

# *Putting your health first in NMOSD*

Anti-aquaporin-4 (AQP4) antibody-positive neuromyelitis optica spectrum disorder (NMOSD) calls for proactive education and working with your doctor to help manage your disease.

Today's presenter: [Name], PEM





# *I'm your Patient Education Manager (PEM), and I'm here to help*

**My focus today is to give you information you can use**

## ▶ **NMOSD education**

I provide an overview of anti-AQP4 antibody-positive NMOSD at meetings just like this.

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## ▶ **FDA-approved treatment option**

I share information about one way to help manage your risk of relapses for this disease.

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## ▶ **Support**

I'm here to give you and your loved ones free, personalized support and connect you to resources.

# ***We're glad you're here!***

## **A few housekeeping items before we begin:**



Please do not take photos or videos during the presentation.  
This will ensure your privacy and that of other attendees.



Please silence your cell phones.



Remember that the information in this presentation is intended to be educational for people living with NMOSD and their caregivers. It does not replace a doctor's independent medical judgment or clinical diagnosis.  
It is important that you speak with your doctor about your NMOSD and any specific symptoms you may be experiencing.

# *Today, we will:*

## *Talk about anti-AQP4 antibody- positive NMOSD*

- Disease basics
- The role of complement
- Relapses

## *Learn about an FDA-approved treatment option for this disease*

- Complement inhibition
- Efficacy and safety
- Vaccinations
- Dosing

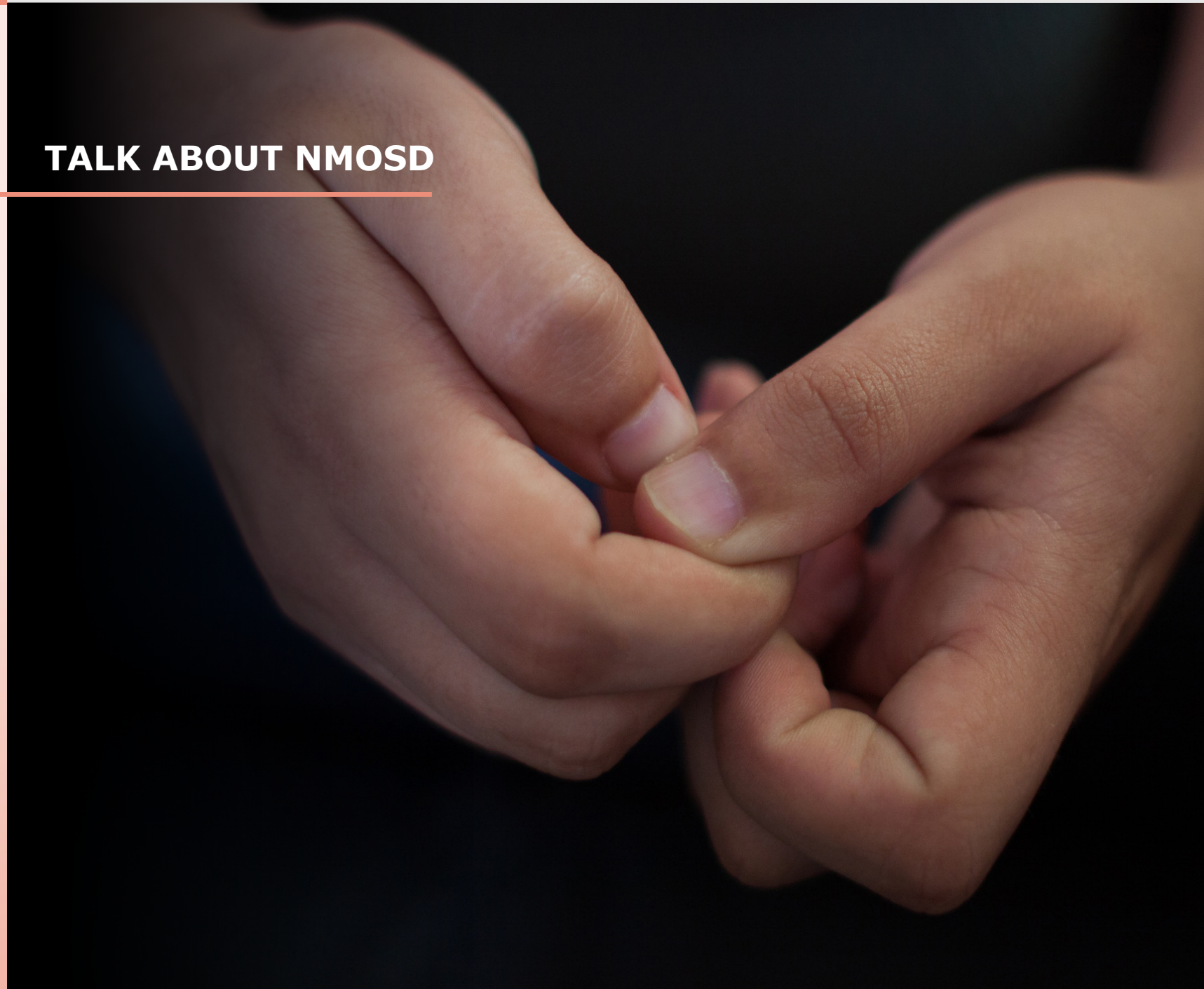
## *Discuss helpful resources*

- OneSource™
- Online tools and resources
- Connecting to other NMOSD patients



## TALK ABOUT NMOSD

***You never  
know when  
your next  
relapse  
may occur***



# Living with NMOSD

## Immune disorder

▶ NMOSD is a rare autoimmune disease that causes your immune system to attack your central nervous system and is characterized by relapses.

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## Potential damage

▶ Relapses are defined as new or worsening neurological symptoms that last for more than 24 hours when you've been stable for at least 30 days. Any NMOSD relapse can potentially cause permanent damage, most commonly to your optic nerves, brain, and/or spinal cord.

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## Uncertainty

▶ Relapses are unpredictable and may be severe and recurrent. Each one has the potential for permanent damage.

