Day Zero

After six days of preparatory chemotherapy, I arrive at Day Zero. Today marks the system upgrade to Robo 2.0, download to commence shortly. It’s my New Birthday.

There are five bags of stem cells, harvested week before last from my own recalcitrant and glitchy old OS, now thawing in an Igor-esque laboratory down the hall. Around 3.3M stem cells, give or take, yessir yessir five bags full to be mixolydianed in with my diminished strain.

The Days Minus-6 through Minus-one were largely uneventful, which is really the way you want things in a joint like this one. No drama. Decent sleep. A distinct lull before the storm, as it were. Dorian afoot, and not so minor as its name might suggest.

We are perched seven stories above ground in a building constructed to the strictest brick-shithouse code, a designated shelter for storm pummeled locals. We have an expansive view over Paynes Prairies to the south, where we trust the storm will travel after it blows Mar A Lago straight to where it belongs. A little concerned about the storm hitting our dedicated house/pet sitters, but whaddyagonnado?

Plenty of time to think and ponder, especially after the 4 a.m. vital signs visit from the attending. Time enough to arrive at this: I am in the best part of *It’s a Wonderful Life*.

I’m alive, Bert! I’m ALIVE!
Yeah, it’s one of my favorites. I’m a sap. Deal.

It is too bad it takes a brush with mortality for me to twig to the immensity of my own Wonderful Life. I know I’ve had it good: vis Stanwyck and the amazing kids. That alone is more riches than Ozymandias ever knew.

But also too: There have been notes, emails, missives of all sorts from people reminding me of kindnesses I have done over the years, small things that I might not remember or maybe did not even realize were actually happening at the time.

I cannot express how much this means to me.

We wander through our days, often, in a grey haze, not always careful in how we act towards each other. All too often, that leads to carelessness and, sometimes – like right now when my laptop will not behave properly – nasty bits of temper that lead to simple acts of unkindness or even cruelty.

Funny how those events tend to stick in memory. I’ve often wondered if my life has not been a string of accidental or intentional unkindnesses punctuated by the occasional

accidental kindness.

But lately, the outpourings of thoughts from my many friends lead me to feel a little like George Bailey. A string of random events, perhaps, that actually add up to my having done something good in this world, that I have had a Wonderful Life.

And that maybe, just maybe, I deserve to live it some more, if only to try to make sure the kindnesses outweigh that other crap. What would Anubis say if he were to weigh my heart against his feather?

I'd like to wait a little longer to find out.

A few minutes ago, I received the first of the pre-meds that will support the stem cell transplant. Some of this is a considerable jolt of steroids, something with which I do not well deal. Between that and this damn laptop, I better sign off before I send the blasted device a-sail across the prairie. I'll post again when I can. Meantime, all inquiries, hail thee wells, and get-over-it-bubs are welcome via whatever messenger route you choose.

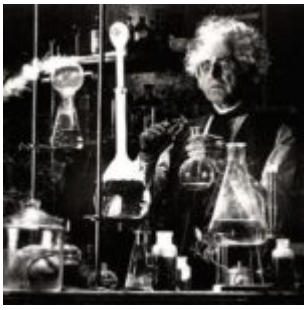
Sincerely, thanks for all the very real and tangible support. We are grateful for our friends and family, grateful to have been a part of your lives and you part of ours, and full of hope that we will all look back on this over some frosty adult beverages and have a good laugh.

Til then, and as always:

LOVE EACH OTHER, MOTHERFUCKERS.

Time is shorter than you think. Get Cracking.

Let Us Pause



I’m enjoying a week between before and after, lots of dog time, music, reading, and writing. Aside from discovering that the dogs pulled apart some of the ductwork under the houseWTF, it’s only money., it has been a lovely way to spend time before I surrender to the cruel intentions of a cabal of mad scientists. So while I have a minute here is what the next 4-8 weeks look like. For all you folks keeping score

Come Saturday the Igors and ~~Redferns~~ Renfields (mea culpa) of the Bone Marrow Transplant unit will begin zapping me with a six-day chemo course called BEAM, a regimen designed to come as close as possible to eliminating all of my bone marrow, platelets, red and white blood cells, and pretty much anything that we more or less recognize as biological necessity for staying alive without actually putting me on the wrong side of the grass.

