



IMPROVECARENOW

Newsletter



Children's
Healthcare of Atlanta

Welcome - In this Issue...

November 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.

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)

We are thrilled to report that **Christian Lawson**, a GI Care for Kids' patient, has joined ICN's Patient Advisory Council (PAC). Read more about Christian and the PAC at http://www.improvecarenow.org/pac_welcomes_six_new_patient_advocates.

ImproveCareNow Network wins the 2016 Drucker Prize! The Drucker Prize is awarded to a non-profit organization for "change that creates a new dimension of performance." Zach First, Executive Director of the Drucker Institute, said "The ImproveCareNow Network has improved outcomes for nearly 25,000 patients across 90 participating centers. Among its impressive innovations is the way it has effectively combined the creative energies and expertise of so many who were previously unconnected with each other." Your participation has made this award possible. By working together, ICN families and clinicians are accomplishing continuous improves in the quality of care for your sons and daughters. See <http://www.drucker.institute/news-post/2016-drucker-prize-winner/>.

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

Ann Malarcher

Pip Spandorfer

Beth Mclean

Administrative Assistant

Susan Eissner

Coordinator

Hannah Oloyede

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%.

⇒ We have included Patient Partners on our Family Advisory Council. We will introduce these folks in the next newsletter :)

⇒ We are testing phone apps for reporting symptoms to your doctor.

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)

Quick Facts:

- ☉ Children's Healthcare of Atlanta helps to fund our participation in ICN
- ☉ There are over 26,000 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 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 from Beth McLean, the newest member of our ICN Family Advisory Council.

I am a daughter, sister and mother of a Crohn's Disease patient. I have been profoundly impacted by this disease since my mother's diagnosis in 1996 and a year later, my younger brother's diagnosis. Watching both my mother and brother suffer in the nineties with this disease was very difficult. They have both been on

Remicade for over 10 years and have been in remission since starting the drug!

This past February, my nine year old daughter Kate was also diagnosed with moderate to severe Crohn's Disease. Her diagnosis hit our family hard. I had inwardly feared this day would come and it had. Kate was very sick and we were very scared. She was in the hospital for about a week and she began taking Remicade. Kate has been in remission since that time.

She is thriving! Kate loves to read, play golf and swim. She is now ten and tells me she forgets she has Crohn's disease! Thank God!

I cannot write this without expressing how profoundly grateful we are for Kate's gastroenterologist, CHOA, and, of course, all those who daily continue to improve the care of IBD patients. When I was asked to be a part of the ICN Council, I could not say no! Beth

What our Patients are Thankful for...

I am thankful for my ability to play sports and my loving family—Henry

I am thankful for doctors who care for your health and do anything to get you better —Landry

I am thankful for GI Care for Kids because they give me my medicine for my UC—Sarah

I am thankful for doctors who care about my health—Christian

I am thankful for those that are serving our country—Lennon

I am thankful for such caring friends and family—Sam

Recipe of the Month—Sage Pork Roast with Parmesan

Butternut Squash Sformato

(Go to IBD Parents tab on GI Care for Kids website for Prosciutto Braised Brussel Sprouts Recipe)

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

Italian is tough on the SCD, but sometimes you crave that flavor profile. You can have Italian flavors without having to go to pasta, and its way easier than it looks. Don't be afraid of the challenging sound of sformato, its much simpler than it sounds.

Note: If you are just beginning the SCD Diet, you may not want to attempt to utilize SCD Legal dairy products for the first few weeks though most report little to no issues from day one with these ingredients.

Sage and Citrus Pork Roast

-Pork Rib Roast or Loin, preferably not tenderloin, sized to fit in a large skillet

-Fresh Sage, 8 Leaves

-Salt and Pepper

-2 Tbl Olive Oil

-2 Tbl Cultured Butter (better for SCD)

-Zest of a Small Orange and a Lemon

-Juice of $\frac{1}{2}$ an Orange and $\frac{1}{4}$ of a Lemon

Preheat oven to 375F.

Season pork with salt and pepper.

Heat a skillet over medium high heat for 1 $\frac{1}{2}$ minutes, until quite hot. Add butter and follow with pork into the pan. Baste until you have developed color, and flip to next side. Continue

doing this until all sides have developed color.

Add sage to the pan and allow it to fry for 10 seconds (step back immediately in case the sage leaves pop). Baste the butter and sage over the pork and place in oven. Baste often and with abandon, its quite fun.

Roast until internal temperature of 155F in the middle of the thickest part of the meat. Cover with the citrus zest and juice, baste with the hot butter and citrus. Allow pork to rest 10-15 minutes before slicing. Top with a teaspoon of citrus/brown butter mixture on each slice.

