ADVOCACY FOR NEUROACANTHOCYTOSIS PATIENTS

TRUSTEES' REPORT AND ACCOUNTS

FOR THE YEAR ENDED 31 AUGUST 2011

Registered Company No:
07000073

Advocacy for Neuroacanthocytosis Patients
REFERENCE AND ADMINISTRATIVE INFORMATION

Directors/Trustees	Virginia Irvine, appointed 25/8/2009 Francesca Roberts, appointed 11/11/2009 Glenn Irvine, appointed 25/8/2009
Chief Executive	Glenn Irvine
Registered office	32 Launceston Place, London W8 5RN
Charity registration number	1133182
Company number	07000073
Solicitors	None
Independent Examiner	G.F. MacAulay F.C.A. 16 York Court Albany Park Road Kingston-on-Thames KT2 5ST

Advocacy for Neuroacanthocytosis Patients

CONTENTS

The board of trustees have pleasure in presenting their annual report on the affairs of the charitable company together with the financial statements for the year ended 31 August 2011.

Structure, Governance and Management

Nature of governing document: Articles and Memorandum of Association

Methods adopted for the recruitment and appointment of new trustees:
During the year the charity put out requests for additional trustees without a response. Subsequently the trustees identified two potential trustees who attended the board meetings in June and September 2011. New trustees will be 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 advanced agenda.
Trustees and officers are volunteers. There is no salaried staff.

Constitution – Articles and Memorandum of Association

Trustees

The trustees, who are also directors for the purposes of the Companies Act 2006, who served during the year were:

Francesca Roberts, appointed 11 November 2009
Virginia Irvine, appointed 28August 2009
Glenn Irvine, appointed 28 August 2009

Advocacy for Neuroacanthocytosis Patients

Objectives and Activities for the Public Benefit

Public Benefit

The Advocacy for Neuroacanthocytosis Patients benefits a group of patients around the world who suffer from very rare chronic neurodegenerative conditions similar to Huntington's disease and Parkinson's disease that begin in early adulthood and leave patients wholly dependent on carers. There are only 10 known patients in the United Kingdom and likely fewer than 500 on earth. The world-wide figure is unknown. The Advocacy works closely with the patient groups for a related disease that affects children; however there is no other charity supporting those with the adult 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.

To this end we publish an e-news letter twice a year that builds a community by sharing patient experiences and information that may be of practical help with the familiar symptoms that affect patients. We help patients to participate in studies that may lead to therapies. Through a multi-lingual website we help patients find and use our resources. Through email, phone and personal meetings we have frequent personal contact with the families of patients and we bring the voices and experiences of patients to the medical community. The Advocacy provides support for a diagnostic service to Ludwig-Maximilians University, Munich that has brought a diagnosis to patients around the world.

2) To advance the education of health professionals and the general public in all areas relating to neuroacanthocytosis. This disease group is so rare that most neurologists will not see a single case in their careers. To overcome this hole in professional knowledge the Advocacy has supported and helped organize five international scientific symposia that have taken place in Europe, Asia and North America. The understanding of the medical community has been broadened by two books that have been published with the Advocacy's financial support and by articles discussing the symposia in scientific journals.

   Education is also about learning and to this end the Advocacy periodically calls for applications for scientific research grants. Such applications are submitted on a form adopted from a leading patient group for a similar disease and are subject to regulations similar to those used by the Wellcome Foundation. A scientific panel of three neurologists, who received no support in the current year from the Advocacy, reviews the applications. They in turn receive opinions from scientists directly involved in the specific field of research. The scientific panel makes recommendations that are considered by the board that takes the final decision.

Achievements and Performance:

Patients and their families regularly express thanks for the regular newsletter as well as the personal contact we maintain. Our direct contact with the families of newly diagnosed patients has encouraged people who otherwise feel completely isolated by this very rare disease. With Advocacy support the international case Registry grew during the year to detailed reports on 38 cases of the disease. We have taken the initiative to expand the Registry by working with professionals to obtain approval for including patient information on the Registry from Institutional Review Boards.

Advocacy for Neuroacanthocytosis Patients

During the period to August 31, 2010 the charity published two editions of it's e-newsletter, NANews that contained much information for sufferers on neuroacanthocytosis (NA) and it was in contact with the families of patients around the world. The Advocacy also financially supported the provision of a free diagnostic service for the most prevalent of the NA diseases. In 2010 the Advocacy agreed to support three major basic science research projects at The Nijmegen Centre for Molecular Life Sciences, the University of Michigan and Dresden Technical University that may shed light on the cause of neuroacanthocytosis. These are early steps toward therapies that will slow-down, halt or cure the diseases. An international patient case registry and further contribution of post mortem brain tissue were also developed during the period.

To advance education relating to NA, a great deal of Advocacy effort went into organizing during 2010 an international medical symposium that was supported by the National Institutes of Health and the Movement Disorders Society. This will take place on October 1-2, 2010 in Bethesda, MD, USA. and attract speakers and scientists from around Europe and the United States as well as a number of patients.

Financial Review

The charity ended its first year with reserves at 31/8/2011 of £37,517. Its policy is to use its full resources to its educational and research work each year. The charity has very limited expenses as the work is done by volunteers using home office facilities.

