SUMMER 2014

The Magazine

TRANSVERSE MYELITIS SOCIETY

Sally Jones – Back In The Saddle

PAGES 5

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LETTER FROM THE EDITOR

In the first issue of the TMS Magazine, way back in February 2012, we featured the 'Life Story' of 22 year old Amy Edwards who was diagnosed with TM at the age of 13. Despite 3 months off school, she achieved excellent results in her exams and went on to University to do a degree in Psychology. In the last paragraph she said she was unsure what the future would hold, but she had a lovely 'life partner', and hoped to have children one day. Well, not only did she marry her lovely man, last month she gave birth to a beautiful baby girl named Violet Summer Aurora. I know you will join me in sending our very best wishes to them. You see, some TM stories do have a happy ending!

We have to thank Andrew Hinder and Leonie Ashenden for taking such copious notes on our behalf while attending the Oxford and Liverpool Conferences respectively. Both events were an enormous success, with over 100 people at each, and we owe a huge debt of gratitude to the organisers for lining up such a stellar list of speakers.

I'm delighted to say that our very own 'TM Kids' are back and you can find what Penny and George have been up to on pages 6 and 7. Both families attended an Over The Wall camp weekend, which, judging by George's account, was clearly great fun. You may have also seen Penny at the TMS Conference in Oxford, which she attended with her father.

It seems that bladder and bowel problems are never far away for us TMers, so we are always interested in possible new solutions. Suzanne Carr contracted TM in 1979 at the age of 12, and has struggled with bladder problems ever since. Leaking, chronic retention, spasms, her bladder controlled everything she did. That is until her urologist referred her to the Uro-Neurology team at the National Hospital for Neurology in London. They thought she was a good candidate for a bladder pacemaker, and you can read her story on pages 8 and 9.

And let's not forget our cover girl, Sally Jones. She came to riding late in life, purchasing her first horse in her late 50s. She had also been a volunteer with the RDA for 5 years, and showed great determination to get back on a horse after contracting TM. There are RDA groups all over the country and some of the Paralympic riders started riding at their local RDA - including double gold medallist Natasha Baker who has TM. You may remember we featured Natasha's story in the magazine in 2012 and followed her progress from GB team hopeful to Paralympic glory.

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

Annie

TMS CONFERENCE OXFORD
ANDREW HINDER REPORTS

The programme consisted of four specialist speakers and four separate question and answer sessions. The Agenda and notes about the speakers can be found on the TMS website at http://www.myelitis.org.uk/news-blog/may-2014-conferences

Firstly Dr Isabel Leite introduced her work into Neuromyelitis Optica (NMO) at John Radcliffe Hospital. The mechanisms, symptoms, and treatment of the 'NMO spectrum' diseases, NMO, ADEM, MS and TM, were examined, with a review of diagnostic techniques including MRI scans and antibody testing. A protein aquaporin-4 (AQP4) was identified as the primary auto immune target leading to inflammation in NMO. Although NMO and TM are often characterised by a single lesion, 'longitudinally extensive TM' can extend over three or more spinal segments, and is often associated with other autoimmune conditions eg. lupus.

Dr Adam Kaplin summarised the research and clinical trials at Johns Hopkins University TM Center. The drug dalfampridine initially trialled for MS patients to improve mobility, is now being trialled for TM patients. Low levels of serum vitamin D in TM patients, may suggest that TM could be treated with vitamin D. Dr Caplin also referred to cognitive changes eg. slow reaction times, and difficulties with multi – tasking. Curiously however, reaction times for TM patients improve with age. Raising levels of the neurotransmitter NAAG increases cognitive performance, and research is taking place for the development of drugs for remyelination. Improvement in mobility can also be achieved by shutting down the immune system in a controlled manner, so that the body activates a completely new immune system. A fun way of treatment is scuba diving which has been found to improve motor function due to nitrogen narcosis at depth during a swim.

Dr Allison Graham of the National Spinal Injury Centre, Stoke Mandeville, spoke about living with TM, programmes of rehabilitation, and coping with fatigue and neuropathic pain. A biosocial model of care and exercise is tailored for each individual patient, and employs a scoring system taking account of factors such as bladder function, bowel function, mobility, and community coping. Crucially a change of mindset is regarded as an essential factor in recovery. Patients should be actively adapting and adopting behaviours with support from health professionals. Repetitive action above and below the site of injury will get the spinal cord to adapt, and repetitive craft activities such as knitting have been proven to be beneficial in terms of pain management and depression. A more curious reference was made to beetroot juice, used successfully by the Sky cycling team to enhance muscular performance. Unfortunately a pint of this strange product has to be consumed each day for any possible benefits to be accrued.

