

## Innovative Treatments in Vision Care

PG 4-5



## Balancing Safety and Sight: The Danger of Vision Loss During COVID-19

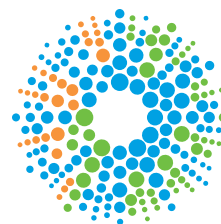
PG 3

The Best in New Vision Research

PG 6

Cycle for Sight: An Unforgettable Day

PG 7



**FIGHTING  
BLINDNESS  
CANADA**

# LETTER FROM PRESIDENT & CEO

## DOUG EARLE



Dear friends,

The last six months have not been easy for everybody. The vision loss community has been impacted significantly. While we are adapting to new ways of life, our mission to fund critical sight-saving research remains stronger than ever.

With your support, through these challenging times, FBC continues to offer hope to Canadians living with blinding eye diseases, and to our researchers so that research discoveries can become treatments.

### Changes and improvements to support the vision loss community have included:

- Making available a Health Information Line to answer questions on COVID-19 and eye health – sharing safe ways to take eye drops and what to do if a treatment has been postponed. Reach the line at **1.888.626.2995** or **healthinfo@fightingblindness.ca**.
- Developing “COVID-19 and Your Eye Health” resources, providing informative and useful tips for living with vision loss during COVID-19. Access resources at **fightingblindness.ca**.
- Going virtual for our annual Cycle for Sight fundraiser. On June 20<sup>th</sup> the event included over 550 participants from across Canada! More exciting details from this event on page 7.
- Providing live virtual health webinars through our new View Point Education Series where participants can learn and ask experts questions. Access recordings at **fightingblindness.ca/get-involved**.

We were thrilled to connect with so many of you online. The success of our virtual events and programs demonstrated our community’s need for valuable information and engagement.

This fall, we are excited to announce seven new View Point webinars and our fundraising event “Comedy from the Couch”, hosted by Steve Patterson from CBC’s The Debaters on October 17<sup>th</sup>! Reserve your virtual seat at **comicvision.ca**.

Your support helps advance new treatments and cures for blinding eye diseases. While we worked to push forward, our revenues funding critical vision research were and continue to be impacted... a \$1 million gap caused by no in-person fundraising events.

We are so grateful for the support we have received and continue to receive in unprecedented times. We could not have gotten this far without you. If you are in the position to do so, please consider making a donation to Fighting Blindness Canada (FBC) today to help improve the lives of over 1.5 million Canadians living with vision loss.

With your support, research can offer hope. For example, the first sight-restoring treatment for an inherited eye disease is being considered by Health Canada right now because of investments in research discoveries that have turned into treatments.

From all of us at FBC, we hope you and yours stay well and safe.

A handwritten signature in black ink that reads "Doug Earle". The signature is written in a cursive, flowing style.

**Doug Earle**  
President & CEO, Fighting Blindness Canada

# BALANCING SAFETY AND SIGHT

## THE DANGER OF VISION LOSS DURING COVID-19

The COVID-19 pandemic has shifted daily patterns of life for everyone, but for some the effect has been more extreme.

This may be the case for older Canadians living with blinding eye diseases such as glaucoma, wet age-related macular degeneration (wet AMD) and diabetic macular edema (DME) who require regular eye injections. For AMD and DME, these injections are called anti-VEGF treatments and they reduce the development of blood vessels that would otherwise grow uncontrollably, leading to vision loss or blindness.

Approximately 100,000 Canadians receive anti-VEGF treatments, many of them seniors living in long-term care homes. COVID-19 has provoked anxiety for this group, with some feeling that it's now necessary to weigh the danger of contracting COVID-19 against the danger of losing vision.

During the pandemic, clinicians have been prioritizing eye injections for critical cases. And to protect their patients, eye specialists are making the injection experience as safe as possible, including pre-screening patients for COVID-19 symptoms, creating space between appointments, and facilitating physical distancing in waiting rooms.

Despite these measures, clinicians are reporting that up to a third of patients continue to miss their injection visit. The ophthalmological community upholds the safety of patients—a recent joint statement from the Association of Canadian University Professors of Ophthalmology (ACUPO) and the Canadian Ophthalmological Society (COS) instructs that, “Physicians should review injection patients’ charts to see if visits can be delayed or

treatment extended based on history alone – before bringing the patient to clinic.”

