



# European NMOSD Toolkit

October 2023

# Introduction

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This European NMOSD Toolkit intends to provide easily accessible information and tips to people impacted by NMOSD in Europe, including individuals living with NMOSD and those that care for them, those that know someone affected by NMOSD, and those who simply want to learn more.

The European NMOSD Toolkit has been created following a series of NMOSD Patient Advisory workshops, which brought together 11 experts by experience, including people living with NMOSD and those caring for them. Discussions at these workshops revealed a lack of information and resources about NMOSD as a key challenge facing people impacted by NMOSD in Europe. This Toolkit seeks to help plug this information gap.

The Toolkit complements existing resources and information and has been co-created with the NMOSD patient community.

This Toolkit has been co-created by the following organisations:



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Although NMOSD is a serious disease, it is important to remember that it is still possible to live a good life and that help is available.

*“ Each patient has a different story with the disease, and yet each has transformed that story with great strength and transformation in their daily lives beyond NMO. Beyond NMO there is life, because there is a story, patients, organizations. We are all together to share and go beyond NMO. You are not alone.*

*The patient experience today is an ode to life, and you’ll find these resources from people who’ve been through it. ”*

Souad Mazari, NMOSD patient, Founder of NMO France

*“ I’m Matthias, Husband, Engineer and Patient of NMOSD for over 10 years now. With the first symptoms, the diagnosis and progressing disabilities I really lost orientation. Easily accessible information is the key to new, positive perspectives of a life with a rare disease. It’s even the base to take the progression of my health back into my own hands. ”*

Matthias Fuchs, NMOSD patient, Sumaira Foundation Ambassador for Germany

*“ I’m Christine and I’m a care giver to an NMOSD patient. Not knowing what amount of help I should provide was one of the hardest lessons I had to learn. Due to the illness we shifted our priorities in life and reached possibilities we never expected before. But it’s also important to take a deep breath from time to time outside of the NMOSD ocean, to get a new focus, fresh energy. So I don’t lose myself. ”*

Christine Fuchs, caring for someone living with NMOSD

*“ It is important to remember that although NMOSD will change your life as you know it, the change doesn’t have to mean less life quality. Change always creates opportunities. You just have to grasp them, don’t get stuck on how it used to be, but how it can be. The NMOSD community will aid you on your journey. ”*

Martin Bresnov, caring for someone living with NMOSD

*“ NMOSD is a serious disease, but it doesn’t define you. With a positive mindset focusing on what you can control and good support, you can still live a meaningful and good life, beyond all the challenges this disease may confront you with. ”*

Leda Bresnov, NMOSD patient, Sumaira Foundation Ambassador for Denmark

*“ Look at your NMOSD as a new part of yourself, which takes you to the next chapter in life and teaches you things about yourself you never knew. See the adventure of it, be curious and enjoy life again on a whole different level. ”*

Els Roelandt, NMOSD patient, Sumaira Foundation Ambassador for Belgium








*“ NMOSD has taught me a lot about myself, and I’ve learned the hard way to get my priorities straight. Today, I work full time. Tomorrow, who knows? I guess I’ll just have to cross that bridge when I get to it. You don’t choose to live with disabilities, but you can choose whether you let them define you as a person or not. ”*

Sofia Knutsson, NMOSD patient, Sumaira Foundation Ambassador for Sweden



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Note that text that is **formatted like this** is a hyperlink to more information. Please note that this PDF contains links to external sites which may not offer the same level of protection as this site. This website is not responsible for the content of any external sites.



# What is NMOSD?

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Neuromyelitis optica (NMO), neuromyelitis optica spectrum disorder (NMOSD) and Devic's disease are different names for the same condition.

## **NMOSD is a treatable autoimmune disease.**

It causes inflammation in different locations of the central nervous system (CNS). The body's own defence cells begin to attack healthy tissue.<sup>1</sup>

The disease can **impair vision and mobility** and can also cause severe nausea, vomiting and hiccups, as well as other symptoms.<sup>2</sup>

- NMOSD affects more than 10,000 people in Europe alone.<sup>3</sup>
- It is nine times more likely to occur in women,<sup>4</sup> usually in their 30s and 40s.<sup>3</sup>
- People of African or Asian descent are also disproportionately affected.<sup>5</sup>

Left untreated, 90% of people impacted will experience repeat attacks within five years of an initial attack.<sup>6</sup> **Timely diagnosis is therefore important** to ensure the most effective treatment and best quality care possible to manage the condition.