In a short question and answer session it was suggested that the support of health professionals mentioned by Dr Graham was sadly lacking in some areas of the country. A reference to the possibility of a link between myelopathy and TM was confirmed by Dr Kaplin, and it was emphasised that more research was needed into the mechanisms of neuropathic pain.

Dr Kaplin returned for a presentation on the psychological and cognitive aspects of TM. It was stated that many TM patients experience depression, as indicated by changes in mood, sleep, energy, appetite, or concentration. Depression antagonises the neurological inflammation in a vicious circle of pain – depression – pain. The suicide rate amongst people with TM is 1000 per 100,000, compared with 168 per 100,000 for people with MS. Lifting depression can be

tackled with fluoxetine or other anti-depressant drugs, and studies have shown some benefits from the use of marijuana. However a social model of treatment is to be preferred. Patients are urged to maintain friendship links, and suicide prevention programmes can employ texting systems to report on mood day by day.

Another question and answer session covered the problem of anxiety, and the benefits of Cognitive Behavioural Therapy (CBT) as opposed to drug therapy. Exercise was mentioned as one of the best ways of reducing depression. Although drugs are used regularly in the treatment of pain, with gabapentin being the cheapest, again CBT was cited as the preferred option. It was emphasised that the target of zero pain is unrealistic. Pain should be low enough for adequate function. Questions were posed as to why so few TM patients have a regular follow up on their pain management, and it was stressed that it is up to us to pressurise our GP.

Dr Denise Fitzgerald of Queen's University Belfast then spoke on the challenges of research into treatment for TM. The pathophysiology of TM was outlined, new methods of arresting the progression of TM were mentioned, and new methods for nerve regeneration were examined. A number of new drugs used with some success for MS, cannot unfortunately be used to the same degree of efficacy for TM. In TM a trigger is needed for oligodendrocyte precursor cells (OPC's) to initiate remyelination where the nerve damage has occurred, and some new drugs are being developed to remove the barriers for this process to occur.

In the final question and answer session, Dr Kaplin suggested that TM research could contribute to MS research, rather than vice versa as it is at present. Dr Fitzgerald, who identified the problem of funding. said that £450,000 is required for a three year research programme. Dr Kaplin fielded a question on the connection between stress and TM, by citing studies which show that chronic stress worsens MS. A question on pain management, water retention problems, and the ideal dose of pregabalin was answered by Dr Leite who emphasised that a balance must be achieved for each individual patient. Pain specialists should be consulted. There was a question on electrical stimulation of the spine to overcome paralysis. This is under development and should be connected with remyelination treatments. A question on whether an inflammatory thyroid condition can lead to NMO was confirmed by Dr Kaplin. Fatigue was then mentioned. Dr Leite emphasised that TM results in deficits which make walking difficult and tiring, and the pain of TM uses energy. Fatigue can also be the result of poor sleep, depression, or the side effects of medication. Energy levels tend to wax and wane, and this could be a focus of future investigation into the reasons for the poor spells. A problem regarding disturbed sleep due to bladder problems was aired, and it was suggested that a urologist could be consulted. A question on whether NMO could be a forerunner to Parkinson's or dementia was met with a denial by both Dr Leite and Dr Kaplin. Barbara Babcock, our TMS chair, questioned whether the NHS could be more effective in funding rehabilitation. We were urged to be more assertive, to change GPs or neurologists if necessary, to write to our MPs to increase awareness of TM, and to be active members of our TMS group.

This was an excellent occasion, with relevant information from the speakers and useful interaction with the audience. Sincere thanks are due to the presenters, to Lew Gray (TMS Secretary) who organised the event, to Zelda Carr who helped Lew and to Barbara Babcock for chairing the event.

TMS CONFERENCE LIVERPOOL
LEONIE ASHENDEN REPORTS

Dr Anu Jacobs presented the ongoing research in TM, NMO and ADEM. The main trials discussed were Fampridine and stem cells.

