InVision

FIGHTING
BLINDNESS
CANADA

SUMMER 2023 HIGHLIGHTS

Bill C-284: To establish a National Strategy for Eye Care.

Canadians now have access to Luxturna!

Ann Morrison retires after 20 years with Fighting Blindness Canada.

We're turning 50 next year!

fightingblindness.ca

Charitable Registration Number: 119129369 RR0001

A MESSAGE FROM DR. LARISSA MONIZ

Dear friends,

Thanks to generous community members like you, Fighting Blindness Canada is investing in more vision research than ever before. In this edition of our InVision newsletter, we are excited to share how your support is translating into life-changing discoveries, how our collective advocacy efforts are paving the way for sight-saving treatments, a special staff farewell and more.

We are delighted that in 2023 we will be expanding our funding through two programs:

Transformative Research Awards

Newly launched this year, the Transformative Research Awards are a $1.7 million investment into best-in-class international vision research, providing large-scale, longer-term funding to attract the brightest and best ideas and innovations from around the world. We will be announcing the winners in our Fall InVision newsletter. Stay tuned!

2023 Clinician Scientist Emerging Leader (CSEL) Award

The CSEL Award aims to strengthen the community of clinician-scientists by enabling the next generation of clinicians to incorporate research into their careers. Past winners include Dr. Brian Ballios, Dr. Matthew Benson, and Dr. Ellen Zhou. Award recipients will be announced at the end of 2023.

Your continuous support makes these award opportunities possible and helps us drive innovative research forward. From all of us at Fighting Blindness Canada, thank you for bringing hope to the 1.2 million Canadians living with vision loss.

Sincerely,

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

BILL C-284: AN ACT TO ESTABLISH A NATIONAL STRATEGY FOR EYE CARE

For years, Fighting Blindness Canada, in partnership with other vision organizations, has advocated for a National Strategy for Eye Care. Thank you to everyone who has joined us in supporting this initiative.

This spring, Bill C-284, an Act to establish a National Strategy for Eye Care was debated during the second reading, on its way to becoming law. The Bill, introduced in 2022 by Honourable Judy A. Sgro, PC, Member of Parliament for Humber River-Black Creek, will have a direct, positive impact on Canadians' vision health now and for generations to come.

Vision is an essential part of everyday life, but vision health has been under-funded and deprioritized in Canada for too long. Bill C-284 will lead to better care and quality of life while supporting Canadian leadership in vision research. The Bill will benefit all Canadians, but most particularly those most in need, including seniors, children, amd underserved populations who currently lack access and treatment options.

If you believe in prioritizing Canadians vision health and eye care, send an email to your Member of Parliament by visiting **eyecarestrategy.ca**. Even if you have emailed your MP in the past, please send another email to support this crucial moment in time.

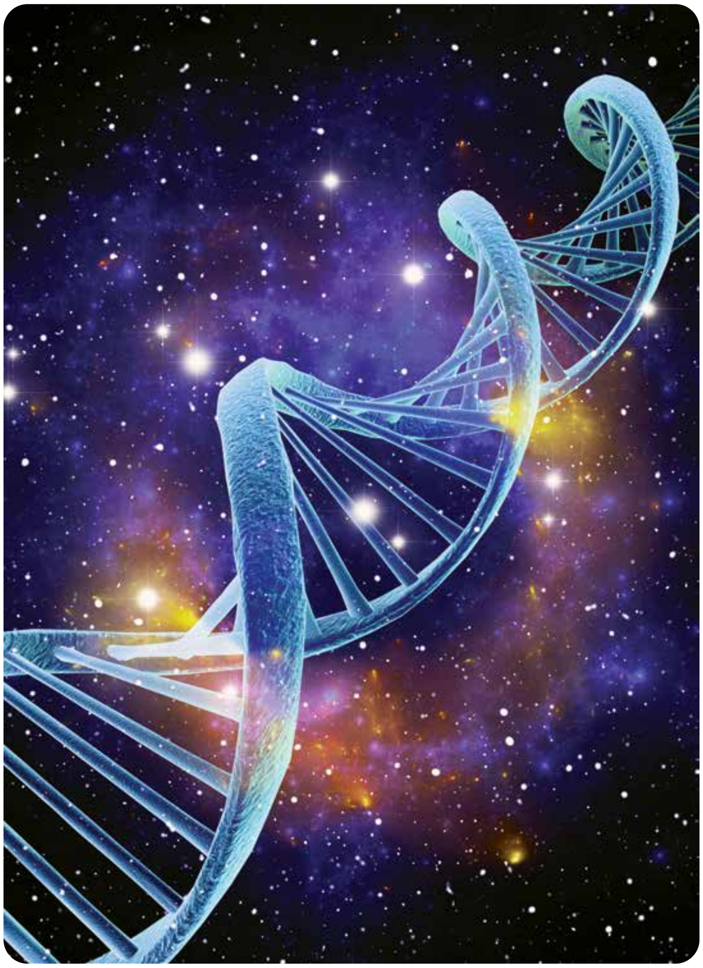
CANADIANS NOW HAVE ACCESS TO LUXTURNA!

