

MSAA

Summer/Fall 2012

# The **MOTIVATOR**

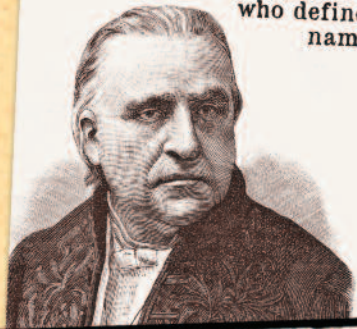
**Bringing Information to People with Multiple Sclerosis**

## **THE EVOLUTION of MS Diagnosis, Treatment, and Care**

*With contributions  
from some of today's  
leading MS experts*

Jean-Martin Charcot

French neurologist  
who defined and  
named MS



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**WHAT'S THIS?**

QR-code enabled smartphone users may scan this image to view this issue of *The Motivator* on their mobile device.



The Multiple Sclerosis Association of America's mission is to enrich the quality of life for everyone affected by multiple sclerosis.

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.

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*Douglas G. Franklin*

**I**t has certainly been an exciting summer for MSAA! At the beginning of the summer, MSAA announced that US Olympic swimmer Missy Franklin had become our new Swim for MS Ambassador. During the London 2012 Olympic Games, my niece Missy not only made MSAA proud, but the entire country! Winning five Olympic medals, including four gold medals, plus setting new Olympic and World records, her performance was inspiring to all. In the coming months, you will hear more about her involvement with MSAA and our exciting Swim for MS program.

In other Swim for MS news, MSAA's Swim for MS Pool Party allowed MSAA volunteer Jeannie Leombruno the opportunity to not only celebrate her birthday, but also to give back to the MS community. Jeannie held her Pool Party on July 27 with great success, raising close to \$1,500 for MSAA! Please visit [SwimForMS.org](http://SwimForMS.org) to start your own Swim for MS event.

In programming news, MSAA is continuing to expand several program initiatives that focus on helping individuals to manage their MS.

- **My MS Manager™**, MSAA's popular mobile phone app (provided free of charge for individuals with MS or their care partners to use on their iPhone), is expanding to all Android platforms in October.
- **My MS Resource Locator** is MSAA's newest program, designed to make your search for MS-related information and resources as easy as possible. After its introduction in late spring, My MS Resource Locator continues to grow and provide a much-needed resource right at the click of a mouse.
- MSAA has launched a **blog called MS Conversations** to provide a forum for the MS community to share tips, stories, or their MS experiences. Please visit [msassociation.org/msconversations](http://msassociation.org/msconversations) to share your thoughts!

I am also very pleased to announce that MSAA received an **APEX Award for Publication Excellence** for our S.E.A.R.C.H.™ webinar. Please visit [msassociation.org/videos](http://msassociation.org/videos) to view this and other MSAA webinars.



Mike Comer/ProSwim Visuals

*Missy Franklin, winner of four Olympic gold medals and MSAA's Swim for MS Ambassador*

On a sad note, MSAA experienced a great loss just prior to printing this issue. Vice President of Finance & Administration Gary Wallace, CPA, passed away after 14 years of devoted service to our organization. The entire staff and many colleagues outside of MSAA are deeply saddened. He was a very kind and generous person; our thoughts and prayers go out to his family. We will publish a tribute to Gary in the following issue of our magazine.

In closing, I would like to thank all of you for your dedication to MSAA throughout the year. It is through your generous support that we can continue to serve so many individuals. ♦

*Doug Franklin joined MSAA as President & CEO in 1999. He has a distinguished career in nonprofit leadership and is a former national trainer in strategic planning for the Peter Drucker Foundation. A published international expert in social marketing and corporate social investment, he is a graduate of four universities. He currently serves on the National Board of the Key Philanthropic Organizations Committee of the American Society of Association Executives; on the Executive Committee of Health First – America's Charities Board in Washington, DC; and as President of the Multiple Sclerosis Coalition.*

# Submit Your Best Work

for MSAA's *Art Showcase*



Khayli Heijkoop,  
Celebration of Life  
2012 Art Showcase

## Get Creative! Exhibit Your Painting in the 2013 MSAA Art Showcase

MSAA welcomes paintings in oil, watercolor, and acrylic, as well as pastels and drawings in pencil and ink for its 2013 Art Showcase.

Artwork will be accepted only from individuals who have MS. Submitted pieces must be two-dimensional. Sculpture, pottery, fabric, and other types of three-dimensional work cannot be accepted.

The Art Showcase will first appear on MSAA's website during March 2013 in recognition of MS Awareness Month.

**Submissions will be accepted between October 15 and December 17, 2012.**

### For more information, contact:

Angel Galiuzzi  
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For submission guidelines, visit [support.msassociation.org/artshowcase](http://support.msassociation.org/artshowcase)

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# The **EVOLUTION** of MS Diagnosis, Treatment, and Care

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Compiled and edited by  
Susan Wells Courtney

Reviewed by Dr. Jack Burks

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## Introduction: A Long and Difficult Road

**T**he evolution of multiple sclerosis (MS) diagnosis, treatment, and care, from the early 1800s to today, has been an extremely long and difficult road for researchers, medical professionals, and members of the MS community alike. Through the 1800s and up until the mid 1900s, without the diagnostic tools of today, some individuals showing signs of MS may not have received a diagnosis during their lifetime.

Additionally, doctors did not know what might be causing MS or if it might be contagious. As more cases came to light over the years, more confusion occurred over what to do and how to treat this mysterious illness. Medical professionals and well-meaning laypeople were grasping at straws to find an effective treatment, relying on trial and error while testing a wide range of unusual medications and unexpected therapies.

Rigorous, randomized, double-blinded studies were necessary for effective treatments for MS to finally be identified. Despite nearly

two centuries of scientific observation and research, the first real treatment did not become available until 1993. Diagnosis was another great challenge, and the tools needed for this did not become available until the mid-to-late 1900s. While the technologies are vastly improved, diagnosis still remains a challenge in some instances.

Members of the MS community may feel some comfort in knowing that their diagnosis can now be made with far more certainty than just a few decades ago. And for those with relapsing forms of MS, nine disease-modifying therapies are presently available to slow disease activity. These treatments have been of enormous benefit to the majority of individuals with MS.

For individuals with relapsing as well as progressive forms of MS, many resources are now available to help with medical care, wellness strategies, rehabilitation therapies, and assistive equipment. These are all aimed at making life with MS healthier, safer, more comfortable, and more productive. Research

into potential treatments for progressive forms of MS, as well as repair of damaged myelin and nerves, continues at a rapid pace.

While no one welcomes MS into his or her life, this is a better time to be faced with the challenge. Between ongoing studies around the world, devoted MS organizations, and incredible teams of neurologists, nurses, and therapists, members of the MS community have more support and more hope for the future than ever before.

## About this Article

This article is a collection of quotes from several top experts in the field of MS, each talking about the important contributions he or she has found to make a difference in the lives of individuals with MS. Some of the experts are members of MSAA's Healthcare Advisory Council, while others are among the medical professionals with whom MSAA has worked previously, assisting with our various educational programs for patients and professionals. Space does not allow us to quote all of the wonderful MS experts with whom we have worked in the past, but we are extremely grateful for those willing and able to participate in this special article.

Our group of experts includes neurologists and researchers as well as nurses and therapists. Following our first two introductory experts, and before our closing message, we have grouped the balance of professionals in the following order: first by field, and then alphabetically within their field. We start with neurologists and researchers, then nurses, followed by therapists. Everyone is of equal importance

in the care of individuals with MS, but grouping them this way allows for a smoother transition between topics.

Our first introductory contributor to this article is Thomas J. Murray, OC, MD – an MS historian who literally wrote the book on MS history! Titled *Multiple Sclerosis: the history of a disease* (Demos Medical Publishing, 2005), this reference, along with Dr. Murray, was of great help in developing our timeline. Many thanks also go to Dr. Randy Schapiro and speech-language pathologist Carrie Bruce for their contributions to the timeline. Space does not allow us to include all of the historical events that occurred during the past two centuries that helped to shape the history of MS, but we have highlighted some of the more notable ones.

In his quote, Dr. Murray gives a very brief history of MS treatments during the 1800s and early 1900s, leading up to the time when an accurate understanding of the disease became a reality. This is followed by our second introductory quote, from MSAA Chief Medical Officer Jack Burks, MD, who gives his insightful view of the past 50 years on the evolution of MS diagnosis, treatment, and care. From there, we have many interesting, informative, and inspiring contributions from 14 other experts.

Finally, we conclude our article with a closing message from Diana M. Schneider, PhD. She is a medical writer, publisher, and researcher – and a regular contributor to our magazine. Dr. Schneider may be best known at MSAA for her annual MS Research Updates. We hope you enjoy this collection of quotes from these highly regarded medical professionals!

# The Evolution of MS Diagnosis, Treatment, and Care



## Thomas J. Murray, OC, MD, FRCPC

Professor Emeritus and former Dean of Medicine at Dalhousie University, Halifax, Nova Scotia, Canada

### *...on the history of MS treatments*

“In 1868, Jean-Martin Charcot defined the clinical features and named the disorder we now know as multiple sclerosis (MS) – and speculation about cause and potential therapies began. Initially, the treatments applied to an MS patient were those used for any serious neurologic disease and included a list of drugs thought to be sedatives and others that were stimulants: foxglove, Indian tobacco, aconite, hemlock, coffee, musk, garlic, asafoetida, valerian, castor, oil of amber, skunk cabbage, alcohol, ether, chloroform, opium, hops, deadly nightshade, henbane, Hoffman anodyne, and extract of hemp. Other prescriptions might be horseback riding, various herbs, moxibuxon, restricted diet, vigorous massage, draining wounds, hydrotherapy, and electrical stimulation.

“William Moxom, the first to publish cases of MS in the English literature (1870s) prescribed meat diet, bleeding, cooling with sponges, galvanic and faradic electrical stimulation, iron, strychnine, quinine, belladonna, calumbae, arsenic, nux vomica, silver nitrate, hyocynamide, atropine, and ergot. He concluded that the results were ‘most unsatisfactory’ and ‘no approach to cure has been made.’

“In the early 20th century, a lot of therapies applied to MS were those found to be helpful in syphilis, such as heavy doses of mercury, periods of time spent in a fever box, fever induction with vaccines, and injection of malaria parasites, all of which would make an MS

patient feel worse. Although most neurologists concluded that nothing helped, they all tried some therapies in hopes that they may offer some benefit.

“Charcot in the 19th century and writers reviewing all remedies, such as Russell Brain (1930) and George Schumacher (1950), concluded that no therapy altered the outcome of the disease. This didn’t stop clinicians from trying an array of treatments, however, and in 1935 Brickner listed more than 150 therapies that had been used in MS.

“Anticoagulants were used after 1940 on the theory that vascular occlusion may be the cause, then antibiotics on the theory that infection was the cause. Other theories of cause led to therapies with low-fat diets and histamine desensitization (histamine is a substance produced by the body during an allergic response). This was followed by a long period of use of immunosuppressants, based on the belief that the problem was a disturbed immune system. Steroids were used for the inflammation in acute attacks, but it was evident that they did not alter the progression of MS. It was common to borrow therapies that worked in other disorders, such as rheumatic or autoimmune diseases, which shared immunologic and inflammatory theories.

“The first therapies demonstrated to convincingly alter the outcome of the disease came with the development of the disease-modifying therapies in the 1990’s, after their long development that began in the 1970’s. As we

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go forward, therapies will be designed to fit our changing theories, and similarly, better therapies will alter theory in order to explain the benefit. That is the nature of the scientific enterprise.”

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*Dr. T. Jock Murray founded the Dalhousie MS Research Unit in 1979 and co-founded the*

*Consortium of MS Centers (CMSC), previously serving as president. He also founded the Canadian Network of MS Centers. Dr. Murray has authored or co-authored four books on MS, including Multiple Sclerosis: the history of a disease. He was made an Officer of the Order of Canada, the country's highest civilian recognition.*

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## Jack Burks, MD

Chief Medical Officer, Multiple Sclerosis Association of America  
President, Burks & Associates Healthcare Consultants, Reno, Nevada  
Clinical Professor of Neurology, Florida International University Medical School  
Member, MSAA Healthcare Advisory Council

### *...comments from MSAA's Chief Medical Officer*

“The dark history of MS therapy has included snake venom, bee stings, malaria, colostrum, magical shoes, and rest (exercise was once thought to make MS worse). In 1970, in the beginning of my neurologic/MS career, many patients were not told that they had MS because the diagnosis was ‘too scary.’ They were told not to expect pain, cognitive problems, or depression. In fact, MS was thought to cause ‘euphoria.’ Now, we not only have disease-modifying medications, but we also have many therapies for MS symptoms – such as pain, changes in cognition, fatigue, spasticity, walking difficulties, emotional changes, bladder and bowel problems, as well as sexual dysfunction.

