

The FOUNDATION FIGHTING BLINDNESS

2012 ANNUAL REPORT

You'll see: **results.**

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THE FOUNDATION FIGHTING **BLINDNESS** IS CANADA'S LARGEST HEALTH CHARITY FUNDING VISION RESEARCH TO UNDERSTAND, **PRESERVE AND RESTORE SIGHT.**

WHAT WE DO

With your support, we provide crucial funds to vision researchers across the country, and offer hope to over 1 million Canadians affected by blinding eye diseases such as retinitis pigmentosa and age-related macular degeneration.

Thanks to Foundation-funded discoveries made possible by generous supporters like you, *you'll see: results*.



DEAR FRIENDS,

Our 2012 Annual Report is just one more way we're accountable to you, our community of dedicated donors, sponsors, volunteers, event participants, researchers, and families living with vision loss.

In it you'll read about the hope your support provides to just three of the 1 million Canadian families living with vision loss. You'll also find updates from our signature fundraising events, Ride for Sight, Comic Vision, and Cycle for Sight, our Vision Quest educational series and, of course, our audited financial statements.

Your donations supported a total of 23 ongoing research projects across the country in 2012 – over \$1.8 million in new Canadian vision research. And thanks to your generosity, Foundation research funding increased 35% in 2012 over 2011. This includes our investment in Canada's first clinical trial of a gene therapy for eye disease and a growing number of translational research projects.

Our 2012 Annual Report is also an expression of our deep gratitude for your commitment to vision research and our mission to understand, preserve and restore sight.

You'll see: results, thanks to Foundation-funded discoveries made possible by generous supporters like you.

Thank you,

Hora Colle

Sharon Colle President & CEO



Donna Green Chair, Board of Directors



FOR ETHAN AND GAVIN'S FAMILY, FUNDRAISING FOR VISION RESEARCH MEANS NOT GIVING UP HOPE.

PAM'S STORY



have two wonderful children, Ethan, age 11 and Gavin, 9, who were both born with profound hearing loss.

Just when I thought things couldn't get any harder, they did.

Both of my children were diagnosed with Usher syndrome, which causes deafness, blindness and balance problems.

Let me tell you about my boys. Ethan and Gavin love to travel, watch Blue Jays games, attend air shows, and play trivia games. They especially love to play sports; baseball, hockey, skiing, swimming and golf are favourites.

Sometimes it's difficult for me to watch them play. Their lack of balance makes some activities hard or even dangerous. Now their diminishing eyesight makes it worse. Despite all this, our family has not given up hope. Research right here in Canada promises to unlock the mystery of Usher syndrome. In fact, there's a strong possibility researchers will discover a way to halt the loss of vision for children like Ethan and Gavin.

One project that inspires us is the work of Dr. Catherine Tsilfidis. She has successfully preserved vision cells, and her team is now moving towards a clinical trial.

I admit, when I first heard "there is no cure" and "there's nothing we can do" I was almost paralyzed with grief. But I realized there is something we can do!

My job, as their Mom, is to be there for my boys – to help them learn to live with what life has given them. But I can also make a difference by asking everyone I know to join us in the fight against blindness and fund research that will one day help not just my boys but every other parent, every other child and every other person facing the loss of their precious sight.



Dr. Catherine Tsilfidis Ottawa Research Institute

Preserving sight for thousands of Canadians, like Ethan and Gavin, is Dr. Tsilfidis' goal.

With a gene therapy called XIAP (X-linked Inhibitor of Apoptosis), her team at the Ottawa Hospital Research Institute has shown they can interrupt apoptosis, the process the body uses to eliminate damaged cells. The therapy successfully preserves vision in laboratory studies.

In 2012, the Foundation Fighting Blindness began funding toxicity studies of XIAP therapy, formal tests required by Health Canada before human testing. These final steps towards human clinical trials were made possible by a generous donation from the Krembil Foundation.

RICK AND HIS FAMILY INVEST THEIR TREASURE AND TIME IN THE FOUNDATION FIGHTING **BLINDNESS TO** END RP.



RICK'S STORY



y family has a dominant form of retinitis pigmentosa, passed on for generations. Of my maternal grand-

mother's eight children, six have RP. In total 18 members of my family are living with RP: myself, my cousins, my aunts, even my own son.

The world is shrinking in on us.

We've all had different ages of onset, degrees of vision loss, and our own unique journeys.

