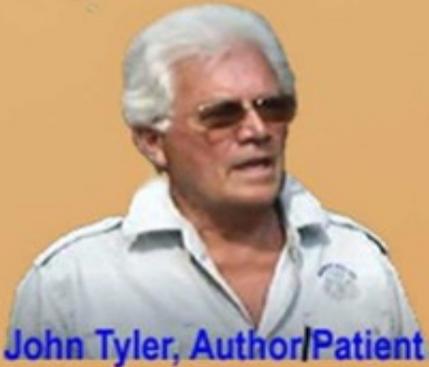


SO, YOU HAVE **CANCER...**
ME TOO!



John Tyler, Author/Patient



Take the journey with me
From **DIAGNOSIS**

UPDATED
ON
JANUARY
26TH
2024

TO REMISSION

BEFORE THE DIAGNOSIS

Life was good on October 1st of 2020... other than the horrible plague foisted upon the world known as Covid-19.

I was about to turn 77 on December 2nd, but was in great shape physically ... no maladies that I was aware of other than watery eyes for the last couple of years and a sore back now and then when I worked around the house fixing things.

On or about November 2nd, I noticed a small cyst of some sort between my right eye and nose. I could wiggle it around, so it wasn't a hard lump.

I did contact my primary physician On November 8th, I wrote this to my primary: - ***"Doc: - My right eye seems to be developing a cataract...blurry. Past 4 years and optometrists can't match a lens to it. Left clear with glasses. Not sure who to see and not sure if United Healthcare covers cataracts. Do you have any ideas?"*** - John Tyler"

She suggested that I put a warm-to-hot face cloth on it for about ten minutes a day. Why she suggested that is not known to me, but we all should follow our doctor's suggestions ... right?

I did that for two weeks, but thought it was time to see an eye guru....perhaps that doctor could tell me what this "small mass" that shouldn't be there was.

On November 16th, I sent my primary a photo of my two eyes and added what the problem was..which was the small cyst (about a quarter of an inch round-ish). Here's that photo....

This is what I wrote on the 16th:- ***"On our last visit, I was saying that my right eye is getting blurry and it waters all day long. I contacted an Opthamologist at Horizon Eye in Charlotte, but they can't see me until December 30th"*** ***"My problem is that the right eye seems to be closing up (see photo) and there's a hard lump where the tear duct should be. Compare with the left eye. Any advice on this physical anomaly?"*** - John Tyler

And, I attached this photo:



I pointed out (on the photo shown above) that my right eye was starting to close in and was not like my left eye. The left eye has a tear channel and it's kind of roundish, but in the right eye, that area was closing up - and starting to give me more of a blurred vision than normal.

Her response on the 17th was, ***"It could be a blocked tear duct. Apply warm compresses and see if the lump gets softer and the naturally resolves. - I put in a referral to see if you can get in sooner with another eye doctor."***

So, she decided to refer me out to a "specialist" at the Eye - Ear - Nose & Throat place in Charlotte, North Carolina.

I saw that Ophthalmologist on November 25th. What I got was an eye exam, but they never used the machine to calculate which prescription to issue. That ophthalmologist's notes seemed to cover their asses, but everything said here (underlined) is fabricated!

He wrote: "Concerned about lacrimal sac mass, needs oculoplastic consult -- Discussed the nature of the OCULOPLASTICS diagnosis, treatment options and prognosis. Explained that if intervention desired, requires consultation with an oculoplastics specialist. Patient elects to proceed with the plan as indicated. -- Discussed the nature of the diagnosis, risks, treatments and alternatives. Indicated that the prognosis as it relates to risks and results for treatment is the same regardless of the timing of the procedure at either an earlier or later stage in the process."

Answered all questions. *Patient elects upon a course of OBSERVATION at this time."*

No, I wanted to know why I had a cyst and what it could possibly be. Instead, I got a prescription for glasses and ordered them.

I threw the glasses away because they were worse than my former prescription!)

When I asked the questions (why I was there in the first place), about the cyst, The Opthamologist said, "*I recommend that you see an eye surgeon and he gave me the name of Katherine Orman, MD.*"

I did not use names of my primary physician or the Opthamologist because it sheds light on their seemingly low level of knowledge.

Dr. Orman, however, knew her stuff.

Note that there is **NO MENTION** of that referral, but there is his prescription. I called that EEN&T place a week later and said, "I would like to have an eye exam once my right eye is fixed."

The new script for the right lens was +50 magnification whereas the old prescription was +150. I wondered, "*How could my right eye need LESS magnification now than two years earlier!*"

THIS SPACE LEFT INTENTIONALLY BLANK

This was my old prescription:

Refraction

Wearing Rx

	Sphere	Cylinder	Axis
Right	+1.50	+0.50	157
Left	+1.50	+0.50	013

And this is the prescription I got - without the use of any eye exam equipment:

Final Rx

	Sphere	Cylinder	Axis
Right	+0.50	+1.25	012
Left	+1.75	+0.50	024

Pupillary Distance: 68.0

When I had my eyes tested for vision two years earlier, they used the following eye exam equipment, but not this time!

The non-use of the equipment for evaluation should have been used but wasn't. My prescription was worthless ... and so were the glasses I ordered using that prescription!



So, from my primary physician to the Ophthalmologist, I have learned that WE should insist on getting good information and good drugs that cure problems and not the ones that cause worse problems.

For example:

About two years ago, I developed a chronic cough.

My primary ordered a chest X-Ray - partly because I told her I hadn't had one in 30 years. I quit smoking on August 3, 1975, so I didn't think I would have lung problems, but the thought occurs to normal people like me....do I have some sort of lung cancer or maybe COPD?

The lung X-Ray was fine... clear, so I was happy with that, but still needed to know why I had the chronic cough!

The primary shipped me off to a "specialist" who deals with Eyes, Ears Nose & Throats.

He asked a few questions, and he deduced that I needed to have a full-on stress test and an ultrasound heart exam.

Oh yes... the co-pay was \$295.00 to get my heart tested using an ultrasound machine after toughing it out at age 76 on the treadmill!



During an ultrasound heart test, they put some sort of jelly on your skin above the heart and move that ultrasound wand over it while observing the arteries, valves etc. opening and closing.

The result of that was, *"Low risk of heart attack".*

The next thing that "specialist" did was order some nasal spray of some sort. I sprayed it into my nose - as directed, and about a week or so later... I developed nose bleeds!

I went back to this specialist for my next appointment and told him that I tossed the nasal spray because I didn't have the complication of nose bleeds before the prescription ... but did after.

I also said, *"I think I'm done here. You seem to keep wanting me to come back, and each time I do... it costs me co-pays and it costs my health insurance company big bucksand I still have the cough, so it appears to me that you are fishing for an answer."* Yes, it was brazen of me to say that, but it's true!

He said, *"You'll be back- I guarantee it."*

It wasn't until my eye problems that cropped up in November of 2020 that I found out how wrong that "specialist" was and how wrong my own primary was.

When I was getting ready to see Dr. Orman..the eye surgeon, her staff asked, during their usual inquiries about health, *"Do you still have the allergy to Lisinopril?"*

Lisinopril and Hydrochlorothiazide are two meds that are prescribed to reduce high blood pressure. I have been taking them since 2006 when I lived in Massachusetts. My primary in North Carolina continued prescribing them - even after I told her that I had the chronic cough two years earlier.

It is she who recommended that I see the "specialist" doctor that would refer me off for a heart test and nasal spray prescription. Dr. Orman's staff asked the question about an allergy to Lisinopril, I said, *"I don't have any allergies to Lisinopril."*

She then said, *"The side effect of taking Lisinopril is chronic cough!"*

I immediately thought, *"Why didn't my primary or her specialist know that?"*

The conclusion has to be... they DID know it and withheld it from me... or, they knew it, but enjoy make money for tests and office visits!

So, I went online to see what the side effects of Lisinopril are. had to see if what Dr. Orman's staff told me was true.

Here's what Google told me: **"One of the telltale adverse effects of ACE inhibitors, including lisinopril, is a chronic, hacking cough - a potential side effect that patients often don't hear about." - and, Productive cough is found among people who take Lisinopril, especially for people who are female, 60+ old , have been taking the drug for 2 - 5 years."**

What they failed to disclose has cost me many extra visits to "specialists" and many extra dollars for co-pays and medications that I didn't need... not to mention the vast sums of money they glean from Medicare and/or health insurers.

They also failed to tell me other things that I found online. Lisinopril (AND LOTS OF OTHER DRUGS) are not handled well by the kidneys!

Did you know that your chances of kidney disease increase every time you take a drug that is known to not be processed by the kidneys?

Here is what studying side effects of YOUR MEDICATIONS can do for you - and that is to give you knowledge that will help you to decide on taking that drug or not. or asking if there is an alternative drug to help your problem. **"A class of drugs well known for inducing dry coughs, a type of a cough that does not produce mucus, is called Angiotensin Converting Enzyme (ACE) inhibitors. Lisinopril is an example of an ACE inhibitor. - According to a study, about 5-35% of patients on ACE inhibitors are likely to come down with a dry, persistent cough which would be unresponsive to pharmacotherapy of any sort.**

Simply put, irrespective of whatever interventions you make, as long as you stay on that medication, chances are the cough would persist. - Though ACE inhibitors are in the forefront of causing a drug-induced dry cough, some other drugs can induce a cough. Nasal sprays containing Fluticasone, Simvastatin, and Carvedilol have also been reported to cause a dry cough."

And, **"Lisinopril and other ACE inhibitors prevent the degradation of bradykinin, a substance that lowers blood pressure, making it abundantly available.**

Bradykinin is known to cause the contraction of non vascular smooth muscle in the lungs."

What I discovered is that the kidneys reject these things called "bradykinins" ... (look at it like they are little particles rejected or not processed by the kidneys).

The kidneys reject bradykinins and release them into the body. The body says, **"I'm not accepting these things either, so send them up into the bronchial tubes in the lungs."**

The bronchial tubes try ejecting them, too, but that is where they stay. Rejecting bradykinins means the bronchial tubes go into spasms....and that's what causes the chronic cough!

If I now KNOW THIS, why didn't my "specialists" or primary physician know? If they don't know... it tells me they are either in the wrong profession - or they have limited knowledge. If they do know, it tells me that they are in the business of making money on patients like YOU and ME!

PASS THIS KIND OF INFORMATION ALONG TO YOU TO MAKE YOU AWARE THAT YOU NEED TO INVESTIGATE EVERY DRUG THAT IS PROPOSED BY SO-CALLED SPECIALISTS BEFORE ACCEPTING THEM.

Let me end this section by giving you two more examples:

When my back was bothering me, my primary ordered Prednisone from my online pharmacy.

I threw that drug away - and three others that she recommended for different maladies because the side effects were horrible — even dangerous.

In 2020, COVID-19 was (and still is) prevalent. Prednisone side effects include this: - "**Prednisone** is a **corticosteroid**. It prevents the release of substances in the body that cause inflammation. It **also suppresses the immune system**. Prednisone is used as an anti-inflammatory or an immunosuppressant medication. "

I contacted my primary and said, "***I am not using Prednisone because we live in a COVID-19 deadly disease world and to suppress my immune system could allow me to contract Covid.***"

I asked myself - once again - "***Why would a doctor order a drug that would compromise my immune system in a Covid 19-pandemic?***"

What might have happened to me if I did contract Covid as a result?

This is why YOU really need to pay attention and study things out BEFORE you take drugs that seem to be ordered willy-nilly.

Sure, my back spasms might have been better....but would I rather have back spasms every now and then - or Covid-19?

My primary also ordered an alternative to Lisinopril called **Losartan**. I contacted her to tell her I'm not taking that because Valsartan, according to the FDA, has a cancer-causing additive called NOMA.

HEADLINE: "***FDA Updates and Press Announcements on Angiotensin II Receptor Blocker (ARB) Recalls (Valsartan, Losartan, and Irbesartan)***" - because of the cancer-causing agent found in them." - ***In July 2018, valsartan was the first blood pressure drug recalled.***"

"Valsartan is a similar blood pressure medication to losartan. A recall on losartan medications soon followed. Manufacturers recalled hundreds of lots of generic losartan over the course of the next year."

"NDMA (n-nitrosodimethylamine) is the probable human carcinogen behind a number of recent drug recalls."

As of July 2020, NDMA has been found in blood pressure, heartburn, and diabetes medications. All unexpired drugs known to contain unsafe levels of NDMA have been recalled, but investigations into this issue are ongoing. "

So, I tossed that prescription and told the doc I needed to stick with the Lisinopril. .. which may be the lesser of two bad pills!

It's pretty bad when you realize that most of the pills doctors prescribe are actually harmful.

To quote from the Bible, **"We are given three score and ten years to live"** ...meaning 70 years on average. Doctors have allowed some of us to outlive 70 by many years - but eventually, our bodies pay for extending life. We end up dying from kidney disease or heart failure because pills have those side effects!

Watch TV ads for the myriad of new drugs that seem to come out weekly. They show a happy person frolicking in the garden or painting flowers in a field while they read, **"may cause kidney failure, heart attack - even death"**. For example - let's look at the **TRUVADA** medicine side effects:

Serious side effects of TRUVADA may also include:

Kidney problems, including kidney failure. Your healthcare provider should do blood and urine tests to check your kidneys before and during treatment with TRUVADA. If you develop kidney problems, your healthcare provider may tell you to stop taking TRUVADA.

Too much lactic acid in your blood (lactic acidosis), which is a serious but rare medical emergency that can lead to death. Tell your healthcare provider right away if you get these symptoms: weakness or being more tired than usual, unusual muscle pain, being short of breath or fast breathing" ...

... " stomach pain with nausea and vomiting, cold or blue hands and feet, feel dizzy or lightheaded, or a fast or abnormal heartbeat.

Severe liver problems, which in rare cases can lead to death. Tell your healthcare provider right away if you get these symptoms:

.....**skin or the white part of your eyes turns yellow, dark "tea-colored" urine, light-colored stools, loss of appetite for several days or longer, nausea, or stomach-area pain.**

Bone problems, including bone pain, softening, or thinning, which may

lead to fractures. Your healthcare provider may do tests to check your bones.

Common side effects in people taking TRUVADA for PrEP are headache, stomach-area (abdomen) pain, and decreased weight. Tell your healthcare provider if you have any side effects that bother you or do not go away.

So....educate yourself about what YOUR meds are and what the side effects are. Then have a consult with your doctor about what you find online - like Web MD or widely recognized medical websites and compare it with what your illness is and what, if anything, you can change.

In a chapter about what I am about to go through, I will show you what drugs are going to be in my chemotherapy cocktail and I will show you the good news - and the bad news (risks) that I will have to take if I want to get my cancer under control or in remission. - For now, however, I should get into what hit me once I got diagnosed with cancer.

Now, my second horror story with a doctor came about forty years ago when I was told to take a stress test on one of those treadmills, and then they put me into some sort of rotating machine. The technician said, "***I think you may have a problem, so I'm referring you to a heart specialist in Providence, Rhode Island.***" I lived across the border in Massachusetts then.

So, scared out of my mind, I saw the heart surgeon/specialist (unnamed), and he had nobody in his waiting room. I overheard him speaking to his secretary about taking his boat out for the weekend, and how his last boat payment was almost done.

He then approached me and said, "***Mr. Tyler, it appears - from your chart, that you have some heart difficulties. I propose that we get you into Merriam Hospital pronto, and I will open you up and insert anywhere from three to five stents.***"

Because it is my HEART - which I really depend on to live.....and because he said his boat payment (probably a yacht) was almost paid for, I said, "***I think I will get a second opinion, doc.***"

I set myself up to go into Boston where the finest of heart specialists are located. The heart surgeon there looked at the findings of the tech who did the stress test, and he said, "***There's NOTHING WRONG WITH YOUR HEART....you will live forever.***" **ALWAYS MAKE SURE YOU ARE SATISFIED WITH A DOCTOR'S DIAGNOSIS!**

THE DIAGNOSIS

Once I determined that putting a hot facecloth on my eye would not cure the obvious cyst or tumor or small mass growing between my right eye and my nose wasn't going to cure the situation, I decided to contact the eye surgeon. She needed to take a look at the cyst and surgically remove it.

So, my appointment to see Dr. Katherine Orman....the surgeon, happened to fall on my birthday - December 2nd. I arrived at her office... paid the \$30.00 co-fee and sat in a waiting area until one of her staff would come down to get me.

A staff lady entered the waiting room where I sat - along with maybe five other people, and she came in singing, "**Happy Birthday to You**"....and the rest of the waiting room cheered and laughed!

I already liked Dr. Orman based on her staff. How did this woman know it was my birthday... and why did she decide to sing to me out loud? Well, it's because Dr. Orman and her staff want to show their patients that all is well... no room for gloom and doom.

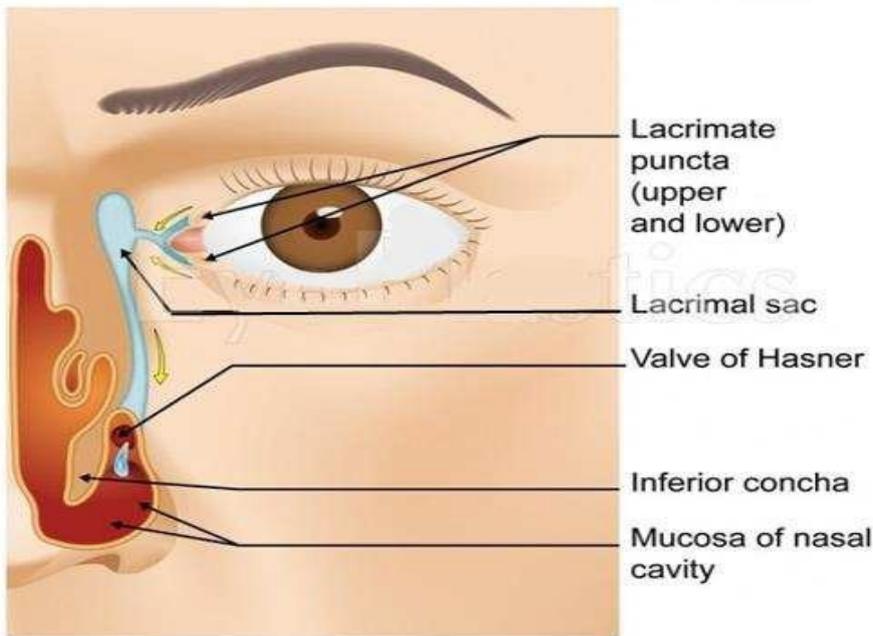
The doctor finally saw me after another staff member took my vitals and asked all of the Covid-19 questions ... like, "*Have you been tested for Covid-19*", etc.

She poked and prodded at the 1/4" round cyst and said, "***I'm going to run you upstairs to get a CT Scan so that I can see where this "mass" is located. I also want to see if it is liquid or solid, and if it has encroached into the nasal bone.***"

I had the CT Scan done and about an hour later, the doctor saw me again.

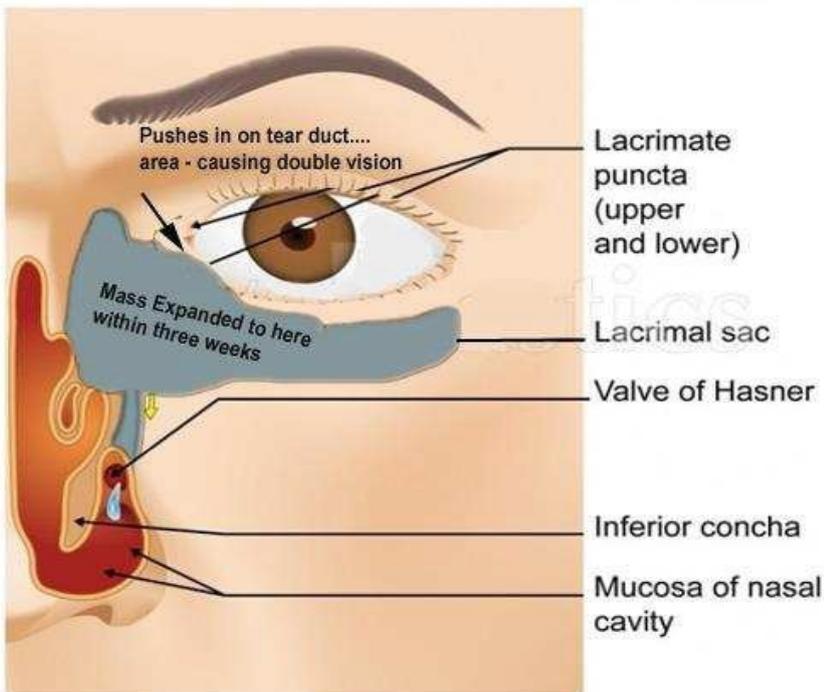
I was surprised (pleasantly) when she first told me that she was going to see this through that afternoon ... even if she had to shift other patients around. She wanted to see the CT Scan. She then showed me the X-RAY that painted the picture she needed. It was located in what is called the lacrimal duct, and it did not encroach the nasal bone. I gathered that if it was in the bone....that would not be a good sign.

The blue area is a normal lacrimal duct. Tears form in the left part of this right eye illustration and they travel through the lacrimal duct to the nose and out in the form of a drip.



But, when the lacrimal duct is blocked by the growth of a cyst, it prevents tears from flowing through it to the nose and the eye will water (like mine do)

When the cyst grows rapidly, it's a bad sign that perhaps an "aggressive large 8-cell non-Hodgkins lymphoma is the culprit. So, this is what happens when the cyst is lymphoma and it expands. The "mass" grows and pushed up toward the nose bone on the left and towards the tear discharge port in the eye... blocking tears from traveling through the duct, but it also (in my case) pushed upwards on the eye socket and closed part of my tear duct area. It then expanded like the next illustration.



Once my surgeon identified the cyst and its location, she said, I'm setting you up for surgery on December 23rd. She mentioned what she was planning to do.

She drew a line down the side of my nose where the cyst was and is....and said, I'm going to cut this line open and take out as much of that as I can, but I have to biopsy any material that I take out because if it's lymphomawe have to go a different route, but if it is benign, I will go back in and remove the rest. Before December 23rd, I paid the \$295.00 co-pay for the use of Presbyterian Hospital in Charlotte, North Carolina, and filled out online forms prior to the surgery.

When I finally arrived at Presbyterian, I was ushered into an area where they took vitals....then they told me they had a bed ready for me. I went behind a curtain where I was told to take off all of my clothes and put a hospital gown on - open in the back.

A nurse tucked me in and said, "When we wheel you to the operating room, we will put you out like a light with anesthesia." She installed an IV port in my left arm.

Once I hit the operating room, I don't remember a thing until I woke up in recovery about an hour and a half later.

I felt fine - but knew that I had surgery on my eye. The doc said, it'll be black and blue and swollen for about a week.

Let me show you what that looked like!



Cute, huh?

You can see the slit that was sewn shut and the puffed out black and blue area under the eye.

She wanted to see me again because - after the surgery, she said, "***I will not know what the results of the biopsy are until the 31st, but come to my office and we shall discuss options based on the pathology.***"

THE BAD NEWS!

Dr. Orman sat me down and said, **"Well, the pathology report says you do have a cancer known as "Non-Hodgkins aggressive B-Ce/1 Lymphoma."**

Of course, this was not the outcome that this religious man was praying for, but one has to face reality - even if the news is bad.

