

THE DIGESTIVE DIGEST

FALL 2016

Volume 7, Issue 2

PHYSICIANS

Joel Rosh, MD—Director

Barbara Verga, MD

Tamara Feldman, MD

Peter Wilmot, DO

Oren Koslowe, MD

Alycia Leiby, MD

Maria Perez, DO

Mohini Patel, MD

Nadia Ovchinsky, MD, MBA

PEDIATRIC NURSE

PRACTITIONER (Editor)

Stephanie Schuckalo, RN, APN

NURSES

Ruth Irizarry, RN, BSN

Annette Langseder, RN, BSN

Meredith McCluney, RN, BSN

Nancy Salmeri, RN, BSN

Donna Karlak, RN

REGISTERED DIETICIAN

Diane Duelfer, MS, RD

SOCIAL WORKER

Charlotte Intile, LCSW

OFFICE MANAGER

Sheryl Giacomaro

ADMINISTRATIVE ASSISTANTS

Carol Pitt

Ellie Smith

Doreen Ruccio

Deirdre Pizzo

Lueshawn Smith

MEDICAL ASSISTANTS

Tyreema Mubannad, CMA

Eileen Ficula

Rosheida Henry, CMA

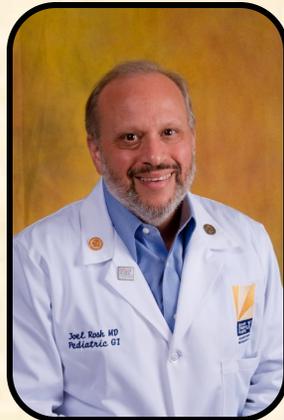
Natalia Filaci, CMA

Stephanie Riveros, CMA

Yris DePierola, CMA

FROM THE DIRECTOR

DR. JOEL ROSH



Biologics and Biosimilars

A biologic medicine is defined by the FDA as an agent derived “from a variety of natural sources – human, animal, or microorganism – and may be produced by biotechnology and other cutting-edge technologies.” Biologics are complex molecules that cannot be copied identically because of their structural and manufacturing complexity. Unlike traditional or “small molecule” drugs, it is not possible to make a “generic biologic” since generics are identical copies of the brand drug.

For biologics, the original agent is called the “innovator” and “biosimilars” are agents that demonstrate no clinically meaningful differences in terms of safety, purity and potency compared to the innovator. It is important to point out that for potency or effectiveness, the FDA has adopted a specific path for biosimilars that is less stringent than that for the innovators but more strict than that for generics. Biosimilars do have to undergo human testing to meet safety standards but they do not have to conduct studies to prove what their optimal best dose is nor that they work the same as the innovator in all disease states. This can be extrapolated from the innovator once similarity is proven, often in a study in just one disease for which the innovator is used. Therefore, in a sense, we will not know whether one agent is better, just that they are similar.

A very important issue in the use of biologics is “interchangeability.” Changing to a generic is automatic unless the prescriber dictates otherwise. This could be complicated for biologics since by their nature, they can prime the recipient’s immune system to make antibodies against the drug—especially during a hiatus from the drug. Therefore, an automatic switch to a biosimilar may invite “bridge burning” or an immune response against the innovator precluding its future use in a patient who is failed by the biosimilar. Gov. Chris Christie has signed interchangeability into NJ law. Patient advocacy groups (eg. CCFA) and our center are concerned about such a change in a patient who is already stable on the innovator. We, therefore, will specify that your child’s biologic be “dispensed as written” and that they are not switched unless their clinical course dictates such a change.

There is no doubt that biosimilars will help drive health care costs down—but at this time it is not clear whether this will just be for payors or patients as well. In addition, biosimilars are mandated to keep long-term outcome registries. Over time, we may learn whether a biosimilar or innovator is the most effective. Until that time, we will need to be watchful for attempts at automatic interchange.



RESEARCH ROUNDUP

WITH ANNETTE LANGSEDER, RN, BSN

An important part of what our IBD center strives for is to be a leader in advancing knowledge of IBD on the global level. Our efforts in these research endeavors is ongoing and while we have several exciting projects in development, we would like to summarize for you our current active studies.

1. Predicting Response to Standardized Pediatric Colitis Therapy (PROTECT Study)

CLOSED

The goal of this study is to improve our understanding of why children develop ulcerative colitis & why some children respond better than others to currently used medications. This is a multicenter study in USA and Canada. It is sponsored by National Institutes of Health (NIH) in coordination with Connecticut Children Hospital and Emory University. Currently enrolling patient's between ages 4-17 years whose doctor believes he/she has ulcerative colitis.

2. A Randomized, controlled trial of Yoga in Pediatric Inflammatory Bowel Disease

This study is conducted to determine if a structured yoga program, in addition to standard medical therapy, improves health related quality of life in pediatric patients recently diagnosed with IBD. Ages of enrollment: 10-17 years of age. The patient will be randomized into one of two groups, answer questions, attend 12 yoga classes, and complete follow-up questionnaires [sponsored by private donor].

