

PEDIATRIC IBD CLINIC



Children's of Alabama

The Pediatric IBD Clinic at Children's of Alabama is committed to helping you achieve remission, avoid flares, and have the best possible quality of life!

Pediatric IBD Clinic

IBD care takes a team???

YES! And that team starts with you! You are the team captain. You know your body best and we always want to know how you feel in every situation – emotionally and physically. However, it does take a team of specialists to help you manage your IBD so that you can always be the best you! We want to partner with you to take the best care of **YOU!**

This new patient packet was created as a starting point to help you take an active role in your medical care. It contains useful information that our IBD team feels will be most beneficial to you at this time.

Our team also includes parent partners that have provided their insight in to what should be included in this packet. Quite a bit of information is included in the packet and we do not want you to feel overwhelmed. When you have a chance, please take a moment to skim through the materials to get a feel for what is there. Later, you can dive deeper into the materials. Please keep this packet in a location that is easy to reach when you want to refer to the materials.

As always, please let us know if you have any questions!

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Meet your IBD Team



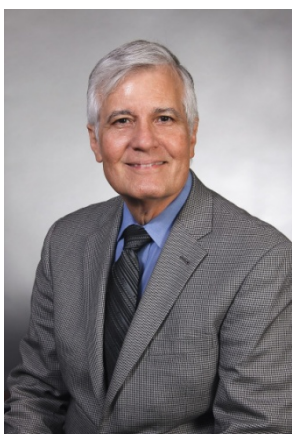
Traci Jester, MD

Dr. Traci Jester is originally from St. Cloud, Florida. She attended Auburn University for undergraduate studies in nutrition and then UAB for medical school, Pediatric residency, and fellowship in Pediatric Gastroenterology and Nutrition. She has been board certified in Pediatric Gastroenterology, Hepatology, and Nutrition since 2012. Her primary pediatric GI interest is Inflammatory Bowel Disease. She is co-Director of the UAB/Children's of Alabama Pediatric Inflammatory Bowel Disease clinic along with Dr. Jeanine Maclin. Dr. Jester is our team Physician Leader for ImproveCareNow, serves on the Pediatric Affairs Committee for the Crohn's and Colitis Foundation of America, and is also site primary investigator for several Inflammatory Bowel Disease related studies. Dr. Jester is married and has twin daughters. Her hobbies and interests include time with her family, running, planning family trips, and sports, particularly college football.



Jeanine Maclin, MD

Dr. Jeanine Maclin is a native of Birmingham, Alabama. She attended medical school at the University of Alabama School of Medicine and then went on to a Pediatrics residency and GI Fellowship at Children's of Alabama. Dr. Maclin has been practicing pediatric Gastroenterology since 2007 and is Board Certified in Pediatric Gastroenterology, Hepatology and Nutrition. She is currently the co-director of the Pediatric IBD Clinic at Children's of Alabama along with Dr. Traci Jester. In addition to her clinical duties, Dr. Maclin serves as the Fellowship Director for the Pediatric Gastroenterology Fellowship at UAB. She is actively involved in the Improve Care Network which our center joined in 2014, and involved in research on IBD and Simulation to improve resident learning. She is married to her husband Carlos and they have a 10 year old daughter. In her free time, she enjoys traveling and reading.



Jose Mestre, MD

Dr. Jose Mestre was born in Guantanamo, Cuba and grew up in Miami Beach, Florida. He attended the University of Florida for undergraduate studies and medical school. He did his residency in Pediatrics at the University of Florida and did his fellowship in Pediatric Gastroenterology at the Medical College of Virginia in Richmond. Dr. Mestre came to Alabama in 1982 and established the Division of Pediatric Gastroenterology at UAB/Children's of Alabama. In 1987 he established Gastroenterology for Children PC and was in private practice until 2015 when he rejoined the Division of Pediatric Gastroenterology at UAB/Children's of Alabama. He is board Certified in Pediatrics and Pediatric Gastroenterology and Nutrition. He is a participating physician in the Improve Care Now network. The CCFA Alabama/ NW Florida Chapter awarded Dr. Mestre the chapter's Humanitarian Award in 2000. He is married and has three children and three grandchildren. In his free time Dr. Mestre enjoys playing with his grandchildren, cooking and traveling. He is a baseball and history buff, and participates in playing trivia games.



