

Therapies for the Treatment of Spinal Muscular Atrophy

Stakeholder List

ICER receives input on its reviews from multiple stakeholders, including patients and their families, patient advocacy organizations, clinicians, clinical societies, insurers, and drugmakers. We invite the public to submit recommendations for stakeholders in any of these categories.

The following is a list of organizations from which ICER has requested input, as well as those that have provided unsolicited public comments during the review. Some organizations on the list may appear only because they were invited to provide input, and it should not be assumed that they have responded to ICER's outreach or agreed to participate in this review.

- Akari Foundation
- Biogen
- Cure SMA
- Cure SMA Canada
- Genentech
- Muscular Dystrophy Association (MDA)
- Muscular Dystrophy UK
- Novartis
- Parent Project Muscular Dystrophy (PPMD)
- Scholar Rock
- SMA Angels Charity
- SMA Foundation
- Spinal Muscular Atrophy UK

We engaged with a range of additional experts in the preparation of this report, including neurologists, physical rehabilitation specialists, and others. Of the experts we spoke with, the following individuals have agreed to be identified as having engaged with ICER:

- **John Brandsema, MD**, Pediatric Neurologist, Division of Neurology at Children's Hospital of Philadelphia
- **Russell Butterfield, MD, PhD**, Associate Professor in the Departments of Neurology and Pediatrics, University of Utah

- **Jenna Klotz, MD**, Clinical Assistant Professor, Neurology and Neurological Sciences, Stanford Medicine Children's Health Specialty Services
- **Tara Lavelle, PhD**, Assistant Professor, Center for the Evaluation of Value and Risk in Health at Tufts Medical Center

To protect patient confidentiality, ICER does not routinely name individual patients or care partners who provided us with input and feedback.

None of these individuals or organizations is responsible for the final content of ICER's report, and it should not be assumed that they support any part of the report, which is solely the work of the ICER team and its affiliated researchers.

For a complete list of key dates and opportunities for input on this project, please visit [ICER's website](#).