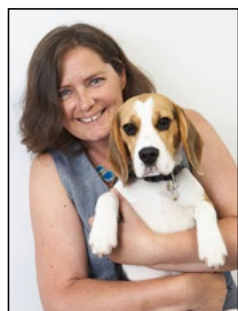


## Seasons Greetings and a Happy New Year



### JO'S BLOG

Once again, this year seems to have sped by and yet we've managed to cram rather a lot in! Usually things go

a little quiet over the summer, but this year was something of an exception. AMEND Counsellor, Kym Winter and I were busy writing and revising an article on MEN2 for publication in the medical journal, Endocrine-Related Cancer (see page 6), and AMEND produced feedback on a consultation by NICE on proposals to remove funding for tyrosine kinase inhibitors for metastatic medullary thyroid cancer (see page 6). Both of these initiatives involved canvassing our membership and beyond and we are very thankful to all those who provided us with input for the former and ammunition for the latter. Personally, I have been juggling all this with training a new member of my family; Dave the Beagle, who, due to the amount of time he spends with Helen and I in the office, has been adopted as an AMEND mascot. At least he's getting me fitter once again with a view to tackling the Yorkshire 3-Peaks weekend challenge next year! You can meet Dave on page 7 as well as read about all the amazing things that people have been doing this year to support AMEND from page 12.

So it seems that, together with the day-to-day running of AMEND and planning for our 15th anniversary year in 2018, there is no time to rest! This newsletter gives you a good feel for everything we've been up to since the last newsletter, and may possibly also inspire you for ways to get involved next year to help celebrate our 15th birthday. Wishing you all a peaceful Christmas and a Happy and Healthy New Year

*Jo*

### THE BIG GIVE 2017



**Big Give 2017 –  
Raising money for  
research Learn  
more on page 6**

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## AMEND HITS 15 IN 2018!!!

To celebrate our increasing age, we are organising a number of exciting opportunities for 2018 and would be delighted for as many of our members, their families and friends to get involved as possible.

### Save the Dates:

AMEND Patient Information Day, Central London (Saturday 12 May)

Yorkshire 3 Peaks Fundraising Challenge (29 June – 1 July)

Celebratory Black & Gold Ball, London (22 September)

**Can you Help With.....**  
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## Annual Patient Information Day 2018

AMEND's 2018 Annual Patient Information Day (#APID2018) will be held on Saturday 12th May in central London. Continuing on from this year, we will be including all those with MEN, SDH and ACC. There will be a nostalgic look back at 15 years of AMEND, together with plenty of other interesting and useful talks, such as preparing for and recovering from surgery, and patient experiences. As usual, there will be a crèche to take care of the little ones and for 2018, to celebrate AMEND's 15th birthday, a drinks reception to round off the day.

The AMEND Annual General Meeting will be held at the start of the lunch-break as usual. This is a chance for all members to come along and learn more about the behind-the-scenes AMEND and express their opinions by voting.

We do hope you can join us and your fellow patients for what is always a great day!

Book your places now via the website: <https://www.eventbrite.com/e/2018-amend-patient-information-day-tickets-34121644758>

We thank all the medical societies who invite AMEND to attend their annual meetings. These events are useful in raising awareness of the disorders we support, promoting AMEND, and networking with other patient groups, clinicians and researchers. We also thank those societies who offer financial help to enable us to attend.

## ESMO (European Society for Medical Oncology) – 8-11 September, Madrid

AMEND rarely attends the European Society for Medical Oncology (ESMO) conference, but our work with the EURACAN European Reference Network (ERN) necessitated it this year. Since it meant that I could also take advantage of the Patient Advocacy stream of talks which ran throughout the conference, my travel and accommodation costs were met by ESMO to whom I extend our thanks. This huge conference was also a superb opportunity to catch up with colleagues from the International NET Cancer Alliance (INCA) as well as from the ERNs.

Our first day began with a fascinating look at Research and the parts that patient groups can play in it. The megafact for the day was that every year, \$85bn is wasted on research – that's 85% of the total spent on research each year. This is down to a lack of knowledge about research

priorities. Patient groups need to be evidence-based and to collect data rather than expressing opinions. We will be beginning to do this shortly through the European MEN Alliance (EMENA) with whom we will be participating in a Europe-wide survey of patient care for MEN. This lack of knowledge of research priorities was reinforced through further talks and examples of changes made by larger charities. This showed that, a move from simply giving out grants to actually commissioning research to address an identified need could be an important step for the future of research funding from patient groups. The advantage of this evidence-based advocacy method means that the focus comes back to how patients will benefit. 'We need DATA not OPINIONS'.

The Endocrine Malignancies session gave a good run-down on current statistics and information. The rather dry-sounding 'Bio-ethical controversies and what they mean to research and European inequalities' was much more interesting than it sounded, as was 'Patient Outcomes Research'; both yielding plenty of information and ideas for the future. After a very long weekend of work at ESMO, a head full of information, and despite the warm sunshine, I was rather relieved to get home!

## European Thyroid Cancer Patient Summit – 2 October, London

I was invited to this one-day meeting regarding thyroid cancer by pharmaceutical company hosts, SanofiGenzyme. Since medullary thyroid cancer (MTC) wasn't to be discussed until after lunch, I managed to squeeze in a quick visit to Great Ormond Street in the morning to meet a couple of families

new to the world of MEN and get back in time for a curly-edged sandwich! SanofiGenzyme were interested in learning more about patient experiences in thyroid cancer and the challenges in the different European countries represented there. It was good to catch up with a few colleagues from around Europe who I had not met for a while, but worrying to hear that the UK and Lithuania would be almost the only European countries that would not have easy access to tyrosine kinase inhibitors for MTC if NICE uphold their recommendation to withdraw them from the Cancer Drugs Fund.

## BAETS – 12-13 October, Belfast

It's a while since AMEND attended the British Association for Endocrine & Thyroid Surgeons' annual meeting, but combining this with a Roadshow meeting for patients the day after made this worthwhile. There were a number of notable absentees from the conference, with several eminent surgeons having retired since I last attended this meeting, our own Chair of the Trustees, Barney Harrison included! Nevertheless, it was a great opportunity to begin to get to know the younger generation of endocrine surgeons currently rising through the 'ranks', including Sheila Fraser at Leeds. The special guest at the meeting was Stan Sidhu from Sydney in Australia who talked about his research into molecular markers of adrenocortical cancer (ACC) and medullary thyroid cancer (MTC) which could become potential new therapeutic targets in the future. It was great to be able to catch up with Fiona Etock who is the endocrine surgeon in Belfast, and to have two of her previous thyroid patients entertain us with singing and dancing at the evening gala dinner at Crumlin Road Gaol. I also took the



Jo Grey with Leeds surgeon, Mr Mark Lansdown at BAETS

opportunity to stay on an extra night in order to meet up with a couple of our members from Northern Ireland – a small but hopefully productive event.

