Impact Report

Patient Community Day

2025

26 September | Barcelona & online

Presented by

ECTRIMS
EUROPEAN COMMITTEE FOR TREATMENT AND RESEARCH IN MULTIPLE SCLEROSIS

Patient Community Day
Impact Report 2025

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Stronger Together: A movement built on connection, knowledge, and patient leadership

Since 2022, Patient Community Day has grown from a modest beginning into a global legacy initiative uniting thousands of people living with MS, NMOSD, and MOGAD with the scientific community that serves them.

In September 2025, the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) hosted its fourth annual Patient Community Day (PCD), as part of the ECTRIMS Congress in Barcelona, Spain at the CCIB Barcelona International Convention Center.

This annual event aimed to place patients at the centre of research and decision-making by empowering patients to manage their own health and participate in the research process, enabling a two-way transfer of knowledge; and building a strong, united MS and related neurological condition community.

Held annually alongside the ECTRIMS Congress, PCD ensures that the latest and most innovative scientific discoveries reach the people who matter most: those living with these conditions every day.

This report captures the highlights and impact of PCD 2025, ensuring that people living with MS and related conditions can benefit from the knowledge shared.

PCD exists to ensure that the people living with MS, NMOSD, and MOGAD are equipped not only with information, but with agency.

> This year, we set out to ensure that every person living with these conditions — no matter where they live — could access the insights shared at Patient Community Day.

Bruno Stankoff
ECTRIMS President

Advancing Our Mission in 2025

PCD's mission is to improve the lives of people living with multiple sclerosis, MOGAD, and NMOSD around the world — by uniting, supporting, and inspiring the global community of patients, researchers, and healthcare professionals.

Achieving our mission would not be possible without the generous financial support of our sponsors*. Their contribution ensures that Patient Community Day remains a beacon of hope and a trusted source of the latest information for people living with MS and related neurological conditions worldwide.

Our Sponsors

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Our goal in 2025 was to create long-term, system-level impact by:

Empowering patients with accessible, actionable science:

From research breakthroughs to emerging therapies, biomarkers, and rehabilitation insights, PCD helps patients understand what new discoveries mean for their daily lives. In 2025, 95% of participants found the programme relevant, while 79% plan to use the information with their healthcare teams — a clear indicator of real-world impact.

Strengthening global partnerships & community infrastructure:

Our 2025 network of 40+ Supporting Partners across 17 countries, double the number from 2024, demonstrates the accelerating momentum behind a more unified global patient community. These partners amplify access, drive local engagement, and help ensure that PCD's legacy extends far beyond the one-day event.

Expanding equity and representation across continents & communities:

PCD 2025 welcomed its first Supporting Partner from Africa, broadened faculty representation to 10 countries (up from six in 2024), and delivered AI-powered translation in 50+ languages, ensuring that knowledge not only travels globally, but lands meaningfully in diverse communities.

**ECTRIMS remains a fully independent organisation. Sponsors are not invited to contribute to, influence, or shape the content or format of this day in any way.*

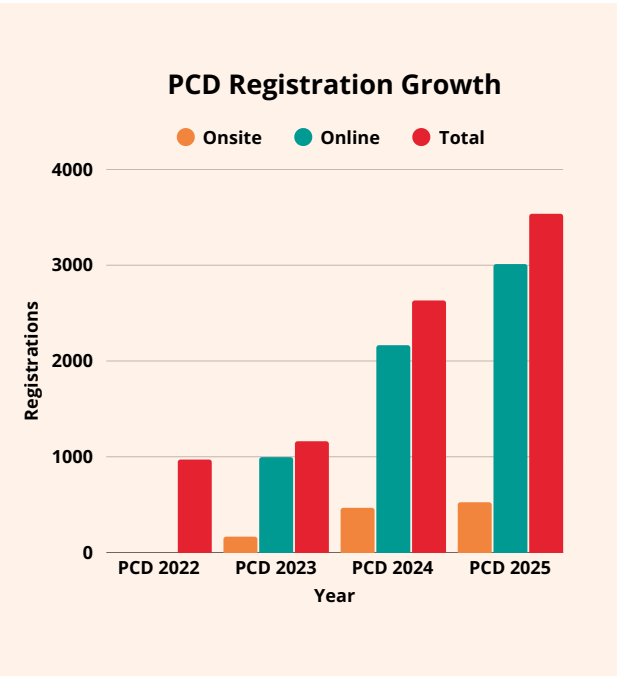
Patient Community Day By the Numbers

PCD 2025 marked the most significant expansion to date. These numbers tell a story of acceleration: more engagement, more inclusion, more global reach, and more investment in patient-centred innovation.

Since 2022, Patient Community Day (PCD) has grown from a modest beginning into a global legacy initiative uniting thousands of people living with MS, NMOSD, and MOGAD with the scientific community that serves them.

What began as an advancement in accessibility and inclusion has become a recognised pillar of ECTRIMS: a bridge connecting cutting-edge research and the lived experiences of the people most affected by neurological diseases.

In 2025, PCD moved beyond a once-a-year experience. The launch of the dedicated PCD website and the PCD Advocacy Blog, along with monthly newsletters and multilingual replay libraries, marked the beginning of a year-round resource hub.



