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The Magazine

TRANSVERSE MYELITIS SOCIETY



Life & Love post TM

PAGES 8-11

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LETTER FROM THE EDITOR



When I first had the idea for this magazine my main worry was running out of ideas after the second edition! But with so many areas of our lives affected by TM, fatigue, depression, bladder, bowel etc., we have never been short of things to write about. The big change in our lives, however, is likely to be the effect TM has on our partners and family, and the emotional problems our new status brings, yet it seems to be the hardest subject to discuss. So I want to say a huge thank you to members who came forward to write about their lives post TM. I suspect all you readers out there will empathise with parts of the 'stories' starting on Page 8, and we would welcome any comments you have.

'Stem cell treatment' is never far away when talking about TM, but how many of us know of anyone who's actually had it? Neil Burton's story, on Page 5 is the most extraordinary story of courage and determination. Neil was told by a neurologist that he would 'either recover or he wouldn't', but this wasn't enough for him so he started exploring

alternative therapies. Stem cell treatment seemed to offer the best hope, and so his 'stem cell journey' began.

Fatigue is one of the most troublesome symptoms suffered by people with TM, so Andrew Hinder's second report from the TMA Symposium makes for very interesting reading. He also writes about the new wonder drug Fampyra (EU brand name), which has already been effective in the treatment of MS patients. It is currently on trial for TM patients in the UK and the USA. Read all about it on Page 2.

9th June is TM Awareness Day in the U.K., and a great opportunity for us all to get involved in raising a voice (and maybe some money as well), for TM, ADEM and NMO. Barbara Babcock has put together some great ideas, but you could just wear something blue on the day, like a TM T-shirt (£15 from the TMS). Find some ideas on how you could help on Page 7. Don't forget to take photos and we'll publish your events in the next edition.

Elsewhere we have another slice of life from Ruth Wood, news from the TMS Committee, and the U.K. Support Groups. I am delighted to see more groups setting up, as I know from personal experience, talking face to face is incredibly liberating. There is someone who just understands without you having to explain anything.

Please also remember the one day seminars in Liverpool and Oxford, details can be found on Page 6.

Please send your stories, comments, and suggestions for future editions to me at annie.schofield@myelitis.org.uk

Annie

TMA SYMPOSIUM

ANDREW HINDER ANSWERS YOUR QUESTIONS

The winter edition of this magazine included a summary of presentations from the Transverse Myelitis Association symposium in Dallas last October. Following my presentation to the London Group on January 18th, answers to some of the questions posed by Transverse Myelitis Society members are now addressed. These questions concern fatigue in TM, therapies for fatigue, how TM affects cognition, recovery from TM, and news of the exciting new drug Fampyra.

Regarding fatigue, it was stressed that many TM sufferers experience sleep disorders. Ideally 8 hours of uninterrupted sleep is required, but this is rarely achieved, especially when bladder function is affected, or spasticity at night is experienced. If the patient has to get up 3 or 4 times in the night for bladder function, then restorative sleep is difficult. Furthermore TM

“TM patients use up to 10 times more energy in taking a single step than someone without TM.”

patients use up to 10 times more energy in taking a single step than someone without TM. There may also be medication side effects, and spasticity medication has a proven sedating effect. Chronic pain and spasms use energy and have an emotional tax. Depression may also be a factor.

Treatment of fatigue can focus on getting regular sleep. If sleep at night is broken, taking an afternoon nap may

help. A regular programme of exercise and stretching both inside and outside the therapy room, with a good diet of energy-giving foods will be beneficial. Fatigue management can include organization of the following day's clothing or work requirements before going to sleep.

TM directly affects cognition. Memory, learning, verbal fluency, and concentration are affected, and these problems interfere with the quality of life. Schoolchildren with TM experience a decline in their academic performance, have problems with memory and attention, and miss school due to pain and fatigue. Furthermore, sleep deprivation as a result of pain, spasms, and urinary problems, has a major impact on cognition. Pregabalin also affects cognition, and the sedative effects of anti-spasticity medications have a short term negative impact on cognition.

