

Re: OT: What's Going On.

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- *From:* BaybreezeRI@xxxxxxxxxx
 - *Date:* Tue, 19 Aug 2008 19:28:24 -0700 (PDT)
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On Aug 19, 5:37 pm, Bill Chandler <dr...@xxxxxxxxxxxxxxxxxxxx> wrote:

Warning up front: this post is utterly off-topic, personal, and contains various words of questionable moral fiber. It's also pretty depressing. That's how my life works these days.

If you proceed further, well, you've been warned.

I ain't gonna type this twice, that's for damned sure.

I have avoided writing this whole thing out, opting instead for emails up until now, but this time I'm just going to put it out here. I don't know how much more I can take.

Many of you know what's gone on for us over the last few years—Carla's parents (grandparents that adopted her as a child) passed away over the last couple of years, then my mother died last year. Bad enough.

Back in November–December of last year, Carla's (my wife) health began seriously failing. She has a strong family history of Huntington's disease; we had hoped when she got past 40 asymptomatic that she dodged that bullet, but with her failing health, slurred speech, gait & balance issues and such coming to a head in January (to the point that she lost her job as a nurse in a psych facility on the lower level of Hell), we feared the worst. Went to the doctor, got the blood test, and at the specialist's suggestion, an MRI. Well, after due time in consideration, they looked at the MRI and found a tumor, about 17mm, in her frontal lobe.

This bit of joy we were given back around April. (It all runs together after a while...) Unbeknownst to us, even at that point in time the neurosurgeon (whose primary desire was to get in there and start cutting, which just ain't gonna happen) was convinced that the tumor was not causing her symptoms. We (FINALLY) got the results from the Huntington's blood test around this time, as well—that came back negative (MAJOR good news!)...but were left in the dark about everything else. Another MRI was done—no tumor growth (that we knew

Re: OT: What's Going On.

about). The surgeon just wants to biopsy, cut, and bombard with radiation and chemo. (The tumor apparently isn't causing the problems...but let's chop her fucking brain up anyway. Doesn't THAT just sound lovely.) (Like I said...ain't gonna happen.) The tumor is what they call a grade 1 glioma—slow-growing.

Come June, and another appointment...follow up with the neurologist we visited before. At last, someone shares with us the fact that not only is there a tumor (so far), she is also suffering from "diffuse cerebellar atrophy". The neurologist called it cerebellar ataxia. Says this is what's causing the motor/gait/speech issues, not the tumor (which Carla named "Fred". Nothing personal, Mr. Shrimmer...). More blood tests...3 out of 4 came back normal; the 4th, which was sent to the Mayo Clinic, seemed to vanish into the ether.

Meanwhile, we've been seeing our family doctor (who is absolutely wonderful!) more than he's seen her in YEARS. He's a colonel in the Army Reserve, so they kept sending him back to Iraq...but he's home now. Put her on Antivert and Ibuprofen, which together are actually keeping the worst of the symptoms and pain under control. As long as she takes them.

August (last Thursday)...yet another appointment. Another MRI...no appreciable growth in the tumor or the cerebellar atrophy...that they mentioned, anyway. We looked at the MRI, and I got copies (of all of them) on CD. Here's the kicker...the results of that last lab test, which had been sitting in their files since July 18th, came back totally whacked. Level of some antibody (which the brain apparently produces in response to such things as tumors) are through the roof...154 when a normal reading should be 19 or less. And the doctors didn't even tell us this...we had to go and get the damned report from medical records and read it ourselves. This is rumored as a possible trigger for the cerebellar ataxia. (Google is our friend. More so than the damned doctors.)

And wait, it gets better! THERE'S A SECOND TUMOR that the fucking doctors didn't even MENTION. It's tiny, and apparently another low-grade one...but the idea that the damned tumor is having babies doesn't fill me with buttery goodness. Once again, Carla found out about this by reading the MRI report a little more closely. They found this one in the April MRI; it hadn't changed since then, the mention of which is how we noticed it this time. But she found this in the report...the damned doctors didn't even mention it. She told me about this yesterday, in the middle of hell day at work. (Monday on the helpdesk. Cut longitudinally, not laterally.)

Aren't doctors (SPECIALISTS!) supposed to review these reports and tell us about them? Carla being a nurse, she understands this stuff a lot more than I do...but I am pretty fucking pissed at these doctors at a major hospital (** Hospital, in Indy) who seem to be sitting on their thumbs, billing obscene (I mean OBSCENE) amounts to our

Re: OT: What's Going On.

insurance (which at least we have...for now...), leaving us with astronomical copays we can't even begin to afford, and leaving us to research this shit on Google??!?!?!!!

Suffice it to say, I'm pretty damned depressed right now. Carla would probably slap me silly if she knew I was posting this...the last thing she wants and needs...but I just need to vent.

Hey, at least it ain't (directly) political...

She's dealing with this better than I am. We're still hoping to be able to make TX-9 in October...she wants to go horseback riding whilst I'm sitting around drinking beer and playing guitar. (Sounds like a plan.)

Right now, I'm just not dealing very well. The band's playing out more over the last several weeks; that helps. But there just isn't enough beer to fix this one. For either of us. (And she doesn't like beer, anyway...)

Thanks for allowing me this opportunity to babble...I'll shut up now. Think we're just going to hide tonight.

Yeah, that's the ticket. There's still some beer in the fridge. I'll get her some Coke on the way home.

Onward...

... "Beautiful story. Kinda gets you right HERE!" -- Q

the above e-mail address remains totally fictional.

the real one is bc9424 AT gmailspamTHIS! DOT com (if you remove spamTHIS!)

...please check out my music at <http://www.soundclick.com/billchandler> some time...

Bill Chandler

...bc...

Bill – I'm very familiar with Huntingtons and glad to read the results were negative. Please know my prayers and thoughts are with Carla and you until you let us know otherwise. It must feel much better not having your feelings all bottled up.

Chuck

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