7th ERN EURO-NMD

ANNUAL MEETING

21st – 23rd February 2024

POSTGRADUATE CURRICULUM ON NEUROMUSCULAR DISORDERS

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Amsterdam, The Netherlands

European Reference Network
for rare or low prevalence complex diseases

Network Neuromuscular Diseases (ERN EURO-NMD)

Funded by the European Union

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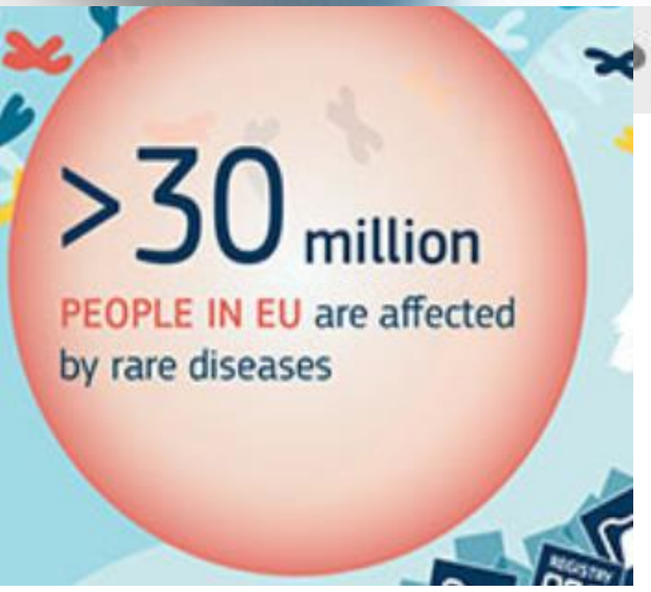
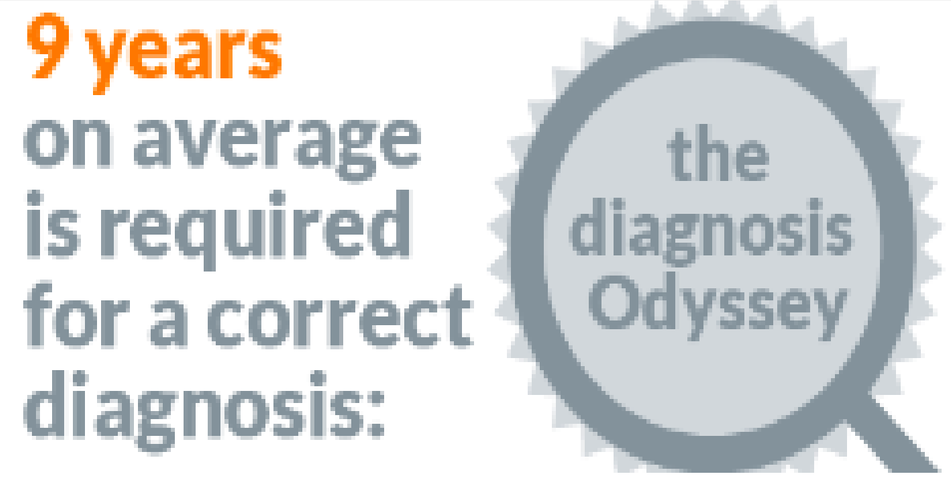
NEED FOR SPECIALIST TRAINING IN RARE DISEASES





Working group on Knowledge Generation and Capacity (ERN-KGC)

The main mission of the ERNs is "patient care"

"Patient Care", particularly for rare diseases, heavily depends upon regularly update knowledge

Priorities and proposed action plan

- Develop a model postgraduate rare disease training curriculum for adoption/adaptation and implementation by each ERN
- Educational webinars and case-based eLearning platforms

European Reference Network | Neurological Diseases (ERN-RND)

EURO-NMD

EpiCARE

- jointly develop
- educational and training programme
- for clinicians
- modular curriculum

