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THE Motivator

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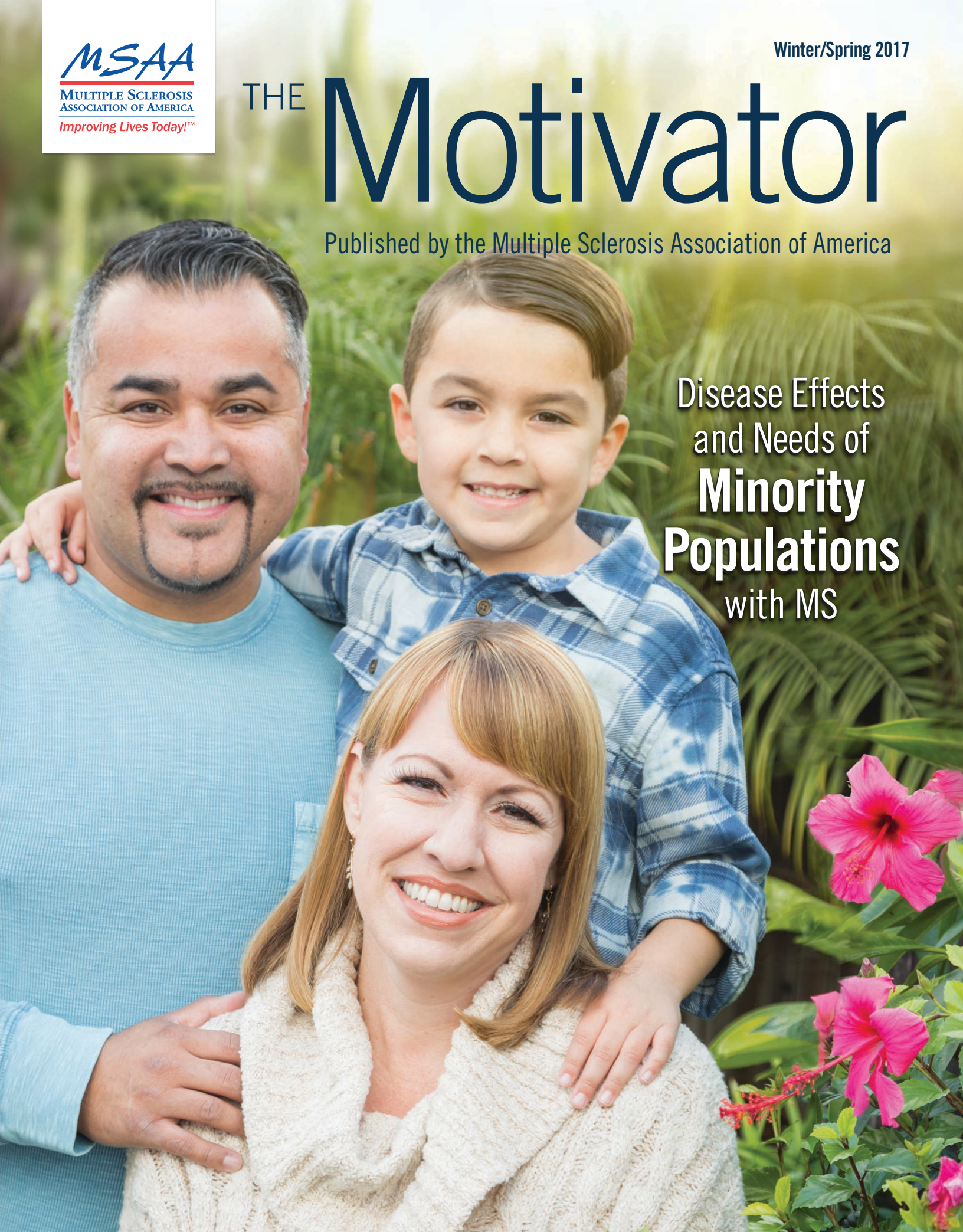

Disease Effects and Needs of **Minority Populations** with MS

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For more information on these events, please visit
support.mymsaa.org/teamMSAA

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President & CEO

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MSAA Multiple Sclerosis Association of America *Improving Lives Today!™*

The Multiple Sclerosis Association of America is a leading resource for the entire MS community, improving lives today through vital services and support.

MSAA strives to provide useful, up-to-date information on matters of concern to MS patients and their families. This material is intended for general informational purposes only, and it does not constitute medical advice. You should not use the information presented as a means of diagnosis or for determining treatment. For diagnosis and treatment options, you are urged to consult your physician.

Springing Ahead

By Gina Ross Murdoch
MSAA President and CEO

As we approach spring, our fiscal year to date has been defined by a number of exciting advancements, new initiatives, and expansion of our MSAA family. The driving force behind all of this progress is the collective efforts of clients, staff, volunteers, corporate partners, and care partners dedicated to **Improving Lives Today** and Every Day.

Just within this fiscal year, we have welcomed four new board members to our MSAA leadership. This brings the total of *new* board members we have welcomed since January 2016 to seven. These incredibly dedicated professionals are from all over the country and walks of life. Their expertise includes finance, retail, technology, higher education, medicine (neurology), insurance, law, and healthcare administration. The commonality between them is both their dedication to MSAA and their desire to leverage their connections, all with the ultimate goal of increasing our impact on so many lives affected by multiple sclerosis.

In this issue, you will see a new focus on the many ways volunteers are making a difference in their local communities. Going forward, you will see examples of what is taking place in cities and towns across the country – all dedicated to Improving Lives Today. From cookie sales to 5K races, golf tournaments to Swim for MS events, our MSAA family members are rallying their local communities to raise awareness about MSAA and how we are here to help. Collectively, your fellow MSAA volunteers have raised more than $150,000 in their local communities!!! That is an incredible amount. Also incredible is the impact these events have had to let everyone affected by multiple sclerosis know MSAA is here to help.

Building on that community spirit, we are launching Team MSAA. This new fundraising initiative offers people across the country the

Gina Ross Murdoch is a seasoned executive in non-profit management. Her career includes leadership positions with chapters of the Leukemia and Lymphoma Society as well as the American Diabetes Association. Earlier, she spent 14 years overseeing development activities at a large chapter of the National Multiple Sclerosis Society, leading explosive growth initiatives and ground-breaking strategic projects. An active member of the community, Ms. Murdoch has held several town positions and volunteers for her college alma mater, Drew University.

opportunity to participate in 5K or 10K races, half marathons, and full marathons in support of MSAA. I personally will be participating in a half marathon, so stay tuned to our social media outreach to see my journey along the way. I am so incredibly proud to run for MSAA! I encourage you to check out our Team MSAA page at **support.mymsaa.org/teammsaa** to see how you can participate as a runner, walker, or spectator to lend cheering support to participants at a local race.

Finally, MSAA continues to move forward with two initiatives we recently announced – My MSAA Community and Antidote Match. Launched in May 2016, My MSAA Community offers anyone affected by multiple sclerosis the opportunity to share ideas, make connections, learn from peers, and know that others are facing the same challenges of living with MS. This support network has grown to more than 1,600 members in only 10 months!

In January, MSAA announced a partnership with Antidote Technologies, allowing us to offer Antidote Match, a clinical trial search tool on our website. This platform provides a customizable way to search for clinical trials anywhere in the country. By answering a succession of questions, Antidote Match creates a list of clinical trials that may be suited to your particular situation. As clinical trials are necessary for advances in research with any disease and the treatment of its symptoms, you can play an important role in bringing the next breakthrough to the MS community.

