Words from Pierre Cochat

Dear IPNA Members,

This Newsletter is issued at the time of the disaster that struck Nepal, the current death toll after earthquake exceeds 8,000, including many children. We have been in touch with ISN and NGOs, and the most critical need was psychological assistance, which is sadly the most difficult to provide…

The last IPNA Council meeting was held in New Delhi, December 3-4, 2014, just before the AsPNA meeting chaired by Arvind Bagga, who made it highly successful.

The most important discussions and decisions were the following:

**IPNA meetings**
- The next IPNA Congress (President: Vera Koch, Brazil) will be held in Iguacu September 20-24, 2016, at the border of Brazil, Argentina and Paraguay, deep in the heart of South America. The preparation is running quite well and we expect having most of you and all those you will stimulate! Independent from the outstanding scientific program in progress (chair: Arvind Bagga, India), Iguacu is a unique place well connected to all major cities in South America.
- Six cities presented their bid for IPNA meeting in 2019, and finally Istanbul was selected to host the congress (President: Rezan Topaloglu, Turkey).
- The 13th International Workshop on Developmental Nephrology will be held in Snowbird (Utah, USA), July 12-16, chaired by Carl Bates. Please visit [http://iwdn.ipna-online.org/](http://iwdn.ipna-online.org/)

**Education**
- In addition to teaching courses supported by IPNA and locally organized, IPNA will collaborate with Regional Societies to introduce teaching courses in very limited resource countries, with no identified pediatric nephrologists, in order to give priority to the care of children with renal diseases all over the world. Francesco Emma (Italy) is in charge of the program.
- IPNA will support all Regional Societies, with an annual grant ranging from $0 to $10,000 according to adequate projects and requirements. Each Society will have to provide annual reports on how the grant is spent.
- The World Kidney Day is an ISN initiative ([www.worldkidneyday.org/](http://www.worldkidneyday.org/)) but IPNA will provide $5,000 each year to one center in developing countries. There will be a selection process for applications, and the report will be published in *IPNA Currents*.
- The Junior Class program (advanced intensive courses, 3 sessions over 3 years, with final IPNA certification) is running well but is currently limited to Europe, so we encourage all other Regional Societies to create similar programs. Rezan Topaloglu (Turkey) is in charge of the program. (…)

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• The fellowship program (6 to 12 month-training period) has served so far more than 200 fellows. This program is very productive and we encourage all of you to stimulate young colleagues to apply. Brad Warady (USA) is in charge of the program.
• The material used in all IPNA educational activities will be available on www.ipna-online.org
• Patient education has become a priority and extensive efforts are required to provide either documents or links to inform patients and their family (chair: Sushmita Banerjee, India). Of course, we are interested by getting any documents you may have in as many languages as possible.
• Most of us are aware of the 0by25 initiative from ISN (http://www.0by25.org/) and IPNA has brought its partnership to this program dealing with a major issue for all children in the world: zero preventable deaths from AKI by 2025!
• IPNA also contributes to the development of Sister Centers together with ISN and SKCF (http://www.skcf.net/).

IPNA worldwide networking
• An IPNA registry activity will start soon, involving all countries, in order to provide major data on CKD, RRT, etc. This project is chaired by Franz Schaefer (Germany) and will certainly benefit to all members through its publication plan.
• In parallel, the Committee for Best Practice and Standards (chair: Detlef Böckenhauer, UK) will also provide guidelines and recommendations through IPNA publications

Other IPNA business
• Both the secretary general and the treasurer will be replaced in 2019, and the Nominating Committee will start preparing this selection.
• The current IPNA Constitution was written in 2002, with an amendment in 2007. The council is currently updating and adapting the text, and a new version will be proposed before the IPNA meeting in Iguazu.
• Three honorary members have been selected for 2015: Robert Chevalier (USA), Otto Mehls (Germany), and Patrick Niaudet (France), in recognition of all what they did for IPNA and for children with renal diseases.

Thank you for keeping in touch through the IPNA newsletter!

And don’t hesitate to send us opinions and suggestions:
contact-IPNA@europa-organisation.com

All my best,

Pierre Cochat, IPNA Secretary General

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IPNA Currents continues its Pediatric Nephrology World Tour with the United Kingdom.

Dr. Christopher Reid, head of service for children's nephrology and urology at Evelina London, honored us with his report.

An Overview of Pediatric Nephrology in the UK
By Christopher Reid, UK

The UK National Health Service
The NHS was launched in 1948, based on the principle that healthcare should be available to all, regardless of wealth. For most of the 64 million population of the UK, the NHS remains free at the point of use. The NHS employs more than 1.6 million people, putting it in the top five of the world’s largest workforces. Funding for the NHS comes directly from taxation.

