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European Training Requirements for Competency

"Rare Neurological Diseases"

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Preamble

The UEMS is a non-governmental organization representing national associations of medical specialists at the European level. With a current membership of 39 national associations and operating through 43 Specialist Sections and European Boards, the UEMS is committed to promote the free movement of medical specialists across Europe while ensuring the highest level of training that will pave the way to the improvement of quality of care for the benefit of all European citizens. The UEMS areas of expertise notably encompass Continuing Medical Education, Post Graduate Training and Quality Assurance. It is the UEMS' conviction that the quality of medical care and expertise is directly linked to the quality of training provided to the medical professionals. Therefore, the UEMS committed itself to contribute to the improvement of medical training at the European level through the development of European Standards in the different medical disciplines. No matter where doctors are trained, they should have at least the same core competencies.

In 1994, the UEMS adopted its Charter on Post Graduate Training aiming to provide the recommendations at the European level for good medical training. Made up of six chapters, this Charter set the basis for the European approach in the field of Post Graduate Training. With five chapters being common to all specialties, this Charter provided a sixth chapter, known as “Chapter 6”, that each Specialist Section was to complete according to the specific needs of their discipline. More than a decade after the introduction of this Chapter, the UEMS Specialist Sections and European Boards have continued working on developing and updating these European Standards in Medical training that reflect modern medical practice and current scientific findings. In doing so, the UEMS Specialist Sections and European Boards did not aim to supersede the National Authorities' competence in defining the content of postgraduate training in their own State, but rather to complement these and ensure that high quality training is provided across Europe.

At the European level, the legal mechanism ensuring the free movement of doctors through the recognition of their qualifications was established back in the 1970s by the European Union. Sectorial Directives were adopted and one Directive addressed specifically the issue of medical training at the European level. However, in 2005, the European Commission proposed to the European Parliament and Council to have a unique legal framework for the recognition of the Professional Qualifications to facilitate and improve the mobility of all workers throughout Europe. This Directive 2005/36/EC established the mechanism of automatic mutual recognition of qualifications for medical doctors according to training requirements within all Member States; this is based on the length of training in the Competency and the title of qualification. Given the longstanding experience of UEMS Specialist Sections and European Boards on the one hand and the European legal framework enabling Medical Specialists and Trainees to move from one country to another on the other hand, the UEMS is uniquely positioned to provide competency-based recommendations. The UEMS values professional competence as “the habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and community being served”. While professional activity is regulated by national law in EU Member States, it is the UEMS understanding that it has to comply with international treaties and UN declarations on Human Rights as well as the WMA International Code of Medical Ethics.

This document derives from the previous Chapter 6 of the Training Chapter and provides definitions of Rare Neurology Disease expert competencies and procedures as well as how to document and assess them.
For the sake of transparency and coherence, it has been renamed as "Training Requirements for Rare Neurological Diseases". This document aims to provide the basic Training Requirements for each competency and should be regularly updated by the European Reference Network for Rare Neurological Diseases, UEMS Specialist Sections, Multidisciplinary Joint Committees, or European Boards to reflect scientific and medical progress. The three-part structure of this document reflects the UEMS approach to have a coherent pragmatic document not only for medical experts but also for decision-makers at the National and European levels interested in knowing more about medical expert training. It is important to note that there is and will be no such medical speciality recognized in the Annexe V. Therefore, we use the term of "competency" instead of medical speciality.

Of note, this Training Requirement has been done in close collaboration with the European Academy of Neurology and the European Pediatric Neurology society that sent representative in the cross-ERN working group (see above).

Rare neurological diseases

While rare diseases (RDs) are by definition of low prevalence, the total number of patients suffering from an RD is high, and the majority of them have neurologic manifestations, involving the central nervous system, peripheral nerve, and skeletal muscle. In 2017, 24 European Reference Networks (ERNs), each focusing on a specific group of rare or low-prevalence complex diseases, were formed to improve the care for patients with a RD. One major aim is to have "the knowledge travel instead of the patient," which has been put into practice by the implementation of the Clinical Patient Management System (CPMS) that enables clinicians to perform pan-European virtual consultations. In the area of neurological diseases, three ERNs have been formed that are ERN EuroNMD covering neuromuscular diseases, ERN EpiCare covering rare and complex epilepsies and ERN-RND covering rare movement and rare cognitive disorders, both for adult and paediatric patients. Other rare neurological diseases such as rare neuroinflammatory and rare neurovascular diseases are covered by the ERNs focusing on rare inflammatory and rare vascular diseases ERN RITA and ERN Vascern, respectively.

The European Reference Network for Rare Neurological Diseases (ERN-RND) provides an infrastructure for knowledge sharing and care coordination for patients affected by a rare neurological disease (RND) focusing on rare movement and rare cognitive disorders. While some of its activities are disease overarching and refer to rare movement and cognitive diseases in general e.g. diagnosis of patients with unclear rare neurological disorders, ERN-RND covers particularly the following rare movement disorder and cognitive disease groups in terms of expertise included as well as disease focus of specific activities: (i) Cerebellar Ataxias and Hereditary Spastic Paraplegias; (ii) Huntington's disease and other Choreas; (iii) Frontotemporal dementia; (iv) Dystonia, (non-epileptic) paroxysmal disorders, and Neurodegeneration with Brain Iron Accumulation; (v) Leukoencephalopathies; and (vi) Atypical Parkinsonian Syndromes. Notably, the majority of these disease are genetically caused.

The European clinical experts for one of these six disease groups are grouped in so-called *ERN-RND disease groups.* Such an *ERN-RND disease group* is the group of the available, highly qualified and experienced clinical experts for the respective diseases in the European Union.

Thus, the ERN-RND disease groups can fulfill the following functions:

(i) Production of quality assured training material for RND
(ii) Consensus of competencies and learning objectives needed for postgraduate training in RND
(iii) Quality assurance for RND training material from external sources such as professional societies and patient organisations.

At the moment, ERN-RND unites 68 expert centers in 24 European countries. In the ERN-RND, also patient organisations represented by a bespoke European patient advocacy group (ePAG) participate (PMID 33519696).

I. TRAINING REQUIREMENTS FOR TRAINEES

1. Trainees in RND

Trainees in RND are medical doctors who have completed their general professional training and are

- either in an accredited training programme to become a recognised specialist in Neurology, Child Neurology or RND related Specialities such as Medical Genetics
- or have a Board Certification on one of these specialities already.