In addition, many eye specialists are expressing the need for treatment options that can be injected less frequently, thereby lessening the burden placed on patients (some anti-VEGF treatments and other treatment options last longer in the eye and are administered less frequently).

In turn, Canadians with wet AMD, DME, and other eye diseases that require other injections can feel more at ease knowing their safety is a priority. We encourage Ministries of Health to raise awareness on public safety protocols to help families, communities, and health professionals feel as safe as possible around sight-saving treatments during the COVID-19 pandemic.

If you or someone you know notices sudden changes in vision, or experiences eye pain, it could be an eye emergency. It is vitally important that you contact your eye doctor or go to emergency as soon as possible.

**Let's make sure we all see each other on the other side of COVID-19.**



# INNOVATIVE TREATMENTS IN VISION CARE

FBC is receiving many questions about different innovative treatments and clinical trials. To help answer some of them, we've put together key information on gene therapy, gene editing, and cell therapy.

## GENE THERAPY



### What is It?

Genes provide the instructions that make a cell work. *Gene therapy* is a treatment where a functional copy of a gene is introduced into retinal cells to replace a gene that isn't working (i.e. mutated) or to put a new gene into the cell. In *gene editing*, molecular tools remove or block the mutation. Gene therapy should be a one-time treatment while gene editing may need multiple treatments.

### Who is It for?

Most gene therapy or editing approaches are for individuals living with genetic eye diseases, including IRDs like retinitis pigmentosa (RP) that are caused by a single mutation. However, scientists are also testing gene therapies that aren't specific to one mutation, such as putting in new genes that stop retinal cells from dying or that produce a therapy such as anti-VEGF. These gene therapies could be used for different types of retinal degeneration, including IRDs, age-related macular degeneration (AMD) and diabetic macular edema (DME).

### The Challenges

It can take a lot of time (and money!) to produce a new therapy for each gene. In addition, gene therapy or editing won't work well if the disease is advanced and retinal cells have degenerated significantly.

### Approved Treatments

Luxturna is the first sight restoring gene therapy approved for an IRD. It is available in the United States, some European countries, and is under review in Canada. It is for individuals with RP or Leber congenital amaurosis (LCA) caused by mutations in both copies of the RPE65 gene.

### Clinical Trials

Here are some of the gene therapy and editing clinical trials that are currently ongoing for IRDs. These trials have strict eligibility criteria and might only be for specific genes or even for a particular mutation.

- achromatopsia (CNGA3, CNGB3)
- choroideremia (REP1\*)
- LCA (CEP290\*, GUCY2D, RPE65)
- Leber hereditary optic neuropathy (G11778A)
- X-linked retinoschisis (RS1)
- RP (PDE6B, RHO, RPE65, RPGR, USH2A)
- Usher syndrome (Myo7A, USH2A\*, USH1C)
- X-linked RP (RPGR)

\* These trials have sites in Canada

There are also clinical trials testing if anti-VEGF gene therapies can replace injections for AMD and DME.

### Your Donations at Work

Thanks to your donations, Dr. Rob Koenekoop has been funded by FBC to understand the genetic basis of IRDs. Drawing on this research, scientists have developed gene therapies and editing approaches which are now being tested in clinical trials, including a gene editing trial in Canada for LCA10 (CEP290), with more to come!



# CELL THERAPY



## What is It?

Stem cells have the unique ability to develop into many different cell types including being able to form new retinal cells (i.e. light-sensing photoreceptor cells). In cell therapy, these new retinal cells are transplanted into the eye to replace cells that have degenerated.

## Who is It for?

Cell therapy is not gene specific and holds the promise of being able to treat many different kinds of vision loss where cells have been damaged or lost, including AMD, IRDs and glaucoma.

## The Challenges

One pressing area of research is how to get new cells to integrate into the retina so that they form the right connections with the rest of the visual machinery. This is a very complex process and is essential to ensure that the visual signals that are sent to the brain are turned into accurate images.

## Clinical Trials

Clinical trials are currently studying different cell therapy approaches for dry AMD, Stargardt disease, and RP with more on the way.

## Your Donations at Work

FBC funded researcher and chair of our Scientific Advisory Board, Dr. Michel Cayouette is studying how to increase the number of photoreceptor cells that stem cells produce in order to increase cell therapy efficiency and success.



# LUXTURNA

## Bringing Hope to Canada

With Luxturna, the first revolutionary sight restoring gene therapy for an IRD being reviewed in Canada, 2020 marks a crucial moment in the history of IRDs.

