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2/10/11

My name is Kailani Gadlin and I am the mother of 10 year old Navaiah Fulk.

Navaiah was born with Gastroschisis and had her first surgery at 4 hours old. The first 18 months of her life consisted of us living at the CT Children's Medical Center hoping that her small intestine would work, waiting for a transplant and finally being transplanted at Mt Siani Hospital, Manhattan, NY in February of 2002.

Due to her very critical medicine schedule, food allergies, and her inability to absorb and retain oral fluids, Elecare has been and will continue to be her primary source of nutrition. Her medical condition changes from time to time. This results in hospital stays ranging from 3 days to 6 months. Her intestines have to struggle 20 times harder to recover than any healthy child after a typical stomach bug, infection or the flu. By just looking at her, one would think that her situation could not be as complex as I explain. In reality, her body fights on a daily basis to retain her fluids.

Navaiah's tube feedings are needed to ensure that she takes in the correct amount of fluids and calories that she needs on a daily basis. Her transplanted intestines do not allow her body to absorb any type of oral fluids or food in the way that they should. We use 19 cans of Elecare a month. If the Age Cap for Elecare to be covered stays at 12 years old for a child here in the State of Connecticut, it would result in an additional \$800 expense to our monthly budget starting in 2012. This would put us in a very difficult financial situation as we have 2 other children to support.

I am speaking not only on behalf of Navaiah and myself, but for all the other families in Connecticut that find themselves in a similar situation. Thank you for your consideration and taking the time to listen.