There is evidence in support of cognitive rehabilitation in MS, but there has been very little research into cognitive rehabilitation for TM patients. Intervention can be based on individual needs. The brain has plasticity in terms of cognition, and rehabilitation can be achieved by the use of pen and paper exercises, computer programmes and video games. MRI scans of MS patients have shown evidence of memory recovery following these programmes of rehabilitation. However if fatigue is a problem, then the improvement of sleep could be prioritized before cognition is addressed.

TMA SYMPOSIUM

ANDREW HINDER ANSWERS YOUR QUESTIONS

More research needs to be done on the interrelationship between the symptoms of TM, and the effects of TM on cognitive function.

Recovery and rehabilitation are possible at any time following injury. Repair and recovery never stops. Activity Based Restorative Therapy (ABRT) is a life long intervention involving repetitive activation of the neuromuscular system above and below the site of the spinal lesion. ABRT promotes muscle strengthening, plasticity, and motor relearning by the use of Functional Electrical Stimulation (FES) cyclic or walking systems, Partial Weight Supported Walking (PWSW) on treadmills, or aquatherapy. The activity programme will be appropriate for the patient's level of function, and will be based on the patient's existing impairments.

Although Dr Cristna Sadowsky advocates a directed therapy regime of 4 hours per day(!), Dr Daniel Becker recognises that an optimum of recovery can be reached, beyond which too much exertion can slow recovery. Attaining that optimum situation of effective repair and recovery is achieved by trial and error for each patient.

Therapy happens outside as well as inside the clinic. There is need for constant repetition and a need to stay with it long term. Intensive walking training may be able to promote walking recovery even if several years have passed since the injury.

“Hope fosters success”.

Dalfampridine (U.S. brand name Ampyra; EU brand name Fampyra) is a new drug, which has already been effective in the treatment of MS patients. It is currently

on trial for TM patients in the UK and the USA.

In TM, the loss of myelin from nerve cells in the spinal cord results in potassium leakage, with subsequent loss and disruption of signals along the spinal cord. Dalfampridine blocks the escape of potassium from the damaged nerve cells, so that hopefully the nerve impulses will pass along the spinal cord normally. For TM patients as well as MS patients, Transcranial Magnetic Stimulation (TMS) is used to clinically assess the activity and function of neurological circuits, and to evaluate the improvement of motor skills during treatment. It is important that the patient combines the drug therapy with an exercise regime, and the patient is encouraged to take an exercise programme home.

The trials of this new drug for MS patients have shown promising results, with 33% of patients showing some improvement in the initial trial, and 42% of patients showing some improvement in the second trial. A new and more 'normal' walking pattern can be achieved after two days, but to date, research shows that Dalfampridine is effective for approximately six months. Thereafter symptoms worsen if the patient stops taking it.

Johns Hopkins University currently has 6 patients enrolled in trials, and are currently seeking a further 24. This is a longitudinal study which will ultimately include both TM patients and Neuromyelitis Optica patients.

(The Dallas symposium presentations can now be viewed in full on You Tube or The Transverse Myelitis Association website).

YOGA IS AS YOGA DOES



“Your hips will love you forever,” the little, elderly woman croons from the front of the room.

“Yeah, right.” I muttered under my breath. Whatever was going to love me it wouldn’t be any part of my body any time soon!

Upon the disastrous news of the closure of my regular stretching place, otherwise known as the toning salon, I’d decided to research where else I could go to keep my body reasonably on track and sort of functioning. When I heard about the yoga classes at the local gym, I thought I’d found the ideal thing.

Wrong

My friends from the MS Exercise Group I attend have been telling me about their yoga experience – but I hadn’t appreciated that their teacher has training in the needs of those of us with slightly less willing bodies, and gives them alternatives, including a chair to lean on when necessary.

Not so here. I try my best to stretch this, balance that, put my head there, and all the time my body is screaming at me, “what do you think you’re doing? It’s not my fault you’ve got TM!”

(Actually it is, but I’m not prepared to argue the point.)

The wizened creature at the front, who looks very comfortable with her legs wrapped around in different directions and her eyes looking straight at me (clever when she’s sideways on) says, pointedly,

“If you can’t manage these simple moves, then just do what you can.”

I try. I stretch my right foot out to the side with my foot at right angles to my body. My other foot stays facing forward. I feel extremely insecure and all my tendons from my waist down are threatening to leave home.

“Just hold it there for a few minutes and feel the nice stretch.”

There is nothing nice about this stretch.

