

TRANSCRIPT OF THE #MDPEOPLE GROUP SESSION WITH DR. LYLAS MOGK 5/29/99

(Edited for length and clarity)

Dan: Dr. Mogk is an ophthalmologist and author of "**Macular Degeneration--The Complete Guide to Saving and Maximizing Your Sight.**" She is a caring professional who has a personal understanding of MD. Dr. Mogk, thank you for agreeing to be our guest today. Before I open the floor to questions, please tell us about yourself and how you came to write your book.

Dr. Mogk: My interest in ARMD and vision loss began in earnest with my father's ARMD. I started a visual rehab center here to address others' needs and immediately realized the dearth of information. Thence the book. Part of what there was a clear need for was emotional support, recognition of coping problems, practical tips, and on a public policy level, Medicare changes, which I've been working on beyond the book. I'm a member of the Vision Rehab Committee of the American Academy of Ophthalmology. I'm 60, and my 61-year-old sister already has drusen, so this is somewhat of immediate personal problem as well. I'm hoping to blend the now separate worlds of blind rehab and O & M with the medical world of OTs. My OT is also an O & M and a certified blind rehab specialist. This allows for insurance coverage for visual rehab just like there's coverage for rehab from a stroke, for example.

Dan: Thank you, Dr. Mogk. The floor is open for questions.

Linda: The book is great, but what about people under age 64?

Dr. Mogk: Linda, the vast majority of my patients are over 65. I think much of the info in the book is relevant to anyone, but it's certainly true that it's based on an older population. I need to learn from you about those under 65.

Dan: You are subscribed to MDList. That is a good place to start.

Dr. Mogk: Right.

Mel: Do you have any information or opinion concerning the Novel therapy in Israel?

Dr. Mogk: No, actually, I don't. What have you read about it?

Dan: This treatment was mentioned the other day for the first time by another subscriber to MDList. I asked Dr. Gislin Dagnelie about it, and he said that it was in the very beginning stages of research--still using animal models at this time, and nothing too promising yet. Dr. Mogk, MD was identified in 1885. Why has it not had much attention until these past 30 years?

and nothing too promising yet. Dr. Mogk, MD was identified in 1885. Why has it not had much attention until these past 30 years?

Dr. Mogk: The tools to identify exactly what's going on in the retina weren't available until the 60s, namely fluorescein angiogram. And, until the advent of lasers, no one figured out anything else to do.

Dina: We had a discussion recently about estrogen...about taking estrogen if you are a lady over 50. Is estrogen a good thing or a bad thing if you have MD?

Dr. Mogk: Estrogen is possibly a good thing for MD. Not completely proven, but it appears to be.

Dina: Okay, thanks. I know your book said that by 2005 more would be known. Thanks.

Pam: Dr. Mogk, I have ordered your book from Amazon. I take a lot of supplements. I have wet MD. Can you say whether Lutein and other supplements are equally good for wet or dry?

Dr. Mogk: No one knows whether taking lutein makes any difference either before you develop MD or after, and no one knows if there's any difference between wet and dry with regard to lutein.

Dan: Dr. Mogk, there has been quite a bit of press regarding lutein lately. Can you give us a brief description of it, and what it does for the retina?

Dr. Mogk: It's a pigment that is in the fovea, which is the center of the macula. The formal name of the macula is macula lutea, which refers to the lutein. It's thought that it acts as an antioxidant to neutralize the free radicals from light hitting the retina.

Dan: And zeaxanthin?

Dr. Mogk: Zeaxanthin is also a similar pigment with the same function. Some lutein is transformed into zeaxanthin in the body.

Dan: Would you also please define "free radicals?"

Dr. Mogk: Free radicals are normal by-products of oxygen metabolism, meaning that any organism that breathes oxygen produces them. They are like wild cards, though, and must be neutralized before they react with tissues and cause damage. Mother nature provided for this by putting the neutralizers (antioxidants) in food.

Dan: Wine has been touted recently as beneficial to the retina. Is this because of its antioxidant capabilities?

Dr. Mogk: Yes, but only red wine; and it's not the alcohol in it that's beneficial.

Dina: I have myopic degeneration and have just heard that it is a form of macular degeneration. Is it?

Dr. Mogk: Yes, it is, although it may be for different reasons.

Dina: I have myopic degeneration and have just heard that it is a form of macular degeneration. Is it?

Dr. Mogk: Yes, it is, although it may be for different reasons.

Dina: Thanks. I have wondered seriously about that.

Dan: Dr. Mogk, can you give us some statistics on the risk of contracting MD?

Dr. Mogk: The numbers vary in different reports, but fairly consistent is the figure of 17% develop it by 65 and 30% by 75. If you have a parent or sibling with it, your risk is tripled.

Pam: Is the hereditary factor proven? I'm the third generation to have it.

Dr. Mogk: It's not yet shown to be hereditary in the sense of an inherited defective gene, but it runs in families. This is probably because families tend to have the same coloring and environmental influences.

