



IMPROVECARENOW

# Newsletter



Children's  
Healthcare of Atlanta

## Welcome - In this Issue...

May 2016

The goal of the newsletter is to share important information about the Improve Care Now (ICN) research study that your child is participating in, introduce key members of the ICN team and what kinds of care they provide, get common questions that parents have answered, and other helpful information. This newsletter was created by the ICN team parents and we want it to be useful to you. Please read on for how to contact us with your newsletter ideas. In this issue of the GI Care for Kids (CHOA)'s and Children's Specialty Services—Egleston/Emory (CHOA)'s newsletter for parents and patients, we are **pleased to introduce Dr. Bonney Reed-Knight our pediatric psychologist**. We also discuss some travel tips for your summer vacations and have a new yummy recipe. The previous newsletter can also be found at [www.gicareforkids.com](http://www.gicareforkids.com) under the IBD Parents Tab.

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## Improve Care Now Updates

The purpose of ICN is to transform the health, care and costs for children and adolescents with Crohn's disease and ulcerative colitis through a sustainable collaborative chronic care network, enabling patients, families, clinicians and researchers to work together to accelerate innovation, discovery and the application of new knowledge. GI Care for Kids (CHOA) and Children's Specialty Services—Egleston/Emory (CHOA) are ICN centers that have established patient treatment goals for improving care.

**ICN has a great Circle newsletter.** Each Circle issue highlights voices from across our community, shares progress, and offers opportunities for you to get involved. You can sign-up at <https://improvecarenow.org/subscribe>. More information on ICN can be found at <https://improvecarenow.org>.

## Meet the ICN Teams

### GI Care for Kids Physician Leaders

Dr. Ben Gold  
Dr. Glen Lewis  
**Medical Staff**  
Clair Talmadge, P.A.  
Dr. Bonney Reed-Knight  
Caroline Adams  
Christina Carter  
**Coordinators**  
Laura Eshee  
Hannah Oloyede  
**Parents**  
Gisele Woodward  
Ann Malarcher  
Pip Spandorfer

### Children's Specialty Services Physician Leaders

Dr. Bess Schoen  
**Medical Staff**  
Dr. Bonney Reed-Knight  
Christine Spainhour  
Bernadette Martineau  
**Administrative Assistant**  
Susan Eissner  
**Coordinator**  
Hannah Oloyede  
**Parent**  
Manisha Chikhliker

## Current Improvement Actions

- ⇒ We welcome Caroline Adams, our new Nutritionist, to GI Care for Kids to help our patients with their dietary needs. Ask your doctor or nurse about making an appointment.
- ⇒ The GI Care for Kids parents and team are posting materials for newly diagnosed patients on the GI Care for Kids website- [www.gicareforkids.com](http://www.gicareforkids.com) under the new "IBD Parents" tab. See "When to call your IBD team" and upcoming medications fact sheet.
- ⇒ 87% of our Crohn's and Colitis patients across both centers have a satisfactory nutrition status.

## Quick Facts:

- ⊙ Children's Healthcare of Atlanta helps to fund our participation in ICN
- ⊙ There are over 24,600 children with Crohn's and Colitis enrolled in ICN nationally
- ⊙ Children's Specialty Services—Egleston/Emory joined ICN in 2007 and GI Care for Kids joined in 2013
- ⊙ Together we care for over 1,100 children with Crohn's and Colitis

## Meet our Parents and Get Involved

In this issue we thought that you would like to hear about living with IBD when your child is in remission from **Manisha Chikhliker, mom of two boys, Nikhil (10) and Kiran (7).**

My son, Nikhil was diagnosed with CD when he was 7 at the end of 1st grade. We were fortunate in that he responded so well to the first treatment we chose with our provider. So, he was not very sick for very long. Of course, I still remember how much my husband and I worried then about whether he would ever get well, tolerate treatment, and IVs, and if he would have to be hospitalized. I remember worrying that he might have surgery, about him not eating, being weak and just generally not thriving. He had been such a smart, active, athletic, and popular kid and it broke our hearts to see him so miserable and listless at times when he was ill. I also remember worrying about whether he would later resent us for choosing Remicade for him because of all that it entailed, and of course I

was so worried about the rare side effects of the medication.