She did comfort me (and my son who was with me) when she told us that **"B-Ce/1 lymphoma can be treated and the outcomes are good."**

She also volunteered to say that she could not take the rest of the "mass" out because it is cancer, and that I would be seeing an oncologist who will be able to formulate a plan after he does lots of testing to get data. She referred me to one of the oncologists at Novant Health.....a large hospital conglomerate.

I met with the oncologist on January 4th, and he said that he was going to do blood tests that day in his office.....and those blood tests are specific to discover more about the lymphoma.

He said, I would then need to have a PET Scan... of my upper body to determine if the lymphoma has spread into the lymphatic system.

I would also be scheduled to have an MRI of my head only, and that is to determine far more than the CT Scan showed. It would see if the lymphoma went beyond the area in the tear duct of lacrimal duct.

He also told me that I would then be set up for chemotherapy and that requires having a "port" installed into my body.

I asked, **"Is this chemo an "R-CHOP" cocktail?"**

Before I saw him, I decided to find out for myself what the new chemo was all about, so I discovered all there was to know about **"R-CHOP"** - and I didn't like any of it! Let me show you why- **BECAUSE YOUR CANCER WILL BE TREATED THE SAME - "R-CHOP" AND MAYBE RADIATION.**

After reading all about "R-CHOP" and the five chemicals that go into the cocktail, I told the doc... **"I hope it's not "R-CHOP".**

He replied, **"Oh - it's "R-CHOP", and we've made strides using it."** - Here's what "R-CHOP" is:

"R-CHOP is a systemic treatment, which means that it spreads through the body. - R-CHOP kills cancer cells, and it is a standard treatment for some types of non-Hodgkin lymphoma (NHL), which accounts for about 4 percent of all cancers in the United States.

"R-CHOP" consists of five (5) different drugs."

- **(R)** rituximab (Rituxan)
 - **(C)** cyclophosphamide
 - **(H)** doxorubicin hydrochloride
 - **(O)** vincristine (Oncovin, Vincasar PFS)
 - **(P)** prednisolone
- Three of the drugs in R-CHOP attack cancerous cells. They work in different ways:*
- *Cyclophosphamide converts to metabolites in the liver. These bind to cancerous cells and interfere with their DNA. **This interference prevents the cancer cells from dividing, which stops the tumor from growing.***
 - *Doxorubicin hydrochloride is an enzyme blocker. Cancer cells rely on an enzyme called topoisomerase 2 to spread.*
 - *Blocking this enzyme slows or stops the growth and division of cancerous cells.*
 - *Vincristine is part of a group of drugs called vinca alkaloids. These drugs prevent cells from dividing, which slows or stops the growth of tumors.*

The other two R-CHOP drugs -rituximab and prednisolone - are not chemotherapy drugs."

What I did not like was the side effects of Cyclophosphamide and Doxorubicin hydrochloride!

From WEB MD - **"Heart problems, including heart failure, are possible risks for people being treated for non-Hodgkin's lymphoma. Two of the R-CHOP drugs -- cyclophosphamide and doxorubicin -- have been linked to problems in one of your heart's chambers. Any side effects are most likely to happen when you first start R-CHOP therapy."**

Yeah, so I was not happy about taking R-CHOP for my type of cancer.

CHOICES

I (and YOU) are faced with two choices when we are told, "**YOU HAVE CANCER**".

We can do nothing - and surely die from the cancer... or, we can try to save our life by going with the treatment plans that DO PUT PEOPLE INTO REMISSION - or cure.

I figured that I'm a dead man if I do nothing, and possibly a dead man if something goes wrong - like I have a heart attack from taking one of those five drugs. The thought also occurred to me that Prednisone diminishes our ability to fight off infections or diseaseslike Covid-19. It compromises our immune system.

So, the oncologist set me up for various pre-chemo diagnostics; the first would be a PET Scan....then there would be an Echocardiogram/Ultrasound to determine if my heart was sound enough to take the chemo and have a "Port" called a "Porta Cath" installed in my upper torso so they can take blood tests and do the chemo sessions.

The third set of data needed would come from an MRI from the neck up to have a more defined look at the lacrimal duct tumor to see if it is localizedor has it encroached into surrounding tissues....or behind the eye (not good)....or has it entered the nose bone....also not good.

Once the heart is sound, and the PET scan is done, the port is installed... it's chemo time!

I have to pause here to show you a photo of the enlargement of the cancer "mass".



Notice that the cancer has rapidly spread to the area highlighted in yellow... including pushing my right nasal cavity to a point of partially blocking it.

That was taken on January 7th. You might notice that the upper eyelid is also puffed out...likely from the pressure of the "mass" pushing everything upward.

And it closed up the tear duct (the almond shape the eye is supposed to be - like the left eye. (you are seeing this photo from a mirror shot, so things are reversed here.

I write this because I had to begin putting Vicks Vapor Rub under each nostril in order to sleep during the nights. That would fade at about a two-hour interval, so I had to get up and put more Vicks under my nose or nose breathing was difficult.

PET SCAN

Today is Monday, January 11, 2021 as I write about going to get a PET **SCAN**.

What happens is they bring you into an office where they take you vitals and tell you to go pee to empty your bladder. They install a small catheter into your vein (opposite the side of my eye lymphoma), and they take a sample out to test the glucose levels in the blood. Mine was 104. 104 is in range but in a "pre diabetic" range. I looked that up and discovered that I can correct that level of glucose by eating less sugar and less carbs....so maintaining a diet is what does it...and diet and exercise can also lower blood pressure.

Most Americans are OBESE ...or certainly heavier than we should be!

The next thing the PET Scan operator did was insert radioactive material into my vein catheter. This would circulate for one hour so that the PET Scan can see where all of the radioactive solution ends up ... from the head to the area just below the waist.

The length of time I was in the tube was 15 minutes, but the actual scan was only 45 seconds according to the tech.



This is the PET Scan tube.

After the PET Scan, I asked if the tech knew the results. He said, *"No, I'm the Scanner guy ... someone else reads the results."*

By the way, here is what the PET Scan is all about:

"A positron emission tomography (PET) scan is an imaging test that allows your doctor to check for diseases in your body. - The scan uses a special dye containing radioactive tracers. These tracers are either swallowed, inhaled, or injected into a vein in your arm depending on what part of the body is being examined. Certain organs and tissues then absorb the tracer.

When detected by a PET scanner, the tracers help your doctor to see how well your organs and tissues are working.

- The tracer will collect in areas of higher chemical activity, which is helpful because certain tissues of the body, and certain diseases, have a higher level of chemical activity.

These areas of disease will show up as bright spots on the PET scan."

So, now I wait to go to the hospital to get my EKG and to have my head examined! That is the HEAD MRI that I have to go through.

FYI - Every time I see some doctor - it's a \$30.00 co-pay. What a racket! Every time I have to use a fancy machine, it's a \$110.00 and hospital visits are a \$295.00 co-pay - so get used to shelling out thousands of out-of-pocket dollars for co-pays! So, this very afternoon - I got **GOOD NEWS** on the PET Scan!

"John, here is your PET result. There does not appear to be any evidence of disease outside of the known right eye region. I will forward this to Dr. Skarbnik. It looks like you see him in 2 days.." - Study Result - IMPRESSION: Right facial lesion is FDG avid with involvement of the orbit, nose, and nasal cavity, probably inferior turbinate. **No additional sites of disease are identified at this time".**

"The inferior turbinate is an elongated, almost tubular structure inside of the nose that is intended to humidify air as it passes through the nasal passageway." - This explains why I had difficulty nose breathing, and it will be important for you to remember this when I get into the chemo section of the book.

MRI & Echocardiogram Day

Today is Tuesday, January 12th, and I have to be at the hospital (30 miles away) by 8:30 AM for a 10:30 AM MRI. They made me fill out (yesterday) all of the questions they keep asking everywhere I go....even to them! And, of course, attached to the questionnaire is always the **co-pay bill** that must be paid prior to my getting the services that they will make thousands on!

The MRI of my head was uncomfortable but manageable.

The first thing the MRI people did was check my vitals, then they brought me into a change room where I slipped a hospital gown on, but they told me to leave my clothes on.

Why they do that is because once I was in the MRI tube (a shorter, fatter tube than the PET Scan tube), they raised my feet up onto a cushion, but asked me to lower my blue jeans down to my knees. The reason they did that is because we have a metal zipper in the jeans and a belt. So, once that was done, the tech put a plastic, slotted mask on my face, and clamped it down.

Here is what that mask looks like:



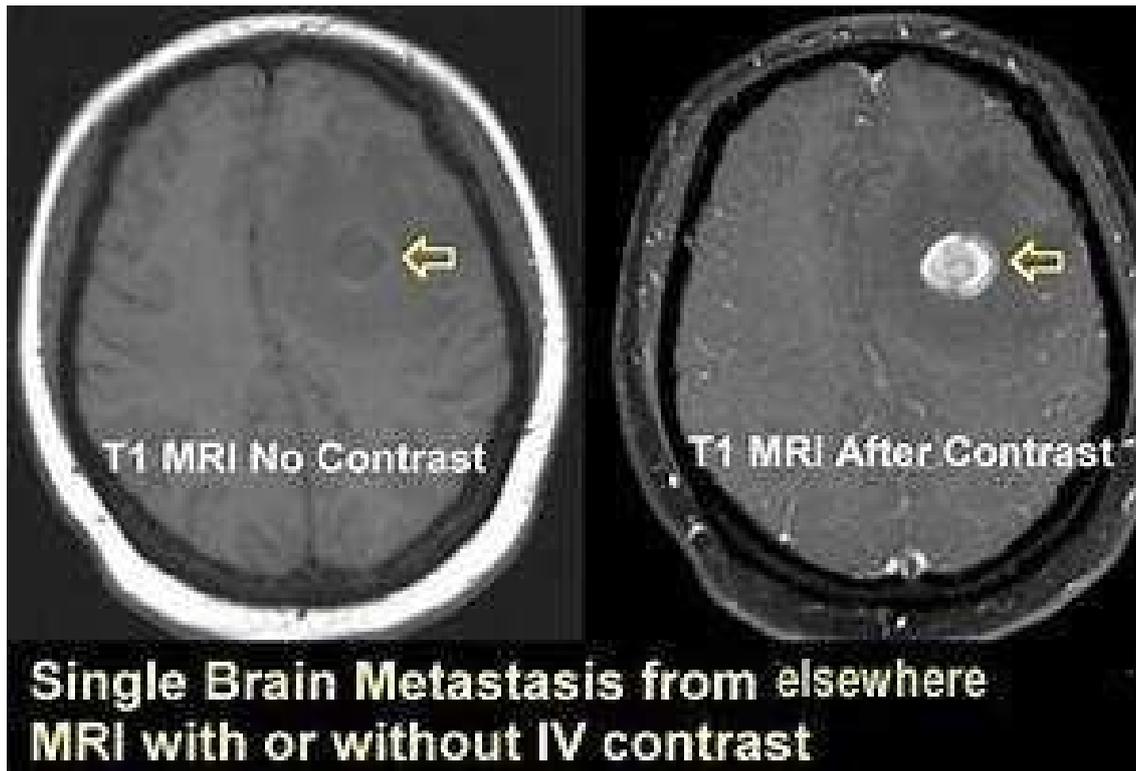
My mask did not have the plastic baggie in it! (This image is of a plastic dummy).

The technician also put a large, well insulated plastic headset on my ears... just before he closed the mask down. He asked if I would like to hear music. I said yes....country music is my choice.

Why YOU should ask for songs to be played is for the same reason I did. Yes, music would be a distraction from the noise, but I know that **many songs take three minutes to complete**, so I divided the half hour into segments of ten songs at three minutes ... so thirty minutes.

It seemed to help because as the first song played through, I knew that nine more songs and I'd be out for a few minutes while they injected the contrast dye. I figured the last fifteen minutes would be five songs. I ended up being right!

The contrast dye is to show up any abnormal tissue to the tech. For example.....



The technician told me that I would be in that tube for a half hour steady... and that I was not to move my head in any direction whatsoever so that the **Magnetic resonance imaging (MRI)** machine could successfully complete the testing. He then told me that I would be pulled out of the machine....and to still remain motionless, and a nurse would inject "contrast dye" into my veins.

So, the MRI is a machine that uses powerful magnets, radio waves, and a computer to make detailed pictures of the inside of your body. Your doctor can use this test to diagnose you or to see how well you've responded to treatment.

The machine started up with all kinds of whirring noises and grinding noises. **VERY LOUD!**

Once the MRI was done... I could leave... and go get some food.

My results that showed up in the **"MY CHART" system** that many hospitals use turned out to confirm what the PET Scan revealed ... the tumor is isolated to the lacrimal duct area. **"IMPRESSION: -Infiltrative mass** (I call it the tumor) **involving the inferomedial right orbit ethmoids, and right nasal cavity.** (right eye lacrimal duct area), **No intracranial extension."** (no encroachment into the rest of my head and brain.)

So, that was very good news for me and for my family and friends!

But... the scary part for me was coming the next morning.....the insertion of what is called the "PORT" or Porta catheter.

THE DREADED "PORT" SURGERY!

So, my scheduled operation to insert a porta catheter into my body was set for 10:30 AM on January 13th, but my instructions were to be at the hospital in Charlotte at 8:30 so they could do more blood work and prep me for the surgery.

They ushered me into a cubicle with a curtain around it and a bed and some machinery in it. This is the waiting area where the nurses come and take your vitals (again) and they insert a "butterfly needle" and it looks like this:



Porta catheter

"An implanted port (also called an implantable venous access port) is a common choice for people with cancer.

The port is placed under the skin of the chest or arm during surgery. With certain types of cancer, a port might be placed in the abdomen (belly) to allow medicine to be given into the area where a tumor is. It stays underneath your skin, but there will be a small bulge where the port is located. "...The port is a small drum made of plastic or metal, with a thin tube (called a line) going into a large vein. The drum is covered with a self-sealing membrane (called a septum) made of silicone.

To use the port, a nurse sticks special needle through the skin and into the port's septum. Ports can be removed when treatment is done, or they can be left in place for months or years." - SOURCE - [Cancer.org](https://www.cancer.org)

My port is the typical chest port. When the nurse was done, the physician who will do the actual surgery came to my cubicle and explained the procedure. Fortunately, I had read up on it from Google and understood all that he said.

The nurses would have me put on the backwards hospital gown, but I could wear my shoes, socks, and pants. They were working from the chest up.

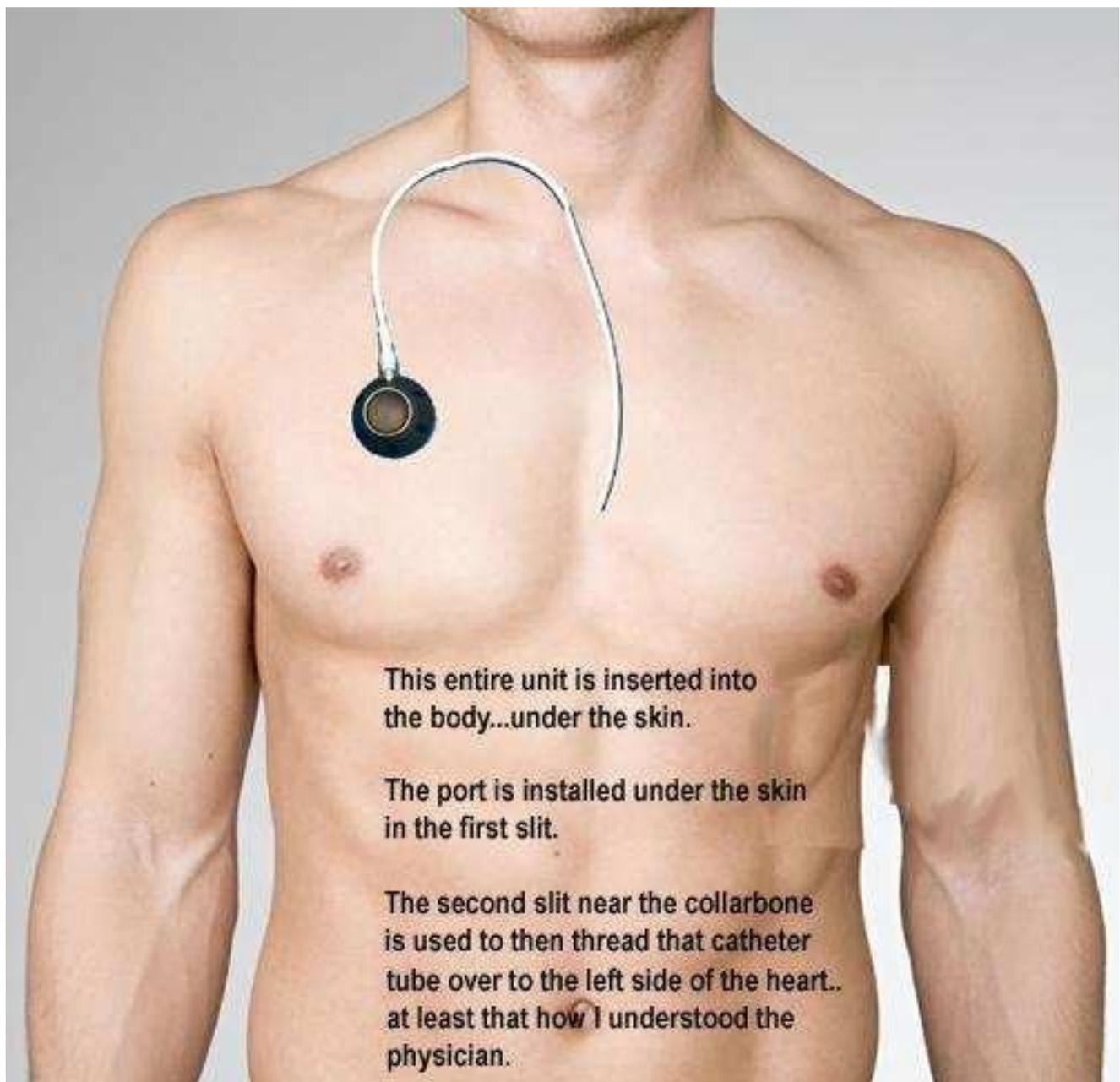
I would lay down on the operating bed, and the nurse would raise my feet with a cushion of some sort, and then the physician would raise the bed in the operating room.

There were three nurses assisting. One would inject my left arm "butterfly needle" with a medicine that would relax me. They gave me a list of those....and it included a pain med.

The physician doing the surgery would then use a wand to find the veins that he wanted to insert the catheter tube into from the port.

Let me get what that setup looks like for you.

Now, if I insert that over a torso....like mine, you can see how the physician would insert the port... and then he would feed the line up to another slit in the skin near the collarbone ... thread that over the collarbone and then thread the rest of the tube to a vein of their choice near the heart.



I was given local anesthesia. Then the nurses placed some sort of cloth over the area to be worked on while leaving an area open that they would insert the porta Gath. One nurse placed a big blue cloth over some X-Ray machine above my head and that prevented me from actually having to view their work. But I didn't feel a thing, so don't worry if you have to have this done.

So, here is what those two slits looked like once the porta catheter was installed inside of me.



Inside the hospital right after the surgery



I wore the tinted glasses because lights made my eyes water.



This photo was taken at home about six hours later. So, you can see where they inserted the port ... and you can see the second slit up at the collar bone . The physician threaded the catheter tubing (marked in **blue**) up to the second slit and over the collarboneand then from that slit the tube is threaded to some vein that the physician targeted to the left side of my heart. This photo was taken in a mirror so everything is reversed from what it really is.

I was then given instructions about the catheter, and how to shower and not get it wet for a couple of days. After those wounds heal, I can go about life as I always did with showering, etc.

The next step for me was to be the next morning. I was scheduled for my first dose of the chemo cocktail known as "R CHOP" on Friday, but tomorrow (January 14th), a nurse has set up a "tele video conference" with me to tell me all about the Chemo injection into the port. Someone I know told me all about it (not all of it made me happy), and what to look for and what to avoid. I can get into that after I have my chemo.

Meanwhile, I will try to tell you all about the tele video conference after it happens.

ONCOLOGIST'S VISIT

My chief oncologist met with me after the port was installed. He wanted to go over the **PLAN OF ACTION** with me now that he finally had the blood work, the PET Scan, the MRI and the Port information at hand.

He gave me (and my son, Jason was there to listen), some good thoughts. First, he said that all of the tests show that the cancer is currently isolated to the "mass" in the lacrimal duct area, so, to me, that news concluded what everyone else may have thought.

He also suggested that we will only try **three chemo sessions** ...one on Friday the 15th of January, and then the second twenty-one days later (February 5th) and the third would happen twenty-one days after that - (February 26th).

The good news was that he said, ***"the enlarged mass" would probably start shrinking within the first week of the first chemo injectionor session."***

The first chemo is monitored closely to see how I will react to the "cocktail" chemo drugs.

I was wondering if the chemo would actually shrink the rather large, growing mass... or would it just stop the growth and kill the cancer there. I wondered if surgery or radiation was in store later to remove the mass that was causing some irritation to my sinuses and definitely to my right eye....with the blurriness and the double vision. You won't have to wonder because I will be talking about that subject later in the book... as things unfold.

I have been watching TV with a pair of glasses that I used black vinyl tape to black out the right eye because the left eye was seeing clearly and the right eye was blurry. Wearing the black eye patch was awful! That led to "eye fatigue" to the point where I had to go to bed around 9:00 PM (instead of 11:30 like I always do).



Today is the day that all cancer patients dread....**CHEMO DAY!**

The dreaded possible side effects of the first round of chemo include: (MEN OR WOMEN)

- "You **usually lose all the hair on your head**. Hair in the eyebrows and other areas may also thin or fall out. The hair loss usually starts after the first or second cycle of chemotherapy, and it is almost always temporary in that the hair will grow back after chemotherapy ends.
- **Nausea and vomiting or feeling sick is common and may occur from immediately after treatment through three days after treatment.**
- **Constipation** may arise due to the vincristine as well as other medications that might be given for nausea and pain.
- **Mouth sores** may appear sometime after treatment, and this can make you more likely to get an infection in your mouth, so oral care is important. R-CHOP may affect your ability to become pregnant or father a child. "...
- "You may be more prone to infection during CHOP treatment, so try to avoid contact with people who have colds or the flu and to wash your hands frequently to help cut your risk of catching a virus or infection.
- (And we are in the pandemic season of COVID-19, so I plan NOT to go to any stores or mix with people other than immediate family - and even they may be subjected to the Covid-19 virus - and not know it.
- **R-CHOP can reduce the number of platelets that help the blood to clot**, so be sure to tell your doctor if you have any bruising or bleeding you can't explain.
- **Prednisone is a steroid and has many potential side effects, including mood swings, weight gain, and swelling."**

So, after reading about the side effects online, I was nervous about getting the side effect of **nausea and/or vomiting** because my brother Verne had multiple myeloma, a bone cancer, and it eventually killed him, but I was the one who brought him to all of his treatments. I saw him stop - just before going into the doctor's office and violently throw up in the hedges out front.

