We hope that this issue of Digestive Digest finds you well and enjoying the summer! We welcome your ongoing and very positive feedback that we continue to receive about the newsletter. I must admit that while I hope that issue #3 is equally informative, I do wish that it also would bring you cooler and dryer days!

One of the more common questions that we are asked is “what is new in IBD research?” In this issue’s Research Roundup, Annette Langseder provides an overview of a few of our ongoing as well as an exciting new IBD research project that we are about to start. We are also very pleased to announce that all three IBD research papers submitted by our Center to the annual meeting of the society for Pediatric Gastroenterology (NASPGHAN) were accepted for presentation! Dr. Mones spearheaded a study that looks at patterns of IBD among affected siblings. This type of research serves a very important role in furthering our understanding of the origins of pediatric IBD. Our other two studies focused on two medical therapies in Crohn’s disease. One demonstrated the long term utility of adalimumab while the other furthered our ongoing interest in the use of methotrexate and showed that this therapy can work relatively quickly in pediatric Crohn’s patients. We are excited to make these important research contributions so as to further our mission to improve the quality of life of those affected with Pediatric IBD until the cure is found!

With our large IBD population we are always looking for ways to improve quality of life. With that in mind we have a number of ongoing research endeavors. We recently received a grant to address an often overlooked component of IBD which is the psycho-social impact on both the individual with IBD, and the entire family. We will shortly begin looking to enroll patients and families with newly diagnosed IBD in a pilot program in conjunction with the Cambridge Professional Center. Cambridge has had a lot of success working independently with families affected with a number of chronic medical problems. An area of focus has been personal empowerment, and we hope to work together with them to identify therapeutic interventions that will benefit our IBD population. Please feel free to contact our office with any study-related questions.

We are excited to announce that the Risk Stratification Project (see Issue #1) has now begun and we have already enrolled 6 newly diagnosed Crohn’s patients. The aim of this research study 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 who are at risk for developing disease-related complications soon after diagnosis.

Clinical Trial Continues
We are continuing to enroll 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.
Travel Tips

Even with the best laid plans, traveling with children can be a challenge. Add to this the medical needs of your child with IBD and things may become a little trickier. Please consider the following tips the next time you travel.

1. Contact the airline ahead of time to let them know of any needs that you might have during the flight, including dietary needs. Alert them that you will be bringing medications on board with you while flying. Bring a letter from your physician listing your medications that you will be bringing. If your child requires using syringes to administer any medications, please make sure that these are listed in the letter as well. If you are questioned by Security, this will provide documentation as to why you are carrying these items. Be sure to have multiple copies of this letter on hand.

2. Carry on all medications in case your luggage is lost or your child requires using their medicine while flying. Again, this can be indicated in the letter from your physician.

3. Bring with you your doctors phone number in case of Emergency or if your child becomes sick.

4. Talk with your hotel about any needs you might have while staying with them. For example, a refrigerator in your room for keeping medications that are temperature sensitive.

5. Pack hand sanitizer with you for times when washing hands isn’t an option.

6. When traveling by air, request an aisle seat near a bathroom.

7. Finally, more specific information about current travel restrictions can be found on the Transportation Security Administration website- www.tsa.gov, or the Crohn’s and Colitis Foundation website- www.ccfa.org.
TRY THIS OUT!

What could be more natural than breathing? You might be amazed to learn that breathing—an act we perform 20,000 a day—can deeply influence your health and happiness. Deep breathing increases our levels of oxygen to all the cells in our bodies—the results range from stimulating our digestive system to increasing mental performance. What can be difficult for some people to do, however, is to relax. Relaxation is something that can be learned.

For some patients, stress can trigger their IBD symptoms. Having tools to manage stress allows you to cope better and hopefully relax. Try this relaxation exercise a few times now and then try to practice it when you start to feel stressed. You might surprise yourself at how good your feel!