SCD Butternut Squash Sformato

-1 Butternut Squash, Medium

-Olive Oil

-1 Tbl butter

-1/3 C Parmesan-1/3 C SCD Yogurt

-2 Tbl Honey

-2 egg yolks

-2 egg whites

-3 eggs

-Nutmeg, 1 pinch

-Cinnamon, 1 pinch

-Black Pepper, 1 pinch

-1 Tsp Sage, minced

-1.5 Tsp salt

Preheat your oven to 375F.

Bring a pint of water up to a simmer.

Slice Butternut Squash in half vertically.

Remove seeds. Oil well and place squash on a sheet pan with flat, cut part facing down. Bake until tender, 30-45 minutes.

Scoop hot filling out of the squash and into a bowl. Mash with a fork. Combine with butter, parmesan, honey, and yogurt and mix well. Whisk in the spices, sage, yolks, and whole eggs. Ensure you have 2 egg whites reserved.

In a separate bowl, whisk (clean whisk!) the egg whites to stiff peaks. Using a flat spatula, fold in egg whites to squash mix without mixing excessively.

Oil or butter a casserole dish with tall sides. You'll want to use a casserole or soufflé bowl that can fit into another oven proof container with tall sides that will hold hot water and the sformatto casserole. Pour in sformato mix and flatten down the top.

Pour hot water into larger container so that the sformatto casserole dish will have hot water halfway up the container.

Bake until an inserted tooth pick comes out clean (50 to 65 minutes).

Enjoy with extra shaved parmesan on top.

IF SERVING HOT, SERVE IMMEDIATELY while its still puffed up. If serving warm or cold, it is equally enjoyable with a richer texture.

Meet your ICN Clinical Research Coordinators

Our ICN Clinical Research Coordinators are important members of our research team. Research coordinators serve as the glue that keeps our ICN program on track to meet its performance goals. Maintaining a master list of IBD patients, tracking which patients need to be consented to participate in ICN or re-consented when they turn 18, uploading data to the ICN database, interpreting population management and data quality reports, providing pre-visit planning reports and coordinating team meetings are just a part of what we do to help improve your child's care. On a typical day, we are working hard behind the scenes to keep the team on track in meeting it's goals to make your child's experience at our Centers the best it can be.

Laura Eshee, MSQA grew up in Marietta, Georgia. She received a Bachelor's Degree in Industrial Engineering and Master's of Science in Quality Assurance from Southern Polytechnic State University. She worked at Shaw Industries for several years before staying home to raise her four children—three biological boys and one girl, adopted at age 15, from Russia.

She has worked at Children's Healthcare of Atlanta for four years as the ICN Research Coordinator at GI Care for Kids. She has a

passion for improving the lives of children with IBD and enjoys working with the doctors, staff and parents.

As a quality improvement coordinator with no previous clinical experience, Laura brings a unique perspective to the ICN team. Her ability to notice patterns, conduct statistical research and determine root causes of gaps in care enable the team not only to see how its IBD patients are doing as a whole, but also, to focus on helping each individual patient.



Hannah Oloyede, MPH is a member of both the Children's Specialty Services team at Eggleston/Emory and GI Care for Kids. She was born in Lagos, Nigeria and raised in Atlanta, Georgia. She received her undergraduate degree in Biology from the University of Georgia in Athens, GA. After a year in the workforce as a retail pharmacy technician, she decided to go back to school and pursue a Master's degree in Public Health at Georgia State University due to

her interests in health sciences. She enjoys Hannah enjoys interacting with the patients and families at both of the Atlanta ICN sites.

Laura and Hannah are thankful for all of the patients and families who are participating in ICN. Our patient care has improved tremendously through your participation!



Holiday Tips to De-Stress by Gisele Woodward

The Holidays are wonderful but also can be stressful....

So you might wonder... at least I do... how can I enjoy the holidays without all the stress?

Every year, I try to plan ahead.

I try to get all my presents early.... Really early. I try to be done by December 1. I might miss on some sales but it is worth it for me to enjoy the festivities with friends and family. By finishing the shopping early, I avoid lines and crowds at the stores.

Now onto the stresses of food during the holidays...

Unfortunately, dealing with a restricted diet is hard when going to party or get togethers...

So again, plan ahead....

Double up on meals, so you can have something already prepared in a few days or simply freezing it.

Double up on batches or cookies, or any other dessert...in order to save time and not spend the holidays in the kitchen.

Eat before you go out.

Bring appetizers and/or dessert with you so you know there will be something safe for your family to eat.

You might feel frustrated at times for the all the preplanning that you might need to do but remember...

The holidays are a time to enjoy the company or friends and family, it's not about the food... and a time to be thankful and embrace a new year...

Simplify, Plan Ahead, Enjoy the Holidays!

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 **Tuesday, December 6, 6:30-7:30pm** (arrive 10 mins early to sign-in) Children's Healthcare of Atlanta - Scottish Rite Main Auditorium, First Floor
1001 Johnson Ferry Road - Atlanta-GA-30342
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