

2023

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 illnesses 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 2023.

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.



Gill Masters
Chair of the AMEND Board of Trustees
4th July 2024

CHANGES TO AMEND AND THE TRUSTEE BOARD

New Trustees:

The following Trustees were appointed to the Board at the 2023 AGM:

1. Shahab Khan

Retiring Trustees:

The following Trustee retired during 2023 and we thank them wholeheartedly for their service to AMEND over the years:

1. Barney Harrison (former Chair of Trustee Board)

Trustee Executive Committee Changes:

Mrs Gill Masters became Chair of the Trustee Board at the 2023 Annual General Meeting.

CHAIRPERSON'S REPORT

My first year in office has proven to be very interesting, busy and a steep learning curve. I am now officially retired and hope to be able to spend more time supporting patients and volunteering wherever I'm needed!

I don't think I ever fully appreciated how busy day-to-day life is at Amend, Jo and Helen are never without a long list of things to do, or places to be. I hope I haven't added to that too much with my questions and queries – and as I learn I hope to become slightly more useful! Thank you both whole-heartedly for your valuable input.

As always, there are opportunities to help in various forms – whether as a volunteer, a fundraiser or contributing to our newsletters with stories – please get involved if you'd like to be part of our amazing charity.

Financially, this year has been probably the toughest since I joined Amend in 2007 – as numbers increase, funds are diminishing due to higher costs and the inevitable tightening of belts. We rely on our fundraisers and supporters more than ever, and our thanks go to everyone who makes it possible to continue to support patients as we do.

As we move into another year, I would also like to personally thank our Board of Trustees who all give their time and knowledge freely to make sure the charity meets its obligations – you are all very much appreciated.



Gill Masters
Chair of the AMEND Board of Trustees
17th June, 2024

CHIEF EXECUTIVE'S REPORT

Dear all,

We had another busy year in 2023, providing information resources and support services to our rare endocrine disease communities. We continued with many of our activities despite the continuing reduction in income amidst the cost of living crisis.

We continued to raise the profile of the charity and the diseases we cover to raise awareness of the inequities in care, treatments and research. At the same time, we saw the usual increase in membership numbers. All members continue to benefit from all our free resources, events and counselling service.

More work was done during the year in relation to our updated Strategic Plan which focusses on ensuring that AMEND is sustainable, both financially and in terms of

personnel well into the future. We thank our Trustees for their continued support with this.

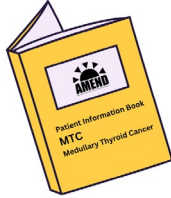
Huge thanks must go to our fundraisers, grantees, and donors who have been essential in seeing AMEND through these recent financially challenging times. Thanks also to all our wonderful volunteers, whose time given to AMEND is immeasurable. Thanks to you all for your continued support from the bottom of our hearts.

A handwritten signature in black ink, appearing to read 'Jo Grey', with a long horizontal flourish extending to the right.

Jo Grey
AMEND Chief Executive Officer
4th July 2024

2023 OVERVIEW

Source of Information



AMEND updated 2 existing information booklets and adapted 2 others specifically for Phaeo Para Support UK

72 members registered to attend the 2023 Annual Patient Information Day in London for free at a cost of £50 per head to AMEND.



For NET Cancer Day (11 November annually) we held a webinar with Professor Karim Meeran called NETs in RETs to explain the link between neuroendocrine neoplasms and Rare Endocrine Tumours and Syndromes



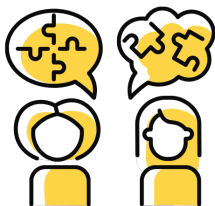
Provision of Support



160 new patient & family members, and 15 health professionals joined AMEND for free in 2023.

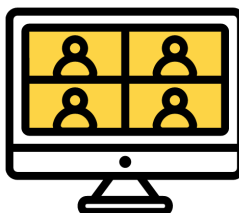
160 membership packs (worth £10 each) were sent out by AMEND to new members costing £1,600





207 counselling sessions were provided to 27 AMEND members by Rareminds at a cost of £60 per session. Rareminds 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.

11 peer support meetings were held during 2023 for the benefit of our members with MEN, PPGL and ACC. 100% of those who responded to the feedback survey found the meetings useful for meeting others and were keen to repeat the experience



Raise Awareness of MEN & Associated Endocrine Conditions



AMEND CEO gave a presentation on Unmet Needs and Patient Expectations in MEN syndromes at the World MEN Conference. AMEND also attended and exhibited at the Society for Endocrinology's Clinical Update and British Endocrine Society conferences.

