2021 FBC Town Hall Transcript  
April 21, 2021

Speaker Key:

MI Morgan Ineson

RA Ramya Amuthan

DE Doug Earle

EH Dr Elise Heon

RK Dr Rob Koenekoop

LM Dr Larissa Moniz

AM Ann Morrison

AW April Watts

LT Lowell Taylor

00:00:03

MI I think we're going to get started. Good afternoon, everyone and welcome. If we haven't met before, my name is Morgan Ineson and I'm the manager of education and research here at Fighting Blindness Canada. And I'm so pleased today to welcome you to our 2021 town hall meeting. It's hard to believe that it's been actually almost a year to the day since our last town hall. And what a year it has been for all of us.

The purpose of today's call is to give you some updates on how Fighting Blindness Canada has fared in the last year and to discuss progress that's being made towards our mission of accelerating and supporting developments in vision research and treatments for blinding eye diseases. Over the next hour, you're going to be hearing from our fantastic Fighting Blindness Canada staff and some special guests.

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As we talk about Canadian vision research, FBC programmes and services and ways that you can join in and support the important and exciting work that we're involved in. After our speakers, there will be time for questions and answers. Please feel free at any time during the session to type your questions into the Q&A box, which is on the bottom of your Zoom window. Or you can always email me at education@fightingblindness.ca.

Without further ado, let's get started. I'm going to turn it over right now to FBC’s president and CEO, Doug Earle, and Ramya Amuthan, who you might know from AMI’s Kelly and Company. She's also one of our Young Leaders’ co-chairs and a long-time friend of Fighting Blindness Canada. I will turn it over to them to kick us off today.

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RA Thank you, Morgan. And thank you Fighting Blindness Canada for inviting me to participate in today's town hall meeting for FBC. As co-host on AMI-audio’s Kelly and Company, I speak daily from 2 to 4 PM Eastern about life and the challenges that matter to the blind and low-vision community. And I must say, Doug, I'm always interested in finding out more about what's happening with Fighting Blindness Canada.

Let's start there. How about we start with the mission of Fighting Blindness Canada for people who are just learning about the organisation?

DE Sure. And thank you for volunteering your time to help us with our town hall today. Of course, Fighting Blindness Canada was founded in 1974. And it was really founded out of love, the love of parents and families that came together because their loved one was diagnosed with a blinding eye disease and they were told that it couldn't be treated. That we didn't understand the biology. That the role that genes played.

And at the time, we didn't have any treatments. And our mission, the families that came together to form Fighting Blindness Canada, was to fund research so that we could accelerate discoveries into new treatments and cures for blinding eye diseases. And fast-forward today, things have really changed.

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RA I can absolutely attest to things having really changed. Because as for myself, as someone who's living with a hereditary eye condition, Leber's congenital amaurosis, it's important, I find, to invest in research. To give people that option for research for giving people that peace of mind that things are being done and conversations are still being held about their eye conditions. And that hope and possibility to maintain sight and/or to restore sight.

I myself participated in a clinical trial for my mutated gene, which is RPE65. And it was conducted by the University of Pennsylvania. And I underwent gene therapy in the lower left quadrant of my left eye. And honestly, it improved quite a bit of vision, noticeable vision, especially in that lower peripheral vision during night-time or during gloomy days. It was an incredible opportunity for me, Doug.

DE You're a trailblazer, truly. To think 11 years ago, through Fighting Blindness Canada’s supportive, Dr Heon, at SickKids and through Fighting Blindness Canada's patient registry for inherited retinal diseases, you were one of five Canadians that participated in that early trial of gene therapy for the RPE65 gene. And I'm pleased to let our supporters know that their donations helped with that Phase One clinical trial.

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And the results of that trial were actually used as evidence to the US and Canadian governments in their decision to approve the first gene replacement treatment for any disease known to humankind. And fortunately for us, it's for an eye disease, with people living with that gene mutation of RPE65. It's called Luxturna. And in just a few moments, we're going to talk with Dr Heon about what's happening since Health Canada approved Luxturna as a treatment.

RA Absolutely. Looking forward to that conversation. It's always so much wonderful information and explanation when I hear Dr Heon talk. That's great. Everyone wants to know, Doug, switching over to current times, how COVID-19 is impacting Fighting Blindness Canada. Can you talk a little bit about that for us?

DE Sure. And it's been a challenging time for all of us, whether you're living in lockdown, as we are in Ontario right now, or have gone through the first three waves of COVID. Our health information line started very early hearing about the pandemic, about people's concerns about their surgeries, their eye treatments being cancelled. We heard about mental health challenges that it was causing for the community.

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And we responded really quickly, putting up as much information as we could on our website and answering people's questions and emails. Financially, thanks to our supporters, we were able to keep research moving forward. And Larissa’s going to talk about that a little bit more. Even despite the fact that not being able to hold in-person fundraising events meant that we had a million-dollar gap in our revenue plan.

And unfortunately, those events are still not going to be able to be held in 2021. We are trying to be creative. We're asking our supporters to help us fill that million-dollar gap to keep research moving forward, to keep our programmes going forward. Our Cycle for Sight, our Comic Vision event, our education programmes now, View Point and Young Leaders, have been moved virtually. And that's actually really opened up our programming across the country.

There's no physical barrier, location barrier to participate. And we're going to be running those events again this year. And thankfully, I really like to thank all of our donors and our volunteers for helping us, because you've stepped up. And thank you. And we're going to hear a little bit more about the exciting times that are happening in clinical trials with Dr Rob Koenekoop very shortly. And Fighting Blindness has invested into bringing clinical trials to Canada so people living with blinding eye diseases have access to those new treatments as quickly as possible.

RA Thanks for sharing, Doug. And really, shout out to all who supported, who continued to keep those connections open and virtual platforms and donations and just continuing this thing forward so it feels like we're not missing much in the last year and a bit. Thank you and thank you to Fighting Blindness Canada supporters for supporting vision research moving forward. And now we're going to hear the conversation that Doug had with Dr Elise Heon.

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DE Hello. Great to be joined here by Dr Elise Heon, the director of the Ocular Genetics Programme at SickKids and a professor at the University of Toronto. Thank you, Dr Heon, for joining up.

EH [Overtalking].

DE I really appreciate you taking the time to talk to our supporters and friends of Fighting Blindness Canada during this town hall today. How is SickKids and Sunnybrook getting ready to deliver this new innovative treatment called Luxturna?

