Keynote: Healing Feeding Trauma, it takes a village

Dr. Anka Roberto DNP, MSN-MPH, APRN, PMHNP-BC

Anka Roberto is a nationally board-certified Psychiatric Mental Health Nurse Practitioner (PMHNP) and certified Eye Movement Desensitization (EMDR) clinician, a licensed RN, and an APRN in the states of North Carolina and Connecticut. Anka Roberto is also an Assistant Professor at the University of North Carolina Wilmington and has authored book chapters and numerous publications on trauma and resilience. With over 20 years of experience as an RN working with children with special needs, she decided to return to school to receive her doctoral degree in nursing practice as a PMHNP from Fairfield University in Connecticut in 2016. She currently has her own private practice, Holistic Healing, PLLC where she provides functional psychiatry and EMDR therapy to target and reprocess negative life experiences across the lifespan. Doing so offers relief from trauma-related symptoms such as anxiety, depression, sleep issues, and harmful coping mechanisms. She sees resilience in each client and aims to foster that as she guides them on their healing journey. She aligns with her clients as she works to provide a foundation of goal setting to guide treatment and helps them to overcome the traumatic somatic experiences impacting their daily lives. She is also a mom of a now 15-year-old (Maya) who was born with congenital heart defects with many feeding issues in her early childhood. Maya has taught her so many things and is the reason she does the work she does.

Financial: Receives a salary from Holistic Healing, PLLC of which she is an owner and provider.

Non-financial: None.

Learning Objectives:

- **1.** Summarize the landscape of medical trauma on the mind and body of children and families.
- 2. Describe strategies to overcome implications of trauma related to feeding challenges.
- 3. Use resources attainable for families impacted by feeding trauma.

<u>Presentation Summary:</u> This presentation will provide a brief overview of the neurobiological impact of medical trauma on children and their families; will offer practical strategies to help children and families heal from trauma, and will empower families to find ways to help their children and family members navigate the Impact of feeding trauma.

Break 1

Session 1: Multidisciplinary Care Approach for Children with PFD

Jessica Sorbo MS, CCC-SLP; Lauren Fiechtner MD, MPH; Victoria Martin MD, MPH; Simona Lourekas MS, RD, LDN, CHES; Meaghan Alexander MS, RD, LDN

Jessica Sorbo has worked at MGH since 2015 and currently sees patients in both inpatient and outpatient settings. In addition to Feeding & Nutrition Center, she has worked in various multidisciplinary clinics serving patients with PFD, including those focused on aerodigestive disorders, Down Syndrome, and post-NICU discharge. Her clinical and research interests include managing complex dysphagia and bridging gaps between inpatient and outpatient care for children with PFD.

Financial: Receives a salary from Massachusetts General Hospital.

Non-financial: None.

Lauren Fiechtner's interests include preventing childhood obesity in the community and improving care for patients with PFD. She has presented her work at the Pediatric Academic Societies, the Obesity Society and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition annual meetings. Her work has been published in the American Journal of Public Health, Childhood Obesity, Preventive Medicine and Journal of National Medical Association.

Financial: Receives a salary from Massachusetts General Hospital and Harvard Medical School. Is a senior health and research advisor for Greater Boston Food Bank and Hunger to Health Collaboratory.

Non-financial: None.

Victoria Martin's clinical and research interests include the developing infant microbiome and its potential role in gastrointestinal food allergic diseases, including allergic proctocolitis and eosinophilic esophagitis. She has a special interest in caring for young infants with PFD in the outpatient setting.

Financial: Receives a salary from Massachusetts General Hospital.

Non-financial: None.

Simona Lourekas has been a pediatric dietitian at MGH since 2021 and has worked in Feeding & Nutrition Center since then. She currently sees a wide range of pediatric outpatients with complex nutrition needs within the Food Allergy Center and general pediatric gastroenterology. She has special interest and expertise in formula types and has regularly presented information to pediatricians and gastroenterologists to help patients with PFD during the 2022 formula shortage and recalls.

Financial: Receives a salary from Massachusetts General Hospital and Franciscan Children's Hospital.

Non-financial: None.

Meaghan Alexander has extensive experience in pediatric medical nutrition therapy. She has worked at MGH since 2009, both as part of their inpatient team and in their outpatient pediatric specialty clinics for cardiology and endocrinology. In addition to her work in Feeding & Nutrition Center, Meaghan has worked in the Raising Healthy Hearts Clinic for pediatric weight management alongside a pediatric cardiologist, pediatrician, behavioral psychologist, and health coach. She teaches a course in Clinical Dietetics to graduate nutrition students at Framingham State University.

Financial: Receives a salary from Massachusetts General Hospital and Framingham State University.

Non-financial: None.

Learning Objectives:

- 1. Describe the necessary components to multidisciplinary care for children with PFD Learning.
- 2. Evaluate barriers to implementation of multidisciplinary care for children with PFD Learning.
- 3. Apply concepts learned to hospital and non-hospital clinical settings.

<u>Presentation Summary</u>: This presentation will overview MGHfC Center for Feeding & Nutrition's model of multidisciplinary care for children with Pediatric Feeding Disorder, including assessment and treatment, for virtual, in-person, and hybrid settings. Attendees will learn how each discipline contributes to care as one of a team with the family at the forefront.

Session 2: Parent Confidence and Competence for Feeding in the NICU: A Qualitative Multi-Site Survey and Process Improvement

Ramya Kumar MS, CCC-SLP, BCS-S, CNT, IBCLC, NTMTC; Louisa Ferrara Gonzalez PhD, CCC-SLP, BCS-S, CNT, NTMTC; Jenny Reynolds MS, CCCSLP, CNT, CLC, BCS-S; Brittany Rush MS, CCC-SLP, CNT

Ramya Kumar specializes in infant & pediatric feeding disorders while practicing in a Level 3 NICU & pediatrician's office in Phoenix, AZ. She is a Board Certified Specialist in Swallowing & Swallowing Disorders, Certified Neonatal Therapist, International Board Certified Lactation Consultant, Neonatal Touch & Massage Certified Therapist & Trauma Informed Professional. Ramya is an internationally sought out speaker & clinical mentor on the topic of neuroprotective care in the NICU & pediatric feeding disorders. She is passionate about helping families create mealtime success through a whole-body lens. More recently, Ramya has been serving as a NICU Developmental Coordinator conducting NIDCAP assessments and championing changes in unit culture, system-wide policy development and supporting transition of NICU families to community-based programs.

Financial: Receives a salary from Abrazo Health.

Non-financial: Member of the Neonatal Therapy Certification Board.

Louisa Ferrara-Gonzalez is a Board-Certified Specialist in Pediatric Feeding/Swallowing Disorders, Certified Neonatal Therapist, Neonatal Touch/Massage Certified and Trauma-Informed Professional. She provides parent education and neonatal care in Private Practice and is a Clinical Researcher at NYU Langone Hospital - New York. She is Chief Clinical Officer at Innara Health. Louisa has published in high-standing peer-reviewed journals and is an internationally sought out speaker on the topic of neonatal feeding/swallowing disorders.

Financial: Receives a salary from Innara Health and NYU Langone Hospital.

Non-financial: ASHA PDF Topic Committee Member.

Jenny Reynolds is currently practicing as Advanced Clinical Specialist at Baylor University Medical Center in Dallas, Texas in the Level 4 Neonatal Intensive Care Unit. Jenny is a board-certified swallowing specialist, certified lactation counselor and a certified neonatal therapist. Jenny's research focus is pediatric dysphagia, specifically infant FEES, which is published in high-standing, peer-reviewed journals. She is an adjunct speaker at several speech therapy graduate programs in the DFW area.

Financial: Receives a salary from Baylor Institute for Rehabilitation.

Non-financial: Member of the NANT Professional Collaborative.

Brittany Rush is an ASHA certified speech language pathologist specializing in evaluation and treatment of feeding and swallowing disorders. Additionally, she is a certified neonatal therapist. She currently serves as a Senior level Speech Language Pathologist for the Physical Medicine and Rehabilitation department at Baylor University Medical Center in Dallas, Texas. Primary patient populations currently served include the premature and medically complex infant within the neonatal intensive care unit in a Level IV NICU. She has received specialty training and mentorship in developmental care/intervention and objective swallow evaluations (MBSS and FEES) within in the neonate and infant population. Her prior experience included services within the Adult Cardio-pulmonary and Transplant ICU/floors and obtained competencies in MBS, FEES, PMV, and speech/language/cognitive evaluations. Interests beyond her clinical duties include standardization of patient care, cultivating a positive teamwork environment and culture, and state/national level education.

Financial: Receives a salary from Baylor Institute for Rehabilitation.

Non-financial: Member of the Neonatal Therapy Certification Board.

Learning Objectives:

- Discuss the common psychosocial experiences and parental stressors in the Neonatal Intensive Care Unit and how they differ across various NICUs.
- 2. Identify 2 parent perceived barriers and 2 helpful strategies that parents perceived as impacting confidence and competence with feeding their infant.
- 3. Identify 2 process improvements in the NICU to better promote parental confidence and competence with feeding.

<u>Presentation Summary</u>: A qualitative multi-site survey was completed by NICU parents towards the end of their stay to identify factors that impacted confidence and competence with oral feeding. Survey results & video testimonials will shed light on gaps & opportunities when meeting parents' oral feeding needs and goals in the NICU and once home.

Featured Lightning Talk Lunch (12 Talks: 1 hour of credit)

A Transdisciplinary Approach To Feeding Affected By Social Determinantes of Health

Stephanie Tran MS, CCC-SLP; Tina Nguyen MOT, OTR/L; Emily Whitgob MD, MEd; Rachel Ruiz MD, FAAP

Stephanie Tran has a Master of Science in Communicative Disorders from San Francisco State University. She has experience working in outpatient clinics, acute hospitals, and schools. Her interests in the field include feeding disorders, early intervention, autism spectrum disorders, bilingual language acquisition, and developmental delays. She is trained in the SOS (Sequential Oral Sensory) Approach to Feeding, P.R.O.M.P.T; ADOS (Autism Diagnostic Observation Scales), and the NBO (New Born Observation Screening). Stephanie is reliable in the NCAST Feeding Scales. Stephanie has specialized training in working with children on the autism spectrum through Project Common Ground, a project supported by the U.S. Department of Education. She is an alumni of the Napa Infant-Parent Mental Health Fellowship. In her free time, she enjoys spending time with her family and friends.

Financial: Receives a salary from Santa Clara County.

Non-financial: None.

