Online Appendix to:

Trautmann et al.
Spectrum of Steroid-Resistant and Congenital Nephrotic Syndrome in Children: The PodoNet Registry Cohort

Information collected in PodoNet Registry

Information on ethnic background and parental consanguinity, any relevant family history, age, clinical symptoms and biochemical features at first disease manifestation, initial and any subsequent renal histopathological findings, extrarenal abnormalities, and the results of genetic screening are recorded. In addition, clinical, biochemistry and medication updates are obtained every 6 months, with additional entries requested at time of major treatment changes. The following information is entered: date, height, weight, a semiquantitative assessment of edema status, serum albumin and creatinine, CsA/tacrolimus blood levels, proteinuria (order of preference: 24-hour protein excretion, spot urine protein/creatinine ratio, semiquantitative urine dipstick), type, dose and date of start, discontinuation and dose change of immunosuppressive medications and RAS inhibitors, and treatment complications including weight gain, hypertension, bone disease, infections, mood disorders, cataract, leukopenia, anemia, hair loss, hypertrichosis, gingival hyperplasia, and diabetes mellitus.

Table S1. Distribution of countries of origin with rates of parental consanguinity, familial disease occurrence and genetic diagnosis. Countries contributing less than 10 patients are summarized as 'Other European' or 'Other Middle East'.
N_{info} = Number of patients with available information on given item.

Country	N	Parental consanguinIty N/N_{info} (%)	Familial disease N/N_{info} (%)	Identified genetic disease N/N_{info} (%)
Georgia	14	0/13 (0.0)	0/10 (0.0)	1/11 (9.1)
Greece	12	0/5 (0.0)	0/11 (0.0)	0/7 (0.0)
Sweden	12	0/12 (0.0)	1/5 (20.0)	0/8 (0.0)
Other European	10	0/9 (0.0)	2/10 (20.0)	2/9 (22.2)
Lithuania	31	0/20 (0.0)	5/23 (21.7)	6/11 (54.5)
Serbia	59	1/47 (2.1)	6/47 (12.7)	6/37 (16.2)
Colombia	43	1/37 (2.7)	4/27 (14.8)	1/11 (9.1)
Italy	261	4/141 (2.8)	30/148 (20.3)	38/189 (20.1)
Poland	226	3/75 (4.0)	46/138 (33.3)	34/175 (19.4)
Chile	65	2/49 (4.1)	6/39 (15.4)	13/59 (22.0)
Portugal	21	2/19 (10.5)	3/18 (16.7)	4/15 (26.7)
France	32	3/28 (10.7)	0/12 (0.0)	15/23 (65.2)
Czech Republic	12	1/8 (12.5)	0/12 (0.0)	2/11 (18.2)
Germany	227	11/47 (23.4)	20/88 (22.7)	58/181 (32.0)
Other Middle East	12	3/10 (30.0)	2/8 (25.0)	3/8 (37.5)
Turkey	477	193/415 (46.5)	109/351 (31.1)	81/351 (23.1)
Syria	61	37/61 (60.7)	23/60 (38.3)	11/51 (21.6)
Iran	80	45/73 (61.6)	3/6 (50.0)	2/17 (11.8)
All	1,655	306/1,070 (28.6)	260/1,014 (25.6)	277/1,174 (23.6)