

# Newsletter



## IMPORTANT DATES

**Celebratory Black & Gold Ball, London (22nd September)**

**Regional Meetings (various dates – see pages 4-5)**

**Annual Patient Information Day 2019, Sheffield (May 11th)**

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## Jo's Blog

I am sat at home today writing this, a fan trained on my rapidly swelling ankles, regularly damping down Dave the Beagle, and otherwise, simply melting in the unrelenting heat wave that has hit the UK this summer.

Weather apps promise that this unbearable heat will relent this afternoon with torrential rain and thunderstorms, but I wait to be convinced and predictions are that the heat will soon return anyway. It's important in these circumstances to ensure that your medication is stored appropriately as many may be temperature-sensitive. Even those that aren't usually affected may in fact be so by extreme heat, so it's always worth checking the leaflets just in case.

A month ago now, it was in such heat that I joined the team of 13 AMEND members and supporters



to climb the 3 famous peaks in Yorkshire. We had passed the flaming Saddleworth moor on the drive up which added to the fear factor, but despite the weather's best efforts, we all made it and raised plenty of funds for AMEND. You can read more on this adventure in this

newsletter. Many other folk have been undertaking a wide variety of fundraising activities too, and we celebrate all their achievements too. This fundraising is so important as it enables AMEND to undertake various projects to hopefully improve the life of our members. One such project is the development of our Regional Volunteers, who were recently recruited and trained to begin setting up and facilitating small, friendly and informal patient get-togethers, possibly in your area. We are excited at this new venture and are very grateful for the 8

volunteers so far who were recruited in just 48 hours earlier this year. There's more news on this inside. Finally, it's time to address the elephant in the room that is Brexit. It is becoming clear that there are potential health-related risks associated with the type of Brexit deal that the UK and EU come to. There are some precautions you may be able to take now, to protect yourself against these potential threats, and we have listed these for you inside.

Best wishes to all!

*Jo*

## CAN YOU HELP?

**Project Rollercoaster for Young Adults at Alton Towers (6-7th October) – see page 6**

**MEN2B Patient Experience Film – see page 8**

## UPCOMING EVENTS

### 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. If there isn't an event near your 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:

**Tyne & Wear** – Sunday 16th September 2018

**Essex** – Saturday 6th October 2018

**East Anglia** – Saturday 6th October 2018

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.



### Black & Gold Ball, London 22nd September

Come and dance the night away at AMEND's birthday party celebration!

Saturday 22nd September is the date. The venue is the magnificent listed Ballroom at the Amba Hotel above Charing Cross Station. Tickets are £80pp (£75pp when bought as entire table of 8) and include a 3-course dinner with 1/2 bottle of wine per person and dancing until late. What a great way to celebrate AMEND's 15th birthday! You can buy your ticket(s) now via [our website shop](#).

## ROUNDUP OF RECENT EVENTS

### AMEND Annual Patient Information Day 2018



The National Council for Voluntary Organisations (NCVO) beside the Regent's Canal in London was our venue where, once again, a record number of people attended our Annual Patient Information Day. As usual there was a lovely, friendly atmosphere throughout the day, as well as information, fundraising merchandise and research tables available to peruse, and a free crèche and great food.

After welcoming everyone, particularly 1st time attendees, the day began with a 15th anniversary review of AMEND's past and future by AMEND's CEO, Jo Grey. Jo reflected on the early days when AMEND first emerged thanks to the efforts of co-founders, Liz Dent and her daughter Emily Fazal. She then moved on to summarising the growth and achievements of AMEND over the last 15 years, and a taste of what is to come in the future, including our Regional Volunteer project which is already well underway and about which you can read more in this very newsletter. In our 'Learning to be a Patient' session, we heard from Consultant Clinical Psychotherapist and AMEND Counsellor, Kym Winter on Dealing with Diagnosis. This was not just relevant for those who were newly diagnosed, but, as Kym said, was relevant every time someone with these rare, complex disorders and cancers experiences the set back of an additional diagnosis or

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

"This was a spectacularly successful professionally orchestrated day. I was so impressed."

disease recurrence. This was followed by a fascinating talk by Venetia Wynter-Blyth, as Specialist Nurse at Imperial in London who was one of a team of health professionals who developed a programme of Prehabilitation. Venetia described how her own patient cohort of oesophageal-gastric cancer patients have benefited from their individualised exercise plans prior to surgery. Prehabilitation has been shown to improve and speed up recovery after surgery and is an area that AMEND will explore in the near future for our own community.

"I thought the session on prehabilitation was excellent as it highlighted some of the practical steps a patient can take to look after themselves"

After our usual speedy Annual General Meeting and a very convivial and delicious lunch, we split into two groups, with patients (in the main) attending the 'Becoming an Expert Patient' session, and carers and partners given a chance to chat, discuss and even vent frustrations at an exclusive session for them called 'Partners and Carers Only'. The latter received an excellence rating of 88% with feedback such as, 'Partners/Carers session very much appreciated – it is good to talk!' In the other room, 'Communicating with your GP' was hosted by Dr Caroline Diacon. Several years ago, Caroline was about to become a Consultant Endocrinologist, but she changed tack is now about to complete her training as a General Practitioner; a job that will enable her to spend more time with her family. In addition, Caroline just happens to be an MEN2A patient! Who better, then, to tackle this hot topic! She teased us with a

list of emotions, such as fear and anxiety, that rare disease patients like us might experience at having to approach our GP. Ironically, the list was in fact a list from a group of trainee GPs who were asked how they would feel when confronted with a rare disease patient. Perhaps then, there are ways we can work together. Caroline shared some tips such as; use double appointments or medication reviews with your GP to educate them about your disease, make friends with your practice pharmacist to keep on top of any medication sourcing issues, write and hand out a short patient CV about yourself and your disease and medications, and ensure that your medical records can be shared with A&E professionals in the event of an emergency.

