



## **PRESS RELEASE**

### Ataxias: International Award for Bonn Patient Care and Research

US Foundation Distinguishes University Hospital Bonn and DZNE

Bonn/Germany, June 26, 2023 – The Ataxia Center at the University Hospital Bonn (UKB) and DZNE have been awarded the title "Ataxia Center of Excellence" by the US National Ataxia Foundation (NAF) for their patient care and research – as the only organization in Europe. The foundation represents patient interests and is one of the world's major non-governmental funders of ataxia research. These rare brain diseases are characterized by progressive loss of balance and coordination, accompanied by slurred speech. It is estimated that this condition affects around 16,000 women and men in Germany.

The NAF awarded the title "Ataxia Center of Excellence" to 19 hospitals and institutes worldwide. The quality of patient care and clinical research were evaluated. Only four organizations are located outside the United States. The tandem of UKB and DZNE is the only honored institution in Europe. "This is a great recognition for the work of our entire team," says Dr. Jennifer Faber, deputy director of the Ataxia Center at UKB and research associate at DZNE. "With outpatient and inpatient treatment as well as interdisciplinary conferences, we offer a comprehensive range of services specifically for patients with ataxias. The close interaction of patient care and research at our site is exceptional and outstanding."

#### Care and Research

For years, Bonn has been a recommended center for the care of people with ataxias and a driving force in ataxia research. More than 250 patients attend the Ataxia Center of the UKB every year. Often, their health development is followed by the Bonn experts for years. In addition, the team led by Prof. Thomas Klockgether – who is also Director of Clinical Research at DZNE and Director of the Department of Neurology at UKB – is running various clinical observational and interventional studies. A European network for research in hereditary ataxias is coordinated from Bonn. More than 150 of the patients participate in study visits at DZNE each year, and thus supporting research in the field of theses rare diseases.

## **Science and Perspectives**

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Up to now, there is no cure for ataxias. All ataxia show amongst other neurodegeneration pathological alterations and consecutive dysfunction of the cerebellum. As a result, power and metric of movements is impaired. Common symptoms are gait disturbances, impaired balance and slurred speech. Physiotherapy has a positive effect on symptoms – but it is only a symptomatic treatment and does not address the causes. However, Thomas Klockgether has hopes that it might be possible to tackle at least some forms of ataxia at their roots. "The pharmaceutical industry has developed experimental compounds that target disease-relevant genes. We are in talks with the manufacturers to participate in testing these substances. Such trials require large and well-characterized groups of patients. We have built up such study cohorts over many years. For pharmaceutical companies, this qualifies us a scientific partner," Klockgether says.

One focus of ataxia research in Bonn is to investigate pathological changes in the cerebellum occurring early in the course of the disease by using magnetic resonance imaging. "As part of our research, we identify structural alterations in the cerebellum that are measurable long before the onset of symptoms, such as gait disturbances," explains Jennifer Faber. "If effective gene therapies become available in the future, such findings will allow interventions even before the onset of symptoms. We hope that such early treatments have the potential to, if not prevent, at least delay the onset of ataxia."

### More Information

https://www.ataxia.org/ACE https://neurologie.uni-bonn.de/schwerpunkte/ataxien (German) https://www.dzne.de/en/news/background/ataxia/

#### Visuals:









## Caption:

## **US Foundation Distinguishes University Hospital Bonn and DZNE:**

Dr. Jennifer Faber (Image above) and Prof. Thomas Klockgether

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About the University Hospital Bonn: The UKB cares for about 500,000 patients per year, employs 9,000 people and has a balance sheet total of 1.6 billion euros. In addition to the more than 3,300 medical and dental students, a further 585 people are trained each year in numerous healthcare professions. The UKB is ranked number one among university hospitals in NRW in the science ranking as well as in the Focus clinic list and has the third highest case mix index (case severity index) in Germany.

# About the Deutsches Zentrum für Neurodegenerative Erkrankungen, DZNE (German Center for Neurodegenerative Diseases):

The DZNE is a research institute funded by the German federal and state governments, comprising ten sites across Germany. It is dedicated to diseases of the brain and nervous system, such as Alzheimer's, Parkinson's, and ALS, which are associated with dementia, movement disorders and other serious health impairments. To date, there are no cures for these diseases, which represent an enormus burden for countless affected individuals, their families, and the healthcare system. The aim of DZNE is to develop novel strategies for prevention, diagnosis, care, as well as treatment, and to transfer them into practice. To this end, DZNE cooperates with universities, university hospitals, research centers and other institutions in Germany and abroad. The institute is a member of the Helmholtz Association and belongs to the German Centers for Health Research. www.dzne.de/en