Tina Nguyen graduated from UCLA in 2010 with a BA in Psychology and a Master's of Occupational Therapy in 2014 from Samuel Merritt University. She has a variety of clinical experiences in multiple settings including psychiatric facilities, inpatient hospitals, SNFs, schools, and outpatient pediatric clinics. Her passion includes working with children with feeding disorders, mental health disorders, and developmental delays. Tina currently works as a psychosocial occupational therapist at Santa Clara County in a pediatric outpatient

clinic and a feeding clinic as part of a transdisciplinary team. She is trained in the Sequential Oral Sensory (SOS) Approach to Feeding, Learning Without Tears, ADOS-2 assessment, SPARK communication, and DIR FloorTime. In her free time, she likes to scrapbook, explore new places, and spend time with her family.

Financial: Receives a salary from Santa Clara County.

Non-financial: None.

Emily Whitgob is a developmental behavioral pediatrician at Santa Clara Valley Medical Center. She got her start in pediatric feeding disorders as a medical student at UC Davis where she spent Friday afternoons with their multidisciplinary feeding clinic. She fell in love with the team approach and the variety of patients and families. Before medical school, Emily was a special education teacher in New York, Boston, and Oakland and has always used the principles of inclusion to guide her. When she is not at work, she is trying new foods with her infant daughter.

Financial: Receives a salary from Santa Clara Valley Medical Center.

Non-financial: None.

Rachel Ruiz is a mom of three, a board-certified general pediatrician, and a pediatric gastroenterologist. She completed her undergraduate at Dartmouth College, doctorate of medicine and pediatrics residency at Vanderbilt University, and pediatric gastroenterology fellowship at Lucile Packard Children's Hospital Stanford. Rachel practices at Santa Clara Valley Medical Center in San Jose, CA and is an affiliated clinical instructor of pediatric gastroenterology at Stanford. While she treats a wide range of conditions, she is extremely passionate about feeding-related disorders.

Financial: Receives a salary from Santa Clara Valley Medical Center and the Lucile Packard Children's Hospital at Stanford. Lead medical director for a baby led weaning company Solid Starts.

Non-financial: None.

Learning Objective: Recognize how social determinates of health contribute to feeding disorders.

<u>Presentation Summary</u>: A Developmental behavioral pediatrician, a pediatric gastroenterologist, an occupational therapist and a speech therapist collaborated to create one that serves the children within our safety net healthcare system. This presentation highlight show a multidisciplinary team serves children with unmet needs that are often compounded by social determinants of health.

An Evaluative Interdisciplinary Model for Predicting Primary Sources of Pediatric Feeding Challenges

Cassaundra Corbett Miller EdD, CCC/SLP; Amy Kurowski-Burt, EdD MOT, OTR/L

Cassaundra Corbett Miller began her career in subacute rehabilitation with a focus on pediatric and pulmonary patients. Next, she spent 10 years providing in-home feeding and language intervention to infants and toddlers through the West Virginia Birth to Three Program. Currently, Cassaundra serves as the speech language pathologist and Clinic Director for the West Virginia University Center for Excellence in Disabilities Feeding & Swallowing Clinic. The interdisciplinary clinic serves rural patients and their families from across the state of West Virginia and also utilizes a one-on-one coaching model to increase knowledge of feeding assessment and intervention in providers across the state. She is also a clinical supervisor for speech pathology graduate students, an instructor for graduate and undergraduate Disability Studies coursework within the WVU Health Sciences Center School of Medicine and serves as Program Manager for the West Virginia Leadership Excellence in Neurodevelopmental Disabilities (LEND) Program. The WV LEND Program prepares graduate students, self-advocates, and family members of individuals with disabilities to become leaders and advocates in the field of disabilities. She is a guest lecturer for the WVU Country Roads Program. Country Roads provides a two-year oncampus experience for non-degree seeking students with disabilities to build independent life skills. Cassaundra's clinical practice and research focus includes rural telehealth access and pediatric feeding and swallowing in children with special health care needs.

Financial: Receives a salary from West Virginia University Center for Excellence in Disabilities (WVUCED).

Non-financial: None.

Amy Burt serves as the program director for the West Virginia University School Medicine Master of Occupational Therapy (MOT) degree program. She is an associate professor in the Occupational Therapy Department and serves as the occupational therapist for the WVU Center for Excellence in Disabilities Feeding and Swallowing Clinic. Amy has been awarded two institution-wide teaching awards and has been inducted into the WVU Academy for Excellence in Teaching and Learning. She was part of an interprofessional education team that was awarded the Go First Award, which recognizes positive outcomes that enhance the missions of the Health Sciences Center through implementation of innovations or quality improvement measures. Her clinical practice focuses on pediatrics, including autism and feeding challenges, sensory differences, and the visual system. Amy is also a faculty member for the WVU Country Roads Program. Country Roads brings non degree seeking students with disabilities onto the WVU Campus for a two-year program designed to maximize independence, career training, and socialization. In addition, she supervises graduate student research projects, serves as a mentor for the Leadership Excellence in Neurodevelopmental Disabilities (LEND) Program, and is a clinical preceptor for graduate fieldwork students.

Financial: Receives a salary from West Virginia University, School of Medicine.

Non-financial: None.

Learning Objective: Examine the convergence of sensory, behavior, development, psychosocial, and medical factors in pediatric feeding.

<u>Presentation Summary</u>: During this talk, we will outline our evaluative interdisciplinary model based on the World Health Organization Framework for Pediatric Feeding Disorder. Using a case study, we will present our model to learners so they can experience how visual representation supports organization for individualized and equitable feeding and swallowing evaluation.

Determinants of Infants' Readiness to Transition to Solids: A Systematic Review

Amanda Khamis B. App Sc SLP, PhD Candidate; Dr. Michelle McInerney; Dr. Katherine Sanchez; Lisa Gieles

Amanda Khamis is a speech pathologist from Sydney, Australia who has worked internationally in the UK, Middle East, and Australia for 15 years. She has a special interest in supporting feeding and communication for babies, children, and adults with complex neurological and developmental disabilities. Amanda has an enthusiasm for life-long learning and is currently completing a PhD, researching instrumental assessments and motor learning interventions for infants with dysphagia who are at risk of cerebral palsy. She also continues to work clinically at Cerebral Palsy Alliance as a senior certified practising speech pathologist. Amanda values life's simple pleasures, like a delicious meal and a good chat, she is dedicated to supporting her clients to have the opportunity to safely and successfully enjoy the same experiences.

Financial: Ms. Khamis is the owner of The Chirpy Swallow, is employed by Cerebral Palsy Alliance, and is a guest lecturer for The University of Sydney and Australian Catholic University.

Non-financial: None

Michelle McInerney is an academic and researcher at ACU and a member of the Speech Pathology Association of Australia. Michelle graduated as a speech pathologist with a Bachelor of Science (Honours) in Clinical Speech and Language Studies from Trinity College Dublin in 2000 and followed with a Master of Science in Clinical Speech and Language Studies (specialising in dysphagia) from Trinity College Dublin in 2008. She was awarded her PhD in November 2020. Michelle has over 17 years' experience working in acute medical, community and disability healthcare settings with 10 years' senior clinical experience working solely with individuals with neuro-disability. Her research interests include paediatric dysphagia and drooling in children with cerebral palsy (CP); intervention effectiveness for children with CP; outcome measurement and clinical education.

Financial: Dr. McInerney receives a salary from the University of Limerick and is a Research Associate with MCRI. Receives a salary from Australian Catholic University.

Non-financial: None.

Katherine Sanchez's research is focused on paediatric feeding disorders, and neurodevelopment in medically and surgically complex children. Her PhD research explored outcomes for children born very preterm. Katherine is a certified practicing speech pathologist and co-owns a private practice, Protea Therapy and also holds a leadership role at the Informed SLP, a company that reviews clinically applicable research for speech pathologists, writing and editing content related to paediatric medical presentations.

Financial: Dr. Sanchez is co-owner of Protea Therapy, is employed by the Informed SLP, The Advanced Pediatric Feeding Mentorship Group, and is a guest lecturer for the University of Melbourne and Victoria University.

Non-financial: None.

Lisa Gieles is a senior librarian with the School of Nursing, Midwifery & Paramedicine at ACU. She holds bachelor's degrees in information science and primary education and a master's degree of information studies. Lisa has been a health sciences librarian for 9 years after a career change from teaching. Her background in education drives an interest in supporting students to develop their information skills and to assist academics with integrating these skills into the curriculum. Lisa is skilled at supporting researchers throughout the lifecycle of their research projects and publications.

Financial: Receives a salary from the Australian Catholic University.

Non-financial: None.

Learning Objective: Attendees will be able to identify evidence-based infant behaviors and skills indicative of readiness to transition to solids

<u>Presentation Summary</u>: Infants are thought to exhibit behaviors indicating readiness for the introduction of solids; however the evidence is poorly understood. A systematic review was conducted and included four cross-sectional studies. Developmental readiness skills included sitting independently, exploring the environment, and interest in food. Additional higher-quality research is needed to guide families.

Interdisciplinary Practice to Support Transition Infants from Naso-Gastric Tube to Oral Feeding

L. Hope Wills MA, RD, CSP, IBCLC; Judy Hopkins MS, OTD; Linda Camacho RN, MSN, CNS, CPNP

L. Hope Wills is a pediatric dietitian and international board-certified lactation consultant. She provides clinical care for children with feeding problems and congenital heart defects. Hope has presented at the national and local level on the topic of feeding and nutrition for children with special needs. In addition to clinical service, she serves as nutrition faculty for the California LEND program and as program director for the Dietetic Internship at Children's Hospital Los Angeles.

Financial: Receives a salary from the Children's Hospital of Los Angeles.

Non-financial: None.

Judy Hopkins has 27 years of experience as an occupational therapist specializing in pediatric feeding and swallowing in medically complex children. She works at Children's Hospital Los Angeles on the acute team. Her areas of expertise include pediatric feeding and swallowing, modified barium swallow studies, lactation support, high risk infant and critical care. Judy has developed several innovative programs to meet the needs of children with chronic illness. She is a frequent presenter at state and national conferences. Passionate about working with children with feeding disorders, Judy enjoys sharing her medical knowledge and intervention strategies with occupational therapists and other professionals to equip them to bring children from diagnosis to dinnertime.

Financial: Receives a salary from the Children's Hospital of Los Angeles.

Non-financial: None.

