



# Transverse Myelitis

S O C I E T Y



**COVER STORY:** THE CHIVENOR  
MILITARY WIVES CHOIR PAGE 3

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## LETTER FROM THE EDITOR



ANNIE SCHOFIELD

**“Above all I see it as a ‘lifestyle’ magazine for those with TM, written by those with TM and associated neurological conditions.”**

### Welcome to the first edition of the TMS Magazine.

I have had TM since 2004 and like many have occasionally felt the isolation of being ‘one in a million’. I set up the South East Support Group in 2010, and it’s been a wonderful way to meet other TMers, but I soon realised that there were many people on my mailing list who for one reason or another couldn’t make it to our meetings. So I started sending out little ‘Newsletters’ to all of those in my catchment area and in return I got lovely e-mails from people telling me how much they enjoyed reading them. Thus the seeds were sown for what you are now reading.

Yvonne, Martin and I got together last July and agreed that a Newsletter for the whole of the U.K. membership would be a good idea. However, what started as a U.K. Newsletter turned into a Magazine when I showed the first draft to my daughter, who said it was far too long for people to read as it was. Well, they always say it’s who you know, not what you know, and she asked her colleague Nakia if she would take on the job of designing our ‘magazine’ as it was to become.

Just because we are a small Charity doesn’t mean we shouldn’t aim big, and just because we have a rare neurological condition doesn’t mean we shouldn’t have a voice. So here is your voice, the first edition of our very own quarterly magazine.

Above all I see it as a ‘lifestyle’ magazine for those with TM, written by those with TM and associated neurological conditions. So I do hope you enjoy reading the uplifting stories from Amy and Suzie, or simply enjoy a giggle at Ruth Wood’s account of life in a wheelchair. This year is very exciting for the Society as we celebrate TM Awareness Day on 9th June. Jo Gilfillan has kindly taken on the role of Co-ordinator and has come up with some terrific fundraising ideas which you will find on Pages 4 and 5. It might seem a long way away, but if you were to do a ‘bring and buy plant sale’ as I am, then you need to be thinking about seeds and cuttings now.

Subjects to be covered in future editions will be dear to the heart of anyone with TM, bladder and bowels problems, chronic fatigue, exercise, nutrition etc. But because this is YOUR Magazine we need your stories to inspire others, as well as your suggestions for content.

We would also welcome your letters – so get writing and between us we can make this Magazine bigger and better.

Please send all your suggestions to me at the following address

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



## A MESSAGE FROM OUR CHAIRMAN

Welcome to this the very first TMS Magazine.

Little did we think in 2004 that we would be bold enough some 7 years later to not only have Support Groups popping up all over the country but now to be setting forth on a new and exciting venture with this our very own lovely Newsletter!

We want you to feel as though this is your publication, and by that I mean we want you to be as involved as possible. Number one, let us know what you'd like to see written in it, or better still, why not your own article? Whether it's an article related to TM, or something more light-hearted, if you enjoy tapping away on your keyboard please don't hold back!

Someone asked me the other day 'what do you do for TMS?' Well, I said it's a long story really - how long have you got? There are some days when it's just a matter of answering a few emails from Committee Members or TMS members. Then again there are those days when I feel as though I have a full time job, when the hours in the day simply aren't long enough.

The job of Chairman of the Society and the London Support Group is without doubt growing like Topsy, there's always something to be done.

**“To my mind, our number one criteria as a Society is to support those who are affected by Transverse Myelitis and as a result I always enjoy these conversations I have with folk who take the trouble to call me.”**

I spend a fair amount of time on the phone to members who, for one reason or another, would like a chat. As we all know, it's not necessarily easy to find or even know someone else who has TM. Unless you have the condition no-one really knows exactly what it's like so if you can empathise you are able to give them a feeling of understanding which they don't necessarily get elsewhere. To my mind, our number one criteria as a Society is to support those who are affected by Transverse Myelitis and as a result I always enjoy these conversations I have with folk who take the trouble to call me. I thoroughly enjoy hearing often remarkable stories and it fuels my interest in TM to hear them.



YVONNE KOLESAR

We are, as I hope you will appreciate, trying to raise Awareness for our little known condition, so don't forget TeaM Awareness Day on June 9th 2012 - of which more later. If we are really to make a difference we need to raise the whole status of the Society for which we ask for your help. The Society is going from strength to strength in its efforts to raise money for all kinds of projects, not least another Conference, supporting new Support Groups and, of course, this Magazine!. So often we hear that the Professionals may know the condition but so rarely appreciate the problems of living with it. So please always remember, the main reason the Society exists is to support one another.

This Magazine is for each and every one of our members and friends of the Society, I would commend it to you, please get involved. Congratulations to Annie and her team for bringing it to us'.

## COVER STORY: THE CHIVENOR MILITARY WIVES CHOIR

THE STORY OF HOW ONE OF OUR MEMBERS FOUND THEMSELVES IN A CHOIR WITH THE CHRISTMAS NO.1 SINGLE

**If someone had told me this time last year that by the end of 2011 I would have sung in front of the Queen, met stars of stage and screen, and be a part of the Christmas No.1 single I would have said you were mad.**

I live a fairly quiet life on a small Royal Marines base in Devon, so when a friend asked if I wanted to join a choir for a TV programme I readily agreed - despite the general knowledge that I was no singer!. So, one cold, chilly night about 40 women converged on the local military church where we were to meet Gareth Malone for the first time. We had been told that our 'Choir' would be broadcast as a three-part series for his BBC 2 called "Military Wives Choir", and our base had been chosen as the men would be away in Afghanistan during the filming.

