



DEVELOPMENT

October 8, 2010	CC: Chapter Presidents
	Information & Resources
	Marketing
<u>FY11 Direct Marketing October Acquisition Mailing</u>	

FY11 October Acquisition Mailing

Project: 2010 Annual Fund Drive

Drop Week: **10/4/2010**

In-Home Week: **10/18/2010**

This mailing will be the first in FY11 for the Acquisition program and the DM team is planning for a successful year ahead. We will be continuing to mail our best performing lists of the past two years in an increased effort to keep cost down, while acquiring the most new donors. It is as important as ever to attract new donors to the file, and we are hoping to begin the fiscal year strong, by acquiring 8,611 new donors.

Here are the objectives for this mailing:

October Acquisition	Outside Exchange and Rental Lists	Internal Altair & Lapsed Direct Mail Lists	Total Campaign Projections
Mailed	940,000	679,000	1,619,000
Gifts	8,611	8,936	17,547
Revenue	\$167,986	\$241,157	\$409,143
Percent Response	.92%	1.41%	1.08%
Average Gift	\$20	\$29.5	\$23

The offer is 2010 Annual Fund Drive to help the donor's neighbors with multiple sclerosis.

An electronic copy of this mailing will be posted to the Direct Marketing section of the Society Intranet for your reference.

Please email or call Sara Dougherty at sara.dougherty@nmss.org, 303-698-6100 x15157 with questions or concerns regarding the acquisition program.



DEVELOPMENT

October 8, 2010	CC:
<u>WalkMS.org and BikeMS.org Event Map Training</u>	
<u>Deadline: October 13, 2010</u>	

Starting in November 2010 all events on WalkMS.org and BikeMS.org will remain ‘evergreen’ on the site, meaning that after event dates have passed the event will remain live on the site. This is in response to user confusion over where our events occur. For example, over the summer less than 10% of our Walks appear on the site, which can make potential participants who are looking into the event for the first time come to the conclusion that there are no events in their local area.

We will have training on how to set up your chapter’s events on WalkMS.org and BikeMS.org sites on October 20th and 21st. These quick, 30 minute trainings will walk you through the documentation on how to set up your events within the system. You will also receive new log-in information for your chapter to access the site. If you are unable to make the trainings there will also be detailed instructions, including screen shots, that should allow you to set up your events without issue.

Each chapter is responsible for setting up their own events and ensuring that they stay up-to-date.

Wednesday, October 20th

1 pm eastern (12 pm central, 11 am mountain and 10 am pacific)

877-875-7554 pass code 25379800#

<https://nmss.webex.com/nmss/j.php?ED=141930412&UID=0&RT=MIM2>

Thursday, October 21st

3:30 pm eastern (2:30 pm central, 1:30 pm mountain and 12:30 pm pacific)

877-875-7554 pass code 25379800#

<https://nmss.webex.com/nmss/j.php?ED=141930607&UID=0&RT=MIM2>

If you have events that need to be entered immediately, please send those to Michelle Larsen at michelle.larsen@nmss.org by October 13th and they will be entered into the CMS.

Please send your events in the format below:

Bike MS Events:

Chapter name

Name of ride (i.e. include presenting sponsor name if applicable)

URL to Bike MS page (actual URL not website address)

Whether or not there's a one-day option

Mileage options

Date(s) for each ride

Start city, state and zip code **for each site**

of expected participants

Difficulty of ride – Easy, Moderate or Difficult

Walk MS Events:

Chapter name

Name of walk (i.e. include presenting sponsor name if applicable)

URL to Walk MS page (actual URL not website address)

Date for each walk site

Start city, state, zip code **for each site**

For questions on the WalkMS.org and BikeMS.org sites please contact [Michelle Larsen](#) or [Todd Culter](#).



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

October 8, 2010

Study Suggests Meditation Improves Quality of Life, Depression, and Fatigue in People with MS

The largest study of its kind shows that mindfulness-based meditation significantly improved health-related quality of life, depression, and fatigue in a study involving 150 people with relapsing-remitting and secondary-progressive MS. Paul Grossman, PhD (University Hospital, Basel) and colleagues report on this study in *Neurology*. (2010;75:1141-1149, <http://www.neurology.org/cgi/content/abstract/75/13/1141>) This controlled study provides important evidence on the value of an alternative treatment for MS symptoms, and highlights the importance of focusing on quality of life issues to improve well being. The study was funded by the Swiss National Science Foundation, the Stanley T. Johnson Foundation, the Swiss Multiple Sclerosis Foundation, Sanofi-Aventis, Merck Serono and Biogen Dompé.

