WINTER 2014/2015

The Magazine

TRANSVERSE MYELITIS SOCIETY

FROM PREGNANCY TO MOTHERHOOD

PAGES 4-5

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LETTER FROM THE EDITOR

I apologise unreservedly for the number of tissues you will need while reading this edition. But the stories of Amy and Danni are so uplifting I am sure you will forgive us. In different ways, both have overcome enormous challenges and it is a privilege to tell their stories.

Amy featured in our very first edition, with her story of contracting TM at the age of 13, but, despite missing months of school, went on to achieve her University degree. Her story has now been updated to include marriage to the lovely Steve, and giving birth to her daughter Violet in June. But TM doesn't just go away, and motherhood has thrown up some unusual issues – like just how do you get the baby out of the car and into the pushchair when you are disabled?

Danni was struck down in 2009 when her baby daughter was just 4 months old, and her husband was working overseas. She hardly left the house for 9 months due to the spasticity and pain, but fought her way back, first of all taking short walks, then challenging herself more and more until she eventually completed her first half marathon in 2012.

One of the most common areas affected by TM is the bladder; we are delighted to include an article by Govindaraj Rajkumar and Muhammad Thufael Uddinmbbs on the causes and effect of TM on the bladder. In our next edition, we will publish the second part of the article, which focuses on possible treatment, including Botox.

Penny and George, our TM Kids, have been busy as usual, find out what they've been doing on pages 8 and 9. They just seem to have the most enormous fun, and it's quite infectious. George loves his ballet, and we're proud to announce that Penny has just won 1 silver and 2 gold medals at the Scottish junior Championships for Physically disabled swimming and sensory impaired swimmers in Grangemouth.

Elsewhere, on Page 6 Colleen Oakley takes a light hearted look at how we should 'manage' Christmas, and on Page 7 we have your fundraising stories. More and more people are spreading the word by fundraising for the TMS, and getting articles printed in journals and magazines. So, if you are doing, or intend to do something to help the cause, please let us know and we'll help advertise it.

Earlier in the year Neil Burton told his extraordinary story, from being almost totally paralysed by TM, to travelling to Germany for stem cell treatment. In his final paragraph he said 'I don't know exactly where this treatment will take me', so I am delighted to report that there has been an improvement in his condition. You can follow his progress by going to his blog ***click here***

And finally, we are delighted to welcome Steve Holden to the editing team, and, just so you know what we all look like, our mug shots are at the bottom of the page (yes, I know, my last one was 20 years out of date!).

Zelda, Steve, Heather and I would like to take this opportunity to send our best wishes to you for this Christmas, and 2015! And, don't forget, we want your stories, comments and suggestions. E-mail me at annie.schofield@myelitis.org.uk

Annie

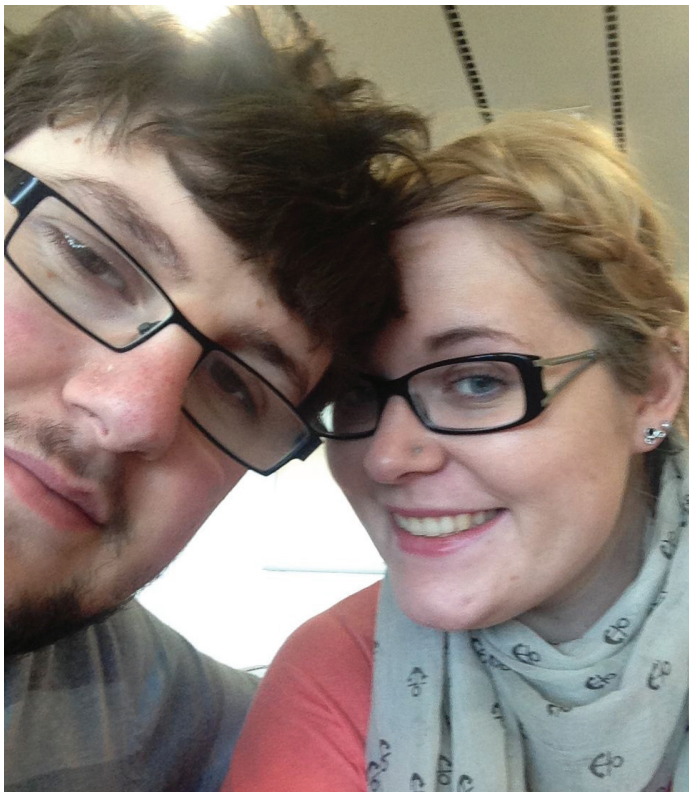
Annie Schofield

Zelda Carr

Steve Holden

Heather Coltman

FROM PREGNANCY TO MOTHERHOOD
AMY CURTIS TELLS HER STORY



My name is Amy. I was diagnosed with TM in 2003 at the age of 13. I have incomplete paraplegia at L2. I am an outdoors wheelchair user and an indoor walker (with a lovely stick!). I graduated from Liverpool in 2010, completed my master's degree in 2013 and am about to start my PhD in Health Sciences. I married my Stephen in June 2013 and this June we welcomed our beautiful baby girl, Violet. Here's all about the joys of pregnancy and motherhood while having Transverse Myelitis.

