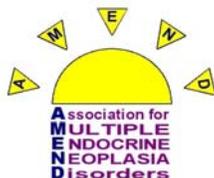




Registered charity No: 1099796

ANNUAL REPORT

FOR THE YEAR 2006



Registered charity No: 1099796

2006 Chairwoman's Report

Executive Trustee Committee Changes

2006 was yet another busy and successful year for **AMEND**. At the AGM in May a new committee was formed when the co-founding Chair, Liz Dent, and Secretary, Emily Fazal, stepped down. Liz and Emily became Co-founder President and Co-founder Vice-President respectively in recognition of their perseverance and hard work in setting up the charity and thankfully remain as active Trustees on the committee. I, Jo Grey became Chair, and Janet French, Secretary.

The reorganisation has resulted in the following structure of the charity:

Executive Committee of Trustees

Liz Dent (Co-founder President)
Emily Fazal (Co-founder Vice President)
Jo Grey (Chair)
Janet French (Secretary)
Sam Meadows (Treasurer)
Dr Stephen Gilbey (St James's Hospital, Leeds)
Mr Mark Lansdown (St James's Hospital, Leeds)
Dr Jonathan Pinkney (Royal Cornwall Hospital, Truro)

Volunteers

Terry Green (MEN1 officer)
Vivienne Martin (MEN2b officer)

Patron

Professor Rajesh Thakker (OCDEM,
Churchill Hospital, Oxford)

Further subcommittees and working groups were formed to tackle specific projects and areas of governance. Trustees, volunteers and other external interested parties participate in such subcommittees as Administration, Patient Support and Information, Finance and Fundraising, Website IT and Data Handling and Production, and Publicity Marketing and Merchandise.

Likewise, working groups such as the **AMEND** Medical Advisory Team (AMAT) and the newly formed MEN Consortium provide invaluable knowledge, advice and support to **AMEND** in many of its activities.

AMEND Medical Advisory Team (AMAT)

Professor Raj Thakker,	Oxford Centre for Diabetes, Endocrinology & Metabolism, Oxford
Dr Caroline Brain,	Great Ormond Street Hospital for Children & UCLH, London
Professor John Connell,	Western Infirmary, Glasgow
Professor Ashley Grossman,	St Bartholomew's Hospital, London
Mr Barney Harrison,	Royal Hallamshire Hospital, Sheffield
Dr Fiona Laloo,	St Mary's Hospital, Manchester
Mr David Scott-Coombes,	University Hospital of Wales, Cardiff
Professor Dorothy Trump,	St Mary's Hospital, Manchester
Professor Tony Weetman,	University of Sheffield Clinical Sciences Centre, Sheffield

I take this opportunity to thank every one of our volunteers who help with every aspect of **AMEND**'s work, and without whose efforts **AMEND** would not function. I would also like to thank our outgoing Trustees, Rev Peter Dunbar and Terry Marsh for their support over the last few years, and Professor Raj Thakker who I am pleased to report remains involved with **AMEND** not just on our AMAT, but also as our very first Patron.



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UK Charity Commission

To add to my already steep learning curve regarding the red tape of running a charity, the Charity Commission randomly selected **AMEND** to take part in an audit of Trustee Eligibility early in the year. We completed the audit in the agreed time and in the process, identified potential problems with and subsequently updated our protocols for future Trustee recruitment.

BES Young Investigator's Award

2006 saw the finalisation of negotiations to set up this annual award at the British Endocrine Societies Meeting which is held each spring. The award of £300 is run in association with the Society for Endocrinology who undertake the judging of entries. The winner will present their research at the **AMEND** AGM, where they will officially receive their cheque, medal and certificate. We hope that this award will encourage interest in and research into MEN and its associated sporadic growths.

Fundraising/Fundraisers

AMEND wouldn't get far without the financial support of its members and friends. The variety of fundraisers held during 2006 never ceases to amaze.