Deep Breathing and Counting Relaxation Exercise

1. Sit comfortably.
2. Close your eyes and focus on your breathing.
3. Inhale slowly and deeply and allow your abdominal muscles to expand.
4. As you exhale slowly, feel your abdominal muscles relax.
5. Inwardly count 1-2-3-4 on the in-breath and...
6. 5-6-7-8 on the out-breath

If this technique does not work for you, at least one type of relaxation will. You will be able to find some way to relax and, with practice, relaxation will become easier. Reading a good book, enjoying a hobby, playing a musical instrument, or participating in a sport or athletic activity including going for a walk can all provide relaxation. Other types of relaxation that you can research online include progressive muscle relaxation, guided imagery, meditation, autogenetics, as well as tai chi, yoga, and pilates.

GOOD EATS

Curried Salmon with Cucumber Raita

1.5# fresh salmon filet (1” thick) 2 Tbsp. canola oil
2 tsp curry powder 1 Tbsp. fresh lemon juice
Freshly ground black pepper to taste

In a gallon-size plastic bag, combine oil & curry powder. Add salmon & completely coat the fish. Marinate for 15 min. Preheat grill/oven to 425°F. Lightly grease grill rack with cooking oil spray & place salmon on it, skin side down. Grill/broil 5 minutes on each side. Remove and sprinkle with fresh lemon juice. Season with pepper taste & serve with cucumber raita.

Cucumber Raita

1 cup plain Greek yogurt 1/2 tsp. ground cumin
1/4 cup cucumber (peeled, seeded & cut into small dice) 1/8 tsp. salt
1 tsp. Fresh chopped mint leaves 1/8 tsp. cayenne pepper (optional)
Freshly ground black pepper to taste
Pour yogurt into a small mixing bowl and beat with a fork until smooth. Add remaining ingredients and chill.

Remember:
some medications such as 6MP & Methotrexate will increase your sensitivity to the sun so protect yourself with sunscreen and clothing that block both UVA & UVB rays.

TRY THIS OUT!

Deep Breath ©Melanie Weidner 2005
This sestina, although derived from my own experience with Crohn’s disease, is meant to be the story of anyone battling with an IBD. It is meant to be an inspiring piece about overcoming one’s greatest obstacles and I hope that I might make a difference by sharing it with everyone.

“Shafts of Light on a Timeless Staircase”
Shafts of light on a timeless staircase
Illuminate the face of a tried young man
Who, dreaming of release, must complete
His daily work wearing heavy iron shoes
Which pull him down, as he bears his burden,
Tearing at his will repeatedly like a chronic disease.

Only recently informed of his irritable disease,
The boy looks up the ominous staircase
And, seeing no summit, feels a doubled weight from his burden,
Which comes down hard on the head of a young man,
Throwing his face to the floor at his iron shoes,
And he stares at them, wondering how to complete

The immense task at hand. “How does one complete
A cure for a cureless disease?”
The boy ponders, looking at his reflection in the iron shoes
And the cold, apathetic steps of the staircase
Which cared not for the tired young man,
Nor for his gut-wrenching burden.

“I must forsake the pains created by my burden,”
Thinks the hopeful young man, “as I have yet to complete
My tiresome work.” And so the young man
Begins to struggle with his volatile disease,
Attempting to lift just one foot up the frigid staircase,
To take one small step, in those large iron shoes.

Slowly does he climb in iron shoes,
As each trembling inch becomes a burden,
And looking up along the endless staircase,
He sees a future yet to be complete.
 Pretending to be free of disease
He takes that step, as a wiser young man.

Boldly now, climbs the strong young man,
Trained by his weighted iron shoes,
Holding back his life long disease,
And with each step, lightens his burden
Of troubles, and aims to complete
His daily march along the speechless staircase.

Bravely, he battles that disease, no longer believing it to be a burden.
A tall young man looks at his iron shoes
And, in new light, sees complete the steps of his long staircase.

Once again, I hope this sestina will remind patients to push forward and defeat their disease. Never give up the fight.

~Drew Shapow
The Cambridge Professional Center (TCPC) is a counseling center for children, adolescents and families in Morristown, NJ. A core specialization is the treatment of mental health and family issues created by gastrointestinal diseases such as Ulcerative Colitis and Crohn’s Disease. The following contributions are from staff members and are a 4-part series for The Digestive Digest.

