# Report of activities of ESPN Working Group

<table>
<thead>
<tr>
<th>Name of Working Group</th>
<th>Glomerular Disease</th>
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<tbody>
<tr>
<td>Year</td>
<td>2021-2022</td>
</tr>
<tr>
<td>WG Coordinator</td>
<td>Antonia Bouts</td>
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<td>WG Board Members</td>
<td>Olivia Boyer, Alexandra Zurowska, Rezan Topaloglu, Antonia Bouts, Marina Vivarelli</td>
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<tr>
<td>Number of WG Members</td>
<td>113</td>
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## Research Activities

### A. Completed Studies (Title, coordinator, short content (max 1-2 sentences)):


Hypogammaglobulinemia in RTX treated children with SDNS or FRNS: results of an ESPN survey (2021, Alexandra Zurowska, Magdalena Rozynska-Duklas, Rezan Topaloglu, Olivia Boyer, Antonia Bouts, Marina Vivarelli).

Clinical practice recommendations for recurrent FSGS/SRNS. (2021, Lutz Weber, Burkhard Tonshoff, Ryszard Grenda, Antonia Bouts, Rezan Topaloglu, ...., Lars Pape)

Guidelines for treatment of SRNS: IPNA SRNS guidelines (Haffner D)

Guidelines for treatment of SSNS: IPNA SSNS guidelines (Haffner D) (completed?)


Pediatric idiopathic SSNS: diagnosis and therapy – short version of the updated German best practice guideline (2021, Weber L)

KDIGO 2021 Clinical Practice Guideline for the Management of Glomerular Diseases. (2021)

Treatment of IgA nephropathy in children: a land without KDIGO guidance (2021)

... 

### B. Ongoing Studies (Title, coordinator, short content (max 1-2 sentences)):
Retrospective study employing the CERTAIN database, in collaboration with the Working Group on Transplantation, on treatment of FSGS recurrence post-renal transplant (Antonia Bouts, Burkhard Tonschoff, Marina Vivarelli)

Survey in collaboration with ERKNet and IPNA: Pediatric cases of ANCA vasculitis: prevalence, renal phenotype, management, outcome (Kjell Tullus, Matko Marlais, Nikoleta Printza, Marina Vivarelli).

Pediatric cases on idiopathic membranous nephropathy (Julien Hogan, Claire Dossier, Marina Vivarelli, Pierre Ronco)

Survey in collaboration with ERKNet and IPNA: Incidence and severity of COVID-19 infection in the population of children affected by kidney diseases on immunosuppression (Matko Marlais, Kjell Tullus, Marina Vivarelli).

Pediatric SLE registry in collaboration with ERKNet (Dieter Haffner, Rezan Topaloglu)

INTENT study (Heidelberg, Germany: L Weber): Initial treatment of INS in children with MMF vs prednisone (recruitment ongoing)

NEPHROVIR-3 (Paris, France: C Dossier): Efficiency of Levamisole in association with prednisone in the treatment of the first flare (Feb 2021 first year follow-up ended, results follow)


C. Planned Studies (Title, coordinator, short content (max 1-2 sentences)):

Relapse NS after corona vaccination, an ERKNET survey. (ESPN?)

Pediatric INS evolution into adulthood. (Giulia Bassanese)

The incidence of HGG in SDNS and FRNS children and the risk factors for its development. (Alexandra Zurowska).

Schimke Immuno Ossous Dysplasia long-term outcome registry (A Waters, O Boyer, A Worth, P Torpiano, B Lipska, A Bouts)

Guideline Projects (Title, coordinator)

Definitions of INS subtypes incorporated into ongoing KDIGO GN guidelines (M Vivarelli, G Deschenes)

Guidelines for treatment of SSNS: IPNA SSNS guidelines led by Dieter Haffner - ongoing

### WG Meetings (Date – Place)

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
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<tbody>
<tr>
<td>May 14th 2021</td>
<td>Online</td>
</tr>
<tr>
<td>Sept 16th 2021</td>
<td>Amsterdam &amp; online</td>
</tr>
<tr>
<td>June 2022</td>
<td>Ljubljana (Slovenia) &amp; online</td>
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### Publications

#### A. Published papers (bibliography):


- Genetic aspects of congenital nephrotic syndrome: a consensus statement from the ERKNet-ESPN inherited glomerulopathy working group. (B Lipska-Zietkiewicz et al., Eur J Hum Gent. 2020)

- IPNA clinical practice recommendations for the diagnosis and management of children with steroid-resistant nephrotic syndrome. (A Trautmann et al., Ped Neph 2020)

- Clinical practice recommendations for recurrent FSGS/SRNS. (L Weber et al., Ped Transplant 2020 Dec)


- Consensus guideline on management of SRNS, Indian Society of Pediatric Nephrology (2021, Bagga A)

- Steroid sensitive Nephrotic syndrome: revised guidelines, Indian Society of Pediatric Nephrology (2021, Bagga A)

#### B. Submitted papers:

.............?

**Presentations at conferences during the year**

**A. Oral presentations:**

10 oral presentations ESPN Amsterdam:

- Efficacy of IgIA in multidrug resistant INS. (Bonneric S et al.)
- Safety and efficay of Ofatumumab in refractory pediatric NS. (Calzada Banos Y et al.)
- Evaluation of genetical features affecting renal outcome in children with SRNS. (Comak E et al.)
- Rituximab bioavailability in pediatric patients with SDNS. (Parmentier C et al.)
- Low-dose prednisolone at the time of an urti does not prevent relapses but may have a health economic benefit: the PREDNOS 2 trial. (Christian M et al.)
- Clinical delineation of the NUP93 glomerulopathy prevalent in central and eastern Europe. (Maciej J et al.)
- Incidence and relapse of INS: meta-analysis. (Veltkamp F et al.)
- Vaccine titers in children with INS on oral immunosuppressive drugs. (Herbez Rea C et al.)
- Safety and efficacy of low-dose Obitunizumab in SDNS. (Dossier C et al.)

And more then 20 pitches on glomerular diseases.

https://doi.org/10.1007/s00467-021-05210-9

**B. Poster presentations:**

+/- 60 poster presentations on glomerular disease

https://doi.org/10.1007/s00467-021-05210-9