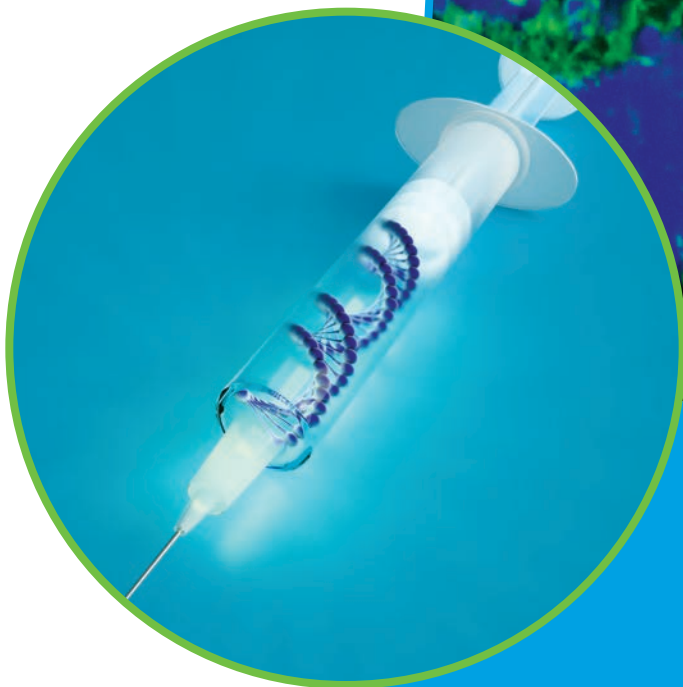
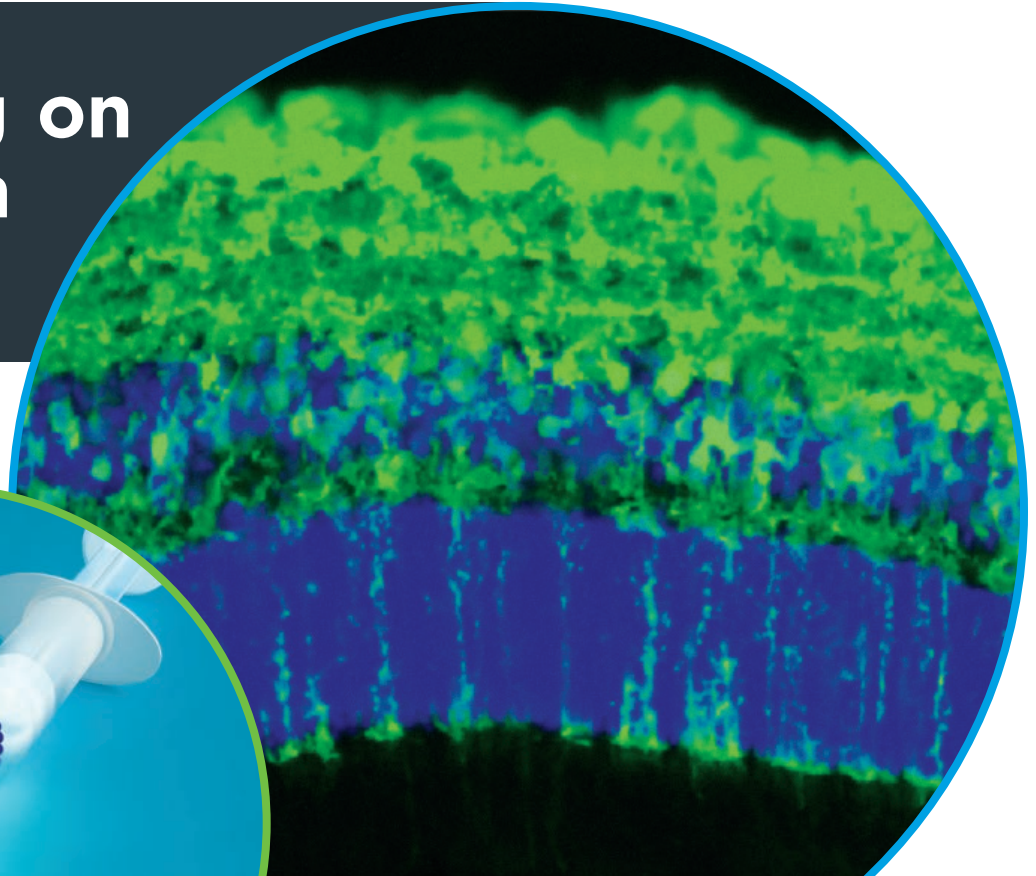


