



feeding matters

WHO WE ARE

Established in 2006, Feeding Matters is the first organization in the world uniting the concerns of families with the field's leading advocates, experts, allied healthcare professionals, and the community at large to improve the system of care for pediatric feeding disorder through advocacy, education, support, and research.

Defined as impaired oral intake that is not age-appropriate and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction, pediatric feeding disorder is estimated to affect more than 2.3 million children under the age of 5 in the United States¹.

For these children, eating, drinking, and swallowing are painful and frightening – ultimately affecting their behavioral, physical, emotional, and cognitive development. Yet, there is no functional system of care for PFD locally, nationally, or internationally.

MISSION

Furthering advances in pediatric feeding disorder by accelerating identification, igniting research, and promoting collaborative care for children and families.

VISION

A world in which children with pediatric feeding disorder will thrive.

VALUES



Innovation.

We are partners in the latest developments to advance the research and treatment of pediatric feeding disorder.



Credibility.

We combine practical experience with a deep knowledge of the medical, social, and personal impacts of pediatric feeding disorder.



Collaboration.

We work with healthcare professionals, families, and the community to ensure all facets of pediatric feeding disorder are addressed.



Determination.

We are deeply committed to promoting awareness and understanding of pediatric feeding disorder and its impact on people's lives.



Understanding.

We provide perspective, context, and compassion for the children, families, and healthcare professionals impacted by pediatric feeding disorder every day.

¹ Manikam R, Perman JA. Pediatric feeding disorders. *J Clin Gastroenterol.* 2000;30(1):34-46. Reau NR, Senturia YD, Lebailly SA, Christoffel KK. Infant and toddler feeding patterns and problems: normative data and a new direction. *Pediatric Practice Research Group. J Dev Behav Pediatr.* 1996;17(3):149-153.



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OUR HISTORY

Inspired by their newborn triplets' struggle to eat, Shannon and Bob Goldwater founded the Parent Organized Partnerships Supporting Infants and Children Learning to Eat (P.O.P.S.I.C.L.E.) Center in 2006 to help children with feeding disorders and create a support system for families. Born 14 weeks early, and each weighing a little over one pound, the Goldwater triplets spent their first four months in the neonatal intensive care unit (NICU). Once released, each child struggled to eat, and all would choke, cough, and gag during mealtimes. Eventually, each of the triplets would need a feeding tube to survive.

Feeding Matters has accomplished a great deal since its inception as P.O.P.S.I.C.L.E. Center in 2006. We remain committed to uniting the healthcare community with families in order to improve care for children with pediatric feeding disorder (PFD). We remain devoted to continuously seeking innovative ways to reach the children who need us most.

2006



The Goldwaters establish the P.O.P.S.I.C.L.E. Center and provide the initial seed funding

Founding Medical Professional Council created

2007



Monthly parent support groups begin

2,700+ hours are donated by four parent volunteers

2009



Offered first educational webinar, which focused on the importance of a team approach in caring for children with PFD

2011



P.O.P.S.I.C.L.E. Center wins both the Investee and Mentor's Choice Awards at Social Venture Partners of Arizona's inaugural Fast Pitch event, a prize totaling \$122,500 towards building the capacity of the organization

2013



P.O.P.S.I.C.L.E. Center is rebranded as Feeding Matters, though the organization's purpose remains the same—making a better world for children with PFD

2015



Over 600 people attend the 4th Pediatric Feeding Conference, both virtually and in person, representing ten countries and a wide variety of disciplines.

2017



Pilot research showing that a subset of Feeding Matters' Infant and Child Feeding Questionnaire (ICFQ) significantly distinguishes a pediatric feeding disorder is published in the *Journal of Pediatric Gastroenterology and Nutrition*

2008

8 feeding experts gather for the first official meeting of the Founding Medical Professional Council. The group identifies the importance of a screening tool, and members begin work on what will eventually become the flagship Infant and Child Feeding Questionnaire®

Expanded focus on national outreach, community advocacy and awareness, and developing educational activities for both parents and professionals

Co-hosted the Pediatric Feeding Disturbances Conference

2010



Launches ten-month series of educational workshops for healthcare professionals and families

Formed the Community Advisors Board

The Medical Professional Council develops the Infant and Child Feeding Questionnaire

2012



The initial parent support groups evolve into the Power of Two mentoring and support program. This expanded capacity allows families worldwide to begin receiving the help and hope they need

2014



The Virtual Health Resource Platform launches on the new Feeding Matters website, allowing worldwide access to the Provider Directory, video libraries, and other digital educational resources.

2016



Work begins on the pediatric feeding disorder Advocacy and Early Intervention Model (AIM), Feeding Matters' model that will transform the system of care for children nationwide.

Internationally renowned feeding experts begin to define the scope and definition of pediatric feeding disorder.

