This is our last issue of Digestive Digest for 2010 and I want to wish the very best of this holiday season to you and your families. I also want to take this opportunity to thank our editor, writer and visionary, Stephanie Schuckalo, who has made this newsletter a reality!

Many of you have likely heard that the Institute of Medicine (IOM) has recently changed the recommended dose of Vitamin D to 600 international units per day. As discussed elsewhere in this issue, Vitamin D is very important for people with IBD, exerting a critical role in bone health. We routinely monitor your child’s Vitamin D levels and may prescribe replacement doses well in excess of these recommendations. Bear in mind that these doses are to replace Vitamin D when there is documented deficiency and such doses are very different than those recently recommended by the IOM for maintenance in individuals who have normal levels of Vitamin D.

I would like to close with a brief word about Remicade appointments. We now have close to 100 children and adolescents receiving Remicade. As you know, this is a labor intensive process performed expertly by our Day Hospital staff. It is vital that you honor Remicade appointments by arriving on time. Failure to do so makes it very difficult for us to find enough time slots for all of our Remicade-receiving patients. Also, the company does provide financial assistance based upon financial need. Please feel free to contact Sheryl, Tina or Ruth via Relay Health for application information if you think you may qualify for this benefit.

An important part of what our IBD center strives for is to be an active participant in advancing knowledge of IBD on the global level. Our efforts to these research endeavors is ongoing and we would like to summarize for you our current studies though we have many more “coming down the pike.”

### CURRENT RESEARCH STUDIES

1. **Remicade**: Prospective registry to collect data over the next 20 years.

2. **Risk Stratification Project**: Goal 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.

3. **Self-Efficacy**: Study investigating the effect of family and individual counseling at the time of diagnosis of inflammatory bowel disease.

### 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.

This book is an excellent reference & guide and discusses such subjects as medications, school, transitioning to an adult gastroenterologist, alternative & complementary medicine, and much much more. We highly recommend this book and can be purchased for around $30 on www.amazon.com.

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### Important numbers

<table>
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<tr>
<th>Service</th>
<th>Phone Number</th>
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<tr>
<td>To cancel a same day appointment after 4pm</td>
<td>(973) 971-7810</td>
</tr>
<tr>
<td>To schedule or change a future IBD appointment</td>
<td>(973) 971-4321 “The IBD Line”</td>
</tr>
<tr>
<td>Radiology</td>
<td>(973) 971-4163</td>
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<tr>
<td>Charlotte Intile (Social Worker)</td>
<td>(973) 971-5958</td>
</tr>
<tr>
<td>Our fax #</td>
<td>(973) 290-7365</td>
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<tr>
<td>After hours emergency #</td>
<td>(877) 424-7734</td>
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**Important information for those receiving Remicade**

- Effective immediately, there will be a $30 charge if you do not show up to a Remicade appointment. We have over 100 children receiving this infusion on a routine basis and cannot forfeit these spots as they are valuable for our families.
- Please notify our office immediately if your insurance changes so that we can be sure your infusion is authorized.

Thank you for your cooperation and understanding.

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The Cambridge Professional Center is a counseling center for children, adolescents & families. They are excited to announce that they will be starting groups for pre-teens & teens this fall. For more details, call 963-961-0660 and ask for Linda Loges.

136 Washington Street in Morristown
Utilizing herbs and spices may provide benefit from their anti-inflammatory effects and can add delicious flavors to the foods you eat. Herbs and spices that may provide anti-inflammatory benefits include: basil, cloves, ginger, turmeric, cardamom, cinnamon, cilantro and parsley.

Remember your comfort foods—try pumpkin pie with ginger, cinnamon, cloves and nutmeg or homemade applesauce with the same four spices.

Homemade Crock Pot Applesauce

10-13 large apples
3 tsp. of cinnamon
1.5 tsp ginger
¾ tsp. cloves
¾ tsp. nutmeg

Wash and cut up apples into the crock pot. 1/3 of the way sprinkle 1/3 of the above amounts of each spice. Do this 3 times. Once the crock pot is full, cover and cook on low heat for 8 to 10 hours. Stir well when finished. Note—a full crock pot will cook/boil down to a little over ½ of the crock pot.

