



# Pediatric Feeding and Dysphagia Newsletter

## Dear Fellow feeders:

Welcome to the October issue. First, I want to thank all those who have attended my feeding course, it's always nice to put a face with a name. If you're interested in coming to the course or even hosting, please go to the Motivations website at <http://www.motivationsceu.com/> to check out the 2007 schedule.

In this issue, we start with a very thorough article about specialized infant formulas. In addition, we highlight the therabite, a case, web highlights and recent literature. Look for the article I co-authored with Dr. Arvedson and Cis Manno in the Oct issue of the SID #13 (ASHA special interest division) newsletter. Share this issue (dedicated to peds) with your non-SLP colleagues. I was also lucky enough to participate on a SID #13 committee focusing on ideal training for SLP's wanting to become competent in Pediatric feeding and dysphagia intervention. Look for that from SID 13/ASHA. Enjoy!

**Krisi Brackett MS SLP/CCC**

## Use of Specialized Infant Formulas: A Thought Process

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There is a thought process that needs to occur when making decisions about the use of infant formulas that are not considered "standard". Standard infant formulas are either breast milk or cow's milk protein formulas such as Similac or Enfamil. Standard cow's milk protein formulas are designed to resemble breast milk as closely as possible. While there is a role for use of special infant formulas, for example in the medical management of allergy or malabsorptive disorders, they differ significantly from breast milk and should be used under professional advisement.

Infant formulas are composed of three macronutrients: carbohydrate, protein, and fat. In specialized infant formulas, the carbohydrate, protein and/or fat component has been modified from the standard in either composition or amount to promote tolerance or absorption. Lactose, the carbohydrate component, is replaced with smaller saccharides which are more readily absorbed than sugars with larger molecules. Cow's milk protein is replaced with hydrolyzed protein, which is hypoallergenic, or free amino acids, which are non-allergenic. A percentage of the long chain fat content is replaced with medium chain triglycerides (MCT oil), which may be helpful in malabsorptive disorders such as chylothorax, short gut, and liver insufficiency. The macronutrient composition of formulas is presented in the following chart.

(Continued on page 2)

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### Special Points of Interest:

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

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### Inside this issue:

Specialized formulas	1-5
Online Resources	5
Mandibular Exercise	6-7
Case by Case	8-9
On the Research Front	10

# Use of Specialized Infant Formulas: A Thought Process

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Formula	Uses	Carbohydrate	Protein	Fat
<b>Standard</b> Enfamil Lipil Ross Similac	Alternative to breast milk	Lactose  *Standard	Whey and Caseine  *Standard	High oleic, Safflower, Soy, Coconut oils  *Standard
<b>Soy</b> Prosobee Isomil	Galactosemia Lactose intolerance <sup>a</sup>	Corn syrup and sucrose *Modification Lactose Free	Soy protein isolate & L-methionine *Modification: Soy protein	High oleic safflower, soy and coconut oils *Standard
<b>Lactose Free</b> Ross Lactose Free Advance Enfamil Lactofree	Lactose intolerance <sup>b</sup>	Maltodextrin and Sucrose *Modification Lactose Free	Milk protein isolate  *Standard	High oleic safflower, soy and coconut oils *Standard
<b>Partially hydrolyzed</b> Carnation	Cow's milk protein allergy <sup>c</sup>	Lactose Corn maltodextrin  *Standard	Enzymatically treated whey protein  *Modification: Enzymatically treated	Palm olein, coconut and high oleic safflower  *Standard
<b>Extensively hydrolyzed</b> Nutramigen	Cow's milk protein allergy Galactosemia	Corn syrup solids Modified corn starch * Modification: Lactose free	Extensively hydrolyzed casein, L-cystine, L-tyrosine, L-tryptophan  *Modification: Hydrolyzed protein	Fat: Palm olein oil, soy oil, coconut oil, high oleic safflower oil  *Standard
<b>Extensively hydrolyzed, MCT oil pre-dominant</b> Pregestimil Alimentum	Malabsorption	Corn syrup solids, dextrose and modified corn starch *Modification: Lactose free	Extensively hydrolyzed casein, L-cystine, L-tyrosine, L-tryptophan  *Modification: Hydrolyzed protein	Medium chain triglycerides (MCT), soy oil, high oleic safflower oil  *Modification: MCT oil predominant
<b>Free amino acid</b> Neocate Elecare	Allergy	Corn syrup solids * Modification: Lactose free	Free amino acids *Modification: Free amino acids: no peptides	Safflower oil, soy oil, coconut oil. Elecare is MCT oil containing