*“ NMOSD turns your world upside down, everything you knew changes. Give yourself the time to adjust. And restart your life with NMOSD as your companion. ”*

Els Roelandt, NMOSD patient, Sumaira Foundation Ambassador for Belgium

*“ NMOSD has changed my life immensely. The most obvious change is my wheelchair, which I use for all trips outside of my home. It is clear to everyone that my illness is associated with a disability. But most of the disabilities of NMOSD patients lie below the visible surface. And it is precisely these restrictions that cost so much strength and energy in everyday life. In particular, concentrating on one's own abilities and accepting help are crucial change processes. ”*

Matthias Fuchs, NMOSD patient, Sumaira Foundation Ambassador for Germany

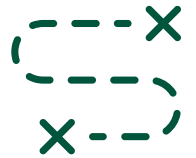
## Additional resources

- The Sumaira Foundation – **What to KNOW** about NMO
- The Guthy-Jackson Charitable Foundation – **About NMO**
- The Guthy-Jackson Charitable Foundation – **10 Steps Forward**
- SRNA – **What is NMOSD?**
- AISM – **Neuromyelitis optica: 10 things you should know**
- Horizon Therapeutics – **NMOSD in focus**
- EMSP – **Diseases similar to MS**
- AINMO – **What is NMOSD?** [*Italian language resource*]
- NMO France – **Neuromyelitis Optic (NMO) and NMO Spectrum Disorders (NMOSD)**. [*French language resource*]

## References

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1. Bennett JL, O'Connor KC, Barrow A et al. (2015). B lymphocytes in neuromyelitis optica. *Neurol Neuroimmunol Neuroinflamm*. 2(3):e104. doi:10.1212/NXI.0000000000000104.
2. The Sumaira Foundation. **What to know about NMO**. Accessed January 2023.
3. European Alliance for Patient Access (2022). **Unmet Needs in Neuromyelitis Optica Spectrum Disorders in Europe**.
4. Wingerchuk DM. (2009). Neuromyelitis optica: effect of gender. *J. Neurol Sci* 286(1-2):18-23.
5. Hor JY, Asgari N, Nakashma I. (2020). Epidemiology of Neuromyelitis Optica Spectrum Disorder and Its Prevalence and Incidence Worldwide. *Frontiers in Neurology*. 11:501. doi: 10.3389/fneur.2020.00501
6. Wingerchuk DM, et al. (1999). The clinical course of neuromyelitis optica (Devic's syndrome). *Neurology* 53:1107-1114.



# The long journey to an NMOSD diagnosis

**Disclaimer:** This Toolkit provides introductory, lay and non-medical information for the European NMOSD patient community audience. Please always speak to your healthcare professional directly, if you have any questions or concerns related to your personal situation.

The process to get diagnosed with NMOSD can be difficult and is often lengthy.

This is because NMOSD is rare, and it is often mistaken for Multiple Sclerosis (MS) because of similar symptoms. The journey to diagnosis can also be related to doctors' experience with rare diseases, their knowledge of NMOSD, and the various types of testing necessary to achieve a diagnosis.<sup>1</sup>

NMOSD is usually diagnosed by a neurologist or neuro-ophthalmologist, based on assessment of symptoms, physical exam, blood tests (AQP4 and other antibody tests), and imaging (for example an MRI scan of the brain and spinal cord).<sup>2</sup>

**A correct diagnosis of NMOSD is important to ensure the best possible treatment and care** can be given according to the person's specific needs.

**Delays in diagnosis can lead to more severe symptoms.**<sup>3</sup> The process to get diagnosed can be difficult, confusing, and lengthy, which can be compounded by a feeling of a lack of information about the disease, leading to uncertainty and sometimes fear.

