

Spring Newsletter 2023

BCM Families Foundation

Thu 5/11/2023 4:30 PM

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



In this Newsletter:

- 1) Charlotte April 29, 2023 – BCMFF Meeting of families with Blue Cone Monochromacy
- 2) Blue Cone Monochromacy (BCM) Simulation Glasses by Dean Monthei
- 3) 60 seconds with... An interview with Robert Finch by Trudi Dawson

Charlotte April 29, 2023 – BCMFF Meeting of families with Blue Cone Monochromacy



On April 29, 2023 adults and children with BCM and their relatives and parents, plus expert BCM scientists, had an intense meeting with several lectures and opportunities to meet with other families. In depth discussion about current status of the gene therapy for BCM occurred between patients and scientists. Current and future projects were also discussed together.

Stories of patients, families, scientists and discoveries, and the BCM community were told throughout the day.

We had the opportunity to remember and commemorate Dr. Samuel G. Jacobson who had worked on BCM with our community of patients for more than 13 years.



We met Dr. Bernd Wissinger of the University of Tübingen, Germany, discussing with him DNA tests for patients and carriers and our longstanding collaboration with his lab.



Then we met Dr. Tomas Aleman and Dr. Artur Cidecyian of the University of Pennsylvania, who explained to us clinical features of BCM and outcome measures of a clinical trial. Dr. Wentao Deng of the West Virginia University, co-

worker of Dr. W.W. Hauswirth, explained to us what a Proof-of-Concept experiment on animal models of BCM is. Dr. Joe Carroll of the Medical College of Wisconsin showed us pictures of the retina obtained with an Adaptive Optics machine. Dr. Jeremy Nathans of the Johns Hopkins University School of Medicine gave an overview lecture on his 1980's discovery of visual pigments' genes and BCM causative mutations. Jeremy Nathans and Bernd Wissinger are members of the BCMFF Scientific Advisory Board. All of these scientists have been involved in a discussion about the future of gene therapy for BCM.



In the afternoon Laura Windsor, O.D., F.A.A.O., gave a helpful, well-received lecture on glare control, low vision, tinted contact lenses and bioptic driving license for BCM. Ben Nelson, a certified Visually Impaired Students' teacher, presented next and was amazing, involving teenagers and explaining the best tips for sight accommodations at school.

Finally, we learned about the BCM Registry, with a tutorial presented by the Registry Manager, Sara Cammarota. Find out more at:

www.blueconemonochromacy.org/patient-registry/

And watch the Registry Manager Tutorial here:

https://youtu.be/x4u4iKcu_MO

Dr. Erik Geslin of the University of Norway presented the demo of his

videogame to identify players who have BCM. You can find the demo here:

<https://cnaplab.itch.io/beyond-blue-mist-demo>

We are full of gratitude to all those who made this meeting so beautiful and important: thank you to all people who participated and supported its organization!

A special thanks to BCMFF Director **Kay McCrary** for her enthusiasm and organization: she worked tirelessly to set up the meeting. Kay, we are all full of gratitude --this event couldn't be done without you.

Thanks to BCMFF Director Barbara Sergent, Angie Honeycutt – for the registration desk and printed materials –, Lindsey Egner for social event organization, and BCMFF Director Marylee Dilling for the organization. Thanks to John Cavitt and BCMFF Ambassador Ned Reade for the Audiovisual Equipment organization and management during the entire day! Thanks to Dean Monthei for discussing his display of low vision tools and for creating the BCM Demo Glasses!



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

Donate

2) Blue Cone Monochromacy (BCM) Simulation Glasses

by Dean Monthei



A person with normal vision can use these glasses to simulate Blue Cone Monochromacy color vision by blocking red light and to simulate poor visual acuity.

