

REGISTERED COMPANY NUMBER: 07000073 (England and Wales)
REGISTERED CHARITY NUMBER: 1133182

Report of the Trustees and
Unaudited Financial Statements
for the Year Ended 31 August 2022
for
Advocacy For Neuroacanthocytosis
Patients

Advocacy For Neuroacanthocytosis
Patients

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for the Year Ended 31 August 2022

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**Advocacy For Neuroacanthocytosis
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**Report of the Trustees
for the Year Ended 31 August 2022**

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 2022. 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

Public benefit

The Advocacy for Neuroacanthocytosis Patients benefits a group of patients around the world who suffer from three very rare chronic neurodegenerative conditions (Chorea Acanthocytosis (ChAc), McLeod Syndrome and Huntington's Disease-like 2 (HDL2) that often begins in early adulthood and leave patients wholly dependent on carers. There are only 12 known patients in the United Kingdom and 45-50 cases in the United States. The world-wide figure is only speculative, but it is likely to be fewer than 1,000. The Advocacy works with patient groups for Huntington's disease and neurodegeneration with brain iron accumulation that includes PKAN, a related disease that affects children. We are the only charity supporting those with the adult neuroacanthocytosis diseases.

The specific public benefit objectives of the Advocacy are:

- 1) To promote and protect the physical and mental health of sufferers of neuroacanthocytosis diseases and their families through the provision of support, education and practical advice.
- 2) To advance the education of health professionals and the general public in all areas relating to neuroacanthocytosis.

Advocacy For Neuroacanthocytosis

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Report of the Trustees

for the Year Ended 31 August 2022

ACHIEVEMENT AND PERFORMANCE

Charitable activities

Promoting and protecting the physical and mental health of sufferers of neuroacanthocytosis diseases and their families through the provision of support, education and practical advice.

1) In November 2021 and February and June 2022 we published our e-newsletter that supports the growth of a community by sharing patient experiences and information that may be of practical help with the debilitating symptoms that affect patients that begin in early adulthood and leave patients wholly dependent on carers. Volunteers help translate it into other languages. Our direct contact with the families of newly diagnosed patients has encouraged people who otherwise feel completely isolated by this very rare disease.

2) Patients have added their stories to the multi-lingual website sharing experiences of things that have both helped patients' well-being and suggested ways for patients to support research to find a therapy. Through email, phone and personal meetings, we have frequent contact with the families of patients and we bring their voices and experiences to the medical community.

3) The Advocacy supports the new VPS13 FORUMS held on line. Arising from the 10th Symposium in March of 2021 the international community of clinicians, scientists and families dealing with chorea-acanthocytosis (VPS13A disease) or McLeod syndrome, respectively, the Advocacy continues the conversations by supporting and publicising the two-monthly virtual VPS13 FORUM. Seven new Forum have been held this year.

4) The Advocacy supports a free diagnostic service offered by Ludwig-Maximilians University, Munich. Since 2006 over 650 patients have had the diagnostic test in duplicate.

Advancing the education of health professionals and the general public in all areas relating to Neuroacanthocytosis.

1) The 11th global NA Symposium will be held in Homberg, Germany in September 2023. Planning has begun with the patient Advocacy joining in the development of the scientific and patient sessions.

2) The Advocacy continues to support the creation of an international patient REGISTRY in which consistent histories of anonymous, diagnosed patients can be studied and eventually be a source of candidates for drug trials. The NA REGISTRY will continue to be hosted under the European Huntington Disease registry (EHDN). A separate registry of VPS13A mutations will be hosted within the open-access Leiden Open Variation Database (LOVD).

3) The Advocacy supported the E-RARE group of researchers by organizing monthly telephone conferences for the researchers and continues these calls to promote the sharing of progress towards a better understanding of the workings of this disease and promote collaborative work among the group.

4) The second Glenn Irvine Prize will be presented in 2023; a calendar of the process to find the winner is being coordinated by the Advocacy and consultants/research Professors. This prize is both a reward for excellent work and intended to encourage further work in the study of Neuroacanthocytosis.

Advocacy For Neuroacanthocytosis Patients

Report of the Trustees for the Year Ended 31 August 2022

FINANCIAL REVIEW

The charity ended the year with reserves at 31/8/2022 of £105,292.26 and €10,065.16. The charity designates funds specifically for any grants where research has already commenced.

