



M.I.R.I.A.D. Biobank

Material and Information Resources for Inflammatory And Digestive Diseases

A Newsletter about Research at Cedars-Sinai IBD

MIRIAD Biobank: Making a Difference for People With IBD

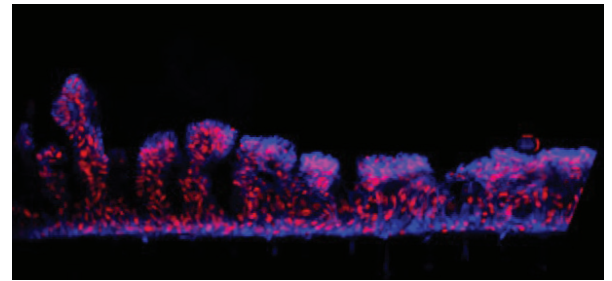
Stem cell research and what it means for IBD – Robert Barrett, PhD

Stem cells are a hot topic in medicine and science, and they're being used or investigated as a new treatment approach in many diseases. The MIRIAD Biobank has created a unique opportunity for stem cell research in IBD. MIRIAD has been in operation for nearly 30 years and contains samples generously donated for research by people who have IBD as well as many who don't (samples from people without IBD are used as experimental controls). The samples are used in scientific studies that can lead to important discoveries into how genetics, the microbiome and the immune system all play a role in IBD. However, it's difficult to study how these all come together in the intestine itself because the intestine is only accessible through invasive procedures such as colonoscopy or surgery. To overcome this obstacle, a team of researchers led by Robert Barrett, PhD, is addressing how the intestine is implicated in this disease by combining stem cell and other innovative technologies.

Thanks to the volunteers who have participated in the MIRIAD Biobank, there are specially stored blood cells from more than 12,000 patients with IBD and individuals without IBD available for research. Barrett has developed a special technique by which these cells can then be reprogrammed to form stem cells. These stem cells are genetically identical to the original donor and can be directed to form almost any cell type in the body.

Barrett's lab directs these stem cells to form mini-intestines, which allows a replica of a patient's intestine to be created in the laboratory. The mini-intestines are subsequently placed into a small device called a "Chip." This Chip allows the continual flow of nutrients through it, which exposes the mini-intestines to conditions that are very similar to those found in the live human body. This simulation makes it far easier to study how other components associated with IBD—such as the microbiome, the immune system and even medications—influence the functioning of this tissue.

Barrett's goal is to recreate an IBD patient's disease course over time in his lab. If this is successful, the hope is that this technology will allow a prediction of the nature of disease a patient will experience in the future as well as to identify personalized treatments most likely to effectively treat or even prevent IBD from occurring.



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IBD Multidisciplinary Programs

Cedars-Sinai IBD offers four multidisciplinary programs. One or more could be right for you!