In 2025, this mission reached a pivotal moment. With 3,537 registered participants (a 34% increase from 2024 and a 264% rise since 2022) and 2,383 attendees, PCD achieved its highest participation in history, extending its reach across 89 countries and every major world region.

This scale is not just a milestone. It is evidence of a growing global demand for trustworthy, understandable, and patient-centred science. And it signals a long-term shift: patients are no longer passive recipients of information; they are partners, leaders, and drivers of research and care.

Where We Stand — and Where We're Headed

PCD is growing, not only in numbers, but in influence. As science advances faster than ever, our responsibility is clear: to make sure the information we pass onto the MS community is clear, easy to understand, and accessible.

Looking forward, PCD's commitment is to build a lasting legacy of impact by:

- Continuing to diversify the global patient voice, including underrepresented regions and communities
- Strengthening partnerships to influence research agendas, funding, and policy
- Expanding multilingual access so that geography and language are never barriers to scientific understanding
- Increasing opportunities for patients to shape, participate in, and lead research
- Elevating the lived-experience voice at every stage of scientific exchange
- Scaling digital tools to reach millions more globally

Our vision: from annual event to year-round ecosystem

PCD is no longer just a day. It is an infrastructure. It is a platform for education, collaboration, and community building that will grow in sophistication and scope over the coming years.

See our full digital PCD Impact Report

A Global Community of Supporting Partners

More than 40 Supporting Partners from 17 countries helped amplify the global reach and impact of PCD 2025. MS and related neurological conditions are global diseases, so PCD needs to have global representation.

Together with National MS Societies and global patient advocacy groups, the Supporting Partner network includes NMOSD and MOGAD communities and educational networks, resulting in greater alignment of content with the needs and priorities of patients worldwide.

Since PCD first launched in 2022, the number of Supporting Partners has doubled, showing that when we all work together, we generate the best outcomes for people living with MS, NMOSD, and MOGAD.

The collective effort of our Supporting Partners has been essential in achieving our mission.

Bruno Stankoff, ECTRIMS President has said of the Supporting Partners network, "Their collective effort demonstrates the power of shared purpose: when organisations come together across borders, we move closer to equitable access to science and care."

Our Network of 40+ Supporting Partners

Learn more about our Supporting Partners

Supporting Partner Spotlight

MS Spain launches inclusive workplaces as "extraordinary legacy" of PCD 2025

Multiple Sclerosis Spain, host organisation of PCD 2025, used the event to announce a new "pioneering project" aimed at raising awareness of and supporting Catalan companies to recruit and employ people living with MS.

Ana Torredemer, President at MS Spain, an umbrella organisation for almost 40 MS societies across the country, said: "More than 55,000 people live with MS in Spain. Although great progress has been made in treatments that allow them to enjoy a better quality of life and remain active in the workforce for longer, stigma and the lack of awareness about their professional capabilities persist.

As a result, only 56% of people with MS are employed: a rate lower than both the global average and the general population."

The initiative, a collaboration between the Multiple Sclerosis Foundation of Catalonia, FEM Barcelona Activa, and the Barcelona Convention Bureau, will consist of an online training programme.

It will "inform and disperse myths" about MS, provide tools to improve diversity management, and promote inclusive and competitive work environments.

> We hope that the legacy of this event will extend beyond these walls, leaving a lasting mark on the city and, more importantly, on the lives of those affected by multiple sclerosis.
>
> Ana Torredemer
> President, MS Spain

Supporting Partner Spotlight

EMSP: Supporting Partners pushing to advance care for everyone

People living with neurological conditions like MS don't just want education – they want to be an active part of improving care. It is why events such as the Patient Community Day are so important, said Elisabeth Kasilingam, CEO of the European Multiple Sclerosis Platform (EMSP).

"PCD helps us collaborate better with researchers and medical professionals," she said. The aim, she went on, is to translate the science in a way that empowers people to be part of the process of driving care forward, whether that involves developing treatments, guidelines, or reimbursement policies.

One of the main objectives of PCD is to bring researchers and patients together in one place. "More and more patients are involved in research," said Elisabeth, adding that PCD acts as "a connector".

As the initiative continues to grow, and more patient groups get involved, "the better we will be able to push together" to advance treatment and care, she explained.

> If we can all stand together in front of the decision makers, and tell them the change we need, we will have a bigger impact.
>
> Elisabeth Kasilingam
> CEO, EMSP

EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Supporting Partner Spotlight

MS Canada: The closer patients are to research, the better

Benjamin Davis, Senior Vice President of Mission at MS Canada, believes that bridging the gap between patients and researchers is essential.

Founded in 1948, MS Canada is dedicated to promoting research and providing education to people with MS and their families and caregivers. Enhancing quality of life is an integral part of its mission.

And being a PCD supporting partner is part of that. “The energy (at the event) is really positive,” said Benjamin. “I think people enjoy being together and learning from one another. The opportunity to hear about research, breakthroughs, and treatments is inspiring, and it empowers people.”

Next year, PCD 2026 will be held on 23 October 2026 in Toronto, Canada, where ECTRIMS is holding its tri-annual joint meeting with its North American counterpart, ACTRIMS. “It’s going to be a wonderful opportunity for those living with MS to come together, to learn about the research, to learn about each other’s journeys, and to understand the advocacy opportunities. Sharing the highs, the lows, and everything in between can be really empowering,” said Benjamin.

