



Pediatric Feeding and Dysphagia Newsletter

Dear Fellow Feeders:

Welcome to our October issue! This quarter we have highlighted a new treatment technique for swallowing, ways to increase calories, and therapy tips for children with oral aversion. Our interview this issue is with Dr. Paul Hyman, a gastromotility specialist from the University of Kansas Medical School who is doing some fascinating and cutting edge work with kids who refuse food and have hypersensitivity. Our case comes from the physical therapist on the feeding team at St. Joseph's Hospital in Paterson, NJ. PT's have a dynamic and important role in the feeding process! We have a special letter

from a Mother whose son has feeding problems and she expressed what it's like to live with those problems. Also included are 2 current journal reviews and an inexpensive resource for up to date nutrition information. Enjoy!

Krisi Brackett MS SLP/CCC



**Pediatric Feeding and Dysphagia Newsletter
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Special Points of Interest:

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

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Bioelectrical Treatment for Dysphagia

by Krisi Brackett MS SLP/CCC

The University hospitals of Cleveland offer bioelectrical treatment for selected patients with dysphagia under the direction of speech pathologist, Mary Freed, CCC-SLP. The use of transcutaneous electrical stimulation as a potential treatment for dysphagia began as a research study in 1993. The treatment has been provided to children since 1996 and has been used with infants as young as 5 days old. The FDA has recently provided its approval.

How bioelectrical treatment for swallowing works: Patients receive mild external stimulation from a specifically designed stimulation unit, about the size of a paperback book and powered by a 9-volt battery. Four small electrodes connected to the stimulation unit are placed on the patient's neck and face to deliver the electrical stimulation. Initially, patient's feel a tingling or pulling feeling on the neck. As stimulation increases, the patient

feels a grabbing sensation (like tape being pulled from the skin). Each treatment session lasts from 50-60 minutes.

The muscles targeted are the strap muscles of the larynx. It is hypothesized that the electrical stimulation strengthens and retrains muscles used for swallowing. Some patients may be able to begin swallowing normally after as few as 3 treatment sessions, however, the number of treatments varies between patient to patient. In some cases electrical stim is combined with dilatation of the UES. A variety of swallowing disorders can benefit from this treatment including decreased peristalsis, a tight UES, and coordinated swallowing.

Research:

Freed, M., Christian, M.O., Seytas, C.M., Tucker, H., Kotton, H. (1995). Electrical stimulation of the neck: a

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Power Packing by Nancy T. Gray, RD, MS, LDN, nancy.gray@ncmail.net

Power packing is the use of additives to make foods and formulas more fattening. Here are some of the additives with their pros and cons.

Fats:

Pros: Fats are "calorie dense" – that is, they add more calories per bite than carbohydrates or proteins. A teaspoon of oil is about 40 calories, a teaspoon of margarine is about 33 calories and a teaspoon of whipping cream is about 17 calories.

Cons: Fats have a high satiety value – that is, a higher fat meal gives a feeling of fullness sooner than a lower fat meal. This may mean that the more fat added the less food eaten, so the net calorie increase is minimal. Also, fats tend to digest more slowly.

Also, fats don't mix well. Butter, margarine and cream mix better than oil. Oil floats easily to the top and may become the last swallow a child gets from a bottle—ugh! Hence the development of Microlipid, an emulsified fat that won't separate out of a formula. However, Microlipid has about ½ of the calories of oil (22.5/tspoon) and is expensive (18 cents/tsp.).

MCT oil is a specialty fat made from **Medium Chain Triglycerides** (most oils have long chain triglycerides). This lets it be absorbed differently than other fats. As a result, it can be life saving for children who lack the enzymes needed for fat digestion, have underdeveloped intestines, or are missing part of their intestines. On the downside, although MCT oil provides the same calorie benefit as other fats, it is very expensive (31cents/tsp. vs. about 1 cent/tsp. for vegetable oil). Using MCT oil as a calorie supplement for a child with normal digestive abilities is akin to using gold filament for dental floss.

Using Fats: If the child eats mostly canned baby

foods, adding butter, canola oil, margarine or cream to the baby food (1-2 tsp. per 4 ounces) is a good idea. It's easy and helps overcome the low calorie density of baby foods and makes them taste better. Fats also work well in blended foods. Avoid adding fats to liquids and leave the addition of Microlipid and MCT oil to the child's physician or dietitian.

