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**Carbondioxide Capture and Storage as a Clean Development  
Mechanism Project: Legal and Regulatory Issues** 9  
*Olawuyidamilola Sunday*

**Linking Community Forestry Projects in India  
with International Carbon Markets:  
Opportunities and Constraints** 30  
*Rohit Jindal and Shailesh Nagar*

**Insect Conservation Under the Endangered Species Act** 47  
*Ezequiel Lugo*

**Anonymization of Sperm Donors for Artificial Insemination:  
An International Data Protection Law Perspective** 69  
*Maria Bottis*

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# Anonymization of Sperm Donors for Artificial Insemination: An International Data Protection Law Perspective

*Maria Bottis\**

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*Donor insemination is regulated by law in most countries. Data protection laws also apply in relation to the data that clinics keep in their records on donor-conceived persons. Until very recently, laws and practices favored secrecy of the donor insemination procedures, so that the donor-conceived children would be considered as the natural offsprings of the couple who raised them irrespective of the secret insemination. Later, practices and laws have begun to support openness of the procedure globally, even if this resulted in a well-documented decrease of the donor pool. The openness of the procedure allows a donor-conceived person to apply for and receive data from the medical record if she learns of her status. The argument from the data protection perspective is, whether it could be considered that, the applicant in this case, the child, could be seen as requiring access to her biological father's and her own personal data. It has been held in Iceland by the Supreme Court that in a similar case, with a deceased father, the daughter was asking for the deletion of his personal data as her own, as well as her father's, due to the consanguinity. We need more information from science to decide whether this data is only a negligible part of some biological material, half of a whole future self or something in the middle of these two extremes.*

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## 1. Introduction

Donor insemination for humans was first reported as early as in 1884.<sup>1</sup> The initial reaction was a general outrage, as donor insemination was seen as a threat to the very notion of a family. The situation is exactly opposite today where donor insemination is widely used in order to help form a family. Internationally, sperm banks offer and sell semen sometimes in a purely commercial and, indeed, stunningly 'frank' way: the particular characteristics of donors are available for search by prospective mothers. For \$64 a customer can buy a package of donor baby photo, audio tape, full personal profile, psychological profile, essay, description of the clinic's staff impression of him and facial features' report; for \$80 for 30 minutes, a prospective mother can also hire an artificial insemination consultant, to help her pick the most suitable donor father for

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<sup>1</sup> Achilles R (1992). "Donor Insemination: An Overview", Royal Commission on New Reproductive Technologies, Ontario, Canada, p. 8.

her child.<sup>2</sup> Moreover, donor insemination is a practice which affects not only couples where the husband has infertility problems but also single mothers and lesbian couples.

Donor insemination is regulated by law. Law has to intervene to delineate parental rights, as otherwise, the donor, who is the biological father, would also have to be the legal father of the child born by donor insemination (and this would, of course, result in legal responsibilities). The law also regulates what, if any, recompense the donor is entitled to, by reason of his donation.<sup>3</sup> This ranges from nothing to travel or other expenses, loss of wages for a day etc. The general trend of the relevant laws internationally is to avoid any notion of 'sale' of semen, while also allowing equitable remuneration, so that there will be no donor shortage.<sup>4</sup>

An issue that has proven strikingly difficult to regulate internationally in the same way is whether the identity of the donor will or will not be revealed to the prospective parents and/or the future child (at some point of her life). The donor insemination records at the beginning were completely confidential and the whole matter of artificial insemination was clouded by secrecy. Secrecy was supported to safeguard the unity and psychological health of the new family and protect against the stigma of infertility of the husband. Also, secrecy meant that the child, who knew nothing about its real genetic origins, would probably be able to form a deep relationship with the father, a relationship which would not be undermined, because of the child's knowledge that the father is not her biological father. The motto "what you don't know can't hurt you" had yet another application in medical law in the case of donor insemination.<sup>5</sup> This trend for secrecy has recently been suffering severe blows, as some countries, with Sweden leading in 1983, decided to allow only open donations (and disallow anonymous ones), and others applied systems of possible open donations (for example, Denmark).

This paper presents the laws or regulations in various countries, enumerate the advantages and disadvantages of anonymous vs. open sperm donations, look into the matter from the view of data protection laws and close with a discussion on the meaning

<sup>2</sup> Buying Babies, Bit by Bit, *The Economist*, available at [http://moscettidaw.com/2007/01/buying\\_babies\\_bit\\_by\\_bit.html](http://moscettidaw.com/2007/01/buying_babies_bit_by_bit.html), last access February 22, 2009.

<sup>3</sup> For example, in Europe the rule is that donors may receive compensation, which is strictly limited to making good the expenses and inconveniences related to the donation. European Union, Directive 2004/23/EC of the European Parliament and of the Council of March 31, 2004 on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells. *Official J. Eur. Union* 2004; L102, pp. 48-58 <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:32004L0023:EN:HTML>. Last access February 21, 2009.

