

How I Got Involved with My Advisory Board

By Dianne Silliman

It all started with a letter I received from the Central Connecticut Cystic Fibrosis Center (CCCFC) in Hartford, Connecticut. They had just attended a national conference where they learned about Patient and Family Advisory Boards. Now, they were inviting me and several others to join them in forming their own Board.

The letter asked us to attend the first meeting with no obligation, just to see what it was all about. I went with the growing idea that this may answer the questions I had about my involvement with cystic fibrosis. You see, my daughter was in her middle teenage years at the time. At each of her visits, I realized she was taking over her health care, as she should. But my role became blurred. I wondered where my place was, and how I could stay on top of CF while moving away from the role of the main caregiver.

At the first meeting, what stood out most was the fact that we were simply a group of people all working towards a common goal: doctors, nurses, nutritionists, foundation directors, social workers, people with CF and parents. (I hope I didn't leave anyone out!)

Many meetings have passed since then. Today, everyone on the Board is on a first-name basis, and all of our ideas, concerns and actions are considered equally important. We work hard not to bring our own personal agendas to the table, although sometimes we use personal experience as a reference point for certain topics.

We work as partners and have mutual respect for what each individual has to offer. There is plenty of discussion—both pro and con—on whatever topic is before us. Yet we always work together to get to an answer.

I feel that the Patient and Family Advisory Board at CCCFC is the most natural progression for me as the mother of a child, now a young adult, with CF. Being on the Board lets me stay in touch with the providers that have become such a part of our lives. It lets me give back to this community, in some small way, what they have given to my family.

I also take great satisfaction in knowing I'm part of an entity that affects change and works to continually improve the lives of so many people. As my husband and I have come to learn over the years, we're not good fundraisers. We always felt guilty about that. But being part of this Board fills the void. Even though I can't bring in a lot of money to fund the research, I know I'm doing my part as a mother.

Most importantly, thanks to the Board, I have come to clearly understand that my role in my daughter's care is as advisor and supporter. And my role in the CF community is team member, helping to provide the best of care possible.