“Exercise and rehabilitation therapies, along with psychological help, have improved the Quality of Life (QoL) for many people with MS. The utilization of an interdisciplinary, comprehensive, healthcare professionals (HCP) ‘team approach’ has greatly augmented the pharmacologic advancements. We now have MS specialists in all aspects of MS care and a

Consortium of MS Centers (CMSC) with healthcare professionals who all work together to advance the science and therapies.

“Many of these advances can be attributed to the implementation of the scientific principles of Evidence Based Medicine (EBM). Now, therapeutic trials are conducted with strict rules of conduct to reduce false hopes and missteps. Interestingly, false hopes, combined with EBM, may actually be helpful at times.

“For example, many of you may not know that the first FDA-approved MS treatment was stimulated by a false hope therapy that was rigorously pursued. In the 1970s and 1980s, MS was proposed to be a viral disease. Gamma interferon is an anti-viral agent, so it was tested in MS in the 1980s. It made the disease worse! Instead of ‘throwing up their hands’ in defeat, scientists went on to test beta interferon, which reduces gamma interferon. This successful clinical trial led to the first FDA-approved treatment for MS in 1993. Without the unsuccessful gamma-interferon trial, beta



# The Evolution of MS Diagnosis, Treatment, and Care

interferon might not have been tested.

“Another challenge of current and emerging therapies is balancing benefits versus potential treatment risks. If new therapies are stronger, will the risks be more daunting? Evaluating the benefits and risks from a neurologist’s perspective may differ from an individual patient’s perspective. Therefore, patients need to be very well informed on all treatment issues before any therapeutic decision is finalized.

“In summary, as new treatments are available, people with MS will be challenged to become more knowledgeable and to be able to actively share in the medical decisions, referred to as ‘shared management.’ This will provide each individual with his or her best therapy, increasingly referred to as ‘personalized medicine.’ The consumers of healthcare services, i.e., patients and their care partners, will have a better opportunity to share in their

medical decisions in partnership with their healthcare professionals.

“Further therapeutic challenges include treatments for people with progressive MS and therapies to reverse the damage already present. Clinical research trials in both of these areas are underway and we look forward to a promising future for everyone with MS.”

---

*Dr. Jack Burks is an international MS neurologist, writer, lecturer, and researcher, who assists with the development of new MS therapies and advises patients, families, MS organizations, and healthcare groups. Dr. Burks is a member of the Clinical Advisory Board of the NMSS. He has written and edited three MS textbooks, as well as numerous chapters and articles on MS. In recent years, he has lectured and evaluated patients in more than 40 countries.*

## The MS Coalition

An article on the history of MS diagnosis, treatment, and care, would not be complete without mentioning the valuable contributions made by the organizations created to help individuals with MS. The **Multiple Sclerosis Coalition (MSC)** was founded in 2005 in an effort to work together to benefit individuals with MS. Since that time, the MSC has grown to eight member organizations, all of whom provide critical MS programs and services. The members are listed below; to learn more please visit [www.ms-coalition.org](http://www.ms-coalition.org).

- Accelerated Cure Project for Multiple Sclerosis
- Can Do Multiple Sclerosis
- The Consortium of Multiple Sclerosis Centers
- International Organization of Multiple Sclerosis Nurses  
(along with its special-interest group, the International Organization of Multiple Sclerosis Rehabilitation Therapists)
- Multiple Sclerosis Association of America
- Multiple Sclerosis Foundation
- National Multiple Sclerosis Society
- United Spinal Association

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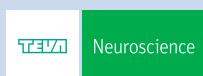
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1350

1850

**1380** St. Lidwina born in Holland; her progressive illness suggests a diagnosis of MS

**1794** Birth of Augustus d'Este, an early case of what would later be known as MS

**1838** Robert Carswell includes an illustration of a case of "a peculiar disease state," showing the features of MS



## Donald A. Barone, DO

Associate Professor and Chief, Division of Neurology,  
University of Medicine and Dentistry of NJ School of Osteopathic Medicine  
Director, MS Center of South Jersey  
Member, MSAA Healthcare Advisory Council

### *...on the evolution of diagnostic criteria in MS*

"Early in my career, with no proven therapy, there was no rush to diagnose MS. Without the right tools, a diagnosis couldn't be reached quickly anyway. Evoked potential studies were eventually developed to assess optic nerve and other central nervous system (CNS) conduction abnormalities. More sophisticated spinal fluid analysis, including tests for immunoglobulin G index and oligoclonal bands, helped to establish the MS diagnosis. Magnetic resonance imaging (MRI) emerged in 1984, but this required several years to become established as the most valuable aid in the diagnosis of MS.

"Criteria evolved over the years, although we still lack an absolutely definitive diagnostic

test for MS. The Schumacher Criteria, dating from the 1960's, required the clinical demonstration of two or more CNS abnormalities separated in time and space. The Poser Criteria in 1983 added evoked potentials and spinal fluid analysis to the diagnostic mix. Finally in 2000, the McDonald Criteria emphasized the importance of MRI evidence in establishing the MS diagnosis, with revisions in 2005 and 2010 – giving the MRI even more importance.

"How things have changed! There is still much more to be done, but it is gratifying to look back on the progress I have witnessed since starting my residency with Drs. Poser and Schumacher in 1975."

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*Dr. Donald A. Barone attended Rutgers College and the Philadelphia College of Osteopathic Medicine. While a resident at the University of Vermont Medical Center, he worked with Doctors Schumacher and Poser, two prominent MS experts. He participated in clinical trials in the 1980s and early 1990s, and completed a fellowship in neuromuscular disorders at Columbia Presbyterian Medical Center in New York. Dr. Barone has directed and taught the neurology courses at the University of Medicine and Dentistry of New Jersey since 1978. In addition to serving on an NMSS advisory committee and lecturing, he has a large MS clinical practice and is a principal investigator in several MS trials.*

**1868** Jean-Martin Charcot gives three lectures describing the features of MS and names it “*sclérose en plaque disséminée*”

A series of cases **1873-1875** are published in London by William Moxom

## Allen C. Bowling, MD PhD

Medical Director of the MS Program and Director of the Complementary and Alternative Medicine (CAM) Service at the Colorado Neurological Institute (CNI)  
Clinical Associate Professor of Neurology at the University of Colorado  
Member, MSAA Healthcare Advisory Council



### *...on wellness and complementary and alternative medicine*

“Over the past few decades, the advances in MS have been remarkable. There has been a revolution in understanding the disease process and remarkable advances in developing drug-based treatments. In addition, through my interest in wellness and complementary and alternative medicine (CAM), I have seen a dramatic shift in non-drug based approaches to MS.

“Previously, information about CAM approaches was limited, of variable quality, and, in some cases, dangerous. In some literature, exercise and other wellness approaches were actually categorized as ‘unconventional medicine.’ Health professionals and patients were divided in terms of their willingness to consider CAM

therapies. Discussing these at educational meetings or medical appointments was sometimes considered ‘taboo.’

“Over the past 15 to 20 years, I’ve seen a transformation in this area. Research has led to a better understanding and increased availability of high quality, MS-relevant information. Wellness and CAM approaches that appear to have low risk and potential therapeutic effects, including exercise, yoga, tai chi, hydrotherapy, and cooling, have now become mainstream and are incorporated into the treatment plan of those with MS. Attitude and knowledge have shifted among health professionals – many are now interested in learning about these approaches and discussing them with their patients.”

*Dr. Allen C. Bowling has written more than 100 lay and professional publications, including four books on MS – one of which is Complementary and Alternative Medicine and Multiple Sclerosis. He has provided consultation or authored publications for many MS and neurological organizations, including MSAA, AAN, NMSS, and the MS International Federation (MSIF). Dr. Bowling is a Phi Beta Kappa graduate of Yale, where he also obtained his MD and PhD degrees. He completed his neurology residency training at the University of California-San Francisco and his fellowship training at Massachusetts General Hospital-Harvard Medical School. He was medical director of the Rocky Mountain MS Center from 2003 to 2007.*

# The Evolution of MS Diagnosis, Treatment, and Care

1880

1885

1890

**1884-1887** Numerous lectures and published case reports; optic neuritis and myelitis described (1884); infection suggested as a cause (1884); family with 12 cases of MS described (1885); toxins suggested as a cause (1887)

**1891** The lumbar puncture technique is developed



## Stephen Krieger, MD

Neurologist at the Corinne Goldsmith Dickinson Center for Multiple Sclerosis  
Assistant Professor of Neurology, Mount Sinai School of Medicine, New York

### *...on the rise of MS therapeutics and resources*

“I am incredibly encouraged by two positive trends in MS in recent years: the development of a multitude of MS therapies, and the rise of empowered, highly-informed patients. These two trends go hand-in-hand, for as clinicians have more numerous and more complex treatment options to offer to our patients, the need for patient education and awareness has become more crucial than ever.

“As MS has become a highly treatable condition, there are also enormous amounts of high-quality, MS educational materials and resources that are now available. These allow patients to be active, true participants

in their MS care in collaboration with their treatment team.

“I think this has been an evolution not just of how MS patients seek and direct their care, but also in the way MS clinicians practice. As medicine becomes more ‘personalized’ and treatment strategies can be tailored to a person’s individual course of MS, we also must prioritize listening closely to our patients and educating them comprehensively. As a clinician-educator, I find this to be one of the most gratifying aspects of working in MS, and I think that with the advent of new therapies, the need for patient education will only continue to grow.”

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*Dr. Stephen Krieger joined the Corinne Goldsmith Dickinson Center (CGDC) for MS as a fellow in multiple sclerosis. He received a 2006 American Academy of Neurology (AAN) Scholarship and a Sylvia Lawry Fellowship in clinical research. Dr. Krieger has a clinical practice at the CGDC for MS, and participates in several MS clinical trials, including those that study oral therapies and monoclonal antibodies. Dr. Krieger is on many advisory boards in the field of MS, and is the neurology residency program director at Mount Sinai. He is an active member of the AAN, who awarded him an A.B. Baker Teacher Recognition Award in 2010.*

1900

1910

1920

**1899** *Oligodendrocytes (cells that produce and maintain myelin) are described*

**1906** *A toxin to myelin is suggested for the breakdown of myelin in plaques*

**1915** *James Dawson publishes his major work on the pathology of the MS plaque*

## Fred D. Lublin, MD, FAAN

Saunders Family Professor of Neurology  
Director, Corinne Goldsmith Dickinson Center for Multiple Sclerosis  
Mount Sinai School of Medicine, New York



### *...on the development of disease-modifying therapies*

“The field of MS therapeutics has been at the leading edge of innovative research into the treatment of neurologic illness. Having nine disease-modifying agents, and a full pipeline of newer molecules that may prove successful in the treatment of MS, have transformed the care of MS.

“We have developed successful clinical trial designs that have provided the validated evidence of efficacy (proof of effectiveness) that is critical for moving the field forward. We will leverage our past and current successes into better future therapies for MS. These

include the treatment of progressive disease and the development of strategies for repair of the damaged central nervous system (CNS).

“Several late-phase clinical trials aimed at treating progressive forms of MS are currently underway, as is the early-phase testing of stem cells for potential repair of damaged nerves. New initiatives in treating the symptoms of MS have also yielded encouraging results. Overall, the future for improving the lives of individuals with MS has never looked brighter.”

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*As a neuroimmunologist, Dr. Fred D. Lublin has a special interest in immune functions and abnormalities affecting the CNS. He is currently involved with several new clinical research protocols on promising agents for treating MS. He has been either a member or chair of many MS committees, professional societies, and advisory boards. Dr. Lublin has published numerous scientific articles and is the co-chief editor of the new journal, Multiple Sclerosis and Related Diseases. He has served as a consultant to the NIH and to many pharmaceutical/biotech companies in all phases of new drug development. He is the principal investigator of the NIH-sponsored multicenter Combination Therapy study in MS.*

# The Evolution of MS Diagnosis, Treatment, and Care

1920

1935

1950

**1933** Animal model of MS (EAE) is developed; folding wheelchair invented by Everest, allowing individuals with disabilities to travel by car and bring their wheelchair

**1950** Roy Swank develops low-fat diet for individuals with MS; first major study conducted in the US and Canada, funded by NMSS

**1951** First use of Cortisone to treat MS



## Randall T. Schapiro, MD, FAAN

President, The Schapiro MS Advisory Group  
Clinical Professor of Neurology, University of Minnesota (retired)  
Member, MSAA Healthcare Advisory Council

### *...on symptom management*

“Life with MS has certainly evolved over the past two decades. MS remains a mysterious disease that clearly has an effect on the brain and spinal cord. It is caused by an attack of the immune system, initiated by some unknown stimulus. Its complexity involves genetics and potentially some unidentified infectious agent. We have learned a number of details surrounding these issues, but the heart of the matter remains unknown.

