DRAFT — IMS 2026 Abstract Submission

Title (141 / 200 characters)

Symptom burden, unmet information needs, and the role of a patient-led support group in POEMS syndrome: a mixed-methods survey of 21 patients

Abstract body (2,990 / 3,000 characters)

Introduction/Background:

POEMS syndrome is a rare paraneoplastic plasma cell disorder with an estimated prevalence of 0.3 per 100,000. Disease directed therapy is increasingly effective, yet patient-reported data on the lived experience of POEMS, including residual symptom burden, information needs, and the value of peer support remain scarce. This patient-led survey was undertaken to characterise these domains and to evaluate a virtual support group established for people living with POEMS.

Methods:

An anonymous online questionnaire combining structured and free-text items was distributed to members of a virtual POEMS support group in October 2025. Items covered demographics, symptom burden, treatments received, perceived disease control, information sources and unmet learning needs, and the perceived impact of the support group on knowledge, healthcare interactions, connectedness, and wellbeing. Responses were summarised descriptively; free-text responses were reviewed thematically. Respondents provided informed consent for anonymous use of their responses.

Results:

21 patients responded; 57% had been diagnosed >5 years previously and 95% had received disease-directed treatment (stem cell transplant 57%, chemotherapy/plasma cell–directed therapy 57%, radiotherapy 43%, corticosteroids/immunotherapy 33%). 96% rated their disease as “very well” or “somewhat” controlled. Despite this, residual symptom burden was high: mobility difficulty (90%), nerve pain or weakness (62%), and fatigue (43%) were the most commonly reported ongoing problems. Diagnosis had typically required multiple opinions (52%) or specialist neurology input (43%).

Specialist clinicians were the dominant information source (90%) but 76% wanted more information on latest research/treatments, 62% on nutrition and exercise, and 57% on symptom management. Among 12 attenders of the support group, 7/12 reported improved understanding of POEMS, 6/12 reported improved wellbeing, and 6/12 felt more connected to others with the condition; however, 8/12 reported no change in confidence discussing their condition with healthcare professionals. Most-valued aspects were meeting other patients (6/21) and learning from guest speakers (6/21). Free-text responses described profound impacts on independence, work, and identity, and identified geographical access and lack of structured content as barriers.

Conclusion:

In this rare-disease cohort, a high residual symptom burden and substantial unmet information needs persist despite good disease control. A patient-led virtual support group delivered measurable benefits in connection, understanding and wellbeing for a majority of attenders, but had less effect on patient–clinician communication confidence highlighting an opportunity for closer integration with clinical services. Patient-led data of this kind can help shape supportive care and information provision in POEMS syndrome.