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<sup>a</sup> While soy formulas have historically been used for "lactose intolerance", actual lactose intolerance is rare in infants. While transient lactose intolerance may occur after a severe bout of gastroenteritis, recovery typically occurs in one to two weeks and use of standard formulas should then resume. Soy formulas should not be used to treat protein allergies or with premature infants.

<sup>b</sup> Use of lactose free products may be beneficial for transient lactose intolerance that occurs after an acute episode of gastroenteritis. Lactose intolerance in infants is rare so routine use of these products is not indicated.

<sup>c</sup> While some infants may respond to use of partially hydrolyzed formulas for the treatment of allergy, their routine use for this matter is not recommended. The term "comfort protein" does not have medical meaning.

It is important to remember that an "adverse reaction" or "intolerance" to a component in a formula is different than an allergy. An intolerance may reveal itself as gassiness or diarrhea as seen in lactase deficiency resulting in lactose intolerance. In reality, lactose intolerance is not common in the infant population and need for soy formulas or lactose free products for this purpose are rarely indicated. While infants have been shown to thrive on soy protein formulas, their protein quality is of lesser biological value than breast milk or cow's milk protein and for these reasons soy formulas should not be used in the premature population. In general, the only indication for use of soy formulas is galactosemia as lactose free formulas are now available. It is also important to realize that lactose plays an important role in the development of lactase and in calcium absorption. As medical professionals, we should be cautious about unwarranted recommendations for switching to soy or lactose free products unless absolutely indicated for these reasons. It is important to make formula changes based on demonstrated infant symptoms and behaviors such as chronic distress with feeding, diarrhea, constipation, symptoms of allergy, and failure to thrive. Changing an infant formula to treat parental distress should be avoided. Consulting with a medical or nutritional professional prior to making infant formula changes is advised.

Different from an intolerance, a food allergy is an IgE mediated response and results in an adverse immune reaction. Soy and cows milk protein allergy are the most common allergies in infants. Of the 8% of children who experience food allergy, 2-3% are allergic to cow's milk protein. 33% of those with cow's milk allergy will also be allergic to soy and 33% will also be allergic to an extensively hydrolyzed protein formula. Since presence of allergy to one protein increases the chances of allergy to another, the American Academy of Pediatrics does not recommend use of soy formulas as a treatment for cow's milk protein allergy. While some infants may do well with a partially hydrolyzed protein formula (Carnation), the current recommendations favor use of extensively hydrolyzed (Nutramigen) or free amino acid based formulas (Neocate, Elecare).

Symptoms of allergy are diverse and differ in degrees of severity. Some infants react rapidly to an exposure of a low dose of allergen (IgE mediated) while others have a delayed response to larger doses of allergen (T cell mediated reaction). Only IgE mediated responses are well understood. Diagnosis typically involves a food challenge and gradual reintroduction of the offending allergen. An endoscopy with biopsy will show inflammatory changes with villous atrophy. RAST and skin testing are not helpful for food allergy detection. It is easier to do a food challenge with infants because their diet consists solely of formula. With older children, it is necessary to use an amino acid based formula, eliminate cow's milk protein and other potential allergens, and then reintroduce foods gradually one at a time.

Organ systems commonly involved in food allergy reactions are the skin, gastrointestinal tract, respiratory tract

*(Continued on page 4)*

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*(Continued from page 3)*

and cardiovascular system. Symptoms include vomiting, diarrhea, hypotension, hives, flushed appearance, itching of the skin or mucous membranes, rhinorrhea, coughing, wheezing, and throat clearing. Dermatitis will occur in 50-70%, respiratory symptoms in 20-30%, reflux in 40%, diarrhea/bloody stool in 50-60%, failure to thrive in 25%, and colic in 27% of infants.

