

# Challenges on accessibility to innovative treatments for FA for EU patients

(The Greek OMAV experience – Challenges – Way ahead)

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Rare Diseases Greece, President  
EuroAtaxia, Board Member,  
European Patient's Forum, Ethics Committee  
ERDERA Ethics Committee

# HEFAA Strategic Framework

**"Together\_for\_a\_cure 2024\_2025"**

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- ① **Strategic Action 1** | Support the mobility of patients with Friedreich's Ataxia for registry enrollment and clinical follow-up within Greece
- ② **Strategic Action 2** | Study of unmet needs and outcome measures for Greek patients receiving treatment with OMAVELOXELONE
- ③ **Strategic Action 3** | Raising public awareness
- ④ **Strategic action 4** | Omap access to Greek Patients

## OMAV access to Greek Patients

- National Institute for Farmaceutical Innovation role
- More than 80% of Greek patients on OMAV. 50% for more than a year
- Separate budget for securing access following negotiations with a local licensee of Biogen in southern eastern Europe.
- HTA and effectiveness assessment constantly, every 6 months
- Need for negotiations on the price and for reimbursement mechanism. The need of 2-3 EU countries.



HEFAA Board meeting with the Greek Minister of Health, January 2024

# Clinical Centers for Patients with Friedreich's Ataxia in Greece



EUROPEAN FRIEDREICH'S ATAXIA  
CONSORTIUM FOR TRANSLATIONAL STUDIES

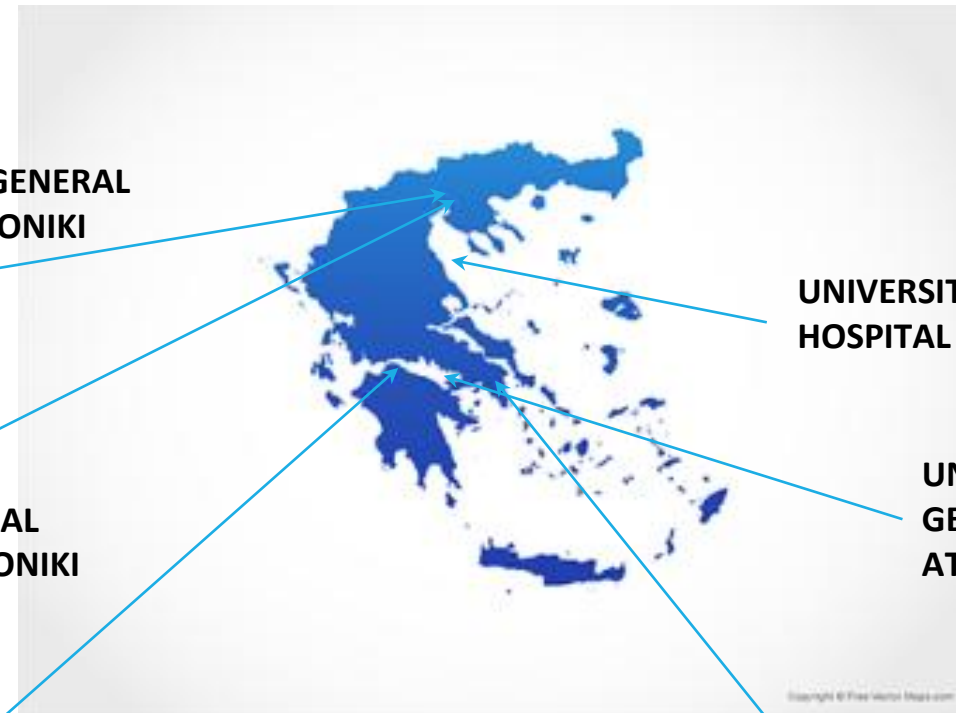


Global clinical trials horizon for FA

AHEPA | UNIVERSITY GENERAL  
HOSPITAL OF THESSALONIKI

HIPPOKRATIO | GENERAL  
HOSPITAL OF THESSALONIKI

UNIVERSITY  
GENERAL  
HOSPITAL OF  
PATRAS



UNIVERSITY GENERAL  
HOSPITAL OF LARISSA

UNIVERSITY  
GENERAL HOSPITAL  
ATTIKON

AIGINITIO HOSPITAL



## HEFAA Projects

- **Contribution to the development of the aquatic therapy guidebook** : HEFAA collaborate on developing a **comprehensive guide** outlining the methods, results, and ways of treating ataxia patients with **aquatic therapy**.
- **Contribution to the development of FA trainings**: We participate in the development and execution of the webinars for FA patients and for healthcare professionals in Greece in cooperation with medical societies and associations. Additionally, we participate in the development of an **individual education plan for FA minors**.
- **Communication activities** to increase reach and maximise the impact, by raising awareness.
- Research and Development for FA in Greece (three grant submissions pending)



# Ataxia Aquatherapy

**Round: Erasmus + Small Scale Partnerships**

**Partners:**

HEFAA

Cyprus Institute of Neurology and Genetics,  
Dr. Mariana Kotzamanidou,  
Pr. Vasileios Panoutsakopoulos

## Project activities

- Develop a **comprehensive guide** outlining the methods, results, and ways of treating ataxia patients with **aquatic therapy**.
- Organization of two **educational seminars** for the two countries involved and all interested EU countries.
- Development of a **website for the project results** presentation

## Outcomes

- Improving the **care and rehabilitation** that patients receive in the two participating countries but also in the EU by providing new and innovative ways to manage their condition through aquatic therapy interventions.



## RESEARCH PROPOSAL FOR THE INNOVATIVE RESEARCH PROGRAM 2024

Title: Targeting Friedreich's Ataxia with gene and non-gene therapy methods  
Intervention II: Business Partnerships with Research Organizations

### Corporate - Research Consortium

- General Hospital of Thessaloniki "G. Papanikolaou"
- Medical School, Aristotle University of Thessaloniki
- Department of Biology, Aristotle University of Thessaloniki
- IIBEAA - Institute of Biomedical Research, Academy of Athens
- Hellenic Association for Friedreich's Ataxia
- Pharmaceutical Company





## Support of a University Spin off

**Title:** Repurposing drug , Therapeutic reactivation of the developmental mechanism in FRDA patients, via daily injections of synthetic ligand

## Corporate - Research Consortium

- University Biotech Start Up
- Department of Biology, Aristotle University of Thessaloniki
- Hellenic Association for Friedreich's Ataxia
- University of Miami
- Pharmaceutical Company
- Angel Investors

# Save the Date: FA Patients Workshop, May 2026 Athens





[www.hefaa.org](http://www.hefaa.org)



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