



# The Digestive Digest

Fall 2020.....Volume 12, Issue 2

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## From the Director Dr. Joel Rosh...



I hope this issue of the Digestive Digest finds you and your family well, not just physically, but in a truly holistic sense. As it becomes clear that the COVID-19 pandemic is ripe to become COVID 19-21, we all recognize the marathon nature of what we need to do. Hopefully we will soon pass the "heart break hill" of this marathon and we will start to see a finish line emerge. Until then, please know that the entire resources of our IBD Center are here for you and

your family.

While the pandemic has persisted, science has continued to move at an unprecedented speed. This includes carefully performed epidemiologic study of COVID and IBD. We have learned that young age and IBD that is in remission confer the best outcomes if one with IBD becomes infected with the virus. In addition, those on biologic therapies seem to do best if they become infected. Further research is needed to know why this is the case, but the fact that these medications are most likely to be associated with true remission, especially in the case of Crohn's disease, is likely contributory.

For Pediatric IBD, a concerning trend has been noted. Quite understandably, with so much going on "something has to give". Unfortunately, all too often, this includes routine health maintenance. Seeing your child's primary care clinician for a yearly wellness visit should still occur. Our General Pediatric and Family Practice colleagues, like us, have gone to great lengths to assure that this can occur in safety. Routine health maintenance should include EVERYONE in the family receiving a seasonal flu vaccine—the concern of someone contracting influenza along with COVID should be taken quite seriously as this can be quite a devastating combination. Along with wearing masks and socially distancing, assuring that we are personally immune to influenza are the steps that each of us can do to assure that all of us have the best chances at staying healthy during these unprecedented times.

As Thanksgiving approaches, there is no doubt that this will be a different type of holiday than years past. Perhaps, the biggest difference is that we have all been forced to look at many parts of our lives differently. It is our hope that this "exhausting pause" has also provided an opportunity for each of us to see the parts of our lives for which we can truly give thanks.

# WELCOME KATIE & GINA TO OUR TEAM

Please help us welcome Katie, our new social worker. She has been a social worker in health care for over 13 years with a focus on children and their families for over 6 years. Her previous position was in our neonatal intensive care unit (NICU) at Morristown Medical Center.

"I am excited to start this new role in the outpatient setting, allowing me to work with patients and their families from diagnosis to young adulthood. When not here, I enjoy the outdoors with my family and my dog, Steve."

To contact Katie directly, email her at [Katherine.Blackbourn@atlantichhealth.org](mailto:Katherine.Blackbourn@atlantichhealth.org) or call her at (973) 971-5958.



**Katie Blackbourn, LCSW**



**GINA ORANCHAK, RN, BSN**

We also send a warm welcome to Gina, our new nurse, to Peds GI. Gina has been a Registered Nurse for over 20 years and brings with her a vast knowledge of caring for children, ranging from in-patient pediatrics, pediatric urology, Maternal/child health, and school nursing.

She received her BSN from The College of New Jersey and is a proud Mom to her son, Connor, and twin daughters, Olivia And Angelia. Gina is so happy to be part of the Peds GI team!

*Fun Fact: Did you know that Gina and another one of our team members went to college together? Look for the answer at the end of the newsletter!*



"I am proud of her but more than anything I am at peace for her."

~Gabby's mom

**I**n February 2018, our little Gabby was not feeling well...It took a doctor visit and a small stool test to realize she was bleeding large blood clots. Months of stomach pains, internal bleeding, colonoscopy, endoscopy, MRIs, 7 doctors, three hospitals, major weight loss, and heartbreak. On April 2018, Gabby was diagnosed with IBD 'unknown' at the age of 7, which did not answer any of our worries, nor did we understand what to do with that. Shortly after, Gabby was relapsing and her symptoms would come back as severely as they were back in February.



It's interesting looking back and understanding the impact this had on her physically. When she was first diagnosed, she had to quit soccer. She was unable to run for a long period of time. She would hold her stomach and curl her body while trying to keep up with the kids. As any parent, you push and push to encourage 'no quitting'.

That summer when she relapsed again we took Gabby for a second opinion at a different major medical center and they did not hesitate and changed her diagnosis to Crohn's disease; I was devastated, I thought they rushed it. How could they see this so quickly when our doctor at that time was 'unknown' about why she was symptomatic? She spent her summer on steroids and finally started IV medications. She signed up for basketball and was getting some of her strength back. Ever seen a child shoot a basketball and think, "wow the basketball must be really heavy?" She couldn't even touch the netting.

"I would like to say I am proud of her but more than anything I am at peace for her."

