

**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 2020**  
**for**  
**Advocacy For Neuroacanthocytosis**  
**Patients**

**Advocacy For Neuroacanthocytosis**  
**Patients**

**Contents of the Financial Statements**  
**for the Year Ended 31 August 2020**

	<b>Page</b>
<b>Report of the Trustees</b>	1 to 4
<b>Independent Examiner's Report</b>	5
<b>Statement of Financial Activities</b>	6
<b>Balance Sheet</b>	7 to 8
<b>Notes to the Financial Statements</b>	9 to 14

**Report of the Trustees**  
**for the Year Ended 31 August 2020**

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 2020. 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.

**Report of the Trustees**  
**for the Year Ended 31 August 2020**

**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 December and July 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 a free diagnostic service offered by Ludwig-Maximilians University, Munich. Since 2006 over 1200 patients have had the diagnostic test.

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

1) The tenth NA symposium was scheduled for March 2020 in Barcelona but was postponed due to Covid-19. However, scientists and consultants continued to explore new avenues for research and collaboration. Three new papers about Neuroacanthocytosis were published.

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 now be hosted on the open-access Leiden Open Variation Database (LOVD). A new grant has been donated to enlarge this study and confirm DNA for over 250 patients.

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.

**FINANCIAL REVIEW**

The charity ended the year with reserves at 31/8/2020 of £90,404.02 and €25,086.60 against potential payments of £45,000 and €17,000 for future research grants. 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.

**Report of the Trustees**  
**for the Year Ended 31 August 2020**

**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 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 Barcelona. 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) Fostering efforts to establish a 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

**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)

**Advocacy For Neuroacanthocytosis**  
**Patients (Registered number: 07000073)**

**Report of the Trustees**  
**for the Year Ended 31 August 2020**

**Registered Charity number**  
1133182

**Registered office**  
39 Coleherne Court  
The Little Boltons  
London  
SW5 0DN

**Trustees**  
Ms N Glynn (resigned 31.3.21)  
Mrs V Irvine  
Dr. S A Peskett  
N A Price  
Mrs D Kempson-Wren Director (resigned 31.3.21)  
Mrs I B L Starling Director  
Ms M E Leigh-Wood Consultant (appointed 4.12.19)  
Dr P G Mills Retired (appointed 4.12.19)

**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 27 May 2021 and signed on its behalf by:



Mrs V Irvine - Trustee

**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 2020.

**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

28 May 2021

**Advocacy For Neuroacanthocytosis Patients**

**Statement of Financial Activities**  
**for the Year Ended 31 August 2020**

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies		116,954	65,000	181,954	179,091
Other trading activities	2	<u>190</u>	<u>-</u>	<u>190</u>	<u>4,000</u>
<b>Total</b>		<b>117,144</b>	<b>65,000</b>	<b>182,144</b>	<b>183,091</b>
<b>EXPENDITURE ON</b>					
<b>Charitable activities</b>					
Research Grants and Symposium payments		90,556	-	90,556	82,159
Other		<u>4,692</u>	<u>5,000</u>	<u>9,692</u>	<u>5,060</u>
<b>Total</b>		<b>95,248</b>	<b>5,000</b>	<b>100,248</b>	<b>87,219</b>
<b>NET INCOME</b>		<b>21,896</b>	<b>60,000</b>	<b>81,896</b>	<b>95,872</b>
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		<b>89,309</b>	<b>41,006</b>	<b>130,315</b>	<b>34,443</b>
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b><u>111,205</u></b>	<b><u>101,006</u></b>	<b><u>212,211</u></b>	<b><u>130,315</u></b>

The notes form part of these financial statements



**Advocacy For Neuroacanthocytosis**  
**Patients (Registered number: 07000073)**

**Balance Sheet**  
**31 August 2020**

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
<b>CURRENT ASSETS</b>					
Debtors	6	41	-	41	41
Investments	7	-	100,000	100,000	-
Cash at bank		<u>111,805</u>	<u>1,006</u>	<u>112,811</u>	<u>130,903</u>
		111,846	101,006	212,852	130,944
<b>CREDITORS</b>					
Amounts falling due within one year	8	(641)	-	(641)	(629)
<b>NET CURRENT ASSETS</b>		<u>111,205</u>	<u>101,006</u>	<u>212,211</u>	<u>130,315</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<u>111,205</u>	<u>101,006</u>	<u>212,211</u>	<u>130,315</u>
<b>NET ASSETS</b>		<u>111,205</u>	<u>101,006</u>	<u>212,211</u>	<u>130,315</u>
<b>FUNDS</b>	9				
Unrestricted funds				111,205	89,309
Restricted funds				<u>101,006</u>	<u>41,006</u>
<b>TOTAL FUNDS</b>				<u>212,211</u>	<u>130,315</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 August 2020.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 August 2020 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 and
- (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.

The notes form part of these financial statements

**Advocacy For Neuroacanthocytosis**  
**Patients (Registered number: 07000073)**

**Balance Sheet - continued**  
**31 August 2020**

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 27 May 2021 and were signed on its behalf by:

A handwritten signature in black ink, appearing to read 'V. Irvine', is written over a horizontal line.

