



IMPROVECARENOW

Newsletter



Children's
Healthcare of Atlanta

August 2015

Welcome To the First Issue!

We are pleased to present this first issue of the Children's Healthcare of Atlanta (CHOA) ImproveCareNow (ICN) Family Advisory Council's newsletter for parents and patients. The goal of the newsletter is to share important information about the Improve Care Now (ICN) research network in which your child is participating, introduce key members of the ICN team and the kinds of care they provide, present answers to common questions that parents have, and other helpful information. This newsletter was created by the ICN Family Advisory Council parents, and we want it to be useful to you. Please read on for how to contact us with your newsletter ideas.

A Quick Refresher on Improve Care Now (ICN)

The purpose of ICN is to transform and improve the health, care and costs for all children and adolescents with Crohn's disease and ulcerative colitis by building a sustainable collaborative chronic care network, enabling patients, families, clinicians and researchers to work together as a health care system to accelerate innovation, discovery and the application of new knowledge. GI Care for Kids (CHOA) and Children's Specialty Services—Egleston/Emory (CHOA) are Improve Care Now centers that have established patient treatment goals for improving care. More information on ICN can be found at www.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

Christina Carter

Hannah Oloyede

Coordinator

Laura Eshee

Parents

Gisele Woodward

Ann Malarcher

Pip Spandorfer

Children's Specialty Services Physician Leader

Dr. Bess Schoen

Medical Staff

Dr. Bonney Reed-Knight

Britney Eyster

Christine Spainhour

Administrative Assistant

Dawn Murrain

Nutritionist/Coordinator

Bernadette Martineau

Parents

Kelli Fulford

Manisha Chikhliker

GI Care for Kids

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Atlanta, GA 30342
404-257-0799

Children's Specialty Services - Egleston/ Emory

2015 Uppergate Drive
Atlanta, GA 30322
404-785-KIDS (5437)

Quick Facts:

- ☉ Children's Healthcare of Atlanta helps to fund our participation in ICN
- ☉ There are over 19,000 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 2013
- ☉ Together we care for over 1,000 children with Crohn's and Colitis

Current Improvement Actions

- ⇒ We are developing a standardized Enteral Nutrition Therapy program for Crohn's Disease patients across both centers
- ⇒ We are in the process of developing an educational book and an IBD passport for newly diagnosed patients
- ⇒ 89% of our Crohn's and Colitis patients across both centers have satisfactory nutrition
- ⇒ We have added a Psychologist (Dr. Bonney Reed-Knight) to both center's teams to help our patients with every aspect of their care. Ask your doctor or nurse about making an appointment.

Meet our Parents and Get Involved

In this issue we would like to introduce 4 of our 5 Atlanta ICN Family Advisory Council parents.

Hi! I'm **Manisha Chikhliker**, mom of 2 boys, Nikhil (9) and Kiran (6) and Nikhil has Crohn's. We live in Peachtree City, I love to run, love to cook and love to watch American Ninja Warrior with my kids! :) I work as a physician at the VA. I am looking forward to IBD families connecting with each other!

Ann Malarcher — Welcome everyone! My son, Chris, was diagnosed with Crohn's disease 4 years ago and is starting college this fall. I recently retired after 23 years at CDC working on helping folks quit smoking. I live in Norcross, and will be gathering tips on how to transition to college.

Pip Spandorfer - I'm a father of 2 kids with Crohn's Disease. I'm on the board of the Georgia Chapter of The CCFA and am a facilitator of the At-

lanta Pediatric, Adolescent, and Family support group. My family is very active in IBD fund raising and reaching out to newly diagnosed families. I'm a general pediatrician and am passionate in helping IBD families. Looking forward to meeting you!

Gisele Woodward —Our family has been managing IBD for a long time since my husband and 2 kids (ages 14 and 12) have Crohn's Disease. Both kids were diagnosed almost 4 years ago. After that time, we started our own Foundation to raise funds for IBD research, in Charleston SC where we live. In our spare time we love to go boating. Looking forward hearing from you!

We plan to become familiar faces through this newsletter—serving as comforting voices as we discover new ways to best support all of our families and assist in increasing communication between families and providers.

We would love to hear from you for your ideas on the newsletter and other projects. Please email us at ICNFamilyAdvisoryCouncil@gmail.com.



Pip Spandorfer, Ann Malarcher, Christina Carter, Marie Gay, Clair Talmadge, Dr. Bonney Reed-Knight, Dr. Gold, Dr. G. Lewis, Gisele Woodward



Britney Eyster, Bernadette Martineau, Dr. Bonney Reed-Knight, Christine Spainhour, Dawn Murrain, Dr. Bess T. Schoen, Marie Gay

Recipe of the Month — Easy Cinnamon Squares

This Specific Carbohydrate Diet Recipe is courtesy of Gisele Woodward at woodwardccf.com

Ingredients (main dough):

3 cups blanched almond flour

1/2 tsp salt (or just slightly under that amount)

1/4 tsp baking soda

1/4 cup safflower oil (or oil of choice)

2 Tbsp honey

2 large eggs

For the filling:

1/4 cup honey (depending on how much sweetness you like)

1/4 cup raisins (optional)

1 Tbsp ground cinnamon

Directions:

1. Preheat heat the oven to 350 degree.
2. Grease with desire oil a square pan 6x6 or round pan of similar size
3. In a large bowl, combine all ingredients - the almond flour, salt, baking soda, the oil, honey, and eggs.
4. Mix (knead) until a smooth dough is formed (*Electric mixer not needed but can be use in medium to low speed*) Spread 1/2 of the dough into pan and spread evenly
5. Add filling mixture and swirl a bit if desired
6. Spread the remiaing dough on top of filling
7. Bake in a 350-degree oven for 15-20 min. PLEASE NOTE: everyone's oven cooks a bit differently. The dough should be golden with a little browning at the top. The dough should not be glossy or appear wet. Unfortunately, a toothpick might not work and appear wet because of the filling
8. When ready, remove from the oven and let cool for at least 10 min. If you try to move them before then, they might break up
9. When cool cut them like brownies and serve... Enjoy

Topic of the Month — Does my child need a 504 plan for school?

The 504 plan is an important communication tool for you and your child. Your child should have a plan that will help them be successful in school while living with Inflammatory Bowel Disease. Having a clear plan eliminates difficult situations that could arise and gives the parent and student the opportunity to partner with the school for a productive school year. It also allows for a protocol to be established for daily issues like frequent bathroom visits, absences due to appointments, treatments or illness and extending assignment due dates due to sick days. You will find teachers, guidance counselors, attendance counselors, coaches and principals are very receptive to the 504 plans as it gives them much needed information to help your child succeed.

Many schools have their own 504 forms to create the plan. Ask the guidance counselor at your child's school for a 504 planning meeting. Work with your Gastroenterologist's office to sign off on the 504 plan and obtain a letter describing your child's condition to help support the plan.

If your school does not have their own 504 planning form, The Crohn's and Colitis Foundation (CCFA) and Just Like Me! Teens with IBD organization has templated 504 plans that you can use as a guide to ensure that your child's needs are being met in school.

For more information about 504 plans and guides, visit these websites.

Just Like Me! Teens with IBD <http://www.justlikemeibd.org/life/school/accomodations.html>

Crohn's and Colitis Foundation <http://www.ccfa.org/resources/template-section-504-plan.html>

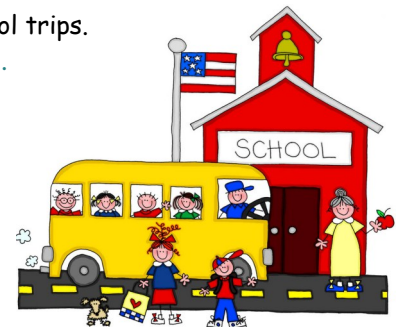
The 504 school accommodation plan comes from Section 504 part of the Rehabilitation Act of 1973. Section 504 is a law that requires the needs of students with disabilities to be met adequately. To qualify, your child must have a long term illness such as inflammatory bowel disease (Crohn's Disease or ulcerative colitis). Christine Spainhour, BSN, RN, CCRC; Improve Care Now Team; Children's Specialty Services

Back to School Tips and Tricks—Accommodations

At the beginning of school, it is good to meet with school officials including your child's teachers, principal, nurse and counselor. By having this meeting, everyone will be on the same page about your child's care. Suggested topics include bathroom privileges. Identify a private bathroom for the student to use if there is one. If not, some children with IBD will still want to use the restroom in private and will not go during breaks when other students are present. It is not uncommon for the IBD student to ask to use the restroom right after class starts. The teacher should understand this concern for privacy and allow the IBD student to have unlimited bathroom breaks. The school should understand that students often have to miss school for doctor's appointments, treatments and tests that are beyond the parent's control. Furthermore, the school should assist the student in making up any missed class time and assignments and try to minimize stress in the student as much as possible. It would be nice to discuss with the school nurse that ibuprofen may not be the first choice for fever or pain in a student with IBD. Remind the school officials that children with IBD need extra sleep and may not bounce back well after overnight school trips.

For future newsletters — Please let us know of other accommodations that are helpful.

E-mail us at ICNFamilyAdvisoryCouncil@gmail.com.



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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@choa.org

Upcoming Events

- ◆ Crohn's and Colitis Foundation of America— the Atlanta Pediatric, Adolescent, and Parent Group will next meet in October. Look for an update in the next newsletter. More information can be found at www.ccfa.org/chapters/georgia.
- ◆ Check-out the new Smart Patients IBD Community which was created in partnership with ICN. This online community is for motivated patients, their families and friends. Patients often become extraordinarily knowledgeable and get better care by learning from each other. You can get help and advice from patients who have your same illness and similar complications and treatments. For more information and to join go to www.smartpatients.com/communities/ibd.

What's Happening

Finally, a great time was had by all who attend CCFA's summer Camp Oasis of Georgia - for more information on next year's camp go to www.ccfa.org/get-involved/camp-oasis/find-a-camp