EH As you know, it's a very exciting time. And over a year ago, as we knew that a submission was made to Health Canada, the company Novartis looked for some treatment sites in the country, and there's Toronto and Montreal. And in Toronto, SickKids has been designated as the paediatric site, whereas Sunnybrook is the adult site. We’ve undergone full training, the pharmacy, the OR, the surgeons, the clinicians, all the care providers, in order for the treatment to be delivered safely and effectively.

We’re ready to go. We've identified the patients and we're just waiting for funding approval, because the drug could not be administered without funding approval. And I understand that’s pending.

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DE We're quite excited that this treatment’s available, but a bit disappointed that it's taking so long for after Health Canada has approved it, that our provincial governments would step up and be able to offer it through each of our provincial drug benefit programmes. What's the impact for those patients that are waiting?

EH I agree. It's very disappointing because the retinal degeneration associated to RPE65 is quite severe. And as the individual is born, they've lost a significant fraction of the photoreceptors, the light-sensing cells behind the retina. And they lose over 10,000 photoreceptors a day. And every day waiting is a significant number of cells lost that could use the treatment. I hope that there's going to be a change sooner than later. Otherwise, it's a real missed opportunity for these patients.

DE How can the vision loss community make their voice heard to try to get the bureaucratic process to speed up?

EH I think, in my experience, as you know, vision impairment is silent and it's invisible. And that has to change. People need to say what they need right now… Just a moment, please. [Unclear] COVID.

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DE All you need to say…

EH People need to say what they need. People are saying it's all right, to see in this context is all right. And this bureaucratic delay is really regrettable. And this should not be happening.

DE I know Fighting Blindness has set up a website that we're launching this month. It's called approveluxturna.ca.

EH That’s great.

DE And people can go on to the website, approveluxturna.ca. They can put their name down. They can fill out their postcode. And their premier, their health minister, their local provincial representative will get an email sent to them to try to urge them to speed up the process. Because as you've said often to me, time equals sight. And there's no reason that people need to be needlessly losing sight after all this time, this moment in time that people have the first approved gene therapy treatment available to them.

That it should be publically funded. That they should be seeing you, being in those ORs and getting this gene therapy happening right now.

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EH I can't thank you enough for your leadership, Doug, because that's what has to happen. They don't want to hear from me. And I've been banging on the doors. They need to hear from the taxpayers, the patients, the stakeholders. What you’re doing is a good thing.

DE We're happy to add our voice.

EH [Overtalking].

DE And I encourage everyone listening today to share this with their friends. We'll be doing a follow-up after the town hall meeting how you can get to approveluxturna.ca. Encourage your friends to send this email. It's so vital. We need our voice to be heard so that we can set the precedent. Because there's so many treatments coming down the pike from the discovery lab into clinical trials that we need to set the precedent today.

Luxturna needs to be funded so that the next treatment doesn't have this type of delays. Is that right?

EH Absolutely. This is standard of care in the United States and Europe. And it's unacceptable that we're lagging so far behind.

DE Thank you for joining us today and sharing this amazing news about the first treatment being ready and ready to go. We just need the government to step up and provide that public funding. Thank you.

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EH Thank you, Doug, for all your efforts. Good luck.

DE Thank you.

MI Thank you, Dr Heon. Next up, Doug will be speaking with Dr Rob Koenekoop about clinical trials in Canada and why this is such an exciting time in vision research.

DE Hello, Dr Koenekoop. Thank you for joining us today. We're really happy to have you as a part of the Fighting Blindness Canada town hall. And of course, for those who don't know, Dr Koenekoop is the director of paediatric ophthalmology at the Montreal Children's Hospital, a part of the McGill University Health Centre. And he is a professor of paediatric surgery at the Faculty of Medicine at McGill University. Welcome, long-time partner with Fighting Blindness Canada.

We really appreciate everything that you're doing to move forward. And I just wanted to take a brief moment. And you're very active in the global clinical trials to validate treatments for inherited retinal diseases. What trials that you're currently involved in and why is it important that those trials be brought to Canada?

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RK First of all, Doug, thank you so much for inviting me. I'm always ready to help Fighting Blindness Canada. As you know, we've been working together for the past 25 years. And it's been an incredible journey, these last 25 years, especially the last two years. Let me tell you that at McGill University and the Children's Hospital, which combines adult and children research, we now have a platform, the centre of innovative medicine.

In the last two years, we've been able to attract nine different clinical trials for different diseases in the inherited retinal degeneration group. We're treating and testing patients with Leber congenital amaurosis. We're testing patients with Usher syndrome. And also, we're testing patients with retinitis pigmentosa. The other thing that's really exciting… Because nine is a lot. And the only reason I can do it is because of the support from the Fighting Blindness Canada foundation and yourself.

But also from a team that surrounds me at the centre of innovative medicine, about 20 people, some of those are also supported by Fighting Blindness Canada. The exciting thing is that we're starting to see improvements in vision. And I can't tell you… After 20 years of seeing patients diminish their vision and lose their vision, children, teenagers, adults, everyone lost their vision. And now for the first time in my career, I'm seeing patients improve their vision.

Initially, it was very exciting and small changes. And now it's very exciting and some very robust changes. What we're doing, Doug, is we're doing different trials. We're doing gene therapy, both gene editing, which fixes the mutation and leaves the gene intact in its surroundings, and we're doing gene therapy by augmentation. We’re replacing the entire gene with the surgical technique. And it's fascinating to see these two techniques side to side in the different populations.

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We're also doing drug therapy. We’re actually doing a drug that is going to hopefully be for everyone and not just for certain genotypes, but for all RP patients, all patients with IRD. And we're also doing some natural history studies. Most of these studies are supported by sponsors. This is often the first time that these sponsors are coming to Canada. And it's fascinating and fantastic for Canadian patients to have access to these trials for the first time.

We're actually treating Canadians or making them better. But the other thing is, we are also able to attract NIH funding for some of these studies. We have one study that you're also supporting with Jennifer Lentz at LSU, which is Louisiana State University, for another type of Usher syndrome.

DE It just must be an amazing time for you and for your patients to have been a part of these clinical trials and have access to these treatments at the earliest possible moment. Looking back on your career, why is this such an exciting time for vision research?