3. A Multicenter, Prospective, Long-term Observational Registry of Pediatric Patients with Inflammatory Bowel Disease

This is a prospective registry to collect data over the next 20 years to record and compare current therapies that children with IBD are receiving. Supported by Janssen (the manufacturer of Remicade), those enrolled must be less than 16 years of age but there is an option to continue collecting data into adulthood. This is a nationwide study of 5000 patients (2500 patients receiving Remicade and 2500 patients not receiving Remicade). Currently enrolling patients with UC ages less than 13 years.

4. Sex Differences in Statural Growth Impairment in Pediatric Crohn's Disease (Growth Study)

This study goal is to improve our understanding of how Crohn's Disease affects growth in children and why Crohn's Disease's effects on growth differ between boys and girls. It is sponsored by NIH in coordination with Weil Cornell Medical College. Enrolling males aged 9-15 years and females 8-13 years who have Crohn's disease.

5. **GEM Study (Genetic Environmental Microbial) Project**—goal is to find causes or triggers for Crohn's Disease. Healthy siblings must have a sibling with CD and be between the ages of 6-30. The healthy sibling will have 2 office visits and follow-up call every 6 months for a health review. Enrollment to start soon.



WE GOT A DOG!!

BY MARY KNOWLES



A few years ago, I was on a panel of parents of children with chronic illness, taking questions from other parents in the same situation. Toward the end, we were asked how our families cope with the stress that goes along with a chronically ill child. I don't remember what I said, but I do remember driving home and being hit with that I should have said: we got a dog.

OK, I understand getting a dog is not a good option for everyone. Other pets can ease stress, too. And not every family is equipped to care for any sort of pet. But for us, a dog has had benefits I never imagined.

When our daughter, Bonnie, was diagnosed with Crohn's disease at age 10, we quickly realized she was going to face all kinds of challenges. I'm not sure we realized how her struggles would impact the rest of the family, so when we discussed ways to ease the burden, it was mostly with her in mind. For several years, Bonnie's fondest wish had been to have a dog. I had a beloved dog as a child, but my husband and his family harbored active dislike of canines. We both work full time, and knew enough to understand that assurances from both our daughters would mean little when it came to everyday care of a dog. We began to soften, realizing that a pet can go a long way to cheer a child up, especially since the initial Crohn's treatments were not very effective. My work-at-home arrangement looked like it was going to last another couple of years, so I'd be around to keep a dog company and walk it during the day. My husband decided he could give it a try, provided we found the right dog. We managed to find her on PetFinder.com: 18 months old (already house trained), 20 pounds (not too small, not too big), a mixed breed that wouldn't shed. And she was adorable.

We adopted Mia right after Christmas 2008, and haven't looked back since. She became a point of positive focus in our home. She isn't just Bonnie's dog; she loves and is loved by all four of us equally. There's the physical patting, the lovely feel of her fur. There are conversations with her, and about her. There's the emotional eye-to-eye connection (which has been shown to cause both person and dog to release oxytocin, a feel-good, bonding chemical). She instigates laughter, even when things are tense or sad. She distracts, she nuzzles, she curls up on beds.

Bonnie had a prolonged Crohn's crisis when she was 12. That's when I really realized how important Mia was to the entire family. We were burdened by stress and uncertainty; she was right there, wagging her tail until we smiled. She "kissed" away tears that were shed, regardless of who was doing the crying. But for me, in particular, one of the main benefits was that she needed my attention. She needed to be walked, to be petted, to be played with now and then during the day. So even when Bonnie was at her sickest, home from school for days at a time, barely able to get out of bed, I had to take a break. I had to get out of the house, even for just 10 minutes, to walk the dog. My husband had to do the same every night (night walks are his duty). Those walks, or tossing a ball for her in the backyard, became important outlets for stress. When your child is so ill, you feel like you should be spending every moment trying to help her get better, or at least get through another day. That's a lot of pressure on a parent, but also on the ill child, herself. In reality, there are times when there is very little you can do. It was better for everyone that I had to take my eye off Bonnie for a bit every day. The exercise alone helped clear my mind. It was good to see that the world was still turning outside, good to smile at a passerby, or pause to share some of my anxiety with a neighbor I might bump into. Sometimes I'd take her to a nature reservation nearby, for 40 minutes or an hour, off her leash. The fresh air, the exercise, the joy of seeing her happily running unencumbered did us both so much good. It gave my daughter a break, as well.

