

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS

England & Wales · Charity number 1153890

Details

Other names AMEND

Status Registered

Legal form CIO

Registered 2013-09-20

Register [View on the Charity Commission register](#)

Contact

Address Amend
Tyler House
58-66 Morley Road
Tonbridge
Kent
TN9 1RA

Phone 01892516076

Email info@amend.org.uk

Website www.amend.org.uk

Activities

Objects: 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.

Activities: AMEND PROVIDES SUPPORT AND INFORMATION TO PATIENTS FAMILIES AND CARERS AFFECTED BY THE RARE GENETIC DISORDERS MULTIPLE ENDOCRINE NEOPLASIA, AS WELL AS TO THOSE WITH ASSOCIATED FAMILIAL AND SPORADIC TUMOURS. AMEND AIMS TO PROMOTE GREATER KNOWLEDGE OF THE BEST CARE AND MANAGEMENT OF MEN AND ASSOCIATED TUMOUR PATIENTS AMONGST THE MEDICAL PROFESSION.

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

| Period end | Income | Expenditure | Assets | Employees |
|------------|----------|-------------|--------|-----------|
| 2024-12-31 | £95,173 | £106,016 | - | - |
| 2023-12-31 | £80,668 | £112,292 | - | - |
| 2022-12-31 | £130,264 | £139,397 | - | - |
| 2021-12-31 | £93,239 | £129,637 | - | - |
| 2020-12-31 | £109,814 | £111,355 | - | - |

Trustees

| Name | Role | Appointed |
|------------------------|------|------------|
| Andrew Price | | 2021-08-14 |
| Dr John Ayuk | | 2020-08-15 |
| GILL MASTERS | | 2013-09-12 |
| Graeme Cohen | | 2022-10-29 |
| Lauren Wheeler ACA | | 2024-08-15 |
| Miriam Asia | | 2020-08-15 |
| PROFESSOR KARIM MEERAN | | 2013-09-12 |
| Robert Millinship | | 2022-10-29 |
| Sarah Norman | | 2022-10-29 |
| Shahab Khan | | 2023-09-28 |

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS

England & Wales - Charity number 1153890

Accounts

**ASSOCIATION FOR MULTIPLE ENDOCRINE
NEOPLASIA DISORDERS (AMEND)**

FINANCIAL STATEMENTS

YEAR ENDED 31st DECEMBER 2024

CHARITY NUMBER: 1153890

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

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ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

REPORT OF THE TRUSTEES

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2024. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

AMEND is a Charitable Incorporated Organisation (no.1153890), governed by a constitution, vesting control, and responsibility in the Trustee Board on behalf of the membership.

AMEND has been registered with the Charity Commission as a CIO since September 20th, 2013, and previously an unincorporated association (no. 1099796) from October 2003. The charity's current Constitution was amended on May 7th, 2016. This amendment was approved by the Charity Commission.

Organisational Structure and Decision Making

The Charity is governed by its Trustees, who are appointed by the Charity membership. Trustees are appointed for a period of three years after which they may seek re-election. The constitution states that there must no less than 3 and no more than 12 Trustees. A process of Trustee elections takes place most years in order to maintain an adequate number of Trustees and to allow for the replacement of those who have completed their term of service. A Chairperson for the Trustees is appointed by the Trustees.

Persons nominated to become Trustees of the Charity must be a member of the Charity and remain a member of the Charity during their tenure.

Trustees are responsible for the strategic direction and operational management of the Charity. When appropriate and necessary the specialist expertise of members and friends is sought to assist in decision-making e.g. in relation to matters of finance, safeguarding and Charity fabric issues.

All elected Trustees will have access to relevant documentation from the Charity Commission pertaining to their responsibilities as a charity trustee, the Charity's policies, and appropriate guidance materials. Pay reviews for staff are conducted annually by the Trustees.

The policies adopted are those of the Charity Commission publications as per the website. Trustees are reminded periodically to review these documents, and new trustees are issued with access to copies for pursual.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

The Charity's 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 with the approval of members of the medical profession who are directly involved in the treatment 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.

Public Benefit

The Trustees have paid due regard to guidance issued by the Charity Commission in deciding what activities should be undertaken by the Charity.

AMEND is dedicated to supporting individuals affected by multiple endocrine neoplasia (MEN) and related endocrine disorders. Our mission is to provide comprehensive support, information, and advocacy to improve the lives of those affected.

Our primary beneficiaries are individuals and families affected by MEN and related endocrine disorders. We support them through direct services, educational materials, and support and advocacy efforts.

AMEND's activities are designed to provide clear public benefit, in line with the Charity Commission's requirements. We regularly review our policies to ensure compliance and effectiveness.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

Activities and Achievements

Source of Information

In 2024 we started a new project to develop webcasts on different topics. We began with a webcast with AMEND Trustee and Medical Advisor, Professor Karim Meeran (London) on corticosteroids, a class of prescription medication used by many within our communities. This helped to explore some of the myths around steroid treatment. In our second webcast for 2024, we chatted with one of our fundraisers, Steph Webb, who had recently taken up running, and had decided to run 8 different fundraising events in aid of AMEND. The webcast project is continuing into 2025.

AMEND's 2024 Annual Patient Information Day was held on Saturday 1st June in central Birmingham. Almost 100 people attended, including 8 speakers. 38 people completed our feedback survey, reporting that for more than 60%, this had been their first experience of an AMEND Patient Information Day. The majority of sessions attended were rated as excellent, in particular the 2-hour disease-specific Q&A sessions.

'Excellent, well-organised and informative. Gives me confidence we are supported.'

We developed A4 tear-off pads containing QR codes for accessing, downloading, and printing all our MEN-related patient information books. These will be for use in clinics to give to patients when they are diagnosed and/or facing treatment. This will avoid the current expense of giving out large quantities of our designed and printed books to hospitals.

On social media, we moved our three accounts (AMEND, ACC Support UK, Phaeo Para Support UK) to BlueSky under a single AMEND account to help increase brand recognition and reach in a less toxic environment.

In late 2024, we began preparations for the redevelopment of the ACC Support UK website, thanks to legacy funding from the family and friends of the late Sally Zelenczuk. This work is expected to complete in Spring 2025.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

Provision of Support

Our 4 wonderful Peer Support Volunteers held 12 Peer Support Meetings throughout the year, supporting approximately 30 people in total. In addition, our Scottish Peer Support Volunteer held a Peer Support and Information event in Scotland featuring a Genetic Counsellor speaker, supporting 6 people. We also trialled meetings for partners or carers which was successful, and which now forms part of our ongoing meetings provision. Our Volunteers also took part in their virtual annual training session in the Autumn. Part-way through the year, we successfully recruited a new Peer Support Volunteer, but another sadly stepped down. We continue to recruit new volunteers on an ongoing basis.

AMEND's psychological support provider, Rareminds, provided 211 one-to-one counselling sessions to a total of 30 members (mean average number of sessions per person x7) at a cost of £13,155. Feedback from 20 users of the service who responded to their end-of-treatment survey was very positive:

- 14 out of 20 (70%) felt that the counselling had been 'very helpful'; 2 clients found it 'helpful'; 4 clients found it 'quite helpful'
- 18 out of 20 (90%) felt that it was very helpful and important to have a counsellor who understood the impact of the condition, 1 client thought it was quite helpful and important., 1 client did not think it was important.
- 19 out of 20 (99.5%) felt better equipped to manage the emotional impact of their condition following their sessions
- 20 out of 20 (100%) would recommend their counsellor to others

"My counsellor was hugely supportive, friendly, and helpful. I felt they had a great understanding of the issues affecting me and understood the complexity of dealing with long term chronic conditions which are very stressful. I would recommend them to anyone as I thought they were brilliant."

