

2021

Annual Report & Accounts

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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 2021.

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

New Trustees:

The following Trustees were appointed to the Board at the 2021 AGM:

1. Andy Price
2. Karen Williams

Retiring Trustees:

The following Trustees retired during 2021 and we thank them wholeheartedly for their service to AMEND over the years:

1. Dr Simon Williams
2. Edel Murphy
3. Joel Russell-Winter

Trustee Executive Committee:

There were no changes to the Executive Committee during 2021

CHAIRPERSON'S REPORT

Key principles of AMEND include - Patient Support and Information / Patient Representation and Disease Awareness Raising / Research Funding and Involvement. There is much activity in these areas at present, best summarised as 'We can always do more'. With three new AMEND Trustees and the skill set that each brings, it is clear that the Charity continues to move in the right direction.



Barney Harrison
Chair of the AMEND Board of Trustees
25th September, 2022

CHIEF EXECUTIVE'S REPORT

Dear all,

Thanks to the rapid adaptations we made in 2020 and despite the occasional restrictions from new surges of coronavirus, we continued with our work as best we could and certainly achieved plenty to be proud of (pages 7-9).

Our adaptability was typified by our determination to ensure production of numerous film resources that we had been planning for some time. Project Rollercoaster's filming of adolescents and young adults discussing issues important to them went virtual during lockdown, with the films interjected with appropriate social media graphics to bring it as close as possible to its demographic. This was followed by location filming as soon as restrictions lifted (but with all precautions taken) to produce 6 excellent films – 3 each about MEN1 and MEN2.

At the heart of everything we do is our membership which continues to grow steadily. Not only do our members use our services and resources, but they also contribute massively to our projects, including all those who have starred in our patient experience films, our Community Advisory Groups members, Trustees, Medical Advisory Teams, fundraisers, and many, many more. You drive us to be better and to do more. Thank you for your confidence in us.

Wishing everyone the best of health,



Jo Grey
AMEND Chief Executive Officer
25th September, 2022

2021 OVERVIEW

Source of Information



AMEND spent over £14,888 on audio visual resources: 6 films about MEN1 and MEN2 costing and 16 short films for adolescents and young adults.

76 members attended the 2021 Annual Patient Information Day in London for free at a cost of £55 per head to AMEND

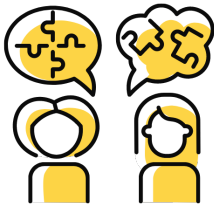


Provision of Support



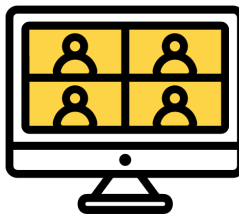
182 new patient & family members joined AMEND for free in 2021

137 membership packs (worth £10 each) were sent out by AMEND to new members costing £1,370



Over 200 counselling and supervision sessions were provided to AMEND members and volunteers at a cost of between £50 to £80 per hour respectively

8 virtual peer support meetings were held during 2021 for the benefit of almost 50 members. 100% of those surveyed were keen to repeat the experience



Raise Awareness of MEN & Associated Endocrine Conditions



AMEND had a presence at 2 in-person UK medical conferences (exhibition stands) and 1 online European conference where AMEND hosted a patient hub session with our Patron, Professor Raj Thakker

AMEND increased its social Media awareness activities, getting involved in World Cancer Day, Thyroid Cancer Month and Phaeo Para Awareness Week, amongst others



The AMEND CEO gave two patient participation lectures to 2nd year medical students at University College London, and an online public talk about patient involvement in research for the University of Birmingham

Advocacy

AMEND recruited 2 patient experts and made submissions to NICE and the SMC for the successful temporary approval of selpercatinib in RET-mutated thyroid cancer

NICE
SMC

Research



AMEND approved funding of 3 research projects (MEN1, PPGL, ACC) worth a total of almost £30,000 (1 invoice for £10,000 outstanding)

AMEND set up and began recruitment for 6 Community Advisory Groups to assist in providing the patient voice to research. The ACC and MTC CAGs began work on relevant research projects.



2022 AND BEYOND

We have a plethora of information resources that are due to be updated in 2022, as well as some adaptations for our other group, Phaeo Para Support UK, including a cartoon for children aged 5-8.

Our project to develop a smartphone app to replace and expand the utility of our MEN Passports across all the disease we support will begin this year. We expect this project to take 2-3 years to completion.

Our project to help reduce the time to diagnosis for our rare endocrine tumours and syndromes is still in the exploration stage but is gradually taking shape and will be recruiting volunteers to assist in due course.

