

THE DIGESTIVE DIGEST

SPRING 2019

Volume 11, Issue 1

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FROM THE DIRECTOR

DR. JOEL ROSH



Therapeutic Drug Monitoring—How to Optimize a Therapy

“Drugs don't work in patients who don't take them.” – C. Everett Koop, Former US Surgeon General

Some have likened our former Surgeon General to Yogi Berra—so many excellent quotes are attributed to him! This famous quip is usually used to refer to a person's adherence to a prescribed therapeutic plan. Perhaps, this important concept is best understood when applied to oral medications that are prescribed to be taken daily. We would all accept that if such a medication stayed in the pill bottle, it would be expected to be less effective than if it was taken as prescribed.

Many of our current therapies for Inflammatory Bowel Disease (IBD), especially the biologics, are provided parenterally, that is either by a self-injection or an intravenous infusion. Adherence here is, perhaps, a little bit more complicated. Not only does the medication have to be taken as prescribed, but the actual dosing used needs to be adjusted to assure that there is an effective amount of the medication present in the recipient's blood from the time one dose is taken until the next. If there is a period between doses where the amount of the biologic circulating in the blood is below the effective level, two issues will arise.

The first is that the underlying inflammation will become active and then diminish with the subsequent dose of biologic. This repetitive increase in disease activity would lead to damage of the bowel over time and result in complications from the underlying IBD. In the past, allowing for these times of clinical disease activity and then quiescence resulted in the use of terms such as “flare” which is an old term and should be avoided with today's much improved therapies. We have learned that the 2nd consequence of the sub-optimal dosing of biologics is that if the level of the drug goes too low and is then followed by a dose of the drug on a repetitive basis, anti-drug antibodies are made. Such antibodies block the ability of the biologic to work and ultimately could lead to allergy against the drug and the inability to continue that particular therapy.

Therefore, to achieve our best outcomes, dose optimization of any therapy, but especially the biologics, is essential to assure our best outcomes. We have learned that there really is no such thing as a high dose or low-dose of biologics. Everyone eliminates these agents at their own personal rate. The only way we know how to dose your child's biologic medication is by doing a blood test to see what the level is. Based upon this information the size of the dose and the interval of time between doses can be appropriately adjusted. Guiding these decisions by measuring the actual drug level will minimize the risk of drug allergy and the formation of anti-drug antibodies, while also optimizing your child's health and provide the best opportunity for excellent long-term prognosis.



Inflammatory Bowel Disease: *Information and Resources for Patients and Families*

Schedule of Events

6:30 - 6:40pm Opening Remarks: *Rolando Rolandelli, MD*

Lectures

6:40 - 6:50pm IBD Overview

Rolando Rolandelli, MD

6:55 - 7:15pm IBD Nutrition

Razvan Arsenescu, MD

7:20 - 7:40pm Family Planning with IBD

Jenessa Dieterle, NP

7:45 - 8:05pm Break

8:10 - 8:30pm IBD Research Review

Joel Rosh, MD

8:30 - 9:30pm Q&A

Consultation Booths

6:30 - 9:30pm

Ashley Salmon

*Crohn's & Colitis Foundation (CCFA),
New Jersey Chapter*

Ellen Robertson

*Yoga Therapy, Meditation & Stress
Management*

Douglas Bloomstein, PharmD

Drug Safety, Effectiveness and Interactions

Kelly Varzea, RD, CSP

Diet, Nutrition, & IBD

Michelle Retik

Squirrel & The Bee, Grainless Bake Shop

Nancy Salmeri, Pediatric IBD Nurse Navigator

Insurance Reimbursement

Taylor James

Organic farmer, Flipside Farm LLC

Toni McTigue & Janet Doyle-Munoz

Wound Care and Enterostomal Therapy

Thursday May 2nd, 2019

6:30 - 9:30pm

Malcolm Forbes Auditorium

Morristown Medical Center

100 Madison Avenue

Morristown, NJ 07960

RSVP to morristownsurgicalsyp@atlanticealth.org

Research with Annette & Mary

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. 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].

2. 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). **CLOSED**

3. 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.

4. 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**

5. 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.

6. Home Infusion Therapy for Pediatric Inflammatory Bowel Disease: The Patient's Experience

This study aim is to evaluate the pediatric patient/family experience regarding home infusions of biologic therapy for IBD. A home infusion survey is being sent to families that have had or currently use home infusion for IBD.



the faces of IBD



Our division cares for over 1,000 children, adolescents, and young adults who are managing IBD each year. They are balancing school, work, taking medication, sports, not letting IBD stop them from having fun and living their dreams. We understand the challenges patients and families face and support them every step of the way. We continue to celebrate our IBD patients and would like to honor them here.