**Finding a community** of others living a similar experience to connect with can help to deal with the loneliness and uncertainty which people living with NMOSD may experience, particularly when first diagnosed. There are support groups for NMOSD in your country, at European level, and globally who are always open and available to help you through your journey. For further information and to find your local support group, please see the chapter on 'Connecting with others in the community'.

*“With rare diseases like NMOSD, it is very fortunate to have a doctor who has heard about this condition. In the urban environment of university towns with medical schools, this case is likely to occur more frequently than in rural areas. NMOSD has many of the external symptoms in common with other inflammatory diseases of the central nervous system. It is all the more important to know about the differentiation so that effective treatment can begin. The long road to the correct diagnosis is therefore really connected with long distances that have to be covered to get to the right specialist. Emotional highs and lows must also be overcome on this journey and dead ends may not be avoided.”*

Matthias Fuchs, NMOSD patient, Sumaira Foundation Ambassador for Germany

*“21st century advances have breathed new life and hope into NMO. Don't stop breathing despite the diagnosis of a serious illness.”*

Souad Mazari, NMOSD patient, Founder of NMO France

## Additional resources

- The Sumaira Foundation – **NMOSD resources**
- The Guthy-Jackson Charitable Foundation – **Resources**
- SRNA – **Signs and Symptoms – Diagnosis**
- AISM – **Neuromyelitis optica: 10 things you should know**
- MS Nurse PRO – **Differentiating between MS, NMOSD, and MOGAD**
- Horizon Therapeutics – **NMOSD in focus**
- AINMO – **NMOSD and MOGAD: Everything you should know.**  
[Italian language resource]
- NMO France – **First steps with the disease.** [French language resource]

## References

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1. European Alliance for Patient Access (2022). **Unmet Needs in Neuromyelitis Optica Spectrum Disorders in Europe.**
2. The Sumaira Foundation. **What to know about NMO.** Accessed January 2023.
3. The Guthy-Jackson Charitable Foundation. **NMO and Multiple Sclerosis: Did you know?** Accessed January 2023.





# After diagnosis: every NMOSD story is unique

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**No two NMOSD patients have the exact same journey.** While some symptoms are common, such as pain and fatigue, there are other possible symptoms which may or may not be experienced.

NMOSD patients may experience issues such as physical disabilities, visual impairment, pain, fatigue, bowel/bladder, cognition, sleep, sexual and psychological issues.<sup>1</sup> It is important to remember that not everyone will experience all of these symptoms, and help is available. Please refer to the “Connecting with others in the community” and “Useful links” chapters for more information on help available.

- **Physical disabilities:** weakness, numbness or paralysis in one or more limbs are classic symptoms. This can affect walking, moving and feeling.
- **Visual impairment:** many people with NMOSD experience reduced vision in one or both eyes.
- **Pain:** NMOSD may reduce, disrupt or exaggerate pain signals within the body. Pain that is caused by NMOSD may be chronic or may flare up from time to time.
- **Fatigue:** this is a common symptom, especially early after diagnosis. Fatigue can be due to the disease itself, to the treatment, or to related factors such as increased stress, pain, or depression.

- **Bowel/bladder issues:** incontinence can be experienced by people with NMOSD when inflammation in the central nervous system affects nerves that control these functions.
- **Cognition issues:** some people with NMOSD report that they lose the ability to concentrate or think clearly, either from time to time or for longer periods of time.
- **Sleep issues:** Insomnia can be due to NMOSD or other factors related to the disease, including pain, depression or stress. In some cases, NMOSD can result in a condition known as narcolepsy – where a person experiences an excessive or uncontrolled urge to sleep.
- **Psychological issues:** a sense of loss, grief and fear are not uncommon in people who have a diagnosis of NMOSD. These feelings can manifest as depression or isolation syndromes that add to the physical effects of these conditions.

Addressing emotional or psychological impacts caused by NMOSD is as important as addressing their medical impact.<sup>1</sup> Please speak to your healthcare professional if you are experiencing symptoms.

**The treatment to manage NMOSD may also be associated with side effects.** It is important to ask detailed questions about the side effects of the medication and how to manage them. For example, reproductive health can sometimes be forgotten. NMOSD and its treatment can make it more difficult to get pregnant or to manage a pregnancy, but with planning it is possible.

