

To all ESPN members

April 2000

Dear Friends and Colleagues,

### **ESPN Helsinki 18th - 20th June 2000**

**Please book early because Helsinki is very booked up in June**

The meeting in Helsinki is not far away and once again it is time for me to write to let you know about plans for the meeting and events during the past 6 months. I have no doubt that Christer Holmberg and his team will arrange an excellent congress.

### **Election of Officers**

Election of officers to replace Kate Verrier Jones (Cardiff, Wales, UK) Secretary General, Jochen Ehrich (Hannover Germany) Assistant Secretary, Pierre Cochat (Lyon France), Fernando Santos (Oviedo, Spain), Rosanna Coppo (Turin Italy), Council members. The following proposals have been received:

<b>Position</b>	<b>Nominee</b>		<b>Proposers</b>
<b>Secretary General</b>	<b>Jochen Ehrich</b>	<b>Hannover, Germany</b>	<b>A Aperia, U Jodal, T Linne, M Broyer, MF Gagnadoux, P Niaudet, J Brodehl, G Offner, K Latta, W Rascher, A Drukker, JP Guignard</b>
<b>Assistant Secretary</b>	<b>Christer Holmberg</b>	<b>Helsinki, Finland</b>	<b>A Aperia, U Jodal, T Linne, M Broyer, MF Gagnadoux, P Niaudet, J Brodehl, G Offner, K Latta</b>
<b>Council member</b>	<b>Alberto Caldas Alfonso</b>	<b>Porto, Portugal</b>	<b>F Santos, M Navarro, H Jardim</b>
	<b>Michael Fischbach</b>	<b>Strasbourg, France</b>	<b>E Girardin, P Cochat, C Loirat</b>
	<b>Sally Hulton</b>	<b>Birmingham, England</b>	<b>D Milford, CM Taylor, P Cochat</b>
	<b>Ulrike John</b>	<b>Jena, Germany</b>	<b>J Brodehl, G Offner, K Latta</b>

	<b>Giuliana Lama</b>	<b>Napoli, Italy</b>	<b>J Ehrich, R Coppo, A Edefonte</b>
	<b>Hilal Mochan</b>	<b>Istanbul, Turkey</b>	<b>J Beattie, S Mir, P Niaudet, CM Taylor, A Watson, J Winberg</b>
	<b>Sue Rigden</b>	<b>London, England</b>	<b>G Haycock, O Mehls, P Niaudet, G Smith</b>
	<b>Alan Watson</b>	<b>Nottingham, England</b>	<b>A Edefonte, J Evans, C Stefanidis</b>

## **Elections for officers will take place at the general assembly in Helsinki**

### **Paediatric Registry**

The most pressing issue over the past 12 months has been the need to make decisions about a European Paediatric Database for children with endstage renal failure on renal replacement therapy. In 1998 it became clear that the EDTA/ERA Registry had collapsed and that it could not continue in its previous form. In the early days the EDTA registry was highly successful and played a vital role in the development of dialysis and transplantation for children. In recent years there were a number of unresolved problems. These included incomplete data collection, poor management of the database, failure to use data collected and financial pressures. There are now so many patients on renal replacement therapy that the need for a Europe wide database has lessened. However, for children who make up only 2-5% of the group there is a continuing need to collect data from a population of 250-500,000,000 in order to monitor the outcome of treatments in this small subgroup. When considering children with rare causes and complications of renal failure this becomes even more important. In February a meeting was held including former EDTA registry members and the ESPN Council to discuss the options available. These were:

#### **1 To establish an independent ESPN Registry**

Some ESPN members have been enthusiastic about this proposal, however there are a number of potential problems with this. In particular, to set up a large registry requires money, computing expertise, epidemiological skills and a major time commitment from key personnel. There was concern that the ESPN would not succeed where the EDTA has failed, particularly since there is less money and expertise available to a smaller society. Data collection through national registries is one possible method that should be considered. Paediatric nephrology is a small subspecialty and those paediatric nephrologists providing renal replacement therapy generally know each other and have the possibility to collaborate to ensure the success of a national registry.

#### **2 Collaboration with the ERA**

Following the crisis in 1998, the ERA have drawn up proposals for a new registry, collecting data from well organised national or regional registries and databases. Countries with poorly organised and incomplete registries will not be eligible unless the data collection improves. The reason for this new approach was because data collection from individual centres and from individual patients had become impossible to achieve from a single European office. Only registries with a high level of completeness will be accepted as participants. The new ERA registry will be based in Amsterdam and supported by epidemiologists and computer specialists. A small core data set will be collected making the possibility of complete data collection much greater and the burden on contributors less. Additional questionnaires can be designed by subgroups to answer specific questions. The ERA is keen to involve the ESPN and to continue to register children. If the ESPN accepts their proposals there will be places for 2 paediatricians on the Registry committee. Dr Douglas Briggs, chairman of the Registry Committee, has spoken to the council and presented his proposals at the recent council meeting in February. In countries where there is no national registry there is a possibility that a paediatric registry can be established and that data from children can be forwarded to the ERA database, provided that the data are complete and of good quality.

