



# Transverse Myelitis

## S O C I E T Y



**COVER STORY:** NATASHA  
BAKER, EUROPEAN CHAMPION  
AND PARALYMPIC HOPEFUL,  
GOING FOR GOLD PAGES 3-4

## CONTENTS

01	<b>LETTER FROM THE EDITOR</b>
02	<b>A MESSAGE FROM OUR CHAIRMAN</b>
03-04	<b>COVER STORY: NATASHA BAKER</b> GOING FOR GOLD
05-06	<b>ENDORPHIN RUSH</b> 3 TMers TELL US HOW THEY KEEP FIT
07	<b>TM AWARENESS DAY UK</b> HOW YOU CAN HELP RAISE AWARENESS
08	<b>CARERS WEEK</b> NEWS ABOUT THE ANNUAL EVENT TO SUPPORT CARERS
09	<b>“WHY CAN’T YOU WALK, GRANDMA?”</b> VETERAN TMer, RUTH WOOD, STRUGGLES TO FIND THE RIGHT ANSWERS
10	<b>NEWSBITES</b>
11-12	<b>THE LOWDOWN ON VITAMIN D</b> CINDY MORELLI SHARES WHAT SHE’S LEARNED ABOUT THE SUNSHINE VITAMIN
13	<b>REACHING FOR THE SKIES</b> COLIN MACNEILL FULFILS HIS AMBITION TO PILOT A PLANE
14	<b>GARDENING</b> TIPS FOR YOUR GARDEN FROM ROSITA SCALES
15	<b>POSTBAG</b> ROUND UP OF YOUR LETTERS AND EMAILS
16-17	<b>NEWS FROM THE UK SUPPORT GROUPS</b> FIND OUT WHAT’S HAPPENING AT A SUPPORT GROUP NEAR YOU
18	<b>USEFUL CONTACT INFORMATION</b>

## LETTER FROM THE EDITOR



ANNIE SCHOFIELD

**Dear Readers,**

First of all, I would like to thank all of you who wrote to say how much they had enjoyed reading the first edition of our magazine. I hope you will forgive us for giving ourselves a pat on the back by sharing a selection of the comments we received on our letters page.

I'm also delighted to announce that I now have a co-editor. Ros Gallagher (whose 5 year old son has ADEM) has offered her services. We are very proud to present to you our second edition.

As the Olympic torch makes its way around the country in time for next month's games, we have a wonderful, topical story to share with you. Last month, a friend of mine phoned to say that she had read an article about a hopeful paralympic dressage rider with TM called Natasha Baker, so I set about tracking her down. The result was a telephone conversation with this amazing 22 year old girl who had contracted TM as a baby, started riding as a hobby/therapy, and by sheer determination has become a member of team GB and took the gold medal at last year's European Championships. Before we spoke, she had no idea that there was a TM Society, or the support network that goes with it. There was nothing in the UK all those years ago, so she and her family just got on with life. I am delighted that Natasha and her mother have agreed to tell us their inspiring story.

It is a well known fact that all of us with a neurological condition

should exercise every day, even when we're suffering from fatigue, and maybe in this Olympic year you will be encouraged to do a bit more. So we hope you will be inspired by our exercise feature on page 5-6. I have been doing Pilates for 2 years now and it has definitely increased my muscle power; my fellow committee member, Carol, has discovered Tai Chi, and of course there's Yoga, swimming, walking....

By the time you read this many of you will be finalising your Team Parties to celebrate TM Awareness Day UK. Apart from raising awareness, it's a great excuse to have a party with your friends – just this time they have to pay for a cup of tea round your house! I have heard of some wonderful takes on the theme - film nights, shed parties, and I'm having a Plant Sale. The beauty of this is that any unsold plants can simply be planted in my garden... Don't worry if you haven't managed to get a party together, just try to spread the word about June 9<sup>th</sup>. And we're always extremely grateful for donations at any time of year.

No doubt many of you, like me, will have taken the advice from Dr Doug Kerr at the Conference last year and had the Vitamin D blood test. I was quite surprised when the result showed I had a slight deficiency (as a Travel Agent I have never been short on sunshine), and decided to find out more. It appeared a lot of other people were joining in the debate, hence our article on Page 11.

We're already planning ahead for our next edition. We want to share some stories about treatments and therapies that members have tried. We're interested in the conventional and the alternative, so please get in touch. We would like to hear of your experiences, especially those treatments you were happy with, and hospitals, doctors or neuro physiotherapists that you would recommend.

We welcome all your letters and emails with your stories as well as comments and suggestions on what you would like to see in future editions. So please get in touch with Ros or myself at the email addresses below.

I hope you all enjoy the summer, and I'm sure you'll join me in wishing Natasha luck in being chosen to represent Team GB - and of course for winning another GOLD MEDAL!!!

**Annie**

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[ros.gallagher@myelitis.org.uk](mailto:ros.gallagher@myelitis.org.uk)**



## A MESSAGE FROM OUR CHAIRMAN



YVONNE KOLESAR

**“Keeping fit... not only makes the body feel better but also keeps the brain more active, which in turn makes us all feel mentally more equipped to deal with the ups and downs of life..”**

**Dear Members,**

When Annie suggested last year that she wanted to produce a ‘newsletter’ for the Society, I quietly enthused with her and hopefully encouraged her to turn the idea into reality rather than a casual thought. After the initial concerns about content, would there be enough to fill a ‘newsletter’, where were we going to derive the articles and all those slightly negative thoughts, before we knew it dear Annie had a full blown magazine on her hands which even as I type seems to be growing by the day. Our editor is bursting with ideas and gradually formulating it into the magazine we hope and trust you the readers would like to see.

In April we held the 8th AGM of TMS in London to a packed audience in excess of 70. I would normally have been surprised to have so many people there as this sort of meeting is not necessarily the best crowd puller. Needless to say it wasn't for my dulcet tones that the audience appeared. We had with us two remarkable medics from the States. They had come across the pond for an extended weekend to speak at a Physiotherapy Conference but thankfully agreed to arrive a day early to visit us.

Dr Daniel Becker (whom many of you will remember from the 2011 Conference) came over with Dr Adam Kaplin, both from Johns Hopkins' Hospital in Baltimore. They created the most wonderful double-act for us all afternoon. Dr Kaplin spoke wisely about the emotional effects of living with TM for both sufferer and carers alike. His sage words seemed to hit home to a good many folk in the audience. Dr Becker mainly answered questions from the floor. As you will imagine these were wide and various, and hopefully a good many people went home that evening feeling a little more assured about their TM.

With the Olympic season upon us it was perhaps apt that both of the speakers focussed on fitness and its beneficial effects. At the London Support Group meetings we often meet members who come to a meeting for the first time feeling very low mentally, lacking in energy and rather despondent. The sooner they are able to get into some form of regular activity they very soon feel lifted and more able to face everyday issues.

