

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 2024
for
Advocacy For Neuroacanthocytosis Patients

Advocacy For Neuroacanthocytosis Patients

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Advocacy For Neuroacanthocytosis Patients

Report of the Trustees **for the Year Ended 31 August 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 31 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).

OBJECTIVES AND ACTIVITIES

Public benefit

The Advocacy for Neuroacanthocytosis Patients benefits a group of patients around the world who suffer from two very rare chronic neurodegenerative conditions: VPS13A disease (Chorea Acanthocytosis) and XK disease (McLeod Syndrome) that often begin 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, and we do have new diagnosed/potential patients or their families or carers from all over the world who contact us as a result of searching for information about VPS13A and XK diseases. The world-wide figure is only speculative, but it is likely to be fewer than 3,000. 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 in the UK 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 Patients

Report of the Trustees **for the Year Ended 31 August 2024**

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 2023, February and July 2024 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. In recognition of these achievements the Public Service Award from the International Parkinson and Movement Disorder Society was granted to the Advocacy Chair Ginger Irvine.
- 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 VPS13A disease and XK disease, respectively, the Advocacy continues the conversations by supporting and publicising the virtual meeting. Four new Forums have been held this year.
- 4) The Advocacy supports a free diagnostic service offered by Dr. Kevin Peikert at the Universitätsmedizin Rostock in Germany. The test is free. Since 2006 over 700 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 was held in Homburg, Germany in September 2023. Scientific and patient sessions were held over three days.
- 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 is hosted within the open-access Leiden Open Variation Database (LOVD).
- 3) The second Glenn Irvine Prize was presented at the Symposium. A calendar of the process to find the winner is continually being coordinated by the Advocacy, consultants and researchers. 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 2024**

FINANCIAL REVIEW

The charity ended the year with reserves at 31/8/2024 of £19,800, and €31.52. 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 full 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. Our Jeans for Genes grant provided funds to improve the website and our presence on social media.
- 2) providing support for communication and tissue acquisition to 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 project was renewed for a third year.
- 4) making future provision in its research grant conditions to continue to encourage collaboration between researchers globally working in the lipodomics field.
- 5) continuing to expand registry development in conjunction with newer opportunities in the field and to coordinate with the US Advocacy.
- 6) launching the next call for the Glenn Irvine Prize to encourage young researchers and scientists to work in rare disease environments.
- 7) setting the Symposia 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 Lausanne in September 2025. Patients and family members will again hear the type of research work which is on-going and the Advocacy is supporting through research grants.
- 8) continuing to communicate and share information with the US Advocacy to expand the efforts of fundraising, communicating with patients and providing support for research projects.
- 9) searching for partnerships with umbrella groups and businesses willing to support the charity by continuing our relationship with Aspire Biosciences, Beacon and Eurordis.

Advocacy For Neuroacanthocytosis Patients

Report of the Trustees **for the Year Ended 31 August 2024**

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.

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 full time employee who commenced on 3 May 2023.

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

N A Price

Ms M E Leigh-Wood - Consultant

Dr P G Mills - Retired

Mrs N Kcat - Scientific Operations Manager at the CRUK & UCL Cancer Trials Centre (CTC)

Professor A Danek – Retired (appointed 13.12.23)

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 2 June 2025 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 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 (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
Orcadia Chartered Accountants

Date: 24 June 2025

Advocacy For Neuroacanthocytosis Patients

Statement of Financial Activities for the Year Ended 31 August 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		45,207	-	45,207	6,922
Investment income	2	<u>842</u>	<u>4,195</u>	<u>5,037</u>	<u>1,925</u>
Total		<u>46,049</u>	<u>4,195</u>	<u>50,244</u>	<u>8,847</u>
EXPENDITURE ON					
Raising funds	3	-	-	-	647
Charitable activities					
Research Grants and Symposium payments		9,000	-	9,000	8,989
Other		<u>37,336</u>	<u>5,672</u>	<u>43,008</u>	<u>24,300</u>
Total		<u>46,336</u>	<u>5,672</u>	<u>52,008</u>	<u>33,936</u>
Net gains/(losses) on investments			<u>7,844</u>	<u>7,844</u>	<u>112</u>
NET INCOME/(EXPENDITURE)		(287)	6,367	6,080	(24,977)
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>81,863</u>	<u>115,483</u>	<u>197,346</u>	<u>222,323</u>
TOTAL FUNDS CARRIED FORWARD		<u>81,576</u>	<u>121,850</u>	<u>203,426</u>	<u>197,346</u>

