

FIFTH WORLD CONFERENCE ON
THE FUTURE OF SCIENCE™



The DNA Revolution

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Should privacy be abolished in genetics ?

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Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine

Oviedo, 4.IV.1997

Article 16 – Protection of persons undergoing research

Research on a person may only be undertaken if all the following conditions are met:

- i. there is no alternative of comparable effectiveness to research on humans;
- ii. the risks which may be incurred by that person are not disproportionate to the potential benefits of the research;
- iii. the research project has been approved by the competent body after independent examination of its scientific merit, including assessment of the importance of the aim of the research, and multidisciplinary review of its ethical acceptability;
- iv. the persons undergoing research have been informed of their rights and the safeguards prescribed by law for their protection;
- v. the necessary consent as provided for under Article 5 has been given expressly, specifically and is documented. Such consent may be freely withdrawn at any time.

Article 17 – Protection of persons not able to consent to research

Article 5 – General rule

An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.

This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks.

The person concerned may freely withdraw consent at any time.

Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine

Oviedo, 4.IV.1997

Chapter IV – Human genome

Article 11 – Non-discrimination

Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.

Article 12 – Predictive genetic tests

Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling.

Article 13 – Interventions on the human genome

An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.

Article 14 – Non-selection of sex

The use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided.

Council of Europe

- **Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine**
- ETS no. 164
(known as Oviedo Convention)
- **Additional Protocol to the Convention of Human Rights and Biomedicine concerning Biomedical Research (opened for signature on 25 January 2005).**
- **Additional Protocol to the Convention on Human Rights and Biomedicine, concerning the Genetic Testing for Health Purposes - May 7th, 2008**
- **Explanatory Report to the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning the Genetic Testing for Health Purposes**

Privacy / informed consent / selfdetermination ?

Permanence (*time*)



Data and information stored
in bio-banks
Genetic data



**Family / Biological group
/ Humanity ...**
(spatial extension)

Familiarity & humanity (a):

Is human genome really *human* ?

Bearing in mind the work carried out by other intergovernmental organisations, in particular the **Universal Declaration on the Human Genome and Human Rights**, endorsed by the General Assembly of the United Nations on 9 December 1998.

Recalling that the human genome is shared by all human beings, thereby forming a mutual bond between them while *slight variations* contribute to the individuality of each human being. Stressing the particular bond that exists between members of the same family.

Source: the Additional Protocol on GT: Preamble (2008)

Article 1

The **human** genome underlies the fundamental unity of all members of the **human** family, as well as the recognition of their inherent dignity and diversity.

Familiarity & humanity (b):

Is human genome really *human* ?

After Human Genome Project

Genes *v.* gene expression

Divergence of *gene expression* can result in phenotypic variation, which contributes to the evolution of new species.

Subhajyoti De, Sarah A. Teichmann and M. Madan Babu

**The impact of genomic neighborhood on
the evolution of **human and chimpanzee** transcriptome**

Genome Res. 2009 - 19:785-794.

Humanimals

John Harris

Which *family* are we talking about ?

Words - Meanings - Concepts

Chapter VI – Tests for the benefit of family members

Article 13 – Tests on persons not able to consent

Exceptionally, and by derogation from the provisions of Article 6, paragraph 1, of the Convention on Human Rights and Biomedicine and of Article 10 of this Protocol, the law may allow a genetic test to be carried out, for the benefit of family members on a person who does not have the capacity to consent, if the following conditions are met:

- a) the purpose of the test is to allow the family member(s) concerned to obtain a preventive, diagnostic or therapeutic benefit that has been independently evaluated as important for their health, or to allow them to make an informed choice with respect to procreation;
- b) the benefit envisaged cannot be obtained without carrying out this test;
- c) the risk and burden of the intervention are minimal for the person who is undergoing the test;
- d) the expected benefit has been independently evaluated as substantially outweighing the risk for private life that may arise from the collection, processing or communication of the results of the test;
- e) the authorisation of the representative of the person not able to consent, or an authority or a person or body provided for by law has been given;
- f) the person not able to consent shall, in proportion to his or her capacity to understand and degree of maturity, take part in the authorisation procedure. The test shall not be carried out if this person objects to it.

Source: the Additional Protocol on GT (2008)

ARTICLE 29 Data Protection Working Party Document on Genetic Data (17 March 2004):

“Due to the special nature and characteristics of genetic data and the impact their use may have on the individual's life and on the members of his family, it is very important to determine the purposes for which genetic data may be processed.

