



Dear Friends, Families, Ambassadors, Volunteers,

Happy Summer and Happy Holidays!

With this letter, I would like to update you on the status of BCMFF's projects and ask for your support in fundraising efforts on behalf of BCMFF.

We have not yet received any contact from Adverum/Lilly regarding the continuation of the ADVN-062 intravitreal gene therapy.

<https://pmc.ncbi.nlm.nih.gov/articles/PMC10362383/>

Meanwhile, we are continuing our gene therapy research with Dr. Deng at West Virginia University. We are currently supporting this research through an \$88,000 grant. More information about our retinal organoid project is provided below.

The No-Cost DNA Test Program for Blue Cone Monochromacy at the Tübingen University has been renewed for 2026. The Wissinger's Lab is the only laboratory in the world able to perform DNA test on BCM for all causative mutations. Thanks to the BCMFF President and the BCMFF, the No-Cost DNA Test Program for BCM has been available since 2009, allowing all members of our community to receive DNA testing at no cost. Every year, several doctors also send samples to the Wissinger Lab for BCM testing. A total of around 55 tests per year are performed on male patients with a clinical diagnosis of BCM and females, older than 18, that want to certify their status of carriers. In 2026 we sent USD 27,500 to the Wissinger's Lab to support the Program.

Our International Patient Registry is active at <https://www.BCMRegistry.org> and there are people working to maintain it online: a Registry Manager, a Data Protection Officer, a Software House and an Institutional Review Board are all working to keep it active. The Patient Registry will remain active in 2026.

There are currently no active projects with the University of Pennsylvania or with Dr. Cideciyan and Dr. Aleman. All projects to identify outcome measures and test their reproducibility have been completed as a result of 14 years of clinical research

conducted by Dr. Samuel Jacobson and his team with the support of the BCMFF. Publications obtained recently: [Outcome Measures and reproducibility](#) .

Wishing you all a happy summer!

Renata Sarno, Ph.D.
President of the BCM Families Foundation

In this Newsletter:

- 1) Stocks and Cryptocurrency donations
- 2) Organoids
- 3) Tips for living with BCM by Dean Monthei

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

[Donate](#)

1) Stocks and Cryptocurrency donations

The BCMFF Board of Directors has recently approved the new [Gift Acceptance Policy](#) that allows the BCMFF to accept Stock and Cryptocurrency donations

Gifts of digital or virtual currency, also known as cryptocurrency, may be accepted only with the prior approval of the Board of Directors.

For any donations in stocks or cryptocurrencies, please contact our treasurer at Barbara.WadeSergent@BCMFamilies.org .

2) Organoids

The BCMFF, together with a team of scientists, is interested in a project to develop human retinal organoids.

Organoids are tiny, miniaturized, and simplified three-dimensional (3D) versions of organs grown in a lab. Derived from stem cells, they self-organize and replicate much of the cellular complexity and functionality of full-sized organs, serving as bridges between traditional flat cell cultures and human testing.

It is possible that some of you who are participating in the BCM Patient Registry will be selected to donate blood samples from which stem cells will be derived. Our President is going to contact you personally to ask whether you are available to donate.

Being able to use retinal organoids with BCM will aid the testing of gene therapies for our disease.

3) Tips for living with BCM

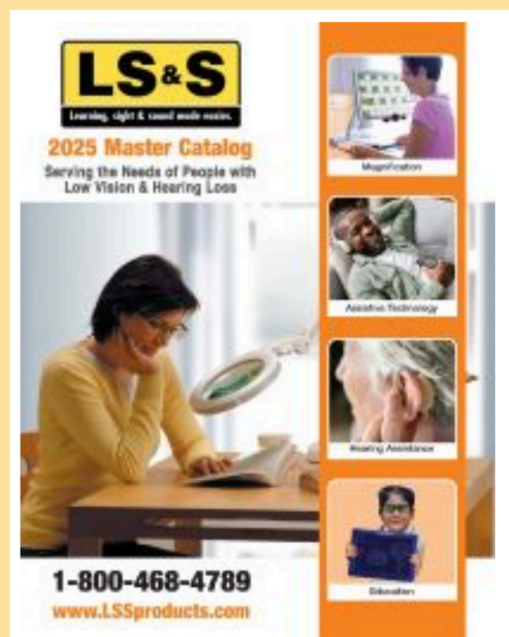
by Dean Monthei



The ultimate goal of BCM Families Foundation is a genetic treatment. Until that happens, my focus has been writing tips to hopefully make BCM a little easier to live with. This article is for people who have joined recently who may not have seen past posts of mine.