When myelin is lost from the spinal cord, potassium - which helps send messages up and down the spine - leaks out. Fampridine helps prevent the leakage of potassium and stimulate the nerves to send faster signals. This could "jump" the scarring in the spinal cord.

Stem cells work by placing a "mesh" of new cells into the scarring caused by the TM; this connects and stimulates the area to regrow. Stem cells can potentially cause unwanted cell growth in other areas of the body. Stem cells can be grown from foetal cells - which are designed to grow therefore should promote growth - or from the patient's own body.

Jennifer Wynne, a physiotherapist, discussed the importance of rehabilitation and exercise after TM. Exercise does not necessarily mean cycling or running, but stretching and achieving things like gardening or collecting the children from school. An activity that applies the "5 out of 7" rule (one that can be done 5 out of 7 days) is ideal. If that's not achievable, then the challenge is too great. She commented that stiffness and fatigue are normal effects of exercise.

Physiotherapy can help with posture and movement. A physiotherapist will be able to help a patient encourage the body to recover, but physios can only help if the individual wants to help themselves.

Kerry Mutch, an NMO nurse, discussed management of fatigue. The main causes of fatigue are disability (damage from TM), sleep (not enough or too much, 6 hours sleep a night is recommended), diet (too much sugar and junk food cause energy levels to drop), medication, mood (stress is like an energy bomb) and exercise.

Kerry commented that sipping water could massively help with fatigue.

Beverly Everton from Coloplast presented Managing Bladder and Bowel Issues. With TM the transit time in the colon is increased, resulting in more water being absorbed making faeces harder to pass. Different levels of spinal injury cause varying bladder and bowel problems.

Beverley mentioned a smart phone app called "WheelMate™", which displays the nearest disabled toilet and parking locations.

Abigail Methley, a psychologist from the NMO Service, discussed coping with TM emotionally. The main point is that everything should be kept in context to the individual and not be compared with others.

She discussed getting the best from life and suggested ways to improve quality of life, such as:

1. Get as much information as possible - Health care professionals will always help where they can and if they can't they will often point you in the right direction.

2. Peer support - People living with TM can use the expertise of others through the TMS and Facebook pages.

3. Coping strategies - Taking time to write a journal can help make sense of feelings and see it from different perspectives. Be proactive with your well-being, especially your mental and physical health.

4. Professional support - Find ways to overcome difficulties.

Collette Power presented Mindfulness to Manage Pain; this can help healing and create a self-directed health plan. This can alter the stress response and can help to control pain and other issues. If you are interested, you can Google "The Three Minute Breathing Space".

Powerpoint slides are available for most of the talks, together with my notes. They can be found at: **www.myelitis.org.uk/news-blog/may-2014-conferences**

SALLY JONES GETS BACK IN THE SADDLE WITH THE HELP OF THE RDA

I started riding at my local RDA in Cranleigh soon after I came home from a 3 month stay in hospital in 2012, where I had been diagnosed with TM.

I'd been a volunteer with the RDA for 5 years, prior to my TM diagnosis. I had purchased my first horse in my late 50s and like many late starters; I was passionate about my new activity. So I was extremely keen to get back on a horse, and set riding as one of my goals before I left hospital.

> ***"I felt such a thrill being on a horse again; it took a little while for my rigid legs to stretch down and relax but soon I was walking round the arena accompanied by 3 volunteers and guided by a qualified RDA Instructor"***

At first I mounted from my wheelchair by means of a hoist, which picked me up, then deposited me slowly on the horse's back. I felt such a thrill being on a horse again; it took a little while for my rigid legs to stretch down and relax but soon I was walking round the arena accompanied by 3 volunteers (one leading the horse and one each side of me) and being guided by a qualified RDA instructor. I ride without stirrups as my TM feet wander out of them, but this is very good for my balance and core strength.

I've graduated to mounting from a ramp, – walking up using my frame, then with help I sit backwards onto the saddle, and a volunteer lifts my right leg over the horse's head and another helps it down the other side. RDA provides the rider with the help that YOU need to ride. Dismounting is even more labour intensive, as I need 4 people to help me off!

I look forward to my ride every week, – mainly because I thoroughly enjoy it, but I also know that it is very good for me. After each ride my muscles are less tight, and my strength and balance improve.

There are RDA groups all over the country offering riding, carriage driving and vaulting to children and adults with disabilities. As well as our group's regular rides there are local and regional Fun Days and competitions. I performed a dressage test at Hickstead last summer, which gave me something to work towards and was an enjoyable and positive experience.

