FROM THE DIRECTOR

We hope this issue of Digestive Digest finds you and your family well and refreshed after a wonderful summer. The start of the school year always seems busy and full of promise: shopping for school supplies, arranging car pools, and setting up after school activities. With good planning comes exciting developments. It is in that vein that I wanted to make you aware of what a “GREAT time” it is for those touched by IBD.

The last 10 years have brought a revolution in our understanding of the underpinnings of IBD. With expanded knowledge comes promise of many new types of therapies. The Food and Drug Administration (FDA) has recognized that there is a large pipeline of agents being developed for IBD and that in the near future, the agency will have to evaluate the safety and efficacy of many new therapies. It is clear that these agents show promise for both children and adults with IBD and the agency wants to be prepared so that their reviews can be accurate and efficient.

Accordingly, the FDA will be hosting the Gastroenterology Regulatory Endpoints and the Advancement of Therapeutics (GREAT) Workshop later this month (https://www.signup4.net/Public/ap.aspx?EID=20123759E). Perhaps the most exciting aspect of this meeting is that Thursday September 20th will be a full day devoted to Pediatric IBD. By setting aside a full day for the invited panel to discuss it, the agency has clearly demonstrated its recognition of the both the uniqueness of PEDIATRIC IBD, the need for therapeutic advancement, and the vast number of therapies being developed to treat it. We are honored that the role our Center plays in Pediatric IBD research has been recognized by the organizers of GREAT as we have been asked to both present and serve on the advisory panels at this Workshop. We look forward to reporting to you the outcomes of this landmark event.

MOVING ONTO ADULTHOOD

Dear Patients and Families,

The Division of Pediatric Gastroenterology is excited to announce that we are in the process of creating a “transitioning” program for our patients. Health care transition is the process that supports adolescents and young adults move from child-centered (pediatric) to adult-oriented health care.

We are looking for your feedback about how we can create a successful transitioning program. In the near future, surveys will be sent through our protected email provider, RelayHealth. Please take the time to have your child complete one of the surveys regarding his/her transition experience. Please be candid as possible and note any additional comments.
Although newer, more effective therapies for the treatment of inflammatory bowel disease have normalized growth and improved gastrointestinal symptoms, a small number of children and adolescents with IBD continue to have slow growth and/or delayed puberty.

Recent research has shown that in IBD, the inflammatory process itself has a direct affect on the cells that make bones grow resulting in a slowing of such bone development. Additionally, growth in children and adolescents affected by IBD may be sub-optimal due to inadequate nutrition related to malabsorption and decreased appetite. Furthermore, prolonged therapy with medications such as prednisone can also cause poor linear growth. The presence of short stature, especially when compared to classmates, is often more apparent in teens with delayed puberty, which is also more common in teens with active IBD.

Health professionals caring for youth with IBD routinely monitor the growth of their patients and graph these weights and heights on standard growth curves at each visit. A change in height or weight percentile or significant difference between weight and height percentiles is cause for further evaluation. Methods to improve growth rate may include improving nutrition by adjusting medical therapy of IBD as well as increasing caloric intake by dietary adjustment and/or initiating supplemental feedings.

Pediatric endocrinology consultation is often initiated for children and adolescents with poor growth, not responding to increased caloric intake and optimal IBD management. Endocrinologic evaluation may include laboratory testing as well as an x-ray of the hand which can be used to estimate an adult height predication and rule out non-IBD causes of poor growth. Studies evaluating the use of growth hormone therapy in children and adolescents with IBD have shown mixed results. Close collaboration between the endocrinologist and IBD team is essential to clarifying causes and initiating optimal treatment of poor growth.

The Pediatric Endocrinology Center at the Goryeb Children’s Hospital is staffed by a team of board certified pediatric endocrinologists and nurse practitioners, as well as a dietitian and a social worker. The team is experienced in caring for children and adolescents with growth and other endocrine disorders and participates in new drug trials and other research studies.

