Dear IPNA members,

First of all, let me wish you all a healthy and happy 2016, bringing peace and respect all over the world!

This year will be particularly exciting for IPNA not only because IPNA will hold its 17th Congress which promises to present an outstanding programme in Iguazu, Brazil, but also because 2016 will be a dynamic year announcing a new era:

> On-going actions from all IPNA committees according to our strategic plan
> A revamped website will be launched by the summer 2016! User friendly and focusing on patient education worldwide, it will present a modern image of IPNA and encourage interactivity amongst the membership thanks to social networks (already active, see on last page!);
> A new membership system now based with EUROPA ORGANISATION in France will allow a smoother association management;
> And the introduction of a new Award Nomination - the Lifetime Achievement Award, to be presented during the next Congress, will recognize individuals who have dedicated their life to promote pediatric nephrology at large.

Yet among all this excitement, I would like to inform you that the vote for the Revision of the Constitution did not obtain the required quorum of 800+ votes despite several reminders!

As at today, only 344 votes were collected, while the article 13.1 of the IPNA Constitution « requires a two-third majority of members attending or by electronic ballot ». Consequently, it is now your last chance to express your opinion and cast your vote for the revision of the IPNA Constitution!

**ULTIMATE DEADLINE January 31st, 2016!**
Please vote here: [https://www.ipna-online.org/ipna-electronic-vote-revision-of-the-constitution/](https://www.ipna-online.org/ipna-electronic-vote-revision-of-the-constitution/)

But I also would like to remind you some other issues which are very important for the life of our Association:
- The IPNA World Kidney Day
- The contest for an IPNA Tag Line
- The Call for Abstracts for the next congress in Iguazu
- The Award Nominations

You can find all those links in this newsletter, so do not hesitate to submit your applications or submissions. And needless to say that your suggestions are always welcome!

Looking forward to hearing from you!

Warm regards
Pierre Cochat
IPNA Supports the World Kidney Day!

IPNA wants to promote education and screening in children with kidney diseases all over the world. Kidney Day is a wonderful opportunity to achieve this goal.

Each year, IPNA would like to encourage such an action by providing USD 5,000 to one pediatric nephrology center from a developing country throughout the World.

Projects including:

- Specific actions (global Kidney Day program, physicians, paramedical staff, advertisement, venues, etc.)
- Screening program (growth charts, BMI, urine dipstick, blood pressure, etc.)
- Educational program (teaching course to physicians and paramedical staff, school program, etc.)
- Educational material (printing of posters and booklets, USB, movies, etc.)
- Adequate medical device (fathom, weighing machine, dipstick, blood pressure device, etc.)
- Etc.

DEADLINE FOR SUBMISSIONS: FEBRUARY 1st, 2016

Click here to download the flyer and the Application Form:
http://www.ipna-online.org/2015/12/ipna-supports-the-world-kidney-day/

Extended deadline for the IPNA Tagline Contest!

It is still time to take part in the IPNA Tag Line contest and win a FREE REGISTRATION to the IPNA 2016 Congress!

IPNA invites you to send your suggestions for its new tagline. The winner will get a free registration to the IPNA 2016 Congress to be held in Iguazu Brazil, from September 20 to 24, 2016.

The tagline should be a key sentence that encapsulates in a few words the purpose of the association, like a catchy mission statement!

Participants must be IPNA 2015 active members

• Only one suggestion per participant will be considered
• Suggestions must be submitted before **January 31st 2016**

Some examples:

- ISN – Advancing Nephrology around the World
- ERA-EDTA – Leading European Nephrology

So be inspired and click here to submit:
http://www.ipna-online.org/ipna-tagline-contest/
Issues and challenges of Pediatrics nephrology in Africa

Amal Bourquia - Casablanca - Morocco
IPNA councillor, Chair of French-Speaking African Pediatric Nephrology Network

