



**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

 **Network**  
Neurological Diseases  
(ERN-RND)

# European Reference Network for Rare Neurological Diseases – ERN-RND

## ERN-RND Information Brochure

|            |   |
|------------|---|
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| Authors:   | Holm Graessner, Alicia Brunelle, Carola Reinhard,<br>Sanja Hermanns, Annemarie Post |
| Diffusion: | ERN-RND members   |

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## Summary and objectives

More than 500,000 people in the European Union suffer from a rare neurological disease (RND) which can sometimes take months or even years to diagnose correctly and for which often no treatment is available. This is an extremely challenging and stressful situation, often referred to as a “diagnostic odyssey”, patients and their families have to go through until they get the correct diagnosis. For that purpose, the European Reference Network for Rare Neurological Diseases (ERN-RND) was set up in 2017 with 23 other networks by the European Commission with the overall aim of supporting patients with rare neurological diseases across Europe in getting a faster diagnosis and access to the right treatment and care. This is achieved by connecting healthcare professionals in Europe and enabling the sharing of knowledge and expertise through the Clinical Patient Management System (CPMS), a secure online platform where clinicians discuss a patient’s case with European colleagues and at organised meetings. The ERN-RND is a virtual network made of healthcare professionals, European Patient Advocacy Groups (ePAGs) representatives and researchers located across Europe. It has 41 members in 21 European countries.

The objectives of ERN-RND are:

1. To significantly increase the overall percentage of RND patients with a final diagnosis
2. To improve and harmonise care of RND patients across the EU
3. To develop, share and implement care pathways and guidelines for all RND groups represented in ERN-RND
4. To support ERN-RND members in designing, implementing and supervising RND training and capacity building activities at the level of member states and of the network.
5. To develop a comprehensive and data based European RND cohort to better understand these conditions and thus improve their management and help developing and testing treatments
6. To define minimum quality and interoperability criteria for data in RND registries allowing data exchange between local registries and use of data from different registries for one clinical trial

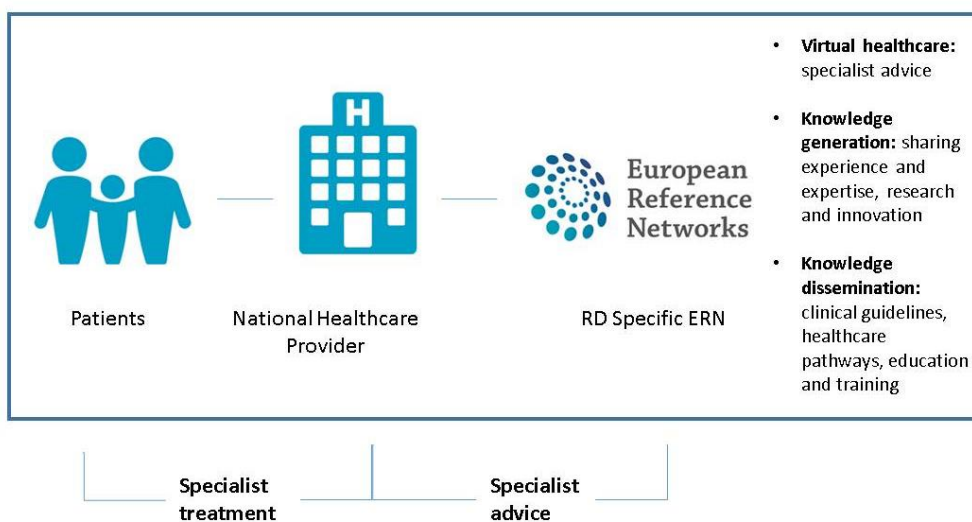


Figure 1: How ERNs work

ERN-RND provides care for approximately 33.500 patients per year (85% adults, 15% paediatric patients), of which 6.150 are new patients (estimate numbers from Grant Application). The Disease Groups covered by ERN-RND are as follows:

- Cerebellar Ataxia and Hereditary Spastic Paraplegias (HSPs)
- Chorea and Huntington’s Disease (HD)
- Dystonias, Neurodegeneration with Brain Iron Accumulation (NBIA) and Paroxysmal Disorders
- Frontotemporal Dementia (FTD)
- Leukodystrophies
- Atypical Parkinsonism: Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP) and Genetic Parkinson’s Disease (genetic PD)

Figure 2 shows the distribution of patient numbers within the different Disease Groups represented in the ERN-RND.