2018

The groundbreaking consensus paper declaring pediatric feeding disorder (PFD) the unifying name and stand-alone diagnosis for the broad spectrum of pediatric feeding struggles is accepted for publication in the *Journal of Pediatric Gastroenterology and Nutrition*

Launched three-year, \$3 million Power of a Name campaign supporting the widespread acceptance and awareness of PFD

HELP MAKE HISTORY, VISIT [FEEDINGMATTERS.ORG](https://feedingmatters.org)



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WHAT IS PFD?

Feeding is an intricate combination and coordination of skills. It is the single most complex and physically demanding task an infant will complete during the first few weeks, and even months, of life. A single swallow requires the use of 26 muscles and 6 cranial nerves¹ working in perfect harmony to move food and liquid through the body. When one or more pieces of the feeding puzzle are missing, out of order, or unclear, infants and children can have difficulty eating and drinking.

Pediatric feeding disorder (PFD) is impaired oral intake that is not age-appropriate and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction. Conservative evaluations estimate that PFD affects more than 2.3 million children under the age of 5 in the United States² each year. For these infants and children, every bite of food can be painful, scary, or impossible, potentially impeding nutrition, development, growth, and overall well-being.

To improve the system of care for these kids, Feeding Matters began work in 2014 to identify and define a universally accepted name and stand-alone diagnosis for the broad spectrum of pediatric feeding struggles. Initially treated as a symptom of over 300 other conditions –such as autism, cerebral palsy, and cystic fibrosis– previous diagnostic models defined pediatric feeding struggles through a single field or specialty and failed to characterize associated functional limitations.

In March 2016, Feeding Matters gathered 18 of the world's most renowned thought leaders in pediatric feeding struggles from various disciplines to determine a name, definition, and diagnostic criteria. The result of this pivotal meeting was two years of collaboration and diligent work to write “Pediatric Feeding Disorder: Consensus Definition and Conceptual Framework.” Published by the *Journal of Pediatric Gastroenterology and Nutrition* in January 2019, the paper declares pediatric feeding disorder the unifying name and stand-alone diagnosis for the field.



1. Bass, N.H. and Morrell, R.M. The neurology of swallowing. In: M.E. Groher (Ed.), *Dysphagia, Diagnosis and Management*. Butterworth-Heinemann, Boston, MA, 1992, pp. 1-29.
2. Manikam R, Perman JA. Pediatric feeding disorders. *J Clin Gastroenterol*. 2000;30(1):34-46. Reau NR, Senturia YD, Lebailly SA, Christoffel KK. Infant and toddler feeding patterns and problems: normative data and a new direction. Pediatric Practice Research Group. *J Dev Behav Pediatr*. 1996;17(3):149-153.



A DAY IN THE LIFE: BRENDA & JAMES

Many are unaware of the impact of pediatric feeding disorder - including members of the medical community.

Here, Brenda shares her son's daily feeding schedule. James, age 3, has pediatric feeding disorder and relies on a feeding tube for his nutrition. Below is a 24-hour diary of her efforts to ensure James is properly nourished.

7:00 AM

Wake up and place James in the highchair. Although he does not currently eat any food orally, I try to instill a sense of normalcy related to mealtimes. I clean, peel, cut, and blend his breakfast of Carnation Instant Breakfast, banana, and a formula base.

7:30 AM

Place blended food in a bag attached to a thin plastic tube. I connect the tube to a plastic "button" that was medically inserted into his belly. Because of the severity of his condition, his food must be inserted directly into his stomach, bypassing his mouth and esophagus.

7:45 AM

Sometimes James does not tolerate his food causing him to gag and vomit. On this particular morning, James vomits. I spend 30 min. cleaning him and the kitchen. I am deflated because he just lost so many critical calories.

10:00 AM

Administer the rest of the banana, instant breakfast, and formula mix as another tube feeding. This time he tolerates the meal! During the meal the medical supply company delivers more feeding tubes and clean "buttons."

12:30 PM

Today, James has one of his many therapy appointments. He cries as the therapist tries to help him overcome his oral aversions. Today went well and he even put the baby food to his lips! I am thrilled. During therapy I give James his blended lunch through the feeding tube.

3:00 PM

I give James another tube feeding and a round of medications in his tube. The medicines do everything from helping him combat reflux, to managing his seizures. He fights and cries again. Even though I know he needs it, it is so hard not to just let him have his way and spend this time playing instead.

5:00 PM

Out comes the blender again. Clean, cut, peel, and blend his dinner. No gagging or vomiting. He's a happy boy!

7:30 PM

James' last tube feeding while awake. Unfortunately he vomits and I need to give him another bath and change his pajamas.

