



FIGHTING Blindness Canada



SPRING 2022 HIGHLIGHTS

Developing a stem cell therapy to restore sight. Funding the best in vision research. Sneak peak: Q&A with FBC researchers. Cathy Haverstock on why she supports FBC.

🚯 🖸 🕲 🕼 fightingblindness.ca

A Q&A WITH OUR PRESIDENT AND CEO DOUG EARLE



As the country's leading charitable funder of vision research, Fighting Blindness Canada is proud to support promising researchers who are driving the development of new treatments and cures for blinding eye diseases.

Our president and CEO Doug Earle is passionate about this mission which is providing hope to over 8 million Canadians living with an eye disease that puts them at risk of blindness. We chatted with Doug about his 2021 reflections, upcoming FBC initiatives, and his highlights from this issue of InVision.

Q: Looking back on 2021, what stands out about last year?

Despite these challenging and uncertain times, our supporters stepped up to keep vision research moving forward. We saw amazing, recording-setting results. Our inaugural vision research competition, 'Eye on the Cure presented by FYidoctors,' was a great success in funding aspiring new researchers.

2021 highlighted the fact that our work is only possible through community. From our supporters who contribute financially, to our community members who share their lived experience stories, to our team who share their talent, community is what drives our success.

Q: What are some of FBC's upcoming 2022 initiatives that you're most excited about?

I'm looking forward to participating in key summits on the topics of Preventing Blindness (February) and Vision Health Care (May). And later this year we'll be launching a new research initiative with the potential to transform vision research. Stay tuned for more information...

I invite you to keep stepping up in 2022. With your help we can remove the financial barrier to receiving Luxturna, Canada's first targeted gene therapy for an inherited retinal disease. Please visit **ApproveLuxturna.ca** to learn more about how you can support the initiative. We're also engaging with the government to urge them to fulfill their promise for a national vision health plan. In May we will be taking this message to Parliament Hill to advocate for more investments in vision research and access to new treatments. Learn more and sign the petition at **StopVisionLoss.ca**.

Q: What are your highlights in this issue of InVision?

We have some exciting new research grant winners to announce, the results of our successful \$2.5 million Restore Vision 20/20 initiative, updates on Luxturna access, and an inspiring donor story.

I hope you enjoy this issue and thank you for your continued support!

Doug Earle President & CEO, Fighting Blindness Canada

DEVELOPING A STEM CELL THERAPY TO RESTORE SIGHT

FBC is pleased to announce that Dr. Gamm and Dr. Beltran have been awarded \$725,000 to continue their ground-breaking research into cell replacement therapy for retinitis pigmentosa, an inherited retinal disease.

The Restore Vision 20/20 program was established in 2018, following a generous \$2.5 million donation from Donna Green, her mother Goldie Feldman, and an anonymous donor. Four research teams were initially awarded two years of funding to test potential therapies for retinitis pigmentosa and other forms of late-stage retinal degeneration. Based on the remarkable progress shown, FBC is now awarding two additional years of funding to the team of Drs. Gamm and Beltran.

The goal of this project is to determine if the cell replacement therapy improves vision in a canine model of advanced retinitis pigmentosa. The team is transplanting induced pluripotent stem cells (iPSCs) into the retina and testing if the iPSCs develop into new functioning photoreceptors to replace photoreceptors that are damaged or lost. Following successful completion of this pre-clinical study, the researchers aim to launch a clinical trial to test this potential treatment in humans.

Dr. David Gamm University of Wisconsin



Dr. William Beltran University of Pennsylvania



"We are truly thankful to Fighting Blindness Canada and its donors for their continuous support. During the past 3 years we have improved the production of iPSC-derived photoreceptor precursor cells, their delivery, and survival time following transplantation. These highly encouraging results now set the stage to further improve retinal integration" says Beltran.

This project has attracted interest from industry leaders. It led to a strategic alliance between Opsis Therapeutics, FUJIFILM Cellular Dynamics, and BlueRock Therapeutics, a subsidiary of Bayer AG. The alliance is a remarkable example of how FBC's funding is being leveraged to accelerate the development of a treatment from the laboratory to the clinic.

As Dr. Gamm expressed, "We are very excited to continue our effort to advance photoreceptor cell replacement therapies for a wide range of inherited retinal degenerative diseases. With FBC funding we will be able to acquire critical data in preparation for future clinical trials."



THE BEST IN CANADIAN VISION RESEARCH!

We started 2022 with the exciting announcement that FBC will be funding 8 new and innovative vision research awards!