WE GOT A DOG (CONTINUED)

There were moments when my own despair filled the house. Once, when I was by myself, I felt so overwhelmed that I sank down on the floor to weep. Who was right there? Mia. In my face, trying to lick away my tears. Right down, next to me, worrying, trying to calm me - forcing me to get a grip so she would relax. At night, as my husband and I talked things over in bed, she'd jump up and we'd have to pause whatever circular discussion we were having to give her a pat or a kind word. And when you're trying to tell a dog that things will be OK, sometimes you even start to believe it.

Bonnie was admitted to the hospital a few times during that period. I camped out there with her. Our older daughter had to make sure Mia was taken care of during the day. That was probably pretty good for her, too.

We made it through that year - finally hitting on a medication that worked for the next 3 1/2 years. For the most part, our lives stabilized. Bonnie continued to have flares, missing school occasionally, sometimes missing out on other things, but moving forward, nonetheless. Our older daughter left for college. I still work from home, and my day is made better by breaks to toss the ball, or just to chat with the dog, or rub her tummy for a few minutes. She lies at the top of the stairs outside my third floor office, on duty as long as I'm at my desk... hurrying in to check on me if she hears my voice reflect some temporary crisis.

Mia's not a perfect dog, despite our attempts to train her. She barks a lot. She jumps a lot. She's ripped more than one screen door. She is a food thief. She harasses my husband when he's trying to relax. That's because he's the weakest link - least able to ignore her when she's insistent about something she wants. He's the first one to give her a snack; her best companion at the dog park, returning with tales of her antics, or other interesting dogs he sees there. Sometimes we yell at her, but mostly we try to remember that just like a child, it's better to talk to her calmly, even when we're annoyed. We try to be our best selves with Mia, since she is usually trying to be her best for us.

That's how having a dog relieved the stress of having a child with Crohn's disease. It took us each out of ourselves. It brought a source of uncomplicated love into our home. She gives affection freely, and is an ever-ready recipient of our affection in return. Those things rub off. They soften the edges, they allow us to laugh together, to love her together, which has helped us all keep it together much better than if we hadn't had her in our lives.

Now Bonnie is about to head off to college. She's 18, she meets with doctors on her own, including a new one near her university. She is happily leaving home, and we are so happy for her. We worry, we know it might not be smooth, we hope the latest medication will result in fewer flares than she had with the last





COLLEGE TIPS

BY ALEX FAVREAU

5 Tips for Parents and Patients Going Off To COLLEGE

Around this time each summer, students going off to college and their parents finally realize that they won't be together for several months in the fall. I remember exactly when it hit me that I was leaving Scotch Plains, NJ for my freshman year at Loyola University Maryland – August 1st. At the end of June and for all of July, I worked as a lifeguard at my local YMCA just to make a little bit of money so I could blow it all at school. I never for a second realized that each day was one day less I had being at home. I remember going from cool as a cucumber to stressed like crazy within 24 hours when the calendar changed to August. My one biggest worry – how would I survive school with Crohn's Disease? For weeks before and into college, the nervousness ate away at me, but now, after experiencing two full years of college, I can safely say I feel as comfortable with Crohn's at school as I do at home. Here are my 5 tips for the parents of IBD patients, and 5 tips for IBD patients themselves going off to college.

Parents

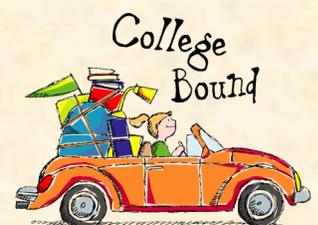
1. *Try not to "mother bird" your child while they are at school.* This is the first taste your child will get of being in the "real world" as an IBD patient. I know the parental instinct is to text things like "how are you feeling", "did you take your meds today", and "when's the last time you pooped" on as constant of a basis as you can ask at home, but giving your child a little independence with their disease while they should be learning about being independent is a necessity.
2. *Try not to chastise their habits.* Unless it is clear that something really negative is going on, college is about your child being able to adjust his/herself and their habits and finding which ones work and which don't. If they try something new or change their lifestyle to something that was not the same as it was at home, it's not the end of the world.
3. *Be understanding of imperfection.* The last thing an IBD patient needs is more stress. The largest increase to a college student's routine (other than Starbucks and Ramen Noodles) is stress. Do your best to not add to the stress that's already there.
4. *There's no need to worry extra.* There's enough about your child going off to college that's worrisome without taking into account their IBD. Worrying more and more could increase *your* stress levels, which isn't good for *you*.
5. *Trust them while they're at school.* Having faith in your child to perform their best, live their best and act their best is integral towards their ability to *be* their best. Let them enjoy their freedoms and have the time they want to have.

