AMD COFFEE CONNECTIONS: OAKVILLE

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Part One: Expert Conversation

Overview and Disclaimer

Morgan Ineson: Welcome, everyone. Thank you so much for joining us. My name is Morgan Ineson, and I'm the Senior Manager of Education and Engagement at Fighting Blindness Canada.

Our program today is in a couple of parts. We're going to start with a short overview of what AMD is with our special guest, Dr. Niro Sivachandran, and then we'll have time for your questions. After that, we'll take a short break, and then we'll be back with a panel of people who are living with AMD, and we'll learn more and have more of a conversation about strategies and all different good things.

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With that, I'd love to introduce our special guest. Dr. Sivachandran is a retinal specialist who completed her medical degree and PhD at the University of Toronto and her residency at McMaster University. She completed a two-year vitreoretinal fellowship at the University of

Ottawa and now practices medical and surgical retina care at the Toronto Retina Institute. Thank you so much for joining me.

Dr. Nirojini Sivachandran: Thank you so much for having me. I love talking science, so it's always a great opportunity to be here. Knowledge is power. There's nothing more powerful than knowledge. The more you know about your health, your health conditions, and how they impact your overall well-being, the more you can advocate for yourself. Not everybody is up to date, and the more you know, the more you can ask your care provider, "Hey, what about this? What about that?" So I think opportunities like this are a great venue for us to better understand what's happening in the field and how it impacts you moving forward. I'm always happy to be here.

What Is AMD? Dry vs. Wet

Morgan Ineson: I wholeheartedly agree with everything you said, and that's why we're here today. We want to leave a lot of time for questions from the audience, but maybe you could start by setting the stage for us. What is AMD? What are these wet and dry types we hear about? Tell us a little bit about the condition.

Dr. Nirojini Sivachandran: Absolutely. I've trained myself in how I think about certain things so that I don't miss anything when I see new patients, and I try to explain age-related macular degeneration in the most simplified way. As the name suggests, the biggest risk factor is age, which we can't control, and it's also a privilege to get older. It truly is a privilege. There are aches and pains, and you're not the same person you were in your 20s and 30s, but it is a privilege to be here and to have this conversation. So I always start with that.

Age is the biggest risk factor, and the other is genetics. Again, you don't control that. Your parents are your parents. So those are the two risk factors. What happens over time, in people who are susceptible, is underneath your retina. Your retina is an extension of your brain. It's brain tissue that allows you to see. It captures the world and sends it back to the back part of the brain so you can see. We are magical creatures. Think about vision. Your eye is like a pinhole camera, and it's so beautifully orchestrated that we get to see this world.

As we age, there's metabolic waste, and somebody explained it to me this way, which I thought was fantastic. It's like garbage bags that need to be removed every week. We have trucks coming down our roads to pick up the garbage. What happens is that the cells that clean up the garbage get weaker as we get older. They don't have enough energy, so they're not able to take out the garbage. It builds up underneath the retina as little bumps called drusen. Over time,

more and more garbage piles up, and that is the hallmark of dry age-related macular degeneration. Everybody starts off with dry AMD, and then one of two things can happen.

The first is that the tissue cells can start to die off, so areas of atrophy, or loss of tissue, can happen. Now we're progressing to advanced dry macular degeneration, which some people call geographic atrophy. They call it geographic because it looks like little islands of tissue missing on the pictures and scans we take. That leads to vision loss, whether it's central or next to the central, so it feels like patches of vision are missing, and you may have to turn your head to get everything into view.

The second thing that can happen is what you've heard called wet macular degeneration. I think of wet macular degeneration as a physiological response to a pathological process. Your eye is simply saying, "Oh my gosh, we're feeling sick. We need more oxygen. Let's make new blood vessels and bring in more oxygen so we can feel better." That's the physiological response, but the underlying cells are sick, which is the pathological process. So the eye grows new blood vessels, and they're not the healthiest blood vessels in terms of integrity. They're very fragile. They leak and they bleed, which is the hallmark of wet macular degeneration, because, quote unquote, your retina is now wet with fluid or blood or a combination of the two. When that happens, you will see a sudden drop in vision, almost like a blackout. It's a sudden change.

It also depends on which eye is affected. Sometimes we see patients who haven't gone in for years because it's their non-dominant eye, so they feel like they're seeing fine. Then they go to their optometrist, who says, "We have a problem here," and when they close one eye or the other, they say, "Oh, you're right." There are many reasons why you may or may not perceive the change.

And wet versus dry isn't black and white. Everybody starts off dry, and the dry continues as the baseline, and then you have wet on top. It's a spectrum. Once you get wet, you still have the dry component, so you can still get tissue loss. You can also get what we call fibrosis, or scarring. If you get a cut, you have a natural wound-healing response, and we heal by forming a scar. The retina does the same thing. When blood vessels leak and bleed, there's a wound-healing response, and it starts to scar. The problem with scarring in a very specialized tissue like the eye is that it impacts your vision. It's a normal response, but it's in the wrong place. The eye doesn't know it's the eye, and it shouldn't scar, because you're going to lose vision. It's just doing what it's supposed to do.

All in all, the earlier you get your eyes checked, the earlier we can intervene, whatever the scenario may be, and the better the visual prognosis, meaning the better we can maintain good vision over a long period of time.

Morgan Ineson: That's such a great explanation. I love your garbage truck analogy. I want to talk about the treatments you're alluding to, but before we do, can we clarify something about the macula itself? It's a very specific part of the retina. Are all of these processes localized to the macula, or can they happen anywhere in the retina? And what does it mean, in a practical sense, for someone's vision when the macula is affected?

