

“Rare orphan conditions are going to illuminate and change the way we think about medicine...and cures.”

—Victoria Jackson, Founder  
The Guthy-Jackson Charitable Foundation



## Dr. OZ Interview with Victoria Jackson

**Victoria Jackson sits down with Dr. Mehmet Oz to discuss neuromyelitis optica on the Dr. Oz Radio Show.**

*Excerpt transcribed from Dr. Oz's live interview with Victoria Jackson on Oct. 5.*

**DR. OZ:** We are going to initially talk about The Guthy-Jackson Charitable Foundation. The reason for that is that Victoria Jackson has a very compelling story about an ailment that many of you have never heard of, but I hope for many of you, will symbolize some of these orphan diseases that children and adults out there [have]. They represent what I think we should aspire to – to try and treat illnesses that still influence us. Neuromyelitis Optica (NMO) as we'll call it. It's also known as Devic's Syndrome. Victoria thank you for joining us. If you don't mind since you have been dealing with this why don't you define for everybody what Neuromyelitis Optica is.

**VJ:** Thank you very much for having me on. It's clearly been an extraordinary journey. As I've said, I've been really on this "Mascara to Medicine" [mission]. About 2 1/2 years ago my daughter Ali was diagnosed with something I had certainly never heard of which was NMO – Neuromyelitis Optica. It's a very rare condition that affects basically the optic nerve and the spinal cord and can result in blindness and paralysis. It hit our family really hard. It was devastating.

It still is devastating and it came out of nowhere. I have three children and I [even got them to stop] taking Tylenol, then all of a sudden, I was presented with this very ominous diagnosis.

**DR. OZ:** Victoria, part of the reason I wanted to have you on is that you bring such substance to the broader concept that not only do we become our own expert of our bodies, but we optimally would drive healthcare to be better for us by getting active in it. I would love to understand how you took this ailment that was hurting your family and you decided to do something about it. Speaking for the many listeners out there who may have some illness in their family that don't have a big organization representing it, how do they sort of get started and how did you get started?

**VJ:** When you're presented with something (as many people are) that's really overwhelming you can go into that mode (which I did for a minute) where I shut down and I cried and said, "Oh my God." Then I thought: wow this is really rare and nobody's going to care. But then, I started to learn about what an orphan disease is. I've heard the term and so many people I've talked to since have no idea what it is. I started talking to more people in the medical profession about these conditions and I decided that these are the ones that are probably going to unlock the mystery of so many other bigger conditions. You know in my

situation, MS (multiple sclerosis) and NMO are really confused a lot of the times. A lot of the patients have been misdiagnosed [as having MS]. Now there are a lot of the listeners out there who might have MS that have had NMO or Lupus or other conditions and they're all autoimmune conditions. These smaller rare orphan conditions are now being looked to which might unlock some of these mysteries. My whole intent was this: I am going to figure this out, not only just for my daughter, but for everybody who suffers with this. I just went into "Mom on a Mission" mode and I've not come out of it. I look at my journey and my life in the world of the beauty business and the money I was able to make – I am literally now funding all the research in the world (world-wide) for NMO, and I'm really not going to stop until I find that cure. What's really been fascinating: I'm somebody who did not graduate high school. I didn't go to college and all of a sudden my first trip [investigating NMO science], I'm at Stanford sitting there amidst molecular medicine with a group of doctors. I'm learning a second language of science and I'm like: okay, I will learn about T cells and B cells or orthogonal array patterns – just name it. I have just been a sponge and I'm taking everything I learned as a business-woman and I'm really recreating a new blueprint for how you cure disease. I'm doing it on my own dime and my own time and in my own way...

*For the complete transcript please go to: [www.guthyjacksonfoundation.org/](http://www.guthyjacksonfoundation.org/)*

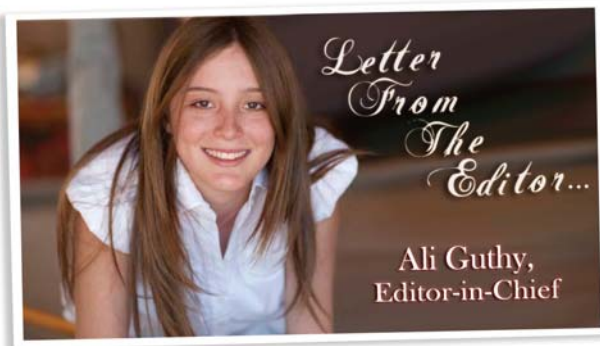
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It's also unnerving to experiment with a cocktail of different medications during the heat of a competitive tennis season, or even during finals week.

