

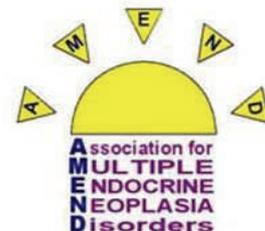
Association for Multiple Endocrine Neoplasia Disorders (AMEND)

Registered UK Charity Number 1099796

2007 Annual Report & Accounts



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Chairperson's Report

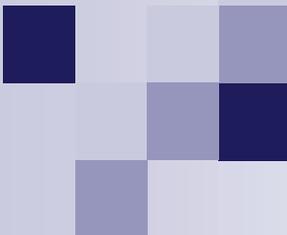
AMEND's 5th year was its most successful yet in terms of its attempts to achieve its Constitutional aims (see Review of 2007 Achievements). As ever, none of the work done would have been possible without the considerable time and efforts of the Executive Trustee Committee and volunteers. Equally, none of this work could have been funded without the unprecedented number of donations and inventive fundraising activities. To all these generous people we owe huge thanks.

2007 saw the identification of the unique situation of the trustees. In larger organisations, trustees and voluntary workers are separate entities. In simple terms, trustees are responsible for ensuring that the undertakings of the charity are done so within legal and Charity Commission guideline limits, and they therefore act as a 'critical friend' to those who do the work. AMEND's size means that the two roles are actually combined. As you may imagine, it can be mind-boggling to separate the two roles and be one's own critical friend! Addressing this situation by recruiting further trustees in order to reduce volunteer workloads is now being incorporated into our fledgling strategic plan.

Finally, 2008 should see further exciting times ahead and AMEND hopes to continue to meet and possibly exceed the expectations of both members and non-members who use our services.

With best wishes for a happy and healthy 2008

Jo Grey
AMEND Chairperson
On behalf of the Executive Trustee Committee
Thursday 20th March 2008

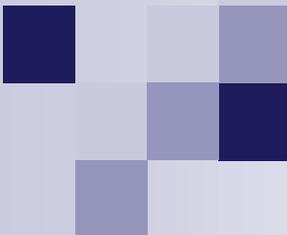


AMEND's Constitutional Aims & Objectives

(as at May 2006)

“.. 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:

- Acting as a reliable and accurate source of information for the public concerning M.E.N. and its associated sporadic growths**
- Promoting a wider knowledge of the illness among the medical profession to assist in early and accurate diagnosis**
- 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**
- 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 & The Trustees

The Executive Trustee Committee present their annual report together with the financial accounts of the Charity for the year ended 31 December 2007.

Structure, Governance & Management

The Society is an unincorporated charitable body governed by a Trust Deed vesting control and responsibility in the Committee on behalf of the membership.

The Trustees hold regular meetings to administer the Society and their terms of office are determined by the Trust Deed.

The term of office for an AMEND trustee is one year beginning from the Annual General Meeting when voting-in takes place.

Statement of Trustees Responsibilities

Charity law requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the Trust's incoming resources and application of resources during the year and of its state of affairs at the end of the year. In preparing these financial statements, the Council have:

- selected suitable accounting policies and applied them consistently;
- made judgements and estimates that are reasonable and prudent;
- stated whether applicable accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements; and
- prepared the financial statements on the going concern basis unless it is inappropriate to presume that the Trust will continue in operation.

The Council's responsibilities include keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and they have determined that the financial statements should comply with the Charities Act 1993. They are also responsible for safeguarding the Trust's assets and hence for taking reasonable steps for the prevention and detection of fraud and breaches of laws and regulations.

