



Pediatric Feeding and Dysphagia Newsletter

Dear Fellow Feeders:

Welcome to Volume 8. In this issue we feature Kay Toomey, Ph.D. writing about the SOS Approach and Claire Miller, Ph.D explains eosiniphilic esophogitis. Catherine Shaker M.S./CCC-SLP, BRS-S answers a question about nipples and also included are an interesting early intervention case study, current research, and resource information.

In this volume, I have started with my first editorial. This is an effort to share some of my opinions (for what they are worth) and for you to get to know me a little better.

Enjoy, Krisi Brackett (Write me: feedingnews@earthlink.net)

An Introduction to the SOS Approach to Feeding by Dr. Kay Toomey

The **Sequential-Oral-Sensory (SOS) Approach to Feeding** is a Transdisciplinary Program for assessing and treating children with feeding and weight/growth difficulties. It's conceptualization began in the early 1990's after a series of articles appeared in the research journals which demonstrated that to fully assess and address the problems causing and associated with feeding difficulties, professionals working in the field needed to join their expertise together rather than to continue to work in isolation and individually within only their own areas of specialization. In 1989, Bithoney, et al. reported catch-up growth in 86 children diagnosed with failure-to-thrive during a prospective study they conducted.[1] This study utilized a multi-disciplinary intervention approach which addressed the nutritional, environmental, and physical (therapeutic) needs of the child, regardless of the original diagnosis (organic vs. non-organic). The rate of growth was similar in both the group diagnosed with "non-organic" failure to thrive AND the "organic" failure to gain weight group ($p=0.297$). This study also "challenged the validity of one traditional diagnostic tenet of failure-to-thrive (FTT) management: that non-organic failure-to-thrive (NFTT) children will gain weight when given an adequate feeding trial, whereas organic failure-to-thrive (OFTT) children will not." [1] In yet another study by Bithoney et al., in 1991, the rate of growth significantly improved for the 53 children followed by a Team from a Multidisciplinary Clinic, compared to 107 children seen only in a primary care setting

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Special Points of Interest:

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

Editorial assistance provided
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Hill

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($p < .001$).[2]

The results from these studies of multi-disciplinary intervention programs suggested that infants and young children demonstrating poor growth would benefit most from a variety of treatment strategies which were all designed together to address the multiple factors which interact to result in long-term growth problems. This trend in the field towards taking a multi-disciplinary approach to feeding and growth problems more recently led Crist and Napier-Phillips (2001) to state that "...a biopsychosocial model in which physiological, behavioral, and social factors are all viewed as contributing to the development of feeding difficulties appears to be replacing the more rigid systems of classification" (organic versus non-organic-failure-to-thrive).[3]

The SOS Approach to Feeding is one such "biopsychosocial model" for assessing and treating feeding difficulties. It has been developed over the course of 15 years through the clinical work of Dr. Kay Toomey, in conjunction with colleagues from several different disciplines including: Pediatricians, Occupational Therapists, Registered Dietitians, and Speech Pathologists/Therapists. This program takes a "Whole Child" approach to feeding which integrates sensory, motor, oral-motor, behavioral/learning, medical and nutritional factors and strategies in order to comprehensively evaluate and manage children with feeding/growth problems. It is based on, and grounded philosophically in, the "normal" developmental steps, stages and skills of feeding found in typically developing children. The assessment component of the program makes sure that all physical reasons for atypical feeding development are examined and appropriately treated medically. In addition, the SOS Approach works to identify any nutritional deficits that may be present, and to develop recommendations as appropriate to each individual child's growth parameters and needs. Skills across all developmental areas are also assessed with regard to feeding, (sensory, motor, oral-motor, cognitive), as well as an examination of learning capabilities with regard to using the SOS program. The treatment component of the program utilizes the typical developmental steps towards feeding to create a systematic desensitization hierarchy of skills/behaviors necessary for children to progress with eating various textures, and with growing at an appropriate rate for them. Success is determined by sustained interest in trying new foods and eating sufficient calories of an age appropriate diet for optimal growth along their own percentile line on a growth curve.

