouraging to meet and exceed a goal than to fall short! Think through what might be achievable.

- √ Think about how you want people to donate
 - Do you expect people to pay in cash? If so, be sure to include that information in your invitations and event reminders.
 - Will you set up a fundraising page on a platform such as GoFundMe, JustGiving, etc.? If so, you'll need to make sure the BSA is listed as a charity on the platform. (More information on this is provided in the "How to Get Funds to the BSA" section.)
- √ Make a timeline to help you keep on track, schedule group meetings so that all of your team feel included and have dates to aim for.
- √ Schedule the event (or launch date, if doing a campaign not around an event).
 - For events, think about what timing might work best for your attendees.
 - For events, think about whether you'll be able to staff it with your current team. Events can be exhausting, so build in breaks for anyone who is volunteering their time.
 - Let the BSA know the date, so we can add it to our community calendar at the appropriate time.
- √ Think about how you will publicize your event. (More about this in the "Getting the Word Out" section.)
- √ Hold the event and collect funds. (More information on this is provided in the "How to Get Funds to the BSA" section.)
- √ Say thank you!
 - You can never thank donors enough!
 - Use social media to do broad thanks, but also follow up individually where you are able to. Let donors know how much their support means to you and the Bloom syndrome community.
 - If donations are made directly to the BSA, the BSA will also follow up with thanks.

4. Fundraising Ideas

There are so many ways to make a huge difference for the Bloom syndrome community. This list is by no means exhaustive! Think about what is unique to you and your family or community and try to make the fundraiser tie in those personal elements.

Bake sale / Lemonade stand

Casual clothes day at school/office

Birthday fundraiser

Car wash



Movie night



Craft fair

Games night

Promise auction

Sponsored walk/run/cycle/
silent retreat

Raffle



Garage/car boot sale



Black tie event/dinner

Events can range from small to large, and larger events will likely be more complex to put on. Think about what might be reasonable for you to do, and what your likely "return on investment" will be (in other words, you don't want your expenses to be more than your anticipated funds raised!). If you have questions about lessons learned from others, contact us!

Examples from the community

- A family in the UK organized a group that committed to run 50 miles each in one month to raise awareness around Bloom syndrome, and to fundraise for their daughter's expenses related to chemotherapy.
- A family in the US organized a "Hot Cocoa for Coco" stand selling hot chocolate for their daughter, whose nickname is "Coco."

5. Getting the Word Out

Once you have an event or fundraising goal in mind, you'll need to share it with people! Since Bloom syndrome is so rare, you'll likely also need to share information on what it is and why fundraising is needed.

Sample Timeline for Publicizing Your Event or Goal

3-4 months before the event: Identify target audience/ donors, inform the Bloom Syndrome Association of your plans. For larger events, send a save-the-date.

4-6 weeks before: Create any posters, leaflets, social media posts, email drafts. For events, send an invitation. Include a link to the BSA's donations page or to your own fundraiser page.

2 weeks before: Do follow up calls, emails, reinforce social media, local radio, to make sure the word is out.

1-2 days before: Do a "dry run" to make sure you have everything you'll need for the event, confirm your helpers are available and ready to participate.

Day of: Do your best to enjoy and not worry! Take pictures and post to social media.

Suggested language describing Bloom syndrome and the BSA

Bloom syndrome was first described by New York dermatologist David Bloom in 1954.

- Individuals with Bloom syndrome often have a facial rash in a "butterfly" shape, although this rash is not present in all individuals and often goes away with age.
- Even among rare diseases, Bloom syndrome is especially rare. Since its discovery, only approximately 300 cases have been reported, and it is estimated that there are a few dozen individuals around the world diagnosed with Bloom syndrome. As genetic sequencing becomes more common, we expect this number to grow.
- Individuals with Bloom syndrome are at a higher risk of developing a wide variety of cancers. Early screening, detection, and treatment of these cancers can greatly improve outcomes

- The Bloom Syndrome Association (BSA) is an international family support and patient advocacy organization for persons affected by Bloom syndrome
- The BSA's mission is to connect, educate, and support the international Bloom syndrome community and stimulate research that leads to longer, healthier lives.

Suggested language: what will donations support?

