(S78) MEETING THE NEEDS OF PEOPLE WITH PRIMARY PROGRESSIVE MULTIPLE SCLEROSIS

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Background: With most of the attention focused on the relapsing-remitting form of multiple sclerosis (MS), people with primary progressive MS (PPMS) often describe themselves as “orphans” of the MS world. Aware of this sentiment, in 2008 the National MS Society and MS Association of America (MSAA) hosted a meeting, bringing together a diverse group from across the country, with one goal in mind—to develop a better understanding of the needs of this population. Objectives: One of the top recommendations to come out of this gathering was to expand and enhance the available programs, services, and resources. Both organizations took on this challenge and developed a range of resources for people living with PPMS and the healthcare community. Results: Primary Progressive Multiple Sclerosis—What You Need to Know is a book that discusses diagnosis, treatment and research, rehabilitation, wellness, family and social issues, and life planning. The companion DVD, “Primary Progressive Multiple Sclerosis—Perspectives on Moving Forward,” profiles four people with PPMS who share their strategies for maintaining a healthy quality of life and planning for life with PPMS. MSAA developed a booklet for the PPMS community, which provides important information on managing symptoms as well as improving function through rehabilitation. Technology and adaptations aimed at making life easier are highlighted, along with strategies for maintaining physical and emotional wellness. Both organizations now have sections on their websites dedicated to progressive forms of MS, including information specific to PPMS. Visitors will find resources on a wide range of progressive MS-related topics to include course descriptions, treatment options, and research. For the healthcare team there is “Talking About Primary-Progressive MS,” part of the Society’s “Talking with Your MS Patients about Difficult Topics” series. Opening Doors: The Palliative Care Continuum in Multiple Sclerosis is a new clinical bulletin covering the spectrum of palliative care and its relevance to the care and treatment of people with MS. Conclusions: The National MS Society and MSAA are committed to expanding knowledge of MS and empowering people with MS to live as independently as possible within the limits of their disabilities and to the maximum of their capabilities. We believe these resources help to achieve this goal.

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