



The FOUNDATION  
FIGHTING BLINDNESS





## ■ OUR VISION

---

# TO RESTORE HOPE AND SIGHT

## ■ OUR MISSION

---

TO LEAD THE FIGHT AGAINST  
BLINDNESS BY ADVANCING  
RETINAL DISEASE RESEARCH,  
EDUCATION AND PUBLIC  
AWARENESS

## TABLE OF CONTENTS

1	MESSAGE FROM THE PRESIDENT & CEO and BOARD CHAIR
2	RESEARCH
4	MOVING VISION SCIENCE FORWARD
7	A CANADIAN FIRST
8	2015 FUNDRAISING EVENTS
9	VISION QUEST 2015
10	2015 LEADERSHIP DONORS
11	2015 CORPORATE EVENT SPONSORS & MONTHLY DONORS
12	2015 FINANCIALS
14	BOARD OF DIRECTORS & SCIENTIFIC ADVISORY BOARD

## MESSAGE FROM THE PRESIDENT & CEO and BOARD CHAIR



Sharon Colle,  
President & CEO



Andrew Burke,  
Board Chair

Dear Friends,

For the Foundation Fighting Blindness, 2015 was a break-through year. Committed supporters like you funded the very first gene-therapy clinical trial for an eye disease in Canada. Over four decades of dedication and research led to this critical turning point.

This clinical trial is just one of the many shining examples of incredible milestones that demonstrate the accelerating pace of vision research. We will be able to go further, faster, thanks to you.

In 2015 alone, your generosity supported a total of 28 ongoing research projects across Canada for a total investment of \$1.64 million. Thank you!

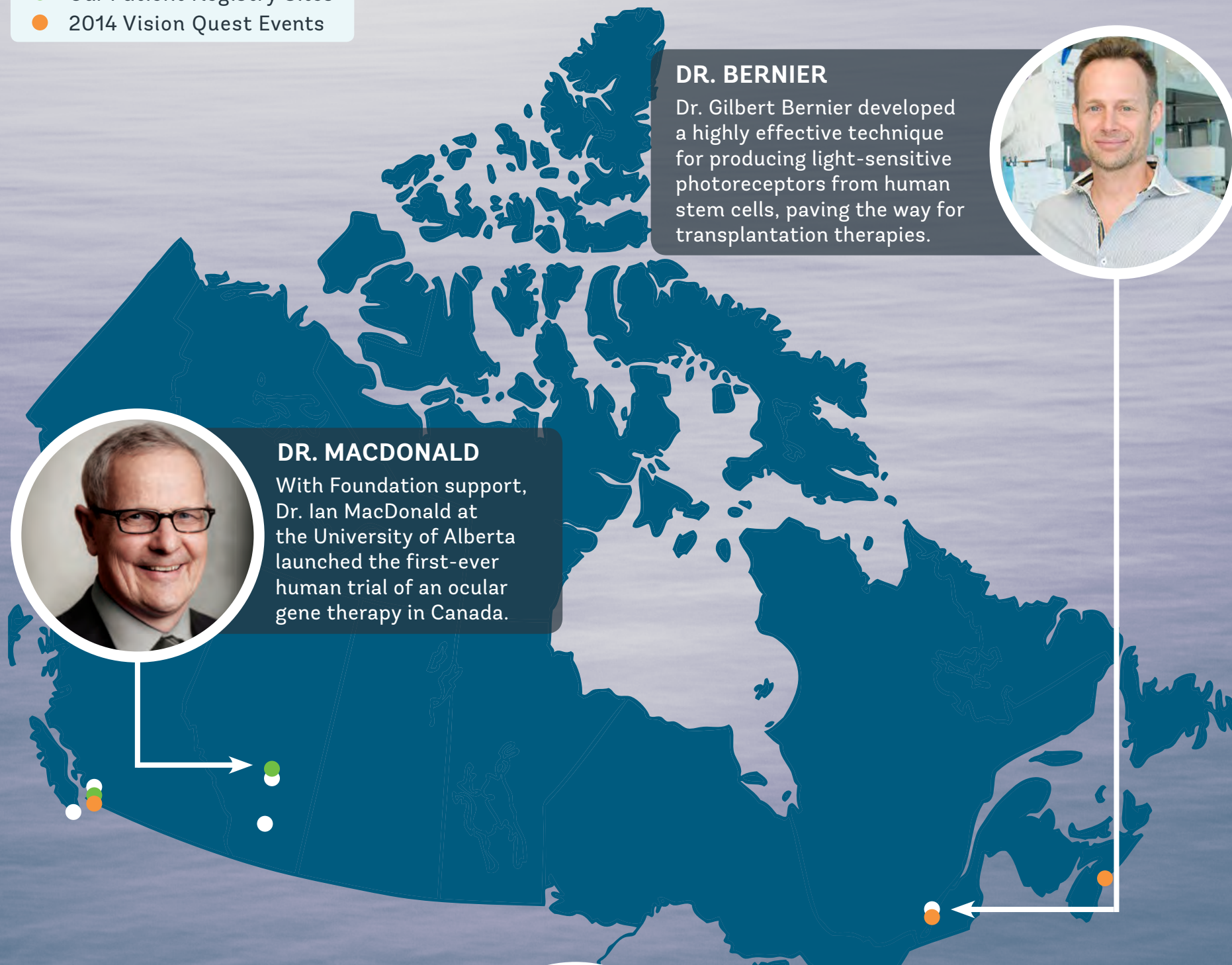
Finding treatments and cures for blinding eye diseases is now possible, and the impact of these discoveries for Canadians living with vision loss will be life changing. As we move forward, we must intensify our efforts, and lean in to the fight against blindness. It's up to us, together, to turn our tremendous hope into reality.