Taylor Knight, CRNP

Taylor Knight was born and raised in Birmingham, Alabama. She attended the University of Alabama (Roll Tide!) where she obtained her Bachelor of Science in Nursing at the Capstone College of Nursing. She worked for over 5 years in the NICU at Children's of Alabama before obtaining her Master of Science in Nursing as a Pediatric Nurse Practitioner at UAB. She has been a part of the GI team since June of 2015 and serves as the Inflammatory Bowel Disease Nurse Practitioner. Taylor and her husband have one daughter and a dachshund. She enjoys spending time with her family, traveling, and all things Alabama football.



Margaux Barnes, PhD

Margaux Barnes, Ph.D., Assistant Professor, Pediatric Gastroenterology, Hepatology & Nutrition, earned her Ph.D. at UAB and completed her fellowship in Adolescent Medicine at UAB's Leadership Education in Adolescent Health Program. Her research focuses on the development of interventions to increase engagement in health-promoting behaviors in youth with Inflammatory Bowel Disease. She is specifically interested in the development of novel diet and physical activity interventions that may mitigate some of the health outcomes associated with IBD, including lean mass deficits, delayed growth, and increased risk for osteopenia/osteoporosis. Clinically she works with patients and families to increase medication adherence, develop healthy coping skills, and address any emotional or behavioral concerns that may influence children and adolescents' quality of life and well-being.



Meg Mosteller-Barnum

After graduating from the University of Georgia with a major in microbiology, Meg moved to Birmingham and began work at UAB. Meg is married with a 19 year old son in college. When not at work, Meg enjoys gardening, cooking and reading.



Kate Rogers, RD

Kate Rogers is the registered dietitian for the Department of Gastroenterology and Nutrition. She completed her dietetic internship and master's degree in Nutrition Science at UAB. While completing her master's degree, Kate participated in the Children's of Alabama nutrition assistantship program. During her nutrition assistantship, she specialized in gastroenterology and renal transplant. Kate has been a part of the GI team since August 2016 and serves as the general GI and Inflammatory Bowel Disease outpatient dietitian.

If you are ever admitted to the hospital for your disease, you may be followed by a different doctor. You may also speak with a different doctor if you have to call after hours or on the weekends.

These are the other physicians in our GI Division you may meet.



Reed Dimmitt, MD



Jan Nogueira, MD



Rachel Kassel, MD



David Galloway, MD

How to Contact the Gastroenterology Clinic

When you call, always let us know that your child has IBD!

Concerns? Contact our office at 205-638-9918

When you call the office, you will hear a message asking you to choose from the following options:

- Press 1 to schedule a new patient appointment
- Press 3 to schedule a follow-up appointment
- Press 4 if you are calling for medication refills or need for a prior authorization
- Press 5 to speak with a receptionist to direct your call to a nurse, doctor, or nurse practitioner.

If you choose option 5 and you have to leave a message, please leave a detailed message with the following information:

- Your name
- Your child's name
- Your child's date of birth
- Reason for your call
- Phone number where you can be reached
- Pharmacy information

All calls will be returned within one business day.

What will happen when I leave a message?

- One of our staff members will call you to discuss your questions and concerns. We can often answer your questions when we call you back.
- For medical questions, we may contact your child's doctor to address concerns and will call you back with a plan.
- Our office hours are Monday – Friday from 8:00 a.m. to 4:30 p.m. We make every attempt to return messages left before 3 p.m. on the same business day. Calls after 3 p.m. may have to be returned the next business day.

