NEWSLETTER



Spring is just over and all ESPN Council members wish you a wonderful summertime, including our next meeting in Krakow, **September 6**th – **8**th **2012.** http://www.espn2012krakow.org

Please Invite Your Colleagues to Become an ESPN Member

- A stimulating scientific society connected with IPNA and ERA EDTA
- Access to ESPN e-information
 Reduced fee for Annual Meeting registration
- Experiences for teachers and trainees
- Access to specific grants Participation at ESPN ERA / EDTA registry activity

Some proposals from the Council...

The council wants to promote an open policy, with direct online registration and payment, and no more recommendation letters. This has to be voted at the AGM in Krakow.

Fees would be as follows:

- ESPN members only: EUR 50 per year
- IPNA member only, including the Print Journal: US \$175 per year
- IPNA member only, with the Online Journal without the Print Journal: 110 USD
- Combined ESPN and IPNA member, including the Print Journal: Eur 50 + US \$115
- Combined ESPN and IPNA member, with only the Online Journal without the Print Journal: Eur 50 + US \$50
- Reduced fees (20 EUR) will be maintained for ESPN membership in developing countries. This has to be voted at the AGM in Krakow.

ESPN as a Charity Organization

In order for ESPN to become a charity organization, according to the German Law, few words in the constitution have to be changed and all ESPN members have to sign that they agree. The text will be distributed (translated in English) at the registration desk in Krakow and the members of ESPN will be asked to sign. We thank Dieter Haffner for his efforts concerning this matter.

Training Grants

ESPN will provide training grants for young paediatric nephrologists or fellows in paediatric nephrology from low resource countries aiming at improving both theoretical and practical skills.

The following criteria have been approved by the council:

- Age below 40 years, working in a developing country, intention to stay in the field of paediatric nephrology, clear training aim.
- Applicants should have at least two years of practice in paediatric nephrology.
- Announcement for training grants should be done in the Newsletter, with a deadine for appplication on March 1st of each year.
- Applications should be sent to the secretary general and will be approved by the council.
- A 2000 EUR training grant has just been approved for Dr. Sofi Saryan (Erevan, Armenia, training in Leuven, Belgium).

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We have received a letter from Dr. Nataliya Bervina who had already received a training grant:

Dear Prof. Pierre Cochat,

First of all I would like to thank ESPN and you for the given opportunity to have an additional training in pediatric nephrology in the University Hospital Leuven under prof. Elena Levtchenko guidance. It was a very great experience to me.

Medical Life in Leuven (Belgium) is quite different from what I'd experienced in the Orenburg regional children's hospital (my native hospital). Leuven's hospital has a wonderful conditions and wonderful equipment and the object of my training was to try to know as much as possible about pediatric nephrology, including deals with renal biopsy, dialysis and kidney transplantation. I worked with almost all Belgium children, having kidney transplant and I had a full access to all articles, published on MedLine. I saw wonderful scientific researches. Elena shared with me many brilliant ideas. This opened up all the possibilities to study genetic defects, biochemical reactions et cetera. It was not only nephrology. It was a part of completely new field (a future of medicine). It was very inspiring. I enjoyed it tremendously. It helped me to update my knowledge in immunesuppressive therapy after kidney transplantation and in patients with glomerulonephritis according to European standards

It was very useful for me to participate in the discussions of patients and cases with kidney diseases .

I also had a wonderful opportunity to see patients with orphan diseases for example such as congenital nephrotic syndrome, Gitelman syndrome, nail-patella syndrome, etc.

During this course I also participated in Nederlandse Nefrologiedagen 2012, in the 13th International Symposium "Transplant for non transplant physicians " and in the Congress of pediatrics of Belgium.

I was introduced to my international colleagues who were very friendly, highly educated and experienced. Communication with them was pleasant and useful for me.

I hope that we will keep in touch in the future and discuss the patients who are seriously ill. Belgium made a deep impression on me. I saw a very beautiful country with interesting history, ancient architecture and delicious cuisine.

I am glad that I had this great experience in Hospital of Leuven which will help me to manage my patients in Russia. Best regards,

Nataliya Bervina, pediatic nephrologist, Orenburg regional children's hospital, Orenburg, Russia

Honorary ESPN members have been selected by the Council:

2012: R. Donkerwolke, S. Ridgen and M. Brandis

2013: C. Holmberg and A. Bakkaloglu

Council Members

Rosanna Coppo has been elected as the next Secretary General Dubrovnik, and she will start her mandate at the time of the Krakow meeting.

Two Council members have to be replaced this year, V. Tasic and R. Topaloglu. Applications should be sent to

pierre.cochat@chu-lyon.fr.

This has to be voted at the AGM in Krakow.

New Members

Applications for regular membership should be sent to pierre.cochat@chu-lyon.fr. <u>Ew members will be approved at the AGM in Krakow.</u>

Registry Committee

Both mandates from Enrico Verrina and Franz Shaefer will end in Krakow. Enrico Verrina cannot be re-elected, but Franz Schaefer can be. Applications should be sent to pierre.cochat@chu-lyon.fr This has to be voted at the AGM in Krakow.

Don't forget the ESPN AGM in Krakow! Scheduled Friday September 7th During Lunch Time Important issues will have to be voted on!

Updates on the Educational Committee

The Educational Committee (EC) consists of Ayfer Gurguven (AG), Marijan Saraga (MS), Velibor Tasic (VT), Peter Hoyer (PH), Johan vande Walle (JvW), and Detlef Bockenhauer (DB).

