

Guillain-Barré & Associated Inflammatory Neuropathies

TRUSTEES' ANNUAL REPORT FOR 2015-16

Reference and Administration Details

Charity name: Guillain-Barré & Associated Inflammatory Neuropathies (GAIN)

Registration number: 1154843 (England and Wales)

Scottish charity number: SC039900

Address: Woodholme House

Heckington Business Park

Station Road

Heckington

Sleaford

NG34 9JH

Tel: 01529 469910

E-mail: office@gaincharity.org.uk

Web site: www.gaincharity.org.uk

Patrons: Air Marshal Sir Ian Macfadyen KCVO CB OBE FRAeS RAF (Retired)
Professor Richard Hughes MD FRCP FMedSci

Founder and Honorary President Emeritus: Glennys Sanders MBE

Trustees:	James Babington Smith MBE*	Chairman
	Christopher Fuller*	Vice Chairman
	David Wada*	Treasurer
	Barbara Bradley*	Secretary
	Jacque Cooper*	
	William Harmer*	
	Paul Waine*	
	Russell B. Hamilton	(retired April 2016)

The Trustees marked with an asterisk (*) produced this report

Director: Caroline Morrice

Main Bankers: CAF Bank, 25 King's Hill Avenue, West Malling, ME19 4IQ

Independent Examiner: Aynesley Walters Cohen Ltd, 16 South End, Croydon CR0 1DN

Related Parties and Subsidiaries

The Charity is independent and has no subsidiaries. It is a member of the Neurological Alliance, the National Council for Voluntary Organisations, Rare Diseases UK, National Voices and the Specialised Health Care Alliance.

The Charity has a Medical Advisory Board (MAB) consisting of: Dr Jane Pritchard (chairman), Dr Yusef Rajabally (secretary), Mike Cumberbatch (specialist nurse), Dr Mark Busby, Dr Rob Hadden, Dr Michael Lunn, Dr John Nixon, Dr Claire White, Professor Hugh Willison, Dr Shakti Agrawal, Dr Simon Rinaldi and the Chairman and Director of GAIN.

The Medical Advisory Board edits the charity's literature to ensure accuracy, responds to members' queries and manages the peer review and assessment of applications for research funding.

Area of Operation

The Charity is constitutionally restricted to operate within the United Kingdom and the Republic of Ireland.

Structure, Governance and Management

Constitution

The organisation is a Charitable Incorporated Organisation. Its Constitution was adopted on 25 January 2014.

Membership

Membership of the Charity is free to anyone supporting the aims of the Charity and these members may vote at General Meetings. The Charity also has non-voting members.

Election and Appointment of the Trustees

The members of the Board of Trustees (Board) are the Trustees under charity law. The Board comprises of up to 12 Trustees of which 3 are officers of the charity.

Trustee vacancies can be filled by the decision of the members at the annual general meeting or appointed during the year as a vacancy arises in accordance with the Constitution.

Trustee Selection and Induction

Potential trustees attend an interview to assess their suitability for the role. At this interview they are also told about the responsibilities of Trustees; the Constitution and other documentation; the financial situation; and existing strategy. If the board is satisfied and the applicant wishes to proceed they are asked to attend the next meeting as an observer. Successful applicants are appointed to the Board in accordance with the Constitution.

Governance

The Board of Trustees is responsible for determining the strategy and the policy of the Charity. It ensures that the Charity both complies with Charity Law and is administered within the principles of the Code of Good Governance for Voluntary and Community Organisations.

Management

The Director is the person responsible for the day-to-day management of the Charity and has powers as delegated by the board. The Director is responsible to the board through the Charity's Chairman.

The Charity has two additional members of staff responsible to the Director: the Fundraising Officer and the Support Officer. The salaried staff may be supplemented by individual volunteers or volunteer management teams.

Management is delegated to ensure that the Charity runs efficiently without the intervention of Trustees but it may neither change existing policy nor make any grants to bodies or individuals.

Risk Management

The Chairman is responsible, together with the Director, for the assessment, review and mitigation of risk. The Risk Register is a standing agenda item at Trustee meetings.