2. Content of training and learning outcome

a. Competencies required of the trainee

The Rare Neurological Disease Competency – as represented by the diseases covered in ERN-RND - is a field of medicine concerned with the investigation, diagnosis, management, treatment, prevention, and research into rare neurological diseases. The scope of patient care activities includes the recognition of these diseases, the early identification of individuals and families at risk, clinically diagnosis, identification of the possible underlying (genetic) defect(s), managing care and treatment of RND patients as well as communicating with and counselling RND patients.
This competency training is aimed at giving doctors qualifications in the field of "Rare Neurological Diseases" to enable them to manage the treatment of patients with RND and their families in light of current and expanding knowledge on the subject, with particular emphasis on understanding the molecular and cellular pathogenic mechanisms of such diseases, and their diagnosis and treatment.

Elements of knowledge base

- Clinical/Medical knowledge and specialist-level skills including
  - Disease etiology
  - Disease presentation, onset, progression and natural history aspects
  - Disease diagnostic methodologies and technologies
- Standards of care as developed, endorsed or affirmed-in-value by ERN-RND
- Patient counselling and communication skills in subjects such as genetics and social aspects
- Laboratory skills
- Maintaining Good Medical Practice
- Clinical research skills

Competencies required to gain by the trainee

- sufficient knowledge and experience to recognize, diagnose and manage a complex rare disease.
- multidisciplinary knowledge required for management of patients and families including social, palliative and psychological aspects
- able to undertake research in the particular rare neurological disease
- good communication and counselling skills.
- coordinating patient routes and follow-up.

The above listed elements of the knowledge base and the competencies to be gained by the trainee are directly derived from the RND syllabus that has been developed using the concept and methodology of Blümcke et al. 2019 (PMID: 30892268). In the respective competency-based educational syllabus, learning domains constitute the framework of the syllabus and contain elements of all teaching levels.
The RND syllabus put forward by ERN-RND covers accordingly five domains:

- General/Theory
- Diagnostics/Genetics
- Specific disease management aspects
- Treatment/Therapy
- Communicating with and counselling patients

A description of the content of the domains is given underneath.

1. General / Theory

- Demonstrate working knowledge of aetiologies for the respective disease group
- Demonstrate general knowledge of clinical presentation, disease onset and progression and natural history aspects

2. Diagnosis/ Genetics

- Demonstrate knowledge of specific diagnostic criteria and measures, differentiating between pediatric and adult patients if appropriate
- Demonstrate knowledge and use of ERN-RND endorsed diagnostic flowcharts including differential diagnosis
- Demonstrate in whom, when and how genetic testing should be applied and why
- Demonstrate knowledge in the interpretation and clinical application of the results from a genetic test report
- Demonstrate a working knowledge of laboratory tests and biomarkers
- Demonstrate a working knowledge of assessment of various disease aspects
- Accurately order and interpret neuroimaging and neurophysiology

3. Specific disease management aspects

Demonstrate knowledge and use of available ERN-RND endorsed care standards: clinical rating scales and guidelines
- Demonstrate knowledge about specific multidisciplinary care aspects of pediatric and/or adult patients
- Demonstrate knowledge of neurogeriatric aspects if appropriate
- Demonstrate knowledge of neurological aspects in palliative care in RND

4. Treatment/ Therapy

- Demonstrate knowledge and use of ERN-RND endorsed therapeutic algorithms
- 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 the respective disease
- Demonstrate working knowledge of non-invasive stimulation techniques if appropriate
- Demonstrate knowledge on advanced therapies in the respective disease
- Demonstrate up-to-date knowledge in the surgical treatment if appropriate
- Demonstrate up-to-date knowledge on indications and limits of Deep Brain Stimulation if appropriate

5. Communicating with and counselling patients

- Know and use ERN-RND 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 diseases
- Communicate information about genetics in an understandable, comprehensible and sensitive way, helping patients to make informed decisions and choices about their care
- Offer appropriate psychological and social support to patients and families affected by a genetic condition.
- Demonstrate awareness on specific social and life style issues and on educational needs related to the respective disease
- Communicate information about the causes and consequences of the disease and its treatments
- Counsel women of childbearing age about the implications and management of RND

d. Level of Competences

As training progresses, the trainee should have the opportunity for increasing autonomy, consistent with safe and effective patient care. The training programme should establish a realistic timetable for development of competencies that are expected as part of training in RND, beginning with observation, continuing with supervised clinical care, and ultimately reaching a level of knowledge, skills and professionalism that are judged to be sufficient for specialised, independent practice. It is recommended that competencies are defined according to the concept of *Entrustable Professional Activities* (EPAs) based on specific units of clinical and laboratory work.

This is reflected by the schedule of the RND training program that uses introduction, readings, online learning path and a 3-6 -month stay at an expert centre for the respective disease group. This schedule will enable the trainee to gradually move regarding knowledge from "knows of" to "knows specifically", regarding clinical skills from "has observed" to "can be trusted to carry out the procedure, independently, without assistance or need for advice" and regarding technical skills from "has observed" to "can be trusted to carry out the procedure, independently, without assistance or need for advice".

Thus, the competence grades that will be applied are:

Competence grades

Knowledge

- knows of
- knows basic concepts
- knows generally
- knows specifically and broadly

Clinical Skills

1. Has observed – the trainee acts as an 'Assistant'. From complete novice through to being a competent assistant. At end of level 1 the trainee:
   - Has adequate knowledge of the steps through direct observation.
   - Demonstrates that he/she can handle the apparatus relevant to the procedure appropriately and safely.
   - Can perform some parts of the procedure with reasonable fluency
2. Can do with assistance - a trainee is able to carry out the procedure 'Directly Supervised'. From being able to carry out parts of the procedure under direct supervision, through to being able to complete the whole procedure under lesser degrees of direct supervision (e.g. trainer immediately available). At the end of level 2 the trainee
   - Knows all the steps - and the reasons that lie behind the methodology.
   - Can carry out a straightforward procedure fluently from start to finish
   - Knows and demonstrates when to call for assistance/advice from the supervisor (knows personal limitations).
3. Can do the whole procedure but may need assistance – a trainee is able to do the procedure 'indirectly supervised'. From being able to carry out the whole procedure under direct supervision (trainer immediately available) through to being able to carry out the whole procedure without direct supervision i.e. trainer available but not in direct contact with the trainee. At the end of level 3 the trainee
   - Can adapt to well-known variations in the procedure encountered, without direct input from the trainer.
   - Recognizes and makes a correct assessment of common problems that are encountered.
   - Is able to deal with most of the common problems.
   - Knows and demonstrates when he/she needs help.
   - Requires advice rather than help that requires the trainer to intervene
4. Competent to do without assistance, including complications. The trainee can deal with the majority of procedures, problems and complications, but may need occasional help or advice.
5. **Can be trusted to carry out the procedure, independently, without assistance or need for advice. This concept would constitute one Entrustable Professional Activity (EPA).** An EPA is 'a critical part of professional work that can be identified as a unit to be entrusted to a trainee once sufficient

competence has been reached'. This would indicate whether one could trust the individual to perform the job and not whether he is just competent to do it. At the end of level 5 the trainee:

- Can deal with straightforward and difficult cases to a satisfactory level and without the requirement for external input to the level at which one would expect a consultant to function.
- Is capable of instructing and supervising trainees.

