



Seasons Greetings and a Happy New Year



The Directors of Barnes Construction fundraise for AMEND page 13

JO'S BLOG

Well, it's December and today Helen and I put the decorations up in the office. Needless to say, this means that we are rather behind on producing this newsletter! Not only are we furiously busy here at the office, organising the 2019 Annual Patient Information Day (see page 2), updating Patient Information Booklets and writing research articles, but also, poor little Dave the Beagle has been a bit poorly this last week. Fortunately, he is back to full strength (and trouble!), although he will need regular interventions for a skin condition. So now I am furiously typing away to catch up! As you will see, there are two huge sections in this newsletter; research and fundraising. Whether or not there has been an explosion in research into our conditions, I am not sure,



but it certainly feels like it and long may it all continue. There has also been so much fundraising going on recently (as you will read) and throughout the year, that I am thrilled to report that the Trustees have agreed a total AMEND Research Fund for 2019 of £30,000 (see page 11). Our last round of funding in 2015 had real impact and research and projects boosted by our grants continue to this day. I hope that we can

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Important Dates

- Regional Meetings (Yorkshire, 19th January 2019)
- 2019 Annual Patient Information Day (Sheffield, 11th)

CAN YOU HELP?...

- Become a film star for AMEND (See MEN2B Film Project)
- Tell your specialist about RET@CRICK (See Research)
- Tell your specialist about the MEN1/PNET Research Registry (see Research)

continue this forward motion and that the continued uncertainty of Brexit will not derail everyone's efforts. Thank you to everyone who has contributed time or fundraising to AMEND throughout 2018 – our 15th anniversary year. You really do make all the difference! Season's greetings to all and best wishes for a Happy and Optimistic New Year!

Jo

Regional Events

We are delighted to now have a number of volunteers around the UK who will be holding free, small, friendly and informal meetings from time to time to help facilitate peer support on a more local level. All meetings will be listed on our [dedicated webpage](http://www.amend.org.uk/patients/support/events/regional-events/) (www.amend.org.uk/patients/support/events/regional-events/).



If there isn't an event near you right now, please keep checking back, as this page will be updated as meetings are arranged. Bookings are now being taken via our website for the following meeting:

- Leeds, Yorkshire – 19th January 2019

If you do not have internet access, please contact Helen in the office to book a place. You can learn more about our wonderful new volunteers in the Projects section of this newsletter.

Unfortunately, there has been a high no-show rate at the meetings held to date. Therefore, this is a polite reminder to contact the office ASAP if you find you cannot attend a meeting that you have booked spaces at. This will help us to avoid unnecessary expenditure on refreshments and potentially venues, as well as avoiding wasted volunteer time.

Annual Patient Information Day 2019

Next year we will be travelling to Sheffield in South Yorkshire for our annual patient conference on Saturday 11th May 2019.

The current draft programme includes the following with some speakers still to be confirmed:

- Review of AMEND's 2018 activities
- Separate information and Q&A sessions on
 - MEN1 (with Professor John Newell-Price)
 - MEN2A and MEN2B (with Professor Steve Ball)
 - SDHx syndromes (with Dr John Ayuk)
 - Adrenocortical Cancer (ACC)
 - Sporadic MTC
- Impact of endocrine diseases on relationships (Kym Winter)
- Complementary and alternative medicine

The AMEND Annual General Meeting has now been moved to the end of the day, leaving us a good lunch-break for socialising with one another. At the end of the day, you are invited to join us for a cash bar drinks reception.

As usual, tickets are free and include all refreshments throughout the day, including lunch. In addition, there will be a free crèche for children under 12 years of age, so that you can get the most out of the day. For more information, how to get to the venue, where to stay, and to book your free tickets, please [visit our website](http://www.amend.org.uk/patients/support/events/nationalevents/annual-patient-information-day-2019/) at www.amend.org.uk/patients/support/events/nationalevents/annual-patient-information-day-2019/. We look forward to seeing you there for another fascinating and popular day.

An absolutely brilliant, well organised and informative day. Very friendly and relaxed with excellent speakers. Thank you all so much!

Regional Volunteers (Project Connect)

We were delighted to introduce you to our new Regional Volunteers in the last newsletter. Since then, they have been busy planning and running their Regional Meetings; something that the majority of our membership has been requesting for many years.

Our Essex Regional Volunteer, Tara Watkin said, 'I very much enjoyed being able to bring the work of AMEND into the community, and knowing that I helped to support a family in need was a wonderful thing. I'm very much looking forward to facilitating the next regional meeting for Essex in the Spring.'



An attendee at the Suffolk Regional Meeting hosted by Julie Fayers said, 'It meant a lot for my family and me to be able to connect with likewise people in a relaxed and friendly environment. Thanks AMEND for making it possible.'

Those who have attended have found these small and informal events very welcoming and useful. Our Volunteers are asked for feedback and suggestions for future training needs. By listening to what attendees and volunteers say, we can make improvements to the meetings where appropriate as we approach our 2nd year of this project. We hope you will support this project and pop along to the next meeting near you.

