



**FIGHTING  
BLINDNESS  
CANADA**



## **2021 IMPACT REPORT**

# **LEADING THE FIGHT AGAINST BLINDNESS**

In 2021, Fighting Blindness Canada advanced vision research, education initiatives, and vision health resources in new and innovative ways.



# OUR MISSION

Since 1974, Fighting Blindness Canada (FBC) has funded the best, most promising vision research to advance new treatments and cures for blinding eye diseases. This investment means that today there are effective treatments that can prevent vision loss for many eye diseases. But we know there is still more to do. For many including those with inherited retinal diseases like retinitis pigmentosa, Usher syndrome or Stargardt disease there are limited, if any, treatments available. And for the 1.2 million Canadians who are living with vision loss, research is needed to restore sight.

With continued support from FBC's generous community, the future is hopeful, with new clinical trials launching every year! Accelerating investment into research is helping vision scientists drive the development of innovative treatments and cures - this ground-breaking work would not be possible without you.

**Thank you** to everyone who found a way to contribute during another challenging year.

"Vision scientists and clinicians are fortunate to have Fighting Blindness Canada, which provides essential funds for vision research to support the critical work being done to restore sight."

- Dr. Robert Koenekoop, Montreal Children's Hospital, FBC Inherited Retinal Disease Patient Registry Steering Committee member.



# FUNDING RESEARCH TO RESTORE HOPE

In 2021 we held four grant competitions to fund world-class sight-saving research. These awards support researchers who are asking bold questions to help us understand why vision loss occurs and to drive the development of new treatments. Thanks to your support, the future has never looked brighter.

## RESEARCH GRANT COMPETITION

This competition provides researchers with funding of up to \$200,000 to test innovative ideas and generate the data needed to apply for larger awards to expand the scope of their projects. Applications were due in July and we held a rigorous peer-review process in the fall. Drawing on the expertise of Canadian and international reviewers, we identified the top projects which are pushing the boundaries of vision research.

## EYE ON THE CURE AWARDS

This new competition raises funds for vision research and inspires Canadians by providing early career researchers the opportunity to compete head-to-head for research awards. Winners were selected by a panel of celebrity judges and an esteemed academy of jurors with an online event that took place in November 2021.

## RESTORE VISION 20/20 AWARDS

This \$2.5 million program aims to develop therapeutic approaches for late-stage retinitis pigmentosa. Since 2018 we have awarded \$1.75 million to four world-class researchers, Dr. Catherine Tsilfidis (Ottawa Hospital Research Institute), Dr. Philippe Monnier (Krembil Research Institute), Dr. David Gamm (University of Wisconsin) and Dr. Richard Kramer (University of California, Berkeley). In late 2021 FBC will award the remaining funding to the team that has a clear plan to move their treatment toward a clinical trial.

## CLINICIAN-SCIENTIST EMERGING LEADER AWARD (CSELA)

Clinician-scientists have research training and play an essential role in developing new sight-saving treatments. FBC's CSELA aims to strengthen the community of clinician-scientists by enabling the next generation of clinicians to incorporate research into their careers.

**We are thrilled to announce four award recipients in 2021:**

**Dr. Tina Felfeli,**  
**University of Toronto:**  
Developing a Better Way  
to Diagnose and Manage  
Non-infectious Uveitis

**Dr. Stephan Ong Tone,**  
**Sunnybrook Research  
Institute:** Testing Virus-  
mediated Gene Therapy  
to Treat Fuchs Endothelial  
Corneal Dystrophy

**Dr. Delphine Gobert,**  
**Université Laval:**  
Investigating the  
Role of Microglia in  
Diabetic Retinopathy

**Dr. Matthew Benson,**  
**University of Alberta:**  
Investigating the Effect  
of a PEX6 Mutation on  
Peroxisome Structure  
and Function



**Funding researchers and ground-breaking projects would not be possible without your support. Vision research funded by FBC supporters continues to transform the lives of millions of Canadians impacted by vision loss.**