The AMEND CEO engaged in the patient participation programme with 2nd year medical students at University College London, gave a lecture to MSc endocrinology students at QMUL, and a presentation on our Community Advisory Groups at the annual Summit of the International Neuroendocrine Cancer Alliance



Advocacy



AMEND was appointed to represent patients on the Society for Endocrinology's (UK) National Registry for Adrenal Tumours Project to develop a Registry and patient phone app

The AMEND CEO was appointed to represent the MEN1 patients with the European Neuroendocrine Tumour Society MEN1 Taskforce



Research



AMEND approved funding of a £10,000 ACC Research grant administered on behalf of the Elliot Dallen Trust.

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



2024 AND BEYOND

The financial situation in the UK for charities continues to be challenging, although is now slowly improving. As a result of our 2023-2026 Strategic Plan, AMEND is focussed on planning for the future through:

- Increasing sources of income to ensure future financial sustainability of AMEND
- Staff succession planning to ensure that the charity is prepared for changes in the future
- More collaborative working to support our main aims of providing information, support and awareness through the Neuroendocrine Life Alliance with Neuroendocrine Cancer UK
- Finding creative ways to provide the same resources and services for less.



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 1384 by the end of 2023 (1249 in 2022), 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.

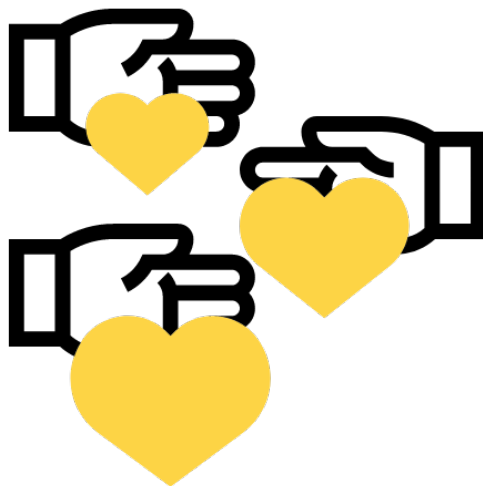
FUNDRAISING REPORT

Huge thanks go to the following for their extraordinary fundraising efforts and financial or in-kind donations during 2023:

Lia Sheriff, James Bell, Gill Masters, Elly Fitzgibbon, Hannah Ker, Finn and Cal Blakebrough, Clare Walton, Charmaine Chantler, Amy Lee, Erin Ruddy, Flora Manson, Tom Dunn, Rachel Mandley, Emily Mosedale, Mark Tolladay and friends, our London 10k runners, Hannah, Dan, Jatinder, Jaspreet, Davinder, Bikramjit and Katherine, and anyone we may have missed.

Thank you to our 2023 corporate or grant-giving supporters: the Houghton Dunn Charitable Trust, the Society for Endocrinology, HRA Pharma, The Barnes Group Ltd Not Fayers Golf Cup Tournament, 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

2023 results. The charity's total incoming resources were £80,668 (2022 £130,264). Given the enormous pressure on public spending and household budgets in 2023, UK charities inevitably saw a dip in income and AMEND was not immune to this. We would like to thank our members and grant funders who continued to support us during this 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 £31,624. Despite this, we managed to fund £12,955 towards our very valuable counselling service and made research grants and awards totalling £15,500 during the year.

Reserves. AMEND's undesignated unrestricted reserves now stand at £38,234 (2022 £49,093). Due to the high-risk nature of our main funding stream (voluntary grants and donations), we aim to retain general funds of around £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
4th July 2024

