National
Multiple Sclerosis
Society
News Sheets

PROGRAMS & SERVICES

May 2, 2013	**CC:** Chapter Presidents
MSSMC PROFESSIONAL CERTIFICATION 2013 TEST	
Action Requested/Deadline: See below	

Background
The Certification in Multiple Sclerosis Service Management (MSSMC) provides formal recognition of a specific body of knowledge necessary to promote independence and quality of life for persons and families affected by MS. It is currently a Society certification requirement in service management to ensure competency in meeting complex needs for people living with MS. The MSSMC exam is administered by the Professional Testing Corporation, www.ptcny.com.

MSSMC Exam Requirements and Registration:
Information on the MSSMC examination is now available at ptcny.com: click on the Test Information page, then scroll down to the NMSS box and select the MSSMC icon. Candidates are required to have a Bachelor's degree. Cost for the examination is $300. Payment may be made by check, money order or credit card. Please see the handbook application page for more information.

Application Deadline:
June 30, 2013

Testing Window:
August 10 – August 24, 2013

MSSMC Test Preparation:
Reference materials are located on the Professional Testing Corporation website at www.ptcny.com with the course content outline, sample questions, and reference materials. Additionally the Service Management course offered through the Learning and Development System is available to provide you with the right knowledge, resources, and support to ensure your success when working with people affected by MS.

A series of **Service Management Exam (MSSMC) Study Group conference calls** will be held as listed below. These conference calls will break down the different parts of the MSSMC exam and will provide participants with opportunities to ask questions, learn about additional study materials, discuss the study guide and network with other test takers.

Call 1: Understanding MS; Interpersonal Communication and Relationships
June 13th 12-1pm ET/11am-12pm CT/10-11am MT/9-10am PT

Call 2: Client and Family Assessment; Disability Rights and Benefits Systems part 1
June 27th 12-1pm ET/11am-12pm CT/10-11am MT/9-10am PT

Call 3: Disability Rights and Benefits Systems part 2; Resources for the MS Community
July 11th 12-1pm ET/11am-12pm CT/10-11am MT/9-10am PT

Call 4: Service Coordination; Final Wrap Up (Test Preparedness, Study Tips)
July 18th 12-1pm ET/11am-12pm CT/10-11am MT/9-10am PT

Facilitators: David LaRue, IRC Senior Manager and Angela Taylor, IRC Senior Manager

Dial-in: 15100 or 1-888-279-3775; 0432#

Register here:
http://mt211.sabameeting.com/main/Customers/nmss/Registrar/NewRegistration.jsp?event_id=00000020bf7169013d00b0b76c0079bd&source

For more information contact Janis Pluss at 303 698-6100, ext. 15284 or Janis.pluss@nmss.org

National Multiple Sclerosis Society News Sheets

PROGRAMS & SERVICES

May 4, 2013	**CC:** Chapter Presidents

Funding Available to Support Continued Implementation of the Relationship Matters Program

The Society has been awarded a grant from Genzyme Corporation to support the ongoing implementation of, *Relationship Matters: A Program for Couples Living with MS*. Chapters hosting an in-person workshop during the remaining months of fiscal year 2013 or as part of the fiscal year 2014 operational plan are invited to apply for a $500 stipend to apply towards program expenses, not including the printed participant workbooks which will be provided at no charge. We are currently able to provide one $500 stipend to 20 chapters, with the potential to fund more depending on outstanding funding requests. Chapters offering more than one workshop may be eligible for more than one stipend, depending on interest.

Relationship Matters is an innovative program that successfully addresses how MS impacts a couple beyond the physical. The overall findings of five-year pilot demonstrate the ability of the program to help couples improve their relationship satisfaction and mental health related quality of life. Outcomes showed direct usage of skills learned due to participation with improvements in communication, conflict resolution, ability to handle MS specific relationship issues, and awareness of Society services and support. This is vital, as actual application of relationship enhancing skills over a period of time is necessary for behavior change.

Relationship Matters is designed so that both partners learn to use a common language for communicating, resolving conflicts and solving problems. The purpose of the program is to enable partners to identify areas of concern, practice ways to express their feelings about those concerns using a common set of skills, and then work together to address those challenges at home. Couples who come together for support and education will find they are not alone in their efforts to find a place for MS in their relationships. The program can be offered as a one-day or overnight. To review the workshop curriculum go to SharePoint>Programs and Services>Family and Youth Resources>Relationship Matters. To read more about the results of the five-year pilot project please see the paper entitled, "Effectiveness of a Relationship Enrichment Program for Couples Living with MS" in the Spring 2013 issue of the *International Journal of MS Care* (http://ijmsc.org.)

To learn more about the application process, to discuss implementation strategies or if you have any additional questions, please contact Kim Koch at Kimberly.koch@nmss.org or 303-698-6100, ext. 15158.

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RESEARCH/CLINICAL UPDATE

May 2, 2013

Positive Results Announced for Aubagio in Phase III Study of People at High Risk for MS

Among 618 people at high risk of developing MS, significantly fewer people taking oral Aubagio® (teriflunomide, Genzyme, a Sanofi company) for two years had developed clinically definite MS than those taking placebo, Genzyme announced in a press release dated April 25, 2013. People entered into this study had experienced a first neurological episode and had brain MRI findings suggestive of MS (clinically isolated syndrome, CIS), but had not been diagnosed with definite MS. Further results of this study, also known as the TOPIC study, are expected to be presented at a forthcoming scientific meeting.

Background: CIS is a syndrome in which a person experiences a single neurological event suggestive of myelin damage, such as focal weakness, numbness, coordination problems, or decrease in vision in one eye, and also shows brain magnetic resonance imaging findings suggestive of MS. People with CIS may never develop definite MS, or it can be a prelude to being diagnosed with definite MS. The indication for several disease-modifying therapies for MS has been expanded by the U.S. Food and Drug Administration (FDA) to include people with CIS based on clinical trials showing benefits in delaying the risk of developing definite MS. (Read more (http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/diagnosing-ms/cis/index.aspx). To date, there is no oral therapy that is approved for treating CIS.

Aubagio was approved by the FDA in September 2012 for people with relapsing forms of multiple sclerosis. Aubagio is an oral compound that inhibits the function of specific immune cells that have been implicated in MS. Read more about Aubagio (http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/medications/aubagio/index.aspx).

The Study: Investigators worldwide recruited 618 people 18-55 years of age with CIS who showed two or more areas of damage on MRI scans and had experienced their neurological symptoms within 90 days prior to entering the study.

Participants were randomly assigned to receive 7 mg teriflunomide, 14 mg or placebo once daily for 108 weeks. The primary outcome measured was whether or not people developed clinically definite MS (as defined by the occurrence of a second clinical attack).

Reporting on the primary endpoint, the press release states that at two years, people taking Aubagio were significantly less likely to develop definite MS. The risk of conversion to definite MS was reduced by 43% among those taking 14 mg of Aubagio, and by 37% among those taking 7 mg Aubagio, compared to those taking placebo. The results of other endpoints are not included in the press release.

The most common adverse events reported in the Aubagio groups were liver enzyme elevations, nasal inflammation, headache, hair thinning, diarrhea and paresthesia (e.g., burning sensations, pins and needles, stabbing pains). There was one death due to suicide in the placebo arm. The rate of treatment discontinuation due to adverse events was 12.1% among those taking 7 mg Aubagio, 9.1 % in placebo arm, and 8.3% in those taking 14 mg Aubagio.

Next Steps: The press release notes that additional results of this trial will be presented at an upcoming medical meeting. A possible next step would be for the company to apply to the FDA and other regulatory agencies for expansion of Aubagio's indication to include treatment of CIS.

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RESEARCH/CLINICAL UPDATE

May 2, 2013

Research Promotion: Resources and Reminders

Publicizing the Society's research and the grantee(s) in your area advancing this research can help to put a face on the important and relevant work happening in your community. Moreover, it links your area research to the mission of the National MS Society worldwide. Here are some new resources – and a reminder about existing ones – to help you in the important work of MS research promotion.

New Resources:
We have posted **a database of research promotion activities** that were shared by chapters nationwide in the 2012 year-end reports. The database is organized by event type (e.g., donor cultivation, featuring local research, media, etc.). These activities reached nearly 400,000 board members, donors, members, staff, and the general public with information about what's new in MS research and how the Society is a driving force of this research.

We also have posted a **new slide show "Research on Progressive MS,"** which covers the challenges of research on progressive MS and what the Society is doing to drive research on progressive MS.

Find these resources in the Research Promotion section of SharePoint:
http://intranet.nmss.org/Topics/cr/Pages/ResearchPromotion.aspx.

Research Advocates Program
The Research Advocates Program provides a local champion of the Society's research mission – a volunteer recruited to work with other local volunteers and staff to ensure timely communication of research information and materials to constituents and local communities. The Research Advocate also helps plan local events and symposia that highlight local or national MS research

activities, and helps staff and volunteers use research as a means of attracting potential donors. A total of 84 research advocates are currently signed up with this program.

If you are interested in recruiting a research advocate for your chapter, please consult the Research Advocates Program section on SharePoint (http://intranet.nmss.org/Topics/cr/Pages/ResearchAdvocatesProgram.aspx) for information including recruiting tips and a sign-up form.

Research Speakers Bureau

The Research Speakers Bureau is a group of high level volunteers, possessing a scientific or medical education, who help the National MS Society increase understanding and awareness of our research amongst people impacted by MS. Members of the Research Speakers Bureau receive specialized training and resources to communicate the Society's research programs and progress and general information on the NOW campaign through presentations to targeted audiences primarily in their region.

If you would like to utilize a member of the Society's Research Speakers Bureau at your next event, please contact Heather Lee at heather.lee@nmss.org.

Sign Up to Receive Emails Relating to MS Research Promotion

We invite chapter staff to sign up to receive emails relating to promoting awareness of research, such as the following items:

- News items about research that are posted on the web site and included in news sheets
- Notices of upcoming events relating to research, such as national donor calls or webcasts
- The bi-monthly Research Promotion Update, which highlights events and resources relating to promoting awareness of Society research efforts.

If you are interested in receiving these emails, please contact Sara Bernstein at sara.bernstein@nmss.org. Please note that these emails already are already being received by chapter staff who act as liaisons to their volunteer Research Advocates.

