

In western Pennsylvania, we have two major health insurance companies: Highmark and UPMC. In the 1990's, UPMC began buying hospitals and doctors' practices in the region, creating an integrated system whereby they were both the insurer and the provider. Among the hospitals they acquired was the Eye and Ear Hospital of Pittsburgh and the Hillman Cancer Center.

By 2012, UPMC owned tax-exempt real estate in Allegheny County worth \$1.6 billion. As a public charity, it avoided paying \$42 million in property taxes to municipalities, schools and the county. This non-tax paying, non-profit - built on tax-payor dollars - made over a billion dollars in 2020.

In 2013, Highmark bought a troubled hospital system and created an integrated system known as the Allegheny Health Network.

UPMC took umbrage at Highmark stepping into their territory and declared that Highmark subscribers could no longer utilize UPMC providers and facilities. Because UPMC had been at the game longer, they controlled the vast majority of specialized services in the Pittsburgh area. Thousands of patients were on the brink of losing access to their physicians.

The Pennsylvania legislature intervened and negotiated a Consent Decree, whereby patients who were under treatment as of June, 2014 could continue to see their doctors for a period of five years. The Consent Decree was set to expire on June 30, 2019, at which time all cross-system services would cease.

In 2013, I began experiencing severe pain in the left side of my face, extending into my left ear. I was diagnosed with trigeminal neuralgia and referred to UPMC Neurosurgery Associates. Two brain surgeries, multiple procedures and medications did not stop the pain. The neurosurgeon wanted to refer me to the UPMC Eye and Ear Institute, however, I have Highmark insurance through my wife's employer, and I was now barred from access to any additional UPMC providers. Over the next 2 years, I saw five in-network ENT's, all of whom told me that it was the nerve condition causing the pain. Then in early 2018, my dermatologist discovered evidence of cancer in my ear. I had been misdiagnosed all along.

With the cancer diagnosis, I fell into an exception in the Consent Decree and I was again referred to the Eye and Ear Institute, but because of the insurance issues, I requested to stay in-network. I had surgery in July of 2018, but by that time the cancer had spread too far for that surgeon's expertise; he could not even identify what type of cancer it was. At this point I was told that I *had* to see the experts at Eye and Ear. In December of 2018, they identified a rare cancer and in early 2019, I underwent a 14 hour operation followed by six weeks of radiation at UPMC Hillman Cancer Center. The pain was finally gone, but so was one of my ears. I cannot help but believe that had I had access to the doctors at Eye and Ear sooner, I might still have them both.

It took 6 years to find a team of doctors who were able to help me, only to face the reality that I would lose them in a few short months when the Highmark/UPMC Consent Decree was set to

expire. This included my team at Hillman Cancer Center. I was told that my only option was the Cleveland Clinic, which is a 2 hour drive from Pittsburgh. The idea of being cut off from my doctors was terrifying.

Patients, local leaders and advocates banded together demanding that UPMC negotiate with Highmark to guarantee access to the providers and services that were in patients' best interests. Highmark was willing to negotiate, but UPMC refused. With Attorney General Josh Shapiro's involvement, at the eleventh hour an agreement was reached and a ten-year contract was signed. That agreement finally allowed me to quit fighting for my healthcare and to begin caring for my health.

These integrated systems are spreading across the country. In the future you may find yourselves back in the private sector, subject to whatever insurance is available to you. The lack of access to care because of the insurance card you carry can literally be a matter of life and death. Giant non-profits cannot be permitted to care more about their profit share than they do about patient care.

Finally, a PET scan in October of 2019 revealed that the cancer has metastasized in my lungs. With this cancer, if metastasis occurs it typically occurs 5 to ten years after the initial diagnosis. Mine occurred within the same year. I believe that the delays described allowed that to happen. As I stated previously, denial of access to the proper care can be a matter of life and death.

I have always said that this is not just about me, it's about thousands like me. If my legacy can be that I helped even one person avoid what happened to me, then I can be proud that I did something important and meaningful in my lifetime.