

Fundacja SMA

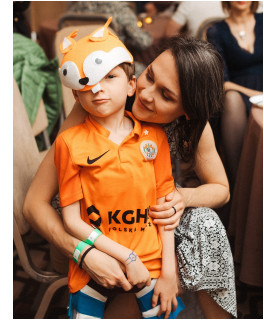
Poland



[Fundacja SMA - Razem pokonamy rdzeniowy zanik mięśni \(fsma.pl\)](https://fsma.pl)

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1. About

Together we will overcome SMA

The Polish SMA foundation, formed in 2013 by parents of children with SMA, gathers almost 30 volunteers from the whole country. Each of us has a different background, skills and possibilities to share, but together we create a dynamic team. During the last decade, we managed to achieve reimbursement of available medicines, NBS, implement many projects for the community and disseminate knowledge about SMA.

2. Mission

The Foundation has the following goals:

- to conduct activities for people with SMA and their loved ones, aimed at combating exclusion, increasing independence and improving their quality of life;
- to increase the awareness of SMA, by disseminating knowledge in genetics, diagnostics, standards of care and treatment methods;

- to increase the availability of methods and techniques for diagnostic, therapeutic, rehabilitative and related products and technology solutions;
- to support system solutions, particularly in health care and social security, taking into account the needs of people with SMA and their loved ones.

3. Focus

- Cooperation with decision-makers
- Spreading knowledge about SMA
- Conducting activities and event for our community, such as:
 - annual international conferences
 - workshops for various groups (sorted by age, by needs, by hobbies) for affected, families, newborns, adults, carriers, siblings
 - training events for physiotherapists and medical doctors of various specialities
 - programme of personal assistance
 - psychological support
 - community integration
 - sport team “Drużyna SMA” who dedicate their efforts to affected by running, biking, hiking, parachute jumping

4. Coming up

- currently we are focusing on introducing the coordinated healthcare system what involves close cooperation with various stakeholders, such as specialist and decision-makers
- we want to put more stress on psychological care within our projects dedicated to affected and their families.



10th anniversary of the Foundation - part of our voluntary team



annual family camp

<https://youtu.be/0MUEhp2C6yw?si=RqNovUohotjXFR4C>



parachuting events - people with SMA and their families were jumping to promote knowledge about disease and fight for reimbursement of treatment in Poland



Photographic project with 12 women with SMA “Shades of beauty” - SMA Foundation calendar

<https://youtu.be/Pa1-kFRS3VE?si=HSj3CCSeFg9ld42l>



special thanks to Ministry of Health during annual international conference “Weekend ze SMAkiem”

<https://youtu.be/QVAImtRJuaA?si=lzBWbWM4uqG7shXi>



Together we defeat SMA!