Objectives and Activities

Objectives of the Charity

The Objects of the Charity are to relieve the needs of persons suffering from Guillain-Barré syndrome (GBS), Chronic Inflammatory Demyelinating Polyradiculoneuropathy (CIDP) and associated inflammatory neuropathies, and of their families and friends. There are three identified processes: direct support, encouraging research, and advancing awareness.

Aim of Activities

GBS, CIDP and associated inflammatory neuropathies are considered 'orphan' illnesses in that they are rare and do not enjoy a high profile. As the only charity that exclusively supports those affected by these illnesses throughout the UK and Republic of Ireland, it is beholden to GAIN to make every effort to raise the profile of the illnesses, actively engage in supporting research activity, as well as providing direct support to patients, their families and friends.

To supplement these charitable activities, GAIN has to organise support activities. These include those of governance, management, and fund-raising.

Objectives for the Year

The following objectives were set:

Governance: To develop a cohesive Board of Trustees with a diverse skills set to lead the charity.

Management: To ensure that the Charity operates in a cost effective manner, prioritising the needs of the GAIN community to ensure that the expectations of our user group are met.

Charitable:

- a. to ensure that registered users receive timely and appropriate support;
- b. to offer free membership to all;

- c. to ensure we have active volunteers to meet the changing needs of our target community;
- d. To update the literature to ensure that we are able to offer the most accurate and reliable information;

Strategies for Achieving Objectives

We will continue to be the first point of contact for information, advice and support for people of all ages suffering from GBS, CIDP and associated inflammatory neuropathies.

We will work to ensure an understanding of the condition by health professionals and others engaged in support of people suffering from this condition

We will continue to expand our support of vital research, leading in time to an understanding of the causes of GBS, CIDP and related conditions, effective treatments and possibly treatments and cures for these life limiting conditions.

Significant Activities

The core activity remains one of providing information and support to those affected by the illnesses.

The facebook community continues to grow and is well administered by volunteers and staff to ensure house rules are adhered to. The website is maintained and updated on a regular basis to give the latest information to the increasing numbers reaching us. Although few of those that use the information found online actually contact us for peer support or hard copies of information we are confident that the information that they are receiving offers reliable and accurate details on the illnesses.

Through our personal grants scheme we continue to help people with costs incurred in visiting their family member in hospital as well as offering items to enable people to return home. All these grants are assessed by a committee made up of trustees and members to ensure that they meet the Charity Commission requirements for spending or whether the item or service is available through another source. On the occasions where awards are declined by the committee the applicant is advised on where best to seek help or support.

We continue to issue information packs for the health and social care professionals. Many members have asked for copies for their GP, hospital or

rehabilitation unit. Hospitals are increasingly asking for leaflets that they can hand to patients and their families which we are happy to provide and actively encourage.

We have run adverts for legacies in our magazines and on the website. It is a sensitive subject to include, but with charity details also being included in the Law Society journal we have been the beneficiary of legacies this year.

Public Benefit

The Charitable Purposes of the Charity clearly fall within description j of the Charities' Act 2011 (the relief of those in need, by reason of youth, age, ill-health, disability, financial hardship or other disadvantage) in that anyone within the United Kingdom and Republic of Ireland affected by GBS, CIDP and related conditions may receive relief from the Charity.

Benefits may be direct (information, support, financial) or indirect (informing health and social care professionals of the conditions and the charity, research etc) and are self-evidently related to the Objects without any known detriment or harm.

The beneficiaries (all those affected by GBS, CIDP and associated inflammatory neuropathies) are self-evidently appropriate to the Objects and there are no geographical (except those defined by the Objects) or other restrictions. No fees are charged for any benefit and membership subscriptions are optional. Those in financial hardship are not excluded and may be eligible for additional benefits through the Charity's Personal Grants Fund. There are no perceived private benefits.

Achievements and Performance

Charitable Activity

Information

There are about 1500 new cases of GBS/CIDP every year in the UK and RoI. In 2015-16, there were 448 registrations for support. This was more than double the registrations for the last financial year, with the majority coming via the website.

Of those who registered, 113 (25%) requested the involvement of a local contact volunteer, which is down from 40% last year. 74 volunteers were utilised in the year.

