Resources & Support


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Resources & Support

6.1 Be Part of the NMO Movement

The mission to cure NMO is a living and breathing effort. Inspired by patients, it grows from family and friends to communities and countries. It is a hope and a plan to conquer NMO through dedication and determination to spread the word and find the answers. The NMO movement has many exciting parts always moving toward the goal of ending this rare disease once and for all. The following sections offer information and choices to participate as an NMO Advocate or Ambassador.

Get in motion with . . .

NMOtion

GET INVOLVED!

Visit guthyjacksonfoundation.org

6.2 Get in NMOtion▸ for NMO

QUICK READ

You are the cure. Everyone has a vital role to play in NMO research, education and awareness to find cures and save lives.

Every day, breakthrough advances in NMO research and medicine are being achieved. All over the world, clinicians, researchers, nurses, caregivers, families and friends are working with patients to learn more about NMO and find new answers. And, **there is much yet to be done to conquer NMO**.

Actively participating in the mission is the key to solve NMO. There are **many ways to participate** in this life-saving cause, and **everyone can do something**. Whether by joining a clinical trial or clinical research study such as the CIRCLES program (refer to Chapter 5), educating the community to raise NMO awareness or advocating on behalf of NMO patients, every hand and every voice counts.

There is a lot of work to be done. For example, **NMO can be unrecognized or initially diagnosed as MS or other disease, leading to inappropriate or delayed treatment**. Many doctors and even community neurologists have not yet heard of NMO or its new diagnostic criteria. Likewise, completing clinical trials relies on patients making informed decisions that can help themselves and other patients. All of these efforts and many others on the mission to cure NMO require education, awareness and advocacy. One of the most active programs toward these goals is **NMOtion▶**.

What is "NMOtion"?

NMOtion (pronounced "in motion") is the worldwide call to action dedicated to advancing research, education, awareness and advocacy for NMO. **NMOtion▶** is a living and breathing network that brings together all

stakeholders with the same goal: **end NMO once and for all**. **NMOtion▶** creates synergies that can help speed life-saving cures for NMO patients.

NMOtion▶ provides simple yet powerful options to take action in the mission for a cure. It is a gateway to clinical research, a platform for education and a podium to let your voice be heard. You can join programs to drive research, education, awareness, and advocacy and save lives, such as:

- Participate in the CIRCLES NMO Biobank
- Lead in the LEAD Campaign for Cures
- Promote the NMOpedia Education Platform
- Give voice to the NMO Ambassador Speakers' Bureau
- Become an NMO Advocate

What is the CIRCLES NMO Biobank?

Refer to Chapter 5 or visit:
guthyjacksonfoundation.org/blood-bank

6.3 Join the LEAD Campaign for Cures

LEAD Campaign for Cures

Everyone can be part of the mission to cure NMO. With so many exciting areas moving forward to cures, the foundation has created a bold new movement call the **LEAD Campaign for Cures**. **This program is about making choices and taking actions based on educating yourself of the latest NMO news.** From clinical trials seeking the first regulatory-approved treatments for NMO, to clinical studies testing new proof-of-concepts, being part of the cure is active not passive. **Each of us can decide how we can contribute to the cures through actions empowered by knowledge.**

The LEAD Campaign for Cures has **four basic steps to help**:

- **L**earn the facts about latest NMO research

  NMO knowledge is growing at an incredibly fast pace based on breakthrough research and clinical trials focused on improving patient lives. Mastering the facts empowers you to take action.

- **E**ngage in the healthy NMO conversation

  Being part of the mission to cure means more than just knowing about NMO. It means lending an open mind, a willing heart and a constructive voice to spread the word about NMO. From friends and families to community leaders, from physicians to philanthropists, everyone needs to know about NMO.

- **A**ssess your options to be part of the NMO cure

  There are many ways you can take the next step to solving NMO. There have never been more opportunities to be part of the NMO success story. Every hand and every voice counts, and the time to act is now.

  NMO patients and caregivers can best assess options regarding specific NMO treatment.

