



## ADVOCACY

<b>December 10, 2010</b>	<b>CC: Programs &amp; Services</b>
<b><u>Sample of FY 2010 State Legislative Priorities and Successes</u></b>	

Advocacy campaigns unite the voices of people who want to do something about MS NOW, and enhance quality of life for those affected by it, until its cure is discovered. FY 2010 state and local advocacy priorities and successes encompassed: Long Term Care; Access to Health Care; Quality Health Care; and Disability Rights. For an overview of FY 2010 state and local priorities and legislative successes, [click here](#).

A sample of state legislative and administrative victories included measures to:

- ✓ Prohibit **NY** regulated health insurance companies from imposing drug tiers based upon expense or disease categories and charging cost-sharing percentages for prescription medication.
- ✓ Preserve \$75,000 in **MA** state funds for the Greater New England Chapter Care Management Program.
- ✓ Delay electricity disconnection and provide easier access to payment plans during the summer months with the **TX** Public Utility Commission.
- ✓ Establish an MS check-off on **OK** and **LA** state income tax returns.
- ✓ Fund the first MS specific **NJ** housing development, with 30 barrier free one and two bedroom apartments.
- ✓ Preserve \$720,000 for the **CT** Home Care Program for Disabled Adults in FY 2010 and 2011 state budgets.
- ✓ Create a **PA** Adult Protective Services Program.
- ✓ Preserve a **MO** state income tax credit for accessible home modifications.
- ✓ Require **CA** pharmaceutical manufacturers dispensing self-injection medications to administer the safe collection and proper disposal of these waste devices.



## CHAPTER PRESIDENTS

<b>December 10, 2010</b>	<b>CC:</b>
<b><u>Goal Steering Team Orientation Call Presentation</u></b>	

A series of Web-Ex orientation calls for all Goal Steering Team members were held November 18, 22 and 23. The purpose of those meetings was to: introduce the Co-Leaders; review the Goal Steering Teams' purpose, team composition and competencies, responsibilities and expectations; and the deliverables and timeline to provide the top strategies for 2012 planning and budgeting.

We welcome you to view the Goal Steering Team Orientation presentation [click here](#) to link to document on SharePoint and/or to listen to the recorded call, [click here](#) to link to the instructions also on SharePoint.

If you have any issues linking to the document or the recorded call, please contact Duanyelle West at [Duanyelle.West@nmss.org](mailto:Duanyelle.West@nmss.org).

We welcome your feedback and thank you for your continued support and participation in the implementation of our strategic response.

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212-476-0406



## MARKETING & DEVELOPMENT

<b>December 10, 2010</b>	<b>CC: All</b>
<b><u>December 2010: E-communications Update</u></b>	

### **December National MS eNEWS**

**Send date: 12/16/10**

**Audience: Full List**

The December National MS eNEWS will be sent on Thursday, December 16. Content includes a feature about progressive MS, as well as information about the January 11 Society live webcast on “Repairing the Nervous System in MS: Progress and Next Steps” and MS Activism success stories.

### **December End of Year E-fundraising Campaign**

**Send dates: 12/21, 12/28, 12/30 & 12/31**

**Audience: ~850,000**

Objective: The End of Year Campaign goal for the four part email series and promotions implemented on the national website is \$250,000.

In an effort to capitalize on the year-end effort, the national homepage will feature two End of Year campaign flash panels throughout the month of December. The first e-mail will serve as a thank you message from Joyce Nelson, as well as, a recap of our 2010 successes and a soft ask. The following e-mails will be a more traditional ask, also from Joyce, with the tax-deductible year end donation serving as the call to action.

Testing: We will be split-testing a financial goal with the EOY campaign. In FY10 we incorporated a fundraising goal of \$215,000 in the copy; in FY09 we did not. We want to learn if a goal increases the response rate and average gift size. Depending on results, we will carry over to FY12.

### **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](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](mailto:gary.sullivan@nmss.org) or 212-476-0538.

For questions about our online fundraising campaigns, please contact Sara at [sara.dougherty@nmss.org](mailto: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](mailto:rich.sarko@nmss.org) or 303-698-6100 x15171.



## MARKETING

December 10, 2010

CC: ALL

### MS Awareness Week 2011 Update & Toolkit Material Available

Multiple Sclerosis Awareness Week 2011 (March 14-20, 2011) marks the Society's sixth annual coordinated MS Awareness Week effort. As the breadth and effort to build awareness about multiple sclerosis and "the movement to create a world free of MS" expands, the Society will focus work toward efforts that best utilize resources to achieving identified outcomes.

