April 2018
Issue 57

AMEND Newsletter

Association for Multiple Endocrine Neoplasia Disorders

HAPPY 15TH BIRTHDAY AMEND

Contents

JO'S BLOG

As I write we are just 3 ½ months into 2018 and yet it's been non-stop! Our 15th birthday year got off to a cracking start with the launch of our fantastic new website in January together with a new information booklet, Working With Your Medical Team. February saw the publication of an AMEND article on Quality of Life & Prognosis in MEN2 in the medical journal Endocrine-Related Cancer, the participation of our newest Trustee, Joel in Rare Disease Day by publishing his online article 'Why I'm Not a Hero', and AMEND initiation into the Endocrine European Reference Network as an European Patient Advocacy Group (EPAG). In March AMEND took part in the International NET Cancer Alliance (INCA) summit followed by the European Neuroendocrine Tumour Society (ENETS) annual conference, chatted about MEN to 2nd year medical students at University College London and began organising AMEND's first Patient Information Day for sporadic MTC in July and our new Regional Volunteers project, Project Connect. Now we're looking forward to our big Annual Patient Information Day and AGM on 12th May, to climbing the Yorkshire 3 Peaks in June/July and to dancing the night away at our Birthday Black & Gold Ball in September. Something tells me it's going to be hard to top 2018!
Read on for more information on all of the above, and get in touch anytime.

IMPORTANT DATES:

- AMEND Annual Patient Information Day, London (Saturday 12th May)
- Patient Information Day for Sporadic MTC, London (Saturday 7th July)
- Yorkshire 3 Peaks Fundraising Challenge (29th June – 1st July)
- Celebratory Black & Gold Ball, London (22nd September)

AMEND Events

AMEND Annual Patient Information Day 2018

Time is running out to register for AMEND's 2018 Annual Patient Information Day (#APID2018) on Saturday 12th May in London. Like last year, the event will welcome all those affected by MEN, SDH and ACC. There will be a nostalgic look back at 15 years of AMEND, together with plenty of other interesting and useful sessions including disease-specific sessions with patient experience talks and a relaxation hosted by our own Counsellor, Kym Winter. This year we have two fascinating new sessions:
1. Pre-habilitation and its beneficial effects on recovery from surgery, presented by Venetia Wynter-Blyth, the leader of the PREPARE programme at Imperial in London.

2. Partners & Carers only, where Kym Winter will help our long-suffering 'other halves' to explore common issues when caring for someone in the family with these conditions.

To view the full programme, please visit the webpage.

As usual, there will be a crèche to take care of the little ones and, to celebrate AMEND's 15th birthday, a drinks reception to round off the day. The AMEND Annual General Meeting will be held at the start of the lunch-break as usual. This is a chance for all members to come along and learn more about the behind-the-scenes AMEND and express their opinions by voting. And finally, there will be an opportunity for those with MEN type 2a and 2b to donate a small blood sample to researchers who are working on developing new treatments for medullary thyroid cancer. This is a wonderful opportunity for attendees to contribute to research that was part-funded by AMEND in our 2015 round of research funding, although you are under no obligation to do so!

We do hope you can join us and your fellow patients and family members for what is always a great day! Book your places now via the website.

We know from our member surveys that, although tickets for this event are free, people may still experience difficulties when it comes to the cost of travel to attend. If you feel that this applies to you we would invite you to contact Jo Grey to discuss accessing our Hardship Fund (UK travel only).

AMEND Patient Information Day for Sporadic MTC

We are delighted to be able to organise another Patient Information Day this year on Saturday 7th July in London. Although we have provided information resources and support services for patients with the non-genetic (sporadic) forms of medullary thyroid cancer for some time, this will be the first event that we have held specifically for this rare patient community. There is a vibrant Facebook community, many of whom have already registered and we look forward to meeting them. This event has been made possible thanks to a grant from SanofiGenzyme. The programme for the day is as follows with expert speakers to be confirmed shortly:

- Dealing with diagnosis and living with MTC
- Surgery for MTC
- Dealing with complications of surgery (parathyroid gland and laryngeal nerve injury)
- Therapies for disease that has spread
- Q&A session

To book your free tickets to this event, please visit our website.

Please note that this event is currently only for people affected by non-genetic / non-MEN related MTC.

Projects

2018 is a very busy year for our project work.

Project Connect: Connecting Patients with Rare Endocrine Conditions

Project Connect

Connecting patients with rare endocrine conditions

Thanks to a grant from the Big Lottery Fund Awards for All scheme AMEND is now working to set up a Regional Representative Volunteer programme. This is something that our members have wanted us to do for years, so it's great to finally get this project underway. We're pleased to report that recruitment of volunteers was rapid and training will take place this summer. Our Regional Representatives will be situated throughout England and will be responsible for organising local area meetings (formerly AMEND Roadshow meetings) as opportunities for mutual support and the sharing of experiences. We hope that our volunteers will also be able to attend their regional specialist centre's MEN outpatient clinics to spread the word about AMEND resources and services with patients attending their appointments. Keep an eye on our website and social media for updates on this project over the summer.