Broadening the interest in basic scientific research into the causes of the NA diseases and moving toward development of therapies. In response to a call for research proposals the Advocacy received three applications from universities that were reviewed and approved by the independent scientific panel. These projects totalled £76,122. The agreement with the recipient universities permits the Advocacy to terminate the grant without cause or notice. Through its own resources and donations made by Advocacy supporters directly to grant recipients approved grants have been paid or are covered by Advocacy cash reserves as of October 1, 2011.

Plans for Future Periods

The charity plans to continue to focus on

- Communication with patients and their families through personal contact by email, phone and visits to encourage and bring news of developing therapies to their attention and to use donations to continue a programme of education and research.
- Supporting a symposium planned for October 25-27, 2012 in The Netherlands and a call for new research grant proposals will made at the end of 2011.
- Providing financial support to the three basic research projects that were approved in 2009.
- Continuing support to the free diagnostic service and the international patient registry.

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The trustees are responsible for preparing the annual report and the financial statements in accordance with applicable law and regulations.

Company law requires the trustees to prepare financial statements for each financial year. Under that law the trustees are required to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). The financial statements are required to give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources of the charity, including its income and expenditure, for that period. In preparing these financial statements the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- make judgments and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

INDEPENDENT EXAMINER'S REPORT to the Trustees of Advocacy for Neuroacanthocytosis Patients

I report on the accounts of the company limited by guarantee for the period ended 31 August 2011, which are set out on the following pages.9-11.

Respective responsibilities of trustees and examiner

The charity' trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year (under section43(2) of the Charities Act 1993(the 1993 Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts (section 43 (3)(a) of the 1993 Act);
- to follow procedures laid down in the General Directions given by the Charity Commissioners (under section 43(7)(b) of the 1993 Act;
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the General Directions given by the Charity Commissioners. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently I do not express an audit opinion on the view given by the accounts.

Independent examiner's statement

In connection with my examination, no matter has come to my attention:

1) Which gives me reasonable cause to believe that in any material respect the requirements:
    a. To keep accounting records in accordance with section 41 of the 1993 Act; and
    b. To prepare accounts which accord with the accounting records and comply with the accounting requirements of the 1993 Act

   have not been met; or
2) To which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Glyn MacAulay, FCA
January 26, 2012

Advocacy for Neuroacanthocytosis Patients

STATEMENT OF FINANCIAL ACTIVITIES
(INCLUDING INCOME AND EXPENDITURE ACCOUNT)

FOR THE YEAR TO 31 AUGUST 2011

	Notes	Unrestricted	Restricted	2,011	2,010
Incoming Resources from Generated Funds		£	£	£	
Income from Donations	2	63,871	1,275	65,146	16,377
Total Incoming resources		63,871	1,275	65,146	16,377
					£
Resources Expended					
Charitable Activities					
Research & Symposium	3	3,189	2,203	5,392	7,664
Governance Costs & Misc expenses		715	600	1,315	30
Education expenses		-	-	-	243
Research Proposal Grants paid in year		29,362	-	29,362	-
Total Resources Expended		33,266	2,803	36,069	7,937
Net income for the year		30,605	(1,528)	29,077	8,440
Fund Balances at 1 September 2010		5,305	3,135	8,440	-
Net Income for Year to 31st Aug 2011		30,605	(1,528)	29,077	8,440
Fund Balances at 31 August 2011		**35,910**	**1,607**	**37,517**	**8,440**
Cash Flow Statement					
Opening Balance at 1st Sep 2010		5,226	3,135	8,361	-
Receipts - Income		63,271	1,275	64,546	16,377
Payments - Expenditure / Grants		29,477	2,803	32,280	8,016
Closing Balance at 31st Aug 2011		**39,020**	**1,607**	**40,627**	**8,361**

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

All of the above results are derived from continuing activities. There are no recognised gains or losses other than those stated above.

Advocacy for Neuroacanthocytosis Patients

BALANCE SHEET

AS AT 31 AUGUST 2011

Company Registration No (England and Wales) 07000073

	Notes	2,011 £		2,010 £	
Tangible fixed assets		4	-		-
Current assets					
Cash at bank and in hand		40,627		8,361	
Debtors	5	79		79	
		40,706		8,440	
Creditors **(amounts falling due with one year)**			(3,189)		-
Net current assets			37,517		8,440
Total assets less current liability			37,517		8,440
Funds					
Restricted funds		1,607		3,135	
Unrestricted funds		35,910		5,305	
Total Funds			37,517		8,440

The accounts were approved and authorised for issue by the Board on November 23, 2011.

Virginia Irvine
Virginia Irvine
Trustee

Glenn Irvine
Trustee

NOTES TO THE FINANCIAL STATEMENTS

FOR THE YEAR ENDED 31 AUGUST 2011

Accounting policies

1. **Basis of preparation.**

   The accounts have been prepared under the historical cost convention and in accordance with applicable accounting standards, the Statement of Recommended Practice, "Accounting and Reporting by Charities", issued in March 2005 and the Companies Act 2006.

   Accounts have been prepared under the Accrual basis.

2. **Incoming resources.**

   All income came from donations and GiftAid. Restricted donations are noted separately.

3. **Research & Symposium.**

   The amount of £3,189 for unrestricted spend related to Autopsy costs for the University of Minnesota (£1,847) and a contribution to the 2012 Symposium (£1,342).

   The amount of £2,203 for restricted spend related to a project at Mt Sinai.

4. **Tangible fixed assets.**

   There are no tangible fixed assets.

5. **Debtors.**

6. This is an amount due from a related trading company.