Registration and Consent

The registration process is simple and consists of two steps:

Creation of your account

A Registry Participant may be any person who has an inherited retinal degeneration or is genetically related to a person with the disease – such as a parent, child, uncle, or other direct relative.

In creating the account you will be asked to create a username and password for the account, which are needed to log into the account in the future. In the second section, we will ask a series of questions that relate to the Participant’s personal profile. Then in subsequent sections there will be questions about the Participant’s diagnosis and medical history. The answers to any of these questions may be changed at any time by logging into your account.

<table>
<thead>
<tr>
<th>Participant</th>
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<tbody>
<tr>
<td>Participant’s First Name (Required):</td>
</tr>
<tr>
<td>Participant’s Middle Name:</td>
</tr>
<tr>
<td>Participant’s Last Name (Required):</td>
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<tr>
<td>Participant's Email:</td>
</tr>
<tr>
<td>Re-enter Participant’s Email</td>
</tr>
<tr>
<td>Username (Required)</td>
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<tr>
<td>Password (Required)</td>
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<tr>
<td>Re-enter Password</td>
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</tbody>
</table>

Is the Participant a minor (under 18 years of age)? ☒ Yes ☒ No
If a minor, provide parent/guardian contact information and relationship.

<table>
<thead>
<tr>
<th>Parent/ Guardian First Name:</th>
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<tbody>
<tr>
<td>Parent/ Guardian Last Name:</td>
</tr>
<tr>
<td>Relationship to Participant:</td>
</tr>
<tr>
<td>Email /Re-enter Email:</td>
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If the participant is a child under the age 18, please print and include the assent form. If possible review it with the child being registered, sign the form at the bottom, have the child sign it if they are able, and return the form to the Foundation Fighting Blindness Registry Coordinator. If you have any questions please call 800-683-5555.

**The FFB Registry Consent Form**

We invite you to take part in the FFB Registry, MyRetinaTracker™. Taking part in this Registry is voluntary. This consent form provides important information about what it means to be involved in this Registry. **People who want to take part in this Registry must read and sign this consent form.** If you have questions that are not answered in this consent form, please contact the Registry coordinator at: 800-683-5555 or Coordinator@MyRetinaTracker.org. You may make changes to this form at any time by going on-line or by contacting the Registry coordinator.

For the purpose of this Consent Form:

"the Registry" will refer to My Retina Tracker™, the FFB Patient Registry.

"Affected person" will refer to the person with an inherited retinal degenerative disease.

"You" and "Your" refers to the participant, the person affected by an inherited retinal degenerative disease (affected person), or the friend, family member, parent, or guardian (the person legally responsible for the care and maintenance of the affected person) providing the information on behalf of the affected person.
What is a registry?

A registry is an organized system for the collection, storage, and sharing of information about people affected with a specific disease or syndrome, or group of diseases. In this case, the Registry will focus on information about people affected with inherited retinal degenerative diseases and their families.

What is the purpose of the Registry?

There are five main purposes of the Registry.

1. Provide a place where you can collect and store information about your inherited retinal degenerative disease that will help you keep track of this information over time and share it with your doctor and other healthcare providers if you wish.

2. Provide a place where you can ask your doctor to record important information about your inherited retinal disease such as the results of specific tests, including any genetic diagnosis.

3. Enable the Foundation Fighting Blindness Registry to provide you with the most up to date information about research of interest to people with your inherited retinal degenerative disease, including clinical trials to evaluate new treatments.

4. Enable the collection and sharing of information about inherited retinal degenerative diseases from a large number of patients, with the research and medical community, so that scientists and doctors can better understand these diseases and how to treat them.

5. Connect scientists studying inherited retinal degenerative diseases with people in the Registry who may qualify for their research studies or clinical trials.

Who can take part in The Registry?

Any adult or child with an inherited retinal degenerative disease can take part in the Registry. In addition, family members who might be genetic
carriers of these diseases can take part in the Registry. People under the age of 18 at the time of consent must have a separate "Assent" form filled in on their behalf and then complete this consent form when they reach the age of 18 to continue to take part in the Registry. If the participant reaches the age of 18 and they choose not to consent at that time, their information will be removed from the Registry.

