

# Role of Families in IBD Care

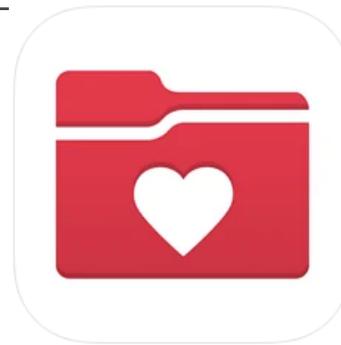
---

IBD FAMILY DAY  
MARCH 20, 2021

# Contacting the IBD Center

---

LAURA E. BAUMAN, MD



# Options for Contacting the IBD Center

---



- Rady MyChart

Non-Urgent



- Call the nurse line

Urgent



- Page on call GI doctor

Urgent  
After Hours

# Rady MyChart Messages

---

Messaging for non-urgent questions, concerns, or needs

Very convenient, no missed phone calls from providers or staff

Allows for longer answers to questions and documented answers you can refer to later

You are able to fill out the IBD symptoms score at any time and send to your provider (PUCAI)

- This will also log the PUCAI score into the system so we can compare your scores in the future

[MyChart - Login Page \(mychartatradychildrens.org\)](https://mychartatradychildrens.org)

Support: 877-902-4278 (M-F 8am-5pm)





# stay connected

*to your child's health*



MyChart Username

Password

### Pay as Guest

**PAY A BILL** on behalf of a patient at Rady Children's Hospital

### Stay Connected

Helping kids—that's our bottom line. Every day, generous donors help ensure that each child gets the finest medical care and that every family receives the compassion and support they



## MyChart 4+

Your secure health connection

Epic

#1 in Medical

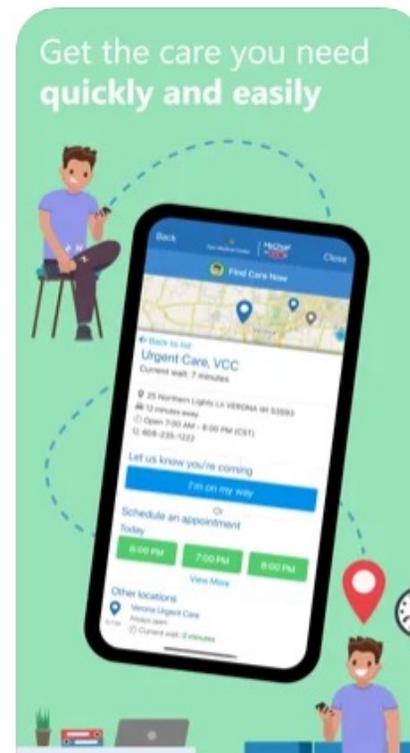
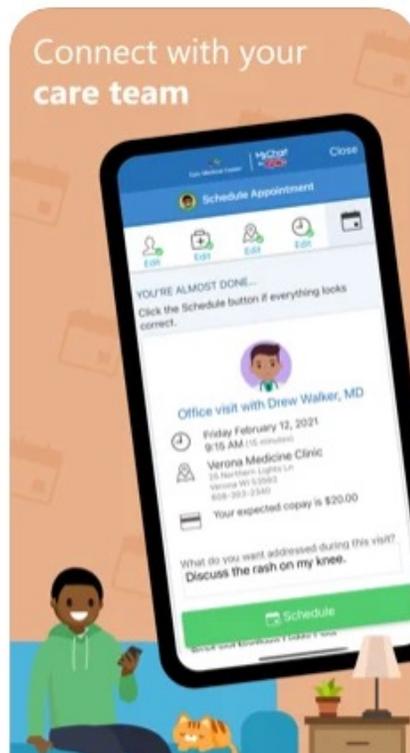
★★★★☆ 3.2 • 6.3K Ratings

Free

# Available as an App!

You can have multiple log ins for different patients and also for different locations (Sharp, UCSD, Rady's) in the same App

### Screenshots [iPhone](#) [iPad](#) [Apple Watch](#)



# Other Benefits of Rady MyChart

---

You can do all of the questionnaires for your visits in advance, on your own time

- Makes the visit shorter!

You can see your test results and your providers notes about the result

Available online or as an App on your phone



# Timeliness of Rady MyChart Messages

---

MyChart messages are read by staff and forwarded to providers as needed- this takes time!

