



*feeding matters*

# 2017 ANNUAL REPORT

*Making A Better World For  
Children With Pediatric Feeding Disorder*



## A LETTER FROM LEADERSHIP

Over the last 11 years, Feeding Matters has worked tirelessly to be the voice for the more than 2 million infants and children navigating pediatric feeding disorder (PFD). 2017 proved to be a year of tremendous growth as we increased our reach to over 129,000 individuals worldwide, including 112 countries.

Much of 2017 was spent collaborating with families, medical and allied healthcare professionals, educators, insurance providers, government agencies, and others to continue efforts to create a functional system of care for these children. From facilitating the authorship of a consensus paper declaring PFD as its own stand-alone diagnosis to family empowerment programs and professional support initiatives, Feeding Matters is committed to our

role as a nationwide, collaborative leader to advance the field of pediatric feeding disorder.

We are grateful to everyone who is joining us in this fight to create a world in which children with pediatric feeding disorder thrive. With our unwavering commitment to making a better world for children with PFD, we will continue our work because of the support from all of you who allow us this privilege.

We thank you for your continued trust, generosity, and support.

**CHRIS LINN**  
PRESIDENT & CEO

**BRUCE WRIGHT**  
BOARD CHAIR

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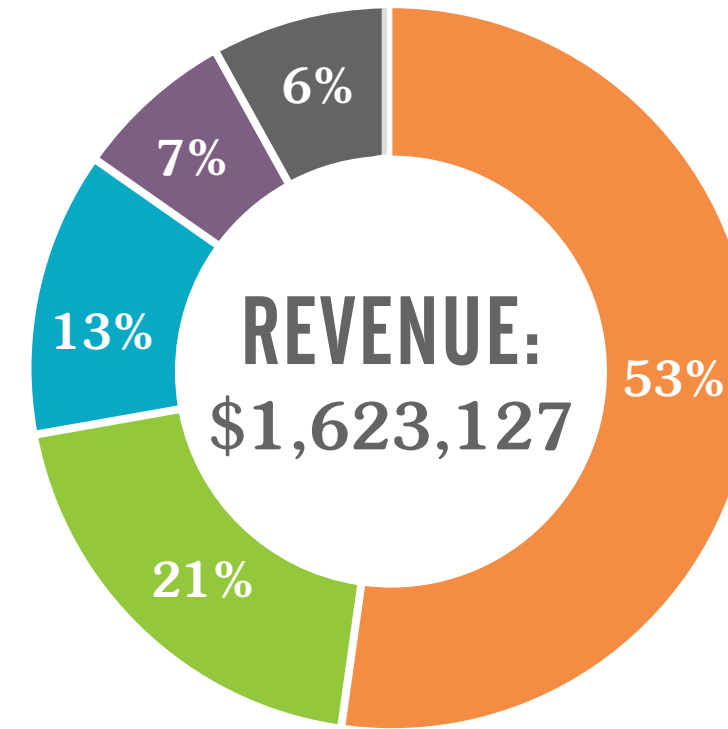
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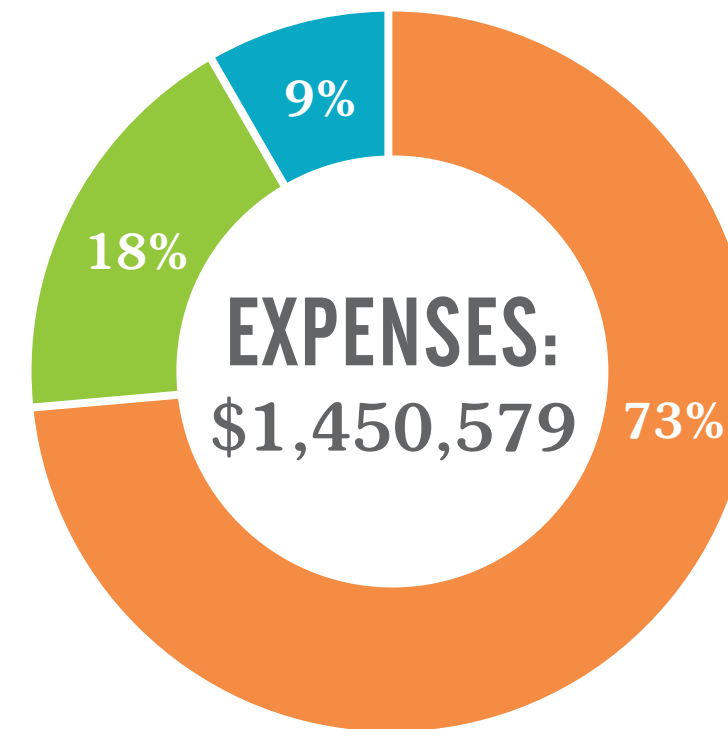
Chuck Whetstine



## 2017 BY THE NUMBERS



- grants  
\$855,050
- fundraising events  
\$339,152
- program activities  
\$208,726
- contributions  
\$112,868
- in-kind donations  
\$101,886
- other revenue  
\$5,445



