

2020

Annual Report & Accounts

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CHAIRMAN'S REPORT

A successful charity is defined by its resources, the enthusiasm / commitment of its staff, volunteers and fundraisers, feedback from service users and the breadth of the projects it supports and develops. I may be biased, but it seems to me that AMEND scores very highly on all these parameters! The fact that the membership is increasing is a clear and objective measure of AMEND's success.

All those who contribute in so many different ways to AMEND will I am sure, on the basis of past experience, continue to do so and they have my sincere gratitude. To Jo and Helen, who have worked so hard in these 'unusual' times, my thanks as always.

A handwritten signature in blue ink that reads "Barney Harrison". The signature is written in a cursive, flowing style.

Barney Harrison
Chair of the AMEND Board of Trustees
30th July 2021

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 2020.

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:

There were two new Trustees, Dr John Ayuk and Mrs Miriam Asia CNS were appointed to the Board at the 2020 AGM

Retiring Trustees:

There were no Trustee retirements during 2020

Trustee Executive Committee:

There were no changes to the Executive Committee during 2020

CHIEF EXECUTIVE'S REPORT

Dear all,

What can we really say about 2020? Events that had been noted on the wall calendar were erased and replaced with 'Cancelled' scrawled across in bright red pen, we locked the door and went home.


Thank goodness for laptops and the internet! Despite the difficulties we adapted rapidly to the new virtual landscape since many of our systems were already online. Nothing could stop us once we bought our Zoom licence! The main priority was to ensure that all our members had as much information on Covid-19 as possible on our websites, something we still update and maintain.

Sadly, all regular, physical fundraising events were cancelled during 2020, resulting in a 36% reduction in income for AMEND (compared to an average year – almost 50% on 2019). Nevertheless, our thanks go to all those who managed to find new ways to fundraise, as well as to those who donated. With reduced activity comes reduced expenditure and in fact, we rode a difficult year with relative confidence.

Special thanks go to the Trustee Board members for their continued support, to our Regional Volunteers, many of whom adapted almost seamlessly to providing peer support meetings via Zoom, and to our Medical Advisory Teams who continued to help guide our medical information resource production, and to provide advice on our Covid-19 resources, despite many of them being caught up in the care of Covid-19 patients themselves.

We remain hopeful that we will see many of our members, Trustees and medical advisors again in person at our rescheduled 2021 Annual Patient Information Day in October 2021.

Wishing everyone the best of health,

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

Jo Grey
AMEND Chief Executive Officer
3rd June 2021

ACHIEVEMENT OVERVIEW 2020

Source of Information

In our continued efforts to 'fill the gaps', 2020 saw the development and launch of resources for our phaeochromocytoma and paraganglioma syndrome community. These included a new identity (Phaeo Para Support UK), a new website (www.phaeoparasupport.org.uk), new patient experience films (completed just before lockdown), new social media channels, and a new patient information booklet, developed with the help of two new specialist medical advisors, Dr Ruth Casey and Dr Scott Akker. These were all launched in August during the inaugural Phaeo Para Awareness Week, masterminded by our good colleagues in the USA, Pheo Para Alliance.

Covid-19 Work

As soon as the WHO declared the pandemic, we were working on developing website resources to help inform and support our members, including videos from medical experts. We also developed a survey of people with MEN who had had covid-19 to find out the common effects of covid-19 in MEN syndromes. Later on we also developed a covid-19 and mental health survey to gauge the emotional impact of the pandemic on our MEN community. Both surveys continued to run into 2021. During the year we answered more enquiries from people who were concerned about the vaccinations than we did about the virus itself and strived to encourage participation in the UK vaccination programme.

Provision of Support

This year saw the sad loss of Regional Volunteer, Geoff Toon, who had not had a chance to hold a meeting of his own. The stars of 2020 really were our Regional Volunteers, many of whom switched to using Zoom to provide virtual peer support meetings throughout the year. We were delighted to award them with a group 2020/2021 Volunteers of the Year award.

The Government's Covid-19 Emergency Funding for charities, administered by the National Lottery, were prompt at granting our application for funding to meet the costs of our Counselling Service throughout the year so that it could continue unhindered. This meant that we were prepared for additional demand to the service although this was minimal.

