PATIENT COMMUNITY DAY 2024

IMPACT REPORT

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STRONGER TOGETHER

ECTRIMS
EUROPEAN COMMITTEE FOR TREATMENT AND RESEARCH IN MULTIPLE SCLEROSIS

One community. One mission.

To improve the lives of people living with multiple sclerosis (MS), myelin oligodendrocyte glycoprotein antibody disease (MOGAD), and neuromyelitis optica spectrum disorder (NMOSD) all over the world.

In September 2024, the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) hosted its third annual Patient Community Day (EPCD). Part of the organisation's annual congress, the event aimed to tear down silos, foster partnerships, and place patients at the very heart of research. This is our first annual EPCD Impact Report. It has been designed to make sure as many people living with MS and related conditions as possible can benefit from the day.

Who is the EPCD Impact report for?

People living with MS and related conditions who want to understand the latest research – and what it means to them. It has been designed to add to patients' knowledge of the current scientific progress. We hope it will help them to fully grasp the implications of developments in areas such as new treatments and lifestyle modifications, and give them a view into what might be next.

What is inside the EPCD Impact report?

Key learnings from the day, which cover the topics:

- Remyelination
- Emerging therapies
- Risk factors
- Symptom management
- Lifestyle modifications
- Diversity
- New MS diagnostic criteria
- Paediatric MS
- MS nursing
- Latest advances in NMOSD and MOGAD

Interviews with patient advocacy group leaders, researchers, and people living with MS and related conditions

The story of EPCD, from the first edition in Amsterdam in 2022 to the third edition in Copenhagen … and beyond

wonderful copenhagen

The EPCD 2024 Impact Report has been kindly supported by a grant from Wonderful Copenhagen.

About ECTRIMS

ECTRIMS is the world's largest professional organisation dedicated to the understanding and treatment of MS and related neurological conditions.

Each year, thousands of researchers and healthcare professionals from around the world attend the ECTRIMS Annual Congress to share and discuss the latest science and advances.

ECTRIMS 2024, held in Copenhagen, Denmark, marked the congress' 40th anniversary.

EPCD MISSION

Unite, support & inspire.

Every year, the ECTRIMS Annual Congress showcases the most ground-breaking and care-advancing research from around the world.

First held in 2022, EPCD aims to:

- simplify and contextualise the research presented at the congress, explaining what it means to patients in their everyday lives
- give researchers the chance to hear from patients so they can focus their future work on solving the problems that matter most
- tear down silos between researchers and patients, so we can work together to improve lives.

THE EVENT

Patient Community Day: A family event

EPCD 2024 was a joint effort. It brought a wide range of patient advocacy groups from around the world together to further a common goal: to educate and empower people living with MS and related neurological conditions.

Partnering to bridge the gap

With ECTRIMS 2024 being held in Copenhagen, we were delighted to welcome Sclerose Foreningen, the Danish MS society, as our primary EPCD partner.

The organisation has a long history of supporting people with MS. One of the world's first national MS societies, it was founded in 1957. Less than two years later, it opened the country's first specialist MS hospital.

"I hope the inspiration we can give each other will move us all forward"

It was the result of a mammoth fund-raising effort that the society, quite rightly, is still incredibly proud of today. "We are so thankful to have been in that position and to have had the backing, not just of people affected by MS, but of the community at large," said Klaus Hom, managing director at Sclerose Foreningen.

More recently, the society has placed an important focus on involving patients in research. "The MS community is financing the majority of independent MS research in Denmark", said Klaus. "Yet, traditionally, people with MS have been a little detached from the process."

Two years ago, the society asked its members where it should be focusing its funding. While there was a clear ambition to "end MS," Klaus said the work also revealed a desire to advance research in managing symptoms such as cognitive impairment, pain, fatigue, and spasticity.

In addition, the organisation also requires all society-funded research projects to produce and distribute a lay summary of their findings.

Exchange of ideas

It is this commitment to bridging the gap between people with MS and researchers that made the goals of EPCD resonate with Sclerose Foreningen.

Klaus said the event was an opportunity for patients, research leaders, and patient organisations to come together to exchange ideas.

“It enables researchers to understand the needs of people who are struggling with MS here and now, rather than only focusing on what we might possibly achieve ten years from now,” he said.

For people living with MS, having a deeper understanding of the science behind their condition allows them to have more informed discussions with their healthcare teams, he added. This helps them take a more active role in their care, both in the in clinic and in terms of self management.

