



Inflammatory Bowel Disease Program

Welcome Packet



Phoenix Children's

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Welcome

Welcome to the Inflammatory Bowel Disease (IBD) Program at Phoenix Children's! We treat children and teens living with IBD - including Crohn's disease, ulcerative colitis, and indeterminate colitis.

Our mission is to provide excellent, personalized, multidisciplinary care to pediatric patients with IBD by using cutting-edge therapies, education programs, community and parent support groups, research and multicenter collaboration, and pathways to transition patients to adult care while remaining at the forefront of global policy and practice change.

At your visit, you will meet multiple members of our healthcare team, including board certified gastroenterologists and pediatric surgeon, a psychologist, registered dietitians, IBD nurse coordinator, and medical assistants. Each of these experts has completed specialty training in pediatric IBD and know how to care not only for your child's disease, but your child and family as a whole.



Getting Started

Receiving a diagnosis of Inflammatory Bowel Disease (IBD) can be overwhelming. It can be tough to navigate the new information about the condition, treatments, and plan of care. Thankfully, you don't have to go on your IBD journey alone! At Phoenix Children's, we have a team of IBD experts who will help take care of you. This team includes doctors, surgeons, psychologists, nurse practitioners, pharmacists, dietitians, nurses, medical assistants, and researchers. Our team also includes another important expert - YOU! We will work closely with you and your child and support you throughout your IBD journey at Phoenix Children's.

What to Expect

When your child receives a diagnosis of IBD, you will get a phone call from our IBD Nurse Coordinator, who will provide education on your child's diagnosis and plan of care, as well as schedule an appointment for your child in our IBD Multidisciplinary Clinic. This is a specialty clinic at Phoenix Children's that provides your child and family with a team of IBD specialists, including a gastroenterologist, surgeon if needed, psychologist, pharmacist, dietitian, IBD Nurse Coordinator, and IBD MA Coordinator. We understand the time of diagnosis can be overwhelming and full of appointments. To assist with this, the IBD Clinic is an important first step in understanding your child's diagnosis and individualized treatment plan all in one place. We will then invite your child back to the IBD Clinic annually to discuss health maintenance and continue individualized care from our team of specialists. Our goal is to support your child and family and make your IBD journey easier.

Your IBD Team

Your Name: _____

Parent/Guardian Name: _____

Fill in the names and phone numbers for the following providers:

IBD Doctor: _____

IBD Surgeon: _____

Psychologist: _____

Dietitian: _____

IBD Nurse: _____

When to Call Your IBD Team

Even with treatment, a person with IBD can experience a flare – an episode when symptoms reappear. It is important that you report your child’s symptoms early so your doctor can provide the best treatment. This will help your child stay well and avoid complications related to IBD. Remember, avoiding a flare is better than treating a flare! Make sure your child takes their medications as directed to help control symptoms and avoid a flare.

If your child is experiencing symptoms, please contact the Gastroenterology Clinic at (602) 933-0940 or send your team a message through the Follow My Health Patient Portal.

Common Symptoms of an IBD Flare:

- Stooling more than 3 times per day
- Abdominal pain
- Blood in your stool
- Nausea and vomiting
- Ongoing bouts of diarrhea
- Unexplained fever lasting more than a day or two
- Unexplained weight loss
- Dizziness or fatigue
- Signs of dehydration
- Change in appetite
- Joint pain

About the IBD Multidisciplinary Team

Our IBD program focuses on the physical and emotional needs of the complex IBD patient. Our team of professionals work closely together to coordinate and personalize your child’s treatment plan. Our providers are dedicated to offering our patients and families the best possible, proactive, and innovative care based on the latest research and national care standards.

Care Coordination

Our IBD program coordinator is a registered nurse who works closely with patients and families during initial diagnosis, acute illness, and inpatient hospitalizations. The goal of care coordination is to provide a point of contact to oversee individualized care plans developed across multiple specialties and ultimately help improve outcomes for our pediatric IBD patients through patient and family support and advocacy.

Gastroenterology

Our team of board-certified pediatric gastroenterologists specializes in the diagnosis and medical management of IBD. They are involved in research studies and clinical trials for new therapeutic regimens for IBD and interested in mechanisms to decrease antibody formation against biologic therapies in pediatric patients. The GI providers rotate into the inpatient system, as well as the clinic setting, to provide seamless care and open communication through acute flare, chronic, and remission phases of the disease. Phoenix Children’s is part of a worldwide quality improvement and research collaboration community called Improve Care Now. Patients, parents, clinicians, and researchers work together to improve the health and care of children with IBD.