Not even four weeks into her IV medication, she developed severe chronic autoimmune issues (psoriatic arthritis and psoriatic psoriasis). She lost majority of her hair, spent the full winter on antibiotics, two different dermatologists in two different states, three different infectious disease doctors and 50 different topical creams, ointments, medicated shampoos and lack of faith in any of them as she cried each morning on her way to school. I would say her diagnosis was the hardest thing to watch your child go through, but that was quickly taken over by the devastation of sending your child to school with half her hair missing and her head filled in medicated oil. Waking her at 6 am to shower and throw alcoholic treatment in her wound to help it heal. It was the lowest of the low for any parent, as you know that any minute you will send your child to school with her head on fire.



continued







As you noticed I shifted, she was no longer addressing her Crohn's as that was ok due to her IV medication, but now we had to fight another battle. The turning point was her new team at Goryeb, medical care, and the new medication that help her body get back to what is 'normal'. It is not only that she has gained her weight back or that her hair grew back to its blond shiny self. No, the turning point is her own self-esteem and ownership of her disease. It's the care of her medical team who speak directly to her when they discuss her health. It's that she is more aware of what trigger foods will cause her harm. It's the fact that she has so much energy, we have a hard time calming her down. She plays so many sports I can't keep up: gold, cheerleading, volleyball, basketball, swim team you name it, she does it. She is so good that she has been asked to join club teams. Its amazing, liberating, and so rewarding to watch her transform. This summer she even raised \$3,500 dollars to Cohn's and Colitis Foundation. It's that she is setting higher goals for herself and already getting better physically but more importantly mentally. She is not crippled by her disease and she is not fond of you mentioning it as if that is a consideration for a decision she makes. No, Gabby is simply Gabby Hoxholli, the queen of tic-tok dances, the best flyer at cheer, everyone's best friend, and the biggest jokester you can find. I would like to say I am proud of her but more than anything I am at peace for

her.

To all parents reading this, this is an autoimmune disease, not every therapy will have the same experience that we had, not every medical team will be right for you. Just like the disease it's all relevant to what is right for you. Keep going until you find your holistic care that is unique to your immune system. I believe we have found ours, and that is what I am so grateful for each day.



# Recent publications by our physicians

Dueker JM, **Rosh JR**. Using IBD-REFER: A Substitute for Clinical Judgement? Crohn's & Colitis 360, Volume 2, Issue 2, April 2020.

Kerur B, Benchimol EI, Fiedler K, Stahl M, Hyams J, Stephens M, Lu Y, Pfefferkorn M, Alkhouri R, Stropole J, Kelsen J, Siebold L, Goyal A, **Rosh JR**, LeLeiko N, Van Limbergen J, Guerrerio AL, Maltz R, Karam L, Crowley E, Kappelman MD (2020). Natural History of Very Early Onset Inflammatory Bowel Disease in North America: A Retrospective Cohort Study. Inflammatory bowel diseases, iza080. Advance online publication. <https://doi.org/10.1093/ibd/iza080>

Mack, DR, Saul B, Boyle B, Griffiths A, Sauer C, Markowitz J, LeLeiko N, Keljo D, **Rosh JR**, Baker SS, Steiner S, Heyman MB, Patel AS, Baldassano R, Noe J, Rufo P, Kugathasan S, Walters T, Marquis A, Thomas SM, PROTECT STUDY GROUP (2020). Analysis of Using the Total White Blood Cell Count to Define Severe New Onset Ulcerative Colitis in Children. Journal of Pediatric Gastroenterology and Nutrition, 10.1097/MPG.0000000000002797. Advance online publication. <https://doi.org/10.1097/MPG.0000000000002797>

Adedokun OJ, Hyams JS, Turner D, Griffiths AM, Terry NA, Padgett L, Jacobstein D, O'Brien CD, **Rosh JR**, Pharmacokinetics of Ustekinumab in Children and Adolescents with Moderately To Severely Active Crohn's Disease: Results from UNISTAR, a Phase 1 Study. Gastroenterology, Volume 158, Issue 6, Supplement 1, 2020, Pages S-131-S-132, ISSN 0016-5085, [https://doi.org/10.1016/S0016-5085\(20\)31008-8](https://doi.org/10.1016/S0016-5085(20)31008-8). (<http://www.sciencedirect.com/science/article/pii/S0016508520310088>)

Gupta N, Lustig R, Andrews HF, Sylvester F, Keljo DJ, Patel AS, Guthery S, Gokhale RR, Goyal A, **Rosh JR**, Cheng-Shiun Leu. Sex Differences in Statural Growth Impairment in Pediatric Crohn's Disease: Early Findings from the GROWTH Study. Gastroenterology, Volume 158, Issue 6, Supplement 1, 2020, Pages S-969-S-970, ISSN 0016-5085, [https://doi.org/10.1016/S0016-5085\(20\)33096-1](https://doi.org/10.1016/S0016-5085(20)33096-1). (<http://www.sciencedirect.com/science/article/pii/S0016508520330961>)