## Focusing on Research

PG 4 & 5



## Bringing the First Inherited Retinal Disease Treatment to Canada

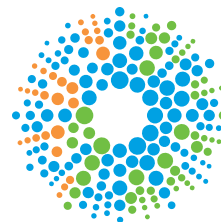
PG 6

Vision Summit 2020

PG 2

A Legacy Gift is Driving Research Forward

PG 7



**FIGHTING  
BLINDNESS  
CANADA**

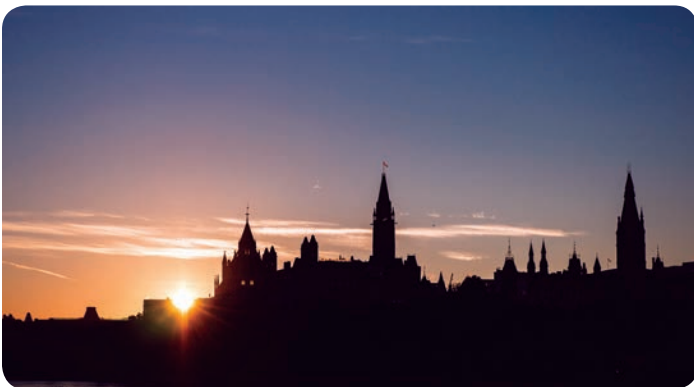
Charitable Registration Number: 119129369 RR0001

# SUMMIT 2020

**The year 2020 is symbolic for the vision loss community, presenting an opportunity to highlight shared experiences, advancements in research, and issues of equity and access to vision care.**

Finding the treatments and cures for vision loss is only one piece of the puzzle. We need to make sure that once researchers discover those treatments and cures, they fit within the broader healthcare and social landscape. We need to make sure they're accessible, affordable, and integrated with existing services and technologies for the visually impaired.

**That's why on February 12<sup>th</sup> the vision loss community came together at the Canadian Vision 2020 Summit in Ottawa.**



Hosted by Fighting Blindness Canada and Canadian Council for the Blind and in partnership with CNIB, Canadian Association of Optometrists and Canadian Ophthalmological Society, the summit was an exciting opportunity for diverse groups—patients, caregivers, clinicians, researchers, policymakers, government and more—to reflect on past achievements and create a clear vision for people with sight loss in 2020 and beyond.

Discussions spanned three themed panels: Living with Vision Loss, Vision Research and Access to Vision Health Care. These were based on white papers that were developed after consultation with the community to describe key developments and challenges facing our community. The panel discussions were an opportunity to reflect and discuss these important issues and the final version of each white paper will be released in March.

Thank you to everyone who came to the event, who participated through Facebook Live and to the many of you who shared your experience with us through our feedback surveys.

The white papers provide insights into what it means to live with vision loss, the current state of vision research, and barriers to equity and access to vision care. They will provide a foundation from which we define priorities in 2020 and beyond, and will play a central role in our discussions with government, including at our day on Parliament Hill in May, during Canada's vision month.

**You can read the white papers at: [fightingblindness.ca/whitepapers](https://fightingblindness.ca/whitepapers)**



## AMI Scores with New Programming

The coming months are exciting at AMI-tv! Look for new series *#IGotThis*, *Level Playing Field* and *Postcards From*. Dave Brown is returning to AMI-audio! On *NOW with Dave Brown*, weekdays at 9 a.m. ET on AMI-tv and AMI-audio, Dave uses community reporters and show contributors to break down the day's events and discuss them in an engaging manner. In March, AMI-tv, AMI-audio and AMI-télé team up for a truly historic event: broadcasting the 2020 Canadian National Blind Hockey Tournament championship game on TV and audio.

