AMD COFFEE CONNECTIONS – HALIFAX

Speakers: Dr. Anuradha Mishra; Morgan Ineson; Ushany Kanagendiran; Judy Carpenter; Pamela Grant

If you have questions about your diagnosis or would like support finding resources, please contact the Fighting Blindness Canada Health Information Line at healthinfo@fightingblindness.ca or by phone at 1.888.626.2995. Our team is available to help you navigate your condition, find relevant clinical trials, and connect you with trusted information and support.

Part One: Expert Discussion

Overview and Disclaimer

Morgan Ineson: Good morning, and welcome! Thank you all for joining us for Coffee Connections. My name is Morgan Ineson, and I'm the Senior Manager of Education and Engagement at Fighting Blindness Canada. Today's program will be in a few parts. We'll start with an overview of AMD and current research with our special guest Dr. Mishra, then open up for questions. After a short break, we'll hear from two community members, Judy and Pamela, about living with AMD.

Please note that the views shared by our speakers are their own and don't necessarily reflect those of Fighting Blindness Canada. Mention of any products, treatments, or services does not constitute endorsement, and today's discussion is for educational purposes and should not replace advice from your own healthcare provider.

Dr. Mishra is an ophthalmologist who specializes in vision rehabilitation and is an Associate Professor at Dalhousie University. Her work focuses on accessibility and breaking down healthcare barriers for people with vision loss, and she's received several awards for her contributions to medical education and the vision loss community. Welcome, Dr. Mishra.

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What Is AMD? Dry vs. Wet

Morgan Ineson: If we can start out really basic — what is age-related macular degeneration?

Dr. Mishra: Think of the eyeball like an old-fashioned camera: light comes in the front and gets focused by the lens. That focused image should land on your retina, which is like the film of a camera, converting light into an electrical signal sent to the brain and processed as vision.

A really important part of that “film,” in the very center of the back of the eye, is called the macula. It does a lot of what we think about with vision — color vision, reading, looking at faces, contrast sensitivity, distinguishing shades of light and dark. A very common disease affecting that area — probably the leading cause of blindness in North America — is age-related macular degeneration or AMD.

Converting light into an electrical signal uses a lot of energy and creates waste byproducts, which normally get flushed out from the back of the eye. In some people, that removal system doesn't work as well as it should, and you start to get collections of a fatty, protein-like deposit called drusen. When I look in the back of the eye of someone with macular degeneration, I see these little yellowish spots — that's drusen.

Having a few drusen is normal as we age. But when there are a lot of them, that's what we call dry age-related macular degeneration. Sometimes so many occur that a portion of the tissue actually dies off — that's called geographic atrophy, because it looks like a little irregular patch of missing tissue. That's dry AMD.

Morgan Ineson: And with wet AMD, the difference is that there's leaking — more blood vessels grow in the back of the eye, and they leak blood and fluid, which is what causes vision loss.

Dr. Mishra: Exactly. The body is trying to be helpful because it senses things aren't working as well, so it turns up a protein called vascular endothelial growth factor, or VEGF. It's actually a little too helpful — it signals the body to bring more blood, which brings oxygen and nutrition. New blood vessels are stimulated to grow, but they aren't very robust; they're leaky. Blood and fluid build up in the back of the eye, the retina

tissue gets distorted, and if it isn't identified and treated, it can scar and cause permanent vision loss.

Treatments for Wet AMD

Morgan Ineson: Building on what Dr. Mishra said — the main treatment for wet AMD is a medication injected directly into the eye, called an anti-VEGF drug. These drugs help control the leakage and growth of those vessels, with the goal of preventing further vision loss. Some people even experience improved vision after these injections.

We get a lot of questions about how often injections are needed — that's an individual decision based on your condition. They're usually given at a regular interval, often starting monthly, and your retina specialist will monitor how your eye responds. If the AMD remains stable, the interval may be extended to five or six weeks; if it's still progressing, injections may need to be more frequent. This can change over time, which is why it's important to keep your ophthalmology appointments.

There are several types of anti-VEGF medication — you may have heard names like Vabysmo, Eylea, or Lucentis. They work in similar ways, but everyone's body responds differently, so you may need to try more than one. Drug coverage also varies by province.