*“When I got sick as a child, no one thought about what side effects the medications would have on my future ability to bear children. It was somewhat of a question mark for years, but with my current treatment I am able to plan a pregnancy. It is therefore important to think about side effects in the long run.”*

Sofia Knutsson, NMOSD patient, Sumaira Foundation Ambassador for Sweden

Every person affected by NMOSD is unique and may experience one or more of these issues or those that are not listed. While some issues are common to almost everyone, such as pain and fatigue, **no two patients have the exact same journey.** Help is available to manage symptoms as well as daily life with the disease.

## Additional resources

- [The Sumaira Foundation – NMOSD resources](#)
- [The Guthy-Jackson Charitable Foundation – Resources](#)
- [SRNA – Newly diagnosed](#)
- [AISM – Neuromyelitis optica: 10 things you should know](#)
- [Horizon Therapeutics – NMOSD in focus](#)
- [AINMO – NMOSD and MOGAD: Everything you should know.](#) [Italian language resource]
- [NMO France – Neuromyelitis Optica \(NMO\) and NMO Spectrum Disorders \(NMOSD\).](#) [French language resource]

## References

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1. The Guthy-Jackson Charitable Foundation. **10 Steps Forward.** Accessed January 2023.



# Living with NMOSD

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Support from community, family members or friends is crucial for people impacted by NMOSD as they adjust to a new way of life. Having a good support system can also help to manage stress, anxieties and uncertainties.

Help is available and there are a number of existing communities and networks in place in Europe where you can connect with people in a similar situation living some of the same experiences and challenges. This can also help you to gather new sources of information. Please see the chapter on 'Connecting with others in the community' for more information.

*“Living with NMOSD demands a lot of adjustments. Having support from community, family members and friends, makes these adjustments much easier.”*

Leda Bresnov, NMOSD patient, Sumaira Foundation Ambassador for Denmark

*“I don't know what I would have done without the love and support from my family and friends. They are the sole reason that I'm able to live a pretty normal life despite my illness. They know me well enough to both encourage me, and to tell me when to slow down.”*

Sofia Knutsson, NMOSD patient, Sumaira Foundation Ambassador for Sweden

People living with NMOSD may find ordinary tasks such as dressing, bathing, and eating very difficult due to the sight and mobility issues which are commonly associated with the condition.

**Specialised equipment can help with this.** For example, long handled sponges, grab bars, portable bath seats, and hand-held shower heads can make bathing easier. For dressing, elastic shoelaces can eliminate the need to tie shoes while other devices can help to put on socks. **Occupational therapists** – who specialise in assessing equipment needs and helping people with limited function perform activities of daily living – can provide advice. A home assessment by an experienced professional is often helpful. Please speak to your healthcare professional to ask about the option of a home assessment.

**Physical therapists** can assist with mobility. Besides teaching people to walk and move more easily, they can recommend mobility aids. This includes different types of canes, walkers and braces. An orthotist can also support with a custom-fabricated orthotic (brace), based on an individual evaluation.<sup>1</sup> Please speak to your healthcare professional about access to a physical therapist.

**All EU countries have measures in place to provide a replacement income for people living with disabilities.** Personal budgets and financial support, including for carers, are becoming a common practice.<sup>2</sup> The support available depends on the country – national sources should be consulted to understand what support is available in your specific country.

In addition to public support, organisations can help to find support systems and navigate bureaucracy of national healthcare systems. Some organisations also provide different types of support, beyond the financial support which can be obtained from governments. For further information and to find your local support group, please see the chapter on ‘Connecting with others in the community’.

In many EU countries, people living with NMOSD can be supported by so-called “social nurses” or social workers, who have expertise in the functioning of the social security system and can help patients find their way along it and have access to all the available resources. Please speak to your healthcare professional about social support. Further, time spent in hospital can be an opportune moment to speak to a social worker and ask questions.

