

Professor Lisa Jardine CBE, Chair, Human Fertilisation and Embryology
Authority - "Decent people trying to do a decent job"

Speaker	Transcript
Professor Lisa Jardine	<p>Thank you so much, Alan for the challenge. Now I knew... I knew this is where I would find myself. This is why I didn't sleep very well last night. I knew I would find myself following the Minister and Sir Alan Moses. And I think I knew they would have charged us at the HFEA with an awful much, which is what they have just done. So I think I knew that my response should be and it isn't any effort for me to say this to you, that my response should be in the spirit of true humility. Because the first thing I want to say to you about us, and there are a lot of members here today including perhaps I would say very new members who have recently been appointed. I want just to characterize us to you and that is to all of you out there and your various relationships with us and it is really fascinating to me how diverse those relationships are. We are a bunch of decent people trying to do a decent job and that I think is my first response and which I think sits well both with the Minister's talk and with Sir Alan's because it is to say it's not to be overly modest, in no sense is it intended as overly modest. It is intended to say that we are exactly what we were appointed to be. Those who stand between the interest groups and the sector and the public and the wider world for whom it is a matter of the greatest importance and urgency how issues surrounding the creation of human life are thought about and resolved and we stand there and we do our best. So that is just my opening remark. We do it. I have to say and I said at the very beginning backed up with the most staggering array of staff support, expertise, brilliant insight, horizon scanning and so on, but at the end of the day, as Lord Justice Moses reminded us, we have to take decisions, which are the kinds of decisions that ought not to be susceptible to legal challenge in that the two of us agree. I am not saying for one second legal challenges are not going to happen over and over again and increasingly so, and I will come back to that if I stick to my script the slightest, in which so far I have not done. We take decisions on the basis of all the possible information available to us and we do it in the context of ethical ambiguity usually that is why we are called upon as an Authority to take the decision. But let me just come back to where I am intended to start. I think – they did not give my title. My title, since I was not going to be out done by Alan was, "Oh Brave New World", another Shakespearian title and I will relieve you the anticipation from the start which is of course that Miranda., Miranda in The Tempest who has seen no human being except her elderly father in her entire</p>

life and suddenly stumbles upon the gorgeous Ferdinand and says “Oh brave new world that has such people in it.” And I think we stand at a place where the world has not had such people in it as we are responsible for watching come to be for the lucky people and watch those who are unable ultimately even with assisted reproduction to have those families that they want, for those who are the product for those brilliant clinicians who manage that extraordinary miracle of creating life for those who believe they will not able to create it, for the scientists who are as the Minister reminded us, not on the brink of solving the impossible problems or seemingly impossible problems of finding cures for the most awful of diseases that beset our society but at least within years of it and heading we believe in the right direction. We, we at the Authority are both answerable to all of those parties. I am a lay chair. When the press raised an eyebrow, that the Professor of Renaissance Studies who did indeed write somewhere though I do not remember where that quote that Alan used about “how we all had to understand science because science came out of the life we lived in, live and fed back to the life we live in, we must all understand it”, and when the press raised an eyebrow that it should be someone like myself who has such the authority, they have not read Mary Warnock’s original explanation of what the HFEA would be. It would be guided by lay people. Every one of our committees, under the statute that sets us up, every single one of our committees is chaired by a lay member, that is by a member who is not of a party of any of the groups whom we regulate and it is the thing I think I am most proud of that is why I am so delighted that Lord Justice Moses should have drawn attention to the fact that we stand in this extraordinary position, we stand on behalf of. At the end of the day, the ordinary person in the street, the lay person who is deeply concerned, the person who is involved with, interested in, in some sense touched by either the research science which might ultimately solve the horrors of Alzheimer’s and Parkinson’s disease say, or touched by the hope that artificial reproduction might allow a person that aspiration to some posterity in their line that they had assumed were automatic and discovered was not. We are responsible for the decisions that are taken in very tricky cases on behalf of all of the above. We serve the treatment sector, patients and clinicians. We serve the research sector including increasingly, and it’s a particular interest of mine, the research sector that wants to make use of data mountain that we have since 1990, of information on the outcome of assisted reproduction, that could be suitably anonymised use of major projects about the future of the human race. We serve donor conceived people and their families. We serve the public at large. We are responsible for informing that public at large and for providing reliable explanations for that public at large. To go back to the treatment sector, I do believe that we are not just responsible for helping people

