

Update on wife's cancer, genetic testing and privacy issues

We're waiting for the results of the genetic testing and immunological info of Karen's biopsy, which will help determine the best course of action. We don't yet know how expansive the testing from Kaiser will be and it's the one area where, if we had to pay \$10k out of pocket just for an expanded genetic panel and consultation from Stanford, we'd do so without blinking an eye.

Karen had a brain scan yesterday morning, and it was clean! So not saying there are no issues upstairs, but at least cancer isn't one of them. Monday afternoon is the PET scan of the rest of her body, and then Tuesday morning a video call with a breast cancer specialist at Kaiser we haven't yet met.

I really need that pathology report before going into that video call. Our bodies carry a ton of genetic mutations that are largely harmless, some nasty, but even the harmless ones hold clues that can help determine which therapy might work better than another. This is an emerging field, and one where privacy issues stand in the way of healing sick people. Privacy issues?

Yes, our concerns about "big brother" knowing if we're likely to come down with this or that disease... that's a legit concern people have. What if an employer had the choice between someone whose genetic makeup made it 20% more likely that he/she would develop personality issues that could be a problem in the workplace, vs another similarly-qualified person without that? Or insurance companies not wanting to deal with people who would cost them more to insure than they'd pay for?

But keeping our genetic information private deprives us of hugely-important information that could result in amazingly-effective treatments for tough diseases. Currently, a medicine that offers, on average 7 months of additional survival for someone with triple negative stage 4 breast cancer (Keytruda) is seen as a breakthrough. Just 7 months. Not everyone gets 7 months; some get much more, some nothing at all. The genetic coding within us may hold the secret of who might get 7 years, and who needs to be looking elsewhere.

This really hits home because my wife is one of those who generally doesn't want others to know things about her they don't have to know. It's none of their business. She has had trust issues going back to childhood, and from my perspective, sees information as something that's inevitably weaponized. Me? Geez, google my name and you get 12,000 entries. My life is an open book. I write about anything and everything. I presume trust, and I believe the more open I am with people, the better they'll understand and help me.

More later.