



Dear Families and Friends of the BCM Families Foundation,

With the arrival of spring, we are entering what promises to be a very active and important year for our community.

I am writing to you while traveling to a key international meeting: the [ERN-EYE General Annual Meeting](#), taking place in Helsinki, Finland, from April 12th to 14th. At this meeting, I will represent individuals affected by Blue Cone Monochromacy (BCM) and Achromatopsia, working alongside physicians and researchers from approximately 60 specialized centers across Europe.

In May 2026, the [Forum for Ocular Diseases](#) will reconvene in the United States. Together with the BCMFF Directors, I will represent our community there as well, continuing to advocate for progress toward effective treatments

and, ultimately, a cure, while strengthening collaboration with leading ophthalmologists.

Regarding research developments, the BCM gene therapy project initiated by Adverum and continued by the Blue Gen Therapeutics Foundation didn't receive funds from CIRM, and we have not yet been contacted by [Lilly](#) the pharmaceutical company that recently has acquired Adverum Biotechnologies. Despite these challenges, our commitment remains strong. We are continuing research at West Virginia University (WVU) on a new viral vector, and in January 2026 we signed a Sponsored Research Agreement for \$88,000 with WVU and Dr. Wentao Deng.

In parallel, we are maintaining two essential programs in 2026:

1) No-Cost DNA Testing Program for BCM

This program continues to offer free genetic testing for Blue Cone Monochromacy. Read more in the following.

Annual cost: \$27,000

2) International Patient Registry

Our Patient Registry, available at www.BCMRegistry.org, will continue in 2026. Read more in the following.

Annual cost: \$6,500

You will also find additional updates in this newsletter about our growing patient community. At present, we are connected with more than 230 families and over 1,000 individuals through the BCMFF, our Facebook groups, and the Ning forum.

Thank you for your continued support and commitment to our shared mission.

With warm regards,

Dr. Renata Sarno

President, BCM Families Foundation



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1) Thank You to Kay McCrary

With deep gratitude and heartfelt appreciation, we honor Kay McCrary for her extraordinary 12 years of dedicated service to our community.

Kay co-founded the BCM Families Foundation in 2014 and has since served as a director on the board of directors and as Secretary. In January 2026, Kay stepped down to dedicate herself to her family.

Although Kay is stepping down from her formal roles, we are delighted that she will always remain an Emerita member of our community. Her legacy, guidance, and spirit will continue to inspire us for years to come.



Kay McCrary



Kay McCrary with family

2) Welcome Linda Van Keuren

We are pleased to welcome Linda Van Keuren to our Board of Directors.

Originally from New York, Linda has a strong personal connection to BCM, with several affected family members, including her brother, grandson, and grandnephews.

A Marist College graduate, she brings years of experience as an administrative assistant and currently serves a local church in Franklin, Tennessee.

Linda is grateful for the BCM Family Foundation and inspired by its mission to find a cure. We are delighted to have her join us.

You can contact her via email at: Linda.VanKeuren@BCM Families.org

Board of Directors



Linda Van Keuren

3) Join the Patient's Registry

Blue Cone Monochromacy affects 1 person out of 100,000 and, at present, has no cure. The purpose of the BCM Registry is to longitudinally collect data from patients with Blue Cone Monochromacy internationally.

The BCM Registry helps us gaining a better description of the clinical features, variations in phenotype and the natural history of this disease, meaning its characteristics, management, and long-term outcomes with or without treatment. Ultimately, this will support both research and care.

Adults and children with genetic confirmation of BCM may participate in the BCM Registry. The registration procedure is easy and fast. Find out more at: <https://www.bcmregistry.org/>

Join the Registry

All donations we collect go exclusively to fund the most promising medical research which have as their purpose the treatment or the cure of BCM.

Donate

4) No-Cost DNA Test Program

We are pleased to announce that the [BCMFF No-Cost DNA Test Program for Blue Cone Monochromacy](#) will continue to be available throughout 2026.

This program provides families with access to genetic testing at no charge in order to help confirm a diagnosis of BCM. A confirmed diagnosis can be an important step toward better understanding the condition, receiving appropriate guidance, and connecting with the BCM community. It also helps support ongoing research efforts aimed at improving outcomes for affected individuals and advancing progress toward future treatments.

More information and access to the program can be found here:

5) Update by Dean Monthei on the BCM Demo Glasses Initiative

In previous editions of this newsletter, we have shared information about the BCM Demo Glasses initiative, also available [here](#).

Type 1 glasses simulate BCM color vision by blocking red light and take approximately 7 minutes to make, while Type 2 glasses simulate both BCM color vision and reduced acuity (blurred vision) and require around 10 minutes of production time.