History of the development of Paediatric Nephrology in the UK
The specialty of paediatric nephrology started in 1950 with the development of the first regional referral unit for children with renal disease in Glasgow, under the leadership of Dr (later Professor) Gavin Arneil. Over the next 20 years individuals started to develop both research and clinical departments in the field of paediatric nephrology. In 1972 at the 6th meeting of the European Society for Paediatric Nephrology, Gavin Arneil initiated a meeting with 7 very well-known colleagues - Martin Barratt, Stewart Cameron, Ian Houston, Roy Meadow, Martin Moncrieff, Michael Winterborn and Richard White - The “Dublin eight”. At this meeting they decided to form an association of professionals interested in renal disease in children. The first meeting was held in London in 1973. There were 15 founder members of the British Association for Paediatric Nephrology (BAPN) of whom 10 were present at the inaugural meeting. Since those early days paediatric nephrology in the UK has grown enormously. There are now 13 units providing tertiary care including haemodialysis and peritoneal dialysis, 10 of which also provide renal transplantation. Ten of these units are in England with one each in Scotland, Wales and Northern Ireland each covering a regional population between approximately 2-12 million total populations. There are 70 consultant paediatric nephrologists in the UK and in (…)
addition a growing number of Paediatricians with a Special Interest in Nephrology (SPINs) who have undergone nephrology modules in their training, who are based in the district hospitals and who work with the specialist teams to provide care for children as close to home as possible through developing regional networks. Each of the tertiary centres is staffed with specialist nurses, dieticians, psychologists, social workers, play specialists, pharmacists and many others who are all integral to providing care for children with renal disease.

The BAPN has also developed significantly. There are now sub-committees for clinical services, research, training, standards & guidelines and registry & audit. The BAPN has always had a strong association with the adult nephrology community in the UK and in 2010 the BAPN became a Division of the UK Renal Association. The President of the BAPN is one of the Trustees of the Renal Association and we have representation on the Renal Association committees. This has strengthened the infrastructure of the BAPN and helps with all aspects of our work. The British Kidney Patient Association has also had an important role in the development of many Paediatric Nephrology centres in the UK through their charitable fundraising activities which have supported both clinical services and the families directly.

**Paediatric Nephrology Training in UK**

Paediatric trainees enter sub-speciality training in Paediatric Nephrology through a National recruitment programme (NTN GRID) following completion of Level 2 training in Paediatrics. Trainees can also enter NTN GRID through an academic route if they are eligible to undertake an Academic Clinical Lectureship programme. Successful candidates complete a minimum of 2 years within paediatric nephrology NTN GRID posts and are then eligible to enter the General Medical Council Specialist Register with a Certificate of Completion of Training (CCT) in paediatrics and paediatric nephrology.

The College Specialist Advisory Committee (CSAC) for Paediatric Nephrology, appointed by the Royal College of Paediatrics and Child Health, is responsible for and oversees paediatric nephrology training in the UK. The number of training posts available is linked to workforce planning and there are currently 11 trainees in NTN GRID posts across 9 available training centres, with 4 further trainees due to commence in September 2015. The curriculum is topic based and trainees are able to link work based assessments (eg directly observed practical procedures, case-based discussions, multi-source peer feedback) with the curriculum using an e-portfolio. Trainees meet twice each year for a 2 day training meeting and are formally appraised yearly at this meeting by the CSAC Chair and Training Advisors. Trainee meetings are vibrant and well attended. They often cover a specific topic, such as transplantation or dialysis, drawing on local expertise of the host centre. They also allow trainees to compare training, share interesting cases and present research. In their penultimate year of training, trainees complete START (Speciality Trainee Assessment of Readiness for Tenure). START is an ‘OSCE styled’ formative assessment based upon 12 unseen scenarios which cover the domains of the GMC’s good clinical practice. Paediatric Nephrology in the UK continues to have a strong and growing academic basis. Trainees have the opportunity to undertake formal research training fellowships and all trainees are encouraged to participate in officially recognised and supported studies.

**The UK Renal Registry**

The UKRR, established in 1995, is part of the UK Renal Association, and has the chief aim of facilitating improvements in the care of patients with kidney disease by audit against national standards, benchmarking, and supporting research, innovation and quality improvement. It is funded by NHS Renal Service Commissioners, through an annual capitation fee paid by each of the UK renal centres, paediatric and adult, submitting data.