“Overall, I hope the inspiration we can give each other will move us all forward,” concluded Klaus.

Designed by the community, for the community

EPCD is one of the most important fixtures in the ECTRIMS Congress calendar, said Brett Drummond, co-founder of MStranslate, host of the ECTRIMS Podcast, and moderator at this year's event.

"All the research that's going on, all the conversations we are having – they are all designed to improve the lives of people with MS and related conditions. We can't achieve that goal without including patients in the process," he said.

Brett has played a leading role in designing the EPCD programme, which featured two, panel-led discussions with representatives from the patient and research communities. The topics, which ranged from remyelination and emerging therapies to MS nursing and NMOSD/MOGAD updates, were chosen because they matter to patients.

"What scientists, researchers, and neurologists think of the highlights of the meeting don't always align with what people living with MS and related conditions are interested in. So we ran some polls and focus groups to find out what people really wanted to hear about," he explained.

The whole idea, he went on, is to "get the message out."

"EPCD allows patients to hear about all the exciting things that will hopefully translate into meaningful change from the source, in a way that is accurate and easy to understand," he said.

"EPCD made me understand how many people from around the world are focused on MS. People with MS are very much on their own, with their own symptoms, and it's very hard to see the forest for the trees. The event really broadens the horizon on the medical condition itself. It has put a battery in my pack, to help improve my own health outcomes in my own ways."

Damian Washington
NoStressMS YouTuber and person living with MS

OUR PARTNERS

SESSION 1

From remyelination to diversity in clinical trials

THE PANEL

- **Chair: Bruno Stankoff,** *ECTRIMS president*
- **Moderator: Brett Drummond,** *co-founder, MStranslate, and ECTRIMS Podcast host*

Panellists:

- **Timothy Coetzee,** *CEO, National Multiple Sclerosis Society, USA.*
- **Malene Kappen Krüger,** *patent attorney, person living with MS, and patient advocate, Denmark*
- **Melinda Magyari,** *director, Danish MS Registry, Denmark*
- **Mar Tintoré,** *professor of neurology and outgoing ECTRIMS president, Spain*
- **Mitzi Joi Williams,** *consultant neurologist, USA*

Remyelination

While there are now a number of treatments that can stop or slow demyelination in MS, none are currently able to repair the damage that has already been done. But that could change in the coming years.

"Twenty years ago, remyelination was almost unimaginable. Now, drugs that could repair myelin are being tested and evaluated in clinical trials," said Mar.

What is myelin?

Myelin is a fatty substance that insulates nerve fibres. It protects the nerve fibres and allows messages to move between nerve cells quickly. If someone has MS, immune cells in the brain and spinal cord attack the myelin sheath and the cells that make it. Doctors call this demyelination, and it causes the symptoms of MS.

Key learnings from the discussion:

- After decades of research into the processes of how the brain repairs itself, remyelination is now a possibility.
- A number of treatments that could repair myelin are now in clinical trials.
- Studies presented at ECTRIMS have shown that cells such as astrocytes and macrophages, which are part of the immune system, play a role in remyelination. This information could help scientists design more myelin repair treatments in the future.
- Researchers are also working on ways to design clinical trials that will be able to detect remyelination. This will help them to test the new drugs.

Question from the floor: Realistically, how long will it be before an effective remyelination therapy is available for use?

"This is a very difficult question to answer," Bruno Stankoff responded, "but we are talking about years rather than decades. We are trying our best to accelerate that by working together at an international level."

Emerging therapies

There have been significant advances in the treatment of MS in recent years, but there is still more work to be done.

Some people living with MS don't respond to some of the existing treatments, and continue to experience disease progression. What's more, there are still very few approved treatments for progressive MS.

Key learnings from the discussion:

- Researchers have learnt a lot about disease progression in MS in recent years. They now know that MS can progress, even when a person does not have relapses. They call this progression independent of relapse activity (PIRA). It has been shown that this process is occurring even at the earliest stages of the disease.
- They also know that the best way to tackle progression is to slow it down, or even prevent it from happening in the first place.
- Results of a Phase 3 clinical trial of a drug to slow progression were presented at the ECTRIMS Congress. They were promising, but there is more work to be done before such treatments are ready for use.

