

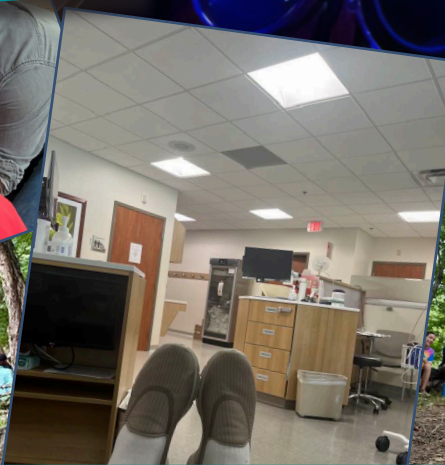
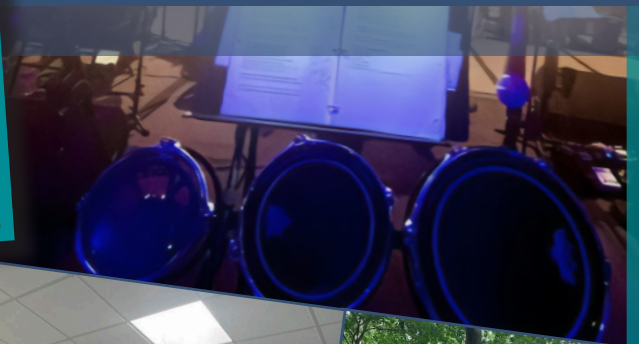


I Was Fine a Minute Ago:

My First Year with Myasthenia Gravis

By: Ron Fredman

supported by:



Introduction

Ron Fredman smacked into myasthenia gravis in mid-2023. Before that, he thought MG was a type of sports car; now he's a living, breathing member of the Snowflake Club. These tales, filled with humor and honesty, chronicle his experiences along the way.

Ron's social media postings on MG and other daily doings have earned a solid following. As he tells it, you can believe about 80 percent of what he says. It's up to you to figure out which 80 percent it is.

Ron enjoyed many years of professional success, including record-breaking seasons as chief fundraiser for the Kansas City Symphony, Houston Symphony, Kansas City Ballet, Phoenix Symphony, and Sacramento Ballet. He retired as a Chief Operating Officer for a financial advisory firm in 2022.

He began his career as a sportswriter at The Kansas City Star and worked in advertising and management consulting. Ron studied political science at the University of Missouri-Kansas City and served as an adjunct faculty member at Lansing Community College in Michigan.

He has been a Scoutmaster since 1981 and is a recipient of the Silver Beaver, the highest recognition a local Boy Scout Council bestows on a volunteer. He sits on the Olathe (Kan.) Public Art Committee, is Recording Secretary for the Kansas City Ballet Guild and is a board member of the Friends of Chamber Music Kansas City, among other organizations. His civic involvement, locally and nationally, goes back decades.

Ron is an avid book collector, outdoor lover, and a fan of curiosities large and small. He writes most days and truly appreciates the joy his stories bring.

Ron, wife Tricia, and dogs Willow and Ten Pounds of Tough Phoebe, live in the Kansas City area. They (Ron and Tricia, not the dogs) have three daughters and a bushel of grandkids spread around the country. In this ebook, Ron uses a conversational, journaling style based on a chronology of days and events with MG. He hopes you enjoy the freewheeling and honest approach to how he has been dealing with MG.



This ebook and its contents solely reflect the experiences, opinions, and perceptions of the author, Ron Fredman, and in no way reflects or represents the specific opinions of the MGFA, its staff members or Board. This content should not be used as medical advice or guidance nor should be construed as a treatment path for MG. Patients should always consult with their own team of doctors and neurologists concerning treatment.

May 20, 2023

Hi all.

Well, ain't this a kick in the pants?!? Seems likely I've developed myasthenia gravis. Good old MG is an autoimmune disease where muscles and nerves ignore each other. Oh, they both work fine. Just not together.

It's like having a great pitcher and a darn good catcher, but the baseball's broken. All they can do is wave. You're certainly not going to strike out too many batters that way.

Speaking of baseball, you could just about fit all of us Americans who have MG inside the KC Royals' stadium (at least they'd have a sellout for a change). There might be another 10,000 or so out in the parking lot, probably tailgating before the Chiefs game kicks off next door at Arrowhead.

I've always wanted to be part of an exclusive club. Somehow, though, this isn't what I had in mind.

The silly thing manifests itself with symptoms like trouble chewing and swallowing, droopy eyelids and face muscles, overall weakness, and blurred vision. Breathing can be a problem in serious cases, but so far so good in that department. I also can't puff out my cheeks or curl my tongue up over my front teeth much anymore. I used to get such joy out of doing both (I entertain easily).

One thing that really bugs me: It's difficult at times to speak coherently. I start off okay but swiftly degenerate into a nasally Elmer Fudd After a Big Night at the Tavern. Oh yeah. And sometimes a drink of water runs up my nose. From the inside. Dandy. Just @\$!*^% dandy.

I guess this has been coming on for a while now – I even wrote a piece a few months back lamenting my lost ability to whistle, though that could be because of some other muscle issues I'm dealing with. But in the last couple of weeks, things have gotten a bit nutso.

It doesn't surface all the time, just when I'm tired or have been talking a lot (which is pretty often). When I rest, it calms down. So weird.

Luckily, it's treatable. There are good medicines out there that can check the symptoms and return me to my fairly normal abnormality. I'm looking forward to starting those pills, though first I have some more tests to do. That includes a return to the House of Horrors and their Electro-Shock-O-Matic 2000 Muscle Twitcher (aka electromyography and single fiber EMG). Whoo hoo. Can't wait.

I have a couple of great docs looking out for me: an internationally recognized expert who runs the neurology department at the University of Kansas Medical Center, and a dear friend who's the resident MG guru at St. Luke's. They've assured me this, too, shall pass (or at least be managed).

Regardless, I'm going to keep on keeping on, doing what I can when I can. Like always.

If nothing else, I have new adventures to write about. That's something, I reckon.

Stay well all... and so will I.

PS. Tricia, my wife, has been grand since this flared up (not that she wasn't before). I'm so blessed to have her at my side. And making chicken soup. Wonderful, super-tasty chicken soup. With homemade noodles, no less. Just another of Tricia's delicious dishes sure to cure what ails ya.

May 26, 2023

One of the "joys" of dealing with my latest health issue is the chance to return to the hospital lab. It's a place of such fond memories - a repository of wild-eyed phlebotomists, harpoon-sized needles, and blood and gore galore.

You know that notch on the other side of your elbow, the part facing you? Well, mine's a lovely red and blue right now, courtesy of a nurse who thought it fun to work her school colors into my skin.

Finally, she hit a gusher. Seven or eight vials of vital fluid squirted right out of me. It was my third blood draw of the week, BTW. The other two were just as much fun.

I know my juice is on its way to parts unknown for review and assessment. Lab techs in some dark, dingy dungeon will spin the blood and squint into their microscopes. They'll toss sulphur in the jar and add powdered eye of newt. They'll dance around a bubbling caldron and shriek at the moon. That's just what they do.

Tricia, a former lab tech herself, assures me they'll find all sorts of interesting things floating about. What they are, I'll know when I know (though reading the reports is about as easy for me as deciphering Akkadian). I'm sure they'll mean something to somebody. Preferably somebody who's a doctor.

Until then, I'll just sit quietly and nurse my wounds. I started to say "lick my wounds" but, by goodness, I still can't lick my elbow.

I can't lick my elbow. I can't whistle. I can't shoot a three-point shot at the buzzer. I'm a mess.

At least I can still laugh.

Stay well, all... and watch out for sharp objects and those who wield them.

PS. By the way, that bend in the elbow, what we mere mortals call the "crook," is the "cubital fossa." "Cubitum" means forearm in Latin; the cubit length is related. The Germans called the forearm "ell," as in elbow (the place where the ell bends). Fossa means "trench" in Latin. It's also a type of Madagascar mongoose-cat thing that hides its anus (I guess that last part's a big deal). The stuff you learn when you're not looking...

May 27, 2023

One of the screwiest things about this myasthenia gravis is the way it messes with my speaking. After a meal or at the tired end of the day, I start blubbering like a fool with his tongue in a vice. Sometimes it happens in the middle of an otherwise normal sentence. I guess at that point, my muscles have just had enough.

Of course, I'm making the best of it, and Tricia and I are enjoying a good laugh. I have learned how interesting it is to spit out certain words (with lots of spit), especially those one would consider not suitable for a family newspaper – if there were such a thing anymore.

Here's an example: Shthiiitpfft. All the letters you need are there. Just get rid of the extra ones.

Tricia enjoys repeating it back to me. Somehow, when she tells me I'm full of shthiiitpfft, it doesn't seem quite so bad.

True, it's a made-up word. I double-dog dare you to find a word that WASN'T made up at some point. So there.

But get this: I found a solution to my vexing glitch. That's right. Before the doc has given me my first pill, before all my testing's even done, I've fixed the speech problem.

All I have to do is rest my chin on my hands and push up along the side of my face.

Ou la! The slurring goes away and I sound nearly normal.

Of course, doing so makes me look like a dork. I know. I checked.

Tricia thinks it would help if I wore a big yellow bow in my hair when I cop that pose. One with lots of black polka dots. And bob my head from side to side.

What a sweetheart.

I tell you what: If she makes me do that, she won't have a BIT of trouble understanding everything I say to her. Hide the children.

Stay well all... and shthiiitpfft to illnesses of all kinds.

May 30, 2023

Among the maddening symptoms of this ailment I'm fighting is double vision. Imagine my chagrin when I looked toward the shed out back and saw double bike wheels.

Then imagine my relief when I remembered we really do have two bicycles. Phew.

Another thing I'm seeing double (and triple, and quadruple) of: the University of Kansas Medical Center.

