



# The Transverse Myelitis Association

[www.myelitis.org](http://www.myelitis.org)



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Hello. I'm Peter Jacobson. I am writing because I have an important request to make of you that will significantly impact you and your loved ones for the rest of your lives.

I play Dr. Chris Taub on the television medical drama House. As Dr. Taub, I am a member of a crack diagnostic team that works to identify various mysterious illnesses that appear in our medical center. There could be no more mysterious or difficult disorders to diagnose than acute disseminated encephalomyelitis, neuromyelitis optica, optic neuritis and transverse myelitis. These are very rare auto-immune disorders that impact the central nervous system. For reasons not yet understood, the person's immune system does something it is not supposed to do; it attacks the brain, the spinal cord or the optic nerves. Medical science understands very little about these disorders.

No one hears about these disorders until they or a loved one is given a diagnosis of ADEM, NMO, ON or TM. The incidence of TM is about 1 in a million. There are only about 1,400 new cases of TM every year in the United States. The geographic distribution almost appears random. What this means is that big city hospitals see a few cases of these disorders every year and many small community hospitals see none at all.

We've likely spent more time on House talking about these disorders than most medical schools devote to presenting these disorders to their medical students. These disorders are often misdiagnosed or the diagnosis takes a long period of time because of this lack of training and experience. Most unfortunately, the best chance a person has for any recovery depends on a rapid diagnosis and the initiation of acute treatments to quiet down the immune system. The longer the immune system has to attack, the greater the likelihood that permanent and irreparable damage will be done.

These disorders can leave a person paralyzed or blind or unable to breathe on their own. Some people have a good recovery after their attack, while others experience no recovery at all. With some of these disorders, there is a risk for multiple attacks, and a person must be placed on a long term therapy of immune suppressants to help keep the immune system from initiating subsequent attacks.

The cells that make up the nervous system do not heal themselves the way other cells, such as bone or muscle, are able to do. The healing process is far less efficient or effective. As a result, if permanent damage is caused by the immune attack, the symptoms from these disorders can become permanent as well. The common symptoms from these disorders include muscle weakness or paralysis, difficult nerve sensations or nerve pain, spasticity, bowel and bladder dysfunction.

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tion, sexual dysfunction, fatigue, cognitive dysfunction and depression. People with optic neuritis can experience significant vision problems and eye pain. Medical science does not know how to repair the brain, the optic nerve or the spinal cord.

Children as young as 4 to 6 months old get these disorders. Many children are paralyzed before they've even had a chance in life to take their first step. People can be diagnosed with one of these disorders into their 70s and 80s. Both males and females can get these disorders and people are diagnosed from every country and continent.

Like many of you, I became involved in The Transverse Myelitis Association when a family member was diagnosed with one of these rare neuroimmunologic disorders.

The TMA is a grass roots advocacy organization for people who have these disorders and their family members. Their more than 8,500 members come from every state in the United States and from more than 80 countries around the world. The TMA provides information and support to its members through a wonderful website and publications, by sponsoring education programs, by encouraging support networks and by sponsoring summer camps for children with these disorders and their families. The TMA also supports important research efforts on these disorders. And the TMA does not charge membership fees.

One of the most important TMA programs is the James T. Lubin Fellowship Fund. This fellowship was established in honor of Jim Lubin, an officer and board member of the TMA since its inception. Jim was diagnosed with TM when he was just 21 years old. He experienced no recovery from the attack high in his spinal cord and has been a full quadriplegic and ventilator dependent for more than 20 years.

There is no greater need in our community than the provision of medical care by neurologists who have experience and expertise in these rare disorders. There is also a critical need to foster the development of scientists who are interested in these disorders. The fellowship will fund a one or two year study program for a physician completing their neurology residency. The fellow would work under a mentor who has a specialization in one of the rare neuroimmunologic disorders. Upon the completion of the program, the fellow would commit to a specialization in these disorders that would include both clinical care and research.

- ◆ There have been no clinical trials or scientific evidence to guide acute treatments for these rare disorders.
- ◆ There are no biomarkers for TM, ADEM and ON; the diagnoses remain a challenge and take too long when time translates into the possibility of greater damage to the spinal cord, brain or optic nerves.
- ◆ There have been no clinical trials or scientific evidence to guide long term therapies for the recurrent types of these disorders.
- ◆ There have been no clinical trials to guide the management of the difficult symptoms from these disorders.
- ◆ As there has been very little research, decisions about treatment are based on expert judgment; and there are not nearly enough experts in this discipline. There are only two TM Centers of Excellence in the world. There are no centers of excellence in ADEM.
- ◆ Research is desperately needed on restorative therapies to heal the spinal cord, brain and optic nerves after permanent damage has been done to the central nervous system.

We are the only ones who can change and improve this situation. By donating to the Fellowship Program, you can directly influence the growth of the number of scientists doing research on these disorders and the number of physicians caring for you and your loved ones. There is no Center of Excellence in these disorders in New York, Los Angeles, Chicago, Paris, London, Toronto or Melbourne. More than any other program the TMA has initiated, the James T. Lubin Fellowship in Rare Neuro-immunologic Disorders represents the most significant investment in all of our futures.

Please make a donation to the TMA for the purpose of funding the James T. Lubin Fellowship and then please make your contributions a regular part of your generous giving. What more pressing or critical issue do you have in your own life or in your child's life than to assure that you or they have the best medical care available and that there are researchers who are interested in understanding TM, NMO, ADEM and ON.

We urge you to make a tax deductible donation by using the enclosed envelope or you can make an electronic donation from the TMA web site. Be sure to indicate on the check that your donation is for the James T. Lubin Fellowship Program.

I hope to be able to make a difference for the wonderful people in this community by raising awareness of these disorders, by helping to raise the funds needed to ensure that people receive the best medical care possible and to support the much needed research to better understand these disorders.

Thank you so much for your support.

A handwritten signature in black ink, appearing to read "Peter Jacobson". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Peter Jacobson