

**EURO-ATAXIA
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 AUGUST 2021**

REGISTERED COMPANY NUMBER: 08187765 (England and Wales)
REGISTERED CHARITY NUMBER: 1149330
REGISTERED OFFICE: 12 Broadbent Close, London, N6 5JW, UK

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Euro-ataxia Annual Report 2020-21

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 31 August 2021. 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).

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

- ④ Driving forward research and treatment of the ataxias
- ④ Encouraging the free flow of information between members on the latest research
- ④ Fostering and improving contacts between practitioners interested in the ataxias, and people with ataxia.
- ④ Investigating social, political and cultural matters connected to the welfare of people with ataxia, and promoting and improving the exchange of this information.
- ④ Promoting co-operation on an international level between national ataxia organisations.
- ④ 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 31st August 2021

Association Belge de l'Ataxie de Friedreich (ABAF)	Belgium
ADCA Vereniging Nederland	Netherlands
Association Connaître les Syndromes Cérébelleux (CSC)	France
Association for families with Spinocerebellar Ataxia	Poland
Association Française de l'Ataxie de Friedreich	France
Association Suisse de l' Ataxie de Friedreich	Switzerland
Associazione Italiana per la lotta alle Sindromi	Italy
Ataxia Ireland	Ireland
Ataxia- Telangiectasia Society	United Kingdom
Ataxia UK	United Kingdom
Deutsche Heredo-Ataxie Gesellschaft e. V.	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
Neuroliitto	Finland
Schweizerische Gesellschaft für Muskelkranke	Switzerland
Vereniging Spierziekten Nederland – Werkgroep	Netherlands

Achievements and Performance

Annual Conference

Our Annual Conference was held online on 18th and 19th June 2021 due to the Covid-19 pandemic.

On the second day there were presentations from Euro-ataxia member charities on new developments in their work, discussions on how members had navigated Covid-19, an update regarding an online Speech Therapy project, and the initial results of a research project looking at the benefits to patients of attending Ataxia Clinics with expert neurologists against attending a general neurology clinic.

Membership of European Organisations & Committees

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

Eurordis	Cathalijne van Doorne
European Federation of Neurological Associations	Cathalijne van Doorne

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 https://www.euroataxia.org/wp-content/uploads/2020/11/Euro-ataxia_Patient_charter_-_the_role_of_patients_in_research.pdf

European SCA3/Machado Joseph disease initiative (ESMI)

The ESMI 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 in discussions with pharma companies who may support the continuation of the funding.

Progression chart of spastic ataxias (PROSPAX) project

The PROSPAX project, launched in June 2020, is a collaborative effort between neurologists across Europe, plus Canada. The project aims to study 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 project will initially focus on ARSACS and SPG7, but will establish a more general research framework that will be applicable to other spastic ataxias over time. Euro-ataxia will be involved in the project as an active partner representing European ataxia patients, with support from Ataxia UK and the German ataxia group DHAG. Julie Greenfield and Ruby Wallis (Ataxia UK) and Andreas Nadke (DHAG) are representing Euro-ataxia. There is a very active Patient organisation group who is leading a Work package who are working on creating a Patient reported outcome measure, by creating surveys and distributing among patient groups, to collect helpful information to be used in this study and for future trials. Euro-ataxia receives some funding for the work being done.

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

This is a study originally funded by the European Commission and that is gathering vital information about the progression of Friedreich's ataxia (FA) which can be delivered to patients to give them a better knowledge of their prognosis and the 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. There are two Euro-ataxia representatives on the Steering Committee for this project, Madeleine Schmeder (AFAF) and Barry Hunt (Ataxia UK).

Cerebellum and Emotional Networks (CEN)

During the year a new Network received funding. It is a Marie Skłodowska-Curie Innovative Training Network funded by the European Research Council investigating the brain circuits that underlie emotional behaviour. The project will create a Virtual Institute of 7 European universities and 7 industry/charity partners, including Euro-ataxia. The training network focuses on the role of a previously overlooked part of the brain, the cerebellum, and its involvement in the control of emotions. The new consortium, called CEN (cerebellum & emotional networks), brings together researchers from across Europe and will address the contribution of the cerebellum in the control of emotions, and in particular fear and anxiety. A central aim of CEN is to share and combine knowledge in the field of cerebellar research and in the field of anxiety disorders. The knowledge gained will inform the development of new therapeutic strategies for individuals suffering from emotional disorders. Emily Cutting (Ataxia UK) is the Euro-ataxia representative in this 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. Euro-ataxia is receiving some funding to support the work undertaken in this project. An overview of this project was presented at the Euro-ataxia virtual research conference in June.

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

This new 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). Both, symptomatic and pre-symptomatic subjects will be included. Participant recruitment is anticipated to start in Autumn 2022. Cathalijne van-Doorne is the Euro-ataxia representative on 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 supports this initiative 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 has also continued to offer support to European networks of researchers applying for grants from European funding streams.

