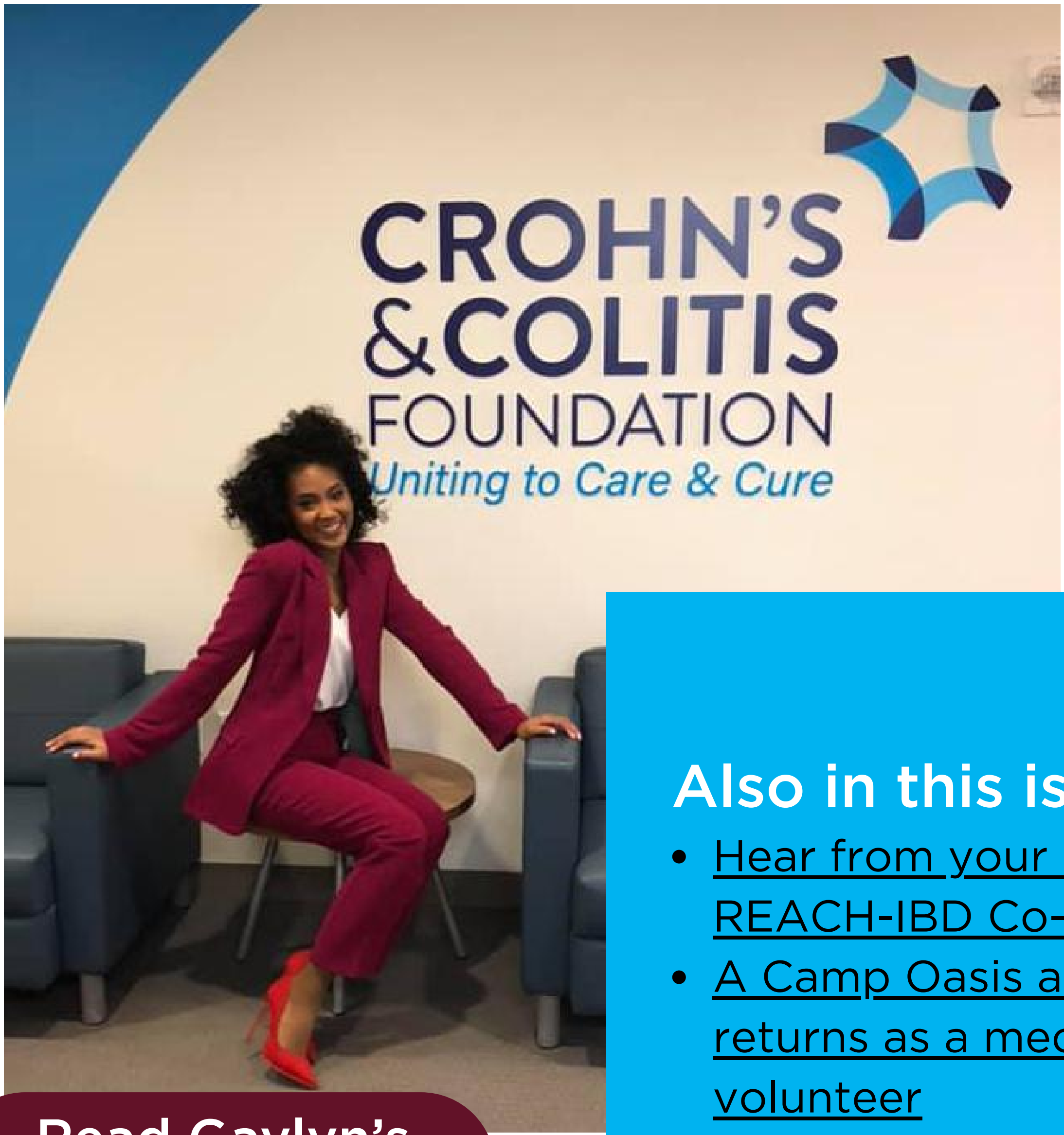
CROHN'S
&COLITIS
FOUNDATION

Summer 2025

REACH-IBD Newsletter



Read Gaylyn's ostomy story

Also in this issue...

