Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about The Michael J. Fox Foundation's work and how you can help speed a cure at michaeljfox.org.

Intro: You're listening to audio from one of our Third Thursdays Webinars on Parkinson's research. In these webinars, expert panelists and people with Parkinson's discuss aspects of the disease and the Foundation's work to speed medical breakthroughs. Learn more about the Third Thursdays Webinars at michaeljfox.org/webinars. Thanks for listening.

Dr. Karen Jaffe: Thank you everyone for joining us. I'm Dr. Karen Jaffe, your moderator for today. I was diagnosed with Parkinson's disease (PD) in 2008 and have since retired from my OB-GYN practice. I'm a member of The Michael J. Fox Foundation Patient Council and I'm also a co-founder of InMotion, an amazing wellness center for Parkinson's patients right here in beautiful Cleveland, Ohio.

Today our panelists are going to discuss a topic that is not frequently recognized as being part of Parkinson's disease, and that is problems that include the eyes and the visual system. We'll begin with a review of what vision changes and eye issues are known to be due to the normal aging process. This will allow us to then give focus on the topic of this webinar where we'll talk about what vision change and eye changes might occur with Parkinson's disease and the impact of those changes. We'll also cover how scientists are looking into the eyes to learn more about Parkinson's disease.

Let's meet our panelists. Joining us from Cleveland, Ohio is John Merchant. John was diagnosed just nine months ago and is an active participant at InMotion. Thanks for being here, John.

John Merchant: Thanks for asking me.

Dr. Karen Jaffe: Great. Dr. Marta Fabrykowski is an optometrist at Manhattan Eye, Ear & Throat Hospital in New York City. Thanks for joining us Marta.

Dr. Marta Fabrykowski: Thank you.

Dr. Karen Jaffe: Also with us today is Dr. Ali Hamedani. He is an instructor in the Division of Neuro-Ophthalmology at the University of Pennsylvania, Philadelphia. Glad you're with us, Ali.

Dr. Ali Hamedani: My pleasure.

Dr. Karen Jaffe: So I think it comes as no surprise to any of us today that visual problems are a common part of aging. As we get older, several diseases of the eyes can occur regardless of whether you have Parkinson's disease. So at age 60 I can certainly attest to this as my vision isn't what it used to be. Dr. Fabrykowski, this first
slide, while not an exhaustive list, must be some of the more common problems you see develop as your patients get older.

Dr. Marta Fabrykowski: Certainly. So, yeah, vision changes happen through life from when we're small to after 40 when we lose the ability to read over time. The average onset of Parkinson's is sort of in the '60s or early 60 and the average age of visual sort of difficulty from cataracts is also 60. Macular degeneration is 65, and glaucoma is roughly 60. So a lot of these things that we see, including dry eye and irritation, and things like that really happen both with aging, so for anyone tuning in who's a caretaker or who doesn't have PD, you may say, "Well, I think I may have some of these, too." It's quite common. We're sort of all in good company in having some of these. Some can be accelerated or they can be sort of worsened by PD but by and large these are quite common in normal aging.

Dr. Karen Jaffe: That's a great review and important for us to have that overview and I'm sure that having this info upfront has already answered some of the questions our listeners have had about having these problems and wondering if any of them are due to or affected by Parkinson's disease. It's interesting to note that they are on the same timeline as getting diagnosed as age 60 is pretty common for Parkinson's disease and if these things are happening at the same time it would seem obvious that people would wonder whether this was from their Parkinson's disease or not.

Let's go on. So this next slide shifts the focus, sorry, no pun intended there, to the many vision changes that can happen with Parkinson's disease. John, let's bring you into this conversation. You were diagnosed with Parkinson's disease less than a year ago but have already had some trouble. Please share with our audience the vision challenges that brought you to see your ophthalmologist.

John Merchant: Well, just like most others, I put off seeing the neurologist on this because I had tremors in 2015 but I also had problems with my back. I had fusion of my back in 2017 and I put off having everything looked at. Once I found out all the problems on my back were behind me or I'll put it this way, what could be done with it, then I mentioned to my doctor, "Okay, now let's look at the tremor part." And so he did, and I found out it was Parkinson's, and I also noticed that over the years I had more pressure in my eyes and everything. So I went to the ophthalmologist this past March and he told me that everything was okay except I had dry eyes now. And so he put me on eye drops every day and it's made a difference in it too, but I'm also 74 years old so that could be a difference, too.

Dr. Karen Jaffe: Yeah. Dr. Fabrykowski, in a Parkinson's patient, is there a specific cause for the dry eye related to the disease itself and is that different from what we see in an aging patient who doesn't have Parkinson's disease?

Dr. Marta Fabrykowski: Certainly. The answer is yes and no. So dry eye comes from a lot of things. It comes from hormonal changes, it comes from our lids not meeting and not blinking as well together, it comes from the lids not sticking to the eyes as much,
it comes from low tear production, and all kinds of glands around our eyes that sort of with normal aging just don't work as well. In PD what we see is people aren't blinking sort of as often. So if the average person in their '60s, '70s, something like that blinks about 16 to 18 times a minute sometimes in PD people are blinking 11 times a minute and every day you blink you lubricate the eyes. So sometimes less blinking in a patient with PD can cause exacerbated dryness. Sometimes it's a tear film quality where the tears have multiple layers. They're not just like a drop of water and certain layers can be sort of dried out quicker than others which in PD can bother the vision a little bit more. So sometimes we can attribute some acceleration of it to PD.

Dr. Karen Jaffe: Are there any special eye drops or ointments that people should be using or is this over the counter?