Raise Awareness of MEN & Associated Endocrine Conditions

Just before lockdown, we managed to complete a set of patient experience films about Phaeochromocytoma & Paraganglioma syndromes which were launched, together with a new identity, new information booklet and a new website during the inaugural Phaeo Para Awareness Week in August.

During the year AMEND was represented at two virtual conferences: the European Congress for Endocrinology (ECE) and the British Endocrine Society (BES) meeting. It's safe to say that, despite providing an interesting video discussion in our booth for the latter, virtual exhibition booths and attendance cannot go even half-way to the real thing!

Research

Sadly, all research in the UK was halted for most of 2020, except for that into covid-19. We therefore delayed our Research Fund Award grants deadline until 31 August. AMEND awarded 2 research grants this year, for projects looking into MEN1 (Nick Fayers MEN1 Research Award), and into phaeochromocytoma and paraganglioma syndromes. The recipients are due to report on their progress during 2021.

2021 AND BEYOND

A total of £40,000 has been agreed once again by the Trustee Board for 2021 Research Awards, including the Nick Fayers and John Pettit awards for MEN1 research. Again, the deadline for this

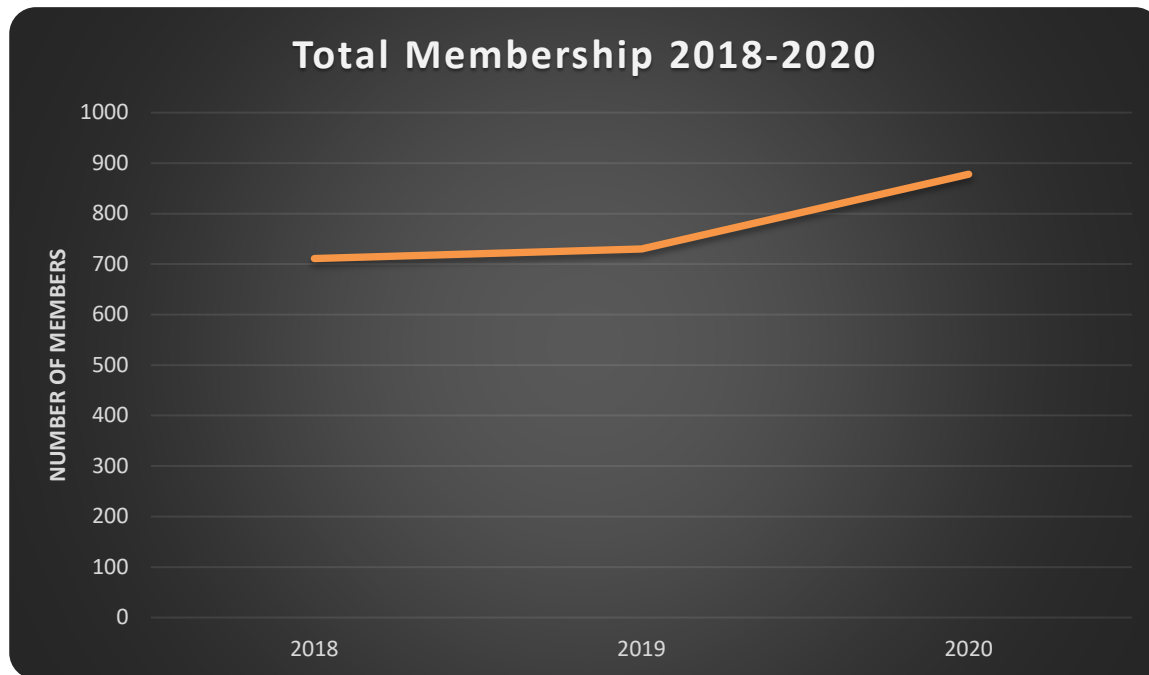
has been pushed back to 31 August. Although we are still at the mercy of the continuing pandemic and virus variants, we are hoping to complete our patient experience films about MEN2 and MEN1 by year end. Our resources for young adults are already complete and were launched on Rare Disease Day 2021. On top of that, research has begun again in earnest and there is much to do to help provide the patient perspective, including the formation of Community Advisory Groups for each disease.