Advocacy & Raising Awareness

Throughout the year, AMEND CEO, Jo Grey, was honoured to be asked to talk about AMEND and patients' perspectives of unmet needs in their care at the following:

- UK & Ireland Neuroendocrine Tumours Society (UKINETS)
- University of Birmingham SIMBA 3.0 Adrenal meeting
- Seoul International Congress on Endocrinology & Metabolism (SICEM), South Korea
- Webinar for the European Reference Network for Rare Endocrine Conditions (ENDO ERN) with Professor Frederic Castinetti (Marseille)
- Society for Endocrinology Clinical Update Meeting

In August, Genomics England removed the *RET* gene (that causes MEN2/3) from their newborn screening research study. AMEND submitted a response expressing disappointment at this decision. We are grateful to Clinical Geneticists, Drs Fiona Laloo and Louise Izatt, for working with the research team on this, which has resulted in *RET* mutation in codon 918 (MEN2B) being reinstated into the study at the next phase.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

We were honoured to be invited by surgeon, Mr Tom Kurzawinski, to co-write an article for the journal, Endocrine-Related Cancer, about patient experiences of living with a RET gene mutation (causing MEN2 and MEN3). Called 'Living with a RET gene mutation: Patients' Perspectives,' the article, co-authored with retired Great Ormond Street Hospital Paediatric Endocrinologist, Dr Caroline Brain, explores the experiences of 4 families through diagnosis and treatment. We highlighted the need for earlier diagnosis, improved psychological support at diagnosis, the importance of wider family predictive genetic testing, and the need for families to be cared for in centres of expertise. We thank all the families involved for their input.

AMEND and Neuroendocrine Cancer UK (NCUK) began negotiations for forming an alliance, called the Neuroendocrine Life Alliance. The Alliance's mission is to align the charities' strategic priorities to raise awareness, educate, support, and advocate for all our neuroendocrine disease communities. The Alliance's aims are to:

1. Share knowledge and resources for the good of neuroendocrine communities
2. Develop joint key strategic projects, including:
 - a. Education programmes
 - b. Support and wellbeing initiatives
 - c. Awareness-raising activities
 - d. Advocacy and policy work

The Neuroendocrine Life Alliance is a work in progress, with 2025 agreed for its launch.

Encouraging Research

Thanks to the Elliot Dallen Trust, we were able to support another £10,000 award for research into adrenocortical cancer (ACC). This was the last year in a 3-year financial commitment to funding research projects through AMEND. The 2024 ACC Research Grant was awarded to Dr Cristina Ronchi from the University of Birmingham for her continuing work to develop a less invasive way to manage ACC patients using blood tests, and minimising use of imaging (Circulating cell-free DNA-based biomarkers for longitudinal monitoring of patients with adrenocortical carcinoma).

As a member of the European MEN Alliance, we distributed their survey on Unmet Needs in MEN Syndromes to our multiple endocrine neoplasia community. This survey is ongoing into 2025. We look forward to being able to use the data gained to raise awareness of issues patients perceive in the care and management of their disease.

We distributed a preliminary research survey by Dr Ruth Casey from the University of Cambridge on pregnancy and starting a family to our multiple endocrine neoplasia community.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)
YEAR ENDING 31st DECEMBER 2024

Fundraising

We send our thanks to all our 2024 fundraisers who took on a range of challenges for sponsorship in aid of AMEND:

- Steph Webb – x8 fundraising runs
- Ella Stevens – Skydive
- Jess and Carl – Three Peaks Challenge
- Steph, Sam, Rick - Saucony London 10k
- Jack Greasley - UWCB Boxing event
- Ryan Keeshan - London Marathon
- Drew and Laura - Norfolk coastline walk (84 miles)
- Emma William's - cycling challenge
- Deborah O'Riordan - Brighton Marathon
- Evie Pearce – swimming challenge
- Nick, Lucy, Scott, Ben & Dom - Bristol 10k run
- Deborah O'Riordan – Brighton 10k run
- Tom and Laura Mann – Norwich 10k run
- Barnes Construction Not Fayers Golf Day

Thanks also to all those who donate on a regular basis, who purchase merchandise from our websites and TeeShop, and who continue to use the free fundraising platforms for online purchases. All income from these methods go to support our work.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

Financial Review

The charity's total incoming resources were £95,173 (2023: £80,668). Given the pressure from the cost-of-living crisis and reduced public spending, AMEND has performed well. There was a significant increase in donations and legacies, indicating successful fundraising efforts and increased donor engagement. This mitigated the decrease in income from charitable activities, where AMEND saw a decrease in demand for events/activities generating revenue compared to the previous year. Investment income increased significantly, reflecting better returns on investments, possibly due to favourable market conditions or improved investment strategies. Other income reduced slightly due to lower merchandise sales, which tends to fluctuate each year.

Total expenditure for the year was £106,016 (2023: £112,292). Despite the increase in income, the charity ended the year with a deficit of £10,843, compared to a deficit of £31,624 in 2023. This is a fantastic result for AMEND as it brings us closer to breaking even and limits the reduction in free reserves.

The increase in expenditure on raising funds suggests more investment in fundraising activities, which may have contributed to the higher income from donations and legacies. Expenditure on charitable activities decreased due to more efficient use of resources and fewer activities conducted during the year. Support costs slightly decreased due to better management of administrative expenses. Overall net expenditure decreased significantly, reflecting better financial management and increased efficiency in operations.

We managed to fund £13,240 towards our valuable counselling service and made research grants and awards totalling £10,000 during the year. We would like to thank our members and grant funders who continue to support us.

AMEND's undesignated unrestricted reserves stand at £76,915 (2023: £38,234). The reclassification of certain funds to unrestricted status in 2024 provides greater flexibility in the allocation and utilisation of resources, especially due to the high-risk nature of the main funding stream (donations and voluntary grants).

Financial Reserves Policy

In 2024, the Trustees reviewed and amended the Financial Reserves policy to state that they considered it prudent to hold a reserve of at least £60,000 (with £10,000 permanently maintained on demand) to ensure that AMEND's core activities could continue for a period of 6 months in the event of unforeseen difficulties. At the year-end, although the bank balance in the various Current Accounts was £28,393, the Trustees consider the position to be satisfactory as there was a further £84,870 held on the Flagstone account; a total of £113,263.

The trustees review this policy every 6 months at Board Meetings.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

Risk Management

The Trustees have a duty to identify and review the risks to which the charity is exposed and to ensure appropriate controls are in place to provide reasonable assurance against fraud and error. Having assessed the risks, the Trustees are satisfied that systems are in place to mitigate exposure to the major ones. Internal control risks are minimised by the implementation of procedures for all transactions and projects. Procedures are also in place to ensure compliance with the health and safety of members, their families, friends, and carers.

For example, two factor authentication is used on all CMS and finance software systems, two signatories are required for financial transactions, and up-to-date internet security services are in place on all IT devices. Trustee and public liability insurance is in place and renewed regularly, along with insurance for the AMEND office.

Going Forward

The 'buzzword' for AMEND's future is 'sustainability.' This work looks at finding more future-proofed and efficient ways to continue to provide all the services we do now into the next few years. Not just this but also ensuring that personnel sustainability is considered through succession planning, and through recruiting volunteers to assist with various aspects of AMEND's work, such as our social media awareness work. Financial sustainability of course is the thread that runs through all of our work; the need to ensure that AMEND does not rely on one main source of income, but rather, that we work towards a more diverse set of income streams. As ever, the fundraising of our members and friends are critical to the future of AMEND.

