

Annual Report of Activities of ESPN Working Group

(To be submitted to ESPN Secretary before January 31, 2026)

Name of Working Group	WG Inherited Kidney Diseases
Year	2025
WG Chair	Max Liebau
WG Board Members	Rezan Topaloglu (2023), George Costea (YPNN, 2023), Martine Besouw (2024), Leire Madariaga Dominguez (2025), Bshara Mansour (2025)
Number of WG Members	79
New members approved this year (2025)	+1

Brief description of the scope of the WG

(May be repeated every year - max 100 words)

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The ESPN working group on inherited kidney diseases aims to improve the care of children with IKD and to foster research on clinical and pathophysiological aspects of IKD in children and adolescents.

Research Activities

A. Completed Studies (Title, coordinator):
<ul style="list-style-type: none"> - Survey on PH – together with ERA (J. Groothoff) - TheRaCil survey on access to genetic testing – together with ERKNet (A. van Eerde) - ADPKD project (D. Mekahli) - ARPKD prediction project (M. Liebau) - ACEI survey for Alport (Williamson) - Transition project – together with ERA (M. Liebau)
B. Ongoing Studies (Title, coordinator):
<ul style="list-style-type: none"> • <i>The role of Copeptin as a biomarker of volume status in pediatric polyuric tubulopathies.</i> study (supported by ESPN research grant). A. Ferrulli, L. Madariaga • Use of NSAID in patients with tubulopathies, F. Emma, D. Bockenbauer • HNF4A survey, P. Schlingmann, F. Emma

C. Planned Studies (Title, coordinator):
Click or tap here to enter text. <ul style="list-style-type: none"> - Survey on Pierson Syndreom (M. Marlais) - Survey on Management and Outcomes of children with <i>RMND1</i>-related mitochondrial disease (M. Marlais) -

Guideline Projects

A. Completed (Title, coordinator)
Click or tap here to enter text. <ul style="list-style-type: none"> - XLH update (published in 2025, NRN), D. Haffner - NDI (published in 2025, NRN), N.Knoers/E. Levtchenko - Dent (published in 2025, NDT), A. Bokenkamp - Transition statement with WG Genes & kidney ERA (published in 2025, NDT), M. Liebau - Alport (supporting an ERA-initiated project), R. Topaloglu for ESPN (published 2025, NDT)
B. Ongoing (Title, coordinator):
Click or tap here to enter text. <ul style="list-style-type: none"> - update ARPKD (together with ERKNet), M. Liebau (submitted to NRN) - Disorders of Na-Pi transporters, D. Haffner + P. Schlingmann - Lowe syndrome (F. Emma)
A. Planned (Title, coordinator):
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WG Meetings (Date – Place)

Click or tap here to enter text. Webinar together with ERA-EDTA Februar 2025: “Kidney Stones” ESPN Speaker: Justine Bacchetta Planned joint webinar with ESPN WG CAKUT – (little feedback on requested topics)
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Publications

A. Published papers:

- Gomez et al., Transition of patients with hereditary nephropathies from pediatric to adult care., Nephrol Dial Transplant. 2025
- Burgmaier et al., Urinary peptide signature distinguishes autosomal recessive polycystic kidney disease from other causes of chronic kidney disease., Clin Kidney J. 2025
- Williamson et al., Are we ACE-ing the early treatment of Alport syndrome?, Pediatr Nephrol. 2025
- Gimpel et al., Insights from ADPedKD, ERKReg and RaDaR registries provide a multi-national perspective on the presentation of childhood autosomal dominant polycystic kidney disease in high- and middle-income countries. Kidney Int. 2025
- Burgmaier et al., A risk score to predict kidney survival in patients with autosomal recessive polycystic kidney disease at the age of two months., Kidney Int. 2025
- Deesker et al., Global access to management of primary hyperoxaluria: a survey on behalf of OxalEurope, G&K Working Group of the ERA and ESPN, Nephrol Dial Transplant. 2025
- Caravajal Ariona et al., The unmet need of electrolyte supplements, Nephrol Dial Transplant. 2025

B. Submitted papers:

- Paper on results of TheRacil Survey (A. van Eerde)
- “The European distal renal tubular acidosis registry: a five year analysis” (F. Emma, accepted at NDT)
- ARPKD clinical praxis recommendations update (M. Liebau, Nature Reviews Nephrology)

Presentations at conferences during the year 2025

Oral and Poster presentations (published abstracts):

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Collaborations with other WGs or Scientific Societies

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ERA WG Genes and Kidney
ERKNet WG Ciliopathies

Grants/finance support during the year 2025 (Start-End date)

Appendix

List of all current WG members in 2025