

NATIONAL MULTIPLE SCLEROSIS SOCIETY
MS LEARN ONLINE INTERNET PROGRAM
RESEARCH 2007
WHAT THE FUTURE MAY HOLD

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

Multiple sclerosis is still a mystery disease, no known cause, no means of prevention and no cure. But today safe effective treatments are available for most forms of the disease, and significant relief of many symptoms can be achieved. In addition, research in MS is accelerating with new findings occurring yearly. It should not be long before important parts of the MS mystery are solved.

Today's web cast is the second of a two-part series focusing on the latest in MS research. We are very pleased to have as our guest for this series Dr. Patricia O'Looney. Dr. O'Looney is Vice President of biomedical research for the National Multiple Sclerosis Society headquartered in New York City.

Once again, welcome to MS Learn Online, Dr. O'Looney.

>>**Dr. O'Looney:** Thank you, Rick. It is my pleasure to be here.

>>**Rick Turner:** There is certainly some exciting research, and it is a campaign called PROMISE: 2010 focusing on four areas of MS research. These specific areas include nervous system repair and protection, pediatric MS centers, a longitudinal study, and the MS Lesion Project. So let's take a few minutes on each of these important areas beginning with nervous system repair and protection. What type of research is being done and what are the research goals in this area?

>>**Dr. O'Looney:** Let me just begin by saying that our current understanding of MS suggests that, of course, the immune cells enter the central nervous system and initiate an attack on myelin resulting in a loss of myelin and also the loss of the underlying axon, a nerve fiber, that the myelin is protecting. What we do not understand right now, of course, is disease progression. What are the mechanisms that contribute to this loss of axon? Although we have known that there has been strong evidence for inflammation or the involvement of the immune system in multiple sclerosis, there has been a shifting in our thinking about multiple sclerosis

in the past three or four years, and that shifting has involved the loss of the axon itself.

As I often say to individuals, think of the myelin protecting an antique table or a precious item; and if you remove the myelin or that protective covering, it does make sense that now you have exposed the underlying mechanism, the underlying body which is the axon in the human body, to whatever the environment was attacking the myelin. So now you have the axon, or the nerve fiber, which is also being impacted by the disease process; and it is occurring earlier than we originally thought in people with MS, which is probably not the best of news, but it certainly has propelled us forward to do something about it. So of course, as you mentioned, the first component of the PROMISE: 2010 campaign is focused on repair and protection, that we now realize how important it is to try and repair the myelin that is lost in MS, but also to protect the axon and obviously then to protect the myelin that you have just repaired.

The MS Society put out a call to the scientific community for proposals focused on repair and protection in MS. Through a competitive process we identified four teams of researchers who are funded with this PROMISE: 2010 campaign. This represents actually an international group of more than 50 investigators focused on this topic.

The question we do not have answers to is how do you repair myelin? Perhaps it might be stimulating the cells that are already in the brain or the damaged area, that something is blocking their ability to repair myelin. Or is it actually injecting cells of some source. But then you have to be able to control the fate of those cells in making sure that they become myelin making cells. So there are still a lot of questions that need to be answered, but there certainly is great progress being done in this area.

>>**Rick Turner:** Traditionally we have always heard that the therapies for MS do not stop the disease. They just prevent it from getting worse, but it sounds like if we could find ways to repair myelin or even the underlying axon, that would be a significant advancement.

>>**Dr. O'Looney:** Absolutely. The scientists feel that the progression of the disease, the disability, is related to the progression of the disease, so our goal, of course, and what you may see in future therapies of people with MS is really a three-front approach: control the immune system, repair the myelin, and to protect both the myelin and the axon. Most scientists and clinicians feel that to really stop

this progression of the disease we are really going to have to go down all three avenues.

>>**Rick Turner:** Alright. Let's move on to the next area of focus in PROMISE: 2010, and that is pediatric MS because it seems like only in the last five years have we begun to hear about pediatric MS with any sort of regularity. What is the goal of these pediatric MS centers, doctor?

>>**Dr. O'Looney:** That is true, Rick, that we often think of multiple sclerosis as an adult neurological disease. But as we have improved our diagnostic ability including particularly the use of MRI, we are now realizing that perhaps as many as 5% of the MS population is comprised of children. That represents maybe as many as 25,000 individuals. As we are learning about this information, of course, what comes to mind is the special needs for children who have multiple sclerosis. What I mean by special needs is can you imagine how difficult it is to be diagnosed with MS as an adult, how difficult it would be if you were a child and you have peer pressure and you are going through schooling. Again, the MS Society, when we try to fill those unmet needs, is we identify the fact that pediatric MS centers were needed to try and network and to coordinate care for children with MS and their families. Again, through a competitive process, there were six pediatric MS centers which were identified a couple of years ago, and they are located in Alabama, California, Massachusetts, Minnesota, and also in Long Island, New York. The goal here, of course, is to coordinate care for children with MS, and the picture indeed is getting much brighter for these children and their families. The first step, of course, was to identify the centers. Then the group came together to build a consensus of what a proper definition of MS is in children. Does it present itself differently than with adults? These centers are now building a network in which they are sharing information, building a data base where data will be collected so we can understand more about the disease in children, and they are also building and developing a protocol for how MRI or scans are read in a very consistent way. That is actually a very crucial part of this process. What is also important is that there are social workers involved because, again, if you think about one of the common symptoms of MS being fatigue, can you imagine what it must be like to be a child with MS and then trying to go through schooling and maybe perhaps being too tired to take a test, and the student nurse and the principal and the teacher are not used to seeing children with MS. So, built into the six-center network is also involving social workers who will reach out to the children's school so they can understand the impact of MS on not only the child but also the family. So these efforts are truly breaking new grounds and providing excellent

care for children with MS, which of course will also help us understand the disease in general, as well.