Sincerely,

Sharon Colle  
President & CEO

Andrew Burke  
Board Chair

- Research Sites
- Our Patient Registry Sites
- 2014 Vision Quest Events



**DR. BERNIER**

Dr. Gilbert Bernier developed a highly effective technique for producing light-sensitive photoreceptors from human stem cells, paving the way for transplantation therapies.



**DR. MACDONALD**

With Foundation support, Dr. Ian MacDonald at the University of Alberta launched the first-ever human trial of an ocular gene therapy in Canada.



**DR. NAGY**

Dr. Andras Nagy's team engineered stem cells to secrete a sight-saving drug that they are testing as a one-time treatment for age-related macular degeneration.



**RESEARCH**

Your support funded 28 ongoing research projects across the country in 2015 – over \$1.64 million in sight-saving research to restore hope and sight.

- |   |  |  |
|---|--|--|
| <b>Dr. Gautam Awatramani</b><br>University of Victoria<br>Uses light-sensing molecules to manipulate vision cells                   | <b>Dr. Jean-Sébastien Joyal</b><br>CHU Sainte-Justine<br>Studies sugars/lipids in the eye to develop drug therapies                    | <b>Dr. Orson Moritz</b><br>University of British Columbia<br>Studies valproic acid and its potential treatment of RP |
| <b>Dr. Gilbert Bernier</b><br>Hôpital Masionneuve-Rosemont<br>Developing photoreceptors for transplantation                         | <b>Dr. Robert Koenekoop</b><br>Montreal Children's Hospital<br>Identifying gene mutations causing childhood blindness                  | <b>Dr. Andras Nagy</b><br>Mount Sinai Hospital<br>Combining gene and stem cell therapies to treat AMD                |
| <b>Dr. Rod Bremner</b><br>Mount Sinai Hospital<br>Harnessing the eye's ability to regenerate  | <b>Dr. Bruno Larrivée</b><br>Université de Montréal<br>Developing more effective AMD treatments  | <b>Dr. Stéphanie Proulx</b><br>Université Laval<br>Developing mechanisms to transplant retinal cells                 |
| <b>Dr. Michel Cayouette</b><br>Institut de recherches cliniques de Montréal<br>Examines the fundamental mechanics of photoreceptors | <b>Dr. Ian MacDonald</b><br>University of Alberta<br>Leading the first human clinical trial of a treatment for choroideremia in Canada | <b>Dr. Christian Salesses</b><br>Université Laval<br>Studies an eye protein necessary for vision                     |
| <b>Dr. Mahyer Etmnian</b><br>University of British Columbia<br>Examining how prescription drugs may influence AMD risk              | <b>Dr. Sarah McFarlane</b><br>University of Calgary<br>Tracking the movements of damaged eye cells                                     | <b>Dr. Mike Sapieha</b><br>Hôpital Masionneuve-Rosemont<br>Studies compounds that could protect nerve cells          |
| <b>Dr. Cheryl Gregory-Evans</b><br>University of British Columbia<br>Developing an eye drop to repair damaged retinal cells         | <b>Dr. Philippe Monnier</b><br>Toronto Western Hospital<br>Developing new drugs to stop damaged cells from dying                       | <b>Dr. Valerie Wallace</b><br>University Health Network<br>Funded for photoreceptor transplantation studies          |

Nine Foundation-funded research projects concluded in 2015.

