



2015
ANNUAL REPORT
& ACCOUNTS

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CHAIRMAN'S REPORT

This year has turned out to be a very challenging one. In line with many charities in our sector and beyond we suffered a downturn in our income from that projected for the year. This is due to a variety of circumstances including a reduction in income from the various Trusts to whom we had been applying for funding for both specific projects and to pay for some of the overheads. This in turn was partially as a result of the fundraiser we were using not being available for most of the year.

The Board has been working hard analysing our cost base to see how we can reduce the costs in line with the reduction in income. At the board meeting in November the Board authorised the CEO to identify and engage with a new fundraiser so that we can restore our income in 2016.

I am making my annual plea for more people to come forward to be considered to become a Trustee of the Charity. In case you feel that you do not have the time or skills it takes to be a Trustee you should know that the work load is very light; two meetings per year and a few Skype-based committee meetings. We are looking for people with plain, good old fashioned common sense, but having specific skills such as an understanding of business, IT, law, etc, would be particularly useful. Contact any member of the Board or feel free to contact me to discuss this in confidence.

Finally I would personally like to thank the Trustees, Officers, Volunteers and Fundraisers for all the hard work they have done during 2015 and are continuing to do in 2016 in support of you, our members.

A handwritten signature in blue ink, appearing to read 'Bob Francis', followed by a horizontal line.

Bob Francis, JP
Chair of the AMEND Board of Trustees (Outgoing)
19th March, 2016

CONSTITUTIONAL AIMS AND OBJECTIVES

The object of the CIO is to relieve people who suffer from Multiple Endocrine Neoplasia (M.E.N.) of all types, their families, friends and carers by all or any of the following means:

- (1) Acting as a reliable and accurate source of information for the public concerning M.E.N. and its associated sporadic growths, by:
 - (a) Working within the approval of members of the medical profession who are directly involved in the treatment of and research into M.E.N.
 - (b) Collecting, collating and distributing appropriate and approved information.
 - (c) Producing the Charity's own patient-aimed approved information.
- (2) Promoting a wider knowledge of the illness among the medical profession to assist in early and accurate diagnosis.
- (3) Providing reliable and accurate information with regard to genetic testing for people with M.E.N. and its associated familial growths, their families, friends and carers.
- (4) Providing emotional support to patients, their families, friends and carers in the form of contact with others in similar situations in order to facilitate the sharing of experiences.

AMEND AND THE TRUSTEES

The Trustee Board present their annual report together with the financial accounts of the Charity for the year ended 31 December 2015.

Structure, Governance and Management

AMEND is a Charitable Incorporated Organisation governed by a Constitution, vesting control and responsibility in the Trustee Board on behalf of the membership. The Trustees hold regular meetings to administer the Charity and their terms of office are determined by the AMEND Constitution. The term of office for an AMEND Trustee is three years beginning from the Annual General Meeting when voting in takes place.

Trustees' Responsibilities for the Financial Statements

The trustees are responsible for preparing the Trustees' Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England & Wales requires the trustees to prepare financial statements for each financial year which 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 for that period. In preparing these financial statements, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation

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 Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. 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.

The trustees are responsible for the maintenance and integrity of the charity and financial information included on the charity's website. Legislation in the United Kingdom governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

CHANGES TO AMEND AND THE TRUSTEE BOARD

There were no changes to the AMEND Constitution during 2015.
Ms Edel Murphy was elected to the Trustee Board at the AGM in May.

"For me, the telephone counselling was exactly what I needed at that moment in time. It was utterly invaluable"
(patient)

"...many thanks for the incredible welcome pack...it seems so packed with useful information & tools and look forward to working my way through it"
(newly diagnosed patient)

"Excellent day, I have felt very isolated but now feel I have a network of support. A big thank you"
(patient about AMEND's Annual Information Day)

CHIEF EXECUTIVE'S REPORT

Dear all,

Every year at this time, I struggle to remember what on earth we did during the previous 12 months. This is when I go back over our newsletters for the year and come away somewhat pleasantly surprised - and wondering if I need to have my brain fog looked into at my next hospital appointment! Indeed, once again, it would seem that there has been plenty going on.

