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Euro-ataxia 2023 European Research Conference on Ataxia  
in cooperation with the  
Hellenic Friedreich's Ataxia Association  
(19 - 21 May 2023-03-23, Pieria, Greece)

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## Programme

All times are Eastern European Summer Time

Saturday 20<sup>th</sup> May: Ataxia international research meeting

**Session chair: Vassilis Karatzias (Hellenic Friedreich's Ataxia Association)**

**9:30 – 9:40** 'Welcome' - Andreas Nadke and Sue Millman (Euro-ataxia President and Secretary), Vassilis Karatzias (Hellenic Friedreich's Ataxia Association)

**9:40 – 10:00** 'Overview of inherited and non-inherited ataxias – advances in diagnosis and treatment' - Professor Marios Hadjivassiliou (Sheffield Ataxia Clinic)

**10:00 – 10:20** 'The importance of natural history and biomarker studies in the ataxias – Using data from the European Friedreich's ataxia study (EFACTS)' – Dr Jörg Schulz (Aachen University Hospital)

**10:20 – 10:30** 'The FA Pipeline' – Dr Myriam Rai (US FARA)

**10:30 – 10:50** 'The potential value of transcranial stimulation for symptom relief in ataxias' – Dr Barbara Borroni (University of Brescia)

**10:50 – 11:40 COFFEE BREAK**

**Session chair: Andreas Nadke (Euro-ataxia President)**

**11:40 – 12:00** 'Biomarkers in the SCAs' – Professor Paola Giunti (University College London, National Hospital of Neurology and Neurosurgery (NHNN) ataxia centre)

**12:00 – 12:20** 'Using animal and cell models to test treatments for ataxias - Update on TREAT-ARCA project' - Dr Helene Puccio (Inserm, Lyon)

**12:20 – 12:40** 'End of life discussions with patients affected by neurogenetic diseases and their caregivers: DIRAGENE study' – Dr Claire Ewencyk (ICM Institute, Paris)

**12:40 – 13:45 NETWORKING LUNCH**

**Session chair: Emily Cutting (Ataxia UK)**

**13:45 – 14:30** Engaging with junior ataxia researchers - flash talks (5 mins each)



- ‘Bench to bed: A story of a novel compound’ - Dr Rosella Abeti (University College London)
- ‘Nanobodies to combat Machado Joseph Disease’ - Dr Ana Claro (i3S, Portugal)
- ‘Cerebellar ataxia and fear extinction’ - Enzo Nio (University Hospital Essen)
- ‘Exploring DNA damage and repair in SCA1’ – Dr Celeste Suart (National Ataxia Foundation)
- Two speakers TBC

**Session chair: Sue Millman (Euro-ataxia Secretary)**

**14:30 – 15:00** Hearing the views of people with ataxia to inform research

**15:00 - 15:20** ‘Management of the ataxia - Speech therapy’ - Professor Anja Lowit (University of Strathclyde)

**15:20 – 15:40** ‘Physiotherapy and exercises for the ataxias – perspective from Greece’  
Marianna Kotzamanidou

**15:40 – 16:00 BREAK**

**Session chair: Hellenic Friedreich’s Ataxia Association**

**16:00 – 17:00** Round Table on Friedreich’s Ataxia Current Status in Greece (Clinical Centres, Treatment Options, Registry)

*Tsigoulis Georgios, Professor in Neurology, National & Kapodistrian University of Athens, President of the Hellenic Neurologic Society,*

*Kimiskidis Vasileios, Professor in Neurology, AHEPA University Hospital Thessaloniki,*

*Zafeiriou Dimitrios, Professor in Pediatric Neurology, Ipokrateio University Hospital Thessaloniki,*

*Koutsis Georgios, Assistant Professor of Neurology and Neurogenetics, Eginition Hospital, National & Kapodistrian University of Athens,*

*Dinopoulos Argyris, Associate Professor in Pediatric Neurology, “Attiko Hospital”, National & Kapodistrian University of Athens,*

*Georgia Xiromerisiou, Associate Professor of Neurology, University of Thessaly, Medical School,*

*Karadima Georgia, Assistant Professor in Biology and Neurogenetics, 1st Department of Neurology, Eginition Hospital, National & Kapodistrian University of Athens*

**Session chairs: Sue Millman (Euro-ataxia Secretary, Ataxia UK), Myriam Rai (US FARA)**

**17:00 – 18:00** Updates from pharmaceutical companies with ataxia clinical programmes

17:00 – 17:20 PTC Therapeutics - TBC

17:20 – 17:40 Anne Neumann, Biohaven

17:40 – 18:00 Chantal Beekman, Vico Therapeutics

**18:00 – 18:15** CLOSING REMARKS AND DISCUSSION

**19:00 DINNER FOR ALL ATTENDEES – SPONSORED BY PTC THERAPEUTICS**



This Networking event has received funding from the European Union’s Horizon 2020 research and innovation programme under the EJP RD COFUND-EJP No 825575

## Sunday 21<sup>st</sup> May – Euro-ataxia and partners meeting

**9:00 – 10:00** *Presentations from member groups and partners on new activities*

- *Ataxia UK*
- *National Ataxia Foundation (NAF)*
- *AFAF (l'Association Française de l'Ataxie de Friedreich)*

**10:00 – 10:30** *Spotlight on other Euro-ataxia members*

**10:30 – 10:45** *'ERN-RND – How Euro-ataxia patient groups can collaborate and interact with this network' – Dr Holm Graessner (online)*

**10:45 – 11:10** *Break*

**11:10 – 11:40** *Discussion of potential Euro-ataxia future activities: Campaigns*

*Gathering FA prevalence data across Europe  
Future Euro-ataxia projects – obtaining funding*

**11:40 – 11:45** *Closing remarks – Andreas Nadke (Euro-ataxia President)*

**11:45 CONFERENCE END**

**11:45 – 12:30** *Euro-ataxia AGM (for members only)*



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