



BUILDING EVIDENCE FOR

SPINAL MUSCULAR ATROPHY

500 Stories. One Registry.

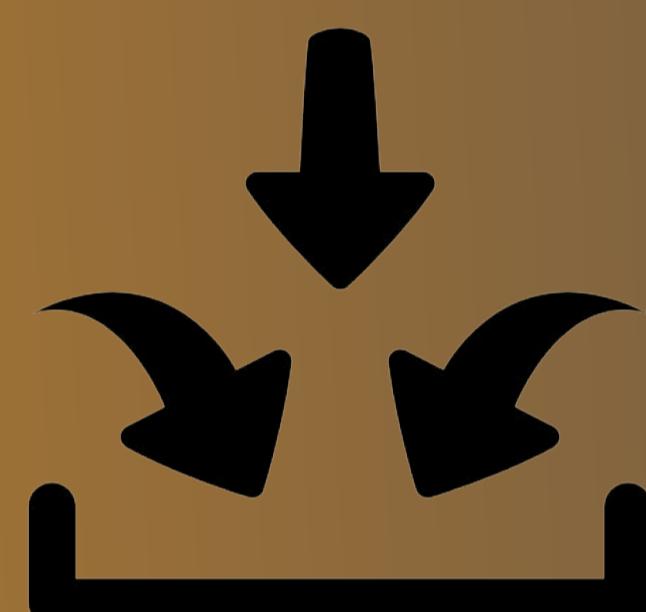


THE INITIATIVE

The Ukrainian SMA Patient Registry was established in 2007 and was founded, maintained, and developed for 20 years by the Foundation Children with Spinal Muscular Atrophy. It is a national real-world data platform collecting structured longitudinal clinical data.

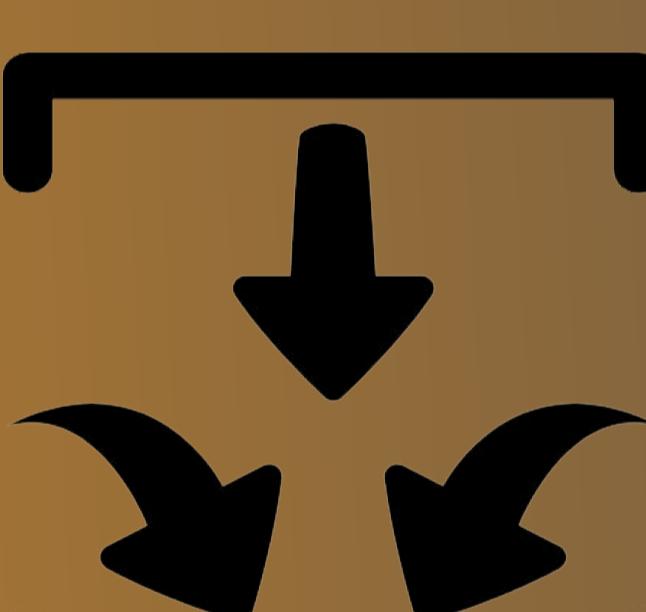
GLOBAL INTEGRATION

Member of the TREAT-NMD Global SMA Registry Network. Is listed among 26 global SMA registries and among 19 implementing the most advanced data standards. Successfully passed all three stages of international validation. Data contributes to international scientific publications and global academic datasets



SCALE & COVERAGE

~500 registered patients *
~80% national coverage of SMA population
20 years of continuous data collection



Real change in rare diseases begins with data.
For 20 years, we built evidence so that every person with SMA in Ukraine counts not only as a story, but as part of a system that can improve

Acknowledgments

We would like to express our sincere gratitude to all participants and their families for their trust, commitment, and invaluable contribution to the Registry. We are deeply thankful to the volunteers and donors whose dedication, generosity, and belief in our mission sustained this initiative over two decades. Their support transformed an idea into a lasting national infrastructure. We also acknowledge the professionalism and perseverance of our team, whose work made this Registry possible despite the challenging conditions

REAL WORLD DATA

The registry captures longitudinal disease progression, treatment history, clinical outcomes, and epidemiological insights. It transforms individual patient journeys into measurable evidence that supports and strengthens the Health Care System.

IMPACT IN UKRAINE

The registry supported national advocacy campaigns, informed state-level decision discussions, and provided structured evidence during pharmaceutical registration processes for SMA therapies. It ensured that policy conversations were based on real data.