“What is known is that the attack results in multiple symptoms – involving mobility, cognition, activities of daily living, and simply living productively in society. Newer medicines have begun to mitigate disease progression to some extent, but the

associated symptoms and psychological issues remain a major problem for individuals with MS, family, and friends.

“Symptomatic management is the backbone of MS management. Refinements in mobility devices, the ability to manage bladder and bowel incontinence, pain management, and the treatment of other MS symptoms, have dramatically improved over the past two decades. Treatments combine pharmaceutical, physical, occupational, and speech therapies with psychological management approaches. The immediate goal is an improved quality of life, with the ultimate goal of curing the disease. Inevitably, we will succeed in our quest to improve life for individuals with MS!”

*Dr. Randall (Randy) T. Schapiro grew up in Minnesota and received degrees there as well as in California. He founded the first private-practice comprehensive MS Center in 1977, renamed “The Schapiro Center for Multiple Sclerosis” at the Minneapolis Clinic of Neurology in 2004. Dr. Schapiro has participated in numerous research studies, helped to develop two MS organizations, served on numerous boards and advisory committees, and lectured and written extensively on all topics associated with MS management, both nationally and internationally. His awards include the Can Do Award, the prestigious Starfish Award, the Lifetime Achievement Award by the CMSC, and has been elected to the NMSS Hall of Fame.*

1960

1970

1955 Kurtzke defines Disability Status Scale

Interferons are discovered 1957

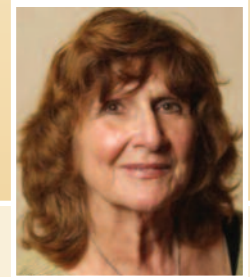
1965 The initial criteria for diagnosis of MS is described

Thieme develops the electric mobility scooter 1968

Acute MS flare-ups are treated with adrenocorticotropin 1970

## June Halper, MSN, APN-C, MSCN, FAAN

Nurse practitioner, MS Center of the New Jersey Medical School and the Bergen Volunteer Medical Initiative  
Member, MSAA Healthcare Advisory Council



### *...on the MS Nurse and certification*

“The MS Nurse is a competent expert who collaborates with those affected by MS. He or she shares knowledge, strength, and hope. As the role of nurses continues to evolve, there is a need to establish a cohesive model of MS nursing practice, along with specific standards in MS nursing care.

“Nursing practice aims to both manage and influence the patient’s illness by: supporting disease-modifying treatments; facilitating symptom management; promoting safe, maximal function; and supporting a wellness-oriented quality of life. Activities that are essential to patient care can be grouped into the following areas: establishing care; continuing care; and sustaining care.

Together, these interwoven areas provide a framework for a comprehensive and cohesive model for MS nursing practice. These can be applied to the care of all individuals with MS, regardless of disease classification or level of disability.

“This model provides the basis for domains of MS nursing that are included in an exam for certification. Questions fall under the umbrella of clinical care, research, advocacy, and education. This examination is offered in several languages, including English, French, Finnish, Dutch, and Spanish. The MSCN certification is internationally recognized as a sign of commitment to and competence in excellence in MS nursing practice.”

*June Halper is a certified adult nurse practitioner specializing in MS since 1978. She founded the MS Center in Teaneck, New Jersey and was the executive director there from 1985 to 2008. She also served as president and is currently the executive director of the International Organization of MS Nurses (IOMSN). Ms. Halper has published and lectured extensively on MS and is a member of several nursing organizations. A founding director of IOMSN, she was the recipient of their first June Halper Award for Excellence in Nursing in Multiple Sclerosis. She was inducted as a Fellow into the American Academy of Nursing in November 1999.*



# I will:

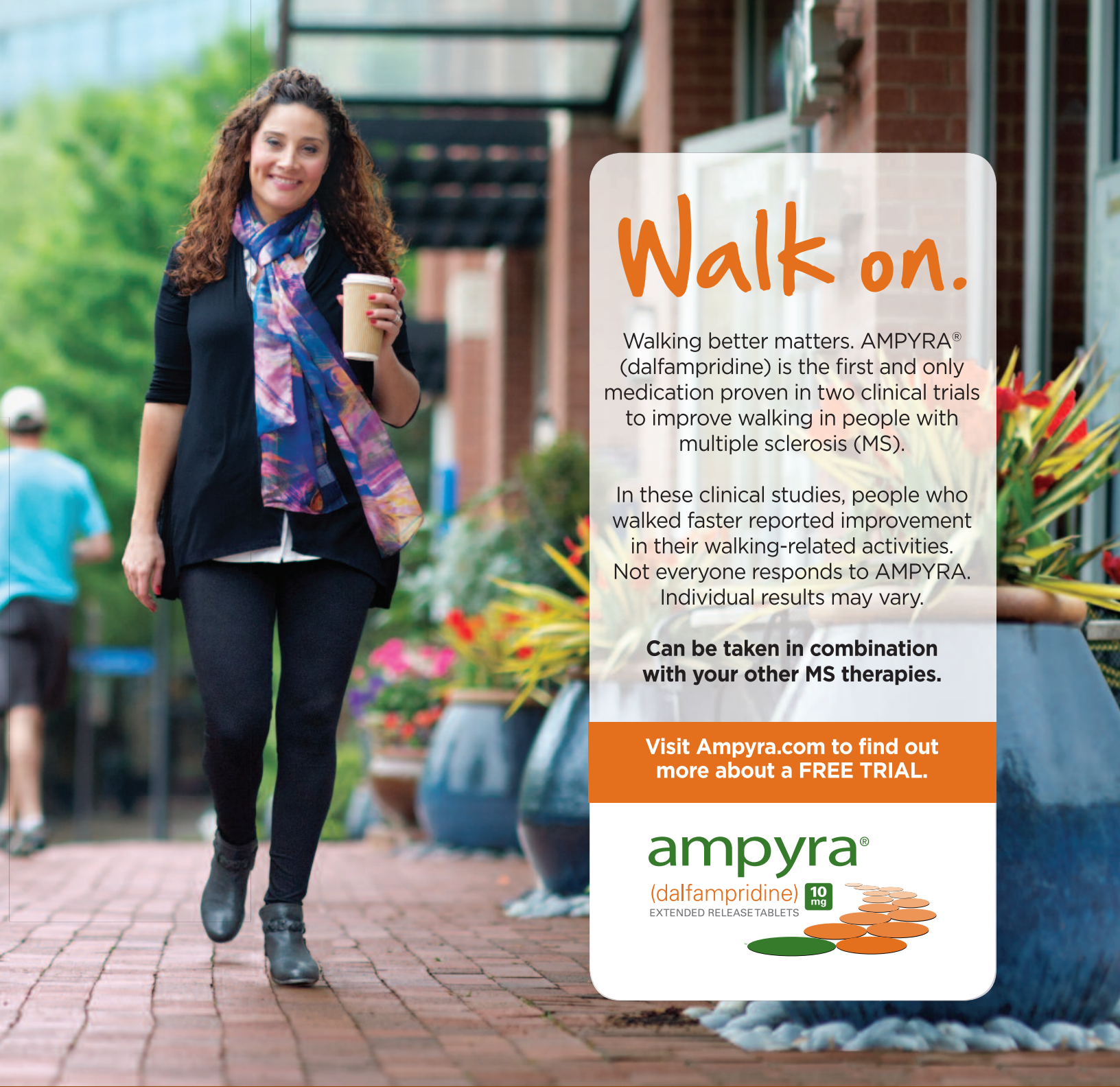
***“The first thing I started to notice as my walking improved with Ampyra was my confidence in my ability to walk to meet my friends.”***

***— Kristie Salerno Kent,  
diagnosed with MS in 1999.***

AMPYRA® (dalfampridine) is indicated as a treatment to improve walking in patients with multiple sclerosis (MS). This was demonstrated by an increase in walking speed.

## **Important Safety Information**

Do not take AMPYRA if you have ever had a seizure or have certain types of kidney problems. The risk of having a seizure is higher in patients with certain types of kidney problems. AMPYRA should not be taken with other forms of 4-aminopyridine (4-AP, fampridine), since the active ingredient is the same. AMPYRA may cause serious side effects, including kidney or bladder infections. The most common side effects of AMPYRA include urinary tract infection, trouble sleeping, dizziness, headache, nausea, weakness, back pain, and problems with balance. The majority of side effects reported in the clinical trials were mild and transient. Take AMPYRA exactly as your doctor tells you to take it. Take AMPYRA tablets whole. Do not break, crush, chew or dissolve AMPYRA tablets before swallowing. If you miss a dose of AMPYRA, do not make



# Walk on.

Walking better matters. AMPYRA® (dalfampridine) is the first and only medication proven in two clinical trials to improve walking in people with multiple sclerosis (MS).

In these clinical studies, people who walked faster reported improvement in their walking-related activities. Not everyone responds to AMPYRA. Individual results may vary.

**Can be taken in combination with your other MS therapies.**

Visit [Ampyra.com](http://Ampyra.com) to find out more about a **FREE TRIAL**.

**ampyra**®

(dalfampridine) **10 mg**  
EXTENDED RELEASE TABLETS



Talk to your doctor to see if prescription AMPYRA is right for you. In two pivotal trials 35% and 43% of patients taking AMPYRA responded to treatment vs. 8% and 9% of patients taking placebo.

up the missed dose. Do not take 2 doses at the same time. Before taking Ampyra tell your doctor if you are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby. Tell your doctor if you are breast-feeding or plan to breast-feed. It is not known if AMPYRA passes into your breast milk. You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.

**For more information, please see the complete Medication Guide on the next page. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

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## MEDICATION GUIDE FOR AMPYRA® (am-PEER-ah) (dalfampridine) Extended Release Tablets

Read this Medication Guide before you start taking AMPYRA 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 medical condition or your treatment.

### What is the most important information I should know about AMPYRA?

AMPYRA can cause seizures.

- You could have a seizure even if you never had a seizure before.
- Your chance of having a seizure is higher if you take too much AMPYRA or if your kidneys have a mild decrease of function, which is common after age 50.
- Your doctor may do a blood test to check how well your kidneys are working, if that is not known before you start taking AMPYRA.
- Do not take AMPYRA if you have ever had a seizure.
- Before taking AMPYRA tell your doctor if you have kidney problems.
- Take AMPYRA exactly as prescribed by your doctor. See "How do I take AMPYRA?"

### Stop taking AMPYRA and call your doctor right away if you have a seizure while taking AMPYRA.

#### What is AMPYRA?

AMPYRA is a prescription medicine used to help improve walking in people with multiple sclerosis (MS). This was shown by an increase in walking speed.

It is not known if AMPYRA is safe or effective in children less than 18 years of age.

#### Who should not take AMPYRA?

##### Do not take AMPYRA if you:

- have ever had a seizure
- have certain types of kidney problems

#### What should I tell my doctor before taking AMPYRA?

##### Before you take AMPYRA, tell your doctor if you:

- have any other medical conditions
- are taking compounded 4-aminopyridine (fampridine, 4-AP)
- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby. You and your doctor will decide if you should take AMPYRA while you are pregnant.
- are breast-feeding or plan to breast-feed. It is not known if AMPYRA passes into your breast milk. You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.

**Tell your doctor about all the medicines you take**, including prescription and non-prescription medicines, vitamins and herbal supplements.

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

#### How should I take AMPYRA?

- Take AMPYRA exactly as your doctor tells you to take it. Do not change your dose of AMPYRA.
- Take one tablet of AMPYRA 2 times each day about 12 hours apart. Do not take more than 2 tablets of AMPYRA in a 24-hour period.
- **Take AMPYRA tablets whole. Do not break, crush, chew or dissolve AMPYRA tablets before swallowing. If you cannot swallow AMPYRA tablets whole, tell your doctor.**
- AMPYRA is released slowly over time. If the tablet is broken, the medicine may be released too fast. This can raise your chance of having a seizure.
- AMPYRA can be taken with or without food.
- If you miss a dose of AMPYRA, do not make up the missed dose. Do not take 2 doses at the same time. Take your next dose at your regular scheduled time.
- If you take too much AMPYRA, call your doctor or go to the nearest hospital emergency room right away.
- Do not take AMPYRA together with other aminopyridine medications, including compounded 4-AP (sometimes called 4-aminopyridine, fampridine).

