**Fighting Blindness Canada 2020 Impact Report – Leading the Fight against Blindness**

In 2020, Fighting Blindness Canada advanced vision research, education initiatives, and vision health resources in new and innovative ways.

# **PAGE 1: OUR MISSION**

Since 1974, Fighting Blindness Canada (FBC) has funded over $40 million in the best, most promising vision research to understand the causes of vision loss and advance new treatments and cures for blinding eye diseases.

This investment means that there are now treatments to prevent vision loss for people living with glaucoma, age-related macular degeneration, and diabetes-related vision loss, and that in 2020, the first sight-restoring gene therapy treatment for an

# **PAGE 2 (A): MOVING RESEARCH FORWARD**

In 2020, FBC worked together with the vision loss community to learn more, share more, and do more for Canadians living with vision loss than it could have ever imagined in such unprecedented times. FBC adapted quickly, taking its education programs and fundraising events to an entirely new virtual level, while also offering more opportunities to share valuable vision health information and resources.

Most importantly, the determination of FBC’s funded researchers kept research moving forward in safe ways. While labs at hospitals and universities across Canada weathered the on-and-off again storm, together with the support of generous donors like you, advancements towards new treatments and cures for blinding eye diseases continued.

# **PAGE 2 (B): WITH YOUR SUPPORT**

This year, we funded 26 grants including 6 new outstanding research projects that represent some of the most ambitious and impactful vision science in Canada.

Support from our generous donors is helping scientists:

* UNDERSTAND how genetic mutations cause vision loss in Usher syndrome and pigmentary glaucoma.
* PRESERVE vision by diagnosing vision loss earlier and developing new drug and gene therapy treatments for diseases like retinitis pigmentosa and congenital blindness.
* RESTORE vision using stem cells to aid corneal healing in neurotrophic keratitis.

In 2019, we expanded our mandate to include research into all blinding eye diseases and we are excited to fund research that will touch more Canadians than ever.

# **PAGE 3: RESEARCH BREAKTHROUGHS**

## **SOLVING A STEM CELL MYSTERY**

A discovery this year by FBC-funded researcher Dr. Michel Cayouette’s team at McGill University has identified two molecules (Pou2f1 and Pou2f2) that drive stem cells to make cone photoreceptor cells, the light sensing cells responsible for detail and central vision.

The generation of functional cone photoreceptors has been a long-standing challenge and this exciting work moves scientists closer to being able to develop an effective stem cell therapy for retinal diseases like age-related macular degeneration and retinitis pigmentosa.

## **NEW DISCOVERIES IN GENE THERAPY FOR IRDS**

World renowned ocular geneticists Dr. Elise Héon (The Hospital for Sick Children) and Dr. Rob Koenekoop (Montreal Children’s Hospital) have been at the forefront of research into the genetic causes of inherited retinal diseases (IRDs) for decades, identifying novel genes and mutations that lead to retinal degeneration.

As members of FBC’s IRD Patient Registry Committee, Dr. Héon and Dr. Koenekoop are now seeing the results of genetic research turning into new treatments. Through their participation in clinical trials they are helping Canadians gain early access to some of these innovative treatments. This includes at least four active gene therapy trials for retinitis pigmentosa, choroideremia, Usher syndrome, and Leber congenital amaurosis, with more to come next year. Dr. Héon and Dr. Koenekoop are also two of the Canadian doctors that will be delivering

Luxturna, the first approved gene therapy in Canada for an IRD!

**To learn more about FBC’s Patient Registry, visit** [**fightingblindness.ca/patient-registry**](https://www.fightingblindness.ca/patient-registry/)

# **PAGE 4: BUILDING CAPACITY: SUPPORTING THE BEST CANADIAN RESEARCHERS**

Over the past 46 years, funding from FBC has been instrumental in supporting and nurturing the Canadian vision research community. One area where there is still a gap is in growing the pipeline of clinician-scientists who focus on vision research. These individuals are critical to the Canadian vision research community, helping move discoveries from the laboratory to the clinic.

In order to address this need, FBC launched the Clinician Scientist Emerging Leader (CSEL) Award. We are proud to be funding four rising stars as they continue their research careers.

