



**European
Reference
Network**

for rare or low prevalence
complex diseases



Network

Neurological Diseases
(ERN-RND)

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:

Thomas Gasser¹, Wassilios Meissner²

Disease group members:

Healthcare professionals:

Alberto Albanese³; Daniel Boesch⁴; Fran Borovečki⁵; Norbert Brüggemann⁶; Yaroslau Compta⁷; Małgorzata Dec-Ćwie⁸; Antonio Elia⁹; Alessandra Fanciulli⁴; Antonio Federico¹⁰; Dušan Flisar¹¹; Barbara Garavaglia⁹; Zoltán Grosz¹³; Henry Houlden¹⁴; Klára Hrubá¹⁵; Liis Kadastik-Eerme¹⁶; Christine Klein¹⁷; Jiří Klempíř¹⁸; Thomas Klockgether¹⁹; Thomas Klopstock²⁰; Maja Kojović¹¹; Pierre Kolber²¹; Norbert Kovacs²²; Florian Krismer⁴; Krista Lazdovska²⁹; Bernhard Landwehrmeier²³; Johannes Levin²⁰; Gerrit Machetanz¹; Kari Majamaa²⁴; María José Martí⁷; Mette Møller²⁵; Huw Morris¹⁴; Anne Pavy-Le Traon²⁶; Bart Post²⁷; Evžen Růžička¹⁸; Susanne Schneider²⁰; Klaus Seppi⁴; Ramona Valante²⁸; Francesc Valldeoriola⁷; Wim Vandenberghe²⁹; Gregor Wenning⁴

Patient representative:

Lubomír Mazouch³⁰

¹ Universitätsklinikum Tübingen, Germany; ² CHU de Bordeaux, France; ³ IRCCS Clinical Institute Humanitas - Rozzano, Italy; ⁴ Center for Rare Movement Disorders / Dpt. of Neurology, Medical University Innsbruck, Austria; ⁵ University Hospital Center Zagreb, University Department of Neurology, Croatia; ⁶ Universitätsklinikum Schleswig-Holstein, Germany; ⁷ Hospital Clínic i Provincial de Barcelona y Hospital de Sant Joan de Déu, Spain; ⁸ University Hospital in Krakow, Poland; ⁹ Foundation IRCCS neurological institute Carlo Besta - Milan, Italy; ¹⁰ AOU Siena, Italy; ¹¹ University Medical Centre Ljubljana, Slovenia; ¹² Foundation IRCCS neurological institute Carlo Besta - Milan, Italy; ¹³ Semmelweis University, Hungary; ¹⁴ University College London Hospitals NHS Foundation Trust, United Kingdom; ¹⁵ Motol University Hospital, Czech Republic; ¹⁶ Tartu University Hospital, Estonia; ¹⁷ Universitätsklinikum Schleswig-Holstein, Germany; ¹⁸ General University Hospital in Prague, Czech Republic; ¹⁹ Universitätsklinikum Bonn, Germany; ²⁰ Klinikum der Universität München, Germany; ²¹ Centre Hospitalier du Luxembourg, Luxembourg; ²² University of Pécs, Hungary; ²³ Universitätsklinikum Ulm, Germany; ²⁴ Oulu University Hospital (OUH), Finland; ²⁵ Aarhus Universitetshospital, Denmark; ²⁶ Centre Hospitalier Universitaire de Toulouse, France; ²⁷ Stichting Katholieke Universiteit, doing business as Radboud University Medical Center Nijmegen, Netherlands; ²⁸ Pauls Stradins Clinical University Hospital, Riga, Latvia; ²⁹ University Hospitals Leuven, Belgium; ³⁰ Spolek pro atypické parkinsonské syndromy (Czech association for Atypical Parkinsonian Syndromes), Czech Republic



Patient leaflet

Patient leaflet on the MDS website: <https://www.movementdisorders.org/MDS-Files1/Education/Patient-Education/Progressive-Supranuclear-Palsy-PSP/pat-Handouts-PSP-v5.pdf>