I – Introduction

It goes without saying that all African countries are either developing or poor with major socio-economic issues associated with limited financial resources, high illiteracy rates, health insurance problems and lack in information and data processing establishments which urge families to turn their back to regular medical check and resort to alternative solutions. Many African children with kidney diseases do not receive adequate medical care due to the critical shortage of paediatric nephrologists (PNs) and resources in numerous African countries. In Egypt for instance, there is one paediatric nephrologist for 500,000 children, one for 4.5 million children in Nigeria and one for each million in Morocco. Due to the limited resources in these areas, most hospitals are not equipped to perform haemodialysis or peritoneal dialysis. For better quality of healthcare for African children with kidney disease, it is essential to promote paediatric nephrology (PN) in Africa which involves the creation of PN units managed by veteran, experienced doctors providing children with access to high-quality medical support at the hands of PN specialists.

Social and economic consequences, the medical problem of treating chronic renal failure is more acute in Africa as the rise of alternative treatments is a problem that remains closely linked to the socioeconomic conditions and health strategies of each country. As such, and given the ever-changing, medical needs of the world, there has been expansion of services to include, in addition to periodic haemodialysis, kidney transplantation, which has emerged as an obvious complementary solution in some countries like South Africa, Tunisia, Morocco and Algeria.

II - Epidemiological data

There is no data on the true rate or the prevalence of kidney disease (KD) in African children. However, it can be argued that in these countries the percentage of KD is underestimated and may be higher than it is in developed countries.

Screening and early diagnosis by prenatal ultrasound and basic screening, including urine dipsticks and measurement of blood pressure are usually not performed, which results in a very late diagnosis of kidney disease in children.

What are the causes of KD in Africa?
The lack of national databases makes it difficult to give accurate statistics. However, some estimates based on single centre studies claim that chronic glomerulonephritis (CGN) is the leading cause of CKD (30-60%) in many countries, which is more common in Africa and appears to be more severe and deadly than in the West. Moreover, the kidney problem represents 2-3% of medical admissions in tropical countries, the majority being of GN. The usual form is the nephrotic syndrome, which usually appears between the age of 5 and 8 years. But, starting from 10 years old, the etiology of KD often remains undetermined given that countless children arrive at an advanced stage of renal failure. The average of children with CKD who receive treatment is drastically low since more than 90% of diagnosed patients from developed countries cannot afford the cost of renal replacement therapy (RRT).

III - State support of the CKD

A- What is the status of support for CKD?
Huge disparities exist and continue to exist between patients according to their socio-economic level and weather they enjoy health care or not. Even those with health coverage receive low-quality, incomplete treatment that does not rise to the required standards: insufficient number of dialysis sessions, no support for drugs or balance sheets and especially the non-inclusion of kidney transplant in health insurance programmes.

Many problems limit access to transplantation, including insufficient funds. A national reflection of each country, with the involvement of all stakeholders is needed to optimize spending and draw as strategy for the future where kidney transplant would be seen as a necessary alternative. The results of the treatment of children with CKD are dependent on the local economy and the availability of healthcare resources. Given that renal replacement therapy (RRT) is difficult in developing countries and access to this therapy is blocked by financial problems and limited resources. This is inherent:

- The national income is insufficient to cover basic needs: low GDP and low health expenditure.
- Health officials have little or no awareness of this problem
- Is nota priority for the planners of health care.
- Some African countries are making efforts to establish programs.
- Specialized infrastructure deficits in facilities and human resources: there are few hospitals dedicated
to children, and few or no units for the treatment of kidney disease in children.
• Shortage of paediatricians and paediatric nephrologists.
• Children who live far from big cities do not have access to a nephrology care.

**Prognosis of CKD**
This situation gives KD a poor prognosis generated by delayed diagnosis, the lack of use of conservative measures, treatments which are often inaccessible and expensive. The referral of patients at later stages: 25-65% in the terminal stage of KD is very troublesome. The delay in the management of patients generates medical obstacles. In this context, 75-85% of children with chronic KD are denied their rights to RRT. While haemodialysis is possible, it prolongs life in poor conditions with frequent infections, malnutrition, iron deficiency, complications with anaemia, short stature, bone involvement and frequent hospitalization causing heightened damages. All these difficulties result in school failure, depression as well as frequent major disabilities.