PREGNANCY AND TM.

In the back of my mind I had always assumed it would take longer for someone with a chronic condition to get pregnant, despite being told it was not the case for those with TM. So after getting married we decided we would stop using birth control and see what happened. Two months later I was pregnant!

I worried a lot about how my TM would affect my pregnancy, or how my pregnancy would affect the TM. At my 12 week scan I was convinced there would be nothing there, or that something awful had happened. But there it was, my baby, all 6 cm of it, with a little heart beating away.

The last few weeks were tough. Poor circulation already in my feet coupled with being heavy meant that my feet swelled so badly I could hardly get my shoes on, so I spent most of my time in a wheelchair. I also had a lot of back pain, but my painkiller choices were limited, so an appointment was made to see if my labour could be started off a bit early. The date was set for June 10th at 10.00am.

That morning, as I was getting dressed for my appointment, suddenly there was what can only be described as a waterfall. All hell broke loose as my contractions were suddenly only a few minutes apart, so we rushed to the hospital.

After 4 hours in the hospital delivery room, and still no baby, they decided to get a doctor. It turned out that my baby was stuck, so I was off to theatre! At 16:21 hours my beautiful Violet was born. She weighed 8lb 6oz and was perfect. I, however, missed it all as I was asleep (I couldn't have an epidural because of my spinal damage).

MOTHERHOOD AND TM

I spent two days in hospital, and came home feeling a little deflated and very sore. My back hurt from labour, and my tummy hurt from being cut open. I was anaemic from losing blood in theatre so I had to inject myself daily. I was also on a range of painkillers. When Violet was 4 days old, Mum and Ste decided to take me out for a coffee. I was determined to walk into the coffee shop, so we parked right outside, and armed with my stick in one hand and my mum on the other, I limped the 7 steps - and then almost fainted. Mum went back to the car for the wheelchair. Mum, who has been a constant in my life since I was diagnosed with TM, gave me a little talking to after that. She reminded me that I had gone through a major operation and that I was disabled before I had Violet, and I would continue to be disabled afterwards. I was so caught up in trying to be a normal Mum to Violet that I was making myself poorly.

> *"All mums need time to adapt to motherhood. No one tells you how to do it, but somehow you figure it out."*

After this, I got myself in a routine. Ste and I live above my Mum so each morning one of them would carry Violet into the living room for me. She would go in her Moses basket or bouncy chair so I could then do most things from there. We got a bottle steriliser. The changing mat is on the floor so I can lower myself from the chair to the floor, change her, then pull myself back up.

It was only when Violet was around three months old that I felt confident enough to take her out on my own. This is the skill I have mastered. I sit in the car's boot and push the pushchair out onto the ground (the boot is level so no lifting). Then sitting next to Violet in the back seat, I unstrap her from the car seat, move her to the side of the car where the pushchair is waiting, then strap her into it. I then, normally, push her into either a Costa's or Starbucks. I can't walk very far but I make sure I take her out often so that she doesn't miss out for the day.

It isn't easy. I'm always exhausted and the house is often a mess. I feel guilty that I can't take Violet for a walk on my own because I simply can't walk that far. But it's getting better. All mums need time to adapt to motherhood. No one tells you how to do it, but somehow you figure it out. I am looking for an electric wheelchair so that I can take Violet out for walks and other activities.

My confidence took a bit of a knock after coming home, but I think it's 80% back now. I'm determined that Violet won't miss out in life. I am sure she won't.

THE BLADDER IN TRANSVERSE MYELITIS

MR GOVINDARAJ RAJKUMAR MS, FRCS & DR MUHAMMAD THUFAEL

MR GOVINDARAJ RAJKUMAR MS, FRCS(Urol) qualified, and completed his Masters in General Surgery in India. He has been in the UK since 1997 and, having qualified in Urology, worked in Leeds and Glasgow Urology units attached to National Spinal Injury centre. He has published in international Urology journals on the role of Botulinum toxin in overactive bladders.