Carbohydrates:

Pros: Carbohydrates (carbs) often make food sweeter and more appealing to many children. Carbs are usually inexpensive: a teaspoon of sugar costs less than a penny and honey costs about 5 cents/teaspoon. They also tend to be more easily tolerated than fats. Dry infant cereal provides a double benefit of calories and thickener. Corn syrup can help ease constipation as well as add calories. Wheat germ is a power packed carbohydrate that adds calories (10 per tsp.) and many nutrients. Specialty carbs like Polycose and Moducal are formulated to be better tolerated and add less flavor than sugar but they cost 3.5 cents and 9.5 cents per teaspoon, respectively.

Cons: Carbohydrates are lower in calories than fats. Honey and corn syrup are the highest at 20 calories per teaspoon and dry infant cereal is the lowest at 3 calories per tsp. Polycose provides 8 calories/tsp. and Moducal provides 10 calories/tsp.

Too much sugar, honey and corn syrup can result in diarrhea when added to formula, especially in a child who is tube fed. On the other hand, infant cereal is associated with constipation. Finally, there is a risk of botulism poisoning in infants given honey.

Using Carbs: Add sugar, brown sugar, corn syrup or honey (not for infants) to solid foods or liquids. 1-2 tsp. per 4 ounces is a good place to start, increasing as tolerated.

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Bioelectrical Treatment for Dysphagia by Krisi Brackett MS SLP/CCC

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new effective treatment for dysphagia. Presented at the Dysphagia Research Society Meeting, Oct 26-28, Virginia. 112 adult patients were divided into 3 groups; electrical stim, thermal stim, and both techniques (failed thermal stim followed by electrical stim). Results indicated that 98% of the electrical stim achieved safe swallowing function, 34% of the thermal stim group improved, and 96% of the group receiving both techniques improved.

Freed, M & Rothstein, F. (1999). Electrical stimulation and cricopharyngeal dilatation for the treatment of dysphagia. Presented at the Society for Ear, Nose and Throat advances in children, Dec 2-5, University Hospitals of Cleveland. 100% of children in study improved with treatment.

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Power Packing

by Nancy T. Gray, RD, MS, LDN, nancy.gray@ncmail.net

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Use dry cereal if thickening foods or liquids is needed, but don't count on it for many calories. Wheat germ can be sprinkled on oatmeal or ice cream for an extra nutty flavor and some fiber as well as calories. It can be added to baking mixes and stirred into casseroles for the same reasons. Specialty carbs can be added to both foods and liquids, but recommending amounts greater than 1 tsp. per 8 ounces should be left to a physician or dietitian.

Proteins:

Pros: Protein can be a good source of calories because it is often accompanied by fat. Peanut butter, cheese, egg yolks and powdered milk are good calorie and nutrient sources, readily available and generally accepted by children. Ground walnuts added to the diets of older children add calories, fiber and essential fatty acids.

Cons: Some of the most severe allergies are to protein foods, so children who have a strong family history of allergies should not be given eggs or cow's milk for the first year and peanuts, nuts or fish for the first 3 years.

Also, too much protein is stressful to the kidneys of young children and puts them at risk for dehydration. For this reason, specialty proteins like ProMod and Casec are not recommended for use solely as a calorie supplement.

Finally, proteins also have a fairly high satiety value, especially when accompanied by fat.

Using proteins: Keeping in mind allergy and choking concerns, proteins are fun to use creatively! Peanut butter can be stirred into pinto beans or for a richer flavor or mashed with banana for a sandwich spread or nutritious pudding. Cheese can be grated onto vegetables or casseroles or stirred into hot casseroles or scrambled eggs for extra richness. Remember, egg yolks should never be used raw because of the risk of Salmonella poisoning, but an extra egg yolk can be added to a scrambled egg for more power or it can be hard boiled and crumbled into casseroles. 2 Tbsp. of powdered milk added to a glass of whole milk adds calories, protein and calcium with little change to taste.

Mixed Calorie Sources:

Pros: Formula powders, Instant Breakfast (IB) powder and Duocal are the primary sources of calories from a blend of proteins, fats and carbohydrates. All mix easily into liquids and soft or blended foods and provide about 14 calories per tsp. Formula and IB powders improve a child's vitamin and mineral intakes and maintain a healthy protein-fat-carbohydrate distribution of calories. Duocal adds a balance of fat and carbohydrate calories without adding protein.