But honestly, I can deal with all that. What's really annoying is the fact that my Google search results have been forever changed. Just type in "Ali Guthy" and what used to be my latest tennis ranking and statistics, is now overshadowed by NMO. Don't get me wrong, I have come to embrace the NMO side of my life, but still, I would like to at least enjoy a nice Google search without being reminded of my condition!

Then again, being an NMO patient isn't all bad. For starters, I really discovered how supportive all of my friends could be. Initially, I kept to myself about the whole rare-disease thing, but once word got out there, I was able to see how amazing and understanding my friends truly are (and I thank all you guys for that!).

But on the other hand, I do have a few complaints. I know there are a select few out there who know what I'm talking about when I say flying on a commercial airliner has become increasingly problematic. Most passengers get stopped by security for having a bottle of water, where as I get detained for carrying an emergency IV drip and packet of steroids (which, unfortunately for me, bear a striking resemblance to cocaine).

On a more serious note, I feel like I live two different lives. In one, I am being probed and prodded by doctors left and right; in the other, I am a high school senior with a lot on my plate and a lot to look forward to.

Being diagnosed with this disease has certainly challenged me, but has yet to overwhelm or define me. And yeah, it sucks to get stuck with a needle for MRIs, IV infusions, or just routine blood draws, but life goes on, it always does.

NMO. I often wish that acronym stood for something more interesting like "No More Oreos," but it doesn't. It stands for something that is much more significant and not quite as tasty: Neuromyelitis Optica.

Since my diagnosis freshman year, I've visited 34 doctors in over six different states. I've also had 58 blood draws, 17 MRIs, and 23 IV infusions. I didn't get it back then, but I understand now all those visits were good for something. I mean, it's a peculiar feeling to feel half of your body go numb and not know whether you'll get it back.

**Q: What are early warning signs that an NMO attack is imminent?**

**A:** The major symptoms of NMO are optic neuritis and transverse myelitis. Optic neuritis causes eye pain and blurring of vision or blank spots in the field of vision, typically in one eye at a time, but occasionally in both simultaneously. Myelitis can cause pain, often a band of burning, searing pain across the torso, often accompanied by weakness or loss of sensation in one to all four limbs. Often, the weakness will begin in one leg and spread to the other leg or to the arm on the same side, but many different patterns are possible depending on the spot in the spinal cord most severely affected. Occasionally, flares of NMO can be associated with fever, and sometimes they can be preceded by severe nausea and vomiting or hiccups\*

**Q: What are some common misconceptions about NMO?**

**A:** Many physicians believed that NMO occurs primarily in persons of Asian ancestry. While NMO was recognized as a distinct and relapsing disease in Japan, it is probably because MS was relatively rare in Japan 50 years ago, and NMO was more easily recognized in Japan being relatively more common in Asia than in western countries. In western countries, NMO was relatively rare compared to MS and was usually misdiagnosed as MS. The specific characteristics that allowed NMO to be distinguished from MS, such as long spinal cord lesions on MRI and aquaporin-4 antibody test, were not recognized until the past 10 years. Most patients in western countries with NMO are white\*

**Q: Have you observed a positive change in the course of treatment for NMO patients over the years?**

**A:** Yes. Just a decade ago, when we reviewed our experience with cases of NMO at Mayo Clinic, we found that there was a high mortality rate in the first five years, usually in the context of attacks of high spinal cord transverse myelitis that caused breathing problems. Now, we have effective treatment for such attacks. We have observed several patients with severe paralysis and breathing difficulties due to NMO who could not be weaned from a ventilator who experienced dramatic improvement following correct diagnosis and treatment with plasma exchange\*

**Q: If you get the blood work done and the results come back negative does it absolutely mean that you do not have Devic's? (My neuro won't look at Devic's definitively without a "yes" on the labs.)**