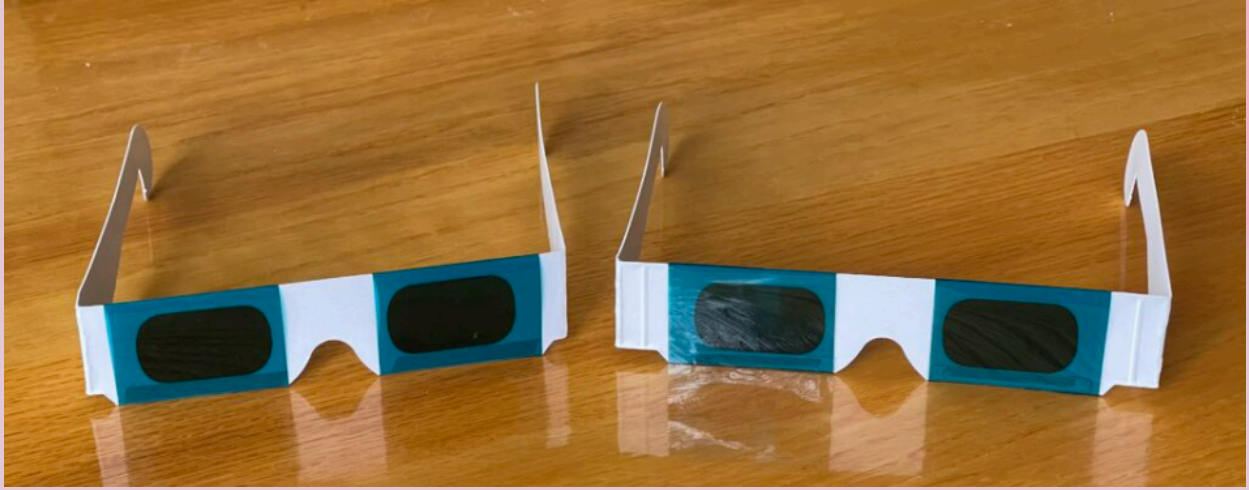
We would like to share an update from Dean Monthei regarding the reach and distribution of this tool. More than 200 pair of glasses have been made and distributed over time. Around 40 to 50 pairs were handed out at a conference in Charlotte, though individual recipient details were not recorded at the time. Glasses have also been sent to several clinicians involved in BCM research and care, including Dr. Nathans, Dr. Carroll, and Dr. Windsor.

Shipments have reached many U.S. states, including Montana, Kentucky, Ohio, Florida, Indiana, Illinois, Michigan, Washington, New York, Tennessee, North Carolina, California, Virginia, Maryland, and Iowa, as well as several countries such as Italy, Greece, Sweden, Germany, the United Kingdom, and Wales.

We are grateful for the continued effort behind this initiative and its contribution to increasing understanding of BCM worldwide.

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There are also two phone apps that simulate BCM color vision that are available called BCMphoto and BCMvideo (see details in Dean's post on the BCM Facebook group November 20th, 2025).



Type 1 and Type 2 BCM Simulation Glasses



Dean Monthei

6) Giving Through Your IRA

For U.S. donors age 70½ or older, a Qualified Charitable Distribution (QCD) is a simple and tax efficient way to support BCM Families Foundation.

A QCD allows you to transfer funds directly from your IRA to a qualified 501(c)(3) organization such as BCM Families Foundation. To qualify, the distribution must go straight from your IRA provider to the charity and the funds can never

pass through your hands.

This type of giving offers two key advantages: the donated amount is excluded from your taxable income and it can count toward your Required Minimum Distribution (RMD).

You can make a QCD at any time during the year, but it must be completed by December 31 to count for that tax year. Because processing may take several days, planning ahead is recommended.

Your IRA provider or financial advisor can help you complete the process.

7) 60 seconds with... An interview with Xavier John

by Trudi Dawson



Name: Xavier John

Age: 16

Where do you live?

Yorktown, Virginia.

How many relatives do you have with BCM?

Three that I am familiar with.

What would you like your job to be?

Business Finance.

What are your hobbies?

Soccer, Fishing, Hunting, Video Games, Cooking.

What is your most useful BCM tip?

Phone magnification is very helpful.

What would you tell younger BCM boys/your younger self?

Do not be afraid to be an advocate for yourself with your teachers at school.

Greatest achievement/proudest moment so far...

Earning junior black belt in Okinawan karate and winning gold medals at the USA Karate National Championships.

Not many people know this about me but.. I like to sing Christmas songs.



Xavier John

Thank you for helping us make progress in our efforts to reach the cure for Blue Cone Monochromacy. Your help is essential and will make a difference!

Donate



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