Luxturna is the first gene therapy treatment approved for an inherited retinal disease in Canada. While it was approved by Health Canada in 2020, provinces have only agreed to publicly fund it in recent months.

This is an exciting moment for the vision loss community and a major step forward in the advancement of vision science. With your continuous support, our advocacy efforts grew strong, calling on all provincial governments to approve and fund this sight-saving treatment.

Together, we have changed the lives of Canadians who need this treatment, including Jack McCormick, a dedicated Fighting Blindness Canada community member and Young Leader who was born with mutations in the RPE65 gene, causing progressive vision loss. Learn his story on the next page.

We can’t thank you enough for signing the petition to approve Luxturna, raising awareness, and being there for those in need every step of the way.



What is Luxturna?

Luxturna is a gene therapy treatment for people who have Leber congenital amaurosis (LCA) or retinitis pigmentosa (RP) caused by mutations in both copies of the RPE65 gene. Luxturna is a gene replacement therapy, providing a working copy of the RPE65 gene to replace the mutated version. Evidence from clinical trials shows that this treatment can safely improve vision, particularly night vision.

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

JACK MCCORMICK SHARES HIS JOURNEY ON RECEIVING GENE THERAPY LUXTURNA

Jack McCormick was interviewed in our first ever Fighting Blindness Canada Podcast episode that aired in April 2023.

In the episode, Jack shares his experience with vision loss and being one of the first Canadians to receive the gene therapy Luxturna. Jack said he felt “amazing” after undergoing the procedure in both eyes. While his main hope was for Luxturna to stabilize the vision he had left, he shared how fortunate he felt to receive significant improvement in his eyesight, including being able to see better in dimmer light, and see more details and colour.

We were delighted to share Jack’s story with the world. Innovative breakthrough science led to the discovery of this sight-saving gene therapy, and with your support, the opportunities for further advancements in vision research are limitless.

“It’s so important for people with vision loss to not lose hope and continue living their lives to the fullest.” - Jack

Hear Jack’s full story in Episode 1 of the Fighting Blindness Canada Podcast.

The episode also includes an in-depth conversation with inherited retinal disease expert Dr. Elise Héon, who reflects on the evolution of inherited retinal disease research and personal experience with the medical system.

Tune-in on your preferred podcast app, or visit fightingblindness.ca/podcast

NAC ATTACK: A PHASE 3 CLINICAL TRIAL TO TEST AN ORAL THERAPY FOR RP

A new clinical trial called NAC Attack will launch this year to test an oral medication, N-acetylcysteine (NAC), as a potential therapy for retinitis pigmentosa.

NAC Attack is a large, Phase 3, multicenter trial, led by Dr. Peter Campochiaro and Dr. Xiangrong Kong (Johns Hopkins University). Excitingly, there will be a Canadian site in Montreal led by Dr. Robert Koenekoop (Montreal Children's Hospital).

About Retinitis Pigmentosa (RP)

RP is an inherited retinal disease (IRD) that causes progressive vision loss and in most cases blindness. Over 60 RP genes have been identified. For the vast majority of individuals with RP, there are no accepted treatments available.

