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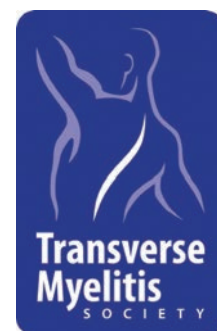


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Winter 2016

The Magazine

TRANSVERSE MYELITIS SOCIETY



BBC
RADIO

1



OUR SUPER HEROES

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LETTER FROM THE EDITOR

WOW, where do I start? TM, NMO etc. are very rare autoimmune conditions, which can have terrible physical and mental repercussions, yet here I am totally blown away by the remarkable number of young people featured in our magazine who have overcome adversity and reached heights that demand total admiration from the rest of us.

Even without the added interest of four TMers taking part, the Paralympic Games was exactly what it means 'parallel to the Olympic Games', with many people tuning in to watch. I don't know about you but I was totally hooked. Who knew that wheelchair basketball and wheelchair tennis could be so

“ This has been a very emotional magazine to put together with all these stories of people winning against the odds. I would like to say a huge thank you to all our contributors who took time out of their very busy lives to write for us. ”

riveting? As for the rowing, I was screaming at the TV when the boats appeared to be so close to each other. I confess that, not being horsey, I don't understand the rules of dressage, but enough to know that horses aren't meant to walk like that! It was just beautiful to watch such elegance from horse and rider.

I would like to add my own special award category; that of Super-Charged Mum. I am going to hand out gold medals to Lorraine Baker, Alison Reid, Natalie Rowles, Sarah Pratt and Suzanne Williams. These extraordinary women have tirelessly given their time, driving their children around the country, sometimes getting up at 4.00am, accompanying them as they took part in competitions around the world, cheering them on, and being there for them during the dark times. Would I do it for my children? Probably.

These Paralympians are exceptional young people who have fought so hard against their disabilities to achieve their goals. But what about the other 98% of disabled people, for whom life is a daily struggle? Getting up when you've been awake half the night with unbearable pain, that no amount of painkillers will touch because it isn't 'real'. Or coping with depression, the dreadful PIP assessment, manoeuvring a wheelchair up kerbs,

in shops etc. If you have achieved one of your goals today, even if it's just to get out of bed, I salute you.

One person who has more than struggled is Niamh Wedlake. I first came across her way back in 2012 when her mother, Suzanne, wrote her story. NMO has not been kind to her, but she has fought her demons, and a year ago set up an Instagram account @youngpeople_chronicillnesses to help other young people cope with chronic conditions. I'm delighted to announce that her work has been recognised and she has just won a prestigious 2016 Radio 1 Teen Award. This is awarded to only four young people each year out of the thousands who apply.

I can't go without mentioning the TMS Family Weekend. As Editor, I try to remain impartial, I feel this is such an important thing for our young people with TM, NMO etc. I can't imagine what it must be like to be a child with one of these rare conditions. No wonder they can feel isolated. The feedback from this year's weekend makes it quite clear that the whole family benefitted from having the opportunity to share their experiences with others – but it costs money! We need to find a way to make sure this is an annual event, so, if you have any ideas for fundraising, please message me.

This has been a very emotional magazine to put together with all these stories of people winning against the odds. So on behalf of our readers, I would like to say a huge thank you to all our contributors who took time out of their very busy lives to write for us.

I would like to take this opportunity, along with my co-editors, Zelda and Heather, to wish you all a very happy and healthy Christmas and 2017!

Don't forget, we need your stories, comments and suggestions for future magazines. Just email me

annie.schofield@myelitis.org.uk

Annie

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**The Transverse Myelitis
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A WEEK IN THE LIFE OF A RADIO 1 TEEN HERO

NIAMH



“That afternoon I was taken to Kensington Palace and greeted by the Duke and Duchess of Cambridge! It was such an honour and one of the coolest things that’s ever happened to me. It’s made all the fights against my body worth it.”



On October 18th I attended the BBC Radio 1 studios in London. The building was so beautiful, very tactile and colourful! It wasn't what I expected at all, it was just very cool and interesting seeing the behind the scenes action! I got the chance to be live on air with Clara Amfo to announce my receipt of the BBC Radio 1 Teen Hero award and to share a little about my story. Afterwards I hung out with Clara for the rest of the show and watched The Two Door Cinema Club in the Live Lounge.

My Mum and I went for lunch and met the other inspirational, courageous teens. I was nominated for fighting Neuromyelitis Optica yet creating an empowering project. I created a page called @youngpeople_chronicillnesses a year ago with a few friends raising awareness of illness, sharing our journeys and spreading the stories of others. Our goal is to end the stigma surrounding illness. We want to show what it's really like but also what you can achieve even though you're struggling. The page saved me and helped me recover from self-harm! I know for a fact it has saved a lot of my followers lives too. The continuous love and support that platform brings is indescribable. That afternoon I was then taken to Kensington Palace and greeted by the Duke and Duchess of Cambridge! Yes that's right, they've heard the words Neuromyelitis Optica! It was such an honour and one of the coolest things that's ever happened to me. It's made all the fights against my body worth it.

Something even crazier was rolling out on stage in front of 10,000 people at Wembley Arena! That day started off back stage which actually wasn't that glamorous, just a cold car park really! We met



A WEEK IN THE LIFE OF A RADIO 1 TEEN HERO

NIAMH



with the staff at Wembley and Radio 1 and were told about the plans for the day. After that we went to be photographed on the red carpet, which was not what I had expected. Flashes everywhere and lots of loud people shouting “Look this way!” The photo turned out lovely eventually though!

“ Then I went on to receive my award. The crowd had just been told my story and heard how even if you’re sick you can achieve anything - you just have to do it differently. The SCREAMING was so loud it made my ears hurt but I was so proud of myself. ”

Before the award ceremony began we spent time chilling out in a room chatting about how amazing the opportunity was and everyone was starting to get nervous. We were, however, surprised with a ‘meet and greet’ with a worldwide famous boy band called The Vamps! It was exciting telling all these people about my story and hearing them tell me bits about theirs. I felt so happy that all my hard work just trying to stay alive has been worth it. Then I went on to receive my award. The crowd had just been told my story and heard how even if you’re sick you can achieve anything - you just have to do it differently. The SCREAMING was so loud it made my ears hurt but I was so proud of myself. I had the shock of my life when Clara announced that Jess Glynne was about to walk on stage. She was so kind and so inspired by what I have done for the chronic illness community.

After the overwhelming feeling from going out on stage subsided, I went back to sit with my best friend, Chloe. Chloe is my long-distance friend who helps as an admin on my page so I couldn’t have asked for anyone one better to come. I wish I could’ve had all the girls! She spent the weekend with us having fun and doing lots of exciting things, which we don’t usually do. We are either in hospital or bed most of the time!

The week was amazing, overwhelming and exciting. It made me realise how much I have actually overcome in my life and I am so proud. Without the endless support I receive online and offline I truly would’ve lost my fight by now.



TMS FAMILY WEEKEND

The TM Society Family Weekend brings together children and young people living with TM, ADEM and NMO, and their families, to share, support one another, learn, and develop friendships.

The event is held at the Calvert Trust, a residential outdoor centre in the Lake District National Park, with the aim of delivering challenging outdoor adventure holidays for people with disabilities.

Its mission is "to enable people with disabilities to achieve their potential through the challenge of adventurous activities in the countryside in order for them to develop, change perceptions and make positive and lasting changes to their lives".

The Calvert Trust endeavours to offer life changing experiences which provide positive results that last long after the stay at the centre. Their experienced staff work to ensure that everyone reaches their potential no matter what their level of ability, building confidence and developing a range of skills, which enables visitors to take up new challenges when back at home.

This is what the TM Society wants for its children and young people who live with TM, ADEM, NMO, as well as their siblings and parents. This year 15 families took part, 15 of whom were children with TM, ADEM and NMO.

The outdoor activities, which are a key feature of the weekend included orienteering, bushcraft, canoeing, zip wire, rock and rope (swinging, climbing, abseiling), riding horses, trap driving, archery, and cycling. There is also an indoor pool, a games room, and opportunities to watch movies, or take advantage of the neuro-physiotherapy sessions on offer.

There was a disco on the Sunday evening and one child, who had brought along his guitar, played and sang for everyone.

A representative from Molton Rock attended with their Boma off-road wheelchair for people to try, and it was a great success. Molton Rock had approached the TM Society to ask if we wanted this when they saw an article about the Family Weekend in our magazine.

This year educational Q&A sessions with medical and healthcare professionals experienced in treating TM, ADEM and NMO were offered to both the parents and children/young people to give them the opportunity to learn more about TM,

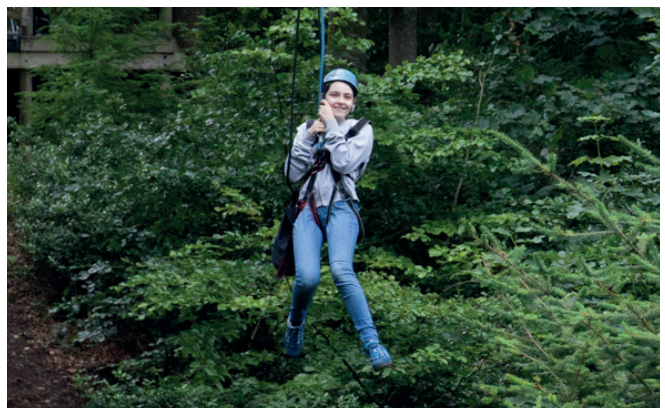
ADEM or NMO and what else they can be doing to manage the impact of the condition.

8 medical and healthcare professionals specialising in working with children attended, including a neurologist, neuro-disability consultant, educational psychologist, urologist, urology nurse, nurse specialist in NMO, and neuro-physiotherapists.

Four of the teenagers aged 14+ were asked to be camp counsellors, giving them responsibility to help with welcoming families, answering children's questions, and generally being there for them. Their help made a valuable contribution to the weekend, and the ethos of making the weekend by families for families grows.

A new feature this year was the 30 minute neuro-physiotherapy sessions. This allowed parents to learn the benefits of neuro-physiotherapy and some have entered the neuro-physiotherapy bursary scheme as a result.

Barbara Babcock's full report can be found by going to www.myelitis.org.uk/report-on-2016-family-weekend.html



TMS FAMILY WEEKEND



A wonderful weekend with our son Danny, who developed ADEM when he was just 4 years old.

What an amazing opportunity to have been able to meet other children, young people and families who have experienced similar circumstances.

We made new friends, participated in fantastic activities and generally were able to enjoy time as a family without having to explain our "quirks" to others.

The accommodation and staff at the Calvert Trust were perfect and the organisation of the weekend was exemplary.

Thank you all so very much.

Dana Petherick



We had a fantastic time at the lakes. Such an amazing opportunity to meet others going through the same daily struggles as us, as well as talk to specialist doctors, nurses and psychologists. Our daughter Soffia was diagnosed with ADEM nearly three years ago. Before the camp we were very alone. Social media was the only means of contact with others dealing with the same issues.

The weekend has helped us as a family in so many ways. Soffia now has a WOBL watch and is totally in control of her own toileting (no more accidents). She also had a physiotherapy session with Aneska, who has a very special way with children. Aneska found she had very poor hand eye co-ordination, core stability issues and poor shoulder control. From this assessment she has now had further sessions locally, funded by the TM Society. To look at Soffia you would never think she had been ill. She really has come such a long way from not being able to walk and talk to being a lovely confident little girl. I'm not sure really what I expected from the weekend but it really did have a positive effect on our lives. We are so thankful to the TM Society.

Leanne

TMS FAMILY WEEKEND



Eliot really loved the weekend and especially enjoyed riding Prince. He also liked the zip wire and archery. He said it was good to be there with other TM children and their brothers and sisters.

For us as parents, it was good to talk to others who had gone through the same, and bounce ideas off each other. The weekend was invaluable to us as new parents of a child with TM. It helped us emotionally to deal with what had happened and gave us hope for Eliot's future.

Barbara was a great support and facilitator, making everyone feel welcome.

The facilities were perfect and the food excellent. The instructors were lovely and built good rapport/relationships with the children. As a result of the weekend and the physio sessions there, we have had a few sessions at the Birkdale Clinic and Eliot's core strength is really improving!

Kerry Wilkinson

We all had a fantastic time at the Calvert Trust. TM has left Owen very disabled and he is unable to do anything for himself. At the Calvert Trust it allowed him to take part in doing things like canoeing, archery, horse riding, rock-climbing, mountain walks, and swimming. These are all things that usually he can only dream about. He is 17 and loves the social aspect of meeting people and making new friends. What we all found really beneficial was the chance to ask the professionals questions and hear about other families' struggles which are often the same as ours. It really helps us not to feel isolated and to see all the children with big smiles on their faces is a real tonic for anyone.

Rosie



TMS FAMILY WEEKEND



PHOTOS COURTESY OF JASON HARGADEN

This year, as one of the older siblings, I was asked to be a camp counselor, along with Katie, Owen and Caitlyn. I was quite nervous about this at first, but once I got there and Barbara told us what to do it was great. We supplied people arriving with name badges and welcome packs, and showed people to their rooms – as we had all been before we all knew our way around - and helped Barbara to direct people, and round up the little ones when it was time to start an activity. It was so nice to meet up with everybody again and to meet some new people too! It's nice for my Mum and Dad to meet other parents that they can talk to about George's TM – they usually just tell people everything is great, but when they meet up with other TM parents they can talk about problems and get advice from people that know what they're talking about!

We'd love to go to camp again next year, and I'd love to help out again if I'm needed.

Hattie

Save the date! The TMS Family Weekend will take place again 14-17 July 2017 at the Calvert Trust in the Lake District. Registration will open around February and if you are member of the TM Society and have a child in the eligible age range of 4-17, you will receive an email about this.

PRACTICAL ADVICE FOR EMPLOYEES WITH TRANSVERSE MYELITIS FACING DISMISSAL

Marsha Thompson is an Employment Solicitor, and has acted on a number of high profile cases, including bringing an unfair dismissal case against a member of foreign royalty and advising a senior employee on a serious whistleblowing case concerning allegations of anti-Semitism. She also has experience of running a pro-bono legal advice surgery (advising employees with disabilities) for a charity in Redhill.

The Transverse Myelitis Society is aware that a number of members are facing dismissal or have been dismissed for reasons relating to their Transverse Myelitis ("TM").

Employees with TM can often find themselves in a difficult situation at work. This is because the symptoms of TM can be all consuming and at some point could impact on their ability to carry out their jobs effectively. As the condition is so rare, formal diagnosis may not take place until months or years after the first attack. As such, most employers may not know how to handle an employee with TM. This can lead to an employee being subject to unfair capability procedures or in the worst case scenario an unfair dismissal. It is important that employees with TM know their legal rights relating to unfair dismissal and disability discrimination.

What Does The Law Say?

Under the Equality Act 2010 ("the EqA"), a person is disabled if they have a physical or mental impairment, and the impairment has a substantial and long-term adverse impact on their ability to carry out normal day-to-day activities.

Many people with TM may be classed as disabled under the EqA. However, this will depend on a number of factors including the severity and duration of their symptoms.

All disabled employees, however long they have worked for their employer, are protected from disability discrimination under the EqA. Dismissing an employee because they have a disability/TM or because of something arising from TM could be unlawful discrimination. Furthermore, dismissing an employee with TM without making reasonable adjustments to prevent them from being disadvantaged at work could also be unlawful.

If you have worked for your employer for at least two years, you also have the right not to be unfairly dismissed, whether or not you have a disability under the EqA. A dismissal relating to the capability of an employee is potentially a fair dismissal, but the employer must act reasonably in all the circumstances, including the employer's size and administrative resources.

This article focuses on some of the steps, which an employer should take if considering dismissing an employee with TM.

Capability

You may need to take time off work during particularly bad episodes of TM. These absences can negatively affect your ability to do your job. In such cases, this can ultimately lead to you being dismissed on the ground of capability (ill health) i.e. because you are no longer capable of doing the job you were hired to do. However, an employer must assess your capability to do the job by reference to your skill, aptitude, health or any other physical/mental quality before dismissing you otherwise your dismissal may be unfair. In addition, if your employer does not assess your capability before dismissing you, it may be discriminating against you because of your TM or for something arising in consequence of your TM.

What does a fair (capability) dismissal process involve?

In order to dismiss you fairly and to avoid discriminating against you because of your TM (or for something arising in consequence of your TM), your employer will need to show that capability was the reason for your dismissal AND that a fair process was carried out in order to dismiss you.

A fair dismissal process would involve careful consideration of:

- The nature of your illness.
- The prospects of you returning to work.
- The likelihood of the recurrence of the illness/prognosis.
- The need for your employer to have someone doing the work you do.
- The effect of your absences on the rest of the workforce.
- The extent to which you were made aware of the position.
- Your length of service.

Before dismissing an employee on the ground of capability, an employer should:

1. Ascertain the current medical position

Your employer should (in most cases) make every effort to ascertain your current medical position before making the decision to dismiss you. This would involve making enquiries with your doctors in order to seek all relevant information regarding your illness. Ideally, your employer should request a medical report from:

- a) Your GP
- b) An Occupational Health adviser

PRACTICAL ADVICE FOR EMPLOYEES WITH TRANSVERSE MYELITIS FACING DISMISSAL

c) A doctor retained by your employer

Your employer may need to request medical evidence from more than one of the above medical experts to confirm your current medical position. If your employer fails to obtain medical evidence or ignores medical advice, this could be considered unfavourable treatment (an act of disability discrimination) because of something arising in consequence of your disability – unless it could justify doing so.

2. Consult with the employee

A fair dismissal will always involve your employer meeting with you to discuss your condition and to establish whether any action can be taken to facilitate your return to work. You should be given the opportunity to discuss the medical evidence with your employer and raise any issues you may have with it. Your employer may also keep in reasonable contact with you during any periods of sickness absence.

Your employer will be expected to follow its capability procedure, whilst offering practical support and assistance. In addition, it may set timescales for improving your attendance and give you warnings where appropriate.

If your employer fails to consult with you or fails to comply with its internal procedures, these could be classed as acts of disability discrimination.

3. Consider reasonable adjustments

Your employer should consider altering some aspects/features of your role if this could avoid the need to dismiss you and/or if this could prevent you from being disadvantaged at work. This shows reasonableness in regards to a fair dismissal and because your employer has a duty to make reasonable adjustments for disabled employees under the EqA. If your employer failed to make reasonable adjustments, this would be considered disability discrimination. This is covered in more detail in the Summer 2016 edition of the magazine.

4. Consider alternatives to dismissal

Your employer should consider whether there is any suitable alternative employment available before taking the decision to dismiss, although it is not normally under a duty to create a job if one does not exist. In some circumstances it may be worth considering whether you are entitled to take a career break, ill health early retirement or claim under a permanent health insurance policy.

Dismissal should really be the last resort once all other alternatives have been explored.

Dismissal

Once your employer has decided, following a reasonable investigation and based on the evidence that it has no alternative but to dismiss you, it should invite you to a meeting to discuss the matter. You should be given sufficient information about the circumstances of your case and the possible outcomes (i.e. dismissal), to enable you to participate meaningfully in the meeting.

At the meeting, your employer should give you the opportunity to present your case against dismissal. Once a final decision has been made, your employer should confirm the decision in writing, together with the reason for dismissal, the effective date of your dismissal and details of your right to appeal. If you decide to appeal, your employer should also offer to hold an appeal meeting to go through your appeal. Any final appeal decision should also be communicated to you in writing.

Lastly, your employer should ensure that you are paid all of your contractual and statutory entitlements including any unpaid but accrued holiday pay.

If your employer dismisses you because of your need to take sickness absence, this could be considered unfavourable treatment because of something arising in consequence of your disability. In those circumstances, you may have a claim for disability discrimination unless your employer can justify dismissing you. In addition, if your employer does not follow a fair process as outlined above, you could also have a claim for unfair dismissal.

Seek Advice

You should talk to your union representative if you are a member of a union. Your union representative can assist you in attendance management/dismissal meetings with your employer and check that you are being treated fairly. It is also important to note that if you have been unfairly dismissed (or discriminated against), you only have three months minus one day from the date of the termination of your employment (or the last act of discrimination) in which to register your potential claim with Advisory, Conciliation and Arbitration Service ("ACAS") before you can lodge a Tribunal claim. Therefore, you must not delay in seeking advice. For more information see: www.ACAS.org.uk

Lastly, if you feel you may have been unfairly dismissed or discriminated against because of your disability and would like advice regarding your legal rights, contact our expert employment lawyers on freephone 0800 916 9060 or www.slatergordon.co.uk



Slater and Gordon are a leading employment law firm with offices across the UK.

TO CRUISE OR NOT TO CRUISE

JONATHAN GREEN



Jonathan Green, a Building Surveyor, is 52 years old, married to Kim with three grown-up boys. He contracted TM five years ago and is now paralysed from T6. His interests include science, photography, reading, music and the great outdoors! He is a former 'Street Pastor' and is passionate about social justice.

Have you ever considered going on a cruise? If someone had suggested this to me, pre-TM, I would have 'laughed like a drain' – especially thinking of all the stereotypical images of 'oldies' shuffling around, attending 'line dancing classes' and singing along to 'red-coat Butlin's style' stage shows, with plenty of stand-up Hi-de-Hi-like comedy!

But, post-TM, and coping with paralysis from T6, is a different matter! Suddenly a cruise had all the possibilities of foreign travel, but in a relatively controlled environment, getting to places I'd only imagined visiting since TM. OK, they can be pricey, but they don't have to be; there are so many options and deals available. Here's a few thoughts, based on our experience.

We went with another couple and opted for a package offered by P&O Cruises, on their huge ship 'Ventura', capable of carrying around 3000 passengers and 1200 crew – a veritable floating town!! But don't let that put you off 'cruising' - as ships can range in size and capacity enormously. This one just happens to be colossal! But, here's the thing; once on board, it didn't seem crowded at all. In fact, when exploring down corridors and circulation areas, it really felt calm and quite quiet. Even at

night, with families on board, the ship was peaceful and quiet.

Out of necessity, we chose a wheelchair accessible cabin, with en-suite wet area shower room, but also one with a large balcony to give us extra space.

Our cabin was not only spacious, it was well appointed and superbly air-conditioned. Serviced by very friendly and considerate staff at least three times a day!

In terms of catering, we opted for 'Freedom Dining', which as the name suggests, gives much more latitude in terms of the 'where' and 'when' for all our meals – which were exquisite in every way... 5-star treatment!

Our cruise took us from **Southampton** (Ventura's home port) to **Cadiz** – Spain, **Barcelona** – Spain, **Cannes** – France, **Civitavecchia** – Italy, Naples – Italy, **Cagliari** – Italy, **Gibraltar** – UK, then back to **Southampton**... 14 nights altogether, with each port visited for just one day. Altogether, we travelled 4680 nautical miles. Wow, it didn't 'feel' like that!

Without exaggeration, P&O did not put a foot wrong, from the moment we turned up at the Southampton port terminal to embark on the cruise, through to disembarking on our return.

Rather than give you a blow-by-blow of the places we visited, I'll limit this article to some of the things that you may want to know about the practicalities of cruising – perhaps what to look out for, together with any noticeable risks that could be limiting factors for you.

First of all, entertainment and stuff 'to do'. There's literally tons of it! From full scale theatre productions (which would not be out of place in the West End) to being pampered in one of their salons. Any feelings of boredom would have been self-inflicted self-pity!

Even when simply 'at sea' during the day, it's possible to watch out for sea life (in my case, I saw some dolphins swimming beside us) as well as taking a dip in one of the four pools on-board if you happen to be able, post-TM. But, there's musical entertainment, cinema, bars and game-rooms etc too.

Accessibility

From a disabled access perspective, P&O have broadly got it totally 'licked', save for two relatively minor points. The access to the uppermost 'sun deck' was straight from the lift through a heavily sprung door, with a rather tricky short ramp on both sides of the door. Without someone assisting me, I found it a rather risky manoeuvre although succeeding on the two times I attempted it alone.

TO CRUISE OR NOT TO CRUISE

JONATHAN GREEN



The other slight issue was the fairly narrow corridors, which although fine for most size wheelchairs, you wouldn't be able to pass another coming from the other direction. In addition, the room service staff had large 'trolleys' carrying all the linen and free accessories, which (quite reasonably) they 'parked' in the corridors adjacent to the rooms they were working in. This left a very narrow gap to get past. My own wheelchair is pretty narrow, but I had to 'scrape' past with no spare space between my chair and the trolley.

The ship is equipped with several passenger lifts which were all in good working order, swift to convey you, and met all the standards you would expect under the Equality Act or Part M of the Building Regulations!

Getting on and off the ship was rather easy, as the 'safety-conscious' staff insisted on providing the 'muscle' to get wheelchair-users safely across the gangplank; always in pairs and giving you a sense of confidence.

Of course, as you might expect, once off the ship, accessibility was variable. Italians were the worst, and have done their 'level' best (haha) to evade all EU Directives associated with access and disabled facilities! Such is life! We Brits choose to 'queue'!

Challenges

As already mentioned, accessibility off the ship was very varied, so it's important to have someone in your party that can help you overcome all sorts of pitfalls – and accept that some might be impossible to overcome. For instance, despite being advertised as 'wheelchair accessible', I found that the vast majority of Pompeii was not possible to get to, just because one section of galvanised steel gangway was missing!

At a more mundane and personal level, we were challenged by the amount of supplies we had taken with us – we literally only just made it (there would have been very limited help available on board or in-port for fairly complex needs, so you need to be

vigilant when 'packing' to go). Before we go away, it always seems as if we're packing for a full scale expedition somewhere remote. But even our 'normal' attention to planning went a bit south on this occasion!

For example, I had an unexpected urinary tract infection, which meant I was using up my intermittent self-catheters at an alarming rate. I fully used up our 'extras-just-in-case' with nothing left to spare by the end. It's very unlikely we would have been able to obtain any catheters if we had actually run out!

One particular challenge that I should have foreseen was bowel trouble! The food on board (albeit 5-star throughout) is obviously very different from our norm – and I hadn't given that a moment's thought! My bowel became bunged-up for several days, eventually requiring help from the 'on-board' hospital.

The hospital on the ship is simply first rate and well equipped in many respects. The staff are also superb but obviously, you don't want to be going there, unless you really have to. It's expensive for one thing, so best think ahead strategically about the kind of challenges you face day-to-day, and if necessary ask questions!

Some people may discount the whole concept because of feeling 'sea-sick' – and on a smaller ship/boat, that might well be a problem, but on Ventura you would hardly know you were at sea! It was constantly moving forward but with surprising stability – the rhythmic movement was so slight as to be negligible. In fact, one side benefit was that my wife was sure the gentle movement rocked her to sleep!

Conclusion

Don't let the stereotypes put you off considering a cruise – I can't recommend it highly enough – and I was your quintessential sceptic initially!

The staff on-board were all outstanding and couldn't do enough to help – and the food was excellent throughout, with an exceptionally good and varied menu every day.

It would have been really hard to find fault with it – and if there were any, it lay at the feet of others and not P&O and the way they operated. It was first class, which also explained why we met several people who were on their umpteenth cruise (26th was the highest I seem to recall of the folk we met). But I can now see why!

This has been our only experience of cruising, but it has left me feeling very positive and confident about it. So, I would not hesitate going on another, or to recommend the experience to others! Why not 'go for it' – and widen your vista on an otherwise 'limiting' world. Don't let TM get in the way!

THE ROAD TO RIO

OUR PARALYMPIAN CHAMPIONS

Weren't the Paralympics amazing? What an amazing sight, so many people with disabilities competing in so many challenging sports. The great news was that we were all able to support four British Paralympians affected with Transverse Myelitis! Yes, four! And all four won medals. As well as overcoming the challenges, which are faced and overcome on a daily basis by all of us with TM, the athletes trained and pushed themselves and triumphed!

Natasha Baker MBE Para Dressage Rider

Natasha contracted TM when she was only 14 months old. On the advice of her physio she started riding at her local RDA and became passionate about it. In 2000 she watched the Sydney Olympics and set herself the goal of becoming a Paralympic champion.

In 2002 Natasha was selected for the World Class programme and since then has won many National and International competitions including Overall under 21 International Champion.

In 2001 she met the horse she has ridden in two Paralympics, Cabral (JP), owned by Christian Landolt. They came to fame in 2012 at the London Paralympics when she won 2 Gold medals, one for her individual Grade 11 dressage test and one for her Freestyle (dressage to music). After that her sights were set on Rio 2016!

Preparations for Rio officially started in July when Natasha and JP were selected to ride in the Paralympics. Following the official launch and celebration the British riders and horses then had some hard work to do. JP's preparation included having hay delivered from America so that he could get used to eating what would be on the menu in Rio. Natasha's included trying on her special competition jacket, her new boots and various glamorous accessories! And of course there was training.

In early September JP set off, via Belgium, for Rio. Natasha followed him a couple of days later. Once reunited they started training again in the unfamiliar climate and new surroundings. Before the competition starts the horses' fitness has to be assessed. They are 'trotted up' – inspected by a team of vets and other specialists – to ensure that they are sound and fit to compete.

Natasha competed as part of the GB Team of four riders as well as individually. All the training and preparation paid off. On 13 September Natasha won her first class (in spite of a slightly spooky JP) and on 15 September she won again thereby collecting two Gold medals, one as an individual and one as a member of the winning team. Then on 16 September she triumphed again by winning her freestyle (dressage to music) class. So Natasha and JP returned from Rio with three Gold medals!

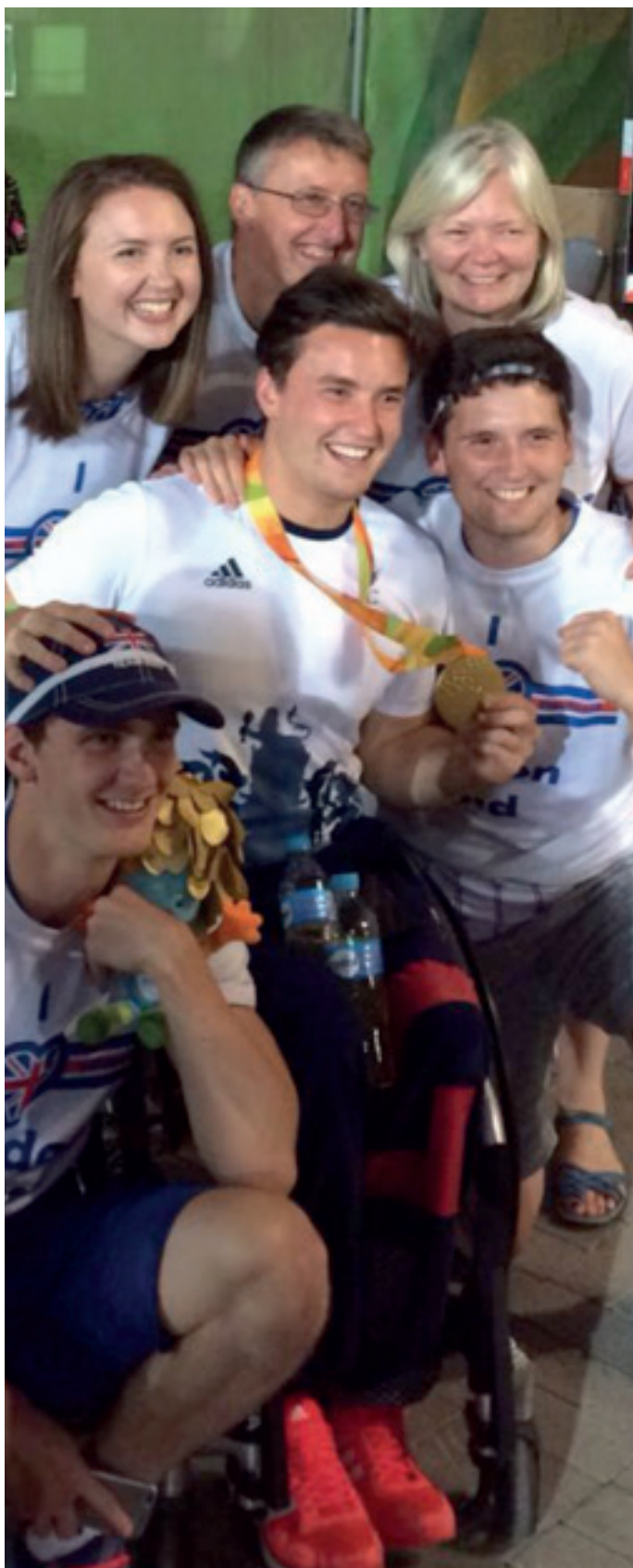
What now? A holiday for JP, celebrations, public appearances and some fun for Natasha - to be followed no doubt by preparations for the next round of competitions and perhaps wondering about Tokyo in 2020.



PHOTOS COURTESY OF JO HANSFORD PHOTOGRAPHY
WWW.JOHANSFORDPHOTOGRAPHY.COM

THE ROAD TO RIO

OUR PARALYMPIAN CHAMPIONS



Gordon Reid Wheelchair Tennis

Gordon 'Gio' Reid is a Scottish professional wheelchair tennis player who is ranked World No 1 in singles and No 2 in doubles.

This gifted tennis player comes from a family of talented tennis players. He started playing when he was six. He was a good junior player at Helensburgh Lawn Tennis Club. In 2004 when he was 13 he contracted Transverse Myelitis. He started playing wheelchair tennis in 2005 at Scotstoun Leisure Centre in Glasgow. In 2006 he was on a shortlist of ten for the BBC Young Sports Personality of the Year. He became the youngest men's Singles National Champion and he also played in Great Britain's junior team which won the World Team Cup in 2007.

When he was only 16 Gordon represented Great Britain at the 2008 Paralympics in Beijing, an achievement of which he is very proud. But this year, 2016, he has risen to even greater heights.

In January he won the Australian Open and then in June he won the men's singles at Wimbledon and the men's doubles with his partner Alfie Hewett. In an interview with BBC Sport he said "I said at the start of the week I wanted to achieve two things. First if there were any kids with disabilities for this to inspire them to take up the sport.