- |   |  |   |
|---|--|---|
| <b>Dr. Belinda Chang</b><br>University of Toronto     | <b>Dr. Kevin Gregory-Evans</b><br>University of British Columbia | <b>Dr. David Picketts</b><br>Ottawa Hospital<br>Research Institute      |
| <b>Dr. Robert Devenji</b><br>Toronto Western Hospital | <b>Dr. Perry Howard</b><br>University of Victoria                | <b>Dr. Uri Saragovi</b><br>Lady Davis Institute for<br>Medical Research |
| <b>Dr. Robert Gendron</b><br>Memorial University      | <b>Dr. Saeed Khalili</b><br>University of Toronto                | <b>Dr. Catherine Tsilfidis</b><br>Ottawa Health<br>Research Institute   |

**Four Patient Registry Enrollment were funded at:**  
IWK Children's Hospital (NS), SickKids (ON), University of Alberta (AB), Vancouver General Hospital (BC)

## MOVING VISION SCIENCE FORWARD

### 2015 RESEARCH HIGHLIGHTS & THE ROAD TO TREATMENTS

Your support in 2015 helped move important research along the path from the laboratory toward the clinic. This path of four overlapping stages starts with *Discovery Research*, progresses to *Pre-Clinical Research* and then into the *Clinical Trial* phase, where potential

treatments are evaluated for their safety and efficacy in people. If successful, we are rewarded with new sight-saving treatments. Below you'll find the notable projects we funded in 2015 in each of these stages, as well as how our education and advocacy efforts are contributing to moving sight-saving science forward - all thanks to you!

#### DISCOVERY RESEARCH

Discovery Research underpins all new treatments by generating knowledge required for therapeutic intervention.

**42** New Discoveries

Our funded scientists made 42 new discoveries in 2015.

**2015 Highlights:**

- DR. AWATRAMANI**  
Discovered how motion and spacial information are stored in the vision pathway.
- DRS. KOENENKOOP & CAYOQUETTE**  
Discovered a new blindness-causing gene that will be essential for developing new treatments.

#### PRE-CLINICAL RESEARCH

Pre-clinical Research is directly focused on collecting information to enable a specific treatment approach to be tested in people.

**23** New Research Tools Designed

Our funded scientists created 23 new tools to fuel research.

**2015 Highlights:**

- DR. BERNIER**  
Developed a new tool for mass-producing human photoreceptors from stem cells for transplantation.
- DR. SARAGОВI**  
Developed tools to show that two new proteins slow the progression of retinitis pigmentosa, glaucoma and diabetic retinopathy.

#### CLINICAL TRIALS

Clinical Research involves testing a new therapy on people to analyze its efficacy and safety.

**2** Exciting Clinical Research Trials

These two projects are our first funded clinical trials.

**2015 Highlights:**

- DR. MACDONALD**  
Commenced Canada's first-ever human gene therapy trial for a blinding eye disease. This study used our **Patient Registry** to select trial participants.
- ARGUS II**  
Ongoing observational trial of 'bionic eye' doubles number of participants.

#### SIGHT-SAVING TREATMENTS

If successful in the clinical stage, treatments have the opportunity to become publicly available.

#### EDUCATION / ADVOCACY

- PATIENT EVIDENCE**  
We submitted patient feedback to government agencies and advocated for access to treatments.
- VISION QUEST**  
Our annual education conference visited five Canadian cities, involving 1100+ participants.

**YOU CAN CONTINUE TO HELP INCREASE THE PACE OF RESEARCH. DONATE TODAY AT [FFB.CA](http://FFB.CA) OR CALL 1.800.461.3331 EXT. 262.**



**“RESEARCH HAS THE POWER TO DELIVER LIFE-CHANGING RESULTS.”**

Photo: L-R: Dr. Riz Somani, Dr. Matt Tennant, Dr. Ioannis (John) Dimopoulos, Prof. Robert MacLaren, Dr. Ian MacDonald, Janice Hengsbach RN, Dr. Markus Groppe and Dr. Paul Freund.

