SPRING 2015

The Magazine

TRANSVERSE MYELITIS SOCIETY

NEIL BURTON
ONE MAN'S STEM CELL JOURNEY

OUR **TM KIDS**

NATASHA BAKER
GOING FOR GOLD

10TH ANNIVERSARY OF THE TMS
THE **10TH** EDITION OF THE TMS MAGAZINE
MORE THAN **1,000** FACEBOOK MEMBERS

CONTENTS

LETTER FROM THE EDITOR

This magazine is a story of 10s, and the milestones represented. The publication is the 10th edition (and the first one to be printed), our Facebook page has just passed the 1000 member mark, and it's 10 years since the TMS became an officially registered charity.

Rewind ten years to May 2004 and visit the journey to date. I was recently diagnosed with Transverse Myelitis (TM) and the only information available was via the US based TMA. Geoff Treglown was the European Coordinator for the TMA, who, supported by Lew Gray, distributed the TMA Newsletter in the UK. Sally Rodohan 'found' them (46 years after she was struck down with TM), in 2004 Sally and Lew arranged the first meeting of the London Support Group. This small beginning gave birth to the Transverse Myelitis Society (TMS) and we celebrate the **TMS 10th anniversary** as a registered charity in 2015!

Amy Edwards (now Curtis) suggested an official TMS Facebook page. The initiative, which started off quite slowly in 2011, has evolved into a site where people can seek advice, share problems, or maybe just have a good moan to people who 'understand'. We now have more than **1000 members** who use the site, and the numbers increase daily.

During this time support groups have spread far and wide around the UK, but despite so much activity, TM can be very isolating as not everyone has, or can get to, a meeting in their area. What we needed was a magazine, full of articles about the everyday problems you encounter, if you have TM, and stories from people with TM and how they manage their lives. I had this vision of someone sitting down with a cup of tea, feeling very isolated, and reading in our magazine about someone else with the same problems, and suddenly not feeling so alone.

Despite my concern that we might run out of stories after the second edition, we seem to have strengthened, with a never ending supply of amazing stories from TMers. In the 2nd edition we told the story of a dressage rider named Natasha Baker who was a GB team hopeful at the time. Natasha made it into the team and went on to win 2 gold medals in the 2012 Paralympics, her story is reprinted on page 10. Fellow TMers travelled to the Olympic venue to support her.

Returning to the '10s' theme, we can't forget the most important one; to have TM is said to be '**one in a million**', but it can be a cruel cross to bear and one that people without TM find hard to understand. It's easier to elicit sympathy or understanding if you have been paralysed by TM, but it's the hidden issues which are the worst, bladder and/or bowels that don't work properly, excruciating neuro pain, banding, or fatigue. Only if you have experienced fatigue can you understand that it's nothing like just being very tired.

Like any rare condition, the more people hear about it, the more likely it is to be understood, so please spread awareness by passing on this magazine, ordering more copies, or accessing it on-line at www.myelitis.org.uk.

I would like to thank those who have helped make this magazine what it is; Martin Nagler, Ros Gallagher, Clare Rowntree, the present editorial team, and my daughter Alice who introduced me to Nakia, our endlessly patient designer, who has to cope with this bunch of amateur journalists.

Don't forget, we need your stories, comments and suggestions for future magazines. Please e-mail me at **annie.schofield@myelitis.org.uk**

Annie

Annie Schofield

Zelda Carr

Steve Holden

Heather Coltman

WHAT EXACTLY IS TRANSVERSE MYELITIS
ZELDA CARR EXPLAINS

Literally translated Transverse Myelitis (TM) means 'situated or extending across' and 'inflammation of the spinal cord'.

Transverse Myelitis is an inflammation of the spinal cord, where the immune system targets the myelin sheath (nerve insulation) causing spinal cord damage. The inflammation disrupts communication along the spinal cord, potentially causing paralysis, along with motor and sensory issues. TM is considered an autoimmune condition, where the body mistakenly attacks the spinal cord.

The medical profession don't know what causes TM but the inflammation is sometimes preceded by viral or bacterial infections. Patients have also reported attacks following a vaccination, which causes an immune response. Other cases appear to be idiopathic, which means the cause has not been identified. TM is normally monophasic i.e. once only occurrence; a small percentage of patients have recurrent TM.

Symptoms can appear suddenly, within hours or slowly over several weeks. Symptoms can be severe and include paraesthesia (strange sensations like burning, tingling and numbness), and paraparesis (partial paralysis of the legs). Dependent on the segment of the spinal cord affected, respiratory issues can also be experienced. TM can affect the autonomic nervous system, which controls involuntary body functions such as heart rate, digestion, urination and respiration. This may result in underlying health problems.

The location of the damage in the spinal cord determines which parts of the body are affected. Please refer to the diagram opposite.

In some people, TM may be the first presentation of other neurological conditions, including Multiple Sclerosis (MS), Acute Disseminated Encephalomyelitis (ADEM) or Neuromyelitis Optica (NMO). MS is normally characterised by short, partial lesions, whereas NMO is characterised by long lesions over a number of segments of the spinal cord - Longitudinally Extensive Transverse Myelitis (LETM).

TM is a very rare condition, (2-300 cases a year in the UK) and many practising physicians have neither heard nor seen a case of TM. When a patient presents at the hospital, normally through A&E, the condition is rarely recognised. Doctors need to take a detailed medical history, perform blood tests and rule out other causes. Many patients are misdiagnosed initially. An MRI greatly assists in the diagnosis of TM, where lesions can normally be observed on the images. Unfortunately there is no 'cure' for TM but fast treatment is essential for patients who are significantly affected by the condition. First line treatment normally consists of high doses of anti-inflammatory corticosteroids, either intravenously or by mouth. The steroids reduce the inflammation thus reducing any further damage. Plasma exchange or other immunosuppressant treatment may be prescribed where steroid treatment doesn't work.

Recovery usually starts within weeks of diagnosis. After the initial treatment, rehabilitation is essential to get the affected limbs mobilised. Improvements often happen quickly within the first six months and up to two years or more. A neuro-physiotherapist will understand the condition better than a standard physiotherapist. The TMS offers bursaries for members to receive two free sessions with a neuro-physiotherapist. One third diagnosed with TM report a good recovery, one third have only a fair recovery (moderate degree of permanent disability), and one third have a poor recovery. Building core strength supports recovery. Many members have found Pilates, Yoga, Tai Chi, riding and swimming beneficial.

