THERAPEUTIC ALGORITHM FOR PAROXYSMAL DISORDERS
Parkinsonism & Related Disorders
Volume 59, February 2019, Pages 131-139

EUROPEAN REFERENCE NETWORKS FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.

Endorsed by ERN-RND: 18th February 2020
Disclaimer:

“The European Commission support for the production of this publication does not constitute endorsement of the contents which reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.”


Luxembourg: Publications Office of the European Union, 2019

© European Union, 2019

Reproduction is authorised provided the source is acknowledged.
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 (RNDs). 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 Disorders and Neurodegeneration with Brain Iron Accumulation
- Frontotemporal Dementia
- Huntington’s Disease and other Chorea
- Leukodystrophies

Specific information about the network, the expert centres and the diseases covered can be found on the network’s website www.ern-rnd.eu.

Recommendation for clinical use:
The European Reference Network for Rare Neurological Diseases strongly recommends the use of the following therapeutic algorithm for paroxysmal disorders.
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.
METHODOLOGY

The endorsement of the therapeutic algorithm for paroxysmal disorders was done by the Disease group for Dystonia, Paroxysmal Disorders and NBIA of ERN-RND.

Disease group for Dystonia, Paroxysmal Disorders and NBIA:

Disease group coordinators:

Tobias Bäumer\textsuperscript{15}, Belén Pérez Dueñas\textsuperscript{21}, Giovanna Zorzi\textsuperscript{11}

Disease group members:

Alberto Albanese\textsuperscript{1}, Enrico Bertini\textsuperscript{5}, Kailash Bhatia\textsuperscript{5}, Elena Chorbadgieva\textsuperscript{6}, Yaroslau Compta\textsuperscript{7}, Adrian Danek\textsuperscript{2}, Alejandra Darling\textsuperscript{7}, Tom de Koning\textsuperscript{8}, Marina de Koning-Tijssen\textsuperscript{8}, Malgorazate Dec-Cwiek\textsuperscript{5}, Maria Teresa Dotti\textsuperscript{10}, Petr Dusek\textsuperscript{23}, Antonio Elia\textsuperscript{11}, Antonio Federico\textsuperscript{10}, Dusan Filsar\textsuperscript{12}, Thomas Gasser\textsuperscript{13}, Kathrin Grundmann\textsuperscript{13}, Kinga Hadzisie\textsuperscript{14}, Petra Havránková\textsuperscript{23}, Robert Jech\textsuperscript{23}, Christine Klein\textsuperscript{15}, Jiri Klemper\textsuperscript{14}, Thomas Kloppstock\textsuperscript{5}, Maja Kojo\textsuperscript{17}, Norbert Kovacs\textsuperscript{14}, Bernhard Landwehrmeier\textsuperscript{18}, Ebba Lohmann\textsuperscript{23}, Katja Lohmann\textsuperscript{15}, Sebastian Löns\textsuperscript{15}, Maria Jose Martí\textsuperscript{7}, Maria Judit Molnár\textsuperscript{19}, Alexander Münchau\textsuperscript{15}, Juan Dario Ortega Escobar\textsuperscript{7}, Damjan Osredkar\textsuperscript{12}, Sebastian Paus\textsuperscript{20},; Bart Post\textsuperscript{22}, Evžen Růžička\textsuperscript{23}, Susanne A. Schneider\textsuperscript{2}, Sinem Tunc\textsuperscript{23}, Marie Vidailhet\textsuperscript{3}, Michel Willemsen\textsuperscript{27}

Patient representative:

Marek Parkovic, AHC 18Plus, Germany

Endorsement process:

- Consent to endorse document by whole disease group – 18.02.2020

1 IRCCS Clinical Institute Humanitas – Rozzano, Italy; 2 Klinikum der Universität München, Germany; 3 Assistance Publique-Hôpitaux de Paris, Hôpital Pitié-Salpêtrière, France; Reference Centre for Rare Diseases ‘Neurogenetics’; 4 Pediatric hospital Bambino Gesù, Rome, Italy; 5 University College London Hospitals NHS Foundation Trust, United Kingdom; 6 University Neurological Hospital “St. Naum” Sofia, Bulgaria; 7 Hospital Clinic i Provincial de Barcelona y Hospital de Sant Joan de Déu, Spain; 8 University Medical Center Groningen, Netherlands; 9 University Hospital in Krakow, Poland; 10 AOU Siena, Italy; 11 Foundation IRCCS neurological institute Carlo Besta – Milan, Italy; 12 University Medical Centre Ljubljana, Slovenia; 13 Universitätsklinikum Tübingen, Germany; 14 University of Pécs, Hungary; 15 Universitätsklinikum Schleswig-Holstein, Germany; 16 General University Hospital in Prague, Czech Republic; 17 University Medical Centre Ljubljana, Slovenia; 18 Universitätsklinikum Ulm, Germany; 19 Semmelweis University, Hungary; 20 Universitätsklinikum Bonn, Germany; 21 Hospital Universitari Vall d’Hebron, Spain; 22 Stichting Katholieke Universiteit, doing business as Radboud University Medical Center Nijmegen, Netherlands; 23 Motol University Hospital, Czech Republic
REFERENCE


Due to the regulations on the protection of intellectual property, we are not allowed to print the actual therapeutic algorithm in this document.