

## Stories of Hope: Neuromyelitis Optica



In June 2008, **Victoria Jackson**, the creator of Victoria Jackson Cosmetics, was all about lip-gloss. Then, her middle child, Ali Guthy, started to lose her vision.

The diagnosis doctors provided was puzzling. The prognosis was worse. Her daughter had neuromyelitis optica (NMO) and she could be blind and paralyzed within four years.

From that moment, Jackson's life would never be the same. And neither would the lives of several researchers.

Jackson and her husband, Bill Guthy, quickly learned that almost no one studied this rare disease, which strikes fewer than one in 100,000 people. They traveled to Rochester, Minnesota, to see the nation's only expert, Dr. Brian Weinshenker, at the Mayo Clinic. But before they even left California, Jackson was beginning to plot.

"I was in action mode."

She told the surprised Mayo Clinic doctor, "I have a checkbook and I'm going to create a foundation and you and I are going to start our way in finding a cure."

Jackson quickly rallied experts in related areas and within weeks, researchers who did not know one another earlier were collaborating on the disease.

She has funded his work ever since through the Guthy-Jackson Charitable Foundation she and her husband created. "My focus went from mascara to medicine," she says. Ali has graduated from college, where she was the student body president, and while she still faces health challenges, she is neither paralyzed nor blind.

"Stem cells would be an important piece of the potential therapeutics for NMO," Jackson says. "The work that CIRM is doing is really important."