Once they have me at the edge of expiration, another crew will tag team in to give me back the 3.3 million stem cells they extracted from me last week. Transplant day is slated for August 30. My new birthday. The hoped for end game is a brand spanking new immune system, preferably one that has no trace of the lymphoma.

The first weeks after transplant are critical. With no immune system, the most benign bacteria or virus could be

catastrophic. I do not use that word lightly. There are tight restrictions on what I can eat and drink, how (and how often) I brush my teeth and shower, and who can enter my room. I know of at least three people who made it through transplant with flying colors only to be felled by pneumonia. That shit does. not. play.

My digestive tract is apparently in for a doozie of a time. Chemo attacks the body's rapidly dividing cells, and pretty much all the cells after the teeth and down through the areshole are the rapid division kind. Extreme weight loss is likely. I'll take that, though I'd recommend the latest Oprah/Dr Oz macroketotic fad over this approach.

My sense of taste and smell are apparently going to be altered exponentially and inversely: I will have no sense of taste, yet my olfactory acuity will make the mildest little whiff of anything smell like a well-ripened durian, or a sewage discharge line gone a-plugger.

They will track every calorie and ounce of liquid that goes in. They will track every ounce of liquid and scat that emerges from my various agonized orifi. They will track the differentials between these values.

They will also monitor all the various chemical and mineral levels in my bloodstream to ensure I do not drop too low on the essentials like calcium, magnesium, potassium, &c.

Because my platelets will be essentially zero, I have to be especially careful about nicks and cuts. No flossing, for example. And especially: No walking anywhere (even the potty) without a guide because, were I to fall and hit my head, I would likely pass beyond the mortal coil before they could get me into surgery.

Hey, if the thunder don't get ya then the lightning will.

Somewhere between 2-4 weeks after the new birthday they will

discharge me to the Cancer Halfway House a few blocks from the hospital where several dozen of us malignancy malingerers will gather for conviviality and comparison of sufferings. For the following 2-3 weeks I will go in for blood and other tests to be sure I'm doing okay. If at any time I run a fever of 100.2*f or higher, I am to go directly to the ER for admission. Eventually they will send me home. They tell me to expect a good year to get back to whatever normal might look like.

Easy peasy. I could do it standing on my head if they allowed gymnastics on the ward.

In the meantime, I've been having a slurry of dreams of extreme ridiculosity. Impossible travel situations, missed connections, getting separated from traveling companions. Finding myself alone in a familiar city that looks nothing like anyplace I have ever been before. Getting lost. Getting accused of a crime I did not commit and chased like I'm Number Six.No big balloons following me. Yet.

Look, ya don't need to be Seigfried Shadyfreude to figure this stuff out. Clearly, lots of anxiety about my current situation bubbling up from the depths where Grindel's dang momma hangs out. This is new.

I have never really experienced this anxiety in my waking hours. Sure, I get worn down by the physical insults of treatment, but I'm mostly optimistic that the Dr. Caligaris on my case know what they are doing and that everything is gonna be alright. I haven't been afraid, not really. No fear of the great beyond or anything like that. And not even really sad about the whole shebang. It has just been a really intense endurance test and one hell of a learning experience.

Until this morning.

We have been getting up way early the past few days, just because we can. Next week, I can't. So a little extra time

with the Stanwyck and the hounds, time to listen to a few more albums per day than normal. More time to read and write. Good damn stuff.

Today, Stanwyck was up ahead of me. I roused around 5.30 to the smell of strong coffee. I woke up, got out of bed, dragged a comb, &c. I walked down the hall distracted by a recent earworm that I cannot escape nor identify.I believe it is a scrap of some obscure comedy album from my tender years, maybe even some kind of church distributed Don't Do Drugs propaganda. The Google has been no help. But I digress. I walked into the kitchen ready to roll.

