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Mayo Clinic Neurologist Reports: “Thousands of NMO Patients are Misdiagnosed with Multiple Sclerosis”

Groundbreaking Conference for Rare Neurological Disease – Neuromyelitis Optica (NMO) – Brings Together World’s Top Doctors, Medical Researchers and Patients in Pursuit of a Cure

Los Angeles (Nov. 11, 2009) — Thousands of [Neuromyelitis Optica \(NMO\)](#) patients are potentially being misdiagnosed with Multiple Sclerosis (MS), according to Mayo Clinic Neurologist Sean Pittock, M.D., largely due to lack of awareness of NMO within the medical community. Dr. Pittock shared this finding with more than 50 of the world’s leading doctors and medical researchers – from Harvard to Oxford – who gathered at the 2009 NMO Roundtable Conference, sponsored by the [Guthy-Jackson Charitable Foundation](#).

NMO is a rare and debilitating disease that attacks the optic nerves and spinal cord, often causing vision loss, paralysis of legs and arms, and sensory disturbances. The [Guthy-Jackson Charitable Foundation](#) has brought together these researchers to help find a cure for this rare disease.

Dr. Pittock came to his conclusion based on ongoing research at the Mayo Clinic. Of the 1,200 blood samples that are sent to Mayo Clinic’s neuroimmunology laboratory for NMO antibody (NMO-IgG) testing each month, approximately 70 new patients test positive for NMO, which is surprisingly high considering it is believed to be a rare disease. Of the 70 patients who have the NMO antibody, Dr. Pittock has found that a majority were previously thought to have MS.

Making the distinction between MS and NMO has been greatly assisted by Mayo Clinic’s recent discovery of this NMO antibody. In fact, this is the first biomarker that has shown to be sensitive and specific for any central nervous system (CNS), inflammatory demyelinating disease.

“It’s important to differentiate NMO from MS as these disorders are treated differently,” says Dr. Pittock. “The identification of this novel antibody marker will hopefully assist neurologists in making a correct diagnosis of NMO, rather than MS.”

Dr. Pittock believes that part of the reason for the lack of awareness of NMO is that there was no biomarker until recently, and traditionally, NMO was considered by many in the medical and research

communities to be a form of MS, a difficult disease to diagnose. Recent clinical and pathological studies now support the concept that NMO is a distinct disease from MS.

“It’s important for the neurologists to be aware that NMO is associated with symptoms other than optic neuritis and transverse myelitis. NMO patients can have intractable hiccups, nausea, vomiting as well as problems with thermoregulation,” says Bruce Cree, M.D., Ph.D., M.C.R. of the University of California San Francisco Multiple Sclerosis Center. “It is important to test for presence of the anti-aquaporin 4 antibody, in the setting of neurological illness presenting with these symptoms as well as optic neuritis and myelitis, even in patients who have abnormal brain MRI findings. Some of these abnormalities can appear to be identical to those seen in MS, whereas others are more distinct of NMO.”

At the conference, Mayo Clinic Neurologist Dean Wingerchuk, M.D., also reported that the prevalence and incidence of NMO have not been firmly established. Based on current data, in aggregate, it suggests that there are likely more than 4,000 people with NMO in the United States.

That is why the [Guthy-Jackson Charitable Foundation](#) is launching a significant medical education campaign to ensure that doctors nationwide are aware of the differences between MS and NMO. Doing so will help patients get the appropriate treatments and will help more researchers collect the best data in their pursuit of a cure.

Cosmetics trailblazer Victoria Jackson established the foundation in July 2008, one month after her daughter’s diagnosis. The foundation’s approach is to provide bureaucracy-free funding to researchers willing to share data to help find a cure.

“I am on this mission for my daughter, and for the thousands of other families who have seen their world turned upside down by NMO,” says Jackson. “Through our work at the foundation, more and more, we are hearing from NMO patients who have been previously diagnosed with MS.”

While the first two days of the conference focused on research, the third day will take an emotional turn. Today, the conference, for the first time, will host a patient session dedicated to those affected by NMO, enabling them to engage in a dialogue with the medical community and to share personal stories with others affected by the same disease. Most of the patients will be meeting other people diagnosed with NMO for the first time.

Patients who attend the conference also will be enrolled in the newly-established Guthy-Jackson Repository for NMO to collect much-needed blood samples. This innovative repository is critical to future research.

“For me, this has been a very lonely journey. NMO needed a voice and a face to make it real for the rest of the world. It has that now,” says Candace Coffee, a young woman who was diagnosed more than six years ago. “Those of us struggling everyday with NMO, feeling the weight of its effect on our lives, finally have an advocate.”

About The [Guthy-Jackson Charitable Foundation](#)

The [Guthy-Jackson Charitable Foundation](#) is dedicated to funding basic science research to find answers that will lead to the prevention, clinical treatments and an eventual cure for Neuromyelitis Optica (NMO) Spectrum Disease (also known as Devic’s Disease), a rare neurological disease that is often misdiagnosed as Multiple Sclerosis (MS). Founded by Bill Guthy and Victoria Jackson in July 2008, the

Foundation was established shortly after their daughter was diagnosed with NMO. The Foundation is committed to funding research to understand the pathophysiology and biochemistry of NMO, providing an online community for those diagnosed with NMO as well as centralized information resources for individuals who want to learn more about this rare disease. Since its inception, it has started and funded eight NMO research projects at top medical research institutions in the United States, hosted an annual NMO dedicated medical conference and set up an NMO repository to collect much-needed blood samples for continued research. For more information, please visit www.guthyjacksonfoundation.org.

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