



## Children's Hospital Pediatric Gastroenterology P.C.

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### ***Hello All!***

Our focus in this edition of our newsletter is on Celiac Disease, as the number of children we see with this disease continues to grow. Celiac Disease is a genetic autoimmune disease in which a person has intestinal damage due to ingesting gluten (a protein found in products containing wheat, barley, or rye). One in 133 people in the US has Celiac Disease, whereas a person's risk is even greater if there is a family member with the disease. In addition, an even higher percentage of the population has gluten intolerance – a condition in which patients experience

the symptoms of Celiac Disease, but without intestinal damage. Treatment for both Celiac Disease and gluten intolerance is through diet modification alone, in that all foods containing gluten must be avoided.

Our practice offers many services to those with Celiac Disease or gluten intolerance, and we use a team approach in order to provide patients with the most comprehensive care possible. While our doctors make the diagnosis based on a combination of clinical, serological, and histological characteristics, the services of two dietitians are also available to aid in education and adherence to the gluten-free diet. In addition, we have a psychologist who is available to assist with difficulties in adjusting to the diagnosis and to a new lifestyle.

Please find more detailed information about Celiac disease and the related services we offer within this edition. In addition, further information concerning IBD is included, to again bring attention to the high prevalence of this disease in our patients. I hope that you will consider the many services we provide should they be beneficial for your patients. Please enjoy this issue, and feel free to contact us with any questions or referrals.

### **THE GLUTEN FREE DIET**

By Ashley Rogers, MS, RD, LDN

Celiac disease (CD), also known as gluten-sensitive enteropathy, celiac sprue, or nontropical sprue, is a genetic disorder that can affect children and adults. CD is a digestive disease that damages the small intestine and interferes with the absorption of nutrients from foods. Common symptoms for children who are gluten intolerant or have CD are: fatigue, diarrhea, constipation, abdominal pain, weight loss/gain, failure to thrive, dark eye circles, gas, anemia, abdominal bloating, and delayed growth. The only treatment for children who test positive for the celiac DNA and have active CD is a gluten free diet. Children who test positive for the celiac DNA will be on a 100% gluten free diet trial for 3-6 months. If the symptoms resolve, it is recommended that the patient remain on the gluten free diet lifelong. Avoiding gluten in the diet can be challenging and stressful. We have two registered dietitians who are highly skilled on consulting with children and families for a gluten free diet. Topics that are discussed while consulting with the dietitian:

- Avoiding gluten in both food and non-food items
- Potential nutrient deficiencies
- Reading food labels
- Substituting gluten free foods for foods in the diet that contain gluten
- Shopping tips
- Dining out
- Preventing cross-contamination
- Activities away from the home i.e. birthday parties, daycare, school

If we can be of any assistance to your patients, our staff would be more than happy to help.

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## Celiac Disease Revisited

by Clarisa E. Cuevas, M.D.



Celiac disease is being considered the “New Kid” on the GI block. As the disease became evident in the adult patient, multiple clinical updates and research studies have been published. As physicians taking care of children, we have been aware of the classic presentation and were prepared to embark on the appropriate diagnostic test. Now we have

joined our colleagues in the pursuit of full understanding of the disease and ways to reach a cure.

Celiac disease is triggered by ingestion of the gliadin fraction of wheat gluten and similar proteins of barley and rye in genetically susceptible individuals. There is a subsequent immune reaction leading to small bowel inflammation. The genetic association with class II human leukocyte antigen HLA genes DQ2 and/or DQ8 is known, being found in almost 100% of patients. Despite their key role in the pathogenesis of the disease, HLA genes account for only 40% of the genetic component of this disease. The search for other genes remains the cornerstone to achieving a better understanding of the pathogenesis of celiac disease and hopefully will result in alternative treatments to the gluten free diet.

The environmental factor that triggers celiac disease is gluten. It is the gliadin fraction of wheat gluten and the prolamins in other grains that are associated with the development of intestinal damage. It is still unclear which epitopes are involved in the T-cell response. The geographical/cultural variation in dietary consumption of cereal may alter T-cell epitope in different ways and therefore can be relevant to T-cell based diagnostics and therapeutics.

