A New Chapter President

MS AWARENESS WEEK
MARCH 3-9

WALK MS STARTING APRIL 5

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From the President

Sitting in the President’s chair for the first time was an amazing experience. Personally, it’s extremely rewarding to be selected by the Board of Trustees to serve as the Greater New England Chapter President. I am so grateful for the opportunity, and am looking forward to maintaining our great tradition of excellence in helping people with MS, while raising even more funds to fuel the MS research engine.

Our chapter enjoys a reputation as one of the best within the National MS Society, thanks to a highly engaged MS community and the hard work of our professional staff, and dedicated volunteers and motivated fundraisers. For 28 years, we enjoyed the outstanding leadership of Arlyn White, who retired at the end of December. Arlyn hired me over 11 years ago, and gave me a tremendous chance to drive the chapter’s fundraising efforts. Her mentorship has prepared me to continue moving the chapter forward, and I am eager to work with all of you to accomplish our shared promise of a world free of MS.

One of the best qualities of the Greater New England Chapter is that we have many staff and key volunteers on the Board and supporting our activities, who have been involved for many years. I believe it’s a testament not only to their personal commitment to the mission, but to the quality of individuals on our team.

We all care deeply for people with MS, and we all support each other to get the job done, even when we have to make personal sacrifices to make it happen.

Being a team really means that everyone does their individual job to the best of their abilities, while also making sure that the needs of their team members are being met. Ultimately, we all have a role to play. Each one is as vitally important as the other, regardless of our titles or position. As Chapter President, I fully accept my role as a “servant leader,” which is a term used these days in business circles and beyond to express the function of an executive to not only set the vision and the goals, but to ensure that their team has the resources it needs to function at their highest level.

To those of you who I’ve met and worked with, I look forward to continuing our journey together. To those I have yet to meet personally, I welcome that opportunity so that we can strengthen our movement and achieve even greater results. Every connection counts toward creating a world free of MS. Let’s create as many connections as we can.

Warmly,

Lori Espino
President

Moving Toward a World Free of MS

PARTNERS IN MS CARE CENTERS FOR COMPREHENSIVE MS CARE

Individuals who are looking for skilled and experienced MS healthcare professionals in their community can now search for Partners in MS Care on the Society’s website. The National MS Society’s Partners in MS Care program recognizes and supports quality MS care. Health care professionals recognized as Partners in MS Care demonstrate knowledge and experience in MS care, have a special interest in treating people living with multiple sclerosis, and work closely with the National MS Society. The program involves health care professionals in the areas of neurology, rehabilitation, mental health and social work, among others, as well as providers of care who provide multidisciplinary care.

A Partner in MS Care designated as a Center for Comprehensive MS Care has additionally shown the ability to offer a multi-disciplinary model of care to address the often complex needs of many people with MS. They offer access to a full array of medical, psycho-social, and rehabilitation services delivered in a coordinated fashion where providers share common goals for patient outcomes.

The Greater New England chapter currently has seven Partners in MS Care. Centers for Comprehensive MS Care, and will be adding more. These Centers are led by clinicians with demonstrated knowledge and experience in the treatment of MS, coordinate the full array of medical, nursing, mental health, rehabilitation, and social services, and have a strong collaborative relationship with the National MS Society. This relationship facilitates quicker referrals to the society’s programs and services, as well as continuing education opportunities for the professionals.

Currently, the following MS Centers are designated as Centers for Comprehensive MS Care:

- The Lahey MS Clinic, Lexington, Massachusetts
- The MS Center at Beth Israel Deaconess Medical Center, Boston, Massachusetts
- The MS Clinic at Newton-Wellesley Hospital, Newton, Massachusetts
- The MS Center at St. Elizabeth’s Medical Center, Boston, Massachusetts
- The MS Center at UMass Memorial Medical Center, Worcester, Massachusetts
- Partners MS Center at Brigham & Women’s Hospital, Boston, Massachusetts
- Partners Pediatric MS Center, Boston, Massachusetts
- The MS Center of Northern New England, Burlington, VT

For more details about these MS Centers, check online at: www.nationalmssociety.org/living-with-multiple-sclerosis/getting-the-care-you-need/partners-in-ms-care/index.aspx, or call an MS Navigator at 1-800-344-4867.

HOME LINKS: ED’S STORY

We know that living with MS can sometimes bring overwhelming challenges to you and your family. The Chapter’s Home Links (Living Indepedently Navigating Key Services) care management program provides short-term care management for people with MS in Maine, Massachusetts, New Hampshire, and Vermont. Home Links care managers works with people to connect them to benefits, services, and community resources that increase independence and safety in the community.

Ed lives in Massachusetts. After a divorce, Ed lost his house to foreclosure and became homeless. Ed was a Master Plumber but was finding it difficult to keep up with his profession due to increasing symptoms like numbness in his right arm, constant pain in his legs, and cramps. Ed took a lower-paying job for a few hours a week, but even that was becoming difficult. He had applied for Social Security Disability Income (SSDI) and been denied. Ed was referred to the Chapter by his neurologist, and began working with Home Links care manager Brian Smith. Brian helped Ed coordinate another SSDI appeal, and Ed was eventually approved and is now receiving monthly benefits. Brian and Ed worked together to complete and submit several housing applications. With his SSDI benefits and his retroactive check, Ed is now renting a room and has a roof over his head for the first time in over two years. Ed opened a checking account for the first time in his life. He is taking things one day at a time, and says, “No one has ever helped me before. Brian is the only one who ever really helped me. I feel like I’m getting a new life.”

