

# MDS patient leaflet about MSA

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 Choreas
- 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 MSA as best patient leaflet about MSA.



#### Disclaimer:

Clinical practice guidelines, practice advisories, systematic reviews and other guidance published, endorsed or affirmed by ERN-RND are assessments of current scientific and clinical information provided as an educational service. The information (1) should not be considered inclusive of all proper treatments, methods of care, or as a statement of the standard of care; (2) is not continually updated and may not reflect the most recent evidence (new information may emerge between the time information is developed and when it is published or read); (3) addresses only the question(s) specifically identified; (4) does not mandate any particular course of medical care; and (5) is not intended to substitute for the independent professional judgement of the treating provider, as the information does not account for individual variation among patients. In all cases, the selected course of action should be considered by the treating provider in the context of treating the individual patient. Use of the information is voluntary. ERN-RND provided this information on an "as is" basis, and makes no warranty, expressed or implied, regarding the information. ERN-RND specifically disclaims any warranties of merchantability or fitness for a particular use or purpose. ERN-RND assumes no responsibility for any injury or damage to persons or property arising out of or related to any use of this information or for any errors or omissions.

## **Endorsement Process**

- Mapping of existing patient leaflets
- Decision of disease group to endorse/affirm the value of the respective guideline
- Consent on document by the whole disease group: July 1<sup>st</sup> 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 Gasser<sup>1</sup>, Wassilios Meissner<sup>2</sup>

#### Disease group members:

#### Healthcare professionals:

Alberto Albanese<sup>3</sup>; Daniel Boesch<sup>4</sup>; Fran Borovečki<sup>5</sup>; Norbert Brüggemann<sup>6</sup>; Yaroslau Compta<sup>7</sup>; Małgorzata Dec-Ćwie<sup>8</sup>; Antonio Elia<sup>9</sup>; Alessandra Fanciulli <sup>4</sup>; Antonio Federico<sup>10</sup>; Dušan Flisar<sup>11</sup>; Barbara Garavaglia<sup>9</sup>; Zoltán Grosz<sup>13</sup>; Henry Houlden<sup>14</sup>; Klára Hrubá<sup>15</sup>; Liis Kadastik-Eerme<sup>16</sup>; Christine Klein<sup>17</sup>; Jiří Klempíř<sup>18</sup>; Thomas Klockgether<sup>19</sup>; Thomas Klopstock<sup>20</sup>; Maja Kojović<sup>11</sup>; Pierre Kolber<sup>21</sup>; Norbert Kovacs<sup>22</sup>; Florian Krismer<sup>4</sup>; Krista Lazdovska<sup>29</sup>; Bernhard Landwehrmeier<sup>23</sup>; Johannes Levin<sup>20</sup>; Gerrit Machetanz<sup>1</sup>; Kari Majamaa<sup>24</sup>; María José Martí<sup>7</sup>; Mette Møller2<sup>5</sup>; Huw Morris<sup>14</sup>; Anne Pavy-Le Traon<sup>26</sup>; Bart Post<sup>27</sup>; Evžen Růžička<sup>18</sup>; Susanne Schneider<sup>20</sup>; Klaus Seppi<sup>4</sup>; Ramona Valante<sup>28</sup>; Francesc Valldeoriola<sup>7</sup>; Wim Vandenberghe<sup>29</sup>; Gregor Wenning<sup>4</sup>

### Patient representative:

Lubomír Mazouch<sup>30</sup>



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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