And so our 'journey' started. We rehearsed about 3 times a week until our first nerve-wracking performance at the end of March in front of 400 service personnel in a draughty hangar, singing 'Sweet Child of Mine' - which surprisingly turned out to be a favourite of Gareth's. This was closely followed by our first 'formal' performance at Barnstaple Pannier Market, where we sang in front of a crowd of 500 onlookers.

Next came Sandhurst Officer Training Academy which was a real privilege as it's very rare that film crews are allowed in. So my evening gown came out of the wardrobe for the first time in 10 years. This time Gareth had changed the music to more classical pieces, and Sam sang a beautiful solo in Latin. I think that's when we realised we were a choir - and we could sing.

Our final (or so we thought) performance was at the Royal Albert Hall, at the British Legion Festival of Remembrance in front of the Royal Family. I did have a fit of the giggles when during rehearsals I looked up and saw the 'Queen', who on closer look turned out to be a body double brought in especially.

**"However our song "Wherever You Are" had captured the hearts of the nation."**

Once filming was complete we assumed that was the end. However our song "Wherever You Are" had captured the hearts of the nation. Written for Gareth and the Choir, by Paul Meador, (composer of a piece for William and Kate's wedding), it's a special song filled with lyrics from letters choir members had written to their partners in Afghanistan. Even the title came from a bracelet one of the Chivenor wives was given by her husband. So, due to public demand, and helped by Chris Evans who

became a huge supporter, Decca decided to record it and release it as a charity single. We spent a day in the recording studio and each section of the choir recorded their bit separately. By the end of the day it was finished and many of us were in tears as we listened to it being played back to us. From then on it was a real roller coaster ride. The Choir was featured on The One Show, Strictly Come Dancing, This Morning, Lorraine, Saturday Kitchen BBC, The Graham Norton Show (where his dog sat on my lap) and in the newspapers! On BBC News I even got my own changing room like the stars, with makeup desk, sofa, TV and even my own bathroom suite.

We sang at the Sun Military Awards, where I got a kiss from Gordon Ramsay, Patsy Palmer wished me luck and Richard Madeley came over to say hi. Oh, and in the front row were David Beckham and Prince William. I definitely seemed to do better than the other women for hellos, so maybe the wheelchair had its advantages.

At a Medals Parade I even met Prince Philip who told me that he and the Queen watched the programme!

Singles were selling so quickly, even some members of the choir were without copies. So when one of the girls phoned our local Sainsbury's to ask them nicely to reserve a copy and the Manager jokingly suggested she pick it up in person with a few other Choir members. Eventually the entire choir performed to a packed out store (who received a phone call from Scotland Yard to discuss the security implications). In just under two hours we sold 1,300 signed CDs. The only signing of my autograph I usually do is my cheque book!

The goal was to make it the Christmas No.1 which was to be announced on Christmas Day, so a number of us agreed to meet up to listen to the charts. Decca phoned half a hour before the official TV countdown to tell us the news that we had won. Selling a single was far above all of our expectations, including Gareth's, let alone going for Christmas No.1. I just can't explain the excitement amongst us the moment we got the call to say we had won. It was hugs, tears and whoops of joy all round. For me personally, it was like being a child again waiting for Christmas day.

As for the future of the choir who knows, all I can do is just enjoy the ride whilst it lasts. As for the husbands of the "Military Wives Choir", well, due to our success they are now being constantly left at home with the kids..... now that is ironic.

Proceeds from the single are going to the Royal British Legion and the Soldiers, Sailors, Airmen and Families Association (SSAFA) charities.

We have received so many kind messages, so a massive thank you from myself and the girls, you can follow us on

**Facebook [www.facebook.com/MilitaryWivesChoir](http://www.facebook.com/MilitaryWivesChoir) and Twitter @milwiveschoir**



TM\_awareness\_UK



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

In this modern age of technology, the Internet has enabled many of us to link up with other sufferers around the world and to have helpful and enlightening discussions about our condition. The next logical and necessary step is to reach the non sufferers who know little about this rare neurological condition. Darlene Mann Robertson of the US has been helping initiate awareness days in various states across the country after her frustration at the lack of knowledge and support after her son was diagnosed in his 20s. She has been encouraging people to share their stories on facebook, and been on national TV talking about the condition and how it affects her son. Inspired by this, I felt that we should have an awareness day in the UK. I suggested this to Yvonne Kolesar at the TMS conference in April, and June 9th was nominated, chosen because this date coincides with the week of the US state days. Last June one of our members Joanne Coleman, let off blue balloons with info about TM attached to them. We also suggested facebook users put a blue ribbon as their profile picture on the day and to share a brief paragraph about what TM is. It was great to see lots of blue ribbons when signing in!

