



## Canaan, Age 2

**Georgia | Very long-chain acyl-CoA dehydrogenase deficiency | Annual costs: \$10512**

Canaan is a thriving, active 2-year-old boy with a rare metabolic condition called VLCAD. He lives with his parents in Georgia. He was picked up on the Expanded Newborn Screening at 6 days old and has done extremely well due to medical nutrition. When Canaan was diagnosed with VLCAD in 2016, we felt relief when the doctors explained that his condition was treatable, and that they expected him to do well on his medical formula, Lipistart. We were in complete shock and disbelief when we received our first rejection letter from our insurance company, denying coverage of Canaan's formula. The fear of not knowing how my husband and I would be able to pay \$876 a month or \$10,512 a year was very real. Thankfully, we were able to receive his formula for free through our genetics clinic while they assisted us with the insurance appeal process. After appealing 3 denials, with letters from our geneticist, research articles proving the medical necessity of this formula, we eventually had to switch to a different insurance plan in order to cover the expense of Canaan's formula. It is so important that children like Canaan have access to their medical formula because it not only helps them survive, but to thrive! Without immediate calories and nutrition during illness, children with VLCAD can spend a week or more in the hospital to prevent kidney failure. Canaan has had 2 lengthy hospitalizations due to being ill and NOT consuming his medical formula. To see him slowly start to consume his formula and simultaneously see his metabolic markers begin to normalize is amazing and proof of the power of medical nutrition to keep him healthy. The cost of his medical formula is a lot less expensive than just one hospitalization! Canaan depends on Medical Nutrition to keep him healthy, strong, and out of the hospital!

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Canaan depends on medical nutrition to stay healthy. Canaan and thousands of others across the country are depending on you to co-sponsor the Medical Nutrition Equity Act. Please contact the offices of Sen. Casey, Rep. McGovern or Rep. Herrera Beutler.