We were delighted to welcome back Dr Vasileios Chortis from University Hospital, Birmingham, who explained how a Multidisciplinary

"You do have a wonderful group of patients (followers?) who were genuinely interested, and interactive. It was a complete pleasure to talk to them." Speaker

Team (MDT) works, using the UHB Adrenal Service MDT as an example. This was followed by AMEND's Trustee and Professor of Endocrinology at Imperial in London, Karim Meeran, speaking about Getting Involved in Research. Prof Meeran emphasised that association between 2 things does not mean that one caused the other or vice versa, and that, in many instances, it is actually poverty that influences research results. Using the example of his current research comparing different types of corticosteroid, he explained how research questions develop and how clinical research trials work.

Later in the afternoon, the attendees

split further into specific disease groups for MEN1, MEN2A, MEN2B, SDHx and Adrenocortical Cancer, some with patient experience talks, most with Q&A sessions and others with discussion. To finish the day we had our traditional relaxation session hosted by Peter Berry.

We would like to express our huge thanks to the following people who were involved in organising and executing such a fantastic day of information and friendship: Steve McDonald, Geoff Toon, Kym Winter, Venetia Wynter-Blyth, Dr Caroline Diacon, Dr Vasileios Chortis, Professor Karim Meeran, Dr Helen Simpson, Dr Scott Akker and Peter Berry. Thanks also to Helen Blakebrough for such excellent organisational skills and to everyone who helped to set up and break down. You are all stars! Big thanks also to Novartis UK for their patient grant to cover some of the costs of the event.

You can view the videos of the following talks on our YouTube Channel (AMEND3):

- [AMEND – Past, Present and Future \(15 Years of AMEND\)](#)
- [Dealing with Diagnosis -](#)
- [Prehabilitation](#)
- [Communicating with your GP -](#)
- [Working with your Multidisciplinary Team \(MDT\)](#)
- [Getting Involved in Research](#)

If this all sounds rather interesting, why not come along to our 2019 Information Day on Saturday 11th May in Sheffield? You can already [book your place\(s\) via the website](#).

"Absolutely outstanding day for all. Such knowledgeable speakers, and so well organised. Great to meet others with the condition too. So helpful and inspiring hearing others' stories."



## AMEND Events (cont.)

### AMEND Patient Information Day for Sporadic MTC



Thanks to a grant from Sanofi, AMEND was able to organise the first ever event for sporadic (non-inherited) medullary thyroid cancer (MTC) on Saturday 7th July. The desire for such an event was frequently expressed on the Meddies UK Facebook Group, in which we are involved, and, encouraged by AMEND MTC volunteer, Kerry Hedges. It therefore seemed timely to run this day at Friend's House in London. It appeared to be completely the wrong time of year to try to find any expert medical speakers but in the end, that didn't matter so much. We reworked the day to include a patient experience talk, guidance on dealing with diagnosis and uncertainty, a Mindfulness taster session, and an interactive workshop to explore ways for AMEND to better support this patient community in the future.

Patient, Michael Purches gave us a detailed patient experience story, which made many of us both laugh and cry. AMEND Counsellor, Kym Winter weaved her magic on the topics of Dealing with Diagnosis and Living with Uncertainty, as well as treating us all to a superb Mindfulness taster session, when several people became so relaxed they almost dropped off to sleep! In the workshop session, we asked everyone to think about their journeys with MTC in relation to what worked well, and what didn't. Our 'to do' list from this includes:

- Educate GPs about MTC
- Provide easier access to information on clinical trials
- Improve access to guidelines and specialist centres for patients
- Develop simplified information for friends and family
- Provide information on sharing medical records
- Campaign routine referral to patient groups and other providers of emotional support
- Explain differences in surgeons and access to data on surgical volumes
- Improve information on medications and side effects

We have already made a start at addressing some of these points and will continue to develop our MTC

"Brilliant, thank-you"

information resources and support services over the coming years. Overall, it was a lovely event; however, we were all very sad that Kerry Hedges had become too ill to attend. To cheer her up, we all took part in her Showercap Challenge and sent her the resulting picture which she enjoyed immensely. Sadly, Kerry died soon after the event and you can read her obituary later on in this newsletter. She was, and will be, greatly missed. We hope to hold another event in 2019, potentially in conjunction with our Annual Patient Information Day on Saturday 11th May, so if you have sporadic MTC, watch this space.



"Thanks ...for organising a high quality, social and informative experience."

## AMEND Projects



### REGIONAL VOLUNTEERS

We are thrilled to be able to launch our Regional Volunteers with this newsletter. Our 8 volunteers were recruited within approximately 48 hours of advertising the vacancies on social media. All have attended training at AMEND HQ and are now busy planning their

first regional meetings for AMEND members. This is a project we've wanted to do for years and it's thanks to the Big Lottery Fund that we can now introduce you to our 8 new Regional Volunteers!

## AMEND Projects

### CHARMAINE CHANTLER (THE NORTH EAST) –

Charmaine was one of our recent Yorkshire 3 Peaks Team. Based in Newcastle, Charmaine has MEN1 but strives to maintain an active lifestyle. She says, 'I'm so proud to now have an active role within AMEND. They have helped me in so many ways so I'm extremely pleased to be able to give something back.'



### JULIE FAYERS (SUFFOLK)

Julie lives in Ipswich and will therefore be covering Suffolk. Together with family, friends and colleagues of her late husband, Julie has been involved in a phenomenal fundraising effort that is ongoing. About her new role, Julie said, 'Becoming a Regional Volunteer means a lot to me as it is a charity very close to my heart. My late husband and our three children were all diagnosed with MEN1. The support and advice I have been given from AMEND has been of great comfort and I would like to enable peer support for others who find themselves in similar situations.'



