



## ADVOCACY

February 17, 2012	CC:
<b><u>Advocacy Tools for Preservation of Home and Community-Based Services in State Budgets</u></b>	

Home and community-based services maximize independence and personal choice for people with multiple sclerosis (MS) and other disabilities, but could be in jeopardy due to fluctuating state revenue forecasts. State Activism Council members Bonnie Danowski (AZ), Terry Farmer (CA) and Jody Garcia (PA) recently developed a series of tools to understand state funding formulas and defend these vital programs and services from potential reductions in funding. These advocacy tools include:

**[Fact Sheet: MS Advocacy and the State Budget Process](#)** – a primer for Society staff and volunteers to generally understand the process of allocating state and federal funding within a state. The state’s budget is the definitive policy statement of the decision-makers in government, according to the National Association of State Budget Officers.

**[Position Paper: Home and Community-Based Services](#)** – a template leave behind for state legislators, to be further developed by Society staff and volunteers to reflect specific state circumstances, that describes the impetus for and definition of home and community-based services.

**[National MS Society Issue Brief on Home and Community-Based Services](#)** – a broad-based background piece for state legislators regarding the scope of home and community-based services, state and federal funding streams for these services and distinctions between home and community-based and institutional services.

**[Glossary of Terms for Home and Community-Based Services](#)** – a reference for abbreviations and definitions related to home and community-based services.

For additional information regarding the economy and its affects, review the December Advocacy Toolkit: [2012 State Budgets – Recovering but not Recovered](#), or contact your Advocacy Department Liaison.

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## MARKETING

February 17, 2011	CC: All
<b>February 2012: E-communications Update</b>	

### February National MS eNEWS

Send date: 2/16/12

Audience: Full List

The February National MS eNEWS was sent on Thursday, February 16. Content included a feature on strategies for getting CAM paid for, as well as a report on the results of a small clinical trial in secondary-progressive MS and pushes to our Walk MS page, the DIY page and a broadcast of Phil Keoghan's "The Ride" on Showtime (February 18).

### February – March Campaign

In the past, we've tested several creative offers during this time frame with limited success in terms of donors and gifts. So this year, we're taking a different approach. We've created a multi-touch effort that begins with a donation request in exchange for a celebratory card to be mailed on the donors' behalf to whomever they wish during MS Awareness Week in March.

### Tribute Offer E-Fundraising (Card back-end premium)

**Dates:** Friday, February 24<sup>th</sup>, initial email  
Tuesday, February 28<sup>th</sup>, reminder email

#### **Audience:**

- Anyone who has given an online tribute or memorial gift in past 24 months (or however long ago)
- Anyone with a classification of friend or relative of someone with MS (who doesn't hit normal event or direct marketing excludes)
- Those with a classification of MS are excluded
- All normal excludes apply

**Objectives:** On Friday, February 24<sup>th</sup> an email will be sent to a targeted audience with a connection to MS or a past memorial/tribute donation history. The email will be inviting constituents to make a donation in tribute of someone they care about in honor of MS Awareness Week. The email will feature the personal tribute card, which will be delivered to their loved ones

mailbox during MS Awareness week. A follow-up reminder email will be sent on Tuesday, February 28<sup>th</sup>, with the same content as the original. If any questions arise regarding the fulfillment or needed changes to the content on the tribute card please contact Sara Dougherty at x15157.

Individuals with 'no email' or 'no email solicitation' classifications on their Altair accounts will be suppressed, along with standard Direct Marketing Program excludes/suppressions.

For questions about our online fundraising campaigns, please contact Sara at [sara.dougherty@nmss.org](mailto:sara.dougherty@nmss.org) or 303-698-6100 x 15171.

### **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.



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

**February 15, 2012**

### **Small Trial of Patients' Own Adult Stem Cells Appears Safe and Hints of Benefit**

Results of a clinical trial involving 10 people with secondary-progressive MS suggest that injecting a person's own bone marrow stem cells (mesenchymal cells) appears safe and may be beneficial in helping to protect the nervous system from injury from MS. Further trials now underway should further establish the safety and potential benefit of this approach for treating MS. The study, by Drs. Peter Connick (University of Cambridge), Siddharthan Chandran (University of Edinburgh) and colleagues, was published in the February Lancet Neurology (2012; 11:150-156. <http://www.ncbi.nlm.nih.gov/pubmed/22236384>).

**Background:** There are many types of stem cells that are undergoing varying degrees of research and which are producing knowledge about their potential usefulness for treating MS. Further study is necessary to determine what kind of cells might prove optimal for treating some or all people with MS.

One approach to stem cell research in MS relates to efforts to repair nervous system damage, or to protect against the damage (neuroprotection). This research is in its infancy, and there is no evidence yet that any type of stem cells can reverse MS damage or protect against it. Adult mesenchymal (pronounced messENkimmul) stem cells are present in many tissues of the body, including the bone marrow and fat. These cells potentially have the ability both to treat immune disorders and promote tissue repair. Studies in rodent models of MS have suggested that injections of mesenchymal stem cells may have benefit, and a few trials are testing this approach in MS and in spinal cord injury.

Since there is an unmet need for therapies for progressive MS, the United Kingdom investigators chose to do this clinical trial focusing on people with secondary-progressive MS. The study was funded by many sources including the Medical Research Council, MS Society of Great Britain and Northern Ireland, and the Wellcome Trust.

