EUROPEAN COMMITTEE ON LEGAL CO-OPERATION
(CDCJ)

REPORT ON THE USE OF GENETIC INFORMATION
NOT RELATED TO HEALTH

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based on the replies of the member States
to the Questionnaire on access to such information

Secretariat Memorandum
prepared by the
Directorate General I - Legal Affairs
1. Introduction

On 11-14 May 2004 during its 79th Plenary Meeting the European Committee on Legal Co-operation (CDCJ) addressed the member States of the Council of Europe with the questionnaire on access to genetic information for questions not related to health. At the same meeting the CDCJ informed the delegations about the work of the Steering Committee on Bioethics in the field of medically assisted procreation (MAP) and the right of a children, born as the result of MAP, to know about his/her origin in order to ensure consistency of efforts and avoid unnecessary duplication at national level.

By 15 March 2005, which was the date by when the replies should have been received, 19 member States responded to this questionnaire.

Compilation of the responses, prepared by the CDCJ Secretariat, was presented to the CDCJ Plenary meeting on 20-22 April 2005. In view of complexity of the topic and notable difference in the substance and depth of the replies received the CDCJ decided to commission an expert in order to prepare a report with the analysis of the responses and examine the feasibility of preparing a new Council of Europe instrument in this field.

The CDCJ underlined the importance of its future possible activities in this field, given the increasing importance of providing legal solutions to issues arising form a very rapid technological development in the sphere of genetics.

In this report the expert will firstly give an analysis of the reports that were received by the CDCJ. Then he will deal with the question whether a new Council of Europe instrument in this field should be prepared.

2. Analysis

Looking at the different contributions from the member states that were received, it must be mentioned that the responses from these states considerably differ from each other. Some describe in detail the legal regulations and procedures with regard to the information to the child with regard to parenthood, while other responses are very brief. Only one country (Romania) mentions the International Declaration on Human Genetic Data (UNESCO, 16th October 2003).

Most countries are in favor of the right of the child to know its identity; usually this becomes clear in regulations with parentage proceedings. In these cases genetic tests serve as a basis for scientific evidence. Usually the obtaining of genetic information is restricted for penal law cases or parentage proceedings.

Looking at the question if it makes a difference if a person from whom the genetic information needs to be obtained is alive or deceased some countries say that it makes a difference (because it is not regulated that the stored tissues or inhumed bones of deceased persons body may be used for parentage testing), some say it does not make a difference. In many countries courts can order genetic information to be obtained.

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1 Austria, Belgium, Bulgaria, Croatia, Cyprus, Denmark, Estonia, Finland, France, Germany, Latvia, Lithuania, Netherlands, Norway, Portugal, Romania, Slovak Republic, Switzerland and Turkey.

2 http://unesdoc.unesco.org/images/0013/001312/131204e.pdf#page=27
Usually, genetic information is used in case of parentage proceedings, but of course it is often used in penal law procedures.

In order to obtain genetic information with a view to parentage proceedings the person who is the party of the case may request this information from the court or the judge may request/order it spontaneously. The persons involved must give their permission, but in case this has been regulated, the judge can order that the person(s) involved, must co-operate in this regard.

Still, in many countries the identity of the donor (of the egg or semen) is to be kept secret, although the number of countries that protect the donors is declining. Some countries report that they do not have comprehensive positive legislation on the access and protection to genetic information.

In increasing number of countries special procedures have been introduced to give the child a possibility, when it has been made clear before the judge or a special commission/institute that it is in the best interests of the child to know its donor(s), to receive medical information about the donor(s) and even to get the identity of the donor(s). Usually the medical staff are under an obligation to ensure that the sperm donor’s identity is kept secret, although there are countries where the information has to be given to a central institute, which may decide upon the information to the child or to the donor.

The protection of human rights and privacy of each individual is usually secured by special laws with regard to protection of the personal data.

A sperm donor shall not be given information concerning the identity of the couple or the child. The treatment of sperm before implantation with a view to determining the sex of the child is allowed only if the woman is a carrier of a serious sex-linked hereditary disease.