### EMILY FAZAL (YORKSHIRE) –

Emily is already well known to AMEND from her roles as co-Founder and as a Trustee for many years. She explains that, 'Having been diagnosed with MEN1 in 1998 and living successfully with its ups and downs ever since, I feel that now is the time to support other local AMEND members.'



### MELINDA HICKS (THE SOUTH WEST) –

Along with other members of her family, Melinda was diagnosed with MEN1 in 2016. Intrigued by the condition she became an 'information gatherer' of all things MEN1 and AMEND has always been the main source of this information. She says, 'AMEND members have given me a sense of strength when everything seems so overwhelming. I hope in some small way I can give something back to this amazing group of people.'



### SHIRLEY MANDER (WARWICKSHIRE)

Shirley has MEN1 and is an Occupational Therapist working in acute settings throughout Warwickshire. She explains her hopes for her new role: 'My motivation to undertake this role is driven from my experiences both on a personal and professional basis, I am a very caring person, socially active, easily approachable, a good listener, and want to share my knowledge and give my help to support others through these regional meetings at a local venue and on a more regular basis.'



### GEOFF TOON (LEICESTERSHIRE)

Geoff is an adrenocortical cancer (ACC) patient. His disease was responsible for his medical retirement from his job of 25 years as a Physical Education Instructor for Her Majesty's Prison Service. Now in remission, Geoff says, 'I hope to bring patients old and new together and help to understand



this very unusual condition. I am proud to be part of AMEND and look forward to supporting other AMEND members.'

### GILL UNDERHILL (LEICESTERSHIRE)

Many of you will already know Gill from her extensive involvement in AMEND as a Trustee of many years, conference involvement, or help at the Annual Patient Information Days. Gill has MEN1 and is very much looking forward to developing the support group in the Leicestershire area.



### TARA WATKIN (ESSEX)

Tara is 'keen to help others on their journey with rare endocrine disorders' after the diagnosis of her 7 week old baby, Asher, with MEN2B in late 2017. Relatively new to AMEND (and MEN), Tara knows how useful contact with other patients and parents in similar situations can be.



The role of our Volunteers is to facilitate localised peer support rather than be a singular provider of support & information themselves. They will therefore be organising periodic meetings within the areas they cover, so that anyone locally can attend and meet other patients for support. Information resources will also be available at these meetings to take away. Check out the Events section in this newsletter or on the website to find out what's happening in your area. If your area is not covered and you are interested in becoming a Regional Volunteer, please contact Jo at the office. Full training and kit are provided.





### PROJECT ROLLERCOASTER – Looking for Workshop Participants



Project Rollercoaster will explore the thoughts of young adults with MEN and produce information resources and support services tailored to the 13-24 age-group. This project is funded thanks to all those who gave to the 2016 Big Give Campaign and to The Lakehouse Foundation who provided match funding.

We will be holding a workshop for young people (aged 13-24 plus a parent/guardian) at Alton Towers theme park on Saturday 6th October (with a free day in the park on Sunday 7th) to find out what young people (and their parents) need from us. Participants' travel costs will be reimbursed by AMEND and overnight accommodation at the Park is also provided. If you are a young person or a parent of a young person, please consider getting involved. This is important work but it should also be plenty of fun! For more information [visit our website](#) or contact Jo Grey in the office as soon as possible.

### PROJECT RESEARCH ROADSHOW



Throughout the next year, AMEND CEO, Jo Grey, and NET Patient Foundation CEO Cathy Bouvier, will be visiting researchers around the UK who are working on neuroendocrine tumours and their genetic syndromes. At the end of the road trip we will be producing a joint report which will be shared with our members, along with an outline of our plans to try to raise some significant funds to support important research like this. We need to understand these tumours better to be able to treat them in the best way according to the individual patient... and we need to do more to help! We have already completed the following two visits:

#### Francis Crick Institute – Medullary Thyroid Cancer and MEN2

On a beautifully sunny but very hot Friday in April, Cathy and I took a trip to the fabulous new Francis Crick Institute building which rises strikingly behind St Pancras Station in London. Luckily for us, it has superb air conditioning! We were here to meet Professor Neil McDonald, Group Leader of the Signalling and Structural Biology Laboratory, and Postdoc, Rakhee Chauhan. Neil and Rakhee research



the MEN2-causing RET gene and were the recipients of an AMEND Research Award in 2015 towards the costs of their work to better map the molecular structure of the RET gene and to identify potential new MTC therapies. This they successfully did, and 2 new potential therapies are now being further assessed

as potential future therapies for metastatic MTC. This work also led to the team successfully bagging an additional 5 years of funding to continue their research: "In-depth exploration of the mechanisms of RET oncogenesis". This next level of work focuses on the fact that not enough is yet known about *how* RET causes MEN2, nor about how interactions between different DNA changes (mutations) cause a MEN2A or MEN2B phenotype. So, this is what Rakhee's current work is trying to understand, and she is now working with a number of UK hospitals, including Great Ormond Street Hospital, to collect blood samples from patients with MEN2 which will be tested to identify the



detailed interactions of mutations in DNA in each patient. It is hoped that the results will lead to further, more individualised treatment options in the future. It was a truly fascinating day which also involved a tour of this most impressive and modern facility. We even saw the MEN2B Drosophila (fruit flies) that have been genetically engineered to have MEN2B to aid research! A convivial lunch followed and we left buoyed with hope for the future and delighted at the choice of our first Research Roadshow visit. Thank you to Neil and Rakhee for their hospitality, continued interaction with AMEND and for all their research efforts into MTC and MEN2. You can read more about the

Francis Crick research that AMEND contributed to on page 9 of the April 2017 newsletter and on pages 5 and 7 of the August 2015 newsletter.

