KIDNEY TRANSPLANTS: the good and bad

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Advancing Nephrology Around the World
Welcome to this edition of ISN News. More new data are becoming available to give us a global perspective on the state of organ transplantation. These figures reveal the good and bad side to what is considered the best and frequently the only life-saving treatment for end-stage organ failure.

Patients get a new lease of life and enjoy more freedom after the restrictions of dialysis. But, in low and middle-income countries, transplant programs are either non-existent or travelling for the procedure has become the only option.

Illegal organ trafficking networks prey on the poor and ill-informed as well as vulnerable individuals desperately in need of a kidney. Doctors face new challenges when presented with patients who are victims of unethical practice.

Our main feature highlights how sharing knowledge and expert advice has already inspired change. As a support mechanism, the Declaration of Istanbul Custodial Group (DICG) advises physicians and raises awareness about unlawful practice, transplant tourism and illegal organ trafficking. It has now set itself the task of guiding doctors and patients about safer travel and transplantation, giving them the tools to make the right decisions.

You will also read that through the partnership of ISN and The Transplantation Society (TTS), the Sister Transplant Center Program has also made advances in training more surgeons to carry out kidney transplant operations. Clear proof that education across borders contributes to sustainable changes and advances in our field.

Adeera Levin
ISN President
The Lancet Kidney Campaign puts the spotlight on kidney health policy

On World Kidney Day (WKD) 2016, ISN and The Lancet launched an online campaign to raise awareness of kidney disease aimed at the international health community.

The Lancet Kidney Campaign brings together the best available evidence to inform strategies to reduce the national, regional and global burden of kidney disease and its risk factors.

‘Despite the devastating impact of kidney disease on individuals, families, communities and healthcare systems, kidney disease is often not part of national health strategies, and does not receive the funding or research attention afforded to other chronic conditions,’ stated the ISN leadership and The Lancet Editor-in-Chief Richard Horton in their joint comment published on March 10, 2016.

This builds on ISN’s 2015 Lancet Commission, which called for eliminating preventable deaths from Acute Kidney Injury (AKI) by 2025. Hosted on The Lancet website, the Campaign brings together research and analysis on Acute Kidney Injury, Chronic Kidney Disease (CKD), and dialysis and transplantation from across the journal’s database.

Also launched, was a new video in partnership with ISN, including interviews with ISN President Adeera Levin, Past President Giuseppe Remuzzi, and President Elect David Harris.

The Campaign will provide monthly updates on advances in nephrology as well as expert commentaries and interviews on key health and policy issues relevant to kidney disease.

Visit: www.thelancet.com/campaigns/kidney

Membership

ISN Membership - make a difference

ISN connects science and humanitarian efforts. Through education, ISN is reaching out to global medical communities, giving them the knowledge and support to reduce the impact of kidney disease worldwide. Membership to ISN supports these activities and provides member specific benefits including exclusive eligibility for ISN capacity building programs, online and print subscription to Kidney International, online training and education, and reduced registration fees to ISN events. Membership is now free for trainees.

Not yet a member? Visit: www.theisn.org/join

Update your membership and profile

To ensure you receive all your benefits, please keep your profile up to date and renew your membership in a timely manner. Access or update your profile at: www.theisn.org/memberlogin
COLLABORATING for safer kidney transplants globally

Organ transplantation is the best and frequently the only life-saving treatment for end-stage organ failure. According to the WHO, almost 80,000 kidney transplants were performed globally in 2013. Although impressive, it is estimated that the activity represents less than 10% of the global need. This situation of acute organ shortage has come with its own set of challenges for kidney donors, recipients and doctors, as has the emergence of organ trafficking, a practice that continues to take place in some countries.

Cases of unethical living and deceased kidney donation are still reported in countries like Egypt, India, Mexico, Pakistan, the Philippines and Turkey. Beatriz Domínguez-Gil, who co-chairs the Declaration of Istanbul Custodian Group (DICG) explains the legal, ethical and clinical implications of transplant tourism. In the home country of patients who illicitly obtained an organ overseas, doctors face a guessing game in caring for them. They have no medical reports and cannot refer to a reliable healthcare professional about the procedure.

“Transplant tourism can also become a threat to public health,” she explains as patients also risk bringing in unexpected infections.

