

## Giving Tuesday Newsletter - BCMFF

BCM Families Foundation <info@bcmfamilies.org>

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To: renata.sarno@hotmail.com <renata.sarno@hotmail.com>

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**NOVEMBER 30 2021**  
**SAVE THE DATE**



GIVING  
TUESDAY

**#cure4BCM**



#GivingTuesday | November 30, 2021

# A FAMILY CONVERSATION ABOUT SUPPORTING **#CURE4BCM**

## CELEBRATING THE SEASON OF GIVING

Traditionally, harvest time is a season of gratitude. Many countries choose to call the fall holiday Thanksgiving. We are also

nearing the end of the calendar year, when many faiths examine meaning in life.

Now, more than ever, families with BCM can clearly see REAL HOPE for finally reaching the last phase of our mission #cure4BCM!

We are also face the wonderful opportunity to raise needed funds that "Giving Tuesday" gives us. This year "Giving Tuesday", the Tuesday after Thanksgiving/November 30, is celebrating its 10th anniversary. BCM Families Foundation members started our annual participation in "Giving Tuesday" nine years ago. It has made a HUGE difference for us to, at last, be successful in raising funds needed to pursue cure for our extremely rare disease! *Welcome to our season of giving to make our dream of cure be realized!*

### *Planning for "Giving Tuesday"*

Many of us know the "3 T's of Giving" very well: *Tithe, Time, and Talent*. All or any of these three of these are needed, and all or any are welcomed by BCM Families Foundation! This issue addresses "giving"/Tithe. In the next issue, the addtional "T's", Time and Talents, will be

**discussed.**

**Recently we have invited all followers of our website [www.BlueConeMonochromacy.org](http://www.BlueConeMonochromacy.org) and Facebook page <https://www.facebook.com/groups/126403907385526> (members only) to participate in our 2022-2024 Strategic Planning. Funding will be important to let us finalize which are our 2022 priorities because, honestly, we were not successful in getting a grant funded and realize, for sure, that we can think of more important and innovative steps than we can afford at the present.**

**Here is a short list highlighting many of these needs:**

- (1) collaboration with a partner biotech for Clinical Trials,**
- (2) outreach to vision professionals to locate other BCM men & boys,**
- (3) fund a proposal to develop a videogame that identifies players who have BCM,**
- (4) have representatives attend and present at key professional meetings,**
- (5) hold local Zoom meetings by regions, plus an in-person meeting in the USA and in Europe,**
- (6) support our BCM Registry and DNA tests,**

- (7) replicate Wissinger DNA lab in the USA,**
- (8) develop a low vision center in Europe that gives access to people in need,**
- (9) update our BCM School Guideline pamphlet,**
- (10) participate in special events publicizing rare & low vision diseases,**
- (11) develop a presence on Instagram & Twitter,**
- (12) continually update BMCFF's presence on Wikipedia, Guidestar & our websites, etc.**

## **HOW TO PARTICIPATE IN "GIVING TUESDAY" NOVEMBER 30th:**

- Step One: To participate you need a Facebook account. If you do not have one, the easiest way to register and set one up is to find a teenager to do it for you, or you can Google "create a Facebook account" to get instructions. Facebook is found at [www.facebook.com](http://www.facebook.com). On your Facebook account click 'Fundraisers' on the left menu and select BCM Families Foundation as your choice of Nonprofit organization. When you have your Facebook account, here's what is needed next:**
- Step Two: The day you read this newsletter begin sharing your personal BCM**

**experiences on your Facebook page — not just your memorable BCM stories, but also your hopes & dreams about BCM, why you personally want/support the BCM Families Foundation mission #cure4BCM. This is to authentically help your friends and contacts understand #cure4BCM's importance. Our personal experiences with BCM are the most powerful influence we have to gain public knowledge & support for #cure4BCM. We *definitely need to create more understanding about BCM than to just to think "I will post my BCM fundraiser no later than November 30"*. Our primary message is actually WHY #cure4BCM matters so much.**

**- Step Three: By November 30th, it will be wonderful if many supporters of BCM Families Foundation post a "Giving Tuesday" Fundraiser to support BCM Families Foundation (but there are other ways to support #cure 4 BCM). Consider inviting your friends by your own fundraiser, to donate directly**

**to [www.blueconemonochromacy.org](http://www.blueconemonochromacy.org) Remember, BCM is extremely rare: more supporters are needed than just those of us who follow our BCM Families Foundation website and our Facebook/BCM page.**

**There is no Matching Funds Donor this year.**

## **CONSIDER THESE BEFORE MAKING A DONATION**

***1. Is this charity's mission one that I support? What priority?***

**This is a personal decision that only you can answer. Many supporters of BCM Families Foundation have BCM and/or have sons or grandsons who have BCM. They have a personal stake in wanting a better future for loved ones. Additional supporters are needed: BCM is an extremely rare disease whose genetic correction can also impact cure of additional diseases.**

