**Memorable Encounters**, by Jane Sweeney Rico, MBA, NP-BC, Ph.D. published in the Worcester Medicine Journal, Jan/Feb 2014

“I don’t have all the answers, but most important, continue to love her as you do. You both are doing a wonderful job caring for her. She looks so happy!”

The neurologist sat close beside me and held Lauren’s tiny hand. We knew something was wrong with my daughter soon after the uncomplicated delivery, but nothing could prepare us for her brain’s imaging results: microcephaly… future unknown. We had seen the pediatrician a few weeks prior but remained hopeful that this initial news was just a bad dream.

We began our journey parenting a child with global delays with the realization there were no clear answers or even a definitive diagnosis. Our love and her happiness were the priority in her plan of care. I hear the neurologist’s words so often, especially during those difficult periods.

The past 22 years have been cruel at times. Lauren would not walk or talk, and the seizures would become more difficult to control. We learned she was legally blind, and her joy in eating suddenly stopped. Function declined with worsening contractures. She had numerous hospitalizations for seizures, pneumonia and orthopedic surgeries, and we became increasingly aware of her medical fragility and our need for constant vigilance. Orthopedics, ophthalmology, cardiology, gastroenterology, physiatry, surgery, genetics and palliative care specialists were slowly added to the list of support, along with our beloved pediatrician, neurologist and nurses. Lauren has had outstanding medical care, and the majority of her physician visits have been wonderful. She is still with us because of this care. This article will share some of the most memorable of these encounters.

The initial news regarding Lauren’s diagnosis came abruptly via phone one evening after a pediatrician’s visit earlier that day. My husband was away on business and I was home alone with 6-month-old Lauren and 2-year-old Michelle. The visit was distressing. Her head circumference showed no growth, and she was not on target with her developmental milestones. I can still hear the doctor’s abrupt presentation done impersonally over the phone. “The X-ray did not show craniosynostosis. This means she is microcephalic. We will schedule a neurology appointment as soon as possible.”

It was bad news, of course, but the way it was presented left me feeling more alone and frightened as I encountered this new world of “special needs” parenting. I wish there had been more thought into the fact I was alone. I wished she had been with me to give me the news.

Lauren began to have difficulty with adequate fluid and food intake and I reluctantly scheduled a GI appointment to discuss G-tube placement. While I maneuvered the wheelchair on the van lift prior to the visit, a man quickly ran over to help. It was then that we met Dr. H., one of the most compassionate and insightful physicians Lauren has encountered. He gently encouraged me to move forward with placing the gastrostomy tube, with the reassurance that I was doing all I could do as a mother to feed her. He then gave me a prescription. It simply read, “Date once a week with husband!” He took the time to listen without the distraction of EMR, phones, pages or the patient schedule. He spoke directly to Lauren and he included her in the conversation. He listened to my issues in feeding and caring for Lauren and acknowledged the almost symbiotic relationship required to care for a child who is non-verbal Memorable Encounters Janet Sweeney Rico, MBA, NP-BC, Ph.D. care of patients with disabilities JAN./FEB. 2014 Worcester Medicine | 19 and unable to do anything for herself. The visit with him was polar opposite to an internal medicine visit I had the following week for my worsening back pain. The lifting was taking its toll, but there was no inquiry into my activities of daily living or stressors. I quickly found a new provider!

Drs. Stacy Kennon and Andrea Urban have been our lifeline, and having provided primary care in the past, I know how busy they are. These pediatricians have certainly gone beyond expectations, and we are forever indebted. From drafting prior authorizations to meeting with intensive care physicians, they have been there to guide us in maintaining Lauren’s quality of life and our sanity! They have provided seamless continuity with specialty practices, called us themselves or had support staff call to check in, advocated for needed services and handled precarious medical situations with competency and expertise.

There have been very few physician encounters that have reminded me of the need to reinforce the importance of listening, patience, compassion, openness and self-awareness. Unfortunately, these encounters are difficult to forget. Recently, a physician who did not know Lauren came into the room and was openly distressed after seeing Lauren sitting uncomfortably in her wheelchair. She then abruptly commented that it would be difficult to see her without her medical records on site. I hadn’t even had the chance to tell her why we were there or that I could easily present the medical history. A resident physician inquired whether I had undergone an amniocentesis and looked surprised to hear I did not. He was even more surprised to learn it would not have told us anything! Although I understood his curiosity, the question made me think he wondered why she was born. My older daughter went with us to many of Lauren’s medical appointments. After one very unsatisfactory visit, she turned to me and said that I should not take Lauren back to see that doctor. At the tender age of 11, she surmised that this physician was not interested in caring for Lauren since she never spoke directly to Lauren nor did she acknowledge Michelle’s presence in the room. Michelle further noted that she was on the computer the entire time!

Physicians have been there for us over the past 22 years, through the good times and the bad. Memorable and cherished physicians consider Lauren as a unique individual who has individual needs requiring creativity and vigilance. Their presence alone is therapeutic. They listen, think holistically, have a non-judgmental attitude, consider quality of life foremost, recognize caregiver burden and maintain humor and realism. They work well on a team in providing care and consider input from all involved. They are self-aware and recognize stress and do not make it harder for us when they are having a hectic day.

We have been blessed to have the pediatric physicians we have caring for our beloved daughter. Our next challenge is to transition her from pediatric to adult services. We are hopeful we will have the same wonderful team of dedicated adult physicians!

Janet Sweeney Rico, MBA, NP-BC, Ph.D., is a nurse practitioner in the emergency department at Massachusetts General Hospital. She is the former director of the Family Nurse Practitioner Program at Simmons College, Boston.