## ■ A CANADIAN FIRST PIONEERING GENE THERAPY TRIAL FOR INHERITED BLINDNESS

Will gene therapy be an effective treatment for blinding eye diseases? Many people who live with vision loss are waiting for an answer while scientists and clinicians test different approaches to gene therapy that aim to replace damaged genes with new, functional copies.

In 2015, Foundation Fighting Blindness donors supported Canada’s first gene therapy clinical trial for choroideremia, a rare blinding eye condition that travels through families on the X chromosome. An affected man has a 50 percent chance of passing the damaged gene to his sons, and his daughters will be carriers of the disease.

In the 1980s, scientists did not know what caused choroideremia, but there was a clear inheritance pattern. Dr. Ian MacDonald was inspired to study the disease by Barbara Owens, whose family was affected. A family tree enthusiast, Ms. Owens identified an affected ancestor who had arrived in Ontario in 1849. Building on her information, Dr. MacDonald was able to trace the genetic inheritance of the disease by identifying 1,800 family members.

Moving research from the laboratory into the clinic takes time, dedication, patience, planning, and a broad network of supporters. In 1985, the Foundation began funding Dr. MacDonald’s choroideremia research. He localized the gene to a particular portion of the X chromosome and helped to develop the first predictive test. In 2015, with support from the Foundation, Dr. MacDonald launched Canada’s first gene therapy clinical trial for choroideremia at Edmonton’s Royal Alexandra Hospital. The trial aims to preserve and potentially restore vision for people

with this genetic disorder. Dr. MacDonald says he’s “absolutely impressed” by the eye’s ability to heal itself and reattach the retina within hours of surgery. “The human body is doing its work. We’re just helping it.”

The first clinical trials for choroideremia took place at the University of Oxford. In 2014, early results in *The Lancet Medical Journal* reported that six months after treatment, the first six patients showed improvement in their vision in dim light; and two of the six were able to read more lines on an eye chart. The ongoing Oxford trial, led by ophthalmologist Dr. Robert MacLaren, continues to deliver promising long-term results. To ensure that the Canadian trial learns from the Oxford study, Dr. MacDonald is collaborating closely with Dr. MacLaren, who traveled to Alberta to help with the Canadian clinical trial.

“This new step forward is extremely meaningful,” says Sharon Colle, FFB President & CEO. “From the beginning, we believed in Dr. MacDonald’s research. This trial affirms the Foundation’s long-term commitment to research because it shows that research has the power to deliver life-changing results.”

This pioneering clinical trial paves the way for the future of gene therapy in Canada, which is vital because of the tremendous potential for gene therapy to treat a variety of blinding eye diseases. Thanks to the Foundation’s donors, we expect to see many more applications of gene therapy to treat vision loss in the coming years, including creative approaches that combine the latest innovations in gene therapy with stem cell science and gene editing.

## 2015 FUNDRAISING EVENTS

RIDE FOR SIGHT • COMIC VISION • CYCLE FOR SIGHT



### CYCLE FOR SIGHT

[cycleforsight.ca](http://cycleforsight.ca)



### COMIC VISION

[comicvision.ca](http://comicvision.ca)



### RIDE FOR SIGHT

[rideforsight.com](http://rideforsight.com)

Every year, people across Canada join the fight against blindness by participating in our signature fundraising events: Ride for Sight, Comic Vision and Cycle for Sight. Thousands of motorcyclists, comedy fans and cyclists coast-to-coast fundraise for vision research, helping to restore hope and sight.

# \$2,057,390

RAISED ACROSS CANADA

## 3409

PARTICIPANTS

## 17

EVENTS  
NATIONWIDE

## 352

EVENT  
VOLUNTEERS

## 58

CORPORATE  
SPONSORS

## 13,000

EVENT  
DONORS

## 12.1

MEDIA  
IMPRESSIONS

## VISION QUEST 2015

IMAGINING A BRIGHTER FUTURE

Our annual education event brought together scientists, clinicians, and individuals and families living with vision loss, to imagine a brighter future. We visited five great Canadian cities:

VANCOUVER | LONDON | TORONTO | MONTREAL | HALIFAX



## 1000+

ATTENDEES

## 130+

VOLUNTEERS

## 56

SPEAKERS

## 47

EXHIBITORS



## 15

Participants in  
our first-ever  
Young Leaders  
Summit



## 9

Corporate  
Partners



Stakeholder  
Engagement



To help build a better future, we asked our attendees to take action. Here's how **530 attendees** want to contribute to the fight against blindness:

- Share their story
- Raise awareness
- Mentor a young person with vision loss
- Volunteer
- Join the *Patient Registry*

## 2015 LEADERSHIP DONORS

Thank you to our generous Leadership Donors: individuals, corporations and foundations who made philanthropic gifts of \$5,000 or more in 2015. Your loyal support funded vital research to preserve and restore sight.

