

The magazine from CMT United Kingdom

Summer 2015

# ComMenT



Charcot Marie Tooth disease (CMT) is an umbrella term that covers many inherited peripheral neuropathies. People with CMT have a problem with the nerves that go to the feet and hands, this causes muscle and sensation loss, as well as difficulty with balance. There are at least seventy eight genes that, when mutated, cause CMT.



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## FROM THE EDITOR

Hello Everyone!

I trust that you are all enjoying the somewhat erratic weather? Still, at least it isn't icy underfoot!

I had planned to write a review of the annual conference but looking at the articles that have been submitted I will be duplicating effort and boring you silly. This was my second conference and I did learn one thing, and that's to travel up the night before! I was exhausted by the time I arrived in Coventry, and drenched as well due to the horrendous weather first thing. Next year will be very different for me as I will be staying up for the gala dinner after the conference and would encourage as many people as possible to do the same. Get the date in your diary – 16th of April. It's the 30th anniversary of the founding of the charity and it promises to be a very memorable evening.

Alongside lots of useful information from the conference we also have some great stories from our fund raisers! It has been a great few months and however large or small the amount raised is, you can rest assured it is all being put to very good use. For those who are working, it is always worth enquiring as to whether your employer offers any fund matching for your efforts. As highlighted in the fundraising section, Nicola Dann raised around £2,000 which was then matched by her employer. It can make a huge difference.

You can also find information about the Family Conference planned for next year over the weekend of the 23rd & 24th of July. The event will take place at the Hilton Hotel in Coventry and has been made possible due to a grant that we received from Jeans for Genes, so a big thank you goes out to them!

Also, please take a look at the piece about lasting legacies. Whilst none of us want to think about shuffling off it is certainly worth considering leaving a legacy to CMT UK if you are able to do so. It would go a long way to funding research and getting us closer to a cure!

One final thing – at the time of writing there are only 161 days until Christmas, so make sure you enjoy the rest of the summer!.

Thank you!

**Andrew.**



## ComMenT needs you!

Please send your letters, group news, feature ideas and inspiring stories to [andrew@cmtuk.org.uk](mailto:andrew@cmtuk.org.uk)  
Deadline date for Winter 2015 Edition of ComMenT will be 1st October 2015

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.

# Announcing a Family Conference

23/24th July 2016, Coventry



Thanks to a grant from Jeans for Genes we're delighted to announce that we'll be holding another Family Conference in July 2016. If you have younger children (under 12s, but there are no rules, so if yours are a bit older, book anyway!) and would like them to meet some more kids with CMT, and to learn from some great paediatric specialists, this might be just for you!

The weekend event is being held over 23rd/24th July 2016 at the Hilton Hotel, Coventry and will run from Saturday lunchtime to Sunday lunchtime and the hugely subsidised cost of £50 per adult, and £10 per child includes two lunches, one dinner, refreshments (not alcohol!) and your

accommodation. The learning/entertainment sessions will be held on Saturday afternoon/Sunday morning and the conference room will be divided to provide a slightly less noisy environment for the parents and a fun area for the kids to play. Speakers will be organised shortly, but will definitely include a paediatric neurologist, an orthopaedic surgeon and a physiotherapist for starters.

This is a member's only event, so log into the Members Area of the website, navigate to Events and click on Family Conference to find the details and the booking forms. If you can't remember your log in details, just ask the office to help you. We'll hopefully see you there!

## Raising Awareness

Raising awareness is always an uphill struggle, isn't it? Well member Douglas Sager has come up with an idea that he needs your help with! He's developed an idea for a humorous video, along with a professional film-maker, based loosely on the Monty Python sketch of the Ministry of Silly Walks! He's desperate to get this film made – and we love the idea too – but to get it made really well, it's costly - £6,000 is a rough cost so far. Douglas has set up a Justgiving page to raise funds specifically for this project, and if you would like to read more, and hopefully – to donate – go to <https://www.justgiving.com/douglas-sager>

## A Photo in a Magazine

Recently I spotted a photo in a magazine. A youthful French politician was bounding up the steps of a Government building. It set me thinking. I am very fortunate in that I am 72 years of age and in good general health. I have CMT type 1a but the

symptoms, whilst worsening, are still not too bad. However, I recently completed a questionnaire concerning the severity of my symptoms. I was asked over a hundred questions, the following made me smile wryly.

“Can you dance?” Can you jump?” Can you stand on one leg?” Well, the answer to the first two is no! The answer to the third is a qualified yes (if I have something to hold on to!). We are often told that those with CMT are not whingers, that we make the best of life. I hope that's true of most of us. But just occasionally, when I see someone doing with ease something I can no longer manage, I feel a pang of loss for what I once had. I realise that there are many with far worse symptoms than mine who do not complain. I salute you all. But, if in private you sometimes feel a bit down, well, I suppose that's normal.

**Clive Harffy.**



# Chairman's C O L U M N

Here I go, once again, talking about the weather – only this time it is more to do with the 'Winds of Change' which are blowing through the charity, rather than the weather itself; glorious as it may be at the moment. As I write, June is indeed busting out all over, temperatures in the low 20's, gin clear (or as I'm in Scotland, should I say whisky clear!) skies and the plants and trees seem to have gone from brown to green almost overnight!

Last time I wrote, I referred to the recent resignation of our Fundraiser Nichola and the activity to find a replacement for her. After several interviews, George Brown was appointed to the post and he commenced his employment in early January. Some of you will have met him at the April Conference and heard his ideas for the charity's future in the fundraising field; others may have spoken to him on the 'phone and exchanged thoughts and suggestions as to how we could move forward.

Behind the scenes, George put a deal of effort into identifying potential funders and trying to match up needy projects with possible income. At the same time, he was learning about CMT, its effects on people and how we all cope with its many different symptoms. No small task as I'm sure you will agree. However, the 'Wind of Change' started to blow and

regrettably, for personal reasons, we had to say goodbye to George last week, thus leaving us back where we were just over a year ago.

Naturally enough, this unexpected turn of events resulted in lengthy deliberation at the Board meeting last Saturday. Our declared Mission Statement of raising £2 million over the next 5 years remains unchanged - however, a major problem also remains - how to achieve this target? I believe we have solved the problem!

The Directors unanimously agreed that our trusty COO, Karen Butcher, would take on the additional responsibility of major Fundraising – after all, she has personal experience of the condition and its attendant problems in daily life (an aspect which both Nichola and George found difficult to appreciate), she has a wide ranging knowledge of the many types of CMT and a very close working relationship with a large number of clinical experts in this field, both in the UK and overseas.

Karen is now able to devote longer hours to the role than was previously possible; an office administrative assistant will also be employed to take on some of the many routine but equally necessary duties in a busy office. Karen will therefore not only continue



Success

as the Charity's Chief Operating Officer but will also devote a lot of her time to cultivating relationships (hopefully lucrative) with the major Funders in the UK.

Please join with me in wishing Karen every success and happiness in this new and vital role.

