LETTER FROM THE PRESIDENT

Together we are stronger! Throughout 2016, we will focus on this theme as we work with you to create a world free of MS. This message is deeply universal. While some individuals have the strength to take action by themselves, when we all work together we accomplish so much more.

Spring is coming! It might be hard to believe when it’s freezing outside, but soon enough we’ll be turning down the heat and stepping out into the fresh air. The National MS Society kicks off spring with MS Awareness Week, March 7 through 13. A team of staff and volunteers are developing opportunities for what we call “actionable awareness.” Much of this activity will take place online in social media, so be sure to “like” us on Facebook.com/MSnewengland and follow us on Twitter, @MS_newengland.

We emphasize actionable awareness because although creating recognition and understanding of multiple sclerosis is vitally important, it’s equally necessary to give people an opportunity to take action against MS. One of the best ways to take action is participating in Walk MS.

Walk MS is a time when we join together with family and friends to support those we love who have MS and to raise money so that everyone affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost, and end MS forever. It’s an inspiring sight that I strongly encourage you to see first-hand. The enthusiasm and joy is contagious. Some families come from far and wide for a reunion at Walk MS every year.

We need everyone’s help to ensure Walk MS is successful. From registration volunteers to finish line cheerers, everyone contributes to our effort to raise $48.8 million nation-wide. What better way to make a statement against MS than to have an army of people with MS present at Walk MS and raising the much needed funds to fuel the mission as we work towards creating a world free of MS. Together we are stronger!

There are many more ways you can create actionable awareness, such as volunteering to help with office work or at a fundraising event or at a program. Perhaps you have a particular skill set or career experience that can add value to the Society’s work. Contact GNEVolunteers@nmss.org to start the conversation about where you can make the biggest difference.

Remember, together we are stronger. So join us and take action this spring to help spread awareness. By coming together, we can help everyone with MS to live their best lives.

Lori Espino
President

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EMPLOYMENT.
UPDATE ON WORK INCENTIVES

BY STEVE NISSEN

As of January 1, 2015, Social Security beneficiaries received a 1.7% cost of living adjustment, or COLA. However, COLA affects more than the monthly benefit check that Social Security Disability Insurance (SSDI) recipients receive. It also affects certain work incentives that may prove useful when people with multiple sclerosis attempt to return to work.

THE TRIAL WORK PERIOD (TWP)

For individuals who receive SSDI, the trial work period (TWP) allows them to retain their full financial SSDI benefits while they test their ability to work. The TWP comprises nine months in a 60-month time period (the nine months do not have to be consecutive). For 2015, the amount that a person with MS can earn to count toward the TWP has been increased from $770 per month gross income to $780 per month gross income. Full benefits continue during this time regardless of how much a person earns.

SUBSTANTIAL GAINFUL ACTIVITY (SGA)

After a person completes their TWP, they can take advantage of the Substantial Gainful Activity incentive, which helps people transition back to work. For 2015, the SGA has been increased from $1070 per month gross income to $1090 per month gross income for non-blind individuals. For individuals who are statutorily blind, the SGA has increased from $1800/month gross income to $1820/month gross income.

DO YOUR RESEARCH

It’s important to note that once a person’s monthly income exceeds the SGA, his or her SSDI benefits may cease. Before doing anything that could jeopardize your benefits, be sure to do your research on what impact work may have on your benefits. Below are some helpful tips:

- Contact your local Work Incentive Planning and Assistance (WIPA) program and speak with a Community Work Incentive Coordinator (CWIC).
- Visit www.socialsecurity.gov/work/WIPA.html for information about the WIPA program.
- Call the National MS Society at 1-800-344-4867 to speak with an MS Navigator who can connect you with your local WIPA program, or visit www.chooseworkttw.net/findhelp/
- Learn more about Social Security work incentives by participating in a Work Incentive Seminar Event online webinar. For information about upcoming events, or to access archived webinars, visit www.choosework.net/wise.

Steve W. Nissen, MS, CRC, is the Society’s senior director of Employment & Community Programs.

NATIONAL MS SOCIETY AND CAN DO MS WEBINAR & TELELEARNING SERIES ON EMPLOYMENT

Tuesday, March 15
THE COMPLETE GUIDE TO SOCIAL SECURITY DISABILITY

- Learn what it takes to get approved for Social Security disability benefits from a social security attorney.
- Hear about the impact work might have on your disability benefits once approved from a Certified Benefits Counselor.

Tuesday, March 29
HOME-BASED EMPLOYMENT: WHAT EMPLOYERS WANT

- Learn from home based employers about what they look for when hiring people to work from home.

Register at nationalMSsociety.org/telelearning or call 1-800-344-4867
RESEARCH

IMAGING THE EYE PROVIDES WINDOW TO MS PROGRESSION

MRI scans of the brain have typically been used to help diagnose MS and to observe disease activity and progression in people with MS. Typical clinical MRI scanning detects areas of damage or activity (lesions) in the white matter, areas of the brain that contain myelin-coated nerve fibers. Typical MRI doesn’t have the power to detect or track shrinkage of specific areas of the brain, or lesions that occur in the outer layers of the brain (cortex, gray matter) containing nerve cell bodies. Mounting evidence suggests that damage to nerve cells underlies long-term progressive disability in people with MS. So having easier ways to detect and track nerve degeneration would help speed the search for better therapies.

