

SESSION 4: PROFESSOR JENNIE HUNT, SENIOR INFERTILITY COUNSELLOR, IVF HAMMERSMITH, HFEA AUTHORITY MEMBER = HFEA PLANS FOR OPENING THE HFEA REGISTER TO FAMILIIES AND DONORS

Speaker	Transcript
S1	<p>So, our first speaker is Jennifer Hunt one of our own authority members and she is going to introduce this session by providing an overview of the issues involved in the opening of the Register and to tell you a bit more about how the HFEA plans for addressing this and I think all I need to tell you about Jennie is that she is Senior Infertility Counselor at IVF Hammersmith and was Founding Chairman of the British Infertility Counseling Association, so over to you, Jennie.</p>
S2	<p>Thank you Lisa, I hope my voice is going to last out. I have been one of the victim of one of this horrible virus going around. I think this is a very important session for the Authority, and in fact for the whole sector because if we do get Royal Assent on the Bill the time when the Authority can begin to regularly receive request for information from the Register, will approach extremely fast and I think that the responsibility for delivering that information in an accurate and timely and sensitive manner is a considerable one but as Lisa said. I am just here really by way of providing a context for the speakers who we have invited today and I am going to be as brief as possible because we invited the speakers on the basis that they can contribute a great deal to knowledge and understanding of the issues that we will need to address. So, I am just going to very briefly, just rapidly go over the relevant versions in the current Bill, identify the changes in the Bill, and outline the arrangements the HFEA currently has in place. This is what you all know but some people do not quite realise that in 2010 every single 18 year old in the UK will have a right to ask if they are donor conceived and if they are, they are allowed to have descriptive identifying information about the donor as well as to ask for details about any genetic half-siblings. They can know the name of the donor if that donor was recruited before April 2005 or if the donor has elected to become identifiable and they can ask if they are related genetically to someone they are planning to marry. The HFEA also uses Discretionary Pass to give some limited information to both parents and donors and this is the kind of information that we know can be very important to young people growing up in full awareness of having been conceived by donation. The new Bill proposes some important changes, the first of which is to reduce the age at which most of this information can be received from 18 to 16. But for anyone who wants to know the name of the donor that would have to wait until they are 18, but the Bill gives people an additional right to just to know</p>

the identity of genetic half-siblings, if there is mutual consent on both sides. The Bill proposes a much more modern approach to the consanguinity issue because really what matters here is the intimacy of a relationship, not merely whether people are intending to marry and the Bill also recognises the importance of informing donors in advance of releasing identifying information about them to donor offspring. Now, you can see from this slide, **(points to projector)** there has been relatively few requests to the Register of any sort related to donation and all the requests we have received in this past year period have been from other donors or parents. And nearly all these people, the interest has been in knowing more about children conceived from a particular donor. But I think what is quite interesting also is the number of donors who have elected to register as identifiable but those donors having originally be recruited during the period when all donors were anonymous. And therefore I think that the HFEA can expect from 2010 for those to be 18 year old who are contacting us simply to say, has the donor agreed to be known to them.

Now at the moment, the only kind of request that the HFEA could respond to from a donor conceived person would be from people who are planning to marry and as you saw from the previous slide we have not had any such request however, we have put together an Interim Policy to cover such an eventuality and it is very simple as laid out here if we received a request from anybody, we will send them out in writing and explanation of what the procedure they needed to go to go through the information and that would also include advising them about the importance of seeking counseling about the implications of receiving any information . If you get an application it will have to be accompanied by ID and we would issue and confirm that ID before we do the register search and response was sent in writing. We would not be able to supply any information unless we have been able to confirm their ID.

Now, as Lisa has just mentioned, we have meanwhile set up a Working Group and its remit is to make recommendations on a long term handling policy for applications for information from the Register and also the principles that should underpin and inform that policy. So that Working Group is charged with reporting back to the full authority in early 2009 and we are looking to have a long term policy well in place before the commencement of the new Act, hopefully in October 2009. Now the Working Group and I am sure everybody in the HFEA is very, very aware of the extreme sensitivity of the information that is held and this is potential to impact very powerfully on any individual applicant and their family. We are also aware that because of the incremental process of legislation and regulations, that

there are going to be considerable differences between what anyone individual person may access from the Register. The most obvious example being between those who may and those who may not know the identity of the donor but we are also aware that there will be differences in the quantity, type and quality of information that is held because of the changes over the last years.

We are therefore mindful of the importance of seeking a way of providing or enabling people to access counseling before they receive this information and indeed after they have had it. Now this has to be taken on the context of the fact that the HFEA is a regulator not a service provider but we certainly want to play our part in ensuring that this counseling services do develop and are suitable for this rather specialist area of work. We will also be looking extremely carefully the training needs of our front line staff and in fact we are very fortunate at present because we do have a member staff who is undergoing Counseling Training,

So, where we are now in our current position is that we have an Interim Policy in place. Our Policy Group has begun work and we will report back in early 2009 and I think this is a very welcome opportunity today to hear from people who really can make some important contributions to us at this stage in terms of our learning and our understanding, and our planning in the coming months. Thank You. **(round of applause)**