To ensure that chapter, regional and Home Office plans are both aspirational and achievable, the development process has included a team of both chapters, regional and home office marketing representatives. This group provides input and feedback into the planning and execution of Multiple Sclerosis Awareness Week activities.

Over the next several years, this campaign will transition to a year-round awareness building effort that has key strategic communication objectives during Multiple Sclerosis Awareness Week, World MS Day and other identified time periods.

**This awareness building effort is designed to:**

- **Demonstrate that the power and importance of the MS movement, that it is a force by and for people living with MS**
- **Create a greater overall awareness and understanding of what it means to live with the disease.**

We are busy putting together toolkit materials for chapters, volunteers and anyone who wants to be a part of the MS movement. The Phase I toolkit materials include the following and are currently available on Sharepoint in the Marketing section and at: <ftp://ftp.nmss.org> in the folders: materials<Multiple Sclerosis Awareness Week 2011, Username: materials password: materials123

- Multiple Sclerosis Plan 2011 and Chapter Toolkit, which summarizes key objectives, strategies, measurable outcomes and topline messaging per audience
- Awareness word treatment and style guide
- Electronic letterhead and Powerpoint templates

- Email template
- MSConnections information

Phase II will be available at the beginning of January and include materials such as:

- Print ads in various formats
- Earned media templates
- Web downloadable materials
  - Banners
  - Badges
  - Icons
  - Wallpaper
- Ecard
- Postcard/flyer template

Chapter brainstorm and idea sharing calls will be scheduled in January.

Questions? Contact:

[Shawna.Golden@nmss.org](mailto:Shawna.Golden@nmss.org)



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## PROGRAMS AND SERVICES

<b>December 10, 2010</b>	<b>CC:</b>
<b>January Telelearning Opportunity for Society Connection Program Volunteers</b>	
<b>Action Requested by January 14, 2011</b>	

The first telelearning for fiscal year 2011 for all Society connection program volunteers (self-help group leaders, peer support and MSFriends volunteers) is scheduled for January 2011. The topic is ***Emerging Oral MS Therapies***.

This training will provide an overview of the newly approved oral medications for managing MS symptoms and modifying the disease course. Participants will learn how these therapies offer options and hope for people with MS, and gain a greater understanding of the challenges they pose for both patients and physicians. The presentation will also describe some of the oral and infused medications in the research pipeline and offer an opportunity for questions.

Our presenter is Rosalind Kalb, PhD. Dr. Kalb is Vice President of the Society's Professional Resource Center, developing and providing educational materials and consultation services for healthcare professionals. As a clinical psychologist in private practice, Dr. Kalb has provided individual and family therapy for people living with MS for more than 25 years.

This learning opportunity is open to all Society self-help group leaders, peer support and MSFriends volunteers.

### **SCHEDULE**

Two calls are scheduled. It is the same agenda offered at two different times.

- Call 1 is Tuesday, January 25, 2011 from 1-2:00 pm ET (12 pm CT, 11 am MT, 10 am PT)
- Call 2 is Saturday, January 29, 2011 from 3-4:00 pm ET (2 pm CT, 1 pm MT, 12 pm PT)

The call will be recorded for those who miss it or would like to listen again. A playback number will be provided for you to share with your volunteers. The recording and associated handout will also be available for download on the self-help group leaders' resource page on the Society's website (<http://www.nationalmssociety.org/living-with-multiple-sclerosis/society-programs-and-services/connection-programs/resources-and-support-for-self-help-group-leaders/index.aspx>.)

## **COST**

There is no cost for this call.

## **REGISTRATION AND CANCELLATION INFORMATION**

The registration form and promotional handout are available on SharePoint: Programs and Services>Social Connections and Support Resources>Self Help Group Materials.

Due to numerous factors, including the need to reserve lines with the conference call company, charges for unused lines, and the distribution of call information and handouts, registration and cancellation deadlines have been established. The **registration deadline** is **Friday, January 14th**. Chapters needing to **cancel a registration** must do so no later than **Friday, January 21st**. Please send all registrations and change notifications to [Selfhelpgroupleaderregistrations@nmss.org](mailto:Selfhelpgroupleaderregistrations@nmss.org)

The Programs and Services Department will e-mail the training handouts to all volunteers registered for the training. Hard copies will be mailed to volunteers without an email address.