Andrew W. Fondell, Maua H. Mosha, Molly Wright, Ross Maltz, Brendan M. Boyle, Barbara Joanna Niklinska-Schirtz, Subra Kugathasan, Meghan E. Gibson, Jason M. Shapiro, Sarah Rosenheck, Annette Langseder, Mary C. Kennedy, **Joel R. Rosh**, Jeffrey S. Hyams, Mo1903 HIGH RATES OF SURGERY PERSIST FOR CHILDREN PRESENTING WITH INTERNAL PENETRATING CROHN'S DISEASE: OBSERVATIONS FROM A MULTICENTER STUDY, Gastroenterology, Volume 158, Issue 6, Supplement 1, 2020, Page S-971, ISSN 0016-5085, [https://doi.org/10.1016/S0016-5085\(20\)33100-0](https://doi.org/10.1016/S0016-5085(20)33100-0). (<http://www.sciencedirect.com/science/article/pii/S0016508520331000>)

Schirmer M, Denson LA, Walters TD, Griffiths AM, Mack DR, Leleiko NS, Markowitz J, Boyle BM, Shah S, **Rosh JR**, Kugathasan S, Vlamakis H, Hyams JS, Xavier R. Gut Microbial Strains and Metabolites in Disease Course of Pediatric Ulcerative Colitis. Gastroenterology, Volume 158, Issue 6, Supplement 1, 2020, Page S-548, ISSN 0016-5085, [https://doi.org/10.1016/S0016-5085\(20\)32067-9](https://doi.org/10.1016/S0016-5085(20)32067-9). (<http://www.sciencedirect.com/science/article/pii/S0016508520320679>)



# Insurance spot

Your child's health is first and we do not want any barriers to them receiving their medication as scheduled.

Read these important tips so that you do not have any surprises from your insurance.



If your child is on an IV medication (Remicade, Entyvio, Stelara), you **MUST** notify us ASAP if your insurance changes.

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 us in a timely manner, it is likely you will have to re-schedule 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.
- 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.

*To view past issues of **The Digestive Digest**, go to [www.atlantichealth.org](http://www.atlantichealth.org) and follow links to Goryeb Children's Hospital to Pediatric Gastroenterology and click on "Newsletters."*

important phone numbers

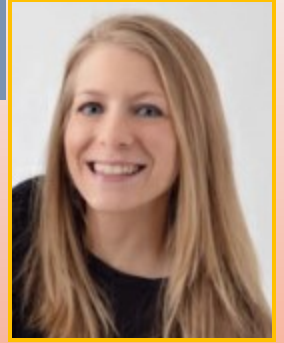


**IBD BACKLINE TO OUR OFFICE:  
973-971-4321**

**MAIN FAX: 973-290-7365**

**INFUSION CENTER: 973-971-6400**





## trend alert!

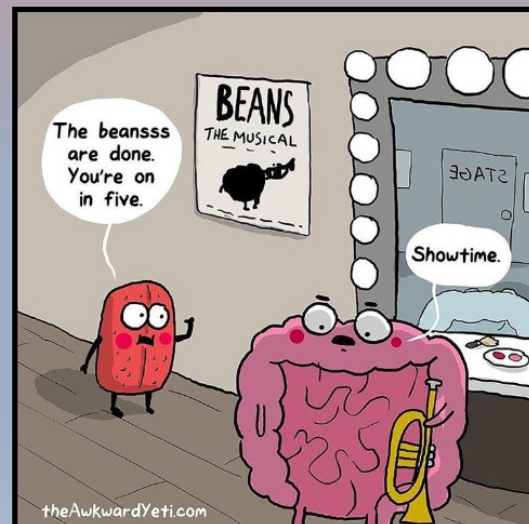
Mason jar salads have quickly become one of my favorite packed lunches. They can be made 24-48 hours in advance, and if you are prepping lunches for the whole family- line your jars up and start stacking your ingredients!

First, select and chop your ingredients. The greater the variety of color, the more the diverse the nutrient profile, and prettier your lunch will look! I would suggest selecting a dressing, 2-3 vegetables, a protein, and a grain.

Once your ingredients are chopped, start off your jar with dressing, followed by the least absorbable ingredient to the most, working your way to the top. This helps keep ingredients that usually get soggy (ie: lettuce) stay crisp!



When you are finally ready to enjoy, shake and dig in!





