

Ms Gwen Skinner  
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26 June 2002

Dear Ms Skinner

Attached is the British Humanist Association response to the consultation on information about donors. Here follows a little information about the BHA and the arguments underlying our response:

The British Humanist Association (BHA) is the principal organisation representing the interests of the large and growing population of ethically concerned but non-religious people living in the UK. It exists to support and represent people who seek to live good and responsible lives without religious or superstitious beliefs. It is committed to human rights and democracy, and has a long history of active engagement in work for an open and inclusive society. The BHA's policies are informed by its members, who include eminent authorities in many fields, and by other specialists and experts who share humanist values and concerns.

Humanists generally support openness and honesty in relationships and for those reasons support openness about the origins of donor offspring. Humanists also believe in examining the evidence and considering the consequences for society and for individuals before arriving at conclusions or opinions.

It could be argued that medical histories and information regarding possible relationship to intended marriage partners (and non-marriage partners too) are the only essential pieces of information to be transmitted to children. However this limited information does not seem to satisfy the needs / demands of children, who appear to want far more information about their genetic inheritance. We favour honesty with children and full information, where possible (i.e. not retrospectively) with safeguards and processes such as those in place for adopted children seeking genetic parents. Research shows that donor-assisted children have coped with the availability of information when they reach 18 in a matter-of-fact way and it has not spoiled relationships within social families. However, the survey samples have been very small as few of these children come forward, and even fewer are from states where information has been available for long (only one, in California, has reached the necessary age). The ending of donor anonymity, where it has occurred, appears to have affected the availability of donors only temporarily.

There are also issues around the rights of donor offspring: to “as far as possible, know... his or her parents” (Convention of the Rights of the Child, 1989) and to access information held about themselves on databases (Data Protection Act).

The figures on the numbers of children that are not told that they are donor offspring raise the question of how to create a culture of openness where the child’s right to know is respected. If details of genetic information are kept in a child’s medical records, and the young person has access to these at 18, this would encourage honesty within families.

However, full information should be given only with the consent of the donor, though this could be sought retrospectively from existing donors. There was an implicit (or even explicit) agreement with donors that information would not be released and this should not be broken as it would be a very bad precedent. For future donations consent to disclosure should be a condition.

I hope this is helpful. This part of our response may also be made public.

Yours sincerely

Hanne Stinson, Executive Director