

Research during COVID-19 pandemic

PG 5



Remembering Fighting Blindness Canada Founders Jay and Malca Marin

PG 3

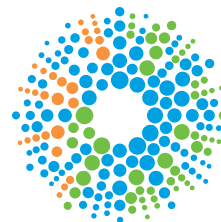


2020 CSEL
Award Winner

PG 4

Hill Couple Donates
\$1 Million to Vision Research

PG 7



**FIGHTING
BLINDNESS
CANADA**

Charitable Registration Number: 119129369 RR0001

DEAR FRIENDS,

As we live through these challenging times, **Fighting Blindness Canada (FBC)** wants to let you know we are thinking of you. Your wellbeing and safety is of the highest importance to us. That's why we have cancelled or postponed our in-person education and fundraising events this spring.



The following are updates to our upcoming events:

- Our Cycle for Sight nation-wide fundraiser is going virtual. Ride a bike, walk, grab a yoga mat and get active with us online June 20th! Learn more at cycleforsight.ca.
- Our signature fundraising Comic Vision events in Montreal, Toronto, and Vancouver, and Last Call Toronto, are now taking place in the fall. Tickets are going fast, reserve your seat at comicvision.ca and lastcalltoronto.ca.
- Our community driven Ride for Sight events across Canada have been postponed. To access updates as they become available, visit rideforsight.com.
- Our do-it-yourself community fundraiser program called "Sight Savers" has been updated and improved to better support you. Ask for donations to FBC from your friends and family in celebration of your birthday or anniversary. Learn more at fightingblindness.ca/sightsavers.
- We have launched a virtual education series called View Point, in place of our in person events. Register for an upcoming webinar at fightingblindness.ca/get-involved.

Our Health Information Line has been receiving calls from the community with questions surrounding COVID-19 and eye health. We've helped answer questions on safe ways to take glaucoma eye drops, what to do if an anti-VEGF treatment has been postponed, and how to support mental health. The line is open to support you and can be reached at **1.888.626.2995** or healthinfo@fightingblindness.ca.

Our critical vision research is continuing under the new COVID-19 reality. Some research activities have slowed down because experiments must be conducted under new safety procedures, or the research requires person-to-person interactions. Our revenues funding FBC vision research and programs have been impacted... a 70% drop in April 2020 alone.

Through these times, it's critical we continue to offer hope to people living with blinding eye diseases and to our researchers so that research discoveries can become treatments.

We are so grateful for your past support. If you are in the position to do so now, please consider making a donation today to help FBC advance sight-saving research and help improve the lives of over 1.5 million Canadians living with vision loss.

From all of us at FBC, we hope that you and your family stay well and keep safe.

A handwritten signature in black ink that reads "Doug Earle". The signature is written in a cursive, flowing style.

Doug Earle
President & CEO, Fighting Blindness Canada

REMEMBERING FBC'S FOUNDERS

The late Jay and Malca Marin began leading the fight against blindness over 50 years ago..



Jay and Malca were a devoted couple that had four children: Joe, Lorne, and twins Reva and Bayla. Jay, business owner of Reliable Silk (inherited from his father) and Northcott Silk (partnered with his brother-in-law), was a skilled business man driven by the importance of care and community.

When their second son Lorne was 16 he was diagnosed with retinitis pigmentosa (RP) a symptom of Usher syndrome (an inherited disease that affects both sight and hearing), the couple became determined to bring sight-saving research to Canada.

In particular, after reading an article in the New York Times describing a new organization in Baltimore (Foundation Fighting Blindness U.S) and their work on vision research, Jay immediately contacted the founder Ben Berman and travelled to Baltimore to meet with him. Ben quickly became Jay and Malca's good friend and inspired them to help advance vision research in Canada.

The couple left their visit with Ben on a mission to establish a vision research centered charity in Canada which they called the RP Foundation (now Fighting Blindness Canada). Their first application to making the foundation a registered charity was declined. Jay undiscouraged, reached out to Dr. McCulloch, who had diagnosed Lorne's RP, and invited him to meet with Ben. A dinner date at the Marin residence resulted in Dr. McCulloch agreeing to be the director of the foundation's Scientific Advisory Board which significantly led to the foundation gaining charitable status.

Jay and Malca set up the organization's office out of their home. Their mission was close at hand and they did not want to delay breaking ground on sight-saving research. While their son Lorne expressed worry that the foundation would take

up the best years of their lives, Jay assured his son that, "it would be the best way to take up our life."