MEN2B Patient Experience Project

We were delighted to receive a grant from the Society for Endocrinology earlier in the year to redevelop our patient experience film on MEN2B. Now, thanks to the AMEND Board of Trustees, who have committed the necessary additional funds to this project, we are now in a position to begin work on developing this film! The new film will be under 5 minutes long and will not only be informative for the newly diagnosed, but will also highlight the early warning signs for clinicians that may indicate a case of MEN2B. We hope that we will be able to launch the new film at our Annual Patient Information Day on Saturday 11th May in Sheffield (see Upcoming Events).

GET INVOLVED!

Subject to finding additional funding, we will be developing new films for all the diseases we support in the same manner as the MEN2B film. If you have MEN1, MEN2A, SDHx, ACC or MTC and are interested in starring in our future films, then please get in contact with Jo in the office at

jo.grey@amend.org.uk

We thank all the medical societies and organisations 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 and organisations who provide financial support to attend.

European Society for Paediatric Endocrinology (ESPE)

Jo Grey is a European Patient Advocacy Group representative for the European Reference Network (ERN) for Rare Endocrine Conditions (ENDO-ERN) at who's invitation she attended this busy conference in a very blustery Athens in late September. Jo gave a presentation about Pituitary Tumours in Children with MEN1, to explain how the ERNs will benefit these very rare patients. With such small numbers of patients, it is essential that such children and teenagers are cared for in centres of expertise, preferably those registered with the EU as Reference Centres. It was a flying visit but a great chance to beat the drum and raise awareness of MEN1.

European MEN Alliance (EMENA) General Assembly



Once again Jo headed to Munich to meet with European MEN Patient Group colleagues. As well as holding the Annual General Meeting, we had ample opportunity to discuss

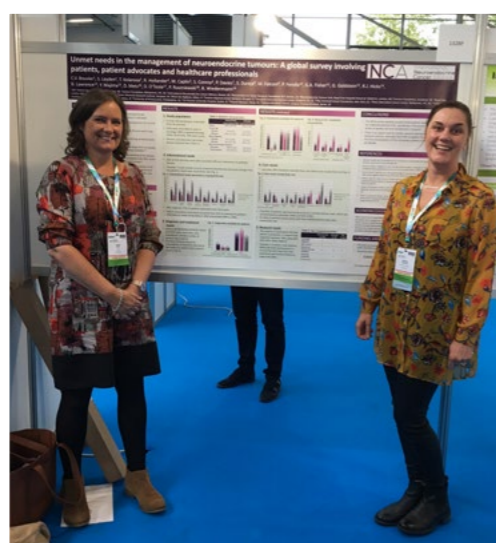


the results of the survey on Quality of Care for MEN Patients in Europe, and even begin planning for the survey on Quality of Life in MEN Patients in Europe which EMENA will be running early in 2019. Thank you to everyone who completed the former survey earlier this year. There was a particularly good response from UK patients and this enabled us to develop 2 posters for display at the British Endocrine Society meeting, comparing UK data with that of the rest of the European countries involved. For more information on these posters, please see the Research section of this newsletter.

European Society for Medical Oncology (ESMO)

We are grateful to the ESMO for a patient group grant to attend this huge annual meeting of mainly oncologists and cancer researchers. As well as attending a meeting of the European Patient Advocacy Group representatives for the Rare Adult Cancer European Reference Network (EURACAN), there were opportunities to attend the main scientific sessions and a range of sessions specifically aimed at patient advocacy groups like AMEND. In a conference of 28,000 delegates, it could easily become overwhelming, but over the years, we have learnt to pace ourselves! There were great sessions on developing podcasts, incentivising innovation in cancer, breaking bad news (for oncologists), and on complementary and alternative medicine and pseudoscience. The latter has inspired the development of a new section of our website which will be published in the New Year, as well as a session at the 2019 Annual Patient Information Day in Sheffield.

In scientific sessions we learned that European Guidelines on the management of malignant pheochromocytoma and Paraganglioma are currently being developed and should be available in early 2019. It was impressed upon the audience that it is not just the hormone secretions from these tumours that are a risk to the patient, but also complications from constipation, and that therefore, both aspects need to be carefully controlled. For malignant, metastatic or inoperable disease, PRRT (Peptide Receptor Radionuclide Therapy) is beginning to show encouraging results.



Any session with the word Immunotherapy in the title usually ends up as standing room only. Immunotherapy is a type of cancer treatment that helps your immune system fight cancer. Kjell Oberg, MD, Professor of Endocrine Oncology at Uppsala University Hospital in Sweden has devoted years of study to this therapy in neuroendocrine tumours (NETs). NETs are unlike many other cancers in that they do not respond well to immunotherapy. However, Professor Oberg has shown that, when used in

combination with other treatments, this response may be improved; however, there is still a long way still go with this research.

An update on the clinical trials for medullary thyroid cancer (MTC) showed similar response rates in the new anti-RET compounds, Loxo 292 and Blu 667. Loxo currently seems to have a lower toxicity resulting in fewer serious side effects although it was stressed that this trial is in the very early stages and it is therefore not possible to fully compare the results yet. We will be keeping an eye on these and letting you know more in due course, but if the Loxo trial is of interest to you, you can [click here to view some reasonably accessible slides used at an earlier conference](#).

It was a long and exhausting conference but offered a great opportunity to catch up with fellow patient advocacy group representatives, including Cathy Bouvier from the NET Patient Foundation, who was presenting a poster from the International NET Cancer Alliance on unmet needs in NET Cancer, using data from the 2016 survey that many of you may have contributed to. Having helped Cathy display the poster, we were delighted to learn that it had won the Best Poster prize for its category.

