



MDS patient leaflet about PSP

July 2021

Date of ERN-RND Affirmation: July 2021

Introduction to the European Reference Network for Rare Neurological Diseases (ERN-RND):

ERN-RND is a European Reference Network established and approved by the European Union. ERN-RND is a healthcare infrastructure which focuses on rare neurological diseases (RND). The three main pillars of ERN-RND are (i) network of experts and expertise centres, (ii) generation, pooling and dissemination of RND knowledge, and (iii) implementation of e-health to allow the expertise to travel instead of patients and families.

ERN-RND unites 32 of Europe's leading expert centres in 13 Member States and includes highly active patient organizations. Centres are located in Belgium, Bulgaria, Czech Republic, France, Germany, Hungary, Italy, Lithuania, Netherlands, Poland, Slovenia, Spain and the UK.

The following disease groups are covered by ERN-RND:

- Ataxias and Hereditary Spastic Paraplegias
- Atypical Parkinsonism and genetic Parkinson's disease
- Dystonia, Paroxysmal Disorder and Neurodegeneration with Brain Ion Accumulation
- Frontotemporal Dementia
- Huntingtons' Disease and other Chorea
- Leukodystrophies

Specific information about the network, the expert centres and the diseases covered can be found at the networks web site www.ern-rnd.eu.

Affirmation of value:

The European Reference Network for Rare Neurological Diseases has affirmed the value of this MDS patient leaflet about PSP as best patient leaflet about PSP.



Disclaimer:

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Endorsement Process

- Mapping of existing patient leaflets
- Decision of disease group to endorse/affirm the value of the respective guideline
- Consent on document by whole disease group: July 1st 2021.



METHODOLOGY

The endorsement process has been performed by the Disease group for Atypical Parkinson of ERN-RND.

Disease group for Atypical Parkinson:

Disease group coordinators:

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Disease group members:

Healthcare professionals:

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The patient leaflets are available in different languages on the MDS website

<https://www.movementdisorders.org/MDS/Resources/Patient-Education.htm>



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