The SOS Approach to Feeding is grounded in four tenets:

TENET 1 = There are several Myths About Eating which interfere with our ability to understand and therefore, treat feeding problems effectively.

TENET 2 = Systematic Desensitization is the best first approach for treating feeding difficulties.

TENET 3 = The "Normal Development" of feeding gives us the best blueprint for creating a feeding treatment plan.

TENET 4 = The choices of the foods we use in treatment, and how these foods are linked together (ie. Food Choices and Food Hierarchies), are critical for making progress in feeding treatment.

The SOS Approach to Feeding focuses on the fact that a child communicates what their immediate physiological experience of the food is via their behaviors. A child's behavior also communi-

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cates what their past experiences have taught them about food and feeding. If the child's feedings have gone well physically and they have had the skills to manage the foods presented appropriately, the child will learn that eating is a pleasurable experience that satisfies their hunger. If the feedings have not gone well, the child will learn that eating is to be avoided as it is not a reinforcing experience for them. What most persons term a "behavioral feeding problem", is actually a constellation of learned avoidance reactions to an experience which does not work physically for that particular child. Learned avoidance "behaviors" are not the emotional reactions or misbehaviors that most parents and professionals interpret them to be, especially below the age of three, although after the age of three there will be an emotional/cognitive component to the problem. Instead, these "behaviors" are avoidance responses which have been learned as a result of the child not having the physical skills to manage the situation. Or, these behaviors allow the child to avoid situations which cause physical discomfort.

The SOS Approach examines what each child has learned about whether eating works or does not work for them, rather than assuming that eating should just occur for the child because eating is thought to be instinctive. One of the myths about eating which interferes with a professionals' or parents' ability to understand why a child is not eating, is in fact, the Myth that feeding is instinctive throughout our lifetime. In actuality, feeding is only an instinctive drive for approximately the first month to month and a half of life, and only if the child has been born with those instincts intact [4] Many children born prematurely or with medical disorders do not necessarily have these instincts intact [5] . After the first month of age, eating is considered to be reflexive (Glass, R. & Wolf, L. (1992). Feeding and Swallowing Disorders in Infancy. Tuscon, AZ: Therapy Skill Builders.) After approximately 6 months of age, the reflexes for eating should become integrated into volitionally controlled actions. As such, after 6 months of age, eating is a learned behavior. Children learn to eat, learn to not eat or learn to only partially eat.

Another Myth about feeding is that it is a two step process; one sits down and eats. However, the SOS Approach to Feeding has identified that there are typically between 25 and 32 steps involved in the process of learning to eat. These steps have been organized into what the SOS Approach to Feeding calls the "Steps to Eating Hierarchy". As organized, these steps can be used as a tool by trained professionals to identify where in the process of learning to eat is a child, as well as what skills the child has yet to achieve. It can also be used to track a child's progress with accepting new foods. There are six major categories for tracking the progress of the child learning to eat: Tolerates, Interacts, Smells, Touches, Tastes and Eats. The goal of each step is to progressively increase the child's skill and feeling of success, leading to a desire to explore, interact, and eat foods and thereby sustain the child's improvements in eating long-term.

Beginning intervention at the level where the child is currently successful is the first step towards building skills. The next step in the SOS Approach to Feeding is to use systematic desensitization to help the child build new skills. The definition of systematic desensitization includes the use of competing relaxation responses during exposure to a graduated hierarchy of anxiety producing stimuli to help a patient learn to overcome their fears. (Reference) Systematic desensitization in the SOS Approach to Feeding includes the concept of sequential steps to assist in skill acquisition from both a sensory processing and an oral-motor perspective. The key is to think about feeding in very small steps; beginning with the ability to come to the table and ending with the successful oral-motor

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and sensory skills involved in eating foods of all tastes and textures.