Thanks to the generosity of our donors, we are able to fund a diverse range of projects. From optogenetics to glaucoma, age-related macular degeneration, retinitis pigmentosa, eye infections, and epidemiology, we really are funding across the spectrum of Canadian vision research perspectives.

Our appreciation goes out to the Canadian vision research community for putting forward so many bold and impactful applications. And to the researchers on our Scientific Review Panel who volunteered their time and expertise to help narrow down the strong field to these 8 projects. These projects will improve our understanding and drive the development of new treatments and cures for blinding eye diseases.

Dr. Rod Bremner

Identifying new drug targets for retinitis pigmentosa Institution: Lunenfeld Tanenbaum

Research Institute | Budget \$200,000

Dr. Bremner is trying to identify proteins that cause rod photoreceptor death in retinitis pigmentosa. The ultimate aim is to use FDA-approved drugs to block death-inducing proteins and increase photoreceptor survival. The innovative screening system could help identify new ways to reduce vision loss for many types of retinitis pigmentosa and for other types of inherited retinal diseases. Dr. Balwantray Chauhan Measuring optic nerve damage in glaucoma

Institution: Dalhousie University Budget: \$192,095



Vision loss from glaucoma is caused by the degeneration of retinal ganglion cells (RGCs) in the optic nerve. It is currently very difficult to measure RGC degeneration. Dr. Chauhan has developed a novel technique that provides more detailed images of RGCs. By identifying new biomarkers of optic nerve health, researchers can use this tool to better test the impact of new neuroprotective therapies on optic nerve regeneration.

Dr. Anna Ells

Setting up a retinopathy of prematurity treatment database

Institution: University of Calgary Budget: \$8,775

Retinopathy of prematurity is a potentially blinding eye disorder that can affect premature infants. It is one of the most common causes of vision loss in childhood. Dr. Ells' team will compile three decades of patient records into a database, allowing researchers to look for trends in how new treatments impact eye health and overall childhood development.

Dr. Julie Lefebvre

Re-wiring circuits in the retina to restore sight in retinal degenerative diseases



Institution: The Hospital for Sick Children Budget: \$200,000

The retina is made of different cell types. The death of light-sensing photoreceptor cells causes vision loss in inherited retinal diseases and other types of retinal degeneration. Dr. Lefebvre, and co-investigator Dr. Arjun Krishnaswamy (McGill University), will study if other remaining retinal cells can still receive and transmit light signals after photoreceptors die. These findings will help researchers develop better sight restoring therapies such as optogenetic and stem cell therapies.

Dr. Michael Salman

Identifying risk factors for septo-optic dysplasia and optic nerve hypoplasia



Institution: University of Manitoba Budget: \$57,171

Dr. Salman is identifying potential modifiable risk factors for septo-optic dysplasia (SOD) and optic nerve hypoplasia (ONH). These conditions are caused by small nerves in the eye and lead to vision loss in children. This research may help identify strategies to prevent the development of SOD/ONH.

Dr. Sachdev Sidhu

Testing a new treatment for age-related macular degeneration and diabetic retinopathy



Institution: University of Toronto Budget: \$200,000

Disruption of the blood retinal barrier in vascular eye diseases like age-related macular degeneration (AMD) and diabetic retinopathy (DR) can lead to vision loss. Dr. Sidhu has developed a new antibody treatment and will test if it can restore the retinal barrier in animal models of AMD and DR.

Dr. Stephan Ong Tone

Identifying unique cell types in Fuchs endothelial corneal dystrophy

Institution: Sunnybrook Research Institute Budget: \$200,000



Fuchs endothelial corneal dystrophy (FECD) causes eye pain, accumulation of fluid in the cornea, and vision loss. Dr. Ong Tone is trying to identify how endothelial cells change during FECD and which subset of cells drives disease development. This research may lead to the development of new treatments for FECD, such as regenerative cell therapy.

Dr. Ajitha Thanabalasuriar



Institution: McGill University Budget: \$200,000

Bacterial keratitis is an infection of the cornea and is common in individuals who wear contact lenses. If the infection becomes resistant to antibiotics it can cause vision loss. This research aims to understand how some bacteria can gain antibiotic resistance and how the eye's immune cells may encourage this process.

Together, let's move research forward. Learn more at: fightingblindness.ca

CELEBRATING YOUR IMPACT

Last fall, Fighting Blindness Canada launched an inspiring video showcasing the impact of your support. To celebrate, we hosted a Q&A featuring FBC-funded researchers.

Q: If you had unlimited research dollars, how would you use them?

Dr. Cayouette: Oh, there's so much that you could do. I would probably design gene therapy treatments for every gene mutation that exists. I think that this is something that is currently limited because it's very costly to develop. Another area that I would invest heavily on would be restorative therapies. There's so much more we need to understand before we can get this to patients.

