



The Transverse Myelitis Association

www.myelitis.org

Welcome New TMA Member! We are pleased that you have found the TMA. Transverse Myelitis is a rare neurological disorder that is part of a spectrum of neuroimmunologic diseases of the central nervous system. Other disorders in this spectrum include:

- Acute Disseminated Encephalomyelitis (ADEM)
- Devic's Disease or Neuromyelitis Optica (NMO)
- Optic Neuritis
- Recurrent TM

The membership of the TMA includes persons with all of these disorders, their family members and caregivers and the medical professionals who treat people with these disorders. The TMA was established in 1994 as an organization dedicated to advocacy for those who have these rare neuroimmunologic diseases.

There are no membership fees; we operate almost exclusively on the basis of voluntary contributions. The TMA has over 6800 members in more than 80 countries around the world. The TMA facilitates support and networking opportunities amongst families; provides educational information and opportunities for persons with rare neuroimmunologic disorders and their families and the medical community; investigates, advocates for and supports research and innovative treatment efforts; and promotes public awareness of the rare neuroimmunologic disorders of the central nervous system.

We have enclosed materials that will provide you with information about TM and about the TMA. All this information - and much more - is available on the TMA website www.myelitis.org. You will find medical and scientific articles, bulletin boards by topic and also h, video presentations from our Conferences, past issues of TMA Journals and Newsletters, Support Group information, fundraising information and much more – all searchable by entering key words.

All UK members (over 900 now) are automatically voting members of the TM Society, a UK registered charity. If you are interested to meet others with TM in face to face, use the enclosed leaflet to contact the Scotland Support Group by contacting Margaret Shearer by email, phone or post (details on enclosed leaflet). The UK section of the TMA website is at www.myelitis.org.uk

You are not alone. Our best wishes to you and your family.

Sanford J Siegel
President ssiegel@myelitis.org

Transverse Myelitis Scotland Support Group

Welcome New Member!

The TM Scotland Support Group is responsible for welcoming new members in Scotland, and distributing TMA Journals and Newsletters. We do this mainly by email, although we also photocopy and post TMA Newsletters, for people with no access to internet.

Like the worldwide TMA, we are a 100% voluntary organisation, with no paid staff and no membership fees, reliant 100% on donations from members and families. If you want to help us sponsor TM research and provide TM support, you can easily donate on our website using a credit card, PayPal or Google Checkout.

TMA Website and Resources

When you go to www.myelitis.org you can click on the Scotland flag at the top of the home page, to go to the Scotland section of the website. Please let us know if you think these pages can be improved or other UK information should be linked, for the benefit of all UK members. Remarks below are a guide to the main (US) TMA website.

Many articles 'About TM' are available on our website www.myelitis.org/abouttm.htm I attach more detail of these articles below in the next section. Obviously some members will be more interested in the 'About ADEM', 'About Optic Neuritis' and 'About Devic's Disease' pages instead, if you have those conditions.

The clearest and most recent article, for *primary care* doctors and therapists but not neurologists, is A Primary Care Guide to Transverse Myelitis. If you want this article in English now (7 pages), click on http://www.myelitis.org/articles/Primary_MD_Guide_article.pdf If you don't have internet access, please write me at 26 Lichtenfels Gardens, Prestwick KA9 1EP, Scotland, confirm your address and I will post you a copy of this article.

If you click on 'Message Forums' on the homepage, and then go to the bottom of the TMA Forum page, under 'Europe' you will find message forums especially for UK and Scotland. If you click on 'Newsletters' you will find a complete archive of TMA Journals and Newsletters. These publications include all our medical and scientific articles, but also interesting accounts of individuals with TM called 'In Their Own Words.' When you click on a Newsletter or Journal in the archive, a Table of Contents will be displayed. A sample Table of Contents is attached at the end of this document.

You can also search the TMA website by entering a search word like 'pregabalin' on the home page at top left.

The most rapidly expanding part of the TMA website is video. If you have a broadband internet connection, you can view the world's leading experts talking on topics like Neuropathic Pain, Stem Cell Research etc.

Meeting Others With TM

The best way to meet others with TM is at a regional Support Group. These Groups have been very valuable for members here. It is both interesting and useful to meet other people with TM face to face, because we all must become 'experts' to cope with TM. If you want to see what the regional Support Groups are doing, go to www.myelitis.org.uk/ukmeetings.htm

If you click on 'Support Groups' on the main (US) TMA website, you will find a list of other web-based groups on Yahoo and Facebook, and also links to special-interest groups (ADEM, NMO/Devic's) and TM Support Groups in other countries.

If you have ADEM or NMO, or you are the parent of a CHILD with TM, please be aware there are special lists to make it easy for these people to contact each other. Email me at the address below if you would like assistance.

Developments in UK for TMers – Second Opinion, Advice and Assistance, Research

A successful first-ever UK TM Conference in 2007 was held in London for members coming to hear Dr Doug Kerr (from Johns Hopkins University in USA) speak and answer questions. Dr Doug Kerr then came to Glasgow, presented his slides and answered questions given by members. Another very successful Conference was held in April 2011. All the Conference slides are available on www.myelitis.org.uk as are some very useful Q&A documents from Dr Kerr, based on questions that UK members had for him, these can be seen on the Scotland Pages as well.