Cons: Too much of these mixed calorie sources will stress the intestines and kidneys and can produce diarrhea, dehydration, metabolic imbalances or all three. They also have a high satiety value, so the actual calorie benefit may be limited. Last, but not least, they can make a formula too thick for tube feeding and are relatively expensive.

Using mixed calorie sources: IB powder can be added to milk in children over 2 at the rate of $\frac{1}{2}$ pack per 8 ounces. Adding formula and Duocal is best left to a physician or dietitian.

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Texas Children's 2001 edition of the Pediatric Nutrition Reference Guide

The newly-revised pocket guide is written by pediatric dietitians and includes pediatric nutrition assessment guidelines; pediatric enteral feeding guidelines; comprehensive infant and pediatric formula composition tables; parenteral nutrition guidelines; infant, child and adult vitamin/mineral supplements; and nutrition support guidelines for premature infants. This is a great resource for up to date information!

To Order: (cost is \$8.00)

Hospital home page: <http://www.texaschildrenshospital.org/>

Direct link to ordering information: <http://www.texaschildrenshospital.org/CntExe/NutritionServices/Main.htm>

Telephone 832-824-5077

Fax number 832-824-5029





Case by Case:

Case Presentation: What to do when positioning is not tolerated

Kristen Owen, MSPT , The Center for Pediatric Feeding and Swallowing Disorders, St. Joseph's Hospital, Paterson, NJ, www.feedingcenter.org

Positioning is one of the first and most effective treatments that can be implemented when an infant is having respiratory difficulty that is negatively influencing feeding. When an infant will not tolerate positioning, Kinesiotaping should be considered as the next treatment.

Background: 7 week old former 37-week infant in NICU diagnosed with Trisomy 21. Additional complications include persistent pulmonary hypertension, pneumonia, and hepatic cyst. The patient was fed via naso-gastric tube following a MBS, which demonstrated a disorganized, weak suck with aspiration during the swallow of thin liquids with no immediate cough and significant amounts of residue in the pharynx. The patient was reported to desaturate during attempts at nipping. A team consultation was ordered to further assess the possibility of oral feedings and to maximize all systems to prepare for oral feedings.

Initial Exam: The patient had facial dysmorphisms consistent with Trisomy 21. The chest was clear, however demonstrated pronounced belly breathing with significant costal border retractions (rib cage instability with negative movement of the chest upon inhalation). Chest wall excursion measurements taken on inhalation measured as follows: over nipple line (+)1mm of movement, over the xiphoid process (-)8mm of movement upon inhalation and over the umbilicus (+) 5mm of movement. While sleeping the respiratory rate ranged 35 – 70 breaths per minute. SaO₂ during rest was 88 – 96%. Pt. demonstrated an incoordinated suck on the pacifier. The suck was maintained for only 2-3 sucks and was then expelled. SaO₂ consistently decreased into the 70's during all nipple attempts. The patient started to arch and gag at the 50cc mark during his n-g tube feeding observation.

Intervention: The team MD diagnosed the patient with reflux and initiated Zantac. The physical therapist positioned the patient in sidelying to address the increased respiratory rate, low SaO₂ and rib cage instability. Sidelying was poorly tolerated due to frequent movements into extension. The patient would not remain in semiprone or sidelying position even while sleeping. To address the respiratory concerns without the ability to use positioning to mechanically stabilize the rib cage, Kinestiotape was applied over the diaphragm. The Kinestiotape was applied for a 5-day trial.

Progress: The patient was seen 3 times during the last week of his inpatient admission. Chest wall excursions over the xiphoid process improved and measured (-)5 mm which was an improvement of (+) 3mm. The RR at rest was consistently lower and ranged 38-46/min. The pt. was able to suck on the nipple with assistance for 1 minute without desaturating by day 3 of treatment. Additionally, on day 3 the speech pathologist was able to initiate nipple feeds of 5cc of formula. By days 5-6 the patient was able to nipple for 2 minutes independently without desaturating. The suck had become more organized. The pt. continued to have difficulty remaining in sidelying. It was recommended that the patient follow-up with the team feeding center as an outpatient. Note: Upon his first out-patient appointment, the pt. was taking 50cc by bottle, 2-3 times per day. Continued Kinestiotape treatment and follow-up with the MD and ST was recommended.