Overall, the first part of the year has been very busy! With your fellow MSAA members across the country, we are helping more people every day. I invite you to add your personal efforts to our mission and continue to help us **Improve Lives Today**! ■

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$10/month ($120/year): a shower chair, bathtub safety rail, and grab bar for one individual with MS

$15/month ($180/year): a four-wheel walker and quad cane for one individual with MS

$25/month ($300/year): cooling vests for two individuals with MS

$50/month ($600/year): a wheelchair for one individual with MS

$60/month ($720/year): an MRI exam of the brain for one individual with MS

Disease Effects and Needs of Minority Populations with MS

By Susan Wells Courtney
Reviewed by Jack Burks, MD

With contributions from
Lilyana Amezcua, MD, MS
Jacqueline Bernard, MD, FAAN
Laura Hancock, PhD

Research has shown that MS is a heterogeneous disease, meaning that the factors involved are diverse. Studies have also shown that genetic predisposition, gender, and environment all come into play with the development and progression of the disease. However, as researchers work to better understand the disease course and identify effective treatment targets, an important detail has become clear: MS is not the same for everyone diagnosed with the condition.

MS Varies among People of Different Ethnic Backgrounds

Until recent years, published studies did not focus on the differences between Caucasians and ethnic minorities in the diagnosis, symptoms, treatment, and progression of MS. As a matter of fact, as researchers review published results of clinical trials, they find that minorities are significantly underrepresented, and this means that the findings as they relate to minorities are often difficult if not impossible to confirm.

For this reason, researchers have turned to information provided through surveys, data collection, MS centers, and MS specialists in an effort to confirm various differences that may exist between the ethnic groups. These findings help the medical community to understand more about an individual's disease diagnosis and progression, how this individual might respond to certain treatments, along with developing an evidence-based treatment plan.

Much of the research presented in this article relates to individuals who are Caucasian American, African American, and Hispanic American, as most of the literature focuses on these groups. Many other factors are involved, including age, gender, and ancestral background. Certain genetic traits are seen in those with European versus non-European background and Asian versus non-Asian background. Additionally, if someone has immigrated to the United States, he or she may have a different disease course compared to someone of the same ethnic background who either immigrated to the United States at a different age, or who was born here. These are all details that will be discussed later in the article.

How MS Differs between MS Subpopulations

Generally speaking, some minority groups tend to be younger at the onset of their symptoms. They may have a greater likelihood of opticospinal MS, which affects the optic nerves and spinal cord more than the nerves of the brain. Non-Caucasians are also more likely to have transverse myelitis, which causes inflammation in one location across both sides of the spinal cord. This can cause a variety of physical symptoms, and similar to relapsing forms of MS, function may return when the inflammation subsides. However, some of its symptoms may not fully subside.

Depending upon one's ethnic background, MS may also be more aggressive – resulting in earlier disabilities – and respond poorly to certain disease-modifying therapies. Through future studies with minorities, researchers may learn more about disease progression in these minorities, and which disease-modifying therapies may be the most effective for each subgroup of the MS population.

In the past, Caucasian Americans were thought to have the greatest incidence of MS. However, in two recent studies – one a retrospective cohort study of 496 newly diagnosed individuals, and another contemporary study of 2,691 Gulf War-era military veterans with MS – African Americans had a higher incidence of MS compared to Caucasian Americans, Hispanic Americans, and Asian Americans. Other studies have shown that minority populations, including African Americans and Hispanic Americans, have a higher incidence of MS in the United States, versus those with the same ethnicity but living in their ancestral countries of origin.

African-American Trends

Compared to Caucasian Americans, African Americans have a greater likelihood to develop opticospinal MS, transverse myelitis, and a more aggressive disease course, as noted

previously. However, African Americans may be older at disease onset, although not all studies come to the same conclusion in terms of age at onset.

Additionally, when compared to Caucasian Americans, African Americans may experience more frequent relapses, poorer post-relapse recoveries, a shorter time progressing from relapsing-remitting MS (RRMS) to secondary-progressive MS (SPMS), and more severe impairment of mobility. T2 and T1 lesion volumes are higher (indicating more disease activity) as shown on magnetic resonance imaging, and other signs of disease activity may also be higher (such as other MRI and cerebrospinal-fluid findings).

Compared to Caucasian Americans, some African Americans may experience greater retinal damage, affecting their vision. This is particularly true for individuals who have or had acute optic neuritis (AON), which may suggest a more aggressive disease course with an increase in inflammation.

While African Americans are believed to experience a more aggressive disease course and not respond as well to certain disease-modifying therapies, readers should note that more studies are needed to confirm these findings, and many of the earlier studies were not designed specifically to identify these outcomes. Additionally, other controllable factors, including access to care and seeing an MS specialist, may result in better outcomes.

In terms of sub-optimal treatment response, studies suggest that African Americans do not respond as well to some of the approved disease-modifying therapies for MS. However, studies are being conducted to see which medications are the most effective for this ethnic group, so that physicians may make evidence-based treatment recommendations for their patients.

Another potential factor is Vitamin D levels, which influence certain genes involved with MS and have also been implicated in the development and progression of the disease. In a study conducted to evaluate the association between Vitamin D and disease severity in African Americans, researchers compared individuals with and without MS; both groups consisted of African Americans. While the study found that the African Americans with MS had lower levels of Vitamin D, and a larger percentage of the group was deficient in Vitamin D, no association was made between this level and disease severity.

Hispanic-American Trends

Hispanic Americans often are diagnosed at an earlier age than Caucasian Americans. They are more likely to present with opticospinal MS, optic neuritis (inflammation along the optic nerve), and/or transverse myelitis. Hispanic Americans have a much lower risk of MS compared to Caucasian Americans and African Americans. Researchers believe that this fact, combined with the tendencies to present with the conditions noted above, may be related to their genetic ancestral variations.

While female MS patients (of any ethnic background) who have had MS for a longer period of time and have walking issues are

more prone to migraine headaches, Hispanic Americans are more likely to suffer from chronic migraines. The authors of that study note the importance of a thorough evaluation and headache treatment by their doctor to ensure the best care for this challenging symptom, which has been shown to impact daily life.

If not born in the United States, the timing of one's migration is a significant determinant of mobility problems in the future. Hispanic Americans who migrated to the United States after the age of 15 and who are diagnosed with MS, have an increased risk of developing mobility limitations. If diagnosed at an early age, particularly if under 18 with pediatric MS, and if born in the United States, such individuals are less likely to experience severe mobility issues in the future.

Similar to African Americans, Hispanic Americans are more likely to have a Vitamin D insufficiency. Also, Vitamin D levels in Hispanic Americans were not affected by season nor associated with more severe disability. Researchers believe that factors affecting Vitamin D levels as well as their recommended doses may be different for the various ethnic groups.

Lilyana Amezcua, MD, MS is the assistant professor of clinical neurology at the University of Southern California (USC) MS Comprehensive Care Center in Los Angeles. She is a neurologist who is fellowship-trained in MS and is studying issues affecting Hispanic Americans with MS.

Over the past eight years, Dr. Amezcua's research has focused on the Hispanic/Latino

population. She has started the first MS registry for Hispanics in the United States at USC. She has been collecting details on patient cases – looking at clinical characteristics, blood samples, and imaging (MRI scans) – and is starting to see if the disease is different among individuals with this ethnicity versus the white (Caucasian) population.

From an epidemiological standpoint, Dr. Amezcua explains that clinical differences seen in different patient populations make a lot of sense according to the regions where these populations originally lived. Geography and racial/ethnic differences impact who gets MS and could also impact disease course. When comparing different groups, they must be from the same geographic region. Hispanics have

Trends for Women with MS

Jacqueline T. Bernard, MD, FAAN is a neurologist with Oregon Health & Science University. She explains, "Several studies in MS suggest a trend of increasing disease frequency in women compared to men during the last decades. Studies in the United States have shown an increasing trend from 2:1 to almost 3:1 in women to men, and this is due to an increased prevalence in women rather than a decreased prevalence in men. This observation has also been found in other countries."

