



**EURO-ATAXIA
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30th August 2024**

Euro-ataxia Annual Report 2024

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 30 August 2024. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019). The Trustees can confirm that the activities of Euro-ataxia are lawful.

Objectives and Activities

The objects of Euro-ataxia are “to relieve those persons affected by ataxia”.

Euro-ataxia is an international association whose member organisations work together to give people with ataxia as normal a life as possible. We do this by building a strong organisation that represents people with hereditary ataxia throughout Europe.

Public Benefit

In compliance with the Charities Act 2011 the trustees of Euro-ataxia have adopted the following statement on Public Benefit:

Euro-ataxia is an inclusive organisation which promotes the wellbeing of all of those affected by ataxia across Europe. We do this by

- Driving forward research and treatment of the ataxias.
- Encouraging the free flow of information between members on the latest research.
- Fostering and improving contacts between practitioners interested in the ataxias, and people with ataxia.
- Investigating social, political and cultural matters connected to the welfare of people with ataxia, and promoting and improving the exchange of this information.
- Promoting co-operation on an international level between national ataxia organisations.
- Raising awareness of ataxia among clinicians, scientists and society.

The trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities the charity should undertake.

Membership as at 30th August 2024

- | | |
|--|----------------|
| • Association Belge de l'Ataxie de Friedreich (ABAF) | Belgium |
| • ADCA Vereniging Nederland | Netherlands |
| • Associação Portuguesa de Ataxias Hereditárias (APAHE) | Portugal |
| • Association Connaître les Syndromes Cérébelleux (CSC) | France |
| • Association for Families with Spinocerebellar Ataxia | Poland |
| • Association Française de l'Ataxie de Friedreich | France |
| • Associazione Italiana per la lotta alle Sindromi | Italy |
| • Friedreich's Ataxia Research Alliance Ireland (FARA Ireland) | Ireland |
| • Ataxia Telangiectasia Society | United Kingdom |
| • Ataxia UK | United Kingdom |
| • Deutsche Heredo-Ataxie Gesellschaft e. V. | Germany |
| • Global VPS13 Efforts | Germany |
| • Federación de Ataxias de España (FEDAES) | Spain |
| • Foreningen for ATAKSI HSP | Denmark |
| • Friedreich Ataxie Förderverein e.V. | Germany |

- | | |
|---|-------------|
| • Hellenic Friedreich's Ataxia Association | Greece |
| • The Israeli Machado Joseph Association | Israel |
| • NASPA (Landsforeningen for spastisk paraparese og ataksi) | Norway |
| • Spierziekten Vlaanderen | Belgium |
| • Schweizerische Gesellschaft für Muskelkranke | Switzerland |
| • Vereniging Spierziekten Nederland – Werkgroep | Netherlands |
| • Ataxiförbundet | Sweden |

Executive Committee

President Andreas Nadke, DHAG (Deutsche Heredo-Ataxie Gesellschaft)

Secretary General Sue Millman, Ataxia UK

Board Members:

Susie Norbury, Ataxia Telangiectasia Society

Madeleine Schmeder, AFAF (l'Association Francaise de l'Ataxie de Friedreich)

Bart-Jan Schuman, FAF (Friedreich Ataxie Förderverein e.V.)

Juan Carlos Baiges, FEDAES (Federación de Ataxias de España)

John Gerbild, Foreningen for ATAKSI HSP

Vasileios Karatzias, Hellenic Friedreich's Ataxia Association

Carlos Neves, APAHE - Associação Portuguesa de Ataxias Hereditárias

Tomer Hillel, Israeli Machado Joseph Association

Scientific Advisor Dr Julie Greenfield, Ataxia UK

Achievements and Performance

• Membership of European Organisations & Committees

Euro-ataxia was represented on several European Organisations & Committees as follows:

- | | |
|--|-----------------------------------|
| - Eurordis | Vassilis Karatzias & John Gerbild |
| - European Federation of Neurological Associations | John Gerbild |

• Euro-ataxia Annual Meeting 2024

Euro-ataxia's Annual Meeting was postponed to December 2024.