The TMS now has a facebook page named TM Awareness Day UK, solely for promoting awareness, which can be shared amongst all your facebook friends. We want you to share your stories on the facebook page and with local and national newspapers, radio programmes or health magazines. This will

### **“We want to encourage people to hold events for family and friends on and around June 9th”**

enable the condition to be lifted into the spotlight, helping the public understand how TM affects those afflicted by it.

We want to encourage people to hold events for family and friends, on or around 9TH June. The suggested theme is to hold TeaM parties which immediately brings to mind cups of tea, cakes and biscuits. But, it needn't be limited to that so, read on to find out more about what you can do...



**JO GILFILLAN**

**TM AWARENESS DAY CO-ORDINATOR**

## **JUNE 9TH 2012** **TRANSVERSE MYELITIS AWARENESS DAY**

### **OBJECTIVE**

To raise awareness of this debilitating condition through:

1. Ongoing education of family, friends and medical professionals.
2. Activities to raise money and understanding of TM.
3. Press articles covering activities and personal stories.
4. Involving a wider audience via social media networking such as facebook and twitter.

### **HOW**

1. Informing individuals and groups through educational material, letters and personal stories.
2. Holding events such as TeaM parties nationwide for family and friends to attend.
3. Contacting local press, radio and TV to get coverage of these events.
4. Approaching local businesses for donations of prizes for your event.
5. Wearing blue clothing on that day and/or TM clothing you may have.
6. Making blue ribbons to sell for people to wear.





TM\_awareness\_UK



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

### EVENT IDEAS

#### TRANSVERSE MYELITIS AWARENESS DAY

The following ideas are given to help those who are less confident to plan their own awareness raising event. Each event will be unique and every host will choose how to customise their event. Some events may use just one of these ideas, others may use a few. Others may come up with completely different ideas of their own!

- **Bake sales** - you can bake yourself, ask family or friends for help or have a bring and buy sale.
- **Face Painting** - kids love to have their faces painted! Even just a few spots or stripes can be enough to keep children happy.
- **Costume parties** - get your guests to dress in your chosen theme. Guests pay an entry fee then give a prize using some of the money raised to the best dressed. You could charge a "fine" to those not in costume..
- **Clothes swap** - this is a great way of clearing out unwanted clothes! Bring along any clothes you no longer wear/fit into, have a mirror available and you can try on other people's unwanted clothes and get yourself a new item or 2 for your wardrobe! Any leftover clothes can be given to a charity shop.
- **BBQ** - instead of baking cakes, light up the barbie and invite your guests over for a burger!
- **Quiz or trivia night** - challenge your family and friends to get together in pairs or teams. You can charge a fee to enter, sell drinks and snacks.
- **Wine tasting** - a fun way to get adults together. You can get guests to blind taste various types of wine, then after reading some tasting notes identify which are which.
- **Film night** - invite friends to come to your house to watch a movie together, then charge for refreshments or ask for a donation (you cannot "charge" to watch the film because of copyright).
- **Decorate a tea pot and use it for collecting loose change.** You could get your friends to join in and offer a prize to the best design.

- **Open up as a shop for a night.** Ask people to donate unwanted quality goods and play shop.
- **Bring and buy plant sale** - a great way for gardeners to share their cuttings and get new one's.
- **Games night** - charge people to enter board game challenges and see who can be the ultimate winner.
- **Silent auctions.** Ask local businesses to donate prizes and then have a silent auction. Golf clubs, football and rugby clubs, fitness clubs, hair and beauty salons, restaurants and shops are often good places to ask to donate prizes.
- **Book sales** - ask around for used books then sell them at your event.
- **Raffle/tombola** - ask around for donations of prizes among family, friends and local businesses
- **Guess how many..** Sweets in the jar, pennies in the jar.
- **Guess the weight of....** The cake, the book, the pumpkin
- **Name the Teddy**
- **Duck racing** - get some rubber ducks, number them and ask guests to buy a number. You can then race the ducks along a nearby stream or river.
- **Balloons** - let off balloons with TM info attached to them.
- **Who's who?** - have a collection of baby photo's and get people to identify who is who... you can use your family and friends or famous people but you need to make it known who is included.

The activities you choose will be influenced by your age and the type of people you are expecting to attend. Those with young children might choose to include guess the name of the teddy or to have face painting. Adults may like the idea of a spot of wine tasting or a plant sale. This will ultimately be your event and so you can choose to organise it as you wish. The main purpose is to raise awareness of the condition and funds for the TMS.

You can discuss your ideas on the facebook page TM Awareness Day UK or email [tm\\_awareness@yahoo.co.uk](mailto:tm_awareness@yahoo.co.uk)  
Happy planning everyone and we look forward to hearing all your stories of your events!

## AMY EDWARDS CONTRACTED TM AT THE AGE OF 13, THIS IS HER STORY



**I was 13 when I was diagnosed with TM**, which was January 13th 2003 (it's insane to think it was this long ago!). Before this time I was a sporty teenager, who played on the school netball team and was one of those annoying children who actually looked forward to those teambuilding weekends away at 'outward bounds' places.

