

The Digestive Digest

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From the Director Dr. Joel Rosh...



I hope this issue of the Digestive Digest finds you and your family safe, healthy and strong. We recognize these to be unprecedented times and, like other challenging eras throughout history, there are lessons we are learning in real time and so many more that we will learn over time and reflection in a more PC (Post Covid) world.

We also realize that there can be additional anxiety that grows out of having IBD and being on immune modifying therapies during the pandemic. This recognition led to the well attended support group meeting we held over Zoom earlier this month. We thank Dr. Chris Lynch for joining us and providing such helpful information and strategies on how to manage the psychological impact of sheltering at home. We also thank all of you for your excellent questions! The over arching themes and answers to the most common questions follow. We hope this is helpful and we look forward to a similar Zoom meeting in May.

Is my child at higher risk for COVID-19 or related complications because he/she has IBD or is taking certain medications? The honest answer is that we do not know. This is called a "novel" virus because it has not been seen before, so we do not have years of research to draw upon to give a full, scientifically-sound answer to these important questions.

That being said, we are not totally in the dark. The COVID-19 pandemic results from infection from the SARS CoV-2 virus, so we know a lot about the viral family to which this novel virus belongs. Based upon the current and evolving knowledge of this novel virus, we do not have evidence that IBD makes one more at risk of becoming infected with the virus. Also, those with IBD should continue their biologic medications during the pandemic to avoid disease complications. If your child becomes actively ill with COVID-19, please notify us to help guide care management while your child is acutely ill. To date, we have approximately 12 instances in our Center, and all have done well. There is global tracking of cases as well, so we will continue to learn more over time.

The International Organization for the study of IBD has put together a global task force to advise and study IBD care during the COVID-19 pandemic. This panel has been meeting weekly and our recommendations (www.IOIBD.org) are very much in line with those that are found on the Crohn's and Colitis Foundation website (www.CrohnsColitisFoundation.org).

Should my child still get his/her Remicade infusion at the Infusion Center?

Yes. Continue your child's usual Remicade schedule. The infusion center is carefully following the latest CDC guidance to assure the safety of our patients, their families, and the staff.

What do we know about people who have IBD and are COVID-19 positive?

As mentioned above, since this is a novel virus, we need more scientific research to be certain about how COVID-19 impacts people with IBD. At this time, there is no evidence that having IBD increases risk. In fact, some IBD medications are being considered as potential treatments for severe COVID-19 disease. It is premature to state that these medications would be effective treatment—but it does suggest that our level of concern and the practice of proven preventative measures (social distancing, handwashing, etc.) should be the same for those with IBD as for everyone else.

Should I, and/or my child, still go to work?

This is both an excellent and complicated question. It is dependent on so many factors including the worker's overall health, essential worker status, financial needs, etc. So, in a very real sense, this is more a personal than scientific question.

Keeping business as usual during this pandemic



To many of us, it feels like the world has flipped upside down. We may not know what day of the week it is. We can't go to our child's lacrosse game or to the movies.

In many ways, the world has come to a standstill. The COVID19 pandemic arrived and what does your team do? We stay flexible, bounce back, and stay committed to you and your families! For the past few months behind the scenes, we've been navigating our way to try to figure out how to best continue caring for you among the restrictions due to COVID-19 pandemic. How are we going to continue to see our patients? Can they still get their infusions? When should they go for labs? How do we help them through these uncertain times?

Although it does not replace a true in-person visit and physical exam, a virtual visit allows us to continue to maintain contact and to provide ongoing care in a safe environment (and from your comfort of your home). If you have an appointment soon, our administrative assistants will be reaching out to convert your appointment to a virtual one. We are still continuing with in-person visits for urgent situations.



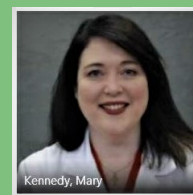
We appreciate your patience as we navigate through this together.

