

# Researcher Terms and Conditions

Effective date: May 10th 2019

These Terms and Conditions regulate the participation in the BCM Registry by researchers, scientists, universities, health and research institutions or associations, biotechnology and pharmaceutical companies and other third parties who have agreed to comply with BCMFF's policies and protocols with respect to the handling and future use of patients' anonymized data (hereinafter, each of them, a "**Researcher**").

## What is the BCM Registry?

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, at present, 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 to develop innovative disease-modifying therapies in the near future. The BCM Registry was established to fill these gaps.

The Registry is a patient-powered registry where patients enroll themselves and input their personal and medical data. However, the patients' treating physicians are requested to check and validate all medical data.

## Why are researchers invited to participate to the BCM Registry?

The BCM Registry was designed to help support basic, clinical and epidemiological research into BCM and the development of new therapies. By collecting data about the genetics, clinical presentations of the disease, patient geographic distribution and several other characteristics, researchers are provided with a unique and invaluable source of organized information that will lay the basis for future discoveries and advancements in the field.

If you are a Researcher interested in studying BCM, we invite you to register and submit your research ideas and objectives to the BCM Registry. Both basic and clinical research proposals are eligible for application.

## How does a researcher register to the BCM Registry?

In order for you to join the BCM Registry under the Researcher profile, you will need to sign in as Researcher and provide yours and your institution's contact details.

Subsequently, you will be asked to submit a research project that will be evaluated by the [Registry steering committee](#). The committee meets quarterly and will review your proposal during the next available session according to the procedures and policies reported here.

## What data does a researcher see?

Once signed in, a Researcher sees only aggregate figures and statistics and is enabled to query the Registry and select a patient cohort of interest.

The data shown is pursuant to the specific data sharing permissions each patient selected when providing informed consent and those are of two types:

- [Consent A](#) to enroll in the BCM Registry – enables the registry manager and clinician to view, insert and modify a patient's data and to contact them. With Consent A patients accept to receive communications from the registry manager and from their selected clinician.
- [Consent B](#) to receive communications from Researchers. For instance, if one researcher wants to reach patients and announce a clinical trial, he/she may send short communications through the Registry. The length of communications is limited to 1000 characters. However, communications can contain urls of external webpages.

If your research proposal is approved by the [Registry steering committee](#), you will be able to send communications to all Patients who provided Consent B via the registry manager or through the Registry for the duration of your approved research project.

There is no cost for you in joining the BCM Registry. Participation is free and voluntary. If you change your mind and want to withdraw from the Registry, you can easily withdraw by following the instructions on this page: [FAQ](#). You acknowledge and agree that BCM 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.

## What if you are a clinician-scientist?

If you are also a clinician and see patients with a diagnosis of BCM, we kindly ask you to inform them about this Registry and support their enrollment. To this purpose, we request you to register under both profiles, "[Researcher](#)" and "[Clinician](#)", the

latter user profile is necessary to enable you to validate your patients' diagnosis and medical data.

## **General provisions**

By participating in the Registry, you agree not to attempt to re-identify participants through the aggregate and anonymized data provided by BCMFF.

To the maximum extent permitted by the applicable law, BCMFF 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.

## **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](http://jamsadr.com)) or AAA ([adr.org](http://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.