



My Most Memorable Case

Janet Cavitt, BSN RN CPON®

The year was 1994. It was the time when O.J. Simpson fled the police in his white Ford Bronco, Lisa Marie Presley married Michael Jackson, gas cost a little more than a dollar a gallon, a movie ticket to see "Forrest Gump" was \$4, and I had been a pediatric nurse for 7 years.

I worked in a colorful, outpatient hematology/oncology clinic called The Park at Children's Hospital of Austin in Texas. The Park was a friendly community of patients with a small, close-knit staff. Even though I had more than 60 primary patients, I knew all of them well—their parent's names, their sibling's names, where they went to school, and much more. I was confident and knowledgeable as a nurse and loved my work.

One of my patients was a toddler, Sara, who had Down Syndrome and was diagnosed with acute lymphoblastic leukemia after a pre-leukemic phase with thrombocytopenia. Sara had fantastic parents who were older than me and a 4-year-old sister. I saw them weekly, at first for labs, and

then more often when Sara started her chemotherapy treatments. I grew very close to the entire family.

One morning, unexpectedly, Sara's parents and her doctor came to The Park and told me that she was in the intensive care unit, "vented" and on "pressors." She was not expected to survive. Sara died shortly after, only days before her second birthday.

Sara's funeral was filled with her favorite things. I could not stop sobbing during the service, but I remember with a smile now a can of SpaghettiOs® that was displayed by the open casket. Sara was the first child I had ever viewed that way.

At that point in my nursing career, I had known several patients who had died, but none of their deaths affected me like Sara's. It was so sudden, and I had grown so very connected to her and her family. The loss of all of them was tremendous to me. It was a very difficult time of my life. After, in somewhat of a reversal of roles, her parents gave me the book *When Bad Things Happen to Good People*.

I am older and wiser now, and I have learned a lot about death and life, boundaries, and self-care. I've attended Initiative for Pediatric Palliative Care (IPPC) trainings and End of Life Nurse Education Courses (ELNEC). We have end-of-life debriefings and other support systems at the hospital now as well as a palliative care and bereavement program. Through the years, I have used the knowledge and experience that I have gained to help me work with many families, including my own.

When I look back on Sara's death, I realize it was a turning point for me. I had to figure out how to work with children who have life-threatening diagnoses and still be able to keep myself intact, which is the piece of nursing that everybody in pediatric hematology/oncology has to negotiate. It can't be taught in a class or read in a book and is an important task of self-discovery. It is what determines if you stay or move on. I'm still here. I hope you are too. ☺



Administrative Tidbits

Kaye Schmidt, MA RN NEA-BC CPON® Column Editor

APHON is always looking to meet the needs of our members, and we have decided to embark on a new path in 2009 with the introduction of this column, which I am honored to have been asked to edit. I have had the honor of working in pediatric hematology/oncology nursing management for more than 20 years. The only thing I can identify as steady in this field is *change!* As we all know, the nature of the pediatric hematology/oncology population continues to change rapidly, and it is challenging to keep up with the ongoing clinical advancements in areas such as treatment and acuity of patients. For those in administrative and management roles, the challenges are sometimes different, and we would like to meet your needs as well. In an administrative role, you may be more focused on the impact of organized labor (i.e., unions), new regulations and accreditation requirements specific to our population, quality and patient-safety efforts, recruitment and retention, or the increased use of electronic

health records and the impact of computerized physician order entry (CPOE) on chemotherapy orders. You may also be more interested in the effects of legislative changes on reimbursement, the crisis state of health care in the United States and how the economic challenges apply to our population, supporting shared governance from a management standpoint, identifying the most effective means of supporting your staff, or dealing with an aging nursing staff. The potential topics are endless. Each of the *APHON Counts* issues has a theme, and we are certain there are administrative topics that may relate to these themes. Our next issue will be focused on family-centered care. Is there something that you would like to share from an administrative standpoint related to family-centered care? Has your organization had success in integrating this model into your culture? What administrative challenges did you encounter, and what advice would you offer to others? Or do you have a family-centered care topic that you would like someone else to address?

The theme for the Fall 2009 issue is staff development. Several topics that might be pertinent to this issue include the aging workforce, recruitment and retention, supporting shared governance, working in union environments, the generational differences that managers encounter in today's teams, and new technology.

The Winter 2009 theme will focus on nutrition and obesity. Regardless of whether there is an administrative topic directly linked to this theme, the options for this column are wide open.

If you have a topic you would like to hear about in this column or are interested in writing an article for Administrative Tidbits, I would love to hear from you. Please contact me at kaye.schmidt@childrens.com, or call me at 214/456-6042. I welcome suggestions and feedback from all APHON members and hope that we can make this a helpful new column for all! ☺