Dr. Harold Starkman
Director, Pediatric Endocrinology

(pictured left to right)
Christine Wagner
(Pediatric Nurse Practitioner)
Connie Shirtz
(Dietitian),
Dr. Daisy Chin, and
Dr. Barbara Cerame

Pediatric Endocrinologists
Dr. Tymara Berry
Dr. Barbara Cerame
Dr. Daisy Chin
Dr. Frances Guevarra
Dr. Lawrence Silverman
Dr. Harold Starkman
An important part of what our IBD center strives for is to be a leader in advancing knowledge of IBD on the global level. Our efforts in these research endeavors is ongoing and while we have several exciting projects in development, we would like to summarize for you our current active studies.

1. A Multicenter, Prospective, Long-term Observational Registry of Pediatric Patients with Inflammatory Bowel Disease
   This is a prospective registry to collect data over the next 20 years to record and compare current therapies that children with IBD are receiving. Supported by Janssen (the manufacturer of Remicade), those enrolled must be less than 16 years of age but there is an option to continue collecting data into adulthood. This is a nationwide study of 5000 patients (2500 patients receiving Remicade and 2500 patients not receiving Remicade). Currently enrolling patients with UC.

2. Risk Stratification and Identification of Immunologic and Microbial Markers or Rapid Disease Progression in Children with Crohn’s Disease:
   The goal of this study is to identify certain biomarkers in the body that help to identify those children with Crohn’s who are at risk for developing disease-related complications soon after diagnosis. This is a multicenter study in the USA and Canada. It is sponsored by CCFA in coordination with Emory University. No new patients to be enrolled.

3. Effect of Targeted Therapy on Self-Efficacy in Pediatric Patients with Newly-Diagnosed Inflammatory Bowel Disease
   This study is investigating the effect of family and individual counseling at the time of diagnosis of inflammatory bowel disease for those ages 8–18 years within 30 days of diagnosis.

4. IBD Registry
   This is a long-term prospective, observational research study to assess the natural history of IBD, treatment regimens, clinical outcomes, and quality of life outcomes in newly diagnosed pediatric patients within 30 days of diagnosis. To be enrolled, patients must be less than 16 years of age at the time of diagnosis.

5. A Randomized, controlled trial of Yoga in Pediatric Inflammatory Bowel Disease
   This study is conducted to determine if a structured yoga program, in addition to standard medical therapy, improves health related quality of life in pediatric patients recently diagnosed with IBD. Ages of enrollment: 12–17 years of age. The patient will be randomized into one of two groups, answer questions, attend 12 yoga classes, and complete follow-up questionnaires.

6. A Multicenter, open labeled study to evaluate the safety of Entocort (budesonide) in children with Crohn’s
   This is a 12 week study to investigate the safety of Entocort in pediatric patient’s age 5 to 17 years with mild to moderate Crohn’s disease. Must be able to swallow pills.

7. Qualitative Research to Develop a Patient Reported Measure for Pediatric Ulcerative Colitis
   This study involves an interview with the patient and/or parent that are audiotaped to document symptoms of patients with Ulcerative colitis. Patients must be between the ages of 5 and 17.

8. Predicting Response to Standardized Pediatric Colitis Therapy (PROTECT Study)
   The goal of this study is to improve our understanding of why children develop ulcerative colitis and why some children respond better than others to currently used medications. This is a multicenter study in USA and Canada. It is sponsored by NIH in coordination with Connecticut Children Hospital and Emory University. Currently enrolling patient’s between ages 4-17 years whose doctor believes he/she has ulcerative colitis.
HAVE YOU JOINED RelayHealth YET???

RelayHealth (www.relayhealth.com) is an online, free, secure & encrypted website that our office is using to communicate online. **We cannot send any emails without using Relay Health.** Preps and information regarding all procedures are only sent through Relay Health.

This helpful website can be used to update your physician (non-urgent only) on your child’s condition or request:
- refills (refills are processed quicker with Relay Health)
- letters, camp forms, lab and radiology prescriptions
- results

No one else is able to access any of your information & your email address is never shared or sold. Many families have told us how efficient and what a time-saver RelayHealth has been.