At the April AGM (Karen will be reporting more on this most enjoyable event) we were delighted to welcome Richard (Rick) Toole as the latest member of the Board (having two Richards can't be a bad thing after all!) Rick has a long and successful background in raising funds for the Army Benevolent Fund and some of you will have seen his expertise in 'finger painting' and its remarkable resulting effect on canvas. Rick, although not a CMT'er himself, is no stranger to disability, having suffered serious back injury while serving in the army. We wish Rick every happiness in this new role and look forward to his input to the Charity in coming months. I hope that the 'Winds of Change' have now stopped blowing, at least for a while, and we can all look forward to an increasingly successful future together.

Before I finish, may I simply say a huge 'thank you' to all our members and supporters who continue to raise funds for our Charity in so many different ways – too numerous to mention here. If you are a supporter, why not become a member and enjoy the full benefits of membership. Look up our website and set up a simple direct debit arrangement, after all, it's only a tad under 50 pence a week! And please don't forget – our recently re-published book 'CMT – A Practical Guide' is available on line to members only or, should you want a hard copy, £6.99 plus P&P (total £10.00 in the UK). With my sincere good wishes to all and enjoy a great summer holiday!

Regards  
**Richard**



# CALLING ALL YOUNG CMTer's



2016 sees the 30th anniversary of CMT UK and to commemorate this monumental event we would like to invite our younger CMT members to take part in a competition to design a logo. So get your creative heads on, get drawing and who knows, you may see your 30th anniversary CMT UK logo in print! The winning design will appear on a commemorative t-shirt and possibly on a tie as well. Remember to keep things simple. Some of the most effective and iconic logos are often simple in their design. Take a look at the Nike and Great Ormond Street Hospital Wishing Well Appeal logos as examples.

Entries should be on A4 paper and the upper age limit for entrants is 15. Make sure that we receive your design by the 31st of October 2015.

The logos will be judged by the trustees and there is a £25 prize for the winning entry!

Send your entries to:-

**Logo Competition, CMT UK, 98 Broadway,  
Southbourne, Bournemouth, BH6 4EH.**



## Annual Conference

**We knew when we decided to invite Professor Mike Shy from Iowa to talk to you that that would make this conference particularly popular, and we weren't disappointed – over 190 people converged on the Hilton Coventry on Saturday 11th April, which was wonderful to see.**

We started the day with a “getting to know you” session, with staff and trustees encouraging discussion and introductions amongst the delegates – about half of the delegates had not been to a Conference before, and it can be a daunting prospect, introducing yourself to total strangers, especially if the diagnosis of CMT is still new to you. This worked really well, and it's something we'll repeat, I think.

Mike Shy then gave us a wonderful update on the research situation to date – I know his talks can be a bit technical, but the subject matter is complicated! He's such a lovely guy and a real supporter of patient groups like ours – he's Chair of the Scientific Advisory Board for CMTA in the States, so has a real appreciation of what we can achieve, if we put our minds to it! You can read a more detailed report on his talk elsewhere in this magazine.

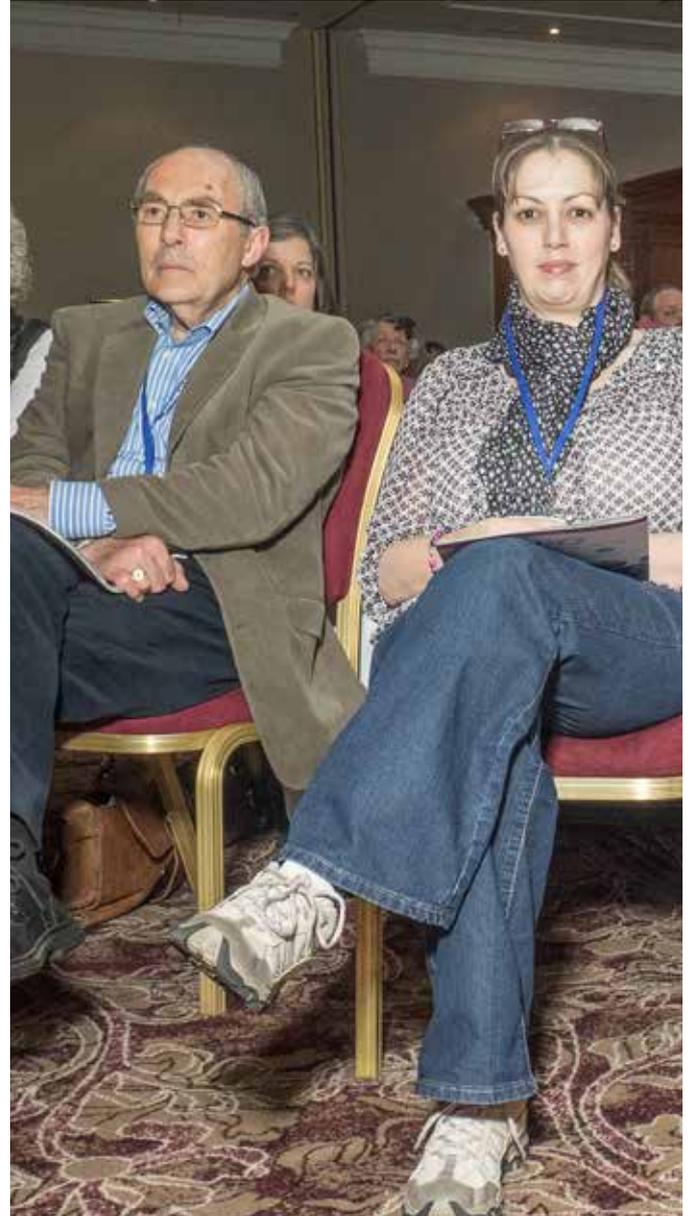
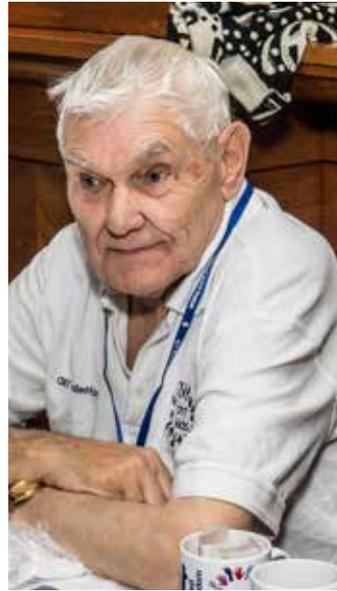
The Annual General Meeting followed, as always. We have this down to a fine art now, taking up as little time as possible! Under the terms of our new Articles of Association, we were able to dispense with proposers, seconders and that formal stuff, which also took up much less time and effort. Karen began by giving the usual review of the year of 2013/14,

showing particular highlights of the year – the Young People's Weekend; the older Kids weekend in March of 2015; the arrival, and subsequent departure of Nichola Hibbert, and much more, including particular thanks to fundraisers who help us so much.

Alex Williamson, our Treasurer, gave a swift overview of the accounts, and started by giving the good news that subscriptions would be held at their current level for another year, which raised a bit of a cheer! Other good news was that our investments are doing extremely well, producing far more in growth than they could have in a deposit account. On the downside, expenditure was considerably increased, but this was due to the increased cost of salaries and recruitment, and more importantly, due to the allocation of over £50,000 to future research projects.

