

## Questions from TMS members for Dr Kerr - October 2007

(with Dr. Kerr's replies in **bold** under each question)

### Clinical Questions (for Dr Kerr) – causes and treatments etc

1. A member in Germany was told by her doctor that medications for osteoporosis - Biphosphonate and/or Parathyrin (Parathormone) we think but not sure - are contra-indicated for someone with TM. The member's osteoporosis is very bad and she wants to know if this is correct.

**No. people who are non weight bearing have increased risk of osteoporosis (thinning of the bones). If somebody has osteoporosis and even if he/she is at risk for it, treatments are warranted. Treatment options include calcitonin, bisphosphonates, vitamin D and others. Everybody with reduced weightbearing should be on at least calcium and vitamin D.**

2. With my cervical TM, I was never offered corticosteroid therapy and I have not made a full recovery. I understand that the prognosis for TM is generally that 1/3 of cases have a complete recovery, 1/3 a partial recovery and the remainder do not improve. Are these figures based on patients who have all been treated with corticosteroids? If so, then have any figures been compiled for untreated cases and if so, how does the outcome compare?

**The 1/3-1/3-1/3 data comes from patients not treated. We believe that patients treated in the acute phase with corticosteroids have a better than 1/3 chance of a complete recovery. But some not treated will do well and some treated will do badly. It's not a perfect therapy.**

3. (The above question was submitted by a member who is attending the Conference. She has another complex question below about pathogenesis of TM, which may be too complex for open session: 'Re. pathogenesis - The initial symptoms of my cervical TM included a burning sensation at the back of my head. The only other person that I know with TM described similar symptoms and his lesion was thoracic. I was told that my subsequent parietal lobe dysfunction could not be associated with TM because any concurrent pathology would have been catastrophic ie. I would have been comatose, which I was not and lesser consequences in this area of the CNS just do not occur and that the only damage is at the level of the TM site and below. One possible explanation for the distal spread of effects of TM is that there is progressively deeper penetration of the inflammation to towards the centre of each spinal tract. Another possible explanation is that the inflammation spreads to affect regions of the CNS above and below the initial site. Do you believe that the inflammation is really as localised as has been suggested?')

**Cervical scalp pain is common at the onset of TM and is triggered by cervical spine inflammation. Nerves from the cervical spine go to the scalp over the back of the head. Increased pain in regions of nerves becoming inflamed by TM is common.**

4. Has any research been done to establish a link between childhood vaccinations and TM? I got TM after my BCG (tuberculosis) vaccination at age 12 – I believe this vaccination has now been stopped. Are other (adult) vaccinations linked with TM? We have other members who believe they got TM as a result of hepatitis vaccinations. Flu vaccinations are recommended for older people in UK, but many members have asked whether having had TM, the flu vaccination might be more dangerous for them than the general population.

**We have not seen a link between TM and adult vaccinations. We have looked hard. In children, it's even harder since kids are more likely to get vaccines and kids are more likely to get TM. Unless somebody has had TM as a direct consequence of a vaccination, I recommend that they get vaccines as the consequence of getting the infection the vaccine was designed to prevent can be fatal.**

5. From a member who couldn't attend: 'Can TM progress slowly over years, as I think mine has done? Originally I was diagnosed with [hydromyelia \(fluid in the spinal cord due to abnormal widening\)](#) in 2001, which caused tremendous pain. Then in 2005 they did a lumbar puncture and found high levels of protein and oligoclonal bands and I was re-diagnosed with TM in addition. Does hydromyelia make TM worse?'

**Hydromyelia is not related to TM. TM does not progress over years.**

6. From another member with Devic's Disease who can't attend (Dorset): 'Can TM be hereditary? My 21-year-old son lost the use of his legs one night in late July. MRI and LP were both clear, but a virus or TM is suspected.'

**TM is almost never hereditary. It is clearly a sporadic autoimmune disorder. We have rarely, if ever, seen it run in families. Same thing with NMO (Devic's disease). MS is a bit hereditary, meaning that if somebody has MS in the family, a first degree relative has a few percent chance of getting MS.**

7. Does Johns Hopkins use the Mayo Clinic NMO-IgG blood test for all patients with Longitudinally Extensive TM (more than 3 spinal segments)? If the result comes back positive, does this affect your treatment of the patient – do you always treat him/her with immunosuppressant drugs? Do you have doubts about the claimed accuracy (70%) of the blood test?

**Yes. If it comes back positive, I think the risk of recurrence is high and I would treat before that recurrence. I think the test is fairly sensitive in that it**

**detects about 70% of true NMO patients. But it only is positive in 30% of LETM patients. I have other doubts about the role of the antibody in NMO...**

8. Does Johns Hopkins use the drug fampridine regularly to treat people with TM? How is it used? Are you satisfied with the result? My neurologist at Charing Cross Hospital says they don't use it in UK because 'We don't think it works.'