- 1) The IBD, PREGNANCY AND FERTILITY PROGRAM** is a medical practice that combines the expertise of OB-GYN physicians specializing in higher risk pregnancies and IBD specialists who have a particular focus on reproductive concerns of women in their childbearing years. Comprehensive counseling and customized management for each patient is available. The program offers fertility counseling, HPV vaccination and cervical cancer screening, and advice on the safety and management of IBD medications before, during and after pregnancy. Options for delivery are discussed and high-risk obstetric care is offered. Mothers are helped to plan for breastfeeding and the program coordinates care with the baby's pediatrician. Our physicians work alongside the patient's primary GI and OB doctors to ensure seamless care throughout this wonderful journey.
- 2) The NUTRITION AND INTEGRATIVE IBD PROGRAM** was established to offer dietary and alternative strategies in IBD. The goal of the program is to optimize quality of life and potentially minimize symptoms and disease activity by integrating specific nutritional and other alternative approaches with established medical therapies. The specialized team explores how to address existing and potential nutritional deficiencies and how to incorporate dietary, lifestyle and other strategies. With very few practices in the world integrating medical and alternative approaches, the Program provides: co-insights of a dietitian and an IBD-focused gastroenterologist and individualized dietary counseling. Patients will have the opportunity to participate in our IBD Nutrition and Integrative Registry. The program respects each patient's existing relationship with his or her regular gastroenterologist, who continues to serve as the primary IBD care provider.
- 3) The IBD, J-POUCH PROGRAM** recognizes that the surgical technique of choice for most patients with ulcerative colitis who require surgery is a restorative proctocolectomy with ileal pouch-anal anastomosis or "J-pouch." This technique allows patients the ability to voluntarily pass stools. However, up to 20 percent of patients with a J-pouch develop chronic inflammation and other potential pouch complications. Our program is designed to provide highly coordinated and experienced care for patients with a J-pouch, including consultation and procedures from experienced colorectal surgeons and IBD pouch specialists. We offer experts with extensive experience with J-pouch surgery, state-of-the-art diagnostic testing for causes of J-pouch dysfunction, and a coordinated team approach to medical and surgical interventions by recognized experts in their fields. The program respects each patient's existing relationship with their surgeon and gastroenterologist.
- 4) The IBD PSYCHOSOCIAL PROGRAM** has the mission of reducing the burden of illness and improving quality of life for individuals with IBD. Most new patient consultations at Cedars-Sinai IBD include assessments for anxiety, depression and wellbeing as well as the determination of need for psychosocial intervention with the assistance of a trained social worker or psychiatric evaluation and management. The complete biopsychosocial assessment involves an understanding of biological factors (such as diet, medications, natural course of illness), psychological factors (such as anxiety, depression, traumas, losses) and social factors (such as financial, vocational, residential), which may predispose, precipitate or perpetuate IBD episodes. While biological factors are usually the focus of the encounter with the IBD physician, the assessment of psychosocial factors is critical to understand the need for psychosocial interventions. Patients are offered these services in conjunction with their initial IBD new patient consultation, either the same day or at a conveniently scheduled time, according to patient's preference and severity of need. For patients who do not require or want psychiatric assessment but who may be candidates for psychosocial interventions, several options are available, including individual or group therapy, education/support groups, occupational or recreational therapy, behavioral therapy and stress management techniques.

For more information about multi-disciplinary clinics or to schedule an appointment, please contact the Cedars-Sinai IBD Center at 310-423-4100, or visit www.cedars-sinai.edu/ibd



FAQ: IBD Nurses

“I’ve met many nurses at the IBD Center. What are their different roles and responsibilities?”

What is the role of the IBD nurse navigator?

Nurse navigators coordinate outpatient care for people living with IBD. Nurse navigators serve as the primary point of contact for patients throughout the course of their treatment to answer any questions they have about their medications, disease, symptoms and health maintenance. Once patients and providers arrive at a treatment plan, nurse navigators obtain authorizations for medications and help to educate patients about self-injections or to coordinate infusion treatments. Nurse navigators coordinate care and are the hubs of communication between patients, their Cedars-Sinai IBD physician, other providers, insurance plans and pharmacies.

What do IBD research nurses do?

Research nurses at Cedars-Sinai IBD are part of a team dedicated to studying new IBD treatments through clinical trials. Research nurse is a specialized nursing position that utilizes both nursing skills and research skills to ensure all clinical trials are being conducted according to established guidelines. This is important for assuring the safety of the patients participating in the trials and also to assure the information collected is accurate, so that effective and safe drugs become available to patients as quickly as possible. Working within the foundation of Good Clinical Practice guidelines, and in collaboration with the rest of the study team, a research nurse collects important study data at specified study timepoints as determined by the study design (known as the protocol), communicates with sponsoring companies and works closely with the patient participants.

The associate director of the IBD Center is a nurse – Tell me more

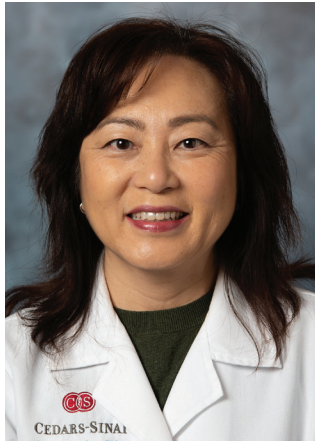
The associate director of the IBD Center is responsible for the daily oversight of the administrative and clinical operations of the clinic to meet the needs of patients, physicians and staff, and to support the vision of Cedars-Sinai Health System. This includes planning, organizing and directing areas of operations as well as serving as the liaison with medical staff and other personnel. The associate director supports IBD research, participates in strategic planning and assures patient advocacy. The associate director also guides staff in meeting customers’ needs consistent with the Medical Center’s philosophy, mission, vision and strategic plan.

Tell me more about IBD nurse practitioners

Nurse practitioners at Cedars-Sinai IBD have an integral and multifaceted role. They have advanced training in gastroenterology and IBD, and are licensed to independently see patients and prescribe medications in the state of California. Nurse practitioners see patients at the IBD Center and provide nonurgent medical care and post-hospital discharge evaluations. In addition to seeing patients in the clinic, IBD nurse practitioners work closely with Cedars-Sinai IBD physicians to provide optimal, efficient and well-rounded care, taking into consideration all aspects of a patient’s experience with their disease. Cedars-Sinai IBD nurse practitioners provide education to patients about the disease process and their medications to promote quality care. The nurse practitioners also instruct staff in evidence-based care for IBD and are frequently sought out as outstanding educational resources for their vast expertise in all things related to IBD care.



Meet Our IBD Nurse Practitioners:



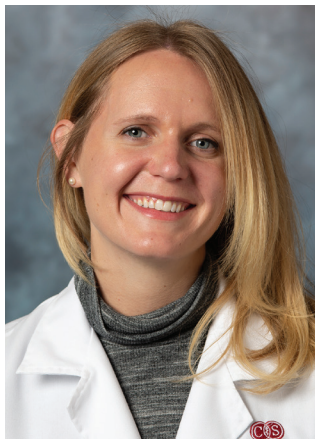
Susie Lee, RN, DNP, FNP-C

Susie Lee is a board-certified family nurse practitioner who has worked at Cedars-Sinai IBD since 1998. In 2017, she earned a doctorate degree in nursing practice. Lee works with IBD specialists, medical trainees and a multidisciplinary team to coordinate well-rounded care for patients with IBD. She's also a specialist in IBD, with an extensive knowledge base. Lee provides direct patient care, in which she sees patients for follow-up clinic visits, disease monitoring and education.

Lee is a strong and passionate patient advocate, and her expertise and experience make her a great resource for patients, nurses and physicians. She's devoted herself to ensuring that all the staff at Cedars-Sinai IBD become knowledgeable in IBD to provide the best possible care to our patients. Lee also is a partner, resource and adviser for the MIRIAD Biobank team, regularly providing input on ways to optimize the research experience for patients who volunteer to participate.

Prior to earning her doctorate from Chamberlain University, she earned bachelor's and master's degrees at California State University, Dominguez Hills, specializing as a family nurse practitioner.

Lee is married and has two grown children, ages 26 and 28. In her spare time, she enjoys hiking, skiing and trying new recipes.



Andrea Banty, DNP, FNP-BC

Andrea Banty is a board-certified family nurse practitioner who earned a doctorate degree in nursing practice in 2016. She joined the Cedars-Sinai IBD team in 2017. Previously, she worked in Connecticut, her home state, in general gastroenterology. Banty works with the multidisciplinary IBD team to provide safe and quality care to patients. She provides direct patient care, in which she sees patients for follow-up clinic visits, disease monitoring and education.

Banty is passionate about empowering patients to take ownership of their chronic disease. She is an excellent and accessible resource for patients. She's devoted herself to staying up to date with the latest evidence to provide the best possible care to our patients.

Before earning her doctorate from Fairfield University, she earned a bachelor's degree from Villanova University, specializing as a family nurse practitioner.

In her spare time, she enjoys hiking, beach volleyball and yoga.



Physician Spotlight!



Meet Nirupama Bonthala, MD

Nirupama Bonthala, MD, joined the Cedars-Sinai IBD faculty in 2016. Bonthala's clinical practice focuses on IBD, particularly pregnancy and women's health. She has teamed with the high-risk obstetrics Maternal-Fetal Medicine division to provide a subspecialty clinic (see page 2) to help women be better informed about the effects of IBD on their pregnancy and future offspring as well as helping women manage the disease. Her research interests include contraception choices, infertility and pregnancy outcomes in the IBD population.

Bonthala received her bachelor's degree from New York University and medical degree at University of Texas Southwestern Medical School in Dallas. She completed her internal medicine residency at University of Illinois at Chicago and her general gastroenterology fellowship at USC. She received additional training in an advanced fellowship specializing in IBD here at Cedars-Sinai Medical Center. After completing her fellowship, she was recruited to stay on as faculty.

When not at the medical center, Bonthala enjoys vegetable gardening, board games and traveling with her family. She is well on her way to her goal of visiting all the U.S. National Parks (currently 34 out of 59), including some as distant as American Samoa. Her favorite thus far is Capitol Reef in Utah. Her son's favorite so far is Yosemite.

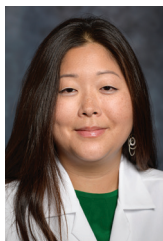


Meet Gaurav Syal, MD

Gaurav Syal, MD, joined the Cedars-Sinai IBD faculty in 2017 after completing an Advanced Inflammatory Bowel Disease Fellowship at Cedars-Sinai. As a gastroenterologist specializing in treatment of inflammatory bowel diseases, Syal strives to incorporate latest scientific evidence in the care of IBD patients with the goal of improving their quality of life. He strongly believes in shared decision-making and spends time educating patients about their disease, thus enabling them to actively participate in their care.

His clinical and research interests lie in the management of inflammatory pouch disorders and optimizing the care of patients hospitalized with severe colitis. He runs the J-pouch program (see page 2) in collaboration with the colorectal surgery team, providing multidisciplinary care to patients with complex pouch disorders. He is collaborating with colleagues from other institutions across the country to study the effectiveness of drug therapy in chronic pouchitis and Crohn's disease of the pouch. He is also a part of the Cedars-Sinai IBD clinical trials team, bringing novel medical therapies to the IBD patients in need, particularly the ones who have failed to respond to other treatments.

Syal is from India. He moved to the U.S. in 2010 to pursue medical training in internal medicine and gastroenterology. In his free time, he loves to travel with his wife as well as hike the beautiful trails in the Los Angeles area.



Meet Christina Ha, MD

Christina Ha, MD, was recruited to the faculty of Cedars-Sinai IBD in September 2017. Ha is the director of the Advanced IBD Fellowship Program at Cedars-Sinai and is an internationally acclaimed educator. She develops and teaches courses for patients and physicians at Cedars-Sinai as well as around the world. Ha is the recipient of multiple honors for her efforts as a teacher and mentor.

Her areas of clinical interest are Crohn's disease and ulcerative colitis, particularly in the population of older patients with these disorders.

Ha graduated magna cum laude from Harvard University and earned her medical degree from Albert Einstein College of Medicine. After completing an internal medicine residency and gastroenterology fellowship at Washington University in St. Louis, she held the prestigious position of Present/Levison Inflammatory Bowel Disease Fellow at The Mount Sinai Hospital in New York. She previously held faculty positions at the Meyerhoff Inflammatory Bowel Disease Center at Johns Hopkins and the UCLA Center for Inflammatory Bowel Diseases.

Ha enjoys days off with her golden retriever, cooking and hiking.



Tell Us How We're Doing!

MIRIAD Participant Experience Survey

Complete this four-question survey no later than April 26 and you will be eligible for a drawing to win one of five \$25 Starbucks gift cards. Winners will be randomly selected.

- **Click on this link:**
Cedars-Sinai MIRIAD Biobank Participation Satisfaction Survey
 - **Or copy this link into your browser:**
[iredcap.csmc.edu/surveys/?s=RCDRDYJCFD](https://redcap.csmc.edu/surveys/?s=RCDRDYJCFD)
-

Important numbers and contact information:

- **Adult Patient appointments**
310-423-4100
- **Research Project Information**
310-423-3550
- **Email address**
MIRIAD.IBDBiobank@cshs.org
- **Cedars-Sinai IBD clinical webpage**
cedars-sinai.org/programs/digestive-liver-diseases/clinical/ibd-center.html
- **Pediatric patient appointments**
310-423-7100
- **Pediatric IBD clinical webpage**
cedars-sinai.org/programs/digestive-liver-diseases/clinical/ibd-center/pediatric.html
- **Cedars-Sinai IBD research webpage**
cedars-sinai.edu/Research/Departments-and-Institutes/IBD
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