#### What are the possible side effects of AMPYRA? AMPYRA may cause serious side effects, including:

- Kidney or bladder infections
- See "What is the most important information I should know about AMPYRA?"

The most common side effects of AMPYRA include:

- urinary tract infection
- trouble sleeping (insomnia)
- dizziness
- headache
- nausea
- weakness
- back pain
- problems with balance
- multiple sclerosis relapse
- burning, tingling or itching of your skin
- irritation in your nose and throat
- constipation
- indigestion
- pain in your throat

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

These are not all the possible side effects of AMPYRA. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

#### How should I store AMPYRA?

- Store AMPYRA at 59°F to 86°F (15°C to 30°C).
- Safely throw away AMPYRA that is out of date or no longer needed.

Keep AMPYRA and all medicines out of the reach of children.

#### General information about the safe and effective use of AMPYRA

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use AMPYRA for a condition for which it was not prescribed. Do not give AMPYRA to other people, even if they have the same symptoms that you have. It may harm them.

This Medication Guide summarizes the most important information about AMPYRA. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about AMPYRA that is written for health professionals.

For more information, go to [www.AMPYRA.com](http://www.AMPYRA.com) or call 1-800-367-5109.

#### What are the ingredients in AMPYRA?

**Active ingredient:** dalfampridine (previously called fampridine)

**Inactive ingredients:** colloidal silicon dioxide, hydroxypropyl methylcellulose, magnesium stearate, microcrystalline cellulose, polyethylene glycol, and titanium dioxide.

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Ardsley, NY 10502

Issued 07/2012

*This Medication Guide has been approved by the U.S. Food and Drug Administration.*

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U.S. Patent Nos.: US 5,540,938 and US 5,370,879

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# The Evolution of MS Diagnosis, Treatment, and Care

1970

1975

**1972** McDonald and Halliday show that conduction is slowed or blocked along demyelinated nerves and use evoked potential methods with MS

**1977** Jacobs gives interferon to MS patients intrathecally; McDonald and Halliday outline new diagnostic criteria for MS; oral baclofen approved to treat spasticity

## Dorothea Cassidy Pfohl, RN, BS, MSCN

Clinical Coordinator of the Comprehensive MS Center of the Department of Neurology at the University of Pennsylvania Health System  
Member, MSAA Healthcare Advisory Council



### *...on the evolution of nursing and treatment tools for MS*

“Looking back to the 1980s, the best we could do was to ‘put out fires’ when caring for the person with MS. By this, I mean treating exacerbations with steroids or ACTH and using physical and occupational therapy to minimize disability. In the 1990s, the disease-modifying therapies were introduced. For the first time, we were able to influence the natural course of MS, but we also had to learn how to best use these medications, cope with side effects, and maximize adherence. With greater effectiveness came higher risk, and once again we needed to educate and support our patients, their loved ones, and the professional community.

“I like to visualize a toolbox, now full of a

variety of pharmaceutical therapies, devices, and interventions. These allow for comprehensive, multidisciplinary, yet personal approaches, with the intention of promoting wellness while treating the underlying disease.

“On a personal note, I have been privileged to see MS nursing evolve into a respected specialty, with certification, through the efforts of the International Organization of MS Nurses (IOMSN) and visionary MS Nurses. Perhaps the future will provide an even more sophisticated set of tools. I know that the passion and dedication of patients and professionals will continue to help us work toward our common goals.”

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*Dorothea (Dottie) Cassidy Pfohl has more than 45 years of nursing experience, and has specialized in MS since 1989. Her current role includes research, clinical practice, and community outreach. She is a member of the NMSS healthcare advisory committee and the highly successful program, Women Against MS (WAMS). A member of several speakers' bureaus, advisory boards, and editorial boards, she is also active in nonprofit organizations, including MSAA, along with other MS and nursing organizations. In 2003, Ms. Pfohl was named to the National MS Society's Volunteer Hall of Fame. In 2010, she was the recipient of the June Halper Award for Excellence in MS Nursing.*

# The Evolution of MS Diagnosis, Treatment, and Care

1980

**1978** *Patterns of myelin repair are demonstrated by Prineas*

**1980s-1990s** *Tegretol® is used to treat pain; Ditropan® is used to treat spastic bladder; as with most symptom-management drugs, these are prescribed off-label*



## Megan Weigel, DNP, ARNP-c, MSCN

Advanced Registered Nurse Practitioner,  
Baptist Neurology, Beaches Division, Jacksonville, Florida

### *...on the importance of taking care of the whole patient*

“I began my career as a nurse practitioner in MS in 2001. Despite having been through three diagnostic criteria changes, I still consider myself new to the disease, because I have never known a time without disease-modifying therapy (DMT).

“Since MS can be diagnosed and treated earlier, we are seeing better long-term outcomes. Anecdotally, I notice a difference at five years post-diagnosis in people who began DMT at the time of their first presenting symptom (clinically isolated syndrome, or CIS), versus those who began treatment after experiencing several relapses and visiting many neurologists. This means, for the most part, that I am taking care of

healthy people, and I want them to stay that way.

“From valuable NARCOMS data, we know that people living with MS are more likely to have certain chronic medical conditions (such as high blood pressure, weight issues, and high cholesterol) and that preventive healthcare is indispensable. In my practice, I put an emphasis on nutrition, exercise, and receiving age-appropriate health screenings in order to preserve health and wellbeing. The role of the MS Nurse has become increasingly important during this decade, in light of the amount of education people need regarding how to live a healthy and long life with MS!”

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*Dr. Megan Weigel is an advanced registered nurse practitioner practicing neurologic nursing for 11 years and has been an MS Certified Nurse for eight of those. She received her Doctor of Nursing Practice degree in 2009, with a focus on preventive healthcare in MS patients. Dr. Weigel was chosen as one of Jacksonville’s “40 Under 40” by the Jacksonville Business Journal in 2010, and received an Outstanding Young Alumnus award from the University of Florida in 2010. She is a member of the board of directors for the IOMSN, the editorial board of the International Journal of MS Care, and a steering committee for the NMSS.*

**1981** First MRI scan of the brain is performed and first MRI images of MS lesions produced; Jacobs reports reduced exacerbations with intrathecal interferon

**1983** Poser criteria described for MS; Epstein-Barr virus suspected of being involved with MS; Kurtzke introduces Expanded Disability Status Scale (EDSS)

## Patty Bobryk, MHS, PT, MSCS, ATP

Certified MS Rehabilitation Specialist  
OrlandoHealth, MS Comprehensive Care Center of Central Florida



### *...on the changing environment of MS rehabilitation care*

“When I first started seeing MS patients in Central Florida 19 years ago, most of the individuals I saw were referred because they needed an assistive device or they were recovering from a significant exacerbation. It was not a climate of being proactive regarding health and fitness when dealing with MS, but merely accommodating to progressive symptoms or functional loss.

“Fortunately, it wasn’t too long after that time that the value of rehab interventions and exercise were recognized as important parts of a comprehensive treatment plan for people with MS. I feel fortunate to be able to see

individuals soon after their diagnosis to establish exercise regimes, provide education about the disease, teach strategies on how to manage symptoms, and to promote health and wellness.

“I believe that we are making an impact on decreasing the many secondary effects of the disease, such as: pain syndromes from poor posture or altered gait patterns; fatigue that can be attributed to lack of conditioning; and weakness resulting from inactivity. I am pleased to be part of a changing environment of MS rehab care – one that takes a positive and active approach to its management.”

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*Patty Bobryk is a graduate in physical therapy at Wayne State University and obtained her master’s degree in neuro-dysfunction from the University of Florida in 1991. Since then, she has worked nearly exclusively with individuals with MS for OrlandoHealth in collaboration with the MS Comprehensive Care Center of Central Florida. She is an MS certified specialist and a certified assistive technology practitioner. Ms. Bobryk has been active in the Mid Florida NMSS Chapter Advisory Committee and has provided educational seminars for professionals and patients nationwide on rehabilitation for individuals with MS. She is chair of the International Organization of Multiple Sclerosis Rehabilitation Therapists (IOMSRT).*

# The Evolution of MS Diagnosis, Treatment, and Care

1985

1990

**1987** Prozac® is approved to treat depression; first SSRI antidepressant

**1988** Medtronic® Synchroned™ pump and infusion system (implanted and programmable) receives premarket approval

**1990** Americans with Disabilities Act signed into law



## Carrie Bruce, MA, CCC-SLP, ATP

Research Scientist, Center for Assistive Technology and Environmental Access at Georgia Tech  
Member, MSAA Healthcare Advisory Council

### *...on the evolution of assistive devices and technologies*

“Looking at the evolution of assistive devices and technologies available for people with MS, one has to realize that ‘state of the art’ is always a moving target. At one point, the folding wheelchair was the latest advancement and people could finally take their chair in the car. Since that time, not only have better wheelchairs come along, but we’ve also seen a broadening of the types of products people with MS need and want – their expectations have grown beyond traditional medical equipment.

“Individuals with MS want to stay active, continue working, engage in educational pursuits, and maintain social connections with

as much ease and independence as possible. They also want to rely less on specialized equipment that is expensive and unattractive.

“The past decade has brought a much-needed shift in product design that gives people with MS more choice. The focus on inclusive and universal design means that it is easier to find cars, homes, computers, cell phones, personal care items, and many other things that are both useful and accessible to more people. While these changes are shaping the current ‘state of the art,’ we need to push for product design that keeps up with the ever-changing needs of people with MS.”

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*Carrie Bruce has worked as a speech-language pathologist in the field of assistive technology and rehabilitation design for almost 20 years. A research scientist at Georgia Tech, she works on grants to develop assistive and universally designed technologies. Her interest in MS began 10 years ago while providing technical assistance to people looking for technologies to help in their daily lives. She connected with MS organizations to learn about their programs and update them on newer technologies and research. Ms. Bruce has written several articles on assistive technology and home modifications and continues to provide input on research and product development that could benefit the community.*

1992

1995

1990s

*Amantidine is used to treat fatigue*

1993

*Betaseron<sup>®</sup> approved;  
Neurontin<sup>®</sup> approved to treat pain*

1995

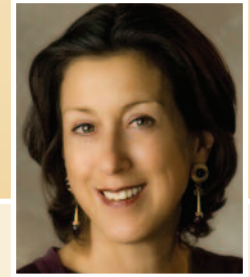
*Copaxone<sup>®</sup> approved*

*Avonex<sup>®</sup> approved*

1996

## Miriam Franco, MSW, PsyD

Professor, Sociology Department  
Immaculata University, Immaculata, Pennsylvania  
Member, MSAA Healthcare Advisory Council



### *...on the emotional and cognitive changes in MS*

“Psychological understanding of MS has evolved greatly since the beginning of the 20th century. For many years, cognitive impairment was rarely distinguished from mental symptoms. The relationship between mood, cognition, and disease course were not known. Early efforts relied on psychoanalytic case histories correlated to findings on the Rorschach (inkblot) tests to try to characterize the type of individual who was prone to MS.

“Well into the 1970s, research continued to identify a standard MS personality or a particular emotional response to the disease. Advances in mental health, neuropsychology, and medical technology in the 1980s discovered that depression was a symptom of MS, as well as a reaction to the life

consequences of having MS. By the 1990s, major advances in neurologic testing detected subtle and specific cognitive changes through brain-imaging techniques. Combined with a greater collaboration between neurologists and neuropsychologists, these advances led to a better understanding of depression and cognitive changes in individuals with MS.

“Gradually, a bio-psycho-social model of MS emerged and psychological treatment approaches to MS were expanded. These not only included symptom management of depression, anxiety, and cognitive changes, but also improvement of social and economic support. Complementary interventions, such as guided imagery and meditation, were also included to lower stress and improve wellbeing.”

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*Dr. Miriam Franco is a psychologist in practice in Wayne, Pennsylvania and is a professor at Immaculata University. She is a certified MS and Guided Imagery (GI) specialist and has published on GI to reduce anxiety and injection anxiety with MS. Dr. Franco consults on improving quality of life for caregivers and persons with chronic illness. She also trains professionals to use GI to lower stress, anxiety, and depression. As founder of The Guided Imagery Foundation (a nonprofit organization), Dr. Franco seeks to develop research funding for GI programs in the community.*




 GILENYA for relapsing forms of multiple

POSSI

## GILENYA. Proven to significantly reduce the

**GILENYA reduced the number of relapses by 52% in a 1-year study versus interferon beta-1a IM. In fact, 83% of people taking GILENYA remained relapse-free versus 70% taking interferon beta-1a IM.**

**GILENYA was also proven effective in a separate 2-year study versus placebo.**

### Indication

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.