The BSA is a 100% volunteer-run organization. It has identified several programs and initiatives it would like to provide for the international Bloom syndrome community over the next few years:

- Hosting biannual Bloom syndrome community conferences
- Developing a "mentorship" program for families and individuals to learn from one another
- Augmenting the registry to enable more research and to allow for future clinical trials should any promising treatments be identified
- Supporting research and development of treatments that could lead to longer, healthier lives for individuals with Bloom syndrome

Suggested language: why is this important to you?

Remember that your donors will be giving because they care about you and your family. In any messages, be sure to tell friends and followers about why you are holding this event, and the difference their donations will make not only to the BSA, but also to you and your family. Tell your story!

Templates

The Fundraising Committee can provide sample emails, social media posts, and thank you notes. Just contact us!

6. Showing Your Results and Building for the Future

Fundraising is an ongoing process, and it doesn't end after your event or campaign!



One of the most important things to do is to follow up with thanking your donors. (If they donated directly through the BSA's website, the BSA will also send them a note of thanks; see more on how this works in Section 7.) Note that if you used a third party platform like GoFundMe or JustGiving, the BSA will not have information on individual donors, so it's especially important that *you* thank them, or they might feel upset their donation was not acknowledged. Let them know how much their support means to you, and to the Bloom syndrome community.



If you took photos or otherwise documented your event, post them on social media. (If the event goes beyond friends/families, please get permission to share photos.) We'd love to see them in the Bloom Syndrome Community Facebook page!



If you collected funds directly or through an online platform, it's important to make sure the proceeds from your fundraiser get to the BSA (see Section 7). If you've collected funds in person, it's a good practice to count money with another person present and also include details of your fundraiser when you send in your proceeds so that the BSA can show off your success and acknowledge your efforts.



Take some time to think about what went well and what you enjoyed the most about your fundraiser – then write them down so that you can use your own tips when you start planning your next one.



If you asked people if they wanted to be added to the BSA mailing list or otherwise identified individuals who may want to volunteer for the Bloom syndrome community, let us know who they are!

7. How to Get Funds to the BSA

There are several different ways to collect funds and to make sure they get to the BSA. Here we'll focus on three of the most common ways, and briefly talk about the pros/cons of each approach. We are happy to talk with you about your fundraiser and help guide you as to which approach might make the most sense for your situation!

Approach 1: Direct your donors to donate through the BSA website

- In this approach, you'd tell your donors to donate here:
<https://www.bloomsyndromeassociation.org/page/donationsfundoptions>
 - They can donate to the "General Fund"
 - In the "Donor Comments" field, you can ask that they mention your fundraiser so that the BSA knows the donation is related to your efforts
 - Donations can be made through PayPal, or by check or mail
- Pros:
 - Funds are not subject to any processing fees
 - Donors will receive an immediate donation receipt
 - Donors will receive an email thank you letter from the BSA
 - Donor information will be saved and can be directly added to the BSA email list to receive updates on BSA activities and Bloom syndrome-related news
- Cons:
 - You will not have direct visibility into who has given in support of your event or campaign, although the BSA fundraising committee can provide updates on a weekly basis
 - You will not have an event-specific website where you can put other materials

Approach 2: Use a technology platform like a Facebook fundraiser, GoFundMe, JustGiving, Fundly, Network for Good, or others.

- In this approach, you set up a fundraiser yourself on one of these sites and select the Bloom Syndrome Association as the

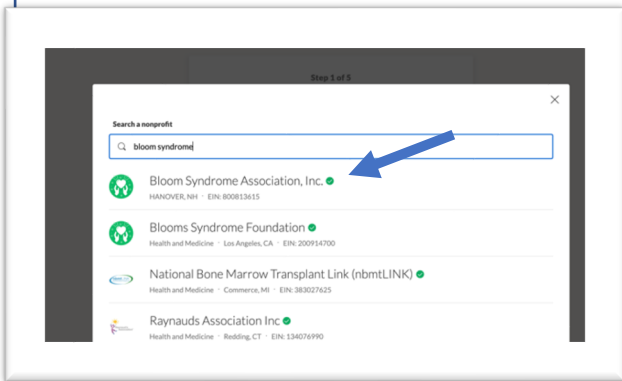
recipient charity. The BSA should already be listed, but contact us if not.