- programs  
\$1,054,101
- fundraising  
\$259,855
- general & admin  
\$136,623

**NET ASSETS: \$520,435**

*“I spent over six years as an auditor and the last seven years as a consultant, working with many nonprofits in Arizona, which uncovered the challenges within the nonprofit community. My husband and I choose to support Feeding Matters each year because they are accountable, financially sustainable, transparent, ethical, passionate, and effective.”*

- Kristen French, Feeding Matters supporter and CPA



## PEDIATRIC FEEDING DISORDER

### *the power of a name*

“Pediatric feeding disorder has historically been severely underserved and misunderstood, leaving families desperate for answers when they can’t feed their child(ren). To ensure these children receive the care they deserve, families, the healthcare community, policy makers, and academia must be part of the solution to create systemic change. From the consensus paper declaring PFD as a stand-alone diagnosis to research on prevalence and curriculum on treatment, a concerted effort from leaders like Feeding Matters will be the catalyst to creating a world where children with pediatric feeding disorder thrive.”

Dr. Praveen S. Goday, MBBS, CNSC, FAAP - Consensus Paper Lead Author  
Director, Feeding, Swallowing and Nutrition Center at Children’s Hospital of Wisconsin  
Professor of Pediatrics, Medical College of Wisconsin

# PEDIATRIC FEEDING DISORDER

Applying the US Census Bureau's 2017 population estimates, approximately 51,000 children in Arizona and over 2.3 million children under the age of 5 in the United States experience severe pediatric feeding disorder annually. For these children, eating, drinking, and swallowing can be painful and frightening—ultimately affecting their behavioral, physical, and emotional development.

Yet, there is no accepted medical definition or stand-alone diagnostic code for pediatric feeding disorder locally, nationally, or globally.

This means that families navigating pediatric feeding disorder struggle to find effective evaluation and treatment while fighting to receive coverage or financial reimbursement from their health insurance. Meanwhile, doctors and allied healthcare professionals are left to source specific education on their own while battling similar funding and coverage challenges with insurance companies.

In 2017, Feeding Matters leveraged its medical professional council and many relationships to continue the facilitation of a consensus paper declaring pediatric feeding disorder (PFD) as a stand-alone diagnosis. In addition to being submitted for peer review and endorsement from the American Academy of Pediatrics (AAP) and the Centers for Disease Control and Prevention in consideration for a diagnostic code for PFD, this proposed diagnostic framework was presented at the 2017 annual conferences for the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) as well as the American Society for Parenteral and Enteral Nutrition (ASPEN).



## CHALLENGES:

- *No identified and accepted medical definition*
- *Consequently, there is no associated stand-alone diagnostic code for healthcare coverage*
- *Lack of awareness in the healthcare community*

## IMPACT:

- *Facilitated a consensus paper declaring pediatric feeding disorder (PFD) as a stand-alone diagnosis*
- *Secured PFD presentation to the Centers of Disease Control and Prevention to propose a diagnostic code for PFD (September 2018)*
- *Created a task force for dissemination of the stand-alone diagnosis and diagnostic code within the healthcare community*



## **SYSTEMIC CHANGE**

*a paradigm shift for the PFD healthcare community*

**“Medical professionals who specialize in pediatric feeding disorder are not seeing these kids early enough. Many children aren’t referred until they are 2, 3 or 4 years old. By then, they may have suffered developmental delays and their families have become extremely stressed over feeding their children.”**

Julie Barkmeier-Kraemer, PhD, CCC-SLP, ASHA Fellow  
Professor, Division of Otolaryngology - Head & Neck Surgery, University of Utah

# SYSTEMIC CHANGE

A lack of longitudinal, evidence-based data and the heterogeneous nature of pediatric feeding disorder have often been cited as barriers to understanding the individualized needs of children with PFD. To address these issues, Feeding Matters partnered with medical experts, healthcare systems executives, insurance companies, and advocacy organizations to examine and better outline the intricacies of creating an effective system of care for pediatric feeding disorder.

Take, for example, the economic impact of PFD. Over the years, families have reported spending hundreds, and sometimes thousands, of dollars on expenses related to their child's pediatric feeding disorder that is not covered or reimbursed by insurance. To fully and accurately capture the financial burden related to pediatric feeding disorder, Feeding Matters collaborated with the market research firm FirstEval to develop and manage an economic impact survey.

The results of our collaboration showed that it's more than just emotional stress that parents endure when their child has a pediatric feeding disorder. Finances continue to be the top stressors, with families managing pediatric feeding disorder spending money on extra childcare, specialty foods, and travel to therapists to receive optimal care. These significant expenditures incurred by the families navigating PFD are not well understood by the reimbursement community, creating a barrier to coverage by most insurance companies.

The data collected from the economic impact survey will be used to inform healthcare professionals and insurance companies through the Advocacy and Early Intervention Model (AIM). Piloted in Arizona, AIM strives to transform the local systems of care in communities across the US by establishing replicable norms for the identification and early intervention of PFD, as well as healthcare reimbursement for children with pediatric feeding disorder. In 2017, the AIM Arizona task force held 14 strategic meetings, 35 support meetings, and 6 meetings at the state legislature.