#### University College London – Varied Neuroendocrine Tumours (NETs)



We had a very interesting morning with the research team at UCL, led by Prof Tim Meyer and Dr Chrissie Thirwell. The team shared with us the work they are doing in NETs, including work on:

1. Defining the Immune landscape. It was amazing to hear that to do some genetic profiling on 1 patient costs £500!
2. Circulating Cancer Cells. This is a fascinating area that looks at cells in the blood stream that can be both prognostic and predictive. NETs are a problematic group of cancers as they evolve and change.
3. Liquid biopsy is another area of study and this looks at the DNA of any circulating cancer cells.
4. NET Epigenomics. This is looking at the molecular level of the tumours. Understanding how and why they form in the first place.

Find out where we go to next on the Research Roadshow journey in December's newsletter!



## MEN2B PATIENT EXPERIENCE PROJECT

We were delighted recently to receive a grant from the Society for Endocrinology to redevelop our patient experience film on MEN2B. Currently, MEN2B experiences are incorporated in a joint film for both MEN2A and MEN2B. Given the significant differences between the two syndromes, particularly with regard to the earlier onset of medullary thyroid cancer (MTC) and the considerable gastric issues experienced, the time felt right to better define the two disorders separately.

If you are in the UK and would be interested in participating in this project, please contact Jo.

## AMEND ATTENDS

*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.*

While it's been quiet on the conference front since the April newsletter, there is plenty to look forward to before December's!

### European Society for Paediatric Endocrinology (ESPE)

Jo has been invited to give a presentation at the European Society for Paediatric Endocrinology (ESPE) in Athens, Greece in September as part of her work with the European Reference

Network (ERN) for Rare Endocrine Conditions. She will give a talk about MEN1 and Pituitary Tumours in Children during a special ERN symposium. Pituitary tumours in children are extremely rare, even in MEN1, but a number of AMEND members have been able to help give a patient perspective to the presentation. Thanks to all those who have helped with this. It is hoped that this sort of work by the ERN will improve patient care and treatment throughout Europe, although AMEND's long-term involvement and the benefits for the UK are under question due to Brexit.

### British Endocrine Society Meeting (BES)

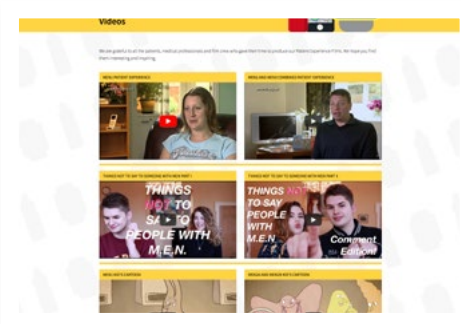
AMEND will travel to Glasgow in Scotland this November to attend and exhibit at this valuable annual endocrine conference. This year we have also submitted two research abstracts on behalf of EMENA using the data from the Quality of Care Survey and may therefore have a poster or two to display. The BES also provides a great opportunity to network with our colleagues from other endocrine-related patient groups to find out how we might work together as well as how can help and support one another.

### European MEN Alliance (EMENA) General Assembly

AMEND will be attending the 2nd General Assembly (AKA an AGM) of EMENA in Munich, Germany in October (no, not during the Oktoberfest!). The General Assembly will address all things regulatory to do with the Alliance, while an Annual Meeting afterwards will discuss the completed Quality of Care survey and plan for the upcoming Quality of Life survey.

## General News

### AMEND WEBSITE – WHAT'S NEW?



- A revamped Videos section where you will find the top videos of interest, together with more straight-forward links to the films on YouTube of our Annual Patient Information Day talks
- Simplified route to information on the diseases that AMEND covers from the main menu
- New Research Opportunities section to help connect patients to research and clinical trials
- New Our Projects section to help inform about and recruit volunteers for AMEND's projects

### NICE DECISION ON VANDETANIB FOR MTC

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

Earlier this year we learned that the TKI therapy, cabozantinib had been approved by NICE for routine use by the NHS in the treatment of MTC that has spread or which is inoperable. This was after a consultation process in which AMEND submitted a response using input from many patients with MTC. The same consultation included another TKI drug for MTC called vandetanib. We have learned that there will be a second, separate consultation for this in the autumn. We are therefore unlikely to learn

whether or not vandetanib will be made available for NHS use like cabozantinib until early 2019.

### THE BREXIT EFFECT

The true effects of Brexit (positive or negative) have never been and are still not known. Much hinges on the actual terms of the Brexit deal: hard, soft, or no deal – which is it to be? With regards to healthcare, the UK has been the home to the European Medicines Agency (though not for much longer), but also to many healthcare professionals and researchers from other EU countries. In addition, many drugs that our members need are made in other European countries or have ingredients from overseas that are covered by EU trade agreements and EU regulations. Below are some important points for information, to consider and possibly address personally where appropriate.

### Drug Availability

The rules, regulations and trade agreements surrounding the production and movement of prescription drugs and ingredients around the EU are far too complex to summarise here. With the reworking of many of these being required now, many organisations are warning of potential shortages of drugs, including insulin and steroids (although there has been recent news that the Pharma giant, Sanofi, is currently stockpiling insulin itself). Clearly, this is situation is extremely worrying and pharmacies are currently discussing stockpiling too to address this potential threat.

**What can you do?** Together with other patient groups like ADSHG, we recommend approaching your GP to request repeat prescriptions of at least 3 months' worth of medications. Submit additional repeat prescription requests regularly anyway, and be sure to store any additional medications



appropriately so that they are protected from temperature extremes.

### European Health Insurance Card (EHIC)

The EHIC is a symbol of the EU reciprocal healthcare agreement, the future of which is now uncertain. This agreement entitles travellers and holidaymakers to free or reduced price state healthcare in the event of an emergency while in other EU countries, but not repatriation. While the existing agreement may remain in place until December 2020 thanks to a proposal by the European Commission, what happens after that date is not yet known.