They are not read on nights or weekends

Can take at least 2 business days to get a response

This is a great communication option, but not for urgent symptoms or urgent needs (i.e. if running out of medications in the next 1-2 days)



# Examples of MyChart Messages

---

Non-urgent questions such as:

- Who do I call to get this referral or imaging appointment?
- Can I take this multivitamin?
- What time should I come to my appointment? What is the address?
- I noticed a small, not very significant side effect that does not inhibit my daily life very much, what do you think?
- When am I due for labs or stool studies? Where did the orders get sent?



Updates-especially good ones (you can attach pictures!)

# Nurse Call Line: 858-966-4003 x3

---

Available Monday through Friday 8am-4:30pm

- Closed for lunch from 12-1. You can leave a voicemail message that will be returned

Speak with a GI nurse who can help answer questions and will message or page your doctor as needed

This is the best option for **urgent needs**



[Photo Credit:](#) Superstock Photography

# Reasons to Call the Nurse Line

---

Urgent questions such as:

- I (or my child) am having a new and significant change in IBD symptoms such as more diarrhea, more blood in the stool, fever
- I have been prescribed a medication by another doctor, should I take it?
- I am trying to decide if I need to be seen in the ER with symptoms



# After Hours Help

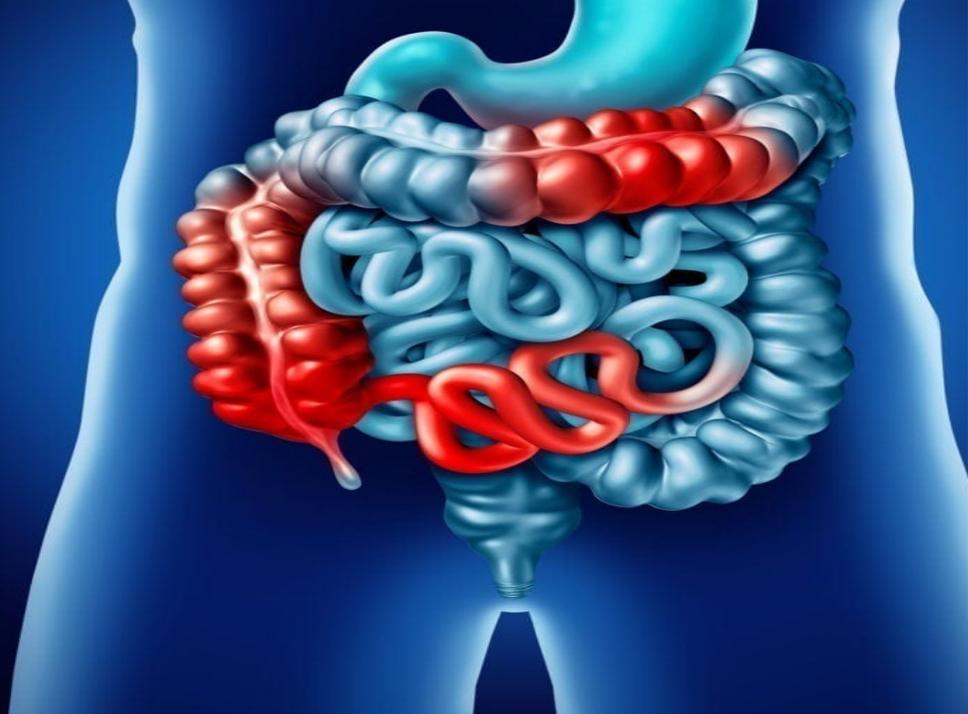
---



For **urgent/emergent needs** after hours or on weekends, you can page the GI doctor on call

- (858) 576-1700 ask for the “GI Doctor on Call”
- Will likely not be your specific provider as we rotate who takes the after-hour calls

As appropriate to your situation, they can order labs and/or medications or send you to the Emergency Room with a referral



# How To Get Vetted Information

---

AMY HEMPERLY D.O.

MARCH 20, 2021

# It can be tough to navigate the sea of information

---

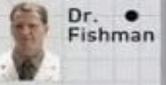
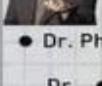


# Living in the age of fake news....



## Should You Trust That Doctor?

CollegeHumor

TRUST WITH YOUR LIFE			
 The Doctor	 Dr. Seuss	 Dr. Strange	 Dr. McCoy
		 Dr. Quinn	 Doogie Howser, MD
 Spin Doctors	 Doc	 Doc Brown	 J.D.
 Dr. Dre		 Dr. Bunsen Honeydew	 Dr. Fishman
 Dr. Horrible	 Zoidberg	 Dr. Mario	 Dr. Oz
	 Doctor Venture	 Dr. Phil	 Dr. Spaceman
 Dr Pepper	 Doctor Evil	 Dr. Robotnik	 Doctor Octopus
		 Dr. Hannibal Lector	
RUN. RUN VERY FAR.			