- Hear from your new REACH-IBD Co-Chair
- A Camp Oasis alum returns as a medical volunteer
- Stoma care for summer
- Roundtable recap
- And more!

A Note from Your New REACH-IBD Co-Chair

I'm thrilled to contribute to this edition of the REACH-IBD newsletter as the newest co-chair, joining Dr. Sonny Qazi in leading this incredible community.

I was first introduced to REACH-IBD as a junior faculty member and vividly remember attending an early Crohn's & Colitis Congress event where I connected with peers also beginning their careers in IBD, as well as senior leaders in the field. Those early introductions evolved not only into valued friendships, but have also helped build fruitful collaborations, brought help in tight spots of all sorts, and initiated further career connections. That experience shaped my understanding of what REACH-IBD can offer: a professional home that fosters growth for those committed to IBD care, research, and education.

This June, we hosted a phenomenal panel featuring Drs. Sandra Quezada, Ariel Jordan, Aline Charabaty, and David Rubin, who led an inspiring roundtable on career development, advocacy, DEI, and leadership. Looking ahead, we're planning a full calendar of educational events, including an in-person gathering at the next Crohn's & Colitis Congress.

In today's environment—marked by rising IBD prevalence and growing treatment complexity—we're also focused on cultivating interest in IBD among GI trainees. To that end, we're launching a new workgroup dedicated to engaging GI fellows and ensuring that REACH-IBD programming supports their professional development. **If you're a trainee, we encourage you to join REACH-IBD through the Foundation's free trainee membership.**

That's just one of several new initiatives we're excited to roll out this year. Above all, our goal is to support you—our members—as your needs evolve. Please don't hesitate to *REACH* out with your ideas, questions, or suggestions.

Warmly,
David Fudman, MD
Division of Digestive and Liver Diseases
University of Texas Southwestern Medical Center

Full Circle: A Camp Oasis Alum's Mission to Improve Life with IBD

Interview with Maggie Murray, MA, LPCC

What inspired you to volunteer at Camp Oasis?

I decided to volunteer because I attended Camp Oasis at age 16, when I was freshly diagnosed with ulcerative colitis. I enjoyed it so much I attended again as a Leader-In-Training (LIT) the following year. Once I became a licensed therapist, I applied to come back as a volunteer so I could help provide the same amazing camp experience I had to today's campers! I had so much fun last year I'm back again 😊

What unique challenges do you see IBD patients facing in a camp setting, and how does Camp Oasis help address them?

I think the best part about Camp Oasis is that what might seem like a “unique challenge” at other camps, isn’t abnormal at Camp Oasis! You need to take medication four times a day? So does this whole group of kids too! You need to go to the bathroom frequently and urgently? Of course, head on over to the very nice bathrooms that are on the camp property! You have dietary restrictions? Me too, let’s go to get our custom plate of food together! Camp Oasis does a great job of both accommodating different needs children bring to camp, as well as taking away the stigma that can come with some of the challenges IBD can bring.

What do you hope each camper takes away from their experience at Camp Oasis, beyond just having fun?

I hope campers feel a reduction in any shame or embarrassment they have around having IBD, more confident in their ability to do whatever they want regardless of having IBD, and feel more connected to & supported by the IBD community!

Tell us more about your experience as a licensed therapist at Camp Oasis.

My experience is unique: I have specialized training in children’s mental health counseling and I’ve also had UC since I was a teen. This helps me balance out knowing what the disease can look like medically with the emotional impact of IBD. I find it easy to connect with kids at camp because I have often been in their shoes!

How did attending Camp Oasis as a camper shape your journey with IBD and influence your career path?

Camp Oasis removed some of the shame and embarrassment I felt around having a chronic illness as a young person. I got to meet other people my age that understood what it was like to go the bathroom more often, have had colonoscopies, had to talk about your poop to so many medical professionals, having a moon face on prednisone, and so many other things I thought no one else had to deal with.