-- Cathy Carlson, Associate Vice President of Research Information
Cathy.Carlson@nmss.org
--Sara Bernstein, Research Information Manager, Research Programs
Sara.Bernstein@nmss.org

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RESEARCH/CLINICAL UPDATE

May 9, 2013

Study Finds that the Incidence of MS Appears to be Higher in African American Women Than in Caucasians, Contradicting Previous Findings

A new study of 496 people newly diagnosed with MS found that the risk of developing MS was 47% higher in African American women, compared with Caucasian American men or women. It also found that the risk was 50% lower in Hispanic/Latino Americans, and 80% lower in Asian Americans. Previous research had indicated that the risk of MS was lower in blacks than whites, so these findings warrant further study in a larger sample. Annette Langer-Gould, MD, PhD, and colleagues (Kaiser Permanente, Southern California, Pasadena) report their findings in *Neurology* (2013;80:1734, http://www.neurology.org/content/80/19/1734.abstract).

Background: Epidemiology is the study of populations to examine disease patterns, including variations in geography, demographics, socioeconomic status, genetics, environmental risk factors, and exposure to infectious agents. Studies of incidence (the number of new cases of a condition diagnosed within a set period of time) are one of the ways to explore who is at greater risk. These studies provide vital information about relationships among various risk factors, so that we can better understand who gets MS and why, identify and explain areas with high or low rates of the disease, and assist in planning for health care and other services. Research shows that MS occurs in most ethnic groups, including African-Americans, Asians and Hispanics/Latinos, but is more common in Caucasians of northern European ancestry.

Lead investigator Dr. Langer-Gould has published previously on the epidemiology of MS, and is currently funded by the Society to investigate factors that may affect the risk of an MS relapse after delivery of a child.

The Study: In this study, funded by Kaiser Permanente Community Benefits Fund, Dr. Langer-Gould and colleagues reviewed the records of people diagnosed with MS at Kaiser Permanente between January 1, 2008 and December 31, 2010. These records were drawn from the database of Kaiser Permanente Southern California, a large prepaid health maintenance organization with

more than 3.5 million members. They identified 496 people in the Kaiser database who were newly diagnosed with MS within this time frame. Of the newly diagnosed, African American women, but not men, were found to have a 47% increased risk of MS compared with Caucasian Americans. Hispanic/Latino Americans had a 50% decreased risk; and Asian Americans had an 80% decreased risk.

Comment: This study suggests that African American women have a higher than previously reported risk of developing MS. "This is an interesting finding that warrants further research in larger numbers of people," says Timothy Coetzee, PhD, Chief Research Officer of the Society. "Studies like this one can help the National MS Society address the needs of people with MS. Understanding more about why such differences in MS risk exist may provide clues that will help us end MS forever."

Read more (http://www.nationalmssociety.org/research/end/index.aspx) about research to end MS.

Read more (http://www.nationalMSsociety.org/AfricanAmericansandMS) about the Society's African American Advisory Council, and visit the MSConnection.org community group for African Americans (http://community.msconnection.org/Groups/The_African_American_Experience_with_MS).

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RESEARCH/CLINICAL UPDATE

RESTORE

May 9, 2013

Studies Report Progress Understanding What Drives Repair of the Brain's Insulating Myelin, Which is Damaged by MS

Researchers at the universities of Edinburgh and Cambridge, and at Stanford, have reported separate studies making inroads to understanding factors that stimulate the repair of myelin, the nerve insulation that is a target of multiple sclerosis. These important laboratory discoveries, supported in part by the National MS Society, are still in early stages and need to be confirmed and expanded, but they could eventually lead to promising new therapeutic approaches to stimulating myelin repair to restore function in people with MS. The studies were recently reported in the journals *Brain* and *Nature Cell Biology*.

Background: Multiple sclerosis attacks the brain and spinal cord, damaging the myelin coating on nerve fibers, and also the cells that make myelin, called oligodendrocytes. This disrupts nerve connections. Nerve fibers stripped of their myelin coating may become vulnerable to destruction. One approach to repairing myelin is to stimulate the body's own healing capacity by uncovering the mechanisms involved in myelin regeneration.

There are pockets of spare, immature cells that reside in the brain and which can mature and serve as replacement oligodendrocytes capable of repairing damaged myelin. This natural healing process occurs in people with MS, but it is usually insufficient to overcome chronic damage.

Edinburgh/Cambridge Study: Drs. Tracy J. Yuen, Charles ffrench-Constant (MRC Centre for Regenerative Medicine, University of Edinburgh), Robin Franklin (University of Cambridge) and colleagues investigated an immune messenger protein called endothelin 2 and its potential role in

stimulating myelin regeneration. They found it in high levels in areas of tissue damage (lesions) in brain samples from people who had MS in their lifetimes.

Through a series of studies involving tissues grown in dishes and the use of mouse models, they also found that endothelin 2 appears to stimulate myelin regeneration, as does a molecule that fits into its biological docking site. Although this is still in the basic discovery stage, this suggests a promising new therapeutic approach to stimulating myelin repair. The team was previously supported through the National MS Society's Nervous System Repair initiative and now has Fast Forward support to test myelin repair strategies. (Read more http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=6767) Their paper appeared in the April 2013 issue of *Brain* (136(4): 1035-1047 http://www.ncbi.nlm.nih.gov/pubmed/23518706*)*

Stanford Study: Drs. Victoria Rafalski, Peggy Ho, Lawrence Steinman, Anne Brunet and colleagues, funded in part by the National MS Society, explored the role of an enzyme called SIRT1, which is part of a family of proteins shown to inhibit the development of immature oligodendrocytes in late stages of development. Through a series of studies, they blocked the activity of SIRT1 and observed that more immature oligodendrocytes were formed both in lab dishes and in mouse models. They also found that mice whose SIRT1 was inactivated showed more robust myelin repair after damage. The researchers note that because SIRT1 has also been shown necessary for immune attacks to subside, and it also plays a role in nerve health, its future potential use in MS might require periodic use delivered to specific parts of the nervous system. This study was published in advance online on May 5, 2013 in *Nature Cell Biology* (http://www.nature.com/ncb/journal/vaop/ncurrent/full/ncb2735.html).

Next Steps: If their results are confirmed through further research, these basic laboratory studies provide important clues to mechanisms underlying myelin regeneration. These clues could eventually be translated to promising new therapeutic approaches to stimulating myelin repair to restore function in people with MS.

National
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MARKETING

May 16, 2013	**CC:** All
☐ *Do Not Post on NMSS.org*	
2014 MS Awareness Week Dates	

MS Awareness Week 2014 – March 3-9, 2014
Please mark your calendars now for MS Awareness Week 2014!

The MS Kills Connection > < Connection Kills MS, or "Connections" campaign, launched in 2012 is the centerpoint of our awareness efforts throughout 2013. Because the campaign continues to generate strong media interest, public awareness, and personal engagement, the 2014 awareness campaign will continue to build on the Connections campaign.

MS Awareness Week 2014 will serve as the launch of the Society's year-round awareness campaign, and an important target for coordinated planning. New tools and opportunities to engage will again be made available to support MS Awareness Week activities, but many 2013 materials – including broadcast and radio PSAs – will carry through into 2014.

Additional information about organizational plans will be communicated in early fall.

Questions?
Please contact Chris.Yankee@nmss.org with questions or comments.

National Multiple Sclerosis Society News Sheets

CHAPTER PRESIDENTS

May 16, 2013	CC:
Society Seeks Research Proposals	
Action Requested/Deadline: Application Deadlines in July and August	

To move toward the vision of a world free of MS, the National MS Society supports a holistic portfolio of basic and applied studies relevant to the Society's Strategic Response to MS and our specific research objectives aimed at stopping MS, restoring function, or ending MS forever.

We are sharing news about the Society's next research grant application deadlines in case there are qualified investigators in your area who might consider applying for research support. We want to support the highest quality research and training in areas related to multiple sclerosis. Our next application deadlines are:

- **July 3, 2013** for small pilot project applications
- **August 7, 2013** for research grants
- **August 15, 2013** for most training fellowships

Who is eligible to apply for funding?
The applicant responsible for the project generally must have a post-graduate degree (PhD, MD, DO, DPT or equivalent), be a fellow or faculty member of an eligible institution, and be considered eligible by the institution to apply for an award.

What institutions are eligible?
For investigator-initiated grants and training awards, the applicant's primary appointment must be with a not-for-profit institution (usually a college, university or teaching hospital), and the payee must be a not-for-profit institution. (For Society-initiated research contracts and partnerships, for-profit organizations are eligible.)

How should an investigator apply for funding?
To submit a proposal for research or training support, investigators must first register with our apply online site (www.mssocietyapplyonline.org) and complete a pre-application. Staff of the Research Programs Department review pre-applications to determine whether the research plan is appropriate and relevant to our goals.

More information is available at www.nationalmssociety.org/researchfunding

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RESEARCH/CLINICAL UPDATE

May 23, 2013

MS Trial Alert:
Investigators Nationwide Recruiting People with All Types of MS for Early, Phase I Study to Determine Safety of Experimental Antibody

Summary: Investigators nationwide are recruiting 60 people with all types of MS for a phase I study to determine the safety and tolerability of rHIgM22, an experimental antibody. The study is funded by Acorda Therapeutics, Inc.

Rationale: Although the body repairs some damage to nerve-insulating myelin that occurs in MS, this repair is insufficient. One strategy under study encourages internal "repair" capabilities of immune-system proteins called antibodies. With funding from the National MS Society, Moses Rodriguez, MD, and colleagues (Mayo Clinic Foundation, Rochester, MN) identified a human antibody -- rHIgM22 – that targets and attaches to oligodendrocytes (myelin-making cells). When given to mice with an MS-like disease, the antibodies promote myelin repair. This is the first study of rHIgM22 in humans.

Eligibility and Details: Men and women between the ages of 18 and 70 with a diagnosis of MS are eligible. Women of childbearing potential must have a negative serum pregnancy test, and both men and women must practice adequate contraception for at least 60 days after being dosed. There are detailed exclusion criteria related to laboratory, cardiac, immune and other factors. For more information on these criteria, please contact the site nearest you.

Investigators are testing 6 dose levels sequentially. For each dose, ten participants are being enrolled; 8 are being randomly assigned to receive active treatment (rHIgM22) and 2 are being randomly assigned to receive inactive placebo, both via a single intravenous infusion. Blood samples will be collected from participants before and at specified times for up to 48 hours after dosing, so participants must agree to remain in the hospital for that time. Participants are being followed for 90 days after dosing.

The primary outcome of the study is to determine the safety and tolerability of rHIgM22 in people with MS. Adverse events are being monitored throughout the study. The investigators will also evaluate how this experimental treatment is absorbed in the body, and how the immune and nervous systems react to it.

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please contact the site nearest you. An up-to-date listing of active sites is available on the trial's listing (http://clinicaltrials.gov/ct2/show/NCT01803867) on clinicaltrials.gov. The listing is updated as new sites are activated.

Currently, sites are recruiting in the following cities: Long Beach, CA, Knoxville, TN, Seattle, WA, and Burlington, VT. Sites will soon be recruiting in Sacramento, CA, Indianapolis, IN, Baltimore, MD, Rochester, NY, Denver, CO, Kansas City, KS/MO, Palo Alto, CA, Providence, RI, and San Francisco, CA.

