

# Privacy Notice to Patients

Effective Date: May 10th, 2019

Welcome to BCM Registry! Your privacy is very important to us. This online registry Privacy Notice applies to (i) information about you/your child that you provide BCM Families Foundation (“**BCMFF**” “**we,**” or “**us**”) when you join the BCM Registry (the “**BCM Registry**” or the “**Registry**”) or otherwise submit patient health information to the Registry. The purpose of the Registry is to collect and compile certain demographic, health, genetic, and other relevant information about persons (hereafter referred to as “**Participants**”) with BCM (“**Blue Cone Monochromacy**”). This Privacy Notice describes how we may collect, use, or share information about you/your child; your choices regarding our use of your/your child’s information; the ways in which we safeguard the information we collect; and how a data subject may contact us regarding our privacy practices.

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## Information We Collect

### *Information You Provide*

We obtain information that you provide to us directly, for example, data you submit on a Participant’s registry form. The information we collect may include personal information (such as your name, surname, and your/your child's date of birth) and contact data (such as mailing address, email address, and phone number). It also may include personal information relating to your/your child's health and genetic data (e.g. information regarding your/your child's diagnosis, symptoms, and clinical results).

You shall provide information that is accurate and correct to the best of your knowledge, and you shall update your/your child's information as necessary in the future to maintain its accuracy.

### *Information Collected Automatically When You Use the Registry*

In addition to information you submit to us, we may collect certain information using automated means such as cookies, web server logs, and other tracking technologies now and hereafter known or devised.

- A **cookie** is a piece of data that a website can send to your browser. The cookie may then be stored on your computer as an anonymous tag that identifies your computer when you visit a website. Many web browsers are set to accept cookies by default, but you may be able to set your browser to notify you before you receive a cookie, or to remove or reject cookies. The cookies used in the Registry are “*technical cookies*”, i.e. those cookies which allow users to navigate and use a website (e.g. to authenticate themselves). They are not used for further purposes and are installed directly by us. Your prior consent is not necessary to install these cookies, as without such cookies the Registry cannot work. Information obtained through such cookies are processed only to pursue our and your legitimate interest in ensuring the proper and correct operation of the Registry.
- Please be aware that if you disable the technical cookies or all cookies, you may not be able to use certain features of the Registry. Also, disabling cookies may invalidate opt outs that use cookies to recognize devices that have opted out.

The types of information we collect may include IP addresses, device identifiers, browser characteristics, operating system details, language preferences, referring URLs, length of visits, and pages viewed. We may combine this automatically-collected information with other information we obtain about you.

Follow the instructions given by the developer of your Internet browser to find out how to control, disable or erase some or all of the cookies:

- **Edge:** <https://privacy.microsoft.com/en-us/windows-10-microsoft-edge-and-privacy>
- **Chrome:** <https://support.google.com/chrome/answer/95647?hl=en>
- **Firefox:** <https://support.mozilla.org/en-US/kb/enable-and-disable-cookies-website-preferences>
- **Safari:** [https://support.apple.com/kb/PH17191viewlocale=en\\_US&locale=it\\_IT](https://support.apple.com/kb/PH17191viewlocale=en_US&locale=it_IT)
- **Opera:** <https://www.opera.com/help/tutorials/security/privacy/>

## How We Use Information

We may use the information we collect about you for the following purposes:

- 1) pursue our legitimate interest to:
  - Respond to requests, comments, or questions;
  - Analyse trends, usage, and activities of visitors to the Registry;
  - Contact you regarding your use of the Registry or, in our discretion, to provide notices of changes to our policies;
  - Verify and/or authenticate a participant's identity;
  - Prevent fraud or other misuse of the Registry;
  - Comply with industry standards and our policies.
- 2) with your consent (“**Consent A**” or “**Minimum Consent**”), processing your / your child's personal data, including your / your child's sensitive data (i.e. health-related data and genetic data) for the purpose of permitting the operation of the Registry. This includes:
  - developing a centralized database for information to be used for statistical analysis purposes;
  - creating a repository of contact information for individuals with BCM to allow researchers to anonymously contact such individuals to solicit their participation in studies or clinical trials;
  - compiling a pool of relevant data about the pathology and effects of BCM, to be used for the advancement of scientific understanding of BCM;
  - linking data of individuals with BCM to their family members who have also joined the Registry and provided their consent to the linkage;
  - permitting BCMFF to allow access to Your / Your child's Registry data by the Registry Managers who will be responsible for the management of the Registry and by the Registry Steering Committee who will be responsible for the governance of the Registry;
  - permitting BCMFF to link Your / Your child's data to the ones of Your/ Your child's family members who have also joined or will join the Registry and received or furnished You a Family ID;
  - permitting BCMFF to anonymize and aggregate Your / Your child's Registry Data and to share the resulting anonymized and aggregated data with researchers and other approved third parties who have agreed to comply with BCMFF's policies and protocols with respect to the handling and future use of that anonymized data. Here anonymized data means data that cannot identify you / your child; here third parties may include researchers, scientists,

universities, health and research institutions or associations, biotechnology and pharmaceutical companies, patients' organizations and patients, interested in working on BCM. Reports containing Registry statistical data resulting by the aggregation of anonymized data may be published on BCMFF' websites and Newsletter;

