AMD COFFEE CONNECTIONS: WINNIPEG

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Part One: Expert Conversation

Overview and Disclaimer

Dr. Larissa Moniz: Welcome and good morning. Thank you so much to everyone for joining us today for Coffee Connections. My name is Dr. Larissa Moniz, and I'm the Director of Mission and Research at Fighting Blindness Canada. Fighting Blindness Canada is dedicated to supporting vision research and connecting people living with eye disease to education, trusted information, and advocacy.

Before we begin, I want to note that the views shared by our speakers today are their own and don't necessarily reflect those of Fighting Blindness Canada. Any mention of products, treatments, or services doesn't mean we're endorsing them, and sponsors do not influence the content of our program. This discussion is for educational purposes only. Any decisions about your eye care should be made with your own eye doctor.

I'd like to introduce Dr. Joshua Manusow, Dr. Joshua Manusow is a Winnipeg-born retina specialist and surgeon and a faculty member at the University of Manitoba, where

he also trains future eye-care specialists. He has extensive experience treating retinal conditions, including age-related macular degeneration, and has received numerous awards for his work in patient care, teaching, and research. Welcome, Dr. Manusow, and thank you so much for being here.

What Is AMD? Dry vs. Wet

Dr. Larissa Moniz: To get us started, could you explain what age-related macular degeneration is and the difference between dry and wet AMD?

Dr. Joshua Manusow: Age-related macular degeneration, or AMD, is a disease that affects the macula, which is the central part of the retina at the back of your eye. The retina is responsible for detecting light and sending signals to your brain so you can see. The macula is the part that gives you your sharp, detailed central vision, which you need for things like reading, recognizing faces, and driving.

As the name suggests, AMD is associated with aging. It's more common as we get older, particularly in people over 65. There are also genetic and environmental factors that influence your risk, including smoking and diet.

There are two main types of AMD: dry and wet.

Dry AMD is by far the most common form. About 90% of people with AMD have the dry type. It typically develops gradually, as deposits of fats and proteins called drusen build up underneath the retina. Over time, the cells in the macula can become damaged, affecting your central vision.

In more advanced dry AMD, we can see something called geographic atrophy, where areas of retinal tissue begin to die off. Unfortunately, once those cells are lost, they don't grow back, and that can cause significant vision loss.

Wet AMD is less common, but it can cause more sudden and severe changes in vision. With wet AMD, abnormal new blood vessels grow underneath the retina. These blood vessels are fragile, and they can leak fluid or blood, damaging the macula.

People might notice that straight lines suddenly look wavy, their vision becomes blurry, or they develop a dark or missing area in the centre of their vision. That's why it's important to report sudden changes in vision to your eye doctor right away.

One thing I always emphasize is that AMD affects your central vision, not your peripheral or side vision. Even with advanced AMD, people generally retain their peripheral vision. That doesn't mean the vision loss isn't significant, but it's an important distinction.

Treatments for Dry and Wet AMD

Dr. Larissa Moniz: What treatments are currently available for the two types of AMD? Perhaps we can start with dry AMD.

Dr. Joshua Manusow: Dry AMD has historically been much more difficult to treat than wet AMD. We haven't had the same kinds of effective treatments that we've had for wet AMD over the last 20 years.

For people with intermediate dry AMD, we often recommend AREDS2 vitamins. These are a specific combination of vitamins and minerals that have been shown to reduce the risk of progressing to advanced AMD in certain patients. They're not appropriate for everyone with AMD, and they won't restore vision that's already been lost, but they can help slow progression in people who meet the criteria.

We also talk about lifestyle factors, including not smoking, eating a healthy diet, and protecting your eyes from sunlight.

One of the newer developments is a treatment called photobiomodulation, which uses specific wavelengths of light to stimulate cells in the retina. It's recently been approved by Health Canada for certain patients with dry AMD, and it's something I'm particularly interested in.

What's interesting is that if you'd asked me about photobiomodulation seven years ago, I would have told you I was completely against it. In fact, I helped write a position paper for the Canadian Ophthalmological Society questioning the evidence behind these treatments.

But medicine changes, and as doctors, we have to be willing to look at new evidence and change our minds when the science supports it. I still think we need to be cautious and continue following the data, but the newer studies have shown some promising results.

The LIGHTSITE clinical trial found improvements in visual acuity in some patients, as well as evidence suggesting that treatment may reduce the progression of dry AMD. For me, the most important potential benefit isn't necessarily making someone's vision sharper. It's whether we can slow down the disease and help people maintain the vision they have for longer.

I've actually purchased one of these machines for my practice, so it's something we're going to be offering and watching closely to see how patients respond.

The downside is that the treatment requires a significant time commitment. Patients receive nine treatments over several weeks, followed by a break of approximately four months, and then repeat the process. That's 27 treatments over the first year.

It's also expensive and isn't currently covered by the provincial health-care system. I'm not sure how many patients will choose to pursue it given the cost and number of visits required, but I hope that if the evidence continues to develop, it may eventually become publicly funded.

It's exciting to finally have another potential option for dry AMD, but I think we need to be realistic about what it can achieve. We're not talking about curing macular degeneration or restoring vision that's already been lost. What I'm most interested in is whether we can slow progression and preserve vision.

Dr. Larissa Moniz: And what about wet AMD? We've seen some significant advances in treatment over the past couple of decades.

Dr. Joshua Manusow: Absolutely. Wet AMD is a very different story. The treatments we have today have completely changed what we can offer patients.