Apple Cake

(Submitted by Elizabeth Draper, mom of David Halkyard 15 years old with Crohn’s)

4-6 firm apples (like McCoon, Cortland or Granny Smith; not McIntosh or Gala)
1 tablespoon cinnamon
5 tablespoons sugar
2½ cups flour, sifted
1 tablespoon baking powder
1 tsp salt
1 cup walnuts, chopped (optional)
1 cup canola oil
2 cups sugar
1/4 cup orange juice
2 1/2 teaspoons vanilla
4 eggs

Preheat oven to 350°F. Grease generously 2 pans or bundt pan. Peel, core, and chop apples into a large dice. Toss with cinnamon and sugar and set aside.

In a large mixing bowl, stir together flour, baking powder, and salt. In a separate bowl, whisk together oil, orange juice, sugar, and vanilla. Mix wet ingredients into dry ingredients. Add eggs one at a time and scrape down sides of bowl to make sure all ingredients are well incorported. Pour half the batter into the prepared pan, spread half of apples on top. Pour remaining batter on top of apples and remainder of apples on top of that. Bake for 1.5 hours or until toothpick comes out clean.
In this issue, we’d like to highlight one of our Administrative Assistants, Sheryl Giacomaro. Sheryl has been with our division since 2007 and is the voice behind our IBD Line (973) 971-4321. She is a valuable asset to our team in the “behind the scenes” activities to help make your appointments run more smoothly. She works above and beyond and lends a sympathetic ear to our families.

When Sheryl is not in the office, she enjoys being at the beach with her family, walking, bike riding, and reading. She’s married with two children, Jimmy and Kelly. Our bellies have profited from her delicious brownies, cookies, and coffee cake! We are so proud of her for recently completing her first 5 mile run fundraiser for her beach town.

Everyone who has IBD should get a yearly flu shot unless you have had a severe allergic reaction to a previous flu shot, have an allergy to eggs, or a history of Guillain-Barre syndrome after receiving influenza vaccine.

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<th>FACT</th>
<th>You cannot get the flu from the flu shot.</th>
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Flu symptoms may include fever, coughing, sore throat, runny or stuffy nose, headache, body aches, chills or fatigue.

To find a location near you to get the flu shot, visit www.flu.gov.

Take everyday preventative measures:
1. Wash hands with warm soap and water for long enough to sing 2 “Happy Birthdays.” Alcohol based hand cleaners are effective too. Carry one in your purse or backpack.
2. Avoid touching your eyes, nose, and mouth.
3. If you have IBD, let your doctor know you have had the flu shot.

You should get a yearly flu shot unless you have had the following:
- A severe allergic reaction to a previous flu shot
- An allergy to eggs
- A history of Guillain-Barre syndrome after receiving influenza vaccine

Flu symptoms may include:
- Fever
- Coughing
- Sore throat
- Runny or stuffy nose
- Headache
- Body aches
- Chills or fatigue

Everyone who has IBD should get a yearly flu shot unless you have had a severe allergic reaction to a previous flu shot, have an allergy to eggs, or a history of Guillain-Barre syndrome after receiving influenza vaccine.

QUESTION:
Should my child get the 2010-2011 flu shot if he/she already had the H1N1 virus last year?

ANSWER:
Yes, last flu season saw the emergence of the H1N1 virus. Flu viruses are constantly changing so it’s not unusual for new flu viruses to appear each year. According to the CDC, while not certain, it is likely that the H1N1 and seasonal flu will cause illness in the U.S. this flu season.
LOGIN AND CHECK IT OUT!

In case you haven’t heard or haven’t signed up yet, we wanted to introduce you to RelayHealth. It’s a free, secure & encrypted, website that Atlantic Health and our office is using to communicate back and forth between our office and our patients.