Enjoy the Summer with extra flag waving for the Diamond Jubilee celebrations, for all our Olympians and of course our very own TM Awareness Day on June 9th!

Yvonne

## COVER STORY

## NATASHA BAKER, GOING FOR GOLD

**European Champion, Paralympic hopeful and TMer, Natasha Baker, and her Mum, Lorraine, share their stories.**

### LORRAINE'S STORY

Natasha was a very contented and intelligent baby. She started talking at a very young age (hasn't stopped since) and was walking confidently by one year. Then, at 14 months, she had her MMR vaccine and within 24 hours became very poorly, with a high temperature and rash. The doctor reassured us that it was a standard reaction to the injection. A week later, she was playing again and although she fell over one evening, we were pleased she seemed on the mend and back to her usual routine.

The following morning, when I went to wake her, I wasn't at all prepared to find a pale, limp little girl who was unable to cry and could not move any of her limbs. We rushed her to A&E where she had a lumbar punch and lots of other tests. The doctor told us it was Guillain Barre Syndrome and she was admitted to hospital. The movement in her arms, hands and upper trunk returned quite quickly but by the time she was discharged 2 weeks later, she still could not move from the waist down.

**“Natasha's physiotherapist suggested that we get her involved with the local Riding for the Disabled Association so at the age of 8, she started riding every week.”**

It was about a year later that we were given a fresh diagnosis of Transverse Myelitis. We were told there was no medical treatment and that the prognosis was looking unpromising. By the time Natasha was 2, there had still been no movement at all in her legs since her illness. So we turned to alternative therapies and took Natasha to see Matthew Manning, a healer. He sat with one hand on her back and the other on her tummy and after 10 minutes, Natasha's legs started to jolt forward and backwards. My husband and I both burst into tears at the joy of seeing them move again. We made a regular trip to see him in Suffolk every month. We always noticed a huge improvement in Natasha's



movement and she came out super-charged and hyperactive, talking non-stop the whole way home.

When she was 3, she slowly started to walk again, using a rollator and callipers at nursery. She went to a fantastic mainstream, junior school where she had all the help and support she needed and absolutely loved school. She continued to make physical progress until she was about 6 and then things plateaued. Natasha's physiotherapist suggested that we get her involved with the local Riding for the Disabled Association so at the age of 8, she started riding every week. Her natural talent immediately shone through and the rest is history...

**“I was only 10 but I knew immediately that I wanted to be a part of it; and to be on that podium one day receiving my Gold medal! I never doubted my ambition. My mum always told me I could achieve anything I set my mind to.”**

## COVER STORY

## NATASHA BAKER, GOING FOR GOLD

## NATASHA'S STORY

My Paralympic dreams started in 2000 when I saw the Sydney Games on tv. I was mesmerised by the dressage: the horses were dancing and the harmony between the horse and the rider was captivating. I was only 10 but I knew immediately that I wanted to be a part of it; and to be on that podium one day receiving my Gold medal! I never doubted my ambition. My mum always told me I could achieve anything I set my mind to; maybe not in the conventional way, but in the "Natasha" way.

My TM means that I have lost sensation and selective movement in my legs. When I ride, I cannot use my legs to influence the horse's movement. I train all my horses to respond to my voice and I also use my weight shift to direct them, moving slightly forwards or backwards to adjust their speed.

Off my horses, my balance is terrible and I cannot walk far. I use a walking stick for short distances and have an amazing pink scooter (called "Jordan") to help me around.

But I have always considered myself lucky. I had a great education at brilliant schools, adore my horses and have a fantastic social life. I couldn't really ask for much more. My motto has always been "everything happens for a reason". Sometimes it takes a while to work out the reason but if it wasn't for TM I would not be where I am now as a rider, and for that I am forever grateful!

**"if it wasn't for my TM I would not be where I am now as a rider and for that I am forever grateful."**

I was hugely honoured to be selected for the European Championships last year, although I could barely believe it. Team GBR are undefeated in international competition since paradressage was introduced to the Paralympics in 1996. I went to Belgium determined to enjoy it and aiming to make the top 5, but with no expectation of a medal. But by the end of day 1, against the odds, I was in the lead (albeit by only two points). The next day, my psychology changed and I headed into the arena believing that I could win. I rode my best test to date. I was one of the first riders so then came the agonising wait by the side of the arena, to see how the other riders performed and frantically totting up points in my head to see if I had done enough. Then the final result came on the board: 1st – Natasha Baker. I burst



**"Then the final result came on the board: 1st – Natasha Baker."**

into tears from the shock and realisation that I was the new European Champion!!

Standing on the podium with the Gold medal around my neck, with the band playing the National Anthem as the Union Jack was raised, was the best moment of my life. I cannot explain how amazing it felt; even writing about it gives me goosebumps. The thought of being able to compete at the London Paralympic Games is mind-blowing. It is so incredibly exciting to envisage my family and close friends supporting me and the whole of the country behind me cheering me the whole way. The selection decisions are made in July. I am keeping my feet firmly on the floor and I know that all I can do is my best. But to the extent it is physically possible, I am keeping everything crossed in the lead up to the Paralympic Games and am praying that my dream does come true...

For more information and to follow Natasha's journey, see

[www.natasha-baker.com](http://www.natasha-baker.com)  
[www.facebook.com/nbakerpararider](https://www.facebook.com/nbakerpararider)  
[www.twitter.com/nbakerpararider](https://www.twitter.com/nbakerpararider)



## ENDORPHIN RUSH

## 3 TMers TELL US HOW THEY KEEP FIT

The benefits of regular exercise are almost universally acknowledged, and there is strong scientific evidence that being physically active can help you lead a healthier and even a happier life. As well as improved cardiovascular fitness, research shows that physical activity can also boost self-esteem, mood, sleep quality and energy, as well as reducing your risk of stress, depression and dementia. "If exercise were a pill, it would be one of the most cost-effective drugs ever invented," says Dr Nick Cavill, a health promotion consultant.

Dr Daniel Becker and Dr Adam Kaplin (TM experts from John Hopkins' Hospital in Baltimore) firmly advocate that those with TM should engage in regular physical activity to maximise recovery and reduce fatigue.

It can be daunting starting an exercise programme at the best of times but for those with a neurological condition, there are extra considerations and this makes it harder to work out what options there are.

**Here, 3 TMers tell us about their favourite exercise pursuits. As the sun shines and our Olympians put in their final weeks of training, there's no better time to get started.**



### Carol Preece likes... Tai Chi Quigong Shibashi

I took up Tai Chi on the recommendation of a neuro-physio, about 20 months after being hit with TM. She told me "to stop using my stick" and instead to try Tai Chi which she described as

a "moving therapy" which would help with my balance.

