



Global SMAAdvocacy Event 2026

Event Guide

held in parallel to the
SMA Europe 5th International Scientific Congress
11-14 March 2026
Budapest, Hungary



All together. One goal.

Together, through greater understanding,
we will create a better world
for all those living with SMA.



SMAcademy

SMAcademy is a SMA Europe capacity building initiative for patient advocates in SMA. SMAcademy provides patient advocates with tools to amplify their efficacy and impact when advocating for a better life for people living with SMA.

Co-create. Peer exchange. Expert opinion.

Patient advocates need knowledge across areas of expertise, from understanding SMA to medicine development, regulatory processes, policy, and access. They also need a vast skillset to bring people together, lobby with key stakeholders, and increase the impact of their organisations. At the same time, patient advocates also have a wealth of hands-on and first-hand experience advocating and living with SMA that makes them invaluable experts in the field.

SMAcademy provides a global platform for patient advocates to:

Learn Together. Teach each other.

Our learning offering includes:

- Global SMAAdvocacy Event
- Webinars and workshops
- SMA Patient Advocates Training
- SMA Patient Organisation Peer Mentoring Programme

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The Global SMAdvocacy Event

The **Global SMAdvocacy Event** is a flagship **SMAcademy** initiative by **SMA Europe**, designed to strengthen the global community of SMA patient advocates.

It brings together representatives from SMA organisations around the world to share experiences, exchange best practices, and jointly develop solutions to the most pressing challenges faced by people living with SMA. The event aims to enhance the effectiveness and impact of SMA patient advocates worldwide.

Discussion topics will include challenges and opportunities in generics for SMA, how to build sustainable and effective patient organisations, and how to leverage political attention to meet strategic goals.

Learn together. Teach each other.

Agenda

Room Liszt

07.45 - 08.30	<i>Registration and welcome coffee</i>
08.30 - 08.45	Welcome and purpose
08.45 - 10.00	Session 1: Opportunities and challenges with generics for SMA <ul style="list-style-type: none">• Framing input: Olga Germanenko, SMA Family Foundation Russia• Interactive session
09.45 - 10.00	<i>Coffee break</i>
10.00 - 11.00	Session 2: Building effective and sustainable advocacy organisations <ul style="list-style-type: none">• Framing input: Christian Mori, Famiglie SMA Italy• Interactive session
11.00 - 11.15	<i>Break</i>
11.15 - 12.15	Session 3: Leveraging political attention. Talking to governments and strategising towards advocacy goals <ul style="list-style-type: none">• Framing input: Portia Thorman and Giles Lomax, SMA UK• Interactive session
12.15 - 12.45	Insights and closing remarks
12.45 - 14.00	<i>Lunch</i>

Patient Advocates' Congress Programme

Enjoy our Scientific Congress at its best!

Join us for **dedicated patient advocates activities** in the Patient Advocates Room in **Room Bartók 2.**

March 11th

- 08.30 - 12.45 Global SMAAdvocacy Event (by invitation only)
14.00 - 15.30 Workshops (see Congress programme)
16.00 - 17.30 Workshops (see Congress programme)

March 12th

- 09.00 - 09.30 **Scientific posters tour***
13.00 - 13.45 **Advocates session:** "The need for basic research in SMA: A discussion between advocates and researchers."
Chairs: Marie-Christine Ouillade, Cécile Martinat.
Patient advocates only.
17.30 - 18.15 **Advocates session:** "Working with industry: What really happens, and where advocates can make a difference".
Chairs: Nicole Gusset, Friedrich Metzger.
Patient advocates only.

March 13th

- 08.00 - 08.45 **Advocates session:** "Global access to diagnosis, treatment, and care: A conversation with advocates and physicians."
Chairs: Yasemin Erbas, Giovanni Baranello.
Patient advocates and physicians welcome.
10.30 - 11.00 **Scientific posters tour***
13.00 - 13.45 **Advocates session:** "The strength of Patient Experience Data (PED): How advocates can use PED strategically for lasting impact."
Chairs: Nicole Gusset, Yasemin Erbas, Steven Bourke.
Patient advocates only.

*Sign up for a scientific posters tour on next page



Scientific posters tour sign up!

Book your patient advocate poster tour:

SCAN ME!



Early-stage researchers Delia Gagliardi, Florian Gerstner, and Leonie Sowoidnich will offer an **exclusive, patient advocate dedicated poster tour** to walk you through what is new and exciting in basic research, SMA treatments, and patient care.