RK When we first started in 1995, we were telling patients, there's nothing we can do. Give me some blood and we'll do some genetic studies. And we were hoping to find out what caused retinitis pigmentosa and the other IRDs, cone dystrophy, Stargardt. We're trying to figure out what causes the cell death by doing genetic studies, by finding genes, figuring out what they do. What protein do they make? What cycle is the protein part of?

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And can we manipulate the cycle? Questions like that. I honestly didn't think in 1995 that we were going to have between five and six viable treatments that are still in study. But this is one of the exciting things. When penicillin was discovered and insulin was discovered, we were banking on just one thing. Here, we are having parallel developments of safety and efficacy of five different types of treatments, including stem cells, which we're hoping to get involved in as well.

DE That's great. We really appreciate your work and dedication and passion to helping improve the lives of your patients and to benefit Canada and around the world. You’re definitely a trailblazer and I know our donors and supporters of Fighting Blindness Canada are so excited with the work that you're doing. And thank you, Dr Koenekoop, for your help.

RK Let me take this opportunity to thank all the donors, current, present, past and future. Fighting Blindness Canada is one of the best organisations that I've ever worked with in my career. And it will be a lifelong, career-long association. Thank you so much to all the donors, but also all the people involved at the foundation, Fighting Blindness, and you as well, Doug. Thank you so much.

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DE Thank you, Rob.

MI Thank you so much to Doug and Dr Koenekoop and Dr Heon for providing those updates to us. I have to say, every time I hear Dr Heon or Dr Koenekoop speak about their work, it really makes me excited. They’re so passionate about what they do. And as Doug said, they are true trailblazers in the vision research community. I'm really looking forward to hearing more about those clinical trials coming up.

And of course, the opportunity for us to all join our voices together to support Approve Luxturna to make this ground-breaking treatment available to all Canadians. Speaking of research, I'm going to be joined now by Dr Larissa Moniz, who is the director of research admission programmes at Fighting Blindness Canada. Thank you for joining us today, Larissa. We received so many audience questions over the weekend.

And they're all about research and what is new and ground-breaking in the field. Of course, today, we won't have enough time to talk about all of our funded research, but could you share with us some highlights in the vision research community from over the past year?

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LM Sure. Thank you, Morgan. I agree, it was really exciting hearing Dr Koenekoop and Dr Heon talk just now. And I thought they both gave a really good overview of some of the gene therapy research and genetic research that's happening in Canada. And just if people are interested, Fighting Blindness Canada is funding other research into both of these topics about rare forms of glaucoma, corneal disease and, of course, other inherited diseases using genetic approaches to understand more or develop treatments.

But I thought I would tell you about another type of innovative treatment today that we're funding which is looking at how we develop stem cells or cell replacement therapies. For people who don't know, stem cell therapies can really help people who have advanced disease. If they have lost a lot of their eye cells or they have a lot of damaged cells that have led to vision loss, this could be for something like damage to the optic nerve and glaucoma.

If they have lost photoreceptor cells and inherited retinal diseases or retinal pigment epithelial cells and age-related macular degeneration. And this would be a non-gene specific type of therapy. Currently, there aren't any approved stem cell therapies for glaucoma, inherited retinal diseases, AMD, although there is a type of stem cell therapy that is available. It's called corneal limbal stem cell transplantation.

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And it is in use for a very specific type of corneal damage, which is caused by injury or disease. But for most of the other eye diseases, there isn't anything out there. And part of the reason is that there's still a number of challenges that scientists are trying to overcome to make stem cell therapy effective and to make sure that it is efficient.

One of the challenges that our chair of our scientific advisory board, actually Dr Michel Cayouette, who works at the Montreal Clinical Research Institute, and McGill is working on, is he’s trying to understand, how can you make a consistent and efficient source of replacement cells from stem cells? You want to make sure that the stem cell can make the type of cell that you want to make. How do you make the stem cell turn into either a rod photoreceptor?

Rods are the photoreceptors that are responsible for seeing in low light and for peripheral vision. Or how do you make it turn into a cone photoreceptor, which is responsible for colour vision and detail and central vision? What he has found is that there are two molecules. And he identified this and published this in a paper last year. And it can control which direction the stem cell goes, whether it makes a rod or it makes a cone, depending on how much of the molecule is in the cell.

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This really interesting paper will allow scientists to make more of the cell type that they need to make, whether it's cones or rods. But he's even now looking to see if he can use this information to turn other retinal cells that are still healthy and are still in the eye into sensing photoreceptor cells. Hopefully, we'll have more to tell you about this project in the years to come. Another really important step in stem cell therapy is understanding how the new cells integrate into the eye and how they form the right connections.

We have another researcher, her name is Dr Sarah McFarlane, and she works at the University of Calgary. And what she's doing is looking to see how retinal pigment epithelial cells, how do they go to the sites of damage in AMD? Retinal pigment epithelial cells, they sit underneath the photoreceptors and they provide support and housekeeping functions to make sure photoreceptors are healthy. But these cells are often damaged in advanced AMD.

In Dr McFarlane’s work, she has found, again, a couple of molecules or proteins that are important to make sure that the RPE cells go to the right place under normal development conditions. And she's taking this information now, her and her team, and they're trying to see if the same thing happens in a damaged retina. In a similar situation that might happen in age-related macular degeneration. And I was actually talking to Dr McFarlane about her project a couple of weeks ago.

And it was really, really nice because she expressed how the support from her FBC grant has been really instrumental in her research, helping her apply for and get a larger grant from a government agency. In this case, it was CIHR. And it helped keep her research moving forward. And it really drove home the crucial role that FBC and the donors play in making sure that Canadian vision researchers are able to start innovative projects where they might not be able to get funding for larger grants.

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They need to gather the data first. And we really provide some of that seed funding that allow the scientists to take high risk, high reward of exploring new avenues. That was really, really nice to hear how useful it has been. That was a really quick thing about some of our stem cell projects. And you can find out more about stem cell and gene therapies as well as clinical trials on our website. And Morgan, I'll ask you to send a link in a follow-up email.

If people are interested in specific trials, they can learn more about that. And of course, if you haven't already, please sign up for our e-newsletter, because it will keep you up to date on all of our FBC funded research, but also really exciting vision research that's happening in the world.

MI Switching gears a little bit, Doug talked about this a little bit at the beginning, but COVID-19 has had such a profound effect on everyone. How has it specifically affected vision researchers? And what are we doing at Fighting Blindness Canada to help support them through this time?