Where are we going? The role of intestinal microflora, the differences in innate and adaptive immune response, new diagnostic tests that will make intestinal biopsy (“gold standard”) obsolete, and the role of capsule endoscopy in early diagnosis. There are multiple studies that will address these and other concerns. Of note are the exciting results of a study of the enzymatic treatment of wheat flour with microbial transglutaminase and lysine methyl ester. In vitro studies show this combination was effective in blocking T-cell mediated gliadin activity and thus a marked reduction of the inflammatory response by intestinal lymphocytes. Also, a glutamine-specific endoprotease combined with a propyl-endopeptidase was deemed active in a gastric rat model and can detoxify gluten before it enters the small intestine.

What can we do now? It is recommended, that high-risk populations be screened. The list of these populations continues to grow in view of the atypical presentation, but this list includes patients with a family history of celiac disease, those with Down syndrome and Turner syndrome, Type 1 diabetes, thyroiditis, and Addison's disease. A high level of suspicion for celiac disease should be entertained in other immune disorders. It has also been suggested that gluten exposure be delayed and that breast-feeding be continued beyond two years of age so that the risk of gluten enteropathy be reduced.

## Adjustment Disorders

by Regina M. Hummel, Ph.D.



Life is a constantly changing process. Good things come our way, bad things come our way. As people, we have a greater or lesser ability to cope with these changes. For some kids with a high need for order and structure in their lives, changes can bring about emotional difficulties.

The general term used for this problem is Adjustment Disorder. However, Adjustment Disorders come in many types: adjustment with depressed mood, adjustment with anxiety, adjustment with depression and anxiety, adjustment with disturbance of conduct, etc. Consequently, there are many ways we expect that a child may show their difficulty with a new situation.

In this edition, we are highlighting Celiac Disease and the changes this illness necessitates in a child's diet. As you know dietary change is a primary form of treatment for a child with Celiac Disease. Despite understanding that foods they used to like are off limits because they will make the child sick, a child may persist in wanting certain foods. Behavioral and mood problems may follow. A child with Celiac Disease can feel singled out. A “Why me?” reaction is very common. The answer to that question can frequently get the child in trouble. “Why me? – Because I'm bad, because I'm stupid, because I did something wrong...” It is also common for a child to develop negative feelings about their body as a result of this illness. It is essential that a child with Celiac Disease understand that it is not their fault they have this illness and that their bodies can function very well for them if they eliminate the foods which irritate their system. Emphasis is placed on the foods they are still able to eat and experimenting with cooking and baking can be re-framed as a positive experience. The process of getting used to something new is always challenging, but with support and encouragement, children can usually adapt to most anything.

I am available to provide one-on-one support to families going through this and similar adjustment processes. Additionally, having access to a support group is a valuable tool in gaining support from others as a child and family work through these changes.

## MARK YOUR CALENDARS:

**November 10<sup>th</sup>** 6:00 pm: Dinner at Outback Steakhouse on North Peters Road, Knoxville. **Guest speaker** is Dr. Al-Tawil, Medical Director of East Tennessee Children's Hospital Pediatric Gastroenterology. Please join us for a question and answer session highlighting the most important topics about Celiac Disease and treatment. R.S.V.P. required due to limited seating availability. Please refer to [www.celi-ACT.com](http://www.celi-ACT.com) to reserve your seat.

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## **Capsule Endoscopy**

by Heather McCarty, LPN

One of the diagnostic studies utilized in diagnosing a variety of gastrointestinal disorders, such as inflammatory bowel disease or celiac disease is a Capsule Endoscopy. A Capsule Endoscopy allows us to view the entire portion of the small bowel, whereas standard endoscopic and colonoscopic exams view only small amounts of the proximal and distal ends of the small bowel. This is also a technique used to study motility and transit time of the stomach and small intestine.

Prior to this study, the patient will need to complete a simple bowel cleansing process. Patients are typically able to swallow the 11 X 26 mm capsule. However, in the event that the pediatric patient cannot swallow the pillcam, the capsule must then be placed during a traditional endoscopy. Images are captured from the pillcam and saved on a data recorder worn by the patient. Capsule transit times have been reported in several studies. The average gastric time is approximately 60 minutes, the average time in the small bowel is 240 minutes, and the average passage time to the colon is 300 minutes. Therefore, the study lasts for approximately 8 hours, which is enough time for complete inspection of the small bowel. During that time, the pillcam will capture an average of 50,000 images, which is about 2 pictures per second.

In conclusion, the Capsule Endoscopy has proven to be a very successful, non-invasive way to diagnose a variety of diseases of the small bowel, and we are pleased to offer it in our office. If you have any questions regarding this study or would like more information, please feel free to contact our office.