1. DR. BRIAN BALLIOS (University of Toronto) is developing better ways to deliver stem cell therapy for retinal regeneration.
2. DR. JACOB RULLO (Queen’s University) is exploring a connection between Vitamin D and age-related macular degeneration.
3. DR. MATTHEW BENSON (University of Alberta) is deciphering the genetic basis of inherited retinal diseases.
4. DR. ELLEN ZHOU (Université de Montréal) is studying how retinopathy of prematurity impacts long term vision.

# **PAGE 5: MAKING HISTORY**

## **GROUND-BREAKING GENE THERAPY APPROVED IN CANADA**

On October 14, 2020, the first sight-restoring treatment for an inherited retinal disease (IRD), voretigene neparvovec (Luxturna®), become a reality for Canadians. The development of this ground-breaking gene therapy was decades in the making, building on global research efforts and the hard work of scientists, clinicians, and patients. While it’s the first treatment for an IRD, we know it won’t be the last and that’s why our mission to fund the best vision research remains vital.

**Learn more about this treatment at** [**fightingblindness.ca/news**](https://www.fightingblindness.ca/news/healthcanadaapprovesgenetherapy/)

## **11 YEARS IN THE MAKING: SUPREME COURT OF CANADA UPHOLDS GENETIC NON-DISCRIMINATION ACT (GNDA)**

On July 3, 2020, the GNDA was upheld as law. FBC participated in the Canadian Coalition for Genetic Fairness to ensure that Canadians’ genetic test information was protected and could not be used against them, to deny them insurance or jeopardize their employment. The coalition had to overcome many barriers, yet community champions prevailed to get the act upheld by the Supreme Court.

**Learn more about this historical event at** [**fightingblindness.ca/news**](https://www.fightingblindness.ca/news/11-years-in-the-making-supreme-court-of-canada-passes-genetic-non-discrimination-act-gnda/)

## **CANADIAN VISION 2020 SUMMIT**

In recognition of the symbolic year ‘2020’, FBC and other national vision organizations hosted the Canadian Vision 2020 Summit in Ottawa on February 12th. This day brought together diverse groups — patients, caregivers, researchers, policymakers, government, and more — to reflect on past achievements and create a clear vision for people with vision loss in 2020 and beyond. Discussions included three themed panels: Living with Vision Loss, Vision Research, and Access to Vision Care, and led to the development of white papers that describe key developments and challenges in each area.

**To access the white papers visit** [**fightingblindness.ca/get-involved/helpadvocate**](https://www.fightingblindness.ca/get-involved/helpadvocate/)

# **PAGE 6: LIVES IMPACTED**

**1.5 MILLION Canadians live with vision loss. 5.59 MILLION Canadians have a disease that puts them** **at significant risk of losing their vision.**

This year, we connected with over 30 million Canadians to raise awareness of the importance of regular eye exams to avoid blindness and the need for ongoing research funding to support the advancement of new treatments and cures for blinding eye diseases.

Here’s a glance at the 2020 triumphs you as a supporter made possible…

* 1,085 Participated in our fundraising events; Cycle for Sight Virtual, Screens off for Sight, Ride for Sight, Comedy from the Couch
* 325 Received support from our Health Information Line. This line provides Canadians living with vision loss and their families a direct avenue to ask questions and receive support. You can reach us at healthinfo@fightingblindess.ca or 1.888.626.2995
* 250 Young Leaders Program views - the program provided opportunities through webinars and a 3-day virtual summit for young people with vision loss to come together, learn, and gain new skills
* 3,000 View Point webinar views - 2020 saw the launch of our new virtual education series ‘View Point’. A total of 17 webinars were offered in 2020, featuring leading vision researchers, clinicians, and experts from across Canada! More webinars coming in 2021
* 115,000 Accessed information on our website - [fightingblindness.ca](https://www.fightingblindness.ca/get-involved/helpadvocate/) is continuously growing with valuable vision health information and the latest in research and community news. From resources to articles, we’re here to help you find the information you’re looking for
* 26,700 Received our monthly e-newsletter - The latest in FBC and vision health news right to your inbox! We were thrilled to share research updates and resources with you, and look forward to sharing more next year. [Sign up for our monthly e-newsletter](https://www.fightingblindness.ca/enewsletter/)

# **BACK COVER**

Your support helps fund amazing researchers who are creating a brighter future for Canadians living with vision loss and blindness.

To learn more and donate visit [fightingblindness.ca](https://www.fightingblindness.ca/get-involved/helpadvocate/)

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