HEALTHCARE | CYSTIC FIBROSIS FOUNDATION

HEALING BY THE BOOK

IN SEARCH OF A WAY TO HELP HER DAUGHTER, A WESTON MOM IS SELLING THOUSANDS OF BOOKS

BY JENNIFER COHEN
Special to The Miami Herald

"Six sticks for breakfast," Ashley Elizabeth Orr calls her disease.

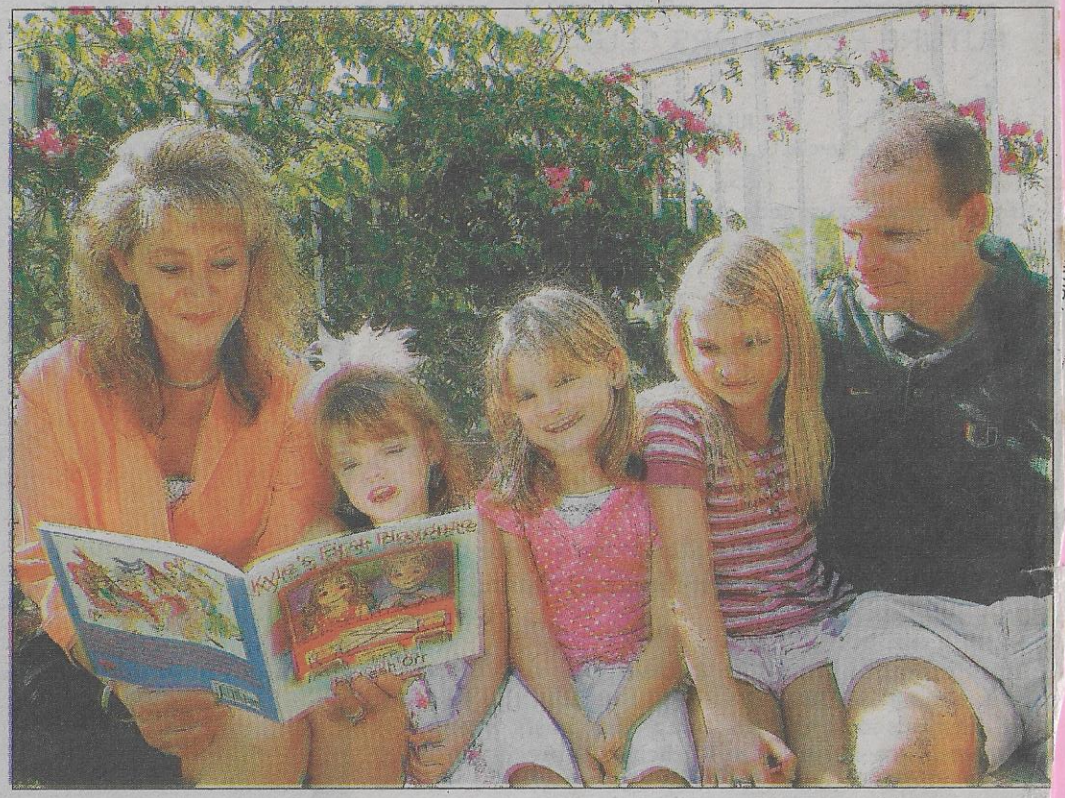
The 4½-year-old was born with cystic fibrosis. Inspired by her daughter, Weston mother Leah Orr wanted to find a way to raise money for the Cystic Fibrosis Foundation while educating people about the condition. So she wrote *Kyle's First Crush,* the story about a little boy's crush on her daughter. Released in 2006, the book has sold 3,000 copies.

Cystic fibrosis is an inherited chronic disease that affects the lungs and digestive system of about 30,000 children and adults in the United States and 70,000 worldwide. A defective gene and its protein product cause the body to produce thick, sticky mucus that clogs the lungs and leads to life-threatening lung infections, obstructs the pancreas and stops natural

Wanting to find a way to raise money to help find a cure, Orr teamed up with her mother, Josephine Lepore, who illustrated the books.

"This is three generations of women who are collaborating to find a cure for cystic fibrosis," Orr said. They self-published their first book with AuthorHouse.

The stories are written from Kyle's perspective.



PHOTOS BY JENNIFER COHEN/FOR THE MIAMI HERALD

FAMILY EFFORT: Weston mom and author Leah Orr, left, reads from her newest book to daughters Ashley Elizabeth, Camy and Aly, and husband Wayne.

enzymes from helping the body break down and absorb food.

DONATE PROCEEDS

Orr intends to write one book every year until a cure is found and is donating all of the proceeds to the Cystic Fibrosis Foundation.

Now Orr is back with a follow-up story, *Kyle's First Playdate,* in an ongoing series that will follow the young couple through their school days and play dates.

"There is a real Kyle," said Orr with a smile, "but we changed his name so we wouldn't embarrass him."

It was not until a fluke test during Orr's pregnancy with Ashley Elizabeth that Leah and husband Wayne learned they were both carriers of the disease. Their daughter, Aly, 9, is also a carrier, and Camy, 7, is not affected at all.

"The books show love through his eyes for this little girl," Orr said. "I wanted to share the joy and importance of young love and great friendship, while at the same time briefly address a disease that affects many children as well as adults all over the world."

Even though Ashley Elizabeth's form of CF is the most severe, she has responded well to drugs. Before she eats anything with fat or protein, she takes a pill that allows her body to absorb them.

"She takes about eight pills each day," Orr said. "She wears a vest that shakes her up to help the mucus get transported out of her body and she uses a nebulizer at night. But other than that, no one would ever know she has CF. She's one of the fastest runners at The Sagemont School where she attends kindergarten."

Between profits from Orr's first book and participation in local CF walks over the past four years, the Orrs have raised more than $250,000 for the foundation.

This year, the Orr Cystic Fibrosis Walk Team raised more than $84,000, making them the No. 10 walk team in the nation.

TEDDY BEAR JUGS

Continuing with her fundraising work, Orr read from *Kyle's First Playdate* Friday at The Sagemont School in Weston. After the reading, Sagemont students officially kicked off their Pennies From Heaven campaign and are dropping their donations in special teddy bear jugs.

"We are honored to support the CF Foundation, and knowing that we are also helping out a student and her family is extra special," Sagemont Lower School Principal Joann Laskin said. "Their passion for this program is truly inspiring."

Orr will read at The Gifted Child in Weston Town Center at 4:30 p.m. Wednesday.

"I had never aspired to be an author," Orr said. "I just wanted to find a way to help my daughter and others with cystic fibrosis. I'll keep writing a book each year until we find a cure."

Kyle's First Playdate *retails for $15 and is available through AuthorHouse and at www.kylesfirstplaydate.com. All profits go to the Cystic Fibrosis Foundation Florida Chapter. To learn more, visit www.cff.org.*

IT'S ABOUT ME: Ashley Elizabeth Orr holds a book written by her mother about a girl very much like Ashley and a boy who likes her.