- **D**ecide how you will make an NMO difference

  Turning hopes into realities takes action. Everyone can contribute to the cure in their own way. It is for each of us to decide how we can help change the world of NMO for the better.

Be an NMO LEADer.

- Fresh challenge activity for **NMOtion▸**
- Main audiences: patients and doctors
- Integrate into GJCF educational assets
- Target for philanthropic development

For more information about the Lead Campaign, visit **guthyjacksonfoundation.org/lead**.

6.4 NMO Education Programs & Resources

NMOpedia Education Platform

NMOpedia is a digital education platform comprising of a series of informational PowerPoint presentations made available for the medical and scientific community by GJCF and its MAB. Each module offers a succinct exploration of the research surrounding NMO with clearly-defined learning goals. NMO Advocates are invited to share NMOpedia with medical personnel who are not familiar with NMO. For more information, visit **guthyjacksonfoundation.org/nmopedia**.

NMO Webinars & Podcasts

Helping to inform the NMO community about research and clinical trials, GJCF hosts online educational webinars and podcasts. NMO clinicians, scientists and industry delegates discuss clinical trials, how they work and what they might mean for NMO, as well as relevant topics in NMO research and education. Access these NMO webinars and podcasts on our website at: **guthyjacksonfoundation.org/podcasts**.

NMO Ambassador Speakers' Bureau

Providing information and educational support to raise awareness of NMO on behalf of patients is key to the cure. NMO is a rare, autoimmune disease that is often mistaken for MS. Yet, NMO is quite distinct from MS in terms of causes, manifestations, diagnosis, treatment and natural history. There may be several reasons for underdiagnosis of NMO, including lack of information or awareness about NMO within the medical professional

LOCATE RECORDINGS OF
NMO Clinical Trial
webinars and podcasts
by visiting NMOtion at:
guthyjacksonfoundation.org/clinical-trials

community. There is also a general lack of awareness regarding NMO in the general community. For these reasons, a critical need exists to enhance basic education and recognition of NMO to help all patients receive the best diagnosis and most appropriate treatment as quickly as possible.

Overview & Goal

The NMO Ambassador Speakers' Bureau is an informal education and program that connects NMO awareness from patients to healthcare professionals, through shared information and experience. The goal of this approach to communication is to facilitate patients receiving the best quality and timely care, and families, friends and communities learning what they can do to help spread the word.

Method

The program recruits and trains committed members of the general public or medical community to give NMO presentations in person to interested audiences. Volunteers register to become NMO Ambassador

Speakers by contacting The Guthy-Jackson Charitable Foundation (GJCF). The foundation offers free training and presentation resources accessible online.

To learn more about becoming a volunteer member of the NMO Ambassador Speakers' Bureau, visit the foundation's website at: guthyjacksonfoundation.org

Become an NMO Advocate

An advocate is anyone who acts on behalf of NMO patients, families or other stakeholders to help find answers that improve and save lives. Advocates are patients, caregivers, friends, family, community organizations, research and medical professionals, and any member of the public who raises awareness or works to find a cure for NMO. The **only requirement** for becoming an advocate is **persistence** and the **desire to make a difference** in the lives of those living with NMO.

To get started, create a free account on the foundation's website at:
guthyjacksonfoundation.org/register

What is an advocate's role?

Advocates work individually or as a group with established organizations to build awareness in their local areas. Efforts can include anything from fundraisers, events and meetings to bake sales, car washes and more. An advocate may be asked to speak to a group of people who are interested in learning more about NMO.

Awareness and education come in many forms:

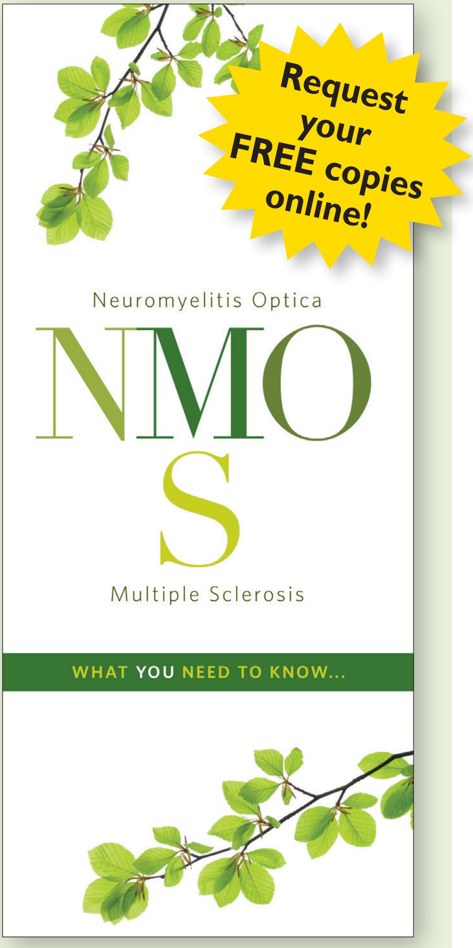
- Hosting educational presentations
- Hosting advocacy events
- Posting on social media
- Talking to friends and family

On **NMOtion▶** you can sign up to receive information about NMO clinical trials, opportunities to advocate for NMO and how to participate in the GJCF NMO CIRCLES biorepository (refer to Chapter 5).

For additional advocacy ideas visit the **NMOtion▶** website at: **guthyjacksonfoundation.org/nmotion**

NMO / MS...What You Need to Know Brochure

Help spread awareness about NMO!



The *NMO/MS What You Need to Know* brochure offers patients, advocates, and healthcare professionals additional resources to assist in considering NMO as a possible diagnosis.

Anyone can order these brochures. It's a great way to help educate:

- Clinicians
- Friends
- Nurses
- Event attendees
- Family
- Anyone else you can think of!

Request your free copies online at:
guthyjacksonfoundation.org/ms-nmo

How does GJCF support advocacy?

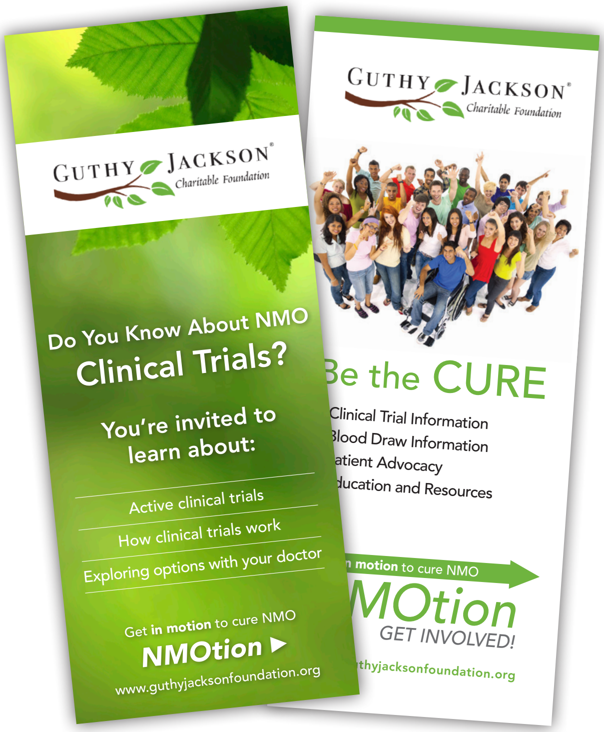
Advocates who are interested in hosting a community event may request an **NMO Share Package** that generally contain the following:

- Clinical Trials Information Card
- Items from the NMO Shop
- Brochures
- CD including:
  1. NMO Patient Resource Guide Card
  2. NMO Clinical Trial Information Card
  3. NMO fact sheet
  4. NMO CIRCLES biorepository fact sheet
  5. Rare disease fact sheet
  6. PowerPoint presentation about NMO and GJCF
  7. GJFC fact sheet
  8. GJRFI Giving Form for financial donations
- DVD with videos about NMO

All of these assets are also available for free download on the foundation's website. Visit **guthyjacksonfoundation.org/tools-for-download**.

