FROM THE DIRECTOR...

WELCOME! We are very excited about our first edition of the Pediatric IBD Center’s newsletter, Digestive Digest. The editorial board has worked hard and I hope you will find the newsletter informative and easy to read. I want to especially thank Stephanie Schuckalo who served as both layout and copy editor for this issue.

These are very exciting times for children and adolescents with IBD both locally and on a global scale. There are more than 90 agents currently being investigated in the treatment of IBD, including those being studied in our own Center and discussed in the “Research Roundup.” Additionally, multi-center collaboration is at a new level. This means that investigators are pooling knowledge and resources in a manner never before seen so that the cure can be found. The Risk Stratification Project discussed in this newsletter is an excellent example of this. While research will make tomorrow better, our Center is committed to take the best care of you and your child. This means not only the clinical or medical issues but we also plan a major expansion of our family and individual support programs. We will be bringing more about this to you in future issues of Digestive Digest.

Finally, this is YOUR newsletter. Please let us know what we can do to improve on issue #1!

RESEARCH ROUNDUP
WITH ANNETTE & RUTH

NEW PUBLICATIONS

The “Retrospective Evaluation of the Safety and Effect of Adalimumab Therapy (RESEAT) in Pediatric Crohn’s Disease” study by Dr. Joel Rosh, Trudy Lerer, MS, Dr. James Markowitz and others was recently published in the Sept. 2009 issue of the American Journal of Gastroenterology. The authors led a team from the Pediatric IBD Collaborative Research Group looking at the use of adalimumab (Humira) in 115 children with Crohn’s Disease. It was found to be well-tolerated and effective to control moderate to severe Crohn’s Disease. Adalimumab is an injectable biologic medication similar to infliximab (Remicade). This is the largest pediatric study of the agent to date.

CLINICAL TRIALS

Our center is currently enrolling patients in a drug trial involving an anti-TNF medication. Participants must have Crohn’s Disease and be between the ages of 6-17 years.

Speak to your child’s doctor during your appointment if you are interested in finding out more.
We are excited to announce that proceeds from The 21st Annual Morristown Memorial Health Foundation Golf Classic will be directed to support our Pediatric IBD Center.

This philanthropic effort spearheaded through the MMH Foundation will assist our efforts to broaden our Center’s patient and family support programs and ongoing research efforts.

We’d love to have our families participate!

If you would like more information, please contact:
Bronwyn Fraser, donor relations manager at bronwyn.fraser@atlantichealth.org or call (973) 593-2440.

To view the beautiful Baltusrol Golf Club, visit: www.baltusrol.org

GOLF OUTING TO BENEFIT OUR IBD CENTER

RISK STRATIFICATION PROJECT

A new exciting project launching in 2010 is called the Risk Stratification Project.
The aim of this endeavor is to identify biomarkers that are found in the blood, stool, and lining of the intestines. These markers help to identify those children with Crohn’s Disease who are at risk of developing disease-related complications soon after diagnosis.

Our Center will be the only site in NJ to join this multicenter study involving pediatric IBD centers across North America. The study is funded by The Crohn’s and Colitis Foundation of America (CCFA).

To be enrolled, participants must be 16 years of age or younger and newly diagnosed with Crohn’s Disease.

MEET YOUR TEAM...

Diane Dueffler, MSRD Dietician
Diane has been working in our department since 2001 and has been an essential asset to our division.

She obtained her Masters of Science in Nutrition & Education at Boston University and taught at the collegiate level for many years.

She helps families navigate through the often complicated world of nutrition and gives recommendations that are individualized for the child.
When she’s not at work, Diane can be found in the pool or hitting the pavement...she’s an avid tri-athlete and enjoys swimming, biking, and running besides the usual weight-lifting.
She’s a mom to 2 grown women and enjoys playing piano, violin & flute.

Did You Know?

