CHAPTER PRESIDENTS

January, 22, 2010	**CC:** Development
2010 Major Giving Winter Meeting – Agenda Highlights	
Action Requested: Plan to Attend	

Staff members responsible for major giving and/or the Golden Circle program are encouraged to attend the 2010 Major Giving Winter Meeting in Denver. This year's training meeting will focus on:

- **Individual Giving Program**

  Learn the status and direction of: direct mail to major gifts; the Common Ground tool and fundraising opportunities for your donors.

- **Assessing Your Fundraising Readiness**

  Assess the progress made on recommendations from the Alford Group's Campaign Planning Study. Identify what we can and must do differently in 2010.

- **Building Donor Relationships**

  Create a shared vision of the Society's future in individual giving. Determine how we will attract and retain members and develop Golden Circle member loyalty.

- **Golden Circle Mid-Year Check In**

  Accomplishments and adjustments in preparation for the Society-wide roll out of Golden Circle in 2011.

- **Meeting Our Shared Objective**

  Learn how to design a plan and put it into action to meet the shared objective of: launching an individual giving program…identifying at least ten new major gift prospects and developing strategies resulting in increases in major gift donations.

- **Creating Ideal Donor Relationships**

  Learn key points of the Disney customer relationship model that we can use to shape our future and influence individual giving.

The meeting will be held at the Denver offices on Thursday, February 18 starting at 9 a.m. and conclude on Friday, February 19, 2010 around noon. Suggested travel arrangements include arriving in Denver anytime Wednesday (2/17/10) and departing on flights after 3 pm on Friday (2/19/10). If you are not able to attend the meting in person, you will be able to hear key presentations and participate in several group conversations virtually. Registration and suggested accommodations will be available soon.

If you have questions or would like additional information please contact Susan Goldsmith at 303-698-6100 ext 15102 or susan.goldsmith@nmss.org

MARKETING

January 22, 2010	CC: Development
2010 Bike MS Jersey Designs & Ordering Information	

The 2010 Bike MS jersey designs are available for viewing on the ftp site. Two vendors will be offering these jerseys, Voler Team Apparel and Proforma MarketPlace. However, your chapter is welcome to use the 2010 artwork with any vendor. Ordering information and specifications are below. If you have any questions, please feel free to contact the vendors directly or Sandra Genova, Marketing Manager, 303-698-6100 x. 15172 or Sandra.Genova@nmss.org

Voler Team Apparel

Voler Team Apparel is happy to offer two jersey programs that are tailored to fit your needs.

1. Semi-Custom stock jersey program: Four stock jerseys that can have logos added to the design.
2. Full custom jersey program: Enables you to create a completely unique design from top to bottom.

Jersey Specification:

- Cut: Available in men's and women's specific cuts.
- Men's and women's jerseys are available in the "club cut" designed to fit the average cyclist. The cut is a relaxed fit and more roomy than a race fit jersey. All jerseys come standard with a high collar, separate side panels, 3 large rear pockets and a 20" hidden front zipper for maximum ventilation. Sizes range from XS-3XL.

Jersey Fabric: Aries Micro Plus is created from 100% micro denier Polyester yarns. These yarns give the fabric a soft comfortable feel and greatly increase the breath ability of the fabric. The micro waffle knit also improves airflow through the fabric.

Semi Custom Ordering:

Available Jerseys are: Rider, Top Fundraiser, Veteran and I Ride.

Semi Custom jerseys can be ordered with a minimum of 5 pieces per order. Each jersey has the ability to have custom logos (including your chapter and event logos)

added to the jersey. Sorry, adding colors or changing artwork is not allowed. Just ask us if you are unsure.

Artwork:
Logos need to be in an original Vector format (.eps) or (.ai). Web graphics may not be submitted (no .jpgs or .gifs, .tifs, or .png). Logos need to use the same colors (or black/white) as the jersey, unless quantities are under 30.

