

Editorial

FDA: One Nation Under God, with Limited Access for All

Nothing illustrates the issue of medical freedom of choice quite so poignantly as parents fighting for the right to choose medical treatment for their sick child. Not since the story of Chad Green (whose parents were forced to take him from their home near Boston in the middle of the night so they could access nontoxic treatments in Mexico) generated national headlines two decades ago has a story like that of four-year-old Thomas Navarro attracted such media attention. Thomas was diagnosed in September 1999 with a brain tumor, a medulloblastoma, which was subsequently removed surgically. Unfortunately, this type of brain tumor typically reoccurs. Thomas' oncologist recommended chemotherapy and radiation as a follow-up to surgery, to prevent a recurrence of the tumor. Fortunately for Thomas, his parents James and Donna did their homework and discovered that this approach offers little hope of a cure and frequently causes some very serious side-effects, including hearing loss, blindness, secondary tumors, and damage to the pituitary gland which results in growth and mental retardation and hypothyroidism, and the list goes on. After extensive research they determined that an unconventional approach, antineoplaston therapy pioneered by Stanislaw Burzynski, MD, PhD of Houston, Texas, seemed to offer the best hope for a cure without harmful side-effects.

Despite published evidence of the efficacy of antineoplastons, including numerous positive case histories, antineoplastons are considered by the U.S. Food and Drug Administration (FDA) to be an unproven, experimental therapy. Burzynski has the approval of the FDA to use the therapy under closely monitored experimental conditions only in cases where chemotherapy and radiation have been tried repeatedly and failed. The Navarros, however, are unwilling to subject their son to treatments that are known to have debilitating and even life-threatening side-effects. Since November 1999, they have been camped out in a hotel near the Burzynski clinic while they continue to petition the FDA to allow Thomas the treatment they feel will save his life. Although Texas' Child Protective Services Agency was initially barking at their door, they have since backed off after meeting with the Navarros and concluding that they are indeed trying to do what is best for their child.

Thomas' story was brought to the attention of the national news media when former Ambassador Alan Keyes, a Republican presidential candidate, raised the issue of the family's plight during his closing statement in a nationally televised debate in January. In mid-February, Rep. Dan Burton (R-IN) and over a dozen of his colleagues introduced in Congress the Thomas Navarro

FDA Patient Rights Act (H.R. 3677). To mark the introduction of the bill the Navarros were on hand at a press conference in front of the U.S. Capitol. Also present were two other children with a history of medulloblastoma: Nicholas, who had received conventional chemotherapy and radiation, and Dustin who had been treated with antineoplaston therapy six years earlier. While Dustin played around like any normal healthy eight-year-old, five-year-old Nicholas lay curled in a wheelchair, lethargic and oblivious to his surroundings.

Rep. Burton's proposed legislation prohibits the FDA from placing clinical holds on the use of investigational treatments as long as the patient or the patient's parents sign a declaration that they are aware of both the conventional approaches and the experimental nature of the alternative. This legislation puts power in the hands of the patient.

A similar proposal, the Access to Medical Treatment Act, has been held up in Congress for several years. While the Navarro Act targets investigational drugs, the Access to Medical Treatment Act seeks to allow Americans the right to use any alternative therapy they choose, whether or not it has FDA approval. The bottom line of both pieces of legislation, however, is the same — to remove the choice of medical treatments from the hands of bureaucrats and return the power to the individuals involved.

Independent journalist, Peter Chowka, who has covered three nationally known medical freedom of choice cases involving children, including Chad Green, was one of the first to report on Thomas Navarro. He summed up the Navarros' situation and its importance: "The unimaginable tragedy of a child sick with cancer is compounded by his family's lack of freedom to use what their conscience and intelligence tell them is the best therapy available. Hopefully, Thomas Navarro's family — and other loving parents — will soon have that freedom, guaranteed by law."

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