

2021

ANNUAL REPORT



CELEBRATING **15** YEARS

IN 15 YEARS...

392,903

INDIVIDUALS SERVED

1,123,016

INDIVIDUALS REACHED

Dear Friends of Feeding Matters,

There was much to celebrate and honor in 2021. It was our 15th year serving families and professionals and was the first official year of the new code(s) for pediatric feeding disorder. For years, the fight for recognition of this condition was tackled by the Feeding Matters team and the many volunteers and supporters who walked with us along this path.

Fifteen Years, the Crystal Anniversary. In 15 years, we went from a small Arizona-based organization with a focused mission on an unclear condition to a large advocacy nonprofit that is the first of its kind. Impacting the entire world, Feeding Matters is making it crystal clear what pediatric feeding disorder is (*#callitPFD*) and what needs to be done to ensure the organization's impact lasts for generations. This will ensure children can receive the care they desperately need.

Another thing that became crystal clear to us was the paramount need of PFD awareness. We have amazing programs for families and professionals, but we can only support those who know what PFD is and who reach out to us. We know that it is not enough, we need to do more. We need to ensure that every person knows what PFD is and is made aware of the struggle that families face (most often in secret) each day as they try to feed their children.

Arizona is our proud home and headquarters. Our local community supports these efforts and has built Feeding Matters into something Arizona can be proud of. We are establishing a global movement right here in the Valley. In the next 15 years, we hope to see better identification of PFD, more research, and even some best practices. Thank you for supporting this crystal-clear vision with us and helping us to create a better world for children with PFD.

Sincerely,



Jaclyn Pederson, MHI
CEO



Todd Pearson
Board Chair

ABOUT US

OUR MISSION

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

OUR VISION

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

OUR VALUES

COLLABORATIVE

We partner to ensure every voice is heard, ideas are openly shared, and we work towards a common goal.

INNOVATIVE

We take the initiative to leave comfort zones, embrace new ideas, and generate change.

INCLUSIVE

We lead with trust and empathy to invite and value all perspectives.

PHILOSOPHY

Families/caregivers are the lead member of the child's treatment team and should be respected in this way.

PFD may impact function in any of the four domains. A comprehensive assessment includes screening or evaluation of 1) medical, 2) nutritional, 3) feeding skill, and 4) psychosocial factors. Professionals from each domain may not be available within a single practice or institution. A comprehensive assessment and management plan often requires multiple professionals working collaboratively to support the family and child.

There are no identified best practices for intervention. This is due to the lack of longitudinal information available in the current research, and the heterogeneous nature of the population of children with pediatric feeding disorder. As a result, we believe it is critical that:

- a) a family's definition of success be incorporated into treatment planning*
- b) treatment philosophies may not be equally appropriate for all children*
- c) families should be well informed about all services that exist*

We believe multiple perspectives are necessary to create a functional system of care. This includes not only families and healthcare professionals but also partners who represent insurance companies, academia, public health, legislators, community-based service providers, and others.