Our aims and objectives are always printed towards the beginning of each annual report, and I suspect are often skipped over given that it's in the 'boring bit'. However; refreshing ourselves about these is always useful in putting our achievements and plans into perspective:

Acting as a reliable source of information on MEN and genetic testing

We have three main ways of approaching this aim: information resources, events and online.

During 2015 we updated and reprinted our patient information booklets for MEN2a and MEN2b. These now include glossaries and a slightly more simplified language in line with current resource development advice. Both now in their third edition, the booklets were updated with the help of the AMEND medical advisory team, and were funded thanks to a Society for Endocrinology Patient Group Grant.

In September, the British Medical Association recognised the innovative work of AMEND in producing information resources for children, awarding our children's cartoons on MEN1 and MEN2 a Highly Commended certificate in their Patient Information Awards.

We are very grateful to volunteer, Luan Cherry, who worked hard to develop transcriptions for our popular website patient experience videos. This opens up this resource more for those with hearing difficulties, in line with the transcriptions already available for our children's cartoons.

Our 2015 Information Day in May was another success, with attendee numbers continuing to grow. Once again, superb speakers were available to help us understand a range of applicable elements to our disorders. Feedback on the event in Leeds was extremely positive but also very useful for our 2016 Information Day preparations. In October we hosted a well-attended Roadshow event in Edinburgh. Thanks to all the medical professionals who give their time freely to be involved at all our events.

AMEND's social media presence continues to grow in popularity in our increasingly mobile age. AMEND's Facebook Page received 1,200 'Likes' during 2015 resulting in a total of 3,482 people following the Page. Favourite posts of 2015 were our #scarproud campaign, kids' cartoons and news of AMEND's 2015 Research Awards totalling £50,000. Our Twitter followers grew rapidly during 2015 too, with a total number of 247 by year end, the majority of who were from the UK. Nevertheless, our website is still valued greatly for its detailed information and downloadable resources. In December we took down our website forum which is now replaced with a private Facebook Group.

Raising awareness about MEN with the medical profession

Throughout 2015 AMEND continued to exhibit our resources and services at a number of professional medical events to raise awareness of what we can provide to patients. We are very grateful to the organisers of the Endocrine Nurse Update, British Endocrine Society, European Neuroendocrine Tumour Society, European Congress on Endocrinology and the International Thyroid Forum meetings for free exhibition and delegate places.

AMEND was delighted to be invited to give two talks this year at the British Endocrine Society meeting in Edinburgh. My own talk aimed to give medical professionals an insight into the importance of information resources tailored specifically for public consumption rather than filled with medical jargon. AMEND Counsellor, Kym Winter gave attending specialist endocrine nurses

a stark insight into the potential mental health issues affecting patients with MEN. Both talks were well received and provided a great opportunity to raise AMEND's profile.

Research awards for MEN are few and far between and thus AMEND's annual awards generate a considerable amount of interest with those doctors who have a special interest in the conditions. This year we were thrilled to be able to offer £50,000 worth of awards, with £40,000 specifically towards research into medullary thyroid cancer in recognition of late member, Chris Murray, in whose name a majority of the 2014 fundraising was done. Four excellent projects were funded and we look forward to hearing about their progress in 2016.

Providing emotional support to patients, families, friends and carers

This year saw AMEND begin a project on emotional well-being. A survey of users of the AMEND counselling service provided plenty of evidence of how important this service is, but highlighted the need for extended hours as well as the need for several publications on a variety of topics. Thanks to funding from the St James's Place Foundation, we were able to expand the hours for the counselling service from 3 to 5 per week. In addition, AMEND's Counsellor, Kym Winter, authored two new self-help leaflets covering two themes common to users; Dealing with Diagnosis and Living with Uncertainty. Kym also oversaw the development of a video and a variety of podcasts on Mindfulness, a meditative relaxation technique that can be useful in helping to alleviate stress and anxiety. As usual, all these resources were made freely available to all.

