

# American Academy of Pediatrics Historic Guidance on Trisomy 13 and Trisomy 18, Validating SOFT's Decades-Long Advocacy

*Landmark report states "no ethical justifications for universal, principle-based differential treatment" based solely on genetic diagnoses*

ROCHESTER, NY, UNITED STATES, August 5, 2025 /EINPresswire.com/ -- [Support Organization for Trisomy 18, 13 and Related Disorders \(SOFT\)](#) celebrates a historic milestone with the American Academy of Pediatrics' (AAP) publication of groundbreaking guidance on caring for infants and children with trisomy 13 and trisomy 18. The report, published online Monday, July 21, 2025 in the journal, *Pediatrics*, represents a fundamental shift in medical practice and validates SOFT's four-decade mission to ensure equitable, individualized care for children with these conditions.

The AAP guidance explicitly states that "there are no ethical justifications for universal, principle-based differential treatment based solely on these genetic diagnoses" and emphasizes that medical decisions "should be based on the best available evidence and appropriately tailored to the individual's clinical context."



SOFT



Trisomy 13

"On Monday, July 21, 2025, the American Academy of Pediatrics, the most prestigious

professional organization in the field dedicated to the health of all children, published a Report online that is truly a landmark in the care of children with trisomy 13 and trisomy 18," said Dr. John C. Carey, Emeritus Professor in the Department of Pediatrics at the University of Utah School of Medicine and SOFT's founding medical professional. "This Report masterfully complements the 2024 Consensus Document of the American Association of Thoracic Surgeons and together these documents advance the efforts to 'change the narrative' surrounding the care of infants and children with trisomy 13 or trisomy 18. But now we have to go further and change practice and implement the central messages of these important documents."

Josh Bradley, President of SOFT's Board of Directors, emphasized the transformational impact of this validation: "This groundbreaking guidance from the American Academy of Pediatrics represents a historic moment for families like ours. Every child with trisomy 13 or 18 has inherent value and deserves medical decisions based on their individual circumstances rather than assumptions about their diagnosis. This milestone gives our families renewed hope and confidence as they navigate these important medical decisions with their healthcare teams."

For Kris Holladay, SOFT's Parent Founder, this moment represents the culmination of decades of advocacy: "For over 40 years, SOFT has worked toward an environment where medical professionals see the child, not just the condition. We've advocated for families to receive complete information so they can make informed decisions with their medical teams. I'm thrilled with this AAP guidance as it is a tremendous validation that will strengthen every conversation our families have with their healthcare providers."

SOFT is honored to share this historic milestone with families worldwide and remains committed to supporting them as the medical community implements these evidence-based care principles. This report marks not an end, but a new beginning in ensuring every child with trisomy 13 or trisomy 18 receives individualized and compassionate care.

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Trisomy 18

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