> Having patients provide input on their experiences, and on the gaps and opportunities, is a really crucial part of the entire process.

Benjamin Davis
Senior Vice President of Mission
MS Canada

MS Canada

Supporting Partner Spotlight

'A Huge Honour:' MS South Africa joins PCD as first African partner

Organisers were thrilled to welcome the first supporting partner from the African continent, MS South Africa, in 2025.

Non Smit, CEO at the advocacy group MS South Africa, said she hopes that being part of the global PCD community will help raise the profile of MS back home, and that this will translate to improvements in education and care.

"In South Africa, we have a very fragmented health system. Around 80% of people do not have access to diagnostics and treatment, and they are suffering," she explained. "We need to be recognised and to be seen. We need epidemiology studies, we need to find the people with MS, and we need to advocate for access and treatment.

"New diagnostics, new guidelines, new ways of interacting, artificial intelligence. All of this is so relevant to what people want to know, so that they can make decisions," she said, adding that it also helps people to have informed conversations with their healthcare teams.

> We need to be recognised and to be seen. We need epidemiology studies, we need to find the people with MS, and we need to advocate for access and treatment.
>
> Non Smit
> CEO, MS South Africa

MULTIPLE SCLEROSIS SOUTH AFRICA

What Participants Told Us — and Why It Matters

Each year, Patient Community Day is shaped by the people who attend it. Their experiences, their priorities, and their feedback help us refine the programme, strengthen our impact, and ensure we continue to meet the needs of the global MS, NMOSD, and MOGAD community. In 2025, more than two hundred participants shared their reflections. Their responses paint a clear and compelling picture of what PCD means to them.

In open responses, attendees shared what mattered most to them. They highlighted, among other things, clear explanations of complex scientific concepts; up-to-date information on therapies and emerging research; the connections with the lived experience panel and patient stories; and the opportunity to hear global perspectives.

What participants said about PCD:

95%

Found the content relevant and meaningful

PCD 2025 delivered information that resonated deeply with the community. Participants highlighted the clarity of explanations, the accessibility of research topics, and the balance of scientific and lived-experience perspectives. Many emphasised how rare it is to hear directly from leading researchers in a format designed for patients.

79%

Said that the programme supports real-life decisions

The impact of PCD goes beyond the event itself — it influences conversations in clinics, hospitals, and homes around the world. A large majority of respondents said they plan to discuss what they learned at PCD with their healthcare team. For many, PCD provided confidence: confidence to ask new questions, to explore treatment options, or to better understand the evolving research landscape.

99%

Want to stay connected to the community

The momentum doesn't stop when the livestream ends. 99% of respondents said they intend to or may attend again in 2026. This loyalty reflects a sense of belonging, and a recognition that PCD is a space where patient voices are represented. As PCD continues to grow, so too will ECTRIMS' commitment to providing opportunities for the community to remain connected.

Session One

Latest developments across the patient journey

Living with MS and related neurological conditions is often described as a journey. And each step is an important milestone with unique challenges. To open this year's PCD, our Panel of Experts took a tour of the patient journey, from diagnosis to treatment and rehabilitation, sharing the latest updates along the way.

This session explored the newest developments in research related to MS, NMOSD and MOGAD that impact on a patient's journey. In particular, discussions covered the topics of diagnosis, emerging therapies, rehabilitation and lifestyle modifications. As well as this, the session placed a focus on the role that nurses play throughout these key stages in the course of the disease.

Meet the Panel

Moderator: Brett Drummond

Panelists:

- **Bruno Stankoff, Neurologist**
  ECTRIMS President, France
- **Gabriel Bsteh, Neurologist**
  ECTRIMS Committee Member, Austria
- **Sudarshini Ramanathan, Neurologist**
  Concord Hospital, Australia
- **Alvaro Cobo Calvo, Neurologist**
  Vall Hebron Institut de Recerca, Spain
- **Amy Perrin Ross, MS Nurse**
  Loyola University Medical Center, USA
- **Joelle Massouh, MS Nurse**
  Harley Street Medical Center, UAE
- **Roshan das Nair, Researcher**
  University of Nottingham, UK

Scan to watch the session replay

Session One

Topic in Focus: Diagnosis

For most people, the journey of living with a neurological condition starts at diagnosis. Often, it follows weeks, months, or even years of uncertainty. In recent years, researchers and doctors have been working hard to improve diagnosis.

Key Learnings

- Better understanding of MS has led to the development of new diagnostic guidelines. The updated McDonald Diagnostic Criteria were published in September 2025. They include new guidance on diagnostic markers, or test results, that can help doctors spot MS earlier.

- Researchers know that people who have central nervous system inflammation (CNS) and antibodies against the aquaporin-4 (AQP4) protein have NMOSD. People who have CNS inflammation and antibodies against the myelin oligodendrocyte glycoprotein (MOG) have MOGAD.

- But what about people who have symptoms representing these diseases, but no AQP4 or MOG antibodies? Doctors call this double seronegative NMO, or double seronegative NMOSD. At ECTRIMS 2025, researchers said there was “space to include” people with double seronegative disease “under the umbrella” of NMOSD. This means more people will have access to care services.