Specific projects for 2025 include the development and launch of the new ACC Support UK website, including the development of patient information for parents of children with ACC.

We will continue our AMEND Webcast project as an efficient and effective information resource for our communities on a range of topics of interest. Already in 2025, we have launched Webcasts on Medical Guidelines, and on Parathyroid Surgery.

We continue our work with our patient group colleagues, including within Europe and the wider international community, to create a louder voice to increase awareness of and research interest in our diseases.

As always, we will continue to work with our Medical Advisory Teams to update our patient information resources, and with our support colleagues at Rareminds, and with our Peer Support Volunteers, to ensure that no one is left to deal with their disease alone.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

Trustee's Responsibilities in Relation to the Financial Statements

The Trustees are responsible for preparing the Trustee's Annual Report and the financial statements in accordance with the Charities Act 2011 and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law applicable to charities in England and 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. The trustees are responsible for keeping proper accounting records and ensuring compliance with the Charities Act 2011, the Charity Regulations 2008, and the provisions of the trust deed.

They are specifically required to:

- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles of 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 charity will continue in operation.

Approved by order of the Board of Trustees on Monday 21 July 2025 and signed on their behalf by:



Gill Masters (Chair)



Lauren Wheeler (Treasurer)

Chairperson's Report

Reflecting on AMEND's sustainability, we are pleased to see that various efforts to increase income and reduce expenditure during 2024 have resulted in a much-improved financial performance in a difficult climate. Grant funding remains hard to come by so the contribution to the charity's income made by our wonderful fundraisers is very important. We are grateful to everyone internally, board members and to our patients and supporters for their ongoing hard work.

We continue to concentrate on educating and supporting patients and their families, raising awareness of the conditions we support amongst medical professionals and providing accurate and up to date information for everyone who needs it. We can only do this with your support – thank you, it is very much appreciated!

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

Chief Executive's Report

At a time when costs are increasing, we are very grateful to everyone who donated, fundraised, or gave AMEND grants or in-kind help in 2024. Accessing grants however remains challenging, with so many other worthy charities applying too. We took a good look at ways to be more efficient and effective, and made a variety of changes to reduce expenditure. As you will have read, we continued our other charitable activities throughout the year with little to no impact from our cost-cutting measures. We could not do what we do without the wonderful help of all our volunteers, including our Peer Support Volunteers, Trustees, Medical Advisory Teams, and anyone who has helped the charity in any way during the year. It truly is a patient group run by patients, just as it was intended to be.

**ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)
YEAR ENDING 31st DECEMBER 2024**

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity Number: 1153890

Principal Office: AMEND, Tyler House, 58-66 Morley Road, Tonbridge, Kent, TN9 1RA

Bank: Charities Aid Foundation Bank, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent ME19 4JQ

Trustees as at December 31 2024

Gill Masters (Chair)

Lauren Wheeler (Incoming Treasurer) – Elected onto Board 15th August 2024

Catherine Hamilton-Woodthorpe (Outgoing Treasurer) (Resigned 15/08/2024)

Shahab Khan

Sarah Norman

Graeme Cohen

Mr Robert Millinship

Andy Price

Dr John Ayuk

Ms Miriam Asia, RN

Professor Karim Meeran

Karen Williams (Resigned 15/08/2024)

Patrons

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

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

Mr Shaun Williamson, Actor

Independent Examiner

Dynamix Accountancy: Dane John Works, Gordon Road, Canterbury, Kent, CT1 3PP

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

Independent examiner's report to the trustees of ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 December 2024.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under Section 145(5) (b) of the 2011 Act.

Independent examiner's statement

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

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

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.

Hussein Bhaiji

Hussein Bhaiji (FCCA)
Association of Chartered Certified Accountants
Dynamix Accountancy
Dane John Works
Gordon Road, Canterbury
Kent, CT1 3PP

Date: 21st July 2025

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

STATEMENT OF FINANCIAL ACTIVITIES

| | Note | Unrestricted | Restricted | TOTAL | 2023 |
|---|-------------|---------------------|-------------------|-----------------|-----------------|
| | | <u>£</u> | <u>£</u> | <u>£</u> | <u>£</u> |
| Income | | | | | |
| Donations and Legacies | 2. | 50,648 | 8,646 | 59,294 | 36,788 |
| Charitable Activities | 3. | 20,000 | 10,000 | 30,000 | 41,369 |
| Investment Income | 4. | 5,451 | - | 5,451 | 1,977 |
| Other Income | 5. | 428 | - | 428 | 534 |
| Total Income | | 76,527 | 18,646 | 95,173 | 80,668 |
| Expenditure | | | | | |
| Raising funds | 6. | 14,791 | - | 14,791 | 9,635 |
| Charitable Activities | 7. | 51,211 | 20,756 | 71,966 | 81,789 |
| Support Costs | 8. | 17,319 | 107 | 17,426 | 17,967 |
| Governance Costs | 9. | 1,832 | - | 1,832 | 2,901 |
| Total Expenditure | | 85,153 | 20,863 | 106,016 | 112,292 |
| Net Income /(expenditure) for the year | | (8,627) | (2,217) | (10,843) | (31,624) |
| Transfers between funds | 17. | 7,539 | - 7,539 | - | - |
| Net Movement in Funds | | (1,088) | (9,756) | (10,843) | (31,624) |
| Reconciliation of Funds | | | | | |
| Total Funds brought forward | | 108,003 | 17,033 | 125,036 | 156,660 |
| Total Charity Funds carried forward | | 106,915 | 7,277 | 114,193 | 125,036 |

Comparative figures for 2023 are in Note 22.

All incoming resources and resources expended derive from continuing activities

The Notes on pages 18-28 form part of the Financial Statements

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

BALANCE SHEET

| | Note | 2024 | | 2023 | |
|--|------|----------------|-----------------------|----------------|-----------------------|
| | | £ | £ | £ | £ |
| Fixed Assets | | | | | |
| Tangible Fixed Assets | 11. | | 583 | | 1,039 |
| | | | 583 | | 1,039 |
| Current Assets | | | | | |
| Stocks | | 2,496 | | 3,166 | |
| Debtors & Prepayments | 12. | 5,646 | | 7,170 | |
| Cash and Bank in Hand | 13. | <u>113,263</u> | | <u>115,729</u> | |
| | | 121,404 | | 126,065 | |
| Current Liabilities due within one year | | | | | |
| Creditors | 14. | <u>(7,794)</u> | | <u>(2,068)</u> | |
| | | (7,794) | | (2,068) | |
| Net Current Assets | | | 113,611 | | 123,997 |
| Total Net Assets | | | <u>114,193</u> | | <u>125,036</u> |
| Charity Funds | | | | | |
| Restricted funds | 16. | | 7,277 | | 17,033 |
| Unrestricted funds: | 17. | 76,915 | | 38,234 | |
| Designated funds | 18. | <u>30,000</u> | | <u>69,769</u> | |
| | | | 106,915 | | 108,003 |
| Total Charity Funds carried forward | | | <u>114,193</u> | | <u>125,036</u> |

The charitable company is entitled to exemption from audit under section 477 of the Companies Act 2006 for the year ended 31 December 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 December 2024 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for:

(a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and

(b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)
YEAR ENDING 31st DECEMBER 2024

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies' regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 21st July 2025 and were signed on its behalf by:



Gill Masters (Chair)



Lauren Wheeler (Treasurer)

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

NOTES TO THE FINANCIAL STATEMENTS

1. Accounting Policies

1.1 Charity Information

Association for Multiple Endocrine Neoplasia Disorders (AMEND) is an incorporated charity whose registered address is Tyler House, 58-66 Morley Road, Tonbridge, Kent, TN9 1RA.