It seems slightly ironic that my attack of TM started on a Monday morning in P.E. I had been dropped off that morning, totally fine. Whilst playing netball I bent over to pick up a ball and there was this burning pain in my back. I wasn't one of those children who was ever ill or injured (apart from the flu I had a few months earlier my Doctor didn't even really know who I was when my Mum took me in) so the teachers took it pretty seriously when I

**"I WASN'T ONE OF THOSE  
CHILDREN WHO WAS EVER ILL  
OR INJURED."** AMY EDWARDS

told them I was in pain, and rang my Mum to come and collect me. When I got home something didn't feel right, I got out of the car and my legs had pins and needles in them. My Mum was on the phone to the doctors, when I suddenly collapsed, no feeling from the waist down, with a nice emptying of the bladder just to further add to the drama. We still joke to this day about my Mum looking down at me on the floor and saying 'Oh, well I suppose I will have to phone an ambulance then'. I don't think anyone could ever prepare for the shock of your child being fine one minute and then without feeling in her legs the next.

So I was carted off to hospital! After a Doctor in A&E tried to

discharge me (insisting I was lying) I was admitted, and following weeks of tests was diagnosed with TM. During this time I stared at the ceiling for weeks on, yet when I went back for an outpatients appointment I didn't recognise the hospital!

Since my diagnosis I have been left with on-going disability. For six months I was in my wheelchair, but one day (when Mum was out for a few hours) I managed to stand up for the first time. After that I started physio at a local district hospital. I learnt to walk a few steps on parallel bars and by holding on to things, but my tendons had shortened so in 2004 I had an operation to lengthen them. This proved to be a massive setback. I had plaster casts over open wounds for six weeks, but in week 5 my feet started to smell. I was taken back to hospital and when they were removed there were two black holes where the back of my feet had been - MRSA. It took a year in all for my feet to heal, (apparently if I had feeling in them I would have been in agony, but also would have noticed sooner). I had my second op on the 21st December last year to pin the clawing in my toes, I was a bit reluctant, but everything went well and now they don't rub on my shoes.

So, where am I now? My indwelling catheter came out some time in 2004 and until early this year I had managed without, but the infections became too much and so I agreed to self-catheterise. My bowel problems probably get me down the most. It can be difficult being 22 and having to leave your friends on a day out to go and change your clothes. I use a stick to walk as my balance is poor, and I keep damaging my knee from falling, and I use a wheelchair for long distances. But honestly, life is good at the moment. I have the nicest car of all my friends through Motability, and when I went to Florida at 15 they treated me like a VIP. And I never have to queue at Disneyland Paris! I have been sit skiing in Sweden, and have tried wheelchair tennis, though not wheelchair netball yet.

I went back to school 3 months after my TM diagnosis and they wanted to put me back a year, but I was determined and despite going part time and missing school for appointments I got all 9 of my GCSE's (grades A\*-C) with a few A's and even an A\*, got B's in my A levels and went off to Uni. I studied for a Psychology degree and am currently studying for a Master's degree. I hope to study for a PhD in the future and become a researcher to look at TM further. I'm not sure what the future will hold, but I really hope to carry out TM research, as it is so lacking. I have a lovely long term boyfriend (the life partner) and I hope to have children one day, but I know my condition may mean I have to work harder at carrying out day to day tasks when I do. I certainly wouldn't change a thing about my life, TM and all. The only thing I truly miss are the heels! Life doesn't stop, it just has to be carried out in a different way.



## NIAMH'S STORY

## A CHILD WITH NEUROMYELITIS OPTICA

**My daughter Niamh is a feisty and determined ten year old girl. She has a condition called Neuromyelitis Optica, or NMO as we know it. It is a rare demyelinating autoimmune disease which can affect both the optic nerves, causing optic neuritis, which often leads to problems with vision. NMO can also cause longitudinally extensive transverse myelitis (LETM).**

In 2005 at the age of four Niamh developed Optic Neuritis that led overnight to permanent sight loss and she is now registered blind. She subsequently had a further episode a few months later. At this time we were distraught as various diagnosis were made - ADEM, Brain tumour, MS and other rare demyelinating conditions. Then, almost a year after her first sight problems she developed TM. A gradual deterioration in her mobility then ensued, with pain, weakness, dizziness, incontinence, headaches - and sheer terror. Over a few days my already blind child became completely immobile. I was terrified, it was a scene that I had imagined previously after reading up on NMO as a possible diagnosis, and I remember thinking at the time, wow I hope she doesn't get that! We were on holiday at the time in France and immediately returned to the UK, where a diagnosis of NMO was made based on her clinical picture. Blood samples were also sent away to be tested for the NMO antibody that is present in around 70% of people with NMO. The test proved to be positive and a definite diagnosis was made in October 2006. Niamh was treated with steroids, immunosuppressant medication, then intensive rehabilitation. She spent her 5th birthday in hospital being wheeled around in a pram as she was still small enough to fit in one. She made a full recovery from the TM, but had another attack in January 2007. However, she again made a good recovery and has had no further attacks in the five years since.