*“ To make the best use of assistance, you need to know what the disease is, thanks to the support of an association; you need to know the impact and after-effects of the disease, so you can better determine the support you need; and you need to know how to identify the right specialties for the motor and/or sensory impairments caused by the disease. Patients must learn to know and accept their body’s new limits, so that they can focus on tomorrow’s goals rather than yesterday’s memories of their abilities. This means setting goals step by step, and getting the help they need. ”*

Souad Mazari, NMOSD patient, Founder of NMO France

## Additional resources

- **The Sumaira Foundation – Voices of NMO**
- **The Guthy-Jackson Charitable Foundation – NMO Patient Resource Guide**
- **SRNA – Long-term care**
- **AIMS – Neuromyelitis optica: 10 things you should know**
- **Horizon Therapeutics – NMOSD in focus**
- **AINMO – NMOSD and MOGAD: Everything you should know.** [Italian language resource]
- **AIMS and AINMO – Parts of the whole**
- **Horizon Therapeutics and NMO France – Living with NMOSD.** [French language resource]

## References

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1. Siegel Rare Neuroimmune Association. **NMOSD: Long-term care.** Accessed January 2023.
2. European Commission (2021). **Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030.**



# Caring for someone with NMOSD

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Carers are precious and essential allies in the day-to-day management of the challenges to independence someone living with NMOSD may face.

Education can be an important tool to help everyone in the immediate social environment become acquainted with the disease and its effects in order to best support the person living with NMOSD. It is also important for wider social bubbles to be informed to understand the situation, because support networks are often broader than family and close friends.

There are a number of existing communities and networks in place in Europe where you can connect with people in a similar situation living some of the same experiences and challenges. This can also help you to gather new sources of information. Please see the chapter on “Connecting with others in the community” for more information.

*“It’s very important that your loved ones and friends understand what’s going on with you. Only then they can support you properly.”*

Els Roelandt, NMOSD patient, Sumaira Foundation Ambassador for Belgium

Challenges in the early recovery period typically include ordering the appropriate equipment, dealing with re-entry into school, work, and community, and coping with the psychological effects of the condition on both the person diagnosed with NMOSD and their loved ones.<sup>1</sup>

Family members, friends, and other people in the life of the person with NMOSD will also find themselves in the position of adjusting to a “new normal” and undergoing lifestyle changes to inform themselves and better care for their loved one. It can be a long journey for all affected to accept these changes and get used to and enjoy the new way of life. **Not only the individual living with NMOSD, but also the family members or others providing care, need a solid support system to help them in this journey,** including if necessary psychological support.

It is important to plan not just for daily challenges, but also how to handle them and what to do in case something unexpected happens. Energy levels can vary a lot, which can be hard for families to understand at the beginning. It is also useful to share experiences on platforms and use those platforms to learn how others deal with daily challenges related to NMOSD.

“ Always have mental fatigue in mind. My wife can manage a lot of activities, but her mental batteries have a lower capacity and faster discharge. ‘Use the energy smart’. Use the energy on the stuff that matters. ‘Prioritise resting periods’. The battery needs recharging.

‘Don’t forget yourself’. Remember to prioritise what gives you energy and makes you happy. Like in the airplane, you have to put your own oxygen mask on before you can help others surrounding you. Share your thoughts and worries with friends and family. ”

Martin Bresnov, caring for someone living with NMOSD

Overall, **it is important to find the right type and level of support for every specific situation.** The right kind and quantity of support might change from one person to another. Families or social bubbles may need to work together to understand how to best help each other and to allow the person living with NMOSD to be able to do as many things as possible, and as desired, by themselves.

Eurocarers – the European Association Working for Carers – has created country profiles for each of the EU27 countries and the UK, which include information on **national and regional public support available for carers**, including informal carers.

## Additional resources

- [The Sumaira Foundation – Voices of NMO](#)
- [AISM – Neuromyelitis optica: 10 things you should know](#)
- [Eurocarers – Country profiles](#)
- [AINMO – NMOSD and MOGAD: Everything you should know.](#) [Italian language resource]
- [NMO France – The voice of the rare.](#) [French language resource]

## References

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1. Siegel Rare Neuroimmune Association. [NMOSD: Long-term care.](#) Accessed January 2023.



# Connecting with others in the community

**Disclaimer:** This Toolkit provides introductory, lay and non-medical information for the European NMOSD patient community audience. Please always speak to your healthcare professional directly, if you have any questions or concerns related to your personal situation.