For information on accessing Home LINKS services, please contact the Chapter at 1-800-344-4867, ext 2.
MAJOR ADVANCEMENTS MADE IN 2013 TOWARD UNDERSTANDING AND TREATING MS

The National MS Society continues to pursue all promising paths to uncover solutions for everyone with MS, wherever those opportunities exist, while focusing on the three priority areas of progressive MS, nervous system repair, and wellness/lifestyle. We continue to see the fruits of previous investments, and we are committed to growing our research funding over time.

Significant research progress occurred over the course of 2013, offering new leads that are driving efforts to stop MS, restore function, and end MS forever. We now have a better idea of what’s causing MS damage and progression, understand more than ever the benefits of early and aggressive treatment, restock physical and mental functions, and help people with MS live fuller lives. Progress is also accelerating in the field of nervous system repair, thanks in part to significant previous investments made by the National MS Society in an international targeted initiative.

Progressing the Society’s commitment to significant previous investments led to ways to prevent the disease: physical and mental function. New studies reported that eating fatty acid fish has the potential to reduce the risk of developing MS, and that smoking increases the risk of developing MS, as does obesity in girls.

To further efforts to end MS forever, in 2013 the Society:

- Recruited experts to launch the Therapeutic Clinical Trials Hub aimed at stimulating myelin repair in people with MS.
- Launched new research funding totaling $2.5 million for an expanded Network of Pediatric MS Centers and data coordination hub, which can be leveraged to answer important research questions to advance our understanding of the disease in both children and adults with MS.

WHERE TO FIND EMPLOYMENT HELP

BY STEVEN W. NISSEN, MS, CRC

Are you considering changing jobs? Have you been out of the workforce, but are thinking about returning? Do you have questions about disclosure in the workplace or how to accommodate symptoms on the job?

CALL AN MS NAVIGATOR

An MS Navigator can address many of your employment-related questions and refer you to helpful resources, including employment-related publications and videos. Call the Society at 1-800-344-4867 and visit www.nationalMSsociety.org/employment.

JAN CAN HELP

The Job Accommodation Network (JAN) is a free service of the U.S. Department of Labor Office of Disability Employment Policy that can provide technical assistance and support regarding accommodations, the Americans with Disabilities Act, disclosure and self-employment for people with disabilities. Contact JAN at 1-800-526-7234 or visit www.askJAN.org for a wide variety of resources and publications.

IN YOUR STATE

Each state has a vocational rehabilitation agency whose goal is to assist individuals with disabilities to gain and maintain employment. For a full listing of vocational rehabilitation agencies, visit askjan.org/cgi-win/TypeQuery.exe?902.

ONE-STOP SERVICES

The purpose of local one-stop employment centers is to assist job seekers, with or without disabilities, in finding employment. However, if you choose to self-identify that you are living with MS, the office may be able to provide some additional support services. To find your closest center, visit www.servicelocator.org.

TARGETED RECRUITMENT

Several online resources feature employers who are actively recruiting qualified people with disabilities, including:


Working with MS is possible and you don’t have to do it alone. Get connected to stay on top of your employment options.

Where to Find Employment Help

By Steven W. Nissen, MS, CRC

Are you considering changing jobs? Have you been out of the workforce, but are thinking about returning? Do you have questions about disclosure in the workplace or how to accommodate symptoms on the job?

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JAN Can Help

The Job Accommodation Network (JAN) is a free service of the U.S. Department of Labor Office of Disability Employment Policy (2002). Backstrom, G. I'd rather be working: A step-by-step guide to financial self-support for people with chronic illness. Backstrom, G. Aimed primarily at current or prospective workers with chronic disabilities, this book is an excellent resource for finding and keeping a job, as well as for creating a work environment that is chronic illness-friendly. Adapting: Financial Planning for a Life with MS (Guidebook available from Chapter or online)

To access any of these resources, call the Chapter, opt. 2.
Many families don’t share one key element of their lives with one another—finances. Whether it’s one spouse who handles the responsibility or parents not including their children in financial discussions, it’s rare for an entire family to discuss financial matters.

However, a collective understanding of financial matters among all members of a family is beneficial in many ways. Discussing these topics in an open and honest fashion can increase knowledge, lower fear, and encourage positive actions.