Beyond 2021, but with preparation beginning already, we will be embarking (subject to funding) on several large projects. We aim to begin to address the one aim of AMEND on which we have not yet sufficiently progressed – that of encouraging earlier and accurate diagnosis. Secondly, we will continue to look at ways to digitally replace our popular MEN Passports. Finally, we will continue with our efforts to ‘fill the gaps’ in our resources by focussing next on improving these for sporadic medullary thyroid cancer.

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 878 by the end of 2020 (730 in 2019). This shows the continued steady increase in membership following our introduction of measures to comply with the European General Data Protection Regulations (GDPR) at the end of 2017.



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 membership benefits. A charge applies to overseas members to cover the cost of shipping Welcome Packs where requested.

FUNDRAISING REPORT

Huge thanks go to the following for their extraordinary fundraising efforts and financial or in-kind donations during 2020.

Thank you to 2020 supporters; the Houghton Dunn Charitable Trust, the Nick Fayers Research Fund, HRA Pharma Ltd, ITM AG, the Society for Endocrinology, the Barnes Group Ltd

Thank you to in-kind contributors who give up their time for us or provide us with cut-price services. Thanks to AMEND's Trustees (Barney Harrison, Gill Masters, Catherine Hamilton-Woodthorpe, Professor Karim Meeran, Louise Breen, Laura Jones, Simon Williams, Joel Russell-Winter, Edel Murphy, Dr John Ayuk and Miriam Asia), AMEND's Medical Advisory Team (Professor Rajesh Thakker, Professor Ashley Grossman, Professor Maralyn Druce, Mr David Scott-Coombes, Dr Fiona Laloo, Dr Caroline Brain), our ACC Support UK Medical Advisory Team (Professor Wiebke Arlt, Professor Nick Reed, Mr Radu Mihai), our Phaeo Para Support UK Medical Advisors (Dr Scott Akker and Dr Ruth Casey), our Phaeo Para Support UK patient experience film stars, and graphic designer, Jill Clark. In the same vein, thanks to all the medical societies who provided free (virtual) delegate and exhibition space to AMEND throughout the year (European Society for Endocrinology and the Society for Endocrinology).

Big thanks to our committed fundraisers who found great ways to support AMEND during such a strange and difficult year: Liam Connery (virtual London Marathon at Selhurst Park), Kerry Godfrey (Flare and Flame crafting), Danny Mayhew – charity boxing event, Will Fayers – Kilimanjaro Trek, Charmaine Chantler, Jason Rogers and Jo Grey – 2.6 challenge, Lisa Johnson – uniform bags for NHS.

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



TREASURER'S REPORT


2020 results

The Covid-19 pandemic was a significant contributory factor to AMEND's income almost halving in 2020 compared with the prior year. The charity's total incoming resources were £109,814 (2019 £204,543) and 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 small deficit of £1,541. Despite this, we managed to designate a further £11,000 towards our Research Fund and made grants and awards totalling £17,996 during the year. Another significant expense for AMEND this year was £11,413 on patient education films.

Reserves

AMEND's undesignated unrestricted reserves now stand at £46,775 (2019 £40,149). 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
29th July 2021

STATEMENT OF FINANCIAL ACTIVITIES

For the Year ended 31 December 2020

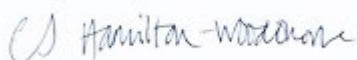
		2020			2019		Total
	notes	Restricted	Unrestricted	Total Funds	Restricted	Unrestricted	Funds
		£	£	£	£	£	£
Income and endowments from:							
Donations and legacies	5	7,079	81,129	88,208	19,760	183,667	203,427
Charitable activities	6	19,636	79	19,715	-	346	346
Other trading activities	7	800	893	1,693	-	517	517
Investments		-	198	198	-	253	253
Total income and endowments		27,515	82,299	109,814	19,760	184,783	204,543
Expenditure on:							
Raising funds	8	-	8,235	8,235	-	6,596	6,596
Charitable activities	9	23,583	60,766	84,349	29,511	83,221	112,732
Support costs	10	-	17,435	17,435	-	19,880	19,880
Governance costs	11	-	1,336	1,336	-	726	726
Total expenditure		23,583	87,772	111,355	29,511	110,423	139,934
Net income / (expenditure)		3,932	(5,473)	(1,541)	(9,751)	74,360	64,609
Transfers between funds	13	1,404	(1,404)	-	2,830	(2,830)	-
Net movement in funds		5,336	(6,877)	(1,541)	(6,921)	71,530	64,609
Reconciliation of funds							
Total funds brought forward		32,265	171,466	203,731	39,186	99,936	139,122
Total funds carried forward		37,601	164,589	202,190	32,265	171,466	203,731