## **Celi-ACT Support**

by Sandy R. Altizer, RD, LDN

Celi-Act is a support group sponsored by Children's Pediatric Gastroenterology, PC. We are located at East Tennessee Children's Hospital, but our meetings and events are open to anyone with celiac disease or their family members. We are an ETN Celiac Support Chapter #120 of the national support group, Celiac Sprue Association.

Meetings are usually held in the **Menschendorf Conference Room, Koppel Plaza**, on the East Tennessee Children's Hospital campus, at 6:00 p.m. on the third Monday of every other month.

On the months that there is not a formal meeting we have developed a "Lunch Bunch" that meets the third Tuesday of the month at various restaurants at 11:30 am. This is an informal meeting where people can casually discuss issues or concerns they are currently experiencing. To learn more about our "Lunch Bunch" meetings please refer to our website at [www.celi-ACT.com](http://www.celi-ACT.com).

**General Public Parking (Parking Garage):** Use the Children's Hospital Parking Garage (*Clinch Ave. between 21st and 22nd Streets*) for all types of visits to Children's Hospital, Koppel Plaza and Children's Medical Office Building. \$2.00 flat fee per day.

To learn more about specific topics please visit the discussion forum at [www.celi-act.com](http://www.celi-act.com). Feel free to post questions or comments about specific concerns.

## **CELIAC Classes**

In addition to our support group, we offer a Celiac Disease Diet Class as a means of providing emotional support to our newly diagnosed celiac patients. This class is open to those patients and their families that have been instructed to begin a gluten-free diet. The goal of the class is to learn how to live gluten-free as well as for the children and parents to meet others that share the same condition. The class is offered bi-monthly on Wednesdays from 8:30-9:30 am. Please contact our office for class dates or additional information.

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## Inflammatory Bowel Disease in Pediatrics

by Alexandra P. Eidelwein, M.D.

We cannot stress enough that we see many patients with Crohn's Disease and Ulcerative Colitis – the topic of our previous issue. As we continue to see the incidence of these diseases grow in our area, we would like to provide additional information in this issue of our newsletter.

Crohn's Disease (CD) and Ulcerative Colitis (UC) are inflammatory bowel diseases (IBD) that can affect the gastrointestinal tract. CD can involve the entire GI tract from mouth to anus, and UC affects just the colon. The most common age of presentation of IBD in children is between 10 and 18 years of age, but there are cases reported even in infants. The most common symptoms of IBD are abdominal pain, diarrhea, and rectal bleeding, but children can present with only poor weight gain, joint pain, and stunting.

The cause of IBD is still under study, but is known to be a combination of genetics and environmental factors. The incidence of CD and UC has been increasing over the last several years. The diagnosis of IBD is made by a combination of clinical suspicion, complete physical exam, including evaluation of perianal disease by rectal digital exam, blood work (CBC, CMP, ESR, CRP, IBD 7 serology), radiologic studies (SBFT, CT enterography), and endoscopic procedures (EGD and colonoscopy). If Crohn's disease is still suspected, and the colonoscopy is normal, capsule endoscopy can be performed.

After the diagnosis of IBD, the goal of therapy is to induce and maintain remission of symptoms, to obtain healing of mucosa, to improve quality of life, and to decrease long-term complications. There are several medications that can be used in the treatment of IBD. For mild disease, the treatment starts with 5-ASA (5-aminosalicylates). In moderate to severe disease, the use of steroids, immunosuppressive therapy and biologics are recommended. Sometimes bowel rest and TPN help to improve outcomes and faster remission. Because of the long-term side effects of steroids, the early use of biologics has changed the progression of the disease in a large number of patients. Infliximab (Remicade) is the most common biologic agent used in pediatric CD and UC, and in general is well tolerated in the majority of the patients. Patients may now receive infusions in an outpatient setting, as we offer this service in our clinic. Possible side effects include: increased risk of infection, reactivation of tuberculosis, and increased risk of malignancy. Other biologics have been developed for the treatment of IBD, including Adalimumab, Certolizumab, and Natalizumab. Infusions can range from every 2 to 8 weeks. After the decision is made to start a patient on a biologic treatment, in general the treatment needs to be continued for several years.

The future and the outcomes of children with CD and UC will continue to change with the discovery of new therapies. The goal of our practice is to continue to offer our IBD patients the best treatment, which includes a multidisciplinary approach that allows our patients to be followed by the physician, dietician, GI nurse, and psychologist. With this approach, we hope to offer these children and their families the necessary support needed during the difficult times that a chronic disease can bring to our patients.



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