“Doctors do not want to report or compromise their patients. Our objective is to give them the tools to help their patients without compromising vulnerable living donors”

Elni Muller, co-chair of the Declaration of Istanbul Custodian Group (DICG)

“Transplant tourism can also become a threat to public health”

Beatriz Domínguez-Gil, co-chair of the Declaration of Istanbul Custodian Group (DICG)

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The DICG was set up in 2010 after the establishment of the Declaration of Istanbul (DOI) on organ trafficking and transplant tourism in 2008. The DOI has helped to define organ commercialization and trafficking, as well as transplant tourism, and its principles have visibly raised awareness among the world’s medical practitioners about illegal organ transplantation.

The DICG has put a strategic plan into place until 2018 to focus on key issues regarding transplantation and set up local strategies to improve ethical transplantation availability in specific countries. It also aims to provide much-needed guidance on travel and transplantation.

“Doctors do not want to report or compromise their patients. Our objective is to give them the tools to help their patients without compromising vulnerable living donors,” adds Elmi Muller, who leads the DICG with Domínguez-Gil.

A workshop organized in Madrid from April 4 to 5, 2016 also focused on creating a potential registration database for these cases. With representatives from 26 countries, this meeting continued to make the medical community aware of irresponsible commercial networks that should be criminalized.

Elmi Muller believes “practices are changing from day to day.”

The DOI has already inspired changes in legislation. For example, in Israel, legislation was modified to define the meaning of travel for transplantation, which led to banning health insurance companies from reimbursing illegal transplant procedures.

The law was also amended in The Philippines, decreasing the number of foreigners heading to the country for illegal transplantation procedures.

Closely collaborating with the The Transplantation Society (TTS) and the Chinese government, DICG has worked to put a stop to the use of executed prisoners’ organs for transplantation in China. In Costa Rica, the DICG was critical in dismantling an organ trafficking ring.

According to Muller, improvements in deceased donation are being described in several countries in South Eastern Europe (under the leadership of Croatia), Latin America and in the Middle East.

In less than two years, the DOI will celebrate its 10th anniversary. Domínguez-Gil explains that the text and definitions will be updated in the same way as the Declaration of Helsinki, (created by the World Medical Association as a statement of ethical principles for medical research involving human subjects) gets updated regularly.

A fitting tribute to the dedicated efforts of this international group of medical professionals who continuously ensure the safety of all kidney transplants patients worldwide.
In 2014, there were about 80,000 kidney transplants from living and deceased donors globally. Deceased donation has increased, especially from donors after circulatory death. This group makes up more than 40% of deceased kidney transplantation activities in the Netherlands. It is also growing significantly in Norway, Spain, the United Kingdom and the United States.

It is in low-to-middle income countries, that there is more concern. Myanmar, Nigeria, Bangladesh, Kyrgyzstan, Libya and Kenya are on the other end of the scale, with no deceased donation programs and counting just a small number of transplants from living donors per million population.

There is hope through education. The ISN and The Transplantation Society (TTS) Sister Transplant Centers Program focuses on sharing transplant expertise across borders.

In March, after months of preparation and coordination, a team from the Liverpool International Transplant Initiative and the Royal Liverpool University Hospital carried out the first two kidney transplants at the An-Najah University Hospital in Nablus, on the West Bank.

Before 2013, there were no transplant services available in Palestine and the first kidney transplant operation in the region was carried out at Al Shifa Hospital in Gaza thanks to the partnership with the Liverpool team.

Moreover, surgeons from the University of Michigan carried out kidney transplant operations at St-Paul’s Hospital, Millennium Medical College (SPHMMC) in Addis Ababa (Ethiopia) in 2015. Further visits every four to six weeks will help with future procedures. In two years, local surgeons will take over.

This is definitively a sign of hope for patients waiting for kidney transplants in many regions where the procedure continues to be unavailable or costly. Collaboration and sharing knowledge is the way forward for doctors and patients alike.

THESE CENTERS BEGAN THEIR PARTNERSHIPS IN 2016

- Jawaharhal Nehru Institute of Medical Sciences (India) and University Hospitals of Coventry and Warwickshire NHS Trust (UK)
- The Institute of Medicine (Nepal) and Monash Medical Centre (Australia)
- Kidney Transplant Unit at Southern Philippines Medical Center and University of Barcelona (Spain)
- An-Najah National University Hospital (Palestine) and Royal Liverpool University Hospital (UK)
- Fundación Valle del Lili (Colombia) and Boston Children’s Hospital (USA)

www.theisn.org/stc
The Lancet publishes AKI Global Snapshot results

The outcome of the Acute Kidney Injury (AKI) Global Snapshot, an innovative web-based global cohort study carried out under the ISN 0by25 Initiative, was published in The Lancet on April 14, 2016.

