



IMPROVECARENOW

# Newsletter



Children's  
Healthcare of Atlanta

## Welcome - In this Issue...

May 2017

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](http://www.gicareforkids.com) under the IBD Parents Tab.

**GI Care for Kids**  
993-D Johnson Ferry Rd.  
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).

## Quick Facts:

The research study evaluating the effectiveness of the Specific Carbohydrate Diet in reducing symptoms in pediatric patients with IBD has been named the PRODUCE (Personalized Research on Diet in Ulcerative Colitis and Crohn's Disease) Study. Members of the ImproveCareNow community collaborated to design the study (to address a need for more information about the role of diet in the treatment and management of IBD) and have now named the study together. [Sign-up for updates at http://www.improvecarenow.org/research\\_opportunities](http://www.improvecarenow.org/research_opportunities). ImproveCareNow celebrated its 10 year anniversary at its Spring 2017 Community Conference in April. ICN's Patient Advisory Council has welcomed 5 new members. Three of them are from Children's Healthcare of Atlanta! [More information on the new members is available at http://www.improvecarenow.org/pac\\_welcomes\\_six\\_new\\_members](http://www.improvecarenow.org/pac_welcomes_six_new_members).

- ☉ Children's Healthcare of Atlanta helps to fund our participation in ICN
- ☉ There are over 27,400 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

### 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, Beth Mclean  
Ann Malarcher, Pip Spandorfer

### Patients

Christian Lawson, Chris  
Malarcher, Abigail Sandifer

### Administrative Assistant

Susan Eissner

### Coordinator

Hannah Oloyede

### Parent

Manisha Chikhliker

## Reaching our Goals

Since January 1, 2017 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%.
- ⇒ Clair Talmadge, our physician assistant, has begun seeing patients at GI Care for Kids in February.

⇒ We are almost ready to begin enrolling for the COMBINE Research Study. This study will compare the outcomes of using a biologic medication, such as Remicade or Adalimumab, alone versus using a biologic medication in combination with methotrexate. If you are interested in learning more about this study, please let your doctor know.

## 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 college from Ann Malarcher, mom of Christopher age 20.

My son, Christopher was diagnosed with Crohn's Disease when he was 14 in the summer before he started high school, and in the summer between 10th and 11th grade had a resection surgery. Since then Chris has been treated with Remicade and has thankfully remained in remission.

In high school, Chris always liked to challenge himself by taking difficult classes and keeping a very full schedule. Although my husband and I respected Chris's interest in challenging himself, we were also concerned how easy it was for Chris to overload himself leading to a lot of stress from huge amounts of homework, the time it took to understand the difficult material, and lots of extracurriculars. As college approached my husband and I hoped that Chris would learn to avoid schedule overload to reduce stress.

Christopher applied to a variety of colleges (both large and small and in-state and out-of-state) and chose to attend Emory University in Atlanta. Choosing to stay in the Atlanta metro area for college allowed Christopher to continue his care with Dr. Glen Lewis at GI Care for Kids which took

a lot of stress off for me and my husband as we did not have to figure out new care givers, deal with potential out-of-state insurance issues, and worry that we could not easily reach him if he became ill.

Chris's transition to college life has gone really well with only a few challenges along the way. Emory and most universities have freshman seminars which do a great job of integrating students into campus life and checking-in on how students are doing.

One of the biggest challenges Chris faced was the roommate situation. Chris's first roommate liked to have all-night parties which didn't allow Chris to get adequate rest. Chris switched roommates for second semester and although the next roommate was not into partying he never left the room except to attend classes and Chris found it difficult to have any downtime alone in his room or to have friends over. So, for sophomore year Chris applied to have a single room (which was a special request for the university). After initially being denied a single room, Dr. Lewis and I wrote letters to the university using an example from the Crohn's and Colitis Foundation's website and Chris was given a single room which he has enjoyed. Chris is having a great time at school and has joined a social club and the Sigma Phi Epsilon fraternity, and

is conducting research with two professors.

Chris has also taken on more and more responsibility for his care over time. When Chris turned 18 I began to ask him if he wanted to see Dr. Lewis alone or have me accompany him. So far Chris sees Dr. Lewis by himself about 50% of the time. Chris has also arranged for routine care through Emory's student health center which reaches out to Dr. Lewis with any questions. Chris ended up getting the all too common mononucleosis with strep throat at the end of sophomore year but luckily already took his finals and miraculously only missed four days of school.

Chris is learning to achieve a better balance with his classes and dropped a course freshman year when he felt overloaded. This summer Chris is going to Spain with his Sociology class. As Manisha said in an earlier column we are taking it one day at a time, and feel blessed for each healthy day and for Dr. Lewis, Cristina, Dr. Lewis's nurse, and Claire and Dr. Gold who saw Chris when he had mono and Dr. Lewis was on vacation.

Ann

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

## Recipe of the Month—Specific Carbohydrate Diet Pizza Crust

*This Specific Carbohydrate Diet Recipe is courtesy of Giselle Woodward.*

### SCD Pizza Crust

2 cups of almond flour

2 eggs

1/4 tsp Italian seasoning

1/8 tsp garlic powder (optional)

pinch salt

1/2 cup shredded Parmesan cheese

4tsp olive oil

Combine all ingredients together and let rest 5 minutes. Stir dough, it should be as thick as a cookie dough, if it isn't add more almond flour, a tablespoon at a time until it is. Line a cookie sheet or pizza sheet with parchment paper. Cover dough with plastic wrap and using hands or a small rolling pin push/roll the dough into a circle. Bake in a 400 degree oven for 7-9 minutes or until barely brown. Add desired toppings/red sauce and bake 5-10 more minutes until golden.