We continue to recruit volunteers for our Community Advisory Groups for MEN2, MEN3 and PPGL syndromes, and look forward to our existing Groups getting involved in more research projects during 2022.

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

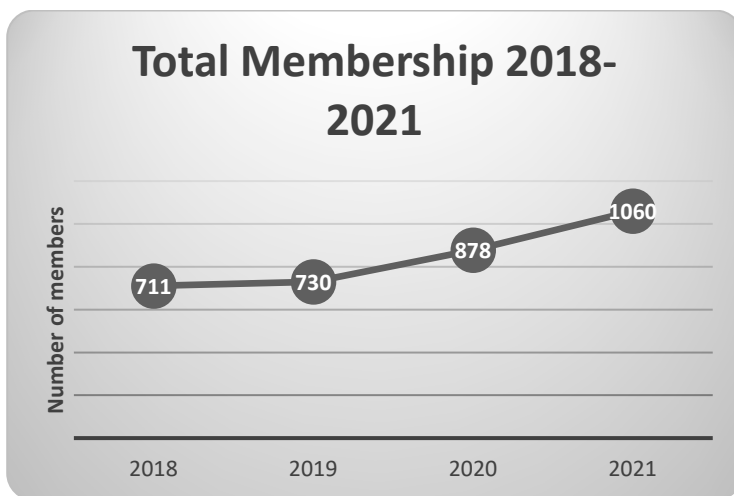


MEMBERSHIP REPORT

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



AMEND's patient/family members totalled 1060 by the end of 2021 (878 in 2020), 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.

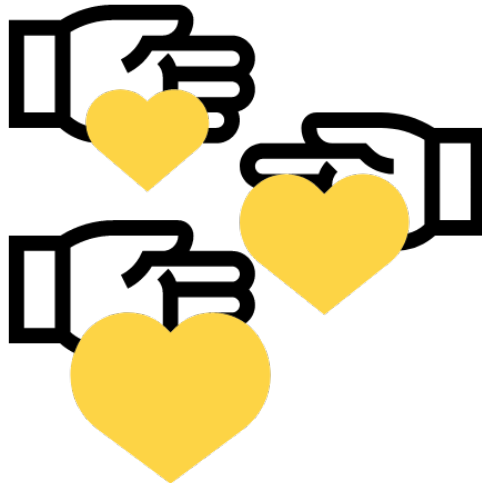
FUNDRAISING REPORT

Huge thanks go to the following for their extraordinary fundraising efforts and financial or in-kind donations during 2021:

Thank you to 2021 supporters: the Houghton Dunn Charitable Trust, the Nick Fayers Research Fund, Ipsen, AAA UK & Ireland Ltd, the Society for Endocrinology, the Barnes Group Ltd

Big thanks to our committed fundraisers who found great ways to support AMEND during 2021: Josh Dickson and Jan Burbie (London Marathon), London 10k runners Jaspreet Bhatiwala, Jatinder Bell, Gurminder Kainth, Nadia Krauhaus, James Donaldson and David Thomas. Paula McGough (Ring of Kerry Virtual Challenge), Emma Williams, Sarah Norman and Lisa Kramer Fit to Fight, Nicki Swindells (Auction and fundraising dinner), George, Isaac, Joe, Harvey and Finn (Duke of Edinburgh Bronze Award fundraising), Danyal and Dilhan Akarca (various fundraising over the year), Anthony and Gillie O'Flaherty (Etape Loch Ness), Jack Maynard (3 peaks challenge), Alan Grey (Isle of Wight trek), William Fayers (Cambridge Half Marathon), Wildridings primary school and Jessica Heyland.

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

2021 results. The charity's total incoming resources were £93,239 (2020 £109,814) – down 15% on the previous year and now less than 50% of 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 another difficult year.

The extent of the fall in income was not reflected by comparable fall in expenses which led to the charity ending the year with a deficit of £36,398. Despite this, we managed to designate a further £9,000 towards our very valuable counselling service and made research grants and awards totalling £19,595 during the year. Another significant expense for AMEND this year was £14,888 on patient education films.

Reserves. AMEND's undesignated unrestricted reserves now stand at £47,821 (2020 £46,775). 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.



