While the average age of diagnosis for patients with multiple sclerosis is in the early to mid-30s, the average age of patients with multiple sclerosis is actually in the 50s. Unfortunately, as we age, other medical conditions can occur in addition to multiple sclerosis. For example, a recent study reported that almost 20% percent of MS patients have hypertension, which can lead to a higher risk of heart disease and stroke. These conditions can then have an impact on MS. A study from Canada demonstrated that the more medical conditions a patient has, the more likely that person is to have disability associated with his or her MS. As a result, those patients are more likely to transition to progressive MS. Specifically, heart disease and epilepsy carried the highest risk, followed by diabetes, lung disease, hyperlipidemia and hypertension. Therefore, Providence MS Center recommends that our patients work closely with their primary care provider for regular health maintenance.

Maintaining a healthy lifestyle is extremely important, as some medical conditions can be prevented or improved by making healthy choices. These lifestyle modifications include eating a healthy diet. The best example of this is the Mediterranean Diet, which emphasizes increasing intake of fruit and vegetables. Currently, there are several studies evaluating other diets for MS patients, but results of these studies are pending. Working with a nutritionist can be helpful in establishing a healthy diet.

Smoking increases the risk of hypertension, heart disease, and stroke. In addition, smoking may increase the risk both of developing MS and of transitioning to the progressive phase of MS. So, quitting smoking is essential to treating MS and for your overall health. If you are currently smoking, please talk to your primary care provider about smoking cessation programs.

Exercise is also extremely important for both physical and mental health. Studies have reported improved energy and mood with exercise. The MS Society of Canada advises that adults with mild to moderate disability get 30 minutes of moderate-intensity aerobic exercise twice a week, with strength training twice a week. Yoga or aquatic therapy can be excellent options for MS patients who are not as mobile or who may be heat sensitive. Providence MS Center currently offers two yoga classes for people with MS. The west side class meets on the third Thursday of each month from 6:30 to 7:45 p.m. at Providence St. Vincent Medical Center. The east side class meets on the third Tuesday of each month from 6:45 to 8 p.m. at Providence Portland Medical Center. These classes are free, and more information can be found in this newsletter. Check out your local community center too, as they may offer yoga classes and aquatic therapy.

...continued on page 3
Today, I had the opportunity to interview Nora Martin Vetto, R.N., who recently joined Providence MS Center.

How long have you been at Providence?
I started working at Providence in July 2019, after moving from Scottsdale, Arizona to downtown Portland with my husband who is originally from Portland.

Prior to coming to Providence, where did you work?
I have been a Registered Nurse for many years in multiple specialties, but the most recent positions were as an educator in a college of nursing and, prior to that, as a staff nurse in surgical services at Mayo Clinic Hospital in the pre-op and post-op (PACU) units. I also have experience as a staff nurse in surgical ICU, ED/Acute Care, triage, an Internal Medicine Clinic and team leading.

So, what is your role as one of the nurses?
I am a phone triage/message nurse. Phone triage nurses receive symptom calls for all neurological patients, but a majority are from persons in various stages of MS. Nurses use protocols to focus the call, determine acuity, and relay messages to the providers for plan of care. Patients are then contacted with the plan. Triage nurses relay medication information, labs and diagnostic results from providers to patients. Nurses also observe patients in the office during first doses of medications, give injections and help medical assistants and waiting room staff with urgent medical situations.

Why did you decide to become a nurse?
I was interested in caring for sick or injured people, and learning the science and art of caring for this population. Patients are in a vulnerable situation that requires accurate assessment, critical thinking, appropriate interventions, teaching, and kindness to help them to a best outcome. People still require “real time” educated, skilled and nurturing nurses to connect with, even in an increasingly digital and technical age. I also knew that a career in nursing offered flexibility to learn about and work in different specialties, requires continued education to remain current, and I like learning.