I struggle through some more stuff, before giving up and sitting down on a convenient window sill at the side.

She comes over – my nemesis – and I feel the rictus grin imitating a smile on my face.

“Are you having problems?” she asks, brightly.

“I try my best to stretch this, balance that, put my head there, and all the time my body is screaming at me, “what do you think you’re doing? It’s not my fault you’ve got TM!””

RUTH WOOD

ONE MAN'S STEM CELL JOURNEY

NEIL BURTON TELLS HIS STORY



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 and 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. 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.

After speaking with many patients around the world who have undertaken stem cell treatment for paralysis, MS, Transverse Myelitis and GBS, plus all the scientific studies I had read, I decided this was a treatment worth trying. When I started investigating clinics it was obvious that 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 who have been treated by

“Over the course of one day my whole body shut down”

them. I found there were clinics who were honest and had a good reputation. I was told many times they

ONE MAN'S STEM CELL JOURNEY

NEIL BURTON TELLS HIS STORY

could not guarantee any success, but I was happy to take on the procedure with this information in hand. 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 extracted from my bone

“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 ”

marrow, multiplied and injected both intravenously into my blood and 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>

1 DAY CONFERENCES – SAVE THE DATE!

To offer our members access to the latest knowledge and research about TM and its associated conditions and the opportunity to ask questions, as well as to develop the TM Society's relationship with leading hospitals in the UK, we will be holding 1 day conferences on:

3 MAY – Walton Centre, Liverpool – key note speaker Dr Anu Jacob

17 MAY – John Radcliffe Hospital, Oxford – key note speaker Dr Adam Kaplin

TRANSVERSE MYELITIS AWARENESS

9TH JUNE



9th June has been designated as **Transverse Myelitis Awareness Day**, an opportunity for us to get involved and become a voice for TM, ADEM and NMO. The intention is to raise awareness of these conditions by:

- On-going education of family, friends and medical professionals
- Activities to raise money and understanding of TM
- Press articles covering activities and personal stories
- Involving a wider audience via social media networking such as Facebook and Twitter

There are a number of easy ways for you to get involved:

- Informing individuals and groups through educational material, letters and stories
- Holding events such as Tea M parties for family and friends to attend
- Contacting local press, radio and TV to get coverage of these events
- Approaching local businesses for donations of prizes for your event
- Wearing blue clothing on that day and/or TM clothing you may have. The TM Society sells t-shirts, contact Barbara Babcock at barbara.babcock@myelitis.org.uk if you would like one. A t-shirt costs £15
- Making blue ribbons to sell for people to wear

To get you started, here are a few ideas

- **Bake sales**
- **Face painting** - kids love to have their faces painted!
- **Costume parties**
- **Clothes swap** - Bring along any clothes you no longer wear/fit into and get yourself a new item or 2 for your wardrobe!

- **BBQ** - invite your guests over for a burger!
- **Quiz or trivia night** - You can charge a fee to enter, sell drinks and snacks.
- **Wine tasting** -
- **Film night** - Invite friends to watch a movie together, then charge for refreshments or ask for a donation (you can't charge to watch the film due to copyright)
- **Decorate a tea pot** and use it for collecting loose change.
- **Bring and buy plant sale** - share your plants/ cuttings and get new ones
- **Games night** - charge people to enter board game challenges
- **Silent auctions**. Ask local businesses to donate prizes and then have a silent auction.
- **Book sales** - ask around for used books then sell them at your event.
- **Guess how many...** sweets in the jar, pennies in the jar, weight of the cake, the book
- **Name the Teddy**
- **Balloons** - let off balloons with TM info attached to them
- **Who's who?** - have a collection of baby photos and get people to identify who's who... you can use your family and friends or famous people

The event you organise will be your event so you can choose to organise it as you wish. The main purpose is to raise awareness of TM, ADEM and NMO and funds for the TMS.

Happy planning everyone and we look forward to hearing all your stories of your events!

LIFE AND LOVE POST TM



The multi-disciplinary team supporting my wife and I during the six months in hospital in 2007 managed many aspects of the life changing events following TM in my c-spine. I went from laying flat on my back, paralysed from the neck down to managing a few steps with walking aids and managing to feed myself.

However once home, it became clear readjusting to life with disabilities was going to be another challenge. At no stage did anyone talk to us about the issues concerning settling back into a home environment and how the condition would impact upon one's married life.

