



# INDUSTRY COLLABORATION



# YEAR END REPORT

2025

Established in 2016, the SMA Industry Collaboration (SMA-IC) is a multi-faceted partnership that brings together pharmaceutical companies, Cure SMA, and other nonprofit organizations to share information, ideas, and data. The SMA-IC works together to address scientific, clinical, and regulatory topics critical to advancing drug development and treatment access for the spinal muscular atrophy (SMA) community. It is currently comprised of our partners at Novartis, Scholar Rock, Biogen, Genentech/Roche Pharmaceuticals, argenx, NMD Pharma, and SMA Europe.

Cure SMA would like to thank the members of the SMA community for your continued support. No single group can research and develop a treatment for SMA alone—it requires collaboration between academics, industry, government, and the SMA community.

During Phase 10, the SMA-IC remained steadfast in our approach to ensure developing treatments address unmet needs, while also supporting efforts to enhance community treatment access. Efforts include:



### SURVEY PARTICIPATION

- 1,012 Adults Living with SMA
- 559 Caregivers
- 240 Healthcare Providers

### PROVIDER AND RESEARCHER ENGAGEMENT

- 1,883 Engagements with the Cure SMA Quarterly Provider Newsletter
- 6 Poster Presentations at National Conferences
- 155 Treatment Sites Engaged to Support Maintenance of the Cure SMA Find a Treatment Center Website

### PEER REVIEWED PUBLICATIONS

- 3 Published Manuscripts
- 10 Manuscripts in Peer Review / in Development

### CURE SMA COMMUNITY OUTREACH

6 Latest News Posts

### CAMPAIGN TO SUPPORT COMMUNITY ACCESS AND AWARENESS OF SMA CLINICAL TRIALS

- 5,776 Engagements with the SMA Registry and Clinical Trial Finder
- 3,943 Engagements with the Cure SMA Clinical Trials Page and Resource Handouts

### 172 PUBLIC AND PRIVATE PAYERS ENGAGED TO EDUCATE ON

- the current state of SMA,
- the impact of SMA treatments,
- remaining unmet needs, and
- the importance of patient choice and timely access.

### HEALTH INSURANCE ROADMAP

Toolkit revised to better support the SMA patient and healthcare provider community when navigating payer denials and appeals