Here are some Dos and Don’ts when it comes to making financial matters a family affair:

**Dos**
- Encourage your children to save their own money to donate to a cause. Share any letters of appreciation and stories you receive with your family.
- Don’t avoid difficult topics. There’s no doubt that discussions about estate planning and wealth transfer can be challenging. Nonetheless, sharing key financial information with spouses, children, and/or elderly parents will serve to reduce fear and uncertainty for all involved. More importantly, it will save significant confusion, stress, and worry in the future should the unthinkable occur.
- Possible information to discuss includes:
  - Names and contact information for your key tax, legal, and financial advisors
  - Personal data (social security numbers, account numbers, passwords for financial websites)
  - The location of important records and documents
  - A summary of your cash and investment accounts
  - Any legal arrangements, such as wills, and who you have designated to carry out key legal and financial tasks
  - Directives (medical and/or financial powers of attorney)
- Don’t hesitate to seek professional advice. If you feel uncertain about how much you know about financial topics, such as budgeting, retirement goals, and investments, reach out to an advisor who can help you understand better, and whose insights you can then share with your family. Consider having family members join you for these meetings. They will be able to ask any questions they may have and feel like active participants. The Society’s Financial Education Partners program offers pro bono financial planning and education to people with special health or financial circumstances.
- Pam Evason, CFA, CPA is Managing Director at Windermere Wealth Advisors, LLC, an investment advisory firm located in Milwaukee, Wis., and a member of the Wisconsin Chapter’s board of trustees.

This article is for informational purposes only. It is not a substitute for professional guidance and assistance in planning your financial future. The matters discussed here are provided as a starting point for further discussions with an investment professional familiar with your specific situation.

**Don’t treat it as a taboo subject**

Bring financial topics up in day-to-day conversation, discuss issues in front of your family, ask them for their input and advice on financial decisions you are facing, and share financial articles or books you’ve read. Work to keep the lines of communication open. With time, such discussions will become second nature.

**Do teach children of all ages about finances**

Start at an early age by discussing age-appropriate financial concepts, such as how to save money in a piggy bank. Build upon these concepts as your children grow. With older children, you can help them open a bank account and begin discussing compound interest and investing. Other great financial topics to talk about with children include careers and income, budgeting, and credit.

**Do share your money journey—the good and the bad**

When discussing your financial history with your partner, spouse, or children, it is easy to omit the less-than-favorable moments. However, a collective understanding of financial matters among all family members to learn from the full range of your experiences. Stay open and honest, and encourage other family members to learn from the full range of your experiences.

**Do involve the family in philanthropic efforts**

For many of us, charitable giving is an important element of our financial lives. No matter the size or scale, donating to causes we care about holds great significance and personal meaning. Involvement of the family in this process can help illustrate how money can be used as a tool to make the world a better place. Consider asking your spouse and/or children to research a charity they would like to support. Encourage your children to save their own money to donate to a cause. Share any letters of appreciation and stories you receive with your family.

**VITAMIN D AND YOU**

**BY DR. BRENDA BANWELL**

During the Society’s webinar, Living Well with MS: Lifestyle, Diet and Complementary Therapies (watch it at www.nationalMSSociety.org/webcasts), we received a number of questions about vitamin D. We sat down with Dr. Brenda Banwell, who is the division chief of Neurology and professor of Pediatrics Neurology at Children’s Hospital of Philadelphia and the University of Pennsylvania, to get answers to the most popular questions you submitted.

**HOW MUCH VITAMIN D SHOULD A PERSON WITH MULTIPLE SCLEROSIS TAKE?**

If you are living with MS, I would recommend that you work with your healthcare provider to obtain your vitamin D blood levels (also called a 25-hydroxy vitamin D), a measurement of the circulating vitamin D in the body. Many people with MS will require much higher doses than are recommended for the general population in order to bring their blood levels up, particularly in the winter. Under the care of a physician, it wouldn’t be unusual for a person with MS to take 3,000 to 5,000 IUs per day. However, those taking vitamin D in doses beyond what is recommended will be monitored by a doctor, as too much vitamin D can potentially be toxic.

Is it better to get vitamin D through nutrition or sunlight? The most effective way of obtaining vitamin D is through sunlight acting on the skin—particularly for people with lighter skin. People with darker skin absorb less vitamin D. If we weren’t worried about the negative effects of sunlight, then it would be a very good way (in the sunnier months) to bring their blood levels up, particularly in the winter. Under the care of a physician, it wouldn’t be unusual for a person with MS to take 3,000 to 5,000 IUs per day. However, those taking vitamin D in doses beyond what is recommended will be monitored by a doctor, as too much vitamin D can potentially be toxic.

**WHAT DOES VITAMIN D DO?**

- **Skeletal health**: It is necessary for bone health and the prevention of osteopenia and osteoporosis. It is also necessary for the proper absorption of calcium from the diet.
- **Neurological health**: Vitamin D plays a role in the development and function of the nervous system. It is important for proper brain function and may be involved in the prevention of neurological diseases.
- **Plates**: Vitamin D helps regulate the immune system and is necessary for the proper functioning of the immune system.
- **Other health benefits**: Vitamin D may have additional health benefits, including a role in the prevention of certain types of cancer and heart disease. It may also help reduce the risk of falls and fractures in older adults.

**Is vitamin D just for people with MS?**

While vitamin D is important for people with MS, it is also important for people without MS. It plays a role in the proper functioning of the immune system and may help reduce the risk of chronic diseases such as heart disease, diabetes, and some types of cancer.

**How do I know if I need vitamin D?**

Your healthcare provider can order a blood test to check your vitamin D levels. If your levels are low, you may need to take a supplement. However, it is important to speak with your healthcare provider before taking any supplements, as too much vitamin D can be harmful.

