**FIGHTING BLINDNESS CANADA SPRING INVISION 2024**

# **HIGHLIGHTS**

* Thank You for 50 Years of Advancing Vision Research.
* Clinician-Scientist Emerging Leader Award Winners.
* Ask the Expert: All About AMD.

# **A MESSAGE FROM OUR DIRECTOR OF RESEARCH, LARISSA MONIZ**

Dear friend of Fighting Blindness Canada,

Welcome to the spring edition of our InVision newsletter! We are excited to share how you are helping Fighting Blindness Canada (FBC) move critical vision research forward, and stories from dedicated community members like Ginny Duff, whose parents helped establish the organization in 1974 and FBC Young Leader Ali Usman, who shares his journey to using a white cane.

On pages 4 and 5, you’ll also learn how your support has provided crucial seed funding and grants to early career researchers who are working towards new discoveries in areas like genetic eye diseases, stem cell therapy, and drug development. And on page 6, in our feature ‘Ask an Expert’ article, retinal specialist

Dr. Bernie Hurley answers common questions surrounding age-related macular degeneration.

I hope you enjoy the information and stories shared in the newsletter and see the difference you are making. Because of your support, more than 1.2 million Canadians living with vision loss have hope for a brighter future.

Sincerely,

Larissa Moniz, PhD - Director, Research and Mission Programs, Fighting Blindness Canada.

# **THANK YOU FOR 50 YEARS OF ADVANCING VISION RESEARCH**



Together we’ve raised over $45 million towards sight-saving research and education. As we enter our 50th anniversary, we pay tribute to the families and community members who helped establish Fighting Blindness Canada (FBC).

Ginny Duff lives with vision loss caused by retinitis pigmentosa (RP). Her parents Grant and Jean Duff were among the founding members of the organization in 1974. Ginny shares with us her journey and how FBC has laid the groundwork for a bright and hopeful future.

“In the late 1960's my parents Grant and Jean met another couple, Jay and Malca Marin, whose son also lives with RP. The Marins were on a mission to support sight-saving research and my parents immediately got on board for what would become FBC. Working with the Marins, my parents organized a retreat for scientists in the hope that they would develop a network of experts interested in vision research. This event was the start of something significant, connecting many top field experts from across North America.

This event led to many others and importantly, connected families in need of support and resources. Admittedly, at first, I didn’t have hope of a cure but interaction with others helped me think about where vision science was going, and I began to feel like I was part of a bigger family.

My dad got me involved with the organization’s Board when I was a young adult, and I had the opportunity to meet people who were not crushed by their vision loss. This was inspiring. I was asked to speak at a conference in 1989, here I learned that I had something to give and have continued to speak at events since.

What do I want for the future of vision research? A cure would be nice, of course. Continuing to support those impacted by vision loss with resources is also invaluable… people need a place to turn to for credible eye disease information and hope for a brighter future.” **— Virginia (Ginny) Duff**

Thank you Ginny for your support and dedication over the years! You’ve provided decades of valuable help to those who need it most.

Throughout the year, we will be sharing stories of inspirational FBC community members and how they’ve shaped the future of vision research. For more stories, research news, and eye health information, visit [fightingblindness.ca](https://www.fightingblindness.ca/research/fbc-funded-research/)

# **YOU’RE HELPING FUND THE FUTURE OF VISION RESEARCH**

Thanks to you, throughout our history, Fighting Blindness Canada has played a pivotal role in launching the careers of many members of the vision research community in Canada. Your support has provided crucial funding and grants to early career researchers who are now preeminent experts in areas like genetic eye diseases, stem cell therapy, and drug development.

As we enter our 50-year anniversary, we shine a light on some of our recent awardees who represent the future of vision research.

## **2023 CLINICIAN-SCIENTIST EMERGING LEADER AWARD WINNERS**

Clinician-scientists can translate laboratory research into the clinic and help bring clinical trials to

Canadian patients.

