Town Hall Meeting – April 22, 2020

Call Script

**SLIDE 1**

Morgan: Good day. My name is Morgan Ineson and I am the Manager, Research and Education at the Fighting Blindness Canada. Thank you for joining us today.

I’d like to welcome everyone to our first Fighting Blindness Canada Town Hall meeting.

The purpose of these calls is to highlight the latest developments here at the Fighting Blindness Canada and provide updates on our progress towards our mission: To lead the fight against blindness by raising and directing funds to accelerate the development and availability of treatments and cures.

On today’s call our President & CEO, Doug Earle, will provide a strategic update and financial review, Ann Morrison, Director of Philanthropy, will an update on our fundraising programs, Larissa Moniz, Director of Research and Mission Programs will share an update on research in this challenging COVID-19 world and highlight our mission activities, and our Chad Andrews, , Senior Advisor, Policy, Equity and Access will speak about our public policy initiatives.

There will be time at the end for questions. To ask your question, you can type your question in the Q&A window – the button for this is on the bottom bar of your screen. Even if we don’t have time to get to every question during the call, we will answer your questions after the meeting and share it with the script for the call that will be posted on the website.

Please do not use the chat window as this can be disruptive to users using screen reading software.

A recording of this Town Hall will be available and fully accessible transcript of this call will be available on our website in the weeks ahead.

**SLIDE 2**

I’d now like to turn the call over to our President & CEO, Doug Earle.

DOUG EARLE: Thank you, Morgan. Welcome everyone, and thank you for joining us for this first Town Hall meeting for the supporters of Fighting Blindness Canada.

On behalf of our volunteer Board of Directors, our staff and volunteers at Fighting Blindness Canada, we hope that you are remaining safe and keeping well during the COVID-19 pandemic. And I would like to share my personal thoughts and prayers to the families impacted by the rampage in Nova Scotia this weekend. We have many challenges facing our country at this time that only by working together will we overcome them and emerge stronger.

**SLIDE 3**

I would like to start today by recognizing the countless volunteers for Fighting Blindness Canada during Canada’s National Volunteer Week. Without, your dedication and commitment of time, Fighting Blindness Canada could not achieve our mission, especially in these challenging times. Thank you for your commitment.

Yes, these are challenging times for everyone as we all work together to flatten the curve and stop the spread of the COVID-19 virus.

For Fighting Blindness Canada, the safety of our supporters, volunteers and staff is our foremost priority. For this reason, our office has been closed for over a month. Our staff are working remotely. We have cancelled our in-person meetings and events until the end of June and are trying new ways to offer our activities virtually and connect with our supporters like today’s town hall meeting. We are monitoring what the summer and fall calendar will look like for our events and our fundraising.

**SLIDE 4**

COVID-19 is impacting Fighting Blindness Canada’s fundraising revenue.

For example, in March 2019, we raised $264,000 compared to this past month in March 2020 where we raised $173,000. This represents a 34% drop in our revenue. Ann Morrison will speak more about our fundraising efforts to fund our mission shortly.

**SLIDE 5**

These revenue challenges are serious for the organization especially because our mission to fight blindness continues despite COVID-19.

Let me share 3 ways our mission is making a difference right now.

First, vision research is continuing but under the new reality of COVID-19. Our researchers have advised us that for some, their research is slowing down. For many researchers, they have advised that the experiments that were underway before the COVID-19 emergency started in mid-March, they are able to continue the experiments but in the new reality. For some of other researchers, they have advised their institutions are not allowing new experiments to start. And others who require person to person interviews, this research has not started. Therefore, research work over the last few weeks has focused on data analysis and research design remotely from their labs. Larissa Moniz will update us on the activities of our researchers shortly.

Second, our Health Information Line is receiving calls about COVID-19 and Your Eye Health. We have developed answers to frequently asked questions that we have received to help people living with vision loss and have posted them to our website FightingBlindness.ca. For example, how to take your daily eye drops for glaucoma, or what does it means to the stabilization of your vision if your next anti-VEGF injection for Age-related macular degeneration, or diabetes-related vision complications was postponed. These medications are critical to avoid blindness for thousands of Canadians and today for many, these appointments have not happened in the past month, and there is uncertainty when the treatments will start again especially given the age group that puts they at a high risk for COVID-19.