There were 625 calls to the Helpline, which shows a decrease on the previous year. The helpline was serviced by 21 volunteers, many of which are new volunteers.

We are seeing an increase in the number of hits on the website which is an average of 2000 per month and currently appears to be around 75% new users. As a result of this we are looking into how we can further improve the website and introduce more interactive sections for our volunteers and make better use of video for those looking at the site.

A marked increase in the numbers accessing data from the charity has to be recognised and commended as we continue to adjust to the ever changing needs of today's society.

The quarterly magazine **gain4all** has received great reviews from the readers. It is available by subscription in both hard copy and digital format, offering our readers the choice. Many people have registered for the digital version and it allows the charity to keep in touch with patients long after they have recovered at no cost to the charity.

Branches and Volunteers

We continue to attract new volunteers, although as the charity adapts to meet the expectations of the service users so does the role of the volunteer. We have had this year to look at our policy and operating methods in light of the recent problems other charities have encountered over insecure data handling resulting in large fines being imposed. A charity of our size could be fined in excess of £50000 for breach of data. New policy and operating procedures for data handling will be introduced in 2016.

Branches are declining with some not meeting at all in this financial year and effectively ceasing to exist. We have one committee lead branch in Lancashire and Cumbria since Scotland members voted to operate as a gathering at the last AGM.

Research

The team headed by Dr Claire White of Kings College London for an assessor blind randomised controlled trial of a tailored home exercise programme versus usual care in people with stable inflammatory neuropathies has now almost completed their work. Many of our subscribers took part in the trial.

Gavin Meehan, a post graduate student at Glasgow University, is coming to the end of his funding for the research project on the analysis of anti-GM1 antibodies in autoimmune neuropathies. Awaiting report.

IGOS, an international collaborative research project was supported by GAIN in year 3. A further grant was awarded, through competition in 2015-16 to complete the work.

All the final reports will be made available to members once they are completed.

Publicity and media coverage

We have had a significant amount of media attention this year, mostly because of the possible link with Zika virus. We have made most papers, magazines and TV. However, the charity name is often left out!

Working alongside other, far bigger, neurological charities has ensured that our name is heard when dealing with Parliament on those occasions where we are trying to ensure that neurology is on the NHS agenda.

One of our members, with our support, is creating a stage show about GBS which go on tour later in 2016. Details of dates and venues will be passed to members.

Despite being a relatively new website we are highly placed on Google search result for 'GBS' and for 'CIDP'.

Governance

One trustee retired during the year, and one was appointed to the Board. The Board is actively recruiting new trustees to ensure a range of skills are met to enable them to lead this charity over the forthcoming years

Management

The office continues to grow and develop new ways to reach and support those affected by the illnesses. As society changes we have to adapt and offer the best solution for the time. We have seen the decline in Branches and attendance at conferences over the last few years. In 2015-16 we held 2 regional events which were well attended, one in Peterborough and one in York. Feedback suggested that those that had been more recently affected found these events beneficial; whereas those that had been diagnosed many years ago would have preferred a more social gathering or even a formal conference.

2016 will see us return to a more traditional event with *gain2gether* Glasgow.

Fundraising Activity

The total of funds raised or donated, including legacies, for the Charity was £229,915.59. The Trustees give their sincere thanks to all those who have organised events, raised funds or made donations throughout the year.

Membership

The number of voting membership is shown as a significant risk to the sustainability of the charity as it has dropped to 285 members. This trend is on the downward slope and as members voted to allow the charity to adopt a foundation model constitution, then Trustees will have this on the agenda to ensure that the charity can continue to operate. In contrast the number of non-voting members has increased to around the 3500 mark and continues to rise.

Financial Review

Trustees' Financial Responsibilities

The Constitution requires the Trustees to obtain independently-examined financial statements for each financial year. These present the financial transactions of the Charity during the year and the disposition at the yearend of its assets and liabilities.

In having these financial statements prepared the Trustees are required to:

- ensure accounting policies are applied consistently;

- make judgments and estimates that are reasonable and prudent;
- act in accordance with the Constitution;
- ensure that the financial statements are prepared on a going concern basis unless it is inappropriate to do so.

