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Worldwide network on PSP/CBD

Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD) are rare neurodegenerative disease with aggregation of the microtubule-associated protein Tau protein isoforms with 4 microtubule-binding domains (4R-tauopathies) in neurons, astrocytes and oligodendrocytes. Both diseases present an overlapping spectrum of clinical manifestations including ocular motor, postural, akinetic-rigid, and cognitive components. Both are rapidly progressive and lead to death on an average of 6-7 years. There are no clinically relevant symptomatic therapies and no approved disease-modifying therapies available. Development of innovative treatment options has been advanced by novel insights into the pathophysiology of 4R-tauopathies in recent years. Rational clinical trial design essentially relies on a solid knowledge on the natural history of the diseases. Such knowledge is reliably available for the most frequent manifestation of PSP, i.e. Richardson's syndrome, but less so for the variant clinical manifestations, and particularly for the earliest clinical course. Therefore, individual high-quality research networks have been established on national basis in various countries. Still, the collected case numbers of early and variant 4R-tauopathies are limited, often too limited to allow drawing meaningful conclusions. Additionally, standardized acquisition of structural and functional cerebral imaging and biosampling is currently done in limited manner. To overcome this limitation, the Movement Disorders Society-endorsed PSP Study Group is currently initiating a global effort to harmonize protocols, to allow interoperability of datasets, to standardize biosampling of the various national initiatives, with the aim to establish a collaborative worldwide network on 4R-tauopathies, thereby fostering research and advancing the development of innovative biomarkers and therapies.