Combining the Steps to Eating Hierarchy with systematic desensitization encourages the child to make small steps when they are ready, moving up the steps towards more complex interactions with the foods. **The child is always in charge of what they do with the food as a part of systematic desensitization.** In the SOS Approach to Feeding, if the child becomes distressed by one level of interaction with the food, they are encouraged to “drop back” to a “safer” level so that they can calm down and reorganize with the support of the therapist and/or family. .

Two formal studies have been completed utilizing the SOS Approach to Feeding program, beyond internal audits of individual children’s progress and parent satisfaction. The first study conducted by Erin Creach (2006) 10 children, ages 17-31 months, were videotaped during a structured mealtime using the SOS Approach to Feeding program. Each participant was presented with the same seven foods in a pre-test and post-test assessment. A behavioral coding scheme was developed to identify categories of behavior including desired behaviors, non-desired behaviors, and neutral behaviors. Frequency counts of the observed behaviors were used for comparison and analyzed using a repeated-measures, one-tailed t-test. The children participating in the SOS Approach to Feeding program demonstrated a significant increase in positive mealtime behaviors ($p < .006$); smiling, positive vocalizations, interaction with caregiver. They also had a significant increase in their interactions with food ($p < .002$); touching, stirring, picking up. There was a significant decrease in negative mealtime behaviors of crying and trying to get out of chair ($p < .001$), as well as in interfering sensory responses such as gagging, vomiting, finger splays, hand retraction ($p < .003$) and food rejection behaviors such as throwing, pushing away and turning the head away from the food ($p < .003$).

The second study by Kim Boyd (2007) looked at the progress children in SOS Feeding Groups made after 12 week segments of treatment. This study of 37 children aged 18 to 61 months, examined how many new foods each child learned to eat, as reported on 3 day diet histories completed by their parents. After their participation in a first round of a 12 week Group SOS program, these children increased their food repertoire by 41%. After an additional second round of a 12 week Group SOS program, the children increased the number of foods they were eating by an additional 17%.

Internal audits of the SOS Approach to Feeding indicate that the children participating in the Group program gained, on average, one pound in weight and one inch in height across the course of 12 weeks of intervention. These gains are in children who were not gaining height or weight prior to entering the program. In addition, the children increased their oral intake by an average of 200 calories a day after the 12 weeks of treatment. It should be noted that this internal audit did not include children on gastrostomy tubes. However, children with supplemental tube feedings are treated with the SOS Approach to Feeding and do learn to transition off of the tube feedings onto an age appropriate diet which includes a wide range of food textures.

In conclusion, the Sequential Oral Sensory Approach to Feeding has been introduced here as a transdisciplinary program based on the principles of and research on the normal developmental

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processes involved in learning to eat . The program utilizes systematic desensitization to help children learn how to tolerate, interact with, smell, touch, taste and eat a wide variety of foods. Teaching the children the skills necessary for eating then allows for them to improve their growth and weight gain.

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Q & A: Subject: New Enfamil nipples

Question: Recently Enfamil replaced their standard single-hole nipple and premature nipple with new softer versions of the nipple. For those of you that use these nipples in your pediatric hospitals, what has your experience been with them? We are finding that they the new nipples are not comparable to the older versions and feedings are actually taking a little longer. Under fluroscopy, neonates and infants are performing very differently with each of the nipples. Any observations you have made would be helpful. We recently had a meeting with our Mead Johnson/Enfamil representatives to discuss this. Thanks!

-Taryn Rogers, M.A., CCC/SLP, CT Children's Medical Center

Response: Catherine Shaker M.S./CCC-SLP, BRS-S, NICU Swallowing/Feeding Specialist

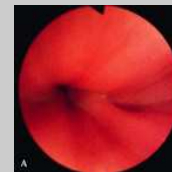
I have always found the standard single hole Enfamil nipple to run faster (have a higher flow rate) in Radiology. Our nursery doesn't stock them per nursing preference as well. The Enfamil slow flow nipple recently released has worked well for our neonates, and I hear similar positive reports as I teach around the country.

