Hadley

Monitoring Macular Degeneration from Home: Notal Vision

Presented by Ricky Enger

**Ricky Enger:** With macular degeneration, catching subtle changes as they happen can have a huge impact on a treatment plan that works best for you. In this episode, CEO Kester Nahen joins us to discuss a powerful home monitoring option from Notal Vision. I'm Ricky Enger, and this is Hadley Presents.

You know, I always love that moment when someone discovers something that makes all the difference for them, whether it’s the right piece of technology, a new treatment approach they didn’t know about, or just something someone said that struck the right chord at the right time. With that in mind, in this episode we have two cool things to share with you. First, we’ll hear from Kester Nahen about a really fascinating and useful option for monitoring macular degeneration at home, and then after that, stay tuned for a short episode from our sister podcast, Insights and Sound Bites. We’ll hear Julia talking about the best thing she ever did after her vision loss diagnosis. If you like what you hear, there’s plenty more stories on the Insights & Sound Bites podcast page, plus you can add to those stories by sharing your own. You can find that page on our website or by checking the show notes. And now, on to the show.

Welcome to the show, Kester. So happy to have you,

**Kester Nahen:** Ricky. Thank you so much for having me.

**Ricky Enger:** Yes, it is wonderful that you could be here with us, and I know we're going to learn a bit more about Notal Vision and what you all do as we move along here. I'm wondering if we can just start out with a quick intro, tell us a bit about you, who you are and what your background is.

**Kester Nahen**: Yeah, happy to. So, my name is Kester Nahen. I'm a physicist by training. I was always drawn to the field of medicine and specialized in a field that's called biomedical optics, which today encompasses everything from laser medical procedures to diagnostic imaging. And really over the last 20 years, I've been very much focused on eyecare in my work and improving the diagnosis of diseases. And so of course it was very drawn when I saw a company Notal Vision, developing diagnostic technologies, not just for the doctor's office, but actually extending the care to patient's homes. That is something that brought me six years ago to Northern Virginia where we operate our remote modifying center for patients and we're going to talk in detail about the programs that we offer.

**Ricky Enger:** Yeah, that's so cool. I always love hearing how people made their way from something that they were generally interested in and then combining this passion with another thing and it works out great. So, in this particular case, we're going to be talking about some ways to maybe improve the diagnosis in the treatment of macular degeneration and how it progresses. I think before we get into how that might work, it would help to sort of be on the same page as far as what macular degeneration is, what does it look like, how does it progress, that kind of thing. So, I'm wondering if you could just give a quick overview of that.

**Kester Nahen:** Yeah, so age related macular degeneration is the leading cause of blindness in the United States and is an age-related disease, as the name says, and it's very slowly progressing over time. At first, patients don't notice any changes, but over time it can lead to first some blurry vision, then to some more distinct metamorphopsia, meaning that lines appear wavy. And in a late stage, which is called the wet form of age-related macular degeneration, there is actually development of vessels that leak fluid into the retina. And this can lead to vision loss. I should also mention that there's a late stage of dry age-related macular degeneration that's called geographic atrophy, and that also leads to vision loss because the receptors die over time and the damage there also expands over time. Here at Notal Vision we're very much supporting patients that have the early to intermediate dry form that then leads to wet age related macular degeneration with a goal to identify the progression to the wet form, the sight threatening form early, and then patients need treatment to better personalize the treatment.

**Ricky Enger:** That makes a lot of sense actually. And that's kind of a nice segue into my next question, which is traditionally how does this work? So, if someone goes to their eye doctor and they get that diagnosis of dry macular degeneration, what happens at that point? So how does the eyecare professional know where the person is in terms of progression, and then how do they figure out when those changes happen?

**Kester Nahen:** So, the eyecare professional will perform a fundus exam or take a photo of the back of the eye. When small lipid deposits, they're called drusen appear on the back of the eye, then that’s an indication that early phase of Dry MD has developed. Now with the progressive development of larger drusen, patients then may be classified as intermediate DMD patients, and this is where the risk of a conversion to the wet form really increases. That's exactly when early disease detection becomes very relevant. In most practices today patients are asked to use what's called an amsler grid. It's a grid of lines that the patient should look at periodically, and if patients notice any distortions or wavy lines in this grid in the subjective assessment, then that's an indication that the disease is progressing. The challenge with this approach is that it's rather subjective and it's not so easy to really identify when there is that abrupt change from dry to wet AMD.