STATEMENT OF FINANCIAL ACTIVITIES

For the Year ended 31 December 2023

		2023			2022		
	notes	Restricted	Unrestricted	Total Funds	Restricted	Unrestricted	Total Funds
		£	£	£	£	£	£
Income and endowments from:							
Donations and legacies	5	-	66,788	66,788	-	92,603	92,603
Charitable activities	6	11,369	11	11,380	36,791	10	36,801
Other trading activities	7	-	523	523	-	416	416
Investments		-	1,977	1,977	-	444	444
Total income and endowments:		11,369	69,299	80,668	36,791	93,473	130,264
Expenditure on:							
Raising funds	8	-	9,635	9,635	-	9,767	9,767
Charitable activities	9	17,756	64,033	81,789	28,727	74,060	102,787
Support costs	10	-	17,967	17,967	-	24,843	24,843
Governance costs	11	-	2,901	2,901	-	1,999	1,999
Total expenditure		17,756	94,536	112,292	28,727	110,669	139,396
Net income / (expenditure)		(6,387)	(25,237)	(31,624)	8,064	(17,196)	(9,132)
Transfers between funds	13	200	(200)	-	1,134	(1,134)	-
Net movement in funds		(6,187)	(25,437)	(31,624)	9,198	(18,330)	(9,132)
Reconciliation of funds							
Total funds brought forward		23,220	133,440	156,660	14,022	151,770	165,792
Total funds carried forward		17,033	108,003	125,036	23,220	133,440	156,660

BALANCE SHEET

As at 31 December 2023

			2023	2022
		note	£	£
Fixed assets	12		1,040	1,979
Current assets				
Stock			3,166	3,683
Prepayments and accrued income			7,170	3,540
Cash at bank				
Deposit account			111,493	140,218
Current accounts			4,236	11,070
			<u>126,065</u>	<u>158,511</u>
Creditors: amounts falling due within one year				
Trade creditors			(1,025)	(2,205)
Payroll taxes			(195)	(503)
Pensions payable			(248)	(522)
Accruals			(600)	(600)
			<u>(2,068)</u>	<u>(3,830)</u>
Net current assets			123,997	154,681
Total net assets			<u>125,036</u>	<u>156,660</u>
Funds of the Charity				
Restricted income funds	13		17,033	23,220
Designated funds	14		69,769	84,347
Unrestricted funds			38,234	49,093
			<u>125,036</u>	<u>156,660</u>
Total Charity Funds			<u>125,036</u>	<u>156,660</u>

These financial statements were approved by the Trustees on [date], and are signed on their behalf by



Catherine Hamilton-Woodthorpe
Treasurer

4th July, 2024

NOTES TO THE FINANCIAL STATEMENTS

For the year ended 31 December 2023

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 –**
 - i. 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.
 - ii. 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.
 - iii. 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 2023

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 £518 (2022: Five trustees; £347) to enable them to attend conferences, the AGM and trustee meetings.

4. STAFF COSTS AND AVERAGE NUMBERS

	2023	2022
	£	£
Wages and salaries	43,923	44,072
Employer pension contributions	<u>1,318</u>	<u>1,322</u>
	<u>45,241</u>	<u>45,394</u>
Management and administration	1	1
Patient Support administrator	<u>1</u>	<u>1</u>
Total	2	2

5. DONATIONS AND LEGACIES

	2023			2022
	Restricted	Unrestricted	Total	Total
	£	£	£	£
Donations and gift aid	-	36,788	36,788	62,103
Grants	-	30,000	30,000	30,500
	-	66,788	66,788	92,603

6. INCOME FROM CHARITABLE ACTIVITIES

Grants for charitable activities	11,369	-	11,369	36,791
Other	-	11	11	10
	11,369	11	11,380	36,801

7. INCOME FROM OTHER TRADING ACTIVITIES

Sale of merchandise	-	523	523	416
	-	523	523	416

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2023

	2023			2022
	Restricted	Unrestricted	Total	Total
	£	£	£	£
8. RAISING FUNDS				
Staff costs	-	7,239	7,239	7,086
Merchandise	-	811	811	628
Other	-	1,585	1,585	2,053
	-	9,635	9,635	9,767

9. CHARITABLE ACTIVITIES

Staff costs		24,365	24,365	23,947
Patient information printing, booklets and websites	1,518	4,834	6,352	5,585
Patient information events and conferences	273	7,800	8,073	9,276
Patient education films	-	-	-	10,321
Patient representation	-	98	98	100
Research grants and awards	10,000	5,500	15,500	28,950
ACC support and ACC research grants	-	402	402	2,499
ACC staff costs	-	9,048	9,048	8,857
Patient support and counselling	5,965	11,602	17,567	13,252
PPS UK	-	384	384	-
	17,756	64,033	81,405	102,787