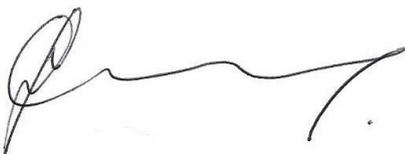
The future

The importance of providing mental health support has been underestimated with respect to multiple endocrine neoplasia for far too long. With AMEND's growing expertise in this area, we are well-placed to continue to raise awareness with the medical profession of the issues and to continue to develop new and innovative resources to help improve the emotional well-being of families affected by MEN.

Other social aspects of living with a chronic genetic condition have been highlighted by AMEND's membership as requiring resources, including information and guidance on such topics as starting a family, returning to work and transitioning from paediatric to adult endocrine NHS services.

All existing and newly developed resources need a new and more accessible platform to house them, and therefore another priority in 2016 will be to source funding and develop a new website and other online applications.

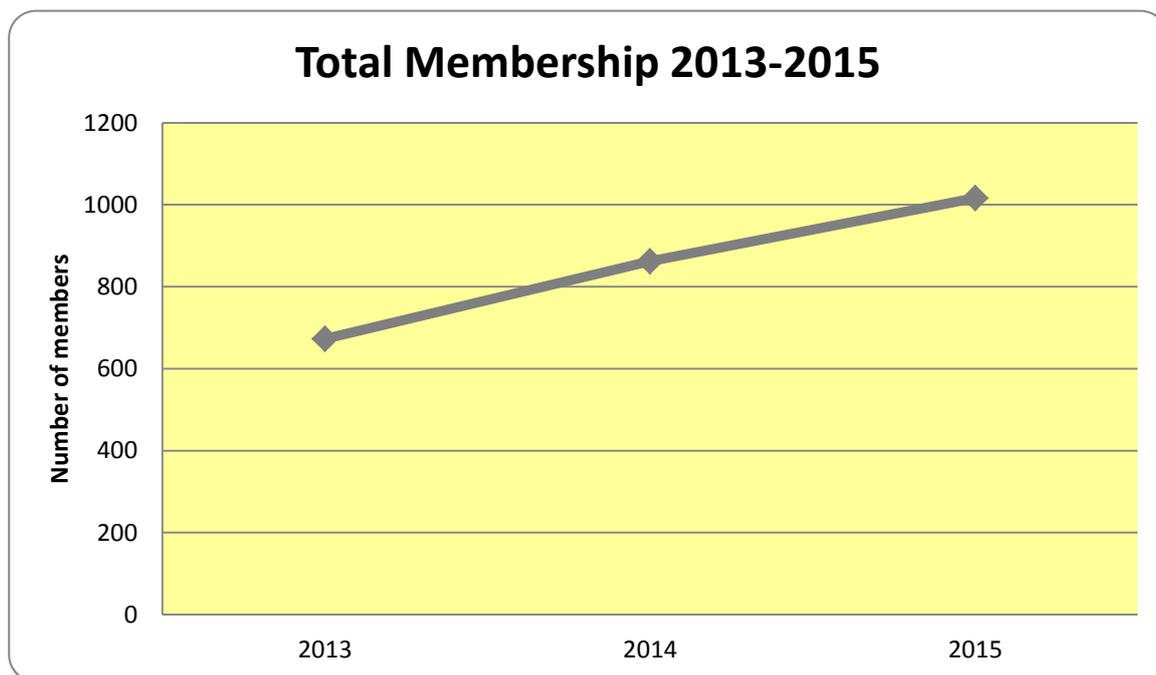
We look forward to starting on our new projects and to achieving many of them by the end of 2016. It's going to be another busy year. However, nothing would be achieved without the considerable input from the Board, staff and volunteers. We desperately need more volunteers so please do contact me or drop in for a visit if you are interested in getting involved in any area of our work. Thanks to everyone who has helped to ensure that AMEND continues to thrive in such difficult financial times.



Jo Grey
AMEND Chief Executive Officer
19th March, 2016

MEMBERSHIP REPORT

2015 saw our continued steady upward trend in membership registrations resulting in a total membership of 1,016 by year end compared with 862 at the end of 2014.



Whilst the majority of our membership base is understandably in the UK, patients from many countries around the world also continue to appreciate AMEND's free online resources and services.

