Welcome - In this Issue...

The goal of the newsletter is to share important information about the Improve Care Now (ICN) research study that your child is participating in. 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.

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. 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.

SAVE-THE-DATES

Transitioning to Adult Care - Children's Specialty Services will be having a clinic on August 23rd for patients who are ready to transition to adult GI. The clinic will have pediatric GI providers and introduce patients to adult GI providers. Please contact Children's Specialty Services scheduling to set up an appointment for that day.

The Fall 2017 Virtual Community Conference will be held on Wednesday, October 11, 2017 at 4:00 PM. This twice-yearly ImproveCareNow conference seeks to connect and grow our community in pursuit of our mission to improve health and care for all children and youth with Crohn's disease and ulcerative colitis.

We invite you to learn more about and get involved with ImproveCareNow by joining these virtual sessions. The sessions are led by members of the Parent Working Group and Patient Advisory Council and will highlight expert speakers (clinicians, improvement leaders, parents, and patients) addressing a range of topics related to improving pediatric IBD care including concrete tools to support patients and families. Information at http://www.improvecarenow.org/fall_2017_virtual_community_conference.

Meet the ICN Teams

GI Care for Kids
Physician Leaders
Dr. Ben Gold
Dr. Glen Lewis
Dr. Dana (Chelly) Dykes

Coordinators
Laura Eshee
Hannah Oloyede

Children’s Specialty Services
Physician Leader
Dr. Bess Schoen

Coordinator
Hannah Oloyede

Medical Staff
Clair Talmadge, P.A.
Dr. Bonney Reed-Knight
Caroline Adams
Christina Carter

Patients
Christian Lawson
Chris Malarcher
Abigail Sandifer

Medical Staff
Dr. Bonney Reed-Knight
Christine Spainhour
Bernadette Martineau
Dr. Jordan Weiztner
Cara Bradberry

Parents
Gisele Woodward
Beth Mclean
Ann Malarcher
Pip Spandorfer

Administrative Assistant
Caldwell Wright

Parent
Manisha Chikhliker

Reach our Goals

Since January 1, 2017 we have reached the following goals:

⇒ We have enrolled between 90% and 93% of our IBD patients into ICN.

⇒ Our Remission Rates are between 75% and 79%.

⇒ Dr. Dykes and Dr. Homekler joined GI Care for Kids and Dr. Weiztner and Cara Bradberry, a nurse practitioner, joined Children's Specialty Services (see p. 3).
In this issue we thought that you would like to hear from Christian Lawson, one of our ICN patient committee members. Christian is 17 years old and attends the Atlanta Adventist Academy.

It’s that time of the year again! Time to prepare for sending us kids back to school. It has been a great summer for me, but I am definitely not looking forward to going back to school. Back to School for me means back to waking up early in the morning in order to make it to school by 8:30 am. It also means that it will be time for me to finish my last year of high school and soon taking over full control of managing my chronic condition, scheduling my doctor appointments, staying track with my medications, visiting my doctor, and the list of the responsibilities that awaits continues.

I would like to give the parents some helpful tips on making sure that your kid(s) are ready for school including...

1. Celebrate - You have dealt with us kids for 3 whole months. Once August comes, that means that you can finally have a little break from us Monday through Friday.
2. Make sure that all your child’s teachers know about his/her chronic illness. If you haven’t already put in place a 504 plan for your child, I would highly suggest you do so. It will help tremendously when your child is in a flare up. (Info on 504 plans can be found at http://www.gicareforkids.com/download-forms/Volume%201-%20Issue-%201.pdf)
3. If you haven’t already talked with the School nurse about your child’s condition, make sure you do! The nurses office will help your child with managing through a flare up, taking medications while at school, and more.
4. Don’t forget about having a Support Group. The Crohn’s & Colitis Foundation (Georgia Chapter) hosts a support group for kids (under 12 years old) and also a group for teens ages 13-18 at Children’s Healthcare of Atlanta Scottish Rite or Egleston location. It’s a great way for your kid(s) to meet other kids with IBD. For more information please visit: www.crohnscolitisfoundation.org/chapters/georgia/support-groups/Atlantafamilygroup.html
5. Pack a lot of healthy lunches and snacks for your kids.
6. Last but not least, have fun! Enjoy watching your child grow right before your eyes. “May the force be with you all until next summer 2018.”

I hope that each of your children prosper and continue to stay in good health! Have a great school year!

Your Friend,
Christian

If you have any questions for Christian please e-mail him at 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.

The PRODUCE Study Update by Giselle Woodward

We are excited to announce that GI Care for Kids together with 11 other ICN centers throughout the nation will be part of the PRODUCE Study. The PRODUCE study will examine how nutrition impacts symptoms and inflammation. The question that will be researched is whether a wholesome diet - the Specific Carbohydrate Diet (SCD) - can be used as a treatment therapy for IBD.

The Specific Carbohydrate Diet is a nutritionally balanced diet focused on removing grains, processed foods, dairy (except for specific aged cheeses and fermented yogurts), and sugars (except for honey). The diet focuses on natural nutrient rich foods including vegetables, fruits, meats, eggs, legumes/beans, and nuts.

To enroll the child must be between the ages of 7-17 with mild to moderate IBD and stable medications. A smart phone and internet access are also required to report daily and weekly information. The PRODUCE Study will compare effectiveness of strict SCD vs. a modified version of SCD in reducing symptoms of IBD during 34 weeks.

