A Welcome from our Medical Director:

Welcome to our inaugural edition of The Scope: The Pediatric IBD Program Newsletter. This newsletter will be made available twice each year to provide perspectives on the activities and news within the UCSF Benioff Children’s Hospital’s Pediatric Gastroenterology Program focusing on Inflammatory Bowel Disease (IBD). We hope the information will give you up-to-date insight into how we, your providers, help these programs achieve our mission: to improve the health and welfare of infants, children, adolescents, and young adults with gastrointestinal, liver and nutritional disorders, in this case focusing on IBD. We will provide you with updated information about our clinical quality improvement projects, research programs, novel treatment strategies, patient education and ongoing support resources that specifically help our current and future children with IBD. We also welcome feedback about our IBD Program and have created an email address so you can contact us with questions and concerns. MyChart remains available for your use, so please ask our office staff for more information about this resource.

We look forward to working with all of you.

Best wishes,

Melvin Heyman, MD
Director, UCSF Pediatric IBD Program

Join us on Improve Care Now!

What is Improve Care Now? IBD unlike many other diseases does not have a single treatment plan that works for everyone. Up to now, each doctor and nurse has decided what is best for each patient depending on the individual’s disease, where each provider applies his or her own knowledge and experiences in treating similar patients. However, now we have the opportunity to combine our experiences with other centers to learn from other providers and patients just like you to see which treatments seem to work best. Improve Care Now (called “ICN”) is a network of pediatric IBD centers that is allowing us to do just that! UCSF Benioff Children’s Hospitals in San Francisco and Oakland are participating in this network of over 65 pediatric centers that are working together to help improve the lives of children with IBD. ICN spans across North America, and now even has a center in London. ICN brings clinicians, nurses, dietitians, researchers, and patients and their families together in one collaborative network that allows sharing of information and ideas to improve treatment of children with IBD.
How Does ICN Work? When patients with Crohn’s disease or ulcerative colitis go to their office visits for follow-up or other evaluations, they will be asked to participate in the ICN network. During subsequent visits, information and data will be collected on each patient. Combining this information with the data collected at other centers allows the network as a whole to find gaps in care or areas for improvement. In other words, imagine how much more we can learn by looking at the data from over 18,000 patients that are currently enrolled in the network, compared with approximately 450 IBD patients at UCSF Benioff Children’s Hospital programs in San Francisco and Oakland. As areas for improvement are identified, the ICN network provides tools and training to help each involved center take necessary steps to improve the health outcomes of their patients.

How Might ICN Help? With the support of the network and the tools provided, our goal is to deliver more reliable and proactive care to you, our patients. For example, one tool that ICN provides for each center is a patient checklist called a Pre-Visit Planning (PVP) form. Information entered from each visit is tracked on this form and will be available to the providers before every visit. The form includes current medications, tests and any notes from previous visits. The PVP form allows our providers to get updated regarding each patient’s history to best prepare for the upcoming visit, so that patients and parents get the most out of each visit. Overall, ICN provides a more succinct and up-to-date method to track each patient’s progress and alert providers to any changes that may need to be made in the patient’s care plan. ICN has shown great success in improving remission rates with these tools, and we intend to reap similar results at our UCSF sites.

How Can You Help? ICN is truly a family-centered network. Quality improvement is changing the way we think about healthcare and opens a place for patients and their families to play an integral role in these improvements. Allowing access to and sharing of chart information by the UCSF IBD teams is a great start; know that all of the shared information will be kept confidential. In addition, both patients and families have plenty of opportunities to get involved with ICN. At UCSF Benioff Children’s Hospital, we are looking for both patient and parent advocates to be a part of this network and share their ideas and help us to develop tools to improve care. Patients and parents offer unique perspectives that are sought and valued by the network. Parents and children can also connect online with the ICN community – that is, with other parents and/or patients. ICN publishes a newsletter, called the Circle, and a blog, called the LOOP, where patients and their families can find valuable information and share stories and ideas with each other.

Please email our QI Coordinator, Ali Wilson at Alix.Wilson@ucsf.edu for more information about ICN.

Follow the links below to learn more about ICN and hear from patients and families that are already a part of this growing network!

The Circle | eNewsletter
https://improvecarenow.org/subscribe CIRCLE is written for patients and families and contains ImproveCareNow News, tips for living with IBD and ways to get involved. Getting CIRCLE delivered to your inbox is easy. Sign up today.

Read posts on LOOP | blog
http://improvecarenowblog.org Everyone has a voice – patients, parents, clinicians & researchers – and LOOP is a place to share all the stories, ideas and innovations. Be sure to leave comments!
Clinical Trials and Research Studies for IBD Patients at UCSF:

- Quality Improvement Initiative called Improve Care Now (ICN) in Inflammatory Bowel Disease (IBD) (now enrolling)

- A Phase 1b Open-Label Trial to Assess the Safety and Pharmacokinetics of Subcutaneously Administered Golimumab, a human anti-TNF-α Antibody, In Pediatric Subjects with Moderately to Severely Active Ulcerative Colitis (UC) sponsored by Janssen Pharmaceuticals (now enrolling)

- Telehealth Enhancement of Adherence to Medication in Pediatric IBD (TEAM study) in collaboration with CCHMC sponsored by the NIH (now enrolling)

