

The Transverse Myelitis Society provides information, support and advice to people living with TM, ADEM, NMO, their family, friends and carers; raises awareness of the public and medical professions of these conditions; and contributes to research initiatives.

At the start of every year the TM Society's committee proactively sets priorities to focus its work and the 2015 priorities are outlined here. The criteria which influence the Committee's decisions included what was already scheduled to take place (for example, the conference and TMS Family Weekend), the output from the member survey conducted in November 2014, current skillset of committee members, time available, complexity of projects, extent of project's impact, and likely cost. Some priorities were also started towards the end of 2014 and so continue into 2015.

These priorities are in addition to what the TMS Committee already does day-to-day to run the charity such as (but not only) welcoming new members, maintaining the website, financial administration, responding to member queries, managing social media channels, supporting research initiatives (the STRIVE clinical trial for example), representing members' needs among charity networks such as the Neurological Alliance and National Voices, and campaigning with the government and NHS for improved treatment and care.

Priorities marked with 'volunteer opportunity' mean that members are encouraged to get involved to help make them happen. Contact Barbara Babcock at barbara.babcock@myelitis.org.uk for more information if you are interested in helping.

Many of the priorities are actual services available to members. More information about these services and how to access them are available via the [Our Services](#) page on the website.

Neuro-physiotherapy Bursary Schemes

To provide members (adults and children) access to neuro-physiotherapy so they can learn what they can do for themselves on an ongoing basis to maintain the benefits from the sessions over the longer-term.

The scheme will continue as it has in the past where a member can receive 2 sessions of neuro-physiotherapy free of charge. The budget for this in 2015 is £10,000.

There are also two additions to the scheme in 2015

- Provide members who have taken part in the scheme in previous years to have 1 top up session in 2015 (an annual reassessment) as long as they took part in the scheme in 2014 and they have not had physiotherapy for 6 months. The budget for this in 2015 is £3,500.
- Children scheme - To provide ongoing neuro-physiotherapy for children to enable them to reach specific milestones in their rehabilitation. The budget for this is £10,000 in 2015 and the maximum spend per child is £3,000.

Equipment Grant Scheme

To provide funding for equipment which is not provided by statutory services and would aid members' rehabilitation, ability to self-care, and/or independence. The budget for this is £8,000 in 2015.

Coaching Bursary

To enable people living with TM/ADEM/NMO and carers to access low-cost and high quality emotional and psychological support to help them adjust to living with TM/ADEM/NMO's impact, resolve any issues they are experiencing or make positive changes in their lives. The budget for this in 2015 is £2,000.

AGM & 1 day Conference - 7th March 2015

Hold an annual member event, which is educational and provides an opportunity for people to meet others living with TM/ADEM/NMO. The budget for this event is £18,000.

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

Hold an event for children with TM/ADEM/NMO, their siblings and parents which provides the opportunity to learn about and achieve one's potential through challenging and adventurous outdoor activities; and to provide educational sessions for the parents with medical and healthcare experts. The budget for this event is £29,500 and the TM Society is aiming to cover this through specific fundraising campaigns.

Support & Support Groups

The Support Groups have historically been a key mechanism by which support is given to members and we have been finding ways to support the establishment of new groups and the development of existing groups. This was a priority in 2013 and 2014 and continues to be one due to the growth in support groups in recent years. The budget for this priority in 2015 is £5,180.

We also appreciate that not everyone can or wants to attend a support group so we are looking at other ways support can be provided. To do this we are building on the ideas members gave us from the survey conducted in November 2014.

Talking Matters Groups

- Members consistently say they wish to meet others living with TM/ADEM/NMO in their local area and when they do they remark on how beneficial it is. This priority is about piloting 2-3 one-off meetings in those areas where there are a high concentration of members but no support groups.
- VOLUNTEER OPPORTUNITY – Help will be needed locally to organise meetings.

Telephone Support Line

- Determine whether providing a telephone support line staffed by member volunteers to answer questions from the patient-experience perspective is feasible to do, i.e. time to develop and run a support line, do we have people interested in volunteering, cost and training required.

Produce information which answers members' questions and can also be used by Support Groups

- Produce information about TM/ADEM/NMO and symptom management to enable members to become knowledgeable about their condition so as to manage the impact; signpost where members can obtain benefits advice.
- VOLUNTEER OPPORTUNITY – Help is needed to produce information.
- Create a how to self-management course 'Managing Your TM/ADEM/NMO'.

Fundraising

To fund its activities, the TMS has historically been 100% reliant on individuals, many of whom are members, conducting fundraising activities and making donations. They have been so generous; it is because of what they do that enables us to do what we do. To ensure that we can keep offering services and activities year to year, we will conduct fundraising campaigns to fund the TMS Family Weekend and ensure a consistent level of general funds. The TMS Fundraising Campaign will be a 'behind the scenes' campaign where the TM Society is making applications to trusts and foundations. The two other campaigns are:

- Supporting the TM Society's runner in the 2015 London Marathon. Our runner is raising monies for the TMS Family Weekend. This is the opportunity where members can get involved in raising money for this activity.
- The 10th Anniversary 10 for 10 campaign which is seeking to raise monies for the TM Society's general funds to ensure we can continue offering the services we do into the future.

Due to receiving more questions from fundraisers on how to fundraise and requests for official posters and leaflets for their fundraising events, we will develop a how-to fundraising guide and a fundraising pack consisting of posters, leaflets and other relevant documents to support our fundraisers. We will also review the fundraising section of the website and Just Giving and Virgin Money pages to ensure the information is complete.

- VOLUNTEER OPPORTUNITY – Help is needed to liaise with and support fundraisers.

The budget for this in 2015 is £1,800.

Governance

Continue to professionalise the TMS's working practices to keep pace with growth and ensure they align to governance principles. This includes things like ensuring we have checked whether certain volunteers need to be DBS checked (criminal record checked), deciding whether to incorporate would benefit the charity, ensuring transparency in how we operate, and ensuring that practices align to good practice. The budget for this in 2015 is £2,500.

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