## SFE BES – 6-8 November, Harrogate

The large British Endocrine Society conference is an annual event for AMEND, giving us a superb opportunity not just to update ourselves, but to reach a wide audience and raise awareness of AMEND's resources and services. It is also an excellent chance to network with old and new faces on the endocrine scene – both healthcare professionals and patient advocates.

This year there was a new initiative: Research Incubator meetings, where researchers presented their project proposals and members of the expert panel and audience asked for opinions and assistance. Despite the 07:45am start time, I was delighted to be asked to sit on the expert panel of the Endocrine Neoplasia



L2R Members of INCA; Catherine Bouvier (NET Patient Foundation, UK), Yoshi Makajima (PanCan, Japan), Jo Grey (AMEND, UK), Teodora Kolorova (INCA Executive Director, Bulgaria)





Syndromes Network meeting to contribute to the discussions surrounding two research proposals relating to MEN1 pancreatic neuroendocrine tumours. We will keep in touch with the researchers and keep you all up-to-date with any progress made in getting these projects off the ground.

I was also pleased to be able to Chair the meeting of representatives from the patient groups attending, hosted by the Society for Endocrinology. This is a good opportunity to pass on ideas and feedback to the Society, but also to discuss matters that affect us all, such as the incoming data protection legislation, biosimilar drugs and so on. Discussion continued over a very convivial dinner later that day.

Gill and I were delighted to meet up with AMEND's 2017 Young Investigator Award winner, Dr Vasilieos Chortis



Dr Chortis (left) with Jo Grey and Gill Underhill

from Birmingham. The award is judged by the Society for Endocrinology as the best abstract in the category of endocrine neoplasia and the winner receives our certificate and award of £200. Our adrenocortical cancer (ACC) members who attended our 2017 Annual Patient Information Day will remember Dr Chortis who was present for the whole of the ACC session that day. His winning abstract was called 'Antioxidant pathway targeting as a therapeutic approach in adrenocortical carcinoma'. See the Research section of this newsletter to read the lay summary of the abstract.

Amidst the madness that is a big conference, AMEND co-founder and MEN1 member, Liz Dent, managed to drop in to say a quick 'hello' since she lives nearby, and I managed to donate some more blood to Imperial's research into prednisolone (our Trustee, Professor Karim Meeran is constantly armed with needles and syringes for just such opportunities!). It was with a window open to the cool night air that I drove the 4 ½ hours home non-stop, tired but satisfied to have attended such a successful conference.

## EMENA General Assembly – 6-7th October, Munich

The European MEN Alliance (EMENA) held its second General Assembly meeting in Munich, Germany, where it is registered as a non-profit. As well as the statutory meeting, we began the planning of a Europe-wide survey of MEN patient experience of care (read more in this newsletter). I would like to thank Dr Paul Newey from Dundee who attended the meetings and was a great help in advising on producing a short, focussed survey. Luckily, before I headed home, there was time for a pint even though Oktoberfest was over, together with a quick chance to explore Munich in the warm Bavarian sunshine before setting off for the airport.



## Shortage of injectable hydrocortisone

Due to production problems, the company Concordia has confirmed that it has stopped manufacture of the 1ml ampoules of hydrocortisone sodium phosphate (liquid injectable hydrocortisone). They do not expect production to restart until around autumn 2018.

The Addison's Disease Self Help Group (ADSHG) suggests that, once the remaining warehoused stocks have been used up, 'anyone who needs to renew their injection kit materials will have to ask their GP to issue a prescription for the alternative form of injectable hydrocortisone:

hydrocortisone sodium succinate (Solu-Cortef) 100mg powder, with a 2ml ampoule of solvent (sterile water)', and that 'patients outside of the UK may also be able to obtain the Act-o-Vial preparation, containing hydrocortisone sodium succinate and water in a chambered ampoule.'

If you are not familiar with the Solu-Cortef preparation, we would recommend that you visit the ADSHG website, where you will find a leaflet for GPs regarding prescribing injectable hydrocortisone, written guidance for patients on preparing and injecting, as well as video instructions.

Visit ADSHG website at [www.addisons.org.uk](http://www.addisons.org.uk)



## NICE Decision on Drugs for Medullary Thyroid Cancer (MTC)

**NICE** National Institute for Health and Care Excellence

As some of you will know, the National Institute for Health & Care Excellence (NICE) opened a consultation into its proposed decision to remove access to the tyrosine kinase inhibitor (TKI) drugs, cabozantinib and vandetanib, for use in MTC that has spread and is inoperable. Together with other groups, AMEND submitted a strong and emotive response. We thank all those who answered the plea on Facebook to submit their individual responses for inclusion.

At the time of writing, NICE has yet to come to their final decision and it is hoped that this delay is due to the pharmaceutical companies who make these drugs, negotiating their prices down to a level that is more acceptable for NICE. Nevertheless, this Consultation has high-lighted the lack of flexibility that NICE has in these processes, in the main due to the criteria they use to assess medical technologies which is heavily biased towards assessing those proposed for use in more common cancers. We have argued that the actual number of MTC patients that may need to use either drug each year is infinitesimally small compared to many cancers, and that this should enable a little more flexibility in price. We await their decision and are prepared with press releases either way. Please watch social media and your email inboxes for further news on this as it breaks.

## Project Rollercoaster Update



We were hugely disappointed that our chosen venue, the theme park Thorpe Park, let us down with just 2 days to go before our event, by forgetting to book accommodation for us all. Our project is therefore delayed and there will be more news on this in the New Year. Thank you to all those who were ready to attend and who were so sadly disappointed. We hope that they can join us at the reorganised event.

Project Rollercoaster aims to look into the issues that young people with MEN may face during transition from paediatric to adult endocrine care. It is funded thanks to the 2016 Big Give Campaign and The Lakehouse Foundation. We would like to involve as many young people as possible so if you have a young person (aged 16-21) who would be interested in this project, then please do contact Jo Grey at the office.



## Big Give Christmas Challenge 2017

Midday 28 November –  
Midday 5 December



Last December we embarked on this fundraising challenge for the first time, raising money for Project Rollercoaster which aims to develop resources for young people with MEN. This year we are using it to raise money for our 15th anniversary Research Fund Awards in 2018. The following generous people and organisations have pledged a total of £3,660 to be used to double donations made during the Christmas Challenge period which runs from midday on Tuesday 28th November through to midday on Tuesday 5th December:

- Professor Karim Meeran
- Professor Rajesh Thakker
- Mr Keith French
- Southborough Centre (Michael Churchward)
- Period Properties (Enderby) Ltd (Gill Underhill)
- Inkpot Limited (Helen Guyatt)
- Agnes Smyth
- Gill Underhill
- Jo Grey
- The Hospital Saturday Fund (Champion Funder)

To donate during the Christmas Challenge, go to <https://secure.thebiggive.org.uk/projects/view/28687/amend-research-fund/>. Thank you to all our Pledgers, including our Champion, The Hospital Saturday Fund, and to all those who donated! We will bring you the final total raised in due course, so keep an eye on your emails.