>>**Rick Turner:** That is great to hear. Another research focus is titled the Sonya Slifka Longitudinal MS study, and its purpose is to understand the impact of MS. Now that sounds a bit daunting, so how are researchers accomplishing this?

>>**Dr. O'Looney:** Obviously for the MS Society to be true advocates for people with MS, we need to know how MS impacts their lives. So to truly understand the impact of MS on people's lives, we needed to ask the people who have the disease multiple sclerosis. The goal of this data base which we actually began six years ago through a generous contribution of Richard Slifka, who is a national board member of the Society, and he made a contribution in honor of his mother, Sonya Slifka who had MS. This is the first study of this kind in the United States in which information is being collected among a sampling of 2000 individuals across the United States, an information repository of information focused on social, medical, economic information about the lives of people with MS. Obviously this information will help us be true advocates for people with MS. For example, we are finding that 30% of people with MS need home care assistance, or the fact that of how many individuals with MS may be unemployed or are lacking insurance. So as we gather this information we can then go to perhaps Congress or the Hill to really have numbers before us instead of just general themes. We can actually have numbers and demonstrate how the impact of the disease has on people with MS and can be true advocates for them.

>>**Rick Turner:** Right. As I understand it, the MS Lesion Project exists to help us understand why people experience MS so differently. Is that a fair explanation, Doctor, and what are they finding so far?

>>**Dr. O'Looney:** That is actually a very good explanation Rick. The MS Lesion Project certainly is probably a daunting title for those who are listening, but that is basically what the focus of this project is. Is the damage in MS different for different people? I think most of the time when you talk to people who study the disease or people who have a disease like multiple sclerosis, there is truly an understanding that there is such a variety in people with MS. That is one of the hallmark characteristics of MS is its variability. We now know that myelin is lost in MS, but is it because myelin is attacked directly by the immune system or are the cells that make myelin also impacted or lost. Of course, if you lose the cells that make myelin then, of course, the resulting fact is the loss of myelin. So is the loss of myelin primary attack or is the loss based on a secondary action?

It was actually a few years ago that we brought a group of scientists together to talk about the use of MRI and radiology type tissues to understand multiple sclerosis, and it was at that meeting that Dr. Claudia Lucchinetti, who is at the Mayo Clinic in Rochester, Minnesota, talked about how the Mayo Clinic has access to hundreds of biopsy tissues from people with MS. Now these are obviously tissue samples from living people who came to the Mayo Clinic without a true diagnosis of MS. But if you were in that room as a scientist listened to the availability of these tissues, it was really quite exciting because to a scientist having biopsy tissue from a living person early in the disease gives us a window into perhaps the early part of the disease process. Now you would not obviously take a biopsy tissue from people with MS because that is a very invasive procedure, but it would give us a picture into the very early time of the disease to find out indeed whether or not the damage is different in different people, and if it is, then you can perhaps have more tailored therapies to try and go along with those different damages.

>>**Rick Turner:** A potential treasure trove of information there.

>>**Dr. O'Looney:** Absolutely. The research groups have already identified perhaps four different types of damage in people with MS, two of which are more immunological and the other two are more degeneration of the cells themselves. It is quite interesting.

>>**Rick Turner:** Fascinating. Well, we have discussed so much over the last couple of webcasts, as a professional in the field of MS research, Doctor, where are you most encouraged about the status of MS research today?

>>**Dr. O'Looney:** I think I am going to answer that with two levels. I am certainly encouraged by the level of enthusiasm from the scientific and medical community. We see more and more scientists now drawn to MS research and the MS Society certainly encouraging that at every level by having our funding programs and our fellowship programs. But what I also hear is that the scientific community and the medical community are encouraged, and they actually receive their inspiration from people with MS because they see people with MS who are obviously craving for better therapies, oral therapy, and that is what inspires the MS research community to go forward.

On another level, I am also encouraged by just the research itself. I know that to those who have MS, it is frustrating at times that we do not have a cure, and we do not have better therapies. But I am certain, as a witness to 20 years now of being

involved with MS research, that the research now is just moving forward at such an exponential way that scientists now are doing things in the laboratory which probably would have been considered somewhat science fiction just five years ago. I do think that this is an incredibly hopeful time for all of us who want to make sure that MS no longer stops people from moving.

>>**Rick Turner:** With that, we are just about out of time, but I want to thank you once again Dr. O'Looney for sharing your time and expertise with us as we strive to understand what is happening in MS research. Thanks again.

>>**Dr. O'Looney:** Thank you, Rick.

>>**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. 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 Multiple Sclerosis Society I am Rick Turner wishing you health and happiness.