



# END OF PROJECT REPORT

December 2011

“AMEND Roadshows  
are a life-saver”



LOTTERY FUNDED

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## BACKGROUND

Anecdotal feedback from a pilot series of informal patient area meetings in 2009/10 had shown them to be useful and popular with those who attended and so a plan was formulated to expand and formalise the idea.

In addition, early indications from a research project subsequently published by AMetcalfe et al from Birmingham, suggested that children at risk of inheriting a genetic condition cope better when there is open and honest communication about the condition within the family\*.

In 2010, AMEND applied for and received funds from the UK's National Lottery Awards for All programme in order to run a series of meetings throughout England for patients, families and friends affected by Multiple Endocrine Neoplasia disorders and associated endocrine tumours. The project was named the AMEND 2011 Roadshow.

*\* Parents' and children's communication about genetic risk: a qualitative study, learning from families' experiences; Metcalfe, Plumridge et al, EJHG (2011)*

## AIMS AND OBJECTIVES

The main aims of the Roadshow project were simple yet, if achieved, could have enormous benefit to those participating:

1. To provide information on the disorders to increase understanding  
*It is generally recognised that those patients who understand their condition often cope better*
2. To provide opportunities for patients to network with others for mutual support  
*An informal method of 'counselling, there is much evidence to suggest that talking to someone with common issues or similar experiences is beneficial*
3. To provide opportunities for psychological counselling where possible  
*Though there is still a degree of unnecessary stigma attached to seeking more formal counselling, the majority of those people who do have found it very helpful*

“AMEND has been an outstanding support  
with managing my partner's condition –  
thank you.”

## THE PROJECT

A series of 8 geographically-spread meetings were planned throughout the UK in order to reach as many patients as possible. Hospitals in the vicinities that were considered centres of experience in MEN and associated tumours were contacted with details of the meeting and asked to inform the relevant patients. Posters for clinic waiting areas and letter and postcards for patients were provided for this purpose. AMEND members in and around the planned venues were contacted directly with information on their nearest event, as well as advertising appearing in AMEND's quarterly newsletters, e-news alerts and on the website. A total of 7 meetings were ultimately held (*figure 1*).



All of AMEND's free educational resources were made available to those attending meetings on an information table and in individual take-away information wallets.

Over a 3-4 hour period attendees were given an update on AMEND's activities and services, took part in round-table introductions and the popular Ask the Doctor Q&A sessions, and, when available, were able to receive free counselling sessions. Free refreshments and lunch were available throughout each meeting.

A total of 116 people registered to attend the 7 events. Attendees were representative of the full range of MEN disorders and associated tumours, as well as carers and family members and included both registered AMEND members and previously unknown patients. A significant proportion of people travelled over 50 miles to attend a meeting (*figure 2*) with the most popular location being our East Anglia meeting (*figure 3*).

## THE PROJECT *(Continued)*

figure 2.

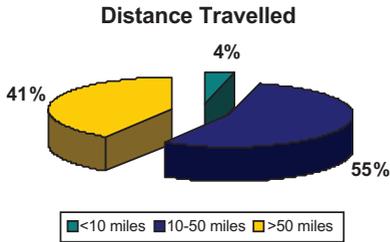
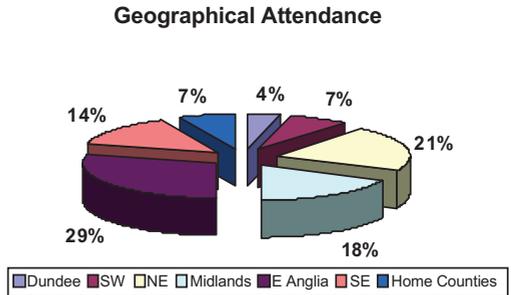


figure 3.