Discussion: When children with low tone present with the respiratory complications of increased RR, desaturation and poor rib cage stability, one of the first and easiest interventions is positioning. For children who do not tolerate positioning as in this case, providing external stability with the use of Kinestiotape is another easily performed intervention that positively influences the respiratory status. Why does the rib cage become unstable? Since infants primarily breathe with their belly (diaphragm) this requires tone in the intercostal muscles to stabilize the rib cage when the central tendon of the diaphragm contracts.

When a baby is required to breathe against gravity (supine, on the back) a harder contraction of the diaphragm is required. This begins the cycle of instability and retraction of the costal borders. Instability in the intercostals makes the baby contract the diaphragm even harder and more frequently to meet oxygen requirements. Positioning in sidelying or semiprone or using Kinesiotaping helps provide external stability and allows for improvement of oral motor function. Learning to tape the diaphragm requires some training but can easily be implemented by PT, OT or Speech Pathologists.

Therapy Tips for Treating Children with Severe Oral Aversion

Carol Elliott, OTR/L & Betsy Clawson, Ph.D., LCP

The challenge in treating pediatric feeding problems is to correctly identify all of the factors that impact the desired behavior/skill. Oral defensiveness, aversion, and hypersensitivity are terms that have been used interchangeably in the literature when describing children who present with food selectivity, food refusal, and/or failure to advance oral motor skills. Oral defensiveness refers to a child's resistance to accept input about the face and mouth by others. The difference from aversion and hypersensitivity is that with hypersensitivity, the child tolerates a variety of self directed input in and around the face and mouth. An oral aversion is consistent for input that is either self directed or imposed by other. With total elimination of the cause and graded consistent input, learning can occur that will enable the child to tolerate the aversive input. Hypersensitivity describes an exaggerated response that is not limited just to the face and mouth, but is present over the entire body. This problem comes from abnormal neuro-sensory processing and requires extensive programming that includes the entire body.

Consistency in the language used when diagnosing and treating this population will help further the understanding of the problems and increase the continuity of care provided by different treatment centers . -Cathy Fox MS OTL/R

Therapy Tips for Treating Children with Severe Oral Aversion and defensiveness

There are many underlying reasons why infants and children become orally "aversive" defensive, but even when the underlying medical causes of these conditions are stabilized and/or resolved many children may continue to exhibit oral aversive behaviors. Oral aversion remains a significant barrier for therapists to make progress with teaching children to eat by mouth or to advance oral motor skills. How can therapists work through the oral aversion?

In the Pediatric Feeding Program at Children's Hospital in Richmond, VA, we treat many children from around the country who have received ongoing therapy but have not managed to decrease their oral defensiveness. With intensive treatment in our day patient program, these children have been successful in overcoming oral aversion and have begun to eat by mouth. Unfortunately, there are many children with this problem that are unable to receive such intensive therapy. Here are some tips we have found useful for treating children with this level of dysfunction on an out-patient basis 1-3 times per week.

1. Slow and steady wins the race. Map out your plan and task analyze the components into small measurable steps toward your goals. Begin with short treatment sessions (10 minutes) and gradually increase the amount of time with your long-term goal being 20-25 minute meal. Track progress with each small step (no

matter how small) toward your goals. This helps you feel like you are accomplishing something.

2. Structured therapy sessions. Predictability helps reduce anxiety. Performing the routine the same way in each therapy session helps a child to know the expectations. Utilize a timer. The child learns to associate the timer ringing with being "all done". This will eliminate the session ending based on negative responses.

3. "Take it one step at a time." For severely orally aversive children you may not even be able to start near their mouth. Work your way from the outer perimeter of the face in toward the mouth, then the outside of the mouth, and gradually work your way into the mouth. Choose oral motor exercises that work on specific muscle groups in the face (we utilize the Beckman Oral Motor Exercises). Choose an exercise program that has a structured routine that you can follow each time with handouts that you can give parents as you teach them how to do these at home. Demonstrate the exercises on the caregiver in front of a mirror and have them practice on you so you can be sure they are performing them correctly. It is hard to demonstrate and practice techniques on an orally aversive child.

4. Reinforce the positive responses. Give verbal praise and tangible reinforcement for the steps that you have identified through your task analysis. As long as the underlying issues are stabilized, you can feel assured about ignoring negative behaviors. Anticipate the length of time that you expect the child will tolerate and set the timer accordingly. Work through the resistance. Don't stop just because you are met with resistance. At least attempt an approximation toward your goal and be quick to provide positive reinforcement (toys, video, praise) for compliance. You don't want to get in the habit of letting escape become the reward.

