

2022

Annual Report & Accounts

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CONSTITUTIONAL AIMS AND OBJECTIVES

The object of the Charitable Incorporated Organisation (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 2022.

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.



Barney Harrison
Outgoing Chair of the AMEND Board of Trustees
4 September, 2023

CHANGES TO AMEND AND THE TRUSTEE BOARD

New Trustees:

The following Trustees were appointed to the Board at the 2022 AGM:

1. Graeme Cohen
2. Bob Millinship
3. Sarah Norman

Retiring Trustees:

The following Trustees retired during 2022 and we thank them wholeheartedly for their service to AMEND over the years:

1. Laura Jones
2. Louise Breen

Trustee Executive Committee:

There were no changes to the Executive Committee during 2022

CHAIRPERSON'S REPORT

During my 11 years on the Board:

1. AMEND has never stopped moving forward in terms of the resources it provides to its users.
2. Despite increased activity and expansion, AMEND has remained efficient and effective.
3. AMEND's reach nationally and internationally has grown.
4. The commitment shown by both Jo and Helen to AMEND is the keystone of the charity's success.

To the Trustees past and present, thank you for your patience with the Chair. Thanks to Jo and Helen for their gentle guidance.

I wish AMEND continued success and have no doubt with Gill taking on her new role the future is assured.



Barney Harrison
Outgoing Chair of the AMEND Board of Trustees
4 September, 2023

CHIEF EXECUTIVE'S REPORT

Dear all,

2022 was another year of continued change, despite the lessening impact of the pandemic. Big changes included moving office half-way through the year, to a smaller and slightly cheaper home in Tonbridge. Later in the year, the Trustees undertook a Strategic Plan review to plan for the next few years when charities, including ours, will face tougher times, particularly financially. This resulted in plans to help secure the sustainability of the charity, alongside our everyday work of providing information resources and support services to our disease communities.

As usual, our fundraisers, grantees, and donors were essential to the success of our work-streams, and we thank you all for your continued support from the bottom of our hearts.



Jo Grey
AMEND Chief Executive Officer
4 September, 2023

2022 OVERVIEW

Source of Information



AMEND spent over £4,750 on an audio visual resource: specifically a cartoon for children aged 5 to 8 years affected by inherited paraganglioma syndromes

66 members registered to attend the 2022 Annual Patient Information Day in Manchester for free at a cost of £50 per head to AMEND

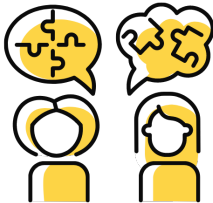


Provision of Support



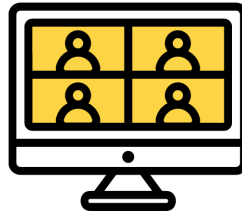
187 new patient & family members, and 13 health professionals joined AMEND for free in 2022.

169 membership packs (worth £10 each) were sent out by AMEND to new members costing £1,690



200 counselling sessions were provided to AMEND members at a cost of £50 per session. Counsellors also provided support sessions to volunteers at a cost of £85 per hour and attended the Information Day to provide support for Young Adults.

8 virtual peer support meetings were held during 2022 for the benefit of our members. 100% of those who responded to the feedback survey were keen to repeat the experience



Raise Awareness of MEN & Associated Endocrine Conditions



AMEND had a presence at 4 in-person UK medical conferences (exhibition stands and a talk) including ECE 2022, where AMEND hosted a patient hub session on behalf of EMENA

The AMEND CEO gave a patient participation lecture to 2nd year medical students at University College London, another lecture to MSc endocrinology students at QMUL, and a presentation on patient experience of MEN syndromes to endocrine nurses at a conference



Advocacy



AMEND was granted affiliated member status of the Society for Endocrinology (UK) and the European Society for Endocrinology

The AMEND CEO was appointed to represent the ACC Community within the Scottish ACC Committee to help improve the patient pathway for those with ACC in Scotland



Research



AMEND approved funding of 2 research projects (PPGL, ACC) worth a total of almost £17,000. A £10,000 ACC Research grant was provided by the Elliot Dallen Trust for administration by AMEND

AMEND continued recruitment for Community Advisory Groups to assist in providing the patient voice to research.