Linda Camacho began her career as a registered nurse in a medical surgical floor at Miller Children's hospital and then went to Children's Hospital Los Angeles (CHLA). She has over 20 year's pediatric surgical nursing experience. Linda graduated from the University of California Los Angeles (UCLA) with her master's degree in nursing. Completed her pediatric nurse practitioner (PNP) and clinical nurse specialist at UCLA June 2011 and has been working with the Division of Pediatric surgery for the past 11 years. She also initiated a pediatric nurse practitioner led outpatient gastrostomy tube clinic. Her latest endeavor is being the led NP in a multidisciplinary nasogastric tube feeding clinic. As a PNP in the pediatric surgery department, Linda has vast experience in the identification, care and management of pediatric surgical patients. Her responsibilities include the care, management, of surgical and trauma patients. One of her passions is educating. She loves to teach nurses, parents, and precept students.

Financial: Receives a salary from the Children's Hospital of Los Angeles.

Non-financial: None.

Learning Objective: Identify 3 key components in developing an interdisciplinary outpatient clinic for transitioning infants from NGT to oral feeding

<u>Presentation Summary</u>: The presentation will provide the audience with key steps required to create an interdisciplinary team to support infants and their families in transitioning to oral feeding. Presenters will review how the team implemented the program; screening candidates and educating staff and families.

It's Not About The Food: Trauma Informed Care and Feeding Young Children

Rachael M. Catt OTR/L, PPOTD

Rachael Catt is an enthusiastic teacher who seeks to spread understanding and empowerment through real-life experience and research-based evidence. Rae has over 20 years of clinical-based experience as a pediatric developmental specialist, feeding specialist, and NICU interventionist. She recently completed her post-professional Doctor of Occupational Therapy, specializing in pediatrics. Her heart desires to welcome all comers in the hopes of spreading understanding and compassion to each learner who may pay it forward to those entrusted into their care.

Financial: Receives a salary from the Providence Kadlec Regional Medical Center. Receives a stipend for international travel and is compensated for her work as a feeding specialist/consultant with Holt International Child Nutrition Program. Is the owner of Research and Experience, LLC.

Non-financial: None.

Learning Objective: Describe and identify early life stress and primary changes which increase anxiety and low thresholds.

<u>Presentation Summary</u>: Early life experiences change brain development. Freedom comes when caregivers acknowledge biological changes that drive behavior. Caregivers can expand narrow definitions of feeding success to include feeling safe, accepted, and free to make choices that impact a lifetime of relationships with the self, caregivers, and food.

Navigating the Transition to Solids: The Experiences of Parents and Preterm Infants

Kelsey Thompson MS, CCC-SLP; Hayley Estrem PhD, MSN, RN; Jinhee Park PhD, RN; Suzanne Thoyre PhD, RN, FAAN

Kelsey Thompson is a doctoral candidate in the Speech & Hearing Sciences program in the School of Medicine at University of North Carolina Chapel Hill. Kelsey's research examines early neurodevelopment with a focus on feeding and speech motor development in preterm infants. She aims to produce clinically informed research that supports clinicians and families. Her current research focuses on how families of preterm infants navigate the transition to solid foods with the goal of developing proactive resources and support. She is experienced in quantitative, biobehavioral, qualitative, and mixed methods research. In addition, Kelsey continues to practice as a pediatric speech-language pathologist in her private practice in North Carolina.

Financial: PhD candidate at the Frank Porter Graham Child Development Institute. Received the James J Gallagher Dissertation Award. Owns and receives a salary from Thrive Speech Pathology.

Non-financial: Kelsey is a member of the Feeding Flock research team and a member of a Feeding Matters committee.

Hayley Estrem is an assistant professor in the School of Nursing at University of North Carolina Wilmington. Her primary research interests aim to improve family-centered care for children with PFD and/or developmental disabilities. In her research program, Hayley combines patient centered outcomes measure development, multi-method integration, qualitative methods, and the goal of family-centered care for infants and children with special health care needs. Her work started with concept analysis of pediatric feeding problems and measure development and she works with interdisciplinary teams to build evidence that addresses the needs of families and children with PFD. She is a member of the Feeding Matters Research Initiatives Task Force and has a child with PFD who inspired her to pursue a career in feeding research.

Financial: Receives a salary from the University of North Carolina Wilmington and the NIH. Dr. Estrem is a funded co-investigator on the study discussed in this presentation (R01NR018192).

Non-financial: Hayley is a parent of a child with PFD, is a founding member of the Feeding Flock research group, and is a member of a Feeding Matters committee.

Jinhee's clinical background is in neonatal nursing. Her research focuses on improving the understanding of feeding problems among vulnerable infants and young children, with an overall goal of supporting their health and developmental outcomes, and helping families manage their complex feeding needs. She has conducted a series of studies to advance science in the health care of infants and young children with feeding problems utilizing a multi-method approach, which includes biobehavioral methods (the integration of physiology and behavioral observation), advanced quantitative analytic methods (trajectory analysis, latent class analysis), mixed methods, symptom science, and the development of measures. Her current work is focused on developing and testing interventions to reduce feeding difficulties in infants with complex medical conditions, including a current trial testing the biobehavioral efficacy of the semi-elevated side-lying position for feeding preterm infants.

Financial: Receives a salary from Boston College and the NIH. Dr. Park is a funded coinvestigator on the study discussed in this presentation (R01NR018192).

Non-financial: Jinhee is a founding member of the Feeding Flock research group.

Suzanne Thoyre is a Professor at the School of Nursing at the University of North Carolina at Chapel Hill. Her research focuses on the development of early oral feeding of typically developing children, young children with Down syndrome, infants who have had surgery

for complex cardiac conditions, and preterm infants. She co-developed a clinician-based assessment tool for early infant feeding skills (the Early Feeding Skills tool; EFS); this tool is used internationally to support the clinical care of infants who are vulnerable to developing chronic feeding disorders. She is the co-founder of Feeding Flock, an interdisciplinary research team focused on management and prevention of feeding problems of infants and young children. Recently her team extended feeding assessment to the post-discharge period with the development of six parent-report assessment tools. These tools measure symptoms of problematic feeding, oral and motor feeding skills, parent perception of the impact feeding problems have on themselves and their families, and parent assessment of family management of feeding problems. A recently awarded R01 will use these tools to extend our understanding of the development of feeding problems of children with complex medical disorders from birth through 2 years of age.

Financial: Receives a salary from the University of North Carolina Chapel Hill and a salary from Pediatric Resources, LLC. Suzanne received a speaking fee to teach the Early Feeding Skills Assessment NIH and is a funded principal investigator on the study discussed in this presentation (R01NR018192).

Non-financial: Suzanne is a founding member of the Feeding Flock research group.

Learning Objective: Participants will describe parent experiences around introducing solid foods and apply parent preferences to their clinical work.

<u>Presentation Summary</u>: The introduction to solids is an important transition with implications for long-term feeding development. Parents of premature infants were interviewed about how they navigated this complex period. Resources, misinformation, and decision-making processes are explored with the goal of improving the proactive feeding support parents receive from healthcare providers.

Non-Nutritive Suck in Full-Term Infants and Developmental Outcome at 12 Months

Alaina Martens MS, CCC-SLP; Morgan Hines BS; Emily Zimmerman PhD, CCC-SLP

Alaina Martens is a 3rd year PhD Candidate under the supervision of Dr. Emily Zimmerman at Northeastern University. She graduated in 2018 with her M.S. in SLP from the University of Nebraska-Lincoln and completed her B.S. in SLP at Texas Christian University. During her dissertation, Alaina plans to examine sucking and feeding development in special populations of infants. She is passionate about improving developmental outcomes for infants with feeding disorders.

Financial: Alaina receives a PhD stipend from Northeastern University.

Non-financial: None.

Morgan Hines is a staff member of Northeastern University. She graduated from Northeastern University in 2019 with a Bachelor of Science in Biology and English combined and has worked in the Speech and Neurodevelopment for several years.

Financial: Morgan receives a salary from Northeastern University.

Non-financial: None.

Emily Zimmerman is an Associate Professor of Communication Sciences & Disorders at Northeastern University. She directs the Speech & Neurodevelopment Lab, which examines the cross-section of sucking, feeding and speech emergence across environmental, maternal, physiological, and genetic factors. Emily is the Principal investigator on several NIH grants examining these themes across patient populations.

Financial: Emily receives a salary from Northeastern University.

Non-financial: None.

Learning Objective: Describe the association between infant non nutritive suck and developmental outcomes.

<u>Presentation Summary</u>: The goal of the proposed research is to determine the association between infant non-nutritive suck (NNS) dynamics at 3 months and developmental outcomes at 12 months of age in fullterm infants. Findings from this work compliment emerging research showing that infant NNS is associated with subsequent cognition and neurodevelopment.

Swallowing and Feeding in Hypoxic-Ischemic Encephalopathy

Roxanne Malan PhD; Jeannie van der Linde PhD; Alta Kritzinger PhD; Marien Graham PhD; Esedra Krüger PhD

Roxanne Malan is a registered speech-language pathologist and PhD candidate at the University of Pretoria in South Africa. Her interests include paediatric dysphagia and early intervention. She is currently working on a research project investigating the feeding, swallowing, developmental outcomes and associated factors of infants with hypoxicischemic encephalopathy.

Financial: Receives a salary from the University of Pretoria.

Non-financial: None.

Jeannie van der Linde is the Head of the Department of Speech-Language Pathology and Audiology at the University of Pretoria. In 2019, she was rated as a National Research Foundation (NRF) South Africa Y2 scholar. Her use of an interdisciplinary approach to improve early detection of developmental delays in underserved contexts has helped her

forge partnerships with Vanderbilt University (US), University of Gavle (Sweden), and with NGOs such as Future Families and The Reach Trust. Through this research, she is also helping to develop custom smartphone applications to detect and prevent developmental delays in vulnerable children.

Financial: Receives a salary from the University of Pretoria.

Non-financial: None.

Alta Kritzinger is an emeritus professor in the Department of Speech-Language Pathology and Audiology, University of Pretoria. Her research and clinical interests are neonatal swallowing and breastfeeding, and early communication intervention. Since her retirement in 2018, she particularly focuses on coaching parents of infants and young children with low birth weight and preterm birth, Down syndrome, clefts, autism and late language emergence. She remains a registered speech-language therapist. Alta continues to supervise postgraduate research, publishes, reviews manuscripts for journals and participates in scientific conferences. Among other topics, she supervised ten master's and four PhD studies in Dysphagia. She volunteers as a consultant in swallowing and breastfeeding intervention at the Kangaroo Mother Care ward at Kalafong hospital. She develops evidence-based material and holds workshops for parents and professionals.

Financial: Receives a salary from the University of Pretoria.

Non-financial: None.

