

## 6 steps to enroll into the BCM Patient Registry !

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



### Start



### 1)Username:

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

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At the **bottom of the Patient page**, fill with the information required: username, password and email address. A username will be automatically generated and you will find it inside the registration form. If you don't like it you can change it by clicking on the "Change" button.

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### 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 come 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:

<https://www.bcmregistry.org/media/Consents.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](mailto:Registry.Manager@BCMFamilies.org). Here you have it:

<https://www.bcmregistry.org/media/Assent.pdf>

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 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 chose your **clinician**, a doctor who can see 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, or 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. Please, go to 'Family Data'. Here you can create a Family ID or you can input a Family ID received from a relative. Please input 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.



## End

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!