



What Does a Hero Look Like???

What does a hero look like to you? Are there capes, tights, lightning bolts, masks? How about just an adorable little boy with a toothless smile, in jeans and a ski jacket with a normal mom, dad and little brother? To The Crohn's and Colitis Foundation of America in Upstate/Northeastern New York, our hero is Liam Carlson.

Liam has strong role models. His dad, Bill, is a Lieutenant for the Cohoes Fire Dept, and his mom, Aimee is a nurse practitioner for Seton Health. They strive for a normal, balanced family life. But, sometimes, life for the Carlsons is far from normal, Liam has Ulcerative Colitis, he is 8. At the age of 3, Liam was diagnosed with inflammatory bowel disease, already dealing with food allergies and asthma. His symptoms were mild and controlled with Sulfasalazine. Initially he did well but after 1 ½ years, at 4 ½, his symptoms worsened. There were more frequent outbreaks involving bleeding and belly pain. By 6, he required hospitalization for transfusions. Different medications and treatments were prescribed; Sulfasalazine, 6MP, Remicade, steroids, bowel rest, IV nutrition via a central line, transfusions, special diets, supplements and probiotics. Consults were obtained in Boston. Despite all of this, Liam just got sicker and was now considered steroid dependent. In May 2008, he underwent surgery to remove his entire colon. His diagnosis was then officially Ulcerative Colitis. This surgery should have solved Liam's daily issues but he continued to get sick. His appetite was poor and he had belly pain. A return to Albany Med diagnosed hemorrhagic pancreatitis. The bleeding worsened due to blood thinners for a blood clot in his central line. His organs began to shut down and his battle was almost lost. Fortunately, children are resilient and Liam bounced back. After 1 month he finally came home.

In September 2008 Liam endured a second reconstructive surgery and has required additional hospital admissions for sepsis, dehydration, a bowel obstruction and another blood clot. In spite of it all, Liam's quality of life seemed better. He no longer complained of pain and was finally growing. He no longer needed the medications that made him feel so sick. The Carlsons were hopeful. But, this past summer, Liam's symptoms returned. A scope done in August found that Liam had pouchitis (ulcerations in the surgically altered small intestine). He began treatment with antibiotics and probiotics with some improvement. Restarting Remicade was considered, but not a great option. Liam is running out of options, at 8 years old. In the last 2 years, Liam has undergone more than most of us will endure in a life time, numerous scopes, central lines, hospitalizations, blood draws, scans etc.

In between, Liam is an active little boy. He is a second grader at Arongen Elementary School in Clifton Park. He plays soccer, takes karate and has become a boy scout. In addition to his friends and family, he receives constant support from the school nurse, his teachers, his doctors, and the nursing staff on the 7th floor of Albany Medical Center, where he has spent a total of over 4 months; 4th of July, his 6th birthday and almost his 8th birthday. They "sprung him" the day before his birthday in November so he could celebrate at home. Liam never complains, loves museums, dreams of archeological digs and becoming a paleontologist. He is smart, articulate, energized and incredibly endearing.

Our hope is a balanced life for Liam, full of family, friends, sports, trips to museums and the ability to make plans without the fear that in a moment, they will change; new treatments, medications and life with ulcerative colitis under control. We share Liam's story so more people will know the impact Crohn's and Colitis has on a family, to give a voice and lend a shoulder to someone at the beginning of their medical journey. Redefining the role of a parent, changing expectations and appreciating what we have and learn along the way. Aimee and Bill join thousands of other families who are reaching out into their communities for support to find a cure, to do more research and to make life more livable. Please do the same...for Liam and for thousands of others battling this chronic disease...daily. Thank you!

PLEASE JOIN US FOR THE "TAKE STEPS FOR CROHN'S & COLITIS WALK ON MAY 1, 2010 AT 3PM AT THE CROSSINGS OF COLONIE. FOR MORE INFORMATION AND TO REGISTER – GO TO www.cctakesteps.org Questions? contact Aimee Carlson aimbell@nycap.rr.com