And then it hit me. I saw Stanwyck and the dogs, our little kitchen table waiting for me to join them. It was so beautiful. And all of a sudden I got really sad and scared about everything, about how when I leave here Friday there is a fair odds chance that I will not come back. That everything I have, and had, and might ever have might be lost forever.

Fuck me, mate. That was hard.

But it passed after lots of woman love, and dog love, and a few hours of really good music. And coffee, which cureth all things. But still: Slap me silly and call me Trump. I did not see that coming.

Later in the day I received access to the upcoming Ken Burns docu about country music for an article I'm writing. It is really, really good, and filled with the kinds of plaintive songs that can salve a troubled man's heart. It is also fucking superb.

Anyway, here's the point of all this, if there is one.

The opening music for episode two is Mavis Staples' version of the Stephen Foster classic "Hard Times". I had to rewind and watch the first five minutes again because Sister Mavis had taken me somewhere else. After the episode I listened to it

again, and then to another half-dozen versions of the song ranging from a 1928 string band to Bill Frisell jamming on it with Elvin Jones and Dave Holland.

But none of them hit me like Mavis. I went back and listened to it a few more times. I'm downloading it to iPodious to take into hospital with me. (Correction: It is not available for download. YouTube it is.)

Tis the song, the sigh of the weary
Hard times, hard times, come again no more
Many days you have lingered around my cabin door
Oh hard times come again no more
I'll post again when I can. Stanwyck is keeping those who know and are known informed. Shout out to her if you want in on those updates. And as always…

LOVE EACH OTHER, MOTHERFUCKERS!

It matters a difference.

Trilliards

I'm nearly done with my second read through of Alan Moore's epic 2018 novel *Jerusalem*. At 1262 pages, reading this book once is quite the commitment. Reading it a second time (while also listening to the audio version, brilliantly delivered by Simon Vance) is most likely a sign of some sort of obsessive

disorder. And yet, I persist.

This book stands alongside *Ulysses*, *Underworld*, *Les Miserables*, *The Divine Comedy*, Milton's mislaid Paradises, and the great Russkie epics as towering constructions of sustained genius. (Among many! Tell me your favorite.)

I don't toss the word genius lightly, especially *sustained* genius. Most of you know that *Infinite Jest* is my favorite novel. But I can't quite characterize it's brilliance as *sustained*. For all its glory, it has evident flaws, passages that make you puzzle just how DFW hornswoggled the editor into letting them pass.

But *Jerusalem* hits the mark. There's not an ounce of flab in its dozen-hundred pages. The voices across a cast of what seems like thousands are each distinct and alive, even – or especially – the ghosts. The detailed attention to history, the digressions on time, theology, free will…all of it rings like brass bells from one sentence to the next. And the architecture of the thing – a labyrinthine structure that is every bit as awesome as the multilayered cosmology of the Universe it purports to explain – is breathtaking.

It took Moore, renowned for his graphic novel masterworks like *V For Vendetta* and *The Watchmen*, ten years to complete *Jerusalem*. One chapter is rendered in the style of Samuel Beckett. Another unfolds in the style of *Finnegan's Wake* to give voice to the mental illness of Jame's Joyce's daughter Lucia; that one took him a full year of working on nothing else.

I know 1200-plus pages seems ridiculous. Who has the time, and can't he just get to the point? The answers are, "You do" and "Getting there (the point) is half the fun." So get cracking.

One of the central plot pegs concerns the four Master Builders, powerful Archangel types responsible for the shape and sustenance of the Universal order. While they go about

their work of building the Past, Present, and Future, these characters simultaneously engage in an ongoing game of cosmic billiards, played out on a table so vast, and with so many balls – each of which represents a human soul (living, dead, and as yet unborn) – that it is called Trilliards to denote its universe-encompassing scale.

It appears that the Master Builders' shots are the force that directs each person's life and death. God may not play dice with the universe, but these guys are damn sure fiddling at snooker.