BALANCE SHEET

As at 31 December 2020

		2020	2019
	note	£	£
Fixed assets	12	511	928
Current assets			
Stocks		3,978	2,585
Trade debtors		200	200
Prepayments and accrued income		1,896	3,864
Cash at bank			
Deposit account		144,878	135,626
Current accounts		52,918	62,923
		<u>203,870</u>	<u>205,198</u>
Creditors: amounts falling due within one year			
Trade creditors		(889)	(1,399)
Payroll taxes		(473)	(456)
Pensions payable		(229)	-
Accruals		(600)	(540)
		<u>(2,191)</u>	<u>(2,395)</u>
Net current assets		<u>201,679</u>	<u>202,803</u>
Total net assets		<u><u>202,190</u></u>	<u><u>203,731</u></u>
Funds of the Charity			
Restricted income funds	13	37,601	32,265
Designated funds	14	117,814	131,317
Unrestricted funds		46,775	40,149
		<u></u>	<u></u>
Total Charity Funds		<u><u>202,190</u></u>	<u><u>203,731</u></u>

These financial statements were approved by the Trustees on Sunday 1 August 2021, and are signed on their behalf by



Catherine Hamilton-Woodthorpe
Treasurer
1st August, 2021

NOTES TO THE FINANCIAL STATEMENTS

For the year ended 31 December 2020

	2020			2019
	Restricted	Unrestricted	Total	Total
	£	£	£	£
5. DONATIONS AND LEGACIES				
Donations and gift aid	7,079	51,129	58,208	153,667
Grants	-	30,000	30,000	49,760
	<u>7,079</u>	<u>81,129</u>	<u>88,208</u>	<u>203,427</u>
6. INCOME FROM CHARITABLE ACTIVITIES				
Grants for charitable activities	19,636	-	19,636	-
Other	-	79	79	346
	<u>19,636</u>	<u>79</u>	<u>19,715</u>	<u>346</u>
7. INCOME FROM OTHER TRADING ACTIVITIES				
Grant of licence to show ACC film clips	800	-	800	-
Sale of merchandise	-	893	893	517
	<u>800</u>	<u>893</u>	<u>1,693</u>	<u>517</u>
8. RAISING FUNDS				
Staff costs		6,236	6,236	5,970
Merchandise	-	1,763	1,763	385
Other	-	236	236	241
	<u>-</u>	<u>8,235</u>	<u>8,235</u>	<u>6,596</u>
9. CHARITABLE ACTIVITIES				
Staff costs	-	21,588	21,588	20,659
Patient information printing, booklets and websites	-	4,306	4,306	4,248
Patient information events and conferences	4,651	(1,448)	3,203	18,210
Patient education films	11,413	-	11,413	15,954
Patient representation	-	851	851	546
Research grants and awards	-	17,996	17,996	21,650
ACC support and ACC research grants	984	863	1,847	8,409
ACC staff costs	-	7,794	7,794	7,462
Patient support and counselling	6,535	8,648	15,183	14,788
International development	-	168	168	806
	<u>23,583</u>	<u>60,766</u>	<u>84,349</u>	<u>112,732</u>

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2020

	2020			2019
	Restricted	Unrestricted	Total	Total
	£	£	£	£
10. SUPPORT COSTS				
Rent	-	12,298	12,298	13,152
Staff costs	-	3,355	3,355	3,219
Printing, postage and office supplies	-	540	540	1,322
Telephone	-	-	-	306
IT support	-	30	30	180
IT software and consumables	-	446	446	793
Insurance	-	611	611	588
Finance charges	-	120	120	72
Miscellaneous	-	35	35	248
	-	17,435	17,435	19,880
11. GOVERNANCE				
Independent examiner	-	600	600	600
Trustee meetings and AGM	-	736	736	126
	-	1,336	1,336	726
12. TANGIBLE FIXED ASSETS				
		Equipment		
		£		
Cost				
At 1/1/20		10,723		
Additions		-		
At 31/12/20		10,723		
Depreciation				
Balance brought forward		9,795		
Charge for the year		417		
At 31/12/20		10,212		
Net book value at 31/12/20		511		
Net book value at 1/1/20		928		