In some countries IVF may be carried out only with the gametes of the couples themselves - neither donor sperm nor donor eggs may be used in conjunction with IVF. In those countries the embryo may be used for implantation only in the woman from whom the eggs originate. The reason to ban egg donation is primarily the interests of the child, as it is argued that egg-donation would deprive the child of a link which is fundamental to its identity. Moreover, it has been emphasized that egg donation breaks the natural link between uterus and egg and makes it possible to manipulate the identity of the mother. So, some authors think that egg donation would open up a whole new series of problems concerning the identity and the roots of the child.

There is no absolute right of children to have access to genetic information. Most of the countries accept the right of the child to get the knowledge of its own parentage. However, the ways in which this right can judicially be achieved in parentage proceedings sometimes differ from each other. This is also the case with regard to the question whether it makes a difference if a person from whom the genetic information needs to be obtained is alive or deceased.

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Linda Nielsen reports that the most radical aspect of Swedish law is the section relating to information about the donor. Sweden was the first country in the world to enact legislation concerned with the practice of donor insemination. It is in the 1984 Act decreed that the child should have the right to obtain identifying information about the donor when the child has reached sufficient maturity. The argument relied upon the concerns for the welfare and interests of the child. It is considered a basic right of a child to know its origin. Without it the child will be deprived of the possibility of having a true conception of him- or herself. The social authorities are obliged, at the request of the child, to assist in procuring such information. The child’s right is not offset by a parental duty to tell the child how it came to be, just as the child’s right is not offset by a right for the donor to know the child’s identity. According to the explanatory memorandum the regulation has taken on board the experience gained from adoption, where children from studies are known to benefit from receiving information about their genetic origin, providing that the information comes from people who like them and respect their wishes. Mention is also made of the fact that secrecy entraps the parents in a lifelong lie. In terms of logistics the child can contact the social services committee and have a talk with a staff member in the same way as happens in the case of an adoptive child. The staff member can then disclose information about the donor. If the child wishes to have contact with the donor, this takes place through the hospital etc where insemination was carried out. The social services officer is of assistance in trying to trace the donor and may even contact him or her.4

3. The right of the child to know its identity. Interests of the child

In literature and jurisprudence usually four basic interests of an individual to know his genetic origin are mentioned:

a. the desire/need to know the medical history of the child and its biological parents;

b. the sociological need for a person to belong to a group of relatives and to identify him/her self to this group;

c. the psychological interest to know its identity;

d. the judicial interest to know its origin.

Ad a. This medical interest can be essential in starting a family, because of the potential serious genetic defects that may be inherited by the future child of a particular person. Besides this, the child with a certain disease can profit strongly if the medical history of its biological parents are known. The medical interests gain in importance with the realization, that if the way of life is adapted to the potential risk of hereditary diseases running in certain families, the occurrence of disease may be either prevented or delayed, or the disease may occur in its less aggravated form. Information on the course of disease and results of its treatment provided to the relatives of the deceased may be of great use to doctors.5

Ad. b. The sociological interest of belonging to a certain family or group can be very important for the individual. To know if someone belongs to that family it is necessary to have information about the biological kinship.

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Ad. c. It has been approved in scientific literature that it can be of enormous psychological importance to identify oneself as belonging to a certain family. Therefore, one needs to know if there is a real biological link to that family.

Ad. d. For legal reasons (the right to establish or deny fatherhood, succession, child support, etc.) it is important to know to what family you belong and whether there is real kinship.

At the opposite of these four different interests of the child we find the interests of the parents that raise and educate the child and the rights of the donor(s). The mother of the child can have her private reasons why she does not want her child to know the truth about its conception. The father can have his personal reasons to keep silence about the begetting of the child and the donor gave the egg or sperm for altruistic reasons and wants to protect his/her private life and his/her new family. The question arises whose interests/rights must prevail. Is there a balance to be found?