“ In January, he won the Australian Open and then in June he won the men's Singles at Wimbledon and the men's Doubles with his partner Alfie Hewett. ”

"And second was to continue to break down the barriers when it comes to disability sport, to showcase the talent in the sport. The coverage and interest we've had this week, it's been a big milestone and hopefully we can build on that."

Well, he certainly built on that in Rio! Not only did he win Gold in the singles, beating his doubles partner soundly 6-2 6-1, but he and Alfie Hewett also won Silver in the doubles championship.

In the wake of Gordon's achievements in Rio, wheelchair tennis in Scotland had another landmark to celebrate with a record 35 players competing in the Glasgow Wheelchair Tennis Tournament at Scotstoun Leisure Centre (where Gordon started playing) in October. "This is down to the Gordon Reid effect that has raised the profile of wheelchair tennis and encouraged people to play the sport. We had players coming from all four corners of the UK" said Andrew Raitt, Tennis Scotland Regional Development Manager South West and Disability.

Gordon's dream of breaking down barriers and showcasing his sport seems to have come true!

THE ROAD TO RIO

OUR PARALYMPIAN CHAMPIONS



Lauren Rowles ***Trunk-Arms Mixed Double Scull***

Lauren comes from Bromsgrove in the West Midlands. When she was 13 she contracted Transverse Myelitis, which left her with no feeling below her chest.

Here are Lauren's own words.

My Road to Rio started in February 2012 when I woke up one morning and was unable to move or feel my legs. Later that day I was diagnosed with Transverse Myelitis and came home seven months later as a wheelchair user. Watching the London 2012 Paralympics inspired me to get back into sport and I began to see my disability as a challenge.

My journey began at the University of Warwick Wheelchair Racing Academy. Two years later I was a 3 mile under 19 women's road champion, under 16 England champion over five distances and a Commonwealth Games finalist.

However, in February of 2015 I found myself in the middle of a lake rowing after being talent scouted by the GB Rowing Team. All it took was one session on the water and I was hooked. After rowing together for less than 5 months my partner Laurence Whiteley and I set out on a mission to place in the top eight at the World Championships in order to qualify our boat to go to Rio the following year. We came away from that Championships with not only the first qualifying spot in the whole of GB rowing team but also a silver medal only being half a second off the three-time world champions, Australia. From the moment we took the first stroke of the 2016 season Laurence and I were focused on the end goal... a Paralympic Gold.

Not only did I have Rio to worry about but I also had my A level examinations coming up and with University on the

horizon I had to learn to perfect the skills of time management and multi-tasking. With every last minute being precious now Laurence and I had to start living and breathing rowing. By the time we got on the plane to Rio we were ready to race and when we touched down we were focussed on one thing only. That gold medal. We opened the racing up on the second day of the games with a new Worlds Best Time and the fastest qualifying sport for the A final only two days away. When my alarm went off at 4am on September 11th 2016 I was ready for battle. The hundreds and thousands of hours we had spent training all came down to 3 minutes 55 seconds and as I look around after crossing the line for a moment time paused. As I looked across at the results board and saw the words "1. GBR" flash up I felt a wave of relief run through my body. I will never forget the first words I said to my partner Laurence... "we did it, we're Paralympic Champions". Once a Paralympic Champion always a Paralympic champion is a phrase I'll never forget and was the last thing said to me before we stood on that podium and watched the Union flag rise. No descriptive powers can ever explain the feeling but all I can say is that every ounce of sacrifice, pain and energy put into that Gold medal was utterly worth it. If you had told me back in 2012 that I would have gone on to become Paralympic Champion four years later I would have told you no chance. Today I say that anything is possible. All you have to do is take every opportunity you are given and commit everything to your dream because one day it will happen no matter how long the road is or the obstacles that get in your way.

THE ROAD TO RIO

OUR PARALYMPIAN CHAMPIONS

Phil Pratt Wheelchair Basketball

22 year old Phil comes from Cardiff. He uses a wheelchair, having contracted TM when he was three years old.

His first sport was wheelchair tennis at which he excelled, becoming the best player in his age group. However, when he was 11 he tried wheelchair basketball, and he was converted! As he was being sponsored he had to choose one sport, and as he loved playing in a team he chose basketball.

He was one of eight players from the GB U22 Team to receive the great honour of being selected to carry the Paralympic Flag into the stadium at the London 2012 Opening Ceremony. Phil made his debut for the GB Men's B Team at the 2012 Standard Life Continental Clash. Two years later, he took to court for the nation's first team at his first major tournament - the 2014 World Championships in South Korea where they came seventh. The following year, playing for the senior team, he won gold at the 2015 European Championships in Worcester.

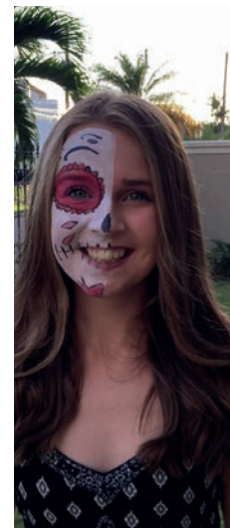
Then in 2016, he was off to Rio, accompanied by members of his family, helping Great Britain to win a bronze medal when they beat Turkey 82-76 after going into overtime – a very exciting finish following a tie of 65-65 at the end of normal time. The match will earn its place in history as one of the most dramatic wheelchair basketball games of the 2016 Paralympics.

With the cheers from the stands in Rio still ringing in his ears, bronze medallist Phil is now pursuing his career with a new team in Italy and no doubt looking forward to future triumphs.



“He was one of eight players from the GB U22 Team to receive the great honour of being selected to carry the Paralympic Flag into the stadium at the London 2012 Opening Ceremony. ”

TM KIDS FOR KIDS, BY OUR KIDS, PENNY AND GEORGE



I went on a trip of a lifetime in October last year to India. Since the last time I wrote in the newsletter myself and my family have moved to Trinidad/Tobago.

In the summer we were given the opportunity to move to the Caribbean and with a spontaneous decision we moved to Trinidad. Unfortunately, this meant that we had to leave the comfort of Robert Gordon's College and move to a brand new school. This was my biggest worry, that I would have to acknowledge a new set of friends with all of my many problems, or that I would not fit into the school. But I needn't have worried. Because of the size of the school there is only ten girls in my year, so everyone is friends with everyone making it a lot easier to make friends. On my first day of school I was given a warm welcome by the school and have made many friends. Another way I have made friends has been by trying and taking part in activities. Some of the activities I have been taking part in are track and field, volleyball, hockey, running and I am hoping to try rugby. One of the reasons that I have really enjoyed attending an international school is all the different cultures. Most people in my class are Trini but there are some Americans, Cubans, Chinese, Indian and many more. This has made learning even more intense, in the sense that they all have a very different view of life than I do.

The best bit of living in Trinidad, so far, is the weather. I really like living in a hot country but sometimes that can backfire. The temperature reaches 30-35 degrees everyday but if you deal with it in the correct way then you are fine. For example,

because we cycle to and from school I can get a little hot sometimes so after school every day I go for a swim in our pool to cool down. Keeping hydrated is another thing that I have to remember to do every day.

Within two months of arriving in Trinidad, Katie (my big sister) came home from boarding school. As a family we decided to take a trip to Tobago. We stayed in a villa for 5 nights with a beach as our playground. While we were in Tobago we took a day out to visit Pigeon Point. When we were there we hired a boat and went snorkelling with stingrays, pufferfish, eels and many other fish.

We also went on a tour of the island in a boat, which was amazing! Then imagine our delight a couple of days after arriving home from Tobago our container turned up. Now we are at the stage of finding homes for everything (which is proving to be rather difficult). I am loving our time on the island. It's a great adventure but I do miss my sister!

Penny x

TM KIDS FOR KIDS, BY OUR KIDS, PENNY AND GEORGE



Hello everyone, it's me, *George*. It's been a really busy summer for me here in Scotland. I am still surfing and loving it, although it is tough on my arms. They are getting much stronger, and I'm not so sore and weak afterwards anymore. I would recommend it to anybody to build core strength, which is what I needed, and of course it's great fun too!!

This summer holiday me and my family went camping – we went to Aviemore and Skye. The last couple of summers I have completed a climb and I wanted to do one on this holiday as well, so we decided to go up the 'Old Man of Storr'. It didn't look that high from the car park but once we started to climb I realised how far we had to go and I wasn't sure if I would manage or not. We had a few breaks on the way up, and passed a sign which warned about falling rocks which made it quite exciting!! Once I had got so far I knew that I had to go all the way and would be really cross with myself if we turned back. When we were at the top, the view was breathtaking – I couldn't believe how small everything looked down below and how small I felt. It was so silent and peaceful I could have stayed there forever. Well, if I hadn't been so ready for my supper!!