<sup>4</sup> The bibliography on selling human tissues is vast. One could note here, however, that there is evidence that the commercialization of semen determines and reflects the type of men frequently recruited to provide semen. This, in its turn, influences the meaning that donors themselves, recipients, offspring, health professionals and society at large attribute to the provision of semen, Daniels K R and Lewis G M (1996), "Donor Insemination: The Gifting and Selling of Semen", *Soc Sci Med.*, Vol. 42, No. 11, pp. 1521-1536.

<sup>5</sup> The other well-known application of this motto in medical law is the (old) therapeutic privilege, where the physician was relieved from the obligation to inform the patient in some cases. On this, see extensively Katz J (1983), *The Silent World of Doctor and Patient*.

of a person's identity, as connected to her right to know her genetic origins (which has been recognized in some jurisdictions).

## 2. Laws on Donor Insemination and Anonymity

The regulation on the issue of donor anonymity in different countries offers us a range of statutory answers to the problem. One answer is a complete absence of the legislator, leaving the matter entirely to the will of the parties involved (that is, the sperm banks, the donors and the prospective parents). In this case, anonymity is neither prohibited nor enforced. On the other hand, exactly opposite is the statutory complete removal of the anonymity of the sperm donors. In this case, no insemination by an anonymous donor is legal and records are legally maintained. In other cases, the prospective parents may, by law, elect either anonymous or non-anonymous donations. No country seems, however, to have enforced a legal obligation of the parents or, alternatively, a representative of the State (as *parens patriae*), to inform the donor-conceived persons of their true genetic origins.

The US follows a system of confidentiality of records on donor insemination. The Uniform Parentage Act of 1973, enacted in 18 states, provides that all papers and records pertaining to the insemination, whether part of the permanent record of a court or of a file held by the supervising physician or elsewhere, are subject to inspection only upon an order of the court for good cause shown.<sup>6</sup> The subsequent Uniform Parentage Act, 2000, enacted in seven states, left the matter unanswered.<sup>7</sup> Few states have instituted minimal record keeping provisions, such as Ohio and New York.<sup>8</sup> There is no legislation, at either the federal or state level that either prohibits or enforces anonymous gamete donation.<sup>9</sup>

It follows that the US legislator leaves these matters to the parties involved: a sperm bank, for example, may adhere to anonymity (actually this is the norm for sperm banks, which also take great care in advertising confidentiality as a guarantee of their service). The policy supports the possibility of a complete confidentiality of records, which was seen as an inevitable result of a long legal tradition of American constitutional law.<sup>10</sup>

However, the American Society for Reproductive Medicine (ASRM) has recently issued guidelines that recommend that the donor information (not his identity) be available upon request to the legal father and mother and the child.<sup>11</sup> In 2009,

<sup>6</sup> Uniform Parentage Act par. 5 a. 1973.

<sup>7</sup> Uniform Parentage Act 2002. available at <http://www.dvmen.org/dv-183.htm>. Last accessed February 20, 2009.

<sup>8</sup> Elster N., "All or Nothing? The International Debate Over Disclosure to Donor Offspring", *Inst. On Biotech. & the Human Future*, available at [http://www.thehumanfuture.org/commentaries/assisted\\_reproductive\\_technology/art\\_commentary\\_elster01.html](http://www.thehumanfuture.org/commentaries/assisted_reproductive_technology/art_commentary_elster01.html). Last accessed February 20, 2009.

<sup>9</sup> Frith L (2001), "Gamete Donation and Anonymity: The Ethical and Legal Debate", *Human Reproduction*, Vol. 16, No. 5, pp. 818-824, at p. 819.

<sup>10</sup> Karow A (1993), "Confidentiality and American Semen Donors", *Int J Fertil Menopausal Stud.*, Vol. 38, No. 3 (May-June), pp. 147-151.

<sup>11</sup> American Society for Reproductive Medicine (2004), "Guidelines for Oocyte Donation", *Fertility and Sterility*, Vol. 82 par. 13-15, Supp. 1

the ASRM Ethics Committee issued a Report,<sup>12</sup> which supports open donation, at least at some level, disclosing important information.<sup>13</sup> For example, the Report encourages disclosing to the child that she is a donor-conceived child. These guidelines are non-legally binding professional guidelines. They, however, seek to raise public awareness about the growing importance and acceptance of at least a much more open donor insemination procedure than ever before in the US.

Sweden, starting in 1984 (Law No. 1140), followed the opposite direction and disallowed anonymous donor insemination.<sup>14</sup> Open-identity gamete donation was mandated. Donor-conceived children were allowed to access identifying information of the donor father. Parents were not obliged to inform the child (an important impediment to the real enforcement of access), but if the child had this information and reached maturity (as an abstract condition, not set at a certain age), then access was secured. Norway followed Sweden, albeit 20 years later and prohibited anonymous sperm donation in 2005.<sup>15</sup>

The UK changed its legislation towards mandatory non-anonymous sperm donation in 2005. Any donor of gametes or embryos has to agree to the disclosure of their identity to any offspring reaching the age of 18.<sup>16</sup> The following information if received by a donor prior to April 1, 2005 must be provided to a donor-conceived offspring, upon application to the Human Fertilization and Embryology Authority (HFEA): sex, height, weight, ethnic origin, eye color, hair color, skin color, year of birth and personal status, ethnic origin of donor's parents, information on whether the donor was adopted, number and sex of donor's children (if any), donor's medical history (if available), donor's religion, profession, areas of interests, skills, motive for donating, any additional information given by the donor so that it may reach the prospective

<sup>12</sup> "Interests, Obligations and Rights of the Donor on Gamete Donation", ASRM Ethics Committee Report, *Fertility and Sterility*, 2009, Vol. 91, No.1, pp. 22-27, doi: 10.1016/j.fertnstert.2008.09.062. Last accessed February 20, 2009.

