# The Foundation Fighting BlindnessAnnual Report 2014

# OUR VISION

TO 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, 2014 was a year of renewal.

We marked our 40th anniversary by looking back on our historical roots, celebrating our inspiring achievements, and embarking on a new era to lead the fight against blindness. And we launched a new vision and mission statement for the Foundation.

Our new Vision – to restore hope and sight – captures the essence of what we are striving to achieve. And our new Mission – to lead the fight against blindness by advancing retinal disease research, education and public awareness – outlines how we will realize this incredible goal every day.

To accomplish this, your support funded 25 ongoing research projects across the country in 2014. You made over $2 million in sight-saving research possible – our largest investment ever! Thank you for restoring hope and sight.

Sincerely,

Sharon Colle
President & CEO

Andrew Burke
Board of Directors, Chair

# TREATING BLINDNESS WITH A PILL:RESEARCHER LEADS BREAKTHROUGH CLINICAL TRIAL

Imagine if a pill could treat blindness. Thanks to your support, this dream is becoming reality.

In July 2014, an international research project, led by Foundation-funded scientist, Dr. Robert Koenekoop, reported that a new oral medication is showing significant progress in restoring vision to people with Leber congenital amaurosis (LCA).

Until now, this inherited retinal disease that causes reduced vision to complete blindness, has remained untreatable. The study was published in the scientific journal The Lancet.

“This is the first time that an oral drug has improved the visual function of blind patients with LCA,” says Dr. Koenekoop, director of the McGill Ocular Genetics Laboratory at the Montreal Children’s Hospital, and Professor of Human Genetics, Pediatric Surgery and Ophthalmology at McGill University. “It is giving hope to many patients.”

The study involved 14 patients with LCA, ranging in age from six to 38 years old. Their blindness was caused by RPE65 or LRAT genetic mutations, leading to a serious defect in the retinoid cycle. The retinoid cycle is one of the most important functions of the human retina because it produces a molecule called 11-cis retinal which has the capacity to capture light and initiate vision. Patients with RPE65 or LRAT mutations cannot produce this crucial molecule so the retinal cells cannot create vision, and slowly die.

“By giving patients with RPE65 or LRAT mutations an oral retinoid, most patients’ vision improved rapidly. We discovered that a certain portion of the retinal cells that were not working could be woken up,” explains Dr. Koenekoop. “Contrary to what was previously thought, children with LCA and defects in RPE65 or LRAT are not born with dead retinal cells; the cells can simply go dormant, and they can remain dormant for years before they eventually die. The oral drug we tested awakened these cells and allowed patients to see.”

Ten out of the 14 patients expanded their visual fields; others improved their visual acuity. And brain scans of these participants’ visual cortex revealed marked improvements in brain activity. Additional research will now be conducted to learn more about dosage and methodology. Your support of the Foundation Fighting Blindness made this breakthrough possible. Thank you!

## GENE THERAPY RESTORES SIGHT

When Dale Turner was six years old, and diagnosed with Leber congenital amaurosis the prognosis was bleak. His parents were told that Dale would be completely blind by the age of ten but, at 21 years-old, Dale became the first Canadian to receive an experimental gene therapy treatment that restored some of his vision.

To read more about Dale’s incredible story, the research we fund and more, visit our website: ffb.ca.

# A NEW KIND OF VISIONARGUS II RETINAL IMPLANT ARRIVES IN CANADA

A highlight of 2014 was the pioneering story of Orly Shamir, the first Canadian to receive the Argus II retinal implant, also known as the ‘bionic eye’.

By the age of 40, Orly’s vision was gone. Diagnosed with Leber congenital amaurosis as an infant, over time the disease slowly stole Orly’s sight. Throughout her youth, doctors told her nothing could stop the progression. As an adult, all that remained was her ability to see light and shadows.

But Orly never stopped believing that research could change this trajectory. She actively supported the Foundation Fighting Blindness through our Cycle for Sight fundraiser – raising over $20,000 for vision research – never dreaming that she would one day participate in this research herself.

