



# Pediatric Feeding and Dysphagia

## Dear Fellow Feeders;

Welcome to our 2nd issue this season. We have packed as much information as we can into these 10 pages! In this issue look for information on barriers to oral eating from Polly Tarbell MS SLP/CCC from the Encouragement Feeding Program in Charlottesville, VA. Bill Roche MS SLP/CCC from The Pediatric Feed-

ing Center at St. Joseph's Hospital, Paterson, NJ writes about what inspired him to start their feeding program, also see articles on DHA in formula, GI resources, and lots of current research! The case this issue is very personal to me, I wrote about the difficulties I had feeding my newest addition, my son

**Pediatric Feeding and Dysphagia Newsletter**  
**Hiro Publishing**  
[www.feedingnews.com](http://www.feedingnews.com)

Volume 4, number 2

October, 2003

## DETERMINING BARRIERS TO ORAL EATING

Polly Tarbell, M Ed. SLP/CCC, Encouragement Feeding Program, Kluge Children's Rehabilitation Center, University of Virginia, Charlottesville, VA MCV2W@hscmail.mcc.Virginia.edu

Feeding disorders that occur in children with physical disabilities, mental retardation, and prematurity tend to be severe and persistent. These feeding difficulties may be severe enough to warrant the placement of a supplemental feeding tube. These children typically experience many months of invasive oral procedures, are unable to regulate their own hunger/satiety, and miss out on the critical or sensitive period of oral exploration and exposure. As a result, they develop oral aversion that leads to continued dependence on a supplemental feeding tube. For some, the medical reason for the tube placement has resolved but the dependence on the tube persists.

In the past, children with feeding disorders have been classified as having organic or non-organic etiologies to their feeding disorders. More recently it is felt that this dichotomy is no longer accurate. Instead these children have a combination of etiologies that include physical, social, developmental, behavioral, and environmental issues. This article describes 5 barriers that have been identified to describe why a child may have difficulty transitioning to oral eating, and which are not usually the etiologic factors.

A retrospective study of 83 children who attended the Kluge children's rehabilitation Center's Encouragement Feeding Program (EFP) was completed in order to determine which barriers contributed to the continued dependence on a feeding tube at the time of their admission. Based on the predominant reason for their inability to wean from their feeding tube, categorization of these barriers allowed clinicians to help individualize treatment options. These barriers were:

**Disrupted hunger/satiety regulation:** Those children who knew how to bite and chew but had never regulated their own hunger/satiety, and therefore did not eat enough to have their tube feedings reduced.

**Inexperience:** Those children who had no experience with eating and needed to be taught how to move food around in their mouths.

**Disordered contingency learners:** Those children with disordered learning. These

*(Continued on page 2)*

### Special Points of Interest:

- Current information
- New products
- Research and publications
- Education

Editorial assistance provided by Elizabeth Crais Ph.D. CCC SLP, Division of Speech and Hearing Sciences, UNC-Chapel Hill and Cathy Fox MS OTR/L, Private Practice, Frederick, MD

### Inside this issue:

|  |      |
|--|------|
| Barriers to Oral Eating                  | 1-3  |
| Question & Answer                        | 3-4  |
| What makes LIPEL different from Enfamil? | 4    |
| Case by Case...                          | 5    |
| If you're Not the Lead dog...            | 6-7  |
| Recommendations                          | 8    |
| Research                                 | 9-10 |

## DETERMINING BARRIERS TO ORAL EATING

Polly Tarbell, M Ed. SLP/CCC Encouragement Feeding Program, Kluge Children's Rehabilitation Center, University of Virginia, Charlottesville, VA MCV2W@hscmail.mcc.virginia.edu

children had difficulty understanding behavioral shaping principals commonly used in therapy to increase oral exploration.

**Sensory/Anxiety:** Those children whose sensory systems were severely impaired and were unable to approach eating.

**Psychosocial:** Those children who had normal oral functional and sensory status but who appeared to have ongoing parent-child interaction or attachment issues.

The above barriers were rarely seen in isolation, but instead overlapped to create a complex feeding disorder that had not resolved despite months of outpatient therapy. However, it was possible to separate out which barrier was the primary reason for the child's lack of motivation to eat orally. Use of the categorization system allowed for additional refinement of the Encouragement Feeding program.

All of the children were admitted to the EFP for 2 to 4 weeks for a day feeding program that was holistic, family centered and intensive. All children had 3 to 4 sessions of oral functional therapy per day by a trained SLP. In addition, they received OT, recreational therapy, preschool and nutritional evaluation and counseling by a registered nutritionist. Parent education was provided as actual opportunities unfolded during meals and therapy sessions.