Prior to TM we had a normal physical relationship. Now to contend with a different dynamic in the relationship with my wife being my primary carer, washing and dressing me. Changing roles between carer and lover was not an easy adjustment and spontaneity in intimacy became a thing of the past for many reasons. Whilst once a caring considerate partner I now found myself clumsy, anxious and needing to plan ahead.

Things to consider were bowel and bladder issues. Prior to making love it was necessary to empty my bladder using (using intermittent self-catheterisation); not exactly romantic. Wearing a sheath with a leg bag results in adhesive needing to be cleaned away.

Loss of sensation, anxiety and depression combined with some of the medication resulted in problems gaining and maintaining an erection. Other medication was available to help with this but also had side effects, typically a headache. Antidepressants added to the problems causing delayed ejaculation.

“Prior to TM we had a normal physical relationship. Now we have to contend with a different dynamic in the relationship with my wife being my primary carer.”

Spasticity and muscle weakness made tenderness and the physical side of making love very difficult. We had to be considerate of each other's needs and adjust to accommodate the physical restrictions now present. It became vital to talk about things and not to expect success on all occasions. This can cause disappointment and add stress. It would have been easy not to try; that was not going to happen. Perseverance brings success. Maybe things not as they once were but in some ways far more rewarding when intimacy brings joy and happiness.

STEVE

LIFE AND LOVE POST TM

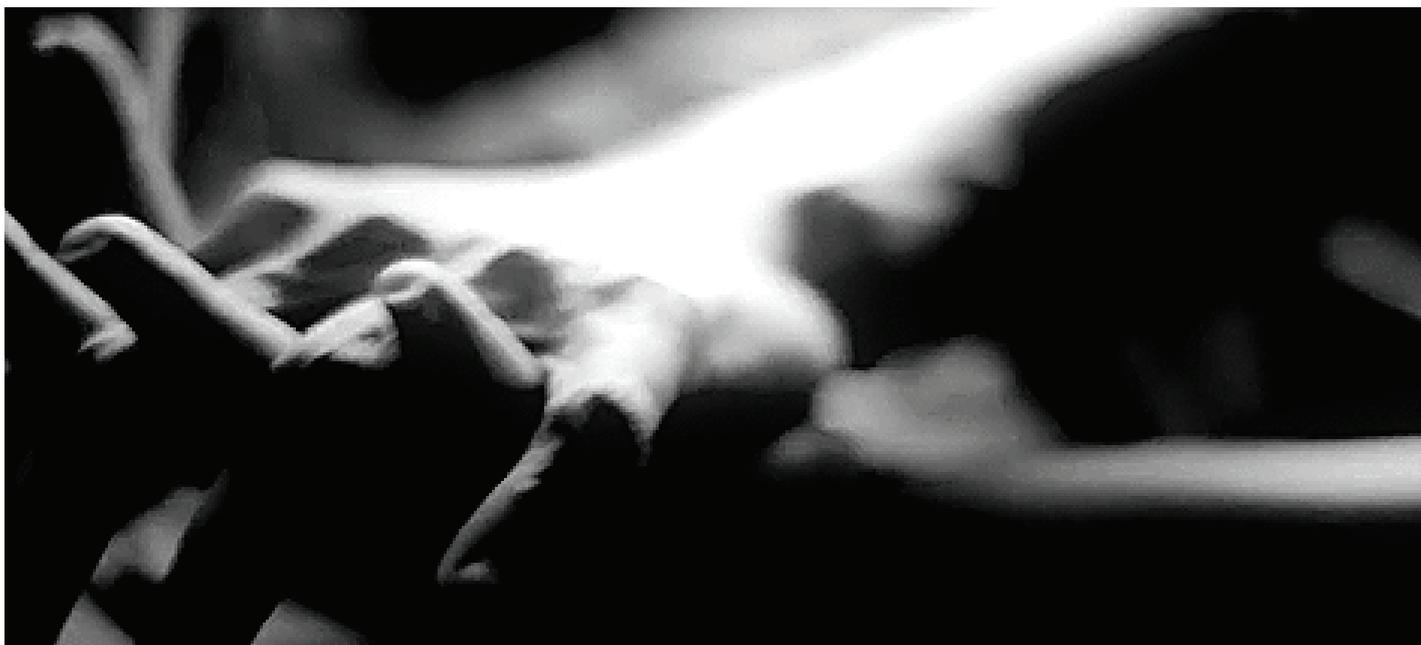
“ After I was diagnosed in 2009 my relationships with my children changed *I went from Mum the carer, to Mum who had to be cared for*. That took lots of adjusting to; after all, Mums are invincible and supposed to fix anything, not be fragile and broken. I felt guilty that I had suddenly become reliant on my children. I felt angry and frustrated, which led to quite a few outbursts, mainly due to not communicating. I'd tried to hide it if I was having a bad day, or if I was in pain.