"There are tools and medications that are showing promising results. But there are also things you can do, aside from going to the doctor and taking your medication, that can impact the health of your brain. Engaging in healthy behaviours will increase your reserve, and protect against progression."

Mitzi Joi Williams
Session 1 Panellist

SESSION 1

Risk factors

Understanding the genetic and environmental risk factors for MS is important for a number of reasons.

It can aid the development of prevention strategies, and help researchers develop more targeted treatments.

Key learnings from the discussion:

- No one thing causes MS. The most likely explanation is that different risk factors work together to lead to the disease.
- Our understanding of MS risk factors has grown a lot in the last year. This was clear in the science presented at the 2024 ECTRIMS Congress.
- One study, for example, looked at genetic risk factors. It found that some people's immune systems work in a way that makes them more susceptible to MS.
- The role of the Epstein Barr virus (EBV) in the development of MS has been under investigation for a number of years.
- EBV does not cause MS, but it does seem to play an important role. Scientists now know that almost everyone with MS has, at some point, been exposed to EBV. It means that an EBV vaccine could potentially prevent MS in the future.

What are risk factors?

Risk factors are things that can make it more likely that a person will develop a particular health condition.

Genetic risk factors are related to our DNA, while environmental risk factors refer to the world we live in. Risk factors can be modifiable, or things we can change, or non-modifiable, meaning things we cannot change. Smoking is an example of a modifiable risk factor, while age is a non-modifiable risk factor.

Question from the floor: Is an EBV vaccination possible and could it prevent MS?

Early trials of EBV vaccines have started, but there are still many unanswered questions.

"In theory, avoiding EBV would have a strong impact on the disease, but we need data," said Bruno.

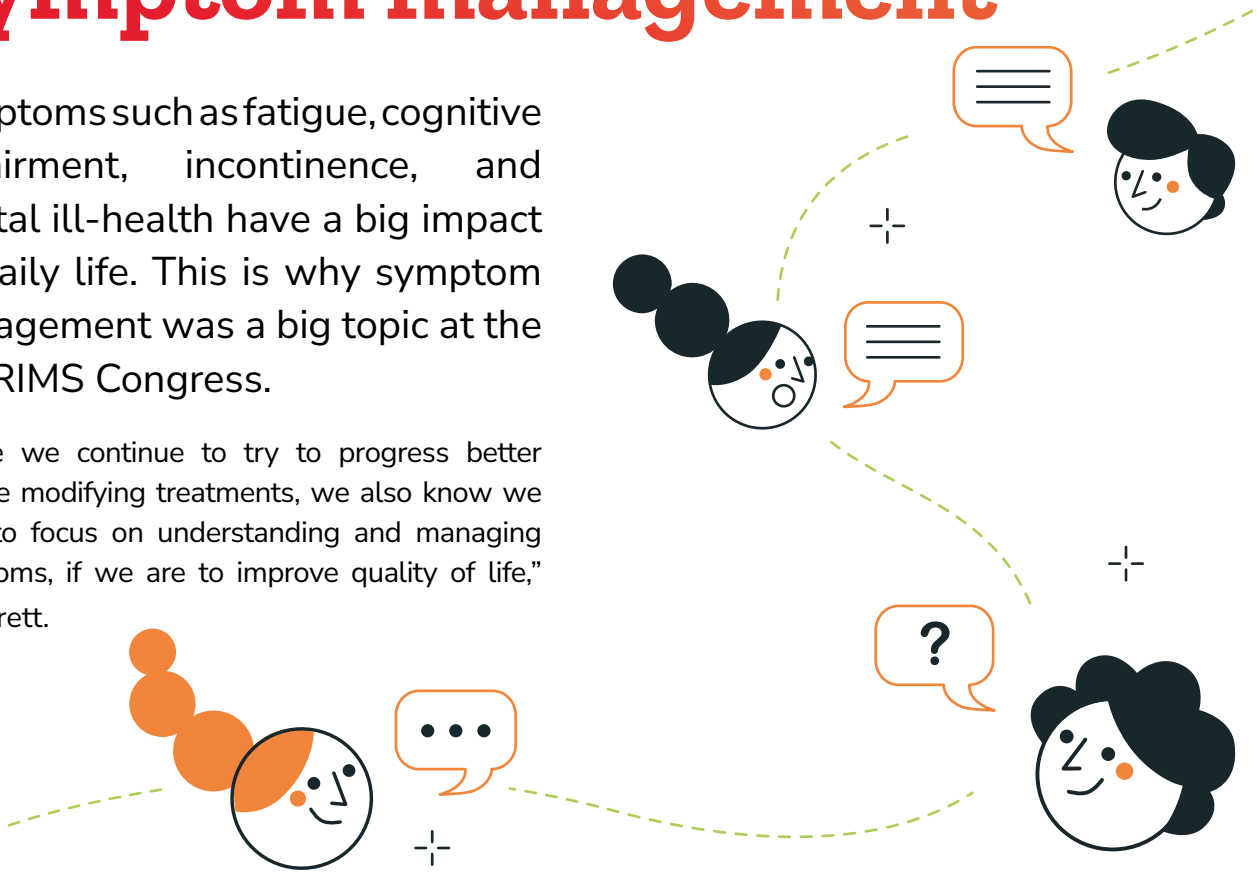
"Infection can happen in childhood, so should we focus on the early phase of life? Should we vaccinate people more than once, or people who have already been infected? There are many questions like this, but it is a very large field of research."