**B- Prognosis of CKD**
Factors contributing to poor prognosis of CKD include:

- Delayed diagnosis because of ignorance, poverty and remoteness.
- The lack of use of conservative measures. Adjuvant treatment often unavailable and expensive.
- The reference of patients at later stages: 25-65% in the terminal stage of CKD with many complications.
- The support or lack retardation generates medical problems and facts in this context, 75-85% of children with ESRD are denied their right to RRT.

When hemodialysis is possible it prolongs life, but other problems persist, including:

- Frequency of infections, malnutrition, iron deficiency, vitamin D deficiency.
- Inadequate Support (anemia, short stature, bone involvement).
- Frequent hospitalization causing increased expenses.
- School failure, depression, major handicap.
- Poor compliance sometimes leading to discontinuation of treatment.
- Mortality is high and the survival rate is low. It runs very difficult for the child and family, often ends in death and generates negative psychological effects.

**C- What to do?**
CKD can prove to be a devastating problem not only on the medical level, but also on the economic and social levels for patients and their families as well. The comprehensive vision, organized and pragmatic CKD IRC can have positive effects as the following:

- Strengthening and extension of dialysis.
- Development of transplant programs.
- Prevention and screening.

**Paediatric dialysis units**
They already exist in North and South Africa: Morocco, Tunisia, Algeria, Libya, Egypt, Sudan, Kenya and South Africa, while they have only just been introduced to Ivory Coast and Benin. These programs are found only in university hospitals and the number of paediatric nephrologists remains very insufficient. Children with KD are therefore taken care of in general paediatric units. When RRT is required, a small proportion is supported (including adolescents), in adult nephrology organizations, knowing that the majority of these countries are equipped with few dialysis units. We are transmitting an overview of the situation, which is experienced by pioneers of this major in their country.

Importance of developing Pediatric Nephrology (PN) units that have the essential role:

**1-Optimizing the quality of care**
- It allows early identification of the CKD before the complications that result in additional costs to ensure proper monitoring and help families.
- Ensure effective HD to all patients: 3 sessions / week, support for preclinical explorations and accessibility to essential drugs on dialysis.
- Adapt to our therapeutic context and work to reduce the cost of dialysis: cancel taxes on equipment, consumables, and dialysis medications…

**2- Development of living donor transplantation**
Over the years, renal transplantation has emerged as the most effective treatment in case of irreversible deterioration of renal function. It not only saves and prolongs life, but it also improves the quality of the latter. Transplantation is an optional treatment for children with CKD in countries where the treatment of ESRD is available. It is therefore essential to convince officials that a transplant is much cheaper that prolonged dialysis, in addition to the huge advantage in terms of quality of life. The rise of kidney transplant has raised many ethical issues making it appear complex and ambivalent in its philosophical basis, social, legal and medical practice.
IV - Kidney transplantation

A- Transplantation a social issue
Organ transplantation is surrounded by a set of cultural representations around the perception of the body, donation and death. Also, is it necessary that citizens be not excluded from the debate, which should not be confiscated by experts? In an attempt to assess the perception of the donation and transplantation of organs by the Moroccan population, we conducted an opinion poll. The main results of this survey show an overall positive attitude towards donation and organ transplantation despite the lack of knowledge of the subject. The survey reveals lack of information on the practice of kidney transplantation in Morocco, ignorance of the techniques used and the types of donors, the absence of any information on legislation, the first of the rare topic in the discussions, erroneous beliefs as well as fears of possible health insecurity. Dissemination of easy-to-understand and accessible information, as well as the involvement of the African population in general and the medical community in particular is becoming a pressing need. Religious denominations now agree not to oppose donation and removal of organs. Renal transplant has made tremendous progress in recent years. In Africa, we have to engage in dialogue between religious, medical professionals, managers and all social actors to jointly explore attitudes to adopt.

B-Ethics and gift
The answers to the different ethical issues raised by the kidney transplant, which may vary depending on the companies involved to take account of a given society, its rules and its feelings. Which makes the ethical issue an extremely broad one.