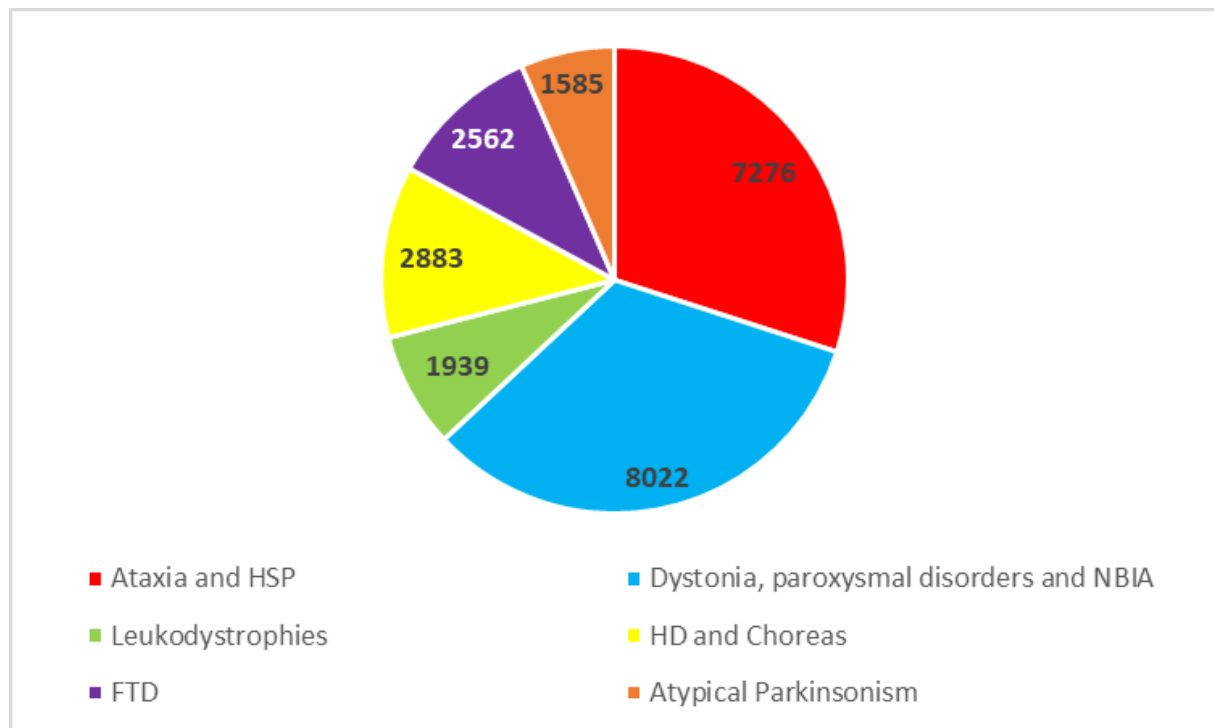


Figure 2: Number of annual patients in ERN-RND (estimation from Grant Application)

## ERN-RND expert centres

|  |
|--|
| AOU Siena, Italy   |
| Assistance Publique-Hôpitaux de Paris, Hôpital Henri-Mondor, France: Reference centre for Huntington's disease                     |
| Assistance Publique-Hôpitaux de Paris, Hôpital de la Pitié-Salpêtrière, France: Reference centre for rare dementias                |
| Assistance Publique-Hôpitaux de Paris, Hôpital de la Pitié-Salpêtrière, France: Reference Centre for Rare Diseases 'Neurogenetics' |
| Assistance Publique-Hôpitaux de Paris, Hôpital Robert-Debré, France: Reference centre for Leukodystrophies                         |
| CHU de Bordeaux, France: Reference centre for MSA  |
| CHU de Toulouse: Reference centre for MSA  |
| Erasmus MC: University Medical Center Rotterdam, The Netherlands,  |
| Foundation IRCCS neurological institute Carlo Besta – Milan, Italy   |
| General University Hospital in Prague, Czech Republic  |
| Hospital Clínic i Provincial de Barcelona y Hospital de Sant Joan de Déu, Spain  |
| Hospital Universitari Vall d'Hebron, Spain   |
| IRCCS Clinical Institute Humanitas – Rozzano, Italy  |
| Klinikum der Universität München, Germany  |
| Motol University Hospital, Czech Republic  |
| Pediatric hospital Bambino Gesù, Rome, Italy   |
| Semmelweis University, Hungary   |
| Stichting Katholieke Universiteit, doing business as Radboud University Medical Center Nijmegen, The Netherlands                   |
| Universitätsklinikum Bonn, Germany   |
| Universitätsklinikum Schleswig-Holstein, Germany   |
| Universitätsklinikum Tübingen, Germany   |
| Universitätsklinikum Ulm, Germany  |
| Université libre de Bruxelles, Belgium   |
| University Hospital in Krakow, Poland  |
| University Hospitals Leuven, Belgium   |
| University Medical Center Groningen, The Netherlands   |
| University Medical Centre Ljubljana, Slovenia  |
| University Neurological Hospital "St. Naum" Sofia, Bulgaria  |
| University of Pécs, Hungary  |
| Vilnius University Hospital Santaros Klinikos, Lithuania   |
| VU University Medical Center Amsterdam, The Netherlands  |

