

Research into TM and NMO (2009)

(Please note this brief summary is a personal view from UK, and has not been reviewed by medical professionals, nor endorsed by the TM Association or TM Society.)

Research at Johns Hopkins, Baltimore MD USA

Dr Doug Kerr founded the world's first Transverse Myelitis Center at Johns Hopkins University in Baltimore USA in 1999. The JHTMC combines multidisciplinary clinical work with research, and this has proved very fruitful. Also Dr Kerr and his colleagues have realised that MS, TM, ADEM, NMO and ON all have similar triggers, mechanisms and symptoms. So it makes sense to study them all together.

In 2004 Johns Hopkins merged their MS and TM clinical and research work into a new Project Restore. You can find out about Project Restore at http://www.hopkinsmedicine.org/neurology_neurosurgery/specialty_areas/project_restore/about_us/ (and subscribe to their e-newsletter if you like).

The Transverse Myelitis Association is a big backer of Project Restore, and Sandy Siegel the TMA President is a member of the Project Restore Board. The UK TM Society and several individual UK members are also active backers of Project Restore. (If you would like to contribute to Project Restore as an individual, and get UK Gift Aid and tax relief, contact TM Society for details how to do this.) Here is a short document from Project Restore (January 2010) entitled A Five-Year Research Summary <http://www.myelitis.org/ProjRestore5YearReportJan2010.pdf>

Dr Kerr visited London for the first UK TM Conference in October 2007, and his presentation slides from London provide a good introduction to TM research <http://www.myelitis.org.uk/2007Conference/KerrConfSlidesOct07.pdf>

More recently, Dr Kerr also summarised the history of TM research and a 'roadmap' to a cure for TM, at the 2008 Rare Neuroimmunologic Disorders Symposium (RNDS) in Seattle. This is a very brief and user-friendly summary, and both video and slides are available on the TMA website (Thursday, July 17th 2008, The RNDS Community: Past, Present and Future) at <http://www.myelitis.org/rnds2008/index.htm>

Probably the most important breakthrough at the JHTMC has been the discovery of an immune system protein (IL-6), which is not only a 'marker' for TM but has also been proven to *cause* TM in animals. JHTMC has identified IL-6 as part of a 'cascade' of immune system proteins, a chain reaction which culminates in the demyelinating TM attack on the spinal cord. Analysis of this cascade opens the way to find drugs which may interfere with the chain reaction, such as thalidomide, erythropoietin (EPO), statins etc.

Also JHTMC has proven that the level of IL-6 found in CSF is a reliable indicator of the eventual degree of disability in TM patients. A diagnostic test

of IL-6 would therefore allow neurologists to identify the worst cases of TM early and therefore use more expensive and dangerous techniques (eg plasma exchange, high-dose cytoxan) than IV steroids which is currently the standard treatment. JHTMC has also pioneered and documented 'High Cy' treatment for steroid-resistant TM cases.

Research at the Mayo Clinic, Minnesota USA

The Mayo Clinic in Minnesota USA is another major centre for neurological research. Dr Weinschenker at Mayo published evidence of the effectiveness of plasma exchange for TM in 1999, although in UK this treatment is generally used only for ADEM and NMO.

The Mayo Clinic has also published a series of breakthroughs in the study of NMO (Devic's Disease) and Recurrent TM in the last few years, including a blood test which is now recommended for all patients with recurring TM and the discovery of the cell-level mechanism by which NMO attacks the spine and optic nerve.

Research in UK at Walton Centre Liverpool

Dr Anu Jacob of the Walton Centre in Liverpool UK has been studying NMO and Recurrent TM since 2004. In 2006-07 Dr Jacob spent a year at Mayo Clinic researching NMO treatments. On his return to UK in 2007 Dr Jacob started the first-ever clinic in UK specialising in Atypical Demyelinating Diseases (TM,ADEM,NMO,ON,CRION etc).

Currently (2009) Dr Jacob is engaged in a clinical review of 200 TM cases at the Walton Centre, which will yield important evidence about recurrence, recovery, symptoms, effectiveness of treatments etc. This research is being funded by the UK TM Society.

Research into Multiple Sclerosis – also relevant to TM

MS research is a very high priority in universities and medical schools around the world. Since the demyelinating mechanism of MS appears very similar to TM and other rarer disorders, there is a high degree of 'crossover' from MS research to understanding and treatments for TM,ADEM,NMO etc.

Stem cell therapies and neuroprotective therapies for MS, which deal with the after-effects and repair of demyelination (remyelination), are even more likely to be applicable to all demyelinating conditions including MS, TM,ADEM,NMO etc. A great deal of research effort is going into these areas. The UK MS Society website provides further information about this research which is very relevant to TM, at <http://www.mssociety.org.uk/research/index.html>

Stem Cell Research

Almost certainly stem cells will be the ultimate 'cure' for TM and other demyelinating diseases including MS. Stem cells can be used to produce new myelin cells, which could re-ensheath nerves damaged by demyelinating diseases such as TM and MS.

For a good introduction to the different types of stem cells and the promise and pitfalls of stem cell research, you should view Dr Kerr's video from the 2008 Symposium at <http://www.myelitis.org/forum/viewtopic.php?f=11&t=3225>

Dr Kerr has already proven that embryonic stem cells can generate motor neuron recovery in rats in 2006. As the film above outlines, two different types of stem cells are now (2009) waiting for FDA approval for human trials in US.

In UK Prof Neil Scolding at Bristol (supported by UK MS Society and The Myelin Project) has started human trials using patients' own adult stem cells from bone marrow.

Stem cell 'therapies' are being offered in China, Ukraine and several other countries, but none of these have any proven evidence of success.

In the past two years in a major breakthrough, scientists have discovered a way to manipulate genes in our own adult skin cells, to transform them 'back' to embryonic-type 'pluripotent' stem cells. This means that the patient's own cells can be used for stem cell therapy, minimising the risk of rejection and also removing the moral objection which many people had regarding the use of embryonic stem cells from IVF fertility treatments.

The UK Medical Research Council (with backing from JK Rowling whose mother had MS) has established a new Centre for Regenerative Medicine at the University of Edinburgh. There are over 100 teams in UK working on stem cell research see <http://www.telegraph.co.uk/technology/5232182/The-miracle-stem-cell-cures-made-in-Britain.html>

In May 2009 the UK MS Society organised a Stem Cell Consensus Meeting in London, bringing together two dozen of the leading stem cell researchers from around the world (including Dr Kerr who flew to London for the meeting). The objective was to agree a Consensus Statement about the potential of various stem cell therapies, to resolve the widespread confusion of people with MS, TM and related conditions. As soon as the Consensus Statement is published I will update TM Society members with the information.

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UK TM Society