

2014 Priorities

Based on feedback from support group leaders and members, the following have been identified as the priorities the TM Society Committee will be working towards in 2014 (and has already started doing so). These are not in any particular order. In addition to feedback received, these priorities have been selected based on the availability of expertise, time and funds, and the likely impact they may have for the majority of members. Also, this is a plan; sometimes unforeseen events can happen, which may require work on any of these priorities to be put on hold or extended into the following year.

Improving communication with Support Groups and expansion of our Support Group network

- This was a priority in 2013 and continues to be one due to the
 - Support Groups being a very important activity of the TM Society and
 - The growth of the number of Support Groups in the UK.
- Improving communication with Support Groups so the Support Group Leaders and members feel they knew what is going on regarding the TMS Committee's activities and have a voice.
 - Support Group Leaders have been made aware of when TMS Committee meetings are taking place so they can request items to be discussed.
 - Support Group Leaders will receive progress updates regarding priorities throughout the year from the Chair.
 - Each Support Group will be visited by a TMS Committee member once a year (at a time suitable for the Support Group).
- We have experienced a surge in interest amongst our members to start new support groups. The TMS Committee and Support Group Leaders have been supporting our members' efforts in this regard throughout 2013 and into 2014.
- Start a dialogue with Support Group Leaders and Support Groups on how else the TM Society can support the Support Groups. For example, would the design and organisation of a 'Managing Your TM/ADEM/NMO', similar in concept to the Expert Patient Programme, be seen as a need and hence welcomed?
- More information on our support groups can be found via <http://supportgroups.myelitis.org.uk/>

Launch Neuro-Physiotherapy Bursary scheme nationally for all members (adults and children)

- 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.
- The bursary consists of two free physiotherapy sessions, an assessment and a follow-up session. You will learn what you can do for yourself at home on an ongoing basis to maintain the benefits from the two sessions.
- This scheme has been launched and for information on taking part in the scheme, please go to <http://www.myelitis.org.uk/tm-and-physiotherapy.html>

Conduct a pilot neuro-physiotherapy workshop for members (adults and children)

- A pilot neuro-physiotherapy workshop will take place in London on 29 March 2014. It will consist of 30 minute 1-1 appointments for individuals who
 - would like to try neuro-physiotherapy can do so, or
 - have taken part in the neuro-physiotherapy bursary scheme and would like a top-up session.

- If successful, this scheme can be expanded nationally.

Assess the feasibility of enhancing the skills of NHS physiotherapists to treat TM, ADEM, NMO

TM Family Weekend in Summer 2015

- The TM Society has booked 10-13 July 2015 for a fun weekend for children aged with TM, ADEM, and NMO and their families at the Calvert Trust in the Lake District - <http://www.calvert-trust.org.uk/lake-district/introduction>

Schedule conferences for members

- Two 1 day conferences are scheduled to take place on May 3 in Liverpool at the Walton Centre and May 17 at John Radcliffe in Oxford. These events are an opportunity for our members to learn the latest thinking with regards to rehabilitation, living with TM and research from leading neurologists and health care professionals in the UK.
- A decision will be taken later in the year on whether or not to hold a weekend residential conference in 2015. In order to run a weekend conference in 2015, we need members with experience of organising conferences and events to come forward and form a sub-committee to organise the conference.

When the parents of children with TM/ADEM/NMO become members of the TM Society, a committee member will proactively reach out to them to understand their needs and how we can best help

Increase the emotional/psychological support for members and their families

- The TM Society joined up with the Backup Trust in late 2013 to make its mentoring scheme available to TM Society members. For more information on this scheme, refer to the article in Issue 6, Winter 2013/2014 of the magazine - <http://www.myelitis.org.uk/the-tms-magazine.html>
- A Coaching Bursary will be made available to members later in 2014. For more information on the coaching bursary, refer to Issue 7, Spring 2014 of the magazine - <http://www.myelitis.org.uk/the-tms-magazine.html>

Create Condition Insight Reports for ADEM and NMO for use by companies that assess people with these conditions for the Personal Independence Payment in the United Kingdom

- A Condition Insight Report for Transverse Myelitis was created in 2013.

Determine an approach for distributing funds to member requests for financial assistance

Fundraising

- Develop knowledge of recommended do's and don't's regarding fundraising for the TM Society, support groups and fundraisers.
- Diversify fundraising streams to enable greater fundraising for larger projects the TM Society wants to do (such as weekend conferences, TM Family Weekend, funding research).

Fund research

- The TM Society will seek to fund research into TM/ADEM/NMO whether that research is taking place in the UK, USA or elsewhere. (As of February 2014, the TM Society is not aware of research into TM/ADEM/NMO that has received approval to take place in the UK).

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

- In 2014, this will entail a review of the TM Society's constitution to ensure it is fit for purpose for now and into the future.
- Develop an agreed approach to governance.
- Expand use of sub-committees consisting of members to progress the work required for these priorities (specifically for a weekend conference and TM Family Weekend).

We continue collaboration with the Transverse Myelitis Association and encourage our members to become members of it. – www.myelitis.org

Members of the TMS Committee continue to represent the TM Society among charity networks such as Neurological Alliance and National Voices and the All Party Parliamentary Group for Spinal Cord Injury. This is an opportunity for charities to learn from one another, collaborate and raise awareness of the TM Society, TM, ADEM, NMO, and the needs of our members.

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. The good news is that a number of items that were on this list in 2013 are now on the priority list for 2014.

Raising awareness

- Prior to starting any awareness campaigns on a national level, we need to determine what we mean by 'awareness' and specifically what we want it to achieve. The next steps would be to determine how this would best be achieved; what could best be achieved on the local level via members and Support Groups and what on the national level via the committee of the TM Society.
- Our members have an awareness pack containing information on the ways they can raise awareness in their local communities on an ongoing basis in addition to what they already do for the TM Awareness Day (writing to their MPs regarding the issues they experience living with TM/ADEM/NMO, becoming involved in local NHS initiatives, etc.).
- GPs, physiotherapists, neurologists and other healthcare professionals to enable quicker diagnosis, treatment, and rehabilitation.
- 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).

Initiate research and centres of excellence for TM and ADEM in the UK

- Two NMO centres already exist in the UK at the Walton Centre in Liverpool and the John Radcliffe Hospital in Oxford.

The TM Society has an advisory board of healthcare professionals

Increase the emotional/psychological support for members and their families

- Assess the feasibility of offering a counselling/psychotherapy scheme in 2015.