



The Guthy-Jackson Charitable Foundation's 2nd Annual Conference for NMO, 2009

"I could go on and on, but this conference was just the beginning of the hope we have that is spreading amongst us....We no longer have to feel alone and we know that research has been fast-tracked and wow, how exciting!"

- Kendall, NMO Patient

## The Guthy-Jackson Charitable Foundation's 2009 NMO Roundtable Conference and NMO Patient Session

"I'm not alone anymore," was echoed across the room by patients attending the Guthy-Jackson Charitable Foundation (GJCF) Patient Session dedicated to NMO patients and caregivers. For the first time in history, a session solely dedicated to people with Neuromyelitis Optica (NMO) Spectrum Disease was held in Los Angeles, CA, on Nov. 11, 2009.



Dedicated to taking "A Rare Approach to a Rare Disease" GJCF hosted the "Living with NMO" Patient Session as part of the

Foundation's second annual NMO Roundtable Conference. Leading NMO scientists and clinicians from all over the world convened to further NMO research collaboration at The

Tower Beverly Hills on Nov. 9 – 11, 2009.

The day-long NMO Patient Session offered patients and caregivers a rare chance to meet and talk with others who live with NMO. During a highly-anticipated Panel Discussion, where nine panelists responded to questions from members of the audience, everyone had an opportunity to ask questions and receive informed responses. Panelists included the Founder of GJCF, Victoria Jackson, as well as leading NMO clinicians, alternative medicine practitioners, and researchers from the Mayo Clinic, the University California at San Francisco, the Colorado Neurological Institute and others.

As the daytime sun faded into evening, members of the audience asked questions one-by-one regarding their personal NMO experiences. Questions from a mixed audience of nearly 130 people were addressed as panel members provided extensive answers, giving NMO patients what

they have sorely lacked: personal attention and time with NMO experts.

"The Guthy-Jackson Foundation sponsored NMO conference was outstanding," said NMO clinician and panelist, Dr. Benjamin Greenberg who works at the University of Texas Southwestern Medical Center in Dallas, TX. "Beyond the exciting science was the quite motivating patient question/answer session. Seeing the many varied faces and hearing the many stories of NMO were inspiring. So many people have been facing this disease with courage and now they have a forum in which to work together. It's outstanding," Greenberg said.

Over 50 people affected by NMO including caretakers, family and friends attended the Patient Session. Many traveled across the United States to reach Los Angeles to participate in the session, during which they found vindication and a sense of recognition as their voices were heard. *Continued on page 7*

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**JOIN OUR COMMUNITY**  
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# Why NMO Matters

by Victoria Jackson, Founder of The Guthy-Jackson Charitable Foundation



A year ago, my 16 year-old daughter was diagnosed with a rare disease called NMO (Neuromyelitis Optica). NMO is what they call an “orphan disease”—meaning, not enough people have it to justify the time, money and energy required to effect a cure. Last year, my husband Bill and I created a Foundation to give grants to doctors and researchers—and bring those “orphans” together.

I knew it would be tough to get the world to care about an illness that so few of us have. Most people are too kind to say that in so many words, but I’d like to tell you why NMO matters. Why caring about Rare Orphan Diseases matters.

That’s the question I always want to be asked first. Because it would probably be the question *I’d* ask. I’ll answer with *another* question: *What are the requirements of compassion?* In the Not-So-Golden Age of reality shows and the 24-hour news cycle, what does it take to get our attention? A police chase? Genocide?

Celebrity scandal? I think what it comes

down to is the *quality* of the attention we choose to give that defines our humanity, our “tribe.” Look, I’m a mom. When my daughter was diagnosed with NMO, I did what any mom would do: after the tears, *I went into battle mode*. But unlike most moms out there, I had the resources to build an army, and create a Foundation.