Orly’s exciting surgery was part of a Foundation Fighting Blindness-funded observational trial of the Argus II at the Toronto Western Hospital, led by renowned scientist, Dr. Robert Devenyi.

Retinal implants, such as the Argus II, surgically attach a chip directly to the retina. The tiny chip’s electrodes stimulate the eye’s nerve cells, providing visual information from an external camera.

This is breaking new ground and receiving the implant has dramatically changed the way Orly feels about the world around her. Though it is not a full restoration of vision, the Argus II allows Orly to recognize outlines and shapes. She can point to bright squares as they appear on a dark screen – something she could not do before receiving the implant.

“I’m so grateful to Foundation Fighting Blindness supporters for your generosity and kind hearts,” says the mom of three boys. “You are making incredible things possible and giving hope to people like me living with vision loss.”

Orly’s story reveals the impact of life-changing vision research, made possible thanks to you.

## HOW THE ‘BIONIC EYE’ WORKS

The Argus II uses an innovative approach to restoring sight. In retinal eye diseases the cells that capture light and pass messages along to the brain – photoreceptors – stop working, eventually leading to blindness. Interestingly, the rest of the retina remains largely intact.

This remaining visual pathway is used by the Argus II to restore some visual function. A tiny microchip is attached to the retina and stimulates the eye’s nerve cells, providing visual information from an external camera. This small video camera is attached to special glasses connected to a pocket-sized computer. The computer transforms the images into signals that are sent wirelessly to the implanted chip. The chip then emits pulses of electricity through the optic nerve and into the brain. With training, Argus II recipients learn to translate this information into visual cues about their environment.

# REAL-LIFE RESEARCH RESULTSWET-AMD TREATMENTS PRESERVE ARTIST’S VISION

At the age of 58, a dark cloud appeared in Patty Gill’s vision. She didn’t think much of it at first, but after numerous visits to her eye doctor, she learned she had wet age-related macular degeneration (AMD) - the most severe form of an eye disease that affects over 1 million Canadians.

As a passionate, life-long painter and illustrator, Patty was terrified that her life as an artist would vanish along with her vision. She worried too about how it might affect her family.

There are two forms of AMD – dry and wet. Together, they are the leading cause of vision loss for Canadians over the age of 50. Dry AMD makes up 90 percent of cases and remains untreatable. Wet AMD occurs when blood vessels in the back of the eye begin to leak fluid. Without immediate treatment, wet AMD can lead to blindness very quickly.

When Patty was diagnosed, there were no treatment options for wet AMD, but soon cutting-edge research developed treatments to slow, stop and in some cases, even reverse progression. She began to receive regular injections in her affected eye and those treatments slowed her vision loss to a near stand-still. Eleven years later, Patty’s other eye was also diagnosed with wet AMD, so her treatment regime expanded.

Patty has continued receiving treatment ever since. Over the years, new wet AMD medications have become available, and research is continually striving to improve their effectiveness, convenience and affordability. Now, at 76, Patty says these medications saved her vision. Today, she is still able to create incredible paintings, and does so with her husband, Hugh. Together, they are using their artistic talents to support the Foundation Fighting Blindness. Proceeds from their paintings support sight-saving research so scientists can seek new, improved treatments for AMD and, ultimately, a cure.

“We give back because we know research will one-day discover a way to prevent AMD from ever stealing people’s sight,” says Patty. “Donating our talents to support the Foundation Fighting Blindness is our way of giving back. Our way to take a stand against blindness.”

“Working to prevent vision loss gives us a greater purpose,” adds Hugh. “Painting with this cause in mind makes us feel part of something crucially important; something extremely meaningful.”

## Discovery paves way for new AMD treatments

In 2014, Dr. Jean-Sébastien Joyal and his colleagues made a ground-breaking discovery. They found that a single receptor plays a critical role in retinal blood vessel growth. This is potentially game-changing because abnormal blood vessel growth causes vision loss in wet age-related macular degeneration (AMD), and is also at the root of many other retinal diseases. Identifying this receptor gives researchers a new target for developing sight-saving drugs. We awarded Dr. Joyal an operating grant in 2014 for this research. Read more: ffb.ca.

