Welcome to The Scope! We are excited to be coming to you from our new location at Mission Bay, where we've settled in and are expanding our staff of doctors and researchers. Please join us in congratulating and welcoming Dr. Sofia Verstraete, who has recently received the Dean's Diversity Fund award due to her commitment to advancing diversity, inclusion, and equity in academic medicine. Here are a few words from her:

"I am thrilled to have recently completed my fellowship here at UCSF and to officially join the IBD team as a faculty member and attending physician. I thank you for always making me feel so welcome and I look forward to continuing to care for you and your family. While clinical care is my top priority, I am also excited to contribute to the many research and quality improvement projects within the IBD program. Within the next year, I plan to incorporate a more streamlined transition program for our older patients as they get ready to begin managing their own care. The ability for our patients to take control of their own health is important, and we intend to help them do so smoothly and effectively. Again, I look forward to working with all of you!"

Best,

Sofia Verstraete, M.D., M.A.S.

Research at UCSF

UCSF is among the world's leading research institutions in health science, and our Pediatric IBD team is dedicated to improving the lives of children through 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. We also have several additional studies that will open to enrollment soon!

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<th>Study Drug</th>
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For more information about the latest research studies in IBD at UCSF, please contact Emily Stekol at (415) 502-3190, or Emily.Stekol@ucsf.edu
What is Improve Care Now?

Improve Care Now (ICN) is a collaborative network of 87 pediatric IBD centers across the United States, England, and Qatar intended to improve the quality of care for children with IBD. With this network, we are able to combine our experiences, learn from other patients and providers, and share and analyze data and ideas to find the best treatments for all types of IBD. Since it began in 2004, the ICN community has greatly improved the quality of care provided to our IBD patients. Each of the 18,000 patients who participate add valuable information and data that allow the network to thrive.

How do you get involved?

ICN could not lead to new discoveries and innovations without participation from our families, so allowing access to and sharing of chart information by UCSF IBD teams is a great start. We welcome patient and parent perspectives at UCSF. Parents and children can also share ideas and connect online with the larger ICN community. ICN publishes a newsletter and a blog where patients and their families can find valuable information and share stories and ideas with each other. Follow the links below to learn more about ICN or to sign up for their newsletter and blog!

**The Circle - eNewsletter**
https://improvecarenow.org/
CIRCLE is written for patients and families and contains ImproveCareNow news, tips for living with IBD, and more ways to get involved.

**Loop - Blog**
https://improvecarenow.org/loop
Loop is a place for patients, parents, families, clinicians, and researchers to share their stories, ideas, and innovations. Everyone has a voice.

Please contact our QI Coordinator, Emma Canepa, at (415) 502-2425, or Emma.Canepa@ucsf.edu for more information.

How can I do more as a parent?

Please join us by getting involved in the parent ICN network! As a parent, you can make a difference in helping your child and others receive the best collaborative care possible. As a part of the parent ICN network, you can participate as a true partner in the ICN community to support one another and share knowledge and ideas with your care team and other ICN community members. We are excited to have you on board!

“I am very thankful to be a part of such an amazing group of parents, medical personnel, physicians, and researchers. As a parent of a child with ulcerative colitis
I am confident that you will too!”

-Laura Speegle
ICN Parent Representative

Please visit the ICN website to learn more at improvecarenow.org, or contact Laura Speegle (UCSF ICN Parent Representative)
Cell: (510) 682 - 1830
E-mail: laura.speegle@gmail.com

Hi there, from your IBD Social Workers!

We wanted to take a minute to explain who we are and what we do so that you can feel comfortable reaching out to us. For starters, we both have master level degrees with a background in health and mental health. While we are not able to provide long term counseling in our clinical roles, we are glad to provide you a referral to get the help that you need. We are here to make sure you feel like a partner in your child's care, and that your voices are heard. We are both passionate about health care and getting services that our families and kids deserve; this can be anything from food to appropriate health care. We often tell people that you can really ask us anything and if we don’t know the answer, we can probably find it for you!

Join us for the next IBD Support Group! Meet other patients your age with IBD in a group discussion setting led by your social workers. Dr. Heyman will hold a Q&A for the parents next door. Hope to see you there!

**Sonia and Sara**

Next IBD Support Group Happening Soon!

Group 1: Ages 12-16
Group 2: Ages 17+

For more information and questions, e-mail Sonia at: Sonia.Milbank@ucsf.edu
Parent Perspective

Shared by a parent of a child diagnosed with Crohn’s Disease at age 9

Our energetic, hilarious, athletic nine year old son rapidly deteriorated before our eyes after being diagnosed with Crohn’s disease. He was hospitalized for more than two months. He was listless, withering, anemic, unable to eat even a bite of food without feeling pain soon afterward. We would help him up from the hospital bed as he urgently needed to wheel his I-V pole back and forth to the bathroom around 20 times a day, as medicine after medicine failed to help. We slept on cots in his room every night, feeling helpless as we watched him suffer. At one point, as my husband and I walked through the hospital hallway on the floor that had become our new home, I broke down in tears and said to him, “I can’t take it anymore.”