Once Upon a Diagnosis
Upon initial diagnosis, like any news—great or devastating, we need time to adjust. Time to understand, share, and think. The good news is that, in most all cases, there is time. And once we feel we have time, we often relax and our mind frees to think of options, possibilities, and creative ways to problem solve. In other words, feeling we have time often aides our adjustment. Just think of it as slowly wading into the pool and giving our body time to adjust to the temperature versus plunging into the deep end. Take the time you need.

Coping skills are critical. For instance, an excellent breathing exercise for this includes sending this or a similar message to yourself for a 2-3 minute time period while taking longer and deeper breaths. The message may simply read: “I have time to figure out what all this means and time to decide how I would like to react.” This short “break” broadens our perspective and also acknowledges our emotional state, which may range from confusion to fear to disbelief to numbness to relief back to confusion and fear, overall, a rather turbulent period of time.

Another first exercise we do with clients at The Cambridge Professional Center, LLC is to draw a 4-part grid and label each area that is or has been affected by the diagnosis. Most often these labels include Physical, Emotional, Cognitive and Social. When we ask clients, “Which areas are you treating?” The majority of clients respond by stating, “Physical.” While it is certainly necessary to treat the physical domain, (TCPC highly recommends no matter what your choice in treating your illness, for IBD as well as additional GI related illnesses, it is critical to be under the care of a physician) the additional areas have a profound affect on health and therefore illness. In fact, the term “Emotional Crohn’s” comes to mind, to accentuate the effect that stress and emotion have on our physical well being with these types of illnesses. Therefore, the sense that there is time to increase your understanding, make informed decisions and adjust is essential in the treatment of your “Emotional Crohns”.

This adjustment to a new diagnosis happens not only to the individual but also the family. There is a readiness on the road to acceptance and we do not travel at the same rate and distance and we certainly do not arrive at the same time. This is particularly relevant to parents with newly diagnosed children. Often parents are at the problem solving ready, “let’s attack this” mode while the patient or child simply needs time to adjust and understand what all this may mean. The Bottom Line—do not be rushed to adjust.

Please email TCPC with questions on this contribution to The Digestive Digest as well as any additional counseling/psychological concerns you may have to: jsumner@cambridgecenternj.com. We look forward to hearing from you.

Look for the 2nd part of this series in the fall issue of Digestive Digest entitled: Whose diagnosis is this?
Thinking about school starting when the summer has just begun may be the furthest from your mind right now. Planning ahead, though, can help avoid unnecessary stress and ease the transition whether moving from elementary school to middle school or onto high school. Remember if your school has any forms to fill out for medications, provide them to our office now so we have ample time to assist in your needs...this includes 504 plans. For more information on 504, contact Charlotte, your social worker, at 973.971.5958 or charlotte.intile@atlantichealth.org.

CCFA has several articles that can help you guide your child through the school years that you may want to review now to prepare for September. Just click on the link at the same time you press Ctrl:
- Taking IBD To School
- Doing Our Homework: A Parent’s Guide to Educational Equity
- The Importance of Planning
- A Guide for Teachers and Other School Personnel
- Guide for Parents

Have a wonderful, safe, and memorable week at Camp Nock-A-Mixon in August. If you want to share some pictures or your experience at camp to include in the fall newsletter, please let us know. Have a great time!

CONGRATULATIONS to all those who participated in the Take Steps for Crohn’s & Colitis at The County College of Morris in Randolph on June 13th!

To make a donation to your Pediatric IBD Center, contact Geraldine Kling at the Morristown Memorial Health Foundation at (973) 593-2414.
Housekeeping

Many families have commented how much they have enjoy the contributions our patients have shared. We need your help to keep it going. If you feel inspired to share a story, a picture, a testimonial, please send it along. If you have any tips or information that you have learned, an experience that would be helpful to other families, advice to share parent-to-parent, a question you would like answered, please feel free to let us know. We would also like to congratulate you on your accomplishments...academic, athletic, and anything else!

Please send all submissions to stephanie.schuckalo@atlantichealth.org. If you did not receive any of the other 2 issues of Digestive Digest, let us know.

Editor: Stephanie Schuckalo, RN, MSN, APN
Contributors: Alycia Leiby, MD & Oren Koslowe, MD