

**Your Support  
is Driving  
Transformative  
Change**

**PG 7**



**Thanks to You, FBC's Grant  
Competition is Fueling More  
Research Than Ever Before**

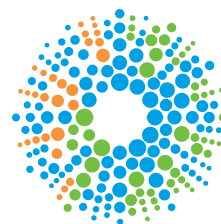
**PG 4-5**

**FBC's Patient Registry is  
Moving Research Forward**

**PG 2**

**How  
We See**

**PG 6**



**FIGHTING  
BLINDNESS  
CANADA**

# THANKS TO YOU, FBC'S PATIENT REGISTRY IS DRIVING NEW TREATMENTS FORWARD!

When Fighting Blindness Canada established its Patient Registry in 2004, it was the first of its kind in the world: a secure medical database that sought to connect people living with blinding eye diseases to emerging treatments and clinical trials.

Today, the Patient Registry is a gold standard database that bridges the gap between researchers and people living with inherited retinal diseases (IRDs). ***Thanks to your support of the Patient Registry, participants are accessing clinical trials that hold true hope for eradicating blinding eye diseases!***

The Patient Registry accomplishes three important goals. First, it empowers people living with IRDs by giving them the earliest possible access to clinical trials. Second, it demonstrates to the biotech industry that there's an immediate need for new treatments. Third, it enables researchers to conduct the clinical trials they need to make their treatments a reality.

***One of the biggest hurdles that slows the pace of clinical research is finding and recruiting trial participants – the Patient Registry makes it simple by providing a one-stop, anonymized database of prospective trial participants.***

The success of our Patient Registry is clear, because other advocacy groups are following our lead: similar patient registries now exist in the United States and Europe. And our Registry is only growing.

## Why is the Patient Registry important?

The Patient Registry connects Canadians living with inherited retinal diseases to ground-breaking research in a meaningful way. When a clinical trial becomes available, participants are the first to hear about it!

The Patient Registry also gives researchers important insights into certain diseases, like how many people in a given region are affected by a specific genetic mutation. This information helps inspire scientists to work on cures for diseases that are impacting Canadians.

Moreover, it enables FBC to demonstrate the need for Canadian-driven research and treatments. For example, an industry partner might tell us they're thinking of bringing a particular therapy to Canada, but they're not sure how many people might need it. Using the Registry, we can give them accurate information on how many people would benefit from it, giving them an added incentive to bring new treatments to Canada!

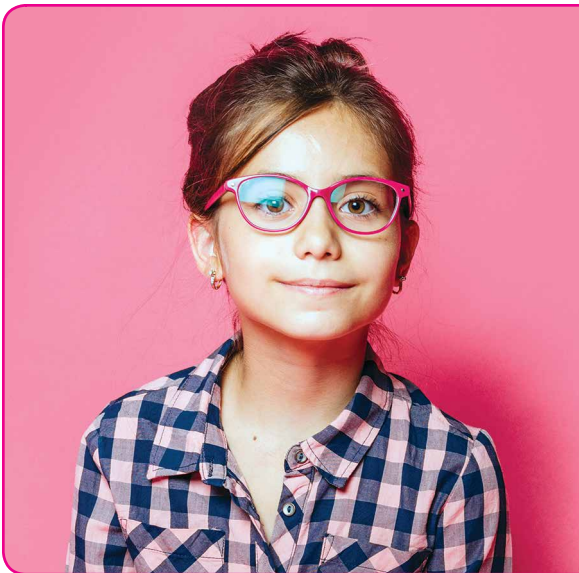
**All of this progress couldn't be possible without your support. Thank you for helping to bring the Patient Registry to life!**



## Accessible Media Inc. Kicks Off Fall Programming

AMI has several exciting announcements, including new seasons of AMI-tv series' *AMI This Week*, *Eyes for the Job*, *Employable Me* and new original documentaries this fall. Catch past episodes of AMI-tv programming at [AMI.ca](http://AMI.ca). AMI-audio is back with all-new instalments of *The Pulse*, *Live from Studio 5*, *Kelly and Company* and *The Neutral Zone*. Look for more information on this, and other news from AMI, in the coming weeks!

