

The magazine from CMT United Kingdom

Winter 2013

ComMenT

Magnetic Resonance Imaging

Strategic Plan

Core Stability



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FROM THE EDITOR

There are lots of interesting articles this issue. (As always, I hope I hear you say!)

Don't miss the article on pages 4 and 5. You may have no intention of riding a horse but core stability is a fascinating subject, and exercise is good for all of us!

The "not to be missed" article by our patron Mary Reilly and her colleagues on page 17, on the use of Magnetic Resonance Imaging, ties in with our Chairman's Column on page 6. Find the link. Keep up to date with the Strategic Plan for the future of CMT United Kingdom by reading the Chairman's Column very carefully, there is a lot going on!

Our Chief Operating Officer Karen Butcher has been her usual busy self as you will see in her 3 page report on pages 12, 13 and 14. What would we do without her? An epic, record

breaking Young People's Weekend is reported in the centre pages and there are special offers on page 7, add a fascinating view on Pregnancy and CMT, Group Reports, a photo montage of Myelin Masquerade and much more and we have a magazine full of interest.

I should like to acknowledge the help given to me in the production of the magazine by our graphics artist Tim Elwood, the "look" of the magazine would be so different without his creative ideas. Catch up with his latest project on page 18.

If you think I'm sounding upbeat, it's because that's the way I feel! There are many challenges ahead, the Government is causing all of us many headaches, but progress is being made in finding new ways to diagnose and treat CMT and that should encourage us all. Thanks for reading the magazine, if you like it, let me know; if something has been missed out let me know that too! This is our magazine; let's make it the best it can be.

Clive.



Cover picture: two mystery guests at Myelin Masquerade Ball



Can you help please?

"We are currently conducting a survey in conjunction with Professor Mary Reilly and her team at the MRC Centre for Neuromuscular Disease regarding the issues surrounding early/medical retirement from work. We are anxious to get as many respondents as possible to this survey, so if you have access to the internet, go to www.surveymonkey.com/s/cmt-and-work to complete the survey. If you'd prefer to do it on paper, just phone the office for a copy (or you can complete it over the phone if that's easier). The deadline for taking part is end of February, and we'll publish the results in a future edition of ComMenT"

ComMenT needs you!

Please send your letters, group news, feature ideas and inspiring stories to clive@cmtuk.org.uk
Deadline date for copy for Spring Edition of ComMenT will be 14th February 2014

To contact CMT United Kingdom HQ: 98 Broadway | Southbourne | Bournemouth | BH6 4EH

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ComMenT is the magazine of CMT United Kingdom. We are always interested in your views and welcome potential contributions for future editions. We reserve the right to edit material. The views expressed in the magazine are not necessarily those of CMT United Kingdom.

APOLOGY

In the Spring edition of ComMenT a major error was made. CMT was referred to, in one article, as a type of motor neurone disease. This is not the case. The error was pointed out to me and I promised an apology would follow in the Summer/Autumn edition. The apology was unfortunately omitted.

So here is a twofold apology. I am sorry that the error was not spotted, and I am sorry the apology was not in the last edition of the magazine. This is the apology that failed to appear.

Editor's note: It has been pointed out to me that there was an error in the opening line of the article by Lauren Milstead in our Spring Edition.

The line read, "Charcot-Marie-Tooth Disease... is a progressive motor neurone disease". This is completely incorrect. Wikipedia states: "Although MND (Motor Neurone Disease) refers to a specific subset of pathologically similar diseases, there are numerous other afflictions of motor neurons that are pathologically distinct from MND, have a different clinical course and should not be confused with MND, such as spinal muscular atrophy, spinobulbar muscular atrophy, Charcot-Marie-Tooth disease, and many others." We are sorry if any confusion or distress has been caused by this error.

To be absolutely clear: CMT is not a type of motor neurone disease.



To the Editor.

Dear Editor,

I am 62 and I have known I have CMT for over 50 years. At times, over most of that period, I've had sensations in the lower parts of the eyelids, where I'm sure I've been able to feel slight twitching. As I read with a magnifying glass I've always put it down to strain. Apart from my knowledge of the mechanics of CMT my knowledge of the nervous system is pretty limited and what I describe could be a completely separate issue.

Recently I've been aware of a particular sensation on the left-hand side of the jaw, about half an inch below the lower lip. Like many people with CMT I've been aware of twitches, tremors and occasionally slight cramps around the affected muscle areas, I'm sure related to further slight weakness, but this sensation feels as though something or somebody is touching that area very slightly, sometimes resulting in a slight itch. Maybe the two sensations are connected; possibly a straightforward trapped nerve.

Probably about a month ago I suddenly noticed a slight numbness on the inner side of the left thumb, presumably resulting from the stress of holding a hardback A4 size book while reading.

For nearly 20 years I've been involved in MRCP (Membership of the Royal Colleges of Physicians of the United Kingdom) work at various hospitals. Other than visual impairment I've never heard of CMT affecting anything other than limb muscles, although one lecturer did mention to his group that CMT can affect all peripheral muscles; I presumed not in a way that would result in muscle loss. As not many of the lecturers specialise in neurology this may not have been a totally accurate statement.