<sup>13</sup> The Report identifies four levels of donor information. These are: (a) non-identifying information (provision of the donor's medical or biographical information, such as a statement or letter to be given early to the recipient couples) (b) Non-identifying contact for medical updates (the donor is willing to be contacted with anonymity maintained to provide medical updates and further information, if requested by the parents also, the donor is willing to contact by his own initiative the program with news about serious genetic or other conditions pertinent to the offspring's health). (c) Non-identifying personal contact with the donor when the child reaches a certain age and both agree to the disclosure and (d) Identifying information (a willingness to have identifying information shared with the offspring when the child reaches the age of maturity and both agree to the disclosure). All options are offered to the parties involved in donor insemination. *Id.*

<sup>14</sup> See extensively Daniels K and Lalos O (1995), "Ethics and Society: The Impact of Swedish Legislation on Couples' Attitudes", *Human Reproduction*, Vol. 10, pp. 1871-1874.

<sup>15</sup> Ernst E, Ingerslev H J, Schou O and Stoltenberg M (2007), "Attitudes Among Sperm Donors in 1992 and 2002: A Danish Questionnaire Survey", *Acta Obstet Gynecol Scand.*, Vol. 86, No. 3, pp. 327-333.

<sup>16</sup> Frith L, Blyth E and Farrand A (2007), "UK Gamete Donors' Reflections on the Removal of Anonymity: Implications for Recruitment", *Human Reproduction*, Vol. 22, No. 6, pp. 1675-1680 at p. 1675.

parents or the offspring. After this date, the identity of the donor (in particular: surname and first names of donor, donor's date and place of birth, a physical description of the donor and his last known address) is added to the information that must be provided.

In the Netherlands, the origins of the removal of anonymity (which occurred in 2004) were, quite controversially, the ideas of certain religious politicians during the late 1980s.<sup>17</sup> They feared the donor insemination of single mothers and lesbians and so, they supported open sperm donations hoping that this would be a blow on the availability of donors, leading to a decrease of inseminations. Legislative attempts which started in 1993 ended with the law of 2004. The statute instituted a central register, controlled by an independent national foundation, which supervises the register. Offsprings older than 16 years who are aware or are suspicious that they may be donor-conceived may apply for information from this register. The register contains information on the donor data, parent data, day and place of treatment (insemination) etc. This data should be kept for 80 years.<sup>18</sup> The satisfaction of the offspring's application for donor information, however, necessitates, in principle, the previous acquiescence of the donor. In case he objects, the Foundation of Donor Data will decide whether to give the information or not, under the circumstances of the particular case.

In Western Australia, amendments to the Human Reproductive Technology Act 1991, permitted the mature donor-conceived offsprings after 2004, the right to obtain identifying information about their donors, and effectively removed the donor anonymity for gametes/embryos.<sup>19</sup>

In Israel, anonymity of the sperm donors is the norm, a fact which is in line with evidence that Israelis have been, until recently at least, very discrete with the subject of donor insemination.<sup>20</sup> The Israeli Public-Professional Commission in The Matter of In Vitro Fertilization (1994) has recommended the creation and perseverance of central unidentified, medical records, of sperm and egg donors. These records should not enable donor identification, but will contain personal details and characteristics,

<sup>17</sup> Janssens P M W, Simons A H M, Kooil R J, Blokzijl E and Dunselman G A J (2006), "A New Dutch Law Regarding Provision of Identifying Information of Donors to Offspring: Background, Content and Impact", *Human Reproduction*, Vol. 21, No. 4, pp. 852-856, at p. 852.

<sup>18</sup> *Id.* at p. 853.

<sup>19</sup> Godman K, Sanders K, Rosenberg M and Burton P (2006), "Potential Sperm Donors', Recipients' and Their Partners' Opinions Towards the Release of Identifying Information in Western Australia", *Human Reproduction*, Vol. 21, No. 11, pp. 3022-3026.