Surgery

The IBD program includes a board-certified surgeon, specialized in surgical intervention and treatment for IBD. Some IBD complications that may lead to surgery include:

- Failure of medical management
- Strictures (Crohn’s Disease)
- Fistula or abscess formation
- Uncontrollable bleeding or other emergent reasons

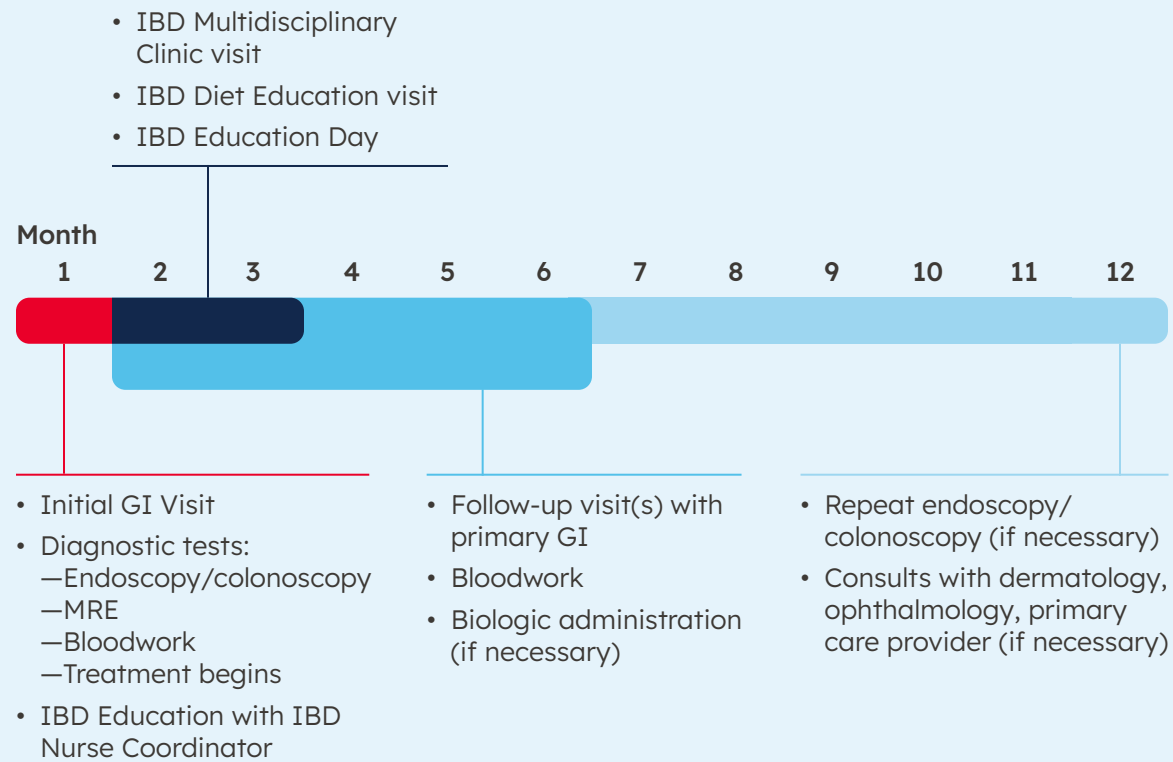
Psychology

The IBD program has a dedicated pediatric psychologist who will meet with each patient during their visit to the IBD Multidisciplinary Clinic. Our psychologist has been trained in clinical child and adolescent psychology with a focus on working with children with special medical needs. Services include improving medical treatment adherence, managing pain, reducing fears and building comfort with medical procedures, and adjusting to and coping with a diagnosis of chronic illness.

Dietary Considerations

Our dedicated IBD dietitian works closely with our multidisciplinary team to evaluate the nutritional status of your child and to develop an individualized diet plan to optimize growth, development, and nutrition. We also use nutrition as a therapeutic and maintenance option through guidance with a registered dietitian.

New Diagnosis Timeline



* This calendar is a general guideline. Please consult your child's gastroenterologist for specific guidelines.



Surgery & IBD

Some people with Crohn's disease and ulcerative colitis may require surgery. The type of surgery you have depends on many variables, including your disease, symptoms, and severity. Ideally, surgery is planned ahead of time, and you are able to prepare by meeting with your IBD team and surgeon. However, there are some instances when your surgeon must act fast and perform an emergency operation to ensure you are safe. In either situation, your IBD team and surgeon are here to support you before, during, and after the procedure. When possible, a minimally invasive approach is used for every operation, with attention to pain control and early recovery. Our hospital uses state of the art equipment to achieve the best possible outcomes. We use a team approach including a pediatric surgeon, gastroenterologist, psychologist, nutritionist, nurse coordinator, and YOU to provide the best possible care for your child and family.