Fundraisers:

- ❖ Classical music concert
- ❖ Charity buffet
- ❖ Marathon
- ❖ Charity barbeque
- ❖ Sponsored bridge walk
- ❖ Glasgow 10km run
- ❖ House sale fee donation
- ❖ May Charity dance – 2006 and beyond
- ❖ BT Charity Trust Application
- ❖ Royal Tunbridge Wells Round Table

Donations:

Another wonderful donation of £10,000 from Mr and Mrs Dunn's Mrs Waterhouse Charitable Trust fund ensured **AMEND's** continued ability to provide support during 2006 and beyond.

Sadly, many donations during 2006 were in lieu of funeral flowers. As well as condolences, thanks were sent to all families for thinking of **AMEND** at such difficult times.

A big thank you to all of those who donated or raised money for **AMEND** during 2006. The committee considers very carefully how to use all monies within the aims and objectives of the charity.

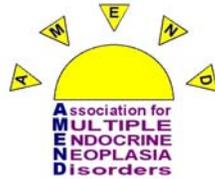
Conferences Attended

During 2006, **AMEND** Committee members and volunteers attended a plethora of professional events in order to raise awareness of MEN and **AMEND** and thereby reach as many patients as possible. This list of events included:

- ❖ UCL 2nd Yr Med Student Public Visitor Education Programme, London, 17th March
- ❖ European Congress on Endocrinology (ECE), Glasgow, 1st-5th April
- ❖ European Cancer Patient Coalition (ECPC) Masterclass, Milan, 13th-14th May
- ❖ Less Common Cancers Workshops, London, 19th June and 19th October
- ❖ British Association of Endocrine Surgeons (BAES) Meeting, 14th-15th September
- ❖ 9th International Thyroid Cancer Survivor's Conference, Florida, 27th-29th October
- ❖ Genetic Testing, Gene Therapy & Insurance, Leeds, 14th November
- ❖ Key Advances Thyroid Cancer Symposium, London, 30th November

Links with Other Support Groups

AMEND continued to forge links with other groups during 2006, and although plans to hold a joint national information event on thyroid cancer had to be curtailed due to lack of interest and insufficient funds, **AMEND** maintains very strong links with both the British Thyroid Foundation and Butterfly Northeast (Newcastle-based thyroid cancer support charity).



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Other patients groups with whom we maintain links include: the Genetic Interest Group, The Pituitary Foundation, Contact a Family, NETFoundation (incorporating Living with Carcinoid), MEN Society (Canada).

UK MEN Consortium

One of the biggest and most exciting projects on **AMEND's** "To Do List" is the formation and running of this working group to look at how improvements can be made in the care and management of all UK MEN patients. Standards and quality of care and management for MEN patients still vary widely within the UK, something that doesn't occur in many other developed countries. The concept of the Consortium originated in 2004 with Dr Steve Ball, a consultant endocrinologist from Newcastle's Royal Victoria Infirmary and in 2006 **AMEND** agreed to pick up the baton, restart the process and keep the momentum going. In December 2006, we received funding from the Society for Endocrinology to begin the process of setting up the Consortium, and we will be looking for continuing help from all our members and will be surveying for opinions and thoughts throughout 2007. I would encourage everyone to have their say so that we can achieve that aim of improving care and management of all MEN patients. As they say, "you gotta be innit, to winnit"!

FEDERMEN

In September 2006, Janet French travelled to Marseille for a meeting with Professor Maria Luisa Brandi from Turin University Hospital and 2 other European MEN patient support groups, to discuss the possibility of forming an international federation of MEN patient groups. It is hoped that such a Federation will make it easier to access funding for research and support initiatives as well as creating the ability to share worldwide expertise and experience. Much work still needs to be done on the organisation of such a Federation and with **AMEND's** current emphasis on working to improve care and treatment of MEN patients within the UK, FEDERMEN is on hold.

Family Route Map Project/Jeans for Genes Appeal

As in 2005, **AMEND** was once again involved in the Jeans for Genes appeal in 2006. Several committee members gave presentations at local schools to raise awareness of genetic conditions and encourage fundraising for the appeal. **AMEND** is working with the Genetic Interest Group (GIG), who were a guest charity of the appeal, to produce 'route maps' of the services currently available to UK MEN patients and their families. This initiative continues into 2007 when we hope to see the results.

