



DIPG comes in the dark, slithering and unfelt, a terrorist intent on beheading its victim. It takes up residence in the brain-stem and begins strangling one nerve-strand at a time. At first the symptoms are so subtle they could be ignored, all the more-so because DIPG's favorite victims are small children who can't really say what they're feeling. Sometimes symptoms will progress quickly to betray the underlying disease, but DIPG can also go unnoticed for months, worsening at nearly an imperceptible pace – something a general practitioner might chalk-up to sleep-loss or fighting a low-grade infection. "Get more rest. Take these pills." Until one day the victim's eyes begin to cross or her movement becomes excessively fumbled. Then the alarm bells go off and tests are ordered.

DIPG stands for "diffuse intrinsic pontine glioma," a cancer which does not form in a mass like a typical tumor. Instead, DIPG attacks the glial cells which surround individual nerve cells – like spaghetti and sauce stirred together and the sauce gets progressively thicker – slowly pinching off the synaptic connections between healthy cells. Victims often experience increasing difficulty with their eyes tracking together. They lose strength and coordination on one or both sides of their body. In the latter stages of the disease, victims might experience increased problems swallowing food. Even something as basic as breathing becomes labored. The progressive loss of autonomic functions and motor-control leaves victims figuratively beheaded. Death by any number of critical-system failures usually occurs within a year of being diagnosed. Fortunately, DIPG is very rare, afflicting only 300 persons and their families in the US each year. Unfortunately, this scarcity makes it less attractive to research. There are no obvious monetary incentives.

What then of treatment? Mainstream medicine offers "standard care" – radiation – which can prolong a patient's life for maybe three to six months but with side-effects that can outweigh the benefit. There are no realistic surgical options – no "gamma knife" – because DIPG and healthy tissue are too intertwined, and chemotherapy has a tough time crossing the "blood-brain barrier," the body's natural defense against common infections getting into the brain. Efforts are being made to bypass the blood-brain barrier, which is hopeful. We also hear good news about immunotherapy – treatments to target malfunctioning genes and help the patient's own immune system fight off the cancer. This approach holds great promise for treating many cancers, but probably not DIPG. Unlike cancers which are triggered by one or two faulty genes, DIPG is a cascading malfunction. Roughly 180 genes are involved, and they don't fail all at once. Instead, scientists believe DIPG morphs throughout its life-cycle, switching various genes on and off as it grows – almost like it's adapting.

DIPG is the Demon King of cancer. It has proven itself almost untouchable, with barely a handful of successful treatments over decades of trying. These rare cases range from one patient's tumor being held at bay for several years using CBD, to a few cases of total remission using Antineoplaston therapy. While no single treatment comes close to a "cure-all," working with treatments that have had an impact seems intuitively obvious. And combining these treatments with those mentioned above and others – including quantum magnetic resonance therapy – could hold the key to making real progress. Any treatment approach that cures DIPG will likely cure most other cancers as well. That's why DIPG research and "Right to Try" laws are so critical. DIPG is a monster, a premature death sentence. It's time to behead DIPG!

Wendy and Dean Fachon, parents of Eugene "Neil" Fachon, who died in 2017 from DIPG.