

To all ESPN members

March 2002

Dear Friends and Colleagues,

In this newsletter the ESPN Council takes the opportunity to inform you about past events and future projects.

In the last year the ESPN council gave priority to some ambitious aims including

1. the reestablishment of the European Paediatric Registry for children on renal replacement therapy,
2. stimulating ESPN collaborative studies on some major diseases like HUS and FSGS,
3. installing an ESPN Archive and Agency,
4. publishing the ESPN Handbook, and
5. planning a joint congress with adult nephrologists in 2003.

Where do we stand in March 2002?

Ad 1 Report on the ESPN Registry given by Kate Verrier-Jones in February 2002 to ESPN Council

1. The reformed registry is now functioning well and meets regularly.
2. There is a formal constitution and legal agreement between the EDTA and the department of epidemiology and statistics in Amsterdam.
3. It has been agreed that there are 2 ESPN representatives on the registry committee, nominated by the ESPN. Our expenses are paid by the EDTA.
4. The first paediatric report was made at the EDTA meeting in Vienna 2001. This report is now almost ready for publication.
5. Two further projects have been proposed for this year and one on transplantation will be presented by Bert van der Heijden in Copenhagen. We are also preparing data on long term survival.
6. There is a slot in the scientific programme of Bilbao for one or two presentations from the EDTA registry.
7. In 2001 there was data on 2000 children from 8 registries population 50,000,000. In 2002 we expect to have 10 registries and 150,000,000 population.
8. The ESPN are invited to suggest projects that can be discussed in future years. Some projects can be prepared from the core data but we are also considering studies that involve a questionnaire. One proposal was for a study of quality of life in adult survivors of renal failure in childhood. Looking at educational achievement, mobility, job success, marriage, reproduction etc.
9. It is essential that the ESPN continue to support the EDTA and urge other registries to participate as quickly as possible. It would be quite unacceptable to switch allegiance to a different system after the decision was made at the general assembly after the proper consultation process.

National Presidents/Secretaries are more than welcome to contact Kate Verrier-Jones at verrier-jones@cf.ac.uk or Albertus van der Heijden at vanderheijden@alkg.azr.nl or the ESPN Secretary General for discussing reporting of their patients. EDTA/ERA has developed national reporting procedures, and these will be discussed during the next meeting with Presidents and key persons in Bilbao 2002.

Information on the results and ongoing activities of the Registry on the ESPN web site, produced by Kate Verrier-Jones, was supported by the ESPN; this could then be accessed by those who have an authorised password (yet to be installed).

EPRDS proposal by Dr. Ardissino

There has been a proposal from IPNA that ESPN should investigate the possibilities of expanding the existing registry by 1. including patients with chronic renal failure, 2. developing a structure for future multi center therapeutic trials, and 3. allowing a cooperation with NAPRTCS. This matter was discussed by ESPN council members with several experts in the field both during IPNA congress in Seattle and during the San Francisco congress. This topic was discussed again in detail during the ESPN Council Meeting in Hannover 2002. A report was given by Dr. Ardissino on the structure of the 3 Italian registries - CRF, Dialysis and Transplantation in children. Furthermore, he outlined the possible structure of a new European Registry for children with kidney diseases (EPRDS). The ESPN Secretary-General read a report by Dr. Verrier-Jones on the current status of the ESPN Registry in Amsterdam. In the discussion following, it was concluded that there is a need for an expanded registry for children with chronic renal failure, dialysis and transplantation, allowing both the collection of demographic data and the performance of multi center trials. This "new registry" should be part of the EDTA/ERA Registry in Amsterdam, thus allowing follow-up of children into adult life.

It was concluded that 1. this ambitious aim cannot be achieved without more financial resources, more personal and larger data sets extending the current patient questionnaire, 2. that it is not the aim of the EPRDS to create a new independent registry, instead it should rather support the existing EDTA/ERA Registry. Last but not least the idea has to be discussed with EDTA/ERA Council.

A committee (Hoyer, Ardissino, vd Heijden, Verrier-Jones) was nominated to explore the possibilities of creating EPRDS. The committee will liaise with EDTA/ERA and NAPRTCS and will report to the ESPN council and GA in Bilbao in September.