NANETS 2018 Annual Multidisciplinary Meeting

Dana Sato and John Metzcar, AMEND USA Treasurer and Board Member respectively, attended the 2018 North American Neuroendocrine Tumor Society's (NANETS) Annual Multidisciplinary Meeting in Seattle, Washington on October 4-6.



At the meeting, we ran an information booth, talking with providers, researchers, students, pharmaceutical representatives and other non-profit organization representatives about AMEND USA and our patient population. We distributed patient information booklets, obtained contact information from providers to ship additional patient information to them, as well as introduced conference attendees to our website and all the information available there. In particular, many people enjoyed the comics and saw them as a great way to talk to and educate children about the MEN disorders.

Additionally, we attended the technical program, which included tracks for researchers, physicians, and allied health professionals. Highlights of the technical program included several sessions on peptide receptor radiotherapy (PRRT) and a history and retrospective view of the MENIN gene, mutations of which cause MEN1, to celebrate the 20th anniversary of its discovery. PRRT is a treatment for pancreatic neuroendocrine tumors (pNETs) and is newly available therapy in the United States, approved January 26, 2018 under the brand name Lutathera. It is a targeted therapy in which a radioactive chemical (Lutetium-177 in the case of Lutathera) is bound to another chemical (DOTA-TATE in the case of Lutathera) that moves to pNET cells due to the unique

biological signature that they have in some cases. There are ongoing discussions within the medical community as to how this new therapy will fit into the set of existing treatments in the US as well as ongoing research to find ways to optimize the general therapy to produce still better health outcomes for pNET patients.

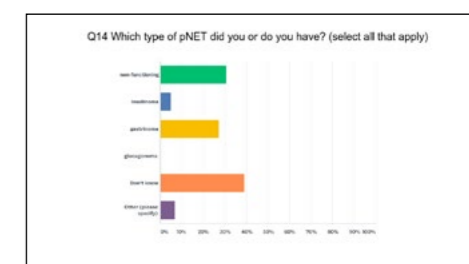
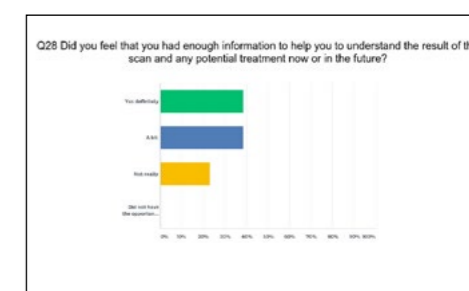
Finally, AMEND USA was able to fund a poster award on the topic of Best MEN Poster. The NANETS Annual Conference research committee selected the poster 'Two in vivo Well-Differentiated G1/G2 PanNET Preclinical Mouse Models' by Dr. Eugenia Xu of the Raymond and Beverly Sackler Foundation Laboratory and the Rutgers Cancer Institute. Her successful work with mice has led to the first experimental system (a mouse model) that reproduces MEN1 like tumors of the pancreas and pituitary gland. This excellent work can be used to study and identify potential new therapeutic interventions for the MEN1 community as well as the pNET community at large.

British Endocrine Society Meeting (BES)

Jo Grey and Gill Underhill attended this busy annual meeting in Glasgow in November. As well as attending several interesting sessions, there were a number of activities requiring our attention, including presenting two posters featuring the results of the European MEN Alliance survey on Quality of Care in Europe (see Research), chairing a meeting of the attending patient advocacy groups, attending a Research Network meeting, and manning AMEND's exhibition stand. We caught up with many familiar faces, and met many new ones.

We were particularly pleased to

contribute the patient voice through surveys that many of you will have helped us with. At the rather early 7:45am Research Network meeting, data from our short survey of MEN1 patients' involvement in a new research project were used to illustrate patients' overall support for the project which will incorporate somatostatin analogue injections and regular screening and imaging, including endoscopic ultrasound (EUS) in patients with stable pancreatic neuroendocrine tumours. At the session, 'Pancreatic NETs: an update', Professor John Newell-Price was able to use data from our survey of patients to illustrate the average level of understanding of patients about their disease and treatments. A surprising number of people could not name the type of MEN1 pancreatic tumour they had indicating that there is still more work for AMEND to do! The data showed that the majority of patients obtain their information from patient groups or the internet, highlighting the need for clinicians to also help to improve access to information resources like AMEND's for their patients. You can view the full results of these surveys on our website.



Thanks once again must go to the ever supportive Society for Endocrinology for judging our Young Investigator Award (see Research), for our free exhibition table and delegate places, and for the travel grant which helps meet the costs of attending this important meeting.

AMEND Website- What's new?