It was a horrible sight, and one that I can never forget, so I didn't want to be nauseated and then throw up immediately after. - Verne took a new drug back in the year of maybe 2009 called **Revlimid**. The side effect of Revlimid is definitely nausea. Multiple Myeloma is normally diagnosed at an advanced age (over 65 years) - Men are more likely than women to get multiple myeloma. - People of African American descent have twice the risk due to recently identified cytogenetic differences. How he discovered that he had this bone cancer was actually lucky... although he fell off a ladder while painting the outside of his ranch-style home.

When he hit the ground - on his back - he had a lot of pain. He went to the hospital and the X-Ray showed that his bones were brittle. The doctor described it as looking like Swiss cheese because his bones were porous... with tiny holes everywhere. "Bone cancer is rare, making up less than 1 percent of all cancers."

Remember: Verne had throat cancer 23 years earlier. He was given not long to live! He went through the old fashioned chemo treatments, radiation, and they took muscle out of his chest area to replace the tissue that they took from his throat area and lower jaw. He definitely should have quit smoking way early in life but smoked until the Week before he died.

He did not die from the first cancer years....and God gave him 23 years from then to quit smoking... but he kept smoking, and that led to the Multiple Myeloma ... bone cancer. He got an additional three years after that but died (I was there to see him go)... in March of 2011.

This was my handsome brother Verne - before the first cancer and while he was an Air Force Police Officer.



This is from somewhere on the Internet... ***"When we read about side-effects of chemotherapy, we must assume that all of the symptoms will hit us and will happen almost immediately."***

Another reason the infusion center nurses want to slowly inject all of the chemo meds is because a few of them can cause immediate reactions ... like "Myocardial damage (commonly known as a heart attack, occurs when blood flow decreases or stops to a part of the heart, causing damage to the heart muscle) can occur with DOXOrubicin hydrochloride with incidences from 1% to 20% for cumulative doses from 300 to 500 mg/m² when DOXOrubicin hydrochloride is administered every 3 weeks."

A healthcare professional will take a blood test before the treatment starts to ensure that the person is well enough to proceed. This is also why your oncologist orders an EKG, a PET Scan and/or an MRI and multiple blood tests BEFORE you get your first chemo series. My series are supposed to be the least - which is three sessions occurring 21 days apart.

Because my lymphoma is just under my right eye, and close to the brain, I will have to undergo a spinal infusion of chemo every two weeks after the regular chemo infusion.

A chemotherapy nurse will oversee the procedure. They will ask about any notable changes in the person's health. A cancer specialist should also be on hand to answer any questions.

A chemotherapy nurse usually gives the treatment through a line. There are three types of line:

- **Cannula** -a short, thin tube that the nurse puts into a vein on the arm or hand.
- **Central line** -a fine tube that enters a vein in the chest.
- **PICC line** -a thin line that goes in the arm and then into a vein in the chest. My chemo and blood testing are always done through the central line from the "port".

So, I arrived at the infusion center of the Novant Cancer Institute at about 9:30 AM on Friday, January 15th for my very first series (of three) of chemo.

The staff said the first chemotherapy takes the longest because they slowly inject the various meds because they want to check for any side effects listed above.

Here is what I looked like inside the Infusion Center....



They felt around the "Port" for three plastic bumps and the triangle orientation. This is for them to push a device with a line up to the various bags of medicines that they planned to slowly inject.



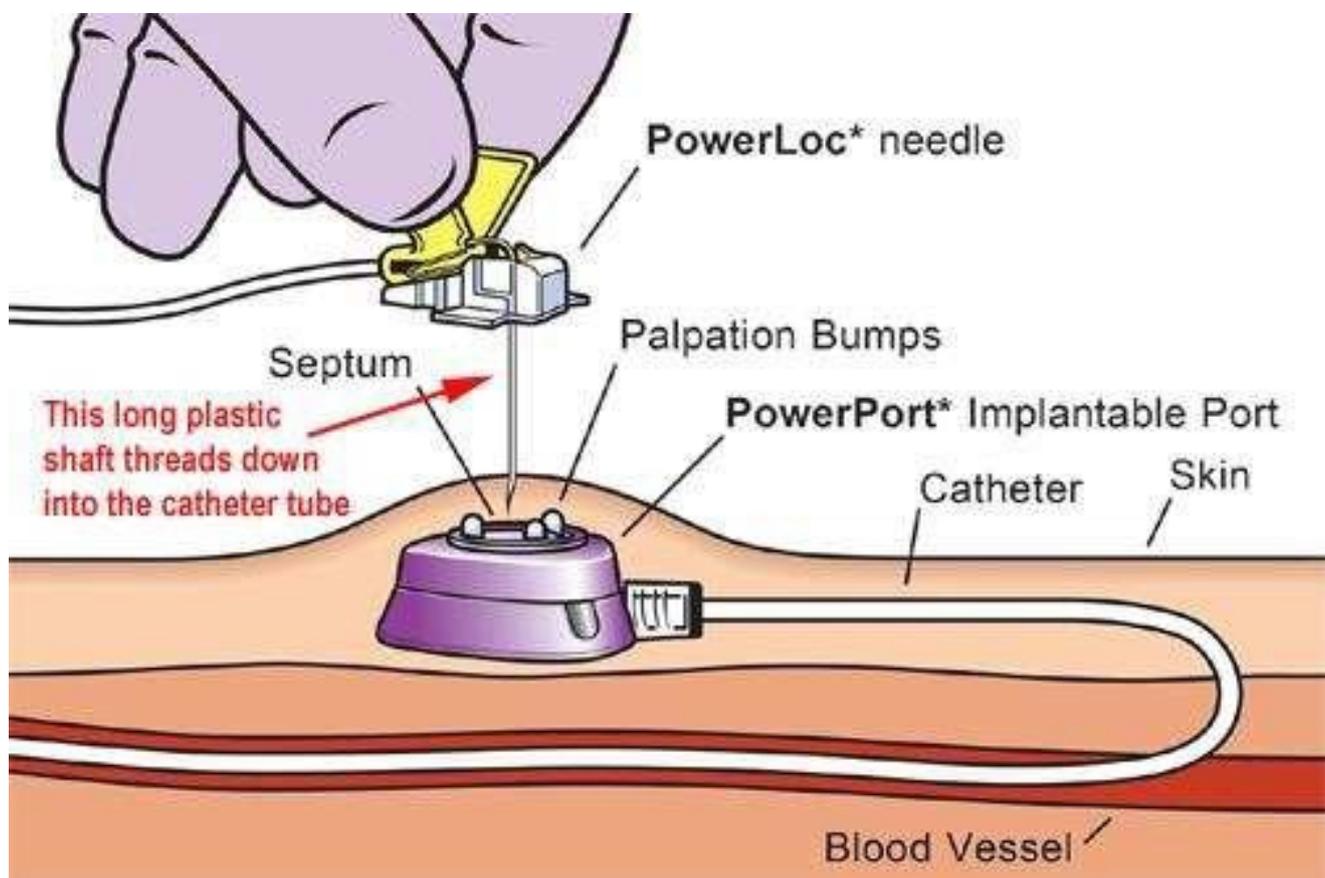
This is what the line looks like installed into the "port":

I was told by a friend who has gone through lymphoma and many rounds of chemo that it will hurt when the nurse inserts the port input device. **He was right - it did hurt** for about one second or two, but I now know what to expect during two more sessions, and it won't be as bad as I had imagined!

Why the sharp pinprick into the porta Cath hurts for a couple of seconds is better understood with a couple of photos.

This is what the device is that pushes down into the porta Cath and bends as led into the plastic catheter line that goes to a major artery to infuse the chemo meds or draw blood... and you will go through many blood tests.

It's that long plastic needle (like a wasp stinger) that the infusion center nurses have to push into the "port" and it travels into the guide that leads to the catheter tube....like so.....



Then, you sit back in the chair while they put bag after bag (small ones) into the feed line from the bags to the Power lock needle and port. For about the first three and a half hours, I got everything but the actual chemo cocktail.

The nurses actually have to wear heavy blue plastic gowns over their clothes to administer the chemo cocktail, and it is in a HUGE BAG. The chemo cocktail is in the huge bag for protection.

When I first saw the huge bag in the person's cubicle beside me, I said to the nurse, **"Are you kidding me? How do they get that much fluid into a person?"**

When they finally administered the chemo cocktail, it was after about four hours had elapsed, and it doesn't take that long to administer. -The cocktail is the brownish colored smaller bag inside the protective bag as shown below.....



The chemo transport bag was about 12" wide by 15" tall... VERY BIG, and it appeared to be full of fluids, but it was just air.

There was one drug that they had to inject into the port line and was red in color and there were two syringes half full of something. All the rest were drip method.

The nurse administering the red drug told me that it is called a "push drug" and I would likely observe pink pee for a while and that I might see pink sweat or tears.

About an hour after I got home, I did "whiz" into the toilet and the pee was definitely pink. They advise us of this so that we don't think we are somehow bleeding when we see pink urine.

SWEATING OUT THE AFTER EFFECTS

I have to admit... I was dwelling on the side effects until I went to sleep the night of the 15th. **"When will I get nauseated and puke my guts up? Will I get dizzy? Will I feel queasy? Will I have a heart attack at some point?"**

The oncologist prescribed many meds that I picked up from my local Walgreens drugstore. I got a bill for the meds of \$89.00. I asked, **"Doesn't my insurance cover these?"** (thinking \$89.00 was a lot of money). The lady at the prescription desk said, **"See the one that cost you \$43.00?"**

"Well, the Insurance Company paid \$349.00 of the \$392.00 for that one bottle of pills."

"Wow, I thoughtalthough I had to pay \$89.00, it looks like it has cost the insurer a whole bunch of money."

I have paid well in excess of \$1,000.00 in co-pays in about a month's time (as previously noted), but when I might have paid a \$30.00 co-pay, the insurer had to shell out \$1,900.00 to one oncologist!

I'm thinking that all of the tests, the machinery used, the professionals who are saving my life - and the hospital are going to be paid in excess of \$50,000.00 to save John Tyler's life.

That said, the website www.Costaide.com says, **"Apparently, there is no standard cost of chemo, but rough estimations can range from \$10,000 to \$200,000. The cost usually depends on the type of chemotherapy, the frequency and duration of the treatment, the drug doses administered and the institution where the procedure is performed."**

The [American Cancer Society](http://www.AmericanCancerSociety.org) also lists other expenses that cancer patients spend on, and these factors affect the overall cost as well."

So, it's a very expensive trip down Cancer Lane!

The day of the 15th slowly passed. I tried to stay occupied by typing some information out on the computer for this book or reworking my webs site at www.JohnTyler.com and my book site at www.RelationshipBooks.com where this book and eleven others are - and they are **FREE** to anyone who wishes to read or download them. I used to get up to \$30.00 for some books, but I read in the Bible, **"Buy wisdom, but do not sell it."** Proverbs 23:23 actually says, **"Buy the truth and do not sell it- wisdom, instruction and insight as well."** So, that is why I decided in 2018 to offer all of my books for **FREE** on that personal website of mine - and especially this one because - like some of the others, they are designed to help the next person who has to go through tough times.

As the day progressed, I took the pills that I was supposed to and when I was supposed to. That list is here:

LIST OF CANCER MEDICATIONS -AFTER CHEMO:

Ondansetron - 8 mg- One tablet per every 8 hours as needed - It is used to with other medications to prevent nausea and vomiting caused by cancer drug treatment (chemotherapy) and radiation therapy.

Valacyclovir 500 mg - 1 tablet TWICE PER DAY. 30-DAY SUPPLY -Used to prevent shingles and chickenpox from occurring during treatments.

Prednisone - 50 mg -Take two tablets every day. 5-DAY SUPPLY - Used to stimulate programmed cell death during chemo. Makes you hungry... causes MOOD SWINGS - ANGER at nothing! - Aches & pains all over happen for two days after the 5-day cycle is complete.

Loratadine (Claritin) - 10 mg - One tab every day for THREE DAYS after Neulasta. It is used to reduce bone pain, which is a very common side effect of Neulasta.

Prochlorperazine - 10 MG - One tab every 6 hours as needed - 30 Day Supply. It is used to control severe nausea and vomiting. Fortunately, I did not have to use the Prochlorperazine, but one other drug they prescribed was **Ondansetron** - used "as needed" to ward off nausea." This one is used every 6-hours - "as and if needed".

Just before I went to bed at about 11:30 PM, I took one of those - in case! I figured, *"Why wake up and puke in a bucket beside the bed?"*

THE FOLLOWING DAY AFTER CHEMO - ROUND ONE:

I was really surprised that I woke up on Saturday morning at about 8:30 AM and had no signs of nausea....and I didn't die in my sleep after all!

Here's why I wanted you to recall the section of the book where I mentioned nose-breathing was difficult and I had to use Vick's Vapor Rub under my nose to open the sinuses.

Well, the same night of the chemo ... I could breathe through my nose without the Vick's! The next day, the tumor had dwindled down to about a quarter of the size we saw in the first photo.

I contacted my son and other family members who would also like to know if I experienced any problems. They all worry about dad. It's got to be tough to watch your parents (or children) go through any medical trauma. My dad died at age 61 of a heart attack... his third. My mother died at age 87 from **Alzheimer's** and my brother Verne died of Multiple Myelomahe was 69 years old.

My father died from smoking Camel cigarettes at the rate of four packs a day. My brother Verne died because he smoked cigarettes - right up to one week before he died! My mother never smoked. I quit smoking cigarettes on August 3, 1975....forty-six (46) years ago!

So, I am now 16 years older than my father lived....8 years older than my brother and ten years younger than my mother!

Have you figured out yet that SMOKING will likely kill you?

As I'm finishing up this page in the book, it is 4:30 PM on the 16th of January and so far... I've been feeling good except for some light-headedness now and then.

I am to take my temperature and blood pressure daily to make sure the temp doesn't climb above 100.5 degrees and that my blood pressure is relatively stable.

Blood pressure (especially the Diastolic (lower) is supposed to be perfect if it is around 120/80. Mine just this moment is as shown:



The higher number (Systolic) 114 is actually GOOD. The Diastolic (lower number) is very good for someone my age.

Last night. ... and why I was a bit light-headed is that my Diastolic was 54.

Anytime the Diastolic gets down under 60, I (and you) will feel light-headed because the pressure is too low. When I stand from a lying or sitting position, I always take a few seconds to focus my eyes and wait until I stand. Standing abruptly really can get you dizzy!

So, I just took my temp again - to make sure it doesn't go above 100.5 degrees. They say that it could go there without a fever! Temp sits nicely at



97.4..

So, that's a wrap for Saturday, January 16th. Tomorrow is an injection of **NEULASTA**.

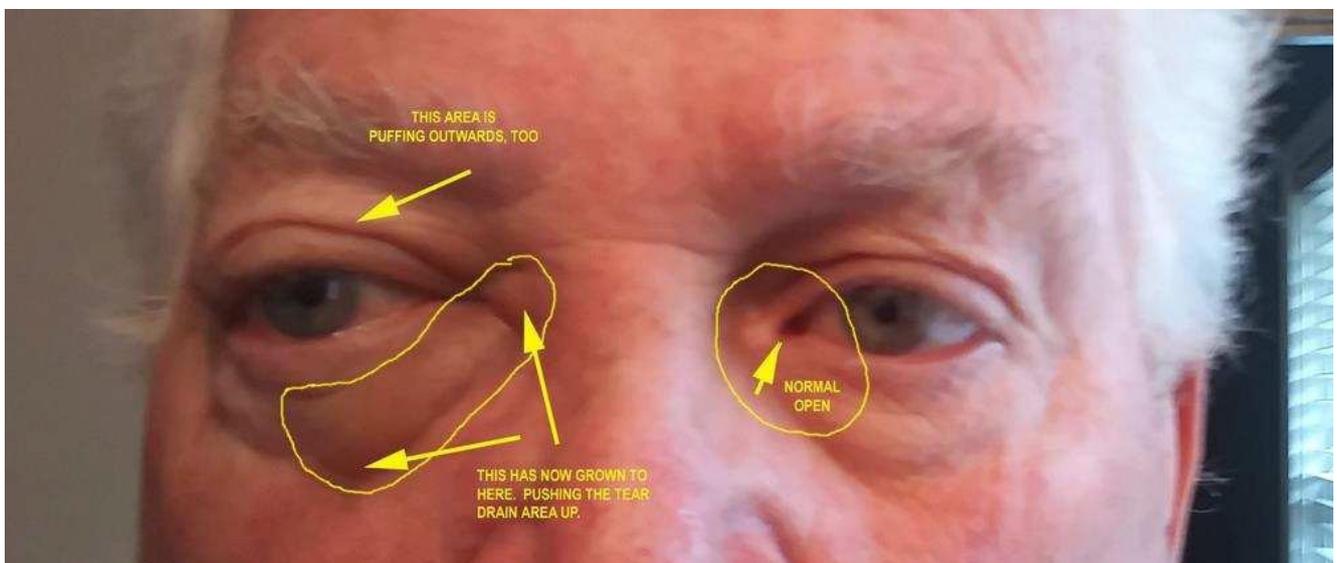
WHAT IS NEULASTA?

"Neulasta (pegfilgrastim) is a man-made form of a protein that stimulates the growth of **white blood cells** in your body. White blood cells help your body fight against infection.

Neulasta injection is a prescription medicine used to prevent neutropenia, a lack of certain white blood cells caused by receiving chemotherapy. - Neutrophils are made by stem cells in the bone marrow. Radiation can cause neutropenia by affecting the way bone marrow works and lowering the production of neutrophils. - **This is likely the come after the R-CHOP chemotherapy.**

So, I will let you know how the Neulasta injection goes tomorrow. My friend who went through chemo before said, ***"John ... pray that they give you Neulasta ...you will feel much better for a while."***

Now, before I visit the Neulasta injection at the Cancer Center in Charlotte, let me show you the remarkable difference in the photo of my right eye lymphoma mass on January 7th... to today... January 16th.



This is the huge "mass" from the tear duct drain area to under my eye as marked in yellow. When the "tumor" pushes up under the eye like that, it caused swelling above the eye and double vision... and blurriness.

When I photographed my eye tonight (Saturday, July 16th.....one day after Chemotherapy, I noticed a vast difference in the size of the mass. It was about the same smaller size as it was when I saw the surgeon on December 2nd. The double vision still exists, but not nearly as bad as it was on the 7th and before the chemo.



The swelling over the right eye (your left because it's a mirror shot) is down but under the eye.....look how small the "mass" has gotten. I don't know how it would shrink that much. I would never imagine that chemo would work that quickly, but there it is... the differences.

The "old guy bags" are about the same now under both eyes... so that comes with age - unfortunately.

It's now 8:00 PM on Saturday night as I write this section, and I am not fatigued. I did start feeling a tiny bit queasy at about 7PM, so I took one of the drugs (shown below) for nausea. Although I didn't have nausea, I was told to take one of these anti-nausea pills (as needed), and I took one.

Now at 8:00 PM, I'm fine no queasiness.

ONDANSETRON - "Take 1 tablet by mouth every 6 hours as needed for nausea."

This is the med I took:

I took one to ward of nausea last night, too....because I didn't want to wake up during the night (other than to pee — like old guys do)....and seemed to escape two full days now of no nausea. I would like to escape them all, but everyone tells me that I'm going to get nausea and vomit. We'll not look forward to that!



NEULASTA INJECTION - Day three after the chemo cocktail:

So, Sunday morning rolled around... three days after my first chemo experience, and my son drove me to the Novant Cancer Institute - 7th floor Infusion Center to arrive at 9:15 for the Neulasta.

We didn't know if it would be another 35-minute bag and port entry or an IV or shot.

Turns out that it was a shot....which is in their pharmacy and is kept refrigerated for reasons not known to me. I did find this out though: -"***Neulasta should be stored in the refrigerator at a temperature between 36- and 46-degrees Fahrenheit.***

Neulasta should not be exposed to light, so keep it in its carton until you are ready to use it. Neulasta should not be frozen, shaken or agitated."

The small amount of Neulasta was administered in a shot needle like this one...



The Infusion Room nurse said that it would just be stuck into the skin on the back of my arm (I chose right), and it would take two seconds and I'd be on my way. She was right!

She cautioned that Neulasta is going to rebuild white blood cells, but it does so in the bone marrow, so I MIGHT experience some "bone pain"... I guess much like when a kid gets growing

pains... but, it's now six hours later and I feel fine.

DAY FOUR AFTER CHEMO - SIDE EFFECTS:

Medical professionals say that we will likely experience some - or many of the side effects of chemotherapy - which include:

+ Increased risk of infection

+ Breathlessness and tiredness

+ Bruising and bleeding

+ Tiredness and weakness (fatigue)

+ Allergic reaction to rituximab

+ Feeling sick or being sick

+ Hair loss

+ Nerve problems

+ Periods stopping

+ Loss of fertility

+ Red or pink urine

+ Sore mouth

+ Skin changes

+ Indigestion

+ changes in blood sugar levels

+ Puffy face or ankles

+ Difficulty sleeping

+ Inflammation around the drip site

+ Runny nose

And, they give a list of occasional side effects of R-CHOP chemotherapy.

+ Allergic reaction to doxorubicin

+ Pain when passing urine

+ Taste changes

+ Nail changes

+ Changes to the heart muscle

+ Diarrhoea

+ Darker veins

+ Skin changes in areas treated with radiotherapy

So, given a huge list of possible side effects, I tended to pray that I would not see any of them....especially the nausea and vomiting!

I did experience the pink urine on the evening of the chemo, so I can check off that side effect.

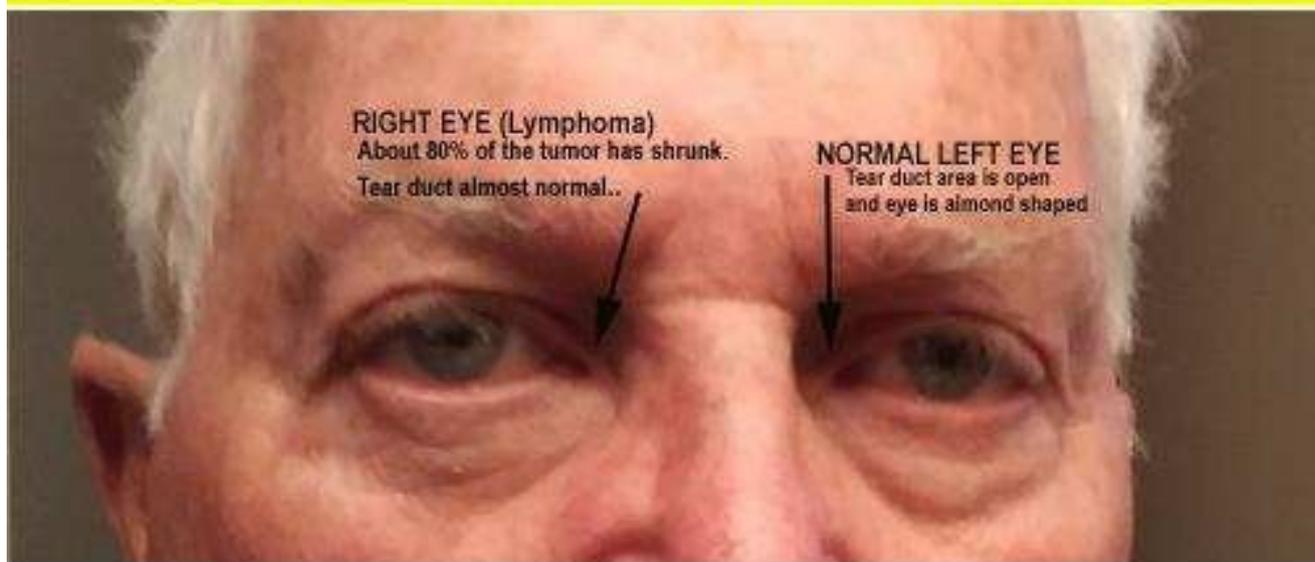
But, chemo day, then day two and three - I felt great! No nausea, no other symptoms or side effects.