Dr. Bernard notes that the topic of "comorbidities," which are the diseases that coexist in people who have been diagnosed with another disease – in this case MS – has received recent attention. Previously published information from MSAA notes the importance of regular monitoring for various women's conditions. Examples include mammograms for early detection of breast cancer, bone-density scans for osteoporosis, and gynecological care for reproductive issues and general women's health. Additionally, depression and/or cognitive issues are more common for women with MS compared to the general population, so being aware of these conditions and seeking help to minimize their effects are important to a woman's long-term wellness.

Several other health conditions are important to be aware of, although some of these are more commonly found in men with MS versus women. According to Dr. Bernard, "One study from Canada showed that the prevalence of hypertension (high blood pressure) was disproportionately higher in men with MS than women. Men with MS also had a disproportionately higher prevalence for diabetes, epilepsy, depression (noted earlier), and anxiety.

"Looking at access to care, one recent study found that women with severe MS disability are vulnerable to significantly less access to preventive care, compared to healthy controls. Doctors must be aware of this fact and bring this up during their visits.

"At least one researcher has shown that the effects of Vitamin D on immunomodulatory activity are more significant in women with MS than men. While this needs further study, it suggests that doctors should make sure patients are taking the appropriate dose of Vitamin D, as recommended by their physician, and that levels continue to be monitored for optimal care."

diversity. As most people know, Hispanics may be from Cuba, Mexico, Puerto Rico, South or Central America, etc., and different factors are involved depending on where they have lived or are currently living. MS is a complex disease and multiple genetic and environmental factors are involved.

Dr. Amezcua points out, "Hispanics thus far present with initial symptoms at an earlier age, approximately three to five years earlier on average. While 80 to 85 percent of Caucasians are initially diagnosed with RRMS, this percentage is significantly higher in Hispanics, with up to 90 percent initially diagnosed with RRMS; however, this may be expected when receiving a diagnosis at a younger age. Approximately 10-15 percent of Caucasian Americans are diagnosed with primary-progressive MS (PPMS), so Hispanics by comparison are less-often diagnosed with this form of the disease.

"We also see a lot more spinal cord involvement in Hispanics; while such studies with this population are sparse, we understand this from clinical observation. Greater spinal-cord involvement correlates to increased disability, more significantly affecting ambulation, but more studies are needed. We do not yet know if the conversion rate from RRMS to SPMS is the same between Caucasians and Hispanics, but hope to have those types of longitudinal studies in the near future.

"In our research, we have two questions that we are seeking to answer. First, through a better understanding of common genetic variables, we want to learn if genetics play a role in reducing the risk of MS. And second, we want to know if the behavior of the disease after diagnosis is more severe, and if the disease course is more aggressive. We need to look at variables such as genetics, environment, social and cultural factors, to determine how they may influence the risk of MS and disease course after diagnosis."

Asian-American Trends

With regard to Asian Americans, MSAA's Chief Medical Consultant Dr. Jack Burks explains, "Three terms are used to describe the different variations of MS in Asians. These include Caucasian/Western-type RRMS, opticospinal MS, and neuromyelitis optica or NMO, which was formerly known as 'Devic's disease.' The primary message here is that Asians do get MS and the prevalence may be increasing.

"Many Asian individuals with MS reside in the United States, United Kingdom, and other Western countries. While MS in Asians is still less common than MS in Caucasians, MS in Asians (opticospinal and NMO) is more likely

to affect the vision and spinal cord, although cerebral lesions in the brain are seen on MRI.

"MS in Asians may be more severe, more rapidly progressive, and may not respond to traditional MS medications as well as RRMS in Caucasians. We do not have enough experience with current disease-modifying therapies within the Asian population, since clinical trials have not been designed to study the effects on Asians with MS. We hope that

Trends for Aging Adults with MS

Laura Hancock, PhD is a neuropsychologist at the University of Wisconsin School of Medicine and Public Health who specializes in MS. According to Dr. Hancock, "The type, severity, symptoms, and disease course of older adults with MS mirrors the middle-aged or younger populations with MS. However, older adults with MS are more likely to have a progressive form of the disease. Research also suggests that age is related to overall disability, although not everyone will experience disability in their older years, especially with the availability of approved disease-modifying therapies.

"Older brains appear to be less resilient to the effects of the MS disease course, essentially meaning that an older brain cannot heal itself as well as a younger brain. Older adults with MS may have more psychological symptoms (such as those associated with depression) than younger people with MS. Cognitively, additional issues come into play as the brain, already altered by MS, begins to age, which will likely have deeper ramifications than the cognitive effects of MS in younger people. This topic still needs to be studied in more detail so we can have a better understanding.

"Regarding treatments in older adults with MS, this is one area that is fairly unclear. Disease-modifying therapies are more often prescribed to younger people with MS, as many older adults with MS have a progressive course. Clinical trials typically exclude people who are more than 60 years old, and so the effects of these treatments are not well understood in this group yet. Some symptom-management therapies may be less likely to be prescribed in older adults with MS due to other comorbidities, including problems with the heart, liver, or kidneys.

"To better serve older adults with MS, we need to understand what MS looks like in this group. We need to provide willing researchers with funding so that we can examine cognitive skills, brain characteristics, biomarkers, and so on. Raising awareness of the needs of this group is also important."

more studies will be conducted in the future to provide greater insight into the disease course and treatment response for Asian individuals with MS."

Barriers Faced by Minorities with MS

A number of issues interfere with minorities being able to receive proper treatment as well as participate in clinical trials. For instance, nearly one-third of individuals with MS who are part of a minority have never gone to an MS specialist. Those who do see an MS specialist, such as a neurologist who specializes in MS, or an MS center with a staff of professionals who specialize in MS, are significantly more likely to be satisfied with their access to high-quality care. Additionally, these individuals are significantly more likely to participate in a clinical trial. They also have family members who are involved and help with obtaining information for the patient.

Education is another barrier faced by many minority members with MS, who may not know where to access information, or who need help in understanding the information. Additionally, some minority members with MS do not speak English and need materials written in another language. These same individuals may also have trouble communicating with their doctor or healthcare team, possibly having difficulty expressing their thoughts and understanding the doctor's responses.

Socioeconomic status and government versus private insurance are predictors of barriers as well. Individuals with more children and who are not on treatment also experience greater barriers to receiving appropriate care. Other barriers to accessing and utilizing specific care include a lack of insurance, lower income, lower educational levels, language (mentioned earlier), and computer literacy.

Other cultural areas that interfere with receiving appropriate care and participating in clinical trials include religious beliefs and distrust in the medical community. First, with religious beliefs, some individuals are opposed to different types of care, such as taking medications, undergoing medical procedures, and receiving blood transfusions. And second, distrust is another big issue among minorities, where patients fear that they may be used as a "guinea pig" with an experimental treatment.

Also of interest is how members of this population differ in their perceptions of the disease. Dr. Amezcua explains that a high proportion of Hispanics with MS who were not on any type of disease-modifying therapy were found to believe that their MS was a result of some type of cultural idiom. For instance, some believed they had developed MS because of a terrible experience as a child, while others attributed the disease to the stress of immigration. Of this group not on any type of treatment, many had MS for more than 10 years, but few understood the biological aspects of the disease.

Solving Problems Faced by Minorities

To precisely identify how the disease affects people of different ethnic backgrounds, and to accurately assess the effectiveness of the treatments, well-designed studies with large numbers of minority patients need to be conducted. As new information becomes

available, advocacy organizations and medical professionals need to raise awareness.

Education needs to be customized for the audience, providing simple access to educational events, webinars, easy-to-read publications, and online information. If appropriate, some of the information will need to appear in another language to assist those who speak English as a second language. Family members should be encouraged to accompany the patient during doctor visits and assist with communicating with the physician and other members of the healthcare team.