And, we have recently been receiving questions related to mental health. Therefore, we developed a series of answers to these questions and posted them on our website to help people stay mentally well during these challenging days.

Third, the government in March asked Fighting Blindness Canada to provide “patient input” into the first sight-restoring treatment for an inherited retinal disease. This treatment is currently being reviewed by Health Canada. They have given us a short deadline of May 15, 2020 to provide our input into their decision. Chad Andrews will discuss shortly how we are working with our vision partners to provide the strongest voice possible into the government’s decision whether to recommend, or not recommend, a new treatment called Luxturna to be publicly funded by our provincial governments’ drug benefit programs.

Luxturna is a gene therapy that improves sight for some individuals with Leber congenital amaurosis, and a specific type of retinitis pigmentosa. Over 90% of the people that participated in the clinical trials for this treatment had improved night vision and gain other visual improvements after the treatment. Luxturna is not a cure, but it can restore significant sight for people living with the targeted gene mutation in the RPE65 gene.

Luxturna is an exciting example of our research mission delivering new innovative treatments that restores sight.

The decision on Luxturna will set the precedent for future innovative gene and cell therapies, so May 15 is a critical milestone for all Canadians being able to have access to future treatments.

Fighting Blindness plays a critical role in the fight to end blindness caused by blinding eye diseases. We are the catalyst in funding breakthrough research and innovative science that provides solutions to prevent blindness, new sight-restoring or stabilizing treatments, and ultimately the cures.

46 years ago, Fighting Blindness Canada was formed by families with a loved one who had a diagnosis of a blinding eye disease. Back then, we didn’t understand the biology of why they were going blind. We didn’t understand the role DNA played, and there were no treatments.

Today, I am pleased to say times have changed. Research delivered anti-VEGF treatments for Canadians living with Age-related Macular Degeneration or diabetes-related vision complications became available in 2006, and we have several glaucoma treatments that can delay the vision complications for many.

And now Luxturna, the first research delivered treatment for an inherited retinal disease is being considered by Health Canada. Times have changed and for the better.

Thank you for your continuing support to make all of this to happen.

**SLIDE 6**

Our work must continue. Our work is critically needed. Our work is not done.

In 2006, half a million Canadians were living with blindness. In 2017, it was over one and a half million. That’s three times more people living with a seeing disability in just one decade.

And note here, that I’m talking about Canadians who are living with blindness.

In addition, there is the number who are at risk of going blind. These are people who are living with eye conditions that put them at serious risk of losing their sight. This number is over five and half million Canadians.

Combined that’s 7 million Canadians.

This is in a nation whose entire population is only six times that number. Or think of it this way: double the number of people living in the City of Vancouver today is the same number of people living with blindness. And then, think about the number of people living in the Greater Toronto area. It is the same number of Canadians at huge risk of losing their sight.

Vision loss has the highest direct health care costs of any disease category in the country. Higher than diabetes, cancer, heart disease, arthritis and mental illness.

Living with vision loss means you face twice the risk of falls, four times the risk of hip fractures and broken bones, three times the risk of depression, a greater risk of auto accidents, and more medication errors. Seniors with vision loss are admitted to nursing homes three years before those without vision loss, with the obvious loss of independence, loneliness and rising personal cost.

The number of people living with blindness will double in a generation by 2031 and the cost of vision health care will double to over $30 billion if we don’t stop avoidable blindness.

Thank you to your continuing support of Fighting Blindness Canada because research promises to change these facts. There is hope to fight blindness. Your support of Fighting Blindness Canada is critical to us making investments in research that are transforming people’s vision today, and holds promise to give treatment options to more people tomorrow in order that they can restore their sight if they so choose.

To conclude my update, I’d like to share a “Mission Moment” an inspirational story that gets to the heart of our mission.

A year ago, I met a young man of 22, Jack McCormick. Jack has been losing his sight since he was born. Jack shared his story with me of his challenging path to a diagnosis that took over a decade to figure out why he was losing his sight. Jack was 15 before he had a genetic test and found out that his RPE65 gene was not working properly.