Dr. Nirojini Sivachandran: Let me use the microphone, because I like to point things out. Imagine this is your eyeball. First, light hits the cornea, the clear dome. Then the light goes through your lens, which focuses it right onto the macula. The macula is five millimeters. Think about how small that is. Within the macula, we have an even finer area of tissue called the fovea. Light has to hit the foveal region for you to see 20/20. That is the optics and physics of how light and tissue all have to be aligned for you to have, quote unquote, good vision. Anything in that five-millimeter region will affect your central vision, because it can encroach onto the fovea. As soon as your fovea is affected, your central vision is impacted, and you may have vision impairment.

Talking about AMD, I would say probably 90% of it is macular. There is a form we call peripheral macular degeneration, formally called peripheral exudative hemorrhagic chorioretinopathy. Of course, we have to keep things challenging, right? I call it "pecker" for short. If you think of the macula as a dot right here, the peripheral form happens around your peripheral vision and does not affect your central vision. That's why most people, even if they have it, won't know, because it's not affecting their day-to-day living. It gets picked up by the optometrist, who sends the patient to us. For those individuals where there's a bleed, we can watch it, because, going back to healing, it starts to scar, and if it scars in the periphery, we're fine because it's not impacting central vision. It's when the central scarring starts to take place that it has negative consequences for vision.

Treatments for Wet AMD

Morgan Ineson: The macula has a very specific function around vision, right? Things like reading, driving, and recognizing faces are often the first things impacted because of where it's happening in the eye. You alluded to injections and treatments. Can we talk, at a high level, about what treatments are or aren't available for wet and dry AMD? I think we can start with wet macular degeneration, because that's more applicable to our Canadian landscape. We can get into the treatments for dry AMD, and the Health Canada approved options, because we could talk for hours on this.

Dr. Nirojini Sivachandran: As soon as there are signs of blood vessels growing, leaking, or bleeding, most people have symptoms, see their optometrist, and get referred to a specialist. At our clinic, if I see somebody with wet macular degeneration, I start treatment that day, or at least I recommend treatment that day, unless it's extrafoveal, meaning outside of the fovea. I give all the information, including the sheets on injections and on macular degeneration. I also give an Amsler grid, and I say, "Use this to monitor your symptoms." I always say this is the poor man's version of the fancy OCT that we have in the clinic. Use it to guide how things are progressing. I like to see patients back within a month, usually even less.

The reason is that with the macula, it's like that saying in real estate: location, location, location. This is prime location. You do not want to let things brew and bleed, because if you have a big bleed, it's hard to rescue. So why not be proactive rather than reactive? There are a lot of other conditions where I'm not so keen to start treatment that day, but with macular degeneration, I don't mess around. I want to get that retina as stable as soon as possible. I want to improve your vision and your distortion, or whatever area you're not seeing, and minimize those things as soon as possible.

These are injections that are given inside the eye. There's research into eye drops, and into injections that you give under the skin, kind of like how people take insulin shots. There are also implantable devices in the works, tiny devices about the size of a grain of rice, like a little depot that you fill with medication, and you're good for maybe six to 12 months. For patients who have to come in every month, those depots might be a fantastic way to go. They're still not readily available, but they're coming in the near future.

An injection is not one and done. It's an ongoing treatment. Some people need treatment every month, some every three to four months, and I have patients who get treatment every five months. So we have the full spectrum. Even with injections, we have various options. You will have heard of Lucentis, Eylea, faricimab, or Vabysmo, and the latest, Eylea HD, which is a higher dose of the original Eylea. How do I choose one medication over another for the patient sitting in front of me? It depends on the characteristics I see on the OCT and on patient factors, like whether they're over 65 or under 65 in Ontario.

That's another thing I could talk about, and I'm just going to breathe, because as a human being living in Canada, where we're working citizens and we pay taxes, you're telling me that if you're 52 and you have wet macular degeneration because of genetics you inherited and can't control, you're not going to have your medication covered? That's not right. So I find a way to make sure that you have access to the treatment you need. This is where collegiality with industry partners is very important. They've given me many samples for my patients. There's a lot you learn in medical school that goes out the window. They teach you that you shouldn't interact with big

pharma, and we weren't even allowed to get coffee from them. But once you get out into the real world and learn how it works, you need to make allies. For the patient sitting in front of me who doesn't have access, I have to make something happen. I don't feel that anybody should have to pay for these kinds of vision-saving treatments. It's just not fair.

You should talk to your care provider if you hear about something, because I know patients talk among their peers. I've had so many patients referred because somebody told them, "Oh, go see her," and they say, "My neighbour told me about you." It's wonderful to hear that. I will say that probably 60 to 70% of patients will benefit from any of the medications, so for most of us, it doesn't matter too much which one. Where it might matter is if you want to go longer between treatments, meaning instead of coming in every six weeks, you want to see if you can do 10 or 12 weeks. That's where switching to the newer agents might be helpful.

Treatments for Dry AMD and Red Light Therapy

Dr. Nirojini Sivachandran: For dry macular degeneration, it depends on the stage. We call the stages early, intermediate, and advanced. For early and intermediate, the traditional standards are lifestyle changes. You've probably heard about AREDS2 vitamins, or lutein and zeaxanthin, which are the key carotenoids that help the retinal cells function at their best. There's nothing you can take that will outdo your diet, and the best form is to get it from your food, because it's naturally available in a form that's absorbable and can be used. A Mediterranean diet is what's recommended. You can look up foods rich in lutein. It's that yellow-orange colour you're looking for, and egg yolks are a great source. Corn is also a great source, but everything in moderation. Dark green leafy vegetables are wonderful. Fatty fish give you omega-3, and if you hate fish, take omega-3 as a supplement. Olive oil is good because it has good fats, and so is avocado. Think good fats, because we know that fat metabolism is impaired to some degree in individuals with macular degeneration, so we want to provide the good fats so those cells work well.