Catherine Hamilton-Woodthorpe
Treasurer
25th September 2022

STATEMENT OF FINANCIAL ACTIVITIES

For the Year ended 31 December 2021

			2021			2020		
	notes	Restricted	Unrestricted	Total Funds	Restricted	Unrestricted	Total Funds	
		£	£	£	£	£	£	£
Income and endowments from:								
Donations and legacies	5	-	81,428	81,428	7,079	81,129	88,208	
Charitable activities	6	10,880	193	11,073	19,636	79	19,715	
Other trading activities	7	10	689	699	800	893	1,693	
Investments		-	39	39	-	198	198	
Total income and endowments		10,890	82,349	93,239	27,515	82,299	109,814	
Expenditure on:								
Raising funds	8	-	8,427	8,427	-	8,235	8,235	
Charitable activities	9	40,966	57,827	98,793	23,583	60,766	84,349	
Support costs	10	-	21,498	21,498	-	17,435	17,435	
Governance costs	11	36	883	919	-	1,336	1,336	
Total expenditure		41,002	88,635	129,637	23,583	87,772	111,355	
Net income / (expenditure)		(30,112)	(6,286)	(36,398)	3,932	(5,473)	(1,541)	
Transfers between funds	13	6,533	(6,533)	-	1,404	(1,404)	-	
Net movement in funds		(23,579)	(12,819)	(36,398)	5,336	(6,877)	(1,541)	
Reconciliation of funds								
Total funds brought forward		37,601	164,589	202,190	32,265	171,466	203,731	
Total funds carried forward		14,022	151,770	165,792	37,601	164,589	202,190	

BALANCE SHEET

As at 31 December 2021

				2021	2020
			note	£	£
Fixed assets			12	1,710	511
Current assets					
Stocks				3,321	3,978
Trade debtors				-	200
Prepayments and accrued income				1,300	1,896
Cash at bank					
Deposit account				155,066	144,878
Current accounts				5,712	52,918
				<u>165,399</u>	<u>203,870</u>
Creditors: amounts falling due within one year					
Trade creditors				(6)	(889)
Payroll taxes				(363)	(473)
Pensions payable				(348)	(229)
Accruals				(600)	(600)
				<u>(1,317)</u>	<u>(2,191)</u>
Net current assets				<u>164,082</u>	<u>201,679</u>
Total net assets				<u>165,792</u>	<u>202,190</u>
Funds of the Charity					
Restricted income funds		13		14,022	37,601
Designated funds		14		103,949	117,814
Unrestricted funds				47,821	46,775
Total Charity Funds				<u>165,792</u>	<u>202,190</u>

These financial statements were approved by the Trustees on 28th September, 2022, and are signed on their behalf by



Catherine Hamilton-Woodthorpe
Treasurer
28th September, 2022

NOTES TO THE FINANCIAL STATEMENTS

For the year ended 31 December 2021

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 2021

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. One trustee received reimbursement of travel and subsistence expenses amounting to £149.65 (2020: Two trustees; £310.85) to enable them to attend conferences, the AGM and trustee meetings.

4. STAFF COSTS AND AVERAGE NUMBERS

	2021 £	2020 £
Wages and salaries	39,109	38,395
Employer pension contributions	<u>1,173</u>	<u>577</u>
	<u>40,282</u>	<u>38,972</u>
Management and administration	1	1
Patient Support administrator	<u>1</u>	<u>1</u>
Total	2	2

		2021		2020
	Restricted	Unrestricted	Total	Total
	£	£	£	£
5. DONATIONS AND LEGACIES				
Donations and gift aid	-	51,428	51,428	58,208
Grants	-	30,000	30,000	30,000
	-	<u>81,428</u>	<u>81,428</u>	<u>88,208</u>
6. INCOME FROM CHARITABLE ACTIVITIES				
Grants for charitable activities	10,880	-	10,880	19,636
Other	-	193	193	79
	<u>10,880</u>	<u>193</u>	<u>11,073</u>	<u>19,715</u>
7. INCOME FROM OTHER TRADING ACTIVITIES				
Grant of licence to show ACC film clips	-	-	-	800
Sale of merchandise	10	689	699	893
	<u>10</u>	<u>689</u>	<u>699</u>	<u>1,693</u>