1- Living Donor
- Consent and freedom to give
Consent must be expressed freely and without influence or pressure. The practitioner must be vigilant about possible constraints and surrounding pressures. Consent is informed when the subject has received all the necessary information to understand the issues of the gift. Free and informed consent is an ethical principle, which implies a duty of information to the donor who must be aware of all the facts before deciding to donate.

- Right to dispose of one’s body
Legal measures governing the transplant from living donors considerably limit the freedom to dispose of one’s body, since, under the law, the gift may be granted only for the benefit of specific individuals. The donor can freely dispose of his body. These laws are made to counter the financial benefits. Thus, the kidney donation was initially, by means of family solidarity, a private matter, which became a public action protected by law against any commercial transaction.

- Psyche and renal transplant
The donation from a living related donor can cause real psychological and relational changes. The donor can live in great anxiety before the surgery because of the risks involved and declaring depression with the feeling of losing a part of one’s. It is important not to forget the disadvantage of the scar, especially among women in our societies.

- Living donor, a social choice
The use of living donors has great disparity between countries. The results with the grafts from living donors are higher than those of the original cadaveric grafts, both for patient survival than those plugins. The living donor can become the choice of our African countries need to be supported by our population.

2- Brain-dead donor
Regarding the brain-dead donor, it is important to consider the beliefs and the cultural and social diversity of individuals. Respect for the remains is a deeply rooted feeling in every culture. The apprehension of what is brain death is a social problem that can delay or even prevent the development of transplantation from deceased subjects in our countries. This decision is even more difficult to take since maintaining artificial organ function does not encourage the acceptance of death.

- The provisions of the law
In all societies, the legislator has always tried to establish a protective framework for the human person and avoid slippage. The dissemination of simple information to the public could help to increase acceptance of the idea of organ donation.

3. Deny commercial donation
The human body is priceless and cannot be subject to financial transactions. A free trade in human body parts would be degrading and morally indefensible. The WHO recommends that the human body and its parts should not at any time be subject to commercial transactions. The delay in the development of this therapy is that our fellow citizens with renal impairment keep trying to look for solutions elsewhere, even in the organ trade. This activity puts doctors before an ethical problem.

V - Preventive measures
It is important to work urgently to reduce this burden:
- Screening in primary health care to reduce the incidence of CKD; early treatment of infectious diseases and fight against tropical diseases and
healers.
- Development of simple preventive measures: use of the urine test strip, BP measurement.
- Treatment of escalators CKD hypertension, proteinuria, other factors (anaemia, hypoalbuminemia.)

A-Awareness and practitioners training
- Ongoing training of pediatricians and general practitioners in PN and their inclusion in these actions (early diagnosis of UTI, screening for congenital malformations and uropathies). Training meetings: Identify specific problems and initiate appropriate strategies.
- Develop cooperation between different specialists involved in the care of the CKD.
- Initiate epidemiological research projects in pediatric kidney disease for strategies adapted to African countries and to encourage international cooperation.

B- Awareness of public authorities
- Departments to address the socio-economic problems and appropriate strategies.
- Collaboration with existing associations, media.
- Assess the distribution of resources between regions and between the different modalities of treatment.
- Monitor the development of CKD treated and forecast needs.
- Adequate information of the population to improve the problems associated with delayed diagnosis, compliance, distance and cultural habits.
- Ethical concerns: unequal access, depending on the social level.

For reflection!
This affection boosts troubles for both patients and professionals: parents with children diagnosed with KD confer on this problem a powerful emotional charge. Health policies on the other hand, are often in struggle with our moral and cultural references. In humanistic terms: children affected by renal diseases are victims of the lack of PN units; and since children with kidney disease represent a minority in our society, they are neglected; which is the way we treat our minorities.

Issues unique to Francophone countries of Africa
Given the large size of the African continent, the distance is a challenge, but another significant challenge is communication. Two main languages are in use across the continent, English and French, in addition to several local dialects. This is a challenge not only for cooperation but also for education and training, especially in poor areas.