It was an arrogant thing to say, as if I had some sort of choice in the matter; as if at some threshold of agony I could say that was quite enough and that it was time for the bad or hard things to magically recede.

My husband’s answer floored me and inspired me. “You can and you will,” he said. “Because we love our son and we will be here for him and do whatever it takes to help him no matter what, for as long as it takes, forever.”

I think that sums up the life of a parent or caretaker of a loved one with a chronic health condition: “We can’t take it anymore — and yet we can and we will.”

"We can’t take it anymore - and yet we can and we will"

After two surgeries, countless medication combinations, a year of intravenous nutrition, bouts of bowel rest, supplemental feeding through a nasogastric tube, and a year and a half of missed school, my son now is thankfully doing the best he’s done since being diagnosed.

Our new family standard for a great day is not being in the hospital. When a child has a chronic health condition, the whole family lives on a knife’s edge. In one moment there is freedom to function as “normal,” to go to work and school and have plans and activities. But in the next, the child may have a flare or debilitating side effect, or a medication that was helping just stops working or complications arise and derail life as we know it. We live in constant fear of the other shoe dropping. Certainly this is true of all people regardless of bowel health. At any moment something can happen to change life as we know it. Living with a chronic illness like IBD magnifies that reality.

I have had to stop working full-time in an office and only take freelance jobs because I never know when my son will be unable to attend school, and he has needs that are too complex for a typical after-school program or babysitter. I know we are also extremely fortunate to be able to get by financially and have medical insurance when other families face serious stress over those issues.

Making plans when you have a family member with a chronic illness is challenging. There is some level of fear or hesitation to buy tickets, plan for future events, or commit to activities because of the ever-present risk of having to bail.

Eventually opportunities and invitations slow down and stop. As a result, one’s world can get smaller and smaller until our lives revolve around doctor’s appointments, diagnostic procedures, blood work, scary medication choices of drugs with black box FDA warnings, flares, hospital stays, surgeries, recoveries from surgeries — lather, rinse, repeat.

This gives the whole household a version of post-traumatic stress disorder, PTSD, except there is no “post.” It is ongoing. OTSD.

When I read Facebook posts from friends on their pediatric parenting dilemmas about how much screen time is okay, it makes me either laugh, cry or filled with envy. Even benign conversations with friends can have emotional landmines. I asked a friend how her baby was doing and she said, “growing like a weed.” It was a standard answer to that question, but one that made tears sting the back of my eyes and my throat swell because my own son struggles to gain weight and grow.

But my son’s situation has allowed us to perform “extreme parenting” — to do things we had no idea we were capable of. We were so freaked out at first when we were tasked with hooking up I-V nutrition for my son every night, flushing the line, keeping things sterile, preparing the solution with an injection of liquid vitamins. But we became so adept at managing the feedings that at one point we hooked up the TPN in the back of a rental car in an airport parking lot. Has anyone ever posted about that on Facebook?

This illness has taught us not only the amazing things that we never knew we could control, but also the many things that we could not.

It has taught us that we can’t outsmart IBD. When it feels like we are literally “picking our poison” choosing which medicine to try next, the big guns ones we fear did nothing and the ones that were safer caused our son a 105 degree fever and muscle pain. We know nothing. Nobody does, really. Though research has come a long way and there are exciting medication discoveries, we still don’t know so much. We don’t know what exactly the illness is, what precisely causes it, why some medicines work, how exactly they work, or why they stop working. There are mind-benders too. We don’t know if our child’s symptoms are from the disease because the medicine is not working or side effects from the medicine that is working or something else entirely, like a virus.

We. Know. Nothing.

This is devastating to us as parents who like to overthink things and do research and figure out strategies, but also at times, oddly freeing. We can only do what we can do. Which is surprisingly a lot more than we ever would have believed.

We are grateful for the doctors and the team at UCSF who have our backs and understand part of the treatment of IBD is to address the psycho-social devastation of this illness on the patient and the whole family.

Our son attended a summer camp for kids with IBD for the last couple of years. This was one of the most profoundly positive developments for our whole family. Our other and we could see he would be OK and even thrive for a week without us. But there are always more medication tweaks ahead, more potential surgery. I would say I can’t take it any more. But I know that I can and I will.
IBD Resources for Patients and Caregivers

Camp Go Beyond
A free camp where kids 7-17 with IBD can have fun in a safe, supportive, and nurturing environment.
campgobeyond.org

Our IBD Program Team!
If you would like to support the research, education, and clinical missions of the UCSF Pediatric IBD Program, please e-mail PediatricIBDProgram@ucsf.edu, or send donations to:
UCSF Pediatric IBD Program,
c/o Mel Heyman, MD
UCSF Pediatric GI/Nutrition, Box 0136
550 16th Street, 5th Floor
San Francisco, CA 94143-0136

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 of America (CCFA)
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.
ccfa.org
justlikemeibd.org
ibdu.org

March 2017