**Ehsan Misaghi - University of Alberta - Understanding the genetic cause of a rare inherited retinal disease.**

“I have always been passionate about pursuing a career as a clinician-scientist-innovator in order to close the gap between bench research and clinical practice. My heartfelt thanks to Fighting Blindness Canada for their support through the Clinician-Scientist Emerging Leader Award, which will help chart my path toward ensuring individuals facing blinding diseases have access to innovative treatments.”

— Ehsan Misaghi,

**Dr. Matthew Quinn - Ottawa Hospital Research Institute - Exploring a link between the microbiome and age related macular degeneration.**

“It is critical to understand the links between systemic health and vision loss in order to develop new treatments and optimize care. This award will fund research that will allow us to better characterize how systemic health events impact risk of macular degeneration progression.” — Dr. Matthew Quinn

**Dr. Jovi Wong - University of Toronto - Does optic nerve damage disrupt sleep?**

“Clinician-scientists provide an essential perspective from having been fully trained clinicians and scientists, therefore understanding the gaps in the field through lived experience as a clinician, and how to develop the best scientific approach to address those gaps.” — Dr. Jovi Wong

## **EYE ON THE CURE RESEARCH AWARDS COMPETITION**

Our 3rd annual Eye on the Cure competition was launched on November 16th, 2023. Viewers across Canada watched as five early career vision research finalists went head-to-head to showcase their projects for the chance to win up to $80,000 in awards. In addition to raising awareness of vision health, viewers were invited to vote for the project that inspired them the most. Five prizes were awarded and the top two prizes went to:

* Dr. Kirill Zaslavsky - University of Toronto - Using AI to understand the immune system’s role in inflammatory eye disease. - FYidoctors Research to Watch Award
* Dr. Qianqian Wang & Dr. Jiaru Liu - University of Montreal - Can insulin restore vision in glaucoma, a Phase 2 trial. Heathbridge Capital People’s Choice Award

**Watch the show at:** [**fbceyeonthecure.ca**](https://www.fbceyeonthecure.ca/)

Today’s young researchers are curious, ambitious, and skilled. We want to ensure that they can establish their careers in vision research. Therefore, in 2024, we are launching two grant competitions that have been made possible because of supporters like you. We are excited to share results of the competitions later this year. Learn more about the research we fund at [fightingblindness.ca/research](https://www.fightingblindness.ca/research/fbc-funded-research/)

# **ASK THE EXPERT: ALL ABOUT AMD**

Age-related macular degeneration (AMD) is the leading cause of vision loss in people over the age of 55, affecting approximately 2.5 million Canadians. There are two kinds of AMD: dry AMD and wet AMD which can impact central vision. Recently, Dr. Bernie Hurley, a retinal specialist from Ottawa, Ontario, joined us live at one of our View Point education webinars to answer audience questions about AMD. Below are top questions that came out of the session…

**Q 1. I receive anti-VEGF injections for my wet AMD. Will I ever be able to stop getting these treatments?**

Anti-VEGF medicines help stop the growth of extra blood vessels at the back of the eye that leak and cause vision loss in wet AMD. Once you start injections, your doctor may be able to gradually increase the interval between injections. Once I get my patients to 12-16 weeks between injections, we can sometimes stop the treatment. However, there is a risk that it will come back. We want to ensure that the disease is totally suppressed and stable before stopping treatment.

**Q 2. Is it common to experience pain in the eye following an injection?**

You will receive anesthetic to prevent pain, and only feel some pressure. We also put anti-septic on the eye that may cause irritation. For this, using an artificial tear drop can be recommended.

**Q 3. What medications can be used for people who have dry AMD?**

There's a new class of medications coming out called complement suppressors (given by injection inside the eye). These have been shown to slow the rate of dry macular degeneration and geographic atrophy progression. They are currently available in the United States, but not yet in Canada.

