

Health Awareness

Taking Steps To Control Life With Chronic Digestive Disease

(NAPSA)—When Amy and Joe Nardini of Fremont, Calif., first heard of ulcerative colitis, they were sitting in a gastroenterologist's office. They had just learned that their previously healthy 12-year-old daughter Megan now had it. All types of emotions came over them as terms such as “colon removal” and “incurable” were thrown into the conversation about this painful digestive disease. Combined with a similar disease called Crohn's, ulcerative colitis affects over 1.4 million Americans—and as many as 150,000 people with these diseases are under the age of 18.

Frank Sileo, Ph.D., a licensed and practicing psychologist who specializes in therapy for people with chronic illness, often sees patients and their families facing a recent diagnosis of these diseases. Crohn's and colitis vary in severity from person to person, making diagnosis even more difficult.

“Usually anger, confusion, frustration and fear are felt during diagnosis,” says Dr. Sileo, who is also author of “Toilet Paper Flowers,” a children's book on Crohn's and colitis. “Not only is it hard for people to talk about because the symptoms are embarrassing, but Crohn's and colitis are often misunderstood. Both are chronic diseases that affect the whole person with all sorts of symptoms.”

The Nardinis left the office with bags of medicine in hand and a prescription for a disease that was to bring them on a roller coaster of a ride over the next several years. As with so many other children with Crohn's or colitis, the side effects of the medicine Megan took often overshadowed their positive effects—bloating, psychosis, sleep deprivation and



Many of the 1.4 million Americans with Crohn's disease and ulcerative colitis are under the age of 18, posing a unique set of challenges.

overeating among them. By age 17, Megan had undergone six surgeries and missed out on most of the typical teenage experiences.

“Megan would try to go back to school, but then have to be home schooled again,” says Amy. “There was always a lot of stress around school because of the illness. Not only was she stressed about the medications' side effects, but about using the bathroom at school and missing so much work.”

The Nardinis learned how to advocate on behalf of their daughter—at school and at the hospital—from other families they met at a support group through the Crohn's & Colitis Foundation. It was the emotional support provided by such a family that helped the Nardinis get through two surgeries, one after the other, at the beginning of 2006. Megan's friend from the support group, who had also had the surgery, held her hand while the friend's

mother cleaned the wound and changed the bag as she explained the process to Amy.

Dr. Sileo says that children often feel guilty about having Crohn's and colitis and can get angry at themselves, especially when it limits other family members. Although it's hard to have full-day family outings, he suggests planning to take breaks.

“Planning and carrying supplies such as a change of clothes and cleansing wipes are ways you can feel more comfortable, and in control of a disease that can make you feel out of control,” says Dr. Sileo. “It's important to learn to live with limitations no matter how it makes you feel. Healthy expression of these feelings is really important.”

These limitations are not bound to family life, says Amy, talking about how digestive disease has made it hard for Megan to maintain friendships with other people her age. “It is extraordinary to ask a child to deal with a friend going through this,” she continues. “This has made Megan more empathetic and opened her up to new friendships with people she wouldn't otherwise have met.”

These friends—from the hospital, the community and camp—are banding with Megan to take on digestive disease. This spring, they will walk alongside thousands of others across the country in the largest event dedicated to fighting digestive disease. Through the Crohn's & Colitis Foundation's Take Steps for Crohn's & Colitis Walk (www.cctakesteps.org), they are raising critical awareness and money to find a cure for Crohn's and colitis so that others can have a future free from these devastating diseases.