## ERN-RND affiliated partners

|  |
|--|
| Center for Rare Movement Disorders / Dpt. of Neurology,<br>Medical University Innsbruck, Austria               |
| Center for Pediatric Rare Neurological Diseases / Dpt. of Pediatrics,<br>Medical University of Vienna, Austria |
| University Hospital Centre Zagreb, University Department of Neurology, Croatia                                 |
| Aarhus Universitetshospital, Denmark   |
| Rigshospitalet Copenhagen, Denmark   |
| Tartu University Hospital, Estonia   |
| Oulu University Hospital (OUH), Finland  |
| Pauls Stradins Clinical University Hospital, Riga, Latvia  |
| Centre Hospitalier du Luxembourg, Luxembourg   |
| National Coordination Hub, Mater Dei Hospital (MDH), Malta   |

Affiliated partners of ERN-RND are healthcare providers that can only come from a country not yet represented by a full member in the network and which are allocated by their respective member state. More information about affiliated partners can be found on the European Commission's website [here](#).

ERN-RND is currently going through an expansion process and its geographical coverage will soon be extended to most European countries.



Picture 1: ERN-RND members at the Annual Meeting 2019 in Siena, Italy

## Achievements

- ERN-RND has collected and generated knowledge to improve care of patients with RND. These disease knowledge documents include:
  - Diagnostic flowcharts
  - Disease scales
  - Therapeutic algorithms
  - Guidelines endorsed by ERN-RND

Respective documents can be found on ERN-RND's website [here](#).

- ERN-RND has established a relationship with EMA – Trial readiness and registry workshop on 18 February 2019 in Amsterdam, the Netherlands

Additional ongoing projects include:

- DG Ataxia and HSP:
  - Development of a guideline for hereditary spastic paraplegia (HSP)
  - Treatabome for early-onset ataxias
  - Validation of clinical rating scales for children with HSP
- DG Dystonia, NBIA, Paroxysmal Disorders:
  - Survey on myoclonus dystonia
  - DBS in dystonia guideline
- DG Chorea and HD:
  - Guidelines for non-HD choreas
  - 'Improve clinical practice for benign hereditary chorea' survey
- DG Leukodystrophies:
  - Rating scales for pediatric leukodystrophies
  - Guideline development for MLD

Furthermore, ERN-RND participates in several collaborative projects with professional societies, such as:

- the European Academy for Neurology (EAN): "development of methodology for preparing guidelines for RND" and
- educational webinar series for RND as well as with
- the [European Brain Council](#): "the Value of Treatment Project"

