

Holidays Newsletter

BCM Families Foundation

Sat 12/24/2022 5:00 PM

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



Dear Friends, Dear Families,

2022 is coming to an end, so I want to send you warmest wishes for a Happy Holiday Season!

And I want to sum up what has happened about reaching BCM cure in 2022, so please sit down because this is a long letter for you with several important pieces of information.

At BCM Families Foundation there are several projects that are moving forward and others that have stalled or need to get started...

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1) Join the BCM Patient Registry

Dear BCMFF Members,

It is with great joy that I wish you happy holidays, may these days be filled with love for you all.

I take this opportunity to thank all of you who have chosen to participate in the [BCM Patient Registry](#), and to invite others to participate as well.

As you know, the Registry keeps the information of all those who decide to enroll, and aims to increase our knowledge of the disease with the ultimate goal of finding a cure for BCM. Everyone who has received genetic confirmation of BCM, adults and children, may participate in the Registry.

Every single person who decides to [join the Registry](#) is important and can really make a difference in the search for a treatment.

With my best wishes,

Sara

[Find me on Facebook](#) or at sara@bcmfamilies.org



[Join the Patient Registry](#)

2) A special thanks to everyone who donated!

We would like to take this opportunity to extend our gratitude to everyone who participated in Giving Tuesday 2022.

The fact that Blue Cone Monochromacy is so rare, estimated to affect 1 in 100,000 people, has been extremely challenging when it comes to raising funds.

This is why your generous donations are instrumental for our mission to achieve a #Cure4BCM.

[Donate](#)



3) Update on electronic glasses by Dean Monthei



I recently became aware of an electronic glasses company called Acesight. The company has 3 models (\$2500 to \$4300). The Acesight VR model looks like it uses a built-in cellphone which is similar to other products on the market (IRISVISION, etc.). Acesight and Acesight S (similar to eSight glasses) are the more expensive models.

Field Of View (FOV) is a critical specification for electronic glasses. It is “how big the picture looks” when using the glasses and is measured as an angle of view. Cell phone based glasses tend to have a nice big FOV of as much as 65 degrees. The eSight glasses are on the low end with a 37 degree field of view.

The eSight 4 model now has everything in the headset (batteries and controls) which makes it much bulkier than eSight 3 and to me looks like a StarWars headset. I prefer the style of the eSight 3 glasses which look more like a tennis visor.

There is a top 10 listing of electronic glasses at the following link. OrCam (#10) does not provide magnification. It uses a camera to read aloud text and can also verbally describe objects in view.

<https://nelowvision.com/top-low-vision-wearable-glasses/>

RETISSA is an exciting new technology that uses lasers to directly project images onto the retina. There is not a product using it yet but it was demonstrated at the CSUN Assistive Technology Conference a few months ago and should help shrink electronic glasses significantly.

<https://en.retissa.biz/retissa-display-ii-e>

Although there are lots of electronic options now available, I use optical magnification most (magnifiers, monoculars, binoculars, and Ocutech bioptics). I do use my iPhone a lot to read restaurant menus that are up behind a counter or flight info displays at the airport. I have tried eSight 3 electronic glasses and have experimented with a free cellphone app called "SuperVision for Cardboard" which is used along with a VR headset (\$20) for hands-free electronic magnification. With optical tools there are no batteries, software updates, or weight and size issues but electronic magnifiers are continuing to improve!

Dean Monthei



4) 60 seconds with... An interview with Tom by Trudi Dawson



60 seconds with.....

Name: Tom Rogers

Age: 25

Where do you live?

Crawley, West Sussex, UK

How many relatives do you have with BCM?

To our knowledge, I potentially have three relatives, with BCM. One definitely (diagnosed, my eldest brother). But I also have 2 cousins (one is a baby so hasn't been diagnosed specifically yet. The other is also mentally disabled so they are unable to conduct the tests).

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

I currently work in the Gym Group, Crawley as the Assistant General Manager. I aspire to be a General Manager at some point down the line.

What are your hobbies?

My hobbies include football, going to the gym and meeting with friends and family.

What is your most useful BCM tip?

I don't really have a useful tip unfortunately!

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

I would tell my younger self of anyone growing up with BCM to

strive to be independent and not to worry too much about feeling embarrassed if you can't see something, etc. I was always so afraid to travel on my own in fear of getting lost. But I now travel independently all across the country for football or to meet friends, etc., and if I'm not sure on something I will ask, generally anyone you ask will help.

Greatest achievement/proudest moment so far...

My greatest achievement happened recently. I got the call up and opportunity to go to an England Development camp with the England Partially-Sighted team. I've always loved football so to have this opportunity is amazing! I'm now training and looking to, potentially, be in contention for a place in the World Games in August 2023.

Not many people know this about me but:

I'm sorry, I really can't think of an interesting fact - I don't do much else!



We are looking for volunteers to join our '60 Seconds Community'.
If you would like to feature here please contact
trudidawson@yahoo.co.uk, a list of questions will be sent to you
and we'll do the rest.

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