We asked community members to complete a survey on the impact of living with vision loss and the importance of treatments like Luxturna. The response was overwhelming with over 500 responses which formed the basis of FBC's submission to the Canadian Association for Drugs and Technologies in Health (CADTH), who are making a pivotal recommendation on whether or not Luxturna should be publicly funded in the fall of 2020.

Thank you for playing a role in this important work. Together, we can make new treatments for vision loss a reality in Canada.

In addition to gene and cell therapies, scientists are studying other innovative approaches to treat and cure vision loss, including using new drugs or devices and artificial implants. The future has never looked brighter with new treatments entering clinical trials every week!

To learn more about available clinical trials and how to get involved, contact our Health Information Line at **1.888.626.2995** or email [healthinfo@fightingblindness.ca](mailto:healthinfo@fightingblindness.ca).

# THE BEST IN NEW VISION RESEARCH

Every year, donors like you support FBC in funding research taking place in hospitals and universities across Canada. This research is the backbone of our community and our primary tool for identifying the causes, treatments and ultimately, cures for eye diseases.

In previous newsletters, we shared stories from four FBC funded researchers and their sight-saving work. In this edition we present the final two 2020 award recipients.



**Dr. Vincent Tropepe**  
**University of Toronto**  
**Awarded \$177,500**  
**towards understanding**  
**retinal degeneration**  
**in Usher syndrome**

Usher syndrome is a genetic degenerative disease that causes hearing and vision loss. Mutations in at least 10 genes have been linked to Usher syndrome. While scientists understand how these mutations cause hearing loss, little is known about how they lead to vision loss. Dr. Vincent Tropepe's FBC funded project will study how mutations in the *pcdh15b* gene cause vision loss in a type of Usher syndrome called USH1.

Dr. Tropepe and his team have created zebrafish with mutations in the *pcdh15b* gene (a gene affecting approximately 20% of those with USH1), and have shown that the zebrafish have retinal degeneration. Using this model, Dr. Tropepe will try to identify which molecules in the cell are affected when *pcdh15b* is mutated. This will help scientists understand how retinal degeneration is occurring and may identify potential therapeutic targets. The team will also explore if gene therapy can be used to restore vision by introducing functioning copies of the *pcdh15b* gene to replace the mutated gene.



**Dr. Susan Leat**  
**University of Waterloo**  
**Awarded \$171,300**  
**towards developing**  
**a new vision test to**  
**diagnose children earlier**

There are many causes of childhood vision loss and early diagnosis can be key to treating or saving vision. By detecting eye disease early, children stand a better chance of receiving sight-saving treatments or support that can improve their quality of life.

Currently, it is hard to accurately diagnose vision loss in children who are younger than three years old because standard tests rely on children being able to identify letters or match shapes. This means that younger children with vision loss might not be getting diagnosed early enough. Dr. Susan Leat is trying to solve this problem by developing a new eye test that is specifically for children between the ages of one and three. With this grant from FBC, Dr. Leat will study if a new test, where children pick the "odd one out" in a series of symbols or faces, is better than current tests. If successful, this will be a new cost-effective test that can be used by clinicians to achieve earlier diagnosis.

These new awards aren't the only research we fund! FBC continues to proudly support a robust research portfolio. Learn more at [fightingblindness.ca/research/fbc-funded-research](https://fightingblindness.ca/research/fbc-funded-research).

# ■ CYCLE FOR SIGHT

## An Unforgettable Day

Cycle for Sight Virtual 2020, held on June 20<sup>th</sup>, saw over 550 participants from across Canada, helping raise an astonishing \$375,000 in support of Fighting Blindness Canada.

Hundreds of vision loss community members showed their Cycle for Sight excitement in true spirit – spreading the word online daily with their family and friends leading up to event day. We can't thank everyone enough for the love and support shared during such unprecedented times. Together, you helped make the success of this virtual event possible.

