



# RAISING OUR SIGHTS

A 50<sup>TH</sup> ANNIVERSARY  
CAMPAIGN TO ACCELERATE  
A BRIGHTER FUTURE



**FIGHTING  
BLINDNESS  
CANADA**



## **VISION**

Ending vision loss caused by blinding eye disease.

## **MISSION**

Accelerating world-class research and providing expert information, advocacy and connection for everyone impacted by blinding eye disease.

# BUILDING ON 50 YEARS OF IMPACT TO CREATE A BRIGHTER FUTURE

From research to education to data mobilization, Fighting Blindness Canada (FBC) has been fueling sight-saving progress for the past 50 years. From our grassroots beginnings in 1974, we have become the largest charitable funder of vision research in Canada, having invested more than \$45 million into research and education.

This year, as we celebrate our milestone 50<sup>th</sup> anniversary, we set out to reimagine how to make the future brighter for people living with a blinding eye disease and their loved ones.

Our community spoke and we listened.

They need us to fund more world-class research that leads to new and improved treatments that stop vision loss, restore sight and lead to eventual cures. And they need us to provide disease-specific educational resources and opportunities to connect with others who have similar experiences, giving them the support needed to navigate their vision loss journey and improve their quality of life.

This is what our bold new vision and mission embodies, providing a strong foundation for everything we will do.

**Now is the time to raise our sights.** But getting there will take time, so we must start today. Every moment spent waiting means people lose more vision while living with continued anxiety and escalating fear.

As we turn our sights to the future and build upon the incredible progress made possible by donors like you over the past half-century, we invite you to consider an additional gift that will help set our bold new vision in motion and accelerate a brighter future for our community.

## THE STARK REALITY OF BLINDING EYE DISEASE

One evening, you see your child bump into the sofa in the dimly lit living room. Thinking they were just clumsy, you brush it off. But when it happens again, you begin to think something isn't right.

It starts with a visit to the doctor, followed by an appointment with an ophthalmologist at the children's hospital. After several examinations and various tests, you get the news.

**Your child has a rare eye disease and will go blind.** You are told there is no treatment. You are told it is genetic.

The feelings are overwhelming, and you are devastated. You can't help but feel guilty and wonder if this is your fault. And you begin to fear for your child's future—will they have to stop playing sports, how will other children treat them, and will they be able to get a job one day?

**It doesn't end there.**

It's a progressive disease, so you are constantly worrying about what is coming next and fearing the inevitable. You do your best to support your child through their own grief, but you can't make it all better.

**You are isolated and scared. So is your child.**

All you both want is a brighter future.



**“It’s heart-wrenching to watch as one of your children slowly goes blind.**

**The impact was hard on everyone in the family. I still remember the day my son confessed to me he was afraid of getting older because then he won’t be able to see, just like his big sister.”**

**— CHRISTINA, mother of two children with Stargardt disease**

# ACROSS CANADA, BLINDING EYE DISEASE IS STEALING VISION AND HOPE

**In Canada, nearly 8 million people are living with a blinding eye disease that puts them at risk of severe vision loss or blindness.**

The most impactful and difficult to treat among them include inherited retinal diseases (IRDs), age-related macular degeneration (AMD), glaucoma and diabetic retinopathy. And they all have one thing in common—a **profound and life-changing impact on a person’s health and wellbeing.**

Despite decades of research focused on these blinding eye diseases, there are no cures and no sure ways to prevent vision loss or restore the vision taken by many of them.

## MENTAL HEALTH IMPACTS

- Recurring state of fear and guilt
- Prolonged anxiety and depression
- Social isolation and loneliness

## PHYSICAL HEALTH IMPACTS

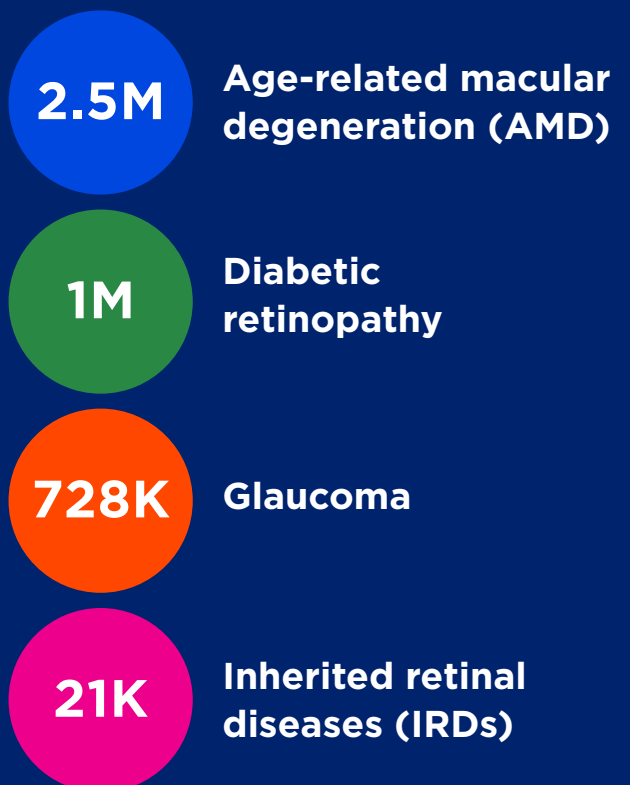
- Loss of ability to navigate the world
- Loss of independence
- Increased stress
- Increased falls and injuries

