

NOW Quarterly Update

MS NOW Our \$250M Commitment

SPRING 2013

An MS Research Revolution



SOCIETY FELLOW MAKES STRIDES IN IMPROVING COGNITION: MEET VICTORIA LEAVITT, PhD



Victoria M. Leavitt, PhD, focuses on understanding and treating cognitive impairment in people with MS. Dr. Leavitt received training in rehabilitation research at Kessler Foundation, through a National MS Society supported Postdoctoral Fellowship. Dr. Leavitt received her PhD

in clinical neuropsychology from Queens College of the City University of New York. A true success story of the Society's fellowship programs, she recently won a full research grant from the Society focusing on understanding and improving cognition in MS.

National MS Society: Why study cognitive rehabilitation?

Dr. Leavitt: Cognitive effects of MS are among the most frequent and challenging symptoms for people living with the disease. The increasing focus on research to understand and treat cognitive impairment in MS is a promising direction for providing real solutions to people with MS. I used to hear the words 'cognitive rehabilitation' and imagine arduous paper-and-pencil tasks with questionable efficacy. Now I know that cognitive rehabilitation can include activities like memory training using imagery and context that can improve brain function, but that also change the brain on the level of structure and neural functioning.

The Society: You recently published a study showing that cognitive performance can be hampered by warmer outdoor temperatures. How can this and your other research help people with MS?

Dr. Leavitt: The work on outdoor temperatures can certainly guide life choices throughout the year. We are also working on a number of projects to explore behavioral interventions to

improve cognition, such as engaging in a regimen of intellectually enriching activities like learning a new language. We are seeing some very encouraging results revealing positive effects of our interventions to improve memory and brain function.

The Society: What lessons have you learned about MS research?

Dr. Leavitt: As a fellow, I spent one day per week seeing patients at an MS center in Manhattan. This was a very valuable experience, as it allowed me to learn about the impact of cognitive impairment from patients themselves. This reminded me that the most important questions to pursue in research are not only the ones I may be asking, but also the ones patients are asking.

The Society: What is the focus of your new Society-supported research grant?

Dr. Leavitt: A frustrating aspect of MS is the lack of tools to predict the course each individual's MS will take. By using functional MRI which allows us to watch the brain at work, we have identified a pattern of activity in the brains of people with MS that may be predictive of future memory decline. With the new grant, I will be able to examine this in a large sample over time to validate this pattern.

The Society: What inspires your work?

Dr. Leavitt: When I came to Kessler, I knew very little about MS. The more I work to disentangle the puzzle of MS, the more excited I am to understand it better to help people facing the challenges of MS. Every day, I get to explore, study, and experiment in order to solve a big puzzle. It is a privilege to do work that has the potential to benefit people in a meaningful way.



OUR THANKS

For people living with MS, life can pose many challenges. Whether it's finding the energy to play with the kids, grasping for that illusive word in a conversation, or enduring pain to complete daily chores, life keeps moving forward and so must our shared commitment to improving quality of life for people living with MS.

Until the day when we achieve our vision of a world free of MS, we must continue to pursue all promising research paths to provide real solutions for people living with MS. For example, as in our interview with Dr. Victoria Leavitt, investigation into cognitive and other symptomatic therapies will help ensure improved quality of life.

WITH YOUR CONTINUED SUPPORT, IT IS ONLY A MATTER OF TIME BEFORE OUR VISION FOR A WORLD FREE OF MS BECOMES A REALITY.

We have committed to raise \$47.6 million this year to fund the most promising MS research. All projects focus on our key Society priorities: **Stopping** the disease in its tracks, **Restoring** what has been lost, and ultimately **Ending** MS forever. To fulfill this commitment, we depend on contributions of all sizes from Society friends like you. With so much positive momentum behind us, we are honored to partner with you in this life-changing work and hope you are inspired by reading about the progress you've helped to make possible. With your continued support, it is only a matter of time before our vision for a world free of MS becomes a reality.



Yours truly,

Cyndi

Cyndi Zagieboylo
President & CEO,
National MS Society

SYMPTOMATIC RESEARCH TO KNOW ABOUT

The Society currently invests in over 350 research projects, fellowships and special initiatives. Below are projects focusing on possible ways to stop MS progression and to restore function by reducing symptoms such as cognitive impairment and balance problems.

STOPPING MS

Can a component from green tea slow progressive MS nerve damage?

In this clinical trial, Dr. Jesus Lovera, Louisiana State University Health Sciences Center, is testing whether polyphenon E, a component isolated from green tea, can slow progression of MS when it's taken with standard MS therapies. Much of the damage to nerve cells in MS may involve "free radicals." This study could show whether this anti-oxidant can help prevent this destruction to slow or stop MS progression. Project Cost: \$359,516

RESTORING FUNCTION

Can blocking an enzyme lead to a new treatment for cognitive problems in MS?

Dr. Adam Kaplin, Johns Hopkins University School of Medicine, is investigating the potential of molecules as possible therapies for treating cognitive problems in MS. His team is testing whether blocking an enzyme can improve cognitive behavior in mice with MS-like disease. This could lead to new therapies to treat cognitive problems experienced by people with MS. Project Cost: \$615,298

Who can benefit from rehabilitation for balance problems in MS?

