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Cosmetics Pioneer Victoria Jackson: Mom on a Mission Adopts “Orphan Disease”

Founder of Guthy-Jackson Charitable Foundation leading quest to find cure for daughter, thousands of Americans suffering from disease unknown by most in medical establishment; bringing together world’s top doctors, medical researchers to share medical findings at 2009 Neuromyelitis Optica (NMO) Roundtable Conference, Nov. 9 – 11 in Los Angeles

Los Angeles (Nov. 9, 2009) — Without the usual search lights, red carpets and celebrities that mark so many premieres in Hollywood, a unique gathering is taking place this week with a human drama quietly playing out, more real and compelling than anything on the movie screen.

During the [2009 Neuromyelitis Optica \(NMO\) Roundtable Conference](#), Nov. 9 – 11 at the Tower Beverly Hills Hotel in Los Angeles, the world’s top doctors, medical researchers and patients are coming together in a collective pursuit for a cure for Neuromyelitis Optica (NMO) Spectrum Disease. NMO, a rare and debilitating disease — a so-called “orphan disease” — is often misdiagnosed as Multiple Sclerosis (MS). NMO attacks the optic nerves and spinal cord, often causing vision loss, paralysis of legs and arms, and sensory disturbances. It is also known as Devic’s Disease.

More than 50 doctors and medical researchers, who arrived from around the world, are presenting and sharing the latest scientific research conducted over the past year. They represent the top medical research institutions, including The Mayo Clinic; Stanford University, University of California, San Francisco; Johns Hopkins University and The Scripps Research Institute.

For the first time, the conference will host a patient session on Nov. 11 for those who have been diagnosed with NMO. Patients who attend the conference will be enrolled in the newly-established Guthy-Jackson Repository for NMO to collect much-needed blood samples for continued research. This new initiative, set up with the Accelerated Cure Project (ACP) and the University of Texas Southwestern, allows people with NMO to enroll into the repository at collection sites located in leading neurology clinics across the country.

Among the attendees is Victoria Jackson, who established the conference and founded the [Guthy-Jackson Charitable Foundation](#). Jackson, a prominent Los Angeles entrepreneur and philanthropist who founded Victoria Jackson Cosmetics, is a self-described Mom on a Mission who is responsible for bringing the doctors and patients together this week.

“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 the Guthy-Jackson Charitable Foundation,” says Jackson.

“I *am* on a mission. I *will* save my daughter. But it’s become much bigger than that. Through the 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,” Jackson adds. “There’s really no such thing as an ‘orphan disease’—if we find a cure for NMO, the chances increase that diseases such as MS will benefit. It’s about curing *and* caring. We’re all in this together.”

The patient session will enable patients to engage with top physicians and to share personal stories with others affected by the same disease. Assisted by the Foundation, the patients have come from across the United States, from Alaska and Maryland to Florida and here locally in California.

“Their decision to attend is an act of courage on a scale that most of us will never have to face,” says Jackson. “And that is why, for each and all of them, a cure must be found.”

Jackson established the [Guthy-Jackson Charitable Foundation](#) in July 2008, one month after her daughter’s diagnosis. After realizing there was little information, funding or research, she and her family knew they were working against the clock and took action. They quickly set up the foundation. Now, it is leading the effort to bring resources to a disease that has been ignored by, and in most cases, unknown within the medical community.

The foundation’s mission is to raise awareness about NMO among doctors, diagnosed and undiagnosed patients, researchers and policymakers. It is committed to being *the home* for NMO where patients and their families, the public and the medical community can find and share life-saving information and the latest medical research.

The foundation’s accomplishments to date are remarkable. In less than 18 months, it has established an annual medical conference dedicated to NMO, created the NMO Repository, and initiated and funded eight top research projects around the United States. More research projects are being considered and activated on a regular basis.

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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