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SPRING 2019

Meet Doug Earle, New President and CEO of the FFB

> \$1.5M Grant Funds Groundbreaking Stem Cell Research into Wet-AMD

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Meet the Recipients of Restore Vision 20/20 Could Vitamin D Impact the Development of AMD?

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The FOUNDATION FIGHTING BLINDNESS

MEET DOUG EARLE New President & CEO OF THE FFB

With more than 30 years of professional fundraising experience at some of Canada's leading health charities, including Diabetes Canada, the Canadian Hemophilia Society, the Canadian Cancer Society, and the Arthritis Society, Doug Earle is excited to lead the FFB into 2020 and beyond.



Doug Earle and Ann Morrison help close the TSX Market for Shorcan Charity Day

We sat down with Doug to welcome him to the FFB and talk about his goals as President and CEO

Q: On behalf of our community, welcome to the Foundation Fighting Blindness! What was it about the organization that drew your interest?

Thank you! I'm thrilled to be here because I'm passionate about working with people in health organizations to change lives through research discovery. Advances in technology and medical science mean that people living with vision loss can be helped in real, tangible ways and the FFB has a vital role to play in bringing those discoveries to Canadians.

Q: How does your professional experience align with the FFB?

I've fundraised for four health charities, two hospitals and two universities, and blindness often hovered at the edges of the work I was helping to fund. When I was at Diabetes Canada, I became quite familiar with diabetic retinopathy. At the University Health Network, I raised funds for vision research at the Donald K. Johnson Eye Institute. Those experiences sparked my interest in finding treatments for eye diseases.



Q: What makes vision loss such an important issue for Canadians?

Five and a half million Canadians are living with eye conditions that put them at risk of vision loss, and the number of people living with blindness is expected to double in the next fifteen years. By working with our community of donors to fund critical research, the FFB can reduce the number of people living with vision loss.

Q: What has surprised you about the FFB so far?

The amazing passion, engagement and dedication of our board, volunteers, staff, and donors, along with the incredible drive of the researchers. With the support of this remarkable community, we can fund research that will lead to treatments and cures.

Q: Where do you see the organization going over the next five years?

We're at an exciting moment in the evolution of the FFB, where the research we're funding

is poised to translate into clinical care aimed at preventing and treating vision loss. Over the next five years, we need to build that momentum by engaging Canadians living with vision loss to raise awareness and fund research that will further drive treatment and care for more blinding eye diseases.

Q: What do you hope will be your most important contribution to the FFB?

I plan to be instrumental in mobilizing the community of people living with eye diseases so that Canadians can have access to new treatments, faster.

Q: What message would you like to give to the FFB community?

We're on the cusp of a new era in the diagnosis, prevention, and treatment of blinding eye diseases, and we're here because of the incredible support of our community of donors. The research we fund moving forward will transform lives. I encourage you to share our story with others so that we can accelerate our ability to make meaningful change.

DR. ANDRAS NAGY: INAUGURAL RECIPIENT OF THE CEDRIC RITCHIE FUND TO CURE BLINDNESS

In October, Dr. Andras Nagy was the inaugural recipient of the Cedric Ritchie Fund to Cure Blindness, a \$1.5 million grant made possible by Cedric's widow, Barbara Ritchie, and the Foundation Fighting Blindness.

The grant has enabled Dr. Nagy to accelerate his revolutionary approach to treating age-related macular degeneration (AMD), the leading cause of vision loss in people over the age of 50.

Dr. Nagy is world-renowned for discovering a method to create stem cells from other cells in the body – a breakthrough in regenerative medicine. His novel approach to treating wet-AMD, the most severe form of AMD, involves a combination of gene therapy and stem cell therapy. With the support of the FFB and the Cedric Ritchie Fund to Cure Blindness, Dr. Nagy and his team are now able to genetically program stem cells to deliver sight-saving proteins within the eye on their own – proteins that would normally have to be manually injected into the patient's eye on a regular basis.