Dr. Marta Fabrykowski: So yes to both. There are over the counter eye drops that can be used. Now, artificial tears come in different formulations. Some are quite watery, some are more gelatinous, some are ointments, some come with preservatives, some come without. So some should be used many times a day, some should be used less often, some just before bed. So there are lots of over the counter options sort of best advised by seeing an optometrist or ophthalmologist and there are actually also prescription drops for dryness which work in some people and not for others and they're indicated for some people and not for others. So, if you look up treatment for dry eye there are dozens and dozens of treatments but which sort of specific treatment relates best to you would come out in a basic exam.

Dr. Karen Jaffe: Who knew there were so many options for eye drops. We have a question from one of our listeners who asks, "Can you safely wear contact lenses if you have dry eyes from Parkinson's?"

Dr. Marta Fabrykowski: So yes and no. Whether you have Parkinson's or not, with dry eye and contact lenses it just takes figuring out the right algorithm for you. So contact lenses naturally soak up tears. So if your eyes are naturally dry and you're wearing a contact lens that can sometimes make it worse, however, that depends on the kind of contact you're using. A one-day lens you put in the eye in the morning, throw away at night, absorbs less tears than a one-month lens. There's different coatings, and different plastics, and different eye drops you can use with or without the contacts. So, there are many ways to have both dry eye and wear contact lenses successfully. It just takes some time to figure out sort of what's best for you, which again would sort of come out in an exam and they'd look at the contacts, they'd look at the drops you're using, look at your dryness and sort of put it all together and what's best for you.

Dr. Karen Jaffe: Great, so Dr. Hamedani, we know that Parkinson's can affect general mobility but can it also impair movement of the eyes?

Dr. Ali Hamedani: Yes it can and it does so in a couple of different ways. The first is that when you want to look quickly from one target to another your eyes have to move very
quickly. That movement can become a little bit slowed in Parkinson's disease, although not that much. We also know that that movement from one target to another may not be as accurate as someone without PD and that's not something that you would necessarily notice directly but comes out in different ways. So for example, reading requires moving your eyes quickly from one word to another, to another, and to another, and people with PD might find that that takes a little bit longer to do because it takes just a split second longer to find the word that you have to go to next. So reading time or kind of the complaint that it takes longer to read than it used to, that is quite common in PD.

Even if the eyes are moving normally they can be misaligned or pointed in two slightly different directions in PD and that causes double vision. So when I say double vision what I mean is seeing two of the same thing, looking at a letter or word and seeing two of them instead of one. And specifically double vision from Parkinson's disease and from any other neurologic disease is double vision that's present only with both eyes open. So you see double but you cover one eye and then the double goes away, or you cover the other eye and the double also goes away but it's only with both eyes that the double vision is present. That's the kind of double vision that I'm talking about.

In PD we think that that happens because of two different reasons. The first is that there are parts of your brain that are responsible for holding the eyes together, and the reason that people without PD or most other people do not see double is because they have two eyes but they're pointed at the same thing and if they're exactly pointed at the same thing then you won't see double but if one is pointed at one thing and the other is pointed a little bit off to the side those two eyes will be seeing two slightly different things and that will register to you as double vision. And so in Parkinson's disease the parts of the brain that are responsible for holding the eyes together may become affected and that can cause them to be pointed in two slightly different directions and to give you double vision.

In addition, it turns out that a lot of people without PD or otherwise healthy people have a little bit of misalignment of the eyes but they don't have double vision because there are other parts of their brain that adjust for that, that kind of fuse the images together and those parts of the brain can become affected in PD. So it's a little unclear whether double vision is sort of a direct eye orientation problem in PD or if it's more kind of putting those two images together. But fortunately double vision in PD, which is actually quite common, a lot more common than people think, it can be up to 20% of patients, are easily treated with a special type of glasses called prisms. These are glasses that basically adjust the image that one eye sees, kind of brings it over so that you don't see double anymore.

Dr. Karen Jaffe: We have a question from one our listeners. If you fix double vision with prism glasses will it get worse and you'll need to modulate the glasses again?
Dr. Ali Hamedani: That's a great question. So double vision from Parkinson's disease is quite amenable to prisms. Any kind of double vision like this can worsen a little bit over time and so periodically an adjustment of prisms may be required, but using prisms does not accelerate that process. It doesn't make things worse, or it doesn't kind of weaken your eyes, or anything like that. If you do get prisms you might find that once you take them off you'll notice the double vision again pretty quickly but then you might adjust to it afterwards. So in other words, using prisms may... like if you start to use prisms you'll notice the double vision once you take them off but the underlying process, the misalignment of the eyes, that doesn't get worse if you use prisms compared to if you don't.

Dr. Karen Jaffe: And are there any eye exercises that people can do besides wearing special glasses that they can do to help this?

Dr. Ali Hamedani: Yeah, so there are a variety of eye exercises that have been offered over the years. Most of them have not been systematically studied in clinical trials the way that, for example, Parkinson's medications have, though it is difficult to tell whether they actually work or not and if they do whether that applies to PD as well as non-PD patients.

Dr. Ali Hamedani: There's one type of eye exercise that can be helpful and has been shown to be helpful but it's only for a specific type of double vision and that type of double vision is called convergence insufficiency. Basically you know that you have that if you have double vision only when you read or only when looking at things up close but not when looking at a distance or looking further away. That type of double vision is amenable to a specific type of eye muscle exercise that are kind of colloquially called pencil push ups. Basically what it consists of is holding a pencil or pen in front of you and bringing it close towards your nose and trying to kind of follow it in. There are eye doctors you can see to help you through these exercises and also a variety of online resources. But again, that's only for a very specific type of double vision, not for all double vision.

Dr. Karen Jaffe: Okay. Doctor Fabrykowski, I'm curious about the loss of dopamine on our ability to distinguish colors as listed here. Is this the sort of color blindness that Parkinson's people develop?

