

Initiative SMA

Germany



Initiative SMA

Gemeinsam für eine Therapie

www.initiative-sma.de



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1. About

INITIATIVE SMA was founded in 2001 by Dr. Inge and Klaus Schwersenz, parents of 2 SMA children with the aim of raising funds for research into this disease. For organizational reasons, the INITIATIVE SMA is part of the Förderverein für die Deutsche Gesellschaft für Muskelkranke e.V.. As part of this association, it also enjoys non-profit status.

To this day, INITIATIVE SMA is driven by volunteers who are either patients or caregivers. It is therefore possible that, apart from minimal administrative costs, the entire income from donations can be used for charitable purposes and, in particular, to promote research. With these donations we have supported many research projects at national and European level. INITIATIVE SMA is one of the main contributors to SMA Europe's Call for research.

Around a dozen volunteers that are SMA patients themselves or family members of SMA patients. As INITIATIVE SMA is not a legal entity itself, we do not have members or staff.

2. Mission

Funding research and raising awareness for SMA

3. Focus

Sponsorship of regional SMA Newborn Screening pilots in Germany, that lead to implementation of NBS for SMA in the German screening program.

(Co-)Funding of many research projects.

4. Coming up

We just approved a contribution of 160.000,00 € to SMA Europe´s 12th round of the Call for Research.