Patients

1. *Be smart.* Don't put your body at risk in ways you know are harmful. You can 100% experience college and experiment a little bit, but beyond that, whatever makes you feel remotely unwell should not become a common ritual.
2. *Keep up with your medicines and your doctors.* Your doctors want to know how you're doing. They want to help you if you need it. If you experience excess pain, stress, anxiety, etc. related to your disease, say something. Don't let anything build up to a point that becomes too bad to deal with.
3. *Be open with your roommates/friends.* No one will judge you for having IBD to any varying degree. If they do, they don't deserve to be your friend anyway. The more open you are, the more understanding people will be.
4. *Not getting a 100 on every test is not the end of the world.* Everyone in college is so worried about grades. Not getting an A can really affect people, however, a lot of people don't realize that a grade is just a number. Your GPA is just a number. Don't stress over a bad grade, don't stress over an exam – the last thing us IBD patients need is to increase stress levels unnecessarily. Just do your best and that's all anyone can ask for.
5. *Talk to your teachers.* I know they can be intimidating, I know they can seem mean, but fun fact: college professors want you to do well, and they want to help you do well. If you need accommodations or you need to miss class, talk to your teachers and tell them about your IBD. Chances are they a) know about it and b) will be very understanding because c) they've had other students with IBD take their classes. Professors are more often than not awesome at being accommodating and helpful.

****Bonus Tip for patients****

6. *Talk to your parents still!* They'll do their best to give you space, but every now and then, it's nice to give mom and dad a ring to let them know how you're doing. Schedule a time to talk and stay in touch – remember, they are the ones who changed your diapers, so staying in touch while away at school is the least you can do for them in return!



NUTRITION NEWS

BY DIANE DUELFER, MSRD

Although outdoor picnic season is coming to a close, it's important to still remember healthy appetizers and snack ideas that we may have used all summer. Fresh fruits and vegetables abound. The fresher the better. This is the perfect time to support local farmers' markets or roadside stands especially with root vegetables. Fresh produce contains more flavor and micronutrients since they have not been exposed to light, heat and time as much as winter produce. When snacking on these fun colorful and flavorful foods, dips can enhance the flavors and intake of these foods. Here is a recipe for a dip to enhance color and flavor of the accompanying snacks.

Beet Hummus

12 ¼ -cup servings

Ingredients:

- 1 15 oz. can white or cannellini beans rinsed and drained
- 1 c chopped cooked beets, drained
- 1 clove garlic, minced
- 1 small lemon, juiced
- ½ Tbsp. tahini
- 1 Tbsp. extra virgin olive oil
- Salt and pepper as desired – optional
- Mint as garnish – optional

Add beans, beets, garlic, lemon juice, tahini and olive oil in blender and blend until smooth

Season as desired.

Pour into a serving container and garnish with mint as desired

Chill until serving time.

Nutrient Analysis: per ¼ cup serving

Calories: 68, Total fat: 2 g, Sat fat: 0 g, Trans fat: 0 g, Cholesterol: 0 mg, Sodium: 114 mg, Total Cholesterol: 10 g, Dietary Fiber: 2 g, Sugar: 1 g, Protein: 3 g.



IMPORTANT NEWS FROM OUR PRECERT DEPARTMENT



URGENT information to all of our patients who are on Remicade you must notify us ASAP if you have had a change in your medical insurance.

We are having patients show up for their Remicade infusion without notifying us prior 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). **Please note preregistration for the Infusion Center at Morristown Medical Center is different from insurance precertification of the medication (which is handled by our office).**

If we are not notified it is likely you will have to reschedule your child's infusion. If patients 18 years or older are coming by themselves for an infusion, they MUST have a 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.



SUPPORTING YOUR PEDIATRIC IBD CENTER

PHILANTHROPY
IT TAKES A TEAM



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

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

JOINING CCFA



The Crohn's and Colitis Foundation of America (CCFA) is a non-profit, volunteer-driven organization dedicated to finding the cures for Crohn's Disease and ulcerative colitis. Since their founding in 1967, CCFA has remained at the forefront of research in IBD. CCFA funds cutting-edge research and publishes the leading scientific journal in the field of IBD.

To join your local chapter of CCFA, visit www.ccfa.org. Your membership is tax-deductible.

MEET MEREDITH CREO



My name is Meredith Creo, I'm a 17 year old senior at the Academy of Saint Elizabeth in Convent Station. On December 24th, 2014 I had to have a colonoscopy and endoscopy at the Goryeb Children's Hospital (GCH) due to stomach pain I was having. After the procedures I awoke to find out that I had Crohn's Disease—not exactly the Christmas present I wanted. After discussion, it was decided that my treatment would include having Remicade infusion treatments at GCH. For me, this involves going every two months for three hours each time for my treatment which includes having the medicine go into to me through a needle in my arm. Like most kids, I don't love needles but the nurses and staff make this process as easy and comfortable as possible. I go into my own private area that has a TV and a comfortable chair

for me and a parent. They provide snacks and drinks for the both of us and have movies, CDs, games, and books to keep me distracted and busy during my treatment.

