

## Parents and Young Patients as Partners in Care

BY RAHUL AGGARWAL, MBBS, and JANE BRISSETT

e have come a long way in pediatric care over the past 35 years, when St. Mary's Medical Center in Duluth, Minn., opened what was then — and continues to be — the region's only Level IIIb Newborn Intensive Care Unit. With 25 beds, we care for 300 infants annually. We long have had an inpatient pediatric unit and an intensive care unit.

Over time, we have added nearly 100 pediatric specialists in cardiology, gastroenterology, endocrinology, psychiatry, neurology, hematology/ oncology, rheumatology, ophthalmology, orthopedic surgery, pulmonology, rehabilitation and other specialties. In 2007, we opened a five-bed children's emergency department, and in December 2010, the hospital earned the only Level II Pediatric Trauma Center designation north of the Twin Cities.

As we expand pediatric services, our leadership has given extraordinary support to the concept of patient- and family-centered care.

Before 2004, our pediatric care was more traditional and process-oriented. Physicians and other medical staff made decisions in the best interest of the patient but did not necessarily involve or seek out parents' thoughts. Our physicians and administrators sought a better model of care, one that is still evolving. Today we work as a team — from the housekeeping staff to physician specialists — to seek out what our young patients and their families need.

We have always tried to treat our patients with dignity, respect, kindness and patience. But our patient- and family-centered care initiative takes those concepts much farther. It shapes programs, policies, facility designs and every interaction we have with our patients and their families. It makes social, emotional and developmental support part of our job because, in truth, they are important aspects of health care.

This approach redefines our roles as providers, making patients and their families our partners in health care. It gives them both dignity and control.

Additions to our staff reflect our commitment to this care model. We also have developed an effective family advisory council that makes a difference in both the hospital and clinic setting.

A grant in 2007 allowed us to see what a patient- and family-centered care coordinator could do. Two years later, our administration enthusiasti-

**Essentia Health-St. Mary's Medical Center** in Duluth, Minn., is one of Essentia Health's 17 hospitals and 64 clinics serving patients in Minnesota, Wisconsin, North Dakota and Idaho. Essentia began fully integrating operations in the summer of 2010, bringing together the resources of its member organizations — SMDC Health System, Innovis Health, Brainerd Lakes Health and the Essentia Institute of Rural Health.

Today we work as a team from the housekeeping staff to physician specialists — to seek out what our young patients and their families need. cally agreed to hire a full-time employee to continue overseeing that initiative, work with staff to implement patient- and family-centered care approaches and meet with our family advisory council to find out what matters to families and what is best for our patients.

Our two full-time certified child life specialists — the only ones in the region — support children and families when they visit our downtown Duluth medical campus as inpatients or outpatients. Child life specialists do a variety of things our vision of the Starlight Kitchen in our newly remodeled pediatric unit and suggested a variety of kid-friendly foods available whenever our young patients feel like eating.

Parents can be present during the induction of anesthesia when their child is undergoing a procedure or surgery. Having the comfort of Mom or Dad — often holding or hugging the child — reduces anxiety and fear as drugs are administered. The family advisory council was key to transforming this simple idea into a new protocol.

## Members' ideas and suggestions reflect their experiences and provide insights that we, as professionals, sometimes don't have.

Our children's emergency department benefited from decorating and remodeling ideas from council members. The exam rooms and play area are separate from the rest of the emer-

to make our young patients comfortable, such as explaining medical procedures in a way children can understand, offering tours before hospital admission, helping bridge the gap between home and school during hospitalization and explaining to parents how they can support their child.

Our family advisory council, developed as part of an effort to expand our children's services, also helped us become members of the National Association of Children's Hospitals and Related Institutions (NACHRI) in 2005. The council is made up of parents, guardians and family members of children who receive care here. These volunteers counsel and educate our staff, departments and committees. They also serve as advisers, educators and mentors to other families.

