

Daylight Savings Time - Lymphomania 2017

Daylight Savings Time 2017 ran from March 12 to November 5. This marked just about the beginning and ending of my lymphomania experience.

However rare, it seems at the beginning of 2017 I developed a fast-growing diffuse large B cell non-Hodgkin's lymphoma tumor in my heart. (As the surgeon told me while I was consciously sedated and I was about to be biopsied arthroscopically down my jugular, "you'll bleed, but don't worry, it's your heart.")

I probably should have taken a hint earlier. I'd had an irregular heartbeat (atrial fibrillation, afib) 20 years earlier when I was working too much, drinking too much coffee, and probably much too anxious. I'd learned then that I'm someone who can feel my heart drumming a syncopated beat. Not everyone can. Odd, but lucky me.

At the beginning of 2017, the irregular heartbeats would come when I jogged the Embarcadero or biked up Columbus Avenue riding home from the office. My calves would hurt, my heart would go afib, and I'd stop. I'd convert to sinus rhythm (a normal heartbeat) and keep jogging or biking. At night I'd take an aspirin. The thought was to thin the blood with aspirin to reduce the risk of a stroke, which is what my physician spouse, Alix, told me 20 years earlier as my heart was racing to a back beat and the fire department and paramedics swooped in to take me to the ER.

We were in Paris for the 2017 Salon d'Agriculture, an annual farm, ag implement, and regional food convention. The exposition runs late February to early March. We biked from our apartment in the 13th arrondissement to the convention center near the Porte de Versailles in the 15th. It's about a 4-mile ride – and it was stunningly cold as I recall now – numb fingers, sphenopalatine ganglioneuralgia (brain freeze). After visiting

the show, Alix, had to pick up something at a pharmacy in a suburb adjacent to Paris. And again, I recall just how crazy cold it was. I left her at the pharmacy to make my way back to our apartment. I had a conference call coming up. I biked for a bit and then walked once I got to the Champs d'Élysée. I recall walking with my bike and my heart accelerating and then going afib. If you're familiar with Paris, you can kind of imagine where I sat down in a bit of a commercial eddy nearing what probably was the Adidas flagship store. My heart wouldn't calm, and I joined my call. During the call, while sitting, my heart converted to normal rhythm and I reminded myself I should take it easier, get some rest.

Back in San Francisco, because I had a runny nose, I thought I had a sinus infection. The doctor I'd seen 20 years earlier about afib (who essentially "cured" my afib by telling me to cut back on coffee) had moved from San Francisco to Palo Alto. He prescribed an antibiotic for what I was telling him was a sinus infection.

In mid-April we flew to New York for Andy Moravcsik's 60th birthday. His friends and family had organized a night of performances at the Poisson Rouge. I hadn't had much time to prepare for the flight. Alix had lined up an apartment on Mercer Street owned by a friend of our daughter's. Flying from San Francisco to New York I had the *New Yorker*. I read through *Goings On About Town* and saw that the Met was performing La Traviata that evening. Landing in Newark and taking a Lyft, I called the Met and got two orchestra seats that had been put back for donation. We drove directly to the Met, stowed our bags at the coat check, and enjoyed the first act. During the intermission we milled about and bought San Pellegrinos (Pellegrini?). With one sip of the cold effervescent water my heart started somersaulting. (Apparently, in hindsight, the tumor was located near my sinus node, my heart had enlarged, and the esophagus was consequently nearer my heart and the change in temperature triggered the cardiovascular gymnastics.)

I didn't tell Alix.

The heart kept up the syncopation.

We sat down for the second act. By the time Violetta heads back to Paris, my heart converted to sinus rhythm. We finished the opera, walked out, took in the planets that some astronomers in the Lincoln Center plaza were tracking, and caught a Lyft downtown to Mercer Street.

The next day, I was fatigued, but we very much enjoyed Andy's party - a sublime combination of music, performance, and good feelings. We were invited to the afterparty. We showed up but I begged off quickly because of exhaustion.

And all the while I thought I had a sinus infection. My nose was running, and I had a strange sense that something wasn't right at the bottom of my left rib cage. Alix suggested walking pneumonia. Returning to San Francisco I made an appointment to see my GP in Palo Alto. This time, the doctor was absent, and a physician's assistant saw me. She changed my antibiotic prescription and suggested I have an echocardiogram of my chest to see if there was anything going on with my heart.

Back in the City, I called to follow up for the echo appointment learning I could show up on either Monday, May 1, or Monday, May 8. Even though work was busy as we were pending regulatory approval for a new trading business, my inclination was to have the echo sooner rather than later.

On Monday, May 1, 2017, I walked to my office on Market and First Street. My echo appointment at Palo Alto Medical Foundation's cardiac offices was in the afternoon. (As fate might have it, May 1 was also the first day of employer health insurance from our start-up.)

I left the office and walked to the train station. The clinic was near the CalTrain University Station in Palo Alto. I could work on the train, do the echo, and be back by dark to walk home.

The cardiac offices are tucked between the railroad tracks and El Camino Real just south of what was once the Holiday Inn and is now the Sheraton. Nothing about the clinic suggests being in the middle of one of the most affluent areas in the world.

A technician dimmed the lights as I took off what was probably 3 layers – I tend to be cold with a turtleneck base, button down collared shirt, and a sweater. She warmed the KY Jelly and squirted some on the transducer to smooth the ride over my chest and ribs. I recall telling her I felt like there was something “infected” under my lower left ribs.

Not too soon after beginning the scan, she asked if I’d been travelling. I told her we had been to France and to New York, but I’m also the guy in the galley doing exercises during long flights. She said, “I’ll be back with the cardiologist”. However ominous that sounded, it didn’t really register that she had found “something”. While wiping the KY off my chest, Dr. Aria DiBiase walked in telling me not to move, “Pal, you have a prune-sized clot in your heart.” She said that if I had someone in the waiting room who could drive me to Stanford Emergency then I should leave now, otherwise, she was calling an ambulance.

I explained I hadn’t told my wife about the visit and that I’d like to call her. DiBiase said, “I’ll give you two minutes of intimacy and then you’re headed to the hospital.” I called Alix and without asking any questions about why I was there or what was going on, she said, “I’m getting in the car and will be there in 30 minutes.” DiBiase checked off on Alix driving down to take me to Stanford and this gave the doctor some time to call Stanford to give them the low-down about my arrival.

Alix arrived and again unquestioningly drove the very short mile to Stanford Hospital Emergency. Intake was accelerated, blood was drawn, and I met with an attending Emergency Room physician who told me I'd be admitted to the cardiac ward for observation. There was clearly something sizeable in my heart. Alix's first instinct was to tell me, "don't worry, you'll be first in line for a new heart." I'm sure Alix appreciated that my age and general good health would put me at the front of the line for a transplant, but her encouragement wasn't encouraging.

I was admitted to the cardiac ward, where there were no private rooms. A thin curtain separated my bed from my roommate's. My first roommate was an elderly man from Palo Alto who had been a well-known graphic designer. Although weak, he was drawing a character study of the hospital hierarchy. At the bottom were the janitors, ascending to nurse assistants, to nurses, to nurse practitioners, to doctors, to hospital bureaucrats. His drawings brilliantly captured the absurdity of the hospital hierarchy.

During the first few days in the cardiac ward, I'd walk around waiting on tests or updates. I was tan (I had sat in the sun at a recent Giants' game) with long curly hair that was just past the edge of going gray. I was monitored so I couldn't walk far so I orbited the ward. My memory is it took 16 revolutions around the ward to make a mile. Admittedly if you're in the cardiac ward at a major research university the prognosis is complicated. I appeared to be an anomaly looking much too well and much too spry for the situation. It was usually the spouse of a patient that asked me or Alix why I was there as if I was there to mock the rest of the patients. When they learned I had a prune-sized tumor in my heart the looks I got on my walks were much less contemptuous and much more sympathetic.

Having been admitted by Sutter Health's Palo Alto Medical Foundation cardiologists, I had a team of Sutter and Stanford doctors on the case. DiBiase had partners who came in and out on my first full day in

the hospital. I recall learning all the little important things a “hospitalist” does. The PAMF hospitalist was a charming man who strolled in with a cane that opened into a seat. He was there to coordinate my care. He was sincere, matter of fact, and pleasant.

At intake in the Emergency Room there was general agreement that the prune wasn't a clot. The unfortunate default assumption was that the tumor was a sarcoma; hence Alix's suggestion of a transplant.

After being admitted on Monday, May 1, I spent my first night in the cardiac ward under observation. Tuesday, Alix and I visited with the hospitalist and the cardiologists (plural). Science was clear about the prune in my heart showing up on the echocardiograph not being a clot. The team concluded the best next step was to biopsy my heart. I was scheduled for the following day. I recall meeting with Alix, the kids, our attorney, and financial friends at Stifel. I ran down a list of things to attend to in case the biopsy turned out to be a sarcoma. These weren't simple conversations or conference calls, but they were business like. I really felt like I needed to land a 767 on an aircraft carrier otherwise Alix, Zoé, and Brice would never figure out just what and just where all the moving parts in our life resided.

While all of this is going on, the blob in my heart wasn't making it easier. My heart rate would fluctuate and sometimes go afib. That night I had what can only be described as a near-death experience as my heart was racing and I was quite certain I was on the verge of a heart attack. What seems to be consistent with the literature about near death experiences is I felt as if I was sliding away. A long white tunnel and I recall witnessing the birth of our daughter and then in the room as our son was born. The sensations were fleeting, but I have a strong mental recall of the evening. I made it to Wednesday. I was prepped for the biopsy with the notion that tissue samples (pieces of my heart) would be snipped and retrieved through my jugular.

(Much later, probably a couple years after being discharged, a college friend who works at Stanford Hospital let me know that the doctor who did my biopsy has "the best hands in the house.")

I was prepped for the procedure and was consciously sedated. I have a strong memory of both watching the procedure on the operating room monitor as well as talking with one of the attending nurses.

I had been told by one of my former business partners whose wife works in the Stanford Humanities Department that Stanford financial donors/contributors are given both "waffle robes" and red blankets at Stanford Hospital. I told the attending nurse I hadn't seen either.

A camera was inserted through my wrist and my jugular was tapped. A senior surgeon, very tightly masked and goggled, looked over the hood and told me, "you've got a 4-lane highway for a jugular. Dr. Lee will biopsy." I had the feeling as I watched the monitor to my left and talked to the attending nurses that Dr. Lee came from house left wearing a fishing hat with flies. He attached a fly and casted down my jugular. I could see what looked like a wire moving down my vein on the monitor.

The surgeon took what I recall was three samples and the procedure wrapped up. I was wheeled into recovery where I had a delightful conversation with a nurse from Guadalajara. We talked regional specialties and my travels in Mexico. She gave me the red blanket and waffle robe. The wise adage that you get the health care you demand could not have rung truer. (I now understand the hospital no longer affords high rolling donors this privilege as I'm sure there's already enough hierarchy in the hospital that another layer among patients isn't really all that useful. Notwithstanding this fact, I appreciated the robe and the blanket, which I now enjoy as souvenirs.)

The next two days were filled with a combination of anxiety and anticipation balanced against continuing to attend to the chore of a work-

a-day punch list of what needed to happen if I weren't around. Alix, Zoé, and Brice were engaged, concerned, and supportive. We went to work to make sure the family knew what was where and how to take care of things if the pathology came back with a sarcoma. We called our estate attorney, CPA, and former partners at Stone & Youngberg who held our accounts. I gave the family information about passwords. The process was very business-like, and we moved through the discussions in a largely matter of fact way that was both efficient and thorough. There was little time wasted on worry or remorse.

Doctors and nurses paraded through to update us, but there was very little to do until the pathology was delivered.

Now, with my waffle robe, I was able to cruise the cardiac ward both looking stupidly healthy and very privileged. While there wasn't obvious contempt I'm thinking there had to be envy because admission to the cardiac ward, again, was hardly a spa vacation. Oh, and I wore a silk scarf to fight the air conditioning. (Later the scarf was admired by an oncologist. Once back in the City, I bought a scarf for him little knowing that there are ethical questions about giving health care workers gifts.)

I think all patients were being monitored in the cardiac ward. As I walked by the central nurses' station, I saw the CRT screens keeping track of heart activity. Away from the station I heard the alarms go off when heart rhythms raced or syncopated or slowed.

On Thursday afternoon Bill Chow from PAMF came in. He was DiBiase's partner at the cardiac clinic. He told us the final pathology wasn't in, but that it looked like the tumor was lymphoma. Alix said, "Lymphoma can be cured....and you can't confuse a lymphoma cell with a sarcoma cell." Bill agreed, but again said the report wasn't final. At this point emotion really broke out as it felt as if a death sentence had been stayed or even lifted.

What was odd through this whole first week of uncertainty was that I felt very much at ease with the notion of dying. I was 59. I'm from rural Southern Ohio. I'd travelled the world, had success in business, and had a loving and accomplished family. Again, it's odd, but given the sensations in my heart, death seemed like a welcome outcome. And through all the first days in the hospital my heart had been doing somersaults. I clearly had had that one near death episode late at night as I recall my heart doing gyrations and visualizing the birth of both children. I can't adequately describe the sensation and sentiment now, but again, death seemed like a welcome resolution.