# Vetted Websites

---

1. <https://www.rchsd.org/programs-services/gastroenterology-hepatology-nutrition/services/inflammatory-bowel-disease-ibd-center/>
2. [www.ccfa.org](http://www.ccfa.org)
3. [www.gikids.org](http://www.gikids.org)
4. <https://www.crohnscolitisfoundation.org/justlikeme>
5. <https://www.improvecarenow.org/patients-parents>

# Gastroenterology, Hepatology & Nutrition

Gastroenterology, Hepatology  
& Nutrition

Team

Conditions Treated

## Services



Celiac Disease Clinic

Center for Healthy Eating and Activity  
Research and Treatment (CHEAR)

Colorectal Surgery Clinic

Cystic Fibrosis/ Gastroenterology  
Clinic

Endoscopy

Eosinophilic Gastrointestinal Disorders  
Clinic

Failure to Thrive Clinic

Fatty Liver Clinic

Inflammatory Bowel Disease (IBD)  
Center

Neurogastroenterology and Motility  
Center

San Diego Intestinal Rehabilitation

## Inflammatory Bowel Disease (IBD) Center

### [New! COVID-19 and Pediatric IBD Questions and Resources](#)

The Inflammatory Bowel Disease (IBD) Center cares for children with inflammatory bowel diseases, which include Crohn's disease, ulcerative colitis and indeterminate colitis.

Visits are longer than typical clinic visits in order to provide a comprehensive assessment and treatment. Children with IBD are regularly monitored in many areas, including nutrition, gastrointestinal symptoms, growth, anxiety/stress management and quality of life. We offer personalized treatment plans that are tailored to each patient and incorporate scientifically proven therapies. All children with IBD who are 12 years and older are enrolled into our transition program, which helps our young adolescents and adults learn necessary knowledge and skills to become their own health advocates.

The IBD Center works closely with colleagues from [Nutrition](#) and [Pediatric Surgery](#) in order to provide all necessary services. We also actively engage community partners, including the Crohn's and Colitis Foundation, and national partners, including the North American Society of Pediatric Gastroenterology, Hepatology and Nutrition, to provide the best standard of quality care.

The IBD Center holds an annual IBD Family Day to provide the community with more information/resources



<https://www.rchsd.org/programs-services/gastroenterology-hepatology-nutrition/services/inflammatory-bowel-disease-ibd-center/>

Search Radys IBD

**What is Crohn's Disease?**

Treatment Options

**What is Ulcerative Colitis?**

Treatment Options

**What is Inflammatory Bowel Disease (IBD)?**

Symptoms to Watch For

Diagnosis and Testing

**Newly Diagnosed**

**Mental and Emotional Well-being**

Pain and Fatigue

**Diet & Nutrition**

**Complementary Medicine**

**IBD Help Center**

**Colorectal Cancer & IBD**

**Youth & Parent Resources**

IBD & Me Activity Center

Planning with Your Child

Taking IBD to School

Navigating IBD as a Teen

For College Students

**Camp Oasis**

**Community & Support**

Online Community

Power of Two

Find a Support Group

**Participate in Research**

Clinical Trials Community

**IBDVisible Blog**

**IBD Stories**

**Financial & Insurance Information**

**Partnering with Your Doctor**

**Crohn's & Colitis Glossary**

**Helpful Links**

**Find a Medical Expert**

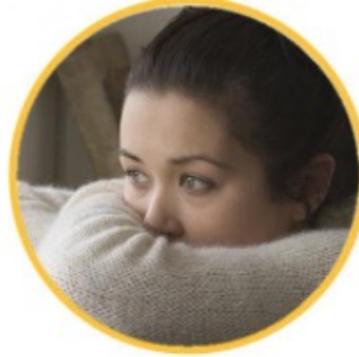
**IBD Journey**



### Diet and nutrition

Living with inflammatory bowel disease (IBD) means paying special attention to what you eat. Maintaining good nutrition can be a balancing act. Learn how to stay on the right track.