Programs need to be created to promote the components of a healthy lifestyle, along with other patient-education topics, such as medication adherence and symptom management. The medical community will also need to find ways to promote trust within the subgroup of patients.

To help fulfill the needs of minorities with MS, MSAA serves on various advisory boards designed to identify and assist underserved populations. MSAA also conducts educational programs dedicated to certain subpopulations of the MS community and plans to continue these types of programs in the future.

In Conclusion

Dr. Amezcua states, "Researchers are working very hard to learn more about the different subpopulations in MS. While we have had a lack of diversity with our data in the past, current and future studies aimed at capturing genetic information will be of great help in identifying genetic markers.

"This type of research, along with longitudinal studies that will provide more information on how the disease behaves over time within the different ethnic groups, will be instrumental in forming a better understanding of MS. This is an exciting time for researchers and the MS community, as we get closer to discovering both a cause and a cure for MS." ■

Resources

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(CONTINUED FROM PREVIOUS PAGE)

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- Slow heart rate, especially after first dose. You will be monitored by a health care professional for at least 6 hours after your first dose. Your pulse and blood pressure will be checked hourly. You'll get an ECG before and 6 hours after your first dose. If any heart problems arise or your heart rate is still low, you'll continue to be monitored. If you have any serious side effects, especially those that require treatment with other medicines, or if you have certain types of heart problems, or if you're taking medicines that can affect your heart, you'll be watched overnight. If you experience slow heart rate, it will usually return to normal within 1 month. Call your doctor, or seek immediate medical attention if you have any symptoms of slow heart rate, such as feeling dizzy or tired or feeling like your heart is beating slowly or skipping beats. Symptoms can happen up to 24 hours after the first dose. Do not stop taking GILENYA without consulting with your doctor. Call your doctor if you miss 1 or more doses of GILENYA—you may need to repeat the 6-hour monitoring.
- Increased risk of serious infections. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping GILENYA. Your doctor may do a blood test before you start GILENYA. GILENYA may decrease the way vaccines work in your body, especially the chicken pox vaccine. Increased risk of infection was seen with doses higher than the approved dose (0.5 mg). Two patients died who took higher-dose GILENYA (1.25 mg) combined with high-dose steroids. Call your doctor right away if you have fever, tiredness, body aches, chills, nausea, vomiting, or headache accompanied by fever, neck stiffness, sensitivity to light, nausea, and/or confusion. These may be symptoms of meningitis.
- Progressive multifocal leukoencephalopathy (PML). PML is a rare brain infection that usually leads to death or severe disability. If PML happens, it usually happens in people with weakened immune systems. It is important that you call your doctor right away if you have any new or worsening medical problems that have lasted several days, including problems with thinking, eyesight, strength, balance, weakness on 1 side of your body, or using your arms and legs.
- Macular edema, a vision problem that can cause some of the same vision symptoms as an MS attack (optic neuritis), or no symptoms. If it happens, macular edema usually starts in the first 3 to 4 months after starting GILENYA. Your doctor should test your vision before you start GILENYA; 3 to 4 months after you start GILENYA; and any time you notice vision changes. Vision problems may continue after macular edema has gone away. Your risk of macular edema may be higher if you have diabetes or have had an inflammation of your eye (uveitis). Call your doctor right away if you have blurriness, shadows, or a blind spot in the center of your vision; sensitivity to light; or unusually colored vision.
- Swelling and narrowing of the blood vessels in your brain. A condition called PRES (Posterior reversible encephalopathy syndrome) has occurred rarely in patients taking GILENYA. Symptoms of PRES usually get better when you stop taking GILENYA. However, if left untreated, it may lead to a stroke. Call your doctor right away if you experience any symptoms, such as sudden headache, confusion, seizures, loss of vision, or weakness.
- Breathing problems. Some patients have shortness of breath. Call your doctor right away if you have trouble breathing.
- Liver problems. Your doctor should do blood tests to check your liver before you start GILENYA. Call your doctor right away if you have nausea, vomiting, stomach pain, loss of appetite, tiredness, dark urine, or if your skin or the whites of your eyes turn yellow.
- Increases in blood pressure (BP). BP should be monitored during treatment.
- A type of skin cancer called basal cell carcinoma (BCC). Talk to your doctor if you notice any skin nodules (shiny, pearly nodules), patches or open sores that do not heal within weeks. These may be signs of BCC.

GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or planning to become pregnant. Women who can become pregnant should use effective birth control while on GILENYA, and for at least 2 months after stopping. If you become pregnant while taking GILENYA, or within 2 months after stopping, tell your doctor right away. Women who take GILENYA should not breastfeed, as it is not known if GILENYA passes into breast milk. A pregnancy registry is available for women who become pregnant during GILENYA treatment. For more information, contact the GILENYA Pregnancy Registry by calling Quintiles at 1-877-598-7237, by e-mailing gpr@quintiles.com, or by going to www.gilenyapregnancyregistry.com.

Tell your doctor about all your medical conditions, including if you had or now have an irregular or abnormal heartbeat; heart problems; a history of repeated fainting; a fever or infection, or if you are unable to fight infections due to a disease or are taking medicines that lower your immune system, including corticosteroids, or have taken them in the past; eye problems; diabetes; breathing or liver problems; or uncontrolled high blood pressure. Also tell your doctor if you have had chicken pox or have received the chicken pox vaccine. Your doctor may test for the chicken pox virus, and you may need to get the full course of the chicken pox vaccine and wait 1 month before starting GILENYA.

If you take too much GILENYA, call your doctor or go to the nearest hospital emergency room right away.

Tell your doctor about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines, called live attenuated vaccines, while taking GILENYA and for at least 2 months after stopping GILENYA treatment.

The most common side effects with GILENYA were headache, abnormal liver tests, diarrhea, cough, flu, sinusitis, back pain, abdominal pain, and pain in arms or legs.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Please see additional Important Safety Information on previous page.

Please see Brief Summary of Important Product Information on next pages.

BRIEF SUMMARY
GILENYA® (je-LEN-yah)
(fingolimod)
capsules

Read the Medication Guide before you start using GILENYA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your health problem or treatment.

What is the most important information I should know about GILENYA?

GILENYA may cause serious side effects, including:

1. **Slow heart rate (bradycardia or bradyarrhythmia) when you start taking GILENYA.** GILENYA can cause your heart rate to slow down, especially after you take your first dose. You will have a test to check the electrical activity of your heart (ECG) before you take your first dose of GILENYA.

   You will be observed by a healthcare professional for at least 6 hours after you take your first dose of GILENYA.

   After you take your first dose of GILENYA:
   - Your pulse and blood pressure should be checked every hour.
   - You should be observed by a healthcare professional to see if you have any serious side effects. If your heart rate slows down too much, you may have symptoms such as:
     - dizziness
     - tiredness
     - feeling like your heart is beating slowly or skipping beats
   - If you have any of the symptoms of slow heart rate, they will usually happen during the first 6 hours after your first dose of GILENYA. Symptoms can happen up to 24 hours after you take your first GILENYA dose.
   - 6 hours after you take your first dose of GILENYA you will have another ECG. If your ECG shows any heart problems or if your heart rate is still too low or continues to decrease, you will continue to be observed.
   - If you have any serious side effects after your first dose of GILENYA, especially those that require treatment with other medicines, you will stay in the medical facility to be observed overnight. You will also be observed for any serious side effects for at least 6 hours after you take your second dose of GILENYA the next day.
   - If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be observed overnight after you take your first dose of GILENYA.

Your slow heart rate will usually return to normal within 1 month after you start taking GILENYA. Call your doctor or go to the nearest hospital emergency room right away if you have any symptoms of a slow heart rate.

