



"As we collaborate on this journey, we have the opportunity to fund basic science research to find answers that will lead to prevention, clinical treatments, and an eventual cure for NMO Spectrum Disease."

*-Victoria Jackson, Founder
The Guthy-Jackson Charitable Foundation*

For more information about The Guthy-Jackson Foundation, please see page 4.

The Guthy-Jackson Charitable Foundation Launches Repository for NMO Patients

Foundation breaks barriers to help advance scientific research for Neuromyelitis Optica (NMO) Spectrum Disease.

Fostering scientific collaboration between research laboratories across the United States and Europe, The Guthy-Jackson Charitable Foundation (GJCF) established the first Neuromyelitis Optica (NMO) patient repository where people who have NMO can volunteer to donate their blood samples for scientific study.

The Guthy-Jackson Charitable Foundation Repository for NMO will be accessible to researchers at

funded institutions including the Mayo Clinic, Stanford University, the University of California, San Francisco, Johns

Hopkins School of Medicine, The Scripps Research Institute and Harvard University.

This sharing of blood samples between participating institutions will speed up the research process by allowing scientists to have access to samples to which they normally wouldn't have access due to budget restrictions.

Partnering with the Accelerated Cure Project (ACP) in Boston, MA, and the University of Texas, SouthWestern Medical Center (UTSW) in Dallas, TX, the NMO Repository will exist as a project within the organizational structure of the ACP. The repository is based upon successful results of the Foundation's initially funded ACP project dedicated to collecting and storing NMO patient samples.

In this new initiative, ACP will promote the continued enrollment of NMO subjects into the NMO Repository, and provide samples from the NMO Repository to qualified scientists whose proposed

research will contribute to the diagnosis, prevention, treatment, and/or cure of NMO.

Volunteers can enroll to donate their blood samples with the ACP at their headquarters in Boston, MA, one of their satellite repository sites, or by accepting an enrollment visit from the UTSW nurse.

Researchers who want to request samples are asked to submit a written proposal using the ACP Samples Request Form. The proposal is reviewed at the ACP and ultimately submitted to an oversight committee for review. Researchers are encouraged to make application immediately upon discernment of need. A response will be forthcoming upon review and recommendation.

For more information and/or application please contact Sara Loud, ACP NMO Repository Director at phone number: (781) 487-0008 or fax number: (781) 487-0009 or visit the ACP website at: <http://www.acceleratedcure.org>.



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Mascara to Medicine

by Victoria Jackson, Founder

The Guthy-Jackson Charitable Foundation

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I've always thought of myself as a "goodwill ambassador for makeup" and empowering women through makeup has been one of my missions in life. My personal philosophy has always been, "When you look better, you feel better. And when you feel better, you can change your life." I often volunteer at women's correctional facilities, hospitals, and youth support venues to spread this message and to teach inner confidence through outer beauty. When women embrace self-confidence, they learn the key to success, and liking who they see in the mirror is a powerful first step in that transformative process. I call this program "The Power of Mascara." Building my cosmetics brand these past twenty years has enabled me to touch millions of women's lives through the power of makeup. What I didn't realize during all this time was that my experience in beauty was organically preparing me for the next phase of my life - "The Power of Medicine."

* * *

N.M.O. Most of us look at these as just letters of the alphabet. In the moment the doctor uttered these three letters, my life, and the lives of my family, were instantly changed forever. It all started when my fifteen-year-old daughter's vision became impaired in her left eye, losing the ability to see color and rapidly getting worse over days to come. We were perplexed and desperately trying to find the cause. Our search brought us to the Mayo Clinic, where my daughter was officially diagnosed with Neuromyelitis Optica (NMO) Spectrum Disease, or NMO. After the initial shock of the diagnosis in June 2008, I immersed myself in researching this disease to understand everything there was to know about it, and how NMO would ultimately impact my daughter and our family.

In addition to literally reading every piece of information and NMO research articles available on the Web, I met with many clinicians to expand my knowledge about the disease. It quickly became evident that not only is NMO considered an "orphan" disease, but that very little research is available. We were fortunate to meet Dr. Katja Van Herle through our research and met with her organization, 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.

