



SUMMER 2015

The Magazine

TRANSVERSE MYELITIS SOCIETY



BEATING **TM** ONE STEP AT A TIME



CELEBRATING TM AWARENESS DAY
9TH JUNE 2015

CONTENTS

03

LETTER FROM THE EDITOR

04-05

TM AWARENESS DAY
A SELECTION OF EVENTS FROM AROUND THE UK

06-07

ONE STEP AT A TIME
STEPHEN CLUTTERBUCK TELLS HIS STORY

08

NUTRITION FOR NEUROPATHIES
COLLEEN OAKLEY

09

I'M STUCK IN A LIFT
RUTH WOOD

10-11

TM KIDS
BY OUR OWN TM KIDS PENNY & GEORGE

12-13

BACK UP
TRANSFORMING LIVES AFTER SPINAL CORD INJURY

14

TM CONFERENCE REPORT
ZELDA CARR

15

THANK YOU FOR YOUR SUPPORT
MORE FUNDRAISING STORIES

16

NEWS FROM THE COMMITTEE

17-19

NEWS FROM THE SUPPORT GROUPS

20

USEFUL CONTACT INFORMATION

LETTER FROM THE EDITOR

Wow, what a year it's been so far. We celebrated the 10th anniversary of the TMS becoming an officially registered charity, and the TMS Magazine was available in print for the first time. It was launched at the TMS Conference in Birmingham, an excellent day, with top class speakers. We have a synopsis on Page 14, but the TMS videoed all the formal presentations, which are very informative, and they are available on the TMS website: <http://www.myelitis.org.uk/report-on-agm-and-conference-march-2015.html>.

Zelda and I also had a wonderful time at the Conference meeting so many of you – particularly some of our contributors. And, after working together on the magazine for 2 years, we got to meet each other as well! The idea of a printed version of the magazine was for people to hand it out to health professionals, spreading awareness of TM and it seems you really took it to your hearts; so much so that we had to order a reprint. We have received so many lovely comments, for which we can't thank you enough, and, all being well, we will do it again next year. The following is typical of the comments we have received.

'I saw my GP, having primed her with a copy of the TM 10th issue magazine. I report with pride that when I asked if she had ever worked with a TM patient in the past, her response was that apart from medical school 20 years ago, she had no experience. She was very impressed with the magazine!' N.B. This was designed as a stand-alone edition, and will remain valid until we print again, so please keep handing it out.

Having got back from the Conference we all turned our attention to TM Awareness Day. 9th June was nominated as TMAD UK a few years ago, but as part of the 10th anniversary it was decided to try and encourage more members to be proactive in raising awareness. Lynn Powell was appointed Volunteer Coordinator, and soon things were really motoring. The Awareness Day page on the TMS website registered dozens of events. Our Facebook page and Twitter went viral, spreading the word, with 'likes' and 'tweets' galore. We only have space for a few of the events that took place around the UK, but our thanks go out to everyone who took part, whether you raised

hundreds of pounds, or simply handed out a magazine.

Naturally our TM Kids took part with a wonderful 'blue themed' day in Glasgow organised by their families.

I first came across the Back Up Trust when I attended a London Support Group meeting and one of their volunteers was the guest speaker. I have to confess I was unaware of the fantastic work they do with people who have permanent spinal cord damage, supporting them through changes they may want to make, whether it's employment, education, travelling, lifestyle, or simply wheelchair skills. We felt they should have a wider audience so I would encourage you to turn to Page 12 where you can learn more about their mentoring service.

Elsewhere we have regular contributor Ruth Wood with her slant on life, Colleen Oakley has written an interesting piece on Nutrition, and Stephen Clutterbuck has a wry take on his TM story. Altogether plenty of summer reading for you!

I'm sure you will all join me in congratulating Gordon "Gio" Reid, a Scottish professional wheelchair tennis player, ranked World No.6 and the British No. 1 who has just won his first Grand Slam Title. He also reached the final of the Men's doubles at Wimbledon.

Support groups are increasing in numbers across the country. Keep a look out for a group near you. For further information on support groups, please see page 16.

The next edition of the TMS magazine will be published in time for Christmas.

We hope that you all have a relaxing summer and the weather is kind to you.

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

Annie Schofield

TMS AWARENESS DAY

A SELECTION OF EVENTS FROM AROUND THE UK

As part of its **10th Anniversary** celebrations, the TM Society Committee wanted to be more proactive about encouraging and helping its members to raise awareness of Transverse Myelitis (TM) and related conditions. They began by appointing a TM Awareness Day Volunteer Coordinator, Lynn Powell, whose mother has TM. She developed an action plan where small ripples of awareness-raising activity came together on and around the 9th June.