<sup>20</sup> See more on Sperm Donation in Israel, available in [www.medethics.org.il/articles/JME/JMEM10/JMEM10.2.asp](http://www.medethics.org.il/articles/JME/JMEM10/JMEM10.2.asp), last accessed February 20, 2009. On evidence of secrecy related to the whole matter of donor insemination see Birenbaum-Carmeli D, Carmeli Y S and Yavetz H (2000), "Secrecy Among Israeli Recipients of Donor Insemination, Politics and the Life Sciences", Vol. 19, No. 1, March 1, pp. 68-76(8). The results (strict secrecy) here are interpreted by the authors as reflecting Israeli pronatalism, traditional concepts of a natural family, as well as elements of a macho culture. The authors propose public education towards the normalization of donor insemination. The paramount role of the medical profession in Israel is also cited as a factor towards the maintenance of secrecy in donor insemination, see Landau R (1998), "The Management of Genetic Origins: Secrecy and Openness in Donor-Assisted Conception in Israel and Elsewhere", *Human Reproduction*, Vol. 13, No. 11, pp. 3268-3273, at p. 3271.

including genetic illnesses. This information will not be available to the donor-conceived child when she grows up.<sup>21</sup>

Austria allows the child to gain identifying information after a federal law in 1992 on medically assisted reproduction.<sup>22</sup> In the statute, it is clear that all information relating to the donor's identification is open to the offspring, after its 14<sup>th</sup> year of age. A special procedure also provides for the release of information to the child's parent or guardian, for proven medical necessity, after permission is granted by the Court. A donor must express in writing his consent to this legal transfer of information.<sup>23</sup>

In Germany, sperm donation and donor insemination used to be clouded by secrecy. The Highest Federal German Court has issued a judgment in 1989 (BVerfG, January 31, 1989) that supports a constitutional fundamental right of a child to know her genetic origins. This right was afterwards incorporated in the German Civil Code, where it is stated that every human being has the right to identifying information on the genetic father that is the sperm donor, at the age of 18.<sup>24</sup>

Switzerland has added an article in the Swedish Constitution (24 novies par. 2) where a person's right to information related to her genetic origins is guaranteed. A special federal law in 1999 institutes a donor-conceived child's right to access the information on her genetic origins. In New Zealand, openness in donor insemination has not been legislated, but there is a general tendency towards recruiting donors with a willingness to be identifiable.<sup>25</sup>

In France, donor anonymity is legally preserved.<sup>26</sup> In Greece, the situation is the same (donor anonymity mandated by law) but the records of the donor insemination may open, only for a medical reason and only upon an application of the donor-conceived child.<sup>27</sup>

It follows that internationally, there is a clear trend towards the acceptance of open sperm donations. In some cases, open sperm donation is enforced by law, and in some

other cases, the trend represents a policy of encouraging participants to accept open sperm donations.<sup>28</sup>

However, two things are to be noted here:

- (a) in no case, the state imposes a positive obligation upon the social parent(s) to inform their donor-conceived child about her genetic origins and so,
- (b) the right of the child to be informed rests upon the discretion of her social parent(s) to actually tell her, at some point of time and one way or another, that she is a donor-conceived child.

There is a chance, of course, that a donor-conceived person may discover the truth about the insemination of her mother inadvertently. In any case, knowledge, or at least, suspicion about one's genetic identity is a prerequisite to the exercise of a right to access information about a possible old donor insemination.

### 3. Disadvantages and Advantages of Disclosing Donor Insemination

Secrets usually need strong justification. Withholding a secret from someone represents the power over that person and a conflict of interest between two parties.<sup>29</sup> This is true even in the cases, like this one, where secrets are presented as 'private matters', 'confidential information', etc., and not strictly, as secrets. Of course, private, confidential information is certainly very well known to the laws of any country. But in this case, we are referring to private information kept private 'from the very person' the information is directly related and not, as usual in the law on confidentiality, to private information as secrets to be kept by parties, where information relates to at least one of these parties (a classic example is the physician/patient privilege).

It is perhaps this exact point (to whom this information really relates to) that has been missing from the discussion on the advantages and disadvantages of secrecy in the donor insemination case.<sup>30</sup> The usual advantages proffered for secrecy are:

- Donors fear legal responsibility for the donor-conceived child and they will decline donations (shortage of donors).

<sup>21</sup> Sperm Donation in Israel, *id.* See also Landau, *id.*, p. 3268.

<sup>22</sup> Morgan D and Bernat E (1992), "The Reproductive Waltz: The Austrian Medically Assisted Procreation Act", *Journal of Social Welfare and Family Law*, Vol. 5, pp. 420-426.

<sup>23</sup> See Kriari-Katrani I (1994), in Sakkoulas (Ed.), *Biomedical Developments and Constitutional Law*, pp. 138-139 (in Greek).

<sup>24</sup> See Thorn P, Katzorke T and Daniels K (2008), "Semen Donors in Germany: A Study Exploring Attitudes, Motivations and Attitudes", *Human Reproduction*, Vol. 23, No. 11, pp. 2415-2420; and Pennings G, "The 'Double-Track' Policy for Donor Anonymity", *Human Reproduction*, Vol. 12, No. 12, pp. 2839-2844, at p. 2839 German Legislation at <http://www.eshre.com/ESHRE/English/Legal-Matters-and-Guidelines/Legal-documentation/Germany/Donor-anonymity/page.aspx/370>, last accessed February 21, 2009.

<sup>25</sup> Daniels K and Thorn P (2001), "Sharing Information with Donor Insemination Offspring", *Human Reproduction*, Vol. 16, pp. 1792-1796.

<sup>26</sup> Kriari-Katrani I (1994), in Sakkoulas (Ed.), *Biomedical Developments and Constitutional Law*, pp. 138-139 (in Greek), at p. 143.

