

Empowering and educating people with multiple sclerosis

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

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,

“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 MStranlate



Photo: Bartosch Salmanski

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nursing practices, and related conditions. With over 300 in-person attendees and almost 1,000 online participants, the event achieved its highest attendance yet.

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.

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

“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

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.

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



Photo: Bartosch Salmanski

LEGACY PROCESS



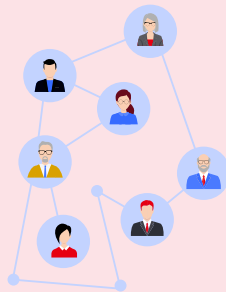
Strategic goals and societal needs

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

A 3-hour interactive event for MS 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 MS patients worldwide.

Copenhagen Legacy Lab and ECTRIMS have released a freely accessible [report](#) summarising key insights from the 2024 EPCD. This report will be shared with organisations across Denmark and Europe to reach MS patients who were unable to attend the event.



Outputs (immediately after the activity)

Participation in the EPCD 2024:

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

After the 2024 EPCD, several initiatives were launched to share the outcome with as many people in the MS community as possible:

- **Q&A:** ECTRIMS launched a [landing page](#) to address unanswered questions from the event.
- **Report:** The [ECTRIMS Patient Community Day 2024 Impact Report](#) has been shared across multiple channels with all ECTRIMS partners and participants and is freely available for all.
- **Podcast:** Highlights from the 2024 EPCD have been turned into an [ECTRIMS Podcast Series](#).



Outcomes (+6-12 months - changed behaviour)

The aim is that MS patients worldwide will read the report and feel empowered and educated, enabling them to actively participate in their health journey. This includes having informed conversations with their doctors and managing symptoms more effectively, thereby improving their quality of life.

While it can be difficult to measure the direct impact of the EPCD and the report, studies show that patient education empowers individuals to manage their health more effectively, thereby improving their quality of life ([ECTRIMS Patient Community Day 2024 Impact Report](#)).



Impact (+1 year – societal value)

Copenhagen Legacy Lab will evaluate whether the learnings from the Copenhagen EPCD have contributed to the development of the 2025 EPCD. It will also be assessed whether the report continues to be effectively disseminated and provides value to MS patients globally.



Potential legacy (+1-3 years and beyond)

To be evaluated.