5. Include the caregiver. Provide caregivers with information about your plan and homework to do in between sessions. Discuss yours and their philosophy about treatment. This helps them feel included in the process. Often caregivers are overwhelmed and anxious about their child's feeding difficulties. Share with them as you track progress, this helps them see even small steps toward improvement that they might otherwise overlook.

6. Once the child has decreased their aversion, begin the process of presenting tastes of food. The next step is teaching the child to open their mouth upon request to take a bite. This is the foundation you will need to make strides towards oral feeding.

For references and correspondence please contact us at Children's Hospital Pediatric Feeding Program, 2924 Brook Road, Richmond, VA, 23220. Phone: (804) 228-5818. Email: Bclawson@chva.org or Celliott@chva.org.

Q & A: Interview with Paul E. Hyman, MD Professor of Pediatrics and pediatric gastrointestinal motility specialist, The University of Kansas Medical School. (Based on – UNC hospitals interview on 4/19/01 and email correspondence)

I'm interested in the pain related to GER (gastroesophageal reflux) and the vagal nerve connection. Please explain visceral hyperalgesia.

In Visceral hyperalgesia, the nerves that carry pain messages from the gut become oversensitive, and send pain messages to the spinal cord after stimulation that would not be expected to cause pain. Normal gastric contraction or stretching of the bowel after a meal may be associated with pain instead of no sensation, or a pleasant fullness. Visceral hyperalgesia is reversible.

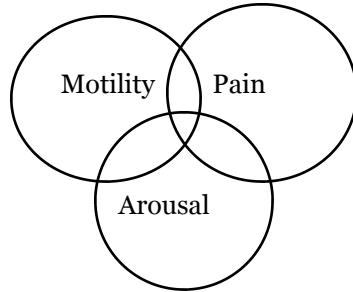
So, reflux is causing esophagitis pain, which over time can cause visceral hyperalgesia, which in turn leads to food refusals, volume limiting, or simply a learned avoidance to pain?

Yes. Toddlers won't eat when it hurts to eat, or when they are afraid it will hurt to eat. Treatment for visceral hyperalgesia can include jejunal feeds for a period of time, sensory integration such as brushing techniques, and tricyclics (medicine) for approximately 9 – 12 months to decrease visceral hypersensitivity. The tricyclic also helps to decrease arousal and kids will sleep better. When pain and fear resolve, many toddlers who failed behavior modification begin eating on their own. Look at the article using a behavioral approach to non-eaters: 50% got better, 50% did not. Why? Possibly pain. (Reference: Benoit, D., Wang, & EL, Zlotkin, SH. Discontinuation of enterostomy tube feeding by behavioral treatment in early childhood: a randomized controlled trial. The Journal of Pediatrics 2000; Oct: 498-503) Gastric emptying may be abnormal secondary to motility problems, pain or from being upset. Once this interplay begins, it can lead to a downward spiral of worsening symptoms.

Dr. Hyman offered this diagram to assist with understanding the evaluation process for GI issues: Look at the interplay of these 3 factors.

Definitions:

1. Motility – movement of food through the digestive tract as result of coordinated contractions and relaxations.
2. Pain – an unpleasant sensation resulting from 1) nociception, the activation of pain nerves and 2) a negative affective response due to perception of the signal in the conscience brain.
3. Arousal – High expectation for pain, heightened awareness, alertness and expectation for activity. The body's neurochemical response to an expectation for important or challenging events, including physiological changes based on a need for heightened awareness and alertness.



Antroduodenal manometry is a motility test used to diagnose motility disorders of the stomach and small bowel. For example with kids who refuse to eat and are fed via g-tube, antroduodenal manometry may discriminate a motility disorder from normal motility, a true vomiting reflex from retching without a CNS component. This procedure can be done as an outpatient. A catheter is inserted through the g-tube and remains in place for 4 to 6 hours. In another test session a computer driven air pump is used to inflate a balloon to determine its volume limit, and see when the kids begin to feel uncomfortable and retch.

What do you think of the pH probe, often considered the gold standard of reflux testing?