Congratulations to Thea!
Thea Gardin *8 years, Crohns*
Recently had her artwork entitled,
"Colorful Dreams," published in
New Moon Girls magazine.

Dara's journey

I was very sick and tired and got fevers every night before I was diagnosed. I had missed so much school it was getting hard to keep up with everyone else when I was there. This was not an easy task for me.

Finally, my grandfather suggested that I take a blood test. When I got the results from that back they said that I was anemic, and then they said that something needed to be done. They sent me to Dr. Feldman. I was so happy something was being done to make me feel better. When I saw Dr. Feldman she said I needed to have a colonoscopy and an endoscopy. The results of these tests showed that I had Crohn's. I did not know what that meant but I understood after Dr. Feldman explained it to me. Now, I go to the infusion center every month to get my Remicade. I have only had 1 flare up and do not expect another. Dr. Feldman has been such a great help, and I look forward to every appointment. The whole experience, from when I started feeling sick until when I was diagnosed, was not an easy experience but my family and Dr. Feldman helped me through. I hope one day someone will find a cure, but for now I feel well taken care of on my journey. Thank you Dr. Feldman and team. :)



Dara, 8 years old

The Need for a Sacrifice

by Bella
17 years old, ulcerative colitis



My name is Bella and I am seventeen years old. I am graduating high school this June. My hobbies include walking my dog, baking, and hanging out with friends. I love going to the beach, traveling, and eating good food. I am in various school clubs and I am always on the sidelines flaunting school spirit. I was recently accepted to Seton Hall University's Nursing College with a generous merit scholarship. I also happen to have Inflammatory Bowel Disease. When contemplating as to how best share my story, I finally decided upon sharing my college essay. My hope is that it gives hope and demonstrates that IBD is not where the road ends.

The Need for a Sacrifice

Allow me to paint a picture for you: my father is Italian and my mother is Syrian. Together, I am an amalgamation of the two cultures. Physically, I am the spitting image of my dark-haired Syrian mother. Emotionally, I am passionate much like my hotblooded Italian father. At times, it can be quite difficult to navigate through the varied languages and cultural norms of these two distinct cultures. Perhaps, that is why more than anything I have grown to love food. Although Syrians and Italians may not see eye to eye on everything, there is one thing they both have in common: a love of food. My family and I are fantastic chefs, bakers, and eaters. Sundays and holidays are composed of unbelievable spreads with traditional recipes that bring my family together and create endless memories. Food is love, food is life, food is everything, or at least it used to be until it became my nemesis. During Sophomore year, I was diagnosed with Crohn's Disease. Within months of my diagnosis I was hospitalized, received several blood transfusions, took steroids and had my hair fall out, and practically became housebound. Not to mention that I also spent a great deal of my time in the bathroom.

**I am the
strongest person
I know.**

Since Crohn's Disease attacks the digestive tract, my passion for tasting and crafting delectable cuisine was put on halt. What I loved most about my life, Christmas brunches and Sunday pasta was destroying me on the inside. Grandma's cavatelli made me nauseous, Mom's mozzarella had me rushing to the bathroom, and Tatie's maamoul (a delicious Syrian semolina pastry filled with dates) left me doubled-over in pain.



Going out with friends and participating in activities also became quite difficult. Before leaving the house, I mapped out the nearest bathrooms and searched restaurant menus to glance over my options. Eventually, I stopped going out altogether since it gave me so much anxiety. I became resentful and frustrated that even to do the simplest of things like going to the mall with my friends I had to plan ahead in case of a potential emergency. I lived in constant fear, and truly was not *living* at all. After numerous failed attempts at eliminating certain foods from my diet, I finally set my mind to making a change. If I was going to start living a healthy and happy life, then I was going to have to give up what I loved most. My well-being would come at the expense of pizza, kanafeh, and anything else that contained gluten, sugar, or dairy. Of course, this sacrifice was easier said than done. At times, I just wanted to give up. The worst moments were during family gatherings. I became frustrated and jealous that I could not partake in the feast, but I quickly realized that if I had not made this change then I would not be able to spend quality time with my family. What's the point of eating cannolis and baklava if you spend most of the night in the bathroom right?