Overview of 2007 Achievements

New Patient Information Book on sporadic medullary thyroid cancer

This book is the fifth in AMEND's series of detailed patient information books which have been written with the help of our Medical Advisory Team. The other titles are MEN1, MEN2a, MEN2b and FMTC. Hard copies are made available free to patients, and are also available free to everyone on the AMEND website. During 2007 all of these publications together with the clinic leaflet and poster were made available to medical professionals on CD-ROM

MEN1 website film

Thanks to the hard work of MEN1 member and freelance cameraman, Andy Smith, the MEN1 patient experience website film was completed and launched on the website, and has received many favourable comments. Both patients and medical experts give their views and opinions on life with MEN1 in order to inform, encourage, and hopefully to inspire others to get the most out of life

Website revamp

Phase II of our website improvement programme was completed which saw the homepage reworked, a change of host and several behind-the-scenes improvements made

MEN Consortium

Official formation of this AMEND working group was finalised and the first two meetings were held with the aim of finding a way to improve the care and management of all MEN patients



"It's nice not to feel so alone in this"



Overview of 2007 Achievements (Continued)

MEN Passport

The concept of a patient diary in which to record appointment and tests dates and results began to take shape during 2007. Inspired by the highly successful Prostate Passport, AMEND believes that this project is well worth undertaking to ensure that all MEN patients can keep track of everything that happens during their 'MEN journey'

Professional Meetings Presence

AMEND was represented at a number of professional medical meetings during 2007, including the British Endocrine Society (BES) annual meeting in Birmingham, The Association of Surgeons of Great Britain and Ireland (ASGBI) annual meeting in Manchester, European Workshop on Centres of Expertise at NOWGEN in Manchester, MEN Symposium in Liverpool and the British Association of Endocrine and Thyroid Surgeons (BAETS) annual meeting in London. In addition, the UK NET Patient Foundation meeting in Hampshire and the International Thyroid Cancer Survivor's Conference in San Francisco, USA were kindly covered by members of AMEND

BES YI Award

Our first ever winner of the AMEND British Endocrine Society Young Investigator Award was Dr Chrysanthia Leontiou from St Bartholomew's Hospital in London for her research into the protein, Ghrelin, which has been found to potentially inhibit the growth of pituitary tumours

"We feel you do a fantastic job of informing and inspiring all of us connected with MEN"

Clinical Trial Travel Assistance

Thanks to a generous donation AMEND have set up this fund to assist patients with their travel costs when participating in clinical trials for new thyroid cancer treatments

Family Route Map

AMEND was one of a small number of patients' groups who worked with the Genetic Interest Group on a prototype 'Route Map' whose intention is to signpost patients to sources of information and help that is currently available. The Route Maps had their official launch in March 2008

Overview of 2007 Achievements (Continued)

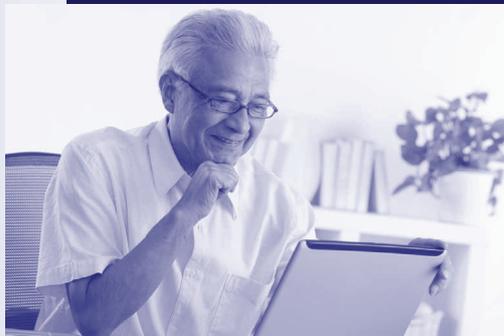
Training

Several members of the Executive Trustee Committee and volunteers undertook training during 2007 to help with their work for AMEND. Training included 3 volunteers undertaking a one-day Loss and Bereavement Workshop, and other one-day courses on Management, Presentations and Public Speaking, Project Management and Volunteer Recruitment and Management

*"I don't know what
we would have done
without AMEND"*

Affiliations

A closer alliance was formed with the NET Patient Foundation, and other existing alliances with Butterfly Northeast, the British Thyroid Foundation and the Genetic Interest Group continued to strengthen. AMEND has found great benefits in networking with other charities, not least of which is to widen the range of support available to both our members and theirs



*Thanks again for everything, your site
is a great help and a wonderful resource!*



Looking to 2008 and beyond

In AMEND's aim to continue meeting its Constitutional objectives, the following highlights are planned for 2008 and beyond

MEN2 film

Plans are already underway to produce a website film regarding patient experiences of MEN2. Some filming has already been done and AMEND hopes that the film will be ready to launch at the end of 2008

MEN Passport

Layout and design issues are almost resolved and the finished passports should become available free to MEN patients during the coming year

Professional Meeting Attendance and Talks

Once again, AMEND will be represented at a range of professional meetings, including the British Endocrine Societies meeting in Harrogate, and at the Association of Surgeons of Great Britain and Ireland (ASGBI) where Jo Grey has been invited to give a talk on 'What I Want From My Consultant'