Ad 2 Collaborative Studies

If you want to know details about the European HUS Research Group please contact Mark Taylor at c.m.taylor@bhamchildrens.wmids.nhs.uk.

For information concerning the European Peritoneal Dialysis Study Group please contact Alan Watson at watpaed@aol.com.

The ESPN encourages all its members to create a forum for collaborative studies supported by the ESPN. Please contact Rosanna Coppo at rosanna.coppo@torino.alpcom.it

Ad 3 ESPN Archive and Agency

The ESPN Archive is expanding and more information will be given in Bilbao.

Ad 4 ESPN Handbook

The advances in the progress of the Handbook have been rather slow recently and about a quarter of articles were still missing at the end of last year. Pierre Cochat is working hard on the preparation of the book and we all hope that it will be ready for publication in Bilbao. For further enquiries please contact Pierre Cochat at cochat@univ-lyon1.fr

Ad 5 ESPN Berlin 2003

The joint meeting of ESPN with ISN and EDTA/ERA in Berlin is proceeding well. Please visit the website at <http://www.Nephrology-2003.org> and mark your calendars for June 8-12, 2003.

Uwe Quefeld will be our Paediatric President during the 2003 congress, and he is a member of the organising committee of Nephrology-2003. Christer Holmberg is a member of the scientific committee 2003. If you have any suggestions for presentations or other items please contact these two directly.

Summary of other activities:

Honorary membership: Honorary membership was awarded to Renée Habib and Cyril Chantler.

New ordinary members: We cordially welcome our new ESPN members (see table).

Election of ESPN officers: Giuliana Lama was elected new council member replacing Albertus van der Heijden.

Membership fees 2002: Please transfer the annual membership fee via Eurocard/Visa (see attached forms).

General Communication via e-mail

In 2001 the ESPN secretariat intended to communicate with you mainly by email, thus dispensing with the high costs of the postal service. Unfortunately this has not been very successful as many **email addresses were either incorrectly documented** in our address list or had been changed since the address list has last been updated. Very few ESPN who are not yet personally online have provided us with **an alternative e-mail address** to which they had easy access.

Please use the **ESPN home page** (<http://espn.uwcm.ac.uk>) to get more information from the ESPN secretariat.

National Presidents/ Secretaries of National Paediatric Nephrology Associations or Working Groups

Please find the database of the primary addresses of the National Presidents/ Secretaries of National Paediatric Nephrology Associations or Working Groups on the attached pages.

Teaching courses

The last teaching course was held **from June 6th –8th 2001 in Vladivostok.**

Further courses are planned.

Training grants

In 2002 ESPN gave 4 training grants. For those who want to apply for 2003 please get your application forms from the ESPN secretariat.

Congresses:

ESPN Bilbao 20-23 September 2002.

More information can be obtained through the internet website
<http://www.espn2002.com>

Joint French-German Paediatric Nephrology Meeting in Strasbourg 15th – 17th May 2003

13th IPNA congress in Adelaide 29th August – 2nd September 2004

ESPN Istanbul 2005 (exact date to be given)

The 14th IPNA congress may be held in Europe.

ESPN contacts with EDTA/ERA in Manchester 2002

Rosana Coppo and Jochen Ehrich met with EDTA/ERA Council in January 2002.

Important request

We need your proposals for future congress sites (2006), honorary members for 2002, council members for the term 2003-2005 (replacing Constaninos Stefanidis, Michel Fischbach, Eric Girardin) Please send your proposals to the ESPN Secretariat until 20 July 2002.

The constitution says:

Meetings: The Society shall hold an annual scientific meeting for the presentation and discussion of papers by members and their guests at a time and place to be decided by the Council.

Honorary membership is conferred as an honour on those who have rendered exceptional service to paediatric nephrology or to the Society. Honorary members

shall not be required to pay an annual subscription to the Society. Honorary members may be elected by a majority of at least two thirds of those present at the Annual General Meeting.