Today- **Monday, January 18th** however, I woke up fine. In fact, my right eye is totally back to the same size and almond shape as the left eye has been. Take a look.....The top photo is before the R-CHOP chemo... the bottom photo is **today....DAY FOUR** after chemol

RIGHT EYE BEFORE THE CHEMOTHERAPY - taken January 7TH



RIGHT EYE - DAY FOUR AFTER CHEMO ...NEARLY AS NORMAL AS THE NORMAL LEFT EYE



I must add that the DOUBLE VISION that I have experienced since about December 2nd or before has gone as of today.

When I would wake up, and go into my bathroom, I would focus on the tile floor with the wood-grain look.

I focused on a knothole in the tile and would always see two of them... one above the other.

If I looked down into the sink, I saw two drains... one above the other.

Today, I saw only one knothole and one drain.

While driving, I used to look left to see if traffic was coming, and it strained my eyes to see left (or right) and I would see double then, too.

Today, I could see perfectly out to the left or right, so that was a huge upside blessing to me.

HOWEVER, I did start the day fine, but about 10:30 AM, I started to get a little bit light-headed. So, typically, I checked my temperature and blood pressure daily. My temperature range has been from 97.2 to 97.5 each day, and today was no different.

My blood pressure range (normally) would be 116 to 132 (Systolic) and 60's to 90's (Diastolic), but since the chemo, it has fluctuated. The Systolic range would be from 132 to 168 and the Diastolic would range from 54 (light-headedness) to above 60 (good).

After I take the prescribed daily meds, I would eat something so that my stomach wasn't just digesting pills! The Prednisone tabs (two a day for five days) taste HORRIBLE, so I usually washed my mouth out with a mix of baking soda and water after brushing to kill that taste.

My blood pressure this morning was 132 over 67, so the Diastolic was normal.

But, to ensure that I wasn't about to go into the nausea side effect, I took one of the anti-nausea pills available to me.

My son wanted to know if I wanted to walk today... about two miles, so I said I would - just to get fresh air and some exercise.

I drove to his house... no problem. We walked the two miles... no problem.

I got back to my house at about 12:00 noon....did a few things on the computer, and then went out to my living room... sort of getting tired or **FATIGUED** at the time. I sat in my recliner until about 1:00 PM, but the **FATIGUE** was starting to overwhelm me, so I decided to go into my room and take a nap. I woke up at 4:00 PM, but felt much better, so I recommend that you take a nap when you feel **FATIGUE** coming on.

I had no other side effects today, so I am feeling blessed about that. I **can check off **FATIGUE** on the side effects list!**

I'm told that if I can get through the first seven days or the first whole week of chemo, I should start feeling my normal self again, but I will let you know.

DAY FIVE AFTER CHEMO

Today is January 19th - my 5th day after chemo. I figured that I should update daily - at least for the first seven days because that's when the professionals say the side effects will happen.

So, I had a decent night's sleep and woke up at 9:00 AM - feeling pretty good. I took my regular Lisinopril and Hydrochlorothiazide tabs for my blood pressure and decided to delay taking the cancer pills until I had a very small bowl of cheerios to quell the horrible taste of the Prednisone tablets.

I always take my temperature and blood pressure and pulse because the medical staff told me to, so make sure you do that, too. They want to especially keep the temp below 100.5 degrees. So, I took a full shower this time... meaning I was afraid to irritate the port somehow, but I'm told that I could have done this earlier.

Then, I ate the cheerios ... saving a few to kill the taste of Prednisone and took the other two pills. The prednisone is only taken for five days - including the day of chemo, so that was the last of those until February 5th when I have to go through round two of three sessions of chemo.

At about 11:00, I took my blood pressure and it was fine at 133/61. My temp was 97.5 and my pulse was 96.

I also had two strips of bacon and one egg. I tried sipping coffee once again, but it is acidic, so about 10 minutes later, my stomach was a little painful as gas moved around in there.

I am feeling a bit queasy ... not nauseated, but I'd call it pre nausea, so I'm going to take one of the prescribed anti-nausea meds now.

They say that we might experience some sort of constipation, but that hasn't happened to me yet.

The better news of today is that the tumor in the lacrimal sac and sinus area has now dwindled down to a pinpoint at the top of the eyelid where there was a lump about the size of a green pea, and the large mass pre-chemo has dwindled down to about a ¼" in size, so surely the chemo is working.

I usually take a photo of the eyes for you to see what I see, and the progress that the chemo seems to be making with the tumor.

If you have multiple tumors, I'm sure the chemo works in the same way by shrinking them, so listen to your oncologist and follow what he or she tells you about their plan for a cure or certainly for remission.



The right eye is to your left (mirror shot), and - as you and I can see, both eyes seem totally normal with both tear duct areas open full and the almond shape is good with both eyes as is the upper eyelid. The right eye still has a little bit of black & blue area in the "baggie" area.

But - full face is smiling on the inside today!



You can still see the slice near the collar bone where they installed the port. It and the port slice are healing up nicely. The oncologist says that I will also have to do some radiation in that area after chemo.

Before that, and at two weeks after chemo, I have to have what is called an Epidural spinal injection with chemo. I'm told that this injection into the spine should prevent spread of the lymphoma into the spinal system including the brain.

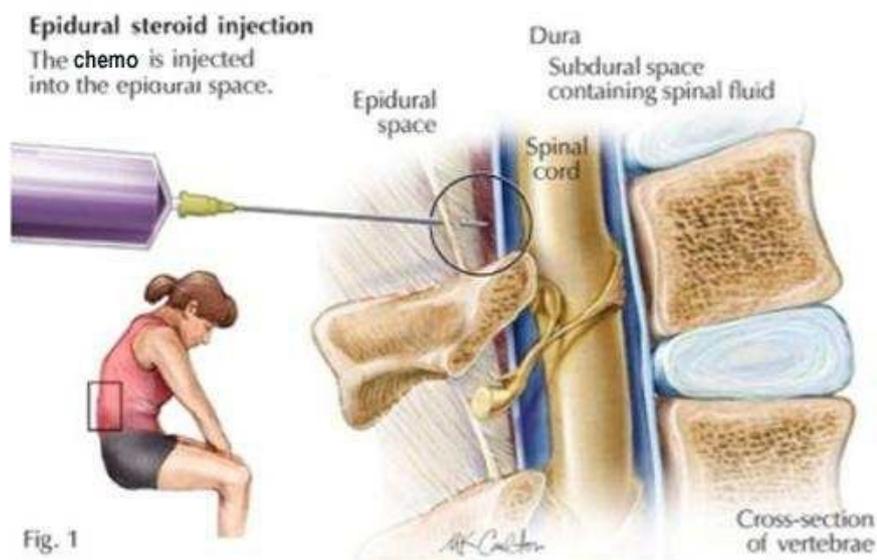
The tumor near the eye is just in front of and below the brain, so I guess it's a safety precaution. I'm told it will hurt a bit, but I have to do it... and that will come three times, too!

It will look like this:

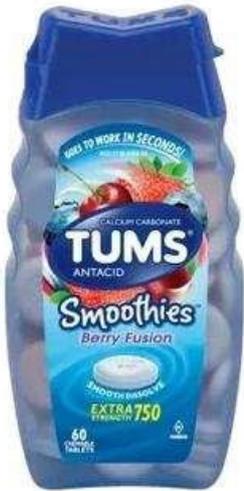


The physician punctures the spine bone in the back and I have to lay face down for about two hours (so I am told, but I'll follow up with the actuals later)... to allow for the chemo to take place.

Here is an illustration of where the epidural space is in the spine:



By the way, I took one TUMS "Smoothie" about an hour ago and it has calmed the gas rolling. I seem to like these over the harder TUMS tabs.



It's noon now and I'm still leaning a bit toward the FATIGUE side, so I'll just be relaxing today to minimize that side effect.

My next appointment is to get an evaluation from my Chief Oncologist on Wednesday, July 12th. I'll update then.

ONCOLOGIST REVIEW

(Wednesday - January 20th) Today is the anticipated day of getting some good news!

I saw the nurse who works for the Chief Oncologist today, and she drew blood again. This is to check to see that glucose levels and other levels are good, bad, or indifferent.

They did a neutrophils test. Segmented Neutrophils (Percent). The optimal result is 47-74%. My results are 85%, so higher than optimal, but I don't have a clue about what it means other than to define it.

"High neutrophil levels, also known as neutrophilia, are usually a sign that your body is fighting off an infection." And, "High neutrophil levels are usually harmless and will return to normal after you recover from the infection or injury or chemotherapy."

So, I was told that my white blood count would diminish with chemo, and it has.

Not worried about it - feeling 100% today.

The "Lymphocytes test" came in at 16%. The results are GOOD.

- "Your Lymphocytes value of 16 % is normal. A good Lymphocytes (Lymphs) is usually between 14 and 46 %. - [ONLINE SOURCE](#).

Neutrophils Absolute count 12.52 (thou/per mcl) normal is 1.90 -

7.20 thou/mcL... so they are high. Again, it's the expected white blood count levels. - *"If the test results indicate that there are more than 8000 neutrophils per mcl or 8.0 mcl,*

7.21

7.22 it means there are high levels of these white blood cells in an individual's body."

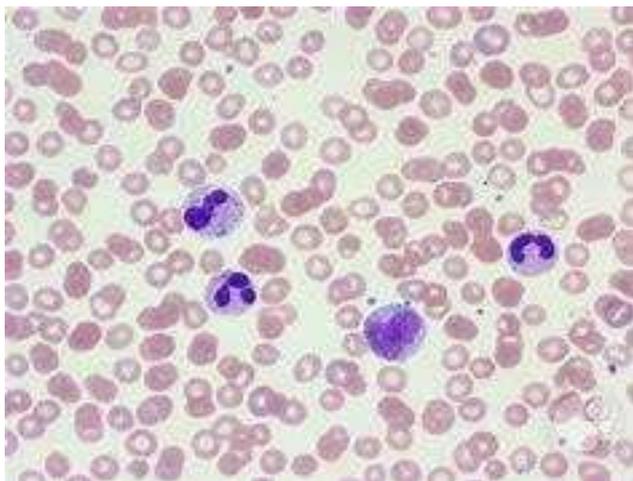
- ONLINE SOURCE-

Platelet Estimate - "Few Clumps Seen" RBC Morph -

"Normal"

Dohle Bodies - "Few"

So, Dohle bodies are really of no concern to me. They are parts of the neutrophils and if there are any, they show up as blue dots.



So, FEW are better than "MANY"!

Glucose and all other blood samples came back fine....and in the normal range.

Glucose was 140 before chemo. Today it is 89 mg/dl - NORMAL

The bilirubin counts are a tad high... Typically, bilirubin levels fall somewhere between 0.3 and 1.2 milligrams per deciliter (mg/dl). Anything above 1.2 mg/dl is usually considered high. Mine are at **1.50** mg/dl.

*Bilirubin - "Bilirubin is a waste product from the breakdown of old red blood cells. It is normally removed from the blood by the **liver**. Its presence in the urine may be a sign of liver disease. But it can be a sign of an infection, a kidney problem, certain medicines, or even heavy exercise. "*

*"Since blood cells, which are made in your bone marrow, also grow relatively rapidly, most chemotherapy drugs cause **a transient decrease in blood cell counts**. These drugs lower the white blood cell count to a greater degree than the counts of other blood cells - red blood cells and platelets -although these are commonly affected, too. "*

So, my Oncologist is not concerned because chemo is doing what it is supposed to be doing.

The Oncologist was happy with the results of the chemo so far - having been only six days since the first session of the chemo.

He noted how the tumor in the eye was basically shrunk down to nothing, and noted how there is now a good eye shape and that the chemo has eliminated the double vision altogether ... so all-in all, it was a good Oncologist Review.

It's nice to now be off for the next nine days - no meetings, no blood work, no chemo.....but I have to go get a lumbar spine injection of chemo on the 29th. Not looking forward to that, but like anything else....I have to keep my eye on the goal.....a cure from lymphoma cancer.

The Oncologist keeps using the word "CURE", rather than remission in my particular case, but I'm savvy enough to know that cancer - once in the body, can come back at a later date to haunt us!

HAIR LOSS?

I was told that in about ten days after my first chemo session, my hair would fall out. It's ten days today, and I still have a full head of hair.....BUT - it is going to fall out completely, and I have no choice about it!

So, I decided to reach out into the world of Google to find out WHEN this will happen. In most instances, it will take place in about 21 days after my first round of chemo, which puts the fallout date to about February 5th - which happens to be my second round of chemo date.

My sources at Google say that the hair gives a clue before it falls out, but when the first clue hits, it's gone in like two days! The clue is that on day one, the hair begins to fall out in clumps, and by day three - it's GONE!

So, what will baldness look like for me?

Well, I took a photo of me now... and then Photoshopped it to make me bald.



So, there I will be on or about the 5th of next month - IF WHAT THEY **SAY IS** TRUE!

I bought three hats, so I guess that's what men wear when they are bald and don't like it.

I'm told (by Dr. Google) that my hair would start growing back about three months to a year after my final chemo session, but that's why I write books... to document what reality is - FOR ME on my trip into "Cancer land."

SIDE EFFECT - ACID REFLUX

About a week after chemo, I am experiencing "*wicked acid reflux*"

KL used to occasionally get acid reflux and would take one of the turns tablets and it would go away, but this time, I experience acid reflux all the time... almost hourly!

So, I looked up if acid reflux was a side effect of chemotherapy and found this:

"Acid reflux-when stomach acid or bile flows up from the stomach into the esophagus, resulting in irritation-is a common digestive condition in general, but your risk of it goes up if you are receiving or have completed chemotherapy."

"The medications used in this form of cancer treatment are potent, as you've likely already discovered, and your gastrointestinal tract is not spared from related side effects. Acid reflux is one and may present with indigestion and heartburn.

These symptoms can flare after meals, during normal activity, or at night when you're to get much-needed rest. Though avoiding all side effects of chemotherapy is not possible, acid reflux is one that you can work to manage."

Why Chemotherapy Increases Reflux

"Acid reflux is common in patients Undergoing chemotherapy and after treatment has ended, and this has to do with how chemotherapy drugs work ... "Chemotherapy drugs target rapidly dividing cells." ..."The problem is that they cannot tell the difference between normal, rapidly dividing cells and cancer cells, so the drugs attack them all.

When follicle cells are affected, hair loss occurs. Suppressed bone marrow leads to blood disorders. Similarly, when cells in the lining of the gastrointestinal tract are damaged, corrosive stomach acid can flow into your esophagus instead of being carefully contained.

When such acid reflux episodes occur, chest pain and a burning feeling are common.² Other possible symptoms include a sore throat or lump in the throat, coughing, a sour or bitter taste in the mouth, difficulty swallowing, and asthma-like symptoms." - Well, that sounds ominous!

IS THERE A WAY AROUND ACID REFLUX?

What to Avoid

"Whether you're currently undergoing chemotherapy or you've completed your treatment and are experiencing acid reflux, it's a good idea to avoid the following to lessen the likelihood of experiencing discomfort.

- Drinking certain beverages, such as alcohol, **carbonated drinks**, **coffee**, or tea. **I cut out the red!**
- Eating foods that are hard to digest such as animal protein and dairy, especially late in the day
- Large meals **(I now do not eat large meals)**
- Lying down or bending over at the waist right a'ft:er a meal: When you feel the need to rest, be sure to prop your head up in bed or on the couch.
- Smoking
- Snacking close to bedtime **Wearing tight clothing or belts. Stopped that, too.**

So, I will see if the acid reflux subsides. I just looked this stuff up on January 25th.

So, the only thing I will continue to do is take the TUMS antacid tabs.

"Antacids function by neutralizing stomach acid. Despite the relative safety of their ingredients, antacids should not be taken in excess of the dosing recommendations on the label or with certain types of chemotherapy due to possible neutralizing effects on chemotherapy and other drug interactions.

Long-term use can result in potential adverse health outcomes."

My **TUMS "SMOOTHIES"** quell the antacid flare-ups... but for less than an hour, so I endure the reflux for as long as possible before taking another one.

The label tells me, "**DO NOT TAKE MORE THAN TEN (10) TABLETS IN A 24 HOUR PERIOD**".

And... **"DO NOT USE THE MAXIMUM DOSAGE FOR MORE THAN TWO WEEKS UNLESS ADVISED BY A DOCTOR."**

So, my oncologist does not yet know that I am experiencing this side effect of acid reflux. I will tell him when I see him on February 4th, 2021. What bothers me about any doctors is that they begin prescribing prescription drugs rather than Over The Counter (OTC) drugs, and prescription drugs have weird side effects of their own... like my Lisinopril!

I also looked up which drugs, if any, may interact with TUMS Smoothies. Lots of them do, but Hydrochlorothiazide and Lisinopril DO! So, I have to ask the oncologist who should know what to do to minimize the acid reflux for the next 90 days.

NEXT STOP is to have chemo injected into my spine on January 29th -stay tuned.

WHAT I'M TOLD BEFORE THE LUMBAR INJECTION - Google

WHY IS THIS NEEDED?

"Chemo is given to kill cancer cells in your cerebrospinal fluid (CSF). CSF is the fluid that surrounds your brain and spinal cord. IT chemo is also given to prevent cancer from spreading to your CSF from other places."

"A lumbar puncture is a procedure to inject chemo into your CSF. ([CSF](#) is a liquid found between the layers of your meninges- or In anatomy, the meninges are the three membranes that envelop the brain and spinal cord.) - It's made inside your brain and helps cushion your brain and spinal cord. The injection is usually given in your lower back. Before an injection, your healthcare provider will numb the area. He may also give you IV medicine to help you relax. He will insert a needle into the spaces between your spine (CSF) and inject the chemo. It may take 10 to 30 minutes to finish the injection. When the injection is done, he will remove the needle and cover the area with a bandage. You will need to lie flat for 30 to 60 minutes after the procedure. This will help the chemo travel throughout your CSF and kill cancer cells. It will also help prevent a headache."

So, my advance knowledge tells me that the injection into the spine won't hurt all that much. I have a fairly high pain tolerance anyway, but I will appreciate *the local anesthetic!*

THIS SECTION SHOULD HAVE BEEN FIRST!

MAKE SURE YOU HAVE GOOD HEALTH INSURANCE!

I have **United Healthcare Medicare Advantage**, and in 2021, they changed the rules so that every patient needs to know up front if cancers are covered ... and the medications that go along with treatment.

Here's what they said when I inquired as my 2020 plan flipped automatically to the

2021 plan.

"Advance notification is the first step in UnitedHealthcare's process to determine coverage for a member. Certain services and plans require advance notification so we can determine if they are medically necessary and covered by the member's plan. We also use the information you submit for case and condition management program referrals. The services that require advance notification are specified in the Plan Requirement documents below.

When you provide us with advance notification, we'll let you know if prior authorization is needed for the service to be covered. If prior authorization is required, we'll also tell you what information we need and help you work through the process.

It's very important that you follow all plan requirements so we can help you get claims paid. Missing requirements may result in claims being denied in whole or in part. If that's the case, the member cannot be billed for those denied services. "

The surgeon was paid in 2020 for the eye operation. I NEVER KNEW how much that little two hour surgery would cost until later... and I write about it later in the book!

In 2021, the oncologist, the hospitals (three of them on the same block in Charlotte - owned by Novant) must have written for pre authorization for their procedures including the PET Scan, the MRI, the Chemo, etc. and in two weeks, they had permission to go ahead with the treatments, and I would be responsible for co pays.

My co-pays are \$30.00 every time a doctor or oncologist is seen. The co-pay is \$110.00 for machines like the PET Scan and MRI to be used. I have to pay a \$295.00 co-pay any time that a hospital is utilized.....like for the eye surgery.

So, I have paid in excess of \$1200.00 in co-pays since December 2nd, and it's only January 26th 2021 now... so this is why I want to inform my readers who have to go through the cancer ordeals, to first make sure that your health insurance is going to cover your procedures.

Many times, some "out of network" anesthesiologist seems to come out of nowhere, and "SURPRISE", you get a huge bill that you didn't expect.

Prior to my December 23rd surgery, I was watching TV and heard about the "surprise billing" of someoneand it was an anesthesiologist that popped in on that "victim's" surgery.

I wrote to the Anesthesiologist and asked if my anesthesia would be covered by United Healthcare. United Healthcare dropped that anesthesiologist because

they charged too much money for services rendered, BUT - because I have United Healthcare Medicare Advantage plan... United Healthcare covered it.

Apparently, for those who are not Seniors, UHC dropped the coverage for those under 65.

I already said that my cancer treatments could run between

\$50,000 and \$200,000, so I'm grateful that I have had United Healthcare since I moved to North Carolina.

I used to have Blue Cross-Blue Shield in Massachusetts ..and then I had them when I first moved to North Carolina, but their rates were higher than a kite on a windy day, so I switched to UHC... saving \$159.00 a month in premiums.

Plus, I get eyeglass coverage, dental coverage for two cleanings and one X-Ray a year and \$50.00 every three months for medical items through Wal-Martand a free gym membership if I want one. BCBS (mostly BS) didn't cover any of those!

Now, Blue Cross is advertising about how dependable and economical they are in NC!

YOU WILL NEED SOME HELP!

I'm an independent cuss, and I usually don't ask anyone for help. I drive everywhere, mow my lawns on a rider, do my grocery shopping and fix stuff that might break around the house.

I built an electric fireplace in my house last year, and I ripped out a bathroom - down to the floor joists because the previous owner should have change the toilet seal ring... but didn't so water leaked and over the years, ate up the sub-floor!



That's the electric fireplace, the surround and Mantle that I built into the Living Room wall.

But, when you have cancer, the chemo and other related therapies WILL REQUIRE that someone drive you to and from the treatment.

The Cherne can have adverse side effects, so the oncologist wants someone to go with you to get you there... stay with your or nearby in case any side effects screw you up enough to where you can't drive.....and they want someone to drive me to and from the spinal injections ... and for the same reasons.

All the other appointments that I do - including the Neulasta injections....I now know I can drive myself there and back home

- no problem.

If after the second round of chemo, I find that I'm not nauseated, I believe I can drive to and from those session, but I'm not willing to gamble without going through one more session.

The spinal... not sure about that because my first one of those is on Friday, and I will likely need someone to drive me back home.

So, have a truly loyal person ready, willing, and able to drive you when you need it.

Fortunately, my son who lives close by has taken it upon himself to take me to and from those appointments requiring a driver. He worries about his dad's health, and he puts himself out there - even though it takes time from his job. He asks his boss if it's okay to drive his dad to chemo, and the boss says yes.