1.2 Basis of Preparation

The Financial Statements have been prepared in accordance with the Charity's governing document, the Charities Act 2011 and "Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)".

The Financial Statements have been prepared under the historical cost convention.

The Charity constitutes a Public Benefit Entity as defined by FRS 102.

1.3 Going Concern

The Trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern.

1.4 Critical Accounting Estimates and Judgements

The preparation of the Financial Statements requires the Trustees to make judgements, estimates and assumptions that affect the amounts reported for assets and liabilities as at the Balance Sheet date and the amounts reported for revenues and expenses during the year. The estimates and associated assumptions are based on historical experience and other relevant factors. However, the nature of estimation means that actual outcomes could be different.

1.5 Income Recognition

Income is recognised in the Statement of Financial Activities on the following basis:

- (a) Donations are recognised when the Charity has been notified in writing of both the amount and settlement date. In the event that a donation is subject to conditions that require a level of performance before the Charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the Charity and it is probable that those conditions will be fulfilled in the reporting period.
- (b) Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the Charity, normally on notification by the bank.
- (c) Income Tax recoverable on donations under Gift Aid is recognised in the period of which the original donation relates to.
- (d) Grant income is recognised when there is reasonable assurance that the grant will be received, and that the charity will comply with the conditions attached to the grant.
Grants received for specific purposes shall be recognised as income in the period in which the related expenses are incurred. Unrestricted grants shall be recognised as income when received or receivable. Grants received in advance of the related expenditure shall be recognised as deferred income and released to income as the related expenditure is incurred.
- (e) Income from the sale of merchandise is recognised when the significant risks and rewards of ownership have been transferred to the buyer. Income is recognised net of any discounts, returns, and allowances.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

1. Accounting Policies (continued)

1.6 Expenditure Recognition

- (a) Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the Charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement, and the amount of the obligation can be measured reliably.
- (b) Expenditure is accounted for on an accrual's basis.
- (c) Expenditure is allocated by activity in the first instance and, where practical, is also allocated to a cost centre.

1.7 Tangible Fixed Assets

All assets costing more than £1,000 are capitalised.

Impairment of assets

At each reporting end date, the Charity reviews the carrying amounts of its tangible assets to determine whether there is any indication that those assets have suffered an impairment loss. If any such indication exists, the recoverable amount of the asset is estimated in order to determine the extent of the impairment loss (if any).

Depreciation

Computer equipment is depreciated over 3 years.
Office furniture depreciated over 5 years.

1.8 Stocks

Stocks of unsold merchandise in the Charity are valued at the lower of cost and net realisable value.

1.9 Taxation

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

1.10 Fund accounting

Unrestricted "General" funds can be used in accordance with the charitable objectives at the discretion of the Trustees.

Designated funds are unrestricted funds earmarked for a specific project or aim: they can be returned to the General unrestricted funds at any time at the discretion of the Trustees. For reporting purposes, they are combined with unrestricted funds and termed "Unrestricted".

Restricted funds can only be used for particular restricted purposes within the objects of the Charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes, and where the funder may require repayment if the conditions are not met.

Further explanation of the nature and purpose of each fund is included in the Notes to the Financial Statements.

1.11 Pension costs and other post-retirement benefits

The Charity operates Defined Contribution plans for its employees. Once the agreed contributions have been paid the Charity has no further payment obligations. The contributions are recognised as an expense when they are due: amounts not paid at the year-end are shown in creditors in the Balance Sheet.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

| | Unrestricted | Restricted | TOTAL | 2023 |
|----------------------------------|---------------------|-------------------|---------------|---------------|
| | £ | £ | £ | £ |
| 2. Donations and Legacies | | | | |
| Donations and Gift Aid | 50,648 | 8,646 | 59,294 | 36,788 |
| | - | - | - | - |
| Total | 50,648 | 8,646 | 59,294 | 36,788 |
| 3. Charitable Activities | | | | |
| Grants | 20,000 | 10,000 | 30,000 | 41,369 |
| | - | - | - | - |
| Total | 20,000 | 10,000 | 30,000 | 41,369 |
| 4. Investment Income | | | | |
| Bank interest | 5,451 | - | 5,451 | 1,977 |
| Total | 5,451 | - | 5,451 | 1,977 |
| 5. Other Income | | | | |
| Sale of Merchandise | 426 | - | 426 | 523 |
| Other income | 2 | - | 2 | 11 |
| Total | 428 | - | 428 | 534 |
| 6. Raising funds | | | | |
| Staff costs | 9,980 | - | 9,980 | 7,239 |
| Merchandise | 870 | - | 870 | 811 |
| Other | 3,941 | - | 3,941 | 1,585 |
| Total | 14,791 | - | 14,791 | 9,635 |

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

| | Unrestricted | Restricted | TOTAL | 2023 |
|--|---------------|---------------|---------------|---------------|
| | £ | £ | £ | £ |
| 7. Charitable Activities | | | | |
| Staff costs | 24,092 | - | 24,092 | 24,365 |
| Patient information printing, booklets, and websites | 3,403 | - | 3,403 | 6,352 |
| Patient information events and conferences | 1,982 | 9,875 | 11,857 | 8,073 |
| Patient education films | - | - | - | - |
| Patient representation | 209 | - | 209 | 98 |
| Research grants and awards | - | 10,000 | 10,000 | 15,500 |
| ACC support and ACC research grants | 384 | - | 384 | 402 |
| ACC staff costs | - | - | - | 9,048 |
| Patient support and counselling | 13,857 | 881 | 14,738 | 17,567 |
| PPS UK | 384 | - | 384 | 384 |
| Total | 51,211 | 20,756 | 71,966 | 81,789 |
| 8. Support Costs | | | | |
| Rent | 9,360 | - | 9,360 | 9,360 |
| Staff costs | 4,316 | - | 4,316 | 4,589 |
| Printing, postage, and office supplies | 996 | - | 996 | 661 |
| Telephone | 504 | - | 504 | 462 |
| IT support | 23 | - | 23 | 18 |
| IT software and consumables | 783 | - | 783 | 897 |
| Insurance | 508 | - | 508 | 625 |
| Finance charges | 91 | - | 91 | 157 |
| Exchange difference | - | - | - | 44 |
| Legal fees | - | - | - | 35 |
| Repairs and maintenance | - | - | - | 63 |
| Subscriptions | 203 | - | 203 | 117 |
| General | 79 | 107 | 187 | - |
| Depreciation | 457 | - | 457 | 939 |
| Total | 17,319 | 107 | 17,426 | 17,967 |

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)
YEAR ENDING 31st DECEMBER 2024

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

| | Unrestricted | Restricted | TOTAL | 2023 |
|---------------------------------|--------------|------------|--------------|--------------|
| | £ | £ | £ | £ |
| 9. Governance Costs | | | | |
| Audit / Independent Examination | 960 | - | 960 | 2,400 |
| Other governance costs | 872 | - | 872 | 501 |
| Total | 1,832 | - | 1,832 | 2,901 |

10. Staff Numbers

The average number of employees during the year was 2 (2023: 2).

