



PHOENIX
CHILDREN'S

®

INFLAMMATORY BOWEL DISEASE PROGRAM

WELCOME PACKET

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INFLAMMATORY BOWEL DISEASE PROGRAM

Phoenix Children's Hospital

IBD Nurse Coordinator: Brianna Procopio, MSN, RN

IBD@phoenixchildrens.com

Phone: (602) 933-5754

MEET YOUR TEAM

IBD Program Supervising Physicians



Ashish Patel, MD
Division Chief
Gastroenterology

Brad Pasternak, MD
Medical Director
Gastroenterology

Lisa McMahan, MD
Medical Director
Pediatric Surgery

IBD Program Team



Gary Silber, MD
Division Member
Gastroenterology

Jenna Rudo-Stern, PhD
Pediatric Psychology



Nicole King, MSN/MBA, RN
Practice Manager
Gastroenterology

Rhonda Burgess, CPC
Practice Manager
Pediatric Surgery

Brianna Procopio, MSN, RN
IBD Nurse Coordinator



Jamie Smith, BS, CCRP
Senior Research Coordinator

Christina Rodriguez
Research Assistant

Liz Langreck, RD
IBD Registered Dietitian

WELCOME LETTER

Welcome to the Inflammatory Bowel Disease (IBD) Program at Phoenix Children's Hospital. 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 through utilization of 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.



ABOUT THE CLINIC

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 providing our patients and families with the best possible, proactive, and innovative care based on the latest research and national care standards.

CARE COORDINATION

Care is coordinated by our IBD program coordinator, a registered nurse, who works closely with patients and families during initial diagnosis, acute illness, and inpatient hospitalizations. Care coordination extends into the ambulatory setting to develop individualized care plans and help coordinate visits with multiple specialists. The goal of care coordination is to provide a point of contact 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 and is available to provide follow-up care as needed. 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 utilize nutrition as a therapeutic and maintenance option through guidance with a registered dietitian.

ABOUT THE CLINIC

SUPPORT

Living with a chronic illness can be difficult for both the patient and family. Thankfully, you and your child don't have to go through it alone! There are numerous opportunities for support at Phoenix Children's and in the community for families and children of all ages:

- **Inflammatory Bowel Disease Clinic at Phoenix Children's Hospital** – A Facebook page for the Phoenix Children's IBD Clinic. We post updates on clinic events, education resources, Q&A with our team, and more!
 - ◆ Find us at www.facebook.com/pchibd
- **IBD Family Support Group - Metro Phoenix** – A support group of children and teens with IBD and their families. The group meets at Phoenix Children's monthly to connect, share experiences, hear from guest speakers, share resources, and participate in group activities.
 - ◆ Find us at www.facebook.com/groups/773234129413158/
- **IBD Parent Working Group** – A group created by parents of children with IBD. PWG hosts regular meetings, works closely with Phoenix Children's clinical staff, and organizes fundraising events for the IBD clinic. PWG also advocates on legislative policies, leads outreach projects, and participates in national IBD conferences.
 - ◆ Find us at www.facebook.com/IBDPWG and www.ibdpwg.org
- **Young Professional Group CCFA** – A support group of young adults (25-45ish) with IBD. The group meets monthly in a social setting for support and networking with the goal to develop awareness of IBD and fundraise for the Crohn's and Colitis Foundation.
 - ◆ Find us at www.facebook.com/YPGSouthwestCCFA/



ABOUT THE CLINIC

CROHN'S AND COLITIS FOUNDATION (CCF)

The Crohn's and Colitis Foundation (CCF) is a non-profit, volunteer-fueled organization dedicated to finding cures for Crohn's disease and ulcerative colitis, and improving the quality of life of children and adults affected by these diseases. CCF is a great resource for patient and family education and participates actively in current research. In addition, CCF holds many support events for patients with IBD and their families including:

- › Take Steps Walk
- › Camp Oasis
- › Support Groups
- › Patient Education Events
- › Fundraisers
- › And much more!

Connect with CCF:

- › **Website:** <https://www.crohnscolitisfoundation.org>
- › **Facebook:** <https://www.facebook.com/ccfafb/>
- › **Arizona Chapter:** <https://www.facebook.com/CCFASouthwest/>
- › **Camp Oasis!:** <https://www.crohnscolitisfoundation.org/get-involved/camp-oasis>



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, psychologist, dietitian, and registered nurse. The visit will typically last 40 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: The IBD Nurse Coordinator will e-mail you surveys and a questionnaire. Please complete these documents and return to coordinator 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 clinic providers and IBD Nurse Coordinator 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 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.