Website

2006 saw our first full operational year with our new-look website which was launched in December 2005. Responses have been extremely favourable and it has now become a well-respected information resource for both patients and medical professionals/students. It has enabled us to reach patients from all over the world to the extent that international 'branches' of **AMEND** are a real possibility for the near future. Inevitably there have been teething problems, most of which have been addressed, and the Discussion Boards are disappointingly underused at present. Further work is planned to improve the site during 2007.

Part of the planned improvement includes the introduction of website video clips to truly bring to life the patient experience. MEN1 member and freelance cameraman, Andy Smith spent much of his spare time amassing film footage of volunteers during the 2nd half of 2006. As well as myself, Liz Dent, Emily Fazal, Terry Green, Dr Steve Gilbey and Professor Raj Thakker all volunteered to be filmed talking about their experiences with and knowledge of MEN. We are extremely grateful to all volunteers, and particularly to Andy for the extraordinary amount of time spent on this project and look forward to seeing some of the fruits of these labours during 2007.

Jo Grey, Chairwoman



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MEN1 REPRESENTATIVE'S REPORT 2006

I continue to receive e-mails from newly diagnosed patients in the UK and around the world via our website (which incidentally is much praised), as well as from patients who have heard about **AMEND** from their medical team. However, my aim in the future is to try and increase the number of UK enquiries. I am still in touch with the Canadian MEN Society but we do need to consider how best to support American and other worldwide patients in the future.

Following on from Andy Smith's request at the AGM in May for volunteers to be involved in the new website video, Terry Green, Emily and myself have each spent a day being filmed and recorded by Andy and Steve respectively. Andy and Steve have both very generously devoted a considerable amount of time in developing this exciting new project.

I have been working during the last year with Jo on setting up the UK MEN Consortium: a professional/patient partnership which aims to improve the care and management of MEN patients throughout the UK. I believe that this **AMEND**-led working group is a very exciting step in the right direction. **AMEND** is very grateful to the Society for Endocrinology for awarding us with a grant of £1,850 in order that we can meet the expenses in setting up the Consortium during its first year.

As a result, Jo and I have met with Dr Steve Ball at Newcastle who asked us to take on and develop his original idea. We have also visited Professor Andrew Hattersley in Exeter where they have the largest MEN1&2 genetic testing labs in the UK and in the future have agreed to send out **AMEND**'s leaflets with each diagnosis report. We have also visited, spoken to and e-mailed many other endocrine consultants and surgeons who have given us much encouragement and pledged their support for this new organisation. I have also arranged to visit Prof John Connell and Victoria Murday (a genetic specialist) in Glasgow in February 2007.

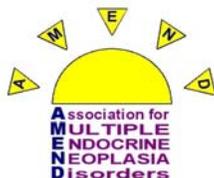
The first MEN Consortium meeting is to be held in Birmingham in March 2007 where we will discuss the remit of the organisation including the compilation of MEN1&2 registers and database, the development of an MEN Passport, production of statistics and identification of centres of excellence.

I attended (together with Jo and two other MEN volunteers) the First Working Group Meeting for the Genetic Interest Group's Family Route Map Project in London last summer, where we discussed the varied experiences of diagnosis and treatment that we had encountered. **AMEND** was granted £1000 by the Genetic Interest Group from the Jeans for Geans appeal for this year's involvement. It is intended to use the finished Family Route Map as a template for patients' pathways of care to be discussed by the MEN Consortium. Emily, Sam and I later volunteered to give school presentations in aid of the Jeans for Genes appeal in October and reported an excellent response from the children.

I also attended a conference in Leeds in November on genetic insurance issues organised by the Genetics & Insurance Committee (GAIC) and the Gene Therapy Advisory Committee (GTAC) and gained some useful information for **AMEND**.

In April, Janet, Sam and Terry attended the European Congress on Endocrinology in Glasgow where they did a great job manning a very busy stand for five days whilst attempting to ensure that the questions from the varied European delegates were not lost in translation.

Together with Jo, I attended the Endocrine Surgeon's Conference in the lovely surroundings of St Anne's College Oxford in September where we were able to gain useful insights into new developments in scanning and surgery techniques as well as meet up with many surgeons supportive of **AMEND**'s work.