Emergencies

For urgent situations after hours or on holidays in which you would like to speak with a physician, please call the After Hours line at (205) 638-9100 and ask to have the on call pediatric gastroenterologist paged. **Please tell this doctor that your child has IBD.**

What to Expect When I Call my GI Nurse

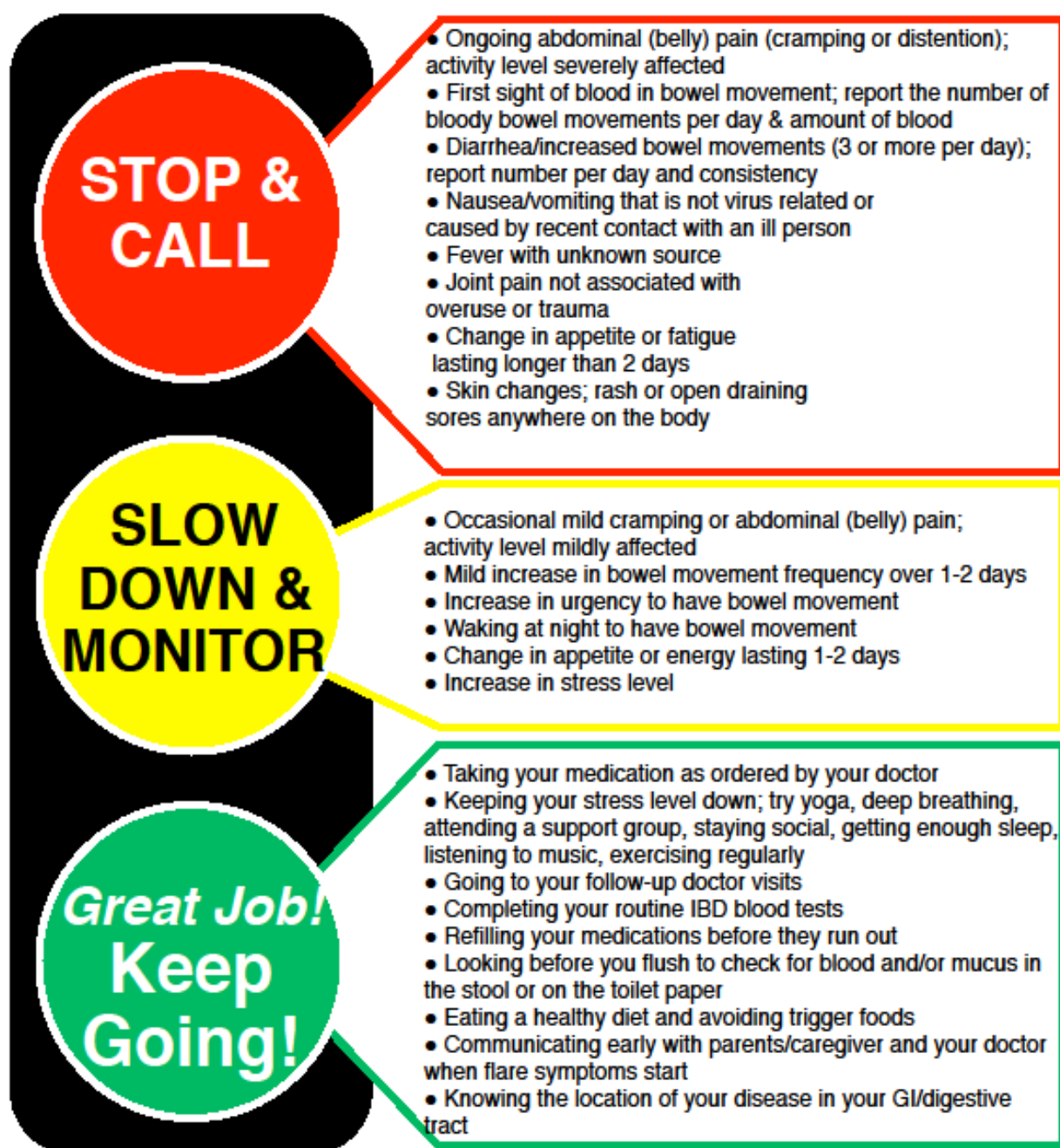
Your nurse may need more information. When your nurse calls back, be ready to talk about:

- Bowel Movements
 - Stool changes
 - Frequency of stools
 - Consistency of stools
 - Presence of blood or mucus
- Pain
 - Location
 - How often does it occur
 - How long does it last
 - What makes it better
 - On a number scale of 1 being mild to 10 being severe
 - Have you taken any medication for the pain
- Fever, what is the child's temperature.
- Review all medications that the child is taking, prescriptive and over the counter or herbals.