Starting this afternoon, I'm a 10-day guest of this fine facility. They're going to scrub the bad

myasthenia gravis crud out of my blood and replace it with good, clean stuff. It's kind of like getting your radiator flushed.

I'll alternate between a day of treatment and a day of rest. That all but guarantees I'll have plenty of time on my hands to get bored and write exciting updates about sitting around and being bored. I'm already very enthusiastic about the third time I'll work my way through the in-room menu. Yum.

My biggest fear is that the juice they put into my blood stream will have some secret KU sauce that turns me into a raving Jayhawker. As a Missourian by birth, I can think of few horribler horrors!

When this is all done, I'll have a series of weekly medicine IVs for a while. Then some maintenance after that. I fully expect to be as good as new.

A special thank you to my caring loved ones, especially Tricia. Fear not. You're stuck with me for a darn long while!

Stay well all... and I'll be seeing you (maybe twice).

PS. I hope the nurses don't wake me up at 3 a.m. to ask about extra pillows or tell me to go to sleep. Been there. Done that.

May 31, 2023

Well, I made it through the first night at KU Med Center in one piece. That's something.

Of course, it was a pretty easy go. I got here and settled into a nice, newish room. I visited with Tricia for a few hours, nibbled at some food and watched the rain blow through. That was pretty much that. The real fun starts today.

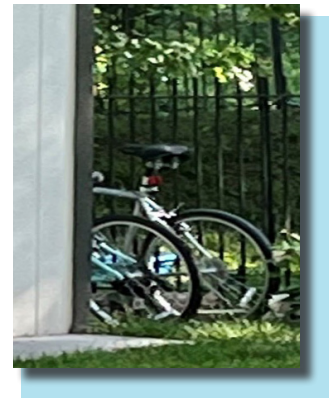
Last night wasn't a total do-nothing, however. I did get a nice bruise on my hand where someone with a needle couldn't find a vein. And I got a CT scan. That was fun.

Actually, the CT scan had me kind of thrilled - at first. The nurse came in and said we're going to give you a "Cat Scan."

Great, I thought. I'm not a big cat fan (I'm a puppy kind of guy) but figured, the way I've been talking by day's end, maybe we could find that darn cat that's got my tongue. As they wheeled me down the hall, I kept looking for felines. I did my best Sylvester the Cat imitation as a spit-filled, "Here kitty kitty" slurred out my mouth.

Nada. As in nada single whisker anywhere (except on one of the nurses, but she kept it nicely trimmed).

Then we entered the room.



Dang. Still no cats. I'd been duped.

There was, however, a giant talking donut in front of me. That looked interesting (though I much prefer glazed to high-tech). They laid me on a conveyor belt, rolled me in and started snapping shots with this whirring, rolling thing zipping around the inside. A few minutes and I was done, and on my way back for a restful night's sleep.

Restful, except for the fact that they kept waking me up to check my "vitals." I guess it was vitally important to see how my blood pressure was doing at three o'clock in the morning. I can tell you what, it would've been a ton lower if they had let me snooze.

But, and here's the highlight so far: At first light this morning, I thought it was a good time to get up and visit the facilities. I whipped off the cover, rotated to the bed's edge and stood up.

You would've thought I had just tried to escape Alcatraz. Alarms started wailing. Red lights under my bed were flashing. It was chaos. Pure chaos, I say.

And — and this is the God's truth — as soon as I said, "the heck with it" and headed to answer nature's call, a giant flash of lighting and roar of thunder crashed outside the window.

"Okay! Okay!" I shouted. "I get it. I'll go back to bed."

Man, these people are serious.

Turns out someone had left the fall-risk alarm on, and my bed was just doing its job. The nurse assured me it was a mistake. Of course, there's a sign outside my door that says, "Fall Risk." And they gave me the yellow "Fall Risk" socks. Seeing all that, I'd turn on the alarm, too.

Stay well all... and stay tuned to my exciting adventures at the Blood Wash later today.

May 31, 2023

It's nearly 8:30 p.m. on my first full day. So far, so good.

I had my Inaugural Blood Washing this afternoon to combat myasthenia gravis. Quite the affair.

It started during breakfast, where they interrupted my "delicious" shoe-leather turkey sausage link with an order to hop on the waiting wheelchair. We were off for a jaunt to the Cath Lab. Half a mile later (no fooling) we arrived, and they stuck me in a holding pen. I waited and waited, missing the sausage link left behind (pretty subtle joke, eh?).

Finally, they pushed me into an operating room where a bunch of students eagerly awaited a shot at my neck. First, they laid me on the table, wrapped me up like a sterile Quick Trip Burrito and commanded me not to move. They even told me to keep my thoughts clean. That became more and more difficult the longer I was on that slab.

One by one they took turns poking me to see who could do the best job shoving a double-hosed catheter into my vein. After an eternity or two, a doctor made a few doctor-like comments, and

drove the thing home. Now I know how a voodoo doll feels.

After that, it was on to the main event.

There's this machine that sucks the blood from me, using the red hose sticking out my neck. It drops it into a spinner that splits the plasma from the rest of the blood. With the plasma goes the bad antibodies causing me trouble. Of course, the good ones hitch a ride, as well... but we'll deal with that later.

Albumin, one of the things in plasma, takes its place as the spiffed-up juice returns via the blue tube. Then rinse and repeat.

This took about two tiring hours and moved nearly three liters of the stuff. I spent the whole time doing nothing. Nonetheless, I certainly felt drained afterward. In more ways than one.

For my KU grad friends and other assorted fans, the sauce they put in me did not change my loyalties. Many of you, in fact, were telling me just to wait until they started running that crimson and blue potion through my veins. It would just be a matter of time before I started shouting "RCJH" or some such something like that.

Sorry to disappoint, but:

The liquid was a golden hue. The labels featured black and blue.

Part Mizzou. Part UMKC Roo. Not a drop of old KU.

I do have four more treatments, so I suppose anything can happen. Don't count on it.

Stay well all... and I can't wait to see what the morrow brings. BTW, I can see Missouri from my window. Great view!

June 1, 2023

Good morning, and happy June!

Today's a day of rest for me. So, what could be more appropriate than a zombie waking me up just past midnight to take my blood pressure? And if that weren't enough of a great start to a soothing 24 hours, they repeated the dream-breaker at 3 a.m. and again at 5 a.m.

At least they care, right?

Actually, I am being treated well here; the folk certainly know their stuff. And I am confident once this five-session Blood Wash is behind me, I'll be well on the road to managing this darn myasthenia gravis.

Because of chewing and swallowing issues that expand as the day wears on (and I wear out), the good doctors changed my diet from "Heart Healthy" to what they call "Soft and Bite-Sized." With true enthusiasm I perused my new menu.

“Hmmm,” I thought. “This could work.”

Heart Healthy had decent options, like a piece of grilled salmon. Sure enough, there it was again among the Soft and Bite-Sized selections. Only, now, I discovered, they cut it up for you first. Such a deal. If I could just talk them into coming in and moving the food-laden fork around like an airplane, I'd be one happy camper.

I think today I'll sample the pureed pancake for breakfast (yes, it's on the list) and maybe some pre-chewed creamed peas for lunch. Yum.

It is funny, though. When I ordered dinner last night (Salmon, “Mommy Style”) I asked if I could have a side of home fries from the “served all day” breakfast roster. “Nope,” I was told. “They're not bite sized.”

Well, first off, what are they doing on the menu (unless they consider them soft, in which case they should call them soggy potatoes)? Good question, eh?

Or, if they didn't want to compromise the taters' tastefully crunchy appeal, why not send them through the very same process that turned a piece of fish into PIECES of fish? A chop here, a chop there, and voila, there you go.

I can understand not understanding most of what's happening when I get my bloodwork reports throughout the day. I have a lot of stuff whooshing around inside of me I never knew existed. If they tell me it's normal, who am I to argue?

But turning sliced potatoes into diced potatoes? Come on. Even I could handle that one.

Stay well all... and bon appetite!

June 1, 2023

I guess I shouldn't have besmirched the Soft and Bite-Sized Menu they put me on here at KU Med Center. Now I'm off of it, and on a feeding tube for a couple of days. Boy, this stinks.

I can tell it stinks because they stuck the thing through my nostril, down my throat, and into my stomach. Yeah, I know: “Up your nose with a rubber hose!” as Vinnie Barbarino would say on “Welcome Back, Kotter”. Ha effin' ha.

The docs are afraid I might aspirate something into my lungs until my swallowing improves, so this takes care of that risk. I'll get all my nutrition and medicine through this tube. I asked the nurse if she could slip a hamburger in there. She asked if I'd like fries with it. Everybody's a comedian.

Get a load of this: As the health gurus discussed this option with me, they also mentioned they'd start me on some myasthenia gravis medicine that sounded for all the world like mastodon. Tricia and our daughter Rachel thought so, too.

Okay.

So now they want to turn me into an elephant. That'll teach me for making fun of Jayhawks, I know I heard them say (I don't crack that easily). And if that weren't convincing enough, they shoved a yellow trunk on me. I swear, I'm going to be begging for peanuts any minute now.

Oh well... I'm sure it's for my own good.

Stay well all... and enjoy your dinner – just don't tell me about it.

PS. So much for a restful day.

PPS. I also get to move to ICU so they can watch my breathing. Now I think they're just piling on!

June 1, 2023

My first piped-in dinner's moving down the tube as I write. It is a gastronomic treat to beat all treats, I can tell you that. My compliments to the chef here at Chez Hospital.

I'm surrounded by opulence at this fine establishment. My private dining room is elegantly lit by glaring fluorescents and enriched by the steady hum of a bunch of machines. The décor? Early, with a decided Barbarian twist. Magnifique!

I must say, the food goes down smoothly, with nary an aftertaste.