**A:** The NMO-IgG (also known as aquaporin-4 autoantibody or "Devic's antibody") test is very specific when positive, but not completely sensitive; in other words, a negative test does NOT rule out the diagnosis. In fact, approximately 30-40% of cases, particularly persons with early symptoms (e.g. first transverse myelitis or optic neuritis) do not test positive for the antibody. Retesting may be of some value after several months or years. Likely, technical improvements will reduce the proportion of patients who are missed, but it may turn out, based on experience with other antibody-induced diseases, that not all cases will be positive even with enhanced testing techniques. In patients who meet all other clinical and radiological criteria, a diagnosis of NMO can be made with reasonable confidence, although physicians should be more careful to reassess the accuracy of the diagnosis in patients with a negative antibody test than in those with a positive antibody test\*

**Q: Can someone please clarify the difference between a flare and nerve damage? I am also experiencing burning sensations in my leg and back, however, my neuro always tells me that it is nerve damage and hopefully in time it will heal. Could this be a flare and do I need to do an MRI and treat it with IV Solu-Medrol?**

**A:** Attacks (also known as "flares", "relapses"...these are all the same thing) represent fresh inflammation that need to be treated promptly with steroids and, if necessary, plasma exchange. Attacks develop quickly and worsen day by day, if not hour by hour. Usually, attacks resolve over weeks to months\*

*\*Answers are shortened. For full Q & A please go to: [www.spectrum.guthyjacksonfoundation.org](http://www.spectrum.guthyjacksonfoundation.org)*

**Q & A**  
about NMO  
with  
**Dr.**



**Weinshenker**



# Scientifically Sound: How Do You Know It's NMO?

By Jeffrey Bennett, M.D., Ph.D.

Professor, University of Colorado Denver

Because neurologic disability in NMO is intimately linked with disease exacerbation, it is critical for physicians to recognize and treat patients as early as possible. To this end, the specificity of AQP4 antibodies for NMO has allowed physicians to identify affected individuals prior to their presentation with the complete diagnostic criteria. These NMO spectrum disorders include monofocal optic neuritis, longitudinally extensive transverse myelitis (LETM), recurrent optic neuritis and unusual CNS demyelinating events. Given the pleiotropic presentation of NMO spectrum disease, it is important for the clinician to be aware of clinical, laboratory and radiographic findings that should prompt consideration and additional testing for findings suggestive of NMO.

These are summarized in the table below:

Clinical Presentation	Suspicious Clinical, Radiographic, or Serologic Findings	Additional Testing
Isolated/Recurrent Optic Neuritis	<ul style="list-style-type: none"> <li>Brain MRI inconsistent with MS or containing atypical white matter lesions<sup>a</sup> <i>And either</i></li> <li>Poor visual recovery (&lt; 20/200 Snellen Acuity)</li> <li>Significant optic nerve atrophy<sup>b</sup></li> <li>Non-caucasian ethnicity<sup>c</sup></li> <li>Clinical History of               <ul style="list-style-type: none"> <li>Transient weakness or numbness</li> <li>Transient bowel or bladder issues</li> </ul> </li> <li>Positive Autoimmune Serology<sup>d</sup></li> </ul>	<ul style="list-style-type: none"> <li>NMO-IgG<sup>g</sup></li> <li>Cervical and Thoracic Spine MRI<sup>h</sup></li> <li>Antinuclear antigen serology<sup>d</sup></li> </ul>
Transverse Myelitis	<ul style="list-style-type: none"> <li>LETM<sup>e</sup> <i>Or</i></li> <li>Brain MRI inconsistent with MS or containing atypical white matter lesions<sup>a</sup> <i>And either</i></li> <li>Non-caucasian ethnicity<sup>c</sup></li> <li>Clinical History of               <ul style="list-style-type: none"> <li>Transient or persistent vision loss<sup>f</sup></li> </ul> </li> <li>Positive Autoimmune Serology<sup>d</sup></li> </ul>	<ul style="list-style-type: none"> <li>NMO-IgG<sup>g</sup></li> <li>Ocular Coherence Tomography</li> <li>Antinuclear antigen serology<sup>d</sup></li> </ul>
Monofocal CNS Demyelinating Event	<ul style="list-style-type: none"> <li>Brain MRI inconsistent with MS or containing atypical white matter lesions<sup>a</sup> <i>And either</i></li> <li>Non-caucasian ethnicity<sup>c</sup></li> <li>Clinical History of               <ul style="list-style-type: none"> <li>Transient weakness or numbness</li> <li>Transient bowel or bladder issues</li> <li>Transient or persistent vision loss<sup>f</sup></li> </ul> </li> <li>Positive Autoimmune Serology<sup>d</sup></li> </ul>	<ul style="list-style-type: none"> <li>NMO-IgG<sup>g</sup></li> <li>Cervical and Thoracic Spine MRI<sup>h</sup></li> <li>Antinuclear antigen serology<sup>d</sup></li> </ul>