Although all of the children received the same therapy regimen, identification of the individual barriers to eating was helpful in individualizing therapy programs within each discipline. The majority of the children demonstrated fairly significant overt refusal to eat by mouth that was observed in the form of limited quantity eaten, pushing away the spoon, crying, gagging, and/or vomiting. It was felt, however, that identifying and addressing the problem or barrier that was resulting in the "behavior problem" resulted in children who demonstrated decreases in their refusal to eat and promoted development of normal for age eaters.

### Hunger and satiety



For the population of children who were classified as mainly needing to establish **hunger/satiety**, all of the therapies focused on food exploration and parent education regarding normal for age toddler development, play and normal for age meal portions. The meals consisted of parent education regarding normal toddler eating habits, mild behavioral shaping and use of contingencies to increase oral intake per meal. These children knew how to chew or eat pureed foods, with over 75% of the children eating some regular textured foods prior to admission. The most important aspect of their admission, was the rapid reduction of tube feedings to help create internal motivation and listening to their own body's cues. Following discharge, this group of children rarely required continued oral functional therapy as they demonstrated oral competence. This population of children achieved great success with over 81%

weaned from their tubes within 5 to 7 months post discharge. The other children in this category are expected to be weaned in the future.

### Inexperienced Eaters

Children, who demonstrated mainly **inexperience**, also had 4 meal times per day, but their meals consisted of intensive oral functional therapy directly aimed at teaching the basic elements of biting and chewing, or moving from eating nothing to tolerating and feeling comfortable with pureed foods. Parents received information regarding the normal progression from pureed to biting and chewing skills as well as information regarding behavior shaping. They also received daily information regarding normal toddler mealtime behaviors. Prior to admission, 75% of these children were totally dependent on the tube for their caloric needs. At this time, 96% of these children are weaned from their tubes. Following discharge, at least half of these children continued to receive regular occupational or speech therapy to address their need to transition from pureed to regular textured foods.

### Learning barriers

The children who were classified as having **learning** barriers were done so based on written information from home therapists, school personnel and was based on educational testing done during their admission. These children tended to have disordered learning profiles, versus delay. Children with cognitive skills at least to the 18-month level were considered for the program. However at times, home information reported skills at an average of 18 months, but in reality some children demonstrated a very scattered profile, with highly disordered learning status. All of these children also

*(Continued on page 3)*

## DETERMINING BARRIERS TO ORAL EATING

Polly Tarbell, M Ed. SLP/CCC, Encouragement Feeding Program, Kluge Children's Rehabilitation Center, University of Virginia, Charlottesville, VA MCV2W@hscmail.mcc.virginia.edu

*(Continued from page 2)*

received intensive oral functional therapy during meal times, however, this population had difficulty understanding the stimulus used to teach biting and chewing. In addition, this population had difficulty with comprehension of contingencies and simple behavior shaping principals. It was felt that with significantly longer admissions, this group of children might have had more success. Only about 45% of these children are weaned from their tubes at this point. These children continued to receive ongoing oral functional and occupational therapy locally.

### Psychosocial issues

Eight children demonstrated significant difficulties with **psychosocial** issues as defined by significant parent-child interaction difficulties. The majority of emphasis during their intervention was placed on improving parent child interactions, especially regarding mealtime management. Recreational therapy time was used to promote normal parent-child play and interactions. In-house Psychology referrals for several of these families and formal attachment evaluations occurred and these families were referred to psychologists in their home communities for ongoing therapy in attachment and parenting skills. These children did not require ongoing speech or occupational therapy services following discharge as they were competent orally and their difficulties with intake were noted to be due to disordered parent-child interactions. 63% of these children are now weaned completely.

### Sensory/anxiety issues

The children classified as exhibiting **sensory/anxiety** difficulties were a very interesting group of children. The majority of the 83 children admitted to this feeding program demonstrated typical sensory defensiveness on an oral, tactile and whole body level to some degree, however, most demonstrated significant decreases in this behavior by time of discharge. The intensive immersion into sensory play on a daily basis appeared to help diminish these sensory problems and eating on a regular basis all but eliminated oral hypersensitivity. The children who fit into this category, however, demonstrated significantly more profound sensory issues. Problems were observed during transitions between activities and physical spaces and extreme food phobia with a "fight or flight" behavior noted during all therapy sessions. Some children were noted to demonstrate self-injurious behaviors during therapy sessions such as pulling out eyelashes, excessive rubbing of eyes as well as physical elements of sweating and gagging at the mention of foods. These children appeared to demonstrate such significant issues with anxiety that the oral aversion appeared to be just one symptom, not the entire problem. Of the most severe, 4 were seen by a psychologist, and in consultation with a physician were placed on anti-anxiety medication. Once placed on medication, three children demonstrated significant improvements with their overall ability to tolerate daily routine and tolerate oral functional therapy and the other showed minimal increases in eating. In addition, these children were referred for continued follow-up with a psychologist after discharge. At this time, 50% of these children are weaned from their tubes.