- In the coming years, researchers hope to discover more antibodies or markers that will help them to better diagnose people with double seronegative NMOSD.

> We talk about faster diagnosis, but it also has to be accurate. It is never perfect, but (with the updated criteria) it will be considerably better.
>
> Gabriel Bsteh
> Neurologist, Austria
> ECTRIMS Committee Member

Session One

Topic in Focus: Emerging therapies

For many people, the next step after diagnosis is getting on to a disease-modifying therapy (DMT). In MS, there are now more than 20 available options.

Key Learnings

- One possible approach that may improve the impact of treatments in MS is developing therapies that are better able to access the CNS, which is the brain and spinal cord.

- Researchers are investigating CAR-T cell therapies. In the context of MS, CAR-T cells are immune cells that have been genetically engineered to find and eliminate the B cells that attack the CNS. So far, although this strategy has started to be used extensively as a cancer therapy, our understanding of if and how it will work in MS is limited.

- Another potential treatment approach is remyelination, or repairing the damage MS does to the myelin in the CNS. At ECTRIMS 2025, delegates learnt more about how the damage happens and how it can be repaired. This knowledge may help researchers develop remyelination treatments.

- Another study looked at two existing drugs, the diabetes medicine, metformin, and the antihistamine, clemastine, in people with relapsing-remitting MS. Early results suggest the combination can repair myelin damage, although the effect was small.

- This is now the third clinical trial to have shown that myelin repair is possible in people living with MS. This is a positive sign, but it is only a first step towards a possible remyelination treatment for MS

- More trials are needed to better understand what compounds are the best and how long they need to be administered for to deliver the most significant benefits

Session One

Topic in Focus: Emerging therapies continued

Researchers are continuing to look for more powerful therapies, with fewer side effects, as well as new medications for NMOSD and MOGAD.

Key Learnings

- In NMOSD, people need ongoing treatment that dampens the immune system. The aim is to stop B cells in the blood from creating the AQP4 antibodies that cause the disease. That's why researchers have been looking at drugs that clear B cells from the blood. Studies have shown that rituximab and inebilizumab, both of which clear B cells from the blood, may reduce relapse rates.

- Researchers have also been looking at treating the inflammation that damages the CNS. Interleukin-6 receptor (IL-6R) antibodies, like tocilizumab and sarilumab, are already used in other inflammatory conditions. So far, studies have shown that they are better than no treatment, but more research is needed to find out exactly how well they work.

- Researchers have also started to look at stem cell transplantation and CAR-T cell therapies in NMOSD, but it is too early to tell if they are effective.

- Some researchers are looking at rituximab as a way to treat MOGAD. It clears B cells, which create the MOG antibodies that cause the disease, from the blood. So far, the results have been mixed. Some studies found it was useful, but others found it was not. More work is planned to find out more.

- Two studies are looking at drugs that aim to stop the body "recycling" the MOG antibodies in the blood: rozanolixizumab and satralizumab. Researchers expect to see the results soon.

> I think the field of MOGAD is younger, but hopefully, in the coming years, we can move that along quickly.
>
> Sudarshini Ramanathan
> Neurologist, Australia
> Concord Hospital

Session One

Topic in Focus: Specialist nurse support

This year's ECTRIMS programme for nurses included a dedicated session on shared decision making, with MS specialist nurse panellists Amy Perrin Ross and Joelle Massouh.

Key Learnings

- People living with MS and related neurological conditions should be part of the conversation about their care.
- The number of DMTs now available for MS can make choosing between them overwhelming. Specialist nurses and advanced practitioners can help people navigate the choices and make informed decisions.
- Healthcare professionals and patients often have very different priorities when making treatment decisions. Amy's advice was to "actively engage in discussion with healthcare providers" so "you can be part of that shared decision making."

> Shared decision making is...actively engaging in conversation with the person with MS, their families, and their care partners, to come to a mutual decision about what is the best treatment for them."
>
> Amy Perrin Ross
> MS Nurse, Loyola University Medical Center

Session One

Topic in Focus: Rehabilitation

This year's ECTRIMS Congress was a joint meeting with Rehabilitation in MS (RiMS), the European network for best practice and research in MS rehabilitation.

Key Learnings

- Mobile phone apps can be used for remote rehabilitation services. This could help to ease pressures on healthcare systems, and ensure people get the care they need no matter where they live.

- Apps can also help monitor the impact of rehabilitation. People can, for example, track their steps on a fitness app to see if their activity levels increase after taking part in a physical rehabilitation programme.

- Some of the things that happen to the brain as we get older are similar to the things that neurological conditions such as MS do to the brain. It can be hard to tell the difference between the two. Some brain health rehabilitation approaches – such as eating a balanced diet and keeping active – can help alleviate cognitive (ie thinking) problems, whether they are caused by ageing or a neurological condition.

- It was emphasised that rehabilitation should be something that is implemented from the earliest possible stages. It is much better to take a preventative approach that maintains and preserves function, rather than trying to regain it after symptoms appear and it starts to get lost.