It is a matter of "years rather than decades" before an EBV vaccine would be available, he added. Tim agreed, explaining: "COVID delivered a new way to develop vaccines that we could not have imagined five years ago. It acts as an accelerator and gives us hope that we could have solutions very quickly." However, researchers will still need to understand if an EBV vaccine could prevent MS, and how. This work could take some time.

Symptom management

Symptoms such as fatigue, cognitive impairment, incontinence, and mental ill-health have a big impact on daily life. This is why symptom management was a big topic at the ECTRIMS Congress.

"While we continue to try to progress better disease modifying treatments, we also know we need to focus on understanding and managing symptoms, if we are to improve quality of life," said Brett.



What is prehabilitation?

Mitzi spoke about the concept of prehabilitation as a way to avoid worsening symptoms for as long as possible.

"When we send someone for surgery, we ask them to strengthen themselves as much as possible so they will be better able to bounce back afterwards," she said.

"Thinking about that in terms of MS, we need to get people in the best shape possible, as early as possible."

Engaging in healthy behaviours from the beginning, "instead of waiting for something to happen" is the best approach," Mitzi added.

Key learnings from the discussion:

- Symptom management is complex. Often, the treatment for one symptom can make another symptom worse.
- People with MS and related conditions should make sure they talk to their healthcare team about their symptoms. Various treatments and interventions are available, and clinicians can help people to choose the right ones for them.
- There is now evidence to suggest that worsening cognitive issues can be a sign of progression. This is another reason why it is important for people to talk to their healthcare team about their symptoms.
- There is also evidence to suggest that exercise can help with fatigue, pain, and depression. Combining exercise with socialising and eating a healthy, balanced diet, can bring even more benefit.

Lifestyle modifications

One of the things that people living with MS often ask is how they can take control of their disease – and one answer is lifestyle modifications. Diet and exercise, which play a key role in overall management plans, are a topic of much research at the moment.

Key learnings from the discussion:

- There were a number of talks on lifestyle modifications in MS during the ECTRIMS Congress.
- One study suggested exercise improved physical capabilities, and may possibly help with cognitive function. Exercise does not have to be running or going to the gym. It can be any physical activity the person enjoys and is able to stick to, even walking more.
- Another found that people with MS have a different gut microbiome than those without the condition. The gut microbiome is the ecosystem of microbes that live in the intestines, and it plays a role in the immune system. Taking probiotics and prebiotics, and eating plenty of vegetables may help to improve gut health, but more research is needed.
- Many people with MS who have changed their diet say it has helped with their symptoms. At the moment, though, there is no evidence to recommend one diet over another. The best recommendation is to eat a healthy, balanced diet, and maintain a healthy weight. That means not being over or underweight.
- Lack of sleep can make fatigue and daytime sleepiness worse. Some people with MS can find it difficult to sleep, but it's important to "do your best". Raising sleep difficulties with your healthcare professional is important, as there are interventions that can be tried that may help.
- Smoking has been shown to play a role in increasing the speed of progression of MS and reducing the body's ability to restore itself. Importantly, research has also found that quitting smoking at any time is beneficial for people living with MS.

> *"We appreciate all of the medical treatments. But we really want to contribute to giving our brains and our immune systems the best conditions for not making us sick and even, perhaps, curing our symptoms."*

Malene Kappen Krüger
Session 1 Panellist

SESSION 1

"Registries are very important because they can collect data on a wide range of people. They can then look at the data from under-represented groups, combine it with data from other countries, and really start to answer some of these questions. Registries are data, data is information, and, with information, we can do good science."

