

How to get genetic testing for inherited retinal diseases in MANITOBA



**FIGHTING
BLINDNESS
CANADA**

What are inherited retinal diseases?

An inherited retinal disease (IRD) is a disorder leading to vision loss that can be traced to a specific genetic cause. People with an IRD will have an eye condition that may run in the family. Symptoms of genetic eye diseases vary depending on which part of the eye is involved. Often, vision loss progresses over time. This diagnosis is usually made by your eye doctor.

What is genetic testing?

Genetic testing involves taking a sample of your DNA (from your blood) and analyzing your genes to find any changes that may cause your IRD and symptoms.

Why should I get genetic testing?

Genetic testing helps confirm your diagnosis. Knowing your genetic mutation may provide information about how your eye disease will progress and what may be done to help. Many new treatments being studied are gene specific. Knowing your gene mutation may improve your chance of being eligible for a clinical trial or gene-specific treatment.

Genetic testing can also tell you how the condition is passed through your family and if other family members are at risk of inheriting the condition.

Do I have to pay for this test?

Every Canadian provincial government covers genetic testing for IRDs. There are a few steps to this process which we have outlined on the next page.

What is a genetic counselor?

Genetic counselors are health professionals with training in medical genetics and counseling. They work with a healthcare team to provide patients and families with information about their genetic diseases. Patients and families may use this information to make informed decisions about their health.

Can I get genetic testing privately?

Access to private genetic testing should be discussed with your doctor or genetic counselor.

What do I do with my results?

Fighting Blindness Canada's IRD Patient Registry is a secure clinical database where information about your clinical and genetic information is collected. This is an opportunity to be connected with clinical trials that may be appropriate for you. Call or [email](#) the health information line to learn more.

Do you have questions? Our health information line is here to help.

healthinfo@fightingblindness.ca • 1.888.626.2995

1	If you have been diagnosed with, or suspected to have a genetic eye disorder, please speak with your optometrist, ophthalmologist, family doctor or nurse practitioner. They can arrange a referral to the Program of Genetics & Metabolism at the Health Sciences Centre in Winnipeg, Manitoba.
2	The genetics clinic will review your medical, and family history. They may ask you, or your referring physician for more information before setting up an appointment. The wait time for an appointment may vary and can range anywhere from a couple of months to 2 years. You will be triaged according to the urgency of the referral. You will meet with a genetic counsellor or geneticist in person, by phone or virtually.
3	It is important to determine if genetic testing is appropriate for you. The genetic counselor or geneticist will collect your medical and family history which helps identify what genes should be tested. The geneticist may also complete a physical exam.
4	<p>If genetic testing is appropriate for you, the details of the test will be discussed with you. You will be asked to provide consent (either written or verbal). Testing requires a blood sample. Genetic testing for eye disorders requires funding approval from a committee. It is not guaranteed that all applications will be approved, although most applications are approved. If testing is approved, Manitoba Health will cover the cost of genetic testing.</p> <p>Genetic testing results usually take between 3 to 6 months to come back.</p>
5	The genetic counsellor or geneticist will review your results with you. They may ask your primary care provider, or other health care providers to arrange appropriate referrals for additional screening and/or management. You may wish to request a copy of your results
6	<p>The next steps are:</p> <ul style="list-style-type: none">• The genetic counselor or geneticist will send a copy of your results back to your referring care provider.• You can ask your counselor about relevant clinical trials. Keep a copy of your genetic results.• Consider joining the Fighting Blindness Canada IRD patient registry: fightingblindness.ca/patient-registry