

NATIONAL MULTIPLE SCLEROSIS SOCIETY  
MS LEARN ONLINE INTERNET PROGRAM

Disease Modifying Agents: Questions and Answers

>>Welcome, and thank you for joining the National Multiple Sclerosis Society's MS Learn Online Internet program. I am Rick Turner your and host and medical correspondent.

The management of multiple sclerosis has been substantially advanced by the availability of the disease modify agents. Today, in our last of four web casts, our guest, Dr. Fred Lublin, will be answering many of the questions we have received from our listening audience on managing MS with disease modifying agents. Dr. Lublin is a Saunders Family Professor of Neurology at Corrine Goldsmith Dickinson Center for multiple sclerosis at Mt. Sinai Medical Center in New York.

Once again, welcome to the program Dr. Lublin.

>>**Dr. Lublin:** Thank you Rick, nice to be here again.

>>**Rick Turner:** As we go through these questions it may be more appropriate for some of them to be addressed by your nursing staff. Our first question comes from someone who would like to know how often an MRI is recommended to track one's response to disease modifying drugs.

>>**Dr. Lublin:** We do not know the answer to that yet and there is not a consensus amongst the multiple sclerosis specialists around the world on this issue. The main problem is that it is a little hard to know what the MRI would have looked like had the individual not been treated. I partially do not perform periodic MRIs on individual once I have started them on therapy but rather get them if something untoward happens or causes some additional concern. This is still an open issue.

>>**Rick Turner:** OK. The next question is from Shelly who writes: Betaseron claims to be a no refrigeration med. We live in California where the temperatures are 80+ degrees for six months of the year. The sheet included with the med says no refrigeration is needed up to 76 degrees. I am assuming I need to refrigerate this med above 76 degrees. Am I correct?

>>**Ms. Morganty:** Hi Rick. My name is Linda Morganty and I am a registered nurse at the Corrine Goldsmith Dickinson Center for MS at the Mt. Sinai Hospital

in Manhattan. Dr. Lublin has asked me to address this question regarding the environmental temperature and storing Betaseron. I actually did check with Pathways which is the patient support program for Betaseron and asked them about refrigeration and temperature. I found out that Betaseron can be stored at temperatures even higher than 80 degrees so it never needs to be refrigerated. It can be stored at very high temperatures without ruining its stability so people do not really have to worry about keeping their Betaseron at room temperature and will actually never have to refrigerate it. So, for traveling or for living in hot and cold places Betaseron seems to be a very stable product. I do recommend when you have questions like this you always contact your patient support line because they are the real experts about the product. They can answer almost any question you would have about their specific product.

>>**Rick Turner:** Charles writes: I am currently taking Avonex and it seems to be working. My question is this: is the drug a long-term drug? Is there a time when I will be able to stop using this drug?

>>**Dr. Lublin:** For the moment these are long-term agents. We plan to treat individuals probably forever not necessarily with the same drugs though. What I tell individuals when they ask how long they are going to have to take it is that they should plan on taking the medication prescribed until we have something better.

>>**Rick Turner:** Until something better comes along. Yes. Karen would like to know how close we are to an oral disease modifying medication for relapsing-remitting multiple sclerosis.

>>**Dr. Lublin:** Several oral agents will go into late phase testing, that is, the type of testing that ultimately if successful leads to approval over the course of this year. Since they are just starting the course of this year it will still take at least three years to sort out the results.

>>**Rick Turner:** Right. The next question says, I have been on Betaseron since 1996 and have had numerous exacerbations which I then treat with steroids. My question is why do I still get exacerbations while on Betaseron?

>>**Dr. Lublin:** We know from clinical trials that none of our available agents are cures, that individuals may still have some attacks but they are fewer, as a group at least, than if they had been on no therapy at all. For any given individual, medication may not be working and one might consider something different.

>>**Rick Turner:** A question from Nina states: I have a mild form of multiple sclerosis but I do have trigeminal neuralgia with it. Do these disease modifying drugs help with trigeminal neuralgia?

>>**Dr. Lublin:** No, they do not change any of the symptoms of MS that someone may already have at the time they start the medication. The disease modifying agents lessen the risk of having new attacks. Any symptoms that were there are not usually affected by these agents.