Melinda Magyari
Session 1 Panellist

Diversity

MS affects around 3 million people globally, and factors such as sex, race, ethnicity, and age have a big impact on the way someone experiences the condition. Despite all of this, clinical trials often fail to reflect the diversity of people living with MS.

Key learnings from the discussion:

- Many things influence the way someone experiences MS and accesses healthcare. These include sex, race, ethnicity, and age.
- The person's background also plays a role. A study from the Danish MS Registry, for example, found that people with lower levels of education and health literacy often waited longer for treatment.
- During the ECTRIMS Congress, researchers also learned that it is more challenging to differentiate between MS and other conditions in Africa, the Middle East, Asia, and Russia, than it is in Europe.
- Clinical trials have strict inclusion and exclusion criteria. It means participants are usually younger adults. However, the face of MS is changing all the time. More older people, for example, are now living with MS and there are more cases of paediatric MS.
- Many researchers are now focussing on how to introduce more diversity into clinical trials.

Question from the floor: With people with MS now living longer, will we see more older people being recruited into clinical trials?

Tim said that clinical trials have typically been designed for younger populations.

"It is not always taken into account that older people could contribute. We need to change attitudes among researchers, among the regulatory authorities, and among the companies that conduct trials. This is something we need to confront as a community, to make sure we have all the voices at the table," he added.

See the full picture

EPCD offers people living with MS and other neurological conditions an opportunity to "see the full picture." That's according to Peer Beneke, CEO of the Multiple Sclerosis International Federation (MSIF), the umbrella organisation for national MS societies.

"It is very important to communicate research to people with MS," he said. "At ECTRIMS, there will always be some new, helpful, research, but it may still take time (for the results) to emerge (in clinical practice)."

EPCD "shows people what is happening, and how all the different parts of the jigsaw fit together." By helping to educate people living with MS and related conditions, such events can also enhance the process of shared decision-making, he went on.

"Shared decision-making is important because people living with these conditions are the only ones who can explain the needs they have. Decisions should not just be about which disease modifying therapy – lots of other things are at play," explained Peer.

"If people can learn about the treatments that are being developed, that will help them in their dialogue (with their clinicians).

The simultaneous translation provided at EPCD, he went on, enabled as many people as possible to draw these benefits.

Even though many people are fluent in English, they find it challenging, particularly with medical or scientific information, to "keep up," he said.

But with EPCD being translated into more than 50 languages, the only thing attendees needed to focus on was feeling empowered.

"EPCD is a win-win. The audience, which was mainly people with MS, learned about the latest research, and the researchers were able to get some feedback from the audience."

Palle Kjaer
EPCD attendee and person living with MS

Education is empowerment

People with MS are eager to learn, and want to know what is going on in their bodies.

Elisabeth Kasilingam, managing director of the European Multiple Sclerosis Platform (EMSP), said: "It was important for us, as a patient organisation, to be involved in EPCD because people want to know the latest developments and what the future may hold.

"There has been so much MS research in recent years, and it's great to be able to translate it to the patients. It's about bringing them around the table as an equal partner. They need to have a voice, but they can only do that if they are educated."

"When people feel empowered – when they are made to feel less like a lab rat and more like a human being – they can express their needs and be part of the discussions"

Asked why it was so important that people with MS and related disorders were involved in the research process, Elisabeth said it was the best way to ensure research outcomes met patient needs.

EPCD is an opportunity to move the discussion beyond sharing the headline research findings, Elisabeth said, adding: "We have the news. Now what more can we do together, as a community?"

SESSION 2

From new diagnostic criteria to NMOSD and MOGAD

THE PANEL

- **Chair: Bruno Stankoff,** *ECTRIMS president*
- **Moderator: Brett Drummond,** *co-founder, MStranslate, and ECTRIMS Podcast host*

Panellists:

- **Sumaira Ahmed,** *founder and executive director, The Sumaira Foundation, USA*
- **Kumaran Deiva,** *consultant paediatric neurologist, France*
- **K-J Lazarus,** *MS nurse, Australia*
- **Ciara O'Meara,** *nursing lecturer and person living with MS, Ireland*
- **Romain Marignier,** *professor of neurology, France*
- **Finn Sellebjerg,** *professor of neurology, Denmark*

New diagnosis criteria

An update to the existing MS diagnostic framework, called the McDonald criteria, was a key topic at ECTRIMS 2024.