## Structure of ERN-RND

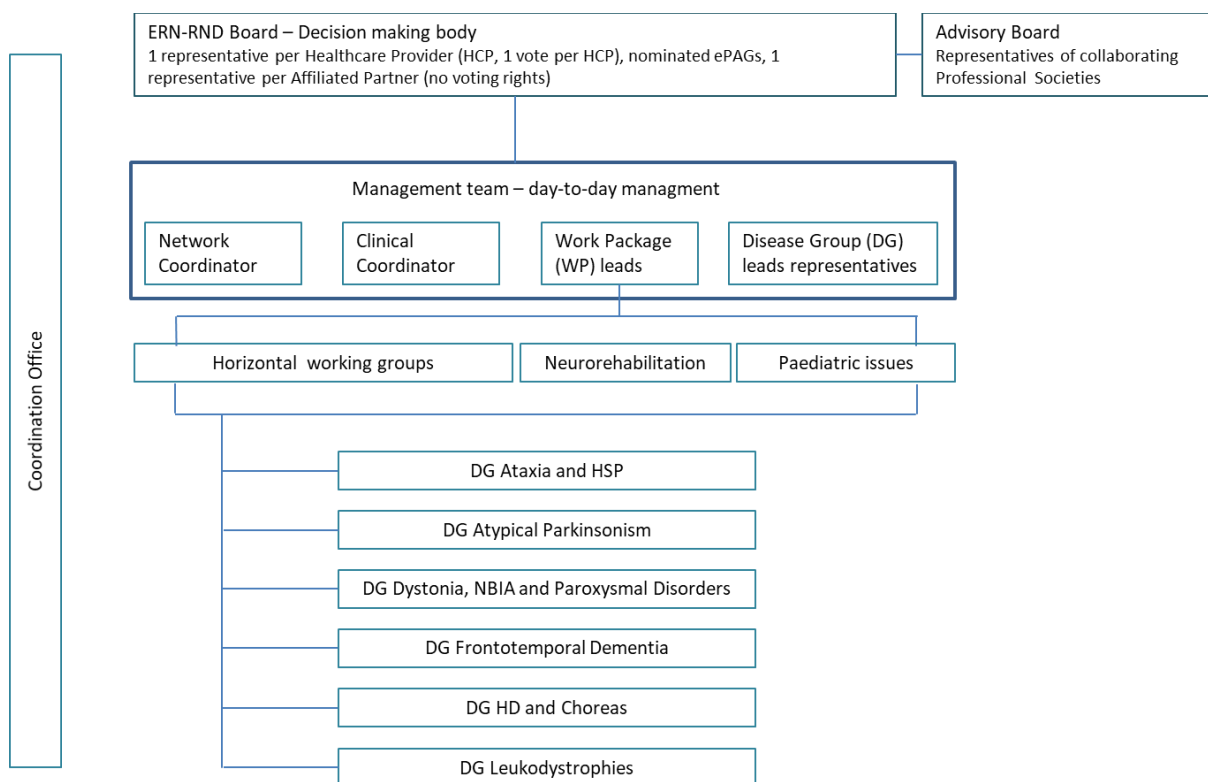


Figure 3: ERN-RND organisational structure

## ERN-RND Board

ERN-RND’s Board is responsible for strategic decisions and for monitoring the activities of the network. It is the main decision body and is chaired by the network coordinator. The membership of the Board includes individual Health Care Provider (HCP)/Expert centre leads (or their nominated deputies) and the nominated ePAG (European Patient Advocacy Groups) representatives. Affiliated partners will participate in the Board meetings but will not have any voting rights. The Board members meet twice a year.

The full list of Board members can be found below:

| Board member        | HCP   |
|---------------------|---|
| Gilles Naeije       | Université libre de Bruxelles, Belgium                      |
| Chantal Depondt     | Université libre de Bruxelles, Belgium                      |
| Rik Vandenberghe    | University Hospitals Leuven, Belgium                        |
| Ognyana Burgazlieva | University Neurological Hospital “St. Naum” Sofia, Bulgaria |
| Jiri Klempir        | General University Hospital in Prague, Czech Republic       |
| Evzen Ruzicka       | General University Hospital in Prague, Czech Republic       |
| Jaroslav Jerabek    | Motol University Hospital, Czech Republic                   |
| Elena Zumrova       | Motol University Hospital, Czech Republic                   |
| Wassilios Meissner  | CHU de Bordeaux, France                                     |



|                             |  |
|-----------------------------|--|
| Anne-Catherine Bachoud-Lévi | Assistance Publique-Hôpitaux de Paris, Hôpital Henri-Mondor: Reference centre for Huntington's disease, France                     |
| Odile Boespflug             | Assistance Publique-Hôpitaux de Paris, Hôpital Robert-Debré: Reference centre for Leukodystrophies, France                         |
| Patrick Aubourg             | Assistance Publique-Hôpitaux de Paris, Hôpital Robert-Debré: Reference centre for Leukodystrophies, France                         |
| Isabelle le Ber             | Assistance Publique-Hôpitaux de Paris, Hôpital de la Pitié-Salpêtrière: Reference centre for rare dementias, France                |
| Bruno Dubois                | Assistance Publique-Hôpitaux de Paris, Hôpital de la Pitié-Salpêtrière: Reference centre for rare dementias, France                |
| Alexandra Durr              | Assistance Publique-Hôpitaux de Paris, Hôpital de la Pitié-Salpêtrière: Reference Centre for Rare Diseases 'Neurogenetics', France |
| Claire Ewencyk              | Assistance Publique-Hôpitaux de Paris, Hôpital de la Pitié-Salpêtrière: Reference Centre for Rare Diseases 'Neurogenetics', France |
| Anne Pavy-Le Traon          | CHU de Toulouse, France  |
| Olivier Rascol              | CHU de Toulouse, France  |
| Holm Graessner              | Universitätsklinikum Tübingen, Germany   |
| Ludger Schöls               | Universitätsklinikum Tübingen, Germany   |
| Thomas Klockgether          | Universitätsklinikum Bonn, Germany   |
| Sebastian Paus              | Universitätsklinikum Bonn, Germany   |
| Alexander Münchau           | Universitätsklinikum Schleswig-Holstein, Germany   |
| Sinem Tunc                  | Universitätsklinikum Schleswig-Holstein, Germany   |
| Thomas Klopstock            | Klinikum der Universität München, Germany  |
| Bernhard Landwehrmeier      | Universitätsklinikum Ulm, Germany  |
| Jan Lewerenz                | Universitätsklinikum Ulm, Germany  |
| Maria Judit Molnar          | Semmelweis University, Hungary   |
| Zoltan Grosz                | Semmelweis University, Hungary   |
| Norbert Kovacs              | University of Pécs, Hungary  |
| Hadzsiev Kinga              | University of Pécs, Hungary  |
| Alberto Albanese            | IRCCS Clinical Institute Humanitas – Rozzano, Italy  |
| Stefania Lalli              | IRCCS Clinical Institute Humanitas – Rozzano, Italy  |
| Caterina Mariotti           | Foundation IRCCS neurological institute Carlo Besta – Milan, Italy   |
| Enrico Bertini              | Pediatric hospital Bambino Gesù, Rome, Italy   |
| Ginevra Zanni               | Pediatric hospital Bambino Gesù, Rome, Italy   |
| Antonio Federico            | AOU Siena, Italy   |
| Nicola De Stefano           | AOU Siena, Italy   |
| Algirdas Uktus              | Vilnius University Hospital Santaros Klinikos, Lithuania   |
| Nicole Wolf                 | VU University Medical Center Amsterdam, The Netherlands  |
| Marina de Koning-Tijssen    | University Medical Center Groningen, The Netherlands   |
| Tom de Koning               | University Medical Center Groningen, Netherlands   |
| Michel Willemsen            | Stichting Katholieke Universiteit, doing business as Radboud University Medical Center Nijmegen, The Netherlands                   |