Identification of barriers to oral eating was helpful in individualizing the emphasis during these children's admissions. Parent education and direct therapy was different depending on the predominant barrier. The above barriers were retrospectively identified and are now being used prospectively to individualize recommendations made prior to

---

### Question and Answer: *(sent from a subscriber)*

2yr.8 month old girl with History: TEF (repaired 8/01), G-tube and Nissen (multiple Nissen repairs), repaired cleft lip and palate, PE tubes bilaterally, and Trach. Keep in mind this child lives in El Salvador and participates in speech therapy 2x/week approximately 30 minutes. Goals seem to include oral/motor, receptive and expressive language. Parents pay out of pocket and cannot afford more therapy. Seems to have age-appropriate receptive language skills. Feeding: She reportedly tolerates tube feedings (6oz. 4-5 times a day, at night 10oz./5 hours). She has thick yellow mucus constantly, and drools. Coughs and chokes on saliva. Parent's wipe nose and mouth at least every 5 minutes. She does not swallow own saliva. SLP works on oral motor stimulation. including gum massage, tongue "tapping", cheek massage. It does not appear that they are working on jaw movements. Do you have any specific ideas or resources that I can relate to the treating SLP via email/report? Trach: she wears a valve consistently. Has a few words e.g., mama, papa. The only consonant I could understand was /m/. The noisy trach makes it difficult to decipher other sounds. What would you do with this kid? As far as the repaired CLP, she enjoys making lip-buzzing sounds, which she would not be able to do if the palatoplasty had not provided her with good velopharyngeal closure. Thank you, Susanna

**Answer:** There are a number of specific resources out there that have detailed information on oral motor work for the face, jaw, tongue, and lips

*(Continued on page 4)*

## What makes Enfamil LIPIL different from Enfamil?

By Nancy Gray, MS, RD, LDN Nutritionist, Boone Developmental Evaluation Center, Boone, NC 828-265-5391, nancy.gray@ncmail.net

Enfamil LIPIL is another attempt to bring infant formula closer to breast milk. It is supplemented with DHA (docosahexaenoic acid) and ARA (arachidonic acid). DHA is contained in varying amounts in fish oils, with oils from cold-water fish containing higher amounts. DHA and ARA are also found in some algae and fungi, eggs, and in human breast milk. Both are long-chain polyunsaturated fatty acids that seem to be important in brain and vision development.

During the last trimester of pregnancy, large amounts of these fatty acids, especially DHA, are deposited in the brain and in the retina of the eyes of the fetus. These levels continue to increase in the months after birth. Breast milk naturally contains these fatty acids and blood levels of these fats are higher in breast-fed babies than in formula fed babies. Since it's been known for some time that breast fed babies score better in developmental testing than formula fed babies, the hope is that this is the reason why.

While infants can make these fatty acids from other "essential" fatty acids in their diet, some studies have suggested that they may not make enough and may benefit more from direct consumption. Premature infants who may have been born before adequate amounts of DHA and ARA are deposited in their brains and retinas may benefit the most. However, the scientific evidence is mixed. Some studies in

infants suggest that including these fatty acids in infant formulas may have positive effects on visual function and neural development over the short term and even through the first year of life. Other studies in infants do not confirm these benefits.

Although the evidence supporting a true beneficial effect of supplementing DHA and ARA was not strong, their addition to infant formula was determined to be safe by the FDA. So, Enfamil LIPIL (and Similac Advance) has been added to the list of formulas, with claims that it is now "another step closer to breast milk." It's important to remember that the ingredients in breast milk, as in most natural foods, work in concert to support health and development. One ingredient by itself may not function nearly as well without the other ingredients, some of which have yet to be identified. On the up side, no problems from using DHA and ARA fortified formulas have been noted (as yet) and the potential benefits are exciting!



*(Continued from page 3)*

(Suzanne Evan Morris, Debra Beckman, Sara Rosenfeld Johnson, Rona Alexander, Marsha Dunn-Klein). The thing that has me wondering is when you ask for resources for the SLP. When I read the history and the problems, I think more about this child's ventilatory pattern and the quality of her cough, breathing and coordination of breathing and swallowing of her secretions. I would first start by slowing down the tube feeding to make sure that the rate is not overwhelming her system. Green food dye can be put into a bag of formula so that if it is being refluxed into the trach, evidence will be easy to see. When a child is having more reflux you can often see "water brash" which is an increase secretion production that is very thin and watery. If the child has nasopharyngeal reflux, nose wiping may increase. Also you may want to check and make sure that the pH of the stomach content is 4 or above to assure that there is adequate acid blockade. If her gut is not fully managed there will be little carry over of oral motor techniques and there may even be more tongue retraction and poor secretion management with intra-oral manipulation. I also would want to know what her postural alignment is and if she has a forward head alignment. This is common in children with significant motor and respiratory issues. Since the trunk, head and neck provide the basis of support for the infra and supra hyoid muscles, it is crucial that the trunk and rib cage are mobilized to support an efficient ventilatory pattern and does not compromise the alignment of the swallowing mechanism. If this is addressed early on in treatment all oral motor work will be implemented on a stable base and will be reinforced through out the day.