Dry AMD: Where Treatment Stands

Morgan Ineson: Dry AMD is more complicated. It tends to progress more slowly as drusen accumulate. There is currently no treatment for dry AMD itself, though some vitamins can help slow progression for some people — Dr. Mishra will speak to that shortly. For the more severe form called geographic atrophy, there's active research underway, and a couple of treatments have been approved in the U.S. to slow, not reverse, vision loss. These aren't yet approved in Canada; one is currently going through Health Canada's review process.

Nutrition and AREDS2 Vitamins

Morgan Ineson: Dr. Mishra, could you talk more about the vitamins? We received a lot of questions about nutrition and how it impacts AMD.

Dr. Mishra: One risk factor for macular degeneration is a diet high in saturated fat — more processed foods. There's been quite a bit of research on the benefits of a healthy diet, and the general recommendation is a Mediterranean-style diet: omega-3s, fatty fish, leafy greens, and colorful fruits and vegetables.

On vitamins — there are a lot of options at the drugstore, so it's important to know what's right for you. A landmark randomized controlled trial was conducted years ago at the National Eye Institute in the U.S. It found that if you have intermediate-stage dry macular degeneration, there's some benefit to slowing progression to the advanced dry form or to wet AMD. If you have early macular degeneration, it didn't make a difference — so it's worth asking your eye care provider whether you're actually in the category that would benefit.

The formulation studied is called AREDS2. If you pick up a bottle, look for that specific name — there are other formulations with added ingredients, but we don't know if those combinations provide additional benefit. There are different brands; if one is hard on your stomach, it's worth trying another. If you have wet macular degeneration in both eyes, you likely don't need the vitamin at that stage. About 80% of people have dry macular degeneration, and roughly 10 to 20% of those will go on to convert to wet.

Emerging Research

Morgan Ineson: One question we get a lot is about what's coming — what's being researched, and what could be possible in the future. There are several promising areas, though these aren't approved treatments yet. For wet AMD, since we already have effective but frequent injections, researchers are looking at ways to extend the time between treatments — new molecules that last longer, or delivery systems like a port that's implanted in the eye and periodically refilled, slowly releasing medication over time.

Another area is gene therapy. While it's probably better known for inherited retinal diseases, it can also be used to deliver other things to cells. For wet AMD, researchers are looking at using gene therapy so the eye makes its own anti-VEGF medication — a single treatment that turns the eye into a small factory producing that medication, reducing the need for constant injections.

For dry AMD, the focus has mostly been on geographic atrophy. New medications target part of the immune system called the complement system, potentially slowing the growth of damaged areas, though they don't restore lost vision. You may have also heard of cell-based or stem cell therapy, used for people with more advanced vision loss, aiming to support or replace damaged retinal cells. Overall, research is moving toward treatments that last longer and can intervene earlier. Most of these approaches are currently in clinical trials.

Protecting the Vision You Have

Morgan Ineson: People often ask what they can do to protect or preserve the vision they have now. One of the most important things is to keep attending regular eye doctor appointments and follow your treatment plan. People with AMD are also often asked to monitor their vision at home using an Amsler grid — we have some on our resource table. You look at the center of the grid with one eye at a time, and if you notice distortions, wiggling lines, or blurriness, that may indicate a change and you should see your eye doctor right away.

Other steps include not smoking — a major concern for people with AMD — along with maintaining physical activity, eating a balanced diet, and managing conditions like blood pressure or diabetes. Sunglasses and hats help keep sun out of your eyes. None of these steps can guarantee AMD won't progress, but they do support your overall eye health. And if AMD starts affecting your daily life, that's where vision loss rehabilitation can help you make the most of the vision you have.

Vision Rehabilitation

Dr. Mishra: Vision rehabilitation is, in a way, exactly what it sounds like — we can't always get back vision or visual field that's missing, but the goal is to maximize the vision you do have. We try to get a good sense of you as a person: your day-to-day life,

what you're finding challenging, and what workarounds might help. Everyone gets a custom plan, since everyone's needs and vision are different.

A great place to start is Vision Loss Rehabilitation Canada — you can self-refer, or your family doctor or eye doctor can refer you. Broadly, the tools that often help people with macular degeneration include magnification — a simple magnifying glass, higher-strength reading glasses, or digital magnification, which has improved a lot with technology.

