InVision

FIGHTING BLINDNESS CANADA

FALL 2025 HIGHLIGHTS

A Research Continuum: Moving from Discovery Towards Treatment

2025-2030 Research Strategy: Research in Focus

Dagmar's Journey of Hope and Resilience

Charitable Registration Number: 119129369 RR0001

A MESSAGE FROM DR. LARISSA MONIZ

Dear friends,

September is Inherited Retinal Disease (IRD) Month, and in this issue of *InVision*, we explore the long history of research into IRDs. At Fighting Blindness Canada (FBC), we believe that every discovery is a step forward—and often, those steps are built on the foundations laid by researchers who came before. In this issue, we're proud to highlight the powerful connection between two scientists we've supported: **Dr. Baohua Liu** and **Dr. N. Torben Bech-Hansen**. Their work, spanning generations of inquiry and innovation, exemplifies how research is a relay—passing the torch of knowledge toward breakthroughs that may one day prevent vision loss or restore sight.

You'll also find a first look at our new research strategy, **Research in Focus: 2025–2030**, a roadmap that reflects our unwavering commitment to supporting world-class research to better understand blinding eye diseases and develop new treatments.

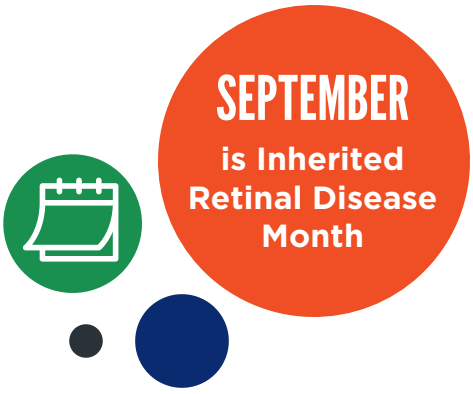
Plus, take a moment to relive the energy and inspiration of **MOVE FOR SIGHT**, our national fundraising event that united supporters across Canada in the spirit of, hope, connection and impact.

And finally, don't miss **Dagmar's inspirational story**—a reminder of why this work matters so deeply, and how your support makes a difference every day.

Thank you for being part of our community. Together, we're not just funding research—we're changing lives.

With gratitude and hope,

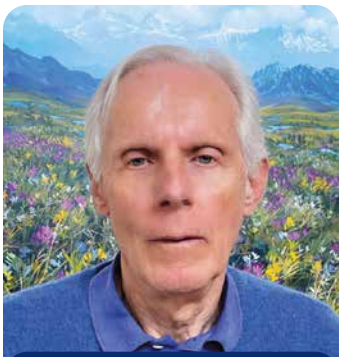
Larissa Moniz, PhD
Director, Research and Mission Programs
Fighting Blindness Canada



A RESEARCH CONTINUUM: MOVING FROM DISCOVERY TOWARDS TREATMENT

More than 30 years ago, geneticist **Dr. N. Torben Bech-Hansen**, University of Calgary, set out to solve a mystery: what causes congenital stationary night blindness (CSNB)—a rare, inherited retinal disease that makes it difficult to see in low light and often leads to other challenges, like myopia and involuntary eye movements. At the time, little was known about the genetic roots of CSNB.

With support from Fighting Blindness Canada (FBC) and in partnership with the late Dr. William Pearce, Dr. Bech-Hansen and his laboratory team collected and analyzed DNA from over 25 families affected with CSNB. In 1998, they made a breakthrough—identifying mutations in the CACNA1F gene as the cause of CSNB2A, a form of the disease that mainly affects males. The CACNA1F gene codes for a protein subunit of a calcium channel in the retina that is critical to how light-sensing photoreceptors in the eye communicate with the brain. Then in 2000, his team discovered that mutations in a second gene, NYX, is responsible for CSNB1A, another form of this disease. Both gene-mutation findings were published in *Nature Genetics* and remain key discoveries in CSNB research.



Dr. N. Torben Bech-Hansen, University of Calgary

Dr. Baohua Liu, University of Toronto Mississauga

These findings in CSNB research were more than scientific milestones—they gave patients and families answers, provided a basis for definitive genetic diagnosis and laid the foundation for future research exploration.

Today, **Dr. Baohua Liu**, a neuroscientist at the University of Toronto Mississauga, and one of FBC's 2024 Research Grant Awardees, is building on Dr. Bech-Hansen's legacy—and is pushing the science into new territory.

Focusing on CSNB2A, the very form of night blindness linked to mutations in CACNA1F, Dr. Liu is testing a gene therapy in animal models designed to restore the retina's ability to process light. Although this research focuses on CSNB2A, it could have wider impact by helping us understand whether the brain can still process light after long-term vision loss—an important question as more sight-restoring treatments are being developed for various inherited retinal diseases, and other causes of vision loss.