[WHAT SHOULD I EAT? →](#)



### Mental and emotional well-being

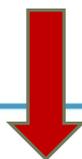
When living with IBD, people may experience difficult times where they feel limited in what they can do, who they can have relationships with, and how they live their lives.

[ABOUT MENTAL HEALTH →](#)

[What is Crohn's disease →](#)

[What is Ulcerative Colitis →](#)

[Newly Diagnosed →](#)



## How can we help?



I am a

- Patient**
- Caregiver**
- Clinician**
- Donor**
- Researcher**

who is looking for



[Sign up for our e-Newsletter](#)

## What is IBD?

Symptoms to Watch for

IBS versus IBD

Diagnosis and Testing

Resources for the Newly Diagnosed

IBD Factbook

# Newly Diagnosed

Facing a lifelong disease can be a lot to take in. Perhaps your mind is filled with questions and concerns. It is entirely normal to have these feelings, but there is help.

Let's start with the basics: Crohn's disease (CD) and ulcerative colitis (UC) are *chronic* (lifelong) inflammatory diseases that affect the digestive system. Together, they are known as inflammatory bowel diseases (IBD). *Crohn's disease* can affect any part of the gastrointestinal (GI) tract from the mouth to anus, while *ulcerative colitis* is associated with inflammation in the large intestine. About 10%-15% of people with inflammation of the colon have *indeterminate colitis*, which means it is difficult to determine whether they have CD or UC. IBD is often confused with irritable bowel syndrome (IBS), but they are different conditions.

The links below will get you started on the path to managing your disease. If you have specific questions, contact our **IBD Help Center!**

- **What is Crohn's disease?**
- **What is ulcerative colitis?**
- **Diet and nutrition**
- **Chapters in your area**
- **Find a healthcare professional**
- **Financial and insurance information**
- **Get support**
- **Resources for parents**

## What is IBD?

Symptoms to Watch for

IBS versus IBD

Diagnosis and Testing

Resources for the Newly Diagnosed

IBD Factbook

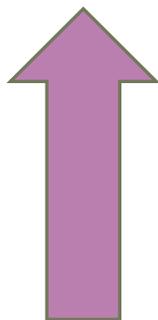
# Newly Diagnosed

Facing a lifelong disease can be a lot to take in. Perhaps your mind is filled with questions and concerns. It is entirely normal to have these feelings, but there is help.

Let's start with the basics: Crohn's disease (CD) and ulcerative colitis (UC) are *chronic* (lifelong) inflammatory diseases that affect the digestive system. Together, they are known as inflammatory bowel diseases (IBD). *Crohn's disease* can affect any part of the gastrointestinal (GI) tract from the mouth to anus, while *ulcerative colitis* is associated with inflammation in the large intestine. About 10%-15% of people with inflammation of the colon have *indeterminate colitis*, which means it is difficult to determine whether they have CD or UC. IBD is often confused with irritable bowel syndrome (IBS), but they are different conditions.

The links below will get you started on the path to managing your disease. If you have specific questions, contact our **IBD Help Center!**

