

PATIENT REGISTRY FOR INHERITED RETINAL DISEASES



What is the Fighting Blindness Canada (FBC) Patient Registry?

The Patient Registry is a secure database for people living with an inherited retinal disease (IRD) including but not limited to, retinitis pigmentosa, choroideremia, Usher syndrome, Stargardt, and leber congenital amaurosis. It helps connect patients to clinical trials, improve patient care, and drive sight-saving research.

Am I eligible to enrol in the Patient Registry?

Pour vous inscrire au You are eligible to enrol if you have been diagnosed with an IRD by a doctor. Genetic testing is not required for enrolment, but it helps your chance of being contacted for a clinical trial or treatment.

How do I enrol?

Please take the following steps:

- ▶▶ **Step 1:** Visit fightingblindness.ca/patient-registry to tell us you are interested. FBC will send you Patient Registry contact information.
- ▶▶ **Step 2:** Contact the Patient Registry by phone or email. They will provide you with a consent form and a data collection form.
- ▶▶ **Step 3:** Complete the consent form. Ask your eye doctor to complete the data collection form about your disease.
- ▶▶ **Step 4:** Submit your completed consent form and data collection form to the Patient Registry. Your information will be added to the database. Personal information like your name will be removed to protect your privacy.

What happens after I enrol?

FBC is working hard to connect with researchers across Canada and the world. When your information is put into the patient registry database, you become searchable by disease and gene mutation. If you are eligible for a clinical trial or treatment, the patient registry will contact you.