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AMEND continues to grow from strength to strength under Jo's chair and it is very encouraging to receive words of praise from patients and professionals alike. This is just one of the examples: from an MEN1 member about our patient information book "words fail me – just brilliant!".

Liz Dent
MEN1 Representative
President and Co-Founder

MEN2 Representative Report 2006

Telephone/Email Patient Support

The receipt of many difficult and emotive calls for MEN2 support over the last year has reinforced to us how valuable the support of our **AMEND** Medical Advisory Team and medical professional Trustees and other contacts is. Without their help and guidance, we would not get far. We are extremely grateful for their continuing involvement and feel reassured that the answer to a difficult question is often only a phone call or email away.

Publicity

Many of the calls mentioned above were received in response to an article in Take A Break magazine in September 2006, written about my own MEN2a "journey". This had been part of the Jeans for Genes Day publicity drive, and I'm delighted that it reached so many people, even if, as was sadly the case, I couldn't help everyone who contacted me.

Patient Information

Following on from our first 4 patient information books comes one on sporadic medullary thyroid cancer, the draft of which was finalised at the end of 2006.

Siddarth's Fund

Towards the end of 2006 **AMEND** provided funds for the genetic testing for MEN2b of a father and son in India. Acknowledging that this will be a rare occurrence, the **AMEND** committee agreed that this should be an ongoing concern and set up Siddarth's Fund for this purpose.

1st Use of The Research Database

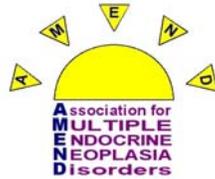
In August, **AMEND** was contacted by medical research company, Gillian Kenny Associates who were looking for medullary thyroid cancer patients to help in a research project. **AMEND** was able to use its research database for the first time by putting patients in touch with them.

Jo Grey
MEN2 and Sporadics Representative

MEMBERSHIP REPORT

1 January 2006 – 31 December 2006

I am pleased to report that in 2006 16 new fully paid-up members joined the **AMEND** 'family', bringing our total number of patient members to 78.



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MEN 1	46
MEN 2A	15
MEN 2B	11
FMTC	2
Sporadic MTC	4
Sporadic Phaeo	0

The total number of people registered with our Research Database was boosted to 58 by 6 Research Only registrations. Recruitment for the Research Database has been somewhat disappointing which perhaps highlights a need for clearer explanation of its aims in the future.

A number of existing members have changed to paying their subscriptions by Standing Order.

We have 6 fully paid-up medical members and a further 38 who support us on a continual basis in other ways, and for this we are extremely grateful. **AMEND** also has fully paid-up overseas members in the United States, one in South Africa, a medic in Hong Kong and has contacts in Canada, Australia, New Zealand, Italy, India and Germany.

Welcome Packs, which include the Tellybuddy Protocol, fund raising tips and ideas, a MEN information tableau, sponsorship form, newsletter, a Patient Information Book, clinic poster, clothing order form, Medic Alert form and an **AMEND** pen are now sent to all new members and get well messages are sent to any members returning home from a spell in hospital. This initiative, as well as calls to family members at these times, has gone down well and will remain a firm fixture for the future

We continue to forge links with other worldwide organisations and were pleased to supply a membership package to the Association of Genetic Support of Australasia Inc. (AGSA) in Sydney who had arranged a MEN2 Seminar for March 2007. A package of promotional materials was sent to the Association as cost and health issues prevented an **AMEND** representative from attending as invited.

Janet French
Membership Secretary

Financial Report for 2006

2006 has been yet another very successful year for **AMEND**. Financially we have made the necessary improvements to our accounting systems highlighted in last year's audit of the accounts which have been beneficial to me as Treasurer and the Membership Secretary amongst others. It has enabled us to account far more specifically and also link expenditure to projects which helps us review where we are and how we are progressing towards our goals.

Yet again it has been pleasing to be able to support a diverse range of projects and activities and keep **AMEND** on a sound financial footing.