If anybody can enlighten me in any way I'd be grateful.

Regards,
Ian Godfrey



Riding for the Disabled

When I was a young woman, I used to ride, but I was totally unaware that I had a rare type of muscular dystrophy (*Ed. CMT was previously classified as a subtype of muscular dystrophy.*) although I'd already had four or five operations on my feet because they had grown twisted and very weak. Even though I'd already had a lot of surgery doctors were generally dismissive about the cause. It was only when I started noticing symptoms in my hands in my mid-thirties, that I insisted that my doctor refer me to someone else to find out what the problem was. My GP was among the many health professionals who had no idea why my hands and feet were weak, painful and shaky and referred me to an orthopaedic surgeon for his advice.

The orthopaedic surgeon said he thought the problem was neurological and I needed a neurologist. He guessed that the problem was Charcot Marie Tooth disease. Named after the three neurologists who identified it, it's a condition where the myelin sheath of the long nerves deteriorates causing problems with the transmission of nerve signals to and from the brain. It affects the long nerves, and therefore the hands and feet, particularly. I had to be referred to a neurologist who confirmed the diagnosis. I have very poor feeling in my hands and feet, they are weak and painful and I fall over regularly. I drop things all the time and struggle to walk any distance, my feet, lower legs, hands and lower

arms are constantly weak and painful. Some of my fingers are now stuck rigid in a curled position and won't move. If forced it really hurts. I feel like I've just walked up Ben Nevis all the time as the effort I need to use just to do normal daily activities leaves me exhausted.

The bad news is there is no cure, it also gets worse as sufferers age and all you can do is manage it. It is normally hereditary although mine wasn't inherited; it's what's known as a new mutation, an error made in my genes which can now be passed on to my children. There are tablets I take daily which go some way to controlling the pain. I can have extra pain relief except too much leaves me sleepy. Physiotherapy and occupational therapy help with different problems. I'd given up riding years ago because I became too weak and tired to look after my horses. I'd given up my work as a nurse and retrained as a social worker because it was less physical.

It was a physiotherapist who first suggested Riding for the Disabled Association (RDA). I was delighted as I'd ridden and owned horses a lot in my past. But I didn't get back on and pick up where I left off. Now age fifty-seven, I was much worse than I ever had been. My body refused to be flexible as you become when you're a regular rider. As a previous rider I knew how my body should move, but it didn't. It was

like putting wooden sticks on a moving animal; I was stiff and rigid and felt very insecure. The problem is that most of the time, if you're not good at walking you spend a lot of time sitting and lying because it's safer and as a result the muscles in your middle get less sensitive and stiffen.

I also had my mother's voice in my mind, not a supporter of riding; she kept telling me I already had one disability, why did I want to risk another? I get very tired when I need to use my lower legs and struggle to pull up horses that lean down and eat grass. I had a setback when I had surgery and couldn't ride for a couple of months so had to start again at the beginning. I'd benefitted from being led quite a lot, even though I had ridden a lot, because I was so stiff and lacking in confidence. Too much can make you a really passive rider but it was a vital stepping stone in my riding recovery.

But over the months my core muscles began to be more flexible as they had been years ago. The physiotherapist told me it would help something called my core stability and I didn't have a clue what she meant. But I can see it and feel it now. If you can imagine someone falling over in slow motion, then there is time, when you fall, to catch yourself by re-adjusting the heaviest part of your body in order to keep it upright. It involves moving the muscles around your middle so you can keep yourself

upright. That's called core stability. When you're riding though, you're exercising your trunk safely and there are many manoeuvres that exercise your core muscles and now I can feel my body better able to rectify itself when I take a tumble.

But there are two big, almost unexpected, benefits from riding with the RDA. The first is how wonderful it is to have fit and able walking legs beneath you to take you where you want. It's too easy to spend too much time home alone and just being out in the open air is a tonic in itself.

The second is the friendship. Our group, and probably most others, is a really friendly team. We sit and have tea after riding; we attend other events together and chat about riding and all things horsey plus anything else that comes up. It's also great to be able to give back and help fundraising and I'd recommend riding or helping with the Riding for the Disabled Association to anyone, whether as a rider or helper.



Chairman's Column

It's hard to believe that 3 months have elapsed since my previous "Column" was written in early June – but then, unless you're much involved with Santa Claus, the summer months do seem to pass more quickly than those at the other end of the year (dare I remind you that there are very few days left till Christmas!). Have you ordered your CMT Christmas cards yet?

For me, summer has passed quickly, not only because we have mostly had a fantastic year of warm weather – and holidays - but also because we have been busy with the revisions to our Business and Strategic Plan and all that this entails.

I was delighted to be able to invite our Group Coordinators to be our guests at the recent Board Meeting in Swindon. Regrettably, some were unable to join us, but those who did attend joined in the discussion and I believe, enjoyed their day. They saw, at first hand, how the Board functions and the sorts of important decisions which are being taken. Important decisions? In the previous edition of ComMenT, I referred to both vital research and professional fund-raising. In the research field, we have seized on a splendid opportunity to help Professor Mary Reilly with the continuation of a ground-breaking programme in her London hospital. The Board unanimously agreed to donate £10,000 to cover the shortfall in the funding required for muscle/fat scanning – a very exciting breakthrough programme which is discussed elsewhere in the magazine. (Editor's note: see page 17).

