

BCM Patient Registry

BCM Families Foundation <info@bcmfamilies.org>

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THE BCM Patient Registry

An easy step by step guide to understand your participation

Six steps to enroll in the BCM Patient Registry

Dear Friends and Families,

The BCM Patient Registry is online, active and several patients have already enrolled.

We are personally writing to you because, as you know, Blue Cone Monochromacy is a rare disease: each one of us carries helpful information to all others. Then, please, we kindly ask you to help today, by enrolling in the BCM Patient Registry and/or calling your relatives that can be interested in it.

We want to provide you with this guide, for you to successfully register.

If you want to register yourself or your sons in the BCM Registry, please follow these easy 6 steps for each patient:



Let's Start !



1)Username:

Go to <https://www.bcmregistry.org/> and click on "Patients" on the left side menu.

At the **bottom of the Patient page**, fill with the information required: username, password and email address. Please note that the username must **not contain any reference** to your personal data such as name and surname. Use a nickname related with your hobbies, interests,etc.



2) Confirmation Email:

At this point you are going to receive a **confirmation email**. Watch out! Maybe the email has ended up in the spam box! Click on the **activation link** you will find on the **confirmation email** you have received.

After having confirmed you can go back to <https://www.bcmregistry.org/login/> and log in.



3) Log-in and Consents

When you have logged in, go to the left menu on the section "**Consents**" and after choosing the consents you want to give, save the choices made. Please find here a PDF copy of the Consent page: [Consent.pdf](#)

At the bottom of the "Consents" page, you will find the **Assent form**, to be signed by your child (**older than 7**) and sent back to the Registry Manager to Registry.Manager@BCMFamilies.org.

Here you can download the document: [Assent.pdf](#).

Now, there are further important and required steps.



4) Personal Data and DNA test

On the left menu, next item is: '**Personal Data**'. Here you will be required to fill your or your son's personal contact information.

Then please select '**Diagnosis**' on the left menu. Here you have to upload your **DNA Test** with the genetic confirmation of Blue Cone Monochromacy.



5) Clinician

Now you have to choose your **clinician**, a doctor who can check and validate your diagnosis. At the moment, doctors inside the Registry are **Dr. Samuel G. Jacobson**, **Dr. Alessandro Iannaccone** and **Dr. Cristiana Marchese**. More doctors are in the process of registering, such as doctors from Moorfields Eye Hospital in London, UK and doctors from University of Tübingen, Germany. If you wish to invite another clinician to join the registry, please let us know and we will contact her/him.



6) Pedigree and your Family

Finally, when you will be accepted into the BCM Registry, you can access other items in the left menu. In '**Family Data**', you can create a Family ID or you can insert a Family ID received from a relative. Please insert the number of your relatives affected by BCM (total and alive). If you have a family **pedigree** you can upload it in this section. If you wish to have a **pedigree** drawn, please contact the Registry Manager for assistance!

We are happy to help you!



At this point you are fully registered!

If you are **registering your children**, you will need to open multiple accounts, one for each child, so go back to Step #1 for your second son!

We are available for further assistance!
Thank you!

Go to the BCM Registry and Enroll now!



The BCM Patient Registry has been created with the support of
Otto per Mille Chiesa Valdese

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info@bcmfamilies.org

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