The main treatment is injections of medications called anti-VEGF drugs, which are delivered directly into the eye. These medications block a growth factor that causes abnormal blood vessels to develop and leak underneath the retina.

Before these medications became available, we had very few effective options for people with wet AMD. Now, we can stabilize vision in the vast majority of patients, and some people even experience improvements.

We've been using these injections for about 20 to 25 years now. Around 2005 is when they became widely used, and in Manitoba we started doing them around 2007 or 2008, because everything always takes a little bit of time.

Injections for Wet AMD

Dr. Joshua Manusow: We've had the injections for about 20 to 25 years now. Around 2005 is when they became widely used, and in Manitoba we started doing them around 2007 or 2008, because everything always takes a little bit of time.

We started with a drug called Avastin, which is actually not designed for the eye. It's an off-label drug. My patients sitting in the room will have heard me talk about this before, but it's actually a drug for your colon, believe it or not. It's a colon cancer drug. The reason we use it is really interesting, and I can talk about that a little further. It's the first-line treatment here in Manitoba, and really in most of Canada, although every province is a little bit different.

Then there are what we call second-generation drugs, which work in the same way, except that they were specifically designed for the eyes. Those are ranibizumab, which you might know as Lucentis, which some of you may have been on at some point, and aflibercept, which is Eylea.

Now we have newer, third-generation drugs. There's one called Vabysmo, which works a little differently but in a similar way, and there's Eylea HD, which is really the same as the second-generation Eylea, just in a much higher dose.

Currently, we don't have access to those drugs through the provincial program. However, the province has just given us access to them starting in January, so we're finally going to have them. We've been using them in people who have private

insurance that will cover the new ones, but for the last little while, most people in Manitoba have gotten Avastin.

The way these drugs work is, remember I told you that with wet AMD you have bleeding, and you have bleeding because new blood vessels are growing where they shouldn't. Just like in a colon cancer, where blood vessels feed the cancer, these drugs basically stop those blood vessels from growing in. That's why we're using a colon cancer drug in the eye. It's the same mechanism, which is really interesting when you think about it. These drugs are generally either antibodies or little proteins that mop up a molecule called vascular endothelial growth factor, which is causing all of these blood vessels to grow.

Your eye is actually secreting this growth factor as a kind of SOS signal. It's saying, "Help me! My macula is degenerating, I'm losing all this tissue, and I need to be better nourished." The body is trying to do a good thing. However, these blood vessels are not good. They bleed. The injections stop that, but the problem is that they wear off. An injection is good for about a month, maybe two or three if you're lucky, and then you have to get another one. So you have to keep coming back, and in macular degeneration, these tend to be lifelong treatments. We use the same drugs for other conditions, like diabetes, where people may only need four or five injections, but for macular degeneration, for most people, it's a lifelong treatment.

Those are the drugs for wet macular degeneration. The third-generation drugs have only been around for a few years, and that's what we're excited about. It's not so much that they work better than the drugs we have, but that they're supposed to last longer. If anyone has been to my office, you've seen the chaos in the waiting room, with so many people waiting for their injection, because there are so few of us that do it and so many of you that need it. The fewer times you have to come to my office, the better for you, because there's always a risk with every injection, and the better for me, because I don't have to see as many patients. It's also cheaper for the government, because there are fewer appointments. We know these drugs work really well for the most part. It's just that they wear off, so the longer we can stretch them out, the better. With these newer

drugs, a lot of people can go at least four months without an injection, which is great. Having three injections a year instead of maybe six is a big improvement.

Treatments on the Horizon

Dr. Larissa Moniz: Building on that, could you talk about some of the potential treatments in the pipeline, such as the implants or gene therapy?

Dr. Joshua Manusow: The implant is, in a way, ready for prime time. It's actually being done in the U.S., and I had lunch with someone from the company that distributes it there. They are trying to get it approved by Health Canada. It's something that we surgically sew into your eye. It's not a big procedure, but it's still a surgery, and it very slowly releases Lucentis, the second-generation drug I was talking about. Because it releases the drug slowly, you don't have to keep getting injections every month or two. It does have to be refilled, I believe every six months to a year. That means getting an injection into a tiny port that sits on your eye. Once it's surgically implanted, you could come into our office and, rather than getting the eye injection, have the port refilled with drug.

It's a slower, steadier release of the drug, as opposed to the ups and downs we get when we inject. I kind of say it's like people with diabetes who get an insulin pump compared to just getting injections. The downside is that you have a permanent foreign body in your eye, so there are risks of infection and bleeding and all sorts of things. I don't think it will be for everyone, but it would be good for a certain subset of people.

Gene therapy is all the rage, and I'll be talking about more gene therapies this afternoon when we talk about inherited retinal diseases. I just got back from one of the European Retina Society meetings, and pretty much for every new treatment for macular degeneration, everyone is talking about different gene therapies. I don't think any of them are close to being widely available, especially in Canada. I think we're years away. But that's certainly where everything is going. There are lots of ideas for causing the cells in your eye to make the drug themselves, the drug we were injecting before, so

your eye becomes a little factory for this drug and prevents the disease from getting worse.

The problems with gene therapy are, number one, that it's very expensive. Number two, it can cause a lot of inflammation in the eye, so there can be side effects just from getting the treatment itself. We don't know a lot about the long-term effects because it's still early and being studied. And the last problem is that it's difficult to get into the eye. Some people are trying to inject it into the eye, like we do with the drugs we currently use, but that doesn't seem to work as well as injecting it under the retina. Injecting something under the retina is a big, somewhat dangerous surgery, so we haven't quite figured out the best way to get the treatment to where it needs to be. That's why I say it's a bit of a ways off, but that's where all the research is going right now.

