



## **Landmark Cost of Vision Loss associated with Inherited Retinal Diseases Underscores Urgent Need for Support**

TORONTO (October 8, 2020) – Groundbreaking [new study](#) released today by Fighting Blindness Canada and Retina International places the total cost of illness from vision loss associated with inherited retinal diseases (IRDs) in Canada at \$1.6 billion– significantly higher than previously estimated. The study’s proponents say these costs, which are expected to increase dramatically in the years ahead, underscore the urgent need for Canada to support research and new treatments for IRDs.

IRDs represent a diverse group of diseases that can lead to severe vision loss and blindness. They are often progressive and degenerative, and are caused by mutations in one or more of over 250 genes. Until recently, there have been no effective treatments.

The \$566 million price tag for vision loss includes \$38 million in direct health-related costs and \$538 million in indirect costs, such as lost productivity and earnings, rehabilitation, and assistive devices. Persons with an IRD in Canada were 24.4% less likely to be in paid employment than the general population.

The study is also the first to attribute a value to the human toll of vision loss on Canadians with IRD’s. This burden of disease adds a further \$1.1 billion to the overall cost of IRDs.

"This landmark study provides clear evidence on how living with an inherited retinal disease causes significant impacts on daily life, well-being, mental health, quality of life, and employment status." says Doug Earle, President & CEO, Fighting Blindness Canada. "It reinforces what I hear from Canadians every day. This is a message to policymakers that new treatments that restore sight will transform lives."



Dr. Robert Koenekoop, Chief, Pediatric Ophthalmology, Montreal Children's Hospital, stated: "This report puts a number on what we as clinicians already know - that having an inherited retinal disease has broad economic and health impacts for individuals, their families and society. As the first treatments for inherited eye diseases are starting to enter the clinic, this data demonstrates the importance of ensuring that they are accessible to Canadians."

Prior to this study the prevalence and impact of IRDs in Canada was largely unknown. Patients, families, and the organizations who represent them along with health care providers have witnessed the reality of life with an IRD, and understand the impact that these diseases have on well-being and mental health, as well as the associated socioeconomic burden. However, the lack of data in this area has been a barrier to the development of treatments, planning and implementation of clinical trials, and delivery of appropriate clinical care. There is still an urgent need for stronger evidence based on the impact of IRDs to support discussions about the value of new therapies that are progressing through clinical trials or being considered by regulatory bodies.

This study demonstrates that the impact of having an IRD is primarily borne by the affected individuals and their families. However, the societal effects and costs of IRDs that are borne outside of the healthcare system are not captured in most drug reviews or health technology assessments, making it difficult to assess the true cost of these diseases. This report goes some way towards filling this gap but it is clear that more work is needed to both understand and account for the burden of vision loss on Canadians as well as the importance of investment in critical genetic testing services and research to drive the development of treatments for this unmet need.

### **About IRD's**

Inherited retinal diseases represent a diverse group of progressive, visually debilitating diseases in which genetic mutations that are critical to retinal function lead to retinal cell death and associated vision loss. For people living with IRDs, there have traditionally been no effective treatments to restore vision although



there has recently been some success reported with reported with neurotrophic factor therapy and gene therapies. This study considered fourteen forms of IRDs: retinitis pigmentosa, Stargardt disease, Choroideremia, Best disease, Usher syndrome, X-linked retinoschisis, Leber congenital amaurosis, blue cone monochromacy, Bardet-Biedl syndrome, Leber hereditary optic neuropathy, achromatopsia and rod-cone, cone-rod and cone dystrophies.

### **About the Study**

The socioeconomic impact of inherited retinal dystrophies (IRDs) in Canada was commissioned by IRD COUNTS, a patient-led multi-stakeholder consortium managed by Retina International that includes Fighting Blindness Canada, Foundation Fighting Blindness USA, AGTC, Janssen Global, and Novartis Phama AG. All partners funded and assisted in the design of the project. The study was conducted by Deloitte Access Economics, a world-leading independent economic consulting firm who are specialists in model-based health forecasting and analysis.

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For a copy of the report “The socioeconomic impact of inherited retinal dystrophies (IRDs) in Canada”:

<https://www.fightingblindness.ca/get-involved/helpadvocate/>