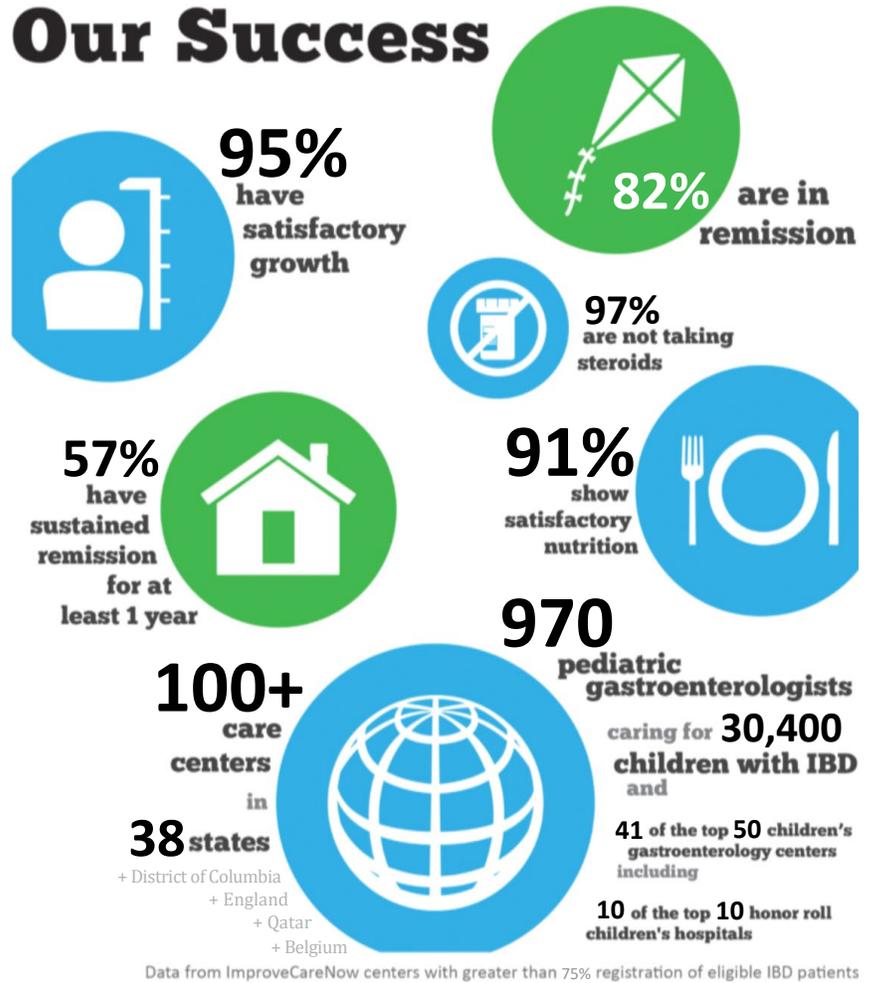
Q: How do I schedule my child's IBD clinic visit?

A: To schedule a visit in the IBD Multidisciplinary Clinic, please call the IBD Nurse Coordinator at (602) 933-5754. Clinics are held on Tuesday mornings and Friday afternoons in the Gastroenterology Department (Clinic C) at the main campus of Phoenix Children's Hospital.

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.

Our Success



Connect with ImproveCareNow online at improvecarenow.org

Updated October 2020

To learn more about ICN or to join the ICN circle, visit improvecare.org.



CONTACT US

The Gastroenterology and Surgery clinics are open Monday through Friday from 8:00am-5:00pm. 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	
Phoenix Children's Hospital Gastroenterology and Hepatology	602-933-0940 fax: 602-933-2468
Phoenix Children's Hospital 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 Hospital Operator	602-933-1000
IBD Coordinator – IBD clinic	602-933-5754

If your child has an acute illness, such as fever, vomiting and/or diarrhea with a fever, respiratory or other viral flu-like symptoms, please contact your pediatrician's office.

For non-life threatening events needing immediate attention, please go to Phoenix Children's Hospital Emergency Department (602) 933-1900 or to the nearest Phoenix Children's Urgent Care.

PHOENIX CHILDREN'S URGENT CARE		
Scottsdale Center	6990 E. Shea Blvd. Scottsdale, AZ 85254	602-933-0004
Northwest Valley Center	20325 N. 51st Ave., Ste. 116 Glendale, AZ 85308	602-933-0003
East Valley Center	5131 E. Southern Ave. Mesa, AZ 85206	602-933-0002
Southwest Valley Center	1665 N. Avondale Blvd. Avondale, AZ 85392	602-933-0005



**Is your child living with
Crohn's disease or ulcerative colitis?**

The Crohn's & Colitis Foundation can help!

Phoenix Family IBD Group

Meets: 2nd Tuesday Every Month (except June, July, Aug)

Time: 6:30pm

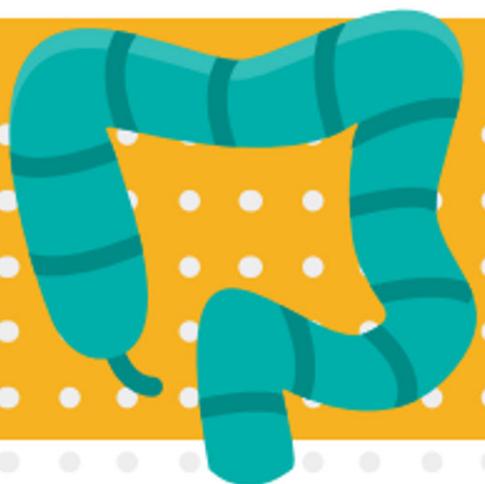
**Email: E. John Fredrich at ejfredrich@graceglendale.org
for meeting info or scan the QR code below**