New webpages:

- EMENA page – learn about our work with the European MEN Alliance (EMENA) via <https://www.amend.org.uk/our-work/emena/>
- ERN page – learn about our contribution to the European Reference Networks (ERNs) for Rare Adult Cancers and Rare Endocrine Conditions via <https://www.amend.org.uk/our-work/european-reference-networks-erns/>

Coming soon:

- Complementary and Alternative Medicine page – exploring the facts and myths about alternative therapies



NICE decision on Vandetanib (Caprelsa) for MTC

NICE National Institute for Health and Care Excellence

After a very long and drawn out consultation, in which AMEND and its members participated, the National Institute for Health & Care Excellence (NICE) made the following decision: "Vandetanib is not recommended, within its marketing authorisation, for treating aggressive and symptomatic medullary thyroid cancer in adults with unresectable, locally advanced or metastatic disease. This recommendation is not intended to affect treatment with vandetanib that was started in the NHS before this guidance was published. People having treatment outside this recommendation may continue without change to the funding arrangements in place for them before this guidance was published, until they and their NHS clinician consider it appropriate to stop." We are obviously extremely disappointed by this decision, since therapies for controlling MTC which has spread are few and far between. The NICE consultation process is renowned for being more suitable for common disease medication decisions, and completely fails to put rare diseases into perspective. We must now look to the future treatments currently in clinical trials (See AMEND Attends ESMO summary).

European Guidelines for the Management of Adrenocortical Cancer (ACC) in Adults

Adrenocortical Cancer (ACC) is a very rare and in most cases, steroid hormone producing tumour, with variable prognosis, for which AMEND and the NET Patient Foundation collaborate to provide information and support services. Back in July, the European Society for Endocrinology launched new guidelines for the management of ACC. The team behind this, including AMEND/ACC Support UK Medical Advisor and Endocrine Surgeon, Mr Radu Mihai, have been working on this for a long while. The guidelines were very well received at the European Congress for Endocrinology earlier in the year, and we were pleased to be involved in reviewing them before publication. The guidelines make 61 recommendations, including the following:

1. We recommend that all patients with suspected and proven adrenocortical carcinoma (ACC) are discussed in a multidisciplinary expert team meeting (including health care providers experienced in care of adrenal tumours, including at least the following disciplines: endocrinology, oncology, pathology, radiology, surgery) at least at the time of initial diagnosis. In addition, this team should have access to adrenal-specific expertise in interventional radiology, radiation therapy, nuclear medicine, and genetics as well as to palliative care teams.
2. We suggest that at any time of decision-making regarding therapy, enrolment in a clinical trial (if available) should be considered. Furthermore, we encourage patients' participation in registries and the collection of biological material as part of structured research programs



aimed at defining biomarkers of diagnosis, prognosis and treatment response.

3. We recommend against the use of an adrenal biopsy in the diagnostic work-up of patients with suspected ACC unless there is evidence of metastatic disease that precludes surgery and histopathologic proof is required to inform oncological management.
4. Open surgery is the standard surgical approach for confirmed or highly suspected ACC. Therefore, we recommend open surgery for all tumours with radiological findings suspicious of malignancy and evidence for local invasion. However, for tumours <6cm without any evidence of local invasion, laparoscopic adrenalectomy (respecting the principles of oncological surgery) is reasonable if the surgeon has sufficient experience in these types of surgery.

The authors themselves highlight the difficulty in developing guidelines based on scant evidence. As a rare cancer, research funding and therefore research itself is scarce. To address these difficulties, the European Network for the Study of Adrenal Tumours (ENS@T) was developed as a collaboration of researchers and clinicians from several countries to achieve significant progress benefiting the affected patients at a European-wide level. The guidelines were developed as a collaboration between ENS@T and the European Society for Endocrinology. ACC members can view the guidelines in their ACC Support UK Secret Facebook Group, but are asked not to distribute these publicly for copyright reasons.

AMEND 2018 Young Investigator Award Winner

This year's winner of the AMEND award is Dr Ruth Casey, Consultant Endocrinologist at Addenbrooke's Hospital in Cambridge

for her abstract, entitled 'In vivo and ex vivo metabolomics in succinate dehydrogenase deficient tumorigenesis' which investigates levels of the succinate dehydrogenase (SDH) enzyme and its potential role for guiding treatment in metastatic disease. Congratulations to Dr Casey who was presented with her certificate at the BES conference in November.

In vivo and ex vivo metabolomics in succinate dehydrogenase deficient tumorigenesis

Ruth Casey¹, Madhu Basetti², Mary McLean², Ben Challis³, Ferdia Gallagher^{2,3} & Eamonn Maher¹

¹Cambridge University, Cambridge, UK; ²Cancer Research UK Cambridge Institute, Cambridge, UK; ³Cambridge University NHS Foundation Trust, Cambridge, UK.

Mutations affecting the mitochondrial enzyme succinate dehydrogenase (SDH) are associated with a wide spectrum of tumours. SDH deficient tumours have a unique tumour metabolome due to the interruption of the citric acid cycle and accumulation of the 'oncometabolite' succinate, which drives tumorigenesis. Investigating the tumour metabolome of SDH deficient tumours has potential translational application. MRI spectroscopy (1H-MRS) was used for in vivo metabolomics analysis and a nuclear magnetic resonance spectroscopy technique; high



resolution magic angle spinning, was employed for ex vivo analysis. Ex vivo analysis was performed

on 40 tumours (8 gastrointestinal stromal tumours (GIST), 32 pheochromocytoma/paraganglioma (PPGL)). Targeted metabolomics analysis of succinate, demonstrated that succinate was several folds higher in SDH deficient tumours