Project Rollercoaster – Looking for Workshop Participants

Project Rollercoaster will look into the issues that concern young adults with MEN and produce information resources and support services tailored to the 13-24 age-group. These can then be housed on our new age-appropriate section of our new website. 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. Participants' travel costs will be reimbursed by AMEND and overnight accommodation at the Park is 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

NET Patient Foundation

AMEND and the NET Patient Foundation are joining forces this year to gather as much information as possible on current and planned research into neuroendocrine tumours (NETs) and syndromes of NETs like MEN. In addition, we will be questioning patients over the summer on where they feel research needs to focus. In this way, we want to gain a better picture of the current research landscape and the types of projects that we might fund in the future for maximum impact.

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.

European Neuroendocrine Tumour Society (ENETS) Conference

Jo Grey, AMEND CEO, and Louise Breen, AMEND Specialist Nurse Trustee and Advanced Nurse Practitioner (Neuroendocrinology) at Guy's & St Thomas's Hospital were fortunate to be able to attend this busy meeting, thanks to funding from the ENETS and INCA. INCA held a special symposium on the last day of the conference to present data from their 2017 survey on unmet needs of NET patients. It was a reasonably well attended session although much of the discussion was not particularly relevant to AMEND members. The most important part of this conference for us is often the session on current and upcoming research projects and clinical trials.

Jo Grey, left, and Louise Breen, right, at the ENETS meeting

Although there were many projects presented, only a few were relevant to our patient community (mainly for metastatic pancreatic NETs such as those that may occur in MEN1, but also for metastatic phaeochromocytoma/ paraganglioma). Consequently, we have ensured that links to the information on European clinical trials relevant to our members are available via our website.

Endocrine European Reference Network (ENDO ERN) General Assembly

This 3-day meeting in beautiful Gothic city of Lubeck in Germany (the home of marzipan!) was a real eye-opener to the phenomenal work being done by the Endocrine European Reference Network (ENDO ERN). I was recently appointed as a European Patient Advocacy Group representative to this ERN, helping on the Genetic Endocrine Tumours Main Thematic Group, alongside EMENA colleague, Petra Bruegmann from the German group covering MEN1. For more information on ENDO ERN, see separate article in the General News section.

INCA Summit

INCA International Neuroendocrine Cancer Alliance

Once again the annual meeting of the members of the International NET Cancer Alliance (INCA) was held just before the ENETS meeting, making this an exhausting week. There's was plenty of important governance work to do this year, particularly revisiting the Alliance's strategy and holding the Annual General Meeting. Many INCA member organisations displayed posters highlighting their NET Cancer Day activities. Unfortunately, AMEND's participation on November 10th last year was minimal and mainly limited to social media activity. We hope that 2018 will be different as there will be survey results more applicable to genetic NET syndromes that we will be able to focus on and share. Otherwise, it was a great opportunity to network with colleagues from across the globe and a privilege to see how far INCA has come, specifically, the inclusion of a combined ENET/INCA Symposium on the last day of the conference.

General News

AMEND
Association for Multiple Endocrine Neoplasia Disorders

General Data Protection Regulations (GDPR) Deadline!

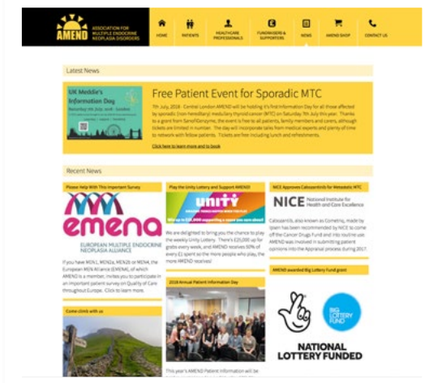
On May 25th 2018 new and more stringent regulations surrounding Data Protection come into force. On that day, AMEND will delete our old mailing list and will have shredded all former paper membership records. If you became a member of AMEND prior to January 2018, you must re-register as an AMEND member to retain your membership and access to your membership benefits, including our newsletters, counselling service and voting rights at the AMEND Annual General Meeting.

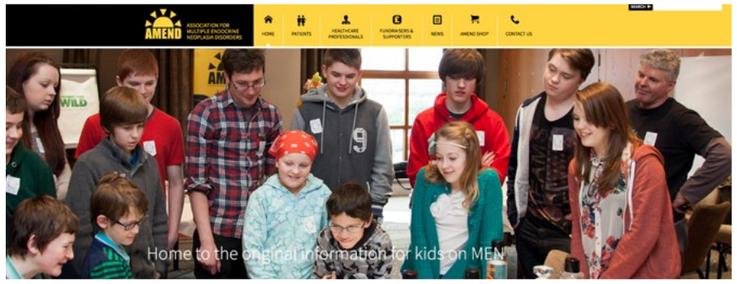
GDPR, as it's commonly referred to, has meant that we have had to review what personal information we store and how we store it, amongst other things. As a result, we have reduced the amount and detail of patient information we store. Specifically, we must now ask for your express permission to do so.