# OUR RESEARCH

Your support funded 25 ongoing research projects in eight cities across the country in 2014 – over $2 million in sight-saving research to restore hope and sight. Thanks to your generosity, Foundation research funding increased to become our largest research investment ever!

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| ONTARIO | Dr. Saeed Khalili University of Toronto Studies retinal stem cells to develop new therapies | Dr. Robert GendronMemorial UniversityStudying protein pathways and how they affect AMD |
| Dr. Belinda Chang University of Toronto Studies the rhodopsin gene’s effect on vision | QUEBEC | BRITISH COLUMBIA |
| Dr. Rod Bremner Mount Sinai Hospital Working to harness the eye’s internal ability to regenerate | Dr. Stéphanie Proulx Université Laval Developing mechanisms to transplant retinal cells | Dr. Orson Moritz University of British Columbia Studies valproic acid and its potential treatment of RP |
| Dr. Robert Devenyi Toronto Western Hospital Leading the Argus II observational trial | Dr. Jean-Sébastian Joyal CHU Sainte-Justine Studies sugars/lipids in the eye to develop drug therapies | Dr. Kevin Gregory-Evans University of British Columbia Studies the molecular factors that lead to vision loss |
| Dr. Valerie Wallace University Health Network Funded for two studies; both investigating cone function and potential treatments | Dr. Robert Koenekoop Montreal Children’s Hospital Identifying gene mutations causing childhood blindness | Dr. Cheryl Gregory-Evans University of British Columbia Developing an eye drop to repair damaged retinal cells |
| Dr. Catherine Tsilfidis Ottawa Health Research Institute Developing a gene therapy to prevent retinal cell death | Dr. Bruno Larrivée Université de Montréal Developing more effective AMD treatments | Dr. Perry Howard University of Victoria Working to improve how photoreceptors are generated |
| Dr. Vincent Tropepe University of Toronto Studying genes that allow the eye to regenerate | Dr. Mike Sapieha Hôpital Masionneuve- Rosemont Studies compounds that could protect nerve cells | Dr. Gautam Awatramani University of Victoria Uses light-sensing molecules to change the response of vision cells |
| Dr. Derek van der Kooy University of Toronto Developing new stem cell transplantation techniques | Dr. Gilbert Bernier Hôpital Masionneuve- Rosemont Improving quality and strength of transplanted photoreceptors | Dr. Mahyer Etminan University of British Columbia Examining how prescription drugs may influence AMD risk |
| Dr. Philippe Monnier Toronto Western Hospital Developing new drugs to stop damaged cells from dying | Dr. Michel Cayouette IRCM Examines the fundamental mechanics of photoreceptors | ALBERTA |
| Dr. David Picketts Ottawa Hospital Research Institute Studies wiring and survival of retinal interneurons to restore sight | NEWFOUNDLAND | Dr. Ian MacDonald University of Alberta Leading the first human clinical trial of a treatment for choroideremia in Canada |

# VISION QUEST 2014OUR LARGEST EDUCATION SERIES EVER

Vision Quest, our annual education series, fosters our informed, educated and empowered community of individuals and families living with blindness. Vision Quest is their opportunity to connect with peers, find resources, and hear directly from researchers and clinicians about the latest breakthroughs in vision science.

* We visited three great, Canadian cities: Toronto, Hamilton and Calgary
* Featured 33 renowned vision experts, along with 41 eye health exhibitors
* Hosted 1,050 attendees

## VISION QUEST 2014 | OUR CORPORATE SPONSORS

Vision Quest is made possible thanks to the generosity of our corporate sponsors:

$25,000:
Bayer Inc.
Novartis Pharmaceuticals (Canada) Inc.
Accessible Media Inc.

$7,500 - $10,000:
eSight
L’Occitane
Bausch & Lomb

$5,000:
SickKids Foundation
AROGA
Rx&D

# 40 YEARS OF DISCOVERYCELEBRATING FOUR DECADES OF SIGHT-SAVING RESEARCH

Forty years ago, a small group of families living with retinal eye diseases formed the Foundation.