If you miss 1 or more doses of GILENYA you may need to be observed by a healthcare professional when you take your next dose. Call your doctor if you miss a dose of GILENYA. See **"How should I take GILENYA?"**

2. **Infections.** GILENYA can increase your risk of serious infections and decrease the way vaccines work in your body to prevent certain diseases, especially the chicken pox vaccine. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping treatment. Your doctor may do a blood test before you start taking GILENYA. Call your doctor right away if you have any of these symptoms of an infection:
   - fever
   - tiredness
   - body aches
   - chills
   - nausea
   - vomiting
   - headache accompanied by fever, neck stiffness, sensitivity to light, nausea, and/or confusion (these may be symptoms of meningitis)

3. **Progressive multifocal leukoencephalopathy (PML).** PML is a rare brain infection that usually leads to death or severe disability. If PML happens, it usually happens in people with weakened immune systems. It is important that you call your doctor right away if you have any new or worsening medical problems that have lasted several days, including problems with:
   - thinking
   - eyesight
   - strength
   - balance
   - weakness on 1 side of your body
   - using your arms and legs

4. **A problem with your vision called macular edema.** Macular edema can cause some of the same vision symptoms as an MS attack (optic neuritis). You may not notice any symptoms with macular edema. If macular edema happens, it usually starts in the first 3 to 4 months after you start taking GILENYA. Your doctor should test your vision before you start taking GILENYA and 3 to 4 months after you start taking GILENYA, or any time you notice vision changes during treatment with GILENYA. Your risk of macular edema may be higher if you have diabetes or have had an inflammation of your eye called uveitis.

   Call your doctor right away if you have any of the following:
   - blurriness or shadows in the center of your vision
   - a blind spot in the center of your vision
   - sensitivity to light
   - unusually colored (tinted) vision

What is GILENYA?

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults. GILENYA can decrease the number of MS flare-ups (relapses). GILENYA does not cure MS, but it can help slow down the physical problems that MS causes.

It is not known if GILENYA is safe and effective in children under 18 years of age.

Who should not take GILENYA?

Do not take GILENYA if you:
- have had a heart attack, unstable angina, stroke or warning stroke or certain types of heart failure in the last 6 months
- have certain types of irregular or abnormal heartbeat (arrhythmia), including patients in whom a heart finding called prolonged QT is seen on ECG before starting GILENYA
- are taking certain medicines that change your heart rhythm
- are allergic (hypersensitive) to fingolimod or any of the other ingredients of GILENYA listed at the end of this medication guide. Allergic reactions, which could include symptoms of rash or itchy hives, swelling of lips, tongue or face, are more likely to occur on the day you start GILENYA treatment but may occur later. If you think you may be allergic, ask your doctor for advice.

If any of the above situations apply to you, tell your doctor.

What should I tell my doctor before taking GILENYA?

Before you take GILENYA, tell your doctor about all your medical conditions, including if you had or now have:
- an irregular or abnormal heartbeat (arrhythmia)
- a history of stroke or warning stroke
- heart problems, including heart attack or angina
- a history of repeated fainting (syncope)
- a fever or infection, or you are unable to fight infections due to a disease or taking medicines that lower your immune system. Tell your doctor if you have had chicken pox or have received the vaccine for chicken pox. Your doctor may do a blood test for chicken pox virus. You may need to get the full course of the vaccine for chicken pox and then wait 1 month before you start taking GILENYA.
- eye problems, especially an inflammation of the eye called uveitis.
- diabetes
- breathing problems, including during your sleep
- liver problems
- high blood pressure
- a type of skin cancer called basal cell carcinoma (BCC).
- Are pregnant or plan to become pregnant. GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or are planning to become pregnant.
  - Tell your doctor right away if you become pregnant while taking GILENYA or if you become pregnant within 2 months after you stop taking GILENYA.
  - If you are a female who can become pregnant, you should use effective birth control during your treatment with GILENYA and for at least 2 months after you stop taking GILENYA.

    Pregnancy Registry: There is a registry for women who become pregnant during treatment with GILENYA. If you become pregnant while taking GILENYA, talk to your doctor about registering with the GILENYA Pregnancy Registry. The purpose of this registry is to collect information about your health and your baby's health.

    For more information, contact the GILENYA Pregnancy Registry by calling Quintiles at 1-877-598-7237, by sending an email to gpr@quintiles.com, or go to www.gilenyapregnancyregistry.com.
- Are breastfeeding or plan to breastfeed. It is not known if GILENYA passes into your breast milk. You and your doctor should decide if you will take GILENYA or breastfeed. You should not do both.

Tell your doctor about all the medicines you take or have recently taken, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Especially tell your doctor if you take medicines that affect your immune system, including corticosteroids, or have taken them in the past.

Know the medicines you take. Keep a list of your medicines with you to show your doctor and pharmacist when you get a new medicine.

Using GILENYA and other medicines together may affect each other causing serious side effects.

Especially tell your doctor if you take vaccines. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines, called live attenuated vaccines, while you take GILENYA and for at least 2 months after you stop taking GILENYA. If you take certain vaccines, you may get the infection the vaccine should have prevented. Vaccines may not work as well when given during GILENYA treatment.

How should I take GILENYA?

- You will be observed by a healthcare professional for at least 6 hours after your first dose of GILENYA. See **"What is the most important information I should know about GILENYA?"**
- Take GILENYA exactly as your doctor tells you to take it.
- Take GILENYA 1 time each day.
- If you take too much GILENYA, call your doctor or go to the nearest hospital emergency room right away.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- Call your doctor right away if you miss a dose of GILENYA. You may need to be observed by a healthcare professional for at least 6 hours when you take your next dose. If you need to be observed by a healthcare professional when you take your next dose of GILENYA you will have:
  - an ECG before you take your dose
  - hourly pulse and blood pressure measurements after you take the dose
  - an ECG 6 hours after your dose
- If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be observed overnight by a healthcare professional in a medical facility after you take your dose of GILENYA.
- If you have serious side effects after taking a dose of GILENYA, especially those that require treatment with other medicines, you will stay in the medical facility to be observed overnight. If you were observed overnight, you will also be observed for any serious side effects for at least 6 hours after you take your second dose of GILENYA. See **"What is the most important information I should know about GILENYA?"**

What are possible side effects of GILENYA?
GILENYA can cause serious side effects.

See **"What is the most important information I should know about GILENYA?"**

Serious side effects include:

- **swelling and narrowing of the blood vessels in your brain.** A condition called PRES (Posterior reversible encephalopathy syndrome) has occurred rarely in patients taking GILENYA. Symptoms of PRES usually get better when you stop taking GILENYA. However, if left untreated it may lead to a stroke. Call your doctor right away if you have any of the following symptoms:
  - sudden headache
  - confusion
  - seizures
  - loss of vision
  - weakness
- **breathing problems.** Some people who take GILENYA have shortness of breath. Call your doctor right away if you have trouble breathing.
- **liver problems.** GILENYA may cause liver problems. Your doctor should do blood tests to check your liver before you start taking GILENYA. Call your doctor right away if you have any of the following symptoms of liver problems:
  - nausea
  - vomiting
  - stomach pain
  - loss of appetite
  - tiredness
  - your skin or the whites of your eyes turn yellow
  - dark urine
- **a type of skin cancer called basal cell carcinoma (BCC).** Talk to your doctor if you notice any skin nodules (e.g., shiny pearly nodules), patches or open sores that do not heal within weeks (these may be signs of BCC).

The most common side effects of GILENYA include:

- headache
- abnormal liver tests
- diarrhea
- cough
- flu
- sinusitis
- back pain
- abdominal pain
- pain in arms or legs

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all of the possible side effects of GILENYA. For more information, ask your doctor or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

General information about GILENYA
Medicines are sometimes prescribed for purposes other than those listed in a Brief Summary. Do not use GILENYA for a condition for which it was not prescribed. Do not give GILENYA to other people, even if they have the same symptoms you have. It may harm them.

