For many families, their first introduction to the term inflammatory bowel disease (IBD) is when their child or adolescent is diagnosed. At our Center, all of your health care team members understand both the impact and the challenges this can create. One such challenge is to quickly gain knowledge and insight about these conditions so that together, we can make the best treatment choices for your child. Fortunately, the treatment options and our understanding of how to best use them is growing.

Therefore, even those who may have IBD themselves or who have another affected family member, need to learn a great deal since so much that we do today differs from the best practices of just a few years ago. The result, thankfully, is that our long-term outcomes for those with IBD are better than they have ever been.

We are firm believers in the concept of shared decision making. Over the years we have cared for thousands of children and adolescents with IBD, but we recognize that your child and your experience is unique. Therefore, it is our goal to share our knowledge and experience to help educate and guide you on your quest to best understand IBD and the potential therapies. We want to assure that you understand the risks of the disease when it is not well controlled. Equally, we want you to understand the risks and benefits of the treatment options. Additionally, we can explain how we can best monitor your child’s condition. Beyond the immediate goal of getting your child to feel well again, we can explain what we mean by a true remission and what are the best options to maintain it. We also need you to educate us! What are your goals, thoughts, concerns, and desires? How are you and your child responding to the therapy? Importantly, beyond the medical decisions, are we adequately assisting you in dealing with the complete impact of IBD on your family?

By sharing our collective experiences and knowledge, together we will be able to make the most personalized and effective treatment choices. We truly believe that by sharing in the decision making, your child will have the best outcome possible.
Dear local business owner,

Our third annual Goryeb’s Got Talent will take place on April 27th, 2017 at Morristown Medical Center. Our goal is to raise money that will be used for the Goryeb Children’s Hospital Division of Gastroenterology and Nutrition. In order to meet this goal, we are asking for sponsorships from local businesses and individuals such as yourself.

By giving to this annual event you’ll be supporting the Division of Gastroenterology and Nutrition and helping us provide assistance to those in our community. We ask that you will consider a sponsorship donation of either $250 or $500, or gift cards or other goods that will be used in a raffle. Your donation will be recognized at our event in several ways. As a sponsor, your name will be placed on our program and promotional t-shirts.

We hope that we can count on you to help support our cause. Last year, we were able to raise over $5000 for the Respiratory Center for Children with the help of businesses like yours, and we are grateful for your consideration. If you have any questions or would like to donate, please feel free to contact me at goryebsgottalentgch@gmail.com.

Thanks in advance for your consideration!

Sincerely,

Joseph Asaro, DO
Pediatric Resident
Goryeb Children’s Hospital
Morristown Medical Center
Examples of past performances include:
- tap dancing
- singing
- playing piano
- theater performance
- ballroom dancing
  The options are limitless!

Patients, residents, doctors, nurses all perform!

It’s a great night and for a great cause—proceeds this year are to benefit our department!

Save the Date

The Third Annual Goryeb’s Got Talent

Thursday April 27, 2017 at 7:00pm
The Malcolm Forbes Auditorium
Morristown Medical Center

Got Talent?

Calling for all ages and all acts to sign up for:

The Third Annual Goryeb’s Got Talent

If interested, email by April 3, 2017:
GoryebsGotTalentGCH@gmail.com
When Derek was first diagnosed with UC (09/2011) he ended up at Goryeb over the long Thanksgiving weekend to be on fluids and IV steroids. When he was released, we were driving home and he said “do you know what I missed the most while I was in the hospital?” I said no, what (thinking he was going to say our cat, his bed, being home, etc.). He said “I missed seeing kids smile”. I was surprised that it affected him so much, so I asked him what he thought we could do about that. He thought about it a little bit and said “can we take them balloons”? That is how Derek started taking balloons to the kids at Goryeb. The first couple of years we took balloons 2 or 3 times a year. About 4 years ago, we had an arrangement with A&P where they donated the leftover super bowl balloons (football shaped) and we bought lots of star shaped balloons (for the kids who didn’t like football) and took them up to the hospital the day after the Super Bowl. Derek wasn’t allowed to hand them out that year because there was a high number of kids with flu and other contagious illnesses, but that was ok, he was just happy that the kids were getting them and he did hand some out in the hallway to kids that were up and about.