## Endocrine-Related Cancer Article on MEN2

AMEND CEO, Jo Grey, and AMEND Counsellor, Kym Winter, were honoured to receive an invitation from Editor-in-Chief, Prof Charis Eng, and two guest editors, Prof Lois Mulligan and Prof Frank Weber, to write a Review article on MEN2 for the medical journal, Endocrine-Related Cancer. The article, entitled 'Patient Quality of Life and Prognosis in Multiple Endocrine Neoplasia Type 2' will be published in a special edition of the journal in 2018, celebrating the 25th anniversary of the discovery of the link between MEN2 and RET gene mutations. Here's a flavour of the article from the abstract:

### Abstract

Multiple endocrine neoplasia type 2 (MEN2) refers to the autosomal dominant neuroendocrine tumour syndromes, MEN type 2A (MEN2A) and MEN type 2B (MEN2B). They are typified by the development of medullary thyroid carcinoma (MTC), pheochromocytoma and parathyroid hyperplasia in MEN2A, and MTC, pheochromocytomas, ganglioneuromatosis and skeletal abnormalities in MEN2B. The aggressiveness of MTC is variable according to genotype, and although it is still the major cause of mortality in both conditions, prognosis has improved dramatically in those diagnosed and treated at a young age thanks to predictive genetic testing. Nevertheless, metastatic MTC, ganglioneuromatosis and a variety of other negative clinical and psychosocial impacts on quality of life and/or prognosis

in MEN2 persist. In the absence at time of writing of any large scale research into quality of life specifically in MEN2, this review includes data from patient surveys and anonymised patient anecdotes from the records of the Association for Multiple Endocrine Neoplasia Disorders (AMEND), for whom the authors work. We recommend that these patients are cared for only in centres of expertise able to provide expert diagnosis, treatment and continuity of care, including psychological and transition support. Only in this way can the clinical advances of the last two and half decades be built upon further to ensure that the care of these complex, lifelong patients can be considered truly holistic.

To read the full article for free online (open access) visit <http://erc.endocrinology-journals.org/content/early/2017/10/24/ERC-17-0335>.

This was a wonderful opportunity to celebrate the advances in treatment and management of those with MEN2 since the introduction of gene testing, but also to highlight some outstanding clinical and psychological concerns that continue to trouble patients. Thank you to everyone who responded to requests for help to inform this piece of work. It was a long and slightly stressful summer, but we are proud of the end result and the way in which it provides a new viewpoint for readers who are interested in this topic.

.....and if you're interested in reading a special edition of Endocrine-Related Cancer on MEN1 which was published in October 2017, visit the website: <http://erc.endocrinology-journals.org/content/24/10/E7.full>



## MEET DAVE THE NEW AMEND OFFICE MASCOT

Called lots of things that are unprintable, but mainly known as Dave the Beagle, AMEND's Office Mascot (as he has been dubbed) became a member of the Grey family during the summer. We feel fortunate that so far we have only had to replace one Broadband cable and one USB speaker (at Jo's expense) and that in fact, he spends most of the time asleep under the spare desk. Dave is providing occasional distraction but also no end of entertainment and would love to meet anyone who is visiting the office. Of course, anyone coming to the office for any reason who is not so keen on dogs should please let us know as we can ensure that he is 'absent from duty' that day! Keep an eye out for Dave on social media from time to time. Not that we're obsessed or anything.....!



## European Survey of Patient Experience of MEN Care



The European MEN Alliance (EMENA), of which AMEND is a founding member and Jo Grey is Board Secretary, is planning to launch a survey shortly. The survey will look to explore patient perception of their care for MEN and compare those perceptions across different countries on the continent. Please keep an eye on social media and your email inbox for more news on this when it launches.

## New Year - New Website

We are very much looking forward to launching our new website in the New Year. The New Year is a generally quieter time of year, giving us all time to get used to the new site, especially for us in the office working on the back-end! The new site is a strong reflection of the AMEND branding and will contain different sections for different age groups, and much clearer routes to the information you want. The shop will also be much improved with the long-awaited shopping cart facility, meaning that you will be able to buy more than one item at a time! We can't wait to share the site with you soon!

## CHRISTMAS OFFICE HOURS

There will be limited cover in the AMEND office from Thursday 21st through to Friday 5th January inclusive due to the Christmas and New Year holidays.



Patient survey – AMEND

AMEND likes to know what its members want and need. To do this, we regularly survey our membership and the benefits are that we can then direct our work where it will have the most impact. In the past, we were told of the need for information on Starting a Family and on Employment & Returning to work. Both of these topics resulted in new information being produced during 2016/2017. We will therefore be distributing our 2018 survey early in the New Year and would be most grateful if as many members as possible would complete this. Watch your email inboxes for more information and for the link!

Data Protection Regulation Updates (GDPR)

Laws surrounding the use of personal information are being expanded and strengthened, in part due to some appalling behaviour over the last few years by a number of very large charities. Rest assured that AMEND has always recognised the importance of the safety of the personal member information it keeps. Because of the new procedures, we will need to check with all our members that they are aware of what information AMEND holds on them and why, and that they are happy for us to hold this. Therefore, please keep an eye on your email inboxes for this important email which we are aiming to send out early in the New Year 2018. Failure to reply may result in loss of membership and membership benefits.

*With thanks to Kerry for her contributions to this newsletter, and for providing personal comments to be used in our submission to the NICE consultation on TKIs for MTC.*

Kerry – Sporadic Medullary Thyroid Cancer

In November 1995 at the age of 26 I was diagnosed with Medullary Thyroid Cancer (MTC). I had discovered a lump in the front of my neck in 1991, but had been misdiagnosed as a 'cyst'. I was married with a daughter who was nearly 2 years old and I was working as a Registered Nurse on surgical wards. Our life was near perfect - but that was about to change. I was immediately referred to Guys Hospital in London. After numerous scans and tests, in January 1996 I had a total thyroidectomy, right sided neck dissection and sternal split to remove extensive tumour from my neck and chest area. This was then followed up by 6 weeks of radiotherapy. I lost my speech and swallow due to a paralysed vocal cord and radiotherapy burns, which caused me to lose 3 stone during this time. I was aware that the cancer had already spread to my lymph nodes and that there was no 'cure', but that there were treatments available. It took almost a year but I learnt how to speak and swallow again and returned to part time nursing. By 1997 I was pregnant