You may have heard, and some of my patients ask me, about red light therapy or MacuMira. We published a case report on somebody with intermediate dry macular degeneration. One of my patients started doing red light therapy on his own. He was a 70- or 72-year-old man who first saw me in 2023, and he had all the bumps. Then, eight months later, he came back for his follow-up, and I looked at his scan and thought, "Wait, what's your name again?" I knew his name, but I was mind-blown by his scans, because the bumps weren't there. I asked him for his date of birth, and then I sent him out to take widefield images, which are like a selfie of the back of the eye, and compared his images from before and after. I asked, "What did you do?" He told me he had started red light therapy, so I asked him to tell me exactly what he did, and I wrote it

down, because I was fascinated that he had this profound positive effect, where the drusen basically melted away.

Now, this is an n of one. We don't know his genetic profile or his genetic risks for AMD. We don't know what his lifestyle is like. He's still working, he's a non-smoker, and he was taking AREDS2 vitamins. So there are a lot of factors at play. It's not just A plus B equals C. But this was the first time I had seen this, and I thought, wow, if we can do that for most people and avoid getting into the advanced stage, how cool would that be? We'd be changing lives for the next 30 years. So we wrote it up and published it. Some people say drusen can go away on their own, and yes, they can. I've seen it in one patient as well, but they were much smaller, not to this degree, not this confluent, meaning lots of drusen. Now I have three separate patients who have used red light therapy, and again, they were not at more advanced stages. They were earlier.

If you already have advanced AMD with tissue loss, then maybe in the next five years. In the current state, we don't have anything that's bringing tissue back. What do we all want? We want better vision. If we have vision loss, we want those areas where we're not seeing to be smaller so we can see better, see in the dark, and do all the functions we need to do. We're not there yet. The one thing that will change that is regenerating cells, which is stem cell therapy. There's lots of work happening around the world, mostly in the States, and they're doing phase two clinical trials in this area, which is very exciting. So the future is very bright in that regard, but we're not there yet.

If you have intermediate AMD, talk to your care provider, because there are things that are possible with MacuMira. There's one small study. My biggest issue with it is that it was done in, I think, 2020, through COVID. Kudos to them for completing a study through COVID. It's basically little electrodes placed on the outside, and it does electrical stimulation that goes to the back of the eye, kind of like kickstarting an engine. I think there's definitely something true about the science, but in that paper there's not a single image, and in this day and age, with imaging everywhere, you've got to show me some imaging. I need to see what's happening to the cells, whether the garbage trucks are coming now and picking up the garbage bags. That was my biggest critique of that paper, but I do think there's something there. I think we need to build more scientific evidence.

Morgan Ineson: We hear a lot of questions about MacuMira, and I think the position of the Canadian Ophthalmological Society and others is that they're still a bit skeptical, just because there isn't enough evidence yet. So we just need more. Is red light therapy the same as photobiomodulation?

Dr. Nirojini Sivachandran: Photobiomodulation is the scientific term for red light therapy. You want to use a 670-nanometre wavelength, or in that range. We're actually studying this in our lab, on a cellular level, trying to understand what happens to retinal cells with this light. In theory, it's supposed to activate cytochrome c within the electron transport chain in the mitochondria. I'm taking you back to undergrad biochemistry 101. The mitochondria are the powerhouse of your cell, and they make all the energy. It's the currency, the moola. Red light is supposed to stimulate aging mitochondria to kickstart and produce more energy, so there's more currency for the cells to function better. But if you already have tissue loss, we're not going to change that. We may prevent further tissue loss, but there hasn't been a study that looked at that specifically.

Morgan Ineson: It's really interesting, especially when we talk about needing more evidence. We were in Winnipeg a couple of weeks ago doing an event like this, and the ophthalmologist speaking there said that if you'd asked him seven years ago, he had written a position paper against photobiomodulation. Now he's bought one for his clinic, because so much has changed in the research over those seven years. I'm not sure about Ontario, but I imagine it's not covered, so you have to pay for it. There are home devices you can use, like Aruna Light.

Dr. Nirojini Sivachandran: The three other patients I mentioned briefly, whom I'm going to put together in a report, used home-based devices. It's a pair of glasses where you push a button and keep your eyes closed. It goes on for three minutes, and then it turns off automatically. We also have to think about the practicality of coming into the clinic. In some of the clinical trials looking at photobiomodulation, you have to go in three times a week for the first three weeks. Let's talk about the practicality and feasibility of getting into clinic three times a week over a month. Some of our patients depend on other people to bring them to the clinic. We have to think about the scalability of treatments. It's great to have treatment options, but you also have to think, from a social context, whether it's going to work. We want to have the greatest impact for the most people, and otherwise we're selecting for people with resources.

So one of the things we want to do is a randomized controlled trial to show the efficacy and utility of Aruna Light, so you can do this in the comfort of your own home. You shouldn't have to go into the clinic three times a week. That's the other thing with photobiomodulation: there's a maintenance phase as well. The maintenance phase might not be an issue if you're going in once every three months for a boost treatment, but the initial phase might be challenging. All in all, the future is brighter, and there are a lot more options, including MacuMira. I do believe there's validity, and it's probably working at the level of the mitochondria. We just need to generate more evidence.

My other issue with MacuMira is the price. We need to push policy and our local MPs and MPPs to get these things covered. How can we charge $2,000 or $3,000 every so often to our seniors? I'm sorry, that's not okay.

Morgan Ineson: And it's different too, because they're devices rather than drugs, so they go through a different approval process. With a drug, it goes through Health Canada, and then it has to go through provincial governments to see who pays for it. Devices go through a different pathway, so they don't get that same rigorous work done. I think we have questions. Let's get into them.

Audience Q&A

2RT laser therapy

Audience Member: Can you give me your opinion on 2RT?