I spoke with the Mead Johnson/Enfamil research and design department, and there is 12 years of research behind this nipple apparently---which is not typically the case. Most nipples on the market have no research back up for being labeled "slow flow". When I have asked the companies for their research, I have typically been told "oh we don't have any research, we just call it that!" I do wish Enfamil had not made the slow flow nipple as soft as it is; I was told by R&D that it was based on nursing request for a soft nipple. The proprioceptive input from a firmer nipple seems from my experience, to enhance intrinsic tongue control.

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Eosinophilic Esophagitis in Infants and Toddlers: What the Pediatric Feeding Therapist Should Know

by Claire Kane Miller Ph.D.



Esophagitis (inflammation and swelling of the esophagus) is known to occur as a manifestation of gastroesophageal reflux disease. Treatment of GERD is necessary to heal injury, reduce inflammation and swelling of the esophageal mucosa, and to help relieve associated pain and discomfort with feeding and swallowing. Usually feeding problems associated with esophagitis gradually resolve in the absence of other premorbid oral motor and underlying sensory issues.

What's the difference then, between esophagitis and *eosinophilic esophagitis*?

Eosinophilic Esophagitis (EE) as a disease was described as long ago as the 1970's, but only in the last decade has it been recognized as a separate entity from gastroesophageal reflux disease (Liacouras, 2003). In the past, the presence of esophageal eosinophilia in conjunction with esophagitis was attributed to gastroesophageal reflux disease. It is now known that there is a definite difference between reflux esophagitis and eosinophilic esophagitis, primarily in relation to etiology. Patients with EE may present with clinical signs and symptoms very similar to GERD. However, eosinophilic esophagitis (EE) requires a different treatment approach for resolution. Infants and children with EE typically do not respond to conventional drug therapy for GERD, which generally includes acid suppression and pro-motility agents (Liacouras, 2004). Untreated EE has been suggested to have significant and serious implications including progressive difficulty with swallowing, development of motor dysfunction in the esophagus, formation of esophageal strictures, esophageal scarring and food impaction.

What are "Eosinophils" and what do they do?

Eosinophils are a type of white blood cell, though they are the least common of the white blood cells, and amount to a small percentage of white blood cell volume overall. Eosinophils may occur at very low volumes in numerous tissues, but normally not in the esophageal region (Ferguson & Foxx-Orenstein, 2007). Eosinophils are only a problem when they increase during an infection, or as a result of an allergic reaction. Eosinophils then release toxins which damage tissue in the area they reside such as the lungs or digestive tract. In EE, high numbers of eosinophils are found only in the esophagus. What results is often swelling, defined as "-itis" - such as *esophagitis*.

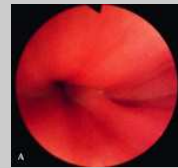
What Causes Eosinophilic Esophagitis?

The exact cause of eosinophilic esophagitis remains unknown though an association with allergies (food & environmental) has been described. Others hypothesize that eosinophils are recruited to the esophagus following an acute infectious process, and subsequently result in the development of EE. Food additives and/or exposure to pesticides have also been described, and a genetic link to EE has also been suggested. Once in the esophagus, the eosinophils may cause ongoing inflammation, which in turn causes the development of dysphagic symptoms.

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by Claire Kane Miller Ph.D.



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How is EE diagnosed?

The diagnosis of EE is made following an upper endoscopy by a gastroenterologist. During the endoscopy, the gastroenterologist examines the esophagus, stomach, and the first part of the small bowel (duodenum) through an endoscope. Multiple tissue samples (biopsies) are taken, and later examined by a pathologist. The number of eosinophils is determined and the esophageal tissue is examined for swelling, injury, or thickening.

What is the treatment for EE?

At this time, treatment approaches for EE may vary according to the practitioner. Once the diagnosis of EE is confirmed, food allergy testing is usually recommended. Once food allergens are identified, an elimination diet (all "positive" foods on allergy testing removed from diet) may be advised. In other cases, an elemental diet (all proteins removed) and the use of a special amino acid based formula is recommended. If esophageal rings or strictures have formed as a result of the eosinophilic esophagitis, esophageal dilation is required. Pharmacologic treatment (oral corticosteroid) and acid suppression is also utilized. Follow-up endoscopy at intervals to determine the effectiveness of treatment may be necessary.