The family advisory council has been active and effective. Members' ideas and suggestions reflect their experiences and provide insights that we, as professionals, sometimes don't have. For example, when we asked the council how we could encourage parents to be our partners, they suggested effective ways that parents could be a

part of daily hospital rounds. Our care teams now do daily rounds at a child's bedside in our pediatric unit and pediatric intensive care unit. It is up to the parent whether to be involved, and many

choose to be. We also ask parents if they would like to participate in our nurse-to-nurse shift reports.

The family advisory council members have been enormously helpful in many other changes. They agreed with us that sick children need access to food 24 hours a day, not just when hospital meals are served. They helped us realize gency department and are decorated in beautiful colors and artwork that help create a quieter environment centered solely on children. Currently, council members are advising on the remodeling of our children's therapy space at Essentia Health's Polinsky Medical Rehabilitation Center in Duluth.

In the neonatal intensive care unit, a dedicated group of parents, some from the family advisory council and others who simply volunteer to help other parents, act as mentors for new families. Mentors help parents make scrapbooks of their babies' time in the hospital and talk with them, parent-to-parent, providing insight and understanding based on their own experiences with a premature or ill newborn.

Many other patient- and family-centered changes are happening as well. In our hospital, we don't view parents as visitors. There are no visiting hours for families. They can come and go at any hour or stay with their child 24 hours a day. Parents take care of their children at home, so why not in the hospital? We now encourage

## We encourage parents to read their child's chart, to raise questions and to discuss their thoughts and ideas with us.

moms, dads, grandparents and whoever else is considered family to help bathe, feed, administer medications and treatments — whatever they're comfortable doing. That gives both the child and family a sense of comfort in what can be a very stressful situation. What they don't know how to do, our staff teaches them.

We encourage parents to read their child's



chart, to raise questions and to discuss their thoughts and ideas with us. Likewise, we train and challenge our health care workers to think about the patient's experiences so the child can be more comfortable in the medical setting.

This culture change — always seeking input from the patient's family and involving parents in

any way they are comfortable — hasn't been easy for everyone. It's often difficult for even the best health care professionals to adopt the mind-set of shared decision-making. There has been some resistance, but once our providers really understand the con-

cept, they grow to like the idea. We have a team of physician advocates that helps colleagues understand patient- and family-centered care. With training, advocacy and time, we have found not only support, but also high levels of satisfaction with our new model.

One aspect that many of us did not anticipate was that patient- and family-centered care actually takes less time for the staff and physicians. Multiple studies show that if a physician simply sits down in a room with the patient and family, talking with them in an unhurried manner and encouraging their opinions and questions, patients feel valued and are more willing to partner with us. That may be the biggest time-saver of all.

But there's more to the patient- and familycentered approach than good feelings. Studies show improved outcomes, shorter hospital stays, reduced costs per patient and medical error rates down by as much as 62 percent when families participate as partners. Furthermore, national leaders in patient- and family-centered care report significant increases in patient volume. Results have exceeded our expectations. Parents have become our partners in making decisions and are more involved with their children's care. Overall lengths of inpatient hospital stays have decreased, and we expect emerging data to show other medical outcomes to be improved. We have also found that putting the patient at the cen-

Parents have become our partners in making decisions and are more involved with their children's care.

> ter of everything does not take more time or stress our staff. Quite simply, it's better for everyone.

> At Essentia Health, our leaders believed that beginning the patient- and family-centered care initiative in children's services was a logical step because children can't advocate for themselves. This initiative has worked so well in pediatrics that it is now moving into other specialties, and we hope that eventually Essentia Health will be known as a patient- and family-friendly health care system across the four states that we now serve.

> Patient- and family-centered care is not a one-time change of policy that we can start and then forget. Rather it's an evolution in how we approach our work. As our Patient- and Family-Centered Care Coordinator Amy Vanderscheuren says, "It's a journey. ... You never really arrive."

**RAHUL AGGARWAL** is a pediatric intensivist at Essentia Health-St. Mary's Medical Center., Duluth, Minn. **JANE BRISSETT** writes for Essentia Health. JOURNAL OF THE CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES

www.chausa.org

## HEALTH PROGRESS®

Reprinted from *Health Progress*, May-June 2011 Copyright © 2011 by The Catholic Health Association of the United States