



Louie, Age 3

Methylmalonic acidemia (cobalamin disorders) | New Mexico | Annual costs: \$3360

Louie was diagnosed when he was one week old. We were told to expect motor delays, intellectual disability, and vision loss, assuming his health was well-controlled. We were using the standard recommended dose for his injection of compounded b12 until he was one and a half. At that time a new study came out, and we increased his dose, almost doubling the cost. Fortunately, our family can afford this, because within weeks he had a major developmental leap in gross motor, fine motor, and speech. Now, at age 3, he still has some motor delays, but does not receive speech therapy. Most exciting, he is testing in the average range for intelligence. He loves to count and will spell and write his name for you. I know many families who are not able to choose a higher dose for their children due to cost. Louie takes a daily 1ml injection of highly concentrated vitamin B12. This is already a fairly large volume for a shot. Insurance says they will cover his medication - at 1/30th the concentration. This would mean his daily injection was 30ml, or 2 tablespoons.

Louie depends on medical nutrition to stay healthy. Louie 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.