What is the Role of the Feeding Therapist?

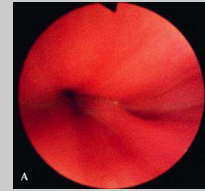
Feeding practitioners should be aware that signs and symptoms of EE will vary but often include unexplained oral feeding difficulty, discomfort with swallowing, a history of reflux that does not respond to the usual therapy, failure to thrive, and a history of allergic disease including eczema and asthma (Pentiuk, Miller & Kaul, 2007). Specific signs and symptoms prompting the initial referral for a feeding evaluation by the pediatric SLP often include feeding refusal, difficulty swallowing, and oral aversion. The referral to the speech pathologist may occur before the EE is diagnosed, during the treatment for EE, or for persisting feeding and swallowing problems once the EE is resolved.

The feeding therapist should be aware that the inflammatory component of EE likely will result in swallowing discomfort, and that children may begin to exhibit a learned aversion to feeding in order to avoid the discomfort. This conditioned response may continue even after the EE is resolved. Children that are put on elemental diets for treatment of EE may have difficulty tolerating the taste of the formula and achieving adequate volume of overall formula intake can be a challenge. The taste of the formula may exacerbate aversive responses toward oral feeding. At times, the use of a nasogastric tube to assist with achieving fluid goals is necessary. Some children have hypersensitive gag reflexes, and the physical presence of the tube can stimulate this response. The use of the NG supplemental feeding may potentially have an effect on the normal hunger satiation cycle, depending upon

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Eosinophilic Esophagitis in Infants and Toddlers: What the Pediatric Feeding Therapist Should Know

by Claire Kane Miller Ph.D.



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the schedule that is put into place. The significant restrictions that are necessary in regard to type of foods allowed in the child's diet may prevent exposure to certain textures that help with development of efficient oral motor skills for feeding. The speech pathologist has much to offer patients with EE by implementing oral motor and feeding treatment strategies that address both sensory and motor issues that may be present. Collaboration with other professionals such as psychology, occupational therapy, and the gastroenterologist is key to implementing an effective therapy plan.

What is the research consensus about EE?

Research specific to EE has been accumulating in the last decade, yet the specific epidemiology and clinical end points for medical treatment remain unknown. Further research is needed to establish evidence-based protocols for management. The speech pathologist can make additional contributions to the research database in regard to the efficacy of treatment strategies utilized in the treatment of the sensorimotor feeding problems that may accompany EE.

**Claire Miller is a clinical/research pediatric speech pathologist at Cincinnati Children's Hospital Medical Center. She was recently named the program coordinator for the Children's Hospital Medical Center Interdisciplinary Feeding Team. Contact her at claire.miller@cchmc.org

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Pediatric Dysphagia Series:

Instrumental Evaluation of Pediatric Dysphagia

Sponsored by the Division of Otolaryngology, Head and Neck Surgery, and Speech Pathology
Cincinnati Children's Hospital

October 19th & 20, 2007

The concentration will be on FEES but will cover VFSS and other swallowing related issues as well.

Contact for registration: bridgett.pauly@cchmc.org



Abd El-Fattah AM, Abdul Maksoud GA, Ramadan AS, Abdalla AF, Abdel Aziz MM. (2007) Pepsin assay: a marker for reflux in pediatric glue ear. Otolaryngol Head Neck Surg. Mar;136 (3):464-70.

The authors evaluated if analysis of pepsin/pepsinogen in middle ear effusions can be considered a diagnostic marker for laryngopharyngeal reflux (LPR) in children with otitis media with effusion (OME). There was a significant positive correlation between the level of pepsin/pepsinogen obtained in the effusions of the 17 children and the number of pharyngeal reflux episodes measured by pH monitoring. The authors concluded that control of LPR may be an essential component in the successful management of OME in pediatric patients. Pepsin/pepsinogen analysis in effusions of children, using ELISA, can be considered a reliable marker for assessment of reflux in children with OME.

