FROM THE DIRECTOR

We are all going to CAMP—Now What?

The Jill and David Farris Family’s Center for Advanced Medicine in Pediatrics (CAMP) will open this summer. CAMP is located in a building adjacent to the Goryeb Children’s Hospital on the Morristown Memorial Campus and will house our new Pediatric Inflammatory Disease Center. After years of planning, this modern and most beautiful facility promises to move all that we do forward.

The novelty of an Inflammatory Center is at the center of our new effort. For too long, subspecialists have worked in artificial “silos” of research and clinical care. By bringing together gastroenterologists, rheumatologists with experts in infectious diseases and immunology we will be able to make important inroads in advancing family-centered, quality care for children and adolescents affected by a variety of auto-inflammatory disorders that include IBD. The new center contains outpatient offices, a family friendly infusion area that includes an outdoor “healing garden,” conference rooms and plenty of comfortable space for informal education programs and psychosocial interventions.

We have many plans for what we should do at CAMP. At the same time, we recognize that we are not the true experts—we need your insights, experience, thoughts and creativity! There is no doubt that what we do together at CAMP will be optimized if we plan it together. We would like to pull together groups of interested families, parents and patients alike, to sit together and think about program development for the new Inflammatory Center. The hope and desire is to be able to support the whole patient and family at CAMP. Who better to tell us how to do that than you!

Please come out to one of our planning meetings or talk to us when you come to the office, or give us a call, send a fax, write an email, skywrite—whatever mode of communication you prefer, we will be here to listen!

Please remember:

- to get your refills at the time of your appointment (including 90 day prescriptions).
- to arrive 15 minutes prior to your scheduled appointment to allow for registration and measurement of your child’s height, weight, and vital signs.
- to notify us if your insurance changes asap. Many medications require prior authorization which may take many insurances up to 30 days or more for a determination.
- to notify us asap if your child requires an updated 504 plan for school.
- A yearly PPD (test to check for exposure to tuberculosis) is needed if you are on Remicade, Humira, or Cimzia. Please have your primary care doctor fax us documentation of the date it was placed, the date it was read, and the result.
JACK & GOVERNOR CHRISTIE: PERFECT TOGETHER

Jack Cudia, 12 years old, recently met Governor Chris Christie at a hockey game where his team played against his son’s team. Jack lives in Ledgewood and is in 6th grade at Lincoln Roosevelt School in Roxbury. He has played hockey for Roxbury as a defensemen for the past 4 years & started skating when he was 6. This picture is from June 8th at Aspen Ice in Randolph where Jack is in the spring league and plays for the Middlebury Grey team (also coached by his Dad). Governor Christie came to watch his son and the rest of the Morristown spring league play against Jack’s team.

After the game, Jack walked up to the Governor, introduced himself, and shook his hand. He got a big kick out of meeting Governor Christie and it’s pretty easy to see with that ear-to-ear smile he’s wearing.

SUPPORTING YOUR IBD CENTER

We are all aware of the current fiscal climate. Such difficult times affect every aspect of the economy, and philanthropic organizations are not immune to this. Many of the patient support and research efforts of the Pediatric IBD Center are funded through philanthropy.

If you have interest in donating to the Center or have other fundraising ideas, we want to hear from you. Please feel free to contact any of us at the Center or Geraldine Kling at the Morristown Medical Center Health Foundation at 973-593-2414 if you would like to find out more.

LINKED IN...SOME WEBSITES THAT MAY HELP YOU

Crohn’s & Colitis Foundation of America (CCFA)  www.ccf.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.ccf.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 patients 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.
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. On June 2nd, 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.

On a beautiful Sunday in June, Team Bellies Are Our Business took to walking Liberty State Park in Jersey City. 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 next year! We look forward to making this a yearly event for our department and would love for more families to join our team. If you are interested, please email Kate at katherine.d’addio@atlantichealth.org.

This cause is very important to all of us and we appreciate your help as we fight for a cure!