4. The right of the child to know its identity. European case law

In Gaskin v. the United Kingdom (judgment of 7 July 1989, Series A no. 160), the applicant, who had been taken into care at a very early age, wished to consult the confidential case records that had been compiled by the local authorities containing reports by everyone connected with the care proceedings. He was not able to gain access to all the information in his file as some of the contributors refused to provide him with information they had given in confidence. The European Court ordered that Mr. Gaskin had the right to know its history. In the case of Odièvre v. France, the French State had not refused to furnish the applicant with information but had taken into account her mother's refusal from the beginning to allow her identity to be disclosed. As in Gaskin, the application in the Odièvre-case concerned two competing interests: the applicant's interest in finding out her origins and the interest of a woman who from the outset did not wish to be regarded as the applicant's mother in preserving her private life. However, the applicant's request did not concern information on “highly personal aspects of [her] childhood, development and history”, as her aim was to make contact with her siblings, whose existence she had only discovered on becoming an adult and whom she had never met. The Government said in conclusion that, as it stood, the applicant's request did not come within the scope of “private life” within the meaning of Article 8 of the Convention, as it concerned information relating to a natural family from which she had been separated since birth following her mother's decision to abandon her. For that reason, the European Court of Human Rights considered it necessary to examine the case from the perspective of private life, not family life (art. 8 ECHR), since the applicant's claim to be entitled, in the name of biological truth, to know her personal history is based on her inability to gain access to information about her origins and related identifying data. The Court reiterates in that connection that “Article 8 protects a right to identity and personal development, and the right to establish and develop relationships with other human beings and the outside world. ... (nr. 29). Matters of relevance to personal development include details of a person's identity as a human being and the vital interest protected by the Convention in obtaining information necessary to discover the truth concerning important aspects of one's personal identity, such as the identity of one's parents (see Mikulić v. Croatia, no. 53176/99, §§ 54 and 64, ECHR 2002-I). Birth, and in particular the circumstances in which a child is born, forms part of a child’s, and subsequently the adult's, private life guaranteed by Article 8 of the Convention.

The Court observed that Mr Gaskin and Miss Mikulić were in a different situation to the applicant. The issue of access to information about one’s origins and the identity of one’s natural parents is not of the same nature as that of access to a case record concerning a child in care or to evidence of alleged
paternity. The applicant in the present case is an adopted child who is trying to trace another person, her natural mother, by whom she was abandoned at birth and who has expressly requested that information about the birth remain confidential.

I quote part No.44 of the Court’s decision in Odièvre v. France:

“44. The expression “everyone” in Article 8 of the Convention applies to both the child and the mother. On the one hand, people have a right to know their origins, that right being derived from a wide interpretation of the scope of the notion of private life. The child’s vital interest in its personal development is also widely recognised in the general scheme of the Convention (see, among many other authorities, Johansen v. Norway, judgment of 7 August 1996, Reports 1996-III, p. 1008, § 78; Mikulić, cited above, § 64; and Kutzner v. Germany, no. 46544/99, § 66, ECHR 2002-I). On the other hand, a woman’s interest in remaining anonymous in order to protect her health by giving birth in appropriate medical conditions cannot be denied. In the present case, the applicant’s mother never went to see the baby at the clinic and appears to have greeted their separation with total indifference (see paragraph 12 above). Nor is it alleged that she subsequently expressed the least desire to meet her daughter. The Court’s task is not to judge that conduct, but merely to take note of it. The two private interests with which the Court is confronted in the present case are not easily reconciled; moreover, they do not concern an adult and a child, but two adults, each endowed with her own free will. 

In addition to that conflict of interest, the problem of anonymous births cannot be dealt with in isolation from the issue of the protection of third parties, essentially the adoptive parents, the father and the other members of the natural family.”

According to the Court’s opinion the French legislation seeks to strike a balance and to ensure sufficient proportion between the competing interests. The Court observes in that connection that the States must be allowed to determine the means which they consider to be best suited to achieve the aim of reconciling those interests. Overall, the Court considered that France had not overstepped the margin of appreciation, which must be afforded in view of the complex and sensitive nature of the issue of access to information about one’s origins, an issue that concerns the right to know one’s personal history, the choices of the natural parents, the existing family ties and the adoptive parents. The European Court concluded that in the case of Odièvre v. France there had been no violation of Article 8 of the Convention.