Euro-ataxia Research conference 2021

Euro-ataxia held an online research conference on 18th June 2021 featuring talks from academic researchers and pharma company representatives. Around 70 people registered for the event. There were talks on some of the projects that Euro-ataxia is a partner in and had updates from Reata and Minoryx on their Friedreich's ataxia programmes, Uniqure on their SCA3 programme and Triplet on their work on triplet repeat expansions. See Euro-ataxia website for further information and presentations:

<https://www.euroataxia.org/research-overview/>

On the 19th June a Euro-ataxia members only virtual meeting took place, to allow the opportunity for member groups to share experiences and discuss projects of common interest, such as the impact of the pandemic on people with ataxia across Europe. External

speakers spoke about speech therapy research on the ataxias, the FA app and the European Brain Councils' Value of treatment project evaluating the benefit of Ataxia Centres as compared to standard care in three European countries.

Financial Review

Financial review

We have achieved a small surplus for the year of £828, and consequently increased the net assets from £1,791 to £2,619. Despite the continued uncertainty surrounding the present pandemic, we are confident that we can continue 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, we are seeking to build up unrestricted reserves to the level of 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	Brexit: What view will the EU take of a European charity registered in the UK?	During 2021-22 Trustees will ensure they are appraised of developments and will be reluctantly considering moving the registration of the charity back to Belgium.
Medium	Reduction in income & continuing deficit	The secretariat and the Treasurer will ensure members pay their subscriptions and consider an increase subscription levels if necessary.
Medium	Inability to meet in person due to Covid-19 restrictions – all meetings being conducted online	Meetings of the Board are now on a regular, more frequent, timetable and an online conference is in preparation.
Low	Reduction of members	Euro-ataxia has continued to increase its membership 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 was held on 11th December 2020 via Zoom due to the Covid-19 pandemic with 14 members present representing 13 member associations.

Three Trustees were required to resign and were re-elected. (See table below)

The meeting thanked Cathalijne van Doorne for her service in the post of President.

Directors and Trustees of the Charity and Limited Company

Cathalijne Van Doorne	ADCA Vereniging Nederland	President	11/12/2020	Resigned as President Re-elected as Trustee
Sue Millman	Ataxia UK	Company Secretary	11/12/2020	Re-elected as Trustee
Susie Norbury	Ataxia Telangiectasia Society	Treasurer	11/12/2020	Elected as Trustee & Treasurer
Madeleine Schmeder	Association Française de l'Ataxie de Friedreich	Trustee	10/11/2018	Elected as Trustee
Andreas Nadke	Deutsche Heredo Ataxie Gesellschaft	Trustee	10/11/2018	Re-elected as Trustee & elected President
Juan-Carlos Baiges	Federación de Ataxias de España	Trustee	10/11/2018	Elected as Trustee
Jon Gerbild	Foreningen for ATAKSI HSP	Trustee	11/12/2020	Elected as Trustee
Bart Johan Peter Shuman	Friedreich Ataxie Förderverein e.V.	Trustee	11/12/2020	Elected as Trustee

Advisors to Euro-ataxia

Research

Dr Julie Greenfield

Head of Research Ataxia UK

Professor Barry Hunt

Scientific Advisor Ataxia UK

Finance

Stephanie Lawrence

Head of Finance Ataxia UK

Reference and Administrative Details

Registered Company Number

08187765 (England and Wales)

Registered Charity Number

1149330

Registered Office
12 Broadbent Close
Highgate, London
N6 5JW

Independent Examiner
HPCA Limited
Chartered Accountants
Station House
Connaught Road
Brookwood
Woking
Surrey
GU24 0ER

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

6 MAY 2022

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 31 August 2021.

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').

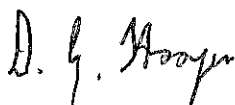
Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act').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

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: 6 May 2022

D.G Hooper FCA
Chartered Accountant
HPCA Limited
Chartered Accountants
Station House
Connaught Road
Brookwood
Woking
Surrey
GU24 0ER

Euro-Ataxia
Statement of Financial Activities
For the Year Ended 31 August 2021

	Notes	Unrestricted Funds 2021 £	Restricted Funds 2021 £	Total 2021 £	Total 2020 £
INCOME AND ENDOWMENTS FROM					
Donations	2	3,430	-	3,430	3,566
Grants	2		2,514	2,514	0
Total		3,430	2,514	5,943	3,566
EXPENDITURE ON					
Raising funds					(353)
Charitable activities					
Charitable expenditure		525	2,514	3,039	455
Other		2,077		2,077	2,426
Total		2,602	2,514	5,115	2,528
NET INCOME		828	0	828	1,038
RECONCILIATION OF FUNDS					
Total funds brought forward		1,791	-	1,791	753
TOTAL FUNDS CARRIED FORWARD		2,619	-	2,619	1,791

The statement of financial activities includes all gains and losses recognised in the year.

All income and expenditure derive from continuing activities.

The statement of financial activities also complies with the requirements for an income and expenditure account under the Companies Act 2006.