To give you an indication of the work of **AMEND** this year I have collated a few of the notable events in no particular order or importance;

ECPC Masterclass – Italy	8 th European Congress for Endocrinology
AGM London	BAES conference
FEDERMAN conference	200 Patient Information Books printed
Bereavement Counselling Training Course	AMEND charity buffet
White Peak Marathon Sponsored run	Bridge Walk Sponsored walk



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Much of our positive financial performance has been thanks to two large Charitable grants received from the Dunn family and GIG. However, our raison d'être continues to be our membership which has seen a steady growth in membership and increase in revenue. Finally there has been lots of hard work by our team of activists in bringing in donations and giving freely of their time and experience, without which, the Charity would cease to function.

It is of particular note that our expenditure has declined significantly over the 2005 figures despite the Charity growing in size and complexity. This is reflective of the reduced investment in our Website which still acts as a focal point for our presence as a Charity.

I would like to thank the committee members for their help and patience while I have grown into the role of treasurer. I have enjoyed seeing the Charity succeed and hope to play my part in 2007.

Sam Meadows
Treasurer



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Accounts for the Year Ending 31 December 2006 Profit and Loss Account

(NEW LAYOUT FROM 2005 ACCOUNTS)

	2006	2005
Income		
Grants – DUNN Family & GIG	11,000.00	15,010.00
Membership Fees	1,024.73	986.30
Donations	1,866.70	1,701.31
Bank Interest	364.33	41.79
Cost refunds	0.00	7.17
	14,255.39	17,746.57
Expenditure		
Administration Costs – changed to		3,321.96
- Postage	346.76	
- Office Supplies	529.66	
- Printing	1,745.67	
Travel & Accommodation costs		641.40
Travel	929.50	
Hotel	728.15	
Meetings – Conference booking	742.36	
Publicity – No longer categorised		5,105.64
Web Site Development – All IT expenses	1,295.62	5,875.00
Telephone Costs – No longer categorised separately from IT		174.48
Sundries	1,839.36	
Depreciation	0.00	0.00
Costs refunded	0.00	0.00
	8,335.11	15,118.48
Excess of Income over Expenditure	£5,920.28	£2,628.09

Balance Sheet

	31 December 2006	31 December 2005
Assets		
Fixed Assets less Depreciation	156.00	0.00
Cash at bank	21,570.07	13,608.73
	21,726.07	13,608.73
Liabilities	0.00	0.00
Retained income	5,920.28	2,628.09
Funds from previous years	13,608.73	11,281.91
Retained Funds	£19,529.01	£13,910.00

Subject to Independent Audit



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AMEND Trustees – 2007

<p>Dr S G Gilbey Consultant Physician Department of Diabetes & Endocrinology The Manny Cussins Centre St James's Hospital Beckett Street Leeds West Yorkshire LS9 7TF</p>	<p>Jo Grey (Chairwoman) 31 Pennington Place Southborough Tunbridge Wells Kent, TN4 0AQ Email: Jo.grey@amend.org.uk Telephone: 01892 525308 Mobile: 07932 643187</p>
<p>Mr Mark Lansdown Consultant Surgeon The General Infirmary at Leeds Great George Street Leeds LS1 3EX</p>	<p>Sam Meadows (Treasurer) Mayfield Moss Road Moss Doncaster, DN6 0HH Email: swmeadows27@aol.com Telephone: 01302 700940 Mobile: 07932 849677</p>
<p>Dr Jonathan Pinkney Royal Cornwall Hospital Department of Endocrinology and Diabetes Treliske Truro Cornwall TR1 3JU</p>	<p>Liz Dent (Founder & President) Ray's Farm Smelthouses Harrogate North Yorkshire HG3 4DJ Email: liz.dent@amend.org.uk Telephone: 01423 780594 Mobile: 07713 148935</p>
<p>Janet French (Secretary & Membership) 8 Barton Manor Apartments Barton Close Bognor Regis West Sussex PO21 4FH Telephone: 01243 261566 Email: janet.french@amend.org.uk</p>	<p>Emily Fazal (Co-Founder & Vice President) 24 Foxglove Fold Ackton Pastures Whitwood Castleford West Yorkshire WF10 5UJ Email: emily.fazal@amend.org.uk Telephone: 01977 557815 Mobile: 07877 390477</p>