NMO Helping Hands

NMO patients and families appreciate knowing that others care. Whether directly affected by NMO or not, everyone can help. NMO Helping Hands is a network of volunteers who are willing listeners who can offer support to NMO patients and families. Members of this network share their contact information on a purely voluntary basis. Typically, Helping Hands volunteers meet one another at NMO educational events or patient days, or maintain connectivity through social media or via phone. To learn more about becoming a volunteer member of NMO Helping Hands, visit the foundation's website at: **guthyjacksonfoundation.org**



NMO Clinical Trial Information Card

NMO Clinical Trial Information Card

Did you know that there are no current regulatory-approved therapeutics for NMO? For a therapeutic to be approved for NMO, formal clinical trial testing is required. There are a number of new NMO clinical trials underway seeking to establish specific treatments for NMO patients. To help raise awareness about NMO clinical trials, GJCF has produced an NMO Clinical Trial Information Card for the NMO community, which is shipped to NMO Advocates in the **NMO Share Package** free of cost. Visit **guthyjacksonfoundation.org/advocate** to become an Advocate and start raising awareness for NMO today.

Raise awareness on Social Media

Social media has become a powerful tool to help raise awareness about NMO. In addition to The Guthy-Jackson Charitable Foundation's Facebook, YouTube, and Twitter accounts, dozens of other NMO social media accounts and groups exist. Below are several hashtag keywords you can use when you post NMO education and awareness messaging on social media:

- #kNOwNMO
- #NMOtion
- #NMOclinicaltrials
- #NMOadvocacy
- #NMOawareness
- #NMOisnotMS

Donate to NMO Science

100% OF YOUR FINANCIAL DONATION goes directly to research for NMO as directed by The Guthy-Jackson Research Foundation, Inc. Visit: www.guthyjacksonfoundation.org/donate to donate today!

6.5 Patient Stories

Oftentimes, nothing speaks louder than genuine, real-life accounts of people living with a rare disease. Personal narratives are an essential part of building upon communication, interpreting experiences and incorporating new information. On the **NMOtion▶** site, the "Patient Stories" section offers reassurance and support from personal experiences shared by patients living with NMO.

Visit **guthyjacksonfoundation.org/stories** to share or read stories shared by our patient community.

6.6 Support Groups & Advocacy Organizations

The GJCF places a high value on its relationships with advocacy organizations in support of providing information, education and resources for those living with NMO. Joining a support group may be beneficial to NMO patients, caregivers, family and friends. New NMO support groups are being established all over the world. There are different types of NMO support groups ranging from in-person to telephone and online communities. You can access information about NMO support groups online at: **guthyjacksonfoundation.org/support-groups**.

Advocacy Organizations

American Foundation for the Blind
New York, NY
212-502-7600
www.afb.org

Christine Ha
The Blind Cook
theblindcook.com
christineha.com

CoachArt
Los Angeles, CA
www.coachart.org
213-736-2850

Craig Photography
craig-photography.blogspot.com

Myelin Repair Foundation
Saratoga, CA
408-871-2410
msfocus.org
Emai: info@myelinrepair.org

National Eye Institute (NEI)
Bethesda, MD
301-496-5248
nei.nih.gov
Email: 2020@nei.nih.gov

National Institute of Neurological Disorders and Stroke (NINDS)
Bethesda, MD
800-352-9424
braininfo@ninds.nih.gov
Email: ninds.nih.gov

National Organization for Rare Disorders (NORD)
Danbury, CT
800-999-NORD (6673)
rarediseases.org
Email: orphan@rarediseases.org

NMO Diaries
www.nmodiaries.com

NMO-UK Rare Illness Research Foundation c/o Neuro support
Liverpool, UK
nmo-ukresearchfoundation.org
Email: info@nmo-ukresearchfoundation.org

No More NMO – Riley's Story
nomorenmo.com

Office of Rare Diseases National Institutes of Health
Bethesda, MD
301-402-4336
rarediseases.info.nih.gov
Email: ord@od.nih.gov

Oxford University NMO Clinic Department of Clinical Neurology
Oxford, UK
01865 234461
www.nmouk.nhs.uk
Email: annaliza.rye@orh.nhs.uk