<sup>a</sup> Diffuse subcortical white matter lesions (enhancing or nonenhancing); "cloud-like" gadolinium enhancement; hypothalamic lesions; thalamic lesions; periaqueductal lesions; atypical appearing brainstem demyelination (Ito et al., 2009; Pittock et al., 2006).

<sup>b</sup> Greater than 15 microns of peripapillary retinal nerve fiber layer loss by optical coherence tomography (Ratchford et al., 2009).

<sup>c</sup> Japanese (Kira, 2003); Indian and Southeast Asians (Chopra et al., 1980; Lau et al., 2002); Afro-Caribbean (Papais-Alvarenga et al., 2002); Middle Eastern (Banwell et al., 2008); and Hispanic (Banwell et al., 2008).

<sup>d</sup> Antinuclear antibody (ANA); Anti-double-stranded DNA antibody; Extractable nuclear antigen (ENA); Sjogrens SS-A or SS-B (Javed et al., 2008; Weinschenker et al., 2006).

Answers are shortened. For full article and references please go to: [www.spectrum.guthyjacksonfoundation.org](http://www.spectrum.guthyjacksonfoundation.org)

## NMO Blood Bank Update

We need your blood!

Our cache of collected samples continues to grow, but we still need blood samples to continue our ever so vital research.

Those living with NMO are invited to schedule a blood draw. Please visit one of our collection sites or, our study nurse will travel to any location within the continental United States.

This is a FREE service paid for by The Guthy-Jackson Charitable Foundation.

### To schedule your appointment please contact:

Martha Mann, RN – Clinical Research Nurse

Phone: 214.645.0543

E-mail: [martha.mann@utsouthwestern.edu](mailto:martha.mann@utsouthwestern.edu)

Website: [www.http://www.guthyjacksonfoundation.org/repository/](http://www.http://www.guthyjacksonfoundation.org/repository/)

### Collection Sites

- Stanford School of Medicine, Stanford: New Site!
- Johns Hopkins School of Medicine, Baltimore
- University of Texas Southwestern Medical Center, Dallas
- Multiple Sclerosis Research Center of New York, New York
- Shepherd Center, Inc., Atlanta
- University of Massachusetts Medical School, Worcester
- Barrow Neurological Institute, Phoenix
- Beth Israel Deaconess Medical Center, Boston
- Ohio State University Medical Center, Columbus
- Rocky Mountain MS Center at Anschutz Medical Campus, Denver

To learn more about the repository, please visit the Foundation's website at: <http://www.guthyjacksonfoundation.org/repository/>

## 2010 NMO Patient Day

The NMO Patient Day is Growing!

The 2010 NMO Patient Day welcomes leading NMO clinicians and scientists as well as NMO patients, caregivers, friends and family from all over the United States.



The Patient Day bridges the gap between the scientific and patient communities. Clinicians and scientists from the top NMO research institutions and medical offices join families affected by NMO in a unique and intimate session that allows real person-to-person connections.

### NMO Institutions Represented:

- Mayo Clinic
- Stanford University
- University of California, San Francisco
- University of Texas Southwestern
- Harvard University
- University of Colorado
- Many more!

### Join Us Online – Nov. 10, 2010

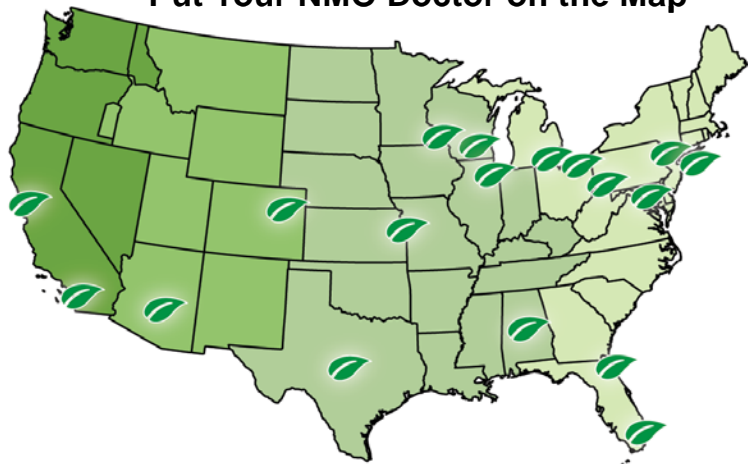
The NMO Patient Day will be streamed live online.