Technical Skills

1. Has observed.
2. Can do with assistance.
3. Can do whole but may need assistance.
4. Competent to do without assistance, including complications, but may need advice or help.
5. **Can be *trusted* to carry out the procedure, independently, without assistance or need for advice (EPA).**

The above detailed classification of Competence Levels could be useful during the process of formative training, when it comes to deciding when an applicant is eligible for the RND Competence Exit examination, it is the evaluation of the EPAs which is essential.

e. List of comprehensive Entrustable Professional Activities (EPAs)

- Diagnose a new patient with a rare neurological disease
- Evaluate and manage a new patient with a rare neurological disease (RND) and coordinate care between healthcare providers across multiple care settings
- Manage the care of patients with RND across multiple care settings
- Lead a family meeting to inform about genetic causation of the disease in an understandable, comprehensible and sensitive way, helping patients to understand the consequences and to make informed decisions and choices about their care
- Recognize and diagnose non-neurological disease aspects (i.e., ophthalmological, psychiatric etc.) and refer appropriately to other specialty care
- Access medical information and knowledge in particular ERN-RND endorsed/affirmed/created to provide evidence-based care
- Know and use ERN-RND Patient Journeys to facilitate the understanding and discussion of patients, their families, and members of the multidisciplinary team
- Counsel patients and families about psychological, social and life style issues related to the respective disease and the respectively available support options

2. Organisation of training

a. Schedule of training

ERN-RND curriculum modules can be taken alongside specialist training or employment. Once enrolled in a module (see below) a trainee will have maximum 18 months for the completion of readings and respective online learning path. For the required 3-6 months stay at an expertise centre including preparation and postprocessing, an additional time of 18 months will be available to perform this stay. The maximum time allowed to a trainee for completion of a module will thus be 3 years.
Of note, periods of sick leave and/or parental leave are excluded from the allowed completion time for each module.

b. Curriculum of training

The general aim of the training program is to enable the RND Expert to work effectively on a consultant level. The trainee must demonstrate the ability to diagnose and manage a RND patient across multiple care settings. The trainee must communicate effectively with patients
and relatives, and be able to pass on both technical information in a way that it can be received with understanding, and distressing information in a sensitive and caring manner. The course of the training program of a RND module will consist of an introduction, readings, an online learning path and a 3-6 month stay at an expert centre for the respective disease group.
The introduction will convey basic disease knowledge as well as technical information for enrolling in and performing the module. Readings will represent the current state of knowledge and will cover the competencies as defined in the curriculum. The online learning path consists of two parts, (i) educational webinars and (ii) virtual patient cases. The role of the educational webinars in module is to convey knowledge according to the Body of Knowledge. The available educational webinars do cover all learning objectives as defined for the respective disease group module.
By processing the patient cases (in an eLearning format), the trainees will actively be applying knowledge. Educational cases will cover typical kinds of the diseases covered in the respective module. Through stays at expert centres the trainees will consolidate and practically apply the respective disease knowledge as defined by competencies and learning objectives. The expert centre which the trainee will visit needs to be an ERN-RND member centre and/or a European nationally recognized expert centre for the respective disease group.

c. Documentation of training

Each trainee should keep an official trainee logbook/portfolio. In this logbook the trainee demonstrates that he/she has educated by RND webinars and educational cases as well as been sufficiently exposed to and dealt with a sufficient number of RND cases in one of the six RND disease group areas, as selected by the trainee. The minimum number of RND cases for which EPA will have to be reported will be 20 according to the minimum annual case load of an ERN-RND expert as defined in the specific conditions that each ERN-RND centre had to meet to be recognized as an ERN-RND member. This will be further specified in the future and according to training experiences. Logbooks should be monitored regularly and undersigned by the trainee and the designated ERN-RND clinical expert. The content of a logbook/portfolio has to include:

- information on training activities and dates in particular webinars and educational cases
- competence-based list of performed diagnosis and care management activities including across multiple care settings, non-neurological disease aspects and transition of care for young patients transferring from pediatric to adult services
- competence based list of performed counselling of patients and families with regard to genetic causation of the disease
- competence based list of performed counselling of patients and families about psychological, social and life style issues
- list of publications

- list of research/clinical presentations at a local, regional, national or international meeting

d. Assessment and evaluation

The European Certificate in Rare Neurological Diseases (ECRND) is intended to be the main knowledge-based assessment tool for training and assessment across Europe and ultimately for the entire continent's experts, with the aim of establishing world class-leading standards in that competency throughout Europe.
ERN-RND plans to introduce ERN-RND determined approach to determining whether an individual is suitable to be recognized as a 'European medical specialist with additional RND competence'. Consequently, there will need to be an assessment of knowledge. This assessment will be linked to the two parts of each training module that is e-learning path and stay at an expertise centre.
The assessment of the trainees in the online learning path will cover

- Educational webinars: 5 knowledge tests, 1 per domain in MCQ format - 80% percentage of questions must be answered correctly
- Educational Cases - 80% percentage of MCQ questions must be answered correctly

Assessments will be formalized and will become obligatory over time. They will consist of Formative Assessments and Summative Assessments, specifically, a competence-based logbook and an Oral Exit Examination after the end of the stay at the expertise centre, respectively.

For Formative Assessments an option would be formal documentation of trainee's development and progress after review of evidence collected.

Summative assessments take place after a specified training period with the purpose of deciding whether the trainee has acquired enough knowledge to proceed to the next domain of knowledge (for the e-learning path) or level of training.