Trustees have a duty under Charity Law to ensure the propriety of transactions and to maintain adequate accounting records to enable them to have financial statements prepared. They are responsible for safeguarding the Charity's assets and taking reasonable steps for the prevention of fraud and other irregularities.

General

Our financial position continues to be good despite the economic downturn. Fundraising by our supporters continues to be of great importance to the charity and continues to yield a fantastic total.

The Trustees have decided to safeguard the financial assets that we must spread the reserves around more accounts, this is to limit the risk of loss of funds above £75,000 should the bank lose the funds. This will be done in the 2016-17 financial year.

The Trustees remain confident that the Charity is well placed and resourced to discharge its objectives in 2016-17.

Policy on Reserves

The Trustees discourage the accumulation of funds for no specific purpose. However, because of the expense of research projects and the need to minimise risk, it has been necessary to accumulate a certain level of reserves.

Plans for Future Periods

To continue to provide information about GBS/CIDP to patients, families and the medical professions that is evidence based, constructive and positive.

We intend to re-define our approach to raising the profile of the condition using a variety of traditional and new forms of media. We are planning a major

gain2gether to be held in Glasgow in 2016 in association with the meeting of the International Nerve Consortium to mark the centenary of Drs Guillain's and Barré's studies of French soldiers suffering from acute GBS.

We will implement our proposals for membership and the dissemination of our publications to ensure that we get maximum benefit from our income.

Signed on behalf of the Trustees by
James Babington Smith, Chairman

A handwritten signature in blue ink, reading "James Babington Smith". The signature is written in a cursive style with a large initial 'J'.

Guillain-Barré & Associated Inflammatory Neuropathies

Independent examiner's report on the financial statements of the Guillain-Barré & Associated Inflammatory Neuropathies (GAIN)

We report on the financial statements of GAIN for the year ended 31st March 2016 set out on pages 1 to 6.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for preparing the financial statements in accordance with applicable law, regulations and requirements.

The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) or under Regulation 10(1)(a) to (c) of The Charities Accounts (Scotland) Regulations 2006 (the 2006 Accounts Regulation) and that an independent examination is needed. The charity is preparing accrued accounts and we are qualified to undertake the examination by being a qualified member of the Association of Chartered Certified Accountants.

It is our responsibility to:

- examine the financial statements under section 145 of the Charities Act 2011 and section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 (the 2005 Act);
- to follow the procedures laid down in the General Directions given by the Charity Commission (under section 145(5)(b) of the 2011 Act); and
- to state whether particular matters have come to our attention.

Basis of independent examiner's report

Our examination was carried out in accordance with general Directions given by the Charity Commission and is in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. 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 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 no opinion is given as to whether the accounts present a 'true and fair' view and the report is limited to those matters set out in the independent examiner's statement.

Guillain-Barré & Associated Inflammatory Neuropathies

Independent examiner's report on the financial statements of the Guillain-Barré & Associated Inflammatory Neuropathies (GAIN) continued

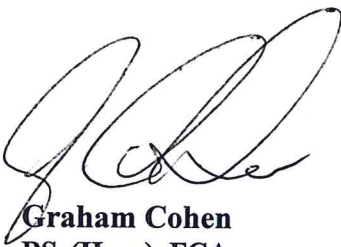
Independent examiner's statement

In the course of our examination, no matter has come to our attention:

1. which gives us reasonable cause to believe that in any material respect, the requirements:
 - to keep accounting records in accordance with section 130 of the 2011 Act and section 44(1)(a) of the 2005 Act and Regulation 4 of the 2006 Accounts and Regulations; and
 - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Act and section 44(1)(b) of the 2005 Act and Regulation 8 of the 2006 Regulations

have not been met; or

2. to which, in our opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



Graham Cohen
BSc(Hons) FCA

Aynesley Walters Cohen Limited
Chartered Certified Accountants and
Registered Auditors

16 South End
Croydon
Surrey CR0 1DN

Date: 10.6.2016

Guillain-Barre Associated Inflammatory Neuropathies (GAIN)
Statement of Financial Activities for the year ended 31 March 2016