Pictured above are members of Bellies Are Our Business: the Dau family, the Terracciano Family, the Pettigrew family, Kate D’Addio, RN & her husband, Alfredo, Meredith McCluney, RN & daughters (Lauren, Molly & Katie), Sheryl Giacomaro (Coordinator), Ellen Romain, RN and her husband, Mark and niece, Michele, Dr. Maria Perez & her husband, Telmo Martins, Eleanor Smith (Administrative Assistant), and Dr. Rosh & his family.
Above: Ellen and her niece, Michele

Right: Ellen and her husband, Mark

Dr. Maria Perez and husband, Telmo.

Sheryl & Meredith
**DELZICOL HAS REPLACED ASACOL (400MG ONLY)**

Crohn’s & Colitis Foundation of America (CCFA) has prepared the following information regarding the discontinuation of Asacol and the change to Delzicol.

As of April 1, 2013, an inactive ingredient was removed from the medication Asacol and therefore this medication is no longer being manufactured. Asacol will no longer be available in pharmacies once they run out of their supply. While “Asacol” is no longer being manufactured; “Delzicol” which is a new medication with the same indications for use as Asacol is now available. Delzicol is produced by the same pharmaceutical company as Asacol (Warner Chilcott) and it is bio-equivalent to Asacol. There was one inactive ingredient which was removed from Asacol known as “dibutyl phthalate” or DBP and another inactive ingredient was added in its place. Because of the removal of this inactive ingredient and addition of another inactive ingredient, the name of the medication had to be changed. There was no safety indication for the removal of this inactive ingredient. The medication Delzicol has the same indications for use as Asacol and is dosed the same. The only difference in dosing instructions from a Food and Drug Administration perspective is that Delzicol should be dosed one hour before a meal or two hours after a meal.

Just as Asacol had been indicated, Delzicol’s point of release is at the terminal ileum and topically treats inflammation throughout the colon. Patients may notice a slight difference in appearance of the medication, as Delzicol is a coated pill and is enclosed by a capsule. This capsule is important in delivering the medication all the way through the digestive tract to the terminal ileum and colon, and therefore the enclosed pill within the capsule should not be removed or crushed. It will most effectively be delivered for treatment in this casing. The safety information and possible side effects are the same as Asacol. Patients may learn more about Delzicol and its use in place of Asacol at: [http://www.wcrx.com/pdfs/pi/pi_delzicol.pdf](http://www.wcrx.com/pdfs/pi/pi_delzicol.pdf). Further, if there are specific questions about this medication, please contact the Warner Chilcott medical information desk directly at 1-800-521-8813 ext. 3236. Please note Asacol HD 800mg is still on the market, recommended as safe and will continue to be available.

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**RelayHealth**

RelayHealth ([www.relayhealth.com](http://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.
FACTS ABOUT FECAL TRANSPLANT

CCFA recently released a position statement in April regarding fecal bacterial (microbial) transplantation (FMT).

The gastrointestinal tract, especially the colon, normally contains over ten trillion bacteria (that’s 10,000,000,000,000). That outnumbers the living human cells in the body by 10x. There are several hundred bacterial species living in our digestive system which lives in a mutually beneficial relationship with the human cells (symbiosis). Digestive bacteria contribute to good health by producing vitamins, processing carbohydrates, providing nutrients to the cells lining the colon, suppressing harmful bacteria, and helping the immune system develop normally.

There is usually a fine balance of “good” and “bad” bacteria in the gut but it can, at times, get disrupted as with antibiotic use which may destroy part of the normal gut bacteria. Over time, there has been a decrease in the various types of bacteria, particularly in the Western world where we live, possible related to sanitation, increased public hygiene, and antibiotic use. This change is thought to be a possible contributor to the increasing frequency of IBD worldwide and especially in the developed and developing countries.

One common consequence of this microbial disturbance is infection with Clostridium difficile (C. diff) bacteria. This infection can cause diarrhea and abdominal pain and can occasionally be difficult to treat. In cases where antibiotic treatment fails, use of FMT has been implemented. This process involves transferring bacteria from the stool of a healthy donor during a colonoscopy, with an enema, or a tube inserted through the nose into the upper gastrointestinal tract. This treatment is not FDA approved. It is considered experimental and long term safety has not been clearly established. However there is increasing consensus that FMT is an acceptable treatment for recurrent, difficult cases of C.diff infection—only if performed at a healthcare center with established expertise.