Contrast sensitivity is often reduced in macular degeneration, so working with your environment to maximize light can help. Specialists can even visit a home or care facility to help make sure the environment is safe. Medication management is another area, especially as people take more medications as they age. It really comes down to understanding your goals and needs, and figuring out the best way to help you overcome the challenges that come with limited vision.

Common Everyday Challenges

Morgan Ineson: What are some everyday challenges you commonly see in people living with AMD?

Dr. Mishra: The number one reason people seek vision rehabilitation is trouble reading, since the macula is so important for that task. Magnification is often a good place to start. Many people wear bifocals or progressives, but the magnification in the near portion usually isn't enough for comfortable reading. Drugstores often only carry reading glasses up to about +3.75 strength; higher-strength options are available at specialty stores like the CNIB store, online, or through your optometrist.

A handheld magnifier is another option, and there are also many digital tools — taking a photo with your smartphone and zooming in, or using a digital magnifier, which offers a wider range of magnification. One thing to keep in mind: the stronger the magnification, the smaller your field of view. Digital magnification often helps overcome that limitation.

Glare is another common complaint, related to changes in contrast sensitivity. A light yellow tint on glasses can help reduce glare from fluorescent lighting, and wraparound sunglasses help protect against light from all directions outdoors. If magnification alone

isn't enough for comfortable reading, audio is another great option — local libraries often have excellent audiobook selections, and there are apps with optical character recognition that can read printed mail aloud.

Q&A: Family History and Genetic Risk

Audience member: My main concern is macular degeneration — I have it throughout my family. I'm wondering about hereditary factors, and whether I might one day be affected.

Dr. Mishra: Yes, genetic factors do play a role, and a positive family history is a risk factor for developing the condition, though it doesn't necessarily mean you will. Other risk factors include smoking, a diet high in saturated fat, age over 60, and high blood pressure. The more risk factors you have, the more likely, cumulatively, that you might develop the condition, so it's worth focusing on managing the ones you can control. There's a lot of work happening around the genetics of macular degeneration, including gene therapy. We don't routinely offer genetic testing for this right now, but that's likely coming.

Morgan Ineson: We get this question about genetic testing for AMD often, and the recommendation right now is not to pursue it, since the information wouldn't necessarily change the outcome. If AMD runs in your family, the best thing to do is maintain regular checkups so any problem is identified as early as possible.

Q&A: UV Exposure and Sunglasses

Audience member: I'm also wondering about environmental factors, like UV exposure.

Dr. Mishra: UV radiation is a risk factor, which is why sunglasses are recommended for everyone. Look for something that blocks UVA and UVB, has a dark tint, and offers wraparound coverage to block as much light as possible from the sides.

Q&A: AREDS2 Side Effects and Zinc

Audience member: My question is about side effects of AREDS2 — my husband and I are both on it, and it really does upset the stomach, which makes it hard to stay compliant. There's also the issue of interactions with other medications.

Dr. Mishra: That's a really good question, and I do hear it from patients. Usually, as a first step, we'll suggest trying a different brand — some people find one tends to be easier to tolerate. It's also worth confirming with your ophthalmologist that you're actually in the category that benefits from the vitamin. If it's making your day-to-day life uncomfortable, focusing on blood pressure control and a healthy diet may offer comparable value without the side effects.

Audience member: Is there a big difference between AREDS2, which has zinc, and other formulations that don't include zinc?

Dr. Mishra: All we can really say is that the AREDS2 formula specifically was the one studied and shown to have benefit. Most of us defer back to that formulation, since it's the one with evidence behind it. That said, we also know a diet rich in those same nutrients is helpful too.

Morgan Ineson: A quick plug while we're on the topic of nutrition — our upcoming October webinar will feature a nutritionist from Tufts University who focuses specifically on nutrition and AMD. You can sign up on our website.

Dr. Mishra: I'll also mention an app called Yuka — a free app that lets you scan a product's barcode and gives it a nutritional score. It can be a really eye-opening way to look at what you're buying.

Q&A: Other Eye Conditions and AMD Risk

Audience member: If somebody has other issues with their eyes — does that make them more likely to experience AMD?

