



## FALL 2022 HIGHLIGHTS

Remembering Sonia Labatt.

The future of vision research is bright!

Canadians begin receiving sight-saving gene therapy.

Never too young... to Cycle for Sight!

# A MESSAGE FROM OUR PRESIDENT AND CEO DOUG EARLE



Dear friends,

I hope the summer has been a time of recharging and reconnecting for you and your families. Here at Fighting Blindness Canada (FBC), we are gearing up for an exciting season of in-person events and new opportunities to share the power of vision research with you and our entire community.

With one in five Canadians at risk of losing their sight, your support is more important than ever. I'm pleased to share that on June 14<sup>th</sup>, the Hon. Judy Sgro, Member of Parliament for Humber River-Black Creek, introduced Bill C-284, "An Act to establish a national strategy for eye care." The Bill calls for a national strategy to support the prevention and treatment of eye disease. The strategy aims to improve health outcomes for the over eight million Canadians living with an eye disease that puts them at risk of blindness. Along with our vision health partners, FBC will work to build on the momentum to make a National Strategy for Eye Care a reality. Please join us by writing to your MP to encourage them to support this Bill.



In this edition of InVision, you'll find the story of twin boys from Brampton, Ontario, who are now able to see the stars after receiving a gene therapy treatment called Luxturna. Three Canadians have received this transformational treatment so far with the support of workplace benefits but bureaucratic delays are creating two-tier health care. We continue to push for this sight-saving treatment to be publicly funded by the provinces to bring hope to the over 40 people on this treatments wait list. Please visit [ApproveLuxturna.ca](https://www.approveluxturna.ca) to send a letter to your Premier and MPP to make Luxturna accessible to those who are still waiting.

I hope you enjoy our announcement of the new FBC Clinician-Scientist Emerging Leader Award recipients. We are proud to fund three more exceptional individuals who are truly the future of vision research. And finally, we fondly look back at the life of Sonia Labatt, who was one of FBC's strongest supporters over the past 20 years. We have been humbled to be the recipient of her kindness and generosity, and want to recognize her and her family's incredible contributions to fight blindness.

From the entire FBC team, thank you for your unfailing support. You make our work possible.

Doug Earle

A handwritten signature in black ink that reads "Doug Earle". The signature is written in a cursive, flowing style.

**Doug Earle**  
President & CEO,  
Fighting Blindness Canada

# REMEMBERING SONIA LABATT

## An Inspiring Supporter Of Fighting Blindness Canada

Sonia Labatt's energy and passion were contagious. A major contributor to Fighting Blindness Canada (FBC), Sonia, along with her husband Arthur, made history with their generosity and in so doing, positively affected the health of thousands of children. Sonia passed away in March 2022 at the age of 84, and she will be sorely missed.

One in three Canadians know someone who is living with vision loss. Sonia personally experienced an eye health issue and witnessed the challenges that others with vision loss face. In 2005, Sonia met 11-year-old Gavin Morrison, the son of FBC's Director of Philanthropy, Ann Morrison. Gavin was diagnosed with a degenerative eye disease as a young child and lives with vision loss. This meeting had a profound impact on Sonia. As a result, Sonia and Arthur made a historic, precedent-setting, and extremely generous commitment to establish the \$1 million Arthur and Sonia Labatt Endowment, FBC's first-ever endowment fund for vision research.



**Sonia Labatt visiting a vision research laboratory at SickKids.**

The Sonia and Arthur Labatt Endowment sparked a new energy among Canada's vision scientists. It was created specifically to ensure the continued support of research directed to understanding the causes of and developing treatments for degenerative diseases of the retina that cause visual impairment and blindness in children.