Fighting Blindness. The community they built has enabled sight-saving research and given hope to countless Canadians living with vision loss.

In the early years, our research efforts focused exclusively on retinitis pigmentosa and other closely related conditions. As our scientific understanding and capacity expanded, so did our mission; now embracing many retinal conditions, including age-related macular degeneration.

Over the past 40 years, the Foundation Fighting Blindness has directed over $25 million from you, our donors, to accelerate Canadian vision research. Together, we have created a powerful vision research community that is helping to shape the international effort to find treatments and cures for retinal eye diseases.

## Celebrating 40 Years of Discovery

Over the past 40 years, Foundation Fighting Blindness donors have contributed their time and money to fund sight-saving research. To mark our 40th anniversary in 2014, we convened a task force of scientists, donors, board members and people living with retinal disease to take stock of our research acccomplishments of the past four decades. This group oversaw a wide-ranging evaluation of what your support has achieved. This included surveying past and presently funded scientists and trainees, and an evaluation of our published research.

What we discovered was truly inspiring! The impact of the research you fund has been felt far and wide, informing and influencing scientific studies both nationally and internationally. This, and more exciting findings have been published in 40 Years of Discovery: Our Report to Donors, available at ffb.ca.

# OUR 2014 FUNDRAISING EVENTSRIDE FOR SIGHT / COMIC VISION / CYCLE FOR SIGHT: $2.3 million raised.

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, bringing us closer than ever to treatments and cures for blindness.

Quick facts:

* Over 3300 participants
* 16 events nationwide
* 470 volunteers
* Over 9 million media impressions
* 99 corporate sponsors
* 16,083 event donors

# OUR 2014 LEADERSHIP DONORS

Thank you to our generous Leadership Donors: individuals, corporations and foundations who made philanthropic gifts of $5,000 or more in 2014. Your loyal support funded vital research to preserve and restore sight.

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| $100,000+Anonymous (1)Anonymous (2)$50,000 - $99,999Mark and Shelagh AnsonEstate of Jeanne Eunice AdamsJean IpKrembil FoundationLedcor Group of Companies$25,000 - $49,999Anonymous (3)Capital One CanadaDeeley Harley-Davidson Canada Donna GreenRenate GreenwoodGlen and Rita PopowichRBC Foundation $5,000 - $24,999Anonymous (4)Anonymous (5)Arthur J.E. Child FoundationDr. David and Rachel BaronBayer Inc.Steve BeattieBochner Eye InstituteEstate of Ernest BradshawChristine and Andrew Burke James CollinsJane CollinseSight Foundation (Community Foundation of Ottawa)Don Ferguson | Estate of Katherine Sharon GerstlJoe and Deborah GrechCatherine and Greg HaverstockOssie Hinds and Anne La RocqueJohn and Kathryn HoldenCheryl and Andrew HowdenMalcolm HunterRobert & Elaine JamesRon Lalonde and Jane HumphreysGideon and Kari Leoganda Nancy MacKellarLeonard and Selma MartinDr. Andrew and Shawna MerkurEstate of Jean PettitPizzaville Inc.Estate of Doreen PowlesJames Riley and Nicole SigouinCam and Michelle RobinsonAnita and Norm RollemanCookie and Stephen SandlerGeorge SheenShorcan Brokers LimitedPhilip Smith Foundation Pat and Bob SteeleDr. Raymond Stein and Nancy VinerDr. Bill and Kathie StellDavid and Donna SweenyTELUS Communications Inc.TELUS Vancouver Community BoardDavid and Deborah Tennant Toby TobiasonTrev Deeley Foundation Buddy VictorClayton and Linda Woitas |

# OUR 2014 CORPORATE EVENT SPONSORS

Our Comic Vision, Cycle for Sight and Ride for Sight sponsors are integral partners of the Foundation Fighting Blindness and essential to our success. Your commitment, generosity, and participation at each of our events is staggering. We are grateful to all of our cash and in-kind sponsors but we have only listed $5,000+ level here.