"It's incredibly rewarding to see how our foundational work has helped shape and inspire Dr. Baohua Liu's research, bringing us closer to real treatments for patients affected by CSNB," says Dr. Bech-Hansen. "Receiving funding from Fighting Blindness Canada was instrumental in allowing us to uncover the genetic and molecular basis of two forms of CSNB. This grant support not only enabled our research, but also laid the groundwork for future breakthroughs."

Dr. Liu agrees that FBC funding has been critical. "It allows us to launch novel research directions and try high-risk/high-gain ideas that are usually not funded by governmental agencies." Best of all, the research will continue to lead to new discoveries down the road. "The potential findings from this project will nurture future collaboration."

RAISING OUR SIGHTS: VISION 2030 UPDATE

Research has always been central to FBC's mission. Investment in research offers **hope**, fuels **innovation**, and drives **progress** for Canadians affected by vision loss. As part of our new strategic plan, FBC talked to donors, researchers, scientific experts and community members to understand how to increase our impact. **The message was clear: research is a highly valued part of FBC's work.**

To strengthen our impact, we have developed our first ever research strategy that will invest in scientific excellence while honouring community and donor interests.

This strategy represents a key milestone in FBC's evolution—bringing greater clarity, accountability, and impact to our research investments.

2025-2030 Research Strategy: Research in Focus

See the infographic on the next page for a visual summary of our research strategy.

2025-2030 Strategic Plan: Raising our Sights

View our full strategic plan to learn how our new research strategy aligns: **fightingblindness.ca/strategic-plan**

RESEARCH IN FOCUS 2025-2030

FBC is the largest charitable funder of vision research in Canada. This new research strategy sets out how FBC will invest in the research ecosystem over the next five years in alignment with our overall Strategic Plan: Vision 2030.

STRATEGIC RESEARCH GOALS

FBC has funded ground-breaking research in our 50+ years—research that has increased our understanding of blinding eye disease and resulted in clinical trials to test potential new treatments. We will continue to accelerate world-class research by:

Building the next generation of Canadian vision researchers

Funding high-quality research with potential to improve outcomes

Fostering collaboration to strengthen Canada's research ecosystem

FUNDING PRINCIPLES

These principles will guide which projects FBC funds:

Community relevance

Scientific excellence

Focused investment

FUNDING MECHANISMS

FBC will accelerate world-class research by funding:

1. **Core grant programs: project and trainee awards**
2. **Special research initiatives**
3. **National Inherited Retinal Disease Patient Registry**
4. **Knowledge translation activities to connect the research ecosystem**

DAGMAR'S JOURNEY OF HOPE AND RESILIENCE

When Dagmar Jamieson was 13 years old, she returned to school after summer break and noticed something wasn't right. Sitting at the back of the classroom, she realized she couldn't clearly see her teacher's face or read the words on the blackboard. Up until that moment, there had been no signs of vision problems.

"I thought maybe I needed glasses," Dagmar recalls. "I was actually worried about having to wear them."

But the visit to the ophthalmologist brought a life-altering revelation: glasses wouldn't help. Dagmar was legally blind. She had a degenerative eye disease—initially diagnosed as macular degeneration but later understood to be cone rod dystrophy, a condition that would continue to erode her vision over time.

For a newly immigrated child—she moved to Canada from the Czech Republic at age eight—just beginning to feel like she belonged, the diagnosis was devastating. But Dagmar didn't let it stop her. "I kept skating, skiing, riding my bike—doing the things I loved," she says. "I didn't want anything to get in my way."

As her central vision faded, Dagmar adapted. She learned to recognize friends by their voices or the way they carried themselves. She avoided telling others she was blind, striving instead to protect her independence. "Sight loss chips away at your independence," she says. "And that was something I was fiercely protective of."

In time, Dagmar found power in accepting her vision loss—not as a weakness, but as part of who she was. "A friend once told me, 'When you're comfortable with who you are, the world will be too.' That stayed with me," she says. "I realized I had become a stronger, more resilient person. I had to think differently, adapt creatively. It made me grow."

Dagmar also found hope in the work that Fighting Blindness Canada (FBC) does. "Hearing that people were actively working toward a cure gave me hope—a reason to stay strong," she says.

Over the years, Dagmar has supported FBC and sight-saving research by organizing numerous fundraisers, leaving a gift in her will and as a monthly donor. "It's a way to ensure this important work continues—to push forward research that could lead to cures."

