

# Personal Statement

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Organisation: BODY (British Organ Donation Society)

Appraisal: Machine perfusion systems and cold storage of donated kidneys

## Personal Contact

In August 1995 I came home to find my stepson ██████ (apparently) asleep on his bed. I was unable to wake him and called an ambulance and ██████'s mother – ██████. The medics were also unable to wake him and after 20 minutes they decided to take him to ██████ Hospital in ██████.

During the journey ██████ stopped breathing and on arrival at the A&E was rushed inside for a brain scan. Here it was discovered that he had had a spontaneous cerebral haemorrhage due to an AVM and the doctor's view was that it would be too dangerous to operate. The doctor also felt that, should ██████ survive, the amount of brain damage sustained would preclude return to any normal life. He explained that although ██████ was on a life support system, there was really no chance of survival. ██████ and I clearly remember ██████ in his hospital bed looking fit and healthy, sun tanned and 'breathing' deeply. He looked in a deep sleep with only slight movements of his arms disturbing his repose. But he was lost to us and we both knew that, although acceptance was harder to encompass.

During this period ██████ and I were asked if we would agree to ██████'s organs being taken to help improve the life of others ("save" the life in one case). We both knew ██████ did carry a Donor card, and had done for years, yet even so the decision was difficult to make. There were no transplant coordinators as such in the hospital at the time and although we both gave permission the whole process was both traumatic and haunting. The why is not really relevant here but what did remain, and is relevant here, is how we perceived the transplantation process in our unconscious reasoning.

We did not see in our minds eye the incisions and removal of the organs as such, what we saw was the rapid transplant of part of our son into the warmth of another living being where it would survive and help them survive.

## Organisational Contact

Late in 1995 both ██████ and I joined BODY, becoming more active in the society as the years went by until I took over as chairman from Dr. John Evans in 2007.

BODY provides support for both donor families and recipients and their families; it also aims to provide information to the public to enable them to make an informed choice. Part of both these aims is BODY's wish to make the public 'comfortable' with the transplantation process. As this also involves the subject of death itself it is a nigh impossible task in the present day.

BODY has spoken to many donor families and many recipients, not on the particular topic of this appraisal but in general about their feelings, views and fears. In addition, when we mount a campaign to promote awareness, we speak to the public at large and listen to their views. It is not a matter of asking them to sign onto the Organ Donor Register (few do there and then in any case) but listening to their reservations. In this way we are speaking to the 'potential donors' themselves and trying to assess their view.

I think it true to say that the public at large rarely think of organ donation or the transplant process. Publicity regarding said process (Presumed Consent, lack of donors etc.) receives passing recognition but generally is felt not to apply to them. I of course exclude donor families, recipients and the charities that support them. In general the public has a perception of transplantation but are mostly removed from the reality.

Unless of course they require a transplant or are in a position to agree to a donation, then any preconceptions will colour their views and decisions.

One of BODY's major worries is anything that could worsen the public's perception of transplantation, an 'Alder Hey' revelation that could turn the best of intentions into a criminal witch hunt.

## **The Appraisal Itself**

BODY and I have neither the expertise nor the wish to comment upon the actual clinical/mechanical process itself. In general any process that can increase the viability of organs or tissues we would welcome. Our consideration, and they may not apply at the moment, lie in how the public will see the process. In particular and in brief:-

The donor's kin: Currently the public see 'cold storage' as the cool box used to transport the organ from one site to another – and they are accepting of this. This is a means to an end, a process of transfer and not storage. Do the processes under appraisal still fall within this framework?

The recipient: Somewhat similar to the donor's kin above. In addition, ideally the best chance of success for a recipient is a living donor, possibly perceived as two operating tables next to each other. Time, distance and method all factors that impact on the recipient's survival rate. A recipient is always aware of the time factor, how long their transplanted kidney will last. Subsequent doubts brought to bear on any transfer factor can severely affect them and their family. The process of testing must leave no loophole for the media to exploit at a later date.

The potential donor: There is a thin line between transplantation and 'spare part' surgery. But this line becomes a chasm between a donor and a 'spare part' provider. Presumed Consent treads close to this as it can represent the organs, and by association the living owner, as a commodity. This is often not helped by the dehumanising terminology employed at times by the health professionals themselves (harvesting, cadaver). Most people sign onto the ODR as an act of faith in humanity, their perception is to give a life back to those in dire need. Is the intention 'cold storage' for transport, or is it 'cold storage' for later use? Logically they come to the same thing; perceptually there can be a world of difference.

In summary, both I and BODY are concerned not with the procedure itself, but how the public will interpret it. Experience has shown that often perception becomes the reality.