Fast forward to October, 2013 when Derek had his surgery for ileostomy closure. It was Halloween (imagine waking up from surgery to nurses dressed like witches!) and in typical Goryeb fashion the Child Life Specialists were helping the kids make the most of being in the hospital by having a party and fun stuff for them to do. Derek had just been put in a room after his surgery and was actually very coherent. One of the Child Life Specialists came in and asked him if he felt up to going to the party and he said no, but she brought him a balloon and a goody bag instead. As she was giving Derek the balloon she said I have a great story that goes with this balloon, a family donates balloons for our parties and it is all because when their son was in the hospital someone brought in a football shaped balloon and gave it to him and he would not let go of that balloon the whole day. He just loved it and the family was so happy that it made their son’s day that they decided they would bring in balloons for the parties at Goryeb (the card on the balloon said something like Donated by Heal-i-um if I remember correctly – I kept the card for several years but can’t find it now). Derek and I looked at each other and said that was us!!! We were so happy that people were paying it forward. It takes very little time to try to help an ill or injured child smile – thankfully more people are doing that from what I see posted on FB. We now take balloons about twice a year – always for the Holidays and typically at one other point during the year.
WE'RE MOVING ACROSS THE STREET

This summer the Goryeb subspecialty practices located on the Morristown campus will be moving to 55 Madison Avenue—across the street from the main hospital. Office hours will be on the 2nd floor along with laboratory and radiology. Our administrative offices will be on the 3rd floor.

Medication infusions will remain in the same location as they currently are—Farris Building 2nd floor (CAMP). Procedures will still take place in the Day Hospital in the Goryeb Children’s Hospital.

Please always verify the location of your appointment when scheduling appointments.

THE JOURNEY TO A CLEARER MIND

Being mindful can be challenging in a world where we are surrounded by smart phones, social media, and the internet. It can even become more challenging when we are faced with our own obstacles with inflammatory bowel disease. If we learn how to stay focused in the present, managing IBD when you are feeling well may become a little easier.

Here are some daily tips to help you decrease your mental load, which may lead to stress reduction:

- Meditation/exercise, when practiced on a regular basis, can be powerful tools in reducing your stress, and calming your mind. It also may provide you with more physical and mental energy to get you through your daily tasks.

- Exercise may be as simple as getting outside, breathing in the fresh air, and becoming mindful of your surroundings.

If you are looking to try meditation to clear your mind, check out “Whil,” a free app found on your smart phones to ease you into the art of meditation. Remember that practice makes perfect, and to allow yourself a few practice sessions before you start to reap the rewards of a clearer mind.
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 are ongoing and while we have several exciting projects in development, we would like to summarize for you our current studies.

1. 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 & why some children respond better than others to currently used medications. This is a multicenter study in USA and Canada. It is sponsored by National Institutes of Health (NIH) in coordination with Connecticut Children’s Hospital and Emory University. Patients between ages 4 -17 years whose doctor believes he/she has ulcerative colitis are enrolled.

2. 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: 10-17 years of age. The patient will be randomized into one of two groups, answer questions, attend 12 yoga classes, and complete follow-up questionnaires [sponsored by private donor].

3. 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 ages less than 13 years.

4. Sex Differences in Statural Growth Impairment in Pediatric Crohn’s Disease (Growth Study)
   This study goal is to improve our understanding of how Crohn’s Disease affects growth in children and why Crohn’s Disease’s effects on growth differ between boys and girls. It is sponsored by NIH in coordination with Weill Cornell Medical College. Enrolling males aged 9-15 years and females 8-13 years who have Crohn’s disease.