For many years the RP Foundation ran with only the support of volunteers consisting of community members and researchers from the RP Foundation's Scientific Advisory Board – many of the costs covered by the couple themselves.

A pivotal moment took place in 1979 at Jacksons Point, Lake Simcoe, Ontario. Today, this event is regarded as the spark of the foundation's research movement. Jay and Malca rented The Briars Hotel and invited every science researcher they could find. Approximately 150 scientists attended with Dr. McCulloch and Ben creating the event's itinerary. This event led to an increased intensity in vision research being done by scientists across North America. Some field experts may describe it as "the beginning of everything."

Today, we remember and honour the hard work and dedication of a humble and devoted couple. Jay and Malca Marin leave behind four children, 5 grandchildren, 2 great-grandchildren, and a life-long gift of hope for those living with blinding eye diseases.

Their son Lorne shares, "The true beginning was on the evening of my diagnosis. We were all in shock and I was now officially legally blind. My parents couldn't sit back and do nothing. My parents had to build what is now Fighting Blindness Canada from the ground up. I'm very proud of the work they did, and the commitment they made over the years to me and to all individuals dealing with vision loss."

Jay and Malca Marin could not be stopped in their mission to find a cure. 46 years later, FBC continues to be inspired by the couples effort, passion, and fight to cure blindness. To join the fight, visit the "Get Involved" section of our website at fightingblindness.ca.

FBC'S 2020 CLINICIAN SCIENTIST EMERGING LEADER (CSEL) AWARD

Dr. Zhou announced as winner!

Dr. Tianwei Zhou is an ophthalmology resident from the Université de Montréal. Mentored by Dr. Patrick Hamel, Dr. Cynthia Qian, and Dr. Flavio Rezende, she is studying retinopathy of prematurity (ROP) – a blinding eye disease in preterm babies caused by abnormal blood vessel development in the retina. ROP is a leading cause of blindness in children in North America and Europe, however, researchers are still uncertain about the long-term consequences of ROP.

The project, entitled “Seeing into the future – understanding the long-term sequelae of Retinopathy of Prematurity,” is a clinical translation of Dr. Zhou’s doctoral thesis. Carried out during her MD-PhD training at McGill University, her project described, for the first time, significant vision loss and signs of premature aging in an animal model of ROP.

As part of the CSEL award, Dr. Zhou will receive a grant of \$60,000 over two years. Her project aims to explore if young patients with ROP are at a higher risk of significant vision loss or other eye diseases as they age. Thanks to the improvement in neonatal care during the 1980’s, more preterm babies survived and many of them are now young adults. Dr. Zhou says, “The timely detection of long-term consequences of ROP provides an early opportunity to intervene and prevent further vision loss.”

Furthermore, Dr. Zhou expresses, “In recent years, the clinician-researcher training pipeline has begun to dwindle, but the research career remains a powerful driving force for clinical innovation. FBC’s CSEL award is an opportunity for ophthalmology residents to pursue their passion in research.”

Grant funding for FBC’s 2020 CSEL Award comes from the late Doreen Marjorie Powles.



Bring a Bright Future into Focus with Monthly Giving!

Help change the lives of people living with vision loss by joining our monthly giving program.

For information, contact Josie Koumandaros
1.800.461.3331 x 262
jkoumandaros@fightingblindness.ca

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What will your legacy be?

Consider leaving a gift to Fighting Blindness Canada in your Will to help future generations.

For information, contact Ann Morrison
1.800.461.3331 x 232
amorrison@fightingblindness.ca

RESEARCH DURING COVID-19

Q&A with Dr. Vince Tropepe

The last few months have been challenging for all, including labs at the forefront of sight-saving vision research. We reached out to FBC funded researcher Dr. Vince Tropepe to learn how the COVID-19 pandemic has impacted his research team and their work in using zebrafish to study a gene mutation in Usher Syndrome.

Q: How has COVID-19 impacted your lab at University of Toronto?