Attending Camp Oasis showed me I wasn't alone and there was a community of people out there that understood my experience and could share stories & tips & successes from their journey with IBD. I also got to see counselors that have IBD and off at college & living in dorms – things that felt undoable to me as a very sick 16 year old and took some of the fear away around what my future might look like with a chronic illness. It can feel isolating to have a chronic disease as a child, and Camp Oasis shows how many other people have IBD and are living happy & healthy lives!

Camp Oasis, and specifically the LIT program, helped me to confirm I wanted to work with children as my career – and now I'm a child mental health therapist!

What is a favorite camp memory?

I took the bus to Camp Oasis my first year of camp and felt so nervous because I didn't know anyone. I found a random girl around my age to sit next to, and she was immediately so kind that I knew right then I had made a great choice coming to camp. I found all three years I've been to camp that all the campers are so welcoming and fun to be around that we have a blast with each other right from the start!

Maggie Murray is a Licensed Professional Clinical Counselor (LPCC) and a school based mental health therapist in Minnesota. Maggie has worked in school settings for the past six years, and has been a school based therapist since 2020. Part of Maggie's job includes working with school counselors and school social workers to help advocate for student accommodations. Maggie is currently working in a kindergarten through 8th grade school in Minneapolis, MN. Maggie also volunteers at Camp Oasis as the Lead Mental Health Specialist.

Special Stoma Supplement

Stoma care tips provided by Michele Rubin, APN, CNS-GI, Associate Director of the IBD Center at University of Chicago Medicine. Michele is a nationally recognized IBD expert with over 45 years of experience in IBD nursing, education, and multidisciplinary care.

Most Impactful Aspects of Stoma Care for IBD Providers to Share with Patients

Empower through education: Understanding stoma type, appliance options, and common troubleshooting builds confidence and reduces anxiety for your patients.

Skin integrity is key: Peristomal skin care is critical. Emphasize:
- using appropriate barrier products
- proper skin cleansing, avoiding harsh soap
- inspecting regularly for irritation or breakdown

Routine changes and fit check: Teach patients to establish a consistent schedule (i.e., every 3-4 days) for changing their appliance , ensuring a good seal to avoid leaks.

Pouching Skin Barrier
Evaluate the back of the skin adhesive barrier to note stool leak and assess why it occurred

Nutrition and hydration guidance: Discuss dietary adaptations post-surgery.

- Chew food thoroughly to avoid blockages from high-fiber foods.
- Ileostomy patients should not drink on an empty stomach. Eat foods first that act like a sponge (i.e., carbs) to thicken stool. If output is watery more than 20% of the time in 24 hours, the patient may be at risk of dehydration.
- Tell patients to think of their GI system like a pipe. How it goes in the mouth is how it will come out the stoma. Drinking only liquids causes fluid to run right through to the appliance, filling it with water and providing no nutritional benefit. Eat a “sponge food” first, then sip on water. The food soaks up the liquid and slows down the transit time long enough for the intestine to leach out the nutrients and fluids, leading to hydration and a thicker stool.
- Oral rehydration formulas such as DripDrop, Liquid I.V, Gatorlyte, Pedialyte, and Nuun can help to replace electrolytes that are lost with all liquid stool output. Ask your stoma nurse for homemade options.

1-Piece vs. 2-Piece Pouching Systems

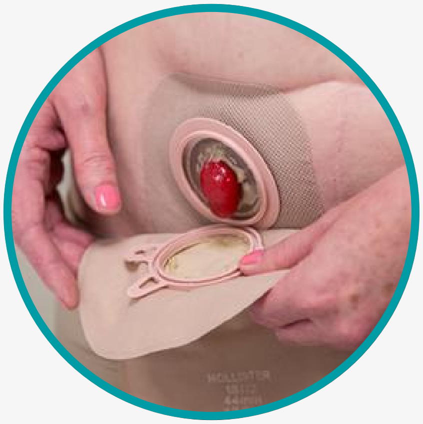
Ostomy Concealment

Emotional support: Don’t wait for the patient to raise psychological concerns, just ask! ·

- Address body image with a stoma
- Encourage the patient to discuss the psychological impact openly
- Remind them: just as your disease does not define you, neither does your stoma
- Stoma support groups can be very helpful

> **“Once they can talk about their stoma, patients are more likely to accept it—and so are their loved ones.”**
> **-** *Michele Rubin, APN, CNS-GI*

Normal stoma



Denuded/irritated peristomal skin

Peristomal pyoderma gangrenosum

When to seek help: Educate on red flags like persistent skin issues, appliance detachment/leaks of stool, signs of dehydration and obstruction. Encourage them to reach out to a stoma nurse or other specialist promptly!

