

## **2013 Priorities**

Based on some feedback from support group leaders and members, the following have been identified as the priorities the TM Society Committee is working towards in 2013.

### **Communicate better with Support Groups and assist them to support more TMS members.**

- A need was identified for enhanced communication between the Committee and Support Group Leaders. Sally Rodohan has taken on the role to be the Committee's liaison with Support Group Leaders.

### **Initiate new Support Groups in those areas of the country where there aren't any.**

- The Northwest, Northeast, Manchester area, East Anglia, and Wales (as examples) have no support groups. We would love to support members to start groups in those areas.
- Rob Reeves is starting a support group in Exeter in June/July.

### **Improve our communication with TMS members, so everyone feels they have a voice.**

- The 'message from the Chairman' page in the TMS magazine will be converted to a 'committee news' page where the committee can update members regarding progress on priorities, introduce new initiatives and highlight member feedback on existing initiatives, invite people to submit their thoughts and feedback, and introduce committee members so people know who is representing them.
- The new website has a news/blog section. In time, we would like to invite members to contribute to the blog.

### **Go live with the new TMS website, which supports our priorities on communication.**

- Expect to go live end of April 2013.

### **Separate management of the London Support Group from the TMS Committee.**

- As of April 2013, this has been achieved. Yvonne Kolesar stepped down as chairman of the TM Society and is the Support Group Leader for the London Support Group.

### **Organise TM Conference or Mini-Conference for 2013 or 2014, and/or Kids Camp for members aged 8-17 in 2014.**

- We have made contact with an organisation that organises kids camps and we will start exploring the possibility of organising one in the UK.
- We have been in touch with neurologists from Project Restore at Johns Hopkins University about exploring the possibility of them coming to the UK for mini-conferences in the north and south of the country. It would also be our intention to invite UK neurologists.

### **Extend Neuro-Physiotherapy Bursary scheme nationally for all members and recruit more neuro-physio therapists to join our network.**

- Neurological physiotherapy (also referred to as neuro physiotherapy and neuro-physio), is the physiotherapy treatment of individuals whose body movement patterns have been affected as a result of a brain injury, spinal injury or the onset of a neurological illness/condition (TM, ADEM, NMO, ON, stroke, Multiple Sclerosis, Parkinson's disease, etc). Neuro-physio can enhance or maximise your functional ability, reduce discomfort, and teach you how to work with your condition, giving you a sense of control and enhancing your physical and emotional wellbeing.
- A pilot neuro-physiotherapy bursary was offered to TM Society members in the London area. A neuro-physio bursary included two neuro-physiotherapy appointments. Early feedback from people who have taken part indicated that the neuro-physio has been incredibly helpful and highly recommend it to our

members. The neuro-physio has helped people improve their balance, gait and that it has made a positive difference to how they manage their TM. The TM Society Committee would very much like to roll the neuro-physio bursary scheme on a national basis. To do this, we need your assistance in identifying neuro-physios in your area.

**Continue collaboration with the Transverse Myelitis Association encourage our members to become members of it.**

### **The future**

The following is a vision of what the Transverse Myelitis Society can be doing and would like to see happening in the UK in the future. This is not an exhaustive list. It is a starting point. This will not be achieved overnight. We are an all-volunteer charity that relies on the goodwill of people donating their time freely and on the donations of members, friends, families and organisations who believe in the work we do. So every year, the members of the TM Society Committee will take a step-by-step approach to achieving this.

**Continue to professionalise the inner workings of the TM Society. This is often the behind-the-scenes procedures and processes our members do not see**

**Continue enhancing communications with support group leaders and our members**

**Have support groups all around the country, particularly in those areas where there are a lot of members**

### **Raising awareness particularly among**

- GPs, physiotherapists, neurologists and other healthcare professionals to enable quicker diagnosis, treatment, and rehabilitation.
- Among charity networks such as Neuro Alliance, of which the TM Society is a member. This is an opportunity for charities to learn from one another and make the TM Society even more known.
- Among the general public, there is at least a 'I've heard that before' recognition of terms like TM, ADEM and NMO (much like the recognition that MS has).

**The TM Society has an advisory board of healthcare professionals**

### **Increased emotional/psychological support for members and their families**

- Coaching, Mentoring, Counselling, Psychotherapy

**Have another conference**

### **Bigger scale fundraising**

- To enable research

### **Fund research**

- We have funded research in the past. Could we do more? Bigger scale fundraising is required to make this happen.