

FEEDING MATTERS

ANNUAL REPORT
2018 - 2019



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, and allied healthcare professionals to improve the system of care for pediatric feeding disorder through advocacy, education, support, and research.

OUR VISION

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

OUR MISSION

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



2018 HIGHLIGHT

In 2018, we continued our efforts to advance pediatric feeding disorder by partnering with healthcare professionals, families, and community members. Feeding Matters is now on the precipice of changing the system of care for children and families with pediatric feeding disorder. Once that dream becomes a reality it will unlock doors to do much needed research, collaboration, insurance reimbursements for families, an education path for healthcare professionals, and system changes for families with children who suffer to eat every day. However, like any other great and lofty goal it takes time, resources, and funding to make dreams become a reality. Therefore, this year we launched our Power of a Name campaign to create sustainable impact, awareness, and acceptance of PFD. We thank you for your commitment and partnership with us as we work to make this vision a reality.

50

States
Reached

123

Countries
Reached

146,218

Individuals
Reached

Expanded Medical
Professional Council
to new PFD Alliance



2019 HIGHLIGHT

Today, very few have heard of pediatric feeding disorder but we are at a pivotal point of transformation for the PFD system in real time. In January 2019, the Journal of Gastroenterology and Nutrition published “Pediatric Feeding Disorder: A Consensus Definition and Conceptual Framework” The adoption of a unifying name and stand-alone diagnosis will be a catalyst to desperately needed systemic change, including earlier identification, qualification for early intervention, opportunities for longitudinal research on best practices, accurate classifications, pediatric feeding disorder curriculum resulting in a larger pool of trained specialists, and the potential for comprehensive insurance reimbursement. There are more than 2.3 million children under the age of five in the United States who experience severe pediatric feeding disorder annually. Yet, there is no universally accepted medical definition, diagnostic code, or system of care for pediatric feeding disorder. Feeding Matters is the first organization in the world dedicated to advancing the research, identification, and collaborative care of pediatric feeding disorder. We are excited to share our accomplishments with you and thank you for your support of this very important issue.

50

States
Reached

147

Countries
Reached

144,905

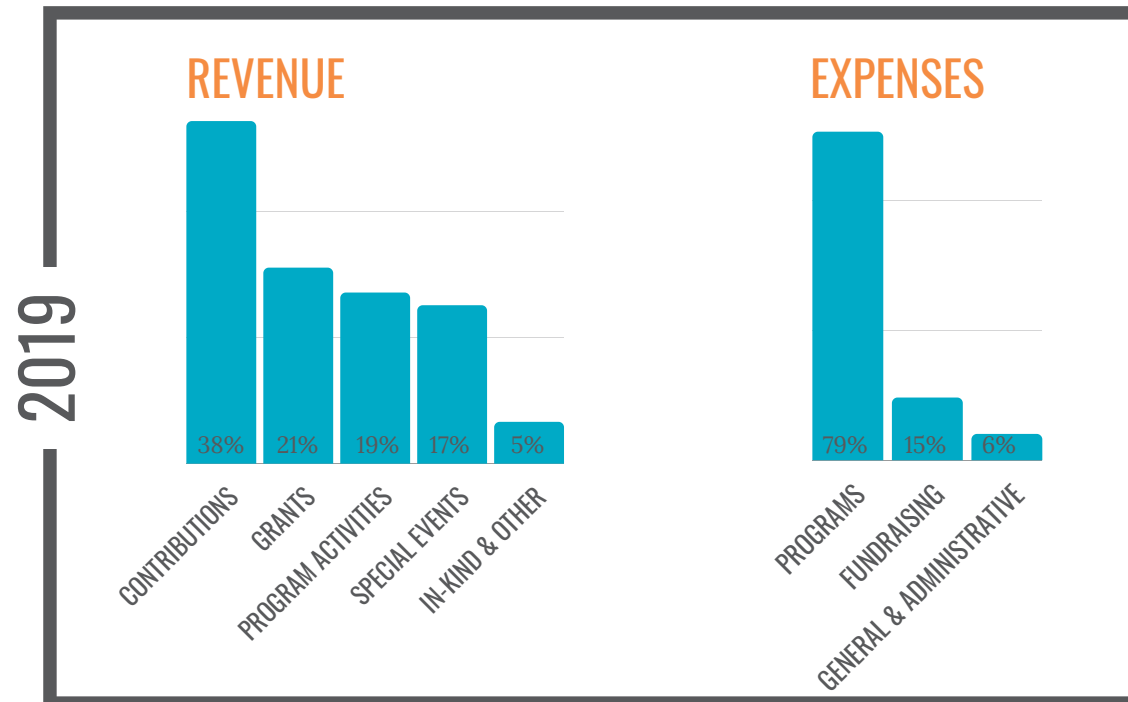
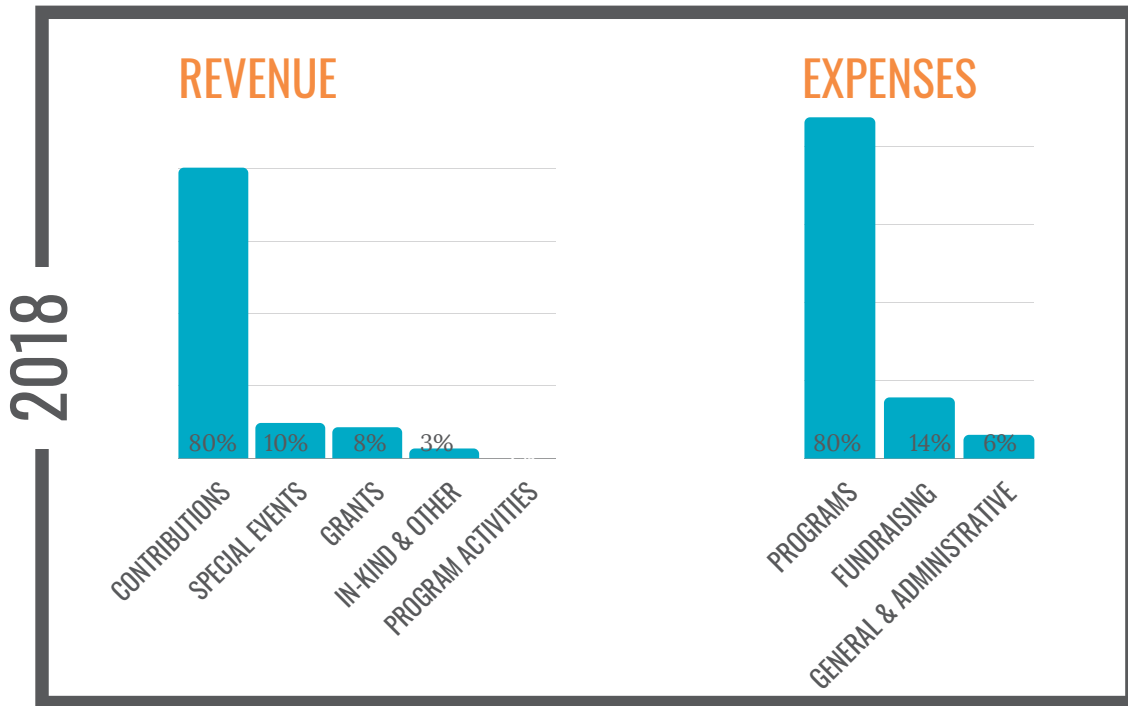
Individuals
Reached

