

Champion of Change

Julie Moretz, Director of Family Services Development, MCG Health System

For Julie and husband David Moretz, everything about the birth of their third child Daniel, was normal. There were no surprises during Julie's pregnancy and immediately after Daniel's birth, everything seemed as it should be. The family planned to celebrate Daniel's arrival with a dinner together in Julie's hospital room. But then a doctor came in, sat down and delivered devastating news. Daniel was born with severe heart problems that would likely cut his life tragically short.

Daniel was immediately transferred to the Medical College of Georgia hospitals and clinics, and that night Julie and David arranged to have their pastor baptize the child. Within a few days Daniel had open-heart surgery. Over the next eight years, he would undergo another 11 heart-related surgeries, receive 150 blood transfusions and three pacemakers, and suffer two strokes. When he was eight, Daniel received a transplanted heart.

Throughout Daniel's medical journey, Julie tried to remain by his side. "I expected to know if there was a crisis. I asked a lot of questions and wanted to be a partner in Daniel's care, and I wanted his doctors and nurses to partner with me. I knew what I expected wasn't the norm."

But, as in almost every hospital in the country, Julie and the rest of Daniel's family were only allowed to be with him during visiting hours, and were asked to leave during medical rounds. When Julie and David were allowed to stay with Daniel after a surgery, they had nowhere to put their clothes or store personal items. Julie recalled sitting and sleeping on the same small stool by Daniel's Pediatric ICU bed for three days after one procedure because there were no accommodations for family members. "It was clear, the hospital just didn't know what to do with us," said Moretz.

Frustrated, Julie approached MCG and asked them to re-examine how they treat families. The hospital leadership responded by asking Julie and 21 other parents to help them design a new \$53 million, 154-bed Children's Medical Center. By all standards, this was an unprecedented decision by the hospital leadership. Never before had families and patients been invited to play such an instrumental role in the development and the operations of a major health care institution. It was a risky and courageous decision but one that these leaders believed needed to be made if they were to improve the quality of care they provide.

Over the next five years, Julie and the other parents channeled their frustrations with a system designed for the needs of providers into creating what has become

an award-winning children's medical center. Among the many features in this remarkable hospital is a detail that is near to Julie's heart. Every room has a pull-out bed for family members to spend the night.

"One of the significant things that has changed over the years is that the parents are no longer the visitors. We can be there with our child whenever we want," she said.

Julie's commitment to partnering with the hospital led to yet another transition - she is now the director of family services development, which includes the children's and the adult medical centers.

"When I'm in administrative meetings, many times I am the voice of the parent. I am the voice of the patients who cannot be there to speak for themselves. The best thing I can do is look at policies and procedures and work with staff so that they embrace patient- and family-centered care," she said.

With the help of Julie and many other patients and parents, the Medical College of Georgia Health System is transforming itself by directly involving more than 130 patients and families in redesigning all aspects of care, from the operating room to a new Neuroscience Unit. The introduction of true "patient- and family-centered care" at this teaching hospital has not only significantly improved patient satisfaction and staff morale, but the concept of partnering with patients and families is being integrated into the training and education of future generations of physicians, nurses and allied health professionals at the Medical College of Georgia.

"When I hear the words patient- and family-centered care, I know as a parent I'm going to be respected. That means everything to us, because we need to focus on helping our children when they are sick," observed Moretz.