SMA Europe Examines Patient Journeys in SMA Through Pan-European Patient Experience Survey[1].

7 September 2026

SUMMARY: SMA Europe is delighted to announce the publication of the results of the European Patient Experience Survey (EUPESMA) on SMA Medicines, Access, and Treatment Journeys, the fifth pan-European patient experience survey in the EUPESMA Series.

Since the European Medicine Agency's approval of the first medicine for SMA in 2017, available treatment options for people living with SMA have multiplied. This has created exciting opportunities, but also a complex landscape for people to navigate. Access to medicines has improved, but inequities persist. The EUPESMA on SMA Medicines, Access, and Treatment Journeys collected the experiences of people living with SMA, family, and caregivers, to make sure that unmet needs are identified and can be addressed.

Through the biannual EUPESMA survey series, SMA Europe generates evidence to gain a deeper understanding of patient experiences and build a collective patient voice that can guide and inform the organisation's advocacy activities.

We invite the SMA community, healthcare professionals, researchers, and everyone working to improve the lives of people living with SMA to explore the findings of EUPESMA on SMA Medicines, Access, and Treatment Journeys and read the full publication on the SMA Europe website.

EUPESMA on SMA Medicines, Access, and Treatment Journeys

EUPESMA on SMA Medicines, Access, and Treatment Journey analysed experiences with SMA medicines in an evolving therapeutic landscape. The survey, fielded in 18 languages, collected responses from 826 participants from 41 countries between January and March 2025, achieving a vast representation of the European SMA community.

The survey showed that, while SMA medicines are now considered standard of care, patient journeys are less linear than imagined. Inequities at diagnosis and on the ability to access, choose, or switch medicines still mark individual journeys and continuity of treatment is not always guaranteed. Treatments bring gains, but not in every domain. The community wishes for multi-system, add-on, and new therapies in the future.

SMA Europe will use these findings to elaborate patient-centred solutions, in collaboration with partners and stakeholders, to best meet remaining treatment needs in the SMA community.

From patient experience to action: the EUPESMA series

As Alice Larotonda, Community Research and Education Manager at SMA Europe states:

> "People living with SMA and caregivers take an active and fundamental role in the design, piloting, analysis, and interpretation of our surveys. This ensures that the surveys remain

[1] The EUPESMA-2025 survey was carried out in collaboration with Tilburg University in the Netherlands and supported by the Cure SMA Industry Collaboration.

> focused on patient-relevant questions and that community priorities are genuinely reflected, adding unparalleled value to the evidence generated.

The EUPESMA Series is a patient-lead initiative that feeds into SMA Europe's key objective to systematically identify unmet needs, disparities, and emerging priorities in the SMA community to translate them into action and address them by informing research, care, policy, and through the organisation's own advocacy work in Europe.

This biannual survey series collects information directly from people living with SMA, their families and caregivers, across Europe and overtime. People living with SMA are not only answering the survey, but take the lead in choosing each edition's focus, understanding the results, and turning insights into action.

Additional information

Read the full EUPESMA-2025 results, explore the findings, and discover the EUPESMA Series on the SMA Europe website: https://www.sma-europe.eu/eupesma-series

About living with spinal muscular atrophy: "SMA Europe | Living with SMA | Support and Resources (sma-europe.eu)

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