|                        |  |
|------------------------|--|
| Bart van de Warrenburg | Stichting Katholieke Universiteit, doing business as Radboud University Medical Center Nijmegen, The Netherlands |
| John van Swieten       | Erasmus MC: University Medical Center Rotterdam, The Netherlands,  |
| Janne Papma            | Erasmus MC: University Medical Center Rotterdam, The Netherlands,  |
| Harro Selar            | Erasmus MC: University Medical Center Rotterdam, The Netherlands,  |
| Joanna Pera            | University Hospital in Krakow, Poland  |
| Borut Peterlin         | University Medical Centre Ljubljana, Slovenia  |
| Dario Ortigozo Escobar | Hospital Clínic i Provincial de Barcelona y Hospital de Sant Joan de Déu, Spain                                  |
| Maria J Marti          | Hospital Clínic i Provincial de Barcelona y Hospital de Sant Joan de Déu, Spain                                  |
| Alfons Macaya          | Hospital Universitari Vall d'Hebron, Spain   |
| Josep Gamez            | Hospital Universitari Vall d'Hebron, Spain   |
| Mary Kearney           | ePAG rep   |

## Management team

The management team is responsible for the management of ERN-RND. It comprises the network coordinator, the clinical coordinator, the Work Package (WP) leads and representatives of the Disease Group (DG) leads. For the names of the Work Package and Disease Group leads, please see below.

## ERN-RND coordination office

ERN-RND's coordination office is comprised of the network coordinator, clinical coordinator, project managers, training and education manager, CPMS helpdesk, communication manager and administrative help.

- The network coordinator manages and interacts with the coordination office on a daily basis by monitoring overall activities, liaising with members and external organisations as well as taking key strategic decisions.
- The project manager is responsible for administrative tasks which ensure the smooth day-to-day coordination of the network such as the coordination of meetings, organisation of the annual meeting, communication with stakeholders, dissemination of outputs and gathering and collating of monitoring data for reporting and presentation.
- The CPMS panel manager and helpdesk is responsible for most things related to the CPMS which include providing training on how to use the CPMS, organising CPMS case discussions with ERN-RND members and liaising with the European Commission in regards to technical aspects of the system.
- The education and training manager is responsible for the analysis of learning needs and planning, implementation and follow-up of suitable training measures for the different disease group in ERN-RND. In addition, she compiles and disseminates across the network relevant information about educational

offers and funding opportunities for training. She actively exchanges with different stakeholders and ERN-RND clinical experts with the final goal to build a repository of training contents and create a postgraduate training curriculum for rare neurological, neuromuscular and movement disorders.

- The communication manager is responsible for the updating of information on the ERN-RND website, the creation of the newsletter and dissemination of information through social media channels.

| Name                | Role  | Email address  |
|---------------------|---|--|
| Holm Graessner      | Coordinator                                   | <a href="mailto:holm.graessner@med.uni-tuebingen.de">holm.graessner@med.uni-tuebingen.de</a>             |
| Ludger Schöls       | Clinical coordinator                          | <a href="mailto:ludger.schoels@uni-tuebingen.de">ludger.schoels@uni-tuebingen.de</a>                     |
| Carola Reinhard     | Project manager                               | <a href="mailto:carola.reinhard@med.uni-tuebingen.de">carola.reinhard@med.uni-tuebingen.de</a>           |
| Matthias Gerberding | Project manager                               | <a href="mailto:matthias.gerberding@med.uni-tuebingen.de">matthias.gerberding@med.uni-tuebingen.de</a>   |
| Sanja Hermanns      | Training and education manager, CPMS helpdesk | <a href="mailto:sanja.hermanns@med.uni-tuebingen.de">sanja.hermanns@med.uni-tuebingen.de</a>             |
| Tamara Martin       | CPMS helpdesk                                 | <a href="mailto:tamara.martin@med.uni-tuebingen.de">tamara.martin@med.uni-tuebingen.de</a>               |
| Annemarie Post      | Communication manager                         | <a href="mailto:communicationERN-RND@med.uni-tuebingen.de">communicationERN-RND@med.uni-tuebingen.de</a> |

## ERN-RND European Patient Advocacy Group Representatives (ePAGs)

EURORDIS, the European umbrella organisation of patient organisations and a non-profit alliance of 798 rare disease patient organisations, has established a [European Patient Advocacy Group](#) (ePAG) for each ERN disease grouping. Patient organisations can become ePAG member organisations and patients can become ePAG representatives.