○ NOTE: Sometimes there may be several Bloom syndrome related organizations registered on a site. Be sure to select the correct organization! [The Bloom Syndrome Association's unique tax ID number is: 800813615](#)

● Funds are collected through the platform, and then are sent as a

bulk donation to the BSA. **This can take up to 60-90 days after a donation is made.**

- Pros:
 - As the fundraiser organizer, you can see donations as they are made and track progress towards your goal.
 - Typically, you can add more materials directly on your fundraiser to explain why you are doing it.
 - For platforms like Facebook fundraisers, your fundraiser can be shared easily over social media.
- Cons:
 - Most platforms charge a processing fee for each donation, meaning less funds are ultimately given to the BSA.
 - Some platforms can approach close to 10% of the donation!
 - Donors will receive a donation receipt, but it will come from the third-party platform, not the BSA.
 - Donations are made to the third-party provider, and the *BSA does not receive information on individual donors, so it cannot thank them or update them on the BSA's work.*
 - This is an important point! Please note that your donors will not receive any acknowledgment from the BSA unless we receive the donor contact information directly from you!
 - Please also note that, as mentioned above, the BSA does not receive funds from the third-party platform until 30-90 days after donations are made. Thus, there is some difficulty in matching donations to individual fundraisers.



Approach 3: Collect funds directly and you donate to the BSA.

- In this approach, you will collect funds directly (in person or sent to you) and then make a donation to the BSA.
 - Once funds are collected, you can make your donation through the BSA website, just as in “Approach 1” above.
- Pros:
 - You’ll be able to see who donated, and when.
 - If funds are given at an event, you can thank your donors in real-time.
- Cons:
 - **Your donors will not receive donation receipts**, which they may want for tax purposes.
 - More work for you to ensure funds are ultimately donated to the BSA, and that your donors are thanked.
 - Unless you provide contact information on your donors, the BSA will not be able to provide a thank you and/or provide updates on BSA activities.

There is no single “right” approach to use, and the BSA is working to make donating as easy as is possible. What is important is that you and your donors know what is possible through each approach. In the meantime, please feel free to contact us with any questions about the process or specific questions about your fundraiser!

8. Other Ways to Raise Funds

There are other ways to raise funds for the BSA, without organising a specific event or fundraiser:

- Connect with local business to see if they host special nights for charities
- Get a match from employers
 - Remind your donors that many employers match donations made by their employees. Your donors can contact their Human Resources department to find out more.
 - This search also tells you if an employer matches donations (it's still worth checking with HR, even if your employer is not listed!):
<https://www.charitynavigator.org/index.cfm?bay=content.view&cpid=1799>
- Ask friends and families directly for support
 - Contact us and we can provide advice and sample language on how to approach people individually for support:
info@bloomsyndromeassociation.org
- Keep an eye out on the Bloom Syndrome Community page for BSA-run fundraisers
- Volunteer with the Fundraising Committee!

9. Frequently Asked Questions

Here are some frequently asked questions, but if you can't find what you're looking for here, please get in touch at info@bloomsyndromeassociation.org

Can receipts be issued to donors at my fundraiser?

If a receipt is required for a donation, the donation has to be given directly to BSA at <https://www.bloomsyndromeassociation.org/get-involved/donate>. If you use GoFundMe, JustGiving or another fundraising platform, those platforms will provide donation receipts. If you will be collecting the funds yourself and submitting to the BSA, donation receipts will not be provided. See more in Section 7.

Can someone from the Bloom Syndrome Association Fundraising Committee help plan or attend my event?

We want to help however we can, so although we can't attend the event in person, please get in touch to let us know of your plans so that we can help publicise your event and offer support from the fundraising committee! info@bloomsyndromeassociation.org

Can the Bloom Syndrome Association contribute towards expenses for my fundraiser?

As a non-profit organisation, the BSA is unfortunately not in a position to contribute towards expenses for individual fundraising events.

Can the Bloom Syndrome Association provide insurance for my fundraiser?

All expenses, insurance, permits, licences are the responsibility of the event organiser and unfortunately cannot be met by the BSA.

Can I use the Bloom Syndrome Association logos for promotion and publicity?

In most cases, we will be able to provide logos for your use. It's just important to ensure in your messaging that you are fundraising *on behalf* of the Bloom Syndrome Association, i.e. that the BSA is a beneficiary, not that the BSA is doing the fundraising directly.

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