### \$250,000+

Anonymous (1)  
Estate of Joyce Conn  
Krembil Foundation

### \$100,000+

Donna Green

### \$25,000 - \$49,999

Alcon Canada Inc.  
Mark and Shelagh Anson  
Estate of Earnest Bradshaw  
Deeley Harley-Davidson Canada  
Renate Greenwood  
Ledcor Group of Companies  
Estate of Gurli Harriet Louw Nielsen  
Estate of Doreen Powles  
Estate of Donald Julian Scott  
Dr. Bill and Kathie Stell  
Bruce Wise

### \$5,000 - \$24,999

Estate of Jeanne Eunice Adams  
Allergan International Foundation  
Anonymous (2)  
Anonymous (3)  
Anonymous (4)  
Dr. Michael Brent  
Christine and Andrew Burke  
Arthur J.E. Child Foundation  
James Collins  
Jane Collins  
Bill and Cindy Court  
Gay Evans  
Jennifer Hancock and John Markell

Joan and Clifford Hatch Foundation  
David Hawkins  
Heathbridge Capital Management  
Dr. Elise Héon  
Ossie Hinds and Anne La Rocque  
(E.) Ben Hochhausen  
Kathryn Holden  
Malcolm Hunter  
Jean Ip  
Ron Lalonde and Jane Humphreys  
Pascal Lavoie  
Gideon and Kari Leoganda  
Beth Malcolm  
Nancy MacKellar  
Paul and Mary Oster  
Deep Patel  
Estate of Vaughnie Pinck  
Glen and Rita Popowich  
Frances and Tim Price  
Estate of Barbara Else Redlich  
James Riley and Nicole Sigouin  
Cam and Michelle Robinson  
Anita and Norm Rolleman  
Marcelle Roy  
Cookie and Stephen Sandler  
George Sheen  
Shorcan Brokers Limited  
Sick Kids Foundation  
Robert Simmons  
Estate of Sally Cohen Standard  
Dr. Raymond Stein and Nancy Viner  
David and Donna Sweeny  
David and Deborah Tennant  
Trev Deeley Foundation  
Clayton and Linda Waitas

## 2015 EVENT SPONSORS

Fundraising and educational event sponsors are integral partners of the Foundation and essential to our success. Your commitment, generosity, and participation at each of our events is staggering. We are grateful to all of our sponsors but have only listed \$5,000+ sponsors here.

### \$50,000+

Accessible Media Inc.  
Bayer Inc.

### \$25,000 - \$49,999

BMO Financial Group  
CIBC  
Deeley Harley-Davidson Canada  
Novartis Pharmaceuticals (Canada) Inc.  
Sirius XM Canada Inc.  
TD Securities Inc.

### \$10,000 - \$24,999

Allergan Inc.  
Peller Estates  
Echelon General Insurance Company  
Essilor  
IBM  
Ledcor Group of Companies

### \$5,000 - \$9,999

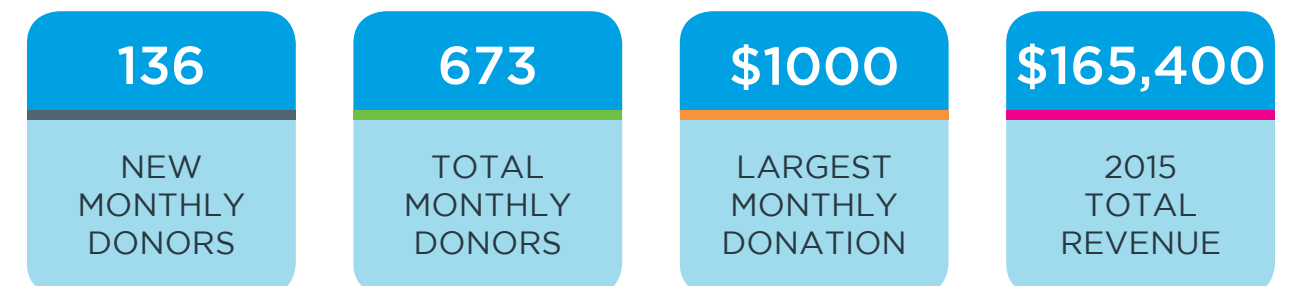
Brown Foreman  
eSight  
Expedia Canada Corporation  
GAMMA Sales Inc.  
L'Occitane  
Independent Financial Concepts Group  
TELUS  
Tridel