They state that a more challenging question is whether fecal microbial transplantation can be a treatment for IBD in the absence of C. diff infection. It is known that there is a difference in microbial flora when comparing those with active IBD to those without IBD or even those with IBD in remission. Although that leads to suggest that fecal bacterial transplantation may be a possible treatment for IBD, there have been no definitive, good quality research studies.

PRESENTED AT DIGESTIVE DISEASES WEEK (DDW)

In May, research performed at our center was chosen to be presented at the yearly Digestive Diseases Week (DDW) meeting. This is the world’s largest gathering of physicians and researchers in the field of gastroenterology. The presentations are below:

- Early Anti-TNFα Therapy Is Superior to Early Immunomodulator Therapy in Newly Diagnosed Children With Crohn’s Disease
- Prolonged Exposure to Prednisone Is Decreasing in Children With Inflammatory Bowel Disease (IBD) During the Last Decade
- Prospective Cohort Study of Methotrexate Use in Treatment of Pediatric Crohn’s Disease
- Ileal RNA-Seq Analyses Reveal Decreased Mucosal Myeloid Cell Immune Responses in Pediatric Crohn Disease Patients With Phagocyte Dysfunction Due to Neutralizing Granulocyte Macrophage Colony Stimulating Factor (GM-CSF) Auto-Antibodies
- Pharmacokinetics of Adalimumab in Pediatric Patients With Moderate to Severe Crohn’s Disease
- Relationship Between Adalimumab Concentration and Efficacy for the Induction of Clinical Remission in Pediatric Patients With Moderate to Severe Crohn’s Disease
- Relationship Between Adalimumab Concentration and Efficacy for the Maintenance of Clinical Remission in Pediatric Patients With Moderate to Severe Crohn’s Disease
- Clinical Outcome of Pediatric IBD Patients After Measurement of Infliximab Drug and Anti-Drug Antibody Levels
- Efficacy and Safety of Standard vs Low Dose Adalimumab Maintenance Therapy As a Function of Disease Severity in Pediatric Patients With Crohn’s Disease: Subanalysis of Imagine 1
CHARITY GALA HONORS SOPHIA & BENEFITS CCFA

On April 29th, Sophia DeSenzo took part in the Beauty & Fashion Charity Gala 2013. It’s an annual event hosted by Salon Amici of Woodland Park with all the proceeds benefiting CCFA (Crohn’s and Colitis Foundation Of America). Sophia was not only one of the fashion models but she was the guest of honor as well. She stood at the podium, in front of 220 plus people and gave a speech detailing her journey with Crohn’s Disease. By the time her speech ended, there weren’t many dry eyes left. Since her initial diagnosis, she has handled herself with such grace and maturity that I sometimes forget she is only 15).

~Dante DeSenzo
Sophia’s Dad

Below is Sophia’s speech she gave during the Gala.

“Hello, my name is Sophia DeSenzo and I was diagnosed with Crohn’s disease in March of 2011 at the age of 12. For those of you who aren’t familiar with the disease, Crohn’s is an auto-immune disease that affects all of the organs of your digestive system. It can cause stomach pain, fatigue, nausea and joint pain. It also causes you to spend lots of time in the bathroom.

As far back as I can remember, I’ve always had problems with my stomach. However, every time I went to the pediatrician, the symptoms never stayed around long enough for anyone to correctly diagnose my condition. I heard things like, “It’s food allergies” or “she just has a nervous stomach.” It was even suggested that I get counseling to help me handle stress better. Still, no one was able to tell me what was wrong, and still the pain in my stomach came and went.

As I started 7th grade, I noticed that my belly pain and visits to the bathroom had become more frequent and I began to lose weight. As we approached the winter break of 2010, the weight loss had become very noticeable. Frustrated and with no answers, my mom asked the school nurse to compare my weight at the beginning of the school year in October to what it was in January. We were all shocked to discover that I had lost 6 pounds. Now 6 pounds may not seem like much, but to a teenage girl who was already underweight, it was a lot. When we added that to the belly pain, constant trips to the bathroom and the fatigue, we KNEW there was a serious problem.

