Health and Social Care Committee Human Transplantation (Wales) Bill HT(Ind)56 - Gloria Owens

15<sup>th</sup> January 2013.

## Response to the Health and Social Care Committee's Inquiry into the Human Transplantation Bill (Wales)

I am writing to support the general principles of the above Bill and to recognise that this legislation will increase the number of organs and tissue donations in Wales and the UK. There is no doubt that there is a shortage of organs for transplantation. The waiting list for a transplant is nearly 400 and in Wales, and approximately 7,000 in the UK as a whole. People die every day needlessly whilst waiting for a suitable organ that will save their lives. I had a successful renal transplant in February 1982, which still functions today. I have had renal illness since 1964, during all this time, there have been numerous campaigns to raise awareness of the need for more people to join the organ donor register. These have had a measure of success, but people still die waiting for an organ transplant.

Recent international evidence supports earlier studies that the introduction of an opt out system is associated with an increase in organ donation rates. This is obviously not the only factor involved. Clearly the necessary infrastructure has to be in place and public attitudes and understanding of the organ donation process need to be addressed. Studies have also shown that the family's wishes play a key role in organ donation rates. The UK family refusal rate being quite high. A review of evidence into the reason why next of kin refuse permission is a largely due to a lack of knowledge of their loved one's wishes.

In response to the main points raised by this Inquiry, I should like to add the following:-

1.

Section 2 The Welsh Assembly has consulted with the Welsh people at every step of the process of introducing the soft opt out law. I agree with the provision in the Bill that Ministers must promote transplantation as a means of improving health. It is essential that people are informed of what transplantation entails, and in particular, the meaning of express consent and deemed consent. The method by which any person who wants to opt out must be clear and readily available.

Section 3 All transplant surgery in the Wales and the UK has been legally carried out under the present system and this Bill will ensure that all future transplant surgery will continue to be legal. There is no place for illegal transplantation surgery under any system or any law in the UK or anywhere in the world

Section 4-8. Consent is the most important part of every organ donation system. This Bill will involve the next of kin in the organ donation process, as they are now under the current system. In addition the Welsh Government have already launched the "Heart to Heart" campaign to encourage families and friends to talk about their attitudes and wishes regarding whether they wish to be considered organ donors after death.

The Welsh Government is committed to raising awareness among the Welsh people leading up to and after the Bill becomes law. This Bill provides for children and those lacking capacity and makes clear the role that the next of kin or the person's representative has in the organ donation process.

Section 9-11 It is essential that the Bill makes clear what account as offences in activities relating to transplantation are. Offences are already legislated for under the present UK law. This will continue in the future under this Bill.

Section 12-20 I have no particular comment on these sections which appear to support the current legislation but make the necessary amendments for the Human Transplantation Bill (Wales)

2.

There is at present an excellent new kidney transplant unit in Wales which is well equipped to cope with any extra organs that will become available following the Bill becoming law. In addition there is such an acute shortage of organs on a UK wide basis that all organs that become available will be used. I see no potential barriers to the implementation of the provisions of this Bill, the main aim of which is to improve the health of people and promote organ transplantation

- 3. There has been much debate about this Bill and some people have indicated that they will remove themselves from the Organ Donor Register. The Welsh Government is aware of this as these views have been voiced both at public debates and through the media. The predicted increase in organ donors that the soft opt out system brings will negate that consequence.
- 4. There is no doubt that transplantation is cost effective. The savings to the NHS in treatment for patients, who would otherwise require years of expensive treatment, will be of huge benefit to the NHS which is currently under immense financial strain. In addition those people made well by transplantation will be able to contribute financially to the country.
- 5. Health has devolved to the Welsh Assembly. The referendum for more law making powers in Wales showed public support. Wales has passed its first law. I see no reason why Welsh Minister have not got power to make the subordinate legislation necessary to passing this Bill

I trust that the HSScommittee will take the above views into consideration when coming to a conclusion on this very important issue that I believe will benefit the people of Wales and the UK.

Yours sincerely,

Gloria Owens (Mrs)