11. Tangible Fixed Assets

| | Computer Equipment | Office Equipment | Total Tangible Fixed Assets |
|------------------------------|-----------------------|---------------------|--------------------------------|
| | £ | £ | £ |
| Cost or valuation | | | |
| At 1st January 2024 | 3,448 | 10,673 | 14,121 |
| Additions | - | - | - |
| Disposals | - | - | - |
| At 31st December 2024 | 3,448 | 10,673 | 14,121 |
| Depreciation | | | |
| At 1st January 2024 | 3,231 | 9,850 | 13,082 |
| Charge | 217 | 240 | 457 |
| At 31st December 2024 | 3,448 | 10,090 | 13,538 |
| Net Book Value | | | |
| At 31st December 2024 | - | 583 | 583 |
| At 31st December 2023 | 217 | 823 | 1,039 |

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

12. Debtors & Prepayments: amounts falling due within one year:

| | Unrestricted | Restricted | TOTAL | 2023 |
|--------------------------------|--------------|------------|--------------|--------------|
| | £ | £ | £ | £ |
| Trade debtors | - | - | - | - |
| Prepayments and accrued income | 5,646 | - | 5,646 | 7,170 |
| | 5,646 | - | 5,646 | 7,170 |

13. Cash and Bank in Hand

| | £ | £ | £ | £ |
|--------------------------|----------------|----------|----------------|----------------|
| Current Accounts | 28,393 | - | 28,393 | 34,947 |
| Deposit Reserve Accounts | 84,870 | - | 84,870 | 80,782 |
| | 113,263 | - | 113,263 | 115,729 |

14. Creditors: amounts falling due within one year:

| | £ | £ | £ | £ |
|------------------------------------|--------------|----------|--------------|--------------|
| Other taxation and social security | 1,425 | - | 1,425 | 195 |
| Other creditors | 4,257 | - | 4,257 | 248 |
| Trade creditors and accruals | 2,112 | - | 2,112 | 1,625 |
| | 7,794 | - | 7,794 | 2,068 |

15. Deferred Income

| | 2024 | 2023 |
|--|-------|------|
| | £ | £ |
| Arising from grants, memberships, events, and training | 4,000 | - |

Deferred income is included in the financial statements as follows:

| | 2024 | 2023 |
|-------------------------------------|--------------|----------|
| | £ | £ |
| Deferred income is included within: | | |
| Current Liabilities | 4,000 | - |
| Movements in the year: | | |
| Brought forward | - | - |
| Released from previous periods | - | - |
| Resources deferred in the year | 4,000 | - |
| | 4,000 | - |
| Deferred income at 31 December 2024 | 4,000 | - |

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

16. Restricted Funds

| | 01/01/2024 | Income | Expenditure | Transfer | 31/12/2024 |
|--|---------------|---------------|-----------------|----------------|--------------|
| | £ | £ | £ | £ | £ |
| Barnes Construction Golf Day | 7,079 | - | - | (7,079) | - |
| HRA Pharma - ACC films | 5,000 | 6,000 | (7,228) | - | 3,772 |
| Licence to use ACC film clips | 800 | - | - | (800) | - |
| Society for Endocrinology | - | - | - | - | - |
| Project Rollercoaster | - | - | (340) | 340 | - |
| National Lottery Community Fund - peer support | 4,154 | - | (648) | - | 3,506 |
| Elliot Dallon Charitable Trust | - | 10,000 | (10,000) | - | - |
| Korean Endocrine Society | | 2,646 | (2,646) | | - |
| | 17,033 | 18,646 | (20,863) | (7,539) | 7,277 |

Restricted Funds

| | |
|--|--|
| Barnes Construction Golf Day | The proceeds from Barnes Construction's Golf Day will be allocated to MEN1 research awards. In subsequent years, Barnes Construction's donations have been unrestricted, with the terms for this funding now released. As a result, this fund has been moved to unrestricted funds starting in 2024. |
| HRA Pharma - AIPD | HRA Pharma provided a grant in 2019 and 2024 to meet the costs of the annual Patient Information Day. |
| Licence to use ACC film clips | Licence given to HRA Pharma for use of ACC patient film clips and to be used against future ACC podcasts. Given that the terms of this funding are no longer subject to restrictions, the fund has been reclassified as unrestricted from 2024. This change reflects the updated status of the funding terms, allowing for greater flexibility in the allocation and utilisation of these resources. |
| Society for Endocrinology | Society for Endocrinology Patient Grant to update resources |
| Big Give - Counselling | Big Give Christmas Challenge Campaign raised funds for our Counselling Service |
| National Lottery Community Fund - peer support | The National Lottery Community Fund provided a grant for our Peer Support Meetings for 2022-23 |
| Elliot Dallon Charitable Trust | The Elliot Dallan Charitable Trust provided a grant of £10,000 for a research grant into adrenocortical cancer. |
| Korean Endocrine Society | The Korean Endocrine Society donated £2,646 to the charity in order to cover a portion of the costs incurred for the CEO to attend and present at the Seoul Internation Congress on Endocrinology & Metabolism (SICEM) event. |

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

| <i>Previous Year</i> | 01/01/2023 | Income | Expenditure | Transfer | 31/12/2023 |
|--|-------------------|---------------|--------------------|-----------------|-------------------|
| | <u>£</u> | <u>£</u> | <u>£</u> | <u>£</u> | <u>£</u> |
| 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 Dallon Charitable Trust | - | 10,000 | (10,000) | - | - |
| | 23,220 | 11,369 | (17,756) | 200 | 17,033 |

17. Unrestricted Funds

| | 01/01/2024 | Income | Expenditure | Transfer | 31/12/2024 |
|------------------|-------------------|---------------|--------------------|-----------------|-------------------|
| | <u>£</u> | <u>£</u> | <u>£</u> | <u>£</u> | <u>£</u> |
| General Fund | 38,234 | 64,527 | (71,913) | 46,068 | 76,915 |
| Designated Funds | 69,769 | 12,000 | (13,240) | (38,529) | 30,000 |
| | 108,003 | 76,527 | (85,153) | 7,539 | 106,915 |

Description of funds

Unrestricted Fund

General:

These are funds available to the Charity for unrestricted use in the furtherance of its charitable aims and objectives. These funds may be revenue (income & expenditure) items or tied up in assets, e.g. Office/Computer Equipment.

Designated Funds (see Note 17.)

These funds outlined below have been designated by the Trustees for the purposes shown whereas, legally, they are unrestricted. For reporting purposes throughout these Financial Statements, they are therefore combined together as "Unrestricted".

| <i>Previous Year</i> | 01/01/2023 | Income | Expenditure | Transfer | 31/12/2023 |
|----------------------|-------------------|---------------|--------------------|-----------------|-------------------|
| | <u>£</u> | <u>£</u> | <u>£</u> | <u>£</u> | <u>£</u> |
| General Fund | 49,093 | 69,299 | (77,450) | (2,708) | 38,234 |
| Designated Funds | 84,347 | - | (17,086) | 2,508 | 69,769 |
| | 133,440 | 69,299 | (94,536) | (200) | 108,003 |

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

NOTES TO THE FINANCIAL STATEMENTS (CONTINUED)

18. Designated Funds

| | 01/01/2024 | Income | Expenditure | Transfer | 31/12/2024 |
|----------------------------|---------------|---------------|-----------------|--------------|---------------|
| | £ | £ | £ | £ | £ |
| Counselling Service | - | 12,000 | (13,240) | 1,240 | - |
| Research Fund | 39,019 | - | - | (39,019) | - |
| Hardship Fund | 750 | - | - | (750) | - |
| Personnel Contingency Fund | 30,000 | - | - | - | 30,000 |
| | 69,769 | 12,000 | (13,240) | 1,240 | 69,769 |

Counselling Service £12,000 is designated annually to provide approximately 200 one-top-one sessions for our members with the psychological counsellor service provider, Rareminds

Research Fund Funds that were previously designated for research funding are insufficient for long-term use and have therefore been undesignated.

Hardship Fund AMEND's official Hardship Fund, previously available for small financial help grants to members, has been discontinued, and previously designated funds have therefore been released into general funds.