Common Surgical Procedures

Crohn's disease

- Strictureoplasty
- Bowel resection
- Ileostomy
- Seton placement for perianal fistula
- Abscess drainage

Ulcerative colitis

- Colectomy and ileostomy
- Proctectomy with ileal pouch-anal anastomosis (J-Pouch surgery)
- Ileostomy takedown

For more information:

Surgery for Crohn's disease

Surgery for ulcerative colitis



Lisa E. McMahon, MD
Section Chief, Pediatric General Surgery
Co-Medical Director of Inflammatory Bowel Disease Clinic



Growth and Nutrition

One of the most common questions asked by patients with IBD and their families is: “What should I eat?” Good nutrition is an important tool to manage IBD. It supports overall health, growth and development, and bone strength. For some patients, food can even be used as a therapy. During the first month of diagnosis, you will be scheduled for an education session with our IBD dietitian. There, you will meet one-on-one with the dietitian who will provide a nutrition assessment, diet education, and create a specialized nutrition plan for your child. This dietitian will serve as your go-to for all nutrition and diet related questions.

What Should I Eat?

It’s not always easy knowing what foods best fuel your body, especially when you have Crohn’s disease or ulcerative colitis. Your diet and nutrition are a major part of life with IBD, yet there is no single diet that works for everyone.

Nutrition affects not just your IBD symptoms, but also your overall health and well-being. Without proper nutrients, the symptoms of your Crohn’s disease or ulcerative colitis can cause serious complications, including nutrient deficiencies, weight loss, and malnutrition.

We have several tips for a healthy diet that’s well-balanced and nutrient rich. These tips are for educational purposes only. You should work with your doctor or a dietitian specializing in IBD to help you develop a personalized meal plan.

Food Preparation and Meal Planning

While there is no one-size-fits-all for meal planning, these tips can help guide you toward better daily nutrition:

- Eat four to six small meals daily.
- Stay hydrated — drink enough to keep your urine light yellow to clear — with water, broth, tomato juice, or a rehydration solution.
- Drink slowly and avoid using a straw, which can cause you to ingest air, which may cause gas.
- Prepare meals in advance, and keep your kitchen stocked with foods that you tolerate well (see list below).
- Use simple cooking techniques — boil, grill, steam, poach.
- Use a food journal to keep track of what you eat and any symptoms you may experience.

Eating When You are in a Flare

There are certain foods you may want to avoid when you are in an IBD flare – and others that may help you get the right amount of nutrients, vitamins, and minerals without making your symptoms worse.

Your healthcare team may put you on an elimination diet, in which you avoid certain foods in order to identify which trigger symptoms. This process will help you identify common foods to avoid during a flare. Elimination diets should only be done under the supervision of your healthcare team and a dietitian so they can make sure you are still receiving the necessary nutrients.

Some foods may trigger cramping, bloating, and/or diarrhea. Many trigger foods should also be avoided if you have been diagnosed with a stricture – a narrowing of the intestine caused by inflammation or scar tissue – or have had a recent surgery. Certain foods can be easier to digest and can provide you with the necessary nutrients your body needs.

Potential Trigger Foods

Insoluble fiber foods that are hard to digest: fruits with skin and seeds, raw green vegetables (especially cruciferous vegetables such as broccoli, cauliflower, or anything with a peel), whole nuts, and whole grains

Lactose: sugar found in dairy, such as milk, cream cheese, and soft cheese.

Non-absorbable sugars: sorbitol, mannitol, and other sugar alcohols found in sugar-free gum, candy, ice cream, and certain types of fruits and juices such as pear, peach, and prune

Sugary foods: pastries, candy, and juices

High fat foods: butter, coconut, margarine, and cream, as well as fatty, fried, or greasy food

Alcohol and caffeinated drinks: beer, wine, liquor, soda, and coffee

Spicy foods: “hot” spices

Foods IBD Patients May Tolerate

Low-fiber fruits: bananas, cantaloupe, honeydew melon, and cooked fruits. This is typically recommended in patients who have strictures or have had a recent surgery

Lean protein: fish, lean cuts of pork, white meat poultry, soy, eggs, and firm tofu

Refined grains: sourdough, potato or gluten-free bread, white pasta, white rice, and oatmeal

Fully cooked, seedless, skinless, non-cruciferous vegetables: asparagus tips, cucumbers, potatoes, and squash

Oral nutritional supplements or homemade protein shakes: ask your doctor or your dietitian about what supplements may fit your nutritional needs

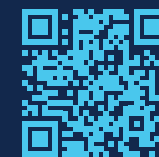


Watch our Facebook Live conversation with Emily Haller, registered dietitian at Michigan Medicine! Scan the QR code on the right to hear Emily review diet facts, debunk myths, speak about restrictions, and highlight ongoing research.



What to Eat When in a Flare

When you have inflammatory bowel diseases (IBD), and are in the middle of a flare, it is very important to avoid foods that may trigger additional symptoms and choose foods that are healing and nutritious. Watch and listen to learn more on dietary recommendations when in a flare.