This helpful website can be used for refills, non-urgent messages such as results or updates on your child’s condition. Rest assured, no 3rd party is privy to information and your email address is not shared with anyone. Many families have already told us how much they love this service.

Coming soon!!
- The registration process for Remicade infusions will be much shorter. You will only need to stop at registration to photocopy your insurance card. The rest will be done behind the scenes earlier via RelayHealth. Please let us know if you have any changes to address, insurance, etc.
- Our office will also be utilizing RelayHealth to order lab work whether your insurance requires you to go to LabCorp, Quest, or Morristown/Overlook Hospitals.

So register now if you haven’t! Simply go to www.relayhealth.com and click on Register.

It’s easy, it’s fast, it’s free, and it helps our office run more efficiently.

CHARITY BEGINS AT HOME

Meredith McCluney, one of our nurses, participated in September in the Danskin Triathlon on Sandy Hook in Highlands. This was her first sprint triathlon: 1/2 mile swim, 12 mile bike, and 3.1 mile run.

Diane Duelfer, our dietician, competed in the Chesapeake Ultraman on September 25th in Maryland. It included a 2.4 mile swim, 112 mile bike, and a marathon (26.2 miles). It is non-profit organization so she supported a number of charities including: The Arc of Howard County, Ulman Cancer Fund for Young Adults, The Blazeman Foundation, The Lance Armstrong Foundation, Team in Training, and others. She finished 2nd in her age group and we can now call her an Ironwoman.

Dr. Oren Koslove ran the Rock & Roll Half Marathon on December 6th on the Vegas strip as part of Team Challenge. Team Challenge is the Crohn’s & Colitis Foundation’s endurance training and fundraising program. Dr. Koslove himself raised over $3000 and the 1600 participants in the half marathon raised over 4 million dollars for CCFA.

Kudos to Dr. Alycia Loby who donated over 15 inches of her hair to Locks of Love (www.locksoflove.org), an organization that provides hairpieces to financially disadvantaged children in the US and Canada suffering from long-term medical hairloss from any diagnosis (but many times it’s alopecia areata, a rare autoimmune condition). This was her third time donating!

Please help us congratulate our Peds GI team in these worthwhile, healthy events and give them some

DRUM ROLE PLEASE...

As you may have read in previous issues of The Digestive Digest, a golf outing was held. Proceeds from the 21st Annual Morristown Memorial Health Foundation Golf Classic recently held in June will be directed to support our Pediatric IBD Center.

This year it was held at Baltusrol Golf Club in Springfield and we are delighted to announce that $150,000 was raised for the Pediatric IBD Center at Goryeb.

This will assist our efforts to broaden our Center’s patient and family support programs and ongoing research efforts.
DOCTORS PRESENTED AT NORTH AMERICAN GI MEETING

Every year in October, there is a several day meeting for members of the North American Society for Pediatric Gastroenterology, Hepatology & Nutrition (NASPGHAN). NASPGHAN consists of over 140,000 pediatric gastroenterologists across North America and, during this week, they present exciting research and knowledge they've learned to one another. We are excited to announce that for the 16th year in a row, several of our doctors were selected to present to their peers.

Dr. Joel Rosh
1. Long-term outcomes with adalimumab (Humira) in pediatric Crohn’s disease: our center organized and served as lead author in the largest study performed to date looking at the effectiveness of adalimumab in pediatric Crohn’s disease. This newer form of therapy is approved for adults with Crohn’s but not yet in pediatric patients. We presented data showing that the drug’s effectiveness can last for many years.
2. Methotrexate—our center has served as a principal site investigating the effectiveness of this agent in the treatment of pediatric IBD. We presented data showing that clinical improvement is fairly rapid when methotrexate therapy is started. In fact, it seems to only take 2-4 weeks.

Dr. Richard Mones looked at various characteristics of siblings that have IBD among our center’s IBD population.

Dr. Alycia Leiby presented 2 poster presentations:
1. A case report about a child with a food protein induced enterocolitis.
2. The results of a pilot project looking at the use of complementary and alternative medicine in children with Irritable Bowel Syndrome and Functional Dyspepsia.