I think this was a disappointing decision, because Mrs. Odièvre was a subject of her mother’s decision to give birth to her child anonymously. It was the choice of her mother to give birth to her child anonymously and the child cannot help that.

Bea Verschraegen reported that artificial insemination by donor seemed to be morally not acceptable in Germany until the seventies and from the eighties the approach to artificial reproduction changed, but remained a rather restrictive one: the technique should not per se be forbidden; it seemed clear, however, that anonymity of the donor would violate human dignity and the rights of the child, who should have the possibility of knowing his/her origins. The German Constitutional Court decided so in 1989 and argued that origins form part of the personality of each human being and knowledge about one’s own origins offers important connecting factors for the understanding and the development of a person’s individuality. This is a

clear-cut decision against the principle of self-determination, against a contractual approach in artificial reproductive technology, and in favour of a person’s integrity and human dignity, the latter being a basic right expressly protected by the German Constitution.7

The right of a person to know his/her own origin is considered to be a fundamental right linked with human dignity.8

5. The questionnaire and the right of the child to know its identity

Most of the countries who responded to the questionnaire have regulations with regard to the right of the child to know its identity, especially in parentage proceedings. However, the way these countries meet the right of the child to know its identity differs form one country to another. Besides this, many countries have regulations in case the person, seeking access to his/her genetic information, is not capable to perform legal acts (e.g. an incapable adult). In those cases the adult person must be represented by a curator or a ‘mentor’ i.e. a kind of guardian or supervisor. Minors, usually below a certain age (e.g. sixteen years of age) are represented by the parents or a guardian.

Of course, it is important to know if the child was conceived by natural way or whether it was conceived by medically assisted procreation, because in the latter case the authorities/administrations are involved in the conception of the child and have to bear their responsibilities for it.

Of course there are cases in which the child sues his/her mother for court to press her (e.g. by penalty) to mention the name of the begetter, but it is easy for her to say that she can not remember this man and that she did not have his name and/or address when she had sexual intercourse during the conception period. Of course, this may lead to serious problems between the mother and the child, but courts and regulations can only urge the mother to tell her child who his/her father is, but it is quite difficult to push the mother to be frank. This might be different, if she has mentioned the name of the father to others persons.

In case the child was conceived with the help of doctors/hospitals I think the authorities are involved in this matter and then they have an obligation to mention the identity of the donor(s) to the child, unless this would not be in the child’s best interests.

6. Who is entitled to order the DNA-test?

It is important to realize that the contesting of fatherhood cannot be based on illegal DNA-fatherhood tests. At this point an important decision has been made by the German Bundesgerichtshof (Supreme Court) in Karlsruhe. In two different cases the Bundesgerichtshof decided that the contesting of the fatherhood was not allowed when the father has illegally taken genetic material from the child without its consent. In both cases the father had acknowledged the child of an unmarried woman. Some years later one father took hair from its child for the testing;

the other used a spit-out chewing gum and spit from the child, without informing the mother and the child and without their consent. The fathers sent the material to be tested to a private laboratory. In both cases the research of the material of the child and its father showed that the legal father could not be the biological father. Then the fathers started a procedure to contest fatherhood, but in both cases the Amtsgericht and later the courts of second instance (Oberlandesgericht in Celle and the Oberlandesgericht in Jena) declined their requests. The Bundesgerichtshof upheld these two decisions from the courts.

- In Germany, like in many other countries, the single statement of a man that he is not the biological father is not enough, while the man has to give more concrete evidence that he is not or can not be the biological father of the child and that another man must be the biological father of the child. A so-called 'underhand' analysis of the DNA-material of the father and the child can not be seen as a legal and objective reason to contest fatherhood.

The German case I referred to was decided by the German Bundesgerichtshof at 12th January 2005. In this case a father wanted to deny his paternity, although the mother said to be very sure about the fact that she had sexual intercourse with this man during the period of the begetting of the child and that she was very sure of his paternity. Nevertheless, the man wanted to be sure about his biological fatherhood and he started a DNA-procedure by having taken away some hair and slime from the child’s mouth. The Court has made completely clear that this material can be seen as illegal evidence.

