

Restore long-term direction in kidney transplantation says the Kidney Alliance

At an event in the House of Commons on Wednesday 7th March 2012 to mark World Kidney Day, MPs and Members of the House of Lords were told that the Government must retain kidney transplantation as a long-term priority to save lives and save money in NHS budgets.

The Kidney Alliance paid a cautious tribute to progress achieved in increasing the number of transplants over the last three years. This was the result of work from NHS Blood and Transplant, driven and directed by a central body, the Organ Donation Task Force.

Deaths

However, the Task Force was disbanded only three years into its five-year plan. The Alliance said it was already clear the Government would fail to achieve the 50% increase in transplant operations promised nearly four years ago, despite some movement towards this modest 5 year target.

Although a transitional body, headed by former National Clinical Director for Transplantation Professor Chris Rudge, will oversee the integration of transplant services into the new NHS structure, the Kidney Alliance said no announcement has been made on the long-term future direction of kidney transplant services and no replacement for the Transplant tsar has been named.

Each day at least one person dies whilst waiting for a kidney transplant. Fiona Loud, Director of the Kidney Alliance and a kidney transplant recipient said: *"With people dying because there are not enough kidney transplants taking place, now is not the time to lose long-term direction. Doing so puts at risk all the progress made so far, it increases costs to the NHS because more dialysis services are needed and it means people will continue to die unnecessarily."*



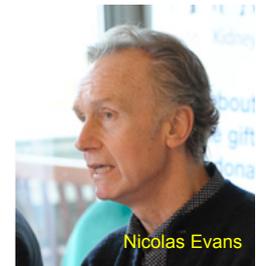
New strategy

Minister of State for Health, Rt. Hon. Simon Burns MP told the meeting: *"...work has already begun to develop a strategy, post 2013. That will build on the Organ Donation Task Force recommendations and link with the new*

NHS commissioning arrangements."

The Minister also confirmed that in the next year the Government will be concentrating on increasing consent rates; encouraging brain stem death testing to support donation opportunities; increasing donation from emergency medicine; increased and more timely referral of potential donors.

Panelist Nicholas Evans, author of numerous international best sellers including 'The Horse Whisperer' and himself a kidney transplant recipient made a plea that living donation be given equal priority to cadaveric donation. He said: *"...even if we had 56 million people on the donation list, it would still probably not satisfy the number of kidneys needed."*



A question from the audience raised the issue of the number of donated kidneys that are not used as a result of relatives not giving consent for their use.



Professor Chris Rudge, Chair of the Transitional Steering Group for Organ Transplantation explained that where death is certified through lack of brain activity, 35% of relatives withhold consent,

where death is determined by the heart stopping, almost 45% say no. He went on to point out that: *"... if the person dying who is a potential organ donor comes from one of the ethnic minority sections of the community, 75% of relatives say no."*

BME patients at greater risk

"BME kidney patients are at greater risk," agreed Robert Buckland MP, Chair of the All Party Parliamentary Kidney Group. *"They constitute a quarter of the total number of people waiting for a*



kidney and they have to wait about 30% longer for a transplant.”

The All Party Group launched a manifesto at the event to address issues relating to organ transplantation in Black and Minority Ethnic communities in the UK.

Dialysis remains specialised service

The large number of people waiting for a kidney transplant puts strain on other specialised services such as dialysis. These patients, along with many others for whom transplantation is not possible, rely on dialysis to keep them alive.

At the meeting, the Kidney Alliance told panellist and National Clinical Director for Kidney Care, Dr Donal O’Donoghue, that it is therefore vital that the proposed changes to the NHS do nothing to disrupt the quality or quantity of dialysis provided.



At present specialised kidney services such as dialysis and transplantation are commissioned at national level. The NHS reforms have meant that all such services are being reviewed and the Kidney Alliance has reason to be concerned that this could lead to these highly technical services being commissioned by GPs locally.

Dr O’Donoghue said: *“Dialysis and transplantation remain specialised services, so will be commissioned directly by the NHS Commissioning Board.”*

Despite this reassurance, the Kidney Alliance remains apprehensive. A number of recent Government consultations have appeared to show signs that this decision is not necessarily finalised. For example the inclusion of proposed dialysis indicators in the Commissioning Outcomes Framework consultation that is intended to guide commissioning in primary care have concerned the Alliance. Fiona Loud commented: *“Either this is a worrying sign that the Government is still considering moving commissioning to GPs or it is a serious lack of understanding of kidney care.”*

“...strong direction”

Over 120 people attended the event. Speaking afterwards, Sally Taber, Chair of the Trustees of the British Kidney Patients Association (BKPA), a member organisation of the Kidney Alliance said:

“This year’s World Kidney Day event has highlighted the diversity of challenges in kidney transplantation. The BKPA supports the Kidney Alliance in calling for the full implementation of all 14 recommendations of the Organ Donation Task Force to be completed and their effects measured. We hope that the new strategy referred to by the Minister will deliver this and will be supported by strong direction. ”

Partnership

Charles Kernahan, CEO of Kidney Research UK, a member organisation of the Kidney Alliance emphasised the importance of partnership working between the NHS and third sector organisations to increase awareness of kidney disease, including transplantation, as well as in research projects to improve care.

Safeguard quality of kidney care

Fiona Loud concluded by calling on the Government to show their long- term commitment to organ transplantation by establishing a permanent strategic independent body and appointing a new National Clinical Director. She urged policymakers to safeguard the quality of kidney care by maintaining full integration of transplantation and dialysis as specialised kidney services. And she asked all MPs and Peers actively to support these calls.



“There is one way that everyone can help this situation,” she said. “Look after your kidneys by eating a healthy diet and exercising to keep down blood pressure. And if you are not already registered, please sign on the Organ Donor Register”.

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The Kidney Alliance is an umbrella organisation that brings together the patients’ voice and professionals committed to kidney care. It promotes prevention and early identification of kidney disease as well as the commissioning and provision of high quality treatment on a uniform basis throughout the UK.

Members: Association of Renal Industry, Association of Renal Managers, British Association for Paediatric Nephrology, British Kidney Patient Association, British Renal Society, Kidney Research UK, National Kidney Federation, Renal Association, Renal Nutrition Group, Royal College of Nursing.