We have not let blindness take away our hopes and aspirations though. My cousin Bill is a senior executive with a large international company. He travels frequently around the world, with his guide dog. My Aunt Theresa is a leading member of a community group that organizes trips for visually impaired people. My Aunt Lil lived alone in her own home for many years, raising spirits wherever she went with song and delicious baking. All of us, and many more, give our time and treasure to the Foundation Fighting Blindness.

Knowing that vision loss had been passed on for several generations, and will continue to be (though we hope that our two grandchildren will be spared), it became very important to us to find an organization that supports research into treatments and cures; if not for our generation, then for the next.

The Foundation Fighting Blindness is that organization. Thanks to research supported by generous people like you, the genetic mutation causing our family's RP was identified. Research is costly and time consuming but we will not give up hope. That is why we donate to the Foundation every month through the Monthly Donor Program.

So many new treatment possibilities are being discovered, nurtured with a sense of urgency by the Foundation. I can almost taste how close we are, for our family and many others.



Dr. Orson Moritz University of British Columbia

With your donations, Dr. Moritz studies autosomal dominant retinitis pigmentosa (RP), the condition that affects Rick's family.

Although people with autosomal dominant disease have one healthy vision gene, their retinal cells are slowly damaged by the effects of a mutated gene. Eventually, vision cells will be so badly damaged that they are destroyed by the body.

However, in 2012, Dr. Moritz discovered that if the mutation was blocked, even badly damaged cells would begin to work again.

This suggests that scientists don't need to fix the gene, and can focus on the simpler task of blocking its action.

YOU FUNDED 23 RESEARCH PROJECTS IN 2012

Your donations to the Foundation Fighting Blindness supported a total of 23 ongoing research projects in nine cities across the country in 2012 – over \$1.8 million in new Canadian research to understand, preserve and restore sight. Thanks to your generosity, Foundation research funding increased 35% in 2012 over 2011. This includes our investment in Canada's first clinical trial of a gene therapy for eye disease and a growing number of translational research projects.





Gautam Awatramani, University of Victoria Probing & Repairing Circuits During Retinal Degeneration

Perry Howard, University of Victoria The Role of Ars2 Inhibition in RPC Differentiation

Kevin Gregory-Evans, University of British Columbia team grant, partnership Novel Molecular Approaches to Combination Therapy

Robert Molday, University of British Columbia *team grant, partnership* Novel Gene Therapy Approaches for the Treatment of Retinal Degenerative Diseases

Orson Moritz, University of British Columbia Autophagy & the Mechanisms of Valproic Acid Therapy for Retinitis Pigmentosa (RP); Mechanisms of secondary retinal degeneration & regeneration in RP: Responses to acute & chronic rod photoreceptor cell death

(3) CALGARY

Alicia M. Ebert, University of Calgary post-doc, partnership FGF Signaling in the Developing Retina

EDMONTON

Ian MacDonald, University of Alberta team grant, partnership Choroideremia: Expanding our Understanding, Exploring Treatments Andrew Waskiewicz & Ordan Lehmann, University of Alberta Investigation of the Role of TGF-Beta Signaling in the Causation of Leber Congenital Amaurosis

B HAMILTON

Judith West-Mays, McMaster University Identification of Autonomous & Non-Autonomous Roles for the AP-2 Genes in Optic Cup Development

(i) TORONTO

Rod Bremner, Don Johnson Eye Centre, University Health Network

Cell Cycle Regulators in the Birth & Survival of Retinal Neurons

Jane McGlade, Hospital for Sick Children The Crumbs Protein Network in Cell Polarity & Retinal Degeneration

Vince Tropepe, University of Toronto Genetic/Molecular Studies of Neurogenesis & Regeneration in the Zebrafish Retina

Derek van der Kooy, University of Toronto Specification & Transplantation of Adult Retinal Stem Cell Progeny

🕖 OTTAWA

David Picketts, Ottawa Hospital Research Institute

Defining the Mechanisms Governing Retinal Interneuron Homeostasis & Circuitry

Catherine Tsilfidis, Ottawa Hospital Research Institute team grant, partnership XIAP Gene Therapy for the Treatment of Retinal Degeneration; XIAP Gene Therapy: Safety & Toxicity Studies for Translation into the Clinic

Valerie Wallace, Ottawa Hospital Research Institute *team grant, partnership* Eye Stem Cells: Biology & Therapeutic Applications