<sup>27</sup> L. 3089/2002, as this statute added a new article in the Greek Civil Code, Art. 1460. See Kounougeri-Manoledaki E and Sakkoulas (Eds.) (2003), *Artificial Insemination and Family Law* at p. 66.

<sup>28</sup> Daniels K R, Lewis G M and Gillet W (1995), "Telling Donor Insemination Offspring About Their Conception: The Couples' Decision-Making", *Soc Sci Med.*, Vol. 40, pp. 1213-1220, Golombock S, Lycett E, McCallum F et al. (2004), "Parenting Infants Conceived by Gamete Donation", *J Fam Psychol.*, Vol. 18, pp. 443-452; Lycett E, Daniels K, Curson R and Golombock S (2005), "School-Aged Children of Donor Insemination: A Study of Parents", *Human Reproduction*, Vol. 20, No. 3, pp. 810-819, doi:10.1093/humrep/deh703

<sup>29</sup> Adams K (2005), "Ethical and Legal Considerations of Donor Insemination in the United States", in Patton P E and Battaglia D E (Eds.), *Contemporary Endocrinology: Office Andrology*, pp. 109-126, at pp. 111-112, Humana Press, Totowa, NJ.

<sup>30</sup> See, as an early example in the relevant literature, Haines E V (1993), "Ethics and Society: Do Clinicians Benefit from Donor Anonymity?", *Human Reproduction*, Vol. 8, No. 9, pp. 1518-1520, stressing that two groups of participants are frequently omitted from discussions and studies of donor anonymity in assisted conception: the children conceived and the clinicians offering the service.

- Donors fear that the donor-conceived child will one day contact them; they fear that their own family privacy will therefore be threatened and so, will decline donations (shortage of donors).
- The revelation of the artificial insemination will also reveal the husband's (and social father's infertility); this will lead to undesirable social stigma.
- The revelation of the artificial insemination will also undermine the bond between the social father and the donor-conceived child; further more, it will undermine the unity of the whole family.<sup>31</sup>
- The revelation of the artificial insemination can also hurt the marital relationship and, therefore, the family; a choice for secrecy should be respected.
- Secretiveness about donation keeps the donor-conceived child away from painful questions about her identity; she is safely a member of a family.
- Facts unknown to the donor-conceived child cannot by themselves hurt the child. We have no evidence, whatsoever, that not knowing either the circumstances of one's conception or the identity of one's donor can cause psychological problems.<sup>32,33</sup> Parental responsiveness and not biological relatedness determines the quality of the child's attachment to the parent and fosters healthy social and emotional development of a child.<sup>34</sup>

Donor shortage is indeed an important issue. Waiting periods for prospective parents that reach two years have been reported.<sup>35</sup> It has been documented in special studies in countries like the UK, comparing before and after the amendment of the law mandating open donation, that there was indeed donor shortage after anonymity was outlawed.<sup>36</sup> It seems that (in the UK especially) after the amendment of the law, there was a sharp shortage of sperm donors.<sup>37</sup> In Western Australia, in the decade

1996-2006, the total number of donors is reported to have halved and the recruitment of new donors declined by 32%.<sup>38</sup> An idea would be to offer more generous 'compensation' to sperm donors, as a balance against loss of anonymity.<sup>39</sup> Some of the reasons offered by the donors as supporting their decision not to donate under non-anonymity standards may probably be addressed.<sup>40</sup> However, it seems that maintaining anonymity is important, or even crucial to a great number of donors.<sup>41</sup>

Studies in the UK also showed a change in the type of the person who would accept to donate: unmarried senior students and young professionals were unwilling to donate after anonymity was lifted, whereas, married men with children of their own (whose motives for a donation were purely altruistic, and not also financial, as in the students' case) declared that they were willing to continue donating.<sup>42</sup> The profile,

<sup>31</sup> Schover L R, Collins R L and Richard S (1992), "Psychological Aspects of Donor Insemination: Evaluation and Follow-Up of Recipient Couples", *FertilSteril.*, Vol. 57, pp. 583-590.

<sup>32</sup> On this, See Daniels K and Taylor K (1993), "Secrecy and Openness in Donor Insemination", *Politics and Life Sciences*, Vol. 2, pp. 155-170.

<sup>33</sup> "...the conclusion that non-disclosure of donor insemination can cause psychological damage seems to be unsubstantiated. For example, it is highly problematic to transfer negative experiences of adult donor offspring to whom their origin had been disclosed to all donor insemination children...", Shilling G and Conrad R (2001), "Secrecy and Openness in Donor Offspring (Letters to the Editor)", *Human Reproduction*, Vol. 16, (October) pp. 2244-2245.

<sup>34</sup> Main M, Kaplan N and Cassidy J (1985), "Secrecy in Infancy, Childhood and Adulthood", *MonogrSocResChildDev.*, Vol. 50, pp. 233-256.

<sup>35</sup> A wait of one or two years is not unusual, see Craft I and Thornhill A (2005), "Would All-Inclusive Compensation Attract More Gamete Donors to Balance Loss of Anonymity?" *Reprod.Biomed Online*, Vol. 10, No. 3, pp. 301-306.