5. GEM Study (Genetic Environmental Microbial) Project—goal is to find causes or triggers for Crohn’s Disease. Healthy siblings must have a sibling with CD and be between the ages of 6-30. The healthy sibling will have 2 office visits and follow-up call every 6 months for a health review.

6. A Long-term Non-Interventional Registry to Assess Safety and Effectiveness of HUMIRA (adalimumab) in Pediatric Patients with Moderately to Severely Active Crohn’s Disease (CAPE)
   This is a registry to evaluate long-term safety of Humira in pediatric patients (between the ages of 6 and 17 years inclusive at the time of enrollment) with moderately to severely active CD who are prescribed and treated according to routine clinical practice. Patients being prescribed and treated with conventional immunosuppressant therapy with no concurrent biologic use will also be enrolled as a reference group.
URGENT request to all of our patients who are on medication infusions (Remicade, Entyvio, Stelara)
you must notify us ASAP if you have had a change in your medical insurance.

We are having patients show up for their medication infusion without giving us prior notification of an
insurance change. Unfortunately, most insurances require precertification which can take up to 15 days for
a decision (more days if it is denied and requires an appeal). Please note preregistration for the Infusion Cen-
ter at Goryeb is different from insurance precertification of the medication (which is handled by our office).

If you do not notify our office of an insurance change, it is likely you will have to reschedule your
child’s infusion. For patients who are 18 years or older, they MUST present their own photo ID and insurance
card information otherwise the appointment will need to be rescheduled.

Thank you for your cooperation and understanding. Our goal is always to put your child’s health first and we
do not want any barriers to them receiving their medication as scheduled.

You can send a MyChart message or call (973) 971-4321 (Mon-Fri 8am-4pm) and ask for the precertification
team. Thank you in advance for your cooperation.

CROHN’S DECISION TOOL

Working with the Pediatric GI Society’s Foundation (NASPGHAN), we have helped create an online educational resource
that explains the current treatment options for Pediatric Crohn’s disease. This 30 minute online educational resource and
be viewed at https://www.my-emmi.com/SelfReg/DECIDEIBD

CONGRATULATIONS TO DONNA

One of our nurses, Donna Karlak, recently earned her BSN (Bachelors of Science in Nursing). She graduated with high honors
from The College of St. Elizabeth. She has been inducted into the International Honor Society of Nursing, Sigma Theta Tau.

Congratulations are in order to Donna!
SUPPORTING YOUR PEDIATRIC IBD CENTER

If you have interest in donating to the Pediatric IBD Center or have other fundraising ideas we would love to hear from you. Please feel free to contact us or Geraldine Kling at the Foundation for Morristown Medical Center at (973) 593-2414 or email her directly at geraldine.kling@atlantichealth.org.

CCFA CELEBRATES IT’S 50TH ANNIVERSARY WITH CHANGE

The Crohn’s and Colitis Foundation of America celebrates its 50th Anniversary. They’ve simplified their name to “Crohn’s & Colitis Foundation,” are incorporating a new brand message “Uniting to Care & Cure,” along with a new symbol. They represent the Foundation’s renewed focus on unifying the IBD community and fighting for cures.

The Crohn’s and Colitis Foundation (CCF) is a non-profit, volunteer-driven organization dedicated to finding the cures for Crohn’s Disease and ulcerative colitis. Since their founding in 1967, CCFA has remained at the forefront of research in IBD. CCFA funds cutting-edge research and publishes the leading scientific journal in the field of IBD.

To join your local chapter of CCFA, visit www.crohnscolitisfoundation.org. Your membership is tax-deductible.