**The following is a list of research grants FBC has funded in 2021:**

**DR. BRIAN BALLIOS**

**J. Ardeth Hill - FBC Professorship**

Improving delivery of cells for stem cell transplantation

**DR. MATTHEW BENSON**

**Clinician-Scientist Emerging Leader**

A potential therapy for an IRD that causes vision and hearing loss

**DR. GREGORY BORSCHEL**

New treatments for neurotrophic keratopathy

**DR. ROD BREMNER**

Finding new ways to treat retinitis pigmentosa

**DR. PETER CAMPOCHIARO**

Understanding how metabolism impacts photoreceptor cell survival

**DR. MICHEL CAYOUCETTE**

Finding better ways to make photoreceptor cells for cell therapy

**DR. BOB CHOW**

Inflammation and Stargardt disease

**DR. ARLENE DRACK**

New treatments for Bardet-Biedl syndrome (BBS10)

**DR. TINA FEFELI**

**Clinician-Scientist Emerging Leader**

A better way to manage non-infectious uveitis

**DR. DAVID GAMM**

**Restore Vision 20/20 Awardee**

Photoreceptor replacement in late-stage retinitis pigmentosa

**DR. DELPHINE GOBERT**

**Clinician-Scientist Emerging Leader**

The role of microglia in diabetic retinopathy

**DR. ROB KOENEKOOP**

Natural history clinical trial for Type 1C Usher syndrome

**DR. RICHARD KRAMER**

**Restore Vision 20/20 Awardee**

A "photo-switch" drug for light-sensitive cells

**DR. SUSAN LEAT**

A new vision test for young children

**DR. IAN MACDONALD**

Gene therapy clinical trial to treat choroderemia

**DR. SARAH MCFARLANE**

Studying cell movement to improve cell therapy for AMD

**DR. PHILIPPE MONNIER**

**Restore Vision 20/20 Awardee**

Promoting photoreceptor survival

**DR. ANDRAS NAGY**

**Cedric Ritchie AMD Fund**

Combined stem cells and gene therapy for AMD

**DR. STEPHAN ONG TONE**

**Clinician-Scientist Emerging Leader**

Gene therapy to treat Fuchs endothelial corneal dystrophy

**DR. JACOB RULLO**

**Clinician-Scientist Emerging Leader**

Impact of vitamin D on AMD

**DR. VINCENT TROPEPE**

Retinal degeneration in Usher syndrome

**DR. CATHERINE TSILFIDIS**

**Restore Vision 20/20 Awardee**

Blocking cell death to prevent disease progression in retinitis pigmentosa

**DR. MICHAEL WALTER**

Investigating the genetic cause of pigmentary glaucoma

**DR. TIANWEI ELLEN ZHOU**

**Clinician-Scientist Emerging Leader**

Does retinopathy of prematurity lead to long term vision loss?

"FBC was instrumental in funding my lab at a key juncture, allowing us to continue to provide salary support to talented personnel and leverage the ideas we were developing to obtain a multi-year Canadian Institutes for Health Research project grant. We would not have been successful without FBC's support. FBC has always taken a very personal approach with their researchers, an approach that has made me feel hugely supported."

- Dr. Sarah McFarlane, University of Calgary, FBC-Funded Researcher



# THE COST OF VISION LOSS

## 2021 REPORT REVEALS ANNUAL COST OF ALMOST \$33 BILLION

**The Cost of Vision Loss and Blindness in Canada Report reveals that vision loss in Canada costs almost \$33 billion annually and impacts all Canadians, including individuals, families, and governments.**

In 2021, FBC, in partnership with the Canadian Council of the Blind, the Canadian Association of Optometrists and the Canadian Ophthalmological Society, commissioned research that identified an emerging crisis of preventable blindness in Canada.

Living with vision loss negatively impacts an individual's financial health and often represents a loss of independence and reduced quality of life. As the population ages, the number of individuals living with vision loss is growing and will increasingly impact the health system and economy.

