National
Multiple Sclerosis
Society
News Sheets

February 11, 2011	**CC:** All
Announcement regarding Joyce Nelson's retirement as President and CEO of the National MS Society	

Following is the announcement from national board chair Tom Kuhn, sent to volunteer leaders Society-wide regarding Joyce Nelson's retirement, effective October 1, 2011. Also included is Joyce Nelson's letter announcing her retirement to staff and volunteers.

If you have any questions or need further communications support, please contact Graham McReynolds at graham.mcreynolds@nmss.org

TO: Members of the National Board of Directors. Chapter Chairs, Chairs Advisory Council members

FROM: Thomas Kuhn, Chair of the National Board

SUBJECT: Joyce Nelson's Retirement

Joyce Nelson, our President and CEO, has decided to set her retirement date, effective October 1, 2011.

I am happy for Joyce and John as they make retirement plans for their future, but saddened for the Society and the loss of her leadership.

Joyce began her career at the National MS Society in 1983 as a READaTHON coordinator in the Northern California Chapter. She went on to provide leadership in a wide range of areas, including as chapter president in the Mid America Chapter, vice president of the national field operations and development departments, and of course, as the Society's President and CEO since 2004.

Under Joyce's leadership the Society launched a range of new initiatives including: our "Join the Movement" brand messaging; the Promise 2010 initiative; our 2007-2010 and

2011-2015 strategic responses to MS; establishment of local and national direct financial support programs for families most severely impacted by MS; establishment of regions; restructuring our remittance processes; establishment of Fast Forward; support for high cost research efforts like the MS genetics project and clinical trials of estriol, and much more.

Joyce leaves the Society in a position of strength. We have survived the challenges of the recent recession and expect to fund all approved research projects, fellowships, pilot grants and research meetings in 2011. The unanimous approval of our 2011-2015 strategic response provides clear direction for the future and the Society's professional staff - locally, regionally and nationally - are the best in the industry.

The process to identify Joyce's successor will begin later this month. Eli Rubenstein, Chair of the Society's Governance Committee, will head the CEO search committee and members of the committee will be recruited shortly.

There will be time to celebrate Joyce's accomplishments in the months ahead. In the meantime, I know you join me in wishing her and her family all the best as they enter this new phase of their lives.

My dear friends,

It is with mixed emotions that I have notified National Board chair Tom Kuhn of my intent to retire from my office of President and CEO of the National MS Society, effective October 1, 2011.

2011 marks my 28th year with the National MS Society, and my seventh year as its President and CEO. It has been a privilege and an honor to serve, for nearly three decades, people living with MS and those who care for them.. Although the time has come for me to formally pass the torch of leadership to another, my love for this work and for the people with whom I've served will never fade.

The vision of our 2011-2015 strategic response, the passion of our chapter, regional and national volunteer leaders, and the commitment and competence of professionals like you who staff this organization give me great confidence that the Society's considerable momentum will continue to grow in the years to come.

I have been enriched by my interactions with each you. Your remarkablecommitment, leadership, integrity, excellence and teamwork provided strength and courage for each challenge. Your sensitivity and compassion made every triumph a shared joy.

National Board Chair Tom Kuhn is sharing this news now with chapter chairs and other volunteer leaders. His cover memo to those individuals, which describes the steps the board will be taking during the upcoming transition, is attached for your information.

People living with MS have touched my life every day for the past 28 years, providing inspiration for the important work to be done. When the final answers are found and the race is won, I can assure you that I will be there with you to celebrate a world free of MS.

Your admiring colleague,

Joyce Nelson, President and CEO
National Multiple Sclerosis Society

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February 11, 2011	**CC:** All
All Society Call on March 23, 2011	

There will be a 30 minute All Society Call on Wednesday, March 23 at 1:00pm Eastern, 12:00pm Central, 11:00am Mountain and 10:00 am Pacific. Please hold this time. More agenda details coming soon.

Host: Joyce Nelson, President & CEO
Special Guest: Phil Keoghan, Host of *The Amazing Race*

The Dial-in number is: 1-866-725-4432, participant code: 38880246
For this call, we will be using a dial in number which does not require a pass code. However, when dialing into the call, you will be asked for either the host (Joyce Nelson) or the conference ID number (**38880246**) so have this information readily available for the operator. To minimize the number of lines being used, please have all of your staff together for this call. (Questions?: Shawna Golden Shawna.golden@nmss.org)

National Multiple Sclerosis Society News Sheets

DEVELOPMENT

February 11, 2011	**CC:** All
February 2011: E-communications Update	

February National MS eNEWS
Send date: ~~2/17/10~~ 2/22/11
Audience: Full List

The February National MS eNEWS will be sent on Tuesday, February 22. The send date has been changed to accommodate other Society-wide email scheduling. Content includes a feature about vitamin D and MS, as well as information about the African American experience of MS and mood changes and MS.