Including 4,000 patients in 72 countries, the study assessed similarities and differences in recognizing and managing AKI globally.

The study found that over half of the patients, developed AKI in the community rather than in hospital settings, pointing to how early AKI recognition and management needs improving in these out-of-hospital settings.

900 patients (22%) were dialyzed, however an additional 244 patients (8%) with clinical indications for renal replacement therapy were not dialyzed due to lack of resources and their inability to afford therapy (Low/Lower Middle Income Countries - LLMIC) or futility (High Income countries - HIC and Upper Middle Income Countries - UMIC). Given the limited availability of dialysis facilities in LIC and LMIC, these data confirm the necessity for continued work with governments to ensure access to treatment for all.

The most prevalent AKI causes were hypotension (40.2%) and dehydration (38.2%) and common etiological factors across all countries were identified, which seems to support a standardized approach for early recognition and treatment.

Overall, AKI mortality at seven days was calculated at 11% and was higher in LLMICs than HICs, meaning that AKI must be tackled in these more vulnerable communities.

Building on these findings, in the next two years, ISN will set up a series of pilot projects in selected health centers in Africa, Asia and Latin America to test education interventions to reduce the number of preventable AKI deaths, especially focusing on community-acquired AKI patients in LLMIC settings.

The findings of these pilot projects will be unveiled at the World Congress of Nephrology 2017 in Mexico City.

More information at: www.theisn.org/0by25
Vincent Garvey received the Affordable Dialysis Prize, taking home US $100,000 for his innovative design – what does this mean for the future of dialysis treatment?

Garvey's dialysis system can fit into a small suitcase and uses a standard solar panel to power a highly-efficient, miniature distiller capable of producing pure water from any source. Work on a prototype is now underway, with sponsorship opportunities actively being sought.

The prize was jointly established by The George Institute for Global Health, ISN and the Asian Pacific Society of Nephrology and supported by the Farrell Family Foundation.

Professor Vlado Perkovic, Executive Director of the George Institute (Australia), explains: "Dialysis has been with us for more than 50 years but there has been no great leap forward in its design or, more importantly, its cost remains hugely expensive and out of reach for millions of sick people."

Conventional dialysis systems cost several tens of thousands of dollars. They are widely available in most developed countries but much less so in countries with limited funds for healthcare. Research published in The Lancet found that while more than nine million people worldwide need dialysis for terminal kidney failure, only 2.61 million currently get this life-saving treatment.

Garvey, a manufacturing engineer from the United Kingdom’s Isle of Man, had little knowledge of dialysis when he entered the competition, but was inspired by the chance to save lives. He said: “I have always loved a challenge and the idea of solving this problem excited me from the start. It’s incredible to win this prize but I am already focused on building the team to tackle the challenges ahead.”
FUNDING SPECIFIC RESEARCH into hydration and the kidney

Following the call for applications, the H4KH Committee has announced the winners of the New Investigator and Hydration and Kidney Health grants.

Last year, the Hydration for Kidney Health (H4KH) research initiative called for candidates from all disciplines relevant to kidney disease with an interest in hydration for kidney health to apply for one of two research grants.

In this edition of ISN News, we are happy to announce who will receive this funding.

Sofia Enhorning, from Skåne University Hospital in Malmö, Sweden who received the Hydration and Kidney Health Grant, explains: “My research focuses on the relationship between an overactive vasopressin system, its disadvantageous effects, and the possible benefits from increased water intake by lowering circulating vasopressin/copeptin levels. The H4KH grant will be a cornerstone in the next two years funding of this research.”

Fabiana Nerbass, from the Fundação Pró-Rim in Joinville, Brazil was awarded the New Investigator Grant for her project on kidney health in Brazilian industrial workers exposed to heat, stress and dehydration.

She is confident that this grant will improve knowledge on the topic, strengthen ties with a very important science institution and provide expertise to keep investigating the relationship between hydration and kidney health in her country.

Increasing global temperatures and the challenged access to dwindling water supplies will ensure that the role of hydration in health is likely to grow in the next 50 years. It will become more important to have research projects and individuals specializing in this area in an attempt to mitigate some of the likely effects.

Visit: www.theisn.org/h4kh

This initiative is a collaboration between ISN and Danone Nutricia Research to stimulate the interest of established and new researchers to explore the role of hydration in kidney health. The New Investigator Grant is worth US$ 70,000 over two years and the Hydration and Kidney Health Grant offers US$ 50,000, also over two years.
WORLD KIDNEY DAY 2016
Kidney Disease and Children

On March 10th, 2016, the world stepped up to raise awareness about kidney health in younger generations.

