



Jerry W. Friedman

As we approach the holiday gift giving season, I want to share the story of the most precious gift our family has ever received. On October 16, my stepson, Christopher, was the recipient of a double lung transplant at Baylor Methodist Hospital in Houston, Texas. He is recovering beautifully from the surgery and, while careful monitoring is required, we are very optimistic and hopeful for a bright future.

Christopher is afflicted with cystic fibrosis. As his lung capacity began to diminish and he entered the final stages of the disease, it became evident that an organ transplant was the only option. While we had been preparing for the procedure for several years, the uncertainty of finding a suitable match and Christopher's declining health made this period extremely frightening and stressful. As both a consumer of our health and human services system and a parent, I am sharing some of the thoughts, observations, and lessons learned from the experience especially because I believe they relate to our work at APHSA.

First, this is a special time to count our blessings. My family feels very fortunate to have the necessary resources to provide for Christopher's needs, to live in an age when medical miracles are more likely to happen, and to have the prayers and support of friends, family, and colleagues. We see firsthand that the system works. From the emergency personnel, social workers, and clinicians to the transplant team and skilled surgeons, the coordination, service delivery, teamwork, and level of care was truly outstanding. For me, this confirms the notion that too often we only hear of the rare failures of our health and human services system while miracles like Christopher's occur routinely without recognition.

Sometimes in the midst of a crisis, one can see things with great clarity—like an accident seeming to unfold in slow motion. When Christopher was at his most critical stage prior to the transplant, I had such an experience. I witnessed something that I instinctively knew—the power and beauty of a mother's love. Over the course of several days, I observed my wife, Jeanette, engage in a tireless bedside vigil, continually whispering encouragement to Christopher, even though medical personnel advised that it was to no avail because he was in a coma. During the critical period when he was being

weaned off a respirator, she provided constant coaching with each breath.

I also saw another side. When the hospital was having difficulty obtaining necessary medical records from another facility, Jeanette grabbed her cell phone and left the Intensive Care Unit only long enough to make a quick call. The records were faxed within a matter of minutes. No bureaucracy can withstand the force of a loving mother on a mission.

The Most Precious Gift

Throughout his life, Christopher has been truly blessed to have the unconditional love, advocacy, and support of his mother. I believe it has made the critical difference in terms of the longevity and quality of his life. Sadly, it also struck me that there are too many children in this country who are deprived of that resource—someone whom they can rely on to advocate in their best interests. So often it falls upon the human services community to fulfill that role and provide a safety net. It is indeed an awesome responsibility that should yield the same positive results as Christopher's for a foster child under the same circumstances.

During the transplant, we were confronted with a difficult dilemma. As Christopher became sicker, his transplant priority status actually improved. Perhaps the most profound moral dilemma for us, however, was knowing that while we were praying for a successful organ match, we realized that another family would be deprived of a loved one. After considerable thought, Christopher's compelling response is that he will live each day honorably and strive to preserve the donor's legacy through good works and service to others. I am very pleased that he has already volunteered to counsel and mentor other patients with cystic fibrosis who are facing transplant surgery.

We learned the donor was a 46-year-old woman who had four adult children and a loving husband. She was, by all accounts, a beautiful person who, in a final act of generosity and with the blessing of her family, gave our son life. Words cannot possibly express our feelings of gratitude and respect for this family. We can only hope that in the midst of their sorrow and grief, they can derive some comfort in knowing their gracious gift gave another family life and hope.

We believe the beautiful spirit of the donor lives through Christopher. She will always be in our prayers.

At the risk of sounding like a bragging parent, I believe I would be remiss if I didn't mention how proud I am of Christopher. He approached this hurdle with grace, dignity, and humor. What he has lacked in physical stamina, he has more than made up for with inner strength and character. He taught us

all a lesson on courage and I believe his positive attitude was a huge factor in this successful outcome.

This obviously is a very personal column and I want to end with a personal plea. The cure for cystic fibrosis, which was the root cause of Christopher's medical problem, is within reach. Researchers have isolated the gene responsible for the disease and are making progress on a treatment mechanism. Cystic fibrosis affects 30,000 children and young adults in this country and is one of the leading causes of childhood death. I urge you to support the Cystic Fibrosis Foundation in its efforts to eradicate this dreaded malady.

Finally, unless you have lived through the experience of waiting for a life-sustaining organ for a loved one, it is difficult to articulate the impact of the donation. Every year, thousands of eligible transplant candidates die due to a lack of sufficient organ availability. Yet, according to a recent *Wall Street Journal* poll, while less than 10 percent of the population objects to organ donation on religious or personal grounds, only one-third have actually taken proactive steps to authorize this gift. For the sake of deserving people like Christopher, please consider this option and, if it feels appropriate, take the necessary steps to declare your intent and possibly save a life. As you search for that perfect gift for a loved one this holiday season, please also consider the most precious of all gifts, even if it's for a total stranger.