[...] Thus, a new, legally relevant social group can be said to have come into existence – namely, the *BIOLOGICAL GROUP*, the **group of kindred as opposed, technically speaking, to one's family**. Indeed, such group does not include family members such as one's **spouse** or **foster children**, whereas it also consists of entities outside the family circle – whether in law or factually – such as **gamete donors** or the **woman** who, at the time of childbirth, did not recognise her child and requested that her particulars should not be disclosed – this right being supported in certain legal systems”.



*What is the extension of the
Biological Group?*



Where should we draw the boundary line? Biology

Two brothers (apart from monozygotic twins who share 100%) have an average share of **50%** of their genome.

Child / grandparent or **child / uncle** tend to share **25%** of the variable portion of their genome.

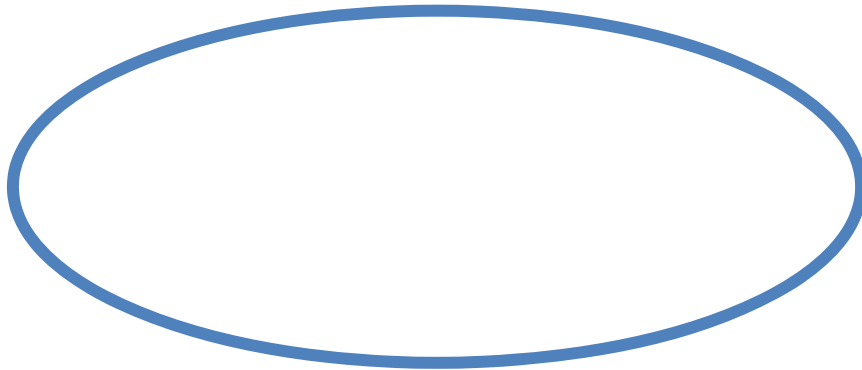
Likewise, **first degree cousins** and **child / great-grandparent** share **12.5%** and, going further in genetic relatedness,

second degree cousins only **3.1%** of the variable portion of their genome.

Where should we draw the boundary line? Law

The Italian Civil Code (1942), Article 77 “Limits of kinship”:

The law does not recognize kinship beyond the sixth degree.

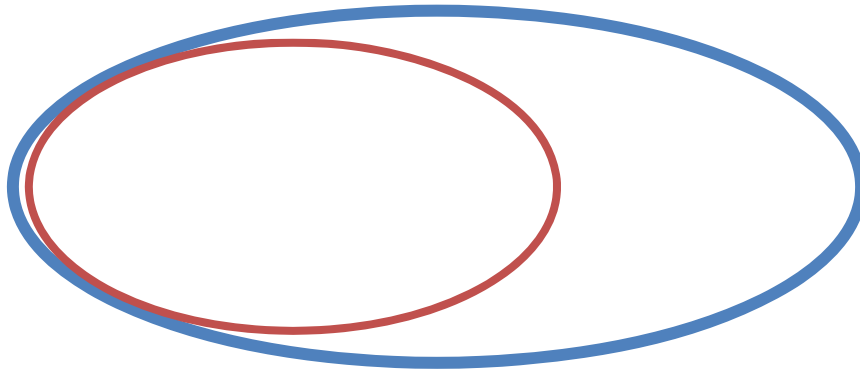


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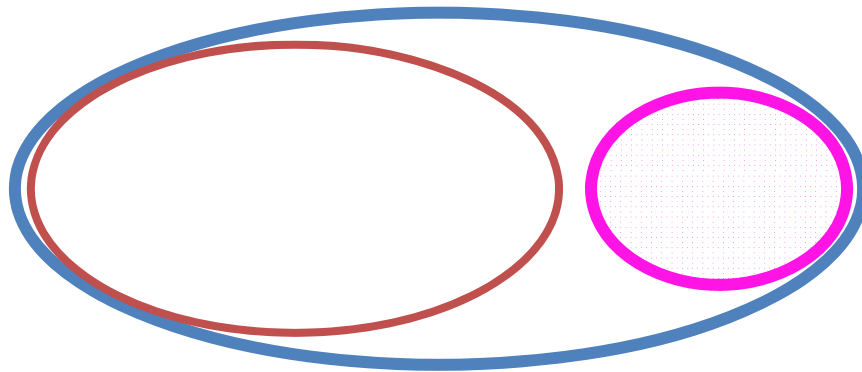
Italian Guidelines on Genetic Medicine (2004), Article 7:

Personal data should not be communicated to
relatives unless the interested person has given
his/her consent [...] the relatives to be informed are
only those within the third degree.



