

THE DIGESTIVE DIGEST

FALL 2018

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FROM THE DIRECTOR

DR. JOEL ROSH



It seems so obvious—IBD must have a connection to diet. After all, a disease that occurs in the intestine must involve what goes in to the intestine. Yet, understanding this connection has proven to be a very complex road. We in IBD research are humbled by Celiac disease—another immune driven inflammatory disease of the intestine that is triggered by ingestion of gluten, a protein found in wheat and other grains. Remove the gluten and Celiac is in remission. We would love to find such a trigger(s) for IBD.

Dietary research is quite complex. Unlike a pharmacologic study where a purified drug is given at a measurable dose, it is more difficult to assure such delivery of a dietary component. Add to this the potential for complex interactions between different elements of the diet as well as individual variation in reaction to these components. Most importantly, what we eat will definitely affect how we feel (I am always reminded of this after a night at the “all you can eat buffet”) —but this is very different than actually affected the gut and healing it. Therefore, it is always critical to remember that diet is very personal when it comes to symptom relief—a very important short term goal. For the long-term, we are looking to see how diet can be used to actually heal bowel and change the natural history of the disease.

Pediatrics has always led the way in IBD diet research. The observation that pediatric Crohn's disease can be put into deep remission (lack of symptoms and bowel healing) by removing all solid food and only using liquid formula has always been a very strong signal. We used to think the formulas were magic—now it seems more clear that this effect results from the exclusion of offending agents and, perhaps more importantly, by changing the bacteria that live in the gut (the “microbiome”). There are now several studies being conducted in the US, Europe and Israel looking at what other diets can have similar effects on the microbiome. The use of techniques to look at the microbiome may serve as the link we have been missing to best understand dietary affects in IBD—especially Crohn's disease. Stay tuned!

Meet your new team members



*Maria Cisneros
Administrative Assistant*

Please help us welcome our new Administrative Assistant, Maria.

Maria has been in the medical field for several years now. She joined Atlantic Health System in 2015 and is happy to be apart of the pediatric gastroenterologist group.

Maria enjoys spending time with her family and friends. She loves traveling to different states with her husband, kids, and her dog Messi. She also loves bike riding, playing tennis, and trying out new foods.



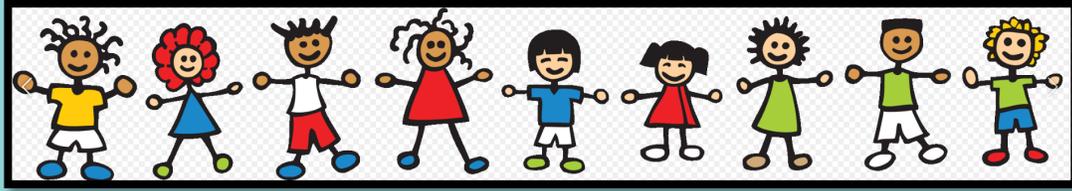
*Mary Kennedy, MSN, APN-C, CCM,
LNCC, RN-BC, FCN
Research Coordinator*

Please help us welcome our Clinical Research Coordinator, Mary Kennedy. Her prior pediatric nursing experience includes a variety of settings; pediatric critical care, pediatric ambulatory care and care of children with special needs. She is certified as both a Certified Pediatric Nurse Practitioner and Case Manager.

Mary is also a Board Certified Faith Community Nurse who volunteers as part of interfaith nursing collaborative, supporting congregations. Mary grew up in New York but spent part of her childhood living in Ireland. Now, living in New Jersey, she returns to Ireland often with her husband and teenaged twins.

Mary is looking forward to working with children and families as part of Peds GI.

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.

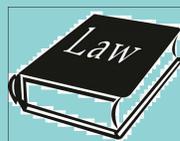


Jeremy and I thought maybe you'd like a photo of success after struggle.

Here is a picture of 25 year old Jeremy at his University of Miami Law School graduation in May, 17 years after his diagnosis of severe Crohn's disease. Despite three surgeries including an ileostomy at 16 years old and a reversal at 17 years old, Jeremy has moved forward with his life. As a young adult, he has learned to manage his illness and his care. The transition to college and adulthood was, and still is, challenging but with persistence and the help of Dr. Rosh and the wonderful nurses and staff in Morristown, Jeremy has succeeded in transitioning to an adult doctor in his new hometown of Miami. Jeremy hopes to be involved with CCFA in Miami and to be able to give back to the Crohn's community. None of his success would be possible without the Goryeb IBD team.