The ERN-RND ePAG representatives are as follows:

| ePAG name         | Patient organisation                                 |
|-------------------|--|
| Astri Arnesen     | European Huntington Association                      |
| Lori Renna Linton | Euro-HSP   |
| Lubomír Mazouch   | Czech Association of Atypical Parkinsonian Syndromes |
| Marek Parowicz    | AHC 18 OLUS e.V.                                     |
| Mary Kearney      | Friedreich's Ataxia Research Alliance Ireland (FARA) |
| Monika Benson     | Dystonia Europe                                      |
| Natalia Grigorova | Bulgarian Huntington Association                     |
| Tobias Mentzel    | ELA Germany  |

You can find more information about our ePAG representatives [here](#).

## Transversal Working Groups

Cross-cutting activities of the ERN-RND are structured Working Groups (WG) each led by an ERN-RND member:

| Title                                     | WP Lead   | Leading HCPs   |
|---|---|--|
| RND diagnostic pathway                    | Alexandra Durr  | Assistance Publique-Hôpitaux de Paris, Hôpital de la Pitié-Salpêtrière   |
| Expert RND care coordination              | Marina de Koning-Tijssen  | University Medical Centre Groningen  |
| Training, education and capacity building | Maria Judit Molnar  | Semmelweis University Budapest   |
| Guidelines, pathways and best practice    | Antonio Federico  | AOU Siena  |
| Registries and research                   | Thomas Klockgether  | Universitätsklinikum Bonn  |
| Neurorehabilitation                       | Annemieke Buizer, Maria Judit Molnar, Antonio Federico, Jorik Nonnekes, Lori Renna Linton, Anna Volkmer | Amsterdam University Medical Center, the Netherlands<br>Semmelweis University, Hungary<br>AOU Siena, Italy<br>Patient advocate euro-HSP<br>University College London<br>Hospitals NHS Foundation Trust, United Kingdom |
| Paediatric issues                         | Caroline Sevin, Nicole Wolf, Juan Dario Ortigoza Escobar  | Assistance Publique-Hôpitaux de Paris, Hôpital Robert-Debré, France<br>VU University Medical Center Amsterdam, The Netherlands<br>Hospital Clínic i Provincial de Barcelona y Hospital de Sant Joan de Déu, Spain      |

## ERN-RND Disease Groups

Disease Groups (DGs) are composed of the respective experts from all ERN-RND partners. They work on Disease Group specific topics such as care standards, specific dissemination of disease knowledge, etc.

| Disease Group (DG) | DG coordinator   |
|--------------------|--|
| DG Ataxia and HSPs | Enrico Bertini (Italy), Alfons Macaya (Spain), Caterina Mariotti (Italy), Rebecca Schuele-Freyer (Germany) |

|  |  |
|--|--|
| DG Leukodystrophies                      | Caroline Sevin (France) Nicole Wolf (The Netherlands)  |
| DG Frontotemporal Dementia               | Tobert Rusina (Czech Republic), Dario Saracino (France), Harro Seelaar (The Netherlands), Rik Vandenberghe (Belgium) |
| DG Dystonia, Paroxysmal Disorders & NBIA | Sylvia Boesch (Austria), Tobias Bäumer (Germany), Belén Pérez Dueñas (Spain)   |
| DG Atypical Parkinsonism                 | Alessandra Fanciulli (Austria), Thomas Gasser (Germany), Florian Krismer (Austria), Johannes Levin (Germany),        |
| DG Huntington's Disease & Chorea         | Anne-Catherine Bachoud-Lévi (France), Juan Dario Ortigoza Escobar (Spain), Bernhard Landwehrmeyer (Germany)          |

The work of the DGs results in disease knowledge documents that can be found on the ERN-RND website: [www.ern-rnd.eu](http://www.ern-rnd.eu)

## Clinical Patient Management System (CPMS)

The [Clinical Patient Management System \(CPMS\)](#) is a secure IT-Platform used by clinicians across Europe to discuss patient cases without the patients having to travel. The ERN Experts (from one or more ERNs) gather in multidisciplinary panels and use CPMS to carry out e-consultations of rare and complex cases. Patient medical documents can be safely uploaded to the CPMS after a consent form has been signed by the patient. Integrated tools in CPMS allow peer-to-peer communication, viewing of digital documents and recording expert contributions. This promotes an active collaboration, sharing knowledge and experience within and across ERNs. The health professionals are ultimately aiming at an outcome either as a diagnosis, treatment, and clinical trial or other.

