March 13, 2022

Dear Praying Family and Friends,

The next few updates are going to be more frequent, shorter, and likely contain a lot of medical information which may interest some of you and bore others. Things are moving fast, and I hope I can keep you up to speed on developments in the next month.

## **EXECUTIVE SUMMARY**

- Since we discovered on January 4 that the lymphoma had come back, a PET scan done four days ago shows dramatic enlargement of lymphoma sites observed in the January 11 PET scan. Increases in size range from 40 to 100 percent over the past two months. I now have an egg-shaped lump on the left side of my face adjacent to the ear.
- In two places (below right armpit, left side of face) the enlargement of lymph nodes is great enough that it triggers unpleasant results pain in right shoulder joint and vertigo from the facial node pressing on the ear canal.
- Lord willing, I'll enter the hospital on March 21 to commence therapy with a brand new immunotherapy drug (see below for how it works). Screening is still not complete nor are the results yet accepted by the drug company that sponsors the clinical trial; but, my oncologist is going the extra mile to get me admitted to hospital in eight days.
- Sometime this week (March 14-18), I'll have outpatient surgery to install an infusion port in my chest.

## A DRUG CALLED BITE and HOW IT WORKS

When the cancer reappeared in January, my oncologist outlined a plan of attack. He said, "First we'll hit it with BITE, and then CAR-T." It burns out that BITE is not yet approved for use in these situations - it's still in clinical trials. And, so, I began a screening process to learn if I were eligible to participate in a clinical trial of BITE.

I set myself to learning all about BITE via the professional medical journals published on the internet. What I found greatly encouraged me! Then I got an email the evening of March 7 telling me that I did NOT qualify for the BITE trial my oncologist had recommended. I was very disappointed!

The next day when conferring with my oncologist I said at one point, "Well, if BITE is off the table now, what sort of . . ." But, he interrupted me with, "We ARE going to use BITE."

"But, you said I was not eligible for the BITE trial!" I protested

"We ARE going to use BITE," he insisted. It's a different *form* of BITE than what I originally chose for you."

I was sort of gobsmacked, as you might imagine!

I had thought that BITE was the name of a *specific* immunotherapy drug, just as *Ford 150 Pickup* is the name of a specific vehicle. It turns out that BITE is the name of an entire universe of immunotherapy drugs (all of them experimental at this point), analogous to the word *cheese* which names an entire universe of coagulated casein from milk.

What a relief! Just part of the roller coaster, I suppose.

BITE is an acronym for *bi-specific T-cell engager*. I'm glad I don't have to come up with names for these things.

Here's how BITE drugs work:

- The BITE molecule is a kind of coupler. One end of it will attach to one of a patient's T-cells, the other end will attach to a cancer cell.
- Once the coupling has occurred, the T-cell will attack the cancer cell and kill it.
- When the cancer cell dies, the T-cell still attached to the BITE molecule will attach to another cancer cell and kill that one.
- This process can go on for several cycles before the T-Cell/BITE combo dissipates.

The BITE drug which they will use on me has the ability to attach to *six* cancer cells, Alternately, six of the BITE molecules can attach to one cancer cell. "In that case, it rips the cancer cell apart," my oncologist explained. "That's why we call this one 'the scorpion."

However . . .

This greatly upgraded, more powerful BITE molecule *has NOT been used in humans before.* After showing much promise in petri dishes and lab rats, it's time to see if it works in humans. I will be one of the 90 patients in North America and Europe to receive this drug. I will be given escalating doses in order to learn (1) if it is safe, and (2) what is the best dose for therapy.

## THE ROLLER COASTER

When I was a young man, I loved roller coasters! Now that I'm an old man (75th birthday on March 5; 41 years married last February 21), a tangible, material roller coaster is impossible to enjoy. I'm simply too frail because of those 75 birthdays!

Our Lord seems to think the opposite is true for Christians who have been in the faith most of their lives (in my case, for about 65 years). The "spiritual roller coasters" He calls old believers to ride are . . . well, sometimes each one gets wilder and wilder!

