MY RETINA TRACKER®
Track Your Vision. **Drive the Research.**

Clinical Data Input Request

FROM: Patient	**TO: Clinician**
First Name:	Clinician First Name:
Last Name:	Clinician Last Name:
Patient Postal/ZIP Code:	Practice Name:
Patient Gender:	Address:
Patient Birth Date: (mm/dd/yyyy)	Phone:

Patient Signature:	**Date:**

Dear Physician, Genetic Counselor, Clinical Support Staff,

I request that you enter the ophthalmic clinical examination and/or genetic testing results you have collected from my most recent clinical exam into my personal retinal profile in the Foundation Fighting Blindness registry, called My Retina Tracker®, as selected below.

I make this request knowledgeably; having signed an informed consent to allow my personal and clinical information to be entered into the registry. My Retina Tracker® is a registry for individuals affected by inherited retinal degenerative disease sponsored by the Foundation Fighting Blindness and approved by Western Institutional Review Board (Study Number 1135196). It specifically allows for the entry of my clinical retinal exam data and my genetic testing results relevant to my retinal condition.

Please (**patient to select by checking all that apply**):

☐ **ENTER** my **clinical** exam data.

☐ **ENTER** my **genetic** test result.

To enter my most recent clinical and or genetic exam results please:

- Open the URL: www.MyRetinaTracker.org in a web browser
- Click on the tab at the top of the page marked “For Clinicians”
  - You require no username or password to enter the data
  - A data matching program and active site curation ensure the data is entered into the correct patient profile
- Select the exam results you wish to enter
- Complete the data entry for each exam, using the drop-down menus
- Review the data
- Then submit.

This should take no more than 5-10 minutes and does not require any charts or images to be uploaded.

You may keep this letter in your records. Thank you.

PERMISSION TO DISCLOSE PERSONAL HEALTH INFORMATION FOR RESEARCH

State and federal privacy laws protect the use and release of your health information. Under these laws, your health care provider cannot release your health information to the research sponsor, Foundation Fighting Blindness (FFB), for use in the FFB Registry (MyRetinaTracker®) unless you give your permission. If you decide to give your permission to allow your health care provider to share your health information for use in the FFB Registry, you should sign this form and give it your healthcare provider. This form describes the different ways that your health information could be used. The Foundation Fighting Blindness will use and protect your information as described in the FFB Registry Consent Form. (www.myretinatracker.org) However, once your health information is released it may not be protected by the privacy laws and might be shared with others, such as researchers who are approved to obtain information from the FFB Registry to conduct research.

If you give your permission and sign this form, you are allowing your health care provider to release medical records related to your inherited retinal degenerative disease to FFB. Your Personal Health Information will be released to the Foundation Fighting Blindness for the following purposes:

1. The purposes described in the FFB Registry Consent Form;
2. To others who are required by law to review the quality and safety of the research, including: U.S. government agencies, such as the Food and Drug Administration, the Foundation's Registry support staff or their representatives, or government agencies in other countries. These organizations and their representatives may see your Personal Health Information. They may not copy or take it from your medical records unless permitted or required by law.

Any research reports that result from the use of your information in the FFB Registry will not include your name, address, telephone or social security number, or Email address. The research sponsor may share data from the FFB Registry with others in the following ways:

1. To perform research;
2. Share data in a de-identified manner with researchers in the U.S. or other countries;
3. Place it into research databases;
4. Use it to improve the design of future studies;
5. Use it to publish articles or for presentations to other researchers;
6. Share it in a de-identified manner with business partners of the sponsor; or
7. File applications with U.S. or foreign government agencies to get approval for new drugs or health care products.

While you will have access to all of your information in the FFB Registry, you generally will not have access to your personal health information related to any specific research until the study is complete. If it is necessary for your care, your health information will be provided to you or your physician.

This permission to release your Personal Health Information expires when the FFB Registry project ends and all required study monitoring is over. Research reports can be used forever.

You can cancel your permission at any time. You can do this in two ways. You can write orEmail to the FFB Registry Coordinator and can ask the Coordinator to give you a form to fill out to cancel your permission. If you cancel your permission, you may no longer participate in the FFB Registry. If you cancel, information that was already collected and disclosed about you may continue to be used. Also, if the law requires it, the sponsor and government agencies may continue to look at your medical records to review the quality or safety of the study.

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