2021 BY THE

117%

INCREASE IN CONFERENCE ATTENDEES

29%

GROWTH IN FAMILIES IN
THE POWER OF TWO COACHING PROGRAM

22%

GROWTH IN FAMILIES SEEKING SUPPORT
FROM FEEDING MATTERS

162,436

NEW USERS TO FEEDINGMATTERS.ORG

8,088

NEWSLETTER SUBSCRIBERS

19,046

ALL CHANNEL AUDIENCE
ON FEEDING MATTERS SOCIAL CHANNELS

750

PROVIDERS IN THE PROVIDER DIRECTORY

THE NUMBERS

609
VOLUNTEERS

1,693
HOURS

\$190,678.58
SAVED THROUGH VOLUNTEER SUPPORT

13,536
AVERAGE MONTHLY USERS
ACCESSING FEEDINGMATTERS.ORG

47
COUNTRIES ACCESSED THE
INFANT AND CHILD FEEDING QUESTIONNAIRE

756
PFD ALLIANCE MEMBERS
(DEDICATED TO ADVANCING THE PFD SYSTEM OF CARE)

4,175
UNIQUE PFD ICD TOOL KIT VIEWS

1,386
INDIVIDUALS ACCESSED THE FAMILY GUIDE

THE FUTURE OF FEEDING MATTERS

DURING 2021, FEEDING MATTERS LEVERAGED INPUT
THROUGH COMMUNITY DRIVEN CHANGE QUESTIONS
TO ITS COMMUNITY OF PARENTS, PROFESSIONALS, AND
SUPPORTERS. THIS INPUT LED THE ORGANIZATION TO
DEVELOP OUR STRATEGIC PLAN THROUGH 2026.



PFD afflicts more than 1 in 37 children under the age of 5 in the United States each year, yet the disorder is still largely unknown and misunderstood. Therefore, the next phase of Feeding Matters' plan is a focus on raising awareness of PFD by educating the healthcare community and informing the public about this often invisible disorder to support early identification.

To achieve the goal of PFD becoming a household name like other childhood conditions, Feeding Matters is focused on three interrelated activities:

DIGITAL FIRST

Spread PFD throughout digital platforms worldwide so audiences know PFD and Feeding Matters, and have the necessary resources to support their family or professional life.

COMMUNITY DRIVEN

Leverage an impassioned base of families, healthcare professionals, and community members to ensure our content, awareness, and consensus efforts are in line with the community's needs. This includes pursuing additional research in the field and supporting the early identification of PFD.

TARGETED MEDIA OUTREACH & STORYTELLING

Tell the PFD story through the media and additional means so that PFD awareness reaches those who are not directly touched by the disorder. Leverage grassroots outreach to build impactful partnerships that grow awareness with the general public.

Everything Feeding Matters has accomplished in its last 15 years has been the result of an incredible amount of passion, commitment, and collaboration from our supporters. Accomplishing this plan will be no different. Over the next several months (and years!), the Feeding Matters team will be asking for your help, but one of the most vital things you can do is to please follow us on social media and like, comment, or share to help us spread our message. This work happens because of YOU and we are excited to step into the future together.

FUTURE OF PFD

While our strategic plan focuses on PFD Awareness, Feeding Matters knows that awareness is a means to an end and remains laser focused on our vision of creating a world where children with PFD will thrive.

To achieve this mission, we are focused on the next 15 years, to create...

THE POWER OF AN IDENTIFIED DIAGNOSIS

← PRESENT STATE FUTURE STATE →

Parents often blamed

No one is blamed

Often identified too late

Earlier Identification

Limited & Inconsistent early intervention

Qualifies for early intervention

Limited public awareness

Recognized household name

Limited research on best practices for care

Longitudinal research on best practices

Often treated as a symptom or side effect

Accurately classified

Consensus on classification

Standalone diagnosis

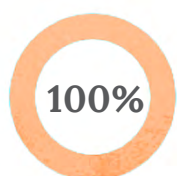
Limited medical curriculum & small specialist pool

