



Kidney Wales Foundation
Sefydliad Aren Cymru

Charity Number 700396

**The Human Transplantation (Wales) Bill
Evidence to the National Assembly for Wales
Health & Social Care Committee
Supplementary Evidence by Kidney Wales Foundation (2)**

On lack of donors from Black, Asian and Minority Ethnic backgrounds

We must draw the Committee's attention to two reports published on 13 of February 2013 by the National Black, Asian and Minority Ethnic Transplant Alliance (NBTA) which show that donors from Black, Asian and Minority Ethnic backgrounds (BAME) must urgently come forward if the prospects for those requiring transplants are to improve.

It is our view given the lack of progress in the UK the only way to do this is by changing the system as proposed by this Bill and ensuring that there are more organs available.

People from a BAME background are three times more likely to need an organ transplant than the rest of the population, but fewer than 2% have recorded their wishes on the NHS Organ Donation Register. Around 90% of white Caucasian patients in need of a bone marrow transplant may find a match, while for BAME individuals the matching rate can be as low as 40%. The best match is likely to come from someone in the same ethnic group as the person needing a transplant, however it is much harder for people from a BAME background because there are fewer people from these groups on the registers. In addition, each different ethnic group is itself diverse, compounding the problem.

For the first time, UK organ and stem cell data on BAME donation has been analysed. The results raise a number of serious concerns about BAME donation that urgently need to be addressed. The findings show:

On organ donation,

- There has been little change in the number of donors after death from BAME background over the last four years. The national figure remains below 50 BAME donors per year.
- There has been an increase in the number of BAME patients awaiting an organ. Around 25% of those on the transplant waiting list are from BAME background.
- While numbers of some ethnicities joining the organ donation register have gone up, there has been no increase in those from a Pakistani, Bangladeshi or African-Caribbean background.

On stem cell donation

- A multi-pronged approach is needed to meet the needs of BAME patients. More BAME donors must be recruited to the registers, more cord blood from BAME mothers should be

collected, and the establishment of registers in countries of origin of BAME people should be supported.

- More must be done to encourage people from BAME background to register as bone marrow donors.

There are supporters of the deemed consent in the Muslim faith. We spend a great deal of time with Muslim families helping them overcome fears of transplantation.

The NBTA reports can be found here www.nbta-uk.org.uk

Every year, 180 people from these ethnic groups die waiting for a transplant because of a chronic shortage of suitable organs.

It is very clear that Faith Groups are in favour of organ donation so why would they not follow other multi faith countries such as Belgium and Singapore in adopting a new progressive approach to organ donation. The new Bill is progressive. Faith Groups have not put up any case to support their claims that the legislation will not work.

The National Kidney Federation note that the findings highlight the fact that a more strategic approach is needed to address the challenges facing patients from BAME background. The responsibility rests with the NHS, NHSBT, hospitals as well as the BAME communities themselves. NBTA has started working with key partners in this area and will closely monitor what happens as the new Organ Transplantation 2020 Strategy is implemented from April 2013 onwards. We believe nothing will be different until there is a fundamental change in the law.

Black and Asian people are dying because there are not enough people from communities coming forward as stem cell or organ donors. This Bill will be the lead Bill for the UK that can change this deplorable situation.

Roy J Thomas

15 February 2013