Friday morning came with the expectation of a lymphoma diagnosis from pathology. A young south Asian doctor came in. She told me the pathology hadn't been confirmed. Alix again made clear that you don't confuse a horse for a car, and you don't confuse lymphoma for sarcoma. The doctor wasn't amused. I couldn't see the doctor's badge. I was in the habit of calling the doctors by their first names to humanize the situation as well as to establish a relationship based on some sort of humanity and equality. When she leaned over, I saw that her badge said, to my great surprise, "Palliative Care and Hospice." She told us once the pathology interpretation was complete; we'd discuss a course of action. When she left the room, we contacted one of the PAMF cardiologists and said we needed to see an oncologist and we'd had enough of the Palliative and Hospice doc.

Neel Gupta arrived. Gupta had recently moved to Stanford from UCSF. Tall, fit, and handsome with a strong confident jaw, Gupta confirmed the pathology. He had a warm demeanor, spoke fondly of the talented nurse practitioners on his team, and inspired confidence in Stanford while also suggesting having another oncologist opine.

Gupta explained that, yes, the meatball (his word) was lymphoma, and the likely course of treatment would be R-EPOCH. I asked for an explanation. He told us about the typical treatment for large B cell diffuse

lymphoma is a monoclonal antibody and chemical cocktail called R-CHOP. R-EPOCH required week-long visits to the hospital for chemical infusions and the doses would be adjusted upward through a series of six, week-long treatments where I'd be infused for one week in the hospital, discharged for two weeks, and then return for another week of dose adjusted chemistry. R-CHOP on the other hand was similar but only required one day of infusion on an out-patient basis. There was no conclusive studied evidence that one protocol was better than the other, but my lymphoma was a bit unique with only one tumor in a major solid organ. (If you want to keep score, my tumor was graded 1E.) R-EPOCH would allow the team to monitor how my heart reacted to the treatment with the thought R-CHOP might be too abrupt or extreme given the sensitivity of the tumor's location.

The components of the protocol are well known. The R stands for a monoclonal antibody -- hence the "mab" suffix -- Rituximab, that should effectively "melt" the tumor. Much of the rest of the cocktail was administered to break down my blood to provide a chance that the lymphoma wouldn't reappear. Prednisone, a steroid, is part of the mix to keep me going as my blood was destroyed by the other elements of the therapy. The infusions required hospital stays and then discharge to home. While home, I'd inject Neupogen daily for 10 days to build my white blood cell count, so I'd be prepared for the next chemo session. The regimen required 6 such seances - my only thought was 18 weeks. And then I learned I had a genetic marker exposed in the pathology that suggested an elevated risk of cerebral lymphoma. The proposed treatment for the genetic marker was an additional series of 4 infusions of methotrexate administered every other week. Methotrexate apparently can cross the blood brain barrier to reduce the chance of a very challenging brain lymphoma. Wash, rinse, repeat.

I listened closely but distractedly as a combination of intimidating new terms and uncertainty moved like a fast-moving tide through the conversation. Alix ably interpreted. Adding it up I was looking at a total of

26 weeks - half a year. It was clear to me that if I started Monday, May 8, I would be done with the R-EPOCH in late August and finished with the methotrexate by the first of November. Laying this all out in a calendar made the treatment clear to me and gave me a pacing schedule that oddly enough felt like just another financial transaction – pursuit, process, close.

On Friday, May 5, after going through the proposed protocol I told Gupta that we should start chemo today. To which he said, “said no one, ever.” Gupta said I had an aggressive lymphoma of the type that often responds quickly and well to treatment. He thought I’d likely be done with the tumor after two rounds of chemo. We’d start treatment on Monday, the 8th. And I’d get a back-to-the-future positron emission tomography or PET scan to check progress in six weeks.

Gupta suggested a second opinion and offered to send me over to UCSF because treatment would be closer to our house in San Francisco. The warm feelings both Alix and I had developed in the first session with Neel along with the familiarity with Stanford -- one of the nurses recognized Alix from a post doc she had had at the Sleep Lab -- meant that we were committed to Stanford and Neel's care.

I was lucky there was no more surgery and no radiation. Lymphoma was indeed the best of all possible problems. However, sincerely uncomfortable with the tumor in my heart, the weekend was a blur dominated by orbits of the cardiac ward, family visits, and Warriors' basketball playoff games.

There was a PET scan and echocardiograms a plenty during this first weekend. I can't recall exactly when or how many. But once we got to the end of the weekend it was time to prepare for the treatment.

Meghan was a no-nonsense nurse practitioner working with Gupta. Tall and stark with long dark hair and full bangs, she was business-like friendly. She again explained my lymphoma carried a genetic marker for

cerebral lymphoma. After Megan gave me the down-low on cerebral lymphoma, the blood brain barrier, methotrexate, and the antidote to methotrexate, leucovorin (folinic acid), she asked if anyone had checked my testicles. I said, "no, but something tells me you're about to glove up for what's next." She also asked if I would mind if I were tested for AIDS. "Well, no. Let's see what we learn!" I told her I had no problem with an AIDS test. And I described living in San Francisco in the early 1980s and eating at the Neon Chicken on 18th at Castro. At the time, AIDS was "gay cancer" and from Polk Street, to Fillmore Street, to Folsom Street, to Castro Street you saw men with Kaposi Sarcoma lesions. At the time, we told ourselves that if the disease were in the air or food borne, we would certainly have been exposed over dinners at the Neon Chicken!



She explained lymphoma can be associated with immunocompromised patients and that lymphoma often shows up in the testicles. (I also learned from Megan that night sweats are a symptom. I'd been having bed drenching night sweats for a few months. I rationalized the soakings by telling myself I was running less, and my body was somehow compensating at night to purge my sweat ducts. Ignorance a plenty.)

Not too soon after the AIDS test, I was told I was negative for AIDS, but I did notice a year or two later when reviewing my medical record that Stanford tested me twice. (And while we're on the subject of sexually transmitted diseases, one of the side effects of the chemotherapy I was about to start is mouth sores. And yes, I eventually got them. I also got sores on my lips. The consensus among the nurse practitioners about the lip sores was herpes. "It's everywhere", they all said. I was tested twice. No herpes, the product of either clean living or a most boring life.

I valued Megan's direct approach. In the short time I got to know Megan I learned she practically commuted to Salt Lake City where her partner was in a hospital medical residency. I offered that I was just finishing up Fawn Brodie's biography of Joseph Smith, No Man Knows My History, and then gave her a copy so she'd have the inside track on talking over all things Latter Day Saints and Reorganized LDS in the shadow of the tabernacle.

Before being infused I was fitted with a peripherally inserted central catheter (PICC Line) that entered a vein in my left arm inside of my bicep that would direct the Rituximab and chemical cocktail directly to my heart. The logic being the toxicity of the chemicals needed to be infused directly into the heart to minimize damage elsewhere in my circulatory system. The tech who threaded the line was from Houston. Like many of the technicians and nurses at Stanford, she was a temporary visiting worker. She shared how much she missed home and how expensive it is to live in the Bay Area, but Stanford paid well, and the stay would only be for a short time. This again was a theme throughout my stay - the staff received good pay, but the cost of living and homesickness were real and, in some cases, sorrowful.

The problem with the PICC Line is it's basically an open wound subject to infection. I found it supremely uncomfortable making it difficult to move, sleep, and shower. Taking a shower was a saran wrap struggle as I was also patched up with heart monitoring diodes. I don't think I was prone to complaining, but the nurses told me I could have the menacing plastic tube removed and a port installed under the skin of my chest that could be hooked up for each infusion.

While getting poked for each infusion didn't seem too appealing, the discomfort and inconvenience of the PICC Line tilted me toward the port.

A dual lumen port was planted in my chest after the second round of infusions. There was a queer sensation when the plastic tube was unthreaded as the cord moved from my heart to my bicep. I still can feel it slithering as it was removed. Why the port is purple makes no sense. It's placed under the skin....pay close attention however to the little attachment gizmo between the purple port and the plastic tube. This catheter locking cap appears later in the story.



The port required that I put lidocaine on my chest before each infusion to make hooking me up "effectively" painless. Effectively being the operative word here, as I recall one nurse who just couldn't get the hooks to go in the port. I was a pin cushion for this guy. As he leaned into my chest for the third or fourth poke, I asked if he needed help. He said no that he does this all the time. It was only later when talking with one of the visiting nurses that I learned that drug abuse among the nurses existed so I'm sticking to the thought this nurse who couldn't pin the tail on the donkey was high.

The first week of infusion was sleepless in the cardiac ward. Sleepless at least in part because of the steroids and in great measure because of relentless complications with the infusion pump and a heart monitor that triggered alarms when my heartrate dropped. Complicating my situation was cancer nurses worked two floors below the cardiac ward. When my infusion pump jammed, a nurse would have to come up and reset the pump. The toxicity of the chemo cocktail meant that not just any nurse could muck about with the infusions. Chemo nurses had to suit up, mask, and glove to handle the cocktail and pump.

I had no obvious reaction to the four-hour infusion of the Rituximab. (Synthesized in 1998 by what became Biogen. Thank you.) The Rituximab basically treats the tumor or tumors. The chemo retools the blood system.

The chemo regimen is well-established with n = many. The monoclonal antibody can be rejected triggering anaphylaxis. Consequently, the preparation drug is a dose of Benadryl. The Benadryl probably provided my best rest the first two weeks at Stanford.

After an unexpectedly long month at Stanford, at Neel's suggestion, we met with Ari Barron at Cal Pacific Medical Center. Ari is a well-respected San Francisco oncologist. Gupta thought it would be worthwhile to have an established relationship with a San Francisco oncologist in case I was unable to make the 40-minute drive to Stanford or if I spiked a neutropenic fever -- a chemo fever greater than 100.4 Fahrenheit or if you're keeping score metrically, 38 Celsius.

Barron's interpretation of the pathology was different than Neel's. Barron saw more tumors than the one prune in my heart and advised the R-CHOP regimen. Returning to Stanford, we discussed Barron's view. Neel felt that because the tumor was in my heart I might not respond as favorably to R-CHOP. R-EPOCH's adjusted dose and continuous infusion was thought to allow my body to adapt more gently to the treatment. Neel was convincing so I stuck to R-EPOCH and medicated life on the Farm.

The first infusion wasn't without excitement. After completing the cycle there was a good bit of back and forth between Alix and the oncology team. The oncology team wanted me to head home, recover, and return. Alix was reluctant to see me go home as my heartbeat had been very erratic. My heart was constantly monitored and, again, at night (or during the day) it was impossible to sleep. The heart monitor would sound an alarm if my heart rate went below 50 beats per minute. My typical heart rate before lymphoma was about 47 beats per minute -- basically always bradycardia, a slow heartbeat. So practically the minute I lay down the monitor would go off. I'd plead to get the alarm reset. First to 45 bpm...then to 40 bpm...then to 35...then to 30. The whole time the nursing team complained. My personal best was 24 beats a minute. And let me tell

you, you feel great at that rate. The big problem Alix kept pointing out was that once the heart stops, it's not going to be easy to restart it.

Alix didn't want to have me come home, have my heart stop, and well, not rejoin the living.

I took care of the decision inadvertently as I was about to be discharged on Sunday after my first week of infusions. Sitting on the edge of the bed, liberated from the drip stand attached to the back of my left bicep, I had breakfast. Raisin bran, a banana, and a glass of milk. The milk was slushy with pieces of milk ice. You don't realize how close your esophagus is to your heart until you have a wad of inflamed lymph nodes in your heart. Drinking a piece of milk ice slid down my esophagus near my sinus node and my heart took off in rapid syncopation! I don't know what sort of code it set off, but 3 staff members rushed in. My heart rate peaked at 220 beats per minute causing much concern to all involved. The cardiologist came barreling in and I was put on a bolus of amiodarone. Asking what the side-effects of amiodarone are I was told that it's useful for getting hearts back into sinus rhythm and that if you really habituate it, it will spoil your liver. At the time that was the least of my concerns. It took roughly 16 hours to get my heart to respond -- I think through all this the Warriors won a playoff game. The game and my family took my mind off the risk of cardiac arrest, even though the nurses kept talking about cardiac arrest. I was exhausted and the hospital agreed with Alix that I should stick around the cardiac ward for two more weeks before my second round of infusions.

Following the first week of diagnosis, the second week infusing the cocktail, and then the third week for cardiac observation, I got home with a monster portable Holter monitor plastered to my chest accompanied by what was like a late 1980s portable phone.



Concluding the first batch of chemo, one of the nurse practitioners gave me the low down on Neupogen. <https://www.neupogenhcp.com/> The chemo infusions wipe out white blood cells and a 10-day cycle of Neupogen stimulates accelerated white blood cell recovery. Not a pill or potion, it's injected in belly fat. With a life-long fear of needles, the prospect of daily injections gave me real pause, but the descriptions of neutropenic fever sparked my courage. A nurse suggested Alix could do the injections, but there was no way I was going to allow Alix to poke me practically daily for 4 months. I gave myself the first shot and once initiated I didn't look back. Intravenous drug addiction could be my future.

