

# Marie Neumann

University of Nebraska, USA

*Session 3C: Optimizing Outcomes in Intestinal Failure and Transplant: C: Incorporating the Patient and Family in Research: Parent Perspective; July 1, 2023; 3:10pm-3:30pm*

*Posters of Distinction Rounds: 59 – Where Do SBS/IF Patients and Caregivers Go to Receive Information, and What Do They Want More Information About: Findings From a Cross-Sectional Community-Driven Survey; July 2, 2023; 4:30pm-4:50pm*



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Marie Neumann, MA, is a social scientist and has conducted research on pediatric palliative care, the parenting of children with medical complexities, and, most recently, how pediatric short bowel syndrome (SBS) impacts the well-being of patients and families. She is currently earning a Ph.D. in health communication and holds a research position at the University of Nebraska Medical Center (UNMC) in Omaha, NE, where she studies quality of life (QoL) for children and families impacted by SBS. Marie's personal journey inspired this work. Four years ago, her youngest child was diagnosed with ultra-short bowel syndrome. Clinician communication at the time about her son's future propelled her to systematically study the experiences of children with SBS/IF and their families. Together with a group of SBS community members, Marie founded the gutsy perspective, an initiative that aims to close the gap between the SBS/IF community and the research that affects its members. The group has recently completed its development of a disease-specific QoL questionnaire for children with intestinal failure (IF), which is currently being applied in a longitudinal study on quality of life with pediatric IF at UNMC.



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