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2020

13. RESTRICTED INCOME FUNDS

	B/forward	Income	Direct costs	Transfer from reserves	Balance
	£	£	£	£	£
Anonymous donor	677	-	-	-	677
Society for Endocrinology	-	4,000	(4,436)	436	-
ACC Support UK	9,124	-	(984)	-	8,140
The Big Give 2016 - Project Rollercoaster	9,158	-	(4,645)	-	4,513
Cartoon Licence	380	-	-	-	380
Sanofi	86	-	-	-	86
Ipsen - MEB2a film	6,420	-	(4,230)	-	2,190
AAA Pharma SDHx films	6,420	-	(7,388)	968	-
ITM Solucin	-	1,636	-	-	1,636
Barnes Construction Golf Day	-	7,079	-	-	7,079
HRA Pharma - ACC films	-	5,000	-	-	5,000
Licence to use ACC film clips	-	800	-	-	800
National Lottery - Counselling	-	9,000	(1,900)	-	7,100
			-		
	<u>32,265</u>	<u>27,515</u>	<u>(23,583)</u>	<u>1,404</u>	<u>37,601</u>

- A trust fund, who prefer to remain anonymous, provided £11,000 in 2018 for redevelopment of the AMEND website.
- The Society for Endocrinology funded 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 Neuroendocrine Cancer UK.
- Project Rollercoaster is a project to develop resources for young people to support them 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.
- Ipsen provided an unrestricted grant which will be used to develop patient films about MEN2A.
- AAA Pharma provided an unrestricted grant which will be used to develop patient films about Phaeo/Para Syndromes
- ITM Solucin provided a grant for the Annual Patient Information Day.
- The proceeds of Barnes Construction's Gold Day are to be used for MEN1 films.
- HRA Pharma provided a grant for the development of patient films about ACC.
- Licence to use ACC film clips.
- National Lottery Covid-19 Emergency Funding for the Counselling Service.

NOTES TO THE FINANCIAL STATEMENTS (continued)

For the year ended 31 December 2020

14. DESIGNATED FUNDS

	B/forward	Income	Direct costs	Staff costs	Balance
	£	£	£	£	£
Counselling service	2,225	-	(2,225)	-	-
ACC Support UK	4,342	2,766	(863)	(6,245)	-
Research Fund	90,000	11,060	(17,996)	-	83,064
Hardship fund	750	-	-	-	750
Personnel contingency fund	30,000	-	-	-	30,000
Research Registry Project	4,000	-	-	-	4,000
	<u>131,317</u>	<u>13,826</u>	<u>(21,084)</u>	<u>(6,245)</u>	<u>117,814</u>

15. RELATED PARTY TRANSACTIONS

There were no related party transactions in 2020 or 2019.

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES

I report on the accounts of the charity for the year ended 31 December 2020 which are set out on pages 12 to 17.

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.

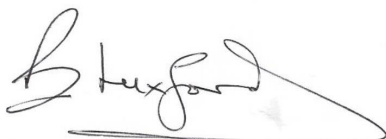
Basis of independent examiner's report

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

28th July, 2021

CONTACT INFORMATION

AMEND

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Twitter: www.twitter.com/AmendInfo (@AmendInfo)

Jo Grey (CEO)	Tel: 01892 516076; Email: jo.grey@amend.org.uk
Helen Blakebrough (Administrator)	Tel: 01892 841032; Email: helen@amend.org.uk

AMEND Trustee Board

Barney Harrison
Catherine Hamilton-Woodthorpe
Gill Masters
Dr Simon Williams
Edel Murphy
Professor Karim Meeran
Mrs Laura Jones
Ms Louise Breen, RN
Joel Russell-Winter
Dr John Ayuk
Ms Miriam Asia, RN

Patrons

Recorder, Mrs Jo Delahunty, QC, 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, Mr Barney Harrison, Dr Fiona Laloo, Mr David Scott-Coombes, Professor Rajesh Thakker

Independent Examiner

Mr Brian Luxford, FCA
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