*SLTP alum and brain cancer patient, Neil Fachon, 20, from Rhode Island presents a Spanish version of The Jester to a young Puerto Rican brain cancer patient at the Burzynski Clinic.*

# Bringing Hope To Patients
## With a Terminal Diagnosis

by Wendy Nadherny

*The use of the word "terminal" limits one's mindset, while the word "curable" opens up a world of possibility.*

While conventional oncologists consider certain cancers, including brain, to be terminal, hope lies in venturing outside the box of conventional thinking. This includes researching and evaluating U.S.-based and foreign-based clinical trials using experimental approaches to treat primary cancers and recurrent cancers with immunotherapy or gene-targeted therapy.

In April 2016, three interesting Food and Drug Administration (FDA)-approved clinical trials were open to patients with diffuse intrinsic pontine glioma (DIPG), a rare and aggressive form of pediatric brain cancer found each year in about 300 children. One of these trials was offered by the Burzynski Clinic in Houston, Texas. This clinical trial was the only one offered to DIPG patients that had declined the standard recommendation of radiation and/or tissue brain biopsy, given to extend life a few months beyond the median survival rate of less than one year from diagnosis. The trial protocol was designed to test non-toxic antineoplaston (ANP) peptide therapy which had been used in previous trials to treat DIPG and glioblastoma (GBM) brains with some level of prior success, indicating that DIPG and GBM are in fact "curable".

The manufacturing and research for ANPs is sponsored by the Burzynski Research Institute (BRI), a publicly-owned biopharmaceutical company working to develop and deliver cancer therapies based on genomic and epigenomic principles. In 1967, Stanislav Burzynski, M.D., identified naturally occurring human peptides which were present in healthy patients and deficient in cancer patients. He concluded that these peptides played a role in preventing the growth of cancer cells. With a Ph.D. in chemistry, Burzynski was able to reproduce the peptides synthetically, and he named them antineoplastons. ANP therapy targets more than 100 genes that affect tumor cells. ANPs switch off certain genes that cause cancer (oncogenes), activate the genes that fight cancer (tumor suppressor genes), and pose no harm to healthy cells, with the most common side effects resulting from electrolyte imbalances, all of which can be managed through regular blood analysis, dietary intake, higher water consumption and potassium supplementation.

Neil Fachon, 19, an engineering student at Northeastern University, in Boston, was diagnosed with DIPG at Massachusetts General Hospital on March 3, 2016, and became the first patient to enroll in the new ANP clinical trial that opened on April 12, 2016. On April 20, after passing baseline tests, he began receiving ANP infusions. That same day, however, the FDA placed a hold on the trial it had given prior approval. Committed to his chosen course of treatment and deeming the FDA objections to be unreasonable, Fachon took legal action, through federal court in his home state of Rhode Island, to overturn an FDA decision that failed to acknowledge his rights. On May 17, Fachon won a temporary restraining order that was later negotiated into a permanent injunction, and he had sound reasons for wanting to pursue this treatment.

DIPG survivor Jessica Ressel, who received her diagnosis in March 1996 at age 11, was successfully treated by Burzynski. Now married and a mother of two, she is one of three long-term DIPG survivors who keep in touch with Fachon and provide encouragement. All three of these survivors were treated with ANP therapy at the Burzynski Clinic. While seeking to assure his own survival, Fachon also wants to play a role in promising scientific cancer research. Presently Fachon is a trial of one; however, he hopes the FDA will remove the hold, or that Right to Try legislation will

be passed to allow other DIPG patients to join him and have a chance at life.

Right to Try legislation gives terminally ill patients the right to try investigational medicines that have not yet received full FDA approval. The FDA drug approval process can take up to 15 years—far too long for dying patients to wait, because terminal time lines are measured in months and weeks. Many potentially life-saving treatments awaiting approval in the U.S. are already available overseas, and have been for years, yet most Americans cannot afford to seek treatment abroad. A Right to Try law gives hope back to those who have lost it. It is not just for children diagnosed with DIPG, but for anyone with a terminal illness hoping to get life-saving treatment before it's too late.

Already law in 30 states, Right to Try legislation is under consideration in 16 more. On May 13, the Rhode Island House unanimously passed House Bill 7156, which would set the foundation to nullify in practice some FDA rules that deny access to experimental treatments by terminally ill patients. The House approved the legislation by a 71-0 margin. It is now in the Senate for further consideration.

On the same day, the Rhode Island Senate passed a separate bill expanding insurance coverage for some experimental drugs. The state already requires insurance to cover certain "off-label" cancer treatments, but this bill would expand that requirement to patients with other diseases that are disabling or chronic and life-threatening. The House also passed this bill, the governor has signed it, and it will take effect on January 1, 2017.

That same week, on May 10, the Trickett Wendler Right to Try Act of 2016 (S. 2912) was introduced in the United States Senate: "This bill bars the federal government from prohibiting or restricting the production, manufacture, distribution, prescribing, or dispensing of an experimental drug, biological product, or device that is: (1) intended to treat a patient who has been diagnosed with a terminal illness; and (2) authorized by, and in accordance with, state law. The federal government may not restrict the possession or use of such a treatment by a patient certified by a physician as having exhausted all other treatment options."

While each bill addresses some aspect of the Right to Try issue, they fail to go far enough. If an experimental treatment shows evidence of more success than conventional treatment, why not allow a patient to bypass the conventional treatment and go straight to the experimental treatment? And if experimental treatment is more successful than conventional, why not allow the treatment to be covered by health insurance?

*Neil Fachon hopes the sharing of his story will raise awareness about treatment options for brain cancer and about a terminally diagnosed patient's right to choose. People can help move Right to Try legislation forward by contacting their senators and representatives. Learn more at RightToTry.org. Learn more about DIPG at CorysCrusaders.org/resources.*

*Wendy Nadherny Fachon is a health educator, a writer for Rhode Island Natural Awakenings magazine and Neil's mother. She can provide helpful information to parents of children diagnosed with brain cancer. Contact at Wendy@NetwalkRI.com or through Facebook.*