It doesn't measure pain. Pain and esophagitis are not correlated. I use proton pump inhibitors to treat functional dyspepsia. Compliance is difficult with H₂ blockers because they must be used 6X per day to be as effective. Everybody refluxes, acid causes pain, so eliminate the acid.

But don't we need acid to break down food?

No. The churning action of the stomach breaks down the food. Although acid begins the process of protein digestion, the intestine is incredibly successful at absorbing protein with or without the stomach acid.

Q & A: Interview with Paul E. Hyman, MD Professor of Pediatrics and pediatric gastrointestinal motility specialist, The University of Kansas Medical School. (Based on – UNC hospitals interview on 4/19/01 and email correspondence)

What about gagging with solid food, is it related to UES function?

This could be an esophageal motor disorder, not always upper esophageal sphincter spasm. For example, approximately 90% of children with Down's syndrome have abnormal esophageal peristalsis. Things get stuck.

How do you evaluate for an esophageal motor disorder? (Dr. Hyman stated that most of the time he's sees kids after the traditional testing has been completed such as an UGI, pH probe, and gastric emptying and after Nissen fundoplication failed to correct the problem).

I use esophageal manometry to evaluate esophageal contractions. If there is diffuse esophageal spasms, Nifedipine, a calcium channel blocker or Bentyl (anticholeric), may be used to decrease the amplitude of spastic contraction.

What about the prokinetics (Cisipride, Reglan, Erythromycin)?

Cisipride increases the strength and number of contractions. Some children have too many disorganized contractions. Cisipride won't work for them. Cisipride helps kids with post-prandial duodenal hypomotility. For example, many pre-term infants have duodenal hypomotility. Intravenous Erythromycin can stimulate gastric motility and open the pylorus, but it's not reliable orally.

Who needs a Nissen?

Hypothetically, a child who has gastroesophageal reflux disease with normal antroduodenal manometry, no vomiting, food refusal, no evidence of a sensory sensitivity or arousal problem needs a Nissen. Example, I recently recommended a child for a Nissen. She had a hiatal hernia, normal esophageal motility but decreased LES pressure, and chronic respiratory disease. I recommend Nissen funduplications about twice a year.

When evaluating for GER, elaborate?

There are many reasons why children vomit. Dyspepsia associated with visceral hyperalgesia will worsen after a fundoplication, but improve with medical therapy. Sometimes children vomit when they are upset, and they get upset a lot. Treatment should aim at solving the problem that is upsetting to them, not surgery to stop the vomiting. I recommend evaluating esophageal motility, sensory and arousal function before considering a fundoplication. Half of the time the child has too many contractions as opposed to not enough or weak contractions.

Prilosec is being used frequently in kids, is it safe?

It is very safe. It has no toxic effects. Prevacid is the first proton pump inhibitor to come in a liquid.

What about appetite stimulants?

Periactin and Megase are commonly used. Use tricyclis to take the pain away, and Risperdal to decrease arousal. Hunger has a hypothalamic connection. Kids with an absent corpus colossum will have abnormal sensation. Many autistic kids have abnormal sensation.

What about pooping?

If a child hasn't pooped and the rectum is full, it slows gastric motility and causes early satiety. Milk of magnesia and Miralax are fine to use, and not dangerous.

What about baclofen?

Baclofen reduces transient lower esophageal sphincter relaxations, the most frequent cause of gastroesophageal reflux events. Unfortunately, Baclofen has sedating effects that make it impractical for therapy in otherwise healthy kids.

What about a typical preemie?

Many preemies have a few weeks of a volume sensitive post-prandial duodenal hypomotility. They have a volume threshold and with increased volume, the rate of gastric emptying decreases.

What about typical CP?

Kids with CP often have neuropathy of the gut, disorganized contraction, poor motility, and sensory issues. These abnormalities predispose the child with CP to a variety of GI symptoms, including heartburn and regurgitation, rumination, and constipation.

Letter from a Mom....

(Spencer is a 4 year old with food refusal, food selectivity (accepts approximately 5 foods), poor weight gain, and a recent diagnosis of corn and rice sensitivity. Except for eating he is a happy, playful little boy. His Mother was kind enough to share her experience with us on the long road to understanding.)

Spencer will be 4 in October. Since his 2-week check up I have known that something wasn't "right". In the past 4 years there have been so many times when I have felt so incredibly isolated. And so many times I have felt like a complete failure as a Mom. Are there any out there that can relate?