We set out to find a doctor who specialized in Pediatric Gastroenterology. After many recommendations and a lot of research, we were very fortunate to find Dr. Leiby and the great people at Goryeb Children’s Hospital in Morristown. After I explained what I had been feeling to Dr. Leiby she felt strongly that we were dealing with either Crohn’s Disease or Colitis, but she wanted to run some tests to be sure. I gave blood samples, stool samples and was scheduled for a colonoscopy and an endoscopy to see if any parts of my G.I. Tract was affected by this disease.

As I was sitting in the hospital bed waiting to go in for my procedure, I was nervous. I had never been put under anesthesia and I was anxious to find out what I had. After all, I didn’t even know what Crohn’s was and how serious it could be. When the results were back, it was clear to Dr. Leiby that we were dealing with what SHE called a mild to moderate case of Crohn’s disease. As my parents and I discussed Crohn’s with Dr. Leiby, we were quickly overwhelmed with

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information: all of the parts of the body that are affected, treatment options and what happens when a person is experiencing a flare-up.

It was during this time that we were introduced to CCFA, the Crohn’s and Colitis Foundation of America. Dr. Leiby knew that we would go home and research Crohn’s on the Internet. She told us to be careful because we would find a lot of misinformation on the web but she did recommend one site that was very reliable, contained accurate information and would help to answer our questions. That website was ccfa.org. The site is filled with so much information on Crohn’s and Colitis. CCFA has been a valuable resource to my family and to me. Not only were we able to find answers to many of our questions, but I was able to make connections with other young girls who were experiencing many of the same things that I was at that time.

Once the initial shock of the diagnosis had settled in, we needed to start some kind of treatment. Over the next 8 months we tried a series of medications in an attempt to get the disease under control. I started out taking Pentasa and shortly after that added entocort. During the times I experienced flare-ups, Prednisone was also added to help with the inflammation. At one point I was taking as many as 10 pills a day, not including Tylenol which I would take during the times I had really bad pain in my joints. On Mother’s Day of 2011, I ended up back in the hospital with severe stomach pain. We realized at that point that my Crohn’s was more serious than originally diagnosed and a stronger medication was needed. To control the inflammation, I was put back on a higher dosage of Prednisone for the summer and then had to wean off of it before I could start the new and stronger medication called 6MP.

I was getting more and more frustrated as nothing seemed to be working. My stomach still hurt, my joints were killing me, I was constantly going to the bathroom and at this point I weighed less than 65 pounds. As a result of the joint pain and fatigue, I was finding it increasingly difficult to do the things that I loved to do like gymnastics, basketball, and softball. To make matters worse, I was told that I had to be on the new medication for 8 weeks before we would know if it would even work.

By November of 2011, my disease had really progressed, even after 8 weeks of new meds. At that point, my doctor gave me an ultimatum...there were only two treatment choices left: yet another even stronger medicine called Remicade, which is given in the hospital through an IV or a treatment called enteral nutrition therapy. Enteral therapy is when you get an NG tube put in your nose that goes into your stomach and you get fed nothing but formula for the next couple of months. You can’t eat anything during that time, giving your intestines a break—and time to heal.

Not knowing anything about either option, my parents went back to the CCFA website to do more research. Not only were we able to find many answers to our questions, I even connected with a girl named Isabel. She was 15 at the time and she had been going through the same thing I was. I had gotten a chance to email her and then we set up a Skype date. Talking to her had made my decision a lot easier. So, after talking to Isabel and all the research we did, I decided to go with the enteral therapy.

The first night with the NG tube was New Year’s Eve. I got really sick and wanted to rip it out and be done with it. I was ready to quit but with my mom’s support and help she got me through the first night. It was hard and I kept gagging. When it was time to take my nighttime pills, I put the first one in my mouth and almost choked because it was so big and I wasn’t used to having a tube down my throat. It was also tough not being able to eat my favorite foods.

Anyway, after a few weeks I had gotten used to it and I even started a blog. I called it, “Soph’s Journey with Crohn’s” just to give support and advice to other people who might be going through the same thing. While all of this was going on, I was absent from school for the first couple of weeks. Then I got something set up called home instruction. Its where all of my teachers came to my house and taught me at home. It was like that for a little over 3 months and when I finally went back to school half day. I got so much support and love.