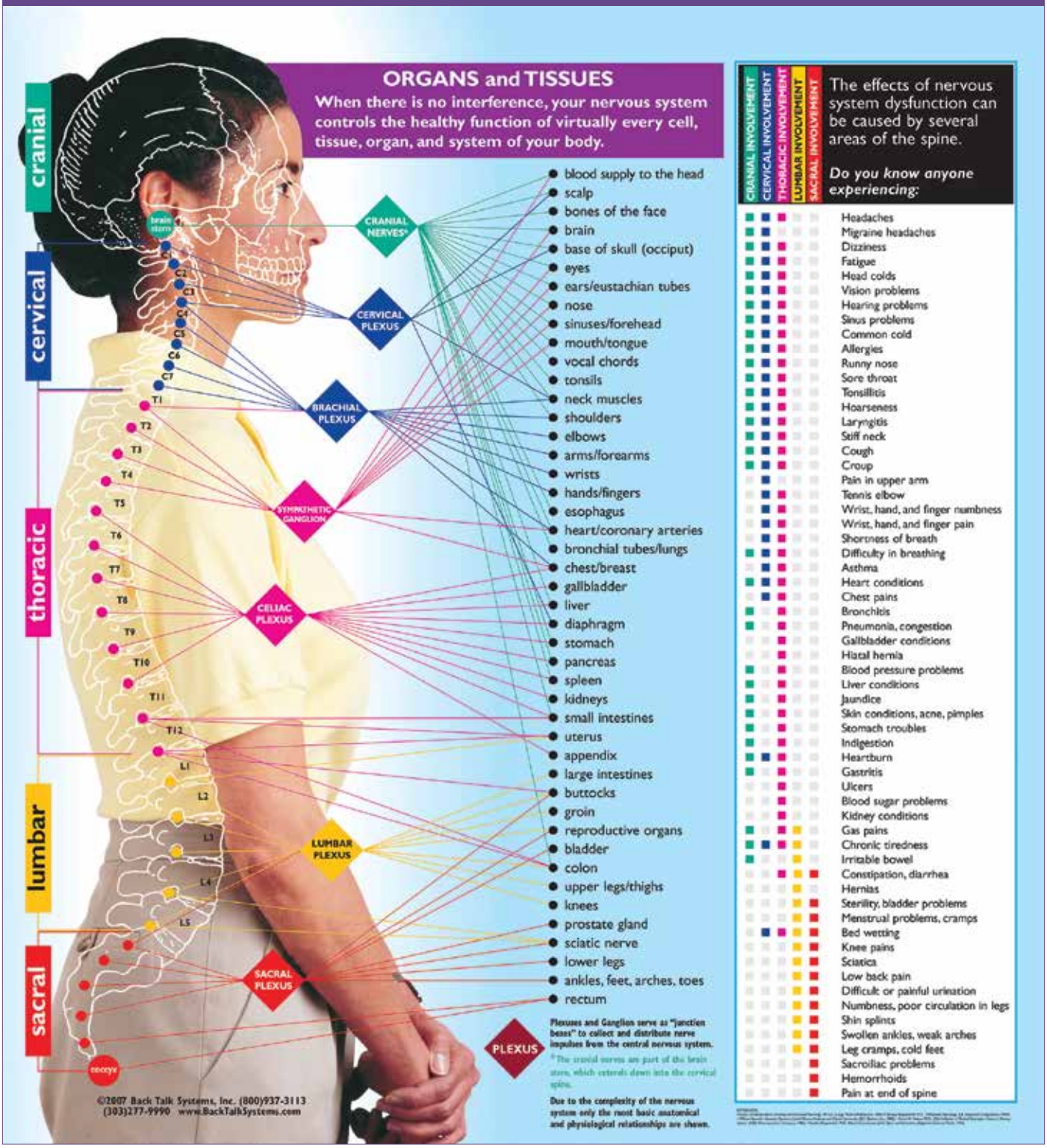
One of the biggest residual problems people encounter is pain so a careful pain management plan is essential. Some people manage pain through alternative therapies but others will need medication to cope with the pain. Fatigue is another challenge people face daily so managing the day's activities is important. The 'Spoon Theory' can help with managing fatigue by saving enough energy for the day.

Educating family members is important as many of us look 'normal' on the outside. Our suffering is not visible. If family members and friends have a good understanding of the condition, their support can help us enormously.

Thanks to Back Talk Systems, Inc. for the image.
www.backtalksystems.com
www.backtalkeurope.com

NERVE FUNCTION

Many things can impair your nervous system and interfere with its function.



ONE MAN'S STEM CELL JOURNEY
NEIL BURTON TELLS HIS STORY

THIS STORY WAS FIRST PRINTED IN OUR SPRING 2014 EDITION

My name is Neil Burton and I am 33 years old. In September 2009, after an episode of mumps, I contracted both Transverse Myelitis & Guillain Barre Syndrome. Over the course of one day my whole body shut down and I was sedated. Upon waking up, I realised that I was completely paralysed and required mechanical ventilation for my breathing - all I could do at that point was blink!

I spent a year in intensive care and a year in a rehabilitation centre before returning home to continue physiotherapy

During that time I managed to regain some movement in my legs/hips/left hand/head, however I was still confined to a wheelchair and reliant on a ventilator for breathing. I visited a neurologist only to be told what unfortunately many people with these conditions get told - I will either recover or I won't and to what extent they don't know. For me that wasn't enough so I started a search for alternative therapies.

I tried Homoeopathy (something I had used before my illness), Chinese herbs, acupuncture & vitamins - all with varying degrees of success, however it was when I came across stem cell treatment that I found the most promise. I wasn't interested in embryonic stem cells for multiple reasons, but was interested in adult stem cells as these cells exist in our own body and the common cells used are from the bone marrow. Studies have shown when the human body is injured the bone marrow releases additional stem cells into the bloodstream to perform repair work, so to harness this potential makes sense. Some people will argue that adult stem cells can only produce fat, bone & cartilage but many studies indicate they can become a lot more than that.

> *"Over the course of one day my whole body shut down"*

After speaking with many patients around the world who had undertaken stem cell treatment for paralysis, MS, Transverse Myelitis & GBS, along with all the scientific studies I had read, I decided this was a treatment worth trying. When I started investigating clinics it was obvious there are many people out there trying to take advantage of vulnerable patients so you have to be careful. Do your research on the clinics and talk personally with patients

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who have been treated with by them. I found there were clinics who were honest and had a good reputation. I was told many times they could not guarantee any success, but I was happy to take on the procedure with this information. I finally settled on a clinic in Frankfurt, Germany and this is where I was to be treated.

The clinic in Germany performed a very standard treatment. Stem cells were to be extracted from my bone marrow, multiplied and injected both intravenously into my blood & into my spinal cord via a lumbar puncture; the procedure was very painful but bearable. I was told that I could start to see improvements in 6 to 8 weeks but could take up to 6 months. I am currently 6 1/2 weeks post-treatment and I have already had pins and needles/electric shock like feelings in my hands/arms/legs/feet – all potentially good signs of nerve recovery. My facial paralysis has eased and improved slightly and the strength in my legs has improved.

I don't know exactly where this treatment will take me. All I know is there is now extra hope whereas before there was very little! You can follow my journey on my blog. **http://stemcellsjourney.blogspot.co.uk/**

FEBRUARY 2015 SECOND TREATMENT UPDATE:

I have now completed my second course of treatment which was a little less painful than the first course. I knew what to expect this time, so it made it all a little easier. I have experienced lots of strange tingling sensations again, which is similar to last year, but it will take a few months for them to really kick in. I have noticed that my trunk control has improved dramatically when I am hoisted onto my sofa (something I've done regularly in the past). It's amazing what belief and experiencing this sort of progress gives you to carry on and push hard!

> *"Studies have shown when the human body is injured the bone marrow releases additional stem cells into the bloodstream to perform repair work so to harness this potential makes sense"*

UNDERSTANDING PAIN IN TRANSVERSE MYELITIS
A Q & A WITH DR. BENJAMIN GREENBERG

Dr. Benjamin Greenberg, MD, MHS from the University of Texas at Southwestern in Dallas, is one of the world's leading experts in TM. **This excellent Q &A was posted on the TMA Blog:-**

IS PAIN A TYPICAL SYMPTOM IN CONDITIONS LIKE TRANSVERSE MYELITIS (TM)?

One of the most common issues that people with transverse myelitis experience is pain. It can come in many forms, but the most common is a burning or stabbing pain that occurs in an arm, leg or around the trunk. It is often described as a burning, aching or stabbing pain. When the pain occurs in the chest or abdomen it is often described as a squeezing sensation. Frequently the pain worsens with exertion, stress, heat or in the evening when trying to go to sleep. It is also frequently experienced in an area that had previous sensory changes. This type of pain is often not present at the onset of TM, but develops in the weeks or months afterwards.

WHAT IS NEUROPATHIC PAIN?

Medically, there are many types of pain that affect human beings. Neuropathic pain occurs when there is damage to a part of the nervous system and after that event normal sensation is replaced with uncomfortable sensations.

> ***"While a person's foot may burn at night, there is no flame near the skin! So why does the brain perceive pain"***

WHY IS NEUROPATHIC PAIN EXPERIENCED IN NEURO-IMMUNOLOGICAL CONDITIONS?

Neuropathic pain has a different cause, and treatment to other types of pain. When you place your hand on a hot stove, it hurts. It is supposed to hurt. A signal moves from your hand to your brain and is interpreted as pain. The wound is painful even during the healing stages. This process is there to protect animals from tissue injury. We are supposed to learn that placing hands on hot stoves is dangerous! The medications used to treat this pain include opiates because the brain's pain centres have large numbers of opiate receptors. When opiate medications bind to these receptors it dampens down the perceived pain. As the medication wears off, the pain returns. In reality, the pain signals are always there – transmitted from the wound to the brain, but are ignored by the brain when opiates are present.