Thank you to our Cycle for Sight host Ramya Amuthan, Team Canada Paralympian supporters, and interactive program leaders for volunteering their time and helping make Cycle for Sight Virtual 2020 a day to remember. Thank you to all who helped raise funds, joined us on event day, and sponsored this event. Your continuous support has helped impact the lives of over 1.5 million Canadians living with vision loss. Watch the event ceremonies and program replay at [live.cycleforsight.ca](https://live.cycleforsight.ca)



# ■ DONOR SPOTLIGHT



**Lesley  
Gedye-Stekewich**  
Pointe-Claire, Quebec

Lesley Gedye-Stekewich, a Pointe-Claire, Quebec resident and aunt to a nephew living with vision loss due to cone-rod dystrophy and retinitis pigmentosa (RP), has been an FBC annual donor since 2017. *“To support my nephew, I decided to add Fighting Blindness Canada to my annual donation list in the hopes that, with continued research, my nephew’s sight may one day be restored.”*

In particular, Lesley’s annual gift helps bring her family hope for greater advancements in stem cell therapy that will one day help her nephew and thousands living with similar eye conditions. She shares, *“My personal hope is that one day my nephew’s sight may be restored and for this reason, my donation to Fighting Blindness Canada means that I may be able to make a difference.”*

Motivated by the vision research and programs FBC supports, Lesley recently decided to also increase her gift to FBC during the COVID-19 pandemic. *“I decided to increase the amount of my donation as my modest attempt to make up for funding shortfalls during these challenging time.”*

To others considering making a gift during these difficult times Lesley expresses, *“If you feel your donation limit to be insignificant, please don’t think that way. Our collective donations together amount to an important and significant achievement.”*

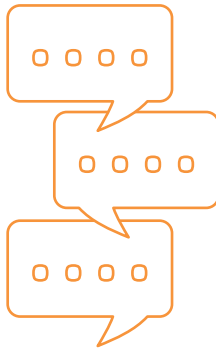
Join Lesley in helping advance new treatments and cures for blinding eye diseases by becoming a donor today! Or consider becoming a Monthly Donor to support vision research year round. To learn more, contact Ann Morrison at [amorrison@fightingblindness.ca](mailto:amorrison@fightingblindness.ca) or **1.800.461.3331 x 232.**

# COVID-19 & YOUR EYE HEALTH RESOURCES



We understand this time of uncertainty is challenging. To support the vision loss community, FBC has developed a series of resources about COVID-19 and your eye health, including a Frequently Asked Questions (FAQ) article, Protecting Your Mental Health guide, Social Distancing in the Dark webinar and more. Access the resources at [fightingblindness.ca](https://fightingblindness.ca).

# OUR HEALTH INFORMATION LINE IS HERE



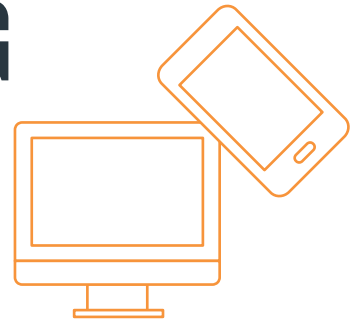
Our Health Information Line provides you with someone to connect with on vision health questions. It can be reached by phone **1.888.626.2995** or email [healthinfo@fightingblindness.ca](mailto:healthinfo@fightingblindness.ca).

## Download the AMI-tv App

Watch all of AMI's original programming, and digital exclusives, on demand by downloading the free, fully accessible AMI-tv App.

**Visit the Apple App Store today!**

# UPCOMING VIRTUAL EVENTS



## View Point Education Series

The launch of our new View Point virtual education series in April 2020 was a success, with over 1700 participants from across Canada tuning in over the spring. We are excited to offer a series of new View Point webinars starting September 10<sup>th</sup>! To register and access recordings from past webinars visit, [fightingblindness.ca/get-involved](https://fightingblindness.ca/get-involved).

## Young Leaders Virtual Program

Our Young Leaders program is a career-oriented initiative that provides individuals aged 17-30 who are blind or partially sighted with tools to develop skills and pursue rewarding careers. This fall, Young Leaders will be going virtual, offering a virtual summit October 16-18 and one fall webinar. Stay tuned for details and register at, [fightingblindness.ca/get-involved](https://fightingblindness.ca/get-involved).

## Comic Vision & Last Call Event Update

We're excited to announce that our highly anticipated Comic Vision & Last Call fundraising events have joined and will be hosted virtually on Saturday, October 17<sup>th</sup>! Comic Vision has been bringing people together since 1999, spreading hope and humour while supporting sight-saving research. COVID-19 has brought forth changes, but the hope continues. Don't miss out, reserve your "Comedy on the Couch" seat at [comicvision.ca](https://comicvision.ca).