## CHALLENGES:

- *Lack of longitudinal research, and data on pediatric feeding disorder*
- *Inconsistencies and confusion with insurance policies, procedures, and coverage*
- *No established best practices or screening exists*

## IMPACT:

- *Established relationships with 7 national organizations that have a vested interest in longitudinal research on and evidence-based care for pediatric feeding disorder*
- *Participated in meetings with 7 prominent insurance companies*
- *Amplified work with the Advocacy and Early Intervention Model (AIM) pilot task force*



## PROFESSIONAL SUPPORT

### *developing trained specialists for PFD*

“It’s not as simple as a broken bone that you x-ray, cast, and move on. This complicated evaluation plays into discovering the best personalized treatment plan because treatment for one child or baby could be completely wrong for another, even if they are exhibiting the same symptoms. The system for treating pediatric feeding disorder causes frustration among families and healthcare professionals alike. The team at Feeding Matters has ignited an interest among healthcare professionals and experts who want to elevate the care, create better systems of care, and develop best practices for this intangible disorder.”

Dr. Matthew E. Abrams, FAAP  
Phoenix Perinatal Associates/Pediatrix Medical Group



# PROFESSIONAL SUPPORT

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.

Feeding Matters is committed to providing the expert knowledge, resources, and education required to deliver collaborative care and improve health outcomes, including the biennial International Pediatric Feeding Disorder Conference, quarterly virtual workshops, and an on-demand knowledge center. Furthermore, the Feeding Matters Medical Professional Council unites leading experts in the field with members of the healthcare community to facilitate shared-collective decisions, insights, and ideas, creating an infrastructure that provides an opportunity for broad participation in education, research, and advocacy to advance the field.

And these efforts have not gone unnoticed. In the 2017 program evaluation, 86 percent of medical and allied healthcare professionals responded that the “Feeding Matters website has given you the insight to work better with families” while 93 percent shared that “Feeding Matters is a resource to find the latest information on pediatric feeding disorder.”



## CHALLENGES:

- *Lack of medical curriculum for PFD*
- *Limited opportunities for continuing education on PFD*
- *Poor organization and communication within the PFD healthcare community*

## IMPACT:

- *Over 500 healthcare professionals from 45 states and 13 countries attended the 2017 International Pediatric Feeding Disorder Conference*
- *189 healthcare professionals participated in Feeding Matters' inaugural series of virtual workshops*
- *Explored expansion of the Medical Professional Council's education, advocacy, treatment, and research offerings*



## **FAMILY SUPPORT**

*empowering families navigating pediatric feeding disorder*

“Although our daughter’s condition is not cured as of yet, we have a treatment plan, a great team of communicative doctors and specialists in place, and are optimistic that she will be eating one day in the future. From our perspective, Feeding Matters has touched our lives with incredible family support. From community partnerships and healthcare professional outreach to advocacy and research, Feeding Matters is pioneering a change to the system of care that we are a part of daily.”

Feeding Matters Parent

# FAMILY SUPPORT

“I want to paint a picture of all the obstacles and frustrations we encountered. Constant skin rashes, some that required hospital stays. Mouth sores. Cracked and bleeding fingers. Stomach and bowel problems. Visits to multiple specialists, even going out of the state and country. Financial strain due to high deductibles and uncovered services. Being reported to Child Protective Services and the fear about what this might mean.” – Feeding Matters Parent

This cycle of abnormality is often the norm for families navigating pediatric feeding disorder and sadly, a story we hear far too often. That’s why Feeding Matters is empowering parents with information and resources such that they are supported and equipped to advocate for their child and ensure their family receives the best care possible.

Through Feeding Matters’ signature Power of Two program, families beginning their journey with PFD are matched with a seasoned parent coach who has been through a similar experience and who can offer support, resources, and guidance on the medical, emotional, financial, educational, and social issues they may face. The Virtual Health Resource Platform, including the online Provider Directory and digital Resource Library, become trusted resources for families establishing their collaborative care team.

Of the families and caregivers that participated in the 2017 program evaluation, it was reported that: 75 percent noted that FeedingMatters.org helped them learn more about PFD; 64 percent found the Feeding Matters Resource Library easy to use; and 51 percent responded that Feeding Matters has saved them time researching their child’s pediatric feeding disorder. Additionally, 73 percent felt that they had found an online community of parents who understand pediatric feeding disorder.

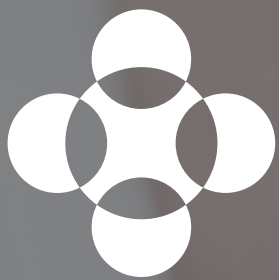


## CHALLENGES:

- *Families may feel isolated and overwhelmed*
- *Limited understanding and awareness of pediatric feeding disorder*
- *Inability to locate tools, resources, and providers*

## IMPACT:

- *120 Power of Two parent coach matches*
- *464 qualified listings in the online Provider Directory*
- *797 items in the digital Resource Library*
- *115,203 Virtual Health Resource Platform users*



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**FEEDINGMATTERS.ORG**