DR MUHAMMAD THUFAEL UDDINMBBS, graduated from the University of Southampton and is a Foundation Year 1 trainee in Urology at Basingstoke North Hampshire Hospital. He is Interested in a career in surgery.

Transverse Myelitis (TM) is a rare neurological disorder whereby - due to various causes, inflammation of the spinal cord occurs across a segment of the spinal cord. This results in symptoms related to impaired nerve function affecting parts of the body below the level of lesion in the spinal cord. One of the most common symptoms caused by this nerve dysfunction in TM is Neurogenic lower urinary tract dysfunction (NLUTD).

WHAT?

Neurogenic lower urinary tract dysfunction (LUTD) may be caused by Transverse Myelitis (TM) depends grossly on the location and the extent of the neurological lesion. Further, it is not easy to distinguish LUTD from LUTD caused by age-related changes of the bladder and other concomitant diseases or medication. Therefore, the true incidence of Neurogenic LUTD in Transverse Myelitis is not known, but data available on the prevalence of LUTD in a variety of similar or related neurological conditions to TM, suggest that neuro-urological symptoms are present in 50% - 90% of patients and there is almost a 100% chance if the lower limbs are affected.

A neurogenic bladder refers to the loss of proper bladder control due to a problem in the way either the brain, spinal cord or nerves to and from the bladder control how it stores and empties urine. The resulting dysfunction in these controls mechanism results in either a spastic (overactive), flaccid (underactive) or mixed type bladder.

In ***spastic (overactive) bladders***, involuntary contractions occur at small volumes of urine. This is usually a result of brain or spinal cord damage above T12. Exact symptoms vary according to site of lesions but typically bladder contraction and urinary sphincter relaxation is uncoordinated (detrusor-sphincter dyssynergia). Symptoms of going more frequently

(frequency), urgency and urgency related incontinence often occur.

A ***flaccid (hypotonic or atonic) neurogenic bladder*** occurs due to peripheral nerve damage or spinal cord damage at S2-S4 level. This results in absent bladder contractions and causes a large volume bladder with low pressure.

Mixed patterns can also occur where there is both spasticity and flaccidity of the bladder, which depend on the site of initial insult on the spinal cord and degree of subsequent recovery.

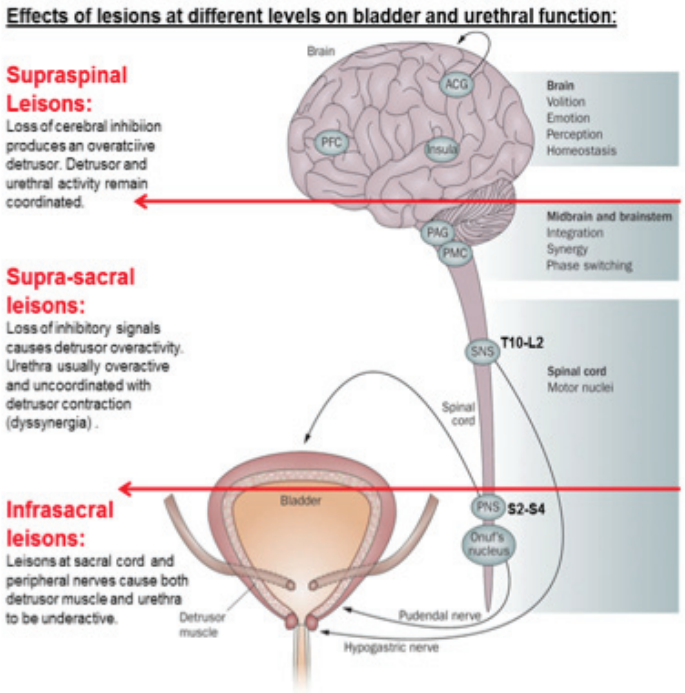
HOW?

In TM, damage to the tracts in the spinal cord results in interruption in both the ascending sensory signals, and the descending motor signals to the nerves directly innervating the bladder which lie in the sacral segments (S2,3 & 4).

In the initial acute phase of TM where all fibres are affected across one segment of the spinal cord, there is suppression of both the somatic (voluntary) and autonomic nervous (involuntary) activity. This results in an acontractile (atonic bladder) ie. Paralyzed bladder that fills without any sensation and urinary retention, which requires catheterisation.