Final completion of a training program should be dependent upon review of the trainee's portfolio as well as success in the final examination. The responsible senior expert together with two additional ERN-RND experts must provide an overall judgment about the trainee's competence and fitness to practice as an independent specialist in RND. This will be done in a final oral (online possible) (exit) examination of the trainee based on domains and learning objectives of module.

e. Governance

The governance of an individual's training programme will be under the the responsibility of the ERN-RND and the respectively assigned senior expert. This senior expert will be from the expert centre at which the trainee will spent the respective 3-6 months stay. The senior expert will be responsible to the ERN-RND for monitoring and delivering the required training in their area of practice. Everything will be conducted under supervision of CESMA, EACCME and NASCE.

II. TRAINING REQUIREMENTS FOR TRAINERS

1. Process for recognition as trainer

a. Requested qualification and experience

ERN-RND uses *ERN-RND disease group*s for recognition of trainers and respective producers of training material. Respective healthcare professionals, researchers and further disease experts need to either belong to an expert centre that is a member of ERN-RND or if this is not the case, the respective specific disease expertise needs to be confirmed by the *ERN-RND disease group.* To this end, ERN-RND has established a process in which the *ERN-RND disease group* Leads as well as the involved patient representative need to confirm the specific expertise of the trainer based on publication, personal knowledge and available training material produced by this trainer.

b. Core competencies for trainers

Required special qualifications of the trainers relate to the expert knowledge they possess for competencies covered by the ERN-RND curriculum. E-learning formats and methodologies required for the e-learning path will be provided by ERN-RND.

2. Quality management for trainers

Quality management for trainers in the ERN-RND curriculum includes two processes: (i) check and confirmation of the expertise required to contribute to the ERN-RND curriculum (see above) and (ii) a structured collection of feed-back collected from trainees and provided to the trainers in order to improve the training material. Furthermore, each *ERN-RND disease group* has installed a group of experts responsible for the respective training module. This expert groups regularly monitors the training content in order to ensure up-to-date-ness and correctness.

III. TRAINING REQUIREMENTS FOR TRAINING INSTITUTIONS (for on-site training stay at RND expertise centre)

1. Process for recognition as training center

a. Requirements for staff and clinical activities

A training center is a place, or number of places including virtual places, where trainees are able to develop/acquire their competencies in rare diseases. Thus, training may take place in a single institution, or in a network of institutions working together such as ERN-RND, to provide training in the full spectrum of clinical conditions and skills detailed in the curriculum. A training institution must have national accreditation, in agreement with UEMS standards, and should possess an adequate infrastructure and offer qualitative and quantitative clinical exposure. Each participating institution in a network must be individually recognized as an RND expertise centre on national and European level. Training centers must have a sufficient throughput of RND patients according to ERN-RND requirements, an appropriate case-mix to meet training objectives, and be adequately resourced with teaching staff. The training must expose the trainee to a broad range of clinical experience.

The training of a trainee will be led and managed by a responsible ERN-RND specialist who will also be the mentor of the trainee. This specialist will be active in the practice, with personal responsibility for the management of RND patients with a specific focus on diseases covered by the respective RND disease group. Within a training center there should be a team of specialists, each with subspecialty expertise and able to supervise and train a trainee. Allied specialties must be present to a sufficient extent to provide the trainee with the opportunity to develop his/her skills in a multidisciplinary approach to patient care. This was and is one of the conditions to qualify as ERN-RND member (compare Annex 3: specific requirements for ERN-RND as defined by the European Commission)

The trainee should be involved in the diagnosis and management process of new patients (outpatients and in-patients), as well as their follow up. A trainee must demonstrate increasing personal responsibility for the global care of patients with RND. There should be written general guidelines within the training institution concerning patient care and patient information (including informed consent), referrals, medical records, documentation, on-call and back-up schedules, attendance at conferences and educational/training courses. The staff of a training center should engage collaboratively in regular reviews and audit of the center's clinical activity and performance. There should be regular multi-disciplinary meetings to determine optimal care for patients, involving both medical and other healthcare professionals. There will be clinical engagement beyond the Center with other clinical groups (see Annex 3). Specialist staff appointed to a training center will have completed all training requirements themselves and will have been trained also in teaching and mentoring trainee staff, and working in a multidisciplinary team with lab and genetic counsellors. This is also part of the requirements all ERN centres have to meet.

b. Requirements for equipment, accommodation

A training center should have sufficient equipment and support to enable the clinical practice that would be expected of a training center and thus provide the necessary educational opportunities for trainees (see Annex 3)

The trainee must have adequate time and opportunities for practical and theoretical study and have access to adequate professional literature. Computing and Information Technology and library resources must be available. All trainees must engage in clinical audits and have the opportunity to engage in research.

2. Quality Management within Training Institutions

Participation of the training institution in a certified quality management program with an external auditing process on a regular basis is consistent with good governance. This will be conducted in accordance to CESMA, EACCME and NASCE guidelines. Criteria of quality management at competency training institutions include the following:

Accreditation

Training institutions need to be accredited with competent National Medical Boards. Additional accreditation on a supra-national level, such as that provided by a European body, is strongly recommended. A training institution must have an internal system of medical audit or quality assurance. Quality assurance must be an integral part of the training program of all training institutions/networks.

Clinical governance
Employee structure at training institutions needs to be designed in a way to accommodate for competency training. Workload has to be managed with a priority on training. The governance of the training program is primarily the responsibility of the responsible senior ERN-RND clinician. ERN-RND and the institution(s) in which the training program tasks are being delivered. For the on-site training, training requirements for trainers, and a Process for recognition as a trainer are expected. Trainers are expected to have achieved the appropriate nationally recognized and certified qualification to allow them to practice as a specialist/consultant.

Manpower planning
Training institutions should appoint a senior clinician (see above, equal to program director) responsible for the composition, implementation and supervision of a competency training program. Roles of trainer and trainee need
to be clearly defined. Allotted time of at least one day per workweek should be implemented for competency training interaction. Manpower planning is under the jurisdiction of each member state and clinical centre.

Regular report
Annual reports on various aspects of an ERN-RND competency training program will be made publicly available.

External audit
Training institutions should appoint a senior clinician who is also responsible for compliance of the training program with current guidelines, directives or regulations of competent medical boards, as well as the local medical school.

Transparency of training programs
Based on national and regional guidelines, UEMS strongly encourages training institutions to formulate defined training programs and make them publicly available (e.g., on their website). ERN-RND will make this document publicly available on its website. It will also publish information about the institutions that are involved in the training program including trainees and responsible clinicians.

Feedback from trainers and trainees
Feedback about program quality from both trainers and trainees must be systematically sought, analyzed and acted upon. Trainers and trainees should be actively involved in using its results for program improvement and development.