This Brief Summary contains the most important information about GILENYA. If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about GILENYA that is written for healthcare professionals.

For more information, go to www.pharma.US.Novartis.com or call 1-888-669-6682.

What are the ingredients in GILENYA?
Active ingredient: fingolimod
Inactive ingredients: gelatin, magnesium stearate, mannitol, titanium dioxide, yellow iron oxide.

GILENYA is a registered trademark of Novartis AG.

Distributed by:
Novartis Pharmaceuticals Corporation
East Hanover, New Jersey 07936

Revised: February 2016

Evaluating the Hereditary Risk of MS

By Dr. Jack Burks
MSAA's Chief Medical Consultant

Q: In the previous "Ask the Doctor" column, with regard to genetic predisposition for MS, Dr. Burks noted that the risk of being diagnosed with MS when a family member has MS is about 2 percent. However, MSAA received a few letters about families with multiple members who had MS, and their risk far exceeded 2 percent. They wanted to know why this has happened in their family.

A: I am always sorry to hear when several members of a family have been affected by MS, and hope these families are able to find some relief through available treatments. These types of occurrences are fairly unique. The figures I quoted are "population averages" and these reflect the overall risk of MS in family members with MS in large-scale population studies, which have been published in the medical journals. Families with much higher rates would be considered an "outlier situation," which is uncommon, but does occur. Outlier refers to a finding that is well outside of the expected range of values typically seen in a large population.

I normally refer to "population averages" when talking about the risk of one's family members developing MS, unless specifically asked about "exceptions." I don't want to confuse and possibly upset the MS community as individuals try to understand their risk. In the past, the familial MS patients I have spoken with understand their unusual situation and tend to agree with me about not creating additional fears.

On average, the risk of MS without other close family members with MS is about one in 1,000 for the general population. With a close family member, the risk increases 20 times to about 2 percent. If a non-identical twin has MS, the risk to the other twin is about 5 percent, and this increases to 30 percent for an identical twin of a twin with MS. One genetic variant in the X chromosome may help explain the increase of frequency of MS in females.

Research efforts are now directed at finding the role of specific genetic links. Various studies have and continue to look at families with a higher risk of MS in an attempt to identify genetic markers that may increase one's risk, and the results of such studies provide important data for researchers. However, there does not appear to be a specific "MS gene," but rather about 200 genes that are linked to immune function and are more frequently found in people with MS.

A small risk of developing MS still exists for children of MS patients – but keep in mind that this risk is significantly less than for someone whose family has been stricken with a hereditary disease. Additionally, as you know, MS research has advanced immensely in recent years. Far more treatments have become available and many studies are pointing to the possible involvement of controllable risk factors, such as Vitamin D, weight and body-mass index (BMI), salt intake, smoking, and other possible factors. Taking all of this into consideration, the future is bright for the MS community as a whole.

Q: I am writing to you with the hope that you can help me with the recommended dosage and frequency for B12 injections. I was diagnosed one year ago with MS and the exhaustion is killing me. My doctors can't seem to tell me what dosage to take or how often. I need the methylcobalamin form of the B12. Any help would be much appreciated.

A: Many factors contribute to the overwhelming fatigue experienced with MS. One major cause of fatigue in MS is when the protective myelin covering to the nerves of the central nervous system (CNS), which functions as a type of insulation, becomes damaged. When this occurs, more energy is required for nerve impulses to travel to their destinations. Other causes can include lifestyle factors such as lack of sleep, too much stress, using too much energy on daily tasks, and those types of things.

You are concerned about low vitamin B12 specifically, which may cause fatigue and other symptoms. A blood test is available to determine if your B12 is low. Regarding dose, I can only give you general dosage recommendations. If your doctor is unsure of the appropriate dose, he or she may also be able to refer you to a vitamin B12 authority in the area, such as a naturopathic doctor.

You specifically mention methylcobalamin, which is a natural form of vitamin B12. While cyanocobalamin is not naturally derived, it is the more commonly prescribed and more affordable version of the vitamin. However, the body quickly converts it to methylcobalamin. I have not seen any published medical information proving that one form is better or more toxic than the other. The recommended oral dosage of cyanocobalamin for vitamin B12 deficiency ranges from 125 to 2,000 micrograms (**not** milligrams!) per day. Oral vitamin B12 is available without a prescription, while vitamin B12 shots are available through your doctor if you cannot absorb vitamin B12 orally. The doses of methylcobalamin range between 500mcgs and 5000mcgs.

I recommend that you learn about vitamin B12 from reputable sources and a good amount of information may be found online. The Mayo Clinic provides helpful information on B12, which may be accessed by going to **www.mayoclinic.org** and searching for "vitamin B12."

Some medications may help with MS fatigue. For example, Provigil® (modafinil) or Nuvigil® (armodafinil) may be effective, although they

are not FDA-approved specifically for MS fatigue. Other drug options are also available, and you would need to discuss these treatments with your doctor to see if any are appropriate for you. Additional strategies include conserving energy, getting better sleep, reducing stress, cooling (for heat-sensitive individuals), and even exercise. For more information about combatting fatigue, please visit MSAA's website section on this topic at **mymsaa.org/ms-information/symptoms/fatigue**. ■

PLEASE SUBMIT YOUR QUESTIONS TO:

MSAA
Questions for Ask the Doctor
c/o Dr. Jack Burks
375 Kings Highway North
Cherry Hill, New Jersey 08034

Questions may also be emailed to **askdr@mymsaa.org**. Please be sure to include "Ask the Doctor" in the subject line.

Jack Burks, MD is the chief medical consultant for MSAA. He is an international MS neurologist, writer, lecturer, and researcher, who assists with the development of new MS therapies as well as new MS centers. He also advises patients, families, MS organizations, and healthcare groups. Dr. Burks is an adjunct professor at Nova Southeastern University and clinical professor of neurology at Florida International University. In addition, he has authored numerous textbooks, chapters, and articles on MS.

FDA Approves First Drug to Treat Two Forms of MS

On March 28, 2017, the United States Food and Drug Administration (FDA) announced the approval of Ocrevus™ (ocrelizumab) for the treatment of two types of multiple sclerosis (MS): relapsing forms of MS (RMS) and primary-progressive MS (PPMS). This is the first time that a medication for MS has been approved for these two types of the disease, and the first time that any medication has been approved to treat PPMS. This is very exciting news for the MS community. To view the FDA's press release, please visit **www.fda.gov** and search for "new drug Ocrevus," which will bring up the press release titled "FDA approves new drug to treat multiple sclerosis."

Prior to this approval, 14 disease-modifying therapies were available for the treatment of relapsing forms of MS, but no treatments had been approved by the FDA for PPMS. As noted, the approval is for relapsing forms of MS (RMS), which are characterized by sudden flare-ups and remissions. RMS includes relapsing-remitting MS (RRMS) as well as secondary-progressive MS (SPMS) with relapses. The approval is also for primary-progressive MS (PPMS), which is a less-common form of the disease and is characterized by a steady accumulation of symptoms.

Medication and Study Information

Developed by Genentech, a member of the Roche group, Ocrevus™ (ocrelizumab) is a humanized monoclonal antibody designed to selectively target CD20-positive B cells. These are a specific type of immune cell that is an important contributor to the MS-disease process. The fact that Ocrevus targets B cells differentiates it from most of the previously approved disease-modifying therapies for MS, which target a different type of immune cell called "T cells."

In Phase III trials, 600 mgs of Ocrevus were given via intravenous (IV) infusion every six months. In most instances, the initial 600-mg dose was divided into two 300-mg doses, given via IV infusion, and separated by two weeks.