- Atlantic Health is a two hospital system including Goryeb Childrens’ Hospital at Morristown and Goryeb Children’s Center at Overlook Hospital in Summit.
- We have a satellite office in Raritan, NJ.
- We are the largest pediatric IBD center in NJ, caring for over 600 patients. Our multidisciplinary team approach offers state-of-the-art care and ongoing support for affected children, adolescents, and their families. Our clinical research program has become internationally recognized and allows for the best care today with ongoing improvements for tomorrow until we find the cure!

NJ CCFA Kids Count Day
Sunday, March 21, 2010
A mixture of education and fun for families living with IBD.
For more info contact CCFA’s NJ Chapter.
Crohn’s & Colitis Foundation of America (CCFA)
www.ccfa.org

CCFA is a nonprofit organization dedicated to finding the cure to IBD through research while providing education and patient support.

NJ Chapter of CCFA:
www.ccfa.org/chapters/newjersey/
newjersey@ccfa.org
(732) 786-9960

My IBD
www.myibd.org

My IBD is a website published by the Foundation for Clinical Research in IBD. It is a nonprofit organization that supports innovative clinical research projects relating to IBD. Their website has resources for families.

North American Society for Pediatric Gastroenterology, Hepatology & Nutrition (NASPGHAN)
www.naspghan.org

NASPGHAN is the largest society in the world dedicated to Pediatric GI. Their website is an excellent resource for IBD as well as other GI diseases.

Blueberry Yogurt Flaxseed Pancakes
2 cups whole wheat pancake mix
½ cup ground flax seed
2 eggs, slightly beaten
(or equivalent egg substitute)
1 cup milk
1 cup plain yogurt
½ tsp. vanilla extract
1 cup blueberries

Directions
1. In a large bowl, combine pancake mix and flax.
2. In a small bowl, beat the eggs with a whisk/fork. Stir in milk, yogurt, and vanilla extract until combined.
3. Fold in blueberries.
4. Place a large skillet or griddle over medium heat and coat with cooking spray.
5. Dollop ¼ to 1/3 cup batter onto skillet. Cook until bubbles appear and edges of the pancake look dry. Flip and cook until golden brown.

Good eats from Diane, your dietitian
This recipe offers 3 nutritional benefits: blueberries (high in antioxidant and vitamins C & E); flaxseed (contains lignin, omega 3 fatty acids, B vitamins and minerals) & yogurt (calcium, vit. D, and probiotics).

2010 UCB Crohn’s Scholarship Program
UCB Inc. is again offering their UCB Crohn’s Scholarship Program for students who are diagnosed with Crohn’s Disease.

The scholarship can go towards an associate, undergraduate, graduate degree or trade school educational program.

The program will award a one-time scholarship of up to $10,000 to 30 lucky winners.

For more information or to obtain an application, visit their website at www.crohnsandme.com or call (866) 757-4440.

The deadline for applications is February 12, 2010.

Good luck to all who apply!

In an effort to conserve paper, please send us your email address so we can email you the next newsletter. You can send it via www.relayhealth.com or sheryl.giacomaro@atlantichealth.org
Most people say, “College is the best four years of your life.” I agree, and I’m happy to say I just finished my 6th year of school. This September, I will be going back to begin year #7—seven years of college and post-graduate living with Crohn’s Disease.

I studied Journalism at Indiana University and realized I wanted to combine my interests in writing with my growing curiosity and knowledge in health and medicine. Since nurses are such an integral role in my patient care and medical education at a young and vulnerable age, I sought out to become a nurse myself. I just graduated from an accelerated 16 month Bachelor of Science in Nursing (BSN) program at the University of Medicine and Dentistry of New Jersey (UMDNJ). I know there is no better feeling than the pleasure of seeing a patient who you have personally helped, personally touched and treated, eventually leave the hospital in a better state than they arrived. I know firsthand, that feelings of hope and survival and bearing witness to these changes are incredibly deep-seeded connections. This passion and reward is the drive behind my motivation to become a Registered Nurse and eventually a Pediatric Nurse Practitioner. My journey continues in September 2010 at The University of Pennsylvania.