Dr. Marta Fabrykowski: So color blindness or like we call it, color deficiency or color weak is sort of a different process. That is something... To be color blind or to be color weak is something you're typically born with. It's typically in both eyes and sort of related to genetics. In terms of colors through life changing part of it can be loss of dopamine in the retina where people notice less contrast too, so that is black on white or gray on gray. So some people notice they have to increase the contrast on an iPad or on a Kindle or on a computer. And sometimes colors can become sort of dimmer is how people describe it.

Dr. Marta Fabrykowski: Now, that also happens with the general sort of slow development of cataracts. Even if you don't have PD and you don't have a loss of dopamine colors can seem a little more washed out and I'm sure some of the listeners here can think
of someone who has had cataract surgery who said, "Wow, the colors are so much brighter," afterwards. So it can be from changes in dopamine in the retina but it can also be through sort of normal cataract growth and sort of color change inside the eye.

Dr. Karen Jaffe: If it’s not due to cataracts do you think... You may not know the answer to this question but do you think that it can affect a Parkinson's patient's ability to how they perform on cognitive tests that require color delineation or recognition?

Dr. Marta Fabrykowski: I mean, potentially. You know, people describe... If you look at pictures sort of people explain that their color has changed. Things do look dimmer. So a green is maybe not as bright green, or a blue is not as bright blue, or a red is not a bright red. So there could be some difficulty with color discrimination and they do have quite lengthy color vision tests where you organize these little caps of colors. There's many, many, many of them. It has been noticed that people with PD sometimes don’t put the caps in the right order when they go from yellow to red to green to blue to purple, you know. So it has been noticed that people have some difficulty with it but in terms of actual life function, I mean, red is still red and green is still green. It's not sort of a total loss. It's just sort of a dimming.

Dr. Karen Jaffe: Right. So John, I’m wondering when you went to your ophthalmologist or your sort of specialist, did they attribute your dry eye problem to aging or to your Parkinson's disease?

John Merchant: He only mentioned Parkinson's, on how people with it do not blink as much and I've actually noticed myself staring more often at things, especially while I’m driving. I've noticed that I will blink more now on purpose than I was before. But as far as the colors and everything I haven't noticed anything changing so far. Hopefully it doesn't.

Dr. Karen Jaffe: Okay. So this slide reminds us that even our eyelids are controlled by muscles that can be affected by Parkinson's. Dr. Hamedani, can you help us to understand what these conditions mean and how effective are available treatments for them?

Dr. Ali Hamedani: Sure. So the first one here, which I think we've already kind of talked about, is decreased spontaneous blinking in PD and that has to do with the parts of the brain that are responsible for telling your eyelids how often to blink. You know, when you think about it we don't really think consciously every time we blink. It's kind of an automatic function, but the rate at which we do that is determined by a number of things including certain parts of the brain that kind of act like a pacemaker for your eyelids if you will. And as Dr. Fabrykowski already discussed artificial tears and other types of eye drops can help lubricate the eye if your eyelids aren't blinking enough.

As an aside, John mentioned consciously blinking more often and that's great when you can do it but I find it's actually kind of hard to do that. We have so
much going on during our day as it is it's kind of hard to remind yourself every few seconds or few minutes to blink. An alternative thing you might think about doing is that it's actually been shown that in Parkinson's you blink more when you're doing something active like reading, or playing a game, or other kind of complex activities like that. That's actually in contrast to people without PD who blink-

Activities like that. That's actually in contrast to people without PD who blink less when they do those things. So what I always tell patients is that kind of living a normal, active, full, healthy lifestyle can kind of indirectly help you blink more and help treat your dry eye a little bit, too.

But getting to the two eyelid disorders that you were talking about, Karen, so the first is something called blepharospasm, which is abnormal involuntary eyelid closure. Basically the eyes repetitively blink or squeeze shut. This is considered a type of dystonia and in the movement disorders world, dystonia just refers to a repetitive or sustained muscle contraction. Both blepharospasm and the other eyelid disorder that I'll talk about in a second, which is called eyelid opening apraxia, both of these are actually more common in atypical causes of Parkinson's symptoms, such as the disorders progressive supranuclear palsy or multiple systems atrophy, if people are familiar with those. Or you may be familiar with the distinction between typical and atypical Parkinson's. These are both more common in atypical Parkinson's, but do still happen in Parkinson's disease as well.

So again, blepharospasm causes this repetitive squeezing or closing of the eyelids. It's often accompanied by sensitivity to bright light and this can usually a manifestation of Parkinson's later in the disease itself, but it can sometimes be... it can either occur sort of at the peak in the setting of dyskinesias, after you take your medication, or rarely it can happen as a wearing off phenomenon as your medication wears off.

In addition to titrating those medications, this condition, blepharospasm, can be treated with botulinum toxin injections in the muscles around the eye. So this is a medication that's injected just under the skin and it weakens those muscles a little bit, such that they don't squeeze and close as much. Then the other eyelid problem that we see-

Dr. Karen Jaffe: So this-

Dr. Ali Hamedani: Yes?

Dr. Karen Jaffe: No go ahead. Finish up.

Dr. Ali Hamedani: Oh. I was going to add that the other eyelid problem we see is something called eyelid opening apraxia, which is after you've closed your eyes, kind of difficulty opening them again or initiating eyelid movements. This is different from
blepharospasm because it’s not that the eyelids are squeezing shut, it’s just that they won’t open.

So for anyone whose had this, what they would experience is actually it often happens in the morning when you first wake up. You wake up, you go to open your eyes, and you’re trying to open them, you raise your eyebrows but then the eyelids themselves take a little bit of time to come up. You can kind of think of it as freezing, which is a term that many with PD will be familiar with, freezing of the eyelids, although that’s not technically correct. It has to do with the signal that goes to tell your eyes to open when you want them to. There are a variety of adjunctive treatments that can help with that.

Dr. Karen Jaffe: So this may seem like a silly question, but what happens when a patient who has Parkinson's who blinks less frequently develops dystonia, which causes excessive blinking? Do they equal each other out?

