

March 22, 2022

Dear Praying Family and Friends,

A report from the trenches, if you please . . .

EXECUTIVE SUMMARY

- I got to the hospital by [4:00 PM on Sunday](#). Intake procedures commenced. Many staff on the isolation floor remembered me and welcomed me back. Not quite like home, of course. But, I'll take familiar over alien anytime.
- Some diagnostic things were done through the night to establish baselines for the effect the drug might have in moving away from the baselines established: lots of blood drawn. Electrocardiograms (ECGs) – done in triplets, five minutes apart. Visits by orthopedics, occupational therapy, endocrinology.
- I immediately discovered that data and orders from the cancer clinic had (1) not arrived before I did, or (2) were lost in transit. They did not even know I was diabetic! No scheduled blood glucose tests. So much wrangling ensued for several hours, and much digging in records (motivated by yours truly) which ought to have been reviewed anyway. Why take records otherwise??

THE REAL FUN BEGINS

I finally got to sleep [at 0400 Monday](#), awakened by another round of vitals and more blood labs at 0 600.

Infusion started at 1010. Immediate sensations of warmth in my ears, spreading around the back of my scalp, over my head from rear to front, then down into my face. Most weird.

At 1020 I asked for a temperature check, as I was feeling warmish. It was 99.0. Five minutes later I asked for another. 99.4. They took another without my asking at 1025. It was 99.8.

At [10:30](#) I experienced the beginning of “chills.” I've had this before when spiking a fever, so I immediately informed the attending staff (three people). The shivering increased rapidly until I was shaking violently in the bed and had difficulty speaking because my jaws were clenched so tightly. My legs were rigid and shaking. Same in upper and lower back. It felt like I was trying to bend forward and backward at the same time!

While all this is transpiring, the staff are hurriedly scanning the protocol to see if this was anticipated and what to do if it showed up. All they could find was a vague reference to “infusion reactions.” Remedy? Benadryl. Or Demerol. They gave me both.

What happened is called *rigor* or *the rigors*. It happens when a whole host of various diseases, injuries, or other conditions trigger the production of chemicals called

pyrogens in the blood which 'turn up' the body's thermostat setting. Pyrogens are produced by our own immune systems in response to various triggers, infection is the most common.

Well, something in the drug was triggering a production of pyrogens. My fever was going up, and the rigors set in as well – violent shaking of my whole body. Spasm after spasm, like waves crashing onto a shore.

The Benadryl and Demerol worked after a few minutes. What a relief! They commenced the infusion again, at a slower pace, and the rigors did not return.

I won't bore you with a list of what I remember over the next hours. Nothing traumatic or dramatic – lots of the taking of vitals (temperature, blood pressure, oxygen saturation). Lots of blood draws. Lots of triplet-ECGs – three that I remember. All through the night.

SURPRISES THE NEXT MORNING

I slept through most of that stuff! For this I credit your prayers and our Lord's kindness to grant them. But, just before breakfast, my room nurse came into draw a single vial of blood. "They need to check something," he said. "One of your counts was way off base and they want to know if it's a correct assay or if it's an outlier."

After breakfast, an especially helpful physician's assistance came in to discuss with me what they were concerned about. At admission, my white blood count (T-cells) was 5, then went up to 7. After the drug infusion, the white count had collapsed down to 0.5! This means that most of my first-line defense against infection had vanished! Where did it go??

"What happened to all the T-cells?" I asked. "We don't know!" they responded.

I'm pretty sure a conference with the drug company folks had already taken place. I also had an idea which I proffered to the helpful physician's assistant. "This drug is an upgraded version of previous BITE drugs. These coupled together one T-cell and one cancer cell, the former killing the latter after they got hooked together by the BITE molecule."

By this time, a physician and researcher in multiple myeloma came into the room. The PA asked me to begin again. "So, the drug you're testing on me is designed to couple SIX cancer cells and up to six T-Cells at once. Can the assay machine in your lab downstairs, the one that 'counts' T-cells, can it 'miss' its counting the T-cells which are coupled with the cancer cell? What if all those missing T-cells are still in there, but the assay cannot 'see' them?"

Later, this was passed to the drug company folks as well. They decided to proceed as if this were what happened (later research must validate that this indeed happens).

Now I get a shot of a drug that stimulates the bone marrow to produce more T-cells at a higher rate. And, I get another infusion of the Bigger Bite drug on Thursday.

THE BIGGEST SURPRISE

This I saved for last: I can detect with my fingers a shrinking of the lymph nodes in my left face, below my right collar bone, under my right armpit, and the bilateral inguinal nodes in my groin. I noticed the last area first, because it had become very uncomfortable to sit down or to rise from a sitting position. That difficulty simply vanished within a couple of hours after the infusion, and palpating those nodes showed me they were just enough smaller for me to detect it. My hand flew to my face. Same with the largish lump between my ear and upper jaw. Same with the node under my ear lobe. That one used to be painful if touched. Not now.

I'm enough of a pessimist about my own judgment to want to discredit these impressions. On the other hand, I am the best reporter of my own symptoms and changes in them.

But, here's the kicker . . . You all have been praying faithfully for me. I have been amongst you as a very interested party. I literally have skin in this game! What if our Father is answering those prayers in such an unexpected and surprising way? What if He's hearing your prayers and mine. If what I ask for is answered (or is being answered), and I am discounting those answers as the imaginations of desperate wish-fulfillment Would that not be truly wicked?

THINGS TO SAY TO GOD

Long ago, when studying prayer from the way the Psalmists did it, one of my seminary profs told me that there are only two ways you can say something to God – you can tell Him things, or you can ask Him for things. Thanksgiving is one of the things we can tell our Heavenly Father. Asking Him for guide me through this trial is what I am asking us all to do. Here's what I'm telling and asking our Father.

Prayers of thanksgiving:

- That I arrived on time through perilous traffic, through tedious intaking, through tedious wrangling with failed communications, and all the other folderol;
- that the Bigger BITE drug did not kill me, nor all of my T-cells;
- that the staff were sufficiently knowledgeable and skillful to arrest the rigors promptly;
- that I sitting here, clothed in my hispital gown, well fed and housed, feeling quite normal;
- And, especially, that I am encouraged by this very tactile evidence that the Bigger Bite drug is doing what it was designed to do – to kill the cancer cells quickly.

Prayers of Asking:

- That Barbara and I will successfully navigate this phase of therapy with the Bigger Bite drug, to the end that the cancer goes into remission again;
- that my oncologist is successful in deploying CAR-T therapy thereafter;
- that this strategy would place me into the very small group of people alive today who have been cured of CLL with Richter's Transformation;
- that cancer researchers would learn things through my therapy which will contribute to more cures in the future;
- that I and all of you who pray with me would grow spiritually through these days of prayer and watching how our Father in Heaven acknowledges to us what we ask Him to do. I admit freely that I have likely advanced in these ways far more in the past year than I had in the decade before them.

Much love in Him,

Fr. Bill Mouser