**WHAT ARE THE EDUCATIONAL NEEDS OF PEOPLE WITH MULTIPLE SCLEROSIS SHORTLY AFTER DIAGNOSIS?**

Catherine Jacobs1, Audrey Osinski1, Kaye Gooch2, Prudence Plummer1

*1University of North Carolina at Chapel Hill, Chapel Hill, NC, United States. 2National MS Society, Greater Carolinas Chapter, Raleigh, NC, United States*

**Key Words:** Physical Activity ● Multiple Sclerosis ● Wellness

**Background:** Research reports that individuals with Multiple Sclerosis (MS) desire more information than they receive, especially at the time of diagnosis. Resources that provide information are available, but there are limitations with utilization and application of these resources including: too many sources of information, uncertainty about what questions to ask, inability to find answers to specific questions, overwhelming time period, unaware of potential resources, and generalized information.

**Objectives:** The purpose of this study is to assess the educational needs of people with MS soon after diagnosis.

**Methods:** An eight-question survey was distributed to individuals with MS. Surveys were distributed through the Greater Carolinas Chapter of the National MS Society, physical therapists, and self-help group leaders to people living in North Carolina, South Carolina, and New York. Questions asked about time since diagnosis, information considered valuable received at time of diagnosis, information that would have been helpful at diagnosis, level of physical activity, interest in wellness information and specific areas of interest regarding health and wellness. Frequency of survey responses were analyzed.

**Results:** Data collection is ongoing. Preliminary results from the first cohort of respondents indicate that time singe diagnosis ranged from less than one year to greater than ten years, and over sixty percent have been diagnosed for at least ten years. Information considered most valuable at time of diagnosis was disease information and medical management. Respondents indicated that they would have liked to receive more information on physical activity, such as exercise routines and the benefits of physical therapy. More than half of the respondents also indicated that psychosocial concerns such as adjusting, influence on employment, and financial concerns were important. Most respondents reported being less active than before their diagnosis, but were very interested in attending a wellness information seminar. Respondents were especially interested in learning more about fatigue, nutrition, exercises to do at home, and cognitive exercise.

**Conclusions:** Preliminary survey results strongly suggest the need for more information especially concerning physical activity at the time of diagnosis. These data will be used to develop a half-day educational wellness event for people with MS in the Greater Carolinas Region.