



2020

ANNUAL

REPORT

# From our Leaders

A year can change a lot. In 2020 alone, Feeding Matters saw significant advancements in our mission, pivoted to COVID-19 support, and had a leadership change as we welcomed a new CEO to guide our efforts. We hosted our elite IPFDC that reached all 50 states and 34 countries which provided vital education on PFD. We were the catalyst for journal publications that showed 1 in 37 children under the age of 5 have PFD. Our *Infant and Child Feeding Questionnaire* was offered to the community for earlier identification of PFD. We had an impactful PFD Awareness Month in December 2020 with four states officially participating and substantially increased our reach online to raise awareness of this unknown issue.

Most importantly, we finally received confirmation that PFD will be a stand-alone diagnosis in the ICD manual. This creates the foundation for insurance coverage and better research so that children with PFD can thrive.

All of this happened this year, during a global pandemic. While it can feel odd to celebrate right now, it is so important to us to honor this success and all of the hard work from our entire community to achieve these efforts. We truly were all in this together and we will continue to be together as we build on these successes and leverage this momentum. Thank you for your support, trust, and partnership.



**Jaclyn Pederson, MHI**  
CEO



**Rhonda Anderson, RN,  
DNSC(H), FAAN, FACHE**  
Board Chair

## 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

## About Us

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.



# Advocacy & Awareness



In 2019, we were proud to share with you the publication of our paper declaring PFD a stand-alone diagnosis -a catalyst for large-scale change. This year we are proud to share a HUGE next step in the journey to bring validity to this condition. Over 400 citations have been made since the publication. In August, we received word that pediatric feeding disorder will have its own diagnostic code in an upcoming edition of the ICD-10 manual -- meaning

that physicians will be able to formally diagnose PFD and children will officially have this on their medical record.

***In August, we received word that pediatric feeding disorder will have its own diagnostic code in an upcoming edition of the ICD-10 manual***

In 2020 alone, we have expanded our support and educational materials for

families, hosted our elite international PFD conference that reached all 50 states and 34 countries providing evidence-based education on PFD, and achieved significant advocacy milestones. To bring PFD to the forefront, we need to support our claims with evidence. Therefore, this year, we published our 2nd phase of research on our *Infant and Child Feeding Questionnaire* in the *Journal of Pediatrics*. This ground-breaking work opens the door for children to be screened for PFD so that we can prevent the long-term outcomes that occur when we don't pay attention to this early enough. In 2020 alone, 3,510 questionnaires were taken.

Then, we were the catalyst to the research that showed that 1 in 37 children have PFD and even more significant: 1 in 3-5 children with a chronic disease have PFD. We have also secured a formal proclamation naming December PFD Awareness Month

from Arizona's Governor Ducey and a few others states.

***We were the catalyst to the research that showed that 1 in 37 children have PFD.***

We now know that PFD will be its own diagnosis which is the foundation that families need for better insurance coverage.

All of this happened this year, during a global pandemic. This is a moment to celebrate!

We have momentum and we are not stopping. This year's accomplishments have a very personal meaning to all of our professionals and families.



## Family Support

2020 Accomplishments:

- Expanded family support to seven days a week
- 72,159 families were reached
- 139 formal matches
- 47 active family coaches



## One Family's COVID-19 Journey

The COVID-19 pandemic has tested resiliency worldwide, pushing people and entire societies far beyond anything they had anticipated. We who have children with pediatric feeding disorder already know what it is like to have something beyond our control readjust our limits far beyond what we thought possible.

Despite this experience, the arrival of COVID-19 and its barely mitigated spread have added cruel new challenges to our struggles with caring for and nourishing our children. In the spirit of sharing and mutual support that runs through Feeding Matters, I'll share some of my family's experiences during the COVID-19 pandemic. I hope the hearing of our story will be as helpful as the telling.

Far and away the most striking similarity of COVID-19 and caring for a child with a feeding disorder is isolation. My son is still an infant, and his feeding refusal began in earnest mid-January 2020. What used to be eight 45 minute sessions with a bottle exploded into elaborate and constantly changing rituals to try to coax him to drink milk and then put him to sleep to dream-feed. With the placement of his NG tube in

mid-February, some of the burden was relieved, only to be replaced with constant fretting and delays to make sure the pump did not trigger vomiting. Remarkably, once the country started to get serious about COVID-19 in March, I had already been almost entirely socially distant for roughly two months. The only difference was that where everyone else was isolating out of self-preservation or solidarity, it was our desperate effort to nourish our baby that had sequestered me and to a lesser extent my wife. We learned how all-consuming feeding disorders are because they cut you off in the same way as when humanity tries to save itself from a devastating disease. While COVID-19 made everyone isolated like us, it also raised the stakes of every cough and snuffle. My son mercifully is not immuno-compromised, but COVID-19 could cause havoc by making my wife or myself ill, and it could kill my mother-in-law, who is staying with us.

Unfortunately my wife's work as a physician means that not only is she required to continue working, but that she is regularly exposed to COVID.

Just last week I came down with what was ultimately just a cold, but until the COVID test came back, I needed to isolate myself from the entire family within our small apartment. I wouldn't want to overstate our hardship, but my son does not understand social distancing, and it was disruptive for me, his primary caregiver, to essentially vanish.

***I can say without hesitation that Feeding Matters is the best antidote to the isolation and doubt of caring for a child with a feeding disorder.***

Unfortunately, we will continue to live on this knife's edge for the foreseeable future. As it became clear that this multi-layered isolation would not end soon, and as we realized that the difficulties and stresses of



our son's would not abate, we finally followed up on our doctor's recommendation of Feeding Matters. I can say without hesitation that Feeding Matters is the best antidote to the isolation and doubt of caring for a child with a feeding disorder. We have been glad to attend the semi-monthly virtual support group meetings, and the staff has been extraordinarily empathetic and attentive in reaching out not just for our initial intake, but several times since. However, without question the most helpful part of the program has been the individual family coach.