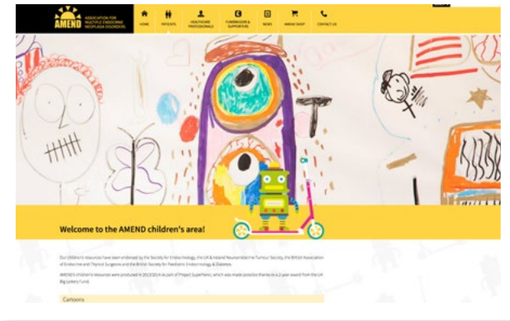
To re-register and remain a member of AMEND, please re-join via our website:

AMEND's New Website – Worth ` the Wait!

We are thrilled with our new website and the feedback so far has been wonderful. As well as better reflecting AMEND's striking branding of black and gold, there are now new sections according to age group where age-appropriate information is available, and will expand as our 2018 projects progress. The Age 5-12 Information section already houses our kid's resources, and the Over 21 section our adult resources. When resources are developed as a result of Project Rollercoaster, these will be included in the Age 13-21 section (currently this is a duplicate of the Over 21 section).

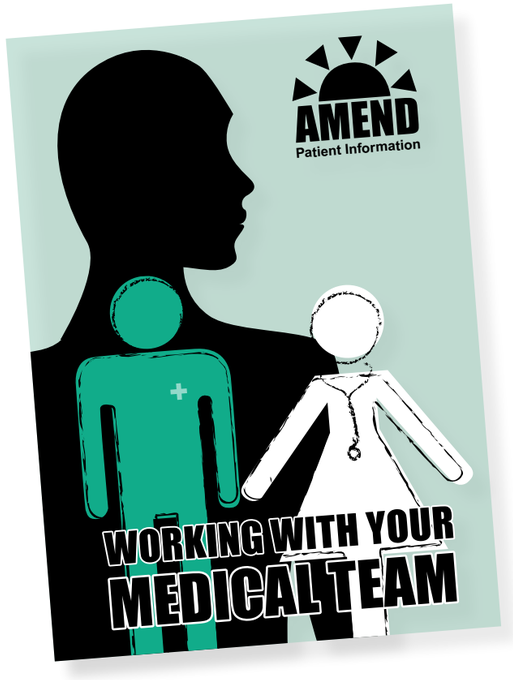






The site is now mobile-optimised for use on your phone or tablet. A new shop for merchandise and for NHS resource ordering is much easier to use now that it comes with a shopping cart facility, meaning you can order more than one item at a time! Additionally, all our emotional resources can now be accessed through one tab. Finally, the membership registration process is GDPR compliant and means that members are more likely to receive our e-news and updates rather than losing them to the spam folder. We hope you enjoy using it as much as we enjoy playing with it behind the scenes and sharing links to pages on social media!

We thank our wonderful funder (who wishes to remain anonymous) and James and Nic at Gulp Creative for their patience and hard work to bring this new incarnation of our vital website to life!



New Publication

Working with Your Medical Team is based on the earlier title called Choosing your Medical Team. The new publication explores in more depth the concepts of the multidisciplinary team (MDT) and centres of expertise, and gives you helpful hints on communication, how to get the most out of your appointments, and what to do when things go wrong. There is also a helpful glossary. Huge thanks again to the AMEND Medical Advisory Team who are always so helpful with our information production. You can view and download the booklet for free from the new website:

NICE Decision on Drugs for Medullary Thyroid Cancer (MTC)

As some of you will know, in 2017 the National Institute for Health & Care Excellence (NICE) opened a consultation into its proposed decision to remove access to the tyrosine kinase inhibitor (TKI) drugs, cabozantinib and vandetanib, for use in MTC that has spread and is inoperable. Together with other groups, AMEND submitted a strong and emotive response from a patient point of view. We thank all those patients who answered the plea on Facebook to submit their individual responses for inclusion in our submission.

At the time of writing, NICE has approved the routine use of cabozantinib by the NHS (subject to an agreed price restriction). This is clearly excellent news and we thank NICE and Ipsen for working together to come to make this possible. We now look forward to hearing the result of price negotiations for vandetanib in due course. Keep an eye on the website and email inboxes for further news on this result.

AMEND Becomes an EPAG on the ENDO ERN

Jo Grey has become a European Patient Advocacy Group representative on the Endocrine European Reference Network (ENDO ERN), joining the Main Thematic Group #4 for Genetic Endocrine Tumour Syndromes. This is in addition to being an ePAG representative at ERN for rare adult solid cancers (endocrine domain), providing a vital opportunity to be a link between the two ERNs.