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LM In a way, it's both really similar and different than what's happened to us. When the pandemic first hit, most scientists had to stop a lot of the research, go home and they had to work from home. Of course, they were allowed to keep some really crucial experiments going. Sometimes they are working on cells or animal models that have taken years and years to develop. They obviously don't want to lose these really precious reagents.

They were allowed to keep some of these things going, but in a much slower way. Definitely huge slowdowns in research. When I was talking to some of the scientists during this time, especially after a few weeks when some of the shock, they got over it, they were starting to see the silver lining in it where they had a bit more time to analyse their data, to actually start writing up papers. I think some people have actually…

I'm not going to say it's a good thing. But I think they've been able to make use of the time that they had to do something different, that's also really going to push their research forward. And for most people, restrictions started to lift in about the summer of 2020. And they started being able to go back to the lab. And I think at this point, most research programmes are largely back up and running with some differences.

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I think a lot of people are still working on shifts. They can't all be in the lab at the same time. To keep social distancing, keep it safe, they might work half days here, maybe three to four days a week. But I think most of the research is pretty much back up to full speed, which is fantastic. When you're talking about research that involves patients, it’s been a little bit different. For some people, the restrictions have gone on much longer.

Some of our researchers haven't been able to start their experiments until the last few months. But for other people with clinical trials, if they were in the middle of a clinical trial and were receiving regular treatments, for instance, anti-VEGF treatments, we were talking to some companies lately who actually haven't seen much stoppage in their clinical trials. Because this is really important treatment that people have to receive.

That has gone on as normal. It depends on which stage the trial was at, I think, how it was affected. And I would say a final thing that we've been noticing is that a lot of researchers are talking about how hard it is to get funding. It's always hard to get funding. It's always a struggle. But right now, understandably, a lot of research funding is being diverted to COVID research. And a lot of health charities have had to cut a lot of grants.

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There's just a lot less money in the ecosystem for the researchers to apply for and a lot more competition. FBC is trying to support the best we can, reaching out to our researchers, keeping in contact with them and just doing what we can to keep research moving forward.

MI Again, it's been a really difficult past year. But we do have some exciting things coming up this year. What can we look forward to in 2021?

LM It's actually really nice to be able to segue out of talking about COVID and things that are hard and being able to announce that we are holding three grant competitions this year, which is so exciting. And I think it's really important now, especially as I mentioned, that just scientists are struggling to find funding. We are really happy to be able to provide some support for them this year. There are three competitions.

The first competition is called our Clinician-Scientist Emerging Leader Award. And it's about supporting clinicians like ophthalmologists or optometrists who are really early in their career, who are also pursuing research along their clinical practice. This is a really important part of our research ecosystem. Clinician scientists really help bring discoveries from the lab and help translate it into clinical trials and bring it to patients.

And building up this pipeline is something that Fighting Blindness Canada thinks is a really crucial part of our mission. And the applications are in. They’re currently sitting with expert reviewers. And we are hoping to announce a successful award in June or July. Stay tuned for that. Our second competition is the second phase of the Restore Vision 20/20 competition. This was a competition that was launched a few years ago.

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And the goal was to develop a treatment for late stage retinal degeneration, but treatments that were getting pretty close to the clinics. We really wanted to fund research that was at a preclinical stage. Bring it a little bit closer to being able to reach patients. In the first phase, we awarded four grants and they touched on a number of approaches, gene therapy, stem cell and a photoswitch strategy, to try to answer this question.

And in the second phase, we're going to award additional funding to the project or projects that have shown the most promise. Really, support the projects that are getting closest to the goal. And the final competition is our 2021 Research Grant Competition. This is the competition where we award grants to the best and the most innovative research. We’re asking scientists from across the country, vision scientists, to give us their best ideas.

And we're really excited to see what comes in across the whole spectrum of vision research. The deadline for scientists to register their interest is next week. We’ll get a good idea of the number of applications we're going to get. Full applications will be due in July. And we're likely going to announce results in January, which seems like a very, very long time. But I want to assure you that it's on purpose, because we really think it's important that the review process is very rigorous.

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We want to make sure that we get the right reviewers, that they have enough time to really delve into each proposal and evaluate it and then come together and discuss it with their peers. We think this is extremely important to make sure that we're funding good science and science that's going to have the most impact on blinding eye diseases. I just also want to say that we really wouldn't have been able to hold these competitions without the donors.

I know Doug talked about how amazing our donors have been this year and how they've really stepped up. But being able to support this exciting research is really down to them. And I actually want to thank you for helping me be able to be part of these exciting competitions. And I'm really looking forward to telling you more about them in the next few months. That's it for my part about research, Morgan. And I really hope that everyone has enjoyed the update on research.

As I said, please stay tuned to e-news if you want more information about anything or go to our website. But Morgan, turning over to you now, I was wondering if you could tell us a little bit about some programmes and educational resources that have been produced over the last year and what's coming up in 2021 on your side.

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MI Absolutely. Thanks, Larissa, for that great update. And the grant competitions are always so exciting. I'm really looking forward to seeing what comes out of that this year. Considering we used to run pretty much exclusively in-person programmes, COVID has definitely presented a major challenge for us on that side. But over a year ago, we decided that we would see it as an opportunity and be able to reach more people across the country and move our programmes online.

As Doug mentioned earlier, by going virtual, we really have been able to reach more people that would not have necessarily been able to come to our in-person events. And we're just continuing to spread awareness and education across Canada. And I'm just really proud of this work that we're doing. I'm running a little short on time, but I do want to just mention a couple of resources that we have, that I want everyone to be aware of.

Of course, if you have tuned in at all to any of our View Points over the last year, View Point is our virtual education series. If you've been a long-time supporter or follower of FBC, you may have come to a Vision Quest, which were our in-person events. We’ve really taken that online now. We record all of our sessions and we’ve really been able to build this really exciting body of work that is now YouTube playlist.

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You can go onto YouTube, search for Fighting Blindness Canada. And we have over 20 recordings on various topics from specific eye diseases like AMD or glaucoma. We have things on gene therapy and genetic testing, even living with COVID-19 and how to take care of your eyes at this time. I will do a bit of a shameless plug for our next session which is on May 6th. We're going to be talking to a panel of caregivers about their experience caring for someone with vision loss.

