Welcome to CAMP

The new Inflammatory Center located in the Jill and David Farris Family’s Center for Advanced Medicine in Pediatrics (CAMP) opened as planned this summer. The excitement over the new facility has been palpable! The new outpatient offices offer our patients many amenities along with space to provide additional educational and family support services. The new infusion area on the second floor has continued to improve both service and comfort for our patients. Improvements such as XBOX consoles and the planned planting of the healing garden this spring coupled with markedly decreased waiting times have made for an even more pleasant and shortened stay. We thank the fantastic staff who work throughout the building for making this new experience as pleasant as we all hoped it could be. Among the new staff is our new Nurse Navigator, Nancy Salmeri, who many of you have already met. Nancy’s charge is to coordinate services for all patients in the Inflammatory Center while keeping a careful eye on assuring the highest level of quality in the care we provide. Her contribution has already been felt and we know that it will only grow over time.

One of the goals of the center has been to establish best practices and improved quality in the care we deliver across all the various conditions cared for in the Center. This process has already been implemented with gratifying results. We especially thank all of you who have given us such important feedback on the Center including ideas for improvements. We truly want this to be a 360° experience so we look forward to hearing from you!

PLEASE REMEMBER:

- to notify us if your insurance changes asap so there is no disruption in your child’s treatment. Many medications require prior authorization which may take many insurances up to 30 days or more for a determination.
- to get your refills at the time of your appointment (including 90 day prescriptions).
- to arrive at least 15 minutes prior to your scheduled appointment to allow for registration and measurement of your child’s height, weight, and vital signs.
**SUPPORTING YOUR PEDIATRIC 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@atlantichealth.org.

**SCHOLARSHIP INFO**

Did you know that scholarship opportunities are available for people with IBD? Gearing up to go to college is an exciting time, but it can get costly. Scholarships can help with these costs and, as an IBD patient, you can apply to opportunities tailored especially for you from UCB Pharmaceuticals, Convatec, and the Patient Advocate Foundation. Visit CCFA’s scholarship page or contact them at info@ccfa.org to learn more.

**MEET YOUR TEAM**

One of the many goals of the Jill and David Farris Family’s Center for Advanced Medicine in Pediatrics (CAMP), is continuing to research and provide up to date evidence based practices for our pediatric patients and families. Patient advocacy continues to be an ever-important measure to CAMP. The Nurse Navigator, a newly emerging role in healthcare, serves to assist patients and their families maneuver through the challenges that exist in managing the complexities that accompany a chronic health diagnosis. To better assist our families and patients in meeting these needs, the Inflammatory Center of CAMP is happy to announce the addition of a Nurse Navigator to our staff.

Nancy Salmeri RN, BSN, has joined the Inflammatory Center’s team in the role of Nurse Navigator as of December, 2013. Nancy has been an employee with Atlantic Health System since 1998. Her career has focused on Nursing and Case Management within the pediatric population. A Pediatric Certified Nurse since 2007, Nancy currently attends Drexel University in Philadelphia, PA where she is working toward her Pediatric Nurse Practitioner degree. Nancy resides for the past 18 years in Sparta with her husband Mark, three college age children Keith, Meghan, Amanda and Fritz their cat.

Nancy Salmeri, RN, BSN
We are proud to announce that the Center for Advanced Medicine in Pediatrics (CAMP) is open and thriving!

The 2nd floor of the Farris Building is where infusions such as Remicade and iron, for example, are given.

The 3rd floor houses rooms for outpatient visits. It is a shared space specifically designed for those patients who have Inflammatory Disorders such as those in gastroenterology, rheumatology, immunology, and infectious disease.

The Farris Building is immediately to the left of Goryeb Children’s Hospital.
"Good afternoon. My name is Julia Schneider and I am thrilled to be a part of such an exciting day. As a former patient who is now a Pediatric Nurse Practitioner, I have first-hand insight into the true importance of the Farris Family Center for Advanced Medicine in Pediatrics.

I would like to share a piece of my journey. In the year 2000, I experienced a moment that forever changed me. It gave me cause to re-evaluate who I was and what I wanted to do with my life. I can remember the day vividly. I was playing tennis. I served the tennis ball deep into my opponent’s court. Whack! Sharp, steady, stabbing pains raced down my esophagus into the pit of my abdomen. I keeled over, nearly blinded by sudden pain. These pains, sharp, unfamiliar, and steady never dissipated as my doubles partner and I battled but lost the New Jersey State Championship tennis match.

