

**CARE-RND 2023**  
19-20 SEPTEMBER 2023



**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

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

**Venue: Provinciehuis Leuven, Provincieplein 1**  
3010 Leuven, Belgium

**SEPTEMBER 19<sup>th</sup> – Day 1**

Zoom link → [https://us02web.zoom.us/webinar/register/WN\\_5j0tsG39RNG7fikpnEv7IA](https://us02web.zoom.us/webinar/register/WN_5j0tsG39RNG7fikpnEv7IA)

Time	Topic	Speaker
<i>10:30 Welcome coffee</i>		
11:00 – 11:05	Welcome	Holm Graessner, University Hospital Tübingen
11:05 – 11:30	Overview of ERN-RND	Holm Graessner, University Hospital Tübingen
11:30 – 12:00	Key Note: The VALOR-Trial – a breakthrough for SOD related ALS	Albert Ludolph, University Hospital Ulm
12:00 – 13:15	Patient journeys	Monika Benson, Dystonia Europe John Gerbild, Denmark Association for ataxia and HSP
13:15 – 13:30	EU login and CPMS account creation	Tamara Martin, ERN-RND coordination office
<i>Lunch (60 min)</i>		
<b>Diagnosis</b>		
14:30 – 15:00	Key note speaker Genetic diagnosis and technological advancements	Alex Hoischen, Nijmegen
15:00 – 15:30	External Quality Assessment for Next-Generation Sequencing Testing in RND	Ales Maver, Ljubljana
15:30 – 16:15	Genetic strategies of the future. Using the example of the Deep Intronic FGF14 GAA Repeat Expansion in Late-Onset Cerebellar Ataxia.	Stephan Zuchner, Miller School of Medicine, Miami
<i>Group photo and coffee break (45 min)</i>		
<b>Highly specialized treatments</b>		
17:00 – 17:30	Key note speaker DBS in dystonia	Sylvia Boesch, Medical University Innsbruck
17:30 – 17:50	Current practices regarding HSCT in metachromatic leukodystrophy in Europe and treatment eligibility panels	Nicole Wolf, Amsterdam UMC
17:50 – 18:10	Ups and downs of therapy development in HD	Bernhard Landwehrmeyer, University Hospital Ulm
18:10 – 18:30	ERN-RND Registry	Ludger Schöls, University Hospital Tübingen
18:30 – 19:15	Drinks “Meet the ePAGs”	
<i>19:30 Dinner <b>Brasserie ‘t Oud Gasthuys</b> (Brusselsestraat 63B, 3000 Leuven)</i>		

**SEPTEMBER 20<sup>th</sup> – Day 2**

<b>Time</b>	<b>Topic</b>	<b>Speaker</b>
<b>ERN-RND internal call projects</b>		
08:00 – 08:30	Flash talks of all funded projects: Development of a MSA clinical deficits scale (Ludwig Maximilian University Hospital, Munich, Germany); Development of CPMS neuroradiology expert advice for diagnostic and management decisions to optimize care in patients with RND (University Hospital Schleswig-Holstein, Lübeck, Germany); Development of an ICF core set based consensus rehabilitation guideline for people with pure HSP (Radboud University Medical Centre, Nijmegen, Netherlands); Development and validation of an optimized clinical Ataxia scale (University Hospital Bonn, Germany); Validating the modified Spastic Paraplegia Rating Scale and establishing minimal important change (Heidelberg University Hospital, Heidelberg, Germany); Towards a European PROM-ADL instrument (Heidelberg University Hospital, Heidelberg, Germany); Towards validated assessment tools for HD and Chorea-syndromes in Europe (University Hospital Ulm, Germany)	
<b>Disease groups parallel session</b>		
08:30 – 10:00	3 DG/WG in parallel: Ataxia/HSP; Leukodystrophies; HD and Chorea-s	Link to individual agendas: <a href="https://is.gd/la91kj">https://is.gd/la91kj</a>
<i>Coffee break (30 min)</i>		
10:30 – 12:00	4 DG/WG in parallel: Dystonia, paroxysmal disorders and NBIA; Atypical parkinsonian syndromes; FTD; Pediatric issues	Link to individual agendas: <a href="https://is.gd/la91kj">https://is.gd/la91kj</a>
<i>Lunch (60 min)</i>		
<b>DG and WG wrap-up on last years activities and new developments</b>		
13:00 – 13:20	Dystonia, NBIA and paroxysmal disorders	Sylvia Boesch, Medical University Innsbruck
13:20 – 13:40	Ataxia and HSP	t.b.c.
13:40 – 14:00	FTD	Rik Vandenberghe, University Hospital Leuven
14:00 – 14:20	Leukodystrophies	t.b.c.
14:20 – 14:40	Chorea-s and Huntington disease	t.b.c.
14:40 – 15:00	Pediatric Issues	t.b.c.
15:00 – 15:20	Atypical parkinsonian syndromes	Alessandra Fanciulli, Medical University Innsbruck
15:20 – 15:40	Wrap-up	Holm Graessner, University Hospital Tübingen
<i>Coffee break (30 min)</i>		
16:10 – 17:10	<b>Board Meeting</b>	Holm Graessner, University Hospital Tübingen Link to agenda: <a href="https://is.gd/la91kj">https://is.gd/la91kj</a>
<i>End of the event</i>		