I was initially sceptical and had images of every one being so graceful with me wobbling around. There are different branches of Tai Chi and I chose Tai Chi Qigong Shibashi, which is very slow moving, with the focus on learning how to be relaxed in body and mind. My teacher stressed the importance of working at my own pace.

For the first 8 weeks I sat for 40 minutes of the 1 hour session. Over the following 6 months, I built it up slowly until I could stand for 45-50 minutes. After a year of classes, my balance had improved sufficiently that I could stand for the whole hour.

**"For the first 8 weeks I sat for 40 minutes of the 1 hour session ... After a year of classes, my balance had improved sufficiently that I could stand for the whole hour."**

I also find that I sleep better for 2 nights following a session and have more energy. The meditation and breathing techniques that I have learned in the class have definitely helped my high blood pressure (caused by steroids for TM). After 2 years of Tai Chi, my blood pressure is now normal and I am looking to reduce medication. I also have reduced joint stiffness and less pain and discomfort.

All the movements are slow, rhythmic and gentle. It's not unusual to find those in the class all doing the same movement but working on a different time scale because we all have different abilities and our own rates of breathing.

I recommend you try to find a small class at first (ideally max of 8) so you get lots of 1:1 input and then try a community class once you're more confident with the moves. I have never stuck to any form of exercise before (apart from swimming) but I am a big fan of Tai Chi and try to practise at home for 15 minutes a day. I thoroughly enjoy it and am confident now that even if I do have a wobble, I am not the only one.

## ENDORPHIN RUSH

## 3 TMers TELL US HOW THEY KEEP FIT

**Julia Line likes... Walking**

I lead a walking group for people with walking difficulties. We are a very mixed bunch with hip replacements, bad backs and various other ailments. The idea behind it was that the walks for health are too fast and too long, so we take things at a much more relaxed pace.

We measure the distance we walk in metres rather than miles and a lot of the activity is in the café afterwards but we make sure we get out and get some fresh air in our lungs.

We meet once a fortnight in the Littlehampton area of West Sussex. We are lucky in this area as we can find completely flat walks with benches to sit down on along the way. We might amble along the sea front or round a local park at a snail's pace. We sometimes use parks with adult gym machines. Occasionally, we visit places of interest out of the area. We took a tour of historic buildings in Arundel where we followed a route shown on a leaflet and learned the history of each building. There is always time for coffee and a chat at the end.

**“We measure the distance we walk in metres rather than miles and a lot of the activity is in the café afterwards but we make sure we get out and get some fresh air in our lungs.”**

I run my group through the U3A and now have about 20 members. Anyone is welcome to join us. I'd be happy to provide more information or to give you pointers if you wanted to set up your own group in your area.

*To get in touch with Julia, please contact the editors (details on the first page).*

**Annie Schofield likes... Pilates**

Pilates is designed to strengthen and restore the body to balance, and it is this holistic approach that sets it apart from many other forms of exercise. It can be beneficial for just about everyone, regardless of age and fitness level. And because it promotes a more efficient and supportive core, it is particularly recommended by the medical profession as one of the safest forms of exercise today.

My class is mostly made up of 'oldies', so it's all 'matwork' (perfect for me as I have lost a lot of muscle power in the pelvic area). A lot of the exercises are very similar to the ones I had done in rehab, except with Pilates the teacher emphasises correct breathing all the time. The exercises are slow, all about stretching the whole body, but best of all for me, they can all be



done at different levels, so I never feel left out. Due to my disability there are a few I simply can't do, but my teacher, Kelly, will always make sure I do an alternative movement that stretches the same muscles.

**“I am now quite evangelical about Pilates... my argument being that I am now 8 years down the line with TM and still making improvements!”**

Annie's teacher Kelly is proud of Annie's progress and told us “When Annie started 2 years ago her movements were quite limited, but she can now lift her right leg a little and do a pelvic tilt sufficiently to raise her body off the mat.”

Annie says: Because I have been taught how to engage my muscles properly I feel stronger and fitter - and really notice how 'floppy' my muscles seem if I miss a couple of weeks. I am now quite evangelical about Pilates and berate my support group members to take it up – my argument being that I am now 8 years down the line with TM and still making improvements!

**Always consult your GP before starting any new exercise programme.**



## TM AWARENESS DAY



## HOW YOU CAN HELP RAISE AWARENESS

June 9th is now fast approaching and as a society we are excited to hear the plans our members have been making. The February issue had an array of ideas which we hoped would inspire you and indeed there are some novel and interesting events being planned!



This is what a few of our members will be up to:

**RUTH WOOD** We've a large garden shed that needs emptying and renovating, so, wearing a blue ribbon and gloves, friends will help empty, mend and paint the shed. Any tools not wanted will be auctioned in aid of TM. I'll provide refreshments plus large amounts of encouragement.

**ANNIE SCHOFIELD** I have grown petunias, sweet peas, poppies, gazanias, and many more from seed. Plus tomatoes, peppers, beans, courgettes.....and lots more. Hopefully posters in High Street shops will encourage those other than just my friends to come along and buy. I have a large deck, so if sun shines we can all sit outside enjoying refreshments and home made cakes– or under the gazebo if it rains!

**POOLE/BOURNEMOUTH SUPPORT GROUP** We are holding a Sponsored Spin, planning to cycle 20km on spinning bikes. Everyone can participate as the bikes can be operated from a chair, with legs or arms. Lots of activities too, so hopefully out in the garden with tombola, cakes etc!

**JOANNE LOKWIYA** Balloon launching in the Park. Blue balloons with TM info attached will be sold for £1 each and released to spread the word. A good friend will be providing cupcakes with the TM logo on.

There is still time for you to get involved even if you haven't planned anything yet. The society relies entirely on donations and all committee members are voluntary so the money raised by events is invaluable to the work of the society for supporting its members and moving forward with research into the condition. However, having an awareness day also gives us the opportunity to educate others into understanding the daily challenges faced by those who have TM and gather more support from those we interact with both personally and professionally. So even if you just raise your voice and make TM stand out on that day you will be playing a crucial role. Send out an email, post on facebook or twitter, wear blue and hand out any information you can get hold of.

Information about the day can be found on the TMS website [www.myelitis.org.uk](http://www.myelitis.org.uk) where you can download fundraising guidelines, sponsorship forms, press release information and get other links to information that you can pass on.

**Let's turn the nation blue on June 9th and get people talking about this rare condition.**



**TM\_awareness\_UK**



**[www.facebook.com/tm.awareness.day.uk](https://www.facebook.com/tm.awareness.day.uk)**



**Carers Week 18th to 24th June 2012** is a UK wide annual awareness campaign delivered by a partnership of eight national charities.

Most of us who have TM find ourselves at some time being supported and cared for by various family members or friends, a new role for us and them. TMer Carol Preece is very grateful for the help and support she has had. She says "I knew my partner was amazing when the patient ran out of patience! It is so crucial that we "do our bit" to help raise acknowledgement of this unpaid role that saves the government millions each year."