Dr. Nirojini Sivachandran: The question was about 2RT. We didn't talk about it, so I'll start by saying I don't do 2RT, but there is a trial that was done on it. Remember the garbage bags I told you about? There are different coloured garbage bags too. Not all of them are black. Some are blue and some are white. That's where the 2RT nuance comes into play, because there are different types of drusen. The most common type in AMD is soft drusen, and then there's pseudoreticular drusen, which has a different appearance. In those patients, 2RT does not work. In fact, it can potentially push the progression. In the soft drusen group, 2RT seems to play a role in removing the drusen, and again, it depends on your stage of AMD. I think there's probably more of a role in the intermediate stage than if you've already got tissue loss. 2RT is not going to bring tissue back. It may help maintain where you are. More evidence has been generated in Australia, where the study originated. There are some people in the GTA who do it, including at my own clinic at the Toronto Retina Institute.

Audience Member: Why don't you do it then?

Dr. Nirojini Sivachandran: Well, one, I don't have access to the machine in Oakville, where I practice predominantly. Two, I just don't feel right charging people to do something that may or may not work. It's not in my conscience. I'm programmed differently, I guess. It's the same with wet macular degeneration. There are people who need treatment and don't have access because they're under 65 and don't have private insurance, and some people will charge them money for Avastin. I will not. I went into medicine to do good, and somebody's care is not going to depend on whether they can afford something. Most of the patients who want 2RT often have more advanced macular degeneration, and they're trying to find a way to stop something, and I

can't guarantee that. If you're going to charge somebody, I feel like you need to get some outcome, and you can't. I do think that if we intervened a bit earlier with 2RT, in the intermediate stage, and generated more data, that would make more sense. The data isn't strong in advanced AMD.

Audience Member: It's very hard to actually find any scientific data on 2RT.

Dr. Nirojini Sivachandran: There are papers, but it's very limited.

Audience Member: Yes, 2018 is the last one, and nothing since then.

Dr. Nirojini Sivachandran: I think people need to do more science to show the efficacy and validity of these things. Even at institutions where people perform 2RT, I've told them, "Pull all your cases and see what the data looks like," because I've seen individual cases where I thought, wow, that's pretty phenomenal. But what does it look like in a bigger group? Is what we're seeing the anomaly, or is it the normal?

Audience Member: Can you explain what the treatment is and what it costs?

Dr. Nirojini Sivachandran: 2RT is a laser treatment around the macula. They go to different spots, not right next to the macula, but around it. The thought is that a low-dose laser stimulates the RPE cells to start working better. The principle is the same for MacuMira, red light therapy, and 2RT: how can we boost the cells? It's like your car battery is dead, and you need to kickstart it. That's the same concept as the 2RT laser, a low-dose boost to get the cells working. As for the charge, I'll have to find out, but I believe it's $700 per eye per session.

Audience Member: And you need seven sessions.

Dr. Nirojini Sivachandran: Yes, several sessions. So again, I feel like I should go into politics, and I hate politics, but I think we need people to advocate. We need more validated treatments, with more rigorous science, and then we need to get our government to fund them. That's the first step. We need the rigorous scientific evidence, but also the voices of people who have had the treatment and what difference it actually made.

Morgan Ineson: Real-life, practical examples of what that has looked like. And, at least for dry AMD, hearing you talk about the different options, it seems like timing is important. It's good evidence for trying to get diagnosed as early as possible, because these treatments that are proven to be effective are really only going to work at a certain point. There are modifiable things you can do early on to slow down or even stop progression to the advanced stage.

Red light therapy and geographic atrophy

Audience Member: If you do have advanced AMD with geographic atrophy, would red light therapy help at all in stopping it from progressing? And secondly, are you aware of any positive feedback on biofeedback therapy? I heard that is being used as well.

Morgan Ineson: In case everyone didn't hear, the first question was: if you have advanced AMD with geographic atrophy, would photobiomodulation therapy be effective? And the second was about biofeedback research.

Dr. Nirojini Sivachandran: For the first question, there has not been a formal study looking at patients with geographic atrophy using red light therapy, following them over, say, a year, and seeing whether the geographic atrophy has been halted or slowed down to some degree. There's no research done. I'll draw on part of another study. The LIGHTSITE III trial looked at photobiomodulation in intermediate dry AMD. Compared to the sham group, the photobiomodulation group had a significant reduction in new-onset geographic atrophy, so it showed that it can slow, I would say slow, the development of new geographic atrophy. You can infer from that, but you really have to do the science. If it can prevent the onset of GA, there's potential for halting or slowing GA in people who have pre-existing GA. One of the groups I'd like to include in our eventual trial, and I really hope we do this with the home-based device, is people with existing geographic atrophy, to see if it helps, because it's something simple you can do from home.

That's in addition to everything else: eating well, taking your supplements, and sleeping well, which is another important thing that we all overlook. You have to get good sleep, because that's when your body heals. And no smoking. There's also alcohol. Anything you can do to live your best allows your body to perform its best. You wouldn't have a heavy night of drinking and then run a marathon, and most people wouldn't, so think about those kinds of things.

Home-based red light glasses

Audience Member: I have wet AMD, and I got one of those red light glasses. They're so convenient. You can use them any time you want, although you don't want to use them all the time. My wet AMD seems to have stabilized. It could be because of the charm of Dr. Sivachandran, or my use of this, or the drugs I'm on, but I think the glasses were either $300 or $500.

Dr. Nirojini Sivachandran: It was $500, the original Aruna Light.

Audience Member: Compared to the cost and inconvenience of having to go in so frequently, it's amazing. Whether this will catch on, and whether a study will find a scientific basis for it, I don't know, but it seems to be stabilizing things, so I encourage you to check it out.