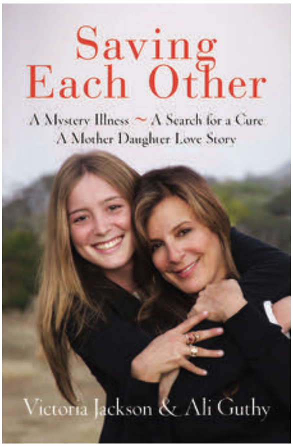
The NMO Clinical and Research Program at UBC Hospital and Vancouver Coastal Health
Vancouver, BC
nmo.vchri.ca

Transverse Myelitis Association
Powell, OH
myelitis.org

The Walton Centre NHS Foundation Trust
Liverpool, UK
www.nmouk.nhs.uk
Email: nmoadvice@
thwaltoncentre.nhs.uk

Visit the NMO Advocacy Network on **NMOtion▶**: **guthyjacksonfoundation.org/advocacy** for the complete list of advocacy organizations.

6.7 Suggested Reading



Saving Each Other

Authors: Victoria Jackson and Ali Guthy

In 2008, Victoria Jackson's daughter, Ali, began experiencing unusual symptoms of blurred vision and an ache in her eye. Her test results led to the diagnosis of a disease so rare, the chance that she had it was only 2%. Neuromyelitis optica (NMO) is a little understood, incurable, and often fatal autoimmune disease that can cause blindness, paralysis, and life-threatening seizures, and can afflict hundreds of thousands of people worldwide. At the age of 14, Ali was given a terrifying prognosis of between four to six years to live.

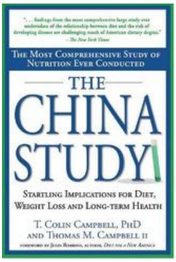
Saving Each Other: A Mother-Daughter Love Story begins just as Victoria and her husband Bill Guthy learn of Ali's disease, starting them on a powerful journey to save Ali, their only daughter, including bringing together a team of more than fifty of the world's leading experts in

100% of all profits directly support scientific and clinical research for neuromyelitis optica through The Guthy-Jackson Research Foundation, Inc.

autoimmune and NMO-related diseases to create The Guthy-Jackson Charitable Foundation, which aims to find a cure for NMO.

6.8 The Bookshelf

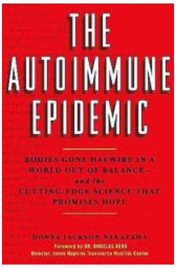
The GJCF welcomes diverse perspectives regarding autoimmune diseases. While it does not claim to agree with or refute their content, the following books may be of consideration for further reading:



The China Study

Author: T. Colin Campbell, Ph.D.

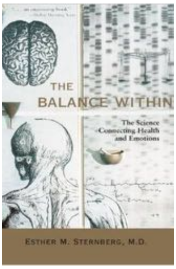
Referred to as the "Grand Prix of epidemiology" by The New York Times, the author examines more than 350 variables of health and nutrition with surveys from 6,500 adults in more than 2,500 counties across China and Taiwan, and suggests a connection between nutrition and heart disease, diabetes, and cancer.



The Autoimmune Epidemic

Author: Donna Jackson Nakazawa

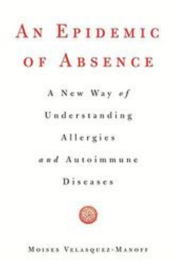
The author suggests how "autogens" — a term denoting chemical, lifestyle, and other triggers of autoimmune disease — may influence the human immune system. Methods to protect the immune system while exploring possible causes and potential remedies for many autoimmune diseases and autoimmune-related diseases are considered.



The Balance Within

Author: Esther M. Sternberg

The author examines how stress may contribute to susceptibility to disease and its potential impact on the immune system. She explores whether understanding of these connections in scientific terms may help to answer questions such as "does stress make you sick?", "is a positive outlook the key to better health?", and "how do personal relationships, work, and other aspects of our lives affect health?"



An Epidemic of Absence: A New Way of Understanding Allergies and Autoimmune Diseases

Author: Moises Velasques-Manoff

The author explores the dramatic rise of allergic and autoimmune diseases and the controversial, potentially groundbreaking therapies that scientists are developing to correct these disorders. The author's exploration includes the "worm therapy," probing the link between autism and a dysfunctional immune system, asking what will happen in developing countries regarding allergic disease and more.

