
2016 Priorities

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 2016 priorities are outlined here. The priorities are like projects that are new or have only been in operation for a year or so. The criteria which influence the Committee's decisions in setting the priorities include a balance between successes of new initiatives in the previous year, member feedback, resource requirements (skills, people's time, costs), complexity of projects, and extent of project's impact. If a previous year's priority was not fully achieved and is still considered important, it continues into the next year.

These priorities are in addition to what the TMS Committee and volunteers already do day-to-day to run the charity. A sample of these activities include: welcoming new members, responding to member queries, maintaining the website, financial administration, managing social media channels, publishing online magazine, supporting the Support Groups, supporting fundraisers, supporting research activities (STRIVE, NMO trials, upcoming UTI study), representing members' needs externally (i.e. Neurological Alliance, National Voices, etc.), and administering the Neuro-physiotherapy Bursary Schemes (Adults, Children, Top-up schemes), Equipment Grant Scheme, Coaching Bursary Scheme, and Travel Bursary Scheme.

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

Support & Support Groups

To provide various forms of support and information for members. This priority started in 2015 and will continue into 2016.

Talking Matters Groups - £500

- Members consistently say they wish to meet others living with TM, ADEM and NMO in their local area and when they do they remark on how beneficial it is. We would like to proactively pilot 2-3 Talking Matters Groups, which are one-off meetings in locations where there are a lot of members but no support groups.
 - Identify via post code mapping the top five areas where there are members but no support groups by the event. Do the first TM group by late spring/early summer. Use the event as an opportunity to find out if there is anyone from any of the areas where a TM group will be held who would like to assist in organising the meeting.

New & Existing Support Groups

- £1,000 has been budgeted for meetings.
- Use the member conference to generate interest in starting a support group and raise awareness of how to run one effectively.
- Determine and implement strategy for support groups that have not met for at least one year.

Membership lists – No costs are foreseen.

- Identify how membership lists can be easily accessed, understood and used by Support Group Leaders and Committee Members.
- Identify how members can identify and self-maintain their preferences on the information they receive from the TM Society.

Telephone Support Line - £25,000

- Decide whether to establish a telephone support line and if yes, next steps. A preliminary feasibility study was carried out on offering a telephone helpline. A more in depth one will be carried out to determine actual costs and work required to establish and maintain one. Sufficient budget has been set in the event the TM Society decides it is feasible to establish a helpline.

Produce information which answers the questions and meets the support needs of members and which can also be used by Support Groups

- Create a self-management course to deliver in-house - £500 is budgeted for a pilot.
- Publish the Frequently Asked Questions documents – No costs are foreseen
- Redesign Resources page on website – No costs are foreseen

TM Society Family Weekend - 8-11 July 2016 at the Calvert Trust in the Lake District

Due to the success of last year's inaugural TMS Family Weekend, the TM Society will hold it again in 2016. Three parents are organising it. The weekend is for children with TM, ADEM, NMO, ON and AFM, their siblings and parents. It provides the opportunity to learn about and achieve one's potential through challenging and adventurous outdoor activities. Educational sessions for the parents with medical and healthcare experts will also be provided. The budget is £25,000.

2016 members' event alongside AGM

Hold a weekend member event in Spring 2016. It will provide an opportunity for members to meet others living with TM and related conditions and will take a support group format and a variety of topics will be addressed. The budget for this event is £25,000.

TM Awareness Day on 9th June 2016 & Fundraising

Continue previous year's activities of offering awareness packs, engaging with members and the public on social media (Facebook and Twitter), and emailing members. The budget is £1,100 for balloons, pens, posters, info leaflets, which is used as part of fundraising/awareness packs.

Campaigning/Advocacy

These initiatives started in 2015 and will continue through 2016. Represent the TM Society at

- TM International Working Group regarding the diagnostic criteria for TM. The budget for this is £2,000.
- Meetings to develop NICE Guidelines for Assessment, Diagnosis and Referral for Neurological Conditions (NHS England). These meetings take place in London and NICE reimburses travel costs.

Non-medicinal Pain Management Bursary

Offer a non-medicinal pain management bursary scheme to members who have received little treatment for their pain or have exhausted all available conventional treatment routes. - £2,000

Neuro-psychology Assessment for Children

Offer to those children whose behaviour and/or development has been impacted by their condition. - £3,000

Educating health care professionals (HCPs)

To provide healthcare professionals, including those who are supporter members of the TM Society, an opportunity to expand their skillset in treating people living with TM and related conditions.

- Pilot a travel bursary for neuro-physiotherapists to attend Birkdale's FES course in Spring. - £2,000
- Pilot running a course specifically for member supporters who are physiotherapists. - £5,000
- Follow up requests from HCPs who attended the SIA study days in 2015 to have a presentation on TM and the work of the TM Society in their hospitals. £1,000 is budgeted for travel.

Governance

Obtain advice re appropriate safeguarding practices appropriate for the size of the TM Society, ensure relevant policies are in place, and training is provided to relevant committee members and volunteers. This will include understanding if any roles require to be DBS checked. - £2,500

Budget for other services and activities

As mentioned on page 1, the following services and activities are available for members and but as they are not new schemes, they aren't priorities. However, we list them here to show you what has been budgeted for each. More information on each scheme can be found on the website under [About us/Our services](#).

Neuro-physiotherapy Bursary Schemes

- Adults Scheme – £10,000
 - To provide adult members who have had little or no neuro-physiotherapy since being diagnosed with TM or a related conditions two free sessions of neuro-physiotherapy. The aim is to equip members with the knowledge and skills to maintain the benefits from the two sessions over the longer term.
 - To provide adult members who have taken part in the neuro-physiotherapy scheme previously an annual assessment session.
- Children's Scheme - £10,000
 - Where ongoing neuro-physiotherapy will help a child's rehabilitation from TM or a related condition, this scheme aims to provide up to £3,000 in a calendar year per child.

Equipment Grant Scheme - £8,000

- To enable members to access funding for equipment which is not offered by statutory services and would aid in their rehabilitation, ability to self-care, maintain or increase their independence, or enhance quality of life. The grants are given to members on a first come first served basis, to a value of 50% of the equipment cost up to a maximum of £1,000.

Coaching Bursary Scheme - £3,000

- Aims to provide high quality cost effective coaching to enable TM Society members to find ways to live well with the impact of the condition they or a loved one have. The scheme is for members aged 18+.

Travel Bursary Scheme - £1,500

- To enable members to attend at least one support group meeting, the Transverse Myelitis Association's Kids Camp, or travel for specialised treatment.

Donation to research - £5,000

- An amount has been set aside to donate to any new or existing research projects.

Publish magazine three times per year including printing one issue - £3,000

Operations/Overheads - £2,500