

When Parents Become Teachers

Thanks to Project DOCC, doctors and nurses learn what special families need from the medical community.

by Jane Schneider

In a small voice that barely fills the hushed auditorium at Le Bonheur Children's Medical Center, Katherine Peatross describes to an audience of nurses and social workers the painful news she received following the birth of her son, Carter, several years ago.

Only five hours after the excitement of welcoming their first born, Peatross and her husband Scott were visited by a geneticist who gave them a devastating diagnosis: their son had Rubenstein Taybi syndrome, a rare genetic disorder (one in 300,000 births) and a form of mental and physical retardation.

The couple stared at her in disbelief. The only consolation the Peatross' could take away that night was the gentle way in which their doctor delivered the news. "She was compassionate, and kind, and gave the right amount of information without overwhelming us. She even gave us her pager number and said to call her if we had questions," says Peatross.

It was a small gesture. But the doctor's empathetic manner made one of their most joyous, most difficult days more bearable. That experience encouraged Katherine to tell her story as a member of Project DOCC (Delivery of Chronic Care), a parent-led training program at the University of Tennessee-Memphis, aimed at helping medical residents, physicians, nurses, and other health-care professionals understand the impact their delivery of care has on families living with chronically ill or disabled children.

It is a unique program, one that empowers parents



Pictured left to right: Parent coordinators Joanne Cunningham, Robin Welsh, and Charlene Harmon train parents for Project DOCC.

community spotlight

to be teachers by sharing their experiences — often with the very medical staff who care for their children. Started in New York in 1994 by three mothers of special needs children, co-founder Maggie Hoffman says she felt doctors-in-training needed to know the struggles families faced, both at the hospital when receiving news about their children's condition, and once they return home to their care.

"Residents haven't been taught what happens when kids are put back into the community with their family. How do parents learn to recognize problem symptoms at home? Where do we go to get medical supplies? Who do we call when there's an emergency?" says Hoffman. "We don't teach the medical part, but we raise awareness about disabilities."

Peatross is one of 32 parents who have been trained as volunteers with Project DOCC, speaking at grand rounds panel discussions, providing home visits, or participating in parent interviews with students. All third-year residents at UT are required to attend the five-hour program. Project DOCC was brought to the school last fall by Drs. Mario Petersen and Carol Greenwald at the University of Tennessee-Memphis. The Tennessee Council on Developmental Disabilities thought the program important enough to lend its financial support to teaching hospitals that adopt it. Through grant funding, parent coordinators and select hospital staff receive training, and in turn, train local parents. The UT Boling Center also provides assistance with staffing and the printing of support materials. Project DOCC

parents receive a \$50 stipend to help defray travel and child care costs.

During their presentation at Le Bonheur, parents discuss a range of topics, including the importance of a good early diagnosis, and referring families to support services in the community. But it is in opening their homes to residents, that parents have the most impact. "We show how our child eats, baths, takes medications, and how our homes have been adapted for our child," says Joanne Cunningham, a parent coordinator and mother of two. "We try to make sure the resident gets a complete picture of the family."

"When the residents go to their homes, this really changes their perspective," says Dr. Mario Petersen, associate professor of pediatrics at UT. "It makes them see the parents and family in a different way — it's eye opening. They know they have to do things differently."

Project DOCC's emphasis is on family-centered care, helping residents understand that when they're treating a chronically ill child, their diagnosis and prescription affects the entire family.

"I thought the message from the family — what they have to do to care for their child and make the family work — was an important one. There's an ongoing need for training around what families need and what they find helpful when working with health-care professionals," says Carol Greenwald, director of interdisciplinary training at the University of Tennessee

Boling Center for Developmental Disabilities. "If we ask a family to do something that doesn't match their needs and priorities, then it's not going to work."

Parents who go through the training must be at least two years out from their original diagnosis. Cunningham says it typically takes that length of time for families to adjust to the many changes that come with having a disabled child. "My experience at first was 'Why me, why my child?' I was angry," says Cunningham, whose son Jacob has cerebral palsy. "So you have to move past the anger to make it a more helpful experience and talk about how the doctors might have done things differently. When you get that first diagnosis, you're dealing with so many emotions."

And those emotions can be dramatically affected by the attending staff at the hospital. For every positive interaction, there are just as many families who've experienced negative ones.

"Some doctors just paint the situation black at the very beginning and it's devastating," says Robin Welsh, a family support coordinator for the University of Tennessee Boling Center for Developmental Delays and a parent coordinator for Project DOCC.

Her twin sons, Christopher and John (now 7), were born nine weeks premature, weighing just over two pounds each. Not long after their birth, Cricket (Christopher's nickname) began experiencing serious health problems that led to a number of surgeries during his first

months of life. Welsh remembers all too well the neurosurgeon who first examined the CAT scan of her son's brain. Welsh, her husband, and mother were at the hospital, where her month-old baby was scheduled to undergo intestinal surgery and the placement of a shunt to relieve the buildup of spinal fluid in his brain.

"The doctor took the three of us to a casting room [where arm and leg casts are made,] and there are 12 residents standing in the room, watching us. He proceeded to put the CAT scan of my son's brain on the wall and examining it, saying over and over again how bad his brain looked, and that we should think about institutionalizing my child," says Welsh. She was devastated. "I remember looking at his shoes the whole time he was talking, thinking I was going to throw up on them."

Welsh's experience is all too common. Parents with Project DOCC hope residents will learn from their stories.

"We're trying to get them to walk a mile in our moccasins, to see what we go through," says Cunningham. If physicians can better understand the family's perspective, she says, "You tend to treat people a little kinder and gentler."

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Interested in having Project DOCC speak with your staff? Contact Robin Welsh, family support coordinator for the University of Tennessee Boling Center for Developmental Disabilities • 448-3737.