Trustee recruitment

Efforts in 2008 will be focussed on recruiting 2 more trustees to the Executive Trustee Committee, where expertise in Law and Accounting are lacking at present

Continuing website improvements

Phase III improvements, including a rework of the Discussion Forum will be completed

Patient Information Books

Further expansion of the Patient Information Book series with the addition of pheochromocytoma and paraganglioma titles

Strategic Plan

Continued development of a strategic plan for the charity

Membership Report

During 2007 AMEND was delighted to welcome a total of 17 new patient/family members, bringing the total to 154. This number includes 61 MEN1 patients, 15 MEN2a, 6 MEN2b, 1 FMTC, 6 sporadic MTC, 9 family members and 56 interested doctors and nurses.

Geographic spread continues, and although the majority are UK-based, we also have 3 members from the USA, and 1 each from South Africa, Canada, New Zealand, Australia, Hong Kong and India.

Sadly we lost 2 members to MEN during 2007. Highlighting the need for more research into MTC and MEN in general, AMEND hopes that the increasing numbers of patients and members registering with the Research Database will see this come to fruition. A total of 66 patients are now registered on the Database, an increase of 8 from 2006.



Fundraising Report

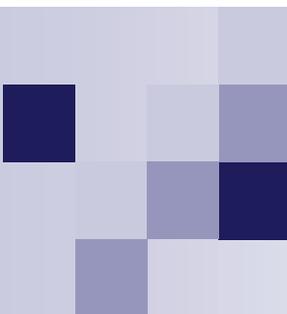
Sadly, many donations were collected in lieu of funeral flowers and thanks were sent to several families for thinking of AMEND at these difficult times.

We were delighted once again to be supported this year by the Mrs Waterhouse Charitable Trust Fund with a donation of £10,000 which we hope to enable us to take on several major projects over the course of the coming few years.

Fundraisers also went wild this year, and included amongst others, Ben Wardle competing in the 2007 Scumball car challenge, Sue Meadow's 60th birthday celebrations and Kerry Williams and Sandra Anderson competing in (and completing!) the Great North Run.

AMEND's own trustees also did their bit: treasurer Sam Meadows participated energetically in sporting events to benefit AMEND, and Emily Fazal, as part of the Leeds Fall Ball Committee, organised and executed a wonderful party in Leeds in September, raising over £4000 for AMEND and in the process raising AMEND's profile in the Yorkshire area quite considerably.





Finance Report

This year has been without doubt the most challenging and rewarding year yet as Treasurer. As you will have already read from the other reports, AMEND members have been involved in a diverse range of activities which have made a significant impact in furthering our charitable aims. Needless to say, these activities have occurred not only because of the generosity of members in giving their time and effort, but also thanks to the donations and membership monies received. Myself and the rest of the trustees would like to thank everyone who has made a positive contribution of time or money over the course of this financial year. Each and every penny is gratefully received and importantly put directly to the purpose it was intended as we continue to operate without overheads or paid staff.

A Summary Financial Review (1st Jan 2007 to Dec 31st 2007);

Income from donations and interest	£23,609 up from £14,255 in 2006
Monies spent in maintaining activities	£9,825 up from £8,335 in 2006
Total monies held in account for activities	£35,510 up from £21,726 in 2006

Full results for the year are set out on pages 14 to 18 of this annual report.

The underlying picture shows membership increasing as the Charity becomes more widely known, and of members donating more towards our efforts, either by regular or by one-off contributions.

As the fundraising report on page 11 mentions, in 2007 we were again fortunate to receive a sizeable donation from the Mrs Waterhouse Charitable Trust and a contribution from the Jeans for Genes appeal, which, along with other gratefully received donations has ensured that AMEND carries ample reserves to meet running costs for the year ahead and beyond.

While our overall costs have risen by £1,490 from 2006, this represents good value when the travel and accommodation costs for the bewildering array of conferences attended and projects undertaken is factored in. A glance through section 5 of the full report demonstrates that the Charity has maintained its good financial discipline and prudent housekeeping which is down to the fact that the Trustees have reviewed the risks of operating the charity and have developed procedures to manage those risks.