The nurses knows how I feel about needles so they take extra time to make sure I'm as comfortable as possible during that time. They talk to me about what's going on in my life and share stories about themselves and their families. This helps me to take my mind off what's going on and makes the process much easier. During the rest of the 2 1/2 hours I keep myself busy doing the various things I mentioned earlier that are available. The nurses and my gastroenterologist come by to see how I'm doing and discuss my specific situation and update any information with me and my parent. During a recent stay in June, I was able to go outside to a beautiful area and sit there and enjoy the nice weather while still having my treatment. I used my Ipad and enjoyed the sunshine and the pretty plants and flowers while getting some fresh air. Having Crohn's isn't my first choice but since I have it my treatment at GCH makes having it a much better and easier experience.

**TAKE STEPS
BE HEARD**
FOR CROHN'S & COLITIS

ANNUAL CCFA WALK A SUCCESS!

Dear Friends,

In June, the Department of Pediatric Gastroenterology, Hepatology & Nutrition once again walked in **Take Steps for Crohn's & Colitis**, the nation's largest event dedicated to finding cures for IBD. Our team, along with thousands of others across the country, raised money for crucial research that would not have even been possible a few short years ago. Beyond raising money for research, Take Steps joins the community in a fun and energetic atmosphere. Participants are encouraged to make noise and be heard—raising awareness of these little-known diseases in their community and across the nation.

This year we are very proud to announce that our team raised \$6111.

If you would like to join us in next year's walk on our team, Goryeb's Gastro Greats, please email Ellie, Team Captain at eleanor.smith@atlantichhealth.org.



Left: One of our nurses, Donna Karlak, RN and Spongebob enjoying the day.
Right: Derek Estrada and his mom, Barbara, with "Team Duty Calls."

KATHLEEN BAKER WINS GOLD & SILVER IN RIO!

Congratulations to 19 year old, Kathleen Baker who brought home Gold & Silver in this year's Summer Olympics in Rio De Janeiro (Gold in 4x100m medley relay; Silver in 100m backstroke)...oh and she has Crohn's Disease!

Her symptoms started in 2010 when she was 13 years old—fatigue, a fever, and losing weight. She told the NY Times, "I love swimming more than anything in the entire world, and I thought my swimming career was over." She experienced some medication failures, significant weight loss, and difficulty with meals.

Her determination made it all that more difficult for her parents, coaches, and doctors to try to persuade her to limit her swim training to one pool practice a day—especially during an exacerbation of symptoms—which she does.

She is not the first American Olympian with Crohn's Disease—retired kayaker Carrie Johnson competed in 2004, 2008 and 2012. They join the list including President Eisenhower, NFL Quarterback David Garrard, NHL player Kevin Dineen, WWE George "The Animal" Steele, actress Shannen Doherty, lead guitarist of Pearl Jam, Mike McCready.

Pictures courtesy of NYTimes.



Above: Kathleen at diagnosis
Below: Kathleen at the Olympics 6 years later



YOUR CHILD CAN BE IN THE GORYEB CALENDAR!

Atlantic Health System "Creative Expressions" Healing Arts Calendar Art Contest 2017



**We are looking for
young artists to
share your "Courage"
with Atlantic Health System.**

Sponsored by:

- › Goryeb Children's Hospital
- › Pediatric Behavioral Medicine
- › Atlantic Health Healing Arts Program
- › Farris Family Center for Advanced Medicine in Pediatrics (CAMP)



Home
Anyia A. Age 8

Who & What: Are you a child or teenager between the ages of 4 and 18? Do you have a chronic illness or experience chronic pain? If so, here is an ideal way for you to express your creative side. Enter your original artwork in the 2017 "Creative Expressions" Healing Arts Calendar Contest.

How: Take out your favorite crayons, markers, paints, pastels, pencils, and whatever else helps you to "express" yourself through art and simply begin. Submit work up to 11"x 14" in size. Submit entry form along with your bio and artwork.

Theme: Create something that represents your courage.

**YOU DON'T NEED TO BE AN
ACCOMPLISHED ARTIST TO ENTER OR
HAVE YOUR PIECE CHOSEN.**

**ALL PROJECTS MUST BE SUBMITTED
BY October 1, 2016.**

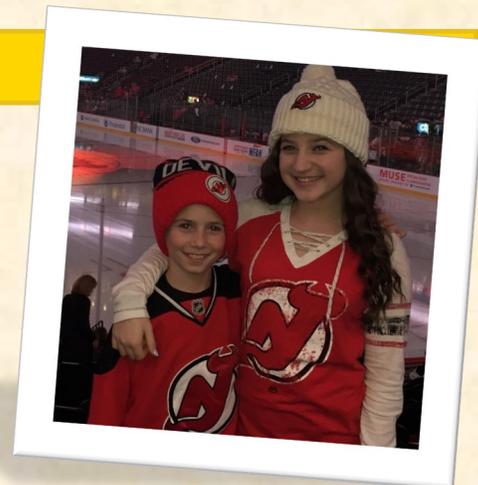
A panel of health professionals will review entries based on visual interest and creative expression. 12 works of art will be selected for inclusion in the calendar. All chosen artists will receive a complimentary Calendar. EVERY PARTICIPANT WILL RECEIVE A CERTIFICATE OF PARTICIPATION. Cover winner will receive gift card to an art supply store.

