

This response was submitted to the consultation held by the Nuffield Council on Bioethics on Give and take? Human bodies in medicine and research between April 2010 and July 2010. The views expressed are solely those of the respondent(s) and not those of the Council.

The Lewis Prior Foundation

Question 16

ANSWER:

Apologies if i am posting this in the wrong box, but you will get it and that's the main thing. After the loss of our son Lewis on April 6th 2004 aged two years and eight months we continually aim to raise awareness regarding the current organ donor system in the United Kingdom. Lewis was born with a serious heart defect which resulted in him being placed on to the transplant list and sadly the call we prayed for did not arrive. please visit www.thelewispriorfoundation.org We personally are unsure as to whether the opt-out system is the way to go in this country, not so much because we feel it would not work as we are sure it would increase the number of registered donors. But we strongly feel that before it is to possibly be brought in to force, more awareness is needed regarding it, the public need to be better educated about how it would work. Whenever the opt-out is debated on television we hear the reporter talking about it and he clearly states that if brought in everyone in the country would automatically be placed on to the donor register. Yes this is true, but what is needed straight away is for the reporter to clearly state that people would then have the option to remove themselves if they so chose to. So many times we are told by friends, family and people we come into contact with that they believe the opt-out system is a big brother system, that the powers that be are telling the public they will be placed on to the donor register. Yes the reporter may state after in his report that people can remove themselves but by then it is to late as many have switched off, or are saying to whoever is with them at the time, that the government can forget that as they are not automatically placing them on any list. From that moment on the public's view of the opt-out system is that it's a rubbish, big brother type system that they won't entertain. Not many fully understand that they would have the right to remove themselves. With this in mind we at Lewis's Foundation firmly believe that a nationwide leaflet campaign & media campaign is needed. The leaflets need to go to every household in the country explaining what the opt-out is all about, with a helpline number if questions are needed to be asked, this is the only way peoples worries, fears and doubts are hopefully going to be squashed. It is possible that the leaflet would be left on the side for a while as people are busy and may not have time to read it, but when at home with their family relaxing it may be then they pick it up and read it, start discussing it with their family in the comfort of their own home. People need to be aware what options are open to them, what the opt-out is all about. The only way to do this and to educate them more is a leaflet campaign to every household, and not just a three minute slot on the news channel once every blue moon. Thank you Karen & Colin Prior.