Brett said: "As we advance, both in knowledge and technology, it is really important to ensure diagnostic criteria remain accurate and appropriate."

Key learnings from the discussion:

- Diagnostic criteria are a framework or toolkit that lists the signs and symptoms of a condition, and the tests needed to diagnose it.
- The last McDonald criteria were published in 2017. The updated version will be published later this year.
- The 2017 version focused on clinical symptoms. Since then, the research community has learnt much more about the biology of MS, or how it looks on the inside of the body.
- The updated criteria allow for doctors to make a diagnosis of MS if they detect changes on MRI scans. It means people will not need to wait for clinical symptoms to develop before they can be diagnosed.
- They also include several technical aspects that will make it easier to detect MS in older people.

Question from the floor: Will optic neuritis be included in the new criteria?

Optic neuritis has been included as being characteristic of MS. However, people with NMSOD, MOGAD, and other conditions can also experience optic neuritis.

"It is very important to take other aspects of the diagnostic criteria into account," said Finn.

"MS is changing from a diagnosis requiring clinical symptoms to a diagnosis based on biological changes in the brain and spinal cord. A biological framework for diagnosing and classifying MS may sound boring, but it really is a breakthrough."

Finn Sellebjerg
Session 2 Panellist

Paediatric MS

Approximately 30,000 people under the age of 18 are living with MS around the world, but the number of approved therapies for this age group is limited.

With early management being so important, there is a huge need to address this problem. Which is why paediatric MS was such a hot topic at this year's ECTRIMS Congress.

Key learnings from the discussion:

- Progress is being made in the treatment of paediatric MS, with three treatments now available. However, there is still more work to be done.
- Clinical trials test how safe and effective treatments are for the people who take part. Traditionally, children are not included in MS clinical trials, so we do not know how the treatments work in children.
- Recent research has shown that the biology of MS in children is similar to that in adults. This suggests treatments currently available for adults may also work for children. However, we need data on whether they are safe, and the best doses to use.
- We have also learnt that there are differences in how children experience MS. They tend to recover better from relapses than adults, and have less disability, but more cognitive impairment.

Question from the floor: What advice would you give a young person being diagnosed with MS?

Kumaran said there were three things he told children and adolescents, and their families, diagnosed with MS:

1. The disease course is not as severe, in terms of disability, as they may imagine it to be.
2. There are things you can do to help yourself. Exercising, eating a healthy balanced diet, and socialising can help to ease some of the symptoms, and prepare your body to fight the disease in the future.
3. There are now three treatments for paediatric MS, and more are expected to become available in the future.

SESSION 2

"With MS, there is a lot to focus on. There are disease modifying treatments, but disease modifying behaviours and learning how to self advocate are also vitally important. MS nurses are well placed to help people navigate that."

K-J Lazarus
Session 2 Panellist

MS nursing

People who regularly see an MS nurse have better health and quality of life than those who do not. Whether someone has an MS nurse, however, can depend on where they live.

"The role of the MS nurse is complicated, and continues to evolve, but they act as a primary point of contact for people living with MS," said Brett, explaining that ECTRIMS 2024 included a number of sessions especially for nurses.

"I trust my MS nurse a lot more than my neurologist, because I meet them on a regular basis. I can confide in them. I can discuss things with them. MS nurses are vital, they need to be there to support the MS community."

Ciara O'Meara
Session 2 Panellist

Key learnings from the discussion:

- Specialist nurses offer tailored support to people with MS. They help them to understand and take their medicine, engage in healthy behaviours, and manage their symptoms.
- In Australia, fewer than half of the 1,500 people with MS who took part in a survey had an MS specialist nurse. They had better medication adherence and less anxiety and depression than those who did not have an MS nurse.
- During the ECTRIMS nurse sessions, nurses from around the world talked about how to work towards making sure more people had access to an MS nurse. Collecting data on how MS nurses help to improve the lives of people with MS is vital, they decided.
- Anyone who does not have access to an MS nurse should ask their neurologist if the hospital or service has someone who provides ongoing education and support.

NMOSD and MOGAD

Like MS, NMOSD and MOGAD are autoimmune neurological conditions. But they have their own unique aspects and characteristics. Understanding these differences is key to providing accurate diagnosis and treatment.

