

# Cook Children's Family News

parents  partners



Gastroenterology Family Advisory Council

Volume 3, Issue 2  
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## Getting to Know the GI Team



Group Photo Back Row: Allison Holt, MSN, RN, CPNP, Nicholas Ogunmola, M.D., Bankole Osuntokun, M.D., Samson Cantu, M.D., Front Row: Jane Keng, M.D., Lyn Hunt, M.D., and Robin Henson, DNP, RN, CPNP-PC Left Photo: Danny Rafati, M.D., Ph.D Right Photo: Lori Thompson, DNP, RN, CPNP-PC

We provide care for children and teenagers with diseases and disorders of the digestive system. Offering educational resources and support to our patients and families.



***Thank you Robin Henson, DNP for 5 wonderful years in the GI Clinic!***

*Robin has accepted a position with Cook Children's Urgent Care. Please contact us at 682-885-1990 with questions or concerns about this transition if your child is a patient of Robin Henson, DNP.*



## What's New at Cook Children's Gastroenterology & Nutrition Clinic

### Social Media...

Join Cook Children's Gastroenterology Group Facebook Page

- ❖ Request to join the private group in FB
- ❖ Stay informed by joining our group



Cook Children's Gastroenterology Group page



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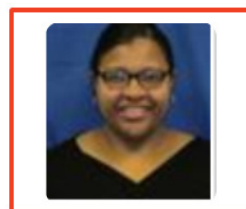


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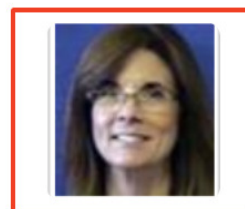
### Welcome Our New Staff & New Roles



**Beth Camacho**  
Clinical Coordinator II



**Danielle Johnson**  
Clinical Dietitian



**Donna Beach**  
GI Program Coordinator



## Special Events & Dates

**February 7 - 13, 2016 - Feeding Tube Awareness Week**, Visit the Feeding Tube Awareness Foundation website today, offering many educational resources. Please visit: [www.feedingtubeawareness.com](http://www.feedingtubeawareness.com)

**February 18, 2016 @ 6:30 pm – 8:30 p.m. – Learn About Section 504**, Cost: FREE. The Parenting Center, 2928 West 5th Street, Fort Worth, Texas 76107. Please visit: [www.theparentingcenter.org](http://www.theparentingcenter.org)

**March 28, 2016 @ 6:30 pm – 8:30 p.m. – Gluten Free 101 Class by Living Well Dallas**, Location: Living Well Dallas office, 14330 Midway, Dallas, 75245. Seating Limited. You must RSVP: 972-930-0260 if you would like to attend. Please visit: [www.dfwceliac.org](http://www.dfwceliac.org) or call 972-930-0260 for more information.

**May 21, 2016 @ 9:00 am – 4:00 pm – Challenge Air Fly Day, Tyler, TX-** Challenge Air hosts one-day events called a Fly Day. The Fly Days are offered at **no cost** to kids and young adults between 7-21 years of age. We invite you and your loved ones to come enjoy an unforgettable experience that forever changes the life of children with special needs. Please visit: [www.challengeair.com](http://www.challengeair.com) or call 214-351-3353 for more information.

## G - Button Classes for Patients & Families

**Dates:** First & Third Tuesdays of every month

**Location:** NICU Classroom (2<sup>nd</sup> Floor)

**Time:** 2:00 p.m. – 3:00 p.m.

**Topics include:** Types, care and troubleshooting

**RSVP to Carol Wise by phone at 682-885-7199 or [carol.wise@cookchildrens.org](mailto:carol.wise@cookchildrens.org)**

Staff are welcome to attend!



## Resources

### RemiStart® ... Patient Rebate Program for REMICADE®

Based on your eligibility, RemiStart® can provide a rebate for your medication out-of-pocket costs, including deductible, co-payment, and co-insurance, for up to 12 months, for a maximum annual benefit of \$8000. Contact our office for details 682-885-1990 or [visit www.remistart.com](http://www.remistart.com)

### Johnson and Johnson Patient Assistance Foundation

Johnson and Johnson Patient Assistance Program may be able to assist you with Remicade costs if eligible. Please check with our office for details at 682-885-1990 or visit [www.ijpaf.org](http://www.ijpaf.org)

# Counseling with Kate

**“Dear Crohn’s Disease: When I first found out about you, I felt betrayed by my body. I felt confused and ashamed. I felt overwhelmed. I’m afraid that you will keep me from my dreams. I’m afraid that I will die because of you. I feel worried about losing my organs. I am hoping for a cure someday.”**