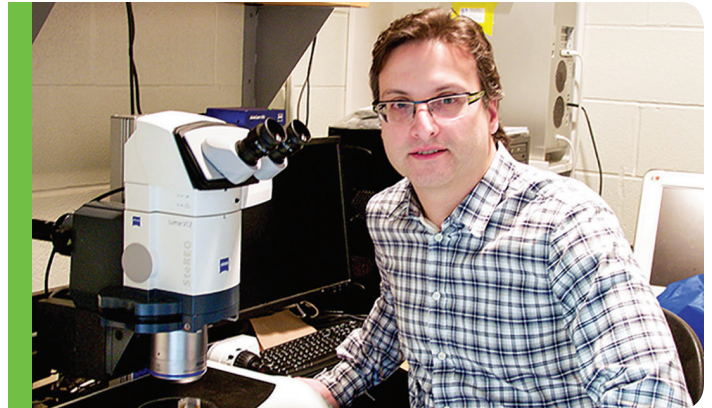
My lab was shut down March 20, 2020. Halting our research is frustrating, especially when we were just ramping up our FBC funded project. However, we have to do our part to control the spread of COVID-19. The best we can do for now is try to keep all of our zebrafish strains alive and well.

Q: Were you able to save zebrafish strains?

Zebrafish sperm can be frozen down, so that is one way to preserve strains long term. However, the technique is very tricky and very few labs can do this successfully. For now, all we can do is keep the fish alive and breed them periodically to produce new generations with a good balance of males and females. We've been told to reduce numbers as much as possible, which is very concerning, but we are managing for now.



Zebrafish retina cells painted by Prof. Bill Harris



Researchers like Dr. Tropepe and his team are facing a vast amount of challenges during these difficult COVID-19 times. FBC is working hard to support award winning researchers like Dr. Tropepe and keep vision research moving forward – we can't do this without you.

Q: Are there any silver linings to this really tough situation?

It's important to maintain a positive outlook. I've asked my students to catch up on reading research articles, writing manuscripts and working on data analysis remotely. It really is a good time to think deeply about one's research.

Q: How will this situation impact vision research in Canada in the long term?

Many funding agencies have recently prioritized COVID-19 based research projects, and these efforts are commendable for accelerating research toward understanding the biology of the SARS-CoV-2 virus and finding innovative solutions for treatment. However, there is a risk that funding resources for critical vision research will take a bit of a back seat, at least for a period of time, and this could impact progress on outstanding vision research across the country.

THE BEST IN NEW VISION RESEARCH

Every year, donors like you support FBC in funding research taking place in hospitals and universities across Canada. This research is the backbone of our community and our primary tool for identifying the causes, treatments and, ultimately, cures for eye diseases. In the previous edition of InVision we announced six new research awards and we are excited to share more details about two of them:

Dr. Gregory Borschel

\$300,000 to the Hospital for Sick Children, Research Institute

Finding new treatments for blindness caused by neurotrophic keratopathy

Neurotrophic keratopathy (NK), is a degenerative disease that affects the cornea (the clear outer layer of the eye). During NK, nerve damage causes the cornea to lose the ability to sense stimulation, leading to eventual vision loss.

Dr. Gregory Borschel was part of the team that pioneered a new surgery that replaces the nerve, and along with cornea transplantation, can improve some vision in patients with NK.

Surgery is currently the only option for treating advanced NK but the search for less invasive treatment options, such as drug treatments, has been held back by a lack of understanding on how the nerve interacts with the cells in the eye and promotes cornea health. This is where Dr. Borschel's study comes in. He has developed the first animal model of NK, which will help answer important questions and will allow his team to try and identify drugs that can increase cornea recovery and possibly help promote nerve growth without surgery.

Dr. Michael Walter

\$216,000 to the University of Alberta

Investigating the genetic cause of pigmentary glaucoma

Pigmentary glaucoma occurs when pigment particles from the coloured part of the eye, called the iris, are released and clog the drainage system in the eye. Left untreated this can cause vision loss or blindness. Dr. Michael Walter and his team at University of Alberta recently discovered a mutation in the PMEL gene that can cause forms of pigmentary glaucoma. This is the first time a genetic cause for this disease has been identified, however it is still unknown how that mutation is causing vision loss. Fighting Blindness Canada has awarded Dr. Walter this grant to find answers to this question.

More specifically, Dr. Walter's research will aim to discover if the mutation changes the shape of the PMEL molecule, and how this will affect the PMEL gene's function in the cell and the eye's drainage system. This research will help provide a better understanding of how pigmentary glaucoma happens at the molecular and cellular level, information that is important to develop new treatments for this disease.

Stay tuned for more FBC award highlights in our 2020 Fall InVision newsletter.

These six new awards aren't the only research we fund! FBC continues to proudly support a robust research portfolio, including studies about retinitis pigmentosa and age-related macular degeneration. Learn about all of FBC's funded research at fightingblindness.ca/research/fbc-funded-research.

HILL COUPLE DONATES \$1 MILLION TO HELP ADVANCE VISION RESEARCH

It started with hello.