**Can I get enough vitamin D from food?**

While it is possible to get enough vitamin D from food, it is often difficult to get enough vitamin D from diet alone. Some foods that are good sources of vitamin D include fatty fish (such as salmon and mackerel), egg yolks, and fortified milk and cereal. However, the amount of vitamin D in these foods may not be enough to meet your needs, and it is often necessary to take a supplement to get enough vitamin D.

**How much vitamin D do I need?**

The recommended daily intake of vitamin D for adults is 600 to 800 international units (IUs) per day. However, some people may need more, especially those with MS. If you have MS, it is recommended that you consult with your healthcare provider to determine the appropriate amount of vitamin D for you.
FAMILY MATTERS
My Meme – Our MS

BY ELIZA EASTMAN

Multiple Sclerosis has been a part of our family for a long time, all of my life actually, 15 years. My Meme (grandmother) was diagnosed with MS when my Mom, her daughter, was just a little bit older than me. I was not even a thought then, imagine that!

My Mom has shared with us that having MS be a part of your family has not always been easy. There was a long time when she was growing up that they did not know what was “wrong” with my Meme and that was probably the hardest part of all. Once they knew, it was a little better, but at times still very hard. There have been times when my Meme could not walk or could not see. Their house was not a place for friends to gather as it was hard for my Meme, very different from my own home.

I am proud of my Meme as she is a strong lady, which I hope to be some day too. My Meme worked as a librarian as long as she could, she loved her job. She loves books and reading and has always tried to get my sister, brother and I to love it too! She loves to sew and we have quilts and other items that she has made for us that we love. She loves to shop (when her legs allow her to) and she loves to spend time with her grandchildren. One time she went sliding with us, giant tubes down a snowy mountain, a day that we will never forget. She is very often found at the soccer field watching me play soccer or at the hockey rink watching my brother play hockey. She is not a person with MS, just a Meme watching her grand kids do something they love.

My sister is a freshman in college, out of state, and she is majoring in design, so she is learning to sew for the first time. My Meme is thrilled! I think Meme is thinking more quilts and my sister is thinking more clothes!

My Meme uses some things that help her now and I am so glad that she does because I think it allows her to be with us, like her walker and her cane. I have never really looked at my Meme as someone who has MS; I am not sure what that person would look like. I know what my Meme looks like and she is someone who is strong, fun and loves her family a lot, so if that is what someone with MS looks like I think that is okay.
MS Awareness Week ■ March 3 – 9, 2014

MS destroys connections inside us. It disconnects the mind from the body and people from each other. But what if we could forge connections that MS couldn’t destroy? What if we could connect more people in more ways around this disease? Would they share more knowledge? More questions? More answers? More hope? Maybe, by connecting enough small victories, we could win some really big ones.

MSSconnection.org

ELECTRONIC BILLBOARD MESSAGES:
IBEW Local 103-93, Southeast Expressway
New England Regional Council of Carpenters 750 Dorchester Ave., Boston

MS FLAGS OF HOPE
Volunteer to plant an MS Flag of Hope representing each person with MS in Maine, Massachusetts, New Hampshire, and Vermont:

MSnewengland.org

Developing treatments that promote remyelination.

The theme for World MS Day 2014 is Access. We want to educate and inform people across the world about the different types of access issues faced by people with MS. www.worldMSday.org will share stories from people with MS about everything from access to treatments and services to mobility and leisure. They’ll ask people to think about barriers to access in their life and to make a wish for something that would help overcome those barriers. To focus on the many issues around access, use the tag-line ‘One Day’.

The Promise of Myelin Repair

BY BRUCE BEBO, PhD

When I started as a laboratory immunologist more than 20 years ago, the major focus in MS research was searching for ways to turn off destructive immune attacks, which resulted in immune-based therapies that can help control relapsing forms of the disease for many people.

While researchers continue to look for ways to improve the treatment of relapsing MS, the focus in MS research is shifting to finding strategies that stop MS progression and repair the damage that causes disability. This is relevant to people with all types of MS, but especially to people with progressive forms of the disease.

Dream to Reality

People are excited by the possibility, once only a dream, that we will find a way to repair damaged myelin. This would be important for restoring function, and many believe that re-establishing the protective myelin coating on axons may even shield them from further harm.

Bruce Trapp, PhD, and his team at Cleveland Clinic have been working hard to advance the field of nervous system repair. They have shown that new MS lesions undergo natural repair much better than older (“chronic”) ones. They also reported that the problem is not a lack of cells capable of making new myelin in old lesions, but their inability to produce new myelin. Work is now underway to figure out what the impediment is and how to jump-start the repair process.

What makes this work on MS lesions intriguing is that it straddles two different parts of the brain – the so-called white matter and gray matter. The team found that chronic lesions in the white matter don’t remyelinate. But chronic lesions in the gray matter show robust remyelination – even in people living with MS into their 70s. This opens up opportunities to make white matter repair itself like gray matter.

In related research, Larry Sherman, PhD, and colleagues at the Oregon Health & Science University found that fragments of a molecule called hyaluronic acid (HA for short) accumulate in chronic white matter lesions and could be at least partially responsible for the stalled remyelination. They have identified an enzyme that chews the HA into fragments and have shown that inhibitors of this enzyme promote remyelination. They are now trying to figure out exactly how this works, in hopes of developing treatments that promote remyelination.