A diagnosis of MS can be overwhelming, and there is a lot to learn about the disease. So, what are some resources that you provide patients?
Providing the best resources for persons diagnosed with MS begins by listening to validate their feelings and concerns, and then determine what resources they need at that time, and asking about their learning style(s). Andragogy includes seeing, hearing and kinesthetic learning, but many adult learners use a combination of these styles. I refer patients to the online National MS Society site, medication sites, and forums to connect with other people who have MS. We have a case management nurse as a great resource. There is an MS Support group that meets the first Thursday of every month at Providence St. Vincent Medical Center, and a new MS Care Partners Support Group, that I facilitate, is offered at the same time. Nurses are available for office visits to give therapy injections or teach patients injection techniques to promote self-confidence. Patient education is an area that triage nurses are hoping to offer to support patients in comprehending and managing their MS (and other neurological disorders). Nurses would use content that promotes independence to normalize living with MS, and guidance for when to contact the office for help. Resources for teaching include evidence-based, best practices that a nurse educator can organize into approachable content for learning. Meeting in person with patients is valuable to customize information for them. When I was a nurse providing discharge teaching in the post-surgery/anesthesia care unit, I highlighted and verbalized key points in the massive instructions packet for patients, especially reasons to contact Providence Brain and Spine Institute | Team Member Spotlight
the provider (signs and symptoms). I evaluated their comprehension of key points using the “teach back” technique, which is more effective than asking, “Do you have any questions?”

What advice do you have for patients?
The staff have the best interest of patients in mind while managing their care and are aware of how difficult a chronic disorder is for the patients. They provide plans for patients to feel as well as possible and supported. I advise patients to review their plan of care, communicate with the providers; ask questions for any needed clarification, and follow the plan to feel their best, but to contact the office if they develop any new symptoms, have questions, or need resources.

What advice do you have for caretakers?
Listen to your loved one who has MS, to evaluate and focus on what they need from you and from other resources, so they have balanced, integrative, comprehensive and safe care. Your role as a caretaker should not replace your initial relationship with the person who has MS, (as a spouse, partner, relative or friend), or it may lead to burn-out and resentment and adversely affect the physical and mental health of the caretaker. Full-time caretaking is not sustainable, no matter the good intent. It takes a collaborative effort to care for a person with MS, as this disease is often progressive over a long period of time. It requires “self-care for the caretaker” to have a healthy relationship with the person with MS. There are online forums and support groups for caretakers, as well as in-person support groups. Caretakers need to be physically well, too, in order to help care for another person.

What do you like to do outside work?
I like to visit with my family and friends, read, listen to music, cook, watch “unusual,” but good streamed movies, travel, and enjoy Portland’s incredible downtown architecture and places by walking or using the excellent public transit system.

What life experience has taught or changed you the most?
Life in general has taught me that there are joyful moments daily, simple or grand, in spontaneous or planned experiences, and that despite the inevitable times of misfortune (that everyone experiences), I cope by seeking or creating aspects of positivity and joy.

Importance of Health Maintenance and Wellness
…continued from page 1

Exercise can also help with stress reduction. Internalizing stress can lead to an increase in MS symptoms or possibly trigger other medical conditions, such as hypertension. Other options which can help with stress-reduction include yoga, meditation, acupuncture and massage therapy. Staying positive is also extremely important. Practicing gratitude daily can help maintain a positive attitude.

Lastly, adequate sleep is key to maintaining health. Many individuals with MS report significant disruptions in sleep and difficulty maintaining a consistent sleep schedule due to pain, muscle tightness/spasms and frequent urination. Sleep apnea is also more common in patients with MS. Seeing a sleep specialist may be beneficial, especially if you snore or if your bed partner reports episodes when you stop breathing. If you are having trouble sleeping, reducing your caffeine intake may be the first step. Alcohol can also disrupt your sleep pattern. Maintaining good sleep hygiene may be helpful too. It is recommended that you go to bed and wake up at the same time every day as well as avoid using electronic devices such as phones or tablets prior to going to bed and while in bed, as the light can be stimulating. For more information on living a healthy lifestyle with MS, please see these additional resources:

http://www.nationalmssociety.org/Living-Well-With-MS/Health-Wellness

http://www.nationalmssociety.org/Resources-Support/Library-Education-Programs/Brochures/Staying-Well
Exercise, particularly aerobic exercise, plays a well-established role in our general health and well-being by improving cardiovascular fitness and regulating sleep, blood sugar levels and hormones, which influence our mood. However, exercise is also particularly important in people with Multiple Sclerosis (MS). Exercise can mitigate fatigue and the effects of deconditioning. Fatigue is a common issue for people with MS and can be exacerbated by stress, heat, sleep and duration of illness. It is also multifactorial and directly related to the disease process due to inflammation and slowing of the nervous system’s metabolism. However, fatigue can also be due to disuse and deconditioning. Many people with MS experience thermosensitivity, which is an intolerance to heat resulting in a temporary increase in neurological symptoms such as weakness or blurry vision. This phenomenon, coupled with disease-related fatigue, often leads people to avoid exercise and become sedentary. This can rapidly lead to deconditioning as the body becomes less efficient in a cardiovascular sense, requiring more energy to complete tasks. Additionally, a lack of weight-bearing exercise (walking, squatting, stairs) can lead to a loss of muscular strength. These factors combine to make activities of daily living, such as cooking and cleaning, more tiresome and difficult to accomplish. This can make it difficult for people to engage in work and/or meaningful social activities.

Aerobic exercise is safe for people with MS and is generally recommended at low to moderate intensity levels. The results of high intensity training in MS are unclear as it not well-studied. Becoming more aerobically fit combats fatigue as it improves oxidative muscle and functional reserve capacities, meaning it makes our systems more efficient. A more efficient system uses less energy, which correlates with less effort to complete tasks. This allows for the ability to do more or walk further before primary fatigue sets in. This often leads to a greater willingness to increase social participation which can also contribute to a greater activity level. More recently, aerobic exercise has also been noted to have an anti-inflammatory effect on our body and increase the release of brain derived neurotrophic growth factor (BDNF). BDNF production has been found to be lower in people with MS, and many studies are looking at its role in nervous system health and protection from further demyelination.

In regards to overheating, we now understand that the effects of thermo-
sensitivity are temporary and are due to poor nerve conduction in demyelinated fibers at increased temperatures. This temporary increase in fatigue or feelings of weakness should cease 30 minutes after exercise. It is ideal to plan on resting for these 30 minutes after aerobic exercise to allow for recovery. Plan exercise at a time of day when you are not already fatigued and minimize over-heating by drinking cool liquids, using fans, or wearing cooling vests or neck wraps to keep the core body temperature down.

A physical therapist can help develop an aerobic exercise program based on current physical fitness and other existing health conditions. It is also important to consult your doctor prior to a new exercise program and have an updated medication list. Low to moderate intensity aerobic exercise is typically 50-70% of a predicted heart rate maximum. For people with more progressive disease presentations, exercise at 20-30 beats above the resting heart rate may be a safer alternative than a predicted heart rate max. Aerobic exercise can take many forms including walking, cycling and swimming. It can also be completed while seated for people who are non-ambulatory via arm exercises. The American Heart Association recommends 150 minutes of aerobic exercise per week (30 minutes 5x per week). However, this frequency may be too high for persons with MS as autonomic changes to the nervous system can result in an inability to exercise to the same capacity as a person without MS. However, aerobic training can still provide the benefits of improved energy even if completed at a lesser rate. Most patients are instructed to work up to 20-30 minutes 3x per week and in patients with MS, 3 ten minute bouts of exercise throughout the day can give the same training effect as 30 continuous minutes. Lastly, keep in mind that there are other important aspects of exercise including balance, strength training and stretching which also provide numerous benefits including decreasing fall risk, improving strength, reducing the risk of injury and managing spasticity.

References:


4. APTA Course “MS and Exercise Implications" By Mary Jane Myslinski, EdD
For more information or to connect with the contacts for any of these trials, please call Jennifer Geranios at 503-216-2736.

Evaluating the Potential Role of Melatonin in Subjects With Relapsing Multiple Sclerosis

**Description:** To date, there is no published data on the role of melatonin supplementation or the appropriate dosage for patients with multiple sclerosis. Because of the potential benefits of melatonin, this pilot study will be an exploratory investigation to evaluate the effect of supplementing melatonin in subjects with multiple sclerosis who are taking an oral disease modifying therapy (DMT) for 6 months or longer. It is our intent that the results of this study will support the rationale and be a prelude to a larger trial which can focus on clinical efficacy of melatonin therapy outcomes.

**Sponsor:** Providence Health & Services  
**Principal Investigator:** Kyle E Smoot, M.D.  
**Contact:** Hannah Voss

Traditional versus Early Aggressive Therapy for Multiple Sclerosis (TREAT-MS) Trial

**Description:** The Traditional versus Early Aggressive Therapy for MS (TREAT-MS) trial is a pragmatic, randomized controlled trial that has two primary aims: 1) to evaluate, jointly and independently among patients deemed at higher risk vs. lower risk for disability accumulation, whether an ‘early aggressive’ therapy approach, versus starting with a traditional, first-line therapy, influences the intermediate-term risk of disability, and 2) to evaluate if, among patients deemed at lower risk for disability who start on first-line MS therapies but experience breakthrough disease, those who switch to a higher-efficacy versus a new first-line therapy have different intermediate-term risk of disability.