LACRIMAL SAC LYMPHOMA TREATMENT

What I found out about the non-Hodgkins lymphoma of the lacrimal sac (tear duct area of my right eye) is this: "*Tumors involving the naso***lacrimal** *drainage system are rare. Greater than 90% of these tumors are of epithelial origin. -* **Epithelial** *tissues are thin tissues that cover all the exposed surfaces of the body. They form the external* skin*, the inner lining of the mouth, digestive tract, secretory glands, the lining of hollow parts of every* organ *such as the* heart*, lungs,* **eyes***, ears, the urogenital tract, as well as the ventricular system of the* brain *and central canals of the spinal cord.*"

Only 16 of 212 lacrimal sac tumors described by Flanagan and Stokes were lymphoreticular tumors. They stated that lymphomas of the lacrimal sac commonly are associated with lymphatic leukemia. This is in agreement with the results reported by Stokes and Karesh et al, who described **lymphomatous lacrimal sac infiltration** *in patients with a systemic lymphatic neoplasm.*"

I do not have "lymphatic leukemia" as demonstrated in both my PET Scan and the MRI from the neck up.

"Primary non-Hodgkin's lymphoma (NHL) of the lacrimal sac is extremely uncommon. (Lucky me!) Therefore, the histologic and clinical features of primary lacrimal sac lymphoma are not well characterized."

In my case, the unifocal right lacrimal sac lymphoma was detected, and the lymphoma was classified as Stage IE using the Ann Arbor staging system.

The test case was of a 70-year-old woman in 1994, so this is old technology. - *"The patient then was admitted to the Department of Radiology for treatment. Radiotherapy was the primary mode of treatment. Four-megavolt linac X-rays were used with a single anterior port with a conventional fractionation schedule of 2.0 Gray (Gy) per day, 5 times per week. The total radiation dose was 50 Gy. After radiotherapy, systemic chemotherapy with three cycles of cyclophosphamide, doxorubicin, vincristine, and prednisone (CHOP) was proposed due to the intermediate-grade histology of the patient's lymphoma but she declined further chemotherapy after one cycle of CHOP."*

Since then, technology now uses **"R-CHOP"** ... a much better system of chemotherapy where "R" or **(R)** rituximab (Rituxan) is now used. - *"Rituximab is a type of antibody drug. It belongs to a class of drugs called targeted therapies.*

Rituximab attaches itself to cancerous cells, which it can trigger the body's immune system to attack."

Then, the **CHOP** part takes over where three of the four chemo drugs seek out those cancer cells and attack them. Other cells are also affected with the chemo cocktail. So, the much-improved chemotherapy of 2020-2021 is far more targeted and that's why the oncologist uses R-CHOP first - then, after chemo... comes the localized radiation therapya PET SCAN and then I should be cleared for takeoff!

BALD BY SUNDAY?

Well, the inevitable is upon me! Baldness definitely comes with chemo, and today... Friday January 29th is the day it starts!

Woke up this morning ... and the first bunch of things I do routinely is pull at my hair to see if any comes out. Yesterday... terrific... no hairs released. Today? Well, today was different - today a lot of hair came out - in small clumps.

If I yank on any of it today...it will come out!

Others who have gone before me say that the hair will clump on one day, and in two days- - - BALD!

So, the good side of that will be that I don't have to shampoo anymore ... and any dandruff problems disappearand I don't have to spend \$20.00 a month for haircuts for a while!

The other upside of this is now I know the chemo is working because when the R-CHOP chemo is injected, it targets and kills the cells with cancer attached ... and the first thing it does is go after the fast-growing cells....which starts with the hair.

MAYO - "Chemotherapy drugs are powerful medications that attack rapidly growing cancer cells. Unfortunately, these drugs also attack other rapidly growing cells in your body - including those in your hair roots."

The **MAYO CLINIC** SAYS, "*Hair usually begins falling out two to four weeks after you start treatment. - It could fall out very quickly in clumps or gradually" "You'll likely notice accumulations of loose hair on your pillow, in your hairbrush or comb, or in your sink or shower drain. Your scalp may feel tender."*

I told the lab tech yesterday that "my hair hurt". I'm guessing this is the "tender scalp" that **MAYO CLINIC** refers to.

Mayo goes on to tell me, "*Your hair loss will continue throughout your treatment and up to a few weeks afterward. Whether your hair thins or you become completely bald will depend on your treatment.*" - I will go bald!

MAYO CLINIC - "*People with cancer report hair loss as a distressing side effect of treatment. Each time you catch a glimpse of yourself in a mirror, your changed appearance is a reminder of your illness and everything you've experienced since your diagnosis.*"

However, I already expected it, and sort of welcome it for the above positive reasons, and because the sooner my treatments are over, the sooner I can get hair back!

I want to repeat that two or three days prior to the clumping, I experienced the feeling of mild scalp pain when I touched my hair.

I figure there must be a reason for "hair pain", and found this: - "***The occurrence of trichodynia in chemotherapy patients corresponded with the onset and duration of hair loss, thus suggesting a possible correlation.***" - "***Trichodynia manifests itself as pain and discomfort in the scalp and hair.***"

I write about his here in the book for the next male or female who will lose their hair through chemotherapy can KNOW about when it is going to happen... three days after "hair pain" I would like to have known this up front.!

The other thing I did not know would be the spinal shot in the back with chemo....so now I know because it just took place!

January 29th - Intrathecal Chemotherapy

Okay so "Intrathecal Chemotherapy" is the fancy way of saying....someone will be stabbing me in the back with a needle full of chemo.

"Intrathecal Chemotherapy is given to kill cancer cells in your cerebrospinal fluid (CSF). CSF is the fluid that surrounds your brain and spinal cord. IT chemo is also given to prevent cancer from spreading to your CSF from other places."

Google says the wrong thing here - *"A lumbar puncture is a procedure to inject chemo into your CSF. The injection is usually given in your lower back. Before an LP, your healthcare provider will numb the area. He may also give you IV medicine to help you relax. He will insert a needle into the spaces between your spine (CSF) and inject the chemo. It may take **10 to 30 minutes to finish the injection.** When the injection is done, he will remove the needle and cover the area with a bandage. You will need to lie flat for 30 to 60 minutes after the procedure. This will help the chemo travel throughout your CSF and kill cancer cells. It will also help prevent a headache."*

The injection was a tiny bit painful as they inserted the needle, but it's going into bone, so it is what it is, but lasts only about three seconds. It took **30 seconds** (not minutes) to inject the chemo into the little catheter into the spine.

After that, they told me to stay in the giant injection bed for one full hour....and I could lay on my back or side - BUT to keep my head low.

Just so nobody is shocked, let's throw up the photo I took of inside my injection room. Oh, by the way... another \$195.00 co pay!



Yup, there is where I laid by head down on the pillow toward the two computer screens with my name on it. The thing above and to the right is the X-RAY (I must glow in the dark by now!)... that the doctor uses to see into my back to locate the exact point of spine entry. Once he found the spot.....STAB!

Wasn't bad, and I had no side effect, but the reason they want us to lay down for one hour is to make sure there are no adverse signs. Some (less than 1%), have experienced some adverse side effects (immediately).

I guess this photo below might illustrate what an epidural spine injection looks like. I'm told that the puncture hurts when they stick that epidural sized needle into your back!



So, to sum up the epidural spine injection - it's no big deal!

I have two more chemo sessions (four hours each) followed by two more Neulasta injections two days after those (10 minutes and I'm out)... and two more spinal injections two weeks after the chemo sessions of February 5th and 26th.

I plan to tell the oncologist that if he has to do radiation after that....fine, but I want (as I said earlier) to have a PET Scan and that is what releases me from all further treatment.

I will likely have to go back for blood tests for at least the next two years to make sure that there are no signs of the lymphoma.

Each visit....to remind you... is \$30.00 from Insurance with United Healthcare\$110.00 for anything that involves certain

machineslike the MRI and PET Scan, \$195.00 for this machine above.....so....lots of money up front. Make sure you budget for up to \$3,600 for co-pays.

I don't really know what I have spent because last year I spent a bunch....including the hospital eye surgery and co=pays to see this guy or that guy....but 2021 arrived and I started again without-of pocket costs.

My United Healthcare Plan charges an annual maximum out-of pocket of \$3,600.00, so once I reach that... and likely will, I am not charged a dime for any further out-of-pocket expenses.

SUNDAY HAIR SCARE?

NOPE! Although I was told that - once my hair started coming out in clumps (last Friday), by Sunday I would or should be totally bald... like an egg!

Well, today is Monday....but about 90% of my hair has "gone with the wind". It's a bit of trauma psychologically but expected.

So, here's the hair scare as of Monday February 2nd.



It starts above your eyebrows and creeps further back each day... The sides and back still go, but those areas are mostly intact. .. for the moment.



The cure for no hair....a hat!

And, that's how we bald eagles roll!

My next event is to see the oncologist on Thursday, February 3rd. He will have reviewed all of the internal data - blood tests and others... and he will evaluate and say that all is well.

I fee great. .. probably because the chemo goes away in three days, and my body must be building up anti-bodies to go to work on the 2nd of three chemo sessions. The next comes up on Friday, February 5th.

I'm not anxious about having them stick that butterfly gizmo into the port because it's painful when they do, but fortunately ... it only lasts for a few seconds. But I feel that if I could handle the first well....the next should be okay.

I'll probably experience the fatigue again - around the 3rd day, but hopefully no nausea. Then it's off to get the Neulasta shot on Sunday - a five second deal. Then I will take pills to prevent bone pain from the Neulasta for three days. I do have a few leg or arm muscle cramps but it's toward the next chemo cycle. So, I had to look it up to see if chemo is the culprit behind the cramping.

Here's what Dr. Google has to say: *"Certain types of chemotherapy affect the small sensory nerves in the feet and hands, causing symptoms such as numbness, tingling, and pain in fingers and toes. Treatment with chemotherapy can also result in weakness, **muscle cramps, and muscle fatigue.**"*

I avoided all the other symptoms listed above except the cramps — which I really call muscle fatigue.....soreness.

Good thing you are reading this book because I have the immediate cure for those pain areas.....and I used to use this stuff after a hard day's work using muscles.

It's called "**MUSCLE RUB**" (by ASSURED) - and guess what? You buy it at Dollar Tree stores for a buck!

Rub it onto the area that is sore or cramping and..honestly - it goes away almost in a minute or two and doesn't flare up.

Here's a picture of that stuff.



I splurgedI bought three for \$3.00!

You just need to rub it on..not thick....and the cramp or soreness disappears.

COMPILCATION ON DAY 19 AFTER FIRST CHEMO?

Not sure what happened exactly on the 16th day after my first chemo session, but I'll know tomorrow when I go to Novant Health Hospital in Matthews, North Carolina.

It started on the 16th. When I cough or swallow, it puts some pressure on my jugular vein area. That's where, if you recall, the Porta catheter is installed.

By the 2nd of Februaryday 18 after chemo, I decided to take a closer look at the area because my jugular actually was getting some sensitivity (mild pain), and the area around it began to be sensitive to the touch. This has not happened up until the 1st day of February.

So, I took a photo of the area and sent it to the oncologist last night.

As it turned out, I'm so glad that I did this because had I not done it, I might be dead in a week!

You must bring any weird things to the oncologist's attention because they are not there with you... only YOU know your own body, so pay attention to things that don't look or feel right.

Rememberthe small cyst in the tear duct was something that I could not let slide!
Good thing!



I Told the oncologist - via my online chart, that the jugular (yellow line) was sore... and that the area shown was swollen... as you are seeing what he saw.

The next morning, I got a call to come in and see him. My regular appointment was for tomorrow, so apparently, he thought it needed to be looked at.

I went in to see his **Nurse Practitioner** today (February 3rd) and the nurse looked me over - poked around - prodded - took some other vital signs, asked if I had a fever, etc.

She then wanted to schedule me in for a dye injected ultrasound so they could look inside of the Port and around that area.

"A nurse practitioner is an advanced practice registered nurse and a type of mid-level practitioner. NPs are trained to assess patient needs, order and interpret diagnostic and laboratory tests."

I always look up what I'm going to expect, so here's what I found.

"One might need contrast when one is having an X-ray, CT, MRI, or **ultrasound exam."**

And, - "Contrast is important because it helps radiologists distinguish between normal and abnormal conditions. This helps them to see what's going on inside of you better. In turn, this allows them to make a more accurate diagnosis, and recommend the best treatment for your specific case. In cases where it is needed, contrast ultimately leads to better care."

So, I will let you know what the results are tomorrow. I did NOT want to go into my next (2nd of three) chemo sessions with a bad port... and infected port, and infected area, a port that is not sanitized via saline solution and/or heparin.

I suspect there might be a "thrombosis" of the jugular - maybe due to the catheter under my skin shifting or migrating, but I hope it is not so!

"Thrombosis (meaning blockage) of the internal jugular (IJ) is a **rare but under-diagnosed condition. Jugular vein thrombosis is most commonly caused by cancer or from a central venous catheter, Thrombosis of the internal jugular vein can occur as a result of complications of head and neck infections, or sometimes related to surgeries or central venous access.**"

So, tomorrow we shall know!

HAIR THINNING!

Meanwhile, the head of hair I used to have about a week ago (comparison photos) is now about 95% gone.



From lots of nice white hair for my Facebook Profile picture.....to.....



Fuzzy Wuzzy on February 3rd!

Oh well, the good news is that the hair will come back for me while otherswho are bald by heredity... not so much.

SO - A BIT MORE BAD NEWS!

I seem to get the "rare" things happening! First, it is considered "very rare" to have a lymphoma in the lacrimal sac (tear duct) area.

Today, when I went to have the port checked because I experienced a soreness around the right jugular vein, and the port checked out fine. The ultrasound didn't. Turns out, I have an internal jugular clot.

"Internal jugular vein thrombosis refers to an intraluminal thrombus (clot) occurring anywhere from the intracranial internal jugular vein to the junction of the internal jugular and sub-clavian vein. It is a rare vascular disease.

The so-called disease isn't really a disease. When they install porta catheters, the catheter tube can cause a blood clot in the inner jugular - which it did.

The oncologist said, ***"still come in tomorrow for the second series of chemo, and I'm ordering Xarelto that should thin the blood to where the clot will dissipate over time."***

"Xarelto is a new generation of anticoagulants known as deep thrombin inhibitors which helps prevent clots that could cause pulmonary embolisms or deep vein thrombosis"

Of course, with any drug, there are side effects.

e"However, like the drug Pradaxa, Xarelto is known to have several side effects, including the formation of blood clots. - and, in general, blood clots can still form if people have diseases which tend to cause blood to clot, such as cancer."

So, it's a double whammy! I'm experiencing the problems of having to go through chemo, getting chemo injections into my spine, and now having a blood clot in the worst place possible

the inner jugular vein.

If the clot dislodges there, in the Internal jugular vein, which is the deeper of the two jugular veins in the neck that drain blood from the head, brain, face and neck and convey it toward the heart, then perhaps I see the good Lord sooner.

The doctor that did the ultrasound today had this to say: ***"IMPRESSION: Dedicated ultrasound evaluation of the right neck. Swelling. - Dedicated scanning of the region of interest demonstrates thrombus (blood clot) within the right internal jugular vein with mild expansion of the vein likely representing acute process. Findings were relayed to the clinical service."***

The oncologist just called and basically said that I'll be on the Xarelto for at least a year! So, that's my news for Thursday, January 4th. Haven't figured out why the year yet, but I will.

When anyone like us has to go through cancers of any type, it's a difficult road to travel, and complications happen. I'm not wild about this one because it's another layer of a drug with lousy side effects that didn't really have to happen (rare - remember?)

Off to Wal-Mart pharmacy to get my Xarelto... (pronounced Zarelto).

FRIDAY - FEBRUARY 5TH - 2nd CHEMO SESSION....

So, today I got better news....I had my second chemo session today and, so far, so good! No side effects yet, but I do expect to have fatigue in three days. I don't expect to have nausea. And, as is supposed to happen, the first couple of times I pee - it will be pink in color. That is because part of the R-CHOP - the H part is "Hydroxydaunorubicin"... ***- It works by disrupting the synthesis of DNA in cancer cells, stopping them from reproducing and spreading malignancy to nearby tissue.***

Doctors and nurses usually administer hydroxydaunorubicin through an intravenous (IV) line once every three weeks for a carefully designated time period."

It is a red colored tube (two of them) administered through the port catheter directly by syringe... and they call it the

"PUSH" ... intending to mean that all the rest of the solutions are drip method into the port, but the PUSH is actually pushed into the catheter "y" port. The "Y" shaped catheter input is utilized so that the drip or the PUSH method can be used.

BETTER NEWS- (maybe).

The oncologist canceled my appointments (two of them) for the spinal shots - partially due to the Xarelto blood thinners.

Apparently the Xarelto and Chemo epidurals can't be used together.

So the better news is that I only have ONE MORE chemo session followed by the Neulasta sessions.....and then the oncologist will order a new PET Scan to see if there is any evidence of the lymphoma anywhere in the upper body... especially at the right eye lacrimal duct and sinus area.

If not.... I might also escape having to do the radiation of that area.

If clean, I might get a pass to just visit the oncologist periodically and do blood tests (platelet counts mainly) to see how well my antibodies are building up again.

Then - I might begin to see some hair follicles starting to grow in the head garden again!

Tomorrow - February 5th, is my Neulasta day. After that ... one more chemo session and one more Neulasta session and I think I'm done.

The oncologist used the word "CURE", but the reality of having cancer once is that it is in "REMISSION" and could reappear at any time in the future....or not, but this is why the oncologists want to see us once or twice or more per year - at least for the first year after going through chemo.

What I want is to get the PORT removed.....another surgery.....and then I will ask for one more ultrasound test of the right inner jugular vein. If it proves to be gone, I will ask how I can be taken off the Xarelto.

With "**BIG PHARMA**" ...I don't trust any of them.

Xarelto says, "Xarelto may also cause blood clots", so my brain tells me, "If it can also cause clotting... this is probably WHY they want me to stay on it for at least one year. It's all about the Benjamins!

At \$549.00 for just a 30-day supply, there are 12-day periods in a year. 12 times \$549.00 is \$6,588.00!

I'm really both a patient - and a paycheck for all concerned doctors, nurses, pharmaceuticals, and my health insurance covers the bulk (thank God) of the things I have to go through to get to the end.

My co-pays are 20% of the actual cost of each event. So, a \$30.00 co-pay means somebody got paid \$600.00 per consult.

If my co-pay is \$110.00 ... someone got paid \$2,200.00 for the use of the facility and the machine....like a PET Scan.

When my co-pay is \$195.00 for a machine and facility and doctor use - as in the MRI machine, someone gets \$3,900.00 for the time.

And, when my co-pay for hospitals is \$295.00, the doctor and facility get \$5,900.00.

This is why we all need really GOOD healthcare plans. Check out YOUR deductibles for the plan and your upper limits.

Mine are outlined here and my limit to out-of-pocket expenses is \$3,600 in a calendar year.

My United Healthcare premiums for their Medicare Plan - called "Medicare Advantage" only costs me \$27.00 a month in North Carolina. Some states charge different amounts ... so check yours.

I am slowly getting my peace-of-mind back (aside from the side effect possibilities of the Xarelto) because I now know that I only have to endure one more chemo session and one more Neulasta shot after that...and I'm nearing the finish line - the goal - remission and a more normal life- with hair!

MORE ABOUT XARELTO

Every drug has side effects... many are serious and include liver or kidney damage - - - to stroke, heart attack or death! Xarelto is one of those drugs. I am preparing the following to hand to my Oncologist once I get the Pet Scan clearance showing that the lymphoma is in remission. That should come by about mid to late March. -Here is the first section of what I wrote....

How should I take XARELTO?

- Take XARELTO exactly as prescribed by your doctor. *
- **Do not change your dose or stop taking XARELTO unless your doctor tells you to.** Your doctor may change your dose if needed. *
- **Your doctor will decide how long you should take XARELTO. ****
- XARELTO may need to be stopped for one or more days before any surgery or medical or dental procedure. Your doctor will tell you when to stop taking XARELTO and when to start taking XARELTO again after your surgery or procedure.
- If you need to stop taking XARELTO for any reason, talk to the doctor who prescribed XARELTO to you to find out when you should stop taking it. Do not stop taking XARELTO without first talking to the doctor who prescribes it to you.

Xarelto was created for AFIB mainly....

If you take XARELTO for:

- **Atrial fibrillation that is not caused by a heart valve problem: NO**
 - Take XARELTO 1 time a day with your evening meal.
 - If you miss a dose of XARELTO, take it as soon as you remember on the same day. Take your next dose at your regularly scheduled time.
- **Blood clots in the veins of your legs or lungs: ** ME**
 - Take XARELTO 2 times a day as prescribed by your doctor.
 - For the 15 mg and 20 mg doses, take XARELTO with food at the same time each day.
- **Hip or knee replacement surgery: NO**
 - Take XARELTO 1 time a day with or without food.
 - If you miss a dose of XARELTO, take it as soon as you remember on the same day. Take your next dose at your regularly scheduled time.
- **Blood clots in people hospitalized for an acute illness: NO**
 - Take XARELTO 1 time a day, with or without food, while you are in the hospital and after you are discharged as prescribed by your doctor.
 - If you miss a dose of XARELTO, take it as soon as you remember on the same day. Take your next dose at your regularly scheduled time.
- **Reducing the risk of serious heart problems; heart attack and stroke in coronary artery disease or peripheral artery disease: NO**
 - Take XARELTO 2 times a day with or without food.
 - If you miss a dose of XARELTO, take your next dose at your regularly scheduled time.

Some healthcare providers say that patients must be on Xarelto for at least a year! This is NOT true! These are the words directly from the multi-page documents that Xarelto published.

Xarelto can be stopped.

In my case, I have one isolated clot in the interior jugular vein right side. After the Pet Scan, I am requesting another ultrasound to see if the clot has resolved. If it has, I wish to have the Xarelto stopped in a safe manner by the Oncologist.

John Tyler

And here is the second section of what I plan to send to the Oncologist.It's from the pamphlet that Xarelto/Bayer sends to patients like me with the first "Xarelto Starter Pack".

<p style="text-align: center;">MEDICATION GUIDE XARELTO® (zah-REL-toe) (rivaroxaban) tablets</p>	<p>This is part of the huge pamphlet that Xarelto sends with each prescription and is directed to patients.</p>
<p>What is the most important information I should know about XARELTO? XARELTO may cause serious side effects, including:</p> <ul style="list-style-type: none">• Increased risk of blood clots if you stop taking XARELTO. <u>People with atrial fibrillation</u> (a type of irregular heart beat) that is not caused by a heart valve problem (non-valvular) are at an increased risk of forming a blood clot in the heart, which can travel to the brain, causing a stroke, or to other parts of the body. XARELTO lowers your chance of having a stroke by helping to prevent clots from forming. If you stop taking XARELTO, you may have increased risk of forming a clot in your blood. <p><u>Do not stop taking XARELTO without talking to the doctor who prescribes it for you.</u> Stopping XARELTO increases your risk of having a stroke. If you have to stop taking XARELTO, your doctor may prescribe another blood thinner medicine to prevent a blood clot from forming.</p> <ul style="list-style-type: none">• Increased risk of bleeding. XARELTO can cause bleeding which can be serious and may lead to death. This is because XARELTO is a blood thinner medicine (anticoagulant) that lowers blood clotting.	<p><i>"Patients, Xarelto may cause serious side effects or death if you stop taking Xarelto."</i></p> <p>** Attached is when and how my doctor CAN allow me to STOP taking Xarelto....for an isolated - NON -AFIB - NON-HEART RELATED blood clot to the interior right jugular caused by the insertion of the Port and associated catheter tube.</p>

Xarelto is a prescription by Bayer that thins the blood to dilute a clot or clots. It also produces clots according to their own published pamphlet that comes with the Starter Pack.