again and had a boy in December of that year. I was kept a close eye on and had regular scans and investigations as well as numerous radioactive treatments; however in the year 2000 I discovered a lump in my right breast. I had a lumpectomy and 4 weeks of radiotherapy to that breast and the lump turned out to be an MTC metastasis. Again, I picked myself up, recovered and returned to work and family life. In 2008 I found out that the cancer had spread from the breast into my right underarm and I had to have surgery to clear all the lymph nodes, giving me lymphedema (permanent swelling) in my right arm. I knew the MTC was spreading but I also knew it was slow growing (I was originally told I had a prognosis of around 10 years). I was aware that I had another lump in a very tricky position, between my trachea and my oesophagus and behind my sternum. In 2012 the surgeon was insistent that we needed to remove this lump as it was growing and was going to cause blockage of my airway and my food intake, as well as possibly putting pressure on my spinal cord. As they started the surgery a main artery to my right arm was cut (due to the radiotherapy sticking structures together). The surgery then became an emergency procedure taking 10 hours, involving full open chest, 15 units of blood, 2 cardiac arrests and they were unable to save my artery. I also had a tear to my trachea as the cancer had latched onto it. I

spent 2 weeks in intensive care, 2 months in hospital, had a further 3 'open chest' operations followed by a further year of healing and rehabilitation. I then returned to part time hours as an agency nurse. In June of 2016 my breathing was worsening and a CT scan confirmed that the MTC was now in my lungs (lymphangitic carcinomatosis) and surgery was no longer an option. My only hope to prolong my life now was to try the tyrosine kinase inhibitor (TKI), vandetanib. Without this drug I was given just weeks to live. I had been very resistant to starting TKI's as I had heard about the side effects via Facebook groups; however I now had no other options. I started taking vandetanib at 300mg daily and my main side effect was severe fatigue. This meant that work as a District Nurse was no longer achievable and I was signed off sick. I also suffered with skin rashes, sore fingers and toes and sun sensitivity. At around 6 months into treatment my dose was reduced to 200mg which I seem to be tolerating well. In addition my disease appears currently to be 'stable' on CT scans. This May I had to let my Nurse Registration go, as I couldn't see myself being well enough to return to nursing. My days are very unpredictable and my energy/stamina levels are not good, but if it hadn't been for the Vandetanib working for me, I would not be here today. I am grateful that this drug was an option for me, and that it has worked and is keeping my disease at bay for the time being. I have had many 'Meddies' (MTC patients) on the Facebook groups express alarm at the NICE recommendation to remove TKIs from the Cancer Drugs Fund. They have said that all the time they are available they feel that they have options for the future. They have



seen me as an inspiration and it helps allay their fears when they hear about my 22 years living with MTC and now about how vandetanib is prolonging my life. I think that with so few options of treatment available to patients with MTC, and certainly no 'cure', to take TKIs away, is to take away our hope! I also believe that when vandetanib stops working for me that cabozantinib should be there as my next option. When this disease starts to get the better of us (despite 22 years of 'battling' it as in my own case), there is some comfort in knowing there is at least an option to try, which could give us more time. Having been a nurse for 30 years and spent my working life 'giving' to others, I have found it incredibly difficult to take on the 'patient' role, but it is now a case of having too. I also have to accept that my life is now different, but that this doesn't mean that it is any less valuable to me, my friends and my family. I was extremely lucky that TKI's have been available to help prolong my life and I believe that every 'Meddie' should have the same options at least until something better is developed.

Coming Soon!

UK National Research Registry for Multiple Endocrine Neoplasia Type 1 (MEN1) and Pancreatic Neuroendocrine Tumours (pNETs)  
"Opening the door to collaborative research"  
Sign up for updates at: <http://eeepurl.com/cGenR1>

AMEND Young Investigator Award Winner 2017 – Vasileios Chortis

This is an annual award given to the highest scoring abstract presented at the British Endocrine Society meeting regarding neoplasia. It is judged in association with the Society for Endocrinology. Congratulations to Dr Chortis from the University of Birmingham who is our winner this year for his continuing research into adrenocortical cancer (ACC).

Antioxidant pathway targeting as a therapeutic approach in adrenocortical carcinoma

Antioxidant pathway targeting as a therapeutic approach in adrenocortical carcinoma  
Cell metabolism involves a vast network of reactions leading to energy generation and providing essential building blocks. During some of these reactions, toxic oxygen molecules with free electrons (reactive oxygen species, ROS) are generated as by-products. ROS production is particularly prominent within



mitochondria, the energy factories of cells. Excessive ROS can cause damage to various parts of the cells (oxidative stress); in severe cases, this may even lead to cell death. To protect themselves against oxidative stress, cells are equipped with an antioxidant machinery (antioxidant pathways) that constantly works to detoxify ROS. This process is particularly crucial for the adrenal cortex, as steroid hormone production (steroidogenesis) is also a major source of ROS within adrenocortical mitochondria. Nicotinamide Nucleotide Transhydrogenase (NNT) is a mitochondrial enzyme which fuels the core antioxidant pathways, providing them with reducing (detoxifying) power. Recent genetic studies showed that patients who are deficient in NNT develop adrenal failure at infancy or early childhood. In most cases, the adrenal gland is the only organ that is affected by the absence of NNT. This suggests that adrenal cells have a selective sensitivity to NNT loss, presumably because of their high endogenous rates of ROS production which necessitate the existence of robust mitochondrial antioxidant pathways. We therefore postulated that inhibiting NNT will cause selective damage to adrenocortical carcinoma cells, exposing them to lethal levels of oxidative stress. To explore this hypothesis, we transiently inhibited NNT, interrupting the expression of the corresponding gene in an ACC cell line in the lab. We found that, within the first week, NNT inhibition increased intracellular levels of oxidative stress; this resulted in a pronounced suppression of cell proliferation and higher rates of cell death. Steroidogenesis was paradoxically stimulated by NNT loss. These results were promising, demonstrating anti-tumour effects

in this setting. Next, we generated permanent silencing of NNT in the same cell line, in order to investigate the longer-lasting effects of NNT inhibition. After a few weeks, cells managed to adapt to NNT loss, lowering their oxidative stress levels. Cell proliferation remained suppressed, but the effect was attenuated in comparison to what we had observed in the transient knockdown model. In order to understand how cells eventually manage to achieve this partial compensation for NNT loss, we carried out further comprehensive analysis looking at the expression of all genes (RNA sequencing), as well as a wide panel of molecules that are involved in cell metabolism (metabolites). We found that cells with permanent NNT loss alter the way in which they process damaged proteins, and they increase the production of a substance called spermine, which can detoxify ROS (anti-oxidant). We also used two drugs that inhibit the function of each one of the two main mitochondrial antioxidant pathways (glutathione pathway and thioredoxin pathway) and found that both display anti-tumour activity against this ACC cell line in the lab, especially when used in combination. Our study provides the first pre-clinical evidence that inhibiting the mitochondrial antioxidant pathways can have anti-tumour effects against ACC, but it also illustrated the plasticity of ACC cells which may allow them to mitigate the initial impact over time. Animal experiments would be required to investigate the effectiveness of such approaches in living organisms.