The Study: Designing a clinical trial to show neuroprotection is difficult because, for one reason, the course of MS is so variable. To work around this difficulty, the research team recruited people who had very specific signs of myelin damage in the optic nerve. Participants included women and men ages 40 to 53 who had lived with MS for an average of 14.4 years. The procedure involved removing the individuals' own bone marrow cells, which were then sorted, multiplied in lab dishes and eventually infused into the vein. Participants received a single infusion of cells based on their body weight.

The team's primary goal was to assess feasibility and safety, but they also evaluated other outcomes such as visual function, MRI scans and disability. They observed participants for at least 12 months before the infusion and at least 6 months afterward. This small proof-of-concept trial was not placebo controlled, and the investigators compared the condition of participants for the 12 months before treatment against their condition after treatment.

Results: The procedure was found to be safe, with no serious adverse events identified. Several aspects of vision appeared to improve after treatment, including visual acuity, sensitivity to contrast, visual signal conduction (visual evoked response latency and amplitude), and optic nerve area. There was also a reduction in the rate of progression on the EDSS, a standard scale that measures physical disability. Other aspects of visual function did not change, including color vision and visual field, and imaging measures of disease activity, such as lesion volumes, retinal fiber layer thickness, and brain volume did not change significantly.

Comment: As the authors point out, the small, uncontrolled nature of the study make it important to verify the results in larger, controlled trials. In an accompanying editorial, Drs. Mark Freedman and Antonio Uccelli, who established the International Mesenchymal Stem Cell Transplantation Study Group, note that although the study is not definitive, it raises substantial interest because of the signs of repair shown in participants with secondary-progressive MS. Further trials now underway should further establish the safety and potential benefit of this approach for treating MS.

This study emphasizes the importance of research to restore function in MS by repairing and protecting the nervous system. Read more: <http://www.nationalmssociety.org/research/research-we-fund/focus/repairing-damaged-tissues/index.aspx>



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

February 17, 2012

### **Rehabilitation Technique Improves Memory and Increases Brain Activity in People with MS**

In a small, controlled study, learning and memory improved in people with MS with a technique that uses stories and imagery to cement learning. For the first time, this improvement was shown to be accompanied by biological changes in the brain indicating increased activation of areas related to memory and learning. Nancy D. Chiaravalloti, PhD, John DeLuca, PhD (Kessler Foundation Research Center) and colleagues report their findings in *The Journal of Neurology* (Published online, January 12, 2012 <http://www.springerlink.com/content/p0357631248h32m2/>). Victoria Leavitt, PhD – a postdoctoral fellow funded through the National MS Society’s Mentor-Based Postdoctoral Fellowship program – presented preliminary findings from this study at ECTRIMS 2011 (<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=5695>) and earned an award for the team’s poster presentation. The study was also funded by the National MS Society, the National Institutes of Health and the Kessler Foundation.

**Background:** Cognitive changes (<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/symptoms/cognitive-dysfunction/index.aspx>) are common in people with MS. Certain functions are more likely to be affected than others, such as memory (acquiring, retaining, and retrieving new information). Researchers are investigating ways to restore function in people with MS who experience cognitive problems, including cognitive rehabilitation techniques.

Kessler Foundation designed a fellowship program to train post-doctoral fellows to conduct such research in neuropsychology, cognitive rehabilitation and cognitive/translational neuroscience. This program is funded through the National MS Society Mentor-Based Postdoctoral Fellowship in Rehabilitation Research, which aims to recruit and train talented clinician-scientists in rehabilitation research specific to MS.

The Study: The team recruited 16 people with MS, and administered neuropsychological assessments and functional magnetic resonance imaging (fMRI). fMRI allows researchers to take active images of the brain while the person is performing memory tasks that require them to learn a list of words or a short story. Participants were then randomly assigned to undergo 10 treatment or placebo sessions, twice a week for five weeks. In the treatment sessions, participants were trained using the modified Story Memory Technique (mSMT), which helps people to learn new information and remember older information using imagery and context. The technique is applied to real-life situations, such as remembering a shopping list or a list of errands. A control group met for 10 sessions as well, working on the same tasks, but by reading and answering questions. Neuropsychological and fMRI assessments were repeated after the sessions were completed.

The results show that the treatment group improved by more than 10% over the control group in the ability to recall information. For the first time, the team was also able to show that fMRI scans revealed increased activation in all participants in the treatment group in areas of the brain related to learning and memory. The fMRI scans did not change after the sessions in the control group.

Comment: This innovative study identifies regions of the brain associated with improvements in learning and memory, and suggests that further research might help to develop therapeutic strategies that increase activation of these regions – and thus increase learning and memory. The authors note that such strategies might use mSMT in combination with pharmacological treatment for maximized effect.

“These findings are a great example of why we need to increase rehabilitation research,” says Nicholas LaRocca, Vice President of Health Care Delivery and Policy Research for the Society. “We need to show that rehabilitation interventions can restore function in people with MS – conclusively – to health care providers and payers. Our fellowship program is helping us to reach this goal.”

The National MS Society’s Strategic Response to MS emphasizes a focus on rehabilitation research aimed at restoring function and improving quality of life. Read more about this research (<http://www.nationalmssociety.org/research/research-we-fund/focus/studying-psychosocial-aspects-of-ms/index.aspx>).