And we have some new exciting sessions that are going to be announced in June on cataracts and a landmark study about the cost of vision loss. The other programme that I'm heavily involved in is the Young Leaders Programme. If you haven't heard about this one, it is, again, gone online. And we're really focussing on careers and networking and leadership for youth, 14 to 30. We have our spring summit coming up next weekend.

If you or someone you know fits in that age bracket, please reach out to me. I'd be happy to give you more information about the programme. And it's going to be a really fun weekend. As Larissa touched on, our website is also a fantastic wealth of information for you as you're looking into information about your eye condition. We have specific eye disease pages, information on genetic testing, innovative treatments.

Definitely check that out. The last thing I want to mention is we do also have some specific COVID resources, both for eye health and for mental health. I don't know about anyone else out there, but I'm finding this third wave a little bit more challenging to deal with. And I think we could all use a little extra support. Please do check that out. And on that note, I also want to let you know that we have partnered with AMI, Accessible Media Inc.

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They are our national accessibility partner. And we are helping them produce a few episodes of their show called The Pulse, which airs on Saturdays at 10 AM. And this Saturday, April 24th, I believe, is our first episode. And it's all about COVID and the effect on eye care. We’d love for you to tune into that show and let us know what you think. I think that's it for me. Obviously, we have so much going on and we'd love for you to be involved.

If you ever have any questions about our programmes, you can email me at education@fightingblindness.ca. And now I'm going to turn it over to Ann Morrison, who's our director of philanthropy, and April Watts, who is our national events manager, to talk a little bit about how you can get involved in the exciting work that we've talked about today.

AM Thanks, Morgan. Hi, everyone. I'm Ann Morrison. And if we haven't met in the past, I'm the director of philanthropy at Fighting Blindness Canada. I'm joined by my awesome colleague, April Watts, who is a national events manager. And we want to give you a snapshot of Fighting Blindness Canada's fundraising efforts. Both April and I have been with Fighting Blindness Canada for many years. And if you have participated in one of our fundraising events, then you've probably crossed paths with April or received an email from her.

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AW Everyone, it's great to be here. We’ll just jump right in. Ann, many of the Fighting Blindness Canada supporters I have spoken to have asked how our organisation did in terms of fundraising last year. Could you speak to that for a minute or less?

AM I'll try. Great question, April. I think everyone supporting Fighting Blindness Canada is curious about the same thing. Our colleagues Jaime Alexanderson, Josie Koumandaros and Doug Smith, who are all part of the Fighting Blindness Canada donor relations team, have been fielding this question too. And the simple answer is that we fared well last year compared to many health charities, considering the challenges we faced with COVID-19 and not being able to hold our in-person fundraising events.

Cancelling those events, as Doug mentioned, created a $1 million gap in funding that continues in 2021. And however, our long-time donors and new friends to the organisation, they really stepped up to show their support. I heard from many people that they wanted to make sure that years of vision research could keep moving forward.

00:38:50

AW It sounds like our donors really made a difference and had a significant impact on our ability to keep funding vision research?

AM Yes, absolutely. And they continue to make a huge difference. It's thanks to all our supporters that we’re able to launch the 2021 Research Competition that Larissa spoke about. And we're excited to see how many new research projects we'll be able to fund as a result of this competition.

AW Ann, then how much funding is there for new projects? And will we be able to fund all the grant applications that we receive?

AM Thanks to the donations from our supporters last year, we'll be able to fund approximately five new projects from this year's Research Competition. Keeping in mind though that we have 27 ongoing projects that we continue to fund from previous years.

AW That is fantastic news.

AM It really is. But the thing that strikes me is that there's always more worthy research projects than there is funding. For example, during our last scientific review process, 21 projects were deemed meritorious and worthy of funding, but we only had funds to support six of them. Sadly, we weren't able to support the other 15 really good research projects. And I always wonder if one of those projects might have led to an incredible breakthrough or a new treatment for blindness.

00:40:15

AW I always wonder the same thing, for sure. With that said, can you tell our audience about some of the ways that they can get involved?

AM Sure. First of all, I'd love to do a quick plug for monthly giving, because it's one of Fighting Blindness Canada's most critical programmes. Monthly donors are one of our core groups of supporters because their donations provide reliable and ongoing funding for future projects and long-term investments in vision research.

AW It sounds like you're inviting everyone to join our monthly giving programme?

AM Absolutely. I hope everyone listening will consider becoming a monthly donor with a gift of $1 a day or $20 a month or whatever amount is meaningful to them. Every monthly gift absolutely makes a difference.

AW It certainly does. Was there anything else you wanted to say about how people can make a difference?

AM Gosh, April, I could talk all afternoon about this topic, as you well know, but I'll only touch on a few more things. One is about honouring those we love. If you have a friend or a family member living with an eye disease, sometimes an occasion arises where a gift to Fighting Blindness Canada is a wonderful way to show you really care about that person. And sometimes people wish to honour a loved one with a memorial gift when they die, like Barbara Ritchie did.

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When Barbara's husband, Cedric, passed away, he was almost completely blind. Barbara saw first-hand the challenges that Cedric faced because of blindness and she created the Cedric Ritchie Fund to cure blindness. And as supporting Dr Andras Nagy, who is a Fighting Blindness Canada funded researcher working in the area of age-related macular degeneration.

AW That is really amazing. But of course, not everyone has the ability to do something like that. How else could they help?

AM You're absolutely right, April. Sometimes folks simply can't afford to support the causes they care about, especially during challenging times. Many people ask me about leaving a gift to Fighting Blindness Canada in their will when they no longer need their assets. And this is definitely an option for everyone. And we also have some really fun and inspiring in-person fundraising events that take place every year.

But of course, because of COVID, we weren't able to get together last year. April, I heard your team used the word pivot a lot in 2020. Can you tell us a little bit about how things went?

00:42:55

AW Sure, Ann, yes. Pivot was the rallying cry for myself, Susan Techner and Sarah Fredrickson, who are on the events team. Both our annual Cycle for Sight and Comic Vision fundraising events had to go virtual for the first time last year. But we were absolutely amazed with how much our community stepped up. For example, through our events, we had more than 4,000 wonderful participants, attendees, donors, sponsors come together to raise over $710,000 for FBC.

And we've just put up some pictures of people participating in Cycle for Sight, as well as comedians at our Comic Vision event. It was just incredible.

AM Wow, that is incredible. Now with COVID still affecting our ability to meet in person, how can people stay involved and get involved with Fighting Blindness Canada events this year?