Recently, a correspondent sent me a quote she had run across from the letters of American novelist Flannery O'Connor. Flannery O'Connor quote:

A faith that just accepts is a child's faith and all right for children, but eventually you have to grow religiously as every other way, though some never do. What people don't realize is how much religion costs. They think faith is a big electric blanket, when of course it is the cross. It is much harder to believe than not to believe. [TheHabit of Being: Letters of Flannery O'Connor]

I am no expert at interpreting O'Connor's prose, but I am fairly sure that her use of the words *religion* and *religious* in that quote mean what most of you would mean by the phrases *Christian spirituality* or *Christian spiritual maturity*. Notice, for example, her virtual equation of *religion* and *faith* in the very next sentence.

What comes to mind first of all is our Lord's comment about the faith of small children (cf. Matthew 18:3-4; 19:4). But, O'Connor is not dismissing child-like faith! She agrees with our Lord that all spiritual life begins this way.

No, O'Connor points to things that are actually difficult to believe, when a believer is in the midst of a trial so big that his faith is challenged by it. *I am in that situation right now!* O'Connor reached the end of her life after seven years of suffering with lupus. Things which a child might easily believe because someone simply tells them its true become hard to believe for the more mature Christian who is facing difficult stress - ideas like "God is good" or "God is love" or "God loves *me*."

And, so, the spiritual teenager or spiritual young adult onders, and especially the spiritual oldster, are apt to find themselves wondering, "If I am God's child, why am I suffering from an incurable disease?" Or, "Why am I being eaten by lions in the middle of a Roman coliseum?"

My friends, if you have never faced such challenges, if you have *never* landed in a situation where *it is hard to believe that our Lord truly loves you* - then you have not yet arrived at the place St. Paul speaks about in Galatians 6:17 - "From now on let no one trouble me, for I bear in my body the marks of the Lord Jesus." Paul's confidence in the Lord arises from the scars Paul has acquired in his Lord's service, marks which are like the ones our Lord Himself bears in His own body *to this very day*.

Why does our Lord lead us into calamites, sometimes one calamity after another? He does this because He aims to **strengthen** our faith in Him, so that we can ride in the *front* car of a wild spiritual roller coaster **and take a nap**! Or, maybe, we can lie in the stern of a boat during a storm so strong that the boat may sink, **and we take a nap there** (cf. Mark 4:39-41).

After Jesus had dismissed the storm with a sharp rebuke, He turned to His disciples and said, "Why are you so fearful? *How is it that you have no faith?*" The Disciples were

freaked out by the storm on one hand and by our Lord's napping on the other hand. They freaked out because (according to our Lord's words) they had no faith in Him.

And, so, now you know something to pray about *for me* as this medical adventure continues- that my own faith in our Lord would grow stronger. It's not a trivial issue. Whatever else our Lord is doing through all this medical *sturm und drang*, He is most certainly working to strengthen my faith in Him. Please, pretty please with sugar on it, pray that He succeeds, that my faith in Him would grow.

## **UNFEIGNEDLY THANKFUL**

Now there's a phrase you don't hear often! That is, unless you worship in a church that uses the 1928 American *Book of Common Prayer* for its liturgy. Then you might hear the phrase every Sunday!

It's found in the concluding prayer in the "Order for Morning Prayer" (on page 19 if you have that Prayer Book):

We bless thee for our creation, preservation, and all the blessings of this life; but above all, for thine inestimable love in the redemption of the world by our Lord Jesus Christ; for the means of grace, and for the hope of glory. And, we beseech thee, **give us that due sense of all thy mercies**, **that our hearts may be unfeignedly thankful**; and that we show forth thy praise, not only with our lips, but in our lives, by giving up our selves to



thy service, and by walking before thee in holiness and righteousness all our days; through Jesus Christ our Lord, to whom, with thee and the Holy Ghost, be all honour and glory, world without end. Amen [emphasis supplied]

Among other things that I win through this trial is the granting of that prayer, a prayer I have prayed with my fellow Anglican Christians for decades.

My Bishop made a graphic based on that phrase. I have it printed on a 16x24 canvas, and

it will hang over my bed in the hospital. My hope is that it will lead to some spiritually productive conversations with the hospital staff who minister to me, who cannot avoid seeing it, and who likely have never heard or read that phrase in all their lives.

For, I am becoming unfeignedly thankful. I've a ways to go, but I'm on a path that arrives there.

Much love in Him,

Fr. Bill Mouser