

By email: “[redacted]”

Tel 020 7269 1960
Web www.hta.gov.uk

Date 7 March 2014

Dear “[redacted]”

Freedom of Information request

Thank you for your request for information dated 20 February 2014, which we received as follows:

“I just wanted to know if there has been any directed altruistic donations in the uk? I also wanted to know how many of these donations have occurred?”

Response

It might be helpful initially to outline the definitions the HTA uses for different types of organ donation.

The HTA defines directed donation as a form of donation where a healthy person donates an organ to a specific, identified recipient with whom they have a genetic or pre-existing emotional relationship, for example husband to wife.

The HTA defines directed altruistic donations (DAD) as those cases which fulfil two conditions (a) the donation is being directed to a specific individual and (b) there is no evidence of a qualifying genetic or pre-existing emotional relationship between the donor and recipient. These cases tend to be characterised by a third party - either a person or other mechanism bringing the donor and recipient together for the purpose of transplantation.

In September 2012 the HTA introduced a framework for the assessment of these cases. Since then the HTA has approved 16 such cases.

The HTA is obliged to consider any application that is submitted; however we consider DAD cases to carry a higher degree of regulatory risk in relation to duress,

coercion and reward and these cases are therefore subject to additional scrutiny. Specially trained enhanced Independent Assessor's (IA) are required to undertake the interviews with donors and recipients in these cases.

The British Transplantation Society (BTS) has produced guidance advising that referrals that arise from paid advertising or via websites where potential recipients pay a fee to register their need for an organ transplant will not be accepted for living donor assessment. The practical implication of this is that donors and recipients using such a service would not be accepted for assessment by clinicians in the UK.

Consequently none of the applications the HTA has received for DAD cases have been from people that have met through social media or via matching websites.

The HTA does not hold data on which approvals proceed to the transplant taking place.

If you are unhappy with the way the HTA has handled your request for information in this case, you may in the first instance ask us for an internal review by writing to us at the above postal or email address.

If you remain dissatisfied with the handling of your request or complaint, you have the right to appeal directly to the Information Commissioner for a decision, at the address below:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF

Telephone: 08456 30 60 60
or 01625 54 57 45

Website: www.ico.gov.uk

There is no charge for making an appeal.

Yours sincerely

"[redacted]"

"[redacted]"

"[redacted]"