With focus on the GI tract, additional symptoms may include eosinophilic esophagitis; which can cause dysphagia, food aversion, and reflux, eosinophilic gastritis; which may cause vomiting and abdominal pain, reflux, irritability, colic, diarrhea, constipation, and bloody stools. Cow's milk colitis can occur in the large bowel. Biopsy shows eosinophilic change and inflammation with villous atrophy. Food allergies can trigger a dysmotile response resulting in reflux or constipation that may be refractory to pharmacologic treatment.

It is important for practitioners to be aware of the symptoms of allergy and be open to a trial of an extensively hydrolyzed or non-allergenic formula. Many infants can be treated with an extensively hydrolyzed formula. However, these formulas do contain peptides of varying length and 10-25% of infants will experience an immune response. The most sensitive infants will require free amino acid formulas which completely eliminate allergens. Some practitioners are now recommending treatment of cow's milk protein allergy with a 14 day trial of a free amino acid, non-allergenic formula initially and then working toward introduction of a hypoallergenic formula when allergy symptoms abate. Potential advantages of this approach include accelerated time to relief of symptoms and a more timely rule out of milk protein allergy.

For the breast fed infant who exhibits signs of allergy, a trial of an elimination diet for the mother may be beneficial. It may take up to two weeks for the offending foods to get out of the mother's and infant's system. Initially, it is recommended that the mother avoid cow's milk and soy protein. A rice based beverage can be used as a replacement. A calcium supplement will be needed. More information regarding elimination diets can be received from the La Leche League. A breastfeeding mother on an elimination diet will need support from a lactation specialist and/or a dietitian.

While Pregestimil and Alimentum are also, like Nutramigen, extensively hydrolyzed protein formulas, they differ in content from Nutramigen and Neocate in that they are medium chain triglyceride (MCT) predominant formulas. These formulas may be used in the management of gastrointestinal disorders such as malabsorption, pancreatic disorders and short bowel syndrome. MCT oil does not require pancreatic enzymes or bile salts for absorption. While these formulas could be used for treatment of protein allergy, their use is really not indicated since the MCT oil component is not needed for allergy treatment. There is recent data questioning the efficacy and/or need of MCT oil predominant formulas with suggestion that more intact, polymeric formulas have a greater trophic effect on the GI tract, maximizing absorptive capacity and recovery.

Identifying nutrition and feeding related problems in infants and children in a timely manner is imperative to avoid long term medical, developmental, and psychological feeding issues. During the diagnosis and discovery phases of

*(Continued on page 5)*

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feeding issues, the clinical dietitian can assist with making appropriate formula choices. Working as an interdisciplinary team, timely and appropriate medical, nutritional, and therapeutic management can help ensure optimal growth and development for infants and children with nutrition related diagnosis.

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## Online Resources:

1. A good video/audio example of an infant cranial nerve exam of infants and general neurological exam of infants can be found at:

<http://video.google.ca/videoplay?docid=-6352718844936995767&q=swallowing>

2. Dysphagia list serve: The dysphagia mail list was started in 1995 to provide a forum for various medical professionals to discuss clinical or research issues, clinical cases, share ideas and news items, ask questions, or ask for resources related to swallowing and it's disorders. Job postings are allowed.

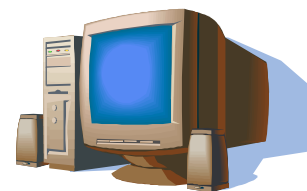
<http://lists.b9.com/mailman/listinfo/dysphagia>

3. Gastroesophageal Reflux Disease Resource Center <http://www.medscape.com/resource/gerd>

4. Two new papers on Feeding and Mealtimes [www.new-vis.com](http://www.new-vis.com) (click on new button)

5. Good interactive tutorials on a variety of subjects

<http://www.nlm.nih.gov/medlineplus/tutorial.html>



6. Feldman's GastroAtlas Online – has over 4,000 clinical, radiographic, pathologic, and histologic images to use in your presentations and lectures. [www.gastroatlas.com](http://www.gastroatlas.com)

# The value of exercise in a pediatric dysphagia population.

By Robert Horst, medical consultant to Atos Medical and founder of former Therabite corp.