QUESTIONS: Please contact Stacy Alper, LCSW Pediatric Behavioral Medicine at 973-971-5785 for further information or questions you may have.



ALICIA & COOPER: CCFA'S HONORED

Siblings, Alicia and Cooper Harris were CCFA's Honored Heroes at their walk in June. Team Harris had around 50 members walking and have raised almost \$24,000. Below is the press release CCFA wrote about the Harris siblings.



FOR IMMEDIATE RELEASE

Contact: Lisa Champion, Walk Manager

SISTER & BROTHER OF WESTFIELD WORKING HARD TO RAISE CRITICAL FUNDS AND AWARENESS FOR LOCAL PATIENTS

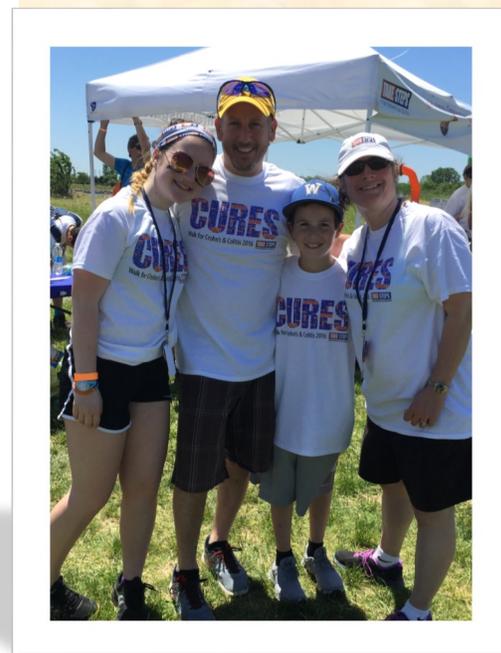
Crohn's Disease Patients and Family Take Steps For Cures on June 12, 2016

Westfield, New Jersey– May 26, 2016 –Alicia & Cooper Harris from Westfield are motivating the local community to find cures by participating in the Crohn's & Colitis Foundation's New Jersey Chapter's Take Steps walk. This year's walk takes place on Sunday, June 12th at 11:00 AM at Liberty State Park. Alicia & Cooper Harris are living with Crohn's disease which combined with ulcerative colitis, are painful, debilitating digestive diseases affecting more than 1.6 million American adults and children, including an estimated 80,000 patients under the age of 18.

Alicia, a 15 year old freshman at Westfield High School, was diagnosed at age 11, after a series of blood tests, a colonoscopy and endoscopy. She found out that she was severely anemic and was diagnosed with moderate to severe Crohn's Disease. Her bloodwork numbers were extremely high so she was put on steroids which her doctor described as a fire extinguisher. She was then treated with immunosuppressive medications which worked well until the spring of 2013. She had a major flare which sent her numbers again through the roof. After more blood tests and a CAT scan at the emergency room, her doctor and parents decided that she should begin a biologic therapy administered intravenously, and she began Remicade® treatments. Because Crohn's Disease is an autoimmune disorder, people who have it are more susceptible to other autoimmune diseases. Along with Crohn's Disease, Alicia has been diagnosed with Juvenile Idiopathic Arthritis and experiences tendonitis and fluid in her knees. She has been on Remicade® for the past three years and her infusions range from every 6-8 weeks at Goryeb Children's Hospital in Morristown, New Jersey.

Last year, her brother Cooper, a 13 year old, was diagnosed with Crohn's Disease. He doesn't get stomach pain like his sister, but his Crohn's damaged his intestines and interferes with his ability to absorb protein and vitamins from his food. He was put on Remicade® right away. For Alicia, the treatments make her feel better. It is tougher for Cooper while he is fortunate not to have stomach pain, he doesn't even feel like he has a disease but he has to get infusions. He doesn't like the IVs, but he has been brave about it and deals with it. The siblings are on different schedules but a few times over the last year they have had their infusions on the same day and they enjoying seeing who finishes first! You can read their stories at <http://online.cdfa.org/goto/aliciaandcooper>.

"Here's the thing about Crohn's Disease: not one person has symptoms like another. Think of it as a snowflake; no two snowflakes are alike." says Alicia. Through all of the complications, testing and treatment, she believes staying positive is the best thing to do.