2023 AND BEYOND

The current and forecast economic climate is worrying for UK charities, with higher costs and reduced donations and grants. Our focus for the next few years is on sustainability of finances and personnel, whilst continuing to address our core aims of providing quality information resources and support services to our communities. The Board of Trustees developed a new strategic plan at the end of 2022 to take these issues into account going forwards.

Plans remain to develop a smartphone app to replace and expand on our MEN Passports, as well as resources on signs and symptoms of our tumours for GPs. We will also investigate more collaborative opportunities with other registered charities to maximise resources.

For anyone interested in getting involved, please visit our website where you will find information on volunteering.

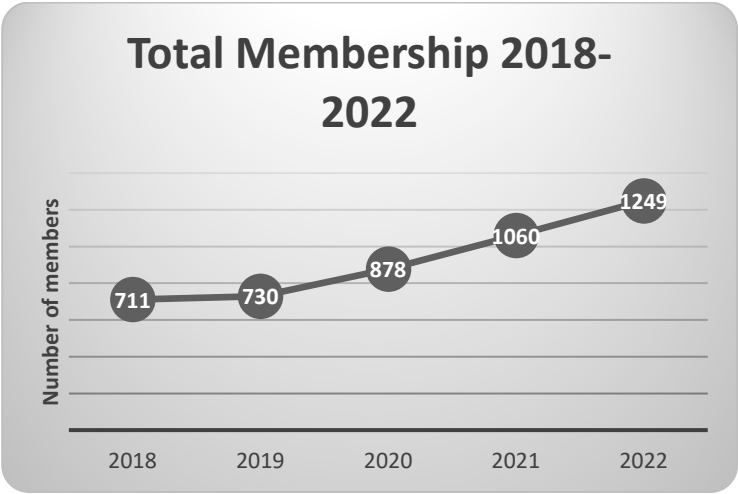


MEMBERSHIP REPORT

AMEND offers free membership to patients, their family and friends, as well as to healthcare professionals. Our patient communities cover multiple endocrine neoplasia disorders, phaeochromocytoma & paraganglioma syndromes, adrenocortical cancer, sporadic phaeochromocytomas and medullary thyroid cancer.



AMEND’s patient/family members totalled 1249 by the end of 2022 (1060 in 2021), showing its continued upward membership registrations.



Whilst much of our membership base is understandably in the UK, patients from many countries around the world also continue to appreciate AMEND’s membership benefits. A charge applies to overseas members to cover the cost of shipping Membership Packs where requested.

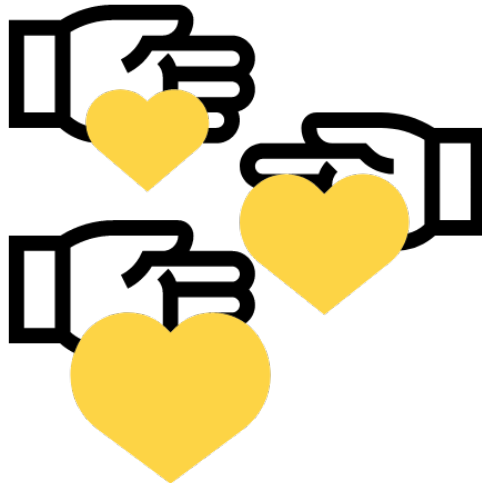
FUNDRAISING REPORT

Huge thanks go to the following for their extraordinary fundraising efforts and financial or in-kind donations during 2022:

Jack Maynard and Team (National 3 Peaks Challenge), Tina Masters and family (Virtual Lands End to John O'Groats), Jason (Twitch), Kerry Godfrey (craft sales), Natalie Keeling (Lockton Charitable Association nomination), Elly Fitzgibbon, Alan Maw, Jatinder Bedi, Haspreet Bhatwal, Gurminder Kainth and Karim Meeran (ASICS London 10k Run), Jo Grey, Alan Grey, Kelly McGee, Kathy Rice and Anna Savin (Petra Trek), Sarah Webb (Cycle the Nile), George Wandless and Marc Donnison (Great North Run), Kate Richmond, Elly Fitzgibbon, Gill Waller and Emma Williams (Great South Run), Amy Atkin (Pavilion Day Nursery Fundraiser), Fern Richardson (Leicester Half Marathon), Kenny Taggart and Sara Wilson (Great Scottish Half Marathon), Not the Fayers Cup Charity Golf Challenge teams.