Dr. Ali Hamedani: That’s actually a really great question. They don’t necessarily cancel each other out because blepharospasm in PD may not be constant. It’s not that the eyes are constantly blinking and squeezing throughout the day. There may be times, especially if it’s medication related that that may happen more than other times.

I guess one point to mention, so I talked about botulinum toxin as a treatment for blepharospasm, if that’s successful and the eyes are blinking less frequently, that could potentially bring out the dry eye problems that we had talked about earlier. That’s important to consider if you’re going to opt for botulinum toxin treatment for blepharospasm to kind of know that dry eye is a potential side effect of that.

Dr. Karen Jaffe: There’s always something, isn’t there? Dr. Fabrykowski, in what point in Parkinson’s disease do people tend to have these eye problems begin? Is it... can it be early on in the disease or are these late consequences of the disease?

Dr. Marta Fabrykowski: Are you referring to the eye movements or just eye things in general?

Dr. Karen Jaffe: Eye things in general.

Dr. Marta Fabrykowski: So that can happen before Parkinson's. If you're diagnosed at 70 and you started to have dry eye at 60, that can happen. That can happen at any point. We don't really know exactly in terms of staging or years after diagnosis when these things happen. We know that some things happen much later in Parkinson’s, like people who have hallucinations or people that have... Dr. Hamedani was just talking about the inability to open the eye, sometimes that can happen later on in the course, but in terms of knowing exactly when things happen, one year after diagnosis, stage one, sort of wherever you are, we're not really sure and we're still sort of learning all about that.
Dr. Karen Jaffe: We have a fair amount of questions so I'll start with you on this, Dr. Fabrykowski on floaters and the link to Parkinson's and if they are linked, are there any strategies to help with them?

Dr. Marta Fabrykowski: So floaters come from the back of the eye. There's a vitreous gel. The eye has two components, two compartments, I'm sorry. There's a front part of the eye liquid and there's a back part of the eye liquid. The back part of the eye liquid is known as the vitreous which is a gel, and when you're born all kinds of things are dissolved in it, proteins, collagens, all kinds of stuff in there, and as we get older those things sort of start clumping together and even as early as your 30s or 40s you can start seeing floaters and then depending on sort of the kind of prescription you have and the length of your eye and things like that, as we get older, 50s, 60s, 70s, 80s that vitreous gel sort of clumps together and detaches from the retina. That does not mean you have a retinal detachment. This is not a retinal detachment. This is just your vitreous moving around, that gel in the back of the eye, and that causes floaters.

Dr. Marta Fabrykowski: That happens whether you have PD or not. In fact, everyone in their lives at some point will get a vitreous detachment where the gel moves away from the retina with age. What you can do for that, if you have a lot of floaters that are sort of really bothering you, you can't see through them to work or to walk or whatnot, there are procedures that they can do to remove those. Those are quite invasive and we generally do not recommend those unless it's absolutely extraordinary.

Dr. Marta Fabrykowski: There's some new procedures like lasers and things that people get for those, but again, those are quite new and we don't generally recommend them so usually what we tell people is when you see these floaters, number one, if they're urgent, if they happened... if you suddenly are noticing a lot of new floaters like 100 new floaters or a shower curtain of new floaters in the last 24 hours go get them checked out and make sure it's just that vitreous and nothing else.

Dr. Marta Fabrykowski: But if you have them for a while what we tell people is usually over time people start to either, A, notice them less, the brain sort of learns to turn them off, or B, they'll fall with gravity below the pupillary line and then you don't notice them even though they're still there. If you can live with them, they're yours to keep and if not then if you see someone who does retina, a retina specialist, they could talk with you about options. But if they're sudden you should go in sort of quite soon and be seen.

Dr. Karen Jaffe: Great. Dr. Hamedani, we're getting a fair amount of questions about DBS and since it typically targets Parkinson's motor symptoms, can deep brain stimulation change or improve vision issues?

Dr. Ali Hamedani: Great question. So deep brain stimulation can potentially help but potentially worsen certain visual symptoms, kind of depending on what your initial symptoms are and sort of where the deep brain stimulation is. So for the dry
eye and decreased blinking, deep brain stimulation can be helpful and that's because it... the blink rate is something that follows the rest of your motor symptoms in PD very well. So if your motor symptoms get well, you're moving more easily and walking more easily, you're probably blinking more frequently as well and so dry eye may get better after deep brain stimulation.

Most double vision after deep brain stimulation does not change much. In fact, sometimes, particularly if your deep brain stimulation is into the subthalamic nucleus, which is one of the two different surgical targets for DBS, sometimes double vision can come out or be made worse after DBS. That has to do with the spread of voltage of the electrical current from the motor target of the DBS into some nearby areas that control eye movement. If that's the case, that can be treated by adjusting the settings of the DBS. In general, I don't think that double vision is a long term complication or problem for most DBS, but it is something to be aware of.

In terms of the eyelid disorders that we talked about, eyelid apraxia so that difficulty opening the eyelids, can come out or be made worse after DBS, usually within the first year if that's going to happen. That's also potentially amenable to adjusting the settings.

Dr. Karen Jaffe: Great. So let's talk about medication. Dr. Fabrykowski, both of the drugs listed here are commonly used, amantadine for dyskinesia and Artane for tremors and dystonia, are these drugs commonly known to cause vision changes and do you think most movement disorder specialists are aware of those?

Dr. Marta Fabrykowski: To address some of those questions, and I would defer to Dr. Hamedani about some of these medication sort of side effects, but they can cause some dry eye. We're all connected, so any medication you're taking, whether it's one of these or a supplement or any sort of medication, we're all connected. So if it's drying you out at any place in your body, that can include the eyes.