### Important Safety Information

You should not take GILENYA if in the last 6 months you experienced heart attack, unstable angina, stroke or warning stroke, or certain types of heart failure. Do not take GILENYA if you have certain types of an irregular or abnormal heartbeat (arrhythmia), including a heart finding called prolonged QT, as seen on a test to check the electrical activity of your heart (ECG) before starting GILENYA. You should not take GILENYA if you take certain medicines that change your heart rhythm.

GILENYA may cause serious side effects such as:

- Slow heart rate, especially after your first dose. An ECG will be performed before and 6 hours after your first dose. Your pulse and blood pressure should be checked every hour while you stay in a medical facility during this time. If your heart rate slows down too much, you might feel dizzy or tired, or feel like your heart is beating slowly or skipping beats. Symptoms can happen up to 24 hours after your first dose. After 6 hours, 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 watched by a health care professional. If you have any serious side effects after your first dose, especially those that require treatment with other medicines, you will stay in a medical facility to be watched overnight and for at least 6 hours after 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 watched overnight after you take your first dose. If you experience slow heart rate, it will usually return to normal within 1 month. Call your doctor or go to the nearest emergency room right away if you have any symptoms of a slow heart rate. If you stop taking GILENYA for more than 14 days after your first month of treatment, you will need to repeat this observation.
- 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. 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, or vomiting.
- Macular edema, a vision problem that can cause some of the same vision symptoms as an MS attack (optic neuritis), or no symptoms. 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.

sclerosis (MS). Discover your

# BILITIES

number of relapses in the first once-daily\* pill.

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.

- 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.

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. Call 1-877-598-7237 or visit [www.gilenyapregnancyregistry.com](http://www.gilenyapregnancyregistry.com) for more information.

Tell your doctor about all your medical conditions, including if you had or now have an irregular or abnormal heartbeat; history of stroke or warning stroke; heart problems; a history of repeated fainting; a fever or infection, or if you are unable to fight infections; eye problems; diabetes; breathing or liver problems; or high blood pressure. Also tell

your doctor if you have had chicken pox or have received the vaccine for chicken pox. Your doctor may do a test for the chicken pox virus, and you may need to get the vaccine for chicken pox and wait 1 month before starting GILENYA.

Tell your doctor about all the medicines you take, including medicines for heart problems or high blood pressure or other medicines that may lower your heart rate or change your heart rhythm; medicines that could increase your chance of infections, such as medicines to treat cancer or control your immune system; or ketoconazole (an antifungal) by mouth. If taken with GILENYA, serious side effects may occur. You should not get certain vaccines while taking GILENYA, and for at least 2 months after stopping.

The most common side effects with GILENYA were headache, flu, diarrhea, back pain, abnormal liver tests, and cough.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

**Freedom from injections is finally an option.  
Ask your doctor if GILENYA is right for you.**



\*GILENYA can result in a slow heart rate when first taken. Your first dose will be given in a medical facility where you will be watched for at least 6 hours. If you stop taking GILENYA for more than 14 days after your first month of treatment, you will need to repeat this observation.

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

**MEDICATION GUIDE**  
**GILENYA™ (je-LEN-yah)**  
**(fingolimod)**  
**capsules**

Read this 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 medical condition or your 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 should stay in a medical facility 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 watched 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 watched.
- 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 watched overnight. You will also be watched 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 watched 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 emergency room right away if you have any symptoms of slow heart rate.

**2. Infections.** GILENYA can increase your 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 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

**3. 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. Macular edema 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 age 18.

**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

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. 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 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
- 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, you can call the GILENYA Pregnancy Registry at 1-877-598-7237 or visit [www.gilenyapregnancyregistry.com](http://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**, including prescription and non-prescription medicines, vitamins, and herbal supplements.

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:

- Medicines for:
  - heart problems or
  - high blood pressure or
  - other medicines that may lower your heart rate or change your heart rhythm
- Vaccines. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain 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.
- Medicines that could raise your chance of getting infections, such as medicines to treat cancer or to control your immune system.
- ketoconazole (an antifungal drug) by mouth

Ask your doctor or pharmacist for a list of these medicines if you are not sure.

#### **How should I take GILENYA?**

- Your first dose of GILENYA will be given in a medical facility where you will be watched 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.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- If you start GILENYA again after stopping for 2 weeks or more, you will start taking GILENYA again in your doctor’s office or clinic.

#### **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:

- **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

The most common side effects of GILENYA include:

- headache
- flu
- diarrhea
- back pain
- abnormal liver tests
- cough

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.

#### **How do I store GILENYA?**

- Store GILENYA in the original blister pack in a dry place.
- Store GILENYA at room temperature between 59°F to 86°F (15°C to 30°C).
- Keep GILENYA and all medicines out of the reach of children.

#### **General information about GILENYA**

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. 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 Medication Guide summarizes 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](http://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.

**This Medication Guide has been approved by the U.S. Food and Drug Administration.**

GILENYA is a trademark of Novartis AG.

Manufactured by:  
Novartis Pharma Stein AG  
Stein, Switzerland

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

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May 2012

# The Evolution of MS Diagnosis, Treatment, and Care

1996

2002

**1998** *Provigil® approved to treat fatigue; Viagra® approved to treat sexual dysfunction*

**2000** *Novantrone® approved*

*Rebif® approved; Zanaflex® approved to treat spasticity in MS*

**2002**



## Herb Karpatkin, PT, DSc, NCS, MSCS

Operates a private physical therapy practice in New York, specializing in the evaluation and treatment of MS

### *...on improving balance and preventing falls*

“Disability in MS is multifactorial. Lesions can occur in any area of the central nervous system (CNS), and therefore a variety of impairments are possible. Balance loss is common in MS because it occurs not only from myelin loss, but also from a variety of symptoms such as weakness, stiffness, sensory loss, pain, and loss of muscle control. Fatigue is a common MS symptom and can be a major reason for falls and balance loss. Research has shown that people with MS are far more likely to fall when fatigued.

“However, falls in MS are to a large extent preventable with exercise programs that are

specifically tailored to the individual’s needs. A falls-prevention program must address the specific causes of the falls, and since falls in MS are multifactorial (depending on how the disease expresses itself), the program must be customized to the specific needs of the person with MS at risk of falling.

“An evaluation with a therapist or physician trained in MS falls prevention and balance can uncover the specific reasons for the falls and construct an exercise program to address them. In the same way that specific medications are given to address specific MS symptoms, specific exercises can be given to address MS balance loss.”

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*Dr. Herb Karpatkin is a physical therapist specializing in multiple sclerosis since 1993. He has presented nationally and locally, to patients, therapists, and physicians on topics related to MS, exercise, and physical therapy. Dr. Karpatkin has published numerous articles on the subject of MS and exercise, and serves on advisory boards for the National Multiple Sclerosis Society and the Multiple Sclerosis Foundation. He owns and operates a private practice in New York, specializing in the evaluation and treatment of MS.*

**2006** Tysabri® approved

**2010** Extavia® approved; Gilenya™ approved; Botox® injection approved for adult upper-limb spasticity; Nuedexta™ approved for the treatment of pseudobulbar affect (PBA); Ampyra™ approved to improve walking in individuals with MS

## Pat Provance, PT, MSCS

Semi-retired physical therapist

Continues to teach and consult on MS rehabilitation nationally

Member, MSAA Healthcare Advisory Council



### *...on exercise and ambulation aids in MS rehabilitation*

“My first MS patient in 1971 had been in a wheelchair for twelve years (recommended right after diagnosis) when she was referred for treatment of a fractured shoulder from a fall. She was highly motivated, the shoulder recovered well, and she requested further treatment for her MS. There was nothing in the literature at that time, but her doctor and I were willing to give it a try in once-weekly sessions. Beginning with simple isometrics and functionally-focused activities, she gradually progressed to standing, parallel bars, a walker, and finally forearm crutches after about six months.

“That was my epiphany as a physical therapist – that this population was misunderstood and de-conditioned as a

result of the fear of fatigue! The medical community now recognizes the importance of customized exercise programs for this population, to improve functional strength, balance, endurance, and quality of life.

“Ambulation assistance has been enhanced as well. Foot drop braces formerly made of heavy polypropylene have been replaced by lightweight carbon products or wireless FES (functional electrical stimulation). Other ambulation aids that were previously bulky, unwieldy, or heavy, have now evolved to lightweight, user-friendly assists. Independence, dignity, and safety, while improving function, are now all possible as we continue to improve with technology and knowledge.”

---

*Pat Provance was in full-time clinical practice from 1971 to 2006, and many of those years were devoted to MS care. In 1982, she started the first MS Rehabilitation Program at Union Memorial Hospital in Baltimore. In 2000, she joined the University of Maryland team and directed the outpatient MS Rehabilitation Program at Kernan Rehabilitation Hospital, which included teaching, research, and consulting with the MS center. Ms. Provance has published numerous articles in journals for MS patients and co-authored Kendall's Muscles, Testing and Function with Posture and Pain. Now “semi-retired,” she continues to teach and consult on MS rehabilitation across the country.*

# The Evolution of MS Diagnosis, Treatment, and Care

2011

2012

2013?

**2011** Botox® injection approved for urinary incontinence in individuals with MS

**2012** Aubagio® approved

**THE FUTURE** Possible approvals of Dimethyl Fumarate (DMF); Lemtrada™; ocrelizumab; daclizumab; Tovaxin®; laquinimod; and many more!



## Kathy Zackowski, PhD, OTR, MSCS

Kennedy Krieger Institute, Assistant Professor

Departments of Physical Medicine & Rehabilitation, Neurology  
Johns Hopkins University School of Medicine

*...on occupational therapy, computer technology, and MS*

“Treatment for individuals with MS has evolved considerably over the years. In occupational therapy, one major advance has been the broad use of computer technology to benefit individuals with MS.

“Initially, simple communication boards were used, allowing a client to choose pictures or point to written words when words could not be easily spoken. This has advanced to the use of sophisticated software that can now speak the words for the client, or even paint or draw for the person who doesn’t have the physical ability to do so. Another example of this is voice-recognition software that can type for

someone who can talk, but can’t use their hands to write or type.

“Unfortunately, the high cost of some of these advances makes it difficult to provide them to all of our clients. My hope for the future is that we, as occupational therapists, will document as objectively as possible the use of computer technology in our treatments and the functional benefits gained by our patients. The hope is that this will encourage more universal funding for the use of, and further advancement of, computer technology as it relates to helping individuals with MS and others with communication challenges.”

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*Dr. Kathy Zackowski earned her BS in Occupational Therapy, her MS in Exercise and Sport Science, and her PhD in Movement Science. She worked as a neuro-rehabilitation occupational therapist before pursuing her doctorate, and is now the occupational therapist in the Johns Hopkins MS Center. She is certified as an MS Clinical Specialist and emphasizes that rehabilitation is essential for all individuals with MS. Dr. Zackowski also has a research laboratory and studies the motor-control problems that occur as a result of neurodegenerative disease processes such as MS. Her long-term goal is to develop more systematic ways to assess and treat disability in individuals with MS.*



## Diana M. Schneider, PhD

President and Publisher,  
DiaMedica Publishing, New York, NY

### *Closing message...on future advances in MS*

“Many of the preceding commentaries rightfully focus on the dramatic and life-changing advances that have been made in MS diagnosis, treatment, symptom management, and quality of life. Together, these have resulted in improvements in overall outcomes for many patients.

“When I first became involved in MS, in the late 1970’s, the picture was very different. Older MS physicians still remembered using the hot-bath test to diagnose MS – based on the fact that sitting in hot water for 20 minutes resulted in a significant worsening of symptoms. Treatment was largely limited to using steroids for exacerbations. In other words, ‘We’ve come a long way, baby!’

“Progress has been made possible largely by advances in two major areas – imaging and other technologies, plus drug development and testing. And the two go hand-in-hand. Without advanced imaging technologies, we wouldn’t have the tools needed to evaluate drug therapies. This technology has also led to earlier diagnosis, and in turn early treatment is linked to better overall outcomes. This process will only continue and grow. For example, new higher resolution MRI scans are making it possible to begin to understand the role that grey matter, versus white matter, plays in better explaining MS progression and cognitive changes.