With a focus on ensuring that high quality expertise in the treatment of rare diseases is provided as close to the patient as possible, these networks will work to share expertise, improve diagnosis, educate care providers, facilitate research and link up with other ERNs with the ultimate goal of improving patient care.

ENDO ERN's Adult Chair, Professor Alberto Pereira, said, 'The creation of these ERNs fulfils a long-felt desire. Patients' associations kept on lobbying for it: care in case of rare diseases must become more accessible and information more transparent. In 2011 the EU passed a law stating that every patient suffering from a rare disease is entitled to the best treatment, even if the expertise is in a different country.'

ENDO ERN serves as an opportunity to advance the treatment of people with rare endocrine conditions while significantly improving the patient experience. With a strong base of collaboration and partnership, the network will span paediatric and adult care ensuring all patients are able to benefit and the lessons learnt will benefit the endocrine community in Europe and beyond.

For AMEND to be part of ERNs provides an ideal opportunity to contribute to joined up efforts to truly achieve that which cannot be achieved alone.

Rare Disease Day 2018

AMEND Youth Trustee, Joel Russell-Winter submitted a written piece and video to the Rare Disease Day campaign website and was featured as Story of the Week on February 6th. Here's his written story:

Why I'm Not a hero

From what I've read, it seems the biggest thing people take away from their rare disease, is the new perspective on life that it brings them. Being appreciative of every day that we aren't in hospital, thankful for the hours that we can forget about our conditions, and savouring every moment when we feel like a hero. Except – I don't want to be called a hero, and I'm going to tell you why. But before we get into that, here's a bit about me.

The genetic lottery I won has given me the rare disease; Multiple Endocrine Neoplasia (M.E.N) Type 1. Now I won't go into too much detail and provide every clinical fact of how M.E.N can affect different individuals, but the general pub-fact-quick-fire M.E.N round would go something like this;

There are three distinct types handily broken down into Type 1, Type 2 and Type 3.

It's a genetic disease passed down from your parents, with a flip-of-a-coin 50/50 chance of you getting it.

It causes your body's endocrine system – glands, to develop tumours. Glands that are affected produce an abnormally high amount of hormones, which as you can imagine, causes a variety of symptoms. (If M.E.N was a person, it'd be that annoying co-worker who goes above and beyond their pay-grade doing more work than they should, not communicating with the rest of the team, and in turn ruining the whole streamline, inter-dependent system, that's been doing just fine without them.)

Now I can't talk on behalf of everybody with M.E.N, and am only qualified to tell you about my own experience, so here it is.

I was diagnosed, along with my younger sister (4 years between us), around the time I started A-Levels. Even though I was under 18, my care was handed over to the adult services - because of NHS budget cuts I imagine. Anyway, this meant having to be driven or catching the train into the arse-end of London every time I had an appointment, blood test or scan. Which are pretty frequent occurrences with M.E.N. I was bounced around from one consultant to the next, all of which needed 'gentle reminding' about what M.E.N actually was, at the beginning of every appointment. But after scraping through my A-Levels, and being transferred to the absolutely amazing St. Bartholomew's Hospital (fun fact: it's the building Sherlock jumps off in the finale of Season 2), getting an incredible & consistent consultant, I got into University. Go me.

Then, around halfway through my second semester of my second year of study. I was called into hospital for an unscheduled meeting with my consultant, who started showing me pictures of my last MRI scan. He poked and pointed at the black and white image, which I was told was the inside of my pancreas - although it could have been an x-ray of a Christmas turkey and I wouldn't have known the bloody difference, but I digress. He continued explaining what was going on with my pancreas; I diligently listened until he explained…

"So unfortunately it has turned cancerous, and spread."

Now, you know in a war film when a grenade goes off next to the protagonist head, and there's that high-pitch noise accompanied with mumbled voices? That legitimately happened to me as he uttered that sentence. The line after that could have been "I'll give you £500 if you hop on one leg and whistle the theme tune to The Office" and I wouldn't have remembered a word of it. So as I stumbled out of that consultation room, I turned to my Mum and said the only thing I could – "well, f-"

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Anyway, as I'm sure any person who has/had cancer will tell you, the world does this really selfish thing and carries on turning as normal as if you haven't just found out you have cancer??? Weird right? This meant spending the rest of my second year;

1. Organising deadline extensions.
2. Worrying that I wasn't going to wake up from my surgery. Or, if I was going to wake up, that it'd be right in the middle of them performing surgery.
3. 3. NOT taking advantage of

all the student booze deals because they told me not to drink before my surgery. I was terrified of breaking this rule because, well, see point number 2.