Annex 1: ERN-RND Syllabus

The ERN-RND syllabus is an outlined summary of major and specific topics to be covered in a training course of a trainee. The goal of the syllabus is to ensure a fair and impartial working material as a connection between the trainers and the trainee. The syllabus is not a road map of the course, nor an organization/direction relaying training policy to the trainees, so the syllabus is not a learning guide. Instead, the syllabus is a supporting reference material with priorities of training. This syllabus has been developed by ERN-RND with a focus on disease group specific syllabi. In Annex 2, for one of the ERN-RND disease groups – ataxias and hereditary spastic paraplegias – a specific syllabus is provided. The development, consensus and update of the specific syllabi is an ongoing activity. Therefore, further specific syllabi as well as updates will be added to this document in the future.

Domain 1 : General/Theory

- Demonstrate working knowledge of aetiologies for the respective disease group
- Demonstrate general knowledge of clinical presentation, disease onset and progression and natural history aspects

Domain 2 : Diagnostics/Neurogenetics

- Demonstrate knowledge of specific diagnostic criteria and measures, differentiating between pediatric and adult patients if appropriate
- Demonstrate knowledge and use of ERN-RND 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 biomarkers
- Demonstrate a working knowledge of assessment of various disease aspects
- Accurately order and interpret neuroimaging and neurophysiology

Domain 3 : Specific disease management aspects

- Demonstrate knowledge and use of available ERN-RND 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

Domain 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 the respective disease
- Demonstrate working knowledge of non-invasive stimulation techniques
- Demonstrate knowledge on advanced therapies in the respective disease
- Demonstrate up-to-date knowledge in the surgical treatment if appropriate
- Demonstrate knowledge and use of ERN-RND endorsed therapeutic algorithms
- Demonstrate up-to-date knowledge on indications and limits of Deep Brain Stimulation
-

Domain 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 RND

Annex 2: ERN-RND Syllabus for ataxias and Hereditary Spastic Paraplegia (HSP)

5 domains:

General/Theory
Diagnostics/Neurogenetics
Specific disease management aspects
Treatment/Therapy
Communicating with and counselling ataxia and HSP patients

21 competencies

96 learning objectives

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1 General/Theory

1.1 Demonstrate working knowledge of aetiologies for Ataxias and HSP

1.1.1 Describe the major aetiologies (i.e. structural, genetic, infectious, metabolic, immune, and neurodegenerative /genetic, lifestyle, occupational, environmental) for Ataxias and HSP

1.1.2 Describe the most common pathophysiologies of Ataxias and HSP

1.2 Demonstrate general knowledge of clinical presentation, disease onset and progression and natural history aspects

1.2.1 Know the current definition of Ataxias and HSP

1.2.2 Describe the classification of Ataxias and HSP regarding aetiology, age of onset, distribution, involvement of other movement disorders etc.

- pure HSP vs. complicated HSP
- pure cerebellar ataxias vs. cerebellar ataxias with involvement of other structures beyond cerebellum/or other clinical manifestation beyond cerebellar syndrome (pyramidal, extrapyramidal syndrome other movement disorders, polyneuropathy, dementia);
- relation between clinical manifestation and aetiology (degenerative, metabolic diseases; mitochondrial diseases);

1.2.3 Describe the classical clinical presentation (clinical symptoms, pattern recognition and red flags), clinical course and spectrum of Ataxias and HSP

1.2.4 Recognize Non-Progressive Congenital Ataxia (NPCA) (signs, co-morbidities and associated outcome)

1.2.5 Identify the main entities in NPCA differential diagnosis

1.2.6 Recognize typical signs and symptoms as well as typical gait patterns in HSP

1.2.7 Distinguish HSP from other motoneuron diseases and movement disorders.

1.2.8 Describe the spectrum of neurological (intellectual disability, epilepsy, other movement disorders, peripheral neuropathy, etc.) and non-neurological features (cardiomyopathy for Friedreich's Ataxia (FRDA); liver disease for ataxias caused by mutations in the Polymerase Gamma (POLG) gene; cancer predisposition and immunodeficiency for ataxias due to DNA repair defects; etc) that are part of the clinical syndrome in common forms of Ataxia and HSP.

2 Diagnosis /Neurogenetics

2.1 Demonstrate knowledge and use of ERN-RND endorsed diagnostic flowcharts

2.1.1 Know and apply the diagnostic flowchart for Ataxia

2.1.2 Know and apply the diagnostic flowchart for early-onset Ataxias

2.1.3 Know and apply the diagnostic flowchart for HSPs

2.1.4 Be able to make differential diagnosis of ataxias and HSPs with emphasis on potentially curable diseases

2.2 Demonstrate in whom, when and how genetic testing should be applied

2.2.1 Propose a diagnostic plan for a patient with suspected Ataxia/HSP
2.2.2 Demonstrate knowledge about indications for genetic testing
2.2.3 Understand variant classification and variant types in genetic testing results, inheritance patterns, and family history
2.2.4 Decide what type of genetic testing to conduct (nDNA /mtDNA sequencing, CGHarray or SNP array, PCR fragment analysis or other techniques for repeat disorders, Whole Exome Sequencing (WES), Whole Genome Sequencing (WGS))
2.2.5 Interpret and apply the results of genetic testing accurately in the clinical context
2.2.6 Demonstrate knowledge in genetic counselling of patients with Ataxia and HSP
2.2.7 Demonstrate knowledge about indication of presymptomatic genetic testing in children in affected families: pro's and con's
2.2.8 Demonstrate knowledge about testing before and during pregnancy in affected families: indications, types of testing
2.2.9 Demonstrate knowledge in population screening in HSP and ataxias – its potential future indications, pro's and con's.

2.3 Demonstrate a working knowledge of biochemical tests and biomarkers in ataxia and HSP

2.3.1 Demonstrate knowledge about indication for laboratory tests in diagnostics and management of patients with ataxia and HSP
2.3.2 Know specifically and broadly about Cerebrospinal Fluid (CSF) biomarkers beyond standard tests
2.3.3 Know specifically and broadly how to interprete laboratory data of blood, CSF and other body fluids or tissue as relevant for neurology

2.4 Demonstrate a working knowledge of assessment of various disease aspects

2.4.1 Knowledge and understanding of basic clinical scales for assessment of cerebellar ataxias and HSP
2.4.2 Knowledge and understanding of oculomotor and vestibular abnormalities in cerebellar ataxias, methods of examinations (videooculography, electronystagmography, speech analysis) and their possible use for differential diagnostics.
2.4.3 Demonstrate knowledge of the assessment of the quality of life of the patient and of PROMs
2.4.4 Recognize and understand speech impairment in hereditary ataxias, possibility of its objective analysis and its role in disease monitoring.
2.4.5 Demonstrate knowledge about the main cognitive and neuropsychiatric features in cerebellar ataxias and HSPs, its association with different subtypes, and their assessment.