I do note the rémoulade was a bit tart, and the twice-baked asparagus could've used a third go-round. But the grilled Porterhouse, medium rare, was nicely seared and finely smoked. It paired wonderfully with an '83 Old Vine Zinfandel. The salads and sides proved serviceable. The Pop Tart desert was a pleasant surprise.

All in all, I give it a solid 2 ½ stars.

Stay well all... and bon appetite!

PS. I'll be here all week. Don't forget to tip your waiters.

June 2, 2023

Top of the morning to you!

It was a decent night here in KU Med Center's Neurology ICU. I dozed between interruptions and didn't have too much trouble with the distractions all around. The medicine they started seems to be moving me in a good direction. My speaking is stronger, swallowing seems okay, and my breathing is getting better.

Now, if I could only convince them to pour a cup of coffee into my feeding tube....

I'm not out of the woods yet, but do feel confident I'm on the right path. The doc just stopped

by and told me if I keep progressing I'll probably go back to the main floor tomorrow. Fingers crossed. Hopefully that means I can return to the yummy chewable stuff that passes for food in these parts.

Today is my second Blood Wash to draw the bad antibodies out of me. I'm here for a total of five. Maybe I'll have them change the oil while I'm there. I'm sure I'm pretty sludgy.

I'm grateful to have such wonderful support from my friends. And a special loving thanks to Tricia and my family for being at my side.

Stay well all... and here's to a good day!

June 2, 2023

If you'd ever want a quick trip to Lala Land, have some liquid Benadryl placed in an IV. They gave me a dose before my Blood Wash this morning. Man, was I drifting.

And what a drift it was. I saw unicorns and puppies and singing flowers. The sky was yellow and grass was blue. I floated in a marshmallow pond and skipped with fishes along the shore.

Frankly, after reading that last paragraph, I'm kind of wondering if that was Benadryl at all. Maybe I got a quart of "the good stuff" instead. It probably was another attempt to convert me to a Jayhawk fan. I might have been in Lala Land, but my resolve stands steady.

Stay well all... and on I go.

June 2, 2023

One of the things I have to do a few times daily here at the KU Med Center is test my lung capacity. It's just one of those simple pleasures making life worth living.

Morning, noon, and night, the Breathing Lady shows up at my room. She pulls out her "Sucknblowmometer" and starts walking my way. This device looks like a crazy concoction made of used auto parts: a pair of hoses, mouthpieces/masks, and little dials with a hand that spins around.

She orders me to blow into one of the tubes. Sure enough, the dial starts dancing. Thankfully I didn't blow that test. Supposedly, my numbers are lookin' good.

Then she asks me to suck in a deep breath as hard as I can on Tube No. 2. Frankly, I suck at sucking. I've a ways to go on that, starting with continued strengthening of my diaphragm.

Tricia is convinced I'm trying to overperform so I can escape ICU. I try to tell her she's got it all wrong. I'm simply an innocent, active participant in my treatments. Of course, I add, I NEVER would try to sweet-talk my way out of anywhere or anything. Not me. Uh uh.

I try to tell her. She gives me the look.

But you know what, dang it? She's right. I guess she keeps her "Popiel Pocket BS Detector 4000" on maximum strength. I should know that already. It's gotten a lot of work over the years.

Thanks to her, now even the docs and nurses have my number. Case in point, a neurologist stopped by this afternoon to see how things were going. I started showing off my newly returned drinking skills and telling him today was perfect – perfectly perfect.

Before I could make my closing argument, this wiseacre with a stethoscope turned to Tricia. "Now," he said, "how's he really doing?"

Hey. You can't blame a guy for trying.

Stay well all... and you know what you call a wizard who walks everywhere barefoot, has poor bone density, and bad breath? Super calloused fragile mystic hexed by halitosis.

PS. And to all, a good night.

June 3, 2023

Happy Saturday! I'm still here at KU Medical Center, but things are moving along quickly.

They've untethered me from most of the wires and tubes that made me look like the back of an old stereo system. They've also turned off the alarms on the chair and bed, so I'll have an easier time sneaking out (Tricia, I'm just kidding).

Overnight I mastered the breathing tests. I had to really work to hit the goal on the inhaling part, but I gave it a sucker punch that pushed me over the top. I'm also talking fairly normally, and swallowing's not much of an issue – though I'll still need to build up my strength.

Even though today should be a day of rest, I'm having another Blood Wash (at least I didn't call it a Blood Bath). It's the third of five. Going a day early could get me home a bit sooner, but we'll know when we know.

I've also heard hints that I'll leave ICU today and return to the regular floor. I might even get this infernal feeding tube removed. The liquid diet through my mouth looks a whole lot better than a liquid diet through a hose.

So far, so good.

Thanks for joining me on this ride. You can't imagine how healing that is!

Stay well all... and I'll see you soon.

June 3, 2023

My Blood Wash treatment's done for the day. The feeding hose is out. My airways are flying high. I ate real food (as in real mushy). My biggest challenge now is to decide which tasteless bullion broth I want for dinner. Double yum.

And here's another joy: They unhooked most of the wires. I feel like dancing around á la Pinocchio and singing, "I've got no strings, attached to me..."

Of course, Tricia's much more practical in that regard.

"Leave the dancing for the dancers," she said. "You're better off in the balcony."

She's right again.

I'm waiting for a room to open up so I can blow this ICU joint. The nurse, however, is trying to talk me out of leaving because I'm her "favorite patient." I bet she says that to all of 'em.

God willing, this progression will continue marching on. I'm ready to return to the land of the living.

I get it. Patience is a virtue. I'm trying to be virtuous. I'll let you in on a little secret: It's tougher than you might think.

Stay well all... and here's to modern medicine!

June 3, 2023

What a good day it's been here. Lots of positives heading my way, not the least of which is the chance to escape from ICU once they find a room for me. Huzzah!

I did have one little dinner-time bump, however.

I am now a proud customer of the Clear/Full Liquid Diet. That basically means if you can chew it, you won't get the chance.

So, I opened the very thin menu (if I'm stuck eating these options, I'm going to be very thin, myself). I looked at my choices and made a call to catering.

"Hello," the Lunch Lady said.

"I'd love some edible dinner," I replied.

"What would you like?"

"How about strained cream of chicken soup?"

"Sorry, that has dairy in it, and you can't have dairy." Darn allergy.

"OK, I'll try the vegetable broth."

"No, you won't. It has corn in it." Darn allergy No. 2.

At this point I was desperate. It was time to turn on the logic. "I CAN have the chicken broth, right?"

“Yes.”

“OK,” I replied. “Chicken soup’s made from chickens?”

“Yes.”

Now for the kill shot: “They feed corn to chickens, don’t they? And I can have THEIR soup. What gives?”

“Excuse me, sir. Please put your wife on the line.”

Sheesh. Tricia’s already working the docs. Now she has the kitchen staff on her side. I don’t stand a chance.

Stay well all... and in case you wondering, I ordered some beef-flavored liquid salt. But wait. Cows eat corn. And they give milk. I’ve seen them do it. I’m so confused...

June 4, 2023

Tricia and I had grand plans for a grand getaway for our 28th anniversary today. Even a special weekend somewhere special would’ve made it a truly singular occasion.

So what do we do instead? Hang out at KU Med Center. Woo hoo. At least I finally got to escape ICU and go back to a room on the regular floor.

But you know what? This was one of the best anniversaries I’ve ever had. It was just me, Tricia, and a sincere sense of togetherness. Now, I wouldn’t suggest this for everybody. Heck, I’m not even going to suggest it for us going forward.

But this one, I’ll remember.

And that makes our anniversary all the much happier!

Stay well all... and find joy wherever you are.

PS. I’m not getting out of this that easily. We’re taking a jaunt once I get my post-hospital treatments behind me.

June 5, 2023

I’m trying to learn about all the stuff they look at with my daily blood draw. I’ve been using an Artificial Intelligence site called Bing for my research. I figured I might as well let it do the heavy lifting.



It's really pretty easy to manage. Pop in a couple of key words, Professor Bing gets to work, and before you know it, there's a footnoted answer. Fascinating.

The program gave me up to 30 questions. So, I started in.

White Blood Cells? Check.

Red Blood Count? Got it.

Hemoglobin, Hematocrit? Yep and yep.

Then I wondered about something labeled MCH.

You know what the computer said?

"I prefer to not continue this conversation."

Just like that. Boom! "Take a hike, mister. We don't serve your (blood) type here."

What a petulant punk.

I jumped right back in its face and asked why it cut me off. You know what Little Bingy Boy told me?

"I'm sorry if I gave you that impression. I'm here to help you with your queries. How can I assist you today?"

Yeah, right. When software starts thumbing its nose at you, there's no impression. It's the real deal.

I gotta tell you: For something labeled intelligent, that was a pretty dumb CYA move.

Oh well. At least Yahoo still likes me.

Stay well all... and have a good week.

June 5, 2023

I just got word that I can start using the full menu for my meal choices here at KU Med Center. Considering just a couple of days ago I was eating through a tube and after that have been on a liquid diet, this is great news.

No more low-salt chicken broth and tasteless cream of wheat for me. Ever. One thing I did discover – and I find this quite interesting – if you pour some broth into the cream of wheat bowl... it makes no difference.

So, in anticipation of my inaugural Real Meal, I grabbed the menu off the shelf. The first thing I noticed: Tater tots! Yeah! Honest-to-goodness, doctor-recommended, mother-approved, tater tots! I see a spudsy feast in my future.

I'm sure I'll enjoy other things as well. Trouble is, I dropped the menu and now it's stuck somewhere in my reclining chair. I've looked and I've looked, to no avail. How can all of those yummy foods just up and disappear?

Maybe this is "National Mess With Your Patients Week" in the healthcare world. That would explain the sniggering when the staff walks by. Then again, perhaps it's just a test to see how I can handle true adversity.

Whatever, I'm fine with it. I might even ask for ketchup.

Livin' the Good Life!

Stay well all... and give your tater tots a hug for me.