I'm sure my eldest felt resentment that they seemed to be doing most of the caring. But we stumbled through things in our own way and worked our way through it but it took about 4 years to get the balance back to something that actually works for us. ”

“ I have had TM for 2 1/2 years now and I can still remember the first thing my husband said “What have you gone and got that for?”. As if I'd planned it. *I felt like I had been completely disowned*; an embarrassment to be seen out with, because I use sticks, and far too slow! Any intimate relationship was a no-no! Things have improved a little over time but nowhere near to what it was before.

My daughter has had to adjust too but she has approached it very differently. At the start she didn't understand why I couldn't run around like before but now she likes to help me where she can and even suggested a 'family night' where we all go and do something like cinema, trip out etc. ”

“ I truly feel that my health was one factor of the *breakdown of my marriage*. I feel that I wasn't fully believed when I was feeling low or in pain. It wasn't just from my ex-husband but also his family. I remember getting an email from my ex's brother saying 'what does she do all day, sit on her arse'. That was so crushing to read. ”



LIFE AND LOVE POST TM

“ When I was first diagnosed with TM in 2011, my husband and children were very understanding, but as I’ve ‘improved’ and the external features of the condition have reduced, the day to day understanding has declined. I continue to work, but the fatigue hits me hard. I suffer lots of sensory issues and weakness. My husband feels rejected when his advances in the bedroom are turned down, mainly due to my fatigue, but also the sensory issues. He tells me that sometimes it feels like he’s making love to a wounded animal. ”

“ I am a paraplegic who has sensations, albeit subdued. The legs are just along for the ride and no longer active participants. Spontaneity is difficult, more like a military campaign; and finding the right person who can accept TM and all of its various hindrances, not just the sexual, is the biggie. *I would be a liar if I said I had finished wanting a relationship which included sex*, it just takes some creative thinking and planning. ”

I am a wheelchair user writing a book on sex, intimacy, relationships and physical disability. I am writing this book because I couldn’t find anything that helped my husband and me navigate our sex life, given that one of us is physically disabled and the other isn’t. We needed ideas about how to be imaginative and playful when we were finding overcoming the physical problems a bit of a challenge.

I would like the book to be about experiences and practical tips, exploring the many ways that people find to make their sex life and relationships work in a way they would like.

I would like to interview people living with or who have experience of a physical disability within a sexual or intimate relationship (short or long term).

I hope this book will answer some of the questions you’ve always wanted to ask. I need you to help find those answers. I would like people to read the book and think ‘yes I’ve never thought of that, I’d really like to try that’, or ‘I don’t think that would work in that way but I might change that bit and then it would be great for me’ or ‘I’m pleased/reassured that it seems other people have felt this way about...’. Might sow seeds, spark ideas, reassure, excite, interest, or intrigue. But to do this I need you, contributors, willing to share thoughts and ideas.



All the information will be anonymous. If this topic interests you, please get in touch.
Email: theintimacybook@yahoo.com or call 07581 645

Alex

LIFE AND LOVE POST TM

TM Ecstasy: If ever two words seemed an oxymoron these are them. But not so fast. Other cultures have made an art-form of physical delight so why not borrow a few ideas from thousands of years of experience? Even the Bible, in the Song Of Solomon, talks of climbing the tree of pleasure and tasting the fruit along the way. So for those TMers who would love to experience ecstasy but have no feeling, or worse yet pain from the point of incident down there is good news.