Before the election of the Directors, Richard thanked Clive Harffy for his work on ComMenT as Clive was retiring from the Board – Clive was then presented with a bottle of something tasty by way of appreciation for his hard work! Richard introduced Andrew Sharpe to the delegates, who has taken on the role of Editor of the magazine.

The election of Directors was the next item on the Agenda, with Richard and Jeeta Ouston and Mary Carter being elected for their second three year term on the Board. Again, under the terms of the Articles, we no longer elect Officers – these are decided amongst the Directors, and whilst theoretically, we could have a different person to chair each meeting,



the Directors have decided that Richard should continue as Chairman. In addition, we had been joined by two new Directors during the course of the year, so Kevin Saunders was elected for two years (since he'd started his term in June of 2014), and Rick Toole, who was filling Clive's vacant space, for one year.

There being no other business, the AGM was formally closed, just in time for a yummy lunch.

After lunch, Professor Mary Reilly gave a short update on the state of play with research in the UK, and then she and Mike answered pre-submitted questions on a wide range of subjects – again, there is a report elsewhere.

They were then followed by member, John Barton, who is a counsellor, who gave an interesting talk on the psychological aspects of having CMT.

And last but very definitely not least, Karen Bull, the Neuromuscular Nurse Specialist from Mary Reilly's clinic in London gave a very practical talk on knotty subjects such as shoes, benefits, pain, gadgets to help and lots more. We have

a review of her talk elsewhere, plus a list of all the website resources she shared with us.

As usual, the Grand Prize Draw closed the show, so to speak. We doubled the prize fund, but reduced the prizes to just the three cash prizes - £500 was won by Jenny Wynn from Cardiff, Andre Edmunds from Southampton won the second prize of £250, and third prize was won by Elizabeth Guest in St Austell. Overall, the Grand Prize Draw raised just over £4,000 for our general funds after expenses (which includes postage and the prize amounts). It should be noted that almost half the proceeds actually are donations that you make on top of your tickets – thank you so much!

So thank you to everyone who made the Conference such a special day! We'll see you all again next year – Saturday 16th April at the Hilton Coventry again. Start saving up, because it's our 30th Anniversary next year, and we'll be having a Gala Dinner/Dance after the Conference, during which we'll be doing our best to separate you from your hard earned cash!! Watch this space for more information!

**Karen**

# The Role of the Nurse in Supporting Patients through Practical Issues

Karen Bull



Karen Bull, a Neuromuscular Nurse Specialist, concluded the 2015 CMT United Kingdom annual conference with an information packed presentation. Karen discussed many topics starting with the practical aspects of self managing a chronic condition to the wider issues of what help and support is available to CMT patients and their carers. A number of tips were given on how to care for one's feet including the advice that regular visits to a chiropodist and podiatrist were desirable and available without charge for those suffering from neuropathy. Another useful tip was to buy shoes in the afternoon when feet are likely to be more swollen and therefore reduce the risk of creating pressure sores by wearing footwear that is too tight.

The specific interventions that Karen recommended were exercise, balance training, orthoses and splints, and fatigue management. The emphasis was firmly on the adage that "prevention is better than cure", treatment of wounds and pressure sores is long and complex so best to avoid damage to the skin as far as possible.

Karen also discussed hand care, a topic that is often overlooked in the management of CMT. The emotional and mental aspects of living with a chronic illness were covered and Karen suggested that Cognitive Behavioural Therapy (CBT) could be a useful intervention for those who found it difficult to manage their condition.

The wider aspects of CMT were then considered including the need to inform the DVLA, and the range of benefits available to assist with everyday life. For younger sufferers there was information about learning to drive from the age of 16 and the financial support available to help them with their studies throughout further and higher education. Throughout the presentation Karen listed numerous websites that could be useful and these will be available on the CMT website shortly. The session concluded with the statement "Disability will inevitably bring new changes and challenges to your life, but it should never stop you having a happy and fulfilled life"; a sentiment that the reviewer heartily endorses.

Here is a very brief but invaluable summary of the resources that Karen shared with us:

### **Handy Hints for Foot Care:**

[www.clarks.co.uk](http://www.clarks.co.uk) - Clarks offer an “odd shoe scheme” for people with very differently sized feet. Ring Customer Care on 01458 899901 or visit the website.

[www.cosyfeet.com](http://www.cosyfeet.com) - Cosy feet provide extra wide shoes that can accommodate some orthotics.

[www.taylormadeshoes.co.uk](http://www.taylormadeshoes.co.uk) - Handmade shoes and boots.

[www.nhs.uk/conditions/cornsandcalluses](http://www.nhs.uk/conditions/cornsandcalluses) - Useful Information on the treatment of corns and calluses.

[www.nhs.uk/conditions/chilblains](http://www.nhs.uk/conditions/chilblains) - Useful information on chilblains.

[www.raynauds.org.uk](http://www.raynauds.org.uk) - The Raynaud’s and Scleroderma support group’s website has lots of products to help keep your feet and hands warm!

[www.amazon.co.uk](http://www.amazon.co.uk) - Get grippers for your shoes to help with ice and snow.

### **Handy Hints for Fitness**

[www.nhs.uk/livewell/fitness/pages/pilates](http://www.nhs.uk/livewell/fitness/pages/pilates) - for gentle exercise.

[www.nhs.uk/change4life](http://www.nhs.uk/change4life) - Life changing hints & tips.

[www.swimming.org/poolfinder](http://www.swimming.org/poolfinder) - Accessible swimming pool finder.

[www.amazon.co.uk](http://www.amazon.co.uk) - Swim shoes at Amazon to help with your confidence poolside.

### **Getting to Exercise Venues** (London Area Only)

[www.transportforall.org.uk/d2d/taxicard](http://www.transportforall.org.uk/d2d/taxicard) - To help with costs.

[www.tfl.gov.uk/modes/dial-a-ride](http://www.tfl.gov.uk/modes/dial-a-ride) - Dial a ride service.

### **Where to Find the Equipment You Need:**

<http://asksara.dlf.org.uk> for personal advice on where to find pretty much any gadget.

[www.dlf.org.uk](http://www.dlf.org.uk) and click on “living made easy”

[www.clos-o-mat.com/index.php/products/shower-toilets.html](http://www.clos-o-mat.com/index.php/products/shower-toilets.html) - For issues with toileting.

[www.cot.co.uk/leaflets/leaflets](http://www.cot.co.uk/leaflets/leaflets) - General advice on how occupational therapy can help.

(And don’t forget to check out the range of gadgets, which is ever increasing, at our web shop – [www.cmt.org.uk/shop](http://www.cmt.org.uk/shop) )

### **Driving**

[www.gov.uk/peripheral-neuropathy-and-driving](http://www.gov.uk/peripheral-neuropathy-and-driving) - Don’t forget you MUST tell the DVLA if you’re diagnosed with CMT, or risk a £1000 fine!

[www.gov.uk/view-driving-licence](http://www.gov.uk/view-driving-licence) - Check your licence if you’ve recently been issued a new licence as there are new restrictions for the tonnage that you’re allowed to drive.

[www.motability.co.uk](http://www.motability.co.uk) - Motability for help with cars, and for younger people, remember those in receipt of the high rate of DLA, they can learn to drive at 16. Motability can also help with the cost of driving lessons.

[www.mobility-centres.org.uk](http://www.mobility-centres.org.uk) - The Forum of Mobility Centres can help you find a centre to do an assessment of your driving.

### **Jobs and Benefits**

[www.gov.uk/looking-for-work-if-disabled/-looking-for-a-job](http://www.gov.uk/looking-for-work-if-disabled/-looking-for-a-job)

[www.shaw-trust.org.uk/individuals/helping-disabled-and-disadvantaged-people](http://www.shaw-trust.org.uk/individuals/helping-disabled-and-disadvantaged-people) - More help at the Shaw Trust.

[www.adviceguide.org.uk/get\\_advice.htm](http://www.adviceguide.org.uk/get_advice.htm) – Citizens Advice Bureaus to help with forms etc.

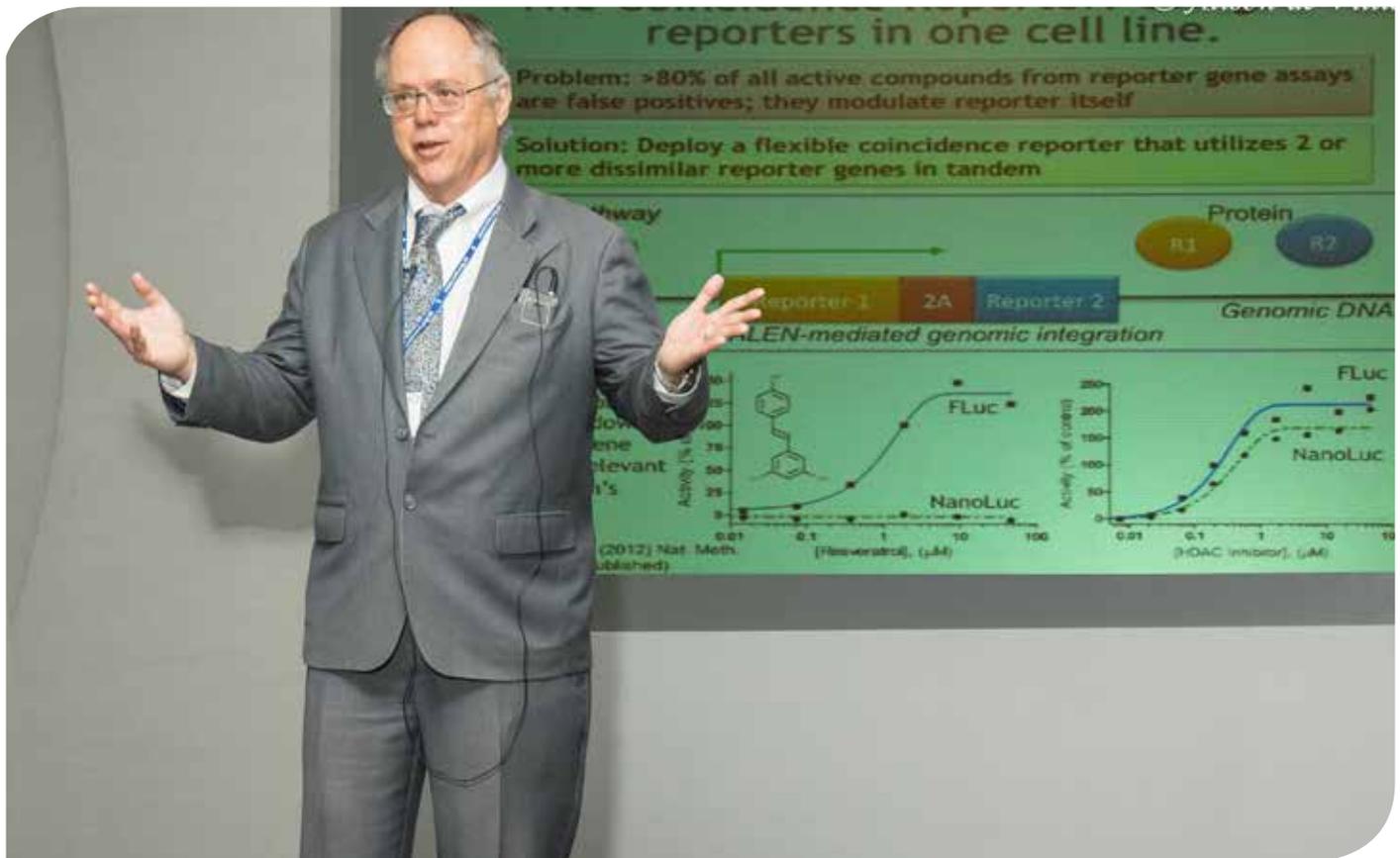
### **Social Care**

[www.gov.uk/apply-needs-assessment-social-services](http://www.gov.uk/apply-needs-assessment-social-services) - Apply for a needs assessment by social services (England and Wales only)



# Mike Shy:

## Research, STAR and CMTA



It was a real treat to have Mike Shy talk to us at our April 2015 AGM. As ever he was upbeat and certainly kept his audience's attention. He feels that CMT is entering a new era, our knowledge is expanding and we now have identified more than 82 genes involved in CMT. Only a short while ago, we only knew of 40. Research is at an exciting stage and we are close to developing treatments. A few years ago, this would only have been a pipe dream

Mike described CMTA's approach, they choose the best projects and the best people and aim to improve the quality of life for patients. He described their STAR initiative – strategy to accelerate research.

Mike went on then to describe different approaches to therapy for three types of CMT.

### CMT1A

Most of us know that this is the commonest form of CMT and it is caused by having 3 copies of the myelin protein 22 gene (we only need 2

copies). So, what we have is a dosage problem and treatments will be aimed at reducing PMP22 levels. Mike then went on to describe some ingenious work whereby Schwann cell lines have been developed and using luciferase from fireflies as markers, the levels of PMP22 in the cells can be measured (luciferase glow strength depends on level of PMP22). These cell lines are then treated with various potential therapeutic compounds and subjected to high throughput screening. It's all done by robots (watch the video on our web site, it's mind boggling). Sanofi-Genzyme, CMTA and NIH are working together on this and are screening some 2 million compounds for efficacy. Likely candidates will then be tested in rat or mouse models prior to clinical trials. Exciting stuff - and Mike reckons we may be only a couple or more years away from trials. WOW!

### CMT1B

This is caused by a mutation in the myelin protein 0 gene which stops myelin folding correctly and therefore not enough myelin is produced. Already a compound has been found which can rescue

the mutation and is now in clinical trials (to be published in Science).

### CMT2A

A mutation in the mitofusin 2 gene prevents mitochondria (the cell's energy producers) fuse and then split. One way of alleviating this might be to produce more mitofusin 1. Candidate compounds have been identified and are now being tested in human stem cell lines and rat models.

What all of this so clearly demonstrates is that at last we have REAL therapeutic approaches for at least some of the forms of CMT. HURRAH!

