

# Transcript of a chat session with Dr. Phil Filner 3/14/98

*(Edited for clarity and length)*

DAN: Welcome, Phil. Would you like to make some opening remarks?

DR. FILNER: Ok. First, keep in mind I am not an M.D. or D.O. Second, I want to open the scope of the discussion possibilities to include access politics, not just technical stuff. Your turn, folks.

DAN: Wilma, you have the floor.

WILMA: Thanks. My dad 84 has MD. His dr has not referred him to low vision specialist. He is not able to drive a car or see well at all. my question: has research on low vision devices shown a help to the extent that dr's are comfortable making referrals?

DR. FILNER: First, people with decreased or lost central vision can be greatly helped by low vision devices. There are a number of people on the MD list who have personal experience which has been good. Many physicians/ ophthalmologists know little about low vision devices because it is outside their training and practice. Most people who know a lot about about low vision devices seem to be optometrists.

Second part of your question: MD compared to RP. In MD, the central vision deteriorates. In rp, the peripheral vision deteriorates. The two kinds of disorders are complementary in a sense. Treatments are woefully inadequate for both types of disorders.

DAN: Judy, you have the floor.

JUDY: I use a number of low vision devices, and they make all the difference in being able to do things or not being able to. I can drive during the day, using my monocular to read signs. I use magnifying reading glasses and hand-held magnifiers, depending on the task. I use a very large face watch. For those who use computers, I recommend the largest monitor you can get. I'm using a 21", and that's a big help. When I go to plays, I use a 7X binocular.

DAN: Thanks, Judy. Merry, you have the floor.

MERRY: Hi. I am typing for my dad, Sid. He has wet MD in right eye for last year. He was just told he also has it in left eye. He is 74. He has a few questions. What is the % of success with laser with wet?

DR. FILNER: It depends to some extent on the surgeon's self-discipline about using or not using the laser.

MERRY: Meaning?

DR. FILNER: Generally, for those for whom laser surgery is indicated as appropriate treatment, about 50% benefit.

MERRY: They did laser in my dad's right eye when it first happened.

DR. FILNER: If the surgeon chooses to use the laser more often than he should, the percentage will go down.

MERRY: And all it did was destroy what little vision he had left in central. How do you make the decision whether or not to do the laser? How does the patient decide?

DR. FILNER: A tough question. Where did you have the laser surgery done previously?

MERRY: Lankenau Hospital, Wynnewood PA. Burb of Phila. Dr. Lov Sarin.

DR. FILNER: The question in my mind is: how much laser photocoagulation work on people with wet form MD does he do? I don't know the requirements for membership.

MERRY: Don't know the answer to either of those questions. also works at Wills Eye Hospital.

DR. FILNER: Laser surgery always does some damage to vision, but it is supposed to be kept to a minimum by careful choices made by the surgeon.

MERRY: Do you know anything about a medicine being used in Canada in place of the laser?

DR. FILNER: The benefit is usually not an improvement in vision, but a slowing or temporary stopping of the decline of central vision. Usually, the benefit lasts about a year, on average.

MERRY: Then can you do it again?

DR. FILNER: It depends on where in the macula the leakage resumed. Going to a major medical center where a lot of it is done would be the best way to ensure it is done as well as it can be done. Also, there are other types of methods being

evaluated for stopping or slowing leakage. These include photodynamic therapy (QLT Phototherapeutics, Vancouver, BC, Canada) There is also work on using xrays and proton beams. None has yet been proven to be effective.

DAN: Bob, you have the floor.

BOB: Phil, most people seem unfamiliar with angiogenesis...please describe in laymans terms the process and the future treatment possibilities in stopping this process in regard to MD.

DR. FILNER: Or at least sufficiently effective to be practical. Angiogenesis means formation of new blood vessels. It is a part of the development of solid tumors, cancers. Cancers promote their own growth by inducing angiogenesis, which brings a rich supply of nutrients to the tumor. Anti-cancer researchers are seeking angiogenesis inhibitors as anti-cancer drugs. Neovascularization is another term for a very similar process in wet form macular degeneration. The hope is angiogenesis inhibitors will also be neovascularization inhibitors.

BOB: Is the surface molecule finding on the new blood vessel growth the same regarding MD?

DR. FILNER: There is almost nothing known about the cellular or molecular details of wet form MD.

DAN: Millie, you have the floor.

MILLIE: How do I find the most qualified in my area for dry AMD...Where do I look...what do I look for?

DR. FILNER: There is no treatment, so I guess the key then is finding someone who will be forthright, and who will tell you about the benefits of low vision devices.

DAN: Merry, you have the floor.

MERRY: Do you know anything about a new med being tried in Canada instead of laser?