compared to wild type (wt) tumours (P<0.001). Untargeted metabolomics analysis demonstrated that concentrations of lactate, glutamate, aspartate and branch chain amino acids, were significantly lowered in SDH mutated tumours compared to wt tumours. The detection of 2 hydroxyglutarate (2HG) accumulation in a single paraganglioma, heralded the subsequent discovery of a somatic IDH1 (R132C) mutation in that tumour. In vivo metabolomics analysis was performed on 12 patients (6 GIST, 5 PPGL, 1 non-functioning pituitary macroadenoma). A succinate peak was detected for 8/12 (66.7%) patients and succinate detection correlated with SDHB immunohistochemistry and/or germline genetic status in 11/12 (92%) cases. 1H-MRS identified a succinate peak in two patients with metastatic GIST without a germline SDHx mutation but an identified somatic SDHC epimutation. Finally, we demonstrated that in vivo metabolomics has a role as a surrogate biomarker to validate therapeutic strategies in malignant SDH deficient disease as succinate accumulation was identified in a patient with a metastatic paraganglioma and a germline SDHB mutation before treatment with lutetium labelled peptide receptor radionuclide therapy, but no succinate was detectable in the same tumour deposit after four cycles of treatment.

RET@CRICK
Initiative Kick-Off
Meeting, June 10th
2019

Germline (in DNA) and somatic (in tissue) RET gene mutations are responsible for a range of rare diseases, including multiple endocrine neoplasia type 2 (MEN2), familial and sporadic medullary thyroid cancer (MTC) and pheochromocytomas, Hirschsprung’s disease (HD), congenital kidney and urinary tract abnormalities and intellectual disabilities. Although individually rare, collectively they carry a significant burden to the patients and health care systems because of their complexity and multiple co-morbidities. Their rarity also affects the ability to conduct research into the mechanism of RET-associated diseases and recruitment into clinical trials. Optimal care is difficult to deliver because patients with these conditions are looked after by a wide variety of centres across the UK. Awareness and understanding of RET-associated diseases can be poor and the majority of patients affected are children. The establishment of a RET Research Collaborative Network has been proposed with the aim of facilitating the exchange of ideas and collaborative initiatives leading to innovative projects and grant applications, and to coordinate research with ongoing clinical care to encourage recruitment into laboratory based projects and clinical trials. We believe that such a network will also enable earlier diagnosis of RET mutations, ensure better treatment options for patients and improve clinical outcomes. The RET@CRICK meeting

is envisaged as a stepping stone towards this goal. The one-day event will bring together scientific and clinical leaders in their field as well as junior doctors and researchers who can present their research in a poster format. The day will consist of four 90-minute sessions, each comprised of a triad of Scientific, Clinical and New Research talks, followed by an open forum discussion and networking breaks. Presentations will cover important aspects of RET-related diseases including MEN2, MTC, Hirschsprung’s disease, animal models and RET targeting in oncology, as well as the role of RET in development and physiology. RET@CRICK is an excellent opportunity for both scientists and clinicians to test new ideas, find potential collaborators and get engaged in world class translational research.

Convenors:
Mr Tom Kurzwinski, Consultant Endocrine Surgeon, University College Hospital, London
Dr Louise Izatt, Consultant in Clinical Genetics and Genomics, Guy’s & St Thomas’



Foundation NHS Trust, London, Dr Rakhee Chauhan, Postdoctoral Research Fellow, Francis Crick Institute Professor Neil MacDonald, Team Leader, Francis Crick Institute

What we love about this meeting is that it brings together former AMEND Research Award recipients, Mr Tom Kurzwinski and the RET research team at the Francis Crick Institute, to further their research in a collaborative and forward-looking way. We can’t wait to see where it leads!

Please let your specialists know about this meeting and that they can book their free place by visiting www.eventbrite.com/e/retcrick-tickets-52393900567. Please note that this meeting is not open to patients; however, AMEND will be represented and will report back to our membership after the meeting.

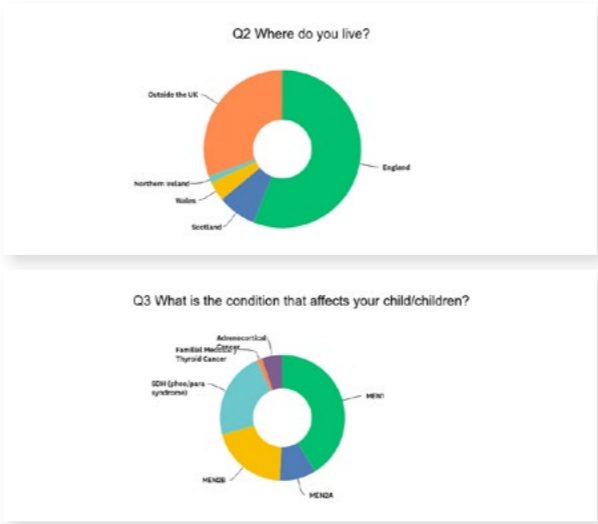
UK Paediatric
Endocrine Research
Group

Along with many other endocrine-related patient groups, Jo Grey attended a meeting in September hosted by the Clinical Research Group of the British Society for Paediatric Endocrinology & Diabetes (BSPED), led by Consultant Paediatric Endocrinologist, Tim Barrett from Birmingham. The meeting was to ascertain what patients’ priorities are for research into our endocrine conditions in children.