10. SUPPORT COSTS

Rent	-	9,360	9,360	12,856
Staff costs	-	4,589	4,589	4,396
Printing, postage and office supplies	-	661	661	1,236
Telephone	-	462	462	318
IT support	-	18	18	810
IT software and consumables	-	897	897	1,292
Insurance	-	625	625	704
Finance charges	-	157	157	294
Exchange difference	-	44	44	(184)
Depreciation	-	939	939	931
Legal fees	-	35	35	35
Repairs and maintenance	-	63	63	618
Travel and accommodation	-	-	-	435
Subscriptions	-	117	117	-
General	-	-	-	37
Office move	-	-	-	1,065
	-	17,967	17,967	24,843

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2023

	2023			2022
	Restricted	Unrestricted	Total	Total
	£	£	£	£
11. GOVERNANCE				
Independent examiner	-	2,400	2,400	-
Trustee meetings, AGM and other	-	501	501	1,999
	-	2,901	2,901	1,999

12. TANGIBLE FIXED ASSETS	Equipment
	£
Cost	
At 1/1/23	14,121
Additions	-
At 31/12/23	14,121
Depreciation	
At 1/1/23	12,142
Charge for the year	939
At 31/12/23	13,081
Net book value at 31/12/23	1,040
Net book value at 1/1/23	1,979

13. RESTRICTED INCOME FUNDS

	B/forward	Income	Direct costs	Transfer from reserves	Balance
	£	£	£	£	£
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	1,591	-	(1,791)	200	-
Big Give - Counselling	-	1,369	(1,369)	-	-
National Lottery Community Fund - peer support	8,750	-	(4,596)	-	4,154
Elliot Dallan Charitable Trust	-	10,000	(10,000)	-	-
	23,220	11,369	(17,756)	200	17,033

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 future ACC podcasts

Society for Endocrinology Patient Grant to update resources

Big Give Christmas Challenge Campaign raised funds for our Counselling Service

The Natinal Lottery Community Fund provided a grant for our Peer Support Meetings for 2022-23

The Elliot Dallan Chaitatble Trust provided a grant of £10,000 for a research grant into adrenocortical cancer.

NOTES TO THE FINANCIAL STATEMENTS (continued)
 For the year ended 31 December 2023

14. DESIGNATED FUNDS

	B/forward	Income	Direct costs	Transfer to unrestricted	Balance
	£	£	£	£	£
Counselling service	9,078	-	(11,586)	2,508	-
Research Fund	44,519	-	(5,500)	-	39,019
Hardship fund	750	-	-	-	750
Personnel contingency fund	30,000	-	-	-	30,000
	84,347	-	(17,086)	2,508	69,769

15. RELATED PARTY TRANSACTIONS

There were no related party transactions in 2022 or 2023.

INDEPENDENT EXAMINER’S REPORT TO THE TRUSTEES



CHARITY COMMISSION
FOR ENGLAND AND WALES

Independent examiner's report on the
accounts

Section A Independent Examiner's Report

Report to the trustees/
members of

Charity Name
Association for Multiple Endocrine Neoplasia Disorders

On accounts for the year
ended

31 December 2023
Charity no
(if any) 1153890

Set out on pages

One to twenty
(remember to include the page numbers of additional sheets)

I report to the trustees on my examination of the accounts of the above charity ("the Trust") for the year ended 31 December 2023.

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 Trust's accounts carried out under section 145 of the 2011 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 which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did 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: *M Bugby*

Date: 12 June 2024

Name: Matthew Bugby

Relevant professional
qualification(s) or body
(if any):

ACCA

Address: A K & Co (Accountancy Services) Limited
19 Victoria Terrace
Hove
East Sussex
BN3 2WB

CONTACT INFORMATION

Association for Multiple Endocrine Neoplasia Disorders (AMEND)

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Tonbridge, Kent, TN9 1RA

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info@amend.org.uk

Website: www.amend.org.uk

Facebook: www.facebook.com/AssociationforMENDdisorders

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



Jo Grey (CEO)

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Email: jo.grey@amend.org.uk

Helen Blakebrough (Exec Admin)

Tel: 01892 841032

Email: helen@amend.org.uk

AMEND Trustee Board 2023

Gill Masters (Chair)

Graeme Cohen

Dr John Ayuk

Andy Price

Robert Millinship

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, Dr Cristina Ronchi, Professor Nick Reed, Mr Radu Mihai

Independent Examiner

Matthew Bugby, ACCA

A K & Co (Accountancy Service) Limited

19 Victoria Terrace

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