

Clinician Terms and Conditions

Effective date: May 10th 2019

These “Terms and Conditions” regulate participation in the BCM Registry by clinicians, doctors, physicians, or other medical professionals who treat patients with Blue Cone Monochromacy who have agreed to comply with BCMFF’s policies and protocols with respect to handling their patients’ data and Patients anonymized data (hereinafter, each of them, a “Clinician”).

What is the BCM Registry and why are Clinicians Needed?

The BCM Registry is an online patient registry dedicated to a rare genetic retinal disease, namely [Blue Cone Monochromacy \(“BCM”\)](#) (“Registry” or “BCM Registry”). The Registry has been created by [BCM Families Foundation \(“BCMFF”\)](#), the only non-profit patient-led organization worldwide with the mission to eradicate BCM.

BCM affects only 1 person out of 100,000 and, currently, has no cure. Because of the low number of patients and the fact that they are scattered around the world, knowledge of the disease is limited and so is the likelihood that innovative disease-modifying therapies will be developed.

Patient registries can be instrumental in accelerating the research into rare diseases and the development of new therapies. Through the organized collection of patient data, registries can bring patients together increasing knowledge of the disease and facilitating basic, clinical and epidemiological research. In addition, registries can be crucial in planning social and health services and ultimately for improving patients’ quality of life.

With these goals in mind and guided by the needs of patients, BCMFF launched the BCM Registry. The success will depend upon the collaboration of all stakeholders and their willingness to share their information.

The Registry is a patient-powered registry where patients enroll themselves and input their personal and medical data. However, for the data to be reliable and usable for research, we need clinicians to validate the data.

- If you have patients with a diagnosis of BCM, inform them about the Registry and support their enrollment.

- If one of your patients asks you to participate in the Registry, you can sign up by completing the registration form and providing your consent – then, you will be linked to your enrolled patients and will be enabled to correct, change, or update their clinical data.

Once registered within the system, you will be able to access the data of all your enrolled patients as well as all aggregate data and statistics.

There is no cost for you or your patients to join the BCM Registry. If you change your mind and want to withdraw from the Registry, you can do so by following the instructions here: [FAQ](#). You acknowledge and agree that BCMFF has the right to terminate your participation in the Registry and freely withdraw from these Terms and Conditions at any time, by sending you a withdrawal communication.

If you are a clinician who does not treat BCM patients but is interested in conducting a research project on BCM please visit the ‘[Researchers](#)‘ web page here.

If you want to access the Registry both as a clinician and as a researcher, you are kindly requested to register yourself twice (i.e. under each user profile).

How do you create your account/profile within the BCM Registry?

In order for you to join the BCM Registry under the Clinician profile, you will need to sign in as Clinician and provide your contact information and work details (i.e. name of your institution, address, etc.). Your phone number is needed in order to send you a PIN that enables you to see your patients identifying information, such as name, surname and date of birth. Without the PIN you can only have access to the pseudoanonymized data.

You can leave the BCM Registry anytime by following the instructions at the webpage “Delete my Participation” in your account menu.

Please know that patients enrolling themselves will find your name within a “Clinicians List” and might select you as their treating Clinician in charge of validating their diagnosis and medical data within the Registry. You should have seen and treated these patients before. However, they may select you even if they are not your patients but they want to be seen by you. In this latter option, you can choose whether to admit the patient and visit him - in order to be able to validate his data within the Registry - or not.

Please note that those of your patients who have enrolled in Registry have consented to (i) the disclosure of their personal, medical and genetic data to you, (ii) your possibility to view, enter, modify and/or cancel ophthalmic clinical examination

reports and genetic test results in their personal profile in the Registry, by also uploading reports of their tests, color tests, and any other tests the you may deem appropriate to upload, and (iii) the fact that you may send them communications by email, postal mail, and/or telephone regarding their participation in the Registry. However, we understand that, before you start filling in the fields related to your patient's diagnosis and medical data, you may want to have a specific consent form signed by your patient.

Once your profile is set and linked to those patients who selected you as their treating clinician, you will be requested to complete their medical data by uploading reports of their ERG tests, color tests, and any other tests you may want to upload. The registry manager can help you through the process and is in charge of ensuring that the Clinician uploaded medical reports do not show patients' names or their personally identifiable data.

How will the data collected in the BCM Registry be used?

Data will be available and accessible to the scientific community as aggregate figures and statistics from analysis of both the entire registry population and/or selected cohorts, as designed by the [Registry steering committee](#). There will be the possibility for researchers to submit basic and/or clinical projects for approval to the [Registry steering committee](#). Upon approval, researchers will be authorized to access further data and/or to contact the eligible patients who consented to be contacted for enrollment in other clinical studies.

General provisions

By participating in the Registry, you (i) represent and warrant that you are qualified and authorized to practice medicine under the laws of your country, (ii) represent and warrant that you have patients with a diagnosis of BCM, (iii) undertake to process the patients' personal data, acting as an independent data controller, in accordance with any applicable law, including any applicable privacy and data protection law, only for the purposes of contributing to the Registry, in accordance with these Terms and Conditions, (iv) undertake to maintain full confidentiality in relation to the patients' personal data.

To the maximum extent permitted by the applicable law, BMCFF does not assume and shall not be deemed to assume any liability with regard to your participation in the Registry and the performance of these Terms and Conditions.

Subject to the "Disputes with BCMFF and Agreement to Arbitrate" section below, (A) these Terms and Conditions and the respective rights and liabilities of the parties, shall be governed, construed, and enforced in accordance with the substantive laws of the State of Delaware without giving effect to its rules regarding conflicts of laws;

and (B) with respect to any suit, action, or proceeding relating to these Terms and Conditions, you irrevocably (i) submit to the exclusive personal jurisdiction of the state and federal courts in Palm Beach County, Florida; and (ii) waive any objection which you may have to personal jurisdiction over you and the venue of any suit, action, or proceeding brought in any such court.