TM Awareness Day Facebook community grows to over 500 and posts reach 10,000+

The Facebook page got activities off to a good start with over 500 'likes'. Thanks to our Facebook community posting their own Awareness Day messages, sharing our messages with their friends, sending us their #HelloTM photos and tagging the TM Awareness Day UK: 9 June page in their messages, our post reach was over 10,000.

Creative awareness-raising activities of all shapes and sizes

This year we had a fantastic selection of awareness-raising activities involving lots of blue hair dye, physical challenges, eating of cake, putting up of posters, sharing of magazines, wearing of TM Society merchandise, and social media activity. A special thank you must go to our favourite weather reader Sian Lloyd for retweeting our TM Awareness Day message to an amazing 110,000 followers!



Congratulations to *Elsbeth Fairgrieve* on **raising £405** at her Edinburgh coffee and cakes morning.



Blue hair was the theme of the day at the *Scotland Group* event. According to Margaret, "Everyone loved it, and we used up 6 cans of blue hair spray". The Scotland Group **raised £500** for the TM Society Family Weekend.

TMS AWARENESS DAY

A SELECTION OF EVENTS FROM AROUND THE UK



Vicky Whittaker from Chewton Mendip, who was diagnosed with Transverse Myelitis in 2014, took part in a Pilates marathon, **raising over £500** for the TMS.



Birkdale Clinic staged a Bakefest - TM Awareness event with posters at surrounding surgeries and in the clinic, balloons, fact sheets, leaflets and magazines on display throughout the week and of course, CAKE! - See more at: www.myelitis.org.uk/tm-awareness-day



Emma O'Prey did an interview on BBC Radio Jersey about TM. They also tweeted a pic of her TM wave with the TM awareness hashtag.

A full report on TM Awareness Day 2015 will be available later in the year, in the meantime you can keep in touch by following us on Facebook or Twitter, or sign up to get TM Awareness Day newsletters by email at www.myelitis.org.uk/tm-awareness-day

A huge thank you to everyone who took part in TM Awareness Day 2015: we couldn't have done it without you.

JOIN US ON
facebook

**The Transverse Myelitis Society
Facebook page now has nearly
1300 members**

ONE STEP AT A TIME

STEPHEN CLUTTERBUCK TELLS HIS STORY

Born December 1960 in Neath, South Wales, Stephen Clutterbuck has done a little bit of this and that in his lifetime. Painter, market trader, carer, drayman, self-employed salesman, and author of two comedy novels. He was diagnosed with Transverse Myelitis in 2014.

It's fair to say in May 2014 I didn't have a care in the world. Full employment, debt free, perfect health, I didn't know my doctor and my GP didn't know me. A non-drinker since 1984, non-smoker since day one, prescription and recreational drug free, plus the physical nature of my employment provided me with regular daily exercise.

Late May - a Monday. Outside the sun was shining brightly in the sky. I decided to take a brisk walk to my local village to withdraw some money from a cash machine. Transaction completed I turned to walk home, and that's when a limp, unsteady sensation in my right leg began.

Like most men of a certain age I decided to ignore it with a 100% certainty that all would be well when I awoke the following morning. Wrong!

"You've had a stroke," my doctor cheerfully announced, before dialling an ambulance.

"It's been nice putting a face to a name after all these years." He smiled.

Three hours later the ambulance arrived.

"It's been a busy old morning, mate," the ambulance driver explained, wheeling me into the back of his vehicle.

"You've had a stroke." A consultant at Northampton General told me after I've been put through a number of tests and asked me to repeat my name, address, and

date of birth repeatedly.

"Please can you tell me where you are exactly?" he asked.

"Hell I suppose," I whispered.

"Not quite that bad. You are in good hands. A member of the Stroke Team will make contact with you shortly, and you will be treated at home. Good day and good luck to you."

"I don't think you've had a Stroke," a Stroke Team physio told me. Six days had passed and I was going downhill fast.

"A stroke is a stroke, but what you've got is on the move." Six days previously I'd had one good leg and one bad leg, but now I had two bad legs.

"The good news is you haven't had a stroke, but the bad news is the Team can't look after you anymore because you haven't had a stroke." The physio smiled.

I was incontinent. I'd been cut in half. The midsection of my body had come out in sympathy with my legs. I didn't know whether to laugh or cry? I could no longer stand let alone walk. Impatient car horns wailed as another ambulance crew carried me into the back of their ambulance, and we're off to Northampton General again.

"It's fair to say I didn't have a care in the world. In perfect health, I didn't know my doctor and my GP didn't know me."