Download a brochure that discusses issues to think about when considering enrolling in an MS clinical trial (PDF).

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RESEARCH/CLINICAL UPDATE

May 30, 2013

Research sheds light on emotional changes in MS

-- Interview with clinical psychologist/researcher Dr. David Rintell

In proclaiming May as National Mental Health Awareness Month, President Barack Obama sought to "shine a light" on the mental health problems experienced by tens of millions of Americans. Emotional changes may be a major concern (http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/symptoms/emotional-changes/index.aspx) for people with MS. Clinical psychologist David Rintell, EdD (Brigham & Women's Hospital, Boston) addresses these issues with people with MS in his practice, and has been funded by the National MS Society's Health Care Delivery and Policy Research (HCDPR, http://www.nationalmssociety.org/research/about-our-research-programs/focus/health-care-delivery--policy-research/index.aspx) program to study ways to help enhance mental health to people with MS.

Do we know enough about emotional changes that can impact people with MS?
Dr. Rintell: No, and it's surprising, considering how prevalent depression and other mental health problems are in people with MS. Very little has been published about what people with MS are looking for in terms of mental health care, and how they feel about the care that they are getting. These types of health policy studies are crucial if we want to improve that care.

What kind of research funding does the Society provide to address these issues?
Dr. Rintell: That's precisely what the HCDPR Program does – it addresses the mental health challenges that MS presents by providing funding to investigators to study that care. The findings of studies like ours are used to provide information to people with MS, caregivers, lawmakers, insurance providers –everyone involved in the process of providing and managing MS care.

What did your project involve?
Dr. Rintell: We were funded by the Society's HCDPR program to identify what people with MS would consider high quality mental health care, and what obstacles may keep people from getting

it. Using questionnaires and focus groups, we surveyed the mental health care experiences of thousands of people with MS. We narrowed these down to determine who had received mental health care in the previous two years, and of those, recruited about 50 people to explore their experiences in focus groups.

So, what is important to people with MS when it comes to mental health care?
Dr. Rintell: People with MS wanted mental health care to be addressed immediately at diagnosis – this is very important for clinicians to understand. The diagnosis itself can be so overwhelming – one participant said it felt like "my whole world came crashing down." People wanted to work with someone who was familiar with MS. They were frustrated if they had to educate the mental health care providers about the disease. Participants also noted that it was helpful to include family members in mental health treatment.

How are these results being used to enhance mental health in people with MS?
Dr. Rintell: The Society has moved in a direction that is fully aligned with the findings of our study – providing support early on to individuals diagnosed with MS and their families. They have developed a training program that targets both mental health and non-mental health clinicians; I have conducted the training program with over 100 mental health providers in New England. I've also developed and tested an intervention for newly diagnosed patients and their families, which we are getting ready to disseminate.

Read more (http://www.nationalmssociety.org/research/about-our-research-programs/focus/health-care-delivery--policy-research/index.aspx) about how research funded by the Society's HCDPR program helps restore function to people with MS.

Read more about emotional changes (http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/symptoms/emotional-changes/index.aspx) that people with MS may experience, and resources provided by the National MS Society, including the MS Navigator program.

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RESEARCH/CLINICAL UPDATE

June 27, 2013

Researchers Co-Funded by the Society Pinpoint Genetic Differences Between African-Americans and Northern Europeans with MS

A nationwide team of researchers has conducted the largest genetic study of people with MS of non-European ancestry, screening for known gene variants in more than 1,000 African Americans with MS, and showing significant differences from white Americans. These differences may help explain differences in disease incidence and activity that are observed between African-Americans and white Americans. Noriko Isobe, MD, PhD, Jorge R. Oksenberg, PhD (University of California, San Francisco) and colleagues from neurology and genetics departments nationwide report their findings in *Neurology* (Published online before print June 14, 2013 http://www.neurology.org/content/early/2013/06/14/WNL.0b013e31829bfe2f.abstract). The authors were funded by the National MS Society and the National Institutes of Health.

Background: Genes are known to play a role in who is susceptible to developing multiple sclerosis, and may also influence the course of the disease. Identifying the exact location of MS genes could help determine who is at risk for developing the disease, and may provide clues to its cause, prevention and better treatment. Research shows that MS occurs in most ethnic groups, including African-Americans, Asians and Hispanics/Latinos; susceptibility rates vary among these groups, with recent findings (http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=7763) suggesting that African American women have a higher than previously reported risk of developing MS. Focusing on ethnic groups with varying levels of susceptibility to MS, and searching for what is common and what is different in their genes may help pinpoint regions that contain MS genes.

The Study: Investigators obtained DNA samples from 1,162 African-Americans with MS and 2,092 African-Americans without MS, as well as 577 white Americans with MS and 461 white Americans without MS. The team looked for similarities and differences in 128 gene variants that had been associated with MS. They confirmed associations of key immune-response genes (HLA)

with MS among African Americans. However, among 73 non-HLA genes that were associated with MS among white Americans, only 8 were associated with MS among African Americans.

Comment: These findings portray significant differences in MS genes between African American and white Americans. This lends further information to efforts to understand differences in MS itself as it is experienced by these two ethnic groups – read more here (http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=117). Additional studies are underway to define all of the genes that help confer susceptibility to MS, which should provide significant clues to understanding how MS is triggered, how it may be better treated, and how it may be prevented.

Researchers Need You: Large number of participants and their families are needed to accelerate this research. People living with MS and their family members can make a difference in studies searching for these genes by donating their DNA from blood samples. If you are interested in participating in this study please read more here (http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=5728) or visit http://msgenetics.ucsf.edu/.

Connect with others: Visit the MSConnection.org community group for African Americans (http://community.msconnection.org/Groups/The_African_American_Experience_with_MS).

Read more (http://www.nationalMSsociety.org/AfricanAmericansandMS) about the Society's African American Advisory Council

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RESEARCH/CLINICAL UPDATE

June 27, 2013

Looking at MS and balance in a new way: An interview with National MS Society Research Trainee Brett Fling, PhD

On July 1, 25 fellows begin research or clinical training fellowships with funding from the National MS Society. The Society funds a spectrum of fellowship programs that allow promising young researchers and clinicians to train with seasoned MS scientists and physicians, facilitating their transitions into independent careers. This training investment has leveraged at least $400 million over the years in MS grant funding from all sources, and launched the careers of some of the most prominent researchers making breakthroughs today.

One of the new fellows is Brett Fling, PhD, whose postdoctoral research fellowship focuses on studying MS and balance with Fay Horak, PhD, an internationally renowned expert in how the brain controls balance, at Oregon Health and Science University.

What can you tell us about balance problems in MS?
Dr. Fling: A growing body of work suggests that balance impairments in people with early stage MS are primarily the result of deficits in "proprioception." Proprioception is the ability to determine your body's position in space in the absence of vision. Imagine closing your eyes and touching your finger to your nose -- this is using your proprioceptive system. Proprioceptive information from the ankles is the primary sensory feedback we use to maintain our balance. Because MS affects the ability of nerves to conduct information, it is likely that problems with transmitting proprioceptive information all the way from the ankles to the brain (and back again) play a big role in deficits in balance control.

What kind of interventions might be helpful to address deficits affecting balance and mobility in people with MS?
Dr. Fling: It is an exciting time for intervention studies due to all of the advances in technology. Training the proprioceptive system is a novel approach to improving balance and we are attempting to make these interventions interactive and engaging. For example, video games

utilizing the Nintendo Wii™ Balance Board allow people to train their proprioceptive system while they are (hopefully!) having a little fun. These balance games require people to shift their weight (right/left and forward/backward) to move their virtual representation on a television screen. In addition to these balance games people can also use the Wii Fit™ yoga games to improve balance and train the proprioceptive system.

Please tell us about your personal connection to MS, and how this connection inspires your work.

Dr. Fling: I have a vested, personal interest in this work because several friends as well as individuals within my own family are living with the debilitating effects of MS. My mother was diagnosed with MS when I was a teenager and her sister was diagnosed just a few years later. Although both have MS, they have dramatically different symptoms and issues, which always fascinated me. This has been a driving force behind my research and keeps me active and engaged in this field.

Your work seems to span highly scientific areas of MS research like neuroscience and imaging, but the results have great clinical impact on balance and mobility – how do you plan to combine these in your long-term career goals?

Dr. Fling: A variety of balance training interventions have been used in people with MS attempting to improve the 3 sensory systems--(proprioceptive, visual, and vestibular **(**inner ear)--that we use to maintain balance. One of the frustrating issues with intervention studies is that some participants improve their balance, while others do not, suggesting that the same balance interventions do not work for everyone. Successful rehabilitation in people with MS requires clinicians to identify the explicit deficits in their patients so that intervention approaches can be specific and effective. In my career as an MS researcher, I want to use neuroimaging (such as MRI) to identify the specific structural and functional neural deficits underlying symptoms such as balance impairment so that we can provide individualized information for rehabilitation.

Please tell us how the Society fellowships are suited to help you fulfill your career goals.

Dr. Fling: This fellowship from the Society is an integral step towards achieving my overall research goal -- to better understand the neural bases of sensorimotor impairments in MS. I believe there is an imperative need to develop rehabilitation approaches that are informed by this research. It is my goal to establish a laboratory with parallel lines of basic and clinically applied rehabilitation research at a major research university. I am grateful to have the opportunity to implement this research.

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RESEARCH/CLINICAL UPDATE

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MS Trial Alert:
Investigators Recruiting 1530 People with Secondary-Progressive MS For Study of Siponimod

Summary: Investigators worldwide are recruiting 1530 people with secondary-progressive MS for a phase 3 study testing the safety and effectiveness of the experimental oral therapy siponimod (BAF312, Novartis Pharmaceuticals AG) versus inactive placebo. The study is funded by Novartis Pharmaceuticals AG.

Rationale: Siponimod is an experimental immune system-modulating therapy that was designed to be a more selective sphingosine 1-phosphate receptor modulator than Gilenya™ (fingolimod, Novartis International AG (http://nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/medications/fingolimod/index.aspx), which was approved in 2010 for adults with relapsing forms of MS to reduce the frequency of clinical relapses and to delay the accumulation of physical disability. Siponimod (BAF312) is a selective sphingosine 1-phosphate receptor$_{1,5}$ modulator. Siponimod previously demonstrated safety and efficacy on MRI scans in a phase 2 study in people with relapsing-remitting MS (*The Lancet Neurology*, Early Online Publication, June 11, 2013, http://www.ncbi.nlm.nih.gov/pubmed/23764350). Siponimod is thought to act by retaining certain white blood cells in the body's lymph nodes, keeping them out of circulation and from entering the central nervous system. Siponimod also distributes effectively to the central nervous system where it may have direct anti-inflammatory or neurobioloical effects.

