

## **Response of the British Transplantation Society**

Thank you for asking the British Transplantation Society (BTS) to contribute to contribute to the consultation on the Human Transplantation (Wales) Bill.

### **1. Individual Provisions set out in the Bill**

#### **(a). Section 2, the Promotion of transplantation.**

The BTS is delighted to see the inclusion of a section mandating the Welsh Ministers to promote transplantation, provide information and increase awareness about transplantation, and inform the public of the circumstances in which consent will be deemed to have been given. Whether or not one supports “Opting out”, there is no doubt that increased public awareness is vitally important as is government support for transplantation. There is a similar requirement in the Human Tissue (Scotland) Act 2006 to “promote, support and develop programmes of transplantation” as well as to “promote information and awareness about the donation for transplantation of parts of a human body”, and the public awareness campaigns in Scotland have resulted in high rates of registration on the Organ Donor Register and a higher rate of consent to organ donation.

This section of the Welsh Bill and Scottish Act is sadly missing from the Human Tissue Act (2004) that currently applies to the rest of the UK.

#### **(b) Section 3, relating to lawful transplantation activities,**

The paragraph relating to storing the deceased person presumably relates to tissue and corneal donation. This seems reasonable. As it reads, the bill might support the removal of organs and tissues for transplantation with “deemed” consent, and these would include the more unusual and emotive forms of transplantation such as hand/arm and face transplants.

#### **(c) Sections 4-8, relating to consent,**

Section 4 paragraphs 1 to 3 are not contentious. Paragraph 4 essentially says that the Welsh system will be a soft opt-out, where relatives may oppose organ donation. If opting out legislation is to be introduced then such “soft” opt-out is the type that is favoured by the transplantation profession in the UK.

Section 5 (Consent: excepted adults) is important. In order to ensure a new resident to Wales becomes aware of the legislation within his/her first six months of residence it will be important to continue a programme of public awareness of the legislation at intervals no less than 6 months. The absence of such an undertaking would be a significant cause for concern.

#### **(d) Sections 9-11, relating to offences,**

No comments on this section

#### **(e) Sections 12-20, which make general provision.**

Section 12a states that it is “lawful (a) to take steps for the purpose of preserving the part for transplantation”. As transplantation advances, all opportunities to recover transplantable organs are being explored. One such relates to potential donors being admitted to an emergency department either dead or in the process of attempted cardiopulmonary resuscitation that then fails. In order to *optimally* preserve organs for transplantation it may be

necessary to administer drugs to the potential donor while maintaining an artificial circulation by cardiac massage, or establishing an extracorporeal circulation of blood to perfuse the organs. Such is the practice in parts of Spain and is also the subject of a pilot in Scotland. The wording of this section would seem to support such interventions in Wales, which go beyond the “minimal steps” permissible under the Human Tissue Act (2004). However the Bill then goes on to say that none of these steps to preserve organs can proceed without prior approval from a coroner (whose jurisdiction will apply to cases of sudden death such as those brought to the emergency department). A requirement for *a priori* approval of a coroner before undertaking “steps for the purpose of preserving the part for transplantation” would effectively prevent such steps from being undertaken in the timely manner that would be required were such donation practices to be explored in Wales.

## **2. Barriers to implementation**

The BTS can see difficulties in ensuring that newcomers who come to live in Wales are provided with the necessary information explained deemed consent. This is not so much a barrier, but a challenge to implementation of the Bill.

## **3. Unintended consequences of the Bill**

Adverse publicity is the major concern of the BTS. If a family were not present at death, but subsequently come forward to say that the deceased did not agree to donation, and that his wishes had been overlooked or that the database recording his wishes (the ODR) was inaccurate (which has happened with the ODR), there would be significant adverse publicity which would damage transplantation not only in Wales, but also the rest of the United Kingdom. The BTS would be reassured to know that contingencies for such an eventuality have been considered and will be in place ahead of such an event.

## **4. The financial implications of the Bill**

The Organ Donor Taskforce report “*The potential impact of an opt-out system for organ donation in the UK*” discussed opt-out legislation in general. One of the considerations during the Taskforce’s deliberations was balancing the high predicted costs of implementation of opting out compared to the lesser costs of a programme of public awareness campaigns, of the sort conducted in Scotland. The predicted costs of introducing opt-out in Wales are, we believe, significantly less than those predicted by the ODTF in their deliberations.

There is no doubt that renal transplantation is a cheaper form of treatment for a patient in renal failure than dialysis, and savings will be made as more patients are removed from the dialysis programmes in Wales. At the moment this is a function of the organ donation activity throughout the United Kingdom, rather than in Wales specifically, since organs are, and will continue to be, exchanged on a National basis to optimise matching and outcomes.

## **5. The appropriateness of the powers in the Bill for Welsh Ministers**

No comment.

**Additional comments**

It appears that, through this bill, Wales will introduce opt-out legislation, and as such will be the first nation in the UK so to do. The BTS would strongly encourage every effort be made to record the process carefully, detailing the costs and the final outcome, so that the other home nations can learn and assess whether it is something they wish to do. It would be tempting for the government to audit the process itself, but it might be better received externally were some independent assessment be included in the process and we would like to encourage this.

The BTS would like to see provision in new transplant legislation such as this for pharmacological interventions in potential organ donors, particular those potentially donating after circulatory death (DCD). Currently heparin cannot be given pre-mortem to such donors, even if the blood pressure is terminally falling and has fallen below 50mmHg. DCD donors now form a third of all deceased organ donors in the UK and an intervention such as this may make a significant difference to the outcome of transplants. It is permitted in parts of North America.