The more information you are able to provide, the better! This allows us to quickly make decisions about your child and not have to play phone tag.

IBD FLARE IDENTIFICATION TOOL

Know Your Body's Signals and Stay Healthy!



Note: The above information is to be used as a patient education guide. We encourage you to call our office if you have any questions or concerns.

What to Expect at My Clinic Visit

Write down any questions you may have for your team prior to your visit. This ensures we can discuss with us everything you had questions or concerns about! We are a TEAM and want your visit to involve you and your child as much as your care team!

You will always see your doctor at each visit. You may also see a

- Nurse Practitioner or Nurse Clinician
- Dietician
- Psychologist
- Social Worker

Please let your doctor know if you would like to see any of these people in particular at your visit.

Be prepared to discuss with the nurse, nurse practitioner, or doctor **any and all problems** or symptoms you have been having since your last visit.

Lab work at each visit or infusion

- Complete Blood Count (CBC) – blood count, checks for anemia
- Complete Metabolic Profile (CMP) – electrolytes and liver enzymes
- C-Reactive Protein (CRP) – inflammatory marker
- Sedimentation Rate Erythrocyte (ESR) – inflammatory marker
- Gamma Glutamyl Transferase Level (GGT) – liver enzyme

You may have additional lab work done but we will let you know which additional labs will be drawn.

Health Maintenance

- DEXA (bone density) scan
 - Every 2 years if normal
 - Yearly if abnormal
- Yearly flu shot (not the flu mist)
- Yearly eye exam
- Vitamin levels at least annually
- Annual TB testing depending on your medications

Diet and Nutrition

Once a child has been diagnosed with IBD, it is common to receive advice from family and friends regarding the “best diet” for IBD, or which foods to remove from the child’s diet. IBD is not a diet or food-related illness. **It is a myth that there are foods that cause the disease.** There is no evidence that any food or diet can trigger a flare. Some patients with IBD, however, may find that certain foods worsen their symptoms at times when they are already having an IBD flare. This is called food intolerance. Some patients have food intolerance while others never do. A food journal may be useful to determine whether or not a patient with IBD has any specific food intolerances. If food intolerance is identified, limiting the “trigger” food during a flare may help ease symptoms. It is important to know, however, that it can be unhealthy or even dangerous to remove foods or entire food groups from the diet to try to prevent IBD symptoms. Any potential dietary changes or limitations should always be discussed with the doctor and/or clinic dietitian. Children and adolescents need well-balanced nutrition to grow.

Dietary tips during IBD flares:

- Eat smaller meals at more frequent intervals.
- Reduce intake of fatty, greasy or fried foods.

These foods can cause diarrhea and gas, and can cause the stomach to empty more slowly, leading to nausea or pain. Patients who have had surgical removal of small bowel may be more likely to have these symptoms with fatty foods.
- Avoid dairy if it increases symptoms.

Some people develop an increase in diarrhea and abdominal cramping when they consume dairy products during a flare. This is because of an inability to digest milk sugar (lactose intolerance) when there is active inflammation in the intestines. It is not usually permanent. If this is the case, dairy should be avoided until the flare is under control. Once the disease is in remission, most people with temporary lactose intolerance can tolerate dairy again. Of course, lactose intolerance is common in many people without IBD, especially if it runs in the family. The best way to find out is to try dairy again. It is important to know that lactose intolerance is not the same as a milk allergy. If the patient has a milk allergy, this has nothing to do with IBD, and he or she should not try dairy without discussion with the doctor first.
- Limit intake of high-fiber foods.

Certain foods like nuts, seeds, corn, popcorn, and raw fruits and vegetables contain a lot of fiber. These foods may cause cramping and/or diarrhea because fiber is not fully digested by the small intestine. The extra fiber may not move through the bowel easily when there is inflammation in the intestines. If there is narrowing or stricture in the intestine, a patient may be more likely to have a blockage if nuts, seeds, or popcorn are eaten.



