



The screenshot shows the homepage of the Blue Cone Monochromacy Registry. At the top left is the BCM Registry logo. Below it is a navigation menu with links for Home, Patients, Clinicians, Researchers, Registry Manager, and Login. The main header area includes the text 'Blue Cone Monochromacy Registry' and 'Blue Cone Monochromacy Patient Registry' with a 'Register now' button. A central image shows a doctor examining a child's eye with a microscope. Below the image is a caption: 'Step 2: His ophthalmologist validates diagnosis and medical data'. To the right is a blue box titled 'Understanding your participation' with text explaining the registry's purpose and a 'Continue reading...' link. At the bottom left of the screenshot is a 'Mission' section.

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, 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 insert 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.

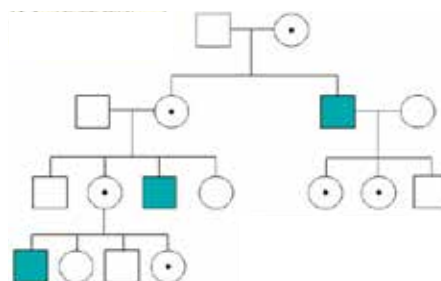
Who has access to my data? How is my privacy protected?

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 works?



Step1: A BCM patient signs up in the Registry



Step2: His ophthalmologist validates diagnosis and medical data



Step3: Scientists work on patients' data to find a cure for BCM

Contacts

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BCM Patient Registry

Web: www.BCMRegistry.org

Registry Manager - Help Desk

Email: Registry.Manager@BCMFamilies.org

BCM Steering Committee

Web: www.blueconemonochromacy.org/Steering-Committee

Steering.Committee@BCMFamilies.org

Research Proposal can be sent to:

Email: Registry.Manager@BCMFamilies.org

Steering.Committee@BCMFamilies.org

Privacy Inquires:

Email: Registry.Manager@BCMFamilies.org

Address: To: BCM Families Foundation,
Privacy Inquires, PO Box 7711 Jupiter, FL 33468-7711 USA



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