FUNDRAISING REPORT

Huge thanks go to the following for their extraordinary fundraising efforts and financial or in-kind donations during 2015:

Adam Barnes, Kevin Masters, Stephanie Fox, David Short, Steph Mather, Sam Meadows, Simon Williams, Alan Grey, Lois Grey, Jo Grey, Professor Karim Meeran, Marium Meeran, Caroline Beasley, Lauren Winsor, Adam Greenwood, Dorota Wozniak, Haleigh Richardson and co, the Catley family, Danielle Broderick, June and David Vickers, Mala Malani (Mindfulness practitioner), Jack Hobbs (Jacket Records), In Kind Direct, Luan Cherry, Novartis Pharmaceuticals UK Ltd, HRA Pharma UK & Ireland Ltd, Society for Endocrinology, The Albert Hunt Trust, The Houghton Dunn Charitable Trust, Advance Security Ltd, European Neuroendocrine Tumour Society, St James's Place Foundation, The Austin and Hope Pilkington Trust.

Thank you also to the families of Richard Dunn, Dulcie Walker, Sylvia Russell and David Murray, who arranged collections in aid of AMEND in memory of their loved ones.

A special plea was sent out to all members in October and we were pleased by the response. Thank you to all those who arranged one-off or regular donations as a result.

Towards the end of the year, donations were made a little easier to do by setting up CAF Donate. This system is linked directly to AMEND's bank accounts and also deals with Gift Aid for us.

TREASURER'S REPORT

2015 results

2015 was a financially challenging year for AMEND with total income decreasing from £178,760 in 2014 to £92,991 in 2015. This significant drop in income meant that we ended the 2015 year with a net deficit of £45,765. When considering this deficit, however, we do need to take into account that we made a significant contribution of £50,000 to research projects focusing on advancing MEN and MTC treatment during the year.

In my 2014 report, I highlighted that one of the challenges for AMEND in 2015 was to secure funding to replace the Big Lottery funding that made a significant contribution to our support costs. Unfortunately, we were not able to achieve this in 2015 but, having taken on additional fundraising support at the end of 2015, we are hopeful that we can achieve this in 2016. We do need this funding in order for us to continue to offer the same level of patient support going forward.

Reserves

AMEND's unrestricted reserves now stand at £72,937 (2014 £78,447). These general reserves are held in case of any sudden decline in income and to ensure that our commitment to provide core patient support activities can continue to be made with some confidence. We aim to retain sufficient general funds approximately equivalent to twelve months' core services expenditure.



Catherine Hamilton-Woodthorpe
Treasurer
19th March, 2016



STATEMENT OF FINANCIAL ACTIVITIES

For the Year ended 31 December 2015

		2015			2014
	notes	Restricted £	Unrestricted £	Total Funds £	Total Funds £
Income and endowments from					
Donations and legacies	5	36,524	53,103	89,627	125,145
Charitable activities		-	2,903	2,903	53,169
Investments		-	461	461	446
Total income and endowments		<u>36,524</u>	<u>56,467</u>	<u>92,991</u>	<u>178,760</u>
Expenditure on					
Raising funds		-	6,200	6,200	9,820
Charitable activities	6	21,492	73,876	95,368	60,234
Support costs	7	5,287	30,370	35,657	37,278
Governance costs	8	-	1,531	1,531	1,768
Total expenditure		<u>26,779</u>	<u>111,977</u>	<u>138,756</u>	<u>109,100</u>
Net income / (expenditure)		9,745	(55,510)	(45,765)	69,660
Reconciliation of Funds					
Total funds brought forward		<u>12,669</u>	<u>128,447</u>	<u>141,116</u>	71,456
Total funds carried forward		<u><u>22,414</u></u>	<u><u>72,937</u></u>	<u><u>95,351</u></u>	<u><u>141,116</u></u>