Thank you to our 2022 corporate or grant-giving supporters: the Houghton Dunn Charitable Trust, the Society for Endocrinology, HRA Pharma, and the Elliot Dallen Trust.

Finally, thank you to everyone who has donated (anonymously or not), or offered their time for free over the past year. You really make a difference!



TREASURER'S REPORT

2022 results. The charity's total incoming resources were £130,264 (2021 £93,239) – up 39.7% on the previous year but still less than the income we received prior to the Covid-19 pandemic. We would like to thank our members and grant funders who continued to support us during the year.

Although our income was up, our expenses were up as well and the charity ended the year with a small deficit of £9,132. The expenditure included £18,950 in research grants.

Reserves. AMEND's undesignated unrestricted reserves now stand at £49,093 (2021 £47,821). Due to the high-risk nature of our main funding stream (voluntary grants and donations), we aim to retain general funds of £60,000. This is a level reasonable enough to ensure that AMEND could continue to operate its core activities for six months while enabling it to identify and utilise replacement funding streams.

A handwritten signature in blue ink, reading "C Hamilton-Woodthorpe". The signature is written in a cursive, flowing style.

Catherine Hamilton-Woodthorpe
Treasurer
4 September, 2023

STATEMENT OF FINANCIAL ACTIVITIES

For the Year ended 31 December 2022

		2022			2021		
	notes	Restricted £	Unrestricted £	Total Funds £	Restricted £	Unrestricted £	Total Funds £
Income and endowments from:							
Donations and legacies	5	-	92,603	92,603	-	81,428	81,428
Charitable activities	6	36,791	10	36,801	10,880	193	11,073
Other trading activities	7	-	416	416	10	689	699
Investments		-	444	444	-	39	39
Total income and endowments		36,791	93,473	130,264	10,890	82,349	93,239
Expenditure on:							
Raising funds	8	-	9,767	9,767	-	8,427	8,427
Charitable activities	9	28,727	74,060	102,787	40,966	57,827	98,793
Support costs	10	-	24,843	24,843	-	21,498	21,498
Governance costs	11	-	1,999	1,999	36	883	919
Total expenditure		28,727	110,669	139,397	41,002	88,635	129,637
Net income / (expenditure)		8,064	(17,196)	(9,132)	(30,112)	(6,286)	(36,398)
Transfers between funds	13	1,134	(1,134)	-	6,533	(6,533)	-
Net movement in funds		9,198	(18,330)	(9,132)	(23,579)	(12,819)	(36,398)
Reconciliation of funds							
Total funds brought forward		14,022	151,770	165,792	37,601	164,589	202,190
Total funds carried forward		23,220	133,440	156,660	14,022	151,770	165,792

BALANCE SHEET

As at 31 December 2022

	note	2022 £	2021 £
Fixed assets	12	1,979	1,710
Current assets			
Stock		3,683	3,321
Prepayments and accrued income		3,540	1,300
Cash at bank			
Deposit account		140,218	155,066
Current accounts		11,070	5,712
		<u>158,511</u>	<u>165,399</u>
Creditors: amounts falling due within one year			
Trade creditors		(2,205)	(6)
Payroll taxes		(503)	(363)
Pensions payable		(522)	(348)
Accruals		(600)	(600)
		<u>(3,830)</u>	<u>(1,317)</u>
Net current assets		<u>154,681</u>	<u>164,082</u>
Total net assets		<u>156,660</u>	<u>165,792</u>
Funds of the Charity			
Restricted income fund	13	23,220	14,022
Designated funds	14	84,347	103,949
Unrestricted funds		49,093	47,821
		<u></u>	<u></u>
Total Charity Funds		<u>156,660</u>	<u>165,792</u>

These financial statements were approved by the Trustees on 5 September, 2023, and are signed on their behalf by



Catherine Hamilton-Woodthorpe
Treasurer
4 September, 2023

NOTES TO THE FINANCIAL STATEMENTS

For the year ended 31 December 2022

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 FRS 102).

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.

j) Donated goods and services

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

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2022

2. TAXATION

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

3. TRUSTEE REMUNERATION

No Trustees received any remuneration in 2022. 5 Trustees received reimbursement totalling £347.45 (2021: £149.65) to cover the cost of travel to attend board meetings and conferences to represent AMEND.