Agreement on EC Statute

It was agreed that the EC is a working group for specific projects of educational nature. The remit of the assigned tasks is decided by the ESPN council.

The EC will usually consist of max 8 members and the chair.

Membership will consist of ESPN councilors (4) and non-council "consultants" (max).

Tenure of membership and chair is flexible and mainly dependent on the assigned project. It is expected that a usual term is about 3 years, but extension can be decided by the EC based on the need of the project and productivity and activity of the individual member.

For the current project "Development of training regulations for pediatric nephrology in the EU" a liaison officer to the European Academics of Paediatrics (EAP) was proposed. The EAP will ultimately have to approve the regulations and suggest to UEMS. JvW was proposed for this project considering his geographic proximity to Brussels.

Training Regulation

The need for high quality regulations that will ensure optimal care for the child with renal disease was emphasized.

It was acknowledged, that some smaller countries/centres may not be able to fulfill all these requirements.

These centres should be encouraged to enter formal partnerships with bigger centres where trainees can receive further training in those aspects not available in their home centre.

The proposed regulations from M Winterborn with modifications by EG were reviewed.

It was agreed that training in paediatric nephrology should be a minimum of 3 years.

It was agreed that no specific numbers of patients/procedures should be detailed in the training regulations.

Rather, average numbers for these should be detailed in the regulations for accreditation of training centres.

Modernisation of requirements with respect to molecular physiology/pathology and genetics was agreed.

An update of these requirements and potential reordering will be prepared by JvdW and AG within the coming month and then discussed wither by videolink or physical meeting.

Collaboration among national pediatric nephrology societies and cooperation with the European Academy of Paediatrics / Tertiary Care Group of UEMS, E-learning, CME will be stimulated.

The final presentation of the Timeline document pediatric nephrologists in the EU should be presented at the General Assembly 2013.

Locations of the ESPN Meetings

Krakow 2012, September 6-8 Shanghai 2013 (IPNA), September 1-4 Porto 2014, September 18-20 xxxx 2015 Iguacu 2016 (IPNA)

The 2015 meeting will be selected in Krakow applications should be sent to pierre.cochat@chu-lyon.fr

This has to be voted at the AGM in Krakow

Actions of Flap Tour

The New ESPN Website including the Online Membership system will be activated.

There will be an ESPN booth at ESPN, IPNA and IPTA congresses in order to promote ESPN membership. A guidline has been created for the selection of ESPN Congress host countries.

44th ESPN Congress in Dubrovnik

A total of 531 attendees have been registered: 310 ESPN nonmembers, 136 ESPN members and 85 trainees, 131 pre-congress course participants. There were 510 abstracts, 52 oral presentations and 458 poster presentations; around 45 abstracts were rejected (~10%). There will be 10 Best Abstracts awards: 5 for oral presentations and 5 for posters.

There were no major problems experienced in Dubrovnik, no visa problems for participants from the Middle East, Africa, Belarus and Georgia. They also had participants from non ESPN countries such as Canada, the US and Australia. ESPN Council was very satisfied with the Dubrovnik congress organization and venue. D Batinic and and Y Frishberg have been thanked by the Council for their work.

Miscallaneous

The ESPN is now registered in the Yearbook of International Organizations (edited by UIA, in formal associate relations with UNESCO) - www.uia.org

Kids Kidney Research

Kids Kidney Research is an entirely voluntary organization raising funds for vital research into prevention and cure of kidney disease in babies and children. The research funded to date has been based at the Institute of Child Health and the renal department of Great Ormond Street Hospital, however we have recently funded renal projects nationwide, both directly and under the guidance of the BAPN (British Association for Paediatric Nephrology).

Kids Kidney Research focuses on paediatric research into the prevention and cure of renal illness and associated areas.

In particular we primarily support research that falls into the following areas:

- Defining the best treatment for those children who suffer from vesicoureteric reflux
- Exploring new therapies which can potentially heal damaged kidneys
- Finding the faulty genes which can run in families and cause kidney diseases

To maximise the benefit of our funding, we agree grants at an early stage of research, often providing pump-priming to initiate research that will be carried forward by larger grant-providing bodies if successful. An example of this is a recent grant to develop a DNA bank developed from babies with kidney disease. This early stage research tests the validity of such an approach. We are, therefore, key in ensuring the initiation of new research.

To mitigate the potential additional risk of such a policy, close scrutiny of every research application is undertaken by our Medical Advisory Panel and several applications have been either modified or rejected as a result. We believe this strategy to be sound, and of critical use to research bodies. The Medical Advisory Panel is made up of six highly regarded renal paediatric consultants.

In addition, the charity is a member of the Association of Medical Research Charities (AMRC), an independent membership organization of the leading medical research charities in the UK. This ensures we run the charity properly, use best practice to select projects to fund as well as helping avoid funding full economic costs resulting in the funds being used efficiently. Following acceptance to the AMRC, Kids Kidney Research adopted a research strategy and code of conduct for the

Medical Advisory Panel (MAP) and refreshed their review practices as follows:

- All research projects are reviewed by our independent MAP
- The MAP is made up of six eminent renal and urological specialists, all of whom have had years of experience in the field and practice. Each appointment to the MAP lasts for a maximum of five years
- All reviews are sent to the Grants Administrator, who collates them, in unattributed format, for distribution to both the Trustees and Applicants. This ensures that reviewers are rigorous in their comments
- Any research project that lasts for more than one year in length is also reviewed by an External Reviewer, in accordance with AMRC guidelines. The External Reviewer is chosen on a case by case basis

All details of our projects and terms and conditions can be found on our website www.kidskidneyresearch.org