Fighting Blindness Canada Town Hall Meeting Q&A

April 22, 2020

**Information about Fighting Blindness Canada:**

**Is the FBC eligible for and/or receiving benefit from any of the government subsidies provided to charities and not-for-profit organizations in response to the COVID-19 financial climate?**

Thank you for your concern, due to the decrease in our revenue during this time, Fighting Blindness Canada may be eligible for the wage subsidy being supplied by the Government of Canada. In addition, while Fighting Blindness Canada does not qualify for funds, we applaud the Community Support Emergency Fund of $350M to help support charities and non-profits assist vulnerable Canadians amidst COVID-19. However, we know that more needs to be done are working with our health charity partners to engage with the government to ensure that we can continue to provide support and fund research during this tough time.

**How many fundraising dollars are you expecting to lose because of COVID-19? How will this affect ongoing FBC work?**

If we are not able to hold our fundraising events this year, that represents about 1.5 million dollars in revenue that we have to replace in another way. This funding is critical in our ability to fund research grants. We do not receive any government funding for our research programs, so we are entirely dependent on donors making a gift. If we aren’t able to hold these events in person, we are going to try and do them virtually, but this will be challenging.

**Can a donor direct funds to a particular area of research?**

Yes, you may restrict your funds to a particular area of research. Our philanthropy team would be pleased to speak to you about your gift interest. Please call 1.800.461.3331 or send an email at info@fightingblindness.ca . Thank you for considering a gift to Fighting Blindness Canada.

**Do we have a Canadian vision/sight day?**

Yes, the month of May is Vision Health Month in Canada. Fighting Blindness Canada will be participating in a vision health promotion campaign called #WhyEyeCare and launching our SightSaver.ca fundraising program during this month to participate in promoting vision health in Canada. More details will follow in our monthly e-newsletter which you can subscribe to through this link - <https://www.fightingblindness.ca/enewsletter/>

**Can you share a couple of successes Fighting Blindness Canada has had as a result of our research?**

There are so many exciting things happening in vision research! You can read about some of these on our website at the links below. To keep up to date on the latest research news we encourage you t[o sign up for our monthly eNewsletter](https://www.fightingblindness.ca/enewsletter/).

[New Vision Treatment May Stop Photoreceptor Cells From Dying](https://www.fightingblindness.ca/news/new-vision-treatment-to-stop-photoreceptor-cells-from-dying/)

[Your Gut’s Influence on the Development of Blinding Eye Diseases](https://www.fightingblindness.ca/news/your-guts-influence-on-the-development-of-blinding-eye-diseases/)

[Celebrating 40 Years of Discovery](https://www.fightingblindness.ca/wp-content/uploads/2019/04/FFB-2014-40-Years-of-Discovery-Report-To-Donors.pdf)

**Vision Research:**

**My mother is 58 years old. She is diabetic for about 10+ years. She got AION in both eyes about 4 years ago and has lost most of her eyesight. Is there any research into this? Where can I keep myself updated with this research?**

AION is a type of optic nerve damage that comes from loss of blood flow to the eye. Currently, managing hypergylcemia is the only known way to slow down further vision loss and unfortunately there haven't been any treatments that show significant improvements in outcome (vision). However, there is some research going on in this area including over 40 clinical trials being conducted around the world (some of these trials have completed) that are testing potential new treatments. You can keep track of clinical trials on clinicaltrials.gov or get in touch with our health information officer at 1.888.626.2995 or healthinfo@fightingblindness.ca to find out more.

**Is the [RP]E65 gene mutation the same as Choroideremia? Or does Chorodieremia fit into the possibilities treated by Luxturna?**

Luxturna is a treatment for people with bi-allelic mutations (mutations in both copies of the gene) in the RPE65 gene. This gene is responsible for causing retinitis pigmentosa and Leber congenital amaurosis. Choroideremia is caused by mutations in the CHM gene which encodes (i.e. makes the instructions for) a protein called REP-1. Luxturna is not a treatment for choroideremia, however there are a number of clinical trials testing gene therapy treatments for choroideremia. One of these is a Phase 3 trial that has sites in Montreal and Vancouver (although these sites are not recruiting yet). Please contact the health information line at 1.888.626.2995 or healthinfo@fightingblindness.ca if you would like more information about these trials.

