

THE DIGESTIVE DIGEST

WINTER 2018

Volume 9, Issue 1

PHYSICIANS

Tamara Feldman, MD
Oren Koslowe, MD
Alycia Leiby, MD
Nadia Ovchinsky, MD, MBA
Mohini Patel, MD
Maria Perez, DO
Joel Rosh, MD
Barbara Verga, MD
Peter Wilmot, DO

NURSING

Ruth Irizarry, RN, BSN
Donna Karlak, RN, BSN
Annette Langseder, RN, BSN
Meredith McCluney, RN, BSN
Mary Pastirik, RN, BSN
Nancy Salmeri, RN, BSN
Stephanie Schuckalo, RN, APN

REGISTERED DIETICIAN

Kelly Varzea, RD, CSP

SOCIAL WORKER

Charlotte Intile, LCSW

OFFICE MANAGER

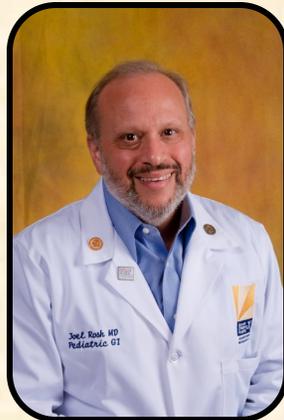
Lakeisha Mack

ADMINISTRATIVE ASSISTANTS

Sheryl Giacomaro
Deirdre Pizzo
Doreen Ruccio
Ellie Smith
Lueshawn Smith
MEDICAL ASSISTANTS
Yris DePierola, CMA
Eileen Ficala
Rosheida Henry, CMA
Tyreema Muhannad, CMA
Stephanie Riveros, CMA

FROM THE DIRECTOR

DR. JOEL ROSH



Pediatric IBD Research—The Dawn of a New Era

Crohn's disease (CD) was described in a paper published in 1932 and the first description of ulcerative colitis (UC) is believed to have been from about 100 years ago. In the last decade, these relative newcomers have seen an explosion of research that has led to a remarkable deepening in our fundamental understanding of their root causes as well as a marked change in treatment outcomes. Some of the most exciting research has taken place in Pediatric IBD. More than 5 years ago, the Crohn's and

Colitis Foundation started funding for a long-term research project called RISK. The primary aim of this more than \$10 million study was to differentiate the different types of pediatric CD and in so doing, reveal the complex interactions between the immune system and the fascinating world of the gastrointestinal microbiome—all the bacteria and other non-human organisms that live in our intestines.

Approximately five years ago, more than a dozen research centers enrolled children into RISK at the time of their CD diagnosis. Perhaps your child was one who we enrolled. We collected tissue from colonoscopy biopsies, blood for genetics and immune system testing, and stool to look at the microbiome. The primary paper from RISK has recently been published in the *Lancet*—one of the world's premier scientific journals. It highlights several findings that have spurred great interest in the IBD research community and, in turn, whole new avenues of investigation. RISK found specific gastrointestinal bacteria that are associated with the complications of pediatric CD—are these the cause or effect? Either way, we have an important lead! In addition, immune and genetic markers were identified that will also guide our pursuit of the cure. Perhaps, the most vital outcome of RISK was proof that multiple research institutions could work together to find the cure to IBD. This collaboration so impressed the National Institutes of Health (NIH) that the NIH has now provided multiple millions of dollars in funding for a similar study in pediatric UC called PROTECT—stay tuned as we are finding equally exciting results in PROTECT!