The question arises whether it is allowed to do DNA testing without the consent of the legal representative of the child, usually the mother and/or the father. The Bundesgerichtshof has done some comparative legal research on this subject and found the following:

- In Australia the order of the Family Court of Australia may request a person to submit to a medical procedure; to provide a bodily sample; or to provide information to the person’s medical or family history (Family Law Act 1975, s 69X (3)). A child under 18 may be tested only with the consent of a parent, guardian or other person responsible (by court order) for the child’s long term or day to day care, welfare and development (Family Law Act 1975, s 69ZA (1); REG 21F).

- In Belgium some bills go into the direction to accept private DNA-analyses from the father an/or the mother, but only in the first year after the birth of the child or in case of a child’s request, within 4 years after his adultness. In all other cases private analyses will not be allowed (see e.g. Art. 5, 6 und 16 from the Proposition de loi visant à réglementer l’usage des analyses génétiques à des fins d’identification en matière de filiation, Parliament of Belgium Belgique, Document Nr. 51 0066/001);

- In France private DNA-analyses without consent of the parties concerned are forbidden (e.g.Art. 16-11 Code Civil, Art. 145-15 und Art. 145-20 des Code de la Santé publique, enacted by the Law Nr. 94-654 from 29. Juli 1994 - Loi relative au don et à l’utilisation des éléments et produits du corps humain, à l’assistance médicale, à la procréation et au diagnostic prénatal juncto Art. 226-28 Code Pénal);
• The same counts for the United Kingdom (section 45 Human Tissue Act 2004) and for Canada (Quebec; see Art. 2858 Code Civil du Québec). In Switzerland too, the court must authorize the analysis of the genetic material in fatherhood-proceedings (see. Art. 5, 6, 32, 34 and 36 of the Bundesgesetzes über genetische Untersuchungen beim Menschen - GUMG - from 8th October 2004 Bundesblatt 2004, 5483; Ablauf der Referendumsfrist: 27. Januar 2005).

It is important to realize that the lawsuit to contest paternity is inadmissible where the husband (or the man who acknowledged the child) has consented to artificial insemination (or any other act) intended to result in procreation, except – in some countries - if the child could not have been conceived as a result of the act. Paternity and maternity tests belong to the field of genetic testing, which is more a social than a medical area. Paternity testing and - by analogy - maternity testing is usually legal in many countries, simply because the definition of blood test in civil proceedings is expanded. Simple curiosity in most instances will suffice for access to such testing in private labs and this in the absence of any legal procedure.

A paternity/maternity test compares the genetic patterns of the father, mother and child to determine the kinship of the individuals. A "genetic fingerprint" is made using DNA from either cheek mucous cells or blood cells. The test produces a unique and unalterable genetic profile of the genes without any identifying characteristics.

Genomic DNA is isolated from the blood sample or the cheek swab. A genetic fingerprint is made by targeted amplification of 16 genetic markers (micro satellite markers) using PCR (Polymerase Chain Reaction). The fingerprint is so specific to an individual that it will statistically only occur once in the entire world’s population. The probability of paternity or kinship is calculated statistically. As a person’s total genetic material (genome) comes from the genomes of their parents combining, the DNA profiles (given by the analysis of the length of the micro satellite markers) must also be a combination of the parents’ DNA profiles. In this way, reliable proof of parentage results.

With the internet it is easy to find private institutions who offer the DNA-test at very cheap prices. However, it should be noted that the test result is merely for personal information of the service user. As the service provider cannot verify the identity of persons for whom samples have been sent, the result is only a statement about the relationship between the persons from whom the samples actually originated. The private analysis carried out by the service provider cannot usually be used in court, i.e. it cannot be used as evidence either for or against paternity. Of course, the samples must be given without any mix-up, because otherwise the test is worthless.

