InVision

FIGHTING BLINDNESS CANADA






FALL 2024 HIGHLIGHTS

50 Years & Counting: View our Key Milestones.

Judy Sgro: An Update on the National Eye Care Strategy.

Where are They Now? Dr. Ian MacDonald.

Charitable Registration Number: 119129369 RR0001

A MESSAGE FROM DR. LARISSA MONIZ

Dear friends,

Fighting Blindness Canada is turning 50 this year! That's 50 years of funding world-class research and 50 years of bringing hope. It's 50 years of generous support from a dedicated community.

We began as the Retinitis Pigmentosa Foundation and expanded our portfolio over the years to include funding research into other blinding eye diseases, including age-related macular degeneration and glaucoma.

We also began supporting our community members in other ways, connecting Young Leaders with mentors to give them career advice, and developing rich information and education programs through our eye disease resources pages and in-depth educational conferences.

We would like to thank you for your support over the years.

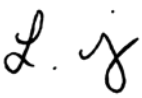
In this issue, we outline some of the key milestones of the last 50 years on pages 4-5. We also take a look at what's ahead in the eye health landscape through our interview with the Honourable Judy A. Sgro who discusses a bill to develop a National Eye Care Strategy.

The gene therapy for an inherited retinal disease (IRD), Luxturna, is a shining example of one of the ways research has made a difference and we touch base with one of the recipients of this first-ever therapy on page 6, a fitting tribute as September is also IRD Month.

To further mark IRD Month, we also look back at the illustrious career of Dr. Ian MacDonald, a clinical genetics pioneer (page 3).

Thank you again for helping to make research like Dr. MacDonald's and so many others possible.

Sincerely,



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

WHERE ARE THEY NOW? DR. IAN MACDONALD CLINICAL GENETICS PIONEER AND PATIENT CHAMPION

Dr. Ian MacDonald's illustrious career began when, as a trainee in clinical genetics he had the opportunity to work on a project funded by Fighting Blindness Canada (FBC).

Choroideremia is an inherited retinal disease (IRD) that develops in the late teens and causes severe vision loss by mid-life. It is an X-linked condition, meaning that it primarily affects men. Choroideremia was one of the first IRDs to be studied by FBC, beginning with funding to Dr. Clem McCulloch in the 1970s. An FBC grant also helped launch the beginning of Dr. Ian MacDonald's career. As a trainee in clinical genetics at the University of Ottawa, he brought a new genetic focus to the field of IRD research.

Dr. MacDonald's first grant from FBC in 1985 helped identify where the choroideremia gene was located on the X chromosome. As Dr. MacDonald said, "That unquestionably started my career and passion for vision research on heritable ocular traits."

This was the early days of genetic research, and when the exact gene that causes choroideremia was identified by a UK scientist, Dr. Miguel Seabra, the two men collaborated to create a test that became a global standard to diagnose the disease.

In the years since, Dr. MacDonald has become an international expert on choroideremia and is the new Suzanne Véronneau-Troutman Chair at the Department of Ophthalmology at the University of Montreal. In 2015 he launched the first Canadian clinical trial for an IRD gene therapy with funding from FBC. He said this was one of the highlights of his career, in addition to being part of the team that brought Luxturna, the first approved gene therapy for an IRD, to patients in Western Canada.

Dr. MacDonald is driven to continue research and to be a strong advocate for his patients with the hope that gene discovery and clinical trials will continue to bring treatments to patients and prevent vision loss.

In 2015, Dr. MacDonald launched the first Canadian clinical trial for an IRD gene therapy with funding from FBC.

SPOTLIGHT ON SIGHT: 50 YEARS OF MILESTONES

FBC is celebrating 50 years of funding vision loss research to understand the causes and effects of eye diseases and to retain, protect and restore vision for people living with vision loss. This timeline marks just a few of our milestones, along with major research developments.

View more milestones at **FightingBlindness.ca/Milestones**

70s

Fighting Blindness Canada (FBC) is founded in 1974 as the Retinitis Pigmentosa Foundation of Canada by a passionate group of families led by the late Jay and Malca Marin who were driven to find treatments for inherited retinal diseases (IRDs).