The Advocacy's policy is to commit its full resources to its educational and research work each year. The charity has very limited expenses as the work is done by one part time paid staff and volunteers using home office facilities.

FUTURE PLANS

The charity plans to continue to focus on:-

- 1) communicating with patients and their families through personal contact by email, Facebook, phone, visits and through the renewed website to increase the communication between patients' families. We will continue to bring news of developing therapies such as deep brain stimulation and to present the opportunity for patients to help with blood and tissue donations for expanding research. Patients' families can exchange messages of experiences and concern through the "Our Patients" section of the website that uses facilities provided by "Rare Connect" to translate message exchanges in ten European languages and three others.
- 2) providing support for communication and tissue acquisition to the European Multidisciplinary Initiative on Neuroacanthocytosis and the related research at Munich, Dresden, Rostock, Verona, Oxford, Nijmegen, Stony Brook, Mount Sinai and Michigan universities.
- 3) promoting new scientific research. Close collaboration has been developed by laboratories into probing the findings of investigators in Dresden and Verona. The Advocacy paid a grant to a Madrid researcher for a year's work on VSP13 and a second grant to a geneticist to search for critical VPS13A mutations in the Munich patient cohort, including revitalisation of the chorein Western Blot service and international patient Registry; both these projects were renewed for a second year.
- 4) continue to promote the efforts of groups of Laboratories to apply for EMINA grants. The Advocacy will make future provision in its research grant conditions to continue to encourage collaboration between researchers in the field.
- 5) setting the Symposiums in locations to encourage interactions, exchange of ideas and networking opportunities among all participants. Young faculty and students use the opportunity to present their work during the poster sessions. The meetings also afford the scientists an opportunity to meet patients first-hand which they will also do in Homburg. Patients and family members will again hear the type of research work which is on-going and the Advocacy is supporting through research grants.
- 6) continue to communicate and share information with the US Advocacy to expand the efforts of fundraising, communicating with patients and providing support for research projects.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, Articles and Memorandum of Association, and constitutes a limited company, limited by guarantee as defined by the Companies Act 2006

Advocacy For Neuroacanthocytosis
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Report of the Trustees
for the Year Ended 31 August 2022

STRUCTURE, GOVERNANCE AND MANAGEMENT

Recruitment and appointment of new trustees

New trustees are elected solely by the present trustees and all trustees will be subject to limited terms of office.

The trustees meet quarterly in a formal meeting with an agenda set out in advance. Trustees and officers are volunteers. There is one part time employee who commenced on 18 June 2018.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

07000073 (England and Wales)

Registered Charity number

1133182

Registered office

39 Coleherne Court
The Little Boltons
London
SW5 0DN

Trustees

Mrs V Irvine
Dr. S A Peskett
N A Price
Mrs I B L Starling Director (resigned 27.4.22)
Ms M E Leigh-Wood Consultant
Dr P G Mills Retired
Mrs N Keat Head of Research Groups (appointed 1.7.22)


Company Secretary

Mrs V Irvine

Independent Examiner

Orcadia
Chartered Accountants
1 - 3 East Road
Kirkwall
Orkney
KW15 1HZ

Approved by order of the board of trustees on 23 May 2023 and signed on its behalf by:


.....
Mrs V Irvine - Trustee

ORCADIA

CHARTERED ACCOUNTANTS



Independent Examiner's Report to the Trustees of Advocacy For Neuroacanthocytosis Patients

Independent examiner's report to the trustees of Advocacy For Neuroacanthocytosis Patients ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 August 2022.

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 (FRS 102)).

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.

Doris Hutchison CA, ATT
Orcadia Chartered Accountants

Date: 26 May 2023

**Advocacy For Neuroacanthocytosis
Patients**

**Statement of Financial Activities
for the Year Ended 31 August 2022**

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		<u>90,098</u>	<u>-</u>	<u>90,098</u>	<u>15,082</u>
EXPENDITURE ON					
Raising funds	2	-	683	683	648
Charitable activities					
Research Grants and Symposium payments		8,468	-	8,468	87,646
Other		<u>7,639</u>	<u>-</u>	<u>7,639</u>	<u>902</u>
Total		<u>16,107</u>	<u>683</u>	<u>16,790</u>	<u>89,196</u>
Net gains/(losses) on investments		<u>-</u>	<u>(8,200)</u>	<u>(8,200)</u>	<u>19,118</u>
NET INCOME/(EXPENDITURE)		73,991	(8,883)	65,108	(54,996)
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>37,739</u>	<u>119,476</u>	<u>157,215</u>	<u>212,211</u>
TOTAL FUNDS CARRIED FORWARD		<u><u>111,730</u></u>	<u><u>110,593</u></u>	<u><u>222,323</u></u>	<u><u>157,215</u></u>

