Purpose and Goals of the Foundation Fighting Blindness Registry

My Retina Tracker® is an international, on-line registry for individuals and families affected by inherited retinal degenerative diseases and is supported by the Foundation Fighting Blindness based in the United States. This includes diseases such as: retinitis pigmentosa, Stargardt disease, Usher syndrome, choroideremia, Best Disease, achromatopsia, X-linked retinoschisis, cone-rod and rod-cone dystrophies, amongst others. The registry is intended to: improve understanding of the types and prevalence of IRDs; facilitate and promote research in the IRDs; and facilitate clinical studies and trials.

Researchers and clinicians (“Investigators”) need to register for access to the registry data. Access for Investigators working for not-for profit organizations is free. Information on access costs for Investigators working with, or in, a for-profit entity, is available from Coordinator@MyRetinaTracker.org.

In using My Retina Tracker®, Investigators agree to provide accurate information during registration. Not-for-profit Investigators agree to register as a for-profit user when accessing the registry in collaboration with, or to assist, a for-profit entity.

Investigators agree not to sell, publish, present or transfer the data to any third party or for any commercial purpose.

Contact with Registry Participants

All participants in the registry have enrolled and completed an online informed consent process approved by an Institutional Review Board. Only data from participants agreeing to share data will be accessible to Investigators. All data in the registry accessible by Investigators is de-identified.

All Investigators agree to respect the de-identified nature of the My Retina Tracker® data and not attempt to identify the registry participants.

To protect patient privacy and ensure participant anonymity, contact with registry participants can only be made indirectly through the Foundation. Any request to contact registry participants is subject to approval by the Foundation’s Registry Data Access Review Committee, as described in the Research Registration Overview. When approved, Investigator access to the registry participants will initially be indirect. The registry coordinator will take the list of registry participant identity numbers, identified by the Investigator as participants of interest, and will contact the participants via email on behalf of the Investigator.

All Investigators agree not to attempt to contact My Retina Tracker® participants directly and to respect the processes and safeguards in place for participant privacy and anonymity.
If a participant, contacted by the registry coordinator on behalf of an Investigator, chooses to contact the Investigator, the Investigator is welcome to continue a direct dialogue without involving the Foundation registry staff further.

Each registry participant owns their own data in the registry and may choose at any time to change their information or remove their data completely.

All Investigators acknowledge that the participants in My Retina Tracker® own their own data. If the registry coordinator contacts an Investigator about data they may have that is withdrawn, the Investigators agrees to use reasonable effort to respect that request whenever possible.

Use of Registry Data

Upon registration and access to the online registry data, the Investigator may query the de-identified data in the database. Results of searches may be downloaded or printed. The data is for the sole use of the registered Investigator. Searches should not be performed for, or shared with, other Investigators unless they are part of the same research team or collaboration. Investigators should not attempt to download or reconstruct the registry.

Use of the registry must be acknowledged in any publications or presentations arising from the use of the registry. The acknowledgement should include a phrasing similar to that below:

“My Retina Tracker®, an international, online registry for individuals and families affected by inherited retinal degenerative diseases, supported and curated by the Foundation Fighting Blindness®.

By using the access provided to My Retina Tracker®, the Investigator agrees to the above Terms and Conditions of Use.