New Hampshire’s Maggie Hassan Honored as the National MS Society’s Governor of the Year

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LETTER FROM THE PRESIDENT

MS DOESN’T STOP ME…

‘Independence’ is the theme for World MS Day 2016, May 25. Before, during, and after World MS Day, we are asking you to tell the world how you maintain your independence by completing the simple phrase, “MS doesn’t stop me...” The idea is by sharing how you maintain your independence, you challenge the preconceptions of others about what people with MS can do and inspire others with MS.

Use the “MS doesn’t stop me...” campaign to shout about all of the things that people with MS are doing every day. Your message to the world will support advocacy around employment, independence, access, and all things important for people with MS.

We all know how frightening it is to hear the words, “you have MS.” And, while the disease can change your life dramatically, it doesn’t mean you have to drop out of life. Sometimes it means finding a new way to do what you’ve always loved doing. Sometimes it means finding a new career path, which is challenging but can be rewarding, too.

People with MS can seek accommodations from their employer in terms of their physical workspace and in terms of their actual job, in order to continue working. Help can also come from many other sources, not the least of which would be your family and friends and other members of your community. The medical community and, naturally, the National MS Society are always available to help people with MS identify resources and opportunities and treatment options that fit the lifestyle you need to keep being you; to keep being independent.

Home LINKS is a services program that we offer in Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont specifically designed to help people maintain independence at whatever level their ‘new normal’ is. That’s why we called it Home LINKS, “Live Independently Navigating Key Services.”

You can share your message with the world by completing the phrase, “MS doesn’t stop me...,” and posting it with photos and your story on social media. Don’t forget to use the hash tag #strongerthanMS. Posts with the #strongerthanMS hash tag will be featured on the World MS Day website www.worldmsday.org, where they’ll map all of the events that are happening around the globe for World MS Day.

Lori Espino
President
A day to celebrate global solidarity and hope for the future, World MS Day is officially marked on the last Wednesday of May every year, though events and campaigns take place throughout the month of May.

It brings the global MS community together to share stories, raise awareness, and campaign with and for everyone affected by multiple sclerosis.

In 2009, the Multiple Sclerosis International Federation (MSIF) and its members initiated the first World MS Day. Together we have reached hundreds of thousands of people around the world, with a campaign focusing on a different theme each year.

This year, the theme for World MS Day is 'Independence'. It will explore how people with MS can be independent, acknowledging that independence can mean different things to different people.

Check out our website at: MSnewengland.org (click on calendar, then click on World MS Day) to download and print the materials to the right. Let us know how MS doesn’t stop you. Put a photo of you and your statement on Facebook or Twitter.
RESEARCH

UNDERSTANDING WELLNESS

BY NICHOLAS LAROCCA, PHD

A big part of my excitement at the annual meeting of the European Committee for Treatment and Research in Multiple Sclerosis, or ECTRIMS, in October 2015 was seeing so many researchers from around the world working hard to find the best solutions for people affected by MS. I found this to be especially true in the growing area of lifestyle and wellness research—exploring diet, exercise, physical activity, and other approaches—all of which people can manage themselves to improve how they feel and possibly how their MS evolves.

NUTRITION AND DIET

The idea of intermittent fasting as a way to fight inflammation is being explored by MS researchers. But anyone who’s tried it knows how challenging it can be to stick with it. That’s why I was intrigued by a small trial involving 48 people with relapsing-remitting MS done by Dr. Markus Bock and colleagues (Universitätsmedizin Berlin).

The investigators studied various diets that may affect “ketone bodies”—molecules in the liver that may protect the brain and spinal cord. Compared to participants who followed their usual diets, participants who followed either a “ketogenic diet” (a high-fat, adequate-protein, low-carbohydrate diet) or a prolonged-fasting diet (an initial seven-day fast followed by a Mediterranean diet) reported improved quality of life. These results are encouraging; hopefully we will see results in larger numbers of participants in the future.

Another interesting study reported by Dr. Aiden Haghiakia (Ruhr-University Bochum, Germany) and colleagues had previously found in mice that gut bacteria giving off short-chain (versus medium- or long-chain) fatty acids could protect against the development of MS-like attacks. To translate these results to human beings, the team administered daily capsules of “propionate,” which contains short-chain fatty acids, to 18 healthy volunteers. They found no side effects, but more importantly, cells that activate immune attacks in MS were suppressed, while other cells, called Tregs, that turn off attacks, increased by 25-30 percent. This early report shows the potential of a nutritional supplement that could be tested for its benefits in people with MS.

EXERCISE AND INNOVATIVE TECHNOLOGY

We are seeing more studies on the benefits of exercise and physical activity in people with MS. As research advances, we’ll share it so people with MS will have the information they need to choose what’s right for them.

Researchers are looking at how exercise may lead to changes in brain function. Dr. Francesca Tona (Sapienza University, Rome) and colleagues looked first at whether 26 people with MS with balance problems would benefit from home-based training using video games and the Wii balance board five times a week for 30-minute sessions over 12 weeks. Many experienced improvements in their balance after the program.

