



**Euro-ataxia Annual Conference and Global Patient Group Meeting Programme**  
Leonardo Royal London Hotel Tower Bridge - Minorities Suite

Day 1 – Friday 15 <sup>th</sup> November		
Time	Session	Speaker
13:00-14:15pm	Lunch in the hotel restaurant	
14:15	Welcome from Euro-ataxia President	Andreas Nadke, President of Euro-ataxia, DHAG
14:20	<p><b>Flash talks from junior researchers attending ICAR</b> (Chairs: Thiago Rezende and Magda Santana)</p> <ul style="list-style-type: none"> <li>-Louisa Selvadurai ‘Further Development and Validation of the Cerebellar Neuropsychiatric Rating Scale (CNRS)©’</li> <li>-Mónica Ferreira “Brain changes over time in SCA3: Their role in treatment and therapy development”</li> <li>-Amy Hulme “Investigating the mechanosensory neurons in Friedreich’s ataxia using stem cell models”</li> <li>-Daiana Machado “Diagnosis journey of Brazilian Friedreich’s Ataxia patients”</li> <li>-Uffaf Khan “Pleozymes: a novel, pleiotropic nanozyme for targeting metabolic deficits in ataxias”</li> </ul>	
14:50 15:10	<p><b>Updates on recent clinical trials:</b> Session Chair: Julie Greenfield (Ataxia UK)</p> <p>Vatiquinone trial in Friedreich's ataxia Troriluzole programme for Spinocerebellar ataxias</p>	<p>Prof Alexandra Durr and Ms Elodie Petit (Sorbonne University Paris, France) Dr Melissa Beiner (Biohaven Pharmaceuticals)</p>
15:30 15:45	<p><b>Current challenges in ataxia trials and drug regulatory approvals</b></p> <p>The challenges of assessing ataxia progression, and consequences for clinical trials and regulatory approvals</p> <p><b>Panel discussion</b> focusing on outcome measures in ataxia trials and experience with regulator interactions – Chair: Julie Greenfield, Ataxia UK</p>	<p>Dr Christian Rummey (Clinical data science GmbH)</p> <p>Panel: Dr Melissa Beiner (Biohaven Pharmaceuticals), Dr Christian Rummey (Clinical data science GmbH), Dr Jon Cherry (PTC pharmaceuticals)</p>
16:30	Break	
16:45	<p>Session Chair: Vassilis Karatzias (Hellenic Friedreich’s ataxia association, Euro-ataxia Board member)</p> <p>Where is ataxia research headed and highlights from ICAR 2024</p>	Prof Massimo Pandolfo (McGill University, Canada)
17:15	The value of Specialist Ataxia Centres	Prof Paola Giunti (London Ataxia Centre UCL/UCLH)

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17:45	Advances in gene therapy	Dr Luis Pereira Almeida (University of Coimbra, Portugal)
18:15	Finish	
19:30-21:30	Dinner	Venue tbc
<b>Day 2 – Saturday 16<sup>th</sup> November</b>		
9:00	Welcome	Andreas Nadke, President of Euro-ataxia
	Session Chair: Julie Greenfield	
9:05	<b>Patient Group presentations</b> (new projects and sharing best practice) - Mary Hogan, SCA27B Ataxia Foundation -Sue Millman, Ataxia UK -John Gerbild, Denmark Association for Ataxia and HSP -Lauren Moore, National Ataxia Foundation -Susie Norbury, AT Society -Arsho Rad, Ataxia Foundation-Sweden	
11:00	Break	
11:30	FA Global Clinical Consortium	Myriam Rai, FARA
12:00	Brain Mouv’: A new physiotherapy app for people with ataxia	Iris Marolleau, Neurologie’K, France
12:30	Lunch in the restaurant	
	Session Chair: Andreas Nadke	
13:30	Living with Inherited Ataxias: Illness perceptions, illness uncertainty, coping and psychological adjustment	Mary Kearney, Research Fellow at the National Ataxia Programme, Tallaght University Hospital
13:50	Patient Advocate Involvement in ERN-RND	John Gerbild, Denmark Association for Ataxia and HSP
14:10	Final Remarks	Andres Nadke and Sue Millman
14:20	End of Euro-ataxia Conference Programme	
14:20-14:30	Refreshments Break	
14:30	Networking Session for Global Patient Groups	Facilitator: Sue Millman
15:30	Euro-ataxia AGM	Euro-ataxia Board Members only

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