The notes form part of these financial statements

Advocacy For Neuroacanthocytosis
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Balance Sheet
31 August 2022

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
CURRENT ASSETS					
Debtors	6	-	-	-	8,510
Investments	7	-	109,587	109,587	118,471
Cash at bank		<u>112,999</u>	<u>1,006</u>	<u>114,005</u>	<u>30,895</u>
		112,999	110,593	223,592	157,876
CREDITORS					
Amounts falling due within one year	8	(1,269)	-	(1,269)	(661)
		<u>111,730</u>	<u>110,593</u>	<u>222,323</u>	<u>157,215</u>
NET CURRENT ASSETS					
		<u>111,730</u>	<u>110,593</u>	<u>222,323</u>	<u>157,215</u>
TOTAL ASSETS LESS CURRENT LIABILITIES					
		<u>111,730</u>	<u>110,593</u>	<u>222,323</u>	<u>157,215</u>
NET ASSETS					
		<u>111,730</u>	<u>110,593</u>	<u>222,323</u>	<u>157,215</u>
FUNDS	9				
Unrestricted funds				111,730	37,739
Restricted funds				<u>110,593</u>	<u>119,476</u>
TOTAL FUNDS				<u>222,323</u>	<u>157,215</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2022.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2022 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

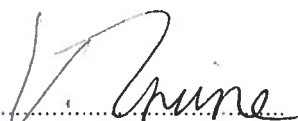
- ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus 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.

Advocacy For Neuroacanthocytosis
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Balance Sheet - continued
31 August 2022

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 23.5.2023 and were signed on its behalf by:



V Irvine - Trustee

Advocacy For Neuroacanthocytosis
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Notes to the Financial Statements
for the Year Ended 31 August 2022

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.

The company makes quarterly payments against the expenses invoices of grant recipients. £8,468 was paid to grant and symposium recipients during the year by the Advocacy of Neuroacanthocytosis Patients.

Taxation

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

Fund accounting

Designated Funds are held in anticipation of requests for financial support of active research projects approved by the Board. The conditions of any grant allowed for an unconditional termination, however, the board feels a moral obligation after such grants have begun.

At 31 August 2022, there were no active research grants provided for as Designated Funds.

Foreign currencies

Assets and liabilities in foreign currencies are translated into sterling at the rates of exchange ruling at the balance sheet date. Transactions in foreign currencies are translated into sterling at the rate of exchange ruling at the date of transaction. Exchange differences are taken into account in arriving at the operating result.

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Notes to the Financial Statements - continued
for the Year Ended 31 August 2022

2. RAISING FUNDS

Investment management costs

	2022	2021
	£	£
Support costs	<u>683</u>	<u>648</u>

3. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 August 2022 nor for the year ended 31 August 2021.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 August 2022 nor for the year ended 31 August 2021.

4. STAFF COSTS

The average monthly number of employees during the year was as follows:

	2022	2021
	<u>1</u>	<u>-</u>
Part time administration		

No employees received emoluments in excess of £60,000.

5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	<u>15,082</u>	<u>-</u>	<u>15,082</u>
EXPENDITURE ON			
Raising funds	-	648	648
Charitable activities			
Research Grants and Symposium payments	87,646	-	87,646
Other	<u>902</u>	<u>-</u>	<u>902</u>
Total	<u>88,548</u>	<u>648</u>	<u>89,196</u>
Net gains on investments	<u>-</u>	<u>19,118</u>	<u>19,118</u>

Advocacy For Neuroacanthocytosis
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Notes to the Financial Statements - continued
for the Year Ended 31 August 2022

5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted funds £	Restricted funds £	Total funds £
NET INCOME/(EXPENDITURE)	(73,466)	18,470	(54,996)
RECONCILIATION OF FUNDS			
Total funds brought forward	111,205	101,006	212,211
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS CARRIED FORWARD	<u>37,739</u>	<u>119,476</u>	<u>157,215</u>

6. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022 £	2021 £
Other debtors	<u>-</u>	<u>8,510</u>