The notes form part of these financial statements

Advocacy For Neuroacanthocytosis Patients

Balance Sheet 31 August 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
CURRENT ASSETS					
Debtors		227	-	227	-
Investments	7	70,842	115,479	186,321	160,977
Cash at bank		<u>13,456</u>	<u>6,371</u>	<u>19,827</u>	<u>38,557</u>
		84,525	121,850	206,375	199,534
CREDITORS					
Amounts falling due within one year	8	(2,949)	-	(2,949)	(2,188)
NET CURRENT ASSETS		<u>81,576</u>	<u>121,850</u>	<u>203,426</u>	<u>197,346</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>81,576</u>	<u>121,850</u>	<u>203,426</u>	<u>197,346</u>
NET ASSETS		<u>81,576</u>	<u>121,850</u>	<u>203,426</u>	<u>197,346</u>
FUNDS	9				
Unrestricted funds				81,576	81,863
Restricted funds				<u>121,850</u>	<u>115,483</u>
TOTAL FUNDS				<u>203,426</u>	<u>197,346</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2024 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.

The notes form part of these financial statements


Advocacy For Neuroacanthocytosis Patients

Balance Sheet - continued

31 August 2024

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 22 May 2025 and were signed on its behalf by:


.....
V Irvine / Trustee

The notes form part of these financial statements

Notes to the Financial Statements
for the Year Ended 31 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.

The company makes quarterly payments against the expenses invoices of grant recipients. £8,489 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 2024, 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.

Advocacy For Neuroacanthocytosis Patients

Notes to the Financial Statements - continued for the Year Ended 31 August 2024

2. INVESTMENT INCOME

	2024	2023
	£	£
Interest received	2,766	21
Dividend income	<u>2,271</u>	<u>1,904</u>
	<u>5,037</u>	<u>1,925</u>

3. RAISING FUNDS

Investment management costs

	2024	2023
	£	£
Support costs	<u>672</u>	<u>647</u>

4. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 August 2024 nor for the year ended 31 August 2023.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 August 2024 nor for the year ended 31 August 2023.

5. STAFF COSTS

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

	2024	2023
Part time administration	<u>1</u>	<u>1</u>

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

Advocacy For Neuroacanthocytosis Patients

Notes to the Financial Statements - continued
for the Year Ended 31 August 2024

6. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	3,422	3,500	6,922
Investment income	-	1,925	1,925
Total	<u>3,422</u>	<u>5,425</u>	<u>8,847</u>
 EXPENDITURE ON			
Raising funds	-	647	647
Charitable activities			
Research Grants and Symposium payments	8,989	-	8,989
Other	<u>24,300</u>	<u>-</u>	<u>24,300</u>
Total	<u>33,289</u>	<u>647</u>	<u>33,936</u>
 Net gains on investments	<u>-</u>	<u>112</u>	<u>112</u>
 NET INCOME/(EXPENDITURE)	 (29,867)	 4,890	 (24,977)
 RECONCILIATION OF FUNDS			
Total funds brought forward	<u>111,730</u>	<u>110,593</u>	<u>222,323</u>
 TOTAL FUNDS CARRIED FORWARD	 <u>81,863</u>	 <u>115,483</u>	 <u>197,346</u>

Advocacy For Neuroacanthocytosis Patients

Notes to the Financial Statements - continued
for the Year Ended 31 August 2024

7. CURRENT ASSET INVESTMENTS

	2024	2023
	£	£
Rathbones	<u>186,321</u>	<u>160,977</u>

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024	2023
	£	£
Other creditors	<u>2,949</u>	<u>2,188</u>
	<u>2,949</u>	<u>2,188</u>

9. MOVEMENT IN FUNDS

	At 1.9.23	Net	At
	£	movement	31.8.24
		in funds	£
		£	
Unrestricted funds			
Undesignated Funds	81,863	(287)	81,576
Restricted funds			
Harvard Donation	650	-	650
Glenn Irvine Prize Fund	111,333	6,367	117,700
Jeans for Genes	<u>3,500</u>	<u>-</u>	<u>3,500</u>
	<u>115,483</u>	<u>6,367</u>	<u>121,850</u>
TOTAL FUNDS	<u>197,346</u>	<u>6,080</u>	<u>203,426</u>

