



**BCM  
FAMILIES  
FOUNDATION**

[www.bcmfamilies.org](http://www.bcmfamilies.org)

BCM Families Foundation  
PO Box 7711 Jupiter, FL 33468  
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# BCM Families Foundation

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## Community Engagement Toolkit

Toward a cure for Blue Cone Monochromacy

BCMFF's event toolkit will help you plan and execute your fundraiser with a step-by-step guide and customized templates. Your event will make a valuable contribution to the work BCMFF is executing around the world. Thanks to supporters like you we are able to empower patients and lead a path towards a cure for BCM.

## ORGANIZATION OVERVIEW

In 2014 we formed the BCM Families Foundation in response to the lack of information and support around the rare retinal disease, Blue Cone Monochromacy. We are a global coalition of families, friends, researchers and ophthalmologists with a mission to eradicate BCM by supporting the most promising biomedical and scientific research.

Blue Cone Monochromacy is rare genetic eye disease affecting 1 in every 100,000 individuals. It is carried through the X chromosome and almost exclusively affects males. Blue Cone Monochromacy (BCM) is one of those rare genetic diseases that has no cure and about which little is known. From birth, a boy with BCM experiences:

- **Low vision, even blindness**
- **Nystagmus (shaky eye movements)**
- **Poor color discrimination**
- **Near-sightedness**
- **Extreme light sensitivity**



Since founding BCM Families Foundation we have been dedicated to collecting all of the necessary data needed to move towards clinical trials. Parallel to this, we also work to educate ophthalmologists, low vision specialists, patients, and the general public.

In order continue to achieve milestones within these program areas we need your help. Through your generosity, you can change the lives of thousands of patients struggling with this rare disease.

# FUNDRAISING HOW-TO

## Ahead of the Event

Come up with a fundraising event idea. Popular events include:

- Sports – Hold a volleyball or basketball tournament or hold a bowling night
- Parties & Dinners
- BBQ
- Pancake breakfast
- Movie night - host a film night at a community center or with a group of friends.
- Lunch & Learn – Host an interesting speaker series for your office, school or community.
- Bake sale
- Concession stand at local sporting event
- Book club
- Lemonade stand
- Ice cream social
- Garage sale and/or yard sale
- Benefit night at a local restaurant
- \$/Km – Ask your friends and family to donate money for every mile you run, walk, swim or bike

### Set Goals

- How many people do you want to attend?
- How much money would you like to raise?

### Pick a date

- Pick a date far enough in advance to give you time to prepare and spread the word. Consider major holidays that may conflict with or help the event. Dates that may help include:
  - Rare Disease Day (last day of Feb each year)
  - International Blue Cone Monochromacy Awareness Day (May 20th)

### Budget

- Estimate the cost of food and beverage, printing, mailing, location and decorations based on the estimated attendance. Try to get as much as you can donated!

### Location

- Find a location that meets your criteria. If not your own house, try local galleries, restaurants, American Legions, churches or schools. Some may even be willing to donate the space.

### Promote Your Event

- Give your event a name. Invite everyone you know by utilizing social media, Evites, e-mail or mail! Create flyers or posters and ask your friends and family to help distribute them.

### Create a Supplies Checklist

- Make sure you have all the necessary materials for the day of the event. (RSVP list, BCMFF informational brochures, information regarding methods of donation, donation tracking sheet, etc.)

## Day of the Event

- Include a fun or interactive way to explain to your guests about BCM (PowerPoint presentation, a patient speech, etc.) and why raising funds is important.
- Speak with all attendees
- Take photos
- Assign at least one person to handle donations - use our helpful donation form to keep track of everything that comes in during the event.

## After the Event

- Thank your guests by email or note
- Submit your proceeds to BCMFF (further information regarding donations can be found in the pages below)
- Don't forget to send your event photos to: [info@bcmfamilies.org](mailto:info@bcmfamilies.org)
- Share your story on social media and don't forget to tag us:
  - Facebook: @BCMFamiliesFoundation
  - Twitter: @BCM\_Families

## FUNDRAISING TOOLS

1. BCMFF logo files available upon request. ([info@bcmfamilies.org](mailto:info@bcmfamilies.org))
2. Brochures available upon request. ([info@bcmfamilies.org](mailto:info@bcmfamilies.org))
3. PowerPoint available upon request. ([info@bcmfamilies.org](mailto:info@bcmfamilies.org))
4. Branded items available upon request. ([info@bcmfamilies.org](mailto:info@bcmfamilies.org))
5. For events of a larger scale, you may wish to recruit volunteers to extend invitations to their friends and networks. Other times, you might need some help during the event. Below please find a sample letter to help you recruit these volunteers.

Dear [friends/family],

As you know, my child/grandchild/friend/I was born with Blue Cone Monochromacy (Insert YOUR story here).

Because of [NAME], I have been inspired to do something to help others with this disease. I am hosting [INSERT EVENT] to raise funds and awareness for Blue Cone Monochromacy and support the vital work of the BCM Families Foundation (BCMFF). I have set a goal to raise [\$\$], and I would love your support!

