

## **Managing Myasthenia Gravis with Immunosuppressive Drugs: Lessons from the Patient Perspective**

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**Objective:** To assess the perceptions of generalized MG patients with regards to their most bothersome symptoms and treatment side effects as they relate to immunosuppressive drugs use.

**Background:** Myasthenia gravis (MG) is a rare autoimmune disease that affects about 60,000 people in the United States and causes fluctuating weakness of ocular, bulbar, and limb muscles.

**Design/Methods:** A 22-item questionnaire, combining multiple-choice and open-ended questions, was administered to 58 individuals with MG at the Myasthenia Gravis Foundation of America National Conference from May 1-3, 2016.

**Results:** Respondents were 25-81 years old, 60% Female, 86% Caucasian, 40% Retired, and 66% received most of their care from a specialized MG Neurologist. The MG symptom with the most significant impact on life was weakness in arms, hand, or legs reported by 64%. The two medications most commonly used for MG treatment were Pyridostigmine Bromide (97%) and Prednisone (79%). The top three most bothersome side effects of treatment were weight gain (41%), mood swings or irritability (34%), and insomnia (33%). Prednisone was reported as the MG medication most associated with side effects by 80% of patients.

### **Conclusions:**

Treatment of MG focuses on improvement of neuromuscular transmission with acetylcholine esterase inhibitors and immunosuppression with drugs such as prednisone. Patients with a greater disease severity require higher doses of prednisone to control their disease. Patients reported most bothersome side effects that were commonly attributed to corticosteroids. Treatment strategies directed at managing symptoms, while also minimizing bothersome immunosuppressive drug side effects, may result in better clinical outcomes as well as greater patient satisfaction.

Patient input is vitally important in the treatment process and allows for mutual treatment goals that lead to better treatment adherence and clinical outcomes. Pragmatic studies are needed to determine which treatment strategies best address the patient centered outcomes identified in this survey.