I also went to TM camp again this summer which was awesome – there were loads more people and I enjoyed meeting new TM kids and meeting up with my friends from last year. I loved seeing Michael and Owen again, and meeting Danny. It's great how everyone gets on so well, and we enjoy all the activities together. The disco was the best. Everyone just had so much

fun, and Michael's guitar playing was awesome – we all got to have a sing along. I can't wait to see everyone again next year, and maybe meet some more new people.

After the holidays, I started my first year at secondary school – this was quite scary. We had a special meeting with some of my new teachers and staff and told them all about my additional needs and Mum made them aware of all the things I might need put in place. I was so scared on my first day – I was worried mainly about getting lost and also going to the bathroom. My Mum bought me a Wobble Watch which she found out about from Michael's Mum to remind me to go on time. I soon found out where all of the bathrooms were, and once I had that nailed everything else fell into place. I've made some great new friends and am really enjoying secondary school.

I have recently stopped taking Oxybutinin, and the Desmopressin, both for my bladder problems, but then I had to go back on the Desmopressin again unfortunately, as I had a bit of a growth spurt. I'll try again in a few months and who knows, I might be able to come off this as well – I'll let you know!!!

THE FLU VACCINATION DEBATE

ZELDA CARR

Should I have a flu vaccination?

We have seen this question raised multiple times in recent weeks on the Transverse Myelitis Society Facebook page. The NHS offers all patients who suffer from neurological conditions a free flu jab or nasally administered vaccine but there may be that little niggle in the back of your head, is it safe?

The flu virus changes every year, so an annual vaccination is recommended to protect people from the circulating strains. The World Health Organisation (WHO) notifies vaccine companies in February of each year of the recommended strains for the next season, so there is an element of uncertainty, as flu strains change over time. The 2014/2015 vaccine was not as effective as previous year's because the anticipated strains were not the actual strains of influenza circulating that year. It takes a number of months to manufacture the flu vaccine. Northern and southern hemisphere flu vaccines also vary. Some flu vaccines are composed of weakened live (attenuated) viruses and delivered through the nose and other vaccines are manufactured from 'killed' virus particles and administered by intramuscular injection.

The flu vaccine is either a trivalent (three strains) or quadrivalent (four strains), and only protects the individual against those strains for that year. The flu vaccine is not designed to provide immunity against the common cold, which is a very different virus.

Many GPs and Neurologists recommend their patients get vaccinated. There are also Neurologists who recommend patients with Transverse Myelitis do not take the vaccine due to the possible implications to our hyper-sensitive immune system. Many people diagnosed with Transverse Myelitis have a flu vaccine with few or no adverse effects.

These are a selection of comments from recent Facebook posts, requesting information on whether a member should have a flu vaccination or not.

'I had mine last week, no side effects so far'

'Have mine every year with no side effects'

'NO, I developed TM after having a flu jab'

'I always have one as my Neurologist and GP both feel it would be worse if I got flu'

'Definitely not, I'm too nervous about the potential link between the onset of TM and various inoculations, I won't take the risk with anything'

'I was told never to get it, as that is what they believe triggered

me to get TM'

'Yes every year'

Most people will not develop any adverse reactions following the intramuscular injection, apart from a sore arm or a blocked nose and the sniffles from the attenuated vaccine administered nasally. There is, however, a small chance that you could experience an adverse reaction from both forms of vaccines. Adverse reactions are ranked under headings of frequency from very common ($\geq 1/10$) – approximately 1 in 10 people vaccinated) to very rare ($< 1/10,000$ – less than 1 in 10,000 people vaccinated). A person cannot get full blown flu from having the flu vaccine, as the virus has either been killed or is weakened.

“ Members who are offered the flu vaccination need to make their own mind up. ”

Members who are offered the flu vaccination need to make their own mind up. It is acknowledged by the flu vaccine manufacturers that nervous system disorders are a rare side effect of the vaccination but are categorized as 'not known', as there is not enough data to provide a risk. The Summary of Product Characteristics (SPC) for some flu vaccines lists Transverse Myelitis as a potential adverse reaction but this is extremely rare and may be listed because a patient or doctor has reported the adverse reaction in a previous season.

What about those of us who already have Transverse Myelitis? Since the flu vaccine is designed to elicit an immune response, it could switch your immune system into overdrive and exacerbate symptoms for a short period of time or even a relapse but there have not been studies providing any information on the risk.

Don't be frightened to ask your GP/nurse for details of the vaccine and ask them to explain any potential adverse reactions and answer your concerns.

Neurologists are more likely to be aware of the potential adverse effects of the vaccine, if you have any concerns.



Annual General Meeting (AGM)

Our 2016 AGM was held on 16th April 2016 at the Novotel near Heathrow. We had over 100 members in attendance.

The Agenda consisted of:

Report on the activities of 2015 – Barbara Babcock, outgoing Chair

2015 Financial Report – Jean Anthony, Treasurer

2016 Priorities – Sally Rodohan, President and Acting Chair
Re-election to the Committee of Rob Reeves

Sally gave warm and effusive thanks to Barbara, out-going Chair, for all her hard work and outstanding achievements over her three years leading the TM Society as Chair.

The PowerPoint presentation of 2015 activities can be viewed from the website (<http://www.myelitis.org.uk/report-on-agm-and-away-day-16-april-2016.html>).

The Rest of the Day

Our vision for the day was two-fold:

1. To have plenty of time for socialising, the timetable had longer coffee and lunch breaks than at previous conferences, and dinners organised for both the Friday and Saturday evenings.
2. To make it a day with interactive workshops, focussing on management of TM and associated issues. We had up to four workshops going on at any one time, so each member could pick the topics that they were interested in.

The Workshops

Symptom Management

Bladder and Bowel Management *

Depression Management *

Exploring Mind-based Pain Management

Fatigue Management *

"Lifting Your Spirits" (based on a book of the same name)

Mindfulness (for pain, fatigue and stress management)

Other Special Interest Topics

Awareness Event Workshop

Carers Workshop

Getting your life back on track post-TM *

Mindfulness for Carers

Parents Workshop

Working with your health professionals

(* These workshops ran twice)

Exhibitors

A number of exhibitors were on hand too. There was advice available on wheelchair skills, benefits, bladder and bowel products, and a representative from the Spinal Injury Association to explain the services that they offer.

Neuro-physio Drop-in Clinic

A big hit of the day was the drop-in clinic provided by Birkdale Neuro Rehabilitation Centre. Many of our members have not had physio sessions in years and have assumed that physio can't help them. Most people who tried it were pleasantly surprised that their balance or gait could be improved or their pain reduced. Following their 'taster' session, several of our members applied for a neuro-physio bursary.

Making a weekend of it

Although the AGM & Away Day sessions all took part on the Saturday, anyone attending were invited to extend the event by staying for a meal on the Friday night and/or the Saturday night. This seemed to work well as we had at least a third of the attendees opting to do this on one or both nights.

Entertainment

And this year we had a real treat! One of our TM Society members, Kai Addams, and her friend Sara Ashley, entertained us by singing after lunch and again during pre-dinner drinks on the Saturday evening. They were a big hit and it really did make the day feel special.

Feedback

Members attending said they learned a lot, both from the sessions and from talking to others. We had deliberately set out to deliver a day that was a departure from the conferences done previously, and that seemed to work for those who came.

What do members want for 2017?

In the past we have had events that were a 'conference' format where we have updates on research, talks from neurologists, urologists, and the medical aspects of pain and fatigue and many of our members have enjoyed these enormously.

Locations have included London, Wyboston, Liverpool, Oxford and Birmingham.

The committee discussed holding the 2017 AGM in London as a half day event with one or two speakers. If you have views on what we should do, or you'd like to help organise the next event, please get in touch via the Contact Us form on the website.

THANK YOU FOR YOUR SUPPORT

MORE FUNDRAISING STORIES



Lowndes Family Fundraiser

Margaret Lowndes was diagnosed with TM in 2013. Her son Joe decided to raise money for the TM Society by participating in the Mongol Rally, from London to Siberia, via Europe, Asia and Mongolia, a distance of 10,000 miles. Participants drive old bangers, with engine size restricted to one litre or less. Joe's car, a Fiat Siecento, nicknamed 'Mia', had a paint job inspired by the TV series "The Inbetweeners", the roof cage was home-made and the pipe on the bonnet a snorkel. He and 2 friends set off from Leek, Staffs. on 12 August, having already raised £231 in sponsorship money. We know they arrived safely, and look forward to hearing how much money Joe managed to raise after his epic adventure

Emma Anderson's Great Eastern Run

In May 2015 Emma's daughter Demmi was diagnosed with TM after spending three months in hospital. Demmi spent a few months in rehab at The Spinal Injury Centre, learning to live as a full-time wheelchair user, paralysed from T10.

