Patient reported perspectives on disease burden and early signs of progression in multiple sclerosis in Germany (data collection MSPerspectives)

Antonios Bayas¹ and Katrin Schuh²

¹Department of Neurology and Clinical Neurophysiology, University Hospital Augsburg, Augsburg, Germany

²Novartis Pharma GmbH, Clinical Research Neuroscience, Nuremberg, Germany

Background:

In clinical practice, SPMS is usually diagnosed retrospectively and the transition period is associated with a considerable period of diagnostic uncertainty. Therefore it is imperative to raise patient awareness to recognize, track and communicate subtle signs of progression early. This data collection (MSPerspectives) is aimed to comprehensively capture the personal patient perspective on the individual disease course.

Methods:

From December 2020, an online survey has been collecting data from German MS patients to capture their perceptions regarding MS symptoms, disability progression and impact on daily life over the past 6 months. The survey will gain insights into the patients` perspective regarding the importance of maintaining essential abilities, the burden of disease and patient expectations concerning modern MS therapy.

Results:

As of Jan 5th 2022, 3519 MS patients completed the online questionnaire. At this data cut 69% had a relapsing remitting, 16% a secondary and 7% a primary progressive course. 30% of patients received the diagnosis of secondary progressive MS within the last 2 years. 68,7% of all patients received any DMT. Fatigue and gait impairment were the most bothersome symptoms. The full dataset will be available for presentation at the congress.

Conclusion:

The data collection will provide personal patient perspectives on the burden of their disease, early and subtle signs of disease progression and the effects on the quality of life of patients with MS. This will help us to better understand patient perspectives and disease development and possibly improve patient-physician interactions.

Disclosure

Project is funded by Novartis Pharma GmbH

COIs

Antonios Bayas received personal compensation from Merck Serono, Biogen, Novartis, TEVA, Roche, Sanofi-Aventis/Genzyme, Celgene/Bristol-Myers Squibb and Janssen; he received grants for congress travel and participation from Biogen, TEVA, Novartis, Sanofi/Genzyme, Merck Serono and Celgene. None related to this report.