

Akron Children's Hospital Gastroenterology Locations

<u>Akron</u>

215 W. Bowery St. Akron, OH 44308

Parking: 199 W. Bowery St.

Beachwood

3733 Park East Dr.

Suite 230

Beachwood, OH 44122

Boston Heights

328 E. Hines Hill Rd. Hudson, OH 44236

Mahoning Valley

6505 Market St. Building A

Boardman, OH 44512

Mansfield

1029 S. Trimble Rd. Mansfield, OH 44907 Marietta

320 E. 8th St. Suite 140

Marietta, OH 45750

Medina

3443 Medina Rd. Suite 108, Door 1 Medina, OH 44256

North Canton

6076 Whipple Ave. NW

Suite 29

Warren, OH 44438

Warren

5000 E. Market St

Suite 29

Warren, OH 44438

Wooster

3807 Friendsville Rd. Wooster, OH 44697

Infusion Center Locations

Akron

215 W. Bowery St. Akron, OH 44308

Parking: 199 W Bowery St.

Mahoning Valley

6505 Market St. Building A

Boardman, OH 44512

Please Note:

All appointments are made by calling the main line: (330) 543-4488



WELCOME to the IBD TEAM

Welcome to our team! In this book, you will find some helpful information to introduce you to IBD and available services at Akron Children's Hospital and beyond.

Please feel free to ask any questions or concerns with our team. Our goal is to offer the most current, up to date and evidence-based treatment plans. Our mission is to support you, guide you and keep you safe as we embark on your future journey with IBD, living with IBD.

Our team has board certified gastroenterology physicians, nurse practitioners, psychologist, nurses, dieticians, social worker and ancillary staff. We look forward to participating in your future care.

Reinaldo Garcia, MD Division Director Akihiro Asai, MD, PhD

Amanda Abou-Fadel, MD Katherine Lamparyk, PsyD

Christine Carter-Kent MD Breaunna Haynes, APRN-CNP

Shivani Gupta, DO Dawn Keilin, APRN-CNP

Sameer Imdad, MD Melissa Lukes, APRN-CNP

Christine Pasquarella, MD Gabrielle Miladore, APRN-CNP

Corey Scherer, DO Stephanie Mullin, APRN-CNP

Carolyn Vespoli, MD Danielle Theaker, APRN-CNP

Kevin Watson, MD Angela Dine, Clinical/ Operations Manager

Matthew Wyneski, MD



NURSING STAFF

- The nursing staff is comprised of 9 Registered Nurses. We assist with procedures, appointments, teach, and take part in telephone triage and communication with patients and families.
- The telephone number to speak to a nurse is 330-543-4488, press option 4. The hours of operation are M-F 7:30 a.m.-4:30 p.m. You may speak to more than one nurse regarding any given issue. Each RN is able to view each child's medical information.
- You may need to leave a voicemail. Please spell your child's first and last name, date of birth, state your name, relationship, and the best telephone number where you may be reached. If there is a better time to call you back, please also leave this information.
- The nurse will gather information from you to send to the provider regarding your questions and concerns. As soon as the provider sends an answer to the nurses, the nurse will call you. This may not be the same day. If the provider you see is not on hand, your message will be sent to another provider.
- You may also talk with us through MyChart. MyChart is to be used for non-urgent messages only. You
 may view lab and test results on MyChart that are performed at Akron Children's Hospital. Lab results
 from an outside facility will not appear in the patient's MyChart account. Also, it may take longer for us
 to get results if labs are done at an outside facility.
- We are unable to leave a voicemail with information on your voicemail due to privacy laws. If your child is 18 or over, a signed release must be in the chart to share information with a parent, guardian, or loved one. The Release of Information form is on the Akron Children's Hospital website or can be signed in the office. You may return this release via MyChart, fax, email at ginurses@akronchildrens.org or in person at any Akron Children's location. It is valid for one year.
- Medications will only be refilled by calling the office during business hours:
 Monday-Friday: 7:30 a.m.-4:30 p.m. Please allow 72 hours for processing prescription refills and all paperwork to process
- If your child is starting a "biologic medication," (which is a special type of medication), it may take 4-8 weeks to get insurance approval.
- If you have any billing questions, please call customer service at 330-543-8500.

Welcome and we look forward to working with you!



IBD NUTRITION SERVICES

- There are 2 dietitians in the department of Pediatric Gastroenterology.
- All of the dietitians at Akron Children's Hospital are registered and licensed dietitians.
- A dietitian will complete an assessment of growth. Then, medications will be reviewed
 and any side effects of medications which may affect nutrition. Dietitians can review
 labs for any deficiencies and help to provide education to correct these. There is not a
 specific diet for IBD but there are diet changes which can be made to help with
 symptoms as well as plans to help with concerns for weight loss. All
 recommendations are reviewed with the patient's provider.
- Often appointments are scheduled with the dietician at the same time as the provider visit to discuss concerns and goals. Then all questions can be answered in one visit.
 Appointments may be scheduled with a dietician by calling the Gastroenterology office during business hours: Monday-Friday: 7:30 a.m. – 4:30 p.m.





IBD SOCIAL SERVICES

Social work services are in the Gastroenterology Clinic Monday through Friday from 8:00 a.m. to 4:30 p.m. Social work can meet with you during clinic appointments or infusion appointments.