Some of the Paralympic riders started riding at their local RDA, including gold medallist Natasha Baker who has TM. Her story is very inspiring – could I set my sights on the next Paralympics in spite of a very late start - ... I wonder?

For more information and to find a local group go to www.rda.org.uk.

TM KIDS

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

Penny ran a biathlon

I took part in school sports day it was great fun. The best event was the three legged race because Sophie and I won the race!!! Yipeeee!

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 friend's houses.

I would recommend Peristeen to other children, although sometimes it takes 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.

OXFORD T.M. CONFERENCE

I went down to Oxford with my Dad, we flew to London from Aberdeen.

It was pretty exciting and I enjoyed meeting Barbara Babcock. It was really fun meeting other people like me. My Dad and I took lots of notes so we could tell Mum all about it when we got home. I was a bit sad that there wasn't anyone else there my age. I am really looking forward to next year when all the kids will be together for the weekend camp. It will be awesome!

I hope everyone has a great summer. We are going to the Commonwealth Games to watch rugby and netball so I can't wait! Have a great summer holidays! Love Penny xx

BANDING

One of the other things that has been happening to me is 'banding'. Banding feels like a rubber band is being squeezed round my tummy and chest. It also feels like ants crawling under my skin and I sometimes get pins and needles in different parts of my body.

I find the best way to send the banding away is to confuse my nerves by putting hot then cold cloths on where it hurts.

I also have a Tens machine I wear to school which helps too. I find when I do too much exercise I can get banding. Is it different for you or the same? Penny x

A COOL FACT ABOUT TM

THE BODY TEMPERATURE OF THOSE WITH TM IS TYPICALLY LOWER THAN A NORMAL PERSON.

Playing ball games in the gym at OTW camp

'Eat your dinner with no hands' challenge at camp

Making an Origami robot with a camp volunteer

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. I was diagnosed with TM when I was 7 years old. I am recovering well, although my bladder is still a pain and I get tired a lot. I love dancing, especially ballet and street dance. My inspiration is Ashley Banjo. TM kids rock!!!

MY TIME AT OTW CAMP

This year me and my family went to the Over the Wall family camp at Tulliallan Castle. It's a camp for families where one of the children has had TM or an illness like TM. When we got there, there was a man dressed up as a chilli pepper with a dragon puppet and we all thought he looked really funny and knew we were going to have such a great time. At the car park we met our two volunteers Jodie and Megan, and they stayed with us all weekend and played with me and my sisters which was great fun. We painted their faces and dressed them up. They taught us camp songs which we sang really really loudly in the lunchroom and everyone joined in. Even my Dad sang one of the songs by himself which was so funny.

At camp there was such a huge selection of activities to do. We did swimming and archery. My sisters, Hattie and Tabitha, went to get their nails painted at the spa and then we all went to the cinema to watch Avengers Assemble and ate loads of popcorn. One day some of the volunteers were challenged to eat their dinner without using their hands, so me and our volunteer Jodie challenged each other to try it too. It was so messy but fun, especially the jelly!!! I loved camp because I shared a room with my Dad and my Mum shared a room with my sisters so we had sleepovers. Also there was really nice food. Also I got to meet up with my friend Penny who has TM as well.

WE LOVED OTW!!!

HOW A BLADDER PACEMAKER CHANGED MY LIFE
BY SUZANNE CARR

Suzanne Carr contracted TM in 1979 at the age of 12. It left her with a weak left leg, foot drop, nerve pain and bladder problems. She now lives happily in Surrey with her two lovely children and a beagle.

In 2012 the urologist at my local hospital had hit a brick wall with my nightmare bladder problems. It had been unresponsive to nearly all the treatments I had been offered over years. Not only did I have chronic retention, my bladder leaked. Sometimes it would empty without any warning and when I tried to self-catheterise, I would get awful bladder spasms. My bladder controlled everything I did.

My urologist suggested I see the Uro-Neurology team at the National Hospital for Neurology and Neurosurgery, Queens Square in London, and a few months later I went to see Dr Suzy Elneil. Dr Elneil thought I was a good candidate for an SMN (bladder pacemaker) and said I had a 62% chance of it working for me. To be honest, whatever she offered I would have said yes; my bladder was ruling my life and I was really depressed.