The situation of PN in French speaking African countries is devastating for PN development. The socio-economic climate of these countries is the main cause behind this since most French-speaking African countries are situated in sub-Saharan Africa, which is known for widespread poverty, limited financial resources and immense medical problems. It requires, therefore, an efficient strategy to come up with the most practical mechanism of cooperation and collaboration between African countries and IPNA.

Networking to facilitate cooperation
Formation of a network of PNs in African French-speaking countries is imperative. The meeting of representatives in Casablanca was the foundation of this network. The objectives of this group are to promote exchange of information, discussions of issues particularly by e-mail (conference and group discussion), which is effortless and inexpensive, although many problems related to Internet access has limited its use in some countries. This cooperation could also include financial support, facilitating patients’ movement; the implementation of collaborative work, training courses.... This cooperation could also include the establishment of cooperative work in the form of training sessions, which appears to be a real opportunity to promote a fruitful exchange for those French-speaking specialists. Our network is primarily a motivation for the group and a zone dedicated for research.

One of our targets was the introduction of the French language in IPNA teaching courses. Hence, the first course took place in Casablanca in 2008; afterwards, 5 additional teaching courses were organized in French speaking African countries to boost this discipline in our continent.

For a better understanding to our commitments, we worked on the identification of medical and logistical puzzles in these countries and provided proposals for local and regional collaborations. Similarly, it seemed important to shed the light on diseases prevalent in sub-Saharan countries, such as renal disease in kidney damage in HIV infection, Sickle cell disease, and malaria. Acute renal failure is characterized by a late diagnosis and treatment, the family usually, frequently use the traditional medicine, and the disease leads to major complications. The development of acute peritoneal dialysis and its increased accessibility to a large part of the African paediatric population will help to solve this problem.

The promotion of PN in this region depends on the establishment of a good strategy to find the most effective ways to encourage cooperation. This must be developed both between African countries and abroad, notably IPNA.
Many African children with kidney diseases do not receive adequate medical care due to the critical shortage of paediatric nephrologists (PNs) and resources in numerous African countries....
2015 Brief Reports of Chinese Society of Pediatric Nephrology (CSPN)

By Wang Fang, Qiu Li-Ru, Jiao Li-Ping, Zhang Ai-Hua, Shen Qian, Yi Zhu-Wen from China

The 17th National Congress of Pediatric Nephrology

The 17th National Congress of Pediatric Nephrology was successfully held in Xiamen from September 24 to 26, 2015 by CSPN. It was the first time that National Congress of Pediatric Nephrology was held in conjunction with Annual Congress of Chinese Pediatric Society.

The Congress consisted of five sections. About 100-200 delegates from all parts of China including Hong Kong participated in each section. The section of let you know kidney, contained 6 topics, attracted more general pediatricians. The remaining 4 sections contained 10 lectures with two speakers from other specialties, i.e. pharmacy and pathology, 4 case discussions and 32 oral presentations selected from 326 abstracts submitted online.

First National Congress of Chinese Pediatric Nephrologist Committee

Attended by 127 pediatric nephrologists from 29 cities and provinces of China, the first national congress of pediatric nephrologist committee was held from June 10-13, 2015, in Yichang (Hubei Provinces), a beautiful city by the Yangtze River. The nephrologists are members of the Branch of Pediatricians under the Chinese Medical Doctor Association (CMDA). The meeting was hosted by the Division of Pediatric Immunology and Nephrology, Department of Nephrology, Tongji Hospital affiliated to Tongji Medical College, Huazhong University of Science and Technology.

The theme of the meeting was “Further Study and Identification with the Profession”. Domestically well-known specialists in pediatric nephrology and diseases of immune system and scholars of related interdisciplinary subjects were invited to give lectures on the new advances in child renal immune diseases and some hot topics of the subject. Tens of symposia and case study seminars were held. This conference was aimed at not only improving the clinical skills and research ability of Chinese pediatric nephrologists, but also exploring the best approach to the training of special doctors in child nephrology. In view of the current shortage of pediatricians in China, the attendees, going beyond academic exchanges, also discussed the ways of how to relieve work-related stress and how to enhance their identification with their profession and the sense of pride as pediatricians.