**“Niamh has had many ups and downs during the past six years but continues to prove to us that she can, and will, do many things.”**

So that leads us to today. Niamh has had many ups and downs during the past six years but continues to prove to us that she can, and will, do many things. We have grieved for all that she has lost but also celebrate each day and all we have gained. Niamh is currently doing really well and attends a mainstream school. She has a 'one to one' support who does an amazing job. She also has full support from the visual impairment team and a



mobility officer. She learns Braille and uses a cane to help with her independence. She is in year 5 at present, so will migrate to high school in 2013, a transition that we are already stressing about! Niamh has just entered a South East Wales research project into demyelinating diseases and has oodles of blood taken each time. She is always willing to try and help others. On a daily basis she suffers lots with pain, pins and needles, fatigue and allodynia (where the most gentle touch or stimulus can cause severe pain). She suffers some horrible side effects due to her immunosuppression medication and we have to try and avoid bugs if possible - not easy when you're ten years old.

I have met some amazing and inspirational people throughout this time. Every day I hope that a cure for TM, NMO and all the other demyelinating diseases out there will be found, but until then we keep up the battle. I am also involved in several support groups, including the Transverse Myelitis Society, and help to maintain a database of kids with demyelinating diseases, so if you not on there get in touch and we can add you. Email [wsuziewms@aol.com](mailto:wsuziewms@aol.com). I also have facebook group [www.facebook.com/paediaticnmo](https://www.facebook.com/paediaticnmo) for Paediatric Nmo Demyelinating Diseases. I am also active in the The Guthy-Jackson Charitable Foundation who can also be found on facebook or at their website [www.guthyjacksonfoundation.org](http://www.guthyjacksonfoundation.org).

I hope to back with further updates on the trials and tribulations of NMO in future issues.

## A LIFE IN THE DAY OF

RUTH WOOD BRINGS HER SENSE OF HUMOUR  
TO THE EVERYDAY LIFE OF SOMEONE WITH TM

So here I am, sitting in the middle of the tools section in B&Q. This is not my preferred place. In fact on a scale of 1 to 10 I would give it about minus 90. But I don't have much choice.

Since I have been in a wheelchair, I have discovered just how very differently men shop as opposed to women. When my carer/chauffeur spots a well stocked tools section, he virtually salivates. In fact, he has all the appearance of a woman in a designer dress shop with the word SALE emblazoned across every rack. I have looked at the drills/screwdrivers/whatever that he is handling with a slightly glazed expression and in the past I have said things like "haven't you got two of those already" and he has said, with a look of incredulity that I could so misunderstand what is going on, "not like this one, no" and I would give up and go and look at the lighting section (I never buy any, I just like to look). Well, that was the past. There's no point saying anything now, partly because he is well over 6 feet tall and I am reduced to the level of a pushchair, but also because he has parked me out of the way and wandered off, so he wouldn't hear me anyway.

Now don't get me wrong. This man has a virtual halo around his lovely head for the way he has been looking after me since I came out of hospital. But I am realising more and more that's it's not so much a question of women come from Venus and men

come from Mars, more a sort of men hunt and gather and buy tools and women do their own thing.

Just before we came in here, we went to a shopping centre – all on the ground floor, disabled toilets (or toilets for the disabled – but it was locked anyway) and every shop only disabled friendly because they can move all the displays that are on wheels. Now I am fairly shy – especially with people I don't know – and even shyer about "making a scene (very "English") – and my preferred method when shopping in a new store is to have a quick gander through the window, decide if they've got the kind of thing I want, suss out how the shop's arranged, then quietly walk in and look around. I never make a fuss and I rarely ask a shop assistant for – well – assistance. What I do not want to do – other than in my worst nightmares – is to be pushed straight into the shop, knocking aside display racks, catching small children on the ankles and forcing the shop assistant to rush over and move all the fittings – even the ones people are looking at. If I had ever wanted this amount of attention I would have found a job jumping out of birthday cakes half naked at all-male parties. But this is

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

what happened in the bag shop. And I can't communicate with my driver because he's way above my head and behind me – and anyway he's deaf and won't wear his hearing aid. The worst bit about all this is that the shop didn't sell what I was looking for anyway – something I would have quickly realised if I'd had time to look through the window. Eventually I made my feelings known (by shouting "they haven't got what I want") and we left.

Of course, another thing about a wheelchair – even the nice one I'm in – is that your feet stick out of the front. My feet are not huge – a narrow size six and a half and quite dainty – but they still jut forward of the footrests. As I found out in Boots when I was pushed straight up to the counter. I know I've not got much feeling in my feet anyway, but it's the principle of the thing.

Having educated my carer/chauffeur in this delicate point, in the next shop he parked me sideways on to the displays.

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

**Traditional medical research has always concentrated on the causes and mechanisms of disease, hoping to prevent or cure it. But research into repair and regeneration has been rare. Since I had TM 27 years ago, my personal interest is no longer in acute treatments. Most of us are far more interested in the after-effects of TM that affect us every day.**

TM is a demyelinating disease as we all know, like its cousins ADEM, NMO, MS and Guillain-Barre Syndrome. So what we all need with these diseases – what we don't have - is remyelination, ie myelin repair. The good news is that the human nervous system is self-repairing. Most of us have experienced some level of recovery from the low point of our TM. So the question is, Why

### **“Cambridge Centre for Myelin Repair has made first-ever breakthrough to understand natural remyelination – with financial backing from UK MS Society.”**

does recovery stop? What makes some people recover more than others? If we could discover how remyelination works, we might be able to improve it.

