

**ERN-RND ANNUAL MEETING ON
SEPTEMBER 29th – OCTOBER 1st 2022**



Venue: Crona Kliniken, room HS 210, Hoppe-Seyler-Str. 3 · 72076 Tübingen (Bus stop Uni-Kliniken Berg)
WLAN "ukt-guest": Username: guest-7177447 · Password: AsXuGH-7667

SEPTEMBER 29th – Day 1

Time	Topic	Speaker	Zoom link
	Scientific symposium <i>N-of-1 Treatments and trials in neurology</i>		
14:00 – 14:20	Welcome coffee, registration		
14:20 – 14:30	Welcome and introduction	Holm Graessner, University Hospital Tübingen	https://us02web.zoom.us/j/88087004693
14:30 – 15:00	n-of-1 trials in Neurology	Bas Stunnenberg, Rijnstate Hospital	
15:00 – 15:30	n-of-1 trials and treatments – study design	Franz König, Martin Posch, Medical University Vienna	
15:30 – 16:00	n-of-1 regulatory issues in Europe	Martina C. Cornel, Amsterdam University Medical Centre	
<i>Coffee break (30 min)</i>			
16:30 – 17:00	n-of-1 drug repurposing	Holger Lerche, University Hospital Tübingen	
17:00 – 17:30	Mutation specific development of ASO for RND	Willeke van Roon-Mom, Leiden University Medical Centre Rebecca Schüle, University Hospital Heidelberg	
17:30 – 18:00	Outcome development for n-of-1 trials and treatments	Matthis Synofzik, University Hospital Tübingen	
18:00 – 18:30	1 Mutation 1 Medicine Network	Holm Graessner, University Hospital Tübingen	

SEPTEMBER 30th – Day 2

Time	Topic	Speaker/moderator	Zoom link	
08:00 – 09:00	Informal breakfast with the ePAG			
09:00 – 09:10	Welcome, agenda, housekeeping			
European Reference Networks – Stakeholders’ Perspectives				
09:10 – 09:30	Why are ERNs important for Europe? Main recent development and challenges for ERNs including the European Health Data Space	Martin Dorazil, European Commission	https://zoom.us/j/99189577623?pwd=ZHpUalRxRVkwMk1Cam9LRzZFKzhKdz09	
09:30 – 09:40	The patients’ expectations	Astri Arnesen (ePAG)		
09:40 – 09:50	“The NEW ERN-RND”: setting the scene	Holm Graessner, University Hospital Tübingen		
<i>Group photo and coffee break (30 min)</i>				
Achievements in the first five years of ERN-RND				
Cross-cutting activities				
10:20 – 10:30	ERN-RND Registry	Ludger Schöls, University Hospital Tübingen	https://zoom.us/j/99189577623?pwd=ZHpUalRxRVkwMk1Cam9LRzZFKzhKdz09	
10:30 – 10:40	External Quality Assessment for Next Generation Sequencing testing for RND diagnosis	Ales Maver, Ljubljana University Medical Centre		
10:40 – 10:50	Training and education	Sanja Hermanns, University Hospital Tübingen		
10:50 – 11:00	Patient Journeys	Natalia Grigorova (ePAG)		
11:00 – 11:10	Clinical Patient Management System (CPMS)	Tamara Martin, University Hospital Tübingen		
11:10 – 11:20	Transition	Caterina Mariotti, Neurology Institute Carlo Besta Milan		
Disease Group Activities				
11:20 – 11:30	DG Ataxia and HSP	DG coordinator		
11:30 – 11:40	DG Frontotemporal Dementia	DG coordinator		
11:40 – 11:50	DG Atypical Parkinsonian Syndromes	DG coordinator		
11:50 – 12:00	DG Choreas and Huntington’s diseases	DG coordinator		
12:00 – 12:10	DG Dystonias, Paroxysmal Disorders and NBIA	DG coordinator		
12:10 – 12:20	DG Leukodystrophies	DG coordinator		
Conclusion of first five years				
12:20 – 12:30	Note of thanks	Holm Graessner, University Hospital Tübingen		
<i>Lunch break (60 min)</i>				
Working meetings				
13:30 – 15:00	DG Ataxia and HSP	DG coordinator	https://zoom.us/j/99189577623?pwd=ZHpUalRxRVkwMk1Cam9LRzZFKzhKdz09	

	DG Frontotemporal Dementia (room B4-220)	DG coordinator	https://zoom.us/j/91352208285?pwd=ei94MmUyQUwyOE8zbFNWK3pLZytXQT09
15:00 – 16:30	DG Dystonias, Paroxysmal Disorders and NBIA	DG coordinator	https://zoom.us/j/99189577623?pwd=ZHpUalRxRVkwMk1Cam9LRzZFKzhKdz09
	DG Chorea and Huntington's Disease (room B4-220)	DG coordinator	https://zoom.us/j/91352208285?pwd=ei94MmUyQUwyOE8zbFNWK3pLZytXQT09
<i>Coffee break (30 min)</i>			
Time	Topic	Speaker/moderator	Zoom link
Future and strategically important topics			https://zoom.us/j/99189577623?pwd=ZHpUalRxRVkwMk1Cam9LRzZFKzhKdz09
17:00 – 17:10	RD Partnership	Hélène Le Borgne, European Commission	
17:10 – 17:20	ERICA	Alberto Pereira, Amsterdam University Medical Center	
17:20 – 17:30	Key performance indicators	Franz Schäfer, University Hospital Heidelberg	
17:30 – 17:40	New CPMS	Tamara Martin, University Hospital Tübingen	
17:40 – 18:00	CPMS registration	Tamara Martin, University Hospital Tübingen	
<i>Dinner in Waldhäuser Hof (Waldhausen 9, 72076 Tübingen)</i>			

OCTOBER 1st – Day 3

Time	Topic	Speaker/moderator	Zoom link
	Working meetings		
08:30 – 10:00	DG Atypical Parkinsonian Syndromes	DG coordinator	https://zoom.us/j/95184820562?pwd=TkVB TINNb3hvZGt5ZWITZ05XL1NoQT09
	DG Leukodystrophies (room B4-220)	DG coordinator	https://zoom.us/j/92171754198?pwd=TGFk Q3FYSWNoWWo2Zys3SzZiTERPUT09
<i>Coffee break (30 min)</i>			
10:30 – 12:00	WG Neurorehabilitation	WG coordinator	https://zoom.us/j/95184820562?pwd=TkVB TINNb3hvZGt5ZWITZ05XL1NoQT09
12:00 – 12:10	Wrap-up	Holm Graessner, University Hospital Tübingen	https://zoom.us/j/95184820562?pwd=TkVB TINNb3hvZGt5ZWITZ05XL1NoQT09
12:15 – 13:00	Board Meeting	Holm Graessner, University Hospital Tübingen	https://zoom.us/j/98658086320?pwd=R25 QSZBuV0kvbktjNWN5ME5lOXF4UT09