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2021`

					2021		2020
					Restricted	Unrestricted	Total
					£	£	£
							Total
							£
8. RAISING FUNDS							
	Staff costs				-	6,445	6,445
	Merchandise				-	657	657
	Other				-	1,325	1,325
					-	8,427	8,427
							8,235
9. CHARITABLE ACTIVITIES							
	Staff costs				-	22,265	22,265
	Patient information printing, booklets and website				-	2,943	2,943
	Patient information events and conferences				10,082	7,820	17,902
	Patient education films				14,888	-	14,888
	Patient representation				-	-	-
	Research grants and awards				-	19,595	19,595
	ACC support and ACC research grants				840	-	840
	ACC staff costs				8,056	-	8,056
	Patient support and counselling				7,100	5,204	12,304
	International development				-	-	-
					40,966	57,827	98,793
							84,349
10. SUPPORT COSTS							
	Rent				-	14,534	14,534
	Staff costs				-	3,516	3,516
	Printing, postage and office supplies				-	846	846
	IT support				-	209	209
	IT software and consumables				-	606	606
	Insurance				-	632	632
	Finance charges				-	122	122
	Depreciation				-	999	999
	Legal fees				-	35	35
					-	21,498	21,498
							17,435
11. GOVERNANCE							
	Independent examiner				-	600	600
	Trustee meetings, AGM and other				36	283	319
					36	883	919
							1,336
12. TANGIBLE FIXED ASSETS							
					Equipment		
					£		
	Cost						
	At 1/1/21					10,723	
	Additions					2,198	
	At 31/12/21					12,921	
	Depreciation						
	At 1/1/21					10,212	
	Charge for the year					999	
	At 31/12/21					11,211	
	Net book value at 31/12/21					1,710	
	Net book value at 1/1/21					511	

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2021

13. RESTRICTED INCOME FUNDS						
			B/forward	Income	Direct costs	Transfer from reserves
			£	£	£	£
Anonymous donor			677	-		-
ACC Support UK			8,140	10	(8,896)	746
The Big Give 2016 - Project Rollercoaster			4,513	-	(6,917)	2,404
Cartoon Licence			380			
Sanofi			86			
Ipsen - MEN2A films			2,190		(5,178)	2,988
AAA Pharma MEN1 Films			-	4,000	(4,230)	230
ITM Solucin			1,636	-	(1,801)	165
Barnes Construction Golf Day			7,079			
HRA Pharma - ACC films			5,000			
Licence to use ACC film clips			800			
National Lottery - Counselling			7,100	-	(7,100)	-
Ipsen 2021 Patient Information Day			-	1,400	(1,400)	-
Ipsen - MEN1 films			-	5,480	(5,480)	-
						-
			37,601	10,890	(41,002)	6,533
						14,022

- 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 Neuroendocrine Cancer UK.
- Project Rollercoaster was a project to develop resources to support young adults through transition from paediatric to adult endocrine services.
- 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
- AAA Pharma provided an unrestricted grant to develop patients films about MEN1
- ITM Solucin provided a grant for the 2020 Annual Patient Information Day, deferred to 2021 due to covid-19 pandemic
- The proceeds of Barnes Construction's Golf 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
- The National Lottery covid-19 Emergency Fund provided a grant to help fund the Counselling Service

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2021

14. DESIGNATED FUNDS						
		B/forward	Income	Direct costs	Staff costs	Balance
		£	£	£	£	£
Counselling service		-	9,000	(3,270)		5,730
Research Fund		83,064	-	(19,595)	-	63,469
Hardship fund		750	-	-	-	750
Personnel contingency fund		30,000	-	-	-	30,000
Research Registry Project		4,000	-	-	-	4,000
		117,814	9,000	(22,865)	-	103,949
15. RELATED PARTY TRANSACTIONS						
There were no related party transactions in 2021 or 2020.						

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES

I report on the accounts of the charity for the year ended 31 December 2021 which are set out on pages 12 to 18.

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.

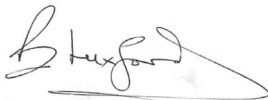
Basis of independent examiner's report

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 Acthave 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.



Brian Luxford
Independent Examiner
Raymond Benn & Co. Ltd
1 Sheffield Road, Southborough
Tunbridge Wells, Kent
TN4 0PD

26th September, 2022



CONTACT INFORMATION

AMEND

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Facebook: www.facebook.com/AssociationforMENDisorders

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



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AMEND Trustee Board

Barney Harrison (Chair)

Gill Masters

Mrs Laura Jones

Dr John Ayuk

Andy Price

Robert Millinship (co-opted 2021)

Graeme Cohen (co-opted 2022)

Catherine Hamilton-Woodthorpe (Treasurer)

Professor Karim Meeran

Ms Louise Breen, RN

Ms Miriam Asia, RN

Karen Williams

Sarah Norman (co-opted 2022)

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 Art, Professor Nick Reed, Mr Radu Mihai

Independent Examiner

Mr Brian Luxford, FCA

Raymond Benn & Co Limited

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