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I had the tube in my nose for about 4 months and it was working great. I was gaining weight and was getting taller. Everything was working out great. I had even reintroduced food back into my body and although it was a little rough at first, it went well. I just had to watch what I ate still. So, I was back in school, eating and gaining weight. I was doing great! A couple of months had passed and I had now had the NG tube in for 7 months total and it was time for the next step. The next step involved getting surgery and a g tube put in my stomach. I had made the decision that THAT’S what we were going to do and set up a surgery date.

Last July, I had the first part of my surgery and the experience was horrible. It was probably the worst day of my life because I had never had anything like that done before. I was sore for a couple weeks but the pain had soon passed and I was back on my feet. I had no longer had the tube in my nose--it was now in my stomach. It was going well and now it was time for high school.

I had had a few problems with the tube in the beginning of the year so, I stopped hooking up during the day and I had no more problems. After three months, it was time for the second procedure--to get rid of the tube and to put in a button. The button looks like the valve on a beach-ball which is much easier to hide under clothes. So, I went in for the second part of the procedure and, thank goodness, it all went well.

Since then I have been doing great. I have been gaining weight and I have been growing taller. From the day of diagnosis, I have gained 35 pounds and I have grown about 5 inches. This whole experience has made me a stronger individual and helped me grow as a person too. I have learned so much and would like to thank the following people: I want to thank my parents for being with me the whole way, to CCFA for being such a great help and resource, my doctor, Dr. Alicia Leiby, and her staff. Monique, for being there for me when I needed her; most of all I would like to thank Lina and Salon Amichi for setting up tonight’s event and for everyone here tonight who donated money to help find a cure. I hope you all enjoy the remainder of your evening and thank you again for coming!”

To follow Sophia’s blog, go to http://soph-sjourneywithcrohns.blogspot.com

**EVERY CLOUD HAS A SILVER LINING**

**BY ANN P.**

My 10 year old daughter was recently diagnosed with Crohn’s Disease and takes methotrexate. She is quite mature and responsible therefore I let her take her medicine by herself. Initially, she took the pills in the morning, but because of side effects, this Sunday, Memorial Day weekend, was the first time she was going to take them at night.

I was in middle of a pre-bedtime activity with her younger sister when I heard a yell. Apparently, a pill went flying when my daughter opened the container. She couldn’t find it. I went into Spring cleaning mode on my hands and knees, as did my daughters. We looked inside every book on the counter, in the tissue box, inside the cabinets, in the stove, under the radiator. We swept, we crawled, we moved furniture, said a prayer, but to no avail. We found a penny, a bead, a goldfish cracker, lots of dust bunnies, but no pill. My daughter was frantic. I really didn’t want to disturb the doctors at night on Memorial Day weekend. We looked up the pharmacies that were open 24 hours a day, hoping they would be open although it was holiday.

The closest one and the first that I called was open. Not the one that filled the initial prescription. Despite this the pharmacist said, "Bring in the vial and I will give you one pill." I never dreamed it would be this easy to solve the problem.

Lesson learned there is silver lining behind every cloud, no problem is insurmountable and there are really kind people.
TEAM HELENA HAS RAISED $33,000 AND COUNTING

“Team Helena” participated in the Take Steps for Crohn’s & Colitis walk in May in Middlesex. So far Team Helena has raised over $33,000 in all their walks. Congratulations!!!!

Some medications such as 6MP & methotrexate will increase your sensitivity to the sun so protect yourself with sunscreen and clothing that blocks both UVA & UVB rays.

Laura Brady also participated in the Take Steps for Crohn’s & Colitis walk on Team “Love Our Laura.”
It was late in January of this year when I ultimately decided to take on the challenge of joining Team Challenge in a race for a cure for Crohn’s and colitis. In retrospect, I don’t think I realized the commitment, both with fundraising as well as training, but it was one of my most memorable experiences, and I look forward to repeating this journey again next year. Prior to January, I had only run only a few miles on the treadmill so to think I could run 13.1 miles seemed more of a fantasy than reality. I was lucky to have two wonderful coaches, Jill Markman and Teri Eckel, who helped me every step of the way. I had the pleasure of running with both Debi Alexander and Lisa Pedicone whom have children with inflammatory bowel disease who are followed within our division of Pediatric Gastroenterology; Justine Markman near and dear to Goryeb also ran. The day had finally arrived; it was 4:45am on June 1, 2013 and we headed out to the Doukenie Winery for the start of the race. I am happy to say by 2hrs:30min I was crossing the finish line with a smile on my face and never looked back since!!