Watch Dagmar share her story in FBC's spotlight series:
fightingblindness.ca/dagmar-story

MOVE FOR SIGHT 2025

This past June, something amazing happened. Hundreds of Canadians across 160+ cities and towns, 10 provinces, and two countries, came together for Fighting Blindness Canada's second annual MOVE FOR SIGHT.

View our photo gallery and learn how this nationwide movement built momentum, inspired hope, and advanced vital vision research and awareness. **MOVEFORSIGHT.ca**

PATH FORWARD FOR XLRP TREATMENT

Fighting Blindness Canada is urging Johnson & Johnson to continue pursuing regulatory approval for botaretigene sparoparvovec (bota-vec), a gene therapy for X-linked retinitis pigmentosa (XLRP). This potential treatment has offered new hope to individuals and families affected by a rare and progressive genetic eye disease that currently has no approved therapies.

Recently, it was announced that while many treated patients experienced meaningful vision improvements, the Phase 3 LUMEOS trial did not meet its primary endpoint. FBC will continue to advocate with J&J and regulators to ensure the community's voice is heard.

Learn more: fightingblindness.ca/lumeos-trial

UPCOMING FALL EVENTS

Join us in person or online for our full fall lineup.

VIEW POINT

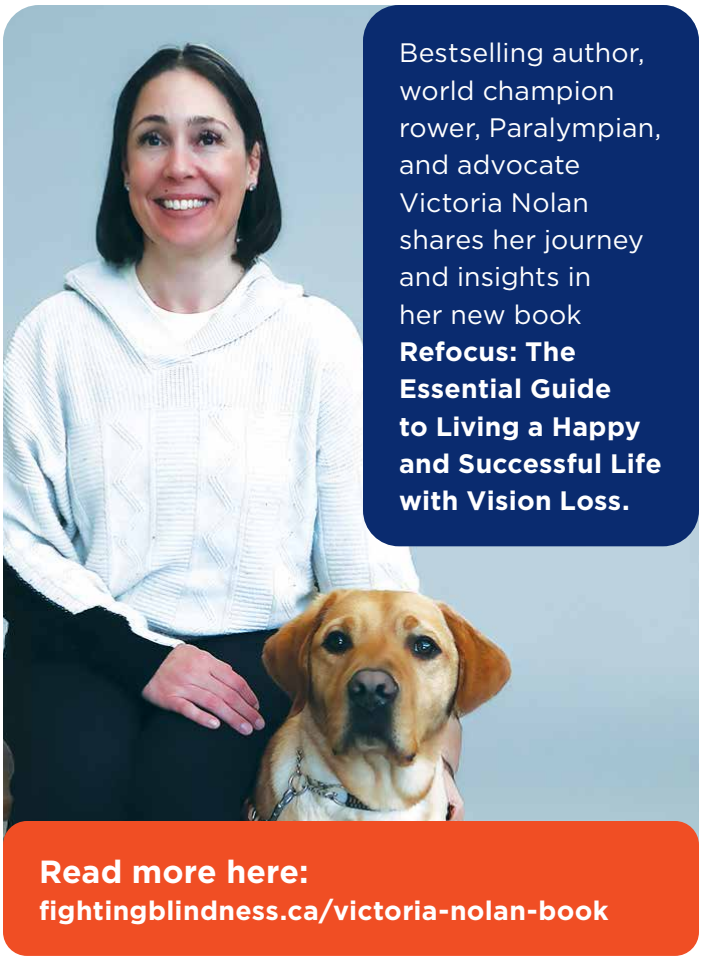
- **Understanding the Bionic Eye and Retinal Prostheses (Webinar)**
  Wed., Sept. 10
- **AMD Coffee Connections**
  Ottawa, Sat., Oct. 4
  North York, Thurs., Oct. 9
- **View Point Toronto: Speaker Symposium (In-person & livestreamed)**
  Sat., Nov. 8
- **IRD Spotlight: Syndromic IRDs (Usher Syndrome & Bardet-Biedl Syndrome) (Webinar)**
  Wed., Nov. 12
- **Dry Age-Related Macular Degeneration (AMD): In Research & Practice (Webinar)**
  Thurs., Nov. 27

Register Now
fightingblindness.ca/viewpoint

YOUNG LEADERS

- **Youth Connects Toronto 2025**
  Sat., Nov. 8
  Sessions aimed at youth, aged 15–35

Register Now
fightingblindness.ca/youngleaders



Bestselling author, world champion rower, Paralympian, and advocate Victoria Nolan shares her journey and insights in her new book **Refocus: The Essential Guide to Living a Happy and Successful Life with Vision Loss.**

Read more here:
fightingblindness.ca/victoria-nolan-book

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**.

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 **Cathy Parry** at **1.800.461.3331 x 271** or at **cparry@fightingblindness.ca**.