

Hope from the Hill

2016 | 2017 » NEWS FROM THE OHSU MS CENTER



VA Study on Lipoic Acid Offers Hope



Rebecca Spain, M.D., M.S.P.H.

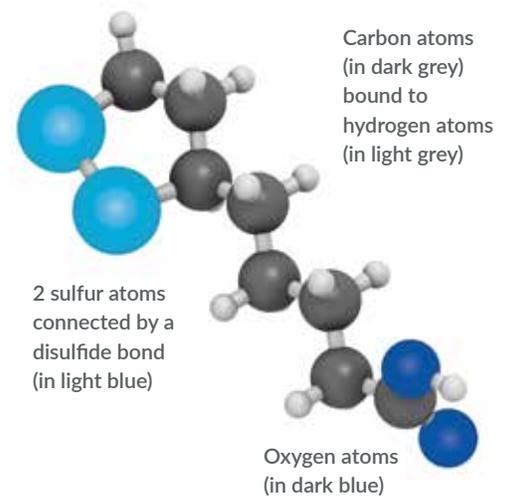
Despite all the breakthroughs in MS research, treatments for secondary progressive MS (SPMS) are still lacking. With the help of many colleagues, I conducted a pilot trial at the VA Portland Health Care System to see if the over-the-counter supplement, lipoic acid, would help SPMS. Lipoic acid is a substance naturally

made by our bodies that has a number of useful actions such as boosting energy production of cells, keeping the immune system from overreacting, and fighting damaging and aging forces (free radicals) in the body.

Although we don't fully understand what goes wrong to cause SPMS, we do know that a loss of energy, altered immune system, and free radicals may all make SPMS worse. Therefore it makes sense to see if lipoic acid could help slow the worsening of disability in SPMS.

In this trial, we enrolled 54 volunteers (21 were veterans) with SPMS in the approximately two-year study. Participants took 1200 mg of oral lipoic acid or placebo (sugar pill) daily on a full stomach. The study was double-blinded, meaning that neither the participants nor any of the examiners knew

A molecule of lipoic acid (also known as alpha lipoic acid [ALA])



who was on the lipoic acid or placebo. The goal of the study was to see if the participants taking the lipoic acid had less atrophy, or brain shrinkage, than the participants taking the placebo. Why is brain atrophy important? Brain atrophy is a normal part of aging that happens to all of us starting in our mid-20s. However, in MS, this atrophy can happen at a faster than normal pace. The extra brain atrophy goes

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Free From Falls

Do you have MS?
Do you fall frequently?
Do falls, or fear of falling, limit your activities? The Free From Falls program may be right for you.



Michelle Cameron, M.D., P.T.

More than 50 percent of people with MS fall, and most of these people fall frequently and have been injured by a fall. People

who fall also tend to have less confidence in their balance, become more socially isolated, and are less likely to work or participate in leisure activities. Although we don't yet know the perfect way to prevent falls in people with MS, based on what we know from older adults, it seems likely that comprehensive programs combining information, education, problem solving and exercise will be most effective. Based on this, the National MS Society (NMSS) developed Free From Falls.

Free From Falls consists of eight weekly two-hour group sessions, each with an hour of education and discussion followed by an hour of balance exercises. The sessions are led by a group facilitator, usually from the NMSS.

The group education and discussion covers a different topic each week, as follows:

WEEK 1 Causes of falls and understanding balance

WEEK 2 Fear of falling, center of gravity and multisensory training

WEEK 3 Optimizing mobility, gait and flexibility

WEEK 4 Managing energy, strength and endurance

WEEK 5 Safety at home and functional fitness

WEEK 6 Safety in the community

WEEK 7 Recovering from falls and personal fitness

WEEK 8 Putting it all together

The balance exercises include a warmup, balance practice, sensory fine tuning, functional activities, strengthening and a cool-down. The exercises are demonstrated by the program instructor and are generally the same each week, with options of adapting to each individual's abilities and for progression over time. Participants are encouraged to perform the exercises between sessions and to continue them after the program.

