

SMA Patient Advocate Training



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What is SMAcademy?



SMAcademy is SMA Europe's capacity-building initiative for patient advocates in SMA that aims to equip patient advocates with the tools and skills that they need to effectively and impactfully advocate for a better world for all people living with SMA.

What is the SMA Patient Advocate Training?

The SMA Patient Advocate Training is SMAcademy's comprehensive foundational training for patient advocates in SMA.

This is the **only training uniquely focused on SMA**, where advocates will acquire:

- a comprehensive understanding of foundational aspects of **patient engagement** and **critical issues in SMA**
- an inclusive view to **represent the SMA community** in its diversity
- tools to **engage with industry, scientific, clinical, regulatory, and policy stakeholders**.

SMA Patient Advocate Training prepares patient advocates to establish and develop impactful collaborations with stakeholders in **all stages of the patient engagement process**. Module 1 covers the basic principles of patient advocacy in the context of SMA, with the goal to learn how to represent a diverse community of people living with SMA. Module 2 focuses on the biology of SMA, SMA treatment mechanisms and care standards for people living with SMA. In module 3, trainees will learn about the medicines lifecycle to understand how a medicinal product goes from “bench to bedside”. Module 4 covers how healthcare ecosystems and access work, including topics like regulatory approval and HTA processes. Module 5 addresses critical issues in SMA through case studies of real-life advocacy experiences.

At the end of the training, patient advocates will have gained a thorough understanding of the medicines research and development (R&D) process with a focus on SMA, of the role of patient experts within this framework, and of opportunities and challenges that present when interacting with other stakeholders.

Trainees who successfully complete the training will receive a **certificate** of completion to testify their expertise as expert patient advocates in the field of SMA.

Why should you take the SMA Patient Advocates Training?



The SMA Patient Advocates Training is an excellent way to efficiently **gain foundational knowledge** about patient advocacy opportunities in SMA and to **understand how you can make an impact** for people living with SMA in your country and internationally.

Organisations in SMA advocacy can invite their representatives to complete this training to onboard them or bring them up to date on crucial issues in SMA advocacy.

With its disease-specific focus, this training provides a **full picture of engagement opportunities** throughout stages of medicine development and marketing, providing a well-rounded background for **both new and established** advocates.

How is SMA Patient Advocate Training designed?

The programme consists of 5 learning modules:

- **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

Modules 1-4 are designed to be taken **online** and **self-paced**.

Module 5 consists of a set of workshops for which **in-person** presence is required¹.

Module order: Participants can take the modules in their preferred order. At the end of each module, participants take an assessment test to verify their knowledge. Participants must successfully pass (80% or higher correct answers) on all tests for modules 1 through 4 to be admitted to module 5.

Time commitment and timeline: The training is estimated to take approximately **50 hours** to complete. By applying to the programme, trainees commit to complete all training modules over the span of **6 months from start date**. A certificate of training programme completion is released after attending the online event and completing module 5.



The first cohort of the programme is set to start in **September 2026**.
Module 5 will take place in March 2027 in Prague.

¹ Accommodations can be identified in exceptional cases due proved inability to travel. Travel destination will be communicated for each edition.

Who can participate in the Programme?

The programme is addressed to patient advocates, people living with SMA, their families and caregivers who are interested in advancing their skills in SMA advocacy. Candidates from any countries, within or outside Europe are welcome.

The programme will admit a selected number of participants.

Eligibility criteria:



- Demonstrated commitment to SMA patient advocacy
- Advanced-level English language
- 18 years old or older
- Direct experience living with SMA, caring for a person living with SMA, or advocating for people living with SMA (new and beginner advocates are welcome).

Trainees must commit to completing all 5 learning modules in the span of 6 months from the start of the programme.

What are the registration and admission process?