The 5th Chinese Pediatric Blood Purification Forum

The 5th Chinese Pediatric Blood Purification Forum which was organized by the Chinese Pediatric Blood Purification Specialist Committee (CPBPSC) was held from July 16-18, 2015 in Sichuan, China. CPBPSC is a branch of pediatric association in Chinese Medical Doctor Association (CMDA). The chairman of CPBPSC is Prof. Ying Shen from Beijing Children’s Hospital, Capital Medical University. The forum had 125 representatives. Thirteen distinguish experts were invited to give lectures and share their experience. The contents of the lectures covered from various pediatric blood purification methods to their future development trend, from standardized treatment to their infection control. Six excellent papers were selected for oral presentation.

On the forum, a report of Clinical retrospective studies about the common mode and current situation of pediatric blood purification in 32 hospitals showed Pediatric blood purification techniques have developed gradually in recent years. Hemodialysis, plasmaphresis, hemoperfusion, immunoadsorption (IA) and Continuous renal replacement therapy (CRRT) were common blood purification method for children in China. CRRT started late, but developed more rapidly; IA application is relatively rare in children and maintenance hemodialysis developed rapidly. There are two pediatric blood purification centers in China. One is in Beijing Children’s Hospital, the other is in Children’s Hospital of Fudan University.

The Chinese pediatric blood purification forum was organized annually since CPBPSC was set up in 2011 which was called the Pediatric Blood Purification Committee (PBPC). It boosted the development of the technology and application of pediatric blood purification in China, and improved the theoretical and technical level of pediatric blood purification. The forum was a platform to exchange views on pediatric blood purification.

The 2nd China International Forum of Pediatric Nephrology

Experts of pediatric nephrology from various countries got together in Beijing in this autumn with the floating aroma of osmanthus blooms. They were invited to the 2nd China International Forum of Pediatric Nephrology on October, 9-11, 2015 in China National Conventional Center, Beijing. This forum, held by Nanjing Children’s Hospital and
Beijing Children’s Hospital, aims to establish an exchange platform to promote the progress of pediatric nephrology. It provides the excellent chance not only to learn from experts domestic and overseas, but also to hear the voice of young scholars, who will be the mainstay of pediatric nephrology in China.

The forum lasts for two days with comprehensive and profound discussions about the themes of Acute Kidney Injury, Chronic Kidney Disease, and Complications and Treatment of ESRD. There were 16 famous professors in this field to make a speech, including Prof. Fangming Lin (Chief of Pediatric Nephrology and the Director for Pediatric Nephrology Fellowship Training Program at Columbia University), Prof. Robert H. Mak (Chief of the Division of Pediatric Nephrology at Rady Children’s Hospital of San Diego), Prof. Wai W. Cheung (Associate scientist at University of California, San Diego), Prof. Chai Luan Low (Clinical Pharmacist at the Veterans Affair affiliated University of California, San Diego), Prof. Zhanjun Jia from University of Utah, Prof. Jie Ding from Peking University first hospital, Prof. Zhuwen Yi from Central South University, Prof. Ying Shen from Beijing Children’s Hospital, Prof. Songming Huang from Nanjing Children’s Hospital, and so on. Four talented young investigators also shared their opinions in clinical and basic research. Over 120 scholars from the whole country took part in the meeting.

In the forum, scholars were not only concerned with the current situation of various kidney diseases but also looking at the future, like the application of precise medicine in nephropathy. They discussed about rare cases in clinic and share valuable experiences in strategy and management of end stage kidney diseases. Within two days, wonderful pathologic figures and comprehensive research data were presented.

The forum successfully exchanged different notions, novel discoveries and insights at home and abroad, making a full picture of clinical advancements and research achievements in these fields of kidney diseases. The communication and cooperation across the world will go on after the meeting.