Launched Family
Assistance Program

Held first PFD Alliance
Town Hall meetings



FINANCIAL OVERVIEW



POWER OF A NAME CAMPAIGN

We all know that during the first 3 years of life, good nutrition is crucial for children to grow, learn, and thrive. However, few people know that in the US alone, 2.3 million children under age 5 struggle to eat and drink.

Now known as pediatric feeding disorder, this condition is finally gaining name recognition. For those affected by PFD, this name will mean proper early diagnosis, standardized treatment and training for healthcare providers, adequate insurance coverage, and support. These children and families know the power of a name.

But, there's more work to do. With your donation, we will accelerate identification, ignite research, and promote collaborative care for children and families.

In 2018, Feeding Matters launched a \$3 million, 3-year campaign to maximize the efforts needed to launch, including a \$1 million gift from the Dorrance Family Foundation.

That's the power of a name.

**\$1.7
million
in 2018**

\$1,710,000 was raised in the first year of the Power of a Name campaign.

[View the report](#) from the first year of the Power of a Name campaign.

ADVOCACY AND AWARENESS

In 2019, *The Journal of Pediatric Gastroenterology and Nutrition* published a field-leading consensus paper proposing a unifying term and diagnostic criteria for the broad spectrum of pediatric feeding struggles. Unlike previous diagnostic paradigms that have typically defined feeding disorders from the perspective of a single medical discipline, “Pediatric Feeding Disorder – Consensus Definition and Conceptual Framework” uses the framework of the World Health Organization’s International Classification of Functioning, Disability, and Health to define pediatric feeding disorder (PFD) as impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction.

Facilitated by Feeding Matters, as conceived by its founder Shannon Goldwater, the consensus paper was written by an international panel of 18 pediatric feeding experts to address the lack of a universally accepted medical definition or stand-alone diagnostic code. Applying the US Census Bureau’s 2017 population estimates, early findings estimate that more than 2.3 million children under the age of 5 experience severe pediatric feeding disorder in the United States annually. [View the complete paper here.](#)

TOP 5 COUNTRIES REACHED

United States
United Kingdom
Canada
Australia
India

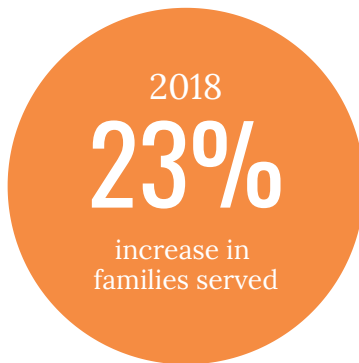
TOP 5 STATES REACHED

Arizona
California
Texas
Illinois
New York

FAMILY SUPPORT

"Just this week, we've told two of our therapists we couldn't afford to work with them as much. You don't know what this means to me and my family. It's like a prayer has been answered. Thank you thank you thank you. I am just blown away and so grateful! The day after you guys called, Owen was scheduled for a swallow study and I just feel so much better knowing we can move forward with tests and therapy. God is good." -Recipient of Family Assistance Program

BY THE NUMBERS



FAMILY SNAPSHOT

I am a mother of four children. My youngest child, Mikarah, was diagnosed with feeding difficulties, better known as failure to thrive, at about 8 weeks of age. She was born at 35 weeks and it was a pretty normal pregnancy. I breastfed, but she was not gaining weight.

