

# Role of Professional Renal Societies

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Board: Saving Young Lives Program

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# ISN Mission

Advancing the diagnosis, treatment and prevention of kidney diseases in the developing and developed world

- Raise public awareness
- Connect professionals
- Support research
- Provide nephrology education and training worldwide
- Reduce the frequency and impact of kidney diseases and their associated conditions

10,000 members in 13 countries

# ISN global outreach programs

## ISN CME Program

- 42 CME courses run worldwide in Developing countries
- Support for travel of 3 opinion leaders to each CME

## ISN Fellowship Program

- 2-12 months fellowship for an individual to visit a developed Nephrology centre
- Range of support, U\$3- \$25,000

## ISN Sister Renal Centre Program

- 6 year training link between a developed and emerging nephrology centre
- Stepwise funding: Years 1-2 U\$3000; Years 3-4 U\$26,000, Years 5-6 U\$34,000
- Bilateral multi-disciplinary training exchanges

## ISN R&P Program

- Grants to support local research projects in developing centres
- Grants range from \$10,000 – 15,000

## ISN Educational Ambassadors Program

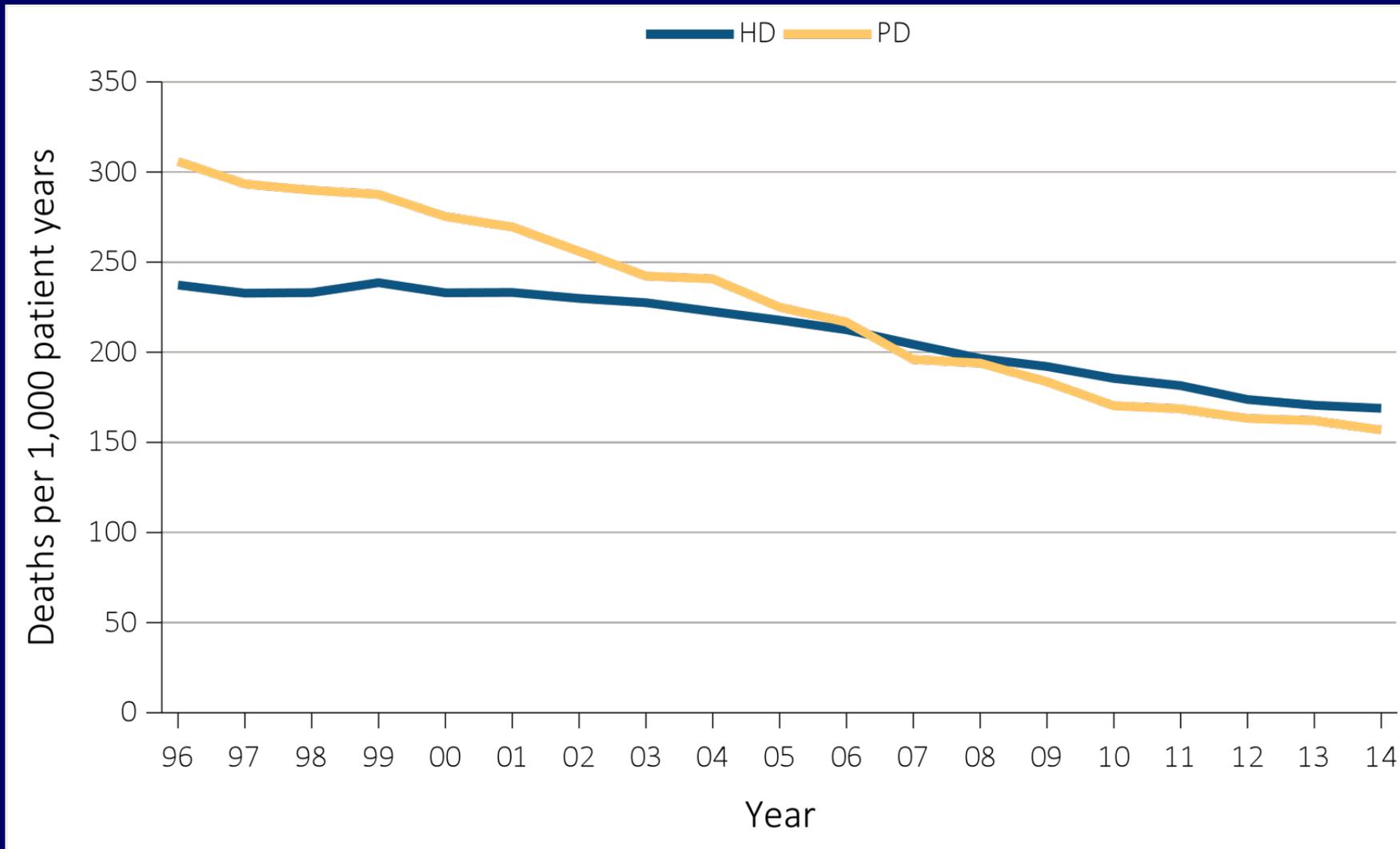
- Support a leading expert to spend 1-4 weeks in a developing centre

# ISPD

- *ISPD* advances the knowledge of peritoneal dialysis and promotes the advancement of such knowledge through international scientific meetings and publications
- Supports research and CMEs
- Provides awards for 2-3 months of training of health care providers in the basics of PD via visits to well established PD programs
- Develops basic guidelines of care

# USRDS 2016

## Mortality of Dialysis Patients



# Ethical Issues In Dialysis Therapy

Vivekanand Jha, Dominique E Martin, Joanne M Bargman, Simon Davies, John Feehally, Fred Finkelstein, David Harris, Madhukar Misra, Giuseppe Remuzzi, Adeera Levin, for the International Society of Nephrology Ethical Dialysis Task Force, Lancet 2017 in press

- Treatment for end-stage kidney disease is a major economic challenge and a public health concern worldwide.
- RRT poses several practical and ethical dilemmas of global relevance for patients, clinicians, and policy makers.