Next, the researchers explored how “functional connectivity”—the connections between different areas of the brain measured using neuroimaging—changed after the 12 weeks. They found increased connectivity in several areas of the brain including the cerebellum, which controls bodily movement. This is particularly exciting because participants didn’t have to go to a gym or healthcare facility; instead, they could access the technology and complete the sessions at home. This study also provided evidence for “neuroplasticity,” the idea that the brain is capable of changing in ways that may improve people’s day-to-day function.

Meanwhile, a team from Denmark and Belgium led by Dr. Ulrik Halgas (Aarhus University) noted that people with MS tend to lose muscle mass and that they have fewer “myogenic stem cells”—cells in the body that help rebuild muscle. The team reported that after a 12-week, high-intensity training program (involving exercise machines for strengthening upper and lower body muscles), the number of myogenic stem cells more than doubled in people...
with MS. This kind of exercise program may not be for everyone, but it’s encouraging to know that such regrowth is possible.

**IMPROVING COGNITIVE FUNCTION**

Finally, I am encouraged to see more studies that show how cognitive rehabilitation can improve learning and memory in people with MS. After all, cognition is an important part of what makes us feel well.

A team from Italy and the United Kingdom, led by Dr. Micaela Mitolo, tested an intensive program designed to target multiple areas of the brain and thus multiple cognitive problems. Among the 15 people who underwent one-hour rehab sessions for five days a week for four weeks, cognitive function improved, even in areas not specifically involved in the training. Brain imaging also showed that compared to the participants who did not undergo the program, those who did experienced increased functional connectivity.

Nicholas LaRocca, PhD, is V.P. of Health Care Delivery and Policy Research at the National MS Society.

**A RARE GLIMPSE**

A new study provides a rare glimpse into the very early stages of multiple sclerosis, even before symptoms begin.

What’s known as clinically isolated syndrome, or CIS, describes a first episode of neurologic symptoms that lasts at least 24 hours and is caused by inflammation and demyelination on one or more sites on the brain and spinal cord. Typically if an MRI scan reveals lesions similar to those seen in MS, the likelihood is higher that the person experiencing CIS will go on to develop MS; conversely, if CIS is not accompanied by MRI-detected lesions, he or she has a lower likelihood of developing MS.

**A “SILENT” SYNDROME**

Some people have been found to have clinically “silent” lesions, meaning that while they aren’t experiencing symptoms, doctors have discovered areas of inflamed or damaged tissue during the course of an MRI scan that the person had for unrelated reasons. Researchers have been increasingly focusing on this phenomenon, called “radiologically isolated syndrome,” or RIS, which—like CIS—may or may not develop into definite MS.

The study, which was published in *Annals of Neurology* (December 2015), examined MRI scans of 453 people with RIS. Of this group, 128 (28 percent) went on to develop a first neurological event consistent with CIS or relapsing MS while approximately 12 percent went on to develop primary progressive MS, which mirrors the frequency of developing this form of the disease as seen in other studies.

Those who developed primary progressive MS were more likely to be men, were significantly older, and were more likely to have MS-like lesions in the spinal cord compared to those who went on to develop CIS or relapsing-remitting MS. This research may help eventually point the way to finding ways to identify and track primary progressive MS earlier. This in turn may help to improve access to care for those living with primary progressive MS.

Learn more at [nationalMSsociety.org/research](http://nationalMSsociety.org/research). Stay up to day by signing up for MS eNews at [nationalMSsociety.org/signup](http://nationalMSsociety.org/signup).

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Clinical trials of specific disease-modifying therapies (DMTs) have led to approvals for their use to treat CIS. However, there is debate as to whether people with RIS would benefit from early treatment with DMTs.
PROGRAMS AND SERVICES
Contact us at www.MSnewengland.org or 800.344.4867 to register or for information about any of our programs.

BECAUSE MS AFFECTS MORE THAN JUST THE INDIVIDUAL DIAGNOSED, OUR PROGRAMS WELCOME FRIENDS AND FAMILY MEMBERS UNACCOMPANIED BY A PERSON WITH MS.

SIGN UP FOR SOCIETY EMAILS
www.nationalMSsociety.org/signup

MS LEARN ONLINE
Free webcasts, podcasts, and online conferences at www.nationalMSsociety.org

KEEP S’MYELIN
The Keep S’myelin Activity Book is an engaging, informative, and reassuring interactive publication to help children and their parents talk and learn about MS together. It is filled with stories, interviews, games, and activities on a variety of topics related to MS. Special separate section for parents. To request a copy, call 1-800-344-4867, or download it at: www.nationalmsociety.org/NationalMSSociety/media/MSNNationalFiles/Newsletters/Keep-S-myelin-Activity-Book-Kids.pdf.

MS NEXT STEP
Take your “next step” toward getting the information and support you want and need after diagnosis. This program includes a booklet and DVD (closed captioning in English and Spanish.) The materials cover what MS is, possible causes, how it is treated, and some of the life challenges a person with MS may face early on, such as disclosure. Learn more about what the Society offers.

