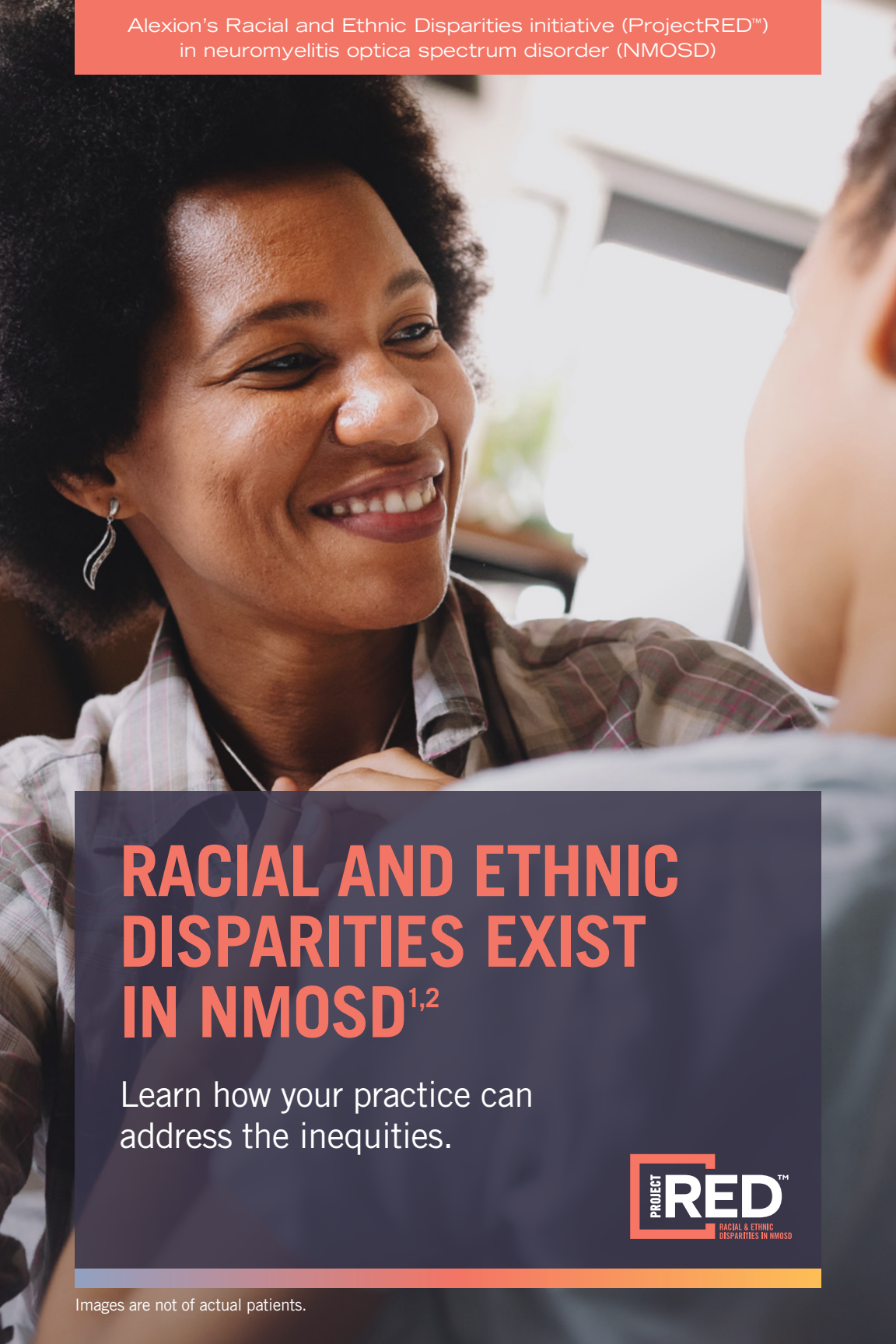
Alexion's Racial and Ethnic Disparities initiative (ProjectRED™) in neuromyelitis optica spectrum disorder (NMOSD)



RACIAL AND ETHNIC DISPARITIES EXIST IN NMOSD[1,2]

Learn how your practice can address the inequities.

PROJECT RED™
RACIAL & ETHNIC DISPARITIES IN NMOSD

Images are not of actual patients.

YOUR PATIENTS OF AFRICAN AND ASIAN ETHNICITIES MAY BE UNEQUALLY IMPACTED BY NMOSD[1,2]*

Consider key disparities while testing or caring for these patients.

AT A GLANCE

What is NMOSD?