Foundation Ostomy Resources

- 📄Ostomy Case Study
- 🎥 Surgical Management of IBD: Goals, Benefits, & Risks Video
- Surgical Overview & Pearls: This resource provides a quick and thorough overview of IBD surgery including common indications for surgery, primary goals of surgery, common surgical procedures, post-operative issues, and finally, clinical pearls as takeaway points.
- Assessment of Patient with Fecal Diversion: This resource will assist you in assessing a patient with an ileostomy or colostomy and will provide suggestions for referrals and/or interventions.
- Ostomy Resources: A list of ostomy organizations and supply manufacturers.

Busting Stoma Myths

Myth	Reality
“I can’t be active with a stoma.”	People with stomas can play sports, swim, skydive, travel, and live fully.
“I’ll never eat certain foods again.”	Many foods can be reintroduced with time, chewing, and hydration.
“Stomas always smell or leak.”	Proper fit and hygiene minimize odor and leaks. Ask for help early.
“I can’t wear fitted clothing.”	Form-fitting clothes and support bands (e.g., Stealth Belt) make it easier to feel secure.

When Should You Refer a Stoma Patient to a Specialist?

Specialist	Key Referral Triggers
Colorectal Surgeon	Stoma prolapse, retraction, parastomal hernia, recurrent fit issues
Plastic Surgeon	Complex hernia repair, abdominal wall reconstruction
Dermatologist	Persistent skin issues (e.g., dermatitis, pyoderma gangrenosum)
WOC Nurse (WOCN)	Early education, troubleshooting leaks, appliance fit, annual check-in
Dietitian/Nutritionist	Hydration support, reintroducing foods, malnutrition concerns