This is a list of services:

- Provide psychosocial assessments and interventions. Create and carry out a care plan.
- Provide counseling services to assist in coping with diagnosis. Develop plans to help with noncompliance issues.
- Advocate for patient and family needs about ongoing care, special need requirements, and added supports.
- Share referral services in the community (Board of Developmental Disabilities, public assistance).
- Help the patient and family with a 504 plan with the school. Also work with the school to help the school understand the needs of the patient.
- Explain the CMH program. Also, ability to access the CMH portal to review diagnosis eligibility for the program and check the progress of the application.
- Coordinate care plan with all Children Services Agencies about foster placement, kinship placement, custody changes, group home settings, and court orders. Work with the case workers to make sure medical care is not affected due to changes in the child's placement.
- Confirm clear legal guardian status due to divorce, death of a caregiver, incarceration, etc. Able to review records to make sure the patient's legal guardian is giving permission to treat the child.
- Work with the family to explain Medicaid transportation services to all medical appointments and able to help with cab rides and gas cards when needed.



YOUR HEALTH CARE TEAM

As a parent, you are part of the team that will take care of your child. Depending on your child's needs and the staff at your hospital and/or clinic, any of the following people may be part of your health care team.

ATTENDING PHYSICIAN

A doctor who has completed medical school and further training in residency and fellowship and now specializes in Gastroenterology. The attending physician directs and supervises the medical care of your child.

CHAPLAIN

A person who is trained to offer spiritual care, support and prayer according to each family's individual needs.

A CHILD LIFE SPECIALIST

A person who has special training in child development and how children react to illness and being in the hospital. A child life specialist helps children to cope with these issues.

CLINICAL NURSE SPECIALIST/NURSE PRACTITIONER

A nurse who has completed an advanced degree program and specialty training in caring for children. The nurse practitioner or clinical nurse specialist may coordinate the medical and nursing care for your child.

CLINICAL RESEARCH ASSOCIATE

A person who is trained to keep track of data related to your child being enrolled and treated on a clinical trial.

DIETITIAN

A person who is trained to evaluate your child's nutritional needs and weight. The dietician also helps to provide teaching and support about eating and drinking when your child goes home.

FELLOW

A doctor who has completed medical school and a residency and is now receiving specialty training in pediatric Gastroenterology.

HOUSE OFFICER/RESIDENT

A doctor who has completed medical school and is now receiving specialty training.

MEDICAL STUDENT

A college graduate who is receiving training to become a doctor.

NURSE

A person who is trained to care for patients during illness and to assist them in regaining and maintaining health. Nurses provide daily nursing care and health education to children and their families in the hospital or clinic.

PHARMACIST

A person who is trained to prepare the medicines and nutritional support that your child will need. The pharmacist may also explain how medicines are to be given.

PHYSICAL/OCCUPATIONAL/SPEECH THERAPIST

A person who works with your child to maintain or restore a level of fitness and the ability to perform activities of daily living or helps with improving speech.

PHYSICIAN ASSISTANT

A person who is trained to assist the physician in coordinating and providing your child's medical care.

PSYCHIATRIST/PSYCHOLOGIST

A doctor or trained specialist who is available to help you and your child cope with feelings. This person may also perform testing to see if your child has learning problems.

SCHOOL TEACHER/LIASON

A teacher who works in the hospital to help your child keep up with schoolwork during the hospital stay. The teacher can also keep in touch with your child's teacher at home.

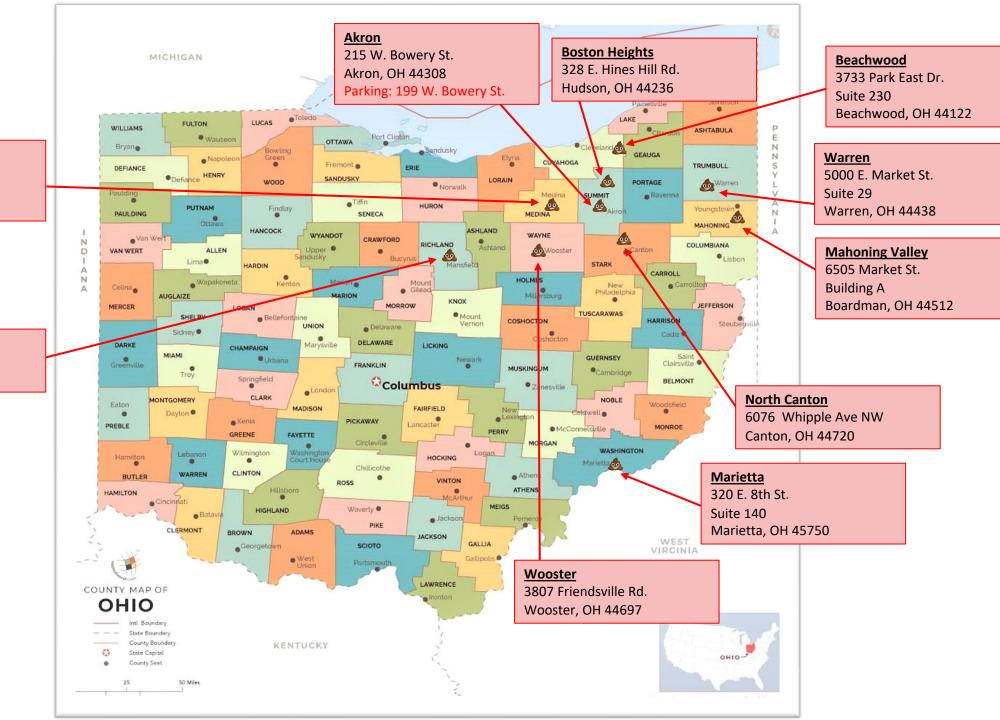
SOCIAL WORKER

A person who is trained to help you and your child cope with illness and hospitalization through counseling, support groups, financial assistance and resource referral.

VOLUNTEER

An unpaid person who is trained to help with non-medical activities.