By participating in the Registry, you are supporting research into the treatment of BCM and will help your patients be part of the first patient-led, clinician-endorsed international initiative on this disease. Your participation will contribute to pave the way to a cure for BCM.

Limited License to Use Site

We only grant you a limited revocable license to access and use the public facing features of the BCM Registry for non-commercial purposes for purposes consistent with these Terms and Conditions and in a manner that does not cause harm to BCM Registry, our site, or services or any other users. You are not permitted to otherwise access or use our site or services, or any content thereon. We may suspend or terminate this limited license in our sole discretion and such license shall automatically terminate upon your breach of these Terms and Conditions.

Disputes with BCMFF and Agreement to Arbitrate

The laws of the State of Delaware, without regard to conflict of laws provisions that would apply other law, shall govern the BCM Registry, these Terms and Conditions and any disputes arising related thereto between us, without prejudice to any provision of the laws of your country protecting patients or consumers, that, in the absence of choice, would have been applicable and cannot be derogated from by agreement by virtue of such laws. To the extent permitted by the applicable law, you and we each agree that any dispute, claim, or controversy arising from or relating to the BCM Registry or these Terms and Conditions shall be resolved by individual binding arbitration, and not through litigation, unless the claim is properly filed in a small claims court on an individual basis. The arbitrator's authority to resolve claims and make awards is limited to claims between you and us alone. Furthermore, claims brought by you against us, or by us against you, may not be joined or consolidated in arbitration with claims brought by or against someone other than you, unless agreed to in writing by all parties. No arbitration award or decision will have any preclusive effect as to issues or claims in any dispute with anyone who is not a named party to the arbitration. **THIS MEANS THAT NEITHER OF US WILL HAVE THE RIGHT TO FILE OR PARTICIPATE IN ANY CLASS ACTION OR REPRESENTATIVE ACTION RELATING TO THE BCM REGISTRY AND THESE TERMS AND CONDITIONS, AND THAT ANY ARBITRATION**

PROCEEDINGS WILL BE LIMITED TO THE CLAIMS BETWEEN YOU AND US. BOTH YOU AND WE ARE GIVING UP ANY RIGHT YOU AND WE MAY HAVE HAD TO A JURY TRIAL, AND ALL OTHER RIGHTS THAT YOU OR WE WOULD HAVE IN COURT THAT ARE NOT AVAILABLE IN ARBITRATION.

This arbitration provision is intended to apply as broadly as possible, and to include all parties and claims that would be included in a case brought in court. Thus, this arbitration provision also requires arbitration as to any other corporate or natural persons who are parties to the claim, such as our corporate affiliates and vendors, and members of your family. This arbitration provision also applies to claims of every kind and nature, including but not limited to counterclaims, crossclaims and third-party claims, and claims based upon torts, statutes, regulations, common law and equity; provided, however, that notwithstanding anything to the contrary in this arbitration provision any dispute over the validity, enforceability or scope of this arbitration provision shall be decided by a court, not an arbitrator and BCMFF may seek injunctive relief from a court to prevent or stop a misuse of its intellectual property or confidential information.

You or we may commence an arbitration proceeding by following the rules then in effect for either JAMS or the American Arbitration Association (“AAA”), as selected by the party commencing an arbitration. For a copy of the rules, to file a claim or for other information, contact either JAMS (jamsadr.com) or AAA (adr.org). In addition to JAMS and AAA, claims may be referred to any other arbitration organization that is mutually agreed upon in writing by you and us, or to an arbitration organization or arbitrator(s) appointed pursuant to § 5 of the Federal Arbitration Act as it may be amended (“FAA”), provided that any such organization and arbitrator(s) will enforce the terms of this arbitration provision. This arbitration provision is made concerning transactions involving interstate commerce and shall be governed by the FAA. If there is a conflict between the applicable arbitration rules and these Terms and Conditions, these Terms and Conditions shall govern. The arbitrator shall apply applicable substantive law consistent with the FAA and applicable statutes of limitations, shall honor claims of privilege recognized at law, and, at the timely request of either party, shall provide a brief written explanation of the basis for the decision. The arbitration proceeding shall not be governed by any federal or state rules of civil procedure or rules of evidence. The arbitrator shall take reasonable steps to preserve privacy and confidentiality.

You will be responsible for paying your share, if any, of arbitration fees, but only up to the amount of filing fees you would have paid to file a claim in the state or federal court closest to your residence. We will be responsible for any additional arbitration fees, even if we win the arbitration. In a dispute involving \$10,000 or less, you may choose to have the arbitration conducted by telephone, based on written submissions from the parties, or in person according to the JAMS or AAA rules. If there is an in-

person arbitration hearing, it shall take place in the federal judicial district that is closest to your residence.

This arbitration provision shall survive termination of these Terms and Conditions or your use of the BCM Registry and any bankruptcy by you or us. If any portion of this arbitration provision is deemed invalid or unenforceable, it shall not invalidate the remaining portions of this arbitration provision; provided, however; that the entire arbitration provision shall be invalidated if the requirement of arbitration solely on an individual basis is deemed invalid or unenforceable. If a court decides that the entirety of this arbitration provision is invalid or unenforceable, the remainder of the Terms and Conditions shall still apply.

Thanks!

Thank you very much for your interest in studying BCM!

The Registry collects data and information that are instrumental to scientific research into the treatments of BCM.

It is your commitment that will make the cure possible.