But we plunged forward and luckily he went into remission after the very first infusion and has remained in remission ever since then! He will have been on Remicade for 3 years this summer and he has been fortunate to maintain response and he has tolerated it very well. He actually likes going for his infusions because it is kind of a "break" from his usual, busy routine. He feels better after the treatment and we make it a special iPad/TV day that he normally does not get. We often share a special meal with him in the city since we drive into CHOA from our home in the suburbs.

Nikhil is now in 4th grade, 10 years old, plays sports all year long including soccer, flag football, swimming, basketball and has done 2 youth triathlons! He plays piano as well and this year he had the opportunity to represent his school at the elementary math bowl, reading invitational, and science Olympiad competitions. He has a ton of friends and loves to read!

People are always very surprised to hear that he has IBD because they see him as so vibrant and healthy! He has grown a good bit since starting his treatment. I now worry about him developing side effects, or antibodies to the medication or him having extra-intestinal disease. I worry already about him getting older and learning to manage his IBD on his own in 8 short years and that terrifies me. As he gets close to middle school, we worry about him being more self-conscious of having IBD and not being as forthcoming with us about his stools and symptoms

But for now, we try to take it one day at a time, and we just feel blessed and thankful for each healthy day that he has and we try to make the very best of it.

Manisha

We would love to hear from you for your ideas on the newsletter and other projects. Please email us at [icnfamilyadvisorycouncil@gmail.com](mailto:icnfamilyadvisorycouncil@gmail.com).

## Meet our Pediatric Psychologist

Bonney Reed-Knight, Ph.D.—a Georgia native—received her undergraduate, masters and a Ph.D. in clinical psychology from the University of Georgia. She completed her pre-doctoral internship at the Alpert Medical School at Brown University and returned to Georgia for a post-doctoral fellowship through Emory University School of Medicine and Children's Healthcare of Atlanta.

Dr. Reed-Knight focuses her clinical interests and research on applying psychological science to improve disease outcomes and quality of life in youth with GI disorders.

As a pediatric psychologist, Dr. Reed-Knight is a member of our treatment team. Pediatric psychologists are specially trained to provide behavioral and mental health treatments in medical settings.

At Children's, we recognize physical health, mental well-being and behavior

cannot be separated. That is why pediatric psychologists are part of the team who serve our patients and their families.

Coping with a medical condition can be stressful. Working with a pediatric psychologist can help children, teens and their families adjust to a new medical diagnosis or treatment, deal with emotional side effects such as anxiety or sadness, discover new strategies to manage behavior, develop health self-management skills, learn new ways to cope with stress, pain, discomfort or anxiety and figure out how to fit treatments and medication schedules into busy lives.

Meeting with a pediatric psychologist can be a routine part of your child's comprehensive care or more targeted on specific challenges with a new diagnosis, following treatments, acting out or withdrawing behavior, coping with stress, and feeling sad, irritable, worried or in pain.

In meeting with Dr. Reed-Knight, she



will review your child's medical record and coordinate with the healthcare team, discuss your goals and concerns, learn about your child's development, social/school/family history, and adjustment to the medical setting. She will discuss psychological treatment options with your family including short-term, outpatient psychotherapy.

Talk to your child's GI doctor or nurse if you are interested in an appointment.

# Travel Tips

With vacation season fast approaching we thought we would provide some travel tips. As we all know, planning for a trip is always a good idea and it is better to be prepared and to not use your contingency plans then to feel completely lost should a medical issue or emergency arise.

## General Travel

- Bring all the medications (including over-the-counter medicines) you think you might need during your trip. Make sure to get enough of prescription medications so that they last the entire trip including extra in case of travel delays. Refilling prescriptions outside of your local area can be difficult.
- Make sure your health insurance will cover you when you travel. Call your insurance provider if you have any concerns. Depending on your insurer this could include domestic as well as foreign travel. Consider purchasing travel health and medical evacuation insurance.
- Keep a few handy nutritional snacks around in case you find your family needs a meal while in transit.
- Make sure you have appropriate accommodations, such as bathrooms for long trips. Bring toilet paper or wipes with you.
- Pack extra clothes and underwear in car or carry-on.
- Consider obtaining motion sickness medication. Ask your doctor for more information.
- Talk to your doctor if you have concerns about your family's travel plans and medical needs.

