

Inflammatory bowel disease in kids is on a mysterious rise

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For 10-year-old Jacob Krause, getting ready for the new school year wasn't a simple matter of back-to-school shopping. It also involved working out logistics for getting to the bathroom as many as 20 times during a single school day.

The Clarksville Elementary School fifth-grader has severe ulcerative colitis, an inflammatory bowel disease that increasingly, and somewhat mysteriously, strikes children.

The number of children afflicted by colitis and another inflammatory bowel disease, [Crohn's disease](#), has increased 50 percent in the past decade, according to the Crohn's & Colitis Foundation of America. About 1.5 million Americans suffer from colitis and Crohn's, about 10 percent of them under the age of 18.

"We're seeing younger and younger children getting it over time," said Dr. Maria Oliva-Hemker, chief of the Johns Hopkins University's School of Medicine's division of pediatric gastroenterology and nutrition.

The reasons for the increase are not clear. But many researchers believe something in the environment must be behind the surge in pediatric colitis, Crohn's and other autoimmune diseases, which have been on the rise generally. One theory is that as the developed world has become more hygienic, the body has become less practiced at fighting off bugs -- and more vulnerable to autoimmune diseases, in which the body attacks

its own cells or tissues.

"Since we know (inflammatory bowel disease) is found in more developed countries, it must be something about the exposures that we are seeing in our day-to-day lives," Oliva-Hemker said. "Probably the fact that we are a more hygienic society, the fact that children, even at an early age, are kept in very clean environments -- not necessarily outside, playing in the dirt, being exposed to very low levels of routine viruses."

If the home environment is "too clean early on," when children start school and are exposed to more bugs, "the immune system goes into overdrive," Oliva-Hemker said.

"As we've gotten rid of many infectious disease, the autoimmune and allergic diseases have steadily increased -- lupus, allergies, eczema," she said. "And in countries where we still see a lot of infectious diseases, we don't see" autoimmune diseases.

Better awareness of the disease might also be leading to more diagnoses, said Karla Au Yeung, a Hopkins pediatric gastroenterologist who treats Jacob.

"GI in general for pediatrics didn't start until the mid-'80s," she said. "The practice is relatively new. I think people are more aware."

A difficult condition even for adults, inflammatory bowel disease poses special problems for young people who come down with it. One is the need for constant bathroom access -- a particular challenge during recess and outdoor physical-education activities in an era when youngsters generally are not allowed to let themselves in and out of school buildings. There's also the likelihood that that disease itself, and some medicines used to treat it, will stunt growth. And there is a good chance that the condition will go undiagnosed for long stretches because many people

don't realize it afflicts children.

"They just think it's an adult disease if they've heard of it at all," said Oliva-Hemker. "It's not that unusual of a GI condition, but a lot of folks feel it's something that's in the adult world and kids can't get it -- even doctors. ... I can't tell you how many children I'm seeing and the diagnosis has been delayed."

There is no cure for inflammatory bowel disease. With colitis and Crohn's, the intestines are inflamed and sometimes pocked with ulcers. The colon alone is affected by colitis; with Crohn's, the inflammation can occur anywhere along the gastrointestinal tract, from the mouth on down. Abdominal pain, diarrhea and bloody stools are common symptoms, and if left unchecked, the condition can cause weight loss and malnutrition because the body cannot properly absorb nutrients.

There is a genetic component, particularly in cases in which inflammatory bowel disease afflicts young patients. Ten percent to 15 percent of adults who have the disease have a close family member who has it; the number is 30 percent for children with the disease. In Jacob's case, both his father and his maternal grandmother have inflammatory bowel disease. His father was diagnosed in 2004, at the age of 29; his grandmother, at age 18. Jacob was diagnosed at the end of third grade, as he was turning 9.

Whatever the cause, the disease can take a terrible toll on adults and children. Some patients can, with medication, keep the symptoms in check. But many suffer periodic "flares," in which gastrointestinal distress makes it difficult to work or go to school.

"When I have a really bad flare, I basically live in the bathroom that day," Jacob said.

Having kept a tally at his doctor's request, he recalled school days when he had to duck out of class 15 or 20 times to go to the bathroom.

Recess was a particular problem for Jacob last year because the school doors were locked when he was out playing. If Jacob needed to use the bathroom, he had to find a teacher outside, borrow her key and find a buddy to return the key to the teacher before he went inside. This year, Jacob's mother worked out a plan with his teacher that allows him to have his own key on a lanyard.

"If I have a flare, the teacher's gonna give me a key," he said.

Jacob takes medication at least twice every day. When his condition flares, he takes stronger, steroidal drugs. He suffers from headaches, possibly as a side effect of medication or simply from the sleep deprivation that comes with having to go to the bathroom all night long. Long-term steroid use can stunt growth and cause other problems. But so can leaving the colitis unchecked. Decreased bone density is common in young patients because it affects the absorption of vitamin D and other nutrients, according to the foundation.

"For pediatrics, growth is probably the No. 1 (problem)," Yeung said. "One reason is, if it's not under control, there's malabsorption of nutrients. And you're not very hungry because your tummy hurts."

It is nevertheless possible to lead a full life with [inflammatory bowel disease](#).

"I have students with this disease that are national volleyball players, football players," Yeung said. "But it's still hard. It's one thing if you have asthma and you can't breathe. It's another thing if you have diarrhea."

Jacob had to give up track and baseball because there were not always bathroom facilities available at meets and games. But he has continued to play Amateur Athletic Union basketball.

"He's in the hospital one day, and two days later plays in tournament," said his father, Dave Krause, 36. "He's been very strong."

Some of the testing done to diagnose colitis can feel as awful as the disease itself. Having trouble getting Jacob to take a barium drink last year, his parents turned it into a game. They had Jacob shoot hoops at the end of his cul-de-sac as he drank. If he made a shot, he'd take a sip. If he missed, he'd have to chug.

While he shot and mostly chugged -- Jacob claims to "own the free throw line," but the drink and the day's fasting took their toll on his aim -- he wished aloud that he could do something so other kids wouldn't have to undergo such an awful test. He and his parents came up with the idea of having a free-throw tournament to raise money for research. Ten weeks later, they put on the tournament and raised \$35,000 for the Crohn's and Colitis Foundation and Johns Hopkins Children's Center.

His second fundraising tournament took place Sunday afternoon at Meadowbrook Athletic Complex in Ellicott City, Md.

The event went on this year despite a new medical challenge for the family. Jacob's mother, Jill Krause, 38, was diagnosed with breast cancer last spring. She had a double mastectomy in June and is undergoing chemotherapy.

"We've got a lot going on," the mother of four said wryly.

"With what's been going on with me, he's been an amazing source of strength," she said. "I had to do barium."

Jacob broke in: "It was the worst thing ever!"

"He got me through barium," Jill Krause continued. "Not that I'd ever want to have this medical bonding with my child. ... You've got to be positive. Positive takes you a long way."

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