If you asked, would curing NMO help unlock the cure for other diseases, like MS? Probably. But let’s take NMO and MS out of it—and ask the question again. *Why should we care?* The answer simply is, “Because caring is the best part of us.” Don’t get me wrong, I’m on a mission. *I will save my daughter*. But it’s become much bigger than that. Through the Guthy-Jackson Foundation, I’ve adopted a *lot* of orphans. I have a whole new family—dads and daughters, moms and sons. *That was something I could never have imagined, and it has filled my heart*. So: *Why should we care? Because caring fills the heart and soul, and is the very best part of who we are—and who we can be.*

—Victoria Jackson



## 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.

To read the full article please visit [www.guthyjacksonfoundation.org](http://www.guthyjacksonfoundation.org)



# Letter from Ali Guthy, Editor in Chief

Dear Friends,

2009 was a great year. Now I don't mean to brag, but I got straight A's on my report card (junior year in high school...not too shabby), I became captain of my tennis team (co-captain, and for next season, but still) and, to top it all off, (I know this is going to

sound cheesy like the bulk of my last letter, but stay with me on this) I discovered a new awareness, a different perspective of myself I had never noticed before.

"The 2009 NMO Patient Session was really a great experience for me on every level - personal and professional - and I came away with feeling so fortunate to be part of the growing NMO family that the Guthy-Jackson Foundation organization has put in place."

- *Dr. Claudia Lucchinetti*

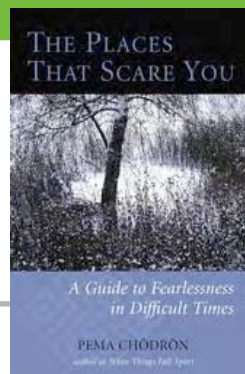
The Symposium in November really opened my eyes to a community I was previously ignorant to associate myself with. The amount of love and support I felt from every individual at that conference was truly awe-inspiring and gave me an even better outlook for this whole thing we've all come to know as NMO. Strangers. People I had never met before had heard of me, wanted to meet me, or were somehow linked to me in this bizarre and funny chain of fate we are creating. We joined together to form one perfect, unified bond that was not once broken throughout our entire time together. For those of you who couldn't attend, for whatever reason, good or bad, I strongly recommend attending in the future. I am not a fan of science and dread going to Chemistry on a daily basis (no offense Mr. Kelleher), but the patient day wasn't about the science. It was about connecting with people just like me, dealing with what I'm dealing with and even feeling what I'm feeling. No one else can relate to me the way they can.

I guess that was my highlight of 2009, believe it or not, because this "disease" has really been a, not exactly fun, but revealing experience. I've discovered how many people care about me and how profoundly I care for them. We are a small group, but a mighty one. We all create a collective unit, and together, we will become known as the little community that could, can, and will.

Yours Truly,  
Ali Guthy



**RECOMMENDED READING...**  
"The Places That Scare You:  
A Guide to Fearlessness in Difficult Times"  
by Pema Chodron





## Q & A about NMO with Katja Van Herle, M.D, M.S.P.H.

*Dr. Van Herle; Clinical Faculty, Endocrinology and Internal Medicine at the David Geffen University of California, Los Angeles (UCLA) School of Medicine*

**Q: Why is NMO called an autoimmune disease?**

A: Autoimmune diseases are defined by the body "attacking" itself. In neuromyelitis optica, the body starts making proteins against specific parts of the optic nerve and/or the spinal cord. Unfortunately, if the attack on "self" is strong enough, the optic nerve and spinal cord become damaged, leading to loss of vision, and/or movement. Why the body attacks itself is not clear. There could be genetic, environmental, hormonal or other factors involved that alter the immune system in a negative way. Like rheumatoid arthritis and lupus, typical NMO is also an autoimmune disease, though it is a rare form of neurodegenerative autoimmunity.

**Q: How can diet and exercise/lifestyle make a difference in NMO?**

A: Since NMO is an autoimmune disease and we know that problems with the immune system can lead to this, then it is important to keep the immune system as "healthy" as possible. In this regard, it is known that diet and exercise are key in keeping our immune system strong. In terms of diet, low-fat, gluten-free food plans with plenty of water and fresh fruits and vegetables are important. Foods with antioxidant values may help also to lower "inflammation" and possibly keep the immune system healthier.