DR. FILNER: I thought I had already mentioned photodynamic therapy and QLT Phototherapeutics.

MERRY: I didn't know that was the same thing. how is that done?

DR. FILNER: Well, it is what fits best with your question, at least..that I know of..

MERRY: Do you know about the implants done in Chicago?

DR. FILNER: There was one press release, and then nothing further about what they were trying in Chicago. If someone has more up to date info, I would like to hear about it.

MERRY: I have a 4 page report on it. I'll get you the url. I was under the impression that there was a medication - pill that was being tried in Canada to stop the leaking.

DR. FILNER: You know more than I about it.

MERRY: So, Phil do you know about any new pill?

DR. FILNER: A pill which is supposed to do what?

MERRY: Stop the leaking. Using a med instead of laser so there isn't the danger or damaging the vision.

DR. FILNER: I only know of one angiogenesis inhibitor which was being tested: thalidomide. News/info about an actual drug shown to work has not yet come up on my radar screen. Some things people think may be able to stop the leaking...None has yet been described, at least which I have read about.

DAN: Thank you, Merry. Judy, you have the floor.

JUDY: From your research, what do you think about nutrition's role in arresting, preventing, or reversing dry MD, including Stargardt's? What do you think of vitamin complexes, specifically for vision, such as OcularX (developed by eye doctors, for which one needs a prescription)?

DR. FILNER: Being rather conservative concerning drugs, I want to see solid evidence from well-degined clinical trials that a drug, diet supplement, vitamin, whatever, actually is beneficial for people with MD.

JUDY: Have you read of any bad effects from some of these multivitamins?

DR. FILNER: Very high levels of some vitamins are known to be harmful.

DAN: Tom, you have the floor.

TOM: Phil, I was accepted in a photodynamic trial, and flunked out of it before the supplies arrive. What do we know thus far about the success of this therapy?

DR. FILNER: Not much. Some preliminary small-scale, short-term studies were done in Europe. The people who started the clinical trials thought that the preliminary results were sufficiently encouraging to justify clinical trials but there wasn't a long enough duration in those preliminary studies to be convincing. The jury is out until some data are published.

DAN: Thank you, Tom. Millie, you have the floor.

MILLIE: What if anything can be done to slow loss of central vision in dry AMD?

DR. FILNER: At present, no procedure or treatment has been proven to be effective against dry form MD. However, in studies of the differences in life styles of people with and without MD, evidence was found suggesting that people who had for a long time eaten lots of leafy green vegetables have about half the probability of developing MD, compared to people with more normal ...

DAN: Oops. Phil has fallen off. he'll be back.

MERRY: And I thought he got sick of us. haha

DAN: Linda, you will have the next question, then Merry, then Judy.

DR. FILNER: Temporarily lost my PPP connection.

DAN: No problem, Phil. Please continue. You were talking to Millie about green vegetables.

DR. FILNER: Why people who eat lots of leafy greens have less MD is not known for certain. It has been speculated that the xanthophylls in the veggies are the source of the benefit, but this has not been demonstrated yet experimentally.

MERRY: Do supplements work as well as veggies?

DR. FILNER: At present, nobody knows. Nobody knows if someone starts eating leafy greens now, whether or not that will slow or stop MD which has already started.

LINDA: Regarding nutrition, do you know of any bad effects on the eye (macula) from too much sugar in the diet? or specifically, too much CHOCOLATE?

DR. FILNER: Concerning sugar and chocolate, if you are a diabetic and do not carefully control your blood glucose level, and dietary intake of sugars, you could become a victim of diabetic retinopathy. Other than that situation, I am not aware

of any hazard to the eye from sugar or chocolate, unless someone throws a sugar cube in your eye.

DAN: Thank you, Linda. Merry, you and Sid have the floor.

MERRY: Who wants to have to give up chocolate, too? OK, back to the research. what do you know about cortisone drugs?

DR. FILNER: In what context?

MERRY: I know it is being tried. I wanted to know if you know anything about the success of it.

DR. FILNER: Some eye disorders which can cause deterioration of central vision but are not macular degeneration involve "inflammation". some are caused by infections. Some corticosteroids are used as antinflammatory drugs. That may be what you are remembering.

DAN: If I may interject, there was a report indicating problems with systemic injection of steroids, which accelerated the separation of the retina.

MERRY: How do you find the right doc? Do you know of any docs who have done the laser many times with success anywhere in the world?

DR. FILNER: I do not know them personally, but you will usually find them at the major medical centers, such as Wilmer, Sheie and Schepens.

MERRY: Are those three the best?

DR. FILNER: Those are eye institutes at Hopkins, Penn and Harvard. I am not in a position to judge.

DAN: Also, Dr. Lawrence Yannuzzi in NYC is reputed to be the best in this field. He is at the Vitreous-Retina-Macula Center in Manhattan.