Many of the experimental treatments for RP that are being tested are gene therapies that will only work for individuals with particular gene mutations. While these treatments have shown great promise, it is currently not possible to create a new gene therapy for every different gene for RP or for other IRDs which can be caused by mutations in over 300 different genes. It's clear that developing therapies that are not gene specific could be game changing for patients.

NAC Attack Clinical Trial

NAC Attack is testing if an oral medication, NAC, can slow or stop vision loss or even increase vision in individuals with RP. NAC is a type of molecule called an antioxidant which protects cells against damage caused by oxidative stress.

Oxidative stress is the result of normal bodily processes, but it can also be triggered by different types of stress. In the retina of RP patients, the rod photoreceptor cells (responsible for night vision) die first. When the cells die they release the oxygen they would have used into the retina causing oxidative stress. This can be toxic to other cells, causing even more cells to die, including cone photoreceptor cells (responsible for central and detail vision).

NAC is a plant antioxidant, naturally found in onions and is already sold as an FDA-approved medication. NAC has been tested in small Phase 1 and 2 studies, which showed that it was safe for patients with RP for up to 6 months. These studies were promising but they did not prove that NAC was safe over the long term or importantly that it reduces vision loss. That is why a larger Phase 3 study is now being launched, to test NAC in a larger population at clinical trial sites around the world.

> "It is very exciting to test an already approved antioxidant drug, NAC, to evaluate its safety and efficacy in protecting or reviving cone function in patients with retinitis pigmentosa. It is equally exciting to be the Canadian site in Montreal, at McGill and the Montreal Children's Hospital, and be part of this multicenter international trial."
>
> **- Dr. Robert Koenekoop**

ANN MORRISON RETIRES AFTER 20 YEARS WITH FIGHTING BLINDNESS CANADA

On June 2, 2023, Ann Morrison, Director of Philanthropy will be retiring. We are so happy for Ann as she starts this next chapter of her life, yet sad to see her go, she will truly be missed.

Ann's journey with Fighting Blindness Canada began in 1998 when her son Gavin at the age of 5 was diagnosed with an inherited retinal disease called retinitis pigmentosa. This life-changing event led her and her husband David to attend a Fighting Blindness Canada patient conference. This experience sparked hope for a brighter future for their son and others living with vision loss.

In 1999, Ann and her good friend Meg Soper co-founded the organization's first Comic Vision fundraiser. It was such a success that it turned into an annual event and in 2003, Ann joined our staff to help make Comic Vision a Canada-wide event. Amazingly, Comic Vision has become one of our highest fundraising events, raising $10 million to-date in support of vision research.

Ann has held a number of roles at Fighting Blindness Canada including her latest role as Director of Philanthropy. She has been a tireless fundraiser and advocate for vision research, helping to secure $2.5 million for the Restore Vision 20/20 Research Initiative. At our annual Cycle for Sight event, she has also led her family and friends team 'The Crankers', raising an astonishing $428,000!

We can't thank Ann enough for her full-hearted dedication and time and know Ann will forever be a friend of Fighting Blindness Canada and so many whose lives she's touched. We wish her all the best in her retirement.

> "I began my journey with Fighting Blindness Canada in hopes of a brighter future for all those impacted by vision loss. I've never once doubted the power of people coming together for a greater cause. I am grateful to have been a part of it and will continue to cheer everyone on as the mission to fight blindness becomes stronger than ever."
>
> **- Ann Morrison,**
> **Director of Pilanthropy**

JOIN US AT AN UPCOMING EVENT...

Cycle for Sight Virtual

Summer 2023

cycleforsight.ca

Ride for Sight

August 2023

rideforsight.ca

View Point Toronto

September 2023

fightingblindness.ca/live-education-events

Young Leaders Summit

October 2023

fightingblindness.ca/events/young-leaders

GIVE BACK TO YOUR COMMUNITY

Join our team of dedicated volunteers. We offer a variety of ways to volunteer. To learn more, contact **volunteer@fightingblindness.ca** or **1.800.461.3331 x 231**

WE'RE TURNING 50 NEXT YEAR!

In honour of this milestone, we are collecting stories from the community to share throughout 2024. If you are living or impacted by vision loss, share about your vision journey and experience with Fighting Blindness Canada for the chance to be featured. Submissions can be made at **fightingblindness.ca/share-your-experience**