This will require knowledge of the trunk, rib cage, ventilatory patterns, and head/neck alignment. The team approach is the best way to address this using intervention from OT,PT, and SLP. Resources to consider may include work by Mary Massery, NDT treatment (see treatment books by Lois Bly, Regi Behm, manipulation techniques in PT literature (Maitlin) and Craniosacral techniques (Upledger).

Answered by Cathy Fox, MS OT/L, private practice Frederick, MD, CfoxOT@aol.com



# Case by Case...Feeding is hard even when you know what you are doing.

By Krisi Brackett MS SLP/CCC

The moral of this story is that feeding is hard. Even when you know the oral-pharyngeal mechanism, understand the GI tract and have a child who wants to eat. My second son was born in May (39 weeks and 8 lbs.) and he was completely content for the first 3 weeks of his life. After that he began to cry for 4-6 hours at a time and spit up 6 – 10 times per feed. Needless to say, his clothes were changed and so were mine multiple times per day.

Having gone through this with my first son and ending up a dairy free breast-feeding mom supplementing with Alimentum, I was not anxious to go through this again. Surely I deserved an easy baby the second go round? I could not believe that my sweet child was turning into a colicky inconsolable spitter. I, of course, went off of all casein and whey proteins, which helped a little and gave my son a small amount of Maalox, which also seemed to relieve some of his discomfort.

Then I turned to my doctor who took one look at his fabulous weight gain and said do nothing. He felt that it was the dreaded colic or immature digestion and to wait it out. I tried to explain that he not only cried for hours, spit up, as many as 10 times per feeding some of which was forceful, but would also awaken me at night with grunting and throat clearing. It was clear to me he was in pain. So I took the situation into my own hands. I demanded a trial of Zantac (and not a wimpy dose but a fair one) to be used as necessary. He complied, only because I could explain the symptoms and why I wanted it. And I relied on my expert friends and colleagues because it's hard to diagnose and treat your own, adding sleep deprivation and hormonal imbalance to the mix.

The Zantac seemed to relieve some of his discomfort but it wasn't THE ANSWER. Differing opinions were tossed around. Was it an allergy to my breast milk? After all, this had happened before. I went on a very bland diet of chicken and rice and he was better but it was hard to stay on those limited foods. Would he be better on an easy to digest formula? We decided to use Alimentum but he didn't want the bottle, he wanted to breast feed despite the fountain of spit up that followed each feeding. We had a tearful week of trying to replace some of the breast feedings with the bottle. Tearful for me because I felt he was hungry but was holding out for the breast. (It was almost impossible not to feed my child when I knew he was hungry and refusing the bottle). We noticed that he did not spit up any of the Alimentum but continued to spit up after breast feedings. Was it the content or the volume? The consensus from everyone was a 1-week trial of formula to determine if it was the breast milk or formula. Everyone that is but me. I knew they were right but to bottle feed for a whole week and not breast feed with all the warm cuddling closeness it brings? Plus at night to have to get up and make bottles? And make bottles and feed and pump to keep the breast milk going just in case? I also had a toddler to chase. It all sounded like too much. I'm afraid I drove everyone a little crazy trying to figure it out.

As a last ditch effort, before the dreaded week trial, I decided to try bottle feeding some breast milk. Eureka- he liked the taste and took the bottle easily and he didn't spit up! A few more trials resulted in the same conclusion – little to no spitting with the bottle and continued spit up with breast-feeding. Perhaps it was a volume issue and he is getting too much when feeding directly at the breast. Interestingly, he has always spit much less when breast-feeding at night – perhaps because he is relaxed and fairly still.

In conclusion, I continued with a combination of bottles of breast milk (and some Carnation Good Start) during the day and breast-feeding at night. With less regurgitation, I believe he felt better and went back to being the happy baby he started out as. We even discontinued the Zantac.

The lessons for me as a feeding therapist/mom were multiple. First, it's frustrating when your pediatrician thinks you're crazy. Stick to your guns and trust your instincts as a mother. We must remember how hard some of our recommendations are for parents to follow. Especially when the parents had a vision of how things should go. Such as the possibility of giving up breast-feeding when that is what the mother wanted to do or asking the parents to try a formula when the baby has a hard time taking the bottle and refuses to eat. I have made those recommendations in the past and will again but I am sympathetic to the emotional pull you have to comfort and feed your baby. I didn't want to stop breast-feeding and never did completely even though friends and colleagues I respect recommended it. In the end, you have to do what is best for you and your baby. And last but not least, feeding is sometimes an intricate mystery that we never quite solve. In the end, we hope the balance between nutrition, comfort, weight gain and maturation has a way of working itself out.