**Yes, sometimes. 4-AP (fampridine) works to allow damaged nerves to function better. Recent data says it is effective in MS in reducing symptoms and improving function. In patients with incomplete damage it can be helpful.**

9. Does Johns Hopkins use chemotherapy treatment in extreme cases of TM? We have heard of this being used at Hope Hospital Manchester but we believe it has potentially fatal side effects.

**Yes, definitely. Sometimes, cyclophosphamide or rituximab or plasma exchange (all used for cancer) can be very effective therapies for TM and we use them routinely.**

10. From another member who can't attend: 'Many operations today are expected to be conducted under spinal anaesthesia. Is this a good idea for people with TM?'

**I have no reason to think there is any reason NOT to do spinal anesthesia.**

11. We have seen cases of TM which affect people who have previously suffered spinal cord trauma, sometimes many years previously. Is there any evidence of a causal relationship between spinal trauma and TM?

**No definitive proof, but we think that trauma may alter how the nervous system 'looks' to the immune system and increases the ability of the immune system to gain access to the nervous system and therefore, may be linked to TM.**

#### Research Questions (for Dr Kerr and Prof Vincent)

12. We read about the discovery of cytokine IL-6 in TMA Journal last year, which was proven to cause TM. What further research has ensued, to translate this breakthrough into practical treatments for TM? What is planned for the future?

**More work to define it's importance in prognosticating outcomes from TM. Ultimately, we'd like this to be a test of how bad the TM is and will ask the FDA to approve it as a test.**

13. In this week's London newspaper an article appeared about a new discovery at the Mayo Clinic, of a one-time injection of human antibody that accelerate myelin repair. This breakthrough is to be presented at the American Neurological Association meeting in Washington DC this week (Prof A Warrington). Preparations for human trials are underway and a treatment might be developed 'within years'. Do you agree this is a breakthrough? Will Johns Hopkins try to apply it to TMs?

**Very early days. Too early to tell. Human clinical trials will begin in a year or two. But it is clear that the idea of remyelination is here to stay and will be important.**

14. The UK MS Society is backing Prof. Scolding's research using bone marrow stem cells – apparently human trials have been in progress for 6 months already. Is similar research going on in US? Do you think simple injections of large quantities (one pint) of bone marrow stem cells will result in remyelination?

**No, but these cells may do other things: they may quiet the immune system, they may allow repair to occur. They may be beneficial. But most importantly, they are unlikely to be harmful. So, full speed ahead.**

#### Rehabilitation/Symptom Questions

15. I have heard good things from other TMS members, about the new continence treatment of botox injections to the bladder. But I wonder about possible side effects, and long-term outcomes. Is this treatment used in the USA, and what is their experience?

**We don't use it that much. It is used occasionally and can be effective and with few side effects. But there are other therapies.**

16. Does the USA do a better job than UK of managing aftercare for TM patients? Here in UK after intravenous steroids, one is released with 14 days of oral steroids to a neuro-physio, for a short course of physio. After that, any future assistance is up to the GP who has probably never seen a case of TM before. Family and friends fill in the gaps. I was fortunate enough to get my GP to refer me to Queens Square for a proper rehabilitation (re-)assessment and programme – but that was sheer luck.

**Yes, I think so. Rehab is a priority. Patients almost always go to inpatient rehab followed by outpatient rehab. It is critical in my opinion. The more physio the better.**

17. Is it usual (expected) that TM symptoms will be worse for women, around the time of menstruation?

**Yes, because any increase in body temperature worsens symptoms. So, just before the onset of menstruation and ovulation, symptoms may be worse.**

18. Many TMers have intractable neuropathic pain. There seems to be some inconsistency in UK, where to turn to seek treatment for this. Some members get treatment from their neurologists, others from GPs. Some TMers get referred to specialist pain clinics but most do not. With neuro-rehabilitation services being moved out into the Community, the question arises whether Community Rehab departments are responsible and/or qualified to deal with neuropathic pain.

**Big question. Very important. But hard for me to comment on UK situation.**

19. Can Dr Kerr please explain whether Spinal Cord Implant surgery is used for TM in cases of untreatable pain? How successful has this treatment been? How big are the risks of surgery?

**Yes, occasionally we will use dorsal column stimulator or intrathecal anti-spasticity meds for intractable pain or spasticity, respectively. In tough cases, it can be a life saver. But it should be reserved for very late cases.**

20. From Italian member: I had TM attack in March 2007. Fortunately in one month I recovered motor function but I still have troubles with sexual, bladder and intestinal functions. I was treated with cyclophosphamide. I wonder what are my chances to recover sexual functionality? According to your TM experience, should I consider catheterisation or electro-stimulation for my voiding urinary problems?

**Talk to me about this. In general, sexual function is the last to come back. Takes at least a year. Before then, I wouldn't do electrostim or anything although Viagra or its cousins may be effective in some cases for men or women.**