As we talked about Neupogen we also talked about some of the drawbacks of the chemo cocktail. The nurse practitioner reminded us to use condoms because of the likely damage to my seed from the cocktail. Thanks. But sex was quite distant from my mind and I'm sure Alix's as my hair would fall out in clumps and I was patched up with diodes connected to the heart monitor. The same nurse practitioner, who was altogether lovely, suggested I should go home after the first chemo cycle. Seeing that my heart was bouncing between 24 and 220 beats per minute, Alix wasn't enthusiastic about sharing a bed with me in San Francisco. The nurse practitioner offered to send us home with a defibrillator and began showing us how it worked. Alix impatiently pointed out that she knew how a defibrillator worked lecturing that it would be useless if my heart just flat out stopped, which seemed to be my inclination when the heart rate went below 30 beats per minute.

The walking around that I was doing regularly convinced the nurses that I didn't need to have daily Lovenox (enoxaparin sodium) injections. Lovenox is a blood thinner. People lying around in beds at a hospital can develop blood clots, complicating whatever else might be causing them to be lying in a hospital bed. Moving kept the blood merrily circulating reducing the odds of a blood clot. Oh, and the side effects of Lovenox

below include (the "coffee grounds" bit is perhaps the most colorful, but "black tarry" tells you a bit too much)....

Common

- Bleeding gums
- [coughing up blood](#)
- difficulty with breathing or swallowing
- [dizziness](#)
- [headache](#)
- increased menstrual flow or [vaginal bleeding](#)
- [nosebleeds](#)
- paralysis
- prolonged bleeding from cuts
- red or black, tarry stools
- red or dark brown urine
- trouble breathing

But wait, there's more, less common

- Bruising
- chest discomfort or tightness
- collection of blood under the skin
- confusion
- continuing bleeding or oozing from the nose or mouth, or surgical wound
- [fever](#)
- irritability
- lightheadedness
- lower [back pain](#)
- [pain](#) or burning while urinating
- [seizures](#)
- swelling of the hands or feet
- uncontrolled bleeding at the site of injection
- [vomiting](#) of blood or material that looks like coffee grounds

In all cases I became close to the nurse practitioners who were endless reliable fonts of valuable information and consistently solid emotional support.

From the very beginning of the experience, I refused to look online at anything about the disease or its treatment. I asked the nurse practitioners to give me information and studies that they felt were most reliably informative about what was going on. The whole point of avoiding the

internet was to avoid anxiety. The nurse practitioners were super supportive of this approach frequently commending me on my restraint. Obviously, Alix having recently completed the Med Boards made her well informed and a key member of the medical team. (And I suppose if you were drawing caricatures of the hospital hierarchy she'd come out on top.)

The question of the methotrexate treatment came up in a conversation with Meghan. I told her my sister was on a methotrexate regimen for multiple sclerosis. Meghan looked me in the eye and said, "your sister is getting whiffs of methotrexate, you'll be taking baths."

I asked another nurse practitioner if he could provide information on the studies surrounding methotrexate. Jevon gave me background and research on the marker I had. It became clear to me from the study that the benefits of methotrexate outweighed the extremely messy costs.

In talking with Gupta about the methotrexate I asked if brain fog or other side effects were worth considering. He dismissed my concerns without hesitation. Oddly enough however, about two months after I ended treatment at the first of November, Stanford's development office put me on a list for a Stanford Health Care magazine that comes out quarterly. The first report I received featured a Stanford study on brain fog and methotrexate suggesting that about 50% of patients experience some sense of neurological loss. At my first post treatment oncology visit in early 2018 I brought this up to Gupta. I told him, I didn't sense an obvious loss of memory and he said, "my, aren't you the lucky one then."

At so many turns I appreciated his approach, humor, and intellect.

The steroid in the regimen basically prevented me from sleeping, allowed me to read a great deal, and to do work. Business proposals were completed, and I stayed in touch with the office. I finished No Man Knows My History early in the hospital stay and picked up Thomas Mann's Magic Mountain. Magic Mountain was indeed the ideal long hospital stay read.

(Telling this to Moravcsik, he told me he read the book in German as an undergrad. Much respect. And much gratitude to Andy for our conversations about his experience as a 17-year-old with a sarcoma.)

As I mentioned, the first chemo infusion started with the Rituximab (generic) or Rituxan (Genentech/Roche commercial name). As a monoclonal antibody I was told I could have a strong reaction to the infusion or not. The infusion began with prophylactic dose of Benadryl. I was exhausted and again I probably got my best rest after the Benadryl waiting on the Rituximab. Winning the genetic lottery in a certain respect, I tolerated the monoclonal antibody well throughout the treatments. Others weren't so lucky, and I got frightening stories while hanging in the lounge in the cancer ward.

And while cancer ward sounds miserable, it was a real step up from the cardiac ward. Cancer patients – mainly lymphoma, leukemia, and sarcoma – seemed to have hope. We were all collectively there to be treated with whatever form of battery acid, radiation, or surgery and hope was there that treatment would be effective. The cardiac ward was a bit more dire. Cardiac patients tended to be older, largely male, and with serious complications that had them at a major research university. In both cases, the care – staff, nurses, and physicians – seemed expert, but the prevailing ambiance was most definitely more chipper in the cancer ward.

And this gets at Heather Soicher's observations on being in the cardiac or cancer wards in the first place. Her question was why not call the cancer ward, the Healing Center? Or the cardiac ward the Heart Health Center? And my question was, who would want to put their name on the cancer ward? Well, some donor named Peterson had his/her name on the wall. Go figure, though I'm sure there's an unpleasant and sad story behind that. The infusion center was a bit more anodyne called the Blake Wilbur Center. Wilbur was a Stanford surgeon from the mid-20th century. (Reading Blake Wilbur's bio you see that he accomplished the exceptionally rare Big 4 Robber Baron trifecta by attending **Stanford**, studying at

Stanford's **Hopkins** marine biology station in Monterey, and then doing medical residency at Harvard's **Huntington** Hospital. Assuming Wilbur banked at Crocker Bank he earned the even rarer Big 4 quadfecta. Wilbur was the son of the 3rd president of Stanford, Ray Lyman Wilbur, whose name graced my undergraduate dormitory complex.)

My first two rounds of infusion were in the cardiac ward. The cardiac ward is on the second floor of what is now the old Stanford Hospital. (The "new" mega cathedral Stanford Hospital was opened in 2019.) During my second week, once the diagnosis and the therapy were determined, I was more at ease and more conscious of the surroundings. I tried to open the window. It was locked tight and sealed. I asked a nurse to assist in opening the window. She said that the windows were indeed locked and not operable. I asked what the hell that was about as fresh air was what I needed. The nurse reluctantly offered that the windows are locked to prevent suicide. Oh.

The Etoposide, Doxorubicin, Vincristine, and Cytosine in the chemo regimen most certainly caused nausea. Moravscik had lost a leg below his knee to a sarcoma when he was 17. This would have put his cancer treatments in the era of the Solzhenitsyn Cancer Ward 1970s. Andy was a great source of support throughout the treatment, and he shared his colorful horror stories of infusions, surgery, nausea, and lingering uncertainty about cancer.

With all the alarms and discomfort of infusions I had trouble sleeping. Once the infusions started, I was the [Mannekin Pis](#). Continuously bags of fluid were pumped intravenously through my dual lumen port, plus we stocked (and I drank) plenty of Perrier when at the hospital because the tap water, if you can imagine Stanford Hospital with contaminated water, was sometimes off limits. Anyway, input led to inevitable output.

As sleep was rare, urination was frequent (very), and getting out of bed and moving the chemistry attached to my arm or chest was a hassle,

the hospital provided plastic quart bottles that hooked on the chemo stanchion. Using the bottles while horizontal was a kabuki. It didn't make it easier that using the bottles involved some urgency. Spills and smells, yes.

I imagined the sleep trouble was because of coffee I drank before being diagnosed. Only later (after a high-cost PET scan or MRI looking for Lymphoma tumors) did I learn that my 59-year-old prostate had enlarged. Boom. Plenty of urine plus a blooming prostate. A great combination. It didn't help I was attached to the infusion pump drip stand. There were so many moving parts to achieve relief. Anyway, it was summer. I generally wore knee length shorts. (Only very rarely did I need to wear a hospital gown.) This may be more than necessary, but expulsion becomes a good part of the hospital experience. When I was mobile, I'd walk dragging the chemo stanchion to the toilet, unzip, and the weak stream falling past the Hoover Dam of my prostate would split. Thinking I was draining into the target I'd inevitably find a rogue stream hooking left to decorate my shorts. This happened all too frequently. The exhaustion brought on by the infusions didn't make it easier to shed the soiled shorts and find a replacement. Oddly, once I was finished with treatment, I had somehow figured out how not to splash the left leg even though the dual stream is now a part of my senior lifestyle.

As a practical matter I gave up coffee and anything caffeine during treatment and this carried over for more than 5 years. Gradually and only occasionally will I now have a caffeinated coffee or tea.

Sleep came at a steep premium often induced by .25 milligrams of Ativan (lorazepam) -- a schedule IV-controlled substance: benzodiazepine. Exhaustion combined with the Ativan put me down very reliably. The smallest dose is .5 milligrams and I cut that in half whenever I took one.

Stanford was generous with this script. One of our neighbors was being treated for breast cancer. Talking with her husband one evening I

learned she was cut off from Ativan. We walked over to our house, and I handed off who knows how many tablets. The unused Ativan went to good use and our neighbor is now doing quite well.

When first diagnosed I was set up with a new prescription home delivery service called Script Dash. Not too soon after making the request, Script Dash delivered a pile of meds prescribed by Stanford. After I'd wrapped up therapy, I bagged up all the unused meds -- just an obscene number of laxatives -- and recycled them at the Stockton Street Northeast Medical Center. Only later did I learn the preferred way to dispose of unused prescriptions is to drop them off at the police station. (For possible resale?)

Script Dash was however efficient. And another friend in the neighborhood was using them for her med delivery. Not too soon after signing up for the service the company changed its name to Alto. Did Door Dash assert some sort of ownership over "dashing"? Did raising buckets of money from SoftBank steer the brand build to Alto? I never got to the bottom of it, but this place could deliver, and I still see Alto driving around.

I made a habit while in the hospital of getting out of bed and forcing myself to make the bed, floss, brush, no need to shave (hey, no hair, anywhere), and then walk around the hospital dragging the drip stand.

A digression on shaving and hair: The first week in the hospital as I was being diagnosed and before chemo, I did shave. Protocol discouraged razors (as well as windows that open - draw your own conclusions from that) so I bought an electric razor. I never fully amortized the Panasonic Rechargeable 5 blade shaver because hair started to fall out at the end of the following week once chemo began. Electric razors are so unsatisfying. Back and forth, back and forth and still there's hardly the close shave that is so loudly advertised.

With morning hygiene out of the way, I would start walking. As I've made clear, I was in the cardiac ward following the initial hospital admission and stayed there through my second set of infusions. The cardiac ward was on the second floor of the old Stanford hospital -- again with sealed windows -- and no private rooms. During the first week, when I was being diagnosed, I'd walk around unimpeded by the drip stand. I had a healthy tan and a full head of hair. Patients in a research hospital's cardiac ward aren't there merely for chest pains and some difficulty breathing. Under these circumstances I just looked too healthy.

All the same, on the cardiac ward I was tethered. I couldn't leave the orbit of the cardiac solar system as the heart telemetry would fade if I snuck off to the lobby, the outdoor deck one floor above, or out the front door to the park surrounding old Stanford Hospital's decorative fountain.

The PET and MRI scans revealed more than you might imagine - the enlarged prostate, spots on the liver, a small hernia, and the meatball in my heart. The early May 2017 scan highlights the extent of the 1E lymphoma tumor in my heart. The attached picture isn't all that shocking until you compare it to the scan taken about 5 weeks later after two rounds of Rituxan. The snap on the left highlights the tumor in deep black at the center of my chest. The image on the right effectively shows the miraculous (well, intended) evaporation of the meatball.



Before



After

Neel had suggested at one of our first meetings that my tumor was aggressive and that mean tumors like mine frequently respond well to treatment. His thought was the tumor would be gone after two rounds of chemo. As you can see above, he was right. The day we met with Neel to discuss the results of the scan I walked into a room of smiles. Neel and the nurse practitioners were high fiving, congratulating me on clearing the meatball. For me this was nothing but confusing. I'd begun the treatment with the expectation the tumor would be gone after 6 weeks. I asked Neel what all the excitement was about, and he said, "Tom, it doesn't always work out the way we think it will." This was obviously sobering, and I saw from Brice's eyes that he shared my blissful expectation. Among the hugs I had a chance to ask if there was any reason to continue therapy now that we had evidence the tumor had dissolved. Neel continued, "Well, not so fast. Lymphoma treatment is very well-established, and no one is given a pass just because a tumor or even two have disappeared. You've signed on for the full ride." This transaction closes November 1 when I'd finished R-EPOCH as well as the bonus methotrexate baths.

Prednisone, a steroid, is prescribed during the infusions so you don't completely feel the damage your body is taking from the doxorubicin hydrochloride (I was reminded by one oncologist visiting the cardiac ward that it's "cardio toxic" and among the cancer *cognoscenti* it's called the "red devil"), etoposide phosphate, cytoxan or cyclophosphamide, and vincristine sulfate (available from your pharmacist under the brand name Oncovin, an alkaline derived from Madagascar Periwinkle plants). Vincristine has some nasty side effects the most obvious to me during the first 2 months was the gradual loss of feeling (aka peripheral neuropathy) in my right foot that went to both hands and then to my left foot. After 3 rounds



of the chemo cocktail, the medical bartenders eliminated Vincristine from my continuous infusions.

