Virtual Consultation:
Clinical Patient Management System

Harmonizing disease management:
Adoption and development of guidelines and pathways

Monitoring performance and outcomes:
Patient registries

Promoting research and innovation

Online disease information

Training:
CMEs, Webinars, eLearning
<table>
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<tr>
<th>Section</th>
<th>Topics</th>
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<td>Pediatric CKD/D</td>
<td>Bartter Syndrome</td>
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<td>Distal renal tubular acidosis</td>
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<td>Nephrogenic diabetes insipidus</td>
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<td>Metabolic nephropathies</td>
<td>Cystinuria</td>
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<td>Hyperoxaluria update</td>
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<td>Methyl malonic acidemia (collab with MetabERN)</td>
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<td>Diagnostic approaches to rare stone forming disorders</td>
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<td>AD structural disorders</td>
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<td>TMA</td>
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<td>Immune glomerulopathies</td>
<td>Monoclonal gammopathies of renal significance</td>
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<td>Hereditary GP</td>
<td>Congenital nephrotic syndrome</td>
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<td>Steroid resistant nephrotic syndrome (collab with IPNA)</td>
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<td>Pediatric Tx</td>
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<td>VUR management update</td>
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<td>TMA</td>
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<tr>
<td>Obstructive uropathies</td>
<td>Diagnosis of urinary tract obstruction</td>
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<td>Pre and post natal management of PUV</td>
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<td>Tubulopathies</td>
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<td>Progression of CKD</td>
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<td>Pediatric dialysis</td>
<td>Pediatric adaptation of KDIGO Transplant guideline</td>
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Notes:
- OUP: Obstructive uropathies
- Metabolic NP: Metabolic nephropathies
- Hereditary GP: Hereditary glomerulopathies
- TMA: Tubulointerstitial nephritis and sclerosis
- CAKUT & Ciliopathies: Congenital anomalies of the kidney and urinary tract
- CAKUT: Congenital anomalies of the kidney and urinary tract
- VUR: Vesicoureteral reflux
Planned Guideline Projects

Nephrogenetic Diagnostics (N.Knoers)
Bartter Syndrome (M.Konrad, F.Emma)
Congenital nephrotic syndrome (O.Boyer-Guillon)
Steroid resistant nephrotic syndrome in children (D.Haffner)
Cystinuria Lead: (A.Servais)
Renal dysplasia/obstructive uropathies (M.Liebau, G.Montini)
Monoclonal gammopathies of renal significance (P.Ronco, J.Wetzels)
Lipid apheresis in children (C.P. Schmitt)
European Rare Kidney Disease Registry

Core Registry for all rare kidney diseases

Objectives:
- To identify current patient cohorts for clinical research
- Performance assessment, benchmarking: Disease-specific key quality and outcome indicators

Open to all European nephrology centers interested in rare diseases

Option to incorporate disease-specific sub-registries: ESPN dRTA Registry

Funding:
Kickoff grant: WGIKD 2017/18
Operational grant: EU-Chafea 2018-2020
Support to sites: Alexion 2019-2021 -> ERA-EDTA
Rare Kidney Disease Webinar Curriculum