When Gilbert and Ardeth made the decision to attend Queen's University for their Bachelor's Degrees in the late 1940s, they did not anticipate the ripple in their life this decision would make. Gilbert, Ottawa born, and Ardeth from Hawarden, Saskatchewan, met on campus and quickly became inseparable. They shared a love for sports, traveling, and adventure, and went on to pursue advanced degrees at Queen's University, and McGill (Gilbert) and the University of Toronto (Ardeth), both developing a keen interest in the biochemical and genetic aspects of disease.

Gilbert and Ardeth's love for one another grew throughout the years. From hitting the ski trails together, to travelling the seven continents of the world, their love of life and one another became everlasting. Now in their late 80s, Gilbert and Ardeth have been married for over 60 years and have three incredibly supportive children; Janet, Andrew, and Margaret.

About 30 years ago, the couple were both caught by surprise when Ardeth began losing her vision.

"Blindness has a tremendous impact on family," explains Gilbert. "People don't understand what it's like until they experience it themselves."

At the early stages of vision loss, Ardeth's vision was being closely monitored at Toronto Western Hospital. Genetic tests were then done at Mount Sinai Hospital in Toronto resulting in Ardeth's diagnosis of retinitis pigmentosa (RP). Today Ardeth can only see shades of light and dark. Working over 50 years in the field of clinical biochemistry, Gilbert continues to be more determined than ever to help find a cure for his wife's eye disease.



"We have a lot to discover and we need to keep supporting Fighting Blindness Canada in finding a treatment and cure," says Gilbert.

The Hills wanted to make a difference in advancing sight-saving research. Today, we celebrate Gilbert and Ardeth's love story and their contribution of over \$1 million towards vision research. Their significant gift will establish The J. Ardeth Hill – Fighting Blindness Canada Professorship in Ocular Genetics Research at the University of Toronto, and pave the way for a new Ocular Genetics Research Centre in Toronto. The centre will be the forefront of genetic eye disease testing and research, and is set to break ground over the next 5 years.

For Gilbert and Ardeth, their gift means sharing their love with the world and making an impact for the over 1.5 million Canadians living with vision loss.

From FBC and the vision loss community, we would like to thank Gilbert and Ardeth and their children for their significant gift and impactful contribution.

COVID-19 & EYE HEALTH FAQs

We understand this time of uncertainty is challenging. Over the last several weeks, FBC has collected top questions and concerns from the vision loss community. To support you, we have prepared two COVID-19 Frequently Asked Questions (FAQs) articles – one focusing on eye health and one on mental health.

Access the FAQs at fightingblindness.ca.

Our Health Information Line is here for you.

We launched a Health Information Line last year to provide our community with someone to connect with regarding their vision health questions. Please reach out by phone **1.888.626.2995** or email healthinfo@fightingblindness.ca and share this resource with a family member or friend that may be in need of support.

Now offering virtual learning!

Community engagement and learning are the building blocks of our events. We recognize that now more than ever is the time to keep connected and share.

We were very excited to announce the launch of our new View Point virtual education series in April 2020. The virtual series offers free vision health related webinars, featuring leading researchers and vision health experts. Join us in exploring new cutting-edge research, treatments for blinding eye diseases and more at an upcoming View Point webinar – to register, visit the “Get Involved” section of fightingblindness.ca.

FUNDRAISING EVENTS

Our fundraising events are critical to advancing vision research. While COVID-19 has brought forth challenges, our staff and dedicated volunteer committees are working hard to offer solutions. With this said, over the coming months, we’re making it fun and easy to participate in virtual fundraising events.

Become a Sight Saver!

Fundraise solo or with a group of family or friends. Offer a gift of sight-saving possibility as your next birthday gift or spark a virtual team challenge. Register to become a Sight Saver at fightingblindness.ca/sightsavers.

Join Cycle for Sight virtually June 20, 2020!

Since 2009, over 4,000 participants have helped raise more than \$5 million to support Fighting Blindness Canada in funding vision research. This year, participants from across Canada will come together virtually to support this community driven event by getting active virtually. Hop on an indoor bike, grab your yoga matt, or unwind the skipping rope and get active with us online June 20th! Learn more at cycleforsight.ca.

In-Person Event Update:

To support the safety and health of our community. We have postponed some of our in-person fundraising events. These include; Last Call (Toronto) postponed to September 17, 2020 and Ride for Sight postponed to 2021. We thank you for your understanding, we will be sure to shares any event updates as they occur.