After the decision of the Bundesgerichtshof from 12th January 2005 I found the following advertisement at the German web: “Am I the father”?
(http://www.bin-ich-vater.de/paternitytesting):

“Your child knows his/her mother - give yourself and your child peace of mind about his/her paternity. Our laboratory offers you our complete support at every stage of the paternity test. Our team, consisting primarily of scientists holding doctorates and highly qualified specialists, will be glad to answer any

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10 GUMG is the German Abbreviation. In french this code is called: La Loi fédérale sur l’analyse génétique humaine (LAGH). See also Françoise Furkel, Généétique et procreation assistées en République fédérale d’Allemagne, in Biomedecine, the Family and Human Rights, Kluwer Law International, 2003, p. 313.
questions you may have about the collection of paternity testing samples, the accuracy of the DNA proof or any other technical issue. Just give us a call.

The paternity test costs from € 269 (see price list). An express test giving you a result three days after laboratory receipt of the sample costs an additional € 199. You’ll be paying far less for the test using our laboratory directly than by commissioning the test through an agency (for example, a detective agency). The quality and accuracy of the tests are absolutely identical.”

At the site I visited there is some protection that the rights of other persons are not violated, but there is no control of that. The service user (the client) must assure the service provider that on commissioning the analysis, the collection of the sample and dispatch of the samples did not violate any third party right. In particular he must affirm that all samples which he sends for analysis are from himself or from third parties who are minors and for whom he is a legal guardian or are from persons of an age and mental development sufficient to have understood the sample collection procedure and to have consented to the sample and its analysis. All adult persons for whom a sample for analysis is being sent to the service provider must thus be service users and be included on the order form with their full address and have given their consent to the analysis.

The method of DNA-testing is very simple: The service provider sends the client (the service user) a test kit to collect body tissue samples. The service user takes the samples from the persons to be tested. The sample could be blood, a cheek mucous membrane swab, hair or any object which carries a sufficient number of body cells to be tested from the person. The service user dispatches the sample to the service provider. The service provider carries out a molecular biological analysis to compare the identifying characteristics of the DNA of the persons being tested. The result is the verification or exclusion of the paternity of one of the persons being tested by another person being tested with a certain degree of probability. The test will be carried out by the service provider so that the probability of paternity will be a minimum of 99.9% when paternity is determined. If paternity is excluded, the test gives this with a probability of 100%. The exact probability has to be calculated for each individual analysis and will be given along with the test result; the probability of paternity is usually a minimum of 99.999% when paternity is determined.

So, if it is that easy to do a private paternity or maternity test, it is easy to understand why the Bundesgerichtshof has made it very clear why these private tests cannot be accepted in court. In my opinion it is the court that has to decide whether a paternity test will be allowed, because a child’s stable family life may become disrupted by the intervention of the father and the decision of the court. The child may lose a father and this father is liable to pay child support and the child has (family and) inheritance rights, which might be lost.

If a father doubts whether he is the biological father of the child and he has sincere reasons to believe that his child is not his child, he can start a legal procedure to contest his paternity. It is the court that must guard the (legal and social) interests of the child (and his mother). If the mother and/or the child do not want to cooperate, the court must decide whether the child and/or the mother must co-operate. This should be done by the court, regardless that the father and the mother have joint custody or the mother has the sole custody of the child. Besides this the court should mention the hospital/institution where the DNA-test must be taken to prevent further problems between the parties involved. The child and the mother should have the right to examine the biological fatherhood too, in case there is serious concern about the question whether the legal father has conceived the child. A difficult question is if the biological father should have the right
for parentage proceedings in case the child is born within the marriage of its mother and her husband and by the legal fact of this the child already has a legal father. The same in case the child has been recognised by a man who (presumably) is not the biological father of that child.