**Has there been much research on Giant Cell Arteritis?**

There is a significant amount of research on giant cell arteritis. This includes preclinical work and clinical trials, some of which are happening here in Canada. If you would like more information about this research, please contact our health information officer. This is a large topic with many different components, and the health information officer may need some more detail to properly guide you in finding resources.

**Has there been much research into optic nerve damage?**

There is a significant amount of research into optic nerve damage happening both around the world and here in Canada. There is research into many forms of nerve damage including into diseases such as Leber hereditary optic neuropathy and glaucoma-induced nerve damage. Some Canadian researchers that are involved in this research include Dr. Leonard Levin (McGill University) (as mentioned by one of the other webinar participants) and Dr. Cathy Tsilfidis (Ottawa Hospital Research Institute). Dr. Tsilfidis is currently being funded by Fighting Blindness Canada for research on gene therapy approaches for inherited retinal diseases like retinitis pigmentosa, but she also studies various types of optic nerve damage. This is just two examples of the many types of research going on into optic nerve damage (not to mention clinical trials). And as we mentioned during the talk, we have just started funding Dr. Michael Walter who is studying pigmentary glaucoma which can lead to optic nerve damage. If you would like more information about this research, please let us know. This is a large topic with many different components, and we may need some more detail to properly guide you in finding research that is most appropriate to your needs.

**Vision Health Policy:**

**Do you have French online survey, and do you still want to hire someone in Dr Keonekoop office for helping French people with FBC service?**

Here is the French version of the IRD survey:

https://www.surveymonkey.com/r/VUEMRH

Here is the French version of the AMD survey:

<https://www.surveymonkey.com/r/VUEDMLA>

Yes, Fighting Blindness Canada is investing to open a new enrollment site for the Patient Registry and support Dr Koenekoop’s clinical trials activities in order to improve access to clinical trials for Canadians.

**Genetic Testing & Clinical Trials:**

**How can I find out if I can participate in a clinical trial?**

This will depend on what your eye condition is and what types of trials are available. In most cases genetic testing is key. For IRDs, most clinical trials focus on a specific genetic mutation. Every clinical trial has specific parameters, so please speak with your opthamologist, retinal specialist or optometrist who will be able to give you more information on what trials you may qualify for. Criteria can include, how much remaining sight you have, your age, other health conditions, the country you live in etc. For more details on this process, please contact our health information officer at 1.888.626.2995 or healthinfo@fightingblindness.ca.

**Where can I get genetic testing done?**

Depending on the province you live in, some of the details of this process may differ. Speak to your ophthalmologist, eye care provider or family doctor about a referral to a genetic counselor for assessment. Either of those health care providers are able to provide a referral. For more details on this process, please contact our health information officer at 1.888.626.2995 or healthinfo@fightingblindness.ca

**I have a long history of AMD on both sides. Should I get genetic testing?**

Speak to your eye care provider or family doctor about getting a referral to a genetic counselor. They will discuss with you whether genetic testing is appropriate for your situation. For more details on this process, please contact our health information officer at 1.888.626.2995 or healthinfo@fightingblindness.ca.

**Has there been any discussion using online platforms instead of in person interviews during this time to further research with clinical trials?**

Absolutely. If the research can be done this way some studies are making the shift. For example, quality of life or lived experience studies can use telephone or virtual interviews to continue their research. However, if the in-person meetings involved specimen collection, eye exams or treatment, they would not be able to move to a virtual space.

In addition, our internal research projects are not clinical studies, but they have been approved by an ethics review board. These projects have been designed in order to submit perspectives to government decision makers and for development into manuscripts that can be published in peer-reviewed journals. This research lends itself to online engagement because it is survey based and then we can follow up with qualitative interviews over the phone or web.