Following treatment, the nurse practitioners suggested B6 would help restore damaged nerves and reduce the neuropathy. Oddly the B6 only seemed to exaggerate the neuropathy. I dropped the B6 and the damaged nerves slowly -- over 3 years -- recovered. Several years later speaking with a German physician about the neuropathy he suggested that the exaggeration I was experiencing from the B6 was likely evidence it was working to heal the nerves. Not being too sure, I'm now back taking every so often a B vitamin supplement including B6.

One of the other side effects of the cocktail is damage to fingernails and toenails. The fingernails just became brittle throughout treatment and recovered relatively quickly once I finished the full chemo cycle. The toenails, not quite the same. By the end of the year, I'd lost both of my big toenails. There wasn't any obvious pain, but it does mean I wanted to protect my big toes from damage like heavy things falling on them or stubbing them. It took a full year and a half to regrow the toenails. And another side effect I soon learned about was the susceptibility to toe fungus created by the treatments. So, the toenails grew back, but both left and right gained fungal friends that still haven't parted. Almost six years after treatment, it's looking like I'll lose both big toenails again.

I didn't lose my appetite because of the Prednisone, so I was basically jacked the week of hospital infusions, so I ate regularly, read voraciously, worked nervously, walked relentlessly, and hardly slept.

I suppose aside from the cardiotoxicity and color of the solution, another reason why doxorubicin is called the Red Devil is because of hair loss. The nurse practitioners suggested hair would start to go after the second round of chemo. My actual mileage varied.

Hair came out in clumps that first night at home. My pillowcase was turned to a mink stole. I called a friend who had had chemo for colon

cancer and asked him how best to manage the coiffure. He was quick to recommend Amazon Prime delivery of a practical set of electric hair clippers. The clippers arrived the next day, but before shearing my pate, I had Alix and Zoe take me to the office for a head shot for our website. From the snap below you can see I'm turning to the side. The pose is largely a consequence of the clump of hair missing on the right side of my head. Alix mowed my head later that afternoon.



March 2017 Salon D'Agriculture



End of May 2017 -- website head shot



July 2017



Thanksgiving 2017



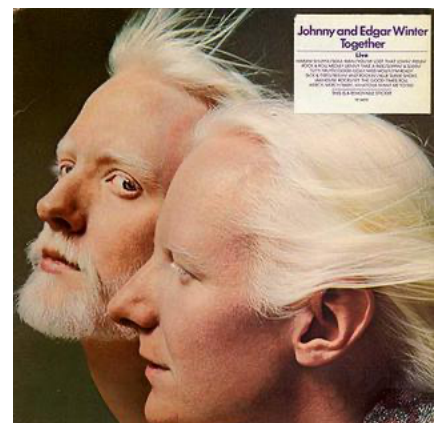
Late April 2018

Hats and cancer couture became important, more for warmth than for sartorial style. I leaned into Japanese blue and white striped skull caps. I tried member of Congress Jeremy Raskin¹ style bandanas, but the look didn't work for me. Coats and ties weren't part of my look either.



The week before going to the doctor in Palo Alto for the suspected sinus infection, the new firm had received regulatory approval to trade. We were updating our website, so I needed a picture. The picture was taken behind our Market Street office on Stevenson Alley. It was terrific advice to dispense with hair, but no one warned me the most profound effect of losing your hair is that you are completely, 100% depilated. Old man ear hair? You're suddenly 12 years old. And one of the queerest consequences is losing your nose hair. The baffling that nose hair does to limit a runny nose is severely under appreciated.

And on the topic of hair, once chemo was wrapped up just before Labor Day 2017, hair does start to grow back. So, by Thanksgiving I was just beginning to appear to be a chia pet. Since puberty my hair had been curly. 6 months of chemo changed that. I imagined my hair would come back snow white as age and chemical trauma would turn me into a 2018 version of 70s blues guitarists Edgar and Johnny Winter. At first the hair pushed toward the sun taking on a green tint. Odd, but noticeable.



¹ Raskin began treatment for diffuse large B cell lymphoma late in 2022. <https://www.cbsnews.com/news/jamie-raskin-remission-lymphoma-cancer/>

It was straight and almost immediately I noticed the new crop was thinner. Balding, not quite like my shins², but nothing like the prior 4 decades. Now almost 6 years into it, there's still oddly not much gray.

The chemo regimen required continuous infusion for 5 days at a time preceded by a four-hour infusion of the monoclonal antibody, Rituximab. Something is desperately wrong with the infusion pumps and inevitably the 5-day infusion would drag on to a 6th day.³ Ok, there was also a conspiracy among the pharmacists to fill the infusion bags just a little too full. So, between the extra doses and pump failures, it just took longer to wrap the infusions up.

While being infused continuously for a week I was being given Prednisone. There's nausea from the chemo cocktail, but antiemetics and the steroids kept me awake, moving, and generally kept me from heaving. The oncologist at the beginning of therapy said, "this is no time to go on a diet. You should keep your weight up." I suppose the thought is you feel so miserable that you won't eat, but again my mileage did vary, and my appetite remained. A typical day in the hospital would be an omelet and an apple for breakfast. Possibly something for lunch. And something Alix and the children would bring for dinner. The gravest menu mistake I made was to go to the cafeteria and order a quesadilla with jalapenos for dinner. Not only does the chemo decimate your blood, but it also wreaks havoc with digestion. The smell of the quesadilla was so appealing, and I thought I could pick out the jalapenos. I couldn't and the price paid for that meal was dear and lasting.

² 10 or 15 years ago I noticed my shins seemed shaved. Odd tufts of hair sprouted from my knees, but the shins were shear. For a time I was concerned thinking that maybe it was diabetes or some terrifically challenging syndrome. A few minutes on WebMD steered me toward "male pattern baldness", which apparently is a thing for male shins.

³ I first pleaded to the nurses to switch the pumps, but the combination of the chemo cocktail's viscosity, the plastic tubing, and the pumps conspired to form air bubbles, which interrupted the flow setting off an alarm that only a trained nurse could restart. Someday, some engineer is going to fix the problem improving sleep and healthcare outcomes in hospitals everywhere.

By the third weekly infusion I'd been moved from the Cardiac to the Cancer Ward. I was expecting a Soviet experience, but the oncologist and the nurse practitioners all suggested the ambiance was much more upbeat in cancer than it is in cardiac. So true this was. There was a strong feeling of camaraderie and a general feeling of optimism. The cancer ward at Stanford had lymphoma, sarcoma, and leukemia patients. I'm sure there may have been plenty of cancer esoterica, but among the lymphoma patients we were generally not masked (pre-Covid, mind you) and all hyped-on steroids. The leukemia patients were less outgoing because they were very much masked and very sensitive to infection. Sitting in the hallway and visitor lounge we made eye contact, acknowledged our shared displeasure with the health challenges we'd been dealt, and generally kept our distance from the leukemia patients.

We lymphoma, R-EPOCH patients, and our families, had days to pass while being infused. When not orbiting the permitted and unpermitted areas of the hospital we gathered in the patient lounge. We swapped stories, family histories, treatments, reactions, complaints, hopes. Early morning walks took me through the ground floor of the hospital, which was like the Toy Story box of broken toys: all sorts of fully amortized equipment, beds, walkers, shelves, etc. I also walked by Pierre Martineau's zebra fish lab and the hospital's Fort Knox -- the main pharmacy.

Walking out after being discharged after my first stay in the cancer ward, one of my new friends, from Marin, pulled me aside to ask if I was having difficulty with my appetite. I told him it's odd, but with the steroids I still looked forward to eating. He offered to share his edibles with me if my appetite waned.

The nurse practitioners frowned on supplements. Before lymphoma I had spent practically my entire life taking vitamin and mineral supplements in the morning: a general multi-vitamin/mineral supplement and a couple grams of vitamin C. Unpacking my toiletries, a nurse spotted a bottle of vitamins. She put the kibosh on the supplements telling me I had enough

chemistry going on with the infusions that it wasn't up to me to confuse the situation introducing supplements. Who knows? Did the lifetime of supplements contribute to my lymphoma? (Or was it 50 years of hair gel?) Regardless, I've given up on supplements aside from a daily dose of 5 grams of fish oil, which I suppose is useful, possibly, maybe for heart health....(Again, in the words of one of the oncologists, "doxorubicin is cardio toxic.") Oh, and the chemo (and age) changed my hair so there is no need now for hair gel.

Aside from melting the tumor with Rituxan and blowing up my blood with EPOCH, treatment include antiemetics to prevent nausea, a side-effect of all the chemistry. Zofran or Ondansetron was the go-to. But the "killer app" for treating chemo nausea is Emend (Aprepitant or Fosaprepitant). These drugs are truly miraculous as without them, I learned the dry heaves only complicate an already miserable experience. Probably during the fourth round of infusions, I was feeling like I didn't need Zofran as I thought the Emend was really doing the lifting. Skipping the Zofran led to an exceptionally miserable day of vomiting and then, again, the dry heaves, which really took the lead out of my pencil in a manner of speaking. Moravcsik told me about his experiences 40 years earlier when antiemetics weren't nearly as available and fine-tuned. Good lord, 1970s cancer treatments were nothing but byzantine. I returned to Zofran doses for the rest of my treatments.

Oh, and one of the side effects of Emend can be an urgency to urinate. Lovely that.

Keeping track of platelets was something I hadn't done before. Who knew that you could spontaneously bleed if the platelet count goes too low? My first thought was, "spontaneously bleeding can't be all that bad. So, what if a hang nail won't stop bleeding." I was brought back to reality by a nurse practitioner who filled me in on the complications and bad horror movie CGI if my brain spontaneously bled.

Zofran and Emend managed the nausea well enough, but ginger is also effective in reducing nausea. Heather and Barry Soicher visited bringing along wonderful messages for wellness and a bag of Heather's ginger snaps. Not having any difficulty with my appetite, I churned through Heather's homemade goodness. With my next blood draw my platelet count had tumbled. Apparently ginger may reduce platelets. So many turns in that summer exposed fascinatingly new information.

Alix visited the hospital daily. She brought chocolate cakes and almond cakes each visit for the nurses' lounge. The chocolate cake was a recipe she picked up from a Swiss friend's daughter who had stayed with us years ago while she was studying English in San Francisco. The cake is rich, moist, slightly salty, and has a chocolaty aroma that makes it irresistible. Butter plays an important role in the cake's appeal. The almond cake had long been a favorite of mine. And here too butter is key to its preparation. The problem with the almond cake was that on several occasions the cakes got left in my room's closet. (We parceled the cakes out. Two might come one day, but one would be put in my closet to be given the next morning.) The smell of sweet almonds grew to be associated with the chemo infusions and it's taken me years to tolerate the aroma and once again eat the cake.

The nurses were however real fans of the cakes. Many recipes were shared. Alix was always a welcome visitor. The staff were amazed at Alix's ability to juggle the visits and prepare the cakes. The unrevealed secret was Francisca was busy at home baking, albeit mostly Alix's recipes under Alix's direction.

Earlier I referred to the tap water. At times it was off limits for drinking for some unexplained reason. We presumed water quality had to do with the construction of the nearby new hospital, but we started out each new week of infusion with a case of Perrier. But beyond Perrier and cakes, Alix also brought bedding. She felt my sleep would be improved if the bed were more comfortable. So, foam padding, extra blankets and

sheets were used to prep my bed. The bazaar we brought in for each infusion was always noticed and borderline ridiculous.

Sleep in the hospital was several different kinds of awkward. With the dual port cup in my chest connected to the finicky infusion pump, pump alarms, heart monitor alerts, noisy roommates (either snoring or the regular wheeze of a CPAP machine <https://www.youtube.com/watch?v=0yro-m53jwI>), blood draws, steroids, and vital checks, I found each weekly infusion at the hospital to be a sleepless, blood shot eyed 18-wheeler drive across country on side roads. By the third stay I'd discovered that I could at least get some auditory relief by using earplugs, pulling my Japanese skull cap over my ears, and then putting over all that noise cancelling headphones - auditory triple witching. I could blue tooth my cell phone's youtube videos of storms, fires, or waves to the headphones to truly cancel out the hospital noise. Interestingly there are long form storms, fires, and wave films on youtube. Here are some highlights:

<https://www.youtube.com/watch?v=xmn0RjUVt1U>

<https://www.youtube.com/watch?v=Bgd17B4IeKo>. This obviously calls into question both the producer and the consumer of these videos, but at least the combination liberated me from the ambient auditory nightmare from 10 pm to 6 am.

Crackling fires, by the way, are superior to waves or storms.

After dinner and after visitors had left and while at home resting, the go to playlists were Beethoven symphonies and Raul Malo's Mavericks' tunes. Beethoven 7th really works wonders to bolster the spirits when coming down off steroids.