I have come to understand that it was simply out of my hands. The dye was cast. That same week, I was hospitalized and later diagnosed with Crohn’s Disease, a serious chronic illness that continues to affect my daily life. Losing the championship match became the “tipping point” and my personal compass turned toward navigating the complex world of multidisciplinary healthcare.

After yearlong battles with various medications, steroids, procedures, and monthly hospitalizations, and knowing where every bathroom was located in the New Jersey and New York region, I beat my disease and became the New Jersey Doubles State Champion in 2002. This personal achievement could not have been accomplished without my family’s support in tandem with my pediatric gastroenterologist and Goryeb Children’s Hospital GI team of nurses, dietician, and medical clinicians who helped me regain strength and rebuild my resiliency. The match must go on.

In the summer of 2004, I had an ileum resection which was my last option. As a result of my surgical experience, I acquired a voracious appetite for medical news, patient narratives, and health care changes. I was selected for an internship with the American Broadcast Company (ABC) morning news program, Good Morning America. I was beginning to consider a career in nursing as a connective bridge to further my education as a patient and my passion for science, health, and medical journalism.

During several years of medical appointments and hospitalizations, the pediatric GI staff became a second family to me. The trust I had in the team helped me channel my fear, frustrations, nerves, and most importantly made me laugh at times when I only thought I had tears. Laughter is the best medicine. I accepted that Crohn’s did not define me and I continue to envision the obstacles as a series of tennis matches and challenges that strengthen my character, innate resiliency, compassion, and eagerness to learn. I took my eagerness to The University of Pennsylvania to pursue my ongoing career endeavors after working for Good Morning America. I graduated and came back to the roots where I grew from, now as a Pediatric Nurse Practitioner.

When I took me on a tour of the construction site last week that we now look upon, I was energized. Seeing such a facility that will serve the close to 1,000 children now seen at Goryeb Children’s Hospital for all types of inflammatory disorders gave me a glimpse into the future. While the care I received at Goryeb was cutting edge in its day, the future is right in front of us. Seeing the vibrant colors and paintings on the walls, the construction workers diligently measuring out the bathroom signs and observing the magic taking place was quite overwhelming. I smiled.
Fortunately, patients with chronic inflammatory illnesses will have access to this stage of modern medicine. The collaborative effort to intertwine what I call and think of as the “Quadruplet Effect:” GI, Rheumatology, Infectious Disease, and Immunology, will only leverage the quality, continuity of care, accessibility necessary for all inflammatory illnesses under one center: The Farris Center.

Additionally, this building represents modern and innovative medicine which all of us in healthcare desire to deliver to all children with chronic illnesses. Hence the “quadruplet effect” enhances the support system families need while they participate in their child’s care to a level that was not available during my era here at Goryeb.

I know firsthand since that feeling of hope and incredibly deep-seeded connection that I bring to my own work everyday. A new seed has been planted right here. The “quadruplet effect,” clinicians, in tandem with families, will advocate together and create a remarkably efficient and effective team.

Atlantic Health has partnered with Pharmatek Systems to help families navigate the different assistance programs that may be available to you to offset co-payments, deductibles, and/or coinsurances for Remicade. You may be contacted by the Pharmatek eligibility specialists to see if you qualify for any type of assistance. If you would like to initiate contact please call Sarah Schanz-Bortman at 201-608-0803.


In the summer installment of Digestive Digest, we told you about 16 year old Paul Lachman and his efforts to raise money for Crohns and Colitis Foundation of America. He created a website, “Rowing Takes Guts,” which explains his experiences with UC and the purpose and objectives of his efforts to raise money in order to find a cure for IBD. At first just friends and family members contributed money, but as word spread, he received donations from strangers who were inspired by his vision. He upped his original goal of $5,000 to $10,000 and to date, Paul has brought in $10,665. He received heartfelt notes from people who heard about what he was doing and were moved to donate. The timing was right for Paul’s endeavor. It happened to be that CCFA would match donations, so the amount that Paul actually raised toward research and finding a cure is over $21,000.