Neuropathic pain is different. Very different! While a person's foot may burn at night, there is no flame near the

skin! So why does the brain perceive pain? The answer has to do with the pain pathways to the brain and pain centres in the brain. When sensation fibres in the spinal cord are damaged by transverse myelitis there is often a loss of normal sensory input to the brain. As a result, the sensation networks in the spinal cord and sensory centres in the brain are left with incomplete input of signals. The brain is used to receiving billions of signals every second from our bodies. Temperature, vibration, pressure, movement, light touch and pain inputs bombard our brain constantly. Every square inch of skin includes thousands of nerve endings responsible for a multitude of signal types. If the pathways responsible for vibration are damaged in the spinal cord, then the brain receives an incomplete "sensory picture" about what is happening to the feet. The spinal cord is left to manage incomplete sensory inputs. As a result of these changes the spinal cord can lead to amplification of some sensations (in an unpleasant fashion) and the brain can "fill in the gap" of missing sensation with unpleasant sensations (burning, squeezing, stabbing pains).

WHY DOES NEUROPATHIC PAIN GET WORSE AT NIGHT?

Many patients indicate that their pain is worse in the evening when trying to go to sleep. You may wonder why this occurs! As the brain "fills in gaps" you might expect distraction to lessen this phenomenon. Thus, while at work or busy, people may not experience the pain, but when less distracted, their brain may be free to 'make things up'! Just as a person tries to relax, their brain kicks into gear and the pain intensifies.

WHAT ARE COMMON TREATMENTS FOR NEUROPATHIC PAIN?

Neuropathic pain is not supposed to be there – no damage to the affected area exists. Rather, the damage is in the nervous system carrying signals from that area. As such, the treatment for this type of pain would be expected to be different to the treatment of other types of pain. Treatment of neuropathic pain usually does not involve opiate painkillers. Often patients with neuropathic pain will say that the use of opiates 'took the edge off', but did not rid them of pain. As such, we usually use antidepressant or antiepileptic medications to treat neuropathic pain. Are patients depressed or having fit? NO! These classes of medications act on cells in the brain and spinal cord to dampen down the 'made up' signals that are interpreted as pain and as

> *"While at work or busy, people may not experience the pain, but when less distracted, their brain may be free to 'make things up"*

such are perfect for neuropathic pain. Examples include amitriptyline, pregabilin, gabapentin and carbamezapine. There are many other options that have been used in patients. Beyond medication, many patients will find benefit from topical anesthetics to reduce all sensory signalling, acupuncture and/or avoidance of pain triggers. A careful discussion with your doctor about your pain is needed to discuss, what it feels like, what triggers it, what has helped in the past and what medications might be indicated. Pain needs to be aggressively treated as it can worsen mood and energy levels. Often multiple agents need to be attempted so that an appropriate one can be found.

MY STORY
NATASHA BAKER MBE, GOING FOR GOLD

Natasha Baker MBE was born in December 1989 and grew into a very happy,intelligent and contented baby, talking at a very young age and walking by one year. At the age of 14 months she contracted TM, resulting in paralysis from the waist down. At the age of 3 she slowly started to walk again with the help of callipers and a rollator, and continued to make progress until she was about 6, but then things plateaued. Her physiotherapist suggested she get involved with the local Riding for the Disabled Association, so aged eight she started riding on a weekly basis.

THE FOLLOWING WAS PRINTED IN OUR MAGAZINE IN JUNE 2012

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! 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 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

MY STORY
NATASHA BAKER MBE, GOING FOR GOLD

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. My motto has always been "everything happens for a reason" and if it wasn't for 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 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 goose bumps.

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

> *"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."*

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.

MARCH 2015

"Since London 2012 my life has somewhat changed. I still have to pinch myself every time I see my two Gold medals and cannot get used to having MBE after my name! My diary is constantly full with competitions or public appearances and I absolutely love it. It's been great to be able to spread the word about TM and how we can change a disability into an ability. With a bit of blood, sweat and sometimes tears, anything is possible. I have recently started receiving Botox treatment in my bladder and it has totally changed my life, thanks to you Annie!! Thank you so much for the recommendation! I love it!!!!!!

www.natasha-baker.com
www.facebook.com/nbakerpararider
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THE BLADDER IN TRANSVERSE MYELITIS

MR GOVINARAJ RAJKUMAR & DR MUHAMMAD THRUFAEL UDDIN

MR GOVINDARAJ RAJKUMAR MS, FRCS

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

DR MUHAMMAD THUFAEL UDDIN MBBS

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.

THE BLADDER IN TRANSVERSE MYELITIS

MR GOVINARAJ RAJKUMAR & DR MUHAMMAD THRUFAEL UDDIN

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.

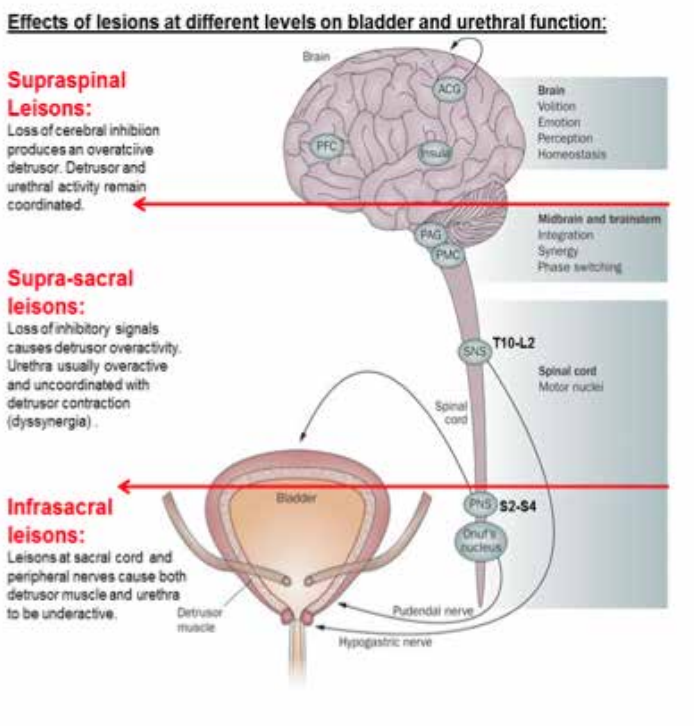
HOW?

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.



TREATMENTS

Treatment options are tailored to individual patients vary and are related to symptoms and urodynamic parameters.. The treatment modalities available can be divided into conservative, medical and surgical.

The primary aims for treatment of neuro-urological symptoms and their priorities however are:

1. Protection of the upper urinary tract (prevent renal failure)
2. Improvement of urinary continence
3. Restoration of (parts of) the LUT function
4. Improvement of the patient's QoL.
5. Avoid other secondary complications like urine infections, renal tract stones.

In the acute phase of TM, the bladder is commonly atonic, flaccid and has to be drained via catheter. Recovery of bladder function is variable dependant on the level and severity of the initial attack of TM.

In the most common form of TM related LUTD, the bladder develops into an overactive (spastic) bladder with symptoms of increased, frequency, urgency and urge incontinence with varying severity. The overactive nature is investigated by urodynamic studies to ensure that the pressure within the bladder is not too high. The aim of management is to prevent transmission of this high pressure towards the kidney, which may result in decreased renal function. After this is established, symptom control with oral medications – anticholinergic class of drugs (Oxybutin, Tolderodine, Solifenacin, Trospium chloride etc) and a newer Beta 3 agonist (Mirabegron) are used with a view to decrease bladder contractility and thereby improve symptoms.

Bladder contractility can also be decreased by intravesical injection of Botulinum toxin A and this is usually the next step in management if oral medications have been ineffective or difficult to tolerate by the patient.

Incomplete bladder emptying is managed by a variety of non-invasive techniques (Valsava manoeuvres, triggered bladder emptying) and invasive methods (intermittent or indwelling catheter) depending on the residual functional capacity of each individual. Electrical or Magnetic stimulation of the bladder has also been tried with very limited success and is usually limited to a few Tertiary specialised centres in the UK. There are no oral medications to improve the contractility of the bladder. Intravesical instillations of substances (Capsaicin and Resiniferatoxin) to improve contractility have only been used in a few trials and are not used clinically due very limited efficacy as compared to Botulinum toxin injections.