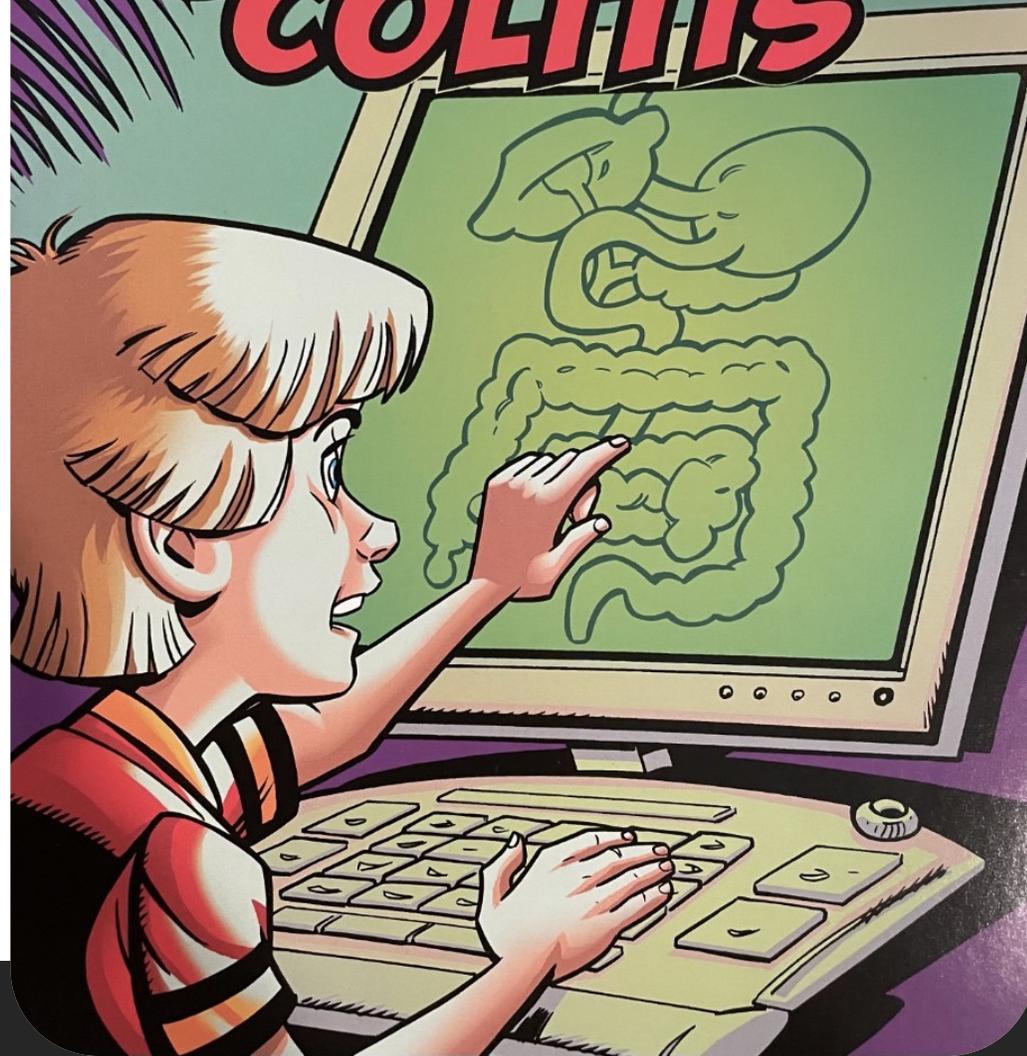
- **What is Crohn's disease?**
- **What is ulcerative colitis?**
- **Diet and nutrition**
- **Chapters in your area**
- **Find a healthcare professional**
- **Financial and insurance information**
- **Get support**
- **Resources for parents**



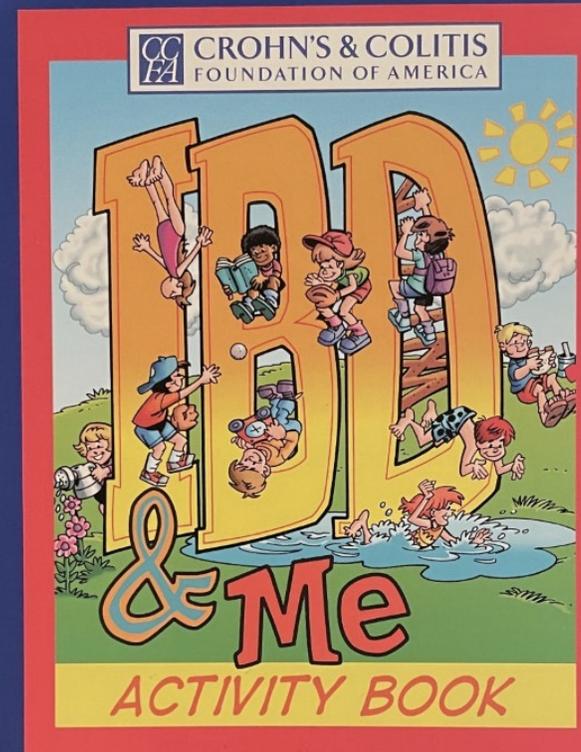
# Inflammatory Bowel Diseases



# PETE LEARNS ALL ABOUT CROHN'S and COLITIS



For Younger Children:



**IBD & Me** is an activity book for children ages 8-13 that will help them to learn about IBD and provides strategies to help them face and overcome challenges. The book includes short passages followed by games and other educational activities. It also contains important tools such as a bathroom tracker and glossary.

You can order **IBD & Me** at [www.ccfa.org/info/brochures](http://www.ccfa.org/info/brochures), or by calling 888-694-8872.