Asked why he does it, Paul answers without hesitation, “There are a lot of people working hard to find a cure. Conducting studies cost a lot of money. Perhaps the money I raise will fund the studies that help figure out the puzzle of IBD. If putting myself out there makes that happen, it will be worth it. With this money raised, hopefully a few years from now kids with IBD will be able to pursue their passion without any limitations.” That is the ultimate victory!

**O N E  P E R S O N  M A K I N G  A  B I G**

**PAUL LACHMAN’S FUNDRAISER: ROWING TAKES GUTS**

**LINKED IN...SOME WEBSITES THAT MAY HELP YOU**

- Crohn’s & Colitis Foundation of America (CCFA)  
  - www.ccfa.org
- My IBD  
  - www.myibd.org
- North American Society of Pediatric Gastroenterology, Hepatology & Nutrition  
  - www.naspghan.org
- UC & Crohn’s (a site for teens)  
  - www.ucandcrohns.org
- GI Kids  
  - www.gikids.org
- Children’s digestive health information  
  - www.gastrokids.org
- Transitioning to adulthood with IBD  
  - www.ibdU.org
- IBD & College life  
  - www.ccfa.org/campus-connection/college-life/
- Free service to remind you to take your meds & when refills are needed  
  - www.mymedschedule.net
- Our website (has past Digestive Digest issues)  
  - www.atlantichealth.org/goryeb/our+services/
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)
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. Effect of Targeted Therapy on Self-Efficacy in Pediatric Patients with Newly-Diagnosed Inflammatory Bowel Disease
This study is investigating the effect of family and individual counseling at the time of diagnosis of inflammatory bowel disease for those ages 8-18 years within 30 days of diagnosis [sponsored by private donor].

3. IBD Registry
This is a long-term prospective, observational research study to assess the natural history of IBD, treatment regimens, clinical outcomes, and quality of life outcomes in newly diagnosed pediatric patients within 30 days of diagnosis. To be enrolled, patients must be less than 16 years of age at the time of diagnosis.

4. 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].

5. A Multicenter, open labeled study to evaluate the safety of Entocort (budesonide) in children with Crohn’s
This is a 12 week study to investigate the safety of Entocort in pediatric patient’s age 5 to 17 years with mild to moderate Crohn’s disease. Must be able to swallow pills.

6. 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 12 years or less.

7. A multicenter, open label study to assess the safety and pharmacokinetics of injectable administered Golimumab, in pediatric patients with moderate to severe Ulcerative Colitis
This is a 2.5 year study supported by Janssen, those enrolled must be between 2 to 17 years of age, meet rigorous criteria and have never received any other biological therapy.
As members of the Pediatric Gastroenterology Division at Goryeb Children’s Hospital, we take pride in the care we provide to over 700 of our patients with Crohn’s and ulcerative colitis. Last year our division participated for the first time as a team in the Take Steps for Crohn’s & Colitis walk to help show our support for our patients and their families. Take Steps is CCFA’s national walk and the nation’s largest event dedicated to finding cures for digestive diseases. Our goal was to raise money and awareness for crucial research, bringing us closer to a future free from Crohn’s disease and ulcerative colitis.

Our team initially started with doctors, nurses, and administrative assistants and their families. We spread the news via email and had multiple families join the team. In the end, our fifty member team (and 2 dogs) raised $3848 for CCFA! We enjoyed the breathtaking views of the New York City skyline, Freedom Tower, and Statue of Liberty. There was food, music, and kid’s activities. But best of all, we met many familiar and unfamiliar faces of those affected by IBD—we are linked by this common thread.

We welcome you to join Team BELLIES ARE OUR BUSINESS this year! We would love for more families to join our team. If you are interested, please email Ellie at eleanor.smith@atlantichealth.org.

This cause is very important to all of us and we appreciate your help as we fight for a cure!
Thank you for your good wishes and support as I prepared to run the CCFA Team Challenge Half Marathon in Las Vegas. It all came to reality last Sunday when I completed the entire half marathon, something I never would have imagined just three years ago. Great news - Team Challenge raised over 2.3 million dollars for the CCFA (and New Jersey was the top fundraiser!!!!). It was the most incredible feeling to know that I was running with people from all over the country who worked hard to raise money to help fund programs and hopefully one day find a cure for Crohn’s Disease and Colitis. I realized I am not alone, there are so many strong people going through what many of us go through with these diseases. I hope the kids who have Crohn’s or Colitis know they too are not alone and that anything is possible!