PFD curriculum & larger specialist pool

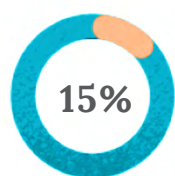
Inconsistent insurance reimbursement

Comprehensive insurance reimbursement

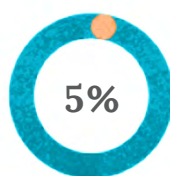
ADVOCACY AGENDA | PROGRESS TRACKER



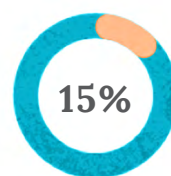
STANDALONE
DIAGNOSIS



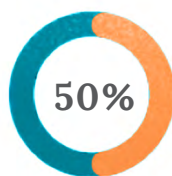
BEST PRACTICES
FOR CARE



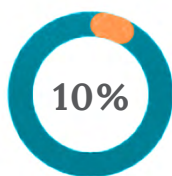
FEDERAL FUNDING
FOR PFD RESEARCH



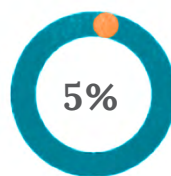
ACCREDITED PFD
SPECIALISTS



PFD SCREENING AT
WELL-CHILD VISITS



PFD QUALIFIES FOR
EARLY INTERVENTION



INCLUSIVE
INSURANCE COVERAGE

EASTON'S STORY

Easton Peterson, now 6, aspired to be like Neil Armstrong and he has become a pioneer just like his hero. Easton was the first child in the US to be diagnosed with pediatric feeding disorder, taking one very significant and giant step for children with impaired oral intake that is not age-appropriate.

At 4.5 months Easton's mother Natalie introduced baby puree and she knew immediately that something was wrong. Easton initially pushed food away and eventually he refused it outright. This continued to manifest as he grew older, from struggling to even eat solids until almost 3 years old, to being very limited in the variety of foods he would eventually eat.

For Easton's family and thousands like them, the medical system was disjointed, and providers were disconnected from one another. When eating is painful and a child will not even touch their first birthday cake a parent internalizes the failure and it all puts an immense strain on the family. Compounding that, when a child is not growing or hitting milestones and insurance coverage is continually denied because there is not one clear-cut diagnosis, it can hard to see a bright future.

Natalie continued to follow her motherly instinct and advocated for Easton. Their struggle led her to Feeding Matters by way of her provider, Desert Valley Pediatric Therapy in Arizona.

While a framework for this battle did not exist when Easton was 4.5 months old, Feeding Matters has been working diligently in the background as the driving force behind notable improvements to the system of care for PFD. Most notably for the Peterson's is the establishment of the ICD-10 codes, which have provided a way for medical providers and insurance companies to communicate about Easton's diagnosis, translating into better, more affordable care for just one of many families navigating PFD.



EASTON
.....
AGE 6

**For Easton's family
and thousands
like them, the
medical system
was disjointed, and
providers were
disconnected from
one another.**