World Kidney Day (WKD) brought together members of the global medical community and general public to highlight the importance of kidney health. This year, the campaign set its sights on communicating about how much adult kidney disease is actually initiated in childhood.

Over 600 events were organized in some 80 countries, including the United States, Hong Kong, Mexico, Brazil, Ghana and Turkey. Tajikistan, located on the borders of Afghanistan, China, Kyrgyzstan and Uzbekistan, took part in celebrations for the first time.

Many participants spread the word on the Eight Golden Rules for Healthy Kidneys and made great use of all the campaign material. The World Kidney Day editorial was published in a record-breaking 70 journals.

As in recent years, there was great social media activity with 44,300 fans on Facebook, 7,670 followers on Twitter, 500 Instagram followers and 77,900 views on YouTube.

In all, #worldkidneyday was shared by 87 million people. On the day, many participants also shared fun and colorful selfies of their feet in action. The #moveyourfeet hashtag reached 2 million people.

“WKD has become a tradition in Mexico. Celebrations were organized by the Asociación Ale, kidney foundations and patient associations in Mexico City, with the Ministry of Health representative, directors from the Hospital Infantil de México and the National Pediatrics Institute, as well as the President of the Health Commission of Mexico’s House of Representatives.”

Guillermo Garcia Garcia, Co-Chair of the World Kidney Day Steering Committee
“In Hong Kong, this year’s celebrations were organized by the Hong Kong Society of Nephrology, Hong Kong Kidney Foundation and Hong Kong Children Kidney Fund. We were joined by the Secretary for Food and Health, the Director of Health and the Chairman of the Hospital Authority who supported us in promoting kidney health in the community.”

Philip Li, Co-Chair of the World Kidney Day Steering Committee

A big thank you to the pediatric societies of nephrology worldwide that participated in WKD this year.

Many thanks to Julie Ingelfinger, guest member of the WKD Steering Committee, for contributing her expertise to the entire campaign and the scientific editorial.

Lastly, thank you to our partners Danone, AstraZeneca and Sanofi Renal, our benefactors Alexion, Baxter, Fresenius Medical Care and Intuitive Surgical as well as our supporter Amgen.
The Global Kidney Health Atlas

The Global Kidney Health Atlas (GKHA), part of the ISN Closing The Gaps CKD initiative, is co-chaired by Professor David Johnson (University of Queensland, Australia) and Dr. Aminu Bello (University of Alberta, Canada).

The purpose is to systematically evaluate the current state of readiness, capacity and competence for delivering kidney health care globally.

World nations are being pushed toward Universal Health Care (UHC). It is unclear what this would mean for Chronic Kidney Disease (CKD) patients and the readiness of countries and regions on the specifics of CKD care organization to accomplish UHC for the growing number of CKD patients.

The GKHA project will collate data on the global status of CKD care structures and organization towards achieving UHC, and devise policy implications for including CKD in the global NCDs agenda.

The specific objective is to define key gaps in specific areas and regions and help develop and implement regional and national strategies to address them in the long term. With repeated surveys over time, there will be a scorecard or ability to track progress.

The first iteration of the survey will be launched in the second quarter of 2016. The initial results will be presented at the World Congress of Nephrology 2017 in Mexico City.

The ISN regional and national leaderships will play a key role in successfully collecting and reporting data. The intended survey audience will be at least three key stakeholders from each country, including national nephrology society leadership, policymakers involved directly with the organization of CKD care and consumer representative organizations (e.g. national kidney foundation or equivalent).

The key stakeholders will be identified either directly by the ISN Regional Boards or nominated delegates (e.g. country representative on the regional board or ISN Affiliated Society contact or other networks).
ISN MEMBERSHIP
Affiliated and Collective Societies

Let’s start off by extending a warm welcome to the Yemen Society of Nephrology and Transplantation, the Association of Cardiorenal Society of Serbia (KARNEF) as well as the Sociedad Boliviana de Nefrología. They have joined our growing network of ISN Affiliated Societies, which now counts 87 members. The Jordan Society of Nephrology and Renal Transplantation has also become an ISN Collective Member.

All Affiliates stand by the Declaration of Istanbul

The DECLARATION of ISTANBUL on ORGAN TRAFFICKING and TRANSPLANT TOURISM

Previously, it was understood that only individuals seeking endorsement for ISN Programs and activities or submitting abstracts complied with the Declaration of Istanbul (DOI) on organ trafficking and transplant tourism.