Medina

Mansfield

1029 S. Trimble Rd.

Mansfield, OH 44907

3443 Medina Rd.

Suite 108, Door 1

Medina, OH 44256

Understanding Inflammatory Bowel Disease (IBD)

What You Should Expect From Us

- To provide you with basic information about IBD
- To explain the specifics of your disease
- To answer your questions

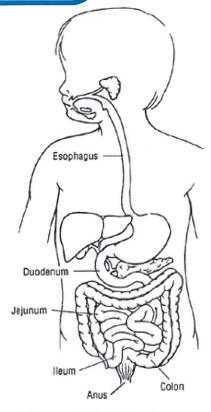
What We Expect From You

- To have a basic understanding of IBD
- To have a basic understanding of your disease
- Ask questions

Why This is Important

Basic knowledge about inflammatory bowel disease will help you better understand your disease and help you recognize your symptoms. This is very important in managing your disease.

Inflammatory bowel disease (IBD) is a chronic inflammation (irritation) of the intestines that is not due to infection. In IBD, the immune system overreacts and leads to injury of the intestines. There are two main types of IBD: Crohn's disease and ulcerative colitis. Crohn's disease can involve any part of the intestine from mouth to bottom. Ulcerative colitis usually involves only the large intestine (colon).



The gastrointestinal system inside the body.

It is estimated that over 1 million Americans suffer from IBD. IBD occurs in both children and adults. Males and females are affected about equally. IBD is thought to be caused by a combination of both genetic and environmental factors which lead to injury of the intestines. There is a lot of research being done to better understand IBD. Do not confuse IBD with irritable bowel syndrome (IBS). Although the symptoms of IBS are sometimes similar to those of IBD, the disorders have very different causes and treatments.

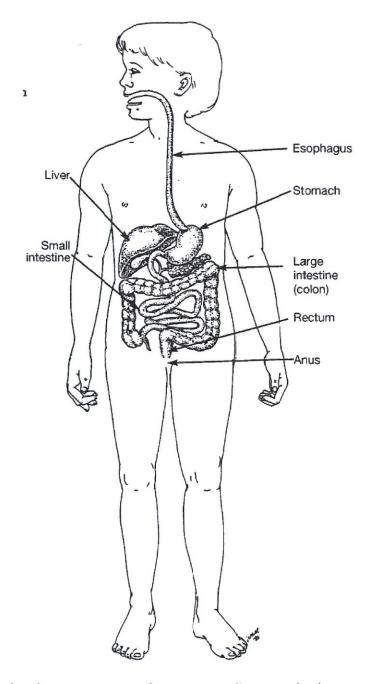
Signs and Symptoms of IBD May Include:

- Abdominal pain
- Diarrhea or bloody bowel movements
- Weight loss or poor growth

- Fatigue/ Decreased energy level
- Unexplained fevers, joint pains, or mouth sores
- Anemia (low red blood cell count)

Your IBD: Where it is Located in Your Body

Diagnosis:



When you meet with the doctor or nurse after you are diagnosed, please ask them to tell you the location(s) of your disease. Use the diagram above to mark the areas of your body that are affected. This diagram can be updated if there are any changes in your disease.



IBD GUIDELINES:

Call **9-1-1** or Emergency Medical Services if you feel your child is in immediate danger

WHEN TO CALL US FOR HELP:

- Change in stools such as stools that become loose, watery, changes in blood in the stool, urgency, up at night to stool for more than one day
- Increased number of stools per day for more than one day
- Nausea for 5-7 days in a row
- Decreased appetite for 5-7 days in a row
- Sudden weight loss of 10 pounds or more in 5-7 days
- Joint, eye or skin irritation, for 5-7 days in a row
- Rashes lasting more than 24 hours
- Mouth sores lasting more than 24 hours

CALL YOUR PROVIDER IMMEDIATELY WHEN:

- Fever of 100.4 F or greater if on immunosuppression medications
- Vomiting is yellow, green or bloody
- Direct exposure to Chickenpox or Shingles occurs



HOW TO CONTACT US:

Weekdays: 330-543-4488 or toll free 1-800-262-0333 (ask for GI clinic)

Evenings, weekends, holidays 330-543-1000 or 1-800-262-0333 ask the hospital operator to page GI provider on call.

MEDICATION REFILLS/PAPERWORK:

- Medications will only be refilled by calling the office during business hours:
 Monday-Friday: 7:30 a.m.-4:30 p.m. Please allow 72 hours for processing.
- Please allow 72 hours for processing paperwork.



IBD LAB TESTS

This page is a list of common lab tests your provider may order and why these tests are ordered. Other lab tests may be ordered by your provider.

<u>CBC (complete blood count)</u>—anemia (low blood count), infection, inflammation

BMP (basic metabolic panel)/CMP (compete metabolic panel) - electrolyte balance, dehydration (fluid loss), renal (kidney function), liver function, medication side effects

<u>Hepatic Panel</u>—liver function, medication side effects

GGT (gamma-glutamyl transferase)—
medication side effects or irritation to the
bile ducts

<u>ESR (sedimentation rate)</u>—non-specific inflammation

<u>CRP (C-reactive protein)</u>—non-specific inflammation

Iron Studies—iron deficiencies

<u>Vitamin B12 or Folate</u>—anemia (low blood count), nutritional status

Vitamin D—bone health

Quantiferon Gold—Tuberculosis screening

<u>Calprotectin</u>—stool study for intestinal inflammation

<u>Lactoferrin</u>—stool study for intestinal inflammation

Stool Culture—stool study for intestinal infection

Stool O & P (ova & parasite)—stool study for parasites

<u>Gastro-intestinal Panel Film Array</u>—stool study for various stool infections

Acute Hepatitis Panel/Hepatitis B Ag/Ab—immunity to Hepatitis B and active
Hepatitis B disease

Varicella IgG (chicken pox IgG antibody titer)--immunity to Chickenpox

Antibodies and medication levels--testing for patients on certain types of medications, measured from time to time

<u>PPD (purified protein derivative)</u>—skin test for Tuberculosis. Must be read 48-72 hours by a medical professional after placement



IBD X-RAY TESTS

Below is a list of common radiology tests your provider may order. Other radiology tests may be ordered by your provider.

