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Pediatric patient overcomes obstacles to raise critical funds and awareness for local patients

Jack Pilbean, 13, urging community to 'Take Steps' on June 10

Ulcerative colitis isn't just a cause for Jack Pilbean. It's something he lives with every moment of each day.

That's why Pilbean is telling his story in advance of this year's Crohn's & Colitis Foundation – Louisville's Take Steps Walk, which will be held on Saturday, June 10, 2017 at 9:00 a.m. at EP "Tom" Sawyer State Park.

Jack is one of 1.6 million American adults and children who live with ulcerative colitis, a painful, debilitating digestive disease that also affects 80,000 patients under the age of 18.

His UC story began when he made his first trip to the hospital in 4th grade. He woke up in the middle of the night with horrible cramping in his stomach and noted blood in his stool.

"I spent the next two months in and out of children's hospitals in Louisville and Cincinnati. I had 2 colonoscopies and endoscopies, a CAT scan, MRI, and too many shots and pills to count before they found out what was wrong. I missed lots of school, basketball, and my science fair, which I had looked forward to since kindergarten. I was 10 years old and I had Ulcerative Colitis. What did that mean?"

"At first, it meant no dairy, no fried foods, and nothing with red food coloring, along with lots of sleeping and lots and lots of trips to the bathroom. Lots of no's but not many yes's and the only yes's were pills and more pills. My face looked like a chipmunk from all the steroids I was taking. I wasn't able to eat much and I got really tired of plain turkey sandwiches. I didn't want to eat because I knew how bad it would hurt when I did."

"Eventually I got back to feeling well enough for school. The days were tough and it was hard for me to go or stay all day. If I did make it all day, I needed a nap when I got home; the last two years have been hard, too. I don't have the energy I used to have to play sports. I take more water breaks than my friends, and sometimes I just have to watch from the sidelines on really bad days. Most mornings my stomach hurts for a couple hours. I try to hide the pain with a smile, but it's hard to fool mom and dad. It's embarrassing sometimes to have to go to the bathroom during school as much as I have to go some days. I have learned to slow down and take it easy on bad days and drink lots of water. At night, my heating pad helps me fall asleep."

"I have met some really good friends who have helped me get better. Dr. Dykes and Nurse Julie at Cincinnati Children's Hospital and Nurse Sandra and the other nurses at Norton Children's Hospital in Louisville where I get my Remicade infusions are all wonderful."

"I was lucky enough to go to Camp Oasis this past summer and met tons of friends. The counselors were great, and the food and activities were amazing. My favorite part was learning that there were kids out there just like me."

"I decided to talk about UC and Crohn's last spring. The 2016 Take Steps Walk was my first one and was incredible. I wanted to walk to help kids like me, and I had lots of fundraisers and lemonade stands to raise money."

"I'm very proud to have been chosen to be the 2017 Louisville Take Steps Honored Hero. I hope you'll join me for this year's Take Steps walk to raise awareness and raise funds to help find a cure for kids like me!"

The Take Steps for Crohn's & Colitis Walk is the nation's largest event dedicated to finding cures and raising awareness for digestive diseases. Our Take Steps walks offer an incredible day for family, friends and the community to celebrate all of the efforts that have been put forth in raising funds towards our mission.

It is a day that combines high energy and fun with access to valuable information and education. More than 40,000 peopled walked for cures last year, raising more than \$10 million for mission-critical research and patient support programs.

To join us, contact Jon Pilbean at 502-648-8388 or e-mail katepilbean@gmail.com

About Crohn's Disease and Ulcerative Colitis

Known collectively as inflammatory bowel diseases (IBD), Crohn's disease and ulcerative colitis affects 1 in 200 people. They are painful, medically incurable diseases that attack the digestive system. Crohn's disease may attack anywhere along the digestive tract, while ulcerative colitis inflames only the large intestine (colon). Symptoms may include abdominal pain, persistent diarrhea, rectal bleeding, fever, and weight loss. Many patients require numerous hospitalizations and surgery. Most people develop the diseases between the ages of 15 and 35; however the incidence is increasing in children.

About Take Steps

Take Steps is the Crohn's & Colitis Foundation's national walk program. These walks raise funds for mission critical research and patient support programs, and help increase awareness of Crohn's disease and ulcerative colitis, two painful and unpredictable digestive diseases. Our walks are family-friendly festivals held in more than 120 communities across the country with activities for everyone including games, music, and great food. Funds raised through Take Steps will help transform the lives of those impacted by these diseases, and support CCFA's critical research, education, and patient support programs. Walk with us today and get started at www.cctakesteps.org.

About the Crohn's & Colitis Foundation

The Crohn's & Colitis Foundation (CCF) is the largest voluntary non-profit health organization dedicated to finding cures for inflammatory bowel diseases (IBD). CCF's mission is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults who suffer from these diseases.

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