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 ~2000 doctors are estimated to be involved at different extent in the care of children with renal disease all over Europe, with ~500 working in about 200 highly specialized paediatric nephrology units.
ESPN History

ESPN is established in 1967 (Glasgow)
1) To increase the communication network among Pediatric Nephrologists in Europe and the 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
ESPN lines of development

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

ESPN can send info to an active list of 2033 doctors interested in Pediatric Nephrology for advertisments on Congresses, Courses, Grants, Fellowships, Educational material available.

~ 60 mailings per year

ESPN/IPNA members have access to restricted member areas
ESPN communication network

Newsletters

March 2016
June 2016
November 2016
ESPN networking policy

Our Future: 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 < 40 y.o. Nephrologists

Including:
- Survey about 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 < 40 y.o. only)
ESPN lines of development

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 between ESPN and ERA-EDTA have been signed

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

2) Collaboration agreement between ESPN and ERA-EDTA: no time limit (E. Levchenko, A. Wiececk)
   - Mutual feasibility on the websites
   - Joint Symposium at each ERA-EDTA and ESPN congress (2 speakers from both societies)
   - 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
NEW: ESPN & European Society of Paediatric Urology (ESPU) Collaboration

• Collaboration within 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 pediatric nephrology sessions

Friday 24th June

14:24 – 15:14: WHERE PEDIATRIC NEPHROLOGISTS AND PEDIATRIC 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
ESPN lines of development

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
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 to be seen 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 (at least by three reviewers)
• Ranking according to scientific quality and compliance with ESPN aims
• A report of advancements is sent each 6 months to the Spring and Autumn Council for update.
• The final report in due 3 months after the end of the first year of economic support (money transfer to the Research Coordinator).
• The final report is published in the website.
• An economical report is provided at the end of the project.
• In all publications it should be reported: «supported by an unrestricted grant provided by ESPN: grant number XXX». 
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 out of 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 for the field. Successful projects will be funded to a maximum of 20 K €.

Project leaders are committed to acknowledge the support of the ESPN 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 evaluation will be announced during the ESPN Assembly General Meeting, September 2016, Iguazu, and will be posted on the ESPN website.

Supported by Industry via 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:
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:

GOLD Sponsors

HORIZON PHARMA

AMGEN®

SILVER Sponsors

Vifor Pharma
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 organize education in pediatric 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: (10x450): 5000 €

• Support is planned for ESPN meeting in Glasgow
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 pediatric nephrology, guaranteeing high quality of training
- 3-years educational program in Pediatric Nephrology for Juniors
- After each course: examination
- After completion of 3 years: IPNA & ESPN Master Diploma

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<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>
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<tr>
<td>Lectures</td>
<td>14</td>
<td>16</td>
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<tr>
<td>CME accreditation</td>
<td>9 credits</td>
<td>12 credits</td>
<td></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>70 accepted applications</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>22 accomplished 3-years cycle</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>
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http://www.espn-online.org/ipna_espn3.php
## CME activities

### CME activities coordinator – Rukshana Shroff

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<th>Working group</th>
<th>Coordinator</th>
<th>CME Lead</th>
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<tr>
<td>Transplantation</td>
<td>Burkhard Toenshoff</td>
<td>Luca Della Strologo</td>
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<td>Dialysis</td>
<td>Alberto Edifonti</td>
<td>Rukshana Shroff</td>
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<td>CKD-MBD</td>
<td>Dieter Haffner</td>
<td>Justine Bacchetta</td>
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<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:

Patients’ 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

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

Network Board
(1 representative per member)

Related ERNs
ePAGs

ERA-EDTA WG Inherited Kidney Diseases
ESPN Work Groups

ERA-EDTA European Renal Best Renal Practice Group

RD-Connect
Why we need industry support?

• Support ESPN networking & policy making
• Support of ESPN research activities
  – Working groups
  – ESPN research grants
• Support ESPN guidelines & educational activities:
  – life learning & E-learning (to be launched)
  – European best practice guidelines
  – Paramedics education (dieticians, renal nurses)
  – patients’ education
ESPN strength

• 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 relation (unrestricted grants for 3 years, to be re-evaluated annually)
• How to create “win-win situation”?
• Advise in policy making, attention for paediatric kidney diseases, bladder dysfunction, drug registration for paediatric use
• Returns for industry
Thank you for your interest!

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