## 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.

Abstract: Preliminary study results being presented at the annual meeting of NASPGHAN this November by Dr. Alycia Leiby

### 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. ONGOING: closed to enrollment.

### 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. ONGOING: closed to enrollment.

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

This 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. COVID-19 confirmed cases ages 0-89. Open to enrollment.

### HOW DOES COVID-19 (Coronavirus) 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. Confirmed and suspected cases, ages 0-18. Open to enrollment.

### 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. Ages 0-18. Open to enrollment.

### PREDICTING RESPONSE TO VEDOLIZUMAB IN PEDIATRIC INFLAMMATORY BOWEL DISEASES INCLUDING DRUG LEVELS: A MULTICENTER PROSPECTIVE PAN-EUROPEAN COHORT STUDY (P-ECCO and ESPGHAN)

This is a multicenter prospective study to explore the short and long term outcomes of VDZ in pediatric IBD (including growth) and to develop a prediction model for treatment. Ages 2-17 years at time of enrollment. Open to enrollment.



## Parenting Tips to Make Virtual Learning Less Challenging

by Gina Oranchak, RN, BSN

Are you feeling the strains of virtual learning? Well, in these unprecedented times, the challenges of virtual learning can create stress for even the calmest parents and kids.

As a mom of 3 children, I've been doing some reading on how I can best help my kids (and myself!) cope with virtual learning.

I came across an article by Clinical Psychologist Kate Eshleman, PsyD, that offers some helpful tips on how to keep anxiety levels down, when the computer turns on.

**Find your calm zone:** It's natural for parents to get upset when their child gets upset. However, the best way to help your child during a stressful time, is to get yourself into a calm state of mind first.

Staying calm means acknowledging and validating your child's feelings in a calm voice. You can say things like: "I know how upsetting this is and we're going to figure it out together" or "It looks like you're feeling frustrated/angry/sad. Let's see what I can do to help you".

It's easy to get frustrated with virtual learning, but the situation is not your child's fault. Do your best not to take your frustration out on them, since they didn't choose the situation and can't help if they're having a hard time with virtual learning. As parents we have the power to model good coping skills when we become frustrated and our kids will learn from them. Dr. Eshleman recommends that instead of yelling, take a few deep breaths and step out of the room for a minute. It's not easy but taking a "time out" is a valuable skill that will help you and your child.

**Tackle the problem:** After you've validated their feelings, address whatever caused the outburst and work through it together. Discuss steps that you and your child can take together, which may include talking to the teacher about whatever the challenging situation is.

**Plan ahead:** Brainstorm ways to prevent future mishaps with virtual learning. Being proactive can help avoid some of the annoyances that push those anxiety buttons. Here are a few prevention strategies: Create a daily schedule with login info for each class. Set alarms for class start times, breaks or other important times. Keep a list of teacher's names and contact info handy. Feel free to add to this list and reinforce the fact that "this too shall pass" and that together you will overcome the adversity.





**Understand that webcams can cause anxiety:** Does your child avoid virtual meetings or get upset when it's time for class to begin? Some children get anxious or self-conscious when they see themselves on a video call and this can interfere with their learning. Dr. Eshleman says that she actually hears about this a lot and recommends that you first try to figure out what is making your child anxious. Is it having their bedroom in the background? Set up the call in another area of the house. Are they feeling self-conscious about their appearance? Make sure the alarm goes off earlier, so there is plenty of time to get ready for school. "We all think everyone is looking at us, but this isn't the case", says Dr. Eshleman. "Tell your child you know it feels uncomfortable, but others aren't staring at them. Their classmates are focused on their own appearance, too."

**Avoid toxic positivity:** Managing anxiety does not mean having a fake, "Susie Sunshine" attitude. "Toxic positivity is when we pretend everything is great, even when it's not," Dr. Eshleman says. "It doesn't allow us space to express frustration, anger or sadness. We don't want to teach our kids that we don't have thoughts or feelings. We need to identify and label our feelings and express them in healthy ways." As a parent I find this one very reassuring, because I don't have to pretend that the pandemic is "easy peasy" and that's a relief! Instead I can share with my kids that these times are challenging, and we'll get through it together.

**Signs of anxiety and depression in children and adolescents:** The coronavirus has been a definite crash course in dealing with stress, however sometimes stress can be a sign of something more. Be aware of the following red flags that may indicate that your child needs medical attention for depression, anxiety or another health concern: Sleeping more or less than usual. Not eating enough or eating too much. Getting upset when a parent leaves (separation anxiety). Loss of interest in activities or friends. Ongoing health problems like stomachaches, nausea or headaches. Episodes of dizziness, trouble breathing, shakiness or sweating. If at any time you feel that your child might need mental health care, don't delay—mental health issues don't go away on their own. Talk with your child's pediatrician or contact your child's school. Most schools have resources such as a school psychologist, school nurse or school counselors who can offer help and guidance.