Conclusions and advice

Genetic tests serve as a basis for scientific evidence. These tests are to be performed when other kinds of evidence collected and presented, according to the procedural legislation, are insufficient, e.g. testimony of witnesses, written evidence (mother and child living together with the supposed father, the shared upbringing and maintenance of a child). Although the child’s paternity may be adjudicated on the basis of facts that have a sufficient evidential value, such as the child’s mother’s and the putative father’s life together, their joint participation in the upbringing and maintenance of the child, and other evidence, DNA-testing is the most secure way to prove whether a child has a biological link with the person(s) involved. If (one of) the parties refuse to undergo expert examination, the court dealing with the case may treat such a refusal as proof of the defendant’s paternity of the child, but of course only in case there is enough other evidence. So, the child’s paternity may be adjudicated on the basis of facts that have a sufficient evidential value, such as the child’s mother’s and the putative father’s life together, their joint participation in the upbringing and maintenance of the child. Although at the World Wide Web a lot of institutes can be found that are willing to do DNA-testing for rather cheap prices, the evidence, obtained by means of these tests, cannot be allowed in court. I refer in this respect to a case of the German Bundesgerichtshof from the 12th January 2005.11

The genetic parenthood of a child conceived through sperm or egg donation and social parenthood are sometimes in competition with each other. The right of the parents to a private and family life, respectively the right of the donor to a private life can stand against the right of the child to get knowledge of its genetic origin. Should the right of the child be paramount to the rights of the parents and the donor of the sperm or egg?

In my opinion, it would be advisable to prepare a European Protocol12 or Recommendation for access to genetic information for questions not related to health.

Why should it be a European Protocol and could it not be regarded as a matter to be dealt with by the different States themselves? Looking at the cross-border developments a growing number of parents is seeking for medical assistance with regard to infertility problems in other countries, e.g. there are now waiting lists or no age limits for in-vitro-fertilisation, no problems with regard to anonymous sperm or egg donation, etc. Persons, who are eagerly looking for a child of their own, go across borders to find help to get a child. In this respect I think that a European Protocol could make it possible that children, who were conceived by means of medically assisted procreation, to have at least the possibility to find out about the (sperm or egg) donation and to ask for some information about the donor (medically, socially) or for all the information (inclusive the identity of the donor) the child needs. With the help of a Protocol, countries that do not (wish to) recognise the right of children to be informed about their origin, can be stimulated to make arrangements for this in order to make it possible that children have access to their genetic information.

11 XII ZR 60/03; see also XII ZR 227/03.
As stated before the person involved can have several vital (legal, medical, psychological and sociological) interests to know its genetic origin and to obtain genetic information. In my view, because the child is an object of the decision of its father and mother, its right should be paramount to the rights of the parents. Only in case where the access would certainly lead to psychological problems for the child, disclosure of this information should be refused or authorised in a very delicate way.

Especially in those cases where the State has been involved in the conception of the child (e.g. in the case of medical assisted conceptions) the State should help the child to get access to this information. Young children and incapable adults should be represented in these cases.

In case of conflict between the child, the parents and/or the donor(s), each party must have access to an independent authority (a court or other institute) to ask for a decision as to whether or not the records of the child should be opened. In case the person from whom the genetic information needs to be obtained is deceased, the consent of the closest relatives should be obtained (perhaps they can give their DNA). In case they refuse, the court may order to take bodily samples from the living relatives (parents, children or siblings) or the human remains.

For minors and incapable adults I suggest the following: In case the genetic information should be obtained from an incapable adult or a minor the legal representatives must give their consent. If they refuse to co-operate, the requesting party must seek the authorisation of the court.

Third parties (e.g. the biological father) requesting parentage information must have a legitimate interest that might, in some cases, prevail the interest of the person from whom the information is to be obtained and the interests of the (possible) other persons involved (e.g. the legal parents of the child). Only a court is the competent authority to deal with these cases.

In case the genetic information was already obtained it can generally only be used for the purpose for which the genetic information was obtained and only with the consent of the person(s) involved. In the case of a refused consent, the court can strike the balance between the interests of the persons involved. If the person from whom genetic information was obtained is deceased, the general rule should be that because of medical secrecy the information may not be provided, unless the information was originally obtained in the case of parentage proceedings.

Because of the difficult ethical, medical, legal and international aspects of this subject I suggest the CDCJ to set up a commission of experts in order to elaborate general principles on the subject of access to genetic information.

Tilburg University, 5th March 2006
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