Having enjoyed a lovely weekend in the Lake District Emma and her friend Rachel decided to challenge themselves to do the Perkins Great Eastern Run to raise money for the TMS and have raised £575 so far. Emma now has twelve months to talk Demmi into the Perkins Great Eastern Wheelchair Race!!

Karen Pearson's Paint and Picnic Day

Karen was diagnosed with Recurring TM 5 years ago. The Paint and Picnic group spent a glorious day in a beautiful English garden sketching and painting their surroundings under Karen's guidance. Attendees brought their own picnics, but there was a fantastic cake sale, second hand art book sale and a raffle to boot. The event raised £700 which has been split between TM Society and Kids for Kids charities. Karen has a silent auction for one of her larger paintings on in the Belfry Shopping Centre, Redhill, Surrey. The bidding ends on 31st Dec 2016 and 100% of the sale is destined for the TMS.

Becky Lewis's TM Fundraising Event

On the 14th October, Becky and her work colleagues held a charity event to raise awareness of TM, raising a total of £700 for the TM Society by holding a raffle. Becky was diagnosed with TM earlier this year and returned to work in August.



Aiden Hitchen

After Aiden's father was diagnosed with TM, he contacted the TMS and was sent a fundraising pack and organised an event on 26 March at his local pub. The whole family got involved, and Aiden went to local businesses and got them to donate items as prizes. They had a tombola, raffle, crafts for kids, stalls, name the teddy, food and music. Their target was £1,500 but they smashed it and raised £1,713.35.

The Wilson Family Sydney Bridge Run

Olivia Wilson's family ran the Blackmores Sydney Bridge run (9k) on 17 September 2016. It was only supposed to be her and her husband, but their babysitter let them down. However, the children said "we can do it with you". They are only 4 and 8 years old so it was pretty big for them! Tim ran the 9k, and she ran the 5k with the children! Olivia had just returned from the UK, so was running with the disadvantage of jet lag! She was diagnosed with TM 10 years ago and was desperate to raise some funds for the Society, and their efforts raised £380.

THANK YOU FOR YOUR SUPPORT

MORE FUNDRAISING STORIES

Annie Schofield's Big Birthday Fundraiser!

Annie had a big birthday in August, but instead of the usual presents, she asked all her friends to donate to the TMS Family Weekend. They did not disappoint, and along with her own fundraiser 'Annie's Pilates/Pool Party', they helped her raise more than £3400. Now she is looking at how to go forward to ensure the weekend is secure for many years to come, so look out for her next fundraising ideas!

Dave Riley Fundraiser

Dave Riley was diagnosed with TM in 2003. So to coincide with his 50th Birthday in March, his family held a fund raiser for the TM Society by hosting various stalls, tombola and a raffle. A total of £1,708.35 was raised. The family thanked all family and friends who helped to make the fundraiser such a remarkable day.

London Support Group BBQ

On Sunday 26 June 2016, the London Support Group, led by Danielle Pomerance hosted its first Awareness Day event in the form of a family BBQ. The aim of the day was simply to bring together TMers, their family and friends, in a relaxed and

informal environment to have fun, whilst raising the awareness and knowledge of TM within the wider community. Guests were charged £7.50 entrance for a full BBQ and raffle ticket. The group set up both a sweetie and a cake stall and placed donation boxes on the tables. Danielle was delighted to report that the day raised £765.



Andee Green's Cycle ride

Andee's main goal after onset of TM in January 2015 was that he wanted to ride again as soon as he could walk. The steroids left Andee needing a double hip replacement & cycling was the best recovery exercise available. Andee aimed stupidly high (his words) and entered the Prudential Ride London100. As TMS didn't have a direct link, he used the MS society to gain a charity placement & then added TM Society to the online fundraising, splitting the funds 50/50 raising approximately £850 for each charity. Andee is riding again next year and in 2018, once the TM Society has registered with the event. Andee hopes to become an integral part of the free ride for the TM Society.



Diane Cotton & Mark Ramsey

Mark had already been chosen to represent the TMS in the 2016 London Marathon on 24 April, running on behalf of his good friend Diane, whose sister has TM. Then Diane herself managed to secure a place in the open ballot! 5 years ago Diane's sister was 34, happily married with a career and 2 young daughters when TM struck very suddenly. She still tries to live life to the full within the bounds of her disability, however without the information and support from the TM Society Diane feels her journey would be a more isolated and less informed one. Not only did they cross the finish line close to their predicted times, they also raised more than £3300 for the TM Society (which including Gift Aid amounts to just under £4,000).

MY STORY

TRISH TUPPER



I'm Trish (37), happily married to Paul (39) and have two amazing sons, Adam (10) and Lewis (8). We may come across as a typical family with young children but it couldn't be further from the truth!

I have always dreamt of being a stay at home mum. Taking the children to school, trips out and fun every day was all part of my big plan. Adam was born eight weeks early but grew into a healthy, cheeky toddler. Lewis was born in 2008 and seemed to be a very healthy little chap despite an early arrival at 35 weeks. Just before Lewis' second birthday we were told that he had Dystonic Cerebral Palsy stemming from a brain injury. We had to try and keep a healthy balance of a normal life whilst trying to manage all of Lewis' medical problems. We became carers, giving physiotherapy, medications, pump feeds and suction to Lewis who had become profoundly unwell and was reliant on us 24/7.

On December 27th 2015, I picked up a hot cup of tea that didn't feel hot. I took a big swig and promptly burnt my mouth, realising I had no feeling in my fingertips. A week later I developed pins and needles in both hands and forearms while in the shower, but it wasn't until I tried to get out of the shower that I realised I couldn't move my legs. It was as if someone had weighed them down and glued them to the bottom of the bath. I also had no feeling or sensation in my pelvic area and waist and I had excruciating pain in my lower back.

After dragging myself downstairs Paul called 111 to get some advice.

By this time the lack of sensation and feeling had spread to my tummy and all down my right leg. The call-handler said an ambulance was on its way. I arrived in A&E with no sensation from my chest down so sitting up was becoming difficult. I was absolutely terrified.

After having bloods drawn, I was taken to the Acute Medical Unit. Although it was a weekend, thankfully a consultant was on duty. After a lot of tests, it was decided I needed an MRI scan urgently, as well as more blood tests and a lumbar puncture.

“ I picked up a hot cup of tea that didn't feel hot. I took a big swig and promptly burnt my mouth, realising I had no feeling in my fingertips. ”

On January 6th 2016 my consultant came in and very quietly said to us that I had a condition called Transverse Myelitis. I had 2 lesions on my spinal cord – one at T1 and one at C3. She said she couldn't tell me what my recovery would be but I would need a three day course of high dose steroids to try to reduce the inflammation. As a final comment she mentioned that I had three subcortical white matter lesions, but they weren't really anything to worry about. No explanation as to what Transverse Myelitis was, how I got it or why it happened so quickly.

I was scared. Was I always going to be like this? How would I care for the boys like this? An emergency meeting was held at home and care every night was approved indefinitely. It was made clear to all at the meeting that I was no longer allowed to carry out any of Lewis' care. It broke my heart. I felt like I was failing my family and there was nothing I could do about it.

On January 6th I received a Skype call from Paul with a really excited Adam behind him. His big beaming face filled the screen and he burst with pride as he told me he had been given 'Star Of The Week' at school and he would receive his trophy in Celebration Assembly the following Monday. After talking with Paul, and a lot of grit and determination from me, I learned to do a car transfer and bear the pain of sitting in a wheelchair.

On January 26th I was transferred to a specialist neurological rehabilitation unit to have intense therapy with the aim of getting home. Before I had time to settle in, Paul arrived and with everyone's help, he got me into the car and we whizzed to Adam's school. Paul and I were all in tears as we saw the elation

in Adam's face. I watched him receive his award with pride. After the assembly it tore me apart having to leave Adam and go back to the rehab unit but I knew that I was on the next part of my TM journey and would hopefully be home soon.

Rehab involved physiotherapy, occupational therapy, core group, and psychologist sessions.

The staff were all absolutely amazing. The only thing I found was that nobody knew anything about TM other than its name. No one could tell me why, what were the chances of recovery and whether I would be at risk of another episode. Also no one could explain why I had lesions on my brain. However, information on the internet about these lesions leant towards Multiple Sclerosis. This terrified me yet no one was able to help or guide me as I didn't have that as a diagnosis.