Much admiration and love!

~Lisa



This is our son **Jack** with the first place trophy his team won in overtime at a hockey tournament in Delaware. He was diagnosed with ulcerative colitis back in 2012 at age 11 and is a patient of Dr. Verga. He really admires Dr. Verga, and we are very lucky to have her as his doctor. He is one of the top students in his class at Roxbury High School, and is looking to get into the medical field. This decision was highly influenced by his diagnosis, and his desire to help others in the same situation. Jack has always had great focus and more importantly a positive attitude. He has not let his diagnosis get in the way of his goals or doing the things he loves.

~Joe



Jack, 17



My son was newly and suddenly diagnosed with ulcerative colitis in January of this year. He was hospitalized at Goryeb for a week, he had two blood transfusions, and scopes. He bounced back pretty quickly and his symptoms were under control within about two months. He maintained straight A's in school and by the spring he returned to playing on his travel soccer team. He was also accepted into an intense three week residential academic summer program, which would be the first time he was away from home.

He has been managed on Pentasa since March, but lately things haven't been so great. In June, he suffered an injury during a soccer game which ended his season early due to ongoing pain in his knee. About three weeks ago, it was determined he needed surgery due to a lack of blood flow in his knee and that is scheduled for tomorrow. In August, he had what we thought was a summer virus but seems to now have turned into a flare which may result in a medication change. Through it all he has remained happy, optimistic, and driven. He completed the summer program and was accepted into the next phase of it and he already has physical goals set for himself once he is fully recovered from knee surgery.

To say that I'm proud of him is an understatement. He has truly shown me the meaning of resilience and although my heart breaks for all he is going through and I have shed enough tears for a lifetime, I know that he is coming out stronger because of it. I may have given birth to him but he gives me life every single day. I hope his story can be a glimmer of hope for someone.

~Vanessa

mom of a 13 year old boy with ulcerative colitis

Blake, 13



Our son **Blake**, now 13 years old, was diagnosed with Crohn's Disease by Dr. Rosh and Nurse Practitioner Stephanie Schuckalo 2 years ago. Pre-diagnosis, Blake's father and I could tell there was a problem because Blake wasn't growing enough, what's called "failure to thrive." During the 3 years before Blake started treatment at Goryeb, he grew only approximately 2.5 inches total. We were expecting 2.5 inches per year! We were especially concerned since Blake was approaching his teenage years, when we anticipated an increasing growth rate! Also, we had tried a number of different avenues before his Crohn's diagnosis, and nothing was working, in fact, the solutions we were trying such as restrictive diets were only making matters worse.

Now, it's a different world. I am so happy to share with you that Blake has grown 7 inches in the past 2 years, thanks to the amazing team of lifesavers at the office and at the Infusion Center. I remember when we were just starting treatment, that I searched for anything and everything I could get my hands on to hear success stories to give me more hope. One of the best resources of information, encouragement and support was this newsletter. I am hopeful that we might be able to give some other families that little extra bit of hope they might need. We are in amazing hands. We owe so much to the whole team for everything they have done and continue to do to support us: the doctors, the nursing and back office staff in the office, and the amazing nurses at the Infusion Center who do such an incredible job treating our children and taking them (and the families) through this process from their first more nerve-racking visit(s), to their ongoing regular visits when they make us feel like close family/friends.

Good wishes to everyone walking this path along with us.

~Michele

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 login 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.





Hi, this is **Lucas's** mom, Paula. Lucas was diagnosed with Crohn's disease in October 2017. Before he was diagnosed he wasn't feeling well—various doctors told me his symptoms were viral and that soon he will feel better. I changed pediatricians three times until finally the last one did some blood work and that is how we found out he had some inflammation and he recommended us to go to a GI doctor. I schedule his appointment right away, and the doctor did more tests. After we got the results of the tests she said it looked like he was having some sort of IBD and that he needed a colonoscopy and endoscopy to make sure what it was. Lucas had both done on the same day, on "Friday the 13," we are not superstitious at all but for some reason Lucas was scared of the anesthesia. Everything went well. The preparation for the test was a little rough because off all the liquid he needed to drink to clean out his body but he took it like a champ!