The report revealed the following costs from vision loss borne by society and individuals every year:

- **Direct health care costs: \$9.5 billion**
- **Indirect health care and other costs: \$6.1 billion**
- **Loss of well-being costs: \$17.4 billion**

Strikingly over 8 million Canadians are living with one of the four major blinding eye diseases (age-related macular degeneration, glaucoma, diabetic retinopathy and cataracts), and either have or are at risk of vision loss – this is 1 out of 5 Canadians. The report also shows 1.2 million Canadians are living with vision loss, with many facing a lack of investment in services and support.

Government leadership in this area is long overdue and despite repeated commitments there is still no national Vision Health Plan for Canada. The federal and provincial governments must ensure that the health care system can meet the growing need for eye care services including comprehensive public coverage of eye examinations to ensure early diagnosis and treatment to prevent unnecessary vision loss.

1 in 4 Canadians with vision loss, including those with inherited eye diseases like, retinitis pigmentosa, Stargardt disease, Usher syndrome or Bardet-Biedl syndrome, also live with the reality that there are few if any treatments for their eye disease and without new innovative research they face progressive vision loss.

We are calling for increased investment in research to support development of new treatments and expediting access to clinical trials and therapies all to preserve and restore sight for more Canadians. Learn more about the report findings at [StopVisionLoss.ca](https://www.stopvisionloss.ca)

**Investment in eye health is more crucial than ever as we face the impact that COVID-19 had on eye health. Due to the pandemic in 2020, there was a delay or cancellation of eye appointments, treatments and surgeries. This has led to vision loss for 1,437 Canadians and it will only get worse as wait times increase. These delays will have an estimated \$1.3 billion impact over the next three years in health care costs and lost quality of life. That is why FBC is engaging with the federal and provincial governments to advocate for essential investment in eye health in the coming years.**



“Every day, I wake up and think, ‘I’m so lucky.’ Without research delivering innovative treatments, I would be blind. In my late 50s I was diagnosed with age-related macular degeneration (AMD). Since then, I have developed glaucoma in my right eye.

I was fortunate to be diagnosed and treated early. Early detection is critical. Because I’ve been able to maintain my sight over the years, I’ve been able to keep working. My vision loss has certainly impacted my life. But I’m so grateful for the treatments to stabilize my sight and stop it from progressing to full blindness... 14 years and counting.”

- Doug Purdy



# BRINGING YOU MORE

Last year, COVID-19 forced FBC to adapt our in-person programs and events and quickly shift towards a virtual connecting space. During this time of uncertainty and chance, we listened to experiences and feedback from the vision loss community and developed even more event opportunities that were accessible for all.

## EDUCATION PROGRAMS

### VIEW POINT

Our View Point Education Series brought participants together from across Canada to hear from acclaimed vision scientists and clinicians who shared on topics like glaucoma, genetic testing, inherited retinal disease, and diabetes. Participants had the opportunity to learn and ask their pressing eye health questions. To access a list of View Point webinar recordings visit:

[fightingblindness.ca/events](https://fightingblindness.ca/events)

### YOUNG LEADERS

Our Young Leaders Program is a career-oriented initiative that provides young people who are blind or partially sighted, with tools to develop skills and pursue rewarding careers. 2021 was better than ever, with interactive webinars, two virtual summits, and a new mentorship program! Check out highlights and recordings from the program at:

[fightingblindness.ca/events](https://fightingblindness.ca/events)

## FUNDRAISING EVENTS

### TOGETHER, WE MOVED!

Cycle for Sight Virtual 2021, held on Saturday, June 19<sup>th</sup>, was an amazing success! With 560 participants joining from across Canada, we raised an astonishing \$438,000.

