

THE DIGESTIVE DIGEST

SPRING 2015

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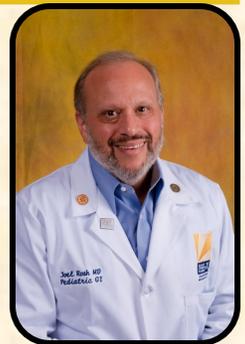
FROM THE DIRECTOR

DR. JOEL ROSH

We hope that you enjoy this issue of Digestive Digest. In it I think you will note several themes that emerge. First and foremost is the importance of research. While our understanding of IBD has never been greater, so is the clear need for ongoing research to improve today's outcomes while we find a cure for those with IBD. We are proud that our Center has been at the vanguard at advancing new insights into therapies such as methotrexate and the newer anti-TNF agents while also calling attention to some of the risks of older therapies. Many of you have already volunteered to be a part of our research endeavors. Now there is CCFA Partners which is a great way for all to take part in important research to enhance the understanding of everyday issues for those who have IBD. We hope you enroll and become part of this vital project.

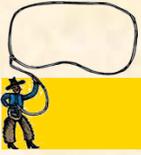
While the Science of medicine is important, so is the Art. We remain dedicated to a holistic approach when caring for IBD whether it be thru our expanding psychosocial support team, addition of a Nurse Navigator, complimentary therapies such as Yoga or perhaps—trying guided imagery! The reproduced editorial that appears in this issue of Digestive Digest was recently published in the premiere Pediatric medical journal and is a national “call to arms”. It is our Center's 2015 goal to look at how we can help you improve not just the “day to day” but the everyday. We are blessed with a fantastic professional team and truly believe that with your help, we can work together to make this a reality.

Finally, we hope that many of you will be able to join our team, “Bellies Are Our Business”, at the CCFA walk in Liberty State Park on Sunday June 14 as we give a shout out to our Honored Hero, Derek. It is always a great day as together we will make a difference by supporting CCFA in a wonderful social atmosphere with others who are affected by IBD or who are dedicated to care for those who have it until we cure it!—Hope to see you there!



NURSE NAVIGATOR CORNER NANCY SALMERI, RN, BSN

The beginning of a New Year can always bring about a host of Health Insurance changes and barriers to overcome for our patients and their families. These can increase anxiety for all involved. One resource our office encourages you to request from your insurance provider is a Nurse Case Manager. Patients who have a more complex medical history can request this service. It not only assures one person within the insurance company has familiarity of your child/teens case, they can also be a great advocate resource when hitting barriers to insurance approved care. We encourage you to contact your insurer at the time of diagnosis to request this service. Identifying great resources available to you and your child/teen can undoubtedly assist in streamlining communication between your healthcare provider and Insurer. For our patients who currently have this service in place, insurance requests, frequently have shown a more expeditious resolution. Please reach out to your insurance providers member service department to request assistance with this service.



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)

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

CLOSED 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].

4. 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 and children less than 13 years of age for Crohn's patients who have not been on a biologic medication.

5. A multicenter, open label study to assess the safety and pharmacokinetics of injectable administered Golimumab, in pediatric patients with moderate to severe Ulcerative Colitis

CLOSED 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.

6. 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. Enrollment to start soon for males aged 9-15 years and females 8-13 years who have Crohn's disease.



MEET YOUR



Rosheida Henry, CMA and Kim Swank, CMA

Rosheida and Kim are our 2 medical assistants who work in the Center for Advanced Medicine in Pediatrics (CAMP) located on the 3rd floor of the Farris Center.

Rosheida Henry, CMA

She graduated from The Mandl School of Allied Health in New York City and upon graduation she worked for an internal medicine practice. Shortly after, she joined the Atlantic Health Team in 2013 and has been working at CAMP.

"Working with children has always been a dream of mine and I am glad to be a part of a team that takes pride in the care they provide for their patients."

Kim Swank, CMA

Kim graduated from SCCC and joined an Internal Medicine/ Infectious Disease practice in Sussex County. With the desire to work with young people, she joined the team at CAMP a year ago and loves working with the children and doctors. Grandmother of six, Kim still teaches special needs gymnastics to children and never misses the chance to watch them compete.



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

2015 Session Dates: August 17-22

Scholarships are available for those who qualify. If you have any questions, please email newjersey@ccfa.org or call (732) 786-9960. There are applications for campers (entering grades 4-11), leaders in training (entering grade 12), and volunteers (>19 years old).