**Q: If just diagnosed how do I go forward?**

A: First of all, know that you are not alone. While NMO is a rare disease, there are multiple places in the U.S. and internationally with NMO centers to help in clinical care. One purpose of The Guthy-Jackson Charitable Foundation is to open the information doors to help all patients with NMO and their families by joining Spectrum, the Foundation's online social networking website:  
[www.spectrum.guthyjacksonfoundation.org](http://www.spectrum.guthyjacksonfoundation.org)

The Foundation is also creating online maps/lists of NMO clinicians around the world. You can locate clinicians, NMO centers and the latest and best information about NMO. Please visit: <http://www.guthyjacksonfoundation.org/resources.nmo.maps.php> to see the online maps locating NMO clinicians and add your NMO doctor to the map.

**Q: What does it mean that NMO is an "orphan disease"?**

A: The term "orphan disease" applies to rare diseases that don't have a cure, affect only a small number of patients and those that don't have large amounts of funding for clinical care or basic science research. NMO falls into this category, with an estimated 4,000 affected patients in the U.S. However, many believe that the number of patients may be much greater and that "resistant" multiple sclerosis patients (those who don't respond well to treatment) may in fact have NMO. The NMO-IgG antibody blood test can help identify these patients.

**Q: How did I get NMO? Is it contagious and/or hereditary?**

A: No one knows exactly how NMO develops. There may be a genetic predisposition to get the disease, though so far, it is not described as a hereditary disease. Likely, there are environmental factors that also came together to "trigger" this form of autoimmunity. Researchers are studying these genetics and possible triggers in hopes of identifying them so that future NMO "triggers" can be avoided. NMO is not contagious and there is no general screening recommended at this time for family members of an NMO patient. The good news is that there is a blood test that can be ordered by your clinician, the NMO-IgG antibody, in suspected patients to confirm the diagnosis. This is key as the disease can be halted in most cases with medical therapies if it is diagnosed and treated early – this seems to be critical to avoid blindness or loss of motor function.

## What Tops My 2010 "To Do" List?

by Victoria Jackson



Photo by MATTHEW ROLSTON

I don't want to do anything too ambitious. Maybe lose 5 pounds. Take a cooking class. Oh. There is one more thing. I'm going to cure a rare disease called NMO (Neuromyelitis Optica). A year

ago, my 16-year-old daughter got the diagnosis. NMO is one of about 7,000 diseases that are so rare that little or no money is spent on research, prevention, medicines or cures -- the bottom line being they don't have profit potential. Last year, my husband Bill and I created a Foundation to do just that. We had a three-day symposium in November, and brought doctors in from Harvard, Stanford, the Mayo Clinic, Scripps, and even England and Japan, but the biggest deal was Patient Day (my daughter's idea; why can't I be more like her?) -- we flew in those who have NMO, and their families.

Now, for the first time, there's an NMO community. One day my daughter said,

"Mom, this is bigger than you and me." She's right. That little piece of wisdom got me right out of my own personal fear and into warrior mode. If we find the cure for NMO, that might be the domino that knocks down MS and a lot of other autoimmune diseases. So NMO is going to stand for NO MORE ORPHANS.

But first things first: MY 2010 TO DO LIST:

- 1) CURE NMO (Neuromyelitis Optica)
- 2) Once that's done, begin curing all orphan diseases
- 3) Start cooking class
- 4) Lose 5 pounds
- 5) Lose five more if cooking class goes well

*This text is a post from The Women's Conference, XX-Effect website. To read the original post please visit: <http://www.womensconference.org/victoria-jackson-2/>*

Questions or Comments about  
*The Spectrum Newsletter*,  
please email us at:

[gjcf@allggf.org](mailto:gjcf@allggf.org)



With a primary mission to cure NMO, The Guthy-Jackson Charitable Foundation has been instrumental in organizing a new community to support NMO - No More Orphan Diseases. Eurordis estimates that there exists between 6,000 – 8000 rare diseases, often called orphan diseases, affecting between 6 – 8 percent of the population. Finding a cure for a rare orphan disease such as NMO can potentially unlock new science behind prevalent diseases such as multiple sclerosis and lupus, paving the way for new treatments and potential cures for diseases that affect millions of people.

For more information about NMO and The Guthy-Jackson Charitable Foundation, please visit [www.guthyjacksonfoundation.org](http://www.guthyjacksonfoundation.org).