Surgical options for management of the bladder outlet include, sphincterotomy, bladder neck incision or resection to reduce bladder outlet resistance. Urethral slings, artificial urinary sphincters are used for continence measures in selected patients. Other surgical options to improve bladder capacity and reduce high intravesical bladder pressure include bladder augmentation with bowel or urinary diversion with the formation of a stoma.

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IN MY DREAMS I'M DANCING
AN EXTRACT FROM RUTH WOOD'S HILARIOUS BOOK

Ruth Wood was a singing teacher and actress before she contracted TM in September 2006, followed by further attacks in 2008, 2009 and 2010. Since then she has taken up creative writing and published a light hearted account of living with TM called 'In my dreams I'm dancing' which we featured in our first edition in February 2012.

So here I am, sitting in the middle of the tools section in B&Q. This is not my preferred place, but I don't have much choice.

When my carer/chauffeur spots a well-stocked tools section, he virtually salivates. In fact he has all the appearance of a woman in a designer dress shop with the SALE emblazoned across every rack. I have looked at the drills/screwdrivers/whatever that he is handling with a slightly glazed expression and in the past I have said things like, "Haven't you got two of those already?" and he has said, with a look of incredulity "Not like this one, no", and I would give up and go and look at the lighting section. Well, that was the past. There's no point saying anything now, partly because he is well over 6 feet tall and I am reduced to the level of a pushchair, but also because he has parked me out of the way and wandered off, so he wouldn't hear me anyway.

Now don't get me wrong, this man has a virtual halo around his lovely head for the way he has been looking after me since I came out of hospital. But I am realising more and more that it's not so much a question of women come from Venus and men from Mars, it's more a sort of men hunt and gather and buy tools – and women do their own thing.

Just before we came in here, we went to a shopping centre – all on the ground floor, disabled toilets (or toilets for the disabled – but it was locked anyway) and every shop 'disabled friendly' only because they can move all the displays that are on wheels. Now I am fairly shy about "making a scene" (very English) – and my preferred method when shopping in a new store is to have a quick gander through the window, decide if they've got the kind of thing I want, then quietly walk in and look around. I never make a fuss and I rarely ask a shop assistant for – well – assistance. What I do not want to do – other than in my worst nightmares – is to be pushed straight into the shop, knocking aside display racks, catching small children on the ankles and forcing the shop assistant to rush over and move all the fittings – even the ones people are looking at. But this is what happened in the bag shop. I can't communicate with my driver because he's way above my head and behind me – and anyway he's deaf and won't wear his hearing aid. The worst bit about all this is that the shop didn't sell what I was looking for anyway – something I would have quickly realised if I'd had time to look through the window. Eventually I made my feelings known (by shouting "They haven't got what I want") and we left.

> ***"It's not so much a question of women come from Venus and men from Mars, it's more a sort of men hunt and gather and buy tools and women do their own thing."***

Of course, another thing about a wheelchair is that your feet stick out at the front. My feet are not huge but they still jut forward of the footrests. As I found out in Boots when I was pushed straight up to the counter. I know I've not got much feeling in my feet anyway, but it's the principle of the thing. Having educated my carer/chauffeur in this delicate point, in the next shop he parked me sideways on to the displays.

Which is why I'm sitting in B&Q with a cricked neck.

2015 'It's been nearly three years since my last recorded TM attack which affected my voice – the nerves controlling the finer movements of my larynx just don't operate any more – and this was the hardest one for me. I've been a singer since I first took to the stage aged only four years old so losing it has been hard, but I'm fighting back'.

Ruth

TM KIDS

COOL FACTS ABOUT TM

The body temperature of those with TM is typically lower than a normal person.

Who is your role model?

I met Anjali Forber-Pratt at the TM camp this summer. She is in the USA Paralympic team and she has TM She was pretty cool. I like Natasha Baker she is amazing! I would love to meet her!

Hobbies

I have just started playing the euphonium, which is a lot of fun, (although a wee bit noisy!) I am a lone guide, (guiding from home via email) I like playing hockey and mucking about outside in the garden.

How has your life changed since TM?

Since having TM I find it harder to do things like running fast with my friends or just going to the toilet by myself. But if I hadn't had TM I wouldn't have met George and Hannah. They are two really amazing TMers!

My name is Penny Winton,

I am 11 years old and I live in Aberdeenshire, Scotland with my Mum, Dad, 2 sisters, a brother and two Border Terriers. I found out I had TM in October 2011 when I was 8 years old.

"I attended the Scottish Disability National Championships in Stirling in January. I thoroughly enjoyed it and loved meeting the Paralympians.!"

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!!!

Editors Note: Penny did really well and came home with one silver and two gold medals.

PERISTEEN

I have just started using Peristeen for my bowel. I used to use a suppository but I often had a sore tummy so my Dr asked me to try Peristeen.

Peristeen is really good because I can now manage my bowel by myself. Peristeen is a water treatment for your bowel. All you are doing is flushing water into your bowel, which then pushes the poo out of your bottom.

It feels a little uncomfortable to start with, but when you flush it all out it feels nice. It makes me feel free as I don't worry now about going swimming or going for a sleepover at a friends houses. I would recommend Peristeen to other children, although sometimes it take a little time (45 min) to work. I do my homework while I wait or even watch a movie! If you want to learn more you can find out more on **www.coloplast.co.uk/**

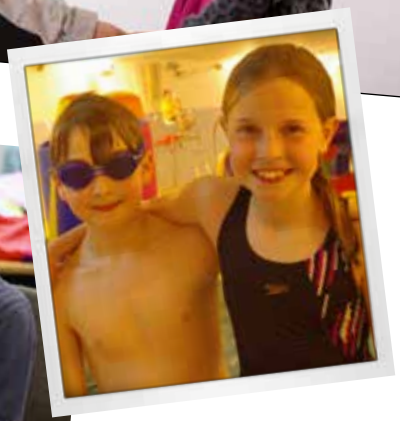
TM KIDS

Who is your role model?
My role model is Danny MacAskill a Scottish Trials cyclist who does amazing stunts. One day I would like to ride a BMX like Danny does

Hobbies
My hobbies are: Ballet, street dancing, weather watching, BMX riding, skateboarding, tennis, swimming and reading about science.

How has your life changed since TM?
My life has changed a lot since TM. My bladder doesn't work very well anymore which is a pain for me. Sometimes my back hurts and I feel tired and sick and I get a lot of headaches. But I am very glad my legs work again and I don't mind if they get sore because I remember what it was like when they didn't work. A lot of good things have happened too though, like meeting Penny and being asked to help with the magazine. Penny and me are good friends now.

My name is George Henry Bowyer,
I am 10 years old and I am from Craigston near Turriff, but I was born in Malton in North Yorkshire. In my family there is my Dad, Richard, my Mum Caren, my sister Hattie and my little sister Tabitha. I was diagnosed with TM when I was 7 years old, I had my 8th birthday when I was in hospital, but now I'm nearly 11, well on the 23rd of March.



COOL FACTS ABOUT TM
TM is really rare, only around 2-5 people per million get it!! That makes us pretty special!!

I LOVE TO DANCE

I am George and I have had TM since I was 7. When it first happened I knew I might never walk again, but worst of all I might not be able to dance again. In hospital, when I used to have my physio, all I used to think about was that I had to get better so that I could dance again, I couldn't think that I might not be able to, I just had to believe in myself that I could. I worked really hard. As soon as I got back on my feet and I got crutches, I always climbed the stairs back to my hospital room after physio instead of taking the lift, even if it was sore or if I was tired and it took a long time, and when I got home I went on the treadmill all the time to make my legs stronger. I went back to ballet classes about a year after I got TM.