Positive results were seen in three Phase III trials with Ocrevus. OPERA I and OPERA II were studies with relapsing forms of MS. Compared to treatment with Rebif® (interferon beta-1a), Ocrevus showed greater efficacy in reducing annualized relapse rates and reducing disability progression that was sustained for time periods of at least three and at least six months.

The ORATORIO study was with PPMS and compared treatment with placebo. The trial showed significant reductions in disability progression sustained for time periods of at least three and at least six months. Reductions in other measures of progressive disease were also seen. In all three studies, Ocrevus reduced the burden of MS lesions as shown on magnetic resonance imaging (MRI).

Adverse events in all three of the Phase III studies were similar between those given Ocrevus and those given either Rebif in the RMS studies or the placebo in the PPMS study. Genentech reports that the most common adverse events seen with Ocrevus were mild to moderate infusion-related reactions and infections. Other rare adverse events, including cancer and progressive multifocal leukoencephalopathy (PML), could potentially occur, but the risk is low and still being investigated. As of the time of approval, no cases of PML had occurred.

Comment from MSAA's Chief Medical Consultant

MSAA's Chief Medical Consultant Dr. Jack Burks explains, "This is one of the most exciting times for the MS community. The addition of this new medication to our current group of approved disease-modifying therapies gives a new option for the treatment of MS, particularly for individuals with PPMS as well as others with relapsing MS whose disease activity could not be well-controlled with other therapies. In addition, the approval of Ocrevus and the results of these studies will help guide future MS research into the disease process and the development of other innovative treatment strategies."

For More Information

For more information about Ocrevus, please call **(844) OCREVUS [or (844) 627-3887]** or visit **www.ocrevus.com**. Genentech also plans to offer patient-assistance programs through Genentech Access Solutions. For more information, please call **(866) 4ACCESS [or (866) 422-2377]** or visit **www.Genentech-Access.com**.

For additional information on MS or to speak with a trained Client Services Specialist, please call MSAA's Helpline at **(800) 532-7667, extension 154**. Questions to MSAA's Client Services department may also be emailed to **MSquestions@mymsaa.org**. ■

Written by Susan Courtney, MSAA Senior Writer

Reviewed by Dr. Jack Burks, MSAA's Chief Medical Consultant

MRI Access Fund Now Fully Restored

By Peter Damiri
Vice President of Programs and Services

As a result of recent funding approvals, MSAA is thrilled to announce we have reinstated a critical coverage component to our popular MRI Access Fund. Individuals with Medicare and private health insurance who cannot meet their co-insurance balance are now eligible to apply for funding assistance for a cranial magnetic resonance imaging (MRI) exam through the program.

Now marking its 15th year, MSAA's MRI program has been assisting thousands of individuals who are uninsured or under-insured to acquire an MRI to help determine a diagnosis of multiple sclerosis or evaluate current MS disease progression. Recently, one of the program's recipients, Sara, appeared in MSAA's new "Changing Lives Monday to Sunday" video and shared her experiences about the Access Fund and the benefits of getting a much-needed MRI exam.

Sara from New Jersey was able to receive a much-needed MRI thanks to MSAA's MRI Access Fund.

"After being diagnosed with MS for three years, my disease was declining," explained Sara. "I needed an MRI to show whether or not there were more lesions, but I couldn't get it. I was laid off from work and my COBRA had expired. I didn't have health insurance and could not afford to pay out-of-pocket for the MRI. I was stuck."

While discussing the situation with her neurologist, Sara's doctor mentioned MSAA's MRI program and suggested she apply for assistance. "The MRI Access Fund was an absolute gift to me," Sara noted. "It was so easy to apply for. I can't say enough about how

Through the generous funding support of Biogen, Sanofi Genzyme, and Teva Pharmaceuticals, MSAA has been able to fully restore the MRI Access Fund and assist qualified applicants in two ways:

- **For people with no health insurance or a high, unmet insurance deductible, the Fund will pay for an MRI through one of MSAA's contracted imaging centers**
- **For individuals who cannot meet their MRI co-insurance balance, the program will cover the remaining cost, up to a specified maximum amount**

patient-friendly they were. No red tape and no wait list. It was a painless procedure to get the MRI – from filling out the form to going to the imaging center and getting the exam."

Following her MRI, Sara went back to her doctor to discuss the findings. "The results verified there was a decline in my MS – there was activity," said Sara. "It made me believe I wasn't making stuff up. This was actually happening to me and I was able to get on the treatment that I needed."

Applicants must meet certain eligibility guidelines, complete the updated 2017 application, and have not received an MSAA-funded MRI within the past 24 months. Also, MSAA does not reimburse for MRIs outside of this program. To learn more and apply, please visit **mymsaa.org/mri** or call **(800) 532-7667, ext. 120**. ■

Don't forget… contact MSAA today for your cooling vest and accessories, before the busy season approaches!

Please visit mymsaa.org/cooling for more information.

Trial Enrolling for MS-Related UI

If you or a loved one experience MS-related urinary incontinence (UI), or involuntary urine leakage, participating in a trial will help provide new treatment options.

Clinical trials help to find new treatments for a variety of conditions, such as UI due to MS, and we would like to let you know about a new trial that is now enrolling.

This trial is testing whether Dysport®, which is already approved for other conditions, can help reduce UI in people living with MS for whom oral medications have not worked well.

You or your loved one may be able to take part if you or he/she:

- **Are between 18 and 80 years of age**
- **Have MS**
- **Have UI due to MS**
- **Have not responded well to oral medications; and**
- **Are routinely performing clean intermittent catheterization**

To learn more and to see if you or your loved one may be able to take part, please visit **mymsaa.org/antidoteUI**

As you may know, MSAA recently partnered with Antidote, a digital health company, to offer a new clinical trial search tool on our website that will make learning about and connecting with MS clinical trials easier than ever. If this UI trial is not of interest to you, we encourage you to check out the search tool at ***mymsaa.org/clinicaltrials*** *and learn more about other MS-related research trials in your area.*

Create Your Own Fundraising Event for MS

By Angel Serrano, CFRE

Each year individuals and groups turn their passions and interests into unique fundraisers to raise thousands of dollars for MSAA. All fundraisers, large and small, play a vital role in raising awareness and funds to help support MSAA's free programs and services.

Simple ideas include bake sales, jeans' day at the office, coin toss, bingo party, or donating a percentage of sales for a day. Other exciting ideas include a car show, polar plunge, "Strike MS" bowling competition, or sporting event such as a golf, soccer, tennis, or basketball tournament. If you enjoy swimming, you can also create your own Swim for MS challenge – check out **SwimForMS.org** for more information! If interested in creating your own fundraiser, please visit **support.mymsaa.org/create** or email us at **events@mymsaa.org**.

To follow are just a few examples of inspirational individuals and groups who have gone above and beyond to improve the lives of those affected by MS.

Nana's Cookies Bake Sale

At the age of nine, Alyssa Lewanowicz from Pennsylvania lost her great-grandmother due to complications from multiple sclerosis. Alyssa decided at that young age that she wanted to do something to help others with MS.

Shown above is 9-year-old Alyssa.

With the help of her mother, Lynne Goldberg, and grandmother, Linda Somers, Alyssa and her family have organized an annual bake sale for MSAA in memory of her "Nana." Now, at the age of 20, Alyssa, along with Lynne and Linda, organized Nana's Cookies 10th Annual Bake Sale. In 2016, this memoriam event raised nearly $3,000 to support MSAA's programs and services.

(L to R) Alyssa, along with her mother Lynne and grandmother Linda, raised nearly $3,000 at her 10th annual Nana's Cookies Bake Sale.

Auburn Kicks for MS

On October 14, 2016, the Auburn University Soccer Team organized their 4th Annual Auburn Kicks for MS event in honor of three Auburn soccer alumni, all of whom were diagnosed with MS. The event takes place at Auburn University in Alabama each year during their regular soccer season. This honorarium event raised more than $3,200 to support MSAA and the MS community.