Personnel Contingency Fund These designated funds allow for the costs of redundancies in the event that the charity can no longer support paid staff, or that the charity is wound up.

| <i>Previous Year</i> | 01/01/2023 | Income | Expenditure | Transfer | 31/12/2023 |
|----------------------------|---------------|--------|-----------------|--------------|---------------|
| 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 |

19. Related Parties

There were no related party transactions in 2024 or 2023.

20. Trustee Remuneration

No trustee received any remuneration. One trustee received reimbursement of expenditure incurred for a DBS Check, amounting to £18 to meet the requirements for becoming a trustee. In 2023, one trustee received reimbursement of travel and subsistence expenses amounting to £518 to enable them to attend conferences, the AGM and trustee meetings.

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)

YEAR ENDING 31st DECEMBER 2024

21. Reconciliation of Net Income/(Expenditure) to Net Cash Flow from Operating Activities

| | | 2024 | 2023 |
|--|-------------|-----------------|-----------------|
| | Note | £ | £ |
| Net income/(expenditure) for the reporting period (as in the Statement of Financial Activities) | | (10,843) | (31,624) |
| Adjustments for: | | | |
| - Depreciation | 11. | 457 | 939 |
| - (Increase) / decrease in debtors | 12. | 1,524 | (3,630) |
| - (Increase) / decrease in stock | | 670 | 517 |
| - (Decrease) / increase in creditors | 14. | 5,726 | (1,762) |
| Net cash provided by / (used in) operating activities | | (2,466) | (35,560) |
| Analysis of Cash and Cash Equivalents | | | |
| Cash in hand and in Bank | 13. | 113,263 | 115,729 |
| | | 113,263 | 115,729 |

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS (AMEND)
YEAR ENDING 31st DECEMBER 2024

22.

COMPARATIVE STATEMENT OF FINANCIAL ACTIVITIES

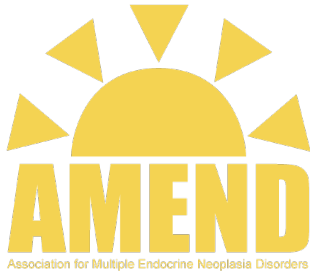
YEAR ENDED 31st DECEMBER 2023

| | Unrestricted | Restricted | TOTAL |
|---|-----------------|----------------|-----------------|
| | £ | £ | £ |
| Income | | | |
| Donations and gift aid | 36,788 | - | 36,788 |
| Charitable Activities | 30,000 | 11,369 | 41,369 |
| Investment Income | 1,977 | - | 1,977 |
| Other Income | 534 | - | 534 |
| Total Income | 69,299 | 11,369 | 80,668 |
| Expenditure | | | |
| Raising Funds | 9,635 | - | 9,635 |
| Charitable Activities | 64,033 | 17,756 | 81,789 |
| Support Costs | 17,967 | - | 17,967 |
| Governance Costs | 2,901 | - | 2,901 |
| Total Expenditure | 94,536 | 17,756 | 112,292 |
| Net income /(expenditure) for the year | (25,237) | (6,387) | (31,624) |
| Transfer between funds | (200) | 200 | - |
| Revaluation gains on investment assets | | - | - |
| Net Movement in Funds | (25,437) | (6,187) | (31,624) |
| Reconciliation of Funds | | | |
| Total Funds brought forward | 133,440 | 23,220 | 156,660 |
| Total Funds carried forward | 108,003 | 17,033 | 125,036 |

ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS

England & Wales - Charity number 1153890

Accounts



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.

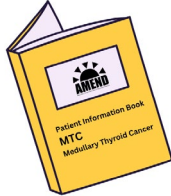
Huge thanks must go to our fundraisers, grantees, and donors who have been essential in seeing AMEND through these recent financially challenging times. Thanks also to all our wonderful volunteers, whose time given to AMEND is immeasurable. Thanks to you all for your continued support from the bottom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



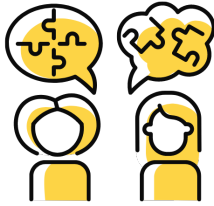
Provision of Support



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.

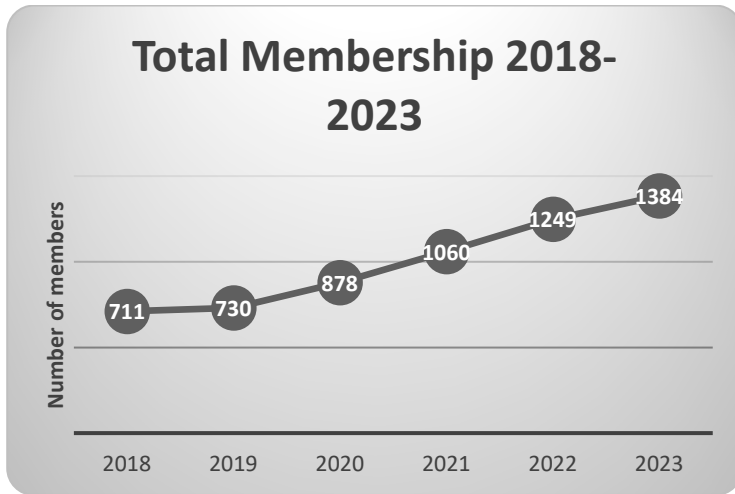


MEMBERSHIP REPORT

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

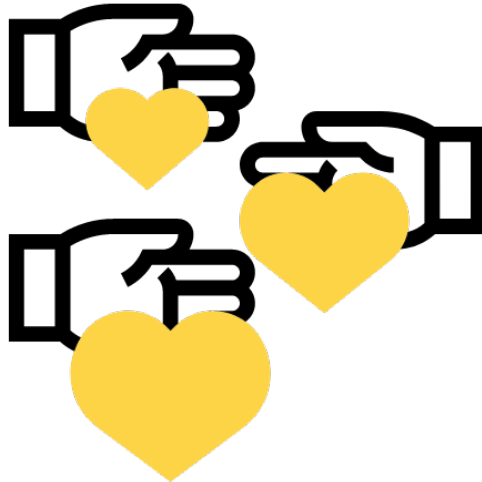
FUNDRAISING REPORT

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 | | <u>123,997</u> | <u>154,681</u> |
| 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 |

| | 2023 | | | 2022 |
|--|-------------------|---------------------|---------------|---------------|
| | Restricted | Unrestricted | Total | Total |
| | £ | £ | £ | £ |
| 5. DONATIONS AND LEGACIES | | | | |
| Donations and gift aid | - | 36,788 | 36,788 | 62,103 |
| Grants | - | 30,000 | 30,000 | 30,500 |
| | - | <u>66,788</u> | <u>66,788</u> | <u>92,603</u> |
| 6. INCOME FROM CHARITABLE ACTIVITIES | | | | |
| Grants for charitable activities | 11,369 | - | 11,369 | 36,791 |
| Other | - | 11 | 11 | 10 |
| | <u>11,369</u> | <u>11</u> | <u>11,380</u> | <u>36,801</u> |
| 7. INCOME FROM OTHER TRADING ACTIVITIES | | | | |
| Sale of merchandise | - | 523 | 523 | 416 |
| | - | <u>523</u> | <u>523</u> | <u>416</u> |

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 |
| | <u>-</u> | <u>2,901</u> | <u>2,901</u> | <u>1,999</u> |

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

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 Dallon Charitable Trust | - | 10,000 | (10,000) | - | - |
| | <u>23,220</u> | <u>11,369</u> | <u>(17,756)</u> | <u>200</u> | <u>17,033</u> |

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

The Elliot Dallan Charitable 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: 

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)

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 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

Hove

East Sussex

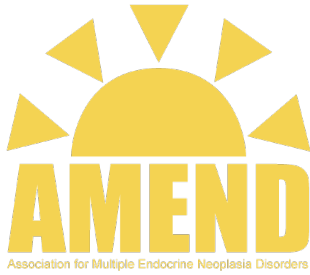
BN3 2WB



ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS

England & Wales - Charity number 1153890

Accounts



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

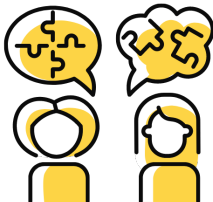


Provision of Support



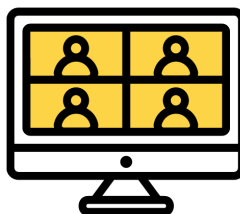
187 new patient & family members, and 13 health professionals joined AMEND for free in 2022.