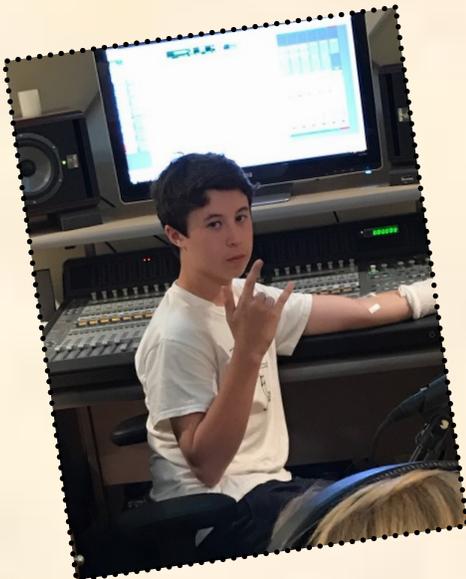
EMMETT'S STORY



My name is Emmett Conklin and I was diagnosed with Crohn's Disease 3 years ago, when I was 12 years old. Prior to that, I had been experiencing symptoms that affected my diet, energy levels, and my overall well being. I knew something was wrong, I could just never find out what. I went through countless tests with several other doctors until I met Dr. Koslowe. He helped get me the answers I was looking for. Finding out was a really scary experience but it was ultimately for the better because now I could get proper treatment.

I didn't know anyone with Crohn's and I didn't know what having it meant and how it would affect my life. I thought that Crohn's would prevent me from doing a lot of the things I loved but I'm happy to say that it hasn't prevented me from doing anything. Part of living with Crohn's is accepting that you have it. For some people, including myself this can be a very difficult task. One important thing I've learned is that while Crohn's is a big part of who I am, it doesn't define me.

If I could tell kids who have recently been diagnosed with Crohn's one thing, it would be to remember that you're still you. Nothing has changed, the only thing that's different is that you have Crohn's Disease. Never let anyone tell you otherwise. Since my diagnosis, I haven't let Crohn's stop me from doing any of things I enjoy doing. I currently play baseball for Montclair High School, run a club with my friends there, have a great social life, and have no limitations on any other activities. Crohn's Disease is just an obstacle that Goryeb Children's Hospital has helped me manage and live with.



"When Emmett's weekly job of recording the high school sports podcast lands on the same day as his infusion, it's no problem. Both get done seamlessly thanks to his amazing in-home nurse, Diane."

-Sarah Conklin



"...while Crohn's is a big part of who I am, it doesn't define me."

ARE YOU COUNTING SHEEP?

STEPHANIE SCHUCKALO, RN, APN



FOOD ✓ SHELTER ✓ WATER ✓ SLEEP??

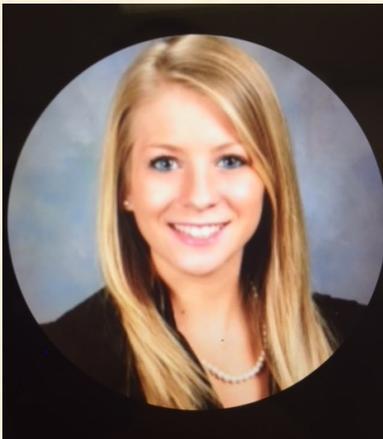
Just as your body needs food, shelter, and water, sleep is also very important for your well-being. Science has shown that lack of sleep can increase inflammation, affect your mood, and mental health.

The National Sleep Foundation recommends that teenagers get 8-10 hours of sleep per night. Here are some things you can do to help you get the sleep your body needs:

- * Exercise everyday if possible.
- * Go to bed and wake up at the same time each day. Have you ever woken up just minutes before your alarm clock? Our bodies have their own internal clock (circadian rhythm) that mirror's nature's cycles of day and night.