Key learnings from the discussion:

- NMOSD and MOGAD are rare conditions. While they both have similarities with MS, there are important differences.
- MS treatments are not as effective in NMOSD and MOGAD as they are in MS. In some cases, they can even be harmful. This is one reason why accurate diagnosis is very important.
- It can be difficult to distinguish between MS, NMOSD, and MOGAD. The updated McDonald MS diagnostic criteria are a useful toolkit, helping clinicians to tell the difference between the conditions.
- New drugs for NMOSD and MOGAD are becoming available. However, they are expensive meaning people in countries with less resources may not be able to access them.
- There are still many unanswered questions. These include how best to measure how well new and existing treatments work in people living with NMOSD and MOGAD.
- Researchers are also working on diagnostic criteria for the two conditions. In the future, this should help clinicians better understand the biology, the symptoms, and the course of NMOSD and MOGAD.

Work in this area is advancing quickly, and the conditions were an important focus at this year's ECTRIMS Congress. The meeting started with a "Pre-day", which included a dedicated session on NMOSD and MOGAD.

"When I was diagnosed with NMOSD 10 years ago, no one was really talking about it. It was almost like a death sentence. To see it is now forming a big part of the largest MS conference in the world, and being discussed at EPCD, is inspiring. It gives me a lot of hope."

Sumaira Ahmed
Session 2 Panellist

"As the patient, your experience is important. As researchers, we have to listen to you because you are the ones who know best what is happening in your body. We have a lot to learn from you."

Romain Marignier, *Session 2 Panellist*

SESSION 2

Shared learning, shared advances

Hearing the latest advances in research and clinical care, and being part of the wider community. All these and more are among the benefits of EPCD, said Sumaira Ahmed, founder and director of the Sumaira Foundation for people living with NMOSD and MOGAD.

"Community is everything," she said. "It is hard enough trying to navigate the complexities of life, but imagine doing that with a rare disease, with no one around you who really knows what you are going through. I hope that everyone who attended EPCD left knowing that they are not on their own – and that there is a global community of doctors, patients, caregivers, and advocates supporting them."

The event also acts to bridge the gap between the research and the patient community, she went on.

"The biggest challenge at the moment is that the scientific community is quite siloed. There is rarely an opportunity for patients, researchers, and clinicians to come together to talk about our common cause. The average patient probably has no idea how much research is going on, and events like EPCD gives them a view behind the scenes."

It is an opportunity for the community to come together and "talk about all things NMOSD, MOGAD and MS". Which, Sumaira said, "could lead to better outcomes".

"As much as we learn from the clinicians and the scientists, we're also giving them information and insights that they might otherwise not be privy to"

"The reality is, as much as we learn from the clinicians and the scientists at events like EPCD, we're also giving them information and insights that they might otherwise not be privy to."

"The more information that is out there, the more peer-to-peer connections, patient/clinical, and association/association connections that are made, the better we will work together."

"I am involved in fundraising for the Danish MS Society, and it's extremely important to show fundraisers who work so hard to collect money what it is used for. It helps to inspire them, and that has a huge impact."

Martin Wolffbrandg
Research fundraiser and person living with MS

An exchange of ideas

One of the main goals of EPCD is to give people the information they need to make informed decisions about their care and treatment, said Romain Marignier, professor of neurology in France.

At the same time, it provides researchers with the opportunity to make sure they are working on problems that actually matter to those people who are living with the conditions, he went on.

"It is about sharing new data, networking, and talking about practical things people can do to manage their health. It is very precious.

"Often, patients who attend these kinds of events know more about the disease than us. We have organised similar events in France. We found them very helpful because we have so much to learn from the patients – how they feel and manage on a daily basis, and the impact of the condition on their family and work life," he said.

"It is about sharing new data, networking, and talking about practical things people can do to manage their health. It is very precious"

A new era?

Asked what he considered the most important research presented at ECTRIMS 2024, he highlighted studies that suggest we may be "entering a new era."

"There are new treatments that might be successful in preventing the progressive phase of the condition. This is very promising," he said.

"There also is work in neuro-reparation, neuro-rehabilitation, and myelin protection, in MS, NMOSD and MOGAD. So developing tools and treatments to help protect the brain and the spinal cord is my highest expectation for the near future."