• Supporting Research

Euro-ataxia members have taken part in the following Research Consortia to provide patient group representation and involvement in line with the [Euro-ataxia Patient Charter](#).

European SCA3/Machado Joseph disease initiative (ESMI)

The ESMI project continues. This consortium has successfully established the largest cohort of systematically characterised patients with SCA3 worldwide. The cohort consists of over 400 SCA3 mutation carriers (with the majority being people with SCA3 and a small proportion of pre-symptomatic individuals) and around 100 age-matched healthy control subjects. The consortium is also playing an important role in the development of biomarkers. This is an extremely useful resource for running trials in Europe. This project has been recruiting participants since 2017 and Julie Greenfield has continued to participate in the Steering Committee as a Euro-ataxia representative. Since the EU JPND funding ended the Consortium has been successful in getting funding from pharma companies to continue some aspects of the study.

Progression chart of spastic ataxias (PROSPAX) project

The PROSPAX project, launched in June 2020, was a collaborative effort between neurologists across Europe, plus Canada. The project ended in August 2024. The project coordinated a comprehensive study on the progression of spastic ataxias over time, in a rigorous and harmonised way - from the clinical to the molecular level, including brain imaging, markers of progression and animal models. The study engaged 331 participants over 890 visits, creating a rich dataset, and resulted in numerous publications. The project focused on ARSACS and SPG7, but outcomes from the research will be applicable to other spastic ataxias over time. Euro-ataxia has been involved in the project as an active partner representing European ataxia patients, with support from Ataxia UK staff and the German ataxia group DHAG. A very active Patient Organisation Group led a Work Package which contributed to the development and validation of Patient Reported Outcome Measures (PROMs) and the SPAX.app (an app designed for remote monitoring of motor tasks). Two surveys distributed via patient groups collected information to be used in this study and in future trials. Euro-ataxia received some funding for the work being done.

Although the funding for this project has ended, the research and infrastructure created during the project will continue beyond the funding period.

The European Friedreich's ataxia Consortium for Translational Studies (EFACTS)

This is a study originally funded by the European Commission which is gathering vital information about the progression of Friedreich's ataxia (FA) which will provide a better knowledge of the prognosis and development of their condition. The purpose is to generate a large FA patient database, alongside an integrated clinical and natural history database; this will be linked to a biological samples repository. It also aims to define a panel of clinical assessment tools for use in future trials. Data from this study has resulted in useful publications and is also being used to plan clinical trials. Work is ongoing to harmonise the data collected in EFACTS with data collected in the US natural history study (FA-COMS), under the FA Global Clinical Consortium. Madeleine Schmeder (AFAF) and Barry Hunt (Ataxia UK) represented Euro-ataxia on the Steering Committee during the year.

Cerebellum and Emotional Networks (CEN)

The Cerebellum and Emotional Networks (CEN) is a Marie Skłodowska-Curie Innovative Training Network funded by the European Research Council investigating the brain circuits that underlie emotional behaviour. The project is creating a Virtual Institute of 7 European universities and 7 industry/charity partners, including Euro-ataxia. The consortium brings together researchers from across Europe to share and combine knowledge in the field of cerebellar research and in the field of anxiety disorders and the role of the cerebellum in the control of emotions. The knowledge gained will inform the development of new therapeutic strategies for individuals suffering from emotional disorders.

The Annual Conference 2024 took place in June in Pavia, Italy. Julie Greenfield (Ataxia UK) attended remotely and presented a talk on science communication and patient engagement in research, aimed at the many young researchers being trained as part of the CEN project.

Designing a toolbox of paradigmatic treatments for a targeted molecular medicine approach to autosomal recessive ataxias - TREAT-ARCA

This project focuses on recessive ataxias and in particular ARSACS and ARCA2. It aims to design and test treatments, including gene therapy in animal model systems of ARSACS and ARCA2. It also aims to develop biomarkers. Andreas Nadke (DHAG) and Emily Cutting (Ataxia UK) are the Euro-ataxia representatives on this project. The patient groups are working with researchers to develop a survey designed to gather information from people with ataxia on their attitudes towards gene therapy. This work builds on a survey already carried out in Friedreich's ataxia, and extends the information gathered to include all types of genetic ataxia and a number

of countries across Europe and North America. Euro-ataxia is receiving some funding to support the work undertaken in this project.