In this study, Dr. Jeffrey Hebert, University of Colorado Denver, is exploring whether balance and eye movement training can improve mobility and fatigue in people with MS. Immune system damage to specific areas of the brain can cause problems with balance. Project Cost: \$536,295

An MS Research Revolution



DR. TIMOTHY COETZEE , PhD, CHIEF RESEARCH OFFICER, REPORTS ON SOCIETY RESEARCH FOCUS IN 2013



The complexity of MS requires a holistic approach and a comprehensive strategy to propel the development of new disease management therapies faster. We must make investments to gain new knowledge, identify new treatments, and stimulate effective healthcare policies. Our areas of research focus for 2013 align with our Strategic Response to MS, and reflect this comprehensive approach. Here are some key areas where we are working to drive progress:

- **Investing in new therapies** — We're supporting an unprecedented number of clinical trials of potential therapies for MS, including tests to see whether lipoic acid or antioxidants isolated from green tea can slow the progression of MS. We're also investing in ways to measure the impact of therapies, including novel imaging and biomarkers that can give quicker indications about whether a therapy can slow MS progression.
- **Addressing the Challenges of Living with Progressive MS through the International Progressive MS Collaborative** — People with progressive MS need specific therapies to stop their disease in its tracks. A critical step in developing new treatments is the development of effective strategies and outcome measures for clinical trials. In February the collaborative brought key research leaders together from around the world to identify what must happen at the first international scientific meeting of this kind. The power and impact of a worldwide collaborative effort is already apparent. Input and expertise of attendees is informing the research strategy and action plan now in development; driving toward solutions for people affected by progressive MS.

- **Identify the prevalence of MS in the United States** — The current prevalence of MS in the U.S. was determined through Society efforts in 2002. The resulting figure of 400,000 individuals estimated to have MS has served as the best estimate for the past decade; although one with a reasonable scientific basis, it is imperfect. While the Society continues to advocate for the establishment of a national system that will track the number of people living with MS, we have made a commitment to re-evaluate, and if necessary, update the estimate to help ensure increased understanding of the prevalence and impact of MS across the nation.
- **Bring together the brightest young minds in MS Research at the 4th Tykeson Fellows Conference in November** — This unique conference facilitates presentation of findings from research and clinical fellows and the opportunity to hear from seasoned experts on many areas of MS research. The experience helps reinforce the fellows' commitment to MS, facilitates new collaborations, and inspires each individual as they interact with people living with MS. It is made possible by a generous donation from Donald Tykeson, Honorary Life Director of the Society's National Board of Directors, who has lived with MS for 50 years.

To drive progress forward, we are always assessing our research programs. As 2013 moves along, we are on track to contribute \$47.6 million for research this year, the largest amount in our history. This support is in line with our commitment to increasing the proportion of income the Society devotes to research. We will continue pursuing all promising avenues, engaging the best and brightest minds, and connecting people, resources and ideas so that we can stop MS in its tracks, restore function to people who have the disease, and end it forever.



AWARDING INNOVATION TO DRIVE PROGRESS



When a family member was diagnosed with multiple sclerosis about 25 years ago, Chuck and Margery Barancik had many questions. So they immersed themselves in reading everything they could about MS and talking

with the leading experts of the time. "We were deeply frustrated at the lack of available treatments, and concerned for the future," Chuck says. As the couple learned more about the disease and the research behind it, their questions began to take the form of a wish list. Why, they wondered, couldn't someone discover a way to freeze this degenerative disease's progress? What if a researcher could develop a vaccine for people who are at higher risk for MS — or even find a cure?

The Baranciks went beyond merely pondering these questions, however. For more than two decades, they have invested substantially in the National MS Society's research portfolio. "We felt that we had the ability — and the responsibility — to help propel research forward," Chuck says. Their contributions have led to significant advances in understanding MS and approaches to treatment.

"We've been very impressed with the Society's rigorous review process in awarding grants and we are especially pleased with its decision to increase funding for research," Chuck says. Chuck recognizes that researchers have made tremendous progress in developing drugs that reduce the frequency of MS attacks and alleviate symptoms, but "the magic bullet has not yet been discovered," he says. "Advances are being made, but we all wish to see the pace accelerated."

In an effort to fulfill their vision of finding a way to halt or cure MS, and to promote awareness of the disease, the Baranciks established the Barancik Prize for Innovation in MS Research. The prize awards \$100,000 annually, with the first prize winner announced in May, to "an exceptional scientist or a team of scientists whose work in MS research demonstrates outstanding innovation and originality." The goal of the Barancik Prize, which is the largest-ever MS research prize, is to attract more researchers to the field of MS, encourage and reward sound creative approaches, and promote greater public and institutional awareness of the disease.

Ultimately, Chuck hopes the prize will spur researchers to take a "shot in the dark" and develop innovative, scientifically sound answers to the wish list of questions about MS that he and Margery first posed nearly a quarter-century ago.



**National
Multiple Sclerosis
Society**

MS TRIAL ALERTS: HELP SPREAD THE WORD! As a MS Research Champion, you can help to bring real solutions to people living with MS by spreading the word on clinical trial alerts. Trials currently recruiting participants include an investigation on a new treatment for spasticity, and trials investigating genetics and the environment. **Visit the National MS Society website for more information.**



NOW and No Opportunity Wasted utilized with permission from NOW, Inc., and in partnership with Phil Keoghan, tireless advocate and Champion for MS Research.

