

# The challenge of contractures in SMA: a transformative approach connecting basic research, clinicians, patients, and biotechnology

Contractures are a common and disabling musculoskeletal complication in SMA, reducing functional capacity, causing pain, and significantly impacting the quality of life of individuals living with SMA. Disease-modifying therapies (DMTs) have transformed the course of SMA; however, contracture management remains a largely unmet clinical need and continues to rely on pre-DMT care standards. In response to this gap, FundAME has promoted a comprehensive 360° strategy to transform the approach to contractures in SMA by integrating Basic research, clinical expertise, patient community insights, and biotechnological research.

Since  
**FEBRUARY**  
2019



## Contractures from the patient perspective

Contractures were identified as an important unmet need through focus group research involving people living with SMA, led by FundAME. Since then, data on their prevalence and impact on daily life have been documented through the PROFuture questionnaire in RegistrAME, the Spanish Registry of Patients with Spinal Muscular Atrophy.



Latest publications on PROFuture    Latest publication on RegistrAME

**NOVEMBER**  
2024

## Scientific evidence on the impact of contractures in SMA

Data collected through RegistrAME on the impact of contractures in individuals living with SMA generated critical real-world evidence—including a prevalence of 44%. These findings were instrumental in raising awareness among researchers and clinical specialists, highlighting the need to further investigate the pathophysiology, progression, and clinical management of contractures in SMA.



**FEBRUARY**  
2025



## Scientific meeting on contractures with national reach

A multidisciplinary group of experts and patient representatives met to promote more effective therapeutic alternatives with a lower burden for people with SMA and their families, fostering a more innovative research approach. The meeting, attended by specialists in neurology, physiotherapy, orthopaedic surgery, rehabilitation, and muscle biology research, highlighted the urgent need to update therapeutic approaches and promote research in this field.

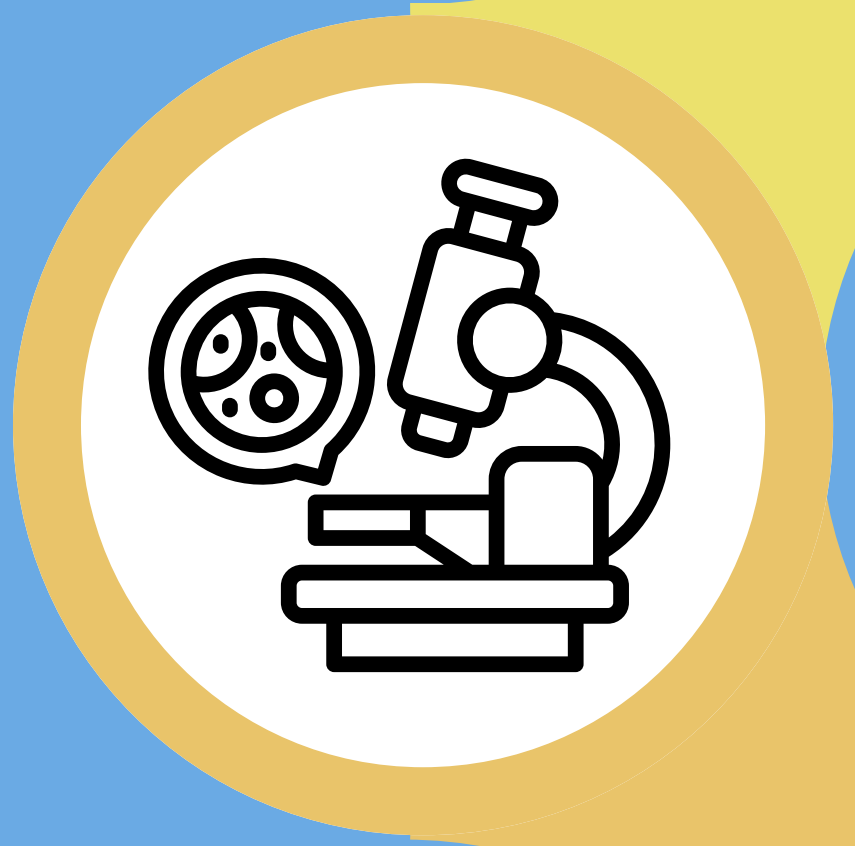
## Clinical consensus on the management of contractures

Objective: To develop consensus-based recommendations for contracture management through a multidisciplinary process involving clinical specialists, physiotherapists, rehabilitation physicians, orthopaedic specialists, and people living with SMA.



Started in  
**OCTOBER**  
2025

**NOVEMBER**  
2025



## National SMA Research Meeting

FundAME highlighted the urgent need to advance research on contractures during this meeting, which brought together leading basic SMA research groups, clinical specialists, and representatives of the SMA community in Spain. The meeting aimed to review the current state of scientific knowledge, identify shared challenges, and promote initiatives to accelerate the translation of clinical and therapeutic improvements for patients.

Started in  
**FEBRUARY**  
2026

## Uncovering the origin of contractures in SMA

FundAME, in collaboration with Fundación Bioavance, is funding a three-year basic research project. This is the first basic research project directly commissioned by FundAME and will investigate the muscle pathophysiology underlying contracture development in SMA. The initiative aims to generate knowledge that will enable new therapeutic strategies.



**MARCH**  
2026



## Contractures in SMA: From Scientific Insights to Therapeutic Targets – Workshop

FundAME, SMA Europe, and the SMA Foundation recognize the urgent need to prioritize the understanding and management of contractures within the global SMA research agenda. During the International Scientific Congress on SMA, a workshop was held to promote rigorous, multidisciplinary dialogue among researchers, clinicians, and patients.

**NOVEMBER**  
2026

## Biotechnology to address contractures

Advances in biotechnology may enhance the management of contractures in SMA. During 2026, FundAME will explore biotechnological opportunities to improve contracture care while ensuring an acceptable burden for patients.