More Possibilities

Increasing evidence suggests that female sex hormones might be neuroprotective and/or promote repair of myelin. I saw two very interesting presentations last October at ECTRIMS, the world’s largest gathering of researchers, which reported that different estrogen-like molecules could stimulate production of new myelin. Both of these projects are supported by the Society.

Another strategy to repair myelin in MS is to introduce new repair cells into the system via transplantation. Of note was a presentation by investigators from Milan, Italy, who used mouse skin stem cells and forced them to become myelin-making cells. After these cells were infused into the spinal cord, they promoted recovery in mice with the MS-like disease EAE. The team found that these cells didn’t actually make myelin themselves, and are starting to identify the growth factors they release that stimulate natural repair and also reduce inflammation. More work is needed, but this type of research gives hope that this strategy may eventually help restore lost function.

Updates on two repair therapies already being tested in human clinical trials were also presented. The first is called anti-LINGO. LINGO is seen in neurons and myelin-producing oligodendrocytes, and blocking this protein with anti-LINGO has been shown to promote remyelination in animal models. An investigative team from Biogen Idec reported that anti-LINGO was well tolerated in people and that no negative effects were seen. This means the company will likely keep pursuing clinical development of this promising repair candidate.

In other news, investigators from the Mayo Clinic are developing an agent called rHgM22 that has been shown to promote extensive remyelination in several different animal models of MS. This agent is now in early clinical trial testing in MS.

We’re not there yet, but recent and ongoing research holds the promise of uncovering new targets for stopping progression and stimulating repair.

Bruce Bebo, PhD, is the Associate Vice President of Discovery Research at the National MS Society.

To find out about trials in Maine, Massachusetts, New Hampshire, and Vermont, go to page 14 or visit www.nationalMSSociety.org/clinicaltrialsGNE

For more information and to learn about activities, visit MSnewengland.org.

Have an idea? Write us at NationalMSSocietyGNE@mss.org

10 JOIN THE MOVEMENT: MSnewengland.org
11 TOLL FREE NUMBER 1 800 344 4867

PLAN GREAT ACTIVITIES FOR MS AWARENESS WEEK

March 3-9, 2014
What are you doing?

☐ Create a video to share your Promise to create a world free of MS. Post on YouTube!
☐ Update your Facebook Status with a message about MS.
☐ Post on Twitter about MS.
☐ Write a letter to the editor of your local newspaper.
☐ Raise MS AWAREness by wearing orange. Need something new? Visit the Society Store online.
☐ Sign up to volunteer at an upcoming chapter event.
☐ Form a team: Bike MS, Walk MS, or MS Challenge Walk.
☐ Donate: Support the Society every donation moves us closer to a world free of MS.
☐ Spread the Word: Tell five people it’s MS Awareness Week and ask them to tell five more people.
☐ Host a community program or set up an information table in your town.
☐ Distribute MS Awareness Week buckslips.

www.nationalMSSociety.org/clinicaltrialsGNE
FDA DENIES APPROVAL FOR LEMTRADATM (ALEMTUZUMAB) FOR RELAPSING MS

The U.S. Food and Drug Administration has denied approval at this time for Lemtrada™ (alemtuzumab, Genzyme, a Sanofi Company) as a therapy for relapsing MS. According to a company press release, the FDA has taken the position that one or more additional clinical trials would be needed for marketing approval of Lemtrada. The company plans to appeal the agency’s decision.

Lemtrada is given by infrequent intravenous infusion — for 5 days initially and for 3 days one year later. Details regarding its potential benefits and risks from two phase III trials can be found at nationalMSsociety.org > news. Lemtrada is currently approved in Europe, Canada and Australia.

“This is disappointing news, given the need for more therapeutic options for people with MS living in the United States,” stated Timothy Coetzee, PhD, Chief Advocacy, Services and Research Officer at the National MS Society. During a November FDA advisory committee meeting about Lemtrada, the committee heard public testimony from people living with MS and patient advocacy groups, including the National MS Society. The Society’s testimony addressed the need for more therapeutic options for people with MS and the importance of empowering people with MS to make their own informed treatment decisions.

The Society will continue to monitor this process and update its constituents of any news at nationalMSsociety.org > news.

Crucial Molecule is Identified in the Nervous System with an Eye Toward Enhancing Nervous System Repair in MS

Researchers have pinpointed a molecule — called “Contactin-1” — that is crucial to the formation of the myelin coating along nerve fibers which is damaged in MS, and which represents a novel target for developing strategies for repairing myelin to restore function in people with MS. Barbara Ranscht, PhD (Sanford-Burnham Institute for Medical Research, La Jolla, CA) and colleagues in California and Sweden report their findings in Proceedings of the National Academy of Sciences USA. This project was supported by the National MS Society, with other support from the National Institutes of Health and the Sweden-America Foundation.

Reversing damage to regain function through nervous system and myelin repair is a priority of the National MS Society’s research efforts to find solutions for everyone who has MS.

In the developing nervous system, the team observed that Contactin-1 was active on myelin-making cells, and also along axons in the area of nodes — clusters of specifically organized proteins that are crucial to nerve impulse conduction. Myelin formation significantly decreased in mice lacking Contactin-1, and the organization of nodes and wrapping of the myelin sheath around axons was dramatically disrupted.