AW Great question. We learnt a lot from our first time virtual experiences last year and are excited to put those learnings into our 2021 events and campaigns. This June 19th, we are encouraging everyone to just move with us for another national virtual Cycle for Sight. And I actually want to share a short video from Paralympic hopeful Lowell Taylor about our plans for 2021.

LT Hi, I'm Lowell Taylor, a visually-impaired cyclist with Cycling Canada and a Tokyo 2021 Paralympic hopeful. I'm fired up to announce that Cycle for Sight virtual is back and will take place on Saturday, June 19th. We are gearing up for another incredible day where we'll come together across the country to do some fun physical activities and to raise money for Fighting Blindness Canada. Registration is free.

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There are no fundraising minimums and there will be athletic challenges and ideas for anyone who's not able to cycle. We just want you to move with us in support of vision research. Register today at cycleforsight.ca and together, let's move on June 19th.

AM I love it.

AW That’s a thumbs up at the end there. As Lowell said, we just want you to move with us. Keep it [?] going. There we go. As he said, we just want you to move with us in support of Fighting Blindness Canada.

AM April, I love Lowell Taylor. That was a great video. Thank you for sharing. Could someone, say, ride a very cool surf bike instead for Cycle for Sight?

AW Yes, for sure. I love that you did that last year for Cycle for Sight. We're showing a picture of Ann with her surf bike last year. It looks like so much fun. And I know you probably missed seeing your team members on event day last year. But was there anything that you really liked about it being virtual and national instead?

00:46:00

AM Great question. I actually loved the fact that our community of friends and supporters all across Canada were able to participate last year. And they could do whatever activity that they wanted, not just cycling. Due to COVID, my team all participated with family and friends close to their homes and they sent me photos. Between the official online programming that you and your team organised, which I loved, and my friends sending me photos and me pedalling across the lake, it was a super fun day. I loved it.

AW It was a super fun day. And this year will be too, for sure. And we've also got some other great campaigns and events happening throughout the year. We'll be launching our first ever online 50-50 raffle in Ontario in May, which is really exciting. Stay tuned for that. And Ride for Sight Central Ontario will be taking place from August 13th to 15th at the Fenelon Fairgrounds. People outside of Ontario can also sign up online, do their own ride and fundraise for vision research for Ride for Sight.

And we'll be bringing back our Comedy from the Couch online show this September to put some, let's say, much needed smiles on everyone's faces. We had a lot of laughs last year. And this year, we'll be adding even more comedy to the show. And we're also launching a new event called Eye on the Cure in November, which will be a friendly head-to-head competition between promising vision researchers and scientists in the early stages of their career.

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Think Dragon's Den, but for researchers and a lot less mean. It should be very interesting. And of course, we are always thankful to people who want to do their own fundraising by signing up to be a Sight Saver and raising money for their birthday or anniversary or to just ask people to support a cause that they are just so passionate about. I think we've covered a lot of ways that people can get involved.

But if anyone has any questions, you can always reach Ann or myself at info@fightingblindness.ca. Thanks, Ann. And we'll pass it over to Morgan now for some Q&As.

AM Thanks, everyone.

MI Thank you so much, April and Ann. That was great. So many excellent opportunities coming up this year. We had so much fun at Cycle for Sight last year. I can't ride a bike. I actually really like the new format where we can do whatever we want to do. And my five-year-old is already getting very excited about fundraising again. Now we're going to take some questions from you, from the audience.

00:48:40

Again, you can type them into that Q&A box at the bottom. I see we have a couple. Of course, you can always email us at education@fightingblindness.ca. I'm going to start with a question that came in over email. This might be for Larissa, I think. Mary Kate asked, could you please talk a little bit about RNA therapies, those that are in clinical trials as well as the potential for future treatments? And do you think the success of the mRNA vaccines for COVID will draw funding into this area of research?

LM That's a really, really interesting question. And I'm particularly interested because I'm getting my non-mRNA vaccine actually in about an hour after this webinar is done. Top of mind for everybody. To start out with, I would say that both the RNA therapies for inherited retinal diseases and the mRNA vaccines, they are both to do with RNA. And I'll explain a little bit what that is. But they are very, very different techniques.

They're not really the same thing. The way that things happen in the cells, you have all the genetic information that is carried in DNA, but that carries information. In your eye cell, it carries all the information for the muscle instructions, heart instructions, eye instructions, but you don't need all that information all the time. What the cell does is it makes specific instructions called RNA. The eye cells will make RNA instructions just for the eye proteins or the eye functions.

And then the heart cells will make heart RNA just for all the functions that need to happen there. You have DNA that gets made into RNA. And then RNA is made into protein. And protein are essentially the machinery of the cell. It helps the cell do all the things it needs to do. In an inherited retinal disease, you'll have a mutation in the DNA that will get transcribed or copied to the RNA. And then that means that the protein that is made doesn't function properly or the mutation might mean that the protein is never made at all.

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The most common type of RNA therapy, which is similar to a gene therapy, it's more of a gene editing approach. It's called antisense oligonucleotide therapy. What it does is it essentially tries to mask that mutation. If there's a mutation in the RNA, it actually basically binds to the RNA and then it helps the cell basically skip over that mutation. And you end up getting a functional protein made. That’s how the RNA therapies work.

And there's one company called ProQR, which is the leader in the field right now. And there's a number of clinical trials out looking at RNA therapies. If you look at mRNA vaccines, it's a little bit different because you're either using DNA, which is essentially the Johnson & Johnson vaccine and I think the AstraZeneca vaccine, or mRNA, which is Moderna and Pfizer. It’s basically using the DNA or the mRNA as instructions.

It's putting the instructions into your body and then those instructions are going to make a protein for the COVID virus. It’s basically the spike protein, is what they call it. And then when the body sees that protein being made, it recognises it as foreign, creates an immune reaction. If you're ever actually exposed to COVID, you basically have a little army of immune cells ready to go that they can just jump in and basically squash down that virus.

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It's a little bit complicated, but I hope you understand how it's very different techniques. I don't necessarily know that because mRNA vaccines are being talked about, that's going to lead to all this new money for RNA therapies for eye disease. But what I think it has shown is, first of all, how very, very important research is. Without basic science research, without translational research, without research getting to clinical trials, we could not have got the vaccines made so quickly.