**Visit [AMI.ca](http://AMI.ca) for more details.**



## Bring a Bright Future into Focus with Monthly Giving!

### Join today!

Help change the lives of people living with vision loss by joining our monthly giving program.

#### For information, please contact

Josie Koumandaros

1.800.461.3331 x 262

[jkoumandaros@fightingblindness.ca](mailto:jkoumandaros@fightingblindness.ca)



## What Will Your Personal Legacy Be?

Consider leaving a gift to Fighting Blindness Canada in your Will to help future generations.

#### For information, please contact

Ann Morrison

1.800.461.3331 x 232

[amorrison@fightingblindness.ca](mailto:amorrison@fightingblindness.ca)

# NEW RESEARCH AWARDS

## KICKING OFF 2020 WITH THE BEST IN NEW VISION RESEARCH

Thanks to your generosity and our supportive community, Fighting Blindness Canada is funding six new research awards in 2020!

Last year, we expanded our mission to include all blinding eye diseases, knowing that advances made for one disease often drive innovation and new treatments for others.

We are excited to introduce the new awards to you and each issue of InVision this year will dive deeper into two of the awards. Of course, these new awards aren't the only research we fund! FBC continues to proudly support a robust research portfolio, including studies about retinitis pigmentosa and age-related macular degeneration.

Find out more about all of FBC's funded research at: [fightingblindness.ca/research/fbc-funded-research](https://fightingblindness.ca/research/fbc-funded-research)

### Dr. Vincent Tropepe

University of Toronto

\$177,500

Retinal degeneration in Usher syndrome



### Dr. Michael Walter

University of Alberta

\$216,000

Investigating the genetic cause of pigmentary glaucoma



### Dr. Susan Leat

University of Waterloo

\$171,300

Developing a new vision test to diagnose children earlier



### Dr. Gregory Borschel

The Hospital for Sick Children, Research Institute

\$300,000

Finding new treatments for blindness caused by neurotrophic keratopathy



**Fighting Blindness Canada,  
Doreen Powles Award**

**Dr. Elizabeth  
M Simpson**

University of  
British Columbia

\$296,747



“I, along with my team, am thrilled to have this opportunity to explore a new approach to treatment of childhood blindness. Its success will strengthen the foundation for a similar approach in children with genetic blindness and other genetic diseases.”

## Using gene therapy to treat congenital blindness

Aniridia is an eye disorder where the iris, the coloured part of the eye, is partially or completely absent. Individuals with aniridia usually have low vision from birth and develop glaucoma and cataracts, which can lead to blindness. Current treatments may slow the progression of aniridia, but there are currently no cures or treatments to maintain vision long term. Dr. Elizabeth M Simpson is looking to gene therapy for a possible solution. The majority of aniridia cases are caused by a mutation in the *PAX6* gene, which plays an important role in eye development. Dr. Simpson’s team will use gene therapy to put a functioning copy of the *PAX6* gene back into the eye of mice who have a mutation in *PAX6* and assess whether this improves or even restores vision. This project is an important step before the treatment can be considered for patients. Dr. Simpson’s research is taking a big leap forward in our search for a cure for aniridia and will also provide important information to help scientists working on gene therapies for other eye diseases.

**Dr. Rod  
Bremner**

Lunenfeld-Tanenbaum  
Research Institute,  
Sinai Health System

\$300,000



“We’re honored to be selected by FBC and commend their dedication to finding new treatments for blinding eye diseases. We put enormous effort into building the key elements for this project and we are delighted all the hard work has been recognized.”

## Finding new ways to treat retinitis pigmentosa

Retinitis pigmentosa is one of the most common inherited retinal diseases. People living with retinitis pigmentosa experience gradual vision loss, which is caused by the death of light sensing cells in the retina, called photoreceptors. There is currently no cure for retinitis pigmentosa, and once photoreceptor cells start to die, a person’s vision will continue to worsen. Dr. Rod Bremner is trying to change this by finding ways to stop photoreceptor cell death. His team will identify proteins that cause the cell to die and then use drugs to stop this happening, so that more photoreceptor cells survive. Previously, it could have taken months to find even one protein that could be a potential drug target. However, Dr. Bremner is using an innovative new technology that lets him study almost 800 proteins simultaneously which should increase the probability of finding a new treatment for retinitis pigmentosa.