2 minute video

Eating When You are in Remission

It's important to maintain a diverse and nutrient-rich diet even when you are in remission and your symptoms have subsided – or even disappeared. Introduce new foods slowly. Remember to stay hydrated with water, broth, tomato juice, and rehydration solutions. Consult with your doctor or dietitian before making any changes to your diet.

These foods can help you stay healthy and hydrated:

- **Fiber-rich foods:** oat bran, beans, barley, nuts, and whole grains, unless you have an ostomy, intestinal narrowing, or if your doctor advises you

to continue a low-fiber diet due to strictures – or recent surgery

- **Protein:** lean meats, fish, eggs, nuts, and tofu
- **Fruits and vegetables:** try to eat as many “colors” as you can, and remove the peel and seeds if they bother you
- **Calcium-rich foods:** collard greens, yogurt, kefir, and milk (if you are lactose intolerant, choose lactose-free dairy products or use a lactase digestive enzyme)
- **Food with probiotics:** yogurt, kimchi, miso, sauerkraut, and tempeh

Eating When in Remission

When you are in remission with inflammatory bowel diseases (IBD), it is very important to focus on maintaining a diverse and nutrient rich diet. Watch and listen to learn more on dietary recommendations when in remission.



2 minute video

More on Diet and Nutrition

Malnutrition and IBD



Vitamin and Mineral



Special IBD Diets



Diet and Nutrition Support



Food Journal

Use this food journal to help you identify any potential trigger foods. Please note this journal should be used under the supervision of a registered dietitian.

Date	Food Tried	Time Tried	Reaction	Time of Reaction

Social and Emotional Wellbeing

Your child’s social and emotional well-being is a key factor to their overall health. Your child will have access to an IBD Psychologist during their visit to the IBD Clinic who may focus on adjusting to and coping with diagnosis of IBD, managing pain, reducing fears and building comfort with medical procedures, and improving medical treatment adherence.

Below are resources many families find helpful.

Increasing Comfort and Confidence with Procedures

1. ImaginACTION – a website that offers a video and worksheet for building comfort a calm with pokes and procedures
2. Video: Preparing for a Rectal Exam – learn strategies to become comfortable, calm, and confident during office exams
3. Blog: Ways to Increase Comfort and Calm – learn strategies to become comfortable, calm, and confident during exams and procedures

Help with Pill Swallowing

1. Article: How to Help Kids Swallow Pills – tips for building your child’s confidence with pill swallowing

Helpful Links

ImaginACTION Building Comfort and Calm

Preparing for a Rectal Exam

Ways to Increase Comfort and Calm

How to Help Kids Swallow Pills

ImaginACTION Audio guides for emotional and physical discomfort

Diaphragmatic Breathing

Lifestyle and IBD

Tips for Managing Stress and Distress

1. TIPP skills for managing distress
 - a. **T** – temperature: you can lower your body temperature by splashing your face with ice water
 - b. **I** – intense exercise: you can lower your heart rate by first doing intense exercise – such as jumping jacks – to raise your heart rate. It will then go down to below baseline after you stop
 - c. **P** – paced breathing: you can take slow, deep belly breaths, maybe practicing box breathing – in for 4, out for 4, hold for 4 – or 4-7-8 breathing – in for 4, hold for 7, out for 8
 - d. **P** – progressive muscle relaxation: you can make your way through muscle groups, first tensing the muscle for a count of 5, then releasing the tension and relaxing the area for a count of 10
2. ImaginACTION – a website that offers audio guides for managing emotional and physical discomfort
3. Tutorial: Diaphragmatic breathing – learn this helpful relaxation technique
4. Website: Lifestyle and IBD – resource created by the Patient Advisory Council of ImproveCareNow with direct patient experience, patient-developed information and resource links, as well as professional information and insights.

Health Maintenance

Did you know there is more to managing IBD than seeing your gastroenterologist? It is important for all children, teens, and adults with IBD – to follow the recommended health maintenance guidelines to make sure you stay healthy and prevent illness. Check out the Health Maintenance Checklists below and ask your child’s gastroenterologist for more specific guidelines on recommended screenings and vaccines for your child.

