

# **Transcript of a discussion between the people of MDList and Dr. Robert Gordon 10/24/98**

*(Edited for length and clarity)*

DAN: Thank you, Doctor, for spending this time with us today.

DR. GORDON: Thank you for inviting me. Though I'm not afflicted with MD, I experience it vicariously every day in my practice. Please call me Bob.

DAN: Thank you, that will help. Please tell us what your main interests are in connection with your practice.

DR. GORDON: My practice is somewhat unique in optometry. I work with visually impaired patients about 40% of the time, and I do research in the design and development of low vision aids, specialty contact lenses, and am working on new techniques for refractive surgery. In addition to that, I teach at the Southern California College of Optometry and work in the clinics of Cedars Sinai Hospital.

DAN: And you will also be able to discuss some of the recent treatments and procedures with us today?

DR. GORDON: I will do my best.

DAN: You mentioned a couple of new low-vision aid devices the other day. Will you be able to let us in on those developments today, or is it too soon?

DR. GORDON: One of the new developments is an instrument called the MAX. It is a hand-held scanner that connects to any television set and allows you to read. The big improvement is the quality of the image, variable magnification, and it costs less than \$500. There was a head mounted instrument called the ELVIS with a camera mounted on top and liquid crystal screens the patient views. This has been discontinued. It was replaced with an instrument called the V-max which is color, has 8-30x magnification, and converts to a closed circuit television system. The V-max is available now. Some time next year there will be a new head mounted device with less than 1/2 the size, which will allow viewing of the computer and television screen and will be much more functional. We are also now using specially tinted contact lenses to cut out blue light and provide higher contrast images to patients with MD which some patients are finding quite useful.

DAN: We have many new people here today, so I would like to open up the floor to questions now.

PAM: Hi, Bob. I'm in the UK. On tv this week we saw an endoscope being used to guide a laser for accurate treatment. Do you know about this?

DR. GORDON: The endoscope wasn't used for laser treatment in the eye was it? It is used for much larger vessels like those around the heart and carotid.

PAM: It was right inside the eye. It had a suction tube, as well, to suck up the hemorrhage.

DR. GORDON: Are you sure it was an endoscope and not a fiber-optic light source with a cutting blade that is used to cut tissue and suck it out of the eye? That's the instrument used in a procedure called a vitrectomy. Vitrectomies are used for hemorrhages in diabetic retinopathy and can peel back a membrane that forms in front of the macula, called an epi-retinal membrane, and also used for a pulling on the macula called macular pucker and for the treatment of full thickness macular holes. I am very familiar with this procedure. It is a reasonably common procedure performed in the US.

PAM: No, endoscope. Only used at two hospitals in the UK. Details are on a web site I can give you.

JOAN: I have Stargardt's with terrible light sensitivity. In three weeks I will see my opdoc to ask for contacts to let me see in fluorescent lighting. I don't know what to ask for.

DR. GORDON: Have you tried some of the selective filters manufactured by corning medical optics?

JOAN: No, nothing yet. No one seems to know anything here.

DR. GORDON: They cut out the light that causes glare in the eye but do not reduce contrast the way a dark gray lens does. Some of these filters can be replicated in contact lenses. My experience has been that patients with Stargardt's do seem more light sensitive than with other types of macular vision loss.

JOAN: Yes. It is the worst part of the disease.

DR. GORDON: I don't know the reason for this, but suspect that some of the yellow flecks that are present on your retina act to reflect more light than just scarred retinal tissue. But that's only my theory. You really should ask to evaluate the selective filters. Magnification devices also work really well for Stargardt's

patients, as they do for most macular degeneration.

JOAN: Is polarization a possibility?

DR. GORDON: Yes, you can get polaroid filters, but I doubt that they will be of particular benefit unless you spend a lot of time on the water.

JOAN: Polarized sunglasses help me a lot in normal outdoor use.