<https://www.youtube.com/watch?v=LA8KsHelm0I>

I Want to Know by the Mavericks was just generally good for considering existential reflection notwithstanding I have no clue why devil's not run dry: <https://www.youtube.com/watch?v=Sp4KFmmueP0>

I want to know what promises to keep
I want to know how guilty people sleep
I want to know if willows really weep
I want to know where's my reward to reap
I want to know why the devil's not run dry
I want to know why politicians lie
I want to know why nobody gets high
I want to know why they don't even try
I want to know if all you need is love
I want to know the word from up above
I want to know what you're thinking of
I want to know when you have had enough
I wonder why we think we're doing well
I wonder what time will be able to tell
We're waiting for someone to turn on the light
So we won't be wrong about everything right
I want to know what it feels like to be king
I want to know if children they don't sing
I want to know if birds should lose their wing
I want to know if we'd do anything
I want to know how we could make ends meet
I want to know when I should stomp my feet
I want to know why history repeats
I want to know how you turned out so sweet

The end of treatment was the removal of the dual chemo port from the right side of my chest in early November 2017. While I thought that brought an end to my Stanford Hospital experience, I was left with a souvenir catheter cap in my chest. The wound from the port removal was sealed up with bandages for a week. When the bandages finally came off, I felt a bump around where the port had been. My first thought was another lymphoma tumor. This thought lingered for three months until I went back to the hospital for a scheduled checkup. I asked the nurse what she thought the bump might be. Everyone in the room felt the bump. The consensus was it wasn't lymphoma, and the blood analysis confirmed that it wasn't. The thesis was it was a scar or keloid.

The routine post therapy is to go in every 3 months for a year to have my LDH (lactate dehydrogenase) level checked. Elevated LDH levels might suggest a return of the disease. Years 2 to 5 suggest a semi-annual visit. After 5 years, if the disease hasn't returned, something else is likely going to terminate me besides lymphoma.

Early in 2022, I started (intentionally) to lose weight after learning my blood pressure was elevated. I lost 15 to 20 pounds over the next 8 months. When I had my next to last visit with the oncologist I asked the routine question about the bump. The combination of more push-ups and the weight loss made the bump more obvious. The consensus in the room was it was "probably something left behind." To me, it was a BIC pen cap.

The prescription was to have an echogram.

Stanford's clinic in Emeryville is both closer to San Francisco and public transit friendly in comparison to Stanford. More or less. On a clear day, a bike ride from West Oakland BART is 20 minutes. My appointment was mid-day, mid-week. Montgomery BART was an easy ride, and the bike ride was nothing but glorious in the warm East Bay Spring sun.

The clinic is small. The staff pleasant. Not overworked. Basically, a friendly affair. A well-inked 30-year-old tech fired up the echogram and quickly said she thought the bump was a catheter cap. She asked me to stand by while she ran the image by a doctor. Before I could even begin to open cabinets to find out what the room stored, she was back confirming the catheter cap lodged in my chest. "Nothing is flowing through it. It should be simple enough to remove."

In a poorly coordinated move Stanford asked me to have an X-Ray to confirm the echo. My next trip to Emeryville found the X-Ray tech out with an illness. I made a new appointment the following week. I called ahead to learn that E'ville was still without an X-Ray tech. I pinged Stanford to find out if I could have the X-Ray taken at world corporate headquarters. It was then that I learned that an X-Ray was useless because a plastic catheter cap isn't "radiolucent" as they say in the trade.

A month later an invoice appeared from Stanford for the echo. Sending a thoughtful note to Stanford Health Care reminding them that I

hadn't left the catheter cap in my chest when the port was removed in November 2017, I soon found the bill evaporated from my account.



And yet the catheter cap remained.

Alix spoke with her ophthalmologist brother about the 5-year internment. He offered a horror story about someone who died removing similar. Alix's anxiety led to much conversation about the competence of the person scheduled to remove the cap. Stanford assigned a 35-year veteran nurse practitioner who seemed to enjoy regular amounts of time off. I appreciated her approach but was eager for removal. We spent a couple months in France over the summer so scheduling before Labor Day was out. My catheter cap removal expert was on vacation for most of September, so removal was timed around Indigenous Peoples' Day 2022.

Alix got an opportunity to relate her story of the unfortunate French death as I was being prepped for removal. It was at this point that I heard the whole story, which involved a doctor removing same or similar from his *own* chest. My expert nurse practitioner suggested that the procedure is routine. When Alix asked if she'd removed a catheter locking cap before we both learned that while many forgotten things had been removed previously by my expert, this was in fact her first cancer infusion chest port locking cap removal.

After a quick shave of my chest -- with an especially nifty and efficient plastic tool -- and much swabbing of betadine or similar antiseptic, I was ready.

Once in the familiar operating room, my nurse practitioner asked the three attending nurses if they were at Stanford in 2017. Looking at each of

them with eye contact, each shook his or her head, no. My NP bent over, looked me in the eye and said, "Mr. Lockard, we're all innocent."

As had been the case previously, I was asked what type of music I'd like. I suggested Country and Western. Spotify needed greater specificity and I said, "why not Johnny Cash?" Regrettably Johnny Cash's final album was selected. The NP said, "oh perfect, Johnny Cash's version of Hurt"; a 9 Inch Nails song that sounded like what someone famous might record as their last album squeezed out to leave something more for their estate. I couldn't wait to have the procedure wrapped up and I think the crew felt the same. While the song could be a metaphor (and the video is actually pretty good), I probably should have picked Motown or 80s French pop. <https://www.youtube.com/watch?v=8AHCfZTRGiI>

Though I had a local pain killer injected for the incision, there was an unusual amount of pushing and kneading required to finally pop the cap. The NP showed me the cap. A bit bloody I could see that the hexagonal locking cap was what had been so irritating for the past 5 years.

I asked if I could have the cap. The first response was sure, but then the team flipped and felt prior experiences suggested Stanford Health Care wouldn't permit me to take it.

I suppose I should never have asked.

Once wheeled into the recovery room to get a complimentary ice pack and to dress, the NP came in with a souvenir locking cap. While not "my" locking cap, there was no way to tell that it wasn't "my" locking cap. I thanked her and told her I'd work the cap into an art project.

A month later Stanford wrote me to say my insurance company balked at reimbursing the procedure. I wrote back reminding Stanford that while the cap had been in my chest for 5 years, it wasn't me who wanted it there. This charge also quickly evaporated. No legal fees necessary.

If you visit us in San Francisco, you'll see in our entrance a life-sized fiberglass Holstein cow. The cow has been there since my fourth chemo infusion. The cow is called Pickles. Children, car services, and delivery workers enjoy the surprise of the cow. Friends from Lausanne brought us a Swiss cow bell with a well-worn leather strap. The bell and the strap are probably worth much more than the fiberglass Holstein.

The cow appeared out front of the Hard Rock Café that opened on Van Ness Avenue in 1984.

<https://www.sfchronicle.com/oursf/article/When-Hard-Rock-Cafe-opened-in-1984-San-Francisco-13248783.php#photo-16201845> Later the Hard Rock Café moved to Pier 39.

There was a routine to recovering from week-long chemo infusions. I'd come back home to North Beach exhausted. Trudge upstairs and spend the first day back in and out of naps. The Neupogen injections started. Each day I'd feel just a little bit better. By day three Alix and I'd would be out for walks. The typical route was to go down to Pier 39. By day four I could muster an orbit around the pier.

Keep in mind too that I was on a protocol called dose adjusted R-EPOCH, which meant the dose of the infusions was intended to increase 20% per session. By the fourth round of infusions I was washed out and warnings about neutropenic fever and being immunocompromised were regular themes of the discharge instructions.

The Hard Rock Café is at the southern edge of Pier 39. Out for a post infusion walk, we had turned the corner to walk along the pier's apron and I noticed the cow in the trash collection area. I said, "hey it looks like the Hard Rock is tossing its cow. It used to be on Van Ness Avenue years ago." Alix immediately said, "hold on, I'll see if we can have it." I believe I came back quickly with "fuck you, I'm finishing my orbit and heading back to the house."

Back at the house I laid my bald head down hoping to nap. Not too soon after lying down, I heard Alix in front of the house instructing a couple guys with a truck on where to put the cow.

Alix had gone over to the Hard Rock, asked to speak with the manager, and asked if she could have the cow. The manager said that the cow was going to be auctioned off to raise money for some “worthy” cause. Alix asked how much the manager expected to raise. \$200 would clear the market and Alix was quick to hit the bid. She paid while explaining we lived nearby on Telegraph Hill and asked if there was any way the manager knew how to get the cow to our house. The manager pleasantly offered an employee with a truck. So, before I could slip into dreamland, the 40-year-old fiberglass Holstein was off-loaded and placed in our entry.

For the record, I wasn’t a fan when the cow arrived and I’m still mildly irritated by its presence. At the time, I thought we might put it on the roof or hang it upside down in the entrance, but the cow has stayed; again, to the pleasure of kids who ask to ring the bell and car share drivers who are easily amused.

Jacob and Keith, our gardeners, come to our house a couple times a month. Jacob immediately asked how we got Pickles in our entrance? We had no idea the cow had a name, but Jacob remembered and was quick to congratulate us on the acquisition.



hobbyDB
Pickles the Cow | Pins and Badges |...

Once back in San Francisco after a week of infusion I'd have to do a blood check in the City. Fortunately, there was a LabCorp office 3 blocks away on Francisco Street. Usually, it was day three after an infusion that I had the stamina to walk down the Francisco steps to have Ashley at LabCorp draw blood. Ashley was a perky, young, well-tattooed phlebotomist who had a friendly spirit. I conscientiously made appointments for the blood draws and Ashley would put us at the front of the line when we came into the office waiting room.

Francisco Street at the base of Telegraph Hill is a bit out of the way and this LabCorp office closed not too long after I was finished with therapy. I still needed to have blood draws for my quarterly or semiannual check-ups. LabCorp has another office on Pacific Avenue in Chinatown as well as on Webster Street in Pacific Heights. The Chinatown office was easier for me and on my way to the office. No Ashleys at this office, however. The user experience at the Chinatown LabCorp was at best chaos. The Pacific Avenue office was on the 4th floor. There was no chance I was going to use the aging elevator. And then once in the office the line of folks with all sorts of what appeared to be difficult medical situations combined with English as a Second Language only contributed to the chaos. The most memorable scene was a lady wielding a bag of her husband's shit. She was there to drop it off for analysis, but the LabCorp crew couldn't get it across to her that her husband's name needed to be on the Ziploc. Hilarity ensued.

I finally realized I could have my blood drawn at Stanford and the analysis could be completed in short order before my oncology visits.

Because of the peripheral neuropathy from the Vincristine, I was told that I probably shouldn't walk barefoot at the beach. As if that was something I do or did. But walking shod on the beach was only part of what I needed to know about the consequences of Vincristine:

People also ask :

What are the side effects of vincristine?

More common

- Blurred or double vision.
- difficulty in walking.
- drooping eyelids.
- headache.
- jaw pain.
- numbness or tingling in fingers and toes.
- pain in fingers and toes.
- pain in testicles.

During the therapy, in talking the various sensations over with my family, Brice suggested keeping track of my feelings with a spreadsheet. I don't know what the doctors and nurses made of my reckoning, but it gave me something to think about and do daily. It also gave me something to talk over with the doctors and nurse practitioners when they made rounds. With the spreadsheet I graded neuropathy, nausea, exercise, fatigue, and my voice.