Health Maintenance Checklist for Pediatric IBD Patients

Recommended Vaccines	Which Patients	How Often
Pneumovax	All IBD patients with altered immunocompetence	<ul style="list-style-type: none"> • Pediatric patients should receive Pneumovax (PPSV23) between the ages of 2 and 18. If not previously given, they should receive Prevnar (PCV13) at least eight weeks prior to receiving Pneumovax • A second dose of PPSV23 should be administered 5 years later
Flu Vaccine (Non-live)	All IBD patients	<ul style="list-style-type: none"> • Give one dose annually during flu season
HPV Vaccine	All males and females at age 11 to 12 years of age, regardless of immunocompetence	<ul style="list-style-type: none"> • A 2-dose schedule is recommended if the patient is vaccinated before their 15th birthday • A 3-dose schedule is recommended for those who are immunocompromised or who start the series after their 15th birthday

Adult IBD Health Maintenance Checklist

Cancer Screening	Which Patients	How Often
Full Skin Screen (Dermatology)	All with altered immunocompetence	Annually
Colonoscopy	All with colonic disease for > 8 years	Every 1 - 3 years
Cervical Cancer Screening (PAP Smear)	All female patients with IBD	<ul style="list-style-type: none"> Annually for sexually active females on immunosuppressive therapy, regardless of age Every 3 - 5 years for sexually active women not on immunosuppressive therapy starting at age 21

Other Screenings	Which Patients	How Often
Eye Exam (Ophthalmology)	All IBD patients	Every 1 - 2 years
Nutrition Evaluation	All IBD patients	Annual visits with IBD dietitian; height, weight, labs and BMI each visit
Mental Health Evaluation	All IBD patients	Annually or when symptoms appear
Smoking Status	All IBD patients	Annually
DEXA Scan	All IBD patients	<ul style="list-style-type: none"> Steroid use > 3 months Inactive disease but past chronic steroid use at least 1 year within the past 2 years
IBD Multidisciplinary Clinic Visit	All IBD patients	Annually
Primary Care Visit	All IBD patients	Annually

DEXA: dual energy X-ray absorptiometry

PPD: purified protein derivative

IGRA: Interferon Gamma Release Assay

1. Source [cdc.gov/vaccines/hcp/acip-recs/general-recs/immunocompetence.html](https://www.cdc.gov/vaccines/hcp/acip-recs/general-recs/immunocompetence.html)

2. Altered immunocompetence is assumed to occur with high-dose prednisone (≥ 2 mg/kg for ≥ 14 consecutive days), azathioprine, mercaptopurine, methotrexate, anti-TNFs, anti-IL-12/23 and JAK inhibitors

Resource for your patients: [justlikemeibd.org/parents/healthcare-maintenance-guide.pdf](https://www.justlikemeibd.org/parents/healthcare-maintenance-guide.pdf)

Developed by Crohn's & Colitis Foundation Professional Education Committee subgroup; Alan Moss MD, Jill Gaidos MD, MariaStella Serrano MD / V2_July_2019

Vaccines and Infections

Influenza: All patients >6 months of age should receive annual inactivated influenza vaccine, irrespective of immunosuppression status.

MMR: IBD Patients not immune to MMR should receive a 2-dose series, at least 4 weeks apart. If immune status is uncertain, IgG antibody titer should be checked. MMR should not be given to patients currently on systemic immunosuppressive* therapy.

Pneumococcus: All patients >19 years age receiving systemic immunosuppression* should receive PCV13, followed by PPSV23 at least 8 weeks later, and a booster of PPSV23 5 years later.

Varicella: Seroprotection status should be checked with varicella zoster virus IgG antibodies in all patients without documented vaccination record or exposure. All patients who are not immune should receive a 2-dose series, 4-8 weeks apart, ≥ 4 weeks before immunosuppression, if therapy can be postponed.

Zoster: All patients receiving JAK inhibitor therapy should receive the recombinant adjuvanted zoster vaccine. Risk of zoster should be considered with combinations of other immunosuppressive* therapies.

TB: Screen for latent TB in all patients with IBD, at baseline. Perform clinical risk assessment for TB exposure annually in all patients with IBD.

Cancer Screening

Colorectal Cancer: All IBD patients with extensive colitis (>1/3 of the colon) for ≥ 8 years should undergo surveillance colonoscopy every 1-3 years, depending on cancer risk;

- IBD patients with a diagnosis of PSC should undergo colonoscopy, starting at the time of PSC diagnosis, and annually thereafter.
- IBD patients with features that are high-risk for developing colon cancer (i.e. prior history of adenomatous polyps, dysplasia, family history of colon cancer and extensive colitis) should have colonoscopies more frequently than every 3 years.

Cervical Cancer: All women with IBD who are being treated with systemic immunosuppression* should undergo cervical cancer by cytology annually (if cytology alone) or every 2 years (if HPV negative).

Skin Cancer: All IBD patients being treated with systemic immunosuppression* should have annual total body skin exams to screen for skin cancer.

Other Protection

Osteoporosis: Screen for osteoporosis by central (hip and spine) DEXA scan in all patients with IBD if ANY risk factors for osteoporosis; low BMI, >3 months cumulative steroid exposure, smoker, post-menopausal, hypogonadism. Repeat in 5 years if initial screen is normal.

Depression/Anxiety: Screen all patients with IBD for depression (PHQ9) and anxiety (GAD7) at baseline, and annually. Refer for counseling/therapy when identified.