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. We also were adamant that 100% of all funding gifts are to be given to basic science research centers.

We interviewed the best medical advisors to join our team, and set forth the first medical roundtable of its kind in November 2008. The Guthy-Jackson Foundation hosted a meeting with a group of top medical advisors, researchers, and clinicians from around the world to help find answers that will lead to the prevention, clinical treatment programs and a potential cure for Neuromyelitis Optica (NMO) Spectrum Disease. This group freely shared their research and clinical information in the spirit of finding answers. It was at this meeting that I realized that my personal mission had made the transition from Mascara to Foundation, but not the cosmetic foundation that I am known for and built my success upon. It was a different kind of foundation this time – a medical foundation. The irony of it all was not lost on me. I always used to say to aspiring makeup artists, "It's not like we are curing cancer," and now, here I am trying to cure a rare orphan disease.

So, what is NMO, you ask? Neuromyelitis optica (NMO) is an uncommon disease—a syndrome of the central nervous system (CNS) that affects the optic nerves and the spinal cord. NMO is sometimes confused with Multiple Sclerosis. NMO is similar to MS in that it is a variant along the spectrum in the world of autoimmune disease, but it is a completely different disease.

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"You need to accept your situation if you want to be empowered to change it...Once you accept that the disease or other misfortune has become a part of your life, you can marshal your forces to eliminate or alter it. If you avoid thinking about it, deny it or feel hopeless, you cannot play a part in changing it and your life. Accepting the situation does not mean accepting someone else's prediction about what will happen to you. No one knows what your future will be...Individuals are not statistics."

-Bernie Siegel, Surgeon and Writer

RECOMMENDED READING...

"Healing: Advice for Recovering Your Inner Strength and Spirit from the World's Most Famous Survivors"

by Jena Pincott

Letter from Ali Guthy Managing Editor



Dear Friends,

My name is Ali Guthy and I was diagnosed with Neuromyelitis Optica (NMO) Spectrum Disease my freshman year of high school. When I had first shown signs of the disease (although I wouldn't so much call it a disease, but more of a lifestyle), I was fortunate enough to have parents who not only could financially provide for the most prestigious doctors to research my case, but also whose never-ending love and support has helped me surmount even the most difficult obstacles.

My mom especially has played a crucial role in becoming my comrade or "first in command" throughout this mini battle I've been facing. She sacrificed her career, her life and most of her hair (unfortunately the coloring lasts no more than a week now, until finally her naturally grey hairs start to seep through the artificial brown locks). Anyway, after a year of disbelief and utter ignorance of the seriousness of my condition, I finally became more open to discussing my new lifestyle. I was inspired by the work my mom had done in the short year I had been diagnosed and I began to feel compelled to do my part in aiding a noble and close-to-home cause.

The idea for the newsletter began during my 10th grade community service assembly. All the speakers discussed charities, which don't get me wrong all seemed great, but nothing really spoke to me. That's when I began to wonder how my hapless circumstance could be somewhat beneficial. So that night I discussed some various options with my mom on how I could get more involved in what is really my charity. I began to think of all the things I would have wanted when I first got the diagnosis. I remember there was no information available. Absolutely none. We had to work from the ground up and I didn't want anyone to go through the same thing I did and thus, the newsletter was born. It wasn't until a couple weeks later when the team started to come together, that I was named their honorary "Managing Editor." It was a position I wasn't quite prepared for, but I think in the end was a position I needed to have. I started thinking about topics that would not only be informative, but also fun and uplifting to both new and previously diagnosed NMO patients. I wanted these topics to show that yes, NMO is a rare disorder, but no, it does not have to stop you from living.

Since I've been diagnosed I have been MVP of my tennis league (not team, but league, which is much better), I've discovered a love for photography, I've been a journalist for my school paper (I will be focus editor next year, which is a considerable step forward) and I've been riding my horse every weekend on the side – you know, just for fun. All these things I had done before my diagnosis and I continue to do now. Of course, there are some days when I'll come back from riding and there'll be a nurse waiting in my room for a steroid infusion, but then later in the day I'll happen to find myself strolling through the mall with one of my friends. Sure, having NMO – well quite frankly – it sucks, but there is hope. No one should have to sit on the sidelines of their tennis match or just watch someone else ride their horse because of some microscopic malfunction in their DNA. I refuse to be restricted or limited by anything, especially not myself and my own body.