Luckily I managed to get my deadlines sorted, threw together a basic plan of what University work I was going to do when, and shovelled down health supplements until I sounded like a human rain stick.
Then, in June of 2016, I went in for my Whipple procedure to remove the cancerous tumours from both my pancreas and liver.
They knocked me out like a light and I slept the whole way through it. I woke up, bleary eyed, feeling fantastic. I know it may seem like I'm being sarcastic, but I woke up and felt like I could knock Tyson out in boxing match. There was no pain and my whole body felt incredible – I was on Cloud 9.
One word – drugs. Lots and lots of drugs.
As the painkillers wore off, it turned out that my body did not feel incredible, there was lots of pain, and Tyson could have exhaled sharply and knocked me to the floor.
The recovery process while I was in hospital was steep, and easily the most physically demanding thing I've ever had to do. I'll go into it in a bit more detail in the video, but after nearly two years' post-op, my stomach muscles are still pretty weak, and pain attacks can occur completely randomly.
Okay great but stop self-indulging, get on with it, why don't you like being called a hero?
Well, a few reasons. Ones which I'd love to hear the rare disease community's thoughts on.
For me, the term 'hero' detracts from the struggle and fight that every one of us goes through. When I think of a hero I think of Superman, or a Marvel protagonist – an infallible alpha-human who reacts impeccably in every situation, someone who was born with power and strength above and beyond their natural ability.
People with rare diseases are the exact opposite of that. We've literally started off on the golf course of life with a handicap, and we are not on track to be scoring a birdie.
It's all to do with expectations. I know some would argue that you only get called a hero once you've earned it, but then what about when you have something else go wrong down the line. Something painful, and difficult, but not as painful and difficult as the thing that earned you that 'hero' title from. You're expected to be able to deal with it. "Well if you can deal with that big terrible thing, then surely this is nothing but a bump in the road!".
Whereas if the same thing had happened to someone who had no previous bad experiences, they'd be showered with sympathy and affection.
Sure, there is a certain element of truth to this concept, practice makes perfect right? Surely the more you go through the more resilient you become to it? Well, yes and no. As I'm sure you all agree, there are some days where you feel like you could beat Conor McGregor in a fistfight because of the struggles you've been through. Then, there are others days, where if someone doesn't thank you for opening the door for them, you feel on the verge of a breakdown. Because some days all I'm doing, is managing. Just as I'm sure you are, and sometimes that's the best we can do, just, manage. Manage the feelings of bitterness towards people who smoke for 83 years but die of old age. Manage the feelings of helplessness, because no one else you know understands the hidden struggles that your condition imposes on you. Manage the anxiety that the smallest amount of irregular pain sends your mind into unhealthy spirals.

Then, in June of 2016, I went in for my Whipple procedure

sometimes that's the best we can do, just, manage

I can't shoot lasers out of my eyes; yes, I could probably pump out a bit of concentrated radioactivity after the amount of X-Rays & gadolinium MRI scans I've had. Sure, I can be incredible on some days. But being a hero is about not making mistakes, having complete control over your emotions when things are tough & laughing in the face of adverse odds.
To me, it sounds like having inhuman responses, to the most visceral human experiences.
So, no. I'm not a hero, and neither are you. We are normal people. And that is what makes our extraordinary actions all the more impressive.

To watch Joel's video blog that accompanied this piece, visit the Rare Disease Day website.

Joel's Vlogs

As well as excellent articles like that above, our Youth Trustee, Joel, produces a regular vlog (video blog) that is often humorous and relevant to those with genetic endocrine conditions. Recently these have included 'What Not to Say to Someone with MEN' parts 1 and 2, and 'MRI Scans: what actually happens?! A 10-step guide' . You can subscribe to Joel's YouTube channel here.

AMEND Cartoons Go International!

Late last year we were contacted by the Dutch MEN Patient Group, Belangengroep MEN, who were interested in AMEND's cartoons for children on MEN. Thanks to their translation help and the artistic adjustments by the original animator, James Munro, we were able to produce cartoons for the group with a new voice-over in Dutch and translated animation text. We would also like to thank Paul Kavanagh from legal firm Dechert LLB in London, for pro bono work on developing a Copyright Licence for use in these situations.
If you know of or run a patient group that would be interested in producing a translated version of our cartoons, please get in touch with Jo Grey for more information on lead times and production and Licence Fee costs.
You can visit our friends at Belangengroep here.

You can watch the Dutch cartoons here

With thanks to AMEND MEN2a member, Sondra and to Cathy for putting pen to paper to tell us about an extraordinary genetic journey (no spoilers – read on!).