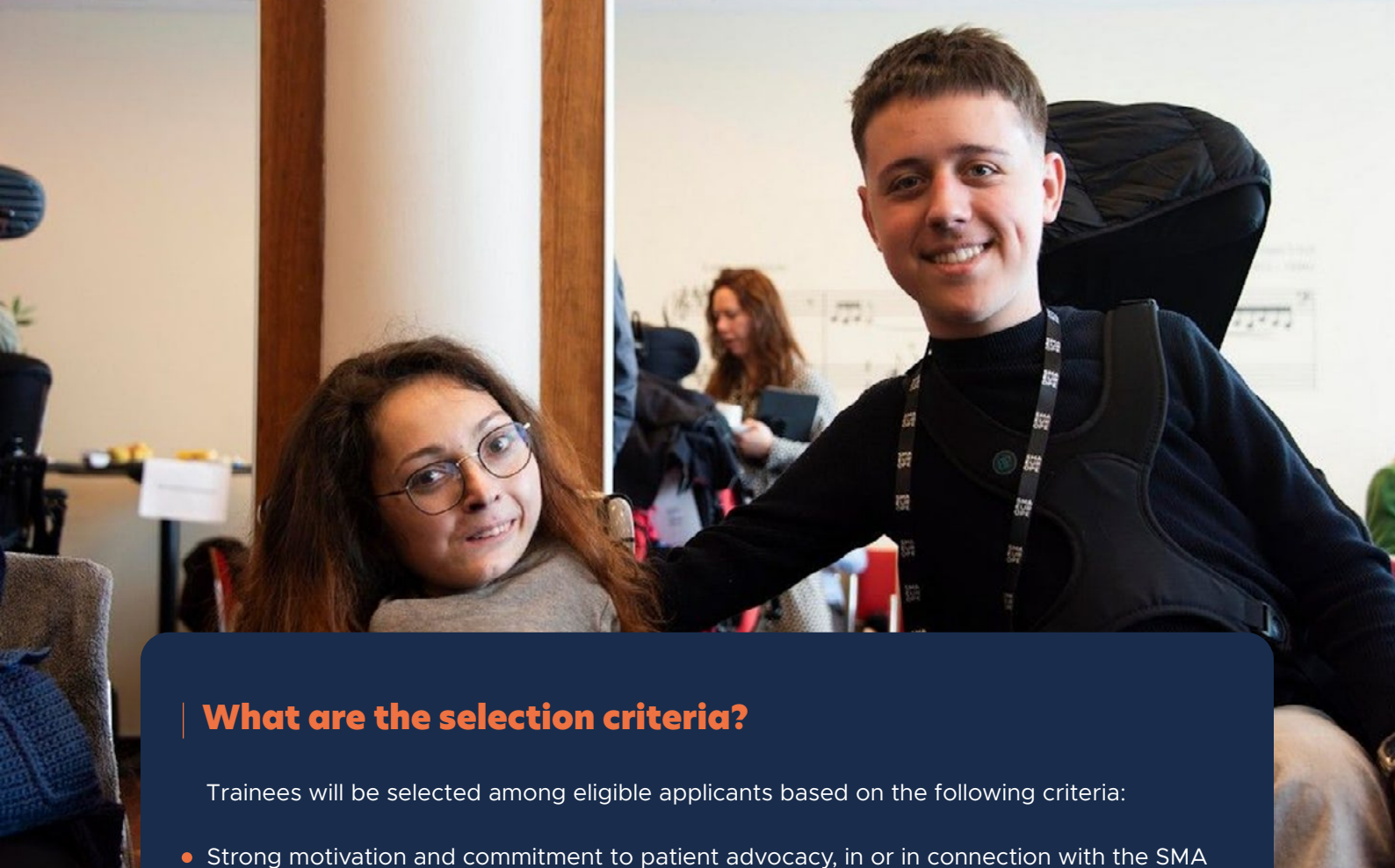


Applications deadline: **30th June 2026**

Admission decisions: **20th July 2026**

Admitted trainees will be notified by email from the following address: smacademy@sma-europe.eu. Please save this email in your contacts to avoid it landing in your spam folder.

The admission email will contain a trainee agreement that trainees must carefully read and timely sign in acceptance of the terms of participation by 24th July to secure their place in the programme.



What are the selection criteria?

Trainees will be selected among eligible applicants based on the following criteria:

- Strong motivation and commitment to patient advocacy, in or in connection with the SMA community.
- Demonstrated ability to actively participate in and complete the full training programme with sustained commitment.
- Capacity to engage with others and commitment to contribute to the wider SMA community through collaboration and knowledge-sharing.
- Ensuring diversity and representativeness across backgrounds, experiences, and perspectives within the selected training participants.

How much does the training cost?



The SMA Patient Advocate Training Programme is **free of charge**.

Trainees will have to **cover travel and accommodation costs** to attend the in-person module.

A limited number of competitive scholarships to help cover these travel expenses is available. Interested candidates will have the opportunity to express interest in their application.

**SMA
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For further info, please contact: smacademy@sma-europe.eu