

CHOP

Family News

Winter 2010

Being There

CHOP Welcomes Family Members into the ED Resuscitation Room

For 36 agonizing seconds, Cindy DePietro stood in the resuscitation room of the Children's Hospital Emergency Department and watched the medical team try to restart her son John's heart. "Thirty-six seconds, and it was the longest period of time I can ever remember. I thought, 'How do you plan a funeral for a 10-year-old?'"

She never had to make those plans. The medical team in the ED that night, led by Angela Ellison, M.D., M.Sc., revived John. Two days later, he had surgery to remove a massive, but thankfully benign, brain tumor that other doctors had been unable to detect. John, now 12, is a happy seventh-grader who enjoys playing baseball and riding his bike.

In those frightening moments, Cindy was able to be with her son because, five years ago, CHOP decided it was best for everyone — the child, the family and the medical team — if parents or caregivers were present in the resuscitation room. Children's Hospital was among the first pediatric hospitals to promote the practice. Studies have borne out the decision, according to Mirna Farah, M.D., attending physician, Division of Emergency Medicine, who has researched and championed the practice.

"The benefits of having family members present during resuscitation are countless," says Farah. "We work to create the most effective communication between the care team and the family during a tremendously stressful time."

Family presence during resuscitations is an illustration of CHOP's commitment to family-centered care. "We count family members as part of the team," says Ellison. "They have something important to contribute."



Cindy and John DePietro

"Although my son John's time in the ED was one of the most frightening and traumatic moments of my life, the staff was there for me as much as for my son," says Cindy. John had headaches that no doctor could explain and when an especially bad one struck on March 27, 2008, she headed to CHOP's ED from their home in Boyertown, Pa. John passed out as they arrived at the ED and was whisked into the resuscitation room — accompanied by his mother.

The ED staff follows an assessment protocol to determine if family members are OK to go into the resuscitation room. Parents who are overly distraught or might be disruptive are asked to wait nearby so their child receives the best care. More than 90 percent of families are with their child during resuscitation, for an average of 250 family-presence events a year. Parents are always accompanied by a social worker or nurse who serves as an intermediary and can explain what's going on.

"I remember them asking me questions," Cindy says. "Could John have taken drugs? Was he allergic to anything? They were always direct and professional, and kind. They kept me informed minute by minute." Getting quick answers for doctors is one of the benefits of having parents or guardians in the resuscitation room.

You can imagine how frightened children are while they're in the resuscitation room. They've either suffered a trauma or are experiencing a rapidly deteriorating condition. A lot of people are racing around them, using strange equipment on them. Parents can soothe their child, which has the secondary effect of making the doctors' job easier.

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The Patient's Perspective

CHOP Treats the Sickest Kids and Teaches Parents, Too

By Kathy Conaboy

A boy. A tree. A life-changing moment.

When my son Stephen was 8, he was playing on a big limb on a backyard tree. The limb snapped and turned into a projectile that smashed into Stephen's midsection when both plummeted to the ground.

A helicopter landed on our street and rushed Stephen to the nearest pediatric emergency room. He was given only a 20 percent chance of living through the night, after surgeons removed 80 percent of his liver. He survived that night, but his condition was dire. A couple of days later, while Stephen was still on life support, we transferred him to The Children's Hospital of Philadelphia.

By the time we arrived, CHOP had assembled an intensive care team to manage Stephen's needs. As I approached Stephen's bed, the doctors and nurses made room for me and asked me to tell them what had happened. That was the moment I became a member of his medical team, and I've participated in his care ever since.

I can smile now and tell you that Stephen is one of those miraculous success stories that occur at Children's Hospital. He survived many lengthy surgeries, massive infections and off-and-on complications. His liver regenerated and is now fully functioning. He's 24 and going to college.

Stephen has transitioned to adult care providers, but it was the people at CHOP who taught us how to keep his medical history, give a full accounting of what he's gone through and advocate for him. We needed those skills when Stephen had medical emergencies outside of the Philadelphia area. I'm a firm believer that parents' participation in their child's care contributes to the best outcomes.

At Children's Hospital, the staff wants parents and caregivers to be part of the team. That means learning as much as you can about your child's condition and treatment options, and giving your opinion and impressions. For me, it also meant dealing with a medical error.

This happened back in Stephen's first few months as a CHOP inpatient. Because of all the trauma to his abdominal area, he was getting most of his

nutrition intravenously. Nurses had been teaching me how to set up the feeding since, once we were discharged, I would be handling it at home. With total parenteral nutrition (TPN), you have to be very careful of the rate at which the "food" goes into the catheter. One afternoon, I noticed the nurse had set the equipment to flow the TPN in too fast.

For a moment I didn't know what to do. The nurse was — and is — excellent and one of our favorites, and she was integral to Stephen's care. I didn't want to get her in trouble or have her get mad at Stephen and me. Would I be branded as a troublemaker? Would they still treat Stephen? These thoughts swirled in my head as I pointed out the error to the nurse. She apologized, fixed it and then reported her own mistake.

The nurse manager on 7 West, Anne Mohan, who is now the Patient Safety Officer for the Department of Nursing, came to talk to me. I remember her saying that CHOP always encourages parents to speak up right away if they ever see anything that is wrong or makes them uncomfortable. The best way to prevent errors in the future is to study mistakes that have been made, learn from them and create strategies to stop them from recurring. Anne told me: "We're committed to your child. We want to hear about anything you see, what you're thinking or feeling. We want to deliver the best and safest care."

And that's what we received in all those outpatient and inpatient visits to CHOP since that fateful November day in 1993 when the accident happened. During one crisis, doctors told us that Stephen had a 1 percent chance of living through the night. During those most difficult times, people like Dr. Elizabeth Rand, Stephen's GI doctor, were there to see us through.

They say CHOP is the place where miracles happen, and in our case it was true.



Stephen, at age 8, is flanked by sisters Cara, 2, and Jillian, 6, on his first day back to school, five months after the accident. Here they are today: Jillian 22, Stephen, 24, and Cara, 18.