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Statement on DNA Sampling:
control and access (1998), HUGO
Ethics Committee: *special*
considerations should be made
*for access by **immediate***
***relatives**. Where there is a high*
risk of having a transmitting a
serious disorder and prevention
or treatment is available,
***immediate relatives** should*
have access to store DNA (..)

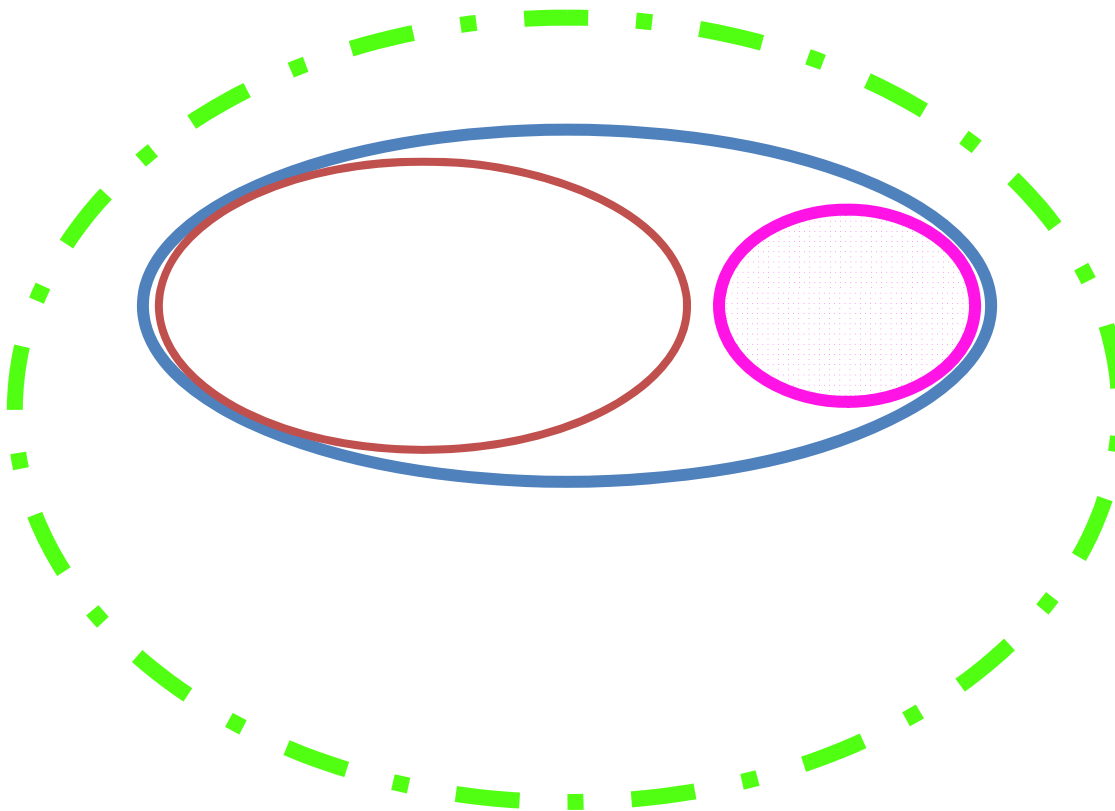
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relatives** should have access to store DNA (..)*

Additional Protocol to the
Convention on Human Rights and
Biomedicine concerning Genetic
Testing of Health Purpose (2008),
Articolo 18 “Information relevant to
family members”, Report
“*with whom the person
concerned has a biological
link”.*