These studies pinpoint the molecule Contactin-1 as an important player in myelin growth and axon health, and may represent a novel target for the development of potential strategies that might repair damage to the nervous system and restore function to people with MS. Additional basic research is needed to further develop these findings. “It is now critical to determine the specific molecular mechanisms by which Contactin-1 regulates the remarkable cellular assembly that constitutes myelin, and evaluate its potential for myelin repair in the central nervous system,” write the authors.

Resources to find Clinical Trials

- ClinicalTrials.gov
- CenterWatch - centerwatch.com
- NARCOMS - narcoms.org
- MS International Federation - msif.org
- CISCPR - ciscpr.org
- Research Match - researchmatch.org
- MS Discovery Forum - msdiscovery.org
- National Institutes of Health - nih.gov/health/clinicaltrials
- Patients Like Me - patientslikeme.com/clinical_trials

One stop shopping for companion information on plans is available for individuals, families and businesses. Despite technical difficulties with enrollment, website assistance is available by phone, in person and by state web portals. If you do not maintain insurance, you may be subject to a tax penalty in 2014. Tax credits and subsidies for insurance premiums are available to some. The Affordable Care Act offers many benefits for people with MS. Be a wise consumer and improve access and reduce costs!

To access insurance options:

- Maine: healthcare.gov or for local assistance covermainewow.com. For in-person navigators, call 800-965-7476
- Massachusetts: Health Connector mahealthconnector.org
- New Hampshire: healthcare.gov or 800-318-2596, TTY: 855-889-4325
- Vermont: Health Connect 855-499-9800 (M-F 8 a.m.-8 p.m., Sat 8 a.m.-1 p.m.) or healthconnect.vermont.gov

THE AFFORDABLE CARE ACT: STATE MARKETPLACES LAUNCHED!

The State Insurance Marketplaces enrollment began January 1st 2014. One stop shopping for companion information on plans is available for individuals, families and businesses. Despite technical difficulties with enrollment, website assistance is available by phone, in person and by state web portals. If you do not maintain insurance, you may be subject to a tax penalty in 2014. Tax credits and subsidies for insurance premiums are available to some. The Affordable Care Act offers many benefits for people with MS. Be a wise consumer and improve access and reduce costs!

To access insurance options:

- Maine: healthcare.gov or for local assistance covermainewow.com. For in-person navigators, call 800-965-7476
- Massachusetts: Health Connector mahealthconnector.org
- New Hampshire: healthcare.gov or 800-318-2596, TTY: 855-889-4325
- Vermont: Health Connect 855-499-9800 (M-F 8 a.m.-8 p.m., Sat 8 a.m.-1 p.m.) or healthconnect.vermont.gov

FUNDING FOR THE MS HOME LINKS PROGRAM

Governor Patrick’s FY15 proposed budget includes funding for the chapter’s care management program. The Chapter is seeking higher funding and key language from the legislature this spring.

JOIN THE MOVEMENT: MSnewengland.org

TOLL FREE NUMBER 1 800 344 4867

NEW CHAPTER ADVOCACY WEBPAGES LAUNCHED!

Check back by the end of February for the new interactive advocacy webpages for full details on our priority issues. Take action and get involved!

SEEKING ACCESS TO CARE CONSUMER STORIES!

1) Are you a person with MS who has encountered physical barriers to accessing care in a medical facility?
2) Are you a person with progressed MS who is married and been denied Medicaid because your spouse’s income puts you over the eligibility guideline?
If either situation applies to you contact Virginia.Morse@nms.org

IMPROVING MA TRANSPORTATION FOR PERSON WITH DISABILITIES

The Massachusetts Statewide Coordinating Council on Community Transportation (SCCCT) will rely heavily on new Regional Coordinating Councils (RCCs) to implement many of the 530 Para Transit Transportation Report’s recommendations to improve ground-level accessible transportation. The RCCs are actively seeking members to join these councils. Learn more at: massdot.state.ma.us/transit/StatewideMobilityManagement/SCCCT.aspx

MS DAY AT THE STATEHOUSE

Check out the chapter’s new advocacy website for the announcement of this year’s State House Day and plan on joining us!

MANHATTAN

JoIn tHe moVement:

MSFundingsupport.

FEATURING

THE AffORDABLECAREACT:STATE MARKETPLACESLAUNCHED!

The State Insurance Marketplaces enrollment began January 1st 2014. One stop shopping for companion information on plans is available for individuals, families and businesses. Despite technical difficulties with enrollment, website assistance is available by phone, in person and by state web portals. If you do not maintain insurance, you may be subject to a tax penalty in 2014. Tax credits and subsidies for insurance premiums are available to some. The Affordable Care Act offers many benefits for people with MS. Be a wise consumer and improve access and reduce costs!

To access insurance options:

- Maine: healthcare.gov or for local assistance covermainewow.com. For in-person navigators, call 800-965-7476
- Massachusetts: Health Connector mahealthconnector.org
- New Hampshire: healthcare.gov or 800-318-2596, TTY: 855-889-4325
- Vermont: Health Connect 855-499-9800 (M-F 8 a.m.-8 p.m., Sat 8 a.m.-1 p.m.) or healthconnect.vermont.gov

PEARL(AMERICAN)

FUNDING FOR THE MS HOME LINKS PROGRAM

Governor Patrick’s FY15 proposed budget includes funding for the chapter’s care management program. The Chapter is seeking higher funding and key language from the legislature this spring.