It's 5 days later and I'm bedridden. An MRI Scan, a lot of tests, and scratching of heads took place before I was

ONE STEP AT A TIME

STEPHEN CLUTTERBUCK TELLS HIS STORY

transferred to the Neuroscience Ward at John Radcliffe Hospital in Oxford.

After a lumbar puncture Transverse Myelitis is soon diagnosed. The concertina structure I used to call legs are strapped upright and straight to a standing board for up to 45 minutes a day. I'm given a wheelchair to gad about in. A long course of steroids is prescribed.

Two weeks later I'm on my way back to Northampton General, wondering what's going to happen next. I, along with five male patients, call our bay home. I'm the only one of the six of us who can remember his own name. Sleeping at night is impossible, but six years of permanent nightshift has come to the rescue as I happily listen to classic rock via iTunes. My comrades sleep during the day, and speak to ghosts during the night. The summer solstice dawns. An old lady walks past my bed. I remove my earphones and listen to her order a taxi with a flip-open mobile phone, half of which had been snapped off.

"What are you doing in here with all these naughty men my lovely? Let's walk back to your hotel room, and perhaps you'll get a better signal in there," the nurse said, playing along.

Six more days pass and I'm moved to a stroke ward. Former stroke victims are now hospital volunteers; they describe to me what it's like to survive a stroke. "My accident insurance kicked in big time and paid off the mortgage of my house. A swings and roundabouts sort of thing really. At least the wife and kids are happy, and that's the main thing," the volunteer said.

Four more days come and go. Another ambulance is waiting outside the main entrance, and I'm soon on my way to Beechwood Rehab Centre in Wellingbrough to learn how to walk again.

"Happy Days!" I thought to myself as I'm wheeled into a nice room all to myself with an en-suite bathroom. Physio is so intense that in ten days I'm walking unsupervised with crutches.

Discharged after spending a total of forty days inside various NHS institutions, I find myself at home again. Living alone I'm trying to live as independently as possible. Family are helping me do what I can't do for myself. Nevertheless I'm building up walking distance by tottering around the block on a pair of crutches, with a phone in my pocket in case of emergencies.

Four weeks pass and I'm fighting the good fight. One Saturday night my back is feeling stiff and sore as I manoeuvre myself into bed. I awake with a scream. Pain is impossible. It takes an ambulance crew three hours to get me out of bed. A total of three morphine injections; one every twenty minutes. Gas and air. Back to Northampton General. Previous diagnosis is up in the air. MS is mentioned. Discitis is diagnosed with my L3 and L4 vertebrae infected.

“The fight continues, and the battle rages on. TM man! You couldn't make it up!”

Nineteen days later I'm back home again. Members of the Independent Care Team are visiting me once a day to drip feed antibiotics via a pick line in my arm. Two weeks later I'm back in hospital. I'm poisoned by the antibiotics. Hepatitis is diagnosed. Thirteen days later I'm back home after spending a total of 72 days in hospital during the summer of 2014.

My symptoms continue, but happily I'm hospital free. Unable to walk unaided, my infection free Discitis feels like I'm living with a squatting house brick in the lower segment of my back. The fight continues, and the battle rages on. TM man! You couldn't make it up!

NUTRITION FOR NEUROPATHIES

COLLEEN OAKLEY

Colleen Oakley has been a TMer since 2010. Dealing with fatigue and constant pain she decided she wanted to take back control of her health and became a 'Living Well' Coach, marketing products that have made a big difference to her. You can visit her at www.Facebook.com/onthefloortired

You may have seen a lot of posts on our Facebook page lately about nutrition, supplements and what works for whom. Let's continue the discussion here, shall we?

We all have TM. That is a given. Some of the jollies that come with the condition are a given too – fatigue, pain, brain fog, muscle weakness, paralysis, spasms, bladder and bowel malfunctions, depression – to name but a few.

The question is, can we improve our health and maybe reduce the severity of some of these nasties through improved nutrition?

My answer is an unequivocal 'yes'. Please note that I said 'Improve and Reduce'. Not get rid of completely. Let's be realistic here.

A while ago, I asked on the forum what, if anything, had worked for you guys. Quite a response. This is what some of you said worked for you:

- **Paleo diet** (<http://thepaleodiet.com>)
- **Wahl's protocol** – pain way down- dropped to 1/3 of medications. Dr. Terry Wahl had very severe Multiple Sclerosis and has done much work in the field of nutrition since becoming ill. You can find a lot of presentations on YouTube by her. (www.terrywahls.com)
- **No sugar** – sugar of any sort acts as an inflammatory agent to the body. Solid science based site <https://iquitsugar.com>
- **Vitamin B12 and Magnesium** – hulled hemp seeds an anti-inflammatory powerhouse. A world expert on this subject is Dr. Dean (<http://drcarolyndean.com/magnesiummiracle/>)
- **Whole30.com** – changed life. Find out more at www.whole30.com
- **Healthy fats, low carb, moderate protein**
- **Improve gut health, magnesium, green juice**

Are you seeing a common thread? Remember, these are people who have what we have, not just some expert out there telling us what to do. Let's look at what one of those experts have to say, though.