I was told that the waiting list was over a year, but I really didn't mind waiting. What was another year or so when you have had the problems for 30+ years!

Finally in February 2014 I went in for stage one (I could have had it done before, but I had an operation for a new knee and was recovering from that too). Before I went in I had to complete a diary of the volumes of urine I could empty. The diary included my bowel movements too as the pacemaker can help the bowels.

Stage one is done under general anaesthetic and can take up to two hours to complete. This stage is known as the testing stage. A temporary test electrode (a thin wire) is placed through the skin and alongside the nerves in your lower back or 'tailbone' (sacrum). This is known as a primary Percutaneous Nerve Evaluation (PNE) test. This electrode will stay in place for a period of four weeks. The electrode is then taped on the surface of your skin and connected to a nerve

stimulator- a small device the size of a radio-pager (an external device worn on a belt or clip). The initial test phase checks your response to the stimulator and helps tell whether you would be suitable for this type of treatment or not. The operation was fine and I didn't feel any pain, just a little sore around the opening site.

The following day, I was shown how to use the stimulator and how to disconnect and connect the cable so I could shower. The feeling is really strange. It feels like a small pulling sensation, but not painful and within a few minutes I had forgotten about it. I was given a follow-up appointment for two weeks time to check the device was working.

I was told it could take up to ten days to feel any benefit, but after three days, I was peeing beautifully! Completely emptying and dry! As you can imagine I was over the moon and to add to my excitement I was sleeping all night.

After four weeks of stage one, I was so pleased to be told I could go onto stage two. This is where the leads etc. are attached internally, so there isn't anything visible from the outside of the body. This operation is quick and I was under anaesthetic for around 40 minutes. The next morning I was programmed to a hand device and sent on my merry way!

It has now been three months and everything is going really well. I have been to the hospital for a six week check and they are really happy too. It is so wonderful to be able to empty fully and to be dry. The next step is a six month check and then it's yearly until the battery dies, which is between five to seven years. Once this happens, you go back to have it replaced.

Things you may like to know:

You can get this operation on the NHS (I did). Privately it costs around £25,000.

You can be referred by your GP to the team.

Last year, Dr Elneil's team operated on 136 people.

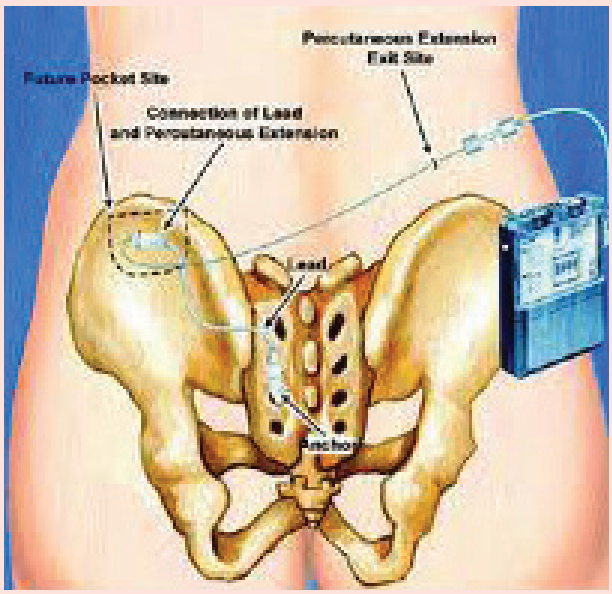
At the time of going to press, Dr Elneil has received funding for fifteen MS/spinal injury patients.

People come for all around the country for this procedure. One lady I met had travelled from Northern Ireland.

It can help with sexual pleasure.

Medtronic makes the device. Lots of information can be found on their website **www.medtronic.co.uk**

Lastly, they discourage skydiving (shame!!!).



THANK YOU
FOR YOUR SUPPORT

Katy O'Leary ran in the Brighton Marathon on 6th April and has so far raised £685 for the TMS. 'My gorgeous niece caught this virus nearly 2 years ago. It paralysed her overnight, just starting from a cough. Sophie spent months in hospital.'

Simon Palmer took part in the Blenheim Palace Triathlon, raising money for the TMS on behalf of his Mother Eileen who contracted TM last year. 'I got up on a Saturday morning and swam 750m across a freezing lake, ran up a hill in a wetsuit, then, at the top, I stripped out of it and jumped on a bike and cycled 19.8km. Finally, for a reason I can't quite understand, I got off my bike and ran 5.7km. Who runs somewhere when they already have a bike? But I did raise more than £830 for the TMS. And, yes, I completed it in 1 hour, 44 minutes and 55 seconds.'