**Sponsor:** PCORI (Patient-Centered Outcomes Research Institute)  
**Principal Investigator:** Elisabeth Lucassen, M.D.  
**Contact:** Will Stott

North American Registry for Care and Research in Multiple Sclerosis (NARCRMS)

**Description:** The North American Registry for Care and Research in Multiple Sclerosis (NARCRMS) is a physician/clinician based registry and longitudinal database of clinical records and patient-centered outcomes.

**Sponsor:** Consortium of MS Centers (CMSC)  
**Principal Investigator:** Stanley Cohan, M.D., Ph.D.  
**Contact:** Lynette Currie
Measurement of Relaxin in the Serum and Cerebrospinal Fluid of Subjects With and Without the Relapsing Form of Multiple Sclerosis

Description: This study will evaluate relaxin levels in patients with multiple sclerosis.

Sponsor: Providence Health & Services
Principal Investigator: Stanley Cohan, M.D., Ph.D.
Contact: Hannah Voss

Evaluating the Efficacy and Safety of Transitioning Patients From Natalizumab to Ocrelizumab (OCTAVE)

Description: The primary objective of this study is to assess the efficacy of Ocrelizumab (OCR) in Relapsing Multiple Sclerosis patients who have been previously treated with natalizumab (NTZ) by evaluating relapse rate, progression on MRI and disability progression.

Sponsor: Providence Health & Services
Principal Investigator: Kyle E Smoot, M.D.
Contact: Genevieve Rollier

Pacific Northwest Multiple Sclerosis Registry

Description: The purpose is to measure MS prevalence in the Pacific Northwest and to create a database for ongoing epidemiological and health services research.

Sponsor: Providence Health & Services
Principal Investigator: Stanley Cohan, M.D., Ph.D.
Project Manager: Tamela Stuchiner

Providence Ocrelizumab Patient Registry

Description: The goal is to collect information from patients receiving ocrelizumab for the treatment of MS to assess its long term utilization, safety, tolerability and efficacy.

Sponsor: Providence Health & Services
Principal Investigator: Kyle Smoot, M.D.
Study Coordinator: Lois Grote
A Systems Approach to Understanding Disease Processes in MS

**Description:** The main purpose of the study is to improve the understanding of MS and to look at the genetic factors that may influence how MS progresses. This study will collect blood and stool samples and information from survey questions and MS-related assessments from study patients over 15 months of study participation.

**Sponsor:** Providence Health & Services  
**Principle Investigator:** Stanley Cohan, M.D., Ph.D.  
**Study Coordinator:** Will Stott

Exploring the safety and tolerability of conversion from oral or injectable disease modifying therapies to dose-titrated Oral Siponimod in patients with advancing forms of relapsing multiple sclerosis: A 6-month open label, multi-center Phase 11b study (EXCHANGE)

**Description:** To assess early phase safety and tolerability of converting patients from approved oral and injectable RMS DMTs to siponimod. The results of this study will guide clinically relevant decisions related to the transition from frequently used RMS DMTs to siponimod and provide clinically relevant data on safety and tolerability for healthcare providers who are considering converting patients from currently approved RMS DMT to siponimod.

**Sponsor:** Novartis  
**Principle Investigator:** Elisabeth Lucassen, M.D.  
**Contact:** Abigail Kernon-Schloss

Observational study assessing the feasibility of the MS Performance Test for assessing functional performance in MS patients (MSPT)

**Description:** The primary objective is to evaluate the feasibility of the Multiple Sclerosis Performance Test (MSPT) in a clinical care setting when used by participants with Multiple Sclerosis.

**Sponsor:** Biogen  
**Principle Investigator:** Kyle Smoot, M.D.  
**Contact:** Francesca Negreanu
Comparing the risk and severity of infusion-related reactions in patients premedicated with Cetirizine versus Diphenhydramine prior to Ocrelizumab infusions (PRECEPT).