Background: Depression and fatigue are common symptoms of MS and can interfere with quality of life. These and other psychosocial impacts of MS can adversely affect what is known as health-related quality of life (HRQOL) or sense of well-being, and their intensity is often independent of the physical aspects of any individual's disease. Although the disease-modifying therapies (<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/treatments/index.aspx>) for MS can impact the disease course, they do not usually cause significant improvement in an individual's HRQOL. For this study, investigators focused on whether a type of meditation, called mindfulness-based intervention, could improve well being in people with MS. This form of meditation is mental training aimed at changing an individual's perception, creating awareness and acceptance of moment-to-moment experiences, with the goal of reducing reactions that may worsen any pain or emotional distress that occurs from health-related changes.

The Study: In this largest study of its kind in MS, a total of 150 participants with relapsing-remitting (<http://nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/relapsing->

[remitting-ms-rrms/index.aspx](http://www.nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/secondary-progressive-ms-spms/index.aspx)) or secondary-progressive MS (<http://nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/secondary-progressive-ms-spms/index.aspx>) were enrolled. Seventy-six were randomly assigned to receive weekly 2½-hour group training sessions in mindfulness-based intervention (MBI) for eight weeks, plus one all-day session and practice homework. A control group of 74 people received regular medical care. Health-related quality of life, depression, and fatigue were assessed using various questionnaires before the study, after the eight weeks of training, and after another six months. Secondary outcomes included anxiety, personal goal attainment, and adherence to homework.

After eight weeks, participants improved significantly more in the MBI group than in the control group across all outcome measures (except for perceived limb mobility). The benefits remained significant at the six-month follow-up, but were less than at the eight-week endpoint. In a subgroup of people who scored worse on scales for depression, fatigue, and anxiety before the study, this group showed an even greater degree of improvement.

Comment: “The results of this solidly designed study underscore the importance of treatment directed at quality of life issues in patients with MS,” note Jinny Tavee, MD, and Lael Stone, MD (Cleveland Clinic Foundation) in an accompanying editorial. Drs. Tavee and Stone do note that one limitation of this study is that the control group received no intervention; if they would have received a “sham” intervention, the group might have improved more due to an increased sense of coping.

Propelling more research to address quality of life issues in MS is a key part of the National MS Society’s 2011-2015 Strategic Response initiatives.

Read more (<http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/symptoms/index.aspx>) about symptoms of MS and ways to cope with them.



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RESEARCH/CLINICAL UPDATE

CC: Chapter Presidents, Programs

October 8, 2010

Phase III Results of AVP-923 (formerly called Zenvia) Published, Showing It Can Reduce Episodes of Uncontrollable Laughing or Crying in MS and Other Disorders

The results of a Phase III trial of an oral drug designed to treat uncontrollable laughing and/or crying (known as pseudobulbar affect), a troubling symptom experienced by some people with MS, ALS, and other neurological disorders, have now been published. AVP-923 (Avanir Pharmaceuticals) significantly reduced the rate of laughing and crying episodes and appeared to be safe and well tolerated. (*Annals of Neurology*, published online September 13, 2010, <http://onlinelibrary.wiley.com/doi/10.1002/ana.22093/abstract>)

According to an Avanir press release dated August 5, the U.S. Food and Drug Administration set a date to complete its review of this drug by October 30, 2010. The company also has submitted trade names to the FDA for consideration after receiving notice that the agency did not accept the name “Zenvia” for marketing use.

Background: A small percentage (around 10%) of persons with MS experience episodes of uncontrollable laughing and/or crying that are unpredictable and seem to have little or no relationship to actual events or the individual’s actual feelings. This condition is thought to result from lesions – damaged areas – in emotional pathways in the brain. It is important for family members and caregivers to know this, and realize that people who experience these episodes may not always be able to control their expression of emotions. Some medications have shown benefit in small clinical trials, but there is no medication approved specifically to treat this symptom.

Avanir Pharmaceuticals has been conducting trials of AVP-923 in its current and related formulations for several years as a treatment for pseudobulbar affect in a number of disorders, including MS, ALS, Alzheimer’s disease and stroke. AVP-923 is a patented, orally-administered combination of dextromethorphan and an enzyme inhibitor known as quinidine;

quinidine is a drug that inhibits the metabolism of dextromethorphan which results in a sustained elevation of dextromethorphan in the brain. In 2006, Avanir received a letter from the FDA indicating that the drug was “approvable” and requesting that additional studies be conducted, leading to the current study.

Study Details: This trial, called the STAR trial, involved 326 individuals (197 with ALS and 129 with MS) across the U.S. and Latin America who were experiencing pseudobulbar affect. Participants either received one of two doses of AVP-923 or inactive placebo twice a day for twelve weeks.

