

# Fighting for Proton Therapy

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## Meet Sherry Shaw

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As a mother, I would have done anything possible to ensure my son, Derek, would not only survive his brain tumor, but go on to live a long, healthy, and productive life. It turned out that the most important action I could take was fighting Derek's health insurer through public exposure to its denial of his physician-recommended proton therapy.

When Derek was diagnosed with a brain tumor in October 2017, things moved shockingly fast. A typical workday took a sudden turn, and over the next few weeks, the MD Anderson neuro-oncology, neurosurgery, and radiation oncology team put into motion a treatment plan that included removing as much of the tumor as possible and following up with radiation and chemotherapy. Derek underwent an 11-hour 'awake craniotomy' in January 2018 that resulted in 40 percent of the tumor being removed.

The remaining tumor was too close to an 'eloquent' area where Derek processes speech, so to preserve neurologic functioning, it could not be treated with surgery. With Derek still recovering from surgery, he relied on me to explain his ongoing treatment options, and we agreed with his MD Anderson oncology team that proton therapy would be the best option for him. As a 34-year-old newlywed and aerospace engineer, we all wanted to ensure Derek had the best chance of a full recovery, and we knew proton therapy's targeted approach was the safest way to treat his very sensitively-located tumor.

To our great disappointment, Blue Cross Blue Shield (Federal Employee Program) denied Derek's claim to receive proton therapy, and the optimal window of time for radiation was close to expiring. We were in a race for time, and MD Anderson's Proton Therapy Center prepared a lengthy appeal in hopes of the prior denial decision being overturned. Because Derek is a federal employee, his insurance plan only allows him to appeal a denial once. When Blue Cross Blue Shield once again denied his proton therapy, we felt we were out of options. Six weeks after Derek's craniotomy, he found himself not only fighting brain cancer but trying to decide whether and how to fight his insurer.



Though Derek was reluctant to sacrifice his privacy and nervous about Blue Cross Blue Shield retaliating if he 'made noise' about the denial, he quickly concluded he might still get the treatment he needed by taking his story to the media. Through an online group of other brain tumor patients, we had learned of other "success stories" of insurance companies reversing denials and agreeing to cover proton therapy after patients took their stories public. This online group led us to the Alliance for Proton Therapy Access. While the decision to go public would have to be Derek's, the Alliance provided the support and guidance we needed to embark on the intimidating process of fighting a huge insurance company.

*"Taking my son's story to the media directly influenced the insurance company's decision to reverse the denial and grant the proton therapy my son needed."*

Once Derek was resigned to taking that uncomfortable step, and we felt informed and empowered enough to follow through, Derek's sister and I reached out to the greater Houston media and received an immediate response from a local reporter. Within a couple of days, Derek's story was on the evening news, and the link to that story was shared throughout social media. As a direct result of that pressure, Blue Cross Blue Shield reopened his case and approved his proton therapy — just one week after Derek's appeal process was exhausted. Derek began proton radiation in March 2018 and completed it in mid-April. In April 2019, he completed his chemotherapy regimen and is back to work as a NASA engineer. We are so grateful to the Alliance and the army of supporters who helped achieve the media campaign that should never have been necessary for a cancer patient in the acute phase of managing a life-threatening disease.