Stoma-Safe Summer Tips for Patients

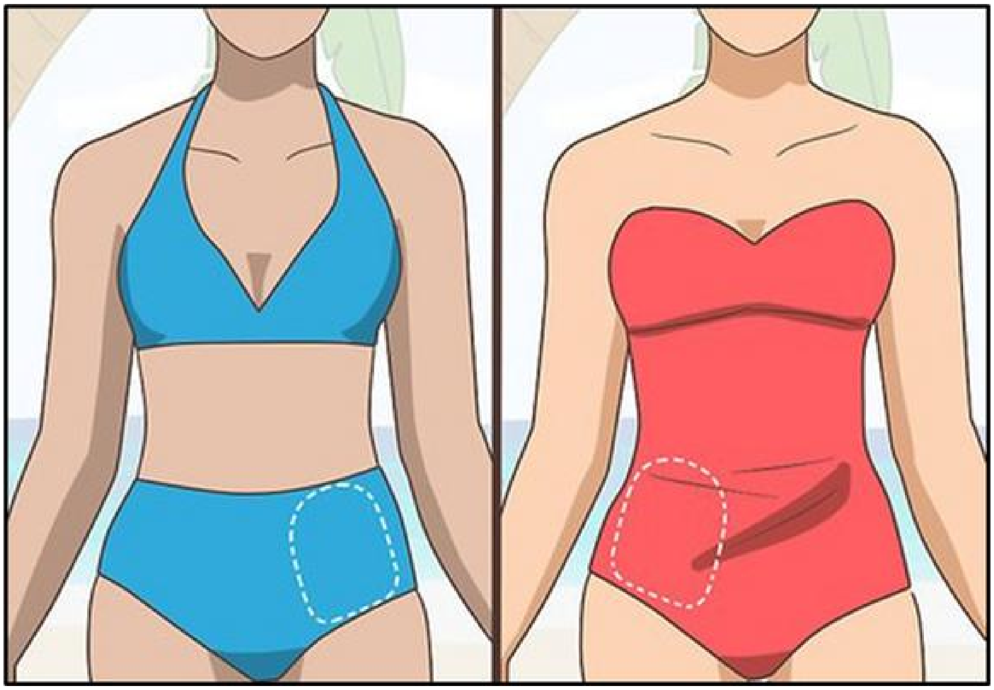
💦 Before You Dive In

- Use waterproof barrier films or flange extenders (e.g., SureSeal, AquaSeal)
- Consider water-resistant, high-adhesive pouching systems (e.g., Hollister Adapt CeraRing, Coloplast Brava)
- Empty pouch before swimming
- Snug swimwear or stoma support garments provide extra security
- After swimming, inspect the seal and dry skin thoroughly before reapplying

🌞 Sun Protection

- Protect the stoma from direct sun exposure using a cloth cover or SPF-free barrier cream to avoid appliance damage
- Adhesives may loosen in high humidity — pack extra supplies
- Staying hydrated is extra important since dehydration can be more pronounced with ileostomies. Remember to snack first, sip second. Oral rehydration formulas also help

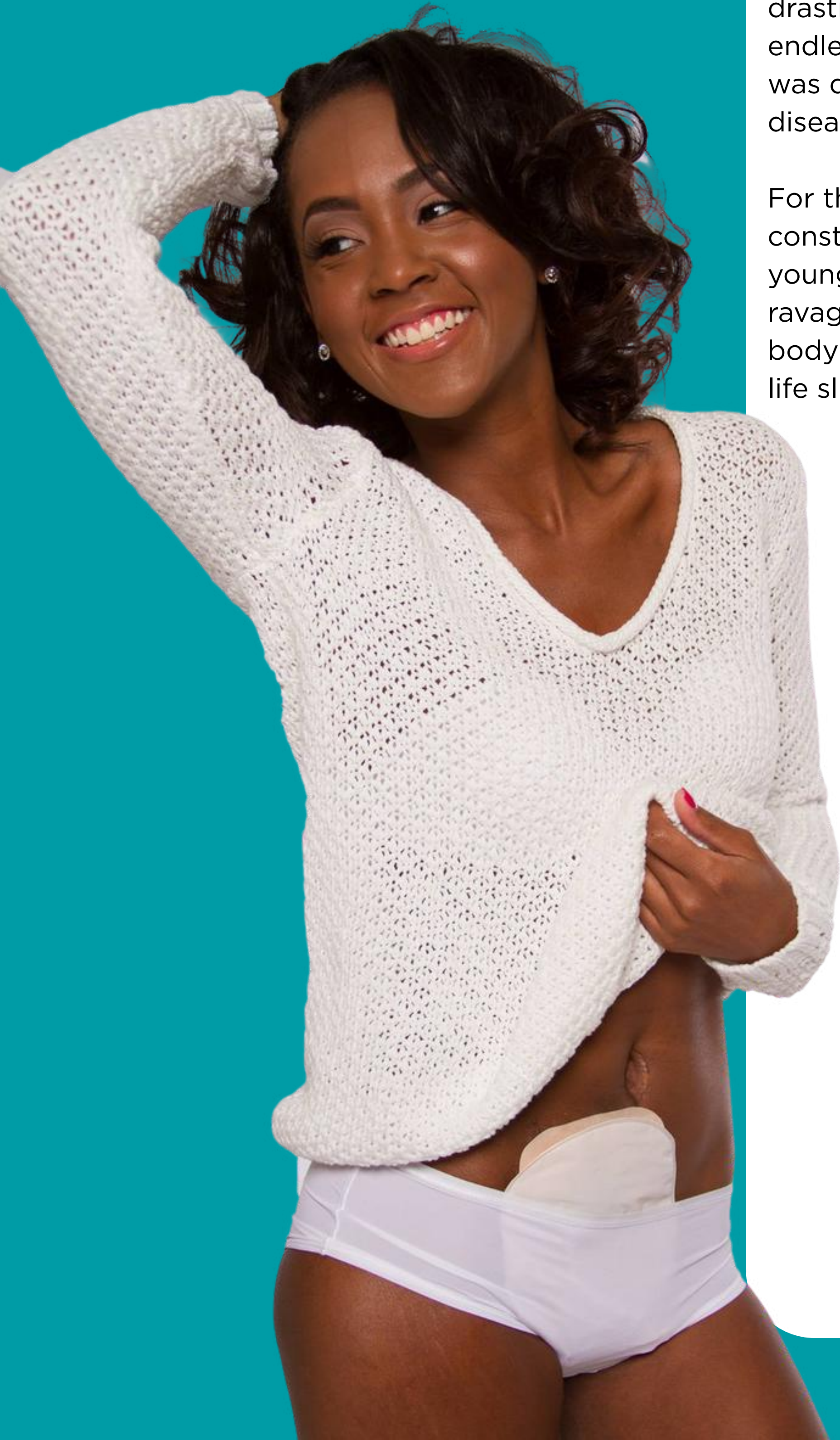
IBD Pro Members can download a one-page PDF of these tips for patients from the Exclusive Resources post on our member portal.