For more information about Eurodis visit: [www.eurordis.org](http://www.eurordis.org) | [The Voice of Rare Disease Patients in Europe](#)

## Calendar

### February 2010

Check out our new Awareness Video for NMO, Video FAQ's from top NMO Clinicians and the 2009 Patient Day Montage on our site. Please visit: [www.guthyjacksonfoundation.org](http://www.guthyjacksonfoundation.org)

### February 28, 2010

National Rare Disease Day of Observance

### April 17, 2010

American Academy of Neurology  
2010 Annual Meeting, Toronto, Canada

### June 19 - 23, 2010

European Neurological Society, Berlin

### July 1 - 3, 2010

3rd Latin American Congress on  
Autoimmunity, Buenos Aires

### ECTRIMS

Oct. 13 - 16, 2010 Göteborg, Sweden

Oct. 19 - 22, 2011 Amsterdam

Oct. 10 - 13, 2012 Lyon, France

### November 8-10, 2010

GJCF 3rd Annual Conference for NMO, Beverly  
Hilton, Los Angeles

## Look What's New at

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

New on our site! FAQ Video on all of your NMO questions from top NMO Specialists from around the World.

Log on to the [www.guthyjacksonfoundation.org](http://www.guthyjacksonfoundation.org) site to view our **video documentary** and **montages** from the 2009 NMO Symposium and Patient Day.



Become our friend on Facebook. Look for updates and meet new friends. Visit the Guthy-Jackson Charitable Foundation's website to connect to Facebook. We look forward to seeing you there! Visit <http://www.facebook.com/pages/The-Guthy-Jackson-Charitable-Foundation/177728509931>

**COMING SOON:** Victoria Jackson and famed director Jesse Dylan present a video to create awareness for NMO. Look for the announcement on Spectrum Online and Facebook!

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

# “A Daughter’s Cure Is Priceless”

A mother spends millions to fund research for neuromyelitis optica, which can leave patients paralyzed or blind.

By Sandy Banks, *LA Times* November 28, 2009

Victoria Jackson doesn't need this weekend's retail sales to satisfy her shopping list. She can afford to spend, with her lucrative cosmetics business and a husband with a billion-dollar infomercial marketing firm.

They've already put \$15 million toward their most important holiday gift, one that can't be wrapped or put under a Christmas tree, because it's not something from the mall or a boutique.

It's the quest for a clean bill of health for their 16-year-old daughter, who suffers from a rare, debilitating disease that has been -- until now -- virtually unknown and ignored by the medical community.

It's easy to begrudge the fortunes of the rich. I admit to a moment of eye-rolling when I first heard of this millionaire mom trying to buy her daughter's way out of an incurable disease.

Then I thought of all the nights I spent hovering over my ailing kids, worrying about headaches and stomach pains that turned out to be garden-variety illnesses. I imagined listening to a doctor tell me that one of those aches might mean my daughter would lose her ability to walk or see.

That's what happened to Jackson last year, when a pain in her daughter's eye landed them in a neurologist's office. The symptoms -- eye pain, fading colors, loss of vision in one eye -- were diagnosed as neuromyelitis optica, a disorder known as NMO that would have terrified Jackson if she had known then what it is.

"I was in 'mom denial,' " she told me. "I didn't have any idea of the seriousness of the world I was entering . . . until I heard that in four years, my daughter could be blind or paralyzed. That we could lose her."

Jackson went from denial into overdrive.

"We spent spring break at the Mayo Clinic," she said, seeking advice from one of the few physicians who has extensively studied the disorder. She told that doctor, "You're doing research. I've got a checkbook. You and I are going to get to know each other."

Jackson is blunt and unaccustomed to failure. Sometimes it takes a desperate parent with deep pockets to bypass convention and jump-start medical advances.

Like the mother in Minnesota who sank six years of profits from her successful tech firms into finding new ways to treat autism. She's convinced that the nonprofit Hyperbaric Treatment Center she funded has improved life for her autistic son and his classmates.

And the Nevada couple whose \$5 million launched a research institute that helped document a viral link to chronic fatigue syndrome, a disorder that mystified doctors and afflicted their daughter.