Statement of Financial Activities for the year ended 31 March 2016

	Notes	2016 Unrestricted Funds	2016 Restricted Funds	2015 Total	2015 Total
<u>Income & Expenditure</u>					
Income Resources					
Donations, Legacies & similar income	2	126,227	29,447	155,674	144,409
Income from Operating Activities	3	87,945	0	87,945	87,507
Interest		486	0	486	758
		<u>214,658</u>	<u>29,447</u>	<u>244,105</u>	<u>232,674</u>
Resources Expended					
Costs of generating funds	4	7,935	0	7,935	19,233
Charitable expenditure	5	66,231	44,434	110,665	138,576
Governance costs	6	9,686	0	9,686	7,567
		<u>83,852</u>	<u>44,434</u>	<u>128,286</u>	<u>165,376</u>
Net Incoming Resources for the year		130,806	-14,987	115,819	67,298
Fund balances brought forward - 1.4.15		206,084	17,842	223,926	156,628
Fund balances carried forward - 31.3.16		<u>336,890</u>	<u>2,855</u>	<u>339,745</u>	<u>223,926</u>

The notes on pages 3 - 6 form part of these accounts

Guillain-Barre Associated Inflammatory Neuropathies (GAIN)
Statement of Financial Activities for the year ended 31 March 2016

Balance Sheet as at 31 March 2016

	Notes	2016 £	2016 £	2015 £	2015 £
Tangible Fixed Assets	7		0		0
Current Assets:					
Debtors	8	17,770		7,693	
Cash at banks and in hand	9	<u>350,562</u>		<u>276,220</u>	
		368,332		283,913	
Current Liabilities					
Creditors falling due within one year	10	<u>28,587</u>		<u>59,987</u>	
			339,745		223,926
Net Assets			<u>339,745</u>		<u>223,926</u>
Funds					
Unrestricted	12		336,890		168,713
Restricted	13		<u>2,855</u>		<u>55,213</u>
			<u>339,745</u>		<u>223,926</u>

The notes on pages 3 - 6 form part of these accounts

The accounts were approved by the Trustees on 23rd. April 2016

James Babington Smith
Chairman

David Wada
National Treasurer

Guillain-Barre Associated Inflammatory Neuropathies (GAIN)
Statement of Financial Activities for the year ended 31 March 2016

Notes to the Accounts for the Year ended 31 March 2016

1. Accounting Policies

(i) Basis of accounting

The accounts have been prepared under the historic cost convention and in accordance with the applicable standards and the Statement of Recommended Practice on Accounting by Charities.

(ii) Fixed Assets

Fixed Assets are included in the Balance Sheet at cost less provision for depreciation.

Depreciation is provided to write off the cost on a straight-line basis over the estimated useful lives of the assets and their anticipated residual values as follows:

Computer Equipment	5 years
Other equipment	5 years

(iii) Stocks

The Group uses promotional items to raise funds. Although the Group carries a small stock of such items, no value has been attributed to these in these accounts.

(iv) Grants payable

The Group's liability to pay grants to third parties is recognised as soon as the obligation arises. In the case of grants which are material to the Group, obligations are only recognised when sufficient funds are to hand to meet the requirements of the project.

(v) Subscriptions, donations & voluntary income

These are recognised on receipt and, as far as is practicable, are reported gross. Income Tax recoverable from HMRC in respect of subscriptions & donations made under Gift Aid is recognised in the year in which the relevant income is received.

2. Donations, Legacies & similar income

	2016	2016	2015	2015
	£	£	£	£
Membership subscriptions		5,432		15,873
Restricted donations				
Awareness - medical	149		17,996	
Research	29,298		2,535	
		29,447		20,531
Unrestricted donations				
In Memoriam	17,998		11,393	
Legacies	62,605		45,872	
Gift Aid recoverable	4,581		4,539	
Gain A Million Appeal	10		7,450	
Other	35,601		38,751	
		120,795		108,005
		155,674		144,409

Guillain-Barre Associated Inflammatory Neuropathies (GAIN)
Statement of Financial Activities for the year ended 31 March 2016

