

Congenital or infantile nephrotic syndrome survey

Birthday (year/month):

Sex:

Diagnosis: Finnish type; Non-Finnish type

Syndrome: Without syndrome

Denys-Drash; Galloway-Mowat; Pierson; Nail-patella,

Others _____

Other symptoms not in the kidneys?

Present; Absent

Eye: _____

Urogenital (Wilms tumor) _____

Malformation: _____

Epilepsy: _____

Mental and/or motor retardation: _____

Others: _____

Gestational week: ____ week ____ day

Height at birth _____ cm; Weight at birth _____ g

Oligohydramnios: Present Absent Unknown

Large placenta: Present (____g) Absent Unknown

Family history: Present (____) Absent Unknown

Consanguineous marriage: Present Absent Unknown

Size of fontanel: at birth ____ × ____ cm Unknown

at 3 months ____ × ____ cm Unknown

Age when fontanel closed: ____ month(s) Unknown

At Onset of Birth

_____year_____month (____years__months old)

Height_____cm; Weight_____g

Serum creatinine:_____mg/dL

Serum albumin: _____g/dL

Serum IgG: _____mg/dL

Proteinuria: _____mg/dL (- / ± / + / 1+ / 2+ / 3+)

Urine creatinine:_____mg/dL

6 months after birth

_____months

Height_____cm; Weight_____g

Serum creatinine: _____mg/dL

Serum albumin: _____g/dL

Proteinuria: _____mg/dL (- / ± / + / 1+ / 2+ / 3+)

Urine creatinine: _____mg/dL

12 months after birth

_____months

Height_____cm; Weight_____g

Serum creatinine: _____mg/dL

Serum albumin: _____g/dL

Proteinuria: _____mg/dL (- / ± / + / 1+ / 2+ / 3+)

Urine creatinine:_____mg/dL

Latest

_____year _____month
Height_____cm; Weight_____kg
Serum creatinine: _____mg/dL
Serum albumin: _____g/dL
Proteinuria: _____mg/dL (- / ± / + / 1+ / 2+ / 3+)
Urine creatinine: _____mg/dL
State of latest: (normal kidney function, pre-renal replacement therapy, dialysis [hemo+peritoneal], after kidney transplant, re-dialysis [hemo+peritoneal])

Complications (Thrombosis, infection, or other):_____

Kidney biopsy: Performed Not performed

Results of the kidney biopsy: _____

Genetic test: Performed Not performed

Medical therapy

Steroid therapy:

- Performed Not performed

Response to steroid therapy:

- Complete remission Partial remission No response

Immunosuppressant therapy:

- Performed (name: _____) Not performed

Response to immunosuppressant therapy:

- Complete remission Partial remission No response

Nephrectomy

Unilateral:

- Performed (Date: _____ year _____ month; Age: _____ years _____ months)
 Not performed

Opposite side:

- Performed (Date: _____ year _____ month; Age: _____ years _____ months)
 Not performed

Bilateral at the same time:

- Performed (Date: _____ year _____ month; Age: _____ years _____ months)
 Not performed

Dialysis therapy

Peritoneal dialysis:

- Performed (Date: _____year_____month; Age: _____years_____months)
- Not performed

Hemodialysis (catheter):

- Performed (Date: _____year_____month; Age: _____years_____months)
- Not performed

Hemodialysis (with fistula):

- Performed (Date: _____year_____month; Age: _____years_____months)
- Not performed

Kidney transplant

Kidney transplant:

- Performed (Date: _____year_____month; Age: _____years_____months)
- Not performed

Peritoneal dialysis after kidney transplant:

- Yes (Start date: _____year_____month; Age: _____years_____months)
- No

Hemodialysis after kidney transplant:

- Yes (Start date: _____year_____month; Age: _____years_____months)
- No

Onset of nephrotic syndrome after kidney transplant:

- Yes (Onset: _____year_____month; Age: _____years_____months)
- No

If yes,

Treatment: _____

Response to treatment:

- Complete remission Partial remission No response