Xarelto would like to keep patients on their product ...and why SOME HEALTHCARE PROVIDERS say, without merit, ***"We think you have to be on Xarelto for at least a year."***

Xarelto costs insurers \$975.00 and the 20% co-pay for patients is \$47.00 for a 21 day supply. In one year, there are 18 twenty-one day supplies: 18 times \$975.00 nets Xarelto/Bayer \$17,550.00. This is why the healthcare providers who have limited knowledge of how the physician is the one who can take patients off Xarelto say that ***"We believe you must be on Xarelto for at least a year."***

From Xarelto - ***"AFib is a long-term condition that increases the risk of stroke, and your risk can increase over time. Only your healthcare professional can decide how long you should take XARELTO®.***

Do not stop taking XARELTO® without talking to the healthcare professional who prescribes it for you.

Stopping XARELTO® increases your risk of having a stroke." I do not have AFIB! Xarelto was designed for AFIB patients, and their TV ads suggest so.

There are no published reports stating that Xarelto MUST be taken for at least one year!
There are, however, warnings - especially to AFIB patients about discontinuing abruptly.

Increased Risk of Thrombotic Events after Premature Discontinuation

Premature discontinuation of any oral anticoagulant, including Xarelto, in the absence of adequate alternative anticoagulation increases the risk of thrombotic events. An increased rate of stroke was observed during the transition from Xarelto to warfarin in clinical trials in atrial fibrillation patients. If Xarelto is discontinued for a reason other than pathological bleeding or completion of a course of therapy, consider coverage with another anticoagulant.

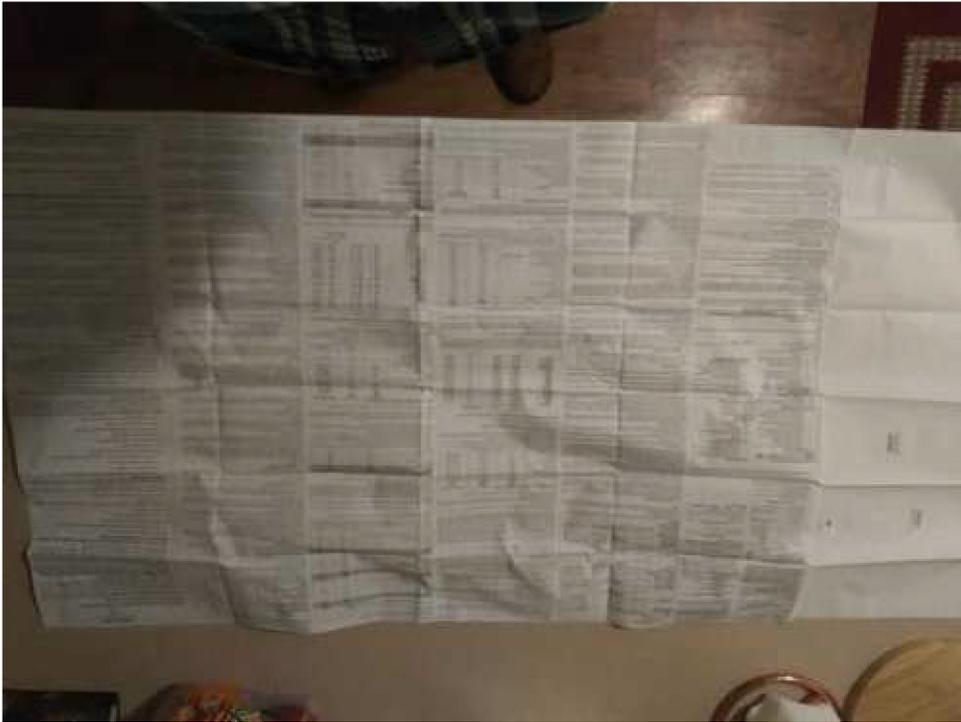
An aspirin regimen is an anti-coagulant.

John Tyler- Patient

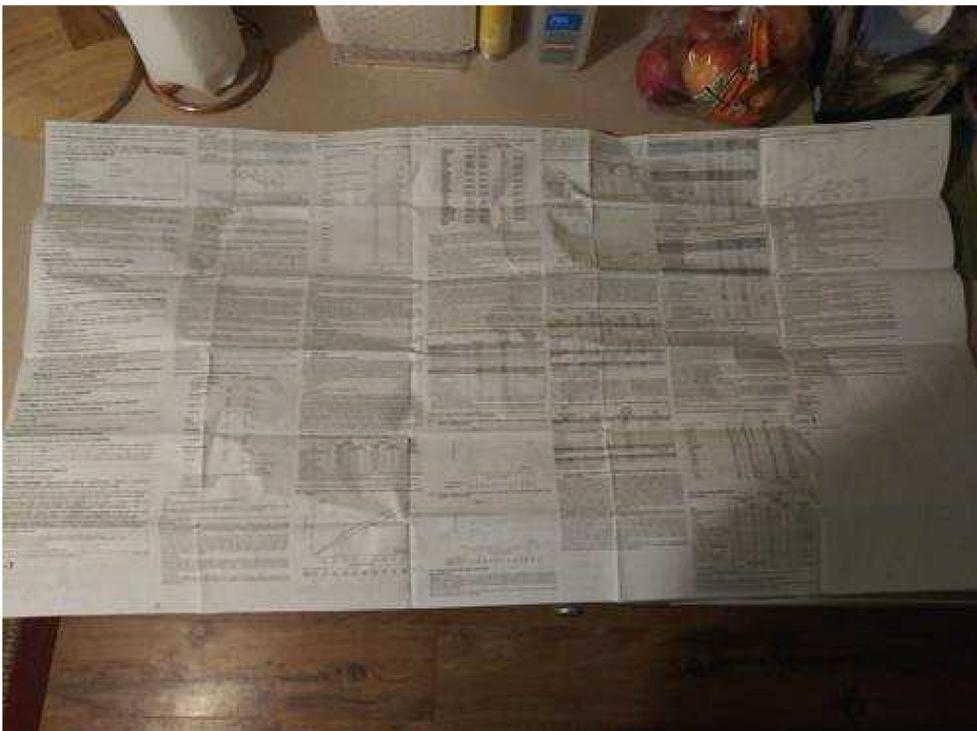
And the above is only a tiny fraction of what Xarelto publishes in the container of the first Starter Pack.....what they write is so huge and tiny, that most people would ignore it...or be confused by it. I took the salient points relating to stopping the use of it from their huge document.

This is a photo of the two-sided document. It's small here, but you should get the drift of what patients on Xarelto are expected to read... and remember ... this information is to users of Xarelto.

Page Oneshrunk to fit here...



Page two...



So, the drift to patients using Xarelto is that you should not stop taking it.....or face serious consequences.

To me, it's because Big Pharma - Bayer in this case, is making \$975.00 for a 21 day supply, and if we are told that we have to stay on it for at least a year (by uneducated healthcare people)... then there are 18 separate 21 day supplies.

18 times \$975.00 means that Bayer/Xarelto earns **\$17,550.00** per year per patient.

My next phase is today... Saturday, January 6th, 2021, and it is only to get the chemo follow-up shot in the arm of Neulasta.. followed by taking a single pill called LORATADINE 10 mg once a day for the next three days.

After that... I start building up my antibodies for my final chemo session on February 26th....a four to five-hour session.

After that, I should be set up for a Pet Scan to see if the single lymphoma cyst in the lacrimal duct is gone, and to see if the lymphoma has NOT spread to any other part of my body.

SESSION TWO OF CHEMO - February 5, 2021

The five-hour session of R-CHOP went well. I have had no side effects from it and today as I write this it is Monday, January 8th.

I had the Neulasta shot yesterday (Sunday), and no side effects.

I actually still have what I call "FUZZY HAIR"....so that's unexpected, and I still have my eyebrows ... also unexpected.

The last time I had chemo - back on January 15th - my FIRST SESSION, I was fatigued by Monday, but I think it's because my son asked me to walk two miles with him.

After that - about one o'clock , I had to take a three-hour nap!

Not this Monday. I've been feeling very good in fact. I did some work around the outside of the house.

I drove to another town about a half hour away, and I drove to McDonalds and had two bacon, egg & cheese biscuits... and water.

The soreness in my neck from the clot stuck in the inner jugular vein seems to have dissipated. The swelling around it is gone, too.

I did manage to dig up more information as to how to get off the Xarelto though, so I will spring that on my oncologist once the third chemo is done on February 26th.

At that point, I will ask that the PET Scan be done, and if cleared, I'd like to have the Porta Cath removed.

To do that... it requires another minor surgery to cut the skin and remove the porta Cath and the catheter tube itself.

To do that, I can't be on Xarelto or I'd be taking a chance of bleeding out!

This is what a medical professional said online about stopping Xarelto:

[Rob Seddon-Smith](#) — Medical General Practitioner
MB ChB FRNZCGP in Medical School, University of Birmingham

"You can simply stop taking the medication. There is no need for a tail-off period. It will be completely gone in 2-3 days."

*You do however need to ask why you were taking it. NOACs like rivaroxaban are usually used to reduce your risk of clots and if you stop taking it, you will be at increased risk of **disabling or fatal illness that might otherwise have been prevented ...**(which I don't have....like AFIB, heart problems, etc.)*

When I am working with patients, I try to calculate the chance of them having an event (say a stroke) prevented by the medication vs the risk of adverse effects like bleeding.

What follows is a quick run through how I calculate the relative benefits or otherwise of treating patients with a NOAC or warfarin for AF and is not personal advice for you - use this to inform discussion with your doctor by all means, but please do discuss it with a doctor. This is not a decision you should make alone.

This is calculated using two scores:

[CHA₂DS₂-VASc Score for Atrial Fibrillation Stroke Risk](#) [HAS-BLED](#)

[Score for Major Bleeding Risk.](#)

So, based on that expert's findings, and knowing that Xarelto must be stopped for awhile before an operation happens, I'm confident I can get off the Xareltoand will - once I am assured that the clot is gone by way of another ultrasound exam.

So, the hair is still there, and I'm a little happier about that!





The fatigue did set in today - late....probably because I did a lot of work - installing a pool pump, cleaning out the garage,etc., so I did rest in bed from 5PM to 7PM.

The other thing that came back was the acid reflux thing. haven't had that since the last time I wrote about it, but it must hit us after the third or fourth day of chemo because there could be no other conclusion.

That said, I'm feeling really good, so I hope that you are too - as you go through your trials with porta catheters, chemo, drugs galore... and I suppose the best thing for us to do is to keep a POSITIVE ATTITUDE along the way... knowing that the outcomes in the majority of cases are good.

THE GOD FACTOR:

I have to admit, I'm one of those guys that believes what the Bible teaches.

In it, I find several places that give us the knowledge to KNOW that when we die (and we all will), we can KNOW that we will go to heaven.

The first requirement I got is found in John 3:3... the most mis understood Bible verse! Jesus is talking to a Jewish Pharisee named Nicodemus, and He said, "**I tell you the truth, unless you are born again,1 you cannot see the Kingdom of God.**"

Therefore, it is critical for one to know what being born - and being born again means if that is the assurance that we can have the **free gift** from God of eternal life in heaven - with Him.

Nicodemus asked the right question for an intelligent Pharisee (**Pharisees are spiritual fathers of Judaism. Their main distinguishing characteristic is a belief in an Oral Law that God gave to Moses at Sinai along with the Torah.**)

So, Nicodemus asked Jesus, **"How can an old man go back into his mother's womb and be born again?"** He realized that to be born human in the first place, one has to have a mother, and a baby is born in the womb.

Jesus is very clear when He said to Nicodemus (and you and me), **"I assure you; no one can enter the Kingdom of God without being born of water and the Spirit. Humans can reproduce only human life, but the Holy Spirit gives birth to spiritual life. So don't be**

I grew up in the Catholic religion and have moved through other religions as well along life's journey. I have discovered - by actually studying the Bible for about fifty years, that many so-called "religions" teach what they want their congregations to believe, and we accept what many of them say believing they are the speakers for God. No... God said what He wanted us to know in His Bible, so it is really up to us - as individuals, to decide for ourselves what is truth.

My Catholic priests would say that to be **"born of water"** means that babies- when they are newborn, must be sprinkled with water, and that will assure them a place in heaven.

But Jesus points out that "born of water"... being born the first time- as a human being, is that being born is a reproduction of human life. Just before a baby is born, you will hear from the mother, **"MY WATER BROKE"**.

Medical science defines this as, **"During pregnancy, your baby is surrounded and cushioned by a fluid-filled membranous sac called the amniotic sac. Typically, at the beginning of or during labor your membranes will rupture —also known as your water breaking."**

THEREFORE, Jesus and Science agree... to be born a human, you must be born of water.

To be clear, the Bible teaches that **REPENTENCE comes first.** ..then Baptism by immersion in water.

Acts 2:38: The men surrounding the Apostle Peter asked him what they need to do to be saved - to be assured of heaven when they die. **"Peter replied, "Each of you must repent of your sins and turn to God and be baptized in the name of Jesus Christ for the forgiveness of your sins. (remission) Then you will receive the gift of the Holy Spirit."**

From this, we must conclude that we first need to be born human **—via water** in the mother's womb, and when we reach the age of accountability and reasonable knowledge that God exists, and the great Apostle Peter tells us all, "If we turn to Jesus Christ and ask Him for forgiveness of our sins (because He paid for them by dying on a horrible cross of crucifixion)....

then....He will give us His gift of the Holy Spirit.....**MEANING BEING BORN AGAIN _ AS** Jesus said, "**but the Holy Spirit gives birth to spiritual birth**". "This is the "**born again**" part of getting into heaven.

So, this was clear to me - way back at the age of eleven when I went to a church youth camp in Steep Falls, Maine.

That preacher read from Romans 10:13...



Whoever means **YOU or ME**. We have to choose to do what Jesus told us in order to get the free gift of the Holy Spirit and access into heaven for eternity when we die.

70 odd years on earth pales in comparison to FOREVER, wouldn't you agree?

Romans 10:13 is a legal term....SHALL be saved. It's not a hope so....it's not a wish... it is SHALL BE SAVED. So, we first need to realize that we need a Savior who can forgive all of our

sins... past, present, and future.

A rich young ruler approached Jesus and asked the same question everyone asks today... "**Teacher, what good deed must I do to have eternal life?**"

Many "religions" teach that it is **GOOD WORKS or DEEDS that get us into heaven** ...negating, of course, the fact that Jesus died on the cross of crucifixion for OUR sins, so to get into heaven through doing GOOD DEEDS means that Jesus died a horrible death on that cross - for nothing!

So, God covers all about **GOOD WORKS or DEEDS** when He had the Apostle Paul (writer of half of the New Testament) this is Ephesians 2:8-9 - "**God saved you by his grace when you believed. And you can't take credit for this; it is a gift from God. Salvation is not a reward for the good things we have done, so none of us can boast about it.**"

Therefore, every "clergy" that teaches that GOOD WORKS or DEEDS can get us into "purgatory" or heaven has lied to you. We need to believe what GOD wrote, rather than what man (or women) teach us in some church setting.

Again... YOU and I are solely responsible for our eternal destiny.

John, another great Apostle of Jesus... one who walked and talked with Him had this to say in John 3:15... "**That whosoever believeth in him should not perish but have eternal life.**"

Therefore, it is quite clear what God (not man) has taught us.

To be assured of Heaven, we must be BORN HUMAN (of water), then we must OBTAIN the second birth (By the Holy Spirit) which we get when we seek out the one who paid for our sins and ask Him to forgive us of our sins... as only He can. Then, once that is done, He promises to give us eternal life with Him in heaven.

There is the UPSIDE of asking Jesus to forgive our sins and save our soul... and there is the DOWNSIDE for failure to abide by what God said in His Word - The Bible.

Here it is in a nutshell: Romans 6:23 - **"For the wages of sin is (eternal) death; but the gift of God is eternal life through Jesus Christ our Lord."**

And, to finish this section up, You need to know that there is **NO OTHER NAME UNDER HEAVEN BY WHICH WE CAN BE SAVED.**

Acts 4:12 - "Salvation is found in no one else, for there is no other name under heaven given to mankind by which we must be saved."

Therefore, it matters not if you are Hindu, Buddhist, Mormon, Catholic, Protestant, Jewish or anything else....there is but ONE WAY to be assured of heaven when you die....and now you have it. Do NOT believe me. Do NOT believe what any man or woman tells you from some church pulpit.... believe what GOD wrote in His Bible.

I said all of the above because, to me - it is fundamental to have the belief system in your heart and mind that PROMISES eternal life when we die - and again - we all die. Ask George Washington!

Knowing that I am assured of going to heaven when I die gives me a very great comfort because this earth, to me, is just a place we pass throughlive life for a short time, raise families, work, do stuff....and then we face death after an unknown time here.

It also gives me comfort to know that God is in charge of my life or death, and He will call me home to heaven when He is finished with what He has planned for me to do and say to others along the way.

Let me reflect back for a moment.

In November, I spotted a small 1.4" cyst starting to grow in the tear duct of my right eye. Yes, the biopsy turned out to be lymphomabut isolated to that tear duct. Had God not put it right there - in plain sight, I might never have known that lymphoma blood cancer was at work in my body.

I took care of things fast.

Then, I would have to go through cancer therapies, port installations, chemo, pills, you name it. I took the chemo, but asked God to spare me of the nausea and vomiting that some get while taking chemo. He did that. I have not had one bout of nausea and have now gone through two chemo sessions and one spinal epidural of chemo.

Speaking of that, the Oncologist said that I would be doing three chemo sessions followed by three spinal epidurals. Then, out of the blue, I got a clot in the right inner jugular vein - brought on by the implanted catheter tube from the port.

That caused the oncologist to cancel the two rounds of epidural spinal injections ...which, to me, I thought was overkill for a cyst just under my right eye....and nowhere else.

So, did God spare me from having chemicals injected twice more into my Central nervous system and brain? I suspect that He did.

And, the best part of this story seems to be that I am feeling really great considering that cancer therapies are supposed to cause all kinds of side effects. In fact, the chemicals and some of the medications subscribed can lead to worse side effects or even death, so we walk a tightrope between life and death along the journey toward remission.

I'd rather walk with God promising to lead, guide and direct me than not.

Proverbs 3:5-6: - **"Trust in the LORD with all your heart; do not depend on your own understanding. Seek his will in all you do, and he will show you which path to take."**

That is my lifetime Bible verse.

FATIGUE WEEK!

During the week of February 15th to the 19th, I have to admit that fatigue set in about every day. But I learned something from the experience so I am passing that on to you.

I decided to do some work around the house... like cleaning out the garage, cleaning out the shed, tossing things that I haven't used in awhile and washing the riding mower.

When the rider didn't start, I had to push it up to one of the cars to jump start it....about 100' from the shed to the driveway.

Everything I did that required some exertion cost me in fatigue.

I felt good, but my mind and body couldn't seem to agree. My mind said, "Go - **do some work**". My body quickly said, **"Hey dummy- if you do... you will pay!"**

So, I researched it and found this on MayoClinic.org:

"Fatigue, usually described as feeling tired, weak or exhausted, affects most people during cancer treatment. Cancer fatigue can result from the side effects of treatment or the cancer itself."

They list a host of reasons why fatigue sets in. Some are just due to the chemo or the cancer itself. Others include a lack of proper sleep.....which I can admit to. Mayo even suggested exercising.....like walking or riding a bike....HOWEVER, when I walked two miles one day with my son... I had unbelievable fatigue. Doing the chores mentioned above fatigued me for the whole week, so you will have to be the judge of your own fatigue when it happens.

Mayo Clinic did admit, **"The exact causes of cancer fatigue and how best to treat it aren't always clear."**

FINAL CHEMO SESSION COMING UP?

The question mark at the end says that I hope so, but I won't know until I see the oncologist on the 25th... one day before what I believe will be my last chemo session according to the oncologist's original report stating, **"1/13/2021 - PET scan personally reviewed. No additional sites of disease outside of the eye region. -- Plan will be to proceed with RCHOP x 3 cycles followed by radiation therapy consolidation.-- Given involvement of orbit, will use IT MTX as CNS prophylaxis with each cycle -- OK to proceed with chemotherapy. - "orders were reviewed and signed 1/20/2021 --- Patient comes for toxicity check after first cycle of RCHOP --- He feels great. - Double vision fully resolved. Canthal mass has significantly decreased in size.-- Follow up prior to cycle 2."**

So, I have decided to send the oncologist my thoughts on getting out of the chemo, the shots, the myriad of pills....all of which have significant downside side effects.

By the time our meeting is over on the 25th, it is my hope that the PLAN of EXIT will be made known ... and I will brief you on what the outcome of that meeting is.

By the way - my hair has still not fallen out nor have my eyebrows disappeared. I have no idea why it hasn't happened - yet. Perhaps sometime after chemo session three it will happen!

ONCOLOGIST MEETING - February 25th - Well, this went well - and then it didn't My last chemo session will be tomorrow, so that was good news.

He said that they can remove the porta catheter in about 21 days, and that I would have to come off the Xarelto for about four days prior to that minor surgery that was good news!

THEN - he said, but you have to have three more epidural spinal infusions of chemo! That was not good news because those needle jabs hurt. There seemed to be no aftereffects when they stuck the needle in or even to this day, but to hear that I have three more (not the original two more bothered me.

He also said that he is arranging to have the radiation treatments done after the chemo epidurals and that he would arrange to have a Pet Scan done after the epidurals. He felt that the epidurals are needed based on the position of the cyst with lymphoma that is in the right eye tear duct....or was.

The eye is close to the brain and regular chemo doesn't enter that central nervous system, but the epidural injections do, so to prevent any possibility of developing brain cancer... the epidurals are warranted.

On Friday..the next day- February 26th, I had my last chemo treatment, and today... Saturday, February 27th, I get my last Neulasta shot and then the port comes out soon!

NO side effects from regular chemo injection other than occasional bone pain that only lasts for about an hour....or leg cramps that I take care of with the \$1.00 tube of Muscle Rub from Dollar Tree. Those go away in just a few minutesthank God! They are really painful things to endure.

Why I want to finally get through all of this is - - - THE PILLS.

Pills wreak havoc in the kidneys because they can't process the ingredients in pills... even the blood pressure pill Lisinopril. Now, add the other six chemo pills, and the kidney levels in the blood labs of higher than normal levels, so the sooner my kidneys stop having to not process these pills, the sooner the kidney blood test labs can diminish.

For example, All of my blood labs come back fine... platelets included, but here are a few of the above normal levels:

MY LOH (not LDL cholesterols) is HIGH..304 U/L but the range is 0-225 U/L.