Blue Cone Monochromacy is a rare genetic eye disease affecting 1 in every 100,000 individuals. It is carried through the X chromosome and almost exclusively affects males. The disease has a debilitating effect on the daily lives of the boys, men and family members affected by it, putting a stress on everyday tasks such as reading, learning, and working. Blue Cone Monochromacy (BCM) is one of those rare genetic diseases that has no cure and about which little is known. BCMFF is the only organization dedicated to BCM education, research, advocacy, and support.

Because you [are such a good friend, are a great party-planner, are a great networker, can design an invitation] I would love your help in planning this event to benefit BCMFF.

Thank you so very much. Your support means a lot to me. To learn more about Blue Cone Monochromacy, please visit: [www.bcmfamilies.org](http://www.bcmfamilies.org)  
I look forward to hearing from you.

All my best,  
[Your name]

6. Below please find sample text which can be used for an announcement, flyer or invitation to the event:

**Please Join Us for a Backyard Barbeque**

**On August 10th, 2018 at 1pm**

**ADDRESS**

**Ticket price (depending on the event, you may wish to charge)**

**All proceeds benefit the BCM Families Foundation**

**Blue Cone Monochromacy is a rare genetic eye disease affecting 1 in every 100,000 individuals. It is carried through the X-chromosome and almost exclusively affects males. Blue Cone Monochromacy (BCM) is one of those rare genetic diseases that has no cure and about which little is known. BCMFF is the only organization dedicated to BCM education, research, advocacy, and support. If you are unable to attend, please consider making a donation either online (insert link) or by making a check out to BCM Families Foundation and mailing it to (your address).**

**To find out more information on this challenging rare disease, please visit [www.bcmfamilies.org](http://www.bcmfamilies.org)**

7. Sample social media posts can be found below. Remember: Use the following hash tags when appropriate: #blueconemonochromacy, #BCM Families Foundation, and #BCMFF.
- Save the date for [XX event] on [XX/XX/XX]. I'm raising money for BCMFF to help those impacted by Blue Cone Monochromacy. My goal is to raise [\$\$] and I would love your support!
  - Have you met my [son/father/brother]? He is the inspiration for my [XX event]? (include photo and story about your inspiration)
  - I am looking for sponsors for my upcoming event! If you can provide food, beverages, invitations, auction items, raffle items, etc. please let me know! (include details)



- So thankful for my friends who are helping me with [XX event] to raise money for BCMFF! We are only [\$\$] away from meeting our goal!
  - Event Day is in [30/14/7] days! I cannot wait! I would love your support for BCMFF – please purchase your tickets or make a donation online today!
  - I am looking forward to seeing everyone tomorrow at the event! It is going to be great! It is not too late to attend or make a donation online today! (include link)
8. It's always important to thank guests following an event, particularly after they donated or volunteered to support your cause. Below please find a sample thank you letter to share with your guests:

**Dear [NAME OF DONOR OR VOLUNTEER],**

**Thank you for [your generous donation OR volunteering OR attendance] at my fundraising event, [EVENT NAME], held on [EVENT DATE] at [EVENT LOCATION]. Your generous gift will help BCMFF to transform the future of the boys and men affected by this rare, overlooked disease. Together, we can support innovative biotechnology and scientific research, but above all, we can lend a helping hand to thousands of families affected by Blue Cone Monochromacy.**

**To learn more about the great work of BCM Families Foundation, please visit [www.bcmfamilies.org](http://www.bcmfamilies.org).**

**Thanks again for supporting my event and the BCM Families Foundation!**

**Sincerely,**

**[YOUR NAME]**

## DONATION INFORMATION

Please follow these instructions for submitting donations to BCMFF.

1. Collect donations at your event or have your donors send contributions directly to you. Please have donors include ALL contact information with their gift. This also ensures that we can properly record their contribution in our database and issue the appropriate tax receipt.
2. All checks/money orders should be made payable to the BCM Families Foundation.
3. Keep track of your donations using the Donation Tracking Form below
4. Bundle checks and mail to BCMFF. Within, please include a sheet stating your name, phone number and email address as well as a summary of the donations enclosed.
5. Please do NOT send cash in the mail. Convert cash to a check or money order made payable to BCM Families Foundation for the amount of cash.
6. Make copies. Before sending donations, make copies of everything and make a note of when you send donations to BCMFF.
7. For guests who would like to donate electronically, please direct them to [www.bcmfamilies.org/donate/](http://www.bcmfamilies.org/donate/). If possible, bring a tablet to the event with this page already set up for ease of use.

All donations must be received by BCMFF within 30 days of your event.

Please mail donations to:  
BCM Families Foundation  
PO Box 7711 Jupiter, FL 33468





## MARKETING GUIDELINES

When referring to the organization the following format should be followed:

- All event communications should be framed as “in support of BCMFF” or “supporting BCMFF” so not to be confused for a fundraising event held by the organization itself.
- Web address (URL) is “[www.bcmfamilies.org](http://www.bcmfamilies.org)”
- when using the BCMFF logo, please keep the proportions the same. Do not alter the colors of the logo (If you need a one-color logo, please ask.) Allow for surrounding space around the logo as indicated below.