Jackson and her husband, Bill Guthy, founded the Guthy-Jackson Charitable Foundation last year to fund research into NMO, which had been considered a strain of the autoimmune disorder multiple sclerosis, but is now known to require different treatment and have a different prognosis.

The disease tends to strike suddenly, progress quickly, and follow an unpredictable path of remission and relapse. NMO is so rare -- with fewer than 4,000 patients, compared with 400,000 with multiple sclerosis -- that drug companies have no financial incentive to study treatments.

In the past, it often took years to diagnose it, leaving patients with irreversible damage to their spinal cords and optic nerves.



Photo by Mahlon

Candace Coffee of Bakersfield woke up one morning six years ago with flu-like symptoms and blurred vision. Within a matter of hours, her vision was gone. "It was like a black curtain going down," she recalled.

Steroids restored her sight temporarily, but months later, "my right eye started to go . . . and my skin felt like it was being ripped off," she told me. Before long, the professional dancer "was stumbling around and blind."

Now, she's learned to recognize the symptoms and seek immediate treatment. She is blind in one eye, but is dancing again. "But if I'd known what it was, I might have been able to save my sight," she said. "That's why getting the word out is so important."

I met Coffee at a conference Jackson sponsored this month in Beverly Hills. She picked up the tab for scientists flown in from around the world, and dozens of patients from around the country. It was the first time many of them had met anyone else with their disease.

"Can you imagine, in this day when everybody's got a support group, for these people to feel so alone? I wanted them to be able to sit down together, talk to one another," Jackson said.

That alone, she said, was worth the money.

NMO is just a tiny blip in the medical cosmos. In this world, where medical choices turn on dollars and cents -- from mammograms for 40-year-olds to end-of-life care for octogenarians -- how wise is it, I couldn't help but wonder, to sink so many millions into something that might help so few?

Then I met Winona Davis, a single mother in Rialto raising two daughters with NMO.

The oldest, now 20, got her first symptoms at 9. She spent her 10th birthday hospitalized; doctors couldn't figure out why she couldn't see. Since then, she has battled paralysis and blindness off and on, traumatized not just by the severity of her symptoms, but by their unpredictability.

Until her family attended Jackson's conference, "we felt like we were aliens," Davis said.

She's hoping that the foundation's work will lead to medical advances to help her daughters. But it's already been a gift, she said, to other families in their small world.

"The other mothers, now they have a chance to know, to tell someone why their kids can't ride a bike. So they can have friends. So the other kids aren't laughing at her when her legs give out, or she wets herself in school."

"Victoria knows," Davis said, how frightening it is, how helpless the disease can make a mother feel. "You don't sleep, you can't think. . . . You can't even tell your child what's wrong. All you can do is try and comfort them."

Unless you're a mother with millions to give.  
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## NMO Roundtable Conference and NMO Patient Session *Continued from Page 1.*

"Meeting all the patients, doctors and caregivers was the best part," said Jesus Loreto who traveled from Florida to attend with his wife Maria. "The day we got to be in the same room with the doctors, specialists, patients, caregivers and all, I shed tears, but tears of hope, faith and mostly tears for being proud of all of them. They are all my heroes."

Contributing to this scientific progress during the Patient Session pre-registered attendees with NMO participated in the Foundation's Blood Draw. A total of 19 samples were collected onsite to be cached at The Guthy-Jackson Repository for NMO. The repository makes NMO blood samples available for scientific study to qualified researchers who work to find a possible cure for NMO.

Those who were not able to travel to Los Angeles to attend the Patient Session logged onto the Foundation's streaming webcast, where users watched live video and typed their questions to the panel.

Other portions of the Patient Session included presentations about the incidence and prevalence of NMO, NMO treatments, NMO community social networking and more. At the end of the session, attendees had a chance to share their stories to members of the press and media to help raise awareness of NMO and tell others that they are not alone in this fight against this rare orphan disease.

"It never ceases to amaze me how powerful human interaction can be," said Dr. Greenberg. "Listening to the stories of individuals and families living with NMO reminded myself and the other clinician scientists why it is we are working to end this condition. It also reminded us that we are partnered with one of the most dedicated and passionate groups of patients in the world."