## AMEND Medical Trustee's Research Rebuffs Previous Claims about Prednisolone

Prednisolone and hydrocortisone are corticosteroids that are prescribed in cases of adrenal insufficiency. In MEN, this may have been caused either by removal of the adrenal glands (MEN2) or the pituitary gland (MEN1). Hydrocortisone is commonly prescribed to replace the steroid hormones lacking in these instances, although other alternatives such as prednisolone are available.

This time last year, a study by Markus Quinkler et al and funded by the pharmaceutical giant, Shire, was published which appeared to show that there should be cause for concern about the use of the corticosteroid, prednisolone. 'Prednisolone is associated with a worse lipid profile than hydrocortisone in patients with adrenal insufficiency' was described by AMEND Trustee, Professor Karim Meeran, as 'a pretty shabby attempt by Shire (who are co-authors and have funded this paper) to make people worry about prednisolone.' Now, a team from Imperial including Professor Meeran have taken a closer look at the suggested link between prednisolone use and risk of heart disease. In their article, 'Prednisolone has the same cardiovascular risk profile as hydrocortisone in glucocorticoid replacement', David Smith et al concluded that 'Prednisolone once daily is more convenient than hydrocortisone thrice daily, and there is no difference in the markers of cardiovascular risk measured. Because prednisolone mimics the circadian rhythm better than other glucocorticoids, it should

be considered as an alternative to hydrocortisone for adrenal insufficiency.' You can read their article for free at <http://dx.doi.org/10.1530/EC-17-0257>. This all shows the need for careful consideration of published research and that just because a study claims to have found an association between two things; this does not mean that one thing caused the other. Always query what you read!

## GET INVOLVED

Imperial's research is on-going and you have an opportunity to get involved. Professor Meeran explains: 'Now we know that prednisolone once daily is as good as hydrocortisone three times daily, we are looking for volunteers on one drug to try the other for a month and see if they notice a small difference in anything, using blood monitoring.' If you are on replacement hydrocortisone (for example 10 + 5 + 5mg) or on prednisolone (for example 4mg once daily) please get in touch with Jo in the office, or subscribe to our email list for further project updates at <http://eepurl.com/daiX3j>.

We were very sad to hear of the deaths of a number of members and friends this October. Thank you to the families who arranged donations to AMEND in lieu of flowers. Please remember the following:

David Marsden,  
Brenda Sawyer,  
Charles Painter,  
Rosie, Russell,

Jeffrey Moley, MD (died 15 October).

Extract from the Washington University School of Medicine in St Louis Obituary, 18 October 2017:

'Jeffrey Fletcher Moley, MD, a highly regarded professor of surgery and chief of the Section of Endocrine and Oncologic Surgery at Washington University School of Medicine in St. Louis, died Sunday, Oct. 15, 2017, at his home in Kirkwood. He was 64. Moley, also an associate director at Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine, died following a sudden cardiac event. He had been married for 30 years to Kelle H. Moley, MD, the university's James P. Crane Professor of Obstetrics and Gynecology.

For more than two decades, Moley was a pioneer in researching and treating Multiple Endocrine Neoplasia (MEN), rare inherited syndromes that often cause an aggressive form of thyroid cancer and other endocrine diseases, particularly in those at young ages. Along with Samuel Wells Jr., MD, former head of the university's Department of Surgery, Moley was part of a team that identified the genetic mutations responsible for MEN syndromes and advanced a preventive procedure that includes surgical removal of the thyroid gland. Moley also operated on patients with

recurrent thyroid cancer and other endocrine diseases.' In memorium donations were directed towards ThyCa and AMEND for which we thank Dr Moley's family and friends.





## Shaun Williamson – Pointless Celebrities 28 October

On Saturday 28th October on BBC1, AMEND Celebrity Patron, the actor Shaun Williamson, together with fellow soap star, Paul Henry, won the Pointless Celebrities jackpot! The pair split the prize money of £2750 between their charities of choice, including AMEND. UK members can watch all the action on BBC iPlayer here: <http://www.bbc.co.uk/programmes/b09dcftd>. In the days afterwards, Kent media followed up with an online and printed story of why Shaun supports AMEND (which you can read here: <http://www.kentlive.news/news/kent-news/sad-story-behind-eastenders-star-707602>). What everyone was unaware of, was that we in the office had to keep quiet for 18 months, which was how long ago the episode was filmed! Nevertheless, as well as the prize money, Shaun's endeavours raised awareness of MEN and AMEND in a way we could never achieve alone. Thank you Shaun!

**A big thank you to everyone who has either, run, walked, cycled or supported a fundraising event so far in 2017 and also to those who regularly donate through standing orders.**

## Stirling Marathon

Back in May AMEND member Fiona Hanson completed her first marathon. Here is what she had to say about her experience.

'The day of the marathon was a bit grey and drizzly but there was very little wind so probably almost perfect running conditions. I actually really enjoyed running the marathon, much better than I anticipated. It really helped knowing that I was running for such



worthwhile causes and this more than anything helped me keep going, when it did get tough. I had hoped to get under 4 hours so was delighted that I managed to do it in 3 hours and 39 mins and have qualified for the London marathon!! Mind

you this was meant to be my first and last marathon so watch this space. People were amazingly generous and I was delighted with managing to raise @ £700 each for Amend and

Pancreatic cancer Scotland.'

*A very big well done from all of us here. Let us know when you do the London marathon!*



## Royal Parks Half Marathon

AMEND graphic designer, Jill Clark and her friend Louisa ran the Royal Parks half marathon in October. Here is what she had to say about their achievement:

'I've been lucky enough to work on the graphic design for AMEND for many years and have always been awe inspired by the incredible work that Jo and her team manage to cram into every day.

While putting together the April newsletter I saw the appeal for people to complete the Royal Parks Half marathon in London on AMEND's behalf

and decided it was the perfect opportunity to contribute something myself, and put my recent new hobby of "running" to good use.

My good friend Louisa and I are lucky enough to have the beautiful Sissinghurst Castle on our doorstep and had been regularly stretching our legs

and heart rates around the grounds after school drop off, and it took little persuasion to get her to take up one of the other places for this slightly nerve wracking, but very exciting challenge. We had a few months to train ourselves up from our current 30 minute trot about, to the 2.5 - 3 hours we expected to take for the full course!

Over the next few months we saw many dewy mornings and many sunsets over the lovely local countryside and gradually found that the seemingly impossible dream of

being able to run such a long way was becoming more and more of a reality.

Soon the summer months were behind us, and rapidly advancing towards us was our date with the 13.1 mile course!