One Thing Led to Another- Discovering Family Through DNA Testing

By Sondra

After my mother passed in July of 2016 I started going through old family photos and happened to come across a photo of my great-grandfather's headstone. His name was James Hazzard Been and he had lived from Sept. 1868 to March 1902 (died age 33). Of course I was curious about the unusual name Hazzard and I wondered if he had died due to being MEN2A positive. My mother had almost died from a heart attack when she was 66 due to an undiagnosed pheochromocytoma and we had not yet been diagnosed with MEN2A. After our family diagnosis of MEN2A it was assumed her father was also MEN2A positive since he had died from a heart attack (assumed pheochromocytoma) at age 64. My grandfather's brother died at age 24. I started some online research of my mother's side of the family and happened to come across FamilySearch.org. This is a free web site with collections of family trees, genealogy records, and research resources maintained by The Church of Jesus Christ Latter-Day Saints. As I like to tell family and friends, one thing led to another and I discovered my mother's Been/Bean/MacBean family tree all the way back to 1267 in Inverness, Scotland.
I was fascinated with all that I was finding as I researched our family tree. I learned that the name Hazzard is an English/French name meaning gambler or a brave foolhardy man willing to take risks. I learned that we were the first settlers of Tennessee back in 1768. As I studied our family tree looking at date of births and deaths there was no rhyme or reason as to who had died of what. Some members died young and some died old. Just as with our modern day family of MEN2A positives, some have died young due to MTC and some have died in their 60's of assumed undiagnosed pheos. I remained curious but was at a loss how to pursue the MEN2A family tree.

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In 2017 my brother decided to do an ancestry DNA test through Ancestry.com. He received a very interesting report confirming our Scottish ancestry on my mother's side and our French ancestry on my father's side. The

report explained how this testing could lead to discovering 2nd, 3rd, and 4th cousins but he just filed the report away after reading it. Then in late 2017 someone emailed my brother to say their DNA showed we might be 3rd cousins. Since I'm the "keeper" of the family tree my brother passed the email on to me. I contacted the person though emails and shared where our family tree met theirs. Their great-grandfather is my great-grandmother's brother (on my mother's side of the family).

Again, after back and forth emails, one thing led to another. I finished one email with just a short comment that I was not only curious to research our family tree and identify family members, I was curious because we had a rare genetic disorder on our mother's side of the family. To which she responded that they also had a genetic disorder on their side. After further emails and names we discovered that we had actually met before at several Thyroid Cancer Survivors' Association (ThyCa) annual conferences. We confirmed the MEN2A , codon 609 diagnoses in both families. Needless to say we were all amazed to discover all of this and to realize what a small world it truly can be at times.

I am so happy to not only discover more family members but to have a big piece of the puzzle, where the MEN2A common ancestor is in the family tree, solved at last. I truly feel that our family has been blessed with all this new information.

My new cousins, Jodie and her sister Cathy have added their part to our story of finding each other.

what a small world it truly can be at times.

By Cathy

Posted to the MTC FB page January 15, 2018

The most amazing thing has happened in my life this weekend. Since being diagnosed in 2009 I have always thought I was the de novo [first] case in our family. My mother was adopted and didn't have thyroid issues and my father was never in my life, but I know he lived to age 89. And we thought both of his parents, my grandparents, died of heart attacks. My sister, Jodie, recently got involved with Ancestry.com, mainly to search for my mother's birth family. After actually finding my mother's birth sister (they are both now deceased but spent their entire lives trying to find each other after they were both put into an orphanage at a young age) my sister started to explore my dad's family.

On my dad's side of the family she found that our grandmother, Anna, died from hypothyroidism instead of a heart attack in 1969. She dug a little deeper and found a "possible cousin" in Denver. She contacted a lady named Sondra who, during the course of exchanging several emails, happened to mention a rare genetic cancer in her family. Long story short, Sondra is none other than the Sondra who is a contributing member on the MTC and AMEND sites. We have met at conferences in Denver and Dallas and Chicago. We have both commented on many of the same posts in the past. She is indeed my 2nd or 3rd cousin and we are descendants from a brother and sister born in the 1860's who both carried the same family ret mutation. My little de novo world has suddenly exploded into a gigantic tree with many people on Sondra's side with the same c609y mutation as me.

I have often wondered about the odds of one of the genetic members on this site being unknowingly related to someone else in the group.

My grandmother was one of 6 children and we have no idea if any of the rest of them or their heirs have MTC. So I doubt my grandmother, Anna, or my father ever even knew they had MTC, but they surely did. My great-grandfather and Sondra's great-grandmother were two of eleven siblings. With the generations that followed, we could have a huge tree of RET c609y.

As far as my MTC branch of the family tree goes, I have one sister and one son. Neither of them have the RET mutation, so it definitely ends with me. Fortunately.

I have often wondered about the odds of one of the genetic members on this site being unknowingly related to someone else in the group. Now I wonder who else of us may be related. Thanks to the genealogy efforts of my sister and Sondra, I now have a much larger family than I ever imagined and I know where MTC came from for Sondra and me! What an amazing world we live in!

My sister, Jodie, recently got involved with Ancestry.com, mainly to search for my mother's birth family.

UK Research Registry For MEN1 & Pancreatic Neuroendocrine Tumours

Updated Links to Research Studies

One of the most interesting sessions at the European Neuroendocrine Tumour Society (ENETS) annual conference is the research session, where we get a run-through of current studies. While many are irrelevant to our patient members, there were a few that were relevant. You can now find links to information on these European studies (MEN1 pNETs, phaeo/para) together with links to a number of important surveys on our website.

