P911 SYMPTOM BURDEN AND ITS IMPACT ON DAILY LIFE AMONG PATIENTS WITH IDIOPATHIC MULTICENTRIC CASTLEMAN DISEASE (IMCD) – FINDINGS FROM AN INTERNATIONAL IMCD PATIENT SURVEY

**Topic:** 14. Myeloma and other monoclonal gammopathies - Clinical

Francis Shupo¹, Nicola Mason², Emily Jones², Grace Wayi-Wayi¹, Mileva Repasky³, Matthew Franklin⁴, John Brazier⁴, Natasa Zibelnik¹, Sudipto Mukherjee⁵

¹ EUSA Pharma, Hemel Hempstead, United Kingdom; ² BresMed Health Solutions, Sheffield, United Kingdom; ³ Castleman Disease Collaborative Network, Paso Robles, United States; ⁴ School of Health and Related Research, Sheffield, United Kingdom; ⁵ Hematology and Medical Oncology, Cleveland Clinic Main Campus, Cleveland, United States

**Background:** Idiopathic Multicentric Castleman disease (iMCD) is a rare lymphoproliferative disorder driven by proinflammatory hypercytokinemia. The presentation of iMCD is heterogeneous and can range from mild constitutional symptoms to chronic burdensome symptoms and in extreme cases life-threatening multiorgan failure. Consequently, disease-related symptoms in iMCD patients are likely to adversely impact daily life. To date, characterization of symptom burden and their impact on daily living in iMCD patients has not been systematically studied.

**Aims:** We aimed to investigate, characterize, and map the symptoms and associated burden on daily life experienced by patients with various subtypes of iMCD.

**Methods:** We developed an international patient-based online survey informed by clinical practice and published literature to elicit the burden of disease-related symptoms and effects of symptoms on daily life from a patient perspective. Eligible patients were > 18 years old with physician-confirmed diagnosis of iMCD-NOS (not otherwise specified), TAFRO (thrombocytopenia, anasarca, reticulin fibrosis of the bone marrow, renal dysfunction, and organomegaly) and POEMS—associated MCD (multicentric Castleman disease with polyneuropathy, organomegaly, endocrinopathy, monoclonal protein, skin changes). This survey was shared with iMCD communities in Australia, Canada, the UK, and the US via the Castleman Disease Collaborative Network (CDCN). Burden of Illness (BOI) was quantitatively measured using a 5-point frequency Likert scale (from 0 ‘Does not affect my daily life’ to 4 ‘Very severely affects my daily life’), and mean impact scores (MIS) were calculated. Ethics approvals/waivers were attained for this one-time, cross-sectional, bespoke 47-question survey.

**Results:** A total of 57 patient responses were collected during April–November 2021. On average, patients experienced 7.0 symptoms (range: 0—22) in the week prior to survey completion. Tiredness was the most frequently reported symptom (77%), followed by physical weakness (44%) and night sweats (40%). Individual symptoms were clustered into clinically relevant categories and frequency of symptom groupings reported by iMCD subtype (Fig 1). Constitutional (82%) and neuropsychiatric (68%) symptoms were most frequently experienced across all respondents in the week prior to survey completion. The average number of symptoms by iMCD subtypes were 7.1 by iMCD-NOS, 5.5 by TAFRO and 8.5 by POEMS-associated MCD. 91% of all patients with iMCD reported experiencing at least one symptom in the week prior to survey completion. When rating their most impacted aspects of daily life due to their symptoms (Table 1), patients with iMCD-NOS reported pain and discomfort (MIS 2.09) and personal relationships (MIS 2.08), patients with MCD-POEMS reported sexual functioning (MIS 3.40) and pain and discomfort (MIS 2.67), while patients with TAFRO reported sexual functioning (MIS 2.44) and ability to travel (MIS 2.22).

**Image:**
Summary/Conclusion: To our knowledge, this is the first study of its kind to characterize and map the BOI in iMCD patients assessed by symptom frequency, symptom burden (multiplicity of symptoms) and its adverse effects on different aspects of daily living. Through our ongoing work we hope to develop a symptom burden score/scale that captures the symptom severity and its impact on daily living which can then be incorporated as a patient reported outcome measure for shared treatment decision-making and response assessment in addition to the laboratory and radiologic parameters.