There are a number of existing networks and support groups in place for the European NMOSD community. Engaging with these can help to feel connected to the community and meet people in a similar situation living some of the same experiences and challenges.

*“Looking back, finding people affected by NMOSD was not easy. In recent years, the Internet has made an enormous contribution to patients connecting and even founding organizations with great personal commitment. As has already happened in the USA, Italy, France and other nations.*

*Addressing fears and worries, exchanging experiences, receiving advice on a personal level is only possible in conversations between those affected. Finding emotional support in a community is often just as important as medical therapy.”*

Christine Fuchs, caring for someone living with NMOSD

*“Connecting with other NMOSD patients shows me that I am not alone. The members of the community teach me different ways to deal with everything around NMOSD.”*

Leda Bresnov, NMOSD patient, Sumaira Foundation Ambassador for Denmark

**The Siegel Rare Neuroimmune Association (SRNA).** Founded in 1994 by family members and individuals affected by rare neuroimmune diseases, the Siegel Rare Neuroimmune Association (SRNA) is a not-for-profit organisation dedicated to the support of children, adolescents, and adults with a spectrum of rare neuroimmune disorders such as Neuromyelitis Optica Spectrum Disorder (NMOSD), Optic Neuritis (ON) and Transverse Myelitis (TM). SRNA is based in the United States, but it has an active presence in Europe.

- The Siegel Rare Neuroimmune Association (SRNA) offers a **Peer Connect Program** to match people with someone who can offer support. This will be a Peer Connect Leader (PCL) – volunteers who have been diagnosed with a rare neuroimmune disorder.
- SRNA also provides **personalised assistance and disease information** by phone and email for those in need.

**The Sumaira Foundation.** The Sumaira Foundation is a US-based organisation dedicated to generating global awareness of NMOSD and MOGAD, building communities of support for patients and their caregivers, supporting research and patient advocacy. The organisation has members and representatives all over the world, including Europe.

- The Sumaira Foundation runs the **Human Collective Project (HCP)** – support group meetings offered to anyone who has been affected/impacted by NMOSD/MOGAD. Sessions are available in multiple geographies and languages, and are driven by Patient and Caregiver Ambassadors around the world. The Sumaira Foundation has a **network of ambassadors** across Europe representing NMOSD patients.
- The Sumaira Foundation also publishes stories of people affected by NMOSD and provides the opportunity to **submit stories** to be included on the site.

**The Guthy-Jackson Charitable Foundation.** The Guthy-Jackson Charitable Foundation is a voluntary, non-profit organisation dedicated to funding basic scientific research to find answers that will lead to prevention, clinical treatment programs and a potential cure for Neuromyelitis Optica (NMO) Spectrum Disease. The Foundation is based in the United States, but it has an active presence in Europe.

- The Guthy-Jackson Charitable Foundation publishes NMOSD **stories** from around the world and provides the opportunity to anyone from the NMOSD community to submit their own story and share their voice. The Foundation also lists **local support groups** around the world, including in Europe, and provides the opportunity to easily submit new support groups for inclusion on the site.

**NMO France.** NMO France is a French-speaking patient association dedicated to people with Neuromyelitis Optica (NMO), NMO Spectrum Disorders (NMOSD), and other rare inflammatory diseases of the brain and spinal cord such as MOGAD. NMO France's main mission is to inform and educate patients about their disease, its management and symptoms, and to help them recognize the care pathways available to them in France, and to work with stakeholders to improve the overall management of their disease.

- NMO France also **publishes testimonials** from people affected by NMOSD in France, and offers the opportunity to submit a testimonial for inclusion on the site. NMO France also offers **educational content** on the website and a **YouTube channel** to educate the public about NMOSD. The aim is to put the patient's life in the spotlight.
- NMO France also runs the **Tribu des Rares** support group dedicated to patients.

**The Italian NMOSD Association (AINMO).** AINMO is a newly formed association, driven by the Italian Multiple Sclerosis Society (AISM), and is the first Italian association dedicated to NMOSD and MOGAD. AINMO's goal is to support the community of people with NMOSD and MOGAD, promoting research, new treatments for a better quality of life, and the sharing of information between patients, their caregivers and social-health workers. Furthermore, AINMO carries out national and local advocacy activities.