V Irvine - Trustee

**Notes to the Financial Statements**  
**for the Year Ended 31 August 2020**

**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. £90,556 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 2020, 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 2020**

**2. OTHER TRADING ACTIVITIES**

	<b>2020</b>	2019
	<b>£</b>	£
Fundraising events	<u><b>190</b></u>	<u><b>4,000</b></u>

**3. TRUSTEES' REMUNERATION AND BENEFITS**

There were no trustees' remuneration or other benefits for the year ended 31 August 2020 nor for the year ended 31 August 2019.

**Trustees' expenses**

There were no trustees' expenses paid for the year ended 31 August 2020 nor for the year ended 31 August 2019.

**4. STAFF COSTS**

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

	<b>2020</b>	2019
	<u><b>1</b></u>	<u><b>1</b></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 £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	138,735	40,356	179,091
Other trading activities	<u>4,000</u>	<u>-</u>	<u>4,000</u>
<b>Total</b>	142,735	40,356	183,091
 <b>EXPENDITURE ON</b>			
<b>Charitable activities</b>			
Research Grants and Symposium payments	82,159	-	82,159
Other	<u>5,060</u>	<u>-</u>	<u>5,060</u>
<b>Total</b>	87,219	-	87,219
 <b>NET INCOME</b>	<u>55,516</u>	<u>40,356</u>	<u>95,872</u>

**Notes to the Financial Statements - continued**  
**for the Year Ended 31 August 2020**

**5. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued**

	Unrestricted funds £	Restricted funds £	Total funds £
<b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	33,793	650	34,443
	<hr/>	<hr/>	<hr/>
<b>TOTAL FUNDS CARRIED FORWARD</b>	<b><u>89,309</u></b>	<b><u>41,006</u></b>	<b><u>130,315</u></b>

**6. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	2020 £	2019 £
Other debtors	<u>41</u>	<u>41</u>

**7. CURRENT ASSET INVESTMENTS**

	2020 £	2019 £
Rathbones	<u>100,000</u>	<u>-</u>

**8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	2020 £	2019 £
Other creditors	<u>641</u>	<u>629</u>

**9. MOVEMENT IN FUNDS**

	At 1.9.19 £	Net movement in funds £	At 31.8.20 £
<b>Unrestricted funds</b>			
Undesignated Funds	89,309	21,896	111,205
<b>Restricted funds</b>			
Harvard Donation	650	-	650
Glenn Irvine Prize Fund	<u>40,356</u>	<u>60,000</u>	<u>100,356</u>
	<u>41,006</u>	<u>60,000</u>	<u>101,006</u>
<b>TOTAL FUNDS</b>	<b><u>130,315</u></b>	<b><u>81,896</u></b>	<b><u>212,211</u></b>

**Advocacy For Neuroacanthocytosis**  
**Patients**

**Notes to the Financial Statements - continued**  
**for the Year Ended 31 August 2020**

**9. MOVEMENT IN FUNDS - continued**

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

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
Undesignated Funds	117,144	(95,248)	21,896
<b>Restricted funds</b>			
Glenn Irvine Prize Fund	65,000	(5,000)	60,000
<b>TOTAL FUNDS</b>	<b>182,144</b>	<b>(100,248)</b>	<b>81,896</b>

**Comparatives for movement in funds**

	At 1.9.18 £	Net movement in funds £	At 31.8.19 £
<b>Unrestricted funds</b>			
Undesignated Funds	33,793	55,516	89,309
<b>Restricted funds</b>			
Harvard Donation	650	-	650
Glenn Irvine Prize Fund	-	40,356	40,356
	650	40,356	41,006
<b>TOTAL FUNDS</b>	<b>34,443</b>	<b>95,872</b>	<b>130,315</b>

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

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
Undesignated Funds	142,735	(87,219)	55,516
<b>Restricted funds</b>			
Glenn Irvine Prize Fund	40,356	-	40,356
<b>TOTAL FUNDS</b>	<b>183,091</b>	<b>(87,219)</b>	<b>95,872</b>

**Advocacy For Neuroacanthocytosis**  
**Patients**

**Notes to the Financial Statements - continued**  
**for the Year Ended 31 August 2020**

**9. MOVEMENT IN FUNDS - continued**

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

	At 1.9.18 £	Net movement in funds £	At 31.8.20 £
<b>Unrestricted funds</b>			
Undesignated Funds	33,793	77,412	111,205
<b>Restricted funds</b>			
Harvard Donation	650	-	650
Glenn Irvine Prize Fund	<u>-</u>	<u>100,356</u>	<u>100,356</u>
	<u>650</u>	<u>100,356</u>	<u>101,006</u>
<b>TOTAL FUNDS</b>	<u><u>34,443</u></u>	<u><u>177,768</u></u>	<u><u>212,211</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 £	Movement in funds £
<b>Unrestricted funds</b>			
Undesignated Funds	259,879	(182,467)	77,412
<b>Restricted funds</b>			
Glenn Irvine Prize Fund	105,356	(5,000)	100,356
	<u>        </u>	<u>        </u>	<u>        </u>
<b>TOTAL FUNDS</b>	<u><u>365,235</u></u>	<u><u>(187,467)</u></u>	<u><u>177,768</u></u>

**Notes to the Financial Statements - continued**  
**for the Year Ended 31 August 2020**

**10. RELATED PARTY DISCLOSURES**

Mrs V Irvine donated £50,000 to the charity in the year and £65,000 for the Glenn Irvine Prize Fund.