Team Challenge participants from across the United States raised over $950,000 to help find a cure for Crohn’s and colitis.
CONGRATULATIONS TO ADAM GREENE
WINNER OF SECOND SINGLES AT
UNION COUNTY TENNIS CHAMPIONSHIP

Blue Devil Adam Greene drew the third seed at second singles and won his first match, 6-0, 6-0, to advance to the quarterfinals where he topped Jensen Butler (GL), 7-5, 6-0. A lot was at stake in his semifinal match with Hilltopper Matt Celona, who had defeated him earlier in the season. This time, however, Greene won, 6-1, 6-2. “I lost to him earlier, so I wanted to beat him here at counties. I played consistently. I attacked his backhand a lot. I got my first serves in and kept the ball in play and waited for him to make errors. My serve was alright today. I was trying to place it more than hit it hard and hit to his backhand, so I could start the point off to my advantage,” Greene said. Greene’s next opponent for the title would be either top-seeded Kevin Maluso (NP) or Raider Mike Rosenheck, who won his first match, 6-0, 6-0, and his quarterfinal match, 6-2, 6-4. “I have beaten both of them every time I played them. I think I just need to play my game, and I will be fine,” Greene said.

courtesy of The Westfield Leader

Adam going to Prom

Good luck to Dr. Oren Koslowe who will be participating in Team Challenge half marathon in Napa in July!
ROWING TAKES GUTS

He can’t remember exactly when it hit him, but for Paul Lachman (16), rising Junior at Mountain Lakes High School, he was struck by a great idea to turn his athletic pursuit of victory into a pursuit of raising awareness and funding for the Crohn’s & Colitis Foundation of America. Paul is an inspiration to his friends and is making a real difference in the lives of others whom he will never meet. He created a fundraiser called “Rowing Takes Guts” and has raised $10,400 thus far toward finding a cure for Inflammatory Bowel Diseases. Paul is a multisport varsity athlete who plays soccer, ski races, and rows on the crew team. His athletic achievements are impressive for anyone, but more significant than most, because he has ulcerative colitis. He was diagnosed in September 2010 and despite some unpleasant complications along the way, Paul has excelled in sports and academics.

This past May, Paul’s crew boat, (the Mountain Lakes men’s varsity lightweight 8+) qualified for the US Youth Nationals in Oak Ridge TN, a championship rowing event for high school rowers from around the country. Paul, along with the seven other rowers and coxswain were ecstatic about the opportunity to row in such a distinguished event. For Paul the accomplishment meant so much more. The challenges he faced everyday at practice throughout the season were physically and mentally straining. The times when he pushed his body so much that he collapsed, drove home from practice feint from exhaustion and then returned the next day to do it again were the moments that came to mind while high fiving his boat mates. He doesn’t want this to be the way it is forever. He wants to get a cure for his IBD. He wants it soon.

Sometime in the celebrating is when he thought he could use the opportunity of the Mountain Lakes Crew Club’s trip to Nationals to raise awareness and funds to help find a cure. His idea was to find people to sponsor his boat and support the cause of CCFA. He knew he was not alone in this desire for a cure for IBD. Another oarsman in his boat, Luke Graham (17), has Crohn’s Disease. Paul and Luke grew to be friends in and out of the boat and could rely on each other to understand certain complications about practice that no one else could quite appreciate, including how to survive on a tiny boat with no bathroom when you really, really needed one!

Paul helped Luke open up and talk about having IBD, something that Luke didn’t do before he became friends with Paul. They talked about foods that they tried and liked, joked about IBD, and shared the locations of secret bathrooms. The only thing that Paul couldn’t quite convince Luke to do, though, was to help him in his pursuit of raising awareness and funding through their race to Nationals. Perhaps because it was still a bit new to Luke (he was just diagnosed with Crohn’s Disease in the fall), or he was afraid of drawing attention to the situation, but Luke was not emotionally ready to join Paul in his efforts. Paul respected Luke’s decision, but worked hard to raise money for their boat anyway.