Dr. Ballios: Putting on my clinical hat for a minute I would invest in establishing centres of excellence where we could engage with patients and the newest therapies. There are so many patients with genetic diseases who have not yet been able to establish a firm diagnosis for why they have a particular eye condition... so (I would invest in) a centre where there is integrated model of care which is uncommon in ophthalmology.

Dr. Michel Cayouette Montreal Clinical Research Institute



Dr. Brian Ballios Krembil Research Institute



You can watch the full event at: fightingblindness.ca/about-us/your-impact

Q: Research never happens in isolation. What other researchers are you cooperating with around the world?

Dr. Cayouette: Well, in normal times we go to meetings, and we talk to each other a lot! Listening to other people presenting their results, but also at the coffee lines, trying to see if there would be a possibility for collaboration. We also see what is happening around the world when people publish their results in peer-reviewed journals. There is a lot of collegiality in the field. Especially in vision research. We are a relatively small community, so we tend to stick together a lot and help each other.

Gene Therapy Access Update

Canadians are one step closer to gaining access to the gene therapy Luxturna, but we're not there yet. On November 25, 2021, provincial governments launched price negotiations for the therapy for retinitis pigmentosa and Leber congenital amaurosis caused by RPE65 mutations. With many losing vision every day, we are encouraging Canadians to keep the pressure on governments to speed up negotiations and agree to fund this treatment.

Lend your voice by sending an email to your Premier and Health Minister at **ApproveLuxturna.ca**. Stay tuned for updates on this precedence-setting treatment.

A LETTER TO FIGHTING BLINDNESS CANADA

After many years of reading personal stories of those living with vision loss, I find it is my turn to share how my husband and I decided to fund Fighting Blindness Canada's (FBC's) research program through estate planning.

Our interest in vision research began when our family was young and I was diagnosed with retinitis pigmentosa (RP). It was not entirely a surprise because my mother had RP; however, it was shocking to hear my doctor say "You will be blind in 2 - 3 years."

But I put the diagnosis behind me and continued with my life, raising three children with my husband, Greg, and working full time. When the effects of RP became more significant in middle age, it was Greg who encouraged me to become involved with FBC and I signed on to FBC's Inherited Retinal Disease Patient Registry, received genetic testing, attended conferences (now called View Point), read the newsletters and joined in fund raising.

I learned that my sister and one of my children also had RP and it became increasingly important to think optimistically, that yes, someday, researchers will find treatments to restore sight or limit its loss. And so we did. Regular monthly donations and later gifting of stocks was our way of supporting vision research with FBC.

I was coping with my vision loss and into our busy retirement years when life changed suddenly in 2018. Greg was diagnosed with a terminal illness. It is difficult for me to recall this time, the few years we had left and the restrictions of the pandemic. So, I will direct my thoughts to the purpose of this letter, how we considered our most recent donation.

As a thoughtful and practical man, Greg was committed to environmental work and medical research. He made FBC the beneficiary of an insurance policy and in his Will, donated a percentage of his estate to FBC. Looking back, it was an easy decision. Simply said, it added meaning to our lives. By making an estate donation, we were able to imagine a more hopeful future for our family and for all those others with vision loss. I know many of you will feel the same.

Cathy Havenstock

Cathy Haverstock, October 2021

Cathy and Greg Haverstock

Bring a Bright Future into Focus with Monthly Giving

Help change the lives of people living with vision loss by joining our monthly giving program. For information, contact Josie Koumandaros 1.800.461.3331 x 262 jkoumandaros@fightingblindness.ca

FBC EVENTS IN 2022

SCREENS OFF FOR SIGHT

Accept the challenge

Give your eyes a break and turn off your screens for 24 hours on March 19 at 6 p.m. For more information and to accept the challenge visit **fbcscreensoff.ca**.

CYCLE FOR SIGHT

Move vision research forward

Move with us and raise funds for sight-saving research by joining an in-person Cycle for Sight event this summer. We're bringing back the perfect one-day ride to a location near you. Or participate in our Virtual Cycle for Sight! Hop on a bike, grab your yoga mat, or choose your favourite physical activity to join in. Register today at **cycleforsight.ca**.

RIDE FOR SIGHT

The ride that started them all

The great Canadian tradition of motorcyclists fighting blindness continues. We are back to in-person rides! It's an exciting time for vision research – saddle up and Ride for Sight... because you can! Register now at **rideforsight.ca**.

VIEW POINT

The latest in vision research

Join us to learn from vision health experts and researchers. This year we are planning both online and in person events. Learn more and register at **fightingblindness.ca/events**.







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!