

Box 13: Cost and Coverage of UCD

[13a] Parent participant (10005): *"In the very beginning I had to do a lot of navigating with [my child's] medication, the sodium phenylbutyrate...They did not want to cover it...I spent many hours on the phone for about a month after [he] was born, having to get him what he needed...The actual cost and coverage with [his] transplant, we have not had to worry about that at all. That was covered. We never got any issues and trouble for it."*

[13b] Parent participant (10030): *"The transplant coverage has been beautiful...After surgery, we accidentally left [medication] in our refrigerator, and we went [on vacation]...Even though we were out of state, the insurance company was more than willing to pay for a small amount of medicine to be made right there...at 10 o'clock at night. Otherwise, we were looking at turning around and coming right home. That's what we would've had to do, and we were prepared to do that...The insurance was like, no, no, we'll pay for five days' worth."*

[13c] Parent participant (10017): *"It's too hard...insurance, and the cost, and the struggle between insurance, and where you work, and getting covered, and it's not just one medication, it's multiple, it's a full-time job just to get medication. The amount of hours that I have spent just to get medication sent to our front door, we've driven all over the place and had things flown in overnight all the time. It's too much...First is what is covered under your insurance. Part of the treatment is medication, but the other part of the treatment is the nutrition. The nutrition many times is not considered medically necessary but is medically necessary...Then you're constantly battling with your insurance company. It's hard enough emotionally to deal with the condition, but then to have to be bullied by insurance companies. So many, my family included, but so many families have given up so much of their time and money. The amount of money that we spent the first five years that [she] was diagnosed, we were living in poverty, but our income was well above poverty...we couldn't comprehend how it could cost this much money out of our pocket to be able to keep her alive....Then your insurance company – every time you get a call, you think this is when they're going to cancel us; this is when they're going to say they're not going to pay for this anymore."*

[13d] Provider participant (20023): *"I've had with families that surprises me they think about this early is cost of care. I've had families who really want to know how many outpatient visits are they going to have per year. How many expected inpatient visits are they going to have per year? What are the costs of the medications? Really very financial detail... we cover such a large geographic area, so it's not uncommon for our patients to be 12 or 14 hours away each way. They're really thinking about time away from work, spending the night, and coming to see us. I've been surprised how many patients have made medical treatment decisions based on those kinds of cost."*