A life, and fiction, in shadow of disease

By Jennifer Anthony

WESTON — Leah Orr was 18 weeks pregnant with her third daughter when her new doctor began asking her questions about her and her husband's heritage. "I didn't understand why — I mean I have two beautiful, healthy daughters and neither of my former doctors went into this," says Orr. During their conversation the doctor discovered that Leah and her husband were of European descent and decided to screen them both as carriers of the gene that causes cystic fibrosis. It was revealed that indeed, each was a carrier and that their unborn child had a 25 percent chance of developing the disease. An amniocentesis was performed at 5 weeks and that was when the Orr's daughter, Ashley Elizabeth, was diagnosed with the chronic disease.

This life-threatening disease, a genetic mutation, causes mucus to build up and clog some of the organs in the body, particularly the lungs and the pancreas. The mucus build up creates breathing difficulty in patients and inflammation in the lungs that can cause infections leading to lung damage. The mucus can also block the digestive tract and pancreas, making food digestion impossible without medication to assist in enzyme replacement.

"Thank God for early detection," Orr says. "Had we not known that she needed these medications at birth there would have been serious growth and weight-gain issues from the start."

Although it was hard to learn that Ashley — who is now "a happy little 3 year-old tomboy who will kiss a fish she caught right on the mouth" — was sick, Leah Orr decided she would learn as much as she could about the disease and do as much as she could to improve the progress being made to find a cure. She joined the South Florida chapter of the Cystic Fibrosis Foundation and became a chairperson for the annual Great Strides Walk-a-thon each May. "I still felt it wasn't enough," Orr says. "And that's how the Ashley Elizabeth book series was born".

Orr's mother, Josephine Lepore, an artist who lives in Boston, joined her daughter in creating a series of children's books starring the adorable Ashley Elizabeth. The first in the set of seven books, *Kyle's First Crush*, details the first blush of romance in the pre-K set when Kyle falls head over heels for sweet Ashley Elizabeth. The series will follow Ashley's adventures from pre-K on up, tackling issues from best friends, to play dates, to first kisses. When purchased online at www.kylesfirstcrush.com, (which has already sold over 400 copies in just three weeks), $7 of the $15 purchase price goes directly to the Cystic Fibrosis Foundation for research and development.

The book is also available through major retailers such as Amazon.com, Barnes and Noble.com, and Borders.com as well as in bookstores. However, only $1 of the purchase price from these locations goes to the foundation.

"Science has made tremendous strides in lengthening the life of CF sufferers," Orr says. "In the 1950s, children did not live to see their first birthday. Now life expectancy can reach into their 50s and 60s. I'm doing what I can try and help find ways to make that number even higher."

For more information about cystic fibrosis, visit the Cystic Fibrosis Foundation at **www.cff.org**.

To purchase *Kyle's First Crush*, visit **www.kylesfirstcrush.com**, where almost half of the purchase price is donated to cystic fibrosis research.