

## **Resource Utilization in a US-based Sample of Patients with Sporadic Inclusion Body Myositis (sIBM)**

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### **Background**

sIBM is a progressive, idiopathic inflammatory myopathy characterized by atrophy and weakness of proximal and distal muscle groups, knee extensors, wrist and finger flexors; and dysphagic processes are frequently involved. Progressive weakness results in loss of independence and need for assistive devices and supportive care. There is a dearth of information on the socioeconomic burden of sIBM in the United States.

### **Objectives**

To better characterize the socioeconomic burden of individuals with sIBM in the United States.

### **Methods**

Registered participants of The Myositis Association 2013 and 2014 Annual Patient Conferences with a confirmed clinical diagnosis of sIBM were invited to participate in studies to better characterize the socioeconomic burden in this population via a direct mail letter or email following IRB approval. Two cross-sectional studies were conducted wherein participants completed a paper or web-based version of the Skeletal Muscle Activity and Resource Tool for Sporadic Inclusion Body Myositis (SMART-sIBM), a measure of self-reported resource utilization designed to characterize out-of-pocket expenses and non-reimbursable items not captured by health care systems. A subset of participants partook in both studies, providing longitudinal data.

### **Results**

In total, 102 sIBM patients participated across both data collection efforts; 31 contributed to longitudinal data. Overall, mean age was 67.2 years (range 49 – 88), and most (62%) participants were male, Caucasian (94%) and well educated (72% with at least some college). Average number of years since diagnosis and years since first symptoms were  $5.3 \pm 4.3$  (range 0 – 18) and  $11.3 \pm 6.4$ , respectively.

Approximately one-third of participants reported being ambulatory without an assistive device; the remaining noted use of an aid/brace (37%), power mobility for long distances (17%), power mobility most of the time (7%), and/or inability to walk or stand (4%). Average number of falls per month and healthcare visits because of falls were  $<1$  (range 0 – 4) and  $0.71 \pm 1.8$  (range 0 – 12), respectively. All participants reported need for frequent health care visits, and 80% indicated need for house/vehicle modifications and purchase of assistive equipment to accommodate sIBM-related disabilities. More than one-third (36%) of participants required paid help with household tasks, and 60% relied on help from unpaid caregivers (87% spouse). Nearly half (42%) reported changes in job status because of sIBM-related functional limitations.

### **Conclusions**

Results of this study, which provides socioeconomic data for the first time in a US-based sample of patients with sIBM, demonstrate a high resource utilization and financial burden experienced by sIBM patients in the United States.