Smoking: Screen all patients with IBD for smoking status at baseline, and refer current smokers for smoking cessation therapy.

*Systemic immunosuppression refers to current treatment with prednisone (>20mg/day for more than 14 days), azathioprine (>2.5 mg/kg/day), mercaptopurine (>1.5 mg/kg/day), methotrexate (>0.4 mg/kg/week), cyclosporine, tacrolimus, infliximab, adalimumab, golimumab, certolizumab, ustekinumab, or tofacitinib.

Crohn's & Colitis Foundation Professional Education Sub-Committee; Jill Gaidos MD, Alan Moss MD, Mariastella Serrano MD, Gaurav Syal MD • 6/10/2020

IBD Resources & Support

There are many resources available to learn more about IBD and connect with other children, teens, and their families. We encourage all our patients to get involved and take advantage of these fun and informational opportunities!

To get started, follow us on Facebook! This is a great way to connect with the IBD Clinic at Phoenix Children's and check out the latest clinic updates, upcoming events, resources, education, patient and employee spotlights, and more.



Find us at facebook.com/pchibd

Crohn's & Colitis Foundation (CCF)

The Crohn's & Colitis Foundation (CCF) is a non-profit, volunteer-fueled organization dedicated to finding cures for IBD and improving the quality of life and patients and families affected by these conditions.

Online resources include:

- My IBD Learning Program
- IBD Visible Blog
- IBD & Me Activity Center
- New Diagnosis Resources
- Local Support Groups

CCF offers a team of information specialists through their IBD Help Center who can help you find specific resources, understand your health insurance coverage, and refer you to other organizations.

- Helpline available Monday through Friday from 9 AM to 5 PM EST
- Call 1-888-MY-GUT-PAIN (888-694-8872, extension 8)
- E-mail: info@crohnscolitisfoundation.org
- Chat with a life specialist
- Power-of-Two Mentor Program
- Info on Local Events!



Follow the CCF Southwest Chapter on Facebook at facebook.com/CCFASouthwest

Learn more at crohnscolitisfoundation.org/community-support/ibd-help-center

CFF Community Events

CCF also hosts many events in the community including:

- Take Steps for Crohn's & Colitis
- Team Challenge
- And so much more!
- Camp Oasis!
- Spin 4 Crohn's & Colitis Cures



IBD Support Groups

There are also a variety of support groups available for you and your child. This is a great opportunity to meet other children and teens with IBD and their families. We encourage all our patients and families to become involved in these great groups!



IBD Caregiver Group

- Support group for parents and caregivers of children with IBD
- For meeting information, contact IBDCaregiverEncouragementGroup@outlook.com



IBD Family Group

- Support groups for kids and teens with IBD
- Oklahoma City Group: contact marthastone@gmail.com
- Tulsa Group: contact teacherpaige@yahoo.com



IBD Young Adult Group

- Peer-led group for young adults ages 18-24
- For meeting information, contact SWYoungAdultIBD@gmail.com
- Instagram: [@AZIBDYoungAdults](https://www.instagram.com/AZIBDYoungAdults)



IBD Parent Working Group

- Parents of children with IBD who work with Phoenix Children’s team to improve outcomes through:
 - Collaboration
 - Advocacy
 - Fundraising
 - Mentorship
 - Education

Improve Care Now

The IBD Clinic at Phoenix Children’s Hospital is a proud member of Improve Care Now (ICN), a collaborative community where clinicians, researchers, parents, and patients are empowered to learn and continuously improve to bring more reliable, proactive IBD care for healthier children and youth.

The purpose of ICN is to transform the health, care, and costs for all children and adolescents with Crohn’s disease and ulcerative colitis by

building a sustainable collaborative chronic care network. Since it began in 2007, ICN has increased the number of children in remission with IBD by encouraging participating centers to collect standardized data during all clinic visits, monitor individual and overall performance, compare outcomes, and share the best evidence and tools for helping patients with IBD get better faster and stay well longer.

ICN Success



Data from ImproveCareNow centers with greater than 75% registration of eligible patients | Updated January 2020



Research

Research at Phoenix Children's GI Clinic

Our Gastroenterology clinic is dedicated to optimizing patient care and education. One way we accomplish this is through our growing research programs. Our providers are passionate about building robust programs that focus on innovative medical care, clinical and translational research, education, and outreach.

What is Research?

Clinical research is a branch of healthcare science that determines the safety and effectiveness of medications, devices, diagnostic products, and treatment regimens intended for human use. These may be used for prevention, treatment, diagnosis or for relieving symptoms of a disease.

At Phoenix Children's, we conduct both interventional and non-interventional research studies.

Interventional Research Studies
 These are generally pharmaceutical trials for medications, procedures/activities, or medical devices that are being investigated for their efficacy and may involve blood draws, vital signs, and other procedures in addition to your standard of care visits and procedures. These are commonly called clinical trials.