Abdominal/Belly X-ray (KUB)-This is an x-ray test to look at the organs and structures in the abdomen. Organs include the stomach, liver, spleen and intestines.

<u>Abdominal/Belly Ultrasound-</u>High frequency sound waves create pictures of body organs and structures in the abdomen.

CT or CAT Scan (computed tomography)-The CT scanner uses x-rays that pass through the body to create computerized images of bones and organs.

<u>DEXA Scan or Bone Density (bone</u> <u>densitometry)-</u>A scan that measures bone health. HIDA Scan (hepatobiliary san)-This scan is a nuclear scan to diagnose liver, gallbladder and bile duct issues.

MRI (magnetic resonance imaging)/MRE (magnetic resonance elastography)-This test takes pictures of the inside of the body using magnetism and radio waves. It makes more detailed pictures than x-rays.

<u>UGI-</u>(upper gastrointestinal imaging)-This test examines the upper digestive tract. Because these organs are not seen on x-rays, barium liquid needs to be swallowed at the start of the test.





IBD PROCEDURES

Below is a list of common procedures your provider may order. Other procedures may be ordered on an individual basis.

<u>Upper Endoscopy (EGD)-</u> An EGD is a test done to examine the lining of the esophagus, stomach and duodenum (first part of the small intestine). The exam is done with a bendable tube called a scope which has a light and a camera on the end. The physician will look for redness, swelling, bleeding, ulcers or infections and will collect small tissue samples called biopsies to be looked at under a microscope.

<u>Colonoscopy</u>- A colonoscopy is done to examine the colon (large intestine). The exam is done with a bendable tube called a scope which has a light and a camera on the end. The physician will look for redness, swelling, bleeding ulcers or infections of the bowel wall and will collect small tissue samples called biopsies to be looked at under a microscope.

<u>Both the EGD/Colonoscopy are done under general anesthesia</u>. The goal is to gain a better understanding of the disease. Most often, these procedures are done outpatient and the patient will return home the same day.

<u>Pill Cam-</u> A capsule endoscopy, also known as a Pill Cam, is a test done to look at the esophagus, stomach and small intestine. The procedure most often involves swallowing a capsule the size of a large vitamin pill. If not able to swallow, it may be placed with endoscopy. The capsule has its own camera. As it tracks through the intestines, pictures are sent to a recorder that the patient wears on their waist. About 12 hours after the capsule is swallowed, it will stop recording. The pictures will then be uploaded to a computer and reviewed. The Pill Cam capsule will pass in a bowel movement. This procedure is done in the Outpatient Clinic unless an endoscopy is used for placement.

MyChart



MyChart gives you secure 24/7 access to your family's health information.



Schedule an appointment



See & print immunization records



Request prescription refills



View clinical, lab & radiology results



Ask your provider a question

Let us help you get started using MyChart today.

With MyChart, you get 24/7 access. Download the mobile app. Visit akronchildrens.org/mychart



MyChart gives you secure 24/7 access to your family's health information.

Signing up is easy! Complete the enrollment form and return it to our office staff.

We're here to help

For questions about how to log in and use MyChart:

Call 330-543-4400 Email mycharthelp@chmca.org





Your MyChart TEMPORARY PASSWORD is:

Once you log in at home, we strongly encourage you to change your temporary password for security purposes.





Financial Services

We understand that navigating medical billing and insurance information can be overwhelming. That's why we make every effort to simplify this process, so you can focus on your child's health, and not on paperwork.

We will directly bill your insurance company or government agency for services your child receives at Akron Children's Hospital. We'll also notify you when we receive payment from your insurance company.

You may pay your bill (co-insurance, deductibles or balances) online, or by cash, check or credit card.

Call 330-543-8500 for questions.

We know medical billing can be confusing and overwhelming, and we're here to help answer your questions.

If you'd like to speak to a financial counselor, call 330-543-2455.

A financial counselor can help you determine whether you qualify for public assistance programs to help you with your medical bills.

When you don't have insurance coverage or are underinsured, our financial counselors will assist you in applying for government-sponsored health insurance or other third-party insurance; applying for free or discounted medical care (based on family income and size); and establishing a payment plan.

For an appointment with a financial counselor, call 330-543-2455.

Please bring the following documentation to your appointment with a financial counselor:

- Driver's license or valid ID
- Utility bill for proof of address
- Pay stubs from the previous month
- Proof of pregnancy (if applicable)
- Health insurance information (if applicable)
- Social security numbers for all family members

Akron Children's Hospital is dedicated to providing medical care to infants, children, teens and burn victims of all ages, regardless of their ability to pay.



Financial Services (Continued)

Purpose

We have prepared the following Plain Language Summary of Akron Children's Hospital's financial assistance policies in part:

- to inform patients and their responsible parties of the financial assistance programs and policies we
 offer
- to be compliant with the Treasury Department and the Internal Revenue Service Section 501(r)(3); 501(r)(6)

Financial Assistance Program

Akron Children's Hospital (Children's) is committed to providing quality care to the patients we serve, regardless of ability to pay. Children's complies with the Emergency Medical Treatment and Labor Act (EMTALA), and the Joint Commission requirements relative to the provision of emergency medical treatment regardless of financial circumstances or their qualification under this Financial Assistance Policy. Furthermore, Children's will not discourage individuals seeking emergency medical treatment and medically necessary care by requiring payment prior to treatment or permitting debt collection activities that interfere with the provision of emergency medical care.

Children's offers a robust Financial Counseling Program to assist families in obtaining third-party coverage including commercial insurance, Medicaid, and other state and local programs. Where there is no coverage available Financial Counseling will assist with pursuing eligibility for financial assistance. Financial assistance will be based upon residence, family income, and size for those patients who are uninsured or underinsured. Financial assistance will be extended only after all available third-party resources have been exhausted or the patient is ineligible for third-party benefits.



