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I would trade the shop's success if it would fix my son's epilepsy

The magic number is 16. So far. That's the number of seizures Kevin's had today while at work. More noticeable than otherwise because it's been a busy day so most have happened in the presence of customers, or while Kevin's been on the phone. My wife's come down to take him to Kaiser ER, where they'll find exactly what? Nothing I expect. He's on a cocktail of meds that has been constant for the past two months, no significant lifestyle changes lately, nothing to give us a clue. They'll run a bunch of blood tests on him to measure the levels of the 4 different epilepsy meds he's on and they'll mark a single point in time that they will say, look at this, it's not quite where it should be. But they won't know if it's in the exact same place it was a week ago, when there were no issues. They can give him stronger anti-convulsant drugs, but while those might reduce or eliminate the seizures, they'll likely also reduce or eliminate his ability to stay awake.

It's frustrating. I want to fix him. That's what I do. I fix things. Problems come up and I figure out how to make them right. But I can't fix this and I can't even get a handle on the way things could turn out. The doctors keep trying, and Kevin gets increasingly frustrated. He's 21, he should be driving. Not that I would actively wish that on anyone, but if he wants to drive, he should be able to. But he can't. And at this point there's more hope that Google might come out with an epilepsy-proof car that takes over automatically in the event of a seizure than there is for a cure.

It's frustrating and it makes me angry too. Because you just don't hear about epilepsy in the news. It might as well be leprosy. Leprosy probably has a better PR firm handling things. Light purple is the color of the epilepsy foundation. How quaint. Let's make it soft and soothing. I think it should be bright red or some other color so garish that nobody can ignore it. I want to read about epileptics rising up in anger over the lack of medical research and the fact that there are tens of thousands, maybe hundreds of thousands, could be a million people with epilepsy who don't let anybody know because they won't be able to drive anymore, or their job might be deemed too dangerous for them.

I should be, and I am, thankful that modern medicine at least has allowed enough control over his seizures that he can work, he can ride a bike, he can go to school. But that same modern medicine is dulling his brain, feeding him chemicals whose sole purpose is to slow down the firing of his synapses so they don't go overboard and into fire-ready-aim mode. It's as if his brain is under attack from friendly fire. There is something called a ketogenic diet that's often been able to keep seizures at bay for those for whom drugs haven't worked, but it's generally a last-ditch effort because the diet is so restrictive and bizarre that nobody ever seems able to stay on it for more than a couple of years. And for the most part, his seizures are controlled, just not in an absolute manner. He'll have a week go by without any, and then a day like this (which was preceded by a couple other similar, but not quite as bad, days).

So this is my wish for Christmas. That I can get some sense that we're getting somewhere positive with Kevin. That I have more appreciation for the fact that God placed Kevin under my care and that I have the resources to help him. Go back a hundred years, a trivial amount of time in history, and he'd be entirely dysfunctional nearly all of the time and fed through a tube. Go back 200 years and he'd likely not have lived this long. But he's strong and will live long enough that hopefully "modern medicine" can come up with something better than drilling holes into your brain or trying to shut the brain down with meds.

Sorry for the rant. I am so thankful to be Kevin's father, and I think I have the means, physically & emotionally & financially, to deal with this. I'm rarely inclined to fall for saying that something "isn't fair." But it isn't. I can take things, emotionally, that others can't, because I'm usually able to displace those emotions so I can better focus on the task at hand. Star Trek's Spock was an early hero of mine. But Kevin? Or for that matter my wife, and my daughter Becky, to whom a fair burden falls upon taking care of Kevin as well.

Enough is enough. Let's just pray and hope that Kevin gets fixed. It's time. I'm ready to exit this trial and move onto something less challenging for all. --Kevin's Dad