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## Risks

▶ People with anti-aquaporin-4 (AQP4) antibody-positive NMOSD face a high risk of relapse, which can be potentially severe and recurrent.

**~73%** of people with NMOSD test positive for anti-AQP4 antibodies.

**Up to 93%** of people with anti-AQP4 antibody-positive NMOSD have relapsed.

# Anti-AQP4 antibodies activate part of your immune system to attack your central nervous system

These antibodies send signals to the complement system to cause damage



**The complement system is like your body's sprinkler system.** When complement detects bacteria or viruses, its job is to eliminate them, similar to how a sprinkler system sprays water when it detects a fire.



**Having NMOSD is like having a sprinkler system that's turned against you.** When you have this disease, complement isn't doing its normal job. The sprinkler is set off even when it's not supposed to be, so it causes damage from all the water.

**Complement system:**  
a part of your immune system that normally helps protect your body from threats like bacteria, viruses, or certain infections.

# ***Your doctor can help you understand the role of complement in anti-AQP4 antibody-positive NMOSD***

Here are some conversation starters for the other topics we've covered

## ***Status***

Ask about your anti-AQP4 antibody status.

## ***Relapses***

Mention all of your relapses, no matter how small.

## ***Risk***

Focus on how to help reduce your risk of relapse.

**Reducing your risk of relapse is an important goal to help manage your disease.**





## LEARN ABOUT AN NMOSD TREATMENT OPTION

**SOLIRIS**<sup>®</sup>  
(eculizumab)  
Injection for Intravenous Use  
300 mg/30 mL vial

**The first and only complement  
inhibitor approved by the FDA for  
adults with anti-AQP4 antibody-  
positive NMOSD**

### INDICATION

#### What is SOLIRIS?

SOLIRIS is a prescription medicine used to treat adults with a disease called neuromyelitis optica spectrum disorder (NMOSD) who are anti-aquaporin-4 (AQP4) antibody positive. It is not known if SOLIRIS is safe and effective in children with NMOSD.

**Please see Important Safety Information throughout and the full Prescribing Information and Medication Guide for SOLIRIS, including Boxed WARNING regarding serious and life-threatening meningococcal infections, provided at this presentation. US/SOL-N/0330 10/21**

## SELECT IMPORTANT SAFETY INFORMATION

**What is the most important information I should know about SOLIRIS?**

**SOLIRIS is a medicine that affects your immune system and can lower the ability of your immune system to fight infections.**