Then the results from the endoscopy and colonoscopy came. I remember the doctor talking to my body; yes my body because my mind was somewhere else. The doctor told me Lucas has Crohn's disease! It was my first time hearing the word Crohn's. I was overwhelmed, nobody I knew suffered from that disease up to that day. At the same time that she was describing what the disease was about, she was discussing treatment options and she prescribed oral medication, 5 pills a day. It was tough, those were big pills but with the help of applesauce he was able to swallow them. This treatment worked for about a month and then his symptoms came back and that's when I decided to change our GI doctor and I had the pleasure to meet the Goryeb team. What a relief! The staff are wonderful; you don't feel alone in this journey. There is always somebody there either on the phone or online to answer your questions and believe me I had tons of questions.

I started to educate myself about the disease (by the way, at home we call it "condition"). I am filling a binder we were given with all his blood work, his doctor visits, and results from the tests. In one of our visits, Dr. Rosh was impressed with the way I was filling that binder to the point that joking he told me if I want to work there, lol!



Lucas, 11

It was recommended that Lucas change medication to Remicade since he wasn't growing at a normal pace. He started his infusions in January of this year and let me tell you he is almost symptom-free. I said almost because he still sweats a lot at night. In the beginning we were a little scared, we were not sure about all the side effects people claim to get with this medicine. So far we are going for infusions once a month, really early in the morning so he doesn't miss too much of school. We go to the infusion center at the Morristown Hospital. Lucas loves it there, the first time he went there he felt he was in a hotel; all the nurses were really nice trying to making feel comfortable. He wants me to tell you the only thing you feel is a little pinch and that's about it. You sit down and relax. You can watch TV, read a book, or in his case, play with his videogames. Then you can go to school or wherever you need to go like nothing even happened.



It has been almost a year since he was diagnosed and let me tell you—Crohn's disease hasn't stopped or slowed him down. He continues with his normal routines and loves challenges...especially in math! Lucas graduated 5th grade last June with a president's education award for outstanding academic excellence, he was in the TAG program (talented and gifted), participated in two sports (soccer and baseball) and got first place in soccer. He loves to read, play videogames, spend time with his dog, Cosmo, and make YouTube videos (YOSHI'S VIDS is his channel).

I hope our story helps newly diagnosed families to understand they are not alone, although currently Crohn's disease doesn't have a cure is easily manageable with the right medicine!



Here's what I've learned...

Here's what I learned about this disease: Whether it's you or your child going through it, it is a piece of you and you have to embrace it. Whether it was "not meant to be" or "came out of nowhere" you have to resolve in the fact that it is a part of your life and figure out your path on how to tackle it and thrive with the diagnosis. When you live in fear of it, it consumes you and defines you. When you look it straight in the face, you can conquer it.. Do I believe in food as medicine? Without a doubt. Do I now understand that there is more to the equation? Without a doubt. I never realized how many people used a combination of medicine, treatments and diet. It's almost a relief. Diet alone put us in remission for almost a year. As a fitness and nutrition activist, I was mesmerized, elated and comforted by its power. Yet this disease has a mind of its own, and you have to find your own path based on how you understand you were afflicted. Do your research, and listen to the journey of others, become smarter, more educated, and an advocate for health. Ultimately chose the direction and solutions that are right for you - it will not be the same as others - it will be one based on the complexity, ambiguity, and successes of your journey. Living in fear jeopardizes the opportunity to enjoy the moment - the trials, the tribulations - the humor and the precious moments in life. It's not a sentence - it's simply a piece of your story and it only defines you if you let it. Tackle it head on - and accept it while learning the bigger lessons from it.



Every moment is precious and every moment is something to cherish.

~Debra

mom of a 10 year old girl with ulcerative colitis

BIG NEWS!!

Eliza Bryen, a senior nursing student at Quinnipiac University realizes her dream of being a nurse at Morristown Medical Center!