Paul is certain a cure is possible and wants to play a part in making it happen. He had a modest goal in mind and when word spread of his efforts, he received donations from so many people, some he knew and others who just heard of his story. So far, Paul has far exceeded his goal of $5,000. He has inspired many others through his narrative of struggles with UC and physical accomplishments. Paul received heartfelt notes from people who heard about what he was doing and were moved to donate in his name.

Not only has Paul inspired strangers to help support CCFA by awareness of his story, he has helped his friend Luke “take steps” toward accepting and dealing with his Crohn’s. Even though Luke didn’t help Paul in his fundraising endeavor, Paul invited Luke to join in the “Take Steps” walk at Liberty Park on June 2nd. After racing on the Hudson River in the morning, the boys made it from Poughkeepsie, NY to Jersey City, NJ as the walk was beginning.

Luke was not eager to join in, but when he got there he saw the friendly smile of Dr. Wilmot and his family who came out to support the cause. He also saw that there were so many others who were eager to find a cure. He then knew his friend was on to something. Luke confided in Paul that one of the hardest challenges in having this disease is wanting to push your body when it just won’t go anymore. (continued)
Our Dietitian, Diane Duelfer, is available to consult with you on any concerns or questions you may have about your eating patterns and habits. The most important fact to remember is that nutrition for IBD is individualized. We will request that you begin taking maintenance vitamin D supplements as recommended in the calcium/vitamin D section of this handout. When reading the label look for vitamin D3 – cholecalciferol.

**Vitamin D**
- **Children 1-8 years old**: 800 IU Vitamin D3
- **Children 9-21 years old**: 1000 IU Vitamin D3

**Calcium**
Generally calcium is required in conjunction with vitamin D. It is important that calcium doses are split. The body does not absorb more than about 500 mg calcium at one time. Try to take your calcium separate from consumption of milk and separate from your iron supplement or multivitamin with iron.

We recommend 1000 – 1600 mg elemental calcium in children older than 4 years old.
- **1-4 years old**: 700 mg elemental calcium
- **9-18 years old**: 1200-1500 mg elemental calcium
- **18-21 years old**: 1000 mg elemental calcium

You can choose any OTC calcium and/or Vitamin D tablet, capsule or soft gel that equals recommended calcium needs (in a split dose) and recommended vitamin D requirements. Below is a list of some of the preparations that many of our families have used with good success. Assume all of the items listed contain vitamin D3 unless otherwise noted:

**Liquid vitamin D**
- Carlson Labs online – Super Daily D 1000 and 2000 IU or for Baby (400 IU)
- Bio-D-Mulsion Forte – online – 2000 IU D
- Baby Ddrops – 400 IU/drop OTC and online
- Kid Ddrops – 400 IU/drop OTC and Ddrops – 1000 IU/drop OTC and online
- Enfamil: Dvi-sol – 400 IU/mL online and OTC

**Liquid calcium and Vitamin D**
- Cal-Quick by Twinlabs – 500 mg calcium (as oyster shell calcium) and 100 IU vitamin D per teaspoon
- Wellesse Calcium and Vitamin D – 500 mg calcium (as citrate and phosphate) and 500 IU vitamin D per Tbsp.
- Nutraceutical Solution, Inc. – 500 mg calcium (as citrate and carbonate) and 200 IU vitamin D per Tbsp.

**Chewable Vitamin D and Calcium**
- Oscal 500 and D chewable – 500 mg calcium carbonate and 500 IU vitamin D
- Viactiv with D – 500 mg calcium carbonate and 500 IU vitamin D
- GNC chewable wafer – 600 mg calcium carbonate and 400 IU vitamin D
- Caltrate soft chews (chocolate or vanilla) 600 mg calcium carbonate & 400 IU vitamin D
- Adora dark or milk chocolate chews – 500 mg calcium carbonate and 250 IU vitamin D

**Tablets or soft gels**
- Caltrate 600 and D tablet – 800 IU vitamin D and 600 mg calcium

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**Feedback**

Please take a minute to send me an email and let us know your thoughts. What do you want to see more of? What did you wish we included? 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](http://www.atlantichealth.org/goryeb/our+services/pediatric+gastroenterology+and+nutrition/connect/newsletters)

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