

The European Society for Paediatric Nephrology NEWSLETTER

Dear ESPN members,

It is my pleasure to introduce this Newsletter, which will be sent only by email. Please do not hesitate to forward it to many people around you.

You will find below i) some comments about the registry who has been wonderfully managed by Jane Tizard and Enrico Verrina, ii) information on the working group on idiopathic nephrotic syndrome in children, iii) proposals for a new logo, and iv) a report on the First African Course of Paediatric Nephrology which had been supported by both ESPN and IPNA.

In addition to that, I would like to remind you some important issues:

New ESPN members should be encouraged, and applications must be sent to Rosanna Coppo (rosanna.coppo@unito.it), including a motivation letter, a short CV and a recommendation letter from two ESPN members.

As you will see on the list below, the next ESPN meeting will take place in Birmingham (September 2-5). See <http://www.espn2009.co.uk>. In 2010, we will meet in New-York city for the IPNA meeting (<http://ipna2010.org/>) and then in Dubrovnik for the 2011 ESPN meeting.

We will have to vote for the **2012 ESPN meeting** and applications should be sent to pierre.cochat@chu-lyon.fr before August 24, 2009. Applications should include details on congress venue, estimated budget, access and safety. There will be a 5 min presentation per application at the General Assembly in Birmingham (Friday September 4th, 18:00), with limited information on local tourism and social events.

Two council members will have to be elected at the General Assembly in Birmingham (Friday September 4th, 18:00) to replace N Webb (United-Kingdom) and A Gür Güven (Turkey): please send a short biography and specific contribution you would bring to pierre.cochat@chu-lyon.fr before August 24, 2009.

See you in Birmingham!

Friendly,

Pierre Cochat, ESPN Secretary General

June 2009

Our annual conference this year it is being held Birmingham, England 2-5th September.
See the web site www.espn2009.co.uk for details and registration.

This conference has some novel features. The first full day of the conference, Thursday 3rd September, will be a joint meeting with the Renal Association of Great Britain. The Renal Association is the longest established nephrological society and has a distinctive tradition of meetings designed to encourage an in-depth understanding of a specific subject. This joint day will be plenary, and focus on cystic kidney disease, and the pathobiology of the primary epithelial cilium/centriole. This organelle, which was ignored for many years, is the "antenna" of the cell, transducing external stimuli about the cell's environment and linking this to cell growth, movement and orientation. The explosion of knowledge in this area is very recent and there will be few of us who had any formal teaching about it. At last one can make logical connections between certain kidney diseases and their extra-renal components such as defective neuronal, liver, cardiac or limb development, or degenerative conditions that affect the retina, or induce diabetes mellitus and the metabolic syndrome. This is has already moved beyond isolated theoretical knowledge, and there are new concepts for treatment for some of these disorders. In the not too distant future paediatric nephrologists will be managing cystic kidney disease in an entirely different way.

The remainder of the conference is more traditional with wide interests, but a focus on nephrotic syndrome on the Friday, and tubular and metabolic disease on Saturday. The invited speakers are terrific and the standard of submitted papers is high. There is a young nephrologists satellite symposium on Wednesday 2nd which is already well subscribed and clearly popular and necessary. A collegiate social program is well advanced. All the organizers look forward to this being a landmark conference in the life of the ESPN.

Mark Taylor

ESPN President Elect

ESPN-ERA registry

The paediatric ESPN-ERA registry has made important progresses during the last three years, thanks to Jane Tizard, Enrico Verrina, Kitty Jäger and Karlijn van Stralen. A start up report has been accepted for publication in *Nephrol Dial Transplant* and another paper will be published in *Pediatr Nephrol* in 2009. There are several developing projects: anaemia, transplantation across Europe, dialysis in young children, nutrition and growth, cardiovascular disease, etc. The paediatric Registry will apply for an ERA-EDTA research grant call, which will be available in September 2009. Meanwhile the ESPN have to think about funding for the future, so that there is a need for additional funding by the national societies, ERA, as well as companies.

A letter has been sent to each national President asking for a contribution of 1,000-3,000 euro each.

The ESPN has signed the contract with AMC and covers the rest of the funding. A clause has been added, stating that at least two papers should be submitted for publication in 2010. After this effort, the Registry must succeed in getting economical supports from Industry or from EU funds. Jane Tizard will end her mandate in 2009. She did a wonderful job with our registry and established dynamic and fruitful collaboration with the AMC in Amsterdam. She has to be replaced and a nomination form is attached in this newsletter. Enrico Verrina has started in 2006 and he can be re-elected for another 3 years term.

ESPN Website
<http://espn.cardiff.ac.uk>

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Nominations for one of two representatives on the ERA/EDTA registry committee

One of the 2 positions on the ERA/EDTA registry committee will be vacant from September 09. This representative will also co-chair the paediatric registry committee and help develop the new paediatric renal registry. Please send nominations to either Jane Tizard e-mail jane.Tizard@UH Bristol.nhs.uk or to Enrico Verrina on enricoverrina@ospedale-gaslini.ge.it

Enquiries may also be directed to the above addresses.