One advantage of the ERA proposal is that in many countries data will be entered automatically into this system. Another advantage is that there will be continuity of data from child to adult in many countries. The principal disadvantages are that there is a theoretical possibility of registry failure or that the minority paediatric registry members may be over-ruled on the committee. However if participating countries establish robust national paediatric registries, as required by the ERA, then in the event of failure of the ERA registry the ESPN will have a strong basis for a separate children's registry. In order to make this system work there should be an ESPN Registry Committee to help establish and support national registries, obtain grants and design and administer mini-questionnaires to deal with current issues. This may have some cost implications for the ESPN but not as much as the cost of setting up a separate registry. For EEC countries there is the possibility of funding through the 5th Framework Quality of life grants which are administered by the European Commission. Many of the problems that can be addressed by the registry now cross the child adult interface and will not be addressed if the registries are separate.

### **3 Collaboration with NAPRTCS**

Some paediatric nephrologists in key centres have been approached by Amir Tejani representing NAPRTCS. Initially his proposals looked attractive but on closer scrutiny they did not offer any advantages to children in Europe or to the science of epidemiological studies or randomised trials. Those who were approached were offered the possibility to collaborate with NAPRTCS, with the added benefit of expenses for trips to meetings in the USA. However if the ESPN collaborates on an equal basis with NAPRTCS there will be a requirement to fund the entire cost of the European side of the operation. This would be beyond the present income of the ESPN and would reduce the opportunity for independent European studies which could be set up to prove or disprove ideas and observations from the other side of the Atlantic. To have all the Western expertise in paediatric nephrology in one pool is not good science. The council saw no merit in this proposal. However the council did not wish to prevent collaboration with NAPRTCS and will strive to maintain good links

with North America in the interest of healthy debate and collaboration where appropriate.

#### **4 Not to support a registry**

There was no support for this option from ESPN members or from the council.

#### **Conclusion**

At the council meeting on 18th February ([see pictures](#)), after consideration of all the evidence, the council recommended that a registry should be supported. The NAPRTCS proposal had no merit for the ESPN and reduced the opportunity for good scientific debate between two comparable groups. The majority of those present recommended collaboration with the ERA through the development of well organised national paediatric registries. The ESPN would then form a registry committee to enable development of these national registries and help with grant applications.

*This important debate will be decided at the general assembly in Helsinki. If you have further questions about these proposals please contact me and I will do my best to answer your queries. Points for discussion must be sent in writing to the secretary general or assistant secretary before the meeting.*

#### **Text book**

Pierre Cochat has circulated the outline plan to prospective authors.

#### **Home page**

The home page <http://www.uwcm.ac.uk/uwcm/ch/espn/> is now well established thanks to the work of Graham Smith and Tim Ferguson in Cardiff. The site is used regularly by people from Europe and the rest of the world (approximately 400 visits per month). Over the next year we hope to extend it to increase awareness of our academic database and eventually the textbook.

#### **Training grants**

Grants in 1999-2000 were awarded to Jurate Masalskeine (Taldomskaya, Russia) to visit Alan Watson in Nottingham, Marina Aksenova (Moscow, Russia) to visit Gianfranco Rizzoni in Rome and Milos Ognajovic (Belgrade Yugoslavia) to visit Malcolm Coulthard in Newcastle.

#### **Training courses**

**Georgia** There are plans for a course in Tbilisi Georgia in September/October 2000, Organisers Irakli Rtskhiladse, Ernst Leumann and Otto Mehls.

**Vladivostok** A course will be arranged in Vladivostok in Autumn 2000 or Spring 2001 sponsored jointly by the ESPN and IPNA. Local course organiser Professor Valentina Luchaninova.

### **Future meetings**

ESPU and AAP*	Tours, France	7 <sup>th</sup> to 10 <sup>th</sup> June 2000
34 <sup>th</sup> ESPN Meeting	Helsinki, Finland	18 <sup>th</sup> to 20 <sup>th</sup> June 2000
IPNA Congress	Seattle, USA	1 <sup>st</sup> to 6 <sup>th</sup> September 2001
35th ESPN Meeting	Bilbao, Spain	Dates to be announced 2002

\* This joint meeting between the European Society for Paediatric Urology and the American Academy of Paediatrics Section of Urology who are planning a special session on the surgical/nephrological interface. The organisers welcome participation from ESPN members.

Further dates can be obtained from the [web site](#).

**Bids for the meeting of 2003 will be decided at the general assembly in Helsinki.**

The possibility of a joint meeting with the ERA and ISN in Berlin in 2003 is under investigation. This meeting will celebrate the career of Professor Ebehardt Ritz.

I look forward to seeing you again soon.

With best wishes

Yours sincerely

Kate Verrier Jones

Secretary General