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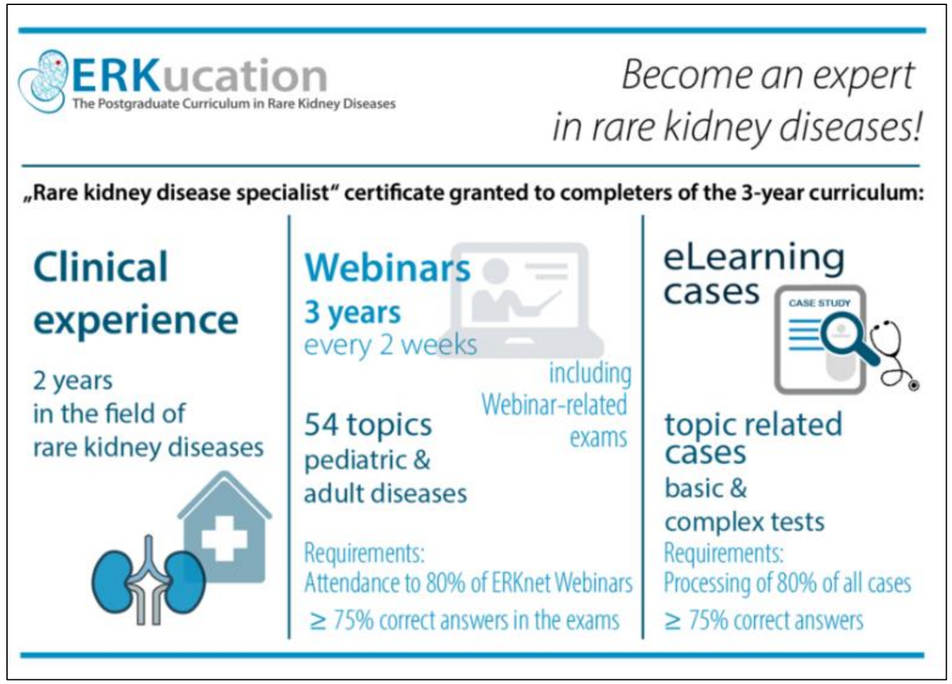
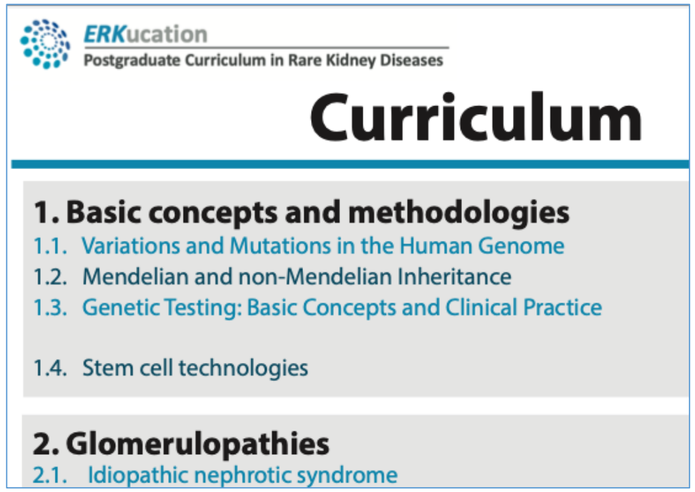
Educational programmes in other ERNs





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European Reference Network | Neurological Diseases (ERN-RND)

EURO-NMD EpiCARE

Working group on Trans ERN Postgraduate curriculum

Adult and paediatric neurologists, patient representatives, educational expert

Chaired by Holm Graessner (Coordinator ERN-RND)
Administrative support by Christine Diaite-Hecht (ERN RND)