4. STAFF COSTS AND AVERAGE NUMBERS

	2022 £	2021 £
Wages and salaries	44,072	39,109
Employer pension contributions	<u>1,322</u>	<u>1,173</u>
	<u>45,394</u>	<u>40,282</u>
Management and administration	1	1
Patient Support administrator	<u>1</u>	<u>1</u>
Total	2	2

	2022			2021
	Restricted £	Unrestricted £	Total £	Total £
5. DONATIONS AND LEGACIES				
Donations and gift aid	-	62,103	62,103	51,428
Grants	-	30,500	30,500	30,000
	-	<u>92,603</u>	<u>92,603</u>	<u>81,428</u>
6. INCOME FROM CHARITABLE ACTIVITIES				
Grants for charitable activities	36,791	-	36,791	10,880
Other	-	10	10	193
	<u>36,791</u>	<u>10</u>	<u>36,801</u>	<u>11,073</u>
7. INCOME FROM OTHER TRADING ACTIVITIES				
Sale of merchandise	-	416	416	699
	-	<u>416</u>	<u>416</u>	<u>699</u>

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2022

	2022			2021
	Restricted	Unrestricted	Total	Total
	£	£	£	£
8. RAISING FUNDS				
Staff costs	-	7,086	7,086	6,445
Merchandise	-	628	628	657
Other	-	2,053	2,053	1,325
	-	9,767	9,767	8,427
9. CHARITABLE ACTIVITIES				
Staff costs	-	23,947	23,947	22,265
Patient information printing, booklets and websites	2,481	3,104	5,585	2,943
Patient information events and conferences	7,310	1,966	9,276	17,902
Patient education films	-	10,321	10,321	14,888
Patient representation	-	100	100	-
Research grants and awards	10,000	18,950	28,950	19,595
ACC support and ACC research grants	2,499	-	2,499	840
ACC staff costs	834	8,023	8,857	8,056
Patient support and counselling	5,603	7,649	13,252	12,304
	28,727	74,060	102,787	98,793
10. SUPPORT COSTS				
Rent	-	12,856	12,856	14,534
Staff costs	-	4,396	4,396	3,516
Printing, postage and office supplies	-	1,236	1,236	846
Telephone	-	318	318	-
IT support	-	810	810	209
IT software and consumables	-	1,292	1,292	606
Insurance	-	704	704	632
Finance charges	-	294	294	122
Exchange difference	-	(183)	(183)	-
Depreciation	-	931	931	999
Legal fees	-	35	35	35
Repairs and maintenance	-	618	618	-
Travel and accommodation	-	435	435	-
General	-	37	37	-
Office move	-	1,065	1,065	-
	-	24,843	24,843	21,499
11. GOVERNANCE				
Independent examiner	-	-	-	600
Trustee meetings, AGM and other	-	1,999	1,999	319
	-	1,999	1,999	919

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2022

12. TANGIBLE FIXED ASSETS

	Equipment £
Cost	
At 1/1/22	12,921
Additions	1,200
At 31/12/22	<u>14,121</u>
Depreciation	
At 1/1/22	11,211
Charge for the year	931
At 31/12/22	<u>12,142</u>
Net book value at 31/12/22	<u>1,979</u>
Net book value at 1/1/22	<u>1,710</u>

13. RESTRICTED INCOME FUNDS

	B/forward	Income	Direct costs	Transfer from reserves	Balance
	£	£	£	£	£
Anonymous donor	677	-	(677)	-	-
ACC Support UK	-	3,333	(3,333)	-	-
Cartoon Licence	380	-	(380)	-	-
Sanofi	86	-	(86)	-	-
Barnes Construction Golf Day	7,079	-	-	-	7,079
HRA Pharma - ACC films	5,000	-	-	-	5,000
Licence to use ACC film clips	800	-	-	-	800
Society for Endocrinology	-	4,105	(2,514)	-	1,591
Big Give - Counselling	-	3,263	(3,263)	-	-
Big Lottery - Regional Volunteers	-	9,090	(340)	-	8,750
HRA Pharma - Counselling	-	2,000	(2,000)	-	-
HRA Pharma - APID 2022	-	5,000	(6,134)	1,134	-
Elliot Dallon	-	10,000	(10,000)	-	-
	<u>14,022</u>	<u>36,791</u>	<u>(28,727)</u>	<u>1,134</u>	<u>23,220</u>