And this is where we come in with a new digital tool that is the ForeseeHome AMD monitoring device that operates very similar to an Amsler grid, although we are artificially presenting distortions to patients and ask them with a mouse on a little screen to identify these distortions. And if patients identify them correctly, these artificial distortions, we know that everything is okay. They recognize when the line is wavy, and that's because the line that is shown to the patient indeed has a little bump. If patients start to click on this little screen on locations where there was no artificial bump, then we know that somehow in the retina there is a change that actually gives the patients the impression of a distortion, and that is caused by changes in the retina initially. These can be the drusen that I mentioned, but if there is an abrupt change and a lot stronger distortions are being seen by the patient, then that's a very strong indicator that the patient may have converted from dry to wet a MD. That is information that we feed back to the prescribing eyecare provider so that the patient can be brought into the office and then seen for further diagnostic testing.

**Ricky Enger:** So, this is really fascinating. A person can look at this Amsler grid at home and they might have an appointment with their eye doctor every six months, every nine months, whatever that is. And whatever happens between those times doesn't really get caught. But with this, you're putting this into the patient's hands, you're not waiting for that appointment that could be four months from now to find out if some progression might have happened. One thing I know is that when you talk about you've got this thing and you're clicking with a mouse, and you're doing it at home, some people are thinking sometimes I need help with the TV because it's super complicated these days and so on. So, can you describe what this device is, how complicated it is to use, and what's the process for, if you get this, how much assistance are you going to have? How complicated is it going to be?

**Kester Nahen:** Yeah, the device is really easy to use. We have over 50,000 patients that have used it over the last decade, and if patients have questions about how to operate it, this is where our monitoring center staff is available. The first encounter when we first provide the device to the patient, we spend 30 minutes, sometimes 45 minutes on the phone with the patient explaining exactly how to use the device. We also educate about the need for daily testing so that we really detect the disease conversion early. So yeah, we're very experienced and we've seen that patients can operate this device really well.

**Ricky Enger:** That's great. It's really encouraging to hear that. So if you are someone who's listening and you think, okay, I've got dry macular degeneration right now, and I think it would be very helpful to be able to monitor my condition and send this data to my eye doctor, if you're curious about this, what's the process then for getting set up with it? So, you all work with the eyecare provider, so how do we get from here to there?

**Kester Nahen:** So, we have a large network of ophthalmologists, also optometrists, who prescribe this monitoring program to patients. So, if patients are lucky, they may already have a provider that has a partnership with our monitoring center. If not, it's always a good idea to visit our website Foreseehome.com to learn more about the program and then share that information with the eyecare provider, that you heard about this program and want to see whether this is really the right thing for a particular patient. Of course, that depends on the correct diagnosis and stage of the disease. And then eye care providers can get in touch with us. We take their contact information, and they can start to prescribe this program.

**Ricky Enger:** That's great. And of course, we'll have that website, that contact info in our show notes, or you can call our 800 number, that's 800-323-4238, and we're happy to give you that info as well. A lot of times when people hear about something that's really exciting, they get hopeful, and then it's like, I might as well not even investigate this because I doubt that my insurance is going to cover this. It's going to be too expensive for me. And so, what's the status of that? Is this covered under Medicare and other insurance? How does that work?

**Kester Nahen:** Yeah, so the ForeseeHome MD Monitor program is Medicare covered, and depending on patients, it may be completely free of charge. If not, there's a copay of $15 for the patient.

**Ricky Enger:** Free is great, but $15 is not so bad either. I think that's really encouraging for people to hear. ForeseeHome is the name of this home monitoring device, and that is available right now. You're already set up with eyecare providers and hopefully adding more all the time, which is amazing. I imagine you haven't stopped there though. Are there other things that you can talk about that may be either coming in the near future or maybe are available right now?

**Kester Nahen:** Yeah, so with the ForeseeHome Monitoring program, we sort of fill the gap between office visits for the intermediate stage of the disease. Once patients convert to wet AMD, they usually receive anti-VEGF injections. This is a drug that is injected into the eye to give physicians insight into disease reactivation and when it occurs and when an office visit and treatment is needed. We have developed a tool that is called the Scanly Home OCT. OCT stands for Optical Coherence Tomography. This is an imaging modality that is very frequently used in ophthalmologist offices today to determine whether patients show disease reactivation and need treatment. Now, wet age-related macular degeneration is a very heterogeneous disease. It's not so easy to predict how long it's going to take for the disease to activate. So having a device at home that uses the exact same technology that's standard in the office setting today allows a retina specialist to exactly identify when the patient needs to be seen in the office. And then standard imaging is performed to make a treatment decision. So, this is a new device that we developed motivated by the advent of longer acting treatment solutions that we've seen in recent years, where the intervals between treatments can be extended from four to eight, twelve, sometimes even more weeks. And so having a safety net available between the office visits and giving the retina specialist a prompter of when to call the patient and bring the patient into the office is seen as a great new way to manage this disease.

**Ricky Enger:** That's great. And what's the timeline for this to be available roughly?

**Kester Nahen:** Yeah, so we received FDA approval last year. We're working right now with Medicare and insurance companies to get this covered and paid for. We are slowly starting to offer this as a cash pay model, so if there are patients interested in this program, they can reach out to us.