**It’s easy, it’s fast and it’s free!!!!**

Thank you to those who have already joined. You are helping our office to run more efficiently for you.

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goodbye & good luck

We sadly say “goodbye” to Elizabeth Marrero who is our registrar at Goryeb in Morristown and wish her good luck in her new position.

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play football on the field at MetLife Stadium!

On Saturday, October 27th, the New Jersey Chapter of CCFA is hosting the 2nd Annual Touch Football Tournament at MetLife Stadium! Teams can register to play in either the afternoon or evening session. In addition, families and children can come out to watch the tournament, participate in a family day/kids camp featuring: punt, pass & kick competitions, games of skill and Halloween-themed activities!

For more info, to register a team or purchase tickets go to [http://online.ccfa.org/2012football](http://online.ccfa.org/2012football).

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MEET YOUR TEAM

Ellie is one of our Administrative Assistants and is the newest member of our GI team although she has been an employee of Atlantic Health for over 4 years.

At home, she enjoys spending time with her 2 dogs Sebastian (hound-mix) and Rocco (Labrador). In her spare time, she enjoys traveling, cooking, and crafting. She also volunteers for the American Cancer Society and National Kidney Foundation.

Professionally, she is advancing her education by pursuing a BS in Management Science at Kean University.

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Ellie Smith
YOUR WORDS

BY ALYSSA BENZIJA

My name is Alyssa Benzija. I am ten years old and I was diagnosed with IBD about 2 1/2 years ago. My family was hit by a bad stomach virus and I wound up in the hospital first for dehydration. Then, once the diarrhea started and was bloody, the doctors decided I needed a colonoscopy to determine what was going on besides the virus. It showed inflammation in my colon.

I was put on oral steroids and then was put on the anti-inflammatory sulfasalazine. I have to say so far, so good. The inflammation has been under control ever since. I’ve been lucky so far.

For the past two years, I have been swimming for the Jersey Flyers Aquatic Club. I love to swim, and the sport helps to keep my body strong. My coaches are very understanding when it comes to my need to leave the pool for the bathroom. There are still those times when waiting to use the bathroom is not an option and it can be difficult when you are in the pool.

Don’t let the disease be the focus of your life. Just take your medicine everyday and then go about your life as normal as possible. Of course, it helps to have a wonderful doctor like Dr. Feldman to help deal with all the ups and downs of IBD!

These pictures of Alyssa were taken at the Heat Madness long course swim meet on June 2, 2012 at Rutgers University.

the Jaffes

(on left from top to bottom: Rebecca, Zack & Marissa)
(on right: Marissa & Zack)

Marissa Jaffe (22 years old), just graduated with Honors from the University of Maryland with a degree in Biology. Marissa is an ulcerative colitis patient who had a total colectomy two years ago. She had 3 surgeries with a bag for a year, her ileostomy was reversed last year, and she has her j-pouch. After a year working at St. Barnabas as a Clinical Information Manager in the Emergency Room, Marissa plans to go to PA school to become a Physician Assistant.

Zack (18 years old) is a Crohn’s patient who just graduated from Livingston High School. He is about to enter the Business School at Rutgers University to pursue a degree in Accounting.
Not only do Michael and Zachary share the same birthday, they have also both lived with IBD. Zach was diagnosed with UC when he was ten years old and Michael with Crohn’s at age 16.

Michael’s disease is thankfully under control at this time. However after years of Remicade infusions, it became apparent that Zach would benefit from surgery. He had the first part of the surgery this past December which left him with an ileostomy. He wore an appliance for over 6 months. He just had the second, and last operation on July 3 and no longer has an ostomy and most importantly, no longer has ulcerative colitis. Believe it or not, he went back to his job just two weeks after the surgery, as a videographer for Campus Kids-NJ and is doing very well. Michael is looking forward to attending Clark University in Worcester, MA this fall, and Zachary will be attending American University in Washington, DC.

Mom and Dad are feeling very proud and grateful!

