

What would you do if your infant son were diagnosed legally blind due to an unknown illness?

Or perhaps, doctors tell you that your son has a rare disease known as Blue Cone Monochromacy and there is no cure on the horizon. As a parent, you anguish. How will he get through school? How will he obtain a normal job? Will he ever drive a car?

As a mother of sons with this rare disease, I could not accept the utter lack of hope that was presented for their future. So in 2014, I formed the BCM Families Foundation alongside Kay McCrary and Barbara Sergent in response to the absence of support around this disease. Since that year, we have grown into an international community of families living with BCM; harboring one steadfast mission: to cure Blue Cone Monochromacy.

In fact, at BCM Families Foundation we have discovered that modern medicine may be able to treat this rare disease. We have now reached a crucial time wherein we can make a difference by bridging the gap between fundamental research and human clinical trials to finally transform research breakthroughs into treatment.

Help us find a cure for Blue Cone Monochromacy and transform the future for these boys and men. Together, we can support innovative biotechnology and scientific research, but above all, we can lend a helping hand to thousands of families affected by this rare disease.

Renata Sarno

Founder and President



PARTNER WITH US

Your support is essential to achieving the goal of BCM Families Foundation. Help us to move towards a greater understanding of this rare disease as we fund medical and scientific research to benefit thousands of boys and men affected by Blue Cone Monochromacy. BCM Families Foundation is a 501(c)(3) public charity, and your donation is tax-deductible.

DONATE

ONLINE: <http://www.bcmfamilies.org>

FOR GIFTS BY CHECK: Make check out to BCM Families Foundation and mail to BCM Families Foundation
PO Box 7711 Jupiter, FL 33468.

BCM Families Foundation is grateful to our dedicated partners for their ongoing support of our mission.



Join our community of advocates dedicating their lives to curing this rare retinal disease. **#Cure4BCM**

 info@bcmfamilies.org

 [bcmfamilies](https://www.instagram.com/bcmfamilies)

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You can learn more about the BCM Families Foundation and BCM Registry at:
www.bcmfamilies.org and www.bcmregistry.org

**Toward a Cure for
Blue Cone Monochromacy**



WHAT IS BCM?

Blue Cone Monochromacy is a rare genetic eye disease affecting 1 in every 100,000 individuals. It is carried through the X chromosome and almost exclusively affects males. The disease has a debilitating effect on the daily lives of the boys, men and family members affected by it, putting a stress on everyday tasks such as reading, learning, and working. Blue Cone Monochromacy (BCM) is one of those rare genetic diseases that has no cure and about which little is known.

From birth, a boy with BCM experiences:

- **Low vision, even blindness**
- **Nystagmus (shaky eye movements)**
- **Poor color discrimination**
- **Near-sightedness**
- **Extreme light sensitivity**

In 2014 we formed the BCM Families Foundation in response to the lack of information and support around this disease. We are a global coalition of families, friends, researchers and ophthalmologists that stand united behind our shared experiences and our shared determination to find a cure.

We encourage our patients to be empowered by connecting them with patients from around the world where they may share tips for success and low vision tools that have allowed them to thrive. As families affected by BCM, we understand what it means live with the disease and we are uniquely qualified to lead the charge for a cure.



Our mission is to eradicate BCM by supporting the most promising biomedical and scientific research.

Since founding BCM Families Foundation we have been dedicated to collecting all of the necessary data needed to move towards clinical trials. Thus far, we have:

- Financed a study at the University of Pennsylvania into the natural history of BCM. The study found that the retina in BCM patients has healthy cells. For the first time in history patients were assured that we could work toward a cure. This study also helped to identify a protocol of clinical visits and outcome measures needed for gene therapy.
- Compiled an international registry of patients affected by BCM at www.BCMRegistry.org
- Financed molecular genetic research at the University of Tübingen which allows for free DNA testing for BCM patients.
- Developed animal models with the two main genetic causes: gene deletion and gene mutation.
 - We have been working with the deletion models to test the reintroduction of the missed protein through gene therapy solutions. Reporting from the lab indicates sight restoration after gene therapy treatments.

Amazingly, all of this information has been discovered on \$2.2 million dollars, but we can't stop there. Your support is needed in order to continue to fund critical research for the treatment and cure of this rare, overlooked disease.

"I hope that a cure for BCM will be found in Zeb's lifetime. A cure, so he and no other children have to struggle their whole life with this rare genetic disorder"

- Marsha, whose son Zeb was diagnosed with BCM at age 6.



AREAS OF FOCUS



Research

We support the most innovative biotechnology and scientific research. Key areas include patient DNA testing, clinical studies, and gene therapy treatment on recently developed animal models.



Advocacy / Awareness

BCM Families Foundation is dedicated to elevating public understanding surrounding this rare disease as well as calling attention to the special challenges faced by BCM patients.



Education

We work to spread information about BCM to ophthalmologists, low vision specialists and other medical professionals in order to build a greater base of understanding surrounding the disease and to prevent misdiagnosis.



Community Building

We introduce families and patients affected by BCM to a wider network of support by linking them to an international group of BCM vision experts, doctors and scientists as well as to other BCM families and patients.

In order to continue achieving milestones within these program areas we need your help. **Through your generosity, you can change the lives of thousands of patients struggling with this rare disease.**