Thank you to all who participated, donated, and supported this event. What we accomplished this year is nothing short of amazing! FBC's 2022 Cycle for Sight fundraising event takes place in June, stay tuned for details at: [cycleforsight.ca](https://cycleforsight.ca)

### TOGETHER, WE LAUGHED!

Our virtual comedy night, Comedy from the Couch, returned on Saturday, September 25<sup>th</sup>, 2021 creating a night of comedy, in the comfort of home, presented by the laugh experts at Just For Laughs. This year, over \$98,000 was raised towards vision research with FBC's online auction contributing over \$11,000. Plans are already underway for a return to an in-person event (we hope) in Fall 2022.





# TIME = SIGHT

**FBC champions the development and delivery of safe, effective treatments for vision loss in Canada. In October 2020, Luxturna, the world's first targeted gene therapy for an eye disease was approved by Health Canada.**

However, Luxturna is currently not funded by provincial health care, putting this ground-breaking treatment out of reach for Canadians losing sight due to retinitis pigmentosa or Leber congenital amaurosis caused by mutations in the RPE65 gene.

Every week that goes by is another week of lost vision and FBC is working endlessly with the support of the vision loss community to not let a bureaucratic process slow down access to this treatment.

The next step to secure public funding of Luxturna stands with the pan-Canadian Pharmaceutical Alliance (pCPA) – the body that negotiates criteria, like drug price, on behalf of provincial governments.

But, over a year after Health Canada's approval, the negotiations haven't started yet. We need your help to make the dream of improving sight a reality for Canadians!

Learn more about our advocacy efforts and share your voice at [ApproveLuxturna.ca](https://www.approveluxturna.ca)



“Now that Luxturna is approved in Canada, they're still negotiating in terms of pricing and all the logistics around it, which is stalling the surgery for my children from happening. In the meantime their vision is gradually decreasing.”

- **Charmain Brown, Vision loss advocate and mother of Adam and Jenna who live with vision loss due to mutations in the RPE65 gene.**

“Adam and Jenna Brown have limited time before it could be too late to restore their sight. They urgently need the economic barrier that is preventing them from receiving Luxturna removed.”

- **Doug Earle, FBC President & CEO**



# LIVES IMPACTED

**1.2 MILLION**

**Canadians live with vision loss.**

**8 MILLION**

**Canadians have a vision-threatening eye disease.**

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.

**A glance at 2021 triumphs that you helped make possible...**

**1,047**

**Participated in our fundraising events**

- Cycle for Sight Virtual
- Screens off for Sight
- Ride for Sight
- Comedy from the Couch
- Eye on the Cure

**401**

**Received support from our Health Information Line**

This line provides Canadians with vision loss a way to ask questions and receive support.

It can be reached at [healthinfo@fightingblindness.ca](mailto:healthinfo@fightingblindness.ca) or **1.888.626.2995**

**530**

**Viewed FBC Young Leaders Program**

This program provided opportunities through webinars and a virtual summit for young people with vision loss to network, learn, and gain new skills.

**9,533**

**View Point webinar views**

9,533 viewed FBC's View Point webinars, featuring leading vision researchers, clinicians, and experts from across Canada! More webinars coming in 2022!

**71,229**

**Accessed information on our website**

71,229 accessed information on [fightingblindness.ca](http://fightingblindness.ca), exploring valuable vision health information and the latest in research and community news.

**33,180**

**Received our monthly e-newsletter**

33,180 received FBC's monthly e-newsletter, learning about the latest in vision health news, research updates, resources, and more.



“I can see in my lifetime the advances that have taken place. Not too long ago there was very little vision research taking place in Canada. There was no hope for those experiencing vision loss. Today, we can see advancements and our support is helping those advancements.”

**- FBC Vision Loss Community and Visionary Circle Members,  
Marilyn & Mort Ritz**





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## **1.2 MILLION CANADIANS LIVE WITH VISION LOSS**

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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](http://fightingblindness.ca)**

To access our Health Information Line,  
call or email:  
**1.888.626.2995**  
**[healthinfo@fightingblindness.ca](mailto:healthinfo@fightingblindness.ca)**

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