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## **Global Ataxia Advocacy Organizations Unite to Host Largest International Congress for Ataxia Research in London**

**LONDON, UK – November 12, 2024** – Today marks the opening of the largest-ever scientific conference on ataxia research — the International Congress for Ataxia Research (ICAR) is welcoming a record-setting 600 attendees. The London-based conference runs through to November 15 and will be a comprehensive scientific review of new research into the ataxias, covering topics from advances in genetics and disease mechanisms to therapeutics approaches, as well as a debate on emerging ataxia research topics. ICAR represents a strong collaboration between global advocacy organizations focused on advancing research for ataxia, including co-hosts Ataxia UK, Friedreich’s Ataxia Research Alliance (FARA), National Ataxia Foundation (NAF), and Ataxia Global Initiative (AGI).

The conference will cover the latest research on Friedreich’s ataxia (FA) and other recessive ataxias, Spinocerebellar ataxia (SCA), and other dominant ataxias and autoimmune ataxias. It will include plenary sessions, parallel sessions, workshops, and poster sessions. This year’s keynote speaker, Dr. Walter Koroshetz, Director of the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health, will present on the NINDS Research Investment in Ataxia.

“Ataxia UK is very excited by the response from the global ataxia research community to this conference,” said Ataxia UK CEO Sue Millman, “The attendance demonstrates increased research interest in the ataxias and the progress that has been made towards treatments through the work of committed scientists. The contributions and exchanges at previous conferences have led to the development of many new, innovative partnerships. The conference also offers the opportunity for researchers to meet patients and patient group representatives to better understand the importance of their work to people who are meeting the challenges of these devastating rare conditions.”

The more than 600 attendees will be coming from 32 countries and consist of academic, clinical, and industry researchers with an interest in ataxia research and drug development, as well as representatives from 12 global ataxia advocacy groups. Academic researchers will make up around two-thirds of the attendees, and industry representatives comprise about 20% of attendees.

FARA CEO Jennifer Farmer said, “We are grateful for the opportunity to collaborate again with our partners at Ataxia UK, NAF, and AGI to cohost ICAR. As advocacy research organizations in the rare disease community, we have limited resources, and this type of collaboration allows us to be more efficient, reach a wider audience, and promote collaborations within the ataxia research community. In 1999, FARA hosted its first scientific meeting on FA, which consisted of 65 academic investigators from around the world and 15 National Institutes of Health scientists. ICAR 2024 represents not only the significant growth in the ataxia research field but also meaningful advances in research.”

NAF CEO Andrew Rosen added, “We are proud to collaborate with our global partners to showcase groundbreaking advancements in ataxia research at ICAR. Our collective commitment to drive scientific discovery and accelerate the development of effective treatments for ataxia brings hope to the families affected by this challenging disease.”

Matthis Synofzik, chair of the Ataxia Global Initiative (AGI), highlighted: “We are in exciting times where ataxias are now moving from diagnosis and genes to targeted precision therapies. The upcoming decade might become a breakthrough decade for a series of pioneering disease-modifying therapies for ataxias. To set this stage, and thus facilitate trial-readiness on all levels, is the main overarching mission implemented by the worldwide multi-stakeholder ataxia trial-readiness network Ataxia Global Initiative. The ICAR 2024 will set yet another milestone on this stringent path towards treatments.”

Key plenary talks will cover advances in genetics and diagnostics, cerebellar neurodevelopment and cognitive disorders, emerging and existing therapeutics, and the voice of people affected by ataxia.

To learn more, please visit [ataxiacongress.org](https://ataxiacongress.org).

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### **About Ataxia UK**

Ataxia UK is the leading national charity in the UK for people affected by any type of ataxia. They fund research into finding treatments and cures, and offer advice, information and support to people affected by the condition. For more information about Ataxia UK, visit [ataxia.org.uk](https://ataxia.org.uk)

**About Friedreich's Ataxia Research Alliance**

The Friedreich's Ataxia Research Alliance (FARA) is a national nonprofit organization dedicated to curing Friedreich's ataxia (FA) through research. FARA grants and activities provide support for basic and translational FA research, pharmaceutical/biotech drug development, clinical trials, and scientific conferences. FARA also serves as a catalyst, between the public and scientific community, to create worldwide exchanges of information that drive medical advances. For more information about FARA, visit [curefa.org](http://curefa.org).

**About National Ataxia Foundation**

The National Ataxia Foundation (NAF) was established in 1957 to help persons with Ataxia and their families. Their mission is to accelerate the development of treatments and a cure while working to improve the lives of those living with Ataxia. NAF's vision of a world without Ataxia will be accomplished through their primary programs of funding Ataxia research, providing vital programs and services for Ataxia families, and partnering with pharmaceutical companies in the search for treatments and a cure. They work closely with the world's leading Ataxia researchers and clinicians, promoting exchanges of ideas and innovation in Ataxia discovery. For more information about NAF, visit [ataxia.org](http://ataxia.org).

**About Ataxia Global Initiative**

The Ataxia Global Initiative (AGI) is a worldwide public-private partnership that has the goal to facilitate the clinical development of therapies for ataxias. For more information about AGI, visit [ataxia-global-initiative.net](http://ataxia-global-initiative.net).