



PROGRAMS & SERVICES

August 31, 2012		CC:
<u>FY 2013 Café con Leche: Conversation and Support for Native Spanish Speakers Living with MS</u>		

Entering into its fifth year, the Society will again be offering the Café con Leche telephone-based support group for native Spanish speakers. The group meets once a month for 90 minutes beginning Tuesday, October 9, 2012 through June 11, 2013. Subsequent dates to be determined. Topics will focus on areas of interest to people living with MS. Additionally; experts from different areas of specialization in MS will join the group to speak about important topics in MS care.

Interested participants can register by calling 1-800-344-4867 and selecting Option 3 (Spanish dedicated phone line.) The group features rolling admission and new members are welcome to join at any time.

Promotional fliers, in Spanish and English, are available on SharePoint at Programs and Services>Social Connections and Support Resources>Self Help Group Materials. The program also will be promoted on the Spanish page of the Society’s website.

For more information about the Café con Leche group, please contact Moyra Rondon, LCSW, Senior Director of Counseling Programs and Hispanic Outreach, New York City-Southern New York Chapter at 212-453-3237 or mrondon@msnyc.org.

A special thank you is offered to the New York City-Southern New York Chapter for their ongoing management of this project.



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RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

August 31, 2012

MS Trial Alert:

Investigators Recruiting for Study of Tysabri in Early Relapsing-Remitting MS

Summary: U.S. investigators are recruiting 300 people with early relapsing-remitting MS (<http://www.nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/relapsing-remitting-ms-rrms/index.aspx>) to detect factors that might help better predict which patients do better on natalizumab (Tysabri[®], Biogen Idec and Elan) in this population. This is an observational study: The investigators are observing people who have been diagnosed with relapsing-remitting MS within the past three years, and have decided to take Tysabri – no study drug will be provided. The study, also known as the STRIVE study, is sponsored by Biogen Idec.

Rationale: Tysabri (<http://www.nationalmssociety.org/tysabri>) is a laboratory-produced monoclonal antibody that is approved for people with relapsing forms of MS to delay the accumulation of physical disability and reduce the frequency of clinical exacerbations. 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. (Click here (<http://www.nationalmssociety.org/research/research-news/news-detail/index.aspx?nid=2308>) to read about Tysabri and its association with PML, a potentially fatal viral infection of the brain.)

Tysabri is generally recommended for patients who have had an inadequate response to, or cannot tolerate, an alternate MS therapy. Its use in the earliest stages of MS has not been systematically studied. The primary purpose of the study is to determine which patient characteristics most reliably predict future favorable disease-free response, to enhance the ability to make benefit-risk decisions for using Tysabri in early-stage relapsing MS.

Eligibility and Details: Participants must be ages 18 to 45. This is an observational study; the investigators are observing people who have been diagnosed with relapsing-remitting MS within the past three years, and have decided to take Tysabri. No study drug will be provided. Individuals who test positive for JC virus antibody (indicating previous exposure to the virus that causes PML) are not eligible to participate.

Participants are being followed for four years. The primary outcome being measured is the proportion of people who are free of disease activity (according to the EDSS scale, MRI scans and relapses) at the end of two years and four years. The investigators are also looking at, secondarily, the factors that might predict disease-free status, as well as other measures including optic nerve fiber damage, cognitive function, capacity for work and quality of life.

Contact: To learn more about the enrollment criteria and to find out if you are eligible to participate, please email neurologyclinicaltrials@biogenidec.com. If you do not have access to email, please ask your physician to contact the study. Sites will be enrolling in these U.S. cities:

Abington, Pennsylvania	New York, New York
Advance, North Carolina	Newark, Delaware
Atlanta, Georgia	Newport Beach, California
Birmingham, Alabama	Newport News, Virginia
Champaign, Illinois	Norfolk, Virginia
Dayton, Ohio	Overland Park, Kansas
Detroit, Michigan	Patchogue, New York
East Lansing, Michigan	Peoria, Illinois
Ft. Collins, Colorado	Plainview, New York
Gahanna, Ohio	Portland, Oregon
Gainesville, Florida	Round Rock, Texas
Glendale, Arizona	Salt Lake City, Utah
Grand Forks, North Dakota	Seattle, Washington
La Jolla, California	Tacoma, Washington
Lake Barrington Illinois	Tempe, Arizona
Latham, New York	Uniontown, Ohio
Lexington, Kentucky	Washington, District of Columbia
Lexington, Massachusetts	Winston-Salem, North Carolina
Lincoln, Nebraska	Worcester, Massachusetts

[Download a brochure that discusses issues to think about when considering enrolling in an MS clinical trial \(PDF\).](#)

Tysabri is a registered trademark of Biogen Idec and Elan.