In 1979, Jim Bentley and the York Wing Motorcycle Club start a charity motorcycle ride called “Ride for Sight,” raising more than $25 million over the years.

80s

In 1984, Dr. Ian MacDonald receives funding for the first molecular genetics project researching choroideremia, a rare X-linked recessive form of hereditary retinal degeneration. In 2015, Dr. MacDonald launches the first Canadian gene therapy trial for choroideremia.

Dr. Jane Green receives funding to enhance understanding of hereditary vision loss in Newfoundland, with a focus on Bardet Biedl syndrome (BBS). In 2018, she is honored with the Order of Canada for her groundbreaking discoveries of the genetic basis of inherited eye diseases.

90s

FBC-funded researchers are at the vanguard of IRD research, discovering the identity and function of genes that cause IRDs, including ROM1 and PRPH2. Today, more than 300 genes have been identified that cause an IRD, including many discovered by Canadian researchers.

Fighting Blindness Canada's first Vision Quest conference, now called View Point, is held in 1994. More than 20,000 people have participated in Fighting Blindness Canada's View Point.

00s

FBC expands its mission beyond IRDs to include age-related macular degeneration (AMD).

FBC launches the IRD Patient Registry — one of the first registries of its kind in the world. Created by Dr. Elise Heon, it has helped more than 50 patients participate in clinical trials or receive treatment.

Cycle for Sight launches in 2009 with more than 4,000 participants raising more than $6 million in its 15 years.

10s

The first Canadian gene therapy clinical trial launches for choroideremia, with funding from FBC.

FBC launches the first Clinician Scientist Emerging Leader award, which goes to Dr. Brian Ballios. In 2021, Dr. Ballios launches an independent career with a research focus on stem cell therapy and starts the first adult IRD clinic in Canada.

20s

Luxturna becomes the first gene therapy treatment approved for an IRD treatment in Canada.

Clinical trial launches to test the ability of a gene-agnostic therapy, similar to optogenetics, to restore vision in retinitis pigmentosa and choroideremia. FBC supports the development of related molecules through a grant to Dr. Richard Kramer.

JACK MCCORMICK: A TRIUMPHANT EXPERIENCE WITH GENE THERAPY

In 2020, Health Canada approved the first one-time gene therapy for an inherited retinal disease (IRD), Luxturna. And in 2023, the provinces began funding this ground-breaking treatment. To mark the first-year anniversary, we caught up with one of its first ever recipients, Jack McCormick, to discuss his experiences.

Jack McCormick's story is inspiring and uplifting. As one of the first Canadian to receive Luxturna, Canada's first approved gene therapy for inherited retinal diseases, McCormick's experience not only reflects his personal triumph but also highlights the expansive potential of modern medicine.

Diagnosed with cone-rod dystrophy as a toddler, McCormick was initially told that his vision impairment was permanent and untreatable. "They told me my vision would not change and that even if we knew the cause of my vision loss, there was nothing that could be done," he says. However, as he entered his teens, McCormick's vision unexpectedly deteriorated, eventually leading him to a new diagnosis: Leber congenital amaurosis (LCA), a genetic disorder that causes severe visual impairment. This revelation — that his condition would worsen without intervention — was daunting.

Determined to not just cope but thrive, McCormick got involved with Fighting Blindness Canada (FBC) as a high school student. "I've been involved with FBC as a volunteer, a donor, a participant, an organizer of the **Young Leaders Program**, and also a beneficiary of the advocacy and research that FBC has contributed to," he says. This culminated in his involvement in FBC's crucial advocacy for Health Canada's approval of Luxturna — the new gene therapy that would end up changing his life.

McCormick's and FBC's perseverance paid off when Luxturna was approved in Canada in 2020. McCormick was fortunate to receive the treatment in 2022, funded privately before provincial health coverage took effect. "Had I waited for governmental funding, my vision might have deteriorated past the point of eligibility for the treatment," he explains.