A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P
Neuropathy and Post Chemo Sensations/Influences															
	Scale	0-10	0 = none and 10 = debilitating		Evaluated end of day										
	Numb	N													
	Tingling	T													
	Weakness	W													
	Nausea	0-10													
Event	Right Hand	Left Hand	Right Forearm	Left Forearm	Right Foot	Right Ankle	Right Calf	Walk in Miles	20 mins Sun	Isometrics	Voice	Fatigue	Nausea	Gen1 Grade	
6/26/17	3rd md + 2 days	7 TN W	5 T	7 W	3	8 TN	8 N	9 N W	2.5	Yes	Yes	5	6	0	weakness 8
6/27/17	3	6 TN W	5 T	6 W	3	7 TN	7 N	8 N W	>3	Yes	Yes	4	6	4	slight cough 7
6/28/17	4	6 T W	5 T	6 W	3	7 TN	6 N	7 N W	2	Yes	Yes	3	8	0	slight cough 7
6/29/17	5	7 TN	5 T	6 W	3	6 TN	5 N	5 W	2	Yes	Yes	5	7	0	slight cough 7
6/30/17	6	6.5 TN	6 T	5 W	3	6.5 TN	4	4	1.5	Yes	Yes	5	7	0	cough 7
7/1/17	7	6.5 TN	5 T	4 W	3	6 TN	3	3	1	Yes	No	6	6	0	less cough 6
7/2/17	8	6 TN	5 T	3 W	3	5 TN	3	3	4	Yes	Yes	6	6	0	6
7/3/17	9	5 T	4 T	3 W	2	5 T	3	2	>4	Yes	Yes	5	4	0	5
7/4/17	10	4 T	4 T	3 W	2	4 T	2	2	>4	Yes	Yes	5	4	0	cough 5
7/5/17	11	3 T	3 T	3 W	2	3.5 T	2	1	>5	Yes	No	5	3	0	cough 5
7/6/17	12	3 T	3 T	2 W	1	3 T	2	1	>7	Yes	Yes	4	2	0	cough 4
7/7/17	13	3 T	2 T	2 W	1	3 T	1	1	>4	Yes	Yes	3	3	0	3
7/8/17	14	3 T	2 T	2 W	1	3 T	1	1	>4	Yes	Yes	3	3	0	3
7/9/17	15	3 T	2 T	2 W	1	3 T	1	1	>4	Yes	Yes	4	5	0	4
7/10/17	Rituximab	3 T	2 T	2 W	1	3 T	1	1	1.5	Yes	Yes	5	4	0	5
7/11/17	Day 1 Round 4	3 T	2 T	2 W	1	3 T	0	0	>3	Yes	No	5	3	0	5
7/12/17	2	3 T	3 T	2 W	1	3 T	0	0	1.6	No	No	6	5	0	6, no cough
7/13/17	3	3 T	3 T	2 W	0	3 T	0	0	2	No	No	5	4	0	5 no cough
7/14/17	4	3 T	3 T	2 W	0	3 T	0	0	2	No	No	7	4	0	5 no cough
7/15/17	5 release	5 T	5 T	5 W	3	5 T	0	0	-0	No	No	8	10	0	9
7/16/17	6	5 T	5 T	5 W	3	4 T	0	0	-0	No	No	7	8	0	8
7/17/17	7	4 T	4 T	4 W	2	4 T	0	0	0	No	No	7	7	1	7 cough
7/18/17	8	4 T	4 T	4 W	2	4 T	0	0	2	Yes	Yes	8	6	0	7 cough
7/19/17	9	4 T	4 T	4 W	2	4 T	0	0	2	Yes	Yes	6	6	2	7 cough
7/20/17	10	4 TN	4 TN	4 W	2	4 T	2	1	3.5	Yes	Yes	5	5	1	5 stuffy nose
7/21/17	11	4 TN	4 TN	4 W	2	4 T	2	1	3.75	Yes	Yes	4	4	0	4
7/22/17	12	3 TN	3 TN	3 W	2	4 T	1	1	3	Yes	Yes	4	3	0	4 nose/cough
7/23/17	13	3 T	3 T	2 W	2	3 T	0	0	3	Yes	No	4	2	0	3 nose/cough
7/24/17	14	3 T	3 T	2 W	2	3 T	0	0	5	Yes	Yes	3.5	1	0	3 nose/cough
7/25/17	15	2 T	3 T	1 W	1	3 T	0	0	>3	Yes	Yes	3.5	1	0	3 nose/cough
7/26/17	16	2 T	3 T	1 W	1	3 T	0	0	>3	Yes	Yes	3	0	0	3 cough
7/27/17	17	1 T	2 T	1 W	1	3 T	0	0	-5	Yes	No	3	0	0	2.5 cough
7/28/17	18	1 T	1.5 T	1 W	1	2.5 T	0	0	>4	Yes	Yes	3	0	0	2.5 cough
7/29/17	19	1 T	1 T	1 W	1	2 T	0	0	>3	Yes	No	3	1	0	2 less cough
7/30/17	20	1 T	1 T	1 W	1	2 T	0	0	0	No	No	2	1	0	2 less cough
7/31/17	Rituximab	1 T	1 T	1 W	1	2 T	0	0	1.5	Yes	Yes	2	3	1	2 less cough
8/1/17	Day 1 Round 5	2 T	2 T	2 W	1	2 T	0	0	1.5	No	No	2	3	0	3
8/2/17	2	3 T	3 T	3 W	1	2 T	0	0	1	No	No	3	4	1	3
8/3/17	3	3 TN	3 TN	3 W	1	2 T	0	0	1	No	No	3	3	1	3
8/4/17	4	3 TN	3 TN	3 W	1	2 T	0	0	1.5	No	No	3	3	1	3
8/5/17	5 release	3 TN	3 TN	3 W	3	2.5 TN	1	0	1	No	No	2	8	1	7
8/6/17	6	4 TN	4 TN	2 W	2	3 T	1	0	0	No	No	2	8	0	7
8/7/17	7	4 TN	4 TN	2 W	2	3 T	1	0	0	No	No	2	7	0	6.5
8/8/17	8	4 TN	4 TN	2 W	2	3 T	1	0	-2	Yes	Yes	2	7	0	6.5
8/9/17	9	4 TN	4 TN	2 W	2	3 T	2	0	-2	Yes	Yes	3	6	0	6, cough
8/10/17	10	5 TN	5 TN	3 W	4	3 T	2	0	-2	Yes	Yes	3	7	0	7, cough
8/11/17	11	5 TN	5 TN	3 W	4	3 T	2	0	2.5	Yes	No	2	6	0	6, cough
8/12/17	12	5 TN	5 TN	3 W	4	3 T	2	0	3	Yes	Yes	2	6	0	6, cough
8/13/17	13	5 TN	5 TN	3 W	4	3 T	2	0	>3	Yes	No	2	6	0	6, cough
8/14/17	14	5 TN	5 TN	3 W	4	3 T	2	0	>3	Yes	No	2	6	0	6, cough
8/15/17	15	4 TN	4 TN	3 W	4	3 T	1	0	>3	Yes	Yes	2	5	0	6, cough
8/16/17	16	3 TN	3 TN	3 W	4	3 T	1	0	>3	Yes	Yes	2	5	0	5, less cough
8/17/17	17	3 TN	3 TN	3 W	3	3 T	1	0	>4	Yes	Yes	2	4	0	4, less cough
8/18/17	18	2 TN	2 TN	2 W	2	3 T	1	0	>4	Yes	No	2	3	0	3, less cough
8/19/17	19	2 TN	2 TN	2 W	2	2 T	1	0	>3	Yes	Yes	2	2	0	2, less cough
8/20/17	20	2 TN	2 TN	2 W	2	2 T	1	0	>3	Yes	Yes	2	2	0	2, less cough
8/21/17	Rituximab	2 TN	2 TN	2 W	2	2 T	1	0	-1	Yes	Yes	2	2	0	2, flush
8/22/17	Day 1 Round 6	1 TN	1 TN	1 W	1	1 T	0	0	-1	No	No	2	1	0	1, Flush
8/23/17	2	2 TN	2 TN	1 W	2	2 T	0	0	>1	No	No	2	3	0	2
8/24/17	3	2 TN	2 TN	1 W	2	2 T	0	0	>1	No	No	2	4	0	2
8/25/17	4	2 TN	2 TN	1 W	2	2 T	0	0	>1	No	No	2	5	0	5
8/26/17	5 release	3 TN	3 TN	3 W	4	3 T	1	0	<1	No	No	2	5	0	5
8/27/17	6	3 TN	3 TN	3 W	4	3 T	1	0	<1	No	No	2	5	0	5
8/28/17	7	4 TN	4 TN	3 W	3	3 T	1	0	<1	No	No	2	5	0	5
8/29/17	8	4 TN	4 TN	3 W	3	3 T	1	0	<1	Yes	Yes	2	4	0	4
8/30/17	9	5 TN	5 TN	3 W	3	4 T	3	0	>1	Yes	Yes	2	4	0	4

It must have been during the first week of infusion that the Stanford social worker visited to ask my thoughts about how I was feeling about meeting the financial obligations of the treatment. She was a pleasant recent college graduate from Massachusetts. Central casting could have sent her – slight of stature, well educated, timid. I told her it was insane, but I had just begun new insurance through our start-up business the day I went to the cardiologist for the echocardiogram. I'd previously been paying for Blue Cross through a COBRA arrangement with Fundrise and our

new company, 280 CapMarkets, had just begun health care coverage offered through Aetna on May 1. (280 was licensed by the regulatory bodies on April 28 and we began official operations on May 1.) From what I could tell, Aetna would be providing coverage and we had the means to pay if for some reason Aetna balked.

Of course, as you're in the hospital infusing battery acid your mind does drift to the cost of the tests, the hospitalization, the treatments, the doctors, nurses, et alia, etc. I don't believe I ever panicked, but at times there was true anxiety.

I didn't let on to the social worker that there was any anxiety and offered that I very much appreciated her concern and offer of assistance, but I was comfortable the financial aspect of my health care and the finances were in much better order than my physical health.

Through the six months that I was in and out of the hospital I'd run into the social worker. During the summer I could see that she was becoming more comfortable with her job. I also witnessed plenty of situations where her services were critical.

Aetna turned out to be more than generous in their coverage. At each turn, when there was any question, Stanford stepped in to justify expenditures. Stanford's advocacy was impressive, but I was more impressed by Aetna's steadfast payments.

Once I was back in the 280 CapMarkets' office in late November I talked it over with Heather, our CFO. I told her that my recollection of costly hospitalizations when I was with Stone & Youngberg was that the insurance carrier dropped the firm at its earliest convenience. I was surprised then that during the end of year re-enrollment in health insurance, Aetna renewed 280's coverage. Our contract was such that Aetna could drop the firm with 30 days' notice. In early January we received the notice that coverage was being dropped. Why Aetna renewed

and then a month later dropped us, I'll never know. It's a credit to our CFO that she was able to line up comparable coverage at reasonable rates after my experience. I know I didn't make it simple for underwriting.

Meeting with the oncologist and his team in early 2018 and debriefing about my treatment I suggested that if we were to contribute to recognize my care, I'd be inclined to send a check to Aetna. He and his team, aghast, began relating insurance company horror stories in a successful attempt to discourage my heartfelt appreciation for my health insurance carrier.

On the heels of the social worker's first visit, central casting sent a "spiritual counselor". A well-dressed gray-haired woman, likely from Atherton and all that Atherton connotes, stepped in my room, and asked if I wanted to talk. Being jacked on steroids and deep into Thomas Mann's Magic Mountain I welcomed her visit. She told me she was a volunteer spiritual counselor. I asked her what denomination she represented, and she told me she was a Christian Scientist. (!?!) This seemed odd to me thinking Christian Scientists tend to turn down medical care, instead favoring prayer. She explained that prayer was important, but that professional medical care isn't ruled out by your Mary Baker Eddy believers. Not wanting to go too deep, I offered that I was an agnostic and not necessarily an atheist because an atheist suggests that I might have a belief or "faith" that there is no higher being. Agnosticism just seemed like a more reasonable attitude.

I shifted the topic to her faith's newspaper, the Christian Science Monitor. I told her my impression was that the CSM had lost a good bit of its influence as daily news media moved online. She countered that the CSM was still going strong. During the rest of my stays at Stanford Hospital she'd stop by and drop off the paper whenever we were both in the cardiac ward or F Ground (cancer ward). Oh, and the jury is in. Like most daily print media, the CSM is a shell of what I recall in the 1970s.

In the grand scheme of modern living, 6 months of chemo treatment isn't even a baseball or basketball season, a full academic year, or enough time to learn another language.

Word of my situation moved around from co-workers and friends. Gurinder at the office offered me one of his daughter's traditional Sikh scarves (a chunni?). (I eventually passed the scarf to Stephanie Rudd, Dave's wife, when she encountered a difficult stay at Stanford Health Care four years later.) Fundrise sent me a huge get-well card from the office dog, Zappa. Heather and Barry brought ceramic owls and ginger cookies. (Who knew ginger is good for relieving nausea? Your mileage may vary, but I also recall that the ginger contributed to my platelet count dropping.) Sister Lilly prayed and offered meditating on Saint Martin de Porres' sweeping. Heather Hall and her mother gave me a Blue Angels baseball cap. (Heather's father was a Blue Angel and sadly was the last Navy air casualty of the Vietnam war on the last day of the Vietnam war in January 1973.) Celia brought Barbarian Summer, an unusually satisfying read as well as a Saint Martin de Porres mini broom. Lauren and Pierre shared lunches. Dawson kept it light. José offered healing from the great creator along with cleansing sage. My brother-in-law and his daughter visited from France, which bolstered morale for the home team. Alan stopped by to talk football and movies. Dave and Jane walked me in San Francisco. Tom, Gyöngy, Teri, and John joined us for dinners. Sohail offered steady encouragement. Cuong visited and we lunched. Noah sent international movies – who knew there were so many recent international films featuring homosexual themes? Alix, Brice, and Zoe brought Perrier in large quantities. (Again, Stanford water on F Ground was contaminated for part of my stay.) Francisca easily made 50 almond or chocolate cakes for the nurses over the course of 6 months.

It must have been in August when José stopped by to visit. José would come by as he travelled the State attending Native events, looking for classic cars that a school in Pomona could renovate, and tracking down Native literature for preservation in his library. I was very bald, very tired,

and very much ready to be finished with R-EPOCH at the end of the month. José was returning from events up north on his way back to his home in Pasadena. In his truck he had a sacred buffalo skull that a native woman had beautifully decorated in what I recall being traditional blue and black designs. José joined us for dinner and offered to imbue me and the house with the powerful spirit of the sacred buffalo and creator. As a dedicated agnostic who had been meditating on the rhythmic motions of St. Martin de Porres sweeping, I was all for what José could offer through his buffalo channeled blessings. José packed the skull up the four stories to our kitchen. (We learned that he also packed the skull to Alcatraz from our house when he was visiting the prior year for the annual Unthanksgiving sunrise ceremony.) The point here is the skull is flat out huge and while not impossibly heavy, it's cumbersome for someone who has had 5 rounds of chemo. José invoked the power of the bison along with the blessing of the creator in a ceremony that profoundly touched both me and Alix.