Eligibility and Details: Participants should be aged 18 through 60, with a diagnosis of secondary-progressive MS (http://www.nationalmssociety.org/about-multiple-sclerosis/progressive-ms/secondary-progressive-ms/index.aspx). Participants cannot have had a recent relapse treated with corticosteroids. Further details on inclusion and exclusion criteria are available from the contact below.

Participants will be randomly assigned to take siponimod (1050 participants) or placebo (510 participants) capsules daily for up to 60 months. The primary outcome being measured by this study is the delay in time to confirmed disability progression as measured by the EDSS scale. Secondary outcomes include disease activity as observed on MRI scans, scales measuring mobility, relapse rates, adverse events, and abnormalities on lab tests.

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please call 1-888-669-6682 or visit the study's clinicaltrials.gov listing at http://clinicaltrials.gov/ct2/show/NCT01665144.

Sites are going to be recruiting in the following cities; contact information for those that are up and running will be available on the clinicaltrials.gov page:

Cullman, Alabama
Mobile, Alabama
Phoenix, Arizona
Scottsdale, Arizona
Berkeley, California
Los Angeles, California
Oceanside, California
Sacramento, California
San Francisco, California
Stanford, California
Torrance, California
Aurora, Colorado
Boulder, Colorado
Centennial, Colorado
Englewood, Colorado
Fort Collins, Colorado
Danbury, Connecticut
Fairfield, Connecticut
North Haven, Connecticut
Newark, Delaware
Washington, District of Columbia
Fort Lauderdale, Florida
Jacksonville, Florida
Miami, Florida
Ormond Beach, Florida
Pensacola, Florida
St. Petersburg, Florida
Sunrise, Florida
Tallahassee, Florida
Tampa, Florida
Grand Rapids, Michigan
Golden Valley, Minnesota
Minneapolis, Minnesota
Las Vegas, Nevada
Lebanon, New Hampshire
Teaneck, New Jersey
Toms River, New Jersey
Voorhees, New Jersey
Albuquerque, New Mexico
Albany, New York
Amherst, New York
Bronx, New York
Latham, New York
Mineola, New York
New York, New York
Patchogue, New York
Plainview, New York
Rochester, New York
Stony Brook, New York
Syracuse, New York
Charlotte, North Carolina
Durham, North Carolina
Akron, Ohio
Bellevue, Ohio
Cleveland, Ohio
Dayton, Ohio
Toledo, Ohio
Oklahoma City, Oklahoma
Portland, Oregon
Philadelphia, Pennsylvania

Vero Beach, Florida
West Palm Beach, Florida
Weston, Florida
Chicago, Illinois
Evanston, Illinois
Flossmoor, Illinois
Palos Heights, Illinois
Lenexa, Kansas
Louisville, Kentucky
Baltimore, Maryland
Boston, Massachusetts
Lexington, Massachusetts
Worcester, Massachusetts
Ann Arbor, Michigan
Detroit, Michigan
Farmington Hills, Michigan
Providence, Rhode Island
Bristol, Tennessee
Cordova, Tennessee
Nashville, Tennessee
Dallas, Texas
Lubbock, Texas
Round Rock, Texas
San Antonio, Texas
Burlington, Vermont
Alexandria, Virginia
Seattle, Washington
Green Bay, Wisconsin
Madison, Wisconsin
Milwaukee, Wisconsin
Waukesha, Wisconsin

Download a brochure that discusses issues to think about when considering enrolling in an MS clinical trial (PDF, http://www.nationalmssociety.org/news/news-detail/download.aspx?id=2583).

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RESEARCH/CLINICAL UPDATE

June 27, 2013

Researchers Explore a Possible Biomarker That May Help Predict MS Disease Progression

Having a simple test to reliably predict the course and progression of multiple sclerosis would greatly inform treatment decisions, but so far such a test or other biological indicator, or biomarker, hasn't been verified for MS. A step in that direction was recently taken by California researchers, in a study co-funded by the National MS Society, examining a molecule called Tob1. Previously they found that when Tob1 is abnormally low in certain blood cells, it leads to a high risk of disease progression, and in this study in mice, they found additional evidence for its role in disease activity. Additional research may lead to the use of this molecule as a predictor of who is at risk for MS progression. Drs. Sergio Baranzini, Schulze-Topphoff and colleagues at the University of California, San Francisco and Stanford University report their findings in the June 24, 2013 issue of the Journal of Experimental Medicine (http://jem.rupress.org/content/210/7/1301.abstract)

Background: Predicting MS onset, disease progression, and response to therapy are critically important for making treatment decisions and improving quality of life for individuals who have MS. Having biomarkers whose presence or absence can serve as an indicator of a particular change in disease is of utmost importance for predicting such changes in MS and for conducting better clinical trials. Reliable predictive biomarkers are not yet available in MS.

Immune cells called CD4+ T cells can make MS worse. In a previous study by the same team, low levels of a molecule called "Tob1," which is seen in CD4+ T cells, were associated with progression from the first clinical attack (known as "clinically isolated syndrome" or "CIS") to clinically definite MS. They reported that 92% of people who had CIS and who also had significantly reduced levels of Tob1 progressed to clinically definite MS within 9 months. In contrast, only 20% of people with normal levels of Tob1 progressed to MS after experiencing the first clinical attack. Thus, low Tob1 may serve as a biomarker for progression from CIS to MS. For the current study, the team further explored the significance of Tob1 by studying a mouse model of MS called EAE.

The study: Through a series of studies, the team found that mice that were genetically engineered to be missing Tob1 in their CD4+ T cells had an earlier onset of EAE, and their disease was more severe, and lasted longer than in mice with normal levels of Tob1. In addition, harmful CD4+ T cells that increase inflammation were present at higher levels, and there were fewer of the regulatory type of immune cells that can dampen inflammation. The researchers concluded that Tob1 appears to directly affect the CD4+T cells that play a large role in EAE and in risk of MS.

Comment: This study offers new evidence that a molecule, called Tob1, associated with immune cells has potential as a promising biomarker that could indicate people who are likely to progress to full-blown MS after a first attack. The study also opens up possibilities for new therapeutic interventions in which increasing Tob1 could possibly prevent full-blown MS after an initial attack, or reduce disease activity in people who already have MS. Additional research is needed to verify and expand these findings.

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RESEARCH/CLINICAL UPDATE

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Joint Medical Meeting (CMSC/ACTRIMS) Focuses on Research Progress and Issues in MS Clinical Care

Multiple sclerosis was the focus of the 27th Annual Meeting of the Consortium of Multiple Sclerosis Centers (CMSC), the 18th Annual Meeting of Americas Committee on Treatment and Research in Multiple Sclerosis (ACTRIMS) and the Fifth Cooperative Meeting of these two organizations. This joint meeting was held May 29 to June 1 in Orlando, FL, and was attended by 1,800 health professionals. Abstracts from both meetings are available online at https://cmscactrims.confex.com/cmscactrims/2013/webprogram/start.html.

Here is a sample of some of the findings reported, among more than 200 presentations on research seeking to stop MS in its tracks (http://www.nationalmssociety.org/research/stop/index.aspx), to restore function to those who have MS (http://www.nationalmssociety.org/research/restore/index.aspx), and to end the disease forever (http://www.nationalmssociety.org/research/end/index.aspx). In most cases, studies presented are considered preliminary. Many of the results will be analyzed more thoroughly, and usually published in peer-reviewed scientific and medical journals. Confidence in a study's findings grows when it is repeated by others, with similar results.

STOP:

Bone marrow transplantation trial: Dr. Richard Nash (Colorado Blood Cancer Institute, Denver) and colleagues are following 24 people with highly active relapsing-remitting MS who were treated with bone marrow transplantation. (In this experimental treatment, people are given infusions of their own bone marrow, which is first extracted and treated, to rid the body of immune cells that drive the MS attack.) The two-year results were reported, showing that both relapses and disease activity observed on MRI scans were significantly reduced. There was significant loss of brain tissue volume at one year, which then stabilized. One person died from loss of neurologic function at 32 months. Adverse events also included one suicide attempt, excessive levels of uric

acid and liver enzymes, and decreased potassium levels. Participants are being followed for a total of five years. Additional research, currently underway, is needed to weigh the risks and benefits of this experimental procedure for people with MS. (Abstract #P20, ACTRIMS)

Gender and disease: MS is more common in women, but men tend to get more severe disease. Sienmi Du and colleagues (University of California, Los Angeles) tested whether male and female sex chromosomes influence the response of the nervous system to injury. In female mice genetically engineered to express the male (XY) or female (XX) chromosome, XY mice experienced a more severe MS-like disease with more nerve tissue damage in the brain and spinal cord. Interestingly, immune responses did not differ. If confirmed in further studies, such findings may help to explain why MS progression occurs faster in men. (Abstract #2.2, ACTRIMS)

RESTORE: Rehabilitation

Stopping Falls in MS: Because of mobility problems and other symptoms, people with MS are at significant risk for falls.

- Debra Frankel (National MS Society) and colleagues reported that participants in the *Free from Falls* (http://www.nationalmssociety.org/multimedia-library/videos--dvds/free-from-falls/index.aspx) program developed by the Society improved in balance and walking, and the psychological impact of falls was reduced. Results were sustained six months after the program, with improvements in confidence and decreases in fear of falling. (Abstract #SX12, CMSC)
- Dr. Jacob Sosnoff (University of Illinois at Urbana-Champaign) found that fall risk decreased significantly and balance improved in 10 people who participated in a 12-week, home-based exercise program focusing on balance and lower limb muscle strength, compared with 12 controls who did not participate. Dr. Sosnoff has additional funding from the Society's pilot program to continue studying how exercise can be used to prevent falls in people with MS. (Abstract#RH05, CMSC)
- Drs. Lisa Vingara (Oregon Health and Science University, Portland) examined falls among 53 people with MS who took from zero to 19 medications. Those taking no medications had a 27% risk of falls, and the odds of a fall increased by 33% with each additional medication. Medications acting on the nervous system were significantly associated with increased fall risk, but not medications affecting the immune or cardiac system. Larger studies are needed to confirm how medications might affect fall risk, so that clinicians can consider this important aspect of MS management to help people maintain mobility. (Abstract #RH36, CMSC)

Read more tips about preventing or managing falls here (http://www.nationalmssociety.org/living-with-multiple-sclerosis/you-can/save-grace-if-you-fall/index.aspx).