Dr. Mishra: Conditions like high myopia, being very farsighted, or having had eye injuries — to diagnose age-related macular degeneration specifically, you need certain features, particularly the presence of drusen. But it is possible to have other forms of macular degeneration from other conditions — for example, myopic macular degeneration in people who are very nearsighted. It is possible to have two conditions at once, and having one likely does make you somewhat more likely to develop a second, since the tissue is already under stress.

Q&A: Ophthalmologists vs. Optometrists

Audience member: You've mentioned both ophthalmologists and optometrists — which do you recommend?

Dr. Mishra: We really work as a team. Optometry is, in a way, like the family doctor of the eye — usually the first step, seen on a one- or two-year basis for a checkup and screening. If they diagnose macular degeneration, some feel comfortable monitoring it themselves until treatment is needed, while others refer to an ophthalmologist sooner. It's not one or the other; it's a team approach. In Nova Scotia, only certain approved ophthalmologists can provide anti-VEGF injection treatment for wet macular degeneration.

Audience member: My wife goes to an optometrist and was told to come twice a year. Is that necessary?

Dr. Mishra: The optometrist visit itself is typically paid out of pocket, while the ophthalmologist visit is covered by your provincial healthcare plan. In Nova Scotia, MSI covers a certain number of optometry visits, and conditions like diabetes, glaucoma, and macular degeneration are generally included on that list, though additional testing like an OCT scan or retinal photography may come with a separate fee. Without seeing her myself I can't say for certain, but if someone is in the intermediate or advanced stage, twice a year isn't unreasonable at all — one eye can convert to wet macular degeneration without a person immediately realizing it, since the other eye compensates. That's why the Amsler grid is so useful.

Q&A: MacuMira — Does It Work?

Audience member: My wife recently had treatments called MacuMira, a new treatment for dry macular degeneration. What's your opinion of that procedure?

Dr. Mishra: For those unfamiliar, this is a proprietary technology using micro-pulsed electrical stimulation in the macula. It's very new, and not something I've personally used or recommended to patients. The Canadian Ophthalmological Society and the Canadian Retina Society recently put out a joint position statement on it, saying there isn't yet enough evidence to know whether there's a sustained benefit or what the long-term effects might be. As of the statement, there had only been one study, funded by the company itself, involving about 19 patients — a small number compared to studies like the AREDS trial, which involved thousands. That study did show a small benefit, but the two organizations feel the evidence isn't strong enough yet to generally recommend it, and there is a cost involved.

Morgan Ineson: I'd add that it is approved for use in Canada, but as a device or technology rather than a drug, which goes through a less stringent approval process than medications. There just isn't enough evidence yet, from a large enough sample, to know how effective it really is or whether the effect lasts.

Audience member: My wife has undergone four treatments and was recommended three more, but hasn't really noticed a difference. Should she continue, or is it not worth it? I think a lot of people go in expecting something closer to a cure, and it's clearly stated that it isn't one — more of a prolonging effect.

Morgan Ineson: That's a really good point about expectations. I've talked to others who've had this treatment, and I think sometimes expectations aren't set correctly going in. I can't recommend what she should do — that's a personal decision, especially with the cost involved.

Dr. Mishra: It really depends on how you're both feeling about it so far. With an anti-VEGF injection, you'd typically see a benefit after one or two doses. Four treatments with no noticeable change is a fair trial — it might be worth weighing the additional time, cost, and potential disappointment against continuing.

Morgan Ineson: More broadly, the drugs being developed right now for dry AMD aren't restoring vision — unlike anti-VEGF treatments for wet AMD, where many people do get some vision back along with slowed progression. Setting expectations correctly before starting any of these treatments is really important.

Audience member: One more question — our eye doctor said these newer dry AMD treatments aren't happening here and doesn't expect it anytime soon. Why would there be such a difference of opinion?

Morgan Ineson: Drug approval processes typically go through the U.S. first, given its larger population, then Europe, then Canada. For these particular dry AMD drugs, the challenge is that they're not actually improving vision — they're claimed to slow the rate of decline. Of the two drugs approved in the U.S., neither is approved in Europe yet; one was declined by Health Canada, and the other is still under review. Some people do travel to the U.S. for these treatments and pay out of pocket, which is very expensive.