Marien A. Graham is a specialist in the areas of assessment and quality assurance, nonparametric statistics and statistical quality control. She is an Associate Professor in the Department of Science, Mathematics and Technology Education at the University of Pretoria. She has made contributions to many disciplines, including education, healthcare, social issues, and agroforestry. She is a Y1-rated researcher with the National Research Foundation (NRF), South Africa, as well as the co-author of Nonparametric Statistical Process Control, published by John Wiley & Sons (2019). Marien furthermore serves on the editorial advisory board of Scientific Studies and Research, Series Mathematics and Informatics, and has published in several accredited international peer-reviewed journals. She regularly presents her research at national and international conferences.

Financial: Receives a salary from the University of Pretoria.

Non-financial: None.

Esedra Kruger is a speech-language therapist, currently working as a senior lecturer and researcher in the Department of Speech-Language Pathology and Audiology at the University of Pretoria. Her special interests include early intervention with infants and young children who have difficulties communicating, neonatal intervention with high-risk infants who have swallowing and feeding difficulties including breastfeeding management, as well as management of infants and toddlers with craniofacial disorders. Esedra is

currently the head of the Clinic for High-Risk Babies at the Department of Speech-Language Pathology and Audiology. Her undergraduate and postgraduate training was completed at the University of Pretoria. She completed a PhD in Speech-Language Pathology in 2019. Esedra is also the proud wife of Christo Krüger, a financial advisor, and the mother of Isabella and Olivia.

Financial: Receives a salary from the University of Pretoria.

Non-financial: None.

Learning Objective: Describe and compare swallowing and feeding of neonates with HIE initially and at hospital discharge.

<u>Presentation Summary</u>: Swallowing and feeding abilities of neonates with hypoxic-ischemic encephalopathy (HIE) were described during hospitalization, using clinical assessments and video-fluoroscopic swallow studies. Most neonates displayed oropharyngeal dysphagia, regardless of HIE severity. Significantly less oropharyngeal dysphagia occurred at discharge compared to initial assessment (p=0.004). Findings may be valuable to neonatal feeding teams.

The Discrete Swallow Initiative: Advancing Pre-Feeding Skills in the Medically Fragile Infant

Emily Rocha OTD, OTR/L, CSRS; Cuyler Romeo MOT, OTR/L, SCFES, IBCLC

Emily Rocha is an occupational therapist. She graduated with her doctorate in May 2022 from Northern Arizona University, Phoenix Biomedical Campus. She was first introduced to the profession through working with kids with special needs, seeing the positive impact it had on the children and their families. After exploring the career further, Emily realized how much it was for her. Her goal is to help people increase quality of life and be able to pursue their passions. She completed her capstone in the NICU, focusing on feeding and swallowing, following a discrete swallow protocol created by her mentor Cuyler Romeo. Emily now works with both babies and adults in the hospital setting. Aside from work, she likes to work out, swim, shop, watch movies, and be with friends and family.

Financial: Emily is a Doctoral Capstone Student OT at Honor Health Hospital Shea Adult & NIC.

Non-financial: None.

Cuyler Romeo has developed a broad clinical understanding of the needs of families and children by serving as an Occupational Therapist and industry expert in pediatric feeding disorder for over 20 years. As the Director of Strategic Initiatives at Feeding Matters, she assists in developing and executing a strategic plan to bring about system wide change for families struggling with pediatric feeding disorder. She utilizes her clinical understanding and leadership expertise to collaborate with constituents in identifying, tracking, and assessing innovative solutions to system problems.

Cuyler also has extensive experience facilitating strategic partnerships and aligning diverse groups of people under a common goal. She designed and executed a state-wide multidisciplinary mentorship program, launched a Community of Practice within the American Occupational Therapy Association (AOTA) and advanced professional development through her position on AOTA's Commission on Continuing Competence and Professional Development (CCCPD). Prior to joining Feeding Matters, she served as a founding partner of a feeding specialty clinic, Mealtime Connections, and rectified system issues on a broader scale as the Director of Clinical Innovation at Therapy 2000. She also treats clinically as a feeding specialist at Banner University Medical Center-Tucson in a Level 3 NICU and speaks professionally.

Financial: Receives a salary from Feeding Matters. Receives hourly compensation from Banner University Medical Center Tucson.

Non-financial: Cuyler Romeo facilitates AOTA's Mealtime Occupation: Feeding, Eating and Swallowing Community of Practice and is an appointed member of the Commission for Continued Competence and Professional Development (CCCPD). She serves on the Board of Directors for the Institute of Perception-Action Approach and is a member of the National Perinatal Association's Interdisciplinary Workgroup and Dissemination Committee. She is a member of AOTA, ArizOTA, and IAPFS.

Learning Objective: Participants will identify and summarize the purpose and method of the discrete swallow initiative to be used with the medically fragile infant.

<u>Presentation summary</u>: This lightning talk consists of education about the discrete swallow protocol in the NICU and its use to establish functional feeding skills with safe, supported, experience-based opportunities to learn suck-swallow-breath coordination. Speakers will discuss a quality improvement project aimed at defining the population to assist their unit in advocating for supportive pre-feeding practices.

The Enteral Nutrition Action Plan, A Low Health Literacy Self-Management Tool

MAJ Patrick T. Reeves, MD, FAAP

Patrick Reeves graduated summa cum laude from Texas A&M University with a bachelors in Biomedical sciences. During his time at Texas A&M, he completed 4 years in the Corps of Cadets and served as the Corps Commander his senior year. He attended medical school at the University of Texas Medical Branch and completed his general pediatrics residency at the San Antonio Uniformed Services Health Education Consortium. There he was awarded intern of the year in 2017 and was inducted to the house staff hall of fame upon graduation in 2019. Patrick has published more than 20 Pubmed cited articles, received 3 grant awards, developed 2 point-of-care medical applications, and created numerous clinical tools with the intent to improve patient care. His primary research focus is the development of medical education curricula and clinical point-of-care instruments to facilitate the care of children. He is a father of 2, consultant Peds gastroenterologist, and an Army physician.

Financial: Major Reeves receives a salary from the Brooke Army Medical Center. This work was prepared as part of the official duties of Dr. Reeves who is employed by the United States Department of Defense.

Non-financial: None.

The views expressed in this presentation are those of the author and do not reflect the official policy or position of the United States Army, Navy, Air Force, Department of Defense, or the United States Government.

Learning Objective: To demonstrate a universal precautions approach to enhance knowledge transfer from medical teams to families managing children with pediatric feeding disorder and complex nutritional needs

<u>Presentation Summary</u>: This Enteral Nutrition Action Plan is a multifaceted tool designed to be used with infants and children with pediatric feeding disorder, poor growth, failure to thrive, or requiring tube feeds. The plan incorporates low health literacy elements like pictograms and automation to reinforce best practices at home.

Turning Thickening Trouble into Triumph!

Laura Melnick MS, CCC-SLP; Susan Tripp MS, RDN, LDN, CNSC; Nicole DePalma Leary DPT, PCS, CNT, NTMTC; Rebecca Hughes MS, OTR/L, CNT; Briana Wrubleski MS, RDN, LDN

Laura Melnick is the Manager of the Department of Speech-Language Pathology at UMass Memorial Medical Center, an academic medical center in Central Massachusetts. She cares for adult and pediatric patients with feeding and swallowing disorders. Laura also teaches as an adjunct instructor at Worcester State University and enjoys combining clinical practice with student education.

Financial: Receives a salary from UMASS Memorial Medical Center and from Worcester State University.

Non-financial: None.

Susan Tripp is a registered dietitian and board-certified nutrition support clinician with over 10 years' experience in neonatal nutrition. She is the lead dietitian in the Neonatal Intensive Care Unit at UMass Memorial Medical Center. In addition to patient care, Susan is involved in development of clinical practice guidelines, nutrition quality improvement projects and education of medical students and residents.

Financial: Receives a salary from UMASS Memorial Medical Center.

Non-financial: None.

Nicole DePalma Leary is a Developmental Specialist at UMass Memorial Medical Center, an academic medical center in Central Massachusetts. She completed American Board of Physical Therapy Accredited Neonatology Fellowship training; and is a Certified Neonatal Therapist and Pediatric Physical Therapy Clinical Specialist who cares for patients in the Neonatal Intensive Care Unit and the NICU Developmental Follow-up Program. Nicole is passionate about the clinical management and continuum of developmental care for high risk infants, interdisciplinary collaboration, Family Centered Care, and engagement in providing multidisciplinary education.

Financial: Receives a salary from UMASS Memorial Medical Center.

Non-financial: None.

Rebecca Hughes is an Occupational Therapist with 23 years pediatric clinical experience. She is a Certified Neonatal Therapist (CNT) and specializes in neonatal feeding assessment and treatment at UMass Memorial Health. Her experience includes practice in the outpatient, school-based, early intervention and hospital settings. Rebecca has a passion for implementing a family-centered approach to help each family and child maximize their full potential.

Financial: Receives a salary from UMASS Memorial Medical Center.

Non-financial: None.

Briana Wrubleski is celebrating her first year as an inpatient pediatric and neonatal critical care dietitian at UMass Memorial Medical Center, an academic medical center in Worcester, Massachusetts. As a new professional in the field of clinical nutrition, she enjoys splitting her time between populations and working with inter disciplinary teams to optimize patient plans.

Financial: Receives a salary from UMASS Memorial Medical Center.

Non-financial: None.

Learning Objective: Identify challenges to thickening liquids for infants in the NICU.

<u>Presentation Summary</u>: We will share with you how our Neonatal Intensive Care Unit (NICU) Nutrition and Feeding Team at UMass Memorial Medical Center has worked together to create a Clinical Practice Guideline (CPG) for infants requiring thickened liquids. This has standardized the approach to prescribing thickened feedings which has improved overall infant feeding safety.

We weren't entirely sure of the plan": Caregivers' Experiences and Recommendations of Having a Child with a Temporary Feeding Tube

Claire Reilly RD, BSc, MSc, PhD Candidate; Maryanne Syrmis SLP; Nadine Frederiksen OT; Jeanne Marshall PhD, SLP; Rebecca Nund PhD, SLP; Kristie Bell PhD, RD; Nikhil Thapar PhD, MD

Claire Reilly is a senior paediatric dietitian at the Queensland Children's Hospital, Brisbane, and a PhD candidate at the University of Queensland. Claire is a member of the Queensland Children's Hospital interdisciplinary feeding clinic and her research focuses on the management of tube feeding in children.

Financial: Receives a salary from Queensland Health and a scholarship from the University of Queensland.

Non-financial: None.

Maryanne Syrmis is one of the Advanced Speech Pathologists in Outpatients at the Queensland Children's Hospital, Brisbane, Australia and holds an Honorary Fellow position at the Child Health Research Centre, University of Queensland. She predominantly works in the Queensland Children's Hospital Interdisciplinary Feeding Clinics and has a graduate certificate in Health Services Management from the University of Technology Sydney.