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| $25,000+Accessible Media Inc. Bayer Inc.BMO Financial GroupCIBCDeeley Harley-Davidson CanadaNovartis Pharmaceuticals (Canada) Inc.Sirius XM Canada Inc. TD Securities Inc.$10,000 - $24,999Air Canada FoundationAlcon Canada Inc.Bochner Eye Institute Gluskin Sheff + AssociatesIBMKnar Jewellery | Ledcor Group of CompaniesThe Optical GroupPeller EstatesShred-It$5,000 - $9,999Calgary Retina ConsultantsExpedia Canada Corporation Four Seasons Hotels GAMMA Sales Inc. iCo Therapeutics Inc. Onward ManufacturingPengrowth Energy CorporationTridel Harry RosenTELUS Yamaha Motor Canada |

# OUR 2014 MONTHLY DONORS

We are grateful to all of our Monthly Donors who generously provide crucial and reliable funds to support vision research on an ongoing basis. In 2014, our loyal monthly donors contributed enough to fund an entire research project for 18 months.

* 136 New Monthly Donors
* 633 Total Monthly Donors
* $400 Largest Monthly Donation
* $151,875 Total Revenue (2014)

# OUR 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)
John Breen (Vice-chair)
Rahn Dodick (Treasurer)
Malcolm Hunter (Corporate Secretary)
Joe Grech (Executive Officer)
Catherine Tillmann (Executive Officer)
Donna Green (Past Chair)

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Michael Ovens
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Raymond M. Stein, MD, FRCSC
David D. Sweeny
Deborah Tennant

# OUR 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

**Rod Bremner, PhD**
Lunenefeld Tanenbaum Research Institute, Mount Sinai Hospital

**Robert Gendron, PhD**
Memorial University of Newfoundland

**Ordan Lehmann, PhD**
University of Alberta

**Brian Link, PhD**
Medical College of Wisconsin

**Orson Moritz, PhD**University of British Columbia

**William Stell, PhD** (Non-voting member)
University of Calgary

**Valerie Wallace, PhD** (Past Chair)
Toronto Western Research Institute,
University Health Network

# OUR 2014 FINANCIALS

Thanks to the dedication of our donors, volunteers, researchers and families living with blinding eye diseases, the Foundation Fighting Blindness continues to be the largest health charity funding life-changing vision research in Canada.

In 2014, the generosity of our 22,975 donors and the commitment of our 485 v olunteers generated a gross revenue of over $4.5 million. Our Major Gift program continued to be our largest revenue source, accounting for over $1.3 million, or 29 per cent of total revenue. Our fundraising events raised over $2.3 million, or 47 pe r cent of total revenue.

In total, over $2.4 million was allocated to achieve our mission, including over $2 million funding 25 vision research projects from coast to coast.

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| REVENUES | 2014 | 2013 |
| Fundraising Events | $2,325,289 | $2,368,999 |
| Gifts & Bequests | $2,008,327 | $1,990,195 |
| Investment / Interest | $233,648 | $193,669 |
| TOTAL | $4,567,264 | $4,552,863 |

|  |  |  |
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| MISSION SPENDING | 2014 | 2013 |
| Research | $2,063,017 | $2,087,738 |
| Education | $348,598 | $303,902 |
| TOTAL | $2,411,615 | $2,391,640 |

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| OPERATING EXPENSES | 2014 | 2013 |
| Fundraising Events | $1,322,796 | $1,249,164 |
| Direct Fundraising | $678,062 | $633,285 |
| Administration | $702,319 | $742,658 |
| TOTAL | $2,703,177 | $2,625,107 |

## SOURCES OF REVENUE

* 29% Major Gifts
* 19% Other Gifts
* 18% Comic Vision
* 16% Cycle for Sight
* 13% Ride for Sight
* 5% Investment & Other

## COMPARISON OF REVENUE TO MISSION SPENDING

|  |  |  |
| --- | --- | --- |
| REVENUES | 2014 | 2013 |
| Total Revenue | $4,567,264 | $4,552,863 |
| Revenue Net of Event / Fundraising Costs | $2,566,406 | $2,670,417 |
| Total Mission | $2,411,615 | $2,391,640 |