2.5 Accurately order and interpret neuroimaging and neurophysiology

2.5.1 Know basic principles and techniques, pitfalls and limitations in neuroradiology and nuclear medicine including CT, MRI, SPECT and PET scanning
2.5.2 Know the most commonly used MR biomarkers for Spinocerebellar Ataxias (SCA): volumetric (structural MRI), microstructural (diffusion MRI), biochemical (MRS)
2.5.3 State the recommended sequences, recognize the MRI patterns, identify common imaging features in ataxias and HSP

2.5.4 Demonstrate knowledge about indication and interpretation of basic neuroimaging in ataxia and HSP

2.5.5 Demonstrate knowledge about indication and interpretation of advanced neuroimaging (e.g.functional, spectroscopy etc.) in ataxia and HSP

2.5.6 Assess the role of imaging in diagnosis of very early ataxias

2.5.7 Know to accurately order and interpret neurophysiological tests such as: Nerve Conduction Study (NCS), EMG, Evoked potentials – mainly used at the beginning of the diagnostic process in both HSP and Ataxia

3 Specific disease management aspects

3.1 Demonstrate knowledge on pediatric ataxias and HSPs including multidisciplinary teamwork

3.1.1 Describe the role of a multidisciplinary team including doctors from other disciplines (general pediatrics, internal medicine, genetics, immunology, cardiology, etc) occupational-, speech and language- and physiotherapists, nurses, dieticians, psychologists, teachers and social workers

3.1.2 Know the methods used by other medical and paramedical specialists.

3.1.3 Demonstrate knowledge of community based care of children with neurological impairments

3.1.4 Demonstrate knowledge of educational provision for children with neurological impairments

3.1.5 Be able to choose and interpret a suitable neuropsychological assessment (particularly important patients older than 5y and in congenital non progressive ataxia that falls in the group of developmental delay conditions) and be able to understand and interpret the results in the context of the clinical presentation of the disease

3.2 Demonstrate knowledge of neurogeriatric aspects in ataxia and HSP

3.2.1 Demonstrate knowledge of clinical assessment of the elderly

3.2.2 Know specifically and broadly of differential diagnosis of common geriatric problems such as visual and auditory disturbances, delirium, depression, dementia, weakness, falls, and transient losses of consciousness

3.2.3 Demonstrate knowledge about maintaining functional abilities and illness prevention in the case of limited resources

3.3 Demonstrate knowledge of neurological aspects in palliative care

3.3.1 Demonstrate knowledge of advanced palliative care planning

3.3.2 Demonstrate knowledge of specific ambulant palliative care management

4 Treatment/Therapy

4.1 Demonstrate up-to-date knowledge in pharmacological treatment of Ataxia and HSP

4.1.1 Demonstrate knowledge of treatable causes/types of ataxia and HSP and basic principles of its management

4.1.2 Demonstrate knowledge of principles of symptomatic treatment in ataxia (spasticity, downbeat nystagmus, urinary incontinence, dystonia etc.) in cerebellar ataxias and HSP
4.1.3 Recommend appropriate therapy (symptomatic and disease-modifying)
4.1.4 Provide information to patients regarding potential adverse effects of used drugs
4.1.5 Know generally about restorative neuropharmacology
4.1.6 Apply principles of management of behaviour disorders including pharmacotherapy, counselling and psychotherapy

4.2 Demonstrate up-to-date knowledge about neurorehabilitation in ataxia and HSP

4.2.1 Demonstrate knowledge of basic concepts and methodologies of neurorehabilitation for paediatric and adult patients
4.2.2 Demonstrate knowledge of functional assessment and defining outcome measures
4.2.3 Know basic concepts about usage of adult and paediatric orthotics, wheel chairs and other forms of adaptive equipment, hearing and vision aids, communication aids, computers, ventilatory assistance etc.
4.2.4 Demonstrate knowledge to make timely and appropriate referrals to other specialists such as psychologists, psychiatrists, speech therapists.
4.2.5 Define selection criteria for spasticity surgery in Ataxias and HSP patients

4.3 Demonstrate working knowledge of non-invasive stimulation techniques

4.3.1 Know various non-invasive stimulation techniques options for HSP and ataxias

4.4 Demonstrate knowledge on advanced therapies in ataxias and HSP

4.4.1 Be able to discuss the pros and cons of gene therapy in relation to a specific disorder and suggest clinical trials, if appropriate

5 Communicating with and counselling ataxia and HSP patients

5.1 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.

5.1.1 Know and use the patient journey in Fridreichs Ataxia (developed by Mary Kearny, FARA Ireland and ERN-RND ePAG representative and members of the ERN-RND Disease Group 'Ataxia and HSP')
5.1.2 Know and use the patient journey for Hereditary Spastic Paraplegias (developed by Adam Lawrence, chair of the UK HSP Support Group and Lori Renna Linton, ERN-RND ePAG representative and members of the ERN-RND Disease Group 'Ataxia and HSP')

5.2 Communicate information about genetics in an understandable, comprehensible and sensitive way, helping patients to make informed decisions and choices about their care.

5.2.1 Demonstrate awareness that genetic information may have ethical, legal and social implications.
5.2.2 Demonstrate awareness that genetic information impacts not only on the patient but also on their immediate and extended family.

5.2.3 Use appropriate communication skills and demonstrates awareness of the need for confidentiality and a non-directive approach.

5.2.4 Is able to explain potential options for treatment or prophylaxis of conditions within own speciality.

5.2.5 Demonstrate an awareness that a patient's cultural and religious background and beliefs concerning inheritance are important to consider in providing care for people with, or at risk of, genetic conditions

5.3 Demonstrate awareness on specific social and life style issues related to Ataxias and HSP

5.3.1 Demonstrate awareness on social issues including school integration, work, legal, and related aspects

5.3.2 Demonstrate awareness regarding lifestyle matters, such as driving, sports, alcohol, stress, sleep, drug use, and non-adherence/cognitive function, prognosis

5.4 Communicate information about the causes and consequences of the disease and its treatments

5.4.1 Communicate to patients and families, as appropriate, about the epidemiology of Ataxias and HSP

5.4.2 Educate patients and family about relevant disease aspects (e.g. prognosis, psychiatric comorbidities etc.)

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Annex 3 : Specific criteria of ERN-RND as applied for the accreditation of the network and its members

II. NETWORK AREA OF EXPERTISE AND ITS OBJECTIVES

(*) Coding Blocks or Specific Disease Codes, as applicable.
(**) An estimate of the number of known patients in Europe.