**CCFA** CROHN'S & COLITIS  
FOUNDATION OF AMERICA

386 Park Avenue South  
17th Floor  
New York, NY 10016

800-932-2423 • [www.ccfa.org](http://www.ccfa.org) • [info@ccfa.org](mailto:info@ccfa.org)

# Taking IBD to School

Section 504 Plan for \_\_\_\_\_

School \_\_\_\_\_

School Year \_\_\_\_\_

## Nature of the Disability

This student has a form of Inflammatory Bowel Disease (“IBD”) called \_\_\_\_\_ (Crohn’s disease or ulcerative colitis). IBD is a chronic disease affecting the intestines. Ulcerative colitis affects the colon; Crohn’s disease can affect any part of the digestive track, from the mouth to the anus. The most common symptoms are diarrhea, abdominal and rectal pain and cramping, nausea, vomiting, fatigue, and arthritis-like joint pain. Although its cause is unknown, IBD involves the immune system and causes inflammation and ulceration of the lining of the intestines. The emotional and physical pieces are interrelated in complex ways, and patients can experience flare-ups during times of emotional tension and stress. Changes in cognitive function including compromised attention and concentration, reduced capacity to process information, disruptions in memory and reduced ability to multitask are also manifestations of this disease. Changes in physiological functioning of the gastrointestinal tract characteristic of this disease can be exacerbated during period of environmental and/or psychological stress. The stress in/and of itself does not cause the disease.

Treatments can include immuno-suppressant drugs that render patients more susceptible to illness and intensify reductions in neurocognitive functioning described above. Patients may be on a restricted diet; may need to eat several small meals per day; and most likely will need to take medication during the school day. Some treatments are provided intravenously in the outpatient hospital setting that may cause a student to miss multiple days of school.

Although surgery is avoided to the extent possible, students affected by IBD may require surgery, including surgical revisions of the digestive track, such as ileostomy and colostomy.

# Taking IBD to School



## Welcome to Campus Connection!

Heading to college? Find and  
connect with other IBD  
patients near you.

**FIND OTHERS** →

# Juggling Work and Your Child's Medical Care

It can be difficult to balance your career and your child's medical needs. As a caregiver, it is likely that you will need at least some absences during the year to care for your child.

## Common reasons for absences from work include:

- Hospitalizations
- Surgery
- Medication infusion
- Flares

To avoid facing consequences at work, or even losing your job, you can take leave under the **Family and Medical Leave Act** (FMLA).

## FMLA Basics

- The FMLA provides up to 12 weeks of unpaid leave in a 12-month period for employers with 50 or more employees.
- Certain states have less restrictive laws, providing FMLA leave for smaller employers and/or for longer periods of time.
- You must request FMLA leave in writing and in advance. You do not have to wait for a crisis before requesting FMLA leave. We recommend you request FMLA leave at the beginning of each year on the basis that you are the caregiver for a child with a chronic, often debilitating illness and some absences are to be expected during the year.
- FMLA is generally unpaid leave. Your employer can require that you apply your paid vacation and sick time to your FMLA leave.
- Once you have FMLA leave, you cannot be fired for using it, as long as you do not use more than 12 weeks of leave each year.

# Community and Support

## Power of Two

Do you need someone to talk with about inflammatory bowel disease (IBD)? **Power of Two** is the Foundation's peer-to-peer support program. It's open to IBD patients and caregivers seeking one-on-one support from a fellow patient or caregiver who may have had similar experiences. Check out our video below to learn more!



# Community and Support

## 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** proudly established Camp Oasis exclusively for children with IBD over 15 years ago.

This residential summer camp program enriches the lives of children with **Crohn's disease** and **ulcerative colitis** by providing them with a safe and supportive camp community. Watch the video below to learn more!



# Community and Support

## Support Group: San Diego, CA Support Group - Health Holistically- VIRTUAL

San Diego, CA 92122

[drpamelanathan@gmail.com](mailto:drpamelanathan@gmail.com)

Greater San Diego and Desert Area Chapter

**Meets:** 05:30 PM - 06:30 PM, Monthly



### San Diego Support Group

Health Holistically  
**currently meeting ONLINE!**

Reach out to facilitator for  
most up-to-date meeting  
schedule and details

Contact Pamela Nathan at  
[drpamelanathan@gmail.com](mailto:drpamelanathan@gmail.com)

  
CROHN'S  
& COLITIS  
FOUNDATION

# Community and Support

[Home](#)[Our Stories](#)[Community Forum](#)[Online Support Programs](#)[Expert Q&A](#)

## Community Forum

Have a question, or want to share your own tips and experiences? Join the discussion in the community forum. You must be registered to participate. Our forums are moderated by Crohn's & Colitis Foundation staff to facilitate a safe environment.

