

Statement from Patricia Carroll RN-BC, RRT, MS

I am both a registered respiratory therapist and a registered nurse. I have clinical experience in critical care, emergency nursing, and home health.

I've taught in nursing, respiratory therapy, and paramedic programs and Excelsior College's health science degree. My favorite class was on Health Literacy.

My life, however, changed when I was diagnosed with primary immune deficiency 8 years ago.

Advocating for my patients was always important to me, thinking I had a good handle on their needs and experiences. But I am here to tell you that until I had to manage my own potentially life-threatening, incurable, chronic, and expensive illness, I realized I had ***no idea***.

After repeated staph pneumonia episodes that didn't clear and deteriorating lung function, I had an immune workup and learned I had a primary immune deficiency. Part of my immune system has stopped working, so I must replace those antibodies. I give myself a 2-hour infusion every week.

The drug costs about \$8000 a month. Insurance companies have different rules for coverage and of course, the joy of high deductible plans. Between managing insurance, keeping track of my medical records, monthly medication orders from the specialty pharmacy, setting aside the time for infusion and recovery, and all the other little things, it's like an additional part-time job.

Since my health has stabilized, I have become the volunteer representative for the Immune Deficiency Foundation in Connecticut. I am now a passionate advocate for including the ***patient voice*** at every opportunity because I ***now*** know that we clinicians ***do not*** know what it's like to ***be*** the patient. I believe I can provide insights that providers blessed with good health may not be able to offer. While they are experts on the disease, the patient is the expert on living with it and all the ramifications of decisions made by committees and workgroups like this.

I thoroughly enjoyed the Hackathon and learned a great deal from participating. As the only patient advocate there, I was able to point out aspects of medication reconciliation and managing polypharmacy that were not on my teammates' radar. Their positive feedback encouraged me. In return, I learned the complexity of solutions that seemed simple to me.

While my experience as a **patient** is with primary immune deficiency, my clinical background gives me a broader understanding of the challenges for all patients with complex conditions.

Please allow this to act as a formal request to join this important committee. I believe my unique perspective can help the committee identify priorities. Then I can contribute to developing actionable solutions to improve the medication reconciliation process for stakeholders statewide.

= End Three Minutes=

Addendum

Our group, assigned to meet the challenges for patients and caregivers, won the Hackathon. I believe it was because of the different perspectives in the group and our ability to work together. Those of us on the patient and caregiver side heard the engineers and technical experts who explained solutions were not as simple as they seem to those of us who do not write them. That feedback allowed us to modify our ask and prioritize our needs.

On the other side, the technical people (and some health professionals) were unaware of the challenges patients face. What seems simple, like telling a patient to take medicine 4 times a day, becomes very complicated when patients have multiple work and family responsibilities. Remembering to take medication is hard. Even women who should take their birth control pill every morning have trouble incorporating the pill into their life's routines. The members of our group were anxious to learn from each other. Suggestions based on technical capabilities combined with the expressed needs of patients and caregivers helped us come up with what the judges

determined was the best solution for medication reconciliation. I believe this model could serve this committee well.

I urge the committee to remember that the patient can be their own medication expert, and the best source of truth about their medication regimen. At every visit, I have to correct the electronic medical record, It can be because the physician did not accept the changes I made from my portal pre-visit, or no one removed old medications, or someone clicked on the wrong drug in a dropdown list that then follows me forever.

I bring a typed list of my medications, color-coded by condition, to every visit. I give the list to the medical assistant or the nurse to correlate with the medical record and save me and my physician the time of going through the med rec process. Even that pro-active approach does not result in an accurate electronic medical record due to workflow and system issues.

Finally, another situation in which the patient is the expert on “the truth” occurred just last week. My PCP sent in a prescription for 90 levofloxacin pills for me for one pill daily related to my immune deficiency. Express Scripts sent me 14 pills. I contacted my PCP to confirm the 90-pill prescription. He, indeed, did send that in and had no idea that I only got 14 pills. He did not get an alert that the dispensed fill did not match his order. As far as he knew, I got 90 pills. If I weren't proactive, I would have thought the 14 pills were what he ordered and not pursued the discrepancy further.