

## Overview of the Current Challenges in Republic of North Macedonia among Neuromyelitis Optica Spectrum Disorders Patients

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### Abstract

**Background:** Neuromyelitis optica spectrum disorders (NMOSD) are progressive inflammatory disorders of the CNS characterized by severe, immune-mediated demyelination targeting optic nerves and spinal cord. The prevalence varies from 0.5-10 per 100,000, predominantly in women. Current treatment practice which involves use of immunotherapies for relapse prevention are not sufficient. But, recent data are encouraging since the novel treatments showed consistently and effectively relapse prevention, and are expected to decrease the mortality rates. Our primary objective was to evaluate the current NMOSD situation; identify the challenges and develop of potential intervention which might improve the current state as secondary objectives.

**Methodology:** Questionnaire containing 22 questions was developed, divided in 5 sections, as prevalence, physician knowledge, AQP4-IgG testing, current treatment approach and funding mechanism. Data was collected and analyzed by four local experienced neurologists and final descriptive report was created.

**Findings:** Due to unavailability of patient registry, disease trend is unknown, where by the current prevalence is ~20 patients. Whole NMOSD management is done by six neurologists employed at the only public healthcare institution for demyelinating diseases. Despite physician's knowledge gaps, ~80% of physicians are willing to switch patients into innovative treatments once available. AQP4-IgG testing is not routinely available which resulted in ~30% testing rate. Approximately 80-90% of all patients are on maintenance with immunosuppressant and corticosteroids are used for acute relapses treatment.



### Biography:

38 years old, experienced medical doctor graduated at Faculty of Medicine, Ss Cyril and Methodius in Skopje, North Macedonia and finishing Master Degree in Marketing. Currently working as Patient Advocacy Lead and Personalized Eco System Partner for Rare Conditions. Experienced leader with a demonstrated history of working in pharmaceutical industry on many different positions on various levels within the Affiliate with regional involvement. Author and co-author of several manuscripts on various topics. Being invited as speaker and panelist on different topics. Awarded several times on Global and Regional level for successfully completed innovative projects.

### Speaker Publications:

1. Wingerchuk DM, Lennon VA, Lucchinetti CF, et al. The spectrum of neuromyelitis optica. *Lancet Neurol* 2007; 6:805.
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4. Mutch K, Methley A, Moore P et al. Life on hold: the experience of living with neuromyelitis optica. *Disabil Rehabil* 2014;36:1100–7.
5. Collongues N, de Seze J. Current and future treatment approaches for neuromyelitis optica. *Ther Adv Neurol Disord* 2011; 4:111.

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