## ***If You're Not the Lead Dog, the View Never Changes***

By William J. Roche M.S. CCC Clinical Director, The Regional Craniofacial Center and The Center for Pediatric Feeding and Swallowing. The Children's Hospital at St. Josephs Regional Medical Center, Paterson, New Jersey  
07503rocheb@sjhmc.org

The concept of "team" is not a novel one; in fact team has become Madison Avenue trendy over the past several years. All one needs to do is look to your retail shops and banks and observe their "associates". These employees are all sporting cloned jackets, shirts, same color trousers or ties. Corporate seeks a unified look to create a national branding, similarities that scream out "we belong together and we are team". Nothing could be further from the truth.

What binds these individuals together is merely their paycheck; choice of occupation or simply that they were assigned to the team. Integration of their membership into this team is further defined by a pecking order, history, policy and procedure manuals, gatekeepers and layers. Sound familiar?

More often than not these administrative teams decrees ignores the basic need to foster an environment where members of the group enthusiastically shape, accept and take responsibility for the mission, the integrity, philosophy and values that define the common fabric of the team. Each must support the purpose for the team's existence.

Simply stated, we organize for a purpose. Twenty years ago as a graduate student fresh out of Columbia University, I routinely observed plastic surgeons and residents make life altering independent surgical decisions on babies with no other focus than aesthetic outcomes. It was then that the words of H.K. Cooper D.D.S., of the Lancaster, Pennsylvania Cleft Palate Clinic resonated "treat the whole patient; not just the hole". With Dr. Cooper's words and the isolated vignettes of surgeon and patient I discovered a purpose to organize. The Craniofacial interdisciplinary Team was created around issues such as kids not getting their lips and palates repaired by an experienced surgeon in a timely manner or a torticollis going untreated in a plagiocephaly baby. Basically these issues were seen as opportunities to create this team. Egos created barriers. Each ego (i.e. Craniosurgeon, Oralmaxillofacial, ENT, Radiology.....) had to be delicately manipulated until the passion each had for contemporary, timely evaluation and treatment for their babies led them to embrace the mission and challenges that lie ahead of them as team players. Issues included leaky ears, underdeveloped mandibles, airway and feeding issues as well as hypernasality, cardiac history, chromosomes, short stature and dollar woes and parental concerns, oh! and did I mention egos? These concerns needed to be collaboratively addressed. One of the most powerful skills a leader has is the ability to meld the individual and the team while making both count. Ernest Becker, the Psychologist often spoke of "dualism". Becker argued that man needed to be a part of something as well as sticking out as an individual. We have a need to be a conforming member of a winning team (i.e. family, church, early intervention team or cranio team) as well as a star in our own right. These two diverse directions were a challenge to collimate. What would drive this vehicle we label team were individuals with contemporary thinking, shared philosophies, a capacity to anticipate, as well as to challenge the accepted and most of all, I think tenaciousness in their pursuit of shared positive outcomes. Finally, I embraced the philosophy of David Glass, the former CEO of Wal-Mart who believes that you seek individuals on your team who are better and brighter than yourself. Surround yourself with individuals who could compensate for your weaknesses and create a balance.

Surrounding myself with intelligent and motivated individuals, the Craniofacial Team evolved over the next seventeen years into the largest Regional Craniofacial Center in the state of New Jersey. The Center now houses the Cleft and Velopharyngeal Inadequacy Team, the Auricular Reconstructive Team, the Plagiocephaly Team as well as the Craniofacial Team. Kids who were once viewed as having an isolated hole in their heads now had ombudsmen with shared purposes.

A natural sequence for me, four years ago, was then to think about establishing a feeding team. Why? I was observing a modified barium swallow study and listening to the Speech- Language Pathologist and Radiologist making feeding recommendations on limited data that came from the swallow test. Dejavue!! My plastic surgery clinic observation seventeen years prior smacked me between the eyes. We had children with PEG tubes in for years. We had vomiters, food refusers, allergy and gut issues and we were relying on swallow studies and our focus was well within the mouth. I went away from that radiology vignette with another purpose. It was not to reinvent the wheel but to take the team building experiences from Craniofacial (without the egos) and transfer the dynamics to a feeding team.