and there will be a number of you in the room desperate for assistance in having an own child, But we are also there to help those who are not going to be able to do so. We have I think and again it's one of, I'm giving you some of the planks in my own if you like platform, and as the recent chair of the HFEA, we have an enormous responsibility to the two-thirds of women who and – let me just speak of the women – to the two-thirds who will not have a successful outcome to IVF. Who will therefore have gone through a process which is involved as many of you will know the kinds of self-scrutiny, the kinds of pressure on their relationship, the kinds of extended difficulty with family, maybe with their faith, maybe with disapproval or raised eyebrows in a community. They will have gone through all of that, they will have reassessed themselves, they will come out as a different person and they will not have a child and we are there for them as well. If we are not there for them as well, then we are certainly not doing what we have been set up to do. For those who are donor conceived, we are there to help them through what will be and I have three adopted nieces and nephews and have therefore watched it with them the turmoil that will be produced in their life at some point when they come to terms or come to grips with... get to grips with whether as a good experience, as a neutral experience or as an appalling experience, come to terms with, the circumstances of their coming in to the world as being not like those of some of their friends and relations. Now having said that, there are two things that I therefore want to say to you that come out of that for me and for the Authority. One is that it is impossible and this just adds another layer to what Alan Moses is talking about. It is out of the question. It is inconceivable that we can please let alone do justice to the interest of all of those simultaneously all of the time. I mean that just follows from that list that I gave you just to give you an obvious and simple example, opening the register, the end of donor anonymity. For one of our constituencies donor conceived people, that can only be a step in a direction that they had always hoped for. There are people shaking their heads but I am only saying, ought not to be a possibility, many, I... I would have thought the majority of donor conceived people would feel that, and yet for donors and possibly for the parents of those children, this might be considered a catastrophe and this considered by some as a catastrophe and by some clinics it's considered to be making it almost impossible to get donors to come forward. So, we stand on the middle of that pool, or pond or morass trying to the best of our ability to balance those interests, to work through the issues that will arise as a result of those issues. And that therefore brings me to the second thing that I think comes out of serving all of these communities. I do believe, I said that we stand at a water shed. I do believe that as a mature Authority, a thoughtful Authority and as I say a decent and I hope suitably humble Authority, we regard our activities as

being in partnership with those groups. Now that's what I expect some shaking heads in this room and we will have presentations today that are skeptical about whether we are ironically laying down the law to the groups that we serve or in genuine open dialogue with them. But open dialogue it has to be for all the reasons that Alan Moses so elegantly raised because there is no right and wrong - I would say since I have been in Authority, one decision a day that I must take. Of course there are routine decisions but I think there is probably one decision a day where there is no right and wrong answer and where the outcome - I am not even going to call it that because it is such a dreadful management speech where the conclusion we reach and the action we propose will not be a box check exercise, it will be a balancing of options. If you are charged with balancing options, listening is the first of your obligations. So consultation, gathering patient experience, gathering clinician points of view, those are all I think a vital part of our - of what we are here to do. I think what I am here to do is at least in part, to raise my voice, to cut through the information jungle. I could look at the journalists in the room but I will avert my gaze to say that even the best journalist working in this sector confuse the public, not willingly or wittingly I hope, but simply because when the cuttings are put together in a piece that goes to the press in a rush, the four bullet points at the bottom of the story no longer reflect the state of affairs as the last judgment, last ruling or the last case and I look at the story and think, "Oh my God we are back with that again", and now I am going to have to sort that one out again cause I cannot sort it out because all I can do is to speak out. And I therefore on that count, just want to explain something to all of you which is to come back to the Minister's talk. The Minister, I think, I thought that was a nice talk, well I would think it a nice talk because she was very nice about us but I thought it was good and clear and I do not know how many ministerial talks you have heard. I hear a lot in education because that is the other field for which work and because I hear a lot in media and sports and they tend to be a brief written by those boys in the front row and that was her speech right down to the delegates asides and what that tells you is that bill is difficult, the bill is being very well steered, but while that bill is being steered, while the HFEA as a nonpolitical body and I as a lay nonpolitical Chair can brief parliamentarians, can provide information, and we provide an enormous amounts of information. I cannot speak out on any of the issues that are currently moot and difficult for the progress of the bill. It is therefore rather being odd for me for my first six months and probably why I am happy to stand up banging onto you here this morning that I have never, I have been unable to speak out on the bill until it becomes the Act. That is simply the position in which I find myself. So I took on this job saying that information speaking out going on every network, local radio station, going on to