In 2005 the UK MS Society set up the Cambridge Centre for Myelin Repair with a grant of £1.5m, and recently funding was renewed for a further 5 years with a further £2.1m. The Cambridge Centre is led by Professor Robin Franklin. Franklin defines the problem: “We know that early on in MS the body is relatively good at regenerating damaged myelin. But for reasons that we don't completely understand, as the condition progresses, the body becomes less able to regenerate lost myelin and that's when we start to see the progressive onset of symptoms that affect so many people with MS.” TM of course is much simpler usually: just a single attack, followed by partial remyelination/recovery.

Robin Franklin's Cambridge team work with the Edinburgh Centre for Translational Research. Translational research is the term given to the work of converting basic scientific research into working therapies. The Edinburgh Centre is run by Professor Charles ffrench-Constant (who spoke at our TM Conference in April). It was set up in 2007 by the MS Society with funding from the Volant Trust (author JK Rowling, whose mother died from MS). About a year ago the Cambridge and Edinburgh teams jointly announced the discovery of a key protein known as RXR-gamma. The Cambridge team spent years analysing approximately 22,000 different genes in rat brain cells (oligodendrocyte precursor stem cells) that spontaneously regenerate myelin. They found elevated

levels of this protein during remyelination. Then they confirmed that the same protein was also elevated at active MS lesion sites in human brains from people who died with MS.

Of course this didn't prove that RXR-gamma actually caused remyelination - it might just be an ‘innocent bystander’. So the researchers then ‘knocked down’ the RXR-gamma in a lab dish and observed that oligodendrocyte precursor cells failed in large numbers to become mature oligodendrocytes (which produce myelin). Then they interfered with the RXR-gamma-producing gene in rats and confirmed that the same thing happened in rat lesions.

Finally the researchers needed to test what happened when they increased the level of RXR-gamma. Very fortunately indeed, there is already a drug which does this! Using this drug (called 9-cis retinoic acid), the team were able to demonstrate an increased number of remyelinated axons, both in lab dish culture and also in live rats.

So now there is proof that increasing RXR-gamma levels will increase myelin repair at least in rats, and there is already a drug that can increase RXR-gamma. So what else needs to be done?

The first problem is how to measure myelin repair in humans. As Professor Franklin says, “It's very easy to measure myelin repair in a laboratory model of MS but not as straightforward in people living with the condition. We're hoping to work with researchers around the UK to tackle this very difficult challenge. Then we'll be in a position to test the theories we've developed in a small scale clinical trial.”

At the same time researchers will need to test the drug in laboratory models, to determine a safe and effective dosage and also to devise a delivery method into the central nervous system (brain or spine). This is the translational research.

It is thought that this work will take about 3 years, after which they can run a small ‘phase 1’ clinical trial involving about 20 people with MS, to see if the drug is safe and effective in humans. However the process for testing drugs and getting approval is long and arduous, and Robin Franklin says “If we can show that drugs...can promote myelin repair in people with MS then we should be around 10 or 15 years from a therapy.” So it's not exactly next year!

Since demyelination in MS and TM is the same, it is reasonable to assume that remyelination will work the same way too. So the discovery of RXR-gamma in UK is a major step forward for people with TM too.

Congratulations to all the researchers, now embarking on their second 5-year phase of work. And congratulations to the UK MS Society who has provided the seed money and the continuity of funding required for this major discovery.





I must state quite definitely that I am no expert gardener, but I am very passionate, and as far as I'm concerned there can never be enough plants in my garden - I must drive my poor husband mad.

I can just about manage to walk, with the aid of my trusty garden wheelchair, as far as the raised bed which my son built for me from scaffolding boards. Its 62x154x18", (that's two boards high, lined with builders polythene, then filled with a good top soil and good compost worked into it (I like a granular mix). At that height I can comfortably sit and work from my chair. I am lucky enough to have two greenhouses, both built in Polycarbonate for safety, as I have been left with no balance after TM. The greenhouse is an extension of my home and double doors allow me to get the wheelchair through – the seat laden with my tools, compost and plants, and water for the all important cups of tea. I love music so the radio is on all day (and into evening too if I am feeling well enough to stay that long). My son-in-law is a carpet fitter and he kindly cuts up leftover squares to make mats for me. I can manage to sit cross legged on these and shuffle around, pulling the chair as I go. My grandchildren say 'grandma's playing in the mud again' and

the neighbours call me the little pixie!

My husband and I created a huge rockery from the mound of soil we had left over from our extension. It's my pride and joy, and quite established now, so I am very interested in alpines. I always divide them to create new plants, I just split them with my fingers and re pot them. I also replant in other areas of the garden, and they also look lovely growing over the sides of pots. They can enhance summer planters and baskets too, and I always try to make each pot completely different and unusual.