LDH means this:

- To measure whether you have tissue damage and, if so, how much
- To monitor severe infections or conditions like hemolytic or megaloblastic anemias, kidney disease, and liver disease
- To help evaluate certain cancers or your cancer treatment

GLUCOSE is high at 121 mg/dL where the normal range is 65-99.Creatinine is

high at 1.39 mg/dl where normal is 0.76 - 1.27

*"A creatinine test reveals important information about your **kidneys**. Creatinine is a chemical waste product that's produced by your muscle metabolism and to a smaller extent by eating meat. Healthy kidneys filter creatinine and other waste products from your blood." ...*

*..."The filtered waste products leave your body in your urine. If **your kidneys aren't functioning properly**, an increased level of creatinine may accumulate in your blood. A serum creatinine test measures the level of creatinine in your blood."*

So, as we can see, kidney functions are diminished by taking pills that they can't process. Eventually, people end up with kidney disease and end up on dialysis.

Logically, at least to this layman, if I can get to the point of NOT having to take pills that the kidneys can't process, and continue drinking plenty of water, my kidney counts should go down. I think once the kidneys are damaged, they don't go "back to normal", but slowing the disease down will help.

Google tells me, "*Your kidneys get rid of waste in your body and help you hold on to the right amount of fluid. They also send out hormones that keep your blood pressure steady, and they play a role in making red blood cells. They even make a form of vitamin D that's good for your bones. - Some medications can make those things hard for your kidneys to do and keep them from working the way they should.*"

So, the goal now is to get through the epidurals (contrast dye used also effects kidney functions!) and get past the epidurals and then all of the extra pills that I have to take during chemo sessions goes away. Whatever kidney damage is done by them will be done but stopping them can possibly slow down the kidney disease caused by them.

I'll continue to keep you posted as things progress towards the eventual remission of this cancer.

Meanwhile, I feel great other than the minor cramps and occasional bone pain.



YES....it appears that I am finally on the road to remission!

REMISSION ROAD

The Oncologist has set these plans in motion as of my meeting with him on February 18th...February 25th -Final session of chemo done. -March 4th - Blood tests to determine platelet counts, etc. March 11th - Blood tests again to see if platelet counts are up. March 15th - Pet Scan to determine if the lymphoma is gone. March 18th - Blood tests to ensure that platelets are good. March 24th -

Xarelto ceases until surgery to remove port. March 29th - Surgery to remove porta catheter.

After that, I am told I will then still have to have three more of those nasty lumbar epidural chemo shots in the spine and probably have a few bouts of radiation, so I'll keep you informed.

So, today is now March 4, 2021, and the blood tests prove out to be really good. They are concerned with the platelet count and one other.

The platelet count is 157 per thousand mcl. The range is between 150 to 400 thousand per mcl.

So, they were pleased to see that the count is above the normal range, and it should increase as the days go forward after my last chemo session seven days ago.

It's during these days that the antibodies begin rebuilding and the blood labs look better. This is usually why they have a 21-day spread between chemo infusions ... so that the body can rebuild platelets and good blood counts.

The other important blood count also has to do with the red blood cells...it's called ROW. - **"Reference Range of the Red Cell Distribution Width (RDW)."**

My ROW count is 51.5 fl and the normal range is 36.0 - 47.0 fl ...so it's a tad high, but of no concern because it's not real high.

"ROW is elevated in accordance with variation in red cell size (anisocytosis), ie, when elevated ROW is reported on complete blood count, marked anisocytosis (increased variation in red cell size) is expected on peripheral blood smear review."

So, the next blood test in next Thursday, and it, too, should prove to be a better count.

The blood test on Thursday, March 11th was okay, but the platelet count was lower than the week before. It was **132** thou/mcl. Remember, last week it was 157 per thousand mcl....so, it's down a bit lower than the normal range.

The BIG DAY is when the PET Scan happens. That will either clear the way for me toward the goal of remission - or something else might show up! That happens on March 15th.

PET SCAN DAY - March 15th

The results of today's PET Scan were great. Here is what the FINDINGS are:

First, I need to give you the medical term for the word "RESOLVED".

"Resolved" - "The medical term "resolved" means that the pathologic process has been stopped and the normal state has returned."

THE FINDINGS:

HEAD AND NECK: Essentially **resolved** FOG avidity in medial right orbital and right nasal cavity region, local SUV max 2.8, previously 20 (means the lymphoma is resolved....there is none.)

CHEST: No hypermetabolism in the lungs, hila, or mediastinum.

ABDOMEN: Physiologic activity in the solid organs and gut. Nonspecific mild FOG uptake throughout the stomach, without mass like enlargement on low-dose CT, probably physiologic. Cholecystectomy. (gas)

PELVIS: Physiologic activity in the bladder and gut. (Physiological activity refers to the normal function of an organism)

BONES AND MARROW: No suspicious FOG uptake. So, to me - and I'm not

the oncologist, it sounds like the

Lymphoma in the right eye lacrimal duct (tear duct) that once

was... is no more. It is **resolved** and there are no other abnormal lymphoma activities anywhere else.

My next date is March 29th where I get the porta catheter removed.

THE COST OF CANCER:

For many, the cost of cancer is astronomical. .. maybe \$200,000 or more.

Below are my direct costs so far - and anticipated:

Visit Accounts [Show all details v](#)

Visit Accounts with Outstanding Balance

Feb 6 2021	OPC INJECTIONS Visit at NH Cancer Institute Infusion (Elizabeth) Hospital Services Provider: Roseann M Barrera, FNP Patient: John Calvin Tyler Primary Payer: Uhc Medicare AccoW1t #3102058053	Two sessions:	Billed Insurance Paid You Paid Pending Insurance Your Balance	\$11,452.51 -\$10,750.27 \$0.00 \$0.00 \$702.24
	Show more details v			
Feb 5 2021	Primary Payer: Uhc Medicare Account #3102039783		Pending Insurance Your Balance	\$0.00 \$648.60
	Show more details v			
Feb 4 2021		GCM FL PORT A CATH CHECK Visit at		NHMMC Radiology Department

Hospital Services
P
r
o
v
i

der: Roseann M Barrera, FNP
Patient: John Calvin Tyler
Primary Payer: Uhc Medicare
Account#t 900889290

Billed \$4,259.65
Insurance -S4,064.09
Paid You -530.00
Paid \$0.00
Pending Insurance **\$165.56**
Your Balance

Show more details. v

Dec
23
2020

Hospital Encounter at Novant Health Charlotte Outpatient Surgery
Hospital Services
Provider: Katherine A Orman
Patient: John Calvin Tyler
Primary PayH: Uhc Medicare
Account #3102018321

Billed \$27,626.27
Insurance -S27,324.67
Pa,d You -S295.00
Paid \$0.00
Pending Insurance **\$6.60**
Your Balance

Show more details v

Your total balance for outstanding visit accounts: **\$1,523.00**

Paid Off Visit Accounts

Oh, the list goes on.....

Feb
3
2021

Patient: John Calvin Tyler
Primary Payer: Uhc Medicare
Account 8400044803

Pending Insurance \$0.00
Your Balance \$0.00

Show more details v

GCM FL LUMBAR INJECTION/W CHRnO Visit at NHPMC Radiology Department ◀ ◀ ◀ ◀ ◀
Hospital Services

Billed \$1,377.23
Adjusted 1-
\$135.27
Insurance Paid -S1,317.50
You Paid 1- -S195.00

Jan
29

Provider: Roseann M Barrera, FNP
Patient: John Calvin Tyler
Primary Payer: Ljhc Medicare
Account #3102041514

Pending Insurance \$0.00
Your Balance \$0.00

Show more details v

Jan
28
2021

Patient: John Calvin Tyler
Primary Payer: Uhc Medicare
Account #8400043189

Pending Insurance \$0.00
Your Balance \$0.00

Show more details v

Jan
20
2021

Office Visit at Novant Health Cancer Institute - Elizabeth (Hematology)
Hospital Services
Provider: Alan P zausner Skarbnik, MD
Patient: John Calvin Tyler
Primary Payer: Uhc Medicare
Account #84-00040927

Billed \$356.00
Insurance Paid -S356.00
You Paid \$0.00
Pending Insurance \$0.00
Your Balance \$0.00

Show more details v

Jan
1
4
2021

20n

Patient:
John
Calvin
Tyler
Primary
Payer:
Uhc
Medicare
Account
#8400039
316

Jan
13

Office Visit at Novant Health Cancer Institute - Elizabeth (Hematology)

Hospital Services
 Patient: John Calvin Tyler
 Primary Payer: Uhc Medicare
 Account #8400038751

Pending Insurance

\$0.00
Your Balance
\$0.00

Billed

\$356.00
 Insurance Paid
 \$356.00
 You Paid

So,DO
 Pending Insurance

\$0.00
Your Balance
\$0.00

Detailed Account Information

Laboratory	\$112.00
Show charges v	
Treatment or Observation Room	\$244.00
Show charges v	
Payments and Adjustments	
Uhc Medicare	-\$356.00

NOVANT BILLING: (Thru February 6th) \$45,076.96

And then there's the anticipated costs yet unknown and the totals so far.....

Anticipated billing:

OPC INJECTIONS Visit at NH Cancer Institute Infusion (Elizabeth) Feb 25th	\$5,726.26
CHEMOTHERAPY Visit at NH Cancer Institute Infusion (Elizabeth) Feb 25th	\$11,847.15
Office Visit at Novant Health Cancer Institute - Elizabeth (Hematology) March 18th	\$356.00
GCM FL PORT A CATH CHECK Visit at NHMMC Radiology Department March 29th (removal)	\$4,259.65
GCM FL LUMBAR INJECTION/W CHEMO Visit at NHPMC Radiology Department	\$1,377.23
GCM FL LUMBAR INJECTION/W CHEMO Visit at NHPMC Radiology Department	\$1,377.23
GCM FL LUMBAR INJECTION/W CHEMO Visit at NHPMC Radiology Department	\$1,377.23

Anticipated Billing: \$26,320.75

Anticipated Co-Pays: \$1,290.42

TBD:

- Office visits - ???
- Labs - ???
- Radiation Treatment - ???

Semi-Total - NOVANT - \$71,397.72

2021 Semi- Total - Co-Pays \$2,813.42

2020 co-pays: \$1,200.00

\$4,013.42

So, as you can see, NOVANT- a billion-dollar corporation with huge buildings everywhere, needs PATIENTS. PATIENTS pay for their buildings, staff of doctors, nurses, clerks, janitors....you name it, and this PATIENT has been worth **\$71,397.72** so far and it appears the goal is \$100,000 minimum.

UPDATE on October 19, 2021 - It ended up costing well in excess of \$200,000!

Living on Social Security and having to pay over \$4,000.00 in co pays hurts. When you tell Novant that you are having a tough time paying because of your limited income....they send out a sheet wherein you fill out your bank account information, your assets, everything ... meaning YOU PAY no matter what.

If you own your home, they want you to take out a mortgage or do a refinance... which is why people go broke!

The killer is this: All of the pills and medications they put you on (between doctors, hospitals and Big Pharma) ... it all leads to kidney and/or liver damage, so the end result of all is that the older we get...the more likely we will experience kidney and/or liver damage -which requires more doctors ... more hospitalizations, and more Insurance company and Medicare billing

The final billing comes with HOSPICE CARE!

That's when you are on your death bed, and the hospitals and doctors say goodbye to their paychecks from that PATIENT.

I hate to sound negative, but I see the whole thing as a money making scheme by doctors, hospitals, and pharmaceutical companies.

Every week, I witness a new drug hitting the market and advertised on TV. Six months from then, the lawyers are suing the makers of those drugs for causing pain and suffering due to harmful or deadly side effects.

When BILLIONS in pills are at stake... like \$549.00 for 30 Xarelto tablets... Big Pharma earns BILLIONS, so shelling out a few hundred million in damages is insignificant.

So, because the Industrial Medical Giant has us where they want us - which is owing them money, I had to sign on for a payment plan to pay the outstanding balance of \$1,523.00.

This will cause Novant to debit my bank account every month starting in April for \$126.92 (see next page).

Of course, this does not include future charges that will occur as we move forward into the Porta catheter removal and three spinal injections at \$1,376.00 each nor will it cover the cost of radiation and my co-pays.

The co-pays for every spinal are \$195.00 - times three will add \$585.00 more to the next billing cycle.

My son said, "**Dad... you are alive - be thankful for the co pays.**" I would agree... but do I need three chemo shots to the brain with no evidence that the lymphoma spread anywhere else?



Account Summary

Novant Health

J-l0s:pita | Serv10:ls

Guarantor #2311065 (Jonn Ca'lvfr1 Tyler)

Patients included: You

Your Balance
\$1,523.00

Auto Pay
\$126.-92

[Pay now](#)

Sc.he:du d for 4/15/2021
Mar-1ag.epay1rntent pfan

Last paid: \$30.00 0113/12/2.021

[View account](#)

[Manage financial assistance](#)

[View last statement \(3/9/2021\)](#)

[Contact customer service](#)

Zero-Dollar Balance Accounts

Novant Health

Physfd n Services

Guarantor #2311065 (Jonn Cailvi.i Tyler}

Patients included: You

Amount Due

\$0.00

-ast paid: \$30.00 011 3/16/2021

[View account](#)

[View last statement \(3/10/2021\)](#)



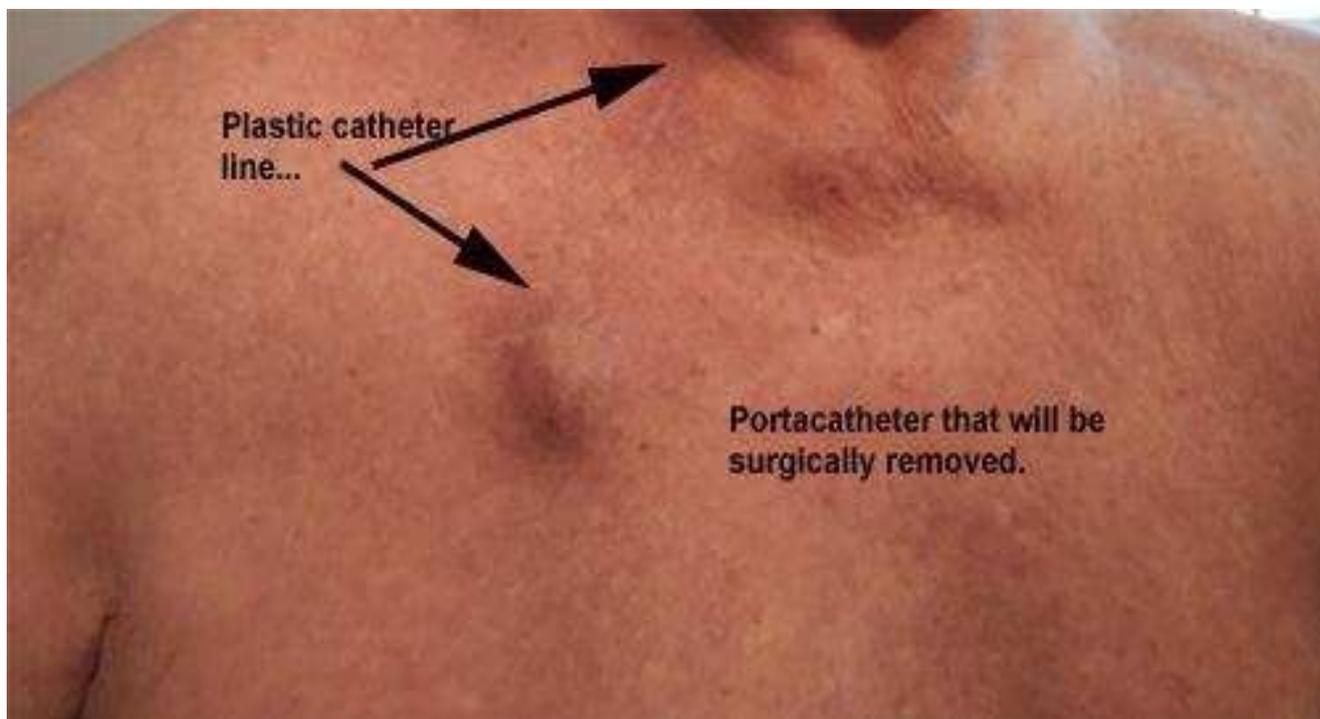
THE MAGIC DAY HAS ARRIVED!

Today is the day I got to see my oncologist! March 18, 2021.

After the PET Scan last Monday, he said, "**John, you are now officially in remission**".

He added, I will see you on June 17th for a review and blood test to make sure we stay in remission! So, I'm all set for three months while my body grows healthier.

The porta Gath is being removed on the 29th of March, so I won't have to put up with that bothersome protrusion and plastic catheter tube sticking out and bothering me when I swallow.



More good news!

The oncologist said, "**You are off the Xarelto on March 25th, and even after the port is removed ... stay off it!**"

So, that's another big, expensive pill that I don't have to take any longer.

In fact, I'm now back to just my two pills for high blood pressure that I was on before all this lymphoma thing began on December 2, 2020.

Now, the journey seems to be one of recovery from all of the medications that I was on during the chemo and spinal shot.

The oncologist seems to have dropped the next two spinal shots from three to two, but the jury (me) is still out on that.

My feeling is that if I am cancer-free, then why would I have to take the risk of having two additional shots of chemo to the Central Nervous Systemthe brain?

- We shall see.

I plan to now start feeling much better. My platelet count today was 263... a really good count and well within the normal range.

My hair should start growing again soon enough, and I plan to go on the diet that I started in November of last year.

The book and the journey, as far as this book is concerned is now over.

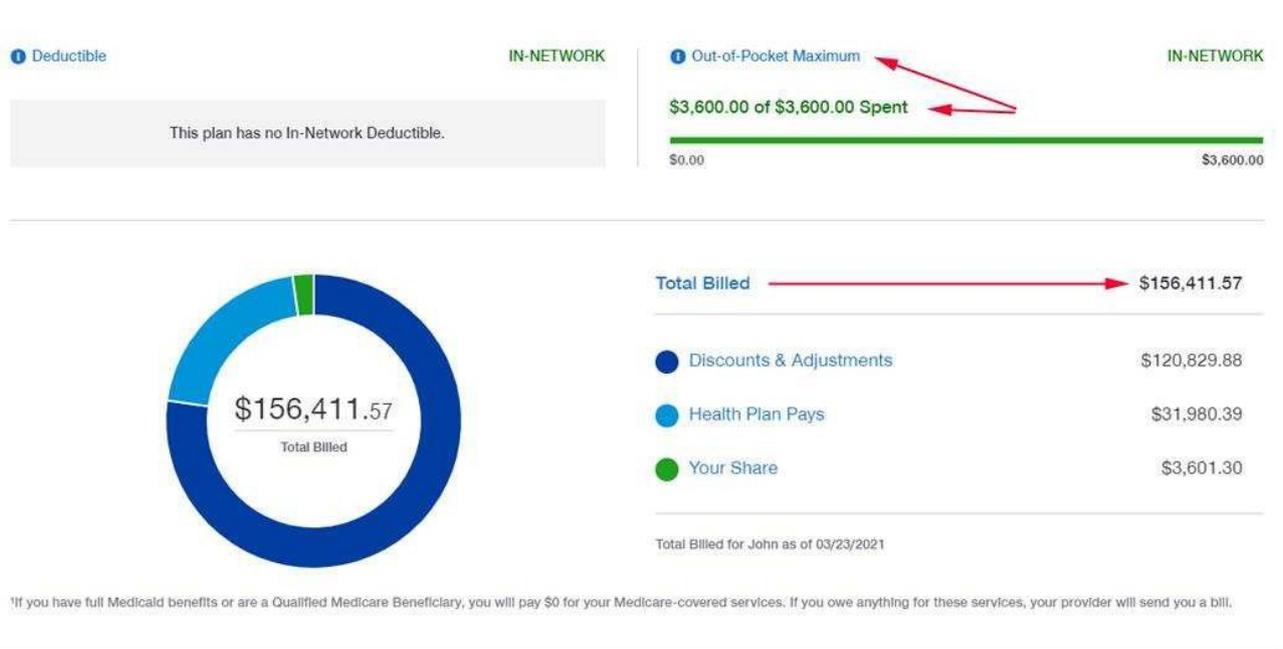
Thank you for reading along and learning all or many of the steps that ALL cancer patients will go through.....from port installations to chemotherapy, to PETS Scans and MRI's or CT scans.....lots of blood draws... and you will see how hospitals and Big Pharma are giant conglomerates that need PATIENTS to fund their enterprise. They will continue to demand big dollars from those who have great insurance coveragesand from you, the PATIENT.

UPDATE: March 24, 2021

The beauty of e-books is that I am able to adjust, edit or ADD things to it for the benefit of the reader.

The update that I have is that I was **WAAAAAAAAAAAAAY** OFF in my belief that Novant Hospital System would run up a total of about \$100,000!

I have yet to have the port removed, and I still have to do radiation and two to three spinal epidural chemo shots (as "preventative protocols dictate), and the bill is over \$150,000 as of yesterday... see the photo.



Yes...\$156,411.57 is the billing to my Insurance Carrier - United Healthcare. Medicare - which means the government. .. which means the taxpayers, pay the bulk of the costs, so this is why the Healthcare System is broken- badly.- UPDATED on 10/19/2021 - The final cost exceeded \$200,000.

Yes, I got the benefit of being able to live rather than die from cancer, but I cringe knowing that I only had three chemo sessions and my insurance was billed over \$200,000. I can't imagine what major lung or breast cancer surgery and chemo would cost insurance companies and the government – meaning **YOU!**

The people who do not have insurance ... or who don't have enough coverage lose their lifetime assets to pay for healthcare, and that's a shame.

I hate to leave on that note, but thought it would be appropriate to announce the true billing that has happened so far. Apparently, the billing did hit the \$200,000 mark when all is said and done.

John C. Tyler, Author

UPDATE -AUGUST 9, 2021

I think I should bring you up to date based on things that have or have not happened since my last writing a few months ago.

I was told to see the radiation people about getting several rounds of radiation. I always thought it would be a situation where I would go in for a consult and the radiation specialist would recommend that I take the minimum radiation dose of "30 gray units" five days a week for about three weeks, and that the radiation would center around where the cyst first appeared ... the lacrimal duct area.

When I arrived for the consult, the specialist scared me half to death!

He said, ***"Well, we're going to give you radiation of 35 gray units and that translates to 3,500 units of radiation therapy. Once we radiate the eye socket***and I stopped him right there.

I said, ***"It's been my understanding that radiation would only be targeted at the tear duct.... not the entire eye."***

He replied, ***"Oh no, we're radiating the entire eye socket and anything over 1000 units will burn the retina and a few other layers within the construction of the eye, so your vision in the right eye will likely start getting blurry and you'll have to have cataract surgery ... and we can't guarantee that your eyesight in that eye will be restored."***

He also wanted to have me go upstairs and start assembling the "mask" that one wears when being facially radiated and he wanted me to do that right after his consult.

I then asked, ***"Aren't you supposed to get pre-authorization from United Healthcare prior to any procedure?"***

"Well, er ah yes that's true, but generally they agree to our program."

"So, does that mean that you have not consulted United Healthcare yet and you want me to immediately go through what sounds like an expensive procedure. So the face mask build must be complimentary?"

He didn't think that was funny!