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 fax or provide us with a self-addressed stamped envelope so we may mail it back to you.



What is CCFA Partners?

CCFA Partners is an online research study designed to improve the quality of life for patients with inflammatory bowel disease (IBD) through research and education. CCFA Partners has been expanded to include children: CCFA Partners Kids & Teens. Given that children are the fastest growing IBD patient subgroup and many children have severe disease, pediatric-focused research is critical.

The goal of this project is to follow IBD patients over time through this online registry for a better understanding of the issues those with IBD face including how you function day-to-day, diet, treatments, and how these factors change over time.

CCFA Partners is purely a research initiative, not a fundraising effort. Participants are asked to complete a survey twice a year to update your health history. It's a convenient and simple way for you to make a contribution to the search for cures.

Am I eligible?

Participants must have been diagnosed with Crohn's disease or ulcerative colitis.

How do I register?

Registering is easy: visit CCFAPartners.org and click on the "CCFA Partners Kids & Teens" tab. This initial confidential survey should only take 20-30 minutes of your time and can be done all in one sitting or you can log off and return to complete it at a later time. Registration for those under 18 years old requires parental consent.

Once you are enrolled, you will be asked to update your medical information in a brief online survey every 6 months. You will receive a quarterly progress reports and relevant information about IBD.

Do I have to answer every question?

No—all questions are optional. You don't have to answer any questions you don't want to and you can withdraw from the research study at any time. Survey questions depend on the child's current age and may include topics such as medication use, disease symptoms, and quality of life. For all patients, parents complete a portion of each survey. Child participation increases as children grow older.

What do I get for participating?

You do not receive any compensation for participating. However, your involvement will advance our knowledge of IBD. Research findings will be published on the CCFA Partners website, in peer-reviewed research journals, and presented at scientific meetings. As of December 2014 there are already 14,000 participants and more are needed to provide a wider sampling of patients with diverse socioeconomic backgrounds, ethnicities, and environments that will provide deeper insights into the disease process and to help identify best practices in patient care.



Atlantic Health System "Creative Expressions" Healing Arts Calendar Art Contest 2016



We are looking for young artists to help celebrate Atlantic Health System's "Year of Community."

Sponsored by:
Goryeb Children's Hospital, Pediatric Behavioral Medicine, Atlantic Health Healing Arts Program and the Farris Family Center for Advanced Medicine in Pediatrics (CAMP)



Stay Strong
Priscilla A. Age 15



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 2016 "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 whatever comes to your mind, whatever you are feeling in the moment. What is your community, where do you find your strength?

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

ALL PROJECTS MUST BE SUBMITTED BY September 1, 2015.

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.



Guided imagery is a gentle but powerful technique that focuses and directs the imagination. It is a form of meditation and involves all the senses—almost anyone can do this. It is not strictly a “mental” activity as it involves the whole body, the emotions and all the senses, and it is precisely this body-based focus that makes for its powerful impact.

Over the past 25 years, the effectiveness of guided imagery has been increasingly established by research findings that demonstrate its positive impact on health, creativity, and performance. It can reduce blood pressure, heighten short-term immune cell activity, lessens pain and headaches, reduces anxiety.

There are three principles of guided imagery: the mind-body connection,

MIND BODY CONNECTION

To the body, images created in the mind can be almost as real as actual events—the mind doesn't quite know the difference. That is why when we think of homemade chocolate chip cookies or our favorite dessert, we start to salivate—how it looks, tastes, and smells; you may even start thinking of the food cooking or the feel of the texture of food as you are chewing. All the while, your body is thinking “dessert is served” and is responding by generating saliva and appetite. The mind cues the body especially well if the images evoke sensory memory and fantasy sights, sounds, smells, feel, and taste when there is a strong emotional element involved.

THE ALTERED STATE

In the altered state, we are capable of more rapid and intense healing, growth, learning, and performance. We are more creative and intuitive, our moods and cognition change. We can do things that we couldn't do in a normal, waking state (ie, lift a tree that has fallen on a car). We wander in and out of altered states throughout the day. Sometimes it is not a conscious choice and we drive past our exit on the highway. It is a state of relaxed focus, a kind of calm but energized alertness. Attention is concentrated on one thing or on a very narrow band of things. When this occurs, we have a heightened sensitivity to the object of our attention and decreased awareness of other things going on around us—things we would normally notice. We are so engrossed, we lose track of time or don't hear people talking to us. The altered state is the power cell of guided imagery.