Dr. Nirojini Sivachandran: You can purchase it online. It's made by a Canadian company out of Halifax, called Aruna Light, and I will provide some instructions. It's supposed to be used every other day, and since we're creatures of habit, I recommend Monday, Wednesday, Friday as your regular routine. It's supposed to be in the morning, not at any time. Your retinal cells are programmed to a circadian rhythm. We wake up from the sunlight, and when the sun goes down, we go to sleep, because there are literal clock genes expressed in our retina. We want those retinal genes and cells working at their peak, so do it first thing in the morning. "Aruna" means sunrise. So on Monday, Wednesday, and Friday, you do your morning routine, go down, make your coffee, put your glasses on, keep your eyes closed, and turn it on. It goes off on its own after three minutes, and you take it off. That's it.

Eccentric fixation and biofeedback

Audience Member: What about biofeedback?

Dr. Nirojini Sivachandran: Are you talking about the implantable device?

Audience Member: No, I haven't had it yet, but I've been in touch with an ophthalmologist, Dr. Needle. Apparently it's a machine where they try to train your eye to look in a certain way.

Dr. Nirojini Sivachandran: Yes, thank you for clarifying, and my sincere apologies, because there's so much to talk about. Remember, I said it's all about location. There is some work being done at Toronto Western. If you lose subfoveal tissue, then you can't see with your central vision. However, we are incredible beings, and we can be trained. This is called eccentric fixation, or biofeedback. You're training the healthy tissue very close to the fovea to start fixating and become your central focus. There is still a lot of neuroplasticity, because the retina is an extension of your brain. I think it's another way of training your cells to see better and gaining back some function, and I think there's a lot of positive potential there. So go for it if you're doing it or planning on doing it.

Prescription and insurance coverage for home devices

Audience Member: For the home device, do you need a prescription?

Dr. Nirojini Sivachandran: You don't need a prescription, because it's not prescription glasses. It's just glasses that deliver red light. You may be able to get it covered through your insurance, though, so you could get a note from your optometrist or ophthalmologist, submit it to your insurance, and see if they'll cover the $500.

Audience Member: And do they come already preset?

Dr. Nirojini Sivachandran: It's all pretty much preset. Did you want to mention anything?

Audience Member: It's just a pair of glasses that you can't see through, and when you press a button, a very bright red light comes on. You close your eyes and wait until the light turns off. As you're wearing it, the red light seems to turn to gray or white, and I wondered if that was my eyes. Once I peeked open my eyes, and no, the darn thing was still red. They're so convenient and easy. There's a rechargeable battery in the glasses, and you plug it in to charge it, like you would any phone. So far, so good, and everything seems to have stabilized. I don't know what it is. It could just be my good living.

Dr. Nirojini Sivachandran: Several optometrists also carry it in their offices now, so you can ask your optometrist as well.

Red light therapy for advanced dry AMD

Audience Member: I have advanced dry macular degeneration. I was wondering why red light therapy can't be used for someone as advanced as I am.

Dr. Nirojini Sivachandran: The question is, if she has advanced dry macular degeneration, why can't we use red light therapy? It's not that you can't use it. There's no formal study that guides us. I always try my best to root things in good science. So can you use it? Probably, but there's no formal study that's been done. This is why we want to include a subgroup with advanced macular degeneration and tissue loss, use red light therapy, and see whether there's a difference in the rate of progression, whether we can slow it down or even stop it. Eventually we will have an answer. Nobody can say you can't use it. I say you can use it, but I have no scientific evidence to back that up.

Stable dry AMD

Audience Member: I have dry AMD, but it's very minimal. It hasn't changed very much in 14 years. Would it be good to be proactive and get these glasses, or would that be a waste?

Dr. Nirojini Sivachandran: This is where it comes down to what type of garbage bags there are, how many there are, and how close they are to the fovea. If it's been stable over 14 years

without much progression, then you may not need them. It's a great conversation to have with your care provider, looking at the images and seeing what type of drusen you have and whether you would benefit. The patients I've seen the most benefit in, among those with intermediate macular degeneration, are those with soft drusen. Those drusen generally seem to melt away nicely over six to eight months. We have time for two more questions, so let's make them quick, and then we'll finish up.

Acupuncture and breath work

Audience Member: I just want to make a comment. I've been going for acupuncture for the last three years, and my dry AMD has stabilized and hasn't deteriorated. I know there's no study for it, but it works for me. I went to the ophthalmologist, and he said it won't get any worse, which I don't believe. The idea of acupuncture is to limit the rate of degradation, not to get better, and that's what it has accomplished for me.

Dr. Nirojini Sivachandran: Then we have to get into the science of acupuncture, because everything is rooted in science if you really think about it. It's not just any random acupuncture. I'm hypothesizing, but it has to be in certain spots that correlate with the eye.

Audience Member: It's based on an acupuncturist in New York who specializes in eye diseases.

Dr. Nirojini Sivachandran: Yes, because there are meridians and points in our bodies that relate to different organs. I'm a big believer in a lot of things. I think our bodies are a lot more capable than we're made to believe, and we have a lot of potential for healing, even just through breath work. Measure your blood pressure before and after five minutes of tranquil breath work, and the effect is tremendous. Think about how much we can do on our own.

Your body doesn't know the difference between your to-do list and being attacked by a bear. Your sympathetic nervous system goes into overdrive, and you have to let your body know, "I'm not being attacked by a bear. I'm safe. I can breathe. I can regulate my physiological responses." A lot of people ask me whether something is related to their eyes, and I say yes, everything is related to your eyes, because we are one being. The eye isn't separate from the rest of the body. I would love to do a study where we did breath work morning and evening and looked at blood flow to the retina with OCTA, which is one of the fancy machines we have now. Would it change after a week, or a month? Macular degeneration also progresses through a lack of oxygenation of the tissues. So could we do better just by doing breath work? I don't know.

Morgan Ineson: And it doesn't cost anything. Everybody would be on board.