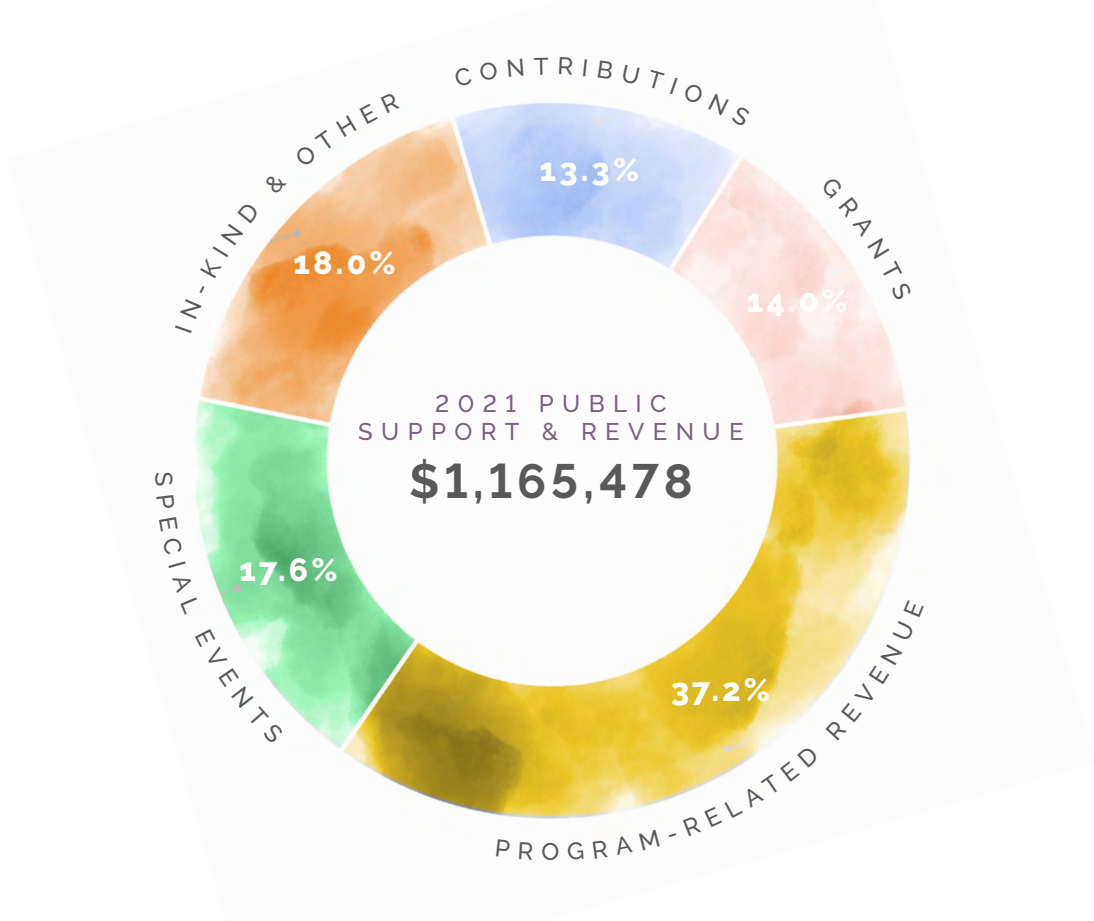


SCAN TO HEAR MORE
OF EASTON'S STORY

2021 AUDITED FINANCIALS

2021 PUBLIC SUPPORT & REVENUE: \$1,165,478

CONTRIBUTIONS	\$154,445
GRANTS	\$162,991
PROGRAM-RELATED REVENUE	\$433,307
SPECIAL EVENTS	\$205,215
IN-KIND & OTHER REVENUE	\$209,520



2021 EXPENSES: \$971,910

PROGRAMS	(\$781,768)
MANAGEMENT AND GENERAL	(\$73,880)
FUNDRAISING	(\$116,262)

ARI'S STORY

For children like Ari Flicek, eating can be an agonizing experience for the whole family. That was the case for the Flicek family as they welcomed home their first and only child.

Ari's mother Athena knew right away that something was off with his feeding. It was monumental if Ari, who struggled with feeding since birth, could actually swallow, chew and eat something without it coming back up. The first time he actually said the words "I'm hungry" he was almost two and the novelty of it made Athena cry.

As a baby Ari was labeled with "Failure to Thrive," "Difficulty Swallowing," "Unspecified Vomiting," and "Malnutrition." Sadly, like many families suffering in silence these labels extended to his parents who felt like they, too, were failing to thrive.

The ongoing struggles to battle insurance coverage, the appeals process and attending all of the therapy sessions were a big endeavor. The fact that Ari could eat merely one food item made him ineligible to receive insurance help to cover any formula. When Ari turned one Athena quit her job to take care of him, and the entire process put a strain on the family dynamics and economics. She had been referred to Feeding Matters and found a feeding therapy team through the organization's Provider Directory.

At 16-months old, Ari's feeding therapy team correctly diagnosed him with pediatric feeding disorder even before the official PFD code was available. He later became the 2nd child in the US to receive the formal diagnosis. The timing of the Flicek family's story intersects opportunistically with the years of work that Feeding Matters has done to bring unparalleled change to the healthcare industry. Because PFD was finally recognized as a condition rather than a symptom that was seen as transient, the Flicek family had a more defined path of care with more predictable insurance coverage. Of equal but different value was the fact that the diagnosis brought validation and recognition to their scenario and helped to quell the feelings of inadequacy.

Having a child with PFD changes a family's life profoundly. So, while Ari's journey continues the horizon ahead looks brighter. Ari used to eat a total of five foods. These days, the list of foods that he will eat is nearly two pages long and their family can now actually dine out in restaurants.

The Flicek's is just one of many stories of resilience and progress that makes all of the advocacy, education, support, and research we do at Feeding Matters so rewarding.