Jack McCormick co-led our Young Leaders program sharing his experiences and mentoring other youth how to overcome the stigma of blindness and find meaningful work. Jack graduated from Wilfrid Laurier University in business about a year and half ago and today works in human resources at the Oakville Hospital.

As a member of Fighting Blindness Canada’s Patient Registry, Jack has been updated on the research that led to Luxturna. And fast forward, if our work is successful in securing public funding for Luxturna, he will have the opportunity to be considered for the treatment to restore his vision without an economic barrier to access the treatment.

This is a story in which many elements of our mission come together: a passionate volunteer leader, our Patient Registry and genetic testing at work, and now our public policy activities to ensure a treatment that research has discovered is available to Canadians to restore sight.

Fighting Blindness is fulfilling its mission in a powerful, comprehensive way.

Every event participant, every donor and volunteer, every person who inquires about genetic testing or registers in our Patient Registry, and everyone who participates in our education programs and public policy surveys is critical to our mission. Success stories are happening thanks to all of you and the advancement of our mission.

It’s why we have advanced from being a Foundation to be a Fighter. Fighting Blindness Canada

**SLIDE 7**

I’d now like to turn the call over to Ann Morrison, our Director of Philanthropy, so she can provide a review of the various fundraising initiatives we have under way to support our mission. Ann.

ANN MORRISON:

Hi everyone, for those of you who don’t know me, I have been a volunteer and then an employee of Fighting Blindness Canada for the last 21 years. I originally got involved as a volunteer when by son was diagnosed with retinitis pigmentosa at the age of 5. I feel so privileged to work and fundraise for Fighting Blindness Canada, and to have played a small part in helping our supporters raise and direct over 40 million of dollars for sight-saving research into blinding eye diseases.

Last year, our Board of Directors developed a five-year strategic plan to accelerate research into treatments and cures for all blinding eye diseases. How will we realize this plan? The bottom line is we must find new ways to raise more money for vision research.

Doug mentioned that over 7 Million Canadians are either living with an eye disease or have a family member with an eye disease or is at risk of developing an eye disease. This is a staggering number. Families and individuals often feel alone when they receive their diagnosis, but once they learn about Fighting Blindness Canada, they become part of a much larger and stronger community. We all know there is strength in numbers. So, if everyone touched by blindness and eye disease comes together and takes action in one form or another, we can, and we will deliver treatments and cures for blindness.

I have been speaking with many of our supporters over the last few weeks as we live and adjust to this new reality of staying at home and social distancing.

There are some of our friends that have been impacted by the layoffs, or they are helping their families cope with a loss of income. We understand that these are challenging times and it may not be the right time for everyone to be thinking about the mission of Fighting Blindness Canada. Their words of encouragement have been heart warming and much appreciated.

**SLIDE 8**

I am also touched by the donors who tell me that they want to support us during these challenging times because we are an organization they care deeply about. They want to do something to make a difference especially now when there are so many other things they can’t control. Last week I was speaking with a long-time supporter and mentioned that we wouldn’t be able to hold our fundraising events this spring and the harsh reality of what this would mean to our finances. I love his response, he said “you can always count on us to do whatever we can”.

Our mission to advance sight-saving research is supported in part by the funds raised at our spring fundraising events. Right now, in order to protect our participants and community, our spring events can't go forward as planned.

**SLIDE 9**

Sadly, the critical funding from these events to support vision research is in jeopardy. We have delayed our Comic Vision Last Call event to September 17. And right now is the most important time for securing sponsorships for our October and November Comic Vision events in Toronto, Montreal and Vancouver. As you can imagine, securing sponsors during a pandemic is trickier than ever.

Our Cycle for Sight and Ride for Sight events usually held in June and the summer months, have always been about bringing people together on a special day to fundraise and raise awareness by either riding a bicycle or motorcycle. We have come too far in the last 46 years to lose momentum with the critical sight-saving research that our supporters have invested in. The only way to keep it going is to keep raising money. So if we can’t gather in groups to fundraise, we asked our community what can we do instead? And they had lots of ideas.

