

# Rare Neuroimmune Disorders Symposium

Sponsored by Siegel Rare Neuroimmune Association

Sunday, October 10, 2021



## CIRCLES & SPHERES: NMOSD Studies

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[WWW.GUTHYJACKSONFOUNDATION.ORG](http://WWW.GUTHYJACKSONFOUNDATION.ORG)

# The Guthy-Jackson Charitable Foundation

**2008 – Present**

**Mission: Fund Research to Treat & Cure NMO**



**Victoria Jackson**

**Bill Guthy**

**Founders**



**Ali Guthy**

**Co-Founder**

# Research: Advancing NMOSD Knowledge

- International Panel for NMO Diagnosis (IPND)
- Relapse Navigator Tool for Adjudication
- International Conferences & Symposia
- Patient Advocacy & Resources
- 1800+ research publications
- SPHERES Longitudinal Study (sponsored by CorEvitas)



# The Guthy-Jackson Charitable Foundation

## CIRCLES: Science Saving Lives

- ✓ Longitudinal-observational study protocol
- ✓ Established & trusted patient study platform
- ✓ > 1 million clinical data elements in databank
- ✓ Biospecimen & data collection 2013 – 2020  
(15 academic centers) > 1,250 NMOSD cases & respective controls
- ✓ LabCorp/Covance – Support CIRCLES study sites, manage biospecimen storage, ship specimens in U.S. & internationally
- ✓ Univ. of Utah Data Coordinating Center - Clinical biospecimen database: biostatistics, research data mining studies

**C**ollaborative  
**I**nternational  
**R**esearch in  
**C**linical and  
**L**ongitudinal  
**E**xperience in NMO  
**S**tudies



# The Guthy-Jackson Charitable Foundation

## CIRCLES: Science Saving Lives

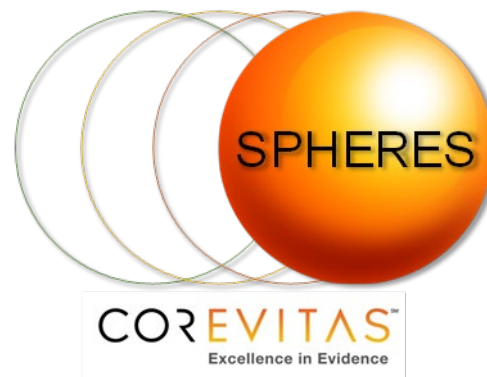
- Research Foundation: 103 Studies
- \$70 million invested
- NMO Bio & Data Repositories | 1100 subjects
- CIRCLES: 50+ research projects
- Facilitate clinical trials
- Intl Clinical Consortium | 112 Members & 30 Countries



# The Guthy-Jackson Charitable Foundation

## CIRCLES INTO SPHERES

A longitudinal NMOSD registry *Synergy of Prospective Health & Experimental Research in Emerging Solutions* will support real-world industry and academic studies on newly approved therapeutic effectiveness, safety and QoL on behalf of the NMOSD stakeholder community. Enrolling NOW.



- ✓ Patient awareness & enthusiasm to be part of a solution
- ✓ CoreVitas expertise & infrastructure in autoimmune space
- ✓ Informed by CIRCLES experience & momentum in NMOSD space
- ✓ GJCF trusted partnerships among NMOSD patients & KOLs



# The Guthy-Jackson Charitable Foundation

## CIRCLES INTO SPHERES

- ✓ Unique collaborative environment that generates regulatory-grade evidence (safety, efficacy, PRO, relapses), research resources, publications
- ✓ Exceptional economy of scale by working within a consortium of pharma partners for core data element & biospecimen acquisition



# NMO Patient Perspectives...

## **Female Patient:**

“Before NMO, I was a very active and happily employed mother and wife. Now I cannot work because of my disabilities and incontinence issues. I have to rely on special transportation services which are often unreliable. Costs of medicines and services are taking a big toll on my family.”

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# NMO Patient Perspectives...

## Male Patient:

As an NMO patient, I am concerned that my condition will worsen to the point I will become a burden to my family physically, financially and emotionally. I do not want to be alone, and I do not want to be a burden to them or anyone.

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# NMO Stories | Hear my Voice

## Patient & Caregiver Vignettes



Patients Helping Patients ~ Caregivers Helping Caregivers

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# NMO Stories | Hear My Voice

A Collection of Patient & Caregiver Vignettes

*In My Words- Donald*



**GUTHY JACKSON®**  
Charitable Foundation

# Call to Action: Patients & Caregivers

- Join us on social media
- Tell your NMO story in our Vignettes Program
- Respond through NMO surveys
- Participate in NMO events
- Encourage donations to help fund research



Thank You

Questions?

Please send to:

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