

SESSION 4: PROFESSOR OLIVIA MONTUSCHI, CO-FOUNDER, DONOR CONCEPTION NETWORK= OPENING THE REGISTER, THE VIEW OF PARENTS'

Speaker	Transcript
S1	<p>Terrific, we do have a lot to learn from you... a lot. Right, well, next speaker, Olivia Montuschi, following the singing of the Ugly Duckling is going a little bit tough I think, but if anyone can do, you can. Olivia is a co-founder of the Donor Conception Network and she is gonna be sharing her thought on the views of parents. Olivia is a parent of two young adults conceived through anonymous sperm donation and her background is in teaching, counseling, and parenting education. And I think...Is that enough do you think Olivia? ...for you?</p>
S2	<p>Thank you very much indeed Lisa, and also thank you for asking me to contribute today's conference. DC Network is really thrilled that the HFEA is taking so seriously the imminent opening of the Register and the contemplation of the range of services that are going to be needed to support donor conceived people and their families. And the first thing I want to say is something about the meaning of this information that is held, I mean you know, since 1991, the HFEA has been gathering all statistics and information about cycles of treatment, donors and children born as a result of assisted conception procedures but these lists as I think someone referred to earlier in the day are not those of a production line in a factory. We are not talking about widgets here. These figures represent the hopes and the dreams of men and women of starting a family and when procedures have been successful, the conception are very much wanted children. When donated gametes have been used to circumvent a fertility problem, the result is the creation of a very different sort of family. It is very personal.</p> <p>Now, here is Walter's and my family. A few years ago now, our kids are much older (flashed a family picture on projector) ... Here we are...and that is just representing all the families that there are for whom the opening of the Register is very meaningful. And as I said, the... it is all parents that conceive children who are affected not just those who have told, not just those who have not told, but everyone indeed. And most likely to view this information available in the positive light will be single women and lesbian families, both of whom have little choice about being open with their children and also have a tendency to wanting their children to have links with half-siblings, they are closely followed by heterosexual couples who have been able to adjust to and accept donor conception as a second choice but does not have to be second best. Now the kind of fears that this group</p>

of parents may have are likely to be about how their child might feel about the information they find if it does not meet their expectations rather than worries about relationships and the family being threatened.

The next group will be those who have been open with their children but possibly still have some sense of failure or stigma about their need to use donor conception. Their feelings about the Register opening may be anywhere on a spectrum from ambivalent to outright fear of rejection by their child in favor of the donor. Those parents who have not yet told their children about their origins may have most to be anxious about. The opening of the Register, if they are aware of it and that raises the whole issue of publicity about the Register opening may be seen as sinister or frightening, threatening the very foundations of family life. Some parents may decide that they now have to tell may or may not seek help in doing this. Others will sit tight hoping that their now adult children who will get to hear of the possibility of checking their genetic background. The shock would be profound, if these young people suspecting that something in the family felt wrong find out from the Register that they are they are donor conceived and then confront their parents as to why they were not told. Some apprehension about infringement of privacy and the integrity of the family is probably shared by all the groups to a greater or lesser degree and as one of the mums who has given DNA to UK donor link because our daughter has registered, I know how they feel.

Then there is the question of prospective partners, I mean worry from many parents who will come as their children form relationships and plan to marry and have children of their own. This may also be a trigger point for those who have not told to do so and of course, a donor conceived individual who is planning to marry can with their partner use the Register to find out if they are genetically related,

Well, Marilyn talked about services and I would say services, what services? As Marilyn said prior to the setting up of UK Donor Link, this never existed any professional service dedicated to the needs of Donor conception families. DC Network has always encouraged openness and supported families in sharing information with their children both from a very early age and with much older children.

In recent years, we have been consulted by parents in a range of very complex family situations with the need has gone well beyond what self-help network can offer. We have been extremely lucky to have the guidance and support of Sharon Pettle who is going to speak in a moment who has sometimes become involved

with these families on a professional basis. But unlike adoption where post adoption services are recognised as providing valuable guidance to all adoption families and intervention services when things go wrong, there is nothing available for the specific needs of donor conception families.

So what does this mean for the HFEA? Well, thinking back to the groups of parents I have just described or may require some level of empathy and support as children seek information from the Register. But for those who have not been open, the ripples of disturbance may spread back through the generations. There is a need for a service as described by Marilyn where parents, their children siblings and potentially grandparents can engage and disengage for periods of time according to where they are in their own process of thinking things through. It is very hard to anticipate what demand might be on any service. Many of the first children to be conceived following the establishment of the Register would be unlikely to have been told from a young age and as there is less likely to be less information to give them anyway, it may be that there will be fewer early applicants but that their situations and needs may be quite complex. As the years proceed more and more adult children will apply who have grown up with the knowledge of their origins. There may be more actual applicants but the need for the services may be less. This is a guess, and we absolutely cannot know this at the moment.

So, what about the future? Well, I have a co-incidence, the conditions that are well recognised as promoting family well-being of the same as those that may contribute to potentially fewer families needing complex services into the future.

These conditions are, parents who are able to talk about and grieve their inability to have a child that is genetically connected to both of them. Parents who are able to make an informed and considered decisions to use donated gametes that includes the conviction that openness with the children is best for every member of the family and being able to carry through that decision with love and responsive to everyday conversation of family life. Parents who feel confident and comfortable with the decision they have made and having dealt with many of their own issues, able to put the needs of their children first including listening to and managing feelings as they arise during the child's upbringing. Whilst some parents will manage this without help, many others will need support to prepare for parenting by donor conception and the role of the clinics in providing the environment in which these conditions may be advanced is absolutely fundamental.

So what does this mean for clinics? Well... in the past, fertility doctors would tell

couples who had undergone donor insemination to go home, make love, and who knows, thus encouraging men and women not to acknowledge the role of the donor in conception. I think these words are unlikely to be uttered in this century, but it is the shadow of these former times when donor conception was considered shameful that still haunts some of the clinics today. There is no doubt, but Clinic Staffs remain hugely influential on how parents think and feel about donor conception. Doctors, nurses, embryologist and counselors who fully understand that using donated gametes is not just another fertility treatment but actually a very different way of founding a family, can be of great value to a couple as they face very difficult decisions about their future. DC Network will actually go further and say that this is a responsibility. It is a part of the duty of care to patients for clinic staff to keep in the forefront of their minds the future well-being of this family not just the achievement for pregnancy when donated gametes are being used.

Part 5 of the Current Code of Practice says Clinics should encourage and prepare patients to be open with their children from an early age about the circumstances of their conception. The new HFEA strengthens the requirement on clinics to prepare would-be parents for openness and the revised Codes of Practice will reflect this.

I encourage all Clinic Staff not just to follow the letter of the new Act but please enter in to the spirit of it as well. Take time to consider the needs of your patients to adjust to using donor conception, where the treatment is taking place in the UK or perhaps especially when they are going abroad and help prepare them for the different way in which they will be making their family. Counseling for individuals and couples will always be an important part of the preparation for donor conception. But in addition to this, DC Network is being funded by the Department of Health to run for pilot preparation for donor conception parenthood workshops in London, Birmingham and Manchester. This will be evaluated and lessons learned will hopefully contribute to future policy and practice. Please tell your patients about them. You can be sure that any would-be parent who attends one of these workshops will be well-prepared for both treatment, the future of their family and anything that they will find on the Register. Thank you very much.