ERN	Main Thematic Group	Related Rare Or Complex Disease(s), Condition(s)	Related Code / ICD / Orphacode Group of Codes*	Prevalence**
RND	**Rare neurological diseases**	Cerebellar Ataxias and Spastic Paraplegias	R27.0, G11.4	<20/100.000
	Rare neurological diseases	Choreas and Huntington's Disease	G10	<4/100.000
	Rare neurological diseases	Dystonias, paroxysmal disorders (non-epileptical ones) and Neurodegeneration with Brain Iron Accumulation	G24.9/G43-47/G23	>15/100.000
	Rare neurological diseases	Frontotemporal Dementia	G31.0	3/100.000
	Rare neurological diseases	Leukodystrophies	E75.2/G24	10/100.000
	Rare neurological diseases	Atypical parkinsonian syndromes: Genetic PD, Multisystem Atrophy, Progressive Supranuclear Palsy, Corticobasal degeneration	G20, G23.1, G23.2, G31.85	>10/100.000
	Rare neurological diseases	Rare inflammatory and oncological diseases		
	Rare neurological diseases	Rare vascular diseases, malformation and further rare neurological diseases		

8a. Please state the activity (minimum thresholds) that Healthcare Providers within the Network will need to meet to maintain competence and expertise, as applicable

ERN	Rare or Complex Disease(s), Condition(s) or Highly Specialised Intervention(s)	Measure: Minimum Number of Patients (Visited, Treated or Followed) Per Year	Measure: Number of New Patients Per Year	Measure: Number of Procedures Per Year
RND	1. Rare Neurodegenerative Diseases in total (if the HCP is not an expertise centre for only one rare disease group (2.-7.))	400	40	
	2. Cerebellar Ataxias and Spastic Paraplegias	100	20	
	3. Choreas and Huntington's Disease	50	10	
	4. Dystonias, paroxysmal disorders (non-epileptical ones) and Neurodegeneration with Brain Iron Accumulation	100	20	
	5. Frontotemporal dementia	50	10	
	6. Leukodystrophies	50	10	
	7. Atypical parkinsonian syndromes: Genetic PD, Multisystem Atrophy, Progressive Supranuclear Palsy/Corticobasal degeneration	60	10	
	Botulinum toxin treatments			200
	Deep brain stimulation for dystonia and in general			20
	Hematopoietic stem cell transplantation for treatment of Leukodystrophies and in general			20
	Genetic testing - these numbers include the interpretation of results (for HCPs that are not a expertise centre for only one disease group)			200

SECTION 8

8d In keeping with activities taking place within the Network and where more than one Healthcare provider is involved , please list the core and extended multidisciplinary healthcare team members required for the complex disease(s), condition(s) or highly specialised intervention(s). Please specify for each sub-thematic grouping, as applicable.					**8f** In keeping with the Healthcare Provider Applicants' expertise and activities taking place within their premises, please list the core and extended multidisciplinary healthcare team members required for the complex disease(s), condition(s) or highly specialised intervention(s). Please specify for each sub-thematic grouping, as applicable.			
Main or Sub-Thematic Areas of Expertise	Rare or Complex Disease(s), Condition(s) or Highly Specialized Intervention(s)	Core Multidisciplinary Team, i.e. Types of Healthcare Professionals	Extended Multidisciplinary Team , i.e. Types of Healthcare Professionals	ERN	Main or Sub-Thematic Areas of Expertise	Rare or Complex Disease(s), Condition(s) or Highly Specialized Intervention(s) covered by the Healthcare Provider*	Core Multidisciplinary Team, i.e. Types of Healthcare Professionals**	Extended Multidisciplinary Team , i.e. Types of Healthcare Professionals
Rare Neurological Disease	Cerebellar Ataxias and Spastic Paraplegias	Neurologist with experience in movement disorders. In centres where children are seen Paediatric neurologist, Physiotherapist, Psychologist, Human geneticist or neurologist with experience in genetics	Neuroophthalmologist, Neuroradiologist, Physiotherapist, Speech therapist	RND	Rare Neurological Disease	Cerebellar Ataxias and Spastic Paraplegias	Neurologist with experience in movement disorders. In centres where children are seen Paediatric neurologist, Physiotherapist, Psychologist, Human geneticist or neurologist with experience in genetics	Neuroophthalmologist, Neuroradiologist, Physiotherapist, Speech therapist, Social care workers, patients groups
Rare Neurological Disease	Choreas and Huntington's Disease	Human geneticist or neurologist with experience in genetics, Neurologist with experience in movement disorders, Psychologists, and Psychiatrists	Psychiatrist, Physiotherapist, Speech therapists, Ergotherapists, Diet specialists, Rehabilitation specialists, Social care worker		Rare Neurological Disease	Choreas and Huntington's disease	Human geneticist or neurologist with experience in genetics, Neurologist with experience in movement disorders, Psychologists, and Psychiatrists	Psychiatrist, Physiotherapist, Speech therapists, Ergotherapists, Diet specialists, Rehabilitation specialists, Social care worker
Rare Neurological Disease	Dystonias, paroxysmal disorders (non-epileptical ones) and Neurodegeneration with Brain Iron Accumulation	Neurologist, Pediatric neurologist, Human Geneticist, Allied health professionals (Speech therapists, Physiotherapists, Occupational therapists)	Neurosurgeon, Specilised nurse, Neuropsychologist, Psychiatrist, Rehabilitation docter, Neuroradiologist, Neurophysiologist		Rare Neurological Disease	Dystonias, paroxysmal disorders (non- epileptical ones) and Neurodegeneration with Brain Iron Accumulation	Neurologist, Pediatric neurologist, Human Geneticist, Allied health professionals (Speech therapists, Physiotherapists, Occupational therapists)	Neurosurgeon, Specilised nurse, Neuropsychologist, Psychiatrist, Rehabilitation docter, Neuroradiologist, Neurophysiologist
Rare Neurological Disease	Frontotemporal dementia	Neurologist with experience in dementias, Neuropsychologist Social care worker	Physiotherapist; speech therapist Psychiatrist with experience in dementias, Nurse Specialist		Rare Neurological Disease	Frontotemporal dementia	Neurologist with experience in dementias, Neuropsychologist Social care worker	Physiotherapist; speech therapist Psychiatrist with experience in dementias, Nurse Specialist
Rare Neurological Disease	Leukodystrophies	Neurologist and pediatric neurologist, Human Geneticist, Biochemist	Interdisciplinary team for supportive treatment (medical doctor, nurse, physiotherapist, psychologist, social worker		Rare Neurological Disease	Leukodystrophies	Neurologist and pediatric neurologist, Human Geneticist, Biochemist	Interdisciplinary team for supportive treatment (medical doctor, nurse, physiotherapist, psychologist, social worker
Rare Neurological Disease	Atypical parkinsonian syndromes: Genetic PD, Multisystem Atrophy, Progressive Supranuclear Palsy/Corticobasal degeneration	Movement disorders neurologist, Cognitive Neurologist/Psychiatrist, Neuroradiologist, Physiotherapy, Logotherapy	Neuro-urologist Sleep medicine expert		Rare Neurological Disease	Atypical parkinsonian syndromes: Genetic PD, Multisystem Atrophy, Progressive Supranuclear Palsy, Corticobasal degeneration	Movement disorders neurologist, Cognitive Neurologist/Psychiatrist, Neuroradiologist, Physiotherapy, Logotherapy	Neuro-urologist Sleep medicine expert
Botulinum toxin treatments	Cerebellar Ataxias and Spastic Paraplegias, Dystonias, Atypical parkinsonian syndromes	Trained neurologists	Trained technicians, Ergotherapist, Physiotherapist		Rare Neurological Disease	Botulinum toxin treatments	Trained neurologists	Trained technicians, Ergotherapist, Physiotherapist
Deep brain stimulation	Dystonias and atypical parkinsonian syndromes	Neurosurgeon, Specilised nurse, Neuroradiologist, Neurologist	Neuropsychologist, Psychiatrist, Rehabilitation docter, Neurophysiologist		Rare Neurological Disease	Deep brain stimulation	Neurosurgeon, Specilised nurse, Neuroradiologist, Neurologist	Neuropsychologist, Psychiatrist, Rehabilitation docter, Neurophysiologist
Hematopoietic stem cell transplantation	Leukodystrophies	Pediatric oncologist Specilised nurse, Pediatric neurologist Physiotherapy,	Chimerism laboratory Neuroradiologist		Rare Neurological Disease	Hematopoietic stem cell transplantation	Pediatric oncologist Specilised nurse, Pediatric neurologist Physiotherapy,	Chimerism laboratory Neuroradiologist
Genetic testing	All rare neurodegenerative diseases	Geneticists Clinical scientists	Trained technicians		Rare Neurological Disease	Genetic testing	Geneticists Clinical scientists	Trained technicians
Specialised Neuroimaging	All rare neurodegenerative diseases	Neuradiologists Neurologists, paediatric neurologists trained in interpretation of brain images	Trained technicians		Rare Neurological Disease	Specialised Neuroimaging	Neuradiologists Neurologists, paediatric neurologists trained in interpretation of brain images	Trained technicians