ARI
.....
AGE 3

Sadly, like many families suffering in silence these labels extended to his parents who felt like they, too, were failing to thrive.



SCAN TO HEAR MORE
OF ARI'S STORY

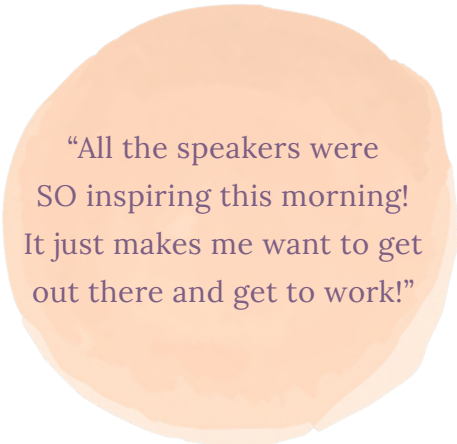
PROGRAMS & STRATEGIC INITIATIVES

COLLABORATING TO ADVANCE PEDIATRIC FEEDING DISORDER AND FACILITATE MAJOR SYSTEM CHANGES TO IMPACT MILLIONS OF CHILDREN.

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 a pediatric feeding disorder. As the team leader, the family requires educational support and applicable resources as they navigate the healthcare system and the community at large.



“All the speakers were SO inspiring this morning! It just makes me want to get out there and get to work!”

2021 EDUCATION PILLAR PROGRAMS

- 8th International PFD Conference including the inaugural Pre-Conference
- Feedingmatters.org
- Educational workshops and on-demand learning

2021 ACCOMPLISHMENTS

- Is it PFD?
- What is PFD?
- PFD ICD Tool Kit
- Educational Blogs
- New On-Demand Workshops
- National Outreach Presentations

FAMILY SUPPORT

For families navigating pediatric feeding disorder, it can be difficult to find resources and understanding.

PFD does not discriminate, and this issue can impact any family. Please know we are here to support you no matter your circumstance.


Through shared experiences, Feeding Matters' Family Support Programs offer emotional support, compassion, resources, education, information, and guidance – reminding parents and caregivers that they are not alone.

2021 FAMILY SUPPORT PROGRAMS

- Power of Two Parent-to-Parent Coaching
- 7 Day Family Support Hotline and Email Inbox
- Free Family Education Series
- Virtual Support Groups
- Family Guide to PFD

2021 ACCOMPLISHMENTS

- Facebook Group for families in the Power of Two program launched to connect families and family coaches: 120 engaged members
- May, June, and October were record breaking months for Family Support in Feeding Matters history
- From Concern to Care Rack card and 4 domains of PFD infographic



“Reading all your posts actually made me tear up. Here’s the thing. I never knew feeding issues like this even happened and no one understands. It’s isolating.”

“Feeding Matters’ conference has helped me to be a better therapist.”

RESEARCH

A lack of longitudinal, evidence-based data and the diverse nature of pediatric feeding disorder (PFD) have often been cited as barriers to understanding the individualized needs of children with PFD. Feeding Matters and the PFD Alliance strive to move the field from utilizing practice-based evidence to relying on evidence-based practice.

2021 RESEARCH PILLAR PROGRAMS

- Research Consensus Initiative
- Infant and Child Feeding Questionnaire®
- Research Collaborations

2021 ACCOMPLISHMENTS

- Created PFD and ARFID Infographic (See below)
- Launched the Research Initiative Task Force identifying research barriers and solutions for the field to impact all children, especially those who have difficulty accessing care.

