ECTRIMS
EUROPEAN COMMITTEE FOR TREATMENT
AND RESEARCH IN MULTIPLE SCLEROSIS

Empowering and educating people with multiple sclerosis

- **ECTRIMS 2024**
- **COPENHAGEN, 18-20 SEPTEMBER 2024**

Photo: Bartosch Salmanski

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RESEARCH DIRECTLY TO PATIENTS

How do you ensure that people living with Multiple Sclerosis (MS) have a deep understanding of the scientific aspects of their condition, empowering them to take a more active role in managing their health? This was one of the focus areas that **The European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS)** wanted to address as part of their 40th annual congress in Copenhagen 2024.

The congress attracted more than 8,500 delegates from around the world to explore critical issues in MS research and treatment, featuring an international lineup of speakers and scientific sessions. Throughout the congress, a substantial amount of knowledge and research from international experts and neurologists was unveiled. However, this scientific information can be difficult for patients to comprehend. To tackle this challenge, ECTRIMS, with support from **Copenhagen Legacy Lab**, opened the doors for people living with MS to participate in a dedicated **ECTRIMS Patient Community Day (EPCD)** with three objectives:

- Translate technical knowledge from the congress into simple and understandable information.
- Facilitate the transfer of two-way knowledge between researchers and patients.
- Bridge the gap between researchers and patients, and unite the efforts to improve the lives of people living with MS.

BRIDGING THE GAP

The patient day featured two interactive sessions, where a panel of experts discussed MS research. Attendees could ask questions during both sessions and later connect with other patients. The first session covered remyelination, emerging therapies, symptom management strategies, and diversity in clinical trial, while the latter focused on MS diagnosis, nursing practices, and related conditions. With over 300 in-person attendees and almost 1,000 online participants, the event achieved its highest attendance yet.

> ***"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."***
>
> Brett Drummond, Co-founder of MStranslate

The event served a dual purpose: It helped patients gain a clearer understanding of their diagnosis and management of their symptoms, while also providing researchers with the opportunity to learn directly from those most affected by MS, guiding future research to better meet patient needs.

> ***"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."***
>
> Attendee and person living with MS

INCREASING ACCESS TO MS RESEARCH

Recognising that not all MS patients from Denmark and around the world could be present at the event, Copenhagen Legacy Lab, together with ECTRIMS, have compiled the key insights from the EPCD into the **ECTRIMS Patient Community Day 2024 Impact Report**. The report covers areas like remyelination and emerging therapies and is designed to assist MS patients in navigating their condition.

> ***"We had more than 300 people in attendance onsite, nearly 1,000 people connecting online (...) This is in sharp contrast to our previous years. This jump in attendance and engagement truly shows the value of collaboration with our Supporting Partners"***
>
> Bruno Stankoff, ECTRIMS President

After the event, ECTRIMS expressed great appreciation for Copenhagen Legacy Lab's support, highlighting the notable increase in attendance compared to the 2023 ECTRIMS Patient Community Day. ECTRIMS plans to further develop their annual EPCD for their future congresses and include the attained learnings from Copenhagen.

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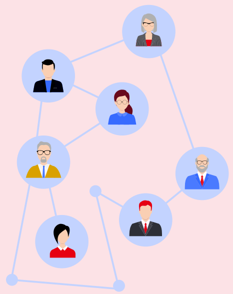
LEGACY PROCESS

Strategic goals and societal needs

MS research is often highly scientific and hard for patients to understand. Traditionally, patients have been detached from the research process, making it difficult to address their needs (ECTRIMS Patient Community Day 2024 Impact Report). The ECTRIMS Patient Community Day aims to mitigate this gap by building stronger connections between researchers and patients, while also educating and empowering MS patients. This aligns with Danish priorities and ECTRIMS' mission to enhance communication, create synergies, and promote research and learning among professionals for the benefit of those affected by MS.

Objective

The objective of the legacy project was to broaden the accessibility of the insights shared during the ECTRIMS Patient Community Day to Multiple Sclerosis patients worldwide.



Stakeholder involvement

ECTRIMS generously opened the doors to people living with MS at their third EPCD, ensuring that the program addressed the most critical issues within MS.

Copenhagen Legacy Lab provided strategic guidance on how to effectively reach and engage people with MS during the EPCD. Additionally, they ensured that the insights from the event were compiled into an Impact Report.

Bellagroup provided the venue for the EPCD and utilised their communication channels, including a press release, to promote the event.

Activities

The ECTRIMS Patient Community Day 2024 was a 3-hour interactive event for multiple sclerosis patients and their caregivers, featuring a panel of medical professionals, researchers, and advocates. The event was live streamed with real-time translations in six languages, making it accessible to multiple sclerosis patients worldwide.

Copenhagen Legacy Lab and ECTRIMS have released a freely accessible Impact Report summarising key insights from the 2024 Patient Community Day. This report will be shared with organisations across Denmark and Europe to reach multiple sclerosis patients who were unable to attend the event.

Outputs (immediately after the activity)

Participation in the Patient Community Day 2024:

- **Onsite:** More than 300 people attended (from 83 in 2023).
- **Online:** Nearly 1,000 people attended (from 390 in 2023).

After the 2024 Patient Community Day, several initiatives were launched to share the outcome with as many people in the multiple sclerosis community as possible:

- **Report:** The 2024 Impact Report has been shared across multiple channels with all ECTRIMS partners and participants.
- Q&A: ECTRIMS launched a landing page to address unanswered questions from the Patient Community Day
- **Podcast:** Highlights from the Patient Community Day was turned into two podcast episodes as part of the ECTRIMS Podcast.

Outcomes (+6-12 months - changed behaviour)

By the end of 2025, the Impact Report has been viewed more than 1,000 times, extending the Patient Community Day's insights to patients worldwide. The podcast has since been developed further and includes more than 60 episodes on treatment and research in multiple sclerosis.

Based on lessons learned in Copenhagen, the Patient Community Day has been further developed and was integrated as a key part of ECTRIMS 2025 in Barcelona. In 2025, participation increased by 34%, and new training modules were introduced to help companies better support employees living with multiple sclerosis. Insights generated at the Patient Community Day in Barcelona have been consolidated in a new 2025 Impact Report.

Impact (+1 year – societal value)

The Patient Community Day concept is a key part of ECTRIMS congresses and will be further expanded at the 2026 edition in Toronto. Participation has steadily increased since 2024, with 99% of 2025 participants indicating they plan to attend again.

The event continues to provide valuable knowledge and insights for multiple sclerosis patients worldwide, benefiting not only patients and their families but also society.

Potential legacy (+1-3 years and beyond)

Today, the Patient Community Day is seen as an integrated and permanent part of future ECTRIMS congresses, demonstrating that the objective of broadening access to valuable multiple sclerosis knowledge for patients worldwide has been achieved.