- receiving communications from the Registry Manager by email, postal mail, and/or telephone regarding Your / Your child's participation in the Registry, as well as communications by email, postal mail, and/or telephone regarding Your / Your child's participation in the Registry, that may be sent by Your / Your child's selected Clinician;
- having Your / Your child's personal be stored and transferred to the United States, where BCMFF has its registered office and may have its servers, having been informed that the United States is a country which does not offer the same level of protection of the privacy which is offered by the European Law and for which adequacy decisions issued by the European Commission do not exist;
- having Your / Your child's personal, medical and genetic data disclosed to your / your child's treating Clinician, an ophthalmologist / physician who participate to the Registry and you select.
- allowing BCM to include in Your / Your child's personal profile in the Registry the ophthalmic clinical examination reports and genetic test results as entered, modified and/or cancelled by Your/ Your child's Clinician, including the reports uploaded by Your / Your child ERG tests, color tests, and any other tests the Clinician may deem appropriate to upload.
- there is a risk that someone in the future might be able to use anonymized and/or aggregated data to identify Your / Your child or possibly Your / Your child's blood relative(s).

We inform you that:

- joining the Registry is voluntary and, therefore, you are not required to provide your consent. However, the Minimum Consent is necessary to participate in the Registry. Refusing to participate or discontinuing participation at any time will involve no penalty or loss of benefits to which you / your child are otherwise entitled.
- 3) with your optional consent (“**Consent B**”), send you communications on behalf of researchers, scientists, universities, health and research institutions or associations, biotechnology and pharmaceutical companies regarding potential clinical trials or research projects. The researchers, scientists, universities, health and research institutions or associations, biotechnology and pharmaceutical companies pursuant to a specific request approved by the [Registry Steering Committee](#), will be enabled to send communications but will

not be provided with identifying information about who is receiving the communications. You may respond to these communications and provide identifying information if you so choose. Providing your consent to receive communications is not required for participation in the Registry and if you decide not to give this consent there will be no consequences whatsoever;

- 4) comply with legal requirements (if any); or
- 5) for any other purpose, with your consent.

**6) Further Declarations**

- you may revoke your / your child’s Minimum Consent and participation and have your / your child’s information removed from the Registry at any time by accessing the web page ‘Delete my participation’. BCMFF will not use or disclosure Registry Data after you have revoked your participation. However, revoking your participation will not affect information that has already been shared with approved researchers, scientists, or other authorized third parties.
- your consent to the collection of Registry Data will expire after one year and if you wish to disclose additional Registry Data to BCMFF, you must provide an additional consent. You understand that the expiration of your consent to collect Registry Data will not affect Registry already disclosed to BCMFF.

We also may use the information we obtain about you/your child in other ways for which we will provide notice at the time of collection.

Consents in the name and on the behalf of minors shall be given by a parent, guardian or other authorized person. When a minor turns 18 (eighteen) years old they will have to provide a new consent otherwise their participant data will be deleted.

## **How We Share Your Information**

We may permit our consultants, and other service providers, including IT services providers, acting as data processors, to access information we collect about you/your child through the Registry to carry out work on our behalf. These third-party consultants/service providers are prohibited from using such personal information for any purpose(s) other than to provide their services we have engaged them to perform.

With your consent (see paragraph “How we use your information” above), we will allow access to your / your child’s Registry data by: (1) your / your child’s treating Clinician(s), who may view, insert, update and/or validate your data; (2) Registry administrators who will be responsible for the management of the Registry; (3)

Registry Steering Committee members who will be responsible for the governance of the Registry.

Further, with your consent, we may share anonymized Registry information with researchers and other third parties who have agreed to comply with BCMFF's policies and protocols with respect to the handling and future use of that data. Here anonymized data means data that cannot identify you / your child; here third parties may include researchers, universities, scientists, research institutions, patients' organizations and patients, biotechnological and pharmaceutical companies interested in working on BCM. Reports containing Registry statistical data resulting by the aggregation of anonymized data may be published on BCMFF's websites and Newsletter.

We also may share your/your child's information: (1) if we are required to do so by law, regulation, or legal process (such as in response to a court order or subpoena); (2) to fulfil requests by government agencies, such as law enforcement authorities; (3) when we believe disclosure is necessary for the establishment, exercise or defense of legal claims; (4) in the event of a joint venture, partnership, merger, or other collaboration with another organization, to the extent permitted by the law; or (5) in the context of a business negotiation or transaction relating to BCMFF or any affiliated entity (e.g., further to a merger, reorganization, liquidation, or any other business transaction), including negotiations of such transactions, to the extent permitted by the law.

