

LEGAL AID SOCIETY
OF MIDDLE TENNESSEE AND THE CUMBERLANDS

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**Court Orders TennCare Bureau to Provide Treatment to
Woman with Rare, Potentially Fatal Disease**

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Fatal Disease

NASHVILLE, Tenn., April 24. A Davidson County Chancery Court has ordered the TennCare Bureau to provide treatment to a woman with a rare and potentially fatal disease. TennCare called the treatment investigational and not medically necessary, although a doctor with Vanderbilt University has used it successfully and said there was no other alternative. This decision reversed TennCare's denial and clarified when TennCare can deny treatment as investigational.

Dickson County resident Jeanetta Deason suffers from a rare disease that hardens the skin and organs and is usually fatal. Fewer than 200 people in the world have this condition. Treating physician Dr. John Zic with Vanderbilt University Medical Center said Deason may not survive without the treatment.

The Legal Aid Society represented Deason on her appeal. In announcing the decision, Clarksville attorney Kevin Fowler said, "This decision brings hope to Ms. Deason and affirms that TennCare should never have denied her treatment."

Davidson County Chancellor Ellen Hobbs Lyle agreed with the opinion of the treating physician. Zic stated that for a disease this rare, all treatment was investigational, but that fact “makes the treatment no less necessary.”

Fowler stated, “We are especially pleased that the court carefully applied the law that limits TennCare’s ability to deny treatment for being investigational. TennCare should never pay for unproven treatments, but in this instance a highly respected doctor recommended the treatment that he had used successfully. No evidence contradicted his recommendation.”

Deason suffers from Nephrogenic Systemic Fibrosis. According to her physician, this condition can be treated effectively only by a process called extracorporeal photophoresis. This requires removing some of her blood, treating it with a drug, exposing the blood to ultraviolet light, and returning it to her body.

The court held that TennCare could not reject a treatment for being investigational if it was also medically necessary. It found that “The record contains no evidence, let alone substantial and material evidence, that would support the Department’s conclusion that the treatment is not medically necessary.”

The Legal Aid Society is a nonprofit regional law firm that gives free legal help to people who have nowhere else to turn. It has eight offices that serve 48 counties throughout Middle and East Tennessee.