If you told an ophthalmologist 30 years ago that they'd be injecting people with a drug, they would have thought you were crazy. Today, a lot of these things seem dangerous, but 10 years from now they may be very commonplace, and we may be very good at them. It's certainly the future. It's just not quite there yet.

Dr. Larissa Moniz: That was a really great description of where we are and where we're going in the near future. I want to open it up to questions from the audience, because I feel like we've got a pretty busy room, and I'm sure there will be a lot of questions. If anybody has one, please put your hand up or call it out.

Audience Q&A

Prevalence in women and men

Audience Member: Is macular degeneration more prevalent in the female population than the male population, or is it equal?

Dr. Joshua Manusow: The question was whether macular degeneration is more prevalent in women than men. Yes, it is a little bit more prevalent in women, not by a lot.

That's at least what the studies say. Empirically, I don't notice that I have more female patients than male patients with macular degeneration. It seems fairly well split to me. But when they look at really big studies, I think it's something like 53% women and 47% men. I'm going to get the number wrong, but it's not a huge difference.

Photobiomodulation

Audience Member: Do you have an idea what the ultimate result would be?

Dr. Joshua Manusow: The question was about photobiomodulation and what the ultimate outcome would be. One thing you can probably expect is a placebo effect. Just going in and getting something done for yourself can sometimes make you feel like you're being proactive, and you can feel better about it. That's the first thing I would say about any of these new treatments. Even with eye injections, I'll notice that a patient's visual acuity hasn't changed at all, but they'll tell me things are much better. I think there's a bit of a placebo effect there too.

The big study was called the LIGHTSITE study, which I kind of like the name of. Some of it was done in Toronto, actually. People gained a line of vision. What that means depends on where your vision was. Some people in the trial had 20/25 or 20/30 vision, and some had 20/80, so overall people gained a line, but some gained less and some gained more. I don't see this as improving vision as much as preventing things from getting worse. What I would like to see is a lesser chance of that person going on to develop wet macular degeneration and needing injections. So I wouldn't necessarily expect a huge sharpening of the vision. After we've been doing it in my clinic for a year or two, maybe we'll notice that, but based on the study, it's an improved line of vision and less chance of progression.

Dr. Larissa Moniz: Can I follow up on that? In the study, was there less progression to wet AMD, or less progression of the dry getting to advanced dry, or both?

Dr. Joshua Manusow: The primary outcome was vision, which wouldn't have been the primary outcome if I had been designing the study, but fair enough. I believe fewer patients went on to develop wet. Their drusen volumes, the number of those little yellow dots, went down a little bit, and their retinal sensitivity increased. That's tested with something called microperimetry, which is a special kind of picture and visual field test. So overall, the retina became more sensitive.

Age-related vs. genetic causes

Audience Member: How do you distinguish between the age-related cause and the genetically related cause?

Dr. Joshua Manusow: They're sort of one and the same. They're both risk factors. Just because you have a gene that predisposes you to macular degeneration doesn't mean you're going to get it, and just because you're getting older doesn't mean you're going to get it. It's multiple risk factors, so there isn't really a way of distinguishing between them.

One thing that was talked about a lot about 10 or 15 years ago was genetic testing for people with macular degeneration. There was some weak evidence that the AREDS2 vitamins might only be good for people with certain genes, and might actually be bad for people with other genes. A bunch of companies came up and pursued commercially available gene testing, but that never really took off, because the evidence was very weak. The people who did the good studies showed that it didn't really make a difference with the vitamins. If we had been worried about making someone worse with vitamins, that probably would have been something we would have clung to, but it isn't done outside of research right now. So we don't really distinguish between the two. We just know that if you have macular degeneration, there's a good chance your kids will also have macular degeneration as they get older, but not necessarily to the same severity or mildness that you do.

Dr. Larissa Moniz: For this afternoon, that's broken down into a separate presentation on genetics.

Dr. Joshua Manusow: That's a totally different disease that we're going to be talking about this afternoon. Macular degeneration is a completely different thing from what we call an inherited retinal dystrophy, such as retinitis pigmentosa. They both affect the retina, but mostly different parts of the retina. Though some of the genes are related, which is kind of interesting.

Dr. Larissa Moniz: One of the ways we talk about it is that there's a genetic component to age-related macular degeneration, but we don't call it a genetic disease, which is sort of confusing. In the diseases we're talking about this afternoon, most are caused by a mutation in a single gene. In something like age-related macular degeneration, you probably have genetic factors affecting multiple genes that together increase your risk. Is that correct?

Dr. Joshua Manusow: Yes. It's a combination of environmental factors, like I talked about, such as your diet, sun exposure, and smoking, then your genetics, and then, of course, getting older.

Treatments for advanced dry AMD

Dr. Joshua Manusow: One thing we didn't talk about was treatments for advanced dry macular degeneration, which is probably worth mentioning because you'll see this on Facebook groups and Google. There are two injectable drugs for advanced dry macular degeneration available in the U.S. However, they're not available in Canada or Europe, and probably never will be, because the evidence behind them isn't great, to be totally honest with you. Health Canada hasn't approved them, nor has the European equivalent. The FDA approved them very quickly, which was a little suspect to some of us. These drugs were supposed to slow down the atrophy, or total loss of tissue. I do have some patients who have gone to Grand Forks and Fargo to get these injections. Again, the evidence is not great.