Cards came from all over. While all the messages were truly appreciated, two stand out with hardly Hallmark sweetness. Lara sent a card Rike questioned as possibly inappropriate. The poop sandwich could not have been more appropriate. And Dorothy sent a card that I think about often when I hear of someone with a challenging diagnosis.



Hidden Stanford – And I Suppose Membership has its Privileges

Before Stanford became a University it was a working farm; hence the metonymy "The Farm" meaning Stanford University. The Stanford family installed an "Arizona" garden of drought tolerant plants – Wikipedia suggests ~500 cacti and succulents. The garden is near the hospital. Alix found the garden when she was a post-doc. The garden became and has been an inspirational oasis when killing time before infusions or in between meetings at the hospital. It's near enough to walk even when feeling pooppy. Visiting is highly recommended even if you aren't scheduling a scan or infusion.



Years ago, Alix became a docent at Stanford's biological preserve to the west of campus off Sand Hill Road called Jasper Ridge. As a docent she has the gate key and a badge. (Stinking badges required.) We were able to relax at Jasper Ridge waiting on treatment or meetings. We practically had the preserve to ourselves as summer classes are rare.



Stanford Hospital soap since 2017 has improved. I suppose the change was due to either a new contract for medical supplies or an evaluation of soaps during the Covid-19 pandemic. Regardless of why, my recent Stanford Hospital visits have been satisfyingly more pleasant (and probably healthier) now that the hand soap doesn't create nausea. Of course, the original odor and its association with the battery acid I was infusing likely influenced my revulsion, but the new soap is pleasingly not fragrant.

At the same time, the cooking oil used in the hospital cafeteria still calls up a nauseating reaction. It was a challenge during the infusions to walk by the cafeteria because the aroma was and is correlated to the gut churning effects of the infusions. A couple years after being discharged I was attending a football game with a friend from Southern California. He was running behind and called to ask me to stop by the bookstore to pick up Stanford souvenirs for his two daughters. We'd then meet at the stadium. The bookstore was on my way. Opening the door to the bookstore I was practically floored by the sickening smell of the hospital's cooking oil! With bookstores being so much less important to the education mission of the University, the store had added a cafe -- so long philosophy and western civ. The Purchasing Department at Stanford obviously made quantity discount purchases with the hospital and the smell of the noxious cooking oil dredged up olfactory memories of R-EPOCH.

Constipation is a side effect of the chemo cocktail. The first week of infusions I was prescribed what seemed like dozens of medications for home delivery. It felt as if most of the prescriptions were for laxatives. Stanford being Silicon Valley, the nurses recommended home delivery from an outfit called ScriptDash -- Door Dash for licit dope. ScriptDash was slick. I'd get a text in advance of home deliveries letting me know when the dasher would be delivering. Within a month of using ScriptDash the company rebranded itself as Alto. The logic being the Bay Area company was going national with a venture capital cash infusion and Alto, in a dead

language called Latin, means higher. High? Their brand expert suggested "elevated", which is what they meant to do with the pharmacy experience. Anyway, Alto means Stop in idiomatic Spanish. The rebranding felt strangely like General Motors marketing Nova cars in Mexico.

I digress from constipation, which was an issue. However, I was soon introduced to the Squatty Potty by one of the brilliant nurse practitioners. The video tells it all. <https://www.youtube.com/watch?v=YbYWhdLO43Q>

We now have Squatty Potties at home and in France.

After all the therapy we managed to go back east. I went to DC to catch up with the team at Fundrise. Ben asked me to hold a lunch-and-learn with the staff to go over the lymphoma experience as well as my career working in a regulated business. The team was curious and engaging and I spoke at length about the fascination of representing Stone & Youngberg in Federal District Court, the 2008 financial collapse, and R-EPOCH. One of the collateral benefits of this visit was Ben introducing me to Kilogram Tea's turmeric ginger tonic.

<https://kilogramtea.com/products/organic-hot-turmeric-tonic-2-oz-box>
Turmeric combined with ginger and black pepper seem to have a profound ability to assist with digestion. It certainly has worked in my situation and I'm forever grateful for the introduction.

As mentioned, I steered clear of going online to spelunk among cancer diagnoses, therapies, support groups, and studies. My reading was biased toward fiction although I received a book about Lymphoma from a young person who had previously worked in my office. Li Zer was let go at Stifel just as his work visa expired - a brutal and shameless move that happened after I had left the firm. Li had gone to Brown and was on the work portion of a student visa. Once he was fired and his visa expired, he moved to Hong Kong. Once back in China he developed a clot in his heart, which is a bit of a theme here. I introduced Li to Stanford, but he ultimately was treated at Cleveland Clinic. (Li obviously had resources.) He was

treated successfully and was in good health. He passed through San Francisco on his way to Omaha for the annual Berkshire Hathaway annual meeting. (Did I mention Li had resources?) He stopped by to visit me at Stanford and brought Living with Lymphoma.

https://www.goodreads.com/book/show/939914.Living_with_Lymphoma I didn't go deep. I grazed the book. And ultimately put it aside.

My treatment fell during a time when Stanford was moving away from infusing Rituxan in the hospital to a separate outpatient infusion center. This meant rather than spending a night in the hospital, I'd arrive at the infusion center, take Benadryl and then the Rituxan. After infusion I'd go home, spend the night, and return the following morning to check into the hospital for a week of EPOCH infusion. During one of the infusions at the outpatient infusion center I met Samu, an oncology nurse. He was

charmed by Alix but also let us know he was a confirmed Francophile. I had to let him know his name, Samu, are the initials for the French ambulance system: Service d'Aide Medical Urgente or the acronym SAMU. Samu was impressed and we encouraged him to continue his studies and become a doctor, which was a common refrain when Alix spoke with nurses.



Back in San Francisco, probably around late July, I walked to the laundry. I ran into a college friend who also lived in the neighborhood. He was shocked to see me pale and bald. I explained what was going on and I told him I would let him know how it all went. A few days later Neil McKinnon sent me a book on cancer diets called Anticancer, a New Way of Life <https://www.goodreads.com/en/book/show/1886829>. I took a quick look through the book. Put it aside. In this regard, I had a variety of theories as to why I developed the disease: eating cheese rinds, generally just eating French cheese, binging on chocolate, drinking milk, eating apple cores, brushing my teeth with Elmex toothpaste, resting the computer on

my chest, or carrying my cell phone in my breast pocket. The standard medical response to my questions about causes was "no, we don't know what causes the disease and think about it, even young children get it." A few years before lymphoma I'd had a helicobacter pylori infection. Possibly related, but also just as possible it was the cheese rinds or apple cores? David Ibarri is a hematologist with a friendly bedside manner and authoritative air. I offered my causes. He listened with some obvious skepticism and then offered "Tom, we don't know what causes the lymphoma, but we do know that ice cream cures it."

Following the R-EPOCH regimen I then had two months of high dose methotrexate infusions. There were four infusions - once every two weeks. After the methotrexate had been infused it was then a race to eliminate the methotrexate in my blood to a safe level before being discharged. In speaking with the nurse practitioners, I learned it can take 2 to 10 days to demonstrate it was safe to discharge me and start on the antidote, leucovorin. The prospect of spending extra nights in the hospital was depressing so I asked the nurse practitioners what they know about the patients who took 2 days to discharge versus 10 days. I was advised to stay hydrated, which meant I guzzled Perrier and spent the better part of two days walking around looking for hospital bathrooms. The purges worked and I was able to make my methotrexate stays short.

The antidote is important, and I had to be on a schedule to take the leucovorin. I don't know what I would have done without alarms on my iPhone. As the methotrexate was not in any way as fatiguing as the EPOCH, I had begun to go back to work. I frequently lost track of time and had I not had the alarms I don't know how I would have stayed on schedule for the all-important antidote.

After completing treatments, I was advised to meet with the oncologist quarterly through the first two years -- statistically the riskiest period for relapse. After two years, the advice was to meet semi-annually. After 5 years, well, annually, but there's just as likely a risk that something

else will arise besides lymphoma, although I understand I have a slightly higher risk of having leukemia now that I've had lymphoma.

After treatment I got around to searching the internet for information on my oncologist, Neel Gupta. Using Google, Neel's first blue link was to a video of his deposition in a RoundUp lymphoma case brought against Monsanto. The case was celebrated because a couple in Pleasanton were awarded \$2 billion by a jury that concluded RoundUp was responsible for their lymphoma. Neel had been their oncologist. Oddly his testimony footed with what he had told me, which was we don't know what causes lymphoma. <https://www.cbsnews.com/news/jury-awards-couple-2billion-monsanto-roundup-weed-killer-cancer-lawsuit-trial-today-2019-05-13/#:~:text=A%20jury%20in%20Oakland%2C%20California,and%20to%20cover%20medical%20expenses>.

During my first post treatment visit I asked Neel if he ever had done a vanity search? He hadn't. I told him I had searched. He shyly said that maybe I saw a video of an interview he gave at a medical conference. He was a bit embarrassed because he said he was exhausted and not particularly eager to be interviewed. I told him, "no, I watched your deposition in the RoundUp case." You would have thought I punched him in the gut. He asked, "where in the world did you see that?" I told him it was the first blue link in a Google Search, and "I can show you." We moved out of the EPIC medical records system and to his browser. We searched "Neel Gupta", and boom, there was the video. Somewhat concerned, he said "I need to speak with legal. This shouldn't be on the web." Soon after the video was down. And so was the med conference interview.

As I was admitted to Stanford, Alix had recently taken and passed the California medical board exams. To be fully licensed to practice she'd need to do a residency. Back in 1990 Alix had also passed the med boards, but the offer to work in venture capital and stay in the Bay Area was more appealing than moving to fulfill the residency requirement. Now as a 59-year-old foreign medical school graduate it was going to be practically

impossible to find a residency. (Residency requires medical school graduation within the past five years.) Earlier I've described the first week of observation and evaluation. I've also described the complications with the hospice and palliative care doctor who visited and couldn't tell me if the prune in my heart was a sarcoma or a lymphoma. Not too soon after this episode, a young doctor came in and asked if I would mind speaking with his first-year med students about the bedside manner experience I'd just encountered. I obliged and in came twelve med students to hear the story about the non-diagnosis diagnosis. We all had some laughs about a very real situation. The students left and not too soon after the young doctor returned to say thank you. Alix was quick to say that she had recently passed the med boards and that she was looking for a residency. She asked if the doctor had any advice. He did: Dr. Neil Gesundheit. (Can't make his name up. He's an endocrinologist at Stanford: <https://profiles.stanford.edu/neil-gesundheit>). I so wanted him to be an ENT. Dr. Gesundheit was handling Stanford residency placements. Neil Gesundheit soon became a friend to Alix and he made a sincere effort to find a placement for Alix, but the deck was stacked with a foreign graduate more than 5 years away from graduation wanting to stay in the Bay Area and so Alix's most important patient turned out to be me.

With me being laid up for what was going to be the summer and then some, Alix missed out on a summer vacation at the beach. I encouraged Zoé to continue with her work that took her to France, Japan, and Bali. Brice was local working for a real estate developer. Summer 2017 therefore wasn't a vacation, but I encouraged Alix to try swimming in the Bay at Aquatic Park. Reluctantly Alix went. Enthusiastically she stayed. She joined the South End Rowing Club and then eventually joined the neighboring Dolphin Club just because she could. Her escape during Lymphomania was therefore frigid swims with warm friends she made at the Aquatic Park swim clubs less than a mile from our house.

Zoé returned in early September from her work around the globe. I had just finished the sixth and final round of R-EPOCH. The week before

she arrived the temperature in San Francisco started to climb. As I recovered from the infusions, I made my way to the back deck of the house to lay in the shade. I had been discharged from Stanford on Sunday, August 27. By Wednesday, the 29th, the City was really sweltering. I'm not sure if it wasn't the heat and not neutropenic fever, but by Friday the 1st, I had a fever just north of 100.4 Fahrenheit, which is the point at which cancer patients are advised to contact a physician. Neutropenic fever can lead to sepsis and at that point cancer becomes a bit of a so what. I called Stanford. They told me to go to the hospital. With the heat, we felt like we'd have a better chance getting into San Francisco's California Pacific Medical Center where I'd earlier established a relationship with the oncology team in case something like this were to happen. We went to the emergency room that was packed with all manner of heat related problems -- faulty air conditioning and dozens of patients seeking relief. I waited. Zoé arrived from the airport, and we all waited more. I was finally put on a gurney. Through the night there were no rooms available, so I was wheeled to a closet and then to a kitchen. I was moved out of the kitchen when the police arrived with a suspect that needed to be kept in a secure room. So, I was put back out in the hallway. From there, back to a closet until 18 hours after I had arrived, I was admitted to a room. In the meantime, I'd had an x-ray. I hadn't slept and I was feeling god's own exhaustion from the fever and the hard day's night of the Emergency Room.