Whether students decide to go to a Big 10 school, an Ivy League university, a State school, or community college, living with IBD is a serious challenge to face. I was diagnosed with Crohn’s Disease two years before I left for college. I struggled with severe intermittent abdominal pain, 21 pills a day, and, to put it gently, “bathroom issues.” When my parents sent me off to Indiana I hadn’t realized how much effort they made in preparing me to be on my own. They sent all my medical files out to Indiana so I could continue to be monitored closely.

When I arrived on campus, my parents and I walked around all the different cafeterias. I quickly learned which one had more vegetarian and organic options and I knew the fast food cafeterias I would steer clear of. I made fast friends with the cafeteria manager in my dorm complex and the staff who made me egg white omelets with mushrooms and tomatoes and backed potatoes (not fried!) while living in the dorms. Visit your cafeterias and talk to the manager! My favorite café was actually the smallest one, located in our gym, because they would make me nutritious smoothies that never let my stomach down. I could always rely on them after a good stress-relieving workout. Nutrition, diet, and exercise are key components to living a healthy lifestyle in college. They were key puzzle pieces during the transition period of freshman year. I still rely on these today.

Another very valuable part of my college transition was informing my roommate of my disease. I tried to explain what my flare-ups were like. I never went to the doctor or hospital alone—I always had a friend by my side. As you transition yourself into college mode, you will find the friend who will be by your side every step of the way. I was lucky. My roommate and my friends became my family and my support system. I let my guard down and let them into my world of living with IBD.

“Diarrhea” became part of everyone’s vocabulary, like it was no big deal. Six years later, my friends still all say it in their everyday sentences, “Ok, just ate the taco salad...time for diarrhea,” and no one thinks twice. Have a sense of humor! Students with IBD are clever; you will find the individual bathrooms near your dorm and around campus...don’t panic!

It’s important to address the academic component of college and living with IBD. I was very serious about my academics and the pressure I put on myself to achieve high grades triggered many flare-ups during my first semester. I made the personal decision to inform every professor I had from day one in college to this day about my IBD. I’d say, “Hi, my name is Julia Schneider, I am in your English 101 class on Tuesdays and I would like to talk to you briefly about my Crohn’s Disease in case I am absent one day.” I missed several classes due to my flare-ups but I communicated with my professors via email or phone call, which enhanced our student-professor relationship built upon trust. Some professors were sympathetic, others were not, but regardless, I was never penalized academically.

One of the biggest challenges I had to face was the drinking lifestyle. It’s hard to avoid frat parties, bars, and going out to dinner in college. This is one aspect I wish someone had talked to me about before I left for college. I never wanted to give myself limitations because of my IBD so I figured out a formula to keep myself healthy and socially happy. Beer and hard alcohol were completely off limits. My insides would be turned inside out and upside down if I touched them. I learned that the hard way. Knowing how to integrate your IBD into your social life is very important...don’t let it limit you. My friends would chow down on pizza and beer late night at 3am. I joined the scene but not once did I touch the pizza and beer combination. For me that was IBD suicide.

Trust yourself and LOVE your body.

Julia Schneider
Kids' Corner

**IBD MEDICATION WORD SEARCH**

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**Our contact info:**

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Fax: (973) 290-7365

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**YOUR WORDS... WE WANT TO HEAR FROM YOU & YOUR CHILD!**

Do you have a question:  
- about a medication?  
- about a study you heard about?  
We’ll give you the answer!

Does your child have a piece of artwork that they would like to share? A poem?  
Does your child want to share a story about...  
- their experience with IBD?  
- getting an endoscopy?  
- getting a Remicade infusion?  
- participating in a research study?  
- going to college?  
- going to camp?

Your child may share as much or as little as they want. Submissions can be anonymous if preferred. 
We’d love your feedback! Was this newsletter helpful? Something different you’d like to see?  
Please send all your submissions to Sheryl at: sheryl.giacomaro@atlantichealth.org

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**Newsletter Editors**  
Tamara Feldman, MD  •  Oren Koslowe, MD  •  Alycia Leiby, MD  •  Stephanie Schuckalo, RN, APN