

Compliance Today – January 2019 Remembering Jesse

by Kelly M. Willenberg

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In 1999, Paul Gelsinger's 17-year-old son Jesse was suffering from a genetic disease called ornithine transcarbamylase deficiency. A buildup of ammonia was making Jesse very sick from dietary choices, including a strict non-protein diet. A carefully followed diet and medication controlled the disease. Given an opportunity to participate in a gene therapy trial designed to test possible treatments for his disease, Jesse decided that when he turned 18, he would give consent. The trial would use gene therapy or an adenovirus to transport a normal gene into his liver. For the most part, Jesse was informed that subjects who had received the adenovirus had not had serious complications. But a mere four days after the gene therapy, Jesse suffered an immune reaction and died.

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