- * Make your room comfortable to rest. Your room is your sanctuary from the stresses of the day. Use your senses to design it so it is a comfortable, positive, and peaceful place to lie down. Remember, light and darkness are powerful cues that tell your body it's time to rest or get you ready for your day. Is it a surprise that light in your bedroom or peeking in from behind a shade has an impact on your sleep? That light sends a message to your brain to suppress the sleep-inducing hormone, melatonin, thereby making it difficult to fall asleep and stay asleep. Consider low-wattage, incandescent lamp on your nightstand to wind down an hour before bed, room-darkening shades, and survey your room for any other sources of artificial light (street lamps, glow from power buttons of remotes or cable boxes). If you need to use the restroom at night, try not turning on the overhead lights—use a nightlight or perhaps turn the shower light on instead.
- * Avoid eating heavy meals or drinks before bedtime especially caffeine. Studies have shown that those who are sleep deprived tend to eat more fat-rich foods, simple carbohydrates, and fewer vegetables, possibly because sleep loss alters chemical signals connected to metabolism and hunger. In fact, some researchers believe sleep deprivation to be a factor in the rising rates of obesity. Eating and sleeping well are two vital components of health that are tied in surprising ways.
- * Remove distractions including TV, ipad, phone, video games and anything else that stimulates your mind. These electronic devices also suppress the sleep-inducing hormone, melatonin largely due to the blue light that is emitted by these devices. The more electronic devices one uses in the evening, the harder it is to fall asleep and stay asleep. It also delays the onset of REM sleep, reduces the total amount of REM sleep and compromises alertness the next morning. This is especially a big problem for teens whose circadian rhythms are already shifting naturally causing them to feel awake later in the night. Over time, these effects can add up to significant chronic sleep deficiency. Power down your electronics an hour or two before bedtime so you can start producing more melatonin. If you need the computer for homework, dim the brightness of the screen or warm up the colors on the screen (away from blues and towards reds and yellows). Avoid using energy-efficient (blue) bulbs in nightlights.
- * When IBD gets in the way of sleep. Because you have IBD, you may sometimes experience symptoms that are uncomfortable and make it difficult for you to get the rest you need. While there may not be an easy solution to the problem, it is important to talk to your parent(s) and healthcare team and get the support you need.
 1. Keep a sleep diary so you can see the affect that lack of sleep can have on your health and your disease. You may notice you are not getting enough rest that you need or perhaps you are having trouble relaxing or perhaps you are physically feeling something?
 2. Take a note of the symptoms you are feeling. Is it abdominal pain? It is frequent bathroom visits during the night? Is it something else?
 3. Take your medications as prescribed and talk to your healthcare provider about it.
 4. Know your limits. If you feel very tired, you must listen to your body. You may be very busy with school and extracurricular activities but if you need to take a break then take one. Try not to overexert yourself.
- * To learn more about sleep here are some more helpful resources: Sleep.org and National Sleep Foundation.

MEET YOUR TEAM



Kelly Varzea, RD, CSP

Please help us welcome our new dietitian, Kelly Varzea. She has more than 3 years of pediatric experience and recently obtained certification as a specialist in pediatric nutrition.

She enjoys spending time with her husband, family and friends. She adores animals and has a puppy, 2 cats and 4 hens. Kelly enjoys learning new things and is trying to learn to play an instrument, a second language and finishing her last course towards her M.S. in Clinical Nutrition. She loves warm weather and spending the day at the beach relaxing.

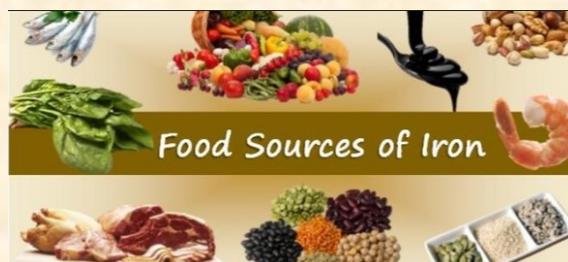
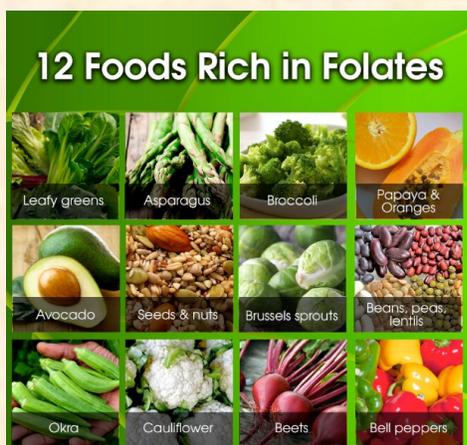


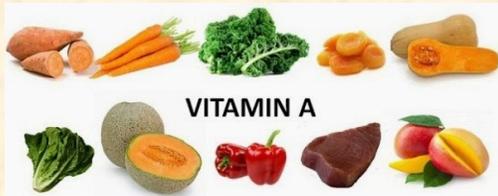
NUTRITION NEWS

BY KELLY VARZEA, RD, CSP

Nutrition is especially important for children with Inflammatory Bowel Disease (IBD). Nutrition needs are individualized based on the condition, which parts of the GI tract are affected, presence of inflammation, and drug-nutrient interactions. In this column, we will focus on vitamins and minerals!