In terms of the vision changes, some of these drugs that are used can change the size of the pupil. It can make it larger, it can change sort of the focusing. In some cases the vision can be changed, a lot of those temporary. But in terms of knowing whether neurologists or movement disorder specialists are aware of this, it's hard to tell. Our neurologists here at Northwell Health in Manhattan are fairly aware and we sort of talk back and forth, but I think both with ophthalmology and with neurology I think we have a lot to learn, and I think that there's a lot of collaboration that we should be doing back and forth between neurology and ophthalmology. We should be telling neurology what we're seeing and neurology should be telling us what medications they're on and what they're suspecting.

I think sort of at the crux of your question, the basic answer is I think we can do a better job working together between ophthalmology and neurology in terms of all these medications. Dr. Hamedani, any sort of follow up with that?
Dr. Ali Hamedani: Yeah, I agree. These medications can cause dry eye because they decrease your
tear production and they can also cause difficulty focusing because of the
pupillary changes that Dr. Fabrykowski mentioned. I think that most
neurologists are aware of these, but they may not necessarily be asking you
about them every time you see them and that's why I think a recurring theme
whenever I see Parkinson's patients is that I've had these visual symptoms but I
didn't know that they could be related to Parkinson's or to my medication, and I
think that's in part because no one asked. I encourage everyone to be vocal
about any symptom you're having, including visual symptom so that your
neurologist can address them or refer them to someone like me if needed.

About these medications, amantadine and trihexyphenidyl, the other thing I'll
add is that rarely they can cause an acute vision problem called angle closure
glaucoma. Glaucoma is an eye disease that has to do with increased pressure
inside the eye and when that happens suddenly, it can cause intense often
unilateral, one sided, or both sided intense eye pain, redness, and vision loss.
That's caused by a sudden increase in eye pressure. If you start one of these
medications and you have any sudden changes in vision or in eye pain, you
should see a doctor right away.

Dr. Karen Jaffe: On that note, do you think that if a patient is having vision changes it's best to
start with their neurologist or to start with an ophthalmologist?

Dr. Ali Hamedani: I think to be honest either would be good. In general, I would start with your
eye doctor, but certainly let your neurologist know and as Dr. Fabrykowski said,
the two should be communicating back and forth. Then there are folks like me,
neuro-ophthalmologists who kind of combine both together that can help as
well.

Dr. Karen Jaffe: Great. Dr. Hamedani, as a neuro-ophthalmologist, you seem like just the right
person to talk to about medications, hallucination, and Parkinson's disease.
What can you tell us about this topic?

Dr. Ali Hamedani: Sure. Hallucinations, believe it or not, are a visual symptom. I know many
people don't think of them as vision related per se, but you are seeing
something and therefore it is vision related. Hallucinations in PD can happen as
part of the disease itself in later stages but can also be made worse by virtually
any medication that can treat Parkinson's disease, although the ones that are
most likely to cause it would be the long acting dopamine agonists like
ropinirole, pramipexole, or rotigotine patch and then the anticholinergics like
trihexyphenidyl can do it as well.

I think one important thing to note is that hallucinations don't necessarily mean
that you have psychosis or other problems. They can happen sort of in isolation
without confusion, some of these other things and in other words they don't
mean that you're "crazy," which is not really a term that we use in neurology
anyway.
Dr. Karen Jaffe: Right.

Dr. Ali Hamedani: In other words, in summary can be part of the disease itself, can be made worse by certain medications. One thing that is something that we’re starting to learn a little bit about but needs more research is that we think that decreased vision, or not seeing as well, from eye diseases such as macular degeneration or glaucoma may be a risk factor for hallucinations in PD. That's based off of several small studies, although it's an active area of research that I'm working on currently.

I think the implication there is that as someone with PD you should still see an eye doctor every year for kind of routine screening and treatment of these eye diseases like glaucoma or macular degeneration or if you have diabetes you should make sure that that's not affecting the eye, both because those are important for preserving your vision and your quality of life but also because maintaining your vision can help you in other ways and one potential way is that it might decrease your risk of hallucinations, again, might.

Dr. Karen Jaffe: Okay. So this slide talks about how the eye changes may help study Parkinson's progress and Dr. Hamedani, is this something you can give us a little bit more insight on?

Dr. Ali Hamedani: Yeah. I think there are two... when we think about imaging or studying the eye and eye movement in Parkinson's, there are kind of two main things. One is to kind of better understand the symptoms of Parkinson's and where they come from and then the other is kind of monitoring the progression of disease and kind of understanding more about the biology of the disease.

I talked at the very beginning about eye movement and there can be a little bit of slowing or a little bit of inaccuracy of eye movement, but it's quite subtle and it can be pretty hard to see just when you're examining someone sitting across from you, but there are ways of recording eye movement using kind of a variety of different goggles and other devices that can actually measure the speed of eye movement and give you much more precise measurements. Actually likewise with blinking, you could count the number of times that someone blinks in a minute, although that's pretty hard to do or something that people are interested in is kind of using videos, videotape yourself at home for example and the video will kind of automatically count your blinks and can give us more information that way.

But there's also a lot of interest in understanding about the pathology, sort of why and how Parkinson's happens that has to do with the eye. There's an abnormal protein called alpha-synuclein that accumulates in Parkinson's disease in the brain and there have been some studies that show that it might also accumulate in the back of the eye which is called the retina.
This is really interesting because unlike the brain, which is very hard to visualize, actually it's impossible to visualize directly, you have to either do a special scan to try and see it or ultimately it's a biopsy or autopsy that shows you the changes in the brain. So unlike the brain, which is very hard to see, the retina is very easy to see if you dilate someone’s pupils and you look in the back of the eye you can take a special picture and you can see their retina right there. That's why some people are interested in ways to kind of measure alpha-synuclein or other changes in the retina in the back of the eye.

