

THE HISTORY OF PEDIATRIC FEEDING DISORDER

Defining PFD

Pediatric feeding disorders lacked a universally accepted definition. A unifying diagnostic term, “pediatric feeding disorder” encompassing medical, nutrition, feeding skill, and psychosocial domains was proposed in “Pediatric Feeding Disorder: Consensus Definition and Conceptual Framework”.



[Consensus Paper](#)

In 2014, Feeding Matters’ Founder and Emeritus board member, Shannon Goldwater, envisioned pediatric feeding disorder as a stand-alone diagnosis, recognizing that the absence of a universally accepted term was the root cause of the system issues that failed her children and many more. Because these children were seen as having symptoms instead of a disorder, there was no comprehensive system in place that included collaborative care, qualified providers, proper insurance coverage, or an educational path to become a qualified feeding therapist.

In 2015, Feeding Matters’ Council approved the initiative to create a definition and identity for pediatric feeding disorders. They began the work to convene a consensus meeting on the disorder, publish a consensus paper, advocate for a diagnostic code within the ICD, and disseminate the information to the healthcare community.

FROM OUR FOUNDER

“Nineteen years ago, my triplets were born 14 weeks prematurely. Feeding them was terrifying and a constant challenge. They would cough, choke, gag, and vomit at every meal, and they eventually required feeding tubes to survive.”

My family’s experiences inspired me to envision a world where all children would be evaluated early and appropriately diagnosed with pediatric feeding disorder (“PFD”) -- rather than be dismissed or treated as a symptom of a different problem.”

Shannon Goldwater

*Feeding Matters Founder and
Emeritus Board Member*



In March 2016, Feeding Matters gathered in Arizona with over 17 experts from around the world to determine a name, definition, and diagnostic criteria for pediatric feeding disorders. This pivotal meeting led to two years of collaborative work to write and publish the paper, “Pediatric Feeding Disorder: Consensus Definition and Conceptual Framework” in the January 2019 Journal of Pediatric Gastroenterology and Nutrition.

The Call for a Code

Once the consensus paper was published, Feeding Matters initiated an advocacy campaign for PFD to become a stand-alone diagnosis in the United States ICD manual. In the United States, the Centers for Medicare and Medicaid Services (CMS) and the National Center for Health Statistics (NCHS) monitor, update, and provide the guidelines for coding and reporting using the International Classification of Diseases, 10th Revision, or ICD-10⁵. The American Academy of Pediatrics partnered with Feeding Matters’ lead authors and Feeding Matters’ past Medical Director, Dr. Phalen to present a proposal for pediatric feeding disorder to receive its own diagnostic ICD code at the U.S. Centers for Disease Control and Prevention (CDC) hearings in September 2019 and March 2020. By being present at both meetings, Feeding Matters ensured the patient voice was represented. Feeding Matters worked closely with professional associations and a coalition to publicly support the proposal in letters of support during the public commentary period for the ICD updates.

On August 20th, 2020, Dr. Phalen contacted Feeding Matters to share that the pediatric feeding disorder ICD code was approved and was to be included in the United States-ICD-10 in October 2021. In just 5 short years, Feeding Matters successfully served as the catalyst to the publication of the stand-alone definition and diagnosis of PFD – a condition so many before us have merely dismissed as a symptom of a different problem.

FROM DR. PHALEN

The current prevalence of PFD in children under the age of five reinforces the critical need for effective public health strategies that promote earlier identification and referral to appropriate specialists for treatment,” said James A. “Jaime” Phalen, MD, FAAP, former Medical Director of Feeding Matters and lead author of Request for ICD-10-CM Code, which he presented to the CDC.

“The establishment of these diagnostic codes is a critical next step in supporting pediatricians, caregivers, families and a child’s entire interprofessional network as they determine best options while managing the evolving financial complexities of the PFD journey,” Dr. Phalen concluded. His article “New ICD-10-CM Code for Pediatric Feeding Disorder” will appear this fall simultaneously in the AAP Coding Newsletter and the AAP News.

Resources



[PFD ICD-10 Toolkit](#)



[When to Refer Infographic](#)



[ICFQ 6 Question Screener](#)