

# Dialysis Without EPO by Celeste Castillo Lee

Pre-reading for MEDCAC committee members

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Have you ever had a really long day? A day that started at 5 a.m. with the serenade of *Play That Funky Music White Boy* blasting from your alarm clock followed by jumping up from the bed, a quick shower, catching an early flight to a major metropolitan city, winding through the city to a morning meeting, then a lunch meeting, an afternoon presentation and a trip in a smelly cab through the clogged arteries of rush hour traffic to the airport conveniently located 20 miles away. You arrived at your gate to discover that the crew for your flight just took off on the previous flight and that you had to wait two hours for another crew to arrive. You shuffled onto your flight—full to capacity—and found your seat next to a sleepy-eyed fellow passenger. The flight finally took off after 20 more minutes, landed, you got your luggage, battled with your stuff getting into your car, drove on an illuminated highway and through your sleeping neighborhood and crossed the finish line into your garage. You tiptoed into your bedroom, afraid to wake up your soundly-sleeping spouse, dropped your bags, performed your nightly ritual of getting undressed and preparing for bed. Finally, you pulled down the covers and climbed into your bed...Ahhh...you gave out a soft sigh, feeling the letting go of the day's exhaustion...

Imagine if you never get the “ahhh,” you never get the feeling of letting go. This is what life feels like for a dialysis patient without erythropoietin. Living—breathing and sleeping—is exhausting. When you are anemic there is no peace or rest for the weary.

In March of 1983, at 17, I began hemodialysis due to Wegener's Granulomatosis, a rare autoimmune disease. I was in my senior year of high school and had always been a very healthy and vibrant person. As my kidneys failed, I began to experience fatigue like nothing else, a heaviness that made me feel like a saturated beach towel. Living on dialysis without EPO and attending Syracuse University as a full time student took as much tenacity and mental strength as training for the Ironman. On those days, when I would be transfused, I would be able to go out with my friends, but most of the time during this chapter in my life, all I can remember was being cold, tired and out of breath. (due to the lack of sufficient red blood cells... I felt like I was suffocating). God, all I wanted to do was to take a deep restorative breath in so many ways. “You can do it” was my mantra as I walked across campus.

My physical restoration took place on May 1, 1986, a truly refreshing May Day for me. But tragically, a young man had to draw his last breath for me to get mine. On that day, I received a kidney transplant and an opportunity to live a life unencumbered by anemia and dialysis. For the next ten years that I had my transplant (thanks to *John Stanley*, my given name for the kidney) I danced aerobics at the Skyclub overlooking the Boston Harbor, I ran through the early morning streets of Boston, swam in the freezing beaches off the coast of Massachusetts in late July, ate ripe summer fruits and drank. I drank a lot. I did partake in ice cold beer, but as most folks familiar with dialysis would know, any beverage is a truly wonderful thing. I drank liters of water, milk and iced coffee. The

pleasure of drinking a simple glass of water was never lost on me during that entire time. The kidney had a good run before it failed and the year 1995 saw me returning to hemodialysis and what I feared would be a life without blood.

I was not dreading the dialysis treatments as much as I was dreading the anemia that I knew would soon follow. However, much had happened since 1986 and I was now getting erythropoietin with my dialysis treatments. What a completely different life I was leading on dialysis in 1995 and continue to lead in 2010 with EPO.

Over the past three years, there has been a great deal of attention given to the safety of EPO. I can't comment scientifically on that debate except to speak on this issue from the unique perspective of a pre-EPO and post EPO ESRD patient. I do want to emphasize the importance of including how a patient feels and functions in assessing the benefits of EPO treatment.. My doctor and I are discussing how I feel every week.

In September I began working at the University of Michigan as a Sr. Project Manager, and prior to that I was the Chief of Staff to the President and CEO of Duke University Health System. I have worked full time since graduating from college. I have hemodialysis Tuesday, Thursday and Saturday mornings. My access to EPO is a crucial factor for my quality of life and my ability to sustain full time employment. I choose life every time I undergo dialysis (without dialysis, and because I have no urine output, I would be gone in about three weeks, give or take), and the quality of my life is as important to me as the quantity of my life. Dialysis without EPO is not an attractive option for me. Why stay around to be an exhausted non-contributing citizen, a cranky wife/step-mom/friend and a drain on my society and my soul? I am not interested.

I am very much an advocate both in terms of my own health care and for my fellow CKD patients, and I am alarmed at the discussion I have been hearing in regards to changing the policy for EPO administration and questioning its safety. I have heard that some are advocating for administering only enough EPO to keep transfusions to a minimum. We all know that is not a viable option. I was transfusion dependent as my kidney transplant failed- and have been on the waiting list for a second transplant since Feb 10, 1992 due to high sensitization.

The simple fact is EPO allows for CKD patients to LIVE a life on dialysis. Period. It is our blood line (pun intended).

The basic process, procedures and technology for dialysis have not advanced much in the last 20 years. There is almost no growth in R&D dollars for dialysis due to lack of financial incentives, clearly not due to the lack of need. We have seen an explosion of the CKD patient population. The only real advancement has been EPO. I know this is a simplistic statement, and clearly I see this subject through the lens of a woman with a 28-year history with dialysis and transplantation who has benefited tremendously from EPO. To be fair, there probably are other improvements, but none has impacted dialysis patients' quality of life as much as EPO. The discussion of changing EPO administration has arisen from the recent literature about the correlation between higher hemoglobin

levels of greater than 12 and adverse cardiac events. This research is important, but it is dangerous to make generalizations of EPO's safety at lower yet therapeutic levels. My fear is that this literature will have regulators call into question the benefit of EPO for the dialysis patient population, even at lower hemoglobin levels, as if EPO is an expendable luxury for the dialysis patient. Both researchers and FDA need to understand the ramifications that limiting EPO would have on the lives of hundreds of thousands of patients and their families. Please remember that clinical trials are based on averages, and we are individuals with real and differing needs.

Barring another kidney transplant, which is as likely as me winning the lottery, dialysis is my means for survival. I will die from something. It might be a cardiovascular event and it might be a bread truck. Dialysis could keep me on the sidelines but EPO allows me to play in the game. And to take this metaphor a bit further, it might, just possibly, allow me to be an MVP.

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