"The more healing you want, the more micronutrients you want. Don't waste calories on food not loaded with vitamins, minerals and antioxidants. Inflammation is the hallmark of autoimmune diseases. Every system in your body interrelates in a way that ultimately causes the manifestation of either health or disease." Dr. D. Pelmutter.

On the subject of supplements, someone asked why we cannot just eat a healthy diet. This is a good question. The challenge is finding healthy foods. By that I mean, foods that contain all the vitamins, minerals and fats that we need. Since our soil is so depleted, our seas polluted and our food chain full of preservatives, antibiotics, toxic chemicals (to name but a few), we have to be very sure of the source of the food to know that it is healthy. This is a large topic, maybe for another article.

Medical intervention is something we all know only too well. How about nutritional intervention? This places power and control firmly back in our own hands. This can be overwhelming and life changing. If this is something you want to try, identify one area you would like to change (mine was fatigue) and make small changes to your diet for a month. Reducing or cutting out sugar is a good way to begin.

Let us know what works for you, please.



I'M STUCK IN A LIFT

RUTH WOOD



I'm stuck in a lift. Not one of your ordinary four-walled ones with mirrors all round so you can see yourself terror-ridden. No. It's one of those awful things which seem to be based on the old-fashioned dumb waiter which carried food up to the dining room from the kitchen in clubs and big old houses.

We're in a newish building in Birmingham and I'm acting as chauffeur for my husband. It's quite a nice thing to do as he's spent the last eight years looking after me, so now I'm driving again, as he can't see properly to drive at night, I've agreed to take him to his monthly Equity meeting.

If I could walk properly I wouldn't be in this predicament. What makes it worse is that several people have piled in with me, all of whom can actually access the stairs.

In case you haven't had the misfortune to come across these, I will attempt to describe them. What you get is a platform with a couple of big control buttons. The platform is situated inside a solid metal oblong tube which towers above you as you look up. When you press the green button – and keep it pressed which is not always easy when you've got hands that don't like to do anything sensible for any length of time – the platform slowly ascends up the tube until you get to the floor you want coming into view.

To add to my problems I'm extremely claustrophobic – when I was having my MRI scans I had to get Valium from the GP to even be able to go into the tunnel – so when the platform started to judder just after it had begun to move, I felt a little apprehensive.

It stops. We've just cleared the door, so are completely surrounded by solid metal. There are five of us in here and the lift won't move in any direction however much I press the button. We're stuck. The others are laughing and taking selfies of themselves to put on Facebook. I have enough presence of mind to duck out of the photo when they try to include me – I like to choose my photos for social media.

I try to allay my panic by repeatedly stabbing at the SOS button, but as that doesn't seem to be doing anything, I then start deep breathing – counting “in – two – three – four – out – two – three – four” to control the threatening panic attack.

But they keep talking to me. “Hey Ruth, you're very quiet.” Yep – I'm quiet. – I'm trying to count!!!

Suddenly a voice calls from above, “Hey – you in trouble down there?” No we always like to hang around in a stalled lift. The others are shouting and laughing – in my head I'm thinking, don't laugh or they'll think it's a joke and we'll never get out, but I can't say it – I'm still deep breathing.

Another voice joins in the merriment. This one is new. One of the staff. Thank goodness.

“I'll have to get the Manager. Can you hang on for a moment?” Do we have a choice? What kind of dumb question is that for people stuck in a lift?

Suddenly there's a lurch and the lift slowly descends again. It seems to take forever, but then the door opens and we spill out. I have to be helped.

I feel deeply thankful that the threatened panic attack actually never happened, but it was a near-run thing. The others go off to find the stairs. As I can't go with them, I choose to sit in the bar downstairs and wait for them.

I begin to write - “I'm stuck in a lift”.

TM KIDS

TRANSVERSE MYELITIS AWARENESS DAY

On 30th May my family and George's family organised a TM awareness day. We invited all our friends and family to come along. It was great fun. We sprayed everyone's hair bright blue and we ran several stalls and had a yummy lunch. We finished the day with a special TM cake and a fun raffle. Thanks to everyone for raising so much money!!!!



I entered the hurdles race this year. We all thought I was mad! I surprised us all by managing to jump over three hurdles.