After your logos have been added to a Semi Custom jersey, an art proof will be e-mailed to you for final approval.

Pricing:
Semi Custom jerseys: minimum of 5 pieces per order.

5-14 pieces: $44.95
15-24 pieces: $40.95
25-49 pieces: $38.95
50-99 pieces: $35.95
100+ pieces: $33.95
Set-ups are included. The only additional charge is shipping.

Order Deadlines:
All orders and artwork will need to be in-house 7 weeks before scheduled ship date. Call the Voler sales department for available dates. Company purchase orders are all that will be required to begin the process. The jerseys will be shipped directly to chapters.

Full Custom Ordering:
This program is a wonderful way for you to make a completely distinctive jersey for your event. Just follow the 4 easy steps below, sit back and let Voler take care of your needs.

1. Call Voler to verify the next available ship date and secure a space in the production schedule.
2. We will send you a reservation card with your due date for the following items. 50% deposit, complete order with sizes and quantities and complete artwork. These items will be due 7 weeks before your scheduled ship date.
3. After receipt of your order and artwork we will send an Order Confirmation and complete art proofs for your final approval.
4. Your jerseys will be shipped out on time according to your scheduled ship week.

Pricing: (Unlimited Colors)

15-24 pc	$53.00
25-49 pc	$48.00
50-99 pc	$44.00
100-249	$36.00
250-499	$31.00
500+	Call

Minimum order is 15 pieces. Prices include art time and set-ups. Shipping is not included.

Art Work Specifications:
Voler uses a Macintosh format and will generate your art in Freehand or Illustrator. We will need all of your sponsors and logos in a digital format. They can be e-mailed or sent on a disk. They need to be saved in their original Vector format saved as a Freehand or Illustrator file. Please note that web site graphics and jpegs are not considered art ready and are unusable.

Contact Ed Fonda
edf@voler.com
Voler Team Apparel
21 Saratoga Ave.
Grover Beach, CA 93433
800-488-6537

Proforma MarketPlace

Proforma MarketPlace is also offering Bike MS jerseys. For prices and minimum orders contact Ryan Neych at proforma.marketplace@proforma.com
Or call 800-446-2215

Proforma Marketplace
39777 Garfield rd
Clinton Twp MI 48038
586-226-1699 or 586-226-1691

MARKETING

January 22, 2010	**CC:** All
MS Awareness Week Updates & New Resources Available	

The MS Awareness Week Team is excited to provide some new materials, resources and updates around national MS Awareness week efforts! We'll continue to provide new information as planning continues to evolve.

New Materials & Resources have been added to the MS Awareness Week Toolkit including:

- Pharma & Corporate Partner engagement recommendations
- Advocacy activity recommendations & sample state proclamation language
- Letter to local newspaper template
- Press release template
- Self Help Leader engagement ideas
- Social Media national strategy & recommendations for chapter social media engagement
- Walk MS & Bike MS Team Captain ideas

These materials can be accessed on the ftp site at: ftp://ftp.nmss.org/
username: materials password: materials123.
All files and artwork are located in the materials<MSAW 2010 folder.

Communications Schedule Around MS Awareness Week: There will be many communications going out to a variety of audiences via e-mail and other channels prior to and during MS Awareness Week. Please check the Constituent Communications Calendar FY10 to see when each of these will be sent out. We always want to be mindful of the numbers of e-mails each of our constituents receive.
http://intranet.nmss.org/Topics/marketing/Documents/Constituent_Communications_Calendar_FY10.xls

National Webpage for MS Awareness Week
The webpage on the national site is live and provides access to resources and actions that constituents can take to "Move It" during MS Awareness Week. Directly link to this page or create a chapter page that involves your local efforts and links to the national page.

http://www.nationalmssociety.org/msawarenessweek This page will be frequently updated as well.