### In Kind Event Sponsorship (\$5000+)

Air Canada Foundation  
Bochner Eye Institute  
Kernels Popcorn Limited  
Knar Jewellery  
Four Seasons Hotels  
Dave Lede Family Charitable Foundation  
Brian and Marion MacDonald  
Onward Manufacturing  
Dr. Raymond Stein and Nancy Viner  
Robin and David Young

## 2015 MONTHLY DONORS

We are so grateful to all of our Monthly Donors who generously provide critical and stable funding for sight saving research every month. In 2015, our dedicated monthly donors contributed enough to fund a research project for 18 months.





## 2015 FINANCIALS

The Foundation Fighting Blindness continues to be Canada's largest health charity funding breakthrough vision research, thanks to the ongoing commitment of our donors, volunteers, researchers and families living with blinding eye diseases.

In 2015, the generosity of our 21,762 donors and the commitment of our 482 volunteers generated a gross revenue of over \$4.7 million.

In total, over \$2.1 million was allocated to achieve our mission, including more than \$1.74 million to the funding and oversight of 28 vision research projects across the country.

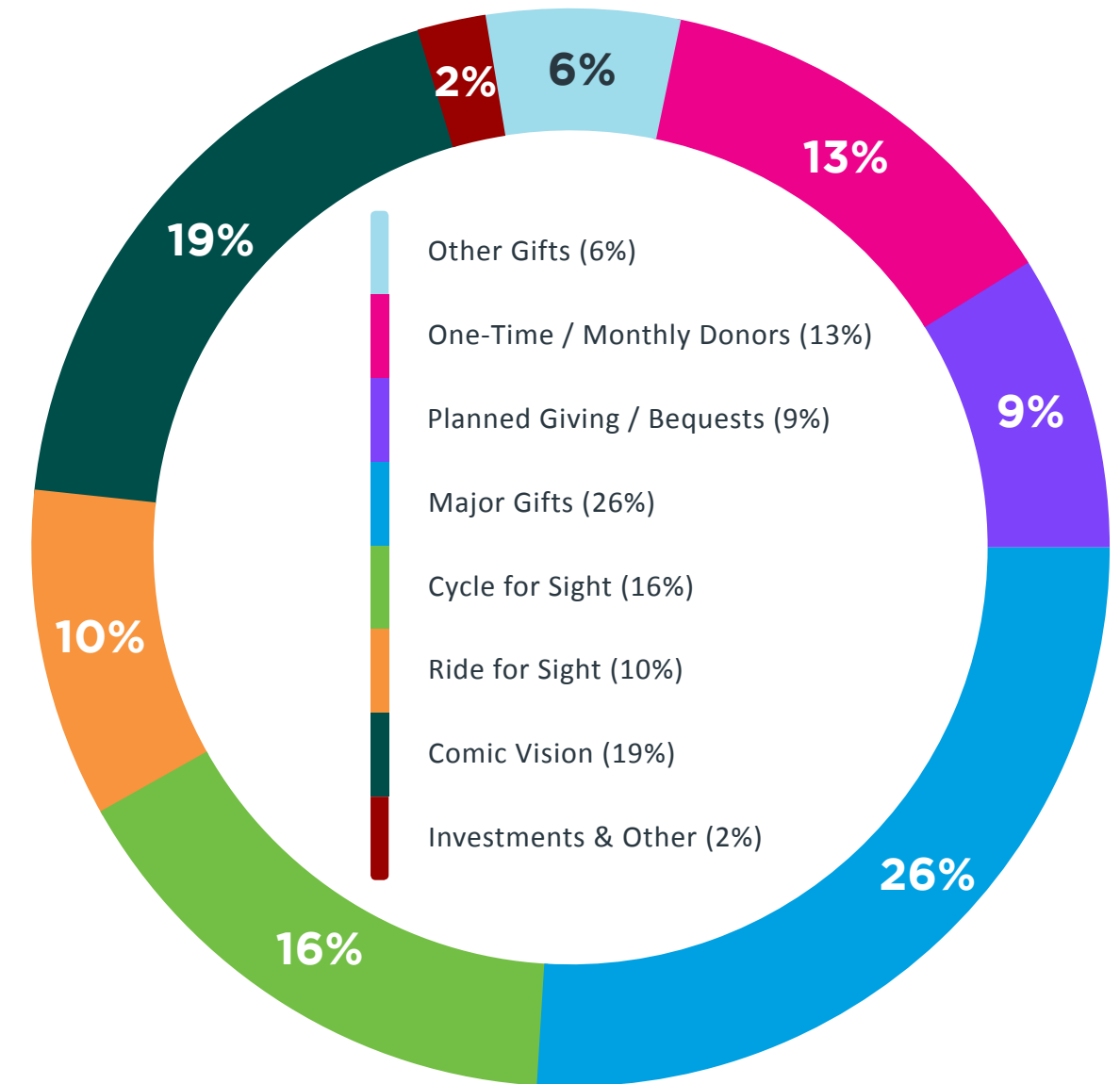
REVENUES	2015	2014
Fundraising Events	\$2,339,193	\$2,325,289
Gifts & Bequests	\$2,301,550	\$2,008,327
Investment / Interest	\$90,721	\$233,648
<b>TOTAL</b>	<b>\$4,731,464</b>	<b>\$4,567,264</b>