Recipies from My Home Kitchen: Asian and American Comfort Food

Author: Christine Ha

Winner of Masterchef Season 3, in her kitchen, Christine Ha possesses a rare ingredient that most professionally-trained chefs never learn to use: the ability to cook by sense. After tragically losing her sight in her twenties, this remarkable home cook, who specializes in the mouthwatering, wildly popular Vietnamese comfort foods of her childhood, as well as beloved American standards that she came to love growing up in Texas, re-learned how to cook. Using her heightened senses, she turns out dishes that are remarkably delicious, accessible, luscious, and crave-worthy.

6.9 Spectrum: The Latest NMO Breakthroughs

Spectrum is The Guthy-Jackson Charitable Foundation's online NMO Library and is one of the largest collections of scientific and clinical NMO abstracts. **Every day, researchers are making more discoveries about NMO.** Learn about key topics like antibodies, aquaporins, astrocytes, therapies and much more. Inside the Spectrum NMO Library you will find also find a collection of topics ranging from diet and nutrition to autoimmunity in the forms of:

- **Scientific abstracts**
- **Videos**
- **Press articles**
- **Books**

The Guthy-Jackson Charitable Foundation's online NMO Library is one of the largest collections of scientific and clinical NMO abstracts.

Selections from the Spectrum NMO Library: Helpful NMO Publications for Clinicians, Scientists & Patients

Treatment of Neuromyelitis Optica: Review and Recommendations

Abstract

Neuromyelitis optica (NMO) is an autoimmune demyelinating disease preferentially targeting the optic nerves and spinal cord. Once regarded as a variant of multiple sclerosis (MS), NMO is now recognized to be a different disease with unique pathology and immunopathogenesis that does not respond to traditional MS immunomodulators such as interferons. Preventive therapy in NMO has focused on a range of immunosuppressive medications, none of which have been validated in a rigorous randomized trial.

However, multiple retrospective and a few recent prospective studies have provided evidence for the use of six medications for the prevention of NMO exacerbations: azathioprine, rituximab, mycophenolate mofetil, prednisone, methotrexate and mitoxantrone. This review provides a comprehensive analysis of each of these medications in NMO and concludes with a set of recommended consensus practices.

Integrative Continuum: Accelerating Therapeutic Advances in Rare Autoimmune Diseases

Abstract

Autoimmune diseases are chronic, life threatening, and of burgeoning public health concern. They rank among the 10 most common causes of death in women, and some have incidence rates surpassing those of heart disease and cancer. Emerging information regarding molecular and cellular mechanisms affords opportunities for the discovery of novel therapeutic strategies or the repurposing of FDA-approved pharmacologic agents. Yet, obstacles to drug development amplify as an inverse function of the incidence of rare autoimmune disease;

Help educate medical professionals
by downloading and sharing
NMO scientific papers and abstracts
from the NMO Library.

challenges include heterogeneous clinical presentation, paucity of definitive biomarkers, and poorly validated measures of therapeutic response. An integrative continuum model to address these challenges is being applied to neuromyelitis optica (NMO)—a potentially devastating neurodegenerative process that has had limited therapeutic options. This model links target discovery with pharmacologic application to accelerate improved clinical efficacy. The application of such innovative strategies may help researchers overcome barriers to therapeutic advances in NMO and other rare autoimmune diseases.

Visit the NMO Library now to download papers and abstracts to share with clinicians, family and friends at:
guthyjacksonfoundation.org/spectrum

6.9 NMO TV

Aimed at helping the NMO community have the latest information at its disposal, **NMO TV** showcases the foundation's extensive video library, featuring **over 100 videos** about NMO. Informational videos about different aspects of living with NMO are easily viewed along with relevant topics suggested to help expand your understanding about topics like scientific research, managing stress and fatigue, NMO FAQs, and much more. Visit **guthyjacksonfoundation.org/nmotv** to view the collection of videos about NMO.