The degree of recovery of the spinal cord differs amongst individuals with TM. Some can make full recovery whilst others make none. As the spinal cord recovers, recovery of sensory fibres allows patients to sense bladder filling and subsequent ability to urinate. However initially emptying will be incomplete due to incoordination of urethral sphincters. Other symptoms include frequency, hesitancy, urgency and some urge incontinence.

In those with little to no recovery in spinal cord function, a bladder reflex usually returns. However instead of the brain being the maestro of micturation, the sacral segments take charge via rerouting of impulses from sensory afferents directly to the motor nerves of the bladder. This results in an erratic and uncontrolled emptying of the bladder that is often incomplete (reflex incontinence). These patients are at higher risk of secondary effects of high bladder pressure, UTIs and eventual kidney damage.



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Part 2, 'Treatments of the bladder in Transverse Myelitis' will follow in the next edition

CELEBRATE THE SEASON TM STYLE
BY COLLEEN OAKLEY

Yay! Christmas – fun, family, presents, food, parties, festivities of all kinds… Exhausted already? Me too. And we haven't even thought about what to wear yet.

Fear not. We shall go to the ball – in TM style!

In the midst of all the madness, how can we make sure we look and feel good without spending loads of precious energy and money? Ready? Here we go…

C - Comfort above all else. Sharp, tight, rough, constricting – forget it! And yes, it is possible to look good and still be comfortable. Colour is also really important. Wear colours that make you look good, rather than those that drain you.

E - Expanding space for all those yummy treats. Loose and lovely rather than tight and terrible. This doesn't mean wearing tents or garments that are too big, but rather well fitting with a little stretching space. Fabric with a bit of stretch is good. (A little aside here – eating and digesting takes a lot of energy, so little and often is the trick.)

L - Layers – lots of us have body thermometers that seem to have no bearing on the actual weather. If this is you, layers are the secret.

E - Embrace the season. Choose the outings, gatherings, parties that you really want to be at and ignore the rest. Wear the same outfit to all of them, just making a few changes each time. More on this later.

B - Be prepared. Like a good scout, prepare for all eventualities. This means having your medication, change of undies, walking aids, prezzies, food etc. ready and sorted in advance.

R - Rule time. Plan your outfits around three colours. A neutral, a bright and an accent. For example: Brown (trousers, shoes) clotted cream colour (top/shirt) red (cardigan). Gold jewellery. This is a great combination for Autumn and Spring choices, for those of you who have had your colour analysis done. For Winter and Summer people, imagine Navy, White and red, with silver jewellery.

A - Accessorize to ring the changes. For example, your chosen outfit is trousers, shirt, cardigan, flat shoes (see how I have done this for men, women and young guys – sneaky hey?)

So, same trousers and shoes throughout. Even the same cardi. Change your tie, add a scarf, change your jewellery, bling up, tone down, be more elegant, formal or casual. I know it sounds daunting, but try looking at your wardrobe objectively. Bring in a friend and get them to do it all for you if you prefer. Keep all the changes together in a bag or on a hanger, so that you can remember what your plan is.

T - Tactile and Snuggly- have something you can cuddle when you are feeling a little tired, sore, or just need to zone out for a bit. For me, this is socks, gloves and a pashmina.

E - Enjoy. Most important of all.

THANK YOU FOR YOUR SUPPORT
MORE FUNDRAISING STORIES

Mrs Ball's Belated Wedding Cake Afternoon Tea

Mrs Ball's Belated Wedding Cake Afternoon Tea. Back in the summer my Mum's friend got married. On the day a disaster happened and the cake was the wrong one and so she didn't have a Wedding Cake on her Wedding Day. My Mum's friend is really kind and didn't get cross about it, she decided to turn the disaster into a good thing. When the real cake finally arrived she decided to use it to raise money for the Transverse Myelitis Society by holding a TM tea party called 'Mrs Ball's Belated Wedding Cake Afternoon Tea'. There were sandwiches and shortbread, cakes and the Wedding Cake. There was a raffle and some stalls, and me and my friend Elliot sold books. In the end we raised £350. So what started out as something bad, turned into something really good and my Mum's friend helped us to let more people know about TM. ***George Bowyer***

The following are just a few of the many people who have been fundraising for the TM Society because they either have TM or someone close to them has. They are keen to raise awareness of Transverse Myelitis and monies to enable us to keep doing the work we do. Without them, we wouldn't be able to do that. So thank you all for running, jumping, cycling, not smoking, accepting donations in lieu of gifts, and everything else you are doing! We appreciate it!

