



After treatment, Julia leads a normal life. At right: with her mom, dad, and brother, Thomas, in 2006.

Arthritis at Age 6

We think of it as an old person's disease, but this chronic condition strikes hundreds of thousands of kids like first-grader Julia Lewis. BY CHARLOTTE HUFF

Julia Lewis had been an energetic preschooler who loved to spend her summers leaping through the ocean waves with her dad, Jay, near her home in Westbrook, Maine. But her life changed suddenly three years ago. One August afternoon, her mother, Becky, noticed that Julia had bruised-looking circles beneath her eyes. Two days later, the 3-year-old developed a pink rash on her arms, legs, and face. The doctor told Becky it was probably just a virus—nothing to worry about.

But Julia's splotches didn't go away. They would fade overnight and then flare up again the next evening, often accompanied by a high fever. Becky's concern turned to alarm a few days

later when her daughter complained that her legs hurt and she couldn't walk. At first, Becky—who was holding her 9-month-old son, Thomas—thought her daughter might simply be looking for some extra attention. But she soon realized Julia wasn't faking it: Her feet, knees, ankles, and wrists were stiff and very swollen. "Mommy, I can't move my hands!" she screamed.

Becky rushed Julia to an urgent-care center. The attending doctor, thinking Julia was having an intense allergic reaction to something, prescribed prednisone, an oral steroid medication, to calm down her immune system. When Julia's symptoms persisted for another week, Becky took her to an

allergist. He ran a series of blood tests, which revealed a severely elevated white-blood-cell count (often an indicator of infection). "He told me that Julia would need to be hospitalized for IV steroid treatment," Becky says. "I was in tears. I called my husband at work and said, 'Come home now.'"

Julia was admitted to Maine Medical Center in nearby Portland for overnight observation. That's all the time it took for Brian Daikh, M.D., a rheumatologist, to reach a diagnosis: She had systemic juvenile idiopathic arthritis (JIA). Her parents were totally shocked. "I thought arthritis was an adult condition," says Jay. "I didn't know it affected kids at all."

A Debilitating Disease

Although Jay's misperception is typical, juvenile arthritis (JA) is actually one of the most common childhood diseases in the U.S., affecting about 300,000 kids. The most common form, JIA, occurs when the body's immune system attacks the internal lining that protects the joints, leading to severe swelling, pain, stiffness, and joint damage. Those with the systemic form of JIA also get a rash and high fevers that come and go.

Children with JIA may struggle to walk and perform even simple movements like putting on a shirt or gripping a ball. Some kids go for years without being properly diagnosed (JIA symptoms can easily be confused with normal growing pains, as well as leukemia or lupus), and without the right course of treatment the disease can cause growth abnormalities, joint deformities, and disability.

The prognosis is far brighter when doctors catch—and aggressively treat—arthritis in its early stages, as they did with Julia. Dr. Daikh put Julia on prednisone first, then added methotrexate, an antirheumatic drug that helps reduce joint inflammation by suppressing a patient's immune system. Within days, her rash and



Julia's rash helped doctors identify her disease quickly.

fever disappeared, but her hands, knees, and ankles continued to throb. "Some days it hurt so much to move my arms that I couldn't draw," Julia, now 6, recalls. Then there were the side effects from the high doses of steroids: Julia had intense mood swings, couldn't fall asleep at night, and gained ten pounds in one month. "Her face got extremely puffy and round," Becky says.

Dr. Daikh recommended that Julia also start taking a biologic drug called Enbrel. Biologics, which block the protein that causes inflammation and joint damage, have been the biggest breakthrough in stalling JIA symptoms.

Becky panicked at first when she heard that Enbrel must be injected into a child's leg. "I was the person in biology class who couldn't dissect the worm because it was too creepy," she says. But she and Jay learned how to give the weekly injections and let Julia decide who would give her the very first shot. She chose her mom. They sat together for a long time until Julia had psyched herself up. "She cried a bit after the shot, but then she told me, 'Okay, I'm done,'" says Becky.

Moving Ahead

The shots got easier for everyone over time, especially since the Lewises could see that Julia's symptoms were subsiding. Within a year, she was



Julia has been a top fund-raiser for the South Portland Arthritis Walk three years in a row, collecting \$4,700 for research.

virtually symptom-free. Julia stopped taking prednisone and methotrexate last year, and if she continues to feel good, Dr. Daikh may eventually try to wean her off Enbrel.

There is no cure for juvenile arthritis. Julia's symptoms may return one day, and she still needs regular blood work to make sure her vital organs are unaffected by the disease. But right now, JIA isn't slowing down the first-grader at all. She pedals her purple two-wheeler all over the neighborhood, runs around with her friends, and swings on the monkey bars. What she loves most are her visits to the ocean, where she can once again leap over the cresting waves with her dad and outrace the surf back to dry sand. "It's amazing—she has no physical limitations," says Jay. "I'd never imagine that a kid with arthritis could be as active and happy as Julia is." □

Fast Facts About Arthritis

Juvenile arthritis isn't easy to diagnose. You first have to rule out other potential causes of inflammation (including a viral or bacterial infection), diseases such as vasculitis (blood-vessel inflammation), and some forms of cancer. Other details about the disease:

*** Specialists are hard to find.** One out of three kids with JIA live more than 50 miles from a pediatric rheumatologist, according to the U.S. Department of Health and Human Services. Their parents must either travel great distances or pick a rheumatologist for adults, who may not be comfortable treating young children.

*** Girls are prone.** JA is about twice as common among girls as boys. Girls are also more likely to be diagnosed with the disease at a younger age.

*** Drugs aren't the only Rx.** Many children with JA require ongoing physical therapy to improve the strength and flexibility of their joints. Regular exercise—especially walking, biking, and swimming—also helps kids with arthritis improve or at least maintain their range of motion.