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.

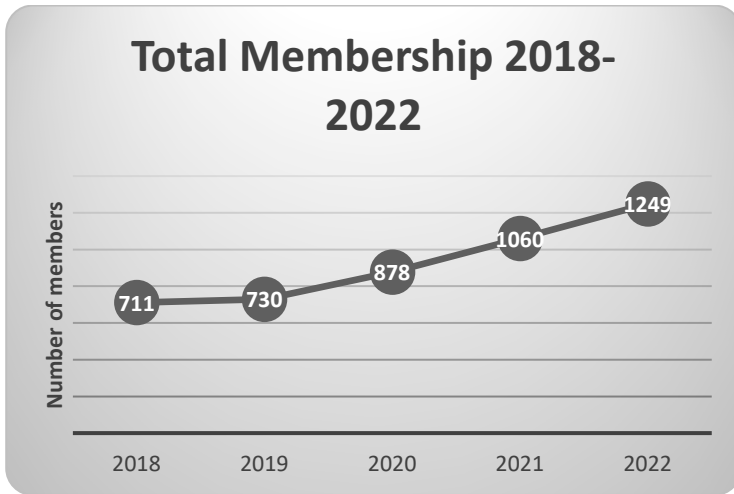


MEMBERSHIP REPORT

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

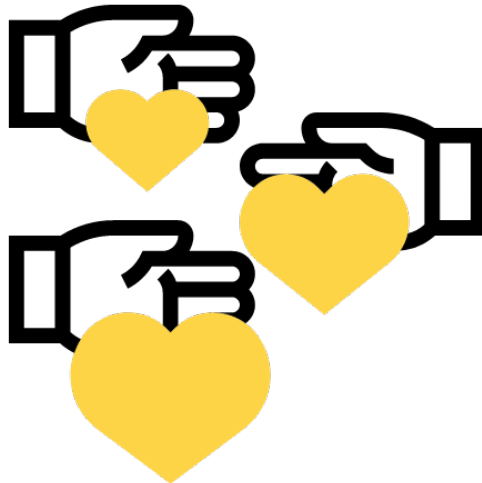
FUNDRAISING REPORT

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 Bhatiwal, 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.



Catherine Hamilton-Woodthorpe
Treasurer
4 September, 2023

STATEMENT OF FINANCIAL ACTIVITIES

For the Year ended 31 December 2022

| | | 2022 | | | 2021 | | Total |
|------------------------------------|-------|---------------|-----------------|----------------|-----------------|-----------------|-----------------|
| | notes | Restricted | Unrestricted | Total Funds | Restricted | Unrestricted | 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 | | <u>11,070</u> | <u>5,712</u> |
| | | <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 | | <u>(600)</u> | <u>(600)</u> |
| | | <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>-</u> | <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>-</u> | <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 | <u>1,200</u> |
| At 31/12/22 | <u>14,121</u> |
| Depreciation | |
| At 1/1/22 | 11,211 |
| Charge for the year | <u>931</u> |
| 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: www.twitter.com/AmendInfo (@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 Casey, 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

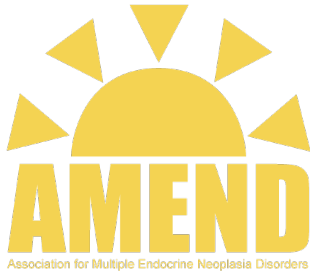
TN4 0PD



ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS

England & Wales - Charity number 1153890

Accounts



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

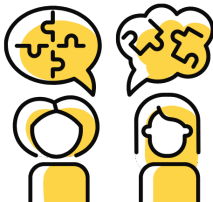


Provision of Support



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.

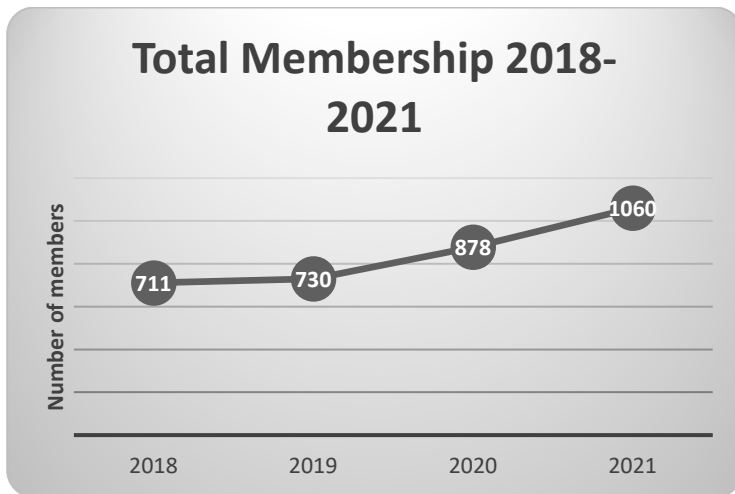


MEMBERSHIP REPORT

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.