- AINMO has an **NMOSD audio guide** in Italian offering useful information for people affected by NMOSD. It also has a **written guide** which can be downloaded online.
- AISM has also published a video and leaflet in English **Neuromyelitis optica: 10 things you should know.**



**NEMOS (Neuromyelitis optica Studiengruppe).** NEMOS is a German-speaking study group that has built up a constantly growing network of regional, national and international clinical and scientific activities on NMOSD/MOGAD and similar rare neurological diseases for medical colleagues and patients.

- NEMOS has several **centres** across Germany, as well as **tools** for patients to remain in touch with the community both online and via in-person events and activities.

**The Multiple Sclerosis (MS) community** is also becoming more engaged on NMOSD given the similarities between the two diseases.

- The Italian Multiple Sclerosis Society (AISM) is particularly advanced in its work on NMOSD. They offer a **free phone line** with experts (including neurologist, legal adviser and social worker) who answer questions on MS and on NMOSD. Questions can also be asked via an online form or email. Furthermore, AISM promotes the agenda of Multiple Sclerosis and correlated diseases through national and local advocacy activities to change the reality of people with MS, NMOSD and MOGAD.
- AISM and AINMO organise every year the #GiovaniOltreLaSM Event. This is a national initiative for young people with MS and with NMOSD and MOGAD, which promotes information and peer to peer meetings. The event is driven by young patients with MS, NMOSD and MOGAD. It is available via streaming but – currently – only in Italian.

- In Spain, GAEM Foundation (Group of People affected by Multiple Sclerosis) is also strengthening its work on NMOSD, for example by organising webinars with experts to talk about the latest advances on preclinical and clinical research, and hosting Q&A sessions between patients and health professionals.
- The Belgian Multiple Sclerosis League (MS-SEP) has recently started working also on NMOSD. In the Netherlands, the Multiple Sclerosis society has even further expertise on NMOSD.

*“The construction of a strong community where people with NMOSD and their loved ones are no longer alone, represents an important opportunity also to analyse people’s needs and start from there to carry out advocacy, information and support activities and to direct research. In this sense, the approach and the experience of the MS Community could inspire the NMO Community to face the future challenges. The connection between these realities could be a value for both.”*

Alessia Villani, Italian Multiple Sclerosis Society (AISM) and Federica Balzani, European Multiple Sclerosis Platform (EMSP)

Given the rare nature of NMOSD, the **rare disease community** is also important to stay close to. The way that NMOSD impacts the lives of those affected is in common with many in the rare disease community and finding and engaging with the relevant community in your country or region is another way to find support from people in a similar situation.

# Useful links

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This chapter includes links to useful resources providing additional information and guidance for people affected by NMOSD, or who want to learn more.

## **The Siegel Rare Neuroimmune Association** wearesrna.org

- Myelitis Helpline
- “Ask the Expert” podcast series
- ABCs of NMOSD podcast series
- Resource library

## **The Sumaira Foundation** sumairafoundation.org

- What to know about NMO
- Voices of NMO
- Imagine my life with NMO
- Demystifying NMO and MOG podcast
- “From the Experts” webinar
- NMOSD resources

## **The Guthy-Jackson Charitable Foundation** guthyjacksonfoundation.org

- NMOSD Patient Resource Guide
- New to NMO
- 10 Steps Forward
- NMO resources
- Resources

## **NMO France** www.nmo-france.org

- NMO et NMOSD (NMO and NMOSD)
- Premiers pas avec la maladie (First steps with the disease)
- La voix des Rares (The voice of the Rare)
- YouTube channel
- Tribu des Rares patient support group

## **Italian NMOSD Association (AINMO)** aism.it/malattie-dello-spettro-della-neuromielite-ottica

- What is NMOSD
- NMOSD audio guide
- NMOSD guide
- AINMO Facebook private group

## **NEMOS (Germany, Austria, Switzerland)** nemos-net.de

- NMOSD

## **Italian Multiple Sclerosis Association (AISM)** aism.it

- NMOSD
- Neuromyelitis optica: 10 things you should know [English language resource]
- Parts of the Whole

## **Horizon Therapeutics**

- NMOSD in focus



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