[COMMUNITY HOME](#) / [COMMUNITY FORUM](#)[RULES](#)

### FORUMS

[Newly Diagnosed](#)[Managing Symptoms](#)[Treatments](#)[Day to Day](#)[Diet & Nutrition](#)[Emotional Wellness](#)[Surgery](#)

### LATEST POSTS

Wed, March 17, 2021 11:09 PM  
By Jamiebeth

Tue, March 16, 2021 10:53 AM  
By charbs

Thu, March 18, 2021 1:15 AM  
By angilamathew011

Mon, March 15, 2021 12:44 PM  
By administrator

Mon, March 15, 2021 12:51 PM  
By administrator

Mon, March 15, 2021 11:41 AM  
By administrator

Tue, March 16, 2021 12:19 PM  
By charbs

---

## 4 results

---

### High School Sports with IBD

December 17, 2018

Written by Curtis, age 18 There is one word that soulfully describes high school sports, fast. The adrenaline pumps through your veins, your heartbeat starts to rise, you are ready to compete. On the field I feel at home, I feel normal, and having this feeling while battling IBD is...

[Read more...](#)

---

### How to deal with accidents

December 17, 2018

Written by Sneha, age 18 -Crohn's and Colitis Young Adults Network Accidents can be embarrassing

# IBD and Me Activity Center

## IBD Heroes

People with IBD can still reach for the stars! Check out these IBD Heroes doing what they love:

### Jake Diekman

MLB relief pitcher Jake Diekman was only 11 years old when he was diagnosed with ulcerative colitis. In 2017, Jake underwent three surgeries to remove his diseased colon and create an internal j-pouch. He missed the first half of the baseball season that year, but returned to the mound after recovering in the fall. That same year, Jake and his wife Amanda founded the **Gut It Out Foundation** to raise funds to support IBD education, research, and pediatric care, and highlight support groups for patients and caregivers nationwide.



### Larry Nance, Jr.

When Larry Nance, Jr. was diagnosed with Crohn's disease at 16, he could barely get out of bed let alone play basketball. His doctor helped him find a medication that worked to help quell his symptoms, and that propelled his life toward achieving his dream. Now, at 6 feet 9 inches tall and 230 pounds, Larry is a forward for the Cleveland Cavaliers. He also cofounded **Athletes vs. Crohn's & Colitis (AvC)**, a non-profit that seeks to raise awareness of Crohn's disease and ulcerative colitis among children and teens, and help children realize their athletic potential despite being diagnosed with a chronic illness.



### Kathleen Baker

Kathleen Baker was diagnosed with Crohn's disease when she was 13 years old. She had always wanted to be a swimmer and compete in the Olympics, but she thought her swimming career was over. Thanks to help from her doctors and coaches, Kathleen figured out the best way to manage her disease while working toward her goals. "I had to learn to train smarter, not harder." Kathleen saw her dream come true when she competed in the 2016 Olympics and earned medals in the 4x100-meter medley relay and the individual 100-meter backstroke. Now Kathleen is training for the 2021 Olympics and wants other patients to know that they can accomplish anything they want – they just might have to go about it differently from others.



### Rebecca Zamolo

YouTube superstar Rebecca Zamolo was a Division 1 athlete in college, running track and field at the University of California, Santa Barbara. It came as a shock to her when her stomach issues turned into something bigger and she was diagnosed with ulcerative colitis. Her health went downhill fast – at one point, she was going to the bathroom up to 50 times a day and was hospitalized every three months.



She met her now husband Matt and they got married and went on their honeymoon. But when she returned, her doctor told her she needed to have surgery to have her colon removed and an internal pouch created. It was then that she decided to start sharing her story publicly and decided to document her journey on video from surgery to running a half marathon just two months after having her colon removed.

# Welcome to the IBD Help Center

Do you have questions about Crohn's disease or ulcerative colitis? **We can help!** The Irwin M. and Suzanne R. Rosenthal IBD Resource Center, also known as the IBD Help Center, provides information and resources to patients, caregivers, and healthcare providers about inflammatory bowel disease (IBD).

