

Fighting for Proton Therapy

Meet Paul Penke



After I was diagnosed with a large brain tumor at 34 years old, the choices my wife and I made seemed both obvious and extremely difficult. While we did a lot of research ourselves, we relied on my expert team of oncologists at the Mayo Clinic to lead my treatment plan. They recommended surgery to remove as much of the tumor as possible, then proton radiation therapy and chemotherapy as a follow-up protocol.

We did even more research once my doctors developed that plan, and felt confident that it was the safest and most effective treatment that gave me the greatest chance at a normal, long life. It came as a shock when my insurance company denied the proton therapy my doctors felt was in my best interest.

It was like a full-time job, trying to appeal Premera's denial not once, but three times — all on a pace inappropriate to the urgency of my situation. During that process, I read about other patients who had succeeded in advocating for themselves by going to the media.

“Going to the news media was my decision, but once I made that decision, Molly and her team at the Alliance were instrumental in equipping me to make that fight the most effective.” —Paul Penke

My wife and I decided proton therapy — and the life it could preserve — would be worth fighting for.

We determined that we really didn't have any choice but to go to the media, even as I was recovering from brain surgery. We felt empowered by other success stories and were bolstered by support the Alliance for Proton Therapy Access provided. At the time, we didn't even really blink or hesitate and, thankfully, the story that eventually aired on my local news station prompted Premera Blue Cross to overturn its denial. We were overjoyed.

While the choice seemed clear at the time, in hindsight there was a lot of nervousness and concern about telling a story that, once in the media, could never be removed. The Alliance guided me through the whole process, equipping me with the tools I needed to talk to the media, and I believe our decision to go public ultimately resulted in me getting lifesaving proton therapy.

I am very thankful for the bright future I believe lies ahead because I got the treatment I needed. However, I feel compelled to continue speaking out because an insurance company should not have the right to ignore expert advice and deny a patient the treatment that is the obvious choice to a patient and their medical team.