Dr. Mishra: It comes down to two different healthcare systems. In Canada, care is largely publicly funded, and Health Canada's approval process tends to be more stringent than the FDA's.

Morgan Ineson: And even once a drug is approved by Health Canada, each province then has to decide whether and how much to pay for it. Part of Fighting Blindness Canada's advocacy work is providing patient perspective during that process to help regulators and provinces understand what a treatment means for patients, even when it isn't restoring vision.

Closing — Expert Session

Morgan Ineson: Thank you so much to Dr. Mishra for joining us and for answering all of your questions.

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Part Two: Lived Experience

Introductions

Ushany Kanagendiran: Welcome back. My name is Ushany, and I'm the Senior Coordinator of Education and Engagement. I have two special guests here today — Judy Carpenter and Pamela Grant — who are going to share a little about their experience living with AMD.

Judy is a retired nurse who spent more than 30 years working in her ophthalmologist husband's office. Now living in Halifax, she enjoys knitting, sewing, swimming, and volunteering. Diagnosed with AMD in one eye, she brings both professional knowledge and personal experience of vision loss.

Pamela is a retired childhood educator who lives in Bedford, Nova Scotia. A mother of two and grandmother of three, she enjoys gardening, painting, and spending time with family and friends. Thank you both for being here.

Ushany Kanagendiran: I'd love to hear more from each of you — a little about yourself, and when you were first diagnosed with AMD.

Judy's Story

Judy Carpenter: My husband is an ophthalmologist, and one day I noticed a bump in the handle of a kitchen drawer that hadn't been there before. He had me look at a door frame and describe what I saw — the top of the frame appeared crooked. He happened to have one Amsler grid left in his drawer, which he kept as a souvenir, and from there things moved quickly. This was around two years ago. A colleague referred us to a specialist, and I had my first injection that same day. It was disconcerting, to say the least — the injection itself isn't nearly as bad as you'd expect, but the dilating drops are something else, and I now have a whole new respect for needing a driver afterward.

I've been fortunate, since I only have macular degeneration in my left eye, and it's not central — it's more to the side — so my good eye tends to compensate, and it hasn't caused a great deal of change yet. I've stabilized with the injections, and my vision is

around 20/25 to 20/30 in that eye. What I do notice is that I fight with my bifocals more, so for reading or handiwork like knitting or sewing, I've found that simple over-the-counter reading glasses actually give me a sharper image than my regular bifocals.

My personal way of tracking progress was to open only my left eye in the morning and look at the ceiling — I'd see various blob shapes where my vision was affected, and over time those shapes got smaller. My doctor is pleased with my progress; I had an injection at the end of August and go for another in mid-December. My most disconcerting part of the process is really just the dilating drops and the few hours of blurry vision afterward.

Pamela's Story

Pamela Grant: I was diagnosed in Ottawa in December 2021, just a few days before I moved to Nova Scotia. I was in shock — I thought I had great eyes. My doctor was very good; she told me about the Amsler grid and gave me a copy, which I posted on my door, and it's still there. She also talked to me about diet — the Mediterranean diet, leafy greens, and mango for helping the body process toxins. When I got to Nova Scotia, I made mango-spinach smoothies faithfully for about six months, though I eventually stopped.

She also had me start taking AREDS2 vitamins, and I've been taking those ever since. One day I noticed straight lines starting to bend, which is frustrating and also makes me a bit dizzy. Nighttime driving has become very difficult for me, so I've had to give that up.

After my diagnosis in Ottawa, I let things slide until 2024, when I finally saw an eye doctor here in Bedford. He reassured me it wasn't something I needed to worry about right now. I also have dry eyes, and some light sensitivity — I see a dark spot in my vision at night, and floaters during the day. My mother also had macular degeneration, diagnosed in her late eighties. Out of fifteen children in my family, I'm the only one who's developed it so far.

Pamela Grant: For a long time, I had my head in the sand and didn't really pay attention to my diagnosis. Being here today, getting factual information rather than

something I might find on the internet, has been a good step for me. I'm starting to take it more seriously now, since my vision is changing.

Tools and Adaptations

Ushany Kanagendiran: What are some tools, technologies, or adaptations that have made the biggest difference in your daily life?