Financial: Receives a salary from Queensland Health.

Non-financial: None.

Nadine Frederiksen is a Clinical Lead Occupational Therapist at the Queensland Children's Hospital, Brisbane, Australia and holds an Honorary Fellow position at the Child Health Research Centre, University of Queensland. Nadine specialises in working with children presenting with significant feeding difficulties on the background of complex medical issues. Working within an Interdisciplinary feeding team, she has completed research in the management of temporary tube feeding, including tube weaning practices, with several peer reviewed papers published.

Financial: Receives a salary from Queensland Children's Hospital.

Non-financial: None.

Jeanne Marshall is a speech pathologist with expertise in paediatric feeding and swallowing. She is currently employed in a conjoint role between Children's Health Queensland Hospital and Health Service and The University of Queensland. Jeanne's research interests include paediatric feeding disorders and dysphagia, telepractice, education, and simulation. Jeanne also has a passion for research translation and building research capacity in the health workforce.

Financial: Receives a salary from the Children's Health Queensland/ The University of Queensland. Is a Conjoint Clinical Research Fellow (Speech Pathology).

Non-financial: None.

Rebecca Nund is a Lecturer and Early Career Researcher in the School of Health and Rehabilitation Sciences, Faculty of Health and Behavioural Sciences. She is an affiliate of the Centre for Functioning and Health Research (CFAHR). Rebecca has received over 2.2M in research fundings and published over 30 research articles and book chapters. The focus of her program of research is on partnering with patients, families and health professionals to understand their experiences to inform health service change. She is a speech pathologist with a special interest in swallowing disorders, head and neck cancer, and qualitative research.

Financial: Receives a salary from the University of Queensland.

Non-financial: None.

Kristie Bell has been an accredited practicing dietitian for over 20 years. She is currently the Acting Director of Dietetics and Food services at Children's Health Queensland and holds honorary research appointments with the University of Queensland, Griffith University and the Queensland University of Technology. As a clinician researcher, Kristie's research interests include topics with direct clinical relevance and impact for improving the health of children and their families. Her research has focused on nutrition, physical activity, growth and health for children with cerebral palsy, and in the nutrition screening and assessment of children with different clinical conditions. Most recently, her current research involves the development and implementation of new models of care for dietetics services to ensure the right care is delivered at the right time to every child and family.

Financial: Receives a salary from the University of Queensland, Griffith University and Queensland Children's Hospital.

Non-financial: None.

Nikhil Thapar is Director of the Gastroenterology, Hepatology and Liver Transplant service at Queensland Children's Hospital, Brisbane, Australia where he leads a specialist statewide multidisciplinary clinical service for children with gastrointestinal motility and functional disorders. He was Academic Lead for Paediatric Gastroenterology and head of the Neurogastroenterology and Motility service at Great Ormond Street Hospital and University College London Great Ormond Street Institute of Child Health (London, UK).

Financial: Receives a salary from Queensland Children's Hospital.

Non-financial: None.

Learning Objective: Appraise the management of temporary tube feeding in children to ensure it is consistent.

<u>Presentation Summary</u>: This presentation describes the results of an open-ended survey completed by caregivers of children with a temporary feeding tube from an Australian tertiary children's hospital. The caregivers' experiences and recommendations are analysed, providing insight into their perspectives and the advice they would give to other caregivers in the same situation.

Session 3: Interdisciplinary Team Training to Support Hospital-to Home Transitions: Foundation in PMAD's and PFD

Tiffany Elliott MS, CCC-SLP, CNT, IBCLC; Mari Mazon MS, RDN, CD; Leslie Butterfield PhD; Sara Circelli MA, IMH-E

Tiffany Elliott is a Speech-Language Pathologist (SLP), specializing in pediatric feeding and swallowing disorders with an emphasis on preterm and medically complex infants and strengthening the caregiver-infant dyad. She is also a Certified Neonatal Therapist (CNT) and an International Board-Certified Lactation Consultant (IBCLC). She was chosen to complete the ASHA Leadership Development program and awarded a Distinguished Professional Achievement Award from her undergraduate university. She currently works at the University of Washington Medical Center, where she co-founded the unit's SLP program which offers an embedded, preventative neonatal therapy model. Without an outpatient therapy component, she noticed the care gap post NICU discharge and has partnered with professionals across Washington state to improve transitions home for these fragile infants and their families. Additionally, Tiffany has worked in two area Children's hospitals, completing instrumental swallow evaluations as well as feeding/swallowing care for primarily infants and toddlers. She enjoys teaching and has lectured locally and nationally on pediatric feeding and swallowing disorders.

Financial: Receives hourly compensation from Seattle Children's Hospital; a grant and hourly compensation from the Northwest Center; and an honorarium from the Rocky Mountain University of Health Professionals (RMUHP).

Non-financial: Tiffany is a steering committee member on the Pediatric Feeding Association. She has participated in ECTA Cross-State Technical Assistance workgroup on Infant & Early Childhood Mental Health (IECMH) and Early Intervention (EI, Part C).

Mari Mazon is a pediatric dietitian in Seattle, WA. She serves the Birth-to-3 population as part of an interdisciplinary feeding team, and children undergoing interdisciplinary evaluation for developmental challenges. Her other works include working with the state on increasing families' access to evidence-based nutrition and feeding services in WA State and serving as nutrition faculty on interdisciplinary training grants.

Financial: Receives a salary from University of Washington Center on Human Development & Disability (UW CHDD) and Kindering.

Non-financial: None.

Leslie Butterfield is a licensed clinical psychologist specializing in perinatal mental health. She provides clinical services to individuals and couples facing the transition to parenthood, perinatal mood and anxiety disorders, perinatal loss, fertility challenges, traumatic birth, NICU stays, and infants with medical complexities. Additionally, she offers therapeutic and training services to healthcare providers and organizations in the childbirth community. For the past 10 years Leslie has provided specialized trainings and presentations for Perinatal Support of Washington, PATTCh (Prevention and Treatment of Traumatic Childbirth), and Postpartum Support International. She has traveled both nationally and internationally in her capacity as a trainer/consultant, offering services to a variety of medical and mental health organizations. She presents yearly webinars for Praeclarus Press and for her private practice, Transition to Parenthood. In her capacity as an educator, she has designed and taught the counseling skills curriculum for student midwives at Seattle Midwifery School and Bastyr Naturopathic University and developed a consultation model for therapists/nurses/doulas/midwives training in perinatal mental health. Leslie is a past Chairwoman and current board member of Perinatal Support – WA; a past President and current board member of PATTCh. In Spring 2019 Perinatal Support -WA and PATTCh co-sponsored and hosted the first American Trauma and Birth conference. Leslie is additionally a state coordinator and trainer for Postpartum Support International.

Financial: Receives compensation for provision of psychotherapy services from Transition to Parenthood for which she is the owner and from Postpartum Support International and Perinatal Support of Washington.

Non-financial: Leslie Butterfield serves on the Board of Directors for Perinatal Support of Washington and also on the Board of Directors for PATTCh (Prevention and Treatment of Traumatic Childbirth).

Sara Circelli, MA, IMH-E is a Family Resources Coordinator and Hospital-to-Home Site Supervisor at Northwest Center, an Early Support for Infants and Toddlers (ESIT) agency. At Northwest Center, she manages a grant-funded project focused on integrating perinatal mental health services within home visiting services for infants and their families. She has received extensive training in recognizing and supporting Perinatal Mood and Anxiety Disorders (PMADs) and received a Compassionate Bereavement Care Certification from the Center for Loss and Trauma. Sara is a certified Promoting First Relationships (PFR) provider, a University of Washington program designed to help caregivers best support their young child's social emotional development. In addition to her work at Northwest Center, she facilitates caregiver support groups for Group Peer Support and Postpartum Support International.

Financial: Receives a salary from Northwest Center Early Supports and is an Independent contractor and facilitator for Group Peer Support.

Non-financial: Sara Circelli volunteers with Postpartum Support International as a Parent Support Group facilitator. She also has her Compassionate Bereavement Care Certification from the Center for Loss and Trauma and is a certified Promoting First Relationships (PFR) provider.

Learning Objectives:

- **1.** Identify unique care needs for infants and caregivers when transitioning from hospital-to-home.
- **2.** Describe novel interdisciplinary training approach for hospital-to-home transition.
- **3.** Choose one to two connections to make to improve your team's hospital-to-home transition process.

<u>Presentation Summary</u>: Infants and their caregivers transitioning from hospital-to-home have specific mental health, feeding and nutrition care needs. Teams serving these families lack interdisciplinary training grounded in caregiver mental health to meet their needs. A 3-day virtual interdisciplinary team training was developed and offered to interdisciplinary feeding teams in Washington State.

Session 4: PEAS Project: Success Transforming Care for Patients with PFD in Alberta Canada

Justine Turner PhD, MBBS, FRACP; Sharron Spicer MD, FRCPC, CCPE; Julianna Harris B.Comm, MS, Prosci Certified

Justine Turner is a pediatric gastroenterologist and Professor at the University of Alberta. Justine completed her General Pediatrics training in 1996 in Perth, Western Australia. She then completed 7 years of sub-specialty training in Pediatric Gastroenterology and Nutrition, including a 2-year Fellowship at the Hospital for Sick Children, and 6 years of nutrition research training. She is currently co-lead of a CIHR funded translational research laboratory at the University of Alberta. She is co-principal investigator for the MNCY SCN HOIF II funded Provincial Eating and Swallowing or PEAS Project across Alberta. Her clinical research interests include infant and adolescent nutrition and the effect of chronic gastrointestinal diseases on nutrition. She has been medical lead for the Pediatric Home Nutrition Support Program at Stollery Children's Hospital, since 2010. Justine is the medical lead for the Celiac Disease Clinic and the Glenrose Rehabilitation Hospital Pediatric Feeding Clinic. She is Associate Editor for the Journal of Pediatric Gastroenterology Hepatology and Nutrition (Nutrition Sector) and is on the Editorial Board for the Journal of Parenteral and Enteral Nutrition.

Financial: Receives a salary from the University of Alberta. Receives a speaking fee from Nutricia North America and grants from the Baxter Cooperation.

Non-financial: Is a member of the PEAS leadership team that is referenced in her presentation and developed materials for this course.

