

SMA Schweiz

Switzerland

www.sma-schweiz.ch

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1. About

Inform. Connect. Challenge.

SMA Schweiz is the Swiss organisation for people living with SMA. Our goal is that all people living with SMA to have access to the care and support that is best for them. And we are committed to support research and to get potential therapies from the laboratory to the person living with SMA as quickly as possible. To this end, SMA Schweiz works closely with all stakeholders both nationally and internationally and represents the voice of the community.

Founded in 2016.

Run on a voluntary basis by members of the community, representing the Swiss SMA community.

2. Mission

Our goal is that all people living with SMA to have access to the care and support that is best for them.

We inform. We make swarm knowledge accessible to the individual. We provide information so that well-founded decisions can be made. We promote innovative solutions that make everyday life easier

We connect. We connect the community. We offer a platform for collaboration. We are internationally active.

We challenge. We understand the needs of the community. We ensure that the opinion of the community is incorporated into decisions about us. We exert the necessary pressure when dialog does not lead to solutions.

3. Focus.

- SMArt Innovation - digital platform to share life-hacks combined with an “innovation accelerator” during SMA Days : innovation.sma-schweiz.ch
- Advocating successfully for access to all three available medicines.
- Support individuals who encounter access barriers incl. participation in trial at the European human rights court.
- Implementation of NBS (per 2024)
- Support a network of NMD specialist centres in Switzerland and the Swiss SMA registry.

- National SMA Days for members and interested partners.
- Support SMA Europe in its projects and activities.
- Support of individuals incl. from abroad (e.g. from Thailand and Ukraine).
- Ensure that the SMA “patient’s” voice is heard in Switzerland.

4. Coming up

- SMArt Innovation - digital platform to share life-hacks combined with an “innovation accelerator” during SMA Days: innovation.sma-schweiz.ch
- Support an individual in his/her fight for access to medicines in front of the European Human rights court.
- Shortage of volunteers in the community who are supporting the organisation with their time.