The Italian Civil Code (1942), Article 77
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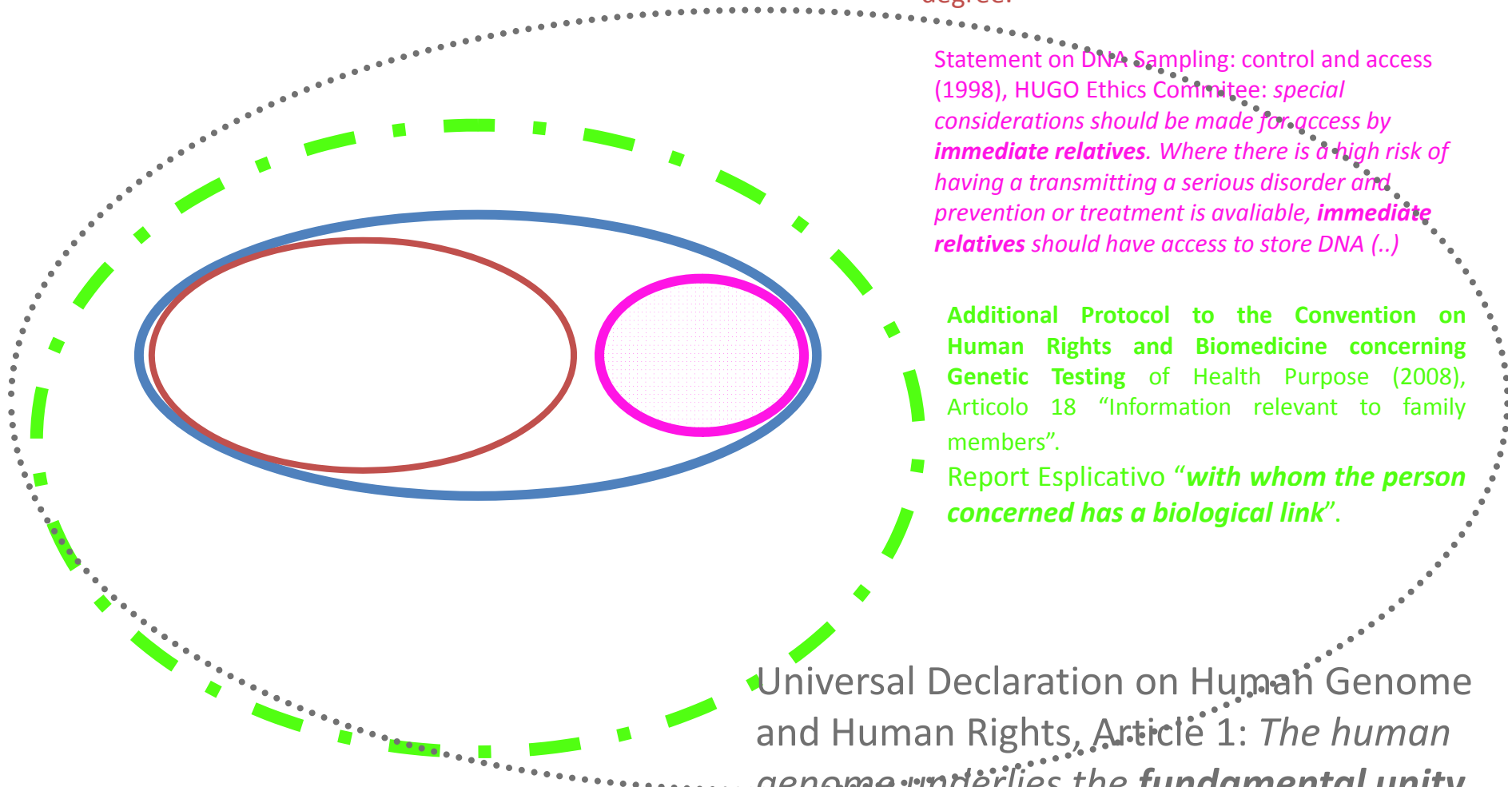
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Genetic Testing of Health Purpose (2008),
Articolo 18 “Information relevant to family
members”.**

Report Esplicativo “**with whom the person
concerned has a biological link**”.

Universal Declaration on Human Genome
and Human Rights, Article 1: *The human
genome underlies the **fundamental unity**
of **all** members of the human family.*



Human family

Family members

Immediate relatives

Extension of the Biological Group

The individual

III degree

VI degree



Privacy

Informed Consent

Selfdetermination



(1890) “Now the right to life has
come to mean the right to enjoy
life, the right to be let alone”
(against external intrusion)

?The Right to Privacy?

Warren and Brandeis

Harvard Law Review.

Vol. IV December 15, 1890 No. 5

... physical interferences ...

Noises, odors, smoke,
vibrations...

