

Fulfilling My Commitment

by Laurie Cooper

I'm very excited and honored to be part of the Family Advisory Council to the Baylor CF care center in Houston at Texas Children's Hospital. I have always been one to contribute my "two cents worth," but I definitely feel worthwhile in this commitment.

My history with CF began in 1983, when my daughter Lauren was diagnosed at just six weeks old. I was a 22-year-old mother of three young children. We had never heard of CF and had no idea what was ahead.

We learned a great deal in those first few years from watching and talking to families who had weathered the storms we knew were ahead of us. I initially got involved the only way I could at the time: fundraising for the Cystic Fibrosis Foundation.

When Lauren was eight, she became committed to making the best of our situation, participating in research for new drugs, helping with fundraising and offering her opinion where needed in the clinic and hospital.

We were lucky, because throughout our 21 years of treatment at the Baylor CF care center, we had a relationship with our caregivers that allowed us to express ourselves honestly about the treatment, the care center and the hospital. But we noticed that not all people living with CF had such a relationship, so we started talking and listening to other families. We wanted to be able to present their views and make a change.

I've always felt that CF families could contribute greatly to the way things functioned at the care center and in the hospital. After years of informal service, I had the honor of becoming the CF parent representative for four years on the first Family Advisory Board developed for Texas Children's Hospital, bringing the needs and opinions of CF families to the administration's attention. I was particularly thrilled to be involved in the first Family Advisory Board for the care center.

As part of this effort, we have developed guidelines for creating a Family Advisory Council and surveys to gain volunteers. Getting involved while caring for a child with CF is difficult, because it involves meeting time, commuting (which can add an additional hour or two!), plus the cost of parking. We have proposed a stipend to cover the parking, and we hope to develop a registry of CF families who would prefer to offer input by phone or email.

Over the years we've seen a great deal of improvement in the Baylor care center. We watched it grow from three or four attending physicians to 11. People with CF can now be certain of seeing one primary CF doctor who manages their care. This change has greatly improved communication.

Unfortunately, our daughter Lauren lost her battle with CF in May 2004. But, as she would have wanted, I remain committed to improving families' relationships with doctors and staff at the care center, and to making every visit more productive.

Having a family member with CF involves a great deal of time management, emotion and fortitude. The better the relationship with the care center, the better the family can deal with the disease. I hope the full cooperation of our care center and our CF families will continue to reap success after success—and ultimately a cure.