Over the years, Sonia's generosity has supported many researchers who are doing pioneering work. This includes two researchers with an interest in inherited retinal diseases (IRDs): Dr. Jane McGlade, a scientist whose project aimed to better understand the molecules that regulate the development of light-sensing photoreceptor (cells with an eye to improving cell replacement therapies), and Dr. Elise Héon, an ocular geneticist whose work has led to the discovery of new genetic causes of IRDs and has also improved the diagnosis and care of children with inherited eye conditions. More recently, Arthur and Sonia's philanthropy was crucial in driving forward work by Dr. Gregory Borschel at SickKids, who has pioneered a new treatment for a rare form of blindness called neurotrophic keratopathy.

Sonia will be remembered by FBC as a kind-hearted woman who brought great hope to families and children wishing for vision health treatments, who was committed to making a difference.

"Sonia was always comforting, always ready for the next adventure, and so very kind," says Sharon Colle, FBC's former president and CEO. "She changed the way we thought about ourselves and raised our sights."

We honour and remember Sonia with great reverence. She was an incredible supporter and friend of FBC.

# THE FUTURE OF VISION RESEARCH IS BRIGHT!

FBC's Clinician Scientist Emerging Leader Awards (CSELA) were launched in 2017 to build the pipeline of ophthalmologists and optometrists who do research. Clinician-scientists help translate laboratory research into the clinic and help bring clinical trials to Canadian patients. Six years on, CSELA winners have undertaken prestigious training fellowships and launched their own independent research careers.

In 2022, we are pleased to announce three new CSELA winners, Dr. Marko Popovic, Dr. Mélanie Hébert and Dr. Kirill Zaslavsky.



**Dr. Marko Popovic**  
University of Toronto

**Comparing Two  
Common Treatments  
for Retinal Detachment**



Dr. Marko Popovic is an ophthalmology resident at the University of Toronto and is currently completing a Master of Public Health in epidemiology at Harvard University.

Dr. Popovic's project focuses on retinal detachment. Retinal detachment occurs when the retina, the light-sensing part of the eye, pulls away from the back of the eye. It is relatively common, with one in every 300 people experiencing it in their life.

Dr. Popovic will be undertaking an epidemiological study to analyze the safety, effectiveness, and cost implications of two common treatments for retinal detachment.

**Dr. Mélanie Hébert**  
Université Laval

**A Clinical Trial to Test  
Two Surgical Strategies  
for Retinal Detachment**



Dr. Mélanie Hébert is an ophthalmology resident at Université Laval. She previously completed a Master of Science degree in biomedical sciences alongside her medical degree.

Dr. Hébert is also tackling the topic of retinal detachment, undertaking a clinical trial to see if combining two common repair and reattachment methods produces better results than one treatment alone. FBC funding will help launch this six-year randomized study.

**Dr. Kirill Zaslavsky**  
**University of Toronto**

## **Finding the Cause of Birdshot Uveitis**



Dr. Kirill Zaslavsky is currently a third-year ophthalmology resident having previously completed a combined medical degree/PhD program at the University of Toronto. Dr. Zaslavsky is studying a rare autoimmune eye disease called birdshot uveitis. Birdshot uveitis is a sight-threatening immune-mediated eye disease. Birdshot uveitis is treated with immune-suppressive therapy. However, the causes of birdshot uveitis are not

clear and treatment response is hard to predict.

Dr. Zaslavsky is trying to understand which immune cells cause the autoimmune reaction. By analyzing and identifying the different types of immune cells from patients with birdshot uveitis he hopes to determine which cells are important in this disease and establish a framework for dissecting other autoimmune and inflammatory retinal conditions.

**THANK YOU, your support has allowed us to invest in these exceptional individuals who are the future of vision research in Canada.**

# **UPDATE ON DR. BALLIOS FBC'S INAUGURAL CSELA RECIPIENT**



In 2017, Dr. Brian Ballios was awarded FBC's first CSELA. Over the course of the award, Dr. Ballios finished his residency at the University of Toronto and completed a fellowship at Harvard. In 2021, he returned to Toronto as an assistant professor in the Department of Ophthalmology and Vision Sciences at the University of Toronto with funding through the J. Ardeth Hill – Fighting Blindness Canada Professorship in Ocular Genetics Research. We caught up with Dr. Ballios who shared more about his research and the launch of the next phase of his career.