Sharron Spicer is a pediatrician who has worked with medically complex children for over 20 years. She led the development of the Hospital Pediatrics program at Alberta Children's Hospital (ACH) and was later the inaugural Section Chief of Pediatric Palliative Care. Sharron now leads the ACH home enteral nutrition program. She is strongly committed to supporting patient safety, ethics, physician health, and leadership development. She has been the Chair of the ACH Quality Assurance Committee, Serious Safety Event Review team and the Ethics Committee. Sharron currently serves on the Canadian Medical Association's Committee on Ethics. She teaches Ethics and Pediatrics at the Cumming School of Medicine. She has been a consultant to the Alberta Medical Association in its physician health program and as a Medical Advisor in Professional Affairs. She is now an Associate Chief Medical Officer with Alberta Health Services. She received the Canadian Certified Physician Executive (CCPE) credential from the Canadian Society of Physician Leaders (CSPL) in 2017 and is the Editor-In-Chief of the CSPL's publication, the Canadian Journal of Physician Leadership. She has been a speaker at numerous conferences and educational events. Sharron combines her interests of travelling and exploring in her pastime of geocaching. She makes it her goal to find a new cache in every city where she attends events.

Financial: Receives a salary from Alberta Children's Hospital.

Non-financial: None.

Juliana Harris is a Patient & Family Centred Care Project Manager at Alberta Children's Hospital. In her role, Juliana consults with internal service providers to help develop appropriate patient and family engagement strategies for the purpose of better understanding their care experiences to help drive quality and safety improvements. Juliana's eldest daughter is the source of her passion and commitment to meaningful engage patients and families. Her daughter has Rett Syndrome, a rare neurological and developmental disorder, and inflammatory bowel disease, which has resulted in an ever changing feeding journey that includes sporting a g-tube and receiving the support of different ACH feeding related services. Juliana has been able to use her blend of personal family experience and professional skill set to collaborate as core member on the PEAS evaluation committee, consult with different working groups, and support the engagement of other families to be involved.

Financial: Receives a salary from Alberta Children's Hospital.

Non-financial: None.

Learning Objectives:

- 1. To explain the importance of engaging stakeholders and specifically families to design and implement improvements to care.
- 2. To identify opportunities to apply the Learning Collaborative approach to implement complex care initiatives.
- 3. To describe the importance of measuring multiple dimensions of quality for a balanced approach to evaluation.

<u>Presentation Summary</u>: The Pediatric Eating and Swallowing Project was a provincial quality improvement project in Alberta, Canada. This presentation will review the key methodologies used in this quality improvement initiative, document the positive quality improvement outcomes and focus on the key role of consultation with the families of children with pediatric feeding disorders throughout the process.

Break

Session 5: Preventing Feeding Disorders from the Start in Premature and Medically Compromised Infants

Melissa Andersen PhD; Natalie Berriz PhD, BCBA; Catherine Joppich RDN, CLC; Megan Schmuckel MA, CCC-SLP, CLC

Melissa Andersen is a pediatric psychologist who completed her doctoral training at the University of Nebraska-Lincoln, pre-doctoral residency in neurodevelopmental disabilities and pediatric psychology at Oregon Health & Science University, and post-doctoral fellowship in pediatric psychology at the University of Michigan. She is an Assistant Professor of Pediatrics at the University of Michigan/C.S. Mott Children's Hospital where she serves as the head of the Cue-Based Feeding Program and director of the home NG Follow Up Clinic. She served as the PI of a large-scale quality improvement grant focusing on improving the hospital-wide approach to promoting oral feeding skill acquisition in hospitalized infants and preventing feeding disorders in this high-risk population. Melissa leads the Infant Feeding Task Force, serves on the Care at Home Task Force, and led the multi-disciplinary development of the hospital wide Infant Oral Feeding Acquisition Feeding clinical practice guideline. She has over 10 years of experience in neurodevelopmental care of high-risk infants and pediatric feeding disorders.

Financial: Receives a salary from Mott Children's Hospital University of Michigan Health.

Non-financial: None.

Natalie Berriz received her bachelor's degree in psychology from Bradley University and her doctoral degree in clinical psychology from Eastern Michigan University. She is also a board certified behavior analyst (BCBA). She completed her predoctoral internship at Marcus Autism Center in applied behavior analysis and developmental disabilities and her fellowship in pediatric psychology at Michigan Medicine with a specialized focus on pediatric feeding disorders. Natalie is one of a handful of psychologists in the state of Michigan with the expertise needed to prevent and treat pediatric feeding disorders. Dual

degrees in Clinical Psychology (specializing in Pediatric Psychology) and behavior analysis provide her with a greater clinical understanding of how to assess and treat the most medically, developmentally, and behaviorally complex patients. She joined the faculty in the Interdisciplinary Pediatric Feeding Program at Michigan Medicine to expand the services offered to children and their families with pediatric feeding disorders. She is particularly interested in the prevention and early intervention of pediatric feeding disorders. Natalie prides herself on having a family centered approach, tailoring interventions and recommendations to what will yield the most success with the patient and satisfaction from the family. As a previous member of a team granted the Evan Newport Hope award for outstanding patient and family centered care, she strives to continue to live up to the standards of that award.

Financial: Receives a salary from Mott Children's Hospital University of Michigan Health.

Non-financial: None.

Catherine Joppich is a registered dietitian nutritionist at C.S. Mott Children's Hospital. She graduated from Central Michigan University with her Bachelor of Science and completed her dietetic internship with a concentration in pediatric clinical nutrition at Michigan Medicine. Following her internship, she worked as an inpatient clinical dietitian floating between services providing long term coverage in the NICU, Pediatric Nephrology, and Pediatric Surgery services. Catherine now works in the outpatient setting for Interdisciplinary Pediatric Feeding Program. She primarily sees infants with NG tubes in the NG Follow Clinic providing nutrition support, growth monitoring, and guidance for tube weaning when the infants are medically and physically ready.

Financial: Receives a salary from Mott Children's Hospital University of Michigan Health.

Non-financial: None.

Megan Schmuckel is a senior speech-language pathologist and certified lactation counselor who has spent the last fourteen years providing assessment and treatment of speech, language, and feeding disorders at Michigan Medicine. During that time, she developed a passion for infant dysphagia, particularly helping families of premature infants, as well as infants with medical complexity. After twelve years of her career focusing primarily on acute care and rehabilitation in the inpatient setting, she took the leap in March 2020 to join the Interdisciplinary Pediatric Feeding Program full time. With this team, Megan has assisted in developing the NG Follow-Up Clinic, a program designed to provide multidisciplinary care to infants and their families being discharged from the hospital with a nasogastric tube.

Financial: Receives a salary from Mott Children's Hospital University of Michigan Health.

Non-financial: None.

Learning Objectives:

- 1. Describe the etiology of pediatric feeding disorders in premature and medically compromised infants.
- 2. Describe the application of cue-based feeding to wean at-risk infants from NG tubes.
- 3. Describe the utility of an interdisciplinary model of care to prevent pediatric feeding disorders.

<u>Presentation Summary</u>: Preterm and medically compromised infants are at high risk for impaired oral feeding progression and long-term tube feeding dependency. An interdisciplinary model of prevention can reduce the likelihood of long-term feeding problems, provide invaluable support to families after hospital discharge, and keep infants on track for normative feeding progression.

Session 6: Shifting our Focus in Pediatric Feeding Toward a Compassionate Lens

Marsha Dunn Klein OTR/L, Med., FAOTA

Marsha Dunn Klein is an occupational therapist who has specialized in pediatric feeding for over 50 years. She has co-authored <u>Prefeeding Skills</u>, First and Second Edition , <u>Mealtime Participation Guide</u> and <u>Homemade Blended Formula</u> with Suzanne Evans Morris, and <u>Feeding and Nutrition for the Child with Special Needs</u> with Tracy Delaney and authored <u>Anxious Eaters</u>, <u>Anxious Mealtimes</u>: <u>Practical and Compassionate Strategies for Mealtime Peace</u>. She has also been a clinician, a clinician owner, an inventor of the Duospoon ® and TeetherHeart®. She is cofounder of a Nourish, a non profit in support of families whose children have feeding challenges in southern Arizona, and cocounder of the Get Permission Institute. Marsha considers herself a food celebrator.

Financial: Receives compensation from Mealtime Connections, LLC of which she is a founding member. Receives royalties from Duospoon and TeetherHeart with Special Supplies. Is the co-founder of Get-Permission Institute.

Non-financial: Is a Feeding Matters founding member.

Learning Objectives:

- 1. List four evidence-based benefits of family mealtimes
- 2. Describe both parent and child roles at the mealtime
- 3. List four international organizations in support of responsive feeding
- 4. List the negative influence of pressure, stress and discomfort on mealtimes
- 5. Contrast internal vs external motivation in pediatric feeding.

<u>Presentation Summary:</u> Pediatric feeding is an advanced practice skill in multiple professions. Clinicians have traditionally sought out information about normal development, the anatomy and physiology of eating and specialty topics such as lactation and breast feeding, oral motor skill training, sensory and learning theory, and feeding skill

training. These are all important foundations for being a feeding professional. This presentation will challenge the audience to expand and shift our thinking compassionately towards empathy, the mealtime over the mouth, the feeding relationship and connection, parent focused therapy, responsivity and communication, sensory and emotional safety, and mealtime peace through what we know about brain research, and a body of evidence and experience that informs these shifts.

The Feeding Matters PFD Alliance Symposium: The Power of Advocacy

Amy Delaney PhD, CCC-SLP; Amber Mieras FAC Chair; Paula Rabaey Ph.D., MPH, OTR/L; Cuyler Romeo MOT, OTR/L, SCFES, IBCLC; Erin Ross PhD, CCC-SLP

Amy Delaney is an Assistant Professor in Speech-Pathology & Audiology at Marquette University. She is the Director of the Neurodevelopmental Feeding and Swallowing Lab focusing on the identification of a norm-reference for feeding development to establish diagnostic criteria and assessment tools for the early and accurate diagnosis of pediatric feeding disorder. Dr. Delaney worked at Children's Hospital of Wisconsin for 20 years in advanced diagnostics and intervention for medically complex children with PFD and dysphagia. She is the Education Pillar Chair for Feeding Matters.

Financial: Receives a salary from Marquette University.

Non-financial: Serves as Educational pillar chair for Feeding Matters. Serves on ASHA's annual conference planning committee.

Amber Mieras is the mother of Jax, 8, and Nayeli, 4. Amber connected with Feeding Matters when Jax was an infant and she was looking for information about feeding challenges. She found a wealth of support and knowledge about feeding tubes, therapies, and connections with other families that impacted her entire family. Over the last 7 years, Amber has continued to utilize the Feeding Matters resources and support, serving as the chair on the Family Advisory Council, as a mentor with the Power of Two program, as well as presenting at the 2021 PFD Conference. Amber was an elementary school teacher, mentor, and professional development facilitator for over 16 years serving the Phoenix area as well as a small community outside of Boston. In her sparetime, she loves running and hiking, cheering on her alma-mater Arizona State University Sun Devils, and her beloved Red Sox. She loves spending time with her family, watching movies, and being outdoors.

