

Adult outcomes of childhood-onset nephrotic syndrome

Aim of the survey

- To describe disease outcome and long-term complications;
- To identify risk factors of relapse at adult age;
- To evaluate outcome in terms of number of relapses/ eGFR co-morbidities;
- Quality of life in patients with a diagnosis of INS who have had an onset in the pediatric age.



Inclusion/Exclusion criteria

1. Age > 18 years old
2. Currently followed in an
3. adult nephrology unit
4. INS diagnosed before 18 years of age



1. Steroid resistant nephrotic syndrome
2. Genetic nephrotic syndrome
3. End-stage renal disease before the age of 18y



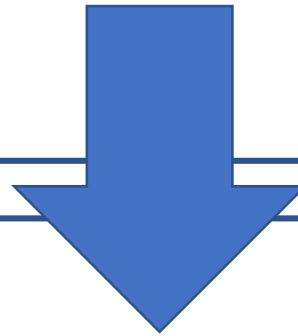
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SURVEY



physicians are requested to complete a **2-minute survey** asking for the numbers of patients under their care:

https://www.surveymonkey.de/r/ERKNet_outcome_idiopathic_nephrotic_syndrome



Therefore, they are invited to complete an **electronic case report form (eCRF)** for each patient

Adult outcomes of childhood-onset nephrotic syndrome electronic Case Report Form (eCRF)

Disease and adulthood

Diagnosis and clinical course of the disease:

- n° of INS relapses/year >18y
- Date of last relapses
- Time to remission with steroids during adulthood

Treatment modality

- If conservative: immunosopressive treatment at last visit
- If in dialysis/transplantation: date of end stage renal disease

Renal function

- Last known proteinuria (g/g)
- Last known serum creatinins ($\mu\text{mol/L}$)
- eGFR (ml/min/1,73m^2 , CKD EPI)
- Blood pressure /antihypertensive drugs

Basic Anthropometric Measures

- Weight/Height
- BMI

Comorbidities → YES or NO

- Dyslipidemia /treatment with statin
- History of any adverse cardiovascular events
- DEXA released
- Diabetes
- Story of severe infections in adulthood (e.g. bacterial pneumonia, abscesses, etc..)
- Story of cataract/glaucoma
- History of neoplasm/malignancy

Quality of life → YES or NO

- At least one child
- Education
- Current occupation



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Please find the survey at

www.ERKNET.org



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