#### Appetite Guided Treatment Approach to Pediatric Enteral Tube Weaning in the Home Setting

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# Background

- Enteral nutrition is defined as the administration of nutrition through a tube into the GI tract.
- When a child's oral intake of energy and nutrients is inadequate, a feeding tube is placed to deliver sufficient nutrition to maintain body composition and growth.
- Prevalence of pediatric patients receiving home enteral nutrition in the United States is estimated at 186,036.
- Because there is no standard of care around weaning enteral feeds, many children remain on enteral nutrition support beyond medical necessity.

## "Hunger" vs. "Appetite"

- Tube weans that focus on "hunger" rapidly cut tube feeds according to a pre-determined schedule over a couple of weeks with the belief that if the child is hungry enough, she will eat.
- Tube weans that focus on "appetite" allow for gradual reduction in tubed calories, looking for the child to respond to the first reduction in energy before moving to the next reduction. This allows the child to correlate feelings of hunger with the satisfaction of eating.

## Growing Independent Eaters (GIE)

- Studies have shown that behavioral interventions which use some type of appetite stimulation are effective in weaning tube dependency in children.
- GIE is an enteral wean program that recognizes appetite and children's trust is the foundation for eating.
- GIE is comprised of an interdisciplinary team that includes social worker, parent coach, feeding therapist, and dietitian.

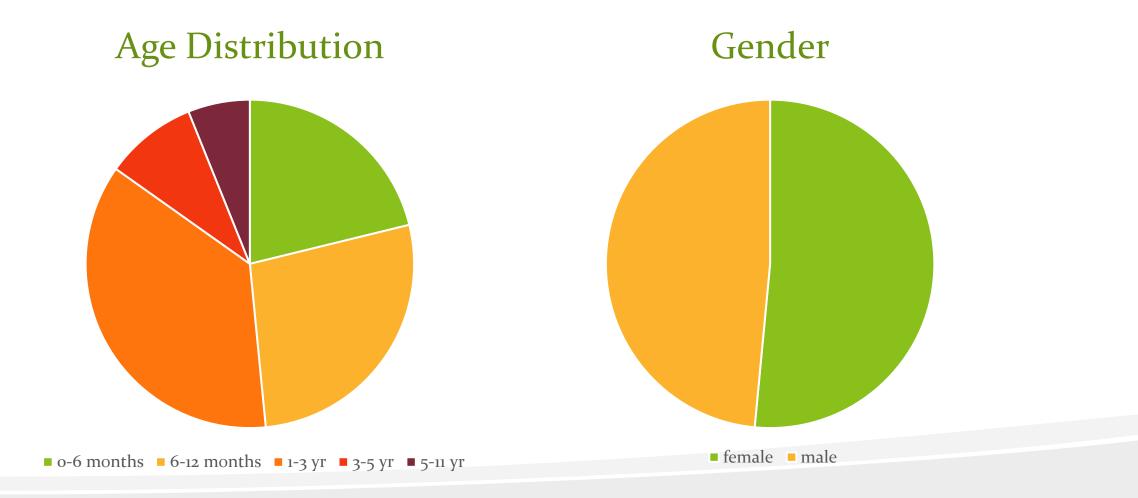


 The aim of my study was to collect data to establish the efficacy of using an appetite guided approach to gradual enteral tube weaning in the home setting that is virtually supported by an interdisciplinary team.

## Methods

- Retrospective review of GIE records between July 1, 2018 and December 31, 2018.
- 81 families met study criteria and received a questionnaire.
- Questionnaire included 60 questions seeking information on growth, length of tube wean, feeding practices, and parental stress during the wean process.
- Received data from 34 families (42% response rate) representing families from 8 countries.

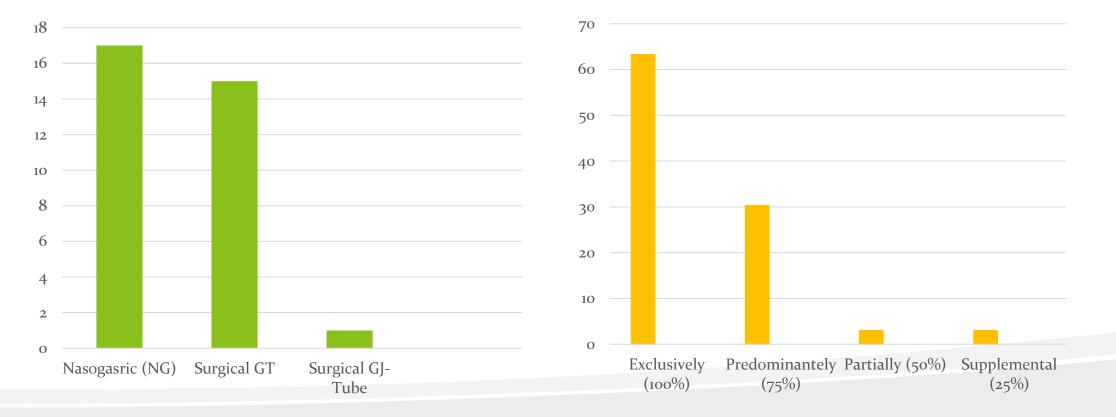






Type of Feeding Tube

#### Level of Dependence on Enteral Support

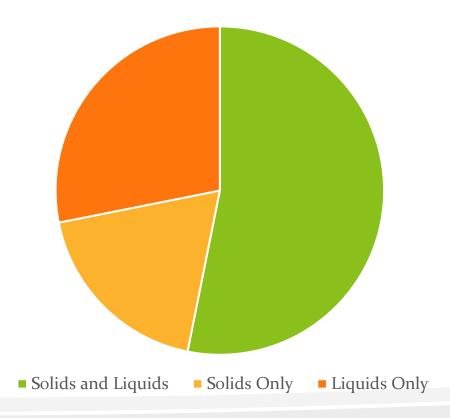


### Results: Wean Duration and Weight

- Wean time was 6-177 days with an average of 57.4 days.
- Infants weaned twice as fast as children. The more feeding and medical complexities, the longer the wean.
- Weight loss during a wean is expected and a loss of up to 10% of total body weight is acceptable.
- 75% of participants lost weight for an average of 9.6% of total body weight.
- 4 participants exceeded the 10% weight loss threshold and had to pause their wean.

# Results: Feeding Practices

#### 32 of 34 participants completed the wean



- 53% (n=17) weaned to a combination of solids and liquids
- 19% (n=6) weaned to solids only
- 28% (n=9) weaned to liquids only

### Results: Post-Wean Growth and Feeding Skill

- 6 months post-wean, 93.3% of parents reported their child had gained weight since tube feeds were discontinued.
- 6.7% of children's weight was reported to be the same for no gain since weaning.
- Improved feeding skill post-wean was reported in 96.9% of children.

### **Results: Parental Stress**

Stress Level	Average Score
Before the Wean	4.1
During the Wean	3.5
After the wean	2.3

90.9% of respondents reported improvement in family time and quality of life since weaning off the feeding tube.



- <u>Research</u>: Combining a child's own appetite with demedicalization of the feeding experience through modification of meal-time behaviors, as well as providing strong, emotional support from the interdisciplinary team, allows children to successfully wean off enteral feedings in the home setting leading to improved quality of life for the entire family.
- <u>LEND</u>: This study exemplifies the interdisciplinary approach to family centered care resulting in successful treatment of the child while emotional supporting the parents and that with these support systems in place, all children have the potential to be successful oral eaters.



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#### Growing Independent Eaters team members:

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