**"My partner was amazing when the patient ran out of patience."**

Carers Week is about recognising and celebrating the contribution made by unpaid carers to the people they care for and their communities.

Carers range from partners, parents, grandparents and children who are all involved in caring for someone in the family who has a long term health condition, illness or disability. We know there are **six million unpaid carers in the UK with approx 175,000 being young carers** under 18 years old.

**The Carers Week website says that**

"Caring can be a rich source of satisfaction in people's lives. It can be life-affirming. It can help deepen and strengthen relationships. It can teach you a multitude of skills and help you realise potential you never thought you had.

**"The theme this year is "In Sickness and in Health" with the focus being on the impact on a carer's own health and well being. ."**

But, without the right support, caring can have a devastating impact. Evidence shows that caring can cause ill health, poverty and social isolation. When caring is intensive and unsupported you can struggle to hold down a job, get a night's sleep, stay healthy and maintain your relationships with friends and family."

Carers Week is supported by celebrities who understand from personal experience the importance of support for carers. To name just a few: Dame Judi Dench, Jonathon Dingleby, Lynda Bellingham, Sir David Jason, Paul O'Grady and Sir Geoff Hurst.

The theme this year is **"In Sickness and in Health"** with the focus being on the impact on a carer's own health and well being. There is an online survey that aims to gather information that can be used to campaign for greater recognition for carers and an improvement in services and resources. Go to [www.carersweek.org](http://www.carersweek.org)

In Carers Week, thousands of events will take place around the UK to support carers. These range from information sessions about support and benefits, social events, trips and pampering sessions as well as launch events for new services.

To see what is going on near you or to get details of how to launch your own event, see [www.carersweek.org](http://www.carersweek.org)

## “WHY CAN’T YOU WALK, GRANDMA?”

TRANSVERSE MYELITIS SOCIETY  
VETERAN TMer, RUTH WOOD,  
STRUGGLES TO FIND THE RIGHT ANSWERS.

Even 6 years in, veteran TMer Ruth Wood struggles to find the right answer for her grandson.

“Grandma – why can’t you walk properly?”

I look down at the small, slim, brown-haired child obediently holding the bar on my walker as we make our slow way down the High Street.

This simple question gives me pause, and as the big, brown eyes look up at me with trusting innocence, I know I have no answer for him. But at the same time I feel, very strongly, that he deserves a reasonable reply.

But what to tell him? He’s very intelligent, but he’s still only six years old.

While I’ve been cogitating, he’s obviously been trying to work it out from his own, limited experience.

“Did you, perhaps, break your leg?” he asks.

“No.” I reply, “nothing like that”.

But he’s on a roll.

“And maybe your leg didn’t heal up properly,” he continues, earnestly, “and that would mean you limped so badly you could hardly walk at all.” He concludes, triumphantly.

**“This simple question gives me pause, and as the big, brown eyes look up at me with trusting innocence, I know I have no answer for him.”**



I look at him, half open my mouth to speak, then decide against it. He’s made up his mind and, subject closed, moves on.

As he continues chattering at top speed, Star Wars, Superman and Doctor Who all melting into each other in a kaleidoscope of enjoyment, I find myself wondering about my own apparent cowardice, and the fact that even after nearly six years and five attacks, I haven’t yet come to terms with having this condition.



RUTH WOOD

In common with most TMers, I’ve almost got used to the fact that complete strangers feel free to make comments about my disability.

“Hip operation then?” I’ve heard from sympathetic taxi drivers, shop keepers – anyone with an opinion based, like my grandson’s, on their own limited experience.

I try putting them right – gently, in a friendly way, with increasing irritation but all too often they’ve already decided on their own scenario.

**“Being honest, my main objection to others thinking I’ve had a hip replacement is sheer vanity.”**

Being honest, my main objection to others thinking I’ve had a hip replacement is sheer vanity. Even now, when my body still doesn’t work properly from the neck down, and bits of me are “missing” as far as my neural senses are concerned, my immediate reaction is usually – indignation. Can people possibly think I’m THAT OLD!!!!



## NEWSBITES

## NEWS IN BITE SIZED CHUNKS



**Matt Dunlop** (pictured front, left) and friends completed the gruelling "3 Peaks Challenge" recently. They battled snow, ice and high winds on Snowdon; minus 6 degree temperatures in the dark, torrential rain and high winds on Scarfell Pike; and high winds and snow with wind chill of minus 18 on Ben Nevis; all with very poor visibility. They had a fair share of injuries and mishaps (with one woman knocking herself out after a fall but determined to battle on when she came round; and one man twisting his ankle). Matt says that everyone was patched up and carried on but their pace was slowed for the rest of the trip. They also got stuck in a traffic jam between Scarfell and Ben Nevis which cost them 90 minutes and with visibility down to less than 15 metres on Ben Nevis, they missed their 24 hour deadline but still managed a very respectable time of 36 hours. Thanks to the generosity of friends, family and work colleagues they raised a total of £2,080 sponsorship and donated £500 to the TM Society, which is very gratefully received.

On Wednesday 18th July, the East Midlands group have a social event with guest speaker Sally Franz. Sally is an award winning humorous author and stand-up comedienne from Portland, Oregon. Her book "Scrambled Leggs: a snarky tale of hospital hooley", tells of her experience in hospital when she was diagnosed with TM. She has promised a very entertaining evening, with food provided - all free of charge. The event will be at Lullington Village Hall, Lullington, near Swadlincote DE12 8EJ. Sally will start speaking at 7pm but there will be tea and chat from 6pm. To reserve a ticket please email [jan.nig@tiscali.co.uk](mailto:jan.nig@tiscali.co.uk)

The Spinal Injuries Association run a series of 1 and 2 day training courses (which are FREE for non-corporate delegates) that are designed to provide information, insight and practical help on a range of specialist topics related to living with spinal cord injury. They are held at the Spinal Injury Centres throughout England, Northern Ireland and Wales and also at SIA's head office in Milton Keynes. The courses they offer include:

**Funding and Managing Your Care Needs**  
**Becoming a Parent After Spinal Cord Injury**  
**Making a Claim Under the Equality Act 2010**  
**Life and Work after Spinal Cord Injury**