Alicia & Cooper's mother has Ulcerative Colitis, a related disease. "We think about the fact that everyone has something to deal with in their lives; Crohn's Disease & Ulcerative Colitis is just our something," say Brett Harris, mother of the kids. Alicia adds: "We are born the way we are and we can't change that. But we need to remember that we can be as awesome as we want to be and we shouldn't let a disease stop us." They are proud to be a part of the CCFA and this year will be the Harris family's 4th year doing the Take Steps

"At last year's walk, they gave bracelets out to the walkers with Crohn's and Colitis, and for our family it was three out of four of us wearing the bracelets. I wasn't surprised how many people that had the diseases, but instead was impressed about how many people weren't wearing bracelets – friends and family supporting those with Crohn's and Colitis." Says Cooper Harris. He and his sister Alicia hope they can continue to spread awareness leading up to this year's walk and raise funds to support CCFA's, with 0.82 cents of every dollar raised going directly to the mission. Alicia and Cooper are looking forward to a crowd of family and friend at Liberty State Park. To walk with them on June 12th join "Team Harris" or donate by selecting any Team member at <http://online.cdfa.org/goto/aliciaandcooper>.

The Take Steps for Crohn's & Colitis Walk is the nation's largest event dedicated to finding cures and raising awareness for digestive diseases. Our Take Steps walks offer an incredible day for family, friends and the community to celebrate all of the efforts that have been put forth in raising funds towards our mission. It is a day that combines high energy and fun with access to valuable information and education. More than 40,000 people walked for cures last year, raising more than \$10 million for mission-critical research and patient support programs.

For more information on how to get involved with Take Steps and to find a 2016 walk site nearest you, please visit www.cctakesteps.org or contact [Lisa Champion](mailto:ljchampion@ccfa.org) at 732-786-9960x2 or ljchampion@ccfa.org.

About Crohn's Disease and Ulcerative Colitis

Known collectively as inflammatory bowel diseases (IBD), Crohn's disease and ulcerative colitis affects 1 in 200 people. They are painful, medically incurable diseases that attack the digestive system. Crohn's disease may attack anywhere along the digestive tract, while ulcerative colitis inflames only the large intestine (colon). Symptoms may include abdominal pain, persistent diarrhea, rectal bleeding, fever and weight loss. Many patients require numerous hospitalizations and surgery. Most people develop the diseases between the ages of 15 and 35; however the incidence is increasing in children.

About Take Steps

Take Steps is the Crohn's & Colitis Foundation of America's national walk program. These walks raise funds for mission critical research and patient support programs, and help increase awareness of Crohn's disease and ulcerative colitis, two painful and unpredictable digestive diseases. Our walks are family-friendly festivals held in more than 120 communities across the country with activities for everyone including games, music, and great food. Funds raised through Take Steps will help transform the lives of those impacted by these diseases, and support CCFA's critical research, education, and patient support programs. **Walk with us today: get started at www.cctakesteps.org.**



PUBLICATIONS BY OUR STAFF

Poster presentations at Digestive Diseases Week 2016 by **Dr. Joel Rosh** et al.

◆ Talks

- Serologic Reactivity Reflects Clinical and Genetic Expression of Ulcerative Colitis in Children. The Protect Study
- Above and Beyond Training: Colonoscopy Learning Curves and Expected Annual Procedural Volume of Credentialed Pediatric Gastroenterologists

◆ Posters

- Surgery in Pediatric Crohn's Disease, 2002-2014
- National Survey of Inflammatory Bowel Disease Patients Identifies Risk Factors for Emergency Department Visits
- Long-Term Efficacy and Safety of Adalimumab in Paediatric Patients With Crohn's Disease

Dr. Maria Perez & Dr. Cynthia Kaphahn

"GI manifestations in eating disorders" - chapter in AAP's Adolescent Medicine State of the Art Review for GI Issues in Adolescents.



YOUR PREP TOOL KIT FOR THE FALL

- ⇒ *Schedule an appointment for the flu shot asap. Remember—no nasal mist as this is a live, weakened form of the vaccine.*
- ⇒ *Request your SOAs now! You can send an email to our social worker, Charlotte Intile, via mychart with any specifics you need.*
- ⇒ *For those at college: if you need a copy of your medical record for your local GI at college, please request asap. You can do this via mychart. Please allow at least 2 weeks for processing.*
- ⇒ *We have a separate phone number for our families with IBD—973-971-4321. You may use this instead of 973-971-5676 Mon-Fri 8a-4pm.*
- ⇒ *Remember to obtain refills at the time of your appointment. Be sure to specify to your doctor if you want the Rx sent to a local or mail order pharmacy and the quantity requested.*



KEEPING UP WITH SCHOOL

BY CHARLOTTE INTILE, LCSW
SOCIAL WORKER

At times, hospitalizations are necessary based on your child's medical status. One of the more frequent questions that I am asked when this is occurring is "But what about school?" Luckily our hospital has some options available.