Video chatting improves exercise behavior: Dr. Lara Pilutti and colleagues (University of Illinois at Urbana-Champaign) were funded by a Society grant to Dr. Robert Motl to examine whether

video-chat sessions with a behavior change coach could improve the results of a 6-month physical activity program. The results show significant improvements in increasing physical activity – as well as reducing fatigue, depression and anxiety – among those participating in the internet-delivered program versus controls who were not in the program. (Abstract #SX23, CMSC)

Urinary symptoms – common and undertreated: Dr. Kristin Khalaf (University of Arizona, Phoenix) and colleagues conducted an online survey of more than 1,000 people with MS and found that 56% reported that urinary urgency or incontinence bothered them "quite a bit" or "a great deal." Among these people, 46% had not discussed the symptoms with their health care providers and 35% had never been treated for them. Individuals can gain control of bladder issues in MS; read more here (http://www.nationalmssociety.org/living-with-multiple-sclerosis/you-can/control-bladder/index.aspx). (Abstract #SX17, CMSC)

RESTORE: Repair

Estrogen and repair: Dr. Stephen Nye (Endece, LLC) and colleagues reported on a study of the molecules that the sex hormone estrogen acts on in the brain and spinal cord. Estrogen is under study for its potential to treat MS (http://www.nationalmssociety.org/research/about-our-research-programs/targeted-research/gender-differences/index.aspx). The investigators reported that the molecule NDC-1308 reduced cell death in the spinal cord of mice with MS-like disease and activated genes important in the development of myelin-making cells. The company is supporting preclinical research to develop NDC-1308 as a possible future treatment for repairing damage in MS. (Abstract #6.2, ACTRIMS)

END

Characterizing disease in Hispanic/Latinos with MS: The Society funded Dr. Jacob McCauley and a team including Dr. Kottil Rammohan (University of Miami) to study 287 Hispanic/Latinos with MS and compare their experiences to 275 non-Hispanic whites. They reported that Hispanic/Latinos were more likely to experience symptoms of motor weakness, ataxia (problems with muscle control) and bladder problems. Hispanic/Latinos responded more favorably to interferon treatments. The team also looked at genetic differences, but only found differences in immune-related genes that are known to differ in these two populations. The Society's Hispanic/Latino Advisory Council advises the Society on strategies and programs to overcome cultural barriers and make resources more available to this community. Read more (http://www.nationalmssociety.org/living-with-multiple-sclerosis/hispanic-latino-advisory-council/index.aspx) about this council and about Hispanics/Latinos with MS.

Examining virus genes in PP MS: Infectious agents have been investigated at various times as possible triggers of MS, but no single virus or bacterium has been proved to cause the disease. Dr. John Kriesel (University of Utah, Salt lake City) was previously funded by the Society to use novel genetics technology to determine the presence of viruses or bacteria that may not have been identified yet in people with MS. In the study reported here, he and colleague Dr. Benjamin Chan and others used a technique called "deep sequencing" to examine 14 people with primary progressive MS and 7 controls without MS. The activity of genes that instruct viruses known as

retroviruses was significantly increased in people with PP MS. Further studies, about to get underway with Society funding, are necessary in larger numbers of people to determine the significance of these findings. (Abstract #P43, ACTRIMS)

The Sonya Slifka Longitudinal MS Study: A unique tool for studying MS: This study was established by the Society in 2000 to study demographic and disease characteristics, use and cost of health services, access to care, quality of life, and treatment, among 4,500 Americans with MS. Dr. Sarah Minden (Brigham and Women's Hospital, Boston, MA) reported that data collected from this study is being made available to qualified investigators, along with the services of the Slifka study team, which includes physicians, economists, statisticians, policy analysts, and programmers. Studies underway include: the direct and indirect costs of MS, impact of out of pocket costs, financial implications of informal caregiving, pregnancy, and mental health treatment. This database is a unique tool for gathering data to support advocacy, programming, and policymaking efforts. (Abstract #P37, ACTRIMS)

Read more (http://www.nationalmssociety.org/research/index.aspx) about research to stop MS, restore function, and end MS forever.

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RESEARCH/CLINICAL UPDATE

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Society's Research Programs Advisory Committee Meets to Advise on Research Funding and Other Strategic Issues

Summary: On June 13-14, 2013, the Society's Research Programs Advisory Committee (RPAC) met in New York City to consider critical research issues and make recommendations regarding funding for research projects and strategic initiatives. Final funding decisions and timing of research funding will be determined by the Society's CEO based on the RPAC's advice. Members and guests also heard about progress made through the Society's Fast Forward drug development initiative; next steps for a study on risk factors that drive progression; critical challenges posed by reduced government support of research; a new Society clinical fellowship program proposed to increase the number of MS specialists; and the status of ongoing research initiatives.

Details: The RPAC is an advisory committee to the CEO, charged with advising on the implementation the Society's strategic research objectives. The committee meets quarterly, twice in person and twice by conference call. The RPAC is chaired by Dr. Anne Cross (Washington University, St. Louis), and members are MS researchers, clinicians and lay leaders, including members of the National Board (http://www.nationalmssociety.org/ms-clinical-care-network/researchers/scientific-peer-reviewers/download.aspx?id=268). The committee oversees the evaluation of research proposals by primary peer review committees, makes recommendations to the CEO regarding which meritorious projects to fund, and provides advice on critical research issues and policy matters.

Leadership Updates

CEO Report – CEO Cyndi Zagieboylo reminded members and guests that her role is to make sure the Society is responding to the concerns and dreams of people with MS, and securing and spending resources effectively.

- She noted that FY2013 efforts are on track, that Society research commitments are rising, and that the 2014 budget goes even further with $50M (23% of Society revenue) to research.

- She discussed the plan for 2014, which outlines 24 strategies in seven goal areas, and aligns and allocates resources and delineates the pace of their implementation. Key focus areas are supporting research; establishing meaningful ways for people to connect to people, information and resources; and fundraising to drive the work.

Ms. Zagieboylo also noted qualities that make the Society the best investment to find MS solutions, including the fact that we:

- fund more MS research than any other patient group in the world;
- drive global collaboration to speed progress; and
- have paved the way for FDA-approved MS therapies and established standards in diagnosis, symptom management, stem cell research, clinical trial strategies, complementary and alternative medicine, pediatric MS and rehabilitation research.

She pointed to the Society's solid infrastructure, unified efforts, increasingly centralized functions, and scientific management among the factors that drive all of our strategic goals.

CRO Report - Chief Research Officer Dr. Timothy Coetzee reviewed the Society's current research portfolio and strategies, and discussed FY 2013 progress and 2014 activities, goals and challenges. Among recent results for FY2013:

- MS Prevalence Work Group has been recruited to advise on implementation of initiative to provide updated estimate of MS prevalence in the US.
- Barancik Prize finalists have been selected; committee meeting end of June to select inaugural winner of this largest cash prize for MS research innovation.
- Planning for the Tykeson Fellows Conference commenced and main speakers recruited for this meeting to be held with the National Conference.
- Support was provided for coordination of UK and US trials of the nerve-protecting therapy Ibudilast for progressive MS so that results will be combined for better information.
- Other activities include planning for workshops by the Society/ECTRIMS International Clinical Trials Committee related to clinical trial measures related to vision, and co-morbidities (other disorders that may impact health and progression of a person with MS).

Dr. Coetzee noted that the 2014 Budget areas related to research focus on the Society's scientific portfolio; the International Progressive MS Collaborative (expected to release a request for research applications in fall 2013); and excellence in scientific review and management. Challenges include reduced federal funding for MS research, increasing number of research applications being received by the Society, and increasing costs to conduct research projects.

Feedback from RPAC - In response to a request from Ms. Zagieboylo that RPAC members share any concerns or issues on the horizon, many noted that ongoing under-funding and recent National Institutes of Health funding cuts are taking a toll on the ability of MS researchers to maintain their labs and studies afloat. Some possible new funding mechanisms by the Society are under consideration to help address this need.

Presentations on Special Topics

Fast Forward - Guest speaker Melissa Stevens of Faster Cures (of the Milken Institute) described the landscape of drug development efforts by patient groups like the Society's Fast Forward, and their partnerships with biotech and pharmaceutical companies to speed development of therapies. Dr. Coetzee, with Fast Forward Board of Managers Chair Peter Tarricone and staff members and consultants, described successes and lessons from the first six years of Fast Forward:

- So far, Fast Forward has invested in 24 projects, committing a total of $10.6 million to date through its General and Collaborative funds (a strategic partnership with Merck KGaA). Fast Forward investment represents about 7 percent of the Society's research portfolio.
- Fast Forward has also formed partnerships with the MS Society of Italy and the Juvenile Diabetes Research Foundation.
- Investments have ranged from studies related to early and late preclinical studies of medicinal chemistry, safety toxicology, brain penetrance, diagnostics, and models, to clinical trials.
- Much of Fast Forward's investment was generated from donors and partners, and this initiative did not appear to divert funding from other research programs.
- Five investments have filed for or have permission to test their therapies, two are already in clinical trials.
- Fast Forward appears to have a halo effect, with five investments achieving follow-on funding, and three attracting new partners for commercial development of their product.

Fast Forward has succeeded in bringing in new companies not previously considering MS, as a connector between academic institutions and industry, and as a next step for drug discovery from the Society's more basic research programs (such as Promise: 2010 follow-on funding to the University of Cambridge to investigate myelin repair strategies). Going forward, research leadership will consider new ways to facilitate transitioning discoveries made at universities toward preclinical stages of development.

Risk Factors for MS Progression Study Review - Guest MS expert Dr. Howard Weiner and RPAC member Dr. Stephen Hauser reviewed progress made in an international feasibility study, originally funded by the Society's Greater Delaware Valley chapter, testing a way to detect factors that influence the progression or worsening of MS. Since the study, known as the SUMMIT study, was started in late 2010, four centers have worked together to establish the infrastructure, data sharing tools, protocols and patient enrollment that would be needed were this study go forward. Next steps would be to hold a planning meeting with other investigators and to determine how to scale up this short-term study to a full-blown, longer-term study.

MS Physician Workforce - Concerns about a growing shortage of neurologists and MS specialists led to a staff proposal for a new clinical care fellowship to add to existing Society training programs. The proposal is for a mentor-based clinical care fellowship in which experienced MS neurologists receive five years of funding to recruit and train eligible physicians. The RPAC recommended this program, and additional strategies are being considered for attracting more physicians to MS care and research.

Consideration of Research Proposals/Next Steps

Over the spring, the Society's volunteer peer review committees evaluated the merit and relevance of 173 research applications and found 36 to be meritorious. The RPAC recommended support for all of these projects if funding was available. The CEO will consider RPAC recommendations in making research funding decisions. Information about the new projects is expected to be announced in newssheets in September 2013.