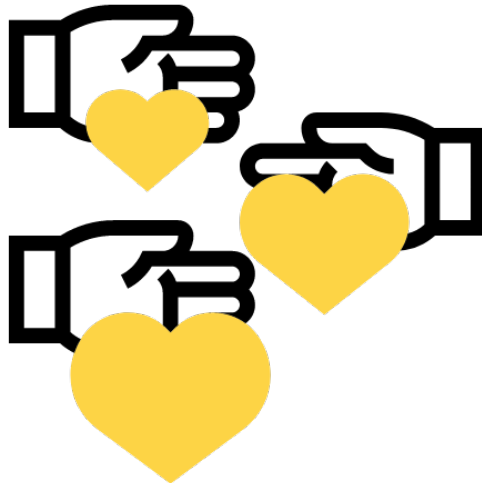
FUNDRAISING REPORT

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

| | notes | 2021 | | | 2020 | | |
|------------------------------------|-------|-----------------|-----------------|-----------------|---------------|----------------|----------------|
| | | 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 |
| | | | <u>165,792</u> | <u>202,190</u> |
| 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>-</u> | <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 | 6,236 |
| | Merchandise | - | 657 | 657 | 1,763 |
| | Other | - | 1,325 | 1,325 | 236 |
| | | - | 8,427 | 8,427 | 8,235 |
| 9. CHARITABLE ACTIVITIES | | | | | |
| | Staff costs | - | 22,265 | 22,265 | 21,588 |
| | Patient information printing, booklets and website | - | 2,943 | 2,943 | 4,306 |
| | Patient information events and conferences | 10,082 | 7,820 | 17,902 | 3,203 |
| | Patient education films | 14,888 | - | 14,888 | 11,413 |
| | Patient representation | - | - | - | 851 |
| | Research grants and awards | - | 19,595 | 19,595 | 17,996 |
| | ACC support and ACC research gran | 840 | - | 840 | 1,847 |
| | ACC staff costs | 8,056 | - | 8,056 | 7,794 |
| | Patient support and counselling | 7,100 | 5,204 | 12,304 | 15,183 |
| | International development | - | - | - | 168 |
| | | 40,966 | 57,827 | 98,793 | 84,349 |
| 10. SUPPORT COSTS | | | | | |
| | Rent | - | 14,534 | 14,534 | 12,298 |
| | Staff costs | - | 3,516 | 3,516 | 3,355 |
| | Printing, postage and office supplies | - | 846 | 846 | 540 |
| | IT support | - | 209 | 209 | 30 |
| | IT software and consumables | - | 606 | 606 | 446 |
| | Insurance | - | 632 | 632 | 611 |
| | Finance charges | - | 122 | 122 | 120 |
| | Depreciation | - | 999 | 999 | - |
| | Legal fees | - | 35 | 35 | 35 |
| | | - | 21,498 | 21,498 | 17,435 |
| 11. GOVERNANCE | | | | | |
| | Independent examiner | - | 600 | 600 | 600 |
| | Trustee meetings, AGM and other | 36 | 283 | 319 | 736 |
| | | 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 | Balance | |
| | £ | £ | £ | £ | £ | |
| Anonymous donor | 677 | - | - | - | 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 | - | - | - | 380 | |
| Sanofi | 86 | - | - | - | 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 | - | - | - | 7,079 | |
| HRA Pharma - ACC films | 5,000 | - | - | - | 5,000 | |
| Licence to use ACC film clips | 800 | - | - | - | 800 | |
| National Lottery - Counselling | 7,100 | - | (7,100) | - | - | |
| Ipsen 2021 Patient Information Day | - | 1,400 | (1,400) | - | - | |
| Ipsen - MEN1 films | - | 5,480 | (5,480) | - | - | |
| | | | | | | |
| | <u>37,601</u> | <u>10,890</u> | <u>(41,002)</u> | <u>6,533</u> | <u>14,022</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 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

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/AssociationforMENDsdisorders

Twitter: [@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 (Chair)

Catherine Hamilton-Woodthorpe (Treasurer)

Gill Masters

Professor Karim Meeran

Mrs Laura Jones

Ms Louise Breen, RN

Dr John Ayuk

Ms Miriam Asia, RN

Andy Price

Karen Williams

Robert Millinship (co-opted 2021)

Sarah Norman (co-opted 2022)

Graeme Cohen (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

Sheffield Stables

1 Sheffield Road

Southborough

Tunbridge Wells

Kent

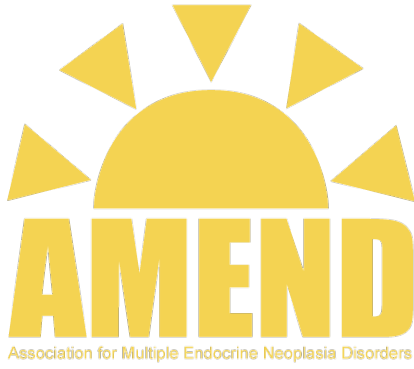
TN4 0PD



ASSOCIATION FOR MULTIPLE ENDOCRINE NEOPLASIA DISORDERS

England & Wales - Charity number 1153890

Accounts



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 style and is positioned above the typed name.

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,



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

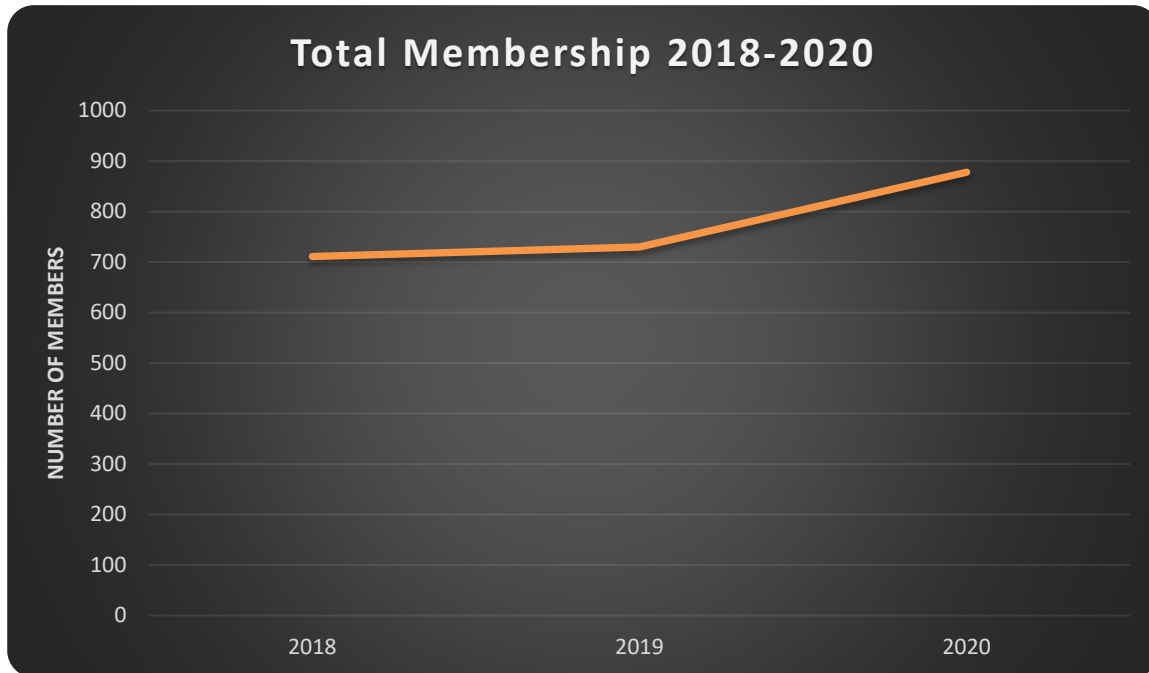
has been pushed back to 31 August. Although we are still at the mercy of the continuing pandemic and virus variants, we are hoping to complete our patient experience films about MEN2 and MEN1 by year end. Our resources for young adults are already complete and were launched on Rare Disease Day 2021. 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

| | notes | 2020 | | | 2019 | | Total Funds £ |
|------------------------------------|-------|-----------------|-------------------|------------------|-----------------|-------------------|------------------|
| | | Restricted £ | Unrestricted £ | Total Funds £ | Restricted £ | Unrestricted £ | |
| 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>202,190</u> | <u>203,731</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 | | | <u>10,723</u> | |
| Depreciation | | | | |
| Balance brought forward | | | 9,795 | |
| Charge for the year | | | 417 | |
| At 31/12/20 | | | <u>10,212</u> | |
| Net book value at 31/12/20 | | | <u>511</u> | |
| Net book value at | | | | |
| 1/1/20 | | | <u>928</u> | |

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.

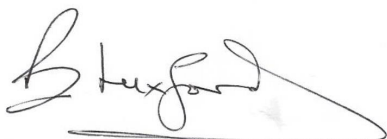
Basis of independent examiner's report

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

The Warehouse, Draper Street
Tunbridge Wells
Kent, TN4 0PG
01892 516076 / 841032
info@amend.org.uk
Website: www.amend.org.uk
Facebook: www.facebook.com/AssociationforMENdisorders
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 Lalloo, Mr David Scott-Coombes, Professor Rajesh Thakker

Independent Examiner

Mr Brian Luxford, FCA
Raymond Benn & Co Limited
Sheffield Stables
1 Sheffield Road
Southborough
Tunbridge Wells
Kent
TN4 0PD