- ***Kate Raggett*** ran the British 10K London Run in July and ***raised £927***
- ***Lynn Winton*** had a special birthday and received ***£1,688 in donations*** *for the TM Society instead of gifts*
- ***Jean Claude Nouchy*** is participating in Smoke Free October as his brother recently contracted TM. ***So far he has raised £177***. His Just Giving page is CLICK HERE
- ***Rik Parkinson*** completed the BAE SYSTEMS Warton to RAF Coningsby Bike Ride in September and has ***raised £850***, exceeding his fundraising target of £55

MY FIRST SWIMMING GALA

I took part in my first swim gala, representing my school in the Schools Swimming Gala for children with additional support needs held in Aberdeen. I was so excited, the minute we drove through those gates I felt a rush of excitement running up my body with the thought of the racing blocks. I walked through the huge glass doors and walked in, not knowing what was waiting for me! I was escorted to the changing rooms and nervously entered the swimming pool. When the rush of heat clung to me, I was waiting for my time to step into the pool to do the race, I had been practicing for such a long time.

That moment came almost too quickly, as I listened to the lady who was calling out everybody's name, I wondered if it was ever going to be my turn! When it was my turn to go, I was so nervous that all I wanted to do was swim and swim forever and not stop. After I finished all my races, I was awarded a medal for my breast stroke, second in front crawl and third in back crawl. I was very happy and I met some really amazing people. I would definitely go back and try again and would also recommend disabled sport to everyone who are interested in having a "go" at something new. I am looking forward to my new challenge in November, when I will be attending the Scottish Disability Sport National Junior Swimming Championship in Grangemouth. Wish me luck!!!

LONES GUIDES CAMP IN EDINBURGH

I attended the Lones Guides (Guides by email) camp in Edinburgh. It was really nerve wracking and I was really worried about going. But in the end, I had a really nice time. I worked on lots of guide badges and we had an indoor campfire sing song which was really good fun! Helen (my leader) sends me badges to do every month and I work on them at home. I would recommend Guiding by email to anyone who finds it tricky to attend their local unit **www.girlguidingscotland.org.uk**

Penny xx

BREAKING NEWS!

Penny competed in the Scottish junior Championships. She did really well and came home with a silver and two gold medals!

TM KIDS

A COOL FACT ABOUT TM

TRANSVERSE MYELITIS CAN BE EITHER ACUTE (DEVELOPING OVER HOURS TO SEVERAL DAYS) OR SUBACUTE (USUALLY DEVELOPING OVER 1 TO 4 WEEKS)

I was diagnosed with Transverse Myelitis (TM) when I was 7. I live in Aberdeenshire with my Mum, Dad and two sisters. I have two friends with TM; Penny and Hannah. We are all 10!!

I LOVE BALLET!!!

My favourite hobby is ballet. I have been taking ballet classes since I was around 2 years old. My Mum took me along with my sister and I just didn't want to leave, and I have been dancing ever since. I have lessons every Monday. I have a lesson with my sister and some other people, and then I have an extra lesson on my own with my teacher Stephanie who is great. The next day my legs and back are very sore and tired, and I get banding which is horrible, but I don't care, I can feel my muscles growing and getting stronger.

My favourite film is Billy Elliot, and one day I want to be just like him and dance on the stage and travel around the world. The thing I was most afraid about when I first got TM was not being able to dance again. It was my main motivation to walk again. My favourite dancer is Ashley Banjo and one day I would really like to meet him.

George

OUR TM PLAY DAY

During October, my Mum, two sisters and I met up with Penny and Hannah and their families for the afternoon, who both have TM. It's great to meet up with other people with TM because it reminds me that I'm not the only one with it. Sometimes at school I wonder why I am the only one that gets tired easily, or whose legs and bladder are a pain, but when I meet up with other TM kids it makes me realise I am not alone. Penny and Hannah are both really cool and I can talk to them about TM stuff, if I want to, but mostly we just played and had a great time. Penny's Mum made lunch and we had some really yummy cake, a banana one and a chocolate one. We played in the garden with Penny's dogs and we made a video of ourselves. It was a great day and I can't wait to meet up with them again.