Dan: Would you agree that the term macular degeneration encompasses all diseases which affect the functioning of the cone cells in the macula?

Dr. Mogk: Technically that's true, so to talk accurately about the macular degeneration that is most prevalent, we should use its first name "age-related" or the acronym ARMD. As the term is used without a first name, it generally is called simply macular degeneration.

Dan: Is there any connection between MD and glaucoma, cataracts, or diabetic retinopathy?

Dr. Mogk: No, one's risk is no higher. One doesn't lead to the other. There is some suggestion that cataract surgery may aggravate the wet form, but that's not yet engraved in stone either.

Dan: Is it true that caucasian, blue-eyed, females are more likely to contract MD?

Dr. Mogk: Caucasian, yes, blue-eyed, yes, females, no. It's just that there are more females at much older ages, so they comprise a greater percentage of the ARMD population.

Dan: What role do you think stress might play in the disease?

Dr. Mogk: Aside from the caveat that stress can do anything, I have not thought nor read that it has anything to do with it. One dilemma with ARMD is that these are the healthy people getting it. The ones who abused their bodies and were totally stressed out often die younger.

Pam: You say there are more older women, but in this group a lot are under 60 and there are men and women.

Dr. Mogk: But it appears that some/many in this group have another form of

Pam: You say there are more older women, but in this group a lot are under 60 and there are men and women.

Dr. Mogk: But it appears that some/many in this group have another form of macular disease, not specifically ARMD, right?

Dan: If I may interject, Pam, that could be the unique demographics of the average computer user. I have sent Web Books to many older people, and most have been women.

Pam: I suppose so.

Dr. Mogk: Now, don't extrapolate from my computer skills that women in general are bad at it!

Dan: You are doing great for your first time :)

Dr. Mogk: Thanks. It certainly would fit that younger men would be more proactive in this regard than older women, and older men too for that matter. Younger in my book is under 70.

Dan: Dr. Mogk, would you please elaborate on the importance of melanin as an absorber of blue light? And what can blue-eyed people do to protect themselves?

Dr. Mogk: The reason people with dark skin don't get fried in the sun is that the melanin absorbs and diffuses it; that's the same reason lighter skinned people get tan. If you don't have much melanin under your iris you have light eyes, and you also probably don't have much melanin under your retina. The lens of your eye absorbs the UV rays, but the visible wavelengths right next to the UV, which are the blue, get through, and it appears they do damage. Is that clear? Blue wave lengths are just a little longer than UV, so on the spectrum they're next to UV.

Dan: I understand. What can be done for good protection?

Dr. Mogk: Blue-blocking sunglasses. A visor.

Dan: Tom, who is with us today, has just been declared "legally blind." Would you give us the accepted definition of that and your opinion on the use of the label?

Dr. Mogk: The legal definition is 20/200 or less in your best eye with the best correction, or a visual field of 20 degrees. The parameters were set in the 20's and called "economic blindness" and the name was changed to "legal" in the 40's. It's an anachronistic term that should be eliminated. An international committee is working on a new way to describe vision and vision loss, on a spectrum from perfect vision to complete blindness, with no arbitrary point like that.

Dan: Along those same lines, you have said that the 20/20 standard of measurement for visual acuity is misleading. Would you please discuss that?

Dr. Mogk: 20/20 doesn't tell you about contrast discrimination, adaptation to glare or lighting conditions, or visual field restriction, and it certainly doesn't allow for

measurement for visual acuity is misleading. Would you please discuss that?

Dr. Mogk: 20/20 doesn't tell you about contrast discrimination, adaptation to glare or lighting conditions, or visual field restriction, and it certainly doesn't allow for factors of alertness, attention, or effort.

Dan: So to be declared legally blind on that measurement alone is not accurate in every sense of the word.

Dr. Mogk: True, but it's the accepted standard, at least for now.

Dan: I have watched Tom maneuver around the city of New York very well. Much better than I could, and my vision is still pretty decent.

Dr. Mogk: Exactly.

Dan: You dedicate two chapters in your book to diet. How important is what we eat in dealing with MD?

Dr. Mogk: I think it's important for three reasons. One is that it may, and probably does, actually have an impact on the disease process, although that's not proven. The second is that if you have some physical challenge to deal with, you can do it better if the rest of your body is healthy. And the third is that I think it's helpful psychologically to intervene in one's own behalf when faced with a problem no one has an answer to.

Dan: In other words, it can't hurt.

Dr. Mogk: It can't hurt your eyes, and it makes your whole self healthier.

Dan: What would you consider to be a good, balanced diet for MD people?

Dr. Mogk: Lots of fruits and vegetables, minimal fat but good fat--like olive oil--and no artificial fats such as in low fat baked goods. Avoid partially-hydrogenated vegetable oils, which are not counted in the labeling of fat, but are listed in the fine print.

Dan: I get hungry reading the great recipes in Chapter 4 of your book...and I don't even like vegetables.

