

Press Release

Thessaloniki, April 4, 2022

**Hopes for a cure for the rare neurodegenerative disease
Friedreich's Ataxia**

**1st International Conference
of the Hellenic Association for Friedreich's Ataxia
May 6, 2022
Athens, Amphitheater of the Pasteur Institute
Online: www.hefaa.org/live**

11:00 – 19:30 (EEST)

The new hopes for a meaningful treatment of the serious neurodegenerative disease of Friedreich Ataxia, will be presented at the 1st Panhellenic Conference, organized by the Hellenic Association for Friedreich Ataxia, on Friday, May 6, 2022. The Conference will be held hybrid from 11: 00 to 19:30 with a physical presence at the Amphitheater of the Hellenic Pasteur Institute in Athens, while it will be broadcasted online from the website of the Association at the link www.hefaa.org/live.

The purpose of the Conference is to present the scientific research and clinical trials conducted worldwide, to highlight the severity of the disease, its rarity, and the urgent need to find appropriate treatment.

Distinguished scientists from Greece and abroad working in innovative therapies, pharmaceutical companies, and related institutions, along with patients considered as role models who inspire our suffering fellow human beings, are present in this effort, supporting the struggle to find a cure and unhindered access to it.

Friedreich's Ataxia is a rare, inherited, neurodegenerative disease characterized by "ataxia" (lack of order and coordination), muscle atrophy mainly of the lower extremities, instability, scoliosis, dysarthria, and fatigue. The disease affects about one (1) in 50,000 people, while in Greece it is estimated that the patients amount to 100 people. The disease is progressively worsening and so far, there is no cure. Within ten years from the onset of the disease, the patient loses the ability to move autonomously, needs support and wheelchair, progressively becomes paralyzed, his nervous system collapses, he loses the ability to see and speak.

The Hellenic Association for Friedrich Ataxia was founded in 2020 in Thessaloniki by parents and patients suffering from this rare neuro-paralytic disease. The Association is the first and only one in Greece for this disease and as a result it has

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undertaken to fully assist patients and their families, cooperate with international organizations, to find treatment and alleviate symptoms and raise society and the State awareness, for legal framework establishment, medical expenses coverage of patients and related special centers organized. The main goal of the Association is the unhindered access of all patients to effective innovative treatments, aimed at the cure and final elimination of this serious disease.

Detailed program of the Conference is available at the link:

For more information please follow: www.hefaa.org/live

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