Dysphagia in children is a particularly distressing condition. Children who cannot swallow properly are at risk of poor dental hygiene at a time in their lives when consequences may be life-long. They are at risk for aspiration, along with its typical sequela. They are at risk of having limited nutrition, just when their muscles, bones and brains need more, not less. And, with limited experience, some children may find it difficult to relate exactly what problems they are experiencing, making it difficult to diagnose the problem.



In some cases, muscle involvement may be a major part of the problem. Muscles of mastication (including temporalis, masseter and pterygoid) may be limited in their range of motion, and the tongue may be unable to form a proper bolus. In cases such as these, stretching, strengthening, and mobilization of these muscles may be helpful. In general, 'normal' opening for children is defined as 40-42mm measured between central incisors (often called "MIO" for Maximum Incisal Opening). It is also generally agreed that a range of motion of less than 35mm is sufficiently compromised as to require intervention. Limited jaw motion may result from a wide variety of causes, but in pediatrics, it often follows from systemic disease, including cancer, hereditary muscular dystrophy, or trauma.

**Case:** Following a fall, in which she sustained an injury to the left side of her face, Debbie age eight, had developed difficulty in opening her mouth. After several months of progressive limitation her mother noticed that she was having problems in eating and swallowing. This observation led her to seek medical care for her daughter.

After a thorough examination, including an MRI of the TMJ, it was determined that fibrous ankylosis of the joint, secondary to the facial injury had led to limited range of motion of his jaw. Over time, this condition worsened as limited motion led to muscle atrophy, which led to more restricted motion. This limited motion also impacted Debbie's ability to chew, as she found it impossible to fully open her mouth, form a proper bolus, or mobilize her tongue properly.

After discussion with other clinicians, the head of SLP decided to try to mobilize Debbie's jaw using a Therabite Jaw Motion rehabilitation system. This device is controlled by the patient, thus giving Debbie the confidence that she would not hurt herself. Debbie was instructed to use the device seven times per day, for about one minute per session. During each session, Debbie was instructed to open and close her mouth using the device for a total of seven openings and closings.

At the start of the first session, Debbie's maximum opening was 16mm. At the end of the first session, mandibular motion had increased to 18mm. However, as is typical in cases in which muscles have shortened, much of this gain was lost within two hours. One of the factors to bear in mind when rehabilitating shortened muscles is that they tend to go back to the shortened state unless stretched on a regular basis.

Debbie found the device to be easy to control, and did her exercises relatively faithfully.

After one week of repeated use, Debbie was able to open her mouth to 20mm. After one month, Debbie had attained 23mm of opening, and was reporting a better ability to chew and swallow. After five weeks, Debbie was able to reduce her regimen to five times per day from seven times per day. After several more weeks, the regimen was further reduced to only four openings and closing per session.

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Treatment continued for a total of ten weeks, by which time Debbie had achieved an opening of 36mm, which is generally accepted to be the low end of 'normal'. Interestingly, swallowing also improved at the same time opening improved.

While clinicians were pleased with the improvement in Debbie's ability to open her mouth, this improvement was expected, given that the exercises directly impacted the muscles of mastication. It was most interesting to observe a concomitant improvement in swallowing. It was concluded that the regular mobilization of the elevator muscles also improved the flexibility and tonicity of the various muscles involved in swallowing. Since no other intervention had been used, this improvement seemed to be linked to the exercise of the muscles of mastication. Swallowing involves a wide array of muscles which are linked directly or indirectly to the masseter, temporalis and pterygoid muscles. As these muscles were strengthened, and their flexibility improved, it seems that other muscles also benefited from the regimen. After three months, Debbie had approached normal opening and had improved her swallow significantly.

The Therabite device helped Debbie to perform her exercises regularly and with good control over the movements of opening, such that she was able to reduce the effects of fibrous ankylosis without the need for surgery, or other invasive procedures. The fact that it combines passive motion with patient-controlled stretching and strengthening is an important part of the success observed in Debbie. By combining stretching of the muscles, with mobilization of the joint and strengthening the other muscles associated with the elevator muscles, significant improvement in range of motion, as well as swallowing were observed.