Dr. Mogk: That's great! Everyone in my office tried them before we put them in the book.

Dan: On another subject, do you feel that doctors, in general, are not sensitive enough to their patients' emotional needs? This has been an ongoing topic on MDList.

Dr. Mogk: That's a big one. I think the training of doctors in this country forces them to ignore their own emotional needs so they are not often very well equipped to deal with others'. Ophthalmologists in particular are used to solving their patients' problems; it's generally considered a "happy" specialty. So they're really stressed

forces them to ignore their own emotional needs so they are not often very well equipped to deal with others'. Ophthalmologists in particular are used to solving their patients' problems; it's generally considered a "happy" specialty. So they're really stressed when they can't do anything and often do not handle that well.

Dan: I have heard it said that MD people do not bring in enough money to the doctors, and this may be a reason why we are often ignored. In other words, there is no treatment, so there is no income. What do you think about that rather negative opinion?

Dr. Mogk: Wow. That's an awful take on it. I really don't think that's the reason. I think it's that there is no treatment and that's what they believe they're there to provide, and they can't provide it. They are facing their own limitations.

Dan: Thank you for allowing me to lay that out on the table. I tend to agree with you that most doctors really do care.

Pam: A comment not a question. I'm in the UK. I'm told, "Nothing can be done. Come back in twelve months, or sooner if you notice change." That's it. No support at all.

Dr. Mogk: I'm actually amazed to hear that, because I have thought that the UK, as well as Scandinavia and much of northern Europe, are way ahead of civilian US medicine in visual rehab.

Dan: I have often said that we expect too much from the doctors. If we expect only technical advice and reasonable diagnoses, then we won't be disappointed. If we also get good emotional support, we are fortunate, but that is relatively rare.

Pam: Because one eye is OK they think I am OK too.

Dr. Mogk: Studies of depression in visually impaired people have suggested that people with loss of one eye are more depressed than those with both.

Dan: What would you say to a person who is severely depressed after receiving this diagnosis?

Dr. Mogk: I would highly urge them to do three things: begin visual rehab actively, get psychological counseling simultaneously, and do not cut back on any activities or social contacts. And I'd like to add one more thing: I would urge them to not put their vision at the core of their self image or self definition.

Dina: I have two comments. If you only have one good eye, you are depressed because you are wondering when the other eye is going to go. And one way to get undepressed is to join the MD List. It worked for me.

Dan: Glad to hear that, Dina.

Dr. Mogk: I believe that's exactly the case; in a sense, the anticipation is more stressful than the reality.

Dr. Mogk: I believe that's exactly the case; in a sense, the anticipation is more stressful than the reality.

Dan: What are some symptoms of depression which friends and family members need to watch for?

Dr. Mogk: Withdrawal, weight loss or weight gain, poor sleeping, crying bouts, lethargy.

Dan: What can we do to help ourselves deal with our loss of abilities and confidence?

Dr. Mogk: Practice the skills, focus on what you can do and do things that way, whatever way it takes. I think the dynamics may well be different for younger people. Adapting to vision loss best are those who disregard rules, are outgoing, and a bit in-your-face before the vision loss!

Dan: This is an important area which is one of the main reasons for the existence of our Internet MD Community. Would anyone here like to comment on their own personal experiences along these lines?

Pam: I have suffered depression in the past, and I know that the List has been a life saver for me.

Donna: Me, too.

Dina: I have never met anyone else with MD. Just knowing I wasn't the only one was great.

Dr. Mogk: The list is a wonderful support group, which I recommend to everyone. (A support group, I mean.) I would love to get my patients on it, but most don't even have computers.

Dan: That is why we offer the Web Books. Through our HumanLink effort, this community is available to everyone. Does anyone have any further comments or questions for Dr. Mogk?

Donna: We need more people to know we're here. Can you help us in that way Dr. Mogk?

Dr. Mogk: I will be happy to tell every one of my patients. Most of them don't have computers, but their kids might. This is a wonderful support group!

Dan: Dr. Mogk's book covers all of the subjects discussed here today. It is available through the LowVis Bookstore on our web site. You may also want to visit her web site at www.macularguide.com for more information on herself and her family.

Donna: Dr. Mogk...get the Web Books Dan just mentioned. They are mainly for people without computers.

Dr. Mogk: Yes, I need to know about the Web Books.

Donna: Dr. Mogk...get the Web Books Dan just mentioned. They are mainly for people without computers.

Dr. Mogk: Yes, I need to know about the Web Books.

Dan: We should also mention that Dr. Mogk' daughter, Marja, co-authored the book and was the person who first got in touch with me about a session here. Dr. Mogk, thank you for meeting with us today. You sound like a doctor whom we all would like to have as our own.

Dr. Mogk: It has been a great pleasure for me. Thanks for having me.

Dina: The book is great, and so was this session.

Dan: And thank you, everyone, for attending. Our next session will be in September. See you again then.