But there have also been moments that were "Aha" moments when truth surfaced. Times I knew with clarity that I am not neurotic, I'm not losing my mind, that I was on the right track and that there are others that are experiencing the same journey. There is such great comfort in that knowledge. I'd like to share with you those realizations:

My concerns about my child's refusal to eat are legitimate. I am not neurotic, hypersensitive, or over-protective!!!! I know my child better than anyone on this earth.....that includes his pediatrician. (OK, I will admit to being over-protective!)

They will eat when they get hungry. How many of you have heard that. I wish I had a dollar for every time. I know from experience that is simply NOT TRUE. It is not normal behavior to refuse food, after all; we must eat to survive. And by refusal, I don't mean, "I'd prefer chocolate ice cream to these carrots you are placing before me." I mean the lack of desire for food, non-interest, no expression of hunger. My son to this day can go days without ever uttering "I'm hungry". He just doesn't get the cues.....so we've learned to point those cues out to him and to help him understand that what he is feeling is hunger.

My child is protecting himself from what he believes to be a threat. Sometimes this acting out can be alarming, or seen as bad behavior. When I understood that he was responding to a threatening situation helped me to be less critical and judgmental of him. Notice I didn't say it made me more lenient. He must still be an active, contributing member of this family. He must still obey his parents. However, we practice grace for each of us. In real life that translates to a tolerance of some behavior I swore I would never tolerate in my child. I still cringe to think of some of my declarations! Yes, our child eats in front of a video and YEAH, at least he's consuming calories while he is doing it. We'll work on dealing with the social skills at a later date and at the last glance at his calendar, he hasn't been invited to a dinner at the White House, so we have time.

My pediatrician doesn't "know" my child. I'm sure you've asked yourself many times if perhaps you are making a mountain out of a molehill. I know I have because my pediatric group just didn't seem concerned about my concerns. I recently went back through my son's recorded first year of life. (I did the recording and yes, I am finally creating that scrapbook) There is an entry at 6 months, which brought it back to life so clearly that I was in tears. My son had started to refuse his formula and in response, I would wait until he was asleep and arouse him enough that he would accept the bottle and drink it. And my pediatric group still didn't perceive a problem. You are the mother feeding that child (or forgive me, you are the father feeding that child) you KNOW!!!!!!

We are not alone. It may take awhile, and it may take some effort on your part, but there are resources available, there are others like yourself facing the daily frustrations that we are facing. There is such peace in knowing and talking (or in the case of e-mail, writing) with others who have traveled or are traveling this road. For me, this companionship is 6 months new, but what a change it brings to my life. I can relax about the future and know that there is hope and help for our son. Seek out this support.

Behavior contrary to that for survival is not normal. I've touched on this previously, but really believe that had I done more to emphasize the severity of refusal I might have been heard earlier. "Failure to thrive" what exactly does that mean?.. "Contrary to survival" seems more to the point. If you don't eat, you don't live! I wish I had been more dramatic in pleading with my Spencer's doctors. (who cares if they think I'm a nut case.....most meal times I felt that way anyway!)

People mean well. So many have said to me, "You mean Spencer doesn't eat? Why doesn't he eat, does he have anorexia?" Or how about this one, "He'll eat when he gets hungry, have you let him get hungry?" Or, "I tied my child to a chair to get them to eat. Have you tried forcing him to eat?" PLEASE!!!!!! So, now I sweetly smile and say, "I hadn't thought of that, thank you for suggesting it, I'll give it some thought." It helps to know that while those on the outside can't possibly understand the insanity we sometimes

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Letter from a Mom....continued

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face, they want to understand and they are trying in the only way they know how. That's why it's so important to have resources that do understand and can be a legitimate support and encouragement to you.

I didn't cause this. I can give myself permission to stop feeling like a failure. I didn't cause it. Practice saying that to yourself. "I didn't cause this". I can stop with the "if only I had.....". I know because I have filled in that blank with hundreds of should of's. And on a bad day I still have to remind myself that I am not the cause of this. My bad days usually stem from my frustration at not being able to fix it either. I want so badly to wave a magic spoon in front of his face and it (feeding behavior) all disappear. We know that won't happen but.....