February E-fundraising Campaign
Send dates: ~~2/15, 2/22 and 2/24~~ 2/23, 3/1 and 3/3
Audience: ~850,000

Objective: The February e-fundraising goal for the three part email series and promotions implemented on the national website will be $60,000.

The three e-mails – send dates have been changed to accommodate other Society-wide email scheduling – will be a brand-focused appeal centered on the mission of the National MS Society and an educational opportunity for donors to learn more about what matters the most to them. The donor will be able to choose from three images embedded within the e-mail, which highlight Society advocacy, research and program initiatives. Once the donor selects an image, she or he will be sent to a customized donation page highlighting the achievements of the topic they selected.

Notes
Individuals with a 'no email' classification on their Altair accounts will be suppressed, along with standard Direct Marketing Program excludes/suppressions.

The FY 2011 Society Constituent Communications Calendar and Schedule is now live on SharePoint at:

http://intranet.nmss.org/Topics/marketing/Documents/Society_Constituent_Communications_Calendar_and_Schedule_FY2011.xls

Contact Information

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

For questions about our online fundraising campaigns, please contact Sara at sara.dougherty@nmss.org or 303-698-6100 x15157.

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

DEVELOPMENT

February 11, 2011	**CC:** All
Phil Keoghan's 'The Ride' Update – Watch it Today!!	

In March of 2009, Phil Keoghan, the host of "The Amazing Race," and our MS Ambassador, left Los Angeles on his bike for a 40 day ride across America that covered over 3,500 miles.

Last week, Phil kicked off a 10-city tour of 'The Ride' – a 90 minute documentary - chronicling Phil's coast-to-coast adventure where he put his 41-year-old body to the test, raised over $500,000 for the MS movement, and inspired thousands.

Our chapters in the 10 markets where the premiere is showing are partnering with Phil to host screenings where all ticket sales are going to the Society and so far, it's been a week of great cultivation events!

If the tour is not coming through your local are, you still can be a part of the 'The Ride' by watching it through Amazon for $3.99 or buying the film for $11.99. Since being available on Amazon, 'The Ride' has consistently ranked in the top 10 movies sold, check it out, add your own positive rating, and promote to your local constituents.

Thanks to the generosity of Regal theaters and Phil and Louise Keoghan, 100% of theatre sales benefit the Society. Following is the list of cities and dates where 'The Ride' is premiering this month to sold out crowds -

Los Angeles, CA - Thursday, February 3 at 8:00pm
Denver, CO, Monday - February 7 at 7:30pm
Minneapolis, MN - Tuesday, February 8 at 7:30pm
St. Louis, MS - Wednesday, February 9 at 7:30pm
Chicago, IL - Thursday, February 10 at 7:30pm
Pittsburgh, PA – Friday, February 11 at 7:30 pm
Philadelphia, PA - Sunday, February 13 at 7:30pm
Boston, MA - Wednesday, February 16 at 7:30pm
Dallas, TX - Thursday, February 17 at 7:30pm
New York, NY - Friday, February18 at 5:30pm

To buy tickets for remaining theatres, visit – www.noopportunitywasted.com.

If you have questions, please contact Becca.Kornfeld@nmss.org or Rachael.Nuwash@nmss.org.

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February 11, 2011	CC:
Information Technology Support Service News	

To address the long term support needs of the Society, the Information Technology Team is building a plan for weekend, after hours and holiday coverage as well as documenting service level agreements for typical support requests to be published in March.

Our current support guidelines are as follows:

- We manage the work on a first in, first out basis except when there is a complete loss of service at the home office or in one of our chapters when that issues moves to the top of the list.
- We aim to respond to all tickets within 8 hours although the vast majority is dealt with far more quickly than that.
- If people are locked out of the system due to a password change or by trying 3 times and getting locked out, we watch for and resolve them immediately.
- For new employee account setup, support for meetings or purchasing requests, we ask for a week's lead time to collect the employee's information, schedule someone for the meeting or to obtain the item information and purchase it.
- The complexity of the issue directly relates to the time it takes to resolve it. The person working on those complex issues should be communicating frequently with the requestor on progress.
- Any issues that must be sent to our vendors take longer to resolve and the IT person assigned to the issue should be communicating frequently with the requestor.

This year we added two additional employees to the IT support team to assist in bringing chapters onto the Society infrastructure. Ultimately, those people will be members of the ongoing support team responding to individual IT issues. It's working well bringing the chapters onboard but with the addition of the new chapters, the support request backlog is growing.