But I think they're exciting in the sense that they're the first of probably many future drugs like this, which will show better efficacy and be approved. Even with the anti-

VEGF drugs, there were precursor drugs in the late '90s that weren't great and didn't work all that well, but were better than nothing. That's kind of what's happening with these drugs in the U.S. right now. They're called complement inhibitors, a sort of immune-type therapy. Eventually a new drug will probably come out that gets approved here.

The other thing for advanced dry is stem cell transplants, transplanting sheets of cells into the back of the eye. These trials have been going on for a really long time, some of them in Canada, and they've shown varying effects. One day we probably will be doing things like that for advanced dry macular degeneration, but we're not quite there yet either. So unfortunately, for that kind, we really have no good treatments.

Dr. Larissa Moniz: We get a lot of questions about the complement inhibitors, especially from people who go south for the winter or live close to the border and see ads from the States. The data did show a reduction in atrophy when you looked at the images, but there was no change that people could recognize functionally, no change on the eye chart or in day-to-day life. So it was hard to say there was a functional effect on vision. Vision loss was still progressing essentially the same way. There was hope that in the long term it would be less, but the trials didn't show that.

Dr. Joshua Manusow: Part of the reason is that the trials were not designed all that well. They chose an outcome that the FDA insists on, but it was probably the wrong outcome. Hopefully in the future they will design better trials for the newer drugs, so those drugs can actually be approved in most places.

The PRIMA implant and retinal prostheses

Dr. Larissa Moniz: We had a question in the audience about an implant. Can you speak to the PRIMA implant, the new retinal prosthesis?

Dr. Joshua Manusow: I don't know a ton about the PRIMA implant. I had more experience with the previous implant, which was more for retinitis pigmentosa and

inherited retinal diseases than for macular degeneration. The idea behind these implants is very high-tech and very sci-fi. It's almost like turning your eye into a bionic eye. They implant a retinal chip, almost like a microchip, either on the surface of your retina or underneath it.

They all work in a different way. With some of them, you have a camera that's connected to the implant in your eye, whether by cable or Bluetooth. It takes the image from the camera and turns it into a pixelated image on the implant. As long as your optic nerve works, the implant creates an electrical signal, remember I told you the retina takes light and turns it into an electrical signal, and your brain interprets it. So you see the outline of something. It's not like looking at a Monet painting and seeing all the colors. But if you were only seeing movement in front of you, for instance, suddenly you'd be able to see a curb, or the outline of a sign. That's where we are right now. As the resolution gets better, we might be able to read with these things.

They did about 10 of them in Toronto when I was a fellow, about 10 years ago. Some of the patients were really happy, and some weren't. Some got really good results, and some had really bad complications, because it's a lot of hardware to put onto an eye. It's really exciting, and as the technology improves, it might be something we would do. But generally it's meant for people whose vision is much worse than what most people with macular degeneration end up with, because it's pretty rare for people to get to the point where they're only seeing light with macular degeneration.

That's one thing I would point out. A lot of people think they're going to go blind, and I say "blind" in quotation marks. The best people to talk about that are the people at CNIB. There are huge degrees of difference in low vision and in what people consider to be a visual disability. There are legal definitions of blindness, but that's for lawyers and governments. It's not for people. With macular degeneration, you can't see things right in front of you, but you can always see things around you. If you had really advanced macular degeneration and looked right at me, you maybe wouldn't see my face, but you'd see everything around my face. You could look at a newspaper and tell there were letters all around, but you wouldn't see what was right in front of you. It never gets

to a point where things are black, where you can't move around. That happens in other eye diseases, but not macular degeneration. A lot of people are really scared of that, and I think it's an important thing to recognize.

Dr. Larissa Moniz: Before we get to more questions, I want to mention that last year we had a webinar with Dr. Daniel Palanker, a professor at Stanford who helped develop PRIMA, which is currently being tested for advanced dry AMD. If you're interested in learning more, go to our website, and you can watch that webinar. There will be a follow-up email with a link to it. We'll also include a link to a session we had a couple of weeks ago about nutrition and age-related macular degeneration, where we had an academic who studies this and a clinician. It was a better session than I expected. I thought it was going to be a bit "woo-woo," like, what are you going to do about nutrition? But it was so specific and good, and it was essentially what you said, just in more detail. If you want more detail, that's a great place to go. Okay, the lady in the brown shirt.

Diet and lifestyle vs. injections

Audience Member: I was just wondering, if you watch your diet and your lifestyle, how much more time do you get by taking a needle as opposed to just living a better lifestyle?

Dr. Joshua Manusow: The question was, if you watch your diet and lifestyle, or maybe take the vitamins, how much longer do you keep good vision compared to taking the injections? Those are treatments for two different stages of macular degeneration. We would never give the needle to someone who had early or moderate dry macular degeneration. We only give it to people who have wet or advanced macular degeneration. Once you get wet macular degeneration, diet and vitamins will do nothing for the wet part. They're still good for the dry part in the background, but if you don't get the needles, we know that you will get permanent damage to the back of the eye. At the moment, there really isn't anything else.

Audience Member: How much does it delay things if you have the needles? My mom took needles for three years, and that was...

