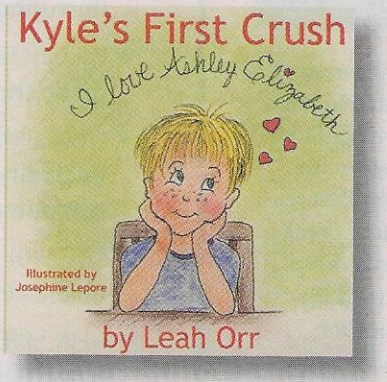
Determined to Make a Difference

MOTIVATED MOM BECOMES A CHILDREN'S AUTHOR TO PROMOTE MEDICAL RESEARCH

As a working mother of three, Leah Orr is accustomed to taking matters into her own hands when she wants to get things done.

That sense of purpose and determination is largely behind the recent release of Orr's first children's book, Kyle's First Crush.



Orr's motivation: she wants researchers to unlock the mysteries behind cystic fibrosis, the life-threatening disease that has afflicted her youngest daughter, 3-year-old Ashley Elizabeth. And she's certainly not going to wait around doing nothing until a cure is found.

Ashley Orr

"With this disease, research is everything," says Orr, a Weston resident. "They're hoping to find a cure for this disease in 10 years. We kept thinking, 'What can we do? What can we do?' "

Orr, the marketing director for her husband's plumbing company, decided to launch a series of children's books, with all proceeds going to the Cystic Fibrosis Foundation. She enlisted the aid of her mother, Josephine Lepore, to illustrate the book.

"We're all so committed to finding a cure for this disease," says Lepore, who lives in Massachusetts.

Orr became involved in the fight against cystic fibrosis almost immediately after she gave birth to Ashley, Lepore says. Genetic tests during the pregnancy had revealed that the baby would have CF. The family considers itself lucky that they had a diagnosis so early. As a result, treatment began from the day Ashley was born in an effort to minimize the disease's damage.

Cystic fibrosis is an inherited condition that affects the lungs and digestive systems of about 30,000 children and adults in the United States. It is caused by a defective gene that prompts the body to produce abnormally thick, sticky mucus that clogs the lungs and can result in fatal lung infections. The mucus also obstructs the pancreas, making it difficult to absorb nutrients in food.

In the 1950s, few children with cystic fibrosis lived long enough to attend elementary school. Today, advances in research and medical treatment have extended the life expectancy of children and adults with CF, and many can now expect to live into their 30s and 40s.

Orr wants to see a cure long before her daughter reaches that age. Ashley, who takes five medications a day and must spend time on a nebulizer, has remained healthy – and Orr wants to keep it that way.

Her book tells the heartwarming story of a little boy who falls in love for the first time in Miss Irene's pre-kindergarten class. The object of his affection is a beautiful girl who is afflicted with cystic fibrosis, and his teacher helps him understand the disease.

Kyle's First Crush is available for $15 online at www.kylesfirstcrush.com. Orr says $5 from the sale of each book purchased through the website will go to the Cystic Fibrosis Foundation to promote research.

Orr plans to release a book every year until a cure is found. And while she already has a whole series mapped out, fewer books would be a wonderful thing.