Atlantic City Polar Plunge

On January 1, 2017, the Atlantic City Polar Bear Club organized the 5th Annual Atlantic City Polar Plunge, which benefits MSAA and takes place each year in New Jersey. Michael Kahlenberg, one of the event organizers, has a friend with a son who was diagnosed with MS, so the club decided to support a nonprofit organization that helps those affected by MS.

This year, it was a beautiful, sunny day and many participants arrived in Atlantic City, New Jersey, on Sunday morning, eager to plunge into the icy waters to support MSAA and ring in the New Year! This unique event raised more than $4,000 with the help of generous sponsors and participants.

Multiple Sclerosis Golf Challenge

In 2007, Bobby O'Brien was diagnosed with MS. The O'Brien family – Joe, Gayle, Bobby, Sean, Catherine, and Christopher – decided they wanted to support an MS organization that helps individuals each day to cope with the symptoms, just as Bobby must do.

On June 17, 2016, the O'Brien Family and close family friend, Matthew Watson, organized the 9th Annual Multiple Sclerosis Golf Challenge in Massachusetts. The event included many generous sponsors, 144 golfers, a 50/50 raffle and silent auction, plus a barbeque, all of which raised more than $11,000. Gayle stated, "The event is a chance for people to come together for a fun day of golf and to support multiple sclerosis awareness."

Pictured is the O'Brien family, organizers of the 9th Annual Multiple Sclerosis Golf Challenge in honor of Bobby O'Brien (near left). Joining him at the event is his sister Catherine, along with his father Joe (near right) and his brother Sean (far right).

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Family Comes First

By Lisa Norman

In November 1995, I entered the specialist's office in Charlotte, North Carolina to learn why my left eye was constantly twitching and jumping. I left with a diagnosis of "you may have" MS. Following an MRI, the "you may have" became the "you do have" relapsing-remitting MS. Unbeknownst to me, this was the start of my depression.

After my diagnosis, episodes of burning pain, uncoordinated walking, and exhaustion began. My daughters, Shannel and Cierra, were young and seemed to demand more of my attention. I thought I was giving them enough and would sometimes become frustrated with them. There were times when remembering and completing the things I needed to do became hard for me.

In 1998, I saw a neurologist who started me on a disease-modifying therapy. I mistakenly thought the injections would stop the pain, and with no immediate relief, a feeling of helplessness and confusion came over me. I now realize that depression creeps up when you are the most vulnerable, and by the time you become aware, has already affected much of how you feel.

Over the years, my symptoms were becoming more frequent and more obvious. I tried to hide my disease from everyone except my family. I gradually started explaining my disease to friends and some seemed to shun away. I felt insignificant. How do I live a normal life, when I don't even know what normal is anymore?

I decided to isolate myself, only spending time with my family. I stopped going out in public. My family understood what I was dealing with, but they did not know about the negative thoughts I was having… feelings of unhappiness, worthlessness, lethargy, and emptiness.

One night in my bedroom, I could no longer tolerate the misery and pain. My daughters were playing in the living room, and my mind was taking me to a dark place. I started to look for a way out – any way I could get it. I noticed the medicine bottles on my nightstand; I had placed several pills in my hand, when suddenly my daughter Cierra screamed out, "MA!" I was so shocked that I dropped the pills and rushed to the living room.

My daughter had dropped a mirror and had a piece of glass in her foot. I became so focused on making sure I removed all of the glass, I seemed to forget about my own situation. My daughters mean the world to me; they love me unconditionally, and they are depending on me. MS has issues bigger than I could have ever imagined, but I needed to find a more appropriate way to deal with my feelings. Family comes first.

I told my doctor about my recent thoughts of suicide, and the other things going on, like angry outbursts, mood swings, seclusion, sluggishness, and no

concern for myself or others. He told me I was going through depression, explained some of the signs and symptoms, and prescribed an antidepressant.

Things were better for a while, but depression returned and I began contemplating suicide again. This time, when I reached for my pills, I could see the label that said, “This medicine may cause drowsiness, dizziness, and SUICIDAL THOUGHTS. If you experience any of these symptoms, call your doctor immediately.” I did. And he got me through this difficult time.

Lisa Norman (center) enjoying the beach with daughters, Cierra (left) and Shannel (right).

Depression can be life-threatening when suicidal thoughts arise. One study found that the risk of suicide was several times higher among persons with MS than the general population. My doctor explained that many treatments are available; we just had to find the one that would achieve the best results for me. I was fearful about what may happen with trying another unknown antidepressant, but my daughter Shannel, who was now older, told me, "You need to put your hope in something." I needed to put my hope into getting well, not just for me, but also for my family.

Fortunately, my doctors were able to prescribe exactly what I needed. I learned that antidepressant medications can be helpful, but each individual has a different response. Various medications and doses may need to be tried before an effective medication, or a combination of medications, is identified.

I was lucky to have had enough gumption to seek medical attention before doing something so terrible that neither my family nor I would have ever recovered. I am now able to maintain a quality of life that is happy, active, well-rounded, and functional… and I even enjoy spending time in public places! I have lived with MS for almost 22 years, and my last MRI report showed no new activity. With guidance from my neurologist, support from my family, and continued use of appropriate medications, I have been in remission for the past 13 years.

I hope my story of adversity, perseverance, family, and emotional wellbeing is an opportunity to encourage others to know that hardships will come, but you don't have to let them define you. Should you ever find yourself in a position where you frequently have negative feelings or even question your will to live, please get immediate medical attention. A change of medication and/or having someone to speak with can change your entire outlook. I would never want my daughters, Shannel and Cierra, to be without a mom. I am so thankful to have their support. I have learned that despite my challenges with MS, I have people who are devoted to me. I have also learned that family comes first. ■

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Swim for MS: Team Enfinity

For her third year participating in Swim for MS, Natalie Domeisen recruited her friends to join in on the fun! Team Enfinity combined Swim for MS with the 2017 Speedo USMS 1-Hour ePostal National Championship this year. While the team swam as many laps as possible in one hour, they recruited donations for MSAA as well.

Natalie states, "We raised $1,000 for the MS Association, to provide services and goods for those with MS, their families, friends, and loved ones, while simultaneously raising awareness for the benefit of hydrotherapy and swimming for those with MS. Hydrotherapy is a critical approach to care for patients with MS. It is important to raise awareness about the benefits of swimming and its low-impact environment for the patients and families coping with MS. As a Division 1 swimmer, I can attest the emotional and physical reward of swimming is unparalleled. As a current medical student and former swimming rehabilitation volunteer, I have witnessed the tremendous healing of the body swimming can provide. This was my third Swim for MS and the money this fundraiser raised brings my personal fundraising total to $3,803.25 since 2009. I hope to have many more!"

Swim for MS: In Honor of Kimberly

Kristy Neal was determined to make a difference in the lives of those affected by multiple sclerosis by joining the Swim for MS challenge in honor of her best friend, Kimberly. Kristy and Kimberly met at a swim meet at the age of 8 and have been best friends ever since. Two years ago, Kimberly was diagnosed with MS. "It is very difficult to watch a loved one struggle with a disease like this, and I feel that Swim for MS is something I can do to help support her in her fight against MS," Kristy says.

In October 2016, Kristy pledged to swim 25 miles as part of her Swim for MS challenge and raised nearly $800. Kristy says, "My favorite part of the challenge is that I am able to raise money for people who struggle with MS, while engaging in an exercise that I love. Participating in this challenge is very rewarding and allows me to honor my friend. If I can't help ease the symptoms of this disease, I can at least help ease the financial burden of it for those in need."

Kristy Neal proudly displays a sign to commemorate 800 laps in honor of her best friend Kimberly.

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