

**FIGHTING
BLINDNESS
CANADA**



2019 IMPACT REPORT

CREATING A BRIGHTER FUTURE

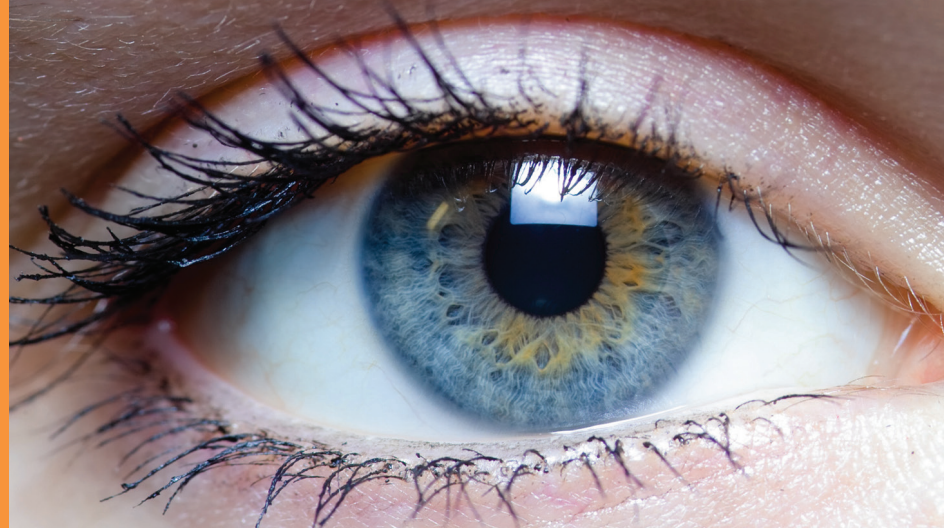
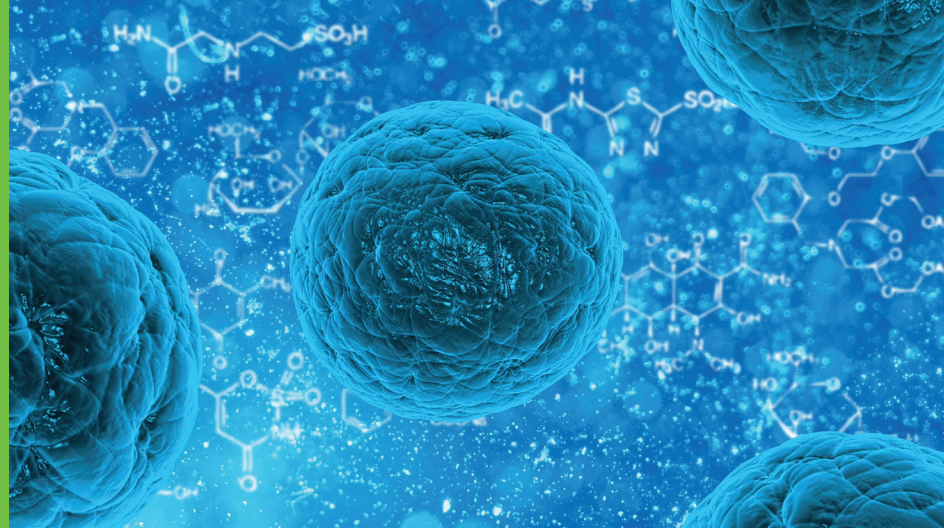
In 2019, Fighting Blindness Canada fulfilled its commitment to creating a bright future for those living with vision loss and blindness.

PRESERVE VISION

RESTORE SIGHT

EDUCATE

ADVOCATE



This report highlights the work of Fighting Blindness Canada (FBC) funded researchers to **PRESERVE VISION** and **RESTORE SIGHT**; showcases outcomes from our programs that aim to **EDUCATE** people living with blinding eye diseases and their loved ones; and demonstrates our commitment to **ADVOCATE** on behalf of our community on the issues that matter most.



PRESERVE VISION

Thanks to the generous support of our donors, who raised over \$5 million this year, our researchers are hard at work discovering ways to slow, stop or reverse vision loss, while increasing our overall understanding of why vision loss occurs.

ENHANCING OUR UNDERSTANDING OF RETINAL CIRCUITRY

Many researchers are exploring the possibility of transplanting new photoreceptors to treat **retinal degeneration**, but successful transplantation relies on properly integrating new photoreceptors with existing neural and retinal cells. **Dr. David Picketts** (Ottawa Hospital Research Institute) is exploring how to connect new photoreceptors to existing retinal circuitry, increasing the future possibility of successful photoreceptor transplantation.

STUDYING THE EYE'S SUPPORTING STRUCTURES

Age-related macular degeneration (AMD) involves the degeneration of cells in the retinal pigment epithelium (RPE), the layer of cells that nourish and support photoreceptors. By identifying how RPE cells function and pinpointing how the RPE prevents abnormal blood vessel growth, **Dr. Sarah MacFarlane** (University of Calgary) and her team are enhancing our understanding of the conditions needed for successful cell transplantation in AMD treatments.

EXPLORING THE LINK BETWEEN STOMACH AND SIGHT

When the eye begins to make too many blood vessels, it can lead to diseases like **macular degeneration** and **diabetic retinopathy**. By examining the gut microbiome of people living with wet AMD, **Dr. Sapiha** (University of Montreal) has concluded that environmental factors contribute to the abnormal growth of blood vessels in the eye. This finding holds broad implications for the development of future treatments.

THE BEST IN THE WORLD ADVISING FBC

The Association for Research in Vision and Ophthalmology (ARVO) is the international body representing over 12,000 vision researchers from over 75 countries worldwide. **This year, three out of the five ARVO international awards for vision research were awarded to members of FBC's Scientific Advisory Board (SAB)!**

RESTORE SIGHT

In August, Fighting Blindness Canada received 48 applications for our 2019 research grant competition: our largest-ever response! While our goal is to fund all meritorious projects, right now we will only be able to fund a handful. That's why every dollar counts in our fight against blindness!