Vitamins and minerals are primarily absorbed in the small intestine. Those with Crohn's Disease affecting the small intestine are most at risk for vitamin and mineral malabsorption, however, everyone with IBD can benefit from knowing which nutrients could be at risk. During symptomatic periods pay particular attention to nutrients like potassium, magnesium, and zinc, which can be lost through diarrhea, and iron, which can be lost with GI blood.





Nutrient	Site of Absorption	Drug Interaction	Crohn's	Ulcerative Colitis	Food Sources
Vitamin A	Duodenum Jejunum		√		Yellow or orange fruits/vegetables, spinach, broccoli, dairy, fish (herring), fortified cereals
Vitamin B12	Ileum		√		Fish (clams, trout, salmon, haddock), meat, eggs, dairy, fortified cereals
Folate	Duodenum Jejunum Ileum	Sulfasalazine	√	√	Green vegetables, fortified cereals, enriched grains (rice, pasta, bread), legumes
Iron	Duodenum Jejunum		√	√	Meat (beef), fish (oysters, sardines), legumes, spinach, tofu, fortified cereals, dark chocolate
Calcium	Duodenum Jejunum	Prednisone	√	√	Dairy and soy products, fortified orange juice, fortified cereal, kale, turnip greens
Zinc	Jejunum	Prednisone	√	√	Fish (oysters, crab, lobster), meat, chicken (dark meat), cashews, chickpeas
Potassium	Duodenum Jejunum Ileum Colon	Prednisone	√	√	Fruits/vegetables (especially potato, banana, oranges, tomatoes, avocado), dairy, legumes
Magnesium	Jejunum Ileum		√	√	Nuts, legumes, whole grains (brown rice, whole-wheat bread, cereals), avocado, potato

References:

Nutrition in IBD: Making Healthy Choices (Presentation). Crohn's & Colitis Foundation of America. Accessed 1/30/18.

National Institute of Health: Office of Dietary Supplements. U.S. Department of Health and Human Services. Accessed 1/30/18



WITH ANNETTE LANGSEDER, RN, BSN

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)

CLOSED

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. Patient 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 answers 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. **CLOSED**

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. **CLOSED**

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.



LET'S TALK SOON!

Let's

Talk!

Hi! My name is Jacob Steinberg. I'm a junior in high school. When I was 16, I was diagnosed with ulcerative colitis. It really stunk (literally). At my sickest point, I spent about a week in bed because it hurt too much to stand up, and I lost 30 pounds. But I got better, and you will too.

I know it can be embarrassing to talk to your family about it. Trust me, I know. So, if you ever need someone to talk to, or ask questions, you can talk to me. I've been through it all, and none of it freaks me out! Feel free to call, email, or text me. Let's talk soon!

Jake

(for contact info, reach out to Peds GI Nursing)



IMPORTANT NEWS FROM OUR PRECERT DEPARTMENT

**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).

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.



PEDIATRIC NURSE NAVIGATOR'S CORNER

BY NANCY SALMERI, RN, BSN



It is unbelievable how quickly the school year flies by. We are well into the school year, yet It feels like only yesterday it was September! For our college bound seniors and their parents, this is a very busy time of year. If your student is on a biologic medication (Humira, Remicade, Entyvio, Cimzia or Stelara) and will be traveling more than 1 hour to college, finding an IBD specialist locally is paramount for continuity of care. We have a large data base that we can refer to in order to help assist with connecting your teen to a local IBD provider.

For those who have a high school senior at home, it is recommended that once they have committed to a college, we work together as a team to locate a provider close to college who can collaborate on IBD care. It is highly recommended that a consultation with this provider, if at all possible, be done prior to July 2018. It is important to be aware that it often can take up to 3 months to secure a new patient appointment with an IBD specialist. Budgeting time for this in the planning schedule will help eliminate some of the stress that comes along with sending your college freshman off and running. Please feel free to contact me @ 973-971-5143, I am more than happy to assist you during this exciting transition.



ARE YOU PLANNING FOR THE SUMMER?