First a word to you with TM. Make your partner read this or read it to them. Better yet needlepoint it and hang it over the bed or tattoo it on your chest: **NO SEX IF I HAVE BEEN STRESSED OUT TODAY!** (This includes airplane travel, a big hairy family drama, or you have been a victim of identity theft.) It takes energy to be sexy and you are now the princess or prince. You can be lots of fun in the bedroom (albeit in a hospital bed in the living room) but you need a bit of pampering first. Soft lights, no handheld media and great sexy music..I am partial to “Blood, Sweat and Tears” but I am over 60.

To quote my book, “Scrambled Leggs” on page 207, there’s good news: “your body can have the equivalent of a climax in any place where a bunch of nerves go close to the surface of your skin.” Let’s concentrate on upper body areas primarily not effected by TM. Oh, and when I say anywhere, I mean it. Don’t believe me? Try rubbing a pencil eraser on the “V” web area along your forefinger and thumb. The lighter the better. There just might be a familiar tingling right there on your hand. Think of how much fun it could be to use a lavender lotion and give each other hand rubs.

Wait we’ve just gotten started. Try having the non-TMer gently nibble you on the back of your neck. Next try light stroking on the collar bone, ears, inner elbows; tongue or finger inside the other persons mouth along the gum line; back and shoulder rubs; chest on both genders. Music playing, massage oils ready, now

spend a few hours (yes hours) simply touching each other. And turn a soft light on and look into each others eyes. It is great when both people are equally present to these activites. That is what folks in India call “soulful connection”.

If you want to try intercourse I suggest that the man lay on his side. Then the woman can position herself perpendicular to her partner with her legs over his hips; necessary parts can engage. This allows contact without a lot of touching skin on skin avoiding nasty hypersensitivity. The person with the most mobility should be the one doing the most moving. This is especially true if the TMer cannot move and physical activity drain their energy. Remember the goal is mutual affection, kindness and fun.

The human body can be a playground of joy as long as you know the secret. Here it is...physical ecstasy is a journey, not a destination.

Sally Franz is an author of 5 humour books, she has a degree in gerontology, and she has had TM for 9 years. You can read more of her humour on her travel blog at ThridAge.com, where she writes about travelling while disabled (and also as a single older TM female).



Thank
you

THANK YOU FOR YOUR SUPPORT

For **Aileen Little** TM was an unexpected 60th birthday present in 2007. But, playing to her strengths (organising events and painting), she hosted a Jubilee garden party for the residents of her street in 2012 which raised £244 for the TMS, and last November raised £410 from an art exhibition and sale of her paintings at her home. She paints postcard sized scenes of holiday destinations – here is an example of her work, 'Autumn in Paris'.



An evening in a village pub netted £450 for the TMS. **Alison Whibley** and friends enjoyed a 'Ladies Only' night with music, dancing, cocktails, canapés and cupcakes. Everyone paid £10 for a ticket with the proceeds going to the TMS

Ministry of Sound nominated the TMS as their charity for the annual Christmas cake sale. Apart from selling cakes in the office, anyone not wearing a Christmas jumper had to pay a fine. The proceeds amounted to £235.

The latest fundraiser by **George Bowyer** and his family was a carol concert in their local church, followed by refreshments, and a raffle consisting of prizes donated by the local community.

"It was much busier than we had anticipated; friends and family rallied round to help out, and we were absolutely blown away by the generosity of our little community, raising just over £900" said Mum Caren.

Ann Hollywood celebrated a special birthday in November 2013 by holding a variety of events including a race night. She raised £4,500 to be used towards the neuro-physiotherapy bursary scheme for children. Ann, we hope you had a fabulous time celebrating your birthday and thank you so much for your fundraising efforts!

JOIN US ON
facebook

Our facebook page is now up to nearly 700 members! Not only can you reach out to other members for advice and tips, it can also lead to some lively debates. And, it's a closed group so your comments are completely confidential. Search for Transverse Myelitis Society on facebook

NEWS FROM THE COMMITTEE



JEAN ANTHONY, TREASURER

I've had TM since 1995 when I was taken ill in Italy. After a week in a Salerno hospital I spent six weeks in Charing Cross and made a partial recovery, gradually learning to walk unaided and I now use a stick. I've recently started a course of acupuncture which I'm enthusiastic about; helping reduce pain and weakness in my legs (and, I hope, fatigue). I've also had five successful treatments of Botox in my bladder.