Eliza, who became inspired to become a nurse by the amazing nurses at the Goryeb Day Hospital when she was 11, is now a Nursing Assistant at Morristown Medical Center. Eliza decided to pursue nursing when she got to know the nurses in the Goryeb Day Hospital where she was a patient for several years. Due to the great care she received there, she became determined to study hard in school, get into a great nursing program, and return to Morristown Medical Center to be a part of the legacy of great nurses there. This past summer her dreams came true. She is now a Nursing Assistant at the hospital and plans to become a pediatric nurse once she graduates in May.

Eliza was diagnosed with Crohn's Disease at age 11 and has been in remission for several years! Once she started feeling better, she ran four half marathons while she was in high school to raise money to find a cure for Crohn's Disease. Her fundraising efforts won her several scholarships and she is grateful for all the ways in which her struggles with Crohn's Disease has brought her positive things, focus and a passion to give back. She is looking forward to helping children deal with their health issues through her role as a nurse and is extremely proud to be working at Morristown Medical Center!



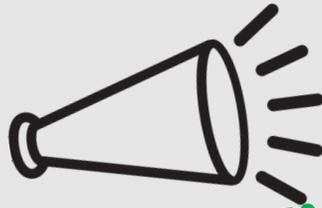
**FIGHT
INFLUENZA**



STOP!

Yes, stop reading right now add **GET A FLU SHOT** to your “TO DO” list. Do it right now...before you do another thing. Pick up your phone and type it in or get a pencil and write it down. Whichever way you chose, just don't forget to do it. You don't want to end up saying “I shoulda coulda woulda.”

Pre-cert!



PRECERT!

Hear all about it!

**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.

Nutrition advice from Dietitian Kelly

Healthy Breakfast Ideas for Busy Mornings

A healthy breakfast is important for everyone. Eating a healthy breakfast reduces morning fatigue, improves your ability to think clearly, and reduces irritability. Many people aren't sure what to eat for a quick and healthy breakfast. Try several quick and healthy breakfast ideas listed below!

Oatmeal: For added nutrition make with low-fat milk instead of water. Add applesauce, cinnamon, or a small amount of sugar or pure maple syrup for sweetness, rather than purchasing the packaged flavored versions. Top with nuts and fruit.

Whole grain bread with nut butter and sliced fruit: Bread can be toasted (optional). Spread nut butter. When choosing a nut butter the ingredients listed should be: the nut, and sometimes oil. Top with sliced apple or banana.

Whole grain pita stuffed with egg and low-fat cheese: Pita can be toasted (optional). Eggs can be prepared any way, but hard-boiling eggs the night before and slicing the egg that morning can save time. Try low-fat cheddar, provolone, or Swiss and limit processed cheeses, such as American.

Yogurt parfait: Choose a low-fat plain yogurt. For added sweetness mix in a small amount of honey or pure vanilla extract. Top or layer with fruit and cereal or granola. For extra protein, choose a Greek yogurt.

Smoothie: Blend $\frac{3}{4}$ cup low-fat milk or milk alternative, 1 serving of fresh or frozen fruit, and 1 tablespoon nut butter. To add thickness, add a few scoops of Greek yogurt. Veggies can also be blended in to provide extra vitamins and minerals.

"Breakfast Bento Box": Foods can be prepared at the beginning of the week, just portion out what you will eat. This is also a great option on the go. Consider including hard boiled eggs, cheese cubes, rolled deli turkey or ham, whole grain crackers, fresh fruit, nuts, and/ or granola.

Additional suggestions:

If you are lactose intolerant, choose a lactose free or non-dairy milk with similar nutritional value as an alternative.

If you have you are allergic to nuts, try a seed (such as sunflower) butter as an alternative.

If you have difficulty tolerating nuts, seeds, dried fruits, or fruits with skins: choose a "creamy" nut or seed butter, avoid dried fruits and remove the skins of whole fruits, whole fruits can be microwaved to soften the fruit.

Several Breakfast Ideas modified from: Power Up with Breakfast. Academy of Nutrition and Dietetics. 2017.



“Creative Expression” Healing Arts Calendar Art Contest 2019 Looking for young artists to share their original “Mandala Design”

The “Creative Expressions,” Healing Arts Calendar 2019 Art Contest is back for children and teens who are diagnosed with chronic illness and chronic 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 that art supports healing on all levels including Mind, Body, and Spirit.