- **SOLIRIS increases your chance of getting serious and life-threatening meningococcal infections that may quickly become life-threatening and cause death if not recognized and treated early.**
1. You must receive meningococcal vaccines at least 2 weeks before your first dose of SOLIRIS if you are not vaccinated.
  2. If your doctor decided that urgent treatment with SOLIRIS is needed, you should receive meningococcal vaccination as soon as possible.
  3. If you have not been vaccinated and SOLIRIS therapy must be initiated immediately, you should also receive two weeks of antibiotics with your vaccinations.
  4. If you had a meningococcal vaccine in the past, you might need additional vaccination. Your doctor will decide if you need additional vaccination.
  5. Meningococcal vaccines reduce but do not prevent all meningococcal infections. Call your doctor or get emergency medical care right away if you get any of these signs and symptoms of a meningococcal infection: headache with nausea or vomiting, headache and fever, headache with a stiff neck or stiff back, fever, fever and a rash, confusion, muscle aches with flu-like symptoms, and eyes sensitive to light.

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## SELECT IMPORTANT SAFETY INFORMATION

**Your doctor will give you a Patient Safety Card about the risk of meningococcal infection.** Carry it with you at all times during treatment and for 3 months after your last SOLIRIS dose. It is important to show this card to any doctor or nurse to help them diagnose and treat you quickly.

**SOLIRIS is only available through a program called the SOLIRIS REMS.**

Before you can receive SOLIRIS, your doctor must enroll in the SOLIRIS REMS program; counsel you about the risk of meningococcal infection; give you information and a **Patient Safety Card** about the symptoms and your risk of meningococcal infection (as discussed above); and make sure that you are vaccinated with the meningococcal vaccine and, if needed, get revaccinated with the meningococcal vaccine. Ask your doctor if you are not sure if you need to be revaccinated.

**SOLIRIS may also increase the risk of other types of serious infections.** Certain people may be at risk of serious infections with gonorrhea. Certain fungal infections (*Aspergillus*) may occur if you take SOLIRIS and have a weak immune system or a low white blood cell count.

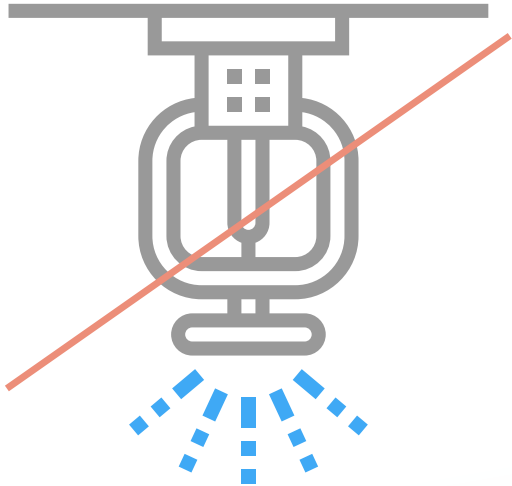
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# ***SOLIRIS<sup>®</sup> (eculizumab) is a complement inhibitor***

SOLIRIS inhibits complement, but the exact manner that SOLIRIS works as a treatment for NMOSD is unknown.



**You can think of SOLIRIS as a way to help stop the sprinkler system from setting off when it's not supposed to.**

SOLIRIS is **the only FDA-approved complement inhibitor** for the treatment of anti-AQP4 antibody-positive NMOSD in adults.

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# ***SOLIRIS<sup>®</sup> (eculizumab) was studied in adults with anti-AQP4 antibody-positive NMOSD***

- ▶ **A 3-year clinical trial, called PREVENT, studied the safety and efficacy of SOLIRIS compared to placebo**
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- ▶ **It tested SOLIRIS in 143 adults with anti-AQP4 antibody-positive NMOSD**
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- ▶ **The primary goal of the study was to determine the time to first adjudicated relapse**

**Adjudicated relapse:** An independent committee of medical experts confirmed that a relapse has occurred.

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# *Details of participants in the PREVENT trial*

## ***Patients***

143 adults with anti-AQP4 antibody-positive NMOSD enrolled (96 received SOLIRIS, 47 received placebo)

## ***Demographics***

White: 49%

Asian: 36%

Black or African American: 12%

Other/unknown: 3%

## ***IST use***

Immunosuppressive therapies (ISTs) such as corticosteroids were allowed, although some people received only SOLIRIS. Many ISTs such as rituximab were not allowed