Eliza Bryen

Last July, Dr. Koslowe participated with about 3,000 runners in the CCFA Team Challenge in Napa. He raised over $4000 while the NJ Team raised over $30,000 just from this race. Team Challenge has raised over $2.2 million nationally. The money raised goes directly to supporting the efforts of CCFA in helping patients, clinicians, and researchers. Thank you to those who helped support TeamChallenge and CCFA in their efforts.
CCFA Camp Oasis provides a sanctuary where kids with Crohn’s Disease and ulcerative colitis are not defined by their illness. All of the campers (and many of the adults) have IBD. The focus is not on the disease, it’s on having fun.

Camp Oasis provides a 24 hour on-site medical supervision by physicians, nurses, and other healthcare professionals with experience treating children with IBD.

It’s a co-ed residential camp program with a mission is to enrich the lives of children with Crohn’s disease and ulcerative colitis by providing a safe and supportive camp community. Since all of the campers (and most of the adults) have IBD, their supportive community allows kids to:

- See that they are not alone
- Try things they never imagined
- Create friendships with people who truly understand them
- Listen and share their IBD experiences
- Gain confidence
- Heal and build their spirit

Location: Camp Nox-A-Mixon in Kintnersville, PA

2014 Session Dates: August 18-23

The fee to attend camp is $275. Scholarships are available for those who qualify. If you have any questions, please email newjersey@ccfa.org or call (732) 786-9960.

Apply online at www.ccfa.org/camps. There is an area for our office to fill out so please do not delay. Please indicate whether you would like us to send the completed form back via Relay Health, fax, or provide us with a self-addressed stamped envelope so we may mail it back to you.

RelayHealth (www.relayhealth.com) is an online, free, secure & encrypted website that our office is using to communicate online. We cannot send any emails without using Relay Health. Preps and information regarding all procedures are only sent through Relay Health.

This helpful website can be used to update your physician (non-urgent only) on your child’s condition or request:

- refills (refills are processed quicker with Relay Health)
- letters, camp forms, lab and radiology prescriptions
- results

No one else is able to access any of your information & your email address is never shared or sold. Many families have told us how efficient and what a time-saver RelayHealth has been.

It’s easy, it’s fast and it’s free!!!!

Thank you to those who have already joined. You are helping our office to run more efficiently for you.
**CONGRATULATIONS DR. PEREZ!**

Congratulations are in order to our very own, Dr. Maria Perez, who received the Top Kids Doc Award from NJ Family Magazine.

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**DO YOU KNOW...**

- approximately 25% of patients with IBD present at less than 20 years of age?
- 5 out of every 100,000 pediatric patients with IBD are diagnosed when they are less than 8 years old?
- whether your child is immune to chicken pox?
- whether your child is immune to Hepatitis B? We have found at least half of our patients with IBD do not have immunity even though they had the 3 vaccine series.
- live viral vaccines are not recommended for people with IBD? Any vaccine should be the deadened form only. This includes the flu shot. A child with IBD should never receive the nasal Flumist.
- active smokers are more than twice as likely as nonsmokers to develop Crohn’s disease? Surprisingly, the risk of developing ulcerative colitis is decreased in current smokers compared with people who have never smoked. The numerous potential harmful health effects of smoking (e.g., cancer, heart disease) largely overcome any benefits of smoking for people with ulcerative colitis.
- IBD is found mainly in developed countries, more commonly in urban areas, and more often in northern climates. However some of these disease patterns are gradually shifting. The highest Crohn’s disease incidence is reported in Canada while highest ulcerative colitis rates are reported for Denmark, Iceland, and the United States.
- an increasing number of susceptibility genes have been identified. The list of genes that have been found to play a role in Crohn’s disease is rapidly expanding. In 2007, eight such genes had been identified. By 2010, that number grew to over 70 genes.
- the importance of what is called the microbiome has been recognized. The microbiome comprises all the microorganisms (bacteria, viruses, fungi, and other microbes) that reside in or on the human body. An important area of IBD research involves identifying the constellation of bacteria that reside in the intestines and understanding how they communicate and interact within the intestines and with the immune system.
“EXPRESSIONS”
Learning How to Cope with Chronic Illness and Chronic Pain
Ashley Greene, MS Art Therapist

“Expressions” is an 8 week art therapy group for children ages 9–12 years old who are diagnosed with a chronic illness or are experiencing chronic pain.