That's all I'll say about it for now, though I expect to come back to this work again and again. There is just so much to chew on, especially if you find yourself agonizing over the apparently deranged randomness of the universe that is the curse of the brooding class. Like me.

But that is not the point of this post. Or maybe it is.

I was glum on the way home yesterday from yet another week of hospital treatment for the dreaded C-word. Damnable random universe, etc. We were late leaving. We were hungry, but since the weather was bearing down on us we did not want to stop and get caught in the storm that was chasing us.

After much dithering we pulled off at the Live Oak exit on I-10 to get snacks at the Busy Bee.Busy Bee is a glorified, Walmart-sized truck stop where people fill shopping buggies with various chips, pecan rolls, trucker hats, and tacky Florida souveneirs. The place has its own Facebook account, ffs. The Bee was swarmed with a line of cars waiting to turn in and some scary looking parking lot jockeying underway. But we were off the highway and hungry, so we turned away from the Bee towards fast food hell.

But lo and behold! There amidst the burger joints and the hate chicken shack was a Moe's, purveyors of better-than-decent burritos. A sign!

Standing in line, I noticed a scruffian just ahead of me who looked familiar, but really and come on, who the hell am I likely to run into in some rando Moe's on I-10?

The best 1-2 guitar combo you never heard.
Yup. My brother in guitaristic arms, Chris Griffin. We've been playing together since 2003 in Bongo Wrench. Over the past 20 years, Bongo Wrench has performed live four times (a grueling pace, I know) and recorded well over 200 CDs. Fully improvised and often quite stunning. Our Motto: We Can't Repeat That. Our other motto is: We Never Play the Same Thing Once. Damn, I miss those guys.

Anyway, other than running into him at a Crim show, I've not seen since Chris in a couple of years, him always on the road with Drivin and Cryin and running his recording and mastering studio in ATL, me in the Panhandle trying to string a few words together. Standing in line at Moe's, he was the farthest thing from my mind.

And then I realized. Called his name. He gawped at me for about ten seconds.

“Chrissie! Don’t ya know me?”

“Robbie!”

And then it was all hugs and holy shits and what the fuck are you doing here you’re supposed to be in the hospital or something. We sat and ate and caught up. Turns out we have a Bongo Wrench YouTube channel now to go along with our 200-CD box set.

We Can’t Repeat This
I was fair and true gobsmacked for the rest of the ride home, one of the coolest things to happen to me in quite a while. We could have left on time. We could have eaten earlier. The Busy Bee could have been less crowded. The Taco Bell – his first choice of destination – was slammed, so they ended up at Moe’s. The slightest variation in any of these utterly unrelated details would have had us just missing one another.

Out of all the bean joints in all the towns in all the world, we walked into this one.

And then it struck me.

Trilliards.

I’ll just be damned. That was one helluva bank shot.

Everything, everything gonna

be alright this morning….

Muddy sez it’s gonna be alright.

When last we met, an unexpected recurrence of lymphoma in my neck derailed plans for a stem cell transplant, which is really the only viable option I have for any kind of long term remission. No sure thing, to be sure, but in this situation you gotta grab the best bet and push your chips onto the table.

They sent me home to have another surgical biopsy, but by the time I met with the surgeon the entire “recurrence” had disappeared. Quote…

> *There really isn’t anything there for me to take out.*

(Fun fact: Five years ago – six months after the Summer of Tick – this same doc was gobsmacked when I showed up for a fourth biopsy and had miraculously shed all trace of swelling. His comment then: “There really isn’t anything there for me to take out.” He was sure I had lymphoma then. He was probably correct.)

Anyhoo, we spoke to our ace oncology pharmacist at Shands, who then spoke to the transplant doctor (the one who said “You have a very aggressive form of cancer, and no good options.”), who then decided that I should come back to Shands straightaway for more scans and tests &c.

The outcome – revealed this afternoon – is that I am clear of

any sign of recurrence. Onward and upward with the transplant!