I've kept the TMS accounts since 2004, and the task has expanded due to increased fundraising and expenditure. Our income level has resulted in the TMS needing to keep more detailed records so our accountant has trained me to use more detailed spreadsheets, which has challenged my IT skills! However, with the help of my family I cope with the evolving nature of the job.

Barry and I find it challenging, juggling our roles as carers to two older relatives and our 20 month old grandson. I love reading, history, art, Italy, good food and wine and walking.

2014 Priorities for the TMS

The TMS Committee has gathered feedback from members and support group leaders to understand what you would like to see the TM Society focus on in 2014. The following priorities were determined based on this feedback and available resources within the TM Society in terms of people's skills, interests, the time they have to contribute to the TM Society, and costs.

- Continue to grow our network of support groups throughout the UK by offering active support to people who express interest in starting a group
- Organise 1 day conferences for members at the Walton Centre in Liverpool and the John Radcliffe hospital in Oxford
- Neuro-physiotherapy bursary scheme for adults and children
- Pilot a neuro-physiotherapy workshop for members in London
- Research what is needed to offer training to NHS physiotherapists in treating patients with TM/ADEM/NMO
- Produce Condition Insight Reports for ADEM and NMO which can then be used by ATOS and CAPITA when they assess these people for the Personal Independence Payment

NEWS FROM THE COMMITTEE

- Fund research in TM/ADEM/NMO
- Assess feasibility of organising a TM Family Weekend for summer 2015
- Increase the availability of emotional/psychological support to members by offering mentoring, coaching and counselling/therapy
- Determine approach and guidelines for distributing TM Society funds
- Diversify fundraising methods
- Continue professionalising how the TM Society operates to keep pace with growth

We have been busy working on the above priorities already and here is the progress that has been made to date on some of them.

Support Groups

Our network of support groups continues to grow – new groups are being planned for Sheffield, Preston and Oxford. A meeting will also be held in Cardiff. If there isn't a support group in your area and you would like to start one, support is available. To learn more, refer to the article 'How to start a support group' in the November 2013 issue of the magazine and contact Barbara Babcock at barbara.babcock@myelitis.org.uk

Neuro-physiotherapy bursary scheme for adults and children

The TM Society has launched a Neuro-physiotherapy Bursary Scheme where it pays for members to have an initial assessment by a physiotherapist who specialises in working with people who have TM/ADEM/NMO (or MS), and a follow-up session.

Please find further details about the bursary on the TM website: www.myelitis.org.uk

If you would like to take part, please register your interest with Lew Gray at lew.gray@myelitis.org.uk.

TM Family Weekend for Summer 2015

We have been researching the possibility of organising a weekend for children with TM/ADEM/NMO and their families and determined this will be possible for summer 2015. Children of all ages will be welcome. If you have a child with TM/ADEM/NMO and your family is interested in attending, please contact

barbara.babcock@myelitis.org.uk

Coaching Bursary

Have you ever felt like there was something you really wanted to achieve, an issue you wanted to resolve, or a question you wanted to answer, but you weren't sure how or even who to have that conversation with? If you are in that position and would like to speak to someone in confidence, a new service of coaching for TM Society members will be launched later in 2014.

Please find further details about the bursary on the TM website: www.myelitis.org.uk

The coaching bursary will involve a fixed number of sessions, which will cost £10 each. The TM Society will contribute £5 towards the cost of each session. If you are interested in the coaching bursary, please contact barbara.babcock@myelitis.org.uk.

NEWS FROM THE U.K. SUPPORT GROUPS

LONDON SUPPORT GROUP

NEXT SUPPORT GROUP MEETINGS: **SATURDAY 12TH APRIL, SATURDAY 26TH JULY,
SATURDAY 25TH OCTOBER – ALL START AT 2.00PM**

N.B. THE TMS AGM WILL TAKE PLACE AT 4PM, FOLLOWING THE MEETING

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. We are a short 3-4 min walk from King's Cross Station. For further details contact Yvonne Kolesar, Yvonne.Kolesar@myelitis.org.uk, Tel. 01737 552869

SOUTH EAST SUPPORT GROUP

NEXT SUPPORT GROUP MEETINGS: **SATURDAY 14TH JUNE, SATURDAY 20TH SEPTEMBER –
ALL START AT 2.00PM**

Venue: Pembury Village Hall, High Street, Pembury, Kent TN2 4PH. It is wheelchair friendly with disabled toilets. 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, Tel: 01435 864 662

