



CHAPTER PRESIDENTS

August 24, 2012	CC: All
Regional MS Awareness Metrics Report	

The [2012 Awareness Implementation Plan](#) is being thoughtfully implemented across the Society. As a key step in evaluating the effectiveness our awareness efforts, these important metrics reports benchmark organization- and region-wide activity levels on the web, in social media, and in traditional media.

The **regional** MS awareness metrics report:

http://intranet.nmss.org/Topics/marketing/Documents/Updated_Regional_MS_Awareness_Metrics_Report.pdf

Organizational MS awareness metrics report:

http://intranet.nmss.org/Topics/marketing/Documents/OrganizationalAwarenessMetricsCY2012_Q1-2.pdf

Moving forward, the Society-wide Marketing Work Team will continue to enhance these reports and work across the organization to ensure the information they contain is fully leveraged in organization-wide planning. If you have questions about the reports and how they can be leveraged to support awareness planning, please feel free to contact Chris.Yankee@nmss.org or any member of the Society-wide Marketing Work Team: Sherri Giger, Holly Anderson, Beth Clark, Marni Deckter, Meghan Finn, Kevin Moffitt, Debbie Pope, Arney Rosenblat, Corrina Steiger, Ericka Tavares, and Chris Yankee.



CHAPTER PRESIDENTS

August 24, 2012	CC: All
<u>Save the Date: 2012 Society Leadership Conference in Dallas</u>	

The 2012 Society Leadership Conference will take place November 8-10, 2012 at the Hyatt Regency, Dallas Fort Worth Airport. **PLEASE NOTE that the conference begins on THURSDAY the 8th and concludes on SATURDAY the 10th.**

The Society Leadership Conference is a unique opportunity for ALL leaders in the MS movement to share, learn and be inspired, both in person and virtually. Volunteers and staff leaders drive our work in governance, research and clinical programs, advocacy, programs and services, and fundraising. The Society Leadership Conference will provide a way for all of these leaders to connect, collaborate and move forward together toward our shared vision.

Registration information and additional details we will be available soon.

For more information:

Chris.Yankee@nmss.org

303 698-6100 x 15161



DEVELOPMENT

August 24, 2012	CC: Chapter Presidents
<u>Combined Federal Campaign (CFC) Kick-Off</u>	
Action Requested/Deadline: Immediate Attention	

Are you ready for the Combined Federal Campaign? Beginning in a few weeks, millions of public and private sector employees will designate their charitable contributions to non-profit organizations nationwide through workplace giving campaigns, such as the Combined Federal Campaign (CFC). Not all campaigns are easy to navigate and there are many sound-alike organizations so it is essential that we educate our donors on how to designate their workplace giving gifts to the National MS Society.

In most workplace giving campaigns, including the Combined Federal Campaign, participating charities are listed by federation. Instruct your donors to look for the National MS Society listed under Community Health Charities. If an individual works for the federal government or a branch of the military and participates in the Combined Federal Campaign, they can simply use the Society’s CFC designation code number: 11409. (If your chapter has a local listing in the Combined Federal Campaign, you may also direct your donors to your local CFC designation code.)

Workplace giving is primarily a local level initiative. As a result, the best way to impact this campaign is through chapter activities. Just a few simple steps can have significant results. In the next few weeks, chapters are strongly encouraged to:

- Contact your state affiliate director of Community Health Charities for information on local kick-off events then designate a volunteer or staff to participate in each event.
- Review and customize the workplace giving webpage on your chapter website. If you haven’t recently updated your chapter website, please review the national webpage on workplace giving and update your local webpage accordingly. (Be sure that your webpage includes the current national designation number, the CHC logo, and all local designation numbers. (The national page is: www.nationalmssociety.org/donate/workplace-giving/index.aspx)
- Feature workplace giving on your chapter homepage from September through December. Be sure to include the Community Health Charities logo and the

- CFC donor designation number: 11409 (The CHC and CFC logos are posted on SharePoint.)
- Use social media such as Facebook, Twitter and enews to promote workplace giving.
 - For the next few months, be sure your chapter's CFC designation number is listed in special event mailings, board mailings and educational mailings
 - Distribute information on CFC designation or corporate workplace giving campaigns to support group leaders and appropriate team captains
 - For additional activities and marketing templates, visit SharePoint.

To support local efforts, the home office will promote our CFC designation number on the homepage of the website in October; through the e-newsletter; in MSConnection and on Facebook. There will also be a half page ad in the fall issue of Momentum. We will target members of the military and federal workers by purchasing advertisements in Military Times and Federal Times Magazines and through a clipsheet service that targets military bases.

For questions related to workplace giving campaigns in your state, please contact your Community Health Charities state affiliate director. (A listing is posted on SharePoint.) For additional questions, contact Laura Uzzle (email: luzzle@msn.com or phone: 303-895-6797.)

The National MS Society's national designation code for the Combined Federal Campaign is CFC# 11409.