Notes to the Accounts for the Year ended 31 March 2016

3. Incoming resources from Operating Activities

	2016	2015
	£	£
Fundraising events	81,181	75,590
Raffle	3,074	4,646
Sale of cards & goods	3,690	7,271
Income from Conferences & Meetings	0	0
	<u>87,945</u>	<u>87,507</u>

4. Costs of Generating Funds

Raffle	1,449	1,514
Cards & other goods	901	1,922
Other	5,585	15,797
	<u>7,935</u>	<u>19,233</u>

5. Charitable Expenditure

(a) Grants payable

Research Grants	0	0
-----------------	---	---

(b) Other

Group Magazines	10,118	12,471
Conferences & Meetings	1,105	3,106
Awareness:		
Group publications & other costs	9,692	15,359
Play (see note 18)	2,500	0
Local contact activity	289	296
Website & Database costs	620	1,576
Welfare	3,250	6,019
Miscellaneous (see note 19)	83,091	99,749
	<u>110,665</u>	<u>138,576</u>

6. Governance Costs

Trustees' Expenses (see note 14)	4,846	2,787
Audit costs	340	280
Office costs	4,500	4,500
	<u>9,686</u>	<u>7,567</u>

Guillain-Barre Associated Inflammatory Neuropathies (GAIN)
Statement of Financial Activities for the year ended 31 March 2016

Notes to the Accounts for the Year ended 31 March 2016

	2016	2015
	£	£
7. Tangible Fixed Assets		
Net book value - 1st. April 2015	0	0
Net book value - 31st. March 2016	0	0
There were no additions to fixed assets during the year		

8. Debtors

Prepayments	13,422	3,157
Accrued Income	4,348	4,536
	<u>17,770</u>	<u>7,693</u>

9. Cash at banks & in hand

Charities Aid Foundation	336,695	261,725
UK Clearing Banks	13,817	14,445
Cash in Hand	50	50
	<u>350,562</u>	<u>276,220</u>

10. Creditors due within one year

Grants & charitable commitments	16,852	53,034
Accruals	10,852	6,070
Funds held on behalf of Branches	883	883
	<u>28,587</u>	<u>59,987</u>

11. Creditors due after one year

There were no creditors due after one year	<u>0</u>	<u>0</u>
--	----------	----------

12. Funds

	Unrestricted	Restricted	Total
Balances at 1st. April 2016	206,084	17,842	223,926
Movements in year	130,806	-14,987	115,819
Balances at 31st. March 2016	<u>336,890</u>	<u>2,855</u>	<u>339,745</u>

13. Restricted Funds	Balance	Movements		Balance
	1.4.15	Incoming	Outgoing	31.3.16
Awareness - Medical	0	148	148	0
Research	17,842	29,299	44,286	2,855
	<u>17,842</u>	<u>29,447</u>	<u>44,434</u>	<u>2,855</u>

Purposes of Restricted Funds

The Group has received donations to support specific activities. The balances at the end of the year represent amounts not yet spent and which are available for the above mentioned categories of charitable expenditure.

Notes to the Accounts for the Year ended 31 March 2016

14. Trustees' Remuneration and Expenses

No trustee received any remuneration from the charity during the year. Expenses incurred by trustees and re-imbursed by the Group amount to :

	2016	2015
	£	£
Charitable expenditure	0	0
Management & administration of the Group:		
Report on Complaint	2,709	0
Travel & subsistence	2,037	2,647
Accommodation	100	140
	<u>4,846</u>	<u>2,787</u>
Number of Trustees re-imbursed	5	7

15. Indemnity Insurance

Gain purchases insurance to protect itself from losses arising from neglect or default of its trustees, employees or agents and to indemnify the trustees against consequences of any neglect or default on their part.

16. Employees

The total emoluments of the Group's employees were £63,100 (2015 - £72,729).

The average number of employees was 3 (2015 - 3). No employees are paid over £60,000 per annum.

17. Administration Costs

The administration costs formed 14.77% of the income for the 12 months to 31.3.16 (2015 - 16.77%)

18. The charity is supporting a play about the Guillain Barre Syndrome in order to improve awareness.

19. Miscellaneous covers adverts, licenses, subscriptions, bank and card charges as well as office costs (salaries, travel and payroll, rent, service charges, sundries and telephones).