**First World Bedwetting Day in China**

Nocturnal enuresis is a common problem in children with a prevalence as high as 15%-20% among children aged 5. Children with enuresis and their parents can be psychologically suffering in day-to-day life, including in school activities. In order to provide standard and top-notch medical services for children with enuresis in China, “Chinese Cooperative Group for the Management of Pediatric Enuresis” was launched in 2013 and Professor XU Hong from Children’s Hospital of Fudan University serves as group leader. In 2014, “Chinese Expert Consensus on the Management of Pediatric Monosymptomatic Enuresis” was published.

October 17th 2015 was the first “World Bedwetting Day”, which was launched and announced by the International Children’s Continence Society (ICCS) and the European Society for Pediatric Urology (ESPU). World Bedwetting Day 2015’s slogan was “Time to Take Action”. Under the lead and proposal of Chinese Cooperative Group for the Management of Pediatric Enuresis, there were integrated activities nationwide in China during the first “World Bedwetting Day”, in recognition that much more can be done to diagnose and effectively treat children with this common medical condition. The activities included:

- During the press conference and satellite meeting in the 3rd Oriental Congress of Pediatrics in Shanghai, Professor XU Hong announced the news of the first “World Bedwetting Day”.
- Hospital gratuitous treatments and patient educations were held in major pediatric hospitals in 19 cities all over China.
- News report and advertorial released by 70+ web-media and newspaper.

**Announcement…**
**Training Course**  
**Dates**  
**Location**  
**Course Director**  
**Email**  

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<th>Training Course</th>
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<td>Jaipur (India)</td>
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<td>IPNA Advanced Program in Children Renal Care in China</td>
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<td>Cotonou (Benin)</td>
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<td>2016</td>
<td>Maharashtra (India)</td>
<td>Uma Ali</td>
<td><a href="mailto:drumaali22@gmail.com">drumaali22@gmail.com</a></td>
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<td>Pediatric Nephrology: An Update</td>
<td>28–29/1/2016</td>
<td>Cairo (Egypt)</td>
<td>Hesham Safouh</td>
<td><a href="mailto:heshamsafouh@hotmail.com">heshamsafouh@hotmail.com</a></td>
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**Poster from the IPNA**  
**Patient Education Committee**  
**Introduction by Sushmita Banerjee**

The IPNA executive council initiated the formation of a Patient Education Committee in 2013. The aims were to develop a strategy for providing patient / parent education about children's kidney disease and information regarding regional support services. In order to assess the availability and requirement of such services, a worldwide questionnaire survey addressed to all IPNA council members was undertaken. The results of this survey and the actions taken based on its results were presented in poster form at the ESPN meeting in Brussels in September 2015. The poster is reproduced below. A comprehensive list of online sites for patient education and support will be available on the IPNA website soon. We request all members to contribute additional information or suggestions, particularly regarding availability of such resources in their country / region.

Email: ppecipna@gmail.com
The Global Requirement of Resources for Patient Education: Strategies from the IPNA Council

IPNA Patient Education Committee, IPNA Council.

Objectives
Providing patient and parental/carer education (PPE) is a vital component of health care delivery particularly in Pediatric Nephrology where risks of serious illness are high and much of the care can be delivered at home.
We aimed to –
(a) Assess existing PPE resources on an international scale and
(b) Propose strategies for optimization through the IPNA platform.

Methods
(a) A questionnaire was sent to all regional and national representatives on the IPNA council. Lists of resources provided by respondents were compiled.
(b) 57 online sites or contact details of service providers for children’s kidney diseases worldwide were reviewed.
(c) Results were presented at the IPNA council meeting in New Delhi, in December 2014.

Questionnaire to all Council Members
1. Name:
2. Country / Region:
3. Do any patient support groups / societies / foundations exist in your region / country
   (Please list Names and Websites):
4. Are any regional patient education materials available online?
   (Please list Topic and Websites):
5. Are there any existing documents / leaflets / brochures available for patient education?
   (Please list Topic and contact details for procurement):
6. Are any regular activities conducted in your region / country for patient education purposes:
   (Please list and provide calendar of any planned during the rest of this year. If there is an online site
   where such activities are posted, please mention.)
7. What are the 5 most common pediatric renal diseases in your region?
8. Do you have any suggestions for PPE activities that would help in educating and supporting
   patients and parents in your region?