Education Inc. is an in-hospital service that can provide tutoring services (also known as "bedside instruction") for patients during their hospitalization. Using an educator from *Education Inc.* would be in lieu of your district hiring or arranging a tutor of their own to provide the service at the hospital. The school would first need to determine if the child is eligible for bedside instruction based on your district's criteria (very often the determinant is anticipated length of absence.) If your child has a 504 Plan or IEP in place, there frequently is an accommodation specific to absences.

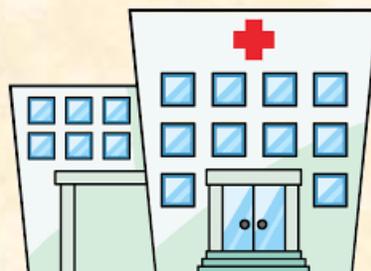
Once you have spoken to the school and have determined with them if your child is eligible for bedside instruction, the process for setting the service up is easy... if you know the admission is occurring in the near future, you can reach out to me and I can contact our educator from *Education Inc.* to alert them of the upcoming admission and provide them with your child's school information. The educator can then reach out to the school to authorize the services ahead of time so that bedside instruction can begin soon after admission. For more emergent hospitalizations, you can either speak to me or one of the child life specialists who are on the Pediatric floor to start the process. School work is sent home from your child's teachers and these are the materials that the educator will work on with your child.

A second option is utilizing technology to keep your child connected with school during a hospitalization. The VGo computer system allows patients to communicate face-to-face within the classroom through cameras and monitors. Similar to Skype, the VGo can be placed within the school so that the patient can not only see what's happening, but be able to participate as well. What's different about the VGo is that it is mobile. The patient can move the system throughout the whole school so that they stay connected and are a part of any experience that they want to... walking down the halls, being a part of lunchtime, or watching a science lab during class. The device itself is brought to your child's school and your child will have a device of his/her own at the bedside where he/she can activate the VGo computer and mobilize it. This is typically done in conjunction with traditional bedside instruction.

Consents must be completed with your school district and the device does require set up, so the school will need their ISS representative available to do this. Finally arrangements would need to be made for the device to be brought to the school, as well as to be returned back to the hospital when done.

Please do not hesitate to contact me should you have any questions or would like any information. (973) 971-5958

Reminder...Please allow a minimum of 2 weeks for any school letters, including diagnosis letters for 504 plans, that your child may need.



IMPORTANT INFO FOR THOSE ON REMICADE INFUSIONS

What's happening?

Many major commercial insurance plans are now requiring patients 15 years and older who have received several Remicade infusions to transition to receive infusions at home or at a free-standing infusion center instead of at Goryeb Children's Hospital.

What does this mean for you?

You may receive a phone call from our precertification team notifying you that your insurance company is requiring you to transition to infusions at home or at a free-standing facility.

What do you do now?

Nothing—unless you get a call from us—then reach out to your insurance company to clarify:

1. is this an optional or mandatory change
2. What facility is in-network with your insurance and in your local area

We have been using the following infusion companies who have comfort with pediatric companies: Bioscrip, CareCentrix, Nextron, Axelacare, Qualitas (mostly Lakewood). Contact the in-network company for any questions you may have regarding the infusion including dates, times, or any other questions you may have since these may vary company to company. Once you have decided on a company call our precert team and let us know of your decision.

We thank you for your understanding as we continue to navigate the changing insurance world with you.



We have had electronic medical records (EMR) for over 2 years now along with all of the other pediatric subspecialties at Goryeb Children's Hospital. Embedded in this system is "MyChart," which is a free, encrypted, HIPAA-secure email system that allows us to communicate back and forth with you for non-urgent matters.

We are requesting that ALL patients join and use MyChart. We are no longer using RelayHealth. To connect you to MyChart, at your next visit we will need the caregiver's (proxy) name and DOB. You will then be given an activation code to sign-up (within 14 days or the activation code expires).

Physicians use MyChart to communicate test results and plans so be sure to sign up right way. We hear over and over again from our families how wonderful this service has been to obtain results, refills, letters, etc. in a timely manner. Families are also giving us updates on their child's condition and are able to upload documents.

<https://mychart.atlantichealth.org>



FEEDBACK

Please let us know what you think? Is there something you would like to see in the next newsletter? We love to announce your child's accomplishments so please continue sending us pictures, stories, artwork, tips or information that you have learned. They are inspirational to many of our families...remember we have "newly diagnosed" families along with our veterans of many years. Send all submissions to email below.

To view past issues of *The Digestive Digest*, go to www.atlantichealth.org and follow prompts to Goryeb Children's Hospital to Pediatric Gastroenterology and click on "Newsletters." Or you can click on the link: <http://www.atlantichealth.org/goryeb/our+services/pediatric+gastroenterology+and+nutrition/connect/newsletters>

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