The Therabite device is designed to be easy for the patient to operate, thus giving adults and children the confidence to take control of their own rehabilitation. It provides passive motion, as well as strengthening and stretching motions. By mobilizing the joint safely through an ever increasing range of motion, up to a maximum of 45mm, the device helps to restore joint health, as well as muscle condition. The pediatric size is designed for persons eight years of age and under, and has been successfully used by patients as young as several months. Of course, in this younger age group, the care-giver mobilizes the device, as the patient is unable to do so. However, patients as young as two years old have successfully used the device.

The Therabite device is typically helpful in cases of limited jaw motion, whether caused by systemic diseases such as cancer, diseases such as muscular dystrophy, or in post surgical cases, or in cases of facial trauma. A training video is available to help the clinician become familiar with the device, while a trained SLP is available on a toll-free line to answer questions during working hours. A web site which covers much clinical information about limited jaw motion is: [www.therabite.com](http://www.therabite.com).

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# Case by Case: Feeding Eval and Initial outcomes

Name: PL

DOB: 10/27/05, 10 months

## **Medical Diagnosis:**

1. Down's syndrome
2. Small PDA, ASD (physician is watching)
3. Hearing loss with bilateral aides
4. hypothyroid (on medication)

## **Medical History:**

**Birth History:** PL was the 6 lb, 12 oz. product of a 34 week gestation by emergent c-section. Pregnancy and birth were complicated by an increase in amniotic fluid. She stayed in the NICU for 3 weeks.

**ENT/ Pulmonary History:** No history of ear infections, pneumonia, bronchitis, or asthma. She is congested occasionally throughout the day. PL has a bilateral hearing loss and wears hearing aides.

**GI History:** PL has occasional spit up but no vomiting, gas or coughing. She has occasional congestion (worse since her colds) and severe constipation. She has never had regular bowel movements and has been constipated since 2 months of age. She may have them once per week with pain. In the past, she has taken a laxative (polyethylene glycol) which helped her to have a daily stool. Recently, she has tried prune juice in her bottle (1 oz. prune juice: 5 oz. Enfamil Lipel formula to total 6-8 oz. of prune juice per day). The prune juice helped her have a daily stool for 3 days and then stopped working. Today it has been 3 days since she has stooled.

**Development History:** PL receives PT and OT. She has good head control but weak upper body and weak trunk support. She is able to roll to both sides, rarely mouths toys, and has started to babble.

## **Nutrition/ Growth history:**

Current Weight = 15 lbs, 7 oz. (50%ile on Downs growth chart); Height = 27 ½ inches (75 %ile on Downs growth chart) No one is concerned about PL weight.

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**Feeding History:** PL was in the NICU for 3 weeks and fed via NG tube. By 6 weeks, she transitioned to oral feeds. She took 22 calorie Enficare for the first 8 months and then was switched to Enfamil Lipel. She takes 5 – 7 six ounce bottles per day. She spoon feeds 1 – 2 times per day and has difficulty with tongue protrusion. Oral motor therapy has worked on improving her oral pattern with spoon pressure on her tongue and use of a syringe to place the puree on her mid tongue.

## **Current Feeding:**

6 – 8 bottles of Enfamil Lipel per day (1 oz prune juice: 5 oz. formula). It takes about 10 – 30 minutes.

1- 2 X/day – 2 – 3oz. puree (she prefers sweet potatoes, apple sauce with cinnamon). Mom reported difficulty spoon feeding due to tongue thrust and therefore avoids it at times.

**Oral-Motor Exam: WNL** Based on observation:

**Observation of eating:** PL was seated in a highchair with poor postural alignment. She tends to use a posterior pelvic tilt with a collapsed upper body. She was fed apple sauce with cinnamon and used a suckle pattern with tongue thrust resulting in oral spill. Note slight increase in congestion during feeds. She latched on well to a bottle using a good suck.

Techniques to decrease a suckle pattern were demonstrated:

1. Allow her to suckle off of the spoon (instead of pulling it away).



## Case by Case:

2. provide pressure to base of tongue under jaw to encourage posterior tongue movement.
  3. deep pressure on tongue with jaw support
- improve positioning during feeds to achieve a 90 degree hip angle.