Cont. on next page
Government Relations Committee

Volunteers Wanted!
The chapter is seeking committed individuals to join us for 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 public policy projects? If any of these describe you, please contact Michelle.Dickson@nmss.org.

Health Care Reform Implementation

New health insurance programs are still offering coverage to uninsured individuals with a pre-existing health condition, including MS. Need assistance understanding this new program or advice about health insurance? Call 800-344-4867 to speak to an MS Navigator®.

Be a digital MS activist

Digital MS activists—like all MS activists—want to drive change and do so by amplifying their voice and connecting with elected officials over social media. At www.nationalMSsociety.org/digiMSactivist, learn how to share your story, connect with other MS activists and build relationships through social media and email. The webpage includes ways to:

- Get informed. Receive e-newsletters and Action Alerts about important pieces of legislation. Send emails with a few clicks of your mouse.
- Rise up. Learn where your elected officials stand. Speak out on issues important to you as a person affected by MS.
- Take Action. Build relationships with elected officials via Facebook or Twitter.
- Recruit. Encourage others to join directing them to ntl.ms/YouCanBeAnMSActivist, or the website above.

A Champion and his Rider

Why did I want to be part of this project? Since I could no longer ride, I wanted another way to still be a cyclist at a Bike MS event. When the Champions Against MS program came along I GRABBED IT. Knowing my bandana was with a cyclist meant a part of me would be there riding along with them. It took a couple of tries till I was matched up with a rider who wanted to correspond. It then became a huge surprise when another cyclist contacted me! Both told me they would be honored to wear my bandana and how they thought of me as their CHAMPION when in actuality, I thought of them as my CHAMPION. We have been staying in touch since the ride last May and one has already offered to ride for me in 2014! It’s been a wonderful way for me to CONNECT with other cyclists who are truly dedicated to finding the cause and funding the cure for MS. I felt like a kid in a candy store receiving emails letting me know that they were riding in my honor. It kind of took my breath away knowing that it truly is all about CONNECTING with others where you find the real true meaning of the human spirit. It is very alive and well; even the difficult journeys of our lives. I feel honored and blessed that I’ve been asked to have this team member wear my 2014 Champion Bandana.

Max Michaud, Self-Help Group Leader, Maine

What a Difference a Day Makes!

Volunteers Needed for MS Day of Service

MS Days of Service are organized through the Chapter. On these days, teams of volunteers complete projects for people living with multiple sclerosis in Maine, Massachusetts, New Hampshire, and Vermont. Days of Service take place in the spring and autumn in all parts of the Chapter area. Exact dates and times are dependent on volunteer teams and project locations. Volunteers work in teams and receive training, orientation and lunch. Please complete a Day of Service Volunteer Application online at www.msnewengland.org

Some of the projects volunteers can assist with include:
- Yard work, small household repairs
- Cleaning gutters (one-story homes only), helping to de-clutter house or garage
- Painting, cleaning out and organizing closets
- Moving furniture, packing and storing items in garage or attic
- Heavy cleaning, transporting donated items to thrift shop
- Handyman chores, running errands

All applications to participate in MS Day of Service must be received in time to complete background checks prior to a scheduled Service Day.

Volunteers needed for MS Day of Service

Volunteers are invited to sign up by visiting the National Multiple Sclerosis Society’s website at ntl.ms or the website above. To learn where your elected officials stand. Speak out on issues important to you as a person affected by MS.

- Get informed. Receive e-newsletters and Action Alerts about important pieces of legislation. Send emails with a few clicks of your mouse.
- Rise up. Learn where your elected officials stand. Speak out on issues important to you as a person affected by MS.
- Take Action. Build relationships with elected officials via Facebook or Twitter.
- Recruit. Encourage others to join directing them to ntl.ms/YouCanBeAnMSActivist, or the website above.

SALE: Invacare TDX Spree Pediatric Wheelchair with EZ Lock. Elevates and reclines. Seldom used. Located south of Boston. $2000. Contact: pittsy119@gmail.com or 781-710-2661 after 3pm.

To post your free ad, contact wendy.feign@nmss.org.

MS DAY AT THE VERMONT STATE HOUSE

Join chapter staff and MS activists at the Vermont capitol on April 15 to meet elected officials and educate them about the needs of people with MS.