In the greenhouse at the moment I have geraniums overwintering and lots of cuttings with Polly bags on. Now here's a tip, instead of buying expensive items I using the packaging from food products, yogurt pots with the lids and even lemonade bottles cut in half make excellent mini propagators. I love planting miniature rockeries using the food trays, just pierce drainage holes and fill with the alpines and small stones. They look very effective

**“instead of buying expensive items I using the packaging from food products, yogurt pots with the lids and even lemonade bottles cut in half make excellent mini propagators.”**

Now's the time to start sowing the first seeds of the year. Each autumn I collect as much seed as possible and seal them into envelopes. But I confess I can't resist the plant catalogues which come through the post at this time of year, there's always some 'must have' plant. I always buy plugs which work out at about 2-7 pence a plant, very good value but, be warned, they do need a lot of care and space. With the mild weather we are having so far this year the garden is a couple of weeks ahead, and some of the primroses are already in flower. The soil is even soft enough for me to plant some left over bulbs (which have to be planted quite deeply because the blackbird family dig up everything).

So, after a busy Xmas and New Year I can't wait to get in the garden for some fresh air and some garden therapy.

In the next issue.....Easter Time is one of the busiest and most beautiful times of my gardening year. Keep the cardboard rolls from toilet tissue and kitchen rolls and I'll show you how to use them for sowing your beans and sweet peas.

"I attended my first meeting of the South East Group a year after contracting TM. I met Annie and the rest of the group – and cried through the whole meeting. It was such a relief to sit in a room and see that other people know exactly how you feel without having to explain it to them. Everyone was so open and understanding and my husband was able to talk to other partners, who again understood what he had been going through, and could relate to his concerns and fears. I think he appreciated it just as much, if not more, than me. We still go to the meetings and every time it's like seeing family again, some old faces, some new, but there's a special bond between us all – we've been through the wars but have come through the other side still fighting. We have good days and bad but we are not alone and there is always someone on the end of a phone or email to talk to a share your worries – a problem shared is always a problem halved." Sarah

### THE LONDON SUPPORT GROUP

SUPPORT GROUP MEETING DATES ARE 14TH APRIL, 21ST JULY & 27TH OCTOBER.

We meet on Saturdays at 1.45 for 2pm in time for refreshments before the meeting starts. Generally we have a speaker, but not always, and topics covered have included top Neurologists, Neuro Physiotherapists, a dietician, experts on Orthotics and FES equipment and most recently Mindfulness. At the January meeting our speaker was Betsan Corkhill from 'Stitchlinks' ([www.stitchlinks.com](http://www.stitchlinks.com)) who inspired us all. Tea and cakes are served around 3pm, we then have a forum of conversation.

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

### POOLE/BOURNEMOUTH SUPPORT GROUP

SUPPORT GROUP MEETING DATES ARE 28TH JANUARY, 28TH APRIL, 28TH JULY 27TH OCTOBER.

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

**Venue:** St Georges Church Hall, Oakdale, Poole, Dorset BH15 3EU from 2-4pm. For further details please contact Group Leader: Mary Bergin [maryfairy@myelitis.org](mailto:maryfairy@myelitis.org) or Secretary: Barbara Houston 01425 673173 [barbs@houston19.freemove.co.uk](mailto:barbs@houston19.freemove.co.uk)

### THE BRISTOL SUPPORT GROUP

SUPPORT GROUP MEETING DATES ARE 4TH MARCH.

We meet four times a year. It is only a small group but the meetings last a good couple of hours with plenty of TM chat fuelled by coffee/tea and humour. Varsha Ghandi who used to work at Johns Hopkins in Baltimore USA and now lives in the South West of England, came along in the summer and as you would expect from someone like that no question went un-answered, she was absolutely fantastic.

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

### TRANSVERSE MYELITIS SCOTLAND

**Venue:** Conference Room opp. Day room, Philipshill Ward, Spinal Injuries Unit, Southern General Hospital, 1145 Govan Road, Glasgow G51 4TF. For further details please contact Margaret Shearer tel no. 01292 476758 or email [margaretshearer@myelitis.org](mailto:margaretshearer@myelitis.org)

### THE SOUTH EAST SUPPORT GROUP

SUPPORT GROUP MEETING DATES ARE 17TH MARCH, 23RD JUNE, 15TH SEPTEMBER & 1ST DECEMBER.

We meet on Saturdays at 2pm (door open from 1.30pm) and refreshments are available before we start as some people travel quite a distance. The highlight of 2011 for us was the presentation by Neuro Psychiatrist Dr. Mayur Bodani on 'TM & Depression – cause or effect' which had us all enthralled. For the first meeting of 2012 we will have a Speaker on Pain Management

**Venue:** Pembury Village Hall, High Street, Pembury, Kent TN2 4PH. It is wheelchair friendly with disabled loos. There are 2 disabled parking bays and 10 further parking places outside. Additional parking on the road. For further details contact **Annie Schofield** 01435 864662, [annie.s@spoilyourself.co.uk](mailto:annie.s@spoilyourself.co.uk), **Peggy Hughes** [mail@peggyj.com](mailto:mail@peggyj.com) or **Carol Preece** [preece.carol@googlemail.com](mailto:preece.carol@googlemail.com)

### THE TELFORD /WEST MIDLAND SUPPORT GROUP

SUPPORT GROUP MEETING DATES ARE 19TH APRIL (AGM) 16TH AUGUST 6TH DECEMBER.