Spinocerebellar ataxias: Advanced imaging with ultra-high field MRI (SCAIFIELD)

This project involves a European Consortium who are developing novel brain scanning biomarkers for spinocerebellar ataxias, using high-field MRI scanning technology. This project is a collaboration between researchers in Germany, Norway and Belgium and includes people with SCA1, SCA2, SCA3 and SCA6 with a focus on the most common (SCA3) and fastest progressing (SCA1). Participant recruitment started in 2022. Both symptomatic and pre-symptomatic subjects will be included. Cathalijne van-Doorne (ADCA-A Vereniging Nederland) was the Euro-ataxia representative on this project. It is due to be completed in December 2024.

EVIDENCE-RND: creating robust evidence for longitudinal progression changes and treatment effects in ultra-rare neurological disease

This project started in 2022 and is funded by the EU EJPRD call “Innovative Methods for Rare Diseases”. There is a scarcity of robust trial design and analysis methods in ultra-rare neurological diseases (RND) affecting small cohorts (< 50) or even single cases. The urgency to find solutions is accelerated as disease-modifying compounds are now on the horizon for a growing number of RNDs, yet methods to generate robust evidence for treatment effects are missing. EVIDENCE-RND aims to develop a toolbox of innovative statistical methodologies designed to fill this gap. As an example, the toolbox will be applied to autosomal-recessive cerebellar ataxias, leveraging registry datasets from major transatlantic consortia (PREPARE, PROSPAX, EUROSCA, ESMI), close communication with patient organisations (Euro-Ataxia) and industry trial expertise (Novartis, AstraZeneca). Continuous interaction with EMA and C-Path will ensure that the overall goal will be readily achieved: to provide EMA with proposals for optimized outcomes, trial designs, and innovative analyses, optimized to be as informative as possible to allow robust evidence in the smallest possible populations.

SIMPATHIC consortium

The SIMPATHIC Consortium launched in 2023. The project is led by the Dutch Radboud University Medical Center and Amsterdam University Medical Centres and is working on a new approach to expedite the use of existing drugs for groups of patients with rare neurological disorders. The consortium was awarded an 8.8 million euros grant from the Horizon Europe program to further develop this innovative method. The researchers will use a new technology to test the efficacy of existing drugs in patients with neurological disorders. Euro-ataxia is one of the patient groups representing people with neurological conditions on this project, and SCA3 is one of the neurological conditions which will be studied. Euro-ataxia is receiving some funding to support the work undertaken in this project.

Ataxia Global Initiative

The Ataxia Global Initiative is a worldwide research platform that has the goal to facilitate the clinical development of therapies for ataxias. Euro-ataxia is a partner organization and has encouraged Euro-ataxia member groups to join.

Specifically, the Ataxia Global Initiative:

- promotes sharing of data and biomaterials,
- contributes to the definition of worldwide accepted common standards for clinical research and interventional trials,
- provides information that is relevant to prepare and conduct clinical trials,
- organises and hosts international meetings and conferences to update and educate the field on key issues,
- provides services that support trial readiness,

- offers training and education programmes, and provides information about clinical research to people with ataxia and the public.

For more information see: <https://ataxia-global-initiative.net>

Euro-ataxia continued to offer support to European networks of researchers applying for grants from European funding streams.

We achieved a surplus for the year of £872 and consequently increased the net assets from £14,532 to £15,404. Despite the challenging economic conditions, we are confident that we can continue to make further strides while continuing to live within our means, albeit at modest levels of activity.

We shall continue to keep the subscriptions levels under review, endeavour to get members to pay them on time, and seek to recruit new members.

In accordance with the trustees' reserves policy, the unrestricted reserves currently stand at slightly more than six months unrestricted operating costs.