Financial Disclosures: None.

Non-financial Disclosures: Chair of the Family Advisory Council; PFDA Support Pillar Lead; and volunteer with Feeding Matters. Amber is a parent of a child with PFD.

Paula Rabaey is Associate Professor of Occupational Therapy at St. Catherine University in St. Paul, MN. She has 30 years clinical experience in pediatric occupational therapy including early intervention, outpatient, home health, feeding, eating, and swallowing, and NICU. Dr. Rabaey's research and scholarship focuses on children with and without disabilities living in marginalized communities both in the US and abroad with a focus on feeding and mealtimes. Her current project is looking at feeding assessments used by

practitioners and the alignment with the PFD diagnosis. She is a feeding technical expert forS POON Foundation and has developed a curriculum to train caregivers in orphanages around the world to safely feed children with disabilities.

Financial: Receives a salary from St. Catherine University. **Non-financial**: Serves as a member of AOTA, WFOT, and SSO-USA.

Cuyler Romeo MOT, OTR/L, SCFES, IBCLC has developed a broad clinical understanding of the needs of families and children by serving as an Occupational Therapist and industry expert in pediatric feeding disorder for over 20 years. As the Director of Strategic Initiatives at Feeding Matters, she assists in developing and executing a strategic plan to bring about system wide change for families struggling with pediatric feeding disorder. She utilizes her clinical understanding and leadership expertise to collaborate with constituents in identifying, tracking, and assessing innovative solutions to system problems.

Cuyler also has extensive experience facilitating strategic partnerships and aligning diverse groups of people under a common goal. She designed and executed a state-wide multidisciplinary mentorship program, launched a Community of Practice within the American Occupational Therapy Association (AOTA) and advanced professional development through her position on AOTA's Commission on Continuing Competence and Professional Development (CCCPD). Prior to joining Feeding Matters, she served as a founding partner of a feeding specialty clinic, Mealtime Connections, and rectified system issues on a broader scale as the Director of Clinical Innovation at Therapy 2000. She also treats clinically as a feeding specialist at Banner University Medical Center-Tucson in a Level 3 NICU and speaks professionally.

Financial: Receives a salary from Feeding Matters. Receives hourly compensation from Banner University Medical Center Tucson.

Non-financial: Cuyler Romeo facilitates AOTA's Mealtime Occupation: Feeding, Eating and Swallowing Community of Practice and is an appointed member of the Commission for Continued Competence and Professional Development (CCCPD). She serves on the Board of Directors for the Institute of Perception-Action Approach and is a member of the National Perinatal Association's Interdisciplinary Workgroup and Dissemination Committee. She is a member of AOTA, ArizOTA, and IAPFS.

Erin Ross received her Ph.D from the University of Colorado in 2007, followed by a 2-year Post-Doctoral Fellowship in the Section of Nutrition at the University of Colorado Denver. Her Master's Degree is in Speech and Language Pathology, from California State University Stansilaus, which she received in 1988. Dr. Ross is currently an assistant clinical professor in the Department of Pediatrics, School of Medicine, University of Colorado and is on faculty at the Rocky Mountain University of Health Professions. She has authored several book chapters and publications related to feeding preterm infants, infants with medical comorbidities, and children with pediatric feeding disorder (PFD). Dr. Ross provides clinical consultation to several NICUs within the HealthONE system in Denver, in addition to providing professional education and research consultation through Feeding

Fundamentals. She created SOFFI®, a training program for caregivers in the NICU and in Early Intervention.

Financial: Receives a salary from Feeding FUNdamentals. Is a speaker for Toomey & Associates. Is a consultant for Gerber Foods and Intertek.

Non-financial: Chair of the Advocacy Committee with Feeding Matters.

Learning Objectives:

- 1. Define advocacy and identify at least 2 methods for identifying key advocacy needs within a community.
- 2. Identify 2 opportunities for change in any one of the 4 domains of PFD within their own communities.
- 3. List at least 3 resources to leverage for system wide change in pediatric feeding disorder.

Presentation Summary: What is advocacy? What is the best method of advocating for change in a complex healthcare system? As an expert in system advocacy, Feeding Matters and the PFD Alliance Pillar Leaders will unite to bring your voice to the advocacy table. Together we will dive into the Feeding Matters' Advocacy Agenda and explore options and choices for next steps in advancing the system of care for children with pediatric feeding disorder. Each PFD Alliance Pillar, Education, Advocacy, Research and Family Support, will share a key lesson from the advocacy playbook enabling community members to leave ready to speak for anyone in the PFD community who needs their voice elevated.

During this unique live event participants will have the opportunity to share challenges and generate ideas through dynamic real-time interaction with other participants, leadership, and families. Participants will leave armed with new ideas and renewed motivation to move the system of care for PFD towards a brighter future.

Break

Session 7: Feeding Therapy and Psychology Co-treatments in Children with PFD

Jenna Mathews MOTR/L; Lina Patel Psy.D

Jenna Mathews is a licensed occupational therapist and the Occupational Therapy Program Coordinator for the Swallow Disorders Clinic at Children's Hospital Colorado. She is also a lactation consultant and specializes in evaluation and treatment of pediatric feeding and swallowing. She has been treating children with a wide range of diagnoses where eating is impacted for over seven years.

Financial: Receives a salary from Children's Hospital of Colorado.

Non-financial: None.

Lina Patel is an Assistant Professor of Child and Adolescent Psychiatry at the University of Colorado School of Medicine, practicing at Children's Hospital Colorado. She is the Director of the Down Syndrome Behavioral Health Collaborative, a virtual clinic providing tele behavioral health services to children, teens and young adults with Down syndrome. She provides consultation with schools, parent training regarding the management of challenging or unsafe behaviors, toilet training, and desensitization to medical devices (such as hearing aids and CPAP) and procedure-related distress. Lina has worked with hundreds of individuals with Down syndrome. Outside of her clinical work, she conducts research as the Director of Neurodevelopmental, Behavioral and Cognitive Assessment at the Linda Crnic Institute for Down Syndrome. Additionally, she has presented to numerous organizations across the country and internationally and is the coauthor "Potty Time for Kids with Down Syndrome: Lose the Diapers, Not Your Patience".

Financial: Receives a salary from Children's Hospital of Colorado.

Non-financial: None.

Learning Objectives:

- 1. Recognize the potential for improved outcomes with a cotreatment feeding therapy approach for certain children with PFD.
- 2. Identify specific strategies for addressing feeding difficulties from both the psychologist's and the feeding therapist's perspective.
- 3. Compare and contrast the effectiveness of in-person sessions versus telehealth sessions for children with PFD and behavioral challenges.

<u>Presentation Summary</u>: This presentation will discuss an innovative, successful cotreatment model between occupational therapy and psychology. The program targets children with Pediatric Feeding Disorder (PFD), developmental disabilities, and who have had little success with traditional feeding therapy models. We will share patient outcomes, therapy strategies, and the importance of cross-discipline collaboration.

Session 8: Training Professionals in Family Centered PFD Care: What Works Well, and Future Findings

Jeanne Marshall B. Sp. Path, PhD; Madeline Raatz B. Sp. Path, PhD; Elizabeth Ward B. Sp. Thy(Hons), PhD, FSPAA

Jeanne Marshall is a speech pathologist with expertise in paediatric feeding and swallowing. She is currently employed in a conjoint role between Children's Health Queensland Hospital and Health Service and The University of Queensland. Her research interests include paediatric feeding disorders and dysphagia, telepractice, education, and

simulation. Jeanne also has a passion for research translation and building research capacity in the health workforce.

Financial: Receives a salary from the Children's Health Queensland and The University of Queensland as a conjoint Clinical Research Fellow (Speech Pathology). **Non-financial:** None.

Madeline Raatz is a clinician-researcher based in Queensland, Australia. She has almost 10 years' experience working with children with pediatric feeding disorder across both community and hospital settings and she is currently employed at the Queensland Children's Hospital and Logan Hospital. In 2021 she completed her PhD at The University of Queensland investigating the feasibility and reliability of using telepractice to provide pediatric feeding assessments. Her current clinical and research interests include pediatric feeding, speech pathology, telehealth and workforce education.

Financial: Receives a salary from Children's Health Queensland and Metro South Hospital and Health Services as a speech pathologist.

Non-financial: Is an honorary fellow of the University of Queensland.

Elizabeth Ward's research program in the field of speech pathology has been the assessment and rehabilitation of the motor functions of swallowing, speech and voice. She currently holds a joint position as the Director of the Centre for Functioning and Health (CFAHR: www.health.qld.gov.au/cfahr), Queensland Health, and is a conjoint Professor with the School of Health and Rehabilitation Sciences, The University of Queensland. She has published extensively during her career, with over 400 publications. Elizabeth has received \$3.8 million in competitive grant funding in the past 5 years across a number of research fields including dysphagia assessment and management, telehealth, head and neck cancer care, motor speech disorders, simulation training, and the implementation of new models of allied health care. Her research has a clinical focus with particular emphasis on projects designed to improve speech and swallowing outcomes in a broad range of surgical and neurogenic populations. She has been awarded multiple UQ teaching awards and has supervised students to successful completion of their research higher degree. In 2014 she was awarded the title of Fellow of Speech Pathology Australia in recognition of her contributions to the profession.

Financial: Receives a salary from Metro South Hospital and Health Service and The University of Queensland. Director of the Centre for Functioning and Health Research (CFAHR), Metro South Hospital and Health Service.

Non-financial: None

Learning Objectives:

- 1. Recognize the importance of both theoretical and practical learning opportunities.
- 2. Summarize the benefits and challenges of different training modalities presented.
- 3. Consider the application of different learning opportunities to personal context and workplace.

<u>Presentation Summary</u>: Pediatric Feeding Disorder is not rare, but many clinicians feel under confident, and this affects service delivery. Further training is needed. This presentation will describe learning solutions researched by our interdisciplinary team, designed to support clinicians with theoretical and practical skill development, in both inperson and virtual modalities.