OUR ARTISTS

Artist: Alyssa Benzija
age 8
**To tell or not to tell...**

With the start of the school year, many children and teens will be entering new schools and meeting new friends. This can be an exciting time but can also be stressful for those living with IBD. When meeting someone new, you must choose whether to tell about your illness or keep it private...when to tell them...and how much to tell them.

**Should I tell the school?**

Yes. It’s important that the school knows. This will alleviate any confusion regarding the reasoning behind absences from school, lateness to class, or reasoning behind missed work. This also will allow you access to go to the restrooms or nurse as needed. The school also is your “eyes and ears” for the hours your child spends there and they may be a good source of passing along information to you about your child’s symptoms that day. We recommend that all children with IBD have a 504 Plan in place at school. For more information on what a 504 is, read the “Doing Our Homework: A Parent’s Guide to Educational Equity” pamphlet which is located on www.ccfa.org.

**Should I tell my friends?**

Disclosing an illness is always a sensitive issue. In general, we recommend that your child does share this with his/her friends. “Hiding” an illness can be very stressful and can be a big burden to carry, especially if they’ve been absent from school or need to use the restroom frequently. When telling others about your illness, you don’t need to share every detail. Short and sweet is a good way to start off—for example, “I was out because I have a stomach issue” and then expand from there. When you tell others, you are providing factual information which may clear up any misinformation others might have. Discuss with your child ahead of time what they want to say and then practice with them. Finally, another benefit of your child telling his/her friends is that it opens up another support system for them and gives them another outlet to talk about their feelings about having IBD. We’re interested in how our patients told others about their illness. If you would like your story included in an upcoming edition of this newsletter, please send to Stephanie Schuckalo at Stephanie.Schuckalo@atlantichealth.org.

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**SCHOLARSHIP NEWS**

The UCB Crohn’s scholarship program is now open. They are offering 30 one-time scholarships of up to $10,000 each in 2011. UCB, Inc., is a global biopharmaceutical company committed to developing innovative treatments for inflammatory diseases and is dedicated to creating unique programs and tools to help people with Crohn’s fulfill their educational ambitions. This program is designed for applicants of any age.

An applicant must be:

- a legal resident of the United States
- diagnosed with Crohn’s disease by a physician
- seeking an associate’s, undergraduate, or graduate degree, or enrolled in a trade school educational program
- an individual who demonstrates academic ambition and embraces a way of life that overcomes the boundaries of living with Crohn’s disease
- enrolled in or awaiting acceptance from a United States-based institution of higher education for the fall semester of 2011.

QUESTION OF THE QUARTER

What role does diet play in IBD?

Very often, one of the first questions parents ask after their child has been diagnosed with IBD is “What should my child eat?” Unfortunately, this can be very difficult to answer because IBD is not caused or cured by a specific food. Some may report that certain foods make them feel worse but these foods vary person to person. We cannot prescribe a certain diet, that will help everyone because available research has no clinical data regarding the role of diet in the development of IBD, and the best diet remains varied for each individual. The only diet that has been shown effective in controlling the inflammation of IBD is based completely on specialized medical formulas which can be prescribed in consultation with your physician. Unfortunately, beyond this change to a completely restrictive diet, there is no conclusive medical evidence that changing one’s diet after developing IBD will control the disease. Although you may see some “special diets” on the internet, they have not been well studied.

That being said, children do need food to help children grow, to give them energy for school and for fun activities. When children are sick, the role of food and nutrition becomes even more important because good nutrition is necessary to help them get better.

Often the initial symptoms of IBD in children and adolescents includes weight loss or failure to gain weight at a normal rate. Many who have IBD find it difficult to eat enough good food. They may feel hungry, but when it’s time to eat, can only finish a small amount. Perhaps the food doesn’t taste good or they may find it difficult to eat. Some may get diarrhea or abdominal pain after eating so they stop eating in order to avoid these symptoms. An inflamed, swollen portion of the intestine acts like a funnel through which food and gas must pass. As they pass, the thickened (and sometimes ulcerated) bowel stretches, causing pain and other symptoms. If your child does not eat well for a long time, weight loss, slow growth, and delayed sexual development can result. Also, intestinal inflammation symptoms can become worse when a person doesn’t eat because the body lacks the building blocks (fats, carbohydrates, protein, vitamins, minerals and water) necessary to heal the intestine.