# Ethical Issues In Dialysis Therapy

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- Treatment for end-stage kidney disease is a major economic challenge and a public health concern worldwide.
- RRT poses several practical and ethical dilemmas of global relevance for patients, clinicians, and policy makers.
- These include how to: promote patients' best interests; increase access to dialysis while maintaining procedural and distributive justice; minimise the influence of financial incentives and competing interests; ensure quality of care in service delivery and access to non-dialytic supportive care when needed; minimize the financial burden on patients and health-care system; and protect the interests of vulnerable groups during crisis situations.
- These issues have received comparatively little attention, and there is scant ethical analysis and guidance available to decision makers.

# Ethical Principles And Goals For Health Authorities And Dialysis Care Providers

- Individuals with end-stage kidney disease should have access to the best available care in renal-replacement therapy and supportive and end-of-life care when required
- Health professionals and policy makers should strive to reduce the costs of dialysis, using simple, safe, and affordable modalities without compromising the quality of care provided to patients

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- Commercial competing interests on the part of policy makers and health service providers, including nephrologists, should be routinely disclosed to the public and patients
- Where rationing of dialysis resources is necessary and unavoidable, access to dialysis should be equitable

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- Commercial competing interests on the part of policy makers and health service providers, including nephrologists, should be routinely disclosed to the public and patients
- Where rationing of dialysis resources is necessary and unavoidable, access to dialysis should be equitable
- Physicians have an obligation to provide information about risks and benefits of dialysis and to support patients or their surrogate decision makers in qualitative evaluation of treatment options

- Decisions about initiation or withdrawal of dialysis should not be considered irrevocable; however, decision makers should be informed of the potential limitation of future options that could be the consequence of initial decisions
- Policies and guidelines governing access to dialysis should strive to avoid futile treatment
- Assure a minimum expected benefit threshold, below which the burdens of initiating or continuing dialysis are considered disproportionate and hence unacceptable (within the sociocultural context)

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- Promote equality of opportunity
- Maximize utility gains from the available resources
- Exclude criteria that are not morally justifiable with respect to allocation decisions, such as race, sex, religion, or social status
- Insure transparency of policies and processes

# Practical Recommendations Regarding Dialysis For Health Authorities

- Efforts to reduce the costs of providing dialysis to those with ESRD disease should occur in conjunction with more cost-effective efforts to prevent development of and to manage end-stage kidney disease within a population—eg, health systems should establish programmes of kidney disease prevention and health promotion, in conjunction with renal-replacement therapy programmes

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- Minimum standards of quality and safety should be established for all dialysis units and regulations introduced where necessary to ensure standards are maintained
- Audit systems should be designed to facilitate and encourage documentation of patient care and transparent reporting of costs and outcomes of care to provide an evidence base for decision making and objective evaluation of performance
- Regulatory safeguards should be implemented where necessary to prevent undue commercial influences on clinical decision making
- Locally appropriate policies or guidelines governing access to dialysis should be developed and transparently implemented in accordance with principles of procedural and distributive justice

# Practice Recommendations For Health Professionals Involved In Dialysis Care

- Nephrologists and renal care nurses should collaborate with other health professionals, social scientists, and ethicists, in the investigation of specific ethical issues at the local, regional, or international level

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- Nephrologists and renal care nurses should collaborate with other health professionals, social scientists, and ethicists, in the investigation of specific ethical issues at the local, regional, or international level
- Priorities for research might include assessment of the impact of costs on clinical decision making in different countries and investigation of burdens of care in special populations such as infants and those with complex comorbidities; such research might inform development of evidence-based communication tools and allocation policies respectively
- Professional societies and medical councils should ensure that health-care professionals working with patients with end-stage kidney disease are familiar with their responsibilities for patient care, including their obligations to provide care to those who might be perceived to pose risks to care providers (eg, from infectious disease) and to provide or refer patients to palliative care services
- Supportive care should be made part of end-stage kidney disease management plans, and appropriate facilities should be developed

- Guidelines for clinical decision making, specifically with regard to withdrawal of dialysis, “do not resuscitate” orders, and time-limited trials of dialysis should be developed; where guidelines exist and have been implemented, sharing of best practices and outcomes across jurisdictions is essential

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- Nephrologists should refer patients to available services when they are unable to provide such care
- Nephrologists should receive education about shared decision making, advance care planning, and end-of-life counseling, and communication about end-of-life care

# Role of Professional Renal Societies

- Provide academic and educational support for the ethical principles elaborated above
- Provide training to support health care providers in implementing ethical CKD and ESRD care
- Support individual initiatives that develop in response to the refugee crisis

# Initiatives

- Expanded PD programs: *cost reductions*
- Self-care dialysis programs: *cost reductions*
- Define basic levels of standards of care: *minimum basic standards*
- Initiation of conservative/supportive/palliative care program: *delay onset of dialysis; care for those not able to get dialysis*

# International Survey of 298 Facilities

Van Biesen et al KI supplements December 2016 (Europe, Middle East, North Africa)

- 95% of dialysis centers felt a moral responsibility to take care of refugees
- 85% felt comfortable offering dialysis to refugees
- 65-70% felt this created tension for the team

# ISN ESRD Initiative: Dubai 2018

- Advocacy: *understand the differences in practice patterns globally and develop an approach to advocate for integrated ESRD care in LMIC*
- Sustainability: *define the optimal and minimum efficacy and safety standards of ESRD care*
- Integrated Care: *address transplantation and conservative (palliative) care as part of ESRD care*
- Equity: *recommend how to initiate and sustain ESRD in LMIC*