## ***Primary goal***

Determine the time to first adjudicated relapse

## ***Average number of relapses***

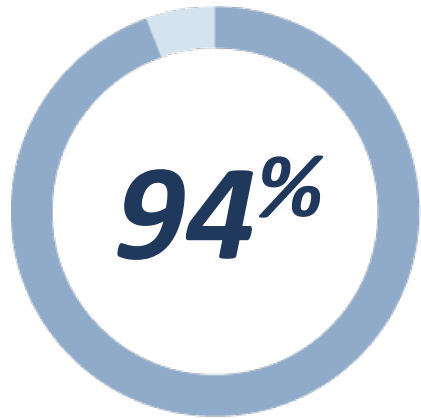
~2 per year in the 2 years prior to enrollment

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# *The primary goal of the PREVENT study was achieved*

**Adult patients who received SOLIRIS® (eculizumab) took longer to have a relapse than those receiving placebo**



There was a **94% reduction in risk of relapse** for patients treated with SOLIRIS vs placebo.

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## **SELECT IMPORTANT SAFETY INFORMATION**

### **Who should not receive SOLIRIS?**

Do not receive SOLIRIS if you have a meningococcal infection or have not been vaccinated against meningitis infection unless your doctor decides that urgent treatment with SOLIRIS is needed.

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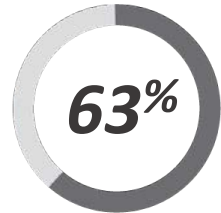


## *The primary goal of the PREVENT study was achieved (cont.)*

**Adult patients who received SOLIRIS® (eculizumab) took longer to have a relapse than those receiving placebo**



In addition, at 48 weeks, **98% of patients treated with SOLIRIS were relapse free**



vs 63% of those treated with placebo

### **SELECT IMPORTANT SAFETY INFORMATION**

**Before you receive SOLIRIS, tell your doctor about all of your medical conditions, including if you:** have an infection or fever, are pregnant or plan to become pregnant, and are breastfeeding or plan to breastfeed. It is not known if SOLIRIS will harm your unborn baby or if it passes into your breast milk.

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# *Safety during the SOLIRIS<sup>®</sup> (eculizumab) PREVENT trial*

**The most common side effects in adults with anti-AQP4 antibody-positive NMOSD treated with SOLIRIS include:**

- Common cold (upper respiratory infection)
- Pain or swelling of your nose or throat (nasopharyngitis)
- Diarrhea
- Back pain
- Dizziness
- Flu-like symptoms (influenza) including fever, headache, tiredness, cough, sore throat, and body aches
- Joint pain (arthralgia)
- Throat irritation (pharyngitis)
- Bruising (contusion)

**Tell your doctor about any side effect that bothers you or that does not go away. These are not all the possible side effects of SOLIRIS. For more information, ask your doctor or pharmacist.**

**Call your doctor for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit MedWatch, or call 1-800-FDA-1088.**

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# Starting treatment with SOLIRIS® (eculizumab)

**You must receive meningococcal vaccines at least 2 weeks before your first dose of SOLIRIS if you have not already had them**

## Why are the vaccines needed?

- Because SOLIRIS is a complement inhibitor (and your complement system normally helps fight infections), it increases your chance of getting meningococcal infections. SOLIRIS may also increase the risk of other types of serious infections
- Meningococcal vaccines reduce this risk of meningococcal infections but do not prevent all of them. These vaccines are required before starting SOLIRIS to make sure it's being used as safely as possible

If you had meningococcal vaccines in the past, you might need additional vaccinations before starting SOLIRIS. Talk to your doctor to make sure you are up to date with your vaccines.

## SELECT IMPORTANT SAFETY INFORMATION

**Tell your doctor about all the vaccines you receive and medicines you take**, including prescription and over-the-counter medicines, vitamins, and herbal supplements which could affect your treatment. It is important that you have all recommended vaccinations before you start SOLIRIS, receive 2 weeks of antibiotics if you immediately start SOLIRIS, and stay up-to-date with all recommended vaccinations during treatment with SOLIRIS.

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# Starting treatment with SOLIRIS® (eculizumab)

There are many locations where you can go to get your meningococcal vaccinations, including but not limited to:

Doctor's  
office

Pharmacies

Local health  
centers  
and health  
departments

Travel  
clinics

Before you start SOLIRIS, talk to your doctor. They will reference the most up-to-date Advisory Committee on Immunization Practices (ACIP) recommendations and prescribe medically appropriate vaccines according to his or her independent medical judgment.

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# How often do you receive SOLIRIS® (eculizumab)?