“Improvements in symptom management can largely be linked to the development of the concept of comprehensive, multi-disciplinary

management strategies and personalized, patient-centered medicine. As with earlier drug treatments, earlier intervention to manage developing symptoms has helped lead to reduced MS-related disability and improved quality of life.

Future advances in MS will be linked to research in a number of areas: new and more powerful drugs to better control the disease and its progression, and – hopefully – to actually develop the long-elusive “cure” for the disease; neurodegeneration, to better understand the process or progression, and to slow or prevent its development; and better management of the many and varied symptoms of MS, both physical and emotional, to enhance overall quality of life and function.

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*Dr. Diana M. Schneider trained as a neurological chemist at UCLA, and subsequently worked for the National Institute of Neurological Disorders and Stroke and the Neurosciences Research Program at MIT. She has been in medical publishing since 1975, founding Demos Medical Publishing in 1986 and DiaMedica Publishing in 2005.*

*In addition to publishing books on a range of patient-related topics on neurologic and other diseases, Dr. Schneider has developed a number of patient-education articles for MSAA and serves as a consultant to the National MS Society for its patient-education publications. Her life-partner of more than thirty years, John, has primary-progressive multiple sclerosis.*



## Should I Consider Stopping Treatment?



*Dr. Jack Burks*

**Q:** When should someone stop a disease-modifying therapy (DMT)? I have not had a relapse for several years, but my doctor has mentioned that I may have progressed

from relapsing-remitting MS (RRMS) to secondary-progressive MS (SPMS), in which case I might not experience relapses anyway. If this is true, I would not need to go to the expense or trouble of taking injections every-other day. However, if Betaseron is contributing to my recent lack of relapses, should I risk stopping it?

**A:** My advice is to weigh that decision very carefully. By stopping your medication, you

would be taking a gamble, which could result in an increase in disease activity. AND (in my experience and not addressed in any scientific way), some patients who go off their successful DMT may develop a more rapid progression of their disease. Even worse, when they return to their original treatment, they do not respond as well as before. My feeling is: “if it ain’t broke, don’t fix it.”

In trying to understand this difficult disease, it appears that SPMS has an earlier, relapsing phase, as well as a later, degenerative stage, without relapses. Betaseron has been shown to be effective in the relapsing phase. Therefore, you may still be benefitting from Betaseron, since the treatment may be responsible for your lack of relapses. I feel the same about other DMTs for other patients.

In other words, Betaseron may still be reducing inflammation, which may be why you are no longer having relapses. If so, your relapses may return if you stop your medication. Unfortunately, we do not know that for certain, but why take a risk? In general, I believe that the effects of DMTs may be keeping patients healthier over the long run. Recent long-term data on Betaseron supports my opinion.

Therefore, I usually do not recommend stopping DMTs if my patients are doing reasonably well. However, if the patient cannot tolerate the DMT or is doing worse than I had expected, I recommend a switch

### To Submit Questions...

Please submit your questions to:

MSAA  
Questions for Ask the Doctor  
c/o Dr. Jack Burks  
706 Haddonfield Road  
Cherry Hill, New Jersey 08002

Readers may also send in questions via email to [askdr@msassociation.org](mailto:askdr@msassociation.org). Please be sure to write “Ask the Doctor” in the subject line.

of therapies. Of course, we cannot always predict the outcome of any MS treatment. Your doctor is your best guide. He or she may want you to get an MRI to check for the rate of disease progression. Or your doctor may suggest a second opinion from another MS expert.

**Q:** In your column in the last issue of *The Motivator*, one reader wrote about their chronic bout with diarrhea. You did not mention celiac disease, so I wanted to ask if this individual and any other person with MS who has unresolved, chronic diarrhea should be checked for celiac disease. I have MS and was often sick with symptoms of celiac, including headaches that required going to the

ER. My husband happened to read an article about celiac disease, and this eventually led to my diagnosis, along with two other family members. We are grateful to know about this disorder and are able to resolve our symptoms through a gluten-free diet.

**A:** You make a good point. While celiac disease is responsible for a very small percentage of diarrhea in MS patients, it is more likely found in individuals with MS, as with other autoimmune diseases, than in the general population. A recent study suggests that celiac disease is five to 10 times higher in MS patients versus the general population. Diarrhea can be caused by any one of a great number (potentially hundreds) of

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## Aubagio® (Oral Teriflunomide) Receives Approval

On September 12, 2012, Sanofi and its subsidiary Genzyme announced that the United States Food and Drug Administration (FDA) had approved their new drug, Aubagio® (oral teriflunomide), for relapsing forms of multiple sclerosis (MS). The FDA had accepted their New Drug Application (NDA) in October 2011. This is the ninth disease-modifying therapy approved by the FDA for the long-term treatment of MS. Of these nine, Aubagio is the second approved medication for MS that is taken orally.

This drug is an immunomodulator that affects the production of T and B cells. It inhibits rapidly dividing cells, including activated T cells, which are thought to drive the disease process in MS. It also may inhibit nerve degeneration by reducing the production of free radicals, possibly decreasing the risk of infections and other complications linked to chemotherapy-like drugs.

Aubagio has been approved in two dose levels: 7 mg and 14 mg. The medication is produced in film-coated tablets and is taken once daily, with or without food. Since the higher dose shows greater effectiveness, this dose may be more frequently prescribed. However, for individuals who may be more sensitive to the drug and experience greater side effects, the 7-mg dose may be more appropriate. The drug is expected to be available beginning October 1.

### Study Results

The TEMSO trial for relapsing-remitting MS (RRMS) compared 7-mg and 14-mg doses of Aubagio in 1,088 individuals. Both doses significantly reduced the annualized relapse rate by approximately 31 percent. The 7-mg dose resulted in a 39.4-percent reduction in brain-lesion volume on MRI compared with placebo, while the 14-mg dose resulted in a 67.4-percent reduction. The 14-mg dose also reduced the risk of sustained disability progression by 29.8 percent relative to placebo. The number of gadolinium-enhancing lesions was reduced with both doses compared with placebo, and there was a trend toward a greater effect with the higher dose.

The TOWER efficacy study is also testing 7-mg and 14-mg doses versus placebo. This study of 1,169 individuals with RRMS is completed and data analysis is ongoing. Its primary endpoint is the annualized relapse rate, with a secondary endpoint of time to disability progression. Top-line results of this trial were announced in June, 2012. In the study, patients receiving the higher dose of 14 mg had a 36.3-percent reduction in annualized relapse rate and a 31.5-percent reduction in the risk of 12-week sustained accumulation of disability, compared to placebo. Patients treated with lower 7-mg dose of Aubagio experienced a 22.3-percent reduction in annualized relapse rate, compared to placebo.

factors, and to list all of these would not likely have been of help to the individual who wrote (mainly) about her vaginal problem. The specific cause is best evaluated by one's doctor or by a specialist in gastrointestinal (GI) diseases, which I noted in my answer. We need to be careful that we don't run the risk of people self-diagnosing their diarrhea as celiac disease when something else may be responsible. It is best to ask an expert in that field.

Celiac disease has a genetic basis, as do most immunological diseases. It is under-recognized in general, and is treatable by reducing gluten in the diet. The workup by a GI doctor includes getting blood tests, and the evaluation may require an upper-GI tract workup, including barium swallow and endoscopy, a barium enema, etc.

**Q:** Can you advise the role of hormonal therapy for women with MS who are menopausal? In my case, I recently had a hysterectomy. Please let me know if taking hormones is safe and if it can have any potential negative effect on my MS.

**A:** As with any treatment decision, we weigh the benefits versus the risks, which vary with each medication and with each patient. Exercise, diet, smoking (versus not smoking), and recreational drugs and alcohol are all important when discussing menopause with a doctor.

Menopause has short- and long-term consequences. Short-term issues include hot flashes, night sweats, emotional stress,

vaginal dryness and pain, decreased libido, bladder problems, and changes with skin and hair. Long-term issues include osteoporosis (bone thinning) and an increased risk of cardiovascular events (heart attack and stroke).

To some extent, these issues may be addressed through symptom-management strategies. Various remedies and products are available to reduce several of the short-term symptoms, such as hormonal and non-hormonal creams for dryness. For the long-term consequences, medications, Vitamin D, and calcium supplements are often used to reduce bone thinning; diet, exercise, and when needed, medications, are useful in reducing the risk of cardiovascular events.

Hormone replacement therapy (HRT) adds lost estrogen and sometimes progesterone, with the goal of minimizing both the short- and long-term consequences of menopause. Certain risks exist with HRT – regardless of whether someone has MS – and these need to be discussed with your doctor.

Estrogen does not appear to have any negative effects on MS. Does estrogen help MS? Some preliminary data show encouraging evidence that estrogen may decrease MS relapses. This theory was developed from the fact that women who are pregnant (and have high estrogen levels) rarely experience MS relapses, but relapses commonly occur shortly after giving birth (when estrogen levels decrease). Definitive studies are underway to observe the effects of

*continued on page 47*

## Adverse Events

Common adverse events include headache, elevations in liver enzymes, hair thinning, diarrhea, nausea, neutropenia (a condition that reduces the number of certain white blood cells that normally fight infection), and paresthesia (tingling, burning, or numbing sensation). More severe adverse events include the risk of severe liver injury and the risk of birth defects if used during pregnancy. A “black box” warning appears on the labeling

of Aubagio, which lists these two risks.

Because of these warnings, physicians must take certain precautions to minimize any risks. With regard to liver injury, blood tests for liver function must be performed within six months prior to starting Aubagio, and then every month for the first six months. With regard to pregnancy, Aubagio may only be prescribed to women of childbearing years if they are using reliable birth control. If liver damage is detected, or if someone

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## DMF and Lemtrada™ Submitted for FDA Approval

### Dimethyl Fumarate (DMF)

In February 2012, Biogen Idec announced that it had submitted an NDA to the FDA for the approval of Dimethyl Fumarate (DMF, formerly known as BG-12) for the treatment of relapsing-remitting multiple sclerosis (RRMS). A decision is expected from the FDA in the very near future.

DMF is an oral medication taken daily. It may have a distinct dual mechanism of action – as an immunomodulator with anti-inflammatory properties, as well as a neuroprotective agent, due to its activation of a substance that is critical for resistance to cellular damage. DMF is initially being studied in relapsing-remitting MS (RRMS).

In the Phase III DEFINE study, DMF was given either two-times (BID) or three-times (TID) daily, compared to placebo. The annualized relapse rate (ARR) at two years was reduced by 53 percent (BID group) and 48 percent (TID group), while the risk

of disability progression was reduced by 38 percent (BID group) and 34 percent (TID group). In the Phase III CONFIRM study, which used the same treatment regimens (plus a separate group given Copaxone® [glatiramer acetate]), DMF reduced the ARR by 44 percent (BID group) and 51 percent (TID group), compared to placebo at two years. In both studies, DMF significantly reduced MS brain lesions.

A continuation study is ongoing, as well as a combination-therapy study. Trials to date indicate that DMF is safe and that its overall tolerability improves with continued use. Side effects include skin flushing and gastrointestinal symptoms.

### Lemtrada™

In June 2012, Genzyme (a Sanofi company) announced that they had submitted Lemtrada™ (alemtuzumab) for approval with the FDA for the treatment of

becomes pregnant while taking this drug, accelerated elimination of the drug is prescribed. This removes more than 98 percent of the drug within 11 days.

### For More Information

For more information about Aubagio, members of the MS community may visit [www.aubagio.com](http://www.aubagio.com). Individuals may also contact Genzyme's "MS One to One" program, which provides access to nurses

experienced with MS patients on Genzyme treatments. This service may be accessed by calling (855) MSOne2One – or (855) 676-6326, Monday through Friday from 8:30 am to 8:00 pm. Information and support is also available at [www.MSONetoOne.com](http://www.MSONetoOne.com). Financial assistance will be available to individuals who qualify.

Members of the MS community may also call MSAA's Helpline at (800) 532-7667 for additional information and assistance. ♦

relapsing forms of multiple sclerosis. Genzyme is developing Lemtrada for MS in collaboration with Bayer HealthCare. This drug has previously been referred to as Campath.

In August 2012, Genzyme received a Refuse to File letter from the FDA. This was in response to its submission for the approval of Lemtrada as a treatment for relapsing MS. Following discussions with the FDA, the agency requested that Genzyme modify how the data was presented, so that the FDA could more easily navigate the application. No additional data or further studies are necessary and the company plans to resubmit its application in the near future.

Lemtrada is administered in one-course yearly by intravenous infusion over three-to-five consecutive days. The drug is a humanized monoclonal antibody that targets a protein present on the surface of

mature lymphocytes and is approved for the treatment of B-cell leukemia. This drug was granted Fast Track status by the FDA in June 2010.