Non-interventional Studies
 These are comprised of registries and observational studies meaning that we are collecting data from standard of care visits or reviewing medical records to collect information that may be useful in future diagnosis and treatment plans for future children. They piggy-back off your standard of care visits.

504 Plans

We recommend every child and teen with IBD have school accommodations in place through a 504 Plan. This is an action plan developed by the school, parents/guardians, and your child containing accommodations to support your child with IBD at school.



Learn more about 504 Plans

Examples include:

- "Stop the clock" testing
- Access to water and snacks during class
- Unlimited restroom access
- Options to make up missed class time without penalty
- Excuse of absences due to flares, clinic visits, infusions, and hospitalizations
- Tutoring after a specific period of absence due to flare



Transition to Adult Care

When your child is 16 years of age, we will begin to discuss the concept of transition of care, which is preparation for their eventual transfer to an adult IBD specialist. We will be with them every step of the way and help them learn important skills in managing their own health care, assist in finding an adult IBD specialist, and transferring medical records to their new medical team.

When your child is 16 years of age, we will begin to discuss the concept of *transition* of care, which is preparation for their eventual *transfer* to an adult IBD specialist. We will be with them every step of the way and help them learn important skills in managing their own health care, assist in finding an adult IBD specialist, and transferring medical records to their new medical team.

There you will find numerous resources on:

- Navigating college with IBD
- Choosing your college
- Disability support services
- Dorm life and accommodations
- Finding support on campus
- Social life
- Nutrition in college
- And more



crohnscolitisfoundation.org/campus-connection

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IBD Phone Apps

- **Our Journey with IBD**
Education tool developed by Phoenix Children's
- **myIBD (Free)**
Symptom logging application for patients with IBD
- **GI Buddy (Free)**
Symptom logging application for patients with IBD
- **GI Monitor (Free)**
Symptom logging application for patients with IBD
- **Colonoscopy Prep Assistant (Free)**
Help with colonoscopy prep
- **We Can't Wait (Free)**
Find a public bathroom near you
- **Toilet Finder app (Free)**
Find a public bathroom near you
- **Sit or Squat by Charmin app (Free)**
Find a public bathroom near you
- **Doc4me app (Free)**
Find an adult GI doctor in your area
- **MyMedSchedule (Free)**
Help with taking scheduled medications
- **OnTime-Rx (Free on ontimerx.com)**
Help with taking scheduled medications
- **Mango Health (Free on mangohealth.com)**
Help with taking scheduled medications
- **Ate Food Journal**
Food journal app
- **Headspace (Free)**
Includes guided meditation exercises and sleep stories.
- **Breathe2Relax**
Teaches the stress management tool of diaphragmatic breathing
- **MyCalmBeat**
Practice paced breathing exercises to help reduce stress
- **MindShift**
Strategies for teens and young adults to cope with everyday anxiety
- **Calm**
Guided meditation exercises and sleep stories to help users manage stress, anxiety, and achieve better sleep

Patient Assistance Programs

Paying for your child's treatments for Inflammatory Bowel Disease can be tough. Thankfully, families that use commercial or private insurance may be eligible for co-pay savings programs:



Janssen Carepath: a co-pay assistance program which can provide support to eligible patients taking Remicade or Stelara up to \$20,000 per patient, per calendar year.

- Visit janssencarepath.com or call **877-CarePath (877-227-3728)**

Pfizer Encompass: a co-pay assistance program which can provide support to eligible patients taking Inflectra up to \$20,000 per patient, per calendar year.

- Visit pfizercopay.com or call **1-844-722-6672**

Humira Complete: a patient support program with co-pay assistance, nurse support, and helpful tips. Eligible patients may receive a Humira Complete Savings Card to help you get Humira for as little as \$5 per month, every month.

- Visit humira.com/humira-complete/support-resources or call **1-800-4HUMIRA (1-800-448-6472)**

Entyvio Connect: a patient support program with co-pay assistance, nurse support, and helpful tips. Eligible patients may pay as little as \$5 per dose every 8 weeks.

- Visit entyvio.com/copay-support or call **1-844-ENTYVIO (1-844-368-9846)**

XELSOURCE: a co-pay assistance program which can provide eligible patients an annual savings of \$6,000 - \$15,000 and pay as little as \$0 per month.

- Visit xeljanz.com/savings-and-support or call **1-844-935-5269**

Rinvoq Complete: a patient support program with co-pay assistance nurse support, and helpful tips. Eligible, commercially insured patients to pay as little as \$5 per prescription.

- Visit rinvoq.com/resources/rinvoq-complete or call **1-800-2RINVOQ (1-800-274-6867)**

Skyrizi Complete: a co-pay assistance program which may enable eligible, commercially insured patients to pay as little as \$5 per quarterly dose.