We are attacking that backlog in two ways; first, we are adding 2 additional resources to respond to individual issues for the next several months. Additionally, we are currently focusing on Track It issues that are more than 3 days old to ensure that those requests are resolved as soon as possible

If you feel that your issues are not addressed quickly enough, Scott Galbreth (scott.galbreth@nmss.org) and Elizabeth Horton (Elizabeth.horton@nmss.org) are points of escalation for you. Scott will escalate issues related to telephone, hardware, desktop software, account creation and purchasing issues. Elizabeth will escalate issues related to Convio, Altair and CMS or other business applications.

The entire IT team is open to feedback on all aspects of our support. We are committed to provide great service and to improve where we need to improve. If you have additional questions or suggestions, please contact Julie Butcher at 303-698-6100 x15175

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February 11, 2011	**CC:** Chapter Presidents
	Programs & Services
National African American Advisory Council Web Pages & Resources	

In recognition of Black History Month, we are pleased to launch new pages on our website, developed with the guidance of the Society's National African American Advisory Council.

The pages can be found at:

http://www.nationalmssociety.org/living-with-multiple-sclerosis/african-american-advisory-council/index.aspx

The National African American Advisory Council was created to advise and support the Society on the best approaches to reaching and engaging the African American community. The varying regional, ethnic and socio-economic subcultures within the community create a unique opportunity for a group of advisors to guide the Society in the development of culturally inclusive materials and programs. The council members include individuals who have a variety of experience, expertise and perspectives including MS expertise, minority health, marketing, business, public relations, advertising, program development and education. There is also the perspective of people living with MS included.

The web pages include two MS LearnOnline videos, the first one is entitled *"MS and the African American Experience: Diagnosis and Clinical Course"* and the second is entitled "*MS and the African American Experience: Reasons for Hope"*. The MS LearnOnline videos feature Dr. Mary Hughes, member of the National Board of Directors and Chair of the African American Advisory Council and Dr. Walter Royal, member of the National Clinical Care Committee and volunteer of the Maryland Chapter.

The third video entitled *"Living with MS: African American Perspectives"* captures the experience and perspectives of African Americans who, despite having been impacted by MS, continue to move their lives forward. This video was initiated and produced by the Eastern North Carolina Chapter, a strong leader in outreach to the African American community.

The web pages also includes a page of personal stories of African Americans who have *"Joined the Movement"* across the country. Some of the individuals featured on this page include Walter

Williams, founding member of the pioneering R&B vocal group The O'Jays. The page also includes Tamia, singer and R&B superstar.

The creation of the web pages align with our strategic goal *to heighten awareness of MS to facilitate understanding, engagement and action to fuel the movement*. The website helps us *to expand the impact of the MS Movement through new and enhanced community collaborations and partnerships*.

We want to acknowledge the Medtronic Foundation, *Patient link Program* for the grant we received to create all of these resources. This foundation has been a real partner to the Society in helping us forge strong relationships with culturally diverse communities.

The Society salutes the achievements of African Americans and celebrates the rich cultural history of the community. We believe these new pages and resources offer wonderful opportunities for outreach. Please share the link with your clinical advisory committees, your programs committees, community based organizations that target the African American community, post on chapter social media paged, or reach out to your state representative from the Office of Minority Health.

For questions about reaching diverse communities please contact Craig Wesley at 212-476-0404. If you have questions about the web pages or marketing opportunities, please contact Shawna Golden at 303 698-6100 X 15168.

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MARKETING

February 11, 2011	**CC:** All
February 2011: E-communications Update	

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Send date: ~~2/17/10~~ 2/22/11
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RESEARCH/CLINICAL UPDATE

	cc: Chapter Presidents, Programs & Services, Development

February 11, 2011

Risk of Having a First Neurologic Event is Decreased with Increased Sun Exposure and Higher Blood Levels of Vitamin D, Society-Supported Australian Study Suggests

– Findings in line with others suggesting these factors may lower the risk for MS

Higher levels of sun exposure and higher blood levels of vitamin D were both associated with decreased risk of having a first demyelinating event that can be the first indicator of multiple sclerosis, in a comprehensive study undertaken in Australia, called the Ausimmune Study. (A first demyelinating event, in this study called FDE, is also known as clinically isolated syndrome (CIS), a first neurologic episode caused by inflammation/demyelination in the brain or spinal cord.) Some of these individuals developed MS during the study and others did not, however findings were similar in either case. Robyn Lucas, PhD, Anthony McMichael, PhD (The Australian National University, Canberra) and colleagues across Australia report their findings in *Neurology* (2011;76:540-548). This study was supported by the National MS Society, the National Health and Medical Research Council of Australia, the ANZ William Buckland Foundation, and MS Research Australia.