**SLIDE 10**

First, I’ll touch on one way that anyone can get involved. Our Sight Saver “dot” ca website is a peer-to-peer fundraising platform that provides our friends an online portal to raise funds for Fighting Blindness Canada. For example, you may wish to create a Sight-Saver page when celebrating a family birthday or an anniversary or some other milestone where you’d rather your friends make a gift to your favourite cause instead of buying you presents. Or you can create your own special event. In the past, friends of Fighting Blindness Canada have used the Sight-Saver program to sell tickets for pub nights, concerts and other fun events. Now due to social distancing we need to get even more creative. Perhaps you will consider holding an online party using zoom or Facetime. It could involve music, card games, baking or whatever you are interested in. When you share your reason for wanting to end blindness and a link to your Sight-Saver page, your friends, family and colleagues will very likely make a donation to support you. Whatever your idea, the new SightSaver.ca website will be ready to launch on May 1 during Canada’s Vision Health Month and it will be available throughout the year for you to use.

**SLIDE 11**

If this has piqued your curiosity, consider putting together of group of 4 friends or family members and join us on April 24th to participate in our first ever 4-2-4 online fundraising day to fight social distancing online. Your group can get together virtually and host a Zoom cocktail party or dinner party. If you want to find out more, visit Sightsavers.ca or email my colleague Susan Techner at info@fightingblindness.ca.

**SLIDE 12**

Back to our Cycle for Sight event.

If you are not familiar with Cycle for Sight, it is known in the community as the Perfect One Day Charity Ride. Recreational “weekend” cyclists, die-hard cyclists, tandem cyclists and volunteers have come together for the last 12 years in St John’s, Ottawa, Toronto and Vancouver to fight blindness and raise awareness of eye diseases. This inspiring cycling event is being impacted by the uncertainty of how long we will be required to participate in physical distancing, jeopardizing $650,000 in funds raised nationally for mission-critical research and programs that allow us to serve our community.

In response, our participants and volunteers suggested we host a national virtual online event on June 20th.  This means no matter where you live in Canada you can now participate virtually in Cycle for Sight.

This is fantastic because it is a known fact that exercise is a key activity for staying mentally and physically well during this extended period of social distancing. Participating in our new virtual Cycle for Sight is your chance to stay fit and help raise awareness and funds for vision research. Remember, only the event is virtual, the exercise is real. So, start your training now. I have!

And my Cycle for Sight colleagues are working hard to create an awesome online experience so on June 20th when we join together virtually, there will be special programming for you while you peddle like mad on your exercise bike, or your bike trainer or walking up and down the stairs – whatever exercise challenge you set out for yourself. It is going to be great. To find out more, please visit CycleforSight.ca

**SLIDE 13**

I can’t end without touching briefly on our Monthly Donor program.

Monthly giving means people give a little each month to support vision research. This steady and reliable revenue enables Fighting Blindness Canada to plan our support for researchers knowing that every month a donation will be received.

If you are already a monthly donor, thank you so much. If you would like to become a monthly donor please call us at 1.800.461.3331, or email info@fightingblindness.ca. You can also sign up by visiting our website at FightingBlindness.ca.

If you go to our donation page, you will see a photo of Steve and Jennifer Celebre and their son, Nicholas. Nicholas was diagnosed with Usher syndrome, and at 4-years-old he faces a future of deafness and vision loss unless research offers new treatments. There is a clinical trial underway in Canada for one form of Usher Syndrome and Fighting Blindness Canada is also supporting a researcher in Toronto who is working in this area. For these reasons, the Celebre family have hope that research will restore Nicholas’s sight

If you are able to give a gift right now, no matter what size, it would be truly appreciated.

Now for an update on Fighting Blindness research and mission landscape, I’d like to turn the call over to Dr. Larissa Moniz, our Director of Research and Mission Programs.

**SLIDE 14**

LARISSA MONIZ:

Thank you, Ann. To introduce myself, as Ann mentioned my name is Larissa and I’m the Director of Research and Mission programs. I joined Fighting Blindness Canada just over 4 months ago and am happy to be here to give you a snapshot of how far we have come in vision research over the past few years as well as telling you about some initiatives we have underway to bring new treatments to Canada and to inform and support individuals living with a blinding eye disease.