The NMSS has delivered this program through their chapters to over 100 participants. Overall, these participants' mobility, balance confidence and balance performance improved between the first and last session and, compared to baseline, six months after the program, 12 percent more participants reported not having fallen in the previous six months. This is all encouraging and suggests the program is helpful.

Here at OHSU, we are studying if the Free From Falls program works better than the current standard of care and if an online version of the Free From Falls program is effective. If you are interested in participating in studies of Free From Falls, please call Andrea Hildebrand at **503-220-8262, ext. 52016**, for more information.

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hand in hand with greater MS disability. Therefore we believe that by slowing the rate of atrophy, we may slow the rate of worsening disability from MS.

The results of the study were very exciting. The participants taking the lipoic acid had 66 percent less brain atrophy than the others taking placebo. In fact, the people taking lipoic acid had less brain atrophy than what might be expected by aging alone.

Because the trial was so small, we didn't expect to find a clinical benefit such as improvement in the neurological exam, cognitive tests, and so forth, and we didn't find any significant changes in these areas. Yet we did see a trend showing that the people taking lipoic acid improved their walking speed while the placebo group did not, although the difference was not statistically significant. Happily, the lipoic acid was safe and overall

well tolerated. As expected, there was more stomach upset in the lipoic acid group than placebo, a side effect known from other trials. Unexpectedly, there were half as many falls in the lipoic acid group than placebo group.

These are exciting results as lipoic acid is inexpensive and widely available over the counter, and because there are no FDA-approved treatments that alter the course of SPMS. However, results of a single pilot study do not in and of themselves prove that lipoic acid is an effective treatment for SPMS. In order to do that, a larger, multisite trial will have to replicate the results and determine if the slowing of brain atrophy makes a difference in a person's day-to-day abilities and quality of life. In particular, we will be paying close attention to walking speed and falls. I will be conducting this larger trial as soon as possible, and will be looking for volunteers in the chosen study cities to help determine if lipoic acid truly is a disease-altering treatment for SPMS.

For more information on MS research and clinical trials, please visit us at www.ohsu.edu/ms.

THE MISDIAGNOSIS OF MS





Dennis Bourdette, M.D., F.A.A.N.

Despite advances in our understanding of MS and the development of MRI, there is no specific test that determines the diagnosis. It is not like diabetes where an elevated fasting blood sugar makes the diagnosis, or hypertension where measurement of the blood pressure makes the diagnosis. MS is what we call a “clinical diagnosis.” A knowledgeable neurologist takes a history, does a neurological examination, reviews MRI, and maybe looks at spinal fluid and blood test results. The neurologist then puts the pieces of the puzzle together to make a proper diagnosis. There are well-established guidelines or rules for making the diagnosis that have been developed and refined over many decades and the neurologist needs to apply these rules to the diagnosis.

However, everything depends on the neurologist having the knowledge and skills to make a correct diagnosis.

We do not know how commonly people are misdiagnosed as having MS. In the OHSU MS Center we see several people every year who have been misdiagnosed as having MS and many others who have been told they might have MS based on an MRI when they do not have MS.

Despite guidelines for making the diagnosis of MS, some people still are misdiagnosed. Along with neurologists from three other academic health centers, we recently published an article in the journal *Neurology* describing 110 people who had been misdiagnosed with MS. The purpose of the study was to determine what the causes and consequences of misdiagnosis were.

The most common cause of misdiagnosis was the misinterpretation of MRI

findings. Many conditions besides MS can cause “white spots” on the brain MRI. The most common scenario was a person with migraine headaches who had a brain MRI to look for a tumor or some other serious condition and white spots were found. These white spots were mistakenly thought to be evidence of MS and the patient was misdiagnosed as having MS. Similar errors were made in people undergoing brain MRI for fibromyalgia or other conditions. Another cause of the misdiagnosis of MS was neurologists misinterpreting transient symptoms and attributing them to MS, when the symptoms actually were not consistent with MS. An example is someone reporting numbness and tingling that lasted a few minutes as a “relapse” of MS when the guidelines for making a diagnosis call for relapses to last more than 24 hours and to be verified by examination. In general, the misdiagnoses of MS were often the result of neurologists misinterpreting MRI findings and the history and not applying the well-established rules for diagnosing MS.