## FINANCIAL HEALTH IMPACTS

- Fewer job opportunities
- Loss of income
- Increased costs for home modifications

## BY THE NUMBERS

People in Canada living with the following blinding eye diseases:



# THE SIMPLE TRUTH—THERE IS SO MUCH MORE THAT NEEDS TO BE DONE

The number of people needing help has never been greater. As Canada's population ages, blinding eye disease will take an ever-increasing toll on families and communities across the country.

**Each person has needs they will face—some for decades and for others, a lifetime.** And it all starts at the moment of diagnosis.

However, there are still significant challenges standing in the way of properly addressing these needs:

## ABSENCE OF EFFECTIVE TREATMENTS

No treatments exist to stop vision loss or restore sight for many people with blinding eye disease. Though treatments options exist for wet AMD, they can be hard to access and uncomfortable to undergo. And for other diseases like dry AMD or almost all IRDs, there are no treatments at all.

**New and improved treatments are urgently needed to stop vision loss and restore sight.**

Until ways to prevent vision loss and cure blinding eye diseases are discovered, these new and more effective treatments will provide the most hope for a brighter future.

## LACK OF KNOWLEDGE AND SUPPORT

Scared and confused. This is how people feel upon receiving their diagnosis because the information and support they need to advocate for themselves and navigate their vision loss journey are not easy to find.

**Access to disease-specific educational resources and opportunities to connect with others who have similar experiences are essential to empowering and supporting people living with blinding eye disease and their loved ones.**

Having knowledge of what to expect and access to a supportive community is essential to alleviating the anxiety of living with a blinding eye disease and making the future feel brighter.





# WE ARE RAISING OUR SIGHTS FOR OUR COMMUNITY

Fighting Blindness Canada is reimagining how to make the future brighter for people living with a blinding eye disease and their loved ones. As we celebrate our milestone 50<sup>th</sup> anniversary, now is the time to raise our sights so we can better meet the needs of our community.

**Ending vision loss caused by blinding eye disease. This is our commitment to you.**

From our grassroots beginnings to creating the world's first IRD patient registry to over 850 research discoveries we have helped make possible, FBC is building upon the incredible progress we have nurtured over the past half-century and turning our sights to the future.

We know that **new and improved treatments aren't possible without far more world-class research** being funded.

We know **we aren't reaching everyone across Canada who needs our help** to make living with a blinding eye disease easier.

Our foundation is strong, and we will overcome our present and most pressing challenges by:

- Funding more high-impact research into diseases like IRDs, AMD, glaucoma and diabetic retinopathy, accelerating new and improved treatments.
- Amplifying disease-specific education resources and opportunities to connect with others with similar experiences, building a supportive and well-equipped community for everyone in Canada living with blinding eye disease and their loved ones.

**Our community needs this. Our community deserves this.**



## **BUILDING UPON A STRONG FOUNDATION OF IMPACT**

When people living with blinding eye disease and their loved ones have hope, knowledge and support, they have a brighter future. This is why FBC's programs are designed to accelerate research leading to new and improved treatments and make living with a blinding eye disease easier.

As we look ahead to the sight-saving possibilities we will create by mobilizing our bold new vision, **we invite you to discover some shining examples of our ongoing work on the following pages—work that will serve as the basis for what's to come.**

## RESEARCH COMPETITIONS

FBC's research competitions invite top scientists from Canada and around the world to compete for funding for their high-potential research projects. We apply a rigorous approach to ensure **only the best projects are funded**—selected based on the highest standards of scientific merit.

We support new investigators—building the research ecosystem to ensure a bright future—and established scientists with a proven track record of success.