The team model that seemed pervasive out in the feeding world four years ago was a multidisciplinary one. Individuals with well-defined competencies independently evaluated and managed their area with a line of reporting but limited on-going communication for collaborative purposes. Occasionally the medical person involved (i.e. Pulmonary, GI, Developmental, Radiology) was brought into the equation but usually this was done by written report. Rarely did I see the medical element ever challenged by the independent Specialists. I could well appreciate by then that expecting competency and positive shared outcomes beyond the area of expertise of an individual practitioner was only asking for failure to diagnose appropriately, protracted treatments and ignoring the layers with which these families

*(Continued on page 7)*

## **If You're Not the Lead Dog, the View Never Changes**

By William J. Roche M.S. CCC Clinical Director, The Regional Craniofacial Center and The Center for Pediatric Feeding and Swallowing. The Children's Hospital at St. Josephs Regional Medical Center, Paterson, New Jersey 07503rocheb@sjhmc.org

*(Continued from page 6)*

presented. Crossing boundaries, collaborative evaluation and encouraging trans-disciplinary management strategies were in my opinion needed to be employed. We were not doing this at our Medical Center. The model was not an earth shattering one, but what moved my world was the change in our philosophy that would create a quality of life change for children and their families with feeding difficulties.

Enter Peggy Eicher, MD, a Developmental Pediatrician. Her medical, behavioral and motor model to identify and treat pediatric feeding problems was my impetuous to build The Center for Pediatric Feeding and Swallowing at St. Joseph's Children's Hospital in Paterson, New Jersey. In a very short time Dr. Eicher's intelligence, humor, compassion and drive to change the world of a family with a child with a feeding problem led me and my colleagues beyond the mouth. A team of fourteen individuals (full-time SLP, OT, PT, ABA, MD, RN, five feeders, child care aide, secretary as well as part-time 3-day week NP and MSW were hired). These individuals were organized and along with the physical plant 1.2 million dollars was initially spent. The Center now relies on an annual budget of \$850,000.00 a year to function. The team organized for the purpose of making sense and then managing a field marked by complexity and one that is always in a state of flux. Their goal was to identify the etiologies, unmask the layers and thoroughly integrate a fully dedicated two-tiered Trans disciplinary team approach (without egos).

Tier 1 was established to treat day-treatment patients and currently the Center averages 6.5 children for a period that averages four weeks. That places the Center at capacity and it's been that way for the past two years. Tier 2 was established to treat outpatients and currently there are approximately thirty-one children seen on a daily basis by multiple team members in the outpatient arm.

Essential to the development of the Center was education of the families and Specialists as well as a medium for one another to communicate. The Center's website [www.feedingcenter.org](http://www.feedingcenter.org) was established.

One of the largest challenges for me, but then again, to any corporation as well as Medical Center or University, is to change consumer-buying habits. Additionally in the medical and University setting the challenge is to change physician referral practices. One can equate both. Consumers often buy branded items (e.g. Nike, Coke). Getting consumers to change is a huge challenge in the corporate world. So too is it in the medical world. Physicians and Medical Center practices often prefer to refer their patients to individuals and this creates a pattern. The goal should be to redirect that referral pattern. The only proven way to do that is creating outcomes that can not be ignored. Deliver proven data based functional outcomes and the referrals will follow. And they have.

Interestingly enough parents become the Team's cheerleaders. They urge Specialists and payers to take notice of the amazingly symmetrical post-op lip, the functional palate repair, increased PO intake, PEG removals and pleased Moms and Dads. Despite the Centers inner city location, outcomes have drawn families from 22 states.

Transitioning now into its third year, alliances have been formed with GI, Radiology, Genetics, Intensivist, Pulmonologist and the like. Staff members of the Pediatric Feeding Center have subordinated their personal prominence to the efficiency of the whole while making the family the hub of the program. I think initially what each individual brings to this table is their skills embellished by other staff members. However, the basic belief in the medical motor and behavioral philosophy was significant in ensuring that our purpose of enhancing a child and family's quality of life would be our predominant purpose.

I will end with the placard that has hung on my office door for 20 years. The words of Margaret Mead could not be more appropriate when she stated... "never doubt that a small band of caring and committed people could change the world. Indeed, it is the only thing that ever has".

### **Top Ten List for Feeding Center Development:**

1. Enthusiasm is contagious.
2. Poop is a necessary four-letter word in a feeding center.
3. Coding issues will always exist.
4. Never underestimate the power of parents.
5. Learn to look around the corner.
6. Don't retain a whiner.
7. Embrace loyalty, integrity, and shared values.
8. Everyone puts their pants on the same way.
9. Once the decision is made the debate is over, team consensus rules.
10. There is another purpose waiting around that corner.

## Pediatric / Adolescent Gastroesophageal Reflux Association (PAGER)

<http://www.reflux.org/>

PAGER is a non-profit **membership** organization that provides information and support to parents, patients and doctors about Gastroesophageal Reflux (GER).