<sup>36</sup> BBC News, "Sperm Donor Anonymity Ends", <http://news.bbc.co.uk/1/hi/health/4397249.stm>. Last accessed February 21, 2009.

<sup>37</sup> Frith L, Blyth E and Farrand A (2007), "UK Gametes Donors' Reflections on the Removal of Anonymity: Implications for Recruitment", *Human Reproduction*, Vol. 22, No. 6, pp. 1675-1680. In relation to egg donors (which are more difficult to find), it is supported Craft I, Flyckt S.

Heeley G, Layland S, Thirnhill A and Kelada E (2005), "Will Removal of Anonymity Influence the Recruitment of Egg Donors? A Survey of Past Donors and Recipients", *Reprod Biomed Online*, Vol. 10, No. 3, pp. 325-329 that removal of anonymity of egg donors is likely to lead to a further restriction of an already unsatisfactory service to patients requiring donated eggs, unless fundamental new initiatives are implemented.

<sup>38</sup> Godman K, Sanders K, Rosenberg M and Burton P (2006), "Potential Sperm Donors', Recipients' and Their Partners' Opinions Towards the Release of Identifying Information in Western Australia", *Human Reproduction*, Vol. 21, No. 11, pp. 3022-3026, at p. 3022.

<sup>39</sup> An idea considered by the UK Human Fertilization and Embryology Authority, see Craft I and Thornhill A (2005), "Would 'All-Inclusive' Compensation Attract More Gamete Donors to Balance Loss of Anonymity?" *Reprod Biomed Online*, Vol. 10, No. 3, pp. 301-306. For an opposing view, against payment, see Shenfield F and Steele S J (1995), "Why Gamete Donors Should Not Be Paid: A Gift is a Gift, or why Gamete Donors Should Not Be Paid", *Human Reproduction*, Vol. 10, pp. 253-255.

<sup>40</sup> Frith L, Blyth E and Farrand A (2007), "UK Gamete Donors' Reflections on the Removal of Anonymity: Implications for Recruitment", *Human Reproduction*, Vol. 22, No. 6, pp. 1675-1680.

<sup>41</sup> For a relevant study in Denmark, see Ernst E, Ingerslev H L, Schou O and Stollenberg M (2007), "Attitudes Among Sperm Donors in 1992 and in 2002: A Danish Questionnaire Survey", *Acta Obstet Gynecol Scand*, Vol. 86, No. 3, pp. 327-333. In 1992, only a 32% of the donors declared that anonymity would not influence their decision to donate, whereas in 2002, the percentage was 25%. We do see a decline of 7%, but still, only a 32% accepts that anonymity would be indifferent to them as sperm donors. In another study in 1991, it was concluded that the withdrawal of the anonymity status for sperm donors would result in a significant decrease in new donors. Robinson J N, Forman R C, Clark A M et al. (1991), "Attitudes of Donors and Recipients to Gamete Donation", *Human Reproduction*, Vol. 6, No. 2, pp. 307-309. This decrease, however, was not found in relation to the already established sperm donors under this study (who would continue to donate). See also Brett S, Sacranie R R, Thomas G E and Rajkhowa R (2008), "Can We Improve Recruitment of Oocyte Donors with Loss of Donor Anonymity? A Hospital-Based Survey", *HumFert (Camb)*, Vol. 11, No. 2, pp. 101-107. Removal of donor anonymity halved the percentage of possible donors (from 34% persons willing to consider donation, if anonymous, to 17%, if open). And as reported by Pedersen B, Nielsen A F and Lauritsen J C (1995), "Attitude and Considerations of Sperm Donors in Relation to Insemination", *UgeskrLaeger*, Vol. 157, No. 32, (August 7), pp. 4462-4465, at least 60% of the donors reviewed declared that anonymity was essential for their continuing functioning as donors.

<sup>42</sup> Daniels K, Blyth E, Crawshaw and Curson R (2005), "Short Communication: Previous Semen Donors and Their Views Regarding the Sharing of Information with Offspring", *Human Reproduction*, Vol. 20, No. 6, pp. 1670-1675, at p. 1671. In the studies presented here, (p. 1672) we read at Table I (reasons for becoming a donor): general desire to help others (6.2%), Specific desire to help others (become parents (84.3%), to expand own gene pool (9.3%), wanting others to share the joy of parenting (25%), feel they were good stock to become a donor (15.6%) and other (25%). The reason 'to expand own gene pool' perhaps reminds us (this is, of course, an exaggeration) the declaration,

therefore, of the donor changes: instead of young single men who do not have children, it tends to be older men who do have children and who see that what they are doing is creating a family, who come forward.

The social stigma of male infertility is difficult to underestimate. Some men confuse infertility with a lack of virility or masculinity and so, they prevent both friends and family members from knowing their infertility.<sup>43</sup> Infertile men carry pain and humiliation for not being able to conceive a child.<sup>44</sup> It seems plausible that, if information of donor insemination is not disclosed, then the social paternal role of the male can be enhanced.<sup>45</sup> In some countries, like Cameroon, male infertility is just not socially acceptable at all.<sup>46</sup> Anonymity is also seen as a device to protect the anomalous family and to protect the ideology of 'family life'.<sup>47</sup> It comes as no surprise, then, that for example, a review of 23 studies between 1985 and 1995 concluded that the vast majority of parents (70-100%) had not informed their children that they were donor-conceived and did not intend to do so in the future.<sup>48</sup> Also, there is no doubt that anonymity protects better the clinic's interests, as it does not have to keep records for decades, for later inspection.