George

MY STORY
BY DANNI REASON

DANIELLE WITH FRIENDS REBECCA AND CARYS

In the summer of 2009, when my daughter was just 4 months old, I woke up one morning and my leg was dead. I thought I had slept funnily so proceeded to walk around to try and 'shake it off', but the numbness didn't go away, so I decided to visit my GP. He suggested that it could be a pinched nerve, or slipped disc, as I had some back pain as well. He tried to get me into hospital for an MRI but they refused, saying I couldn't have an MRI unless I lost bowel function. The numbness and tingling then spread into the other leg and up my torso to a clear 'sensory line' at armpit level. Very perplexed with what was going on I visited a chiropractor. He worked on me but he didn't think it was a slipped disc. That night I went to the toilet and I couldn't urinate. I had the urge but I literally could not go. I rang the GP in the morning, who told me to go to A&E immediately. I went to Addenbrookes who quickly got a Neurologist to see me. I was fitted with a catheter and taken for MRIs of my spine and brain. The MRIs showed lesions on my T and C spine but none on my brain. I was then admitted to the neuro ward where I stayed for two weeks. By this point I could no longer

> *"I would set myself challenges each day; I continued to do this until I could walk for 15mins solidly."*

tell the difference between hot and cold, pin prick and feather touch, was in a lot of pain, could not urinate and barely walk. I was put on IV steroids and within a few days the catheter was removed, but the sensory issues and weakness remained; I was given a steroid tablet taper to continue taking at home for a week.

It was around this time that severe spasticity set in and it was excruciatingly painful to walk. I could barely walk 2 metres and had to go up and down stairs on my bottom. I was put on baclofen and gabapentin, however, I stopped taking baclofen as it was making my arm muscles too weak so I couldn't even pick up my daughter. The spasticity stayed with me for 9 months and in that time I barely left my house as I could not walk without severe pain. My husband was overseas at the time so I moved in with my in-laws to help me with the baby. Eventually the spasticity subsided and I was able to take very short walks. I would set myself challenges each day; I continued to do this until I could walk for 15mins solidly. Challenging myself helped me a lot, so I decided to start swimming again as it was the only exercise I could do that didn't cause me pain. The next challenge was to swim Lake Windermere for charity. This was part of the Great British Gas Swim series to swim a mile in open water. I did the swim in 2011 and was one of the very last to complete it from my heat, but I did it. I was so proud of myself I decided I wanted a new harder challenge, I wanted to run. I had never run before, even before my TM diagnosis. I still had some sensory issues but my spasticity had all but gone so I knew there was nothing stopping me. I completed the 'couch to 5k' programme and fell in love with running. There's nothing like losing the ability to walk to make you appreciate having movement like that! In 2012 I signed up for my first half marathon which I completed in 2hrs28 minutes. It was one of the most amazing days of my life. I was so emotional at the finish line I cried tears of happiness to have come so

> ***"I run for myself and for all TMers who suffer every day, and who have not had recoveries like mine. They keep me going and keep me motivated."***

far. I have done numerous 5k and 10k races since and completed my second half marathon on October 5th in Cardiff in 2hrs 15minutes. I count myself very lucky that I have made such a good recovery and I will never take the use of my legs for granted ever again! I run for myself and for all TMers who suffer every day and who have not had recoveries like mine. They keep me going and keep me motivated.

NEWS FROM THE COMMITTEE

ANNUAL GENERAL MEETING & CONFERENCE – SAVE THE DATE!

The TM Society will hold its AGM and conference on 7th March 2015 at Aston University in Birmingham. Check the website ***www.myelitis.org.uk*** and Facebook groups for more information.

EQUIPMENT GRANT SCHEME

The Equipment Grant Scheme enables members to access funding for equipment which aids in their rehabilitation, ability to self-care, and/or maintaining their independence. The grants are given on a first come first served basis, to a value of 50% of the equipment cost, up to £1,000 maximum. For more information, go to

CLICK HERE

COACHING BURSARY SCHEME

If you want to find ways to:

- Adjust to living with TM/ADEM/NMO
- Regain your confidence
- Manage stress
- Go back into education or work
- Deal with issues at work that are bothering you (or maybe you want to go for a promotion or new role)
- Change your career
- Positively deal with the impact TM/ADEM/NMO has had on your family and relationships
- Increase your independence and wellbeing
- Get back into your favourite hobbies and activities or find new ones
- Look after yourself as a way to manage your symptoms
- Focus on yourself as the carer
- Figure out what you want out of life

This new service of coaching is available to you, whether you have TM/ADEM/NMO, are a carer, or a parent of a child with TM/ADEM/NMO. Coaching is a series of confidential purposeful conversations between you and a coach where you work together to figure out what you want to achieve and develop an action plan to do that. The Coaching Bursary consists of 6 coaching sessions with an experienced qualified coach and costs £60, of which the TM Society will subsidise 50%. For more information, go to

CLICK HERE

JOIN US ON facebook

Our facebook page is now up to ***916 members***! Not only can you reach out to other members for advice and tips, it can also lead to some lively debates. And, it's a closed group so your comments are completely confidential. Search for Transverse Myelitis Society on facebook.