- A Multicenter, Randomized, Double-Blind, Placebo-Controlled Study of the Human Anti-TNF Monoclonal Antibody Adalimumab in Pediatric Subjects with Moderate to Severe Ulcerative Colitis sponsored by AbbVie (now enrolling)

- A Phase 3, Double-Blind, Placebo Controlled, Multicenter Study of the Efficacy and Safety of Etrolizumab During Induction and Maintenance in Adult Patients with Moderate to Severe Active Ulcerative Colitis who are Refractory to or Intolerant of TNF Inhibitors sponsored by Genentech (enrolling soon)

- Risk Stratification and Identification of Immuno-genetic and Microbial Markers of Rapid Disease Progression in Children with Crohn’s Disease (CD) sponsored by the CCFA (patients in follow-up)

- A Multicenter, Prospective, Long-term, Observational Registry of Pediatric Patients with Inflammatory Bowel Disease (IBD) sponsored by Janssen Pharmaceuticals (patients in follow-up, enrolling patients under 12 years old)

- Predicting Response to Standardized Pediatric Colitis Therapy: The PROTECT Study for Children with Newly Diagnosed Ulcerative Colitis (UC) sponsored by the NIH (now enrolling at diagnostic colonoscopy)

- Registry Study of Pediatric Patients with Acute Recurring and/or Chronic Pancreatitis called the INInternational Study Group of Pediatric Pancreatitis: In search of a cuRE (INSPPIRE) sponsored by the NIH (patients in follow-up)

We are also very excited to be affiliated with Children’s Hospital Oakland (CHO) and looking forward to collaborating on clinical and research projects for IBD in the near future.

For more information about the latest research studies at UCSF, please contact Liz Garnett at (415) 514-4423 or via email liz.garnett@ucsf.edu.

If you would like to support the research, education, and clinical missions of the UCSF Pediatric IBD Program, please email PediatricIBDProgram@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.”
Patient Perspective: Andrew’s Story

It was the spring of 2007, and I was finishing up my junior year of high school. It had been the hardest year of my life with classes becoming increasingly more difficult and a mysterious illness plaguing my body. With daily diarrhea, debilitating stomach cramping, anemia, and other severe problems (which I will spare you), it became clear that something was seriously wrong — substantially more was wrong with me than the gluten sensitivity and irritable bowel syndrome that had previously been diagnosed. The illness was hitting a tipping point and my quality of life had decreased dramatically.

I finally underwent a colonoscopy and subsequently, the mystery was solved: moderate to severe Crohn’s colitis. While I was relieved to have a diagnosis, I was also extremely disappointed that it had taken nearly a year to do so. How much needless suffering had I endured? Soon after my diagnosis and a failed surgery, I made the transition to the UCSF pediatric IBD clinic, directed by Dr. Mel Heyman. This may have been the most important decision of my life. Dr. Heyman, along with Laura and a team of other medical professionals, placed me on effective medications, referred me to an exemplary surgeon at UCSF and ordered additional tests. Over the following months, the substantial decrease in my overall symptomatology was nothing short of miraculous. It was similar to emerging from a confining and painful space to one that was warm and safe.

Over the years, I have felt empowered to take an active role in the treatment of my illness. Some of my modifications have involved: a gluten and dairy free diet, the intake of potent probiotics, and ample exercise. I am an avid surfer, and enjoy tackling the sometimes rough waves of our very own Ocean Beach here in San Francisco. I have also recently become interested in how psychological stress may negatively impact patients with IBD, and would like to investigate this further.

Andrew graduated from the University of California, Santa Cruz with double degrees in Neuroscience and Psychology. He plans to attend medical school starting in the fall of 2015. Andrew is volunteering some time to the UCSF Benioff Children’s Hospital Pediatric IBD Program and created the graphic layout and took many of the photos seen in this newsletter.

Care Corner with Nurse Laura:

Appropriate vaccines can keep you healthy, especially when you are using IBD medicines that decrease your immune system (“immune suppression”). It is important that you complete vaccinations soon after diagnosis of Crohn’s disease or ulcerative colitis.


It is VERY IMPORTANT to avoid any live virus vaccines while taking immunosuppressive medicines. Vaccines with live viruses should be given at least 2 months before starting to take any immunosuppressive medicine (for examples: prednisone, azathioprine (Imuran®), 6MP (Purenithol®), methotrexate, infliximab (Remicade®), adalimumab (Humira®), certolizumab (Cimzia®)). Live vaccines should not be given while you are taking immunosuppressive drugs, or within 2 months after these drugs are stopped.

LIVE vaccines include: nasal flu, varicella (chicken pox), MMR, rotavirus, oral polio, smallpox, yellow fever, and oral typhoid.

Always discuss vaccination plans with your Primary Care Provider and your Pediatric Gastroenterology providers.

UCSF Benioff Children’s Hospital is moving!
Starting January, 26th, 2015 all clinic visits and hospital stays will be at the new Mission Bay Campus located at The Gateway Medical Building at 1825 4th Street, San Francisco, CA 94158-2350.

We hope you enjoyed our first newsletter. If you have questions about the Pediatric IBD Program at UCSF Benioff Children’s Hospital, or if you have suggestions for our next edition of this newsletter, please phone (415) 514-4IBD or email us at: PediatricIBDProgram@ucsf.edu.