Medical Records

Our Health Information Management department processes, stores and retrieves patient medical records. Current patients may also access their health records through MyChart. To sign up for MyChart, request an enrollment form at your next appointment.

How to request medical records:

To request a copy of your medical record or your child's record for personal use, please send a signed authorization form or a handwritten request to:

Akron Children's Hospital	or Fax form to:	or email form to:
Health Information Management	330-543-5060	records@akronchildrens.org
One Perkins Square		
Akron, OH 44308		

Be sure to include the patient's full name, date of birth, the specific records requested, and treatment dates. Also include your name, address, phone number and relationship to the patient. All requests must be signed and dated. We must have a written request to release any records.

Additional fax information:

- Patients, parents, guardians and third party requesters: 330-543-5360
- Healthcare professionals: 330-543-3886

Copies for doctors and other care providers are free, otherwise customary charges will apply.

Call Health Information Management at 330-543-8552 for more information.



Medical Coping Clinic

Managing a chronic illness can be a challenge for children and their families. To help, Akron Children's Hospital has a Medical Coping Clinic in the Division of Psychiatry and Psychology.

Our psychologists work closely with your medical team to help you and your child manage their chronic illness. They are available to help your family cope with a new diagnosis, improve daily management of a disease and address barriers to treatment including stress, mood and anxiety.

To schedule an initial appointment:

Please contact the Pediatric Division of Psychiatry and Psychology at (330) 543-5015.

After listening to the options, press "1" and ask for an appointment in Medical Coping Clinic.



GASTROENTEROLOGY SCHOOL ATTENDANCE INFORMATION

School excuses will only be given for appointments, scheduled tests and procedures.

Below are the new school attendance laws for the state of Ohio. They are split into groups of excessive absenteeism and habitual truancy.

Excessive absenteeism is now defined as 38 or more hours in one month with or without a valid excuse or 65 or more hours in one school year with or without a valid excuse.

Habitual truancy is now defined as 30 or more hours in a row with or without a valid excuse or 42 hours in one month or 72 hours in one school year.

A website is listed below for more information: education.ohio.gov/getattachment/Topics/Data/House-Bill-410-FAQ.pdf.aspx



SCHOOL ACCOMMODATIONS FOR IBD

SCHOOL ACCOMMODATION (504) PLAN & INFLAMMATORY BOWEL DISEASES (IBD)

The symptoms of inflammatory bowel disease (IBD) can be unpredictable and may vary in severity. Students may need help to ensure they can be successful in school. IBD and treatments may affect school attendance or academic performance. Children may miss school for medical appointments, illness, disease flare-ups and side effects of treatment. However, students are still responsible for learning and completing their schoolwork. To help students with IBD achieve their academic goals, it is important to have a school accommodation plan in place. This accommodation plan is commonly known as a 504 Plan. The Crohn's & Colitis Foundation of America (CCFA) recommend that all students with IBD have a plan in place at the beginning of the school year, even if they are feeling well. IBD is a disease in which symptoms change over time. Your child can be symptom free (in remission) and doing well at the beginning of the school year, but may experience active symptoms (flare-up) later in the school year. Just because you have a plan in place, does not mean you must use all of the accommodations.

What is a 504 Plan?

Section 504 is the part of the Rehabilitation Act of 1973 which applies to persons with disabilities. Section 504 is a civil rights act which protects the civil and constitutional rights of persons with disabilities. A "504 Plan" is an action plan developed by the school, the parents/guardians and the student. The plan attempts to provide accommodations to and prohibit discrimination against students with disabilities, so that they may achieve their academic goals. It also contains a list of accommodations, or adjustments which may be required by a child with IBD to ensure that they are treated fairly and have the same access to education as other students. This law typically applies to public schools - but can also apply to private schools, if the school receives federal funding.

What is an IEP?

The Individualized Educational Plan (IEP) is a plan or program established for a child who has an intellectual or learning disability and requires specialized instruction and related services. For students who require specialized instruction, the Individuals with Disabilities Education Act (IDEA) controls the procedural requirements, and an IEP is developed. The IDEA process is more involved than Section 504 of the Rehabilitation Act and requires documentation of measurable growth.

What is the difference between an IEP and a 504 Plan?

If a student has an IEP for special education, AND the student also has IBD, the 504 accommodations for IBD will be incorporated into the IEP.

Does a medical diagnosis of an illness automatically mean a student can receive services under Section 504? No. The illness must be chronic and cause a substantial limitation on the student's ability to achieve their academic goal and impact at least one major life activity.

What types of accommodation can be helpful for students with IBD?

- Unlimited restroom access
- Stop-the-clock-testing
- Options to make up missed class time for medical appointments and illness without penalty
- Tutoring after a specific period of absence due to disease flare up
- Full participation in extracurricular activities even after classroom absences



CHILDREN WITH MEDICAL HANDICAPS APPLICATION (Previously known as BCMH)

Oftentimes medical evaluations can be costly, even with insurance. Sometimes families have copays or deductibles that need to be met. If you are worried about this, there is a program that could help, called CMH.