Thank you to all those members who contributed to the short survey we ran to finalise our priorities.

This data will feed into a national strategy for paediatric endocrine research. A similar approach was employed by an arthritis network, resulting in an increase in secured research funding. It is expected that there will be a further meeting in February, after which we hope to bring you a further update.

Results of the survey:



Top 3 research priorities in order per disease:

MEN1 – 1st) Age of genetic testing; 2nd) less invasive testing; 3rd) a National Research Registry

MEN2A – 1st) a National Research Registry; 2nd) new treatments for MTC; 3rd) less invasive testing

MEN2B – tied 1st) earlier diagnosis, new treatments for MTC, new treatments for ganglioneuromatosis; 2nd) a National Research Registry

SDHx – 1st) How the gene may affect someone in the future; 2nd) age to begin screening; 3rd) a National Research Registry

FMTc – 1st) age of genetic testing; 2nd) less invasive testing; 3rd) age for thyroid surgery

ACC – 1st) earlier diagnosis; 2nd) new surgical techniques; 3rd) better treatments

To what extent parents were happy for children to be involved in research:

	YES	NO	MAYBE	TOTAL	WEIGHTED AVERAGE
Sharing medical notes with a Research Registry	91.67% 33	2.78% 1	5.56% 2	36	1.14
Provide a saliva sample	94.44% 34	2.78% 1	2.78% 1	36	1.08
Provide a blood sample	77.78% 28	2.78% 1	19.44% 7	36	1.42
Provide a tissue sample (either from biopsy or during scheduled surgery)	77.78% 28	5.56% 2	16.67% 6	36	1.39
Testing new medicines	27.78% 10	16.67% 6	55.56% 20	36	2.28
Try new types of surgery	19.44% 7	22.22% 8	58.33% 21	36	2.39
Try new types of scan	66.67% 24	5.56% 2	27.78% 10	36	1.61

Parents were most happy to share medical notes with a Research Registry (despite this not being a consistently highly prioritised research tool), and with providing a non-invasive saliva sample. Nevertheless, many were open to their children’s involvement in most ways, except for trialling new surgical techniques.

UK Research Registry For MEN1
& Pancreatic Neuroendocrine
Tumours

This national Research Registry is collecting patient data for use in research. If you are interested in participating by sharing your medical information with the Research Registry then please contact Jo Grey at AMEND HQ for the full Information Leaflet, Consent Form and GP Letter. Alternatively, download them from the website.



Quality of Life in Patients with
Hypoparathyroidism as a result of
Surgery

“Assessment of quality of life in patients with long term post-surgical hypoparathyroidism (PoSH)”

There is still time to contribute to this study being run by the University of Sheffield and Sheffield Teaching Hospitals which aims to determine patients’ quality of life following surgery for either thyroid or parathyroid disease. The survey will take 10 minutes to complete. To participate in the survey please click on the following link: <https://redcap.shef.ac.uk/surveys/?s=PYKF74KHFF>

For further information or to be sent a paper copy of the questionnaire please contact Mrs Sarah Hillary, Clinical Research Associate and Chief Investigator for the study (s.l.hillary@sheffield.ac.uk).

EMENA Quality of Care Survey

Thank you to everyone who completed this survey earlier this year. A total of 284 usable results were gathered from those with MEN1, MEN2A and MEN2B. A good response was seen from the UK, Italy, Germany and The Netherlands, with another 12 European countries also represented. As expected, the majority of responders were female and over half were aged between 41-60 years.

You told us that your average time to diagnosis from the development of first symptoms was 2 years, with an average of 2 doctors visited during that time. Most of you reported being cared for in a specialist centre by an endocrinologist as part of a multi-disciplinary team (MDT). The frequency of outpatient appointments, blood and urine tests and scans were all very similar, even between different types of MEN.



There was a significant difference between the availability of Clinical Nurse Specialists between the UK, where they are more common, and the rest of Europe.

The majority of you feel listened to by your specialist, involved in decisions about your care, that your team are knowledgeable about MEN care and monitoring. In addition, the majority of you trust your medical team and follow their advice. Nevertheless, the overall standard of care was most commonly rated good, although many also rated their care as excellent.

You can view all the results and the posters themselves, as well as learn more about EMENA [via our website](#)

Corticosteroids Research to begin Recruitment Soon

AMEND Trustee and MEN expert, Professor Karim Meeran and his team are planning a Research Study to see if there are any major differences between taking the glucocorticoid hydrocortisone vs prednisolone. In cases of MEN, these drugs are prescribed when both adrenal glands have been removed (MEN2 and MEN3) or when the pituitary gland is removed (MEN1).

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 3-4mg 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>.

You can hear Prof Meeran talking about this research project in his talk from our 2018 Annual Patient Information Day which you can view on our [YouTube channel](#).

2019 AMEND RESEARCH AWARD FUND INVITING APPLICATIONS

Thanks to some phenomenal fundraising by members and supporters of AMEND throughout 2018, we are delighted to announce that we are able to invite applications for our 2019 AMEND Research Awards. A total of £30,000 worth of grants is available: £20,000 is exclusively for research relating to MEN1 and the tumours occurring as part of MEN1, and £10,000 is available for general applications relating to any of the tumours or conditions for which AMEND provides information and support.