Red light therapy with wet AMD in one eye and dry in the other

Audience Member: With red light therapy, I have one eye that is wet and the other dry. Would red light therapy be bad for one or the other?

Dr. Nirojini Sivachandran: In the context of AMD, red light therapy has been evaluated in dry AMD. I'm not aware of any big studies on wet macular degeneration, although there may be little case reports here and there.

Audience Member: I have one wet and one dry. I don't know that it's working, but it's worth a try.

Audience Member: I'd just want to make sure there wouldn't be any harm to the wet eye.

Dr. Nirojini Sivachandran: Red light therapy has also been used in diabetic macular edema, where there's fluid in the retina, and in central serous chorioretinopathy, where there's also fluid in the retina, and it showed some benefit. So we can infer that it's unlikely you're going to do harm, and it may even be beneficial. You're giving me more thoughts to include in my pilot trial.

Morgan Ineson: I know we could probably stay and chat all day, but Dr. Sivachandran has clinic, and we have other things to do as well, so we're going to wrap it up there. Dr. Sivachandran, you're able to stick around until 12?

Dr. Nirojini Sivachandran: Yes, I'll stick around until 12.

Morgan Ineson: Perfect. We'll take a break and be back at 12. Please help yourself to coffee and muffins, chat with your neighbours, and if you have any questions, we'll be around.

Part Two: Lived Experience Panel

Introductions

Ushany Kanagendiran: Hi, everyone. My name is Ushany Kanagendiran, and I'm the Senior Coordinator of Education and Engagement at Fighting Blindness Canada. If at any point it sounds too quiet or you can't hear, just give me a little wave, and we'll get the volume of the mics up in the back there.

We're moving into our next session, the lived experience panel, and I've got my two superstars with me here. I'm going to start with Ed Timeranis. Ed has been living with dry age-related macular degeneration for approximately 10 years while continuing to work as a licensed real estate agent. He uses a range of tools, strategies, and support to manage his vision loss, maintain his independence, and continue working.

I also have Jennie Gulinski here with us today. Jennie was diagnosed with age-related macular degeneration in her early 60s and lives in Burlington, Ontario. With support from CNIB, she uses assistive technologies and adaptive strategies to maintain her independence and stay active in her community, enjoying activities such as mahjong, discussion groups, and shopping. My favourite, too.

To start off, I'd love for both of you to introduce yourselves in your own words and share a little bit about when you were first diagnosed with AMD.

Diagnosis and Early Experiences

Jennie Gulinski: When I first came to know of AMD, my mother had it, and that was probably in my 50s. My sister was her caregiver, and I only took her to her ophthalmologist twice. I knew of AMD, but I didn't know anything else. My brother got AMD as well, and he just wouldn't talk about it at all, so I had no idea.

Then I went to my optometrist to get a new pair of glasses, and she asked if anybody was looking after my left eye. I said, "What's wrong with it?" And she said, "Well, you have problems." She sent me to an ophthalmologist, and I found out that this eye was bleeding. But as long as I could see out of my right, dominant eye, I didn't really worry too much about it. I wasn't frightened about it at the time.

As time went by, around 2009, I was coming home from work, and I couldn't see the stoplights. I didn't know what colour they were. There was a car about five cars ahead of me, and I couldn't read the license plate of the car in front of me, and that frightened me. I decided I had to know more about this disease, and that's when I started doing some investigative work into AMD.

Ushany Kanagendiran: Thank you, Jennie. And Ed, would you like to share a little bit about yourself and when you first received your diagnosis?

Ed Timeranis: Hello, everybody. It's nice to share experiences and hopefully give all of us hope to continue. Very simply, my dad was 75 when he was diagnosed with macular degeneration, and I anticipated that at that age I might get it, it being hereditary. Unfortunately, it came early. Ten years before that, I was driving a car on Long Island at night, and my wife said, "Why are

you merging on the highway at 40 kilometres an hour?" And I said, "Well, I can't see." When I got back to Toronto, I continued to drive, and I lost one eye first, and then I lost the second one six months later.

When I went to the ophthalmologist and asked why it hit early, he asked, "Did you smoke when you were young?" And I said, "Yes, I smoked from the time I was 14 until I was 30, and I smoked two and a half packs a day as I progressed, because I'm an obsessive compulsive." I quit smoking at age 30, but he said that was one of the big reasons mine came on early. And I said, "Well, why didn't they put that on a cigarette pack instead of cancer?" I wasn't worried about cancer, but if you'd told me I'd go blind, I might have listened.

Anyway, I continue to work as a realtor all this time, but I've hired people to drive a car and people to do my paperwork. I can still negotiate and analyze things. So for all of you, if you have a non-Apple product, go and put ZoomText on your computer, which will enable you to enlarge the print to whatever size you need to read. That's number one. Number two, to function independently, have an Apple iPhone or one of the other ones. As long as it has Siri, it can call an Uber, read all your texts, read all your emails, and send your emails, so it keeps you fairly independent.

The idea of being here and sharing with you is that we form a group and build more relationships about how we're coping and what devices we use. As an example, we all have coffee pots and we all have a little teaspoon. The coffee maker is black and the teaspoon is black, and I can't see that, so I promptly wanted a white teaspoon. Those are the things we need to share to cope and keep going. I still jog, and I still ride a bike, but I can't drive a car.

To answer anybody's question about the most difficult thing, it's losing your independence. Before, you got in your car and said to your wife, "I'm going to work," and it didn't matter where you went. Now I say I'm going out, and she says, "Well, where are you going, with Uber?" Whereas before, I could disappear. So losing your independence is number one. Number two, what I miss most is the solitude you used to have in your car commuting to work or wherever. Those are the two big adjustments I found.