MS COMPUTER OUTREACH PROGRAM
Stay connected! COP provides simple computers to individuals isolated in their own homes or living in long-term care facilities without access to a computer.

SOCIAL SECURITY DISABILITY BENEFITS: WHAT YOU NEED TO KNOW
Are you currently unable to work? Are you wondering if you should apply for Social Security Disability Income? Do you qualify for benefits? What is the process? Dayce Moore from the University of Massachusetts Medical School’s Disability Transition Strategies (DTS) team will discuss options and strategies and answer questions you may have about accessing benefits. Hosted by the Southbridge Self Help group.

June 7 / 6:30-8:00 p.m.
Tri-Community YMCA, 43 Everett St., Southbridge
Please register in advance. Space is Limited.

EMPLOYMENT AND BENEFIT RESOURCES
SSDI: Do you have questions about SSDI? Check in with someone who is in the know at 781-693-5155 to schedule a phone consultation.
ASK THE EMPLOYMENT SPECIALIST:
Get answers to: workplace disclosure, social security benefits, reasonable accommodations, thinking about returning to work, and more!
Send your employment issue questions to:
EmploymentQuestions@nmss.org
An Employment Specialist will respond within 48 hours.

FINANCIAL ASSISTANCE
The National MS Society provides financial assistance to help alleviate some of the financial burden for people with MS. Support may be available for medical equipment, homemaker services, or other categories. Any person diagnosed with MS living in our chapter states may apply for financial assistance.
- Call 800-344-4867 for a financial assistance application.
- Submit completed application and documentation.
- Applications must be approved before the purchase of goods and/or services. The chapter does not provide reimbursement for items previously purchased.
- A Chapter staff member will contact you regarding your application for financial assistance.
GET FIT! HAVE FUN!

Studies show that regular exercise can increase muscle strength, reduce fatigue and depression, and improve bladder and bowel control. Exercise is also an important element in managing MS.

PHYSICAL WELLNESS REIMBURSEMENT

If an instructor is part of our network of trained providers, you are eligible for reimbursement to help pay for your classes or membership! Check our website for providers and reimbursement. Don’t see your instructor on the list? Have your instructor visit ntl.MS/fitwellpros to take a FREE online training course, receive CEU credits, and become part of our network!

WHEELCHAIR HEALTH IN MOTION (WHIM)

WHIM is a free peer-driven program. It provides the tools for increasing quality of life and promoting wellness in individuals living with a physical disability through innovative chair exercises and peer support. For more information, contact WHIM at 603-938-2562 or WHIM4wellness@gmail.com.

MS ENCOMPASS - YWCA CENTRAL MASS.

The Chapter collaborates with the YWCA of CentralMass., Worcester to make available their accessible pool, cardio equipment, accessible weight training equipment, and aerobics classes. Childcare is available at the facility for a nominal fee. Registration is required through the National MS Society. Fee: $10 per month. To register, contact Amber.Stalker@nmss.org or 1-800-344-4867.

MS WELLNESS PROGRAM - HOCKOMOCK YMCA

Developed specifically for people with MS, the program focuses on regular physical activity and improved nutrition. Program available at these three branches: Foxborough, North Attleboro, and Franklin, MA.

For information: Contact the PHL (Prescription for a Healthy Lifestyle) Coordinator, 508-772-1310 or email phl@hockymca.org

B.FIT! - THE BOSTON HOME, DORCHESTER

An innovative wellness program for adults with MS and other advanced neurological diseases. Socialize and access outstanding care and assistive technology. A sliding fee scale is available. Contact: Glory Wideman-Hughes, 617-825-3905 x300 or gwideman@thebostonhome.org.

INTRODUCTION TO MS FOR FITNESS AND WELLNESS PROFESSIONALS

FREE ONLINE COURSE

0.4 continuing education credits provided by the American Council on Exercise (ACE). Designed for fitness and wellness instructors, including aquatics instructors, yoga teachers, coaches, personal trainers, and others who want to learn more about MS. Encourage your instructor, gym, or local providers to join our network! Visit ntl.MS/fitwellpros for information about online wellness instructor trainings.

CONNECT WITH AN MS NAVIGATOR

GET YOUR QUESTIONS AND CONCERNS ANSWERED

Submit a request to generalmailbox@nmss.org. Include your name, mailing address, and phone number. Or call 1-800-344-4867 Monday - Friday, 9 a.m. to 5 p.m. Our MS Navigators are highly skilled professionals who can help you navigate the challenges of MS by providing:

- Up-to-date Information
- Practical Resources and Referrals
- Find information about MS
- Deal with a crisis
- Connect with others living with MS
- Find what you need to maintain independence
- Access comprehensive educational programs

PROGRAMS CONT. ON PAGE 09
MONEY MATTERS

NEW FINDINGS ON EMPLOYMENT & MS

New studies funded by the National MS Society surveyed people with multiple sclerosis to explore whether the Americans with Disabilities Act (ADA) has improved employment issues for people with MS. The results of these studies, published in Work (November 2015), may help provide data to influence public policy and offer practical ways to address employment concerns.