As the scope of the Charity has widened we have become involved in and instigated a number of projects for which the trustees have budgeted certain amounts of monies. The trustees have the responsibility to ensure that:



Finance Report (Continued)

- 1) these projects are not burdensome on the charity - i.e. cost a lot without delivering tangible benefits
- 2) costs are recorded and justified
- 3) project costs act as a financial indicator for the future

Currently there are two main projects: the MEN consortium to which we have committed £2,010 for 2007/8 (2006/7 costs were met by a special grant from the Society for Endocrinology); and, the further development of the website, for which we have allocated the £4,000 Fall Ball earnings in order to continue this vital resource.

Treasurers' Proposed Aims for 2008

If re-elected, I aim to do the following:

- 1) ensure that all gift aid monies from previous years are reclaimed from HMRC
- 2) raise the awareness with members of the importance of gift-aid in all donations however small and to establish a system where gift-aid can be claimed simply with the minimum of bureaucracy to the collector
- 3) raise my awareness of Charity Commission good practice for charity accounting and establish procedures and policies where necessary
- 4) keep everybody informed so that the accounts do not seem a "Dark Art" akin to a Hogwarts school lesson.

Finally I huge thank you to all of you who have assisted me in some way this year. I look forward to another year of success for AMEND and good health to all the members and trustees.

Sam Meadows
AMEND Treasurer
On behalf of the Executive Trustee Committee

Bankers: HSBC, High Street, Pateley Bridge, Harrogate, HG3 5AW

Accountant: AMJ Ball (chartered accountant), 75 Banner Cross Rd, Sheffield, S11 9HQ

Statement of Financial Activities

For the year ended 31st December 2007

	notes	2007 Total Funds £	2006 Total Funds £
Incoming resources			
Incoming resources from generated funds			
Voluntary income	4	22,457	13,891
Investment income		1,152	364
		<u>23,609</u>	<u>14,255</u>
Resources expended			
Charitable activities	5	9,575	8,335
Governance costs	6	250	0
		<u>9,825</u>	<u>8,335</u>
Total resources expended		<u>9,825</u>	<u>8,335</u>
Net incoming / (outgoing) resources		13,784	5,920
Total funds brought forward		21,726	15,806
Total funds carried forward		<u>35,510</u>	<u>21,726</u>

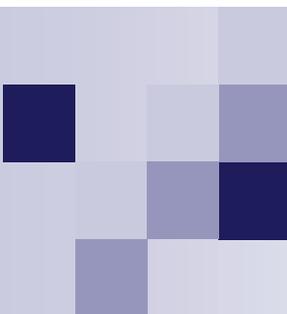
Balance Sheet

As at 31st December 2007

	note	2007 £	2006 £
Fixed Assets	7	310	156
Current Assets			
Prepayments and accrued income		896	0
Cash at bank			
Deposit account		4,211	5,189
Current account		1,057	1,381
Term deposits		<u>29,286</u>	<u>15,000</u>
		<u>35,450</u>	<u>21,570</u>
Current Liabilities			
Outstanding expenses		<u>(250)</u>	<u>(0)</u>
		<u>(250)</u>	<u>(0)</u>
Net Current Assets		<u>35,200</u>	<u>21,570</u>
Net Assets		<u>35,510</u>	<u>21,726</u>
Accumulated Funds			
Unrestricted general		35,510	21,726
		<u>35,510</u>	<u>21,726</u>

The financial statements were approved by the trustees on Thursday 20th March, 2008 and are signed on their behalf by

S W Meadows
AMEND Treasurer



Notes to the Financial Statements

As at 31st December 2007

1. ACCOUNTING POLICIES

The financial statements have been prepared under the historical cost convention and in accordance with applicable accounting standards and with the revised Charities Accounting Statement of Recommended Practice (SORP 2005).

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. Other income and expenditure

Other income and expenditure is accounted for on the accruals basis.

c. Investments

All investments stated as current, being monetary assets, are stated at cost.

d. Stocks

No value is placed on the stock of unsold publications because the Trustees do not consider that the stock has any value until sold.

e. Fixed assets and depreciation

Fixed assets are capitalised and depreciated over the estimated useful life as follows: 25% on cost

2. TAXATION

As a registered charity, the Association does not pay tax on its income.