For more information and to apply, please visit our website where you will find application forms and examples of projects that we have funded in previous years.

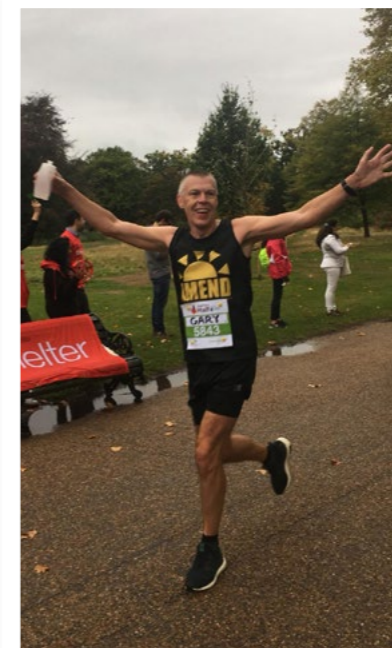
<https://www.amend.org.uk/healthcare-professionals/amend-research-fund/>

A big thank you to everyone who has either, run, walked, cycled or supported a fundraising event so far in 2018 and also to those who regularly donate through standing orders.

Royal Parks Half Marathon

AMEND had 3 lovely people running for them in the Royal Parks Half marathon in October. Here is what they had to say about their experience:

Gary Flint: "It was a great



experience. A cold and wet day but a great route and despite the rain there was great support and encouragement around the course. This was only my second half marathon and I completed it in a time of 1:39 and in the process raised £502 for AMEND."

Emily Barber: "On the 14th October I ran the Royal Parks Half Marathon in memory of Nick Fayers, who sadly passed away late last year. It has been absolutely heart breaking to watch my best friend and her wonderful family go through such a difficult time but they have all been so strong and so brave. Over the last

year they have tried to do as much as they can to raise money for this amazing charity so, in support of this, I decided to step completely outside of my comfort zone and run a Half Marathon. It was probably the most physically challenging thing I have ever done and during the training there were times where I thought I wouldn't be able to do it but it was definitely worth it as I managed to raise £700 and hopefully lots of awareness to those around me, that didn't know about AMEND before."

Francesca Hunt also ran for AMEND in memory of her mother and raised £250.

Thank you very much to all of you for the fantastic fundraising and for completing the half marathon – well done from us all.

Mad for Movie musicals

The Ice Cream Farm in Chester, Cheshire hosted a performance organised by Greg James in aid of AMEND. They sent us the following update about the event:

"On the 7th September we hosted the 'Mad for Movie Musicals' performance at The Playhouse, in aid of the charity 'AMEND'. It was a huge success and we wanted to share this with everyone to show our support for a great cause and our appreciation for our talented staff and of course all the wonderful performers involved!

The event was organised by two of our outdoor and retail staff Greg James and Kelly Stevens and featured talented young musical theatre performers (including our very own Greg and Kelly) from all over the North West of England and North Wales; singing favourite songs from your most loved movie musicals – I think you could tell from the sheer silence of the audience how spectacular these voices were!" Over 100 people attended and over



£700 was raised for AMEND. A fantastic result from plenty of fun. Huge thanks to Greg James and The Ice Cream Farm for their support.

The Play that goes wrong

The Play That Goes Wrong in London's West End kindly held some bucket collections for AMEND following performances over one weekend. They raised a staggering £2,055.19. Thanks to everyone involved.

Nadia Krauhaus runs numerous runs for AMEND!

Nadia is completing a series of runs for AMEND despite saying on her fundraising page that she is 'not a particularly confident runner'. Here is what she has to say about the challenges undertaking and the ones coming up.

"I am completing a series of races in memory of Nick Fayers, whose family has been supported greatly by AMEND. On 20th December, it will have been a year since Nick

passed away and all those who loved him will continue to keep his memory alive. So far I've completed the Bournemouth Marathon Festival 10k and the Great South Run, and coming up I have the Runthrough Victoria Park Half Marathon and the Edinburgh marathon. I'm also looking to book further half marathons at the beginning of 2019 to support my marathon training. It's been tough so far following an ankle injury at the GSR, but I'm determined to continue and raise as much money for AMEND as possible."

Nadia has so far raised over £1200 for AMEND including £500 from her employer, NATS through their Footprint Fund. If anyone would like to sponsor Nadia please visit her Virginmoneygiving page <https://uk.virginmoneygiving.com/NadiaKrauhaus>

Thanks Nadia – we are all seriously impressed with how much you are doing for AMEND in memory of Nick Fayers.



Warrior Adrenaline Race 5k

AMEND member, Ali Templeman, ran a warrior Adrenaline 5k for us back in September. Ali said the following about the race:

"The fundraising gave me an incentive to run. I had a difficult birth 2 years ago and my daughter Luna was born well other than a very fast heart. She is now under the care of GOSH and they think she has a phaeochromocytoma which causes her symptoms and tachycardia. I wanted to raise money for a charity that can help families with this and who understand the difficulties of this. If confirmed it will be unusual as there appear to be no documented cases of anyone having this from birth or in this case possibly in utero. I am very grateful for all the support and know it's going to an excellent cause. A friend gave me the confidence to get fit and this race seemed an excellent way to keep me incentivised. It was hard with many muddy, wet and high obstacles but was also rewarding knowing I could do it and to know I'd raised the money. I hope to continue raising money for AMEND and hope that other families like us will benefit from your great work."