**SLIDE 15**

Just like many of us, Fighting Blindness Canada-funded researchers are adjusting to the COVID-19 situation. Many of them are working from home with only essential lab work going forward. The work that is still happening will ensure that they don’t lose data from experiments that have already been set up and which in some cases may have been years in the making. Some of the researchers are also clinicians and they are working hard to support their patients and colleagues.

So while research hasn’t stopped, it has slowed down.

And we need your help to make sure that once this is over, the research can start back up again as quickly as possible. Fighting Blindness Canada is predicting an unprecedented drop in our fundraising this year. If you are in position to help, we appreciate your support more than ever to ensure that we can continue to invest in this ground-breaking work.

At Fighting Blindness Canada, our goal is to drive the development of new sight-saving treatments for blinding eye diseases. I am proud to report that, thanks to generous supporters, we have funded more than $40 million in vision research, are delivering education programs for our community and are having a real impact on public policy to ensure Canadians have access to new treatments.

As Doug mentioned when Fighting Blindness was founded 46 years ago, we didn’t know much about blinding eye diseases. We didn’t know what was happening to the cells in the eye to cause vision loss and we didn’t have cures or even treatments for many of these diseases.

Now fast forward to today. We have a much better understanding of the biology of these diseases and we have effective treatments for some of them including anti-VEGF treatments which have changed the landscape for Canadians with age related macular degeneration and diabetes-related vision complications, such as diabetic macular edema. Glaucoma medications and surgery are also offering ways to stabilize sight loss. And for individuals who have an inherited retinal disease we are finally at the moment when treatments are being tested and even approved. We are so excited that the first treatment for an inherited retinal disease, Luxturna, might be coming to Canada soon.

However, with all this progress there is still more to do. For example, we know that inherited retinal diseases are actually made up of many sub types and can be caused by mutations in over 300 genes. While Luxturna offers great hope it only works for individuals with one specific mutation. And while anti-VEGF, glaucoma and cataract treatments have been game changers unfortunately they aren’t effective for everyone and 1 in 4 people are still at risk of losing their sight. Thinking back to the sobering statistics that Doug shared, we know that even with these treatments available many Canadians will still lose their eyesight this year.

And that’s why funding vision research remains a priority and why Fighting Blindness Canada continues to fund studies across all areas of vision research, from more basic science that is trying to understand why vision loss occurs, to drug discovery and pre-clinical work, to support for clinical trials coming to Canada.

I’d like to share a little about some of our newest research investments which nicely illustrates this breadth of research. This year, thanks to our donors, we were able to launch 6 new research grants that reflect Canada’s vision research community and our mission.

**SLIDE 16**

Dr. Michael Walter, University of Alberta. His team has previously identified a gene that causes a pigmentary glaucoma which occurs when pigment particles from the coloured part of the eye, called the iris are released and clog the eye’s drainage system. This funding will be used to understand more about what the gene does in the cell and how the mutation causes glaucoma.

Dr. Vincent Tropepe, University of Toronto, is studying the most severe form of Usher syndrome, USH1, which causes both hearing and vision loss starting in childhood Dr. Tropepe has now created a new animal model in a type of fish called a zebrafish and his team will use this to test new treatments including potentially gene therapy for USH1

**SLIDE 17**

Dr. Rod Bremner, Lunenfeld-Tanenbaum Research Institute, Toronto, is looking for new drugs to treat retinitis pigmentosa (RP). RP is caused by death of light sensing cells in the eye, called photoreceptors. Dr. Bremner is looking for molecules in the cell that cause the cells to die and then will try to identify treatments that can stop cells dying.

Dr. Elizabeth Simpson, University of British Columbia is studying a form of congenital blindness called aniridia, where the iris is partially or completely absent. Most cases of aniridia are caused by mutations in the PAX6 gene and Dr. Simpson is testing if gene therapy can be used to put a functional copy of PAX6 back into eye and improve vision in animal models.

**SLIDE 18**

Dr. Gregory Borschel, Hospital for Sick Children Research Institute is looking for new treatments for a degenerative disease called neurotrophic keratopathy which occurs when the cornea loses the ability to feel, leading to injury, scarring and ultimately vision loss.