DR. GORDON: Is it the polarization or the color of the lens that helps?

JOAN: Polarization + AR coat on glasses underneath.

DR. GORDON: There is a company that has a unique polaroid filter that rotates and lets you block out anywhere from 0 to 100% of the light, depending upon the glare and how bright it is. As you know, overcast days are the absolute worst.

JOAN: Bob, I see better on overcast days.

DAN: Do you have the name of the company for the record, Bob?

DR. GORDON: I believe it is Franel Optical, but I'm not positive.

JOAN: Thank you. I'll look around.

TOM: Bob, I was told at a low vision aids store in NYC that the prototype of MAX did not allow easy switching from camera to normal TV. Has this been fixed?

DR. GORDON: I assume that was at the NY Lighthouse for the blind?

TOM: Yes

DR. GORDON: That is correct. It actually doesn't allow you to view tv directly because the cycles/sec of tv are different than the cycles/sec in the camera, so you get an interference pattern. The next generation of the V-max will rectify this problem, and from what I know, will be a significant advancement in low vision care.

JOHN: Bob, are there any advantages to contacts over conventional glasses for MD patients?

DR. GORDON: Only if the filtering aspect of the contact lens provides for more visual comfort, or if you are very nearsighted. Glasses shrink the image you see about 15% making distance viewing even more difficult, and contact lenses can

correct the nearsightedness without reducing the image size.

JOHN: Thanks. Anything for golfers?

DR. GORDON: I tell patients to carry a shovel and dig a trench to the hole.

JOHN: I was afraid of that. Thanks.

DR. GORDON: Seriously, yellow filters and/or a yellow ball might make following the ball easier. I have a couple of patients who benefit from golfing with orange balls, also.

DONNA: Bob, I have severe imaging or mirroring from my bad eye to the not-so-bad eye? Any help for that our there?

DR. GORDON: It is not uncommon for a patient who has significantly better vision in one eye to have the weaker eye interfere with what both eyes see together. I have found that either an occluder (plastic that blocks the vision in the worse eye) works well for prolonged reading, but what i like even better is a contact lens occluder. It is a contact lens that has a small black spot in the center that blocks the central vision in the weak eye so it doesn't interfere with detail vision, but allows you to use your peripheral vision for walking around and mobility. They are difficult to adapt to, but work well if you can.

DONNA: Where could I get that?

DR. GORDON: You should ask your doctor to try a lens on to evaluate if it will help. Almost all contact lenses can be sent to one of several specialty contact lens tint labs to have this applied.

DONNA: Would I still wear my glasses with it?

DR. GORDON: You can have your distance refractive correction (nearsighted, farsighted and astigmatism) incorporated into the contact lens, and then you wouldn't need distance glasses.

DONNA: So a lens for both eyes right?

DR. GORDON: If I can editorialize for a moment. We in low vision through the years have gotten trapped into thinking only about magnification for MD. there are other alternatives, like contact lenses and filters. To answer your question, Donna, yes, contact lenses for both eyes

DONNA: Thank you, Bob

JOAN: Can I kiss the doc?

DAN: Not yet, Joan :)

DR. GORDON: Anytime!!!

DAN: Bob, several of our subscribers are interested in the experimental photodynamic study. Do you have any comments on that treatment?

DR. GORDON: The first phase of photodynamic treatment was met with a great deal of hope. Initially the treatment worked. You injected a light absorbing dye and could use low power laser energy to destroy bad vessels or seal leaks. The problem was that the correction was only temporary, lasting about 4-6 weeks. CIBA pharmaceuticals has just received approval to continue the study to allow for multiple retreatments if needed. You could only treat once during the initial clinical study. Now we have to see if performing more than one low energy treatment will act as a permanent fix. I believe the next phase of clinical trials are beginning as we speak. I have three patients who have been accepted for this second round of treatment. I assume that everyone knows that the reason these light absorbing dyes are used are to allow the retinal surgeon to use less laser energy and thereby prevent extensive damage to the pigment epithelium on the retina causing loss of vision.