WELCOME MARY PASTIRIK, RN, BSN

Please help us welcome a new nurse to our Peds GI Family, Mary. She comes with many years of experience in Pediatric GI. She is an animal lover and volunteers at local shelters. She also loves to travel.
It's been a year since Noah Sokaler opened his own shop on Etsy called Wild Wolf Woodworking. Visit his page on Etsy "WildWolfWood" to see and shop his homemade crafts. At just 16 years old, he was inspired by his wood shop teacher. Awesome!
Editors’ note: The role of diet in both causing and serving as a treatment for the actual inflammation of IBD is an area of active research. In the meantime, many individuals find that specific dietary factors can trigger gastrointestinal symptoms. Accordingly, finding a diet that works best is often a personal journey. We are happy to share such a journey from one of our Center’s patients.

I was diagnosed with colitis about 19 months ago, on June 11th 2015. A few months prior, the symptoms began with moderate pain after each meal, which would quickly subside. Before long, my symptoms progressed; I would spend hours in bed in pain and I felt constantly exhausted. I tried elimination diets to glean whether or not my intense pain was linked to a particular food, but did come up with an answer. My condition continued to worsen, which led my parents to make an appointment for me to see Dr. Maria Perez and her team at Goryeb Children’s Hospital. I immediately felt comfortable and reassured as Dr. Perez and the Goryeb staff quickly gathered information about how I was feeling through discussion, examination and blood work. Though I was clearly sick, I never felt scared or nervous. After our lengthy appointment, I was scheduled for a colonoscopy for the following day and I reluctantly began preparing for it. It was then that the cause of my symptoms was identified as Ulcerative Colitis.

Initially, medication helped to begin my body’s slow healing process and provide some symptom relief. Along with this form of treatment, my mom and I did some extensive research and decided to make dietary changes as well. I started out eating only light, easily digested foods, such as white rice, melon, bananas, along with steamed zucchini, squash and sweet potatoes. I slowly began to feel better and add more foods back into my diet; I had more energy and I was no longer in pain. Slowly but surely, I expanded my diet one plant based food at a time, watching to see how my body responded to each. Currently, I am a plant based, gluten-free, no oil vegan. While my diet back in July of 2015 made me feel extremely limited in terms of where I could eat, what I could cook, and how I could be creative with my body’s boundaries, I now feel completely different. I’ve embraced my eating and with it, I’ve found new interest in cooking, baking, and finding fun, interesting healthy plant-based recipes. To me, it’s all about the healthy food that I can eat, and not what I can’t eat.

Continued...
Being a vegan, along with taking my anti-inflammatory medication, has truly transformed my Ulcerative Colitis. What once was a burden and something I felt uncomfortable discussing and explaining is now something I embrace and feel empowered by. I feel incredibly grateful for how healthy I have felt over the past year and a half and that my UC has not encroached on my day-to-day activities. Most recently, I was fortunate enough to go on two community service trips, one to Guatemala and one to Hawaii. I was able to handle my food situation in these places due to lots of planning and attention to detail. Though it took some navigating, I was without any complications for both two-week adventures. I gained great confidence in my ability to travel and continue to seek new adventures, regardless of my dietary restrictions and my UC. None of this would have been possible without the help of Dr. Perez and her team. Everyone at Goryeb has been understanding, attentive, and incredibly thorough since my first appointment. Additionally, Dr. Perez and her team have done a great job at integrating my dietary/holistic care with the more traditional, medical aspects of my care. Everyone has been supportive of the decisions I have made and always seek to make me as comfortable and healthy as possible.

Black Bean Veggie Burgers

1 small white or yellow onion, chopped
1 cup fresh or frozen and thawed corn kernels
1 1/2 cups cooked black beans (or 1 can black beans, drained and rinsed)
1 cup cooked brown rice
1/4 cup oat flour (or finely ground, rolled oats)
1/3 cup tomato paste
1 teaspoon cumin powder
1/2 teaspoon smoked paprika
1 teaspoon chili powder
3/4 teaspoon salt
Black pepper or red pepper flakes to taste

Instructions
1. Saute corn and onions over medium heat for 7 minutes until soft.
2. Place the rice into the bowl of the food processor. Add skillet mixture, oats, spices, and 2 tablespoons of water. Continue to pulse until it is combined but there should still be texture. If it’s too dry add another tablespoon of water.
3. Shape mixture into 4-6 patties. Bake for 20-25 minutes at 350F.