Creating art promotes relaxation and studies show that art supports healing on all levels: Mind, Body, and Spirit. Members of Expressions will create pieces of art that will instill relaxation, increase self esteem and self awareness, and promote health and healing.

WHEN:
Thursdays: February 20, 27, March 6, 13, 20, 27, April 3, 10, 2014
6:00 to 7:30pm

WHERE:
Goryeb Children’s Hospital
100 Madison Avenue
Morristown, NJ 07960

Farris Family Center for Advanced Medicine in Pediatrics CAMP (3rd floor)

HOW:
To register for “Expressions” please call Stacy Alper, LCSW Pediatric Behavioral Medicine Department at 973-971-5785

Ashley Greene, MS in Art Therapy, has a wealth of experience utilizing art as a way of healing for children. Ashley has shared the healing aspects of art with children battling cancer for over 5 years. She also facilitates numerous art therapy groups throughout Atlantic Health System.

Cosponsored by both Pediatric Behavioral Medicine and Healing Arts.

There is a $10 Registration fee
(Those who attend all 8 sessions will have the $10 registration fee refunded to them.)

Goryeb Children’s Hospital
ATLANTIC HEALTH SYSTEM
WHAT IF?  
AN ANONYMOUS MOM

Notable milestones are good times to assess decisions made and opportunities taken or lost in life. There aren’t many times when it is so clearly calculated by measureable means exactly where one stands, as when applying to college. My son is a high school senior and at that watershed moment in his life. Going through the college application process is stressful enough without added anxiety from a chronic health condition.

As my son answers the Common App questions and writes and rewrites his supplemental essays, I spend a lot of my time thinking of the “what ifs,” mostly centered on his health issues. The GPA is tallied, standardized tests are scored and extra curriculars are listed. His numbers are his numbers. But what if he didn’t get diagnosed with Crohn’s Disease when he was sixteen? What if he was concentrating on pre-calculus his junior year instead of worrying about how quickly he can make it to the nearest bathroom? Maybe he would not have gotten that C that is a barrier to admission at some schools. What if we recognized the signs and symptoms earlier? What if we weren’t so fearful of the big scary medicines and started him on them sooner? I know these questions are futile and do nothing other than make me sad, but I cannot stop myself.

Having spent so much time reflecting, I can see clearly how we (my husband, my son and myself) took a long time comprehending and accepting the realities of what living with Crohn’s Disease fully means. Never, ever wanting to be identified as someone who is sick, my son worked harder than anyone else on his team; moreover, he never skipped practice no matter how he felt. He pushed through the pain everyday. He scheduled lab work for early mornings or free periods so that he would not miss classes. We were proud of him and we took his lead. That stoic posture, however, was deceiving us. He never complained and felt “fine” when asked. This attitude contributed to my own sense that as long as he said he was okay, I eased up on the worrying and stopped thinking about limitations.

The problem is, life periodically throws punches at you and sometimes they clobber you all at once. He took the blows and ultimately is facing a future that is different than the one he had visualized a few years ago. He still hopes to be recruited for athletics, but coaches at some colleges have voiced their concerns about his health. That hit him hard because he is determined to not be regarded as weak or inferior to the other candidates. He is aware of preconceptions now, but is not giving up. He wants to prove that CD will not prevent him from achieving his goals.

I am tired of the phrase “it all works out in the end.” I hate those words because they bring me back to the “what ifs.” I so very much want to believe that it all will work out for him. Sometimes it is hard to see that it will.

I have spent way too much emotional capital on the past and need to focus on moving forward. He just started on Remicade. Hopefully that will bring him to a better place both physically and mentally in regard to his acceptance of Crohn’s Disease. I am working on accepting it myself. I have a new version of the “what ifs” and it starts with, what if this new medicine works for him? What if he gets accepted into a college? What if there is a coach who recognizes potential and understands the power of hard work and perseverance?

I will take each milestone as they come. What if it all works out in the end?