**Calories**
According to some reports, children with IBD eat only about half the calories they require for their age. A rough estimate of calorie intake is:
- Girls: 2,000-2,200 calories a day
- Boys: 2,300-2,600 calories a day

Medications that undo the inflammation increase the width of the intestine thereby allowing the food to pass more easily. When your child is first diagnosed, some children find it easier to eat several small meals and snacks in a day, rather than 3 large meals. Making sure your child gets enough calories and nutrients to continue gaining and growing is more important than how many meals he/she eats.

**SPECIFIC NUTRIENTS**

**Iron** The most common nutritional problem for those with IBD is iron deficiency which can lead to anemia (low red blood cell count). This can occur from not getting enough iron from food, decreased iron absorption from the intestine, and increased iron losses from bleeding. If deficiency is found, oral or liquid iron supplement are typically provided since dosage requirements cannot be met with food alone.

**Calcium** and phosphorus give bone its strength and is important in passing nerve signals along and in muscle contraction. Everyone must consume their daily requirement of calcium to ensure normal development of bones and prevent osteoporosis (porous bones). The amount of calcium needed varies upon age and are highest in children entering puberty when they are growing fast. Calcium requirements are:
- Between ages 1-9 years: 500-800mg calcium per day
- Between ages 9-18 years: 1,200-1,300 mg calcium per day

For those with lactose intolerance, you can choose products that have low lactose content such as aged cheeses, calcium-fortified juices or Lact-aid supported foods. Note that it does require 4 servings of milk or calcium fortified yogurts to meet the 1200 mg calcium requirement daily.

**Fiber** is made of plant materials that humans cannot digest. It helps normal bowel movements and helps prevent diseases such as cancer, heart disease, obesity and diabetes. Unfortunately, most Americans do not eat enough fiber. The recommendation for the amount of fiber a child has is:
- Between ages 1-9: (5+ child’s age) grams of fiber per day
- Between ages 9-18: 25-30 grams of fiber per day
**Vitamin D** helps the body absorb calcium in the intestine. The body produces Vitamin D naturally when the skin is exposed to sunlight (note: skin protected with sunscreen will produce only a little Vitamin D). Few foods (cod liver oil, salmon or mackerel) are a natural source of Vitamin D and some are fortified with Vitamin D such as milk or yogurt. Children who do not feel well and remain indoors are at risk for Vitamin D deficiency as well as those living in northern areas during the fall and winter seasons.

**Folic Acid** is a form of Vitamin B and must be given as a supplement for those who are on methotrexate or sulfasalazine (azulfidine) since these medications can inhibit the absorption and utilization of this nutrient.

**Vitamin B₁₂** deficiency can develop in those who have had surgery to remove an inflamed lower ileum (ileitis) because the ileum is where Vit. B₁₂ is specifically absorbed. It can take months or years for this to develop because the body stores a large amount of Vitamin B₁₂ in the liver. A simple blood test can check for this deficiency if your child has had this surgery.

It's a good idea for your child to take a multivitamin. However, it is important to discern that a multivitamin is not a replacement for good nutrition. The best source of nutrition is from food since food provides multiple phytochemicals and antioxidants beneficial to overall health and well-being.

(excerpts from *Your Child with Inflammatory Bowel Disease: A Family Guide for Caregivers*. See page 2 for more info.)

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**And finally...**

The Digestive Digest welcomes ideas and suggestions from our readers. If you feel inspired to share a story, a picture, a recipe, a testimonial, a recipe, 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 in “Question of the Quarter,” 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 3 issues of The Digestive Digest, let us know.

Editor & Writer: Stephanie Schuckalo, RN, MSN, APN