



www.pedsibd.org

YOU NEED NOT WALK ALONE

*Reprinted with the permission of the author, Dr. Stanley Cohen
(Adjunct clinical professor of pediatrics, Emory University School of Medicine;
Director of IBD Research, Children's Center for Digestive Health Care;
Chief of Gastroenterology and Nutrition Clinics, Children's Healthcare of Atlanta at Scottish Rite Hospital in Atlanta, GA)*

You may have seen the art projects, where the children and teens with Crohn's and ulcerative colitis expressed themselves visually. Brandon drew a bubble that surrounded himself. His friends and family were around him, but on the other side of his enclosed environment. No question, he doesn't want his life that way, but he feels the distance and the differences. Pain keeps him home from activities and school at times.

If he's like so many with Inflammatory Bowel Disease, he needs to know where the closest bathroom is every moment. He feels different too, with ballooned cheeks and a swollen appetite. Bad enough for an adult-for a child or a teenager, these obvious distinctions can be devastating as peers' unwanted attention and unwarranted comments erode his or her self-image and self-esteem. For many this seems like cruel and unjustified punishment, not for something they've done but for what's happened to them. In a very real sense, insult has been added to injury.

But the truth is that as isolated as Brandon feels, he isn't alone. Others completing pictures for the art project depicted the exact sentiment. They drew houses where they sat inside while everything was going on outside, or they showed friends that were otherwise engaged, ignoring them and their troubles.

We can help-we can let them know they are not weird kids with a rare disease. When they look in the mirror, their faces are magnified. It's hard to see anything beside themselves. But there are a million others in the United States with the same condition. Other children and teens have said nearly the same thing on the internet as they communicate across the country.

What we as parents, friends, physicians can help them remember is that this is happening at a time when teens are undergoing adolescent angst that will help them define their personal identity, and that does make it seem worse. But some of the things are happening to their friends too, even the ones who aren't ill. You can tell them your own stories of your own pity parties, when you were growing up and how awful someone felt when they didn't get to go to a party or a special event, when they suffered in other

circumstances. Parents can share a wonderful book with their daughters called Reviving Ophelia. My own daughter had me read it. Mothers often recognize their own preteen and



www.pedsibd.org

pubescent years as well as their daughters as the book describes these developmental phases.

But often these kids need someone to talk to other than their parents. So mostly, what we can do is help them connect. Allow them to talk to you about their disease and their feelings, and encourage them to talk to others. Some will be willing to open a discussion with their friends; others will feel threatened by the very idea; others may try but get less back from their peers than they'd expect. If so, that's where your physician and CCFA can come in, to open doors so they can talk to professionals or others who have lived through what they have. The CCFA has support groups, has a web page and chat room that are always accessible (CCFA.org) and other sites that are active too (Jpouch.org).

Now we have a whole contingent of young volunteers with Crohn's and colitis that have offered to talk with new patients and those who want or need an available ear. These kids are fantastic. They have already opened themselves up to others at Camp Colitioscope, sharing their stories and hearing others. They have bonded together as a group trying to make their own lives better and willing to help when they can. It's easier for girls. They talk amongst themselves already and provide warm hugs of comfort. And the boys are growing into that phase where they can shoulder and support each other, often with compassion beneath a cool exterior.

They can tell each other that they know how rotten these diseases are, how awful it is to take a handful of pills or to look at surgery as a possible blessing, to miss fun activities, to endure and endure. And probably the most important part of the message is that no child with Crohn's or Colitis is alone and we can work together to try to make their lives better.