“The CSELA was a foundational award that allowed me to expand my research,” says Dr. Ballios. “I credit much of my progress over the last few years scientifically to FBC’s support. There aren’t many opportunities for that kind of early-career support in our health care research funding system in Canada. FBC created a truly unique program.

I was excited to come back to Canada and to bring

these perspectives and opportunities that are happening internationally to Canadian patients.

I wear many hats, clinically and in research. I have a laboratory where I perform basic science research into stem cell biology in the context of genetic eye conditions, and I have a clinical practice where I see patients who have these same conditions. I try to help my patients find correct diagnoses and navigate a pathway to engage with these new treatments that are emerging in gene therapy and stem cell therapy.

The larger aims of my research and clinical programs are to provide choice, opportunity, and new therapies to patients with rare diseases who had no options in the past.

Stem cell therapy is really the next frontier of all of medicine, not just ophthalmology. I’m pleased to bring these new opportunities to my patients and to have the support of FBC, which for decades has been a great advocate of patients with vision loss.”

# CANADIANS BEGIN RECEIVING SIGHT-SAVING GENE THERAPY

Over the past few years we have been sharing about the excitement and challenges of bringing the first gene therapy for an eye disease, Luxturna, to Canada. We continue the journey, sharing a story of hope about some of the first Canadian patients to receive this treatment.

Luxturna is a gene therapy for individuals with retinitis pigmentosa or Leber congenital amaurosis (LCA) caused by mutations in the RPE65 gene. It is a one-time treatment that can slow the progression of vision loss and may also restore some vision, specifically night vision.

Luxturna was approved for use in Canada in 2020, however we are still waiting for this gene therapy to receive public funding. This delay in securing access has been frustrating, especially for those who, while waiting for public funding, are experiencing progressive vision loss. However, there have been rays of hope as a few individuals have been able to access treatment, taking advantage of coverage through work health insurance plans.

Andre and Nathan, 13-year-old twin brothers from Brampton, Ontario, were diagnosed with LCA at age seven. Their parents Christina and Kevin began advocating for the treatment as soon as it was approved by Health Canada. In April, the family received life-changing news: Kevin's trade union agreed to pay for Luxturna. Andre and Nathan finished their treatment at SickKids in July and are already reporting noticeable improvements in their vision.

As Christina explained, "Shortly after the first eye was treated, Andre and Nathan noticed colours were more vivid and bright, specifically our pet dog Toby who they noticed more sharper with the treated eye. In recent trips to the movies Andre and Nathan were able to make a bathroom trip alone in a dim setting. Something they were unable to do prior to treatment."

"We are now optimistic that Andre and Nathan will live a future without blindness and be able to experience many things they never knew were possible in a dark setting - being outdoors with friends and family after dark, and a possibility of a drivers license which would never be possible otherwise."

Dr. Elise Héon (SickKids, Toronto) is an inherited retinal disease expert who performed the Luxturna surgery for Andre and Nathan. She reflected on the experience:

"It's a bit surreal, and at the same time it feels like a home run. What we thought was impossible is now possible. It's a new era. When I started my career in 1991, we knew of only three genes that caused an inherited retinal disease. Now there are over 250 known genes. The only thing that has been missing are treatments. We all used to tell patients that there would be a treatment in 5 years... It has been a humbling journey."

We are thrilled for Andre and Nathan and wish them a speedy recovery and best of luck with their future eye health. FBC continues to advocate so that all Canadians have access to this and other sight-saving treatments as they become available. Stand with us by sending an email to your MPP at [ApproveLuxturna.ca](http://ApproveLuxturna.ca).