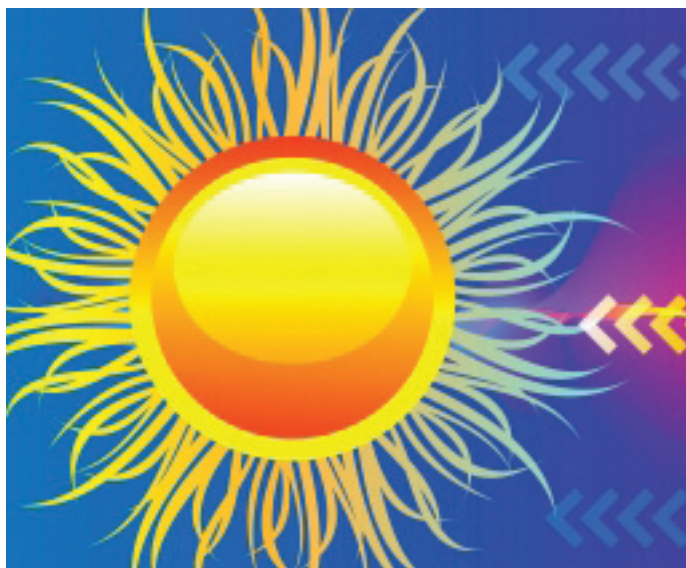
For more information visit the website [www.spinal.co.uk/page/sia-academy](http://www.spinal.co.uk/page/sia-academy) where you can make an online booking or contact Karen Mikalsen at [k.mikalsen@spinal.co.uk](mailto:k.mikalsen@spinal.co.uk) or 0845 678 6633 ext 221

**Peggy Hughes** from the South East Support Group will be one of the Olympic Torch bearers. If you want to cheer Peggy on, she will be doing her 300 metres in Hastings on Wednesday 18 July 2012.



And finally.... in our last edition, we featured the inspiring story of **Amy Edwards**. We are delighted to announce that Amy is to be married next year. Steve, old romantic that he is, proposed on Valentine's day and they are planning for their big day on 26 July 2013 before honeymooning in Disneyland, Florida. Congratulations and a lifetime of happiness to them both. X

Since the article in our last edition, **Sue Dingle and the Military Wives Choir** are going from strength to strength. They have followed their Christmas success with a number 1 album and are now set to sing for the Queen at the Jubilee celebrations!!



Most of us know something about vitamin D - it is the 'sunshine' vitamin that helps build strong bones and teeth. Historically, a lack of vitamin D was associated with rickets (underdeveloped, weak bones in children), a disease that was rampant through the 1920s and 1930s in America and Northern Europe. Since the government intervened in the 1940s, certain foods have been supplemented with vitamin D, and rickets has been more or less eliminated in the Western world.

In the last ten years or so, there has been a renewed interest in vitamin D. Studies suggest that low vitamin D levels are associated with a variety of chronic diseases including several types of cancers, multiple sclerosis, heart disease and diabetes. There is growing recognition about the link between vitamin D and improved immunity. The 'alternative' health sources make additional claims that low levels of vitamin D have a correlation with muscular weakness, chronic musculoskeletal pain, fatigue and easy tiring, SAD and depression.

Some of the published information on vitamin D levels is from

**“The ‘alternative’ health sources make additional claims that low levels of vitamin D have a correlation with muscular weakness, chronic musculoskeletal pain, fatigue and easy tiring, SAD and depression.”**

highly respected medical organisations like the Institute of Medicine (IOM) in the USA, the New England Journal of Medicine and the NHS. For information targeted at the general public, you only need to do a search on Amazon to see that there are scores of books asserting a correlation between vitamin D and a range of health benefits, including improvements in the immune system and increased longevity, as well as links with specific diseases including cancer, autism, MS, diabetes, and rheumatic conditions. There is, however, a general lack of empirical proof: it is incredibly difficult to perform regulated tests given the nature of the diseases, the unknown level of vitamin D generally and the fact that most situations can only be looked at retrospectively. Even if some of the claims can't be proven, you could take a view that there's just too much written about it to be entirely ignored!

### VITAMIN D 'BASICS'

Strictly speaking, vitamin D is not actually a vitamin! It's commonly referred to as one because it's often added as a supplement, but by definition a vitamin is a substance that is essential for the body but cannot be produced by the body. Vitamin D3 can be produced naturally by your body. And, unlike most other vitamins, it is fat soluble and can effectively be collected in the summer months and used throughout the winter.

### SOURCES OF VITAMIN D: SUNSHINE, SUSTENANCE OR SUPPLEMENT?

#### • SUNSHINE

Your skin makes vitamin D3 when it is exposed to sunlight. Using the sun as a source of vitamin D is far and away the best source of vitamin D, but this method is recommended cautiously because of the risk of cancer. In any case, there are additional problems in getting sufficient amounts, particularly in the UK. The factors that influence how many UVB rays that you are exposed to are: **Latitude** (in the winter, unless you live somewhere less than 35 degrees latitude you won't be able to get enough vitamin D; London is at 57 degrees latitude), **Season** (summer or winter), **Time of Day**, **Air Pollution levels**, **Cloud Cover**, **Altitude**, **Use of sun block** (anything over SPF 8 blocks about 95% of the UVB), **Colour of your skin** (dark skin has a lot of skin pigment which blocks absorption), **Age** (the elderly do not process it as well), **Weight** (excessive fat cells hinder absorption), and the **Amount of your skin that is exposed** (in particular, cultural apparel). When you think about it, we don't get nearly as much sun as we used to. Kids are driven to school and play indoors more and women's makeup often contains sun protection. In fact, sources suggest that for most people, in good summer sunshine, you need very little time in the sun – as little as 12 minutes at mid-day three

## THE LOWDOWN ON VITAMIN D

## CINDY MORELLI SHARES WHAT SHE'S LEARNED ABOUT THE SUNSHINE VITAMIN

times a week would probably be enough, but the sun does need to be out that day!

### • SUSTENANCE

You can get vitamin D3 from food, but you'd have to eat 2 to 3 portions of salmon every day to get your minimum recommended dosage. Foods that are high in vitamin D3 are fatty fish, eggs, liver and cheese. Some foods, like cereals, margarines and formula milk are fortified with vitamin D3.

### • SUPPLEMENTS

Vitamin D3 is available as a supplement that you can buy over the counter. It is made by processing lanolin and is usually the preferred formulation. You can also buy vitamin D2 supplements (which are made from plant products, usually yeast based) and then your body needs to convert that into vitamin D3. The dosage of our over the counter supplements are often given in milligrams. 25mg = 1000 IU (International Unit).

### MEASURING VITAMIN LEVELS: 25D AND 1,25D3

Vitamin D3 is processed by the liver and produces 25D. It is the measurement of 25D in the blood that establishes your vitamin D level. Some of the 25D works with your immune system and some of the 25D is further processed by your kidneys to produce 1,25D3. It is 1,25D3 that is used to regulate bone growth.

< 25 nmol/L	<b>Deficient</b>
25-50 nmol/L	<b>Insufficient</b>
> 50 nmol/L	<b>Sufficient</b>

A deficiency of vitamin D cannot be remedied by just taking the recommended daily dose. Treatment is relatively straightforward but needs to be done under the care of your GP. Either large doses will be given orally or vitamin D can be administered intramuscularly. Your GP will also establish whether there may be other medical complications and will 'check progress' at intervals.

