

Dear sirs

Please find pasted below the NKF's Policy covering this matter :-

## **Passed by the NKF September 1999 (amended 2008)**

### **ORGAN DONOR SYSTEMS**

#### **The gift of life**

The National Kidney Federation supports the concept of altruism in organ donation whereby organs for transplantation are a gift by the deceased donor.

The system supported by the NKF (which currently does not operate in the UK) is known as 'opting-out', or presumed consent, whereby a person is assumed to consent to donation unless they register their choice not to donate. Such choice would be maintained on a Register. The Federation actively campaigns for this change to the "opt out" system.

Donation from someone who consented to donation whilst alive no longer requires the approval of the next of kin, although in practice this is sought.

In the meantime the Federation continues to encourage those who wish to donate organs after their death, to ensure that their name is on the NHS Organ Donor Register.

Organ Donation is overseen by the "Human Tissue Authority" and operated by UKTransplant.

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#### **Note(s)**

The system, which currently operates in the UK, is known as 'opting-in'; the making of a conscious choice by an individual to donate to save life or improve the quality of life of others, by taking steps individually to place their name on the central register of organ donors.

The alternative to the UK system and supported by the NKF is 'Opting out' and is the system described above. Many European countries operate such a system and whilst the evidence of its effectiveness is unclear, it should at least ensure that relatives know that their loved one had not specifically elected not to donate.

A survey of Federation members in November 1994 showed a majority in favour of an 'opting-in' system of organ donation; however, recognising that there was an increasing shortage of organs for transplantation in the UK, the National Kidney Federation carried out a further survey via its Kidney Life Magazine in summer 1999 which showed a significant majority favouring the opt out system. The Federation

then voted at its September 1999 Council meeting to support an 'Opting-out' system in the UK, providing that all necessary safeguards for the donor and donor relatives remained in place. The decision was made soon after the BMA announced that it had decided to support an 'opting-out' system.

The publication (and full acceptance by Government) of the 2008 Organ Donation Task Force report, promises important changes to the Transplantation infrastructure within the NHS so that Transplantation becomes the usual – not the unusual. It is thought that these changes when fully implemented will increase the number of transplantation operations by 50% over a five year period commencing in 2008. In the NKF's view the number of operations then being performed will rise to 75% of the known need.

The Federation will encourage members of the public who wish to donate organs after their death to join the NHS Organ Donor Register, whichever system is in place.

### About The NKF

The National Kidney Federation is unique because, although there are a large number of kidney charities, the NKF is the national kidney charity actually run by Kidney Patients for Kidney Patients – it covers the whole of the UK.

Most Renal units have a **Kidney patient Association (KPA)** specifically attached to that unit, however, in 1978 these independent charities realised that they needed a national organisation to fight their cause as renal provision was in dire difficulties, overstretched, and under resourced. If ever there was a case of post code provision, renal disease was it! Currently there are 69 KPAs and they come together as the controlling Council of the National Kidney Federation, the KPAs are both the ears and the eyes of the NKF and its controlling force. Patients are the Officers of the NKF, the Executive Committee of the NKF and the workforce of the NKF. Apart from six members of staff, all other personnel are either Kidney patients or carers of Kidney patients.

Unlike other kidney charities, the NKF has only two roles campaigning for improvements to renal provision and treatment, and national patient support services.

### **Campaigning**

The NKF lobbied for, and got, an **All Party Parliamentary Kidney Group** of 174 MPs and Lords established in Parliament and they feed that group on a day to day basis with the information needed to keep renal disease in front of the nose of Government.

They maintain a continuous dialogue with Ministers and the Department of Health. They attend all of the main Political Party Conferences, and they joined with others under the BMA umbrella to be founder members of the **Transplant Partnership**.

When the Government announced that 34,000 renal patients were too small a group to warrant a **National Service Framework** the NKF took action. They formed with others a new charity **The Kidney Alliance**, and then worked with other members of it to create a Dialysis version of a National Service Framework (NSF) of their own. Then, they launched this document within the House of Commons in front of the very Ministers who had rejected the idea of an NSF. The Government took only 4 weeks from that day, to reverse their decision and announce a Renal NSF of their own. Quite a victory for any group, let alone a group of very ill patients! Part 1 of the Renal NSF was published by the Department of Health on 14 January 2004 ([click here](#) for more information) with part 2 following in February 2005. The NKF provided considerable support and input to the Department of health during the preparation of these two vital documents.

## Patient Support Services

The National Kidney Federation provides and maintains a **website** which has rapidly become the hub of the renal community. This website [www.kidney.org.uk](http://www.kidney.org.uk) is vast, being larger than 5,000 pages and viewed by more than 200,000 patients, carers, renal professionals, doctors and nurses worldwide every year. The site is even more incredible when it is realised that like the NKF itself, the website was built by kidney patients. If the subject is renal, the answer is on this fantastic website. Above all the website has brought patients real information about their condition, and it has put patients in touch with each other. It has given kidney consultants, doctors and nurses a chance to talk with each other, and with patients, about issues and concerns that before the website they may have been completely unaware of.

For those that do not have access to computers, the NKF runs a low call cost **National Kidney Patients HELPLINE** (0845) 601 02 09 which takes about 200 calls a week from patients, carers and healthcare professionals, and the NKF distributes its own magazine *Kidney Life* completely free of charge four times a year to more than 19,000 renal patients.

Because the Medical Information on the NKF website is so comprehensive, the Federation decided that the website would become the basis of all future **Kidney Disease leaflets**. Within two years of that decision the NKF became the largest provider of renal leaflets in the UK. Whether you are an individual facing a Kidney Biopsy and just want one leaflet, or a Renal Unit requiring three thousand leaflets on Anaemia, the solution is simple. You ring the Helpline and say what you need, then the information is downloaded into a set format, printed out, and put in the post that very same day. Thousands of different leaflets are possible, from travel insurance and holidays, to dialysis, transplantation and living donors.

Sadly problems continue for many renal patients and frequently the Helpline finds it necessary to refer the matter to its own **Advocacy Officer team**, who then brings into play their experience of the issues, the problems and the frustrations of current provision. Many patients and carers have been helped by the National Advocacy Officer and many KPAs have taken up a local fight with his assistance. The Advocacy Officer also represents the NKF at many management and Commissioning meetings.

Once a year the NKF holds its own **National Conference** to which more than 400 renal patients attend over a three day period. This is a very special occasion and one that takes much organisation. However, it is very successful and it provides a platform for the NKF to listen to patients, and for patients to tell the NKF where the shortcomings are in renal provision. Frequently, Government ministers and healthcare professionals are on hand to hear for themselves the issues, but above all it is an opportunity for a thorough exchange of views.

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