> Mental health and psychological well-being is sometimes a taboo subject... but there are lots of people who experience difficulties. The key thing is to monitor yourself and how you are feeling because there are things that can be done.
>
> Roshan das Nair
> Researcher University of Nottingham, UK

Lived Experience Panel

Facilitating an important two-way dialogue

The People With Lived Experience Panel invited people from around the globe to share their personal stories and highlight the ways in which they are actively shaping research.

Whether through patient advocacy, working with national and international organisations, taking part in registries and clinical studies, or amplifying underrepresented voices, each speaker demonstrated the crucial role of patients in the research process. More than personal stories, these were powerful calls for partnership, inclusion, and equity in research and care.

Meet the Panel

Moderator: Brett Drummond

Panelists:

- **Eduard Pletea**
  Person living with MS, President of the Romanian MS Society; Executive Committee Member of EMSP, Romania
- **Amy Thompson**
  Person living with MS Founder and CEO of MS Together, UK
- **Graham Walker**
  Person living with MS President of MS Taranaki, New Zealand
- **Ana Torredemer**
  President of Multiple Sclerosis Spain
- **Marion Jones**
  Person living with NMOSD, Ambassador, The Sumaira Foundation, United States

Scan to watch the session replay

Lived Experience Panel

Voices Shaping the Future of Research, Treatment, and Care

A powerful message came through at this year's PCD: meaningful progress happens when the perspectives of people living with MS, NMOSD, and MOGAD are actively included at every stage of research.

This year, PCD featured a Lived Experience Panel that brought together panellists from across the MS, NMOSD, and MOGAD communities. Each offered a distinct lived reality, yet all shared a commitment to strengthening the connection between scientific discovery and the experiences of the people most affected by these conditions.

The panel opened with reflections from Eduard Pletea, who spoke about what it truly means to be an "expert by experience," describing how the day-to-day realities of living with MS shape a deeper understanding of what effective research, treatment, and care must achieve.

That idea carried forward as Amy Thompson shared her perspective on being diagnosed at a young age, noting how easily certain groups can be overlooked and how important it is to make research more accessible, relevant, and open to those who want to take part.

.

> Invite us to take part from the very beginning — not just as participants, but as partners...Because when patients become partners, science turns into solutions.
>
> Eduard Pletea
> Person living with MS, President of the Romanian MS Society, Executive Committee Member of EMSP, Romania

Lived Experience Panel

The conversation continued with Graham Walker, who reflected on how quickly people become experts in their own condition and how that expertise evolves into a perspective that is indispensable for shaping decisions about future research and support. His experience illustrated how lived insight helps identify what truly matters to people navigating these conditions every day — priorities that might otherwise be overlooked in purely clinical conversations.

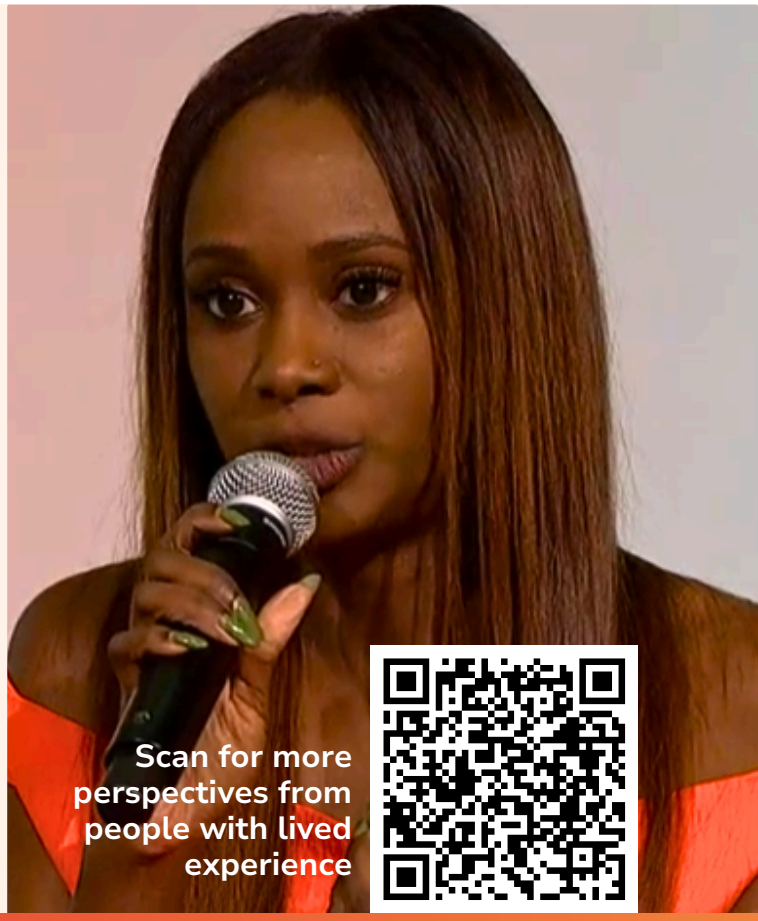
Building on that theme, Marion Jones brought the discussion to issues of equity and representation.

She spoke about the responsibility to ensure that communities disproportionately affected by NMOSD are not only included in research, but empowered to participate in studies and clinical trials. Her perspective underscored the importance of broadening who is seen, who is heard, and who benefits from emerging treatments.

