



IMPROVECARENOW

Newsletter



Children's
Healthcare of Atlanta

Welcome - In this Issue...

August 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. The previous newsletters can be found at www.gicareforkids.com under the IBD Parents Tab.

GI Care for Kids
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Suite 440
Atlanta, GA 30342
404-257-0799

Children's Specialty Services - Egleston/Emory
2015 Uppergate Drive
Atlanta, GA 30322
404-785-KIDS (5437)

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. [More ICN information can be found at https://improvecarenow.org.](https://improvecarenow.org)

At **GI Care for Kids** we have a new form for patient care called the Review of Systems form. The next time you come into the office, you will be given this new form on lavender paper. Your completion of this form will provide your doctor with an idea of how you/your child has been doing since your last visit. It will give your doctor an idea of whether or not you/your child knows your current medications; what, if any, difficulties you are having in remembering to take your medications; when your last eye exam was performed; and several other items. **Please do your best to complete the entire form and be ready to discuss it with your doctor :)**

Children's Specialty Services-Egleston/Emory now holds their Population Management meetings once a month to discuss better ways to improve patient care. We are now also part of the ICN Engagement Campaign in order to learn ways to increase parent/patient involvement.

Quick Facts:

- ☺ Children's Healthcare of Atlanta helps to fund our participation in ICN
- ☺ There are over 25,400 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 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

Children's Specialty Services Physician Leaders

Dr. Bess Schoen

Medical Staff

Dr. Bonney Reed-Knight

Christine Spainhour

Bernadette Martineau

Coordinators

Laura Eshee

Hannah Oloyede

Parents

Gisele Woodward

Ann Malarcher

Pip Spandorfer

Beth Mclean

Administrative Assistant

Susan Eissner

Coordinator

Hannah Oloyede

Parent

Manisha Chikhliker

Reaching our Goals

- Since January 1, 2016 we have reached the following goals:
- ⇒ We have enrolled 1047 of 1186 = 88% of our IBD patients into ICN.
 - ⇒ Our Remission Rate has increased from 74.6% to 77.8%.
 - ⇒ Our Percent of Patients Not Taking Prednisone Rate has increased from 94.0% to 95.1%.
 - ⇒ Our Percent of Patients With a Documented Visit Within the Last 200 Days has increased from 75.9% to 79.6%.

Meet our Parents and Get Involved

In this issue, we thought that you would like to hear from Pip Spandorfer, one of our ICN Family Advisory Council parents who is a father of two kids with Crohn's disease about his work with the Atlanta Pediatric, Adolescent, and Parent IBD Support Group which provides a supportive forum for IBD patients and their families.

Through my work with the Atlanta IBD Support Group I have found that almost every parent of a child with IBD has similar feelings and often times feel very overwhelmed following this diagnosis. Frequent questions that parents ask include: When will my child feel better? What happened to the kids they used to be? What does this diagnosis mean? Will my child achieve remission? What is remission? Will my child grow up to be a happy and healthy adult? Then there are the questions that the kids with IBD ask - what does this mean? Am I the only one with IBD? What do I tell my friends? The siblings of IBD patients might ask, am I going to get it too?

Based on all the uncertainties that families with IBD are faced with, a pediatric IBD support group is a great place to turn. The Atlanta group was created with the help of the Crohns and Colitis Foundation of America (CCFA) and has become a

model group for the country.

At the Atlanta group, both children with IBD and their parents (siblings welcome too) have a place to go to not feel so isolated, and get support for their concerns. The Atlanta support group meets every other month and has become a very uplifting and empowering hour. The support group is the furthest thing from a group of kids sitting around saying, "Ow, my stomach hurts...". To the kids, it is almost a camp reunion of kids who went to Camp Oasis with the addition of other kids who want to share their experiences. From my experience, it is the kids who are the ones encouraging their parents to go to each meeting.

The kids break into two groups, one for the adolescents and one for the younger kids, and there is a separate parent group. The discussion flows easily in each group. Everyone is welcome to come and share their experiences and tips for managing IBD. With the assistance of child life specialists, we are able to provide great programming for the children to express themselves.

To sum up what the kids think about the support group, in the last group they wrote letters to newly diagnosed patients. The universal theme that the kids shared was, "You are not alone". What a nice and uplifting atti-

tude these kids have about their disease. There is so much positive that comes out of the support group for kids and parents. It is our hope that the group will help the kids to eventually take ownership of their disease management as they get older.

Everyone is always welcome at support group.

Pip

Next Meeting of the Atlanta Pediatric, Adolescent, and Parent IBD Group –

Wednesday, September 14, 6:30-7:30pm (arrive 10 mins early to sign-in) Children's Healthcare of Atlanta - Egleston 1405 Clifton Road NE. Atlanta, GA 30322. Classrooms on main floor.

Contact: Ellen Spandorfer at pipln@yahoo.com

More information is available at

<http://www.ccfa.org/chapters/georgia/support-groups/Atlantafamilygroup.html>

Recipe of the Month—Red Pepper Sauce with Your Favorite Fish, Shrimp or Chicken

This Specific Carbohydrate Diet Recipe is courtesy of Chef Matthew Lewis.

This recipe works with a wide variety of fishes, including snapper, grouper, halibut, and salmon. Its also a very nice method to prepare chicken or shrimp. Pro Tip: Try baking chicken in this sauce with SCD legal cheese on top for a very satisfying meal. Another idea is to cook your shrimp in the sauce and use it for lettuce wraps with your favorite SCD legal slaw.

