Pediatric inflammatory bowel disease (IBD), which includes ulcerative colitis and Crohn’s disease, affects about 250,000 children and adolescents in the U.S. Ulcerative colitis produces inflammation, swelling or irritation in the lining of the large intestine and rectum. Crohn’s disease is a related condition that produces inflammation in any part of the gastrointestinal tract, although the ileum is most commonly affected. Both diseases are chronic and usually require lifelong management.

The onset of inflammatory bowel disease in children typically occurs during the pre-adolescent or adolescent years — a critical time of life for physical, emotional and social development. The pediatric IBD program at UCLA recognizes the special needs of pediatric patients and provides care in a compassionate setting with access to a team of specialized health professionals.

Significant benefit from early diagnosis

IBD can be difficult to diagnose. Symptoms include growth failure, unexplained fever, weight loss, diarrhea, and rectal bleeding or abdominal pain in combination with any of these symptoms. Early detection and intervention provide the best chance to help slow the progression of the disease and can help prevent operations to remove scarred intestinal tissue or the entire colon. Patients presenting with more severe disease may be refractory to milder first-line therapies.

Caring for the whole child

"Pediatric IBD occurs during a particularly vulnerable time of life and may take an emotional, developmental and physical toll on children and adolescents. By providing care in a multidisciplinary center established to address their unique needs, UCLA’s pediatric gastroenterology team cares for the ‘whole’ child," says David Ziring, MD, assistant clinical professor of pediatrics and director of the UCLA Pediatric IBD Center. "We offer cutting-edge care in a holistic manner that involves the entire family," he explains.

Patients and family members are encouraged to become partners with the healthcare team in charting the course of care.

“We think it is important for families to understand that this is a life-long disease that can carry significant morbidity,” Dr. Ziring says. “The drugs we use may be quite aggressive as they are matched to combat a particular disease activity. But we are very careful to spend the time counseling, educating and talking with families to make sure they are comfortable in making these treatment decisions together.”
The initial diagnostic work-up includes blood and stool testing followed by upper endoscopy and colonoscopy to provide a definitive diagnosis. The extent of the disease is determined using radiologic studies. While most specialists continue to rely on fluoroscopic X-ray technology that has been the standard of care for decades, UCLA has developed protocols for using magnetic resonance enterography to obtain highly detailed images of the intestine and colon without the radiation exposure. This is important to patients who, over the course of a lifetime, may be exposed to numerous radiological scans.

**Biomarkers support the treatment plan**

Patients undergo periodic stool-sample tests to analyze specific biomarkers that indicate levels of inflammation. The use of biomarkers has advanced the field significantly by allowing physicians to recognize signs of inflammation even in the absence of symptoms. These tests are also used to monitor patient response to therapy, optimize the use of each medication and adjust medication levels to maintain remission and prevent complications that may require an operation.

Few centers provide the kind of rigorous medication monitoring offered at UCLA. A carefully designed protocol of medication management, custom-tailored to each patient, allows gastroenterologists to recognize signs that the patient is developing antibodies to a medication or that the drug is not performing adequately.

Operations for complicated Crohn’s disease are reserved for intestinal obstruction, fistulas, and persistent bleeding despite medical therapy. While standard operative intervention for ulcerative colitis is restorative proctocolectomy with J-pouch, these patients at UCLA are treated using minimally invasive techniques. At UCLA, low rates of surgical intervention reflect the success of the program’s strategy of vigilant monitoring of disease activity.

**Psychosocial support is important**

Children and adolescents with inflammatory bowel disease face significant psychosocial challenges. Some medications may lead to changes in physical appearance while the disease may limit participation in normal childhood activities. At UCLA, patients have access to a nutritionist with expertise in IBD as well as social workers and psychologists. Comprehensive support enables children to enjoy normal lives. A new electronic IBD home-care program is available to provide patient education and allow the healthcare team to more effectively monitor patients in a cost-efficient manner. The iPhone or Android application allows patients to set goals for improved disease management and gauge their progress.

The presence of an adult IBD program and significant research infrastructure at UCLA benefit pediatric patients. Some therapies for inflammatory bowel disease are approved only for use in adults, but may be accessible to pediatric patients at UCLA through clinical trials. The pediatric IBD program is a leader in adopting the most innovative treatments, including a clinical trial on autologous stem cell transplantation, which is currently open to patients who have failed medical therapies.