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

We aim to have Speakers and make these decisions together as a group. Over the years our Speakers have included Dr P Newman, a pain nurse and a lady from the hypnotherapy group in Telford.

**Venue:** Ketley Community Centre, Holyhead Road, Ketley, Telford, Shropshire, TF1 5AN. The venue is wheelchair friendly with easy access. For further details please phone **Anna Paulsson-Habegger** on 07581708597 or email [annaph@blueyonder.co.uk](mailto:annaph@blueyonder.co.uk) or the website: [sites.google.com/a/myelitis.org.uk/telford-west-midlands/](http://sites.google.com/a/myelitis.org.uk/telford-west-midlands/)

### THE EAST MIDLANDS SUPPORT GROUP

SUPPORT GROUP MEETING DATES ARE 3RD MARCH AND 16TH JUNE.

Meetings are held in March and September from 2pm - 4pm, although the hall is open from 1pm to welcome anyone who has had to travel a distance with a refreshing cuppa! We start with members updating each other on their progress since the last meeting. We also try to have a speaker, usually after our break for home made cakes, tea and coffee. We hope to have a physiotherapist at our March Meeting. We also have an additional meeting this year, in June, when we plan to have a Speaker on the changes in DLA payments.

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

### THE NORTHERN ISLAND SUPPORT GROUP

SUPPORT GROUP MEETING DATES ARE 26TH APRIL 2012 AT 6:30PM.

We usually have sandwiches and tea/coffee on arrival and make time to introduce ourselves. In the past had speakers such as Kerry Mutch..NMO Specialist Nurse from The Waton Centre, Denise Fitzgerald Lecturer and researcher from Queens university and Maria McGrogan, Continence specialist and representative for Coloplast continence products. The group members decided that at the next meeting they just wanted to talk and compare symptom management and treatment with the help of Tony Murphy Volunteer support person for NMO from The Walton centre.

**Venue:** The Dunsilly Hotel in Antrim, Easily accessible via the Motorway, it is also wheelchair friendly. We aim to finish by around 9.00pm. For any further details please contact **Eileen Bradley** [ebtm@hotmail.co.uk](mailto:ebtm@hotmail.co.uk) or 02829557114.



## USEFUL CONTACT DETAILS

**Bladder & Bowel Foundation**

0845 345 0165

[www.bladderandbowelfoundation.org](http://www.bladderandbowelfoundation.org)**Brain & Spine Foundation**

0808 808 1000

[www.brainandspine.org.uk](http://www.brainandspine.org.uk)**Carers Direct**

0808 802 0202

[www.nhs.uk/carersdirect](http://www.nhs.uk/carersdirect)**Carers: The Princess Royal Trust**

0844 800 4361

[www.carers.org](http://www.carers.org)**Continence Foundation**[www.continence-foundation.org.uk](http://www.continence-foundation.org.uk)[info@continence-foundation.org.uk](mailto:info@continence-foundation.org.uk)**Depression Alliance**

0845 123 2320

[www.depressionalliance.org](http://www.depressionalliance.org)**Disability Information****Advice Line (DIAL)**

01302 310 123

[www.dialuk.info](http://www.dialuk.info)**Disability Law Service**

0207 791 9800

[www.dls.org.uk](http://www.dls.org.uk)**Disabled Living Foundation**

0845 130 9177

[www.dlf.org.uk](http://www.dlf.org.uk)**Disability Now Magazine**

01454 642 444

[www.disabiltynow.org.uk](http://www.disabiltynow.org.uk)**Driving: Disabled Motoring UK**

01508 489 449

[www.disabledmotoring.org](http://www.disabledmotoring.org)**Driving Licences:****DVLA Drivers Medical Unit**

0870 600 0301

**Mobility aids: Just Mobility**

01923 265 577

[www.justmobility.co.uk](http://www.justmobility.co.uk)**Motability Car Scheme**

0845 456 4566

[www.motability.co.uk](http://www.motability.co.uk)**Neuromyelitis Optica (NMO)****[Formerly Devics Disease]**[www.nmouk.nhs.uk](http://www.nmouk.nhs.uk)**NMO: The Walton Centre, Liverpool****Nurse Specialist**

0151 529 8357

**NMO Service Coordinator**

0151 529 8131

[nmo.advice@thewaltoncentre.nhs.uk](mailto:nmo.advice@thewaltoncentre.nhs.uk)**NMO: John Radcliffe Hospital, Oxford****Nurse Specialist**

01865 231 905

**NMO Service Coordinator**

01865 231 900

[nmo.advice@orh.nhs.uk](mailto:nmo.advice@orh.nhs.uk)**Pain Concern**

0300 123 0789

[www.painconcern.org](http://www.painconcern.org)**Pain: British Pain society**

0207 269 7840

[www.britishpainsociety.org](http://www.britishpainsociety.org)**Welfare & Disability Benefits  
(Dept. of Work and Pensions)**

0800 882 200

[www.dwp.gov.uk](http://www.dwp.gov.uk)**Transverse Myelitis Society**

35 Avenue Road

Brentford TW8 9NS

[www.myelitis.org.uk](http://www.myelitis.org.uk)

U.K. registered charity 1108179

Contact Yvonne Kolesar

(chair) 01737 552869 or

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