TRANSITION DAY FROM P7 - S1

I woke up with butterflies in my stomach; it was my first day in senior school. We all gathered together in the dining hall and we were put into our form groups with our guidance teacher. We kick started the day with some taster lessons, which included three sciences, Latin and History. Boy, there is a lot to learn!!! The afternoon was spent participating in some fun team building exercises at the playing fields.

A few weeks later a transition meeting was organised with support for learning, guidance and school nurse. It was very successful as now they understand more about TM.

I had a few worries which may seem strange to some people but I'm sure other TM kids will totally get it!!

1. Where are the nearest toilets depending on the building? Solution : I'm going on a "toilet tour" next week!

2. Is there anything we can do to conserve energy? Solution: Lift pass if I need it.

3. How can we make my bag lighter? Solution: locker to store equipment in and iPad so my books are digital.

4. How are we going to manage my lunch time tablet? Solution: I'm allowed to keep it in my blazer and take it when I need it, but the nurse will check if I have remembered it!

5. School residential trip worried about sharing with a stranger when using catheters and peristeen. Solution: Guidance teacher will place me in a room with someone I can trust!

Now I feel happy and excited about moving up to senior school. I'm looking forward to a fun end of term with my primary school friends. Happy summer holidays!!!

CIVIC TRUST PHOTOGRAPHY AWARDS

I just wanted to tell you that I entered a competition through school for photography. I just received the letter today to tell me that I was commended for my photo and I have to attend an awards ceremony in Glasgow which is where my photo will be displayed in The Lighthouse, Scotland National Centre for Architecture and Design. Here's the link if you would like to have a look at my picture.(It's under RGC Primary) <http://www.scottishcivictrust.org.uk>

Lots of love from Penny

TM KIDS

OVER THE WALL CAMP

Hello, it's George here again. I have been keeping really well, well apart from my bladder. I've been really busy recently with school. I went with my family to Over the Wall family camp again this year which was brilliant. I felt a lot more confident this year and all of the volunteers said that I had come out of my shell a lot. It was nice to see all of the volunteers again and some of the friends that I met last year. I knew all of the songs already this year too so I could sing them really loudly!! I got to try a few new things like the giant sling shot, which I was really good at and we got to stay up late with our families and play board games. We played Kerplunk, Happy Families and Frustration which was hilarious. But a lot of the time I just chatted to my friends. We also had water guns to get the grownups with. The best part was spending all afternoon on Saturday in the big swimming pool with my Mum, Dad and two sisters. We had such a great time. We love OTW!! Next week we will be going to TMS camp, so maybe I will get to meet some of you reading this magazine.



MY LAST WEEK OF SCHOOL

This week was my last week at school before the summer which has been really exciting. On Thursday we had a big day. It was sports day, family picnic and prize giving all in one day. I got a certificate for getting my silver badge and I won quite a few races, but my biggest achievement of the day was winning the long running race which was twice around the edge of the playing field. I was so pleased to win this out of the whole of the big class!! When I got TM I didn't think I would be able to win a running race again! But the best part of the day was my big surprise. My school does a lot of fundraising activities throughout the year and at the end of the year the P7s get to choose a charity and this year they chose the TMS. I got a big cheque presented to me at prize giving for two hundred pounds which is a lot of money for my little school to raise. I felt so proud. I love my school and all the teachers and my friends. I'm really lucky to go there.



BACK UP

TRANSFORMING LIVES AFTER SPINAL CORD INJURY



Ben Cook was just twelve years old when Transverse Myelitis changed his life forever. At first, he was determined to beat the condition and managed to do what many thought impossible, he learnt how to walk again. However, two years after being diagnosed, he suffered a relapse that took away the use of his legs. Ben felt isolated and depressed but a charity called Back Up gave him the confidence he needed to move forward.

Back Up is a national charity that has helped thousands of people of all ages and backgrounds rebuild their confidence and independence after spinal cord injury. Their wheelchair skills training, mentoring service and residential courses are run by people affected by spinal cord injury themselves. They also support people to overcome the challenges of returning to work or school.

Ben, 20, heard about Back Up at Stoke Mandeville Spinal Unit, where he was doing rehabilitative physiotherapy. Stuart, a Back Up volunteer with a spinal injury at a similar level, approached Ben and introduced him to Back Up and its courses, including their wheelchair skills training, which Ben attended. The training provides people key wheelchair skills to get around and participate in normal life. Wheelchair users learn everything from pushing techniques to back-wheel balancing.

Ben felt nervous and anxious before the course and meeting new people was quite hard for him. However, knowing there would be people that had a spinal cord injury helped. After the course, he was amazed by the things he was capable of doing. "Looking back at everything I had achieved, seeing what I could actually do made me a lot happier and gave me a brighter outlook on life," Ben says.

