

The FOUNDATION FIGHTING BLINDNESS



ANNUAL REPORT 2014

DR. VALERIE WALLACE

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OUR VISION

TO RESTORE HOPE AND SIGHT

OUR MISSION

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

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MESSAGE FROM THE PRESIDENT & CEO and BOARD CHAIR



Sharon Colle, President & CEO

Andrew Burke, 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,

Charon Calle

Sharon Colle President & CEO

Adu Ba

Andrew Burke **Board Chair**

The oral drug we tested awakened retinal cells and allowed patients to see.

DR. ROBERT KOENEKOOP

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TREATING BLINDNESS WITH A PILLRESEARCHER 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**.



I'm so grateful to Foundation Fighting Blindness supporters... You are making incredible things possible.

ORLY SHAMIR

A NEW KIND OF VISION ARGUS 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.

We give back because we know research will one day discover a way to prevent AMD from ever stealing people's sight.

PATTY GILL

REAL-LIFE RESEARCH RESULTS WET-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 cuttingedge 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**.

Research Sites

- Our Patient Registry Sites
- 2014 Vision Quest Events

DR. KOENEKOOP

The Foundation continues to fund Dr. Robert Koenekoop's efforts at the Montreal Children's Hospital to identify genetic mutations responsible for childhood blindness.



DR. MACDONALD

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

THE DEDICATION OF OUR DONORS, VOLUNTEERS AND RESEARCHERS MAKES THE FOUNDATION FIGHTING BLINDNESS THE LARGEST HEALTH CHARITY FUNDING SIGHT-SAVING RESEARCH IN CANADA.

DR. DEVENYI

Dr. Robert Devenyi at Toronto Western Hospital is leading an observational trial of the Argus II - a retinal prosthetic that has returned partial sight to totally blind patients.



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!

ONTARIO

Dr. Belinda Chang University of Toronto Studies the rhodopsin gene's effect on vision

Dr. Rod Bremner Mount Sinai Hospital Working to harness the eye's internal ability to regenerate

Dr. Robert Devenyi Toronto Western Hospital Leading the Argus II observational trial

Dr. Valerie Wallace University Health Network Funded for two studies; both investigating cone function and potential treatments

Dr. Catherine Tsilfidis Ottawa Health Research Institute Developing a gene therapy to prevent retinal cell death

Dr. Vincent Tropepe University of Toronto Studying genes that allow the eye to regenerate

Dr. Derek van der Kooy University of Toronto Developing new stem cell transplantation techniques

Dr. Philippe Monnier

Toronto Western Hospital Developing new drugs to stop damaged cells from dying

Dr. David Picketts

Ottawa Hospital Research Institute Studies wiring and survival of retinal interneurons to restore sight **Dr. Saeed Khalili** University of Toronto Studies retinal stem cells to develop new therapies

QUEBEC

Dr. Stéphanie Proulx Université Laval Developing mechanisms to transplant 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. Mike Sapieha Hôpital Masionneuve-Rosemont Studies compounds that could protect nerve cells

Dr. Gilbert Bernier Hôpital Masionneuve-Rosemont Improving quality and strength of transplanted photoreceptors

Dr. Michel Cayouette IRCM Examines the fundamental mechanics of photoreceptors

NEWFOUNDLAND

Dr. Robert Gendron Memorial University Studying protein pathways and how they affect AMD

BRITISH COLUMBIA

Dr. Orson Moritz

University of British Columbia Studies valproic acid and its potential treatment of RP

Dr. Kevin Gregory-Evans University of British Columbia Studies the molecular factors that lead to vision loss

Dr. Cheryl Gregory-Evans University of British Columbia Developing an eye drop to repair damaged retinal cells

Dr. Perry Howard University of Victoria Working to improve how photoreceptors are generated

Dr. Gautam Awatramani University of Victoria Uses light-sensing molecules to change the response of vision cells

Dr. Mahyer Etminan

University of British Columbia Examining how prescription drugs may influence AMD risk

ALBERTA

Dr. Ian MacDonald University of Alberta Leading the first human clinical trial of a treatment for choroideremia in Canada

VISION QUEST 2014 OUR 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 **3 great Canadian cities**. TORONTO / HAMILTON / CALGARY

Featured **33** renowned vision experts. Along with **41** eye health exhibitors.

Hosted



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 DISCOVERY CELEBRATING 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.

SUPPORTING THE FOUNDATION FIGHTING BLINDNESS IS THE MOST POWERFUL WAY FOR CANADIAN DONORS AND VOLUNTEERS TO MAKE SIGHT-SAVING TREATMENTS A REALITY.