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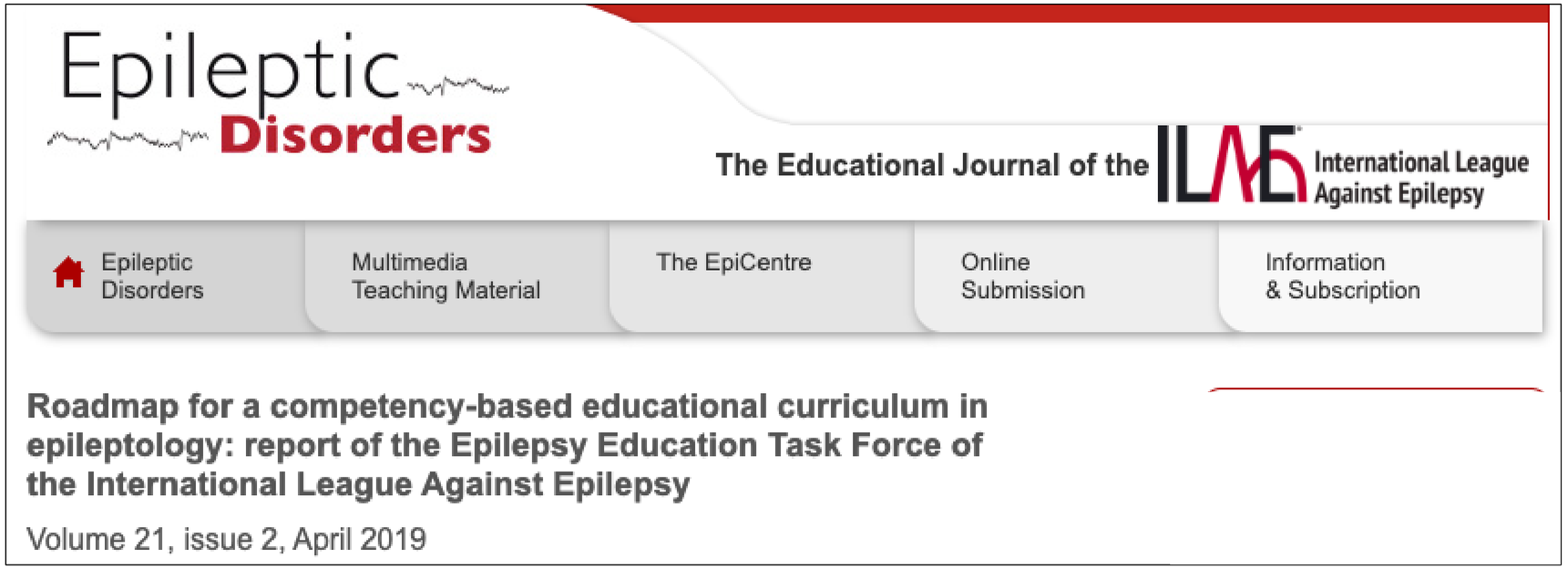

Consensus on:

- Competency-based educational programme
- Blueprint: Roadmap of ILAE
- 5 domains summarizing competencies
  - General/Theory
  - Diagnosis/Neurogenetics
  - Specific Disease management
  - Treatment/Therapy
  - Communicating with and counselling patients

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POSTGRADUATE CURRICULUM FOR ERN EURO-NMD

- XX Modules - - one per DG

1. Motor neuron disease and SMA
2. Acquired and heriditary neuropathies
3. Neuromuscular junction disorders
4. Acquired and hereditary myopathies
5. Mitochondrial diseases

- Module contains domains

→ Competencies 5 domains | X competencies | X learning objectives

→ Learning objectives

Code	Domain	Specification
1.0	General/Theory	Competencies and learning objectives
2.0	Diagnosis	Competencies and learning objectives
3.0	Disease Management	Competencies and learning objectives
4.0	Treatment	Competencies and learning objectives
5.0	Patient perspective	Competencies and learning objectives

- Align with EAN, EPNS, UEMS, ESHG curricula

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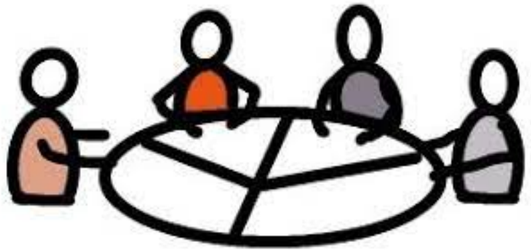
Neuromuscular working group



EPNS
Francesco
Muntoni

WMS
Benedikt
Schoser
(co-chair)

EAN
Antonio
Toscano
(co-chair)