Ingredients:

- 1 Tablespoon Extra Virgin Olive Oil
- 2 Red Bell Peppers, Small Diced
- 1 Large Yellow Onion, Small Diced
- 4 Large Cloves Garlic, Minced
- 1 Teaspoon Ginger, Minced
- 1 1/3 Cup Water or Home Made Chicken Broth
- 1 1/2 Tablespoon Butter

- Juice of 1/2 Lemon
- 6 Leaves Basil
- Salt and Pepper
- 4 Fillets of Your Favorite Fish, Shrimp or 2-4 Boneless, Skinless Chicken Breasts

Method:

1. In a sauce pot or high walled pan, heat cooking vessel over medium high heat for 1 minute. Add olive oil, peppers, onion, garlic, and ginger. Season with 1 ½ teaspoons of salt. Stir frequently while sautéing vegetables until soft, about 3-4 minutes.
2. Add water to the cooking vessel and bring to a simmer. Continue cooking until liquid is reduced by about half.
3. Pour the cooked vegetables and liquid into your blender, and blend to smooth. Start with the slowest setting
4. In a casserole dish that fits your fish or chicken without much extra room, to the side, pour in the pepper sauce until it comes halfway up your chosen protein. Try not to get sauce on top of your fish or chicken. Season the top of your protein with salt and pepper.
5. Bake at about 350F until your fish or chicken is cooked through. For chicken, the sauce may dry out a little during cooking so add just a little water to bring it back to a nice consistency.

Meet our Pediatric Dieticians

Our pediatric dieticians are important members of our treatment team. Clinical dieticians/nutritionists are specially trained to provide medical nutrition therapy as part of the overall clinical care plan. Eating a healthy diet and maintaining good nutrition is important in inflammatory bowel disease. Working with a pediatric nutritionist can help children, teens and their families assess the patient's diet and see if there are any suggested recommendations towards meeting your child's dietary needs.

Meeting with a pediatric nutritionist can be a routine part of your child's comprehensive care. In meeting with Caroline or Bernadette, she will review your child's medical record, coordinate with the healthcare team and discuss your child's diet, nutrition goals, and concerns. Having regular meetings with a dietitian for dietary adjustments and monitoring of growth and nutritional status is crucial for children with IBD.

Caroline Adams, MS, RD was born and raised in the mountains of North Carolina as the oldest of 4 children. She attended Western Carolina University, close to her hometown of Franklin, before she transferred to the University of Georgia to finish her undergraduate degree.

After working in fashion and retail for several years post graduation, she went on to complete a Masters of Science degree from Georgia State University in Nutrition. She has worked at Children's Health Care

of Atlanta for the last several years and during this time she worked as Dietitian on the GI floor of Scottish Rite. Through her work, she gained an interest in patients with Inflammatory Bowel Disease and the role of nutrition in their disease—as malabsorption can impair growth and development.

Caroline now works primarily at GI Care for Kids and will assist your family to ensure proper nutrition.



Bernadette Martineau, MS, RD is a member of the Children's Specialty Services team at Egleston/Emory. She is a Massachusetts native and received her undergraduate degree in Biology from St. John Fisher College in Rochester, NY. After several years in the workforce, she decided to go back to school and pursue a Masters degree in Nutrition, to combine her love of food with science. She completed both her nutrition course work and supervised practice at Georgia State University.



Talk to your child's GI doctor or nurse if you are interested in a clinic visit with Caroline or Bernadette.

Back to School Tips

Remember it is your decision about who you let know about your child's disease. In situations such as school or college, even if you do not want any special arrangements made for your child, it may help to decrease your stress and that of your child to at least know that options are available to you and your child. School is another area of your life that will require planning ahead and organization, your two best allies when dealing with the stress of IBD.

Here are some tips that we believe might be helpful for you.

⇒ Make sure the nurse's office is informed of any and all medications your child takes or any other treatment plan.

- ⇒ Make sure your child knows that the nurse's office is a safe place for him to go if he/she is having any discomfort or symptom even if it is just to lay down for a few minutes.
- ⇒ Inform the school if there needs to be any special provisions for field trips, classroom or during testing.
- ⇒ Consider asking your school to put together a 504 plan, which allow for special accommodations for your child dealing with IBD (which is considered a disability under the law).

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>

Please see Volume 1 of our Newsletter at <http://www.gicareforkids.com/> Under the "IBD Parents" tab for additional information on 504 plans and accommodations.

Children's Healthcare of Atlanta

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Children'sSM
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.

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

Upcoming Events

- ◆ **Crohn's and Colitis Foundation of America— the Atlanta Pediatric, Adolescent, and Parent Group** will meet **Wednesday, September 14, 6:30-7:30pm** (arrive 10 mins early to sign-in) Children's Healthcare of Atlanta - Egleston 1405 Clifton Road NE. Atlanta GA 30322. Classrooms on main floor.
More information is available at <http://www.ccfa.org/chapters/georgia/support-groups/Atlantafamilygroup.html>
- ◆ **GI Care for Kids website update**— We added new information on Patient Treatment Options under the IBD Parents Tab. Please go to www.gicareforkids.com and click on the IBD parents tab.
- ◆ **Children's Health Care of Atlanta website update**—Our new site makes it faster and easier to find the information you need. Please visit <https://www.choa.org/>

What's
Happening