



September Marks Inherited Retinal Disease Awareness Month, Recognizing Genetic Eye Diseases Leading to Vision Loss

TORONTO, September 1st 2022 – Canada is marking September as the first annual Inherited Retinal Disease Awareness Month, resulting from advocacy efforts by Fighting Blindness Canada to Health Canada to recognize individuals living with genetic conditions that lead to vision loss. Inherited retinal diseases (IRDs) are caused by a specific genetic mutation or mutations that impact how retinal cells work and survive which impact vision.

“Researchers have found more than 300 genes that cause IRDs, which cause damage to the retina in the back of the eye and ultimately lead to vision loss, either at birth or later in life,” explains Doug Earle, President and CEO of [Fighting Blindness Canada](#) (FBC). “However, research is constantly changing the outcomes for people living with these conditions. There are new treatments that can slow down, stop or even reverse the progression of disease, giving people immense hope of a future without blindness.”

FBC commissioned Deloitte Access Economics to deliver “IRD Counts” in 2020 that identified the annual socio-economic impact of IRDs in Canada as \$1.6 billion. Over eighty (80%) percent of the impact is borne by families living with IRDs.

Although there are differences between IRDs, they all result in vision loss due to retinal damage in the back of the eye. Among the more than 20 types of IRDs include retinitis pigmentosa, Stargardt disease, Usher syndrome, and Leber congenital amaurosis. [Genetic testing](#) may help pinpoint which mutation causes an IRD and can provide important information as more clinical trials and treatments are developed.

As part of IRD Awareness Month, FBC is inviting Canadians to participate in the following:

- Join FBC’s Facebook Live on IRDs with Dr. Rob Koenekoop, Paediatric Ophthalmologist at Montreal Children’s Hospital on **Friday, September 23 at 12:30 pm EDT**
- Attend FBC’s [“Gene Agnostic Therapies” View Point webinar](#) on **Thursday, September 22, 3 pm EDT**
- Attend FBC’s in-person View Point Toronto all-day event on **Sunday, October 2, 2022** [Register here](#)
- Download [FBC’s IRD Awareness Month social media toolkit](#) and use #FBCIRDMonth to join the online conversation
- Visit FBC’s [genetic testing webpage](#) for information on how to get tested for an IRD

To learn more about IRDs and the work researchers are doing to improve outcomes for individuals with IRDs, visit [FightingBlindness.ca](#).



**FIGHTING
BLINDNESS
CANADA** | **VAINCRE
LA CÉCITÉ
CANADA**

About Fighting Blindness Canada:

Fighting Blindness Canada (FBC) is the largest charitable funder of vision research in Canada. Over our 48-year history, FBC has contributed over \$40 million in funding for the development of sight-saving treatments and cures for blinding eye diseases. Thanks to our supporters, FBC is helping drive forward research to understand why vision loss occurs, how it can be slowed, and how sight can be restored. To learn more, visit fightingblindness.ca or call 1-800-461-3331. For vision health inquiries, call 1-888-626-2995 or email healthinfo@fightingblindness.ca to reach FBC's Health Information Service.

Contact:

Jackie Rosen

Executive Assistant to Doug Earle

416-360-4200 Ext. 246

jrosen@fightingblindness.ca