🗿 MONTRÉAL

Gilbert Bernier,

Hôpital Maisonneuve-Rosemont

Stem Cell Transplantation Therapy for the Treatment of Retinal Degenerative Diseases

Michel Cayouette, Institut de recherches cliniques de Montréal

Specification of Temporal Identity in Retinal Progenitor Cells

Robert Koenekoop, McGill University

Identifying Novel Retinal Degeneration Genes by Novel Strategies

H. Uri Saragovi, Lady Davis Institute – Jewish General Hospital

Genetic & Pharmacological Validation of Neurotrophic Targets for Therapy of Retinitis Pigmentosa Translation into the Clinic

(9) ST. JOHN'S

Robert Gendron & Hélène Paradis, Memorial University

Tubedown Signaling Pathway Regulating Retinal Endothelial Permeability



Dr. Gilbert Bernier Hôpital Maisonneuve-Rosemont

Dr. Bernier's research aims to give new vision to people blinded by age-related macular degeneration (AMD), like Joan. Your generous donations support his work.

Dr. Bernier aims to reverse blindness by transplanting vision cells into the eye. Currently, less than 1% of transplanted cells survive. Think of this as seeds scattered on stony ground.

Dr. Bernier has a possible solution. He will grow sheets of retinal pigmented epithelium cells in the lab and connect them with sheets of vision cells. Then he will transplant these combined sheets into the eye.

This is like starting seeds in potting soil and then planting them – they are more likely to survive, because they are rooted to a food source.

JOAN'S STORY

am an 87 year old greatgrandmother living with wet age-related macular degeneration (AMD), but I won't let blindness stop me from doing the things I love. My attitude toward AMD is "I've got it, and I deal with it."

Ten years ago I had routine cataract surgery only to learn I had wet AMD – the aggressive form of this eye disease. I immediately began monthly injections. My vision has stabilized at 20/200 in my left eye, and 20/400 in my right, but I make the most of what I have.

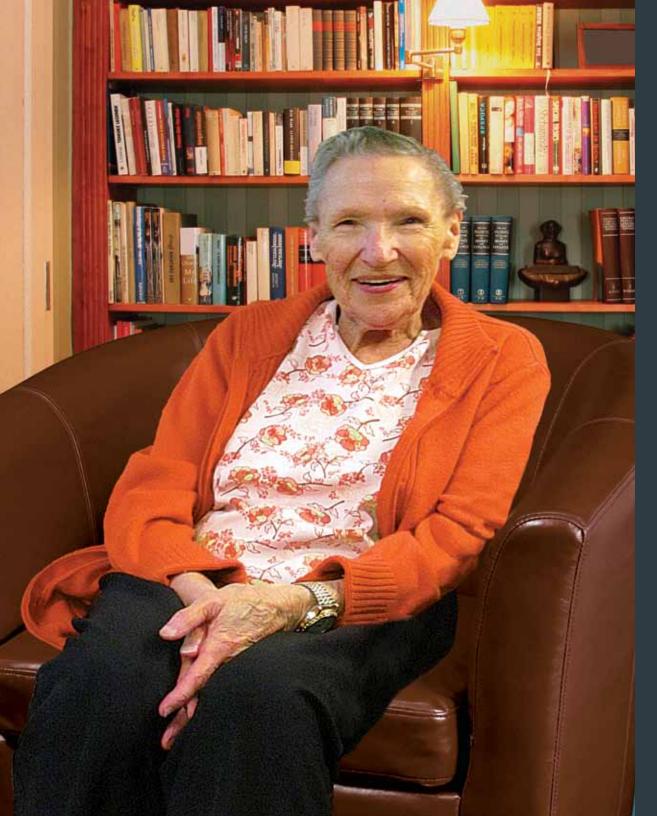
I want to remain independent so if I'm having trouble I say to myself, "You can solve this, if you just sit and figure it out."

I've figured out a number of solutions. I count coins by feeling the edges. I sew brightly coloured string into my socks so I can match them. Magnifiers and large print books allow me to continue reading my beloved James Patterson detective novels. I live in a nursing home (I am 87 after all!) and I like to share my solutions with other residents living with vision loss. But I'm probably best known here for my dance parties. I love to turn up the music – Bob Seger and the Rolling Stones are my favourites – invite the nurses, and rock out in my room!