**Andre and Nathan enjoy playing hockey.**

# NEVER TOO YOUNG... TO CYCLE FOR SIGHT!

On Saturday, June 18<sup>th</sup>, FBC-funded researcher Dr. Stephan Ong Tone swapped his white coat for a cycling jersey to raise funds for vision research at FBC's Cycle for Sight Toronto. Dr. Ong Tone was a member of University of Toronto's Department of Ophthalmology and Vision Sciences team, which has collectively raised over \$14,500! Dr. Ong Tone was joined by his young son, showing it's never too early to get started!

Dr. Ong Tone is an early career clinician-scientist at Sunnybrook Health Sciences Centre & Sunnybrook Research Institute and an assistant professor at University of Toronto, with expertise in corneal diseases and surgery.

Dr. Ong Tone's research focus is Fuchs endothelial corneal dystrophy (FECD), an age-related disease affecting approximately 4% of the population over the age of 40. FECD causes fluid accumulation in the cornea, the transparent front portion of the eye, leading to eye pain and vision loss.

We are proud to support Dr. Ong Tone's work and thank him for supporting vision research through his work in the clinic, in the laboratory, and now on his bike fundraising for Cycle for Sight! Dr. Ong Tone explained his motivation for participating this year, "We had a great time as a family participating at our first Cycle for Sight. Celina and myself want to demonstrate to our kids the importance of living an active lifestyle, and also contributing back to the community and supporting vision research. We are already looking forward to next year's event!"

Cycle for Sight wrapped up with our final in-person event in Paradise, Newfoundland on July 10. Thank you to all our cyclists, hikers, yoga posers and movers – young and old – your commitment to vision research raised over \$500,000! And we too are already looking forward to next year!

Register for Cycle for Sight 2023 at [cycleforsight.ca](https://cycleforsight.ca)



**Dr. Ong Tone and his son sporting shades at Cycle for Sight.**



**Tandem cyclists on the course at Cycle for Sight.**

# FBC FALL EVENTS

## VIEW POINT TORONTO

**Sunday, October 2**

Join us in-person for a full day of informative sessions from leaders in vision research. Speakers include:

- Dr. Richard Kramer (UC Berkley):  
Novel therapies for retinal degeneration
- Dr. Peter Kertes (Sunnybrook Hospital):  
Age-related macular degeneration: new research and treatments
- Dr. Brian Ballios (University of Toronto):  
Update on clinical trials for inherited retinal disease

There will also be sessions on glaucoma, cataracts, corneal disease and more!

Your ticket includes access to all sessions, the exhibitor fair, opportunities to meet with other people and families living with vision loss, and a continental breakfast and boxed lunch.

Space is limited, register today at [fightingblindness.ca/live-education-events!](https://fightingblindness.ca/live-education-events!)

If you require assistance, you can email us at [education@fightingblindness.ca](mailto:education@fightingblindness.ca) or call **1.800.461.3331**

## COMIC VISION RETURNS

**Toronto: Thursday, October 27**  
**Vancouver: Friday, November 4**

We're excited to announce the return of our in-person Comic Vision fundraising events this Fall. Join us in Toronto with Canada's own, Rick Mercer! In Vancouver, the laughter will be flowing with a hilarious line up of seasoned comedians. Stay tuned for more info. Tickets on sale now at [comicvision.ca](https://comicvision.ca).

## EYE ON THE CURE

**Friday, November 18**

Peek behind the curtain as vision researchers present their projects in our latest competition, Eye on the Cure. Think Dragon's Den meets TED Talks! On Friday, November 18, watch select vision researchers battle it out in front of our esteemed judges and a panel of jurors for \$100,000 in awards to support their research. For a minimum donation of \$50, you too can have your say and vote for the People's Choice Award - program viewing is complimentary. Learn more at [fightingblindness.ca/eyeonthecure](https://fightingblindness.ca/eyeonthecure).

### 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](mailto:jkoumandaros@fightingblindness.ca)

### Interested in a rewarding volunteer opportunity?



If you would like to share some time or get more involved, we would love to have you! To learn more, contact

**[volunteer@fightingblindness.ca](mailto:volunteer@fightingblindness.ca)**  
or **1.800.461.3331 x 231**