DAN: They are just beginning Phase III at Wills Eye Center.

DR. GORDON: And several other centers around the country.

DAN: Can you tell us of any new developments with the microcurrent stimulation study near you?

DR. GORDON: The microcurrent concept . . . is now undergoing study in Palo Alto. Initially, it was an in-office treatment where an electrical stimulator, a tensor unit, was used around the eyelids and cheek on the theory that this small electrical current could stimulate pigment epithelium. The new protocol is to have patients take home tensor units to stimulate themselves and see if vision loss can be halted, or hopefully improved. The problem with this kind of study is that it will take a significant amount of time before we really see if it is effective. I have two patients who are in there third month of using the tensor. They both tell me they are seeing better, but I have been unable to obtain any improvement on the clinical measurements we do in the office, such as visual acuity, contrast sensitivity, or the size of their blind spots. I learned long ago though, that what we measure in a clinical setting is not real world, and if, in fact, they are functioning better, then the treatment may be successful for them. I have tried to find some literature that validates the premise that tensor works, but have not been able to find any. That's

not to say it won't work, but I am sceptical.

DAN: Are you familiar with magnification software? If so, which would you recommend? Many of our listers use Zoomtext. Others use WindowEyes and Monologue.

DR. GORDON: As far as magnification software is concerned, my patients seem to find ZoomText the easiest to use.

DAVE: Is it true that this tensor treatment will only be started if you do NOT have wet MD?

DR. GORDON: As far as I know, the current protocol is only for dry macular degeneration.

DAVE: I thought I heard that it had to be very early stages of dry MD, also.

DR. GORDON: Dave, I understand that they will take any patient with MD into the study as long as it is dry ARMD.

JOHN: How do I become a patient in the tensor study?

DR. GORDON: You need to write to the doctor in Palo Alto, whose name escapes me for the moment. I'll send it to Dan for inclusion in the transcript

DAN: I can send that info to you, John. The name is Dr. Miller.

JOHN: Thanks much.

DAN: Your welcome.

DR. GORDON: That's correct.

DAN: Bob, tell us a little about your work with low-vision children.

DR. GORDON: We have found that early intervention with children who are visually impaired significantly improves their ability to learn. I like to take 1-2 year old children and get them started using binoculars and magnifying glasses from Toys-R-Us, or any other toy store, so they learn the concept of magnification. Most visually impaired children do not need large print textbooks. All large print texts are, are books with 2-3x magnification which we can easily provide with optics. It is important for visually impaired children to be given the skills needed to compete outside of school, and one of those skills is reading regular print. When you go from reading large print to regular print, the movements from word to word change from

head and neck movements to saccadic (small angle) eye movements, and this skill takes time to learn. It is also important for a child to participate in class activities, so starting them early with binoculars allows them to watch the teacher and other students.

DAN: I am impressed with all of the work you are doing in that field. Do you think computer training and internet access instruction for low-vision senior citizens are areas where work needs to be done? There is so much knowledge and support on the net that this age range is missing out on.

DR. GORDON: There is no question that we should make this much easier for visually impaired seniors. I couldn't imagine doing this with a visual impairment, and I really respect and admire each of you for putting out the tremendous effort it must take to watch this screen. There is some actual good news, albeit expensive, on the horizon. The new flat computer screens are starting to come out in about the 35 inch size. This would mean that most of you would not need magnification software, but they are over \$3000 now. Also, I am working on a new low vision device that will magnify the computer screen 6-8 times, let you see the entire screen, and this would also reduce the need for magnification software. I don't know if we will ever get all of the bugs out of it, but it is one of my most important current research activities.

DAN: That is good news for the future. Will we be the first to know when it is developed?