**What can you do?** The EHIC was never a replacement for good travel insurance and travellers were always advised to have both. Arranging suitable travel insurance will therefore be more important than ever. Unfortunately, if the UK loses its access to the EU reciprocal healthcare agreement, you can expect insurance premiums to rise by approximately 10-20%. This will be on top of already commonly expensive premiums for patients with pre-existing conditions. Shopping around will be more important than ever, but a good place to start is [our website](#)

Undoubtedly, there will be updates on the situation and Brexit's likely effects on healthcare over the coming months. We will try our best to keep you informed, so please keep an eye on your email inbox, on social media and on the website.

## UK Research Registry For MEN1 & Pancreatic Neuroendocrine Tumours



The Registry is now up and running and already collecting patient data for use in research! Here is an excerpt from the Patient Information leaflet:

*The main purpose of the study is to establish a national database of patients with endocrine and metabolic disorders. This information can be used to try to identify dietary, environmental and therapeutic factors that can influence these problems. These conditions are due to over-production or under-production of hormones. Hormones are produced by glands, and can cause endocrine and metabolic conditions when they are not regulated normally. This is because disturbances in hormones can affect the body's metabolism, resulting in different disorders that include those of the digestion, bowels, weight, blood pressure, heart, kidneys, bone, sexual function, mood, thirst, and breathing... The aim of this study is establish a national database of patients*



with endocrine and metabolic disorders, as this will help to: 1) provide important clinical information that will help us to understand the epidemiology, natural history and genetic causes of these diseases; 2) understand the use of investigations and how effective certain treatments are; 3) formulate clinical practice guidelines that will improve patient care; and 4) further our understanding of the mechanisms underlying these disorders. We wish to collect medical and other information about people who have endocrine and metabolic disorders, and their relatives. This information will be stored on the Endocrine Registry and made available for researchers to use where appropriate. This work is funded by the Medical Research Council (MRC), Wellcome Trust (WT), National Institute for Health Research (NIHR), Kidney Research UK (KRUUK), European Union (EU) grants, NIHR Oxford Biomedical Research Centre (NIHR OxBRC), and Marshall Smith Syndrome Research Foundation.

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](#).

### EMENA Quality of Care Survey



Thank you to everyone who completed the European Quality of Care Survey produced and

distributed earlier this year by the European MEN Alliance, of which AMEND is a founding and active member. The data is being analysed and has already been used to submit two abstracts for consideration by the Society for Endocrinology for the British Endocrine Society meeting in November. We hope to share more on this in the next newsletter. Additionally, EMENA will be working on developing a European Quality of Life Survey for patients with MEN later this year. Please keep an eye on the website and social media as to when this launches and you are able to take part once again.

### 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](#).

We were so very sad to learn of the recent death of Kerry Hedges from sporadic medullary thyroid cancer (MTC), aged 49. Kerry lived in Kent and had originally been a nurse for many years before her disease burden meant that she had to medically retire. In fact, she had been dealing with MTC for over 20 years and had been due to participate in a clinical trial but rapidly became too unwell to do so and sadly died peacefully on 14th July surrounded by her family. Her oncologist was in the process of applying for the TKI, cabozantinib, when she died. There is a sad irony to this, since Kerry was such an important and enthusiastic participant in AMEND's work to respond to NICE in late 2017 in an attempt to retain two important drugs in the fight against MTC; cabozantinib and vandetanib (that she had already taken previously). Kerry provided a very strong and emotive personal story to support the mainstream availability of these drugs, despite NICE's proposal to remove access. Together with other submissions and negotiations, Kerry's testimony was key in helping to persuade NICE to grant a licence for access to cabozantinib through the NHS. You can read Kerry's My Story article in our December 2017 newsletter. Kerry was also the inspiration for AMEND to organise the first Information Day exclusively for sporadic MTC patients in the UK on 6th July, to which she had hoped to come. Sadly, she was too ill to attend but was delighted to see a photo of the participants collectively taking part in her Shower Cap Challenge. Many attendees knew Kerry from her work in moderating the UK MTC Facebook Group (UK Meddies – Medullary Thyroid Cancer), where she was a warm, wise and welcoming presence to everyone. In the words of her brother, Radford, Kerry had 'a



constant wish to do anything she could to help fellow MTC sufferers and spread hope and strength'. She certainly achieved that and will be dearly missed by all who knew her. Rest peacefully Kerry.



**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.**

### AMEND 'Bosses' the Yorkshire 3 Peaks!

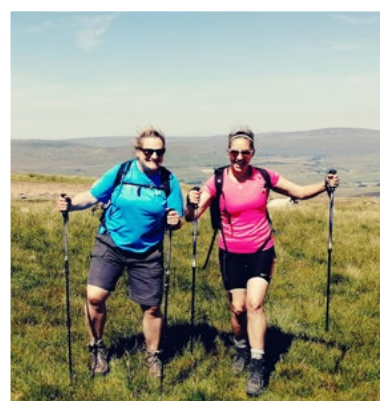


Back in June, 13 intrepid climbers undertook the Yorkshire 3 peaks challenge. This challenge was organised exclusively for AMEND as part of our 15th Birthday activities and celebrations. The Yorkshire Three Peaks, in the Yorkshire Dales, represents a challenge for the keenest of walkers. To scale three mountains in two days is no mean feat and provides an exhilarating and demanding trek in some of the most spectacular countryside England has to offer. This fundraising event was a tough, bespoke (AMEND-only) fundraising weekend, made harder due to the hot weather (over 30 degrees) and lack of shade. AMEND CEO and team member, Jo Grey, wrote the following: 'After our first night of camping where the wind made sleep fitful, 13 intrepid explorers set off at 8am on Saturday 30th June to tackle Ingleborough, ascending from the steep side, involving some serious rock climbing up the outrageously named 'Humphrey Bottom' (it got called worse things!). After a