As an online participant, you will be able to view presentations and email questions that might be selected to be read aloud. Sign up on Spectrum to watch and participate in the 2010 NMO Patient Day live webcast!

[www.spectrum.guthyjacksonfoundation.org](http://www.spectrum.guthyjacksonfoundation.org)

# Connect The Docs

## Put Your NMO Doctor on the Map




### Clinicians Who Treat NMO


#### California

-  Bruce Cree, M.D., Ph.D.  
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-  Jeffrey Dunn, M.D.  
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-  Dean Wingerchuk, M.D.  
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List is abbreviated.

For a full listing visit:


[www.spectrum.guthyjacksonfoundation.org](http://www.spectrum.guthyjacksonfoundation.org)

Put your NMO Doctor on the Map: [info@guthyjacksonfoundation.org](mailto:info@guthyjacksonfoundation.org)


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## The 2010 Women's Conference

### Victoria Jackson: An Architect of Change

Excerpt taken from *The Women's Conference website*

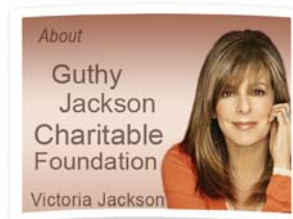
#### From Mascara to Medicine: My Life's Unexpected Evolution

Two and a half years ago my perfectly healthy teenage daughter was stricken, without notice, by a very rare and often misdiagnosed, life-and-death autoimmune disease called NMO (Neuromyelitis Optica). It shook me to my very core. Originally known as Devic's disease, NMO is a disease of the central nervous system that usually affects the optic nerve and spinal cord, which can lead to blindness and/or paralysis. It took every ounce of my being to stand taller than this disease and to educate myself, to become fearless in the face of the unknown.

I didn't have a background in science or medicine, but I knew the only way I could help my daughter was to become a "Mom on a Mission." I started a foundation with my husband to provide resources for adults and children with NMO and to start a movement for other orphan diseases. In the U.S. an orphan disease is classified as one that affects fewer than 200,000 people. There are currently more than 7,000 such rare disorders. Our goal was to create a platform to give NMO and related orphan diseases a voice. Our mission became clear: To fund research in the search to understand the pathophysiology and biochemistry of NMO Spectrum Disease. We wanted to support and provide opportunities to develop programs for prevention, clinical treatments and an eventual cure for NMO.

Read the entire article at:

<http://www.womensconference.org/from-mascara-to-medicine/>



The Guthy-Jackson Charitable Foundation is dedicated to funding basic science research to find answers that will lead to the prevention, clinical treatment programs and a potential cure for Neuromyelitis Optica (NMO) Spectrum Disease.

The decision to create our Foundation came from a personal family crisis. Our daughter was officially diagnosed with NMO in June 2008. Since that time, we have met with many clinicians and researchers in order to understand what this means for our beautiful daughter and our family. Additionally, we have gathered and read every piece of information and NMO research article that is available on the Web. We are now beginning to understand that NMO is not only considered an "orphan" disease, but that very little research is available.

We met with the All Greater Good Foundation in early July 2008 when it became clear that there is little-to-no funding available to research this rare and often misunderstood disease. We joined hands with the All Greater Good Foundation to immediately begin our work, and thus, The Guthy-Jackson Charitable Foundation was born.

The Guthy-Jackson Charitable Foundation is dedicated to funding biomedical research in the search to understand the pathophysiology and biochemistry of NMO Spectrum Disease. It is our greatest hope that together we will reverse the effects of NMO and eventually cure this disease.

Sincerely,  
Bill Guthy and Victoria Jackson, Founders

We want your feedback! Please send questions or comments about The Spectrum Newsletter to [info@guthyjacksonfoundation.org](mailto:info@guthyjacksonfoundation.org)

This Newsletter is for informational and entertainment purposes only and is not a substitute for medical advice, diagnosis or treatment.