ESPN Council meets Industry

Elena Levchenko, ESPN Secretary General

Web URL: http://espn-online.org/
ESPN Council 2017

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ESPN/ERA-EDTA Registry
European Registry for Children on Renal Replacement Therapy
Chair: Jaap Groothoff
The purpose of the Society shall be to promote the knowledge of paediatric nephrology and research in this field and to disseminate such knowledge at meetings and elsewhere (ESPN Constitution).

Currently an estimated 2000 doctors are involved to some extent in the care of children with renal disease throughout Europe, with up to 500 working in almost 200 highly specialised paediatric nephrology units.
ESPN History

ESPN is established in 1967 (Glasgow)
1) To increase the communication network among Paediatric Nephrologists in Europe and collaboration with IPNA
ESPN MEMBERS FOR 2016  91 members
ESPN & IPNA COMBINED MEMBERS FOR 2016  257 members
NEW MEMBERS FOR 2016  57 members

ESPN membership developing countries : 7 members
ESPN membership : 84 members
ESPN & IPNA combined membership developing countries : 14 members (online journal)
ESPN & IPNA combined (online journal) : 141 members
ESPN & IPNA combined membership developing countries : 4 members (online & print journal)
ESPN & IPNA combined (online & print journal) : 98 members

348 MEMBERS
1) To increase the communication network among Paediatric Nephrologists in Europe and collaboration with IPNA:

ESPN can send information to an active list of over 2000 doctors with an interest in Paediatric Nephrology, covering advertising for Congresses, Courses, Grants, Fellowships and Educational material.

~ 60 mailings per year

ESPN/IPNA members have access to restricted member areas
Newsletters:
March 2016
June 2016
November 2016
ESPN Networking Policy

Our Future: The Young Generation

ESPN has joined the Young Nephrology Platform (YNP) launched by the ERA-EDTA, linking the two websites and sharing common activities addressed to Nephrologists under 40 years of age.

Including:

- Survey on needs and hopes presented at ESPN 2015 in Brussels
- Information exchange among young people working in the same area.
- Young nephrologist symposium during ESPN congress 2017 (for Nephrologists under 40 years of age only)
1) To increase the communication network among Pediatric Nephrologists in Europe and the collaboration with IPNA:

2) To increase the scientific interaction & collaboration at European level with adult nephrologist (ERA-EDTA) and other scientific societies
2016: Two agreements signed between ESPN and ERA-EDTA

1) ESPN/ERA-EDTA Pediatric Registry:
   Business Plan 2016-2018 (K. Jager, AMC)

2) Collaboration agreement between ESPN and ERA-EDTA:
   no time limit (E. Levchenko, A. Wieck)
   • Mutual feasibility on websites
   • Joint Symposium at each ERA-EDTA and ESPN congress
     (2 speakers from each society)
   • Collaboration between Working Groups
   • Young nephrologists platform
Joint Symposium ERA-EDTA & ESPN
(European Society for Paediatric Nephrology)

Chairs: Dieter Haffner, Hannover, Germany
Markus Ketteler, Coburg, Germany

ADPKD: from Adult to Autosomal Dominant Polycystic Kidney Disease?
Ron T. Gansevoort, Groningen, The Netherlands

Management of cystic diseases from childhood to adulthood
Djalila Mekahli, Leuven, Belgium

KDIGO CKD-MBD Guideline Update 2016: Considerations in adults vs. children
Markus Ketteler, Coburg, Germany

HDF - should this be the standard of care for children?
Rukshana Shroff, London, United Kingdom
ESPN & European Society of Paediatric Urology (ESPU) Collaboration

• Collaboration with CAKUT Working Group
• Joint symposia during Annual Meetings

Program proposed by two societies

ESPN 2015 : Joint Session ESPU & ESPN Chairs: D. Stefanidis & E. Merlini

Renal stone disease Nephrological aspects K.P. Schlingmann (Muenster, Germany) Urological aspects S. Tekgul (Ankara, Turkey) Antenatal hydronephrosis Urological aspects G. Manzoni (Milan, Italy) Diagnostic aspects A. Piepsz (Brussels, Belgium) Congenital Life-long Urology working group P. Hoebeke (Ghent, Belgium)
ESPU 2016: 2 Paediatric Nephrology Sessions

