



MARKETING & DEVELOPMENT

January 18, 2012

CC: All

January 2013: E-communications Update

January National MS eNEWS

Send date: 1/17/13

Audience: Full List

The January National MS eNEWS was sent on Thursday, January 17. Content included a feature about how eye scans can help track MS activity, as well as information about the January 30 webcast on 2013 MS research and an MS risk factor study currently seeking participants. Readers were also encouraged to watch the “Mood Changes and MS” MS Learn Online video series and alerted to a Feb 1 deadline for IRA charitable tax-free gift opportunity.

Contact Information

For editorial questions or suggestions regarding our National MS eNEWS, please contact Gary at gary.sullivan@nmss.org or 212-476-0538 (or 10538).

For questions about our national e-communications strategy, please contact Rich at rich.sarko@nmss.org or 303-698-6100 x15171.



PROGRAMS & SERVICES

January 17, 2013	Chapter Presidents
	Marketing and Development
<u>2013 Scholarship Program Information</u>	

The deadline for accepting online scholarship applications for the 2013 Scholarship Program has closed (January 15, 2013), and it's time to start gearing up for next steps.

Scholarship Manual: Please find the Scholarship Manual on SharePoint under Topics>Programs & Services>Scholarship Information. The manual includes program procedures, FAQs, and a timeline of tasks, which is especially helpful to have on hand over the next several months.

Reviewer Guidelines and Scoring Sheets: Now is a good time to start recruiting your application review committees and preparing the reviewer materials. Please see the Scholarship Manual for details on how to conduct a local review. Reviewer guidelines and scoring sheets are also posted separately on SharePoint.

Fees: As a reminder, the flat fee to receive all applications is \$800. If you offer renewals, the cost is \$75 per renewal. As described in the budget package, scholarship fees are "usage fees" and are not incorporated into NPE for 2013. Chapters will be invoiced for scholarship awards and fees in early June.

Bimbo Bakeries USA Scholarship Campaign: Bimbo Bakeries USA (BBU) raised \$77,136 for scholarship through their fall "Help Erase the Impact of MS" back-to-school bread promotion. As communicated in the July 16 news sheet, BBU launched the campaign throughout Sam's Club locations with the goal of raising \$400,000 to benefit Top Scholars and chapter scholarship applicants nationwide. Although falling short of their target, these generous funds received from BBU will be utilized to support 2013 Top Scholar recipients representing chapters across the country.

Questions? Contact Wenda Carlson at 303-698-6100, ext. 15152 or wenda.carlson@nmss.org.



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RESEARCH/CLINICAL UPDATE

January 17, 2013

Researchers Recruiting 5,000 First-Degree Relatives of People with MS for Genetic/Environmental Research Study

Researchers from the Harvard Medical School, Brigham and Women's Hospital, and Partners Multiple Sclerosis Center are recruiting 5,000 subjects who have at least one first-degree relative with a diagnosis of MS. The goal of the study is to identify the genetic, environmental and immune profiles that may increase a person's risk of developing MS. A first-degree relative could be a parent, sibling, or child of a person with MS, and the study is limited to those between 18 and 50 years of age. The GEMS (Genes and Environment in MS) study is led by primary investigator Philip De Jager, MD, PhD, a Harry Weaver Neuroscience Scholar of the National MS Society, and co-investigator Zongqi Xia, MD PhD, a recipient of the National MS Society and American Brain Foundation Clinician Scientist Development Award from the National MS Society.

Background: An individual's risk of developing MS increases several-fold if a close family member has MS. There is currently no way to predict which family members will develop MS. Genetic, environmental and immunologic studies to date have identified key markers that are associated with the risk of MS. The GEMS Study is gathering genetic material (DNA) and environmental exposure history from participant as well as blood samples and brain magnetic resonance imaging (MRI) as an option. Investigators are testing the performance of a new method of identifying persons at risk for MS. Identifying high-risk individuals will influence the design of effective preventive strategies for MS.

The Study: Investigators are recruiting 5,000 first-degree relatives of MS patients. A first-degree relative could be a parent, sibling, or child between 18 and 50 years of age. The first-degree relative may or may not have an existing diagnosis of MS, but must have the ability to provide consent and be willing to participate in the study.