Using data from the National Weather Service, we determined that the hottest day in San Francisco's history occurred on **September 1, 2017** when the city hit a blistering 106 degrees. We know that areas outside of the city can be even hotter on days like this, and that was true in 2017 too. May 24, 2022

My room in oncology was pleasant enough and the staff was terrifically attentive. Apologies were frequently offered about my extended visit to the ER and its lobby. And I finally had some time to rest. September 3, was my birthday, turning 60. The morning of the 3rd was tough. I was weak and could barely move. I recall sitting on the toilet hoping to faint. I had been given ciprofloxacin in case of infection. My big birthday gift turned out to be a large cold bag of 0+ blood. This was the first and only time during the treatments that I was transfused. While I

imagined I had received a pint of Heroin Henry's blood, the transfusion bolstered my system. I recall being discharged on the 4th. The weather had broken and so had my fever. I didn't take any more cipro thinking that the last thing I needed in this condition was to have the side effects of the antibiotic. Some of which I knew could be nasty:

- [tendinitis](#) and ruptured tendon
- nerve damage
- central nervous system (CNS) side effects, such as:
 - [depression](#)
 - [seizures](#)
 - [suicidal thoughts](#) or behaviors

Away from spiking a fever and heading to the ordeal that was a heat-stricken ER, Andy Moravcsik 's wife, Anne-Marie Slaughter passed through as her professional life was being challenged. Anne-Marie stayed at the apartment as we all decamped for the ER. The hell that was that weekend passed and Anne-Marie survived her week in social and popular media purgatory.

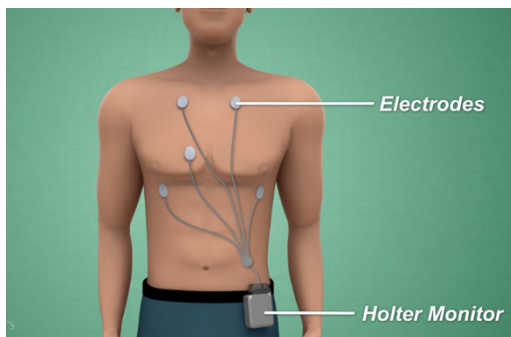
<https://www.nytimes.com/2017/09/01/us/politics/anne-marie-slaughter-new-america-google.html>

Regarding side effects, when my heart had taken off to 220 beats per minute and DiBiase had called for a bolus of amiodarone I asked the cardiac nurses (Althea and Ryan) about consequences of amiodarone. They told me the drug is common for patients with afib, but that long term use would likely lead to liver damage. Oh, and, don't eat grapefruits or drink grapefruit juice as grapefruit will amplify the negative side effects of the drug.

I continued to take amiodarone until sometime in August. Oddly through that entire period I craved grapefruit.

The only dosing error experience in the hospital that I can confirm was receiving an extra measure of amiodarone. It was in the morning when a nurse came in with pills. I asked what I was taking, which was something I always asked before swallowing. (That's a pro tip, by the way.) The nurse told me amiodarone and I told her it was twice my usual dose. She insisted it wasn't, so I went ahead and swallowed. (Amateur move that, and a reminder that you get the health care you demand.) An hour later she came to tell me that I was right. She was wrong and she apologized. I think the overdosing also set off all sorts of administrative alarms, form filings, and possibly reprimands. I appreciated her forthright honesty and contrition.

On the topic of getting the health care you demand; Alix was insistent that we have some attention paid to my afib. She pulled in Stanford's



leading electrophysiologist for a consultation. The doctor projected competence and professionalism, but the best advice he could offer was to wear a holter monitor. I had become accustomed to wearing these as the holter monitor is the go-to prescription for a first visit to a cardiologist. My actual mileage saw my

heart rhythm return to a happy, regular beat by May of 2018, one year after the diagnosis.

And in the regard, I think an error I made was I had known that my system is sensitive to caffeine. After treatment we went to France for the holidays. At a tea shop I found some exceptionally tasty mint. For the next several months I'd have an afternoon cup. Probably around April of 2018, I discovered the mint was mixed with caffeine-rich black tea, which probably accounted for the afib I experienced between ending treatment and May 2018.

I've saved the paperwork and medical materials. Someday I'll work up an art project. (I did however toss the hat with hair that Klaus and Rike gave me. At the time, it was wonderful. But with time, it sat in my closet as an inefficient dust mop and creepy reminder!)



While jacked on steroids I was able to read a good bit. Celia surprised me with a visit from Chile when she was in town for her daughter's graduation. She dropped off Barbarian Days. And Magic Mountain is the quintessential hospital read. And the Joseph Smith story provided interesting conversations about Mormonism. I can't recall how I was introduced to Neil Gaiman's American Gods, but it was a wonderful read. I shared the narrative with Alix who seemed to enjoy my descriptions more than you might imagine. She regaled the nurses with the story. Post-lymphoma I've plowed through most if not all Gaiman's books. Empire Falls was recommended, and it was a grim downer. I finished the novel only because I hadn't brought anything else with me for that week in the hospital.

Roommates and EPOCH cohort friends were important sources of short-term friendship and shared commiseration. I can't recall all their names, but one of my first roommates was a deputy sheriff from Humboldt County. A giant of a person he seemed to take 2x whatever I was taking. Checking into my room at the beginning of an infusion I came across a pair of his shoes he had forgotten in the room locker. Who knew there was a size 17?

I shared a room for a couple weeks with a Japanese American toxicologist our daughter knew because she had interned in his poison control clinic at San Francisco General. Beyond poison control he was passionate about deep sea fishing. And stalking him on the internet today I see that he's back doing what he enjoys in the Pacific.

Not all my roommates had such good outcomes. Toward the end of my stay at Stanford, I shared a room with a former president of Levi's international division. He had been teaching business ethics at the Haas School at Berkeley. He had a wicked sense of humor and a real outrage over Trump. As we were both jacked on steroids we'd talk late into the night. I asked a young friend who was studying at Haas if she knew him. She didn't, but she did say that she had his son in classes. She also let me know that my former roommate passed not too soon after I finished treatments.

The most difficult roommate was an older man (well, older than I) who entered the room saying obnoxiously, "I'm the healthiest sick person here." He didn't respond well to treatment, mainlined Cokes and cookies, and had an uncomfortable relationship with his much younger wife and mixed-race daughter. Ick.

I spent one round of infusions with a Spanish speaking laborer from the Central Valley. Whenever a doctor or nurse came in, a translator was needed to be patched in by speaker phone. As I was leaving after a week of infusion, Brice came to assist me with packing up. Brice started speaking Spanish with the man and his wife and I think Brice learned more about his condition in 45 minutes than the doctors and nurses did in a week, which is intended to be a commentary on how non-English speaking patients were tended.

Dave Klein and I shared a room a few times. Dave was a coach and athletic director at the high school in Patterson, California. He had earlier had a sarcoma on his foot. At the time, it was recommended that he have his foot amputated. Dave chose chemo as he didn't want to lose the ability to play golf. (Coincidentally, Dave played golf at Diablo Grande. A residential development near Patterson that in the office we called the "Big Devil". Diablo Grande was an infamous public financing project that included \$50 million in public infrastructure debt that ultimately went into a

spectacular default.

https://en.wikipedia.org/wiki/Diablo_Grande,_California) Dave's situation improved with the chemo, but a sarcoma reappeared later on this hip. This led to several hip surgeries and chemo. All in all, a terrifyingly miserable experience. We got to know Dave and his wife, Liz, well. After I was discharged, I continued to meet with Dave and Liz when they would be at Stanford for an infusion. As Dave neared death, we visited in Patterson. We continue to stay in touch with Liz and the family.

Coincidentally back in May 2017, as I was being diagnosed at Stanford, a friend in San Francisco was admitted to Kaiser. Anne Halsted was also diagnosed the same week with non-Hodgkin lymphoma. There are something like 40 different non-Hodgkin lymphomas. Anne's was different than mine. She was placed on R-CHOP therapy and throughout continued to be actively involved civically. She didn't respond well to the therapy and then went through two different experimental trials before finally succumbing in March of 2021. Anne had employed me at US Leasing as an intern in 1983. She and her husband Wells Whitney lived in our neighborhood. After Anne's death, Wells moved to Glen Ellen after selling their beautiful home on Montgomery Street to friends. We live in a small town. (And Anne's remembrance service in San Francisco in 2021 featured Senator Feinstein, which ultimately made more news than Anne's passing: <https://sfist.com/2022/04/15/dianne-feinstein-defends-herself-as-chronicle-editorial-board-piles-on/>.)

As far as small towns go, Joey Chait and I met in my office at the Ferry Building probably around 2010 when we were developing a special tax district including his office building at 5th and Mission. We met again at Stanford's F Ground Cancer Center where Joey and I shared similar cycles of R-EPOCH. Joey had a special spirit that became the nucleus for several of us going through infusions -- including Ebbe Altberg and Jafar Hussain. Our families met in the lounge as we infused. When our families weren't around, we roamed the halls and conspired to exit the hospital to sit outside by the ornamental fountain or in the prohibited areas outside of F

Ground. Joey and I ended treatment at the same time. As I was about to take methotrexate infusions, Joey joined me by the fountain to visit. We stayed in touch. Our families had grown close. Within two months of discharge, Joey's lymphoma had returned. We were in France in December 2017 and spoke with Joey just before he died. His life ended quickly and by Thanksgiving he knew he was terminal. His death was devastating for us. A remembrance was held once we were back in the Bay Area in January. And in the words of the man who hired me at Stone & Youngberg, Ben Baum, "if you want a big funeral, die young." Joey died young.

At the remembrance I was able to catch up with Ebbe, Jafar, and a wonderfully pleasant and outgoing nurse, Elizabeth Dovi. A sad time was very much had by all. Ebbe died a few years later in June 2021. Ebbe had an unusual sarcoma. Covid prevented us from attending a remembrance service, but we did participate through Zoom.

During the four months of R-EPOCH I had a few chances to get out for a lunch. Tom and Gyongy met us at Boulettes. Cuong Pham passed through, and we had an animated lunch as I got ready for another round. Bill and Joanie Huck came through San Francisco, and we yukked it up over lunch at Il Fornaio in Levi's Plaza. In August 2017 we were eating outside at Boulettes on a Saturday during the Farmers' Market. I was pale, bald, and tired. I was surprised to see college friends Carol and Gail Blumberg walking by. I hadn't seen either of them in decades. I was reluctant to say hello given my condition. Oddly enough though, several months later in 2018 I ran into their parents, Peter and Isabel, as I was running along the Embarcadero. I stopped and said hello. I'm sure they were surprised as we probably hadn't seen one another in nearly 30 years. Peter's first words were, "Carol died in December." I was gob smacked. When I got home, I tracked down Gail, her sister. It seems the day I saw Carol and Gail was the last time Carol was out. She was being treated for a glioblastoma and the brain tumor took her before the end of the year.

On a much less somber note, I was at the 2022 Big Game - the Cal - Stanford football game at Stanford Stadium. At half time I stood up and turned around to see Jafar Hussain seated directly behind me. We were both just about 5 years away from final treatment. We shared our apparent statistical success and reminisced as the second half kicked off.

To celebrate the 5-year anniversary of remission and statistically important threshold, we gathered at Boulettes. Neel was the guest of honor along with his wife Kelly. Stalwarts during the whole experience attended. Gratitude all around.



As we prepared for the Boulettes' dinner, I had hoped to pull in the nurses and Nicole Wadley, who represented Stanford hospital administration - and not development. Nicole was always cheery and engaged willingly to assist in recognizing all of the people who pitched in to deliver my care: Alison Morris, Rachel Landgrebe, Amber Rickner, Megan (glove up) Harrington, Jevon Gregg (Winchester Symphony), Mitchell (?), Alisa Kearney Heitman, Marie Rinaldi (very much a pro), Quan "use condoms" Thai, Christine Shen, Lindsey Stringer, Betty Le (my Stanford MyHealth email pen pal), Chelsie Miyao, Elizabeth Dovi (F Ground Circus Ring Master), Jigme (think Cher or Bono), Rachel Scott (and her wickedly funny husband Adam), Althea Rogers (rock climbing Alaska fishing boat captain), Ryan Daughtery (you want him in the room when your heart beats at 220 bpm), Theresa Cotter (queen of SHC cardiac ward), Lauren Maeda,

Rondeep (call me Randy) Brar, David Iberri, Samantha Kramer, and Neel Gupta. I know for certain I've overlooked some names, but the sentiment is there, and I still carry faces with these names. They all meant a great deal to me.

And one of the nurses dated Sean Zak in my office. I can't recall her name regrettably. During one of the infusions, she spent an afternoon telling us about her exploits kite flying at Ocean Beach and in the Bay. Sean and I were driving to a meeting in Sacramento in 2018. He too was an insane (seriously) kite surfer. I told him about the kite flying nurse. He said, wait, he had dated her. As we drove, he called her, and we caught up. Again, another instance of how connected the town can be.

Thinking about the dinner I'm reminded of how so many people came together to support us through the illness. Tom, Gyöngy, Johnny, Teri, John, Pat, the Faynes, Harry, Bridget, Yoav, Sohail, my family in Ohio among many others who all shared in our hell.

I learned that it's not exactly ethical to gift a physician. I had planned on giving Neel a watch. We donated to his research instead. I did however go ahead and give Franck Mueller Crazy Hour watches to Alix, Zoé, and Brice. Joey's jewelry and pawn business could find just about anything. In August 2017 I asked Joey if he could find a Cartier Crash watch that I could give to Alix as a memento. He recommended the Crazy Hour over the Crash. Later, Joey's son, Marcus, was able to find the watches at a shop in Detroit. I don't know if the children will ever wear the watches, but the watch became a hit for Alix and a wonderfully precise memento of the crazy hours of Day Light Savings Time 2017.



Crazy or Crash?