3. TRUSTEES REMUNERATION

Members of the Committee received no direct remuneration or expenses other than reimbursement of direct expenses incurred on behalf of the Association.

Notes to the Financial Statements (continued)

For the year ended 31st December 2007

	2007	2006
	£	£
4 VOLUNTARY INCOME		
Membership	890	1,025
Donations	10,762	1,866
Grants	11,000	11,000
Other income	<u>957</u>	<u>0</u>
	<u>23,609</u>	<u>13,891</u>

5. CHARITABLE ACTIVITIES / SUPPORT COSTS

Printing, postage and office supplies	984	877
Newsletters & leaflets	1,161	1,746
Promotions	926	0
Insurance	319	0
Meetings and conferences	3,031	2,399
Website development	1,234	1,296
Training	156	0
Depreciation	259	0
Miscellaneous	<u>1,505</u>	<u>2,017</u>
	<u>9,575</u>	<u>8,335</u>

6. GOVERNANCE

Independent Examiner	<u>250</u>	<u>0</u>
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7. TANGIBLE FIXED ASSETS

	Equipment
	£
Book value brought forward	156
Additions at cost	<u>413</u>
	<u>569</u>
Depreciation charged	<u>259</u>
Net book value	<u>310</u>



Independent Examiner's Report to the Trustees

I report on the accounts of the Trust for the year ended 31 December 2007, which are set out on pages 14 to 17. I do not report on the comparatives or the opening balances.

Respective responsibilities of Trustees and Examiner

As the charity's Trustees you are responsible for the preparation of the accounts; you consider that the audit requirements of section 43(2) of the Charities Act 1993 (the Act) does not apply. It is my responsibility to state, on the basis of procedures specified in the General Directions given by the Charity Commissioners under section 43 (7) (b) of the Act, whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the General Direction given by the Charity Commissioners. 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 an unusual items or disclosures in the accounts, and seeking explanations from you as Trustees concerning such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently I do not express an audit opinion on the view given in the accounts.

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
 - a. to keep accounting records in accordance with section 41 of the Act; and
 - b. to prepare accounts which accords with the accounting records and to comply with the accounting requirements of the Act

have 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.

A.M.J. Ball
Chartered Accountant
Thursday 20th March 2008

Contact Information

Main Postal Address

PO Box 89, Tunbridge Wells, Kent, TN2 9GL

Main Email

info@amend.org.uk

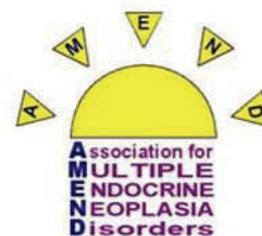
Main telephone numbers

MEN1 - Liz Dent: 01423 780594

MEN2/Sporadics - Jo Grey: 01892 525308

Website Address

www.amend.org.uk



Executive Trustee Committee

Jo Grey (Chair)

Tel: 01892 525308

Email: jo.grey@amend.org.uk

Janet French (Secretary/Membership)

Tel: 01243 261566

Email: janet.french@amend.org.uk

Sam Meadows (Treasurer)

Tel: 01302 302562

Email: sam.meadows@amend.org.uk

Liz Dent (Co-founder/President)

Tel: 01423 780594

Email: liz.dent@amend.org.uk

Emily Fazal (Co-founder/Vice-President)

Tel: 01977 557815

Email: emily.fazal@amend.org.uk

Dr Stephen Gilbey

(Consultant Physician, Department of Endocrinology & Diabetes, Leeds)

Mr Mark Lansdown

(Consultant Surgeon, Department of Endocrinology & Diabetes, Leeds)

Dr Jonathan Pinkney

(Consultant Endocrinologist, Royal Cornwall Hospital, Truro)

Volunteers

Terry Green (MEN1 Officer)

Vivienne Judge (MEN2b Officer)

Patron

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

Medical Advisory Team

Professor Rajesh Thakker, Dr Caroline Brain, Professor John Connell, Professor Ashley Grossman, Mr Barney Harrison, Dr Fiona Lalloo, Mr David Scott-Coombes, Professor Dorothy Trump, Professor Tony Weetman