**Ricky Enger:** And could you just provide, once again, contact for your organization where maybe people can check out information on both of these options?

**Kester Nahen:** Yeah, so for that, it's best to visit our website notalvision.com, where information about both the ForeseeHome and the scan, the Home OCT monitoring program can be found.

**Ricky Enger:** Awesome. I want to thank you so much for joining us and sharing a bit about these really exciting options for home monitoring, making sure that you're not waiting all this time between visits when things could be happening that could be addressed immediately. I think that's such an important thing. Again, I really appreciate your stopping by and sharing info.

**Kester Nahen:** Thank you so much, Ricky. It's been a pleasure.

**Ricky Enger:** Thank you all so much for listening. And now, stay tuned for a short episode from our sister podcast, Insights & Sound Bites. And remember, if you want to hear more like this, you can visit the Insights & Sound Bites podcast page on our website where you’ll find lots more stories like Julia’s, plus, you’ll be able to submit one of your own. Alright, let’s hear from Julia as she shares the best thing she ever did to help her to cope and adjust.

**Julia Spencer:** My name is Julia Spencer. I'm originally from New Jersey and just a year ago, I moved down to Myrtle Beach to be with my daughter. But I'm still a Jersey girl.
I'm 91 years old, so there's no short story, I have a long story, but I’ll shorten it.
My first idea of vision loss is retinitis pigmentosa, which is hereditary, and my sister had it. There were nine of us and my sister was the only one that had it.

I found out I had it by accident. I was getting a pair of glasses when I was about 45, 47 or something like that. You know when you need glasses just because of getting to that age and you just need a pair of glasses for distance. Well, the doctor said that he saw a tiny little bit of retinitis pigmentosa. So, I went to a hospital in New York, Columbia. The doctors there, they said that my vision, my RP gene was so small, so little, for a woman 50 years of age, that I would never go blind. So, I believed him.

I had no problems for years. In 2002, I had a problem with my eyesight with cataracts. I got them removed and all of a sudden I couldn't see a little bit, and I was very upset. My husband was worried about me driving and I just kept telling him, I'm never going blind. I'm fine. I can drive. And I kept driving. All of a sudden, I started having a little problem at night, I couldn’t see at night, so I stopped driving at night. He kept saying you're going to stop driving during the day, please. And I said no, I'm not. I'm independent.

And one day I was sitting in a chair in the living room, and I called out to him, “Ralph.” And I thought he was in the bedroom. So, I shouted. And I heard a voice say, “I'm right here in front of you.”

My heart stopped. My biggest fear was to kill somebody. I said to him, “If I was driving the car, I would have killed you.” And he said, “I know.”

And that minute I gave it up. I was just so frightened of killing someone. He said, “Don't worry about it, Hun. We're a team. You know I'm here. I can take you wherever you want to go,” and I said, “It's not the same.” I didn't want to give up my car, but I had to. So, I did, and that was the beginning of it.I was walking into the election with my husband and holding his arm and using a cane. A person passes by that my husband knew and she stopped and said, “Why doesn't your wife have a guide dog?” She was a trainer for guide dogs. “Why doesn't your wife have a guide dog?” Well, right there I didn't like the person because I hate when someone talks to my husband or anybody about me in front of me.
And I want to say to them, “I'm not stupid. I'm just blind. And please talk to me.” And anybody who's blind knows that feeling. You have to fight with doctors or anybody you walk in, and they talk to the other person like you're not there.
So I said to her, “Uhm, I'm right here. Please, you can talk to me.” And she said, “Why don't you get a guide dog?” I said, well, “I don't really want a guide dog. But I'm not completely blind, so you can't get a guide dog. I still have sight.”

She said, “Are you legally blind?” I said, “Yes, I'm legally blind.” So, she said, “OK, you can get a guide dog,” and gave me a card.
I got a guide dog. That was the best thing I ever did in my life. I'll tell you why. When you're walking down the street with a cane, and you're sweeping the sidewalk to make sure you don't fall into a hole or something or curb. If people see you and they're walking towards you, they'll cross the street because they don't want to just get involved with you sweeping along. And they didn't realize I could see that they crossed the street.
But when you go down the street with a guide dog, people stay right there. In fact, they cross the street to meet you, and they want to talk to you. They say hello. They smile because I have sight, I could see. They smile at the dog and would be so thrilled to see a guide dog. I made more friends from just walking any place with the guide dog and with my husband even, and everybody would stop and talk to us.It was fabulous.

**Ricky Enger:** Got something to say? Share your thoughts about this episode of Hadley Presents or make suggestions for future episodes. We'd love to hear from you. Send us an email at podcast@hadleyhelps.org. That's P-O-D-C-A-S-T at HadleyHelps.org or leave us a message at 847-784- 2870. Thanks for listening.