An excerpt from Zachary’s college essay:

"On December 20th, I will undergo the first of three surgeries that will give me a chance to live my life without this horrible disease and the obstacles that I have fought to overcome for so long. Once I recover, I will be able to move on with my life, and as I approach college, my fight for normalcy is the one I am most intent on winning."
It’s important to start this story by saying that our family was very fortunate in that we were never in a position where surgery for Zach was an urgent matter that had to be done right away. However, had we waited much longer, it may have become urgent.

Instead this story is about deciding and preparing for when the time is right for major procedures ... in our case, an ileostomy and J-pouch reconstruction. Our son, Zachary was diagnosed with Ulcerative Colitis 8 years ago at the age of 10. The road to where we are today was long and full of many curves, kind of like the small intestine that now serves as Zach’s J-Pouch.

We remember attending a CCFA function several years ago, where the keynote speaker was Rolf Benirschke, a name that might only be familiar to die-hard football fans and daytime television addicts. Rolf was a place kicker for The San Diego Chargers in the late 70’s and early 80’s until his career was interrupted by Ulcerative Colitis. An amazing return to the field and a later stint as host of the daytime version of The Wheel of Fortune were all detailed in his inspirational book, Alive and Kicking.

Rolf took the time to speak to Zach at the function and we were proud to get an autographed copy of the book. Zach devoured it in no time. The stories were inspiring and left a deep impression. So too, did the photos in the center of the book. Several were graphic pictures of Rolf’s post-surgery stomach which featured more nasty looking staples than one would expect. Keep in mind that this was 1979 and needless to say, techniques have improved considerably since then. However, the impressions that were left in a young mind were deep.

Several years into Zach’s treatment with various drug protocols, the talk of surgery was presented by our doctors as the best option. Zach was reluctant. Little did we know the impact that those 1979 black and white photos made on him. So we continued with monthly Remicade and iron infusions. We even put Zach on a gluten free diet (as a last ditch effort) which robbed him of the pleasures of the bagels and pizza that were not only part of his diet, but his social life as well.

About a year ago Zach went down to the Jersey Shore with some friends where they were hosted by a family whose father owned a bagel store. You can guess how the weekend played out. Pizza for dinner. Fresh bagels for breakfast. And a young man dying not to be different from his friends going through all sorts of emotional turmoil. Zach came home from the weekend and within a short time, announced to us that he was ready for surgery. (The thought process of the adolescent male continues to surprise us).

Now that Zach was ready, the question became “were we?” We had obviously been advocating the surgery for a long time. But when Zach gave his approval, we had to suddenly deal with so many issues that had long been dormant in our minds. When was the right time to perform the surgery so as to minimize disruption to Zach’s life? To our lives? And to the lives of his two brothers? (Can’t forget about the siblings). How would he get used to have a colostomy bag, both physically and emotionally? How would we? Should we reconnect with families who had the surgery done years earlier to see if they were still doing well? And which surgeon should we trust with our son’s future?

Preparation was underway. Old contacts were reestablished. Phone calls were made. Web sites were browsed. Blogs were digested. Every piece of information was put into perspective. Appointments were made. Second opinions were secured. Prayers were said. And pretty soon, we had a date for Phase 1 – the removal of Zach’s colon which would lead to a cure. We all felt a little more emotionally and intellectually prepared for the challenges that lie ahead of us.

(continued on next page)
One year later, we are thrilled that Zach is recovering from his second surgery – the J Pouch Restoration. He is doing well and is preparing to begin his college education at American University. In the process, his parents have been educated as well. Here is some of what we have learned:

- **Communicate, communicate, communicate.** No matter how good a relationship you have with your child, there are some things that they feel uncomfortable about discussing. Always make sure that you leave an open door for discussion and let them know that whatever they may be feeling is quite normal and has been experienced by hundreds before them.

- To foster this communication, attend CCFA meetings and visit on-line forums. It is important for your child to know that not only have others shared their physical problems, but their emotional ones as well.

