

Table SI. Key characteristics of participants. Mean age of the 26 participants was 16.1 years (range 13–22 years)

No.	Sex	Transplanted organ	Underlying disease	Participation in telephone survey
1	M	Kidney	IgA nephropathy, C1 esterase inhibitor deficiency	No
2	M	Kidney	Tubulo-interstitial nephritis due to urinary tract infection, nephrogenic hypertension	Yes
3	M	Kidney	Renal hypoplasia	Yes
4	M	Kidney	Congenital obstructive uropathy	Yes
5	M	Kidney	Nephrectomy due to neuroblastoma	Yes
6	M	Kidney	Urethral valve syndrome, terminal kidney failure	Yes
7	M	Liver	Liver failure of unknown origin	No
8	M	Heart	Hypoplastic left heart syndrome	Yes
9	F	Kidney/liver	Polycystic kidney disease (type ARPKD), liver cirrhosis	Yes
10	F	Liver	Glycogenosis type 1a	Yes
11	F	Kidney	Nephrotic syndrome (FSGS)	Yes
12	M	Liver	Hepatocellular carcinoma	Yes
13	M	Liver/kidney	Primary hyperoxaluria type 1, terminal kidney failure	Yes
14	M	Liver	Biliary atresia	Yes
15	F	Liver	Wilson's disease	No
16	F	Liver	Wilson's disease	No
17	F	Kidney	Chronic kidney disease, urethral stricture	Yes
18	M	Kidney	Nephrotic syndrome	Yes
19	M	Kidney	Congenital obstructive uropathy	No
20	M	Kidney	Megacystitis-megaureter syndrome	Yes
21	M	Kidney	Henoch-Schönlein purpura	Yes
22	M	Kidney	Juvenile nephronophthisis	Yes
23	M	Kidney	Congenital nephrotic syndrome	Yes
24	M	Kidney	Bilateral renal hypodysplasia	No
25	M	Kidney	Dysplastic kidneys	No
26	F	Kidney	Reflux nephropathy	Yes

ARPKD: autosomal recessive kidney disease, FSGS: focal segmental glomerulosclerosis; IgA: immunoglobulin A; M: male; F: female.