It's been actually an amazing shout out for science. I think everybody's aware of it. It also shows what happens when there's funding. You put funding at a problem and look what we can do. It is so amazing. I think research is going to be front of mind. And I hope those raised awareness for how important research is going forward.

MI Thanks, Larissa. We've had a lot of questions, both through email and in the Q&A about genetic testing. People saying that they're trying to get their genetic testing or it's taking too long or how do we get our genetic testing. Does someone want to comment about that? I can provide a link also in the chat too on a resource that we have for Fighting Blindness Canada.

00:53:10

LM I can jump in, if anybody wants to add on. We have some really great resources on fightingblindness.ca. Please go there. And it gives you step by step instructions about how to get genetic testing in your different provinces. It is very complicated. You often have to get a referral from your healthcare provider, whether it's your eye doctor. It depends on each province. It can be your eye doctor. It can even be your primary healthcare practitioner in some cases.

But there are long waiting lists. And that is the way it is unfortunately right now. Part of it is there just aren't enough genetic counsellors out there to deal with the demand. I know somebody had asked, I saw on the chat, about if there are other ways to get it. There is options of private testing. Again, talk to your healthcare provider if you're interested in this route. The one thing that we tell people is that you want to make sure that you're getting genetic counselling to go along with your genetic testing.

That is really, really important because without somebody talking to you and explaining the process and then afterwards, explaining what the results mean, in some cases, it can be almost, not useless, but it's really hard to know what it means. There are different avenues, but the genetic counsellor is a really, really key component of this. Make sure that you have somebody who can really explain the results to you when you get it.

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And unfortunately, I don't have an easy solution. It just is something that we are working with and we're working with genetic counsellors across the country, trying to understand where some of their pinch points are to see if we can help in any way. But it's a tough situation. But when you do get genetic testing done, please join our patient registry. That is a way that if you've got an inherited retinal disease, if you let us know, you get put into a medically secure database.

And then if new clinical trials are coming to Canada, we will be able to contact you. And it also shows companies and researchers that there are people out there with specific mutations so they know that they should come to Canada and start clinical trials here.

MI And I’ve posted in the chat a link to that specific page on our website. And if you scroll down to the very bottom, there's a list of all the provinces. Because as Larissa said, it's all a little bit different. At least that can help you get started with the process and thinking about what steps need to happen to get that testing done. I have another question here in the Q&A. I'm going to send this one over to Ann. This is from Mike.

00:55:34

And he said, I might have missed it, but is it possible to leave a donation to Fighting Blindness Canada in my will?

AM That's a great question, Mike. Thanks so much. Yes, I did mention that in my spiel. And absolutely, it's something that everybody can consider because we don't need our assets when we leave this world. It’s something that everybody accumulates while they're living. And it is a way that you can remember your family, but also you can remember the causes that are meaningful to you. A gift in your will is certainly something that I would be happy to speak to anybody about.

Or my colleague, Doug Smith and Doug Earle, we'd all be happy to chat with you about that. Thanks for bringing that up. It's a subject that's hard to talk about sometimes, but not really when you really care about a cause and you want to make sure that the work that you've helped them do during your lifetime continues.

MI Thank you, Ann. I have another question here from David. David is saying, both of his sons have X-linked RP. They're both legally blind, but able to function reasonably well in daylight. He’s said that he's aware of four clinical trial studies involving the RPGR gene, which he found on our website, which is great. He’s just asking, are all of these four studies essentially the same? Is any one of those treatments more promising than the others?

00:57:08

Should we be optimistic for significant improvements to daily living? And what timeframes look like between now and Health Canada approval. I'm not sure if, Larissa, you can answer all those questions exactly. But I think this speaks to a lot of questions that we get in. How do people distinguish between these trials? What is the process for getting these trials through to actual treatments that reach people?

LM Those were a lot of questions, a lot of great questions. I quickly looked to see the trials as well, because I don't know them off the top of my head. And I would say that all the four trials are very similar in that they're using a gene replacement strategy, similar to what Dr Koenekoop talked about, and what is used for Luxturna. So, putting a functional copy of the gene back into the cell. Where they differ is the way they're delivered.

They're encased in different, what we call vectors, which means that how efficiently they're delivered to the eye cell might be different. Maybe some of the side effects might be different. But in general, very similar. Is one more promising than the other? Fortunately, I can't say that right now. I think a few of them are at Phase One and Two and some of them are Two and Three. We’ll really have to wait to see what the results are.

I know some early results from the Phase Two, Three trial looked promising, where vision seemed to improve a little bit. But how that impacts, I think, the point about day-to-day life is really important. I really don't know. I would say something that will maybe impact how effective some of these treatments are is the individual person who is receiving the treatment. If you have a lot of photoreceptor cells left, if you haven't lost a lot of your vision, it might be better at restoring your vision or keeping your vision and stopping it going down.

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But if you've already lost a lot of vision, it isn't clear for some of these treatments how much restoration you'll get. Again, it should probably preserve your vision, but will you regain a lot of it? We really can't say. And it will depend on the gene. It will depend on the person. Timelines, I would say… This is a rough estimate. It’s different for every trial. I say that it usually takes six to eight years to get from the start of a Phase One clinical trial, through to the end of a Phase Three clinical trial where everything is going pretty well.

And then it can usually be two to four to five years before it goes through all the regulatory steps of getting approval, especially in Canada. As Doug and I think Elise mentioned, we're currently in that process for Luxturna, trying to make sure it's been approved by Health Canada. It's not funded by the provincial governments yet. We're looking at that as a case study. If we can get Luxturna funded, it will make it much easier for other treatments to get funded.

That's why, we already said it, but please go to approveluxturna.ca and tell the government that we need innovative treatments. Not only Luxturna, but all the other ones that are coming. It’s so important to make sure they are coming to Canadians as quickly as possible. And I think I answered all the questions?

01:00:10

MI I think so. Thank you so much. That was a lot of questions. I appreciate that. I have a couple questions here. Actually, they're right next to each other in the Q&A, which I think are related. Brenda is saying that she's had genetic testing. Her gene has been identified and she has RP. And she's asking, once she's had her gene identified, what next steps would you recommend? And then on the flip side of that, I have another question here from Conrad, who's saying that he's had his genetic testing done.

But unfortunately, his mutation was not identified. He did find the genetic counselling helpful. But what would be the next steps if your gene is not identified? Both sides of that coin. What happens after you get genetic testing?