Friday 24th June

14:24 – 15:14: WHERE PAEDIATRIC NEPHROLOGISTS AND PAEDIATRIC UROLOGISTS SHOULD JOIN FORCES?
   Chairs: G. Bogaert & G. Montini
14:24  S. Weber            Genetics of congenital anomalies of kidney and urinary tract (CAKUT)
14:49  N. Ahmad            Surgical aspects of renal transplantation in small children

Saturday 25th June

8:30 – 10:00  ENURESIS / VUR
   Chairs: J. Vande Walle & S. Tegkul
8:30  S. Rittig            Nephrologic aspects of nocturnal enuresis
9:00  C. Vanherzeele        Are sleep disorders just comorbidities in nocturnal enuresis?
9:30  G. Montini           How to PREDICT utility of AB prophylaxis in children with vesico-ureteric reflux
1) To increase the communication network among Pediatric Nephrologists in Europe and the collaboration with IPNA

2) To increase the scientific interaction & collaboration at European level with adult nephrologists (ERA-EDTA) and other scientific societies

3) To stimulate collaborative research in paediatric nephrology across Europe
ESPN Working Groups

- Transplantation
- Dialysis
- CKD and metabolic bone disease
- Inherited kidney disorders
- CAKUT/UTI/bladder dysfunction
- Nephrotic syndrome
- Immune mediated renal diseases

Yearly reports can be viewed at:
http://espn-online.org/espn_working_groups.php
ESPN research grants

Regulations for the ESPN Research Grant, approved by ESPN Council

General rules

• Peer-reviewed research proposals (by at least by three reviewers).
• Ranking according to scientific quality and compliance with ESPN aims.
• A report of progress is sent every 6 months to the Spring and Autumn Council for update.
• The final report is due 3 months after the end of the first year of economic support (money transfer to the Research Coordinator).
• The final report is published on the website.
• A financial report is provided at the end of the project.
• In all reports it should be stated:
  «Supported by an unrestricted grant provided by ESPN: Grant number XXX ». 
ESPN Research call

Call for proposals 2016

ESPN board announces a call for research proposals on pediatric kidney disorders.

The aim of the call is to stimulate collaboration between pediatric nephrologists in Europe and to promote clinical or basic projects pertinent to children with renal disorders.

Applicants should be ESPN members working in Academic or Hospital Centers in Europe. Applications on behalf of the ESPN working groups or collaborative projects on behalf of the individual researchers from at least three European countries will be considered.

The applicant should complete the attached form.

The proposals should be submitted electronically to espn@espn-online.org.

Closing date for submission: April 30, 2016

The applications will be evaluated by the ESPN board on the basis of merit, scientific excellence, and relevance in the field. Successful projects will be funded to a maximum of 20 K€.

Project leaders are required to acknowledge the ESPN support in any publication or presentation resulting from their work. They may be asked to present their results at the ESPN congresses or ESPN teaching activities.

Results of evaluations will be announced during the ESPN General Assembly Meeting, September 2016, Iguazu, and will be posted on the ESPN website.

Supported by Industry by unrestricted grants
Awarded grants 2014

Awards Winners 2014

**Dieter Haffner (CKD-MDB WG)**
Vitamin D supplementation and hyperphosphatemia control in children with CKD
Vitamin D supplementation and hyperphosphatemia control in children with CKD Report, September 2015 (PDF File, 256 KB)

**Stefanie Weber (CAKUT, UTI & bladder disorders WG)**
European CAKUT Registry and biobanking
European CAKUT Registry and biobanking Report, September 2015 (PDF File, 215 KB)

**Elena Volokhina & Kathleen Claes**
Sorting complement dysregulation in renal disorders
Sorting complement dysregulation in renal disorders Report, September 2015 (PDF File, 303 KB)
Sorting complement dysregulation in renal disorders Report, January 2016 (PDF File, 315 KB)