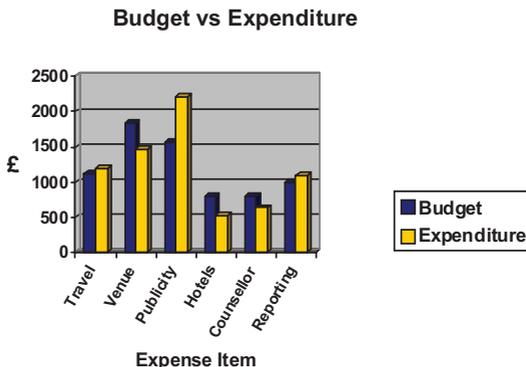
A variety of issues were encountered throughout the course of the project which AMEND will be looking to address in the future:

- 22 'no-shows' were recorded, many without explanation
- AMEND's counsellor was available for only 3 meetings due to unforeseen surgery
- 2 meetings were without medical advisors due to lack of availability
- advertising beyond membership was more difficult than anticipated due to varying NHS Hospital Trust patient contact policies
- 1 meeting was cancelled due to lack of NHS Trust cooperation

## EXPENDITURE

AMEND's already-established rigorous bookkeeping practices were invaluable in tracking expenditure during the Roadshow Project, enabling us to achieve an accurate budget vs expenditure ratio, despite slight changes in item expenditure (*figure 4*). Our total grant from the National Lottery Awards for All programme was £7130, and total project expenditure was £7133.10.

figure 4.



## HOW DID WE DO?

Feedback was sought from all attendees by way of written questionnaires and in an online survey. We were delighted with our very respectable response rate of 47% which showed in broad terms that the AMEND 2011 Roadshow project successfully achieved its aims.

**96%** number who would attend AMEND events again in the future

**96%** rated the event they attended as 'good' or 'excellent'

**83%** felt that the AMEND 2011 Roadshow achieved its aims and objectives

**9** number of new members registered after attending an event

Some of the additional comments received:

“I found the whole experience very useful. I felt that I was on my own beforehand trying to come to terms with my condition. It was very helpful that I was able to share and chat about issues, concerns and listen to others' issues that they have had and in many cases have overcome. I felt everybody was very helpful and very welcoming also which made the whole afternoon much easier to cope with. I shall be coming to more events in the future because it is so important that we all share this information together.”

“AMEND Roadshows are a life-saver. They provide fantastic and clear information and radically reduce feelings of panic and isolation that goes with a rare disease.”

“It was such a helpful meeting. Really happy to have attended.”

“I found the whole experience very useful and it was great to meet people who also have first hand experience of MEN1. Thank you for all your hard work, it's been great for me and my family.”

## CONCLUSIONS

AMEND is delighted at the success of the 2011 Roadshow. However, as always, we have learnt many lessons whilst managing the project. Not least of those lessons is the need to reduce the number of events per year in future in order to encourage greater participation whilst decreasing volunteer workload.

We have already successfully piloted this type of event in the USA back in October 2011 and will encourage AMEND's sister organisations around the world to continue these in the USA and New Zealand. In addition, requests have been received from patients for a Roadshow-style meeting in Northern Ireland / Eire; something we hope to achieve in 2012.

## ACKNOWLEDGEMENTS AND SPECIAL THANKS

This project would not have happened without the generous grant from the UK National Lottery Awards for All programme.

Special thanks go to the main AMEND Roadshow organiser, Janet French for all her hard work as well as to our other representatives who managed to attend the majority of events to support others.

AMEND is fortunate to have the support of many leading medical experts without whom we could never produce patient information and support of the high standards we have achieved. We are particularly grateful to the following for giving up their free time to attend our 2011 Roadshow events:

- Mrs Debbie Papadopoulou, SpRN (endocrinology), Charing Cross Hospital, London
- Professor Ashley Grossman, Consultant Endocrinologist, Oxford
- Dr Stephen Gilbey, Consultant Physician, Leeds
- Professor Alastair Mackie, Consultant Physician, Dundee
- Dr John Ayuk, Consultant Endocrinologist, Birmingham
- Dr Karin Bradley, Consultant Endocrinologist, Bristol





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