

## Sharing Information, Pursuing Perfection

by Honor Page

My new washer was delivered in a 30-minute window. Hybrid cars are getting 40-plus miles to the gallon. My current cell phone has more memory than my first computer. People are always looking for better ways to do things.

My daughter has cystic fibrosis. We're lucky to have a CF care center nearby at Cincinnati Children's Hospital, where the staff is always seeking better ways to provide care. In 2001 they won a grant to "Pursue Perfection" in CF care delivery. I was invited to participate in the quality improvement process.

It has been a journey of team building, hard work and change. People living with CF, families and caregivers have shared perspectives and worked side by side in our effort to build "perfect CF care."

An important first step was learning about transparency—openly providing data about outcomes to families. Transparency is uncomfortable for some caregivers and families, yet it's vital for success. It can point out areas for improvement and reinforce the honest commitment to this work.

Our care center taught us about the Cystic Fibrosis Foundation Patient Registry and shared the Cincinnati Children's Hospital CF outcomes data with us. The Foundation enabled us to speak with other care centers that excelled in areas of interest to us.

We learned that excellent CF care doesn't look the same everywhere. There was no magic bullet, no easy roadmap to perfection. We were able to identify key areas we wanted to improve and gathered some great ideas to get started.

Five years after beginning this process, I have seen improvement in my daughter's care. For example:

- Her throat/respiratory cultures are more frequent
- We have learned more breathing techniques from our respiratory therapist
- We have a detailed written summary after our clinic visits
- We receive flu-shot reminder cards
- We have an online portal to access her medical record
- We are more aggressive with her nutrition issues
- We are learning self-management skills to ensure future success with her treatments

We also have a Parent-to-Parent Network for support. However, our quality improvement work is not done. Until the cure arrives, people at our care center will be seeking better ways and working together to improve outcomes. I hope other care centers will join us and accelerate our progress toward delivering the best care possible.