



## Foundation Fighting Blindness National Retinal Degenerative Disease Registry

When a new treatment or clinical trial is available for you or a loved one, you'll want to be the first to know. The Foundation Fighting Blindness National Registry is designed to collect basic information about individuals with retinal degenerative diseases such as retinitis pigmentosa, macular degeneration, Stargardt disease, Usher syndrome, and related diseases. When critical information about a specific disease becomes available, FFB will alert individuals in the registry via email and/or regular mail. The registry also provides crucial statistical information to our researchers and helps FFB obtain financial support for research projects and educational services.

While you may receive occasional correspondence or contact directly from FFB, your personal information **will never** be released to **any** outside organization without first receiving your informed consent. By participating in this registry you can help speed the pace of research and be assured that you are staying in touch and informed.

**By completing this form and signing below, you indicate your willingness to be part of the FFB National Registry database. Minors (under 18) should have the form signed by a guardian.**

Signature of patient (or parent or guardian) \_\_\_\_\_

Date \_\_\_\_\_ Print name and relationship if not patient \_\_\_\_\_

Name of patient: First: \_\_\_\_\_ Middle \_\_\_\_\_ Last \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_ Country \_\_\_\_\_

Phone \_\_\_\_\_ E-mail address \_\_\_\_\_

Date of birth \_\_\_\_\_  Male  Female

**Retinal Disease** – Please check the most specific diagnosis.

Provide age at diagnosis and inheritance pattern **if known**. Inheritance patterns can be autosomal dominant (**AD**), autosomal recessive (**AR**), X-linked recessive (**XL**), and unknown (**U**).

| Disease   | Age Diagnosed | Inheritance Pattern |
|---|---------------|---------------------|
| <input type="checkbox"/> Age-Related Macular Degeneration<br>Type of ARMD: <input type="checkbox"/> Wet <input type="checkbox"/> Dry <input type="checkbox"/> Both <input type="checkbox"/> Unknown |               |                     |
| <input type="checkbox"/> Atypical RP  |               |                     |
| <input type="checkbox"/> Bardet Biedl (Laurence Moon)   |               |                     |
| <input type="checkbox"/> Best disease   |               |                     |
| <input type="checkbox"/> Choroideremia  |               |                     |
| <input type="checkbox"/> Cone dystrophy   |               |                     |
| <input type="checkbox"/> Cone rod dystrophy   |               |                     |
| <input type="checkbox"/> Congenital stationary night blindness  |               |                     |
| <input type="checkbox"/> Gyrate atrophy   |               |                     |
| <input type="checkbox"/> Juvenile inherited macular degeneration  |               |                     |
| <input type="checkbox"/> Leber congenital amaurosis   |               |                     |
| <input type="checkbox"/> Refsum disease   |               |                     |
| <input type="checkbox"/> Retinitis pigmentosa   |               |                     |
| <input type="checkbox"/> Retinoschisis  |               |                     |
| <input type="checkbox"/> Rod cone dystrophy   |               |                     |

continued on back

| Disease  | Age Diagnosed | Inheritance Pattern |
|--|---------------|---------------------|
| <input type="checkbox"/> Sorsby fundus dystrophy   |               |                     |
| <input type="checkbox"/> Stargardt disease   |               |                     |
| <input type="checkbox"/> Usher syndrome<br>Type of US: <input type="checkbox"/> Type I <input type="checkbox"/> Type II <input type="checkbox"/> Type III <input type="checkbox"/> Unknown |               |                     |
| <input type="checkbox"/> Other –<br>Please print. _____  |               |                     |

Are other members of your family affected by an inherited retinal disease?  Yes  No

**If Yes, please list** their names, their year of birth, their relationship to you and the disease that affects them. If you prefer, you can omit their names. (The names of family members will not be added to a mailing list unless they complete a registry form or they contact the Foundation in some other way.)

| Name | Relationship | Year of Birth | Eye Disease |
|------|--------------|---------------|-------------|
|      |              |               |             |
|      |              |               |             |
|      |              |               |             |

If you would like FFB to send Registry forms to those family members listed above or others affected by an inherited retinal degenerative disease, please provide their names and addresses.

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_ Country \_\_\_\_\_

E-mail Address: \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_ Country \_\_\_\_\_

E-mail Address: \_\_\_\_\_

By providing the name and address of your doctor, FFB can provide him/her with the latest research developments and information on upcoming clinical trials.

Name of Ophthalmologist: \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

E-mail Address \_\_\_\_\_

**Please insert the completed and signed form in the enclosed business reply envelope marked “Confidential Registry Enclosed.” If no envelope, mail to Foundation Fighting Blindness National Registry, 11435 Cronhill Drive, Owings Mills, MD 21117**

If you have questions about the FFB National Registry, contact the Registry Coordinator.  
410-568-0150 • 800-683-5555 • 410-363-7139 (TDD) • 800-683-5551 (TDD)