Avoidant Restrictive Food Intake Disorder (ARFID) And Pediatric Feeding Disorder (PFD)

“ If a patient has a diagnosis of ARFID, it may be worth reassessing from the pediatric feeding disorder (PFD) perspective to see if the cause of feeding difficulties might include a medical or skill dysfunction, and not be purely behavioral. ”
-Dr. Richard Noel, Feeding Matters Volunteer Medical Director

	ARFID	PFD
THERAPEUTIC END USER	Primarily mental health providers	Multidisciplinary
DIAGNOSIS DEVELOPMENTAL ORIGIN	Designed to replace and extend the DSM-IV diagnosis of feeding disorder of infancy or early childhood, also driven by desire to better represent patients' needs with EDNOS receiving treatment within eating disorder programs	Designed based on International Classification of Functioning, Disability, and Health (ICF) framework, recognizing that multidisciplinary care across four core domains represents the standard of care for PFD
TYPICAL AGE OF ONSET	No age criteria defined	Pediatric age range, but no specific age criteria defined
COMORBIDITIES	Mental health disorders, with anxiety being most common	Any medical or developmental disability

Developed by Feeding Research Initiatives Task Force with Chair, Dr. William Sharp

ADVOCACY & AWARENESS

Historically, pediatric feeding disorder (PFD) has been significantly underserved and misunderstood. In collaboration with respected clinicians, researchers, caregivers, educators, healthcare professionals, and more, the advocacy pillar facilitates global change to improve the lives of children with pediatric feeding disorder—including a stand-alone diagnosis, government awareness, and inclusive insurance coverage.

2021 ADVOCACY AND AWARENESS PILLAR

- Awareness Campaign
- 3rd Annual PFD Awareness Month
- PFD identity initiative
- Early intervention crosswalk

2021 ACCOMPLISHMENTS

- 9 states declared May PFD Awareness Month
- Launched PFD Storytelling Campaign
- Codes for Pediatric Feeding Disorder became available in the United States on Oct 1, 2021

GEOGRAPHIC REACH

Feeding Matters is a national nonprofit organization headquartered in Phoenix, Arizona with international reach. The organization focuses its system changes on the United States healthcare system but strives to serve as a conduit for clear and consistent information on pediatric feeding disorder for the entire world.

TOP FIVE COUNTRIES:

1. UNITED STATES
2. AUSTRALIA
3. UNITED KINGDOM
4. CANADA
5. INDIA

TOP FIVE STATES:

1. CALIFORNIA
2. TEXAS
3. ARIZONA
4. NEW YORK
5. VIRGINIA



RAISING FUNDS

FEEDING MATTERS COULD NOT DO THIS IMPORTANT WORK WITHOUT THE SUPPORT OF OUR COMMUNITY.



FEEDING MATTERS 9TH ANNUAL COMMUNITY EVENT

RAISED OVER \$200,000 AND REACHED MORE THAN 600 INDIVIDUALS

“Wonderful and inspiring. We have tears in our eyes.”

IAN AND TARA RAKOW

HOSTED THEIR FRIENDS AT A MICRO-EVENT TO RAISE FUNDS FOR FEEDING MATTERS FAMILIES AND CHILDREN

“Glad to give back to an organization that has given our family so much.”

YOUR KIDS Table

YOUR KID'S TABLE

10% OF CLASS SALES IN NOVEMBER DONATED TO FEEDING MATTERS

“We love all the work that you are doing!”

If you are interested in hosting an event in support of Feeding Matters' mission. Please reach out to events@feedingmatters.org

In addition to the events held to support our organization, we are also incredibly grateful for every single person who donated to our mission in 2021. We truly could not do this work without you.



DONATE TO FEEDING MATTERS TODAY

Scan the QR Code to visit our donation page.

Text **GIVE** or **DONATE** to 602-975-3669

HELPING FAMILIES WITH FEEDING SINCE 2006



Inspired by their newborn triplets' struggle to eat, Shannon and Bob Goldwater founded Feeding Matters 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. All three would eventually require feeding tubes to supplement their nutrition. Today, the triplets are in college and are still an inspiration for Feeding Matters to continue working towards its mission. We remain devoted to continuously seeking innovative ways to reach the children who need us most. As Shannon shared: "What started as a dream in my living room in Scottsdale, AZ has grown into a worldwide collective of like-minded people, striving to create a world where children with PFD with thrive!"



feedingmatters.org