**Speakers:** ERKNet / WGIKD / ESPN Experts

**Announcements:**
- ERA-EDTA Flash (n=5,000)
- ESPN Newsletter (n=2,000)
- ERKNet Newsletter (n=400)

**Live streaming:** Every other Tuesday, 4 pm

**Format:**
- 30-40 min lecture, 15 min Q&A
- 3-5 interactive questions
- Post-hoc evaluation

**Live attendance:** 75-150 per session
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<tr>
<th>Date</th>
<th>Speaker</th>
<th>Topic</th>
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<tr>
<td>Feb 13</td>
<td>Francesco Emma</td>
<td>Non-cystinotic renal Fanconi syndrome</td>
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<tr>
<td>Feb 27</td>
<td>Marina Vivarelli</td>
<td>C3 glomerulopathy</td>
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<tr>
<td>Mar 13</td>
<td>Olivia Boyer</td>
<td>Genetic forms of podocytopathies in adults</td>
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<td>Mar 27</td>
<td>Detlef Bockenhauer</td>
<td>Disorders of water</td>
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<td>Apr 03</td>
<td>Rukshana Shroff</td>
<td>Nutritional management in CKD</td>
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<td>May 15</td>
<td>Jaap Groothoff</td>
<td>Primary Hyperoxaluria: a never benign and often underdiagnosed disease</td>
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<td>Jun 05</td>
<td>Gema Ariceta</td>
<td>Familial hypomagnesemia with hypercalciuria and nephrocalcinosis</td>
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<td>Jun 12</td>
<td>Roser Torra</td>
<td>Renal involvement in TSC</td>
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<td>Jun 26</td>
<td>Claus Schmitt</td>
<td>Optimising PD in children</td>
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<tr>
<td>Sep 04</td>
<td>Max Liebau</td>
<td>A primer to cystic kidney diseases and ciliopathies</td>
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<td>Sep 18</td>
<td>Marius Miglinas</td>
<td>Spectrum of complement-mediated TMA after kidney transplantation</td>
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<tr>
<td>Sep 25</td>
<td>Justine Bacchetta</td>
<td>CKD-MBD – pathophysiology and management</td>
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<td>Oct 09</td>
<td>Paul Winyard</td>
<td>Perinatal aspects of CAKUT/Ciliopathies</td>
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<td>Nov 06</td>
<td>R.Lennon/J.Groothoff</td>
<td>Microscopic haematuria</td>
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<td>Nov 13</td>
<td>Giuseppe Remuzzi</td>
<td>Unravelling the pathophysiology of HUS in light of recent complement discoveries</td>
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<td>Nov 27</td>
<td>Jack Wetzels</td>
<td>Membranous nephropathy</td>
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<tr>
<td>Dec 11</td>
<td>Nicola Persico</td>
<td>Prenatal Management of LUTO</td>
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Webinar Attendance

First 11 Webcasts: 100 mean, 624 total
Past Webinars

2018, February 13: Non-Cystinotic Renal Fanconi Syndrome (F.Emma)
2018, February 27: C3 Glomerulopathies (M.Vivarelli)
2018, March 13: Monogenic Podocytopathies in Adults (O.Boyer)
2018, March 27: Disorders of Water (D.Bickenhaever)
2018, April 3: Nutritional Management in Children with CKD (R.Shroff)
Past CME Courses

- Hot Topics in Tubulopathies and Metabolic Nephropathies
  - International CME Course
  - MARITUS College, Maastricht, Netherlands

- Management of Polycystic Kidney Diseases from Childhood to Adulthood
  - Saturday 2 December 2017, 9:00 – 16:00 hrs
  - Universiteitsh. Kamerlingh Onnes 22, 3000 Leuven, Belgium

- CME COURSE 10
  - WGIKD (Working Group on Inherited Kidney Disorders)
  - Diagnosis and management of inherited kidney diseases: What’s new?

- Epidemiological and Clinical Research in Pediatric Nephrology
  - A Workshop of the International Pediatric Nephrology Association
  - March 24–26, 2017

Past Webinars

- 2018, February 13: Non-Cystinotic Renal Fanconi Syndrome (F.Emma)
  - PDF

- 2018, February 27: C3 Glomerulopathies (M. Vivarelli)
  - PDF

- 2018, March 13: Monogenic Podocytropathies in Adults (O. Boyer)
  - PDF

- 2018, March 27: Disorders of Water (D. Bockenhauer)
  - PDF

- 2018, April 3: Nutritional Management in Children with CKD (R. Shroff)
  - PDF
Patient Information

- 99 brochures
- 519 hyperlinks to information sites

<table>
<thead>
<tr>
<th>Glomerulopathies</th>
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</table>

- Metabolic NP
  - 25 brochures
  - 74 hyperlinks
  - 99 total

- Tubulopathies
  - 4 brochures
  - 98 hyperlinks
  - 102 total

- Ciliopathies
  - 28 brochures
  - 142 hyperlinks
  - 170 total

- CAKUT
  - 8 brochures
  - 50 hyperlinks
  - 58 total

- TMA
  - 7 brochures
  - 32 hyperlinks
  - 39 total

- Ped CKD
  - 1 brochure
  - 7 hyperlinks
  - 8 total

- Ped D
  - 2 brochures
  - 5 hyperlinks
  - 7 total

- Ped Tx
  - 2 brochures
  - 9 hyperlinks
  - 11 total
Gap analysis:
Topics/languages with missing patient info documents

Development of uniform template for info documents

Translation/adaptation of existing documents

Production of new info documents wherever missing
Virtual Consultation: CPMS Platform

- Implementation phase started
- ERKNet CPMS HelpDesk operational by November 2018
ERKNet: Expansion Expected

Current ERKNet membership:
38 healthcare providers
32 pediatric, 18 adult units

2nd call II/2019:
15+ centers to apply for full membership
3+ centers to apply for Affiliated Partnership

-> Coverage to increase from 12 to 19 EU countries