After a few months of suffering through this change in diet, I was finally starting to realize that the benefits outweigh the costs. Crohn's Disease made its mark in my life, both good and bad. However, I refuse to let it define me. After trying countless treatment options, I am currently in remission. Even though my disease has made my high school experience tough, it shaped me in a positive manner. My years of being a patient have inspired me to pursue a career as a nurse practitioner. I live a healthier lifestyle and eat less junk food in order to prevent a flare up. Most importantly, Crohn's Disease taught me that I am strong and can face anything, including my own body fighting itself. I am the strongest person I know.



Donations and proceeds go
to the Departments of
Rheumatology and Physiatry

Goryeb's Got Talent!

Do you sing, dance, or play an instrument? Are you a magician?
ARE YOU IN A BAND? Are you an actor? Can you ride a unicycle?

Come and show us your talent!

Wednesday, May 15th at 7pm (doors open at 6:30pm)

Morristown Medical Center

Malcolm Forbes Amphitheater, level B

Hosted by Goryeb Children's Hospital Pediatric Residents

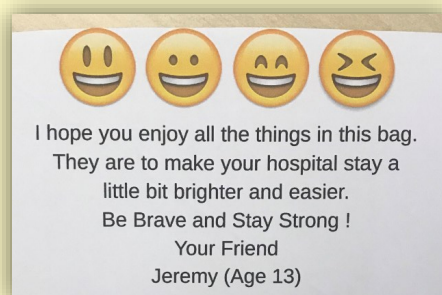
“BE
BRAVE
AND
STAY
STRONG”
- Jeremy



Jeremy was diagnosed with Crohn's disease when he was 7 years old and has been a patient of Dr Leiby and the Infusion Center ever since. This year he turned 13 and became a Bar Mitzvah. Part of his preparation was to make a "mitzvah project."

Jeremy decided he wanted to do something for the children at Goryeb Children's Hospital and the Pediatric Infusion Center. He chose fun items like slime, stickers, tic tac toe boards, squishies, and rubber bracelets with inspirational sayings on them and made "Bravery Bags" for the patients. He enclosed a note so the patients would be reminded they are not alone. On March 11th, we delivered 25 Bravery Bags to Goryeb. Jeremy hopes these bags will help young patients pass the time and stay brave during their hospital stay or infusion appointment.

~Hope (Jeremy's mom)



CONGRATULATIONS CALENDAR CONTEST WINNERS



You may remember in the last newsletter, there was a contest to enter your artwork in the Creative Expressions Healing Arts Calendar. This contest was for children and teens who are diagnosed with chronic illness and pain. Art allows a child to enter into their own imagination to create a world that can be fun, therapeutic, and express emotions that would be difficult to say in words. Creating art promotes relaxation and studies show art supports healing on all levels including Mind, Body, and Spirit. This year, they submitted an original mandala design (a mandala is a Sanskrit word loosely meaning circle—a form of self-expression or exploration of their internal world). Kudos to Ava and Mackenzie whose art was featured in the calendar!



Balanced life
Ava P., age 13

My name is Ava. I was diagnosed with Crohn's disease when I was 6 years old. While I have Crohn's, I try hard not to let it stop me, which isn't always easy. I have found many ways to express myself even when I have to have downtime and that is with music and coloring, and with my 2 dogs Bongo and Penny.

I Love My World
Mackenzie R., age 5

Mackenzie is 5 years old and in Kindergarten. She enjoys dancing, gymnastics, cheerleading, swimming, and playing with her sister and friends. Mackenzie was diagnosed with ulcerative colitis at age 2. She has never let her diagnosis slow her down. She is a happy, energetic 5-year-old girl. She lives with her mom and dad, little sister, dog, and fish.



STAY TUNED COMING IN MAY... "CREATIVE EXPRESSIONS" 2020 ARTS & HEALTH ART CONTEST

your GI team digesting the holidays together

Who says Halloween is just for kids??

Your pediatric GI team are kids at heart



Top row left to right:

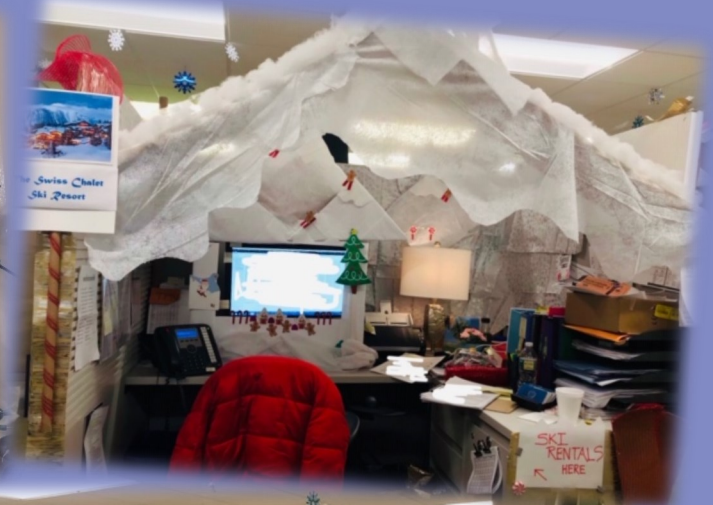
Dr. Alycia Leiby ■ Mary Pastirik RN BSN ■
Nancy Salmeri, RN, BSN ■ Mary Kennedy, MSN, APN-C ■
Lakeisha Mack