Euro-Ataxia
Balance Sheet
For the Year Ended 31 August 2021

	Notes	Unrestricted Fund £	Restricted Fund £	2021 Total Funds £	2020 Total Funds £
Fixed Assets					
Intangible assets	6	-	-	0	100
Current Assets					
Debtors	7	2,528	-	2,528	4,823
Cash at bank		15,682	-	15,682	11,724
		<u>18,210</u>	-	<u>18,210</u>	<u>16,547</u>
CREDITORS					
Amounts falling due within one year	8	<u>(1,031)</u>	-	<u>(1,031)</u>	<u>(2,162)</u>
NET CURRENT ASSETS		<u>17,179</u>	-	<u>17,179</u>	<u>14,385</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		17,179	-	17,179	14,485
CREDITORS					
Amounts falling due after more than one year	9	(14,561)	-	(14,561)	(12,694)
NET ASSETS		<u>2,619</u>	-	<u>2,619</u>	<u>1,791</u>
FUNDS					
Unrestricted funds	10			2,619	1,791
TOTAL FUNDS				<u>2,619</u>	<u>1,791</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2021.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2021 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 6 MAY 2022 and were signed on its behalf by:



Susan Millman

EURO-ATAXIA
NOTES TO THE FINANCIAL STATEMENTS
for the year ended 31 August 2021

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 31 August 2021

2 DONATIONS & GRANTS

	Unrestricted Funds	Restricted Funds	Total	Total
	2021	2021	2021	2020
	£	£	£	£
Donations and gifts	3,430	-	3,430	3,566
Research grant	-	2,514	2,514	-
	<u>3,430</u>	<u>2,514</u>	<u>5,943</u>	<u>3,566</u>
For the year ended 31 August 2020	<u>3,566</u>	<u>-</u>		<u>3,566</u>

3 NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2021	2020
	£	£
Independent examiners' fees	792	792
Website costs amortisation	100	600
	<u>100</u>	<u>600</u>

4 TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 August 2021 nor for the year ended 31 August 2020.

Trustees' Expenses

There were no trustees' expenses paid for the year ended 31 August 2021 nor for the year ended 31 August 2020.

5 INTANGIBLE FIXED ASSETS

	£
Cost	
At 1 September 2020 and 31 August 2021	<u>6,000</u>
Amortisation and impairment	
At 1 September 2020	5,900
Amortisation charged for the year	100
At 31 August 2021	<u>6,000</u>
Carrying amount	
At 31 August 2021	<u>0</u>
At 31 August 2020	<u>100</u>

EURO-ATAXIA
NOTES TO THE FINANCIAL STATEMENTS - continued
for the year ended 31 August 2021

6 DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR:

	2021	2020
	£	£
Subscription debtors	2,528	4,823

7 CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR:

	2021	2020
	£	£
Accruals	1,031	2,162

8 CREDITORS: AMOUNTS FALLING DUE AFTER MORE THAN ONE YEAR:

	2021	2020
	£	£
Loan Ataxia UK	14,561	12,694

The loan is from Ataxia UK and has no fixed repayment terms.

9 RELATED PARTY DISCLOSURES

Ms. S. Millman, a trustee, is also the Chief Executive of Ataxia UK.

EURO-ATAXIA
NOTES TO THE FINANCIAL STATEMENTS - continued
for the year ended 31 August 2021

10 MOVEMENT IN FUNDS

	At 01.09.20 £	Net Movement in funds £	At 31.08.21 £
General fund	1,791	828	2,619
TOTAL FUNDS	1,791	828	2,619

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
General Fund	5,943	(5,115)	828
TOTAL FUNDS	5,943	(5,115)	828

Comparatives for movement in funds

	At 01.09.19 £	Net Movement in funds £	At 31.08.20 £
General fund	753	1,038	1,791
	753	1,038	1,791

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
General Fund	3,566	(2,528)	1,038
TOTAL FUNDS	3,566	(2,528)	1,038

A current year 12 months and prior year 12 months combined position is as follows:

	At 01.09.19 £	Net Movement in funds £	At 31.08.21 £
General fund	753	1,866	2,619
	753	1,866	2,619

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
General Fund	9,509	(7,643)	1,866
TOTAL FUNDS	9,509	(7,643)	1,866

There are currently no restricted funds.

EURO-ATAXIA

NOTES TO THE FINANCIAL STATEMENTS - continued for the year ended 31 August 2021

11 Restricted Funds:

A grant of £2,514 was received from Deutsche Heredo Ataxie Gesellschaft towards the personnel costs of the PROSPAX research project. Euro-ataxia engaged the services of Ataxia UK to carry out the work. The grant was fully expended during the year.

Euro-Ataxia
DETAILED STATEMENT OF FINANCIAL ACTIVITIES
For the Year Ended 31 August 2021

	2021	2020
	£	£
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	113	-
Membership subscriptions	3,317	3,566
	3,430	3,566
Other trading activities		
Research grant	2,514	-
	2,514	-
Total Incoming resources	5,943	3,566
EXPENDITURE		
Support Costs		
Management		
Website costs	525	455
Research Services	2,514	-
Sundries	79	-
Amortisation of intangible fixed assets	100	600
Subscriptions	172	228
Total	3,391	1,283
Finance		
Bank charges	74	85
Other		
Loss on exchange	859	368
Governance costs		
Independent examiners' fees	792	792
Total resources expended	5,115	2,528
NET INCOME	828	1,038

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