



**National
Multiple Sclerosis
Society**
Public Policy
Conference

Testimony for the Written Record

Hearing of July 20, 2017

Subcommittee on Health

Committee on Energy and Commerce

United States House of Representatives

“Examining Bipartisan Legislation to Improve the Medicare Program”

Chairman Burgess, Ranking Member Green, and Members of the Subcommittee:

Thank you for this opportunity to submit testimony for the written record on behalf of the National Multiple Sclerosis Society (NMSS, the Society) on the issue of Medicare outpatient therapy caps discussed during the Committee’s hearing, “Examining Bipartisan Legislation to Improve the Medicare Program.” Our testimony focuses on the experiences of Medicare beneficiaries living with multiple sclerosis (MS) and their need for access to rehabilitation therapies including skilled physical, occupational and speech/language services. Additionally, we offer the Society’s observations as advocates of Medicare beneficiaries living with MS regarding Medicare policies that can limit beneficiaries’ access to them, particularly as they relate to medically necessary rehabilitation therapies.

The Society mobilizes people and resources so that everyone affected by multiple sclerosis can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward. Last year alone, through our comprehensive nationwide network, the Society devoted \$122.2 million to help more than one million individuals connect to the people, information and resources they need. To move closer to a world free of MS, the Society also invested \$54 million to support more than 380 new and ongoing research projects around the world.

Multiple sclerosis is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, and a person with MS typically experiences the same approximate life expectancy as those without the disease. These facts and more make the challenge of planning for one's future medical, mobility, housing, transportation and quality of life needs highly complex. The lifetime financial cost of MS, including both direct and indirect cost of the disease, has been estimated at \$1.2 million. Fortunately, advances in research and treatment are leading to better understanding of the disease and are moving us toward a world free of MS.

The Role of Rehabilitation in Quality MS Care

From the time of diagnosis onward, rehabilitation specialists provide education and strategies designed to promote good health and overall conditioning, reduce fatigue, and help those living with the disease to feel and function at their best. If symptoms begin to interfere with everyday activities, rehabilitation can address problems with mobility, dressing and personal care, driving, functioning at home and work, and participation in leisure activities. Rehabilitation experts can also provide evaluation and treatment of speech and swallowing difficulties, and problems with thinking and memory. Notably, some rehabilitation therapists choose to specialize in treating people with MS, and enjoy the process of developing expertise in the challenging and unique needs of this population of patients. The Society strongly encourages clinicians in training to consider specializing in MS through fellowship programs, targeted research, educational resources and more.

The goal of rehabilitation therapy in the treatment of MS is to improve and maintain function. For people living with MS, achieving that goal often means maintaining the ability to stay employed, to walk without assistance, drive a car, run a household or live independently in the home of one's choice. As such, the role of rehabilitation for a person with MS is different than it is for a person recovering from an injury or surgery, whose treatment progress is generally characterized by improved mobility, the obvious restoration of function, and reduced pain. By comparison, successful rehabilitation therapy for a person with MS is characterized by slowing the functional deterioration associated with disease progression, or simply stated, not getting worse. As a result, payers and others unfamiliar with MS often fail to appreciate the value of professional rehabilitation therapy in quality MS care, resulting in un-informed decisions to limit benefits or unrealistic criteria as a condition for authorizing additional treatment.

Medicare Benefits for Outpatient Rehabilitation Therapies

Medicare is the primary source of health coverage for roughly one half of all people in the U.S. currently living with MS. (Malachy, 2017) Preliminary results of a recent study of working age individuals with MS (between the ages of 18 and 65) revealed over 30% relied on Medicare for their access to care. The population of people under age 65 qualify for Medicare because they have been determined to be disabled by the Social Security Administration, and have been receiving Social Security Disability Insurance payments for at least 24 months. As such, they are no longer able to work at their previous capacity, and are more likely to have severe disease and complex care needs, often compounded by other health conditions.

Rehabilitation therapists specializing in MS report that most of the Medicare beneficiaries they treat for the effects of MS do not have trouble in obtaining coverage for the full amount of physical, occupational and/or speech pathology services they need. But certain individuals present clinicians with extraordinary needs and face major obstacles to medically necessary treatments due to one or more current Medicare coverage policies.

