

Giving Tuesday Fundraising

BCM Families Foundation <info@bcmfamilies.org>

Fri 10/20/2023 5:00 PM

To:renata.sarno@bcmfamilies.org <renata.sarno@bcmfamilies.org>



Dear Supporters of a #Cure4BCM,

On November 28, 2023, join us for Giving Tuesday Fundraising!

Donate

Renata Sarno, President of the BCM Families Foundation invites you to join in the fundraising efforts to support the following ongoing BCM projects:

1) Dr. Tomas Aleman and Dr. Artur V. Cideciyan - University of Pennsylvania

This project involves performing clinical studies and obtaining the documents and reports useful in the event of a clinical trial for gene therapy.

The foundation has agreed to give a funding of \$148,759. So far, we have sent \$49,586. We need your help to deliver other 2 installments for \$49,586 and \$49,587.

2) Dr. Wen Tao Deng - West Virginia University (WVU)

This project, where colonies of BCM mice are maintained, has started all tests on AAV vectors.

The funding we have agreed to give is \$130,888. So far, we have sent \$100,000. We need your help to send the remaining \$30,888. BCMFF is considering whether to buy IP Rights on these AAV vectors for our possible use in Clinical Trial.

3) Finally, Dr. Mathieu Quinodoz - a senior scientist in bioinformatics at the Institute of Molecular and Clinical Ophthalmology Basel (IOB) – alongside Dr. Bernd Wissinger and Dr. Susanne Kohl at the Tübingen University, has a project with the goal to insert BCM inside Next Generation Sequencing DNA Tests. This is the first project he started, named Opsin Miner and he has asked us \$8,500. We need your help to finance it.

Every contribution counts and brings us closer to

making a difference.



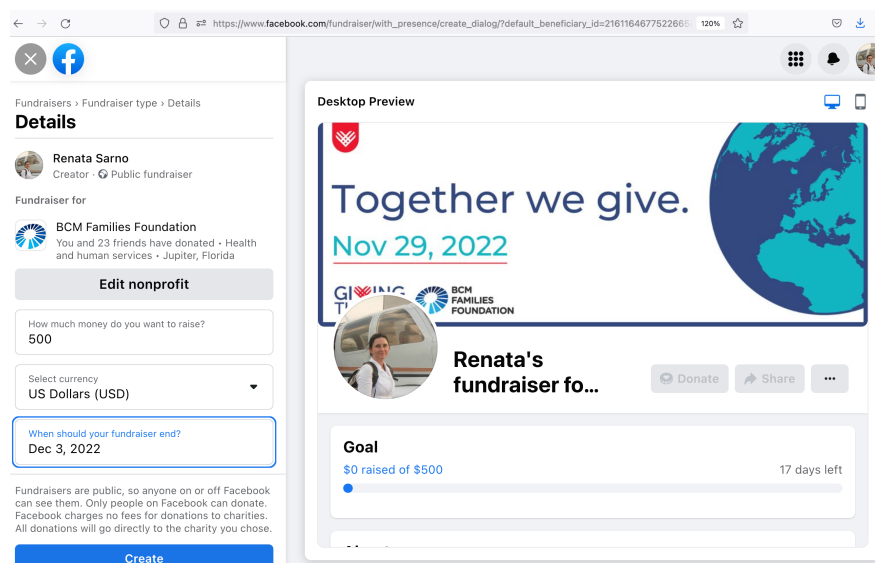
How to become a donor:

1. You are able to directly donate to our 501(c)(3) charity using Credit Card, Pay Pal or sending a check payable to "BCM Families Foundation".

Donate

2. Create a Fundraiser on Facebook.

You need a Facebook account at www.facebook.com. Click 'Fundraisers' on the left menu and select BCM Families Foundation as your choice of Nonprofit organization.



Facebook will change how donors' money is sent to a charity after October 2023, but Facebook users will continue to be able to have a new style of fundraiser, to

be announced later by Facebook.

Our heartfelt thanks to you for your support.



Frequently Asked Questions

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 Silver 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 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.

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 28th. 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

<https://www.blueconemonochromacy.org/donate/>

using Pay Pal or any major credit card.

Monthly Donors are people committed to ongoing support of our mission.

Monthly Donors may conveniently use Pay Pal so that our charity will be directly notified of your gift.

Donate

GIVING
TUESDAY



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info@bcmfamilies.org

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