The \$1.5 million grant is the result of an individual commitment from Barbara Ritchie, whose late husband, Cedric Ritchie, lived his final years without sight due to complications from AMD and glaucoma. Mrs. Ritchie cared for her husband as he struggled to navigate a life without vision, and her experience left her with a profound sense of the burden that blindness entails for not only those who live with it, but for loved ones and caregivers as well.



Dr. Sabiha Hacibekiroglu, Malcolm Hunter, Barbara Ritchie, Andrew Burke and Dr. Andras Nagy

Mrs. Ritchie believes in the enormous potential of Dr. Nagy's science, which is a novel combination of two of the most promising approaches in vision science. This intersection is made possible by Dr. Nagy's decades of foundational scientific investigation, which he plans to leverage to bring his work into the clinical trial phase.

With the support of the FFB and the Cedric Ritchie Fund to Cure Blindness, Dr. Nagy will be able to go to clinical trials in five years – a very short period within the often-plodding timeframes of scientific discovery. This would be impossible without Mrs. Ritchie's generosity.

"Cedric never let vision loss get in his way," said Mrs. Ritchie. "I know that if he were here today, he'd want a similar principle applied to Canada's vision science. He'd want the best science to be supported, and he'd want it maximized to impact as many people as possible."

RESTORE VISION 20/20 RECIPIENTS

Thanks to Visionary Donors, Four New Research Teams are on the Road to Restoring Sight.

Before it was a carefully designed research competition, Restore Vision 20/20 was a dream. It was an idea to take research further. It's goal was to help the most promising discoveries move from the laboratory into the clinic: a transition that would enable them to be tested as experimental treatments. *Wouldn't that be incredible?!* The challenge was that funding this kind of later-stage research requires a significant financial commitment.

Thanks to the incredible generosity of Donna Green and her mother Goldie Feldman, as well as backing from an anonymous donor, Restore Vision 20/20 was launched as a **\$2.5 million initiative** to drive the development of new sight-restorative treatments for retinitis pigmentosa (RP), an inherited retinal disease that affects 1/4000 Canadians, many of whom are diagnosed at a young age.

We are thrilled to announce the first four research teams that will receive funding through Restore Vision 20/20! Each team is focused on developing a new therapy that has the potential to restore vision for those with RP, and each has promise to be relevant to other diseases as well.

Lead researchers from three of the new projects are shown in the photos below. The fourth team is led by **Dr. Richard Kramer from the University of California, Berkeley, who was awarded \$300,000 over three years** to develop a "photo-switch" drug with the potential to restore sight by "switching" cells that are *not* light-sensitive into cells that *are* light-sensitive.

We are proud to be funding Dr. Kramer in partnership with the Foundation Fighting Blindness in the United States. Although we share a name with our friends south of the Canadian border, we are distinct organizations. We occasionally collaborate because we share the goal of driving the development of new sight-saving treatments.

Each exceptionally talented research team was awarded funding because their work has tremendous potential to restore vision to patients living with RP, as well as many other blinding eye diseases!



Dr. Catherine Tsilfidis from the Ottawa Hospital Research Institute was awarded \$335,000 over two years to develop a gene therapy that can stop the death of photoreceptors, the eye's light-sensing cells.



Dr. David Gamm from the University of Wisconsin-Madison was awarded \$800,000 over two years to develop a stem-cell based photoreceptor replacement therapy.



Dr. Philippe Monnier from the Krembil Research Institute was awarded \$200,000 over two years to develop a drug that stops the death of photoreceptors.

COULD VITAMIN D IMPACT The development of age-related Macular degeneration?

Dr. Jacob Rullo from Queen's University is studying the connection between vitamin D inside the eye and age-related macular degeneration (AMD), the leading cause of blindness in the aging population.

The eye is designed to focus light on the retina. As a result, the retina is exposed to damaging UV light, and potentially vitamin D, daily. How do our eyes deal with this damage, and how is it related to the progression of AMD?

