

ESPN-ERKNet Lupus nephritis registry

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Background:

- Children presenting with lupus nephritis (LN) are treated with various immunosuppressive protocols.
- Data on renal outcome and treatment toxicity are scarce.
- The recent analysis of German LN-registry (1993 bis 2015) showed*:
 - Renal outcome of children with proliferative LN at 12 months was “good” (CR 38%, PR 41%)
 - irrespective of induction mode (MMF vs IVCYC)
 - Corticosteroid toxicity was very high (42%)

*Suhlrie et al *Pediatr Nephrol* 2020

What is the aim of the European registry?

- To create an European registry with large patient numbers to allow adequate statistical analyses of:
 - long term renal outcome and its determining factors in childhood onset LN (including transition)
 - disease and treatment associated comorbidities
- In order to allow benchmarking, develop research hypothesis, improve treatment and outcome



Which patients are eligible for the registry?

- Biopsy proven Lupusnephritis
- Childhood onset SLE, i.e. diagnosis ≤ 18 years

Visits:

- Initial visit with yearly follow-ups (at least for 5 years)
- Basic data
- Visit sheet
- Medication
- Extracorp. Therapy



Basic Data

- <https://www.erknet.org/patients-registry/registry> (opened in April 2021)
- ERKNet: Date of informed consent/which consent
- Date of birth (mm/yyyy), gender, ethnicity, date of first symptoms, date of first presentation to center, Immunological blood results
- Clinical symptoms at time of diagnosis (based on SLEDAI Score)
- Primary renal diagnosis and histopathology diagnosis is prefilled (childhood onset In)
- When was diagnosis considered confirmed → date of biopsy



Visit sheet

- Visit date
- Current treatment modality (conservative/medication, dialysis, transplantation)
- Blood results (renal function, immunology), urine results →
Cave: if you don't find the unit used in your center please contact us
- complications (hypertension, steroid associated, disease associated comorbidity, e.g. Infection, Diarrhea, Menstrual disorder etc)



Medication and Extracorp. Therapy

- Preselection: search for your medication, then enter start date, single dose, frequency, route (i.v./p.o.) and stop date or leave empty when ongoing → please update at each visit!
- Extracorporeal: CVVH, Immunoadsorption, Plasmapheresis → if dialysis then enter in visit sheet (Current treatment modality)

Ethical approval

- the new informed consent form developed by EJPRD are currently under ethical and data protection review
- A template for ERKNet and non ERKNet members will be attached to the registry → please make sure to get a positive ethics vote at your center



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