My Ostomy Story

Finding Relief after a Decade of Pain

Gaylyn Henderson



The symptoms began just before my freshman year of high school: intense abdominal pain, frequent diarrhea, drastic weight loss, exhaustion... and endless trips to the bathroom. At 14, I was diagnosed with severe Crohn's disease.

For the next ten years, I endured constant, overwhelming pain. I was still a young woman, but Crohn's disease ravaged my body and mind. Over time, my quality of life slipped away.

Prior to my proctocolectomy, I had multiple surgeries — sigmoid resection, fistulas, and abscesses – but nothing gave me relief. I was so determined to avoid ostomy surgery that I tried everything else. But my body made the decision for me. At my doctor's insistence, I finally conceded to a temporary ostomy to let my lower colon and rectum heal.

After my temporary ostomy, I felt so much better – I knew I was never going back. I didn't realize my disease was still progressing rapidly, and eventually, I had my entire colon and rectum removed. Today, I live with a permanent ileostomy. I truly wish I'd had my ostomy surgery sooner.

Overcoming Fear and Stigma

Since my previous surgeries had not helped, my biggest fear was that ostomy surgery wouldn’t work either. Reversal wasn’t an option; it felt so permanent.

I had a series of concerns: Would it smell? Would I stink? Could I wear certain clothes? What would people think? Negative stigma was front of mind. As a young woman, I didn’t know anyone my age with one. Even medical providers fed the stigma, advising me against it for a variety of reasons.

But just days after my first ostomy surgery, my pain was gone, along with my fears. I couldn't believe I allowed the stigma surrounding ostomies to influence my decision to get one and, ultimately, affect my quality of life. I felt so much better, I didn’t really care what anyone else thought about it.

What I Wish My Provider Had Told Me

Everybody adjusts to an ostomy differently. Some, like me, adjust quickly. But it’s a major surgery. It’s important to connect ostomy patients with the right support, such as experienced mental health providers that have training in chronic illness or GI Psychologists.

One thing I wasn’t psychologically prepared for was having rectal “area” pain without a rectum. I spent almost a decade after surgery trying find answers. Being diagnosed with pelvic floor dysfunction finally allowed me to find relief.

How Ostomy Changed My Life

Prior to ostomy surgery, I was underweight, consistently losing weight due to very severe disease. I was afraid to eat and use the rectum. I was constantly in pain, missing out on college fun with friends.

After surgery, all of that changed in an instant. I gained 10-20 pounds within a month. I was so excited to not be in pain. Being able to experience life events with friends did wonders for me emotionally and psychologically.

Day on the Hill with Crohn's & Colitis Foundation CEO Michael Osso

Since having an ostomy for almost 20 years, it has become second nature. I get up, go to the bathroom, wash my face, and get dressed; I just so happen to use the bathroom differently than the average person.

On days I may not have easy access to a restroom easily, I may take loperamide so I don't have to empty my ostomy appliance as much. If I will be away from home, I pack a little pouch of extra ostomy supplies, just in case. If I am traveling by air, I always make sure these items are in my carry-on.