National Multiple Sclerosis Society News Sheets

DEVELOPMENT

June 27, 2013	
☐ *Do Not Post on NMSS.org*	
2014 Bike/Walk Blueprint Enhancements	

The following material outlines key changes in the 2014 Walk MS and Bike MS Blueprints from their 2013 counterparts. Additional information about Blueprinting may be found on the Intranet by clicking on the following links:

- Blueprint Flowchart – provides a visual diagram of the Blueprint process
- Job Aid 1 of 2 – Walk MS Blueprinting
- Job Aid 2 of 2 – Walk MS Blueprinting
- Job Aid 1 of 2 – Bike MS Blueprinting
- Job Aid 2 of 2 – Bike MS Blueprinting
- Adding Local Social Media Icons
- Adding a Local Presenting Sponsor

Functionality

- Contacts/Donors link added to the Home page of the Participant Center
  - This is a new feature allowing participants to go right to choose their contacts *prior* to creating an email, so as to avoid confusion
- $1000 level has been added to the donation form for both Walk and Bike
- Event Details removed from left hand navigation
- Ability to add corporate/national sponsors logo
- Volunteer conditional content
- Instructions on how to send email from PC2
- Social Media Icons
- Created new PB pages (About BikeMS, BikeMS Passport Program, Rookie Riders, Where the Money Goes, FAQs)
- Bike: Added All Events button, Two Day ride type, custom suggested messages, DOB is now a mandatory field

- Last year's donors easier to find
- Walk: Create a custom view now at the top of the page
- Layout option changed to one photo
    - Scheduled feature – (Early August 2013)
- Ability to hide donor amounts in scrolls
    - Scheduled feature – (Early August 2013)
- Ability to create a personal note to participant on donation page
    - Scheduled feature – (Early August 2013)

Bike MS Changes

2. Fundraising Options

- 6 – Multiple Registrations box checked (but not locked)
    - Allow a participant to register additional participants in one registration payment

3. Event Options

- A. Define Fundraising Options
    - Max number of Milestones increased from 6 to 15
    - Enable Donations processing for registration transactions (locked)

Walk MS Changes

3. Event Options

- A. Define Fundraising Options
    - Enable Donations 2 processing for registration transactions (locked)

4. Team Options

- Donors can now make gifts directly to teams instead of specific participants

5. Auto Responders

- Updated ARs will be provided in late July

National Multiple Sclerosis Society News Sheets

INFORMATION TECHNOLOGY (IT)

June 25, 2013	**CC:** All
☐ *Do Not Post on NMSS.org*	
Remedy Ticketing System Upgrade	

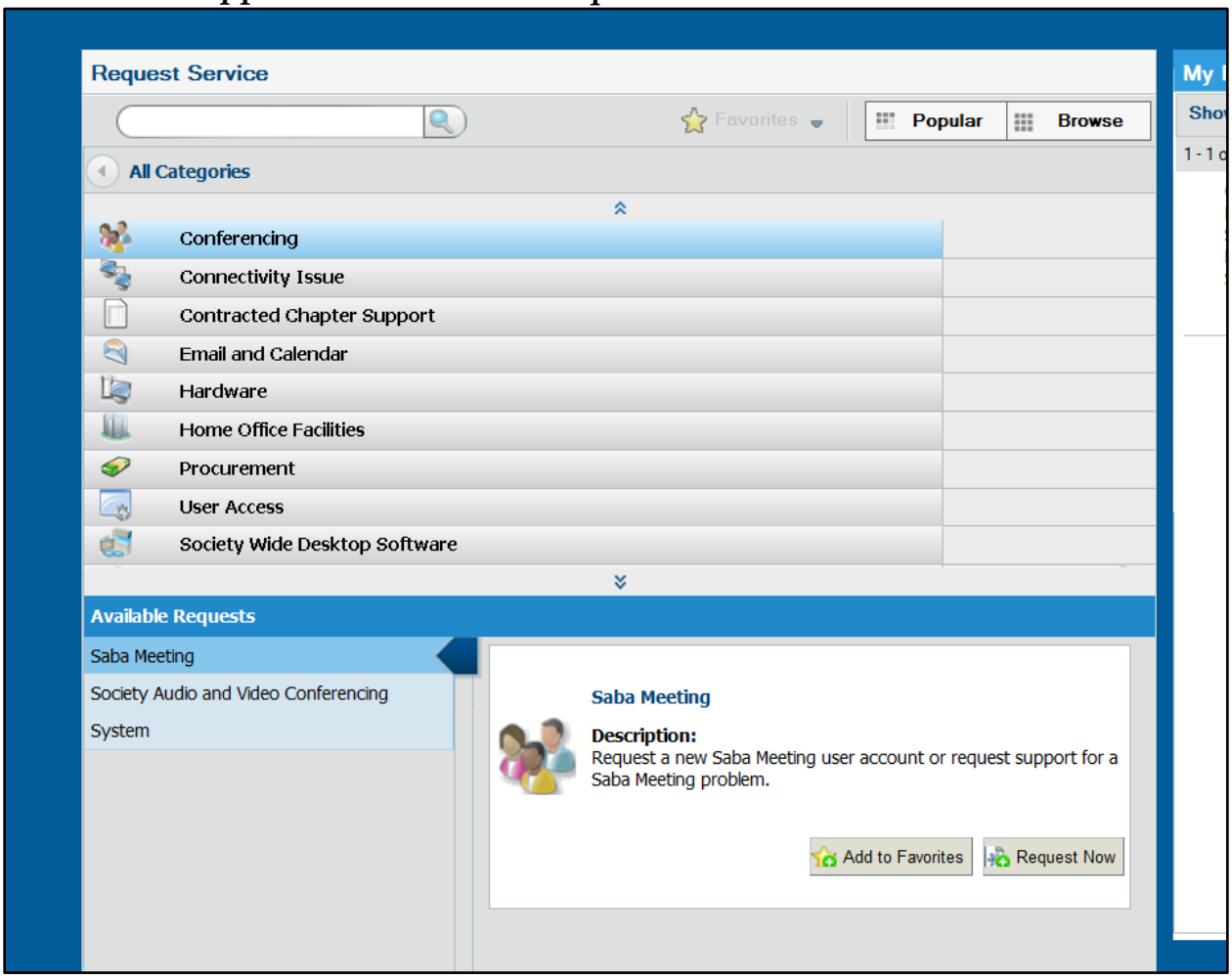
The Remedy Ticketing System, used to report Information Technology requests and issues, will undergo an upgrade in early July 2013. To improve performance and build efficiencies, this upgrade contains several new features focused on ease of use, enhanced category selections and better ticket management.

Training is now available in the Learning and Development System and can be taken at your leisure. The course name is "Remedy Request Training" and the course number is (00002613). The link to training is:
https://nmss.sabanow.net/Saba/Web_wdk/Main/index/preloginclassic.rdf

Additionally, "Open Houses" are scheduled Monday July 1st, at 1:00 PM MT and Tuesday July 2nd, at 10:30AM MT and 1PM MT. To access registration for an Open House, click on http://mt211.sabameeting.com/SiteRoots/main/Public/Events.jsp?locale=en_US&domain=/Customers/nmss&sessionid=S5J7QCWYH4HQGMX and register for one of the "Remedy Ticketing System Open House" sessions. The Open House sessions are designed to answer questions you have about the updated system and to document your feedback and comments on the new features.

To help you become familiar with new functions, certain features will be highlighted in each of the upcoming communications about the Remedy upgrade. This week's highlighted function is:

Streamlined Appearance of Ticket Request Items



- What it is – An updated look to the system improves the usability and navigation of the system.
- Benefits: Using Information Technology industry best practices, we have created more intuitive selections when defining your Information Technology request. The new appearance and category selections are designed to more easily define the work you are requesting.

For additional information or questions, please submit a Remedy ticket or call The Support Center at ext. 16171.

National
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RESEARCH/CLINICAL UPDATE

July 11, 2013

Small Study Suggests Possible Benefit for Skin Patch to Reduce Immune Activity in Multiple Sclerosis

Polish researchers reported results of a small clinical trial in which a skin patch containing myelin peptides (portions of the substance that insulates nerve fibers and is a target of the immune attack on the brain and spinal cord in MS) were administered to 20 people with relapsing-remitting MS via a skin patch, resulting in significant reductions in disease activity on imaging scans and relapses, compared with 10 people given an inactive placebo patch. Over one year, the treatment was found to be safe and well tolerated. Further studies in larger numbers of people are necessary to determine whether this method has potential as a safe and effective treatment approach for people with MS. Agata Walczak, MD, PhD, and Krzysztof Selmaj, MD, PhD (University of Lodz, Poland) and colleagues report their findings in *JAMA Neurology* (Published online July 1, 2013, http://archneur.jamanetwork.com/article.aspx?articleid=1704351).

Background: In MS, immune cells called T cells attack and destroy myelin, the substance that protects nerve fibers, and cause other damage in the brain and spinal cord. These attacks lead to clinical symptoms. In people who don't have MS, these T cells do not attack myelin because it is recognized as part of their own body, and their immune systems are trained to be "tolerant" to myelin and so do not attack it. One goal in MS therapy is to selectively restore normal tolerance to one's own myelin, leaving the rest of the immune system intact. In previous studies, researchers have administered a myelin protein (myelin basic protein) orally to mice with EAE, an MS-like disease, and succeeded in suppressing disease, but a clinical trial of this approach involving people with MS was not successful.

The skin is the first line of immune defense, and contains large numbers of immune cells. Applying myelin peptides to the skin of mice with an MS-like disease resulted in suppression of disease (Journal of Autoimmunity, 2007;28:208, http://www.ncbi.nlm.nih.gov/pubmed/17442539). The current study tested this approach in a small study in people with relapsing-remitting MS.

The study: Investigators enrolled thirty participants with relapsing-remitting MS, and randomly assigned 16 to receive a 1-mg patch containing a mixture of three myelin peptides (myelin basic protein, proteolipid protein, and myelin oligodendrocyte protein), four to receive a 10-mg myelin peptide patch, and 10 to receive an inactive placebo patch. The adhesive skin patch was placed on the right upper arm and was changed once a week for 4 weeks and then once a month for 11 months. MRI scans were performed at the start of the study and every three months until the end of the study.

The primary outcome measured was whether treatment reduced new disease activity seen on MRI scans significantly more than placebo, and secondary outcomes measured included other MRI findings, annual relapse rate, the proportion of relapse-free patients, and the proportion of patients who experienced 3 months of confirmed disability worsening, as measured by the EDSS disability scale.

The investigators reported that for those on the 1-mg patch, disease activity on MRI scans was reduced significantly, a reduction that was detected at three months of treatment. The annual relapse rate was reduced by 69.3% versus placebo. The proportion of relapse-free patients was 63% of the 1-mg group, versus 10% of those on placebo. The proportion of those with worsening disability decreased by 51%. The 10-mg dose was less effective. No serious adverse events occurred. A mild local skin reaction was observed in some people receiving the myelin peptide patch but resolved without treatment. Laboratory test results also did not show any blood, liver or kidney abnormalities.