Human emotions

Incorporeal rights

Circulation of portraits
(*photographs and newspaper*)

That the individual shall have full protection in person and in property is a principle as old as the common law; but it has been found necessary from time to time to define anew the exact nature

Thus, with the recognition of the legal value of sensations, the protection against actual bodily injury was extended to prohibit mere attempts to do such injury; that is, the putting another in fear of such injury. From the action of battery grew that of assault.^[1] Much later there came a qualified protection of the individual against offensive noises and odors, against dust and smoke, and excessive vibration. The law of nuisance was developed.^[2] So regard for human emotions soon extended the scope of personal immunity beyond the body of the individual. His reputation, the standing among his fellow-men, was considered, and the law of slander and libel arose.^[3] Man's

This development of the law was inevitable. The intense intellectual and emotional life, and the heightening of sensations which came with the advance of civilization, made it clear to men that only a part of the pain, pleasure, and profit of life lay in physical things. Thoughts, emotions, and

Recent inventions and business methods call attention to the next step which must be taken for the protection of the person, and for securing to the individual what Judge Cooley calls the right "to be let alone" ^[10] Instantaneous photographs and newspaper enterprise have invaded the sacred precincts of private and domestic life; and numerous mechanical devices threaten to make good the prediction that "what is whispered in the closet shall be proclaimed from the house-tops." For years there has been a feeling that the law must afford some remedy for the unauthorized circulation of

Privacy

Informed Consent

Selfdetermination



(1890) “Now the right to life has come to mean the right to enjoy life, the right to be let alone” (*against external intrusion*)

”



Individual’s right to decide on his/her health and life
(selfdetermination in critical decisions)

”



Individual’s right to control information related to his/her health, life and personal compass
(informational privacy)

The individual



- interfering with personal compasses of other members of his/her biological group
- extending his/her interests in the future

COUNCIL OF EUROPE

COMMITTEE OF MINISTERS

Recommendation Rec(2006)4 of the Committee of Ministers to member states on research on biological materials of human origin

*(Adopted by the Committee of Ministers on 15 March 2006
at the 958th meeting of the Ministers' Deputies)*

CHAPTER III

Obtaining biological materials for research

Article 10 – Obtaining biological materials for research

1. Biological materials should be obtained for research in accordance with the provisions of this chapter.
2. Information and consent or authorisation to obtain such materials should be as specific as possible with regard to any foreseen research uses and the choices available in that respect.

Article 15 – Right to change the scope of, or to withdraw, consent or authorisation

1. When a person has provided consent to storage of identifiable biological materials for research purposes, the person should retain the right to withdraw or alter the scope of that consent. The withdrawal or alteration of consent should not lead to any form of discrimination against the person concerned, in particular regarding the right to medical care.

When identifiable biological materials are stored for research purposes only, the person who has withdrawn consent should have the right to have, in the manner foreseen by national law, the materials either destroyed or rendered unlinked anonymised.

a) On information and consent:

How to deal with the conflicts within the biological group?

The paradox:

- if sharing data gives each “shareholder” a right of (not)disposal of other shareholders’ data, we would no longer have any genetic privacy.

the relatedness between **two brothers** (apart from monozygotic twins who share 100% of their genome sequence) is **50%** on average.

Child / grandparent or **child / uncle** tend to share **25%** of the variable portion of their genome.

Likewise, **first degree cousins** and **child / great-grandparent** share **12.5%** and, going further in genetic relatedness,

second degree cousins only **3.1%** of the variable portion of their genome.

On Liberty
by John Stuart Mill

“... there is a sphere of action in which society, as distinguished from the individual, has, if any, only an indirect interest;

~~comprehending all that portion of a person's life and~~
conduct which affects only himself, or, if it also affects others, only with their free, voluntary, and undeceived consent and participation.”

“... the appropriate region of human liberty...”

On Liberty
by John Stuart Mill

“It comprises, **first**, the inward domain of consciousness”

“**Secondly**, the principle requires liberty of tastes and pursuits; of framing the plan of our life to suit our own character; of doing as we like, subject to such consequences as may follow; without impediment from our fellow-creatures, so long as **what we does not harm them** even though they should think our conduct foolish, perverse, or wrong.”

On Liberty
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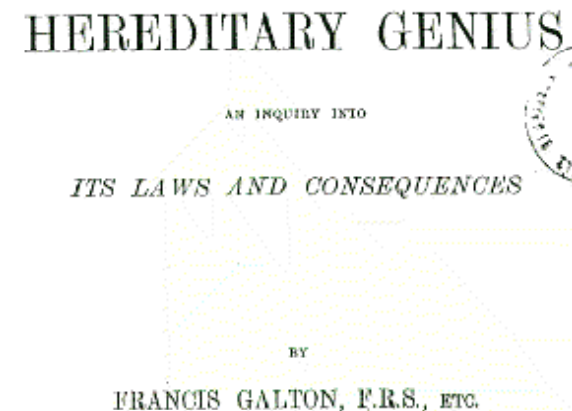
Two basic assumptions

a) Society v. individuals

b) Individual v. each other individual

‘Neither must we be misled by the word ‘individuality’, because [...] our personalities are not so independent as our self-consciousness leads us to believe.