- Visit skirizi.com/skyrizi-complete or call **1-866-SKYRIZI (1-866-759-7494)**

PROMETHEUS Links: a cost reduction program for PROMETHEUS testing. Assistance with handling the claims process, managing questions or requests for information, and covering or lowering your costs of PROMETHEUS testing.

- Call **888-892-8391**



If you have questions or need further assistance, please contact the IBD Nurse Coordinator at **(602) 933-5754**.



Follow My Health Portal

Your child's health information is now online

Manage your child's personal medical records with 24/7 secure online access from any computer, smartphone or tablet.

How to register for FollowMyHealth®

- 1 If you or your child have been a patient at Phoenix Children's Hospital, we've reserved an account just for you. All we need is your email address.
- 2 Provide your email address at appointment or hospital check-in and watch for your secure login invitation via email.
- 3 Once registered, if you are logging in as a proxy, go to the top of the screen next to 'hello _____' and select your child's name from the drop down box.



Make Connections

- Secure email your providers any time
- Refill prescriptions
- Set up proxy accounts for dependents under age 13 (additional authorization for 13 or older)



View Records

- Get lab results faster
- Phoenix Children's medical history
- Summary of doctor visits
- Hospital discharge summary



Keep Notes

- Keep your own notes on symptoms, instructions and more
- Connect to accurate health resources from Phoenix Children's and other trusted sources
- Download the FollowMyHealth® mobile app for anywhere access

Need Help? Contact (602) 933-1490, Option 2 or email patientportalsupport@phoenixchildrens.com. Informational guides are also available on the patient portal page at phoenixchildrens.org.



Frequently Asked Questions

Q: Is the IBD clinic different than a routine follow-up visit with my child's gastroenterologist or surgeon?

A: Yes. The IBD clinic appointment will include members of the multidisciplinary team, including a gastroenterologist, surgeon (if necessary), psychologist, dietitian, and registered nurse. The visit will typically last 60 minutes and can be in place of a routine follow-up visit depending on your child's plan of care.

Q: As a parent/guardian, what can I do to prepare for my child's IBD clinic visit?

A: Please complete any surveys/questionnaires by the evening before your IBD clinic visit. If you cannot complete these documents online, please arrive at least 20 minutes prior to your scheduled appointment. You can also write down questions for your team and take notes during the clinic visit. In addition, please bring any recent test results, vaccine history, and documentation from your child's other specialists and pediatrician as well as a current list of medications, over-the-counter supplements, and current insurance information.

Q: What can my child and I expect from their visit with the psychologist?

A: Following your appointment with the medical team, our pediatric psychologist will conduct a brief assessment interview and discuss individualized coping skills as needed. The psychologist will give feedback and

recommendations about behaviors such as stress management, sleep, nutrition, physical activity, and social support. In addition, the psychologist will help your child learn skills and decrease fears related to medical procedures, medications, hospitalizations, and surgeries. You will also have an opportunity to schedule additional appointments with this provider if needed.

Q: My child is nearing or over the age of 18. Can my child still be seen at Phoenix Children's Hospital?

A: Our IBD team will work closely with your child to transition to adult care when it is appropriate. This transfer of care usually occurs before age 22 but is ultimately a decision made with your primary GI provider. We will help to transition your child at a comfortable pace and provide you child with the names of adult IBD providers and surgeons based on your child's treatment plan, past medical and/or surgical history, and the city in which your child lives.

Q: How do I schedule my child's IBD clinic visit?

A: To schedule a visit in the IBD Multidisciplinary Clinic, please call the IBD MA Coordinator at (602) 933-4053. Clinics are held on Tuesday mornings and Friday afternoons in the Gastroenterology Department (Clinic C) or Surgery Department (Clinic D) at the Main and Mercy Gilbert campuses of Phoenix Children's Hospital.

Contact Us

The Gastroenterology and Surgery clinics are open Monday through Friday from 8 am - 5 pm. Phone calls are triaged according to medical urgency and will be returned within 24 to 48 hours. The best way to reach your provider's nurse is through the patient portal.

After hours, you may leave a message or if urgent, you may remain on the line to reach the on-call provider.

In case of emergency, call 911.

Important Numbers

Gastroenterology, Hepatology, and Nutrition
602-933-0940
fax: 602-933-2468

Pediatric Surgery
602-933-0016
fax: 602-933-4309

Radiology Scheduling
602-933-1215

Endoscopy Scheduling
602-933-0384 or
602-933-3361

Financial Counseling
602-933-0262

Medical Records
602-933-1490

Phoenix Children's Operator
602-933-1000

IBD Nurse Coordinator
602-933-5754

IBD MA Coordinator
602-933-4053

Notes

Notes



Phoenix Children's®