

Dear Future Physician

On a cold January day in 1999, my two month old son was admitted to the Pediatric Intensive Care Unit in respiratory distress. Five months later, he left the PICU with a tube in his neck, a tube in his stomach and connected to a ventilator to support his breathing. My son was born with a congenital muscular dystrophy and, as a result of his disease, he has severe muscle weakness and is ventilator dependent 24/7. As the parent of a child with chronic and complex medical needs, it's not only important to find a physician who is knowledgeable and skilled in his or her specialty, it's perhaps more important to find a physician who will give me and my child his or her time, who will listen, and who is willing to go the extra mile in this time of managed care. It's important to find a physician who cares.

As my child's physician, you need to understand that I was sent home with a medically fragile child and I had no choice but to learn how to care for him. I am capable of changing out a tracheostomy tube and replacing a gastrostomy button. I know how and when to suction my child's airway, give breathing treatments, and hook up the oxygen. I can bag my child through a period of respiratory distress. I can adjust ventilator settings and troubleshoot a ventilator. If my child requires a hospital stay, don't treat me as though I don't know how to care for him and don't prohibit me from being an active participant in his care. Remember that I am part of the team and my vote counts in all decisions to be made. While I didn't go to medical school, I know more about my child and his medical condition than you do. When I bring something to your attention, please genuinely consider it. Respect me.

Recognize that sometimes all I need for you to do is to listen as I vent my frustrations and fears. I don't need you to have all the answers, I just need you to care. Make yourself accessible. Give me your email address and don't be opposed to answering my questions in writing. Return my phone call the same day I leave a message. I will only email or call you when I really need your help.

Be honest and forthright with me, but don't give me the worst case scenario only. Take the time to share all the possibilities and options and give me time to process the information. Don't take it personal if I seek a second opinion or choose a different course than the one you recommend. Understand that a diagnosis is an opinion, not a prediction. Never underestimate the importance of hope.

Because of his disease, my son cannot walk, talk or breathe on his own. Yet my son is a human being with feelings. When you walk into the room, acknowledge my son. Talk to him — he can hear. Look into his eyes — they will speak to you. See his smile — it will light up the room.

Over the last nine years, I've had the opportunity to spend a great deal of time in the presence of physicians. I've encountered the good, the bad and the indifferent. But, by and large, I've had the privilege of dealing with an exceptional team of physicians who have provided the best of care to my son. One of my biggest fears the day my son and I left the PICU was of being abandoned by the people who—from my perspective—put me in this

position in the first place. I've not been abandoned, I've been embraced by several very special physicians who have always done everything they can to ensure that my son and I have the best quality of life under the circumstances. They have not only cared for my son, they have cared for me. They have supported me, educated me, guided me and, in doing so, they have truly made it possible for me to "keep on keeping on."

I'd like to share one particular encounter with a physician that I will always remember:

Early one morning as I was sitting in the chair next to my son's bed, the PICU intensivist came over to talk with me. What will always stay with me was this physician's simple act of kneeling down so that he was eye level with me, rather than looking down on me, when he spoke. To most, this may seem like a meaningless, trivial gesture. On the contrary, it is indicative of the special person this physician is. He is unassuming, he is respectful and he is kind.

To this day, this physician remains a part of our team — not as someone who provides direct care to my son, but as someone who is there to listen and offer words of support and encouragement. He is a physician who exemplifies what it means to practice medicine from the heart. Be that kind of physician.

Allow kindness and compassion to guide you and, above all else, be a physician who cares.