**Assessment:** PL is a 10 month old female with Down's syndrome who presents with a moderate feeding disorder characterized by:

1. **Oral Motor:** an immature oral motor pattern (suckle pattern with tongue thrust, weak jaw).
2. **Swallowing:** No clinical signs of swallowing difficulty. Noted slight increase in congestion with feeds.
3. **Respiration:** appeared stable at rest.
4. **Gastrointestinal Issues:** Hx of constipation, inconsistent intake and slight congestion throughout day.
5. **Motor:** Low trunk tone and weak upper extremity.
6. **Nutrition:** Proportional for height and weight.
7. **Behavior:** Accepts the spoon and wants to eat.

### Goals:

1. **Improve stooling pattern to have a daily easy bowel movements.**
2. **Increase volume and variety of purees accepted.**
3. **Improve motor skills and positioning for postural alignment during feeding.**
4. **Improve oral motor pattern to be age appropriate.**

### Recommendations:

1. Formula trial – try PL on Nestle Good start Formula to determine if it helps with her stooling pattern.
2. Positioning: PL needs to be positioned with a 90 degree hip angle with trunk support to allow for the best oral motor pattern. PT will assist with this.
3. Feeding: use techniques to decrease suckle pattern and provide jaw stability.
4. Referral to Pediatric GI to assist with obtaining regular stooling pattern and evaluate for possibility of GER (low tone and congestion).
5. Use combination of babyfood puree and tablefood puree (homemade for better flavor and texture).

### Outcome:

1. PL tried Nestle Good start but reduced her intake and was switched back to Lipel.
2. The PT is making a foam insert for her highchair to assist with positioning.
3. Visit with GI doctor resulted in correct dose of mirilax resulting in daily stool and trial of prevacid for GER (may reduce congestion).
4. Consistent jaw support and change in spoon presentation resulted in reduced tongue thrust and better control of puree.
5. PL is easier to feed and mom is enjoying feeding much more.
6. PL receives feeding therapy 2X/month.

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*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.*



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## On the Research Front:

**Suskind DL, Thompson DM, Gulati M, Huddleston P, Liu DC, Baroody FM. (2006) Improved infant swallowing after gastroesophageal reflux disease treatment: a function of improved laryngeal sensation? Laryngoscope. Aug;116(8):1397-403. PMID: 16885743**

The objective of this study was to describe improvements in pediatric swallowing after GER treatment. All patients had clinical evidence of GERD as well as evidence of dysphagia with aspiration (laryngeal vestibule and/or trachea) or hypopharyngeal pooling on flexible endoscopic evaluation of swallowing and sensation testing (FEESST) or videofluoroscopic swallow study (VSS). Each child underwent either medical or surgical intervention for control of their GERD. A significant improvement in both swallow function and sensory testing was demonstrated after GERD treatment. GERD may result in decreased laryngopharyngeal sensitivity, which may contribute to pediatric swallowing dysfunction. Control of GERD may improve swallow function. These findings have important clinical implications that need further study.

**Hazel, R. (2006) The psychosocial impact on parents of tube feeding their child. Paediatr Nurs. May;18(4):19-22. Review. PMID: 16719037**

This is a review of 13 papers examining parents experience of long term tube feeding. Making the decision to tube feed was difficult and often parents feel that they're "giving in". However, once tube feeding was established there can be a positive impact on their lives. There is a need for consistent accurate information and support.

**Garcia-Careaga M Jr, Kerner JA Jr. (2005) Gastrointestinal manifestations of food allergies in pediatric patients. Nutr Clin Pract. Oct;20(5):526-35. Review. PMID: 16207693**

GI allergic manifestations can be classified as IgE mediated, "mixed" GI allergy syndromes, or non-IgE-mediated. All these conditions share a common denominator: the response of the immune system to a specific protein leading to pathologic inflammatory changes in the GI tract which can lead to symptoms such as diarrhea, vomiting, dysphagia, constipation, or GI blood loss, symptoms consistent with a GI disorder. The detection of food allergies and treatment are discussed.