### WHAT IS THE RECOMMENDED DAILY ALLOWANCE FOR VITAMIN D IF YOU ARE NOT DEFICIENT?

There are a number of guidelines issued from different sources and they are all slightly different. The mainstream medical professional will usually say between 600-800 IU per day, with a Tolerable Upper Limit of 4000 IU. One source recommended

none in the summer and 2000 IU in the winter. Older guidelines (produced when vitamin D was thought only to have an effect on bone growth) suggest a lower level.

### WHY VITAMIN D LEVELS MIGHT BE INTERESTING TO TMers?

At last year's conference, Dr Doug Kerr explained that he routinely tests all his newly diagnosed TMers for vitamin D deficiency and often suggests they take D3 supplements. In the UK, GPs do not routinely test vitamin D levels, but it would seem with a bit of explanation, most GPs will do a test for you. It's a simple blood test, with results usually available in 7-10 days in most areas.

**“It's a simple blood test that you  
can ask your GP to do for you.”**

It has long been suggested that MS is affected by vitamin D – the lowest occurrence of MS is in those areas closer to the Equator and the highest incidence is in Northern Europe, in places like Scotland and Finland. TM is now thought to have a reoccurrence rate of between 10-25% and in a low number of cases, a transition from TM to MS. There was a study mentioned in the last TMA journal that there is a possible correlation between low vitamin D levels and recurrent TM [www.myelitis.org/newsletters/j6/journal-6-04](http://www.myelitis.org/newsletters/j6/journal-6-04).

In any event, we all need to be as healthy as we can and the links between vitamin D and the immune system are quite well established.

*This article was kindly prepared by Cindy Morelli after a review of publicly available books, articles and other literature. It is not a substitute for medical advice. You should always consult your doctor before taking any supplements.*







**Colin MacNeill speaks to us about the day he finally fulfilled his ambition to pilot an aircraft, proving that having a disability need not hold you back.**

I'm an aviation enthusiast and it has been a life long ambition to pilot a plane. But despite being in the RAF and working around aeroplanes for the best part of 30 years, I have always been ground crew, responsible for supplying components and logistics. I only once had the opportunity to sit at the front of a plane and never to actually touch the controls. But this year I finally realised my ambition, took a trial flight with Aerobility and had a truly memorable day, piloting a light aircraft around the Staffordshire countryside.

**“The biggest surprise for me was how easy it all was.”**

I was diagnosed with TM in March 2006 and despite intensive rehab I have severe mobility problems and can only walk short distances with the aid of a stick. I lost more power from my legs and started experiencing nerve pain in 2008 after what the doctors termed “a bad cold” and so these days I am becoming more reliant on a wheelchair.

But none of this concerned the Aerobility staff. They are hugely knowledgeable and enthusiastic about what they do. They are fully trained to use hoist equipment; and they have a range of aircraft available, some of which are specially adapted. I believe their assurance that no matter what your disability, they will find

a way of getting you into an aircraft.

The flight itself massively exceeded my expectations. At best, I was hoping for a thrilling ride as a passenger perhaps with a quick touch of the controls here and there. After a lifetime of supplying the components for the planes, it would have been a real treat to see them all in use up close. But the reality was far better. The aircraft had dual controls and so my instructor, Craig, gave me a short safety briefing and got us up in the air but then it was over to me. I spent half an hour properly in charge of the plane, steadying the nose, making turns (or “banking”) left and right over some spectacular scenery. It was truly breathtaking to be seeing everything from the air knowing that I was piloting the plane. Craig did the actual landing but I had to get the plane set up, steer the aircraft for the approach and slow to the proper speed.

The biggest surprise for me was how easy it all was. The controls are straightforward and within minutes you can actually be in charge of a plane. Whilst in the air, most of the control was done with my arms which was no problem. Some of the plane's movements like working the flaps are controlled by the legs in a standard plane so I found that part tricky with limited power. But there are special adaptations if I took up flying more regularly.

I would love to carry on and obtain a full pilot's licence but it's an expensive hobby so we will see. But I thoroughly recommend anyone with a flicker of interest to have a go. It is probably the best £60 I have ever spent.

Visit the Aerobility website [www.bdfa.net](http://www.bdfa.net) to find out more.

## GARDENING

## TIPS FOR YOUR GARDEN FROM ROSITA SCALES



ROSITA SCALES

This is the busiest time in the gardening calendar. Now is the time I take cuttings from last summer's geraniums, which I have kept overwintered in their pots. These are so easy to do: take your secateurs, cut off a new green shoot, plunge it in water, then rooting powder, pop in to a small pot, and watch it grow!

I have taken a lot of different shrub cuttings too, but this time I used the basal method. Cut a short, healthy, new soft stem from the mother plant, about 2-3 inches long, then cut off the leaves except for about 2 at the top. I fill pots with a multi purpose compost mixed with one third Perlite (very tiny balls of polystyrene) which helps to keep the compost aerated. Dip the new cutting into rooting powder and place round the edges of the pots. The compost should be kept moist, but not wet. I use a spray with a mixture of water and Cheshunt Compound, this prevents 'dampening off disease' which can rot the seedlings. Place into a Propagator, or simply put a clear poly bag over the pot and hold in place with an elastic band. It could take days, or weeks, but with luck you will be rewarded with new plants which have cost you virtually nothing!

Earlier this year I sowed small punnets and pots with different lettuce seeds, and now we are enjoying our own 'mixed salads'. Sow new pots every 3 weeks and you'll have salad right through the summer. The joy of eating your own produce is so fulfilling, and will taste and keep so much better than those expensive bags of leaves from the supermarket

I save plastic trays and yogurt pots for use as seed trays. The trays can also be used to sit the plants on for watering from the bottom. And lemonade bottles, cut in half, make mini propagators. The greenhouse looks very colourful with all the assorted pots and trays, and it keeps costs down. If you do not own a greenhouse a sunny window sill is ideal, just watch for scorching, and keep rotating the pot to keep the plants growing upright

To prevent drying out and distressing the seedlings I never place trays on the top shelves, or in direct sunlight, for fear of scorching the fragile growth. When the seedlings are large enough to handle, hold by the leaves (never the stems) and gently prick out into larger pots. This is either therapeutic or very tedious, but I happen to enjoy it.

To start beans, peas and sweet peas, I use the cardboard inside from toilet rolls. Stand them up in an appropriate sized plant pot, fill with the compost then sow your seeds. Ideal for long rooted plants these can go straight in the ground when the time is right.

Gardening articles are always referring to 'hardening off' your plants. All this means is getting the plants used to the outside temperatures before being planted in their final positions, be it tubs, baskets or borders. Cold frames, as they are called, can be expensive, but my husband has created a row of cold frames using breeze blocks set in squares with polycarbonate sheets or polythene to cover. Lift the covers on warm days, always putting them back down on an evening, because even if there's no frost, nights can still be chilly.

