National
Multiple Sclerosis
Society
News Sheets

ADVOCACY

January 27, 2012	**CC:** Development
Walk MS and MS Activism	
Action Requested/Deadline: Thursday February 2, 2012	

One aspect of the We are Activists Strategic Response Implementation Plan is to develop a more consistent process that is utilized throughout the organization to recruit and engage volunteer activists. Learn more about how one common tactic – staging an ***MS Activism Photo Booth at your Walk MS events*** can raise awareness about advocacy, and engage walkers in MS Activism. Join us for the February 2012 Government Relations Roundtable discussion. We'll review easy-to-do next steps to implement this tactic and hear from chapters that have already met with success using it.

Government Relations Roundtable Discussion
Thursday February 2, 2012 at 3:00 pm ET/2:00 pm CT/1:00 pm MT/12:00 pm PT

1-888-279-3775; 0108#
Or
15100; 0108#

Attendees may enter the event by going to the URL below, and entering the event ID.

URL: http://mt211.centra.com/main/Customers/nmss/

Event ID: RKJ493734

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CHAPTER PRESIDENTS

January 27, 2012	**CC:** Development
Save the Date: 2012 National Conference	

Save the Date!
The 2012 National Conference will take place November 8 - 10, 2012.
Please note the conference will end on a Saturday this year. We made a schedule shift this year because volunteer leaders, top fundraisers and top donors have shared that time away from careers can be challenging and we would like to honor their request.

Location
We will gather in Dallas again this year - Hyatt Regency, Dallas Fort Worth Airport.

Who Should Attend?
The National Conference will provide a great opportunity for everyone who is a part of the MS movement to share, learn and be inspired. Peers from around the nation will gather for three days of motivating sessions and informative workshops. Please provide this amazing opportunity to YOUR frontline.

Who is on the frontline of the MS Movement?

- Team captains
- Fundraising champions
- Volunteer leaders
- Top Donors
- Staff

Budget

- Room rate: $185
- Conference registration: $395

Registration information and more details we will be coming soon. Contact Krista Byers if you have questions Krista.byers@nmss.org.

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CHAPTER PRESIDENTS

January 27, 2012	**CC:**
Title of News Sheet: We are Activists Implementation Plan Approved	
Action Requested/Deadline: Sharing with all chapter staff	

I am pleased to announce that the Senior Leadership Team has approved the 2012 We Are Activists Strategic Response Implementation Plan. You can access the plan, posted in the Activism section of Share Point here. This direction captures the intent of the Goal Steering Team which identified a ***leadership*** initiative as critical to the future success of the activist agenda for the Society.

I would like to extend a special recognition to the members of the team who are identified on the last page of the plan. Through engagement of this group and their outreach to other key voices in the Society, we heard many perspectives on what we should do to accelerate the systems-changing work that will improve the lives of people affected by MS, while incorporating a realistic and thoughtful roll-out of some specific leadership strategies based on capacity.

One of the key organizational milestones identified by the Implementation Team is that activism is recognized as a responsibility of all Society staff and volunteers. During this coming year we will engage more people as activists; and we will all recognize how advocacy truly empowers us to change the world within which people affected by MS live, work and achieve fulfillment.

Look for more opportunities throughout the year for how you can be an activist.

David Chatel, EVP Advocacy
202-408-1500

Robin D'Andrea, Co-lead

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CHAPTER PRESIDENTS

January 27, 2012	**CC:** ALL
All Society Staff Call on January 17 – Recording Available	

The All Society Conference Call held on Tuesday, January 17 was recorded and can be downloaded on SharePoint under the HR Section< Announcements.

The quarterly All Society Call is for all National MS Society Staff and is an opportunity for the entire organization to join together to celebrate our progress, learn how our organizational priorities have real impact for our constituents, and look ahead to important work that moves us closer to a world free of MS.

On this call, Cyndi Zagieboylo and John Scott highlighted progress in 2011 and looked forward to key initiatives in 2012. Also, Lisa Taylor Skutnik and Denise Belle shared information about the importance of our Rural Health Care initiative.

Chris Yankee
Chris.Yankee@nmss.org

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CHAPTER PRESIDENTS

January 27, 2012	**CC:**
2012 NPE Policy Review Committee	

Background

The NPE Policy Review Committee has begun its work. Its charge is to review the NPE policy and mechanics, based on our first two years of experience, identify any policy gaps, adjustments or needs for clarification and propose potential NPE policy changes to the Chapter Relations and Finance Committees. Subsequently, it will develop and implement an effective Society-wide communication plan regarding the NPE process and any approved changes.

Issues identified to date include:

- Treatment of donations received at/or directed to the home office (sometimes as the result of a collaborative chapter campaign or as part of the NOW campaign)
- Definition and treatment of honor roll gifts
- $100K benchmark for large gifts and honor roll consideration; exclusion of revenue for calculation of future NPE
- Direct marketing campaign income distribution and treatment
- Use of tiers in calculating NPE (rationale)
- Treatment of collaborative program grants for multiple chapters
- Significant, one-time locally restricted gifts
- Treatment of Charitable Gift Annuities
- Fees for Service: When to incorporate Fees for Service into NPE per Blue Ribbon Panel recommendation and determine effective communication regarding its impact on NPE.

