



## PROGRAMS & SERVICES

August 26, 2011	CC:
<b><u>Service Provider Database Reminders</u></b>	

Please refer to newssheet dated 7-22-11 for an update on our soon-to-be-released Service Providers Database Standard Practices. As you work on updating service providers and continue to do so in FY 2012, we want to remind you of a few key points that may impact your activities in this area:

- Community Resource Categories will be changing in FY 2012. As noted in the 7-15-2011 (Partners in MS Care Update) and 7-22-2011 news sheet, we are streamlining the service provider categories and response types- focusing on the categories and provider types about which clients most frequently inquire. As a result we will be “inactivating” some response types and other response types are changing as a result of the implementation of the Partners in MS Care program. Changes to the Community Resource Categories should reduce the number of service provider records that chapters need to maintain in Altair.
- Secondly, the 2011 certification standards require that chapters *“fully utilize our enterprise-wide data tools for program and service data, including populating resource information with robust detail...”* in the top ten categories and response types for FY2011. These are: (excerpted from the FY2011 Certification Standards, pages 7-8):
  - 1) Emotional Support:
    - Self Help Groups (in-person)
    - Support Groups Affiliated with Chapter (professionally led)
    - Counselors Professional
  - 2) Doctors:
    - MS Centers or Clinics

- Neurologists
- 3) Independent Living: Centers for Independent Living
- 4) Financial Assistance – Referral:
  - Private Financial Assistance
  - Rent, Mortgage, and Utilities
  - Emergency
  - Government
- 5) Medical: Assistive Technologies
- 6) Housing: Affordable Accessible Housing
- 7) Employment: Vocational Rehabilitation
- 8) Legal: Community Legal Services
- 9) Medical: Equipment/Loan Rental
- 10) Accessibility: Builders/Construction

If you are updating other provider types in addition to the required ones, please remember that some types will no longer be maintained in Altair. (Some will be maintained by the IRC in a nationwide and statewide database, some are being inactivated and some have changed.). See Community Resources document FY 2012 for this information. [http://intranet.nmss.org/Topics/programs\\_services/Documents/Service\\_Provider\\_Resources\\_Community\\_Resource\\_Categories\\_FY\\_2012.pdf](http://intranet.nmss.org/Topics/programs_services/Documents/Service_Provider_Resources_Community_Resource_Categories_FY_2012.pdf)

**Moving forward, chapters will focus on/maintain only those service provider types that have “Altair” listed next to them as a location.**

In 2012, the certification standard regarding service providers will read: *Use a robust and quality service provider database that is consistent with Society-wide standards and practices...* So, all staff and volunteers will be expected to use the new Society-wide service provider database standards in 2012.

We will be finalizing the manual and conducting Society-wide trainings this fall. You will not be expected to re-create existing provider records, but as you update providers and identify new ones, we will all use the same processes.

If you have questions please contact contact Sarah Clark, IRC Technology Manager at [sarah.clark@nmss.org](mailto:sarah.clark@nmss.org).



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

**August 26, 2011**

### **MS Trial Alert:**

### **Investigators Recruiting for Study of Tysabri in Secondary-Progressive MS**

**Summary:** Investigators worldwide are recruiting over 800 people with secondary-progressive MS (<http://www.nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/secondary-progressive-ms-spms/index.aspx>) to determine the effectiveness of natalizumab (Tysabri®, Biogen Idec and Elan) at reducing the progression of disability in this population. The study, also known as the ASCEND 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.)

Relapsing forms of MS include people with relapsing-remitting MS (<http://www.nationalmssociety.org/about-multiple-sclerosis/relapsing-ms/relapsing-remitting-ms-rrms/index.aspx>), and people with secondary-progressive MS who are experiencing relapses. In this study, Tysabri is being tested for its effectiveness at reducing the progression of disability in people with secondary-progressive MS who are not experiencing relapses.

**Eligibility and Details:** Participants must be ages 18 through 58, with secondary-progressive MS. There must be documented confirmed evidence of disease progression independent of clinical relapses over the one year before enrollment. The Tysabri pre-infusion safety checklist

is being administered to determine contraindications to taking Tysabri. Further enrollment criteria are available from the contact information listed below.

Participants are being randomly assigned to receive either Tysabri 300 mg or placebo intravenously every four weeks for 96 weeks. The primary objective is to determine whether treatment with Tysabri slows accumulation of disability not related to relapses, using a combination of clinical measures. Secondary objectives include determining any effects on walking speed/ability, quality of life, manual dexterity, brain volume, and progression of disability.

**Contact:** To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please email [neurologyclinicaltrials@biogenidec.com](mailto:neurologyclinicaltrials@biogenidec.com). If you do not have access to email, please ask your physician to contact the study via email.

Sites are enrolling in the following U.S. cities:

Advance, NC	Minneapolis, MS
Akron, OH	Nashville, TN
Allentown, PA	New York, NY
Aurora, CO	Newark, NJ
Baltimore, MD	Oklahoma City, OK
Burlington, MA	Palo Alto, CA
Charlotte, NC	Pasadena, CA
Charlottesville, VA	Peoria, Illinois
Chicago, IL	Phoenix, AZ
Cleveland, OH	Pompano Beach, FL
Clinton TWP, MI	Portland, OR
Columbus, OH	Raleigh, NC
Fort Collins, CO	Sarasota, FL
Fullerton, CA	Seattle, WA
Indianapolis, IN	Teaneck, NJ
Kansas City, KN	Tucson, AZ
Lake Barrington, IL	Uniontown, OH
Latham, NY	Washington, DC
Lexington, KY	Worcester, MA
Milwaukee, WI	

[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.