### Clinical trials

Mike then went on then to discuss the criteria needed for clinical trials. Objective measure are

needed to assess the efficacy of treatments. CMT is a slowly progressive disease and it is vital that all patients are assessed using the same measures. The Inherited Neuropathy Consortium (CMT UK is a member) have developed the CMT Neuropathy Score and the MRI study at Queen's Square (CMT UK part fund this) has shown promising results for objectively measuring very small changes in muscle wastage. A CMT neuropathy score for kids has also been developed now which is of necessity rather different to that for adults.

**Finally, clinical trials need lots of participants to be truly robust, so if you haven't done it already, SIGN UP TO THE PATIENT REGISTRY**

[www.rarediseasesnetwork.org/INC/register](http://www.rarediseasesnetwork.org/INC/register)



# Twelve And A Half Thousand Reasons To Smile!





**On the 30 March 2015 Harry Venton did a skydive in Dubai in memory of his Dad, Jeremy. Raising sponsorship for CMT UK, he raised a staggering £12,528.87!**

#### **Harry writes....**

"I was on holiday there with my family and was really excited at the thought of launching myself out of a plane! The main reason for doing it was to raise awareness and money for 'CMT UK'. My Dad passed away in August 2013, he suffered from CMT and I've seen first-hand how the disease weakens and takes control of someone's body, it is terrifying and I wouldn't wish it on anyone. The dive itself was amazing, a fabulous experience and I am thrilled to have been able to help support this wonderful charity."

#### **Jeremy's Story**

My Dad, Jeremy Venton suffered from CMT, it didn't really seem to affect him until his late 40's. He was a fun loving, energetic person who was passionate about anything he put his mind to. As a youngster he played tennis at county level and he was a keen golfer playing off a handicap of 4 for some time. He had a passion for fly fishing too. By profession he was an Insurance Underwriter and owned a hugely successful underwriting agency with offices in London and Bermuda.

Up until around 2000 he was a very active man, always finding new adventures to keep busy, but that year CMT started to have a larger impact on his health, which only got worse as time went on and eventually stopped him from being able to enjoy many of his passions. Unfortunately he also suffered from diabetes later on, which only added to his bad health and resulted in the amputation of his lower right leg in 2006. My younger brother was only 6 at this time.

CMT was taking its toll on Dad's body, his muscles were wasting away, he had very little or no feeling in his hands and legs and he would regularly lose his balance. This all made it a struggle for him to even stand, let alone walk, after the amputation he was completely wheelchair bound. It was a soul destroying turn of events for us all, especially for Dad. We were told that after having an amputation people can go through a process of 'grieving' similar to losing a loved one, but Dad being the extremely caring, loving and selfless individual he was didn't show any signs of this, he was actually surprisingly upbeat. Everyone knew he was putting a brave face on to try and protect Mum, my sister Alice, my brother Charlie and I, but deep down we knew he was devastated. Except for having the four of us around him, his life had unfortunately stopped.

From then on life changed completely for us all, he became increasingly reliant on us to help and care for him. In the last two and a half years of his life Mum and I became full time carers and I was also working full time in London.

Seeing my Dad suffer like he did was absolutely heart breaking and an incredibly traumatic time. One of the most important things I learnt on this awful journey was how you can't take anything for granted, especially your health! Make the most of life and enjoy being with your loved ones as you're only here once and you never know when it's going to end.

For anyone wishing to donate to Harry's page after reading this story, please click on the link below:

[www.justgiving.com/Harry-Venton](http://www.justgiving.com/Harry-Venton)

# Fundraising!

## London Marathon

### Matthew Pont



Proud mum Hazel got in touch to let us know that her son Matthew ran the London marathon to raise money for CMT UK. He got round in 3hrs

39mins which was a great time as he hadn't been running so well in his training and had a problem with his knee. "My husband Bernard, Karen (Matthew's wife) and Lily 4yrs stayed up in London on Saturday night to support him on the run. We saw him at the 8, 12 and 21 mile to cheer him on so we are all very proud of him. He has raised £670 + gift aid and his fund raising page is still active so hopefully will have a few extra donations to add to this before it closes."

<https://www.justgiving.com/Matthew-Pont1/>

### Jackie Bye



Jackie Bye, whose son Graeme is significantly affected by CMT, also ran the London Marathon for us, and despite being rather poorly and feeling horrible during the run, managed to push through and finish in 5 hours and 50 minutes. Despite her challenges, her Justgiving page stands at over £1600! She has sworn to

run for us again - but never a Marathon! Shorter distances from now on, and we can't argue with that!

<https://www.justgiving.com/Jackie-Bye3/>



### Debbie & Joe Harwood

Debbie and Joe also took part in the marathon and, having just recovered from their exertions, entered the ballot for 2016! Deborah finished in a very respectable 6 hours & 52 minutes, whilst Joe came home in 5 hours & 5 minutes.

Their son Matthew has CMT, and they have offered their services for further fund raising efforts!

## Bath Marathon

### Nicola Dann (pictured right)

Not London, but further West! A brilliant effort from Nicola Dann who ran the Bath Half Marathon for us on 1st March, despite having CMT herself! She ran it in an amazing time of 2 hours & 52 minutes, and has raised just over £2,000 – with another £2,000 to come from a donation matching scheme from B.A.T, the company that she works for! Thank you for your inspirational efforts.

## Silence is Golden!

Sssshhhhh! Grace Fairgrieve wanted to raise money doing a sponsored silence and she thought long and hard who to raise the money for. Luckily for us she decided that CMT UK was a very worthy cause.



Grace is 10 years old and from Loughborough in Leicestershire. This is the first time she has done a sponsored silence and whilst she managed to stay silent for 4 hours it was very hard work! She raised £70 and we suspect that her parents were delighted with the quiet time!

Well done, Grace - and thank you so much!



## Charlie Stanton-Stock

Charlie was diagnosed with CMT type 5 last year at 13 years of age, and it was quite a shock as no one in our family have any similar conditions and we had never heard of CMT!

After his diagnosis we felt it best to give up club rugby but Charlie has decided to see just how strong, fit and able he can be. He had always been a good long distance runner until his gait started to change. He also enjoys riding a bike and whilst he hates swimming he accepts that it is a good exercise for CMT. With this in mind he decided to attempt Triathlon. Last September he entered a Children's Para-triathlon where the distances were quite short but he did get a small taste of what it would be like. He then entered children's duathlons (run, bike, run) in Jan, Feb and March and the organisers helped by adjusting the run distances for him so that he could be competitive.

There are very few para-triathlon's for children so he needs to compete in normal children's triathlons until at least next year. Charlie recently completed his first youth triathlon and decided to try to raise some money for research into CMT, and also try and raise awareness for this condition. At the time of going to print Charlie has raised an amazing £2438.77!

Charlie has signed up for some more triathlons including one at Basildon - East Essex Kids Triathlon, where the swim and run are a bit longer! He has also decided to try his first open water triathlon at Mallory Park later this year!

<https://www.justgiving.com/CharlieStanton-Stock/>



# Positive Mental Attitude!



Here is another story from one of our members who battled back after her initial diagnosis of CMT to fulfil many of her dreams and goals.

Being told at 23 that you'll never work again because of this neurological disease you've inherited does something to a girl. You see being diagnosed after 21 years on the planet was a great relief; well at first!