Applications are accepted in areas such as:

- Research Grant: accelerates the development and availability of treatments and cures for blinding eye disease
- Early Career Research Grant: supports exceptional early career researchers
- Clinician-Scientist Emerging Leaders Award: strengthens the community of ophthalmologists and optometrists who incorporate research into their careers

### **IMPACT STORY: PROVIDING HOPE FOR LATE-STAGE RETINITIS PIGMENTOSA WITH GROUND-BREAKING RESEARCH**

Time is not on your side when you have late-stage retinitis pigmentosa (RP). Your world becomes smaller day by day. And because there are no ways to stop it from progressing, you live in a constant state of anxiety about what has been, up to now, the inevitable.

**Every day spent waiting for a new treatment means losing more vision.**

But researchers are working tirelessly every day to change that. Drs. David Gamm and William Beltran were challenged to develop a new cell therapy approach so vision loss in late-stage RP can be prevented and even restored.

They gathered a world-class research team to do something on the cutting edge. They started by figuring out how to create cells that can grow into new photoreceptors. After this groundbreaking success, they made progress in finding the best way to deliver these cells to the retina.

**Now, they are testing how safe and effective this cell replacement therapy is.**

Using a canine model of RP, the team has been trying to replace damaged photoreceptors with new, healthy ones. They are also studying if there are better ways to deliver the cells. The success of these experiments has already moved this therapy towards the launch of a clinical trial to test its potential as a treatment for advanced RP.

In fact, because this research has been so robust, it has attracted interest from industry which has helped it move toward clinical trials even faster. Having just received approval, when it launches it will be the first ever clinical trial to test the replacement of photoreceptor cells to restore vision.

**This could be the new treatment that is so desperately needed.**

Drs. Gamm and Beltran’s research is made possible by funding through our research competition—and the results could be life-changing. For people living with late-stage RP, there is now hope that one day, there could be a way to restore sight.



Dr. David Gamm



Dr. William Beltran

## EDUCATION

FBC's education programs **provide reliable knowledge and support from a trusted source** to help make living with blinding eye disease easier.

We provide helpful information, curated and delivered by experts, including a comprehensive look into blinding eye diseases. Resources include what to expect along your journey, the latest research discoveries and up and coming treatment options. We also enable opportunities for people to connect with others living with the same eye disease to become part of a supportive community.

Examples of these programs include:

- View Point Education Series: brings the latest information about vision health and research, community resources and living well with an eye disease through in-person conferences and online webinars
- Health Information Line: connects you with an empathetic person who can listen to your concerns, help answer eye health-related questions and assist you to find relevant resources.
- Young Leaders Program: provides young people with access to resources, guidance and support on the path to pursuing rewarding careers and finding fulfilling employment

### **IMPACT STORY: TURNING FEAR INTO CONFIDENCE WITH THE HELP OF INFORMATION AND COMMUNITY**

Fiercely independent and vibrant, Mary filled her days with joy and curiosity. She walked every day, took exercise and later life learning classes online, listened to a wide variety of music including classical, oldies and country, and sang in a choir. At 65, she and her husband showered love on their three children and six grandchildren.

One day, Mary headed off to the optometrist for her routine visit. She hadn't noticed anything different with her vision and showed up expecting it to be uneventful. So, she was shocked when she was told:

**“You have dry AMD.”**

Devastated and confused, Mary left her appointment with an Amsler grid to keep tabs on her vision changes. But what she didn't leave with was an understanding of what her future might be. Would she lose her independence? Would she see her grandchildren grow up?

When she was trying to read or watch TV, things became blurry for Mary. And when she pulled out the grid and couldn't see the bottom half of it, she knew something was wrong. This time, the retinal specialist told her she needed to start injections immediately for the bleeding and fluid in her eye.

**“I was scared with a whole lot of thoughts floating around in my head,”** said Mary.

Even after starting treatment, Mary still felt adrift and didn't have a full understanding of her condition. It was her neighbour who encouraged her to reach out to FBC and when she called, the compassionate staff listened to her story and invited her to a View Point event.

**It was life-changing when Mary found our View Point education series.**

Attending View Point was transformative—for the first time, she was in a room where others had the same eye disease as her. She started to feel empowered and supported. Learning more about AMD and what was being done to try and improve her future from medical experts and researchers gave her the confidence to speak up and ask questions.

Most importantly, Mary became part of a community with a support network. Now, at 76, she is “feeling positive about the future because of the research that's going on and the good things that are happening.”

Meeting others and hearing their stories also ignited in Mary the desire to support research. She hopes her children and grandchildren won't face the same challenges she has.