What information will be collected in the Registry?

The Registry will collect the following:

- personal information including, but not limited to, your name, date of birth, city of birth, country of birth, address, phone, and email address,
- information about your inherited retinal degenerative disease including, but not limited to, your specific diagnosis, your vision test and exam results, and your genetic test results and,
- information about your personal and family health history as it relates to inherited retinal degenerative disease.

How will the information be collected for the Registry?

You will enter information into the Registry through a secure, password protected website or by submitting a completed printed form of the consent and questionnaire. With your permission, your doctor and other retinal healthcare providers will be able to enter information about your retinal degenerative disease into your record, using the same secure, password protected website. If you see more than one doctor, or retinal healthcare provider, you can give permission to as many of them as you choose, to enter information into your personal retinal health record in the Registry, but you are not required to do so. You may also provide your doctor with forms, printed from the web site, where your doctor can record the information requested and send it to the FFB Registry coordinator to be entered into your record. Please note, it is not required that you give your doctor or other retinal healthcare providers permission to enter medical information into your Registry record in order for you to participate in the Registry.
Do you give permission for your healthcare providers to access your personal retinal health record and enter your information in the Registry? (Please check one.)

___ Yes
___ No

How will my information be stored in the Registry?

Your information will be stored in a secure, electronic database. When you register you will be given a unique identification code and all the information in the Registry will be coded with that unique identification code. Only a limited number of the Registry staff will be able to link your identity to the personal information you provide. Your information will be stored in the Registry indefinitely unless you ask to withdraw from the Registry.

Who will my information in the Registry be shared with?

If you give permission, your de-identified and coded information may be shared with scientists studying inherited retinal degenerative diseases. Before your coded information is shared, the scientists must get permission from the FFB to access your information. If your coded information is shared, the scientists will not be able to identify you personally.

Do you give permission for your de-identified and coded information to be shared with scientists? (Please check one.)

___ Yes
___ No

If you give permission, your de-identified and coded information may be shared with other databases in order to develop global knowledge of rare diseases that may lead to new research studies, clinical trials, and clinical treatments. If your coded information is shared with other registries or
databases, the people who work for the other registries or databases will not be able to identify you personally.

Do you give permission for your coded information to be shared with other registries and databases? *(Please check one.)*

___ Yes
___ No

Some scientists studying inherited retinal degenerative diseases may be looking for people with specific diseases to provide samples for research studies. With your permission, we will contact you to let you know when researchers identify you as a potential participant in their study and would like you to contribute a sample (such as blood, saliva, etc.). Please note that contacting you about a laboratory study does not mean the FFB recommends you take part in it and being contacted does not mean you must participate. Please note that you will have to complete a separate, study specific consent form before donating a sample.

Do you give permission for the FFB to contact you with information about laboratory studies that may require a blood, saliva or tissue sample? *(Please check one.)*

___ Yes
___ No

Some scientists studying inherited retinal degenerative diseases may be looking for people to take part in their clinical trials. With your permission, we will contact you to let you know about clinical trials you may qualify for based on the “de-identified” or “coded” information you have in the Registry’s research database. Please note that contacting you about a clinical trial does not mean the FFB recommends you take part in it.
Do you give permission for the FFB to contact you about clinical trials that you might qualify for? (Please check one.)

___ Yes

___ No

What are the risks of taking part in the Registry?

There is minimal risk in taking part in the Registry. The Registry includes questions that can be sensitive and you may feel uncomfortable answering. You do not have to share any information you do not want to. Although every effort will be made to protect your identity, there is a small risk for loss of confidentiality.