Our goal is to ensure a balanced diet and adequate calories to help with proper growth. We have a dietitian available to assist with any concerns that arise about a child’s diet, growth, and nutrition.

Emotional Health and Social Support

Inflammatory Bowel Disease (i.e. Crohn's disease and Ulcerative Colitis) like any chronic condition, impacts the entire family. Having IBD can be hard at times, and we want to help your family with all the aspects of your life that can be affected by IBD. It can be stressful to have to deal with a chronic illness, come to frequent office visits and remember to have your child take all of his or her medications, all while trying to live a "normal" life. Your child may deal with pain, anxiety, fear, depression, anger, body image changes and other emotions through the course of this condition. These factors are normal for anyone dealing with a chronic illness. Our goal is to support each child and family and teach strategies to cope with these issues as they may arise.

It is important to remember that, if they happen, these reactions are a response to the disease. It is also important to know that most children are resilient and adjust to their new diagnosis as they begin to feel better and as they learn what things help them to manage their disease better.

Sometimes additional help is needed, especially if you are noticing prolonged symptoms of worry or sadness or if your child is having difficulty functioning at home, school, or with friends.

The emotional support provided by healthcare professionals can go a long way toward reassuring your child. At times, a counselor or pediatric psychologist may be helpful in helping your child to regain the self-confidence that can be affected by chronic illness. If it takes much more work for your child to get good grades, keep up with friends, enjoy things they used to, your child may benefit from short term educational and/or psychological interventions.

Our IBD psychologist, **Dr. Margaux Barnes**, is available to meet with you and/or your child to discuss any of these concerns and provide treatment recommendations as needed.



SCHOOL & IBD

The pressures that all students feel during the school year can be magnified when IBD is part of the curriculum. Kids with Crohn's or colitis face additional challenges such as how their disease might affect their grades and their relationships with teachers and classmates. Education and communication can help to ease these concerns.

Resources to Help You Educate and Communicate

- **Crohn's Disease & Ulcerative Colitis: A guide for teachers and other school personnel**
 - A guide to help teachers and other school personnel understand these chronic intestinal illnesses.
 - Ask your teachers, school nurses, & guidance counselor to download this guide. It has information specifically to help them understand IBD, its effect on you, and what they can do to help.
 - Guide located at <http://www.ccfa.org/assets/pdfs/teachersguide.pdf>
- **Taking IBD to School**
 - <http://www.ccfa.org/resources/taking-ibd-to-school.html>
- **Just Like Me: Teens with IBD – School & IBD**
 - Learn more about: Tips for School, Talking to Teachers, School Accommodations
 - <http://www.justlikemeibd.org/life/school/>

Education Accommodation Plans

You have the right to education regardless of the fact that you have IBD, through Educational Accommodation Plans. This right is protected by laws including Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA), and the Individuals with Disabilities Education Act (IDEA). These laws allow the schools to provide any necessary accommodations, from preschool through college.

- **504 Plan:** This is a legal document created between the student, parents, and the school, that lists any of the accommodations needed to address a child's health difficulties. Some accommodations often used with IBD include an unlimited bathroom pass, carrying water/snacks in school, and options for assistance in making up missed work. CCFA.org has a great list of ideas for accommodations* you may need. The first step is to contact the school guidance counselor to request a Section 504 Meeting. They will probably require documentation from the doctor. Please call our office for assistance.
- **Individualized Education Plan (IEP):** This is a step up from a 504 plan, designed to include special education services. This may be more helpful than a 504 if your child is dealing with significant academic difficulties (i.e. failing classes) in addition to health issues. Ask your school guidance counselor for more information.
- **School Letters:** Occasionally when children have frequent absences or a decline in school performance, teachers or administrators may suspect the child is making up or exaggerating symptoms. Often a simple letter from our team explaining the diagnosis of IBD can help them understand and be more sympathetic. This is not a substitute for an accommodation plan, but can save a lot of time and frustration. Let us know at any time if you need such a letter. Also be sure to pick up a school excuse letter at the check-in desk whenever your child misses school for an appointment.
- **Section 504 Plan for Children with Inflammatory Bowel Disease Template & Accommodations* List**
 - <http://www.ccfa.org/resources/template-section-504-plan.html>
- **Doing Our Homework: A Parent's Guide to Education Equity**
 - <http://www.ccfa.org/assets/pdfs/edequity.pdf>