# LUXTURNA TREATMENT ACCESS

## RESTORING VISION BECOMES A REALITY

**World's first approved targeted gene therapy is turning the dream of vision restoration into a reality.**

Luxturna (voretigene neparvovec) is the world's first approved sight restoring gene therapy. It has been available in the United States since 2017 and costs \$850,000 (US dollars) for both eyes. Recently, the National Health Service in England announced it will fund the gene therapy for an estimated 100 people starting in January 2020.

Luxturna is a treatment for people who have mutations in both copies of the RPE65 gene, which cause Leber congenital amaurosis (LCA) and retinitis pigmentosa (RP). Luxturna provides a working RPE65 gene to act in place of a mutated RPE65 gene. This working gene produces a protein that improves the visual cycle and helps the photoreceptor cells in the retina sense light.

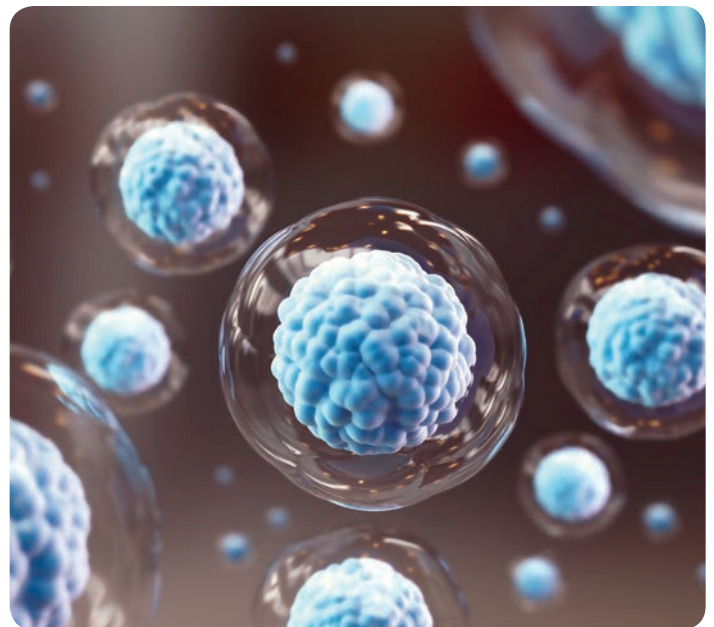
We are anticipating that Luxturna will be submitted for approval in Canada this year. It's crucial that the government understands the impact that vision loss has on individuals, families and the health care system when they are making the decision on whether or not to approve a new treatment, and whether the treatment is publicly funded. That's why FBC is funding studies that will give voice to the experience of Canadians living with inherited retinal diseases (IRDs), its impact on their lives and the cost of vision loss for individuals and society.

We are conducting this research to inform our discussions with government. The results will be the foundation of our input to the regulatory body to support both this and other innovative treatments for IRDs that are being developed.

### Transform Lives of Canadians Living with IRDs

But we need your help! One of the studies is a survey about the experience of living with an IRD to help describe the impact that new treatments could have for individuals and families. We will be sending it out in the coming months and we ask that you take the time to answer the survey and share it with your network. The more voices we have the more powerful our message.

And stay tuned for more updates and opportunities to get involved as we move through 2020 so that we can ensure that Canadians living with IRDs have access to this and future sight saving treatments.