The primary endpoint established for this trial was the rate of self-reported laughing or crying episodes over the course of the trial. Both doses significantly reduced episode rates by about 47-49 percent compared to placebo. Secondary outcomes, including patient diaries and episode-free days, also suggested significant benefit among groups taking AVP-923, and those on the higher dosage also showed improved measures of social functioning and mental health.

The medication was relatively well tolerated. The adverse events more frequently reported by those on therapy (especially the higher dose) versus those on placebo were dizziness, nausea and diarrhea. There were seven deaths in the study, all occurring in participants who had ALS, and all of which were classified by an independent committee as being likely due to progression of respiratory problems related to the disease.

Follow-up: In an extension of this study, 253 people took the higher dose of AVP-923 for 12 more weeks, during which safety and tolerability were assessed. The drug continued to be well tolerated. (Abstract #P06.128, American Academy of Neurology Annual Meeting, 2010)

Comment: “The availability of a therapy that could safely and effectively treat uncontrollable laughing and crying would be a real breakthrough for those with MS and other neurological conditions who experience this troubling symptom,” said Dr. Nicholas LaRocca, a clinical psychologist who directs the National MS Society’s research programs in patient management and health care delivery and policy.

Read more (<http://www.nationalmssociety.org/about-multiple-sclerosis/symptoms/emotional-changes/index.aspx>) about MS and emotional changes.

A Clinical Bulletin for physicians, providing details about pseudobulbar affect and its treatment in MS (<http://www.nationalmssociety.org/for-professionals/healthcare-professionals/publications/clinical-bulletins/download.aspx?id=143>), is available on the National MS Society’s Professional Resource Center.



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

October 8, 2010

Study Shows MRI-Detected MS Disease Activity to be Higher in Spring and Summer ***-- Highlights influence of environment on MS***

Disease activity measured by serial MRI scans in 44 people with MS was increased two- to threefold during the months of March to August compared with other times of the year. Increases in disease activity correlated strongly with warmer temperature and increased solar radiation levels. The study, by Dominik Meier, PhD, and colleagues (Brigham & Women's Hospital, Boston), highlights the influence of environmental factors on MS and also suggests that seasonal variations should be accounted for in future clinical trials. (*Neurology* (2010;75:799-806, <http://www.neurology.org/cgi/content/abstract/75/9/799>).

Background: Among the approaches taken to find the cause and cure for MS is research into triggering or risk factors that influence whether a person develops the disease and whether it progresses. Research of populations to study disease patterns, including variations in geography, demographics, socioeconomic status, genetics, environmental risk factors, and exposure to infectious agents, is called "epidemiology." These studies provide vital information about relationships among these factors, so that we can better understand who gets MS and why, identify and explain areas with high or low rates of the disease, and assist in planning for health care and other services.

Previous studies had identified seasonal variations in MS disease activity. The current study, while small, adds the precision of frequent magnetic resonance imaging scans to detect lesions, or spots of disease activity and/or damage, in the brain.

The Study: The team analyzed MRI scans performed in 31 people with relapsing-remitting MS (<http://nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/relapsing-remitting-ms-rrms/index.aspx>) and 13 people with progressive MS (<http://nationalmssociety.org/about-multiple-sclerosis/progressive-ms/index.aspx>) over one year in the Boston area. The scans

were performed in the early 1990s before there were approved disease-modifying therapies, excluding the probable influence of such therapies on disease activity. The participants underwent weekly to monthly MRI scans, with a median of 22 scans per person. Clinical examinations were performed as well, to record the occurrence of clinical relapses. Boston-area meteorologic data (peak daily temperature, solar radiation, and precipitation) for the study time period was obtained from the U.S. Historical Climatology Network.

New areas of disease activity on T2-weighted MRI scans (which are used to provide information about disease burden, meaning the total amount of tissue damage) were two to three times higher in the months from March to August than during the rest of the year. New T2 activity correlated strongly with temperature and solar radiation levels. Clinical relapses were not increased significantly during these months. New T2 disease activity peaked toward the spring months in those subjects with progressive MS.

Comment: In an editorial accompanying this study, Anne Cross, MD, and Becky Jo Parks, MD (Washington University in St. Louis) comment on how the findings help confirm the role of environmental factors at play in MS, noting that, “If the critical environmental factors could be identified, this information would undoubtedly provide important clues regarding the mechanisms of disease progression in MS.” The authors also note that seasonal variation in MS should be considered in the design of future clinical trials that utilize MRI as an outcome measure.

Read more about how the National MS Society is searching for MS triggers through the study of epidemiology (<http://nationalmssociety.org/research/research-we-fund/focus/searching-for-triggering-factors/index.aspx>), and through advocacy efforts (<http://nationalmssociety.org/news/news-detail/index.aspx?nid=3913>) as well.