The impact of Luxturna on McCormick's life has been profound. His vision has not only stabilized but improved, enhancing his ability to see in low light and to perceive a broader spectrum of colours. "The way it has impacted me the most, though, is that it has taken a huge weight off my shoulders," he says. "I'm no longer worried about what could be — there's more certainty in terms of what I'll be able to see in the future."

Today, McCormick is actively involved in numerous disability and blindness organizations. In recognition of his dedicated volunteer work with FBC, McCormick received the 2019 Ontario Medal for Young Volunteers, the highest honour a young person can receive from the Government of Ontario.

"I've had to learn ways to excel in a world that's not built for me," says McCormick.

NATIONAL EYE CARE STRATEGY ON TRACK TO PASS

Judy Sgro Discusses the Progress of Bill C-284.

When the Honourable Judy Sgro's aunt lost her sight in her 90s, she was too old to adapt to her new circumstances. She no longer had independence, and she felt isolated and frustrated.

"Her life as she knew it ended when her sight ended," said Sgro, who introduced the National Eye Care Strategy, Bill C-284, to parliament in 2022. "We take our eyesight for granted, and it's only when we start to lose our sight, that we start taking more precautions to protect it." Sgro, who is the MP for Humber River — Black Creek, hopes the bill will make Canadians more proactive.

Bill C-284 passed all three readings within the House without opposition and most recently passed the second reading in the Senate. Sgro is confident that when parliament goes back into session in September the bill will quickly move through its final reading and onto Royal Assent.

"I'm quite excited and looking forward to that happening. There's no opposition to the bill — it's more the procedures it has to go through," Sgro said. "There are thousands of people who are currently unaware they need to take better care of their vision. We need to help people prevent vision loss and blindness through education and awareness."

As both her aunt and grandmother were blind, Sgro understands the costs that can come with vision loss. "I've seen the struggle that they both had."

There are currently eight million Canadians living with a blinding eye disease. Vision loss can lead to isolation and depression. And often it becomes difficult to continue your level of employment, Sgro said.

Early diagnosis and access to treatment, however, could help prevent blindness.

The Public Health Agency of Canada is already working on what a National Eye Care Strategy would look like, so they will be ready to begin as soon as the bill passes, Sgro said. One of the first steps will be consultations with stakeholders such as Fighting Blindness Canada and its community.

"There are thousands of people who are currently unaware they need to take better care of their vision. We need to help people prevent vision loss and blindness through education and awareness."

— The Honourable Judy A. Sgro, Member of Parliament

JOIN US FOR VIEW POINT & YOUNG LEADERS IN TORONTO

VIEW POINT TORONTO

Saturday, Sept. 28

Location: Toronto Reference Library, 789 Yonge St. Toronto or join us virtually by live stream

Time: 1-6 p.m. ET

View Point Toronto will feature a keynote about gene agnostic therapies with Dr. Daniel Chung, Chief Medical Officer, SparingVision. There will also be Ask the Expert panels on the aging eye and inherited retinal diseases, and a lived experience panel focused on advocacy. If you can't join in person some of the sessions will also be livestreamed!
Learn more: FightingBlindness.ca/ViewPoint

YOUNG LEADERS TORONTO

Saturday, Sept. 28

Location: Toronto Reference Library, 789 Yonge St. Toronto,

Time: 1:30-5 p.m. ET
Networking Dinner: 7-10 p.m. ET

The Young Leaders Program is coming to Toronto this fall and will include a networking dinner to make new connections. There will be limited travel bursaries available for Ontario residents outside of Toronto.
Learn more: FightingBlindness.ca/YoungLeaders

Dr. Daniel Chung will be giving a keynote on gene agnostic therapies at View Point Toronto.

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** or call **1.888.626.2995**

Donate to Support 50 Years of Putting a Spotlight on Sight

As we celebrate our 50th anniversary, we invite you to help us create an even brighter future by making a special contribution of $50 to help support further groundbreaking research and innovation.
Go to: FightingBlindness.ca/Donate or contact Josie Koumandaros 1.800.461.3331 x 262 jkoumandaros@fightingblindness.ca