**Forget mistakes and keep trying:** Staying calm, cool and collected during a pandemic and virtual learning meltdown is easier said than done. As with any skill in life, it will take conscious effort and practice. It will get easier with time. Yes, there will still be bad days, but they'll happen less often. When those bad days creep in, put them behind you and let them go—there will be tomorrow to try again. The best part is, we can all use these calming practices in other areas of our lives, long after this pandemic is over. Stay strong parents and kids...you're not alone. :)

# let's meditate

let's meditate

## 5 reasons to meditate

1. To understand your pain
2. To lower your stress
3. To connect better
4. To improve focus
5. To reduce brain chatter

When we take time to meditate, we can lower our stress levels, we get to know our pain, we connect better, we can improve our focus, and we're kinder to ourselves.

With meditation, we are looking to be more mindful and being in the moment. We are practicing (and yes, it takes A LOT of practice to be able to do it) bringing attention to our breath and then back to our breath when we notice our attention has wandered.

Let's walk through the basics on how to meditate.

1. **Find a place to sit that feels calm and quiet to you.** You can sit in a chair with your feet on the floor, you can sit loosely cross-legged, you can kneel—whatever you are comfortable with. Just make sure you are stable and in a position you can stay in for a while.
2. **Set a time limit**—if you are just starting you might limit it to 5 minutes. As you improve in this skill you can add more time.
3. **Focus on your breath.** Where do you feel your breath most? In your belly? In your nose? Try to keep your attention on your inhale and exhale.
4. **Follow your breath.** Take a deep inhale, expanding your belly, and then exhale slowly, elongating the out-breath as your belly contracts.
5. **Be kind to your wandering mind.** Don't judge yourself or obsess over the thoughts you were having if your mind wanders. Just return back to the breathing.
6. **When you're ready open your eyes.** Take a moment and notice any sounds in the environment. Notice how your body feels right now. Notice your thoughts and emotions.

So...what happened? How long did it take until your mind wandered away from your breath?

Did you notice how busy your mind was even without consciously directing it to think about anything in particular?

Did you notice yourself getting caught up in thoughts before you came back to reading this?

We often have little narratives running in our minds that we didn't choose to put there, like: "Why DOES my teacher want to meet with me tomorrow?" "I should have studied more yesterday for that exam today." "I miss my boyfriend" or (the classic) "I don't have time to sit still, I've got too much stuff to do."

If you experienced these sorts of distractions (and we all do), you've made an important discovery: simply put, that's the opposite of mindfulness. It's when we live in our heads, on automatic pilot, letting our thoughts go here and there, not being present in the moment. But that's where most of us live most of the time—and pretty uncomfortably, if we're being honest, right? But it doesn't have to be that way.

We "practice" mindfulness so we can learn how to recognize when our minds are doing their normal everyday acrobatics, and maybe take a pause from that for just a little while so we can choose what we'd like to focus on. In a nutshell, meditation helps us have a much healthier relationship with ourselves (and, by extension, with others).

- ◆ Set a reminder on our phone to meditate.
- ◆ For more info, you can search online—there are many websites and apps that can help you practice meditation and mindfulness.



## IMMUNIZATIONS

We are so happy to be a part of your child/teen's healthcare team! Annual follow-up with your Primary Care Physician to complete an annual physical is always recommended by our IBD center. One of the important parts of this visit is for your child/teen to receive a comprehensive wellness check along with the opportunity to discuss and provide updated immunizations. It is important for your Primary Care Physician to get an update from you and your child on how his/her IBD therapy is going and how he/she is feeling.



In the coming months, our IBD center team will be requesting an updated copy of your child/teen's immunization records for review. For our patients diagnosed with Inflammatory Bowel Disease, one of the important aspects of treatment is assuring all vaccines are up-to-date. You may be receiving a MyChart message with a request from your Gastroenterologist with recommended vaccine updates based upon guidelines from the Center of Disease Control (CDC) and American Academy of Pediatrics and the Advisory Committee on Immunization Practices (ACIP). A copy of this information will also be forwarded to your Primary Care Physician. Should you have any questions regarding our IBD Center's vaccine recommendations, please feel free to reach out to our office and we will be more than happy to discuss. Once your child/teen has received vaccine updates, please have your Primary Care Physician fax an update vaccine record to our office at 973-290



## TRANSITIONING TO COLLEGE

It is unbelievable that we have moved forward to another school year! In light of the COVID-19 pandemic, we recognize that for our teens entering their senior high school year, there are many unknowns. Some students will start to make more solid decisions throughout their senior year regarding plans for higher level education. While you and your senior will undoubtedly spend a good part of the upcoming year making big decisions in choosing a college, one important aspect to keep in mind is how do we incorporate their IBD diagnosis and treatment therapy into this equation.