The Council of the Society shall consist of the Secretaries, the Treasurer, the President of the Congress, the President-elect of the next Congress and seven councillors; not more than two councillors shall live in any one country. Councillors shall be elected annually by the members to serve for a period of three years, beginning on the day subsequent to the Annual Scientific Meeting at which they were elected. For a period of three years following retirement a former councillor will not be eligible for re-election to Council. A candidate for Council may (with his written consent) be proposed in writing to the Secretary General by any three members not less than two months before the AGM. In the event of more candidates being proposed than are required, election will be by secret ballot of members of the AGM.

Voting in Council and at the AGM shall be by a simple majority of those present except when alteration of the Constitution or dissolution of the Society is concerned when a two thirds majority of those present shall be required. The President of the Congress shall have a casting vote at any meeting. The quorum for a General Meeting shall be fourteen members and the quorum for a Council Meeting shall be four members. In any year when the AGM is held outside Europe (see Appendix i) the election of the Council members, and if necessary of the Secretaries, shall be by postal ballot of all members.

Alterations to the Constitution

- a) Amendments to the Constitution must be proposed in writing to the Secretary by any five members or by the Council not less than six months before the next AGM.
- b) The Secretary shall notify all members of the proposed amendment not less than five months before the next AGM.
- c) Any member may submit written counter-proposals to the Secretary, not less than three months before the next AGM.
- d) The Secretary shall notify all members of any counter-proposal not less than one month before the next AGM.

With best wishes

Yours

Jochen H.H. Ehrich Christer Holmberg

Secretary General Assistant Secretary

Enclosure/attachments (5)

ESPN Membership- Fees: form for money transfer

Member's Address list to be updated (*only sent by e-mail*)

Address list of National Presidents to be updated (*only sent by e-mail*)

New members in 2001

Dr Marina AKSENOVA	Moscow Institute of Paediatrics & Children's Surgery	Nephrology Department, Taldomskaya 2	127412 MOSCOW	RUSSIA
Dr Zelal BIRCAN	Kazim Ozalp Sok	5/9 Suadiye	81070 ISTANBUL	TURKEY
Dr Francesco EMMA	Bambino Gesu Children's Hospital	Nephrology & Dialysis Piazza S. Onofrio 4	00 165 ROME	ITALY
Dr Guido FILLER	University of Ottawa Children's Hospital of Eastern Ontario	401 Smyth Road	ON K1H 8L1 Ottawa	CANADA
Dr Ryszard GREUDA	Children's Memorial Health Institute, Dept Neph & Kidney Transplantation	Al. Dzieci Polskich 20	04-736 WARSAW	POLAND
Dr Enver HASANOGLU	Gazi University Medical Faculty		06500 Besevler /ANKARA	TURKEY
Dr Michael HLADIK	University Hospital , Dept of Paediatrics	TF. 17. Listopadu 1790	70852 OSTRAVA	CZECH REPUBLIC
Dr KONRAD Martin	Kinderklinik Marburg	Duetschhausstr 12	35037 MARBURG	GERMANY
Dr PRIKHODINA Larissa S.	Nephrology Dept, Institute of Pediatrics	Taldomskaya 2	127412 MOSCOW	RUSSIA
Dr RAES Ann	University Hospital	De Pintelaan 185	9000 GENF	BELGIUM
Dr SALEEM Moin	The Bristol Royal Hospital for Children	Children's Renal Unit, Upper Maudlin St	Bristol BS2 8BJ	UK
Dr SZCZEPANSKA Maria	Clinic of Nephro, Endo & Metabolic Diseases of Childhood	Dialysis Division 41 3 Maja 13/15	41-800 ZABRZE	POLAND
Dr SZPRYNGER Krystyna	Clinic of Nephro, Endo & Metabolic Diseases of Childhood	Dialysis Division 41 3 Maja 13/15	41-800 ZABRZE	POLAND
Dr WEBB Nick	Royal Manchester Children's Hospital	Pendlebury	MANCHESTER M27 4HA	UK

Secretary General: [Jochen H.H.Ehrich](#), **Assistant Secretary:** [Christer Holmberg](#), **Treasurer:** [Peter Hoyer](#), **President Elect:** [Juan Rodriguez-Soriano](#), **Council Members:** [Michel Fischbach](#), [Eric Girardin](#), [Giulianan Lama](#), [Sue Rigden](#), [Constantinos Stefanidis](#), [Aleksandra Zurowsk](#)