

The Birth of an Advisory Council

Jennifer Keller and her husband Don Kreis, founding members of New Hampshire's Cystic Fibrosis Patient/Family Advisory and Advocacy Council (CFPFAAC), are the parents of a daughter affected by CF. Here they share their journey of getting involved in quality improvement efforts at their CF care center.

How did you get involved in quality improvement?

Our care center at Dartmouth-Hitchcock Medical Center (DHMC) has a strong and lasting commitment to quality improvement. In 2003, DHMC learned of other care centers that were involving people and families affected by CF in quality improvement initiatives. Our care center readily embraced the idea of starting a similar endeavor at DHMC.

Why did you get involved? Were you unhappy with the care you were receiving at DHMC?

To the contrary, we were impressed by the DHMC care center's interest in delivering the best care possible and achieving measurable quality improvement. Our daughter had recently been hospitalized for a course of IV antibiotics. It was a successful stay, but a lot of little things seemed to go wrong. We were in a great position to point those things out, but it would not be worth our time if we weren't convinced that DHMC was willing to take us seriously.

How did your team get up and running?

Through lots of dedicated recruitment, the nurse-coordinator of the care center's pediatric program, Lynn Feenan, made sure we achieved a critical mass of members and held regular meetings. She was not hesitant to seek financial assistance from interested drug companies, several of which have been generous in their support.

How does CFPFAAC interact with the care center staff at your hospital?

We're in an active partnership. At least one of the professionals on the care center staff is at each of our meetings. Everyone participates, and we've had some great discussions. Care center members collaborate with us on specific projects, generating a blizzard of emails and phone calls. And the care center makes a point of inviting the CFPFAAC to part of their annual retreat.

How did your team learn to do quality improvement work?

It started when representatives of the Cincinnati Children's Hospital's group for people and families affected by CF visited DHMC to share their video and talk about their work. Our hospital is affiliated with Dartmouth Medical School's Center for Evaluative Clinical Sciences, which is passionately committed to quality improvement. We're eager readers on the subject and not shy about reaching out to the Cystic Fibrosis Foundation. And we're still learning!

What have been some of the challenges for CFPFAAC?

Building the trust necessary for success does not come automatically, particularly for caregivers who are not used to being so open with nonprofessionals about shortcomings. On the layperson's side, it takes some self-coaching to learn to speak up confidently about concerns that will be heard as criticisms by caregivers—people whose help and goodwill are so important to us. Plus, a sense of community within the CFPFAAC doesn't always come automatically, since CF is such an unusual thing to have in common with families who come from all walks of life.

Are logistics a challenge?

A big challenge. Even in a small state like New Hampshire, getting everyone in one place for a meeting is hard—and, of course, infection control can require people to be isolated. We're exploring video conferencing and other technologies to overcome these challenges.

What progress have you made? What is better because of CFPFAAC?

We're happy to say we can form a list of items:

- **Newborn screening:** In a joint effort with the State of New Hampshire's Department of Health and Human Services and our care center, our Council successfully lobbied the state legislature to require CF screening for all newborns in the state. Screening began in March 2006.
- **Hospital admission:** Our Council worked with the pediatric sedation unit, the pediatric inpatient unit, admissions, the IV team and interventional radiology to create a smooth process for sedation plus PICC line insertion on the day of admission during exacerbations.
- **Hospital-wide influence:** The CFPFAAC is at the table where many issues are discussed and decisions are made, including hospital care for CF, financial reimbursement for care and palliative care team involvement at the end of life.
- **Education:** The CFPFAAC has presented at care center meetings and regional conferences on various topics. We've studied the HIPAA regulations, the Cystic Fibrosis Foundation's infection control guidelines and many other materials. We've given caregivers insights about how key issues play out from our perspective.
- **Outreach:** The team has been instrumental in organizing Patient and Family Night. We've collaborated with the care center on how to make the event interesting, accessible and relevant. We've taken the lead in presenting DHMC's annual CF Registry data, which is both a measure of the hospital's commitment to transparency and an opportunity for building insight into the importance of this data.
- **Infection control:** The group has brought together inpatient and outpatient nursing staff, as well as pediatric and adult caregivers to evaluate guidelines, to educate staff regarding the details and to encourage adherence to policies and practices.
- **Networking:** Members of the team have traveled around New England to meet others affected by CF who are interested in forming similar groups and to learn from their experiences. Members have also attended the North American Cystic Fibrosis Foundation Conference to present in symposia and research other groups' activities.
- **Nutritional Issues:** The team has raised awareness among caregivers and people affected by CF, and has improved nutritional intake by such advances as making refrigerators available to people with CF while they are inpatients.
- **Team building:** The team supports each other as we participate in various CF-related activities, whether they are fundraisers sponsored by the Cystic Fibrosis Foundation, such as GREAT STRIDES, or local fundraising and awareness-raising activities.

Would you encourage others affected by CF to get involved in quality improvement?

Absolutely. Professor Rosemary Quigley, who was a wise and passionate medical ethicist until she died of CF at only 33, once wrote that: "Disease has given me license to be outrageous and demanding; those who don't have the context for these characteristics cannot grasp me."

Quigley said she was discouraged by people who simply admired her accomplishments as a person with a chronic illness, proclaiming: "I seek supporters who never think I have done too much, who will push me further for as long as possible." Quality improvement is the perfect outlet for that kind of energy and drive—a chance for people affected by CF to make a real difference.