On October the 8th, spurred on by our families who came to cheer us on, and the amazing generosity of friends and family who sponsored us in our quest, there was nothing left to do but put one foot in front of the other (about 27,000 times according to our Fitbits) and drink in the fantastic atmosphere while viewing the capital city as you rarely get to see it. Famously traffic clogged

streets like The Mall and The Strand were closed off to vehicles as the many thousands of runners streamed along the tarmac and through the parks on the beautiful sunny day. To be honest we had been



hoping it would be cool and overcast with perhaps a little refreshing rain, but the bright blue sky was a perfect backdrop to the sights and scenes that we came across- Pearly Kings and Queens cheering on the runners, guards on horseback, drumming bands and a merry band of Morris dancers who danced around the entire course complete with an accordion-playing front man. In the last few hundred metres we were overtaken by a runner dressed in a giant T-REX outfit which may be a reflection on our rather heavy legs by that point, but despite the

achy feet it was a really wonderful experience, we were proud to show our young children what their Mumma's are made of, and more than that, very, VERY proud to be raising money for such a truly fabulous charity.'

*Thanks so much Jill and Louisa. There will be spaces available on next year's run!*

## Himalayan Mountain Assault

Adam Beckles and Ashley Morgan undertook a phenomenal challenge for AMEND and 4 other charities. Here is what Adam had to say about their Himalayan adventure.

'So, how it all began. The expedition of a lifetime, a feat not for the faint hearted - scaling the rocky roads in the Himalayas; the home of Mt Everest - and how do you decide to attempt this? On the golf course! 18 months ago we decided to embark on the expedition in aid of ticking something off the bucket list alongside raising money for charity. Most weekends and evenings leading up to this were consumed with countless amounts of training both locally and across the nation's best 'hilly bits'!

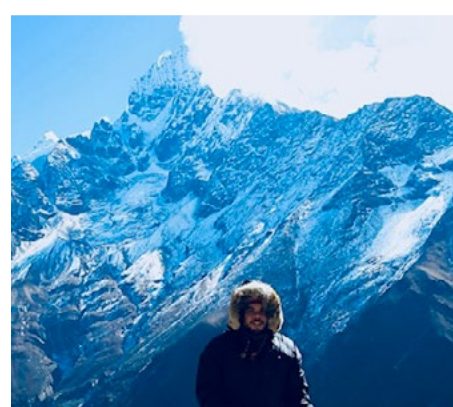
The expedition took just shy of four weeks and started in Kathmandu in Nepal. We faced some of nature's more extreme weather conditions but also got to experience nature's true beauty.

Our time in the Himalayas was nothing that we could ever expect, from the kindness of local people to the adaptive creativity to complete tasks most Westerners take for granted. No such thing as click and collect on the mountain!

An average day consisted of scaling the 'Himalayan flats' allowing our bodies to adjust to altitude, gawping at the scenery and of course drinking the locals favourite lemon tea!



The trip and kit was fully self funded and we managed to raise £2,472.51 for charity, just shy of our overall goal of £2,500. The money will be split across five charities, all of which have a personal reasoning behind why they were picked. Now back in the UK I am still trying to digest the epic feat we partook in, but one thing is for sure - I will definitely return. 'Thank you both so much, what an achievement. There is always the Yorkshire 3 peaks challenge next year if you feel the need to do some more climbing!'



## Richard Atkins Primary School

AMEND member Elisa Albuquerque's daughter attends Richard Atkins Primary school in London. The school has been fundraising and raising awareness of AMEND. The assistant head teacher for inclusion Kim Litchmore explains what they have been doing. 'As part of Religious Education around Hinduism, pupils learned the 7 basic principles of good works which includes taking responsibility for others. It was then they were introduced to the idea of how they could try and support both the sufferers and survivors of AMEND. Through the use of comic book literature provided by AMEND, pupils gathered information relating to the condition. The students then applied their own comic strip style to posters and book marks. These are currently displayed within the school reception area where visitors are encouraged to make a donation and in return, collect a book mark. Many thanks for the opportunity to raise awareness and develop a shared sense of social responsibility.'

## Oxford Federation of Young Farmers

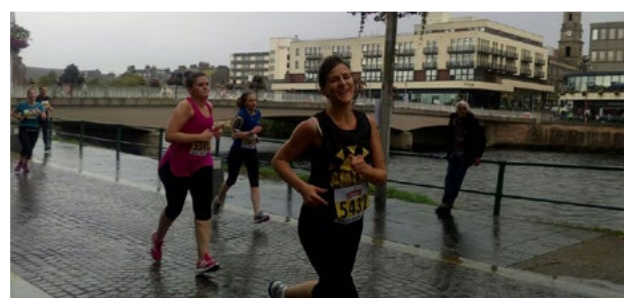
Alice Austin has given us some more information about her fundraising this year. 'Oxfordshire Federation of Young Farmers' Clubs (OFYFC) is Oxfordshire's largest rural youth organisation, where young people aged 10-26 have a wealth of new experiences and opportunities. These include taking part

in a varied competitions program, getting involved with the local community, travelling abroad, enjoying a dynamic social life and having a voice on rural issues, of which Faringdon is part. Members enjoy a well-established and immensely varied social life and the opportunity to compete in a huge range of activities as well as an exchange programme and travel scholarships. We compete at almost anything, from traditional disciplines like public speaking and stock judging right through to Tug-Of-War, football, fencing & bricklaying to name a few! During the year each club selects a charity for which they aim to raise money by doing various fundraising activities. The largest fundraising event of the year is the Club Ball. This year the charity of our choice was AMEND. This has a personal connection to Farringdon Club and Oxfordshire, as a past member, Julian Austin - my father, sadly passed away from MEN 1 unexpectedly in 1996. I also have MEN 1 as do several family members. I have been part of Young Farmers for several years from the Junior Club to Seniors. We were delighted to raise over £1500.00 for AMEND.'



## Baxters River Ness 10k

Erika Jalcakova and Sophia Schindler ran the Baxters River Ness 10k in September. 'Myself and Sophia are pleased to say, we did it :) It was



amazing day and we were proud to do the run in support of AMEND. We experienced people really interested in AMEND, even from one of the runners while running the 10K. We did two small events to fundraise, afternoon tea (and a raffle) and a gin cocktail evening. In total we managed to fundraise over £800.' Thank you both very much.



## Nether Green Junior School

Last summer term, Caroline Diacon's son Matthew who attended Nether Green Junior School raised £200 for AMEND. 'As part of their maths work and to help them understand more about the world around them, the children in Y6 at Nether Green Junior School were given the opportunity to take part in a £5er challenge. The children had to set up a mini business to create products or services which they could sell/ deliver at a profit to the school community during an Enterprise Market on the afternoon of 13th July 2017. The children decided donate a percentage of their profits to a charity. Matthew (age 11 now) presented AMEND as a worthy charity and the 90 children in the year voted. He was up against a number of bigger charities and hospitals/pet rescue centres. He clearly did an amazing job as I understand his suggestion won by a landslide after his speech. 'Great job Matthew!'