In the latest annual report of the UKRR in 2013, a total of 891 children and young people less than 18 years of age with established renal failure (ERF) were receiving treatment in the UK. At the census date, 80.2% had a functioning transplant, 11.7% were receiving haemodialysis and 8.1% were receiving peritoneal dialysis. In patients aged <16 years, the prevalence and incidence of ERF was 58.2 and 9.3 per million age related population, respectively. All data was collected electronically by digital transfer from the 13 Paediatric centres to UKRR.

**References**

1. A detailed record of the first 30 years of the BAPN was written by RHR White and is available on the BAPN website [www.bapn.org](http://www.bapn.org).
4. [http://www.britishkidney-pa.co.uk](http://www.britishkidney-pa.co.uk/).
6. [https://www.renareg.org](https://www.renareg.org/).
A vigorous boost to the development of pediatric chronic dialysis particularly peritoneal dialysis in China

2015 Shanghai Pediatric Dialysis Update Course & the 4th Ministry of Health Training Course for Pediatric Peritoneal Dialysis SOP
by Qian Shen, Children’s Hospital of Fudan University, China

109 medical personnel, including 69 doctors and 40 nurses from over 50 hospitals in 24 provinces, autonomous regions and municipalities of China joined the Shanghai Pediatric Dialysis Update Course & the 4th Ministry of Health Training Course for Pediatric Peritoneal Dialysis Standard Operating Procedure (SOP) which was hosted by Prof. XU Hong in Children’s Hospital of Fudan University, Shanghai, China from April 9th till 12th.

As the “Pediatric Peritoneal Dialysis Training and Demonstration Unit” certificated by Ministry of Health of the People's Republic of China, this was the fourth time for Children’s Hospital of Fudan University to organize the national training course on pediatric dialysis, especially on peritoneal dialysis, in order to further strengthen and standardize the management and quality control of chronic renal failure in children, as well as effectively improve the life quality of children with chronic renal failure in China through better medical care quality. The contents were rich and practical, from pharmacokinetics to SOP and continuous quality improvement in dialysis, from prescription of dialysis to dialysis related complication management, from catheter insertion to nursing training. During the training course, the arrangement for visiting and practicing on dialysis brought the participants to further understand of the related operating and technology. All the participants gave the feedback that they had deeper understanding of chronic dialysis for children through heated discussions with experts and peers.

We firmly believed that they could enjoy the great benefit in their future work and better boost the development and improvement of nationwide pediatric dialysis technology, thus further improve the life quality of children with renal failure in China. During the training course, “LifeSpring to the Country” Project sponsored by Shanghai LifeSpring Kidney Foundation was officially launched simultaneously. Through the establishment of childhood chronic renal failure dual referral mechanism and the development of national cooperation network, further promoting the rapid development of pediatric chronic dialysis and charities for children with chronic diseases in China. On one hand, establishing the cooperation network and launching training projects and extensive communication; on the other hand, successively establishing the LifeSpring dialysis sub-centers all over the country, especially the less developed areas. During this course, 4 pediatric dialysis bases became the first group of sub-centers in this project, including Children’s Hospital of Chongqing Medical University, Children’s Hospital of Zhengzhou, Children’s Hospital of Shanxi, Wuhan Medical & Health Center for Women and Children.
Obituary of PAUL ROY 1939-2014
By Steve Alexander and Elisabeth Hodson

At a time when specialist paediatrics barely existed in Australia, and overcoming strong opposition from the medical establishment and government, Professor Paul Roy founded the first children's renal unit in 1978, at the Royal Alexandra Hospital for Children (RAHC) in Camperdown. The unit relocated to the Children's Hospital at Westmead in 1995.

Today the renal unit is a world class facility, which provides a full range of services for children with diseases of the kidney and urinary tract, including kidney dialysis treatment and kidney transplantation. The unit has supervised kidney transplants in over 150 children, and each year its Renal Treatment Centre provides over 1500 dialysis treatments. It is active in clinical and basic research, and has trained paediatric nephrologists who now practise in Australia and around the world.

Born in Rockdale on April 15, 1939, Paul Roy graduated from the University of Sydney as a Bachelor of Medicine, Bachelor of Surgery and Bachelor of Medical Science. In 1970, he accepted a scholarship from the university's Postgraduate Foundation of Medicine.

He studied as the Overseas Research Fellow at the University of Minnesota, which was one of the world's leading paediatric nephrology facilities at the time. There, he trained in all aspects of kidney disease in children, including dialysis and transplantation. It was also here that he started his research career.

Returning to Australia in 1972, Roy was appointed Staff Physician in Nephrology at RAHC. At this time, renal failure in infancy and childhood meant nothing more than a progressive and unrelenting fatal illness.