PLEASE HELP WITH THESE IMPORTANT SURVEYS

2018 seems to be turning into the year of the survey! It is easy to give in to 'survey fatigue' but in fact we never share a survey that will not be useful in helping AMEND and other patient advocacy organisations as well as researchers to achieve their goals. So please do take a few minutes to complete the surveys below. Results will be shared with patients, policy makers and medical professionals to effect real change in the patient journey. Thank you!

- European Reference Network (Endocrinology) survey on Patient Information Resources: https://ec.europa.eu/eusurvey/runner/ENDO-ERN-WP-1-Patients-Survey
- European MEN Alliance (EMENA) Survey on Quality of Care for MEN in Europe: https://ec.europa.eu/eusurvey/runner/EMENA_MEN_Survey

Coming soon! A new survey on MEN1 pancreatic neuroendocrine tumours (PNETs). Keep an eye out for news on our website or via your email inbox.

Research Project on Hydrocortisone vs Prednisolone 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.

Recent Publications of Interest

These are some articles that have caught our eye over the last couple of months:

- Endocrine-Related Cancer: special MEN1 edition (2017) - http://erc.endocrinology-journals.org/content/24/10.toc (all Reviews are open access)
- Endocrine-Related Cancer: special MEN2 edition (2018) - http://erc.endocrinology-journals.org/content/25/2.toc (all Reviews are open access, including the one written by AMEND)
- European Journal of Endocrinology: SDHx mutations: beyond pheochromocytomas and paragangliomas- http://www.eje-online.org/content/178/1/R11.long (open access)
- University of East Anglia: Researchers sequence human genome using pocket-sized device - http://www.uea.ac.uk/about/-/human-genome-sequenced-with-pocket-sized-device

Fundraising

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.

Brighton Half Marathon

AMEND member Lucy Sweeney ran the Brighton Half Marathon for AMEND in February. Here is what she had to say about the event:
'It was a gloriously sunny but cold day, and luckily was before the extreme snowfall in the South which started the following week.
The run was such a beautiful route down from Brighton seafront through to Hove Lawns and I ran it in 2 hours and 43 mins which I was pleased with (and delighted to finish!) since I had my most recent op in December and had to take a 2 month break from training.
I was really proud to be running for AMEND and am looking to take part and organise a relay team for next year!'

Lucy raised over £2000 for AMEND which is an amazing total. Thanks so much Lucy!

Christmas Sale

Long time AMEND fundraiser Dorota Wozniak held a Christmas Sale in December.
"On a cold day in December, a group of enthusiastic volunteers set up a table of beautiful decorations and gifts for sale at a xmas fair in Canterbury organised by L'Arche Kent, a local charity.
My friends and I had met for 3 evenings beforehand to create the items together. We made many beautiful things and enjoyed the shared experience of creating together (along with eating cake and drinking mulled wine!).
The fair itself was a very well organised and enjoyable event with a great atmosphere. We were delighted that we managed to raise £220. Many people were interested in AMEND, asking questions and watching the MEN 1 and MEN 2 cartoons.
I appreciated the support I felt from friends and family who helped me to make the sale a success."

Thanks for all your support Dorota.

David and Alex Hawley wedding

David and Alex Hawley got married last October and managed to think of fundraising for AMEND amidst all the preparations.
"We were first introduced to AMEND by my consultant following treatment I received in 2015 for MEN1 and we thought it was excellent that a charity had been established for support and knowledge sharing for the small population of us with the condition. When my wife Alex and I tied the knot in October 2017, we decided that rather than give our guests favours, we would donate £1 for every guest attending to AMEND. My father passed away from MEN1 and we wanted to honour him on our Wedding day and thought this

was a fitting way to do it. Jo very kindly provided cards that we could put on every guests place setting to acknowledge the donation. Not only was this a nice way to inform our friends and family, it helps spread awareness. Little did we know that during the speeches, a group of our friends arranged a sweep stake for all of our guests! Each guest gave £2 with their time estimate. When the winner was announced, they graciously recommended that the money also be donated to AMEND. With the help of the Big Give over the festive season, we doubled the amount collected at the Wedding and were able to donate a further £675 to the charity! We had a wonderful and memorable wedding day and we are delighted to have been able to donate some money for such a worthy and important charity! We want to say a huge thank you to Jo and the team for all their hard work in everything they do for us all. We are looking forward to our future together knowing we have a support network to help us through any future challenges."

Thanks for thinking of AMEND and many congratulations on your wedding.

Proctor and Gamble charity awards event

Kate Petitt works for Proctor and Gamble and in February they held a community awards night presenting £31,000 to various local and UK based charities for employees who had taken part in charity fundraising. Kate kindly nominated AMEND after she took part in the London 10k run last July. AMEND was awarded £1000.
Thanks for nominating us Kate and for all your fundraising over the last few years.