Optical Coherence Tomography (OCT) has been increasingly used as a research tool to detect damage that occurs to the nerves in the back of the eye. OCT is a scan of the nerves in the back of the eye. It is done with a small machine that can fit into an examining room, is relatively inexpensive, painless and well tolerated. Growing evidence has suggested that OCT findings can mirror MS-inflicted damage that occurs in the brain, but it has not been clear how or whether thinning of the nerve at the back of the eye reflects brain shrinkage (atrophy) and nerve degeneration overall or in specific areas of the brain.

A collaborative team of 15 researchers at six institutions in the U.S. set out to track and compare changes in nerve layers at the back over four years with changes in brain tissue integrity and degeneration. The team conducted high-definition OCT scans twice annually and high-powered (3T) MRI brain scans annually in 107 people with relapsing-remitting, secondary progressive or primary progressive MS.

After four years, a comparison of the long-term MRI and OCT results suggested that the rate of tissue thinning seen on OCT reliably mirrored overall brain degeneration, with a specific layer of the retina (“ganglion cell and inner plexiform layer”) showing atrophy at similar rates as specific brain regions (whole brain, gray matter, white matter and the thalamus) seen with MRI. These similar rates of atrophy between OCT and MRI were more strongly associated in progressive MS for most areas of the brain.

These findings suggest that OCT findings reflect underlying disease progression, and further validate the usefulness of OCT as an important tool for tracking MS and the impacts in clinical trials.

TRIAL SUGGESTS HIGH-DOSE VITAMIN D IS SAFE AND REGULATES IMMUNE RESPONSES

Multiple sclerosis involves immune attacks on the brain and spinal cord. A number of genetic and environmental factors influence whether a person will develop MS. These factors may also impact the severity of the disease. There is growing scientific evidence that low levels of vitamin D in the blood are a risk factor for developing MS. In lab mice, vitamin D can reduce the effects of EAE, an MS-like disease, and some evidence suggests it may impact ongoing disease activity in people who have MS.

An important initial step to pursuing this lead was to
determine whether taking large doses of vitamin D was safe and provides any hints of impact against the immune activity that is associated with MS. A team at Johns Hopkins University undertook this preliminary step to determine whether a larger-scale clinical trial was warranted.

Investigators randomly assigned 40 people with MS to receive either 800 IU of vitamin D, or 10,400 IU, daily for six months. Participants were maintained on standard disease modifying treatment throughout the course of the study. Blood tests were done at three and six months to determine whether the dose increased the levels of vitamin D in the blood, and immune system effects. Blood and urine were assessed for calcium levels, since an excess of calcium can be a side effect of high-dose vitamin D supplementation. The primary goals of this study were to determine safety and effects on immune activity markers.

The investigators reported a few adverse events that did not differ between the groups, and they were all minor. Vitamin D levels increased more in the high-dose group, to a level that has been suggested as the optimal target for people with MS. Immune cells known as Th17 cells – which have been suggested to be major players in the immune attack on the brain and spinal cord in MS – were reduced in the high-dose group, but not in the low-dose group. Investigators also found that the higher the levels of vitamin D in the blood, the greater the reduction of Th17 cells.

This team is now conducting a larger trial at several centers nationwide, in which they are recruiting 172 people with relapsing-remitting MS to compare the effectiveness of 600 IU of vitamin D supplementation versus 5000 IU vitamin D supplementation at reducing MS disease activity, when added to standard therapy with glatiramer acetate (Copaxone®, Teva Pharmaceutical Industries).

**WHY SOME PEOPLE WITH MS FALL DOWN**

A common effect of MS is difficulty walking due to a variety of factors including balance problems. Because of mobility challenges and other symptoms, people with MS may be at significant risk for falls and the potentially life-changing consequences of fall related injuries. This is particularly significant since people with MS are at greater risk than the general population for osteoporosis. Studies have shown that approximately half of middleaged and older individuals with MS experience at least one fall over a six-month period.

Nearly 100 clinicians, researchers, engineers and others from around the world gathered in Oregon in September for the 5th International Symposium on Gait and Balance in MS. This year’s meeting focused specifically on falls in people with MS – how often people with MS fall, why they fall, how to detect falls, and how to prevent them. Here are a few highlights:

- While assistive devices such as canes are intended to improve walking and prevent falls, studies show that use is associated with increased falls in people with MS. Reviewing the literature, the team found that using assistive devices increases the attentional demands of walking, so “multi-task” training may reduce falls. Also, some devices may increase energy demands more than others, increasing fatigue that may then increase the risk of falls. Using devices that require less energy expenditure could minimize fall risk.

- Although some people with MS had significant deficits in postural control compared with people without MS, they were equally able to improve, and this ability correlated with activity in certain areas of the brain. This study demonstrates that postural training may strengthen gait and balance and reduce falls in people with MS.

- Wireless sensors are useful for assessing gait and balance. Using these sensors, it was shown that patterns of foot and trunk acceleration during walking occurred differently in people with MS than in people without the disease. Exploring these differences further may yield important information on why people fall.
LIVING WITH MS
IS IT HARDER TO WORK WITH MS?
BY JULIE STACHOWIAK, PHD

Many people with multiple sclerosis find it difficult to continue working, even in the early years of the disease. Tasks that seemed challenging before MS can become seemingly insurmountable afterward. The fluctuation of daily symptoms and unknown levels of future disability make mapping out a strategic career path a challenge, to say the least. We simply do not know what the future holds around our ability to perform a job.

I am lucky enough to be able to work from home. I am able to work more when I feel good, less when I feel bad, and take a quick nap if needed. There are days when I can work a full day, but there are many days when I do not feel productive at all — when even looking at the computer screen feels like torture.

I know that as each year has gone on, the problems that I have had in trying to work efficiently seem to get worse. However, recent research indicates that some people who are newly diagnosed or have had an episode of a clinically isolated syndrome may already need to adjust their time at work.

Researchers in the Netherlands wanted to look at how MS-related cognitive dysfunction affected work in people who are recently diagnosed with MS. In the Cognition and Socio-Economics (COGNISEC) study, the researchers studied 45 people who had been diagnosed with MS or had a clinically isolated syndrome within the past two years and have been on disease-modifying therapy for less than six months or not at all.

WHAT THEY FOUND

- People with higher levels of fatigue and disability all decreased their working hours within 12 months following diagnosis.
- Lower long-term memory scores correlated with a lower number of hours and days spent working during the week.
- People who scored lower on “focused attention” and “speed of memory” were more likely to say they “wished to work less.”

Scores on tests assessing depression (Beck Depression Inventory) did not correlate at all with quantity of working hours.

While its findings need to be replicated in larger studies, so far this research shows that cognitive dysfunction can negatively impact the capacity to work, even in the very early stages of MS.

WORKING A BALANCE

What does this mean? Let’s face it, even jobs that we love can lose some of their luster when we have to negotiate symptoms that add to our physical disability. While it is tempting to keep pushing ourselves to do more and overcome some of these challenges, it is important to remind ourselves that we may have very real cognitive symptoms related to our MS that are impacting our abilities to work the same way we did in the past.

On the other hand, many people with MS continue working long after their diagnosis. Disease-modifying therapies, new technologies, better symptom management, legal employment protections and community resources can help you remain in the workforce — and education and preparation can be your most powerful tools for success.

Diagnosed with MS in 2003, Julie Stachowiak, PhD, is the author of The Multiple Sclerosis Manifesto and www.ms.about.com. Originally posted at blog.nationalMSsociety.org

TOOLS TO WORK

If you’re struggling to keep up at work, but aren’t ready to throw in the towel just yet, visit www.nationalMSsociety.org/employment or call an MS Navigator at 1-800-344-4867 to learn more about your options and get connected with employment resources in your area.

The Job Accommodation Network at www.askjan.org also offers information on a range of subjects for working people with disabilities.
PARTNERS IN MS CARE

MUL TIPLE SCLEROSIS CENTER AT LAHEY HOSPITAL & MEDICAL CENTER

Lahey Hospital & Medical Center

The Multiple Sclerosis Center at Lahey Clinic in Burlington, Massachusetts has been a Partner in MS Care, Center for Comprehensive care since 2010, and has a long history of collaborating with the National MS Society on patient education programs and professional training. Dr. Claudia Chaves, an MS-trained neurologist started the MS Center at Lahey in 2004, and has seen an increase in MS patients each year. Together with Dr. Maryann Camac they see approximately 900 MS patients from the greater Boston area. The Center staff also includes a nurse coordinator, a physiatrist, neuropsychologist and social worker, and patients have access to rehabilitation therapies, providing access a multidisciplinary team for all needs.

The center hosts its own monthly patient support group, hosts an annual education symposium each year, and participates in WalkMS. The center is pleased to provide comprehensive and coordinated MS care for its patients, and remains committed to providing this high quality care in the future. ■

16 Hayden Street, Lexington, MA
(781) 372-7194

The National Multiple Sclerosis Society’s Partners in MS Care program highlights individual providers and MS Centers who demonstrate a high degree of MS expertise, a close working relationship with the National MS Society and those MS centers that provide comprehensive, collaborative and coordinated care. All potential Partners in MS Care providers are screened by a local review team, and MS Centers are also screened by a national review team. For a listing of Partners in MS Care providers, call 1-800-344-4867 to find Partners in your area or visit www.msnewengland.org and type in “Partners in MS Care” in the search box.

The National MS Society is pleased to recognize the Multiple Sclerosis Center at Lahey Clinic in Lexington, Massachusetts and the Rhode Island Hospital Multiple Sclerosis Center in Providence, RI, as Partners in MS Care, Centers for Comprehensive MS Care.

RHODE ISLAND HOSPITAL MUL TIPLE SCLEROSIS CENTER

The RI Hospital MS Center is the largest provider of MS care and is the only Partner in MS Care, Center for Comprehensive MS Care in Rhode Island. The experienced staff provides the full continuum of services from diagnostic consultations to long-term multidisciplinary care, and access to the most clinical trials and therapies in the state. There is an on-site infusion center and patients have access to rehabilitation therapies and social work to address physical and psychosocial needs. The MS center also offers complementary Reiki therapy for its patients once/week. Dr. Syed Rizvi, the director of the MS center is an MS neurologist that has been with the MS center for over 15 years, and serves on the chapter’s Healthcare Advisory Committee. In 2011, Dr. Jonathan Cahill joined the MS Center team. Dr. Cahill completed his MS fellowship training at the University of Massachusetts MS Center, prior to joining the RI MS Center. Dr. Cahill is a chapter trustee and also an active member of the Healthcare Advisory Committee. Kim Perez, is a board certified physical therapist, registered nurse, and holds her certification as an MS Specialist. Kim coordinates patient care for the MS Center, insuring that needs are addressed. Together the MS Center provides high quality comprehensive care to over 1,000 MS patients from the state and neighboring areas. ■

2 Dudley St, Suite 530, Providence, RI
(401)-444-3032
FAMILY MATTERS

ENGAGING THE ENEMY

BY: EMMETT HUGHLETT

Dee and I were living in Munich, Germany. It was 1986 and we were married 7 years. We were having a great time. The weather that summer was finally warm and dry, welcome after seemingly endless rainy summers before. I was working as an engineer for a German company, and Dee and I spent our free time with friends we'd made as ex-patriots in Europe.

One morning, Dee awoke and kind of giggled her way through the morning because her right foot had “fallen asleep”. It spread. After several weeks in hospital, the symptoms subsided, and we returned home to Vermont, where I told Dee that the doctor in Germany had waited for our departure to tell me that she had MS.

We didn't know what to do, but Dee seemed fine, just a little tired in the afternoons. We learned about MS. It wasn’t good. This is before the advances in disease modifying drugs (DMD) and the scary literature of the 80’s ominously said “the disease will run its course”.

I wanted to save my wife from this. I wanted to fix it somehow. MS is a humbling experience for me. Here’s the woman I love, and I can't protect her from this thing. I watched as this steely resolve began to form in her. Her faith in God grew, her faith in the future, and in us. She has a source of optimism and determination I had not recognized. She took the wheel, and drove us down two parallel paths. One is to actively fight MS and the other is to live her life fearlessly.

Dee’s fight initially was to enter trials for the early DMDs such as Avonex (big needle!) and Tysabri. Now Dee is active at University of Vermont, as a “practice patient” in an exercise program that gives PT students hands-on experience with MS people. It seems to me that the most tangible benefit of “engaging the enemy” like this to banish the feeling of helplessness. Another is her collection of like-minded friends who are also toe-to-toe with MS. Pretty cool people. I notice that when they get together they laugh a lot… what’s up with that?

Dee is fearless. Some MS people keep their diagnosis to themselves. Not Dee. She’ll tell you as easily as she’ll tell you the time of day. Sometimes, early on, I wondered why she told people she has MS when she showed no visible symptoms. I guess she just wanted to get it out of the way to enable growth in her relationships. I realize, of course, that some people are forced to be in the “MS closet” for good reason. But that’s another discussion.

Now we’re in our 60’s, and after 30 years post-diagnosis we’re still us. MS is a part of our lives, no doubt, but so are our now-grown children and grandchildren, our church family, and our MS friends. We look forward to the next decades, and pray for the cure.

Emmett & Dee have been married for 37 years. Emmett is a contract electrical engineer and has volunteered for MSWorld and the Society for many years as a peer supporter, panelist and workshop facilitator.

EVERYDAY MATTERS SELF-HELP GROUP TOOLKIT - TWO-PART MEETING

- The first meeting is about laying the groundwork with a discussion of the findings and tenets of positive psychology — the why.
- The second meeting is a deeper dive into the principles themselves — the how — when group members to share how they are or will apply the principles to live their best life with MS.

Learn more: www.nationalmssociety.org/Resources-Support/Library-Education-Programs/Everyday-Matters
I was diagnosed with MS in November 2004 shortly after moving to Vermont from New Jersey. After being diagnosed I learned several important things: that I need to stay active and that I need to stay connected to existing friends, and make friends who have MS. I also learned quickly that there is always someone who is worse off than I am.

My friend and physical therapist told me that his mom had MS and she had stopped doing a lot of things. Her inactivity led to a point where she could no longer use her arm. He made me promise to continue going to PT or to be physically active. I have kept my promise.

I learned the importance of staying in touch with my friends and involving myself with people who have MS as they can truly understand what I mean by “I’m tired or I just have no energy today”. My first real connection with someone with MS was a colleague in New Hampshire. We were both happy to finally have someone to talk to who understood what the other was going through and the true meaning of “it is one of those MS days”. My other friends say they understand, but, they do not.

I soon started going to MS functions like the annual Education Day and dinner meetings with guest speakers. At these events, I met wonderful people that I am still friends with eight years later. I met staff at the National MS Society (NMSS) and started volunteering at the Burlington MS Bike and Walk. Three years ago I started volunteering at the Williston Vermont NMSS office as my way of saying thank you to the society and the staff, Adele and Shanna, for all they do. I think of both Adele and Shanna as friends and they are a very important part of my life.

In addition to physical therapy, in the last several years I have been going to the I.D.E.A.L. exercise program at University of Vermont. This is an individualized exercise program for people with special exercise needs which keeps me active and has been yet another way for me to connect and make new friends with MS. A group of us get together once a week after the I.D.E.A.L. class for coffee, tea or lunch and just to chat. We talk about our families, trips or anything going on in our lives, but, unless there is a specific question, MS is not something we usually discuss. When one of us is sick or hurt, we are there for each other to lend a hand, keep each other in the loop on our friend’s condition, or just to visit. We are friends in every sense of the word and I do not know what I would do without them!

Above all, I have learned the importance of staying positive. My friendly positive attitude can help lift someone who is having a harder time than me; I have learned that first hand.

Jody was diagnosed with MS in 2004 and lives in South Burlington VT. Jody finds positivity through friends and staying active.

MS FRIENDS AND PEER SUPPORT

The MSFriends® program connects you with volunteers living with MS. Connect today by calling the MSFriends helpline at 1-866-673-7436.

Through the Peer Connections program you can search for and connect with a peer support volunteer who has “been there” and can provide you with helpful tips, suggestions and emotional support for the challenges that MS throws at you. For more information: peerconnections@nmss.org.
MONEY MATTERS

AUTHORIZING CARE

For many people with multiple sclerosis, the need to obtain “prior authorization” might seem like yet another hoop to jump through before they can access medications or imaging tests such as MRIs that have been prescribed or recommended by their healthcare providers.

WHAT IT IS

Prior authorization, also called pre-authorization or pre-approval, requires that a prescription or procedure be approved by a person’s health insurance plan before it can be provided. In this process, the insurance company determines member eligibility, benefit coverage, medical necessity, location and appropriateness of services. Under current law, requiring prior authorization is entirely within insurers’ legal rights.

WHEN IT’S A BARRIER

While prior authorization is legal, it is not standardized between insurance companies. Each insurance company requires a different form to be utilized for each prior authorization request, which can feel like extra red tape to navigate. And many symptom management medications now also require prior authorization. An insurance company may require a prior authorization every six months, which can increase the burden on your healthcare provider — and make accessing prescriptions take longer.

If a prescription happens to be denied by a health insurance company, your physician may complete an appeal. (A toolkit for clinicians who want to appeal a health insurance decision may search for “Health Insurance Appeal Letters” at www.nationalMSsociety.org). However, appeals may take two weeks to four months, without guarantee of success.

WHAT TO DO

At top of mind is whether prior authorization requirements for MS disease-modifying or symptom management medications and imaging services remain reasonable and easily accessed. To that end, MS activists are working to support legislation that would ensure that all private insurers’ prior authorization forms are standardized and that there is reasonable timeline for responding to prior authorization requirements for routine care.

If you are facing challenges with your health insurance and accessing the care you want, an MS Navigator can help. Call 1-800-344-4867 to speak with an MS Navigator in person or visit www.MSconnection.org to ask questions via the “Ask an MS Navigator” discussion board.

MS AWARENESS WEEK

TOGETHER WE ARE STRONGER

MARCH 7-13, 2016

Make Your Connection Count
MSconnection.org

WAYS TO CONNECT:

- Visit MSnewengland.org
- Be an MS Activist. Sign up for Action Alert. nationalMSsociety.org/MSActivist
- Sign up today! walkMS.org, bikeMS.org, challengewalkMS.org, or muckfestMS.org
- Wear orange or an orange ribbon to raise MS awareness.
- Tweet @MS_newengland
- Hold a program or event in your community!
- Volunteer!
- Distribute bookmarks to local libraries and book stores. To request bookmarks, email communicationsgne@nmss.org
Nearly 100 people were evaluated with MS using the Timed Up and Go Test (measuring the time that a person takes to rise from a chair, walk 10 feet, turn around, walk back to the chair, and sit down). The results showed that people who walked and turned more slowly were at higher risk for falls, indicating that prevention strategies should seek to increase speed in those areas.

Falls in people with MS in wheelchairs was studied (most studies focus on people who are ambulatory) and found that more than half had fallen in the past six months. The results call for special attention to preventing falls in this segment of people affected by MS.

People with MS below age 50 who reported urinary incontinence with urgency were significantly more likely to experience recurrent falls in the following 3 months; further research may determine whether treating bladder problems can reduce falls.

Information was presented about the comprehensive falls prevention program, “Free from Falls.” This program significantly improved confidence, decreased falls, concern of falling, and activity curtailment, in a pilot study of 19 sites nationwide. Nearly 70% of more than 100 participants are now engaged in a regular exercise program and nearly 40% are using mobility devices more effectively.

This meeting highlighted an urgent area of MS rehabilitation research – finding solutions to prevent potentially disabling falls. The International MS Falls Prevention Research Network has been created, which includes MS rehabilitation researchers from the U.S., Ireland, Italy, and the United Kingdom. The goal of this group is to work together to maximize falls prevention research efforts, and they have already begun to publish recommendations on how to advance research and treatment programs.

The National MS Society, Greater New England Chapter, is committed to helping people with MS in Maine, Massachusetts, Rhode Island, New Hampshire, and Vermont maintain their independence and quality of life through our Financial Assistance program.
Share your story to educate lawmakers

Do you live in Maine, Rhode Island, or Vermont and have encountered or expect to encounter difficulty affording to modify your dwelling to be safe and more accessible? Have you made modifications that are a financial burden or could you only afford partial modifications? Did you need to relocate to a more accessible place, but your preference would have been to remain in place? If so please share your story with us or learn how to lend your voice to advance legislation. 1-800-344-4867 option 2 or:

- Maine: jody.vandussen@nmss.org
- Vermont: shanna.mccabe@nmss.org
- Rhode Island: meredith.sheehan@nmss.org

ADVOCACY

SPOTLIGHT ON STATE HOME MODIFICATIONS TAX CREDIT LEGISLATION

The National MS Society is committed to assisting individuals with MS and their families to remain more safely at home. A shortage of affordable, accessible options combined with a significant percentage of older housing stock pose barriers for many. Legislation initiated by the chapter is in process to create a state tax credit for the home owner, to offset the cost of home modifications. We are grateful to the bill sponsors and support various disability and housing organizations, senior advocacy groups to help advance the bills to be enacted into in each state.

MAINE

L.D. 365 allows a person with a disability with low to moderate income to claim a credit up to a maximum of $ 9,000 on their state income tax. The bill awaits funding by the Appropriations Committee.

RHODE ISLAND

Legislation establishing a tax credit for accessible home modifications is being re-filed during February for the new session. Many thanks to Representative Robert E. Craven Sr. (District 32) and Senator Donna M. Nesselbush (District 15) for sponsoring the legislation.

VERMONT

HB238/ S. 176 would create an income tax credit up to a maximum of $ 9,000 for making one’s accessible home modifications.

MASSACHUSETTS

Priority Issues updates

State funding for Home LINKS. The annual appropriation was granted in the amount of $75,000 to support the chapters information and care management program thanks to MS activists

SB 1323 An act relative to the Massachusetts Architectural Access Board to better align with the ADA. The bill has been voted favorably out of committee.

HB800 An act promoting continuity of care for multiple sclerosis treatment to ensure patients can remain on their disease modifying treatments. The bill has been sent for a detailed fiscal analysis.

HB 1021 An act relative to accessible medical equipment. Status unchanged

Governors Executive Order 560 on employment. Report with recommendations pending.
NEW HAMPSHIRE

The government relations committee is still determining its priorities for the new session in January which will include strengthening accessible parking laws extending the sunset for Medicaid expansion and continuing to advocate for expanded health insurance network of providers. Do you have an idea to address a gap in care or support services or barrier to improving the quality of life for individuals with MS? Contact Michelle.Dickson@nmss.org.

ACTIVISTS MAKE A DIFFERENCE

WANTED: STATE GOVERNMENT RELATIONS COMMITTEES

The chapter is seeking committed individuals to join our monthly meetings in person or by teleconference to help determine our priority issues and activities. Are you a person with MS or have a connection to the disease? Do you have professional expertise in the area of law, medicine, insurance, disability, fundraising, policy, or community organizing? Are you willing to speak before government officials, at public hearings or with the media? Are you committed to working as a team and working on projects? If yes, please contact virginia.morse@nmss.org or 1-800-344-4867 option 2.

WANTED: MS CONGRESSIONAL DISTRICT ACTIVIST LEADERS

Have you met with your elected official and shared how MS affects you? Are you interested in growing this relationship to keep people with MS front of mind as he or she considers legislation? As a volunteer District Activist Leader, you will build and foster critical relationships with the elected officials in your legislative district. You will serve as a liaison between these officials and the Society, helping to develop a reliable grassroots movement across the state and the country. Complete the application online at: www.nationalmssociety.org/Chapters/NCT/Volunteer/Volunteer-Opportunities/District-Activist-Leader

MS STATE HOUSE DAYS

Join chapter staff and activist leaders in increasing awareness of MS and the needs of individuals affected by MS by visiting state lawmakers this spring. Learn more at www.MSnewengland.org. Can’t attend in person? Contact us to take action and join our efforts virtually!

- **Maine**  April 14, Hall of Flags Maine State House, Augusta 8 a.m. - noon  jody.vandussen@nmss.org
- **Massachusetts**  May 18, Great Hall MA State House, Boston 9 a.m. - 1 p.m. virginia.morse@nmss.org
- **New Hampshire**  March 30, Cafeteria NH State House, Concord 11:30 a.m. - 1 p.m. michelle.dickson@nmss.org
- **Rhode Island**  March 9, House and Senate chambers, RI State House 4 - 6 p.m. meredith.sheehan@nmss.org
- **Vermont**  March 10, Card room VT State House, Montpelier 8 a.m. - 2 p.m. shanna.mccabe@nmss.org

ELECTION CORNER

WHO REPRESENTS ME?

Not sure who your current elected officials are? If you have not made connections yet to your elected officials, please locate their information and introduce yourself. They work for you!

Massachusetts:  [www.wheredoivotema.com/bal/myelectioninfo.aspx](http://www.wheredoivotema.com/bal/myelectioninfo.aspx)
New Hampshire:  [www.gencourt.state.nh.us/house/members/wml.aspx](http://www.gencourt.state.nh.us/house/members/wml.aspx)
Rhode Island:  [sos.ri.gov/elections](http://sos.ri.gov/elections)
Vermont:  [vtelectionresults.com](http://vtelectionresults.com)
ADVOCACY
THE FOREFRONT OF CHANGE

Since her daughter Alison was diagnosed with multiple sclerosis in 1998, Pat Thomas has kept herself, as she describes it, at “the forefront of change.”

She advocates for Alison and other people who live with MS, telling their family’s story to legislators. “Advocacy gave me something really meaningful to do about MS,” says Pat, who lives with her husband Leon in Columbia, Maryland. Each year, the family goes to their state capital of Annapolis and sometimes also to Capitol Hill as part of the Society’s annual Public Policy Conference, to raise crucial awareness. “A lot of [legislators] really didn’t know that much about MS. We changed that,” she says.

After she stopped working three years ago, Alison now joins her parents on their visits to legislators, making it a family activity. “She’s been able to come and see what her parents were doing all these years,” says Pat. “It has been eye-opening for her.” But the impact is mutual. When Alison shares what it’s like to live with MS every day, Pat says the legislators also have their eyes opened. “To put a face to their policy is so important for them,” she says.

In 2013, Pat reached out to her sorority, Delta Sigma Theta Sorority Inc., to create a partnership with the National MS Society. The sorority, which is committed to public service with a primary focus on the black community, has more than 200,000 members nationwide. In 2015, the sorority deepened their commitment, announcing the partnership as a strategic priority. “The real meat of it is to get out the information that [African Americans] have MS,” says Pat. “This is our disease too.” To that end, the sorority is reaching out about MS-related resources and programs, and recruiting volunteers for Society events. (To locate Delta chapters in your area, visit www.deltasigmatheta.org).

“Leon and I want to see a cure before we leave this earth,” says Pat. “I hope we do.”

Visit www.nationalMSSociety.org/MSactivist to get involved in MS activism.

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MS ACTION ALERT

- Join the MS Action Alert Network, the center for advocacy at the National Multiple Sclerosis Society.
- Together, we represent the interests of people with MS as important policy decisions are made in both the public and private sectors.
- The MS Action Alert Network works on important issues at the federal, state, and local levels.
- Your voice matters. One link will register you to receive federal and state e-alerts to take action and contact your elected officials on key issues impacting people with MS. Recruit a friend!
- Or visit: www.nationalmssociety.org/Get-Involved/Advocate-for-Change/Take-Action
- For more information or to join the MS Action Alert network, email: GNEadvocacy@nmss.org
TOGETHER WE’RE STRONGER. VOLUNTEER!

Want to help the cause but don’t know how?

Come and volunteer at one of our Spring events!
We need volunteers to help run every one of our events. We could not succeed without your help!
Register today to take part in a dynamic team of individuals and to help us stand up to the fight against MS.

Volunteering is a great way connect with the MS community, be part of a team, make new friends, and try out new experiences. Be a part of something fun and meaningful!

SIGN UP TO VOLUNTEER TODAY!
Walk MS: www.walkms.org
Bike MS: www.bikems.org
Other volunteer opportunities: www.MSnewengland.org

We’re looking for individuals at our events to:
- Help with registration
- Distribute T-shirts
- Setup and Breakdown
- Cheer-on walkers
- Staff the mission table
- Photograph the walkers and volunteers
- Medical professionals
- Drivers
- and more!
There are countless opportunities available.

Have questions? Need help registering for an event?
Please contact Sarah Chuckran, Volunteer Manager, sarah.chuckran@nmss.org or 781-693-5156.
THE MS CAPED CRUSADER

To look at him, you’d never know Patrick Garrett of Derry, N.H., has MS. He’s strong, fit, and takes to endurance sports like a duck to water, or perhaps like a bat to a cave. His nickname is Batman.

“I saw the Michael Keaton movie in the 80s like a bagillion times,” said Garrett.

He has a Batman license plate for his car and one for his motorcycle. He even has a Batman tattoo.

“I have done the Climb three years now. The first year I wore my Batman mask, a cape, and an extra 25 pounds,” said Garrett, 50, who was diagnosed with MS about 11 years ago.

By “Climb,” he means “MS Climb to the Top,” presented by Biogen and hosted by Boston Properties, a chip-timed race up 61 flights of the 200 Clarendon Tower in Boston. On March 5, nearly 700 people will join Garrett for the annual fundraising event. It’s a chance for Garrett to show people one of the many faces of MS.

“I want people to know that I have it [MS] and I want their help to raise awareness and find a cure. I want people to know that just because they can’t see the effects of it on some people that doesn’t mean they aren’t there.”

And just because someone isn’t wearing a mask, doesn’t mean he isn’t a super hero underneath.

He also participates in Bike MS fundraising rides wearing a special “I Ride With MS” jersey as part of a campaign sponsored by Sanofi Genzyme. The jersey is meant to engage others riders who might not have a personal connection to someone with MS.

For more information about MS Climb to the Top, to sign up to race or to volunteer, visit www.climbMSgne.org.

MARCH 11 • NOON - 2:00 P.M. BURLINGTON, VERMONT

Take advantage of this unique opportunity to meet best-selling authors.

For more information: MSnewengland.org
802-871-5231

MileStones Gala 2016
Honoring DR. PETER CALABRESI
Recipient of the MILESTONES IN RESEARCH AWARD
MAY 4 SHERATON BOSTON BOSTON, MASSACHUSETTS

For tickets, contact Staci.Colby@nmss.org
2016 EVENTS
WALK WITH US TO CREATE A WORLD FREE OF MS

REGISTER TODAY!  walkMS.org or 1-800-344-4867

Every step. Every person. Every second spent and dollar raised. They all add up to an experience unlike any other: Walk MS. This is our time to unite and stand strong. Register now; together we will change lives.

**New Hampshire**

- **April 16**
  - Portsmouth

- **April 17**
  - Manchester

- **May 1**
  - North Conway

- **May 7**
  - Nashua

- **September 17**
  - Laconia

- **September 24**
  - Keene

- **September 25**
  - Journey of Hope (Concord)

**Vermont**

- **April 2**
  - Burlington

- **May 14**
  - Montpelier
  - Rutland
  - Upper Valley

- **September 24**
  - St. Johnsbury

**Rhode Island**

- **April 17**
  - Providence
  - Narragansett

- **May 1**
  - Bristol

**Maine**

- **April 9**
  - Brunswick
  - Camden

- **April 10**
  - Augusta

- **April 23**
  - Portland

- **April 30**
  - Brewer
  - Lewiston

- **September 10**
  - Caribou

- **September 25**
  - York

**Massachusetts**

- **April 2**
  - Easton
  - Newburyport

- **April 3**
  - Boston
  - Concord
  - Dartmouth
  - Plymouth

- **April 9**
  - Marblehead
  - Worcester

- **April 30**
  - Cohasset

- **May 1**
  - Hyannis

- **May 7**
  - Springfield
  - Journey of Hope (Natick)

- **May 14**
  - Berkshires

- **May 15**
  - Northampton

- **June 18**
  - Wakefield

- **September 17**
  - Sturbridge

- **September 25**
  - Falmouth

**Connecticut**

- **September 17**
  - Ridgefield

**New York**

- **September 17**
  - Baldwinsville

**Pennsylvania**

- **September 17**
  - Pittsburgh

- **September 25**
  - Yorktown

- **September 25**
  - State College

- **September 25**
  - Harrisburg

- **September 25**
  - Scranton

- **September 25**
  - Allentown

- **September 25**
  - Erie

- **September 25**
  - Philadelphia

- **September 25**
  - Scranton

- **September 25**
  - Harrisburg

- **September 25**
  - Allentown

- **September 25**
  - Erie

- **September 25**
  - Philadelphia
2016 EVENTS

CLIMB TO THE TOP - BOSTON
MARCH 5
REGISTER AT CLIMBMSGNE.ORG

200 CLARENDON TOWER
Race for time, climb for pride, celebrate your victory.
Open to elite climbers and casual striders.
Chip-timed. Fundraising prizes.

MS PLANE PULL
JUNE 11
REGISTER AT MSNEWENGLAND.ORG
PORTLAND JETPORT, PORTLAND, MAINE

BIKE MS
REGISTER AT BIKEMSGNE.ORG

RIDE THE VINEYARD
SATURDAY, APRIL 30
Martha's Vineyard High School, Vineyard Haven, MA
- 15, 30, and 60 mile scenic routes featuring quaint charm and beautiful ocean views

RIDE THE RHODE
SATURDAY-SUNDAY, JUNE 18-19
University of Rhode Island, Kingston, RI
- 35, 75 and 100 mile route options on Saturday, 75 miles on Sunday
- Enjoy the beautiful coast and winding country roads throughout Rhode Island

CAPE COD GETAWAY
SATURDAY-SUNDAY, JUNE 25-26
UMass Boston to Provincetown, MA
- 75 and 100 mile route options on Saturday, 75 miles on Sunday
- Largest MS Ride in New England with more than 2,000 riders

MINUTEMAN RIDE
SATURDAY, JULY 16
Concord District Court, Concord, MA
- 25 and 60 mile route options through Metro-West towns

GREEN MOUNTAIN GETAWAY
SATURDAY, AUGUST 6
Community Drive Technology Park, South Burlington, VT
- Routes include 25, 60, and 100 mile options

GREAT MAINE GETAWAY
SATURDAY-SUNDAY, AUGUST 13-14
University of New England, Biddeford, Maine
- Saturday routes include 25, 50, 75, and 100 mile options
- Sunday choose between 25, 50, and 75 mile routes

NH SEACOAST ESCAPE
SATURDAY, AUGUST 27
Stratham Hill Park, Stratham, NH
- Route options include 25 and 60 miles

Be a Hero
Name the National MS Society in your estate plans and move future generations closer to a world free of MS.
www.beaMShero.org
Once in a while, a challenge calls that you simply must answer. Challenge Walk MS is the perfect way to embrace a personal challenge of spirit and strength, while making an important difference in the lives of people living with MS.

**REGISTER TODAY & GET A HEAD START ON FUNDRAISING**
As soon as you register, you’ll have access to our online fundraising tools that make fundraising easier and more convenient than ever! A minimum fundraising goal of $1,500 is required, but we’ll be with you every step of the way.

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*MuckFest® MS Boston* is the **FUN mud & obstacle 5K**. No special training required!
We’re also on a mission to end multiple sclerosis: **100% of your fundraising dollars benefit the National MS Society**. Have a blast and make a difference!

**MAY 14, 2016 | MAY 15, 2016**
Willard Athletic Complex, Antietam St. & Sherman Ave. Devens, MA 01434

**REGISTER AT MUCKFESTMS.COM**
March 5..........................Climb to the Top: Boston
March 7-13.............................MS Awareness Week
March 8................How Treatment Decisions are Made
March 8..............Managing Your Complex MS Symptoms
March 11............Authors’ Luncheon, Burlington, VT
March 15...........The Complete Guide to Social Security Disability
March 29 ..............Home Based Employment: What Employers Want
April 2 ..............Walk MS: Burlington, VT; Easton & Newburyport, MA
April 3 ..................Walk MS: Boston, Concord, Dartmouth, & Plymouth, MA
April 9 ..............Walk MS: Brunswick, Camden, & Kennebunkport, ME; Marblehead & Worcester, MA
April 10 ..............Walk MS: Augusta, ME
April 12 ......................Research Updates
April 16 ..............Walk MS: Portsmouth, NH
April 17 ..................Walk MS: Providence & Narragansett, RI, Manchester, NH;
April 18 .................Marathon Strides Against MS
April 23 ..................Walk MS: Portland, ME
April 30 ...... Can Do MS JUMPSTART, Danvers MA
April 30 .............. Walk MS: Lewiston & Brewer, ME; Cohasset, MA
April 30 ..................Bike MS: Ride the Vineyard, MA
May 1 ..............Walk MS: Briston, RI; Hyannis, MA; North Conway, NH
May 7 ......... Living Well with MS, Warwick, RI
May 7 ..............Living Well with MS, Stowe, VT
May 7 ............. Walk MS: Nashua, NH; Springfield, MA; & Mass. Journey of Hope
May 14 ...........Walk MS:Berkshires, MA; Montpelier, Rutland, & Upper Valley, VT
May 14 & 15 .........................MuckFest MS
May 15 ..............Walk MS: Northampton, MA
May 15 ........ Run MS: 5K Rhode Race, Bristol, RI
May 19 ..............Traveling with MS
May 21 ..............Living Well with MS, Concord, NH
June 5 ..............Living Well with MS, Portland, ME