If the results of any studies of your genetic make-up were to be accidentally released, it might be possible that the information we will gather about you as part of this research repository could become available to an insurer, an employer, a relative, or someone else outside the Registry. Even though there are discrimination protections in many states and Federal Law, there is still a small chance that you could be harmed if a release occurred. A federal law called the Genetic Information Nondiscrimination Act (GINA) generally makes it illegal for health insurance companies, group health plans, and most employers to discriminate against you based on you genetic information. Be aware that this federal law does not protect you against genetic discrimination by companies that sell life insurance, disability insurance, or long term care insurance. GINA also does not protect you against discrimination if you have already been diagnosed with the genetic disease.
What are the benefits of taking part in the Registry?

The only direct benefit of your participation in the Registry is having a secure place for you and your doctor to store information relevant to your inherited retinal degenerative disease. We do not expect there will be any other direct benefits of participation but information in the Registry is expected to help researchers learn more about inherited retinal degenerative diseases.

Will I receive results from research that uses my information?

Most research using your Registry information is not expected to return new information that would be helpful to share with you personally. However, if a scientist learns something that he or she thinks might be important to you, there is a chance that you may be re-contacted by the FFB Registry coordinator. With your permission, we will contact you with results of studies using your information.

Do you give the FFB permission to contact you with results of research using your information? (Please check one.)

___ Yes
___ No

Will I be asked to give the Registry more information in the future?

Yes. The Registry is most valuable for scientific research when it is kept up-to-date. With your permission, you will be asked to update your profile and information once a year. You, or your retina healthcare provider, can also update your record in the Registry whenever there is a change in your information. Failing to update your record in the Registry does not lead to removal from the Registry. All your data will remain in the Registry unless you ask for it to be removed.
Do you give the FFB permission to contact you once a year to update your information in the Registry? (Please check one.)

___ Yes

___ No

How long will be information be stored in the Registry?

The information in the Registry is stored permanently. It will not be removed unless you specifically ask to be removed from the Registry (to do this see the question below). We will be using the information you provide for many years to come. We will be allowing researchers who are designing projects to study inherited retinal diseases to use some of the medical information you and your doctors provide. However you may choose to end your participation at any time.

Can I remove myself from the Registry?

Taking part in the Registry is voluntary. You can withdraw your information from the Registry at any time. Please note that information shared with scientists before your request for removal cannot be retrieved from researchers that have already accessed it. To withdraw your participation in the Registry, please contact the Registry Coordinator at Coordinator@MyRetinaTracker.org or call 1-800-683-5555. If you ask to withdraw from the Registry, your information in the database and any printed information you have sent to the Registry will be destroyed and cannot be recovered.

Are there any costs to take part in the Registry?

No, participation in the Registry is free to all participants.

What are my choices if I do not want to be in the Registry?

You do not have to join the Registry. Taking part is voluntary.
Who should I contact if I have questions?

If you have questions about the Registry, please contact the Registry Coordinator at Coordinator@MyRetinaTracker.org or at 800-683-5555.

To report problems that result from your participation in the Registry, contact the Registry Coordinator at: Coordinator@MyRetinaTracker.org or at 800-683-5555.

If you have questions about your rights as a participant in the Registry, contact The Western Institutional Review Board the IRB for this study at: help@wirb.com or call 800-562-4789.

For more information about the terms and conditions of the FFB Registry or the privacy policy please go to Terms and Conditions | Privacy Policy at www.MyRetinaTracker.org

I have read the consent form for the FFB Registry and I agree to voluntarily take part in the Registry as described. I understand that I may withdraw from the Registry at any time. Any questions I have about taking part in the Registry have been answered and I know how to contact the Registry Coordinator at Coordinator@MyRetinaTracker.org or at 800-683-5555 with any questions I have in the future. Lastly, I know how to access this document on the FFB Registry web site or by contacting the FFB Registry coordinator in the future if I want to review it or make any changes.

Signature: 

Please print name: 

Date: 
Send the signed Consent Form by fax, mail or email to the attention of the Registry Coordinator.

Fax: 410-872-0574

Email: Coordinator@MyRetinaTracker.org

Mail:
Registry Coordinator
Foundation Fighting Blindness
7168 Columbia Gateway Drive, Suite 100
Columbia, MD  21046