Results: Overview
(a) What is available
   – Online
   – Offline
(b) Results of the questionnaire based survey
(c) Identifying the gaps ……suggestions from council members
(d) Strategies and Proposals

Results: questionnaire survey
24 replies from 21 countries
   21. USA

Results: questionnaire survey
Most common diseases encountered

Results of review of online sites
(a) IPNACouncil members proposed that the IPNA website contain links to
   – Regional support services referenced according to country and
   – Specific disease information sites referenced according to disease.
(b) Amanda existing online disease information websites, the UK site InfoKID was the most
    comprehensive. The site also has the option of downloading information in brochure form.

Strategies
(a) A list of online and off-line global resources for PPE and support in pediatric renal diseases
    was made and is being prepared for publication on the IPNA website.
(b) Efforts have been initiated to collaborate with InfoKID to provide a more international
    perspective.
(c) As a first step towards encouraging PPE workshops and programs, an initiative has started to
    support one child oriented PPE activity per year globally, on world kidney day.
(d) Worldwide PPE activities to be placed on IPNA notice board / calendar of events

Proposals
(a) Representation of Regional Languages – involve regional societies
(b) IPNA support / endorsement for
   – Patient education activities, workshops
   – Websites / online information in regional languages
   – Brochures and pamphlets

Conclusions
(a) The majority of representative pediatric nephrologists from different countries of the world
    recognize a lack of existing resources for PPE.
(b) IPNA is committed to develop and support Patient and Parent Education resources.

Email : ppeipna@gmail.com for comments/suggestions

IPNA CURRENTS 11/10
SAVE THE DATE:

Spread the word: the IPNA Congress is coming to Brazil!

➔ The “Call for abstracts submission” is now open. Please submit your abstract here (deadline Tuesday, 15 March 2016):
http://resumes.europa-organisation.com/ipna2016/

➔ Submit an Award Nomination here (new deadline 31 January):
http://www.ipna-online.org/members/congress-award-nominations/

➔ Registrations will open soon! Keep visiting:
http://www.ipna2016.com/content/registration

Calendar of 2016 congresses

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<tr>
<th>Date</th>
<th>Congress</th>
<th>Location</th>
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<td>January 20 - 22, 2016</td>
<td>18th International Conference on Dialysis, Advances in Kidney Disease 2016</td>
<td>Miami, USA</td>
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<td>March 3 - March 6, 2016</td>
<td>5th Global Congress for Consensus in Pediatrics and Child Health (CIP 2016)</td>
<td>Xi'an, China</td>
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<td>April 3 - April 6, 2016</td>
<td>11th International Podocyte Conference</td>
<td>Jerusalem, Israel</td>
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<td>July 15 - 17, 2016</td>
<td>2nd International Neonatalogy Association Conference</td>
<td>Vienna, Austria</td>
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<td>July 19 - 22, 2016</td>
<td>13th International Symposium on Urolithiasis (ISU 2016)</td>
<td>Makuhari, Japan</td>
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<td>August 17 - 22, 2016</td>
<td>28th International Congress of Pediatrics (IPA)</td>
<td>Vancouver, Canada</td>
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<tr>
<td>August 18 - August 23, 2016</td>
<td>26th International Congress of The Transplantation Society (TTS 2016)</td>
<td>Hong Kong, China</td>
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IPNA goes digital!

IPNA has now moved into social media! We hope to provide you real time news about our society, events, and stories of interest. As social media grows for our organisation we aim to drive advocacy and education through regular streaming of relevant content. The Facebook page and Twitter account are currently active. We are excited to engage with our membership and other followers in this new environment.

Click the logo to be directed to the Facebook/Twitter page:

Find us on facebook

Follow @IPNA_PedNeph

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Joseph Flynn, USA

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