But the big thrill of the past couple of days has been the several sessions of nurses and doctors reciting the possible negative outcomes of stem cell transplant.

Yesterday, the nurse presented this info with a terrifically inappropriate kind of chipper happy talk. Imagine the following in an octave higher-than-normal-sing-song voice you might use to coax a toddler into taking a nap.

“So, first thing is, the transplant could, um, take your life.”

She went on from there to describe tingling fingers and lips; lack of fine motor coordination; fatigue; mouth, throat, and intestinal lesions; confusion; bone pain; skin rash and itching; dizziness; constipation and/or suddenly explosive diarrhea; and organ failure. She averred that she had never seen *any* of these unpleasant outcomes in her whole career, which upon questioning stretches all the way back to 2016.

Alrighty then.

All of this pleasantry was delivered in a sing-song punctuated by reminders to tell the nurses if anything feels wrong, the admonition that “we do not play ‘suck it up buttercup’ around here” recurring at disturbingly frequent intervals. It was like a sitcom tagline, Steve Martin shouting “Well Excuuuuuuse Me”, or Fran Drescher laughing.

By the fourth time she said it, I was ready to scream. By the eleventh recitation, unpremeditated manslaughter was on the menu. I restrained myself, but only just.

Today, we had to endure the same litany from the Head Honcho Doc, followed by me signing documents attesting that yes, indeed, I understand all the crap things that could happen. Now this is a guy that might be considered ‘on the spectrum’

(as ‘they’ say). In contrast to the nurse’s delivery, Dr. H spelled it all out in a largely affect-less delivery. Same info, but no buttercup happy talk. As Sgt. Friday would say, just the facts.

Funny thing. After the nurse’s chipper presentation, I was a fucking wreck filled with dread and premonitions of disaster. Terrified, really. But after meeting with doc today – just the facts, ma’am, no happy talk assurances – I felt reassured and ready to go.

So then. For now, we are back home with the dogs, a cold IPA at hand, the Sons of Kemet blasting Go listen to this scorching set from this year’s Big Ears. NOW! while we wait for the next chapter(s).

On Saturday, we begin the stem cell harvesting process, aka *apheresis*. For four days, I will receive twice-daily injections of a bone marrow stimulant (*neupogen* for the detail oriented). On the third day (oh, poetic portent!) they will install another port in my chest, this one with three dongles, a sort of Cerberus of access to my internal jugular vein.

On the fourth day we will harvest stem cells. I will be attached to a machine that takes blood out, spins it like a motherfucker (paging Dr. Brakke!), and then returns it to my system. Six hours, no detaching. The worst side effect of this process is boredom.

Then they send me home for a week. And then the real shit starts.

When I return to hospital, I will not step back out into sunlight and unconditioned air for at least 4 weeks, maybe as many as eight. First step in this is chemotherapy program (BEAM, for the curious) designed to pummel my immune system into nothingness. After six days of this (and this is where many of the more unpleasant side effects are likely to begin), they will reinject my stem cells to kick start my immune

system from the proverbial ground up. My new birthday will be August 30.

If all goes well, I will then face 2-3 weeks in hospital and 2-3 weeks as an outpatient which requires me to stay in Gainesville. If all does not go well, my stay in hospital and Gainesville may be longer, or, if things go terribly wrong, I could find myself on the wrong side of the dirt at any point along the way.

Just the facts, yo.

Still in all, I feel more positive tonight than last night when I tossed and turned all night in our hotel bed, visions of explosive bowels and sudden organ failure dancing in my head.

Tonight my vision is of beating their estimates of how long I have to stay in stir. Tonight my vision is of putting this shit behind me and moving on like a beastly motherfucker, ready to kick ass and take names. That’s where I see myself going. I might be deluded, but it beats the alternative of figuring that shit is going off the rails.

So for those who wish to help: We have some of our time away covered as far as dog and house sitting are concerned, but we still have some gaps in the calendar. Get in touch if you or anyone you know might be able to help.

Also too, and as always:

LOVE EACH OTHER, MOTHERFUCKERS!

That is an order.