My favorite vegan websites are:
* ohsheglows.com
* cookingwithplants.com
* minimalistbaker.com

A yummy vegan meal: zucchini noodles with tomatoes and avocado sauce
In our quest to find relief from IBD, we continually turn to diet as a way to manage symptoms. Knowing each person responds differently to diet is both a blessing and a curse. We wish to rely on “tried and true methods” but find these methods may not be fruitful to our individual needs. Relying on our own food record trends tends to be skewed with personal favorites and societal advertising/norms.

We know that IBD involves chronic inflammation of the GI tract. This can be accompanied by ongoing pain, cramping, diarrhea, rectal bleeding, weight loss, and fatigue. All of these symptoms deter us from consuming an “all around” healthy diet. We tend to stick with old favorites and limit our possibilities.

Research is slowly emerging regarding specialized diets. Diets with potential interest include the Anti-inflammatory diet, SCD (specific carbohydrate diet), FODMAP (fermentable oligosaccharides, disaccharides, monosaccharides and polyols), the Mediterranean diet, and Gluten-Free diets. The general theme is to “EAT CLEAN.” This means choosing food in its most natural form without any processing. Avoid added sugar, added fats (particularly trans-fats) and any additives or preservatives.

Refer to “choosemyplate.gov” for guidelines for meals and snacks. Choose from all food groups at mealtime and choose 1 carbohydrate (fruit, vegetable or whole grain) and 1 protein (protein or dairy) for each snack. Each meal should include a healthy fat which can include: olive, flaxseed or canola oil, olives, avocado or nuts/nut butters. Most importantly be sure to consume adequate fluids. Fluids include 16-24 ounces of milk or milk substitute and enough water in ounces to meet about half your weight in pounds (eg. a 100 pound person would consume 50 ounces). Best method is to check the color of your urine. Urine should be pale to clear after first morning urine.

The general theme is to “EAT CLEAN.” This means choosing food in its most natural form without any processing. Omitting whole food groups omits necessary nutrition. Be mindful of your choices. All micronutrients are needed to carry out various body functions. Consuming a MVI or a balanced meal 1 time daily does not ensure adequate nutrient availability 4-6 or 8 -10 hours later. Hence consuming from all food groups at all meals ensures availability of a variety of micronutrients continually throughout the day. Omitting food groups limits the ability of our body to function at full efficiency. Since our bodies grow and develop structurally the first 21 years of our life, we are more particular about complete nutrition at each meal to develop to our full potential.

Diet can be very individual since each person presents with different symptoms, times of remission, times of increased disease activity, and location of disease. Keeping a detailed food record helps one identify patterns, tolerances, and individual concerns. Trial of a specialized diet should be done with care and careful review. Omitting full food groups is not recommended. Substituting different grains, ...

...continued
different milks, appropriate protein sources as well as allowed fruits and vegetables at each meal is even more important. Creativity and preparation technique is required. Consult your medical team including your doctor and registered dietitian.

When choosing fruits and vegetables remember you need a full ½ cup cooked or 1 cup raw choice at each meal. Fruits and vegetables, if irritating or at a time of increased disease activity, can be peeled, seeded or sautéed for ease in consumption. They should not be eliminated. Soluble fiber dissolves in water and forms a gel-like consistency. It allows for slower transition of food through the small intestine. Insoluble fiber does not dissolve in water but pulls water into the intestine causing food to move more quickly through the GI tract. Anything stringy or not broken down by normal chewing should be omitted during flares.