Recipes to Beat the Summer Heat

This Specific Carbohydrate Diet Recipe is from Danielle Walker’s Against All Grains Celebrations book

Heirloom Tomatoes, Watermelon and Basil Salad

Ingredients:
1 small seedless watermelon (3-4lbs)
2 lbs of heirloom tomatoes
2 kirby or other cucumber
3 tablespoons extra virgin olive oil
1 tablespoon champagne or wine vinegar
½ cup chopped fresh basil
Sea salt to taste

(Serving 8)

Toss the watermelon, tomatoes, cucumber, olive oil, vinegar and basil together in a wide bowl. Season with salt. Refrigerate for 2 hours, then serve chilled.

Homemade Frozen Soft Serve “Ice Cream” by Giselle Woodward

Ingredients:
1 frozen spotted banana
5 frozen strawberries
1 tsp of honey

(Serving 1)

Toss the banana, strawberries and honey in a blender. Use tamper to push fruit down and create a creamy mixture. Serve immediately.
Meet our New Doctors

Children's Specialty Services at Egleston/Emory is pleased to announce that Dr. Jordan Weitzner has joined our group and the ImproveCareNow network.

Jordan Weitzner, MD, joined Children’s Healthcare of Atlanta in July 2017. He received a Bachelor of Arts in Biology and Psychology at Washington University in St. Louis and a Doctorate of Medicine at The Medical College of Georgia. Dr. Weitzner completed residencies in Pediatrics at The Medical College of Georgia/Children’s Hospital of Georgia where he also served as Chief Resident, followed by a fellowship in Gastroenterology at Emory University School of Medicine/Children’s Healthcare of Atlanta.

During his fellowship, Dr. Weitzner performed research projects investigating the pediatric microbiome in inflammatory bowel disease under the mentorship of Subra Kugathasan, MD, a world renowned IBD researcher. Dr. Weitzner has a passion for all gastrointestinal disorders, with specific interests in inflammatory bowel disease and nutrition. An Atlanta native, Dr. Weitzner enjoys cooking, sports, outdoor activities, and spending time with his wife and daughter. He looks forward to caring for children and families in his hometown.

GI Care for Kids is pleased to announce that Dr. Dana (Chelly) Dykes and Dr. Tatyana (Tanya) Homekler have joined our group and the ImproveCareNow network.

Dr. Dykes is excited to be part of our ImproveCareNow Team. She writes:

“I have recently joined the GI Care for Kids group after moving from Cincinnati, OH. I was one of the lead IBD center physicians at Cincinnati Children’s Hospital and was the director of quality improvement and the ImproveCareNow physician leader there.

One of the greatest parts of my job is to help improve the lives of my patients in whatever way I can. One key part of my patient care has been using quality improvement techniques to improve care delivery both in the clinic setting and between visits.

Dr Tatyana Homekler is looking forwarded to meeting and working with our IBD patients by joining our ImproveCareNow Team. She writes:

“I have lived in the Atlanta area since I was a child. I received a Bachelor of Science in Biology from Emory University and a Doctorate of Medicine from Morehouse School of Medicine. I completed my internship and residency in Pediatrics at Emory University as well as my fellowship in Gastroenterology, Hepatology and Nutrition.

During my fellowship, I focused my research on pediatric inflammatory bowel disease and nutrition, publishing in several peer reviewed journals and presenting several posters at national meetings.

After my fellowship, I joined the faculty at Emory University and became the director of the Intestinal Rehab of Children’s Healthcare of Atlanta. I completed a Masters in Clinical Research during that time.

I am board certified in pediatrics and pediatric gastroenterology, hepatology and nutrition. I have a passion and interest for Inflammatory Bowel Disease, nutrition and other gastrointestinal disorders.

While not working to better the lives of pediatric patients, I enjoy jogging, painting, finding new foods, exploring the outdoors and spending time with my husband and two sons.”
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.

Register Now for the Crohn’s and Colitis Family Education Day—sponsored by CHOA and the Crohn’s and Colitis Foundation of America (CCFA) - It will be held from Saturday, August 19th from 9:00am-2:30pm at Children’s Healthcare of Atlanta-Tullie Circle 1680 Tullie Circle- Atlanta-GA-30329
*Off 1-85 and North Druid Hills Road
Continental breakfast: 8:30-9:00 a.m.
Program: 9:00 a.m. to 2:30 p.m. (lunch is provided)
Join parents, teens and children affected by Crohn’s disease and ulcerative colitis for a fun-filled day of activities and learning!

Breakout sessions designed specifically for parents, teens and children will focus on topics such as:
- The basics of Crohn’s and colitis
- Nutrition (with cooking demos!)
- Treatment and medication options
- Yoga for kids and teens,
- Inspirational speakers, Art projects, and more!

To register go to http://www.crohnscolitisfoundation.org/chapters/georgia/events/family2017.html

Crohn’s and Colitis Foundation of America—the Atlanta Pediatric, Adolescent, and Parent Group will meet Wednesday, September 13th (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.crohnscolitisfoundation.org/chapters/georgia/support-groups/Atlantafamilygroup.html

GI Care for Kids website update— We will add new information on Addressing Psychosocial Issues under the IBD Parents Tab. Please go to www.gicareforkids.com and click on the IBD parents tab.