In opposition to all the arguments for secrecy, arguments that have sustained secrecy until recently, the discussion about anonymity has changed focus. Authors speak now of the right of the donor-conceived children to know their genetic origins; alternatively, they turn to the well-known family law 'best interests of the child' standard<sup>49</sup> and propose that learning the truth and as early as possible, is in the children's best interests. The German Highest Federal Court's judgment in 1989, recognizing a fundamental human right of every person to know her genetic origins,<sup>50</sup> reinforces the

argument; the United Nations Convention for the Rights of the Child of 1989 clearly provides, especially for children, the same right (Art. 7: the right to know one's parents).<sup>51</sup>

The donor-conceived persons' reaction, when they learn the truth about the way they were conceived, also seems to support arguments for disclosure. They speak about being 'robbed' half of their identity, and half of their medical history; they express deep disappointment, anger, resentment, frustration and mistrust against their parents, for having lied to them, on such a matter; they experience profound shock and feel "like a trap-door opened under their feet", others develop fantasy images (dreaming their genetic father as a duke, etc.) as coping strategies to block the threat to their identity by the revelation.<sup>52</sup> When the relationship with the social father had turned out problematic, the donor-conceived person expresses, at disclosure, feelings like relief or liberation (for not being genetically connected to the social father); in this case, the change in the view of identity was positive. But even when donor-conceived children are not told the truth, they tend to pick up 'hidden clues' related to the secret and damage to family relationships may occur.<sup>53</sup> It is supported that not knowing 50% of your biological origin has social consequences and can cause those who experience it great emotional pain, made worse by the awareness that this was not accidental happening but set up intentionally to mask their parents' infertility and is sanctioned by current legal provisions.<sup>54</sup>

Donor-conceived persons tend to look for the donor, when they learn the truth.<sup>55</sup> There is, of course, need for well-controlled studies to replace bias and supposition with data of outcomes of donor inseminated children and families.<sup>56</sup>

#### 4. A View from Data Protection Laws

Access to personal data is regulated in European countries by the European Directive for the protection of personal data 95/46/Ec.<sup>57</sup> This 'Privacy Directive' of the European

<sup>51</sup> United Nations (1989), "Convention for the Rights of the Child", United Nations, Geneva, available at <http://www.unhcr.ch/html/menu3/b/k2crc.htm>, last accessed February 22, 2009. Art. 7, par. 1 states: "The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and as far as possible, the right to know and be cared for by his or her parents". (Italics mine).

<sup>52</sup> Turner A J and Copyle A (2000), "What Does It Mean to Be a Donor Offspring? The Identity Experiences of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy", *Human Reproduction*, Vol. 15, No. 9, pp. 2041-2051.

<sup>53</sup> Karpel M (1995), "Family Secrets", *Fam. Process*, Vol. 19, pp. 295-306, McWhinnie A M, "A Study of Parenting of IVF and DI Children", *Med. Law*, Vol. 14, pp. 501-508.

<sup>54</sup> Turner and Coyle, *id.*

<sup>55</sup> Goldberg C (2008), "The Search for DGM 2598, More Children of Anonymous Sperm Donors Want to Know Who Fathered Them", November 23, *The Boston Globe*, Boston, MA, available at <http://www.encyclopedia.com/doc/1P2-19394293.html>

<sup>56</sup> Adams K, *id.* p. 122.

<sup>57</sup> European Council Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data (1996). See [http://europa.eu.int/eur-lex/en/ll/dat/1995/en\\_395L0046.html](http://europa.eu.int/eur-lex/en/ll/dat/1995/en_395L0046.html), last accessed February 25, 2009.

by the 1960 Feversham Committee in the UK, that "sperm donating is an activity which might be expected to attract more than the usual proportion of psychopaths", see Frith L (2001), "Debate: Gamete Donation and Anonymity, the Legal and Ethical Debate", *Human Reproduction*, Vol. 16, No. 5, pp. 818-824, at p. 820.

<sup>43</sup> Herz E K (1989), "Infertility and Bioethical Issues of the New Reproductive Technologies", *PsychiatrClinNorthAm.*, Vol. 12, pp. 117-131.

<sup>44</sup> Daniels K and Taylor K (1993), "Secrecy and Openness in Donor Insemination", *Politics and the Life Sciences*, Vol. 12, pp. 155-170.

<sup>45</sup> Shenfiled F (1997), "Privacy Versus Disclosure in Gamete Donation: A Clash of Interests, of Duties or an Exercise of Responsibility", *J. Assist. Reprod. Genet.*, Vol. 14, pp. 371-373 and Shenfiled F and Steele S (1997), "What are the Effects of Anonymity and Secrecy on the Welfare of the Child in Gamete Donation", *Human Reproduction*, Vol. 12, pp. 392-395.