BALANCE SHEET

As at 31 December 2015

	note	2015 £	2014 £
Fixed Assets	9	-	-
Current Assets			
Loan to AMEND USA		5,000	5,000
Prepayments and accrued income		1,562	1,766
Stock		1,500	1,500
Cash at bank			
Deposit account		96,585	117,500
Current accounts		977	17,794
		<u>105,624</u>	<u>143,560</u>
Current Liabilities			
Creditors		(9,923)	(2,094)
Accruals		(350)	(350)
		<u>(10,273)</u>	<u>(2,444)</u>
Net Current Assets		<u>95,351</u>	<u>141,116</u>
Total Net Assets		<u>95,351</u>	<u>141,116</u>
The Funds of the Charity			
Unrestricted funds		72,937	78,447
Designated research fund		-	50,000
Restricted income funds	10	<u>22,414</u>	<u>12,669</u>
Total Charity Funds		<u>95,351</u>	<u>141,116</u>

These financial statements were approved by the Trustees on 19th March 2016, and are signed on their behalf by



Catherine Hamilton-Woodthorpe
Treasurer
19th March, 2016

NOTES TO THE FINANCIAL STATEMENTS

For the year ended 31 December 2015

1. ACCOUNTING POLICIES

The financial statements have been prepared under the historical cost convention and in accordance with applicable accounting standards and with the Charities Accounting Statement of Recommended Practice (SORP 2015).

a) Grants and voluntary income

All grants and voluntary income are accounted for in the year when they are received unless receipt has become certain at the balance sheet date.

b) Deferred income

Income which has been received for a purpose which has not been commenced at the balance sheet date is deferred to a future period.

c) Other income and expenditure

Other income and expenditure is accounted for on the accruals basis.

d) Resources expended

Resources expended are recognised in the period in which they are incurred, and include attributable VAT which cannot be recovered. Expenditure is allocated by activity in the first instance and, where practical, is also allocated to a cost centre.

e) Allocation of costs

Costs directly related to an activity are allocated to that activity. Support costs which are necessary to deliver an activity but do not themselves deliver the activity, are allocated in proportion to the benefit attributable based on an internal assessment of time spent and resources used.

Governance costs are those costs incurred in meeting statutory and constitutional requirements.

f) Investments

All investments stated as current, being monetary assets, are stated at cost.

g) Stocks

Promotional merchandise, held for sale, is valued at cost.

h) Fixed assets and depreciation

Fixed assets are capitalised and depreciated over the estimated useful life as follows: 33% on cost.

i) Funds

- Unrestricted funds are those which are received from funding bodies and other donors and can be spent on the general objectives at the discretion of the trustees.
- Restricted funds are those which are given for a specific purpose or project as defined by the funder, and where the funder may require repayment if the conditions are not met.
- Designated funds are unrestricted funds which have been earmarked by the trustees for specific, usually short term, purpose within the general objectives.

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2015

j) Donated goods and services

Donated goods and services are included at their value to the charity as determined by the trustees.

2. TAXATION

As a registered Charitable Incorporated Organisation, the association is not liable to income or capital taxes.

3. TRUSTEE REMUNERATION

No trustee received any remuneration. 5 trustees received reimbursement of travel and subsistence expenses amounting to £827.02 to enable them to attend conferences, the AGM and trustee meetings.

4. STAFF COSTS AND NUMBERS

	2015	2014
	£	£
Wages and salaries	34,138	33,790
National Insurance	506	619
	<u>34,644</u>	<u>34,409</u>
Management and administration	1	1
Patient Support Administrator	1	1

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2015

	2015	2014
	£	£
5. DONATIONS AND LEGACIES		
Donations and gift aid	15,627	34,089
Grants	74,000	91,056
	<u>89,627</u>	<u>125,145</u>
6. CHARITABLE ACTIVITIES		
Project Superhero	-	24,123
Payroll	17,322	17,204
Patient information printing and booklets	5,836	1,832
Patient information events and conferences	7,453	3,145
Research grants and awards	51,861	12,081
ACC support	6,831	-
Patient support and counselling	5,912	651
International development	153	1,198
	<u>95,368</u>	<u>60,234</u>
7. SUPPORT COSTS		
Rent	11,820	11,820
Payroll	17,322	17,205
Printing, postage and office supplies	2,439	3,862
Telephone	323	602
IT support	762	690
Insurance	703	572
Finance charges	83	-
Marketing and publicity	1,361	1,207
Miscellaneous	844	1,320
	<u>35,657</u>	<u>37,278</u>
8. GOVERNANCE		
Independent Examiner	350	350
Trustee meetings and AGM	1181	1418
	<u>1531</u>	<u>1768</u>