NEWS FROM THE COMMITTEE

TM SOCIETY FAMILY WEEKEND – 10 - 13 JULY 2015

The TM Society will hold its first family weekend 10-13 July 2015 at the Calvert Trust in the Lake District ***www.calvert-trust.org.uk/lake-district/introduction*** for our children with TM/ADEM/ NMO, their siblings and parents. The Calvert Trust promotes learning and the development of self-confidence through challenging outdoor activities, the experience of which can enable our families to take up new challenges back at home. Medical and healthcare professionals will also offer educational sessions to the parents. Attendance at this weekend is free; families only need to pay for getting themselves to and from the venue and travel insurance. Registration will open in January. There will only be 60 places available and will be offered to TM Society members on a first come first served basis.

London Marathon

Every 5 years the TM Society gets one place in the London Marathon and we are pleased to announce that Katy O'Leary will be running for us in 2015. Katy is a personal trainer and runs marathons for a hobby! She is keen to support the TM Society as her teenage niece has TM. She has a fundraising target of £2,000 so let's get behind Katy and support her in this effort! You can make a donation via Katy's Just Giving page at

CLICK HERE

RESEARCH NEWS

SPINAL CORD INJURY PRIORITY SETTING PARTNERSHIP

The Transverse Myelitis Society has been part of this effort to identify and prioritise the most important research questions for anyone with an interest in Spinal Cord Injury, including those with Transverse Myelitis. The purpose is to enable researchers to address topics in the future that are demonstrably important to the wider SCI community. Many of you completed the survey and we thank you for your participation. The top 10 research priorities have been identified and one focuses on TM! Many of the other priorities are also relevant to our community. You can view the priorities here - CLICK HERE

STRIVE CLINICAL TRIAL

A new clinical trial called STRIVE will start throughout the UK in November 2014. It will seek to evaluate if additional, and early, treatment with intravenous immunoglobulin (IVIg) is of extra benefit in TM and NMO when compared to the current standard therapy of intravenous steroids. Adults and children can be recruited to the study up to 21 days from onset of symptoms if definitively known. The idea for this trial was initially conceived by UK neurologists at our 2011 conference. More information can be obtained by going to

CLICK HERE

NEWS FROM THE U.K. SUPPORT GROUPS

LONDON SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SATURDAY 17TH JANUARY 2.00PM**

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

NEXT SUPPORT GROUP MEETINGS: **SATURDAY 6TH DECEMBER (CHRISTMAS LUNCH) AT 12.00 & SATURDAY 21ST MARCH 2.00PM**

Our annual Christmas lunch is always a great hit with our members. So why not come along and enjoy a great social occasion? Friends and family are all w elcome.

Venue: Pembury Village Hall, High Street, Pembury, Kent, TN2 4PH. This is a wheelchair friendly venue with disabled toilets. There are 2 disabled parking bays and 10 further parking spaces outside. Additional parking on the road. For further details please contact Annie Schofield, **annie.schofield@myelitis.org.uk** or telephone 01435 864662 or 077888 94648

EXETER SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **CHECK TMS WEBSITE FOR UPDATE**

Venue: Holiday Inn Express Exeter, Guardian Road, Exeter EX1 3PE. Meetings take place in the main reception area. For directions go to **www.supportgroups.myelitis.org.uk/exeter**. For further details please contact Rob Reeves, **rreeves@myelitis.org.uk.**

POOLE/BOURNEMOUTH SUPPORT GROUP

NEXT SUPPORT GROUP MEETINGS: **WE MEET QUARTERLY ON LAST SATURDAY OF JAN, APR, JUL & OCT AT 1PM.**

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

NORTH EAST SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **CHECK TMS WEBSITE FOR UPDATE**

Venue: Walter Best Hall (within Cornerstones), Chester-le-Street Methodist Church, North Burns, Chester-le-Street, DH3 3TF. See **www.cornerstonescentre.co.uk**. Cornerstones is situated in the centre of Chester-le-Street and has full disabled access including provision of changing place facilities for people with severe disabilities. Car parking is available within the town at a rate of £1-10 per day indicated by the 'P' on the map. For further details please contact Doreen Cawthorne, **doreencawthorn@btinternet.com** or phone 0191 4193161 or 07737 705458

YORK SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **CHECK TMS WEBSITE FOR UPDATE**