**Q 4. What can I do between appointments to monitor my vision?**

We can control AMD, but not cure it. We can suppress fluid production, but sometimes those cells continue to atrophy. Something you can use at home to see if there are any new distortions in your vision is an Amsler Grid. If your vision gets worse, you need to see your eye doctor.

**Learn more about AMD and other eye diseases on our website at:** [**fightingblindness.ca/eyehealth**](https://www.fightingblindness.ca/eyehealth/)

# **A WHITE CANE STORY: FEATURING ALI USMAN**

Ali Usman attended our Young Leaders Calgary program in May 2023 to connect and learn from other young adults living with vision loss. Ali lives with retinitis pigmentosa (RP), and is a scientist pursuing a PhD in experimental physics. We connected with Ali to learn more about his vision loss and white cane journey.

**When were you diagnosed with RP? How did the loss of vision make you feel?**

Over the years, my vision slowly deteriorated, eventually leading to the diagnosis of RP in 2021. This occurred during a challenging period, compounded by the geographical distance from my family and the peak of the global pandemic. The diagnosis triggered deep feelings of depression, stress, and anxiety. Navigating the challenges was made even more difficult by a profound sense of isolation, as I started this journey without knowing others facing similar struggles.

**Before using one, what were your thoughts about using a white cane?**

Following my diagnosis, I embarked on learning accessible lifestyle techniques. However, from the early stages of my vision loss, a persistent fear loomed—the fear of appearing visibly disabled to those around me. This apprehension, fueled by cultural stigma and past unpleasant experiences during disclosure, contributed to my hesitancy in adopting a white cane. The white cane represented a tangible symbol of my disability, and my concerns were rooted in how others might perceive and interact with me.

**What sparked your interest in using a white cane?**

The pivotal moment that ignited my interest in trying out a white cane emerged from a transformative experience at FBC’s Young Leaders Calgary Summit in 2023. Meeting people from diverse cultures, age groups, and professional backgrounds—all navigating limited or no vision—had a profound impact. The majority were white cane users. Through conversations with these individuals, I underwent a shift in perspective, recognizing that my vision impairment bestowed unique strengths. This realization prompted a newfound confidence, leading me to embrace my vision impairment openly. Motivated by this transformation, I began using a white cane.

**How has using the cane helped?**

The inclusion of a white cane in my daily life has been transformative, especially in travel and busy settings. It allows me to navigate confidently and enhances my limited vision. Crucially, it has altered people's reactions, fostering increased consideration in crowded spaces. Acting as a social cue, the cane prompts assistance without explicit disclosure of my vision impairment. This newfound independence and confidence has empowered me to travel solo across four continents, eight countries, and over a dozen cities, all facilitated by the invaluable support of my white cane.

# **JOIN US AT VIEW POINT THIS SPRING**

SATURDAY, APRIL 20, 2024

1 – 6:30 p.m.

Robert H. Lee Alumni Centre, University of British Columbia.

Free to attend live and virtually!

Fighting Blindness Canada presents VIEW POINT, an educational conference bringing you the latest information in vision health and research. Hear from experts, connect with others affected by vision loss, and visit our exhibitors to learn about new resources.

## **FEATURE SESSIONS**

* A keynote on gene therapy from Dr. Paul Yang, Casey Eye Institute
* Ask the Expert sessions on age-related macular degeneration and inherited retinal diseases
* A Young Leaders session for youth aged 15 to 35 impacted by vision loss
* A panel about living well with vision loss

This event will include an exhibitor fair and a social hour! For full program details and to watch recordings of past VIEW POINT events, visit, [fightingblindness.ca/viewpoint](https://www.fightingblindness.ca/viewpoint/)

## **Ad:**

Our Health Information Line is here to help. Do you have an eye health related question? Contact our Health Information line at [healthinfo@fightingblindness.ca](mailto:healthinfo@fightingblindness.ca) or call 1.888.626.2995

## **Ad:**

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

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