**Description:** This 6 month randomized controlled pilot study will determine whether there is some evidence that Cetirizine is better than Diphenhydramine without an increase in infusion related reactions (IRR’s).

**Sponsor:** Genentech, Inc  
**Principal Investigator:** Kyle Smoot, M.D  
**Contact:** Alaina Randerson
Research has shown that yoga practices like body awareness, breath work, mobility and mindfulness can improve MS symptoms. Our instructors lead 60 minutes of gentle yoga practice, followed by 15 minutes of community connection and healthy habit sharing. Classes are FREE, but space is limited, please pre-register.

**WHEN:** 3rd Thursday of each month, 6:30 p.m. to 7:45 p.m.
**WHERE:** Basecamp at Providence St. Vincent Medical Center: 9427 SW Barnes Rd, Portland, OR 97225

REGISTER: 503-574-6595 OR PROVIDENCE.ORG/CLASSES
MS YOGA - PROVIDENCE EAST

Are you living with Multiple Sclerosis and seeking ways to manage symptoms and improve wellness? Join our yoga class!

Research has shown that yoga practices like body awareness, breath work, mobility and mindfulness can improve MS symptoms. Our instructors lead 60 minutes of gentle yoga practice, followed by 15 minutes of community connection and healthy habit sharing. Classes are FREE, but space is limited, Please pre-register.

WHEN: 3rd Tuesday of each month, 6:45 p.m. to 8:00 p.m.
WHERE: BodyWorks at Providence Portland Medical Center: 5127 NE Hoyt Street, Portland, OR 97213

Diana Hulet, e-RYT, YACEP
Diana has been practicing yoga for nearly 30 years. She earned a teaching certification in 2004 and has also studied yoga history and philosophy since 2008. She currently teaches full time at locations around Portland and, as a person living with Multiple Sclerosis, Diana offers a unique perspective for fellow yoga practitioners navigating the disease.

REGISTER: 503-574-6595 OR PROVIDENCE.ORG/CLASSES
Providence Multiple Sclerosis Center, the only center of its kind in Oregon, is the state’s leading care provider for people with MS. Our medical director, Stanley Cohan, M.D., Ph.D., was an investigator in the original, pivotal trial of beta interferon 1-A, one of the key medications for treating multiple sclerosis. He continues to play a leading role in MS research and founded the Pacific Northwest Multiple Sclerosis Registry Project, which will be used to help advance treatment of multiple sclerosis.

Our goal at Providence Multiple Sclerosis Center is to provide persistent, proactive, focused treatment that minimizes the effects of MS on your life. Patients benefit from comprehensive services that may include medication therapy, physical rehabilitation, counseling and other support. In addition, patients have access to the newest therapies through regional and international clinical trials.

Providence Multiple Sclerosis Center team specializes in:
- Comprehensive MS care
- Neurology
- Neuro-ophthalmology
- Nursing
- Physical therapy
- MS research
- Support and wellness programs

OUR CLINICIANS:
- Stanley Cohan, M.D., Ph.D., Neurologist, Medical Director of Providence Multiple Sclerosis Center
- Kyle Smoot, M.D., Neurologist, Co-Medical Director of Providence Multiple Sclerosis Center
- Justine Brink, D.O., M.P.H., Neurologist
- Vitalie Lupu, M.D., Neurologist
- Elisabeth Lucassen, M.D., Neurologist
- Leah Gaedeke, F.N.P., Multiple Sclerosis Nurse Practitioner

OUR NURSES:
- Sam Brighton, R.N., B.S.N., Clinical Case Manager
- Kiana Oskooii, R.N., B.S.N., Clinical Support Specialist
- Kimberly Tracyk, R.N., B.S.N., Clinical Support Specialist
- Nora Vetto, R.N., M.S.N., Clinical Support Specialist

OUR SERVICES:
- Highly advanced diagnostics
- Personalized treatment plans
- Attentive use of medications
- Rehabilitation with therapists who specialize in MS care
- Continence treatment for bladder and bowel dysfunction
- Emotional support and psychological counseling
- Opportunities to receive investigational medicines through clinical trials
- Close coordination with your primary care physician
- The Pacific Northwest Multiple Sclerosis Registry Project, a database created for epidemiological and health services research
- An MS Network that allows physicians to collaborate on MS treatments
- Community and provider education forums throughout Oregon

Thanks to clinical research, people with MS are living longer, stronger, healthier lives.