PREVENTING PHOTORECEPTOR DEATH THROUGH DRUG THERAPIES

Dr. Philippe Monnier (University of Toronto) discovered that increased amounts of a particular protein in the eye triggers photoreceptor death in **retinitis pigmentosa (RP)**. By finding ways to neutralize the eye's production of that protein, Dr. Monnier and his team hope to prevent photoreceptor death—and therefore vision loss.

Gene therapy is on the verge of changing the standard of care for people living with specific blinding eye diseases.

Dr. Catherine Tsilfidis (Ottawa Hospital Research Institute) is conducting pre-clinical trials to test the safety and efficacy of XIAP* gene therapy, which promotes photoreceptor survival—a finding that could impact all blinding eye diseases.

*X-linked inhibitor of apoptosis protein.

EXAMINING RETINAL MUTATIONS

Valproic acid has been suggested as a treatment for **RP**, but **Dr. Orson Moritz** (University of British Columbia) has discovered that while it works to prevent vision loss in some forms of RP, it can worsen it in others. By looking at how underlying genetic mutations in different forms of RP affect autophagy—the cleaning out of damaged cells and regeneration of new ones—Dr. Moritz is hoping to “group” RP into categories that might require similar treatments.

TRANSPLANTING STEM CELLS TO RESTORE SIGHT

Stem cells offer an exciting possibility for the development of replacement photoreceptors for people living with **blinding eye diseases**. **Dr. David Gamm** (University of Wisconsin-Madison) is using specialized “induced pluripotent” stem cells to create replacement photoreceptor cells and RPE cells, with the objective of successfully transplanting them into the human eye.

DESIGNING PROGRAMS FOR YOUNG PEOPLE WITH VISION LOSS

Drawing on our Young Leaders Program's focus on career development, FBC is collaborating with Retina International to design a youth initiative that will be a key part of their 2020 World Congress.



EDUCATE

Did you know that 1.5 million Canadians have a seeing disability that impacts their daily life, while another 5.59 million have a disease that puts them at significant risk of losing their vision? This year, we connected with over one million Canadians to educate people on the importance of vision research and sight loss prevention.

VISION QUEST

Vision Quest, our premier educational speakers' series, brought together over 600 members of our community at events across the country! We also shared Vision Quest online: our sessions with scientists, industry leaders, genetic counselors, patient advocates, and low-vision specialists reached over 50,565 people in Canada!

YOUNG LEADERS

Thanks to the support of RBC Future Launch, FBC's Young Leaders Program was able to expand its in-person events to three national Summits, bringing together over 80 young people living with vision loss from coast to coast! This year also marked the launch of our youth-driven social campaign, #SeeMeAs, which encourages employers to challenge preconceived notions about vision loss and employment.

PATIENT REGISTRY

This year, our Patient Registry began doing what it was designed to do: connect people living with inherited retinal diseases to relevant clinical trials. We have been tracking 59 clinical trials for inherited retinal diseases over the past year. Through a strategic investment, we have enabled three of these trials to be launched in Canada this year, with more to come. By connecting eligible participants to emerging trials and studies, our Patient Registry is changing the landscape of vision research and setting the stage for future breakthroughs!

HELPING YOU ADVOCATE FOR YOUR CARE

2019 marked a new evolution in FBC's Vision Care Pathways with the launch of our dedicated Health Information Line. Now, members of FBC's community can navigate the complex world of vision healthcare with the assistance of our online resources and can phone in to our dedicated Health Information Line for counsel on advocating for their best possible care.

OPTIMIZING OUR WEBSITE

To communicate our expanded mandate to all Canadians, FBC launched a new website in April, which integrates best-in-class accessibility features, Readspeaker technology, and French language translation.



ADVOCATE

FBC invests in cutting-edge research to develop new treatments for blinding eye diseases, and we're committed to ensuring that those treatments reach the people who need them. We advocate on behalf of Canadians living with, and at risk of developing, blinding eye diseases so that treatments will be accessible and affordable across the country.

DESIGNING INNOVATIVE POLICIES

As our population ages, it's critical that we have strong policy solutions in place to meet the growing need for vision healthcare across the country. That's why FBC called for comprehensive vision health strategies in BC and Ontario, and provided six-point plans for delivering those strategies.

UNDERSTANDING THE IMPACTS OF VISION LOSS

In 2019, FBC stepped up its efforts to engage people living with vision loss through our Vision Care Pathways Surveys. These surveys will help us better understand how best to engage with our community and will enable FBC to give voice to our community in order to guide government and industry stakeholders in the development of new treatments and policies.

MAKING YOUR VOICES HEARD

FBC submitted reports on living with blinding eye diseases to government bodies including the Canadian Agency for Drugs and Technologies in Health (CADTH), the Institut national d'excellence en santé et services sociaux (INESSS), and Health Quality Ontario (HQO). We provided key insights into families' lives that will help shape future policies to access new treatments. In 2019, FBC became one of the first patient organizations to have its feedback incorporated into an official CADTH report on a treatment category for glaucoma, and was invited to present a best practices case study in patient engagement at CADTH's annual conference in Edmonton.

FROM FOUNDATION TO FIGHTER

Inspired by the impact that so many of our research investments were having on the broader sphere of vision research, our Board of Directors decided to expand our organization's research scope to include all blinding eye diseases. To communicate this expanded mission to Canadians, we changed our name from Foundation Fighting Blindness to Fighting Blindness Canada!



**FIGHTING
BLINDNESS
CANADA**

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**

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