In addition to flexible appointments, case discussion meetings open to all ERN-RND members are scheduled every second month for each disease group, allowing to discuss cases on a regular basis and additionally serving an educational purpose.

For further questions please do not hesitate to contact the CPMS Helpdesks:

| Name           | Email address  |
|----------------|--|
| Sanja Hermanns | <a href="mailto:cpms-helpdesk_ern-rnd@med.uni-tuebingen.de">cpms-helpdesk_ern-rnd@med.uni-tuebingen.de</a> |
| Tamara Martin  | <a href="mailto:cpms-helpdesk_ern-rnd@med.uni-tuebingen.de">cpms-helpdesk_ern-rnd@med.uni-tuebingen.de</a> |
| Alisa Jemelka  | <a href="mailto:Alisa.jemelka@uksh.de">Alisa.jemelka@uksh.de</a>   |

## Collaborative Platform

The Collaborative Platform (CP) is the secure online repository for all relevant network documents (deliverables, meeting minutes, contact, etc.). It is restricted to ERN users only (need to request access from coordinator) and is not to be used for the exchange of patient data.

## Training and education

### Webinar series

ERN-RND organizes educational webinars on rare neurological, movement and neuromuscular diseases - in collaboration with the [European Reference Network for Rare Neuromuscular Diseases \(EURO-NMD\)](#) and the [European Academy of Neurology \(EAN\)](#). The webinars cover all 6 disease groups represented in ERN-RND and alternate adult and pediatric contents. In addition, several webinars with a focus on neurorehabilitation and advanced therapeutics are offered.

Various aspects from more general topics as clinical features, examination, disease diagnosis, therapeutic interventions and disease management to specific ones as use of scales or imaging are discussed in an interactive manner.

More information about our webinars can be found [here](#).

### Fellowship exchanges

- (i) **The European Joint Programme on Rare Diseases (EJP-RD)** offers fellowships for research purposes linked to rare diseases:
  - **research mobility fellowship** for young investigators affiliated to an ERN institution to undertake a short scientific visit to an ERN host institution (2 calls per year)

When available, information on these calls will be made available [here](#).

- (ii) The **Short Exchange Programme 2021-2022**, funded by the European Commission, aims to support the sharing of knowledge and stimulate collaboration between health care professionals in ERNs. Healthcare Professionals affiliated to ERN institutions receive organizational and financial support for short secondments with clinical objectives in ERN expert centers other than their home institution for minimum one and up to four weeks. ERN-RND especially (but not exclusively) supports exchanges with the following foci: neurorehabilitation, DBS for dystonia and autonomic failure in atypical parkinsonism. ERN-RND centres offering to host fellows on these topics can be found online. For more information and application, please visit [our website](#).

### Research training workshop EJP-RD

- EJP-RD offers funding for the organisation of a **research training workshop** with a cross ERN-added value for an ERN full member or ERN affiliated partner institution (2 calls per year: one in spring and one in autumn). Information on open calls can be found [here](#). For more information on the workshops selected until now, visit the [EJP-RD website](#).

## Training events in collaboration with other professional societies

- **German Academy for rare neurological disorders (DASNE):** Yearly meeting to discuss interesting solved and unsolved neurological cases as well as cases for the molecular therapeutic board. The meeting also includes training workshops for young neurologists in the field of rare neurological disorders. Currently, monthly online case discussions complement the annual meeting. More information about DASNE can be found [here](#).
- **European Academy of Neurology (EAN):** The EAN coordinating panel for rare neurological diseases organizes a yearly training course in Eastern Europe.
- **Winter School in collaboration with the European Paediatric Neurology Society (EPNS)**

The ERN-RND & EPNS Winter School is an opportunity for young neurologists/residents who are interested in rare neurological disorders to receive in-depth training from internationally-recognized rare neurological disease experts.

Students will attend overview lectures with question-and-answer sessions, as well as hands-on training. They will also be given the opportunity to present their own cases. The Winter School is free of charge for two participants per healthcare provider. Costs for accommodation or travel will be covered by ERN-RND.

The topic of the next Winter School will be 'Neurorehabilitation. It should take place at the end of January 2022 in Budapest. Up to date information can be found [here](#).

## Projects with ERN-RND involvement

### Solve-RD

There is currently no joint ERN infrastructure specifically targeting unsolved RD cases.

To tackle this issue, a core group of four ERNs (ERN EURO-NMD, ERN-GENTURIS, ERN-ITHACA and ERN-RND) have jointly set-up the Solve-RD project to form the basis for a joint diagnostic research infrastructure for unsolved RD cases.

