The Mastocytosis Society (TMS) Mast Cell Activation Syndrome (MCAS) Patient Perceptions Survey

**ABSTRACT**

Background: Mast cell activation syndrome (MCAS) has been increasingly diagnosed in adults for whom clinical signs of health problems. The Mastocytosis Society (TMS) conducted a large-scale survey to characterize the population.

Methods: From 9-28 April 2019, patients/Licensed practitioners searched clinical research registries (N=38) and returned surveys (N=1702). A total of nine survey components were distributed and collected: demographics, clinical signs and symptoms (85.3%), mast cell stabilizers (55.9%), and comorbidities (47.5%). This report is focused on survey findings related to demographics, clinical signs and symptoms, and mast cell stabilizers.

Results: In the sample of 1702 respondents, 657 respondents (38.8%) were severely affected by anaphylaxis, 60 respondents (3.5%) were extremely affected, and 163 respondents (9.6%) were moderately affected. The most common symptoms were: skin rash/itching, joint pain, and muscle pain and/or stiffness. The most common diagnosis was in the skin (53.7%) and the second most common diagnosis was in the respiratory system (29.1%). The following symptoms were frequently reported: skin rash/itching, joint pain, and muscle pain and/or stiffness. The most common medications were: antihistamines, mast cell stabilizers, and corticosteroids.

Conclusions: This survey highlights the importance of understanding MCAS more thoroughly. Differences in outcomes have been identified among respondents based on age and sex, suggesting that age and sex should be considered in future research. Further, the survey results should be used to develop targeted outcomes for future clinical trials and to inform research and care.