As the panel's stories converged, Ana Torredemer offered a reminder that while research propels scientific discovery, its purpose — and its impact — always begins and ends with people. She emphasised that the voices and experiences shared throughout the discussion give meaning to the science, guiding it toward outcomes that genuinely improve lives.

> I am extremely passionate about health equity. People like me – a woman, an African American, a minority – are disproportionately affected by NMOSD, so it is really important to be a part of studies and clinical trials.

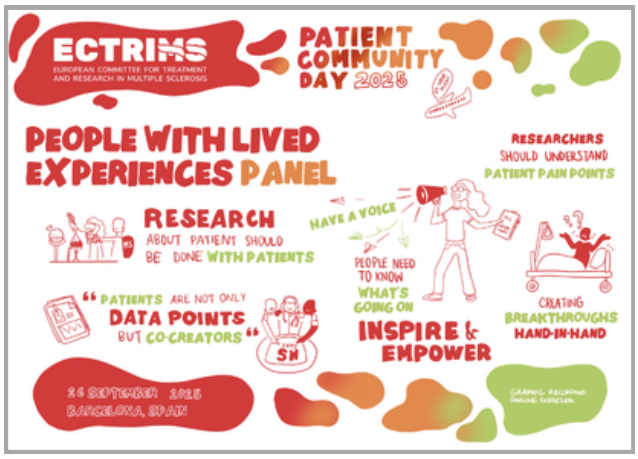
Marion Jones
Person living with NMOSD, Ambassador, The Sumaira Foundation, United States



Lived Experience Panel

New to Patient Community Day this year was a live visual element that added a deeply personal perspective to the program. Sketch artist and PhD researcher Pauline Gieseler, who lives with MS, captured the day's discussions through illustrations that reflected both the science and the lived experience behind it.

Drawing on her own journey, Pauline highlighted the systemic challenges facing people with MS. "The problem is not MS," she explained. "The problem is access to diagnostic tests, access to therapies, access to clinical trials." Her reflections echoed many of the themes raised by participants throughout the day. Through her work, Pauline underscored the importance of identity, hope, and empowerment.



Sketch by Pauline Gieseler, Person with MS & PhD researcher who attended PCD 2025.

"People sometimes forget the person they were before MS – but they are still the same person," she said, expressing her hope that shared knowledge and positive stories would spark a shift in mindset and leave participants feeling informed and empowered.

> This year, PCD had a patient insight session for the first time, which I absolutely loved. Our voice also needs to be heard. Patients love to hear from other patients. And for the neurologists and other clinicians in the room, it's important they hear those insights.
>
> Roxy Murray
> Person living with MS, Multiple Sclerosis Fashionista, PCD Supporting Partner, United Kingdom

Session Two

Advances in Hot Topics

In this session, our seven Expert Panellists dove into various "hot topics" – defined as those topics that matter most to people living with MS and related conditions – from everyday challenges such as cognition, to breakthroughs in biomarkers, genetics, and artificial intelligence.

The discussion highlighted how advances in research are deepening understanding of MS and informing more personalised approaches to care. Panellists explored how emerging biomarkers, insights into smouldering disease, and the growing role of artificial intelligence and genetics may improve disease monitoring, treatment development, and long-term patient wellbeing.

Meet the Panel

Moderator: Brett Drummond

Panelists:

- **Olga Ciccarelli, Researcher**
  ECTRIMS Vice-President, UK
- **Ali Manouchehrinia, Researcher**
  University of Manitoba, Canada
- **Mitzi Joi Williams, Neurologist**
  Joi Life Wellness Group, USA
- **Daniel Ontaneda, Neurologist**
  Cleveland Clinic, USA
- **Jeannette Lechner-Scott, Researcher**
  University of Newcastle, Australia
- **Liliana Patrucco, Neurologist**
  Centro de Esclerosis Múltiple de Buenos Aires (CEMBA), Argentina
- **Xavier Montalban, Neurologist**
  Multiple Sclerosis Centre of Catalonia (Cemcat), Spain

Session Two

Hot Topic: Biomarkers

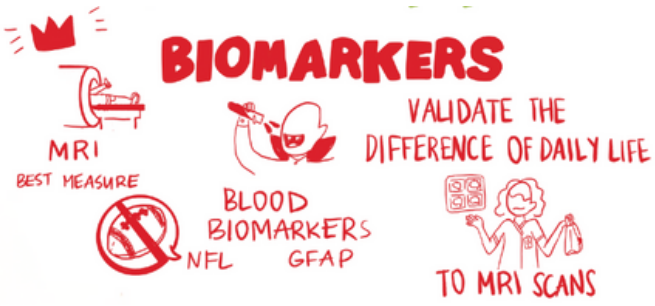
Biomarkers are measurable signals of a normal or abnormal process, or of a particular condition. Doctors may look for biomarkers in the blood, the spinal fluid, or on imaging scans, and use them to understand what is going on inside the body.

Key Learnings

- Biomarkers may be able to help doctors predict who will experience slow worsening of their disease, and measure some of the silent symptoms that people experience. That includes things like cognition issues, fatigue, numbness and tingling.