Canterbury 10k run

Carol Hall recently completed her first 10k race running for AMEND. Here is what she had to say about the experience:
'I made it! My first ever 10K run on 18th March was a fantastic experience. The sub-zero temperatures just encouraged me to run faster to keep warm! It was a beautiful route along the River Stour between Chartham & Canterbury. It

helped that I know the route well (although previously from walking or cycling it) and the Kilometres seemed to fly by. Thankfully, the wind was behind us on the way back and I was very happy with my sub-1 hour time (56.34 minutes to be precise). It was great to be able to raise some money for AMEND in the process and I am very grateful to everyone who donated. The Virgin Money giving page was a very straightforward way to manage it. I am confident that the money will be used well to support people with these conditions.'

Thanks so much Carol who has to date raised over £360 with money still coming in.

Other fundraising

Anna Hudson held a charity night in January and raised nearly £350 for AMEND. Many thanks from us all.

Andorran Spartan Ultra Beast Race

On the 23rd June, Ed Curtis and Fin Dixon are taking part in the brutal Andorran Spartan Ultra Beast Race. This is a 30 mile race up and down the Andorran mountains where they will have to complete 50+ obstacles. Ed took part in the Bath

Marathon last year for AMEND famously running in his speedos. The boys are running in equally eye catching outfits for this challenge as you can see from the picture! You can follow their training updates on Instagram https://www.instagram.com/2chumsvultraruns/
And if you wish to sponsor them please visit their Virginmoneygiving page.

Good luck boys, we are loving your Instagram updates in the office.

Edinburgh Marathon

AMEND member Cerys Akarca's son Dan is running the Edinburgh marathon for AMEND in May next year if you would like to sponsor him please visit his Virginmoneygiving page.

Sky Dive

At the end of April, Hannah Fayers is taking part in a Sky Dive in memory of her father Nick Fayers who sadly passed away in December 2017.
If you wish to sponsor Hannah in her brave fundraising event then please visit her Virginmoneygiving page here. She has so far raised over £1000 –thank you very much Hannah and good luck from all of us.

Yorkshire 3 peaks fundraisers

We have a number of members signed up for the Yorkshire 3 peaks challenge in June this year. Links to their fundraising pages are listed if you wish to sponsor any of them. Thank you to all who have signed up – we still need a minimum 10 more people to take part in the trek.
For more information and to register, please visit our website.
Fundraising pages:
Crystal MacLeod
Maralyn Druce
Jo Grey
Charmain Chantler
Laura Jones

Fundraising Activities for 2018

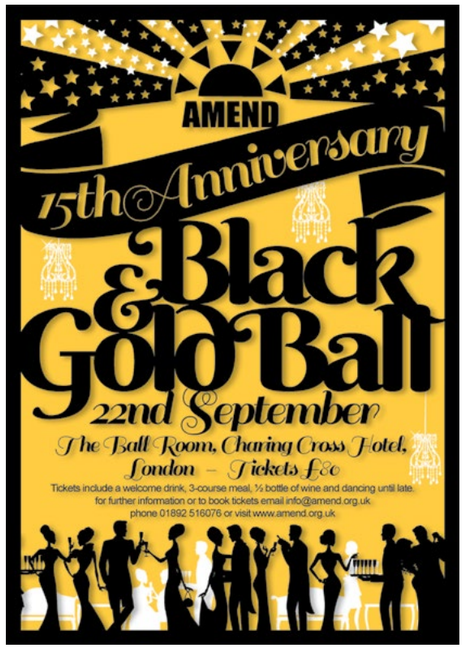
Yorkshire 3 Peaks Challenge – Desperately Seeking Trekkers!

Join our intrepid team as they tackle the Yorkshire 3 Peaks on the weekend of 30 June-1 July this year. We need a minimum of **another 10 trekkers** to join what will be a challenging, memorable but undoubtedly fun weekend fundraiser.

For more information and to register, please visit our website:

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

Black & Gold Ball, London (22 September) – Celebrate With Us!



Come and dance the night away at AMEND's birthday party! Saturday 22nd September is the date. The venue is the magnificent listed Ballroom at the Amba Hotel above Charing Cross Station. Tickets are £80pp 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

Can you help?

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

Pesky Coins 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.

Save Trees – Use DontSendMeACard.com!

If like many people, you are trying to cut down on your use of paper, 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

New Charity Lottery Initiative – 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

DONATE TO AMEND

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

Text Giving

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

CAF Donate

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

Virginmoneygiving

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

Standing Orders

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

Cheques

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

Legacies

A Legacy means that you leave a gift to AMEND in your Will. You will need to provide your solicitor with the information required to do this, which is available on our website or via the office.

Visit our webpage for more details and to download standing order forms.

Easy fundraising