June 6, 2023

I'm just now coming off my tater tot high from dinner. Coupled with a LaLa Land Benadryl at my afternoon Blood Washing, I had quite the party last night.

And quite the "uuggghhhh" this morning. I guess I'm too old to go on a hotsy-totsy Benadryl bender.

Thankfully, today is a day of rest for me (I could use a good nap), followed by my last treatment tomorrow. It's been an experience, but, so far, it's working.

I can't wait to get home and back to "accidentally" dropping morsels from the kitchen table whenever my pups Willow and Phoebe are under foot. Which, of course, means every meal. It is true: You most appreciate your blessings when you are separated from them.

Okay. I have a confession to make. And this isn't easy, so bear with me. A couple of days ago, when I was on the strict "Salty Soup and Pitiful Porridge" diet? I popped a York Peppermint Patty in my mouth. I even swallowed it.

I know. I know. Follow the rules.

I also know Tricia now knows because I let it slip yesterday. Oopsy.

I tried to explain it was just an involuntary muscle spasm. Good luck with that. I thought I made a fine point by saying it wasn't nearly as sweet as she. Try again. I started tapdancing. Straight toward the door.

My one saving grace in all this? Tricia supplied the mints. I just don't think she thought I'd grab one before I was supposed to. Of course, she should know better by now.

Stay well all... and here's to a good day!

June 6, 2023

It's been a dandy day today. Rest, comfort, and no hassles. Except...

The young neurologist who's been tracking me stopped by mid-afternoon. She ran me through my paces: squeezing and pushing and prodding to see how my muscles were doing. She was pleased, and so was I.

As she was leaving, she stopped, turned, and paused. "I don't watch a lot of movies," she said. "But you remind of an actor."

Okay, I'm thinking. This could be good.

"You know Lord of the Rings?"

I knew where this was going.

"Yes," I said. "You must be thinking of Legolas, that tall, long-haired, blond Elf, right?"

She chuckled. "No. The short guy with curly hair who smokes a pipe."

Great. She thinks I'm a stinking Hobbit. And for this, she went to medical school?!?

Hey. I DON'T have hairy feet! I don't even smoke my pipe anymore. You can look it up.

Funny thing is, I've heard it all before.

I tell you what, though. If I could, I'd skip this joint in a flash and head straight to the Shire. Oh Lord, that has a nice ring to it, doesn't it?

Stay well all... and watch out for Orcs in doctors' garb.

June 7, 2023

Yee ha! I'm outta here! Homeward bound. Free as a bird. Back among the living.

The turn-around is nothing short of amazing. I came to the KU Med Center a week or so ago unable to speak coherently, unable to chew, unable to swallow, unable to see without blurry double vision, unable to take a deep breath. I was, to be honest, a royal mess and more than a little scared.

Myasthenia gravis will do that to you. I probably had hints of it for the last couple of years, but when the symptoms exploded, I was floored. I barely knew this autoimmune disease existed. Now I'm a reluctant expert.

I've had my blood washed five times, separating out the plasma and the bad antibodies it carried. I've eaten through a hose, I've sipped salty broth and gagged on water, I've sounded like I was pinching my tongue when trying to speak, I've spent a night or two in ICU, I've watched my eyelid droop like a lowering window shade. And those are just the highlights.

But now... wow!

I am so grateful for the knowledgeable doctors and compassionate staff here. I am overwhelmed by the support I have received from friends near and far. I am thankful beyond words for the love of my family, and especially for the unyielding wonderfulness of Tricia. The Good Lord had his arms around us all.

I am so very blessed.

This disease will be a permanent companion; they've not yet figured out how to eradicate it. I'll be on medicines forever. I'll also have to learn new body cues to stay atop it. So be it. Thankfully, it's quite manageable.

I suppose it could flair up again at some point. If it does, I'll face it with the same good spirit that got me this far. And of course, I'll keep up my fun and silly postings because, well, because that's what I do.

Time to pack my bags and blow this popsicle stand. I know Willow and Phoebe are waiting for their treat-treats. Gotta run.

June 8, 2023

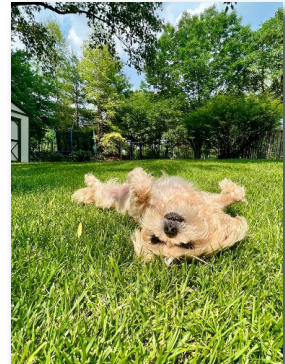
I must say, when I returned home yesterday, I expected a tail-wagging, circle-running, tongue-slobbering greeting from our little dogs. So what did I get?

Willow flopped on her back and said, "Oh, it's you. Start rubbing."

As for Ten Pounds of Tough Phoebe? She trotted off to the corner to bark at Dobermans and German Shepherds. She has a reputation to uphold, you know.

And I wouldn't have it any other way.

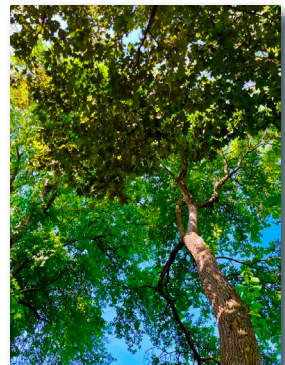
Stay well all... and there really is no place like home.



June 9, 2023

Things are looking up! Feeling better every day!

Stay well all... and TGIF!



June 10, 2023

A gentle rain on canvass is a most-relaxing treat! I certainly appreciate a decent rest. I tire so easily.

I slipped down to Scout Camp in the Missouri Ozarks for a gathering of the honor-camping organization Micosay. It's also a test run to see if I might be able to take a shot at 10 days with my troop this July.

I'll know when I know.

Stay well all... and one step at a time.



June 13, 2023

I started a new medicine yesterday, a fancy infusion to combat the weakening aspects of myasthenia gravis. It's a four-dose treatment, one pop a week.

I hear it's a wonder drug. The only thing I'm wondering is if it really works. At the price tag the insurance company is swallowing, it darn well better! So far, so good.

As the doctors explained it, it does something to the something that's doing something keeping my muscles and nerves from chatting with each other. You'd be surprised how many somethings I have going on. And anti-somethings. I even think I have an anti-anti-whatever floating around in there somewhere.

Of course, anti-anti would be a double-negative. That makes it a positive. Good. We could all use some positive in our lives!

At any rate, this treatment thing was pretty easy. I showed up at the KU Infusion Center, gave them my name, and walked back to a large room filled with a couple of dozen "stations." Stations: That's medical jargon for a reclining chair and TV. They also had cookies.

I settled into Station No. 3, back by the windows, and waited my turn. Soon a nurse took my vital signs, confirmed I still had some vitality, and drove an IV pointy thing into my left arm. Once she finally drilled it below the surface, it wasn't too bad. She thought she was being clever by calling me "thick-skinned." Thick-headed, maybe. Thick-skinned, not so much. Ouchy.

The rest of the procedure was a breeze. They dripped the stuff into me for an hour while I reclined and kind of dozed. Then they watched me for another hour, while I continued to recline and kind of doze. And ate cookies. That was it.

Luckily, I didn't have any bad reactions. I return next week for dose número dos. And more cookies.

There was one thing I found just a bit off. I was at a University of Kansas facility. It said so on the door. But I was in Missouri. Hmm... Looks like the Jayhawkers stuck their beaks across State

Line Road and established an outpost a few blocks in.

It's not that big a deal now, I suppose. Mid-1850s...? It would've been a whole different ballgame.

I guess it's a fair trade. KU planted its flag in Missouri. I consider our little half-acre plot here in Olathe, Kansas an extension of the Show-Me State of my youth. What's good for the goose (or certain other birds) is good for the gander, eh?

Stay well all... and here's to healing medicine, wherever it's delivered!

June 20, 2023

It's a never-ending saga, this saga I'm on. Over the last 16 months – first my heart, now this muscle stuff, with a bit of a bout of COVID in between – I've battled nasty needles and noxious nose hoses. I've fought slicing scalpels and jolting electrodes. I've endured pokes and prods and pills aplenty.

I've suffered all sorts of sorted things that would make a ghoul go goofy.

But never – never until yesterday, that is – have I brawled with a chair. That's right, a supposedly relaxing, seemingly innocent, reclining chair. That wolf in furniture's clothing was my most uncooperative companion during myasthenia gravis drug infusion no. 2.

Oh, it looked innocent enough: a brown, bulky contraption you might find in Bubba's Basement Beer Palace. The sneaky thing even let me kick out its footrest, no problem. A yank of the crank, and it was set.

Trust me. It was a trap.

I wanted to recline. It IS a recliner, after all. So, I moved it into a satisfying position and settled in. It took, oh, maybe no seconds, before the chair decided it was going to have none of that.

“Nope, not today,” it groaned. “Back to the upright and locked position you go.”

This demon had an attitude. A darn bad, stinking one at that. Thank goodness its arms were nailed down, or they would've been around my throat.

I pushed.

It pushed harder.

I forced it.

It said, “Fahgetaboutit.”

Back and forth, forth and back we tussled. I shoved. It rebounded. I arched. It bent me forward. I screamed. I yelled. I cussed.

It was an epic clash of man vs. machine.

For two stinking hours.

To add insult to injury, the beast tried to eat my phone. Right down the crack next to the arm rest. Poof. I had to pound on the nurse call button for help. They came running, all excited like they've never been buzzed before (at least not that early in the day).

"Get me a tire iron," I barked. "I'm going to knock the Nauga right out of its hide."

The nurse looked at me knowingly. "Oh," she said. "You're in THAT chair."

That chair... THAT CHAIR...!?! What the heck?!? My chair has a reputation!?!

Now I know why they keep this aberration in a private room rather than out with its two dozen cooperative cousins. It's a menace. A revolting, non-reclining menace.

To the folk who run the University of Kansas Infusion Center (yes, the one in Missouri for some inexplicable reason): Ship this monster out the door. Send it somewhere far away, maybe to a school with a decent football team or something. I think there's a couple of 'em up in Michigan.

