

*At the National Meeting of DC Network in March 2008, co-founder and current Network Manager Olivia Montuschi reflected on the founding principles of the Network, the ending of anonymity for donors and the current trend towards going abroad for egg donation...*

I was 60 last year, today is the Network's 15<sup>th</sup> anniversary. Milestones in a life's journey both of them. So much has changed since Walter and I started down our personal road to family creation by donor conception about 27 years ago. Our son William will be 25 in June, Zannah our daughter 22 in August. The Network has been a thread interweaving with all our lives over the past 15 years. It has probably played an important role in our marriage, being a joint project we both feel passionate about, and something Will and Zannah have had to live with, whether they liked it or not. They are actually quite proud of what we do but at many times during their growing up could have done without conversations about sperm and eggs having had such a prominent place in household conversations! Why am I rambling like this?

Well, anniversaries are a good moment for reflection and as we contemplate how different the donor conception world is now, it feels like a good moment to re-visit the principles and values that guided the five founding families 15 years ago.

I will be addressing the main topic of this morning – the choices and challenges of donor conception abroad – but I wanted to put this in the context of Network members over the years grappling with the move from anonymous to identifiable donors, the response of the medics to the ending of anonymity and how going abroad throws up parallel challenges to those faced by the founding families all those years ago. I will be focusing on egg donation as this is the main donor treatment that is sought abroad, but the principles apply just as much to sperm, embryo or double donation.

To go back to the beginning ... The original families came together because we all believed that it was in the best interests of our children that we should be open with them about their origins...that secrecy was not a good basis for lasting and loving family relationships. Over the years Professor Ken Daniels from New Zealand has helped us keep our focus on families rather than simply on children, reminding us that you can never think of a child without thinking about the family context in which he or she is being raised. If a child is brought up by a parent or parents who are comfortable and confident with the decisions they have made and are able to create an

atmosphere in the family that communicates these feelings, then that child is likely to grow up with the resilience to deal with whatever life throws at it – including all the feelings that may or may not arise in later years about donor conception.

Honesty with children about donor conception has now become mainstream. Although some parents are still not ‘telling’, no-one in the UK actually recommends secrecy any more. Some doctors still sit on the fence, saying to intending parents that it is up to them what they tell their children but overwhelmingly the message is that openness is best.

But let’s return for a moment to the guiding principles of the Network and how our emphasis on the well-being of children and families led us not only to advocate openness but over the years to support the ending of anonymity for donors as well. This was not an easy transition. Many parents, including some of the founding members, felt very uncomfortable with the idea of donors being identifiable. Some believed that this could be threatening to family life with a young person of 18 wanting to go off and find their ‘real’ mother or father. Others were more worried about the expectations a child could have of who their donor might be and the possibility of the terrible let-down of finding he or she was someone they didn’t really like or have anything in common with. The issue also sparked off a series of articles in the newsletter revisiting the age old nature/nurture debate with arguments that making donors identifiable would be elevating the status of ‘blood’ connections over social and emotional relationships.

But the evidence from donor conceived adults was compelling. Even if they didn’t feel distraught and angry at having had the secret kept for so long, most were very clear that it was their right to be able to CHOOSE whether or not they had information about, and possibly contact with, the person who had provided a vital ingredient for their conception and half their consequent genetic make-up. As our guiding principle from the beginning had been that we were a parent led but essentially child centred organisation, it became inevitable that we must support the ending of donor anonymity.

A test case in the High Court brought by a donor conceived adult and an unnamed child established that Article 8 of the Human Rights Act, the right to a Private and Family Life was engaged and as a result the Government committed to holding a public consultation on whether or not anonymity for donors should end.

Unfortunately, the vast majority of fertility doctors failed to take the consultation process seriously. Most of them assumed that ending anonymity for donors would mean the end of gamete donation in the UK and they could not believe that the government would ignore their proclamations about this. Many did not bother to take part in the process at all, let alone listen to ideas about beginning to recruit a different sort of donor in the case of sperm donation, or re-think their strategies for encouraging women to donate eggs. When the law actually changed in April 2005 many fertility specialists behaved as if the news had come out of the blue and instead of accepting the inevitable and changing their practices accordingly, many just stopped recruiting donors altogether.

