

GIVERS



Ashley Orr was diagnosed with cystic fibrosis before she was born. COURTESY PHOTOS

Loving Ashley

Mom, grandmother raise funds to battle cystic fibrosis

By Kathie Ragsdale
kragsdal@cnc.com

Leah Orr and her husband Wayne already had two healthy children when their doctor gave them disturbing news about the latest baby Leah was carrying.

An amniocentesis had revealed the child had cystic fibrosis (CF), an inherited chronic disease that affects the lungs and digestive system, often clogging the lungs and leading to life-threatening lung infections. Until recent years, a diagnosis usually meant a greatly shortened life span for an afflicted child.

The couple also learned that they were both "car-

By the numbers

1,000 Approximate number of new cases diagnosed each year
70%+plus Number of patients diagnosed by age 2
45%+plus Percent of CF patients 18 or older
Mid-30s Predicted median age of survival for a person with CF

SOURCE: CYSTIC FIBROSIS FOUNDATION

riers" for CF, meaning there was a 25 percent chance any other child they had would be born with the disease.

"I was shocked," Leah Orr recalls of that day seven years ago.

Rather than sink into



The cover of Leah Orr's newest book, "Messy Tessa"

helplessness and despair, Orr – who formerly owned a greeting card company with her mother, Josephine Lepore – decided to do something