All 5,000 participants are being asked to donate a saliva sample for DNA analysis and complete a questionnaire about neurologic history, family history and potential environmental exposures. Based on answers to this questionnaire and the DNA analysis, the team will be collecting blood samples and MRI scans from a subset of participants who chose to participate in that part of the study. The team will contact all participants every three years for up to 20 years to obtain an updated questionnaire.

There is no cost to participate in the study, and participants can reside anywhere in the United States because no travel is required to enroll in the study. Some travel may be required for the optional MRI portion of the study and the participant will be reimbursed for travel cost.

All participants are assigned a unique study identification number to ensure complete confidentiality.

Using this information, the investigators plan to pinpoint specific genetic, environmental, and immunologic factors that may increase a person's risk of developing MS. These findings may allow for earlier intervention to slow down MS or help to develop strategies for preventing the disease.

Contact: For more information about this study, please contact the research coordinator:

Emily Owen

Phone: (617) 264-5980

****E-mail (preferred for more rapid response):** bwhmsstudy@partners.org

Study Web site: http://dejager_lab.bwh.harvard.edu/

Facebook page: <http://bitly.com/GEMSstudy>



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RESEARCH/CLINICAL UPDATE

January 17, 2013

Research Committee Meets to Advise on Funding and Other Critical Issues

Summary: On January 3-4, 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, fellowships and strategic initiatives. RPAC members evaluated results of proposal reviews by our volunteer peer review committees and made funding recommendations of up to 65 meritorious projects for multiyear commitments of up to \$18 million. They also heard from invited experts about issues including marijuana in MS, possible ways to increase the number of neurologists who specialize in MS, activities of the International Progressive MS Collaborative, and the status of other 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. It includes MS researchers and 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 RPAC oversees the evaluation of research proposals by primary peer review committees, and makes recommendations to the CEO regarding which meritorious projects to fund. In addition, the RPAC provides expert advice on critical research issues and policy matters.

This was the last meeting chaired by Dr. Richard Rudick (Cleveland Clinic Foundation), who as outgoing chair will serve for one more year while incoming chair Dr. Anne Cross (Washington University) takes over volunteer leadership of the RPAC.

Leadership Updates

CEO Cyndi Zagieboylo summarized some of the year's successes as the Society continues to evolve as a unified organization, including increasing research spending in 2012 by nearly \$4 million over the previous year. She noted that research priorities must revolve around finding solutions for people living with MS.

Chief Research Officer Dr. Timothy Coetzee reviewed our current research portfolio and discussed goals and challenges for 2013. These include:

- The increasing numbers of research applicants coming to the Society for support
- The importance of supporting the International Progressive MS Collaborative
- Investigating a process by which an updated estimate of U.S. MS prevalence can be identified
- Aligning the Society's Fast Forward and Discovery Research activities
- Exploring complementary and alternative medicine strategies
- Finding a way to strategically balance commitments to laboratory vs. translational research

Presentations on Special Topics

Marijuana - In light of recent initiatives decriminalizing the use of marijuana in some states for medicinal or recreational use, the RPAC heard from experts about what is known about its potential benefits and risks for treating symptoms experienced by people with MS, and the hopes and concerns of people with MS expressed through the Information and Resource Center and social media sites regarding this topic. The RPAC agreed that exploring new research approaches to poorly managed symptoms such as pain merits focus. This issue will also be explored by the Society's medical advisors. The Society will also convene a group of experts to consider additional research strategies that would inform the Society's position on the use of marijuana and its derivatives to treat MS symptoms.

MS Physician Workforce - The Society commissioned RTI International to study ways to enhance recruitment of MS specialist physicians to better ensure quality care. Initial findings suggest that early exposure of medical students/residents to people with MS and to research tend to attract physicians to the field. A few Society chapters have special programs for medical students to provide such experiences. Additional analysis of the study by RTI is ongoing, and additional strategies are being considered by the Society's Clinical Care department.

International Progressive MS Collaborative - Special guest Dr. Paola Zaratin (MS Society Italy) along with RPAC member Dr. Alan Thompson discussed the Collaborative and the aims of its first scientific meeting to be held in early February.