At this time the waiting lists for egg donation in the UK were up to two years long. Some women had started going abroad, particularly if there were cultural or faith issues with matching in the UK, and a small number of others had felt that as donation was anonymous in the UK and abroad, but the availability of eggs was much greater in places like Spain, then it may not make much difference anyway. The ending of anonymity in the UK, however, brought about a phenomenon that would make going abroad something that almost every woman needing egg donation would need to consider. Instead of attempting to recruit their own donors, UK clinics started to make connections with clinics abroad and even if they didn't have a particular link, they encouraged women to search the internet for clinics in Europe and beyond that seemed to have an endless supply of donated eggs. Suddenly, with their doctors encouraging them, many more women and their partners felt empowered to explore the possibilities of foreign clinics...and they liked what they saw...modern, ultra-clean, well-equipped clinics with doctors and nurses who were friendly, responsive and spoke English! And best of all, a deeply longed-for pregnancy suddenly felt like a real possibility because there was very little waiting time for a donated egg and the success rates were fantastic. Why would anyone want to do anything else?

Well, I know that for many of our members the decision to go ahead with egg donation abroad, despite all the apparent advantages, was a very fraught one indeed. Unlike the UK doctors who encouraged them, they understood and continue to understand that the differences between donation in the UK and Spain (for instance) is not just one of length of waiting lists. Donors remain anonymous in most of the countries where women are being sent or choosing to go for egg donation. In most places, outside of the US and South Africa, very little information is available about donors – considerably

less than in the UK – and matches are mostly made by doctors rather than as the choice of would-be parents. There is no central register of donors and recipients in any of these countries and records may perish when a clinic closes. Donors are paid up to 1000 Euros, which may or may not be thought of as a coercive sum. And last, but definitely not least, counselling, with the opportunity this offers to think through all the issues, is rarely available in clinics abroad and only sometimes on offer in UK clinics to those going abroad.

Why does any of this matter when the resulting child will be deeply wanted, loved and cared for? Well, the truth is that we don't know if it will matter or not, but we have gone to a lot of trouble in this country to give choices to future donor conceived adults to know something about the person who gave a piece of themselves to help make them who they are...and most children conceived abroad will not have this choice. Will this be any different to children who were conceived prior to April 2005 or even before the first HFE Act in 1990? We just don't know and won't be able to know until a significant number of children conceived abroad have grown up and are able to tell us!

For me, as someone who has been part of the process of change over the past 15 years, it makes me sad to see what feels like a step backwards taking place, although I would be the first to say that I completely understand why members and others are taking the decisions that they are. Waiting lists remain very long in most places in the UK.

What feels important is that intending parents have all the information available to them about the differences between treatment here and in other places and the possible long-term implications of any decision they make. There are many things we still do not know but what we definitely do know from research by people like Ken Daniels and our own past experience, is that it is the confidence that parents have with the decisions they have made that makes the difference to how they convey information to their child and what that child (as a child) makes of the information. But really solid confidence is likely to come out of a full understanding of the implications and possible consequences, rather than from a more fragile kind which might come from seizing a solution and proceeding without thinking things through fully. This is true for all donor conception of course and many other things in life.

What of the children? Some will be interested and perhaps intrigued to know that they have a genetic connection outside of this country... this applies of course to some sperm and egg donors in the UK as well. Others may have a less enthusiastic response. Some will want to know about their donor and her place of origin, others may have very little interest. Parents will need to be ready to manage a range of feelings...but this is true of all families anyway...full genetic connection does not guarantee an easy passage through the long haul of parenting. Once again, being able to take pride in and have confidence about choices made and decisions taken, is likely to mean that this sense of comfort is conveyed to our children, who will gain strength from this to deal with future feelings and questions, should they arise.

As in all parent-child relationships, the best outcomes will emerge from confident parents tuning in to the needs of each individual child and meeting those needs in ways that are possible for each family.

Nothing is certain in life and what we can all be sure of is that there will be many surprises along the way... but what I can give a definite assurance about is that we as an organisation recognise and acknowledge the dilemmas that intending and current parents face and are with you and in it for the long haul for all our member families, no matter where children have been conceived.

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