We also need Fighting Blindness to send out emails or whatever, so we can share how to cope and adjust with the handicaps that we have. Like the stupid thing I do everywhere because I can't see things: I put white paper towels everywhere, and then I put my black phone on top so I know where it is. But my wife goes nuts with paper towels all over the house. Anyway, that's me.

Accepting and Adapting

Ushany Kanagendiran: Thank you so much, Ed. You talked a lot about some adaptations you've found throughout your time, but I want to hear a little bit about when you first received your diagnosis. Did you find it difficult to accept, or were you able to adapt pretty quickly?

Jennie Gulinski: I was able to adapt because it was in the family already. There are three of us in our family, and I was just hoping it would skip me and go from my brother to my sister, but it didn't. It went from my brother to me. My sister doesn't have it, but it's in the family.

You adapt with paper towels. My son lives with me, and he is extremely helpful in that way, because my house looks like it has measles. We have red dots everywhere so I can see. I have red dots on my keyboard, on the keys I use the most. I have dots on my stove. I don't do a lot of cooking anymore because it's too difficult for me, and I would forget the pot. That probably has nothing to do with macular degeneration. It's just that I'm old and I forget. I also have dots on my microwave and anywhere else I need them.

Since I know I can't do anything about this disease other than get the medical help I'm getting, I'm very aware of what's around me. I have other disabilities besides my eyes, so I have to be careful where I walk and be aware of my surroundings so I don't injure myself, walk into a wall, or trip on something. That's the big thing when you're an elderly person with vision impairment. It's so easy to trip over a curb if you're not aware. I have all sorts of tools that I use, and I'll get to those when you ask.

Ed Timeranis: I found it when I experienced vision loss to the point where I couldn't drive my car. That was the most devastating thing for me.

Jennie Gulinski: That's the big thing.

Ed Timeranis: From an independence standpoint, my background was that I was a car enthusiast. I've owned 50 cars, and all of a sudden I couldn't drive. That's the worst thing. I spend about $1,000 a month on Uber for work and so forth, and the Uber drivers are all terrible. I'm waiting for Waymo to come here, where we don't have to talk to the driver or give them instructions, and it gets you there at a slow, safe speed.

Ushany Kanagendiran: Two more years, right?

Ed Timeranis: Yes. But also, for all of you, I was seeing the chief surgeon at Toronto General every six months, and they gave you 30 seconds. They did the blood pressure and the photo of the eye, and then he said, "Yep, okay." The second year, I had my wife go with me, and we said

to him, "What can I do to be better, or to keep it from deteriorating further?" And their response was, "Nothing. Just come back next year."

Along the way, I was at a LensCrafters store in Sherway, and I was lucky enough to meet an optometrist. When we completed the test, he said, "Go to a low vision clinic." I said, "What's a low vision clinic?" He said they have all these devices to assist you. For those who don't know, there's one outside of Square One and one in Kitchener. Just Google "low vision clinic." It's an optometrist with all the other devices there. And when we've been to the conventions, there are vendors with different devices you can use. I use one of these to read my iPhone. All of these things can make your life a little more independent, rather than asking your wife, "What does that say?" Or when I go shopping, I have to stop people and say, "Could you tell me the expiry date on this pineapple?" So it makes you more independent. You just have to keep going. Exercise and diet.

Tools, Technology, and Adaptations

Jennie Gulinski: I share a lot of what he has said, but I go a slightly different route, probably because I live in Burlington and there isn't that much available there. I signed up with CNIB right away, as soon as I knew I was having vision difficulty. CNIB has all sorts of tools, and they have mobile services that go to different places, and if you call them, they'll tell you where they are. They have a variety of magnifier glasses. I use 4x because it has more clarity. The higher you go, the more blurry it gets. I use it when I play games.

I also have a CCTV, and I can read everything with it. The only problem is that both my eyes are different, and prolonged reading hurts my eyes. CNIB provided it, and the government pays 75% and you pay 25%. I also have a device with audio reading and a magnifier, and I can go up to 1000 to see when I do jigsaw puzzles on my computer. I also signed up for Handi-Van. The reason I have all these things is that if my son ever had to go into the hospital or went on vacation, I need to be self-sufficient, and to do that, I have to have things around me that I can use myself.

I don't usually use Uber, but I have an Apple phone, just like he does, and it's audio. I just press the button and I can call anybody, a taxi, or my son Michael. I also have a Metropass, so if I need to walk to the bus, I use that to get where I want to go. I've had some silly things happen, but I try to be as independent as I possibly can, and so far it's been working. In Burlington, I have a scooter, but that's because of my mobility disability, not my eyes. I shop at Fortinos and Burlington Mall and everywhere. I take the bus pass. But if I have to go beyond the perimeter

where my scooter goes, I have Michael, and I'm very fortunate that he takes me wherever I want to go.

Otherwise, you have to live with this disease. You have it, you can't fix it, so you have to make the best of it. I agree with what Ed said: diet is so important. You have to eat a lot of green things, the foods that will help your vision. I had a tart today, but I'm also a type 2 diabetic, so I can't eat those sweets. I cheat once in a while. I think everybody has to, just to keep safe and not depressed. And be around people. I like being in discussion groups. When I first knew I couldn't see, I explained to the groups that I have vision impairment. I said, "I can't see your faces, but I see you. Don't worry about it. It's not like I'm blind." I'm not going to go blind. But people don't think about that. They come up to you and show you a cell phone and say, "See, this is my granddaughter," and I say, "Very nice, but I can't see that well enough." They think that because I can't see, I can't hear either, so they talk louder, as if talking louder is going to improve your eyesight.

There are lots of people like that. When I went on my own, before I lost my vision and my license, I'd go to a service desk, and they'd hand you something and want you to read it and sign it. You say, "I can't see that," and they look at your eyes, expecting them to change colour or something. So now I have CNIB signs on my walker and my scooter that say "Traveller with low vision." I'm seriously thinking of getting a cap that says it too, so they don't ask any questions. That's just some of what you have to put up with. And never, ever become a recluse.