Our team of information specialists can:

- Help you find specific resources
- Refer you to other organizations
- Help you understand health insurance coverage

Our helpline is available Monday through Friday from 9 a.m. to 5 p.m. EST

Call us: 1-888-MY-GUT-PAIN (888-694-8872, extension 8)

Email us: [info@crohnscolitisfoundation.org](mailto:info@crohnscolitisfoundation.org)

**Chat live with a specialist.** Available Monday, Tuesday and Thursday from 9 a.m. to 5.p.m. EST

## **Download free brochures**

Our free brochures cover a wide range of topics relating to IBD, including surgery, diet and nutrition, and possible complications. To receive hard copies of these brochures through the mail, **fill out our brochure order form.**



# Inflammatory Bowel Disease

HOME / INFLAMMATORY BOWEL DISEASE (IBD)

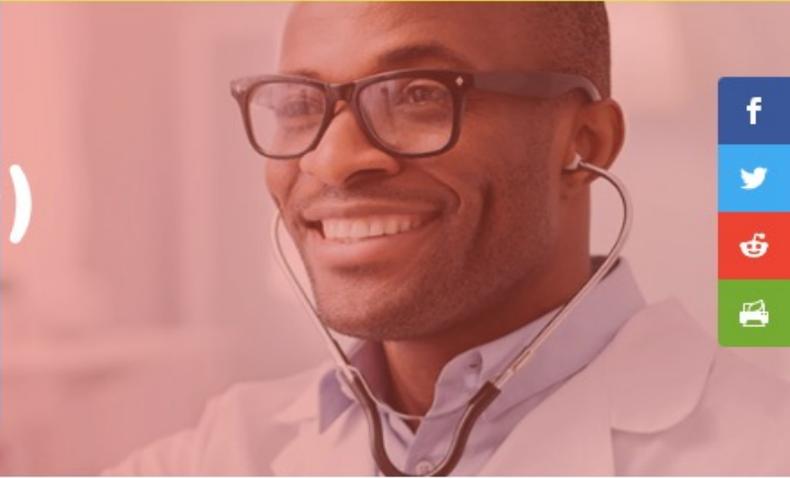
SYMPTOMS & DIAGNOSIS

TREATMENT & MANAGEMENT

COPING

TRANSITIONING

RESOURCES



Inflammatory Bowel Disease (IBD) is a chronic inflammatory disorder of the intestines that does not have an identifiable cause (such as infection). Pediatric IBD causes the immune system to become inappropriately active, causing injury to the intestines.



[Digestive Topics A-Z](#)

## Audio

### Maintaining Healthy Nutrition in Pediatric IBD Patients

During this series, we will discuss the important role diet plays in the management of IBD focusing on maintenance of good nutrition, enteral nutritional therapy as well as the Specific Carbohydrate Diet. You will hear from medical professionals as well as two parents who have first hand experience implementing enteral nutritional therapy and the Specific Carbohydrate Diet. Additionally, we have included a podcast on navigating independence when transitioning to college or the work force.

### Podcast Series

 [Click for an audio highlight of the parent interview](#)

 [IBD Nutrition Episode 1](#)

 [IBD Nutrition Episode 2](#)

 [IBD Nutrition Episode 3](#)

 [Navigating Independence](#)



[About](#) ▾ [Get Involved](#) ▾ [Tools](#) [Patients & Families](#) ▾ [Healthcare Professionals](#) ▾ [Research](#) ▾ [Members](#) [Donate](#)

Patients & Parents

[www.improvecarenow.org](http://www.improvecarenow.org)



IBD SURGERY DECISION-MAKING  
TOOLKIT



SELF-MANAGEMENT HANDBOOK



VISIT PLANNERS



GROWING UP WITH IBD



STAYING HEALTHY WITH IBD



TOOLKITS, GUIDES & OTHER  
RESOURCES

Accommodations for IBD

Body Image and IBD

Clinical Research 101

College & IBD

Disordered Eating Toolkit

Finding a Mental Health Provider for Your Child and Teen with IBD

Nutrition and IBD

The Ostomy Toolkit

Smart Patients

Talking about IBD

Transition and Transfer to Adult Care

Travel Toolkit

# Other Patient and Parent Resources

---

- Your IBD binder
- Your transition medical summary
- Transition handouts/resources
- Connect with your IBD provider
- Yearly IBD family day