If you want to apply, please read below for more information:

- CMH is insurance for children who are being tested for and/or diagnosed with certain medical conditions (i.e. Crohn's Disease, Ulcerative Colitis, Reflux, Celiac Disease, and many others).
- There are two parts to the CMH program
 - Diagnostic: This part covers diagnostic testing for children who are suspected
 of having certain medical conditions. It will cover visits with the provider, lab
 work, genetic testing, and radiology tests (MRI, X-ray, bone age) during a
 diagnostic period.
 - Treatment: If your child is diagnosed with an eligible medical condition, you
 can then apply for this part of the CMH program. This part covers the
 treatment needed for certain medical conditions. It will cover visits with the
 provider, prescription medications, lab work, and hospitalizations related to
 the diagnosis.
 - Please note there are financial eligibility standards for the treatment part of the CMH program. You will need to fill out a financial packet that CMH will send to you once you apply.
- If you have insurance (private or Medicaid), CMH acts as a secondary insurance to help with co-pays and deductibles, as well as some treatments not covered by your primary insurance.
- If you lose your insurance, CMH will become your child's primary insurance for anything related to the diagnosis.
- CMH is through the Ohio Department of Health and financial eligibility standards are quite high to help the greatest number of families. It is always recommended to apply to see if you qualify.
- CMH is renewed yearly and covers children ages birth to 21 years of age.
- CMH is an accepted insurance at most retail pharmacies and DMEs' (durable medical equipment suppliers). Make sure you check with your pharmacy/DME with questions.
 The only mail-order pharmacy currently contracted with CMH is Caremark.
- There is no cost to use this program.



Financial Assistance Programs for Medications

Many pharmaceutical companies provide assistance to patients who need financial support to pay for IBD medications. Some medications have Co-Pay Card Programs available as well. Please note - eligibility varies from program to program so please check the guidelines carefully.



https://avsolasupport.com

1-866-264-2778



https://www.entyvio.com/ financial-support

1-844-368-9846



https://www.abbvie.com /patients/patientassistance.html

1-800-448-6472

https://www.humira.com/ humira-complete/costandcopay?cid=ppc_ppd_ggl_h umira_complete_humira_c opay_card_Exact_64N1938 516



https://portal.trialcard.co m/sandoz/hyrimoz/

1-833-497-4669



https://inflectra.pfizerpro. com/support-andresources/reimbursementand-support

1-844-722-6672



http://www.jjpaf.org/

1-800-652-6227

https://www.janssencarep ath.com/sites/www.jansse ncarepath.com/files/remic ade-savings-programoverview.pdf

1-877-227-3728



https://www.organonacce ssprogramrenflexis.com/hcp/financia l-assistance/

1-866-847-3539

https://www.organonacce ssprogramrenflexis.com/hcp/copayassistance-program/



https://www.rinvoq.com/r esources/save-on-rinvoqcosts

1-800-274-6867



https://www.skyrizi.com/s kyrizicomplete/landing/crohnsways-to-save

• 1-866-759-7494



http://www.jjpaf.org/

1-800-652-6227

https://www.janssencarep ath.com/sites/www.jansse ncarepath.com/files/stelar a-savings-programoverview.pdf

1-844-494-8463



https://www.xeljanz.com/ savings-and-support

1-844-935-5269

FLYING HORSE FARMS



WHO WE ARE

Flying Horse Farms provides magical, transformative camp experiences for children with serious illnesses and their families—free of charge. Located in Mt. Gilead, Ohio, camp first opened its gates in 2010 and hosts about 900 children and families each year.

We are a registered 501(c)(3) nonprofit organization. 100% of our year-round operating budget of \$4.9 million is underwritten by the generosity of others. We are funded by gifts from individuals, corporate partners and foundations.

Flying Horse Farms is the first camp in the Midwest to become a full member of the SeriousFun Children's Network. Founded in 1988 by actor, philanthropist and Ohio native Paul Newman, the Network is a community of independently managed and financed camps and programs creating opportunities for children with serious illnesses and their families. The Network has evolved from one camp to a global community serving over one million children and families across five continents.



We serve children ages 8 to 17 and their families, from across Ohio and beyond.

The children have medical conditions including cancer, heart conditions, rheumatoid arthritis, blood disorders, asthma, gastrointestinal disorders and facial anomalies.

We have partnerships with eight Ohio children's hospitals—Akron Children's Hospital, Cincinnati Children's Hospital Medical Center, Cleveland Clinic Children's, Dayton Children's Hospital, Mercy Children's Hospital (Toledo), Nationwide Children's Hospital (Columbus), ProMedica Toledo Children's Hospital and University Hospitals Rainbow Babies & Children's Hospital (Cleveland)—as well as Children's Hospital of Pittsburgh.

BY THE NUMBERS

\$0 Cost to campers and families

1 Mind-blowing, adrenaline-pumping, gravity-defying, soul-lifting high-ropes course

- 4 Teepees teen campers sleep in for one night of camp
- 6 Weeklong camps every summer
- 8 Weekend camps every spring and fall
- 12 Cabins stocked with bunks and homemade guilts
- 15 Medical volunteers living at camp every weeklong session
- 70 Campers attending every weeklong session
- 850+ Campers and family members served every year
- 1,800+ Camp and event volunteers give their time to change lives every year









LET'S CONNECT!

FlyingHorseFarms.org









Camp Oasis



A Fun Place for Learning, Playing, and Healing

Dealing with inflammatory bowel disease (IBD) as a child is even more challenging. That is why the Crohn's & Colitis Foundation (http://www.crohnscolitisfoundation.org/about/) proudly established Camp Oasis over a decade ago. This co-ed residential summer camp program enriches the lives of children with Crohn's disease (http://www.crohnscolitisfoundation.org/whatare-crohns-and-colitis/what-is-crohns-disease/) and ulcerative colitis (http://www.crohnscolitisfoundation.org/what-are-crohns-and-colitis/what-is-ulcerative-colitis/) by providing them with a safe and supportive camp community. Watch our video (https://www.youtube.com/watch?v=zzzrSUeMdNw) and see what your children can experience.