Consideration of Research Proposals

Over the fall, the Society's volunteer peer review committees evaluated the merit and relevance of 251 applications. The RPAC considered the portfolio of meritorious grants and fellowships and recommended that the Society fund (12 Pilot Awards, 22 Grants, 28 research, clinical and rehabilitation fellowships, 2 Special Initiatives, 1 Collaborative MS Research Center). Funding all of these projects would represent multiyear commitments of up to \$18 million.

Next Steps – The CEO will consider RPAC recommendations in making research funding decisions. Once the investigators are notified of their success, there are several steps involved in getting acceptances and certifications from their institutions, and getting the projects summarized and reviewed by the investigators. Information about the new projects is expected to be announced in newsheets in March 2013.



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RESEARCH/CLINICAL UPDATE

January 17, 2013

UCSF DNA Bank Seeks Participants to Help End MS

People living with MS may hold the key to curing this disease. They, and often their family members, can make a difference in studies of the genes that put people at risk for MS by donating their DNA from blood samples. Understanding the role of genes in MS could revolutionize the way this disease is diagnosed and treated, and ultimately lead to ending MS forever through its prevention.

The National MS Society has been supporting a DNA Bank at the University of California at San Francisco (UCSF) for many years. This bank is a shared resource that is feeding many of the genetic breakthroughs happening today. The UCSF Multiple Sclerosis Genetics Group is a founding member of the International MS Genetics Consortium seeking to understand the genetic basis of MS. A large number of participants are needed to accelerate discovery. **Please note:** this is a nationwide study; and people everywhere can participate without living near or traveling to San Francisco, CA.

Family MS Study

The UCSF MS Genetics Group is looking for participation of two types of families: single-case and multi-case families.

- Single-case families are those where only one member is diagnosed with MS. Participation will require a one-time donation of blood from the individual with MS and, if available, a control. The control cannot be a family member but can be a spouse or friend. Preferably the control will be of the same ethnicity and approximately the same age as the individual with MS.
- Multi-case families are those where multiple living, family members have been diagnosed with MS. For these families, the group collects blood samples from all affected family members, unaffected siblings, and both parents of individuals diagnosed with MS. If not all of the individuals requested are able to participate, enrollment is still possible and will be discussed by phone.

African-American MS Study

Different populations are being studied to learn why some ethnic groups develop MS at higher rates than others. The MS Genetics Group is asking for the donation of a blood sample from African-American individuals with MS and controls without MS. It is not required, but the participation of certain family members is preferred as well.

What is Involved?

Participants for either study will be asked to:

- Read and sign a consent and authorization form
- Sign a form to release medical records (only individuals with MS)
- Complete a family information form
- Donate a blood sample (approximately five tablespoons)

At all times, records and other information that is shared with the investigators are handled in a confidential manner. There will be no charges for participation in this study.

To participate or request additional information, please complete this brief intake survey (<https://redcap.ucsfopenresearch.org/surveys/?s=RPKGc4>)

OR you may contact the DNA bank directly:

UCSF Clinical Coordinator
675 Nelson Rising Lane, Suite 235A, Box 3206
San Francisco, CA 94158
Toll Free Phone: 1-866-MS-Genes (1-866-674-3637)
Email: msdb@ucsf.edu
Website: <http://msgenetics.ucsf.edu/>



VOLUNTEER MANAGEMENT

January 17, 2013	CC: All
Leader in the Movement: Teresa Rapozo, Greater Northwest Chapter	

Teresa Rapozo is truly a **Leader in the Movement!** With her volunteer leadership evident in advocacy, fundraising and programs & services Teresa's commitment to the MS movement is inspiring! Although her official work status is retired, she has followed a career path of volunteer leadership with a focus on our shared vision of a world free of MS.

Click [here](#) to read the story!

We invite all to share your **Leaders in the Movement** with us, and with your colleagues across the country. Do you have volunteers leading and training other volunteers? Are your volunteers empowered to use their skills and make a difference in the lives of people living with MS? Do you engage a volunteer who has unleashed their creativity to inspire others to join the movement?

Send stories to:
Michele Groden
Manager, Volunteer Leadership Development
Michele.groden@nmss.org