

## Do Something Great

BCM Families Foundation <info@bcmfamilies.org>

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To: info@bcmfamilies.org <info@bcmfamilies.org>

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**What are you waiting for?  
Join the BCM Patient Registry now!**

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

### Why should you register?

**Blue Cone Monochromacy affects 1 person out of 100,000 and, at present, has no cure. The Purpose of the BCM Registry is to longitudinally collect data from patients with Blue Cone Monochromacy internationally. Through the BCM Registry, we will help to gain a better description of the clinical features,**

**variations in phenotype and the natural history of this disease, meaning its characteristics, management, and long-term outcomes with or without treatment. This will ultimately support research and care.**

### **Who can take part in the BCM Registry?**

**Adults and children with BCM may participate in the BCM Registry. You must have a report with genetic confirmation of BCM. During registration, you have to upload your genetic test report and indicate who your doctor is. You will be enrolled after your doctor confirms your diagnosis. If your doctor doesn't confirm your diagnosis, you will not be able to participate in the Registry.**

### **How to register?**

**The registration procedure is easy and fast. Start from <https://www.bcmregistry.org/> where you can find general information and links to **FAQs and Privacy Notice**. Then, please visit the webpage: <https://www.bcmregistry.org/patients/> and after having read all information, Sign-Up as a patient at the end of the page.**

### **What information will be collected in the Registry?**

**The Registry will collect the following:**

- **Personal information from individuals with BCM including, but not limited to, name, date of birth, city of birth, country of birth, address, phone number, and email address;**
- **Information about your diagnosis of BCM including genetic test, vision tests, and exam results;**
- **Information about your personal and family health history as it relates to BCM and your family pedigree.**

**Find more information at [www.BCMRegistry.org](http://www.BCMRegistry.org) or ask for help and information to the Registry Manager, Sara, contacting her via email at [Registry.Manager@bcmfamilies.org](mailto:Registry.Manager@bcmfamilies.org)**



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