A Life Changing Experience

Since all of the campers (and many of the adults) at Camp Oasis are living with IBD, our supportive community allows them to:

- · See that they are not alone
- · Try all sorts of new sports and activities
- · Create friendships with people who truly understand them
- · Gain confidence and independence
- · Put aside their troubles, and just be a kid

Outstanding Medical Care

Our volunteer physicians, nurses, and other health care professionals (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/safety-medical-care.html) are available for 24-hour care, and work to ensure campers follow the regimen prescribed by their doctors back home.

A Quality Program

Camp Oasis was built upon the highest standards of care, and offers activities that appeal to every taste:

- · Visual and performing arts
- · Land and water sports
- · High ropes and other outdoor adventures
- <u>Leadership development</u>
 (http://www.crohnscolitisfoundation.org/ge t-involved/camp-oasis/leaders-intraining.html) (for our oldest participants)



Our schedule also allows your children plenty of time to relax, get to know one another, and share the best medicine of all — laughter!

Dedicated Staff

The Foundation carefully screens and trains all volunteer staff (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/volunteer-support/) — many of whom are adults also living with IBD. These responsible and empathetic individuals work hard to ensure that every camper feels safe, comfortable, and has the time of their lives.

Apply Today!

Remember, you and your child are not alone in the IBD desert. Find a Camp Oasis nearest (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/find-a-camp/)

Camp Oasis FAQ

What are the dates of Camp Oasis?

Sessions run throughout the summer. Visit find a camp (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/find-a-camp/) to learn more.

Where is Camp Oasis located?

There are a total of 12 Camp Oasis locations throughout the country. Please visit find a camp (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/find-a-camp/) to find the one closest to you.

How is camper eligibility determined?

Any child with medically stable Crohn's disease (http://www.crohnscolitisfoundation.org/what-are-crohns-and-colitis/what-is-crohns-disease/) or ulcerative colitis (http://www.crohnscolitisfoundation.org/what-are-crohns-and-colitis/what-is-ulcerative-colitis/) is invited to apply. Campers can only attend one Camp Oasis session a summer. Campers should apply only to the location that serves their chapter or region. If your child is unable to attend the camp in your designated area due to medical or other reasons, please contact your local chapter (http://www.crohnscolitisfoundation.org/chapters/) to explore other options.

Age requirements, capacity, session dates, and application deadlines vary by site. See find a camp (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/find-a-camp/) for more information.

What is the LIT Program?

The Leaders in Training (LIT) Program (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/leaders-in-training.html) is a special leadership development program for camp's oldest teenagers. It runs for the duration of each session, and combines the fun of camp with additional age-appropriate responsibilities and leadership building activities. On a typical day, LITs might attend a leadership meeting, assist with a special activity, help entertain a group of younger campers, and participate in several camp activities alongside their fellow campers. The age range for the LIT Program varies by site, so please visit find a camp (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/find-a-camp/) for more information.

Is there on-site medical care?

Each camp is equipped with a 24-hour on-site health center, staffed by physicians, nurses, and mental health professionals experienced in working with IBD patients. Careful steps are taken to ensure that campers follow the medical regimen prescribed by their doctors back home.

How does Camp Oasis select its staff?

Many of the staff at the Camp Oasis sites are adult volunteers (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/volunteer-support/)with IBD, who have experience working with kids. Many have worked at Camp Oasis before, and some have even been campers. All are carefully screened and trained to ensure a safe and comfortable setting.

What do campers do all day?

The typical camp day starts around 8:30AM and ends at approximately 9:30PM, though bedtimes vary by age. The daily schedule usually includes several activity periods (swimming, arts and crafts, team sports, etc.) and an Evening Activity (campfire, Talent Show, Scavenger Hunt, etc.), as well as three meals, a snack, a rest hour, and time for showering and cabin clean-up.

How does the camper application process work?

First, complete the online application for your chosen location via the find a camp (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/find-a-camp/) page. (*If you completed an online application in the past, you must still complete an application each year you wish to attend. Most of the fields will be pre-populated to reflect the information you supplied previously, so you will only need to update it as necessary.)

Once you have submitted the online portion of the application, you will receive a confirmation email containing additional hard copy forms which must be downloaded, completed by the designated parties, and then submitted to the Foundation's National Camp Office.

Applications must be received by the specified deadline, and are only considered complete once all of the required hard copy forms have been received.

Each complete application will be reviewed by a designated medical professional to confirm the camp is equipped to care for the child. Applicants for the LIT program will undergo an additional review, related to their separate 1-page LIT Application and phone interview, to determine whether the child has the qualities necessary for this more specialized program.

Parents will be notified by email as soon as the review process is complete, and will be provided additional camp information as applicable.

For a visual explanation of the camper/LIT application process please view the Camper/LIT Application Process Flowchart (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/documents/Camp_Oasis_CamperLIT_Application_Process_Flowchart.pdf).

Is there a fee to attend camp?

Yes, there is an attendance fee. Scholarships are available to those who qualify. To apply for a scholarship, simply fill out the scholarship form located within the application. Additional information regarding the attendance fee and scholarship program can be found here: Camp Oasis Attendance Fee & Scholarship FAQ (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/documents/camp-oasis-attendance-fee.pdf)

How do I donate?

If you would like to make a donation to Camp Oasis you can do so online (http://www.crohnscolitisfoundation.org/get-involved/donate-to-ccfa/) or over the phone: (646) 943 - 7480.

How can I stay in touch with my camp friends in the off-season?

A great way to keep in contact and get together with your Camp Oasis friends is by creating a Take Steps Camp Oasis Team (http://www.crohnscolitisfoundation.org/get-involved/take-steps.html). Invite your family, friends and fellow campers to join your team and join with others across the US as we raise money for a cure. Visit www.cctakesteps.org (http://www.cctakesteps.org/) and choose the Camp Oasis National Team.

Can I apply as a camper or volunteer if I don't live in the United States?