I'd been the clumsy child, the weak child, the non-sporty teenager who just loathed and dreaded physical education lessons. Something hadn't been right all of my life but no one knew what that something was until my Dad was diagnosed at 54. Given the nature of the condition it was inevitable that me as his only daughter would need to be tested, but before the results even came back I knew it was obviously what I had. Everything made sense and clicked into place.

By the age of 23 I'd had two pregnancies pretty much back to back and boy did my body suffer the consequences of such a demanding experience! With two children under the age of three, the muscles really had been pushed to their limit and decided they weren't happy to function properly anymore. I was medically retired from my work in health care

and told by a DWP worker that "I was unemployable and would never work again". Being 23 and faced with the prospect of never having contributed to society through my career, sent me into a depression. I sat around all day in pain, having nothing to get dressed up for and life became a daily routine of scraped back hair, dressing in jogging bottoms and watching children's TV.

However, I've never been the kind of person to take negative circumstances as a given and once I'd got over feeling sorry for myself, and a lot of soul searching, I realised that now was the time to do the things I'd never been able to do as I had neither the finances or the time. So, propped up in a computer chair with pillows to support me I started studying for a business degree. Five years later and after a huge amount of personal development, I qualified. What an immense feeling, walking across that stage and collecting my certificate!

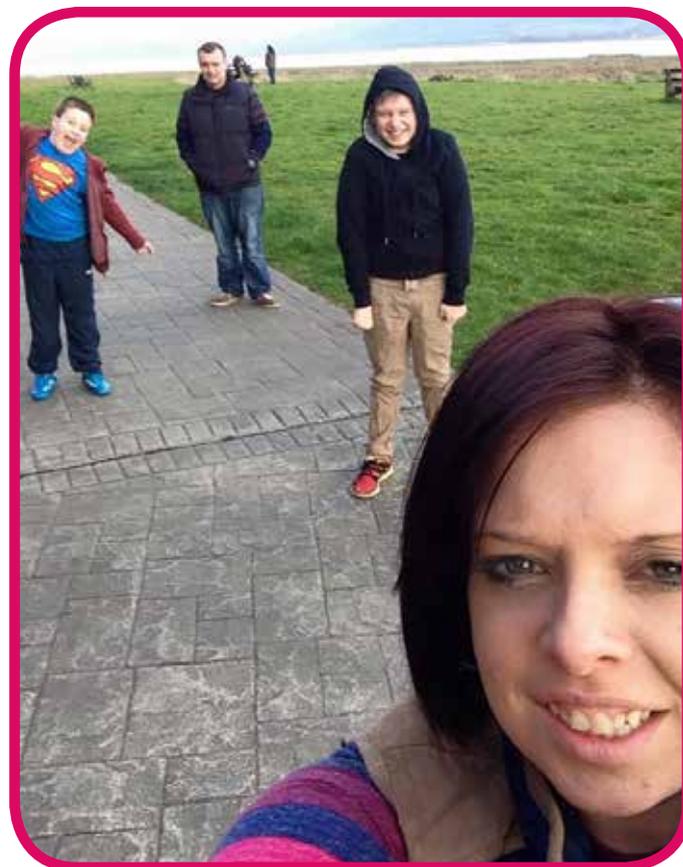
While studying for my degree I realised that working for myself would be a great way to get back into the world of work without having to conform to someone else's timetable and demands. I started my first business in 2011 and the feeling of self-worth really contributed to my rehabilitation. I had something

to get out of bed for, I felt that I was inputting my skills and knowledge and making a difference. Being my own boss was such a boost for my confidence. I couldn't have done any of it without my husband who to this day is still the physical hands and feet in the business. He is my chauffeur, my personal assistant, my child minder and house keeper, basically he keeps me and the family running so that the business can succeed.

I've had a number of successful business since 2011, all have sold all of them one with one exception. I'm now coaching and supporting people who want to start their own home based business. Who better to work with someone than the very person who has been there before them?

In the ten years from being told I'd never work again, studying for my degree and starting my businesses, I'd still battled with the symptoms and effects of CMT until a business colleague introduced me to some natural products said to help with pain, inflammation and fatigue. I didn't really think they'd work but being polite I agreed to give it a go. A year later and I found myself no longer needing any medication to support the symptoms, I'd found something that worked for me.

So now life with CMT has changed hugely. I am now driven by being able to make a difference in other's lives and to be the example to my boys (who both have the disease) that CMT is just another life issue that if you let it, gets in the way of you living your life to the full. It's an amazing honour to be the representative for CMT members in Wales and



I'm looking forward to supporting and signposting existing and newly diagnosed members to the help and support they need. I'm really lucky that my whole family have been behind me 100% and I know that not everyone has that support. If anyone in CMT UK would like help to start a business then get in touch I'll gladly help anyone get started, or if you simply need a listening ear connect with me on Facebook (Sara Pardoe Flay) or email me on [wales@cmtuk.org.uk](mailto:wales@cmtuk.org.uk).

**Remember together we are stronger!**

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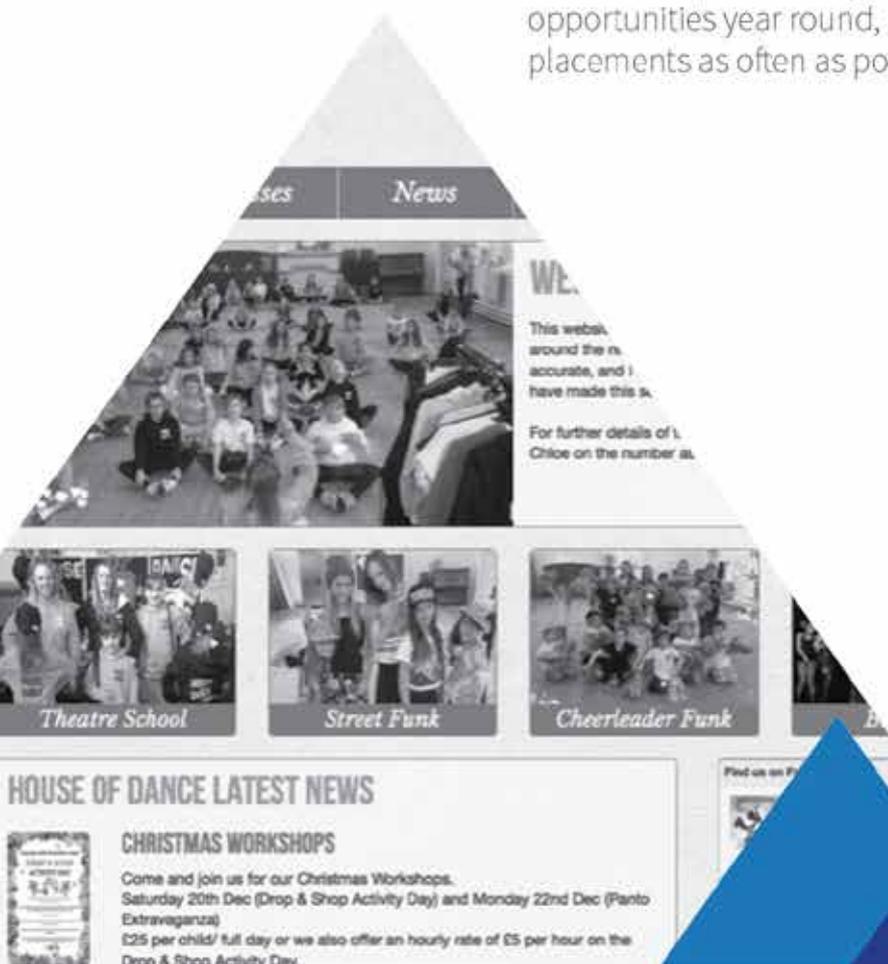
## Do you have a passion for graphic design?