Reckitt/Mead Johnson Lunch-time Chat with Guest Speaker (no credit hours earned)

Session 9: Improving Access to Care Through an Interdisciplinary Feeding Group for Caregivers

Sonia Trejo OTD, OTR/L, SWC; Vasni Briones MA, LCSW

Sonia Trejo is an Assistant Professor of Clinical Occupational Therapy at the University of Southern California. She is a bilingual, licensed pediatric occupational therapist and the coordinator of an interdisciplinary feeding assessment clinic within a specialty mental health program at Children's Hospital Los Angeles. She specializes in working with children with feeding challenges and enjoys educating and collaborating with professionals and families alike to best support a child (and their family) in their eating journey. Sonia received her Bachelor's, Master's, and Doctorate of Occupational Therapy degrees from the University of Southern California. She also has her Advanced Practice in Swallowing Assessment, Evaluation, and Intervention in California.

Financial: Receives a salary from the University of Southern California.

Non-financial: Is a member of AOTA Mealtime Occupations: Feeding, Eating, and Swallowing Community of Practice and a member of the Feeding Matters Southern California Community Council.

Vasni Y. Briones is a Licensed Clinical Social Worker with a Master's degree in Social Work from University of Southern California (USC) with an emphasis in children, youth and families. Vasni has over 10 years of experience working with children and families. She currently works with the Child and Family division of Children's Hospital Los Angeles (CHLA)/University of Southern California University Center for Excellence in Developmental Disabilities (USC-UCEDD). Vasni has developed a special interest in working with children and their families that need feeding related support. Since then, she has collaborated with other disciplines, including occupational therapists, in individual, group, and collateral formats to support children with feeding difficulties.

Financial: Receives a salary from Children's Hospital of Los Angeles.

Non-financial: None.

Learning Objectives:

- 1. List 2 caregiver group topics to support families and their children with feeding difficulties.
- 2. Identify 1 barrier to group participation and 1 strategy to support participation.
- **3.** Identify 1 positive outcome of group participation as reported by caregiver participants.

<u>Presentation Summary</u>: This presentation will discuss a virtual caregiver group approach to help support families and their children with feeding difficulties. Topics to be presented include a review of group structure and content, lessons learned, and future considerations. Group participant perspectives will also be shared, including caregiver impressions and feedback.

Session 10: The Healthcare Burden of Pediatric Feeding Disorder: What hurts the kids hurts the system

Dr. Nikhila Raol MD, MPH

Nikhila Raol is an Associate Professor of otolaryngology-head and neck surgery and health services researcher at Emory, as well as a pediatric otolaryngologist at CHOA. She completed her medical education at the University of Texas southwestern medical center and her otolaryngology training at Baylor college of medicine. She then completed her pediatric otolaryngology training at the Massachusetts eye and ear infirmary, during which time she obtained her Master of Public Health degree at the Harvard T. H. Chan School of Public Health. Her primary research and clinical interests center on the management of children with pediatric feeding disorder and obstructive sleep apnea. When she's not obsessing about how other people's kids eat and sleep, she obsesses over how her three kids and husband and dog eat and sleep. She and her family also love spending time reading, rooting on their favorite sports teams, and enjoying the outstanding Atlanta performing arts scene.

Financial: Receives a salary from the Children's Healthcare of Atlanta.

Non-financial: None.

Learning Objectives:

- 1. Recognize the system level healthcare burden created by PFD.
- 2. Describe barriers to improving cost and utilization associated with PFD.
- 3. Identify potential solutions to decreasing the population level burden of PFD.

Presentation Summary

The healthcare burden associated with pediatric feeding disorder is significant and continues to climb. The cost of temporizing and treating PFD is immense and warrants further expediency in researching and addressing this condition. Systematic and early intervention may be key in decreasing the cost and utilization of PFD.

Break

Session 11: Session 11: Progress in Pediatric Feeding Disorder: Collaborative Approach with Physical Therapy

Laura Loveless MS, CCC-SLP, BCS-S, CLC; Heather Greene MS, CCC-SLP, CLC, CBIS; Karen L. Crilly PT, DPT, MAPT, CBIS

Laura Loveless is a speech language pathologist working primarily with infants and children with feeding and swallowing disorders. She practices in a variety of pediatric settings including acute care, NICU, outpatient, and group feeding therapy programs in addition to performing video fluoroscopic evaluations of swallowing. Laura is a Board-Certified Specialist in Swallowing and Swallowing Disorders. Her clinical interests include feeding and swallowing disorders related to a variety of diagnoses including prematurity; cleft lip/palate; cerebral palsy; genetic disorders; oral-motor disorders; as well as gastrointestinal, cardiac, and airway concerns. Laura is passionate about supporting families and assisting children in working towards achieving their potential with oral feeding.

Financial: Receives a salary from the Texas Children's Hospital.

Non-financial: Is a volunteer on the Feeding Matters Pre-Conference Committee.

Heather Greene is a speech-language pathologist at Genesis Health System. She has experience working with children ages birth to 21 years of age in early intervention, NICU, inpatient and outpatient clinical settings, as well as experience completing pediatric videofluoroscopic swallow studies. Her clinical interests include pediatric feeding/swallowing disorders, acquired brain injury and tracheostomy/ventilator dependent.

Financial: Receives a salary from the Genesis Health System.

Non-financial: Is a volunteer for the Dysphagia Outreach Project and Feeding Matters.

Karen Crilly is a Doctor of Physical Therapy who has dedicated her professional life to forming a strong background and expertise in the assessment and treatment of infants and children with chronic and complex developmental and/or neuro-motor impairment. She possesses extensive experience in a great variety of pediatric areas, among them are pediatric outpatient, home health, early intervention, pediatric aquatic therapy, school systems, sensory gyms, pediatric acute care at Level I trauma hospital/NICU Level 4 and pediatric in-patient rehabilitation. She also serves as a National Instructor for Summit Professional Education covering pediatric neurodevelopmental topics. Above all, Karen is a strong advocate for patients' rights and safety, educating and assisting the families to find the resources needed to allow their child to succeed. She takes great care in the day-to-day management of her patients, encouraging her patients to participate actively in their healthcare, with the purpose of seeking and providing opportunities for learning and help

the children reach their maximum potential. She is a patient, caring therapist who believes that each child must be given the opportunity to develop to his/her fullest gross motor potential. When assessing and treating children she looks at the child as a whole and incorporates all areas of development to promote functional movement and growth in a child. She has worked with a great variety of diagnoses including but not limited to the following: Cerebral Palsy, Down's Syndrome, Torticollis, Developmental Delay, Neurological Disorders, Sensory Integration, Orthopedic Issues, Prematurity, Cognitive Delays, Seizures, Hypotonia/Hypertonia, Arthrogryposis, Hydrocephalus, Visual/Hearing Impairments, Traumatic Brain Injury, Genetic/Trisomy Disorders, Spinal Cord Injury, Brachial Plexus Injury, Toe Walking, Coordination/Balance Deficits, Postural Imbalance, Congenital Amputations, Congenital Club Feet, Microcephalus, Hypoxic ischemic encephalopathy (Birth Trauma). Her current research interest is in the developmental of new treatment strategies for the pediatric neurorehabilitation of the child with chronic and complex conditions.

Financial: Receives a salary from the Texas Children's Hospital. Receives royalties from Summit Professional Education for seminars delivered as an instructor.

Non-financial: Is a board member of BalletForte Ballet Company.

Learning Objectives:

- **1.** Identify 3 ways gross motor development correlates to feeding and swallowing skills.
- **2.** Recognize 3 ways collaboration with a physical therapist can improve feeding-swallowing outcomes.
- **3.** Review and apply newly learned knowledge/strategies from evidence-based interventions to presented case studies.

<u>Presentation Summary</u>: Interdisciplinary collaboration is key in providing adequate assessment and developing a treatment plan for children with PFD. This session reviews how gross motor development correlates to feeding-swallowing skills and outlines how building working relationships between SLPs and PTs can lead to improvements in prognosis prediction and overall feeding swallowing outcomes.

Session 12: PFD Beyond Preschool: Preparing Parents and Providers for What's Next

Presented by the Family Advisory Committee: Dana Kizer MS, OTR/L, Amber Mieras FAC Chair; Yomi Ogedegbe and Liz Wiseman

Dana Kizer is a pediatric occupational therapist who specializes in feeding and sensory processing. She grew up accompanying her younger brother Sean to feeding therapy. Her personal experience with PFD over many years inspired her to pursue occupational therapy to help other families navigate the complex world of feeding disorders.

Financial: Receives a salary from Texas Children's Hospital.

Non-financial: Serves on the Feeding Matters Family Advisory Committee. Dana is a sibling of a young adult with PFD.

Amber Mieras is the mother of Jax, 8, and Nayeli, 4. Amber connected with Feeding Matters when Jax was an infant and she was looking for information about feeding challenges. She found a wealth of support and knowledge about feeding tubes, therapies, and connections with other families that impacted her entire family. Over the last 7 years, Amber has continued to utilize the Feeding Matters resources and support, serving as the chair on the Family Advisory Council, as a mentor with the Power of Two program, as well as presenting at the 2021 PFD Conference. Amber was an elementary school teacher, mentor, and professional development facilitator for over 16 years serving the Phoenix area as well as a small community outside of Boston. In her spare time, she loves running and hiking, cheering on her alma-mater Arizona State University Sun Devils, and her beloved Red Sox. She loves spending time with her family, watching movies, and being outdoors.

Financial: None.

Non-financial: Chair of the Family Advisory Council; PFDA Support Pillar Lead; and volunteer with Feeding Matters. Amber is a parent of a child with PFD.

Yomi Ogedegbe is mom to Joshua and Joanna. Joshua (7) has had feeding challenges since he was 2 and was recently diagnosed with oral dysphagia. He is currently in feeding therapy and we still have a long journey ahead but he is gradually making incremental progress.

Financial: None.

Non-financial: Is a member of the Feeding Matters Family Advisory Committee. Has a child with PFD.

Liz Wiseman Smith is a parent of two amazing children. She is passionate on all issues related to pediatric feeding disorder. She hopes she can use her own experience to help other parents and practitioners. When not planning new foods to introduce to her kiddo, Liz is a working professional.

Financial: None.

Non-financial: Is a member of the Feeding Matters Family Advisory Committee. Has a child with PFD.

Learning Objectives:

- 1. Identify 3 common transitions that families face with older children who have PFD.
- 2. Compare and contrast differences that affect younger vs older children with PFD.
- 3. Summarize at least two key challenges faced by parents and providers who have/work with older children who have PFD.

<u>Presentation Summary</u>: In this session participants will get a comprehensive firsthand account of how pediatric feeding disorder manifests and changes throughout the child's lifespan. A panel of parents and professionals from the Family Advisory Committee will outline their experiences with PFD; show videos and first-hand accounts from children; and share considerations for navigating PFD as it matures and changes with the child.