IDENTIFYING ISSUES

In one study, less than 40 percent of 1,924 people with MS who responded to a questionnaire were paid employees at the time, even though 98 percent had a history of working and 82 percent were working at the time of their diagnosis. The respondents said they were not satisfied with current employment policies and practices in these areas:

- disclosing disability status;
- discussing job accommodation needs with employers;
- requesting a review of accommodation needs without fear of retaliation;
- understanding ADA employment protections;
- exploring reassignment to other positions within the same company; and
- understanding the Affordable Care Act (ACA) and how it relates to employee benefits.

Researchers then sent a second questionnaire to the same group to determine relationships between quality of life and illness, and employment and psychosocial factors. Respondents indicated a higher quality of life with increased education levels, employment status, and job satisfaction.

FINDING SOLUTIONS

The researchers, led by Phillip Rumrill, Jr., PhD, (Kent State University) suggest that employers work with rehabilitation professionals to determine how accommodations can enable people with MS to stay in their current jobs and that support be provided when reassignment to a new position becomes necessary. The Society offers many employment-related resources, including a webinar, “Navigating Career Change: Working with MS is Possible!” at nationalMSsociety.org/telelearning. Or visit nationalMSsociety.org/employment for guides to disclosure decisions and accommodations in the workplace, a video series and toolkit on managing MS in the workplace, a video for employers on managing MS in the workplace, and more. For referrals or assistance with employment, benefits or health insurance concerns call an MS Navigator at 1-800-344-4867.

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

NEUROLOGIST

ERIC KLAWITER, MD, MSc

The Society is pleased to announce that Eric Klawiter, MD, MSc. is now a Partner in MS Care, Neurologist. Dr. Klawiter is a board certified neurologist and completed his neuroimmunology and multiple sclerosis fellowship at Washington University in St. Louis at the John Trotter Multiple Sclerosis Center. He started practicing at the Massachusetts General Hospital in 2010 and sees approximately 400 individuals living with MS and MS-related disorders each year. Dr. Klawiter understands the importance of comprehensive care and has developed his network of preferred rehabilitation therapists, mental health providers, and social workers. He utilizes the society’s services, referring his patients to the society for information, support, and Home Links, the chapter’s short-term care management program.

Dr. Klawiter is a National MS Society funded researcher whose interests include studying MRI to better understand, diagnose, and treat MS. He is a close collaborator with the Society, having spoken at the Chapter’s annual meeting in Vermont, and as a member of the Healthcare Advisory Committee, providing input and strategy to help people with MS access the medical care they need.

Appointment info: Massachusetts General Hospital, Boston, MA,  617-726-8639.

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.

TELECONFERENCE SERIES 2016

Telelearning provides information and guidance on current matters essential to living one’s best life with MS. Register online or call 1-800-344-4867.

www.nationalmssociety.org/Resources-Support/Library-Education-Programs/Telelearning-Program

MSCONNECTION.ORG

Share what you know at MSConnection.org, the Society’s online community. You can share information about the topics that are most important to you, connect with people, and have expert MS information and opinions right at your fingertips. Join today!

MANAGING BLADDER & BOWEL ISSUES IN MS - NEW HAMPSHIRE

Tuesday, June 21  5 - 6 p.m.

Dartmouth Hitchcock Medical Center, Lebanon

Speaker: Kelley Hamill Lemay, APRN, MSN,
Dartmouth Hitchcock Medical Center, Urology

Advance registration is required.  FREE

Attend the monthly meeting of the Upper Valley/Lebanon Self-Help Group following the program.
FAMILY MATTERS
BY PAM LITTELL

My story began in the summer of 1988. My daughter, Amy, newly graduated from Boston University; an athletic girl, competitive figure skater, on the BU Crew squad, and an honors student, came home complaining about some numbness in one hand which quickly spread to half of her body. The neurologist’s tests indicated possible MS. Eventually Amy got married and had a little girl. When the baby was 11 months old, Amy woke up one day with optic neuritis and then we knew for sure. My beautiful daughter had MS, and my life changed forever.

I grieved over her diagnosis for two months and became very depressed; I thought her life was over. One day, I made a call to the National Multiple Sclerosis Society. They helped me get back on my feet with the intellectual and emotional support I needed to become productive again. In 1996, I decided to try my hand at fundraising. Having no computer, I handwrote my Walk MS fundraising requests! My first letter campaign brought in exactly $180. I was so excited; it could have been a million dollars as far as I was concerned! That experience ignited a spark that has carried me though 19 years of fundraising and my personal fight against MS.

By 2003, after honing my talents for convincing people to get behind my cause, I finally achieved my goal - I became the top Walk Fundraiser in Maine. I expanded my fundraising ideas from everything to selling stuffed animals in stores, medical offices, Sam’s Clubs and Shaw’s supermarkets to running raffles twice a year- offering the opportunity to win a week’s stay at my beach house in Kennebunkport, ME. Whenever I needed help with my computer skills, ideas, materials, or other support, my friends at the National MS Society were there to help. I have been the Chapter’s Top Walk Fundraiser for 12 years now, and after raising $150,000 I was honored to receive the Norman Cohn Hope award, amid tears and a standing ovation from all my MS family. Last year I reached my fundraising goal of $250,000, a dream of dreams. It has been a tough journey and true labor of love.

