Supplementary Table 1: Demographic data for focus group participants

N 28	% 100
	64.3
9	32.1 3.6
•	5.0
16	57.1
7	25.0
4	14.3
1	3.6
27	96.4
1	3.6
0	0.0
28	100.0
1	3.6
7	25.0
7	25.0
8	28.6
2	7.1
1	3.6
1	3.6
1	3.6
2	7.1
3	10.7
2	7.1
13	46.4
1	3.6
6	21.5
1	3.6
3	10.7
4	14.3
5	17.9
	28 18 9 1 16 7 4 1 1 27 1 1 0 28 1 1 7 7 8 2 1 1 1 1 1 2 3 4 4

	>90K	11	39.3
	Decline	5	17.9
Region of Residence			
	Midwest	8	28.6
	Southeast	14	50.0
	Southwest	1	3.6
	West	4	14.3
	Outside US	1	3.6
Number of Affected Children			
	1	24	85.7
	2	4	14.3
Status of Child(ren) (Alive/ Deceased)			
	Alive	23	82.1
	Deceased	5	17.9
Age Range of Affected Children (years)			
	<1	2	7.1
	1-4	14	50.0
	5-7	4	14.3
	8-10	3	10.7
	11-13	3	10.7
	14-17	2	7.1