Jacqueline Harris donated the fees she charges people to attend one of her training events. The event was a walk and training event - 'Easy Steps for Handling Difficult People'- in Oxfordshire on 6th June. In addition, she started a 'Just Giving' page for those people who could not attend the event but wanted to make a donation - http://www.justgiving.com/BreathofFreshAir-TMS.

You may be interested to know that a facebook page has been set up for parents, carers and families with children living with TM, ADEM, NMO, ON or DEVIC'S. The hope is to be able to interact and share with other groups for children with these conditions around the world.

www.facebook.com/groups/ParentsofChildrenwithTransverseMyelitis2ADEM3NMO

JOIN US ON facebook

Our facebook page is now up to 840 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.

CINDY MORELLI, COMMITTEE MEMBER

I'm 67 and recently retired. I mainly worked in the IT industry (often as a Project Manager) but more latterly with a ladies fitness centre and plastic recycling! Born in the Midwest of the USA, I grew up outside of Boston, but 'wandered off' in 1969 to go to Africa. I say 'wandered off' because when thinking about it now, it seems a flighty idea and I never got there but ended up in the UK instead! I attended my first Support Group meeting in October 2010 after receiving an email that caught my attention because it said that there would be a speaker on 'balance'. At that same meeting, the Wyboston conference of April 2011 was announced and I volunteered to become part of the team organising it.

Although I was diagnosed with TM in 2001, visible in an MRI scan at T3, my TM had never followed what seemed to be the classic description. For a start, it wasn't monophasic because I had had an episode five years earlier and had ended up in hospital, numb in both legs. On both occasions the onset was over weeks, not a day or two. Then In 2007, I was diagnosed with MS. In hindsight, I think attending the Wyboston conference was useful for me because I met other people with similarly diverse experiences of TM. I also tried a Bioness foot drop device which I now have and use most days.

Following the conference, Yvonne Kolesar, the then Chair, asked me if I would join the Committee and help get a new UK website up and running.

The purpose of the TMS is 'to provide information and support' and for many people, the first port of call for information is the internet. Having a website that gives comprehensive information and support is crucial. Our most frequently visited pages are under the heading 'About TM' and for the 'Newly Diagnosed'. We are also a place to find recent news. We've had 37 News Blogs since going live and we have added half a dozen support groups.

At present, the 'Resources' page is a long list of links to other sites. The plan is to expand this in three ways: (1) add new informational areas (Benefits, FAQs), (2) provide some explanatory pages on managing symptoms (pain, fatigue, continence, depression) and (3) next to every link that goes to another website, write a couple of sentences about what to expect to find there.

> *"The purpose of the TMS is 'to provide information and support' and for many people, the first port of call for information is the internet"*

If anyone wants to help by writing or reviewing some sections (no 'technical know-how' required), please drop me a line at cindy.morelli@myelitis.org.uk.

Apart from doing the TMS website and other activities like the recent spring conferences, I'm a volunteer tutor for self-management UK (previously called Expert Patient Programme). I have an old greyhound called Daisy Belle named after my grandmother. I always tell people that she is my best physio because she needs a walk, rain or shine.

NEWS FROM THE U.K. SUPPORT GROUPS

LONDON SUPPORT GROUP

NEXT SUPPORT GROUP MEETINGS: **SATURDAY 26TH JULY, SATURDAY 25TH OCTOBER, 17TH JANUARY 15 SATURDAY 18TH APRIL – ALL START AT 2.00PM**

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 20TH SEPTEMBER – STARTING 2.00PM**

SUZANNE CARR WILL SPEAK ABOUT HOW A BLADDER PACEMAKER CHANGED HER LIFE

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 or 077888 94648

EXETER SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **SATURDAY 9TH AUGUST 1-3PM**

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 JULY FROM MID-DAY**

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

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 7TH SEPTEMBER 2-4PM**

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.

Venue: The Reception area of the Holiday Inn, north Bristol. Directions are.....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 Steve Collins, steve.collins@blueyonder.co.uk

YORK SUPPORT GROUP

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 4TH OCTOBER 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 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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