Often, this time of year in the deep winter, some people start thinking of their summer plans. Whether a short road trip to the NJ shore, a fabulous Caribbean vacation, or perhaps a trip overseas, looking forward to the upcoming months often helps to keep the winter doldrums at bay.

If you are new to our practice, you may not have heard of Camp Oasis which is the Crohn's and Colitis Foundations' co-ed residential 1 week summer camp. All of the campers (and many of the adults) are living with IBD which gives a great perspective of someone else "walking in your shoes" and allows you to see you are not alone.



The NJ Chapter of the Crohn's and Colitis Foundation participates at Camp Oasis in Pennsylvania. This year's dates are August 13-18th in Camp Nock-A-Mixon in Kintnersville, PA. Eligible campers are those who are entering grade 4-11 this fall. Leaders in training would be entering 12th grade this fall.

SUPPORTING YOUR PEDIATRIC IBD CENTER

PHILANTHROPY
IT TAKES A TEAM



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@atlanticehealth.org.

CAROL PITT RETIRES

Carol was always the first administrative assistant in the office in the morning, she came early, she stayed late, and she took thousands of phone messages. She was all of our adopted mom/grandma.

With grateful hearts,
we wish Carol
**A HAPPY
RETIREMENT!**



Remember to use MyChart for all your non-urgent needs. MyChart is a free, encrypted, HIPAA-secure electronic message system that allows communication for such issues as letters, refills, non-urgent updates or questions.

If you are not on mychart yet and want to be, ask for your activation code at your next appointment.

A few important points to remember:

- ◆ When your child turns 18 years old, parental access to MyChart automatically terminates. Your child can have his/her own access. We request you speak with your child for his/her logon and password information if you would like access as well.
- ◆ **for any urgent issue during office hours, always call our office and use the IBD Line (973) 971-4321.**
- ◆ MyChart messages are only reviewed during office hours which are Monday through Friday, 8am-4pm.

The screenshot shows the MyChart Atlantic Health System patient portal. The header includes the MyChart logo and the Atlantic Health System name. The main content area is divided into four service tiles: 'Communicate with your doctor's office', 'Access your test results', 'Request prescription refills', and 'Manage your appointments'. Each tile includes a brief description of the service. On the right side, there is a login section with fields for 'MyChart Username' and 'Password', a 'SIGN IN' button, and links for 'Forgot Username?', 'Forgot Password?', and 'New User?'. Below the login section is a 'SIGN UP NOW' button. At the bottom, there are links for 'Frequently Asked Questions', 'Privacy Policy', 'Terms and Conditions', 'Request Technical Support', and 'Patient Portals and Bill Pay Options'. The footer includes the App Store and Google Play logos, and a copyright notice for MyChart licensed from Epic Systems Corporation.

HAPPY 18TH BIRTHDAY!



When a child becomes a legal adult at 18 years old, it is important to realize that we will need a signed disclosure if the request is made to speak with anyone other than the patient regarding his medical condition. By law, all medical discussions need to be conducted by him/her and their healthcare team. Please be proactive and have him/her fill out and sign a Disclosure of Information form which designates to whom our office may speak to regarding their medical care if that is their desire.

In addition, on your child's 18th birthday, a parent's access to his/her MyChart account will automatically be revoked. We can give a new activation code to your child to register as an adult. If you also would like access to MyChart, we request you have a conversation with your child to discuss this.

WWW.JUSTLIKEMEIBD.ORG --A WEBSITE FOR TEENS

The screenshot shows the top of the Crohn's & Colitis Foundation website. The logo is on the left, and navigation links for 'What are Crohn's & Colitis?', 'Living with IBD', 'Treatment', and 'Join the Community' are in the center. On the right, there are links for 'Search' and 'For Parents'. Below the navigation is a large blue banner with the text 'Don't let IBD stop you from being you.' and a 'Get Started' button. The banner also includes a quote: '"Just Like Me IBD" connects you with the information and resources you need to enjoy life and all that comes with it.'

WHAT DO YOU THINK?

I hope you enjoyed this newsletter. If you have a few seconds, please let me 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>

Editor & Writer: Stephanie Schuckalo, RN, MSN, APN (stephanie.schuckalo@atlantichealth.org)