LOCUS OF CONTROL

When we have a sense of being in control, that, in and of itself, can help us to feel better and do better. Feeling in control is associated with higher optimism, self-esteem, and ability to tolerate pain, ambiguity, and stress. Alternatively, a sense of helplessness lowers self-esteem, our ability to cope, and our optimism about the future.

Because guided imagery is an entirely internally driven activity, and the user can decide when, where, how, and if it is applied, it has the salutary effect of helping us feel we have some control.

GENERAL TIPS

- Your skill and efficiency will increase with practice. The more you use it, the less and less it will take for it to work.
- It works best in a relaxed, unforced atmosphere. Don't get too intense about “doing it right.” There are many ways to do it right.
- Let your own images come up and work for you.
- Music can increase the effects of imagery. You will know what music is right for what you need.
- Imagery that elicits emotion is more effective than imagery that doesn't.
- You don't have to be a “believer” in order for imagery to help. Positive expectancy helps but even a skeptical willingness to give it a try can be quite sufficient.
- Use the same posture or hand-positioning with each imagery session (breathing deeply or putting your hands over your belly each time) so it will condition you to respond immediately to the posture. That way, you can use this posture at school, while in the car, or resting and your body will respond the way it did during the imagery.
- Don't worry if you keep “spacing out” or losing track. A wandering mind comes with the territory.
- You may tear up, get a runny nose, yawn, feel heaviness in your extremities, get tingling at the top of your scalp or in your hands and feet. These are entirely normal responses.
- After imagery, your voice will be deeper and lower, slower, and more relaxed.
- Doing this first thing in the morning or right before bed are usually convenient and great times to do this.
- Kids are naturals at guided imagery as are adolescents.



PRACTICE GUIDED IMAGERY ON YOUR OWN

1. Begin by taking several slow deep abdominal breaths.
2. Invite an image to form of a special place where you have felt relaxed and peaceful.
3. Experience this special place with each of your senses to deepen the experience.
4. See yourself relaxing in a comfortable place and become aware of what is around you. Notice colors, textures, landscapes.
5. Listen to any sounds that may be present.
6. Smell the aromas in the air, if there are any.
7. Feel the temperature of the air and any other bodily sensations.
8. Taste any food or drink you may be having.
9. Become aware of how you feel in this special place.



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@atlantichalth.org.

Let us know if your insurance changes asap

so there is no disruption in your child's treatment. Many medications require prior authorization which can take insurances up to 30 days or more for a determination.

RECENT PUBLICATION BY DR. DOTSON & DR. ROSH

It Is Prudent to Assess Psychosocial Functioning in Children with Inflammatory Bowel Disease

Approximately one-quarter of the 1.4 million people with inflammatory bowel disease (IBD) in the US present during childhood.^{1,2} Unfortunately, pediatric IBD is recognized as being a more severe, extensive, and aggressive disease compared with that seen in adults.³ A multidisciplinary approach is essential for optimal management and best outcomes.

The medical team (eg, doctors, nurses, psychologists, dietitians, social workers) must partner with the patient, caregivers, and school to maximize treatment outcomes and overall patient well-being.

The goals in the management of IBD in adult and pediatric patients are similar: inducing and maintaining remission, minimizing therapeutic complications and side effects, minimizing disease-specific complications, and improving quality of life. However, in children, perhaps one of the most important goals is to assure normal growth and development. This not only includes height, weight, and body mass index, but also puberty and cognitive development. For example, corticosteroid use impairs linear growth and can affect sleep and mood. Treatment plans involve patients and their caregivers, which can affect medical and surgical management, adherence, frequency of endoscopic examinations, and the transition process. Pediatric gastroenterologists are striving to change outcomes for children and adolescents with IBD through research, quality improvement, and excellent clinical care. Indeed, the emergence of biologic therapy at the end of the last century has had a markedly positive impact upon the outcomes of the most severely affected children with IBD.⁴

An important aspect of wellness includes social functioning. The psychosocial issues in IBD can sometimes be overlooked by patients, caregivers, schools, and physicians. It has been noted that up to 25% of children and adolescents with IBD suffer from anxiety and depression.⁵ The common developmental and social issues of adolescence become all the more complicated in the face of a chronic disease with symptoms that can be embarrassing, and medications that can have cosmetic side effects. Social difficulty is a common problem in pediatric IBD, affecting up to one-third of youth.⁶ Psychosocial factors have been shown to be better predictors of absenteeism than disease-related factors.⁷ Mackner et al published a comprehensive clinical report regarding psychosocial issues in pediatric IBD, which addresses psychopathology, health-related quality of life, and social, family, and

school functioning.⁵ This is a helpful reference for pediatricians, family practitioners, and pediatric gastroenterologists.