IBD PARENT WORKING GROUP

we strive to improve
the outcomes of families &
kids living with Inflammatory
Bowel Disease through
education
advocacy, fundraising
& social events



CONTACT US

LEARN MORE, CONNECT WITH RESOURCES
& ATTEND UPCOMING EVENTS

IBDPWG.ORG



Get Involved

- **Local Chapters:** Access education programs, support groups, fundraising events, and volunteer opportunities. www.crohnscolitisfoundation.org/chapters
- **Take Steps:** Join our family-friendly walk program and connect with your local IBD community. Find a walk near you. www.cctakesteps.org
- **Team Challenge:** Fight back against IBD, for yourself or a loved one, by training with us for a 10K, half marathon, marathon, triathlon, or cycle event. Join the team for support and make a difference. www.ccteamchallenge.org
- **spin4 crohn's & colitis cures™:** Join the new movement and participate in our indoor cycling relay to support IBD research. You'll never go farther on a stationary bike. www.spin4.org

Make Your Voice Heard

- **Become an Advocate:** Accelerate progress toward curing and preventing IBD by joining our Advocacy Network. Urge your legislators to support IBD research and improve access to care. www.crohnscolitisfoundation.org/get-involved/be-an-advocate
- **Influence IBD Research:** Propose, discuss, and vote on research questions through the IBD Partners program, a revolutionary research network for individuals with IBD. www.ibdpartners.org

Join the conversation

-  facebook.com/ccfab
-  twitter.com/crohnscolitisfn
-  youtube.com/ccfa
-  instagram.com/crohnscolitisfoundation

Support of this resource is provided through the Crohn's & Colitis Foundation annual giving program and through our donors.

For more information, please contact your local chapter:

Or contact our national office:

Crohn's & Colitis Foundation
733 Third Avenue, Suite 510
New York, NY 10017

888-694-8872

info@crohnscolitisfoundation.org

www.crohnscolitisfoundation.org

The Crohn's & Colitis Foundation offers a comprehensive array of services to patients and caregivers touched by inflammatory bowel diseases. We also fund cutting-edge science, nurture young investigators, and finance underdeveloped areas of research.

Our Mission: to cure Crohn's disease and ulcerative colitis and improve the quality of life of children and adults affected by these diseases.



12/2019



Education & Support for Patients with IBD



IBD Help Center

The Irwin M. and Suzanne R. Rosenthal IBD Resource Center (IBD Help Center) is here to provide information, support, and guidance to help you manage your disease and take charge of your life.

Through the IBD Help Center, you can:

- Speak to a caring Information Specialist
- Get all of your questions answered
- Access the latest information on treatment options, coping strategies, and symptom management
- Order free brochures and fact sheets
- Get help in 170 different languages

Call or visit us online, Monday through Friday, 9 a.m. to 5 p.m. ET.

Phone: 888.MY.GUT.PAIN (888-694-8872)

Email: info@crohnscolitisfoundation.org

Live Chat: www.crohnscolitisfoundation.org

Enhance Your Knowledge

- **Local Events:** Our chapters host education programs featuring community experts throughout the year.
- **Virtual Education:** Videos, webcasts, and interactive tools can easily be viewed and downloaded from our website.
- **Brochures & Fact Sheets:** Disease-specific publications are available free of charge, both online and in print.
- **Managing the Costs of IBD:** Provides valuable information on health insurance and financial assistance programs in order to help you manage the cost of paying for IBD treatments. www.crohnscolitisfoundation.org/managingcosts
- **Social Media:** Tips, resources, and stories are regularly shared on Facebook and Twitter.



Visit www.crohnscolitisfoundation.org for more information.

Find Support

- **Support Groups:** Our chapters host monthly opportunities for you to connect with others in person.
- **Power of Two:** Our peer-to-peer mentor program allows you to speak to a mentor by phone or through an online chat.
- **Crohn's & Colitis Community Website:** Our Crohn's & Colitis Community provides patients and caregivers with a place to share their experiences and get support. www.crohnscolitiscommunity.org
- **Camp Oasis:** A coed program designed to enrich the lives of children with IBD.

Additional Online Resources

- **IBD Medication Guide:** A searchable tool that provides information on medications for Crohn's disease and ulcerative colitis. www.ibdmedicationguide.org
- **Teen Website:** Provides age-appropriate information and support to help teens manage their disease. www.justlikemeibd.org
- **College Website:** Provides tips and resources for students, as well as an opportunity to connect with others from campuses around the country. www.crohnscolitisfoundation.org/campus-connection
- **Clinical Trials Community:** Offers information, videos, and a searchable tool to find studies where patients can enroll to help advance research. www.crohnscolitisfoundation.org/research/clinical-trials-community



**PHOENIX
CHILDREN'S**

Your child's health information now online

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

Make Connections



Secure email your providers any time



Refill Prescriptions



Set up proxy accounts for dependents under 13 yrs (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

How to register for FollowMyHealth®

- 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.
- Provide your email address at appointment or hospital check-in and watch for your secure login invitation via email.
- 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.

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