Cuttings can be taken at any time of the year, but the reason for doing it now is that they will root readily. So start now and soon you'll be taking cuttings from cuttings!

Happy gardening!


## POSTBAG

## A ROUND UP OF YOUR LETTERS AND EMAILS

**We have had an amazing response to our first edition of the magazine. Here is a selection of the comments that we have received.**

Thank you for sharing your excellent magazine. Of course, the first thing Jim said to me was "why aren't you producing something that looks this good?" Awesome job on your inaugural magazine. You've set a high standard for the rest of us ... I will now be spending the foreseeable future trying to get our publications to look as good as yours! **Sandy Siegel, President of TM Association, USA**

Well done, an excellent mix of humour and factual information. A great read. **Facebook user** 

Annie, you and the team have done an amazing job - I loved the first edition and can't wait till the next - thank you so much xx **Facebook user** 

Wow, what a nice mix of information, real life and humour! Thank you so much for this, it's much appreciated. My one comment would be that I much prefer a pdf to a hard copy, as sometimes my eyesight gets blurry and I can make the font bigger on pdf. Well done everyone! Xx **Facebook user** 

All our magazine editions are available in pdf format on the main TM website: [www.myelitis.org.uk](http://www.myelitis.org.uk)

Well done and thanks for the mag guys, very professional presentation. I try to deny I'm a TMer but reading articles such as Lew's are irresistible, while the story of the little girl put my minor problems into perspective. **Ian Pepper**

Just finished reading the first edition of the magazine. ABSOLUTELY BRILLIANT!! What a WONDERFUL step forward for the Society! A great way to deliver news and updates from (and to) the TM world. It helps me to not feel so alone when I read of others who struggle with the dreaded bladder and bowel problems - an affliction that seems common to all us TMers!! Anyway, keep up the excellent work!! **TMer from London**

I'd just like to congratulate you on this fabulous magazine, I know how much hard work has gone into this. I have copied it and passed it onto people that have been to our clinic with diagnosis of TM. Thank you for the NMO mentions. Between us hopefully we will continue to raise awareness for our rare conditions. **Kerry, Neuromyelitis Optica (NMO) Specialist Nurse, Walton Centre**

I have refrained from contacting you regarding the magazine whilst you were in the process of putting it together because I

wanted it to be 'your baby'. Now that I have received and read it I believe I was right. Your daughter, Nakia and yourself have produced a publication that I am so delighted with. Reading what fuelled the idea in the first place reminded me of how the TM Society started. Thank you so very much. (Words cannot really express my gratitude). This has taken us to another level of communication and the responses you have received already highlights the pleasure you have given to so many of our members. In your own words, everyone loves a magazine. **Sally Rodahan, President TM Society**

### **PCT funding for botox - can you help?**

We have had a plea from one of our members. Julie, a TMer from West Sussex, has just been refused funding from her PCT for botox on her bladder. If anyone has had a similar experience and successfully managed to appeal and get the decision reversed, Julie would be very grateful to hear from you. Please contact Annie or Ros if you can help and we'll put you in touch with each other.

**We love to hear from you so please keep your letters and emails coming. You can share your stories, tell us the funny or not so funny moments and maybe inspire others.**

And it's not just about the patients. As we all know, TM is a diagnosis that affects the whole family. We would also love to hear from those of you with a partner, child, parent, grandparent or sibling with TM. You don't have to share your life stories. Children and young people might want to share their emotions through poems, artwork, music or just share something amazing about your life.

We're guided by you, so if you'd like to see something in a future edition of the magazine, please let us know.

**Annie & Ros X**

[annie.schofield@myelitis.org.uk](mailto:annie.schofield@myelitis.org.uk)  
[ros.gallagher@myelitis.org.uk](mailto:ros.gallagher@myelitis.org.uk)



**DID YOU KNOW  
THERE IS A TM  
FACEBOOK PAGE?**

It now has more than 300 members. It can be a useful and relatively informal way to reach out to other members to ask for advice and tips to deal with whatever is troubling you. This can lead to some lively debates. Rob Reeve and Amy Edwards are the page administrators. Search for Transverse Myelitis Society on facebook.com to join the closed group.



### LONDON SUPPORT GROUP

SUPPORT GROUP MEETING DATES ARE **21ST JULY, 20TH OCTOBER**

At our next meeting we have two speakers. Akiko Yoshioka is not only a TM Member but also specialises in facial Reflexology. This will be a fascinating talk and practical demonstration which may well prove to be a very restful alternative treatment for TM sufferers. Natalie Woodman, a Neuro Physio, is also coming to tell us about her new clinic in Wimbledon and all that she and her company are doing for TMers.

Please feel to come on your own or with family/ friends. This is your opportunity to speak to other TMers and the guest speakers. We meet at 2.00pm and there will be refreshments at the beginning and cake at teatime!

**Venue:** ECHQ, 34 York Way, London N1 9AB. The venue is wheelchair friendly, and car parking is FOC from 1.30pm on Saturdays in York Way. There is no London Congestion Charge on Saturdays. ECHQ is a short 3-4 min walk from King's Cross Station. **For further details please contact Yvonne Kolesar, [yvonnegk50@msn.com](mailto:yvonnegk50@msn.com) tel. 01737 552869 or Lew Gray, [lewgray@blueyonder.co.uk](mailto:lewgray@blueyonder.co.uk)**

### SOUTH EAST SUPPORT GROUP

SUPPORT GROUP MEETING DATES ARE **23RD JUNE, 15TH SEPTEMBER & 1ST DECEMBER (CHRISTMAS LUNCH)**

We had a great start to the year (and our 2nd Birthday), with our largest turnout ever to listen to our 2 speakers, Bronwyn Tetley, Colorectal Nurse and Adele Brody, the South East representative for Coloplast (continence products). Our June meeting will include a discussion on the proposed 'TM Profiles' that our group is going to roll out, then our September Speaker will be a Neuro Physio.

**Venue:** Pembury Village Hall, High Street, Pembury, Kent TN2 4PH. It is wheelchair friendly with disabled loos. There are 2 disabled parking bays and 10 further parking places outside. Additional parking on the road. **For further details contact Annie Schofield, [annie.schofield@myelitis.org.uk](mailto:annie.schofield@myelitis.org.uk), Carol Preece, [preece.carol@googlemail.com](mailto:preece.carol@googlemail.com), or Peggy Hughes, [mail@peggyj.com](mailto:mail@peggyj.com)**

### BRISTOL SUPPORT GROUP

NEXT SUPPORT GROUP MEETING IS **3RD JUNE**

We meet four times a year, starting at 1pm. It is only a small group but the meetings last a good couple of hours with plenty of TM chat fuelled by coffee/tea and humour.

