



Cystic Fibrosis Research, Inc.

Bayside Business Plaza

2672 Bayshore Pkwy. • Suite 520 • Mountain View, CA 94043

(650) 404-9975 • Fax (650) 404-9981 • cfri@cfri.org • www.cfri.org

“Your child has Cystic Fibrosis.”

These are words a parent never wants to hear. We heard them when our daughter Claire was 15 months old. Until she was six months old, Claire appeared to be healthy. And then at Christmas of 2003, she was hospitalized for eight days with pneumonia.

How well I remember Christmas Day of that year. My husband Blake and I had taken turns staying night and day at the hospital to hold and comfort Claire. The one of us who was not at the hospital was at home with our then 2-year-old son Kevin, trying to keep his life as normal as possible. Blake had been at the hospital during the night, so I was with Claire on Christmas Day. Her

fever was very high. I remember my terror as I held her that day - my daughter was extremely sick and none of the doctors seemed to know what was wrong with her. Seeing your child so sick and vulnerable is terrifying. After Claire was finally released from the hospital, she continued to be sick off and on for the next nine months. Even the slightest cold would turn into a terrible lung infection. Finally, she was diagnosed with Cystic Fibrosis in September of 2004. As shocking as that diagnosis was, it at least enabled Claire to begin receiving the proper type of treatment she so desperately needed.



Cystic Fibrosis (CF) is the most common fatal hereditary disease in the U.S. Approximately 30,000 people in the United States have CF. An additional 10 million more - or about one in every 31 Americans - are carriers of the defective CF gene but do not have the disease. CF affects the cells that line the lungs, small intestine, sweat glands, and pancreas. Those with CF spend hours a day to stay healthy by using medications, daily airway clearance therapy, and digestive enzymes. In the 1950s, few children with CF lived to attend elementary school.

Today, advances in research and medical treatments have further enhanced and extended life for children and adults with CF. Many people with the disease can now expect to live into their 30s, 40s and beyond. However, these adults struggle to balance the demands of school, career, and family with the many hours needed each day to maintain their health. Many develop CF related diabetes, and some require lung and other organ transplants. ***One precious life a day is lost to this terrible disease.***

Cystic Fibrosis Research, Inc. (CFRI) is working to cure this disease and provide support for those whose lives are affected by CF. Since 1975, CFRI has awarded \$7.8 million dollars in CF research grants. Huge advances have been made in CF treatments, and many drugs that show great promise for treating and potentially curing CF are on the horizon. Just last year, CFRI played a key role in passing legislation requiring that all infants born in California be tested for CF. Hopefully this will eventually be done in all 50 states. Early detection and treatment of CF will facilitate better health and avoid the type of suffering and uncertainty that Claire faced in her early stages of life.

Today Claire is doing well, thanks to the many advances made in CF treatment. She is now four years old and full of life and energy. She goes to preschool, swims and plays soccer. She is a light in our lives. Some days she would rather play with her brother than do her hours of therapy or take her medications, but she knows that with CF, she has to work hard to stay healthy.

I ask for your help in supporting CFRI. With your help, we can improve the lives of those with CF and work to cure this disease. ***Any gift you can give today will be greatly appreciated.***

Sincerely,



Lou Ann Alexander

P.S. – CFRI depends on your support to meet the needs of our CF community. With your gift you are making a difference in the lives of children, youth and adults with CF.

Thank you!