**Visit [AMI.ca](http://AMI.ca) to learn more.**



## Bring a Bright Future into Focus with Monthly Giving!

### Join today!

Help change the lives of people living with vision loss by joining our monthly giving program.

#### For information, please contact

Josie Koumandaros

1.800.461.3331 x 262

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



## What Will Your Personal Legacy Be?

Consider leaving a gift to Fighting Blindness Canada in your Will to help future generations.

#### For information, please contact

Ann Morrison

1.800.461.3331 x 232

[amorrison@fightingblindness.ca](mailto:amorrison@fightingblindness.ca)

# FINDING AND FUNDING THE BEST IN VISION RESEARCH

**EVERY YEAR, FBC INVESTS IN  
THE MOST PROMISING RESEARCH TO  
DRIVE NEW TREATMENTS AND CURES**

**Every year, FBC invites researchers from across the country to submit their research proposals to our grant competition. It's a competitive process, and while every project is carefully considered, only the most promising research receives FBC funding.**

How do we choose which projects to fund? The answer is peer review – a tried and true method used across the globe to critically evaluate new research.

We ensure that the research projects we fund are of the highest quality thanks to the generous input of our Scientific Advisory Board (SAB), an independent panel of top vision researchers that volunteer their time and expertise to carefully evaluate every proposal submitted to the grant competition. It's a tall order: this year, Fighting Blindness Canada received over 70 research proposals, all with interesting and exciting potential to change the field of vision research!

Fighting Blindness Canada's annual grant competition supports independent investigators and research teams from Canadian institutions that share our goal of developing new therapies that have the potential of transforming the lives of people living with vision loss. Based on a 24-month period, FBC's grant funding allows scientists to move their research forward, either from the theoretical world to the physical, or from hypotheses in real-world laboratories to treatments in clinical trials.

Research applicants can apply to one of four research categories: Discovery research, translational research, clinical research, and vision rehabilitation research. Regardless of which category the research falls into, each project is focused on accelerating the development and availability of treatments and cures.

**Did You Know: Our Scientific Advisory Board contains leading vision scientists from institutions all over the world, including Harvard!**

## FBC's four research categories:

### Discovery

Foundational research into the basic building blocks of vision science



### Vision Rehabilitation

Research into how to assist people living with blinding eye diseases



### Clinical

Research that determines the safety and efficacy of new medicines, devices, and treatment regimens



### Translational

Research that seeks to produce applicable treatments to improve vision health



What's clear is that, together, these categories create a continuum: a circle that drives from the very earliest discoveries about the eye, right through to delivering treatments for blinding eye conditions. By making our grant competition broad enough to encompass all aspects of the vision research continuum, we make sure that projects with the most promise can fall within our research scope.

This year, FBC's grant competition is more important than ever. Cuts to research funding mean that scientists have fewer opportunities to receive the capital they

need to push their research projects past the finish line. But thanks to donors like you, FBC is independently funded – which means that we don't receive any government funding for our important work.

**We're grateful for your support, because it's donors like you who make all the difference in funding sight-saving research!**

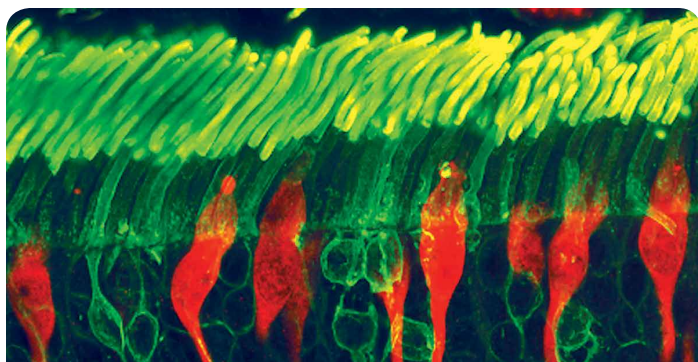
# ANSWERING COMMONLY ASKED VISION SCIENCE QUESTIONS

At Fighting Blindness Canada, our funded researchers are answering vital questions about the science of vision. To celebrate the back-to-school season, we sat down with some of our researchers to ask a few basic questions about how we see.

## 1. What are photoreceptors?

Photoreceptor cells are critically important because they are the only light-sensitive cells in the eye that can convert light into information for the brain.