***We needed a relatable connection to someone who has had to live with our issues and has come out the other side.***

Physicians and therapists have so far generally been kind and full of advice, but we needed a relatable connection to someone who has had to live with our issues and has come out the



*Dustin's wife and son*

other side. Our family coach has been warm and friendly, and has gone beyond simple mentoring to virtually open up her home and her family to us. She has even had her mother talk with my mother-in-law about the ins and outs and do's and don'ts of helping us help our son. After all this time of lonely ounce counting and desperately hoping for a break-through, this contact with someone who understands has been literally indispensable.

From the bottom of my family's heart, we would like to say thank you to Feeding Matters.

-Dustin

# Education

## 2020 Accomplishments:

- 69,152 healthcare professionals were reached
- Hosted our 7th International PFD Conference virtually January 24-25, 2020 with 774 virtual registrants reaching all 50 states and 34 countries.
- Launched Learning Accelerated through Collaborative Initiatives (LACI), an inter-professional mentorship cohort designed to identify key constructs in PFD assessment and management competency through collaborative discussion and clinical application activities.

*"LACI provided me access to other local professionals who I can problem solve with now and in the future in order to best serve my feeding clientele. LACI encouraged me to dive deeper into my understanding of PFD and discover the holes in my current knowledge in order to more thoroughly help my clients from more than one paradigm."*

- Hannah Brennan  
LACI cohort member



# Research

## 2020 Accomplishments:

- Facilitated the presentation and confirmation of PFD to the CDC to be considered as a stand-alone diagnosis.
- Published a national prevalence study showing that 1 in 37 children under the age of 5 have PFD annually.
- Supported a pilot research project seeking to understand how clinicians use screening and assessment tools for children with PFD.



*“Never in a million years did we think our biggest challenge would revolve around eating, nutrition and growth. I really wish there had been more education and preparation in the hospital, and most importantly, resources before and after discharge. Hospitals need to be better equipped to deal with these types of issues both for the child, and the psychological and emotional issues that the family faces. Hospitals are just not there yet and don't know how to be a guide and resource for families with g-tubes and feeding issues.*

*Luckily we found you!”*

*-Parent of a child with PFD*

# Annual Community Event

In 2020, the global COVID-19 pandemic forced us to re-imagine our 8th Annual Community Event. With the support of our trusted partners we were able to shift our programming and host a virtual event that included guests from all 50 states and 12 countries. The event honored Judy and Bill Schubert with the Visionary Award for their longtime support of our mission. Special thanks so to our presenting sponsors Jaburg and Wilk Law Firm and Mead Johnson Nutrition.



Honorary Event Chairs David and Kristen French shared their experience having a child with PFD.



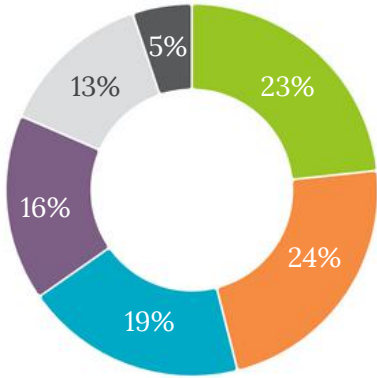
The 2020 Annual Community Event featured Ram (pictured above) and his family and their experience with his PFD diagnosis.



Feeding Matters Founder + Emeritus Board Member Shannon Goldwater (left) and 2019 Visionary Award Recipient Jacquie Dorrance (right) presented the 2020 Visionary Award to Judy and Bill Schubert (center).

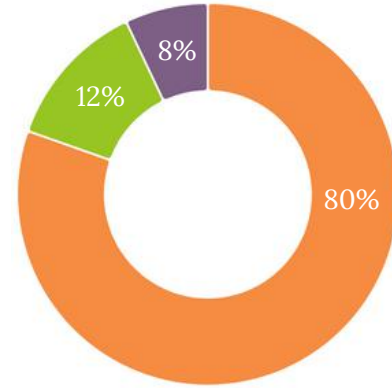
# 2020 by the Numbers

## Revenue



Program Activities	\$208,821
Special Events	\$210,118
Contributions	\$145,487
Grants	\$45,356
Payroll Protection Program	\$173,162
In-Kind & Other	\$115,086
<b>Total Revenue</b>	<b>\$898,030</b>

## Expenses



Programs	\$894,506
Fundraising	\$138,441
General & Administrative	\$76,877
<b>Total Expenses</b>	<b>\$1,109,824</b>

Feeding Matters undergoes an independent financial audit annually and provides comprehensive information in a timely manner in response to reasonable requests for information.

For Feeding Matters, financial management is interdependent. It is a part of every aspect of Feeding Matters governance, planning, programs, evaluation and fundraising. Budgeting sufficient revenue to cover administrative expenses is key to ensure effective accounting systems, internal controls, competent staff, and other expenditures critical to professional management are also key.



*"Resilience has been redefined for many of us this year! We are finding our lives turned topsy turvey because of matters outside our control. It is frustrating; it is debilitating. It is the exact feeling that families who have children with feeding disorders have experienced for a long time..... until Feeding Matters stepped up to come to the forefront. Resilient defines these families. They know now how to step up, join hands and hearts, identify and define.... overcome. Finally see light at the end of the tunnel. Breathe again. We are in awe of all the work Feeding Matters is doing and are proud to support the Power of a Name Campaign."*

*-Bill & Judy Schubert*



*feeding* **matters**