EPCD: The story so far

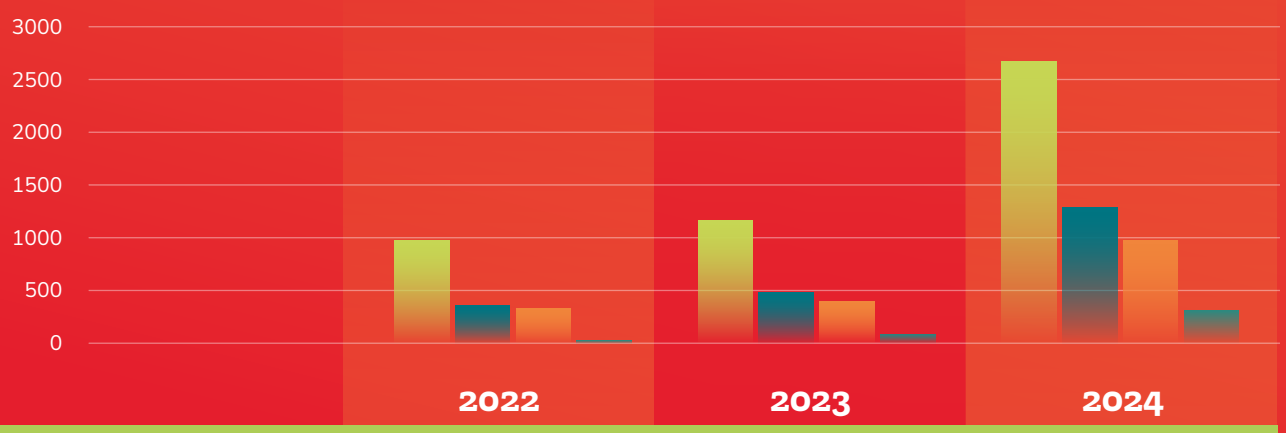
Since 2022, EPCD has gone from strength-to-strength. This year's event was the most well attended yet.

More than 50% more people from across the community took part in 2024 than in 2023.

ECTRIMS PATIENT COMMUNITY DAY:

- Empowers patients to manage their own health and participate in the research process
- Enables a two-way transfer of knowledge
- Helps build a strong, united MS and related neurological condition community

Number of participants



	2022	2023	2024
Registration	971	1162	2674
Total attendance	361	482	1288
Attendance online	331	399	978
Attendance in person	30	83	310

Main registration categories

1,907 Patient
106 Caregiver
108 Non-profit organisation
124 Healthcare Professional

Around the world in 2024

74 Countries
6 Continents
32 Languages

450

Questions and comments in the online chat during the event

Inclusion and diversity

The EPCD 2024 programme was developed in partnership with patients, advocacy specialists, and researchers.

Working with our partner organisations, we hosted roundtable discussions and conducted surveys to understand what matters most to people living with MS and related conditions.

We also worked hard to make sure as many viewpoints as possible were heard, and as many people as possible could take part:

- All panel discussions included patients, advocates, and researchers. The event was held in English with AI-powered simultaneous translation of more than 50 languages.
- Attendees could participate either onsite or online.

LOOKING AHEAD
SAVE THE DATE

Patient Community Day 2025 will be held **on 26 September in Barcelona, Spain.**

Check the ECTRIMS website closer to the time for more details and to register.

↗ ectrims.eu/ectrims2025

Learn more

Our patient advocacy group partners provide a wealth of information and support for people living with MS, NMOSD, and MOGAD.

Visit their websites to learn more:

- ↗ Sclerose Foreningen
- ↗ MSTranslate
- ↗ The Sumaira Foundation (NMSOD and MOGAD)
- ↗ MS Ireland
- ↗ MS-Selfie
- ↗ Shift.ms
- ↗ Guthy Jackson Charitable Foundation (NMSOD)
- ↗ The Nerve of My Multiple Sclerosis
- ↗ The National MS Society
- ↗ European Multiple Sclerosis Platform
- ↗ MS International Federation
- ↗ France Sclerose En Plaques
- ↗ NMO Brasil
- ↗ theMSguide.com
- ↗ MS Together
- ↗ Multiple Sclerosis Association of America

Our sponsors

A special thank you to our EPCD sponsors, whose involvement ensures the event remains a beacon of hope and a source of the latest information for the patient community.

Grant providers are not invited to give input on topics, speakers, or content for ECTRIMS educational offerings.