Pamela Grant: For me, it's being able to use a computer and my phone — it's really important for doing research and using technology built into your home. I take a picture of things I'm unsure about, like a spot on the ceiling, to check whether it's actually there or just a visual artifact. That's really helped with reading, though unfortunately it hasn't helped with knitting — I can't knit anymore, I can't drive anymore, and I don't cook very much anymore. It's had a real impact, but you have to live with it. I use an e-reader and read a lot, since that's been important to me with everything else I've had to give up. I've completely lost vision in one eye, though the other still works to some degree.

Judy Carpenter: What you're saying is important. Having worked in my husband's office for over 30 years, when I was first diagnosed, my instinct was to worry about not being able to knit, sew, or quilt anymore. Fortunately, getting into treatment right away and starting injections early has meant I've leveled off, and I'm very grateful for that. I'd also stress how important it is to arrange a driver for appointments, since even with one eye dilated, you're not safe to drive.

Morgan Ineson: This is such an important conversation. There are often alternatives — I actually learned to knit to help facilitate a blind knitting group, and the people in that group, who were completely blind, were still knitting. Vision Loss Rehabilitation Canada can help with tools like that. There's also a helpful, low-tech tool — a headlamp — that can make a big difference for close-up work like sewing or knitting.

Audience member: You can find those at Princess Auto or Canadian Tire. Ask for one with a halogen bulb — you can dial up the brightness until it's strong enough to read by.

Morgan Ineson: Something else I share with people often is to learn the skills before you need them. If reading is becoming difficult, it might be worth learning how to access

audiobooks through the library, or how to use magnifier apps, before you actually need them, so you're already comfortable with the tools when the time comes.

Support Systems

Ushany Kanagendiran: What role has your support system — family, friends, or community — played in helping you manage AMD?

Pamela Grant: Honestly, my family doesn't really know much about it, since this is all fairly new for me — mostly they just know I can't drive at night anymore. I also had to stop painting, which is a real passion of mine, because I can't see well enough to do it anymore.

Judy Carpenter: I think I have the best support system in the world, having a professional living with me — though even so, we've had to sit down and talk through what steps we'd take at different stages. My husband also has dry macular degeneration and doesn't like driving at night anymore, which is actually pretty common as we get older regardless of vision. My advice is to talk to your family and make them aware of the potential for things to change, even if you're not experiencing much difficulty yet.

Pamela Grant: That reminds me — I just received a driver's license renewal that asks questions about your health and eye health, and I'm honestly not sure how to answer it.

Judy Carpenter: You can actually drive legally with one eye, as long as your vision meets a certain standard — it's worth talking to your doctor about their opinion on where you stand.

Advice for the Newly Diagnosed

Ushany Kanagendiran: What advice would you give to someone who's newly diagnosed, or feeling a bit overwhelmed?

Judy Carpenter: For me, the big thing is to educate yourself. It's not uncommon to want to avoid it at first, but eventually it helps to look at a couple of reputable sites — that's actually how I found Fighting Blindness Canada. Educating yourself means you

know what questions to ask your physician, since it's easy to walk out of an appointment and realize afterward you forgot to ask something.

Pamela Grant: Get to a doctor and get help, and find out the likely progression of your condition. I use humor to get through it. But I do agree with Judy — you need to do your research and actually listen to what you're learning, rather than ignoring it the way I did at first.

Ushany Kanagendiran: Before we move to closing remarks, I want to mention that Fighting Blindness Canada has a Health Information Line — you can call or email, and we have professionals who can help find answers to your questions. We have cards with that information at our FBC table.

Closing

Morgan Ineson: Thank you, Ushany — and thank you so much to Judy and Pamela for sharing today. Our volunteers will be bringing around surveys, and we'd love your feedback on what worked and what didn't. We'll send an electronic version by email after the event, along with a transcript of today's session, information about our upcoming October webinar, and other resources.

There are lots of ways to stay involved with Fighting Blindness Canada — volunteering at events or sharing your story with our community. We also run webinars throughout the year, and information on all of our programs, including Move for Sight next June, is available on our website. Fighting Blindness Canada is a 100% donor-funded organization, so if you have the interest and ability, we'd always welcome support. And if you do nothing else after today, I hope you'll consider signing up for our e-newsletter at fightingblindness.ca. Thank you all for being here.

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