- A trust fund, who prefer to remain anonymous, provided £11,000 in 2018 for redevelopment of the AMEND website.
- ACC Support UK is for a standalone group for patients in the UK with adrenocortical cancer, in a joint venture with the Neuroendocrine Cancer UK.
- A cartoon licence was granted to Belangengroup MEN in The Netherlands to translate and use our children's cartoons on MEN.
- Sanofi provided a patient group grant towards the costs of sporadic medullary thyroid cancer patient event in 2018
- Ipsen provided an unrestricted grant to develop patient films about MEN2A
- The proceeds of Barnes Construction's Gold Day are to be used for MEN1 research awards
- HRA Pharma provided a grant in 2019 to produce ACC patient films
- Licence given to HRA Pharma for use of ACC patient film clips and to be used against ACC podcasts in 2023

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2022

13. RESTRICTED INCOME FUNDS (Continued)

- Society for Endocrinology Patient Group Grant to update resources
- The Big Give Christmas Challenge Campaign raised funds for our Counselling Service
- The National Lottery Community Fund provided a grant for our Peer Support Meetings for 2022-2023
- HRA Pharma provided a grant to help with the costs of our 2022 Annual Patient Information Day and Counselling Service
- The Elliot Dallon Charitable Trust provided a grant of £10,000 for a research grant into adrenocortical cancer.

14. DESIGNATED FUNDS

	B/forward	Income	Direct costs	Transfer to unrestricted	Balance
	£	£	£	£	£
Counselling service	5,730	10,000	(6,652)	-	9,078
Research Fund	63,469	-	(18,950)	-	44,519
Hardship fund	750	-	-	-	750
Personnel contingency fund	30,000	-	-	-	30,000
Research Registry Project	4,000	-	-	(4,000)	-
	103,949	10,000	(25,602)	(4,000)	84,347

15. RELATED PARTY TRANSACTIONS

There were no related party transactions in 2021 or 2022.

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES

Independent Examiner's Report to the Trustees of the AMEND Charity

I report to the charity trustees on my examination of the accounts of the charity for the year ended 31 December 2022 which are set out on pages 12 to 18.

Responsibilities and basis of report

As the charity's trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 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.

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.

Signed:

Chris Lamb, FCA
Independent Examiner
Raymond Benn & Co. Ltd
1 Sheffield Road, Southborough
Tunbridge Wells, Kent
TN4 0PD

5 September, 2023



CONTACT INFORMATION

Association for Multiple Endocrine Neoplasia Disorders (AMEND)

Tyler House, 58-66 Morley Road

Tonbridge, Kent, TN9 1RA

01892 516076 / 841032

info@amend.org.uk

Website: www.amend.org.uk

Facebook: www.facebook.com/AssociationforMENDisorders

X: [@AmendInfo](https://www.twitter.com/AmendInfo)



Jo Grey (CEO)

Tel: 01892 516076

Email: jo.grey@amend.org.uk

Helen Blakebrough (Exec Admin)

Tel: 01892 841032

Email: helen@amend.org.uk

AMEND Trustee Board

Barney Harrison (Outgoing Chair)

Gill Masters

Dr John Ayuk

Andy Price

Robert Millinship

Graeme Cohen

Catherine Hamilton-Woodthorpe (Treasurer)

Professor Karim Meeran

Ms Miriam Asia, RN

Karen Williams

Sarah Norman

Patrons

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

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

Mr Shaun Williamson, Actor

AMEND UK Medical Advisory Team (AMAT)

Dr Caroline Brain, Professor Maralyn Druce, Professor Ashley Grossman, Dr Fiona

Laloo, Mr David Scott-Coombes, Professor Rajesh Thakker, Dr Scott Akker, Dr Ruth

Casy, Professor Wiebke Arlt, Dr Cristina Ronchi, Professor Nick Reed, Mr Radu Mihai

Independent Examiner

Mr Chris Lamb, FCA

Raymond Benn & Co Limited

Sheffield Stables

1 Sheffield Road

Southborough

Tunbridge Wells

Kent

TN4 0PD