Comments: This study used a novel and intriguing attempt to induce the immune system to stop attacking the nervous system in people with relapsing MS. Further studies in larger numbers of people are necessary to determine whether this method has potential as a safe and effective treatment approach for people with MS.

Read more (http://www.nationalmssociety.org/research/about-our-research-programs/focus/research-on-the-immune-system/index.aspx) about novel immune system research in MS.

Read more (http://www.nationalmssociety.org/research/stop/index.aspx) about efforts to stop MS in its tracks.

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RESEARCH/CLINICAL UPDATE

July 11, 2013

MS Trial Alert:
Investigators Recruiting For Study of Lower Dose of Gilenya Versus Copaxone In MS

Summary: Investigators worldwide are recruiting 2550 people with relapsing-remitting MS to study the safety and effectiveness of a lower dose of Gilenya® capsules (fingolimod, Novartis Pharmaceuticals AG) versus the approved dose as well as the daily standard dose of Copaxone® (glatiramer acetate, Teva Pharmaceutical Industries, Ltd.). The study is funded by Novartis Pharmaceuticals AG.

Rationale: Gilenya was approved by the U.S. Food and Drug Administration (FDA) in 2010 for adults with relapsing forms of MS to reduce the frequency of clinical relapses and to delay the accumulation of physical disability. Gilenya (http://nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/medications/fingolimod/index.aspx) is a new class of medication called a sphingosine 1-phosphate receptor modulator, which is thought to act by retaining certain white blood cells in the lymph nodes, thereby preventing those cells from crossing the blood-brain barrier into the central nervous system. Preventing the entry of these cells reduces inflammatory damage to nerve cells.

Gilenya was approved at a .5 mg dose; this study is testing the effectiveness of a lower dose, .25 mg, versus the approved dose and compared to another approved disease-modifying therapy, Copaxone.

Copaxone is a synthetic protein that simulates myelin basic protein, a component of the myelin that insulates nerve fibers in the brain and spinal cord. It seems to block myelin-damaging T-cells through a mechanism that is not completely understood. Copaxone is approved by the FDA to reduce the frequency of relapses in patients with relapsing-remitting MS and is also approved for use in individuals at high risk for MS.

Eligibility and Details: Participants should be aged 18 through 65, with a diagnosis of relapsing-remitting MS. Further details on inclusion and exclusion criteria are available from the contact below.

Participants will be randomly assigned to take Gilenya capsules daily at either the approved dose (0.5 mg) or at a reduced dose (0.25 mg), or Copaxone (20 mg injected daily under the skin) for 12 months. The primary outcome being measured by this study is the annual relapse rate. Secondary outcomes include drug safety and tolerability, disease activity as observed on MRI scans, brain tissue volume loss and a treatment-satisfaction questionnaire.

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please visit the study's clinicaltrials.gov listing at http://clinicaltrials.gov/ct2/show/NCT01633112.

Sites are going to be recruiting in the following cities; contact information for those that are up and running will be available on the clinicaltrials.gov page:

Albany, NY
Alexandria, VA
Altoona, PA
Amherst, NY
Bellevue, OH
Boston, MA
Buffalo, NY
Charlotte, NC
Cullman, AL
Dallas, TX
Denver, CO
Derby, CT
Evanston, IL
Fairfield, CT
Farmington Hills, MI
Flossmoor, IL
Freehold, NJ
Hammond, LA
Hershey, PA
Houston, TX
Huntsville, AL
Indianapolis, IN
Jacksonville, FL
Kansas City, MO
Louisville, KY
Memphis, TN
New York, NY
Newark, DE
Northbrook, IL
Oklahoma City, OK
Philadelphia, PA
Phoenix, AZ
Pompano Beach, FL
Providence, RI
Quincy, MA
Richmond, VA
Saint Louis, MO
Seattle, WA
Sherman, TX
Spartanburg, SC
Springfield, MA
St. Louis, MO
Tampa, FL
Toledo OH
Torrance, CA
Tulsa, OK
Washington, DC
West Des Moines, IA
West Palm Beach, FL

Download a brochure that discusses issues to think about when considering enrolling in an MS clinical trial (PDF, http://www.nationalmssociety.org/news/news-detail/download.aspx?id=2583).

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RESEARCH/CLINICAL UPDATE

July 1, 2013

National MS Society Commits $2.5 Million to Support Research by Pediatric MS Network

-- Nine pediatric MS centers across the country will benefit from continued Society investment

The National Multiple Sclerosis Society has just committed $2.5 million to support research by the Network of Pediatric MS Centers (NPMSC) beginning July 1, 2013. Funding for the nine-center network provides essential infrastructure to facilitate research, including searching for the cause of MS by studying risk factors for the disease in children, close to the time of exposure. This support for data coordination can be leveraged to answer other important research questions to advance our understanding of the disease in this most vulnerable group.

The Society's renewed investment supports research activities of the individual centers and the University of Utah Data Coordinating and Analysis Center, which is responsible for patient registry and center collaboration. It also gives NPMSC members — Children's Hospital Boston, Loma Linda University, Massachusetts General Hospital, Mayo Clinic College of Medicine, State University of New York at Buffalo, Stony Brook University Medical Center, Texas Children's Hospital, University of Alabama at Birmingham and University of California San Francisco — the chance to leverage additional funding sources for specific research questions.

"This investment provides the infrastructure and research support needed to keep this unique network — with the largest group of well-characterized pediatric MS cases in the world — moving forward," said Dr. Timothy Coetzee, National MS Society chief research officer. "Driving research to improve the care of children affected by MS and determining what triggers this disease is part of our commitment to all people living with MS."

The NPMSC was launched with Society funding in 2006 to set the standard for pediatric MS (http://www.nationalmssociety.org/about-multiple-sclerosis/pediatric-ms/index.aspx) care, educate the medical community about this underserved population, and create the framework to conduct critical research — both to understand childhood MS and to unlock the mysteries of MS in adults. This initiative, funded through the Society's Promise: 2010 campaign, laid the

groundwork for current studies by the NPMSC to measure clinical and cognitive manifestations of early-onset MS, and track environmental and genetic triggering. In contrast to adult MS, pediatric MS appears to have a narrower window of onset with more rapid and pervasive cognitive symptoms, which need to be better understood if effective treatments are to be provided.

The network has a close alliance with global research efforts through the International Pediatric MS Study Group (http://www.nationalmssociety.org/about-multiple-sclerosis/pediatric-ms/international-pediatric-ms-study-group/index.aspx), convened by the Society in 2002, and which now includes leadership from the MS International Federation, other MS societies, and medical and scientific leaders from more than 15 counties.

"The Network of Pediatric MS Centers is a strategic investment that will help us achieve our most important goal — a world free of multiple sclerosis," said Cyndi Zagieboylo, president and CEO of the National MS Society. The network will continue to systematically expand to other centers to enhance research efforts.

National Multiple Sclerosis Society News Sheets

ADVOCACY

July 11, 2013	**CC:** Chapter Presidents
	Programs & Services
July 16 Webinar on Health Insurance Exchanges and Open Enrollment	

As previously announced, the Healthcare Reform Implementation Team will hold a webinar on Tuesday, July 16th at 3:00 pm EST on 'Getting the Word Out About Health Insurance Exchanges and Open Enrollment'. The intent of the 60 – 90 minute webinar will be to familiarize Society staff and interested others about the October 1st launch of the Health Insurance Exchanges and other upcoming changes to health coverage resulting from the Affordable Care Act.

It will include an overview of the Society's involvement in ACA implementation to date, key messages for people with MS, preparations for the Exchange start-up, and what Society staff and chapters can do to help get the word out.

There is no registration for this 60 – 90 minute webinar, which will be recorded for later viewing through the Learning & Development System. All are welcome, although Government Relations and Programs & Services staff are particularly encouraged to participate.

Use the link to attend the meeting on July 16th.

http://mt211.sabameeting.com/GA/main/00000164b1430000013f897d7534889c

Dial-in information:
Phone Number 1: 1-888-279-3775 (external) or 15100 (internal), plus Access Code: 10450

Contact Kim Calder for additional information.

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DEVELOPMENT

July 11, 2013	**CC:** Marketing
Update on National Team Weeks / Blitz Days	

As chapters finalize Walk MS, Bike MS and Challenge Walk campaign plans for 2014, we know you all will be incorporating Team Weeks and Blitz Days into these plans. We want to provide an update as this continues to be a core strategy for our special events as outlined in the Special Events Implementation Plan.

The Special Events Implementation Team will be reviewing the Team Week program as it now stands. We recognize the need for Team Weeks and Blitz Days to be strategically executed and based on the dates of your events to be effective.

We will still hold National Team Celebration Week during November, along with Team Captain Cultivation Week in January (for Spring events) and a Team Week during MS Awareness Week. The remainder of the Team Week program will be addressed in the forthcoming Bike MS and Walk MS Acquisition, Retention and Cultivation Plans. Email templates will still available for use by all chapters.

2013-2014 Team Weeks
National Team Recognition Week – November 11-15, 2013
Team Captain Cultivation Week – January 6-10 , 2014
MS Awareness Week – March 10-14, 2014* (MS Awareness Week)

**Dates for MS Awareness Week are not yet confirmed; this date may change*

If you have questions, please contact: Sarah Klein at sarah.klein@nmss.org or 303.698.6100 x15170

National Multiple Sclerosis Society News Sheets

PROGRAMS & SERVICES

July 18, 2013	**CC:** Chapter Presidents
2013 North American Education Programs- Shipment of Materials	

This year's North American Education Program (NAEP), Making Treatment & Lifestyle Decisions: Managing Benefits & Risks, **will ship to both chapters and self-help group leaders in late August.**

NAEP MATERIALS:

This year's chapter shipment will include 5 DVDs and 25 program booklets, except for those chapters that have already communicated a different quantity. Additional program materials are available from chapter supplies.

The self-help group meeting in a box tool kit includes:

- Cover letter
- Facilitator's guide
- 1 DVD
- 15 Program Booklets
- 15 Program Outcome Surveys

All materials including the cover letter, facilitator's guide, program booklet and video link will be available for download on SharePoint and on the Resources and Support for Connection Program Volunteers page of the website. Group leaders in need of additional program materials will be instructed to contact their chapter liaison with those requests.

In the coming weeks we will email connection program liaisons instructions on updating your self-help group toolkit mailing list in Altair. The deadline to complete updating will be August 2.