>>**Rick Turner:** A listener named Lane wants to know: of the present medications available, how do we know we are taking the ones that would do the most good for us?

>>**Dr. Lublin:** We do not know the answer to that yet. One of the questions that we are trying to answer in clinical trials that are getting started now is how can we determine who is and who is not a responder to any given agent. It is a very important question and we hope to get an answer in a few years.

>>**Rick Turner:** Don wants to know if there is any benefit in taking one of the approved drugs for relapsing-remitting MS if you have primary progressive even though none has been validated for the treatment of that.

>>**Dr. Lublin:** I addressed this issue in an earlier broadcast. I would say my own belief is that it is worth trying one of the agents even though we do not have good data that they would be effective.

>>**Rick Turner:** It necessarily would not hurt to try.

>>**Dr. Lublin:** Well, again it is a little difficult to answer. So does it hurt to try? In a sense it does if you are taking an agent even while with very few side effects for something that is not going to help, then that is not very good. We do not know for certain whether any of these agents would help primary progressive MS. My own belief, and this is just my feeling, is that it is worth trying.

>>**Rick Turner:** Good. Gail wants to know if there is any way to get help to pay for these disease modifying agents.

>>**Dr. Lublin:** There is. Each of the companies that produce the agents we have has a special access program for individuals with limited means. Gail needs to

contact the company of the agent that she is planning to take or maybe even several of the companies to see whose program she qualifies for.

>>**Rick Turner:** Generally, how expensive are these drugs Doctor?

>>**Dr. Lublin:** They are quite expensive in the order of \$1,000.00 a month. give or take.

>>**Rick Turner:** We have had several questions on the topic of low-dose Naltrexone. Tell us what Naltrexone is Doctor, if it has treatment benefit and if it is a viable option for people with MS.

>>**Dr. Lublin:** Naltrexone is a narcotic antagonist. That is, it blocks the effects of narcotics and it can reverse those effects if someone, for example, has an overdose of narcotics. There is no controlled clinical trial evidence that it is of any benefit at all in multiple sclerosis, so there is no data such as we have for interferon or glatiramer acetate. There are lots of advertisements on the internet but I do not know of any information confirming that it is of any value in patients with multiple sclerosis.

>>**Rick Turner:** We have a question from Trish in Oklahoma who writes: I am in the Campath three-year study comparing Rebif and a low dose and a high dose of Campath. I know that Campath is monoclonal antibody. I know that Tysabri is also a monoclonal antibody. Should I be worried about being in the Campath study?

>>**Dr. Lublin:** No. The side effect that occurred with Tysabri related to that specific monoclonal antibody. There are not any concerns when one takes other monoclonal antibodies because the side effects are specific to the target of the monoclonal antibody. The target in Campath is very different from the target with Tysabri.

>>**Rick Turner:** Basically, what is Campath?

>>**Dr. Lublin:** It is a monoclonal antibody that attacks T cells and destroys them. That is very different from Tysabri which targeted a molecule that was involved in moving cells out of the blood stream and into the nervous system.

>>**Rick Turner:** Our next question is from Kari who says: I would like to know the theory supporting the use of CellCept as an MS treatment. What results have

been reported, whether any ongoing studies are being conducted and what the expectations are for it?

>>**Dr. Lublin:** CellCept is an immunomodulator or immunosuppressant, somewhere in between. I do not know of any controlled data showing that it is a benefit multiple sclerosis. There are individuals using it anecdotally, that is just based on their own experience. I do not know if there are ongoing controlled trials with CellCept.

>>**Rick Turner:** Dr. Fred Lublin, thanks again very much for helping us with some of our listener questions today. It has been very informative.

>**Rick Turner:** The National MS Society is proud to be a source of information for you about multiple sclerosis. Our comments are based on professional advice, published experience, and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice consult a qualified physician. If you have a question that was not addressed, please E-mail us at [mslearnonline@nmss.org](mailto:mslearnonline@nmss.org). If you would like more information on multiple sclerosis, click on the resources link on your screen or call the chapter nearest you for an answer to your question. You can reach your chapter by calling 1-800-FIGHTMS. That is 1-800-344-4867. You may also want to check the National MS Society's web site where you will find more information about today's topic and a menu of other web casts available to participate in.

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For the National MS Society I am Rick Turner wishing you health and happiness.