We also made a unanimous decision to go ahead with our proposed plan to employ a professional fund-raiser. The position will be advertised in relevant papers and magazines and we hope to employ a suitable candidate fairly early in 2014.

The individual concerned will spearhead our quest for external funding from Trusts and charitable foundations and be responsible for fulfilling our vision of raising:

£2 Million over the next 5 years.

Please, however, don't overlook the vital contribution to the fund-raising effort which many of our members have made. The "Awareness Month" campaign has gained us recognition in the Press and Radio and even on TV and a big **THANK YOU** is due to all who took part during September. Equally, everybody who persuaded their local store or hospital or GP Surgery Manager, for example, to display a CMT poster, played a very important part in our effort to instil a better understanding and wider appreciation of CMT.

And the money is coming in – all sorts of events have been taking place across the country and each one brings in more funds – from Masquerade Balls to Wheelchair Challenges, from Tea-parties to Cross-country Marathons, to name but a few.

At the recent Board Meeting, I asked for ideas on specific projects for which funding would be necessary and give purpose to the Fund-raiser's activities in the future. Many suggestions were forthcoming and we will be looking closely at their relative merits and needs in the coming weeks. In short, there are lots of ideas as to how we can best progress and increase the Charity's income in order to meet our mission of:

Working to support people affected by Charcot-Marie-Tooth disease

It may seem a little premature but this is my only opportunity to wish everybody a very Happy Christmas and a wonderfully exciting New Year.

With my Best Regards

Richard



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CALON

One of our members has decided to make a drastic lifestyle change! There isn't room for more than just a "taster" in this issue, but I hope to run a longer article in the Spring issue of ComMenT.

"Despite my CMT", says Paul, "I took the brave (or mad) decision to sell my house, give up my career and buy a smallholding in West Wales where I have a few chickens and organically grow lots of fruit and veg. The only source of income is the B&B, which my partner and I run from the house."

The website address is www.calonholidays.com. There are buttons on the home page for you to like the Facebook page, follow us on Twitter, read the blog, etc. Calon, which means heart, is in beautiful countryside near Newcastle Emlyn.

Calon would like to offer a 20% discount to all ComMenT readers. Please email us before booking to take advantage of this offer.



CMT and Preg

CMT and pregnancy is a delicate topic. In my parents' generation, little was known about the inheritance of CMT, but times have changed and nowadays we know about the 50/50 risk. Despite the challenges that CMT presents, I have always been of the opinion that I'd rather be born with CMT than not at all, and that CMT doesn't mean you can't have a wonderful life. I take the view that even people born with a healthy body can end up with illnesses later in life and so I accept what life gives out and try to make the best of it.

When I found out I was pregnant, I was delighted, but also a little scared. I expect that, CMT or not, most women feel the same. However with CMT there is an added complication. As we all know, life with this condition can be challenging enough, added to that the changes of pregnancy and I really wasn't sure what the next few months of life had in store for me! I was curious about how my body would manage with pregnancy, how I would get through childbirth, and, of course, would my baby be ok? I was also concerned about potentially having to explain

CMT to various medical professionals at a time when I might not be in any fit state to be explaining (i.e. in the middle of labour). Since the inheritance in my family comes from the male line, I didn't know any other CMT women who'd been pregnant, so it was a new journey for the entire family...

Well, as things turned out, pregnancy caused pregnancy related issues- such as vomiting for 7 long months - but it didn't really cause a big issue as far as the CMT was concerned. Yes, I was very tired and slept a lot, and yes, the night-time leg cramps were long, but I put this down to pregnancy itself. From about 20 weeks I started to notice increased difficulty walking and balancing, particularly on the stairs, but I'm talking about a slightly increased challenge, which continued as the pregnancy progressed, but was never completely unbearable. I did have to start my maternity leave earlier than I would have ideally liked, but I found that this made a huge difference as I could take life at my own pace with adequate rest. From a CMT point of view, pregnancy wasn't actually that bad and it was certainly a LOT better than I was ever anticipating.

In the end, I gave birth by a planned caesarean section. I elected the procedure for a few reasons, but mainly because I just didn't feel I had the stamina for a natural birth. A C-section is a major operation which carries risks, but I weighed up all the

gnancy: My Story

pros and cons for my situation and I was happy with the decision. The recovery from surgery was very painful indeed, but as I found out, other C-section mothers were able to use the strength in their legs to hoist themselves up and manoeuvre about. Without being able to use your extremities to compensate for the core in the same way, and with the falls that I also experienced, the recovery was long and hard. I even ended up having to use a wheelchair for a few weeks, but I got there in the end. I also found myself presented with a whole new set of physical challenges to overcome. Despite the fact that my recovery from the surgery was not easy, I have no regrets about any of it. I don't think pregnancy has changed my CMT either.