Venue: Acomb Methodist Church, 20 Front Street, York, YO24 3BX. For further details contact: Leigh Cooke on 07958902710 **leighpea@aol.com**

EAST MIDLANDS SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SATURDAY 21ST MARCH 2015 2.00PM**

Venue: The Village Hall, Lullington, Nr Swadlincote, DE12 8EG. For further details please contact Janet Ashenden. **Jan.nig@tiscali.co.uk**

NEWS FROM THE U.K. SUPPORT GROUPS

BRISTOL SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SUNDAY 14TH DECEMBER 2-4PM**

Venue: We hold our meetings in the main reception area 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 **stevecollins@blueyonder.co.uk**

TELFORD SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **CHECK TMS WEBSITE FOR UPDATE**

Venue: Horseshoes Inn, Holyhead Road, Ketley, Shropshire, TF1 5AE. Wheelchair friendly with easy access. For further details please contact Anna Paulsson-Habegger on 07581 708597 **annaph@blueyonder.co.uk**

TRANSVERSE MYELITIS SCOTLAND

NEXT SUPPORT GROUP MEETING: **CHECK TMS WEBSITE FOR UPDATE**

Venue: Conference Room, Philipshill Ward, Spinal Injuries Unit, Southern General Hospital, 1145 Govan Road, Glasgow, G51 4TF

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 Margaret Shearer on 01292 476758 or email margaretshearer@myelitis.org

SOUTH WALES GROUP

Look out for further details of a new group for South Wales at www.myelitis.org.uk

OXFORD SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SATURDAY 31ST JANUARY 2015 2.00PM**

Venue: Tingewick Hall (foyer), John Radcliffe Hospital, Headington, Oxford, OX3 9BQ. Easy access with disabled facilities. For further details please contact Zelda Carr **Zelda@cqc-ltd.com**

PRESTON SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SATURDAY 28TH MARCH 2015**

Venue: Venue TBC. TMS website for update.

SHEFFIELD SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **CHECK TMS WEBSITE FOR UPDATE**

WEST MIDLANDS SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **CHECK TMS WEBSITE FOR UPDATE**

Venue: Stourport Community Centre, Stourport Memorial Park, Lower Lickhill Road, Stourport on Seven, DY13 8RW. See **www.stourportcommunitycentre.co.uk** for directions.

EAST ANGLIA (NORWICH) SUPPORT GROUP

THE FIRST SUPPORT GROUP MEETING: **SATURDAY 15TH NOVEMBER 2014 – STARTING 2.00PM (DOORS OPEN AT 1.00PM) CINDY MORELLI (TMS COMMITTEE MEMBER) WILL BE IN ATTENDANCE**

Venue: The Therapy Centre, Delft Way, Norwich, NR6 6BB. It is an MS Centre therefore completely disabled friendly. There is plenty of parking places outside. For further details contact Gill Rice, **gillian.rice@myelitis.org.uk**, Tel: 01603 461028 or 07867 781096

Meeting details may change and new groups formed so we recommend obtaining the latest information on the TMS website **www.myelitis.org.uk** by clicking on 'Get Involved' and then 'Support Groups'.

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*
0844 800 4361
www.carers.org

_*Continence Foundation*
www.continence-foundation.org.uk
info@continence-foundation.org.uk

_*Depression Alliance*
0845 123 2320
www.depressionalliance.org

_*Disability Information Advice Line (DIAL)*
01302 310 123
www.dialuk.info

_*Disability Law Service*
0207 791 9800
www.dls.org.uk

_*Disabled Living Foundation*
0845 130 9177
www.dlf.org.uk

_*Disability Now Magazine*
01454 642 444
www.disabiltynow.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*
0845 456 4566
www.motability.co.uk

_*Neuromyelitis Optica (NMO) [Formerly Devics Disease]*
www.nmouk.nhs.uk

_*NMO: The Walton Centre, Liverpool Nurse Specialist*
0151 529 8357
NMO Service Coordinator
0151 529 8131
nmo.advice@thewatoncentre.nhs.uk

_*NMO: John Radcliffe Hospital, Oxford Nurse Specialist*
01865 231 905
NMO Service Coordinator
01865 231 900
nmo.advice@orh.nhs.uk

_*Pain Concern*
0300 123 0789
www.painconcern.org

_*Pain: British Pain society*
0207 269 7840
www.britishpainsociety.org

_*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
Contact Barbara Babcock
(chair) barbara.babcock@myelitis.org.uk
Lew Gray (Secr) 020 8568 0350
Email: lew.gray@myelitis.org.uk

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