

Health and Social Care Committee  
Human Transplantation (Wales) Bill  
HT(Org)11 - Welsh Kidney Patients Association



# Welsh Kidney Patients Association

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### **Health and Social Care Committee Inquiry: Human Transplantation (Wales) Bill**

#### **Introduction**

The WKPA which is run entirely by unpaid volunteer patients and carers, is the only independent renal charity covering the whole of Wales. The Association aims to work on behalf and to the benefit of its membership of over 2,500 renal patients, including pre-dialysis, dialysis and transplant patients (and carers), throughout Wales. The WKPA magazine '*Kidney Matters Wales*' is currently sent to 1,350 individual patients and to every dialysis unit in Wales.

Our Association provides a means of liaison and consultation with the various organisations with responsibility for providing renal services across Wales. At every opportunity, we provide input from the patients' perspective and aim to highlight and raise awareness of their needs. The WKPA undertakes regular surveys and questionnaires to ascertain the views of its members on all aspects of their renal care enabling us to represent our members in the most effective manner and campaign for improvement. During 2007 and 2009, we conducted surveys of our members with regard to the introduction of the soft opt out system in Wales. In both these surveys approximately 80% of our membership voted in favour of introducing the 'soft opt out law' in Wales. The WKPA's response to the Inquiry into Presumed Consent on Organ Donation, held by the Assembly in 2008, supported the introduction of the soft opt out law. In addition the WKPA submitted responses in favour of the soft opt out law to the Welsh Government White Paper (Proposals for legislation on organ and tissue donation) in January 2012 and to the Draft Human Transplantation (Wales) Bill in September 2012.

The letter of acknowledgement (Oct 8<sup>th</sup>2012) for the latter response states:

*“We are very grateful for all the point you raised. In particular, your comments about the role of the family and questions on residency issues are very helpful and will be given careful consideration as we move forward.”*

As an Association we are pleased to have received specific feedback clearly indicating that our comments highlighting concerns on the issues quoted above have been duly noted for future reference.

On behalf of WKPA members we hereby submit the following response to the Health and Social Care Committee’s Inquiry/ Consultation into the above Bill.

2

## **1. The Individual provisions set out in the Bill.**

*Section 2: relating to the promotion of transplantation.*

The WKPA supports that it must be the duty of Welsh Ministers to:-

- a) promote transplantation in the UK and is pleased that it is recognised by the WG that transplantation is a means to improving the health of people in Wales. In addition, because any organs that become available for transplantation in Wales will be allocated by NHSBT on a UK wide basis, this will include improving the health of people in the UK as a whole.
- b) It is essential that Welsh people are aware of transplantation and the related issues involved in organ donation and thereby able to make informed judgements and decisions.
- c) The public must be made aware of the changes that the Human Transplantation (Wales) Bill will make to the organ donation system in Wales. Equally there is a need to provide clarification that specific aspects of the manner in which transplantation proceeds will remain unchanged in accordance with the Human Tissue Act of 2004 (eg. consultation with and regard for families’ wishes). Particular care must be taken to ensure that everyone in Wales who may “qualify” as “potential donor” is aware of the need to “opt out” of the system should they so wish. The meaning and difference of “deemed consent” and “express consent” should be explained in simple language so that there is no confusion in people’s understanding of the law. Additionally, the relevance of the expression ‘soft’ opt out must be emphasised.

*Section 3: relating to lawful transplantation activities.*

Transplantation in Wales has been lawfully carried out to date under the Human Tissue Act (2004) the WKPA supports the authorisation of all lawful transplantation activities as described in this section of the Bill.

*Sections 4-8: relating to consent.*

In its response to the Draft Human Transplantation (Wales) Bill in September 2012, the WKPA stressed the need for the Welsh Government to explain in language that can be easily understood all the issues relating to consent, both deemed or expressed. In addition, there must be clarity on issues concerning the consent of children and those lacking capacity. Legislation requires that terminology used be such that makes the law infallible. The WKPA trusts that all the necessary safeguards have been included to prevent any organ or tissue being removed from a body without the consent of the deceased or the next of kin.