I discovered the Foundation Fighting Blindness at Vision Quest. I attended to learn more about my eye disease, and was impressed with the research the Foundation supports. I decided I wanted to be a part of that.

The research might not help me, although I'm hopeful, but maybe it will help my children, grandchildren and greatgrandchildren. I donate \$50 a month through the Foundation's Monthly Donor Program. That's \$10 for each of my children (I have three daughters and two sons and so many grandchildren and great-grandchildren I couldn't possibly calculate my donation based on their number!)

I choose to be positive about my vision loss and supporting the Foundation's research is one way I remain hopeful.



JOAN WAS SO **IMPRESSED BY FOUNDATION-FUNDED RESEARCH SHE** JOINED OUR **MONTHLY DONOR** PROGRAM.

GET INVOLVED!

At the Foundation Fighting Blindness, our fundraising events define our organization, raising critical funds for sight-saving research as well as awareness about retinal eye diseases. Join one today or create your own community event!



\$700,000 raised!

and Labrador

rideforsight.ca

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EDUCATION & OUTREACH

Our Vision Quest 2012 education series stopped in Edmonton, Toronto, and St. John's. Our community of donors, sponsors, researchers, and affected individuals and families learned about the latest sight-saving research in Canada and around the world, and it was our most ambitious format in years, featuring multiple keynote speakers and dozens of sessions.



VISION QUEST 2012 SESSIONS ARE AVAILABLE ONLINE. VISIT FFB.CA TO LISTEN TODAY.

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YOUR RETURN ON INVESTMENT IN 2012, FOUNDATION FIGHTING BLINDNESS INVESTMENT IN CANADIAN RESEARCH:

INCREASED 35% over 2011 to \$1.83 MILLION



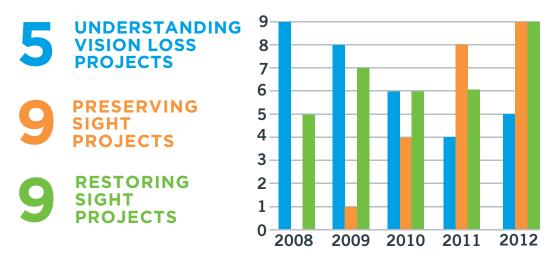
SUPPORTED

RESEARCH TEAMS FROM VICTORIA TO ST. JOHN'S

CREATED PARTNERSHIPS WITH GOVERNMENTS & NON-PROFIT ORGANIZATIONS __ TO TURN \$382,556 OF YOUR DONOR \$ INTO \$1.72 MILLION

MAXIMIZING THE IMPACT OF YOUR DONATION

IN 2012, YOUR DONATIONS FUNDED 23 SIGHT-SAVING PROJECTS.



We're now funding more research to translate our understanding of retinal disease into treatments.

In 2012, the Foundation invested in our first clinical project, a human trial of a potential therapy for choroideremia.

RESULTS

THANKS TO YOUR SUPPORT, DISCOVERIES ARE HAPPENING!



YOUR DONATIONS MAKE A DIFFERENCE.

Over the past 10 years, research produced by Foundation-funded scientists has been used and credited by other scientists from around the world over **7,500** times.

100% of Foundation-funded scientists remained in Canada working on retina-related projects.

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LEADERSHIP DONORS

We thank all our donors for their commitment to sight-saving research and education in 2012. Every gift is meaningful and deeply appreciated but space limitations make it impossible for us to list all our generous donors. We are pleased to recognize the following individuals, corporations, and foundations that made contributions of more than \$5,000.

\$100,000 +

Anonymous (1) Anonymous (2) Krembil Foundation Maxwell & Gaylene Munday

(\$50,000 - \$99,999)

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(\$5,000 - \$24,999)

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CORPORATE EVENT SPONSORS

We are proud to recognize our corporate partners for their generous support of our fundraising events. This list does not include our sponsors who donated generous gifts in-kind or our promotional partners. We are extremely grateful for all contributions.