These are the questions that motivate Dr. Rullo. He studies how AMD affects levels of vitamin D in the eye and examines whether vitamin D levels in the eye are lower in patients with AMD. Considering the burden AMD has on the aging population, determining the role vitamin D plays in its development could have enormous treatment potential.

At the FFB, we are thrilled to announce that Dr. Rullo will be conducting this research with funding provided by the FFB Clinician-Scientist Emerging Leader (CSEL) Program. Funded by Bayer and the Bank of Montreal, this initiative was designed to strengthen the community of ophthalmologistclinician-scientists, who are ready to help accelerate the development of new sight-saving treatments.



"The field of ophthalmology has many unexplored areas that could have a tremendous impact on our patients' health."

- Dr. Jacob Rullo

"The field of ophthalmology has many unexplored areas that could have a tremendous impact on our patients' health," says Dr. Rullo. "Clinician-scientists are uniquely positioned to make valuable observations and generate important research questions that have the potential to directly impact patients."

By the year 2040, the number of people with AMD is expected to double. Despite the development of ground-breaking treatments for wet-AMD, we still do not know exactly what causes the disease or how to prevent its progression. This is why the FFB is proud to be funding AMD research and supporting the next generation of clinician-scientists who will play a vital role translating new research discoveries into sightsaving treatments for Canadians.

MEET OUR Community

Abdul Rashid, from Cambridge, Ontario, is a monthly FFB donor whose two children were diagnosed with retinitis pigmentosa (RP), one of the most common inherited retinal diseases.

When the diagnosis of his two children left him feeling isolated and alone, Abdul began looking for answers and found the FFB's Vision Quest, a nation-wide educational series that shares the latest breakthroughs in vision science with supporters and families affected by vision loss. Abdul attended a Toronto Vision Quest in September 2018, where he, along with an audience of 250 guests, learned about inherited retinal diseases from some of the country's leading specialists.

The experience helped Abdul overcome his feeling of isolation by providing a gateway to a community of patients and families in similar situations. Before Vision Quest, he felt uncomfortable talking to others about his son and daughter's vision loss. Now, he engages with other families in the vision loss community and, like those families, has hope that new treatments will be developed that could save his children's vision.

Abdul is now a monthly FFB donor. "As a father, I feel I owe it to my children to donate to help fund vision research," he told the FFB. "Not only to help my own children, but also to help others living with vision loss."



Abdul Rashid and his wife, Ghazala Shaheen, attend Vision Quest with their son Hasan (13) and daughter Saman (18)

Imagine the hope you can give by joining our Monthly Giving Program

Help fuel research discoveries. Join today!

Contact Josie Koumandaros 1.800.461.3331 x 262 | jkoumandaros@ffb.ca

Even if you plan to live to 150, you still need to make a plan

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VISION QUEST EDUCATION SERIES EVENTS

Join thousands of patients, clinicians, researchers, industry experts and low-vision specialists as we share the latest breakthroughs in vision science.

UPCOMING VISION QUEST 2019 EVENTS

Winnipeg	Lunch & Learn: AVL & IRD	February 27
Kingston	Lunch & Learn: AVL	March 27
Vancouver	Conference: AVL & IRD	April 27
Toronto	Lunch & Learn: AVL	May 29
Halifax	Symposium: AVL & IRD	September 14
Calgary	Conference: AVL & IRD	October 26
Toronto	Symposium: IRD	November 9

AVL: Age Related Vision Loss **IRD**: Inherited Retinal Diseases

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COMIC VISION

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RIDE FOR SIGHT

From its humble beginnings as a local fundraising event, Ride for Sight has become a great Canadian motorcycle tradition raising funds to end blindness! rideforsight.com



Whether it's a pub night, a road hockey tournament or a party, we encourage you to put your unique mark on supporting vision research in Canada! **Call April Watts, Senior Manager of Events** 416.360.4200 x 231