Ben is now one of Back Up's Youth Advisors. This group provides feedback on the services young people use at Back Up, and offers ideas and improvements to help Back UP reach out to more children and young people who are paralysed and make sure their needs are met. According to research, every year 40-50 children in the UK sustain a spinal cord injury through accident or illness. Back Up is the only charity in the country that provides dedicated services for young people and children under 18 who are paralysed.

Spinal cord injury has a significant psychological impact on the person with the injury and their family. Many people feel depressed and anxious as they don't know what life will be like after leaving hospital – including whether they will be able to work again. Research shows that as little as 17% of people who are paralysed are in employment. And while a recent survey published by Back Up found that a quarter

BACK UP

TRANSFORMING LIVES AFTER SPINAL CORD INJURY

of people start thinking about returning to work within a few weeks of sustaining their injury, 44% of people said they were not encouraged to consider work as an option while in hospital.

With the right support there is no reason why a healthy person with paralysis cannot work. This is why in 2007, the charity launched Back Up to Work, a course dedicated to helping people with spinal cord injury get back to work. This course offers people the chance to enhance their CVs, practise interview techniques and receive advice on job hunting in a supportive and encouraging environment. Results are positive - 72% of people who attended a Back Up to Work course are in volunteering, education or employment. The residential courses take place three times a year in different locations.

“With the right support there is no reason why a healthy person with paralysis cannot work.”

Alex, a Back Up to Work participant, had an accident in August 2011, which left him permanently paralysed from the waist down. When Alex finished university, he spent a year unsuccessfully looking for work. “I felt I had lost the skills required and it would be difficult to find employment in a wheelchair,” he says. After attending a Back Up to Work course hosted by Back Up’s corporate partner, Savills, Alex’s future started to look more hopeful. “The course has taught me that the skills I have are relevant and gave me the confidence to stick at it and find my dream job,” Alex says.

Finding a job is just one of the many obstacles people face after spinal cord injury. That’s why Back Up has a unique service that provides all people and their families with the support they need to overcome these obstacles and to adjust to life after spinal cord injury.

The mentoring service matches people with volunteer mentors with similar experiences who offer practical and

emotional support. Kim had a spinal stroke after a car accident in 2009. She was at Stoke Mandeville Spinal Unit for six months, when she came across Back Up. Kim was matched with Mel, a Back Up mentor, who was able to tell Kim what her life would be like after the injury.

“When I came out of hospital in 2010, I was overwhelmed by everything,” Kim says. “The sounds were so much louder and everything was so much further than when I was in hospital.” Back Up mentoring helped Kim to put things into perspective. “They lifted me out of being someone really miserable and gave me hope for the future,” Kim says.

A Back Up course was also a turning point for Yasmin Sheik, who was paralysed from the chest down after a spinal stroke/TM in 2008. Yasmin attended the Edinburgh City Skills course in 2008, which was led by volunteers who were paralysed. Yasmin says, “Here was a bunch of well adjusted, successful and happy people who made me believe that I could live a full, independent and happy life again. I realised it was about doing things in a different way – focusing on what you can rather than what you can’t do. Afterwards my friends and family remarked that the ‘old Yas’ was back.”

Yasmin has become a Back Up Schools Advocate and visits schools across the UK to raise awareness of spinal cord injury. Advocates give young people and their families the voice they need. They act as positive role models, challenge perceptions of disability, and inspire people to transform their lives.

The 35-year-old, who is also a Back Up Ambassador, is now a disability and diversity consultant, working mainly with international law firms, including her previous employer. “My work is so fulfilling. It’s exciting to know that I can use my experience and knowledge in a field that I feel passionate about. It’s good for business too. The future doesn’t seem as scary now and it’s comforting to know that Back Up is there for me,” Yasmin says.

You can find more information about Back Up including its residential courses and mentoring service at www.backuptrust.org.uk

TM CONFERENCE REPORT

ZELDA CARR



The two editors meet for the first time.

The Conference was held at the Aston Conference Centre on 7th March 2015. The weekend started on Friday evening, when members who arrived early met for dinner, where new and old acquaintances renewed friendships and made new friends. The TMS Facebook had been a useful tool with increased chatter about the meeting and for members to discuss plans ahead of the meeting.

After dinner, members helped set the conference room up for the next morning, compiling delegate packs, sorting badges and rearranging furniture. To commemorate the TMS 10th anniversary, combined with the 10th edition of the TMS magazine, the publication was printed for the first time and offered for sale at the meeting. The TMS Committee and editorial team were excited to see the magazine in glossy print for the first time.