As for Amy? Well, she quickly put herself through graduate school, got her Master’s degree, her Doctorate in Clinical Psychology, a private practice in Kennebunk, taught at the University of New England, and became a Chaplain. Amy also teaches water aerobics, yoga, and enjoys riding her three horses. In 2005, she adopted a baby girl from China, who is the light of her life. Amy has MS, but MS doesn’t have her, nor does it have me.

Pam Littell is a retired teacher and fundraiser for the National MS Society’s Greater New England Chapter. She resides in ME.

FROM LEFT: CHLOE LITTELL-SIMPSON (AMY’S DAUGHTER), AMY LITTELL, AND PAM LITTELL

IN TOUCH PHONE GROUPS
Professionally facilitated phone groups. Listen, learn and talk to others with MS from the comfort of your own home. For those who cannot attend a traditional support group. Two from which to choose:
Day: 2nd Monday/month, Time: 11 a.m. - Noon
Day: 2nd Tuesday/month, Time: Noon - 1:00 p.m.
Contact: Meredith.sheehan@nmss.org or 1-800-344-4867
I was diagnosed in 2003. Not a terrible surprise since I had been exhibiting symptoms for a while. In a way I was relieved so I could go on with life and reaffirm what was important. I learned that MS was going to affect my life, but I also learned there are ways to cope. I learned that attitude and spirit are keys to living life to the fullest and that I would have to remind myself of that from time to time. And it was reaffirmed for me that I have a loving wife, terrific kids, and family and friends who help me navigate through a sea of the unexpected.

Life did change. My mobility was severely impacted - first a cane, then a walker, and now a wheelchair. Shortly after my (earlier than planned) retirement, I received a call that an informational meeting was being held to see if there was interest in an MS support group. I went to the meeting and was impressed and surprised by the number attending and the enthusiasm of the leader from the National MS Society. Before I knew it, I was drafted as the new group facilitator. I had enough sense to say I would accept only if there was a co-facilitator. Luckily, two great people stepped forward.

The three of us met several times to plan our group, Keep S’myelin - Mid-Coast MS Awareness Group, which was born in the fall of 2006. Like others, we had our early bumps but settled into a comfortable routine. From the beginning, we emphasized that MS didn’t define who we were; we were individuals who just happened to have MS. Most importantly, we were committed to keeping our meetings upbeat and fun. This was not an attempt to minimize the devastation MS can cause, but to keep everything in perspective.

Well, we are in our tenth year! We are a strong and varied group and I look upon these people as my second family. They are caring and helpful. We have learned so much from each other; we share sadness, we laugh a lot and that feels good. I am happy that I’ve had a part in the creation of this group, but it really is the members who keep it thriving and moving forward.

Tom Bosica attended Saint Michael’s College in Colchester VT. He retired after 32 years as Vice President Human Resources for Pen Bay Healthcare, Rockport, ME.
Advocacy

MS Public Policy Conference: 25 Years of Impact!

In March, chapter staff and activists gathered with more than 350 other activists on Capitol Hill in Washington, D.C. to make our voices heard in support of key priority issues: Funding appropriation requests were made for the National Institutes of Health and Department of Defense’s Congressionally Directed Medical Research program (CDMRP) to support MS research and to request Congress hold a public hearing for consumers to provide testimony regarding the cost of MS medications. The conference celebrated the impact the many accomplishments activists have achieved. The chapter delegation visited 25 congressional members and were well received on the issues. Members of the MS Caucus include Senators Collins (ME), Markey (MA), Sanders (VT), Whitehouse (RI), and Representatives Capuano, (MA), Cicilline (RI), Kuster (NH), Lynch (MA), McGovern (MA), Neal (MA), Tsongas (MA), and Welch (VT).

Make your voice heard by joining the MS Activist Network and receive periodic updates and requests to take action on key federal and state issues. www.nationalmssociety.org/Get-Involved/Advocate-for-Change

Maine

Victory! LD 365 Home Modification Tax Credit Bill is Now Law!

In 2014, the chapter introduced legislation, known as LD365 to create a state home modification tax credit to assist Mainers with disabilities of any age to afford accessible home modifications to make their residence safer and easier to navigate. On April 29, 2016 the Maine legislature unanimously overrode Governor LePage’s veto of the bill by a vote of 182 to 0. The bill is now law and will go into effect 90 days after final adjournment of the 127th Legislature’s second session. The bill sets aside an annual appropriation of $1 million. Eligibility will be determined based on the cost of the modifications as well as the federal adjusted gross income of the taxpayer. The credit will be nonrefundable and could be carried forward for up to four years. The tax credit program requires time to set-up and funding to administer so it won’t be available for another year or two. We wish to thank bill sponsor Representative Arthur Verow, supporter Representative Steadman Seavey and the entire legislature for enacting this important legislation. Thanks also to the tireless efforts of MS activists and our partners from AARP, Alpha One Independent Living Center, and the National Association of Social Workers.
MASSACHUSETTS

Highest Priority Issues:

State funding for Home LINKS. Thanks to MS activists, the FY’17 annual appropriation was included in the House and is waiting for approval in the Senate to support the chapter’s case management program.