I'm not sure who's in charge of this - there must be a chairman or two hanging around some meeting room - but I'm going to sit right down and write a letter. I'll just sit somewhere else.

Stay well all... and watch your backside. Especially if it slips into THAT chair.

June 21, 2023

Happy Summer!

Here's a hack that's worth bragging about.

You see, I have this fancy app on my phone that monitors daily steps and distance. It even tells my pace and all sorts of other info that must matter to someone (else).

To motivate me, I pick a calorie goal and the fancy app illustrates progress with an arrow-sporting red circle. The more I travel, the fuller the circle becomes. Those of you in Kansas City, think of the Western Auto sign on the downtown skyline.

I confess, the circles have been pretty lacking as of late. Look. It's not easy getting off the couch. Sometimes I'm doing well if I make it to the kitchen and back - though that's mostly because I'm a lazy bum at heart.

Well, yesterday morning - filled with enthusiasm and a fresh set of go-get-'em pills - I decided to tackle the backyard jungle. I fired up the Cub Cadet and began a blade-whirling journey through the heather. (Actually, it's bluegrass, fescue, and a few stubborn weeds, but heather sounds so much lovelier.)

My phone, fancy app and all, rode my hip. Up and down the back 40 we traveled, turning the lawn into a carpet of perfection. I was a proud papa indeed when I, at last, tucked the mower back in its

stall.

I pulled out my phone to see what momentous mutterings I missed during my labors. There was war news and stock-market collapse and sons of famous people plea-bargaining their guilt. You know. A typical news day.

But then, I noticed a note from Mr. Fancy App: “Congratulations,” it said. “You are almost to goal.”

Whoa doggy! I don’t think I’d taken 50 paces all day. But sure enough, it claimed I already had walked 4,975 steps and covered 1.75 miles. What gives?

Then it dawned on me. The riding mower travels at a speed not unlike me walking downhill with a stiff breeze at my back. It shakes and vibrates, much as I do when my muscles shift into the second of their remaining two gears.

The Cub Cadet, my trusty steed, had faked out the app! Huzzah and halleluiah!

This is great. I can game both technology and Tricia by letting them THINK I’m doing my daily workout. Yet the whole time, I’ll really be yee-ha-ing around like a happy pup, chasing squirrels and flower-eating rabbits. I’ll just have to make sure I look all miserable and spent when I stumble back in.

Oh, such sport. Oh, such fun.

Stay well all... and hop aboard. I’m gassed up and ready to roll. So is the mower.

June 28, 2023

Special Medicine Drip No. 3 of 4 is in the books (and in my bloodstream). The deed took place yesterday after lunch at the University of Kansas Infusion Center - the one in Missouri.

I can tell you the brew, plus the tons of other medicines I’m on, has done wonders to curtail my myasthenia gravis symptoms. I still CAN’T tell you why KU has a facility in someone else’s state.

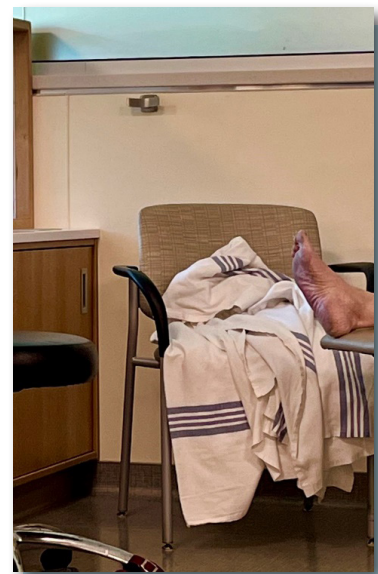
The two-hour ordeal started as they always do. I settled into a nice, cooperative-this-time, easy chair. The nurse sauntered over, squeezed out my blood pressure, and stuck an IV needle in my left hand.

“Ouch,” I cried.

“Did I hurt you?” she asked.

“No. But you could’ve.”

Then I noticed the small hose coming out the back of her needle. “Hey look. You made it bleed.”



“That,” she said, “is the whole point.”

“Nope,” I replied. “The whole point’s under my skin. And some of the tubing, too, I think.”

She mumbled something about a big baby, but it’s probably a good thing I couldn’t quite hear the rest of it. She then hooked up the Bag o’ Get Well Juice and wandered away.

There was a sign on the wall of my station – Station No. 2, I might add – that begged us to be respectful of our neighbors. I thought it was a great sign. I clearly was in the minority.

A station to the south, good old No. 3 from my first visit, was blaring out some daytime TV-babble game show. It had applause and bells and gongs, and cheering about who knows what. I’m sure it was a gripping drama. I know I was dramatically gripping my pillow to my ears.

Catty cornered from me, in Station No. 4, I could hear an enthralling conversation ambling from pot stickers for dinner to someone named Sally, then on to her mother and maybe a trip to Oregon.

Off to my right, in Station No. 5, I could see someone’s feet.

The person behind me, in Station No. 1, was in for her first iron infusion. She asked the nurse if there were any side effects. I told her to watch out for rust.

Then an IV machine from Station No. 4 began to wail. “Beep beep. Beep beep.” Then a “boop boop” just to change things up a bit.

Not to be outdone, and this is too awful to make up, machines around the room started chiming in. They were a’ beepin and a’ boopin like a frog convention in some southern swamp. To add insult to injury, Station No. 3’s TV joined the chorus. “Dling eh eh” is all I could make out. And that someone won a new washer and dryer or a pony or something.

Even I added a bit to the mirth and merriment, providing a steady beat by bashing my head against the wall.

Finally, the young TV fans slipped away. No. 4 hung up her phone. The IV machine ceased its chiming.

I was left alone, surrounded by serenity. I closed my eyes. I dozed. I finally was content.

Then a screech from my IV machine jolted me awake.

Stay well all... and next time, I’m bringing earplugs.

PS. As an added bonus, the wide, stretchy bandage the nurse used to lash a cotton ball to my hand after removing the needle featured dark blue trucks.

July 3, 2023

A lovely byproduct of this myasthenia gravis is a hefty dose of brain fog. I can tell you, it's a real treat. Your thoughts burble like a hose with a small leak. Stuff drips out, but all it does is make a mess.

Luckily, it's only happened to me once or twice, including at a nice dinner with Tricia early last week. Wow.

Want to know what it's like? Imagine a film-noir dockside. Dark. Misty. Ominous. With a foghorn. Gotta have a foghorn. You certainly have the fog. There's this tough guy in a cap, hands in pockets, collar turned up against the night. He's slinking past wooden warehouses and dim lights, looking for some stiff to bonk and toss in the drink.

Now picture my brain as that stiff.

Whack! Splash! What hit me?

Evidently, not the disease itself, according to those who still can think with a clear mind. MG likes to toy with the voluntary muscles by blocking signals from the nerves. I can assure you there is little in my head that works voluntarily anymore. Some days, there's little that works at all.

But messed up muscles do cause fatigue and sleep issues. And when you're beat and tired, cognition's ignition goes on the fritz. Don't believe me? Ask me at 3:30 a.m., just about any morning. I'll be awake. Not sure you'll understand my answer. But at least you can ask.

BTW, "on the fritz" probably came from the Katzenjammer Kids, a newspaper cartoon in the first years of the 20th century. One of the kids was named Fritz, and he was, to be kind, a troublemaker.

At any rate, I think I have it pretty easy, all in all. Some folk live their lives in a fog. I'm just an infrequent visitor.

I've got to tell you, though, when it hits, it hits hard. The pressure builds, the world goes thick, and you can almost feel some brute pulling out his blackjack for a swing at your noggin. I guess I better learn to duck.

Stay well all... and see you in the movies.

July 5, 2023

A couple of months ago, as the docs were trying to figure out what was going on inside of me, I took a genetic test. The result finally came back. Get a load of this: In my genes they found, "a variant of uncertain significance."

Put into normal English, they saw something but have no idea what it means to the "function or health of an organism." I, of course, being that organism.

Ain't that something? Not only am I a walking mutant, but, according to those who know these things, no one knows anything.

If I were to review the research, dive into databases or peruse piles of periodicals, I'd likely find exactly zilch about it. Crickets. Chirp chirp. Chirp chirp. Makes a guy feel kinda puny and pitiful when even his irregularities aren't worth the paper they're printed on.

So, what is this oddity? Will I grow a third arm? Will my eyeballs come out my ears? Will it allow me to see into the future or speak Klingon or something?

Beats me. And evidently everyone else - not that anyone cares. After all, it has "uncertain significance."

Frankly, if it's in me, I think it has a heck of a lot of significance.

You know, if I had led a wild life, if I were sniffing mushrooms or hanging by the ankles from streetlights or something, I might understand this un-understandable anomaly. But heckfire, I'm a good kid. I wash behind my ears. I'm in bed early. I limit my liquid libations to whenever opportunity arises.

I guess maybe someday science will unravel this. Who knows? They might even name the whackydoodle gene after me.

My luck, they'll probably name the disease instead in Latin. You know: Weirdious Geneosesus Fredmanus. Has a nice ring to it, eh?

Stay well all... and it's pretty warm out. I think I'll go take a dip in the gene pool.

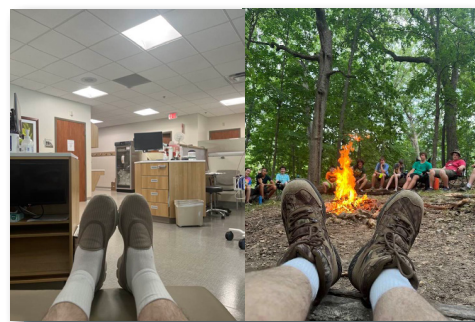
PS. Since I mentioned crickets (and heat), here's a cricket trivia for you. Count the number of chirps in 15 seconds, add 40, and you have the temperature in Fahrenheit. Crazy, eh? I guess their weather gene works just fine. Unless it's below 55 degrees. Even crickets aren't stupid enough to run around the woods when it gets too chilly.