## **Information Security**

We maintain reasonable safeguards to help protect personal information collected through the Registry from loss, theft, misuse, or other unauthorized access, disclosures, alteration, or destruction. Although we use reasonable efforts to safeguard information, transmission via the Internet is not completely secure and we cannot guarantee the security of your/your child's information collected through the Registry.

## **Links to Other Websites**

The Registry may include links to other websites for your convenience and information. Websites that are operated by entities not affiliated with BCMFF may have their own privacy policies or notices, which we strongly suggest you review. BCMFF is not responsible for the content or privacy practices of any linked websites that we do not control.

## **Children's Privacy**

Although parents or guardians may choose to submit information about their children, or on behalf of their children, the Registry is not intended for, nor targeted to, children under the age of 18, and we do not knowingly or intentionally collect information from children under the age of 18. If we learn that we have received information directly from a child who is under the age of 18, we will delete the information to the extent required by applicable law.

## **Retention period**

Information that is submitted for inclusion in the Registry may be retained subject to our retention policies and procedures unless and until the Patient, or a parent or guardian acting on behalf of a minor Patient, requests the removal or deletion of such data from the Registry.

## **Your Rights/How to Update, Change, or Delete Your Information**

You (including your child) have the right to exercise at any time, free of charge and without formalities the following rights: the right to request access to personal data (or the right to obtain from us the confirmation that data concerning you/your child are being processed and, if so, to obtain the access to personal data, obtaining a copy of them) and correction (i.e. the right to correct inaccurate data concerning you/your child or the integration of incomplete data) or the deletion of the same (meaning the right to obtain the erasure of data concerning you/your child, in the cases permitted by applicable privacy law) or the limitation of the processing related to you/your child (meaning the right to obtain, in the cases provided for by the applicable data protection law, the marking of data retained with the aim of limiting their processing in the future), in addition to the right to data portability (i.e. the right, in the cases permitted by the applicable privacy law, to receive from us, in a structured, commonly used and machine readable format the data concerning you/your child, and to transmit it to another data controller without impediments). You also have the right to withdraw your consent at any time. The withdrawal of consent does not affect the lawfulness of the treatment based on consent before revocation. You also have the right to object at any time, on grounds relating to your particular situation, to the processing of your/your child's personal data, based on legitimate interest, including profiling. We remind you that you always have the possibility to lodge a complaint with the competent Data Protection Authority.

You can exercise the above-mentioned rights by contacting BCMFF by mail or by email as indicated in the paragraph entitled “How to Contact Us” below.

You can also directly update, correct, or delete your/your child’s information collected through the Registry by signing in and following instructions.

You may unsubscribe from receiving newsletters and promotional emails from us by following the instructions provided in those email communications. Please note that even if you opt out of receiving such communications from us, we may continue to send you non-promotional emails, such as communications regarding our ongoing relationship with you.

## **International Transfers**

We operate the Registry in the U.S. and the information we collect is governed by U.S. law. If you are accessing the Registry from outside of the U.S., please be aware that information collected through the Registry may be transferred to, processed, stored, and used in the U.S. Data protection laws in the U.S. may be different from those of your country of residence. Your use of the Registry constitutes your consent to the transfer to and from, processing, usage, sharing, and storage of your information, including participant data, in the U.S. as set forth in this Privacy Notice.

## **DPO and representative in Europe**

We inform you that we have appointed a Data Protection Officer, which you can contact as follows for any question or information relating to your privacy and the protection of your personal data: avv. Marco Leone (by mail to “*CMS Adonnino Ascoli & Cavasola Scamoni, Via Agostino Depretis, 86, 00184, Rome, Italy, to the attention of avv. Marco Leone*” or by e-mail to [dpo@bcmfamilies.org](mailto:dpo@bcmfamilies.org)).

We also inform you that we have appointed a representative of BCMFF in Europe (Italy), that you can contact as follows: Dr. Renata Sarno, by mail to “Renata Sarno, Viale Tito Livio 76, 00136, Rome, Italy” or by email to [Renata.Sarno@BCMFamilies.org](mailto:Renata.Sarno@BCMFamilies.org).

## **U.S. Visitors**

Your web browser may have settings that allow you to transmit a “Do Not Track” signal when you visit various websites or use online services. Like many websites, the Registry is not designed to respond to “Do Not Track” signals received from



browsers. To learn more about “Do Not Track” signals, you may wish to visit <http://www.allaboutdnt.com/>.

We do not share personal information as defined by California Civil Code Section 1798.83 (“Shine the Light law”) with third parties for their direct marketing purposes.

## **Changes to this Privacy Notice**

We may prospectively change this Privacy Notice from time to time. If we make changes, we will notify you by revising the date at the top of this Privacy Notice. We encourage you to review this Privacy Notice whenever you visit the Registry to stay informed about our information practices.

## **How to Contact Us**

If you have questions regarding this Privacy Notice you may email us at:

[Registry.Manager@BCMRegistry.org](mailto:Registry.Manager@BCMRegistry.org)

or write to us at:

BCM Families Foundation  
Attn: Privacy Inquiry  
P.O. Box 7711  
Jupiter, FL 33468-7711 USA