- provides plain English explanations of the disorder, treatment, diagnostic tests and medications
- provides a forum for you to share your experiences and learn from each other
- is collecting demographic information for GER research purposes
- is soliciting individuals to participate in studies about GER
- is conducting the first ever study of genetic reflux (hereditary acid reflux) in collaboration with Allegheny General Hospital, Center for Genomic Sciences.
- has volunteers waiting to return your phone calls and e-mails.

### Membership Level:

Family/Individual Membership - \$25 per year

Group/Practice - \$100 per year

### Videos for sale:

[Pediatric Gastroesophageal Reflux Disorder: Indications for Testing](#)

Dr. Benny Kerzner MD, Chief of Gastroenterology at Children's National Medical Center, Washington DC

[Breastfeeding the Child with Reflux](#)

Laura Barmby and Beth Anderson, PAGER Board Members

Laura is the author of the booklet, Breastfeeding the Child with Reflux

[Beyond the Silver Spoon, Developmental Perspectives on Feeding and Swallowing](#)

Peggy Eicher, MD, St. Josephs Children's Hospital, Patterson NJ

Formerly with the feeding team at Children's Seashore House in Philadelphia

Dr. Eicher is a developmental pediatrician who sees many children with reflux, many have other issues as well. She describes how reflux, breathing and feeding all influence each other. The early part of the video is quite technical but then she uses specific children to illustrate her points.

*Suggested Donation = \$20.00*

<http://www.powerpak.com>

## Pediatric GERD tutorial

A physician I work with me passed this along to me. Power-Pak C.E.™ is a product of /alert Marketing, a healthcare communications company that provides information and education programs to healthcare professionals and consumers. They have online courses for professionals (not SLP, OT or PT as far as I can tell) to assist them in meeting requirements of relicensure. They have a nice tutorial on Pediatric GERD that I recommend checking out. The information is good and the tables are really nice.

1. Go to their website at [www.powerpak.com](http://www.powerpak.com)
2. From the Topics menu choose: gastroenterology
3. Pick the tutorial titled [Pathophysiology, Epidemiology, Diagnosis, and Management of Gastroesophageal Reflux Disease \(GERD\) in Children](#)

### Sections:

1. Lesson - a nice tutorial on pediatric reflux including diagnosis and management options
2. Answer/questions – I am not a registered user and skipped this section
3. Tables – nice handouts and printable

TABLE 1. COMMON SYMPTOMS AND SIGNS OF GERD IN INFANTS, CHILDREN, AND ADOLESCENTS

TABLE 2. DIAGNOSIS OF GERD IN THE PEDIATRIC AGE GROUP

TABLE 3. TREATMENT OF GERD IN INFANTS, CHILDREN, AND ADOLESCENTS

TABLE 4. OUTCOME OF EFFICACY STUDIES WITH USE OF PROTON PUMP INHIBITORS IN PEDIATRICS (1997-2001)

4. References – a thorough list but published in 2002 so recent studies won't be included.



## On the Research Front....

**Patel AS, Pohl JF, Easley DJ. Proton pump inhibitors and pediatrics. *Pediatrics in Review*. 2003; January,24 (1), 12-15.**

This is a nice review of the current use of proton pump inhibitors (PPI) with pediatric patients. The authors explain that Histamine<sub>2</sub> receptor antagonists (such as Zantac or Pepsid) do not completely block gastric parietal cell acid production. PPI's demonstrate consistent pH control because they target the gastric or proton pump in the parietal cell membranes. Therefore the PPI's inhibit the final step of gastric acid secretion by blocking proton production.

PPI's require an acidic environment for activation and should be given on an empty stomach 30 minutes before a meal. The coating on the granules dissolves only at a pH of 6, which allows for release of medication in the duodenum. Currently 5 PPI's are available in the US: omeprazole (Prilosec), lansoprazole (Prevedid), rabeprazole (Aciphex), pantoprazole (Protonix), and esomeprazole (Nexium). Research reports minimal risk for patients with long term use.

Each brand of PPI is discussed in the article and technical differences are explained. Pediatric data is available for omeprazole and lansoprazole. Omeprazole comes in 10, 20, and 40 mg capsules. 4 preparations are recommended; mixing granules with H<sub>2</sub>O, acidic fruit juices, or foods such as yogurt or applesauce to prevent removal of the protective coating. Also a sodium bicarbonate suspension which allows the granules to dissolve is ideal for use in tube fed patients or when administering directly into the intestine (an alkaline environment). Lansoprazole comes in 15 and 30 mg doses as well as a liquid suspension and should be administered similar to omeprazole. Pantoprazole is unique in that it had been approved for oral and intravenous administration. There is much potential for PPI use in pediatrics because of the effectiveness of this drug class in reducing acid secretion.