July 7, 2023

Out of the frying pan and into the (camp) fire.

Infusions are done. Scout Camp has begun. If I can manage the heat here in the Missouri Ozarks, I'm in for a good 10 days.

Stay well all... and happy camping.



July 8, 2023

Just a moment ago our Scout Troop entered the woods for the annual cross-country trek from Scout Camp to Iconium, Missouri, the Peach Nehi Float Capital of the World. The “Ico Hike” is about a three-mile jaunt each way, especially since I take them cross-country rather than along the roads.

I say, “I take them,” but I’m not taking anyone anywhere this year. By unanimous consent of the troop, I’m walking all the way to my car, then driving over to meet them in a couple of hours. Dang it.

This time last year, after recovering from a February heart attack, I promised myself I’d be ready to make this journey. I’ve been doing it for more than four decades, and I wasn’t going to let a few little bypasses trip me up. Well, my latest bout of ill humors put the old kibosh on those plans.

Goodness knows, I tried to sneak in.

I hid behind a tree and slipped to the back of the line. Busted. I pretended I was a new Scout (not tough considering half of them already are taller than me). I didn’t get far. No matter what strategy I employed, the huddled masses outsmarted me at every turn.

So, instead, I sit and write, pining away for that venture over hill and dale. I guess it’s not all bad. If nothing else, it’s quiet here in the campsite for a change (except for my tent partner, who’s doing a pretty good number on his banjo).

That doesn’t mean I can’t at least take the walk in my mind. So here goes.

Things actually started this afternoon, when I taught the new Scouts how to use a compass and read a topographic map. As you can see from one of the pictures, I had them in rapt attention. One boy was asleep, another was looking off into space, a few others were giggling, two more were swinging an axe at a rotted log, and three of our young adults – geezers in training – were harassing me from behind. Pretty typical.

With dinner over, our Senior Patrol Leader and one of the young adults gathered the troop and headed them down a steep hill. At the bottom, there’s a rocky creek. If they follow the plans we mapped out (assuming anyone actually paid attention to the map), they’ll turn right at the creek.

They’ll follow it for a bit until they intersect the trail that leads to the middle of three large camps that make up the H. Roe Bartle Scout Reservation, here in the Missouri Ozarks. If they miss the trail, they’ll just have to dead-reckon it to the east. Can’t be that hard. We’ve done it before.

Once they hit that second camp, they’ll stop at a crooked tree likely bent by the Osage Indians as a trail marker. They then will cut across camp and pick up the path again. Down they’ll climb into a wooded hollow, following a fairly slippery slope to the base.

The trail takes them deeper into the woods, then across a creek near a steep bluff known as Scorpion Hill. The brave ones will climb the rock face; the more timid will whimper and whine...

then climb the rock face. Let's face it, they gotta get up it whether they like it or not.

By then, the younger Scouts will have started complaining how tired they are. At least one will say he's hungry. Another will say he saw a mountain lion or Gila Monster or something. It's too bad I'm not there to egg them on. It's such good fun.

After a breather, the 40 brave souls will continue their jaunt onto a slightly inclining trail that heads into the third of three camps. Along the way, they'll stop at Gamblers' Cave and threaten to throw someone in. By then, there'll probably be a few popular candidates.

Onward they'll march through the darkening gloom. Winds will whisper in threatening tones; biting flies will gorge on the blood of stragglers. Foot by foot, yard by yard, they will trudge onward, ever onward. A false turn will trick them (I told them they should've paid attention to the map). A sudden flood will drown their hopes.

But somehow, some way, this ragtag band of survivors will reach that third camp. They'll struggle past its gawking residents, and head across the high-grass field to the wooden fence and the promise of a clear trail on its other side.

A quick left, a quarter mile to the cemetery that has a larger population than the town, another left, and finally, success. Looming in front of them, in all its 1880s small-town glory: Scott's General Store, a beacon of warmth, an oasis of goodies galore. They will collapse under the hummingbird feeders, happy, thankful, and eagerly awaiting their pre-ordered treats.

An hour later, their strength renewed, they will head back to our campsite, to their waiting tents and the open arms of their cushy sleeping bags.

It's going to be a quiet night around here. The boys will be knocked out as soon as they hit their pillows.

A good walk in the woods will do that to you. Maybe next year, it'll do it for me, as well.

Stay well all... and whenever you can, go take a hike!



PS. One good thing for the troop, without me there to stop at every tree and rock and bug to tell its life story, they'll probably knock 45 minutes off the walk. Maybe I'll make them run back.

July 16, 2023

I made it. A week and a half in a tent, in the woods, in the heat and in a very happy place.

Candidly, I had some doubts as I headed to Scout Camp in the Missouri Ozarks. It wasn't that long ago,

after all, I was flat on my back in a hospital room, fighting this menacing myasthenia gravis.

Friends warned me to be careful. Family wondered if I were just a bit nuts (by now, they shouldn't be wondering). MG, which messes with the communication between nerves and muscles, can be tough on a guy in perfect conditions. Summertime around here hardly presents perfect conditions.

Nonetheless, I had to try. I had to go.

Camp is an island of respite for me, a time to return to my youth while sharing it with youngsters of today. This was No. 42 as an adult leader, with another four as a boy. (If I'm not careful, I'm going to start sounding really old. Not acting it, mind you. Sounding.)

Surprisingly and thankfully, I managed just fine. Oh, sure, I curtailed some of my activities. I didn't lead the usual long march through the rocky woods. I hitched a ride on a golf cart to a couple of far-flung activities. I doused myself in cooling water until I squished. I took my pound of pills punctually. And I worked double hard on my Sleeping Merit Badge (I passed).

Yet here I am, back home, still in one piece and feeling very, very good. For that (and for everyone who kept checking on me – and kept me in check), I am deeply grateful.

Last summer, I went through a similar “Screw it, I'm going to ignore better judgment and go to camp” routine – that time less than half a year after a heart attack. This summer, it was a couple of months after my latest bout with the system. I'm two-for-two in the victory count. I hope there's not a third time... ever.

I will tell you one thing: I'm still not sure whose food is worse, hospitals or camp. Even though we get to sing songs and act silly with 500 other people in the dining hall, a couple of camp meals did make me miss the feeding tube KU Med Center stuck in my nose.

As always, our troop did very well: Lots of rank advancements, special honors, merit badges and



new skills gained, winners of the cardboard boat race in the pool, loud applause for our final-night campfire skit, learning, laughing, slushies, camaraderie, dirt, bugs, and fun. Loads of fun. And loads of bugs. But more loads of fun, though it was close.

It sure makes it easier when you have a darn good group of Scouts – from 11-year-old first-timers to those nearing their 18th birthday, the end of their journey. Try as we might, we didn't lose a one.

Senior boys led us – experienced, confident, and elected by their peers. A cadre of young adults, Eagle Scouts who grew up in the troop, provided hands-on mentoring. An exceptional team of grown-ups supported them all.

To each: Huzzah for making this camp such a success for us. And for me.

Stay well all... and here's to happy campers (and air conditioning)!

PS. A special, loving thank-you to Tricia, who not only encourages my camping each year, but had enough care to be concerned and enough love to let me do it anyway.

July 20, 2023

Among the great victories in the history of mankind, this certainly doesn't make the top 10. But for me, it was a red-letter moment.

Last night, I whistled – the first time in months. While enjoying a friend's great stereo system. And a slab of ribs. And an adult beverage.

Maybe I've discovered a magic cure.

Stop the presses! Call the FDA!

My pal's a neurologist. Doc, I'm happy to come back over for another round of "treatment" (in the name of science, of course). That's one infusion I can handle. Make mine a double.

Mind you, I managed just a snippet of a tune – a few notes of the "Polovtsian Dances" from the opera Prince Igor. You might recognize the melody as "Stranger in Paradise." I recognized it as a real song, a real whistle, and a real breakthrough.

Huzzah!

Even before I was diagnosed with myasthenia gravis, I noticed I'd lost the ability to pucker up and squeeze out a sound. Try as I might, the best I could muster was a weak, windy whisper. So, to have anything was really something.

I guess this disease continues to mess with my facial muscles. Getting the right shape for a note isn't as simple as putting my lips together and blowing (as Lauren Bacall famously said).

Since leaving the hospital, I've tried daily to whistle, seeing it as a test of my recovery. Though the rest of me is doing fairly fine, my cheeks and lips still are a bit draggy.

You know what, though? If the worse that happens going forward is my whistler's busted, I'll take it.

And I'm not just whistling Dixie!

Stay well all... and keep a tune in your heart.

July 27, 2023

I paid a visit to my myasthenia gravis doctor earlier this week. Time for a check-up.

He went through the usual round of pushings and proddings, pokings, and poundings. Neurologists just love that kind of stuff. He squeezed my face and knocked my knees. He stuck a finger in my eye and twisted my toes. He pulled my hair, whacked me with his hammer, and had me count backward in Greek.

And that was just the warm-up.

It was all, I'm sure, for my own good. Just like the three gallons of blood the lab folk drained later in the day.

Then he was ready to get down to business. "How you feeling?" he asked.

"Great," I replied.

That was the perfect answer from where I sat. I try to face my challenges with a smile and a denial. But to be honest, it might not be the best strategy. Especially since my loving wife has a medical background and a no-nonsense approach. It's gotten me into trouble more than once. This was one of those times.

I cast a sideways glance at my personal Minister of Truth.

"Well..." she began.

Ten minutes later, reality lay bare on the floor. My objections were rejected, my supplications tossed aside.

Turns out, things have been a bit rougher lately than I'd like to admit. I'm tiring easily. My face seems a little heavier every day. A slight slur slips into my speaking; a fog covers my brain. Breathing is not always a breeze. Other stuff is popping up.