Note: Determining the annual NPE percentages for each tier that are required to fund the overall NPE budget is the responsibility of the CEO with input from the Budget Review Committee and is not under the purview of this committee.

The NPE Policy Review Committee would like to know if there are additional issues not mentioned that should be considered. **Chapter Presidents are asked to consult with their key volunteers and/or staff and communicate any additional issues for consideration ASAP to: Craig Weber at craig.weber@nmss.org preferably by February 6th but no later than February 29th.**

The NPE Policy Review Committee is accountable to the Chapter Relations Committee (CRC) of the National Board of Directors and will present its recommendations to the CRC as they are developed. It is the Committee's goal to make possible recommendations in time to incorporate them into the FY2013 planning and budget cycle. However, some recommendations may not be incorporated until FY2014 and later planning and budget cycles. The committee is chaired by Dick Knutson, who is a member of the CRC and serves both on the National Board and the Upper Midwest Chapter Board, and consists of 21 individuals including representation from each region.

Task Force Members

Dick Knutson: Midwest Region. Dick has served on the Upper Midwest (formerly Minnesota) Chapter Board for 16 years including a term as Chair and multiple terms as Chapter Treasurer. He joined the National Board in 2008 and serves on the Chapter Relations and Finance Committees and Insurance sub-committee and formerly chaired the Nominating Committee. He is COO of Larkin Hoffman Daly & Lindgren Ltd. He has a personal connection to MS.

Jack Betkoski: Northeast Region. Jack serves as Connecticut Chapter Chair and as a member of the Northeast Region Volunteer Leadership Council. Involved with NMSS for the past 8 years and has a personal connection to MS.

Don Burton: Southeast Region. Don is the past Chair of the Eastern North Carolina Chapter which is now enlarged as the Greater Carolinas Chapter, and is a member of the Southeastern Region Volunteer Leadership Council.

Tami Caesar: East Region. Tami is the Greater Delaware Valley Chapter President. She has served the NMSS for 20 years in three different chapters – as Director of Operations in the former Greater Washington Chapter and as Chapter President of the Mid Florida Chapter before becoming Chapter President of the Greater Delaware Valley Chapter. Tami also served on the Charting Our Future Task Force. She has a personal connection to MS

Jim Cantalupo: Southeast Region. Jim has served on the Mid Atlantic Chapter Board (now Greater Carolinas Chapter) for 24 years including a term as chair. He has served on the National Board for eight years and currently serves as Treasurer and Chair of the Finance Committee as well as serving on the Executive Committees, and the Fast Forward Board of Managers. Jim has many wonderful friends that live with MS.

Mike Elkow: Executive VP, Northeast Region. Mike has served the NMSS for 15 years in Mid Jersey and then subsequent to the realignment with Greater North Jersey as the New Jersey Metro Chapter President. He assumed his current role in the Northeast Region in January 2010. Mike also served on the Blue Ribbon Panel.

Peter Galligan: Northeast Region. Peter has served on the Greater New England Chapter Board for 26 years including terms as Chair and Vice Chair. He has been a member of the National Board of Directors for nine years. He served on the Charting Our Future Task Force and currently serves as a member of the Finance Committee and Chair of the Chapter Relations Committee as well as Chair of the Blue Ribbon Panel.

Carl Hertrich: East Region. Carl is the Delaware Chapter Board Chair and involved with NMSS for 9 years. He is a member of the East Region Volunteer Leadership Council. He was a partner with KPMG for 30 years and currently an adjunct professor at Drexel University. He has a personal connection to MS.

Ernest Johnson: South Central Region. Ernest has served on the South Central Board for the past seven years, has attended the Delegate Assembly for the past four years and is the Chair-Elect of the chapter. He is Executive Vice President of PM Realty Group in Houston. He has a personal connection to MS.

Colleen Kalt: Midwest Region. Colleen has served the Wisconsin Chapter for 30 years starting as a volunteer and including 25+ as Chapter President. She has served on numerous committees during her tenure, most recently as a member of the Blue Ribbon Panel.

Dean Munger: Midwest Region. Dean is the Chair, Michigan Chapter and has been on the Board for 9 years. He also serves as Chair, Midwest Region Volunteer Leadership Council. In 2010 he retired from his position of Executive Director of Labor Relations for General Motors. Has been involved with the NMSS for 25+ years due to a personal connection with MS

Melissa Perlin: Home Office, VP, Finance. Melissa has worked with the Society first as a consultant and more recently as a staff member for 15 years. She was responsible for the implementation of the Society's accounting software, Platinum and works closely with chapter finance staff Society-wide. Has a close family friend who has MS.

Cynthia Perazzo: West Region. Cynthia has served on the Pacific South Coast Chapter Board for seven years and is a member of the West Region Volunteer Leadership Council. She is the Sr. VP for Strategy and Business Development at Hoag Memorial Hospital in Newport Beach, CA.