Advocacy For Neuroacanthocytosis Patients

Notes to the Financial Statements - continued for the Year Ended 31 August 2024

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	46,049	(46,336)	-	(287)
Restricted funds				
Glenn Irvine Prize Fund	4,195	(5,672)	7,844	6,367
	<hr/>	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>50,244</u>	<u>(52,008)</u>	<u>7,844</u>	<u>6,080</u>

Comparatives for movement in funds

	At 1.9.22 £	Net movement in funds £	At 31.8.23 £
Unrestricted funds			
Undesignated Funds	111,730	(29,867)	81,863
Restricted funds			
Harvard Donation	650	-	650
Glenn Irvine Prize Fund	109,943	1,390	111,333
Jeans for Genes	<hr/> -	<hr/> 3,500	<hr/> 3,500
	<hr/>	<hr/>	<hr/>
	110,593	4,890	115,483
TOTAL FUNDS	<u>222,323</u>	<u>(24,977)</u>	<u>197,346</u>

Notes to the Financial Statements - continued
for the Year Ended 31 August 2024

9. MOVEMENT IN FUNDS - continued

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	3,422	(33,289)	-	(29,867)
Restricted funds				
Glenn Irvine Prize Fund	1,925	(647)	112	1,390
Jeans for Genes	<u>3,500</u>	<u>-</u>	<u>-</u>	<u>3,500</u>
	<u>5,425</u>	<u>(647)</u>	<u>112</u>	<u>4,890</u>
TOTAL FUNDS	<u><u>8,847</u></u>	<u><u>(33,936)</u></u>	<u><u>112</u></u>	<u><u>(24,977)</u></u>

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

	At 1.9.22 £	Net movement in funds £	At 31.8.24 £
Unrestricted funds			
Undesignated Funds	111,730	(30,154)	81,576
Restricted funds			
Harvard Donation	650	-	650
Glenn Irvine Prize Fund	109,943	7,757	117,700
Jeans for Genes	<u>-</u>	<u>3,500</u>	<u>3,500</u>
	<u>110,593</u>	<u>11,257</u>	<u>121,850</u>
TOTAL FUNDS	<u><u>222,323</u></u>	<u><u>(18,897)</u></u>	<u><u>203,426</u></u>

Advocacy For Neuroacanthocytosis Patients

Notes to the Financial Statements - continued **for the Year Ended 31 August 2024**

9. MOVEMENT IN FUNDS - continued

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	49,471	(79,625)	-	(30,154)
Restricted funds				
Glenn Irvine Prize Fund	6,120	(6,319)	7,956	7,757
Jeans for Genes	<u>3,500</u>	<u>-</u>	<u>-</u>	<u>3,500</u>
	<u>9,620</u>	<u>(6,319)</u>	<u>7,956</u>	<u>11,257</u>
TOTAL FUNDS	<u>59,091</u>	<u>(85,944)</u>	<u>7,956</u>	<u>(18,897)</u>

10. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 August 2024.

Advocacy For Neuroacanthocytosis Patients

Detailed Statement of Financial Activities for the Year Ended 31 August 2024

	2024 £	2023 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	45,207	3,422
Grants	-	3,500
	<u>45,207</u>	<u>6,922</u>
Investment income		
Interest received	2,766	21
Dividend income	<u>2,271</u>	<u>1,904</u>
	<u>5,037</u>	<u>1,925</u>
Total incoming resources	50,244	8,847
EXPENDITURE		
Charitable activities		
Research Grants & Symposium	9,000	8,989
Other		
Glenn Irvine Prize	5,000	-
Support costs		
Finance		
Rathbones fees	672	647
Bank charges	199	205
Exchange rate gain/losses	<u>(110)</u>	<u>622</u>
	<u>761</u>	<u>1,474</u>
Information technology		
IT Expenses	307	369
Carried forward	15,068	10,832

This page does not form part of the statutory financial statements

Advocacy For Neuroacanthocytosis Patients

Detailed Statement of Financial Activities
for the Year Ended 31 August 2024

	2024 £	2023 £
Brought forward	15,068	10,832
Other		
Wages	35,863	21,964
Sundry Expenses	171	171
Accountancy	906	969
	<u>36,940</u>	<u>23,104</u>
Total resources expended	52,008	33,936
	<hr/>	<hr/>
Net expenditure before gains and losses	(1,764)	(25,089)
Realised recognised gains and losses		
Realised gains/(losses) on programme related investments	<u>7,844</u>	<u>112</u>
Net income/(expenditure)	<u>6,080</u>	<u>(24,977)</u>

This page does not form part of the statutory financial statements