Phil Keoghan Radio PSA: We are thrilled that Phil Keoghan agreed to record radio PSAs for MS Awareness Week. We are providing these to Clear Channel and other national media contacts and they are available for your use as well. There are two versions of this radio spot -- one with MS Awareness Week dates and one that is evergreen. :15, :30 and :60 second versions are provided and can be accessed at http://www.nationalmssociety.org/press-room/psas/index.aspx
http://www.nationalmssociety.org/press-room/msaw-psas/index.aspx or
http://www.nationalmssociety.org/get-involved/events/ms-awareness-week/index.aspx
You may continue to also use the "Terri Garr" radio spots as well. Direct reporters to any of these links for their print and radio PSA needs.

Clear Channel Communications: Clear Channel is once again supporting MS Awareness Week efforts on a national level! What this means is that we are providing Clear Channel with both web banners and radio PSAs to distribute across their network of radio stations. While Clear Channel does not "mandate" what PSAs are played locally or posted on local radio stations websites, we have received strong traction in past years. We are not distributing billboards nationally this year due to limited budget resources. However, we have provided Clear Channel outdoor with artwork for remnant digital billboards. If you have a relationship with your local Clear Channel radio or outdoor contact or are looking for an opportunity to introduce yourself to your local contact, we encourage you to reach out to them to discuss ways that Clear Channel can support your market. We can also help facilitate local market introductions through our national contacts.

Developers Diversified Realty: We are pleased that Developers Diversified Realty (DDR) is also continuing their national support of MS Awareness Week! This year, they will be producing and placing signage at their centers across the country. Further, they will be posting web banners on their websites and distributing an email to their customer database encouraging people to Move It during MS Awareness Week.

Congressional Resolution: U.S. Congresswoman Barbara Lee (CA) & U.S. Senator Bob Casey (PA) will be introducing the 2010 MS Awareness Week Resolution in both the House and Senate shortly, where they hope to gain co-sponsors and have it voted on in each chamber during MS Awareness Week.

Idea Share & Questions: Please continue to idea share with the MS Awareness Week Team. We'd like to make sure that collectively we are leveraging and sharing great ideas during the week. Chapter ideas will be continually added and updated to the toolkit document. Please contact Shawna Golden at Shawna.golden@nmss.org

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RESEARCH/CLINICAL UPDATE

	cc: Chapter Presidents, Programs

January 20, 2010

Positive Results Published on Clinical Trials of Oral FTY720 (Fingolimod) for Relapsing MS -- *Novartis Applies to FDA and European Regulatory Agency for Approval*

Positive results from two large-scale phase III clinical trials of oral fingolimod (FTY720) have been published showing it significantly reduced multiple sclerosis relapse rates, and one of the trials also suggested it could slow the progression of disability. The sponsor, Novartis International AG, has announced that it applied for marketing approval in the U.S. and European Union in December 2009. There are currently no approved oral disease-modifying therapies (http://www.nationalmssociety.org/about-multiple-sclerosis/treatments/index.aspx) for MS. The papers were published early online in the *New England Journal of Medicine* (http://content.nejm.org/cgi/content/full/NEJMoa0909494 and http://content.nejm.org/cgi/content/full/NEJMoa0907839) on January 20, 2010, along with a separate paper that describes results from a clinical trial of another orally administered experimental therapy, cladribine.

About Fingolimod: This is a new class of therapy in development for treating multiple sclerosis. FTY720 binds to a docking site (sphingosine-1-phosphate receptor, or S1P receptor) on immune cells, including T cells and B cells, that have been implicated in causing nervous system damage in MS. The drug appears to induce immune cells to remain in lymph nodes, where they can do little harm, preventing them from migrating into the brain and spinal cord.