Within Solve-RD, the ERNs will share phenotypic and genetic data of unsolved RD cases, based on patient consents and ethical approvals for working with Solve-RD.

For more information, please visit the Solve-RD website [here](#).

### The European Joint Programme on Rare Diseases (EJP RD)

The European Joint Programme on Rare Diseases (EJP RD) brings over 130 institutions from 35 countries to consolidate research, care and medical innovation on rare diseases in Europe and globally.

EJP RD's mission is to promote rare disease research and thus to enable effective access and use of rare disease information, research data and services to optimize exchange of knowledge between research and clinical practice. Further goals are to foster rapid scientific progress in the field of rare diseases (RD) through funding of collaborative research projects, to accelerate the translation of high potential projects as well as to improve outcomes of clinical studies. Ultimately and most importantly this project aims to decrease unnecessary hardship and prolonged suffering of RD patients.

The EJP RD brings together the resources at the national and European level involving research funders, universities, research organisations, research infrastructures, hospitals and patient organisations.

All 24 European Reference Networks are involved in the EJP RD with at least one healthcare provider per Network as official EJP RD partner.

Through them, the programme links with expert centres providing highly specialized care in more than 300 hospitals across Europe, thus ultimately enabling that rare diseases patients receive the highly specialized healthcare they need. In addition, EJP RD will provide training for ERNs on cross-cutting topics and EU-wide streamlined educational program on RD research to all interested stakeholders.

For more information, please visit the EJP RD website [here](#).

### European Brain Council (EBC) Value of Treatment project

In 2018, the European Brain Council (EBC) launched a second round of case studies "VoT 2" related to Rare Neurological Disorders (RNDs) focusing upon Ataxias, Dystonia and Phenylketonuria. Overall VoT2-RNDs research objective is to converge case study data analysis to policy recommendations on how to provide optimal care in the RNDs under study.

ERN-RND actively contributes to the case studies focusing on Ataxia and Dystonia.

### ERICA

The aim of the ERICA consortium, in which all 24 European Reference Networks (ERNs) take part, is to build on the strength of the individual ERNs and create a platform that integrates all ERNs research and innovation capacity.

Through knowledge sharing, engagement with stakeholders in the rare disease domain and assembly of transdisciplinary research groups working across the global health spectrum, ERICA strives to reach the following goals:

- new intra- and inter-ERN rare disease competitive networks;
- effective data collection strategies;
- better patient involvement;
- enhanced quality and impact of clinical trials;
- increased awareness of ERNs innovation potential.

ERICA will strengthen research and innovation capacity by the integration of ERN research activities, outreach to European research infrastructures to synergistically increase impact and



innovation. This will result in efficient access and safe therapies for the benefit of patients suffering from rare diseases and complex conditions.

## ERN-RND online dissemination tools

### Website

Information about ERN-RND can be found on the website: [www.ern-rnd.eu](http://www.ern-rnd.eu) which contains information on ERN-RND members and centres, CPMS and disease knowledge resources useful for clinicians and patients. It is important that this URL is shared with anyone interested or affected by a rare neurological disease in Europe so please feel free to forward it to your contacts. Please email [communicationERN-RND@med.uni-tuebingen.de](mailto:communicationERN-RND@med.uni-tuebingen.de) for any edits to the website.

### Social media

Twitter account: [ERN\\_RND](#)

Facebook account: [@ernrnde](#)

YouTube account: [ERN-RND](#)

LinkedIn account: [ERN-RND, European Reference for Rare Neurological Diseases](#)

Hashtag: **#ernRND**

### Newsletter

We send a monthly newsletter to keep you up to date with the latest ERN-RND activities. You can sign up to the newsletter [here](#).

## Acknowledgement to be used in ERN-RND publication and dissemination activities

| Acknowledgement  | Situation  |
|--|--|
| 1. " The two (or more) of the/several author(s) of this publication is/are (a) member(s) of the European Reference Network for Rare Neurological Diseases - Project ID No 739510." | A general option that members can use regardless of there being 2 or more HCPS involved. This gives attention to the existence of ERN without it acknowledging any direct input from it. |
| 2. "This work is generated within the European Reference Network for Rare Neurological Diseases - Project ID No 739510."   | An option that a partner can choose to add if the work has come into being by the work carried out by at least 2 or more ERN members working within the structure of the network.        |

|  |  |
|--|--|
| <p>3. "This study/project/publication/Guidelines/survey* has been supported by ERN-RND, which is partly co-funded by the European Union within the framework of the Third Health Programme "ERN-2016 - Framework Partnership Agreement 2017-2021."<br/>*choose appropriate wording</p> | <p>If funding is allocated to a publication/project/etc. This will eventually apply but it is not yet the case for the moment.</p> |
|--|--|

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