Bottom row left to right:

Donna Karlak, RN, BSN ■ Tyreema Muhannad, CMA



This winter, our administrative office turned into a winter wonderland! Below is a sample of the imaginative creations of some of our staff: Annette's Homage to Rudolph, Donna's Swiss Chalet Ski Resort, Mary's Gingerbread Pub, and Meredith's Gingerbread Inn.



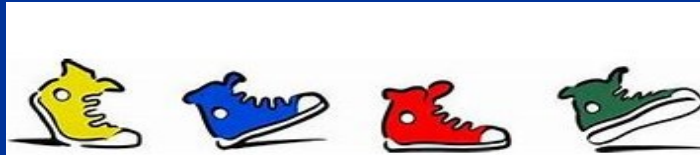


**JOIN THE LIBERTY STATE PARK
TAKE STEPS FOR CROHN'S COLITIS
ON SUNDAY, JUNE 9TH**

10am check-in & festival start

11am walk start

- *By joining Take Steps, you will become part of the IBD community, who not only provide support to each other, but who, together, are actively raising money to support the Crohn's & Colitis Foundation fund research into better treatments and ultimately cures for IBD.*
- *You can join our team, Goryeb's Gastro Greats, walk as an individual, or form your own team.*
- *For more information, search Take Steps Liberty State Park.*



precertification news

**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 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.



Nutrition advice from Dietitian Kelly

During an exacerbation of symptoms with Crohn's or ulcerative colitis, it can be difficult to consume enough calories, protein, and vitamins needed to maintain good nutritional status. Below is a recipe that includes foods containing key nutrients for IBD health and healing.

POWER-UP SMOOTHIE



Ingredients:

2 cups baby spinach leaves, or to taste
 1 banana
 1 carrot (peeled and chopped)
 ¾ cup plain fat-free Greek yogurt, or to taste
 ¾ cup ice
 2 tablespoons honey



Directions:

Put spinach, banana, carrot, yogurt, ice, and honey in a blender; blend until smooth.

*Breakfast Banana Green Smoothie. All Recipes. <https://www.allrecipes.com/recipe/233980/breakfast-banana-green-smoothie/>. Accessed 3/29/19.



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.

PEDIATRIC NURSE NAVIGATOR'S CORNER BY NANCY SALMERI, RN, BSN

Many of our patients are on specialty medications for treatment of their IBD diagnosis. Even with insurance, patient out of pocket responsibility can be costly. Most of the pharmaceutical companies offer patient assistance programs to help defray out of pocket costs. These are easy to access by going to the appropriate website listed below (based upon your medication). You can sign up and will be provided with a copay or rebate card. The websites will explain how their program works. If using the copay card for self-injectable medications, provide your specialty pharmacy with your copay card ID information prior to paying your out of pocket cost so the discount can be credited to your account. As always, if you have any questions or need assistance, please reach out and I am happy to assist.

- Remicade: CarePath. Janssen Pharmaceuticals- Crohn's Disease and Ulcerative Colitis
<https://www.janssencarepath.com/patient/remicade/patient-support>
- Stelara: CarePath- Janssen Pharmaceuticals- Crohn's Disease
<https://www.janssencarepath.com/patient/stelara/patient-support>
- Humira- Abbvie- Crohn's Disease and Ulcerative Colitis
<https://www.humira.com/humira-complete/cost-and-copay>
- Entyvio- Takeda Pharmaceuticals- Crohn's Disease and Ulcerative Colitis
<https://www.entyvio.com/financial-support>
- Simponi- CarePath- Janssen Pharmaceuticals.- Ulcerative Colitis
<https://www.janssencarepath.com/patient/simponi/patient-support>
- Xeljanz (oral) - Pfizer—Ulcerative Colitis
<https://uc.xeljanz.com/financial-support>

To our newly diagnosed families:

*Our office needs your child's immunization record.
Please be sure it is forwarded to us. Thank you!*

supporting your peds IBD center...helping us to help you.



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

**One more
thing!**

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."

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