MERRY: Thanx, Dan.

DAN: Any questions from anyone else?

WILMA: Any research sources discussing variables favorably associated with the referral and utilization of low vision rehabilitation services and devices?

DR. FILNER: Very good question. Not enough such research has been done. The

Macular Degeneration Foundation very recently received a request for help in finding people for such a study, I believe in Pittsburgh. We haven't yet posted the announcement of the study. The National Eye Institute, a unit of the National Institutes of Health has the subject in its 5 year plan, but I have not seen much evidence of implementation of that part of the plan. It is an area where much more should be done, because the benefits would be sooner rather than later for people with MD.

DAN: Thank you, Wilma. Merry, you have the floor.

MERRY: What will happen if he does not do the laser?

DR. FILNER: At best, a laser treatment temporarily slows or delays the decline of central vision. Without the laser treatment, you can be fairly certain that further decline will occur in the course of a year or two, maybe sooner.

DR. FILNER: Maybe I misunderstood the question, because I just looked over my answer and I would not change it.

DAN: Tom, you have the floor.

TOM: I have just been put in touch with the VA rehab center in NYC for low vision? Do you know anything about other VA rehab operations?

DR. FILNER: A little. In Northern California, they provide training in the use of computer-based magnification systems, and will provide the system as a free benefit for veterans with MD.

TOM: Sounds about like what there is here. Veterans might want to check it out. I do.

DAN: Thank you, Tom. Anne, you have the floor.

ANNE: What do you know of the treatment of Triamcinalom injected into the eye in Australia?

DR. FILNER: Nothing. Tell me more.

ANNE: Its a steroid, and they are having some success depending on when you start the treatment.

DR. FILNER: Can you clarify what you mean by success, and what is the evidence?

ANNE: Well they seem to inject steroid into eye once and follow with tests. It seems to delay the degeneration. I am not the expert, wondered if you knew of it.

DR. FILNER: Will see what I can learn about it after this session.

DAN: Thank you. Any further questions?

MERRY: I was asking about the treatment in Canada. Is that the photodynamic therapy that you were talking about with Tom? That is not the treatment that I was referring to in Canada. The PDT is also being done in the U.S. What I am talking about is not in the U.S., only Canada.

DR. FILNER: Can you be more specific about this Canadian treatment?

MERRY: Do you know anything about THAT? That was my question.

DR. FILNER: It does not ring any bells in my head.

DAN: Please remember, that--as Phil stated at the beginning of the session--he is not an OD or MD. Some of our questions today have been more or less out of his field. any questions about research, development, or political issues related to low-vision?

MERRY: What is he?

DR. FILNER: I am a Ph.D. biochemist/molecular biologist.

MERRY: Isn't that what I'm asking, Dan? Isn't that a research scientist?

DR. FILNER: Essentially.

MERRY: So who do I ask about these research things that I have read about? How about the X-rays being done at Cedars? They seem to be having success with it.

DR. FILNER: I don't know which "Cedars" you are referring to. There are many hospitals with that name in the U.S.

MERRY: Cedars Sinai in LA.

DR. FILNER: The evidence for X-rays as a treatment for wet MD is quite controversial, because most of the studies are poorly designed, lacking necessary controls. It was shown last year that the finding of 65% of treated patients had no further decline in central vision after 1 year, was not significantly different from the result obtained with a large untreated group.

DAN: Thank you, Merry. Barbara, you have the floor.

BARBARA: Thanks. I wanted to ask a question for daddy concerning his wood working. He says he wonders is there is anything that would help him about arm's length to see the machinery he is using?

DR. FILNER: His best bet would be a combination of an optical magnification device, and training himself to make more use of his peripheral vision, i.e, not look directly at the machine, but rather look at it sideways.

BARBARA: Thank you, Phil.

DAN: Thank you, Barbara. Gary, you have the floor.

GARY: Phil...would it be safe to say that other than laser treatment there are few if any additional treatments that are effective in treating either wet or dry forms of MD?

DR. FILNER: You understand the situation exactly.

DAN: Judy, you have the floor.

JUDY: Going back to the difference between MD and RP for a second. MD people don't usually have the mobility problems that RP have, because of their often severely narrowed field of vision.

DAN: Thank you, Judy. We look forward to having you as our guest in April. the session has gone for two hours now, and we will be ending soon. Any final questions?

DR. FILNER: Also, people with RP lack night vision, i.e. cannot see in dim light.

DAN: Okay, if there are no more questions, I would like to thank Dr. Filner for being our guest. It has been a very fast and full two hours.

DR. FILNER: Thanks to all of who who hung in there throughout the session.

DAN: Thank you all for attending.