At the end of his speech for about an hour... telling me that the radiation is given to make sure there is no cancer in that area.

I told him that my Pet Scan revealed that there is no sign of cancer.

He said, ***"Well, there COULD BE microscopic cells that a Pet Scan would not detect, so that's why we radiate the eye area."***

At the very end of the consult, he asked if I was ready to go upstairs and start the face mask. To me, it meant that the face mask procedure would guarantee him the fees for his services and that if I did the mask now... it means I'm allowing the radiation therapy.

I said, "No, I'm not going to take on the mask at this point, I want to think about your consult. You say I will lose vision in my right eye based on the thought that there COULD BE some stray cancer cells there, but my vision is fine in my right and left eye, so that's a known fact right now. If I radiate, I can't see out of my right eye..and I need my eyesight to drive or to do things around my new house that I bought."

He seemed a little perturbed that I wasn't complying with his desire to get me into his program immediately.

He then said, "Okay... but we need to get going so let me know soon if you plan to go through with the radiation."

I already knew my answer, and it would be that my eyesight is good now... his theory that a few micro cells of cancer might be lurking in the eye socket ... and that he was rushing to give the procedure without getting pre-approval from my insurance company told me all I needed to know to tell him... ***"NO way, Hosea."***

I consulted with my family and told them what I just told you and they all agreed that it was better NOT to get the radiation.

I then contacted my oncologist that night and told him I was not going to go through the radiation therapy. I received no response... until my meeting with him on the 17th of June. At that consult he asked why I refused the radiation and I told him that I sent a long note to his office the day of the radiation consult, but then I repeated my story that I just wrote to you.

He seemed upset at the radiation specialist for telling me that I would lose my eyesight (whether temporary or permanently was not known), but he said, ***"Well, it's been a couple of months since then, so radiation would be of no value at this point. If the lymphoma comes back, I guess we'll have to treat it again the same way we did when it was first diagnosed."***

So, I never went through any radiation therapy... and I feel great!

I did develop something from the chemo regimen and it's called **"peripheral neuropathy"** which means when I walk, both feet feel like I'm walking on sponges, and my finger tips are in "tingle mode" and sensitive. Peripheral means extremities and neuropathy means nerve damage.

So, that is something I have to live with for the rest of my life. can take drugs to relieve it, but there's no pain involved only weird spongy feelings when I walk. I'm not into taking all kinds of prescriptions because in the end... all they do is kill your kidneys and you end up on dialysis or dead!

And the best news is that all my hair grew back in... and I got my first haircut since December of 2020 on August 6th!

I worked on my new house by installing an electric fireplace, painted every room in the place and tore the kitchen apart so that I could add more cabinets and paint all the doors white instead of the ugly 1961 brown!

I also built my "green screen studio" again in the new house where I can now enjoy doing my hobby... which is to produce videos for my YouTube channel at www.Youtube.com/jtylermusic.

I do Country & Western songs there, and have a following of over 2,500 people, so I can't sing that badly! The more recent video that I just did on August 8, 2021 shows my virtual office - using my green screen studio, but it shows all my beautiful white hair all grown back in... and this is after the haircut last week!



Yes... the office is fake....the desk is fake, but I make everything look real using the green screen technology that I have always used to make it appear that I can be anywhere that my imagination can take me! @

It's something that I enjoy doing....whether singing or doing videos about how to change copper plumbing over to the new Shark Bite or Pex technology or doing this video about end of days prophecy (which we are definitely in), or singing songs.

I have also written 13 books believe it or not....(www.RelationshipBooks.com) - but none since the cancer, but I was busy fixing the house and now doing videos once again, so I'm enjoying life because we never know when God calls our name to be present with Him.

UPDATE - SEPTEMBER 16, 2021

The good thing about an e-book is that I can update the progress (or lack of progress) at the time I receive information about my lymphoma!

As you now know, I refused to take the radiation treatments because the radiation doctor from another hospital organization than Novant told me I'd lose my vision to one extent or another almost immediately after the treatments.

I reported this to my Oncologist at Novant during my June scheduled consult. The Oncologist decided to see for himself what, if any damage was done to the eye, the eye socket. .. to my sinus areas... to the nose area... to the tear duct area and even to my brain. He scheduled an MRI that would happen on September 8th - one week before my September 15th consultation.

The results of the MRI are:

MRI OF THE BRAIN AND ORBITS WITHOUT AND WITH IV CONTRAST - Marked decrease in size of the previously demonstrated lesion at the medial right orbit.

COMPARISON: January 12, 2021 FINDINGS:

Orbits:

The previously demonstrated large infiltrative mass lesion involving the inferomedial right orbit is significantly decreased, nearly completely resolved.

No definite findings of intracranial extension.

Noting the stated history, the lacrimal glands appear overall symmetric. No current MR evidence of a mass lesion at the lacrimal glands.

The optic globes appear overall symmetric. The extraocular muscles appear within normal limits. - No pathologic signal alteration or abnormal enhancement of the intraorbital optic nerves is demonstrated.

No suprasellar mass or mass lesion in the cavernous sinus is demonstrated. No mass effect on the optic chiasm is demonstrated.

Brain:

The ventricles are overall symmetric and borderline prominent, similar to the prior examination.

There is no evidence of an abnormal intra-axial mass lesion, significant mass effect, midline shift, recent hemorrhage, or pathologic extra-axial fluid collection.

The included portions of the paranasal sinuses and mastoid cells appear predominantly clear.

I reviewed the findings the day the MRI was performed ... which was 30 minutes in the tube with head-pounding noises....then a contrast dye infusion... then twenty more minutes of time in the tube with the head-pounding noises.

I sent the findings to the Oncologist who I know gets the findings when they post on the "MY CHART" website available to the patients and physicians.

When I met with the Oncologist yesterday - September 15th, he reported to me what I already knew and that is that there were NO PROBLEMS associated with any of the areas suspected of having any lymphoma whatsoeveryet lymphoma can come back in the future... and I hope it never does.

He said, "***See you in December, and congratulations on the good findings.***"

I thanked him and I said, "***Doc, you've got to pat yourself on the back because your treatments for the cancer seem to have produced the desired results ... remission.***" (At least I hope that remission is for real!)

He patted himself on the back and said, "***See you in December ... and again - congratulations***"

They always take blood samples to ensure that there are no elevations or decreases from the norm. This blood testing is key to an early sign that further information might be needed.

My blood tests have been excellent - all within normal ranges since the last chemo session happened back in February. I won't post those results here because the data is meaningless to anyone not familiar with the types of testing that goes on, but anyone can understand that if the limits are in range of the norms, it's all good.

The Oncologist also said, "***John ... see you in December, but there are no tests or MRI imaging or anything lined up beforehand***"

That tells me that if blood tests appear normal ongoing ... maybe one day the Oncologist might say, "***See you in six months!***"

So, I've been through the battle with cancer, chemotherapy and portacatheters installed, blurred vision, painful eye surgery, horrible leg cramps....and the latest is the nerve damage causing peripheral neuropathy in my feet. I still get horrific leg cramps every now and then, and have to live with the "weird feet" feeling forever....but - I'm alive, so for that I am thankful.

That's a wrap for now.....have to see the oncologist on December 15th again, and starting in 2022, my co-pays will go back to where I have to pay up to \$3,600.00 out of pocket for things that have to be taken care of.

Hopefully, the lymphoma will stay in remission.

John Tyler, Author

I asked myself, "***How did I contract large B-Cell Lymphoma at this time in my life?***"

It appears that it happened to me after using Roundup, and I think I know how it happened. I've used Roundup in the regular, more expensive gallon bottles with a battery-operated spray mechanism all through the years from about 1975 December while living in Massachusetts through the time I moved to North Carolina in 2016.



The attached sprayer on the bottles may lessen the impact that Roundup would have on lungs or eyes because it's sealed and the sprayer would be several feet from the body and I'm not a medical expert, so it's just my guess.

When I bought a 2-acre house in Monroe, NC in 2017, the property had a lot of weeding to do around the house, under the large deck out back and also along my 540' long gravel driveway.

I sprayed Roundup on all the areas you can see in the aerial view of 5007 Myers Road in Monroe, North Carolina....around the garage and pool areas...and down the 540' long gravel driveway.



The gravel drive would “weed up” about every two weeks, so I would spray from the center and right side - to the street, then work my way back from center to right toward the house.

During my stay in North Carolina, I noticed that Lowe's prices for the spray bottle was over \$20.00 a gallon...and 5007 Myers Rd. would use two gallons...and right below the spray bottles were gallons with no sprayer they were refills, but under \$15.00.

Of course Lowes sold Roundup sprayers in a two-gallon size, and they required pouring the Roundup refills into the larger sprayer.

So, to save the money, I would buy Roundup refills and bought the sprayer which I kept in my garage.



I would have to refill the gallon lawn and week sprayer two times for every two week weeding event.

That went on from July of 2017 to March of 2021 when I sold that house and bought a house at 1102 Virginia Avenue in Monroe.

While pouring the REFILL gallon into the top of the sprayer, I recall that it stung my eyes and was harsh on my lungs.

I had no idea since 1975 that Roundup has a carcinogen so I never thought I'd need gloves or a mask to use it....until It became a news media article.

That was after I was diagnosed with lymphoma on December 23, 2020 and went through chemotherapy during 2021 and had to take four spinal infusions in my central nervous system to prevent the lymphoma from spreading to my brain.

Once I was finished weeding – using the first gallon, I would release the red vent on the sprayer to reduce the pressure inside – to add the second gallon.

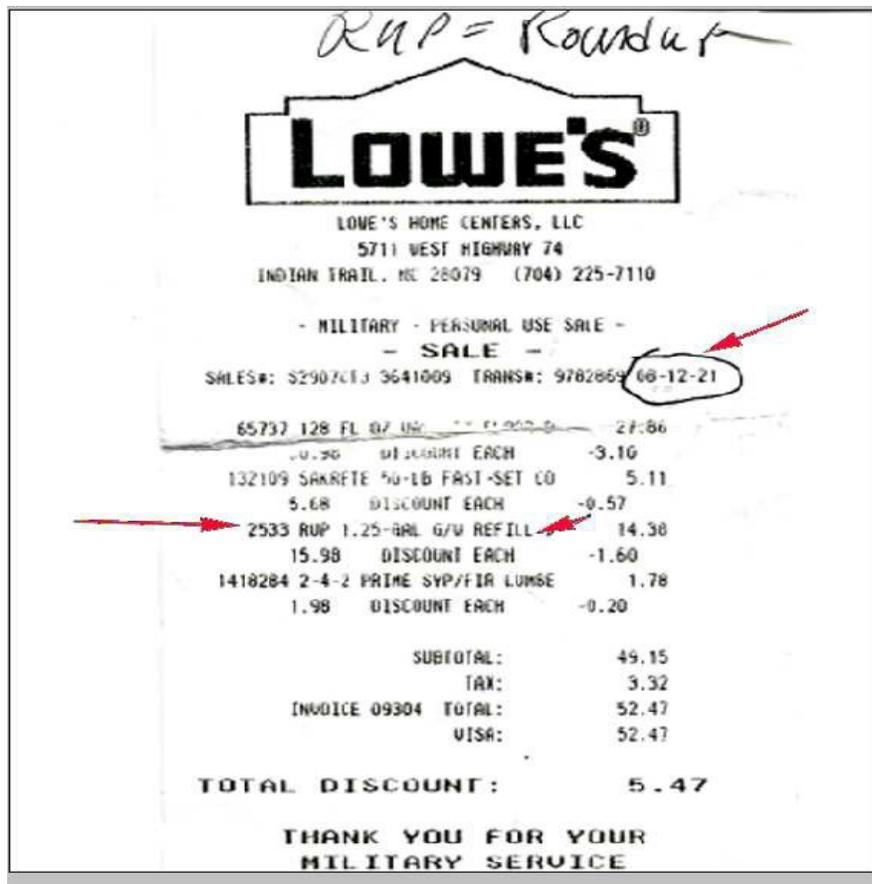
The fumes released from the bottle also caused my eyes to burn and breathing it in was unavoidable. I also vented the sprayer after using the second gallon for those three years at that house.

In November of 2020, I saw a cyst under my right eye. I consulted my physician and she told me to put ice on it or a wet cloth and see if the cyst shrinks! She then told me that I should see an eye doctor because my right eye was getting blurry.

And, from there, you have already read the major part of my book detailing the time from diagnosis to now...although NOW means that the Lymphoma can come back at any time so I have to see the oncologist every six months...probably forever.

Once people have cancer..and I'm speaking for myself, we know that the possibility of seeing the cancer come back is always there always a threat.

Lowe's calls Roundup as "RUP" on their receipts. and I found one from 2021.



UPDATE – January 26, 2024

Sometime in October of 2023, I noticed a small growth on the right side of my forehead. I paid little attention to it because I figured it would disappear soon enough.



Well, during my six month physical check, my general practitioner, Dr. Elizabeth Murray, asked, ***“So, what is that on your forehead?”***

“How long has it been there?, she asked. - ***“About three months”,*** I said.

She said, ***“I’m sending you to a dermatologist.”***

I saw David Dorenfeld- the Dermatologist in Matthews, North Carolina and he said, "I'm going to numb your forehead and take a slice of that and send it out for biopsy because it looks like **"Squamous Cell Cancer"**.

Not having any idea what squamous cell carcinogen is, I Googled it and discovered this:

I heard about Basal and Squamous cell skin cancers from a nurse friend of mine whom I went to high school with.

Google revealed, - *The most common type of skin cancer, [basal cell carcinoma](#), affects the basal layer of your [epidermis](#), or the outer layer of your skin. This cancer is caused by a change in the DNA of your basal cells that makes them reproduce too many times. This is usually caused by an over-exposure to ultraviolet (UV) rays from sunlight or tanning beds. A genetic condition known as basal cell nevus syndrome can also increase your chance of acquiring this condition.*

Basal cell carcinoma tends to appear like a pink little bump surrounded by blood vessels, but it can also develop a lavender hue. This kind of skin cancer doesn't tend to [metastasize \(or spread\)](#) to other areas of your body, but it can grow anywhere on your body that's been exposed to sunlight. Basal cell carcinoma is also slower-growing than squamous cell carcinoma.

"Because these grow very slowly, a lot of people just dismiss them and think of them as little pimples that aren't healing," says Dr. Poblete-Lopez. "Depending on where they are on your skin, they can also look red or scar-like."

And Google further explained "Squamous Cell Carcinogens...."[Squamous cell carcinoma](#) is the second most common form of skin cancer caused by a genetic mutation that leads to an over-production of squamous cells near the top layer of your epidermis. Like basal cell carcinoma, this genetic mutation is caused by an over-exposure to UV rays.

Squamous cell carcinoma can appear anywhere on your body, but it's more commonly found on the parts of your body that are exposed to the sun like your hands, arms, head and neck and the parts of your face that protrude like your nose, cheeks and ears.

Squamous cell carcinoma can appear as a dry, itchy or scaly pink patch of skin. Sometimes, it causes a growth or bump to appear that has a depression in the middle. This type of cancer also tends to bleed and scab in response to minimal trauma and tends to cover a larger surface area than basal cell carcinoma.

*"Squamous cell carcinoma tends to be more pink and scaly," notes Dr. Poblete-Lopez. **"If you notice any pink or scaly patch that isn't healing appropriately, you should bring it to a dermatologist's attention."***

Who knew?

Well, now YOU and I both know, so be careful to notice any changes in your skin....especially sun worshippers!

I was not a sun guy, although I never wear a hat while mowing my lawn and I don't usually sit out in the hot sun, so I looked to see if it had anything to do with my Lymphoma.

I found this: From the National Library of Medicine

*“The link between immunosuppression and skin cancer has been well described. **The two most common situations involving immunosuppression-associated skin cancer are solid organ transplantation and non-Hodgkin lymphoma. - Patients with lymphoma are more likely to have development of a secondary malignancy, with skin cancer being the most common.** The most common types of skin cancer in patients with NHL/CLL include melanoma, **squamous cell carcinoma**, basal cell carcinoma, and Merkel cell carcinoma.*

My nightmare of continuous cancer treatments started to bother me – again!

The biopsy came back and it was “**Squamous Cell cancer**”!

The dermatologist set me up to see a “MOHS surgery doctor in Charlotte- scheduled for January 26, 2024 at 8:45 AM.

I had to Google “MOHS surgery” to find out what I was in for.....
and this is good for YOU to know as well.

*“Doctors use Mohs surgery (also called Mohs micrographic surgery) to treat **skin cancer**. The goal is to remove as much of it as possible while saving the healthy tissue around it. Layers of **skin** are removed one at a time and examined under a microscope until all the **cancer** is gone. This reduces the chance of needing future treatments or surgery. -A doctor named Frederick Mohs developed the treatment in the 1930s. While newer ones have come along in recent years, many surgeons still rely on this procedure to treat **skin cancer**. It is considered the most effective treatment for two of the most common **types of skin cancer: basal cell carcinoma (BCC) and squamous cell carcinoma (SCC)**. It can also be used to treat other kinds of skin cancers.”*

So, it appeared that I would have to go see the specialist to have the cancer cell removed. Little did I know how deep the guy would go!

I arrived on time in Charlotte on the 26th (I'm typing this on January 27th ,,the day after) so it's very fresh in my mind.

A nurse brought me into a room with a large reclining chair and told me to lean back...which I did. She then handed me a metal paddle looking thing. I asked what that was for as she laid it on my stomach,

“That's a metal paddle and when I cauterize your wound later, it generates a shock so the paddle is a negative or grounding device.”

“Whaaaaa? I asked myself! - I'm going to be cauterized? Bleeding? Blood”

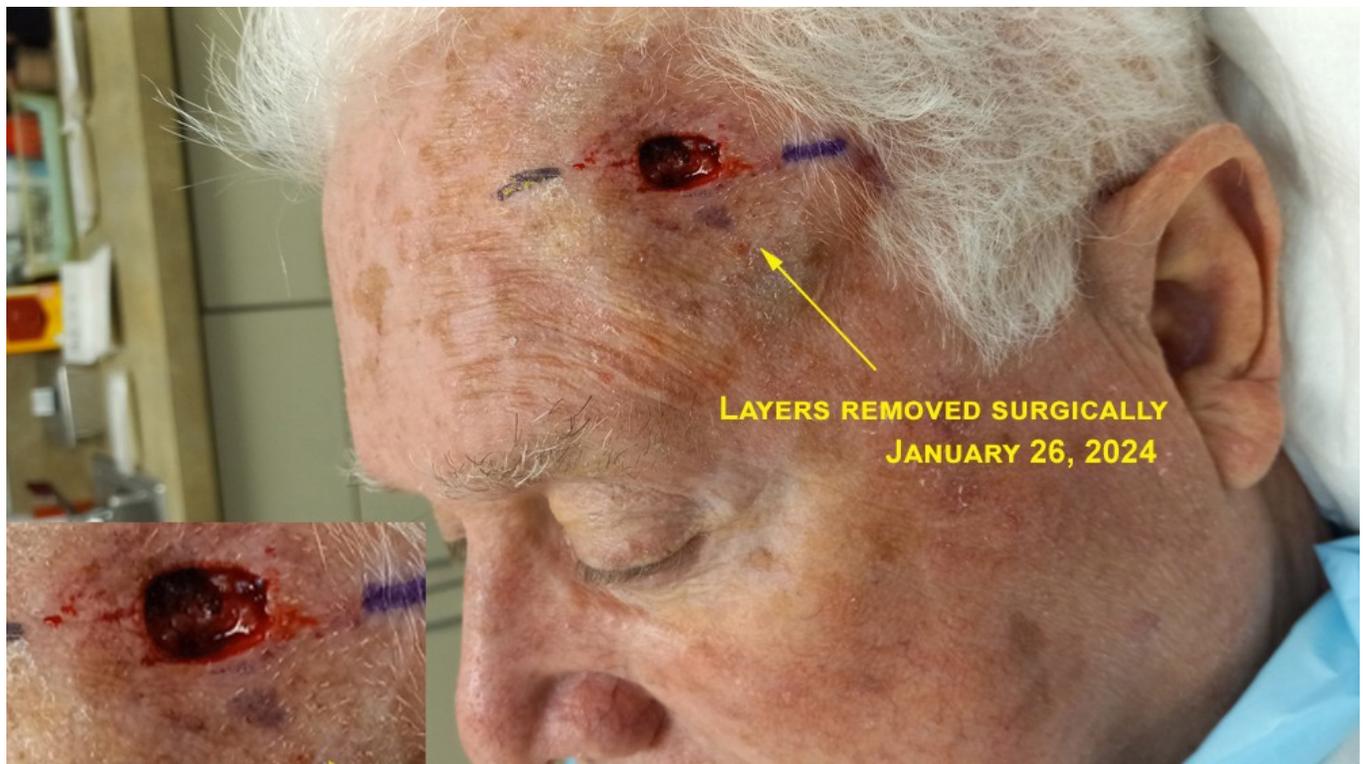
The surgeon came in after I received several shots of lidocaine to numb where he was about to slice the skin....and once numb, he began to take some skin off.

I didn't feel it. - The nurse sent me into a waiting lounge with coffee, water, orange juice and crackers to wait about an hour for the biopsy to be done.

“Well, we got most of it, but there's still a bit of the cancer left so the doctor will have to take more skin.”

Back to more lidocaine and another scalpel job.....

I asked the nurse to take a photo after she cauterized the bleeding blood vessels...although I really didn't want to see the photo then!



I'd say this wound is pretty gross!

If I expanded the wound area - it...well maybe I will. As gross looking as it will be I wanted to show you readers something..... You will see a white “Y” shaped thing in the wound.....it turns out that it's my skull!



Sorry – I know it's gross, but this is what I live with these days.

It turned out to be a much larger wound than I ever thought it would be!

However, the GOOD NEWS is that the cancer on the forehead is now gone.....and the surgeon stitched “cat gut” into the deep part of the wound and he had the nurse finish stitching the top layer of skin to completely close the wound up.

She finished, and put a huge bandage on the wound. She prescribed an antibiotic medicine – a five day supply and I would take two horse size capsules once a day. She told me to come back on Friday, February 2nd to have those top stitches removed.

I'll show you the bandaged wound next and after that the morning after I removed the bandage. I was supposed to (and did) put Vaseline that they gave me on the wound and put a band-aid on it until the stitches were to be removed, but the cloth part of the band-aid was too small so the sticky part would cover the stitches. I didn't use the band-aids because I didn't want to pull the stitches out prematurely.



The wound measured "4 centimeters" which is 1.56 inches wide!

I noticed that the surgeon cut further to the left and right of the wound so that he could sew the stitches into the deep part of the wound and then have the nurse sew th lighter stitches in an effort to fold the kin over the wound. They did a great job in my opinion, and I believe it'll heal up nicely over the next few weeks or a month.

I'm really hoping that this Lymphoma stuff doesn't keep bringing about these Squamous cells anymore. It's been a rather long ordeal thus far and it's no fun having to go through it. That said, I am also hoping that YOU will gain some knowledge about Lymphoma...about Roundup and about skin cancers.

Also, I plan to wear a hat – no matter what when I mow my lawn or I'm out in the sun for more than 15 minutes...just in case!

I'll update if anything new happens....

John Tyler, Author

closing on January 27th at 3:45 PM