The first thing doctors do is try different kinds of formula or to make the formula high in calories. In my daughter's case, she still was losing weight. We were sent to a GI doctor to get a better understanding of why she could not gain weight. She was diagnosed with aspirating and laryngomalacia, which means floppy airway. Therefore, by this time, they place an NG through her nose to go to her belly. They reinsured us as parents that she will be able to feed and get all her nutrition and she should gain weight.

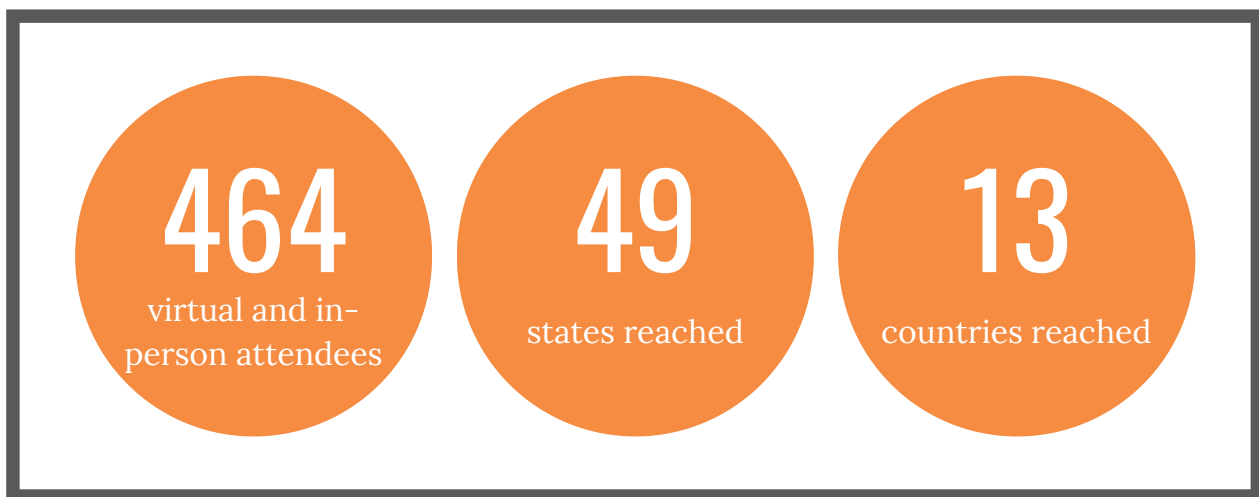
[Read the rest of Mikarah's story.](#)



EDUCATION

INTERNATIONAL PEDIATRIC FEEDING DISORDER CONFERENCE

In January of 2019, Feeding Matters hosted the 6th International PFD Conference in Arizona. With 464 virtual and in-person participants and reaching 49 states and 13 countries.



LACI: LEARNING ADVANCED THROUGH COLLABORATIVE INITIATIVES

Feeding Matters' program, the Professional Collaborative: LACI (Learning Advanced through Collaborative Initiatives) was launched in 2019. The program was a 6-month virtual learning experience for occupational therapists and speech-language pathologists in Maricopa County, Arizona. Funded by the BHHS Legacy Foundation, LACI was designed to unite professionals, mentors and mentees, as they build critical thinking skills within the context of family-centered care for pediatric feeding disorder.

Participants engaged in monthly learning activities, analyzed complex cases as a team, and received insight from families who have been impacted by PFD. [Read the report](#) from the first year of LACI.

RESEARCH

ECONOMIC IMPACT REPORT

Applying the US Census Bureau's 2017 population reports, early findings estimate that more than 2.3 million children under the age of 5 experience severe pediatric feeding disorder in the United States each year. Additional reports estimate that up to 25% of developmentally typical children and up to 80% of those with developmental disabilities have feeding problems.

Yet, there had been no studies to quantify the assorted costs, medical and otherwise, incurred by families navigating PFD. PFD is defined as impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction.

Feeding Matters' Economic Impact Study identifies the economic burden of PFD on families who have insurance. From medicines, supplies, and expert childcare to specialized education, travel to appointments, and lost time, managing PFD can come with significant economic costs to families. Furthermore, parents and caregivers – herein referred to as “caregivers” – may experience lost or decreased income due to time required for PFD care. This study describes those costs. [View the study.](#)

"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."



feeding matters

www.feedingmatters.org