- Actively involve your child in the decision making regarding their treatment. And if they are old enough, they should have the final call. After his parents and doctors agreed that surgery was the best long term option, it took Zach a couple of years to get on board. Fortunately, we were not in a life and death situation, but rather a quality of life situation. With Zach committed to the process, it went much smoother.

- If you feel you need to speed up the process, you need to speed up the communication. Whether it be heart to heart talks with a parent or other family member, conversations with peers who have gone through the similar situation, on-line chat resources, or the involvement of social workers or mental health professionals, hearing from caring empathetic people with varying levels of experience is a must.

- Not everything you read should be treated with equal weight. While there are many stories out there about procedures not going according to plan, you should try and filter out those from people who were treated by doctors and surgeons with minimal experience in dealing with your child’s condition. They can cause undue anxiety that you simply don’t need.

- Finally, we cannot emphasize enough how important it is to find the right doctors and staff. Besides medical competency, professional staff can provide many of the components that were discussed above. We extend heartfelt thanks to Dr. Rosh and his team for their compassion and support over the last few years.

Janice and Len Blaifeder

Per Mrs. Blaifeder, feel free to reach out to her at JankieSue@aol.com if you have any questions.

**APPS TO KEEP YOU ON TRACK & WEBSITES TO CHECK OUT**

**WEBSITES** (feel free to click on address & the link will bring you to the website)

- www.gastrokids.org
- www.ibdl.org
- www.sickkids.ca/ibdacademy/
- www.sickkids.ca/pdfs/IBDAcademy/55541-GOOD2GOPOSTER.pdf
- www.sickkids.ca/pdfs/IBDAcademy/55578-IBDand%20me%20CICRA.pdf
- www.ccfa.org (recently redesigned)

Our website (also has links to past issues of The Digestive Digest):

www.atlantichealth.org/goryeb/our+services/pediatric+gastroenterology+and+nutrition/
Justine Markman
15 years old
Justine ran her first 4-mile race this summer at the Firecracker 4-miler in Cranford. She is going to be the Honoree for the CCFA NJ Team Challenge in December. Her positive attitude while living with ulcerative colitis should push the Team Challenge runners across the finish line too. Her mom also ran it in June along with other parents from our practice.

Right now, they are recruiting people to run and walk in the Rock “n” Roll Las Vegas Half Marathon on December 2nd. Dr. Oren Koslowe will be there for the third year in a row. Will you? To donate to sponsor Dr. Koslowe click here: http://www.active.com/donate/njLV12/NJOKoslowez

If you want to hear firsthand about a parent’s personal experience with Team Challenge, you can contact Jill Markman (Justine’s mom) at jillmarkman@verizon.net.

ABOUT TEAM CHALLENGE
Crohn’s & Colitis Team Challenge is a half marathon training program that sends people – all-expenses-paid – to exotic locales to participate (run or walk) in a half marathon. Participants commit to raising funds to help find cures for Crohn’s and colitis, and the Foundation provides training to them and provides them with fundraising advice and assistance. When participants meet their fundraising goal, the Foundation covers the costs of traveling to the half marathon.

ABOUT TRAINING
• Training takes place at a local venue on the weekends
• Participants are trained by professional run and walk coaches as a group
• Training lasts approximately 16-weeks and participants build up endurance to complete 13.1 miles

ABOUT FUNDRAISING
• Participants are given a free easy-to-personalize web site
• Staff provide expert fundraising advice and assistance

ABOUT RACE WEEKEND
• Participants travel as a group to the race
• They experience the city and celebrate with their team at pasta and victory parties.

If you would like to join Team Challenge or have any questions, contact: Ashley Chandler
Work: 732-786-9960 extension 4  Cell: 646-276-7217
Email: achandler@ccfa.org
David Halkyard
17 years old
Pictured to the left and right are David Halkyard and Dr. Peter Wilmot. David asked Dr. Wilmot to be a member of his Eagle Scout Court of Honor.

Helena Lindner
10 years old
Off to sleep away camp for a week!

Goryeb Children’s Hospital is on Facebook. “Like” us to stay up-to-date on Goryeb Children’s Hospital news & events.
Still “bulking” those fruits and vegetables?

