

# Insights from the Multiple Sclerosis Patient Advocacy Front, With Bari Talente, JD



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**AJMC®:** Does the National Multiple Sclerosis Society have recommendations regarding improving access to and affordability of medications for the management of multiple sclerosis (MS)?

**TALENTE:** The MS Society does indeed have recommendations regarding access to medications. These recommendations, which were developed by the Society's Advisory Committee on Access to MS Medications, are available online at [www.nationalmssociety.org/Treating-MS/Medications/Make-MS-Medications-Accessible/Recommendations-Access-to-Meds](http://www.nationalmssociety.org/Treating-MS/Medications/Make-MS-Medications-Accessible/Recommendations-Access-to-Meds).

In developing the recommendations, the Society used feedback from a survey completed by >8500 patients with MS and talked with many stakeholders across the prescription drug supply chain. There are 3 components to the recommendations: (1) affordability; (2) simplicity; and (3) transparency.

**Affordability:** Innovation in MS has changed the lives of many people with relapsing MS and innovation must continue to change lives. People need to get medications in a timely and affordable way to benefit from them.

- Limit price increases for medications that have been on the market for a considerable time.
- All available medications for a particular disease must not be on a specialty tier with co-insurance.
- Limit total out-of-pocket costs for prescription medications in Medicare.

**Simplicity:** Getting your medication shouldn't feel like a full-time job. Living with MS is already difficult for individuals who often experience debilitating fatigue and cognitive challenges.

- Prior authorization should happen before the person with MS leaves the healthcare provider's office, or in a very short, defined timeframe.
- Step therapy should make sense, and not result in detrimental delays accessing appropriate medications. Individuals should not be required to fail on similar mechanisms of action, similar routes of administration, or a medication they have failed previously.
- Develop a uniform patient assistance application for patient assistance/co-pay programs across the manufacturer and nonprofit programs.

**Transparency:** People with MS need more information to make informed choices, and we all need greater information to improve the system. Formulary coverage, including cost-sharing, must be easily accessible, understandable, and searchable (if online) when people with MS are choosing a plan. Greater understanding and transparency of the varying prices across the system and internationally are needed to effectively reduce costs and increase access to care.

**AJMC®:** What is the Society's involvement in disease management?

**TALENTE:** We view our role as being a trusted source of information for both patients and health care providers (HCPs). It is important to understand that the

Society provides factual information and does not provide patient-specific advice. We urge patients to have conversations with their HCPs about the currently approved US FDA disease-modifying treatments (DMTs) in order to make informed decisions that promote long-term adherence. During these discussions, we encourage patients not only to discuss efficacy and safety data with their HCPs but also to discuss how the DMT will affect their life activities (such as employment status, home life, travel, extracurricular activities). This is a very important discussion because patients may be less adherent with DMTs when the products negatively impact their life activities. In a recent survey, patients reported that their top 3 considerations when discussing DMTs with their HCPs are the product's effect on: (1) annualized relapse rate; (2) disease progression; and (3) continuing working/normal activities.

**AJMC®: What is your perspective on cost-driven decisions?**

**TALENTE:** Some of the biggest challenges in the MS arena revolve around enabling patients to afford, receive, and stay on their MS medications. As patient costs increase, adherence decreases. This is very concerning because the DMTs do not work unless patients take them. The data clearly show that patients need to start on MS medications as early as possible and stay adherent to limit new MS activity and protect the brain from irreversible damage. Additionally, value-based insurance design and value contracting cannot achieve optimal treatment outcomes and lower costs if patients cannot get the right drug, at the right dose, at the right time.

**AJMC®: What major challenges do patients face?**

**TALENTE:** Again, the primary challenge patients face is the ability to afford, receive, and stay on the right medication. We believe that treatment decisions and treatment changes should be driven by a shared decision-making process between the MS health care provider and the individual. This decision should take into consideration medical issues, adverse effects, risks, lifestyle, and adherence. Too often, the medication decision is determined by what is covered by an individual's insurance.

Step therapy processes are more and more common with plans. We advocate for a "common sense" step therapy approach. For example, if a patient failed Drug X previously and changes health care plans, why should the patient be required to fail Drug X a second time before being able to receive the product that their physician thinks is best? We encourage plans also to use a "common sense" approach when it comes to appeals. For example, a patient who presents with aggressive disease may be better suited for one of the oral agents or infused products

versus one of the first-generation injectable products. The appeals process should be easy and provide an answer sooner versus later.

Costs are also a huge concern. The average price of the FDA-approved DMTs in 2018 will be approximately \$80,000. This is a lot of money, especially considering price increases we have seen in recent years and that individuals with MS need other medications and services such as physical therapy.

**AJMC®: Do you have any thoughts on the topic of nonadherence?**

**TALENTE:** Adherence with DMTs is a major topic. We need to recognize that adherence is impacted by things like out-of-pocket costs and working to make sure the DMT fits within each patient's lifestyle. We do see nonadherence not only with the first-generation injectable medications but also to a lesser degree with orally administered medications. Insurance design that takes patient preference factors into account would help. Also, patients may need encouragement to be adherent with medication regimens and reminded that the medications do not work unless they are taken!

**AJMC®: What are current unmet needs?**

**TALENTE:** People with MS need a thorough understanding of MS, including neurodegeneration and brain atrophy that can affect both physical and cognitive function. Additionally, we need continued research to better understand the MS disease process, including the factors that influence the development and progression of the disease.