First in-depth study results published: One paper, by Ludwig Kappos, MD (University Hospital, Basel, Switzerland) and colleagues, describes results from the large-scale, two-year phase III trial known as FREEDOMS, involving 1,272 people with relapsing-remitting MS. Over two years, fingolimod at either of two doses was able to significantly reduce relapse rates (the primary endpoint of the study) and slow disability progression (a secondary endpoint) compared to those on inactive placebo. Relapse rates were 0.18 for the lower dose, 0.16 with the higher dose, and 0.40 for those on placebo (a reduction of 54% and 60% over placebo, respectively). Disease progression was measured by standard MS clinical rating scales known as the EDSS and MSFC, and after 24 months both doses showed slower progression over those

on placebo. Secondary measures of disease activity and progression also favored both FTY720 doses, including MR imaging to detect tissue injury and brain atrophy.

The second paper, by Jeffrey A. Cohen, MD (Cleveland Clinic, Cleveland, Ohio) and colleagues, details positive results from a one-year clinical trial, called the TRANSFORMS study, comparing two different doses of fingolimod with Avonex® (interferon beta-1a, Biogen Idec). That study involved 1,292 individuals with relapsing-remitting MS. Both doses of FTY720 were able to reduce relapse rates over one year (the primary endpoint of the study), and also reduced disease activity on MR brain imaging. The annualized relapse rate in those taking the lower dose of FTY720 was 0.16, compared to 0.33 in those on Avonex (a comparative reduction of 52%). Those taking the higher dose of FTY720 experienced an annualized relapse rate of 0.20 (a reduction of 38% compared with Avonex). Time to sustained disability progression was no different in the FTY720 and Avonex groups.

Safety: In both studies, the lower dose of FTY720 was better tolerated. A few participants experienced a transient reduction in heart rate and blockage of heart conduction (atrioventricular conduction block) which generally normalized after the first dose. There was a slight elevation of blood pressure starting during the second month of therapy. Macular edema (swelling of the center of the retina inside the eye) occurred more frequently with those on the higher dose of FTY720 in both studies. Skin cancers were reported more frequently in those on FTY720 in the one-year TRANSFORMS study, but more malignancies in general were detected in those on placebo in the two-year FREEDOMS study.

Elevations in liver enzymes, without accompanying symptoms, were common in those receiving FTY720. In both studies, a small number of serious herpes infections occurred, including two deaths from herpes infections that occurred in the TRANSFORMS trial in people taking the higher dose of FTY720.

Next Steps: According to the company, these and other data were used to support applications for marketing approval for the lower dose of FTY720, which were submitted in December 2009 to the U.S. Food and Drug Administration and to the European Medicines Agency. Results from a second large-scale trial called FREEDOMS II (http://clinicaltrials.gov/ct2/show/NCT00355134) have not yet been released. Other phase 3 clinical trials of fingolimod, including one involving people with primary progressive MS (http://clinicaltrials.gov/ct2/show/NCT00731692), are still under way, as are extension studies involving those who've completed trials. These should provide additional data on safety and efficacy.

Comment: "The published results and the company's application for marketing approval for fingolimod are wonderful news for people with MS," said John R. Richert, MD, Executive Vice President of Research and Clinical Programs at the National MS Society. "Having oral therapies in the MS pipeline is real progress, and it should increase the number of people who choose to begin therapy earlier and who stay on therapy, which our experts say is the best way to combat future disease activity."

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RESEARCH/CLINICAL UPDATE

	cc: Chapter President, Programs

January 20, 2010

Results Published from Phase 3 Study of Oral Cladribine in Relapsing-Remitting MS

Details of positive results from the phase III trial of oral cladribine (EMD Serono), known as the CLARITY study, have now been published, showing that the drug reduced relapse rates significantly more than inactive placebo in a study involving 1,326 people with relapsing-remitting MS. The results were published early online in the *New England Journal of Medicine* (http://content.nejm.org/cgi/content/full/NEJMoa0902533) on January 20, 2010, along with separate papers that describe results from clinical trials of another orally administered experimental therapy, FTY720 (fingolimod).

