*Supplementary Table.* Focus Group Themes

|  |  |  |
| --- | --- | --- |
| **Theme** | **Exemplar Quotes** | **Endorsed by (n)** |
| Hypervigilance | *It's just everything. Every day … There's just so much to worry about and it's all important … You can't say, "Oh now I'm good for a week," because you're never there. It's an hour by hour thing.*  *It’s almost just like having an infant. You have to be constantly tethered to the snack bag. No spur of the moment, “Oh, let’s go hike,” whatever. You have to be prepared … if we go to do an activity or to constantly be on the lookout for if they’re changing the way they’re acting. Just to be constantly aware of if their blood sugar is low or if they’re running high.* | 12 |
| Worry/Guilt | *I trust him to check it, but I worry about him being at a point where he can’t check it … We had a lot of problems at school last year … Teachers would stop him in the hall and give him detention because he was trying to get to the nurses office to check his sugar.*  *For the longest time, I’m talking eight years, I wouldn’t let them stay with anybody. Not spending the night with a grandparent, not leaving my side. I wanted complete control over what was going on … It’s scary not knowing if someone is going to take as good of care of your child as you can.* | 10 |
| Increase in Independence  Negative    Positive | *It’s just that whole ‘pushing the limits’. She’s at the age where she wants to see what she can get away with. If she can get away with not taking it she’s not going to take it.*  *“She wants a lot more independence but at the same time we’re having these problems that would seem to dictate less independence.”*  *My 10 year old – He wants to be as independent as his 12 year old sister and his 14 year old brother … So he goes and he checks it and before you know it he’s calculated his carbs and given himself a shot … And 9 times out of 10 it’s spot on … And I appreciate the independence and the way he owns it but at the same time I’m like, “Can I just see that syringe?”* | 10 |