**Venue:** The Reception area of the Holiday Inn, north Bristol. **For further details please contact Steve Collins, [steve.collins@blueyonder.co.uk](mailto:steve.collins@blueyonder.co.uk)**

### EAST MIDLANDS SUPPORT GROUP

NEXT SUPPORT GROUP MEETING **16TH JUNE**

We had a really good meeting on 3rd March, with 45 people attending. Farshideh Bondarenko came along and gave a brilliant presentation on neuro physiotherapy, leaving us all with a much more positive outlook. At our next meeting, on Saturday 16th June at 2pm, our speaker, Suman Antcliffe, will talk about benefits including the new PIPS payment if things have been finalised by then.

**Venue:** The Village hall, Lullington, Nr Swadlincote. DE12 8EG. **For further details contact Janet Ashenden, [jan.nig@tiscali.co.uk](mailto:jan.nig@tiscali.co.uk)**

### POOLE/BOURNEMOUTH SUPPORT GROUP

SUPPORT GROUP MEETING DATES ARE **28TH JULY & 27TH OCTOBER**

We are a large friendly group who meet the last Saturday of January, April, July and October. The Poole Group was formed in 2005 and has over 80 members. It offers support and advice to members, their family and friends. Come along and enjoy our lovely homemade tea and cakes and meet others affected with a variety of neurological conditions from TM to NMO, ADEM and MS.

**Venue:** St Georges Church Hall, Oakdale, Poole, Dorset BH15 3EU from 2-4pm.

**For further details please contact Group Leader: Lance Harris, [lv.harris@hotmail.com](mailto:lv.harris@hotmail.com) or Secretary: Barbara Houston, 01425 673173 [barbs@houston19.freemove.co.uk](mailto:barbs@houston19.freemove.co.uk)**

### TELFORD SUPPORT GROUP

SUPPORT GROUP MEETING DATES ARE **16TH AUGUST & 6TH DECEMBER**

We are the oldest support group in the country, set up in 1996, and meet on Thursdays between 2-4pm. There is always lots of laughter around the table as we try to share our experience since we all have varying degrees of disabilities. Family and/or friends are more than welcome. We also have members with TM related disorders. We aim to have Speakers and make these decisions together as a group.

**Venue:** Ketley Community Centre, Holyhead Road, Ketley, Telford, Shropshire, TF1 5AN. The venue is wheelchair friendly with easy access. **For further details please contact Anna Paulsson-Habegger on 07581708597 [annaph@blueyonder.co.uk](mailto:annaph@blueyonder.co.uk)**

### NORTHERN IRELAND SUPPORT GROUP

We usually have sandwiches and tea/coffee on arrival and make time to introduce ourselves. In the past we have had speakers such as Kerry Mutch (NMO Specialist Nurse from The Walton Centre), Denise Fitzgerald (Lecturer and researcher from Queens university) and Maria McGrogan (Continence specialist and representative for Coloplast continence products).

**Venue:** The Dunsilly Hotel in Antrim, easily accessible via the Motorway, it is also wheelchair friendly. **For any further details please contact Eileen Bradley, [ebtm@hotmail.co.uk](mailto:ebtm@hotmail.co.uk) or 02829557114**

### TRANSVERSE MYELITIS SCOTLAND

**Venue:** Conference Room opp. Day room, Philipshill Ward, Spinal Injuries Unit, Southern General Hospital, 1145 Govan Road, Glasgow G51 4TF. **For further details please contact Margaret Shearer on 01292 476758 or [margaretshearer@myelitis.org](mailto:margaretshearer@myelitis.org)**



## USEFUL CONTACT INFORMATION

**Bladder & Bowel Foundation**

0845 345 0165  
[www.bladderandbowelfoundation.org](http://www.bladderandbowelfoundation.org)

**Brain & Spine Foundation**

0808 808 1000  
[www.brainandspine.org.uk](http://www.brainandspine.org.uk)

**Carers Direct**

0808 802 0202  
[www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)

**Carers: The Princess Royal Trust**

0844 800 4361  
[www.carers.org](http://www.carers.org)

**Continence Foundation**

[www.continence-foundation.org.uk](http://www.continence-foundation.org.uk)  
[info@continence-foundation.org.uk](mailto:info@continence-foundation.org.uk)

**Depression Alliance**

0845 123 2320  
[www.depressionalliance.org](http://www.depressionalliance.org)

**Disability Information  
Advice Line (DIAL)**

01302 310 123  
[www.dialuk.info](http://www.dialuk.info)

**Disability Law Service**

0207 791 9800  
[www.dls.org.uk](http://www.dls.org.uk)

**Disabled Living Foundation**

0845 130 9177  
[www.dlf.org.uk](http://www.dlf.org.uk)

**Disability Now Magazine**

01454 642 444  
[www.disabilitynow.org.uk](http://www.disabilitynow.org.uk)

**Driving: Disabled Motoring UK**

01508 489 449  
[www.disabledmotoring.org](http://www.disabledmotoring.org)

**Driving Licences:  
DVLA Drivers Medical Unit**

0870 600 0301

**Gardening**

[www.gardeningfordisabledtrust.co.uk](http://www.gardeningfordisabledtrust.co.uk)

**Mobility aids: Just Mobility**

01923 265 577  
[www.justmobility.co.uk](http://www.justmobility.co.uk)

**Motability Car Scheme**

0845 456 4566  
[www.motability.co.uk](http://www.motability.co.uk)

**Neuromyelitis Optica (NMO)  
[Formerly Devics Disease]**

[www.nmouk.nhs.uk](http://www.nmouk.nhs.uk)

**NMO: The Walton Centre, Liverpool  
Nurse Specialist**

0151 529 8357  
**NMO Service Coordinator**  
 0151 529 8131  
[nmo.advice@thewaltoncentre.nhs.uk](mailto:nmo.advice@thewaltoncentre.nhs.uk)

**NMO: John Radcliffe Hospital, Oxford  
Nurse Specialist**

01865 231 905  
**NMO Service Coordinator**  
 01865 231 900  
[nmo.advice@orh.nhs.uk](mailto:nmo.advice@orh.nhs.uk)

**Pain Concern**

0300 123 0789  
[www.painconcern.org](http://www.painconcern.org)

**Pain: British Pain society**

0207 269 7840  
[www.britishpainsociety.org](http://www.britishpainsociety.org)

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

0800 882 200  
[www.dwp.gov.uk](http://www.dwp.gov.uk)

**Transverse Myelitis Society**

35 Avenue Road  
 Brentford TW8 9NS  
[www.myelitis.org.uk](http://www.myelitis.org.uk)  
 U.K. registered charity 1108179  
 Contact Yvonne Kolesar  
 (chair) 01737 552869 or  
 Lew Gray (Secr) 020 8568 0350  
 Email: [lewgray@blueyonder.co.uk](mailto:lewgray@blueyonder.co.uk)

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