DR. GORDON: That's actually up to the manufacturer. In low vision research, because of the limited, but growing market, we donate our research efforts, get the manufacturer to cover the hard costs (materials and test materials), and then the manufacturer gets to determine how to distribute the low vision device. I love what I do, and I wouldn't trade my practice life for anything!!!!

DAN: FYI, there are over 1000 people on the MD and RP lists combined who use computers like this on a daily basis. Any of us would be more than happy to test new devices for you. :)

JOAN: Comment: Lots of ways to make computer easier to use than print. Mine talks, too. Can we BETA test your new magnifier? Seriously, we would be a good BETA test group.

DR. GORDON: We first need to get the kinks out of the prototype. The problem with the optics now is that your head must be absolutely parallel to the screen, and your line of sight perpendicular to the screen. Even the slightest head movement causes you to lose the image, and the distance from the screen must be exact. It is not a practical instrument yet, and I'm not positive we can overcome it's

shortcomings, but we are working on it.

DAN: As you can see, Bob, we are all very willing to help, combined with a touch of desperation :)

DAVE: Comment. Your optic problems sound just like our world is everyday. We would be glad to assist in any way we can.

DR. GORDON: I understand that. Don't think that doctors are not sympathetic to your problems. We suffer frustration from not being able to fix your eyes, we get frustrated when you don't like the incumbrances from our low vision aids, and we would do anything we could to help you.

DAVE: And we REALLY appreciate it!

DR. GORDON: Thanks.

DAVE: All of the low vision specialists that I have see are the only people that gave me any hope.

DR. GORDON: I guess that is because the nature of our practices is to try and provide you with assistance to utilize your residual vision.

JOHN: Any comments on vitamins, etc?

DR. GORDON: I can comment on vitamins. First of all, and this will sound like my usual disclaimer. There are no long term studies that show that vitamin therapy is beneficial for retinal problems. There is probably longer data for retinitis pigmentosa then for macular degeneration. For RP, the RP Foundation in Baltimore, and Dr. Berson, recommends that RP patients take 15000 units of vitamin A palmitate only. John Heckenlively, the head of the RP clinic at the Jules Stein Eye Institute, studied his data and others, and recommends only 5,000 units of vitamin A, along with vitamin E. Dr. Berson says vitamin E makes RP worse, so who do you believe? As far as MD is concerned, most of are telling patients that taking vitamins won't hurt, as long as they are not in the toxic levels. From what I have read, I recommend that patients take lutein and xanthophyl (blue light blocking pigments), anti-oxidants, zinc but no more then forty mgs, as over forty can cause memory loss. And then [I recommend] other things like ginko, grape seed extract, or bilberry, turmeric acid, glucosamine, etc. if they desire. There is just no good long term study to show if these are effective, so I guess I would rather admit to a patient ten years from now that the vitamins I recommended did nothing, and have them get mad at me for that, then to say in ten years to them that I wish I had recommended vitamin therapy. That is what I tell each of my patients.

JOHN: Thank you so much, Bob.

DAN: Dr. Gordon, you have given us a great deal of excellent information today. Is there anything you would like to say in closing?

DR. GORDON: I would just like to thank you all for sticking with this today. We all hope there will be a cure for MD in the near future, or at least more information that will lead to a cure. In the meantime, don't be too frustrated by the incumberances your visual impairment give you. Losing independence and relying on others, not being able to do simple chores, frustration in reading -- these are all things that we will hopefully be able to help you overcome in the near future with the new low vision devices that will be coming out, and that we have today. Please don't give up hope. Thanks again for this great opportunity to chat with you. It's my first experience on a chat line.

DAN: Thank you for being an outstanding guest, Doctor, and for spending these two hours for our benefit. An edited transcript of this session will be permanently posted on our web site by this evening for many other people to enjoy.

PAM: Thank you so much.

VESTA: Thanks for taking the time to chat with us.

DONNA: Please return again, Doctor.

DAN: Thank you all for coming. Coffee, tea, and cookies will be served immediately in your various kitchens.