Dr. Joshua Manusow: Everybody's different. In about 95% of people, the disease stabilizes on the needles. We know that from the big studies, which are a little old at this point. When these drugs first came out, they did long studies, and about 95% of people stabilized, and about 40% gained three to four lines of vision. These are really miracle drugs, because before that, people literally lost their central vision when this happened. We had nothing to offer them.

Does everyone keep their vision long term? No, absolutely not. You can miss an appointment and get a bleed because the drug wears off. Or you can develop a bit of tolerance to the drug you're on, and it stops working as well, and we need to switch you to another drug. The other thing that can happen is that you can still develop advanced dry macular degeneration while you're being treated for the wet. You may not be losing vision because of bleeding or swelling, but you can lose vision because of tissue loss. That's why, in a perfect world, and I think 20 years from now, we'll probably have dual therapies that combine the complement inhibitors used for advanced dry with the anti-VEGF drugs. What I see most in patients who lose vision from the wet kind is that the anti-VEGF drugs work very well, but over time those patients develop the advanced dry kind, and we don't have a treatment for that.

I started my practice here 10 years ago, in 2016. I have patients I've been injecting since then who still have the same vision they had in 2016, and I also have patients who can now only count fingers in front of them. Everybody is different, and a lot of that has to do with whether they develop the advanced dry kind.

If you hate needles, that's another exciting thing about the port delivery system, or the implant, although if you hate needles, you'd probably also hate having surgery to have it implanted. But it would mean not coming for as many needles. I can tell you, lots of people hate needles. The injections are really not as bad as they sound, and you won't believe me unless you actually get them. It sounds awful, but most patients say after

they get them a few times that they don't love them, but it's not the worst thing in the world.

I have over 10,000 patients in my practice, and I have only one patient who cannot get injections in my office, and whom we have to take to the operating room and sedate to get needles every two months. He has such a severe fear of anyone getting near his eye that he'll swing his arms and try to punch me in the face if I get near him. He's tried everything: hypnosis, psychotherapy. He doesn't want to go to the OR every two months to get sedated, but there's just nothing else, so for him, we do that. That's one out of over 10,000 people. I have patients as young as seven years old who will get needles done in my chair without any sedation, not for macular degeneration, but for other things. So most people can do it, but I totally respect that people hate needles and that people have severe phobias.

Progression from one eye to both

Dr. Larissa Moniz: The gentleman in the gray vest, and then the gentleman in the blue afterwards.

Audience Member: A lot of your advanced future techniques sound a little sci-fi, and probably are only going to be a benefit to those young folks over here in the green hats, looking at the demographics in this room. My question has to do with the progression of AMD from one eye to both. Is that an inevitability, or is there any literature that talks about the likelihood of it spreading, for lack of a better word, to the other eye?

Dr. Joshua Manusow: It's usually a bilateral disease. That's the first thing I would say. Whether both eyes develop advanced disease is another matter. There is literature on it, and I couldn't quote you the exact numbers without looking at the papers, but there are a few things to say.

When someone comes into my office and suddenly has wet macular degeneration and starts getting needles, they often make a lot of lifestyle changes all of a sudden. Maybe

they weren't taking the vitamins before, and now they are. They're eating better. Maybe they quit smoking. They get a good pair of sunglasses. I think to a certain extent that helps delay or prevent it from going to the other eye, because it's a wake-up call. Anecdotally, because I can't quote you exact numbers, on a regular day at least close to half of my patients getting injections are getting them in both eyes. It's extremely rare for it to start out that way. It usually starts with one eye, and then we check the other eye every once in a while, and sometimes it happens. So it's not so much an inevitability, but it tends to be bilateral.

Cataract surgery and drusen

Dr. Larissa Moniz: And then the gentleman in the blue.

Audience Member: I'm wondering what impact cataract removal has on existing drusen on the retina, if any.

Dr. Joshua Manusow: That's a really interesting question. For those of you who don't know what a cataract is, your eye has a lens inside it that helps focus light onto the retina. As we get older, the lens becomes cloudy and more yellow, and it becomes difficult to see through. The cataract gets removed, and a synthetic lens is put in its place. It's the most commonly performed surgery in the world. It's very safe, and people get great results.

We think that part of the reason we develop a cataract as we get older may actually be to protect the macula against macular degeneration. As the cataract yellows, it blocks blue light, and we know blue light is really bad for the macula. It may have been a natural, evolutionary thing, it's just that humans weren't designed to live to 95. Your cataract was supposed to outlive you, not the other way around, which is how it is now.

About 20 years ago, we started putting yellow-tinted lenses into the eye, with the idea that they would block blue light and prevent macular degeneration from getting worse. It didn't seem to make a difference, which was interesting, because from a scientific and

physiological point of view it makes sense that it would. They've stopped making those lenses now. Some of you may have them in your eyes. People didn't notice the yellow tint. We were just talking about this last week at rounds in our department. There are a lot of people in the city with one eye with a yellow-tinted lens and one eye with a regular lens, and they don't even notice. I feel like I would, but people don't. So we don't worry so much about cataract surgery and drusen.

I don't know specific data on whether drusen volume gets worse after cataract surgery, and I don't think so. We certainly don't tell people with macular degeneration to put off getting cataracts. In fact, with anyone with low vision, cataract surgeons are sometimes hesitant to remove a cataract because they'll say, "You don't have such great vision anyway in that eye." As retina specialists, we always have to advocate for those patients, because just getting more light into the eye can make a huge difference. Lighting is so important when you have impaired vision. We didn't really get into the environmental things you can change when your vision goes down. That's something CNIB, and Dr. Friesen back there, would counsel people about, but having really good lighting in your home when you're trying to do something makes a huge difference. So if you have macular degeneration, it's a really good thing to get your cataract out once you need it. I would never counsel someone not to do it.