Liaison
Cross-ERN WG
Judit Molnar

Representative
EURO-NMD
Peripheral Nerve WG
Shahram Attarian

Representative
EURO-NMD NMJ
WG

Patient
representative
Jean-Philippe
Plançon

Representatives

- Electrophysiology WG (Shahram Attarian)
- Pathology WG
- Imaging WG
- Genetics WG
- Multidisciplinary Management & Care WG – Nicole Voet

EURO-NMD
Coordinating Centre
Teresinha Evangelista
Houda Ali

2 representatives
EURO-NMD
MND WG

Representative
EURO-NMD
Mit. Diseases WG

Representative
EURO-NMD
Muscle WG
Marianne de Visser
(chair)

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Module – Inherited neuropathies (example)

Introduction	
Level (Basic/ Advanced)	
Domains and Competencies (cf. BoK)	1 General/Theory - Demonstrate working knowledge of aetiologies for Inherited Neuropathies - Demonstrate general knowledge of clinical presentation, disease onset and progression and natural history aspects 2 Diagnostics/Neurogenetics - Demonstrate knowledge of specific diagnostic criteria and measures, differentiating between pediatric and adult patients if appropriate - Demonstrate knowledge and use of EURO-NMD endorsed diagnostic flowcharts including differential diagnosis - Demonstrate in whom, when and how genetic testing should be applied and why - Demonstrate a working knowledge of lab tests and neuroimaging - Demonstrate a working knowledge of assessment of various disease aspects - Accurately order and interpret neuroimaging and neurophysiology

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Module – Inherited neuropathies (example) - cont'd

3 Specific disease management aspects

- Demonstrate knowledge and use of available **EURO-NMD** endorsed care standards: clinical rating scales and guidelines
- Demonstrate knowledge about care of pediatric and/or adult patients including multidisciplinary teamwork
- Demonstrate knowledge of neurogeriatric aspects if appropriate
- Demonstrate knowledge of neurological aspects in palliative care

4 Treatment/Therapy

- Demonstrate up-to-date knowledge in pharmacological treatment of the respective disease
- Demonstrate up-to-date knowledge about multidisciplinary care and neurorehabilitation and non-pharmacological treatment in **Inherited Neuropathies**

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Module – Inherited neuropathies (example) - cont'd

	5 Communicating with and counselling patients - Know and use Patient Journeys as working documents to identify gaps in care and adapt care pathways and better meet the needs of patients living with rare neurological disease - Communicate information about genetics in an understandable, comprehensible and sensitive way, helping patients to make informed decisions and choices about their care - Demonstrate awareness on specific social and life style issues related to the respective disease - Communicate information about the causes and consequences of the disease and its treatments - Offer appropriate psychological and social support to patients and families affected by a genetic condition. - Counsel women of childbearing age about the implications and management of **Inherited Neuropathies**

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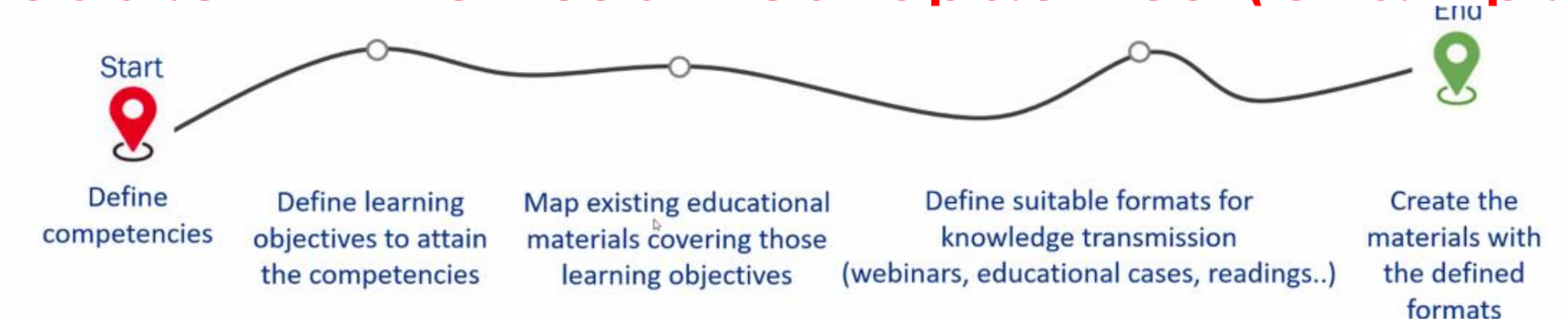
Module – Inherited neuropathies (example) - cont'd