I guess this is pretty normal for the MG community. It's still new to me.

Rising to my defense, I mentioned I'm not due for my next miracle-drug infusion for 10 days or so. The good stuff is wearing thin. That could be all it is.

And there's this heat, I argued. It's taking its toll, even when I just crack open the door to chase away the magpies (we don't actually have magpies, but it's a fun word to say). Heckfire, it was 106 degrees outside yesterday. For you readers in Centigrade-centered lands, 106 Fahrenheit is hot. Darn hot. Melt-the-sidewalks hot. And MG and hot don't get along.

On a roll, I also tried to blame our two dogs – the poor, loving, innocent dogs. One of them wakes up in the middle of the night, which wakes me up, which wakes up Tricia. Except Tricia says I'm the first domino in that line. Since she's the last to wake up, I don't quite know how she can so easily point her finger my way. But why lose yet another argument?

"Here's an easy fix," the doc said, scribbling in his notebook and nodding sagely. "Send either you or furry little girls to the doghouse at night so everyone can get a good sleep." Tricia suggested there's enough room for them AND me. I think she kind of liked the idea.

"But here's your real problem," he continued. "You have a Type-A brain that's slipped into a Type-B body."

I suggested that recently it's been more like a Type C or D. Maybe even a D-minus.

He kept talking: "You can't be cutting the grass in the morning and going to two meetings in the afternoon."

(Guilty.)

"You can't be running around like you're a kid."

(Who, me?)

"You were outside at Scout Camp... for 10 days?!? Who does that?!?"

(Hey, you said I could go!)

"Slow down! Pace yourself."

It's good advice, I'm sure. After all, the turtle did beat the hare. But how do you suddenly shift from a 100-mph existence to a crawl? That's a good way to drop a transmission or something.

Look, I tried after my heart attack in February last year. I even retired. Wasn't long before I was volunteering for all sorts of things and busier than ever. Same with this latest ailment. If my calendar's not full, I feel empty.

I guess I just have to tell my brain my body's not young anymore. I'm not the speed demon I once was. Pieces are rusting; the engine is clogged.

If only I could realize rest is the key to health, I could see that taking it easy would make life that much easier. Frankly, that's probably going to be the toughest part of this whole thing. That, and being honest with myself.

I do have to admit, though, it is kind of nice to have a free pass to nap whenever the mood strikes.

What I wouldn't have given for that luxury when I was working and running as fast as I could.

Stay well all... and catch your breath now and again. You'll thank yourself for it later.

August 5, 2023

I finally paid a visit to the gym yesterday, the first time since I was hospitalized a couple of months back. It was an exciting reunion, I can tell you that. I felt right at home among all those dumbbells.

What I realized, right off the bat, is that I'm still old, I'm still tired, and I'm still nowhere near making the U.S. Olympic team. Of course, considering that Somalian lady who ran a 21.81-second 100-meter dash in the World University Games a few days ago, maybe there's hope for me yet. Not so much for her aunt, however, the now-former chair of the Somali Athletics Federation.

At least I have an excuse. This Myasthenia Gravis messes with my muscles by disconnecting them from the nerves that make them work. So, even though medicines have me mobile, I wasn't expecting much.

I didn't disappoint.

I started by chatting with a high-school friend who was trotting on the treadmill. I think I burnt off a calorie or two just watching her keep up a brisk pace. After that, I was on my own.

I dragged myself upstairs to the track and began my jaunt. Actually, it was more of a crawl. I thought I was doing really well... until the lady with the walker passed me.

Four laps later, I was ready for some real excitement. I bounced back down and headed to one of my favorite machines. I call it the Push Me-Pull You. You sit down (already a plus) and start pushing your legs back and forth on some big pedals. At the same time, a pair of handles move forward and back, the opposite of the legs. You grab those and hold on as it works you top and bottom.

I told myself I'd make it until the first commercial on the news-filled TV above me. That lasted about 38 seconds (talk about timing).

"Even I can do better than that," I thought. "Keep going."

Back and forth. Forth and back, I went. Blah blah blah from the TV talking heads. Push. Pull. Blah. Blah. It was a workout for the ages.

Finally, another commercial. Off I slid.

I moved over to the weight machines.

"Nah."

I kept moving.

I found a chair and sat. It was a nice chair, all soft and comfy. It gave me a chance to look around. Why is it that every teen and 20-something is healthy looking, with their tight workout clothes and rosy cheeks? And more to the point, why was the gym filled with them? Shouldn't they be in school, or working or something?

It just ain't fair.

At that point, I would've gone back upstairs and challenged Miss Walker Lady to another round, but even thinking about it was too much work. Instead, I found a pair of hand-held weights. Each had a No. 3 on it. I assume that was their poundage.

"Easy peasy," I thought. "I'll show those youngin's I still have what it takes!"

Well, it takes a lot more than I thought. Three pounds might as well have been three tons. I struggled. I grunted. I grimaced. But I did lift them.

Heck, who am I fooling? I twirled them like a drum major on an October football field.

Then I dropped them.

Luckily, I missed my foot. Of course, had I hit it, I would've had a good story to tell in the emergency room.

"Yeah, doc," I'd say. "I was trying for a personal best. It was the clean and jerk. 450 pounds if it were an ounce."

"Sure it was," the white-coated medic would reply, smiling as he patted my head.

After that, I gathered my wits, returned the weights to the rack, and sauntered out. I've got to tell you, I felt great. Top of the world. Bring it on!

Tomorrow, I might even return. Watch out, Walker Lady. I'm gunnin' for ya.

Stay well all... and stay healthy.

August 8, 2023

I returned yesterday to the University of Kansas Infusion Center – the one still in Missouri. It was time to start round two of the Magic Medicine flowing through my veins. I'll go three more Mondays, then rest a month. Until some smart person discovers a cure for myasthenia gravis, I suspect I'll be a steady customer.

While the nurse was sticking me with needles and attaching hoses all around, she started talking about her car battery. Seems the thing died, and if it weren't for a friend there with AAA, she'd have to walk home. (She repeated the same story to everyone she served, so it must've been true.)



I tell you, I could relate.

The last couple of weeks, I've felt like my battery was drying up as well. Simple tasks became less simple. I could sense the droop return to my face, the lisp to my lips, the fatigue all around. I was running on fumes.

I kept up a positive façade, telling everyone I was doing dandy. Toward the end, I'm sure not too many believed me – I know I sure didn't believe myself. But I gotta keep smiling! Thank goodness Tricia's around to steer me straight.

Once the good stuff started dripping into me, though, I knew I would be fine again. And sure enough, at least this morning after, I can say it's working.

As was the case a month or so ago, I was camped in Station No. 6 – a cozy cubicle with a lovely view of the restroom and the blanket-warmer cabinet. Did you realize the blanket warmer also has a blanket cooler built right in?!? I sure didn't. It has a cold top and a warm bottom. I've known some people like that. What will they think of next?

There was one final bit of drama, though. After I was disconnected and simply being watched, my infusion machine decided to start beeping. A noisy, obnoxious screech of a beep.

First one nurse, then another, tried to hush it. They pushed buttons and unplugged cords. They turned dials and swapped plugs. No luck.

Finally, in desperation, they flung open a little door in the front.

Silence.

"How strange," one said. "I guess it doesn't want to be closed."

Personally, if I were in charge, I wouldn't let some stinking machine tell me what it wants. Especially if it were acting like a spoiled two-year-old.

"Don't like it?" I'd tell it. "Get over it." Then I'd stick it in timeout.

But of course, not being a member of the medical community, I didn't say a word. It's always better to leave the important stuff to the trained professionals.

Stay well all... and here's to modern medicine!

August 15, 2023 _____

I just returned home from an early morning visit to the University of Kansas Infusion Center for round two, dose two of the Magic Medicine that seems help keep my MG in check.

Most of my other visits have been filled with high drama – everything from uncooperative chairs to beeping machines, from unwashed feet in the next cubicle to pincushion attempts to get a needle into me. That's why this most-recent foray was such a treat.

I had graham crackers. Two packages, in fact. And I got the green elastic bandage with the blue dinosaurs.

“You have a choice,” my nurse said. “You can have this, or boring beige.”

Frankly, it wasn’t much of a decision.

“I think I’ll go wild,” I nearly shouted with glee. “Let’s do the dino.”

In all of my recent medical adventures, this is only the second time I’ve had that wonderful wrap. Oh, now and again I’d get hot pink or baby blue, but usually it’s el blanco for me.

Not today, though. Whoo hoo! Living the good life!

I must say, the nurse was enthusiastic. She ripped off a foot-long strip of the stuff and started covering my hand like I was some Egyptian Pharaoh. Across my wrist. Atop my knuckles.

Wrappings and frappings. Twists and turns.

Her eyes glazed over. She seemed in a trance.

“Who’s your mummy?” she screamed.

That brought a few curious folk into the area.

“I’ll have what she’s having,” the lady two stations over giggled.

Half an hour later, I was bundled up and ready to roll. And as for all that tape... Big gash? Open wound? Terrible sore?

Nah. A stinking little cotton ball.

They sure take their work seriously over there.

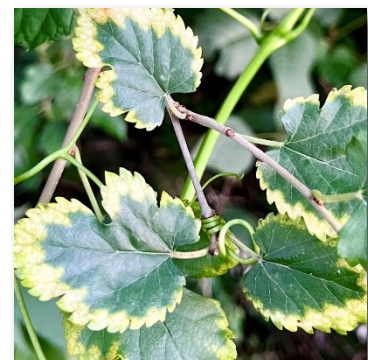
Stay well all... and when life gives you options, always Do the Dino!

August 20, 2023

I don’t recall seeing a plant whose leaves seem to be draining their color quite like this. Maybe it’s a portent of autumn; maybe it’s just an oddity waiting to be explained.

Whatever’s going on, I know how the guy feels. There are days when my energy wanes and my tint slowly fades away.