LEARN HOW YOUR SUPPORT HAS MADE A DIFFERENCE >>>



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



12



RAISE

OVER 3300 16

PARTICIPANTS

EVENTS NATIONWIDE 470

EVENT VOLUNTEERS



MEDIA IMPRESSIONS

CORPORATE **SPONSORS**

99

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.

\$100,000+

Anonymous (1) Anonymous (2)

\$50,000 - \$99,999

Mark and Shelagh Anson Estate of Jeanne Eunice Adams Jean Ip Krembil Foundation Ledcor Group of Companies

\$25,000 - \$49,999

Anonymous (3) Capital One Canada Deeley Harley-Davidson Canada Donna Green Renate Greenwood Glen and Rita Popowich RBC Foundation

\$5,000 - \$24,999

Anonymous (4) Anonymous (5) Arthur J.E. Child Foundation Dr. David and Rachel Baron Bayer Inc. Steve Beattie Bochner Eye Institute Estate of Ernest Bradshaw Christine and Andrew Burke James Collins Jane Collins eSight Foundation (Community Foundation of Ottawa) Don Ferguson Estate of Katherine Sharon Gerstl Joe and Deborah Grech Catherine and Greg Haverstock Ossie Hinds and Anne La Rocque John and Kathryn Holden Cheryl and Andrew Howden Malcolm Hunter **Robert & Elaine James** Ron Lalonde and Jane Humphreys Gideon and Kari Leoganda Nancy MacKellar Leonard and Selma Martin Dr. Andrew and Shawna Merkur Estate of Jean Pettit Pizzaville Inc. Estate of Doreen Powles James Riley and Nicole Sigouin Cam and Michelle Robinson Anita and Norm Rolleman Cookie and Stephen Sandler George Sheen Shorcan Brokers Limited Philip Smith Foundation Pat and Bob Steele Dr. Raymond Stein and Nancy Viner Dr. Bill and Kathie Stell David and Donna Sweeny **TELUS Communications Inc. TELUS Vancouver Community Board** David and Deborah Tennant **Toby Tobiason Trev Deeley Foundation Buddy Victor** Clayton 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.

\$25,000+

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

\$10,000 - \$24,999

Air Canada Foundation Alcon Canada Inc. Bochner Eye Institute Gluskin Sheff + Associates IBM Knar Jewellery Ledcor Group of Companies The Optical Group Peller Estates Shred-It

\$5,000 - \$9,999

Calgary Retina Consultants Expedia Canada Corporation Four Seasons Hotels GAMMA Sales Inc. iCo Therapeutics Inc. Onward Manufacturing Pengrowth Energy Corporation Tridel Harry Rosen TELUS 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



TOTAL MONTHLY DONORS



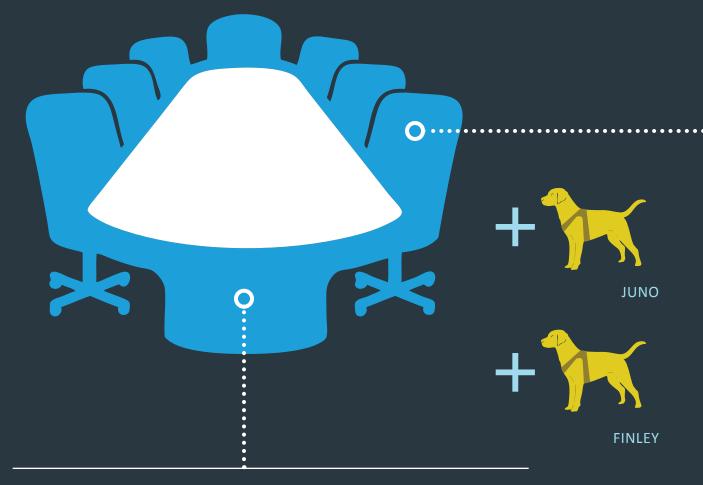
LARGEST MONTHLY DONATION



2014 TOTAL REVENUE

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

| Chair | Andrew Burke | |
|---------------------|--------------------|--|
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*Not pictured: John Breen, Michel Cayouette (PhD), David Drury, Sherif El-Defrawy (MD, PhD, FRCSC), Kevin Gregory-Evans (MD, PhD, FRCSC, FRCOphth), Peter J. Kertes (MD, CM, FRCSC), Lorna L. Rosenstein

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

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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 volunteers 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 per 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.

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

| 5% | 18% | 13% | 29% | |
|-----------------------|--------------|----------------|-------------|--|
| Investment & Other | Comic Vision | Ride for Sight | Major Gifts | |

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 |

16% Cycle for Sight 19% Other Gifts



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