We Interrupt Regular Programming…



I promised daily posts from the Big Ears hoolie. I failed. I promised an all-encompassing roundup that connects the dots between Africa, Appalachia, jazz, and the Euro-derived sonic explorations of the likes of Lucier, Budd, &c. I failed. Mea culpa.

I apologize for not getting back to you sooner, but I've been busy having cancer.I made a point of not posting this on April 1.

The short(ish) story: I've been feeling crappy for a few months. Not sure when it really started, but I remember that Cromp had to really push me to do the last RoboCromp gig in October. I just had no desire to play a guitar. I had told Stanwyck years ago that if she ever found me disinterested in playing that something was probably wrong. I was right.

My energy level was crap. I was having night sweats. My lymph nodes started to swell in some curiously asymmetrical ways. But I figured I would eventually fight off the crud, hopefully in time for the Big Ears trip.Priorities, people.

A couple of months and several quarts of well-examined body fluids later, no answer. Lymphadenopathy continued apace. I knew I was in for some drama when my general practitioner's eyes nearly popped out of her sockets at the sight of my anterior nodes. It is never a good feeling to have your doctor look alarmed.

So they packed me off to an oncologist who removed a slab of tissue for analysis. The result: Angioimmunoblastic T-Cell Lymphoma, a diagnosis so rare that my slab was forwarded to a specialist in San Antonio for verification. Turns out it was correct.

Hooray for me! I am a medical fucking mystery yet again.

Within two minutes of telling us this news, our local oncologist declared himself unequipped for treating this. At a rate of 500 cases per year globally, there are damned few who ever see this variety. As it happens, one of the docs who has seen this more than a few times practices at the University of Florida, just two hours down the road. Off to see the specialist, but not before I extracted a promise from Stanwyck that we would defer treatment until after Big Ears.

Like I said: Priorities.

The timeline looked like this. Two weeks before Big Ears began, I received a diagnosis. One week out, I saw the specialist and worked out a plan. The day before the festival began, we scheduled my first treatment.

The Festival was essential, everything I could have hoped for to prepare myself for a long and arduous treatment. I'll write about Big Ears 2019 in another post. It was a ridiculously rich experience, especially the hour-long interview with Rhiannon Giddens my first afternoon there. I'll work that up for publication soon. It was a delight. (It was also the moment I realized that I did not have the juice for my normal Big Ears campaign. More on that later.)

By the end of the festival I was feeling generally horrible. The day after the festival we drove home. The next day, we drove to UF where I began treatment. I had a semi-permanent port implanted in my chest for infusion and extraction. I spent five days tethered to a chemotherapy pump that managed to beep loudly at regular intervals overnight. Hospitals are

the worst place to try to sleep.

Because my medication is essentially a biohazard, I was not allowed to leave the ward. I walked laps around the hallway with my tower of IV bags, 14 laps per mile. I read two and a half thick books. I listened to 460 pieces of music, delivered at random by iPodious.

I slept. I ate like a horse, especially when decent food was smuggled in from the outside. I had an expansive view of the UF campus from my 8th floor perch. The staff was top notch, professional and extremely kind and reassuring. We started to joke about it being a luxury spa. I could not fucking wait to get out of there.

Yesterday we came home for a two week stretch, then we go back again for another five days of turning my bloodstream into a Superfund site, then home two weeks, for six full cycles.

So far, everything is as it should be. Initial treatment relieved most of the lymph swelling, aches, and night sweats. I no longer look like John Goodman in *Barton Fink*. I actually feel better than I have in months.



Side effects from chemo have been mild so far, but I have to stay away from people and germs and life and everything. The dogs are not allowed to lick my face, a grievous sacrifice in quality of life. But I gots no real complaint.

We arrived home to find our house scrubbed from top to bottom. The yard looks better than it has in a long time, thanks to good friends. The offers of food and running errands and such are incredible. We have got a team, y’all, and it rocks.

(We also have adequate insurance, for which I am both grateful and humbled. Everybody should have access to this kind of care. Someday, the rampant goatfuckery of our society will twig to this and deliver.)

Then there is Stanwyck herself. An amazement on her worst day, on her best day she is a fearsome force of nature, an implacable bulldog. Fair warning to any health care professional or bureaucrat who thinks they can half-ass around Stanwyck: She will have your head on a pike. Jes sayin…

Enough! This is some sloppy ass writing here, but I wanted to get this out of the way so we could get back to the stuff that matters: Music, books, movies, food. Love. I promise to write more better prettier next time.

Til then, in the immortal words of Patti Smith:

