

Box 9: Peer-to-Peer Interaction

[9a] Parent participant (10008): *"I probably wrote back and forth with probably about six, or seven, or eight different moms for a couple months. Just hearing their experiences, asking if they feel that dealing with transplant life is easier than a UCD life, and all of them told me that they absolutely thought the transplant parent life was better than UCD life. A lot of their opinions really helped make my decision."*

[9b] Parent participant (10017): *"Recently, a girl that is 14 that's had a really hard time for the past 5 years, she was transplanted. That's someone that is close to [my daughter's] age, someone that [my daughter] has known... Seeing that and hearing how well she's doing, I think that's going to make her process a little easier."*

[9c] Parent participant (10014): *"There is a girl... We met her at a urea cycle disorder conference... Wonderful young girl and she got a liver transplant, and she is doing wonderful... It's neat because [my daughter] is like you're just like me. You're just like me."*

[9d] Parent participant (10015): *"I had talked to one parent who had lost her child with ASA when she was 18 years old, and other caregivers whose kids' livers were doing really poorly in their teens, and I thought, I should just preempt this now. I'm not going to do this struggle of trying to get him to have nutrition, watch his brain deteriorate when it's not preventing the hyperammonemias, and just to get him to a teenager where he's going to die anyway. That made me request the transplant."*

[9e] Parent participant (10011): *"A good friend of mine lived nearby in. Their daughter was transplanted. She died. It was a bad – things just went poorly the whole way through... I don't think she ever even came home from the hospital after being transplanted. That left a bad taste in my mouth, and between that and the fact that our doctor was very adamantly opposed to doing a transplant, for a long time we didn't even really give it much thought."*

[9f] Parent participant (10013): *"We've lost touch with them because now they're on a different track; they're being followed... post-liver transplant. From what I understand, it hasn't been an easy road for them at all. She's been stable... but it hasn't been easy at all. It, in my opinion, reaffirms why we never went down that path. What I've heard from other people going to various conferences is that it's trading one set of issues for another set of issues. If we don't have to find out what those other set of issues are, why would we? That's our thought process."*

[9g] Parent participant (10027): *"We felt like we were all alone, and then all of a sudden, these people just pop up, and here they are. They have this son who is... I think he was five at that point. It was just incredible... This mom was like, 'Look, this could be [your son]. This could be [your son] in five years.' It was a completely different outlook on what we were thinking... They're handing our infant to us, and we're thinking that he's going to die. Then all of a sudden, we have this other family that says, 'No. Look. Look. We have this son. It hasn't been easy but look at him. He is beautiful and healthy.'"*