## Air Travel

- Always carry all of your children's medications and important medical information (including brief medical history) in your carry-on luggage.
- Get special written notice from your doctor, if needed for liquid medications or formula to be taken on an airplane and past security. Check with your airline for further information.

## Foreign Travel

- Go to [wwwnc.cdc.gov/travel](http://wwwnc.cdc.gov/travel) for official U.S. government travel health recommendations provided by the U.S. Centers for Disease Control and Prevention. Enter the country you plan to visit and the site will provide information on vaccines, how to eat and drink safely, a healthy travel packing list as well as travel health notices.
- Carry a list of Doctors and Hospitals at your destination. Be knowledgeable of some basic language in the country you are visiting, especially phrases like "where is the bathroom?" or words like "hospital", "pharmacy" and "doctor". Consider keeping a cheat sheet in your phone, wallet or purse.

## Recipe of the Month—Fruit Muffins

*This Specific Carbohydrate Diet Recipe was adapted from [pecanbread.com](http://pecanbread.com).*

### Ingredients:

2 1/2 cups almond flour  
2 large eggs  
1/4 tsp salt  
1/2 tsp baking soda  
1/2 tsp vinegar  
1/4 cup honey  
1/3 cup chopped apples  
1/3 cup blueberries  
1/2 cup mashed bananas  
2 Tbls chopped walnuts  
Cinnamon to taste

### Directions:

1. Preheat heat the oven to 350 degrees.
2. In a large bowl, combine ingredients through the honey - the almond flour, eggs, salt, baking soda, vinegar, and honey.
3. Divide batter into three equal parts.
4. Add apples to one part, blueberries to another part, and bananas and walnuts to the last part.
5. For each part, spread the batter



6. into muffin tins 2/3s of the way full. Yield is 18 muffins (six of each flavor).
6. Bake in a 350-degree oven for 28 min. PLEASE NOTE: everyone's oven cooks a bit differently. The muffins should be golden with a little browning at the top.
7. Serve and Enjoy—you can also try different fruits!

## Children's Healthcare of Atlanta

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**Children's**<sup>SM</sup>  
Healthcare of Atlanta

## Dedicated to All Better

Whether treating a toddler in an emergency or supporting a teen through chemotherapy treatments, we are dedicated to the care of each patient. It's through teamwork at every level of Children's Healthcare of Atlanta and with you, the family, that we are able to achieve excellence in pediatric care.

If you would like to receive this newsletter via e-mail please send an e-mail to [icnfamilyadvisorycouncil@gmail.com](mailto:icnfamilyadvisorycouncil@gmail.com).

## Upcoming Events

- ◆ **Crohn's and Colitis Foundation of America— the Atlanta Pediatric, Adolescent, and Parent Group** will meet from 6:30-7:30 PM on Tuesday, May 24 and Tuesday, July 26 at Scottish Rite Hospital. This free group is for families with children and teens that have been diagnosed with Crohn's disease or ulcerative colitis. The entire family is encouraged to attend. More information and future dates can be found at [www.ccfa.org/chapters/georgia/supportgroups/Atlantafamilygroup.html](http://www.ccfa.org/chapters/georgia/supportgroups/Atlantafamilygroup.html)
- ◆ **GI Care for Kids website update**—We've added a new tab for IBD Parents. Click on the tab and find a new IBD resource list and information on when to call your IBD team. Please go to [www.gicareforkids.com](http://www.gicareforkids.com).
- ◆ **Family IBD Education Day at CHOA—Save the Date: Saturday, August 20.** Further details will be announced on [ccfa.org/chapters/georgia](http://ccfa.org/chapters/georgia).
- ◆ **CCFA Camp Oasis**—a co-ed residential summer camp for children with Crohn's disease and ulcerative colitis will be held at Camp Will-a-Way in Winder, GA from June 19th - 24th for campers (grades 2-10), Leaders in Training (grades 11-12), and volunteers (age 19+). For more information go to [www.ccfa.org/chapters/georgia/events/camp-oasis.html](http://www.ccfa.org/chapters/georgia/events/camp-oasis.html)

What's  
Happening