My dreams have not changed and the chances of my success are still as strong as they've ever been. So to all of you who are facing what seems to be an insurmountable barrier, remember there is always hope, and that hope will never cease to exist until the battle is won and a cure is discovered. That is the mission of The Guthy-Jackson Charitable Foundation and it is now also my personal mission. I know how it feels to be the one in the hospital bed. I know what it's like to sit in five different doctors' offices in one day. I know what it's like to have a bunch of different people come up and probe you like some guinea pig on an operating table. And sure, it's not fun, but now I know I'm not just suffering through it for me anymore. This whole foundation is not just about me anymore. It's about each and every person whose lives have been affected by NMO. So now every time my mom tells me I have to go to the University of California, Los Angeles (UCLA) to draw some blood after school or I'm going to have to visit a doctor at the Mayo Clinic during spring break, I think about all the people I'm potentially going to help, all the lives that are not going to have to experience the same thing I did. I guess in the end, I'm sort of glad this all happened to me. At least I know I can handle anything this disease is going to dish out at me and I know that no matter what, I will always have people to love and comfort me the entire time. So I guess in the end, that's why I wanted to start this whole newsletter. I thought that if everyone with NMO banded together, really thought about what we are fighting for, we could find a cure (and a lot faster too). Working together is the pathway to the cure and I'm confident that if we all come together as a community we will succeed. NMO, ha, those three letters will never bring me down again. Thanks for all the support.

Your Managing Editor,
Ali Guthy

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Individuals with NMO can go on to develop optic neuritis, which causes pain in the eye and vision loss, and transverse myelitis, which causes weakness, numbness, and sometimes paralysis of the arms and legs, along with sensory disturbances and loss of bladder and bowel control. NMO leads to loss of myelin, which is a fatty substance that surrounds nerve fibers and helps nerve signals move from cell to cell. The syndrome can also damage nerve fibers and leave areas of broken-down tissue. In the disease process of NMO, for reasons that aren't yet clear, immune system cells and antibodies attack and destroy myelin cells in the optic nerves and the spinal cord.¹

I am working closely with my daughter's primary care physician, a pioneer in NMO research, in managing her clinical care. My daughter is doing well at this point, and I am thankful for that. She continues to thrive at school, and remains active in sports. She is my one and only daughter – a one of a kind, beautiful, smart, spirited and loving girl.

As the Founder of the Guthy-Jackson Charitable Foundation, I am unwavering in my commitment and quest to find a cure for my daughter and all those afflicted with NMO Spectrum Disease. For more information about Neuromyelitis Optica (NMO) Spectrum Disease, please visit www.guthyjacksonfoundation.org.

¹ Excerpts taken from: NINDS Neuromyelitis Optica Information Page. To view the complete article, see:

<http://www.ninds.nih.gov/disorders/neuromyelitis>

Healthy Living New Paradigms in Medicine

“ENERGY MEDICINE AND THE EVALUATION OF TOXICITY”

By Michael Galitzer, M.D.

When a patient goes to see a physician for an evaluation of "I don't feel well," the traditional approach is to look at a person's PHYSICAL structure through a physical examination, X-rays, CT Scan, MRI, mammograms and biopsies. Patients are also evaluated CHEMICALLY through blood tests. This will rule out whether or not a disease is present or impending. However, this will frequently not give us information as to how healthy or not healthy a person is. Traditional medicine sees health as the absence of disease, whereas energy medicine (or electrical medicine) sees health at one end and disease at the other end, with most patient complaints lying somewhere in between DISEASE AND HEALTH. As an example, fatigue and insomnia are not diseases, and yet are certainly not associated with good health.

Energy Medicine seeks to evaluate the energy of the cells, organs and glands of the body. Are the cells making enough energy? Are the cells able to hold on to the energy that is being created through oxidative phosphorylation?

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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.