Name _____

Address _____

E mail _____

Nominated by

Name _____

Address _____

Please send in nominations by July 31st 2009

ESPN-IPNA meetings

1967	Glasgow	Gavin Arneil	1991	Paris	Renée Habib
1968	Utrecht	Harmen Tiddens	1992	Jerusalem	Alfred Drukker
1969	Helsinki	Niilo Hallman	1993	Heidelberg	Karl Schaerer
1970	Heidelberg	Horst Bickel	1994	Amsterdam	Raymond Donkerwolke
1971	Paris	Pierre Royer	1995	Santiago	Carlos Saieh-Andonie
1972	Dublin	Seamus Dundon	1996	Lausanne	Jean-Pierre Guignard
1973	Strbske Pleso	Ferdinand Demant	1997	Athens	Constantinos Stefanidis
1974	Lausanne	Oscar Oetliker	1998	London	Cyril Chantler & Martin Barratt
1975	Cambridge	Steward Cameron	1999	Prague	Jan Janda
1976	Barcelona	Luis Callis	2000	Helsinki	Christer Holmberg
1977	Helsinki	Niilo Hallman	2001	Seattle	Bruder Stapleton
1978	Kyriat Anavim	Harry Stark	2002	Bilbao	Juan Rodriguez-Soriano
1979	Capri	Carmelo Giordano	2003	Berlin	Uwe Querfeld
1980	Philadelphia	Alan Gruskin	2004	Adelaide	Ken Jureidini
1981	Antwerp	Karel van Acker	2005	Istanbul	Aysin Bakkaloglu
1982	Stockholm	Anita Aperia	2006	Palermo	Silvio Maringhini
1983	Hannover	Johannes Brodehl	2007	Budapest	Tivadar Tulassay
1984	Dubrovnik	Milana Popovic-Rolovic	2008	Lyon	Pierre Cochat
1985	Lisbon	Antonio Torrado	2009	Birmingham	Mark Taylor
1986	Tokyo	Katsuyoshi Murakami	2010	New-York	Frederick Kaskel
1987	Budapest	Domokos Boda	2011	Dubrovnik	Danica Batinić
1988	Manchester	Ian Houston	2012	TBD	
1989	Toronto	Gerald Arbus	2013	Shangai	
1990	Rome	Gianfranco Rizzoni			

Working group on Idiopathic Nephrotic Syndrome in children (ESPN-WINS)

WINS initiative was started during the Annual ESPN congress in Lyon 2008, following the request of Nephcure International (<http://nephcure-international.org/>). Nephcure is an organization of patients/parents of patients with idiopathic nephrotic syndrome aspiring to enhance public awareness, stimulate research, improve communication and harmonize medical care for patients with nephrotic syndrome. WINS serves as a medical advisory board of Nephcure and aims to coordinate and to facilitate initiatives in the field of nephrotic syndrome in Europe. The initiators are P Niaudet (chair), J Vande Walle (secretary), JHH Ehrich, JC Davin, F Emma, PF Hoyer, E Levchenko (liaison ESPN), L Massella and M Saleem.

During the ESPN council meeting in March 2009, WINS was approved by the council and received the name ESPN-WINS.

All ESPN members interested in this initiative are welcome to participate in the ESPN-WINS meeting during the Annual ESPN congress in Birmingham (on the 5th of September, exact time and location will be confirmed).

Proposals for a new logo that will be selected (vote) in Birmingham



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La Société Marocaine de Néphrologie Pédiatrique
Moroccan Society of Paediatric Nephrology

Premier Cours Africain de Néphrologie Pédiatrique
First African Course of Paediatric Nephrology
Sponsored by

International Paediatric Nephrology Association European Society of Paediatric Nephrology African Paediatric Nephrology Association

16 – 18 October 2008 – Casablanca – Morocco

The Moroccan Society of Paediatric Nephrology organized the **First African Course of Paediatric Nephrology** Sponsored by the International Paediatric Nephrology Association, the European Society of Paediatric Nephrology and the African Paediatric Nephrology Association from 16 to 18 October 2008.

The meeting was a good African interface around important themes of paediatric nephrology. The program reviewed some topics as the nephroprotection, glomerulonephritis, urinary tract infection, uropathy, urolithiasis

and the renal failure: Topics of daily preoccupation and topics of news. There were some workshop and a seminar of nurses. All speakers had a very high educational level and they provided big efforts in the conception of talk that were with a very high level making real clarification on topics, and respecting our engagements to put slides in French if the language of speaker is English (French/English).

Participants: the practitioner attended the course was: paediatric nephrologists, paediatricians, nephrologists, paediatric surgeons, training paediatricians, nurses in paediatric. The total number of participants was 213 with a daily middle presence of 120 to every session (extreme 94 and 141).

Countries: Algeria, Libya, Egypt, Sudan, Ivory Coast, Saudi Arabia. Many African colleagues registered can't attend the meeting for difficulties to pay plane tickets in spite of offering them the hotel accommodations.

Financial support: The IPNA and the ESPN support help us to have the speakers and local pharmaceutical sponsor help us to provide a hotel accommodation for the African colleagues.

Editions: A CD of conferences has been distributed to participants at the end of the course. A special volume of the Moroccan paediatric journal dedicated to the African course planned for 2009.

Assessment: An evaluation can help us to perform the next courses.

Recommendations

- Put a unified program of continuing education between African countries adapted not only to the paediatric nephrologists but also for general paediatricians. Need an adapted didactic material.
- Work to sensitize the public in collaboration with the existing associations: media, NGOs...
- Participate, in partnership with the scientific societies, to sensitize for early diagnosis.
- Develop cooperation between specialists implied in charge in children with renal diseases: create a work group (radiologists, urologists' paediatricians, biologists and as far as possible health economists): to develop cooperation between the African countries, epidemiological research, initiate local registers...
- Take contacts with government, ministry, ONG... to approach socioeconomic problems.
- Provide training of young paediatrician; ask IPNA and ESPN help.
- Encourage African paediatric nephrologists to begin a member of IPNA, and help African Paediatric nephrology Association to initiate a directory of African specialists and the different existing structures. A membership application for IPNA and AFPNA were distributed for participants.
- Diffusion of these recommendations and looking after their application.
- Expected the second course in 2010.

Pr A. Bourquia, Coordinatrice Cours Africain, membre du conseil de l'IPNA. amal.bourquia@gmail.com
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