In the CAMMS223 Phase II study of 334 individuals with early, active RRMS, the relapse rate in patients on Lemtrada was about one attack in nine years. This is the lowest relapse rate ever reported for an MS drug. More than 50 percent of the Lemtrada-treated patients actually improved. An extension study showed that at a five-year assessment, 87 percent were free of sustained disability accumulation, 72 percent were relapse-free, and 65 percent were free of clinical disease activity.

Side effects include a reduction in blood clotting, thyroid disorders, infusion reactions, and infection. Patients need to be monitored closely due to risk of significant toxicities. ♦

## MRI Institute Marks 10 Years of Service

MSAA is proud to mark the 10-year anniversary of one of our most sought-after programs: the MRI Institute. Supported by EMD Serono, Inc. and Pfizer Inc since the program's inception in 2002, the MRI Institute provides cranial MRI scans to MS patients who otherwise could not afford the test due to lack of insurance or steep coverage limits. Over the past decade, this critical program has benefited more than 7,500 individuals with MS across the country.

MRI scans play an essential role in the management of the ever-changing course of multiple sclerosis. With the valuable information provided by an MRI, physicians are able to make better treatment decisions and monitor the effectiveness of prescribed treatments, making adjustments as necessary. Unfortunately, many people have neither the necessary insurance coverage nor the financial means to acquire an MRI to evaluate the status of their illness. The MSAA MRI Institute was established to meet this important need.

"Today, the MRI is recognized as one of our most powerful tools to gauge the effectiveness of therapy and monitor the progress of the disease," explains MSAA President and CEO Doug Franklin. "MSAA would not be able to provide this extremely valuable service without the support of our partners at EMD Serono and Pfizer. We greatly



*At the 2012 Consortium of MS Centers' Annual Meeting, MSAA Chairman of the Board Tom Vassallo (left) and CEO Doug Franklin (right) present EMD Serono President Jim Hoyes with a commemorative award marking their 10-year commitment and support to MSAA for the MRI Institute program.*

value their long-standing dedication and commitment to this program as well as other MSAA services that enable us to continue serving the MS community and make a truly positive impact on their quality of life."

According to MSAA client Emily Johnson, the MSAA MRI Institute assisted in providing a much-needed resource in managing her MS. "As a young person with relapsing-remitting MS, my expenses associated with my MS, especially medication and medical procedures, such as an MRI, are often a burden," states Johnson. "I was so excited to learn that the MSAA MRI Institute could possibly help me

obtain a needed MRI. The assistance provided meant one less concern for me. I am truly grateful for the MSAA MRI Institute.”

To learn more about the MRI Institute and to receive an application, please visit our website at [msassociation.org](http://msassociation.org) or call (800) 532-7667, ext. 120.

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### Stay on Top of Your MS

With the arrival of fall, MSAA's regional offices are preparing to launch a full year of informative public education programs designed to give you and your family the latest updates on MS therapies, effective symptom management treatments, and proactive strategies for living your best.

“The world of MS is constantly changing with new information being discussed and reported nearly every day,” explains MSAA Chief Operating Officer Robert Rapp. “It is extremely important for individuals with MS and their families to become and remain proactive rather than reactive when faced with the many challenges of this lifelong journey.”

Ranging from the latest advances on disease and symptom treatments, to new strategies on managing employment, relationships, and other life issues, MSAA's educational programs provide an excellent opportunity to connect our clients with many of the country's leading MS healthcare professionals. Often planned as small dinner programs, these events provide information in an easy-to-understand, conversational format that strongly encourages open dialog between clients and presenters, while allowing plenty

of time for questions and answers.

“We recognize our clients have important questions and concerns they want to share with the presenters as well as discuss with their peers,” says Rapp. “For many, it represents a chance to ask questions they might not have time for during a routine doctor's visit, or the opportunity to learn from an MS expert who practices outside their area. This lively discussion also seems to create a comfortable and trusting environment.”

MSAA's educational programs planned for this coming year include: cognition and MS; updates on exciting emerging therapies for disease management; new advances in the treatment of bladder function, spasticity, and other symptoms; and the benefits of shared management, which encourages patients and healthcare providers to work together to achieve better health outcomes. MSAA recently launched a number of innovative tools to assist with shared management including our My MS Manager™ (a mobile phone application), My MS Resource Locator online database, and the S.E.A.R.C.H.™ initiative to assist with treatment discussions. MSAA's regional offices are also actively planning information and outreach programs to address the underserved communities of Hispanic and African-American MS populations as well as clients in rural areas who have unmet healthcare needs.

To learn more about MSAA's educational programs in your area, please visit our Calendar of Events at [msassociation.org](http://msassociation.org), email us at [MSquestions@msassociation.org](mailto:MSquestions@msassociation.org), or call (800) 532-7667. ♦



## Planned Gifts

Most gifts to MSAA are random. They come as people think of adding to the quality of life for someone affected by MS, or are prompted by a letter or telephone call.

Random gifts are appreciated. MSAA thanks all donors for their thoughtfulness and generosity. We could not offer many of our vital programs and services without them.

Planned gifts are of a different breed... A special breed! By definition, a planned gift is one that is purposeful and considered. It promises extra advantage for the donor and the charity. It provides both with a sense of structure.

The donor has the ability to frame his or her gift. Decisions rest on whether one intends to make an outright gift, continue to support MSAA after one's passing (through a bequest or ongoing trust), or derive some income while supporting a favored charity.

The donor can plan his or her gift around an overall financial strategy, perhaps discussed with an attorney, a financial advisor, or someone from MSAA. Mutual benefit is the aim. Donors settle on a planned gift that suits their intentions and needs while deriving the satisfaction that they have significantly helped the charity continue its mission. The donor's personal goals and the charity's objective to sustain its valuable programs and services have both been met.

The charity's benefit is immeasurable. With random gifts, the charity can project that it will generate enough income to do its basic

work and continue its benefit to the people who need its help. With planned gifts, a charity can project a lot further. Planned gifts are predictable. A charity has a more definite idea of revenue to come. Knowing we can depend on a specific amount of income from donors who have stated firm intentions to give a certain gift in a particular period of time, MSAA can expand services, explore initiatives, and react quickly to situations we learn about during Helpline conversations or in assessment surveys.

The donor's planned gift leads to MSAA's planned strategy. It translates to more mobility, security, convenience, and access to vital information for people who cope daily with the chronic and unpredictable challenges of MS.

MS may be unpredictable. Planned gifts are the opposite. Their predictability allows MSAA the wished-for opportunity to better measure the scope of what it can do for the people it serves.

### Timely Giving

Before going into some of the ways donors can structure planned gifts, it's important to mention something that they can do before December 31, 2012. All gifts to MSAA are tax deductible, so any gift made before the end of the year can yield the donor a tax advantage. Donors who are age 70½ or older may also save on taxes by transferring funds from their IRA and other retirement plans to a charity, like MSAA, by New Year's Eve.

While the donor cannot claim the gift as a charitable deduction, he or she will not pay income tax on the amount transferred to a public charity. This provides a solution for people who, by law, must withdraw money from tax-deferred accounts but either have no need for the mandatory funds or want to avoid the tax implications of the withdrawal. Because the gift generates neither taxable income nor a tax deduction, even those who do not itemize on their tax returns can receive the benefit.

### Outright Gifts

Significant gifts to MSAA can be made in several ways. The simplest is to give online, using MSAA's secure online donation form at [support.msassociation.org/donate](http://support.msassociation.org/donate). Some people prefer to write a check, and that's an easy way to give as well. If this gift were a planned gift, MSAA would know about it in advance, and recurrence might be arranged on a regular basis.

Some donors prefer to make a major contribution to MSAA's mission by spreading a handsome gift over time. For instance, the donor will pledge \$10,000 a year for five years, allowing MSAA to plan on applying the full sum of \$50,000 in a specific, useful way.

Another popular way to make a major gift in small doses is the sustainer gift, a monthly gift that is usually deducted directly from the donor's bank via electronic fund transfer or applied to a credit card. This turns \$25 per month into a \$300 annual gift. Sustainer gifts are a good option for donors who desire to make a significant gift but find it more feasible to send smaller gifts.

### Bequests

Providing a legacy through a bequest or an ongoing trust is worth considering for donors who have made gifts to MSAA for many years and would like to continue to support the Association's mission in a meaningful way.

Language for including MSAA in one's will can be found on our website at [support.msassociation.org/plannedgiving](http://support.msassociation.org/plannedgiving). You may want to talk to an attorney or financial advisor if you are interested in benefiting MSAA with continuing gifts as a legacy.

Legacies can also be used to support or sustain a program in the manner that people endow chairs to universities. MSAA is always open to a discussion about this option.

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### Annuities and Trusts

Charitable Gift Annuities and Charitable Remainder Trusts allow a donor to benefit a favored charity while deriving income from his or her gift.

A gift annuity provides a contractual amount of return paid by MSAA to the donor in return for his or her contribution. The creation of a gift annuity is a way to establish a contracted quarterly income for you that is not affected by financial markets. The rate the donor receives is based on his or her age at the time the annuity is created and provides income for the donor's lifetime.

A gift of \$20,000 could, depending on the donor's age and interest rate at the time, earn the donor more than \$1,000 per year for life.

Charitable trusts are more complex and can yield a fixed or variable rate of return depending on the donor's choice. They can also be arranged to be of mutual benefit to MSAA and to the donor in the form of annual income.

Planned gifts give both the donor and the charity a sense of assurance and continuity. If you are interested in discussing a planned gift, please call MSAA at (800) 532-7667 and ask to speak to Kim Goodrich (MSAA's senior director of development, at extension 101), or Neal Zoren (MSAA's director of development, at extension 128). Either of these staff members would be happy to speak with you and help you to determine if a planned gift is the right option for you. ♦

## THE PHILANTHROPY CIRCLE

*The following thoughtful corporations and foundations have contributed generously to MSAA to help enrich the quality of life for everyone affected by multiple sclerosis. Organizations providing gifts of \$10,000 or more are shown in this listing.*

### **GUARANTORS** (\$500,000 and up)

EMD Serono, Inc. and Pfizer Inc  
Teva Neuroscience

### **CHAMPIONS** (\$100,000 to 499,999)

Allergan, Inc.  
Acorda Therapeutics  
Biogen Idec  
Genzyme Corporation  
Novartis Pharmaceuticals Corporation  
Questcor Pharmaceuticals, Inc.

### **VISIONARIES** (\$50,000 to \$99,999)

Avanir Pharmaceuticals  
Bayer HealthCare Pharmaceuticals  
Bayer USA Foundation  
Genentech Foundation  
Genentech, Inc.

### **INNOVATORS** (\$25,000 to \$49,999)

Allergan Foundation  
Medtronic Foundation

### **ADVOCATES** (\$10,000 to \$24,999)

Catholic Human Services Foundation  
The Chatlos Foundation  
Kessler Foundation  
The Virginia Dashiell Foundation

## Aquatic Therapy and Aquatic Exercise

*What are the Benefits for People with MS?*

By Maryann B. Hunsberger

Aquatic therapy, a sub-specialty in the fields of physical or occupational therapy that is done in a swimming pool, can benefit people with MS by improving flexibility and motion, allowing muscles to relax, and reducing pain. Aquatic exercise – exercises done in a pool – can also help achieve these same results. Knowledge of swimming is not required for either aquatic therapy or aquatic exercise.

The two fields are similar and can work together, explains Barbara Batson, an AEA-certified exercise specialist in Tennessee. “Insurance limits the number of physical or occupational therapy sessions a person can have, so after the therapy visits are over, it’s good for a person to then switch to aquatic exercise, which costs less. People without insurance coverage for therapy can start with aquatic exercise instead.”

Aquatic therapy can only be facilitated by a physical therapist or occupational therapist, while aquatic specialists typically lead aquatic exercise classes. Although aquatic specialists are generally not required to have any specific certification, most aquatic specialists take classes through the Aquatic Therapy & Rehab Institute (ATRI) or the Aquatic Exercise Association (AEA). Some facilities, such as the YMCA and the Arthritis Foundation, also require training through their own program. Other facilities sometimes require that the aquatic specialist be a personal trainer.



***Aqua specialist Donna Adler (left) assists Lara Hempler through aquatic exercise***

Aquatic specialists and aquatic therapists can receive specific training to work with people who have MS through ATRI’s online class at [www.atri.org](http://www.atri.org).

