



MARKETING

May 21, 2010

CC: All

Face of MS

Action Requested/Deadline: 5/21/10

www.FaceofMs.org was launched in 2005, as an initiative to ensure that people living with MS had a channel through which they could tell their story. The site facilitates story sharing, and then catalogues the stories by type and with a search function. Additionally, those submitting stories can also share a photo, which is then utilized to create a unique front-page mosaic.

While the site has served its purpose well in connecting and providing inspiration to the MS community, we believe we now have better online tools and resources to provide these services. Therefore, we are discontinuing FaceofMS.org by May 21, 2010.

Please remove any and all references to the FaceofMS.org site from all chapter Web pages, communications, etc. immediately.

Please invite all constituents to join the variety of other online community sites sponsored by the Society including:

Facebook – www.facebook.com/nationalmssociety

YouTube – www.youtube.com/nationalmssociety

Flickr – www.flickr.com/nationalmssociety

Twitter – www.twitter.com/mssociety

LinkedIn - www.linkedin.com/companies/national-ms-society

MySpace – www.myspace.com/mssociety

MSWorld – www.msworld.org

TheMSMovement – www.themsmovement.org

For questions about the retirement of FaceofMS.org, please contact Todd Culter at Todd.Culter@nmss.org

For questions about the Society's other online community sites, please contact Beth Clark at Beth.Clark@nmss.org



MARKETING

May 21, 2010

CC: All

Website Enhancements – RSS Newsfeeds and Share this Page Toolbar

On Tuesday, May 25, 2010, we will be adding two new features to the chapter and national Web pages. Both features will allow users to more easily share and distribute information they find on the Society website. **These are template changes, and no action is required from chapter or national personnel.**

RSS Newsfeeds

We are adding clickable RSS icons to the various national and chapter news sections. Users will be able to click and then subscribe to the RSS feed. News sections include: National News, Chapter News, Research News, Press Room, MS Clinical Trial Alerts, Treatment Updates, Government Affairs/Advocacy News, About the Society.

RSS stands for “Really Simple Syndication,” and allows users to receive a “feed” from our website that they can access via an RSS reader or that they can embed into their own sites to display the Society’s most up-to-date content. It allows users to receive and/or display Society news the moment it is posted to our site.

The RSS buttons will look like this: 

Share this Page Toolbar

We are adding a “Share this Page” toolbar to all Society templates, including chapter and national Web pages.

Currently, the site has a feature on each page entitled “Email this Page” that allows users to email a particular page. This functionality will be changed in two ways:

1. “Email this Page” will be changed to “Share this Page”
2. When users mouse over “Share this Page” they will get a social media share toolbar that allows them to choose where they want to share the page. Selections include Facebook, MySpace, Twitter, etc. It also allows them to e-mail the page if they choose.

Below is a screenshot of both new tools on a chapter page:

The screenshot displays the website interface for the Delaware Chapter. At the top, there is a navigation bar with the MS logo, a search box, and links for 'Sign In' and 'Create Profile'. Below this is a secondary navigation bar with links for 'About the Society', 'Find A Chapter', 'Government Affairs & Advocacy', 'News', 'Multimedia Library', 'Store', and 'For Professionals'. The main navigation bar includes links for 'About MS', 'Living with MS', 'Research', 'Get Involved', 'Online Community', and 'Donate'. The page content includes a sidebar with a 'Delaware' menu, a main content area with a 'Lace Up!' banner and a 'Share this page' toolbar, and a right-hand news section. A share toolbar is overlaid on the page, showing various social media and sharing options. Red arrows point from text annotations to the RSS button and the share toolbar.

Users can click this RSS button to subscribe to individual news feeds.

Share toolbar allows users to share every page on the site with their social networking sites.

MS News
Chapter News
Baywood Greens' award-winning grounds home to Delaware shore Walk MS
May 17, 2010
more local news

National News
safety grow
clinical none
g to dated
onal news

Share / Save | **E-mail** | **Add to Favorites**

Facebook | Twitter
Delicious | Digg
Google Bookmarks | Google Buzz
MySpace | Reddit
Yahoo Buzz | Windows Live Favorites
StumbleUpon | Yahoo Bookmarks

Powered by AddToAny

Women Against MS
An Evening Exploring the senses of a woman
Thursday, June 3, 2010
5:30 p.m. – 7:30 p.m.

Click here to take the 2009 Bike to the Bay Survey!