## Fundraising (cont...)

long and increasingly hot descent (which included another smaller and unwelcome ascent), we stopped for our lunch while under the shade of a wall and some trees, then set off again in 32 degree heat to take the long ascent up Whernside. At the top – a howling gale that threatened to blow us over the edge! We found the summit marker but no shade over a wall where at least there was respite from the wind for a short break, before a stepped and increasingly steep and dangerous descent needing intense concentration. By this time, leg muscles were very tired and it is a wonder that none of the team fell. Thankfully, everyone was down safely by 6:30pm and we walked the last few hundred metres back to our campsite for a welcome shower, tea, cake and dinner. Painkillers and an early night were needed for most as there was another 8am start on Sunday 1st July. The next day we approached Pen-y-Ghent from the steep, stepped side which looks impossible to ascend on first glance. We were lucky that the temperature was only around 28 degrees that morning as there was plenty of vertigo-inducing rock climbing needed to scale this



mountain, but the views and the gradual descent were worth the effort. To celebrate our achievement, we all sat together in a field, drinking tea and eating cake, before taking our final team photo. Despite the sore muscles and

aching joints, everyone agreed that they had enjoyed being part of our small group and getting to know their fellow trekkers. There was less of a consensus on whether or not they had enjoyed the climbing experience, but everyone was very pleased to have survived and to have raised almost £15,000 in the process! Here are a couple of other quotes from two other members of the 3 peaks team:

**Charmaine Chantler** - 'The Yorkshire Three Peaks challenge was quite possibly one of the hardest things I've done in my life. The heat (around 32 degrees) made it all the more challenging. If it had been a weekend away that I'd booked just for 'fun' I would



have turned around and went home! The generosity of the people who had sponsored me and the others in the team are what really kept me going. I met some of the most amazing, wonderful people that weekend and although it was incredibly tough I wouldn't change a thing. I feel honoured to have shared that weekend with the best team mates I could have wished for and all for an AMAZING cause. To say it was emotional would be an understatement! I swore I would never do anything like that again. But if I was asked to do it again, would I? Of course I would!

**Laura Jones** – 'The Yorkshire 3 Peaks really was a weekend to remember! It was very challenging, particularly in the extreme heat & difficult sections to climb, however the team spirit supporting one another when it got particularly tough was wonderful! Thank you to the group for encouraging me up those steep sections, you definitely got me through it! Finally, thank you to everyone who sponsored me / the team, we are so grateful and what a difference your donation will make! #TeamAMEND'



### Andorra Ultra Beast Spartan Race

Ed Curtis and Fin Dixon went above and beyond with the challenge they set themselves this year. Please read about their amazing achievement which has left us all in absolute awe of them. Thanks so much for your fantastic fundraising. We have loved watching your training updates and pictures of the race day itself on your [Instagram page](#). We are wondering how you could top this achievement but think you really do deserve a rest for now!!

'It's 28th December 2017, Fin and I have just had a fantastic Christmas, full of celebrations, wining and dining. Having enjoyed these festivities, we were feeling rather motivated for the new year, so motivated in fact that we wanted to set ourselves a challenge for 2018. Something that would really push us further than we had experienced before and give us the opportunity to raise money for two charities very close to our hearts, British Heart

Foundation and AMEND. It was on this day that we discovered the Spartan Ultra Beast series. We were immediately enthralled and knew that this would be a great challenge, so we signed up for the Andorra Ultra Beast Spartan Race in mid-June 2018.

What is the Spartan Ultra Beast Race? It's a 30-mile trial run, with over 50 obstacles to complete. Fin and I had never done an obstacle course race before nor run over half-marathon distance, so we knew we had our work cut out and would have to get training straightaway. From early January we started running twice a week as well as going to the gym 2-3 times a week alongside our competitive hockey seasons. Given the nature of the race, a mix of obstacles and long distance running, we had to become patient and light on our feet but remain strong enough to complete all the obstacles, or face many sets of the painful obstacle failure punishment; 30 burpees.



Fast forward a month and we faced our first speedbump. Fin had been carrying a shoulder injury for a few years and an opportunity arose to have some long awaited surgery. The result of this was that he faced a month off his feet and despite the surgeons optimism, his physio thought that attempting to do a Spartan race in June was a touch ambitious. To add to Fin's pain, I soon realised that I did not like running as much as I first thought so Fin also had to deal with me whining daily about training. Fin, being the trooper that he is, soldiered on cautiously and with some luck we both reached our target of completing a 30-mile run with a month to go before race day.

The weekend of race day finally arrived and we were in great spirits when we flew out to Andorra; we both felt in a good space and we were just shy of raising £2000, smashing our original target of £1500. However, our smiles soon disappeared as a wave of anxiety hit us at the Ultra Beast race briefing. We soon realised how difficult the race was going to be; this year's course would see us climb 3500 metres and we would be dealing with single figure temperatures in the morning. The race organisers were expecting a drop-out rate of around 70% with the average time to complete the course at 14 hours. As we tucked into what must have been our 100th bowl of pasta of the week that evening, we nervously started discussing whether we were actually going to be able to finish the race.