Sunglasses

Dr. Larissa Moniz: Can I follow up on your comment about blue light? You mentioned sunglasses and eye protection. There are lots of different tints and types of sunglasses. Are there some that are better than others, in terms of the color of the lens or otherwise?

Dr. Joshua Manusow: I don't know so much about the color of the lens. What you want is something that blocks UVB light, and you can talk to your optician about that. When I say sunglasses, I don't mean go to the gas station, although that's better than nothing. If you're really worried about it, go to an optician and say, "I have macular degeneration,

and I'm looking for the best type of lens to help." But any kind of sun protection is good. You want something that blocks UVB light.

Light bulbs and color temperature

Audience Member: A little bit off that subject. Talking about light, do you have an opinion on the light color that we see happening? The regular light bulb used to be 2700K, then 3000, up to 5000. You put it in your living room and you think you're in an operating room. I'm wondering what your view is on that kind of thing.

Dr. Joshua Manusow: My personal view is that I find it annoying, because I like the old incandescent light that gave off a nice warm glow. I don't know that anyone has done good eye studies to say these new light bulbs are necessarily bad for your eye. Luckily, a lot of them are on dimmers, so you can dim them down. In some ways they're good, because if you need better lighting when you have lower vision, you can get that with these lights compared to the old ones.

Dr. Larissa Moniz: I'm going to do two more questions. First, the lady in the white shirt at the back, and then right in the front here, and then we'll have to take a break.

Screening and early detection

Audience Member: It's extremely interesting. You try to catch all of this with an older brain and retain it. I hope there's a recording that we can watch over and over again at home.

Audience Member: I have been living with macular degeneration for about 20 years now. I was wondering, when you go for glasses, can the optician see if you've got macular degeneration starting? I didn't know about it until one of my eyes turned wet, and I said, "Nobody told me I had it. I know I could have been doing something." I'm also concerned that my dad had it, to the extreme, and my daughter, who is now 47, is on that railroad track. She probably could have it. Shouldn't an optician be informing

her? Nobody started any kind of treatments for me, or mentioned starting particular vitamins at that time, and I really want to help prevent it.

Audience Member: A little funny: my dad had macular degeneration for a long time. I took him to CNIB, and the nurse there was checking his eyes. He had his glasses on, with the charts on the wall, and she said, "Fred, read all the letters." He got to a point where he couldn't do it anymore. She said, "Okay, take your glasses off," and, "Fred, look at my forehead." And my dad, without glasses, with macular degeneration, read every single letter on that chart, even the small stuff at the bottom. So at least we're blessed that we'll still have peripheral vision.

Dr. Joshua Manusow: That's right. That was the point I was making before, that it's never something where everything goes black.

I think your question was about early screening and how we pick up macular degeneration. The first thing is to understand the difference between an optician, an optometrist, and an ophthalmologist, because people really don't understand that, and there is a big difference between all three. An optician is someone at the glasses store. They help you pick out frames and lenses, and maybe a tint on the lens, and they adjust things and make sure it fits you. They don't diagnose any kind of eye disease. They're purely there to make your glasses and give you contact lenses.

An optometrist goes to university, gets an undergraduate degree, and then goes to optometry school, a specific school for optometry. They're the primary eye care provider, like the family doctor of eyes. When most people say, "I go to my eye doctor," that's who they're talking about, like Dr. Friesen, who is sitting back there. They measure you for glasses, and they do the primary screening. When they measure you for glasses, they'll often look in the back of your eye and the front of your eye. They might be the ones who initially diagnose a cataract, or notice that you have dry macular degeneration, and they are generally the ones who might start you on vitamins.

An ophthalmologist is someone like me. We go to school for undergrad, then to medical school and become medical doctors, and then we specialize in eyes. We spend anywhere from five to seven years doing a residency and fellowships to specialize in eyes, and we treat the more advanced eye diseases. The optometrist would refer you to me when you need an invasive treatment. We are the only doctors who do surgery and laser and those things on the eye. So no, you wouldn't expect the person in the glasses store to do any type of screening for macular degeneration. I would expect your optometrist to be able to tell you if you have it.

Just like ophthalmologists, dentists, and plumbers, there are good ones and there are bad ones. Some are very good at picking up the fine things in the back of the eye, and some aren't, so it depends on who you go to. It's important to have your eyes dilated at least once every one or two years as you get older, because it's really tough to see the back of the eye without drops to dilate them. A lot of optometrists will also take pictures of the back of your eye, which can be very helpful. They're really the ones who initially pick things up. But sometimes people do just come in with wet macular degeneration. They may have had very subtle dry macular degeneration for a long time, and things can change suddenly, unfortunately.

Retinal detachment

Dr. Larissa Moniz: Thank you. And the last question, up here in the front.

Audience Member: I wonder if there is any relationship between macular degeneration and retinal detachments.

Dr. Joshua Manusow: No, not that we're aware of, and luckily, because you wouldn't want to have both, although sometimes people do. The only relation is that every time you stick a needle in someone's eye, there's a risk of developing a retinal detachment. So it's not from having macular degeneration, but from having an invasive treatment. The risk is very small. We think it's probably one in 1,000 to one in 10,000, but we do a

lot of injections, so it's possible that a needle in your eye could cause a retinal detachment. Again, that's extremely rare, but it can happen.