**Licia Peruzzi (Immune mediated renal disorders WG)**
European Registry of children with Henoch Schonlein nephritis to detect risk factors
European Registry of children with Henoch Schonlein nephritis to detect risk factors Report, September 2015 (PDF File, 251 KB)

**Max Liebau**
European ARPKD Registry
European ARPKD Registry Report, September 2015 (PDF File, 256 KB)

Unrestricted grants to ESPN 2014 from:

- **GOLD Sponsors**
- **ALEXION**
- **HORIZON**
- **SILVER Sponsors**
- **NOVARTIS PHARMACEUTICALS**
- **BRONZ Sponsors**
- **BELLCO**
Awarded grants 2016

Awards Winners 2016

**Burkhard Toenshoff (Renal Transplantation WG)**
Polyomavirus Infection and Nephropathy in European Paediatric Renal Transplant Recipients

**Rukshana Shroff (CKD-MBD WG)**
Assessing calcium balance in children with chronic kidney disease to optimise treatment strategies (Cal-Bal study)

**Dr. Djalila Mekahli and Dr. Max Liebau (Inherited Renal Disorders WG)**
ADPedKD: a European web-based database for longitudinal data registry of children with ADPKD

Unrestricted grants from:
1) To increase the communication network among Pediatric Nephrologists in Europe and the collaboration with IPNA

2) To increase the scientific interaction & collaboration at European level with adult nephrologists (ERA-EDTA) and other scientific societies

3) To stimulate collaborative research in pediatric nephrology across Europe

4) To further education in paediatric nephrology
• 772 participants: 708 + 64 free registrations

• CME ACCREDITATION
  • The EACCME has granted CME credits
  • 48th Annual Scientific Meeting of the ESPN 18 CME credits
  • 1st IPNA ESPN Master for Junior Classes 12 CME credits

• ABSTRACTS
  • 560 accepted abstracts
  • 67 oral presentations
  • 493 poster presentations
50th Anniversary Meeting of the European Society for Paediatric Nephrology
7-9 September 2017, SECC Glasgow

Congress President: Heather Maxwell
Chair of the Scientific Committee: Richard Coward
Chair of Local Organizing Committee: Christian Martin
ESPN Educational activities

ESPN meeting in Brussels 2015
for young fellows/trainees
- 10 Travel grants: (10x500): €5000
- 11 Abstracts awards: (11x450): €4950

• Support is planned for the ESPN meeting in Glasgow 2017
Training grants

• 2015: N. Bervina, 3 months training in Leuven, Belgium (3000 €)

• 2016: A. Rashisan, Romania, Lyon, P. Cochat (3000 €)
2016 combined IPNA-ESPN CME course

V SOUTH EASTERN EUROPEAN PEDIATRIC NEPHROLOGY WORKING GROUP MEETING

June 10-12, 2016
IPNA-ESPN Junior Classes

Rezan Topaloglu, IPNA Chair, Junior Classes Committee

- Aim: harmonize education in Paediatric Nephrology, guaranteeing a high quality of training
- 3-year educational program in Paediatric Nephrology for Juniors
- On completion of each course: examinations
- On completion of full 3 years: IPNA & ESPN Master Diploma

<table>
<thead>
<tr>
<th>Date and Place</th>
<th>First IPNA-ESPN Junior Classes</th>
<th>Second IPNA-ESPN Junior Classes</th>
<th>Third IPNA-ESPN JC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lectures</td>
<td>14</td>
<td>16</td>
<td>70 accepted applications</td>
</tr>
<tr>
<td>CME accreditation</td>
<td>9 credits</td>
<td>12 credits</td>
<td>22 accomplished 3-years cycle</td>
</tr>
<tr>
<td>Applications</td>
<td>49</td>
<td>79</td>
<td></td>
</tr>
<tr>
<td>Attendees</td>
<td>47</td>
<td>68 (29 attended 1st)</td>
<td></td>
</tr>
<tr>
<td>Nationalities</td>
<td>18</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Median age</td>
<td>35</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td>Final exam questions</td>
<td>28</td>
<td>32</td>
<td></td>
</tr>
<tr>
<td>Completed exam</td>
<td>45 attendees</td>
<td>66 attendees</td>
<td></td>
</tr>
<tr>
<td>Median score</td>
<td>80 (67-87)</td>
<td>77 (33-93)</td>
<td></td>
</tr>
<tr>
<td>Social program</td>
<td>Faculty dinner</td>
<td>Faculty and attendees dinner + walking tour</td>
<td></td>
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</tbody>
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http://www.espn-online.org/ipna_espn3.php
# CME Activities