<sup>46</sup> Njikam Savage O M (1995), "Secrecy Still the Best Policy: Donor Insemination in Cameroon", *Politics and the Life Sciences*, Vol. 15, p. 87.

<sup>47</sup> Haines E (1990), "Recreating the Family? Policy Considerations Relating to the 'New' Reproductive Technologies", in McNeil M, Varcoe M and Yearley S (Eds.), *The New Reproductive Technologies*, pp. 154-172, Macmillan, Basingstoke, UK.

<sup>48</sup> Adams K, *id.* p. 115. Recent studies however indicate a growing trend towards disclosure, see Paul M and Berger R (2007), "Topic Avoidance and Family Functioning in Families Conceived with Donor Insemination", *Human Reproduction*, Vol. 22, No. 9, pp. 2566-2571, at p. 2566.

<sup>49</sup> Van den Akker O (2006), "A Review of Family Donor Constructs: Current Research and Future Directions", *Human Reproduction*, Update 12, pp. 91-101.

<sup>50</sup> See above, footnote.....

Union had its influence well beyond Europe<sup>59</sup> although the US remained anchored on the safe harbor rules for data protection. But even before the Directive's implementation, countries like Brazil, Paraguay, Chile and Argentina had also implemented rights to the protection of personal data, sometimes as fundamental constitutional rights, as an amendment to the Constitution itself (*Habeas Data* clauses<sup>59</sup>).

Examining the issue from the view of data protection laws, one discovers at least two conflicting interests and rights: on one hand, the donor may insist on confidentiality of his personal data, as a fundamental constitutional right to his data, guaranteed at least by the laws of all European countries. This should normally be respected, at least in the cases where the initial 'deal' was an anonymous donation. The private life and liberty of decision of a donor, promised anonymity, should come before the claim of the donor-conceived child to learn the identity of the donor. The donor's freedom to control his own personal data in this case is in line with the constitutional, in many European (and other countries') guarantee of personal control over who, when, how and under what conditions will have access to another's personal data. At the time the donation occurred, the future child doesn't exist; there is not even any certainty that any future child will exist in connection with this donation.

On the other hand, the donor-conceived person may equally insist that the biological father's/donor's personal data are, simultaneously 'her' data as well. This means that the claim to the data will 'not' come as a claim to access 'another' person's personal data (the donor's), a claim which, of course, finds satisfaction under certain conditions of data protection laws. On the contrary, what is interesting is to examine the case where the donor-conceived child, now mature or even adult, demands access to the donor's personal data, 'as her own' personal data, due to the biological bond. This interpretation has been accepted by the Icelandic Supreme Court in an Icelandic case, interpreting the European Directive for the protection of personal Data 95/46/EC. The case dealt with a daughter's claim to remove her (deceased) biological father's personal data from a DNA database where it had been included. The Icelandic Supreme Court accepted this interpretation; 'half' of the daughter's 'self' was contained, under an admittedly liberal reading of the opinion, in her now deceased father's DNA data, which had been entered, without her knowledge or consent, in the Icelandic Health Sector DNA database. The application to remove the data from the database was accepted.<sup>60</sup>

In this case, probably the fact that the father was at the time of his daughter's application was dead may have influenced the outcome. In the donor insemination

case, the donor was promised anonymity and it is presumed that, when the matter of granting access to his data arose, in the Clinic's records, he may very well be still alive. Under the European Data Protection Directive, personal data encompasses information that relates to an identified or identifiable person, like the donor. The tension about access to genetic data between an individual and her family, her biological parents, creates great difficulties of fair resolution,<sup>61</sup> at least until science offers us more certain information about what we really inherit from a biological-only parent (the donor). Is it only a little negligible part of some (necessary for a new life) biological material, or is it the half of a whole future self?<sup>62</sup> We cannot yet be sure whether the line is between these two extremes, for example exactly in the middle, and whether, if this middle is correct, what is then the answer about the donor-conceived child in relation to her right to know her genetic origins and what is then the legal position of the donor in respect to his own data protection rights?♦

Reference # 13J-2009-04-06-01

<sup>59</sup> As for example, in India, see *The Information Technology Act, 2000*, available in <http://nicca.nic.in/pdf/itact2000.pdf>, last accessed February 25 2009.

<sup>60</sup> See Guadamuz A (2001), "*Habeas Data vs. the European Data Protection Directive*", *The Journal of Information, Law and Technology (JILT)* Vol. 3. See <http://elj.warwick.ac.uk/jilt/01-3/guadamuz.html>, last accessed February 25, 2009.

<sup>61</sup> See analysis of this case in Gertz R (2004), "Is It 'Me' or 'We'? Genetic Relations and the Meaning of Personal Data Under the Data Protection Directive", *EJHL*, Vol. 11, No. 3.

<sup>62</sup> Sandor J (2003), "Genetic Information: Science, Society and Legal Norms", in Sandor J., (Ed.) *Society and Genetic Information: Codes and Laws in the Genetic Era*, p. 22.

<sup>63</sup> For a seductive discussion on this, see Lewontin R (1993), *Biology as Ideology: The Doctrine of DNA*, Harper Perennial Series, HarperCollins Publishers.