Lisa Risi: Home Office, Chief Financial Officer. Lisa has held a variety of key financial roles for 15 years both at the chapter and the Society level, and provided staff support to the Blue Ribbon Panel.

Annette Royle-Mitchell: West Region. Annette has served the NMSS as the Utah-Southern Idaho Chapter President for the past five years and has led the chapter through the realignment of Utah and the Southern Idaho office of the former All America Chapter.

John Scott: Home Office, Chief Field Services Officer (CFSO). John has served the NMSS for 24 years, initially with the Minnesota (now Upper Midwest) Chapter in the fundraising department, and then in a variety of roles in the Greater Delaware Valley Chapter, including Executive Vice President and Chapter President. In 2009 he was appointed East Region EVP and became the CFSO in 2012.

Arthur Schramm: West Region. Art is a 17 year member of the Southern California & Nevada Board of Trustees. He has a personal connection to MS. In addition, his wife was a founding member of the MS Achievement Center in Los Angeles.

Jim Tidwell: Jim has been an active member of the South Central (formerly Lone Star) Chapter board for the past decade, including a term as chair. For most of those years he has been the top fundraiser in the BP MS 150 Bike Tour from Houston to Austin, raising over $1,000,000. Jim joined the National Board in 2006 and serves as Audit Committee Chair and also on the Blue Ribbon Panel and on the Investment Committee. In addition, he formerly served on the Chapter Relations Committee and the Fast Forward Board of Managers. He is President & CEO of Wedge Group, a private investment firm based in Houston, and has a personal connection to MS.

Craig Weber: Home Office, VP, Chapter Relations. Craig has served the Society for 22 years, first as Executive Director of the Southern California Chapter (2 years) and subsequently in a variety of positions in the Field Operations Department and now with the Finance Department.

Paul Weiss: Home Office, Chief Operating Officer. Paul has served the Society in several key capacities for over 12 years during a 20 year period, with an 8 year intermission, including Controller, Chief of Staff and Vice President, Fund Raising. He provided staff leadership to the Charting Our Future Task Force and the Blue Ribbon Panel. He has a personal connection to MS.

Cyndi Zagieboylo: Home Office, President and CEO. Cyndi became CEO on October 1, 2011. She has served the NMSS for 25 years, initially with the Massachusetts (now Greater New England) Chapter in the client programs department, and then in a variety of capacities including Chief Field Services Officer, overseeing Field Operations, Programs & Services, Advocacy and Clinical Programs departments.

Consultant:
John Paul, Association Works, Inc. John has been a consultant for the MS Society for over 10 years in a wide variety of capacities starting with the Organizational Effectiveness Task Force and most recently with the Strategic Response development and implementation process.

Craig Weber
Vice President, Chapter Operations
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RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs, Development

January 23, 2012

FDA Updates Tysabri Label to Include Lab Test that Helps Identify Person's Risk of Developing PML

The U.S. Food and Drug Administration has approved a change to the prescription label for Tysabri® http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/medications/natalizumab/index.aspx (natalizumab, Biogen Idec and Elan) to show that a laboratory test that detects antibodies to the JC virus can help determine a person's risk of developing PML, a severe brain infection. This virus is responsible for PML, which has emerged in some people who have taken Tysabri. (Read more about natalizumab and PML http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=2308.) The availability of the lab test should enhance the ability of people with MS and their physicians to weigh risks and benefits of this therapy. Read http://www.fda.gov/Drugs/DrugSafety/ucm288186.htm the FDA announcement

The presence of antibodies indicates that a person has at some point been infected by or exposed to the virus, which usually lies dormant. In studies of patients who have developed PML on Tysabri, all of those for whom test results were available had serum antibodies prior to the onset of PML. Based on research findings, patients who have a positive antibody test are at higher risk of developing PML. Previous findings have also shown that prior use of immune-suppressing drugs and taking Tysabri for more than two years each increase a person's risk for developing PML.

The revised label suggests that the risks and benefits of starting or continuing Tysabri should be carefully considered in patients found to be antibody positive and have one or more additional risk factors. Those found to be antibody positive, have used Tysabri for less than two years, and have no prior use of immune suppressing drugs are estimated to have a risk of PML of less than 1/1000; those with all three known risk factors have an estimated risk of PML of 11/1000.

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 FDA's announcement http://www.fda.gov/Drugs/DrugSafety/ucm288186.htm stresses that patients who test negative for anti-JCV antibodies are still at risk for the development of PML due to the potential for a new JCV infection or a false negative test result. It also notes that doctors should consider testing patients prior to treatment or during treatment if antibody status is unknown, and that periodic re-testing should also be considered.

"This label change marks an important advance in assisting people with MS and their physicians to make better-informed decisions concerning the challenges of balancing effectiveness with safety," commented Nicholas LaRocca, PhD, vice president of health care delivery and policy research at the National MS Society.

The lab test, called STRATIFY JCV, is available from Quest Diagnostics.

Read more about Tysabri http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/medications/natalizumab/index.aspx
Read more about Tysabri and PML http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=2308
Read more about research that led to the label change http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=5812

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.