



Therapies for the Treatment of Spinal Muscular Atrophy: Public Meeting

Friday • August 1, 2025 • 10:00 AM – 4:00 PM CT

Virtual Meeting Agenda

Register for the Zoom Meeting [here](#)

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10:00 AM – 10:20 AM CT	Meeting Convened and Opening Remarks Sarah K. Emond, MPP President and CEO, ICER
10:20 AM – 11:00 AM CT	Presentation of the Clinical Evidence Jeffrey A. Tice, MD Professor of Medicine, University of California, San Francisco
11:00 AM – 11:40 AM CT	Presentation of the Economic Model Linda Luu, MSc Research Scientist, Department of Pharmacy, University of Washington
11:40 AM – 12:00 PM CT	Public Comments and Discussion
12:00 PM – 12:50 PM CT	Lunch Break
12:50 PM – 1:50 PM CT	Midwest CEPAC Vote on Clinical Effectiveness and Value Moderator: Jill Johnson, PharmD Professor, Pharmacy Practice, University of Arkansas for Medical Sciences
1:50 PM – 2:00 PM CT	Break
2:00 PM – 3:30 PM CT	Policy Roundtable Moderator: Sarah K. Emond, MPP, President and CEO, ICER
3:30 PM – 4:00 PM CT	Reflections from Midwest CEPAC
4:00 PM CT	Meeting Adjourned

ICER Staff and External Collaborators	Conflict of Interest Disclosure
Josh Carlson, PhD, MPH , Professor, Department of Pharmacy, University of Washington	Josh Carlson has received consulting fees from Genentech that are not related to SMA.
Hui-Hsuan Chan, MHS , Research Assistant University of Washington, School of Pharmacy	No conflicts to disclose.
Sarah Emond, MPP , President and CEO, ICER	No conflicts to disclose.
Grace Ham, MSc , Senior Program and Events Coordinator, ICER	No conflicts to disclose.
Max Lee, PharmD , Associate Director of Pharmaceutical Intelligence, ICER	No conflicts to disclose.
Woojung Lee, PharmD, PhD , Associate Director of Health Economics and Decision Modeling, ICER	No conflicts to disclose.
Linda Luu, MSc , Research Assistant, Department of Pharmacy, University of Washington	No conflicts to disclose.
Dmitriy Nikitin, MSPH , Senior Research Lead, ICER	No conflicts to disclose.
Marie Phillips, BA , Research Assistant, ICER	No conflicts to disclose.
David Rind, MD, MSc , Chief Medical Officer, ICER	No conflicts to disclose.
Sol Sanchez, BS , Research Assistant, ICER	No conflicts to disclose.
Temiwunmi Shobanke, MS , Program Manager, ICER	No conflicts to disclose.
Jeff Tice, MD , Professor of Medicine, University of California, San Francisco	No conflicts to disclose.

Midwest CEPAC Members	Conflict of Interest Disclosure
Bijan Borah, PhD Professor of Health Services Research, Mayo Clinic College of Medicine and Science	Dr. Borah has received a consulting fee of <\$5K from Boehringer Ingelheim in 2025.
Kurt Vanden Bosch, PharmD System Formulary Lead, St. Luke's Health System	No conflicts to disclose.
Donald Casey, MD, MPH, MBA, MACP, FAHA Associate Professor of Internal Medicine, Rush Medical College	No conflicts to disclose.
Sneha Dave Executive Director, Generation Patient	No conflicts to disclose.
Stacie Dusetzina, PhD Professor of Health Policy, Vanderbilt University Medical Center	No conflicts to disclose.
Jayani Jayawardhana, PhD Associate Professor, University of Kentucky	No conflicts to disclose.

Jill Johnson, PharmD Professor, Pharmacy Practice, University of Arkansas for Medical Sciences, College of Pharmacy	Dr. Johnson receives royalties from UAMS Bioventures for intellectual property generated as part of the Evidence-based Prescription Drug program (EBRx), a service division of the UAMS College of Pharmacy. She leads a Pharmacy & Therapeutics Committee to discover the peer-reviewed, published evidence with emerging and existing drugs and to report these findings to our committee who votes on which drugs to recommend coverage for using the lowest net cost approach. Through this service arm, part of her salary is covered in addition to the IP income (about \$450/month) which comes from RxResults, a private pharmacy risk management company. Additionally, she serves as a consultant to Stephens Insurance and receives \$25,000 per year. However, she does not take part in the drug selection process.
David Kim, PhD Assistant Professor, University of Chicago	No conflicts to disclose.
Bradley C. Martin, PharmD, PhD Professor, University of Arkansas for Medical Sciences	Dr. Martin receives royalties of approximately \$7,500/year from Trestle Tree for the commercialization of an opioid risk prediction tool. He has no other potential conflicts to disclose.
Timothy McBride, PhD Washington University in St. Louis	No conflicts to disclose.
Reem Mustafa, MD, MPH, PhD, FACP Professor of Medicine, Division of Nephrology & Hypertension, Director of Evidence based Practice and Impact Center (EPIC), The University of Kansas Medical Center	No conflicts to disclose.
Rachel Sachs, JD, MPH Professor of Law, Washington University in St. Louis School of Law	No conflicts to disclose.
Stuart Winston, DO Patient Experience Consultant, Trinity Health IHA Medical Group	No conflicts to disclose.

Policy Roundtable Participants	Conflict of Interest Disclosure
Thomas Crawford, MD , Professor of Neurology and Pediatrics, Johns Hopkins Hospital	Dr. Crawford has served as consultant on advisory panels to pharma Biogen, Avexis, Scholar Rock, Muscular Dystrophy Association, SMA Foundation and CureSMA. Dr Crawford has received compensation for continued conductance of clinical trials by Biogen, Novartis/Avexis, Sarepta, and Scholar Rock, as well as monetary support for participation in advisory boards by Biogen and Scholar Rock in the last 36 months.
Giles Lomax , CEO, Spinal Muscular Atrophy UK	SMA UK received 15.6% of income from pharmaceutical companies including Scholar Rock, Biogen, Novartis and Roche in 2024/2025.

Hugh McMillan , Professor of Pediatrics/Pediatric Neurologist, University of Ottawa/Children's Hospital of Eastern Ontario	Dr. McMillan serves as a consultant for Novartis, Roche and Biogen. He also serves as the Principal Investigator for clinical trials for Novartis, Roche, Biogen, with funds provided to the institution.
Lindsey Samera, PharmD , Associate Director, PDL Strategy, UnitedHealthcare	Dr. Samera is a full-time employee of United Healthcare.
Portia Thorman , Head of Advocacy and Community, Spinal Muscular Atrophy UK	SMA UK received 15.6% of income from pharmaceutical companies including Scholar Rock, Biogen, Novartis and Roche in 2024/2025.
Emily Tsiao, PharmD, BCPS , Medical Policies Clinical Pharmacist, Premera Blue Cross	Dr. Tsiao is a full-time employee of Premera Blue Cross.