- **Risk Assessment**

The Trustees have identified the following risks to the charity

Level of Risk	Nature of Risk	Mitigation
High	The potential for European Union Institutions to take a negative view of a charity registered in the UK and for this to have a negative impact on income or activities.	The Trustees have now resolved to eliminate this risk by moving the registration of the charity to Germany. This is in progress.
Medium	Reduction in income & continuing deficit.	We have increased subscription levels from €1 to €2 per member with ataxia, capped at €700.
Low	Reduction of members	Euro-ataxia has increased its membership to 22 patient groups and will be increasing its activity to ensure its worth to the European ataxia community.

Structure, Governance and Management

Euro-ataxia is established as a charity registered with the Charity Commission number 1149330 and as a Limited Company number 8187765. Its founding documents are Articles of Association adopted in August 2012. Membership of Euro-ataxia is open to any organisations and individuals the Board decides to admit into membership. The charity holds an AGM annually. In between AGMs the charity is managed by Board Members who are elected annually at the AGM.

- **Annual General Meeting**

The AGM covering this period was held on 3rd December 2024 at which the accounts were agreed for 2022 – 23.

- Directors and Trustees of the Charity and Limited Company**

Andreas Nadke	Deutsche Heredo Ataxie Gesellschaft	President	19/10/2021	Re-elected as Trustee & Elected as President
Sue Millman	Ataxia UK	Company Secretary	27/06/2022	Re-elected as Trustee & re-elected as Co. Secretary
Susie Norbury	Ataxia Telangiectasia Society	Trustee	27/04/2022	Re-elected as Trustee
Madeleine Schmeder	Association Française de l'Ataxie de Friedreich	Trustee	10/11/2018 resigned on 3/12/24	Elected as Trustee
Juan-Carlos Baiges	Federación de Ataxias de España	Trustee	10/11/2018 20/05/2023	Elected as Trustee Re-elected as Trustee
John Gerbild	Foreningen for ATAKSI HSP	Trustee	27/06/2022	Re-elected as Trustee
Vassilis Karatzias	Hellenic Association	Trustee	27/06/2022	Elected as Trustee
Bart-Jan Schuman	Friedreich AtaxieFördervereine.V.	Trustee	20/05/2023	Re-elected as Trustee

- Advisors to Euro-ataxia**

Research

Dr Julie Greenfield

Head of Research Ataxia UK

Professor Barry Hunt

Scientific Advisor Ataxia UK

- Reference and Administrative Details**

Registered Company Number: 08187765 (England and Wales)

Registered Charity Number: 1149330

Registered Office 12 Broadbent Close Highgate, London N65JW

Email address: smillman@ataxia.org.uk

Independent Examiner: Shaw Gibbs Chartered Accountants, Wey Court West, Union Road, Farnham, Surrey. GU9 7PT

Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature




Full name

Andreas Nadke
President

Susan Millman
Secretary

Date

15th July 2025

15th July 2025

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF EURO-ATAXIA

Independent examiner's report to the trustees of Euro-Ataxia ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 30 August 2024

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination, I have followed the directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS102)).
5. I can confirm that the Company's activities are lawful.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Date: 15th July 2025

D.G Hooper FCA Chartered Accountant

Shaw Gibbs Chartered Accountants

Wey Court West,

Union Road,

Farnham, Surrey.

GU9 7PT

EURO-ATAXIA
Statement of Financial Activities
For the Year Ended 30th August 2024

	Unrestricted Funds 2024	Restricted Funds 2024	Total Funds 2024	Total Funds 2023
INCOME				
Donations-membership subscriptions	1412	0	1412	3663
Income from charitable activities	<u>25142</u>	<u>0</u>	<u>25142</u>	<u>16692</u>
	<u>26554</u>	<u>0</u>	<u>26554</u>	<u>20355</u>
EXPENDITURE				
Charitable expenditure	22947	0	22947	9743
Support and governance costs	<u>2735</u>	<u>0</u>	<u>2735</u>	<u>1164</u>
	<u>25682</u>	<u>0</u>	<u>25682</u>	<u>10907</u>
NET INCOME	872	0	872	9448
RECONCILIATION OF FUNDS				
Total funds brought forward	<u>14532</u>	<u>0</u>	<u>14532</u>	<u>5084</u>
TOTAL FUNDS CARRIED FORWARD	<u>15404</u>	<u>0</u>	<u>15404</u>	<u>14532</u>

The Statement of Financial Activities includes all gains and losses recognised in the year.