I have been dancing since I could first stand up when I was a baby, whenever I would hear music I would bounce up and down. When I was a toddler I started ballet and have been dancing ever since. Now I like all types of dancing. I do street dance and I often do shows in front of hundreds of people which I love. A while ago I did a ballroom dancing competition with my friend Sophie. It was all of the schools in our area. We came second with our quick waltz and got a silver medal. It was a great day and made me more determined to be a famous dancer one day, even if I have got TM, I won't let it stop me.

DEPRESSION AND TRANSVERSE MYELITIS

DR. MAYUR BODANI

Dr Mayur Bodani FRCPsych FRCP Edin is Consultant Neuropsychiatrist for West Kent & Medway based at Sevenoaks Hospital. He is the current Vice Chair of the Faculty of Neuropsychiatry, Royal College of Psychiatrists. He is trained in both General Medicine and Neuropsychiatry. He has extensive experience in the psychiatric management of individuals with long-term neurological conditions and acquired brain injury. Here, he talks about the relationship between depression and TM.

Transverse Myelitis (TM) and clinical depression are two different conditions. The pathological changes caused by TM can be imaged using magnetic resonance imaging (MRI) of the spine. The changes in the brain that lead to depression are less focal, and involve the circuits connecting brain areas, including the prefrontal cortex, hippocampus and cingulate gyrus.

We know that neurological conditions like TM, MS and Parkinson's can cause depression as a secondary consequence. This can be triggered by the sudden onset of physical disabilities and deterioration in physical skills. Unremitting pain, especially if unresponsive to standard painkillers, can lead to feelings of profound helplessness and depression. Depression (or anxiety) can also be a possible presenting symptom of neurological disease, as in the case of dementia. However, there remains poor understanding of the correlation between specific neurological lesions in the brain and the presence of depression.

> ***"The time taken for changes in brain neurochemistry as a result of antidepressant use can typically be several weeks, although side- effects occur over days."***

The symptoms of TM will be very familiar to readers of this journal. Depression can manifest with both biological

symptoms (such as sleep disturbance, loss of appetite, weight loss, and reduced energy), and psychological symptoms such as loss of enjoyment, social withdrawal, and poor motivation.

The management of both TM and depression involve the use of drugs and rehabilitation approaches. Drug use in TM (such as steroids) is aimed at potentially reducing inflammation or immune system activity.

Psychotropic drug use to manage depression has a less obvious target, but is thought to help boost brain neurotransmitters implicated in mood disorders, such as serotonin, dopamine and noradrenaline. The treatment of depression in neurological disorders usually requires combination antidepressants.

There are many classes of antidepressants, some old and some new. The older antidepressants include tricyclics (such as amitriptyline, imipramine, lofepramine, and trazodone); and monoamine oxidase inhibitors (such as phenelzine, and moclobemide). More commonly used classes today are SSRIs (Selective Serotonin Reuptake Inhibitors, e.g. fluoxetine, and citalopram); SNRIs (Serotonin and Noradrenergic Reuptake inhibitors, e.g. venlafaxine, duloxetine); or novel mechanisms (e.g. mirtazepine).

All antidepressants have beneficial effects, and both class and individual side-effects. For example, tricyclics are associated with sedation, and weight gain, and anticholinergic side-effects (e.g. constipation, urinary retention); SSRIs with gastroenterological side-effects, and occasionally cardiac (e.g. QT interval prolongation). The choice of drug used presently is determined by experience, and assessment of possible tolerable and intolerable side-effects. In the future (next decade) the science of genomics will much more accurately determine the choice of drug prescribed and will be based on an individual's genetic profile i.e. drugs likely to be effective or predicted to cause side-effects.

There is little point to the use of antidepressant medication under six months. The time taken for changes in brain neurochemistry as a result of antidepressant use can typically be several weeks, although side-effects occur over days. The benefits of antidepressant use depend on dose used, compliance with treatment, and effective monitoring for efficacy. Too often GPs start a drug, fail to demonstrate a benefit, and switch to another, also at initiation dose, repeating the cycle of failure. Drugs need to be titrated up, and under specialist supervision, classes are commonly combined synergistically for better outcomes.

"In the future (next decade) the science of genomics will much more accurately determine the choice of drug prescribed and will be based on an individual's genetic profile."

Drugs are not a complete answer. Whether coping with the symptoms of TM or depression, there are benefits from parallel psychological approaches. Carer and general support is vital, particularly that found in the sharing of experiences through voluntary organisations and support groups.

Antidepressants can have a withdrawal syndrome (e.g. tricyclics); but addiction in the sense of tolerance with a requirement for increased dosing simply to avoid withdrawal is not a feature. The latter is commonly misunderstood and often the reason why patients will inappropriately refuse treatment, to their own detriment.

DIVING INTO THE DEEP
MARGARET SHEARER

Margaret Shearer was diagnosed with TM in 2002 (T2 / T8) requiring a body brace and splints on legs and arms. She had reoccurrences in 2006 and 2007 with lesions up to C3. She is a founder member of the TM Scotland Support Group which was started in 2003.

Scuba diving may not be the first new hobby to come to mind when you have been paralysed by TM, but in 2003 I read the story of Cody Unser (USA),(paralysed by TM at the age of 12), who took up scuba diving, and is now dedicated to sharing the physical and mental benefits of the sport. So I decided that would be my challenge, I would become a fully qualified scuba diver! My 2 older sons (both divers) were cautious about my wish but I started training with a physio at a local swimming club for people with disabilities and gradually increased my stamina so I could swim the required 25 lengths of the pool. I then convinced my consultant to allow me to try out the scuba equipment as I needed a medical certificate to do so.

That August, I completed my ocean dives in the warmer waters of the Mediterranean to gain my Open Water Scuba Diving Certificate. The fact that I was in a wheelchair made no difference, it was simply carried aboard with me in it! My instructors never let me get away with anything less than they expect from able bodied divers, so having checked my equipment with my 'buddy' while seated, I get on my hands and knees, or slide along the floor, to the diving platform at the rear of the boat. Once on the platform I put on my fins, BCD vest and tank equipment, then with assistance I fall overboard. When the dive is up I take off BCD vest and tank in the water (taking advantage of buoyancy), hand them over to an assistant, then using waves to propel me onto the platform, I remove my fins and crawl back into boat - exhausted!!. Normally divers shouldn't make too much arm movement, but only my left leg obeys brain signals. As my arms have to do the rest of the propulsion through the water, and my right arm has decreased strength, I wear gloves with webbed fingers that allow my movement to have better effect, yet be as streamlined as possible. Due to weakness on the right, my left side was much stronger, so I had to be careful when underwater that I did not go round in circles, and did take a certificate in buoyancy to be more aware of my personal issues.

> ***"The fact that I was in a wheelchair made no difference, it was simply carried aboard with me in it!"***

In 2004, in Australia, I progressed to Advanced Level and specialised certification in Deep Sea Dives exploring shipwrecks and aeroplanes, at depths below 33 metres.

In 2010 on a diving holiday to the Red Sea my youngest son also took up diving and within a few weeks able to be my "buddy", making the holiday more memorable. We have since 'buddied' on the Great Barrier Reef too.

Contact ***Scubatrust@hotmail.co.uk*** for info on their trial dives to see if it's the hobby for you. Good Luck.

STRIVE
A TRANSVERSE MYELITIS CLINICAL TRIAL IN THE U.K.

A multicentre randomi**S**ed controlled **TR**ial of **I**ntra**VE**nous Immunoglobulin (IVIg) versus standard therapy for the treatment of transverse myelitis in adults and children.

STRIVE's primary objective is to evaluate if early treatment with intravenous immunoglobulin (IVIg) added to standard therapy (steroids) is of extra benefit in patients who present with symptoms of TM for the first time. The trial will take place in 16 hospitals throughout the UK over 3 years. Publication of outcomes is expected in summer 2018. The trial is being funded by the UK National Institute for Health Research.

WHY THIS TRIAL?