Dr. Susan Leat, University of Waterloo, is developing a new vision test for young children. With current tests it’s hard to diagnose children who are younger than 3 because the tests rely on them knowing the alphabet or matching shapes. In the new test, children as young as one will have to identify the odd one out in a series of symbols of faces. If this works this will allow earlier diagnosis.

**SLIDE 19**

We have also just announced our newest Clinician Scientist Emerging Leader Award which invests in the next generation of ophthalmologist-researchers. This award aims increase the number of clinician researchers who are crucial to drive clinical innovation. Fighting Blindness is funding 4 young ophthalmologists including our newest awardee Dr. Tianwei Zhou. Dr. Zhou is currently in her ophthalmology residency at the University of Montreal and will be studying retinopathy of prematurity which can cause blindness in preterm babies. This work is a clinical extension of her previous PhD work and we are very proud to support her as she embarks on her research career.

**SLIDE 20**

Our supporters are key to us being able to fund these research projects. And we are excited about the work that Fighting Blindness-funded researchers are doing to drive new treatments. And that is where our next challenge comes in. Making sure that Canadians have access to these new treatments. Chad will talk more about how we’re working to bring Luxturna, the first treatment for an inherited retinal disease, which is already available in the US and in some European countries to Canada.

Another important part of these efforts is Fighting Blindness Canada’s Inherited Retinal Disease Patient Registry. The registry is a secure medical database and we are asking anyone living with an inherited retinal disease to join the registry and get their genetic testing. By getting these two steps done we can keep you up to date about new treatments and clinical trials and you will help us demonstrate that there is a market to bring new trials to Canada. Thanks to our donors, Fighting Blindness has been able to play a key role in bringing new clinical trials for inherited retinal diseases to Canada in 2019. We are keeping track of 5 clinical trials and hope that there will be more coming soon!

**SLIDE 21**

I will finish off with a look at some of Fighting Blindness Canada’s other mission programs which aim to educate and support Canadians about their eye health. Our Health Information Line is open and we are very busy answering questions about new treatments and research discoveries and more recently the impact of COVID-19 on things like appointment or availability of medicines. If you have questions about COVID-19 and your eye health or other vision concerns, you can reach the Health Information line at 1-888-626-2995 or email healthinfo@fightingblindness.ca.

You can also access information about eye diseases and support living with vision loss on our website where we have health education resources to help you manage and navigate your vision health care.

**SLIDE 22**

Now because of COVID-19, we have had to cancel our in-person Vision Quest events this spring. But I am happy to tell you that we have replaced them with a new virtual education series called View Point.

View Point is free of charge and is a combination of live webinars and pre-recorded sessions covering a range of topics such as gene therapy, pharmaceutical treatments, age-related vision loss, and inherited retinal disease.

We held our first session last Thursday with Dr. Netan Choudhry who talked about MANAGING EYE CARE IN THE COVID-19 ERA. And this session is now available to watch on our website.

Our next live webinar will be on Monday, April 27 at 4:00 p.m. (EST). It will be hosted by optometrists Dr. Selena Friesen and Dr. Michael Nelson who will provide insights on some of the most popular low vision devices available and how they can help you to maximize your vision.

And on Wednesday, May 6, also at 4 p.m. EST we will present a pre-recorded panel discussion where scientists, clinicians, and industry experts discussed key research efforts that are underway in Canada and around the globe to develop new sight-saving drugs.

You can watch previous sessions or find out more about our upcoming View Point events by visiting the “get involved” tab at fightingblindness.ca. Join us in the upcoming weeks to explore cutting edge vision research, new treatments for blinding eye diseases, and more.

Finally, you can keep in the loop about all of Fighting Blindness Canada’s programs by joining our monthly e-newsletter through our website.

**SLIDE 23**

After that whirlwind overview of our Mission programs I’ll turn this over to Chad Andrews, Senior Advisor, Policy, Equity and Access to update us on Fighting Blindness Canada’s current public policy initiatives.

**CHAD ANDREWS:** Thanks Larissa. It’s an exciting time for people living with blinding eye diseases. Thanks to funding from our donors and various partners, we have a robust set of initiatives underway to make sure people living with vision loss have their voices heard by government and policy decision makers.