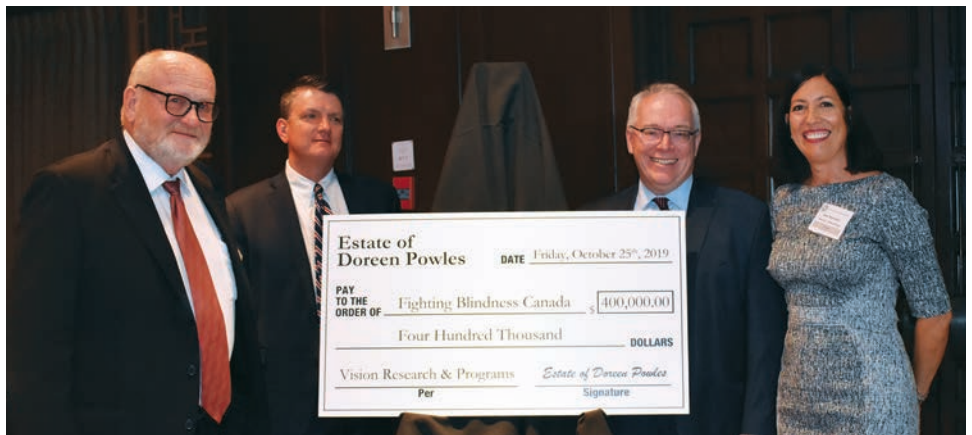


# A LEGACY GIFT TO DRIVE SIGHT-SAVING TREATMENTS

## IN HONOUR OF DOREEN POWLES



Doreen Powles



Robert Smyth (executor for Doreen's estate), Mike Seed (FBC board member), Doug Earle (FBC President & CEO), and Ann Morrison (FBC Director of Philanthropy)

Robert Smyth, executor of the estate of Doreen Powles presented a cheque to Fighting Blindness Canada in the amount of \$400,000 at a donor reception at the Calgary Petroleum Club on October 25, 2019. This generous gift will be Doreen Powles' Legacy and will fund the most promising vision research to help end blindness.

Doreen spent her life in Banff, Alberta where she lived with a blinding eye disease. Her father was a successful local businessman who went to great expense trying to find a treatment or cure that

would restore her eyesight. Despite his efforts, vision science hadn't advanced enough at that time to help Doreen. Doreen was an only child and lived in Banff until her passing on November 22, 2003. She left her entire estate to financing eye research, providing scholarships, and helping people living with blindness.

We are honoured to announce that the Fighting Blindness Canada, Doreen Powles Award has been awarded to Dr. Elizabeth M Simpson at the University of British Columbia for her project titled Using Gene Therapy to Treat Congenital Blindness.

For more about the research project named the Doreen Powles Award, see page 4

# VISION QUEST

## Age Related Vision Loss Tea & Talk

Ottawa: Tuesday, February 11, 2020

Winnipeg: Thursday, May 21, 2020

## Inherited Retinal Disease Speaker Series

Montreal: Thursday, September 10, 2020

## Saturday Symposiums

London: Saturday, April 25, 2020

Edmonton: Saturday, May 23, 2020

Toronto: Saturday, September 26, 2020

# YOUNG LEADERS

Edmonton: May 23-24, 2020

Montreal: September 12-13, 2020

Toronto: October 3-4, 2020

To learn more about Vision Quest or Young Leaders call Morgan Ineson, Officer, Research & Education at 1.800.461.3331 x 258

# GET INVOLVED

Visit [fightingblindness.ca](http://fightingblindness.ca) or call us at 1.800.461.3331 to learn more!

# EVENTS

Join an incredible nationwide community of fundraisers at one of the FBC's many events across Canada!

## Comic Vision

Comic Vision is Canada's favourite comedy fundraising tour, spreading hope and humour coast to coast since 1999. Join us in laughter and help us restore hope and sight!

[comicvision.ca](http://comicvision.ca)



## Cycle for Sight

Bring your family and friends to join hundreds of sighted, blind and partially sighted cyclists on the Perfect One-Day Ride!

[cycleforsight.ca](http://cycleforsight.ca)



## Ride for Sight

From its humble beginnings as a local fundraising event, Ride for Sight has become a great Canadian motorcycle tradition raising funds to end blindness!

[rideforsight.com](http://rideforsight.com)



## Host Your Own Event

Whether it's a pub night, a road hockey tournament or a party, we encourage you to put your unique mark on supporting vision research in Canada!

To learn more call April Watts, Senior Manager of Events at 1.800.461.3331 x 231