

# You, Too

Category: Me, Too

written by Sarah Liu | February 1, 2023

Bradycardia (heart rate 41) one day, tachycardia (heart rate 168) the next, just sitting in bed, before ... during ... after a seizure. My epilepsy is refractory-resistant to treatment—and this incident scares me. But I hesitate to make an appointment, scared as well about the bill.

I can no longer afford private medical insurance, I'm too "poor" for Covered California and too young for Medicare, so I'm stuck with Medi-Cal—the state system that differs from county to county. If only I lived two miles north! But here in Berkeley, I have only two options available, both HMOs, so every appointment and procedure with my epilepsy care team at UCSF requires referral and authorization from my new nurse practitioner PCP.

Do I really need to see the specialists across the Bay? My first brain tumor. Local surgery, mistakenly closed with staples, a no-no for irradiated skin. The chance of surgical infection just 0.5% to 3%, but six weeks later I developed osteomyelitis, requiring a second craniotomy, debridement, an implant, and three months of Vancomycin through a catheter. The onset of epilepsy. Need I say more?

Medi-Cal authorizes an appointment with hematology-oncology, but my PCP warns that neurology is notoriously tough to transfer to. My patient advocate and I agree: UCSF is one of only two Level 4 epilepsy centers in the region, offering the care my whacked-out brain needs. A radiologist benefits from comparing previous images to a current scan—can I continue to have my semiannual MRIs in the same department? Should I stay with the neuro-oncologist who has followed me for years?

But this conundrum is peanuts compared to the one faced by my friend M, who's had rheumatoid arthritis since we were teenagers and is now too debilitated to work. Her son has a protein C deficiency requiring a \$300,000 infusion per month—yes, five zeroes. Her husband's company just folded, so they now have to buy private insurance but can't afford the co-pay for the drug on which their son's life depends. M's father, suffering from Alzheimer's, recently moved to a care home, breaking her mother's heart. Scylla and Charybdis: Will M move to France, her husband's native country, which has socialized medicine, or will they stay here, near her beloved family?

We all know the U.S. health care system is a wreck—but it's all talk, no action for real change. Everyone has a story like this, or knows someone who does. Bankruptcy, debt, between a rock and a hard place: the cliché a truth, the myth a reality.

Me, too. You, too. Us all.

*Sarah Liu  
Berkeley, California*