The Foundation gives special recognition to The Annenberg Foundation for its generous financial contribution supporting the 2009 NMO Roundtable Conference.

## SPECTRUM - The GJCF NMO Online Community Website



Make new contacts, keep up with friends, blog, research NMO and more with Spectrum, The Guthy-Jackson Charitable

Foundation's online NMO community.

Sign in, create your profile and begin sharing your story today!

Please visit:  
[spectrum.guthyjacksonfoundation.org](http://spectrum.guthyjacksonfoundation.org)  
to begin your new NMO online experience.

## Healthy You - Vitamin D and NMO

by Dr. Allen Bowling, M.D., PhD.

Recent studies have significantly changed our understanding of the role of vitamin D in health and disease. In the past, it was assumed that most people have adequate vitamin D levels and that the effects of vitamin D are restricted to regulating calcium absorption and maintaining bone health. However, studies over the past decade have proven that these views are incorrect. It is now recognized that there is an epidemic of vitamin D deficiency in many countries, including the United States, and that, in addition to its effects on bones and calcium, vitamin D exerts important actions on many other body systems, including the immune system.

Vitamin D has not been rigorously studied in NMO. It has been fairly extensively studied in MS. Multiple studies suggest that vitamin D may have a beneficial effect on the disease process of MS. In the animal model of MS, disease severity is worsened by vitamin D deficiency and improved by supplementing the diet with vitamin D. Multiple studies indicate that the risk of developing MS is increased in those who have low vitamin D levels. For those who have MS, low vitamin D levels have been associated with higher risk for attacks and more severe disability. Large, rigorously conducted clinical trials of vitamin D supplements in people with MS are planned but have not yet been conducted.

As noted, MS is generally thought of as a more T cell directed disease. In terms of B cells, which appear to be more centrally involved in NMO, scientific studies indicate that vitamin D has regulatory effects on B cell function. In addition, there is suggestive evidence that vitamin D may have beneficial effects on some "B cell diseases," including lupus and rheumatoid arthritis.

**Fatty Acids** Fatty acids, the compounds that make up fats, have important actions on multiple body systems, including the immune system. There are two main types of fatty acids. Saturated fatty acids, or saturated fats, are hard at room temperature and are what we generally think of as *fat*. The fat on red meat is an example of a saturated fat. The other major type of fatty acid is unsaturated fatty acid, which is liquid or soft at room temperature and is commonly referred to as *oil*. On the basis of chemical structure, unsaturated fats are referred to as *monounsaturated fatty acids* (which are present in olive oil) or *polyunsaturated fatty acids*. The two main forms of polyunsaturated fatty acids, also known as *PUFAs*, are omega-six fatty acids, which are found in sunflower and safflower seed oils, and omega-three fatty acids, which are present in fish oil.

Fatty acids affect immune system function. Immune system suppression, which could be beneficial for NMO, is produced by omega-six fatty acids and especially by omega-three fatty acids. This effect on the immune system appears to involve T cells as well as B cells.

Although omega-three and omega-six fatty acids have not been studied specifically in NMO, they have been studied in other immune diseases. In investigations of MS, some studies of large populations, known as *epidemiologic studies*, suggest that a high intake of omega-three fatty acids may be associated with a lower risk of developing MS.

The remainder of Dr. Bowling's Article on *Diet and NMO: A Three-Step Approach* can be found on our website at [www.guthyjacksonfoundation.org](http://www.guthyjacksonfoundation.org)





## THE GUTHY-JACKSON CHARITABLE FOUNDATION FIRST ANNUAL PATIENT DAY

NOVEMBER 11, 2009



### Did You Know?

41 Doctors and Researchers from 4 Countries attended the 2nd Annual NMO Conference

56 Patients and your families and friends attended Patient Day





## Living With NMO Q&A from the 2009 NMO Patient Session

**What is the comparison of a mild attack and a severe attack?**

Dr. Bruce Cree: I think we've probably all experienced this now. When we first were dealing with patients who had Devic's or