The Statement of Financial Activities complies with the requirements for an income and expenditure account under the Companies Act 2006.

EURO-ATAXIA

Balance Sheet For the Year Ended 30th August 2024

	Unrestricted Funds 2024	Restricted Funds 2024	Total Funds 2024	Total Funds 2023
Current assets				
Debtors	1475	0	1475	4414
Cash at bank	<u>29387</u>	<u>0</u>	<u>29387</u>	<u>29851</u>
	<u>30862</u>	<u>0</u>	<u>30862</u>	<u>34265</u>
Current liabilities				
Creditors-amounts falling due within one year	<u>-3698</u>	0	<u>-3698</u>	-4290
Net current assets	27164	0	27164	29975
Creditors-amounts falling due after more than one year	<u>-11760</u>	<u>0</u>	<u>-11760</u>	<u>-15443</u>
NET ASSETS	<u>15404</u>	<u>0</u>	<u>15404</u>	<u>14532</u>
TOTAL FUNDS	<u>15404</u>	<u>0</u>	<u>15404</u>	<u>14532</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 30th August 2024

The members have not required the company to obtain an audit of its financial statements for the year ended 30 August 2024 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

(a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006

(b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 15th July 2025 and were signed on its behalf by:

Susan Millman

EURO-ATAXIA
NOTES TO THE FINANCIAL STATEMENTS
for the year ended 30 August 2024

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received, and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings, they have been allocated to activities on a basis consistent with the use of resources.

Taxation

The charity is exempt from corporation tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

EURO-ATAXIA
NOTES TO THE FINANCIAL STATEMENTS – continued
for the year ended 30th August 2024

2 CHARITABLE INCOME

Research grants and sponsorship	25142	5370
Donations	<u>0</u>	<u>11322</u>
	<u>25142</u>	<u>16692</u>

3 NET INCOME

Net income is stated after charging;		
Independent examiner's fees	<u>1740</u>	<u>780</u>

4 TRUSTEES' REMUNERATION AND BENEFITS

Trustees received no remuneration or benefits for the year ended 30th August 2024, nor for the previous year. No trustees' expenses were paid [2023; nil].

5 DEBTORS

Subscription debtors	1475	3315
Conference income	<u>0</u>	<u>1099</u>
	<u>1475</u>	<u>4414</u>

6 CREDITORS-AMOUNTS FALLING DUE WITHIN ONE YEAR

Income in advance	2498	0
Accruals	<u>1200</u>	<u>4290</u>
	<u>3698</u>	<u>4290</u>

**CREDITORS-AMOUNTS FALLING DUE AFTER MORE THAN ONE
7 YEAR**

Loan Ataxia UK	<u>11760</u>	<u>15443</u>
The loan has no fixed repayment terms.		

8 RELATED PARTY DISCLOSURES

Ms. S. Millman, a trustee/director, is also the chief executive of Ataxia UK.

9 MOVEMENTS IN FUNDS

All funds and fund movements in the year, and the previous year, were unrestricted.

Detailed Statement of Financial Activities

For the Year Ended 30th August 2024

	Total Funds 2024	Total Funds 2023
INCOME		
Membership subscriptions	1412	3663
Sponsorship	22586	11322
Grants receivable	<u>2556</u>	<u>5370</u>
	<u>26554</u>	<u>20355</u>
 CHARITABLE EXPENDITURE		
Grants payable	16110	900
Conference expenditure	6532	8843
Subscriptions payable	<u>305</u>	<u>140</u>
	<u>22947</u>	<u>9883</u>
 SUPPORT AND GOVERNANCE COSTS		
Office costs	161	138
Bank charges	636	94
Exchange loss	198	32
Independent examiner's fees	<u>1740</u>	<u>760</u>
	<u>2735</u>	<u>1024</u>
 NET INCOME	<u>872</u>	<u>9448</u>

This page does not form part of the statutory financial statements.