**SOLIRIS goes directly into your veins via intravenous (IV) infusion and is administered by a trained healthcare professional**



*dosing  
schedule*

## Dosing occurs in 2 phases:

- 1** For the first 5 weeks, you'll receive SOLIRIS once per week.
- 2** Thereafter, you only need to get an infusion once every 2 weeks.

SOLIRIS was studied as an ongoing therapy. Your doctor will discuss the treatment timeline with you since it's important to follow the prescribed schedule. If you miss a SOLIRIS infusion, call your doctor right away. If you have an infusion-related reaction, your doctor may decide to give SOLIRIS more slowly or stop your infusion.

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# How long will your SOLIRIS<sup>®</sup> (eculizumab) infusion take?



**35 minutes**

You can expect your infusion to last about 35 minutes, plus 1 hour of monitoring by a healthcare professional for infusion-related reactions.



## Interested in home infusion?

It may be an option based on your insurance coverage and location.

## SELECT IMPORTANT SAFETY INFORMATION

### What are the possible side effects of SOLIRIS?

**SOLIRIS can cause serious side effects including serious infusion-related reactions.** Tell your doctor or nurse right away if you get any of these symptoms during your SOLIRIS infusion: chest pain, trouble breathing or shortness of breath, swelling of your face, tongue, or throat, and feel faint or pass out. If you have an infusion-related reaction to SOLIRIS, your doctor may need to infuse SOLIRIS more slowly, or stop SOLIRIS.

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**The most common side effects in people with NMOSD treated with SOLIRIS include:** common cold (upper respiratory infection), pain or swelling of your nose or throat (nasopharyngitis), diarrhea, back pain, dizziness, flu like symptoms (influenza) including fever, headache, tiredness, cough, sore throat, and body aches, joint pain (arthralgia), throat irritation (pharyngitis), and bruising (contusion).

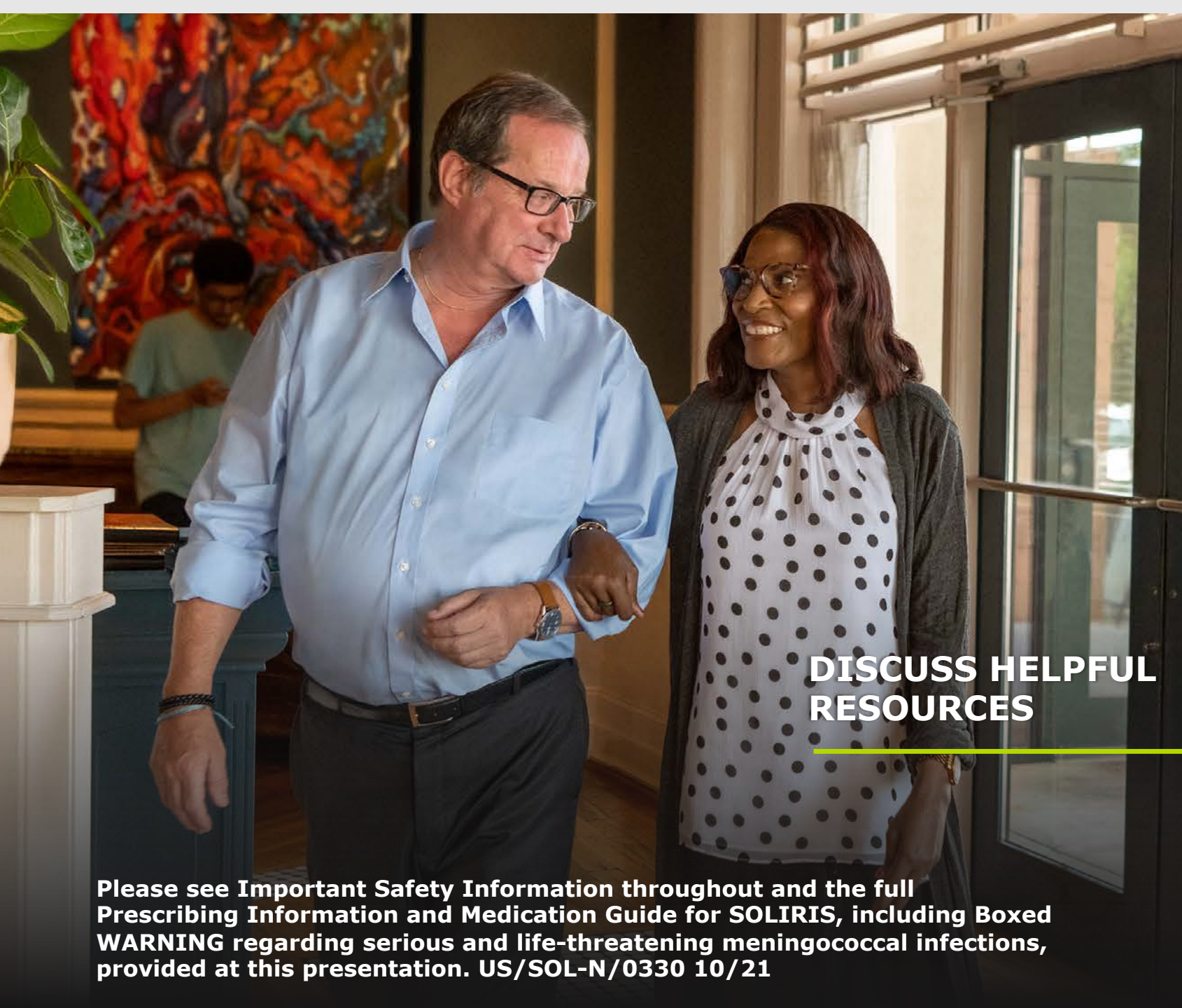
Tell your doctor about any side effect that bothers you or that does not go away. These are not all the possible side effects of SOLIRIS. For more information, ask your doctor or pharmacist. Call your doctor for medical advice about side effects. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit MedWatch, or call 1-800-FDA-1088.



