



Blue Cone Monochromacy Registry

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## Blue Cone Monochromacy Patient Registry

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### Mission

### Understanding your participation

If you are a person who has been diagnosed with Blue Cone Monochromacy (BCM), we invite you to participate in the BCM Registry. However, before you enter personal and other medical relevant information into the BCM Registry, please carefully read this section which explains what is involved and what will be done with the information you provide.

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The BCM Registry is an online patient registry dedicated to Blue Cone Monochromacy (BCM), and established by the BCM Families Foundation (BCMFF). The BCMFF is the only patient-led organization worldwide with a mission to eradicate BCM. Established in 2014 in the United States, the Foundation has gathered a community of more than 300 people (130 families) from around the globe.

BCM affects 1 in 100,000 people, primarily males, who experience loss of visual acuity, photophobia, myopia, nystagmus, impaired color vision from birth and, therefore, a significant challenge to quality of life. BCMFF provides research funds and infrastructures that aid discovery of new treatments and improvement of current ones.

By collecting and analyzing many patients' personal and clinical data, the BCM Registry is a milestone along the path toward clinical trials of innovative therapies.

The BCM Registry is available at [www.BCMRegistry.org](http://www.BCMRegistry.org), and it is owned and financially managed by the BCMFF through the Board of Directors. The Registry is governed by a Steering Committee that includes renowned clinicians and researchers, as patient representatives.

## Purpose

The Purpose of the Registry is to collect data over time from patients with BCM from all over the world. The Registry aims to increase knowledge about:

- Clinical features of BCM
- Natural course of BCM
- Long-term outcomes of BCM
- And ultimately help create a cure for BCM

When you join the Registry, with the help of your doctor, you will share your own personal medical record that, combined with those of other people with BCM, creates the BCM Registry. In order for you to join, your diagnosis must be confirmed by genetic testing, and your medical data must be validated and occasionally updated by your doctor.

## Who is eligible for the BCM Registry?

Adults and children with BCM may participate in the BCM Registry. You must have genetic confirmation of BCM. During registration, you have to upload your genetic test report and indicate who your doctor is.

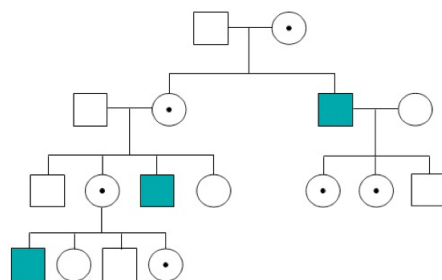
## Who has access to my data? How is my privacy protected?

BCMFF is committed to protecting the privacy of Registry Participants. All the information you provide will be kept in a secure online platform, and any personal information that could identify you and your family members will only be seen by the Registry staff and your selected doctor.

Your personal and medical data collected in the BCM Registry belong to you, and you have the right to remove your data at any time.

## Families with BCM

If more than one member of your family has BCM, the first family member who registers can create a family identification code. That person can give the family identification code to his family members, and they can use it during their registration process. Each family member who registers will have their own separate account, provide their own consent, and enter their own data.



## How does the Registry work?



Step 1: A BCM patient signs up in the Registry



Step 2: His ophthalmologist validates diagnosis and medical data



Step 3: Scientists work on patients' data to find a cure for BCM

## Contacts

### BCM Families Foundation

PO Box 7711 Jupiter, FL  
33468-7711 USA

Web: [www.blueconemonochromacy.org/](http://www.blueconemonochromacy.org/)

Email: [info@BCMFamilies.org](mailto:info@BCMFamilies.org)

### BCM Patient Registry

Web: [www.BCMRegistry.org](http://www.BCMRegistry.org)

Registry Manager - Help Desk

Email: [Registry.Manager@BCMFamilies.org](mailto:Registry.Manager@BCMFamilies.org)

### BCM Steering Committee

Web: [www.blueconemonochromacy.org/Steering-Committee](http://www.blueconemonochromacy.org/Steering-Committee)

Email: [Steering.Committee@BCMFamilies.org](mailto:Steering.Committee@BCMFamilies.org)

### Research Proposals can be sent to:

Email: [Registry.Manager@BCMFamilies.org](mailto:Registry.Manager@BCMFamilies.org)

Steering.Committee@BCMFamilies.org

### Privacy Inquiries:

Email: [Registry.Manager@BCMFamilies.org](mailto:Registry.Manager@BCMFamilies.org)

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