There’s also been some studies showing a little bit of thinning of the retina and that's using a widely used available technique which is called an OCT, or optical coherence tomography but it's a laser scan of the eye basically and that can show you the different layers of the retina and show that they may be a little bit thin in Parkinson’s compared to people without. This is still an area of ongoing research so none of these are used as diagnostic tests for PD yet, although it's possible they may be used in the future.

With thinning of the retina, the interpretation of that test can be difficult because a little bit of thinning is normal with age and is also normal with thinning of the brain, so it's kind of hard to know which of those happen first and there's a big chicken and egg question in Parkinson’s. What part, where did the disease begin? Does it spread to other areas, that sort of thing.

Dr. Karen Jaffe: Are any of these things seen in the years before somebody gets diagnosed with Parkinson's?

Dr. Ali Hamedani: The truth is that no one really knows because it's kind of hard to identify patients for research before they've developed symptoms of PD. The one exception would be individuals with genetic forms of PD where they may know ahead of time that they’re going to get it based off of a strong family history, but those really haven't been studied that well so I don't think anyone knows the answer to those questions yet.

Dr. Karen Jaffe: I think as we move into the phase of identifying patients at risk that these are kind of populations that we'll be able to do these tests on and we'll see whether they develop any of these signs before they actually develop Parkinson's disease. It will be an interesting thing to watch for. Okay. Well wow. We're here at our last slide here already before we take some of the listeners' questions. John, let’s talk about how you’re managing your vision issues and what sort of impact it's having on your quality of life. While I doubt that you are an avid needle pointer, I'm curious if you are still able to do some things that require visual acuity.

John: Well I do a lot of woodworking and so the combination of the sawdust and now that I know that I have dry eye anyways without sawdust, it makes me more aware of wearing my goggles and glasses as I'm working with the wood. One thing I was wondering though, whether wearing goggles, safety glasses, would
dry out the eye more than just regular glass, doctor, if you could answer that please?

Dr. Karen Jaffe: Anyone want to take that one?

Dr. Ali Hamedani: Yeah, so I think neither glasses would cause your eye to dry out and I do think that if you're woodworking that wearing those safety goggles is a great idea. The last thing you would want is a piece of wood to fly into your eye which could scratch it and make the dryness and all those problems much, much worse. Eye protection is very important.

Dr. Karen Jaffe: Dr. Fabrykowski. You know what? We are getting a lot of questions about the change in depth perception that people have. I think that a lot of people find that especially it applies to their ability to drive. And so, could you discuss that, why people have that depth perception issue and how that would impact their ability to continue driving.

Dr. Marta Fabrykowski: Certainly. So, I'm actually going to reach back to something that Dr. Hamdani said earlier. With PD, without PD, but also certainly with PD, when your eyes sort of don't work that well together, or they start to have trouble here and there, your depth perception is affected. So, instead of using both eyes to look at a far distant point or to be able to see things that are overlapping, the eyes may not work quite well together.

Now, some of those things can be corrected with glasses. So sometimes, if the glasses are not optimal, or if there is a difference in vision between the eyes, having a different kind of glasses can help with the depth, and having a different design of glasses that can be key. For example, what I mean by that is that if you have glasses that are progressives which are quite convenient because it means you have distance vision in the top of the lens, computer in the middle and reading on the bottom. Those are great because they are convenient. You can put them on and see just about everything; however, with PD and sometimes with the vision, sorry, the eye muscles not working well together, it can be difficult to get into those specific, those very small sometimes, area of vision.

So, what we recommend sometimes is just single vision glasses for different tasks, whether its depth perception at the computer when you're typing, whether its eating and putting down a glass, whether its driving far away and seeing how far a car is and in which lane and things it is, it could be best to have just a separate pair of distance, separate computer, and separate reading glasses, because then even if the eyes are not working perfectly well together, you functionally have that whole lens of that same distance to focus versus having a centimeter and a half or whatever it is in terms of a progressive lens.

So sometimes it just takes evaluation with that and sometimes if you know that your depth is not good in situation A, B, C, sort of whatever you're doing, just being extra aware of that and taking your time looking at the angle of a
cupboard or exactly where things are placed sort of in your surroundings, just taking that extra time can help too. So, some of these, with evaluation and sort of minor tweaks can be helped, but certainly in terms of driving specifically, in many states, I know in New York for example, there really is only a vision that you have to be better than in order to drive. So that's all we test and when your vision is better than a certain amount, you're okay to drive. So it's really an individual decision and it has much more to do with than just vision. We can measure someone and be 20/40 which is sort of the cut off in New York but they could still not feel safe driving, or they could feel like they don't have good depth perception, or they could feel like they're having issue A, B, or C.

Driving is much more than just vision and we usually defer to the patient to say how safe they're feeling, maybe limit it to going to the grocery store or whatever places you know within a mile and on a bright day when things are a bit, you know. So vision and driving is sort of a complicated question with no sort of easy answer, and vision is really only just part of it.

Dr. Karen Jaffe: Well it's interesting because I have a progressive lens prescription for my glasses, but I find they are very difficult to use for the near reading. I have to take them off. And I'm wondering how many general optometrists or ophthalmologist's are aware of this issue with Parkinson's and having that be, their depth perception issues. I would think that probably it's not very well known to people in general who don't deal with that many Parkinson's patients that that would be the case. Certainly, depth perception can lead to falls. As you mentioned, you should know what your surroundings are and even taking the stairs, there is an impact on that, that is must be one of the reasons people fall as much as they do down the stairs.

Dr. Marta Fabrykowski: Certainly. And some of that has to do with contrast too. If you're looking down the subway stairs, and all of the stairs are the same color and you have difficulty seeing the shadows and the depth, that may not have anything to do with your eye muscle movements, that could just have to do with contrast and going from light to dark and things like that, so being careful with mobility with all of these things is paramount, so, to have your eyes in the best sort of optimal health where things are not blurry because they're dry, things are not blurry because it's the wrong progressive or the right progressive or what have you, sort of best optimizes you and positions you to best get around.