This year we are looking for children between the ages of 4 and 18 to enter an original mandala design. A mandala is a Sanskrit word loosely meaning circle. They can be a form of self-expression or exploration of your internal world. Creating a mandala can be a wonderful activity that can be centering, meditative and can aid in emotional expression and self-soothing. The process of creating a round symmetrical image is beneficial for healing.

Start: Think about what you want your mandala to say to yourself and to its viewers. For visual examples google mandala designs. Here are some ideas:

Favorite activity	Ways you cope with chronic illness or stress	What makes you calm
Favorite hobby, or	Your strengths	Your other ideas: _____
Favorite book	Your family	
Favorite colors	What makes you happy	

Next: on a piece of paper no larger than 11” x 14” draw or trace a circle (you may also trace a plate). And create your inner world inside the circle.

There is no right way or wrong way to do this. Make it your own and have fun with it. Most of all, know that you do NOT need to be an accomplished artist to enter or to have your artwork included into the calendar.

All projects, entry forms and biographies must be completed by November 1st, 2018 to Stacy Alper, LCSW Pediatric Behavioral Medicine. 100 Madison Ave (Box 29), Farris Family Center 3rd floor, Morristown NJ 07962 or to Stacy.Alper@atlantichhealth.org.

*** Please do not email artwork to the Healing Arts email address located on the entry form. This address is no longer an active email account.**

Please contact Stacy Alper, LCSW at 973-971-5785 to request an entry form or for further information. There is also an entry form attached to this email.

WE LOVE OUR VOLUNTEERS



In June, we were most fortunate to have staff from Deloitte come to our hospital to provide a day of community service. This was the tenth year that Deloitte graciously provided their time and energy to help improve our hospital environment. This year the volunteers for Deloitte's Impact Day donated, decorated, and planted flower pots which were distributed by our hospital volunteers to hospital inpatients. They also donated supplies and assisted with the assembly of our IBD binders. We provide IBD binders to all our newly diagnosed patients. These binders have information that our new IBD families can count on to be credible resources. Initial diagnosis is such an emotional time for these families. It is important during the initial phase of diagnosis when the desire for information is at its peak that we can provide this invaluable information to our families. This is a heartfelt thank you to Deloitte and their volunteers for their unwavering support in enhancing the services we provide here at the Goryeb Children's Hospital.



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**"ALONE WE CAN
DO SO LITTLE;
TOGETHER WE
CAN DO SO MUCH."**
- Helen Keller

PEDIATRIC NURSE

NAVIGATOR'S CORNER

BY NANCY SALMERI, RN, BSN

Many of our IBD patients receive infused biologic therapy. In addition to our patients who receive infusions on our Goryeb campus at the Farris Center for Advanced Medicine in Pediatrics, we also have many who now receive such therapy in the home. If you are currently receiving home infusions, you may be receiving a large envelope. We are initiating a study to better understand home infusion services. We would appreciate if you could take just a few moments to complete the questionnaire and send it back to us in the provided self-addressed stamped envelope. We are looking to use this information to learn how we can best communicate with our home infusion companies and improve on the currently provided services. Thank you in advance for your consideration in participating in this important study.



To our newly diagnosed families

Our office will be looking for your child's immunization record and will be discussing them with you at your visit. Please be sure it is forwarded it to us. Thank you!

supporting your peds IBD center

If you have interest in donating to the Pediatric IBD Center or have other fundraising ideas, we would love to hear from you.

Please feel free to contact us or Geraldine Kling at the Foundation for Morristown Medical Center at (973) 593-2414 or email her directly at geraldine.kling@atlanticealth.org.





What is happening with construction at the 55 Madison Ave, Morristown location?

We are coming closer to the completion of renovations to our 55 Madison Avenue location! In addition to the 2 current elevators we have, we are installing an additional 2 elevators which are stretcher-compatible. There are also going to be an additional 29 parking spaces created to provide more ample parking.

Thank you for your patience during the construction.



Check it out!
www.justlikemeibd.org
It's a website just
for teens with IBD!

Oh! 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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