Kelly BN, Huckabee ML, Jones RD, Frampton CM. (2007) The first year of human life: coordinating respiration and nutritive swallowing. Dysphagia. 2007 Jan;22(1):37-43. Epub

This study provides the first documented report of the maturation of breathing-swallowing coordination during feeding in ten healthy term human infants through the first year of life. A total of 15,073 swallows were obtained across ten assessments between 48 h and 12 months of age. Midexpiratory swallows represented the dominant pattern of breathing-swallowing coordination within the first 48 hrs, but the prevalence of this pattern declined rapidly in the first week. Inspiratory-expiratory swallows increased with age, particularly between 9 and 12 months. Between 72.6% and 75.0% of swallows were followed by expiration in the latter 6 months, which is an adult-like characteristic. These data suggest that while postswallow expiration is a robust feature of breathing-swallowing coordination from birth, two major shifts in the precise patterns occur: the first after 1 week of postnatal feeding experience and the second between 6 and 12 months, most likely due to neural and anatomical maturation.

Campanozzi A, Capano G, Miele E, Romano A, Scuccimarra G, Del Giudice E, Strisciuglio C, Militerni R, Staiano A. Brain Dev. 2007 Jan;29(1):25-9. Epub 2006 Jul 14. Impact of malnutrition on gastrointestinal disorders and gross motor abilities in children with cerebral palsy.

Children with cerebral palsy (CP) often demonstrate abnormal feeding behaviours, leading to reduced food intake and malnutrition. Moreover, most of them present with gastrointestinal disorders, such as gastroesophageal reflux disease (GERD) and/or chronic constipation (CC), and poor motor function rehabilitation. The authors concluded that malnutrition and gastrointestinal disorders are very common in children with cerebral palsy. Improved nutritional status, particularly fat free mass gain, appears to have an impact on motor function in children with CP.

Q&A Continued *(Continued from page 5)*

Regarding impact on feeding times, taking longer to feed is not necessarily a bad thing; for many of our babies, it helps improve coordination when the bolus size is smaller or the flow is more manageable. I have yet to find a baby where a faster flow or faster feeding really enhanced the safety and integrity of the swallow.

I also explain to nurses that a slow flow nipple doesn't mean it is harder for baby to get the fluid out, or that he has to "work hard"; it means a smaller bolus is delivered with each suck.

Catherine, Catherine S. Shaker M.S./CCC-SLP, BRS-S, NICU Swallowing/Feeding Specialist, Manager - Pediatric Rehab
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Case by Case... Early Intervention Case of a Difficult Feeder

By Lynette Pond M. Ed. M.S. CCC-SLP

Background: KH, a 12 month old male, was referred for a feeding evaluation due to parental concern that he was “not eating well”. At the time of the evaluation, it was determined that he had age appropriate motor skills, and cognitive skills. He had reflux as an infant and was on medication, however, this was stopped at 9 months as it did not seem to be helping and he no longer was vomiting. His weight, height, and head growth were within normal limits, but parents were concerned that with his current eating pattern this would change quickly. Parents complained that he was a fussy baby, who had never slept through the night, and needed lots of cuddling. He had some constipation, but his parents were not concerned about this.

Now at 12 months, KH was eating solids in a grazing pattern throughout the day, and was mainly accepting whole milk with carnation instant breakfast in a sippy cup, yogurt that he would only eat with his hands, and he intermittently accepted offers of dry cereal, crackers, peanut butter, and applesauce. He refused spoons and other utensils.

Intervention and Outcome: Parents were instructed to eliminate grazing and have KH sit in the high chair for consistent snacks and meals. The pediatrician honored KH’s mother’s request for a trial of reflux medication and put him on Axid and Miralax. Now on these medications, KH began to sleep through the night. Parents also reported a marked improvement in his disposition, with a decrease in clinging and whining. His mother reported that with these changes, KH’s father “actually liked him for the first time since he was really little.”