Please address any registration-related questions to Heather Webb-Jones in the Programs and Services Department at 303-698-6100, ext. 15176 or [heather.webb@nmss.org](mailto:heather.webb@nmss.org).

Topics and dates for future telelearnings will be announced in upcoming news sheets.

Additional questions or suggestions for FY 2011 telelearning topics can be directed to Kim Koch at (303) 698-6100, ext. 15158 or [kimberly.koch@nmss.org](mailto:kimberly.koch@nmss.org)

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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

December 7, 2010

### **Research Funded in Part by the National MS Society Identifies Key Player in Nervous System Repair**

Researchers co-funded by the National MS Society have identified a molecule that appears to stimulate the brain's natural ability to repair myelin in rodents. Myelin is the insulating coating on nerve fibers that is damaged in MS. The finding, which needs further research to translate to human disease, resulted from a massive hi-tech screening system to identify new strategies to repair nervous system damage in MS. Jeffrey K. Huang, PhD, Charles ffrench-Constant, PhD, Robin J. M. Franklin, PhD (University of Cambridge, University of Edinburgh, and others) and colleagues report their findings in the December 5 advanced online publication of Nature Neuroscience

(<http://www.nature.com/neuro/journal/vaop/ncurrent/abs/nn.2702.html>). This team (<http://www.nationalmssociety.org/research/research-we-fund/targeted-research/nervous-system-repair/ffrench-constant-repair-team/index.aspx>) was funded by the National MS Society's Promise:2010 Nervous System Repair and Protection Initiative, the MS Society of the UK and Northern Ireland, the ARSEP Foundation, and others. This Initiative is part of a comprehensive approach the Society is taking to stop MS progression, restore function, and end MS forever.

**Background:** MS involves immune-system attacks against the myelin coating that insulates and protects nerve fibers in the brain and spinal cord. The nerve fibers themselves are also damaged, and so are the cells that make myelin, known as oligodendrocytes. Research indicates that some natural myelin repair occurs in people with MS, but often fails for unknown reasons. There are several approaches being investigated to repair the nervous system in MS. One approach being tested in animal models is to transplant replacement cells in attempts to restore function. Another approach is to find ways to take advantage of the brain's warehouse of immature oligodendrocytes known as oligodendrocyte precursor cells (OPCs) to stimulate natural repair processes.

The Study: This team has been exploring both approaches. In this study, the team investigated factors responsible for natural repair processes. They induced myelin damage in laboratory rodents and then isolated tissue samples at various time points during the subsequent natural repair process. They analyzed these samples using gene chip technology to identify levels of RNA (ribonucleic acid, the chemical that delivers the instructions from a gene to a cell). This created a “transcriptome” – a complete picture of RNA activity during spontaneous myelin repair. The transcriptome directed them to 8,754 genes that were active over three time points.

In particular, the results showed high levels of activity for the gene that controls a molecule called retinoid acid receptor (RXR)-gamma. The team then followed up with a series of experiments in lab dishes and in rodent models. They showed that the transformation of OPCs into mature oligodendrocytes capable of making myelin was severely inhibited when RXR-gamma was blocked. Administering molecules that mimic RXR-gamma to rats following myelin damage resulted in increased repair of myelin.

Comment: This study points to a possible target for the development of repair strategies in MS, which will need additional research to determine its translation to human disease. It also introduces a new, valuable resource for the study of such repair strategies. “The remyelination transcriptome will be a useful resource for the neuroscience and regenerative medicine community to better understand the signaling networks and factors required to repair the injured brain,” say the authors.

The National MS Society’s grant to this and three other international teams (<http://www.nationalmssociety.org/research/research-we-fund/targeted-research/nervous-system-repair/index.aspx>) of investigators involved in the Nervous System Repair and Protection Initiative has stimulated many new findings, tools and resources. For example, this Cambridge/Edinburgh team recently received a \$15.5 million grant from author J. K. Rowling to create a regenerative neurology center at the University of Edinburgh. This generous gift leverages the work and collaborations developed by this team so that they can take the crucial next steps to develop ways to repair MS damage and restore function to people with MS.

Read more (<http://nationalmssociety.org/research/research-we-fund/focus/repairing-damaged-tissues/index.aspx>) about research on repairing damaged tissues in MS.