

A - Minimum consent

Note: This consent is needed to participate in the Registry.

I am an adult or I'm the parent or guardian of a minor whose information I am submitting for inclusion in the Registry. I authorize BCMFF to store and process my personal data / my and the minor's personal data (including health and genetic data, collectively "Registry Data") for the purpose of allowing me / the minor to participate in the Registry, in accordance with the online [Registry Privacy Notice](#). I authorize BCMFF to allow access to my / my 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.

I consent to link my Registry Data to the ones of my / my child's family members who have also joined or will join the Registry and received or furnished me a Family ID.

I authorize BCMFF to anonymize and aggregate my / my 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's websites and Newsletter.

I consent that my/my child's Registry Data will be stored and transferred to the United States, where BCMFF has its registered office and may have its servers, having being 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.

I consent that BCMFF can include my / my child's personal profile in the Registry the ophthalmic clinical examination reports and genetic test results as entered, modified and/or cancelled by my / my child's Clinician, including the reports uploaded by my / my child ERG tests, color tests, and any other tests the Clinician may deem appropriate to upload.

I consent to receiving communications from the Registry Manager by email, postal mail, and/or telephone regarding my / my child's participation in the Registry, as well as communications by email, postal mail, and/or telephone regarding me / my child's participation in the Registry, that may be sent by my / my child's selected Clinician.

- By checking this box, I authorize BCMFF to collect and process my / my child's Registry Data as explained above.

- By checking this box, I do NOT authorize BCMFF to collect and process my / my child's Registry Data as explained above.