Grab your spot, places are limited!

Meeting point on the Gallery level [.5 minutes before your session.](#)



SMA Patient Advocates Training

SMA Europe's **SMA Patient Advocate Training** is a **unique, SMA-focused learning programme** designed to provide patient advocates with essential knowledge and skills to represent people living with spinal muscular atrophy (SMA).

This programme equips SMA patient advocates from all around the globe with the tools they need to act as informed partners in patient engagement collaborations with a wide range of stakeholders, from industry to clinicians, governments and beyond.

The training is structured in five self-paced e-learning units that cover a comprehensive overview of SMA, patient advocacy principles, the medicines lifecycle, healthcare systems and access pathways, and key challenges in the SMA landscape.

Upon completion of all dedicated modules, trainees receive the **SMA Patient Advocate Training Certificate** issued by SMA Europe, as proof of their expertise.

- **Module 1:** Introduction to Patient Advocacy in SMA
- **Module 2:** What is SMA?
- **Module 3:** Medicines' lifecycle
- **Module 4:** Healthcare systems and access
- **Module 5:** Critical issues in SMA (*in person)

Stay tuned!



Applications open: June 2026

Programme start for admitted trainees: September 2026



SMA Patient Organisation Peer-Mentoring Programme

Ready to grow stronger together?

Strengthen your network and sharpen your skills alongside peer SMA patient organisations!

Our **peer mentoring programme** will match pairs patient organisations to maximise opportunities for knowledge sharing. No matter your level of experience, you will have plenty to learn and some to teach!

Over the course of 2026, you and your peer-mentor organisation will:

- Meet quarterly to discuss shared challenges, experiences, and strategies.
- Join a yearly drop-in session with all participating organisations and SMA Europe.
- Receive support from SMA Europe through our dedicated tools.

Apply here by 15 April 2025:

SCAN ME!





The Global SMAAdvocacy Event is sponsored by:

Biogen

At Biogen, we are committed to the rare disease communities we serve and to pioneering innovative science that transforms patients' lives. Founded in 1978, Biogen is a global biotechnology company delivering breakthrough therapies across areas of significant unmet need. We apply deep understanding of human biology and leverage different modalities to advance first-in-class treatments or therapies that deliver superior outcomes.

At the 5th International Scientific Congress on Spinal Muscular Atrophy, we invite you to visit the Biogen booth to meet our teams and learn more about our work in SMA. Biogen will also host a parallel workshop: "Every Motor Neuron Matters: Biomarkers and Treatment Choice in SMA" on Wednesday 11 March, 16:00–17:30. For more details, please visit the event program.

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Novartis

Novartis is a global innovative medicines company. Our purpose is to reimagine medicine to improve and extend people's lives. We focus on delivering medicines that address significant disease burdens, supported by science-based innovation and advanced technology platforms. We work with partners across healthcare to help bring advances to more patients and improve outcomes, today and in the future.

Our ambition is to create a meaningful impact for people living with severe neurological conditions and their caregivers by discovering, developing and delivering innovative medicines that change the course of disease progression. We believe all those diagnosed with SMA should be able to benefit from cutting-edge technology, through turning promising transformative medicines into proven treatments.

www.novartis.com

**SMA
EUR
OPE**

**20 YEARS
TOGETHER**

Roche

Founded in 1896 in Basel, Switzerland, as one of the first industrial manufacturers of branded medicines, Roche has grown into the world's largest biotechnology company and the global leader in in-vitro diagnostics. The company pursues scientific excellence to discover and develop medicines and diagnostics for improving and saving the lives of people around the world. We are a pioneer in personalised healthcare and want to further transform how healthcare is delivered to have an even greater impact. To provide the best care for each person we partner with many stakeholders and combine our strengths in Diagnostics and Pharma with data insights from the clinical practice. Neuroscience is a major focus of research and development at Roche. Our goal is to pursue groundbreaking science to develop new treatments that help improve the lives of people with chronic and potentially devastating diseases. Together with our partners, we are committed to pushing the boundaries of scientific understanding to solve some of the most difficult challenges in neuroscience today.

www.roche.com

Scholar Rock

Advancing SMA care—together.

Progress starts with commitment. For over a decade, Scholar Rock's dedication to the SMA community has fueled our work to bring innovative solutions to life. We share your passion for serving those living with SMA, and we are here to support you in finding new ways to create possibilities.

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