Donna Adler, an Arizona-based aqua specialist and continuing-education provider for both the AEA and the ATRI, states that aqua exercise “is on the bridge between fitness and therapy.” She works with many people with MS who have spasticity and pain. “When muscles are tight, the body doesn’t move the way it’s supposed to. With individuals who lack range of motion, exercise will tire them more quickly, so we perform AquaStretch™ to improve their range of motion. AquaStretch is a technique performed in water that is three-to-four feet deep, where the therapist applies gentle pressure to the client’s skin and the

connective tissue restriction underneath the skin, which facilitates or accentuates the client's intuitive movement. In general, people can exercise in the water without the pain they would feel on land, since water allows them to have less pressure on their joints. They can move more freely since buoyancy lifts and pulls them up."

Carolyn Sprehe, an aquatic specialist in Indiana, points out, "Water exercise helps gross and fine motor skills, flexibility, the sensory system, the cardiovascular system, the pulmonary system, the musculoskeletal system, bone strength, lung capacity for

someone who is always in a wheelchair, and it increases breath control."

Water therapy and water exercise also have psychological benefits. Sprehe says, "It improves the quality of life for people with MS. Moving better, getting out of the house, socializing at the pool, having fun, and relating to other individuals with MS are all important aspects." Adler adds, "It's something different from going to doctors' offices. It gets people with MS out of the depressive cycle. Socializing is one of the most important attributes of aqua exercise, even if a person can't do every step."

## PHYSICAL BENEFITS OF AQUATIC THERAPY

**Buoyancy:** In shoulder-deep water, about 90 percent of the body's weight is removed from the body's joints. This means a person submerged to the neck weighs one-tenth of their regular body weight. This causes increased blood supply to joints, reduces joint stress, and reduces pain. This also allows for a larger range of motion. Buoyancy reduces the risk and fear of falling, which improves confidence and decreases incidences of injury. Adler says, "When someone is up to chest level in water, they are able to function differently. I find that people with MS who can't walk on land can often walk in a pool. I have seen it over and over again."

**Hydrostatic Pressure:** Water applies pressure against the body, acting like compression support hose during water exercise, which reduces swelling. When the body is in shoulder-deep water, hydrostatic pressure shifts 60 percent of the blood to the heart, allowing the heart to work with less stress. The reduction in swelling of the lower extremities helps to minimize pain.

**Resistance:** According to the American Council on Exercise (ACE), water provides ten times the resistance of air, which forces individuals to work more muscles during exercise. This resistance strengthens and builds the muscles and fosters both trunk stability and postural alignment.

**Turbulence/Water Surface Tension:** The body's movement through water creates turbulence. As participants learn to stabilize their bodies against the turbulence, it allows weak muscles to gradually strengthen. This also challenges and improves balance, stimulates increased peripheral blood flow, and refreshes and energizes the individual.

— Maryann B. Hunsberger

As with other forms of exercise, people with MS should obtain medical clearance from their physician before participating in any aquatic exercise program. A physical therapist, occupational therapist, or aqua specialist should conduct a thorough physical evaluation to determine the level of required assistance, the appropriate methods of pool entry and exit, as well as the correct exercises.

Despite accreditation not being required for aqua specialists, Sprehe said aqua specialists with ATRI/AEA certification, particularly those who have taken the ATRI MS class, are more knowledgeable. Therefore, individuals with MS should check the credentials of any aqua specialist before embarking on water-exercise classes. According to Batson, people with MS considering taking part in aquatic therapy with an occupational or physical therapist should also ask if the therapist has received additional education in performing aquatic therapy.

An aqua specialist or therapist should be able to identify the individual's MS symptoms and determine how these symptoms will affect that person's ability to partake in aquatic exercise. Anyone facilitating water exercises should also be knowledgeable about pain, whether MS-related or not. This information should be used as a benchmark to assess pain during or after exercise. In addition, a baseline measure of strength, fitness, spasticity, and range of motion should be used to monitor exercise outcomes.

"It's important to know this to understand how to treat the person," said Sprehe. "An aqua specialist will usually recommend a

regular aqua exercise class for a person at a higher functional level, who has mild or no symptoms. However, if someone uses a walker or wheelchair, it's important that they seek out a physical therapist, an occupational therapist, or an aquatic specialist with knowledge of MS."

Finding a completely accessible facility is important for people with MS. Adler recommends looking for elevators, lift chairs, and shallow steps. "Everything should be designed so people can be as independent as possible." Sprehe further explains, "Pool chair lifts are now required to be in all [public] pools. The lift looks like a chair that rotates and goes into the water. Individuals should look for a facility that allows a personal-care attendant to help the person to transfer, if needed, and to go into the pool with them, if necessary." Sprehe points out that wheelchair users will need PVC wheelchairs to access pools with beachfront entries. "If a facility doesn't have this, the individual should ask for accessibility to the pool."

Because MS symptoms can worsen with overheating, individuals with MS need to consider pool temperature. "Some people can't handle the heat," says Adler. "Therapeutic pools are usually set between 88 to 90 degrees in wellness settings. In hospital settings, the temperature can be up to 96 degrees. I prefer no more than 86 degrees for people with MS. It depends on the client and his or her preferences." In general, Sprehe uses a pool temperature of 84 to 86 degrees when working with people with MS. "Warm water helps reduce pain because an individual with a contracture can relax in it." But care

needs to be taken that the pool is not too warm, i.e., above 86 degrees, to avoid the symptoms of overheating for individuals with heat-sensitive MS.

People with MS should also consider their fatigue level before starting a water-exercise program. Adler shortens the length of exercise time for people who experience fatigue. “I don’t want them to be exhausted.” Sprehe adds, “People naturally try to do too much without a specialist, so they need the help of a professional.”

Most facilities have the equipment that individuals will need to take classes – such as noodles, small barbells, and kickboards. Individuals can check with the aqua specialist who will be teaching an aqua exercise class to be sure.

When looking for an aquatic exercise

program suitable for people with MS, Adler recommends checking out the gentle aquatic exercise classes given by the Arthritis Foundation at [www.arthritis.org/aquatics.php](http://www.arthritis.org/aquatics.php).

Sprehe also recommends researching local YMCAs as well as city and community recreation facilities to find aqua exercise classes suitable for people with MS. “Call where water exercise classes will be held and ask if the trainer is experienced in working with someone with MS,” says Sprehe. She points out that swimming is also beneficial for people with MS. “Higher functioning individuals who want to swim and move through the water will find this to be a great form of exercise. An aqua specialist can monitor so they don’t fatigue themselves. Since aqua exercise, aqua therapy, and swimming help with pain, fatigue, and depression, any of these activities can be very beneficial for people with MS.”

According to Batson, aqua exercise serves to improve the quality of a person’s entire life. “People need to exercise so they can do the things in life that make them happy, like getting down on the floor with the grandkids and being able to get back up, or shopping, or traveling. People with MS are not exempt from the illnesses that the general population gets, such as diabetes, high blood pressure, heart disease, or untimely strokes. Much of this can be minimized or avoided by maintaining a healthy weight, exercising daily, and maintaining healthy relationships. So, bring yourself to the water where you can safely exercise in a group setting with people who will come to know and love you.” ♦



**Swim for MS** is a national ongoing fundraiser in which volunteers are encouraged to dive into action and create their own swimming activity or challenge while collecting pledges and online donations toward their goal. Activities can range from individuals swimming laps or a distance over a set period of time, to similar group swims organized by clubs and teams, from youth through college and beyond. Whatever you decide to create for your Swim for MS fundraiser, make it fun, make it challenging, and make it yours! To learn more and register, please visit [SwimForMS.org](http://SwimForMS.org) or call (800) 532-7667, ext. 157

continued from page 34

estrogen on a woman's MS. Estrogen does not appear to have any negative effects on disease-modifying therapies (DMTs), so this factor should not be a concern.

The final decision is between the physician and the patient. Additional risks and benefits should be discussed. If a patient and her gynecologist decide on using HRT, as a neurologist, I would have no problem with that decision.

*Dr. Jack Burks is an international MS neurologist, writer, lecturer, and researcher, who assists with the development of new MS therapies and advises patients, families, MS organizations, and healthcare groups. Dr. Burks is a member of the Clinical Advisory Board of the NMSS. He has written and edited three MS textbooks, as well as numerous chapters and articles on MS. In recent years, he has lectured and evaluated patients in more than 40 countries.*

Additional questions and answers for Ask the Doctor may be found online at [msassociation.org/publications/summer-fall12](http://msassociation.org/publications/summer-fall12)

## RESEARCH UPDATE

MSSA's annual MS Research Update is being printed separately from *The Motivator* this year. This special publication will be mailed to all recipients of this magazine later this year.

### Introducing a Practical Solution for Hip Flexion Weakness

## The HFAD

### The Hip Flexion Assist Device

The Hip Flexion Assist Device (**HFAD**) is intended for individuals with Multiple Sclerosis (MS) who are currently ambulatory, but have difficulty initiating swing due to hip flexor weakness. The Hip Flexion Assist Device is designed to improve gait and consists of a comfortable waist band and two dynamic tension bands that attach to the shoe. The device may be worn over or under clothing and should only be used under

the direction of a physical therapist or orthotist.

A recent study<sup>1</sup> funded by the National MS Society, and published in the *Archives of Physical Medicine and Rehabilitation*, indicated that for ambulatory patients with MS, the **HFAD** significantly improved gait performance, as well as **improved strength** in the limb fitted with the **HFAD**. Furthermore, the use of the HFAD was found to result in **increased daily activity level**.

1. Sutliff, Matthew H., PT; Jonathan M. Naft, CPO; Darlene K. Stough, RN; Jar Chi Lee, MS; Susana S. Arrigain, MA; and Francois A. Bethoux, MD. "Efficacy and Safety of a Hip Flexion Assist Orthosis in Ambulatory Multiple Sclerosis Patients." *Archives of Physical Medicine and Rehabilitation* 89 (2008): 1611-1617.



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# Spread the Word

## *The Can Do Multiple Sclerosis Guide to Lifestyle Empowerment*

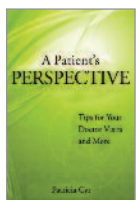
Edited by Patricia Kennedy, RN,  
CNP, MSCN

Published by Demos Health

MSAA Book # 12



The staff at Can Do Multiple Sclerosis has put together this wonderful book to empower individuals with their organization's message of "You are more than your MS." Each chapter, written by experts in the field of MS, addresses a different aspect of the whole person, whole health, and whole community approach to living with MS. With topics such as motivating and goal setting, symptom management, physical activity, eating well, and caring for total health, this book provides a foundation to determine what you can do to maximize your health and quality of life.



## *A Patient's Perspective – Tips for Your Doctor Visits and More*

Written and published by Patricia Cyr

MSAA Book # 16

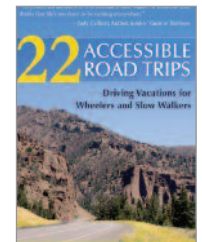
The author of this valuable resource has coped with her own chronic illnesses for more than 25 years. Over the years she kept notes about each of her medical appointments and procedures, and from these notes, has written this book. Cyr covers such important topics as appointment issues and obstacles upon arrival, meeting with the doctor, invisible illness, taking tests, clerical errors, having surgeries performed, physical therapy, legal issues, and more.

## *22 Accessible Road Trips: Driving Vacations for Wheelers and Slow Walkers*

Written by Candy B. Harrington

Published by Demos Health

MSAA Book # 20



Author Candy Harrington has a wealth of experience with accessible travel, having completed several books on the topic, along with writing for magazines, speaking at conferences, and conducting workshops. This new book talks about the advantages of road travel and provides numerous road trip tips and resources. The chapters cover road travel within different regions of the United States, highlighted by helpful details and many beautiful (black and white) photos.

## *MSAA Lending Library*

To borrow books featured in this column or any other book in MSAA's Lending Library, please visit [msassociation.org/programs/lending\\_library](http://msassociation.org/programs/lending_library) to view a list of books available and to complete a form. When ordering a book, please reference the book number listed. Readers may also call MSAA at (800) 532-7667 for more information.

MSAA and its clients greatly appreciate any donations made to help build the Lending Library. If you would like to donate one or more books to the Lending Library, please send these to:

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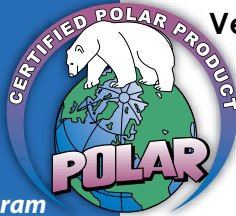
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Visit [resources.msassociation.org](http://resources.msassociation.org) to get started!





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My MS Manager

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**Please note:** MSAA is *not* distributing free mobile phones. A mobile phone application (or “app”) through the iTunes store is available as a free download to individuals with MS or their care partners to use on their iPhone, iPad, or iPod touch.