- One study presented at ECTRIMS 2025 found a link between a combination of 13 different proteins in the cerebrospinal fluid (CSF) and progression independent of relapse (PIRA). This information may help researchers build tools that can spot people at risk of PIRA, or even guide the development of new treatments

- Another study found that glial fibrillary acidic protein (GFAP) may be able to tell doctors about disease progression. People with high levels of GFAP in their blood appear to have a slow worsening of MS over time, it said. This finding could lead to new ways to prevent or treat progression.



> When we get into the more progressive phase of the disease, there are more subtle things that may be occurring on MRI that we cannot measure in the clinic.
>
> Mitzi Joi Williams
> Neurologist, Joi Life Wellness Group, USA

Session Two

Hot Topic: Smouldering MS

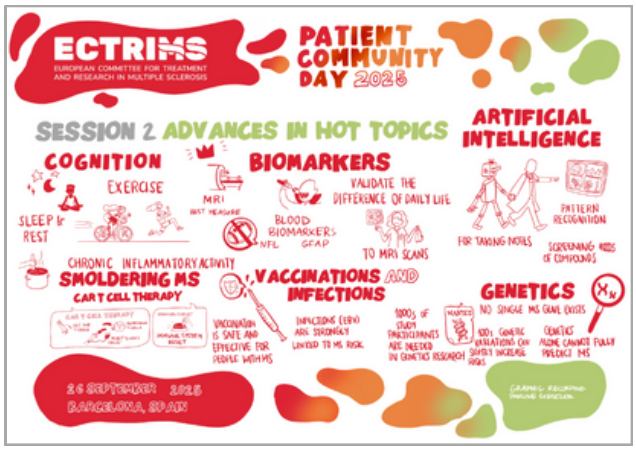
Smouldering MS, or MS that gets worse but not because of relapses, was a main focus of ECTRIMS 2025. Smouldering MS describes chronic, or ongoing, inflammation in the central nervous system (CNS).

Key Learnings

- Smouldering MS is something that researchers are learning more about all the time. They are finding new ways to measure and detect it, and even ways to treat it. Not everyone with MS will experience smouldering MS.

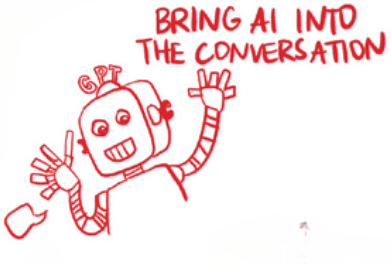
- At ECTRIMS 2025, researchers heard about possible new treatments for smouldering MS. They include Bruton's tyrosine kinase (BTK) inhibitors and CAR-T cells. These treatments may be able to cross the blood-brain barrier to reach the inflammation in the CNS.

- Panellists highlighted a phase III clinical trial of a BTK in people with secondary progressive MS with no relapses. It found the drug could delay the progression of disability by 31%, compared to placebo, or a dummy treatment.



Sketch by Pauline Gieseler, Person with MS & PhD researcher who attended PCD 2025.

> If this drug is approved, it will add a new option to our armamentarium," he said. "There are two or three other BTKs coming, perhaps even more specific, probably efficacious, and perhaps with fewer side effects.
>
> Xavier Montalban
> Neurologist Multiple Sclerosis Centre of Catalonia (Cemcat), Spain



Session Two

Hot Topic: Artificial intelligence

Artificial intelligence (AI) is playing a key role in the research world, helping investigators to gather and understand more data than ever before. It can combine multiple types of data, such as MRI, genetics, biomarkers, and clinical information, spotting patterns in a way the human brain cannot.

Key Learnings

- AI is being used across the healthcare system. AI-powered transcription tools, for example, can record doctor–patient conversations and generate clinical notes. Some healthcare professionals feel this helps them concentrate on the person they are talking to.
- Researchers are using AI to screen thousands of compounds or molecules at a time. It means they can find the most promising, least toxic drug candidates in a fraction of the time.
- In research, the more people involved in studies, the more reliable the results. AI can work with datasets of tens of thousands of people.
- This makes predictions more accurate. It will be particularly important to ensure that AI systems are trained across a diverse range of participants.
- Diversity in MS clinical trials has been a hot topic of conversation and this will continue to be important as the role of AI increases in these studies.
- In other diseases, including Alzheimer's, researchers are using AI to speed up clinical trials. One way they are doing this is by using the technology to find people who are most likely to respond to the treatment being studied.

Watch the video replay

Watch the complete PCD 2025 programme on YouTube and on our website hear experts dive into the latest advancements to offer valuable context and depth to the themes summarised in this report. Connect the insights directly to emerging trends in care, research, and patient advocacy. Videos are available in both English and Spanish.

YouTube @ectrimsYouTube

Session Two

Hot Topic: Genetics

One of the biggest questions people often have is why some people develop MS while others do not. Or why the condition progresses more quickly in some people than in others. Part of the answer lies in genetics.

Key Learnings

- While no single MS gene exists, researchers have identified hundreds of genetic variations that can slightly increase the risk, and are starting to identify genes that increase the risk of accelerated disease progression.

- People with certain genes may be predisposed, or more likely in given circumstances, to develop an autoimmune disease. MS is just one example of an autoimmune disease.