Navigating Children's of Alabama

Clinic 10 (GI Clinic)

5th Floor of the McWane Building
(Park in the 7th Avenue parking deck)

Referred Testing

2nd Floor of McWane Building – walk to the right once you cross the crosswalk from the parking deck

(Park in the 7th Avenue parking deck)

This is where you will go if you have to have lab work done or turn in stool studies outside of your clinic visit. You will have to register in referred testing then they will direct you to lab or take your sample.

Clinic 5 (Infusion Clinic)

1st Floor of the McWane Building
(Park in the 7th Avenue parking deck)

Park Place Infusion

Ground Floor of Park Place
(Park in the 5th Avenue parking deck and take the elevators in the parking deck to the ground floor)

Clinic C – Children's South

It is not common that you will have to go to Children's South. However, if you have an appointment here, it will be in Clinic C which is to the right when you walk in. You are also welcome to have lab work done or turn in stool studies at Children's South, just let me know that this is your preference.

Other places you may have to go ...

Imaging – this would be where you need to go if you are having a MRE or DEXA scan done
Ground Floor of the Benjamin Russell Building (next to the Emergency Department)
(Park in the 5th Avenue parking deck)

One Day Surgery – this where you will go when you have to have an upper endoscopy or colonoscopy done.

2nd Floor of the McWane Building
(Park in the 5th Avenue parking deck)

Peds Rx Pharmacy – we do have an onsite pharmacy if you would like to use it to fill your medications before leaving from your clinic visit

1st Floor of McWane Building
Phone number – (205) 983-8727

Admitting – this would be where you go if you ever have to be admitted to the hospital (and you have not been in the Emergency Department or Clinic 10)

2nd Floor of the Benjamin Russell Building



IMPROVECARENOW

The cure for waiting for the cure!

Children's GI Clinic is an ImproveCareNow Center

What is ImproveCareNow?

A community focused on getting kids with IBD better! ImproveCareNow is a nonprofit growing network of more than 80 pediatric gastroenterology centers spanning 36 states and London, with 765 pediatric gastroenterologists caring for 24,600 children with IBD. These centers are all working together to improve the care and outcomes for kids with inflammatory bowel disease (IBD). ImproveCareNow is a collaborative effort that is working!

Since 2007, the percentage of patients in remission at ImproveCareNow clinics has increased from about 55% to 80% without new medications!

How Does This Collaborative Work?

By sharing data and working together to get better! ImproveCareNow centers collect information* about patients during clinic visits. Information from all of these centers is pooled and studied so that we can understand the best way to treat children with IBD. Knowledge is shared across the network and individual centers receive reports twice a month to review their own performance and compare it to other centers and the entire network.

How Does This Improve Patient Care?

This kind of health network means we all work together – care providers, researchers, patients and families – using scientific data to drive improvements for kids with Crohn's disease and ulcerative colitis. We use the collected data and quality improvement tools to find gaps in care and close the gaps. Pre-visit planning meetings and tools are used to ensure that you get what you need when you come to a clinic visit. **"The result will be more reliable, proactive and individualized pediatric IBD care."**

How Can You Help?

Every patient and every parent is an expert! As a strong family-centered network, ImproveCareNow values the critical role that parents and caregivers play as the people who most intimately understand their children beyond the clinic. To find out more about ImproveCareNow and how together, we can outsmart IBD, please visit http://wwwdev.improvecarenow.org/get_involved

Why bring together a community focused on getting kids with IBD better? Because thousands of children & young adults nationwide fight Crohn's disease and ulcerative colitis every single day. Because every kid deserves the very best chance at remission, normal growth & development, avoiding steroids & finding a treatment that works for them. Because we want them to become their own best health advocate & achieve their goals. And because we know we can do more together than we can alone. There is strength in our numbers!