(\$50,000 - \$99,999)

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(\$5,000 - \$24,999)

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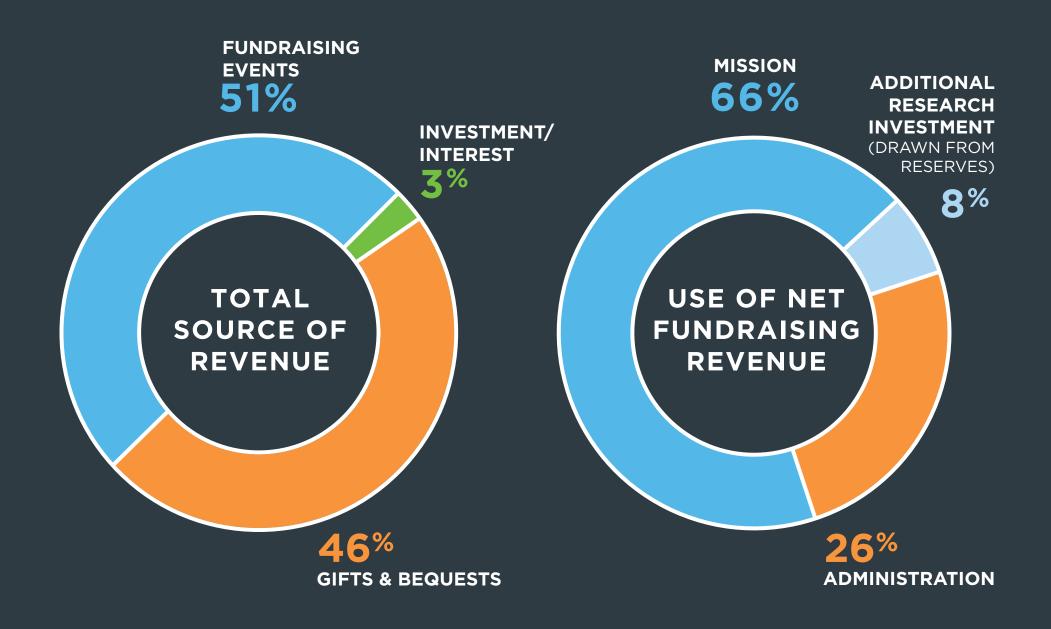
2012 AUDITED FINANCIAL STATEMENTS

REVENUES	2011	2012
FUNDRAISING EVENTS	2,352,570	2,233,276
GIFTS & BEQUESTS	1,668,071	2,019,825
INVESTMENT/INTEREST	73,093	148,697
TOTAL	\$4,093,734	\$4,401,798

TOTAL	\$1,622,537	\$2,174,547
EDUCATION	269,827	344,607
RESEARCH	1,352,710	1,829,940
MISSION	2011	2012

TOTAL	\$2,100,325	\$2,258,341
DIRECT FUNDRAISING	425,269	491,506
FUNDRAISING EVENTS	840,867	911,071
ADMINISTRATION	834,189	855,764
EXPENSES	2011	2012

FOUNDATION RESEARCH FUNDING INCREASED 35% IN 2012.



OUR 2012 BOARD OF DIRECTORS

The Foundation Fighting Blindness is overseen by a board of outstanding and committed individuals. Our board governs major decisions, approves research grants, and provides direction for organizational practices.

Executive Committee and Officers

Directors

Donna Green Chair Ken Kirk Vice Chair Rahn Dodick Treasurer Andrew Burke Corporate Secretary John Breen Executive Officer Wade Oosterman Executive Officer Catherine Tillmann Executive Officer Joe Grech Executive Officer Kevin Gregory-Evans MD PhD FRCS FRCOphth Elise Héon MD FRCSC Jane Humphreys Malcolm Hunter Peter J Kertes MD CM FRCSC Michael Ovens Lorna L Rosenstein Raymond M Stein MD FRCSC David D Sweeny Deborah Tennant Valerie Wallace PhD Sharon M Colle President & CEO, ex-officio

OUR 2012 SCIENTIFIC ADVISORY BOARD

The Foundation Fighting Blindness Scientific Advisory Board is comprised of exceptional scientists actively engaged in sightsaving research. They provide volunteer scientific leadership, evaluate research grant applications, and support our education programs. Rigorous peer-review ensures your donations fund the most promising research.

Valerie Wallace PhD, Chair	Ordan Lehmann MD PhD
Rod Bremner PhD	Brian Link PhD
Michel Cayouette PhD	Orson Moritz PhD
Robert Gendron PhD	William Stell PhD, Ex-officio



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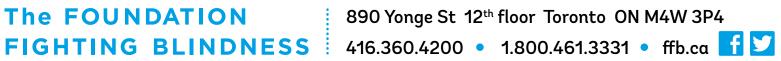
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