A significant number of our IBD patients do decide to attend an out-of-state school. This is an amazing opportunity for them to grow in independence and take on new responsibilities. Our plan is always to assure that our adolescent patients have a solid understanding of their diagnosis, treatment plan, and self-awareness of when they may be having symptom exacerbations and should seek medical attention. Teaching them to reach out early for medical attention is paramount in keeping them well. For students that are planning to go to college out-of-state, we recommend reaching out to our office early in the college decision process. We will review how to collaborate with an IBD clinician closer to the school. Our office has a list of many providers that are local to out of state colleges. The Crohn's & Colitis Foundation also has a provider list on their website (<https://www.crohnscolitisfoundation.org/find-a-medical-expert>). This list can help you to access gastroenterologists who have experience in treating IBD. Once your teen has decided on a college, it is important to contact our office as soon as possible so we can facilitate the transition of care to a college provider preventing any lapse in care. This is especially important for patients who are receiving infused biologic medications. It can take a few months to obtain an appointment with a gastroenterologist who specializes in IBD. It is for this reason that planning early will make leaving for college in the fall less stressful. You will have confidence that your teen's IBD treatment plan has already been organized by both your primary and college gastroenterologists.

Wishing all the families the best in the upcoming school year. I also look forward to working with our senior students in setting them up with what ever services they may need during their college years.

## Therapeutic Drug Monitoring

Nancy Salmeri, RN, BSN  
Nurse Navigator

If your child is receiving biologic medication therapy, it is our practice, when necessary, to recommend your child/teen complete blood work for therapeutic drug monitoring (TDM). We do this testing to assure we are optimizing your child/teen's medication dose and that the medication level is therapeutic. This testing is time-sensitive and should be drawn no more than 1-2 days prior to your child's medication dose. You may get a MyChart message with the following information (see below). We most frequently use Prometheus labs for these tests. At this time, Prometheus labs has a program where they will charge families no more than \$75 out-of-pocket if coverage is denied by your insurance. The Prometheus program may be changing. When we get more information regarding the changes in cost, we will pass this along. Frequently, these specialty labs are not covered by insurance. Lab Corp, Quest, and Atlantic Health System in many cases offer the same testing. As everyone's insurance policy is written differently, we are unable to tell if your insurance will cover TDM or not. If advised by your gastroenterologist that a therapeutic biologic drug level is being ordered, please see the below information regarding testing including the CPT test codes you can provide to your insurance company if you are further investigating your insurance coverage for these specialty tests.

### LabCorp

infliximab (Remicade): (CPT: 80230,82397); adalimumab (Humira): (CPT:80145,82397); vedolizumab (Entyvio): (CPT: 80280,82397); ustekinumab (Stelara): (CPT:80299,82397); certolizumab (Cimzia): (CPT: 80299,82397).

### Quest

infliximab (Remicade): (CPT: 83520,80230); adalimumab (Humira): (CPT: 83520,80145). They do not have testing available for Ustekinumab (Stelara), vedolizumab (Entyvio) or Certolizumab (Cimzia).

### Atlantic Health System

infliximab (Remicade): (CPT: 80230,82397); adalimumab (Humira): (CPT: 80145,83520); ustekinumab (Stelara): (CPT: 80299,83520); vedolizumab (Entyvio): (CPT: 80280,82397); certolizumab (Cimzia): (CPT: 80299,82397).

### Prometheus Lab

infliximab (Remicade) (CPT: 84999); adalimumab (Humira) (CPT: 84999), vedolizumab (Entyvio) (CPT: 84999); ustekinumab (Stelara) (CPT: 84999).