I can help my child recover. I am my child's advocate. I don't need to sit here and tell you that you need to seek out help for your child and your family. You know that. What I am doing is sitting here being your cheerleader. Press on until you are satisfied that you are on the right track for help. Don't take NO for an answer. If it means you get a medical education in the process, good for you. I for one never believed that I would learn so much about our medical community and medicine in general. Do not be intimidated by your physicians or your insurance company!!!! You are hiring their services.....if you need to think of it in that way. They work for you and your child. (Or just picture them in their underwear.....whatever works!) Press on until you completely understand what it is your child is going through and then don't stop until you find a doctor who will listen and understand as well. Press on.....because there are factors that define how quickly you get the help you desire for your child. (Insurance appeals which require referrals.) And remember, the younger your child is, the easier it is to modify behavior. (How about a Top 10 list for getting your insurance company to say YES to treatment?)

My child is a survivor. I typed this heading and tears sprang into my eyes. He has endured so much in his almost 4 years of life. More than so many have experienced in their entire lives. He is strong willed and determined. He knows how to take a stand and not waiver. He's a trooper. These are the traits that make it so frustrating in treating his feeding disorder. However, what incredible traits to have to succeed in life. I am determined for his sake to see the glass as half full instead of half empty.....because he surely does. And I know in my heart, in the very near future, my son will ask me for a peanut butter and jelly sandwich and I'll be a blubbering idiot over it! I know that day is coming!

On the Research Front...

Abadie, V, Andre, A., Zaouche, A, Thouvenin, B, Baujat, Gand Schmitz, J. Early feeding resistance: a possible consequence of neonatal oroesophageal dyskinesia. Acta Paediatr, (2001), 90: 738-45.

This study evaluated infants with early feeding disorders that had no clear organic basis. Their feeding resistance was severe enough to justify hospitalization and was characterized by; early onset of poor sucking and swallowing skills, prolonged bottle feeding, bottle refusal, excessive regurgitation, unexplained crying, and excessive regurgitation. The authors identified 16 infants with abnormal feeding behavior who also had abnormal esophageal manometry. Thus they named the disorder "neonatal oroesophageal dyskinesia". The manometric data was compared with age match norms (children who had manometry for other reasons).

Their esophageal manometry was abnormal showing

in 70% of the cases specific anomalies; lower esophageal sphincter hypotonia and/or partial failure to relax, and giant waves of the esophageal body. Anomalies not seen in the control group.

All children received a hypercaloric and thickened diet using a soft nipple with a large hole and spoon feeding was begun early. 6 infants had to be supplemented with NG feeds for a short period. Medical treatment for reflux was tried in all infants with mixed results.

Their course was good and feeding difficulties decreased around 1 year with the acquisition of normal voluntary mastication. The authors suspect that the origin for the feeding disorder lies in the central pattern generator (CPG) in the brain stem. Because, all organs involved are innervated by the same CPG, because the clinical picture improves when cortical afferences of voluntary feeding appear, and finally because these children have clinical and manometric similarities with children with malformations for which neonatal brainstem dysfunction is suspected.

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On the Research Front:

(Continued from page 9)

Hawdon, JM, Beauregard, N, Slattery J, & Kennedy, G. Identification of neonates at risk of developing feeding problems in infancy. *Dev. Med and child Neuro*, (2000), 42: 235-239.

This was a prospective study of 35 neonates (median gestational age at birth was 34 weeks) admitted to a NICU over a 3 month period. The authors have identified a high incidence (14/35) of immature or abnormal feeding patterns when infants were assessed at 36 – 40 weeks postmenstrual age. It appears that neonates who have the most severe or complex conditions are the most at risk for dysfunctional feeding, many had neurological or respiratory disorders. Neonates with prolonged respiratory rate and delayed enteral and oral feeding were most affected.

The authors stated that other factors yet to be identified may be contributing to feeding problems such as subtle neurological problems or gastroesophageal reflux which was felt to be under diagnosed. Another point was that it is difficult for nursing or medical staff to identify babies with immature or disordered feeding patterns and that the role of an experienced therapist and dietitian is crucial for the long term intervention required with these infants.

Compared with neonates who have normal initial feeding assessments, infants with disorganized or dysfunctional feeding were 6 times more likely to vomit and 3 times more likely to cough when offered solid foods at 6 months of age. At 12 months, significant differences were also found in tolerating lumpy textures and enjoying meal time. It is hypothesized that these feeding problems contribute to failure to thrive and psychosocial distress after discharge from the NICU and proposals for measures to reduce their incidence are suggested.