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Were there any consequences to the misdiagnoses of MS? There are of course the psychological and social problems caused when individuals believe they have MS when they do not. In addition, 70 percent of the misdiagnosed patients had received one or more MS therapies and most of these patients had been treated for many years. This needlessly exposed these individuals to expensive drugs with side effects. Some patients had treatable diseases in which the appropriate treatments were not given because of the misdiagnosis. All in all, making a wrong diagnosis of MS has significant consequences.

We do not know how commonly people are misdiagnosed as having MS. In the OHSU MS Center we see several people every year who have been misdiagnosed as having MS and many others who have been told they might have MS based on an MRI when they do not have MS. So it is more common than it should be.

If you have been diagnosed with MS, do you need to worry about a mistaken diagnosis? If you have been diagnosed or had your diagnosis confirmed by an MS specialist, such as the neurologists at the OHSU MS Center, it is unlikely you have been misdiagnosed. Many community-based general neurologists are very good at making a proper diagnosis but in general it is a good idea to have a second opinion from an MS specialist.

The OHSU Multiple Sclerosis Center is grateful to our wonderful supporters who make our work possible. Philanthropic support from people like you is helping us make tremendous progress in better understanding the cause of multiple sclerosis while improving the lives of patients and their families. For more information about how to make an outright or estate gift to the MS Center, please contact Maddy Abulencia at 503-552-0663 or abulenci@ohsu.edu.