- NMOSD is a rare autoimmune disease of the central nervous system[3,4]
- It is characterized by unpredictable, recurrent, and potentially life-threatening attacks[5,6†]
- Attacks may contribute to cumulative disability[4,7]

Demographic data

5:1 Female to male ratio[8]

Patients of African and Asian ethnicities have a higher NMOSD prevalence rate than other patients[3]

DISEASE ONSET

Mean age of symptom onset[1‡]

33 years African ethnicity

36 years Asian ethnicity

44 years Caucasian ethnicity

Patients of African and Asian ethnicities experienced symptoms at a younger age than Caucasian patients.[1]

Attack at onset

Patients of African ethnicity had a severe attack at onset more often than Caucasian patients.[1]

MORTALITY

Overall mortality rate[9§]

Deaths

90% African ethnicity

10% All other ethnicities

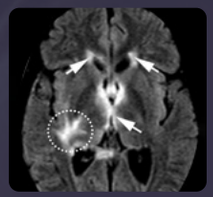
While patients of African ethnicity made up 41% (175/427) of the NMOSD population in one study, they accounted for 90% (27/30) of deaths (P<0.0001).[9]

Average age of death

The average age of death was younger in patients of African ethnicity than Caucasian patients.[9]

MRI RESULTS

Patients of African and Asian ethnicities exhibited more frequent brain abnormalities on MRIs compared to Caucasian patients.[1]



Reprinted with permission from *Radiographics*, 2018;38(1):169-193. ©RSNA[10]

Abbreviation: MRI, magnetic resonance imaging.

*Based on a prospective study of 441 anti-aquaporin-4 (AQP4) antibody-positive NMOSD patients across 4 countries with varied ethnicities who collectively experienced 1976 attacks.[2]

†The terms "attack" and "relapse" are used interchangeably.

‡A retrospective review of 603 patients with anti-AQP4 antibody-positive NMOSD identified from 2006 to 2017 from 6 treatment centers across Denmark, Germany, South Korea, United Kingdom, United States, and Thailand.[1]

§A retrospective study of 427 patients with NMOSD, as defined by the 2015 International Panel for NMO Diagnosis, seen at Johns Hopkins Hospital and New York University.[9]

CONSIDERATE, TIMELY CARE IS CRUCIAL FOR THESE PATIENTS[1,9]

Patients could face circumstantial barriers that may further complicate their NMOSD journey.

Circumstances and challenges that may exist:

HISTORICAL HEALTHCARE MYTHS

It is untrue that patients of color have a higher pain tolerance than other patients and that women dramatize their symptoms.[11,12]* It is important to take pain and symptoms seriously regardless of any historical misconceptions.

LANGUAGE

Not every patient may have English as their first language. If there is a language gap, The Guthy-Jackson Charitable Foundation has multilingual NMOSD resources that may help.

See back cover for more resources.

RESPONSIBILITIES AT HOME

Most NMOSD patients are female, and for minority patients, average symptom onset occurs during childbearing and family planning ages.[1,8,13] Consider the at-home factors and emotions that may also influence these patients' NMOSD journeys.

*The results of survey-based studies of hypothetical pain-reporting behavior indicated that patients of color do not have a higher pain tolerance than other patients, and women do not tend to overreport their pain severity.[11,12]

LEARN MORE ABOUT THE IMPACT TIMELY CARE CAN HAVE

Visit **NMOSD.com** to listen to a patient with NMOSD, who is also a physician, share their diagnosis story.

TEST FOR NMOSD AS SOON AS CLINICAL CHARACTERISTICS ARE PRESENT[14]

For your high-risk patients, diagnosing NMOSD as early as possible is critical.[1,9]

There is a risk of misdiagnosing NMOSD as MS[6]

42.5% of patients with NMOSD (31/73) were initially misdiagnosed with multiple sclerosis (MS) according to available data in a retrospective study[6]*

***The wrong diagnosis of MS became less common after anti-AQP4 antibody testing became commercially available in 2005 (20% vs 54.2% before 2005; *P*<0.007).[6]**

~73% of people with NMOSD are anti-AQP4 antibody positive[15]

These antibodies are not present in MS patients.[16]

Diagnostic criteria for patients with anti-AQP4 antibody-positive NMOSD[14]

1. At least 1 core clinical characteristic
   - Optic neuritis
   - Acute myelitis
   - Area postrema syndrome
   - Acute brainstem syndrome
   - Symptomatic narcolepsy or acute diencephalic clinical syndrome with NMOSD-typical diencephalic MRI lesions
   - Symptomatic cerebral syndrome with NMOSD-typical brain lesions
2. Positive test for anti-AQP4 antibodies
3. Exclusion of alternative diagnoses, such as MS, sarcoidosis, or neoplasm

Conducting a full diagnostic workup—including a complete medical history and physical exam, antibody testing with a cell-based assay, electrophysiological analysis, and imaging studies—is key to confirming NMOSD.[14,17]

ProjectRED™, Alexion's Racial and Ethnic Disparities initiative, and key resources

ALEXION IS TAKING MEASURES TO REDUCE DEMOGRAPHIC-RELATED DISPARITIES IN NMOSD

ProjectRED aims to address some of the diagnostic and care disparities faced by NMOSD patients of African and Asian ethnicities by raising awareness and partnering with various NMOSD organizations.

Alexion hopes that with the help of healthcare providers like you, we can make a difference in the lives of patients who are unequally impacted by this disease.[3]

ProjectRED RESOURCES FOR YOUR PRACTICE AND PATIENTS

To find NMOSD resources translated into 13 different languages, visit
GuthyJacksonFoundation.org

For more information on NMOSD and its diagnostic process, visit
NMOSD.com

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ALEXION
AstraZeneca Rare Disease