Parts of the curriculum	1) [*number*] Webinars 2) e.g. 3 Patient Cases 3) Stay at expertise centre ?
Assessment	1) Webinars: e.g. 5 knowledge tests, 1 per domain (differentiated between basic and advanced) 2) Educational Cases: certain percentage of questions must be answered correctly 3) Confirmation by expertise centre
Authors	1) Webinar Speakers 2) Authors of the Educational Cases
Recommended Readings	
Schedule/ Process	1) List of Webinars to watch (with learning objectives, cf. BoK)
	2) Patient Cases
	3) Stay at expertise centre

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Implementation - to be discussed

- Platform: EanCampus
- Entry level: Basic, Advanced
- Target audience: (paediatric) neurologists, ?geneticists, ?physiatrists
- Duration: 1-3 years
- Stay at expertise centre
- Certification (UEMS)

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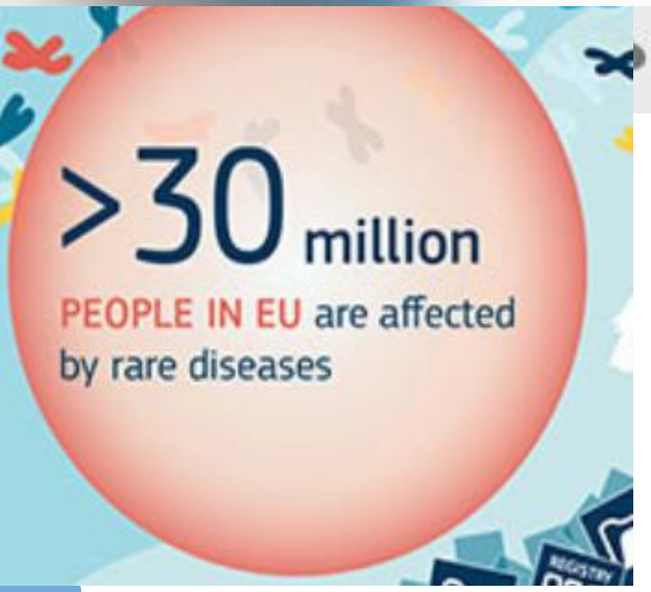

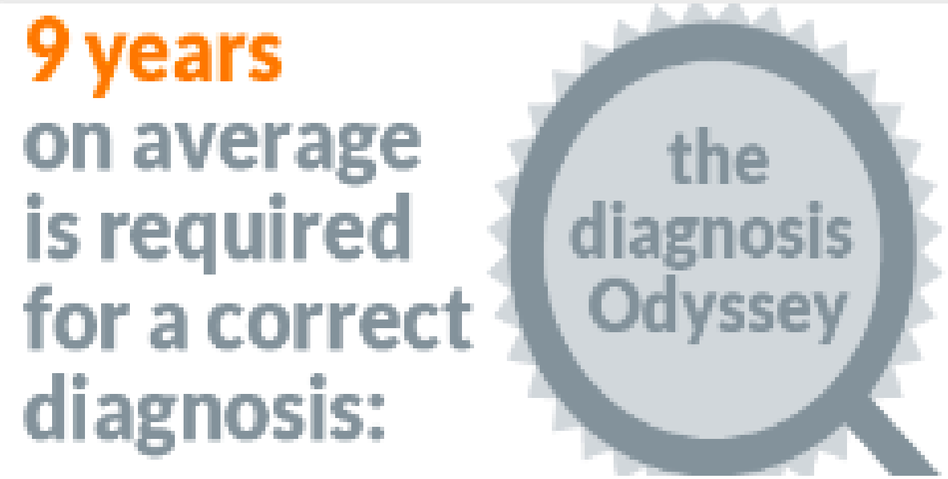

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