INVISION SUMMER 2022 NEWSLETTER

# A Message from our president and CEO Doug Earle

Dear friends, In this edition of InVision, we’re sharing some of the work that your support has made possible, highlighting our new FBC-funded research grants and advances in age-related macular degeneration (AMD) research. You’ll also find a personal story from a Quebec man who benefited from a sight-saving clinical trial, and an in memoriam to a dear friend of FBC’s. I hope you enjoy.

I’d also like to share some of the latest initiatives that took place during May Vision Health Month, to advance vision health research, make more treatments accessible to Canadians and prevent vision loss.

This year, FBC was back on Parliament Hill with the vision loss community top of mind. Along with our vision health partners, FBC has been advocating the federal government to fulfill its promise of creating a National Vision Health Plan. Canada is experiencing a crisis of preventable blindness. Over 8 million Canadians are currently at risk of blindness, with this number expected to rise to 13.9 million by 2050. This has only been made worse by the pandemic. Together we can, and must, stop this crisis. Please visit [**stopvisionloss.ca**](http://www.approveluxturna.ca/) to sign the petition advocating for a National Vision Health Plan.

With your support, FBC is also championing the need for increased investment in vision research to address our country’s vision health care challenges. Our Cost of Vision Loss and Blindness in Canada report shows that government funding agencies are spending only $21 million on vision research annually – a paltry amount given the billion-dollar plus budget of the Canadian Institutes of Health Research, and the $32.9 billion social and economic impact that vision loss has on Canada each year. As government’s investment is lacking, our community’s support is more critical than ever.

Because of your commitment, FBC was able to play an important role in getting the world’s first gene therapy for a blinding eye disease, Luxturna, approved by Health Canada. Unfortunately, it’s still not publicly-funded. Please visit [**approveluxturna.ca**](http://www.approveluxturna.ca/) to send an email to your Premier and Health Minister urging them to expedite access to Luxturna today. Thank you for lending your voice to ensure that more Canadians have access to sight-saving treatments.

Doug Earle

President and CEO,

Fighting Blindness Canada

# Your Support In Action

In 2019, we expanded our focus from retinal diseases to include all blinding eye diseases. Today, as we reflect on the research we are funding, it’s clear that your generosity has allowed us to fund discoveries that will touch even more Canadians while not diminishing our support for retinal research.

Thanks to our donors, this year we are investing over $2.6 million in 34 research projects. From Vancouver to Halifax, FBC-funded scientists are driving innovative research forward. Without you, this would not be possible. The image below shows the vision research your generosity is supporting

# Advances in AMD Research

Highlights from View Point

In February, over 240 community members tuned in to our View Point webinar to learn about age related macular degeneration (AMD). Here are some highlights from the expert panel.

## Geographic atrophy: Dr. Peter Kertes, Sunnybrook Health Sciences Centre

### What is geographic atrophy?

There are two forms of AMD: wet and dry. With the dry form most people have minimal symptoms, but some can develop severe vision loss with a condition called geographic atrophy.

In geographic atrophy, the layer under the retina called the retinal pigment epithelium (RPE) begins to wear out. Photoreceptors rely on this layer for nutrition and when the RPE disappears, photoreceptors die and ultimately cause vision loss

### Are there any treatments for geographic atrophy?

Currently there are no approved treatments for dry AMD or geographic atrophy [but] there are new treatments being developed in the lab and in clinical trials.

In geographic atrophy the immune system goes awry and causes damage to the central retina. There are some drugs in development that will block this immune reaction and hopefully slow the progression of dry AMD. This treatment is not yet approved in Canada or the US but we anticipate approval soon.

Stem cell therapy also shows promise for the treatment of geographic atrophy. In these therapies, cells that have died will be replaced and this may be able to not only stop the progression of the disease, but also restore some vision. However, these treatments are some years off from being available to patients.

## A potential antibody treatment for wet AMD: Dr. Levi Blazer, University of Toronto

Fighting Blindness Canada recently awarded Dr. Sachdev Sidhu a research grant to support development of a potential new treatment for wet AMD. Dr. Blazer, a member of the Sidhu lab joined us to discuss the project.

### What is the blood-retinal barrier and why is it important in AMD?

The blood retinal barrier is a system that protects the sensitive cells in the eye from substances that circulate in the blood. It is a series of tightly connected cells that only allow certain molecules through. For example, they control the amount of water in the eye to help maintain eye pressure. In wet AMD, the blood retinal barrier can break down and lead to damage to the retina and vision loss.

### What is an antibody and why are you looking at these to develop new treatments?

Antibodies are a type of protein that are made by our immune system. These proteins travel around the body and identify things that shouldn’t be there, like bacteria. When they find an intruder, they bind to it and signal the immune system to remove it.

We have engineered antibodies that do not interact with intruders but instead bind to other cells. We are testing antibodies that can bind to cells in the blood retinal barrier. The antibodies activate these cells to repair the barrier. Antibodies are incredibly specific in recognizing proteins in the body in a way that most drugs are unable to do.

## Introduction to biosimilars: Dr. Bernard Hurley, University of Ottawa Eye Institute

### What are biosimilars?

To understand biosimilars we can compare them to generic drugs. Common medications like Tylenol are made up of simple molecules. Because these drugs are relatively simple, another company can copy the recipe, and make an exact replica of the drug, which we call a generic.

There is another category of drugs called biologics, and these contain larger, more complex molecules. These drugs cannot be simply put together by combining ingredients, but instead rely on a biological system to synthesize the drug. Biosimilars are copies of biologic drugs. Because the systems that make biologics and biosimilars are complex, there may be tiny differences between the original biologic and the biosimilar “copy.”

Therefore, biosimilars are not exactly identical (to biologics) but have the same effect in the body.