MISSION SPENDING	2015	2014
Research	\$1,741,614	\$2,063,017
Education	\$359,529	\$348,598
<b>TOTAL</b>	<b>\$2,101,143</b>	<b>\$2,411,615</b>

By 2011, the Foundation Fighting Blindness had accumulated a significant surplus due to a number of unexpected large gifts in prior years. In keeping with the wishes of our donors, the Foundation used the surplus to invest more heavily in research from 2012 to 2014. In 2015, the Foundation resumed balanced budgeting, resulting in a lower mission expenditure compared to 2014.

FUNDRAISING & ADMINISTRATION EXPENSES	2015	2014
Administration	\$698,461	\$702,319
Fundraising - Events	\$1,176,960	\$1,322,796
Fundraising - Gifts & Bequests	\$684,815	\$678,062
<b>TOTAL</b>	<b>\$2,560,236</b>	<b>\$2,703,177</b>

## SOURCES OF REVENUE



## COMPARISON OF REVENUE TO MISSION SPENDING

REVENUES	2015	2014
Total Revenue	\$4,731,464	\$4,567,264
Net Revenue of Event / Fundraising Costs	\$2,869,689	\$2,566,406
Total Mission Spending	\$2,101,143	\$2,411,615

## ■ BOARD OF DIRECTORS

The Foundation Fighting Blindness Board of Directors is comprised of extraordinary and dedicated individuals who generously volunteer their time to guide the Foundation in its mission.

### EXECUTIVE COMMITTEE

Andrew Burke (Chair)

Joe Grech (Vice-Chair)

Rahn Dodick (Treasurer)

Malcolm Hunter (Corporate Secretary)

John Breen (Executive Officer)

Catherine Tillmann (Executive Officer)

Donna Green (Past Chair)

### BOARD MEMBERS

Michel Cayouette, PhD

David Drury

Sherif El-Defrawy, MD, PhD, FRCSC

Peter Farmer

Jane Humphreys

Peter J. Kertes, MD, CM, FRCSC

Gary Mandel

Michael Ovens

Lorna L. Rosenstein

George Sheen

Raymond M. Stein, MD, FRCSC

David D. Sweeny

Deborah Tennant

## ■ SCIENTIFIC ADVISORY BOARD

The Foundation Fighting Blindness Scientific Advisory Board is comprised of exceptional scientists actively engaged in sight-saving research. They volunteer their time and scientific leadership to evaluate research grant applications and support our education programs.