Early efforts to establish a renal unit for children were met with significant resistance, and funding was difficult to find. Undaunted and committed to the development of paediatric kidney disease treatment in Australia, Roy established a basic unit on a shoestring budget, with a handful of nursing staff. Gradually, as funding slowly became available, dietitians, social workers and other medical staff were appointed to assist with development of the unit. Margaret English, and then Jill Farquhar were his two principal nurses, and both were instrumental in the successful establishment of the unit.

With the support of doctors John Sands, James Johnson, David Tiller, Dennis Arnold, Ross Shiel and John Horvath, haemodialysis for children was commenced by late 1973. The first successful kidney transplant on a child was performed at the Royal Prince Alfred Hospital (RPAH) in January 1975. By 1978, full facilities and equipment for dialysis were available at RAHC.

While at RAHC Professor Roy was Head of the Department of Medicine, and heavily involved in the Nurses' Education, Peer Review, the Quality Assurance Committee and the Medical Advisory Committee among various other appointments. Following the Children's Hospital's move to Westmead, Roy was appointed Director of Paediatric Services for Central Sydney Area Health Service (now Sydney Local Health District), and was based at RPAH. He remained a member of the Department of Nephrology at the Children's Hospital at Westmead, both as a clinician and as the Principal Investigator of clinical studies of urinary tract infection, and of kidney and heart health in Aboriginal children, both funded by National Health and Medical Research Council.

Paul Roy had a deep commitment to research. He published over 100 articles and papers on paediatric nephrology and other associated areas, including articles in The Lancet, The New England Journal of Medicine and The Medical Journal of Australia. He undertook large programs to study blood pressure levels in children, including a survey of 10,000 children in 1980, providing data that is still used today.

In collaboration with Dr John Knight, he established the kidney research unit at the RAHC in the 1980s. This became the Centre of Kidney Research at the Children's Hospital at Westmead, which is today a world renowned centre.

In the late 1980s, Roy formed what became a lifetime relationship with the Manildra Group chief, Dick Honan. Honan shared Roy's pioneering spirit and provided significant support and funding to his renal unit over many years.

A dedicated teacher and mentor, Roy was appointed as Clinical Associate Professor in Paediatrics at the University of Sydney in 1993. He lectured regularly in the United States of America, and throughout Europe and Asia.

He received several awards and honours through his career, including the Royal Australasian College of Physicians Medal. In 2005, Roy was admitted to the degree of Doctor of Medicine by the University of Sydney, the highest degree offered by the medical faculty, for lifetime contribution to research.

Since his retirement, he remained a senior examiner with the Australian Medical Council and continued teaching at Sydney University, until ill health in 2012 prevented him from continuing with these activities. While he primarily focused on medicine, Roy had wide-ranging interests in all aspects of science and the humanities, gardening, sports and, when younger, loved long-distance running and marathons.

Roy was a direct descendant of First Fleet convict John Nichols, whose 1784 trial was the first trial by jury in London. John Nichols prospered, becoming a magistrate and landowner.

Paul Roy died on December 10, in Sydney. The cause was complications arising from injuries sustained from a fall while travelling in Europe. He is survived by his wife, Joyce, his son, Simon, daughter, Jane and three grandsons, Nicholas, Maximilian and Liam.

Joyce says that her husband spent his life committed to improving the lives of children, and that he leaves a profound legacy of professional courage and kindness, that helped create the wonderful tradition of paediatric renal care we all take for granted today.

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**Announcements**

**Save the dates for IPNA 2016!**

**September 20-24, 2016**

As you know Brazil will host the 17th Congress of the International Pediatric Nephrology Association, IPNA 2016, from September 20 to 24, 2016.

The Congress venue will be located in one of the most amazing cities in the country, Foz de Iguacu, world famous for its dramatic waterfalls.

The Scientific Committee is developing a program that meets the needs of participants from across the world. The Congress will be preceded by concurrent meetings on Critical care nephrology, Nephropathology, Rare diseases and Research methodology. These sessions are intended to update current knowledge and skills in specific areas and should be extremely useful for fellows-in-training and practicing pediatric nephrologists.

Practical pediatric nephrology will be emphasized through 12 early morning master classes. It will also be our endeavor to provide current knowledge and research directions through state of art lectures, plenary sessions and 30 concurrent symposia during the three days of the Congress. There will be many opportunities for free papers, either as oral communications or poster presentations.

Mark you calendar and come to Brazil to share with us the very best in pediatric nephrology, immersed in the atmosphere of one of the most beautiful and welcoming countries of the world!