**SLIDE 24**

To do this, we really need to hear from you, the individuals who are affected by vision loss and blindness on a day-to-day basis. To collect and synthesize insights, we are asking Canadians living with a blinding eye disease to fill out our new “living with vision loss” surveys, which are designed to learn more about the physical, psychological, and practical impacts of vision loss. By filling out the survey, you’re telling policymakers what it’s like to live with vision loss, providing crucial perspectives that help explain why it’s so important that new treatments are made available and accessible to all Canadians.

We are completing a living with glaucoma study right now for publication. It received over 300 responses from Canadians living with that disease. Once published, the information will be shared with a broad audience to influence research and public policy development.

The glaucoma survey is still live if you are eligible to fill it out. And you can find all of our other surveys on our website at [www.fightingblindness.ca/news/2020-fbc-surveys/](http://www.fightingblindness.ca/news/2020-fbc-surveys/)

The three other surveys that are active are:

* Living with an inherited retinal disease (IRD)
* Living with age-related macular degeneration (AMD)
* Living with diabetes-related vision complications: diabetic retinopathy (DR) or diabetic macular edema (DME)

Later in the year, we hope to launch another survey called IRD Counts, which will provide data to complete a socio-economic cost of illness report with the help of Deliotte Economics.

Your responses to any one of these surveys are anonymous and confidential, and you can complete multiple surveys if you have more than one eye condition.

The surveys will remain open for a number of weeks.

That said, data from the Living with an inherited retinal disease survey will be pulled around May 1 to be analyzed to provide “patient input” to the government about whether Luxturna should be public funded by our provincial drug benefit programs.

This is very tangible example of how these surveys impact government decision making. The more people we have completing the surveys, the stronger our case for Luxturna and similar innovative treatments to be approved for public funding.

Luxturna costs $850,000 US if you were to have the treatment completed in the States. At Fighting Blindness Canada, we believe economic barriers should not deny someone access to a new treatment to restore sight. These surveys will help us build the case that Canadians need equitable access to safe and effective vision treatments—just like in the UK where Luxturna is already publicly funded.

If you know someone living with these eye conditions, please encourage them to visit fightingblindness.ca or call 1.800.461.3331 to find out about our surveys.

The more feedback we collect, the greater the impact. Thank you.

**SLIDE 25**

MORGAN: Thank you very much Chad. Now we are going to answer questions.

Q&A -- To ask your questions please type your question in the Q&A window – the button for this is on the bottom bar of your screen.

We have a couple questions that were submitted in advance, so we'll start with those, then we'll go to Q and A box. The first question I'll address to Larissa was submitted in advance. The question is how do I find out if I can participate in a clinical trial?

LARISSA:

Genetic testing is key. If you have not had your genetic test, then call Health Information Line at 18886262995 or email healthinfo@fightingblindness.ca to learn how to get tested in your province. And then join our Patient Registry. Registry members will be search and review by each site lead.

PLEASE SEE Q&A Document for answers to questions asked in the townhall.

**SLIDE 26**

MORGAN:

Thank you everyone. We are so grateful that you joined us to speak about the important work of Fighting Blindness Canada to change the future of vision care.

Bringing innovative sight-saving and sight-restoring treatments to Canada is at the very core of our mission. It’s why we do what we do! Research is expensive and it’s a long-term investment, but the results are life-changing.

If you enjoyed todays webinar, I encourage you to visit our Virtual Events page on the Fighting Blindness website to sign up for other topics of interest. After today’s live broadcast there will also be a link to view the video on our page under past events. Please share with people in your networks and spread the word about the work that we do.

On our website you can also find information about our internal research initiatives. I encourage you to visit our survey page to fill out a confidential survey about your experience living with vision loss. We currently have surveys about AMD, IRDs and Diabetic eye disease.

Lastly, please consider making a donation to help support sight-saving research and our mission programs. People are always surprised to learn that we don’t receive government funding. All of the work that we do is made possible by the incredibly generosity of our donors.

Thank you again for joining us. To find out more about Fighting Blindness Canada, please visit [www.fightingblindness.ca](http://www.fightingblindness.ca), call 1.800.461.3331 or email info@fightingblindiness.ca.

I hope you stay safe and healthy. Thank you.