



**BCM
FAMILIES
FOUNDATION**

Toward the cure of Blue Cone Monochromacy
PO Box 7711 - Jupiter FL 33468-7711 USA



Wishing you all a
Happy Easter!

Dear Families,

We would like to thank you all for the continuous support toward a #cure4BCM, and we would like to bring you our latest news.



The BCMFF Patients Registry

We want to warmly thank each one of you who kindly donated to reach our **annual goal** for the Registry.

We are almost ready to launch the Registry and we will keep you updated about it.

We want to thank the donors: **Robert, Angela, Orlando, Elena and Ferdinando, Ceci, Danika and Mike, Paolo, Daniel, John, Janice and Kathy.**

As you know, **we need financial support** to keep the Registry alive. It takes **\$15,000** per year. This is the cost it takes to host, run and maintain the Registry, its website and its software and to pay the Data Protection Officer.

The Registry is an essential tool to foster the research towards a cure. We need everyone to get active. If every family did one **fund-raising activity**, no matter how small, we would easily reach our goal.

How can you help?

You can help BCMFF to afford and fund the Patients Registry by:

- [Donating to the BCMFF](#)
- Organizing your local event and raising funds. You can reach to our [Ambassadors](#) for ideas and help
- Set up your fundraiser on Facebook;

- Contact us for more ideas!
- Our target for keeping the Registry alive is **\$15,000 per year!**



[Find Out More](#)



2019 Rare Disease Day



We all know how important it is to spread awareness on our condition. On the twelfth Rare Disease Day we reached hospitals around the globe, handing our informative flyers to Clinicians.

We want to thank those of you who joined on the 28th of February this year. Your effort could very well help someone get an early and accurate diagnosis!

Kay McCrary visited and provided our flyers to ophthalmologists and residents at the Department of Ophthalmology, University of South Carolina School of Medicine.

Thanks to Ceci Alquati, who handed our flyers to Dott. Paolo Colliardo, UOC Oculistica, Azienda Ospedaliera San Camillo Forlanini, Rome, Italy.

Our friend Nicole Jung-Wan Kim met with Dr. Falsini and his team at Gemelli Hospital and with Dr. Iarossi at Bambin Gesù Hospital in Palidoro, Italy.

[#RareDiseaseDay](#) [#ShowYourRare](#) [#cure4BCM](#)





2019 Rare Impact Award Nomination, Houston



The NORD Patient and Family Forum is coming to Houston, Texas, June 21-23, 2019.

Patients and families will gain insights and practical tools through sessions and discussions created just for them, with topics to include stress management, gene therapy, insurance, clinical trials, Medicaid access and more. Check out the web site for more details: rarediseases.org/

Scholarships (hotel and registration fee) are available for interested BCM families.

You can contact us for scholarship details: info@bcmfamilies.org

Presenting our new BCMFF Directors

We are happy to welcome two new Directors on our Board. You might know them already and have met them around the world during our Meetings.

We welcome Marylee Dilling Mohn and John Cavitt! Last January they joined Renata Sarno, Kay McCrary and Barbara Sergent on the BCMFF Board of Directors.

[Meet our Directors](#)



Marylee Dilling Mohn

Marylee's son, father, and two cousins have BCM. Like most affected families, the correct diagnosis wasn't made until 2017 when her son was diagnosed by molecular genetic testing. Marylee is an alumn of UNC-Chapel Hill and Jefferson Medical College and completed residency at Baylor College of Medicine.

Her goal is to raise awareness and funds to find a gene therapy cure for BCM.



John Cavitt

John and his wife Leah have three children affected by BCM. John is dedicated to spreading awareness of our disease and ensuring a cure for future generations. Outside of the office, John is passionate about moving the bar forward in BCM research and growing support globally for this rare condition.

60 Seconds with...



By Trudi Dawson.



Name: Oscar Fred Dawson

Age: 10 years old in 3 days time

Where do you live: East Sussex in England

How many relatives do you have with BCM?

None. My great-great Grandfather was described as 'not being able to see colour and not being able to see very well', so we assume he also had BCM. I have a brother (and a sister) who does not have BCM, uncles, cousins, none of whom has BCM. I am very special in my family.

What would you like your job to be?

Rock or Heavy Metal guitarist.

What are your hobbies?

Playing guitar and drums, gaming and sometimes drawing.

What is your most useful BCM tip?

To not worry about your differences. And to bring things closer to you, rather than you closer to things.

Greatest achievement/proudest moment so far...

Performing on stage in The Big Dance last night in front of hundreds of people.
And learning to surf in Sri Lanka.

Not many people know this about me...

I like to climb. And when I was born I nearly went down the toilet!

[Find Out More](#)



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