Patient Assistance Programs - Advanced IBD Therapies

Medication	Website	By Phone
Adalimumab (HUMIRA)	Abbvie Patient Assistance Foundation http://www.abbviepaf.org/apply.cfm	1-800-222-6885
Certolizumab pegol (CIMZIA)	UCB Patient Assistance Program https://ucb-pap.enrollsource.com/	1-877-785-8906
Golimumab (SIMPONI)	Johnson & Johnson Patient Assistance Foundation http://www.jjpaf.org/resources/jjpaf-application.pdf	1-800-652-6227
Infliximab (REMICADE)	Johnson & Johnson Patient Assistance Foundation http://www.jjpaf.org/resources/jjpaf-application.pdf	1-800-652-6227
Infliximab-dyyb (INFLECTRA)	Pfizer Patient Assistance Program www.pfizerxpathways.com/sites/default/files	1-844-722-6672
Infliximab-abda (RENFLEXIS)	Merck Patient Assistance Program https://www.merckaccessprogram-renflexis.com/hcc/merck-patient-assistance/	1-866-847-3539
Tofacitinib (XELJANZ)	Pfizer Patient Assistance Program (XelSource) https://www.xeljanzuchcp.com/	1-844-935-5269
Vedolizumab (ENTYVIO)	EntyvioConnect Patient Assistance Program https://www.entyvio.com/financial-assistance	1-855-368-9846
Ustekinumab (STELARA)	Johnson & Johnson Patient Assistance Foundation http://www.jjpaf.org/resources/jjpaf-application.pdf	1-800-652-6227



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. Below is a summary of our current studies.

A RANDOMIZED, CONTROLLED TRIAL OF YOGA IN PEDIATRIC INFLAMMATORY DISEASE

This study is being 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 is 10-17 years. ENROLLMENT IS CLOSED.

A MULTICENTER, PROSPECTIVE, LONG-TERM OBSERVATIONAL REGISTRY OF PEDIATRIC PATIENTS WITH INFLAMMATORY BOWEL DISEASE

This 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. ENROLLMENT IS OPEN.

SEX DIFFERENCES IN STatural IMPAIRMENT IN PEDIATRIC CROHN'S DISEASE (GROWTH STUDY)

This study's 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 the National Institutes of Health (NIH) in coordination with Weill Cornell Medical College. We are currently enrolling males ages 9-15 years and females 8-13 years who have Crohn's Disease. ENROLLMENT IS OPEN.

GENETIC ENVIRONMENTAL MICROBIAL (GEM) PROJECT

The goal of this study is to find causes or triggers for Crohn's Disease. Healthy siblings must have a sibling with Crohn's Disease and be between the ages of 6-30 years old. The healthy sibling will have 2 office visits and a follow-up call every 6 months for a health review. ENROLLMENT IS CLOSED.

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 inclusive at the time of enrollment) with moderately to severely active Crohn's Disease who are prescribed and treated according to routine clinical practice. Patients being prescribed and treated with conventional immunosuppressive therapy with no concurrent biologic will also be enrolled as a reference group. ENROLLMENT IS CLOSED.

SURVEILLANCE EPIDEMIOLOGY OF CORONAVIRUS UNDER RESEARCH EXCLUSION (SECURE) IBD REGISTRY

This registry is an international registry that will rapidly be able to define the impact of COVID-19 on patients with IBD and how factors such as age, comorbidities, and IBD treatments impact COVID-19 outcomes. ENROLLMENT IS OPEN TO ALL CONFIRMED AND SUSPECTED CASES OF ALL AGES.

HOW DOES COVID-19 2020 OUTBREAK INFLUENCE PEDIATRIC IBD?

We aim to collate, as rapidly as possible, all cases of children with IBD who were exposed to COVID-19 from the PIBD centers affiliated with the Porto and Interest group of ESPGHAN, to issue guidance on managing pediatric IBD during the outbreak. ENROLLMENT IS OPEN TO ALL AGES.

PIBD SET QUALITY SAFETY REGISTRY

This is a worldwide registry that identifies any rare and severe complications of pediatric IBD. Its aim is to identify incidence and prevalence of these complications on their treatments. The long-term aim is to both predict and reduce these complications in the future. ENROLLMENT IS OPEN TO AGES 0-18.

precertification NEWS



This is an URGENT request to all of our patients who are on medication infusions
(Remicade, Entyvio, Stelara)

YOU MUST NOTIFY US ASAP IF YOUR INSURANCE CHANGES

- Patients have been showing 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.
- Patients who are 18 years and older MUST present their own photo ID and insurance card information otherwise the appointment will need to be rescheduled.
- 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 with pictures of both sides of your card or call (973) 971-4321 (Mon-Fri 8am-4pm) and ask for the precertification team.

Thank you in advance for your cooperation and understanding.

