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New study sheds light on multiple sclerosis in America

PHILADELPHIA –Despite more treatments than ever before, one of every three people diagnosed with multiple sclerosis goes untreated due to costs. This is despite the fact that the National MS Society recommends seeking treatment as soon as possible. In fact nearly 60% of those diagnosed begin using a FDA-approved treatment within one month.

Multiple sclerosis is an unpredictable disease that robs individuals of their independence and overall quality of life. Here in the Greater Delaware Valley, over 14,000 individuals are affected by MS with more than 2.1 million affected worldwide.

A recent study published online on MultipleSclerosis.net entitled “MS in America” was conducted over the internet from November 2012 until January 2013. The primary goal of the study was to establish an understanding of the current state and trends of patients affected by MS.

The survey included over 100 questions on a broad range of topics. A total of 3,437 people started the survey while 2,562 people completed the survey resulting in a high completion rate of 74.5%. To participate in the study, the subject had to be an MS patient, over 18 years old, US citizen (living in US or abroad) or US resident. The study was solely developed and funded by Health Union, LLC which does not manufacture, sell or market any product to diagnose, prevent or treat MS or any other disease.

Relevant findings:

- Most participants first experience MS symptoms in their 20s or 30s but aren't diagnosed until their 30s or 40s
- Numbness, tingling or other altered sensations are most common initial MS symptoms
- 82% of participants were initially diagnosed with Relapsing-Remitting MS. Of those, 68% still have a Relapsing-Remitting MS diagnosis
- **58% of patients started treatment within one month of diagnosis**

- MS has a wide-ranging impact on people's lives and varies greatly by MS type: 78% reported being unable to do as much as they used to and 46% reported being on disability. 80% of those on disability reported having Secondary-Progressive MS
- MS patients report experiencing a wide range of frequent symptoms including fatigue (90%), walking difficulty (77%), numbness and tingling (71%), pain (63%) and muscle spasms (61%). Less common but nevertheless more prevalent than first thought, bladder dysfunction (51%), dizziness (42%) and sexual dysfunction (38%)
- **89% of those surveyed indicated having health insurance, but over a third have avoided treatment due to cost**
- 61% of participants indicated having spent \$1,000 or more every year out of pocket, for MS-related treatment and therapies, including medical care but excluding health insurance premiums
- Nearly 50% of those surveyed reported having used a manufacturer-sponsored financial assistance program to help pay for their MS treatment
- Multiple non-medicinal approaches are also commonly used: 53% reported trying physical therapy while 70% reported taking vitamin D as a complementary/alternative therapy to treat MS
- Although a majority of respondents have a loved one or family member that is actively involved in their treatment, 44% do not
- The internet and social media are widely used for education and management of MS with 78% of respondents reporting visiting MS-specific websites for information and 41% using social media outlets like Facebook

The complete study can be found at <http://multiplesclerosis.net/ms-in-america-2013/>. For more information or to schedule an interview with a person with MS, a local researcher or a National MS Society representative, please contact Yarissa Reyes at 215-271-1500.

About the National MS Society

MS stops people from moving. The National MS Society exists to make sure it doesn't. We do this through our home office and 50-state network of chapters by funding more MS research, providing more services to people with MS, offering more professional education and furthering more advocacy efforts than any other MS organization in the world. Join the movement at nationalMSSociety.org or by calling 1-800-FIGHT-MS.

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Media contact:

Yarissa Reyes

215-271-1500, ext. 24110

yarissa.reyes@nmss.org