## Woolly Affair Knitwear Sale

AMEND member and super knitter Denys Ryalls held a sale of bespoke hand knitted items in early November. Here is what she had to say about the sale and the reason for setting it up: 'In July 2013 my son (then aged 34) was diagnosed with MEN1 and carcinoid tumours and we thought we were going to lose him. However, after extensive operations and 5 months in Barts Hospital London, under the care of Professor Maralyn Druce and the team, he was finally able to go home in time for Christmas. During the time my son was in Bart's, my husband and I made weekly trips to London visit him and I always took my knitting with me. I find knitting great therapy and it helped me to de-stress and stay calm at that very worrying time. I knitted as we travelled on the coach, on the tube, on the buses. I knitted in the hospital waiting rooms and whilst my son was in surgery.... you've guessed it, I knitted and into every stitch I knitted love, willing him to get better. I had knitted so much that everybody in the family received a lovely pair of mittens and a hat for Christmas! I have always been very keen on collecting fabrics and yarns and in January of this year, whilst sorting through my stash of wools trying to decide what to make, I wondered how I could support the AMEND Charity. AMEND has been so supportive to my son and family over the last 4 years and with this in mind, I set myself the enjoyable task of knitting hats & mittens to sell and



raise money for AMEND. Out came the patterns and knitting needles and the "Woolly Affair" charity event started to take shape. I planned to knit something every week and since January I have produced many beautiful bespoke items; hats, mittens, cowls, legwarmers for adults and children using quality designer yarns. My local Castle Cary knitting shop "The Wool Room" run by Clare and Anna, have helped me in my project and their knitting group got busy with the needles to produce some great head gear for the sale event. Also 2 of my friends got into the knitting frenzy and have made a selection of lovely socks and fun animal kids hats. I'm pleased to say we raised £208 on the morning and I am sure we have raised the profile of AMEND as several people told me they had googled AMEND as a result of seeing the event advertised. The day was a little slow to start as we had heavy rain, but the sun came out half way through the morning and encouraged people turned out for the event. I would like to say a big thank you to my helpers





## London 10k Rough runner

Grace Morrice and her sister Lydia-Anne took part in London's 10K rough runner in September. The challenge was an obstacle course, combining distance running with a variety of obstacles to tackle on the way. 'We had a fantastic time! We completed the 10K course and tried our hardest at all the obstacles we faced (the traveller being the toughest). We ended up running the whole 10K soaking wet and very cold after falling in at the second obstacle, however the motivational atmosphere coming from the crowd and other runners pushed us through. As well as, knowing that we had raised money and are running for AMEND, who mean a lot to us and many others. We are already planning our next challenge!'

*They also managed to raise over £1000 so we are very grateful!*

without whom I could not have managed. They were my husband Denis, my daughter Michaela and granddaughter Erin, also to Clare and Anna from The Wool Room. (PS. in 2016 against all the odds my son and his wife had a beautiful baby boy and, of course you guessed it, I am a very proud KNITTING Granny!)

*A really big thank you to all involved from all of us here at AMEND.*

### STOP PRESS!

Denys had a lot of interest in her products from people who could not make the sale and she has therefore set up on 'eBay for Charity' to sell some of her knits in aid of AMEND. You can find the items for sale here: <http://www.ebay.co.uk/egw/ebay-for-charity/charity-profile/AMEND/84153?so=2> INSERT



## The Wolf Run

Cerys Akarca and a team from Tate Fitness Titans ran the Wolf Run in September.

'Earlier this year my wonderful Bootcamp family team went and did a crazy assault course race called The Wolf Run for me to raise money for AMEND. I managed to do one of these races myself before ACC; what a muddy mess but, a lot of fun! We raised around £500 and the team are all such a lovely bunch of people. Thank you Tate Titans from all of us affected by a Neo Endocrine Disorder' *A big thank you from all of us too!*



## Edinburgh Marathon

Cerys Akarca's son Dan is running the Edinburgh marathon for AMEND in May next year if you would like to sponsor him please visit his [Virginmoneygiving page](#) Good luck Dan!

### Other donations:

We received a large donation of £1000 from Gwendylen Bennett mother of the late AMEND member Rosie Russell. Thank you very much for thinking of AMEND. The Lord Faringdon Charitable Trust awarded AMEND £1000. This was through Alice Austin and the Farringdon Young Farmers. Sally Bleathman donated £50 to celebrate the fact that it has been 6 years since her Whipples operation. She said, 'I feel very blessed that I feel so well despite hiccups along the way. Thanks to everyone at AMEND!' Thank you Sally.



## FUNDRAISING EVENTS FOR 2018



### Yorkshire 3 Peaks Challenge (29 June – 1 July)

Join the AMEND team who will be taking on 3 of Yorkshire's highest peaks on the weekend of 29 June. If the much longer Sahara Trek in 2012 is anything to go by, it will be enormous fun, but the difference this time is that you get maximum challenge with minimum time off work!

On Friday 29th June, we meet late afternoon at our campsite near Chapel-le-Dale, nestled between two of our three peaks. After dinner and a thorough trip briefing we prepare our kit and get a good night's sleep, ready for tomorrow's strenuous challenge!

On Saturday 30th June, after a good fuelling breakfast in camp, we set off, walking south through the broad green dale, criss-crossed with dry-stone walls. Ingleborough's stepped shape - due to its alternating layers of limestone, sandstone and shale - rises before us. Whernside, our second peak, dominates the landscapes behind us. We pass through the village of Chapel-le-Dale and soon reach the base of Ingleborough (723m), where a stepped path zig-zags fairly steadily to the summit of our first peak. We soak up the views over the surrounding dramatic landscapes, an area of rocky outcrops and limestone scars, and the impressive sight of the famous 400m-long Ribblesdale Viaduct, built in the 1870s. We then descend along a ridge to the valley



below, where we walk parallel to the Settle – Carlisle Railway, enjoying a flattish section! We pass through Ribblesdale, at the head of Chapel-le-Dale, and can admire the Viaduct from close quarters. From here we can also see the distinctive whale-back shape of Whernside (736m). We pass numerous limestone escarpments and outcrops; this amazing scenery provides wonderful motivation to keep our legs moving! We gradually begin our ascent, following a slabbed path all the way to the summit. The last section is particularly steep but our efforts are rewarded with the views – on a good day you can see across to Morecambe Bay on the west coast – and the knowledge that it's not far back to camp! After a short break we come down steeply off the mountain and trek the relatively short and flat distance to camp, where we enjoy a great evening meal in camp with our fellow trekkers. Night camp. (Trek approx. 12 miles: 6-8 hours) On our final day, a short transfer (15-20 mins) takes us to Horton in Ribblesdale, where we take the Pennine Way towards our third and final peak – the distinctive stepped



outcrop of Pen-y-Ghent. As we ascend, we enjoy good views back towards Horton and across to yesterday's achievements: Whernside and Ingleborough. Clear, well-worn paths lead us quite steeply up to the summit; there are some steep stone steps too. We enjoy time at the summit (694m) to take in the views before taking a westerly path down off the mountain and loop round to Horton once more (exact route may depend on group ability), feeling pretty pleased with ourselves and our accomplishments! After the short transfer back to camp, we say goodbye to the new friends we've made and the incredible scenery we conquered, and head home, taking a huge sense of achievement with us. (Trek approx. 6-8 miles: 4-5 hours)