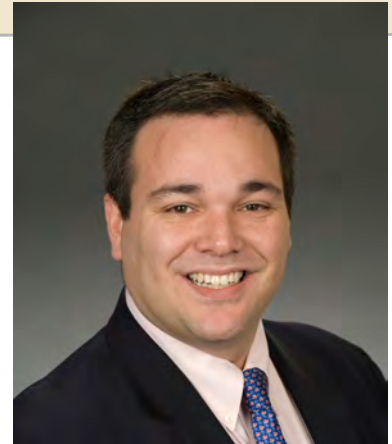
Sincerely,
Bill Guthy and Victoria Jackson, Founders



Photo by MATTHEW ROLSTON

Q & A about NMO with Ben Greenberg, M.D, M.H.S.

University of Texas, SouthWestern



Q & A WITH BEN GREENBERG, M.D., M.H.S. University of Texas, SouthWestern Medical Center

Q - What are the most effective treatment options?

To date there are several options for treating neuromyelitis optica, such as rituximab (Rituxan®), mycophenolate mofetil (Cellcept®), and azathioprine (Imuran®). There have been no head-to-head trials of these agents, but they all have data to support their use in NMO. Choosing amongst them is based on pros and cons that are specific to each individual patient.

Q - What are the long-term effects of treatments including steroid infusions?

The long-term effects of treatments are dependent on the treatment used and can be quite variable. In general, here is a partial list of known long-term effects that should be considered:

1. Steroids – long-term exposure to steroids can increase the risk of diabetes, hypertension, high cholesterol, cataracts, osteoporosis and infections. The risks are related to both the duration of exposure and dosage used.
2. Rituximab (Rituxan®)– There are no long-term studies looking at risks of exposure to rituximab. In the short term, the biggest risk is of infections. There have also been reported cases of a brain infection, called PML (progressive multifocal leukoencephalopathy) in patients on rituximab, although the link is unclear.
3. Mycophenolate mofetil (Cellcept®) and Azathioprine (Imuran®) – The major long-term risk of these agents is infection. In studies that followed transplant patients who were receiving these drugs for 10 years or more, there was an increased risk of certain cancers – including lymphoma and melanoma. This risk seems to be

lower with mycophenolate, but this data is limited. Based on the risks, patients on one of these agents should wear hats, sunscreen and have annual dermatologic exams.

Q - Are there side effects to so much exposure to MRIs (such as cancer)?

Great question. The short answer is, “No.” MRIs are very different than X-rays and CT scans – there is NO radiation. MRIs have been around for more than 20 years. While there have been no formal studies tracking patients over time, there are also no indications that repeated exposure to a MRI machine increased any health risks. There are dangers to a MRI if you have implanted devices or metal, because it uses such a huge magnetic force, so discuss the short-term safety with your doctor if this applies to you.

Q - What is the most effective treatment for stopping attacks?

I wish I knew. Anecdotally, rituximab, mycophenolate mofetil and azathioprine probably are about equally effective, but there are some patients who clearly have a better response to one or the other drug. We can tell who is who yet, so in general we say start with one and switch if a relapse occurs or side effects occur.

Q - How does diet affect most NMO patients?

We don't know! There are no studies assessing the role of diet in groups of NMO patients. From experience, I can tell you that the better the general health of a patient, the better they do with the ups and downs of NMO. Some patients find a selective diet they feel help their disease and this is fine, as long as there is adequate balanced nutrition.

Q - What is the current main approach to curing NMO?

There are many active NMO programs around the world trying to

cure this disease. Our treatments are good, and for some they are potentially cures. But some patients continue to have relapses despite therapy. New drugs are being evaluated all the time and new treatment modalities are in clinical trials. The approach to a cure is very individualized. I recommend that if a patient is not responding to one of the first-line therapies mentioned above, that they seek care at a tertiary center with specific programs in NMO.

Q - Anything else?

The one thing I would add is that there is tremendous hope in the world of NMO. I would argue, potentially more hope than in diseases such as MS. Understanding this disease is accelerating and new treatments are on the horizon. The medical and scientific processes can never go fast enough for our patients struggling with these issues every day, but it is moving. There is every reason to believe that true cures for this disease will be found.