A chance meeting with another patient gave me the chance to look into things from another angle. She was being supported by the Spinal Injuries Association as she had Cauda Equina Syndrome and when she was talking to a peer support worker from the SIA he mentioned the injuries they supported. Transverse Myelitis was one of them. She came to tell me straight away and put me in touch with someone from the organisation who could chat to me about my illness and give me some direction for support. I learned more from him in one hour than I had in eight weeks of being ill. After going to the TM Society weekend, he gave me a copy of the TM magazine which had a great insight to the condition and where help and support was available.

During my rehabilitation I was taught how to strengthen my core muscles, to take steps with a walking frame and how to manage my indwelling catheter. I was given a wheelchair by wheelchair

services so I could regain some independence. A home visit a month before I was discharged was the most torturous thing I have ever done. I had to try bum shuffling up the stairs as I was unable to lift my leg more than half an inch. I tried and no matter how much the physio and OT tried to pull me up the steps, I just couldn't do it. I knew that if I could not get up the stairs I

couldn't come home. Lewis thankfully has a wet room attached to his bedroom downstairs, so at least I had a toilet and shower. It almost seemed pointless if I couldn't get up the stairs on my own. My Mum contacted my Dad and the decision was made that we would purchase a stair-lift so I could come home.

On April 29th I was finally discharged home into the care of my family. So many people thought settling back in at home would be fine for me but it wasn't and I really struggled. I felt like a stranger in my own home. It destroyed me watching the relationship between Lewis and his carers, knowing that I was no longer allowed to do anything to help him. They all seemed so close to him whereas I felt like a distant stranger. I struggled to bond again with Adam, and to be honest, we are six months into me being home and we still struggle to manage the bond between us. We say I love you every day to each

other, but I find it hard being in control when I feel so seriously out of control with everything.

I'm still scared, angry, frustrated, incredibly slow, forgetful, drop things, cry but I have learned that I am Mummy and a wife and I am Trish.



“After going to the TM Society weekend, he gave me a copy of the TM magazine which had a great insight to the condition and where help and support was available. ”

UK SUPPORT GROUP INFORMATION

London Support Group

Venue: ECHQ, 34 York Way, London, N1 9AB

The venue is wheelchair friendly and car parking free of charge from 1.30pm on Saturdays in York Way. There is no London Congestion Charge on Saturdays. We are a short walk 3-4 minutes from King's Cross Station. For further details please contact **Danielle Pomerance**, danielle.pomerance@myelitis.org.uk

South East Support Group

There will be a meeting in the new year run by a committee member once we have found a venue and sorted out a date. In the meantime if you have any queries you can email **Sally Rodohan**, sally.rodohan@myelitis.org.uk

Bristol Support Group

Venue: We hold our meetings in the main reception area of the **HOLIDAY INN**, Filton and they are very informal; any friend or family members are more than welcome. Look out for Jean's blue balloon.

Directions: Leave the M4 at junction 19. Take the M32 towards Bristol and leave at junction 1. Take the third exit on the roundabout (A4174) heading towards Filton and Parkway Train Station. The hotel can be accessed via a slip road approximately 800 yards up on the left. For further details please contact **Steve Collins**, stevecollins@blueyonder.

Cumbria Support Group

Venue: Eaglesfield Village Hall, Barkers Meadow, Eaglesfield, Near Cockermouth CA130RN. For further details please contact **Eileen Palmer**, Eileen.palmer@myelitis.org.uk

Poole/Bournemouth Support Group

Venue: The MS Society Bournemouth Branch, The Osborne Centre, Church Lane, West Parley, Ferndown, Dorset, BH22 8TS. For further details please contact **Lance Harris**, **01202 515216** or email lv.harris@hotmail.com

Northeast Support Group

Venue: Walter Best Hall within Cornerstones, Chester-le-Street Methodist Church, North Burns, Chester-le-Street DH3 3TF. For more information please contact **Nikki Macleod**, nikki.macleod@myelitis.org.uk or **07875 335798**

Telford/West Midlands Support Group

Venue: The White Lion Inn, Holyhead Road, Kelley, Telford, TF1 5DJ. For more information please contact **Anna Paulsson-Habegger** annaphabegger@gmail.com or **07581 708597**

UK SUPPORT GROUP INFORMATION

Exeter / Taunton Support Group

Venue: NOTE **HOLIDAY INN** not **HOLIDAY INN EXPRESS** Taunton. M5 Jct 25, Deane Gate Avenue, TA1 2UA. Future meetings in a private room. For directions go to <http://supportgroups.myelitis.org.uk/exeter>. For further details please contact **Rob Reeves**, reeves@myelitis.org.uk

Norwich East Anglia Support Group

Venue: The Therapy Centre, Units I & J Icenti Court, Delft Way, Norwich, NR6 6BB. There are plenty of car parking spaces. For further details contact **Gill Rice**, gillian.rice@myelitis.org.uk, Tel: **07867 781096** or **07867 781096**

East Midlands Support Group

Venue: The Village Hall, Lullington, Nr Swadlincote, DE12 8EG. For further details please contact **Janet Ashenden**. Janet.ashenden@myelitis.org.uk **01827 373997** or **0753 551661**

Oxford Support Group

A new venue is being looked into, so when that is sorted it will be on the website and in the next edition of the magazine. This venue will be suitable for members from Northamptonshire, Oxfordshire, North Buckinghamshire, South Warwickshire. For more information please contact **Zelda Carr**, Zelda@cqc-ltd.com

Telford Support Group

Venue: The Horseshoe Inn, Holyhead Road, Ketley, Telford, Telford and Wrekin, TF1 5AE. For further details please contact **Anna Paulsson-Habegger**, on **07581 708597** annaph@blueyonder.co.uk

Sheffield Support Group

Venue: St Mary's Church Hall, South Road, Walkley, Sheffield, S6 3TE. For further details contact **John Peckett**, johnpeckett@hotmail.co.uk

Transverse Myelitis Scotland

Venue: Dates of our meetings are posted on our webpage www.myelitis.org/scotland where travel directions can be found by clicking on the Events link. For any further information please contact **Linda Cornwall**, linda.cornwall@btinternet.com or **01324 579274**

USEFUL CONTACT INFORMATION

Bladder & Bowel Foundation

0845 345 0165
www.bladderandbowelfoundation.org

Brain & Spine Foundation

0808 808 1000
www.brainandspine.org.uk

Carers Direct

0808 802 0202
www.nhs.uk/carersdirect

Carers: The Princess Royal Trust

England 0844 800 4361
Scotland 0300 123 2008
Wales 0292 009 0087
info@carers.org | www.carers.org

Continence Foundation

www.continence-foundation.org.uk
info@continence-foundation.org.uk

Depression Alliance

0845 123 2320
www.depressionalliance.org

Scope

0808 800 3333
www.scope.org.uk

Disabled Living Foundation

0300 999 0004
www.dlf.org.uk

Disability Now Magazine

0207 619 7323
www.disabilitynow.org.uk

Driving: Disabled Motoring UK

01508 489 449
www.disabledmotoring.org

Driving Licences:

DVLA Drivers Medical Unit
0870 600 0301

Gardening

www.gardeningfordisabledtrust.co.uk

Mobility aids: Just Mobility

01923 265 577
www.justmobility.co.uk

Motability Car Scheme

0300 456 4566
www.motability.co.uk

Neuromyelitis Optica

www.nmouk.nhs.uk

The Walton Centre, Liverpool *Service Coordinator*

0151 529 8131
nmo.advice@waltoncentre.nhs.uk

John Radcliffe Hospital, Oxford *Service Coordinator*

01865 231 900
nmo.advice@ouh.nhs.uk

Pain Concern

0300 123 0789
www.painconcern.org

Pain: British Pain society

0207 269 7840
www.britishpainsociety.org

Prescription Prepayment Certificates

Nhsbsa.nhs.uk/1127.aspx

RADAR (The Royal Association for Disability and Rehabilitation)

<https://crm.disabilityrightsuk.org/radar-nks-key>
The National Key Scheme (NKS) offers disabled people independent access to locked public toilets around the country.

Riding for the Disabled Association (RDA)

www.rda.org.uk
info@rda.org.uk

Welfare & Disability Benefits *(Dept. of Work and Pensions)*

0800 882 200
www.dwp.gov.uk

Transverse Myelitis Society

35 Avenue Road Brentford TW8 9NS
www.myelitis.org.uk
U.K. registered charity 1108179
Lew Gray (Secr) 020 8568 0350
Email: lew.gray@myelitis.org.uk

Editorial Team

Annie Schofield, Zelda Carr, Heather Coltman
Design by **Nakia** at www.summermoonandco.com
nakia@summermoonandco.com

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