Ali raised over £600 for AMEND – thanks for taking on such a challenge for AMEND Ali.



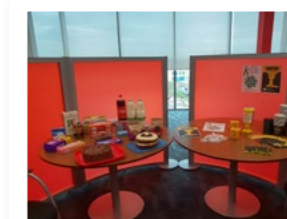
100 Mile Charity Bike Ride

The Directors of Barnes Construction have recently completed a 100mile Charity Bike ride in memory of their former Managing Director, Nick Fayers who sadly passed away in December 2017 due to MEN1. The 100mile route was undertaken over two days across the Suffolk countryside starting at Barnes Head Office in Ipswich and ending up at the Bury St Edmunds Premier Inn at the end of day 1. The second day took a different route back to Ipswich but proved to be more challenging due to the wet and windy weather conditions. In total, the ride by the team of 7 has raised over £6,000.00 for AMEND.

A HUGE thank you from all of us at AMEND for the continued extraordinary fundraising in memory of Nick Fayers.

NET Cancer Day

A number of AMEND members held coffee mornings for NET Cancer Day on or around the 10th November. NET Cancer Day is an annual international event held on the 10th of November to raise awareness of Neuroendocrine (NET) cancers and to provide a voice to the NET community for improved diagnostics, treatments, information, care and research. To date, Regional Volunteers, Geoff Toon has raised over £500 and Charmaine Chantler has raised £115. Thanks so much to everyone who took part.



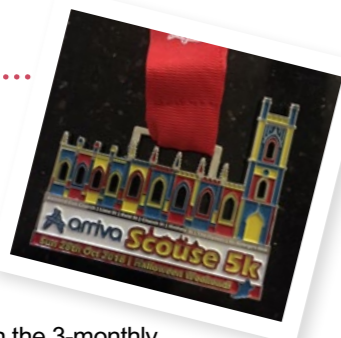
Scouse 5k

Amanda Green took part in the Scouse 5k in October. She said this about her experience:

"My husband, Al, was diagnosed with ACC in January of this year, after his operation in December 2017. He scoured the internet for support in the early days and he came across your FB page and the ACC Support UK page. We have gained so much support from both and came to the Patient Information Day in May in London with

my goal, it seemed like an ideal opportunity to do some fundraising for you.

The good news is that we have recently just returned from the Christie Hospital in Manchester with AI being given the 3-monthly all clear once more. So we can now look forward to a much better Christmas & New Year than last year, when AI was in the Royal Hospital in Liverpool from 18th Dec - 4th Jan!" *That's brilliant news Mandy and AI! Thanks so much for running for AMEND.*



Cake Sale

AMEND member and Regional Volunteer, Tara Watkins, held a cake sale in October. She said, "I raised £70.62 for AMEND with my cake sale today. Thank you to all who gave so generously, I hope you enjoyed the cakes!" Thanks for your continued support Tara.



Want to Fundraise for AMEND in 2019?

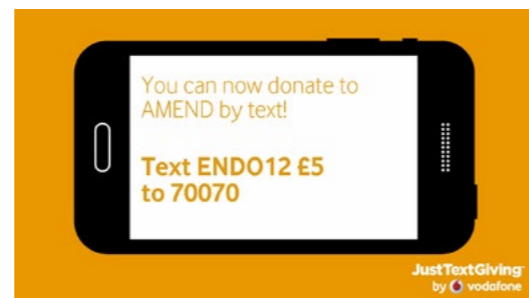
AMEND has places at a number of annual fundraising events, including the British 10k London Run in June each year. Keep an eye out on [our website for more information on opportunities](#)

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 donate to AMEND via JustTextGiving, but only until March 2019 when it closes. 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.



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](#).

Coin Collection Boxes

If your coins are weighing you down, why not order one of our free coin collection boxes from our webshop? At 9cm3, these cute little boxes come flat-packed and easy to post out, and are simple to pop together. Collected coins can then be banked and donated to AMEND. Order from our website: <https://www.amend.org.uk/product/coin-collection-box/>



DontSendMeACard.com

If like many people, you are trying to cut down on your use of paper and save trees, why not try ecards? AMEND is registered with DontSendMeACard.com where you can use a selection of e-cards and then donate to AMEND the

Easy fundraising



cost that a paper card would have been. There are e-cards for birthdays, Christmas, Valentine's Day, Easter, Father's Day, Mother's Day and to say 'thank you'. Visit <https://www.dontsendmeacard.com/charities/14bWJ>



Unity Lottery

By playing the Unity Lottery, not only do you stand a chance of winning a weekly prize of up to £25,000, but

you are also supporting AMEND! AMEND receives at least 50p in every £1 spent on lottery tickets

through Unity. For more information and to buy tickets, you can either request a leaflet from Helen, or alternatively, visit: <http://www.unitylottery.co.uk/>

AMEND Website Shop

If you prefer paper Christmas cards, need a T-shirt, fleece or baseball cap, or want to give someone a small gift such as a keyring, why not take a look at our [Website Shop](#)? All profits from sales of merchandise go to support AMEND's work.