woman's hour, going on and out of state wherever anyone wanted to talk about infertility and the HFEA, I have not been able to do that but I watch this space, watch this space when the bill goes through, that is the thing that I want and I think above all to do. It is part of my intellectual formation to believe that every person in the street is competent and entitled to make judgment themselves on the basis of all the evidence available put to them in the clearest possible way and I saw that happened with human admixed embryos. I saw that happened as the nature of the choice between using human eggs for research when eggs are in such short supply, the nature of the social research that is going to be done with human embryos and the nature what actually took place and the nature the process was explained to parliamentarians, was explained to journalists, was explained to people in the street, – what is annoyingly always referred to as the yuck factor receded. I want no yuck factor. There are no areas where I feel responsibly we should allow there to be a yuck factor. There is always a way to explaining this so people cannot leave to take informed decision and I therefore concur with Alan Moses in saying that any of you out there who feel that our decisions are not the ones that you would have wished us to have arrived at, could you please come to us before you go to judicial review? I do not think the law resolves this issue, that is exactly what we have been told. It is not its function to nor does it have the particular mandate to be able to resolve those issues because precisely they are not susceptible to a yes/no answer. They are ethical decisions, they are based – we hope on our part on deep scrutiny, deep thought, all the consultation we can do but if the decision is not the decision that was hoped for or expected, I do believe that we should use just the way in my own period the 16th or 17th century mediation in the local community was used, we should use more moderation, more mediation, Judicial Review, it takes us onto the realms of huge cost of settlement that are pyrrhic victories of people parading their victories which are actually not in the interest of their client and certainly not in the interest of the wider community, that is all I say on the law but I am going to add with one more contentious statement before I tell you what a great day we have ahead of us. The bill has not become law. I am not a political person. I am here as lay Chair. The bill ought to have become law in the summer but there is one area of the bill which prevents its doing so and that is the part of the bill that concerned with abortion. The part of the bill has nothing to do with us. It has nothing to do with the HFEA. It has nothing to do with the individual members. It has nothing to do with our staff or our experts. It is a historical accident that it finds itself able to be part of the bill. Some parliamentarians have made it their business to use that opportunity, to try either for strengthening the laws on abortion or liberalising the laws on abortion. And I have only one thing to say here

without any statement of where I would stand on that and that is that personally I am offended that the bill whose object is to help those who are unable to have children to do so, to help the research that will give hope to people with illnesses that currently have no cure, that we should be sitting on our hands waiting to resolve issues of huge importance that cannot be resolved until that bill goes through because of an opportunism in relation to something has nothing to do with the spirit and intention of the bill. I am allowed to say because I'm not a politician. I hope some of you may agree, you don't have to agree but I am at the beginning of this day we go forward with this devout hope, the devout hope that the bill will be on the statute book by the end of October that it will come into force when we finish all the regulations and the code of practice and so on October 2009 and I do believe that we are then in a brave new world. It is not a question of all the issues being resolved that would never be the case for the same reasons that Alan Moses explained. But we will be in A Brave New World. Today is about discussing the issues that lead up to that new world and I salute all the people in this room who in their very many and diverse ways are involved with assisted reproduction or are trying to benefit from assisted reproduction or have given their efforts in the light of their positive or negative experience in that area to making it a better experience for others. I hope you are going to have a wonderful day and I look forward to meeting a lot of you individually in the course of it. Thank you very much.