Early recognition, diagnosis and treatment are integral to the management of TM given it poses a significant demand on UK health resources and can affect people in the prime of their working life. Although diagnostic criteria exist and have helped clinicians and scientists improve the diagnosis of TM and accurately select patients to evaluate treatments, there have not been good studies to determine the best treatment. Treatment typically involves strategies to suppress the immune response to reduce irreversible spinal cord damage - steroids, intravenous immunoglobulin (IVIg) and plasma exchange (PLEX) – but they are based on expert panel recommendations rather than the results of well controlled intervention trials. Administering PLEX is also technically difficult and challenging to deliver within the NHS. IVIg is increasingly being used in the management of a range of neurological conditions and those relevant immune mechanisms made better by IVIg are likely to be present in TM, thus providing a strong rationale for its use. IVIg is also easy to administer and may potentially be more cost effective when compared to PLEX.

WHAT WILL THE TRIAL ENTAIL?

A sample size of 170 patients is needed. 85 patients will be randomised to the control arm and 85 to the intervention arm. These numbers assume that 10% of patients will leave the trial early.

- The control group will be prescribed intravenous methylprednisolone in line with local clinical practice.
- The intervention group will additionally receive IVIg for up to 5 days.

Patients must be recruited from within the hospitals where the trial is being conducted. If you are newly diagnosed with TM or NMO and are within 21 days of experiencing the first symptoms, you can have your GP or consultant refer you to one of the hospitals taking part that is nearest to you.

To measure the effectiveness of treatment, a variety of tools that evaluate disability and patient's quality of life will be used during follow-up appointments. The evidence generated will inform clinical decision making in the NHS.

FOR FURTHER INFORMATION

TM SOCIETY
http://www.myelitis.org.uk/research.html

NATIONAL INSTITUTE FOR HEALTH RESEARCH
http://www.nets.nihr.ac.uk/projects/hta/11129148

CLINICAL TRIALS REGISTER
http://www.isrctn.com/search?q=12127581

CLINICAL TRIAL MANAGER, ROSEMARY HOWE
rosemary.howe@kcl.ac.uk

NAVIGATING PIPS
LEONIE ASHENDEN

Leonie Ashenden is a carer for her Mum who has had Transverse Myelitis (TM) for ten years. Together they run the East Midlands Support Group. Since her Mum was diagnosed, she has jumped head first into helping people with disabilities, including undertaking training on PIP.

Disability benefits for everyone in the UK changed on 13 June 2013. Since then, all new claims for disability benefits are covered by Personal Independence Payment (PIP). The only exceptions are people under 16, who remain on DLA until their 16th birthday, and people over 65 who will remain on attendance allowance.

Like DLA, PIP has two components – daily living and mobility. Both components are payable at standard or enhanced rate, which is decided during the PIP process where the ability of a claimant to complete a number of key everyday activities is assessed. Individuals receive a point score for each activity. The total score determines the rate at which PIP will be awarded. The entitlement threshold is eight points for the standard rate and twelve points for enhanced rate.

The activities assessed for the daily living component includes preparing food and taking nutrition; managing therapy or monitoring a health condition; washing and bathing; managing toilet needs or incontinence; dressing and undressing; communicating verbally; reading and understanding signs, symbols and words; engaging with other people face to face and making budgeting decisions.

For the mobility component, levels of basic mobility is assessed, as well as an ability to plan and accomplish a journey.

To make a new claim for PIP you need to telephone a free phone number. When renewing a DLA award, you will be contacted and may be asked to telephone the same free phone number within one month. If you fail to make the call within the one month period, it will be assumed that you no longer wish to claim the benefit.

During the telephone call, claimants with TM should tell the advisor that they have a rare neurological condition and how it affects them. Capita and ATOS have been given a condition insight report which can be found at **http://bit.ly/1DyR7Sa**

The DWP will send out a form called 'How your disability affects you' by post. You have one calendar month to complete and return the form to the DWP in a pre-paid envelope.

Questions ask about whether the person uses aids or appliances or has help from another person to carry out activities. The section on the form called "Extra Information" can be used to explain how your health condition affects your ability to carry out activities, the difficulties faced and help required.

The PIP booklet suggests that claimants may want to write a diary recording any help needed, plus difficulties generally experienced and in the run up to the assessment.

In most cases you will be invited to attend an assessment, although sometimes this is done over the telephone. All claimants are encouraged to take someone along for support, as they may be able to clarify their needs and general physical abilities.

During the consultation you will be asked about your health condition, disability and how it affects your daily-life. The health professional may carry out a short physical examination, but claimants will not be forced to do anything that causes pain, embarrassment or discomfort.

If PIP is to be awarded they will decide the level and length of the award. All PIP awards will have a time limit. If PIP has not been awarded, the letter will have the same information as on an award letter, including explaining the reasons for the decision. The letter will also explain what the claimant needs to do if they are unhappy with the decision and how they can request a mandatory reconsideration. After the decision letter has been issued, and if a claim has been disallowed or an existing award reduced, the DWP decision maker will try to phone the claimant to discuss the decision and explain the reasons for the decision. The reason for the call is to ensure that the claimant understands why PIP

has not been awarded or has been reduced, and to give the claimant the chance to ask any questions about the decision.

QUESTIONS FROM MEMBERS ON THE TMS FACEBOOK PAGE:

Q: It seems that many people who have TM are not awarded PIP because the condition doesn't appear to fall within certain categories. I'm going through a change of circumstances and have been told I have to wait up to 6 months for a decision!

A: When applying for PIP, remember to include any difficulties you have preparing a meal as perhaps you cannot bend down to the cooker or carry heavy pans. Indicate if you need assistance to take medication or encouragement to do so. Planning a journey would be difficult if your ability to remember where you are meant to go or you become too fatigued to do the whole journey. Points would be given for all of these things. The timescales are slowly improving, and by bringing up the condition insight report at some stage before the assessment, you may find that yours is done by telephone.

Q: I have been on ESA for a year. I can't survive financially. I also receive housing benefit but I'm still dropping behind. My job came with a car, etc. I really want to go back to work but have no idea how I'd cope or how understanding an employer would be. Does anyone have any advice?

A: You can claim ESA and PIP. If you are awarded the higher rate of Mobility in PIP you could 'exchange' this payment for a mobility car. Have you had your house assessed by the Council for lower rate of rent and Council Tax due to being disabled? That is worth looking into if not.

Q: I have received my dreaded PIP paperwork! It says you are meant to get reports, results, scans etc to add evidence to your claim. How has everyone else gone about this as I asked my GP today and got a blank look, she hadn't heard of PIP?

A: To get any information from Doctors or Consultants they may charge a fee. I would just send off the condition insight report to explain how TM affects you.

EDITOR'S NOTE: ***You have to ask your GP or consultant for a copy of scans and reports and you should not be charged for test results during the assessment phase and if there are any concerns, contact the DWP on 0345 850 3322.. You may need to chase the GP/ consultant for scans and reports. Ask for the support of trusted family and friends to help you get through this process. You can also include the TM condition insight report which helps to explain how TM affects you; it is available via the Resources section of the TMS website (www.myelitis.org.uk).***

JOIN US ON facebook

The Transverse Myelitis Society Facebook page now has well over *1000 members!* Here members are able to ask personal questions, without judgment. The answers may give a level of assurance that the symptoms they are experiencing are not uncommon and offer some help from their own experiences. The page is actively used and carefully moderated by the administrators so comments are completely confidential. Although the TMS page was established for people in the UK, people from all over the world are welcome to join.

TMS FUNDRAISING CAMPAIGNS FOR 2015

As the TM Society starts to offer more services, it wants to ensure it can continue offering them in addition to its existing activities, and be in a position to offer new services in the future. Also, we noticed we are starting to receive more questions from members and non-members who wish to fundraise and would like guidance on how to get started. We really want to support their efforts because what they do allows the TM Society to continue doing what it does. So the TM Society has started working with a professional fundraiser who is advising us on what we need to do and helping us to raise money for specific projects.

The TM Society is conducting three fundraising campaigns this year, two of which you will see and another that is happening behind-the-scenes.

TMS FAMILY WEEKEND

Our professional fundraiser is approaching trusts and foundations, which traditionally give money to charities for services and activities that support children and families, to request financial support for this event. This campaign is happening behind-the-scenes.