Mary has come a long way since her journey started, and our View Point education series continues to be vital. She is doing everything she can to preserve her vision with the comfort of knowing a community of support is behind her.

## IRD PATIENT REGISTRY

FBC's patient registry is designed to **help advance the development of new treatments** and cures for IRDs and quickly **bring these promising new treatments to Canada.**

Blinding eye diseases like retinitis pigmentosa, choroideremia, Usher syndrome and Stargardt are rare, meaning a focused effort is needed to gather data from within this small community. By inviting people in Canada to register their genetic and medical information, we are able to:

- Drive new research: without the centralized collection of data from within this small community, new research simply would not happen
- Connect registrants to clinical trials and research: registrants are contacted when relevant trials are available so they can participate and help further new treatments
- Improve access to new treatments: making new treatments available in Canada can be painfully slow, but data from the registry helps accelerate the process

### **IMPACT STORY: RESTORING CHILDHOOD AND VISION WITH NEW TREATMENTS AND RAINBOWS**

Excited and joyous, Sitka and David came home from the hospital with their newborn daughter, Nora. For five weeks, they delighted in being new parents, even with the sleepless nights and numerous diaper changes.

Suddenly, Nora's eyes began to flicker uncontrollably. Frightened, Sitka and David rushed Nora to the hospital's emergency room. And nothing could have prepared them for what the neurologist would say,

**“Prepare yourself for lifelong blindness.”**



In utter shock, these parents of just over a month believed this was the beginning of what was an inevitable end. They couldn't help but grieve for Nora's future.

At the age of two, Nora was diagnosed with Leber congenital amaurosis (LCA) and genetic testing confirmed the RPE65 gene mutation.



**This was when Nora joined our IRD patient registry.**

Over time, being able to eat, draw and play became increasingly difficult for Nora. Brighter lighting at the kitchen table, in the bathroom and along hallways, as well as the assistance of a magnifier, did help some. But the most heartbreaking thing to watch was when the sun set each day and Nora was forced indoors while her friends played outside.

A looming fear of blindness continued to cast a shadow over her vibrant, young life. **Until finally, there was hope.**

In 2023, Luxturna became available, a new gene therapy that could help Nora. It was with the help of Sitka that we relentlessly advocated to bring it to Canada so that Nora and others in the patient registry could access it as soon as possible.

Nora bravely received her treatment soon after. And the results were beyond what anyone had dared to hope. She no longer needs intense indoor lighting; she can play outside with her friends in the twilight; and she can read fine print.

**“It’s mind-blowing how good her vision is now. She got to see a rainbow for the first time this spring,”** says Sitka.

Thanks to being part of our IRD patient registry, Nora now sees the world in vivid contrast and has the carefree joy of an eight-year-old girl, full of laughter, curiosity and boundless enthusiasm. This is a huge relief for Sitka and David, as the fear and anxiety they carried for so long has lifted as they watch Nora doing so amazingly.

## YOU CAN ACCELERATE A BRIGHTER FUTURE FOR OUR COMMUNITY

From research to education to data mobilization, Fighting Blindness Canada has been fueling sight-saving progress for the past 50 years. Now, we are celebrating this milestone year as a pivotal moment where we can raise our sights even further to improve outcomes and fulfill our vision of ending vision loss caused by blinding eye disease. Our community needs and deserves this.

**We invite you to consider amplifying your support for Fighting Blindness Canada by making an extra gift to celebrate this special year—one that will help set in motion our bold new vision and accelerate a brighter future for our community.**

Getting there will take time, so we must start today. Every moment spent waiting for new and improved treatments means more vision loss, while the longer people living with a blinding eye disease and their loved ones wait for information and support means continued anxiety and escalating fear.

Our community needs your help to ensure promising world-class research doesn't go unexplored. They need your help to provide everyone in Canada with the knowledge and support to make living with a blinding eye disease easier.

**Without you, it simply isn't possible.**



Your gift will make a real and tangible impact across our priority areas; for example:



**\$200K**

**Cost of one  
Research  
Grant**



**\$50K**

**Cost of one in-  
person View  
Point conference**



**\$15K**

**Average cost of  
IRD Patient Registry  
in one province**

With your extra gift this year, Fighting Blindness Canada can fund more high-impact research into new and improved treatments that stop vision loss and restore sight. It will also increase educational resources and foster connections between people living with blinding eye disease and allowing them to become part of a supportive community.

**On behalf of our community, thank you for helping us in Raising Our Sights. Together, we can create lasting change and a brighter future for all.**



**FIGHTING  
BLINDNESS  
CANADA**

**5**



**YEARS &  
COUNTING**

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