PROGRAM SURVEY

A program outcome measurement tool has been created for this year's NAEP to be used for at your in-person programs (hard copy and Survey Monkey.) You can download a copy of the program survey from SharePoint and the FTP server in the NAEP 2013 folder at ftp://ftp.nmss.org/.

Username: *materials*

Password is *materials123*.

The Survey Monkey version is available at www.surveymonkey.com/s/GFDXCG7.

NAEP PROMOTION

Marketing tools, including a postcard template and email blast template with header and suggested copy, will be available on the FTP server in the NAEP 2013 folder by the end of August.

Questions? Contact Doris Lill at doris.lill@nmss.org or 303-698-5167 (internal 15167#)

National Multiple Sclerosis Society News Sheets

PROGRAMS & SERVICES

July 18, 2013	CC:
Summer Issue: MS Clinical Care Connection	

The e-version of the Summer issue of *MS Clinical Care Connection* will be distributed on July 25, 2013. The PDF version will also be posted on the Society's website (http://www.nationalmssociety.org/for-professionals/index.aspx).

The topic of this issue is Disease Modifying Therapies. In this issue we highlight Tecfidera®, the newest disease modifying agent for MS to be approved by the FDA, discuss Lemtrada™ and pegylated interferon which are likely to be approved this year and offer resources to clinicians about collaborative decision-making with their patients.

Please copy and distribute the PDF version of the newsletter to those health care professionals for whom we do not have e-mail addresses. And, please make every effort to collect e-mail addresses for those clinicians and others who might wish to receive the e-version. Our distribution list is growing steadily—thank you for your efforts in this regard.

As a reminder, the e-mail addresses are pulled from Altair from the following records:

- Service Provider Records in the following categories:
  - Partners in MS Care
  - Allied Health
  - Physicians
  - Emotional Support: Counselors (Professional)
- Customer Service Records in with an Interest Code of 'Health'

Duplicate records are removed but only for exact duplicates (e.g. bob.smith @neurologyassociates.com—from the service provider record and bob.smith@gmail.com--from the customer record, would not be de-duped, even if they are the same person.) Please let me know if you have questions about these reports.

As always, we appreciate your feedback about the newsletter and also welcome ideas for future topics. Please talk to your Clinical Advisory Committee and other health care professionals in your community to solicit their ideas and feedback.
Questions? Contact Deb Frankel at debra.frankel@nmss.org or 212-476-0408 (10408).

National Multiple Sclerosis Society News Sheets

CHAPTER PRESIDENTS

July 18, 2013	**CC:** All

Volunteer Engagement Survey

A Volunteer Engagement Survey was sent to 39,000 current and prior Society volunteers in the first quarter of FY2013. The survey was designed to solicit feedback and measure volunteer satisfaction. After collecting and analyzing all of the responses, an Executive Summary was compiled as a way to share the information.

Survey respondents told us that we are doing well in some areas and that we have opportunities for improvement in others. Two themes emerged as the key areas of focus for increasing volunteer satisfaction:

- Communication
- Meeting the Needs of Volunteers

The Society is addressing those areas for improvement by implementing the Volunteer Engagement Implementation Plan. Key elements of the plan are:

- Training of Society staff, developing the knowledge and skills to more fully engage volunteers
- A Society-wide orientation that will provide information about who we are, what we do and how we do it, and be easily accessible on the internet
- Specialized training will be developed and delivered for all Society volunteers serving in some of the key, common volunteer roles
- A recruitment toolkit will provide Society staff with the tools to ensure that we are fully utilizing the talents and skills of our volunteers, in ways that are most meaningful to them
- A recognition toolkit will be developed as a resource for Society staff, addressing the need for ongoing volunteer recognition.

A document containing the detailed survey responses is also available on Share Point, including nearly 800 responses to the open ended question: Do you have any suggestions regarding how the Society can better engage volunteers?

For more information, please read the Executive Summary.

Contact:
Michele Groden
Michele.groden@nmss.org

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RESEARCH/CLINICAL UPDATE

July 22, 2013

National MS Society Joins with the National Institutes of Health to Fund a Major Trial of a Re-Purposed Therapy in Progressive MS

Investigators at the Cleveland Clinic Foundation are launching a phase II clinical trial of ibudilast (MN-166, MediciNova, Inc.), an oral anti-inflammatory agent, in 250 people with progressive forms of MS. The study is principally funded by NeuroNEXT Network, a clinical trials initiative of the National Institutes of Health, with additional support by MediciNova, the company that will supply ibudilast. The National MS Society actively advocated for this uniquely collaborative trial, and is also providing funding support because it aligns with the Society's strategic focus on progressive MS, and may answer important questions about the best ways to measure the benefits of therapies aimed at protecting the nervous system from MS. The trial will be conducted at 28 sites across the U.S. under the leadership of Principal Investigator Robert Fox, M.D., M.S., FAAN, Staff Neurologist at the Mellen Center for Multiple Sclerosis at Cleveland Clinic. The National MS Society will provide additional information about how to volunteer for this trial when the centers are ready to begin recruiting participants.

"There is a significant, unmet need for treatments that can benefit people with progressive forms of MS," said Timothy Coetzee, PhD, Chief Research Officer of the National MS Society. "This clinical trial of ibudilast will provide important information on a potential way to stop MS damage, as well as how to measure treatment benefits, and aligns well with the Society's research agenda for stopping MS progression." This could lead to shorter, more effective trials and the potential for getting new therapies to people with MS faster.

Background: Ibudilast inhibits an enzyme called phosphodiesterase, resulting in suppression of inflammation. While considered a "New Molecular Entity" in the United States and Europe, ibudilast is marketed in Japan and Korea to treat cerebrovascular disorders and asthma. It is being investigated in the U.S. for its potential to treat drug addiction.

In a previous study, ibudilast did not reduce relapses or MRI-observed new lesions in a phase II trial of 292 people with relapsing MS. However, some evidence that this agent could protect the nervous system from damage (neuroprotection) was observed. Frederick Barkhof, MD, PhD (VU University Medical Center, Amsterdam) and colleagues published these findings in Neurology (2010;74:1033 http://www.neurology.org/content/74/13/1033.abstract).

This Study: Dr. Fox and his colleagues at Cleveland Clinic will collaborate with co-investigators at 28 academic medical centers in the NeuroNEXT Network. The trial is expected to require approximately three years for enrollment, treatment, and data analyses. The trial will be recruiting individuals who have either primary-progressive MS (http://www.nationalmssociety.org/about-multiple-sclerosis/progressive-ms/primary-progressive-ms/index.aspx) or secondary-progressive MS (http://www.nationalmssociety.org/about-multiple-sclerosis/progressive-ms/secondary-progressive-ms/index.aspx) and who meet specific entrance criteria. Like the Society's previous investment in a clinical trial of estriol (http://clinicaltrials.gov/show/NCT00451204), this trial is an example of how the Society can join with multiple partners to facilitate testing of an "on the shelf" therapy in people with MS.

The National MS Society will provide additional information about how to volunteer for this trial when the centers are ready to begin recruiting participants.

Read more about progressive MS http://www.nationalmssociety.org/about-multiple-sclerosis/progressive-ms/index.aspx

Read more about research in progressive MS http://www.nationalmssociety.org/research/about-our-research-programs/research-in-progressive-ms/index.aspx

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RESEARCH/CLINICAL UPDATE

July 25, 2013

Trial Results: Dronabinol, an Oral Cannabis/Marijuana Derivative, Did Not Slow MS Progression

Results have been reported from a clinical trial testing whether dronabinol (a synthetic Cannabis/marijuana derivative) slows progression in people with primary-progressive or secondary-progressive MS. This three-year trial, conducted based on previous lab studies suggesting these types of "cannabinoids" may protect the nervous system, was unable to show benefits against progression. Results of the CUPID trial were announced in 2012, and were published early online on July 13, 2013 in *Lancet Neurology* (http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(13)70159-5/abstract) by Dr. John Zajicek (Plymouth University Peninsula Schools of Medicine and Dentistry) and colleagues in the United Kingdom.

Background: Well known for its mind-altering properties, marijuana is produced from the flowering top of the hemp plant, Cannabis sativa. Various derivatives and synthetic versions of Cannabis, and the plant itself, have been tested for different MS symptoms, with mixed results. The National MS Society is currently supporting a clinical trial of different forms of Cannabis products to test their ability to relieve spasticity in people with MS. This California-based trial is currently recruiting (http://clinicaltrials.gov/ct2/show/NCT00682929) participants.

The CUPID study reported here was based on data from the laboratory suggesting that cannabinoids may offer protection against nervous system damage such as that caused by MS. The CUPID study was funded by the UK Medical Research Council, UK MS Society, MS Trust and others. Dronabinol is a synthetic version of tetrahydrocannabinol, taken orally as a capsule.

The study: Dr. Zajicek and colleagues conducted the multi-center CUPID (cannabinoid use in progressive inflammatory brain disease) trial involving 498 people with primary- or secondary-progressive MS. Participants had varying degrees of gait impairment and other symptoms.

Two-thirds of the participants were administered oral dronabinol, and one-third took inactive placebo, for three years to see if dronabinol could slow progression of MS.

The primary outcomes that were measured after three years were progression in the EDSS (expanded disability status scale) score and change in a portion of the MS Impact Scale related to physical impact (MSIS-29-PHYS; self-reported by the patient). Imaging of the brain using MRI was also performed to look for shrinkage (atrophy) of the brain and to measure MS disease activity. Disease progression was checked at 3 and 6 months and then every 6 months for 3 years.

Results: Although no serious safety concerns were identified, unfortunately, dronabinol was unable to stop MS disease progression or brain atrophy, and did not affect the occurrence of new areas of disease activity in the brain. Analysis of a subgroup of people in this study suggested a possible benefit from dronabinol in those who began the trial with milder disability, but not in those who began the trial with more severe disability. The observation of no effect on brain shrinking suggests that dronabinol does not protect the brain, at least in these circumstances and in this population. Whether dronabinol can protect the brain during earlier stages of MS remains to be tested.

The authors note that participants in both the treatment and placebo arms experienced less disease progression than was expected over the course of the trial. This makes identification of a treatment benefit more difficult to detect.

The EDSS itself has limitations, and the National MS Society is supporting efforts to find better ways to assess disability (http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=7680) and to identify biomarkers to more precisely and objectively measure possible therapeutic benefits.

The search for treatments that can stop MS disease activity and progression is an important research priority for the National MS Society, and the Society is currently sponsoring several clinical trials of neuroprotective therapies in people with MS. Download a fact sheet about National MS Society research efforts in progressive MS (http://www.nationalmssociety.org/research/about-our-research-programs/research-in-progressive-ms/download.aspx?id=41410).

Read more about research in progressive MS (http://www.nationalmssociety.org/research/about-our-research-programs/research-in-progressive-ms/index.aspx)