New MS therapy — a game changer?

The year 2017 saw a landmark advancement in the treatment options for MS. For the first time in the history of MS therapeutics, there was approval of a pharmaceutical drug, called ocrelizumab (Ocrevus), for the treatment of the primary progressive form of MS (PPMS). PPMS is a type of MS that can affect up to 15 to 20 percent of people with MS and for which no treatment has previously been shown to be effective in slowing the disease progression. In addition to PPMS, ocrelizumab, an infusion therapy that is given every six months, is highly effective for the relapsing remitting form of MS.

Ocrelizumab belongs to a class of drugs known as monoclonal antibodies, which selectively kill specific white blood cells known as B cells. While the drug is highly effective, it also needs cautious selection and monitoring of the patients who will benefit from its use, since there can be some serious side effects as well.

Ocrelizumab binds to a molecule called CD20 on the surface of B cells and depletes those cells from the circulation. The result appears to be a reduction in MS activity while still leaving the immune system capable of fighting off infections. (source: themswire.com)

Vijayshree Yadav, M.D., M.C.R.

At the OHSU MS Center, our team of well-trained clinicians, nurse and staff is dedicated and prepared to providing the best care for each and every patient we see, and believes that each and every patient with MS has the potential to live a very productive life.

The efficacy of ocrelizumab also showed a novel way to look at the way MS affects the immune system.
There is growing interest in the role diet might play in MS, an interest long held by the former OHSU neurology chairman, Dr. Roy Swank.

Although there are several diets that are popular among people with MS, such as the Swank, McDougall and Wahls diets, not enough research exists to prove that they help MS. Yet common sense tells us that eating a healthy diet that benefits overall health will likely also help MS. Studies show that obesity may be a risk factor for developing MS, and that having high blood pressure, high cholesterol and diabetes causes MS to progress faster. Because diet can affect those conditions, it may also influence MS in some way.

How diet might help is uncertain. Although there is likely not one particular “MS diet,” dietary interventions may be able to help with the targeted management of disabling symptoms such as fatigue.

Dr. Vijaysheer Yadav recently completed a randomized trial of dietary intervention in people with MS. In the study, participants following a low-fat, vegan (plant-based) diet experienced significant reductions in fatigue relative to those following their standard diets. Adherence to the diet was difficult. As a follow-up to this study, Dr. Yadav and Dr. Michael Lane have planned a trial investigating the impact of a less restrictive low-fat dietary intervention in people with MS on fatigue and overall health. The current study diet, while still largely plant-based, will permit chicken, fish and eggs provided participants keep daily fat intake below 20 percent of total calories.

In preparation to start the diet, study participants will take part in a series of interactive lectures, cooking demonstrations and even a grocery store tour, and will have access to individualized support from the Wellness Center’s Carly Vong, M.P.H., R.D., C.S.R., L.D., I.C.C.E., a registered dietician. A wait-list control group will continue
In honor of Don Tykeson

OHSU MS Center and its dedicated research and clinical team would like to pay a rich tribute to Mr. Don Tykeson, a renowned native Oregonian and a generous philanthropist who contributed hugely to the cause of MS throughout his lifetime. Mr. Tykeson was a pioneer in Oregon's broadcasting industry and a cofounding director of C-Span, and his passing means the loss of a great well-wisher of the OHSU MS Center, who nurtured and helped grow the center to its current reputation in research, clinical care and education. Don's association with the OHSU MS Center goes back decades to when he supported the establishment of The Tykeson Lab, under whose umbrella cutting-edge research flourished. The Tykeson lab dedicated itself to studying how the immune system causes MS and developing new treatments. A generous contribution from Don Tykeson also started the Tykeson MS Fellows Conference, which focuses on expanding worldwide collaboration to accelerate research in the field of MS. Don was a huge proponent of the use of wellness approaches in MS management and supported the MS Center to advance cutting-edge research in this field as well.

Don was afflicted with MS when he was a young adult but never let it get in the way of leading a hugely successful and long life as an entrepreneur, businessman and dedicated family person. Don was very proud to say that having MS made him a stronger person, and he regretted not having started early enough to support people with his philanthropic work. Don's legacy will continue to impact many lives. OHSU is thankful for his vision and support in advancing MS research. Don Tykeson is a source of inspiration to those living with MS and to those working in the field. Don Tykeson passed away on July 12, 2017, at 90 years of age.

Interested in wellness research at OHSU?
Call 503-494-3549 for research opportunities.
When is the right time to stop a disease-modifying therapy?
Although all 12 of the MS DMTs approved in the U.S. are approved to treat the early, relapsing forms of the disease, most have not been shown to be greatly effective in later progressive stages or in older patients. Thus, older individuals whose disease has been stable for many years often question the need to stay on therapy.

The MS Center at OHSU is one of 15 institutions across the country collaborating on a study to investigate this important question. The study is funded by the Patient Centered Outcomes Research Institute (PCORI) and led by a team of investigators at the University of Colorado in Denver. The study is recruiting individuals over the age of 55 who have stable MS and who have been taking a disease-modifying therapy for at least five years. Half of the participants will stop taking their DMT, while the other half will continue their usual treatment. All participants will be followed for two years, with MRI scans every six months, assessments of disability and cognition, and questionnaires about MS symptoms.

Although there are established guidelines for when to start a therapy (most patients diagnosed with relapsing forms of MS are advised to begin treatment early), the question of when to stop therapy has not yet been evaluated in a randomized, controlled trial.