LONDON MARATHON

The TM Society has one place in the London Marathon every 5 years. This year Katy O'Leary, whose niece has TM, is running for the TM Society and is aiming to raise £2,000 for the TMS Family Weekend. If you wish to support Katy and the TMS Family Weekend, you can make a donation via Katy's Just Giving page - **www.justgiving.com/Katy-O-Leary1**

10TH ANNIVERSARY 10 FOR 10 CAMPAIGN

As this year is the TM Society's 10th anniversary since it registered as a charity, we want to mark how far we have come, ensure that we can continue doing what we do, and build on it for the future. So we are conducting the 10 for 10 campaign, (explained on page 25), to raise money for the TM Society's general funds. These monies will go towards offering services such as the neuro-physiotherapy and coaching bursary schemes, equipment grants, conferences, general operating expenses, and more. You can use this campaign idea for any TM Awareness Day activities you plan for 9th June.

To support our fundraisers in the ways they have requested, we are developing a:

- HOW TO FUNDRAISE GUIDE – This will contain ideas for fundraising activities; how to conduct different type of activities such as raffles, collections, and events; what people need to keep in mind so activities fall within recommended practice; and hints and tips that can help make fundraising activities a success.

- FUNDRAISING PACK – This will contain posters, a leaflet and other relevant documents that our fundraisers have been requesting so their events look professional and official.

We will also review the fundraising section of the website and Just Giving and Virgin Money pages to ensure the information is complete.

If you like what you have read and want to get involved, get in touch by emailing Barbara Babcock at **barbara.babcock@myelitis.org.uk**. We are looking for volunteers who can help with implementing the above-mentioned fundraising campaigns and day-to-day jobs to support our fundraisers.

TMS FUNDRAISING CAMPAIGNS FOR 2015

10TH YEAR ANNIVERSARY CAMPAIGN - 10 FOR 10!

This year is the Transverse Myelitis Society's 10th Anniversary!

In 2004 the TM Society was founded and in 2005 it officially registered with the Charity Commission for England & Wales.

During this time, the TM Society has been all-volunteer led and funded almost entirely by individuals fundraising and giving donations.

During this time we have grown into a network of support groups throughout the country and also offer information, activities, and services that enable our members to live well with the impact of the rare neurological auto-immune conditions we support – Transverse Myelitis (TM), Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica (NMO) and Optic Neuritis (ON). In recent years, we have expanded the type of services and activities we offer.

To deliver on our planned activities for 2015 and beyond, what if this year

Each of us gives £10

And if you want, ask 10 family, friends and colleagues to give £10 each

A Member could raise up to £110 (and if donors are tax payers, we can claim £0.25 for every £1 donated)

If this many members get involved, this is what we can raise for the TM Society's general funds:

100 members	500 members	1,000 members	1,500 members
£11,000	£55,000	£110,000	£165,000

Think of the **IMPACT** you can make.

£11,000	£55,000	£110,000	£165,000
CAN PAY FOR	PLUS	PLUS	PLUS
Neuro-physiotherapy Bursary Scheme for adults and children for one year	Ongoing neuro-physiotherapy for children	Annual Family Weekend for children with TM, ADEM, NMO, and ON their siblings and parents	Commissioning a small research project
	Annual member conference	Telephone Support Line	
	Equipment Grant Scheme	Donation to research	
	Coaching Bursary Scheme		
	Create new support groups		
	Create information booklets		

Let's make a difference together. Visit the links below to make your donation

TM Society website - **www.myelitis.org.uk/donate-now.html**

Just Giving - **www.justgiving.com/transversemyelitis**

Virgin Money - **uk.virginmoneygiving.com/charities/myelitis**

If you would like to donate regularly, you can set up a standing order via Just Giving or Virgin Money.

THE HISTORY OF THE TRANSVERSE MYELITIS SOCIETY

SALLY RODOHAN, PRESIDENT

I was diagnosed with Transverse Myelitis (TM) in 1958 when I was 12 after being paralysed from the neck down. 13 months later I was discharged from hospital, walking with two sticks. I'd never heard of the condition and the look on people's faces, including doctors, when I mentioned it told me other people hadn't either. I started to walk without sticks and got on with my life. A slight limp was the only visible clue to the TM.

Fast forward 46 years, a newspaper headline caught my eye. There was a photograph of a little girl in a wheelchair who had been diagnosed with Transverse Myelitis. I couldn't believe it! There was a website for the TMA. Desperate to find out more I contacted the president Sandy Siegel in USA, who updated me with the work being carried out at Johns Hopkins University. He referred me to Geoff Treglown who distributed the TMA newsletter in the UK and Europe with Lew Gray's assistance. I was filled with hope.

Geoff was the first person I ever spoke to who had TM. He suggested I start a London Support Group. I wasn't sure. I didn't need "support", but I did like the idea of meeting other TMers. Around that time Karina Garcia Casil from Computer Associates (CA) in Slough, contacted Geoff regarding adopting TM as their charity. Karina's daughter Zoe had TM. We needed to be a UK registered charity for CA to donate. We organised a meeting in Wembley and 30 people attended. It was very emotional.

We circulated a questionnaire to the 220 UK TMA members to see if people felt that a UK Charity could help them. We had 89 replies with 74% of people in favour of a charity and plenty of ideas about what to do. Top of the list was raising awareness.

The second meeting was a more modest group but no less important. Lew Gray and Cindy Morelli, so crucial to the future of the society were there. We decided to start the process of registering with Charity Commission. Lew and I went to Lichfield to meet Geoff Treglown, and we agreed to name ourselves the Transverse Myelitis Society.

Sadly, Geoff has passed away but his passion and hard work inspired us all.

The application was prepared, the constitution and objectives approved and the Committee elected in February 2005 at the first AGM. I would be Chair and Lew Gray, Secretary. Jean Anthony and Yvonne Kolesar were also elected Trustees. The Charity Commission approved our application and The Transverse Myelitis Society UK became Charity No 1108179 (officially).

Our first big event was the 2007 Conference and Dr Doug Kerr's first visit to the UK from Johns Hopkins University. The Conference was organised by the Committee and chaired by Simon Kolesar and myself. Post Conference, membership increased rapidly and we learned the importance of meeting each other.

Ten years on, the charity has continued to evolve and progress. Thanks to our Support Group Leaders, the backbone of the Society and to our members for their support and encouragement.

I stepped down as Chair in 2008, happy to hand over to the very capable Yvonne Kolesar. In the following 6 years, more funds were raised allowing us to host a wonderful 2 day conference in 2011, attended by over 150 people. A far cry from our humble beginnings

In April 2013 our current Chair, Barbara Babcock was elected, providing another push forward for the charity, but that is another story!

Sally Rodohan
President TMS UK

Providing life-long support to everyone touched by spinal cord injury.

At the Spinal Injuries Association (SIA) we understand that damaging your spinal cord is a life changing injury. No matter how the damage is caused, whether through an illness or accident, the impact is monumental and affects every aspect of your life, as well as the lives of those closest to you.

SIA is dedicated to helping spinal cord injured people achieve their everyday goals. Our charity strives to empower people to live a full and active life post-injury. We achieve this by supporting a person's physical, emotional, psychological and social needs through our services. As an organisation we are ever evolving to ensure that spinal cord injured people are getting all the help and support they need to live independently.

Much of this support is provided by those who have experienced first-hand the many challenges faced post-injury, such as returning to work, starting a family, going on holiday, or any other of life's milestones that might be taken for granted before sustaining such a life-changing injury. For the complete list of services offered, stop by our website or give us a call, our membership is free and open to all.

All of this is made possible thanks to the kind and generous individuals and organisations that run, cycle, sponsor and hold events in aid of SIA, all year round.

Access our support and/or become a member at
sia@spinal.co.uk
www.spinal.co.uk

9TH JUNE IS TM AWARENESS DAY!

This is your opportunity to do something, however small, to raise awareness about TM and its related conditions. Why not hold a tea party for friends and family, a bring and buy plant sale, kids face painting, a clothes swap, or simply wear something blue for the day, such as a TM t-shirt (details on how to buy, sizes etc. contact Barbara.babcock@myelitis.org.uk).