Why is it that we avoid fruits and vegetables; yet, have no trouble consuming simple carbohydrates? Could it be we are lazy chewers or is it that they simply take too much time to prepare? Or we just do not like the taste? Whatever the case, Americans are still consuming only about 50% at most of the recommended servings of fruits and vegetables daily.

Why the fuss and what can we do to improve those odds?

The new “MyPlate” icon suggests that half of our plate should contain fruits and vegetables. Yet most of us have cereal for breakfast and a sandwich at lunch. Our contribution at this point to the 5-9 servings per day that are recommended may include a few slices of banana on the cereal and a slice of tomato and lettuce on our sandwich if we remember. Sadly enough, this is barely one serving.

For the person with IBD we have increased concerns with fruits and vegetables secondary to past references suggesting these foods contain too much roughage and can be irritating to the GI tract. We now know that there is no need to avoid any food or food group unless it worsens symptoms in that individual. It is always best to restrict as few foods as possible in order to increase the chance of getting a balanced nutritious diet.

At this point you may still be wondering what fruits and vegetables really provide. Most of us are aware that these foods provide necessary vitamins and minerals which are required for many of our body’s metabolic processes. What we are not as familiar with is the increased importance related to their anti-inflammatory properties and help in limiting oxidative stress. Fruits and vegetables provide important phytonutrients and anti-oxidants as well as vitamins and minerals. Phytonutrients magnify the positive effects of vitamins and minerals as well as help to decrease inflammation. The anti-oxidants found in fruits and vegetables help strengthen the immune system.

A variety of fruits and vegetables is always the best approach. Some people find that the cruciferous vegetables such as cabbage, broccoli and cauliflower can cause GI distress whereas others find the fiber in raw apples irritating. If that is the case, you can always steam or bake vegetables and fruits or peel their skins.

Preparation may be key. If we stop thinking of fruits and vegetables as a “blob on the plate” or a boiled mushy mess, life may improve! When you bring the fresh fruits and vegetables home clean and store them immediately. All you need is a sharp knife, clean water, a clean cutting board and some time. Immediately cleaning, peeling and roasting vegetables in olive oil and a bit of seasoning allows you to store them for ready use or to add to meals or snacks.

You need not always boil or steam vegetables. Try them grilled, roasted, seared, pureed or sautéed. Try them breaded alone or with tomato sauce and melted cheese. Add them to chili or your favorite sauce and always as a base for a stir-fry. Use them in a smoothie. Add them as topping to your favorite pizza. The choices are endless. Just enjoy and be creative! You may surprise yourself.
My name is Jeremy Baum. I am 19 years old and have been living with Crohn’s disease since I was diagnosed at 8. Growing up with Crohn’s disease has been difficult as I endured countless medications and three major surgeries. I was determined to live my life to the fullest while coping with Crohn’s. I went to sleepaway camp for six summers, I worked hard at school, played sports, and hung out with my friends. With the support of my family, friends, Dr Rosh, and his outstanding staff I was able to progress and become healthier and stronger.

As a high school student I was able to give back to the Morristown Children’s Day Hospital by creating a program called Read for Recovery, a mobile library for the kids in the day hospital. While recovering from my third surgery I began my senior year of high school and applied to and was accepted at my dream school: the University of Miami. As I begin my sophomore year in Miami, I am an active member of the Miami young democrats and a manager for the basketball team but more importantly I feel well. Thanks to my family’s support and Dr Rosh’s sense of humor I was able to achieve my goals and move toward my future. As an added bonus I am a 2012 recipient of the UCB Pharma Crohn’s scholarship, a substantial financial award available to college students with Crohn’s disease. Dr Rosh encouraged me to apply and I am thrilled to be one of a small number of winners.

Crohn’s disease is going to be with me forever, along with the medications necessary to keep me healthy, but with the love and support of family, friends and amazing doctors and surgeons I am confident it will only be a small part of my reality.
Rebecca Bulko
14 years old
Rebecca is pictured here with her mother and sister at her 8th grade graduation.