### RACE DAY

Despite the concerns the night before the race, we woke up raring to go and determined that we would get around the course whatever it took. Our heat started at 8am and it was about 6 degrees. The first 2 hours of the race did not have many obstacles but instead was almost all made up of climbing steep ski slopes. After this we dropped into the valley and face a barrage of obstacles, including wall climbs monkey bars and weight carries. Once we completed these, it was back to climbing steep hills with the odd obstacle dotted here and there. Just before halfway, we faced what was by far the hardest obstacle of the day, a 3km circuit where we had to carry a 15kg concrete block and if that wasn't tough enough, the first 1km of this was straight uphill. After

passing the 15mile mark, we started to feel the effects of the endless hills. I was cramping every time we stopped for an obstacle and Fin's knee, which had been troubling him since his return to running post-surgery, was forcing him to walk the high-impact downhill sections of the course. It was at this point, we decided to split up and I tried to avoid cramp by pushing on. We briefly saw each other again at the bag drop where we could change some clothes and take on some more substantial food, but after this it became a lonely grind to the finish line as we spent the last 4-5hrs battling by ourselves. However, we knew that we had made it into the final 10 miles with a good time, well inside the cut-off point, so we were confident that we were going to finish. Despite this, the last couple of miles were probably the toughest, mainly because the marshals cruelly told us we only had 1 to go, but also because the race organisers very kindly saved a nice steep hill as well as 5 tough obstacles for the end. With both of us running on empty in the final mile and with cramp creeping up

on most muscles in our body, we can thank purely the desire to finish for getting us over the line. Emotions were running high as we finished, both Fin and I thought about who we were running in memory of, Fin's grandad Maurice and my uncle, Chris, who were our inspirations for the challenge. The realisation that we could finally have a beer after 6 months of hard work both training and fundraising soon cheered us up! We also received an extra surprise after finishing the



race. It turned out that we had run very quick times and had come 4th and 1st in our age group category.

So after 30miles run, 50 obstacles completed, 3500m climbed, 70,000 steps, 8000 calories burnt and countless blisters, was it worth it? ABSOLUTELY.

We must not sign off without a few thank yous. Firstly to the companies that donated and sponsored us; Budgy Smugglers, TRIBE and Bateman's Sports. Thank you to both charities, our families and our Instagram followers for the support throughout training and race weekend, and finally, thank you so much to everyone who donated - you fuelled our motivation throughout and ultimately helped us raise a total of £2,560.22!!!!

### Edinburgh Marathon



Dan Akarca ran the Edinburgh marathon back in May for AMEND. Here is what he had to say about the event:

"On the 27th May 2018 I ran the Edinburgh Marathon on behalf of AMEND raising just over £1300. I struggle to put into words just what it was like to cross the line knowing that this money would be put to such

a great cause. Thank you to all that donated, it means an incredible amount and the entire family are so grateful. I wish the very best for all those supported by the kind work of AMEND. In the slim chance someone else out there would like to do the same, here are some photos of the event."

### Nick Fayers Memorial Fundraising

AMEND member and MEN1 patient Nick Fayers sadly died in December 2017. Since then, his family and friends have undertaken some extraordinary fundraising activities and below, his wife Julie, daughter Hannah and work colleagues at Barnes Construction explain how some of this fundraising has been achieved.

#### Julie Fayers

As a devoted wife and mother of three wonderful children the last three years have been tough. In 2015 my husband was diagnosed with a lung NET and metastases to the liver. It then became apparent that my husband together with our three children all suffered from MEN1. After a courageous battle my husband sadly passed away in December 2017.

Nick was a prominent character within the local construction industry and over 450 people attended his thanksgiving service. It soon became apparent to me that he was very well thought of within the construction industry and there were several colleagues and friends who wanted to do all they could to help us as a family and to keep my husband's memory alive. We therefore set up a committee to raise funds and awareness of AMEND, a charity which I have called upon many times to give me advice and support. It has been a busy year so far and we have raised a staggering £23,000 to date. We have achieved this impressive figure by carrying our

various fundraising events including a quiz night, football tournament, corporate golf days, corporate dinners, dress down day, a charity walk and my youngest daughter also managed a skydive. Within the committee we have also set up a twitter account for our big blue piggy which is a large piggy bank that travels around East Andlia



attending events and visiting various companies. You can follow his progress by visiting @BigBluePiggy on twitter.

We have other events planned for the coming months such as a curry night, race night and casino night and we are continuing to work together as a committee to develop more fundraising ideas. We have planned a Fundraising dinner and live auction to be held in January 2019 in memory of my husband and to celebrate our fundraising achievements over the year. As a family we have been overwhelmed by everybody's generosity. We continue to strive to raise awareness of MEN1 and hopefully this money will go some way to support anybody affected by these heredity conditions.

### Skydive

Back in April, Hannah Fayers took part in a skydive in memory of her father Nick. Here is what she had to say about the experience.

'At 4:16 AM, on the 20th December 2017, I felt an indescribable pain; a pain that hurt every piece of me



## Fundraising (cont...)

and seemed to fill the whole room hurting everyone in it. My Dad had peacefully passed away after almost two years of suffering with neuro-endocrine cancer.

The cancer had stemmed from a rare hereditary condition called MEN1 (multiple endocrine neoplasia Type 1). A condition that my brother, my sister and I all share.