9:00 PM - 7:00 AM

I wake up every so often to check that his feeding tube is safely away from his neck while he sleeps. He is on continuous feeds at night, meaning food is slowly being pumped into his tummy to ensure he gets enough calories. The bigger and stronger he gets, the less my inventions to keep the tube away from his neck seem to work. I would do anything for my precious son and I will continue to fight to ensure he receives the best care possible!



LEARN MORE AT [FEEDINGMATTERS.ORG](https://FeedingMatters.org)



FAMILY TESTIMONIALS

“Our story is 14 years in the making. We have lost everything because pediatric feeding disorder was not (and overall is still not) looked at as a severe issue. It takes an astronomical amount of money to raise a special needs child with PFD in a middle income family.”

“We sold our home, moved to a rental house and ultimately had to file bankruptcy to be able to afford for me to work part time rather than full-time and to afford my child’s weekly therapy visits. Even though I have a bachelor’s degree and professional career, I took a job as a nanny (making significantly less than I made previously) so that I could have the flexibility to take my child to therapy and to stay home with him when he was too sick to go to school. The pressure of trying to manage my full-time job while he was sick and had so many appointments was simply too much for me.”

“We have to purchase a new recliner every 6 months for safe feeding positioning that gets ruined by reflux and feeding accidents. Bed covers, bed positioning slabs, pillows every 2-3 months.”

“I am killing myself trying to work full-time to support my daughter as a single parent. My parents had to move from out of state to help, and even with them here I am exhausted from trying to coordinate supplies, therapy, and her care while maintaining full-time employment. I want to quit and give up every day, but I can’t. It is maddening.”

GIVE A GIFT, MAKE A DIFFERENCE:
[FEEDINGMATTERS.ORG/DONATE](https://feedingmatters.org/donate)





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PFD ALLIANCE



Uniting the field's leading advocates, medical experts, allied healthcare professionals, families, and more.

Feeding Matters' Pediatric Feeding Disorder (PFD) Alliance –formerly known as the Medical Professional Council– ignites unprecedented change to the system of care through shared-collective decisions, insights, and ideas. The PFD Alliance's cooperative efforts are centered on three key pillars of development: advocacy, education, and research.



ADVOCACY

Historically, pediatric feeding disorder has been significantly underserved and misunderstood. In collaboration with respected clinicians, researchers, caregivers, educators, healthcare professionals, and the community at large, the PFD Alliance facilitates global change to improve the lives of children with pediatric feeding disorder – including a stand-alone diagnosis, government awareness, and inclusive insurance coverage.



EDUCATION

For the medical and allied healthcare professionals who care for children with pediatric feeding disorder, finding higher education and certifications can be difficult. There are limited academic programs that offer courses on pediatric feeding disorder and no known specialized degrees. This leaves many of these dedicated professionals on their own to source and participate in continuing education opportunities.

Family members often find themselves serving as lead advocate for their child with PFD. As the team leader, the family requires educational support and applicable resources as they navigate the healthcare system and the community at large.

Feeding Matters and its PFD Alliance are committed to providing the expert knowledge, resources, and education required to deliver collaborative care and improve health outcomes, including the International Pediatric Feeding Disorder Conference and an on-demand learning center.



RESEARCH

A lack of longitudinal, evidence-based data and the diverse nature of pediatric feeding disorder have often been cited as barriers to understanding the individualized needs of children with PFD. Feeding Matters and its PFD Alliance strive to identify, fund, and facilitate research and clinical studies that address these issues and move the field from utilizing practice-based evidence to relying on evidence-based practice.

TO CREATE CHANGE VISIT [FEEDINGMATTERS.ORG/PFD-ALLIANCE](https://feedingmatters.org/pfd-alliance)



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INTERNATIONAL PFD CONFERENCE

JANUARY 24 - 25, 2020

ENTIRELY
VIRTUAL IN
2020!

Since 2008, Feeding Matters' International Pediatric Feeding Disorder Conference (IPFDC) has been a leader in providing education for the evaluation and treatment of pediatric feeding disorder (PFD) with intermediate and advanced-level sessions from internationally renowned feeding experts, as well as a digital poster session. Held entirely virtually for the first time in 2020, and with access available on-demand for 30 days post-conference, physicians and allied healthcare professionals will receive groundbreaking access to the latest developments and research in PFD from the comfort of their home or office. Registration opens Summer 2019.

Common IPFDC attendees include allergists, behavior analysts, dietitians, gastroenterologists, nurses, neonatologists, occupational therapists, pediatricians, pulmonologists, psychologists, speech and language pathologists, and students.

	<i>Early Bird Rate:</i> Before October 1	<i>Standard Rate:</i> After October 1
Community Members	\$99	\$149
Healthcare Professionals	\$199	\$249
Physicians	\$249	\$299



LEARN MORE AT [IPFDC.ORG](https://www.ipfdc.org)