**IPNA 2016 Organizing and Scientific Committee**

**IPNA treasurer named as the Henry L. Barnett Award Recipient by the AAP**

Section on Nephrology

Dr. Bradley A. Warady, IPNA treasurer, has been recently honored by the American Academy of Pediatrics, Section on Nephrology, for his remarkable career dedicated to the advancement of clinical care and education in the field of pediatric nephrology.

Please join us in congratulating Dr. Warady!

**Survey on Pediatric Nephrology Survey**

The Renal Research Institute (RRI) is conducting an international survey on pediatric nephrology training across the world.

We thank you in advance for your participation in the online survey that will only take 5 minutes to complete:

https://unc.az1.qualtrics.com/SE/?SID=SV_6QhbU1HN07Z1qD3

Results will be published in a forthcoming issue of IPNA Currents

**Survey on Renal Replacement Therapy**

The European Society for Paediatric Nephrology (ESPN) would like to ask your opinion regarding the controversial issues of Renal Replacement Therapy (RRT) in children with a severe mental disability. The online survey will take no longer than 5 to 10 minutes from your time.

https://www.surveymonkey.com/s/LFBB3ZY

Be assured that all answers you provide will be kept in the strictest confidentiality. The results will be discussed at the plenary session during the upcoming ESPN congress in Brussels, September 5.

You are invited to share his survey with the other members of your multidisciplinary team.

ESPN thanks you very much for you input.
Second IPNA - ESPN Master for Junior Classes
Leuven – Belgium, September 1st-2nd, 2015

This new IPNA-ESPN educational program started last year in Porto and is specially dedicated to Paediatric residents, Paediatrician’s with special interest in Paediatric Nephrology, fellows in Paediatric Nephrology and young Paediatric Nephrologists. The whole program includes three meetings in three consecutive years, the full attendance will allow the achievement of the IPNA-ESPN Master. A CME certificate will be distributed after each meeting, also for the ones who will not be able to accomplish the whole cycle.

The Scientific Program is already available online, please visit the 48th ESPN Annual Meeting website (http://www.espn-2015.org)

This is a new educational offer, do not miss it!
We will accept up to 50 applications.

Applications
All applications will be evaluated by receiving Short CV of the candidates (birthdate mandatory) to the below email addresses:

• Rezan Topaloglu - Chair, IPNA Junior Class Committee (rezantopaloglu@hacettepe.edu.tr)
• Ana Teixeira - Junior Represent for ESPN (anafteixeira@gmail.com)

Deadline: July 1st, 2015

Calendar
2015

May 28-31 52nd ERA-EDTA Congress London, United Kingdom
June 11 46th annual meeting of EWOPA Lille, FRANCE
June 18 - 20 50th Annual Meeting of the Japanese Society for Pediatric Nephrology Kobe, Japan
July 12-16 13th International Workshop on Developmental Nephrology (IWDN) Snowbird, UT, USA
July 16-18 8th International Conference on PCRRT London, United Kingdom
August 19-21 First congress of renal transplantation and dialysis in children in Iran Tehran, Iran
September 3-5 48th ESPN Annual Meeting Brussels, Belgium
September 17-20 EAP 2015 Oslo, Norway
October 17-20 13th Congress of the International Society for Organ Donation and Procurement Seoul, Korea
November 3-5 ASN Kidney Week 2015 San Diego, CA, USA
November 11-13 2015 Transplantation Science Symposium (TSS 2015) Lorne, Australia
Pediatric Nephrology

- New, expanded and updated edition of the standard reference in the field
- Covers all clinically relevant aspects of congenital and acquired pediatric kidney diseases
- Documents up-to-date treatment guidelines based on the latest research findings
- Includes many clinical algorithms to improve understanding of children’s kidney disease and guide appropriate treatment

This new edition of Pediatric Nephrology, now in three volumes, has been extensively updated and also contains much new material. Its organization flows logically from renal physiology to clinical evaluation. Discussion of the development of kidney structure and function is followed by sections on basic and translational research and on clinical methods, including laboratory tests, diagnostic imaging, and renal pathology. Comprehensive chapters then cover each of the childhood kidney diseases, grouped according to major disease categories. All of these chapters make new genetic information easily understandable for the practitioner and use many algorithms and diagrams to describe appropriate clinical evaluation of symptoms, differential diagnosis, specific diagnostics, and currently available therapies.

Over the course of the previous six editions, Pediatric Nephrology has become the standard reference text for students, trainees, and practicing physicians (pediatricians, nephrologists, internists, and urologists), subspecialists, and allied health professionals seeking information about children’s kidney diseases. It is global in perspective, reflecting the fact that the international group of editors are all acknowledged world experts. This book serves as a superb reference and is an invaluable asset during clinical encounters with children having all forms of kidney disease.