NMC Design+Print is a **social enterprise** operating as part of the NeuroMuscular Centre; a Centre of excellence for people with muscular dystrophy. We offer modern, creative graphic design and a competitively priced printing service. Established over twenty years ago, we have built up a wide and varied portfolio of clients, including Hope House Children's Hospice and Frank Roberts Bakery. We have a good reputation and offer a great service, but we are a little bit different...

### All of our designers have muscular dystrophy.

We have an on-site care team and offer an accessible environment so that people with MD can work confidently and comfortably. Many of our employees were trained by our own training department, and they all have regular access to our physiotherapy team.

It is important to us to offer opportunities to adults and young people who have a passion for graphic design. Subsequently, we offer training opportunities year round, as well as work experience and work placements as often as possible.



One of our most talented students, Katherine Avery, has CMT and has been coming to the Centre for physiotherapy for eight years. During this time she developed an interest in design and decided to enroll on our Level One Graphic Design course. From there, she worked her way up to an Edexcel BTEC Level 2 Certificate in Creative Media Production, and is focusing on website design. Katherine is now partway through completing this qualification and has already started designing websites for friends and family in her spare time.

## Katherine Avery

*'At NMC I am able to train part time around family commitments. I am really enjoying my course, and hope to pursue a career in web design.'*

We are interested in meeting more people like Katherine, so if you love design and have been inspired by her story, we would love to hear from you. We are also interested in hearing your experiences, so if you have MD and work in the design industry please get in touch!

For enquiries about **training** please contact Dee Valkering:  
[dee.valkering@nmcentre.com](mailto:dee.valkering@nmcentre.com)

For information about **work placements, the design company, or for QUOTES** please contact Alison Evans: 01606 863464  
[alison.evans@nmcentre.com](mailto:alison.evans@nmcentre.com)



# Group News

## Hampshire Group

Hello from Hampshire! I hope that everyone is enjoying the summer; it does not seem possible that we are talking about our Christmas lunch.

We hope that our friends in the Wessex group will be joining us for a picnic in Hamble Country Park, near Southampton, in July. Then we look forward to a talk by Dr. Caroline Hutchings, a Rehabilitation Consultant who is part of the the Solent Neurological Rehabilitation Service, on Saturday 12th September. We will be interested to learn what the rehabilitation service can do for us and her opinion on whether that on diagnosis patients with CMT should be referred to a Rehabilitation Consultant or a Neuro Rehabilitation

unit for assessment. This would ensure that an appropriate exercise regime can be established before the condition is too advanced, including aids if required. We are also hoping on Saturday 14th November to, have a talk from a psychologist regarding adjustment to and coping with our condition.

If you would like to come along to any of our meetings, you would be most welcome. You will find us friendly and lively. Alternatively, if you would just like some information please feel free to contact me on: Telephone – 0845 872 9514 or Email – [terry@cmtuk.org.uk](mailto:terry@cmtuk.org.uk) .

## Climb Every Mountain!



**Pen-y-Fan** is the highest mountain in Southern Britain, and features heavily in the SAS selection process. Not to be outdone by Britain's finest, our very own Clive Harffy thought he would give it a go. He assures us it's quite easy to ascend with just a little bit of effort! Over to you Clive...

'I am a member of a Welsh Male Voice Choir and we had the brilliant idea of walking up the mountain and "Singing on the Summit" for Cancer Research. I had no doubt about my fitness but I did wonder just how long it would take me. In

order to find out, my wife Angela and I decided to climb Pen-y-Fan on our own to see how well I would do.

The mid-April day was bright and warm and we reached the summit in 2 hours. The views were magnificent. We felt quite pleased with ourselves. We had a picnic and decided to make a slight detour to another nearby peak, Corn Du. This too went well. Now for the descent.

At this stage everything changed! My CMT affected legs were tired, my balance was shot and travelling

downhill on uneven jagged rocks is taxing even with a stick. It took me three and a half hours to descend the mountain and I was scared of falling the whole time. Angela said I was walking like a 90 year old and that's what it felt like too! The choir made the hike up the mountain on 9th May. I made my apologies! I couldn't go through that again! It took me about a week to recover fully. The good news is that my sponsors coughed up even though I went up Pen-y-Fan on a different day to the one stated on the form! I raised £90.00 for Cancer Research.'

# DO SOMETHING AMAZING

Paralympic Shooter Ben wears **SAFO**<sup>®</sup>s to increase his **stability** and alleviate his symptoms of **drop foot** caused by CMT.



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## Members Story

*Josie Simister contacted us about sharing her experience of living with CMT Type 1a*

I'm a 48 year old perimenopausal woman with Type 1a, and want to inform you of my experiences and what I did about it, and how I think it would help a great many!

I was feeling very tired and melancholy and thought it was a mix of the CMT and menopausal symptoms. I went to my brilliant health shop, Natures Corner, in Newbury, and I was put on Rhodilan complex, Magnesium 300mg and Optibac for immunity, and Vitamin C for immunity support. I also had a smooth to mix in a "Mrs Green Mix" which looked like pond scum, and had spirulina and chlorella in it (excuse the spelling!) I began to feel better in a week – however, the melancholia and the sweats continued. So, I dropped alcohol, and I went to see a nutritionist who advised Vitamin D3 (4000iu) and Probi, a billion live microbe supplement. I became greatly better in a matter of a fortnight, making it overall about 2 months to see a positive result. I was a Paleo diet convert for a year before upping my protein, keeping my carbs low and eating good fats – the rind on an organic beef cut does no harm, I believe, and eating mostly oily fish, green vegetables, almonds, nuts and soya with added calcium and vitamin K. I think it all helps rather than not.

I just want to convey to those who think they are going mad, feel overwhelmed, to see what I now firmly believe. Cognitively I found a massive improvement, and I am angry that general medical advice does not extend to pre- and pro-biotics and microbe enzymes. I now think it's not just what you eat, it's how it's digested in YOUR own gut! I hadn't been told that up to 70% of our feel-good factor comes from the gut, NOT from the balances in the brain. I am totally staggered that this was never explained to me, that in years gone by, when I used to go to GP surgeries, they saw me tired (I did before all my research began, looked online for adrenal gland information, and I ticked many of the boxes for signs of adrenal gland depletion), so they saw me as cognitively dull, and of course, stress makes you feel down – so they thought "antidepressants". I went down that path for a very short while and I will NEVER do it again!

Now I know that that "gut feeling", that sentient feeling one gets in the stomach when feeling anxious, has a great deal to do with how the gut breaks down foods, and whether the bacteria in the gut is working effectively or not.

If anyone would like to email Josie about her experiences, please send them to Karen, and she'll forward them onto Josie.

# Don't let it pass to our children



Charot-Marie-Tooth disease is hereditary and passed down to our children. With medical research at the forefront we stand a chance of finding a cure.

Legacies are of great value to us, and greatly appreciated: your gift will be to all who have and may have CMT - it's a truly lasting legacy.

If you would like to support us in this way, please consider making a gift in your will to CMT. Any gift, large or small, is of great significance.

Find out more by visiting [www.cmt.org.uk](http://www.cmt.org.uk) or call Karen on 01202 432048

# CHARCOT MARIE TOOTH DISEASE AND OCCUPATION: RESULTS OF A PATIENT SURVEY IN THE UK



T. Withers<sup>1</sup>, M. Laurá<sup>1</sup>, M. Skorupinska<sup>1</sup>, Karen Bull<sup>1</sup>, Karen Butcher<sup>2</sup>, CMT United Kingdom<sup>2</sup>, M.M. Reilly<sup>1</sup>

<sup>1</sup>MRC Centre for Neuromuscular Diseases, UCL Institute of Neurology, London, UK, <sup>2</sup>Charcot Marie Tooth United Kingdom



## Introduction

Charcot-Marie-Tooth (CMT) Disease is the most common inherited peripheral neuropathy. Clinically CMT is a heterogeneous disorder characterised by distal weakness and sensory loss in the upper and lower limbs<sup>1</sup>. Many CMT patients become gradually less able to perform tasks requiring manual dexterity, heavy labour or jobs involving long periods of time standing up.

## Aims

- To evaluate how CMT might affect the ability to find work, to perform and to maintain a job
- To assess the reason of retirement in CMT patients

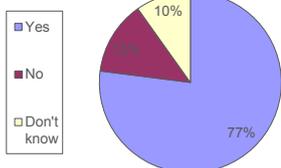
## Results

- Over a 12 month period 301 responses were received. 117/301 (39%) of the respondents were male and 184/301 (61%) were female. The median age of participants was 52, ranging from "under 16" to "65+" (<http://www.statcan.gc.ca/edu/power-pouvoir/ch11/median-mediane/5214872-eng.htm>). Participants came from across the UK and from a wide variety of occupations.
- Most participants (57%) suffered from CMT1; 17% suffering from CMT type 2 (CMT2), 9% listed their subtype as intermediate CMT, x-linked CMT, HSN or HNPP and 17% did not know their genetic diagnosis.
- 173/301 (57%) participants described themselves as moderately to severely affected in their hands or arms and 253/301 (84%) described their legs or feet as moderately to severely affected. Symptoms described by each patient varied (Table1).

### Effect of CMT on ability to perform the job

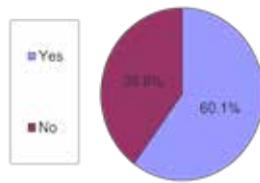
- For 205/266 (77%) of participants CMT had an impact on the ability to perform the job (Graph 1).
- For 181/301 (60%) CMT had restricted them from finding work (Graph 2) and 66/266 (25%) of respondents were forced to change career entirely because of CMT.
- In 197/266 (74%) patients fatigue affected their work (Graph 3) and in 114/266 (43%) patients tasks requiring manual dexterity were most difficult.

Do you feel that CMT makes/made your job harder



Graph 1

Do you feel CMT restricts (or has restricted) you from obtaining work?



Graph 2

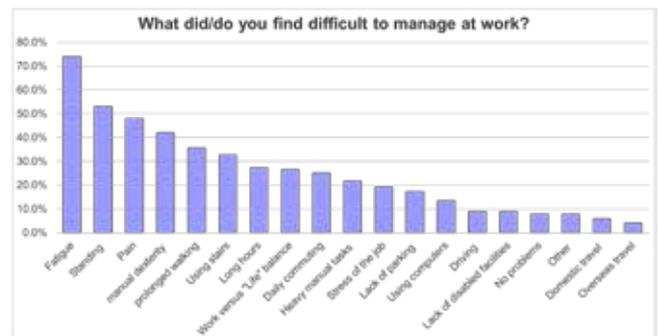
## Patients and Methods

An online survey was designed in collaboration with the charity Charcot Marie Tooth United Kingdom (CMTUK) and open to approximately 1500 members of CMTUK for 12 months. The survey consisted of 41 multiple choice questions including questions on diagnosis, main symptoms or functional problems, and how the disease impacted the patients' ability to work. Participants were also asked about factors that might affect how they were perceived in the workplace and whether they felt discriminated because of the condition.

Retired members of the charity were asked to answer a further set of questions regarding their age of retirement and the factors involved in their decision to retire.

Table 1

Symptoms	N	Percentage (%)
Foot drop - distal weakness	198	66.4
Hand weakness/poor dexterity	164	55
Cold hands/feet	190	63.8
Balance problems	253	84.9
Severe sensory loss	83	27.9
Fatigue	249	83.6
pain	132	44.3
cramps	144	48.3
Breathing difficulties	39	25.2
Sleep apnoea	43	27.7
Vocal cord paralysis	18	11.6
Hearing difficulties	25	16.1
Back problems (inc scoliosis)	104	67.1



### Patients' perception of work environment

- 116/266 (42%) patients found their colleagues supportive
- 67/266 (25%) found their immediate colleagues to be indifferent
- 7/266 (2.6%) described their colleagues as bullying or abusive
- 74/266 (28%) suffered discrimination at work because of CMT (Graph 4)
- 81/266 (30%) of participants had not disclosed their condition to their employers

### Retirement

- 134/301 (44.5%) respondents were retired and only 8/129 (6%) retired at the normal retirement age in the UK (65 years) (Graph 5).
- 48/129 (37%) retired between the ages of 55 and 64 and 16/129 patients (12%) retired before age 35.
- 74/129 (57%) of retired participants retired entirely because of CMT and 31/126 (24%) listed CMT as a contributory factor (Graph 6). However, 24/126 (19%) of those who retired because of CMT did not receive "medical retirement" with the associated benefits.

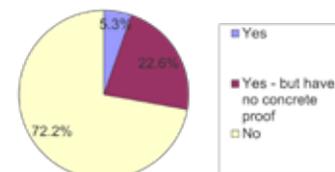
## Discussion

- CMT affects patients' career choices and their ability to work
- CMT is a common reason for early retirement, however a significant proportion do not receive medical retirement
- The findings raise important questions about how society needs to evolve processes to help people work and stay at work.

### References:

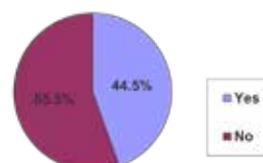
1. Reilly MM, Murphy SM, Laurá M. Charcot-Marie-Tooth disease. JPNS 2011 Mar;16(1):1-14.

Have you ever suffered discrimination at work because of CMT?



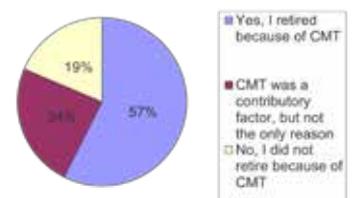
Graph 4

Are you retired from work?



Graph 5

Did you retire because of CMT?



Graph 6



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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](http://www.cmt.org.uk)