#GoFullCIRCLE | Let's outsmart IBD, together!

Watch the video at <https://youtu.be/aKy7UN9liMk>

*We will explain further during a clinic visit and ask for your permission to include your child's information in this registry.

Internet and Smartphone Resources

The internet and smartphone apps are great tools for information, research, disease management, and support. With all of the sites available it can sometimes be hard to know if the information you find is trustworthy. We have put together the following list of doctor approved links to trusted online resources or smartphone applications for you to check out.

Internet Links

- CCFA GI Tract Guide: Brand New Interactive Resource gitract.ccfa.org
- Crohn's & Colitis Foundation www.crohnscolitisfoundation.org
- Crohn's & Colitis Foundation Alabama/Northwest Florida Chapter www.crohnscolitisfoundation.org/chapters/alabama
- Empowered by Kids www.empoweredbykids.com
- GIKids: A Resource for Pediatric Digestive Disorders www.gikids.org
- IBD University: A Site for Older Teens with IBD www.ibdu.org
- I'll Be Determined www.ibddetermined.org
- ImproveCareNow www.improvecarenow.org
- ImproveCareNow Exchange is a place where you can pin ideas and see what other parents, patients, and care teams are doing around the ImproveCareNow Network. www.improvecarenowexchange.org
- Just Like Me! Teens with IBD www.justlikemeibd.org
- SmartPatients is an online discussion forum and support community of **parents** and **patients** over the age of 18 who come together to share their experiences IBD. Parents and patients learn from and support each other, and there are no healthcare providers offering medical advice. www.smartpatients.com/communities/ibd
- You and IBD: An Animated Patient's Guide to Inflammatory Bowel Disease www.youandibd.com



Smartphone Apps

- **GI Buddy** (Free for Desktop, iPhone & Android): GI Buddy has everything you need to stay on top of managing IBD. It is designed to help you easily and conveniently track important aspects of your inflammatory bowel disease and create comprehensive views of your health to share with your healthcare team.
- **Toilet Finder** (Free for iPhone & Android): Locate all the toilet facilities around you in a quick glance! Reference includes more than 150,000 toilet facilities! Find restrooms that are free, handicap accessible, and rated 5 stars by other users.



Education Materials, Fact Sheets, & Support Programs

As part of the mission of the Crohn's & Colitis Foundation of America (CCFA) to improve the quality of life for patients living with Crohn's disease and ulcerative colitis, the CCFA Alabama/NW Florida Chapter supplies free educational brochures and fact sheets. These resources provide current information on a variety of IBD topics including treatment, diet and nutrition, surgery, medications, and more.

We are proud to share these valuable educational materials to IBD patients and their caregivers. We have picked a few of CCFA's resources that we feel will be most beneficial to you at this time, and included them in this packet. We have also included the link to the online copy for your convenience.

- The Facts About IBD
- IBD & Me Activity Book
- Crohn's disease & Ulcerative Colitis: A Guide for Parents
- Crohn's disease & Ulcerative Colitis: A Guide for Teachers & Other School Personnel
- Managing Flares & Other IBD Symptoms
- A Guide for Teens with IBD
- Camp Oasis Brochure
- Pill Swallowing Techniques for Kids and Teens Fact Sheet

You can view CCFA's most popular materials and download PDF versions at <http://www.ccfa.org/science-and-professionals/programs-materials/patient-brochures/>. Materials can be ordered (free of charge) online by visiting online.ccfa.org/BrochureRequest.

CCFA also sponsors a number of patient education programs, support groups, special events and youth/family programs including Camp Oasis; a summer camping program for children with IBD. Please visit the Alabama/NW Florida Chapter website for information about upcoming events and programs at www.ccfa.org/chapters/Alabama.

If you have any questions, please feel free to contact Emily Richter at erichter@ccfa.org or (646) 387-2149.

*This mission of the Crohn's & Colitis Foundation of America is to cure Crohn's disease and ulcerative colitis,
and to improve the quality of life of children and adults affected by these diseases.*