But then I tell myself this, too, shall pass; I’ll be blooming again in no time. I say it’s because of good attitude, good medicine, and good



living. Tricia probably would say it's because I'm full of fertilizer. Of course, she'd wouldn't EXACTLY use the word "fertilizer..."

Stay well all... and may all your leaves stay green.

August 22, 2023

I was back at the University of Kansas Infusion Center in Missouri yesterday for round two, dose three of my Magic Medicine. The stuff does seem to work, so I certainly didn't mind the trip or investing a couple of hours getting it dripped into me.

For the most part, things went very smoothly. No problem with the needle. No problem with the infusion. No problem with much of anything. Just like I like it.

...For the most part.

There was that lady in the next station. She had one of those voices you develop after years of smoking and hard drinking. You know, kind of like a cement truck. She sure loved to talk. About dogs. And being a former nurse. And did I mention dogs?

Now, I don't have anything against dogs (or former nurses, for that matter). Some of my best friends are dogs. But 60 minutes of, "Hack hack, gravel and grit, I used to be a nurse, here's another picture of my dogs" does kind of wear on a guy.

I'll give her nurse a lot of credit for patience. She stuck it out like a trooper.

Mercifully, Miss Foghorn eventually left, clearing both the air and my aching head. After that, it was an easy glide to the finish line.

I suppose some people just never learned their "library voice." Of course, these days library voices are about as soft as a rock concert. At least we still have libraries. With books and everything. We should take our victories where we can find them - no matter the volume.

Stay well all... and let me know if you want to see another picture of my dogs.

Aug. 23, 2023

It's been 30 minutes already, and I'm still sitting here winded. Tough workout? Mini-Marathon? Three-round bout with the neighborhood heavyweight champ?

Nope.

I wheeled a plastic bin half-filled with grass clippings from the side of the house to the front. Half-filled. Not even enough to make a decent pile of compost. But boy oh boy, did it pile on me.

In my defense, I hadn't had my morning meds yet. I was running on last night's fumes, and that's never a good thing. It's like when your laptop dings and pops up a warning that you better plug it back in. You've got a few minutes, then all goes black.

Thanks for nothing, myasthenia gravis.

Now, mind you, I did have to travel up a slight hill. Thirty feet, maybe, until I hit the relative comfort of the driveway. It was filled with patches of crabby crabgrass nipping at my heels as I trundled by. And had a heavy dew soaking the path, the inevitable result of living in a sauna-infused heat dome the last few days.

This was no walk in the park, that's for sure. Well, maybe one of those national parks. With the mountains and goats and things. But not your nice little flowery park.

My feet grew heavy, my heart began to race. "I can do it," I told myself, not fully believing. "It's no big deal. Easy-peasy."

There was nothing easy or peasy about it.

Step by aching step...

Hungry buzzards circled overhead. Coyotes howled their dinner call. The breeze blew hot, the flying sand stung my parched lips.

Onward I stumbled. Past the wilting bushes. Under the scorching sun. A bleached skull mocked me. Scorpions and snakes shook their heads in jest.

"Why have you forsaken me?!?" I cried to the heavens. Silence answered my plea.

I fell to my knees. All was lost.

Then, with my last breath, I shouted: "This is stupid. Get off your @\$@ and finish the job, you drama queen!"

That's all it took. With renewed vigor, I skipped the green bin up the hill, onto the drive and to the curb. Now, it's the city's problem. Let its big truck come by and dump the grass into its bowels. Someday, those clippings will make a nice pile of dirt. But as far as I'm concerned, today, this day, they're yesterday's news.

Stay well all... and may all your peasies always be easies.

Aug. 25, 2023

Adrenaline is such a good thing sometimes. It got me through 90 minutes of drumming last night without an ache, flopping muscle, or drooping eyelid. I'm thankful. Percussion's the heartbeat of any musical ensemble, and I certainly didn't want us to go into cardiac arrest.

Of course, after the place emptied and I started tearing down the hardware, the plug popped out. I went as flat as a torn tire. Pppfffttt. I'm melting..... What a world. What a world. Medicine and coffee can only get you so far.

But until then, boy was it fun. My seven bandmates and I were the featured "background

music” for Jewish Family Services’ 120th anniversary gala here in Kansas City. That means we played while people ate, drank, talked, and had a grand old time. We got together for this event and happily donated our performance.

All the bigshots were there: politicians and philanthropists and media moguls and civic leaders of all stripes. There were a bunch of them. But it was mostly just good, caring people. More than 650, in fact. That’s quite the crowd.



First off, congratulations to JFS. They do such important things for our entire community, without regard to who or what you are: mental-health services, aging-in-place programs, food and housing security, and so much more. The event, moved twice because it kept growing, raised more than \$770,000. That’s a dandy take.

Our 25 songs spanned the gamut from “Minnie the Moocher,” “The Way You Look Tonight,” and “Moon Dance” on one end, to “Ain’t No Sunshine,” “Angel from Montgomery” and “Evil Ways” on the other. We even had a pair of originals a couple of us wrote.

One thing I quickly realized is how tough it is to be background music. I often have trouble staying focused in a small crowd because of all of the competing sounds. Heck, sometimes I have trouble hearing Tricia when we’re alone in a quiet place (not that I would ever purposely ignore her, of course). But in a room that jammed, with a band jamming in front of me, it was, shall we say, interesting.

I guess I’m used to more staid environments. When I actually played regularly – back in high school and as a young adult – I was in concert band and community orchestras. The folk in the audience were there to hear us, and were, for the most part, paying attention. The performances Tricia and I attend now – usually symphonies and ballets – don’t typically encourage shouting and talking.

You know what, though? It was worth every gloriously noisy minute, on stage and for the five months we rehearsed. Not only did we help a great cause, but we made people happy. As long as I can muster the energy to do that, I’ll be happy, too.

Stay well all... and keep a song in your heart.

Aug. 29, 2023

I had my fourth of four doses of round two of the Magic Medicine yesterday. As always, I was at the University of Kansas Infusion Center in Missouri. As always, that still makes no sense to me.

For the most part, things went fairly well as we tackled my MG. The same nurse found the same vein in my hand for her needlework. She made the same apologies for the pain inflicted, and the same joke about it not hurting her a bit. Such great bedside manner.

And, as usual, I was surrounded by the most interesting and erudite neighbors.

One of them decided there was no better time to cough. Which she did, in raspy sets of threes. The whole stinking time. Hack hack hack. Pause. Hack hack hack. Pause. Etc. Etc. Etc. Ad infinitum. Ad nauseum. Add me to the do-not-disturb list.

Another loudly declared she was leaking. She wanted to make sure everybody in the county knew it. I didn't look for the puddle but did keep my feet elevated, just in case.

And, to top it off, the fellow across the aisle had a phone that sounded like a duck whenever it rang. He got a lot of calls.

Between Hacky, Yacky, and Quacky, I was going wacky. Man, it almost made me miss the lady from last week who droned on and on and on and on about canines. Almost.

Every once in a while, when I'm in for my infusion, they also take a blood draw. Might as well. The plumbing's already connected.

Turns out the test yesterday raised a few red flags. Bright, big, blood-red flags. Seems all of a sudden some of my numbers went from normal to whoa doggy. In particular, my kidneys and liver (and onions) were not happy campers.

My doctor's nurse left a message that fundamentally said the sky was falling and I better duck. Stop one of my medicines immediately, she wrote. Get to see a specialist ASAP. Guzzle a gazillion gallons of water.

She didn't suggest I should worry. She didn't need to. I did that just fine on my own.

While waiting for a return phone call from her office, I sent the results to one of my neurologist friends. He's very smart and deals with a lot of myasthenia gravis cases.

"Nothing to be too concerned about," the good doc said. "I see this all of the time."

Of course, I wanted to reply, tow trucks see wrecks all the time, too.

Turns out it's likely I'm just having a reaction to the now-yanked med. Things should clear up soon. That's good to hear.

But he also told me I have to push the experts on this. "Take control," he admonished. "Don't be stoic."

Stoic. That's fancy talk for stubborn as a mule.

Where did he get that idea?

Stay well all... and stay tuned.

Aug. 30, 2023

Three months ago today I entered the hospital for myasthenia gravis. A quarter of a year already. How time flies when you're having fun.

I was going to write a story about the ups and downs of my journey so far. But I won't. I was going to talk about the strange feelings and oddities that have jumped me time and again. But I shan't. I even thought about listing all of the dozens of pills I have to take every day now. Nah.

You see, I finally have some good medical news. And for someone who's falling apart quicker than a wooden bridge at a termite convention, that's something.

I went to the eye doctor this morning for my annual checkup. She ran me through the paces. I squinted at miniature letters across the parking lot. I followed her finger and blinked at flashing lights. I had a puff of air pushed into my eyeballs and got to decide which settings on that funny multi-lens thing made pictures look sharper.

After all that, the doc looked at me, took a deep breath, and told me my eyes were boring.

"Boring?" I asked. "Boring?!?"

"Yeah," she said. "Perfectly boring."

And that, she added, is perfectly good.

Yay!

I guess in this case, boring is pretty exciting. Who needs to talk about messed-up health when you finally find something that still works?

Stay well all... and I'll be seeing you (with very boring eyes).



Our Vision: A World Without MG

Our Mission: Create Connections, Enhance Lives, Improve Care, Cure MG

Myasthenia Gravis Foundation of America (MGFA) is the largest, leading patient advocacy organization solely dedicated to finding a cure for the rare neuromuscular disease myasthenia gravis while improving the lives of people living with MG.

More than 70,000 are diagnosed and living with MG in the United States alone. Those with myasthenia suffer with profound, debilitating physical symptoms such as extreme fatigue and muscle weakness that impact a person's ability to see, swallow, smile, walk or breathe.

MGFA funds promising research discoveries for better treatments and a cure while providing impactful programs, guidance, and education to help support members of the MG Community.

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