A correlation to absenteeism in school-age children is absenteeism in the work-force by adults. Adults miss work because of a variety of reasons, including medical appointments, hospitalizations, surgeries, and endoscopies. Financial loss, adjusting and coping, as well as anxiety and depression have a negative impact on quality of life and disability. In adults with IBD, fatigue has been associated with lower health-related quality of life, work disability, and depression.⁸ A Dutch nationwide survey found that 18% of patients with Crohn's disease were fully disabled and nearly 9% were partially disabled (5% and 5%, respectively, for ulcerative colitis). Older patients, lower educational attainment, depression, chronic back and joint pain, penetrating disease, and surgeries were associated with work disability.⁹

Recognition of the social impact of IBD in children has led to the provision of increased resources in most pediatric IBD centers to help patients reach their complete potential. It is in this light that the study by Singh et al¹⁰ in this issue of *The Journal* provides hopeful data. The authors demonstrated that Canadian pediatric patients with IBD had overall good outcomes based on grade 12 academic performance compared with controls.¹⁰ Moreover, exposure to specific IBD medications or surgeries did not appear to lead to sub-optimal performance when looking at this longer-term outcome. It is reassuring to have evidence that our current treatment paradigm is allowing our pediatric patients with IBD to reach their academic potential and not evolve into disabled adults seen in a prior generation. It is important to note that mental health problems and lower socioeconomic status were predictors of worse educational outcomes. This study is well performed, novel, and contributes to the paucity of literature on this topic. The authors specifically highlight the necessity of screening and the involvement of mental health professionals, with a particular focus on those children and adolescents with underlying mental health issues at the time of IBD diagnosis.

It is imperative that we work together, as a multidisciplinary team, to treat pediatric IBD aggressively and screen for psychosocial factors in order to achieve optimal outcomes as our patients mature into high-functioning young adults. ■

See related article, p 1111

IBD Inflammatory bowel disease

The authors declare no conflicts of interest.

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Dear Friends,

On June 14, 2015, the Department of Pediatric Gastroenterology, Hepatology and Nutrition will once again be walking in **Take Steps for Crohn's & Colitis**, the nation's largest event dedicated to finding cures for digestive diseases. Our team, along with thousands of others across the country, will raise 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.

Last year we were awarded as the top corporate fundraising team. Our goal was \$6,000 and we raised over \$9,000 for CCFA. We are very proud of this and our goal this year is to raise \$10,000. We hope you can help us achieve this. This is an opportunity to do something good in the community and take a step toward a future free from Crohn's and colitis. Start today, by:

- Joining our Take Steps team
- Making a contribution to our team
- Start your own personal fundraising

You can register today by visiting www.cctakesteps.org, and follow the prompts to register for our team **Bellies Are Our Business** at the **Jersey City** walk on June 14th. When you register, you will receive valuable fundraising tools and information from the Crohn's & Colitis Foundation, in addition to your own personal fundraising Web site.

T-shirt Info

We once again will be ordering T Shirts to match the shirts from the past two years. Team shirts will cost \$10 and are available to order in Youth (XSmall, Small, Medium, Large) and Adult (Small, Medium, Large, XLarge and XXLarge). All payment for shirts is due by May 1st. Once the shipment comes arrives, you will be able to pick up your order at the Morristown office by June 1st or at the Walk. If you are interested in purchasing these shirts please send me an email (eleanor.smith@atlanticealth.org) with the number of shirts/sizes you will be ordering. Payment by check is required.

Please make your check out to: Eleanor Smith **Memo:** Pediatric GI/Shirts...**and mail to:**

Eleanor Smith
Morristown Medical Center
Pediatric GI Box 82
100 Madison Avenue
Morristown, NJ 07962

We hope that you will join us in supporting our team, "Bellies Are Our Business". Together we'll raise money for important research and raise awareness of two painful and unpredictable diseases that affect millions of people. Thank you in advance for your support!
Sincerely, Ellie (Team Captain)

**Liberty State Park
in Jersey City
on Sunday, June 14th
check-in at 9am**



MEET YOUR HONORED HERO, DEREK



Derek Estrada is this year's "Honored Hero" at the CCFA walk in Liberty Park in June. Below is his inspirational story.