**Note:** The dough once baked for the first 7 minutes can be freeze and used at a later

time. Store in airtight container and freeze. When ready to use, just thaw, add toppings and bake.

# Meet your ICN Patient Committee Members

Our ICN Patient Committee Members are important members of our Family Advisory Council. Patients share their experiences in living with IBD, identify patient needs and concerns, and propose ways for health care improvement. For this issue we would like to introduce **Christian Lawson** one of our three patient committee members.

Hi, my name is **Christian**. I am 17 years old and I attend Atlanta Adventist Academy. I am very involved in my church, school, anything video production, student leadership positions, and more! I love staying active and always doing things to help and serve others.

At the age of eight, I was diagnosed with Crohn's disease. It's been an up and down hill battle, and I consider that it's almost like riding a rollercoaster. In 2015, I faced a horrible flare up. I lost function of my joints and could not do anything for myself. While in the hospital, the test and procedure results came back showing I had six to 10 inches of my small intestines that were 80-90% closed. They told me that I would need to have surgery in order to remove the diseased part. I was so scared and had read all of the stats, which made me worry more. BUT, I had surgery and my recovery

was quick! A couple of days after my surgery, I was even eating solid foods and doing laps in the hallway. Today, I am doing well! My weight is wonderful, my appetite is awesome, and my Crohn's is in remission. I am currently on immunosuppressants and biologics.

Last summer, I received a phone call from GI CARE FOR KIDS, asking me if I would be interested in joining the ImproveCareNow Family Advisory Council (FAC), and I gladly accepted. The reason I joined the FAC is because I want to share my story with other IBD patients within my center. I want to make an impact in my center, and all over the world. IBD is a tough disease to have, but with the help of doctors, nurses, and more you are able to make it through. I believe that peers can also help with the transition process for those who are newly diag-



## Yoga for Children's Health A Mindful Child Yoga and Wellness [www.amindfulchild.net](http://www.amindfulchild.net)

The ancient practice of yoga and breath work may hold new treatment insights for inflammatory bowel diseases including Crohn's and ulcerative colitis. While modern medicine is constantly seeking anti-inflammatory medications to help control flare-ups, research is showing how a yoga-based lifestyle can improve the efficacy of medication, provide reduction in inflammation makers and provide a means of lifelong management of triggers and symptoms.

There is a complex interaction between psycho-neuro-endocrine-immune systems, otherwise called the brain-gut interaction, that shows a two-way influence between the brain and the gut microbiome. One of the key mechanisms is through the autonomic nervous system (ANS), the system of involuntary nerve impulses that regulates basic functions including the heart, the digestive system and the respiratory system. Made up of two opposing systems, the sympathetic and parasympathetic, the ANS often gets turned on by stress either from the mind or the gut, generating further stress and inflammation. The parasympathetic system is the off switch, down-regulating the chemicals that triggered the sympathetic system.

Recent research shows that yoga and breath work help to stimulate the para-



sympathetic system. For example, recent studies on breast-cancer survivors found that regular yoga practice had strong associations with a reduction in fatigue, an increase in feelings of vitality and a decrease in inflammatory markers tumor necrosis factor alpha (TNF- $\alpha$ ), interleukin-6 (IL-6), and interleukin-1 $\beta$  (IL-1 $\beta$ ), the same makers that are often associated with inflammatory bowel disease. Moreover, the increase in the frequency of yoga practice also led to an even bigger decrease in the interleukin cytokines. Several studies have shown that consistent yoga practice over time created a baseline of health that kept markers of inflammation and poor health on a lower level than people who did not engage in yoga.

In yoga, pranayama or breath work means literally control of the life force.

Deep breathing fundamentally alters the physical, emotional and chemical landscape of our minds and bodies. It allows for more oxygen to circulate throughout our bodies and it can immediately lower blood pressure, triggering a cascade of anti-stress, anti-inflammation hormones and chemicals as that is circulated to the brain and other body systems.

Yoga is also a way to build self-trust and body awareness in an individual. When practiced together as a family, it brings unity, openness, and trust between family members. It is a great way to have fun as a family and strengthen family bonds as well as helping to keep lines of communication open.

**INHALE ALL THE POSITIVE, EXHALE ALL NEGATIVE.**

*A Mindful Child Yoga and Wellness offers integrated programs specializing in children and families that struggle with medical issues, trauma and learning difficulties. Contact us at [www.amindfulchild.net](http://www.amindfulchild.net) or Michele Colburn at 770-875-7681 or [michele@amindfulchild.net](mailto:michele@amindfulchild.net).*

## 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).

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).

## Upcoming Events

- ◆ **Camp Oasis of Georgia** —sponsored by the Crohn's and Colitis Foundation of America (CCFA) will be held from Sunday, June 11 - Friday June 16, 2017 at Camp Will-a-Way, Winder, GA. **Campers and volunteers can apply now at** <http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/find-a-camp/>
- ◆ **Take Steps for Crohn's and Colitis** — This walk, sponsored by the Crohn's and Colitis Foundation of America (CCFA), will be held on May 21, 2017 at Brook Run Park, Dunwoody, GA. **For more information and to sign-up go to** <http://www.crohnscolitisfoundation.org/get-involved/take-steps.html>
- ◆ **Crohn's and Colitis Foundation of America— the Atlanta Pediatric, Adolescent, and Parent Group** will meet **Wednesday, May 10th** (arrive 10 mins early to sign-in) at 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](http://www.gicareforkids.com) and click on the IBD parents tab.

What's  
Happening