Parents new to BCM should be aware that while BCM can be difficult, it does not hold us back from most things in life. You won't be a fighter pilot with BCM but there are thousands of jobs, hobbies, and lifestyles that we are capable of. I worked as a senior engineer in cellphone electronics for 35 years and had many jobs as a teen and in college. I have skied cross-country and downhill. I do woodworking, photography and even fly drones. I have traveled to 12 countries, mostly overseas for work. I have a few patents and have written a published textbook. While I do not drive, many people with BCM do drive. I have managed to create a life where I did not need to drive.

For parents with BCM children, the most useful thing to help kids is to make sure they have magnifiers and close-focus monoculars to help with school. Use of cellphones and tablets are also increasingly important. These devices have accessibility features built-in for magnifying, inverting colors, changing colors, and voice navigation. Many vision aids are available from [LS&S products](http://LS&Sproducts.com), [MaxiAids](http://MaxiAids.com) and [SEEMOREVISION](http://SEEMOREVISION.com).





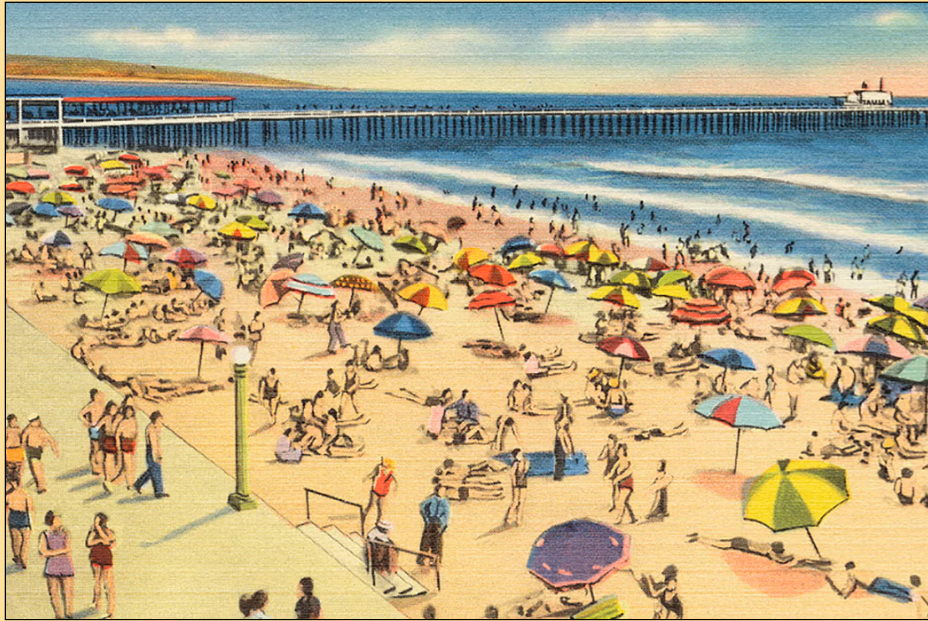
For more information on vision aids, search my name (Dean) on the BCM Facebook group page (click the magnifier icon in the upper right to search). Also, be sure to look through the “Files” section of the [BCM Facebook group page](#) (click the “Files” tab at the top of the page).

For additional information on vision aid suppliers, see [this link](#) on the BCM Families Foundation website.

[Find Out More](#)

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](#)



Copyright © 2021, BCM Families Foundation. All rights reserved.

Our mailing address is:

info@bcmfamilies.org

Want to change how you receive these emails?

You can [update your preferences](#) or [unsubscribe from this list](#).

BCM Families Foundation · PO Box 7711 · Jupiter, FL 33468 · USA