7. CURRENT ASSET INVESTMENTS

	2022 £	2021 £
Rathbones	<u>109,587</u>	<u>118,471</u>

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022 £	2021 £
Other creditors	<u>1,269</u>	<u>661</u>

9. MOVEMENT IN FUNDS

	At 1.9.21 £	Net movement in funds £	At 31.8.22 £
Unrestricted funds			
Undesignated Funds	37,739	73,991	111,730
Restricted funds			
Harvard Donation	650	-	650
Glenn Irvine Prize Fund	<u>118,826</u>	<u>(8,883)</u>	<u>109,943</u>
	<u>119,476</u>	<u>(8,883)</u>	<u>110,593</u>
TOTAL FUNDS	<u>157,215</u>	<u>65,108</u>	<u>222,323</u>

Advocacy For Neuroacanthocytosis
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Notes to the Financial Statements - continued
for the Year Ended 31 August 2022

9. MOVEMENT IN FUNDS - continued

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

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
Unrestricted funds				
Undesignated Funds	90,098	(16,107)	-	73,991
Restricted funds				
Glenn Irvine Prize Fund	-	(683)	(8,200)	(8,883)
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>90,098</u>	<u>(16,790)</u>	<u>(8,200)</u>	<u>65,108</u>

Comparatives for movement in funds

	At 1.9.20 £	Net movement in funds £	At 31.8.21 £
Unrestricted funds			
Undesignated Funds	111,205	(73,466)	37,739
Restricted funds			
Harvard Donation	650	-	650
Glenn Irvine Prize Fund	<u>100,356</u>	<u>18,470</u>	<u>118,826</u>
	<hr/>	<hr/>	<hr/>
	<u>101,006</u>	<u>18,470</u>	<u>119,476</u>
TOTAL FUNDS	<u>212,211</u>	<u>(54,996)</u>	<u>157,215</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Gains and losses £	Movement in funds £
Unrestricted funds				
Undesignated Funds	15,082	(88,548)	-	(73,466)
Restricted funds				
Glenn Irvine Prize Fund	-	(648)	19,118	18,470
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>15,082</u>	<u>(89,196)</u>	<u>19,118</u>	<u>(54,996)</u>

Advocacy For Neuroacanthocytosis Patients

Notes to the Financial Statements - continued
for the Year Ended 31 August 2022

9. MOVEMENT IN FUNDS - continued

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

	At 1.9.20 £	Net movement in funds £	At 31.8.22 £
Unrestricted funds			
Undesignated Funds	111,205	525	111,730
Restricted funds			
Harvard Donation	650	-	650
Glenn Irvine Prize Fund	<u>100,356</u>	<u>9,587</u>	<u>109,943</u>
	<u>101,006</u>	<u>9,587</u>	<u>110,593</u>
TOTAL FUNDS	<u><u>212,211</u></u>	<u><u>10,112</u></u>	<u><u>222,323</u></u>

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 £	Gains and losses £	Movement in funds £
Unrestricted funds				
Undesignated Funds	105,180	(104,655)	-	525
Restricted funds				
Glenn Irvine Prize Fund	-	(1,331)	10,918	9,587
	<u> </u>	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u><u>105,180</u></u>	<u><u>(105,986)</u></u>	<u><u>10,918</u></u>	<u><u>10,112</u></u>

10. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 August 2022.

Advocacy For Neuroacanthocytosis
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Detailed Statement of Financial Activities
for the Year Ended 31 August 2022

	2022 £	2021 £
INCOME AND ENDOWMENTS		
Donations and Legacies		
Donations	<u>90,098</u>	<u>15,082</u>
Total incoming resources	90,098	15,082
EXPENDITURE		
Charitable Activities		
Research Grants & Symposium	8,468	87,646
Support Costs		
Finance		
Rathbones fees	683	648
Bank charges	209	155
Exchange rate gain/losses	<u>100</u>	<u>(703)</u>
	992	100
Information Technology		
IT Expenses	912	263
Other		
Wages	5,550	-
Sundry Expenses	164	322
Accountancy	<u>704</u>	<u>865</u>
	<u>6,418</u>	<u>1,187</u>
Total resources expended	<u>16,790</u>	<u>89,196</u>
Net income/(expenditure) before gains and losses	73,308	(74,114)
Realised recognised gains and losses		
Realised gains/(losses) on programme related investments	<u>(8,200)</u>	<u>19,118</u>
Net income/(expenditure)	<u>65,108</u>	<u>(54,996)</u>

This page does not form part of the statutory financial statements