NMO, we used severe optic neuritis, severe acute transverse myelitis where there was loss of motor function and eventually loss of bowel and bladder. Now we realize there can be relapses, particularly in the setting of treatments that are not as severe as the attacks that we typically have associated with the disease. For example, a patient could have pain or loss of sensation in an area and then imaging of the spinal cord will reveal a contrast-sensing lesion with Neuromyelitis Optica. So you may not have any motor impairment and normal bowel and bladder, just some changes in sensation and that can be a flare. We have seen with serial MRI, in one patient in particular, there can be evident inflammation in a setting even without any active symptoms. We are still in the process of learning more and more about the disease. If you have a new symptom that has come on that really lasts for more than a day and it's something different from what you really experienced before, that type of thing, whether it be a sensory change, motor weakness or change in bowel and bladder or change in vision, they need to be evaluated by your neurologist. If you are getting those sorts of things it's probably feasible to consult with your neurologist, get examined.

**Is there anyone working on a way to get back what has already been done? For instance, being blind in one eye?**

Dr. Benjamin Greenberg: I think it's being worked on potentially. There are multiple avenues. We talked about prevention. Once you are diagnosed with the disease, you undergo therapies. The overall flavor of your question is on regeneration from damage. The regeneration is going to take two flavors. One is research being done in cell-based therapies, stem cell research. And the other avenue is a molecule drug that would promote repair. There is research being done on both. For example, if somebody's optic nerve has the wires intact, but the insulation gone, so the myelin gone, this term is called "demyelinating." The wire is intact - there is actually tremendous hope. That is a great target for stem cell therapy. Between the optic nerve and the spinal cord, the optic nerve is a great place to go. It's accessible, minimally invasive. What we are starting to do is imaging studies to separate out patients who have intact wires, but damaged insulation. They are going to be great candidates for these therapies versus ones that might need more extensive repair. On the small molecule side, there are a couple of acts moving to Phase 1 clinical trials where the actual drug helps grow new myelin. These are things that are really no longer scientific functions. We are partnering hard trying to get our patients ready and keep them ready, hard on the prevention side. We don't want new damages for individuals talking about spinal cord issues. Same question about regeneration. We are talking with everyone to make sure you are exercising - make sure you are active, make sure there is nothing wrong with joints or muscles. When I go to repair a spinal cord, we have to have something to correct to. You have to do your part as much as possible to stay healthy while we are doing our part to get the therapies. That would be my approach.



## GJCF NMO Repository Update

**The cache of collected samples continues to grow at the Guthy-Jackson Repository for NMO!**

Those living with NMO are invited to schedule a blood draw. Our study nurse will travel to any location within the continental United States. Samples can also be drawn at one of our collection sites. **This is a free service paid for by The Guthy-Jackson Charitable Foundation.**

**To schedule your appointment please contact:**

Sara Loud - Repository Director at the Accelerated Cure Project  
Phone: 781.487.0032 Fax: 781.487.0009

Email:

[sloud@acceleratedcure.org](mailto:sloud@acceleratedcure.org)  
[www.acceleratedcure.org](http://www.acceleratedcure.org)

### Sample Collection Sites

- Johns Hopkins School of Medicine, Baltimore
- University of Texas Southwestern Medical Center, Dallas
- Multiple Sclerosis Research Center of New York
- Shepherd Center, Inc.,

### Atlanta

- University of Massachusetts Medical School
- Barrow Neurological Institute, Phoenix
- Beth Israel Deaconess Medical Center, Boston
- Ohio State University Medical Center, Columbus
- Rocky Mountain MS Center at Anschutz Medical Campus, University of Colorado Denver

### Pediatric Sample Collection Sites

- Johns Hopkins School of Medicine, Baltimore
- University of Texas Southwestern Medical Center, Dallas
- Multiple Sclerosis Research Center of New York
- University of Massachusetts Medical School
- Barrow Neurological Institute, Phoenix