Contact Shanna.McCabe@nmss.org
Moving Toward a World Free of MS

Join the Movement: MSnewengland.org

toll free number: 1 800 344 4867

Fundraising

RIDE WITH US IN 2014

RIDE THE VINEYARD
Saturday, May 3 - Martha’s Vineyard High School Vineyard Haven, MA
- 15, 30 & 60 mile scenic routes featuring quaint charm and beautiful ocean views

RIDE BAR HARBOR
Saturday, May 17 - Bar Harbor, ME
- 25 & 60 mile routes in Maine’s scenic vacation spot

CAPE COD GETAWAY
Saturday-Sunday, June 28-29
UMASS Boston to Provincetown, MA
- 75 & 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 19 - Concord District Court, Concord, MA
- 25 & 60 mile route options through Metro-West towns

GREEN MOUNTAIN GETAWAY
Saturday-Sunday, August 2-3
University of Vermont, Burlington, VT
- Saturday routes include 20, 50, 80 & 100 mile options
- Sunday choose between 45, 75 & 100 mile routes

GREAT MAINE GETAWAY
Saturday-Sunday, August 9-10
University of New England, Biddeford, Maine
- Saturday routes include 25, 50, 75 & 100 mile options
- Sunday choose between 25, 50 & 75 mile routes

NH SEACOAST ESCAPE
Saturday, August 23 - Stratham Hill Park, Stratham, NH
- Route options include 25 & 60 mile options

BIKE & HIKE THE BERKSHIRES
Saturday, September 20 - Jiminy Peak, Hancock, MA
- Ride 25, 50 or the 100-mile Mt. Greylock challenge
- Hike one of two trails to the summit of Mt. Greylock

To Register:
bikeMSgne.org or 800-344-4867

Honoring David P. Meeker, MD
Recipient of the Corporate Milestones Award

David Meeker is President and CEO of Genzyme, overseeing and providing the company’s vision for its Rare Diseases and Multiple Sclerosis business units, and for its patient community relationships and nearly 10,000 dedicated employees.

May 14
6:30 - 9:30 p.m.
Boston Sheraton Hotel
Boston, Massachusetts

For tickets, contact Lori.Espino@nmss.org

Fundraising

MuckFest™ MS Boston, a mucky romp full of obstacles, mud & athletic hilarity.

Saturday, April 26, 2014

Rally your friends and family to join you in support of the National MS Society and its mission to create a world free of MS.

100% of the fundraising dollars go to the National MS Society.

Register Now at MuckFestMS.com
SEPTEMBER 5-7, 2014
3 DAYS. 50 MILES.
CONNECT TO END
MULTIPLE SCLEROSIS

REGISTER TODAY & BEGIN FUNDRAISING
As soon as you register, you’ll have access to our online fundraising tools, making 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.
Register to walk or volunteer as...
- An individual participant
- A member of an existing team
- A team captain (set up a team)

TEAM UP FOR MORE FUN
Forming a Challenge Walk MS team is an opportunity to share a great experience with friends, family members, or co-workers — all while moving us closer to a world free of MS.

ROUTE
Day 1: 20 miles from Hyannis to Brewster, via Yarmouth.
Day 2: 20 miles through Orleans and Eastham, then back to Brewster
Day 3: 10 miles to Dennis and return to Hyannis

ACCEPT THE CHALLENGE!
A WORLD FREE OF MULTIPLE SCLEROSIS
NATIONAL MULTIPLE SCLEROSIS SOCIETY
GREATER NEW ENGLAND CHAPTER

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.

JOIN US ON A JOURNEY OF HOPE
Funds raised from Journey of Hope are distributed directly to participating MS Clinical Centers that are formally affiliated with the Chapter.

May 17 Massachusetts Journey of Hope, Natick
September 28 New Hampshire Journey of Hope, Concord
National Multiple Sclerosis Society
Greater New England Chapter

Subscribe to MSConnection Online!
www.nationalMSsociety.org/newsletterGNE
Same Stories...No Postage
Summer & Winter online only.
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Donate your used car!

IMPROVE HEALTH AND WELLNESS WHILE YOU RAISE MONEY TO END MS!
Purchase discounted LifeExtension® vitamins and nutritional supplements, and a portion of the proceeds are donated to the National MS Society.
Order online only: https://www.levitamins.com/27261/Home

To participate in current studies, clinical trials, and MS surveys visit the chapter online at www.MSnewengland.org

Calendar

March 1 - Climb to the Top: Boston
March 3-9 - MS Awareness Week
March 6 - Employment Teleconference Series - Federal Hiring Initiatives for People with Disabilities
March 7 - Authors’ Luncheon, Vermont
March 20 - Employment Teleconference Series - Home Based Employment: What You Need to Know
March 30 - Bernie & Phyl’s Harley-Davidson Raffle

April 3 - Employment Teleconference Series - Disability Application Secrets
April 5 - Walk MS: Easton & Worcester, MA
April 6 - Walk MS: Boston, Concord, Fairhaven & Plymouth, MA
April 12 - Walk MS: Bangor/Brewer, Brunswick, Camden, Kennebunkport & Lewiston ME; Berkshires, Marblehead & Newburyport, MA; Portsmouth, NH; Burlington, VT
April 13 - Walk MS: Augusta, ME
April 21 - Marathon Strides Against MS
April 26 - Muckfest MS, Devens, MA
April 26 - Walk MS: Portland, ME

May 3 - MS Action Day on Beacon Hill
May 3 - Walk MS: Cohasset & Northampton, MA; Nashua, NH
May 3 - Bike MS: Ride the Vineyard
May 4 - Walk MS: Hyannis & Springfield, MA; Manchester & North Conway, NH
May 10 - Walk MS: Laconia, NH
May 10 - Living Well with MS Conference, VT
May 14 - MileStones Gala, MA
May 17 - Bike MS: Ride Bar Harbor
May 17 - Walk MS: Montpelier, Rutland & Upper Valley, VT