The conference was opened by the Chair, Barbara Babcock and the meeting started with the AGM. Barbara provided an overview of the priorities and progress in 2014 and shared the priorities for 2015, Sally Rodahan, president of the TMS was re-elected to the Committee.

The meeting comprised of a mixture of formal presentations by TM experts, combined with workshop sessions offering

members the opportunity to gain further information on specialist areas and a diverse selection of exhibitors providing free expert advice to attendees.

The speakers and topics were as follows:

Prof Carolyn Young, Consultant in Neurology and Consultant in Rehabilitation Medicine, The Walton Centre, Liverpool

'Rehabilitation after TM - a journey with many different routes'

Dr Allen DeSena, Neurologist and Assistant Professor from the Cincinnati Children's Hospital

'Rehabilitation & TM: Recovering from and living with TM'

Dr Ming Lim, Consultant Paediatric Neurologist at Evelina Children's Hospital, London

'TM Research in the UK: STRIVE clinical trial'

Dr Bernhard Frank, Consultant in Pain Medicine, The Walton Centre, Liverpool

'Managing Pain and Fatigue'

Dr Mayur Bodani, Neuropsychiatrist, Sevenoaks Hospital, Kent

'Depression in long term neurological conditions'

Dr Saiju Jacob, Consultant Neurologist, Clinical Service Lead at University Hospitals of Birmingham

'The "fuzziness" of TM/ADEM/NMO'

The TMS videoed all the formal presentations, which are available on the TMS website and are very informative: <http://www.myelitis.org.uk/report-on-agm-and-conference-march-2015.html>

Copies of the presentation slides discussed during the workshops are also available on the website.

THANK YOU FOR YOUR SUPPORT

MORE FUNDRAISING STORIES

In May of 1983, at the age of 17, *Geraldine Riley* was paralysed from the chest down as a result of Transverse Myelitis. Happily she learned to walk again but does have some persisting symptoms. On 2nd May 2015 Geraldine married Michael Booth at Gorton Monastery. They asked for cash donations instead of presents on the basis that they would give an equivalent amount to the Transverse Myelitis Society. The total raised was £5,235.00 plus Gift Aid. Geraldine and Michael have rounded that up to £5,500.

Photo by Toni Darcy.



Simon Hoskins, a keen am-dram actor with ACTS in Oxfordshire took to the mud to run the 10km Vision Wild Run after director Val was diagnosed with TM in November 2013 while visiting family in Australia. Repatriated in a wheel chair, within a month she was back on wobbly legs directing Calendar Girls. ACTS decided that TM needed support so Simon took to the mud, completing his run in 1 hour 38 minutes. His sponsorship raised £687. A raffle at ACTS Murder Mystery evening raised £220 and a member of the audience made a donation to bring the total raised to £1000.

Helen Hampton was so pleased with the welcome her parents received at a TM support group meeting that she got out her running shoes to take part in the 10-for-10 campaign. Her idea was to run 10 miles a week for 10 weeks, then compete in a 10km race on 5th July and raise £500 for the TMS. Unfortunately in week 8 she sustained an injury, bad enough to cancel all training from then on. However, she has already smashed her target, with £600 raised already, and, undeterred, is planning to do a run later in the year. We wish you a speedy recovery Helen.



NEWS FROM THE COMMITTEE

What the TM Society is doing to educate healthcare professionals about TM and related conditions

*In the 2014 member survey, 47% of respondents said the TM Society could be providing information and learning sessions for healthcare professionals. The TM Society is pleased to announce it is working with the Spinal Injuries Association to help deliver its new study day for healthcare professionals: **The Non-Trauma Perspective**. It covers the physical and psychological impact of non-traumatic spinal cord injuries (those incurred through an illness like TM), the importance of timely diagnosis, the care pathway, and TM and the TM Society's work. 58 health care professionals attended the first study day in Birmingham on 24th June. It will also be delivered again in London on 3rd September and Manchester on 5th November. Healthcare professionals can book their place via <http://www.spinal.co.uk/page/study-days-booking>.*



Support Group Sub-Committee – New initiative to strengthen the Support Group network

To strengthen our Support Group network, a Support Group Sub-Committee has been launched. Its role initially will be to improve two-way communication between Support Group Leaders and the TM Society Committee, develop and communicate best practice, and help establish new groups.

Rob Reeves, who sits on the TM Society Committee and is the Support Group Leader for the Exeter/Taunton Support Group, has kindly volunteered to head this sub-committee. He has invited Gill Rice, Support Group Leader of the Norwich Support Group to work with him.