If we have sent you a Prometheus lab slip for TDM testing and you determine your insurance company covers the test at either LabCorp, Quest or Atlantic Health Systems, please let us know so we can update the lab order and provide you with a new prescription. Please understand that our office does not submit requests to insurance for pre-authorization. Unfortunately, we have found through past experience that this is not helpful in getting these specialty tests approved. Further inquiry on out of pocket costs can be directed to LabCorp: 800-223-0631; Quest: 877-291-7521; or Atlantic Health System client services: 973-971-5271. If calling LabCorp, Quest, or Atlantic Health to determine out of pocket test costs if not covered by your insurance, you will need the specific test number:

**LabCorp Test Codes: Infliximab (503870); adalimumab (503890); ustekinumab (504594), vedolizumab (504567) or certolizumab (504627).**

**Quest Test Codes: infliximab (36311) and adalimumab (36296).**

**Atlantic Health Test Codes: Infliximab (INFXM); adalimumab (ADALM); ustekinumab (USTEM), certolizumab (GENRC), vedolizumab (FVEDM).**

We most frequently send your Prometheus lab slip under the letters tab in MyChart (if your child is less than 12 years of age). **If your child is older than 12 and does not have an active MyChart account under their own name, please contact us so we can assist in the sign-up process.** Having your child signed up under their own personal account allows patients full access to their medical chart (including letters tab). If your child has not signed up, we will either mail the prescription to your home address or if you have a secure fax we can send it in that manner. Due to HIPAA laws, we are unable to forward copies of these prescriptions through general email. If using Prometheus labs, you will need to provide their specialty lab slip to the mobile phlebotomist the day of your testing. If testing is done at either LabCorp, Quest, or Atlantic Health, the orders are entered electronically.



The Crohn's & Colitis Foundation is a non-profit, volunteer-funded organization dedicated to finding cures for Crohn's disease and ulcerative colitis, and improving the quality of life of children and adults affected by these diseases.

Originally founded in 1967, they have invested more than \$384 million into finding the causes, treatments, and cures for Crohn's disease and ulcerative colitis.

To learn more about the NJ Chapter of the Crohn's & Colitis Foundation, visit:

<https://www.crohnscolitisfoundation.org/chapters/newjersey>



## Managing your IBD at school

"The best preparation for tomorrow is doing your best today." H. Jackson Brown, Jr.

It is possible that your IBD and treatments may one day affect your school attendance or performance. For example, you may have to miss school when you have medical appointments or if you're not feeling well. Since we all know you are still responsible for learning the required subject matter, it may be a good idea for you to have a 504 (Accommodation) Plan. This plan can help make adjustments that you might need such as:

- The freedom to go to the bathroom whenever you need to
- Permission to use a private bathroom, like the one in the nurse's office
- A place to keep your emergency supplies, maybe near that bathroom in the nurse's office
- Permission to take regularly scheduled and emergency medication at the nurse's office
- Permission to eat snacks and drink liquids throughout the day
- Get help with classwork that you missed and have quizzes, tests, and projects rescheduled
- "Stop the clock" during tests so you can use the bathroom and not lose any test-taking time
- Excused absences due to illness, medical appointments, and treatments
- A home tutor if you have to be out of school for a while
- Allow an extra set of books at home