Now the application form has been updated so all societies applying for recognition as an ISN affiliated society must overtly state that they also subscribe to the principles of the DOI.

Free ISN membership for health professionals from low-resource countries

Doctors, scientists, nurses, dietitians, pharmacists, social workers, and technicians from countries categorized by the World Bank as low income can now join ISN as either free members (only doctors and scientists) or free associate members. They receive ISN member benefits including access to ISN Education and can participate in the ISN Programs.

Current members from eligible countries will benefit from the free membership offer at the time of their membership renewal.


These countries are categorized as low income according to the gross national income (GNI) per capita calculated using the World Bank method.

Visit: www.theisn.org/about-isn/partners-and-affiliates/affiliated-societies

Free ISN membership or associate membership for health professionals from low-resource countries.

Visit: www.theisn.org/membership
ISN Initiatives

SYL video report on nephrology in Senegal

A new video has been released about the activities of the Saving Young Lives (SYL) initiative in Africa and more specifically how the project is helping nephrology services in Senegal through a training workshop on dialysis.

The Aristide Le Dantec hospital in Dakar hosted the activity with the Senegal Society of Nephrology. Peritoneal and hemodialysis were the main focus. A SYL session presented the challenges and opportunities of setting up an Acute Kidney Injury treatment program in Western Africa, while it emphasized the value of peritoneal dialysis (PD).

This initiative has helped develop acute PD programs in eight centers in Africa, where dialysis was previously unavailable. It is now working to establish treatments in three other sites.

Between January 2013 and September 2015, 175 children and adults received dialysis in these centers. Challenges continue to be the high costs of transporting consumables in a sustainable way. In many cases, the only solution is to use locally made supplies and improvised catheters.

Watch the video report: www.theisn.org/syl

2016 Science Writing Academy set for September

The Mario Negri Institute is happy to announce that there will be another round of the Scientific Writing Academy, taking place from September 12 to 18, 2016 in Ranica, Bergamo, Italy.

“Our academy hopes to help physicians and researchers to better communicate findings and move research in the field of nephrology forward more quickly and efficiently, ultimately benefitting patients, who can receive better, cutting-edge care as a result,” says Giuseppe Remuzzi who heads the Mario Negri Institute.

Since last year’s workshop, many participants have stayed in contact and are trying to get joint research projects off the ground, continue to collaborate and write together.

Given its ongoing experience in the field, the institute remains the perfect point of reference for scientific writing training. Participants will be taken through the process of writing a manuscript and preparing it for submission by 2017. Tutor Martin de Borst will bring his personal experience of writing and working in the field to participants in the course.

“Our academy hopes to help physicians and researchers to better communicate findings and move research in the field of nephrology forward more quickly and efficiently...”

Giuseppe Remuzzi
Forefronts Vienna: abstract submission and registration open

Send your abstracts and register for the ISN Forefronts symposium taking place in Vienna from December 9 to 11, 2016. The theme for this meeting is regulatory RNAs and the kidney.

Non-coding RNAs regulate normal cellular functions but are also critical regulators of disease processes. Therefore, they are being explored as biomarkers and novel therapeutic targets.

Interventions targeting non-coding RNAs have shown great promise, including successful phase 2 studies in patients with HCV-hepatitis. Over three days, this meeting will cover all aspects of non-coding RNAs and all their biological and potential therapeutic features will be elucidated in depth.

ISN Forefronts Symposia focus on emerging and ground-breaking research. They gather nephrologists and active investigators from surrounding medical areas to explore new scientific domains and review the latest developments in kidney disease.

Visit: www.isnforefronts.org/vienna

Check out ISN Education webinars
As well as ISN events, you can also catch the latest ISN Education webinars, visit: www.theisn.org/education

ISN Forefronts Symposium 2016
The Metabolome and Microbiome in Kidney Disease
September 23-25, 2016, San Diego (CA), USA
www.isnforefronts.org/sandiego

ISN Forefronts Symposium 2016
Regulatory RNAs and the Kidney
December 9-11, 2016, Vienna, Austria
www.isnforefronts.org/vienna

ISN World Congress of Nephrology 2017
Sustainability and Diversity
April 21-25, 2017, Mexico City, Mexico
www.wcn2017.org
ISN WORLD CONGRESS OF NEPHROLOGY 2017
April 21-25, 2017
Mexico City, Mexico
www.wcn2017.org

Focus 2017: Diabetes and Kidney Disease