We don't know if our baby has inherited the condition (of course, we hope he hasn't), but we will find out when the time is right, and what will be will be. What we do know though, is that we have the most delightful, beautiful and happy little baby boy. We are so pleased to have him, and wouldn't change him for the world!

Yes, CMT and pregnancy is an issue that evokes debate, but my message is that if you want to have children yourself, then go for it and don't be afraid or put-off, you'll get through it and have the most amazing little person at the end!

Alexander Brenton-Saunders 8 months.



CMT Kids W its not a Dr



Dream Flight is a charity which takes disabled and seriously ill children to Florida for 10 days to enjoy sunshine, theme parks and Disney. Children are nominated then to just sit back and enjoy 10 days of being spoiled and treated like VIP's without having to lift a finger, sounds lovely.....

CMT Kids' adventures are NOT like Dreamflight holidays ! ;)

Our CMT Kids are not seriously ill, many don't consider themselves to be disabled by their CMT, (to be disabled means that you have a health condition which has a substantial and long term negative effect on your day to day living) . Most struggle with some activities such as running, walking a long distance, playing football, etc . However, all of them have the same thing in common – attitude! The attitude that makes you fight the naysayers, fight the pain, fight the difficulties to get on and enjoy life, and that is exactly what they do!



Our CMT Kids work hard everyday just to get through, and when they hit that climbing wall, I just wish you could all see that look of determination which comes over their faces, as they scramble and pull themselves up inch by inch, fighting to get higher and further than last year. They all have their own personal targets, which they reveal throughout the weekend and which are a constant source of motivation to them. Their pride and satisfaction when they surpass last year's achievement are almost tangible and so beautiful to watch. They all have long-term targets as well, and many of them are well on their way to achieving those by working hard at school and college and setting off on the road to independence at university. I know that the CMT related battles they fight will give them the strength to carry on. I feel so proud of them all, watching them grow and develop into strong independent young men and women.

Don't get me wrong, they are all aware of CMT and how it is affecting them, but as they talk about their struggles with AFO's or the less than helpful teaching assistant, the rest of us 'get it'! We understand on a level that no school friend or medical professional can. They talk about that look which they receive from non-CMTers when they try to explain what CMT is and why they



Weekend 2013

Teamflight!



So we climbed, we canoed, we swam, we built fires, we dressed up in very silly costumes and busked for money in the middle of Keswick whilst getting wet through! We swung, we sung, we laughed, danced and played games until it was time to leave, hopefully with enough of a boost to our CMT systems to carry us through for another year ;-)

Lessons learnt this weekend –

There's a bat in the conservatory but it won't hurt so – man up!!

When you watch the movie Thor or future Marvel creations, look out for the models created by our very own CMT Kid Nathaniel!!

When hiring a minibus to drive from one end of the country to the other, try to avoid the one restricted to 58mph!

If you're interested in joining us in future, please contact me on cmtkids@gmail.com

won't be wearing flip flops on the beach, or why they fell down the stairs at school, yet again! The conversation dissolves into squeals of laughter and agreement as stories are swapped and everyone offers solutions and smart answers to quell the pitying. They don't have to explain CMT to anyone else, because we all just accept it! We all agree that at least you can relax and just get on with enjoying the weekend when you're with your CMT Kids' friends!



Chief Operating

Where is this year going? I can't believe it's October already! The time since the Conference in April has just flown by, in a blur of all sorts - some of which I'll try to tell you about here!

The highlight for June was the International CMT Consortium meeting in Antwerp. This is the biennial scientific meeting, part funded by CMTA and the ENMC, where scientists from all over the world get together to share their findings, start or strengthen collaborations and generally network. This year's was special, because it had been decided to invite ALL the international support groups, and start an informal consortium of those too.

So on 21st June, following another meeting in London the day before, I drove to Antwerp, via the Eurotunnel - I'd not been through the Channel Tunnel before, so that was an adventure in itself. Then I drove the 150 miles or so

to Antwerp. Thank goodness for satnav is all I can say! My car has a built in satnav but it doesn't have European maps, but fortunately my husband has a TomTom one with maps for the whole of Europe built in - I don't think I'd have found the hotel without it. I'd elected to stay at a Holiday Inn Express in Antwerp, rather than the more expensive hotel being used for the Conference, so there was a 6 or 7 mile drive between the two each day.

I'd allowed myself a day for sightseeing, but it's really difficult knowing where to go, what to do (and where to park the car), when you're on your own, and the weather isn't too kind. I just admit to rather a lot of aimless driving around Antwerp! I'm sure it's a very nice city, but I was glad when some of my colleagues from

other support groups turned up at the hotel, and I had someone to talk to! I really didn't need to allow so much "spare" time!

The consortium meeting kicked off on Wednesday 24th June, with the usual high level of scientific presentations that leave my head spinning! But the support groups also got together during the same day, which was great - wonderful to put names to faces! There were people there from CMTA, CMT Association Australia, CMT France, CMT Belgium, VSN (a neuromuscular network in Holland), ACMT-RETE and AICMT - both from Italy, and a lady from Spain, where they're trying to start a



new network for CMTers. We had a good long meeting, discussing, in the main, CMT awareness, and what we can do together to improve the situation. There are obviously no easy answers; we face the same problems wherever we're based. We did agree on the same logo for Awareness Month, and to collaborate and share information wherever we can.

One topic that did crop up was how do we support people in the developing world? None of the organisations have the resources to provide on-going support, but if we could put together a database of medical professionals from some of these countries, like India and China, we could at least point them in the right direction. If anyone has any ideas as to how or where to

Officer's Report

start with this, please do get in touch.

I have to say there was nothing earth-shattering to report on the research front - advances are being made - mice, rats, fruit flies and zebra fish are used extensively in CMT research, and when CMT (or something very like it) is induced in these animals, various chemical compounds are being used to try to correct the problem - and some are working, but unfortunately would be toxic in humans. The next step, of course, will be to find a drug that will do the same job, but with less toxicity. You'll appreciate it's a long, and very painstaking process.

be granted the Hon Code Seal of Approval - this is an accreditation provided by a Swiss organisation called Heath on the Net Foundation (www.hon.ch), which provides certification to medical websites, reviewing the websites to ensure that people can trust the health-related information provided. Their Seal will appear on our homepage in due course.

So September... What can I say about Awareness Month this year? Paula decided to try to concentrate her efforts on national coverage this year, and we were fortunate that an extensive piece went on to the Press Association news-wire. It was picked up by a number of regional

papers, but also.

... Sky News! I got a phone call at about 3.30pm on Sunday, 1st September, asking if Catherine (my daughter) and I would like to be on Sunrise, their breakfast show the following morning! Well, we both quaked a bit and said



Following the end of the conference, I packed up and headed home. How come I can drive halfway across Europe without any problems, but as soon as I hit the M25, I end up in the usual traffic jam??

August was spent, as it always is, preparing for Awareness Month. It's surprising just how much effort goes into it, really - especially as Paula Hunter, our PR consultant, does most of the hard work! But there are resources to update and produce, new information to put onto the website, and all manner of odds and ends to sort out, and all of that is on top of the usual stuff that happens to keep the organisation running smoothly.

Talking of the website, we've been very fortunate to

"OK"! So we were up at 4.30am (ugh) to drive up to the Sky News Studios in West London, on the Monday. We were interviewed live by Eamonn Holmes at 8.15am! It was a very surreal experience - casually entering the "green room" to chat to Nicki Chapman and another guy (who I ought to know, but don't) who were preparing for their piece just before 8am! You can see the video of the interview on our YouTube channel at www.youtube.com/user/CMTUnitedKingdom.

Other coverage during the rest of the month was equally good - a great piece in the Daily Express (online version only) on Gary Tannahill, a double page spread in Woman's Own, featuring Nigel Holland, and Trustee Jeeta Ouston featured in a number of papers in Scotland, as

she was promoting a humongous fundraising challenge that she did on 7th September, raising £2000 along the way. Karin Rodgers was in the Manchester Evening News, my daughter Catherine was in the Bournemouth Daily Echo, Sue Ward in the Southampton Echo, Amanda and Emily Haylock were the original subjects of the Press Association piece, so they've been featured in a few different regional papers, Sabrina and Nathan Robinson in the Sunday Post in Scotland, Karen Kondo in the Coventry ? And there are probably others I've not seen or heard about.

Thank you to EVERYONE who gave their time and stories to help us spread awareness. It really does make a huge difference. Please contact Paula on paula@cmtuk.org.uk, if you'd like to help at any time.

Phew.... What a month! And the last weekend of the month was taken up with another "foreign" adventure for me - an invite to speak at ACMT-RETE's Annual Conference in Bologna! There are two Italian CMT organisations, and ACMT-RETE is one of them - and they very kindly paid all my travelling expenses too! How could I say no? So I had a lovely weekend in Bologna at the beautiful Admiral Park hotel where they held the conference. I did have my own personal translator, in the form of the fiancé of one of their committee members, who translated my talk to their delegates. They hold their conferences over three days - I don't think I've eaten so much delicious food in a long time! I adore Italian food! The highlight of my talk to them - so I was told - (which was basically about CMT United Kingdom

and what we do) was the section on our Young People's Weekends, with a number of people asking about it afterwards. They have nothing available for their young people, and several wanted to know if their kids could come to one of our events!!



And so the awareness spreading goes on.... We attended Physiotherapy UK 2013, the annual conference of the Chartered Society of Physiotherapists in Birmingham in October, and handed out hundreds of leaflets on CMT to the delegates there. Thanks to Gita Ramdharry for conjuring a brief leaflet out of thin air aimed specifically at physios. If anyone would like a copy, just contact the office as usual.

And that brings us pretty much up to date! The office will be closed for two weeks over Christmas, closing at 12 noon on Friday 20th December, and reopening on Monday 6th January 2014.

And the Annual Conference is on Saturday 5th April, at the Hilton Hotel, Swindon, right by junction 16 of the M4. The lead speaker is confirmed as Mr Senthil Kumar, an orthopaedic consultant from Glasgow (he's a great speaker), and Mary Reilly will be doing another "Q and A" workshop. Papers will be sent to members in early January, or you can download a form from the members' only section of our website.

Hope you have a great Christmas and New Year!

Regards,
Karen.





Group News



Hampshire Group

September 2013

Hello from Hampshire, I hope that you all enjoyed the summer. Seventeen of us enjoyed a farm visit to Lyburn Farm Cheesemakers, as is evident in the picture. Following a tour on a tractor trailer around fields of organic vegetables and the cows, we viewed the cheese making process and finished with an excellent supper using locally sourced food, with wine or juices, featuring their cheeses. We are now looking forward to our picnic in the New Forest where we hope to meet our friends from the Wessex Group.

We had another excellent question and answer session with Suni Narayan, the Hampshire Neuromuscular Coordinator for Hampshire. She outlined how her job was going and her aim is to work towards a multi-disciplinary clinic where we may be able to self-refer. She also felt that we should more access to Neuro Physiotherapy and hydrotherapy. Suni is a Neuro Physiotherapist so we had some good advice on exercise.

We look forward to our Christmas Lunch on Saturday 14th December 2013. If you would like to join us or come to our meetings, which are friendly and informal, please contact me. If you have a group near you go along to their meetings, you will find it rewarding. No local group? why not start one?

Terry Dean 0845 872 9514

London Group

September 2013

The inaugural meeting of the newly-formed Central London CMT Group was a great success. We met on the fifth floor balcony of the Royal Festival Hall on London's South Bank which offered superb views over the River Thames and the city skyline.

We had a good turnout—20 people in all, 15 with CMT—and what was striking was how lively, varied and interesting the group was: so many fascinating stories, perspectives and ideas.

Alex Williamson, CMT UK's treasurer was on hand to update the group on CMT matters, including news from the CMT UK executive committee meeting held a week earlier.

There was also a lively group discussion about where, when and what we all wanted the group to be—we agreed that we would try to arrange some sort of gathering in the run-up to Christmas. Details to follow.

Mostly, however, we all enjoyed meeting each other and sharing stories, experiences and support. For some attendees, it was the first time they had ever met anyone else with CMT.

If anyone would like to join our group—all are welcome—please get in touch.

John Barton 0845 013 2704

CMT North East Group

My name is **Darren Scorer**. I had an operation in Christmas 2012 and it took me months to get better, so I decided, as my health had worsened, to become the North East Co-coordinator, thanks to Karen.

I wasn't sure what was expected from me as I've never done this kind of work before. I used to be a chef but had to give it up because of the problems with my legs. The only other work I have done is voluntary at St Oswald's Hospice and I have helped there for over 6 years, health permitting. The first job I did there was on the collection line where I answered the telephones and arranged for furniture items to be collected from homes and sold in their shops. Now I sell the lottery in the fundraising department of the hospice, when I am feeling up to it.

This year Karen Butcher wrote to the people that are local CMT members and I have only had 1 small meeting so far. 2 of these people wanted a support group and 2 didn't. Lawrence Saville from Dunston said he would raise money for his anniversary, instead of getting presents and people kindly donated £250 to CMT UK. One of the ladies worked full time and said she was unable to meet until after her operation and I haven't heard from her since. I have met Lawrence for lunch and I went to see Elsie in Durham as she has been very unwell. Also Lawrence's brother is looking to get funding to write a book and a poetry competition which is being funded by an external source and all the profits will go to CMT UK.

I asked Karen Butcher to send me some leaflets which I distributed around various hospitals and doctors' surgeries round my area and I have asked Lawrence to do the same. Also I sent some to a lady named Janey Crisp who I talk to through my CMT email and she is handing some out in Wooler, Northumberland. Karen is going to give me some at the meeting to save CMT postage.

LOCAL CONTACTS

| | | | |
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| Bristol | Jon Leonard | 0845 872 9522 | jon@cmtuk.org.uk |
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| Cheshire | | 0845 872 9507 | |
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| Devon | Jonathan Chase | 0845 872 9506 | jonathan@cmtuk.org.uk |
| Dorset | Annette Masser | 0845 872 9515 | annette@cmtuk.org.uk |
| Essex | Sara Durose | 0845 013 2706 | sarah@cmtuk.org.uk |
| Hampshire | Terry Dean | 0845 872 9514 | terry@cmtuk.org.uk |
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| Lincolnshire | Tony Arnold | 0845 872 8952 | tony@cmtuk.org.uk |
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| London | Hannah Cronin | 0845 872 9510 | hannah@cmtuk.org.uk |
| SE London | Ozzie Hall-Osman | 0845 872 8954 | ozzie@cmtuk.org.uk |
| Manchester | Hazel Maguire | 0845 872 9521 | hazel@cmtuk.org.uk |

I have also written to about 10 businesses to ask for donations and I have received some forms to complete. I have to go round the other local supermarkets and ask if I can have some donations and they only do it from the local shops. I did some earlier in the year but lost the info as my pc broke. The list of the latest follows.

CMT Donations letter sent 3rd of September 2013

Iceland Foods LTD, Second Avenue, Deeside Industrial park, Deeside, Flintshire, CH5 2NW

Wilkinsons, Charity Department, Wilkinson JK House, PO BOX 20, Worksop, Nottinghamshire, S80 3YY-Response, I had to fill out a helping hands form.

John Lewis, 171 Victoria Street, London, SW1E 5NN

Tesco Stores LTD, New Tesco House, Delamare Road, Cheshunt, Herts, EN8 9SL

Asda House, Southbank, Leeds, LS11 5AD. They asked me to go into the local store.

Boots, 1 Thane Road West, Nottingham, NG90 1BS

Sainsburys Supermarkets LTD, 33 Holborn, London, EC1N 2HT. They asked me to call into the local store.

Arcadia Group, Colegrave House, 70 Berners Street, London, W1T 3NL

Lush, Newcastle upon Tyne, 1B Chevy Chase, Eldon Square, Newcastle upon Tyne, NE1 7XP

Fenwick, 39 Northumberland Street, Newcastle upon Tyne, NE99 1AR. They said no.

The last thing is that hopefully in the autumn I'll be working with the Centre of Life Genetics department and hopefully be doing a CMT workshop at which I will set up a little stall to promote and give information about CMT UK.

Darren Scorer 0845 872 9507

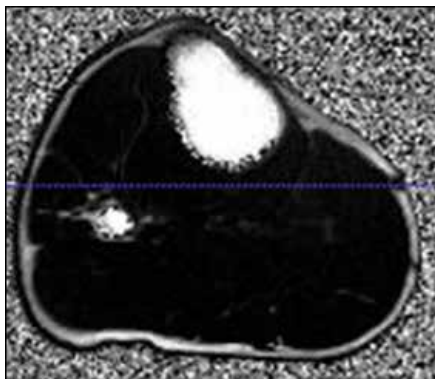
North Shropshire/North Wales Group

Alan Barker, formerly of the Shropshire/West Midland Group hopes to establish a North Shropshire/North Wales Group in the near future.

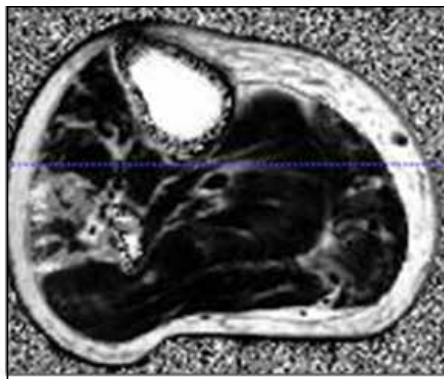
| | | | |
|----------------------------|----------------------|---------------|----------------------------|
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| Shropshire | Alan Barker | 0845 872 9503 | alan.barker@cmtuk.org.uk |
| South Somerset | Valerie Corbett | 0845 872 9509 | |
| Staffordshire | Margaret Byatt | 0845 872 8957 | margaret@cmtuk.org.uk |
| Surrey | Alex Williamson | 0845 872 9500 | alex@cmtuk.org.uk |
| Swindon | Geoff Elliott-Howell | 0845 013 2703 | geoff@cmtuk.org.uk |
| West Sussex | Jackie Burlison | 0845 872 9513 | jackie@cmtuk.org.uk |
| | Naomi Perilli | 0845 872 9518 | naomi@cmtuk.org.uk |
| Wiltshire | Helen Palmer | 0845 872 9512 | helen@cmtuk.org.uk |
| Yorkshire | Sam Lewis | 0845 872 9524 | sam@cmtuk.org.uk |

The use of Magnetic Resonance Imaging (MRI) in patients with Charcot-Marie-Tooth disease

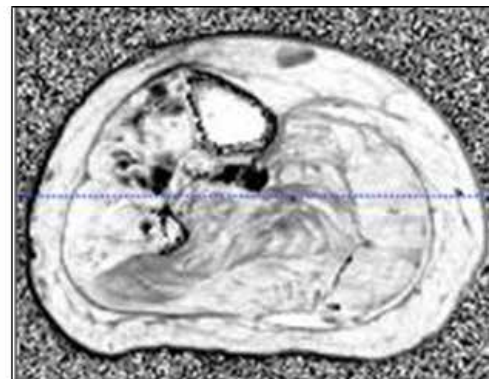
Jasper M Morrow, Matthew RB Evans and Mary M Reilly MRC Centre for Neuromuscular Diseases
Department of Molecular Neurosciences, UCL. Institute of Neurology, London, UK



19 year old with CMT1A
Overall average fat = 1.3%



37 year old with CMT1A
Overall average fat = 17.9%



53 year old with CMT1A
Overall average fat = 77.5%

One of the major challenges in developing new treatments in CMT is accurately measuring how much worse the disease gets over time. Although this is readily apparent to both patients with CMT and their doctors, to be able to perform a trial of a new treatment, disease severity needs to be recorded as a numerical value. Of utmost importance in slowly progressive conditions such as CMT, this value must change over a couple of years so that it can be determined if the new treatment stops disease progression. Currently used measurements of severity in CMT, such as the CMT Neuropathy Score used in the Vitamin C treatment studies, showed only very small changes over two years. Recent research at the MRC Centre for Neuromuscular Diseases has been looking at whether MRI can rise to the challenge to provide sensitive and accurate severity measurements in CMT.