Matthew Bilas
11 years old
Pictured below on vacation in South Carolina.

Katherine Campbell
15 years old
Katherine is taking a kick at the Jefferson Cup Soccer Tournament this spring.

“The purpose of life is to live it, to taste experience to the utmost, to reach out eagerly and without fear for newer and richer experience.”
“Sam was finally able to go on his Make-a-Wish Trip to Maine. As he has been waiting for this since the summer of 2010, I thought it would be great to send you these photos. His wish was to go on a Geological dig with a professional geologist. The Make-a-Wish chapter in NJ along with the Make-a-Wish chapter in Maine, put together digs at three different locations in Maine. We were escorted to private mining sights and all came home with interesting specimens and all learned a great deal. Now that he has a good liver he has been eating like crazy and the last night in Portland he was treated to dinner at Nosh Kitchen Bar—it was featured on Man vs. Food and Sam wanted to go there. The Maine office put that together as an extra. We can't say enough about the organization and what they do. Sam felt like a King and had a trip of a lifetime. Just what it is supposed to be. The “Mainers” were all so kind to the three of us. Sam inspires me everyday with his incredible spirit.”

—Lisa Goldman

“Taking my Make-A-Wish trip this summer was unbelievable. Literally everything about it was splendid. I got to meet some very charismatic people, do some once in a lifetime activities, and eat some hightbrow food. While I still have IBD and I probably always will, the trip really allowed me to relax and forget about my symptoms. I always had toilet paper with me, so I was always comfortable. I had a normal vacation, although I have IBD.”

—Sam Goldman
IN THE NEWS

- On August 2nd, Massachusetts became the 13th state to pass the Restroom Access Bill into law which will require businesses with at least 3 employees to allow those with IBD to use an employee-only restroom if public facilities aren’t available.

- According to the newest data presented at the 2012 DDW, there is no increased risk of birth defects among newborns of women who take certain biologic (infliximab, adalimumab and certolizumab) or immunomodulator (azathioprine and 6-mercaptopurine) therapy to control their IBD. These results are from a national registry of 1100 women from a CCFA-sponsored trial. The biggest risk during pregnancy is a disease flare, not the medication. The risk of flaring during pregnancy is the same as in the non-pregnant IBD patient – approximately 33 percent per year.

- Carrie Johnson represented the United States at the 2012 Olympics (her third Olympic games) in pursuit of the gold medal in women’s sprint kayaking. She also has Crohn’s disease. On a recent CNN interview, Johnson talked openly about her Crohn’s disease.

- Ken Baumann: actor from “The Secret Life of an American Teenager” recently announced he has Crohn’s Disease.

- CCFA recently redesigned its website….if you haven’t been on recently, check it out: www.ccf.org

FAMILY ADVISORY COUNCIL

In the last edition, we mentioned the Family Advisory Council is actively recruiting family advisors to serve on its council. Their goal is to improve the patient experience here at Goryeb Children’s Hospital.

Council members meet monthly to provide feedback from the parent’s point of view and assist in planning new programs and policy review.

As a result, we’ve had 1 family reach out to Lisa but they are looking for more. For further information, contact Lisa Ciarrocca (Certified Child Life Specialist) at lisa.ciarrocca@atlantichealth.org.

WHAT DO YOU THINK?

Please take a minute to send us an email and let us know your thoughts. What do you want to see more of? What did you wish we included?

We love to announce your child’s accomplishments so please continue sending us pictures, stories, artwork, tips or information that you have learned. They are inspirational to many of our families...remember we have “newly diagnosed” families along with our veterans of many years.

Send all submissions to stephanie.schuckalo@atlantichealth.org.

To view past issues of The Digestive Digest, go to www.atlantichealth.org and follow prompts to Goryeb Children’s Hospital to Pediatric Gastroenterology and click on “Newsletters.” Or you can click on the link: http://www.atlantichealth.org/goryeb/our+services/pediatric+gastroenterology+and+nutrition/connect/

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