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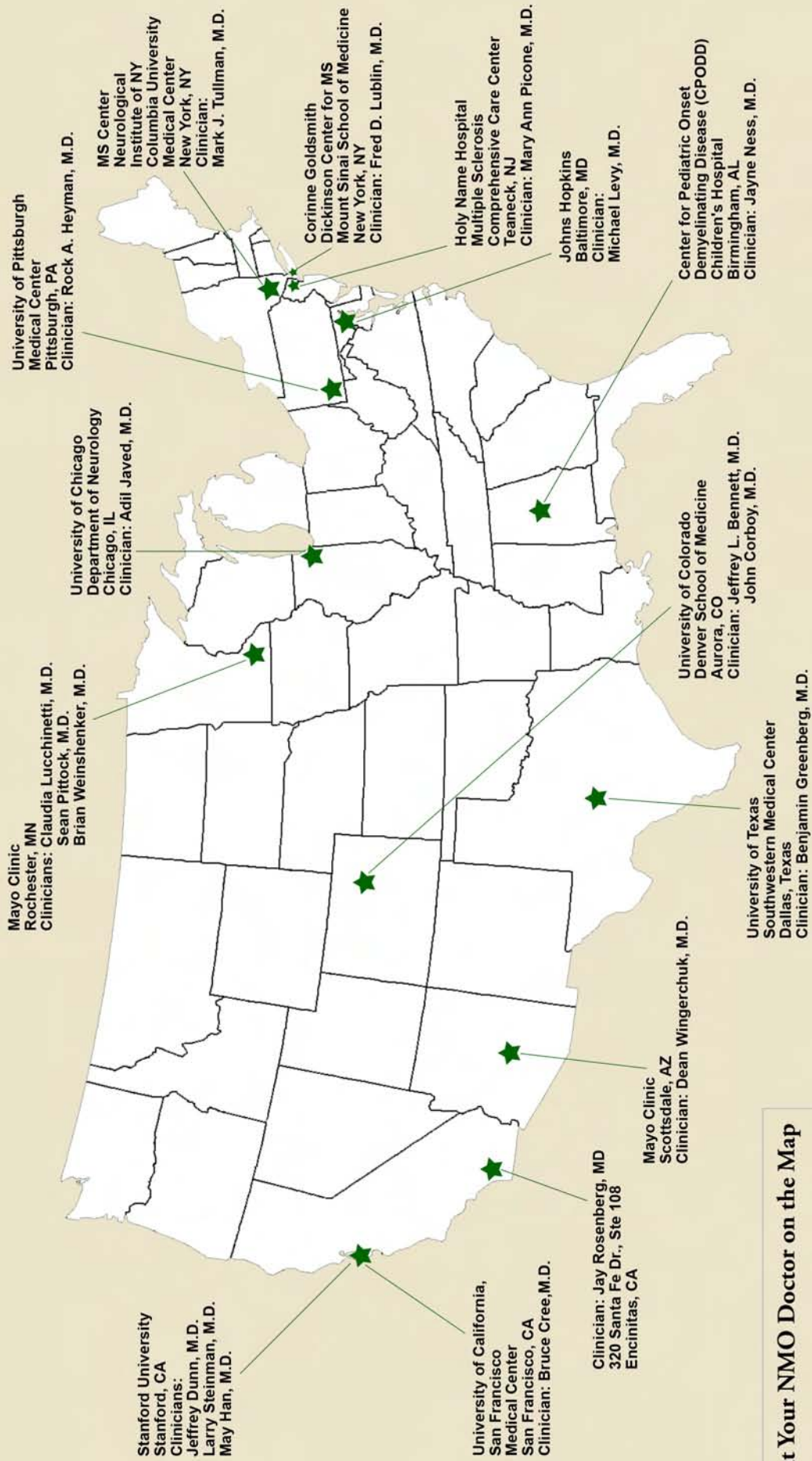
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# U.S. Map of NMO Clinicians



**Put Your NMO Doctor on the Map**

If your doctor(s) treats NMO and is not listed on this map, please email us at: [gjcf@4greatergood.org](mailto:gjcf@4greatergood.org)

Please provide: 1. Doctor(s) Name; 2. Clinical Site Name; 3. Clinical Site Location 4. Appointment phone/fax number 5. Permission from your doctor(s) to be listed

For more maps please visit: <http://guthyjacksonfoundation.org/resources.nmo.maps.php>



*Photo by MATTHEW ROLSTON*

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



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TO: