Welcome to The Scope! We are excited to bring you our second newsletter, and bring you all the new updates from the IBD team! Please join us in welcoming our newest team member, Hassan Hamandi M.D., who joined our UCSF group in August 2017. Dr. Hamandi earned his M.D. at University of Virginia and completed pediatric residency at Case Western Reserve University in Cleveland and a fellowship in Pediatric Gastroenterology, Hepatology and Nutrition at The John Hopkins University in Baltimore. In addition to providing clinical care, Dr. Hamandi has interests in research evaluating therapies for children with Inflammatory Bowel Disease, as well as projects related to endoscopy and raising quality of care. As a member of the UCSF Pediatric Inflammatory Bowel Disease Program, he joins other members of our group as a participant in ImproveCareNow, an international group of centers that takes a collaborative approach to elevating the treatment and well-being of children with Crohn’s disease and ulcerative colitis. Here are a few words from him:

"I am thrilled to be the newest member of the Pediatric Inflammatory Bowel Disease Program at UCSF! It is a dynamic time to be taking care of children with IBD with the advent of novel therapies and clinical approaches, and I hope to be at the forefront of treatment. I am also striving to contribute to the growing body of research in this field in hopes of ultimately finding a cure. Your child or young adult will receive care in a team based approach, and I will advocate on your behalf to receive care that will ensure your child or young adult enters remission and resumes a sense normalcy in their life. I look forward to working with you in the near future!"

Hassan Hamandi, M.D.

Research at UCSF

As a world leader in health science research, UCSF and the Pediatric IBD team strive to improve the lives of children by developing innovative clinical interventions and ways of monitoring disease. Below is a chart showing our current enrolling research projects and which patients might be eligible for them.

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For more information about the latest research studies in IBD at UCSF, please contact Emily Stekol at Emily.Stekol@ucsf.edu
The Scope: UCSF Pediatric IBD Newsletter

IBD Education Days and Support Groups: Past & Present

Mind, Body, IBD Day!
At our most recent Education day in July, we gathered a group of specialists to give talks and demonstrations on topics to help improve mental health when living with IBD. These included:

- Life Balancing a Chronic Illness
- Cognitive Behavioral Therapy & Pain Education
- Massage Therapy
- Yoga & Meditation
- Art Therapy

Back to School IBD Education Night and Support Group
The start of school can be a stressful time for many students & families, especially those dealing with IBD. No matter what grade your child is entering, it's important to start the school year on the right track! Join us at our next IBD Education Night on November 8th at 6:00 or 7:15PM to learn more about:

- Setting up a successful 504 Plan for your child
- Navigating the accommodations process
- Accommodations available to IBD patients

Coming November 8th!
After our presentation, you'll have a chance to talk with our panel of GI doctors, patients, and parents about their school-year tips!

In addition to our back to school presentations, you will have the option to attend a support group hosted by our amazing social worker, Sonia Milbank!

Within our IBD community, we strive to offer many forms of care, including regular support groups for patients and parents to attend! Support groups provide an opportunity for patients and families to meet with professionals and other families that are living with Crohn’s disease, Ulcerative Colitis, or other IBD diagnosis for an exchange of ideas on a range of IBD related topics in a supportive environment.

Questions, comments, or would like to RSVP? Email: pibd@ucsf.edu

Support Groups
Join us for an IBD Support Group! Meet other patients your age with IBD in a group discussion setting led by your social workers.

IBD Support Group SF
Where: Mission Hall, 550 16th St, San Francisco
When: Thursday, November 8th 2018
Ages 12-15: 6:00-7:00 PM
Ages 16+: 7:15-8:15 PM
RSVP and Questions to: Sonia.Milbank@ucsf.edu

IBD Support Group Oakland
Where: OPC1 basement (room OPC-A)
744 52nd St,
Oakland, CA 94609, USA
When: Every 2nd Wed, monthly
Ages: 11-17
Time: 6-7:30PM
RSVP and Questions to: sjasmer@mail.cho.org

October 2018
Join our PFAB Community!

The Patient and Family Advisory Board (PFAB) was created to help support pediatric IBD patients and their families. We all have experience, knowledge, and guidance to share--by collaborating with one another, we can help improve lives!

**Rosa Kelekian, Patient Lead:**
Hi, I'm Rosa! I've dealt with autoimmune conditions my whole life, and was diagnosed with Ulcerative Colitis 13 years ago, when I was 11 years old. I started getting involved with the UCSF Peds GI team about a year ago, because I wanted to use my experiences with chronic illness to support other patients and help make their journeys easier. Even though I'm no longer in pediatric care, I'm extremely passionate about the patient advocacy/support projects I've worked on with the UCSF Peds GI team - I'm currently applying for my MSW (master's degree in social work), and hope to work at UCSF in the near future!

**Maria Tribble, Parent Lead:**
My son's symptoms appeared at the young age of 1½ years old. After two years of testing, labs, hospital procedures, you know the drill, he was diagnosed with Crohn's (imagine trying to potty train a 4-year-old with Crohn's!) He's now 15-years-old and doing well. By the request of his fabulous Nurse, I became part of this group. Because I want to help new parents transition into this new world of IBD, I said “yes” to her request. It's an honor to be part of this group and as Rosa stated, “I want to use my experience” to guide new parents.

With over 25 years of IBD experience between us, and the knowledge of the Pediatric GI team, PFAB was created to help patients and parents navigate the realm of IBD. Here are just a few ways in which we hope PFAB will enrich your life:

**Support:**
* Help provide emotional support to families and patients during diagnosis, treatment, surgeries, and hospitalizations
* Assist with IBD education programs and fundraisers

**Community:**
* Connect families with similar demographics (location, disease, age, treatments)
* Create a safe space for patients & families to interact and share their stories

If you are interested in connecting with Rosa and Maria, or would like to learn more about PFAB, please join us for our next social and/or IBD education night, scheduled for November 8th. If you’d like to be in contact sooner or are unable to join us that evening, please reach out to us: ucsfpfab@gmail.com

We hope to meet you and your family soon!

Both of our amazing PFAB members presented at the most recent ImproveCareNow Community conference! Their presentations were: Digital Tools to Support Your Team: Virtual Meetings, On-line Organizational Tools, and Communications Platforms and Quality of Life with IBD: A Guide to Supporting Your Patients with Accommodations.
Our IBD Team!
If you would like to support the research, education, and clinical missions of the UCSF Pediatric IBD Program, please e-mail pidb@ucsf.edu, or send donations to:
UCSF Pediatric IBD Program,
c/o Mel Heyman, MD
Pediatric GI/Nutrition
PO BOX 0136
University of California
San Francisco, CA
94143-0136

Camp Go Beyond
A free camp where kids 7-17 with IBD can have fun in a safe, supportive, and nurturing environment.
Next summer camp will be August 4th through August 9th, 2019. Applications available online in mid January 2019
campgobeyond.org

GI Kids
Easy to understand information about the treatment and management of pediatric digestive conditions for children and parents
gikids.org

American College of Gastroenterology
Reliable information on IBD with many child/teen specific resources.
patients.gi.org/topics/inflammatory-bowel-disease/

Smart Patients
A disease-specific online community for caregivers and patients (18 years and older). A safe place to learn, share, and help each other.
improvecarenow.org /smart-patients

Crohns and Colitis Foundation
Information and resources for patients with IBD, including Just Like Me for teenagers with IBD, and IBDU with tips and info to transition into adulthood.
crohnscolitisfoundation.org
justlikemeibd.org
ibdu.org

October 2018