**Michel Cayouette, PhD** (Chair)

Institut de recherches cliniques  
de Montréal (IRCM)

**Seth Blackshaw, PhD**

John Hopkins University School of  
Medicine

**Rod Bremner, PhD**

Lunenfeld-Tanenbaum Research  
Institute, Mount Sinai Hospital

**Sylvain Chemtob, PhD**

Maisonneuve-Rosemont  
Hospital Research Centre

**Ordan Lehmann, PhD**

University of Alberta

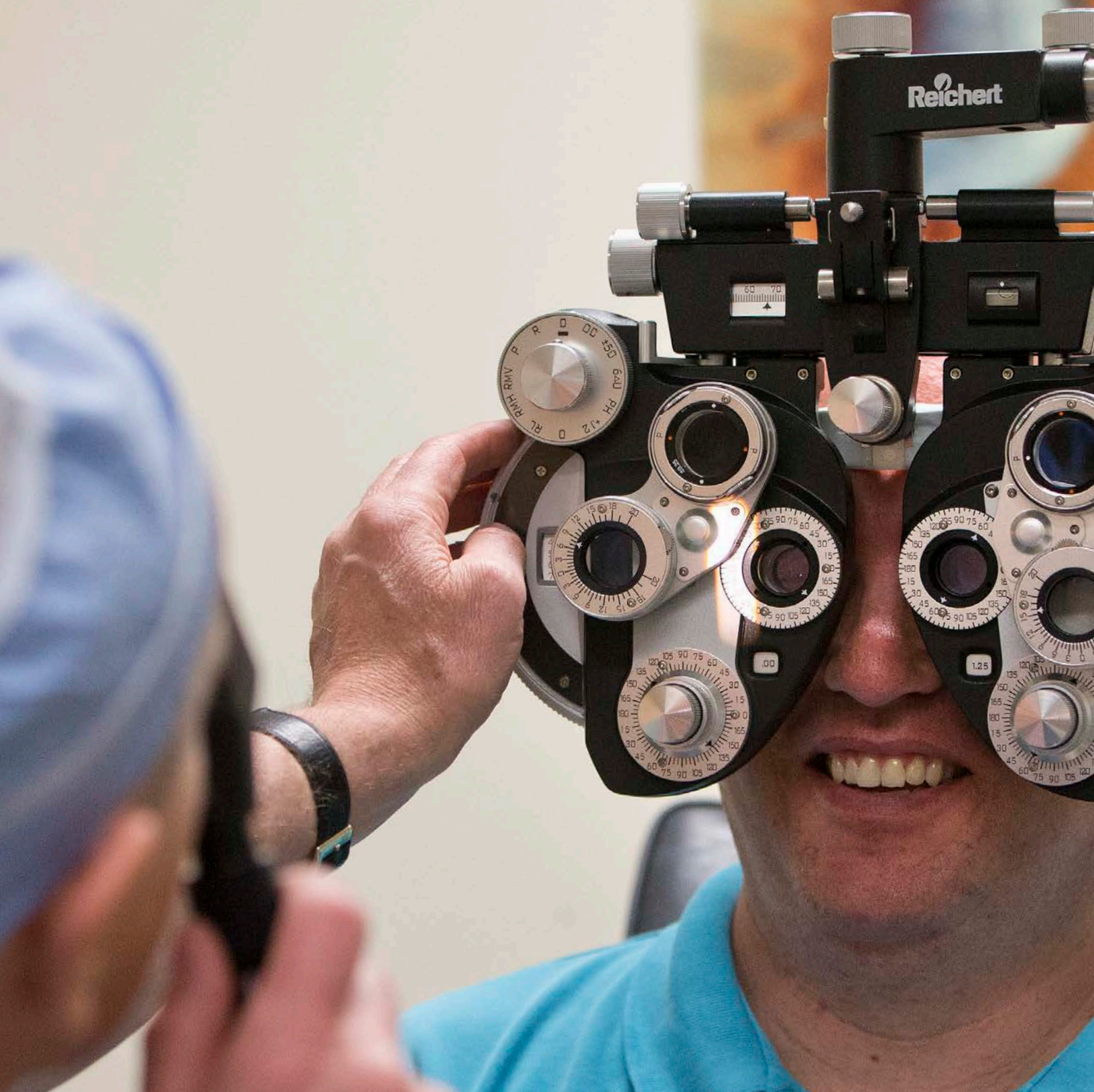
**Brian Link, PhD**

Medical College of Wisconsin

**Orson Moritz, PhD**

University of British Columbia





**The FOUNDATION  
FIGHTING BLINDNESS**

890 Yonge St. 12<sup>th</sup> floor  
Toronto ON M4W 3P4

   
ffb.ca