LM I'll start with the second question. I'm sorry you didn't get a result. It's unfortunately somewhat common. I think it is about maybe up to 30 to 40% of people who go for genetic testing, we aren't able to identify the gene. And that's partly because we maybe haven't found that gene yet or scientists haven't found that gene yet. I would say the next step is, obviously, keep going to your eye doctor. Keep track of your eye health.

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And if you notice any changes, it's really important to talk to your doctor about it. But also, you might want to, in a few years, talk to your doctor about if it's time to revisit genetic testing. Every year, we're learning more and more and more about the genes that are involved. Every year, there'll be more genes essentially on the panel. And if you'd gone genetic testing ten years ago, there would be many fewer genes than there are today.

If it's been a while since you've got genetic testing, maybe now's the time to revisit it. But if you just got it, maybe in a few years, I would suggest thinking about it again. For the second question about what do you do once you have your genetic testing, you might want to, again, talk to your eye doctor about knowing your gene mutation. Does that tell you anything about the progression of your disease, something that would be useful for you when you're planning how your disease might progress?

Of course, for stuff like family planning and what impact it might have on your family, that's also really important. But again, I guess, a plug for our patient registry. Please join it. That is, we think, one of the easiest ways for you to put your hand up and say, I have this gene and this gene’s important. And it will really help us bring more research to Canada, bring more clinical trials to Canada and then tell you as soon as possible if there are treatments or clinical trials available.

01:02:38

DE And could I add in also? Larissa, of course, with your gene mutation, please join the FBC patient registry. And that way, we can keep in touch or the researchers can keep in touch with you. If there is a clinical trial, we can let you know and get your permission to be considered for it.

MI I've got another question here from an email. And they're saying that their child or little one is a year old and has ROP, which is retinopathy of prematurity. And the doctor’s telling them that it's not currently treatable. And they're just wondering if there are any potential treatments for future for their little one.

LM I also just noticed somebody popped up in the chat and asked if we provide links. And we will provide links, because I know we've been talking about go here, go there, go to this website. We will provide all the links in a follow-up email. If you haven't caught them from the chat, don't worry about it. In terms of the person who wrote in about retinopathy of prematurity, that is an eye disease that affects young children or babies.

And often, if they're born premature, it leads to uncontrolled growth of blood vessels in the eye, which can lead to blindness. Currently, there aren't any clear treatments. People can use laser treatment to make it a little bit better. I know there are some research looking at using anti-VEGF treatments, which are used for diseases like age-related macular degeneration or diabetic macular oedema. There’s some studies looking at that for treatment.

01:04:25

As well as, as I mentioned earlier, stem cell therapy. That would be in the future. It's not available right now. But we're very hopeful that we're getting to the point where stem cell therapy will potentially be able to restore sight for people who have a lot of damage and have lost a lot of cells. We're also funding actually a researcher right now, one of our Clinician-Scientist Emerging Leaders, Dr Ellen Zhou, who is an ophthalmologist and studies retinopathy of prematurity.

And her focus is trying to understand, if you have ROP, how your vision progresses as you get older. Hopefully, being able to reduce even more vision loss as you get older. I would say that's what I know about the field right now. There’s definitely a lot of research happening out there. Very hopeful that there will be treatments. But I can't point to anything very specific right now that's at a clinical trial level or really around the corner.

MI Sorry, I just tried to unmute myself and muted Larissa instead. Sorry, Zoom error. I also would just love to throw in a plug there that actually, Dr Ellen Zhou did a View Point with us last year. And she talks all about ROP, what it is and what her research is looking at. Definitely encourage you to have a look at that as well for a bit more information. I have another question here. And this one is good for April. How can we keep updated about all of these awesome events that are in the centre?

01:05:56

AW Good question. The e-news was mentioned earlier. That is a great resource. You'll get monthly updates from FBC that will include our upcoming events. That’s definitely a place. And then fightingblindness.ca, if you go there, we have an events tab if you want to get involved. And also the individual events have newsletters. If you want to just learn specifically about Cycle for Sight, on our website cycleforsight.ca, you can go there and sign up for the e-newsletter for that or for Comedy from the Couch.

Lots of different ways that you can stay in touch with us and learn more about the events.

MI Thank you so much, April. We are running a little [inaudible] and we’re a bit over. I know there's a lot of questions, unfortunately, that we haven't got to and I apologise. But if we didn't get to your specific question today, I do encourage you to visit our website, we've talked about it a lot today, where we have information on clinical trials, genetic testing, all of those great things. And if you are looking for specific medical advice related to your condition, we encourage you always to have a dialogue with your doctor about that.

01:07:03

And we're here to help you as well. We talked a little bit, I think, earlier about our health information line. You can reach out to us at healthinfo@fightingblindness.ca. And we can even help you formulate questions for your doctor to make sure that you're getting all of the information about your eye disease that you need. We’re going to do one last question, which I think is for Doug.

Someone's asking here, how has the strategic mission changed in the last year with COVID? Are there any more changes coming into our second year of COVID-19 pandemic?

DE I'm intrigued. I'm not fully understanding the question. But I would say that in 2019, the mission of our organisation did expand. We became Fighting Blindness Canada and our mission is to support the acceleration of new treatments and cures for all blinding eye diseases. And we grew from starting out as inherited, to all retinal space diseases, to now all blinding eye diseases. Because we were finding in our research that it had implications for all diseases, eye diseases, that were leading to blindness.

01:08:21

But we weren't asking Canadians to support us if they had an interest in a particular disease. Our mission is to expand our research. And we're funding the best, most promising research that's available in Canada and beyond. And that is the goal for our 2021 Research Competition, is to inspire those questions, the curiosity, give enough funding that we can get some pilot data that would enable researchers to apply for grants from the government agencies that can make a difference.

And really may accelerate trying to understand the mysteries of the eye and what is leading to blindness. That’s our mission. It's not changing. And our donors are stepping up and supporting it. And we really appreciate all of our supporters who give up their time, give up their talent and give up their treasure too.

MI I think that is a wonderful way to end our session today. Thank you so much to everyone out there for joining us and to continue to support us. Again, we can't express our gratitude enough. Please, to everyone out there, stay safe, stay healthy. Come to View Point. Let us know if you have any other questions. We're here for you. And hope you all have a wonderful day. Take care.

DE Thank you.

LM Thank you.

MI Bye. Thanks.

01:09:48