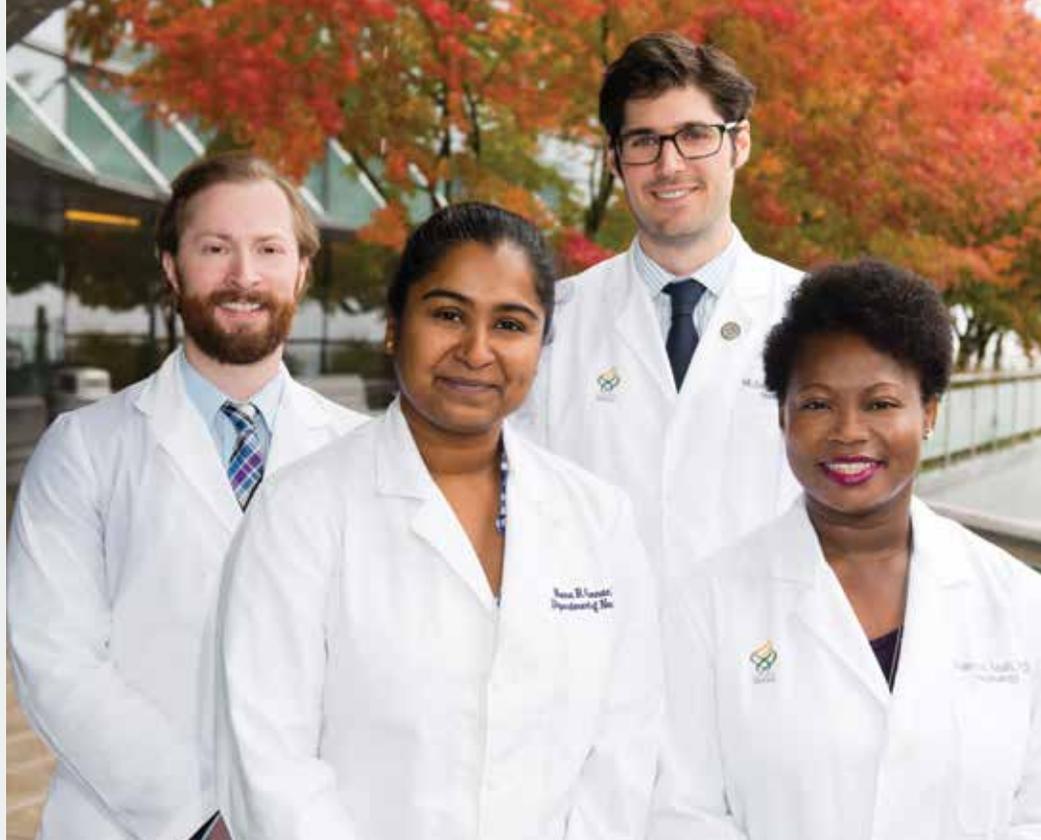
Welcoming Dr. Jacqueline Bernard

Dr. Bernard has recently joined the OHSU MS Center. She comes to OHSU from the University of Chicago Department of Neurology. Her passion is providing cutting-edge care to patients and bringing knowledge forward, through clinically based research, to provide the best possible care for our patients. Her interests include treating aggressive MS and NMO (neuromyelitis optica), studying cognitive dysfunction in MS and caring for women with demyelinating disorders across the reproductive life span. Dr. Bernard has participated in numerous clinical trials and has a special interest in optical coherence tomography (OCT) in neurological disorders.

MS clinician scientists: the next generation

Michael Lane, M.D., grew up in Prescott, Arizona, and went to medical school at Ross University in Roseau, Dominica, of the West Indies, with medical school rotations primarily in Miami, NYC and Baltimore. He did his neurology residency at Dartmouth Hitchcock Medical Center in Lebanon, N.H. Michael chose OHSU for its great community, and he felt he could learn a substantial amount from the OHSU Neuroimmunology Department given the variety of physicians and range of management strategies. “OHSU providers utilize a combination of holistic and conventional clinical approaches that I would like to learn to emulate when I eventually practice on my own, in addition to a strong research department that I hope to assist in increasing the fund of knowledge of MS and neuroimmunology.”

Shannon Seals, M.D., comes from Louisiana by way of Cincinnati, Ohio, where she completed a neurology residency at the University of Cincinnati Medical Center. She chose neuroimmunology as a result of her personal experience of having a sibling with multiple sclerosis



and her desire to give people hope in light of such a debilitating disease. Dr. Seals realizes that this can only be achieved through a comprehensive medical approach, which is one of the many reasons that she chose to come to OHSU.

Frank Bittner, D.O., is in the second year of his fellowship at Oregon Health & Science University seeing patients and working on new research projects. He is originally from Ohio and completed neurology residency in Morgantown, West Virginia. He chose OHSU for additional training as “OHSU was the place I found that was leading the way in new trials for alternative interventions for MS and translating them to the clinic”. His research focus is on fatigue and supplemental intervention.

Meena Kannan, M.D., M.P.H., is currently a second-year fellow in MS at Oregon Health & Science University. She is originally from Mobile, Ala. She completed her medical school training at the University of Alabama at Birmingham and her internship and neurology residency training at Emory University in Atlanta, Ga. She chose to pursue additional training in MS and neuroimmunology at OHSU largely because of the dynamic nature of the field and the wealth of clinical and research opportunities. Her research focus is on using information technology to improve access to care for people with MS.

Left to right: Drs. Frank Bittner, Meena Kannan, Michael Lane and Shannon Seals.



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Upcoming events

MS Brown Bag Lunch Series

Join the OHSU MS Center team for our Multiple Sclerosis Brown Bag Lunch Series on the second Friday of every other month from 11:30 a.m. to 1 p.m. at the Center for Health & Healing. This free educational series is provided to those with MS and their family members and caretakers. A different topic is presented from a professional in the field each session. Lunch is included with registration. RSVP at least one week in advance to Dawn Christensen at 503-494-7661 or chrisdaw@ohsu.edu. For more information, visit www.ohsu.edu/msbrownbag.

Save the date – June 24, 2017

OHSU MS Center's annual MS conference, "At the Frontier & Beyond," held at the DoubleTree by Hilton, Portland, provides practical information about managing, treating and living with MS.

OHSU MS Center neurologists come to you

Coming to a location near you, MS Center neurologists participate in educational forums throughout Oregon. "On the Horizon: Updates in MS" forums take place from March until June 2017 at several cities in the state. Receive the latest information on treatment and research and talk directly with experts in the field. All forums are free with registration and include lunch. Registration is required to attend. Check out the MS Center events website for locations and dates near you.

For more information about OHSU MS Center events, visit www.ohsu.edu/ms/events.