The current annual limit on outpatient therapy services is insufficient for certain Medicare beneficiaries with MS. For example, Travis G. is a 43-year-old father of two from Minnesota who lives with advanced MS. His case illustrates the harsh impact the \$3,700 cap on physical and/or speech pathology services can bring to a person with MS. As Travis' upper body has weakened over the years, his ability to chew, swallow, speak and breath properly has declined, putting him at high risk of choking and aspiration pneumonia from food particles entering his lungs. The risk of these rare but life-threatening effects of MS can be minimized through a therapy program to strengthen ventilatory muscles and enhance respiration. In recent years however, Travis has been hospitalized numerous times for aspiration pneumonia after his therapy was stopped as he reached the annual limit on benefits. When asked about documenting his case and the need for additional therapy benefits to continue his therapy, his physical therapist reported she has been un-successful despite repeated attempts and concerted efforts. Although Travis tends to reach the capped level during the summer or fall of every year, his therapist now routinely provides a limited amount of treatment to him on a pro bono basis. Nonetheless, Travis still experiences emergencies requiring ER visits every summer or fall.

The combined annual limit of \$3,700 for physical therapy (PT) and speech-language pathology (SLP) *in combination* exacerbates the problem of arbitrary dollar limits even more. Not only is the amount insufficient for certain individuals with unusually high-cost needs, the fact that it is imposed as a cap on physical or speech/language pathology alone or in combination leads beneficiaries to choose one need over the other, and often without a full understanding of the implications. Speech-language pathologists report cases involving Medicare beneficiaries with MS who realize and act on their need for speech pathology services only to learn they have

used up their annual allotment of covered therapy on physical therapy. Their only option is to pay out of pocket for speech pathology, delay treatments until the new year, or go without these needed treatments altogether.

As mentioned, most Medicare beneficiaries with MS are adequately served through the current amount of rehabilitation benefits allowed within a single year, but exceptional cases do exist. These must be considered and accommodated to assure beneficiaries have access to medically necessary therapies. The common scenarios in which the current limits adversely impact people with MS include:

- Individuals like Travis who live with severe forms of MS, or in advanced stages of the disease;
- People who experience severe exacerbations of the disease, or new and unexpected symptoms that require extraordinary amounts of therapy immediately in an attempt to slow deterioration and restore as much function as possible;
- Beneficiaries that suffer heart attacks, strokes or injuries unrelated to their MS who require other types or courses of rehabilitation therapy for that condition in addition to their MS.

The Society has been a longtime supporter of the exceptions process to enable those with greater needs to receive necessary and timely treatment. Yet the current system is meaningless if beneficiaries with extraordinary needs for care that exceed the cap limits cannot rely on reasonableness when making their case for requesting additional services. The time has come for Medicare to implement permanent and improved patient-centered processes for obtaining medically necessary outpatient therapies so that none will suffer the way Travis, his family and providers now do.

Medicare Improvement Standard

While not a subject of the committee's July 20th hearing, the other major impediment to adequate coverage of rehabilitation therapies in the Medicare program has been the so-called "improvement standard." Stemming from an erroneous interpretation of Medicare law, for years Medicare carriers denied coverage of prescribed rehabilitation therapies to people with MS and others who were determined not likely to improve with additional therapy. As previously described, people with MS do not "improve" from rehabilitation in the same manner as many other patients. The Society was pleased to be among the organizational plaintiffs in the class action suit '[Jimmo v. Burwell](#)' which resulted in a settlement and Medicare's agreement that "consideration of the need for skilled care, not the potential for improvement, should govern Medicare coverage determinations – for skilled nursing facility, home health, and outpatient therapy." Such determinations continue to this day, and have been the subject of a

second suit against HHS for non-compliance with the settlement. We are optimistic that unwarranted denials of coverage for beneficiaries not likely to improve will cease now that the court has ordered a “corrective action” by CMS, including greater outreach and education about proper coverage determinations. It is important for Committee members and others to understand the impact of the improvement standard as a confounding variable in the administration of Medicare’s outpatient therapy benefits, and help Medicare beneficiaries by encouraging enforcement of the court’s orders. People with MS and their providers are understandably confused by denials for coverage or reimbursement when they could be attributed to the therapy caps, improvement standard, or both. The lack of clear and consistent coverage policy and appeals process creates additional confusion, additional paperwork and administrative burdens for patients, providers and Medicare carriers alike.

Conclusion

The Society urges all members of the Committee to repeal Medicare’s therapy caps by supporting HR 807/S 253, the Medicare Access to Rehabilitation Services Act of 2017 and assure that any replacement of it facilitates access to extraordinary levels of care when necessary. While the exceptions process is imperfect, the Society supports its extension if consensus on an improvement and replacement for it is not possible before the end of 2017.

If you have any questions, please contact the Society’s Director of Health Policy Kimberly Calder at kimberly.calder@nmss.org or 212-476-0450.