Dr. Greenberg is the Deputy Director of the Multiple Sclerosis Program and Director of the new Transverse Myelitis and Neuromyelitis Optica Program at University of Texas SouthWestern Medical Center.

Interview conducted by Ali Guthy

Questions or Comments about *The Spectrum Newsletter*, please email us at: gjcf@4greatergood.org

How You Can Donate to GJCF...

Thank you for your consideration to donate to the Foundation. If you choose to donate, your gift directly supports the innovative scientific research of scientists who are working to find solutions for Neuromyelitis Optica (NMO) Spectrum Disease. 100 percent of your donation goes directly to science research. The Guthy-Jackson Charitable Foundation does not allocate any donated monies to administrative support of the Foundation.

Once your contribution has been processed you will receive a thank you letter in the mail that you can use as a tax receipt. The Guthy-Jackson Charitable Foundation for NMO is a non-profit 501(c)(3) organization Tax ID # 26-6461545.

We accept all forms of monetary donations; please visit our website at www.guthyjacksonfoundation.org/donate to donate using a credit card. For all other forms of donations, please contact the All Greater Good Foundation at:

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8910 University Center Lane, Suite 725
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Email: gjcf@4greatergood.org

Healthy Living, Continued from page 4.

The human body is an orchestra, and the organs and glands are instruments in that orchestra. Some are in tune and some are out of tune. In order to get the music right, everything must be in tune.

As an example, let's look at the emotion of Anger. In Chinese Medicine, anger is associated with an imbalance of the liver. If one was to do a liver scan in order to evaluate this person's physical liver, it would be normal. If you drew blood tests, looking at the chemical liver (ALT, AST, GGTP), they would also be normal. That anger would manifest in certain clinical symptoms such as insomnia, with that person likely to awaken between 1 and 3 a.m. Or, the angry person might complain of headaches or migraines, another indicator of liver energy imbalance. To summarize, energy medicine would conclude that the emotion of anger has an effect on the energy of the liver, manifesting in symptoms such as headache or insomnia. Just as the electrical QRS complex of an EKG precedes the physical heartbeat, so do electrical (or energetic) changes in the organs precede chemical and physical abnormalities.

New NMO Clinical Trial Now Enrolling at the Mayo Clinic

Mayo Clinics in Minnesota and Arizona have launched a new clinical trial for NMO patients. The purpose of the database is to determine if eculizumab, a monoclonal antibody that interferes with complement activation, reduces the frequency of NMO attacks or improves outcome.

The Primary Outcome Measures the reduction in number of NMO attacks and determines safety for NMO. The Secondary Outcome Measures improvement in the quality of life, visual function and walking, and determines drug levels in blood and CSF.

Experimental Drug Intervention:

- The patient will receive eculizumab at a dose of 600mg intravenously (by infusion into the vein) each week for 4 weeks, 900mg intravenously at the fifth week, and 900mg every 2 weeks for 48 weeks.
- The first infusion will be given at Mayo Clinic (Minnesota or Arizona); subsequent infusions will be administered at home by a nurse employed by Coram Home infusion services (coordinated by a Study physician).

Eligibility

- Patients must be NMO-IgG seropositive, and have a diagnosis of NMO (defined by 2006 criteria) or an NMO spectrum disorder (recurrent optic neuritis or longitudinally extensive transverse myelitis).
- **Clinical evidence must document at least 2 relapses in the past 6 months or 3 relapses in the past 12 months (at least 1 relapse in the preceding 6 months).**
- The patient must be at least 18 years old.

If you are interested in this study and would like to hear more about it, please contact the investigators at the following locations.

Mayo Clinic - Arizona Principal Investigator: Dean M. Wingerchuk, M.D.
Contact: Irene Galasky 480-342-6104
galasky.irene@mayo.edu

Mayo Clinic - Minnesota Principal Investigator: Sean J. Pittock, M.D.
Contact: Karen Brekke 507-538-3761
brekke.karen@mayo.edu

Contact: Connie Brekke 507-266-3196
brekke.connie@mayo.edu

See <http://clinicaltrials.gov/ct2/show/NCT00904826>
for more information