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.

HB 800 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 has not advanced out of committee.

Governors Executive Order 560 on employment was issued this Spring with recommendations that the Chapter is currently reviewing.

NEW HAMPSHIRE

HB 471 Modifies requirements for walking disability placards and parking for persons with disabilities. This bill also establishes an additional fine payable to the city or town for violations of parking restrictions.

HB 1696 which reauthorizes the NH Health Protection program scheduled to sunset this year was signed into law in April. The new law ensures continued health coverage for the 48,000 low-income citizens with no access to insurance coverage. Activists gathered in March for the annual MS State House day to increase awareness of MS and advocate for priority issues. Rep. Larry Philips addressed comments about MS on the House floor.

RHODE ISLAND

The chapter reintroduced home modification tax credit legislation, HB 7980 / SB 2623, to create an appropriation in the state budget of $500,000 for individuals to make their home more accessible due to disability or physical hardship.

SB 2499 would expand the state definition of off label prescription drug coverage to include drugs to treat chronic conditions, including MS.

The Capitol Dome was lit in orange as activists gathered at the Capitol in March during MS Awareness Week to meet lawmakers and be recognized on the floors of the House and Senate.

VERMONT

HB 238 / S 176 These companion bills would create an income tax credit up to a maximum of $ 9,000 for making modifications to make one’s residence more safe and accessible. Despite a strong coalition of support neither bill advanced out of committee. Activists vow to continue to advance the issue. Activists gathered in April for the annual MS Day at the State House, advocated for the bills. Rep. Bob Krebs, sponsor of bill HB 238, introduced a MS resolution read on the House floor during the event.

ACTIVISTS MAKE A DIFFERENCE

State Government Relations Committees

The chapter is seeking committed individuals to join our monthly meetings in person or by teleconference to help determine and advocate for our priority issues and activities. Are you a person with MS or have a connection to the disease? Or 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 opt. 2.
GOVERNOR OF THE YEAR

New Hampshire Governor Maggie Hassan has been named National Multiple Sclerosis Society’s 2015 Governor of the Year. Governor Hassan, as the mother of a child living with severe physical disabilities, is an ardent and long-time advocate for the full inclusion of people with disabilities in our workforce and communities. Her bold leadership shaped the bipartisan expansion of New Hampshire’s Medicaid program, which increased access to health coverage to as many as 50,000 hard-working people of the Granite State, including people who live with MS. In 2014, under her leadership, the New Hampshire Insurance Department began the process of reviewing current regulations and seeking public input to revise and improve network adequacy rules and transparency.

EXPANDING ACCESS TO HEALTH COVERAGE IS A KEY PART OF MY VISION FOR A NEW HAMPSHIRE WHERE ALL OF OUR CITIZENS ARE INCLUDED IN OUR SHARED SUCCESS AND PROSPERITY.

“Governor Hassan works tirelessly to ensure that the people of New Hampshire can live their best lives,” National MS Society President and CEO Cynthia Zagieboylo says. “Her work toward inclusion of people with disabilities in our workforce and communities is admirable and the Society is proud to name her Governor of the Year.”

“Expanding access to health coverage is a key part of my vision for a New Hampshire where all of our citizens are included in our shared success and prosperity,” says Governor Hassan. “I am proud to be able to support our citizens living with MS and other disabilities, and I am honored to be recognized as Governor of the Year by the MS Society.”

In 2013, Hassan proclaimed October Disability Employment Awareness month in New Hampshire. Each July, she officiates the New Hampshire Americans with Disabilities Act Award that recognizes the outstanding accomplishments and leadership within a business, organization or individual that supports independence, inclusive, accessible environments and services for individuals with disabilities, above and beyond normal requirements and business responsibilities.

Bestowing its highest honor for elected officials, the National MS Society presented Governor Hassan with the Governor of the Year award during its 25th annual Public Policy Conference in March of this year. The event brings close to 350 MS activists from across the country to D.C. to educate elected officials about the needs of people affected by MS.

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
New Hampshire: www.gencourt.state.nh.us/house/members/wml.aspx
Rhode Island: sos.ri.gov/elections
Vermont: vt.electionresults.com
VOLUNTEERS

COX CHARITIES COMMUNITY HERO

Peter Lamberton, of East Providence, a National Multiple Sclerosis Society volunteer, has been named a Cox Charities “community hero.” The National Multiple Sclerosis Society will receive a $3,000 Cox Charities grant to mark the recognition. The Cox Charities “community hero” program recognizes Cox employees who actively volunteer with a nonprofit organization in the community.

Lamberton, a Cox Media marketing manager, has been involved with the Society for more than 20 years, serving on the board of directors and acting as various committee chairs over that time. He has been heavily involved in an array of fundraising events and activities.

SIGN UP TO VOLUNTEER TODAY!

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

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

PROGRAMS CONT. FROM PAGE 09

SELF-HELP GROUPS AND COFFEE AND CONVERSATION MEETINGS

Get a Connection! Meet and network with others living with MS? Find a support group or coffee & conversation meeting near you at MSnewengland.org /Groups and Discussions.

ANNUAL SPRING EDUCATION CONFERENCES

Each event includes a resource EXPO as well as interactive workshops and general sessions on topics of wellness, treatment, symptom management and more. All conferences are FREE and include morning refreshments and lunch. Pre-registration is required

New Hampshire: Living Well with MS
Saturday, June 5 9 a.m. – 2 p.m.
Grappone Conference Center, Concord

Rhode Island: Living Well with MS
Saturday, May 21 8:30 a.m. – 3:30 p.m.
Radisson Airport Hotel, Warwick

EVERYDAY MATTERS: LIVING YOUR BEST LIFE WITH MS

The Everyday Matters program is a tool to assist people living with MS find those strategies to support ongoing happiness, even in the face of adversity. Positive psychology focuses on growth and well-being and Everyday Matters will help individuals understand and develop their personal strengths. Attendees are asked to attend all sessions. Advanced registration is required. A light meal will be provided.

Vermont: National MS Society Office, Williston
Every Wednesday for 6 weeks from Aug. 10 - Sept. 14
5:30 to 7:30 p.m.

Maine: Kennebec Valley Comm. College, Fairfield
Saturdays, July 16 and July 30
Time: 9:30 a.m. - 1:00 p.m.
AUTHORS’ LUNCHEON

March 11, Burlington, Vermont. The third annual Authors’ Luncheon was held at the Hilton Burlington Hotel. 250 people attended and the event raised over $32,000. There was also a VIP dinner the night before attended by the authors, Thomas Christopher Greene, Ann Hood, and Richard Russo. Sarah Kelly, Chapter Trustee from Vermont, and Co-Chair Lisa Ventriss, President of Vermont Business Roundtable thanked everyone for attending, while committee members from the MS Center of Northern New England updated attendees on clinical trials in Vermont.

MS CLIMB TO THE TOP

March 5, Boston. We had our best Climb to the Top to date! More than 675 people climbed 61 stories to raise over $350,000. 98 teams and 16 Fire Departments participated. One person came from North Carolina to climb! The age range of participants was from 5 to 70 years old.

MARATHON STRIDES AGAINST MS

On April 18, 49 runners, many who have MS, participated in the 120th Boston Marathon®. Not only did they train for and run 26.2 miles, they raised more than $375,000.

ANIME BOSTON

(FAR LEFT) LORI ESPINO, PRESIDENT AND (2ND FROM RIGHT) SARAH ADAMS, CHAPTER STAFF AT ANIME BOSTON FOR OUR 10TH AUCTION. DREAM WORKS AND STEVEN UNIVERSE WITH THEIR DONATED ARTWORK. $20,000 WAS RAISED.

MILESTONES GALA

May 4, Boston. At this year’s MileStones Gala, the MileStones in Research Award was presented to Peter A Calabresi, MD, a recipient of the prestigious Barancik Prize for Innovation in MS Research.

(L-R) CATHY MACPHERSON, DR. PETER CALABRESI, PIPER MCNEALY, & BOB KEELEY
2016 WALK SEASON

The 2016 Walk MS season began on Saturday April 2. Our spring walks have done very well, but we still need your help to reach our $2.5 million goal. Join a fall walk near you and start a team!

THANK YOU TO OUR SPONSORS

THANK YOU TO OUR PREMIER NATIONAL SPONSOR

THANK YOU TO OUR NATIONAL SPONSOR

THANK YOU TO OUR LOCAL SPONSORS

JOIN WALK MS THIS SUMMER

MASSACHUSETTS: June 18: Wakefield

JOIN WALK MS THIS FALL

MAINE
September 10: Caribou
September 25: York

NEW HAMPSHIRE
September 17: Gorham & Laconia
September 24: Keene
September 25: Journey of Hope, Concord

VERMONT
September 24: St. Johnsbury

WHAT IS THE GOLDEN CIRCLE?

Golden Circle members are fueling progress by annually giving $1,000 or more to the National MS Society.

Golden Circle is comprised of a nationwide community of leaders who share a passion for a world free of MS. A leading benefit of Golden Circle membership is the opportunity to connect with these remarkable individuals nationally and in your local area.

Golden Circle members are also connected to updates and information about the advances in research and care that are most meaningful to them.

To learn more about the Golden Circle or to join please visit nationalMSsociety.org or contact Audrey Jensen at audrey.jensen@nmss.org.
BIKE MS TWO-DAY RIDES
REGISTER AT BIKEMSGNE.ORG

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

CAPE COD GETAWAY
Presented by SANOFI GENZYME
SATURDAY-SUNDAY, JUNE 25-26
Quincy 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

GREAT MAINE GETAWAY
SATURDAY-SUNDAY, AUGUST 13-14
University of New England, Biddeford, Maine
- Saturday route options: 25, 50, 75, and 100 miles;
  Sunday route options: 25, 50, and 75 miles
- Sunday includes a traditional Maine lobster bake

BIKE MS ONE-DAY RIDES

MINUTEMAN RIDE
SATURDAY, JULY 16
Concord-Carlisle High School, Concord, MA
- 25 and 60 mile options through Metro-West towns
- Stay for post-ride barbecue

NH SEACOAST ESCAPE
SATURDAY, AUGUST 27
Stratham Hill Park, Stratham, NH
- Routes: 25 and 60 mile options
- Ride through southern New Hampshire’s scenic villages and bustling seaside towns

GREEN MOUNTAIN GETAWAY
SATURDAY, AUGUST 6
Community Drive Business Park, So. Burlington, VT
- Saturday route options: 25, 60 and 100 miles
- Enjoy the beauty of Vermont and a barbecue lunch

MS PLANE PULL
JUNE 11
A showdown to determine whose team reigns supreme in strength, endurance, and spirit.
PORTLAND JETPORT,
PORTLAND, MAINE

LINK UP FOR MS
AUGUST 15
Lunch, Shotgun Start, Dinner, Raffles, and an Auction!
IPSWICH COUNTRY CLUB,
MASSACHUSETTS

MS JET PULL
SEPTEMBER 24
A rope, a tow bar, and a FedEx 757 aircraft. No problem!
T.F. GREEN AIRPORT,
RHODE ISLAND

REGISTER AT MSNEWENGLAND.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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**August 19-21, 2016**

Three days of sailboats, tugboats, and lobster boats—under the banner of the MS Harborfest—all to benefit the National Multiple Sclerosis Society.

**Friday, August 19**

*MS Harborfest Benefit Auction*

The Portland Company

**Saturday, August 20**

*MS Regatta*

Portland Harbor & Fore River, Portland

**Sunday, August 21**

*MS Tugboat Muster & Races*

Portland Ocean Terminal/Maine State Pier, Portland

*MS Lobster Boat Races*

The Portland Company, Portland
CALENDAR - EVENTS AND PROGRAMS

June 7 .......... SSDI Benefits: What You Need to Know, Southbridge, MA
June 10 .......... Team Zrike Fundraiser, Everett, MA
June 11 .......... MS Plane Pull, Portland, ME
June 13 .......... Swing Fore MS, Brewster, MA
June 14 .......... Traveling with MS, online
June 18-19 .... Bike MS: Ride the Rhode, Kingston, RI
June 18 .......... Walk MS: Wakefield, MA
June 19-24 .......... MS Vacation Week, Hebron, CT
June 20 .......... Fatigue: Take Control, Freeport, ME
June 21 .......... Managing Bladder & Bowel Issues in MS, Lebanon, NH
June 25-26 .......... Bike MS: Cape Cod Getaway, Quincy, MA
July 12 .......... Understanding and Managing Your Spasticity, Online
July 16 .......... Bike MS: Minuteman Ride, Concord, MA
August 6 .......... Bike MS: Green Mountain Getaway, Burlington, VT
August 9 .......... Workout Your Worries: Anxiety and Stress in MS, Online
August 10 .......... Everyday Matters: Living Your Best Life with MS, Williston, VT
August 13-14 .......... Bike MS: Great Maine Getaway, Biddeford, ME
August 15 .......... Link Up for MS, Ipswich, MA
August 17 .......... Everyday Matters: MS, Williston, VT
August 19-21 .......... MS Harborfest, Portland, ME
August 24 .......... Everyday Matters: Williston, VT
August 27 .......... Bike MS: New Hampshire Seacoast Escape, Stratham, NH
Sept. 7 .......... Everyday Matters: Williston, VT
Sept. 9-11 .......... Challenge Walk MS, Brewster, MA
Sept. 10 .......... Walk MS: Caribou, ME
Sept. 13 .......... Health Insurance: What Everyone Needs to Know, Online
Sept. 14 .......... Everyday Matters: Williston, VT
Sept. 17 .......... Walk MS: Gorham & Laconia, NH; Sturbridge, MA
Sept. 24 .......... Walk MS: Keene, NH; St. Johnsbury, VT
Sept. 24 .......... Jet Pull, Warwick, RI

Information provided by the Society is based upon professional advice, published experience, and expert opinion. Information provided in response to questions does not constitute therapeutic recommendations or prescriptions. The National Multiple Sclerosis Society recommends that all questions and information be discussed with a personal physician.

The Society does not endorse products, services, or manufacturers. Such names appear here solely because they are considered valuable information. The Society assumes no liability for the use or contents of any product or service mentioned.

STAY INFORMED. READ MSCONNECTION ONLINE AT MSNEWENGLAND.ORG
You may request a printed newsletter if you have impaired vision or if you do not have Internet access. Call 781-693-5133

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