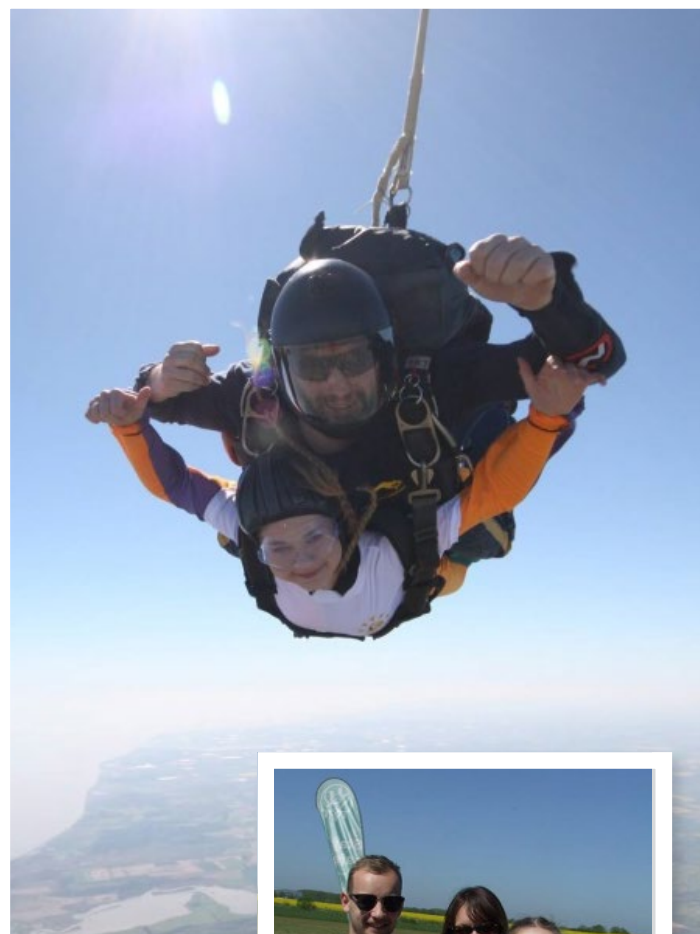
Losing my Dad is the worst thing that could have happened to me and we are all left with a hole in our lives that will never be filled.

Although this is the toughest time in my life, I felt motivated to push myself to live life to the full and do something to make Dad proud.

On the 6th May, I took myself out of my comfort zone and jumped out of a plane at 13,000 feet high to raise money for AMEND. AMEND has helped my family so much throughout the past two years and I felt it was important to do as much as I could to support them and others who may find themselves in a similar situation to me.

Through the kindness and generosity that I received, I managed to raise a staggering amount of £2,500. I did the skydive in Dad's name for not only our family but for anyone else affected by MEN1.'

*A very big thank you to you all for your fantastic fundraising at such a difficult time.*



### Great East Run

The Barnes Group Ltd will take part in the Simply Health Great East Run on Sunday 16th September 2018, and have 18 runners taking part in this Half Marathon in Ipswich, all wearing the AMEND colours. They should get noticed. They will be raising funds and awareness of MEN1 for AMEND as part of their fundraising for The Nick Fayers AMEND Fundraisers group. You can support the team via their [Virginmoneygiving page](#).

### London Marathon 2019



AMEND has just one place in the iconic London Marathon every 5 years! After a slightly competitive process involving multiple excellent applicants, we are delighted to announce that our London Marathon runner for 2019 will be AMEND member and MEN1 patient David Hawley. You may remember David from our previous newsletter where we reported on his marriage in October last year to his now wife, Alex. The pair decided to make a donation to AMEND for each wedding attendee in lieu of the traditional wedding favours. If anyone would like to sponsor David, please visit his [Virginmoneygiving page](#)  
*Good Luck with the training David!*



### Royal Parks Half Marathon



AMEND currently has 3 people running the rather beautiful Royal Parks Half Marathon this October.

If you wish to sponsor them please use the following virgin money giving pages.

[Emily Barber](#)

[Francesca Hunt](#)

[Gary Flint](#)

### Can't stretch to a marathon yet?

Why not try a half?! We have 2 spaces left in this event if you wish to take part please contact Helen in the office ASAP as they need to be filled by the 24th of August.

### It's a Rock 'n' Roll Riot!

MEN1 member, Melanie Tiernan and her husband, Andrew, held two fantastic Rock 'n' Roll Riot fundraising events recently. The first, a Rock 'n' Roll Riot, was held on Sunday 27th May in Louth which raised an amazing £1300 for AMEND. In the wee hours after the event, musician Andrew said, 'What an amazing time thank you to everyone who helped make it possible. I'm suffering now as I ended up drumming for 4, yes 4 bands.' Melanie, who is a fan of Shaun Williamson, had hoped that the AMEND Celebrity Patron would be able to attend the event, but unfortunately it was not to be. She was chuffed, however, to receive a video from Shaun wishing everyone well for the event. A further £280 was raised at their second event on 3rd June; a beer and music festival at the Heanage Arms in Hainton. Thank you to Andrew, Melanie and everyone else involved in these events. We hope you all enjoyed yourselves!



## 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.

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



**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!

### Coin Collection Boxes

If your coins are weighing you down, why not order one of our free coin collection boxes from our webshop? At 9cm<sup>3</sup>, 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](http://www.dontsendmeacard.com)



### DontSendMeACard.com

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

## Cookery Corner

If like Jo, you have a glut of courgettes (zucchini) this summer, then this is the refreshing and healthy recipe for you!



### Courgette, feta and mint frittata

#### Ingredients

- 2 medium courgettes
- Handful fresh mint leaves
- 1 small onion
- Olive oil for shallow frying
- 8 medium free-range eggs
- Good pinch cayenne pepper
- 60g feta
- Fresh chilli (optional) to serve

#### Method

1. Grate the courgettes into a bowl. Reserve a few mint leaves, then roughly chop and add the rest to the courgettes. Season well. Finely chop the onion, then stir in well.

2. Heat a large frying pan with a little olive oil and add the courgette, mint and onion mixture. Fry for 5 minutes until softened.
3. Heat the grill to high. Beat the eggs in a bowl with the cayenne pepper and a little seasoning. Crumble the feta, then stir about two-thirds into the eggs. Pour into the pan, letting the egg flow evenly through the courgette mixture. Cook for 4-5 minutes until the egg begins to just set on the base, then put under the hot grill and cook until just cooked through and golden.
4. Scatter the remaining feta over the frittata with the reserved mint leaves and the sliced fresh red chilli, if you like. Take the pan to the table and cut into 4 to serve.

Source: *Delicious magazine*