Audience Member: For someone who has had a detachment, is there a higher incidence of macular degeneration?

Dr. Joshua Manusow: Not that I'm aware of, no.

Closing

Audience Member: Could we get the doctor's name, please? I did not catch it.

Dr. Larissa Moniz: Absolutely. It's Dr. Josh Manusow, M-A-N-U-S-O-W. Dr. Manusow is going to be here for the next half hour while we take our break, so feel free to come and ask him a question. Let's give a round of applause to Dr. Manusow. Thank you.

I think the last conversation was great for pointing out all the different resources you may want to look into. On the break, I highly recommend that you talk to our friends at CNIB and Vision Loss Rehabilitation Canada, and to Dr. Selina Friesen, who is also one of Fighting Blindness Canada's board members. We're really happy to have her here. She's an optometrist. We'll take a break for about 25 minutes and come back here then. Please help yourselves to drinks, and to any snacks that are left. Thank you.

Part Two: Community Conversation (Lived Experience)

Opening

Morgan Ineson: For the next part, I'm going to try to guide us through some questions, but this is meant to be a more informal exercise. In other places where we've done this, we've moved everyone around one or two tables, but there are so many people here

today, which is wonderful, so we'll have to shout out. There's no pressure to speak. You're welcome to just listen, but we'd love it if people are willing to share.

What Brought You Here Today

Morgan Ineson: For the first question, I'd like to ask: for how many people here is this your first Fighting Blindness Canada event? Okay, most of you. That's wonderful. Thank you so much for being here. Would anyone like to share a little about themselves and what brought you here today? The gentleman in the back.

Audience Member: If I were to use one word, it would be fear. What am I facing? Where is this going? What are the impacts on my lifestyle going to be? That's probably the predominant one. The other is an interest in how people are dealing with the various challenges we're experiencing now. Last night, I was looking around the family room, realizing that the lighting was that low, comfortable lighting we'd had for many, many years, and how much less of that room I can now see. So there need to be adjustments, but looking to the future and where things are going is probably what drew me here most.

Morgan Ineson: Thank you so much for sharing that. I imagine a lot of people in the room feel the same way. Does anyone else relate to that? Yes, here in front.

Lighting at home

Audience Member: We had an electrician come into our house, and he put little strips of lighting along the side of a few closets. Now when I open them, it's like a fridge door in the middle of the night. It's wonderful. You can tell the difference between blue and brown and black, and black and red too. It's just a little strip, and the light comes on when you open the door. It makes a difference in what you do after.

Audience Member: We also put in additional pot lights, and it really wasn't that expensive. LED technology is so amazing, so it's worth doing. There's such a

difference. We thought we had lots of light until we did this. The crew that did it for us were just amazing.

Audience Member: I was wondering about spotlights, because my husband put more in the ceiling, and I still can't see.

Audience Member: Did they have to go into the attic?

Morgan Ineson: They did have to go into the attic. That's always a bit of a challenge, because you don't want people messing around with the insulation, but they usually do a good job of putting it back.

Audience Member: Who did you use for the electrician?

Audience Member: It was recommended to us by someone who had already done it, so we knew these people were great. I'd be glad to share that with you anytime.

Audience Member: Did you put the lights in every room?

Audience Member: Only the living room and the areas where we felt we needed more light, the living room and the dining area. Just a couple of extra lights, and they're also on dimmers.

Audience Member: I want that in my closets.

Morgan Ineson: That's a great example of something you can do now. Even if you're just starting to notice that your living room is darker, you can do this early on, knowing it will be helpful later, so that when you need it, you have it. Does anyone else want to share? Yes, over here, in the blue and red sweater.

Diet and supplements

Audience Member: I grow marigolds, and I read online that baseball players eat marigold petals to help their eyes when they play. I've been growing them for three years. Every time I look at my curtains and they look wavy, I eat some marigold petals, and it's amazing. In three to four minutes, the line is straight. Like I said, I read it online, and it really helps. Marigolds are very high in lutein. If anybody wants to try it, go for it, because it works.

Audience Member: How do you take it?

Audience Member: You just eat the petals. I dry the petals for the winter, and my solarium is full of them. They say the red and orange ones are higher in lutein than the yellow ones. It lasts most of the day, and I eat marigolds three times a day. It's been working for three years, and it's still working.

Morgan Ineson: That's a tip I've never heard at one of these before, so that's really interesting. Thank you.

Audience Member: Do you take [supplement name unclear] as well?

Audience Member: No, because it's very high in lutein, and I don't want to overdose. I take the maximum dose of what I'm on already.

Audience Member: I don't take the capsules. I was told not to, because they go through your system faster.

Audience Member: Actually, I chew mine. I chew every medication I have.

Morgan Ineson: If you're interested in diet and vitamins, we'll include a link in our follow-up email. We had a really interesting webinar just a couple of weeks ago with a lot of information about vitamins and how different supplementation can potentially

affect AMD. Is there anyone else who wanted to share what brought them here today? No? Okay, I'll move to the next question.

Learning About Your Diagnosis

Morgan Ineson: I'm curious how many people here were diagnosed within the last year. Raise your hand. A few. Maybe the last two to five years? And more than five years? Okay, so a range. Thinking back to when you first learned about your diagnosis, what was that experience like for you? What was going through your mind, and what questions did you have? Yes, in the back.

Audience Member: My mom had macular degeneration, so I knew what the symptoms were. When I was diagnosed, I was just hoping it wouldn't turn wet, because then I'd have to go for the needles, like she did. So far, it's still dry.

