

# Table Of Content

<b>European Reference Network for Rare Neurological Diseases</b> .....	2
<b>Summary</b> .....	3
<b>Coordinator, Leader contact and partners</b> .....	4
<b>Outputs</b> .....	5

# European Reference Network for Rare Neurological Diseases

JA2015 - GPSD [705038]

START DATE: 06/03/2017

END DATE: 05/03/2022

DURATION: 60 month(s)

CURRENT STATUS: Finalised

PROGRAMME TITLE: 3rd Health Programme (2014-2020)

PROGRAMME PRIORITY: -

CALL: European Reference Networks

TOPIC: ERN-2016 - European Reference Networks – Framework Partnership Agreement

EC CONTRIBUTION: 0 EUR

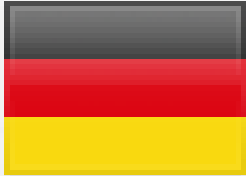
KEYWORDS: Coordination And Knowledge Transfer, Evidence-Based Management, Infrastructure For Diagnosis, Patient-Centred Network, Rare Neurological Diseases, Research And Collection Of Patient Data, Treatment, Treatment

PORTFOLIO: Rare diseases

## Project abstract

ERN-RND is a network of 32 Healthcare Providers from 13 EU member states. ERN-RND builds on existing expert centres and mature networks dedicated to rare neurological diseases (RND) as well as established rare disease infrastructures such as Orphanet, EURORDIS and RD-Connect. Through coordination and knowledge transfer, ERN-RND shall establish a patient-centred network to address the needs of patients with RND of all age groups, with or without a definite diagnosis, by implementing an infrastructure for diagnosis, evidence-based management, treatment and collection of patient data. The network will develop, disseminate, implement and supervise best practice guidelines and care pathways to optimize patient care and facilitate training and capacity building in the field. A special effort will be aimed to member states with less developed infrastructure for caring for RND patients, where no current partners are located, or with only affiliated or collaborative partners. ERN-RND will inform planning of European and national health care in RND, facilitating translation of research activities into clinical practice and the development of future therapies. ERN-RND's strategic objectives for the first five year period are: 1. To increase by at least 20% the overall percentage of RND patients with a final diagnosis; 2. To improve care of RND patients, reaching at least a 20% improvement in established outcome measures; 3. To develop, share and implement care pathways and guidelines for all RND groups represented in ERN-RND; 4. To create, develop and enhance constituents' capacity to design, implement and supervise RND training, education and capacity building measures so that health care providers (HCP) of all EU member states actively participate in ERN-RND in the future; 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.

## COORDINATOR



Universitaetsklinikum Tuebingen (UKT)

Geissweg 3  
72076 Tuebingen

Germany

WEBSITE: <http://www.med.uni-tuebingen.de>

## PARTNERS

No partners related to the current project