Hi! My name is Derek and I am 13. I was diagnosed with Ulcerative Colitis when I was 10 years old. I was a regular kid playing sports and having a great time in school until UC came upon me. When just starting 5th grade and learning that you are being diagnosed with a disease that affects how your body functions you get a little scared. I used to play baseball for our town's recreational team and was learning to be a great catcher. When I was diagnosed, I had to stop playing baseball because I had to go to the bathroom a lot and didn't want to let my team down. I was out of school a lot with stomach problems and I got behind in my school work to the point where I needed a tutor. I stopped hanging out with my friends and became less social with everyone in my school. Now, to tell about my story and the long trip ahead.

When I was told I had UC I realized this would be a trip on a long road until I can be in remission. I first started off with several medicine choices to try to relieve my UC. My Pediatric GI started me on a Sulfa drug that is supposed to relieve the pain from UC and it seemed like it was starting to work! After I started the Sulfa drug, me and my Mom went on vacation to Disney and from the day I got there to the day we left I was sick from this med. I developed a rash and a high fever and could barely enjoy anything and ended up in the ER. At this point I started high doses of Prednisone, we proceeded to try lots of other meds – Remicade infusions, methotrexate, 6MP along with the high doses of prednisone, none of them worked. I was in and out of the hospital several times and had lots of doctor visits and testing done. There were also bad side effects to some of the meds I was on that made me sick along with the UC issues. I felt like nothing was working, the medicine didn't help me and I was left with one option, surgery.

The first step of the surgery was to have most of my colon removed and to have an ileostomy bag. I had the ileostomy bag hanging off the side of my body for 3 months until my new J-Pouch healed. The second step of the surgery was after the new J-Pouch healed I was able to have the ileostomy bag removed and the opening in my side closed. The ileostomy bag was probably worse than the actual surgery for me, I had many complications from the bag falling off or even overfilling. It was very embarrassing at times but I went through all of this to get better as this was the final step to helping me be in remission.

To this day I feel so much better and better than I ever thought I would have felt ever again. I'm medicine free and pain free which is the best! I am back to all the activities I had to quit when I was diagnosed, I am hanging out with my friends more, and most importantly back in school more and enjoying 8th grade!

WE'VE MOVED TO



Last July, all of the pediatric subspecialties at Atlantic Health Systems switched from paper charting to electronic medical charting. Embedded in this system is "MyChart," which is an email system that allows us to communicate back and forth with you.

We are requesting that all patients move to MyChart and discontinue using RelayHealth. To connect you, at your next visit we will need the parent's (proxy) name and proxy's DOB. You will then be given a printout with instructions and an activation code that expires in 14 days so please be sure to sign in the first day. This will help our office be more efficient for you.



Join us as we RUN, WALK, and RAISE FUNDS for a CURE for IBD!

To benefit the Crohn's and Colitis Foundation of America, the 2nd Annual **CURE for IBD 5K and Fun Run** offers people and families SEVERAL ways to participate and help in the fight against Crohn's and ulcerative colitis...

Register and join us IN-PERSON on Sunday, May 3rd in Basking Ridge.

Register and participate VIRTUALLY... run or walk at a time that's convenient for you!

Recruit friends and family to join you and fundraise...prizes will be awarded for TOP FUNDRAISERS and TOP FUND-RAISING TEAMS!

Add a business as an event sponsor (ask for details).

Become a FAMILY SPONSOR... donate \$100 and get YOUR FAMILY'S NAME on the event t-shirt!

Join us as a VOLUNTEER at the event, or just help spread the word (flyers available upon request).

EVENT DETAILS

When: Sunday, May 3rd

1 mile Fun Run starts at 9am

5K starts at 9:30am

Where: Mountain Park (2 Mountain Road, Basking Ridge, NJ)

Register online by April 10th to guarantee an event t-shirt or register on-site before the event (8am-9am).

For more information or to register go to www.cureforibd.com

Email questions to Chris Pedicone at: cureforibd@gmail.com



NEW WEBSITE FOR TEENS

CCFA, in partnership with the NASPGHAN Foundation for Children's Digestive Health and Nutrition has developed a new website "Just Like Me" (www.justlikemeibd.org) for teenagers (ages 13-18) with IBD. The interactive site will feature stories and videos from teens with IBD as well as information on school, dating, stress, diet, and research.

Journeys

Our Experience with Pain, Illness, and Hope



Calling All Writers!

Pediatric Behavioral Medicine is putting together a literary journal about the experiences of children and teens who live with chronic illness and chronic pain. We need your help!

