



# TENNESSEE CANCER PATIENT COALITION

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## Tennessee cancer patients denied state-of-the-art cancer treatment

**March 22, 2017 (Knoxville, TN)** - - Alexa Gash had recently moved to East Tennessee with her husband, Peter, and one year old daughter. Peter had accepted a job as an Assistant Coach for the University of Tennessee Chattanooga Men's Basketball team. She was settling into her new life and going about a normal day when she discovered something strange while brushing her teeth - a painful growth in the back of her throat. Visions of the worst-case scenario raced through her mind which were soon confirmed. It was cancer, oropharynx squamous cell carcinoma to be specific.

Alexa quickly began the confusing, overwhelming educational journey familiar to most cancer patients. Her journey led her to multiple clinical opinions and a number of potential treatments. One of the early favorites was radiation therapy where X-ray beams would be directed through her body to destroy the tumor. However, this came with some pretty scary side effects. Alexa learned that patients treated with conventional radiation therapy for her cancer typically suffer from a painful condition called mucositis caused by the excess radiation dose delivered outside of the tumor. Mucositis often leads to an inability to eat and significant weight loss. In some cases, patients require a feeding tube because they can no longer swallow. In more severe cases, patients never regain the ability to swallow. Most certainly Alexa would not be able to care for her one-year old daughter with these types of side effects.

Fortunately, Alexa's journey did not end there. She discovered that she was a candidate for [proton therapy](#) and nearby Knoxville is home to one of only twenty-five proton therapy centers in the United States. Protons have a unique physical property that allows a radiation oncologist to deliver radiation to a patient's tumor while sparing healthy tissue, avoiding many of the painful side effects of conventional radiation therapy that had so concerned Alexa. Her mind was easily made up. She would travel to Knoxville and get treated with protons for approximately seven weeks.

It was then that she realized there was another big hurdle to overcome before she could get cured. She had to obtain approval from BlueCross BlueShield of Tennessee to cover the cost of her treatment. She expected this to be a given considering the significant benefits proton therapy offered, especially when both her insurance company and the proton therapy center were non-profit East Tennessee companies committed to the public good ... her good.

Despite her physician's adamant support, BlueCross BlueShield of Tennessee denied the request for coverage for her proton therapy treatment, calling the treatment experimental even though it has been FDA approved since 1988, and has been used to treat cancer since 1954. Alexa appealed and followed the multi-step process her health plan required. This included a "peer review" by a physician retained by the insurance company with no background in oncology, let alone the specialty of radiation oncology.

The appeal process lasted almost 90 days. The growth protruded inside her throat making swallowing difficult and was a daily reminder of her predicament. BlueCross Blue Shield denied all of Alexa's additional requests. Effectively denying decades of research, they claimed that benefits of less radiation have not been proven through randomized control trials. Even though Medicare has covered proton therapy for more than twenty years and the National Comprehensive Cancer Network guidelines have expressed support for proton therapy in the treatment of head and neck cancer, BlueCross simply said NO.

Alexa was at a loss. Her family had paid their insurance premiums for years and now, when she finally needed the insurance company to fulfill its side of the bargain, they abandoned her. If Alexa were in Florida and covered by the BlueCross affiliate there, her treatment would be covered. If she were old enough to receive Medicare, she would be covered.

In recognition of the gap in coverage and the beneficial impact that proton therapy can have for cancer patients, several legislators have introduced legislation in the Tennessee General Assembly that would require insurance companies to cover proton therapy under specified conditions at no additional cost to the insurance companies. These Bills have been introduced by Senators Doug Overbey ([Senate Bill 0367](#)) and Dr. Mark Green ([Senate Bill 0210](#)) and Representatives Bob Ramsey ([House Bill 0523](#)) and John Holsclaw, Jr. ([House Bill 0883](#)) respectively. There is an additional Bill carried by Representative Mark Pody ([House Bill 0899](#)) and Senator Mae Beavers ([Senate Bill 0758](#)) that, if passed, would prohibit insurance companies from holding proton therapy to a higher standard of clinical evidence than other forms of radiation therapy that preceded it.

Currently, the insurance company lobby is fighting the legislation and continues to shirk their responsibility to modify their coverage policies to keep up with technological improvements that offer the best treatment available. Instead, they wear out their own insureds with an endless appeal process forcing frustrated patients, their families and healthcare providers to seek redress in the courts or the legislature. Over the coming days and weeks, the bills will be heard in the Joint Pensions and Insurance Committee chaired by Chattanooga's Senator Bo Watson, the Senate Finance and Labor Committee chaired by Franklin's Senator Jack Johnson and the House Insurance and Banking Subcommittee chaired by Representative Keisling from Pickett County, Tennessee. Senator Johnson has previously spoken out in favor of proton therapy in publicly supporting the development of Tennessee's third proton center in his district.

Hopefully, the State Legislators can see through the insurance companies' ploys of denying cutting edge treatment to cancer patients under the guise of a purported lack of clinical evidence and advance the bills supporting proton therapy. Fortunately, Alexa's family worked out an arrangement with the [Provision Proton Therapy Center](#) to obtain treatment. [Alexa fared well during her treatment](#), avoiding serious side effects and maintaining her weight throughout the process. Hopefully, future patients will not have to fight the same battle because the pending bills before the General Assembly will be passed, allowing the patient and their physician to determine their best course of treatment.

The non-profit patient advocacy group [Tennessee Cancer Patient Coalition](#) is encouraging cancer patients and caregivers to [contact their representatives](#) in support of the bills mentioned above.

Learn more about proton therapy at: [proton-therapy.org](http://proton-therapy.org)

Visit the Tennessee Cancer Patient Coalition at: [TNCancerPatient.org](http://TNCancerPatient.org)

Read Alexa's Proton Story at: [ProtonStories.com](http://ProtonStories.com)