Morgan Ineson: Are there many people who have a family member who also had macular degeneration? Quite a few. So you were familiar with it ahead of time, and you knew what to look for and what to ask. Yes?

Audience Member: Not really. My father was in the United Kingdom, and he was 90 when he first developed macular degeneration. He was very cross, because he liked to watch the golf and football on television, and he couldn't see it. But the Royal Institute for the Blind were very, very good. They sent him a clock that he could touch to tell him what time it was, and CDs to play the football games and the golf games, and what he called the Mickey Mouse show, which was the Houses of Parliament.

Audience Member: So when I got it, it was a fait accompli. I only had it in one eye until I was about 70 or 71, and then I got it in my second eye. So I've had it for 20 years.

Morgan Ineson: Are you listening to CDs, or to audiobooks?

Audience Member: I have the Daisy player, and it's wonderful. I've had it for years. I had to change it last year, because CNIB switched to Wi-Fi, and my daughter set it up

for me. I haven't used the computer in years. I can't dial the telephone. There are lots of things I can't do, but I can still go out in my garden. You live with it.

Tools and Tips That Help

Morgan Ineson: I think that's a nice segue into my next question. You talked about the Daisy player and the things your dad had. There are high-tech and low-tech things. Our friends here from CNIB and Vision Loss Rehab, and Dr. Friesen in the back, have lots of examples on their tables today. What are some of the things you've found most helpful in your everyday life as your vision has changed? It could be something simple and non-tech, or it could be something technological. Yes.

Lighting

Audience Member: I'm a nurse, and I used to work in a nursery, and the fluorescent lights were terrible. I used to wear my dark glasses all the time because of them. In my home, I found the soft fluorescent lights, a very soft color, and that made such a difference to my eyes. If I could have done that in the nursery, I would have, but I didn't think I could.

Audience Member: Do you mean soft white lights, or soft yellow lights?

Audience Member: They're very soft. I went to a lighting store and said, "I need the softest light you can have that is not hard on the eyes," and I changed all the fixtures in my house because of that. You can't do that in a hospital, so we compensated by wearing dark glasses. I did that for a long time.

Audiobooks and technology

Morgan Ineson: Yes, the gentleman here.

Audience Member: Speaking for Lynn and me, thank goodness for our libraries, because we both have tablets, and Lynn is able to download the talking books and we

can take them with us. The only drawback is that I have to listen to her choices, but it really enhances the togetherness of occupying hours and hours of good time.

Morgan Ineson: Audiobooks are so good.

Audience Member: I have trouble seeing the TV now. [Unclear] I find it really hard to watch TV, so I like the books.

Audience Member: Anne and I were talking earlier. One of the things that makes a big difference for me is the zoom and magnification on phones and tablets. It has made prescription bottle labels and a whole bunch of other things much more manageable. Like many other people, I have this thing grafted to my body most of the time, so I have the capacity to overcome something that would otherwise be unreadable. Technology is huge, especially because we all carry these tiny computers around with us all the time.

Morgan Ineson: If you have a smartphone, there are so many features built into the phones now without extra apps, and there are so many apps that are really helpful too. I know Anne is nodding along. If you have questions about that, it's definitely something to ask Vision Loss Rehab about. Do you offer training for apps and things like that?

Vision Loss Rehabilitation Canada Representative: Absolutely. My partner and I in the low vision clinic can assist with that. And beyond that, if you're looking at VoiceOver and things of that nature, having a phone or tablet talk to you, we have assistive technology specialists who can provide training.

Morgan Ineson: That's great. That's another one of those things I always counsel people on: learn before you think you need it, because then when you need it, you have it. You're not trying to learn at that point. Any others? I'm going to go over here to the gentleman.

Audience Member: We have a first-generation iPad sitting there, not being used. It has a wonderful magnifier, and that's all we use it for. So if you have an old iPad lying around, it can be put to use.

Morgan Ineson: Absolutely, yes.

Small print

Audience Member: Even junk mail. Yesterday, a fast-food coupon flyer came, and I opened it up and couldn't read a thing, so they had a picture of the burger. The print on all of this stuff is so much smaller now, and I find it very frustrating that they're just not considering what's going on for people in the world.

Audience Member: Are you talking about your phone?

Audience Member: No, just the paper stuff, like coupons. Any kind of printing, they're making it smaller and smaller.

A tip from an optometrist

Morgan Ineson: Dr. Friesen, I'll put you on the spot. We don't have a lot of time, and I know you have so many cool things back there that people can come and see, but do you have one tip, or one thing you often recommend to people?

Dr. Selina Friesen: I don't have one go-to. Sorry. I think we're all sitting against a glare source right now, so glare, and how you modify your light. You mentioned lighting in your house. Where it's located and how well it's done makes a big difference to quality of life. Then it depends on whether someone is familiar with iPads and phones, or whether they need to go the more traditional magnification route. You also mentioned mobility, and going into crowds and feeling comfortable in crowds. So I look at what part of someone's quality of life is most stressful and keeping them back, and then start going in that direction and look at which tools would fit with the least adaptation. You're learning to use your new eyes and your new vision, so I try not to add too many new skills at once, because that can be overwhelming.

Closing Remarks

Morgan Ineson: Thank you so much to everyone who shared. I really appreciate you speaking up and sharing your tips and tricks with us. I want to end on time, because I know people have rides coming. Thank you so much for being here today.