MRI is well established in other areas of neurology with the advantages of being painless, non-invasive and not involving exposure to radiation. Although MRI is a relative newcomer on the neuromuscular scene, it already has an established role in assisting in diagnosis of a wide range of nerve and muscle diseases. It is a unique form of medical imaging which harnesses the innate magnetic properties of hydrogen atoms found in all tissues in the human body. These hydrogen atoms line up with the

magnetic field when the person goes into the machine, and give off signals when the magnetic field changes during the scan. These signals are recorded by the MRI and reconstructed to create a picture of the part of the body which is of interest, in this case the legs. The hydrogen atoms generate different signals depending on what kind of tissue they are in (fat, muscle, nerve, skin) which creates contrast between these tissues, but also differentiates normal from abnormal tissue.

In CMT, although the nerve is the site of initial damage and changes in the nerves have been demonstrated on MRI of patients with CMT; there are also secondary changes in muscles as they lose connection with their nerve supply. As these muscles become involved, they slowly reduce in size and become infiltrated with fatty tissue. With advances in medical physics, novel MRI techniques have been developed which allow precise quantification of the percentage of fat in any tissue. Measurement of fat in leg muscles is therefore potentially a good marker of disease severity in patients with CMT.

With this in mind, the MRC Centre for Neuromuscular Diseases at Queen Square has been developing quantitative MRI as a potential severity measure to be used in CMT treatment trials for patients. In 2011, 20 patients with CMT and 20 volunteers (without CMT)

were enrolled in a longitudinal study to measure progression of the disease using MRI. To date, patients and volunteers have been examined clinically and by MRI at two time points separated by 12 months. The preliminary results from this study are very encouraging, showing that there was an abnormally increased amount of fat in leg muscles of CMT patients and that this measurement correlated with other markers of disease severity including muscle strength. Most importantly MRI was accurate enough to show change in this measurement over 12 months follow-up in some CMT patients, whereas the volunteer measurements didn't change at all. MRI therefore appears able to detect disease progression in CMT over a 12 month period in some patients, where other measurements cannot, and therefore has the potential of being an excellent outcome measure for treatment trials involving CMT.

We aim to continue this study for several years to obtain as much information as possible regarding the use of MRI in CMT, and specifically to determine the minimum number of years needed to detect change in all patients with CMT, so that MRI can be used in clinical trials. This is a very exciting development in CMT research, and may revolutionise the way in which CMT patients are monitored both clinically, as well as in future trials involving new treatments.



Ballet Calendar raises awareness & funds

Many members may have met, Tim Elwood from Scholarship Press, doing the AGM photography. Tim together with his assistant Lauren have been shooting an Urban Ballet Calendar to raise funds for CMT UK.

Tim said – ‘I’ve always been so impressed by the speed with which some CMTers hit the dance floor at events, even though dancing must be difficult for many people, I thought it would be great to do a dance themed calendar.’

The calendar features 4 fantastic dancers in central Nottingham. The project creates a juxtaposition of the delicacy and beauty of dance within the harsh settings of the city. Lauren said that ‘the calendar was created

to represent the freedom and beauty in movement which many people take for granted.’

The Scholarship Press sent out a number of press releases and got featured in the Nottingham Post, Nottingham Trent University and BBC Radio Nottingham all of whom knew nothing about CMT – well they do now!

Calendars may be purchased from www.funfundraisingcalendars.com and cost £10.99 with £1 being donated to CMT UK



Awareness month 2013

Manchester



Photo of members Margaret Birks from Lymm, Steven Shawcross and vice chair Karin Rodgers both from Timperley, manning a stand at Wythenshawe Hospital .

Thanks to John Birks from Lymm who is already a volunteer at Wythenshawe hospital in the heart department, Karin, John, Margaret and Steve were able to have a stand in the busiest part of the hospital at the main outpatients’ registration point for 2 days in September. Posters were approved and put up in 15

main areas of the hospital and the electronic poster and information was displayed on the staff intranet and newsletters. Much interest was shown by patients and staff, in particular the physio and occupational therapists. The outpatients’ department is also next to the physiotherapy department, and so we managed to hijack all the physios as they came out for their lunch break! We managed to answer lots of questions and raise awareness of CMT and would like to thank Jan, the Volunteer Co-ordinator for all her help .

Myelin Masquerade

RAISING AWARENESS OF CHARCOT MARIE TOOTH DISEASE



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Charcot-Marie-Tooth (CMT) is an hereditary (genetic) condition that damages the peripheral nerves. These nerves are responsible for passing on commands from the brain to the muscles in the arms and legs, and for passing information back to the brain about sensation – pain, heat, cold and touch. It causes the muscles in the legs and arms to waste, which can cause problems with walking, standing and balance. Hand function and strength are also affected. CMT is not curable and slowly worsens over time.

To find out more about the condition visit www.cmt.org.uk