Being a Patient Advocate

The Foundation has been instrumental in my journey living with Crohn's disease, from attending Camp Oasis as a camper to returning in leadership roles. I have participated in Take Steps and volunteered with my local chapter.

I have advocated on Capitol Hill with the Foundation, sharing my story to inspire and make real change for myself and other patients. I served on the Inaugural Patient Advisory Committee, I served as a Social Influencer for the National Crohn's and Colitis Foundation and I am now a Social Media Ambassador with the Foundation. I am very proud to be awarded the first ever Catalyst for Online Community Engagement Award by the Crohn's and Colitis Foundation.

2019 Day on the Hill with the late civil rights activist and venerated U.S. Representative from Georgia, John Lewis, making good trouble in the fight against IBD!

So much exciting work is on the horizon with the Foundation and we are always looking to expand to reach as many patients as possible, from all walks of life. This fall, I'm helping launch a Foundation support group for Black and African American women living with IBD in the Southeast Region.

The Crohn's & Colitis Foundation has been foundational in my disease journey for over 20 years, since early diagnosis. In that time I have grown from being a patient to becoming a patient advocate. I have been empowered by every connection I have made through the Foundation, and now I use my voice to raise awareness, support, and education for those who may still be struggling to find their voice. IBD impacts so much of our lives every day in every way. As a patient advocate, I am committed to making sure no one faces this disease alone.

REACH-IBD Recap: “Empowering the Next Generation of IBD Experts” Roundtable Highlights

Nisha Loganantharaj, MD, and Michelle Rosario, MD

Diversity & Inclusion

Dr. Sandra M. Quezada

Challenge: Prevalence of IBD is rising in minority groups who have higher odds of facing worse outcomes in IBD.

How can we create change?

- Empower patients with knowledge
- Encourage open discussion about barriers
- Utilize patient assistance programs and multidisciplinary approach
- Expand IBD knowledge through national programs and case discussions
- Advocacy, advocacy, advocacy!

Advocacy

Dr. Ariel Jordan

Anyone can advocate. **Start small**. Start now.

4 Steps to Action:

1. Pick an issue (Get informed + listen to patients)
2. Have a strategy (Set goals, map allies/opponents)
3. Craft your story (Clear, compelling, personal)
4. Meet your rep (10–20 min, team up with others)

Career Advancement

Dr. Aline Charabaty

Purpose = Passion + Mission + Vocation + Priorities

Find *your* path:
- 🧭 Sailboat: Adapt to new winds
- 🪜 Ladder: Traditional steps
- 🛝 Jungle Gym: Nonlinear exploration

💡 **Invest in yourself. Set boundaries. Be bold.**

Leadership Development

Dr. David Rubin

Leadership = Purpose + Action + Growth

🛠️Your Toolkit:
- Keep patients at the center
- Find your North Star
- Show up and deliver
- Be a team player
- Embrace new ideas
- Network with purpose

Have you gotten your digital membership card yet?

Add your card to Apple or Google Wallet from your member profile on our **portal**... or join today!

Announcements from REACH-IBD members

From Elie Al Kazzi, MD, MPH:

Are you a provider who takes care of IBD patients who are members of the LGBTQIA+ community? We are interested in your perspective on high-quality care for our patients!

Learn more

CROHN'S & COLITIS CONGRESS

JANUARY 22-24, 2026 • LAS VEGAS

Important Dates

Registration

Registration Opens: Wednesday, July 23, 2025
Early Registration Deadline: Tuesday, September 2, 2025
Advanced Registration Deadline: Tuesday, October 21, 2025
Discounted Registration Deadline: Tuesday, December 9, 2025
Standard Registration Deadline: Tuesday, January 20, 2026

Abstract Submission

Abstract Submission Opens: Wednesday, August 13, 2025
Abstract Submission Deadline: Wednesday, September 24, 2025
Abstract Notification: Monday, November 17, 2025

We’re building something new

Want in?

We’re piloting a new discussion space for IBD professionals—and we’re looking for a few early-career members who want to help shape it.

If you’re the kind of person who asks great questions, shares useful resources, or just wants to connect outside of meetings… we’d love to have your voice in the mix.

📝 **Drop your name to get involved**