Dr. Karen Jaffe: Wow. It all adds up, doesn't it? So I think we're going go ahead and take some questions here. We have one question that the person says they have the opposite of dry eyes; their eyes weep continually. Is this linked to PD? Dr. Fabrykowski, I'll ask you that question.

Dr. Marta Fabrykowski: Oh sure. So when your eyes are watering, that actually tells me they are dry, and they're watering because their dry oftentimes. And that seems counterintuitive and people are saying, "How are my eyes watering if they're dry?" or "How are they dry if they're watering? I have too much tears."
Well, what happens is for many reasons, when your eyes are dry, the natural response of the eye is to water, is to help it, but the tears that it makes reflexively are not good tears. They’re not the kind of tears that you want to sort of keep on your eyes. So, it could be that your eyes are actually dry and could it be from PD? Of course. Could it be from aging? Of course. It could be that your lids aren’t meeting quite well together, so when you’re blinking, it’s not a full blink, and that little area is drying out. Sometimes what we find is something called lid imbrication, where the upper lid and lower lid may not meet head on, they may meet a little bit skewed, in which case the tears are falling off the eyes, because the lids aren’t keeping them on. So the eyes watering can actually be a sign of other things, your eyes are trying to repair something on them.

Dr. Karen Jaffe: We have a question about whether contact lenses can have prisms?

Dr. Ali Hamedani: Unfortunately, no. Contact lenses cannot have prisms so using prisms for double vision really does require moving out of contact lenses and back into glasses. One thing I will add though, is that the double vision from PD may not be present at all times and just to kind of emphasize what I was talking about earlier, it may only be present with certain activities, such as reading for example. So you could conceivably wear contact lenses at distance during the day if you were driving or something, but then to read, if you were going to read the newspaper in the evening, then you might need to switch. So, that switching back and forth can be quite difficult which is why I, in general, if someone is going to need prisms, we generally recommend moving out of contact lenses and back into glasses. And as Dr. Fabrykowski said, contact lenses can make dry eye worse and requires some extra steps to kind of deal with that anyway.

Dr. Karen Jaffe: And I assume that there’s a difference between hard and soft contact lens wearers. Not that there are many hard lens wearers left but there is probably still some that hang on to those.

Dr. Ali Hamedani: My understanding is that hard lenses are reserved for very specific situations, so as you said, they are not used that often, but they have their own set of care associated with them.

Dr. Marta Fabrykowski: Yeah, I agree with Dr. Hamedani. Hard lenses are great and the vision is excellent, so they’re actually coming back into vogue if you can believe it or not. Because the vision, the clarity of vision if you’re fitted with good hard lenses is extraordinary. It’s better than soft lenses, it’s better than glasses, your vision is very good. The downside is discomfort and having to get used to them, and it sort of comes with its own territory. Can dryness happen with both hard and soft lenses? Of course. Is it worse with one or the other? Well it depends on modality. Both hard lenses and soft lenses are made of dozens of different plastics, different coatings, different designs. They could be too big, they could be too small, they could be too loose, they could be too tight. So any of that can exacerbate it, but it can also be fine to wear. Like Dr. Hamdani said, with some modifications of things, either one can be made to be more comfortable.
Dr. Karen Jaffe: Dr. Hamdani, people are asking where they can actually purchase prism glasses.

Dr. Ali Hamedani: So prisms can be obtained anywhere that you get glasses. And the way they work, so they’re prescribed by a doctor, so you would go to. First of all, before you get prisms, you should also have your regular prescription rechecked by your eye doctor. In addition, that doctor, or another doctor, an ophthalmologist, for example, would add on to that a prescription for prism and then you would take it anywhere that you get glasses and they would be able to do them for you. One kind of cautionary note though is that prisms can be expensive depending on what kind they are and where you try to get them. So, before you get prisms you should do a little bit of price comparison at different places, and you should also ask for them to give you a warranty so that if the prescription needs to be changed for any reason, let’s say the amount of prism wasn’t correct the first time and needs to be adjusted, that that is covered under a warranty.

Dr. Karen Jaffe: Important to know. People have questions on night vision. How does Parkinson’s disease affect people's ability to actually see at night time.

Dr. Ali Hamedani: So, night vision gets back to the contrast sensitivity that Dr. Fabrykowski was talking about earlier. So at night or in dim lighting there is less difference in lighting, or in color if you will between two different things that you see. So, as Dr. Fabrykowski said, it is the difference between white and black versus light gray and dark gray, and so, night vision is important for everyone and I think especially for people with PD who may be frequently getting up in the middle of the night to go to the bathroom. So a really important point is that if you are getting up at night, you should always, always turn the lights on when you do so. And I know that’s a little extra step and you may be worried about waking up your partner or something like that, but it’s important to be able to see where you’re going and also to minimize the risk of falls at night if you’re not able to see well and might be tripping on things in front of you.

Dr. Karen Jaffe: That’s true. People want to know whether Parkinson’s disease affects glaucoma at all?

Dr. Ali Hamedani: That’s a really good question that we don’t really know the answer to yet. So as Dr. Fabrykowski said, glaucoma is a common eye disease that increases in prevalence with age and Parkinson’s also increases with age. So because they both increase with age, it can be hard to tell whether glaucoma is more common in PD than not. There have been a couple of studies trying to address this and some have suggested that perhaps PD may be a slight risk factor for glaucoma and conversely, maybe glaucoma is a slight risk factor for PD. Although, again, these are several studies with their own limitations, so I think the jury is still out on this. Glaucoma is in a sense thought to be somewhat of a neurodegenerative disorder so it’s degeneration of the optic nerve and Parkinson’s, of course, is a neurodegenerative disorder too so there is reason to think that they might be related, but currently we don’t know that for sure. The same can be said of age related macular degeneration too.
Dr. Karen Jaffe: Dr. Fabrykowski, somebody asked whether Parkinson's can cause blindness?