HELPFUL COVID-19 REFERENCE WEBSITES

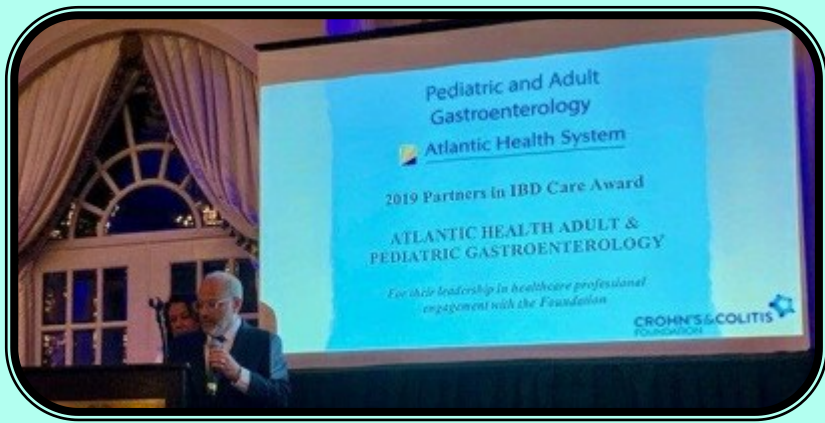
HERE ARE A FEW WEBSITES TO VISIT FOR THE MOST UP-TO-DATE INFORMATION.

- ⇒ **CROHN'S & COLITIS FOUNDATION:** [HTTPS://WWW.CROHNSCOLITISFOUNDATION.ORG/CORONAVIRUS/WHAT-IBD-PATIENTS-SHOULD-KNOW](https://www.crohnscolitisfoundation.org/coronavirus/what-ibd-patients-should-know)
- ⇒ **CENTERS FOR DISEASE CONTROL (CDC):** [HTTPS://WWW.CDC.GOV/](https://www.cdc.gov/)
- ⇒ **ATLANTIC HEALTH SYSTEM:** [HTTPS://WWW.ATLANTICHEALTH.ORG/](https://www.atlantichealth.org/)

help us
to
help you

If you have an 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

CONGRATULATIONS ...to us all!



Last October, our division along with Adult Gastroenterology were honored to receive Crohn's & Colitis Foundation, New Jersey Chapter's Champions of Hope *Partners in IBD Care Award*, during their Cheers To A Cure event. This annual event directly supports the mission of curing Crohn's Disease and ulcerative colitis and improving the quality of life of children and adults affected by these digestive diseases.



Top left: Anetta Burdzy (Practice Administrator), Dr. Joel Rosh (Director), Lakeisha Mack (Office Coordinator)



Top right: Dr. Barbara Verga, Annette Langseder (Research Coordinator), Dr. Tamara Feldman, Dr. Maria Perez



Middle left: Kelly Varzea (dietician), Ruth Irizarry (Nurse), Stephanie Schuckalo (Nurse Practitioner)

Middle right: Dr. Oren Koslowe, Dr. Barbara Verga



Bottom left: Mary Kennedy and Annette Langseder (Research Coordinators)

Bottom right: Lakeisha Mack, Nancy Salmeri (Nurse Navigator), Dr. Mohini Patel



NUTRITION BITES *with Kelly Varzea, RD, CSP*



Most of our families with children diagnosed with Inflammatory Bowel Disease understand the importance of a balanced diet and try to provide a variety of nutritious foods. Due to the COVID-19 pandemic, many have found this challenging due to limited food availability and increased food cost. Here are some budget-friendly tips to help you provide your families with nourishing foods during this period of uncertainty.

Choose How To Shop

Many are unable to find available slots to pick up or get their groceries delivered. While this is a great service, consider pros (limits exposure risk) and cons (time/stress searching for an open slot, cost, and out-of-stock items). If you will be doing your own grocery shopping, follow the government's recommendations regarding wearing protective gear and social distancing.

Decide When and Where To Shop

Decide how often you will need to get groceries. Try to limit the number of trips by choosing foods that have a longer life. You can also limit the number of trips by choosing a store that typically has the best food availability and going at a time that tends to have less traffic and restocked shelves. Keep in mind that several restaurant supplies have opened their doors to the public and did not increase their prices. Buying in bulk is one way to keep costs down and stretch the time between grocery trips.



Have A Flexible Grocery List

Plan how many servings you will need of fruit, vegetables, protein, grains/starches, and dairy each time you get groceries. Having a flexible list allows you to buy what is most affordable and available.

Simplify Meal Prep

Have a few basic recipes that are easy to change based on available ingredients. No recipe? Choose a protein, a vegetable, and a starch for each meal. Vary the cooking methods: sheet pan dinners in the oven, stir-fry dinners on the stove, and as the weather gets nicer—take out the grill! Dried herbs and seasonings can be used as a substitute for fresh and will add flavor. Adding in fruit can also add natural sweetness.



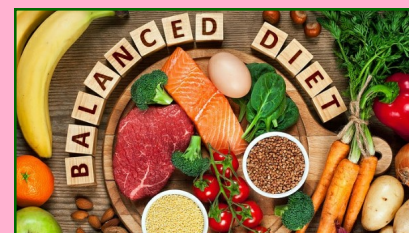
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First Virtual IBD Support Group A Success!