**“Dear Ulcerative Colitis: I feel angry that I haven’t been in remission for two years. I feel angry that I miss out on friends and allow myself to become introverted. My first thought about you was ‘What are you? You are here to hurt me. Why? This is terrible. I hope you can handle tacos. What did I do to deserve you?’”**

The words you just read are from letters written by Gastroenterology patients. I have 90 more letters just like these in my file cabinet from patients with Crohn’s Disease, Ulcerative Colitis, Celiac disease, and multiple other diagnoses. To understand our patients, your children, means we have to understand the intimate connection between mind and body. Every single patient I see- every diagnosis I see- is worsened by feelings like anxiety, fear, anger, and depression. One study of adults with Crohn’s Disease or Ulcerative Colitis (known together as “IBD”- Inflammatory Bowel Disease), even showed psychosocial factors can be better predictors of IBD outcomes than disease factors. This study hasn’t been replicated with kids, but we can venture to make a guess.

When compared to healthy children, patients with IBD have significantly more absences from school, higher rates of homeschooling, more interference with exams, and more difficulties in pursuit of higher education. 50% of kids with IBD report being unable to play with friends, and depression rates have been found to be as high as 25% higher compared to children with no chronic condition.

Common behavioral issues in any GI patients can include frequent complaints of stomach pain, school refusal, drop in grades, medication refusal, oppositional & defiant behaviors, negative thinking- especially about their future, decreased interest in activities, isolating, changing in sleep & eating habits, fears & anxieties in social situations, difficulty toilet training, and anxiety.

But this “Counseling with Kate” entry isn’t being written to discourage you. It is being written to help normalize your child’s feelings about being diagnosed with a chronic illness. Just like everyone grieves a death differently, everyone adjusts to a chronic illness differently.

Your child may be happy as a lark one day but yelling and cursing your name the next- and that’s okay. However they feel is okay. However you feel is okay. Feelings are just feelings- they come and go, but whatever they are, they are okay. Whether your child is feeling sad, mad, happy, frustrated, exhausted, enraged, ashamed, overwhelmed, lonely, confused, let them know that it is normal to feel this way. There’s no right or wrong way to feel after receiving news that you have a chronic illness. But you can assure them that you are here for them, your Cook Children’s treatment team is here for them, and they are going to be okay. They are not alone in their feelings, in their frustrations, or in their fight.

-Kate Jennings, L.P.C.

*If you think your children may benefit from visiting with our Clinical Therapist, please call Kate at (682) 885-4829.*



Kate Jennings, M.Ed., L.P.C. | Clinical Therapist





## GUTS Support Group

Open to parents of Gastrointestinal Patients.

*Volunteers available to sit with young children during group with advance notice.*

**Cook Children's Medical Center  
Family Support Meeting Room A  
3<sup>rd</sup> Tuesday of EVERY MONTH  
6:00pm-8:00pm**

**Please RSVP to Jill Finto  
Call Jill at 682-885-4258 or email  
Heather.finto@cookchildrens.org**

## Crohn's and Colitis Pediatric Support Group

**Crohn's & Ulcerative Colitis Parent & Patient Support Group**

**Cook Children's Medical Center  
Pavilion Classrooms-rooms will vary (Parents) &  
Child Life Zone (Patients)  
3<sup>rd</sup> Tuesday of EVERY MONTH  
6:00pm-8:00pm**

**Please RSVP to Brenda Sonnier, CCLS  
Call Brenda at 682-885-4822 or email  
brenda.sonnier@cookchildrens.org**

## Strawberry Smoothie Recipe

*Note: This recipe is designed for vegetarians and vegans, or teens with lactose intolerance, who need to limit or avoid dairy products.*

This tastes great with fresh fruit, but can also be made with frozen fruit. If you don't have any strawberries on hand, use any other type of fruit you find tasty!

**Prep time:** 10 minutes

### **Ingredients:**

- ½ cup vanilla soy yogurt
- ½ cup strawberries
- 2 ice cubes
- 2 teaspoons vanilla extract

**Directions:** 1. Blend all ingredients in a blender until smooth.

**Serves:** 1

**Serving size:** 1 cup

*Reviewed by: Rupal Christine Gupta, MD*

*Date reviewed: August 2015*

**\*\* Recipe from [www.kidshealth.org](http://www.kidshealth.org) Recipes for Teens With Lactose Intolerance**

### **Nutritional analysis (per serving):**

102 calories  
3 g protein  
1.6 g fat  
0 g sat fat  
20 g carbohydrate  
2 g fiber  
0 mg cholesterol  
14 mg sodium  
30 mg calcium  
0.6 mg iron



**Note:** Nutritional analysis may vary depending on ingredient brands used.

**Variations and suggestions:** If you would like to make it sweeter and full-bodied, add a ripe banana.