

Joint conference on primary-progressive MS focuses on unmet needs

by Diana M. Schneider, PhD

People with primary-progressive MS (PPMS) are almost orphans in the movement to end MS. Only 10–15% of people with MS have PPMS, the type of MS that slowly progresses from onset. They never have remissions—or relapses—and rarely if ever benefit from any of the FDA-approved medications designed to reduce relapses.

To better address their medical and social needs, the National MS Society and the Multiple Sclerosis Association of America (MSAA) held an historic joint conference in Dallas late last winter, chaired by Dr. Nancy J. Holland, vice president of Clinical Programs at the Society, and Robert Rapp, vice president of Programs and Evaluation at MSAA. The conference was underwritten by Genentech, Inc.

The goal was to develop recommendations for improving care and support services. Before the conference started, detailed information about what people with PPMS see as their major needs was obtained from three major MS databases—the Society’s Sonya Slifka Longitudinal MS Study, the MSAA’s comprehensive membership-needs assessment, and a

Distinct differences and specific needs characterize people living with primary progressive MS. The Society and the MS Association of America are striving to meet more of these needs by working together.

NARCOMS (North American Research Committee on Multiple Sclerosis) study. In addition, people with PPMS, their caregivers/carepartners, neurologists, nurses, social workers, and psychologists met in a series of Web-based focus groups to articulate their experiences and perspectives.

A picture of people with PPMS

Both the data and the focus groups showed that people with PPMS:

- Include a higher percentage of men—nearly 50%—as compared to 25–35% in the general MS population
- Tend to have significant symptoms that include loss of mobility, fatigue, progressive weakness, spasticity, pain, depression, bowel and bladder issues, and cognitive changes
- Tend to be more disabled and to require more assistance with activities of daily living
- Tend to be older at the time of onset
- Are older as a group
- Are less likely to be working and
- Are much more likely to be receiving Social Security Disability Insurance (67% of people with PPMS vs. 41% or those with relapsing-remitting or RRMS). They are also somewhat more likely to be on SSDI than people with secondary-progressive MS, a later stage of relapsing-remitting MS (67% vs. 62%).

What are the major issues?

The number one issue identified by everyone was a serious lack of information about this form of MS. People with PPMS and their families asked for more information of every sort. They suggested developing a newsletter and possibly other publications in print on this form of the disease. They recommended that all the exist-

Lack of Definition

Differentiating PPMS from RRMS and SPMS is challenging, in part due to the apparent lack of an agreed and accepted definition of what constitutes “primary” and the perceived lack of clinical criteria. There is a strong need to tighten the definition of PPMS. This is not merely of academic interest. Earlier and more accurate diagnosis could help everyone focus on the needs of people with PPMS earlier in the course of the disease.—D.S.



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Paintings by Sylvia Moss: “Evening Meditation 3” and “Evening Meditation 4” (both 30" x 22", mixed media on paper). Former UCLA professor, author and artist Sylvia Moss was diagnosed with MS in 2003. Her paintings are included in over 300 private collections and have been shown in over fifty exhibitions.

ing materials in print and online be reviewed and updated, that the information be easy to read and understand, and easy to find by having a clearly identified place on the National MS Society and the MSAA Web sites. Some of this is evident on the Society’s redesigned Web site, but more needs to be done.

Another key need everyone noted is help “navigating the system” in order to access existing resources. The Society’s MS Navigator™ program is designed to do exactly that. (Just call **1-800-344-4867** and ask.)

MS professionals noted a lack of adequate clinical information. They suggested that regional and

local professional conferences would improve their knowledge, create networking and enhance their clinical expertise.

Employment, insurance, and financial assistance also loomed large on the list of needs. People with PPMS who want to continue working need job counseling and help obtaining workplace accommodations and benefits. Individuals and families need assistance in obtaining financial aid for necessary services and equipment. Problems with under-insurance were also identified. Most of these issues affect people with all forms of MS—so outreach efforts to help people with PPMS find and use

existing programs were seen as part of the solution.

People with PPMS also want social networking with others facing similar challenges. Conference participants recommended developing self-help telephone groups, Web chat rooms and bulletin boards.

According to people with PPMS, their emotional response to the disease is a kind of helplessness, as opposed to their perception of people with relapsing forms of MS, who may live with anxiety and fear of the next attack but who have treatments that actively combat the disease. This is an important perspective for counselors to understand as

they support people with PPMS and their families. Individuals with PPMS often have a wider range of underlying medical and social issues than others with MS. They believed that counseling would have been helpful at the time of diagnosis. They may not feel comfortable or be able to participate in programs if they are not specifically tailored to their limitations. And because people with PPMS tend to have more disability than others with MS, the professionals expressed a need for information about home care, adult day programs, respite programs, long-term care, and nursing homes.

Programs for family caregivers

Members of all the groups felt that preventing family caregiver burnout should be a priority. Support groups specifically for family caregivers of people with PPMS would be very helpful, especially if offered online. Wellness programs for family caregivers should include respite arrangements so caregivers can receive regular medical care, as well as exercise, stress management and nutrition counseling.

The National MS Society and the MSAA pledged to work together on the most pressing need: to improve the quality and availability of information about primary-progressive MS.

Dr. Diana M. Schneider is a publisher and science writer with more than twenty years experience in the field of MS. Her husband lives with PPMS.

Guide for family caregivers

Caring for Loved Ones with Advanced MS:

A Guide for Families, edited by Dorothy E. Northrop, MSW, ACSW, and Debra Frankel, MS, OTR, offers guidance for families when a family member has advanced MS so severe that the person can not be left alone for any extended period and has complex issues. A PDF of this 112-page book can

be downloaded at nationalmssociety.org/advancedms or call **1-800-344-4867** and ask for a free copy.