About Cladribine: Cladribine can interfere with the activity of lymphocytes, a subset of white blood cells that underlie the immune attacks that cause the unpredictable symptoms of MS. Among its other activities in the body, cladribine also reduces the levels of immune messenger chemicals (cytokines) capable of increasing inflammation. Injectable cladribine is used to treat hairy cell leukemia. Positive results from the phase III CLARITY study of oral cladribine were originally announced in a press release in January 2009, and were presented at the American Academy of Neurology's annual meeting later that year.

In addition to the completed CLARITY study and a two-year extension study of CLARITY, other ongoing studies of oral cladribine funded by EMD Serono include the ONWARD study, an investigation of the safety and effectiveness of adding high or low doses of oral cladribine to interferons in a trial recruiting 260 people with relapsing forms of MS (this study is ongoing, but not recruiting participants http://www.clinicaltrials.gov/ct2/show/NCT00436826); and the ORACLE MS study (http://clinicaltrials.gov/ct2/show/NCT00725985), designed to evaluate the safety and effectiveness of oral cladribine in people who have experienced a neurological episode that puts them at risk for developing MS (this study is currently recruiting participants). EMD Serono has established a long-term safety registry (http://www.clinicaltrials.gov/ct2/show/NCT01013350) of people with MS who have participated in cladribine studies.

In November 2009, EMD Serono announced that it had received a "refuse to file" letter from the U.S. Food and Drug Administration for an application requesting approval of cladribine

tablets for the treatment of relapsing MS. This usually means that the FDA deems the application incomplete. According to a press release at the time, the sponsor planned to meet with the FDA to determine what would be required for the application to be accepted for review.

This Study: As described in the paper authored by Gavin Giovannoni, MB, BCh, PhD (Queen Mary University London) and colleagues, for the first year of the CLARITY study, 1,326 participants were randomly assigned to receive a low dose of cladribine tablets (two treatment cycles per year, each cycle consisting of one tablet per day for four to five consecutive days), a high dose (four cycles) of cladribine, or inactive placebo. In the second year, both treatment groups received a low dose of cladribine. The primary endpoint was the drug's effect on relapse rate at two years compared with placebo. Secondary endpoints included effects on disease activity, as detected by MRI scans, the proportion of relapse-free participants, and disability progression.

The relapse rate was reduced significantly compared with placebo in both treatment groups -- by 57.6% in the low-dose group and by 54.5% in the high-dose group. In secondary measures, the proportion of participants who remained relapse-free over 96 weeks was 79.7% in the low dose group, 78.9% in the high-dose group and 60.9% among those on placebo. The risk of a 3-month sustained change in the EDSS scale that measures MS-related disability was reduced by 33% in those on the low dose and by 32% in those on the high dose compared to those on placebo. Cladribine also reduced disease activity as indicated by MRI scans – including fewer active (gadolinium-enhanced) lesions (areas of inflammation).

Safety: One of the most frequent adverse events occurring more frequently in the both groups treated with cladribine was lymphocytopenia (a reduction of a subset of white blood cells), which was mostly mild to moderate. This occurred in 21.6% of those on the low dose, 31.5% of those on the high dose, and 1.8% in those on placebo. Based on the agent's mode of action, this might be expected, and may require monitoring if the drug becomes an approved therapy. Herpes zoster infection occurred in 20 people (2.3%) treated with cladribine and in none of those on placebo.

There were three cases of cancer in the low-dose group – a melanoma and carcinomas of the pancreas and ovary. One additional case of cancer occurred during a 6-month monitoring period after the trial ended, and one case occurred of a pre-cancerous cervical lesion. The authors comment that given the small number of cases, it is not possible to establish whether a cancer risk is associated with cladribine from this study.

Comment: "These published results are a true step forward in the development of oral therapies for MS," said John R. Richert, MD, Executive Vice President of Research and Clinical Programs for the National MS Society. "Having oral therapies in the MS pipeline is real progress, and it should increase the number of people who choose to begin therapy earlier and who stay on therapy, which our experts say is the best way to combat future disease activity."