In 2008 Dr Anu Jacob at the Walton Centre, Liverpool, set up the *first-ever* UK specialised clinic for TM, NMO etc, called Atypical Demyelinating Diseases (A.D.D.) Clinic, held fortnightly see www.thewaltoncentre.nhs.uk If you live in the Northwest and want a neurologist *specialising* in TM/NMO/ADEM/ON, or if you want a *second opinion*, your GP can refer you to Dr Jacob from anywhere in the UK.

Best wishes,

Margaret Shearer

Chairperson

TM Scotland Support Group

margaretshearer@myelitis.org

(Recurrent TM since 2002)

Further Information Available About TM

All of the articles listed below are available from the TMA website in the 'About TM' page www.myelitis.org/abouttm.htm

Most computers already have Adobe Reader, to read .pdf documents. However if you have any difficulty reading the articles, contact me at margaretshearer@myelitis.org.

For any member who does not have internet access, I will print off and post a copy of any article. Please write me at Margaret Shearer, 26 Lichtenfels Gardens, Prestwick, KA9 1EP, Scotland, UK, confirm your postal address and tell me which articles you want.

For Primary Care Doctors (GPs) and Other Medical Personnel and Therapists (2007)

The clearest and most recent article (2007), for *primary care* doctors and therapists but not neurologists, is A Primary Care Guide to Transverse Myelitis (7 pages), written by a US doctor who has TM herself, working with a top neurologist from Johns Hopkins. There is a very brief summary (Article at a Glance) on page 4. Go to http://www.myelitis.org/articles/Primary_MD_Guide_article.pdf

Introduction to TM Symptoms, Causes, and Diagnosis for TMA Members – by Dr Lynn

This is our original introduction to TM, very brief and clear. Go to <http://www.myelitis.org/tm.htm>

Introduction to Rehabilitation (Recovering and Living with TM) – by Dr Levy

Although written in 1997, this article is still very useful. It addresses the emotional and psychological impact of recovering from TM, and gives good general guidance on rehabilitation including bladder problems, sex, spasticity and pain. Go to <http://www.myelitis.org/treatment.htm>

There are several other useful articles about particular TM symptoms on the About TM page of the website, at the bottom of the list of documents. Frequently Asked Questions and Answers is a good starting point. There are also articles about Urological Problems, Sexuality, Spasticity, Depression and Chronic Pain.

A Brief Update on TM for TMA Members – from Johns Hopkins TM Center (2006)

This article is from TMA Journal Volume 2 April 2007, originally published in Current Neurology and Neuroscience Reports 2006, and is very brief. It summarises the work of the TM Center at Johns Hopkins University in Baltimore USA (led by Dr Doug Kerr). The JHTMC saw 356 TM patients between 2002 and 2005. 64% were idiopathic TM. The risk of recurrence is discussed with warning signs. The importance of diagnosing and treating depression is emphasized. Acute treatments are listed, together with some novel treatments being tested at JHTMC. This article can be found at <http://www.myelitis.org/newsletters/journal-2-12.htm>

For Neurologists: Current Therapy in Neurologic Disease – Dr Kerr's chapter on TM (2001)

Dr Kerr is the world's leading expert on TM and the author of many medical articles. This article is a chapter on TM, from a recent 'popular therapy book' which concentrates on

therapeutic solutions. Because this article is short, with just over 3 pages of text, many members will be able to read and understand it. The chapter covers both the acute phase treatments and also chronic treatments for all the main symptoms eg pain, bladder problems etc (see page 3). There are two very clear charts on page 5 (diagnosis and treatment of TM) and page 6 (*chronic* management of TM, agenda for rehabilitation) which are particularly useful. Go to <http://www.scribd.com/doc/2581918/KerrCurrent-therapy-chapter-with-figures>

For Neurologists: TM: Pathogenesis, Diagnosis and Treatment (Frontiers in Bioscience,2004)

This is probably the most complete article on TM for neurologists (17 pages). There is a useful table of contents on page 1, so you can read sections of the article easily, such as sections on recurrent TM (6.2) and prognosis (6.3). There is much more detail on diagnosing TM, distinguishing it from other conditions, and treating TM in the acute phase. Section 8.4 covers Long Term Management. Table 6 Early Rehabilitation Principles (weeks to months) and Table 7 Late Rehabilitation Principles (months to years) are especially useful. Go to <http://www.scribd.com/doc/2581845/Frontiers-in-Bioscience-review-article>

More Medical Articles on TM for Neurologists

Two other 2002 articles are available for neurologists on the 'About TM' of the TMA website.

Members of the TMA Medical Advisory Board and others interested in improving diagnosis of TM, so treatment could be offered more quickly, formed the Transverse Myelitis Consortium Working Group. The TMCWG wrote an article entitled Proposed Diagnostic Criteria and Nosology of Acute Transverse Myelitis. This article is only 7 pages. Dr Kerr co-authored the other article entitled Immunopathogenesis of Transverse Myelitis. This article is 9 pages long.