We welcome everyone who wishes to attend or volunteer at camp to apply. You can apply to any of our camps, but please be aware that precedence will be given to campers and volunteers (http://www.crohnscolitisfoundation.org/get-involved/camp-oasis/volunteer-support/)who reside in the camp's region. After you have applied please contact the camp's local chapter office (http://www.crohnscolitisfoundation.org/chapters/) to make them aware of your situation.

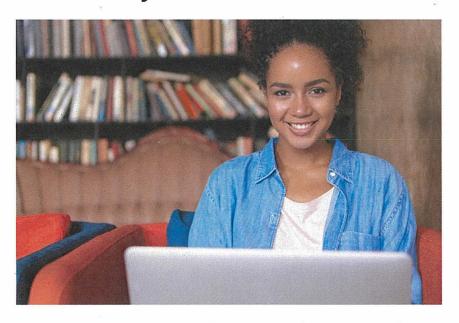
I have additional questions about camp. Who should I contact?

Please contact National Camp Manager, Daniel Marinoni, at (646) 943 - 7480 / camp@crohnscolitisfoundation.org (mailto:camp@crohnscolitisfoundation.org)



Akron Children's Hospital > For Families & Patients > Health Info > Family Resource Center

Family Resource Center



If you want information about a specific disease or condition, Akron Children's Family Resource Center can help you. Call 330-543-8180 or email your request to the center at family@akronchildrens.org.

Hours: Monday - Friday, 8 a.m. to 4 p.m.

Akron Children's Family Resource Center provides pediatric consumer health library services for patients, families, health professionals, service provider agencies and the community. Located off the Atrium Lobby at Akron Children's Hospital, it is a member of the National Network of Libraries of Medicine.

Among the many services available through our Family Resource Center:

- Lending library of over 1,500 health books and audiovisual materials; see many of the available items on our LibraryThing Catalog
- Subscription to the National Organization of Rare Diseases database
- Internet health information sources
- Information delivered to patient rooms or sent by mail, fax, or email
- Librarian assistance with health information searches

- Information on local support groups and community resources
- Information packets and Internet resource lists on common conditions
- Access to health information in other languages
- The center has computers available so patient family members may:
 - · Create and update a CaringBridge Web page
 - Access the NORD rare disease database
 - Use Boardmaker software to create communication boards

Health Education Lesson Plan Kits

Health Education Kits are "lessons in a box" for teachers, scouts, church groups or anyone to use. These creative, hands-on kits contain multiple activities, children's books, realia, DVD's and more to teach kids about a variety of health topics. Call us to reserve a kit for your group.

Searching for health information

Searching for health information on the web can lead to confusing results. MedlinePlus, a service of the U.S. National Library of Medicine, has created a webpage that teaches us how to search and then evaluate health information on the web: Evaluating Health Information.

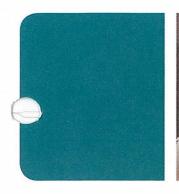
The center librarian is also available for group presentations on finding and evaluating Internet health information.

Call 330-543-8180, or email your request to the center at family@akronchildrens.org.

Our History

Akron Children's Family Resource Center honors Dr. Louis Lame, who was a well-respected pediatrician at Children's Hospital. Upon his retirement in 1986, grateful patients and families established the Lame Fund as a tribute to his many years of devoted service. Contributions to the Lame Fund help keep the materials current.

Contact the Children's Hospital Foundation at 330-543-8340 if you would like to make a donation.





IMPORTANT INFORMATION ABOUT IBD

- Treatment plans will be created for each patient. At that time, you will receive information about specific medications for your plan.
- Keep an up to date medication list with you at all times.
- Always have a working thermometer in your home.
- Never give your child Advil, Aleve, Aspirin, Ibuprofen, Motrin, Naproxen or any anti-inflammatory medications.
- Tylenol/Acetaminophen may be used following the recommendations for your child's weight and age on the bottle.
- Contact your Gastroenterology provider before your child receives any immunizations.
- Notify your Gastroenterology provider if your child is started on antibiotics by another provider.
- If your child is taking any over the counter supplements, vitamins, or prebiotics/ probiotics, please share this information with your Gastroenterology provider.
- Broad-spectrum waterproof sun protection is recommended, 30 SPF or higher.
 Re-apply every two hours.



Transition Policy

Akron Children's Hospital

Pediatric Gastroenterology

The Department of Pediatric Gastroenterology at Akron Children's Hospital is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at age 14, and their families to prepare for the change from a 'pediatric' model of care (where parents or guardians make most of the decisions) to an 'adult' model of care (where the patient takes full responsibility for self-management and decision-making). This means that we will start spending time during the visit with your teen alone, with the parents'/guardian's permission, in order to assist your teen in becoming more independent with their own health care.

We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the patients ages 18 and over, with their signed consent, will we be able to discuss any personal health care information with family members. If the youth has a condition that prevents them from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making (i.e., Legal guardianship).

We will collaborate with youth and families regarding the age for transferring to an adult provider and recommend that this transition occur before 22 years of age. We acknowledge that certain patients with special health care needs or circumstances will need a more individualized approach to transfer at a different age. We will assist with the transfer process.

As always, if you have any questions or concerns, please feel free to contact our office at 330-543-4488.

Reinaldo Garcia, MD Division Director Amanda Abou-Fadel, MD Christine Carter-Kent MD Shivani Gupta, DO Sameer Imdad, MD Christine Pasquarella, MD Corey Scherer, DO Carolyn Vespoli, MD Kevin Watson, MD Matthew Wyneski, MD Akihiro Asai, MD, PhD Katherine Lamparyk, PsyD Breaunna Haynes, APRN-CNP Dawn Keilin, APRN-CNP Melissa Lukes, APRN-CNP Gabrielle Miladore, APRN-CNP Stephanie Mullin, APRN-CNP Danielle Theaker, APRN-CNP

Revised 10/6/2023