National Multiple Sclerosis Society
733 Third Avenue
New York, New York 10017-3288
Tel +1 212.986.3240
Fax +1 212.986.7981
E-mail nat@nmss.org
Nationalmssociety.org

RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

August 24, 2012

National MS Society Task Force Launches Ambitious Project to Change How MS Disability and Progression is Measured

In line with key goals of its Strategic Response to MS, a National MS Society task force is launching a far-ranging collaboration to analyze how MS is measured in clinical trials that involves a new method for measuring disability related to MS and resulting progression. The goal of finding new therapies to stop MS progression requires new or improved tools that will be able to track benefits of therapies more quickly in people, using better assessment tools that are accepted by drug regulatory agencies. The task force reports its initial progress in the *MS Journal* (2012;18:1074-1080, <http://msj.sagepub.com/content/18/8/1074.abstract>).

Background: Disease progression, or gradual worsening, experienced by people who have MS usually occurs over many years, and it is often difficult to track with the standard clinical measurement scales used by doctors to assess disease activity. Based on the recommendations from a previous meeting (<http://www.nationalmssociety.org/news/news-detail/index.aspx?nid=6363>), an international team of research advisors recommended establishing a task force to revise the MS Functional Composite (MSFC) – one measure currently used to measure MS disability.

The MSFC Task Force includes experts representing the clinical trials arena, academia, industry, regulatory agencies and patient advocacy groups. This team is shepherding the process of revising the MSFC scale for use as a primary outcome measure in MS clinical trials.

Task Force Progress: The MSFC task force met late last year, and established its goals. Members agreed that a key aspect of the project is to analyze data that have already been collected using the current version of the MSFC during the course of the past 15-20 years, primarily from industry-sponsored pivotal clinical trials.

It became clear through discussions that a collaboration with the Critical Path Institute (C-Path) would be of great value to the goals of the project. C-Path is a nonprofit partnership with the U.S. Food and Drug Administration, whose aim is to accelerate the pace and reduce the costs of medical product development by creating new standards for evaluating the safety and effectiveness of new therapies. C-Path currently has five such collaborations including one with the Coalition Against Major Diseases, which focuses on Alzheimer's and Parkinson's Disease.

Following the 2011 meeting, the MSFC Task Force sought a proposal from C-Path to complete this work. This proposal involves creating a database of aggregated, clinical data, and analyzing these data in order to arrive at a consensus on the optimal components for inclusion in a modified MSFC; and then advancing a revised clinical outcome assessment drug development tool based on the MSFC to the FDA and EMA (European Medicines Agency) for regulatory approval.

Comment: “The potential partnership with C-Path will align our efforts with regulatory agencies such as the FDA and EMA,” says Nicholas LaRocca, PhD, the Society's Vice President of Health Care Delivery and Policy Research, and a member of the MSFC Task Force. “This is critical – these agencies must approve of the measure if we are to use it in clinical trials.”

“The MSFC Task Force is making significant strides toward the effort to change how MS disability and progression is measured,” adds Chief Research Office Timothy Coetzee, PhD. “This work addresses a glaring need for a way to quickly evaluate the ability of potential therapies to stop or reverse MS progression.”



Read more (<http://www.nationalmssociety.org/research/stop/index.aspx>) about efforts to stop MS in its tracks and restore function (<http://www.nationalmssociety.org/research/restore/index.aspx>) to people with MS.



National Multiple Sclerosis Society
733 Third Avenue
New York, New York 10017-3288
Tel +1 212.986.3240
Fax +1 212.986.7981
E-mail nat@nmss.org
Nationalmssociety.org

RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

August 24, 2012

Fast Forward and the University of Cambridge collaborate to find new drugs that will repair the nervous system in people with MS

Fast Forward, LLC, a not-for-profit subsidiary of the National MS Society, is funding research at the Universities of Cambridge and Edinburgh, UK to screen for compounds that can stimulate myelin repair in MS. Myelin is the substance that surrounds nerve fibers and is a target of the immune attack on the brain and spinal cord in MS.

The project, which will be directed by Robin Franklin, PhD, DVM, grew out of findings from a Nervous System Repair and Protection Initiative funded through the Society's Promise:2010 campaign. Drs. Franklin and Charles ffrench-Constant, PhD (University of Edinburgh) found a molecule called RXR-gamma that is "turned on" following myelin damage, and which play a role in forming new myelin. Now Dr. Franklin is being funded to find molecules that can stimulate RXR-gamma. The award provides Dr. Franklin with \$200,000 over a 12-month period that started July 13, and like other Fast Forward partnerships, payments will be contingent upon the completion of specific milestones.

Dr. Franklin and colleagues are working with Domainex, a drug discovery company that has an exceptional track record of drug candidate delivery. Dr. Franklin's team and Domainex are using a proven virtual screening method that will allow them to identify a library of about 1,000 molecules that can promote RXR activity.

"We are thrilled to collaborate with the world class team of scientists led by Dr. Franklin," said Dr. Timothy Coetzee, Chief Research Officer at the National MS Society. "Driving research to restore function in people with MS is a critical component of the Society's research strategy."

Read more (<http://www.nationalmssociety.org/fast-forward//index.aspx>) about Fast Forward.



Read more (<http://www.nationalmssociety.org/research/restore/index.aspx>) about efforts to restore function to people with MS.