For questions about these new functions, please contact Todd Culter at Todd.Culter@nmss.org



MARKETING

May 21, 2010

CC: Chapter Presidents

Development

FunClick's Facebook® Poker Game WPT® Texas Hold 'Em Poker Gives Back to MS Research with Chips for Charity Promotion

WPT® Texas Hold 'Em Poker, the most popular poker brand in the world, and which is now available on Facebook as a free-to-play game developed by FunClick, is conducting a two-week "Chips for Charity" promotion to benefit the National MS Society and MS Hope for a Cure.

Chips for Charity provides fans of WPT® Texas Hold 'Em Poker on Facebook with the opportunity to buy premium chips to help raise money and awareness in support of MS research.

WPT Texas Hold 'Em Poker Facebook players are encouraged to buy special \$5 Chips for Charity packages. 100% of proceeds will be donated to the National MS Society and MS Hope for a Cure (www.mshopeforacure.org). Every contributing player will instantly receive 75,000 game chips into his or her account. If proceeds reach in excess of \$50,000 during the promotional period, all players will receive a special gift for their avatar profile to further encourage donations and increase awareness of World Multiple Sclerosis Day on May 26.

To become a fan of WPT Texas Hold 'Em Poker please visit <http://www.facebook.com/playwpt> or follow @PlayWPT on Twitter. To play the game: http://apps.facebook.com/wpt_poker/

The promotion runs May 24 through June 7.

The Society will be highlighting this promotion on its national home page and through social media. A press release will go out on the national news wire on May 24.

Questions?

Becca Kornfeld Becca.Kornfeld@nmss.org

Shawna Golden Shawna.Golden@nmss.org



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

May 21, 2010

Resource: Clinical Trials in Multiple Sclerosis 2010

We're pleased to present our annual listing of [Clinical Trials in MS 2010](#) (PDF), featuring ongoing MS trials, as well as those that are being planned or that have been recently completed. This year's list of 129 studies indicates an exciting time in MS research, with therapies progressing through the drug development pipeline. Here are some of the highlights:

- 58 studies of oral drugs for treating MS or its symptoms, up from 37 in 2008
- Novel agents being tested for neuroprotective capabilities, including two trials of green tea extracts and one of the pain reliever fluripitine maleate; and a study of the antioxidant idebenone in people with primary-progressive MS.

This list is prepared from materials provided by investigators, published literature and public presentations. While we strive for accuracy and completeness, there are trials that were not included because we were unable to gather sufficient information about them, and there may be inaccuracies due to changes in protocol.

Clinical Trial Participation Resources on Our Web Site

Because recruitment information changes frequently, we do not indicate which studies on this list are enrolling patients. For that information, go to the Clinical Trials section of our Web site, where there is a database of recruiting studies that is searchable by state, type of MS, or keyword, and MS Trial Alerts about specific studies. This section also includes a brochure and an online course to guide people through the process of deciding whether to enroll in a clinical trial. Read more at nationalmssociety.org/clinicaltrials.

Reminder: If you are approached about recruiting for a clinical study in your area and you are not sure what steps to take, please refer to this news sheet posted on SharePoint (http://intranet.nmss.org/Topics/cr/Lists/Critical%20Info/Attachments/7/Recruitment_Requests.pdf) or contact Sara Bernstein, Manager of Research Information (sara.bernstein@nmss.org; 212-476-0419).

-- Research and Clinical Programs Department



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

May 21, 2010

Small Phase I Safety Trial of Bone Marrow Stem Cells in MS Completed **-- IV cell therapy reported safe but effectiveness inconclusive**

British researchers report results of a Phase I safety/feasibility clinical trial involving six people with long-standing multiple sclerosis, testing intravenous injections of the patients' own adult bone marrow cells containing a mix of stem cells. After one year, the investigators found the treatment safe, but because it was a small, open-label trial with no controls, they report that firm conclusions cannot be drawn about its effectiveness. The study, by Neil Scolding, MD (University of Bristol, United Kingdom) and colleagues, is published in online on May 5, 2010 in *Clinical Pharmacology & Therapeutics*.

(<http://www.nature.com/clpt/journal/vaop/ncurrent/abs/clpt201044a.html>)

Background: MS involves immune attacks against the brain, spinal cord and other tissues that make up the central nervous system. For years, researchers have been investigating bone marrow transplantation as a way to reconstitute the immune system in people with aggressive MS whose immune cells have been purposely destroyed, in hopes of stopping the MS immune attacks. This approach is still being investigated as an experimental treatment of MS. Recent studies, largely involving animal models, have suggested that adult stem cells contained in the bone marrow might have the capacity to inhibit destructive immune activity and possibly stimulate tissue repair.