Dr. Marta Fabrykowski: Parkinson's itself, directly, cannot cause blindness. There are conditions that can be sort of exacerbated by PD, like dryness, maybe some sort of thinning in the retina, that Dr. Hamdani was talking about, but nothing, sort of blindness related, certainly.

Dr. Karen Jaffe: Right. Some of the other questions that we have. Somebody wants to know whether Parkinson's disease can cause eye lids to open some, but not all the way. Dr. Hamdani?

Dr. Ali Hamedani: I think what you're getting at there is something called eye lid drooping, or ptosis, and that's when you open the eyes, but they don't open as much as you'd like. That's not usually caused by Parkinson's. It can occur just as a part of normal aging. There are a lot of other conditions that can cause it as well. Sometimes it can be hard to tell whether that's because the eye lids are drooping or whether it's almost like an eye lid opening apraxia, that they're not fully opening. But I think if I'm understanding it correctly, if it's just that when your eyes are open, when you're awake, your eye lids droop or they kind of come down more than normal, that is probably not related to PD.

Dr. Karen Jaffe: Would Botox help that?

Dr. Ali Hamedani: No, in fact Botox would make that worse. It might cause the drooping to worsen then. The treatment for that is sometimes there is a little kind of attachment to glasses that can go to help lift the eye lids a little bit which are called eye lid crutches, but if not, surgery to elevate the eye lid is how you would treat that. Again, if someone is going to go down that route of getting eye lid surgery, you would want to really make sure that that doesn't affect the ability of the eye lids to close when you blink, which Dr. Fabrykowski talked about earlier as being really important for preventing dry eye, so there is always a risk of dry eye, really with any eye surgery of any kind, but especially surgery on the eye lids.

Dr. Karen Jaffe: Dr. Fabrykowski, are there any supplements that can help treat vision problems? Somebody specifically asked me about fish oil.

Dr. Marta Fabrykowski: So there are lots and lots of supplements that are sort of designated for the eyes, so when you walk into CVS, Walgreens, fill in the blanks, sort of whatever, pharmacy, there are tons and tons of oral supplements you can take. Some are indicated for certain purposes like fish oil and Omega 3 are known to help for blepharitis.

But just because they're a supplement, doesn't mean they don't come with side effects. Sometimes these supplements can cause thinning of blood, they can cause stomach ulcers and things like that. So before starting anything, it's important to talk about it, 1) with your doctor or neurologist, and 2) with your eye doctor or ophthalmologist, to see, "Do I need these?" So, people who need
Omega 3, they typically have blepharitis, their glands are sort of clogged up. Do you have that? It's hard to tell until you get an exam. There are some supplements for the retina that they have found in certain cases can prevent the acceleration of macular degeneration. It doesn't prevent the inception of it, but people that already have it, it's helpful to stop its progression.

So there are vitamins, but it sort of takes some discussing and sort of deciding whether, 1) it's warranted for whatever your condition is, and 2) should you be taking those with the other medications and things like that.

Dr. Karen Jaffe: Dr. Fabrykowski, how often should eye exams happen?

Dr. Marta Fabrykowski: The only guidelines we have are the American Academy of Ophthalmology recommends that under the age of 55 you come every other year, and then above the age of 55, it's every year, just for a general check up. Some people come more often. So for example, let's say you came today to the eye doctor and they said, "You know what? You've got some dryness in the eyes? Are you bothered." "Yes, I am bothered." "Well, let's try these eye drops and then maybe we'll follow up with you in 6 weeks to see if it's working," and then you sort of come more often. Like Dr. Hamdani says, we see you for double vision and we prescribe some prisms, usually we like to check up on you afterwards to see how the prisms are working, did we give you the right quantity, are they the right direction, are they fitting you well? So, I generally tell people to start out with once a year and then depending on what the discussion is, depends on how bothered you are with what's happening, and what the treatment is, maybe more often.

Dr. Ali Hamedani: I would add to that, Dr. Fabrykowski, is that there are certain conditions, medical conditions, that if you have them, increase the frequency of your eye exams, or rather you should start getting them yearly sooner and those are if you have diabetes or if you are at risk for glaucoma, which means you either have a family history of glaucoma or you're of African-American or Hispanic ancestry. Those are reasons that you would start doing those yearly exams even younger.

Dr. Karen Jaffe: Well, here we are already at the end of the hour and in review, with the help of our panelists, we have learned that Parkinson's can cause many symptoms ranging from dry eyes to double vision and even hallucinations. Not only can visual disturbances interfere with reading or driving, they can worsen walking and balance problems and even contribute to hallucinations. And while vision problems can be due to Parkinson's disease and the medications used to treat it, seeing an ophthalmologist may be needed to determine if it's due to Parkinson's disease or to unrelated conditions of the eye or eye lid. I wanted to thank all of our listeners for joining us today, as well as to thank our patient representative, John Merchant.

Thanks to Dr. Fabrykowski and Dr. Hamdani for sharing their expertise. I'm sure that our audience today would agree that this was truly an eye opening
webinar. We will be sending a link to the webinar on demand to listen again or share as you'd like. Please mark your calendars for our next webinar on May 16 where we'll discuss efforts to look deep into selves to better define measure and treat Parkinson's disease, and we'll have staff behind the scenes to answer your questions. So that you again to our panelists.

John Merchant: Thank you.

Dr. Ali Hamedani: Thank you for having us.

Dr. Marta Fabrykowski: It's been a pleasure.

Dr. Karen Jaffe: It's been very informative. I'm sure lots of people learned lots about the eye that they didn't know beforehand. So everybody have a great day. Signing off.

Michael J. Fox: This is Michael J. Fox. Thanks for listening to this podcast. Learn more about The Michael J. Fox Foundation's work and how you can help speed a cure at MichaelJFox.org.