# **THE FOUNDATION FIGHTING BLINDNESS2015 Annual Report**

OUR VISIONTO RESTORE HOPE AND SIGHT

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

# **MESSAGE FROM THE PRESIDENT & CEO and 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,

Andrew Burke, Board Chair

Sharon Colle,
President & CEO

# **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.

**Dr. Gautam Awatramani**

University of Victoria

Uses light-sensing molecules to manipulate vision cells

**Dr. Gilbert Bernier**

Hôpital Masionneuve- Rosemont

Developing photoreceptors for transplantation

**Dr. Michel Cayouette**

Institut de recherches cliniques de Montréal

Examines the fundamental mechanics of photoreceptors

**Dr. Mahyer Etminan**

University of British Columbia

Examining how prescription drugs may influence AMD risk

**Dr. Cheryl Gregory-Evans**

University of British Columbia

Developing an eye drop to repair damaged retinal cells

**Dr. Jean-Sébastian Joyal**

CHU Sainte-Justine

Studies sugars/lipids in the eye to develop drug therapies

**Dr. Robert Koenekoop**

Montreal Children’s Hospital

Identifying gene mutations causing childhood blindness

**Dr. Bruno Larrivée**

Université de Montréal

Developing more effective AMD treatments

**Dr. Ian MacDonald**

University of Alberta

Leading the first human clinical trial of a treatment for choroideremia in Canada

**Dr. Sarah McFarlane**

University of Calgary

Tracking the movements

of damaged eye cells

**Dr. Philippe Monnier**

Toronto Western Hospital

Developing new drugs to stop damaged cells from dying

**Dr. Orson Moritz**

University of British Columbia

Studies valproic acid and its potential treatment of RP

**Dr. Andras Nagy**

Mount Sinai Hospital

Combining gene and stem cell therapies to treat AMD

**Dr. Stéphanie Proulx**

Université Laval

Developing mechanisms to transplant retinal cells

**Dr. Christian Salesse**

Université Laval

Studies an eye protein necessary for vision

**Dr. Mike Sapieha**

Hôpital Masionneuve- Rosemont

Studies compounds that could protect nerve cells

**Dr. Valerie Wallace**

University Health Network

Funded for photoreceptor transplantation studies

Nine Foundation-funded research projects concluded in 2015:

**Dr. Belinda Chang**

University of Toronto

**Dr. Robert Devenyi**

Toronto Western Hospital

**Dr. Robert Gendron**

Memorial University

**Dr. Kevin Gregory-Evans**

University of British Columbia

**Dr. Perry Howard**

University of Victoria

**Dr. Saeed Khalili**

University of Toronto

**Dr. David Picketts**

Ottawa Hospital

Research Institute

**Dr. Uri Saragovi**

Lady Davis Institute for Medical Research

**Dr. Catherine Tsilfidis**

Ottawa Health 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 FORWARD2015 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.

Our funded scientists made 42 new discoveries in 2015. Here are some 2015 highlights:

DR. AWATRAMANI
Discovered how motion and spacial information are stored in the vision pathway.

DRS. KOENEKOOP & CAYOUETTE
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.

Our funded scientists created 23 new tools to fuel research. Here are some 2015 highlights:

DR. BERNIER
Developed a new tool for mass-producing human photoreceptors from stem cells for transplantation.

DR. SARAGOVI
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.

These two projects are our first funded clinical trials:

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.

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 OR CALL 1.800.461.3331 EXT. 262.**

# **A CANADIAN FIRSTPIONEERING 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**

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 was raised across Canada
* 17 major fundraising events were hosted nationwide
* 3409 participants took part in our national fundraising events
* 352 event volunteers lent a helping hand
* 58 corporate sponsors support the Foundation’s fundraising efforts
* 13,000 people donated to our fundraising events
* Over 12 million media impressions were generated on TV, radio and online, and in newspapers across Canada.

# **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

Here are some of the great statistics from our Vision Quest events:

* Over 1000 people attended Vision Quest events
	+ Including: healthcare experts, donors, caregivers, and people and families living with vision loss.
* 130 volunteers joined in to help host the events
* 56 expert speakers presented and answered questions
* 47 exhibitors were on hand with incredible blind and low vision services, groups and products
* 15 youth took part in our first-ever Young Leaders Summit

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:

* 28% want to share their story of living with vision loss to inspire others
* 35% are going to help raise awareness of blindness and of blindness research
* 17% will join the Foundation Fighting Blindness *Patient Registry*
* 10% will volunteer for the Foundation in the future
* 10% will mentor a young person with vision loss

# **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 ConnKrembil 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 Woitas

# **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
Kernals Popcorn Limited
Knar Jewellery
Four Seasons Hotels
Dave Lede Family Charibtale 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.

Here are some incredible Monthly Donor statistics from 2015:

* 136 New Monthly Donors joined us
* … bringing us to 673 total monthly donors!
* $1000 was our largest monthly donation in 2015
* $165,400 was contributed by Monthly Donors in 2015!

# **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.

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| --- | --- | --- |
| **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 |
| TOTAL | $4,731,464 | $4,567,264 |

|  |  |  |
| --- | --- | --- |
| **MISSION SPENDING** | **2015** | **2014** |
| Research | $1,741,614 | $2,063,017 |
| Education | $359,529 | $348,598 |
| TOTAL | $2,101,143 | $2,411,615 |

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 |
| TOTAL | $2,560,236 | $2,703,177 |

## **SOURCES OF REVENUE**

* Other Gifts (6%)
* One-Time/Monthly Donors (13%)
* Planned Giving/Bequests (9%)
* Major Gifts (26%)
* Cycle for Sight (16%)
* Ride for Sight (10%)
* Comic Vision (19%)
* Investments & Other (2%)

|  |  |  |
| --- | --- | --- |
| **COMPARISON OF REVENUE TO MISSION SPENDING** | 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, Lunenefeld-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