Costs involved are a non-refundable registration fee of £50 and a minimum fundraising target of £500. Provided you reach the minimum fundraising target, AMEND pays for your trek! To book your place, visit our website:

(This event is organised by the award-winning, AITO and ABTA approved, Discover Adventure)



## Celebratory Black & Gold Ball, London (22 September) – Come Party With Us!

A 15th birthday sounds like an excuse for a party, so we're going to be organising one of our legendary Black & Gold Balls. We will be partying in the Grade 1 listed Ballroom of the Charing Cross Hotel in the West End of London.

Tickets will be £80pp to include a welcome drink, 3-course meal, ½ bottle of wine and dancing until late. Can you help?

We will be holding a silent auction to culminate on the night and would be grateful to hear from anyone who can help with suitable prizes. If you or your employer can donate an auction item, please get in contact with Helen.

## Charity Christmas Cards

There's still just time to order your Christmas Cards in time for the final UK post dates! These beautiful, bright seasonal designs were produced exclusively for AMEND by our graphic designer, Jill Clark in 2016. They come in packs of 8 with 2 cards of each striking design together with 8 envelopes, all for £4 including P&P. Order now via the website: <http://amend.org.uk/index.php/get-involved/amend-uk-shop/amend-uk-shop-2>

## DONATE TO AMEND

If you have benefited from AMEND's work over the years and would like to give something back, then we have a variety of different ways in which you can make a one-off or regular donation to AMEND:

### Text Giving

You can now donate to AMEND via JustTextGiving. Whatever mobile network you are on, to donate, you simply text ENDO12 and add an amount of £1, £2, £3, £4, £5 or £10 to 70070 (standard message rates apply). For example, to donate £5, you would send the message ENDO12£5 to 70070. You will also have the option to add Gift Aid to your donation to further increase your donation to AMEND at no cost to you. We'd be very interested to hear your feedback on this new donation method if you use it!



### CAF Donate



This method is run by the bank (CAF Bank) where AMEND has its bank accounts. Through CAF Donate, you can set up a direct debit or make a regular or one-off donation using cards and Paypal and the appropriate Gift Aid will be dealt with for us by CAF.

### Virginmoneygiving

This donation platform accepts cards and Paypal, and will deal with Gift Aid for us; however there are also small charges that apply to each transaction.



### Standing Orders

Set up a regular donation through your bank using a standing order which makes an electronic payment directly into AMEND's bank account. Gift aid has to be dealt with by AMEND, so please use the forms on our website and follow the instructions to ensure that we can keep track of all donations.

### Cheques

The old fashioned but reliable way to donate or send money raised through fundraising. Cheques should be made payable to AMEND and sent to the main office address.

### Legacies

A Legacy means that you leave a gift to AMEND in your Will. You will need to provide your solicitor with the information required to do this, which is available on our website or via the office. Visit our webpage for more details and to download standing order forms.

### Easy fundraising

Please see below for how you can help raise hundreds of pounds for AMEND just through your normal shopping online. It is so simple and it really does add up. Please visit the easyfundraising website and register. You can make a huge difference without doing anything differently!

# EARN FREE MONEY FOR AMEND



REGISTER AT [WWW.EASYFUNDRAISING.ORG.UK](http://WWW.EASYFUNDRAISING.ORG.UK) AND AMEND WILL EARN COMMISSION EVERY TIME YOU SHOP ONLINE FROM OVER 3100 SHOPS INCLUDING AMAZON, ARGOS AND JOHN LEWIS.

THE AVERAGE HOUSEHOLD COULD RAISE OVER **£100 PER YEAR!**

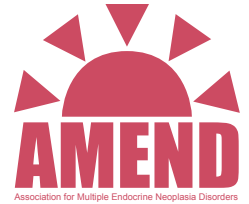
FREE MONEY FOR OUR CHARITY AT NO COST TO YOU.

IT REALLY IS THAT EASY. PLEASE REGISTER TODAY!



## AMEND UK

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Tunbridge Wells, Kent,  
TN4 0PG, UK**  
**T: 01892 516076/ 841032**  
**E: [info@amend.org.uk](mailto:info@amend.org.uk)**  
**W: [www.amend.org.uk](http://www.amend.org.uk)**  
Registered UK Charity: 1153890



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### Confidential Telephone Counselling for AMEND Members from Kym Winter

**T: +44 (0)1727 752147 (GMT) /**  
**E: [kym@kymwintertherapy.co.uk](mailto:kym@kymwintertherapy.co.uk)**



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#### Edel Murphy (MEN2b Rep)

Laura Jones (MEN1)

Louise Breen (Endocrine Nurse)

Joel Russell-Winter (Youth Rep)

### AMEND UK Patrons

Recorder, **Mrs Jo Delahunty**, QC, MA (Oxon)  
Jurisprudence(AMEND)

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

**Mr Shaun Williamson**, actor

### AMEND Medical Advisory Team (AMAT)

Dr Caroline Brain, Professor Maralyn Druce, Professor  
Ashley Grossman, Mr Barney Harrison, Dr Fiona Laloo, Dr  
Paul Newey (EMENA Advisor), Mr David Scott-Coombes,  
Professor Rajesh Thakker

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#### AMEND New Zealand

**Siobhan Conroy** (Volunteer)

Tel: 021 354 342 (before 8pm)

Email: [siobhan@unicornfoundation.org.nz](mailto:siobhan@unicornfoundation.org.nz)

### Other Useful Organisations

Addison's Disease Self-Help Group (for adrenal  
insufficiency): [www.addisons.org.uk](http://www.addisons.org.uk)

British Thyroid Foundation: [www.btf-thyroid.org](http://www.btf-thyroid.org)

Hypopara UK (for hypoparathyroidism): [www.hypopara.org.uk](http://www.hypopara.org.uk)

Pituitary Foundation: [www.pituitary.org.uk](http://www.pituitary.org.uk)

NET Patient Foundation: [www.netpatientfoundation.org](http://www.netpatientfoundation.org)

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