

## RAAP LEARNING HUB PRESENTATION: “ADDRESSING ACCESS ISSUES FOR RARE DISEASE PATIENTS”

The Rare Access Action Project (RAPP), sponsored and ran a panel during the Learning Hub portion of the National Conference of State Legislatures (NCSL) Legislative Summit held in Indianapolis, IN. NCSL is the largest gathering of bipartisan legislators and legislative staff in the U.S.

RAAP’s Learning Hub panel discussion, titled, “Addressing Access Issues for Rare Disease Patients,” focused legislators and staff attention to the challenges and issues presented to everyday Americans with rare diseases. The panel included patient advocates and legislative leaders who shared their stories and how they were tackling this growing challenge. Mindy Cameron, Duchene Muscular Dystrophy advocate; Melissa Horn, rare disease advocate Co-pay Accumulator State Group of Arthritis Foundation; the Honorable Brian Patrick Kennedy, Speaker Pro Tempore and Representative RI-D and incoming President of NCSL; and the Honorable Curt Bramble, Senator, UT-R outgoing President of NCSL led the discussion. The event was moderated by long time rare disease expert and strategic advisor to RAPP, Paul Stickler.

We express our gratitude to our panelists for their participation and insights. And thank you to NCSL leadership for their support. Speaker Kennedy and Senator Bramble have been champions of innovation as well as ensuring access to therapies for patients in need. The rare community appreciates their leadership and insights.

RAAP is a non-profit coalition of life science and patient advocate stakeholders focused on developing innovative solutions to patient access issues for rare diseases.