If you are interested in starting a support group in your area, please contact Rob and Gill at rob.reeves@myelitis.org.uk and gill.rice@myelitis.org.uk.



TM Society's Family Weekend at the Calvert Trust, Lake District – 10-13 July 2015

By the time The Magazine has been published, the TM Society will have run its inaugural Family Weekend at the Calvert Trust in the Lake District on 10-13 July. Children and young people aged between 4-17 years who have been diagnosed with TM, ADEM, NMO or ON, their siblings and parents will have participated in adventurous outdoor activities and educational sessions with medical professionals. The weekend provided an opportunity for everyone to realise their potential as individuals and as a family unit despite the challenges they face. More information about the weekend will be on the website!

Need a fundraising idea? How about the 10th Anniversary 10-for-10 Campaign!

Don't forget our 10-for-10 fundraising campaign which celebrates the TM Society's 10th anniversary since it registered as a charity. We want to mark how far we have come and ensure that we can continue doing what we do, so we are raising money to continue funding the various services we offer members.

The idea is if each of us gives £10, and then ask 10 family, friends and colleagues to give £10 each, we could each raise up to £110. For more information, read the article in Issue 10 (Spring 2015), page 25. You can easily integrate the 10-for-10 fundraising idea into any fundraising activity you are planning. And don't forget to check out the many new resources we now have available to our fundraisers.

NEWS FROM THE UK SUPPORT GROUPS

LONDON SUPPORT GROUP

NEXT SUPPORT GROUP MEETINGS: SATURDAY 17TH OCTOBER

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 26TH SEPTEMBER AT 2PM &
SATURDAY 6TH DECEMBER CHRISTMAS LUNCH

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/TAUNTON SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: 24TH OCTOBER 1.00 TILL 4.00PM

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

Venue: NOTE: Holiday Inn (not Holiday Inn Express) Taunton. M5 Junction 25, Deane Gate Avenue, TA1 2UA. Held in the restaurant area. Future meetings in a private room.

For directions go to <http://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 24TH OCTOBER AT 2.00PM REFRESHMENTS AVAILABLE.

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

NORTH EAST SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: CHECK TMS WEBSITE FOR UPDATE

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

NEWS FROM THE UK SUPPORT GROUPS

EAST MIDLANDS SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: SATURDAY 10TH OCTOBER 2.00PM - 4.00PM

Doors open 1.00pm for refreshments. The group shall be holding some small satellite meetings. For further information contact Janet Ashenden

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

BRISTOL SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: SUNDAY 6TH SEPTEMBER 2.00 - 4.00 PM &
SUNDAY 6TH DECEMBER

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

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

TELFORD SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: SATURDAY 10TH OCTOBER 2.00PM

Venue: The White Lion, Holyhead Road, Ketley, Shropshire, TF1 5DJ. 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 MEETINGS: SATURDAY 25TH JULY IN GLASGOW
AGM – (SATURDAY 28TH NOVEMBER IN EDINBURGH)
5TH DECEMBER PLEASE CHECK FOR UPDATES

Venue: Dates of our meetings are posted on our webpage www.myelitis.org/scotland where travel directions can be found by clicking on the Events link. For any further information please contact **Margaret Shearer** on 01292 476758 or email margaretshearer@myelitis.org

SOUTH WALES GROUP

NEXT SUPPORT GROUP MEETING: 25TH SEPTEMBER AT 2.00PM (TBC)

Venue: Bridgend Designer Outlet (TBC) Look out for further details. Contact **Sami** on samibear65@gmail.com

NEWS FROM THE UK SUPPORT GROUPS

OXFORD SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: 25TH SEPTEMBER MEETING AT OXFORD
5TH DECEMBER MEETING AT EVENLEY

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 or **07795 155205**

Doors open 1.45pm see <http://evenley.info/villageLife/location.php> This venue is suitable for members from Northamptonshire, Oxfordshire, North Buckinghamshire, South Warwickshire and is easy to travel to. Frances Reader a rehabilitation Pilates teacher will give us a presentation and opportunity to practice Pilates, whether seated in a wheelchair or laying on the floor.

PRESTON SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: CHECK TMS WEBSITE FOR VENUE AND UPDATE

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: CHECK TMS WEBSITE FOR UPDATES

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'.

TALKING MATTERS

On 2nd July Ruth Wood arranged a small get together for a coffee and a chat – and it was so enjoyable they have decided to do it again!!! Open to all TMers and their families, friends and carers. 'We'd love to see you (the first coffee is on me) – Ruth'

NEXT MEETING: SATURDAY 12TH SEPTEMBER

Venue: The Apollo Hotel, Hagley Road, Birmingham

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@thewaltoncentre.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

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