**Alarcon, PA, Lin, L, Noche, M, Hernandez, VC, Cimafranca, L, Lam, W, Comer, GM. Effect of oral supplementation on catch up growth in picky eaters. *Clinical Pediatrics*, 2003, April, 209-217.**

Picky eaters are defined as children who demonstrate food avoidance and eat a limited number of foods. 92 children (ages 3 - 5 ½) who had picky eating behavior and poor growth were randomized to receive either nutritional counseling alone or nutritional counseling plus a nutritional supplement of Pediasure (study group) for 90 days. Nutritional counseling involved the development of strategies individual to the subject based on a 3 day diet history. Parents were counseled on techniques to enhance eating behaviors such as eliminating soft drinks and juices, use smaller more frequent meals, note time of day when their child eats the most and provide high calorie meals, use brightly colored foods, provide a pleasant mealtime environment, and offer praise for the consumption of foods. The study group had significantly greater weight and height increases. There were no significant differences between the groups in appetite change, activity level, or GI symptoms score. There was an improvement in the study group with fewer kids developing upper respiratory infections. The authors surmise that a nutritional supplement with counseling promote catch up growth and may contribute to lower rates of infectious disease in children with picky eating.

**Nishimura, T & Suzuki, K. Anatomy of oral respiration: morphology of the oral cavity and pharynx. *Acta Otolaryngol*, 2003; Suppl. 550:25-28.**

In obstructive sleep disordered breathing, airway obstruction occurs at the soft palate and tongue root during sleep and is often accompanied by mouth breathing inducing apnea and snoring. Mouth breathing during sleep tends to induce depression of the tongue root during inhalation, which is disadvantageous to respiration. Children with severe adenoid hypertrophy have characteristics such as a dull expression with open mouth, a sagging lower lip, narrow nostrils, smoothing of the nasolabial groove, and relaxed facial muscles due to impaired nose breathing. The hard palate loses support by the dorsum of the tongue and receives lateral compression by the cheeks resulting in a short axis and deep arch. The upper incisors protrude anteriorly for easier mouth breathing which results in malocclusion and malalignment which can cause masticatory dysfunction. The thorax can show poor growth due to shallow breathing movements resulting in a flat long shape or pigeon shape.

The authors sought to examine mouth breathing associated anatomy of the oral cavity and pharynx in adults. When comparing anatomical states between wakefulness and sleep, sleep showed a slight depression of the tongue root and slight narrowing of the oropharynx and hypopharynx during sleep. Narrowing or obstruction of the middle pharynx and hypopharynx is more marked in patients with obstructive sleep disorder breathing than in normals. The most advantageous state for respiration was nose breathing.

© all rights reserved.

Hiro Publishing  
607-B North Greensboro Street  
Carrboro, NC 27510  
www.feedingnews.com  
Phone: 919-966-8047  
Fax: 919-843-3280  
Email: Kbracket@mail.unch.unc.edu

**Special for Feeding Therapists and Professionals!**

Questions, comments, submissions, and suggestions are all welcome. Please be vocal, the hope is that this forum will be educational and will help to connect us as professionals working together.



**Lalakea, ML & Messner, AH. Ankyloglossia: does it matter?, *Pediatr Clin North Am*, 2003, 50, 381-397.**

Ankyloglossia or tongue-tie is a congenital anomaly characterized by an abnormally short lingual frenulum, which may restrict mobility of the tongue tip. The clinical significance of this anomaly and the best method of management have been the subject of debate for some time. Much of the controversy is related to the lack of significant data demonstrating the efficacy of intervention. The purpose of this article is to summarize fact, fiction, and areas of controversy about ankyloglossia.

Incidence is reported as ranging from .02% - 4.8% and is more common in males and may be seen associated with certain congenital syndromes. Opinions regarding clinical significance vary widely with some authors feeling that it is rarely symptomatic and others believing it may lead to a host of problems including feeding difficulties, speech disorders, and social issues related to the inability of the tongue to protrude. One study reported that ankyloglossia may adversely affect breast-feeding in selected infants. There is general agreement that it does not interfere with bottle feeding or solid food consumption. The same difference of opinions occurs with speech related problems. Although, the authors site a study that indicates a higher incidence of articulation errors in a group of children with tight frenulums.

Diagnosis is made based on physical exam findings of the tongue and may be characterized by a heart or notch shape on protrusion, poor elevation, poor excursion past the dentition, decreased lateral motion etc. Several authors have suggested more formal ways to classify the problem. Frenotomy or simple release of the frenulum and frenuloplasty or release with plastic repair are the two most common procedures used in treatment. Appropriate age for intervention and patient selection has not been determined.

*This material is provided for informational and educational purposes only; it does not contain specific medical advice. If you have specific health questions or problems, consult a health care professional for personal medical advice.*