***2. Does this charity manage donations well according to impartial oversight measures? Does the charity value & publicly share external oversight (have “public transparency”)?***

**Yes. BCM Families Foundation, a 501(c)(3) public charity, is available on GuideStar, a website used by many Secretary of State offices in the USA to evaluate applicants seeking to fundraise in their state. GuideStar**

**is also a resource for potential donors to check whether a charity manages its donations ethically and wisely. BCM Families Foundation has earned GuideStar's Gold Medallion rating.**

***3. What percentage of donations are spent on the mission, versus on staff salaries + expenses?***

**100% of donations are spent on our mission #cure4BCM. 0% of donations are spent on staff salaries. Volunteers operate BCM Families Foundation. The Board of Directors are all unsalaried volunteers who donate both their time and money to the Foundation.**

***4. What is this charity's track record of making progress toward achieving its mission?***

**Superb! Since applying to become a 501(c)(3) public charity, a plan of specific sequenced steps has been in place to follow in order to reach a cure for Blue Cone Monochromacy. A BCM support and education website [www.BlueConeMonochromacy.org](http://www.BlueConeMonochromacy.org) was**



**developed and is operated continually by our founder Dr. Renata Sarno. A Board of Directors as well as a Scientific Advisory Board of expert BCM Researchers were recruited, established, and continues. Development of mice having Opsin deletion BCM and mice with C203R BCM were arranged and funded by BCM Families Foundation along with a method for their distribution to researchers. Membership in NORD (National Organization for Rare Disorders, Inc.) was achieved at the Platinum level. A BCM Patient Registry has been designed, established, and is fully operational.**

***5. Are there special challenges this charity faces that deserve any special consideration?***

**The fact that Blue Cone Monochromacy is so rare, estimated to affect 1 in 100,000 people, has been extremely challenging in multiple ways but especially in raising funds.**

***6. How has this charity raised funds in previous years?***

**From a few large donors —most of these**

**people have now reached the maximum donation amount for our charity to remain a 501(c)(3). Thankfully, a few others are emerging.**

**From people wishing to make a one-time donation.**

**From Recurring Donors, including a growing number of committed Monthly Donors.**

**From supporters' fundraisers such as "instead of birthday gifts", "instead of Christmas gifts", "in lieu of sending flowers to a loved one's funeral", "instead of 50th Wedding Anniversary gifts", "instead of wedding gifts", as well as supporters' annual "Giving Tuesday" fundraisers on the Tuesday after Thanksgiving.**

**After you have passed age 70 and a half years old, you may be required to make annual withdrawals from your IRAs and other tax-deferred accounts. Your tax professional or financial advisor can advise you of ways that you can gain substantial tax benefit by donating portions of these Required Minimum Distributions (RMDs) to recognized 501(C)(3) charities, for example BCM Families Foundation.**

**From grants or sponsorships, such as the Waldesian Church's grant that has previously**

**supported some ongoing expenses, and, currently, our member Robert Severs' generous sponsorship of the BCM Registry's expenses for 2022.**

***7. How aggressively does this charity seek donations? Does it pressure donors? Does it ask anyone to "give until it hurts"?***

**No pressure. BCM Families Foundation seeks to explain, rather than pressure, hoping that potential donors will understand and evaluate how they wish to distribute their available donation dollars to the charities and the missions that they value. We hope our mission is among these. Affordable small donations are definitely valued by our Foundation! —So many of the contacts to our websites are young parents whose baby has just developed nystagmus: definitely for us, it is about more than raising money. But to reach our mission, necessary expenses are reality.**

***8. What is the best way I can financially support the mission of BCM Families Foundation?***

**Two ways! Become a Recurring/Monthly**

**Donor, please, giving the amount you can comfortably afford. To maintain our 501(c)(3) status, the number of donors matters as well as amount of donations raised annually. BCM Families Foundation is very grateful for our growing number of committed Monthly Donors. Be aware that regular, expectable donations allow our Foundation to better plan our budget & expenditures.**

**Also, a second way is to participate actively in our "Giving Tuesday" fundraiser on November 30th. Please help multiply our outreach by posting a "Giving Tuesday" fundraiser for BCM Families Foundation on your personal Facebook page.**

***9. Is there a recommended way to donate to the BCM Families Foundation?***

**BCM Families Foundation gratefully accepts donations in any method preferred by our donors. Checks may be sent to BCM Families Foundation P.O. Box 7711 Jupiter, FL 33468-7711 USA. Donate Online at the [www.BlueConeMonochromacy.org](http://www.BlueConeMonochromacy.org) 's Donate page using PayPal or any major credit card.**

**Monthly Donors are people committed to**

ongoing support of our mission. Monthly Donors may conveniently use PayPal so that our charity will be directly notified of your gift.



**The BCM Patient Registry, previously sponsored through the generosity of Otto per Mille Chiesa Valdese, is currently funded through the generosity of our active member, Robert Severs.**

**FOLLOW US ON OUR SOCIAL NETWORKS**



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