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**DISCUSS HELPFUL  
RESOURCES**

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***Resources  
to consider  
in your  
NMOSD  
journey***

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# *OneSource, a valuable resource along your journey*



## **Disease information**

- Educational and useful information related to your rare condition, such as brochures and website resources
- Questions about treatment logistics



## **Ongoing support**

- Help when your treatment location or insurance coverage changes to make your transition go smoothly
- Support during life events like getting married, planning a vacation, getting new insurance, or getting a new job



## **Health insurance navigation**

- Information to understand your insurance plan and your coverage options
- Information on alternative funding options and resources if you have funding concerns or gaps in coverage



## **Community connections**

- In-person and online meetings and events
- Patient support meetings
- Advocacy groups
- The opportunity to connect with other individuals living with your condition

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Neuromyelitis  
Optica Spectrum  
Disorder



**PEER  
CONNECTS**



## Every person living with NMOSD has their own story to tell

Now there's an easy way to talk one-on-one with another adult living with anti-AQP4 antibody-positive NMOSD.

Alexion's Peer Connects can:

- **Help you understand NMOSD**, its impact, and how to live with it
- **Offer personal stories** and experiences
- **Provide support** and an understanding voice

Enroll in Peer Connects at  
**NMOSDPeerConnects.com**  
**1-877-576-7589**

These programs are sponsored by Alexion Pharmaceuticals, Inc. and intended only for US patients and caregivers who are 18 years or older.

***“Peer Connects is something I do because I really understand how it feels to live with anti-AQP4 antibody-positive NMOSD. When I talk with someone on the phone, they can bring up issues and I can share my point of view. Sometimes, I just listen. Other times, I can offer support or insight.”***



**Glenice C.**

LIVING WITH NMOSD  
CURRENTLY RECEIVING  
SOLIRIS® (eculizumab)

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# ***Giving priority to your health***

**Beyond managing your anti-AQP4 antibody-positive NMOSD,  
you need to think about your overall health**

## **Talk with your doctor about:**

- 1** Physical health
- 2** Emotional health
- 3** Lifestyle and wellness
- 4** Support groups

### **Living a healthy lifestyle**

You might use exercise, stretching, splints, or other assistive devices to stay safe and healthy.

For more ideas, you can visit **WeAreSRNA.org**



# *Your journey, your way*

## ▶ **Meet others who understand**

You don't have to feel alone. I can help you reach out to others in the rare disease community.

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## ▶ **Get connected**

I can give you more details about our Peer Connects phone-based program.

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## ▶ **Stay connected**

OneSource program can send tips and support right to your inbox.





# *Thank you for your attention*

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Talk to your doctor to see  
if SOLIRIS® (eculizumab) is  
right for you.

For more information, visit

**SOLIRISNMOSD.com**

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