Note that grains include rice, potatoes, corn, beans as well as bread, cereal and gluten free grains such as quinoa and amaranth. Remember wheat grains tend to be B-vitamin and iron fortified. If omitting this category try to choose B-fortified “other” grains and be certain to include poultry, eggs and iron rich green leafy vegetables, nuts and seeds in your diet. You may include well-trimmed red meat in your diet 1-2 x weekly as well. When utilizing a plant source of protein, be sure to include a vitamin C source (orange, grapefruit, baked potato, tomato, green pepper, cabbage, mango, etc) at that meal for better absorption of iron.

Protein foods need not be just animal sources. Proteins include nuts and seeds, beans, eggs, tofu, fish and seafood as well as poultry, meat and cheese. Dairy includes milk and yogurt and milk/yogurt substitutes. Cheeses are in the protein group since we are looking for adequate vitamin D and calcium per serving. You would need to eat 4 ounces of cheese to obtain calcium and vitamin D found in 8 ounces of milk and 6-8 ounces of yogurt (check your labels).

Eating well need not be complicated if you remember to choose from all food groups when meal planning. Chili with a fruit smoothie for dessert is a great way to include all food groups in 1 bowl. Power-packed pancakes or muffins can mix nutrition into 1 serving as well. Add extra eggs, milk (non-fat dry milk powder), nuts or nut butter, fruit (fresh or dried) and pumpkin/butternut squash or grated carrot/zucchini with seasonings as desired for a hearty breakfast muffin or pancake. Be creative, have fun and enjoy wholesome meals and snacks. Most importantly try to eat real foods and utilize “choosemyplate.gov” for guidance in meal planning.
Congratulations are in order for Dr. Rosh who, as of March 2017, has been elected to the National Board of Trustees for the Crohn’s and Colitis Foundation.

Alex Favreau won a Poster of Distinction Award at the National IBD meetings in Orlando in December 2016 for his research on intravenous iron therapy in IBD. Congratulations Alex!

CCFA Online Chat—Support Group for Caregivers & Patients

CCFA Online Support Group connects people with IBD who face similar challenges. This four-week series consists of weekly chat sessions that covers IBD-related topics and allows participants to share their views on each topic. By sharing experiences and learning from one another every week.

Each session is 90 minutes long and is guided by a CCFA moderator. Each support group is limited to 25 participants. Monthly opportunities to participate are offered.

To learn more, visit: http://www.ccfacommunity.org/CHATSERIES.ASPX to find out the schedule for March offerings and signup.

Kudos to Dr. Rosh

Congratulations are in order for Dr. Rosh who, as of March 2017, has been elected to the National Board of Trustees for the Crohn’s and Colitis Foundation.
BIRTHDAY BOY DONATES TO YOUR IBD CENTER

Recently a young patient of ours decided that for his birthday, in lieu of gifts, he wanted to collect money and donate it to the Pediatric IBD Center at Goryeb. He spoke at his school during their week-long campaign on kindness about his $1610 donation.

We would like to thank him and his family on his generous donation. We will plan together how to best use his wonderful donation.

HAPPY BIRTHDAY

We have had electronic medical records (EMR) for over 2 1/2 years now along with all of the other pediatric subspecialties at Goryeb Children's Hospital. Embedded in this system is "MyChart," which is a free, encrypted, HIPAA–secure email system that allows us to communicate back and forth with you for non-urgent matters.

We are requesting that ALL patients join and use MyChart. We are no longer using RelayHealth. To connect you to MyChart, at your next visit we will need the caregiver’s (proxy) name and DOB. You will then be given an activation code to sign-up (within 14 days or the activation code expires).

Physicians use MyChart to communicate test results and treatment plans so be sure to sign up right way. We hear over and over again from our families how wonderful this service has been to obtain results, refills, letters, etc. in a timely manner. Families are also giving us updates on their child's condition and are able to upload documents.

https://mychart.atlantichealth.org

Please let us know what you think. Is there something you would like to see in the next newsletter? 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 email below.

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/newsletters

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