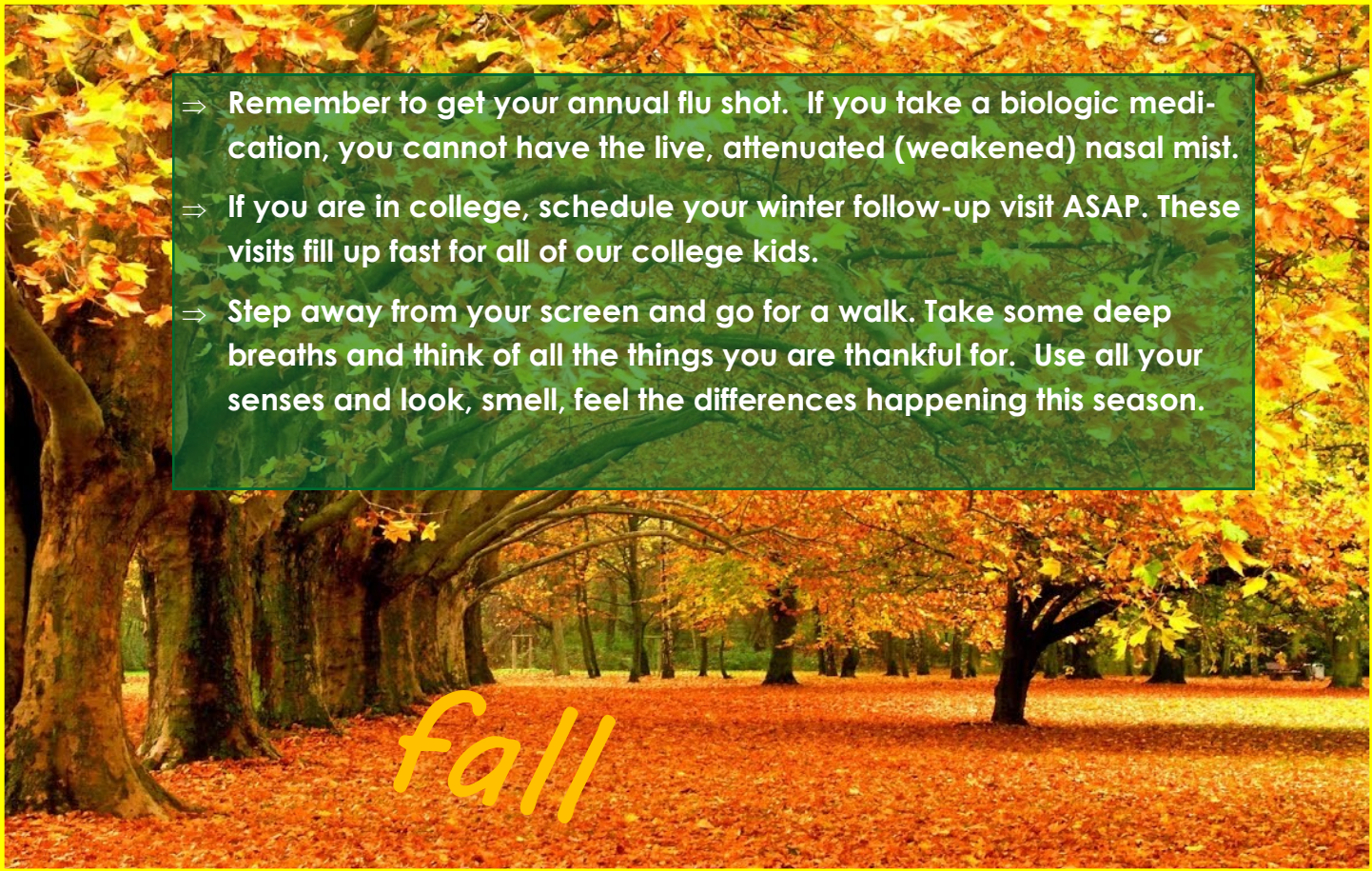


Even if you are doing well and do not feel like you need a 504 Plan, it is always good to have it in place—just in case.

Here is a link to an excellent fact sheet from the Crohn's & Colitis Foundation that reviews school accommodations and 504 plan: [504 plan](#)

**If you would like a 504 plan for your child,  
send a MyChart message to Katie, our social worker.**



- 
- ⇒ Remember to get your annual flu shot. If you take a biologic medication, you cannot have the live, attenuated (weakened) nasal mist.
  - ⇒ If you are in college, schedule your winter follow-up visit ASAP. These visits fill up fast for all of our college kids.
  - ⇒ Step away from your screen and go for a walk. Take some deep breaths and think of all the things you are thankful for. Use all your senses and look, smell, feel the differences happening this season.

fall



winter

- \* Don't overdo the holiday goodies -- maintain a healthy diet.
- \* Get plenty of rest. Teenagers need 8-10 hours of sleep each day to function best. Studies show only 15% slept 8.5 hours on school nights.
- \* Wash your hands. Blow your nose a few times a day to clear out pathogens in there.
- \* Don't share food or drink containers.
- \* Don't kiss on or near anyone's cold sores—and don't let them near yours if you have any.

Project  
PREVENT



**Flu shots save lives!**  
**Virtual education on influenza vaccination**

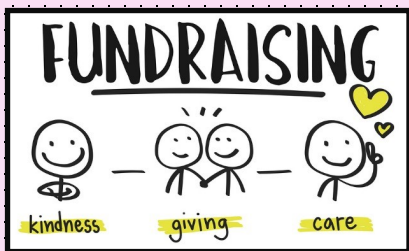
Open camera on your phone and hold it above the QR code. You will see a link on the top to click on.



Follow this QR code to virtual dynamic education on the latest recommendations for influenza vaccination

- Clear, concise and unambiguous messaging on who should be vaccinated
- Easy to understand animated education on when and why influenza vaccination is important
- Content developed by physicians with patient input on addressing barriers, knowledge gaps, and myths around influenza vaccination





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 (973) 593-2414 or email her directly at [Geraldine.Kling@atlantichealth.org](mailto:Geraldine.Kling@atlantichealth.org)



Keep an eye out for an email invitation to join our 3rd Pediatric GI Educational Peer Session via Zoom

Answer to riddle on page 2 (who Gina went to college with):  
Stephanie, our pediatric nurse practitioner.

From left to right: Stephanie Schuckalo and Gina Oranchak (TCNJ, 1998)



We would love to hear from you! What would you like to see in the next newsletter? Do you have something you would like to contribute? Trust me--families LOVE to read about others who are walking in the same path. Please email it to me! If you have a few seconds, please give some feedback. Send all submissions to my email below.

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