The findings provide additional support for previous suggestions that sun exposure and vitamin D may help protect against developing MS. It remains to be seen whether safe and effective strategies can be developed that utilize this potential protection without the risks involved in overexposure to the sun or overdoses of vitamin D supplements, and whether these findings have relevance for individuals who already have MS.

Background: In all parts of the world, MS is more common at latitudes that are farther from the equator and less common in areas closer to the equator. This latitude effect has been under investigation for many years. Previous studies have found evidence suggesting that higher lifetime exopsure to sunlight (through which the skin makes vitamin D) and higher blood levels of vitamin D may reduce a person's risk of developing MS. This is an active area of continued research.

The National MS Society is proud to be a source of information about MS. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.

The Ausimmune study was undertaken to investigate whether increased exposure to sunlight in those living closer to the equator and the vitamin D that is produced in part by sunlight may be protective against MS. Rather than studying people who had already been diagnosed with definite MS, which could alter a person's lifestyle and recollection of past events, the team investigated sun exposure and vitamin D levels in people who had not yet been diagnosed with MS, but who had experienced a CIS. A CIS often, but not always, leads to a diagnosis of MS.

The Study: The investigators recruited participants who were aged 18–59 years and lived in four geographic regions of Australia between November 1, 2003, and December 31, 2006. The four regions were characterized by differing distance from the equator. A total of 216 people were enrolled who had experienced a CIS. A total of 395 controls were randomly selected from the Australian Electoral Roll and matched to the CIS cases in age, gender, and study region.

Sun exposure was measured in several ways, including by participant reports on how much time they spent in the sun during different periods of life starting from age 6, and also by more objective means, such as examination of the skin for sun damage (actinic skin damage) and measurements of skin pigment (melanin). The latitude and longitude of participants' residence were also recorded as an indicator of ambient ultraviolet (UV) light. Vitamin D levels were measured by a blood sample taken at entry into the study.

The results show that higher recent or lifetime sun exposure and higher blood levels of vitamin D at study entry were independently linked with a reduced risk of CIS. The investigators reported that people with most evidence of skin damage from sun exposure were 0% less likely to develop a CIS than those with the least damage. People with the highest levels of vitamin D at entry also were less likely to have a CIS than those with the lowest levels. As reported in other parts of the world, this study confirmed a latitude effect in Australia. Taken together, differences in sun exposure, vitamin D levels, and skin type accounted for a 32.4% increase in CIS incidence from the low to high latitude regions of Australia.

Read the complete bulletin on SharePoint, at:
http://intranet.nmss.org/Topics/cr/Pages/Ausimmune_Study_Results.pdf

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RESEARCH/CLINICAL UPDATE

	cc: Chapter Presidents, Programs & Services, Development

February 11, 2011

New Guidelines for the Use of Plasma Exchange Therapy in MS

New guidelines from the American Academy of Neurology (AAN) recommend that clinicians consider using plasma exchange (also known as plasmapheresis, a blood-cleansing procedure) for a number of conditions for which it has shown benefit. In MS, the guidelines suggest it may be effective as a secondary therapy for exacerbations unresponsive to corticosteroids in people with relapsing forms of MS, and may be useful for severe, rapidly progressive MS and similar disorders (acute fulminant demyelinating CNS disease). The treatment was not found to be effective for secondary-progressive MS or primary-progressive MS. Irene Cortese, MD, and colleagues from the AAN's Therapeutics and Technology Assessment Subcommittee published the guidelines in *Neurology* (2011;76(3):294-300 http://www.neurology.org/content/76/3/294.abstract).

Plasmapheresis is a process in which whole blood is withdrawn from an individual; the liquid portion or plasma is removed from the blood and replaced; and the blood, with all its red and white blood cells, is transfused back into the person. This process is a successful method for treating some autoimmune diseases such as myasthenia gravis and Guillain-Barré syndrome, because it removes the circulating antibodies that are thought to be active in these diseases.

Because MS may also involve an autoimmune process—where the body is attacked by its own immune system—and because damaging factors have been found in plasma from people with MS, plasmapheresis has been tried as a treatment for MS. The authors reviewed the medical literature from 1995 through 2009 to reassess the role of this strategy for treating neurologic disorders, and revised the previous set of AAN guidelines to include recommendations for MS.

The vast majority of people experiencing acute attacks respond well to the standard high-dose corticosteroid treatment. According to the guidelines, plasma exchange should be considered a

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treatment alternative only for the few who do not, and only for a short time. Potential side effects include infection and blood clotting problems.

Read summaries of the new guidelines from the AAN (PDFs) for patients http://www.aan.com/practice/guideline/uploads/472.pdf and for clinicians http://www.aan.com/practice/guideline/uploads/471.pdf.

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