Recently, we had our first virtual IBD Support Group and it was a success! With the COVID19 pandemic, our office was flooded with questions and concerns regarding their children and their potential risk to complications due to COVID19 infection. We identified a need for additional support and a Zoom session was quickly put together.

With over 58 participants, the hour long Zoom session featured two speakers, Joel Rosh, MD and Christopher Lynch, PhD. followed by a question and answer period.

First Dr. Rosh gave a brief overview of IBD including a few ongoing research studies, predicting response to treatment, targeting therapy to type of disease, and how to improve outcomes.

Next, Christopher Lynch, PhD, the Director of Pediatric Behavioral Medicine, discussed coping and resiliency while sheltering at home during the pandemic. He discussed how to address fear and anxiety with the pandemic, the importance of maintaining academic success as well as the importance of reducing media exposure, practicing stress reducing techniques, and using pleasant distractions.

Feedback received from families was that it was informative and families loved the online platform. We are in the planning stages for the next virtual support group. We hope to be able to tape future Zoom sessions so those who cannot attend can view at a later date.

- ◆ If you have any questions you would like to submit for the next support group, please email Stephanie at the address below.
- ◆ Also, if you did not get an invitation, that means we do not have your email address. Please email Stephanie to be included on the next invite as well as any important mass emails we send out.

stephanie.schuckalo@atlantichhealth.org



CHANGES TO OUR TEAM



My name is Kay Aponte and I am the newest member to the Pediatric GI team as a MOA/Pre-Cert level II.

I have over 12 years of experience in the medical field. In addition, I have obtained my degree in Cardiovascular & Health Science Studies. I have always had a passion for pediatrics as well which has led me to the opportunity to work with the Peds GI Department. It has been an interesting experience thus far and I am looking forward to continue learning and evolving in my position with such admirable professionals.



Please help us welcome our newest nurse, Michelle Ferrara, who recently joined our practice. She comes to us from the pediatric inpatient unit. She divides her time between the Goryeb Children's Day Hospital, Infusion Center, and our division.

Michelle comes to us with a wealth of knowledge in nursing experience and thrilled to have her!



Last month we said "Goodbye and Good luck" to Charlotte Intile, our social worker who has been with our department since its inception in 1994.

We thank her for all her expertise over the years, will miss her and wish her all the best at her new role at Overlook Medical Center!

A vibrant beach scene with a blue sky, white clouds, and turquoise waves. In the foreground, the word "SUMMER" is spelled out in large, blue, 3D block letters on the sand. A white sailboat is visible on the horizon.

REMEMBER TO WEAR SUNSCREEN—SOME MEDICATIONS MAKE YOU MORE SUN-SENSITIVE AND BURN QUICKER.

SUBMIT YOUR CAMP FORMS TO US ASAP

SEND US A REQUEST IF YOU NEED AN UPDATED 504 PLAN FOR SCHOOL.

IF YOU'RE GOING TO COLLEGE—REQUEST 90 DAY SUPPLY OF MEDICATION TO TAKE WITH YOU

A scenic view of a forest with trees in full autumn foliage, displaying shades of red, orange, and yellow. The trees are reflected in a calm body of water in the foreground. The word "FALL" is written in large, yellow, hand-drawn letters across the center of the image.

FALL

GET YOUR FLU SHOT—THE SEASONAL FLU SHOT IS AVAILABLE IN AUGUST. GET IT BEFORE YOU GO TO COLLEGE.

SCHEDULE YOUR WINTER BREAK FOLLOW-UP—THESE BOOK FAST BECAUSE ALL OF OUR COLLEGE KIDS ARE HOME AT THE SAME TIME.

A slight change in scheduling procedures

Currently, all elective procedures (upper endoscopies and colonoscopies) are on hold. When we resume procedures, we wanted you to be aware of a slight change to our scheduling process.

As usual, you will be contacted by our scheduling staff to coordinate a date. Although we will make our best efforts to accommodate a date request, please understand there are multiple departments that need to be coordinated so we cannot guarantee a particular date or time.

The new change is that you will not receive a procedure time until about a week prior. Approximately 2-7 days prior to the scheduled date, you will be contacted to confirm the procedure and be given both an arrival time and a procedure time.



Thank you for your patience and understanding.

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."



ONE
MORE
THING!

We hope you enjoyed this newsletter. If you have a few seconds, please give some feedback. Is there something you would like to see in a future one? We love to announce your child's accomplishments so please continue to send us pictures, stories, artwork, tips, or information that you have. They are so inspirational to other families...remember we have many newly diagnosed families along with our veterans of many years. Send all submissions to my email below.

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