In some cases there are clear signs that a therapy should be changed or stopped, such as continued relapses, worsening disability, intolerable side effects or inconvenience. However, several features of MS make it difficult to assess whether a therapy is working. Because MS symptoms naturally wax and wane over time, it can be impossible to determine if clinical stability means the medication is working, or if a lack of relapse is a sign that the disease is in remission.

In the absence of clear guidelines or safety data about when to stop a medication, providers may be reluctant to broach the topic: Surveys show that discussions about stopping treatment often occur only after a patient has requested them. As a result, most patients remain on treatments indefinitely, which can be associated with undesirable side-effects, high costs (the average DMT costs $60,000 per year), inconvenience and unknown long-term risks.

Decisions regarding treatment require open discussions and shared decision-making between patients and providers. OHSU MS Center neurologists carefully weigh medical data and safety information, but also work with patients to consider factors including cost and convenience. This process is important as patients and providers may have different priorities when it comes to making decisions about treatment. And since the risks and benefits of being on a treatment can look different to patients or to providers, an important aspect of the study is getting input from patients about how satisfied they are with the therapy they are using (or how they feel after stopping their DMT).

This study represents an important step in answering questions about treatment, which should help facilitate dialogue between patients and providers about the benefits and drawbacks of continuing treatment.

If you are interested in learning more about this study, or about MS research at OHSU, please call 503-494-3549 for more information.
Lipoic acid for progressive MS

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

This summer, results of a two-year trial of the oral supplement, lipoic acid, in people with secondary progressive MS were published in Neurology: Neuroimmunology & Neuroinflammation (2017;4:e374). Rebecca Spain, M.D., M.S.P.H., led the study, which enrolled 51 participants randomly assigned to either 1200 mg lipoic acid or a placebo (sugar pill). At the study’s end, those taking the lipoic acid had less brain atrophy, or shrinkage, on their MRI than the placebo group. These results were presented at national and international MS meetings to great interest from both MS researchers and people with MS. Dr. Spain has received funding from the Department of Veterans Affairs and the national MS Society to conduct a follow-up trial to determine if lipoic acid will maintain walking speed and/or help other clinical measures like falls, hand dexterity, pain or mood. The trial is planned at seven sites across the U.S. in order to make sure the study is enrolled quickly and to discover whether the effects of lipoic acid hold true for people with MS in all parts of the country. Dr. Spain expects to enroll 15 to 20 people with either secondary or primary progressive MS at the Portland VA Medical Center in early 2018. Stay tuned for information at www.ohsu.edu/ms.

The backbone of the OHSU MS Center

Debbie Guess, R.N.

Debbie joined the OHSU MS Center in 1996, over 20 years ago. Her role as an MS nurse is to help with care coordination, symptom management, medication management, education and phone triage. She has been a research nurse coordinator in over 20 MS studies, some of which have led to approval of treatments for MS. She says the best part of doing research is developing relationships with the study participants, and is grateful to them for making a significant commitment to research.

Kristine Perry, M.A.

Kristine is the administrative medical assistant for the MS Center. She provides triage calls, manages medication refills and authorizations, and performs any other work that assists the nurse and physicians to allow them more time with patients and research. Kristine had a maternal aunt with multiple sclerosis, witnessing firsthand how devastating it was to not have any therapies available in the early 1970s. She was excited to join the MS team six years ago, and to witness the therapy advances that have happened in just that time.
In his second year of fellowship at OHSU, Dr. Lane is involved in research in multiple sclerosis and the influence of diet on the gut microbiome and resulting wellbeing. Originally from Prescott, Arizona, Dr. Lane attended medical school at Ross University in Roseau, Dominica, of the West Indies, with rotations primarily in Miami, NYC and Baltimore. His neurology residency was at Dartmouth Hitchcock Medical Center in Lebanon, New Hampshire.

Elizabeth Silbermann, M.D.

Dr. Silbermann grew up in Des Moines, Iowa, and went to medical school in Providence, Rhode Island, at Brown University. She then completed her neurology residency at Washington University in St. Louis. She chose to pursue fellowship training in neuro-immunology because she is passionate about providing longitudinal and holistic care to her patients. Her research interests include new disease-modifying therapies and investigating the impact of multiple sclerosis on vision.

Lindsey Wooliscroft, M.D.

Dr. Wooliscroft is from Carrollton, Texas. She attended medical school at Texas Tech University Health Sciences Center in Lubbock, Texas, and completed her residency at Washington University in St. Louis, Missouri. She chose an MS fellowship after being drawn to neuroimmunology during residency due to the expanding knowledge of MS, neurotherapeutics and imaging techniques.

Giving to OHSU If you are age 70½ and older, you may make charitable gifts directly from an IRA to the charity without having to pay taxes on the distribution. These distributions can count toward all or part of your annual Required Minimum Distribution (RMD). Please contact the OHSU Foundation Office of Gift Planning with questions or to notify us about your gift at 503-228-1730. OHSU Foundation Tax ID # 23-7083114. Address: 1121 S.W. Salmon St., #100, Portland, OR 97205
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. Space is limited and registration is required. To register, contact Dawn Christensen at 503-494-7661 or chrisdaw@ohsu.edu. For more information, visit www.ohsu.edu/msbrownbag.

Save the date – June 23, 2018

OHSU MS Center’s annual multiple sclerosis conference, At the Frontier & Beyond, held at The DoubleTree by Hilton Hotel, 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 April until June 2018 at several cities. 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.