A behavioral feeding program was implemented to address the refusal of utensils. Initially, the mother chose to offer KH ice chips on a spoon, (which she knew he liked), and reinforced acceptance with toys and play. He learned the program very quickly and was accepting a wider variety of foods from the spoon. His mother also noticed that during meal times, he was eating more quantity of solid foods with his hands and accepted the presence of a spoon on his tray although he would not use it. He also was accepting a wider variety of foods; trying foods he had refused in the past.

He experienced two set backs in his progress with the onset of a flu, and a cold. In both of these instances, he returned back to accepting only the whole milk with carnation instant breakfast in a sippy cup. After the illness had passed however, he gradually returned to eating as he had before the illness. These setbacks were very upsetting to his mother. However, upon learning that this was a typical response following an illness she relaxed and watched for signs of his returning health.

Discharge: Now, at 16 months, KH is eating age appropriate foods, with a wide variety of flavors and textures. He spoon feeds himself cereal, and purees. KH has been discharged from feeding therapy.

Editorial: Finding Your Feeding Mojo (a few thoughts)

by Krisi Brackett MS SLP/CCC



Feeding problems are complicated. For most of us we have piecemealed our learning. We have picked up tips and techniques in a variety of places; our degree programs, at conferences, through literature, and from other professionals to name a few. And last but not least is experience. Hopefully, we are learning and growing as therapists with each client we treat.

There are many feeding intervention techniques available to us. How do we decide what is going to work? How do we measure success? It's taken me years to hone my skills and I have learned slowly over time. There are patients I think back on and feel if I knew then what I know now, I could have been more effective.

I can remember being a new clinician; doing my first modified barium swallow study on a toddler who graciously sat on the foot plate of the x-ray table because we didn't have an appropriate seat at the time. I recall asking an experienced clinician how to do an oral motor exam on an infant in the NICU.

I am finally at a point where I feel that I am a competent diagnostician and interventionist in this field. I know my strengths and weaknesses. And if some one asks me what my philosophy is, I can tell them. I use an integrated approach (a medical, motor, and behavioral approach) to treat feeding disorders. I can explain the literature and research that supports the techniques I use. I also know therapeutic techniques from other programs to pull in if needed or other therapists to refer too if I need another opinion or specialist.

And I continue to be fascinated by these interesting children. I recently evaluated a complicated child with Down's syndrome who refused to eat and was living on a bottle at 2 years of age. My impression was that he would be very difficult to treat and would need medical intervention, motor work for postural alignment as well as behavioral therapy.



Due to scheduling conflicts, it was 2 months before I spoke with his Mother again. She reported that he was doing much better-eating a variety of foods and asking to eat. She heard me say during the evaluation that I felt he needed to go back to his GI doctor for some reflux and constipation management. She worked with her doctor, achieved a better stooling pattern and he started to eat. I was happy to be wrong about my initial assessment.

Lastly, I am grateful to my mentors and the amazing people who work in this field. I have created a virtual team of mentors and professionals scattered all over the country that I go to for advice, commiserate with and share successes with as well. You know who you are –thank you! They are my mojo.

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Email: feedingnews@earthlink.net

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.

Special for Feeding Therapists and Professionals!



Useful Resources: Searching the WEB

dysphagia.com mailing list

- This is a subscription email list serve focusing on all types of dysphagia issues. Questions are posted to the group and any member can answer. It's a great format for posting questions, learning from other professionals, and a place to hear about upcoming events and courses. You can subscribe for daily emails or digest-style delivery or disabling delivery altogether (e.g., for a vacation), and so on.
- To sign up or change your registration contact: mailman-owner@dysphagia.com.
- For more info, send a message to the '-request' address of the list (for example, mailman-request@dysphagia.com) containing just the word 'help' in the message body, and an email message will be sent to you with instructions.

www.kidswith tubes.org

- This is a parent run organization offering support services for caregivers of tube fed children. Their mission is to provide a forum for sharing information through bringing families together, quarterly seminars, and a newsletter, *Kids With Tubes News*.
- Newsletters can be accessed via their website and focus on a variety of topics pertaining to the tube fed child.