If you are a child or teen who has chronic illness or pain we want to hear your story. Please consider submitting a piece to be included in the journal. Here are some ideas to help get you started...

- › How did you feel when you discovered that you had an illness?
- › What are some of the things that you need to do to keep healthy?
- › What are some of the biggest challenges you have to face?
- › What do you worry about?
- › What have you learned from having a chronic illness?
- › How do friends and family react to your illness?
- › How do you tell people you are just meeting?
- › What are your interests, hobbies?
- › Who or what has inspired you to not give up?
- › What do you do when you feeling like giving up?
- › If a child or teen was just diagnosed with a Chronic Illness what advice would you give them?

To Enter

1. Email your writing to Stacy.Alper@atlantichhealth.org
 2. Drop off your writing to the Farris Family Center, 100 Madison Ave 3rd floor
- Questions: Please contact Stacy Alper, LCSW at 973-971-5785



Journeys

Our Experience with Pain, Illness, and Hope

Entry Form:

Writer's Name: _____

DOB and Age: _____

Email: _____

Title of Entry: _____

Parent Agreement for Minor Child to Submit Writing

Parent Name: _____

Parent Signature: _____

Parent Email: _____

Please answer the following questions by circling your response:

I agree for my child's first and last initial to be on his or her writing **yes no**

I agree for my child's first name to be on his/her story **yes no**

I do not want my child's name on any writing he/she has done **yes no**

Journal Entry Guidelines

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NUTRITION NEWS

BY DIANE DUELFER, MSRD

Diet continues to be a concern for patients with IBD. To date, there are no studies supporting diet as causing or curing IBD; however, diet may help to reduce symptoms or promote healing. Adequate nutrition to include calories, macro and micronutrients certainly affect how we feel and our energy levels on a day to day basis. Without proper nutrition our various enzyme and metabolic pathways might be compromised resulting in decreased efficiency for basic functions such as respiration, digestion, cardiovascular and neurological needs.

The best model available for nutrition planning can be found at the site: ChooseMyPlate.gov. Each component of the plate can be formulated to meet each individual's specific needs. We should not choose to ignore any one component of the diet over time if we wish to support our health and well-being.

During illness it is more difficult to meet these basic needs. During inflammatory periods decreased absorption of nutrients and fluids can occur even with good nutrition. Some supportive measures to consider when one is not feeling well include (1) small frequent meals – limit to fist-size portions to include 1 carbohydrate and 1 protein at each meal (2) Reduce gassy or greasy/fried foods which can cause gas or diarrhea if not properly digested (3) be aware of whether or not you might be experiencing temporary lactose intolerance- utilize Lact-Aid milk or Lact-Aid enzyme with meals. (4) avoid hard-to-digest high fiber foods such as nuts, popcorn, or corn particularly if you have narrowing of the bowel. Sometimes fluids or dry carbohydrates are easier to handle. If fluids are acceptable, consider soups where you can puree or add many nutrients to enhance the caloric and nutrient density of foods consumed. One example is the butternut squash soup recipe below. You can change or add many of the items in the recipe to suit your taste and needs.

Butternut Squash Soup Recipe: note - pumpkin can be substituted if desired

| | |
|-------------------------------|--|
| 2 Tbsp extra-virgin olive oil | 4 cups cubed butternut squash (fresh or frozen) |
| 1 carrot diced | ½ tsp thyme |
| 1 celery stalk diced | 4 cups chicken broth |
| 1 onion diced | ½ tsp fine sea salt and/or ½ tsp black pepper to taste |



Heat oil in soup pot and add carrot, celery and onion. Sauté until soft. Stir in butternut squash, thyme, chicken broth, salt and pepper. Bring to a boil and reduce heat and simmer until squash is tender – about 30 minutes. You can puree with an immersion blender or utilizing an upright blender to desired consistency.

Variations:

- Stir in 1 cup applesauce to pureed soup. Garnish with blue cheese, toasted almonds (if tolerated) and a few pieces of thinly sliced skinned apple
- Stir in 2 tsp chopped fresh ginger. Add 1/2 to 1 cup coconut milk to broth. Garnish with toasted coconut flakes and/or chopped fresh cilantro.
- Stir in 1 x 3-6 oz package cream cheese until melted to increase calories and naturally thicken puree



FEEDBACK

Please take a minute to send me an email to let me know what you think of this newsletter. Is there a particular area of interest for the next edition? 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>

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