EXETER SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SATURDAY 10TH MAY 1.00 – 3.00PM.**

Venue: Holiday Inn Express Exeter, Guardian Road, Exeter EX1 3PE. The meetings will take place in the main reception area. For directions go to: <http://supportgroups.myelitis.org.uk/exeter>. For further details contact Rob Reeves, rreeves@myelitis.org.uk

POOLE/BOURNEMOUTH SUPPORT GROUP

NEXT SUPPORT GROUP MEETINGS: **SATURDAY 19TH APRIL 2.00PM & SATURDAY 19TH JULY**
WILL BE OUR OPEN DAY, WITH 'PAMPER DAY' PHYSIOTHERAPY, A
BARBECUE AND REFRESHMENTS

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

NORTH EAST SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SATURDAY 22ND MARCH 2.00PM**

Venue: Walter Best Hall (within Cornerstones), Chester-le-Street Methodist Church, North Burns, Chester-le-Street, DH3 3TF. www.cornerstonescentre.co.uk. Cornerstones is situated in the centre of Chester-le-Street and has full disabled access including provision of Changing Places facilities for people with severe disabilities. Car parking is available within the town at a rate of £1.10 per day indicated by the P on the map. For further details: Contact Doreen Cawthorne, doreencawthorne@btinternet.com, phone 0191 419 3161 or 07737 705458

NEWS FROM THE U.K. SUPPORT GROUPS

BRISTOL SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SUNDAY 1ST JUNE 1-3PM**

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

YORK SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SATURDAY 29TH MARCH 3-5PM**

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 15TH MARCH 2-4PM**

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

TELFORD SUPPORT 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

TRANSVERSE MYELITIS SCOTLAND

NEXT SUPPORT GROUP MEETINGS: **SATURDAY 24TH MAY, SATURDAY 30TH AUGUST,
SATURDAY 29TH NOVEMBER – ALL START 2.00PM**

Venue: Conference Room, Philipshill Ward, Spinal Injuries Unit, Southern General Hospital, 1145 Govan Road, Glasgow G51 4TF
Dates of our meetings are posted on our webpage www.myelitis.org/scotland and travel directions can be seen by clicking on the Events link. For any further details contact: Margaret Shearer on 01292 476758 or email margaretshearer@myelitis.org

USEFUL CONTACT INFORMATION

Bladder & Bowel Foundation

0845 345 0165
www.bladderandbowelfoundation.org

Brain & Spine Foundation

0808 808 1000
www.brainandspine.org.uk

Carers Direct

0808 802 0202
www.nhs.uk/carersdirect

Carers: The Princess Royal Trust

0844 800 4361
www.carers.org

Continence Foundation

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

Depression Alliance

0845 123 2320
www.depressionalliance.org

Disability Information Advice Line (DIAL)

01302 310 123
www.dialuk.info

Disability Law Service

0207 791 9800
www.dls.org.uk

Disabled Living Foundation

0845 130 9177
www.dlf.org.uk

Disability Now Magazine

01454 642 444
www.disabiltynow.org.uk

Driving: Disabled Motoring UK

01508 489 449
www.disabledmotoring.org

Driving Licences:

DVLA Drivers Medical Unit
0870 600 0301

Gardening

www.gardeningfordisabledtrust.co.uk

Mobility aids: Just Mobility

01923 265 577
www.justmobility.co.uk

Motability Car Scheme

0845 456 4566
www.motability.co.uk

Neuromyelitis Optica (NMO) [Formerly Devics Disease]

www.nmouk.nhs.uk

NMO: The Walton Centre, Liverpool Nurse Specialist

0151 529 8357
NMO Service Coordinator
0151 529 8131
nmo.advice@thewatoncentre.nhs.uk

NMO: John Radcliffe Hospital, Oxford Nurse Specialist

01865 231 905
NMO Service Coordinator
01865 231 900
nmo.advice@orh.nhs.uk

Pain Concern

0300 123 0789
www.painconcern.org

Pain: British Pain society

0207 269 7840
www.britishpainsociety.org

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

0800 882 200
www.dwp.gov.uk

Transverse Myelitis Society

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

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