Ushany Kanagendiran: Thank you so much, Jennie. You both jumped ahead a bit and read my mind with my next question: what are some tools, technologies, or adaptations that have made the biggest difference in your daily life? I know you've talked about quite a few, but if there's anything else you'd like to share.

Ed Timeranis: For those of you who lose your license or are certified blind, first of all, there's a tax deduction of about $5,000 on your income tax. But also, have your ophthalmologist send a note to CNIB. Then, as Jennie said, you're eligible for computers. You just make an appointment and go there. You can get all kinds of things, like a computer or a reader, and they'll pay up to 75% of it and you pay 25%. I got my computer there, and that's where you can specify things like a yellow keyboard, anything to help your low vision.

Another thing I was sharing today: go to your local library and get a program called PressReader. It's free. They'll put it on your computer or your iPad, and you can read all the newspapers and magazines, and each article can be read to you aloud, which I think is great.

Another thing I found out is that once you're certified blind and you're a senior, when you use the GO Train, they'll put a sticker on, and your companion goes free. If you want to see a play at

Mirvish, your partner goes free if you tell them that you're blind and show them the card. The same goes for flying on an airplane, where your partner goes free, and for the railways. I haven't done it, but even with your phone, with Rogers, I have to submit a form, but then you get a 10% reduction on your iPhone. So there are certain benefits to make our lives better.

I still say I want Fighting Blindness to create a way for us to share whatever we've experienced, like red light therapy or any of this stuff, so that we can pick and choose what would make our lives better.

Jennie Gulinski: I just want to say that this is my third one of these seminars. They're only once a year, in November. I would very much like to do what Ed says and have group discussions in various cities, like Milton, Oakville, Burlington, Hampton, places like that. For me, it's an age problem. I'm too old to get involved in a lot of these things, but I think people in their 50s or 60s could start a discussion group, because we could share what someone else has learned. That's how I got everything I know: I come to the Fighting Blindness seminars, and I'm on the webinars. I always go on the webinars and listen, and I find out what tools are available to help me get around and make my life a lot easier.

Audience Contributions

Ushany Kanagendiran: Thank you, Jennie. Thank you, Ed. I'm going to throw this question into the audience as well. If there are any tools or technologies that have helped you navigate, we'll start with you.

Audience Member: The CELA Library is through CNIB. It's a free service for anyone who has vision issues.

Jennie Gulinski: Isn't that the mobile one that goes to different places?

Audience Member: No, the CELA Library is connected with CNIB. They provide books, and if you have an Amazon device, you can get these books and music and all that for free. My mother is totally blind.

Ushany Kanagendiran: Is it like Alexa? It sounds like it's similar to PressReader.

Audience Member: Yes, they're connected with the CNIB library, and you get all these books and music for free.

Jennie Gulinski: That is something I'd be interested in finding out about. Thank you very much. My secretary over there is going to take notes.

Audience Member: It's like Spotify, which has audiobooks, but you have to pay for it. If my mother can't read the book and she's interested in something on Spotify, I put it onto her computer and she can just listen to the audiobook instead of reading. This is free, though.

Ed Timeranis: That's even better.

Jennie Gulinski: I can do puzzles while I'm listening to an audiobook.

Audience Member: The Alexa speaker is connected. Most local libraries also have what they call Libby, with e-books and audiobooks, and those are free as well.

Jennie Gulinski: Thank you for that. That's good information to know. I didn't know about that.

Ushany Kanagendiran: Sorry, I'm going to jump in here, because I've been given the sign that we're running out of time.

Ed Timeranis: One last thing I'd like to say to everybody here. We all know about Alzheimer's. In Canada, there are only 870,000 people who have Alzheimer's, and 2.5 million have our eye disease, so we need to get more awareness. And, as that doctor said, we need more funding for injections at an earlier age. It's 10 times that in the USA, and it's only going to get worse as we baby boomers age.

Ushany Kanagendiran: Amazing. Morgan is going to come up for closing remarks, but we have one more comment.

Audience Member: My vision is not so bad. I can still drive, and one of my daughters got me all these seeing devices, and they're great. They really help. I also found an AI app you can put on your phone. It's great: you can walk around a room, and it will say, "There are chairs right here. There's an opening right in front of you. There's a person on the left and a person on the right." And when you get up close to a person, it will say something like "a very attractive lady," and it says everybody's attractive, so they could be very friendly with you.

Jennie Gulinski: Is that Seeing AI?

Audience Member: Yes, Seeing AI.

Morgan Ineson: I love that it's calling people attractive, because I remember, in the early days when it came out, I worked at CNIB and we were testing it. You'd hold your face up, and it would say, "That's an 80-year-old woman," and I'd say, "Excuse me, how dare you?" I think they learned their lesson.

Vision Loss Rehabilitation Canada Representative: Can I just add one thing? We've been saying a lot about CNIB. CNIB is still there, but the rehab services, which are your daily living

skills, the low vision assessment, computer assessment, and mobility, are actually provided through Vision Loss Rehabilitation Canada. We still work together, and I know everyone still recognizes us as CNIB, but the actual name of the rehab service is Vision Loss Rehab.

Morgan Ineson: That's a fantastic point, and we get confused with you all the time as well. There are very different roles. CNIB has a guide dog school, does a lot of advocacy, and has some programming. Vision Loss Rehab is your one-stop shop for orientation and mobility, getting around safely, adapting your home to make sure you can cook and do laundry and all those things, and tech. Our work is more around eye diseases specifically. We do a lot of work around eye disease-specific education, so we have webinars and these in-person events.

Closing Remarks

Morgan Ineson: Thank you again for being here. It's been lovely meeting you.