- Genetics alone cannot fully predict MS. Lifestyle and environmental factors, such as smoking, low vitamin D, and viral infections such as the Epstein-Barr virus (EBV), also play a role. Researchers call the area where genetics and environmental factors meet epigenetics. Epigenetics may be more predictive than genes alone.

- At ECTRIMS 2025, researchers shared information on new AI-based models that combined genetic information with clinical and biological markers. The aim was to better understand how people develop and experience MS. This could eventually lead to more personalised treatments

- Many thousands of study participants are needed to move this field of research to the next step. The International MS Genetics Consortium has been incredibly successful at enabling global collaborations, using data from people living MS around the world, to help start to answer these questions.

It is really important for MS genetics research to bring in a mixture of nations. We need, for example, to bring in African Americans who have been under-represented in MS genetics. We are hopeful that all this information will help us understand the disease better."

Ali Manouchehrinia
Researcher University of Manitoba, Canada

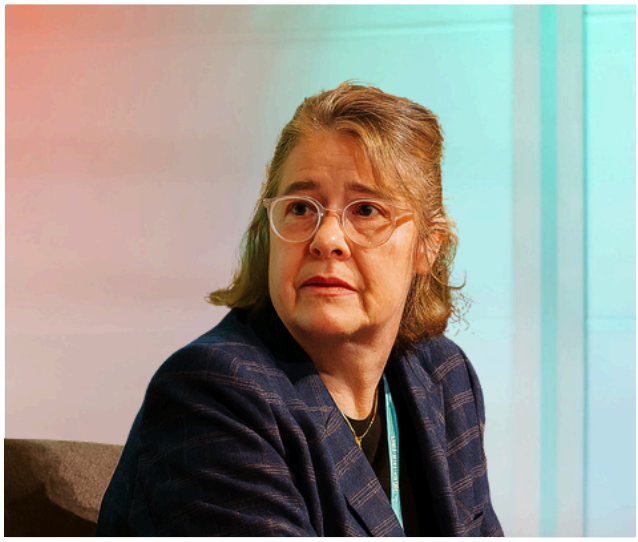
Session Two

Hot Topic: Infections and vaccinations

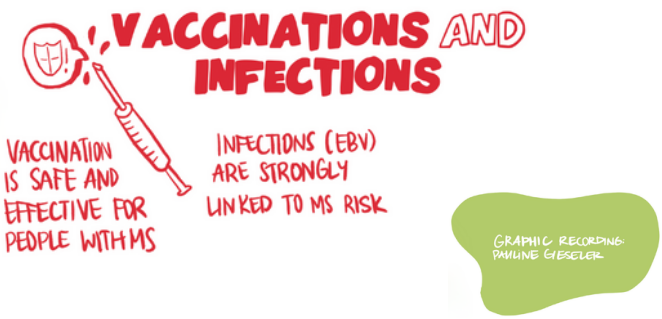
Infections, especially EBV, are strongly linked to the risk of developing MS. At the same time, vaccinations play a crucial role in managing MS safely, particularly when patients are starting treatments that affect the immune system.

Key Learnings

- Several trials are underway to develop a vaccine to EBV. Researchers hope that preventing EBV infection could reduce the number of people who develop MS in the future.
- It is important for people with MS to have all recommended vaccines before they begin DMTs. This is because a person's response to a vaccine may be weaker after treatment begins, as DMTs supress the immune system and can make people vulnerable to infections.
- There is strong evidence to show that vaccination is safe and effective in people with MS.



> The majority of infections related to the use of high-efficacy therapy are mild or moderate, and we can deal with them perfectly well. The treatments are safe, and vaccines are safe.
>
> Liliana Patrucco
> Neurologist, Centro de Esclerosis Múltiple de Buenos Aires (CEMBA), Argentina



Ask the Expert

Ask the Expert online session offered global connectivity

PCD 2025 included an Ask the Expert segment to give remote participants around the world more time to pose questions directly to expert neurologists Alan Thompson, Mar Tintoré and Romain Marignier.

The PCD Ask the Expert session was an open exchange of ideas that captured the heart of PCD: connection, learning, and hope. Topics covered included diet and the microbiome in MS, the impact of perimenopause on MS. ageing and MS, and the impact of co-morbidities.

This year's PCD Ask the Expert session brought that spirit to life on a global scale. A total of 2,063 people joined the live broadcast, engaging with the program in real time through comments and questions. During the dedicated Ask the Expert segment, participants submitted thoughtful questions that were addressed directly by the panel, reinforcing the session's interactive and inclusive nature.

PCD's global reach continued to grow, with participants tuning in from North America, Latin America, and the Asia-Pacific region. Strong engagement from Spain, Brazil, the United States, and Canada reflects increasing international awareness, while emerging participation in Eastern Europe and Latin America highlights PCD's expanding accessibility and relevance for communities worldwide.

Meet the Panel

Panellists:

- **Alan Thompson, Neurologist**
  University College London, United Kingdom
- **Mar Tintoré, Neurologist**
  Multiple Sclerosis Centre of Catalonia (Cemcat), Spain
- **Romain Marignier, Neurologist**
  Hospices Civils de Lyon, France

Scan to watch the session replay

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