*Sections 9-11: relating to offences.*

Again, transplantation has been a legal activity in Wales to date under the Human Tissue Act (2004) and as such, the WKPA supports the Human Transplantation (Wales) Bill's commitment to ensure that there will continue to be no offences committed regarding the illegal use of organs or tissues in Wales.

*Sections 12-20: which makes general provision.*

The WKPA has no comment to make on the above sections except to state that it realises the need to amend and/or incorporate parts of the Human Tissue Act 2004.

3

## **2. Any potential barriers to the implementation of these provisions and whether to Bill takes account of them.**

The WKPA can see no potential barriers to the implementations of these provisions. Opt out systems are operating successfully in other countries. Studies have shown that, where there is an opt out system on organ donation, organ donation rates are higher. It has been stated that these higher rates are not solely due to an opt out system and that the necessary infrastructure plays a part in these higher donation rates. However, in Wales both through establishment of Health Board Organ Donation Groups to implement and introduce the recommendations of the ODTF, and the excellent facilities available at the new transplant unit at UHW, more transplant operations are currently being performed than was envisaged. In addition, the allocation of organs will still be made under the guidance of NHSBT, any increase in numbers of organs becoming available following the introduction of the Bill will be used throughout the UK.

## **3. Whether there are any unintended consequences arising from the Bill.**

The WKPA does not envisage any unintended consequences arising from the Bill.

In its response to the White paper on the proposals for legislation on organ and tissue donation submitted in January 2012, the WKPA states the following:-

*"The WKPA supports the new soft opt law safe in the knowledge that there will be ample opportunity for people to opt out and loved ones will continue to be consulted about donation. Over the years our members have trusted NHS staff to advise and oversee their treatment and to act ethically and within the guidelines for organ donation. There is no reason to believe they will not continue to act responsibly and sensible in implementing this change in procedure here in Wales"*

## **4. The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum (the Regulatory Impact Assessment), which estimates the costs and benefits of implementation of the Bill)**

Paragraph 93 of the Explanatory Memorandum states:

*“This Regulatory Impact Assessment appraises the impact of the WG’s draft Human Transplantation (Wales) Bill. It is found that the benefits associated with an increase of one donor per year more than offset costs incurred”*

The RIA also states:

*“the cost of a kidney transplant is £50,000 at 2011/12 prices, and there is a follow-up cost each subsequent year of £8,000. Each year there is a saving in kidney dialysis avoided of £28,000.”*

A kidney transplant has an average life span of approximately 11 years, thus making a saving of £308,000 per patient. The Assessment continues to make assessment on the cost benefits of other major transplant operations e.g. liver, heart.

However to any transplant recipient, the benefits of a successful transplant are immeasurable and cannot be quantified in terms of value. In addition, following transplantation, sick people are able to return to work and contribute to society in normal ways, e.g. paying taxes.

4

**5. The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation( as set out in Part 1, paragraph 90 of the Explanatory Memorandum, which contains a table summarising the powers for Welsh Ministers to make subordinate legislation).**

The WKPA has no comment to make regarding the powers in the Bill for Welsh Ministers to make subordinate legislation other than to trust that the legal aspects of the Welsh Government to pass such a law has been thoroughly researched and that the WG has the capacity and power to do so.

**Concluding Statement**

The WKPA has supported the initiative to introduce a soft opt out law on organ and tissue donation in Wales since 2007. The Association has had representation on the Welsh Government’s Voluntary Stakeholder’s Group meetings, and is represented on the communications sub group of the All Wales Donation and Transplantation Advisory Group. We will campaign for the introduction of the ‘soft opt out law’ with the conviction that it will benefit the people of the UK as a whole.

John Reever

Chair

17<sup>th</sup>, January 2013