The retina – the thin layer of tissue at the back of the eye – processes light through a layer of light-sensitive **photoreceptor cells**. These cells detect colour and light intensity, then convert that light into signals to send to the brain. There are two types of photoreceptor cells – **rods** and **cones**. They each have an important part to play in converting light: rods are responsible for night vision and cones give us colour perception and central, high-acuity vision.



Photoreceptors are the light sensitive cells in the retina that convert light into information for the brain.

Image courtesy of the National Eye Institute

## 2. How do doctors diagnose eye conditions?

Eye specialists use different imaging techniques and technologies to gather clues about what's happening in a patient's eye. One of the most common tests is called **optical coherence tomography (OCT)**, which uses light waves to take detailed pictures of the retina. **Fluorescein angiography** is a procedure where fluorescent dye is injected into the bloodstream so doctors can see and photograph the blood vessels in the back of the eye. **Electroretinograms** detect whether the retina is functioning properly by measuring how photoreceptors are responding to light. Together, these tests (and others!) allow doctors to gather as much information as possible about a person's eye health, giving them the best possible chance for diagnosis and treatment.

## 3. What can I do to take care of my eye health?

There are many proactive things you can do to protect your sight: eat a diet rich in antioxidants, exercise regularly, and give up smoking. But above all, visit your eye doctor regularly! People over the age of 60 are more susceptible to developing blinding eye diseases, so it's important to get regular checkups. Changes in eye health are often undetectable without the help of a specialist, so get your eyes examined early and often!

# FUNDING A BRIGHT FUTURE THROUGH MONTHLY GIVING

## FOR DEBBIE AND ROB CONN, VISION LOSS IS PART OF THEIR EVERYDAY LIFE

They live with vision loss when they're dropping 17-year-old Makayla off at her part-time job at the library. They live with it when they're attending 13-year-old Dalaynie's dance recitals. Why? Because both of their daughters have retinitis pigmentosa (RP).

They first realized that Makayala was having vision troubles when she was unable to navigate low-lit hallways as a child. She was diagnosed at seven years old; a few years later, Dalaynie's diagnosis followed.

Living with vision loss has been a difficult adjustment for the Conn family, but Debbie and Rob are giving their daughters the tools they need to thrive, with or without vision. Both Makayla and Dalaynie have learned Braille and are active in their community. Both girls have been involved in social justice groups at school, attend music camp and downhill ski.

"Like most parents, our goal is to raise confident, positive, independent, strong daughters. We may just have a few more hurdles to jump in the process," says Debbie. "This disease definitely puts physical, psychological and emotional barriers in place, but we work daily to break down those barriers. Rather than dwelling on the possibility that our daughters eventually might not have sight, we're helping them embrace the capable, wonderful people they are."



The Conns found Fighting Blindness Canada through their daughters' vision resource teacher, who invited them to join Cycle for Sight. As a family, they have been participating in Cycle for Sight on tandem bikes for the past five years, and have become monthly FBC donors.

"As a family, we need to feel that we are taking an active role in helping not only our daughters but all those living with vision loss," Debbie continues. "Being part of Cycle for Sight always leaves us feeling inspired and hopeful that, with continued support for research, we will find a cure!"

# VISION QUEST EDUCATION SERIES

Join thousands of people living with blinding eye diseases, along with clinicians, researchers, industry experts, and low vision specialists, as we share the latest breakthroughs in vision science!

## Upcoming 2019 Vision Quest Events

**Halifax | Symposium**  
September 14

**Calgary | Conference**  
October 26

**Toronto | Speaker Series**  
November 12

# YOUNG LEADERS

FBC's Young Leaders Program is a career-oriented initiative that works to provide young people who are living with blindness with the tools they need to envision and pursue rewarding careers.

## Upcoming 2019 Young Leader Events

**Halifax | Young Leaders Summit**  
September 14-15

**Toronto | Young Leaders Summit**  
October 5-6

# FUNDRAISING EVENTS

Join us in Vancouver for Comic Vision: Canada's original and most beloved stand-up comedy fundraising tour!

**Vancouver | Comic Vision**  
November 1

# GET INVOLVED

Visit [fightingblindness.ca](http://fightingblindness.ca)  
or call us at 1.800.461.3331  
to learn more!