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	8g Please list for each of the core and extended multidisciplinary team members the necessary human resources and the professional qualifications essential to the quality of patient care.				8i Please list of the specialised equipment, infrastructure, and information technology required to support the rare or complex disease(s), condition(s) or highly specialised intervention(s) and describe the importance of each.		
	(*) According to Directive 2005/36/EC on recognition of professional qualifications, where applicable.						
ERN	Healthcare Professional (type)*	Training & Qualifications (any further appropriate requirement based on area of expertise)	Minimum # of Procedures / Patients / year	**ERN**	Sub-Thematic Area of Expertise	Rare or Complex Disease(s), Condition(s) or Highly Specialized Interventions covered by the Healthcare Provider*	Specialised Equipment, Infrastructure, and Information Technology
RND	Neurologist or paediatric neurologist for cerebellar ataxias (CA) and herediary spastic paraplagias (HSP)	Consultant level (i.e. medical degree and completion of neurology training), with experience in movement neurology	20	**RND**	Rare Neurological Diseases	Cerebellar Ataxias and Spastic Paraplegias, Huntington's disease and choreas	MRI, accredited genetics laboratory
	Human geneticist or neurologist with experience in genetics, Rehabilitation physician, Physiotherapist, Social care worker for CA and HSP	Consultant level	20		Rare Neurological Diseases	Frontotemporal dementia	MRI/PET, EMG/NCS, Battery of neuropsychological tests, accredited genetics laboratory
	Neurologist for Huntingtons' disease and choreas (HD)	Consultant level , Involved in the life-long management of the patients and their families	50		Rare Neurological Diseases	Dystonias, paroxysmal disorders (non-epileptical ones) and Neurodegeneration with Brain Iron Accumulation	Neuroradiology facility (CT scan, MRI), Nuclear medicine facility (SPECT or PET scanning.), Botulinum toxin clinic, Neurosurgery (equipped for Functional steretactic surgery) , accredited genetics laboratory, Neurophysiology lab
	Human geneticist or neurologist with experience in genetics for HD	Extended knowledge on HD and training in genetics	10		Rare Neurological Diseases	Leukodystrophies	Biochemical, accredited genetics laboratory, MRI, neurophysiology lab, Hematopoietic stem cell transplantation facility
	Psychiatrist for HD	Consultant level, Involved in the life-long management of the patients and their families	30		Rare Neurological Diseases	Atypical parkinsonian syndromes	Neuroimaging (SPECT, PET, MR)
	Therapists (physio, ergo, speech) for HD	Treatment of patients in mild-moderate stages of the disease still able to understand and follow the therapy.	10				
	Psychologist for HD	Consultant level	10				
	Nutrician advice specialist for HD	Treatment of patients with weight loss	10				
	Adult neurologist for dystonias	Training in botulinum toxin injections	50				
	Child neurologist or metabolic pediatrician for dystonias	Pediatric movement disorder training	50				
	Neurophysiologist for dystonias	Electrophysiological training	20				
	Neurosurgeon for dystonias	Training in DBS	25				
	Neuroradiologist for dystonias	Training in neuroradiology/ tractography/special neuroimaging techniques for dystonia	20				
	Neurorehabilitation doctor for dystonias	Specialised in movement disorders	20				
	Human geneticist or neurologist with experience in genetics for dystonias	Trained in analysis and interpretation of the gene panel and WES results	40				

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