CME activities coordinator – Rukshana Shroff

<table>
<thead>
<tr>
<th>Working group</th>
<th>Coordinator</th>
<th>CME Lead</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transplantation</td>
<td>Burkhard Toenshoff</td>
<td>Luca Della Strologo</td>
</tr>
<tr>
<td>Dialysis</td>
<td>Alberto Edifonti</td>
<td>Rukshana Shroff</td>
</tr>
<tr>
<td>CKD-MBD</td>
<td>Dieter Haffner</td>
<td>Justine Bacchetta</td>
</tr>
<tr>
<td>CAKUT / UTI / Bladder dysfunction</td>
<td>Ann Raes</td>
<td>Paloma Parvex</td>
</tr>
<tr>
<td>Inherited renal disorders</td>
<td>Francesco Emma</td>
<td>Djalila Mekahli</td>
</tr>
<tr>
<td>Nephrotic syndrome</td>
<td>Marina Vivarelli</td>
<td>Marina Vivarelli</td>
</tr>
<tr>
<td>Immune mediated disorders</td>
<td>Rezan Topaloglu</td>
<td>Esra Baskin</td>
</tr>
</tbody>
</table>
New website

http://www.espn-online.org/

- Developed by FlapTour (part of PCO service, free of charge)
- Modern design
- Professional identity
- User friendly
- Great navigation with drop-down menus
- Access to other societies
- Easy membership registration & access to membership area
- Works from different devices including mobile phones and tablet
- Requested adaptations are performed within hours
Application available at android and apple store
European Rare Disease Policy:

Patient-centered care based on collaboration between European Expert Centers
Coordinator: Franz Schaefer
ERKNet European Rare Kidney Disease Reference Network

Network Advisory Board

Coordinator
Network Secretariat

Executive Board
(coordinator, 1 representative per workgroup, ePAG)

Thematic Work Groups
- Hereditary glomerulopathies
- Immune glomerulopathies
- Tubulopathies
- Thrombotic microangiopathies
- CAKUT
- Ciliopathies
- Metabolic nephropathies
- Pediatric CKD & Dialysis
- Pediatric Tx

Task Forces
- Molecular diagnostics
- Pathology & Imaging
- Transition & QoL
- Registries & Outcomes
- Education & Training
- Guidelines & Pathways

Network Board
(1 representative per member)

Related ERNs
- ERA-EDTA WG Inherited Kidney Diseases
- ESPN Work Groups

ePAGs

Related ERNs
- RD-Connect
- ERA-EDTA European Renal Best Renal Practice Group
Why do we need industry support?

• To support ESPN networking & policy making
• To support ESPN research activities
  – Working groups
  – ESPN research grants
• To support ESPN guidelines & educational activities:
  – Live learning & E-learning (to be launched)
  – European best practice guidelines
  – Paramedic education (dieticians, renal nurses)
  – Patient education
ESPN Strengths

• Network of paediatric nephrologists in Europe and around the globe (~2000 doctors)
• Networks of paediatric nephrologists according to specific interests (thematic working groups)
• Involvement of young colleagues (young nephrologists platform)
• Experience in studies, developing guidelines, consensus papers
• Networking with other paediatric and adult societies
Discussion

• Long-term relationship (unrestricted grants over 3 years, to be re-evaluated annually).
• How to create a “win-win situation”?
• Advice on policy making, focus on paediatric kidney diseases, bladder dysfunction, drug registration for paediatric use.
• Returns for the industry?
Thank you for your interest!

Web URL: http://espn-online.org/