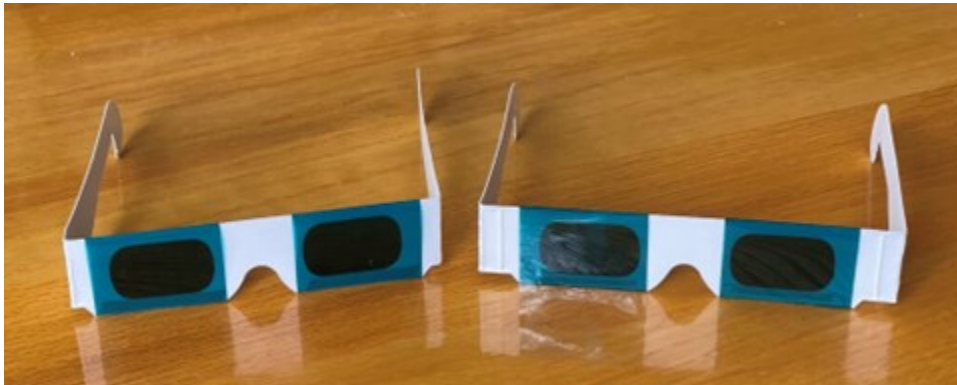


Figure 1: Type 1 and Type 2 glasses

Main symptoms of BCM include poor ability or inability to distinguish colors, and poor visual acuity, between 20/200 and 20/63 (poor detail vision).

There are 2 versions of the glasses available.

Type 1 – Simulates BCM color vision by blocking red light (made with 2 layers of a red blocking filter ROSCO #2005 Cyan)

Type 2 – Simulates BCM color vision and poor acuity (blurry vision) (made with

2 layers of ROSCO #2005 Cyan and 1 layer of ROSCO #132 diffusion filter)



Figure 2: Normal Vision



Figure 3: Type 1 BCM Sim Glasses



Figure 4: Type 2 BCM Sim Glasses

These glasses should be used over any glasses or contacts a normally sighted person uses. This provides a starting point close to 20/20 vision in the US or 10/10 in Europe. You can also use these glasses over a cell phone camera lens to get representative photos of BCM color vision. This is how Figures 3 and 4 above were made.

The Type 2 glasses are for worst case vision for someone with BCM (poorest acuity). There are 2 ways to make customized glasses to more closely match a particular individual's acuity by adding the red blocking filters to reading glasses.

For details on how to do this, what the limitations are, and the technical discussion about how they work, see the write-up on the BCM Families Foundation website at:

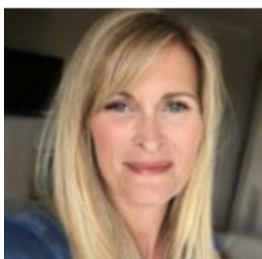
<https://www.blueconemonochromacy.org/bcm-demo-glasses>

HOW TO REQUEST BCM SIMULATION GLASSES

Please send an email to info@bcmfamilies.org containing the address to send the glasses to and the number of copies. For small orders there are no costs for both shipments in the United States and abroad.

3) 60 seconds with... An interview with Robert Finch

by Trudi Dawson



60 seconds with.....

Name: Robert Finch

Age: 69

Where do you live?

Hadleigh, Suffolk, England.

How many relatives do you have with BCM?

Four.

What is your job/would you like your job to be?

I am retired from paid employment but:

- I gained a BSc. in Mechanical Engineering (without seeing the board once).
- Worked 15 years for a major UK Telecoms manufacturer as a Project Manager and later divisional management.
- With my brother (also BCM) started a construction equipment parts company and developed it into a £6M company winning three Queens Awards along the way.
- I now have a property company.

My early dream job was a long-haul airline pilot.

What are your hobbies?

Computing, Electronics & practical work in the workshop.

What is your most useful BCM tip?

Ignore it.

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

Ignore your disability as far as possible, you are not special and need to make your own way in the world. You will meet prejudice, discrimination and even hostility, get used to it, you will also meet kindness in abundance. On a more practical level think ahead, plan a bit more than others, for example, choose a home and workplace where you don't need to drive and can compete and socialise with less disadvantage.

Greatest achievement/proudest moment so far:

Competing with others in a tough commercial business and winning the Queen's award for Enterprise and attending a reception in Buckingham Palace.

Not many people know this about me but..

Best left unanswered.



Robert with his wife Lorna

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

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

This email was sent to renata.sarno@bcmfamilies.org
[why did I get this?](#) [unsubscribe from this list](#) [update subscription preferences](#)
BCM Families Foundation · PO Box 7711 · Jupiter, FL 33468 · USA