### How do you expect the introduction of biosimilars to impact people living with AMD?

The anti-VEGF drugs that are used to treat wet AMD are biologics. The first anti-VEGF biosimilars are likely to be approved for use within the year in Canada. The clinical trial data from these drugs demonstrate that they are molecularly similar and work the same way as the traditional biologics.

Like generics, biosimilars will provide a less costly alternative to traditional biologic drugs and they could represent a huge cost savings to the [healthcare] system. The overall concept of having options for medications is positive, but it will depend on how they are implemented within the system.

To learn more about View Point and watch past recordings, visit [**fightingblindness.ca/events/virtual-events**](https://www.fightingblindness.ca/events/virtual-events/)

# Access to Sight-Saving Clinical Trials

FBC community member Pierre Langlois shares on clinical trials

“When I became officially blind at age 32, it changed my life completely. The life I had planned for myself disappeared. I had studied in trade school as a machinist and mechanic and worked on repairing airplane engines and machines in my younger years. But to be a mechanic, you need good eyes.

Ever since my vision began to deteriorate, I’ve had a keen interest in research on genetic eye diseases. By the age of 64, I’d given up hope of ever getting to benefit from any such innovations. But I was lucky, and I was chosen for a clinical trial on choroideremia thanks to Dr. Robert Koenekoop.

Through this study, I had a sight-restoring operation. After the operation, I noticed with great emotion that I could see things that I couldn’t before. At the hair salon, I noticed the barber’s pole, with its rotating blue, red, and white stripes. I could suddenly see the dark green of the grass, and the twinkling Christmas lights that I install outside every year.

I have four children and six grandchildren, who I’m very proud of. My children didn’t inherit my disease but my two daughters carry the gene, and one of them passed the gene to both of her two sons. This is part of why research is so important to me, and why I agreed to participate in the clinical study. I do it for myself, for my grandsons, and because I believe in it. I’m also convinced that research into these gene therapies for the eyes will prove useful for research on other genetic diseases.”

Pierre Langlois

# Remembering Sam Zunder

The late Sam Zunder, who passed away peacefully on February 12, 2022, at the age of 95, was a pillar of his community and a dear friend of Fighting Blindness Canada (FBC).

Sam and his beloved wife, Sandra, were long-time supporters of FBC. In his mid-twenties, Sam was diagnosed with retinitis pigmentosa, which eventually took his vision. As a result, he and Sandra became very involved with the Retinitis Pigmentosa Foundation of Canada (now FBC). Sandra was the secretary of the Ottawa Gatineau Chapter, which Sam co-created in 1970, and Sam also served on the Foundation’s National Board, from 1982 to 2004.

Sam and Sandra were also generous FBC donors and long-time fundraisers. Sam helped his son Philip fundraise annually for Cycle for Sight Ottawa, reaching out to everyone in his retirement home for their support.

Sam will be remembered as a community-oriented gentleman who cherished his relationships. Together with his siblings, Sam owned and operated Zunder Fruitland – a fixture in Ottawa, where he was born and raised. A proud member of the Ottawa Jewish community, he was a regular participant at Shabbat services at Agudath Israel (now Kehillat Beth Israel) and a long-time member of the Jewish Community Centre, where he used the gym. Everywhere he went, Sam loved meeting and talking to people, and he always had a story or joke at the ready.

In fact, Sam’s sense of humour was legendary. As his son Philip recalls “When he was being prepped for quadruple bypass surgery, the surgeon told him that he should be able to drive in six to eight weeks. He said to the surgeon, ‘Had I known that sooner, I would have had the operation a long time ago!’ Of course, the surgeon hadn’t realized that Sam was blind.”

Described by colleagues as a force of nature infused with optimism and curiosity, Sam made an impact on those he met, personally and professionally.

“Sam was just so much fun and brought joy to everyone he encountered,” says Sharon Colle, the former president and CEO of FBC. “He was tenacious, loved his family, and built his community. We treasured his support and advice at FBC. There’s no doubt that when treatments and cures for blinding diseases are found, Sam, with Sandra, will share in that lasting legacy. He was a great man and we are terribly saddened by his loss.”

# FBC Events in 2022

## Cycle for Sight

Together, let’s move!

Join us virtually or in-person! We’ll be gearing up in-person in the following cities...

MOVE with us and raise funds for sight-saving research by joining an in-person Cycle for Sight event near you or virtually. Hop on a bike at an event or on your own, grab your yoga mat, unwind the skipping rope, or choose your favorite physical activity. Join in the fun and help us MOVE vision research forward. Register at [**cycleforsight.ca**](http://cycleforsight.ca/).

**West Coast, Langley, BC** – June 11

**Toronto, Alliston, ON** – June 18

**Newfoundland/Labrador, Mount Pearl, NFLD** – July 10

**Virtual Event** – June 18

## 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! Learn more and register at [**rideforsight.ca**](http://rideforsight.ca/).

## Comic Vision

Share the laughter, see the hope

The laughter returns to in-person Comic Vision events this Fall. Save the date for our Toronto event, **October 27** with special guest, Rick Mercer. In Vancouver this November, we’ll bring back the laughs all in support of vision research.

Learn more and email us to reserve your spot at [**comicvision.ca**](http://comicvision.ca/) [**mcomicvision@fightingblindness.ca**](mailto:mcomicvision@fightingblindness.ca)**.**

## View Point

The latest in vision research

Join us to learn from vision health experts and researchers on topics including age-related macular degeneration, glaucoma, inherited retinal diseases, innovative therapies and more. This year we are planning both online and in person events. Save the date for our in person Toronto event**, October 2, 2022.**

Learn more and register at [**fightingblindness.ca/events**](http://fightingblindness.ca/events)