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2015

9. TANGIBLE FIXED ASSETS	Equipment £
Cost	
At 1/1/15 and 31/12/15	<u>9,473</u>
Depreciation	
Balance brought forward	9,473
Charge for the year	<u>-</u>
At 31/12/15	<u>9,473</u>
Net book value at 31/12/15	<u>-</u>
Net book value at 1/1/15	<u>-</u>

10. RESTRICTED INCOME FUNDS

	B/forward £	Income £	Direct costs £	Support costs £	Balance £
Anonymous donor	832	5,000	(416)	(416)	5,000
Society for Endocrinology	2,995	-	(2,684)	-	311
ACC Support UK	8,842	10,524	(6,831)	-	12,535
Austin & Hope Pilkington Trust	-	1,000	(575)	-	425
St James's Place Foundation	-	10,000	(5,857)	-	4,143
Novartis Pharmaceuticals UK	-	10,000	(5,129)	(4,871)	-
	<u>12,669</u>	<u>36,524</u>	<u>(21,492)</u>	<u>(5,287)</u>	<u>22,414</u>

The anonymous donor funds a patient support administrator.

The Society for Endocrinology is funding an update of four patient information titles.

ACC Support UK is for a standalone group for patients in the UK with adrenocortical cancer, in a joint venture with the NET Patient Foundation.

The Austin & Hope Pilkington Trust provided £1,000 towards counselling and patient support services.

The St James's Place Foundation provided £10,000 to pay for 230 counselling sessions.

Novartis Pharmaceuticals UK provided a patient group grant towards the costs of the AMEND 2015 Patient Information Day

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES

I report on the accounts of the charity for the year ended 31 December 2015 which are set out on pages 8 to 13.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. 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) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act;
- follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act; and
- 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 Commission. 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 statement below.

Independent examiner's statement

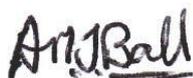
In connection with my examination, no matter has come to my attention:

1 which gives me reasonable cause to believe that, in any material respect, the requirements:

- to keep accounting records in accordance with section 130 of the 2011 Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 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.



AMJ Ball
BA, FCA, FCIE
75, Banner Cross Road
Sheffield
S11 9HQ
1st March, 2016

CONTACT INFORMATION

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Twitter: <https://www.twitter.com/AmendInfo>

Jo Grey (CEO)

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AMEND Trustee Board

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Catherine Hamilton-Woodthorpe

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Gill Underhill (MEN1 Rep)

Tel: 01455 553437; Email: gill.underhill@amend.org.uk

Dr Simon Williams (outgoing)

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Edel Murphy

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Mr Barney Harrison

Consult. Surgeon, Sheffield (retired)

Professor Karim Meeran (outgoing)

Professor of Endocrinology, Imperial College, London

Patrons

Recorder, Mrs Jo Delahunty, QC, MA (Oxon) Jurisprudence

Professor Rajesh Thakker, May Professor of Medicine, OCDEM, Churchill Hospital, Oxford

AMEND UK Medical Advisory Team (AMAT)

Dr Caroline Brain, Professor Ashley Grossman, Mr Barney Harrison, Dr Fiona Laloo, Professor Tom Lennard, Mr David Scott-Coombes, Professor Rajesh Thakker

Accountant

Mr A M J Ball, BA, FCA, FCIE

Chartered Accountant

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UK

2015 SPONSORS

Our thanks go to the following for their generous financial or in kind assistance during 2015:

Charitable Trust Funds – The Houghton Dunn Charitable Trust, St James's Place Foundation, Austin & Hope Pilkington Trust

Pharmaceutical Companies – Novartis, HRA Pharma

Society for Endocrinology (SfE) – free event exhibition and delegate spaces at annual BES, ENU and Clinical Update meetings throughout the year

International NET Cancer Alliance – travel expenses to attend INCA members' meeting

UK & Ireland Neuroendocrine Tumour Society (UKINETS) – free event exhibition and delegate space at annual meeting

Advance Security Ltd – continued inter-office fundraising

Huddle Inc. – free licence software