This Study: Six people who had had MS for a duration ranging from 9 to 20 years, and who had moderate to significant disability (scores on the EDSS disease activity scale ranging from 4.5 to 6.5), participated in the study over one year. Each participants' own bone marrow cells were removed, then filtered and then infused into the vein. None required an overnight hospital stay for the procedure. Rather than separate out a specific type of bone marrow stem cell (such as mesenchymal cells that have received attention as possible repair cells), the

research team determined there was sufficient evidence to suggest possible benefit of infusing a mix of whole bone marrow cells.

According to patient reports, they found the procedure tolerable, and no severe adverse events were reported. After the infusion, one participant had postoperative urinary retention, and two had a transient increase in lower limb spasticity. One participant had an MS relapse two months after the infusion.

After one year, five participants were judged to have remained stable, without disease progression, and one was judged to have progressed by 0.5 points on the EDSS. No statistically significant improvement (comparing pre-infusion with one year post-infusion) was seen in the MSFC (MS Functional Composite, a scale of disease impact) and some other objective measures. The investigators were encouraged by apparent improvement seen on global evoked potentials, which measure nerve conduction. These improved at 3 months and were sustained to one year. However, they point out that this since there were a small number of patients and no controls, firm conclusions cannot be drawn about the effectiveness of the procedure.

Conclusion: This safety study of bone marrow stem cells is one of the first to be conducted in people with MS. Larger, controlled studies, which are getting under way or in planning stages, should provide further information on the potential value of this cell therapy approach to treating MS. The publication of this small safety study coincides with the release of an international consensus on the future of stem cell transplantation research for people with MS, paving the way for more coordinated global research efforts and potentially better, and quicker, patient access to stem cell clinical trials. The guidelines, developed by an international panel of MS experts with input from MS Societies around the world, spell out hope for the future of MS stem cell research and debunk myths about overseas stem cell clinics claiming to cure the condition. Read more (<http://www.nationalmssociety.org/research/research-news/news-detail/index.aspx?nid=3161>)

Download a guide (<http://www.mssociety.org.uk/document.rm?id=7495>) to research on stem cells in MS (.pdf)

-- Research and Clinical Programs Department



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

May 21, 2010

MS Study Alert:

Study Recruiting 8,000 People to Study JC Virus Levels in People Taking Tysabri

Summary: Investigators nationwide are recruiting 8,000 people with relapsing MS who are taking Tysabri® (natalizumab, Biogen Idec and Elan Pharmaceuticals). The primary goal of this study is to better understand whether the incidence of PML (progressive multifocal leukoencephalopathy, a severe brain infection caused by JC virus) in Tysabri-treated patients who do not have detectable antibodies to JC virus (antibody negative) is lower than in patients who have detectable antibodies to JC virus (antibody positive). This is a research question and it is not known whether detection of antibodies to JCV in an individual can predict their risk of developing PML. For this reason, the test result from this study should not be used in treatment decisions. The study is sponsored by Biogen Idec.

Please note: This is not a clinical study of an MS therapy, but rather a research investigation related to MS.

Rationale: Tysabri is a laboratory-produced monoclonal antibody. It is designed to hamper movement of potentially damaging immune cells from the bloodstream, across the “blood-brain barrier” into the brain and spinal cord. Tysabri was approved by the U.S. Food and Drug Administration in 2006 as a monotherapy (not to be used in combination with another disease-modifying therapy) for the treatment of patients with relapsing forms of MS to delay the accumulation of physical disability and reduce the frequency of clinical exacerbations. According to information released by Biogen Idec, as of May 6, 2010 there have been 49 confirmed cases of PML among people who have used Tysabri after it became available for prescription. At this point, there is no way to determine the risk for developing PML in people taking Tysabri.

Scientists at Biogen Idec have developed a blood serum test that would detect antibodies to the JC virus. The presence of antibodies indicates that a person has at some point been infected by the virus, which usually does not cause symptoms but lies dormant. In a study of 13 patients who developed PML on natalizumab, all had serum antibodies prior to the onset of PML. The team has tested 800 serum samples and has found this test can distinguish between people with MS who are negative for antibodies (about 40 to 50%) and those who are positive (about 50 to 60%). (Abstract S31.003, American Academy of Neurology Annual Meeting, 2010) The company is now conducting further studies of the test in people starting or already taking natalizumab therapy to determine whether it can reliably predict a person's risk for developing PML, which may help doctors and patients make more informed treatment choices.

Eligibility and Details: The study is enrolling people with MS who are taking Tysabri, or who are considering taking Tysabri. People who are enrolled in clinical trials of Tysabri are not eligible.

Blood samples will be collected at the beginning of the study, and annually for two years. The primary outcome is to determine whether the incidence of PML is lower in people who test negative for JC virus antibodies.

Contact: To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please call 1-800-790-7198, or email STRATIFY@biogenidec.com.

-- Research and Clinical Programs Department