T. TM_awareness_UK
F. www.facebook.com/tm.awareness.day.uk

NEWS FROM THE U.K. SUPPORT GROUPS

LONDON SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SATURDAY 18TH APRIL 1.45PM FOR 2.00PM** (& 18TH JULY & 17TH OCT)

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 21ST MARCH AT 2.00PM** (SAT 20TH JUNE, SAT 26TH SEPT & CHRISTMAS LUNCH SAT 6TH DEC)

Our Guest Speaker at our March meeting will be Consultant Neurologist Dr Gerry Saldanha from Tunbridge Wells Hospital , Pembury

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: **SATURDAY 25TH APRIL FROM 1.00 TILL 3.00PM**

In 2015,the Exeter Support Group will be combined with a new group in Taunton. A Support Group meet will be held quarterly throughout 2015, with the venue alternating between Exeter and Taunton: 25th April Exeter, 11th July Taunton & 24th October at Exeter

Venue: Holiday Inn Express Exeter, Guardian Road, Exeter EX1 3PE. Meetings take place in the main reception area. Meetings for Taunton at Holiday Inn Express Taunton. M5 Jct 25, Blackbrook Business Park, Taunton, TA1 2PX. 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: **SATURDAY 20TH JUNE AT 2.00PM** (& 24TH OCT) OUR JUNE MEETING IS PLANNED TO BE A PAMPER DAY.

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: **SATURDAY 14TH MARCH 2.00 TILL 4.00PM** (REFRESHMENTS FROM 1.30PM)

Venue: 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 for £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 2.00PM TILL 4.00PM.** (DOORS OPEN 1.30 FOR REFRESHMENTS)

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

NEWS FROM THE U.K. SUPPORT GROUPS

BRISTOL SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SUNDAY 22ND MARCH 2.00 TILL 4.00PM** (7TH JUNE, 6TH SEPT & 6TH DEC)

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** See also **www.whitelionketley.co.uk**

TRANSVERSE MYELITIS SCOTLAND

NEXT SUPPORT GROUP MEETING: **SATURDAY 30TH MAY IN ABERDEEN TBA** – THIS IS OUR LUNCH MEETING. (SAT 25TH JULY IN GLASGOW AGM, & SAT 28TH NOV IN EDINBURGH)

Venue: To be confirmed. 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: LAST MEETING HELD 7TH FEBRUARY WHERE FRANCES READING GAVE A TALK ON THE BENEFITS OF PILATES. CHECK THE WEBSITE FOR DETAILS OF NEXT MEETING. PLANNING ON 3 MEETINGS ANNUALLY.

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: Check TMS website for update.

SHEFFIELD SUPPORT GROUP

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

Venue: St Mary's Church Hall, South Road, Walkley, Sheffield, S6 3TE

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.

NORWICH (EAST ANGLIA) SUPPORT GROUP

THE FIRST SUPPORT GROUP MEETING: **SATURDAY 21ST MARCH DOORS OPEN AT 1.30PM**

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

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

_Depression Alliance
0845 123 2320
www.depressionalliance.org

_Scope
0808 800 3333
www.scope.org.uk

_Disability Law Service
0207 791 9800
www.dls.org.uk

_Disabled Living Foundation
0300 999 0004
www.dlf.org.uk

_Disability Now Magazine
0207 619 7323
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
0300 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

_Riding for the Disabled Association (RDA)
www.rda.org.uk
info@rda.org.uk

_Welfare & Disability Benefits (Dept. of Work and Pensions)
0800 882 200
www.dwp.gov.uk

_Transverse Myelitis Society
35 Avenue Road Brentford TW8 9NS
www.myelitis.org.uk
U.K. registered charity 1108179
Contact Barbara Babcock
(chair) barbara.babcock@myelitis.org.uk
Lew Gray (Secr) 020 8568 0350
Email: lew.gray@myelitis.org.uk

Editorial Team
Annie Schofield, Zelda Carr, Steve Holden and Heather Coltman
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NEWS FROM THE COMMITTEE

The TMS Committee sets priorities annually to focus its work and the 2015 priorities are outlined here. Priorities marked with 'volunteer opportunity' indicate that your help is needed; contact Barbara Babcock at barbara.babcock@myelitis.org.uk for more information.

Neuro-physiotherapy Bursary Schemes

To provide members (adults and children) access to neuro-physiotherapy so they can learn what they can do for themselves on an ongoing basis to maintain the benefits from the sessions over the longer-term.

Equipment Grant Scheme

To provide funding for equipment which is not provided by statutory services and would aid members' rehabilitation, ability to self-care, and/or independence.

Coaching Bursary

To enable members living with TM/ADEM/NMO and carers to access low-cost and high quality emotional and psychological support to help them adjust to living with TM/ADEM/NMO's impact, resolve any issues they are experiencing or make positive changes in their lives.

AGM & 1 day Conference - 7th March

Hold an annual member event, which is educational and provides an opportunity for people to meet others living with TM/ADEM/NMO.

TMS Family Weekend -10-13th July 2015 at the Calvert Trust in the Lake District

Hold an event for children with TM/ADEM/NMO, their siblings and parents which provides the opportunity to learn about and achieve one's potential through challenging and adventurous outdoor activities and educational sessions.

Fundraising

To continue offering services and activities every year, we will conduct fundraising campaigns to fund the TMS Family Weekend and ensure a consistent level of general funds. To support our fundraisers, we will develop a how-to fundraising guide and a fundraising pack consisting of posters, leaflets and other relevant documents. We will also review the website's fundraising and donation sections and Just Giving and Virgin Money pages to ensure information is complete. VOLUNTEER OPPORTUNITY – To liaise with and support fundraisers

Support & Support Groups

Support Groups have historically been a key mechanism by which support is provided and we have been developing our approach to support the establishment of new groups and development of existing groups. This was a priority in 2013 and 2014 and continues due to the growth of support groups.

Since not everyone can or wants to attend a support group, we are looking at other ways support can be provided. To do this we have drawn on the ideas members provided in the survey.

Talking Matters Groups

• Members consistently say they wish to meet others living with TM, ADEM and NMO in their local area and when they do they remark on how beneficial it is. This priority is about piloting 2-3 one-off meetings in those areas where there are a high concentration of members but no support groups.

• VOLUNTEER OPPORTUNITY – Help will be needed on the ground to organise meetings

Telephone Support Line

• Conduct a feasibility study to determine if providing a telephone support line staffed by member volunteers is possible to do.

Produce information which answers members' questions and can also be used by Support Groups

• Produce information about TM/ADEM/NMO and symptom management to enable members to become knowledgeable about their condition so as to manage its impact; signpost where members can obtain benefits advice. – **VOLUNTEER OPPORTUNITY**

• Create a how to self-management course 'Managing Your TM/ADEM/NMO'.

Governance

Continue to professionalise the TMS's working practices to keep pace with growth and ensure they align to governance principles.

New Research into the treatment of NMO/ NMOSD

Do you have NMO or NMOSD?

Have you experienced a relapse in the last 12 months?

If the answer to both of these questions is Yes, you may be able to take part in a new clinical research study.

The SAkura**Sky** study is looking at the safety and efficacy of an investigational medication for Neuromyelitis Optica and Neuromyeltis Optica Spectrum Disorder (NMO/NMOSD) that is given as an injection under the skin once a month along with your current therapy.

You may be eligible to take part in SAkura**Sky** the study if you:

- Are between 12 and 74 years of age, **and**
- Have been diagnosed with NMO or NMOSD, **and**
- Are currently being treated with one of the following agents:
    - Azathioprine, **or**
    - Mycophenolate mofetil, **or**
    - Oral corticosteroids
- Do not have any evidence of MS or other demyelinating disease, and
- Do not have an active infection (excluding fungal infections of nail beds or dental infection) within the last 4 weeks.

At each visit, the study team will monitor your symptoms and health. If you decide to participate in the study you will either receive the new investigational agent or a placebo injection. This study will last for about 18 months and will include visits once a month to the study center. You will be reimbursed for your travel expenses.

If you are interested in learning more about the SAkura**Sky** study, please contact:

SA237 Clinical Trial: sakuraskyinfo@chugai-pharm.co.uk

For more information on the trial, please visit:
https://www.clinicaltrialsregister.eu/ctr-search/search?query=SA237%20

SAkuraSky