



## **Kidney Alliance position statement**

### **Living organ donors**

This position statement has been created in response to the proposed European Parliament Amendment 31 to Article 15 – paragraph 1a of the Draft European Directive on Organ Donation and Transplantation.

More than 1 in 3 of the 2,497 kidneys transplanted in the 2008-2009 period in the UK came from a living donor<sup>1</sup>. That is to say a healthy volunteer freely donated one of their kidneys for transplant.

European Commission Amendment 31, (Article 15, paragraph 1a - new) to the Draft Directive proposes that, throughout all Member States:

*1a. Living donations shall be seen as subsidiary to post-mortem donations and only serve as a last resort where no suitable alternative such as an organ from a deceased donor is available. Living donations shall in principle be restricted to donations among close relatives and spouses due to the implicit danger of exploitation.*

We believe that if this amendment were to be upheld, it would have a significant impact on organ donation in the UK. Not only would the exclusion of unrelated, non-spouse donations result in a drop in live donations of over 10%<sup>2</sup>, but it would also be likely to prevent many other live donations from taking place where an organ from a deceased donor is available.

The Kidney Alliance believes that voluntary donation of organs by living donors is a vital part of the organ transplant programme. At March 2009, there were 7,174<sup>3</sup> people on the active transplant lists in the UK waiting for a donor kidney. This illustrates the widely known deficit in the availability of donor organs compared with those needing a transplant. Live donations have a superior outcome to cadaveric, especially non-heart beating donations. Kidney transplantation requires multiple organ sources and a single source will not fulfil an ever-growing need. The Kidney Alliance is strongly against putting additional pressure on the UK system by further reducing the number of available organs where there is no good reason to do so.

The Kidney Alliance believes that voluntary organ donation should not be impeded or discouraged where donation is independent of financial or other incentive and where the decision to donate has been made freely and without coercion or other undue influence. An individual should have the freedom to make their own decision as to whether or not to donate, subject to medical considerations.

Consequently the Kidney Alliance strongly opposes the proposed Amendment 31 to Article 15 – paragraph 1a of the Draft European Directive on Organ Donation, as the current wording of the amendment would make it significantly more difficult for relatives and spouses to provide live donation and would rule out donations by other unrelated donors. The effects of this in the UK would:

---

<sup>1</sup> Transplant Activity in the UK 2008-2009, NHS Blood and Transplant, P11 Table 2.6

<sup>2</sup> Data from Kidney Research UK

<sup>3</sup> Transplant Activity in the UK 2008-2009, NHS Blood and Transplant, P9 Table 2.3



- Significantly reduce the total number of donor organs available at a time when there is a chronic shortage of such organs.
- Discourage all living organ donation.
- Remove a valid, important choice and impede an individual's freedom freely to donate an organ where there is no medical reason why they should not.
- Increase the numbers on dialysis and therefore the economic burden of healthcare in the UK.
- Result in poorer outcomes for patients.

The Kidney Alliance agrees with the overriding principle that any donation should be made without any undue influence on the donor and we believe that the UK has robust and adequate systems to ensure that this is the case. We do not agree that the risk of exploitation of living donors in the UK is sufficiently great to warrant the restrictions in the proposed amendment.

The Kidney Alliance would prefer to see a more flexible European approach that allows for differences in the safeguarding systems present in each Member State. Therefore the Kidney Alliance supports the reworded amendment put forward by The European Kidney Patients' Federation (Ceapir), which reads as follows:

*"Member states should make their own policies on living donation, in particular whether it is complementary or subsidiary to deceased donations and whether it should be restricted to close relatives, spouses, partners and close friends or expanded to altruistic donation and donation pools etc. However, each member state should ensure that the competent authority respects the potential for poorly or unregulated living donation to bring living transplantation into disrepute, Each member state accepts it has a responsibility to its fellow member states to ensure that living donations are regulated in a way that minimises its potential for exploitation".*

We believe this would prevent unrelated, non-spouse living donation where adequate safeguards do not exist but would not stand in the way of its going ahead under appropriate conditions. Under this wording, there would be no impact for the UK.

The Kidney Alliance calls on all Parliamentarians, policy makers, health care professionals and patients to support this reworded amendment and to ensure that this is strongly represented at European level.

**Kidney Alliance  
February 2010**

---

The Kidney Alliance is an umbrella body representing the interests of patients, charities, industry and professional groups. The aim of the Kidney Alliance is to bring together the patients' voice and professionals committed to renal medicine. Its membership includes:

Association of Renal Industry  
Association of Renal Managers  
British Association for Paediatric Nephrology  
British Kidney Patient Association  
British Renal Society  
British Transplant Society

Kidney Research UK  
National Kidney Federation  
Renal Association  
Renal Nutrition Group  
Royal College of Nursing