We may look upon each individual as something not wholly detached from its parent source. There is decidedly a solidarity as well as a separateness in all human, and probably in all lives whatsoever [...]



A conceptual clash ?

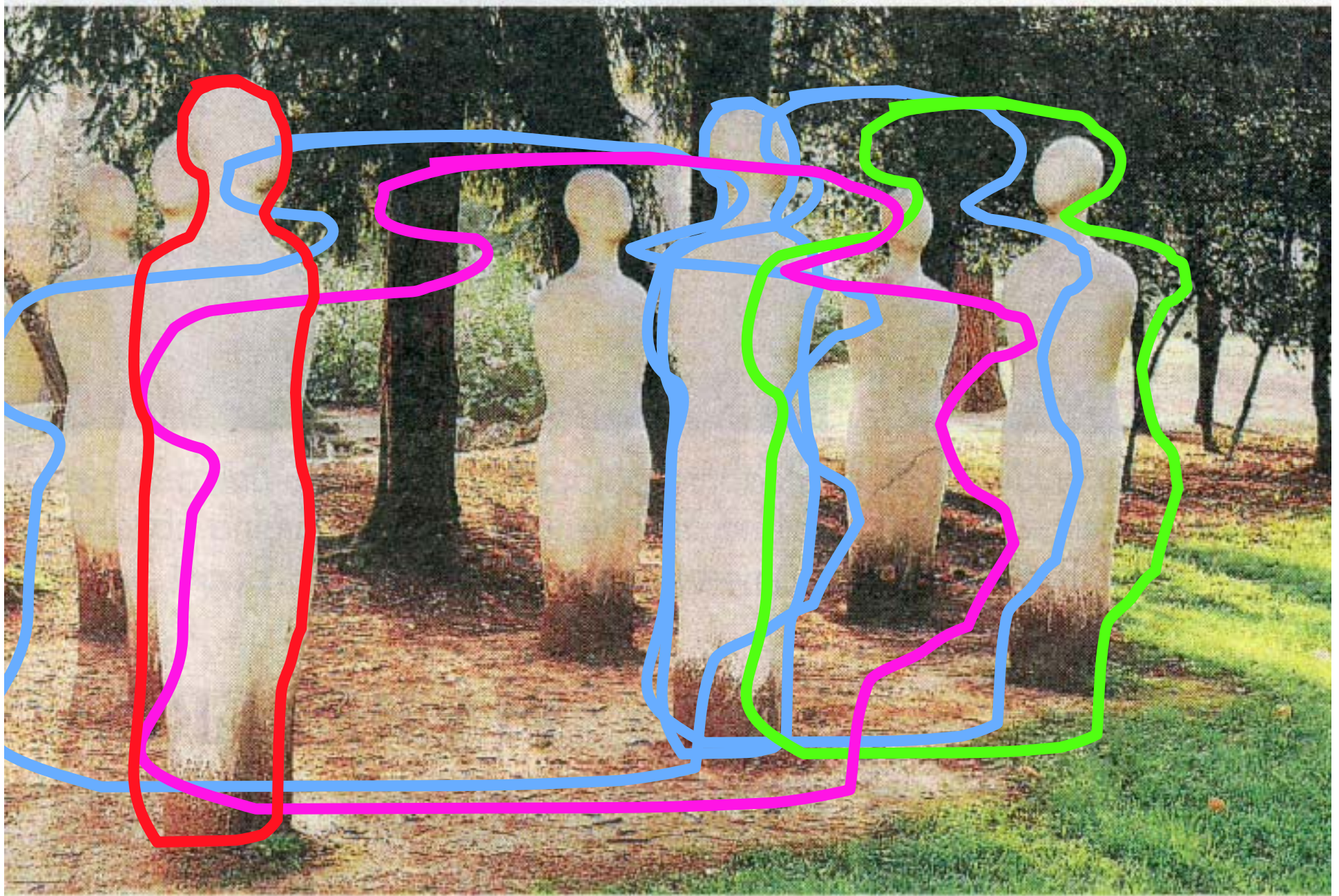
Francis Galton 1869

Hereditary Genius → (biological) solidarity

1859 John Stuart Mill

(legal) individualization ←

On Liberty

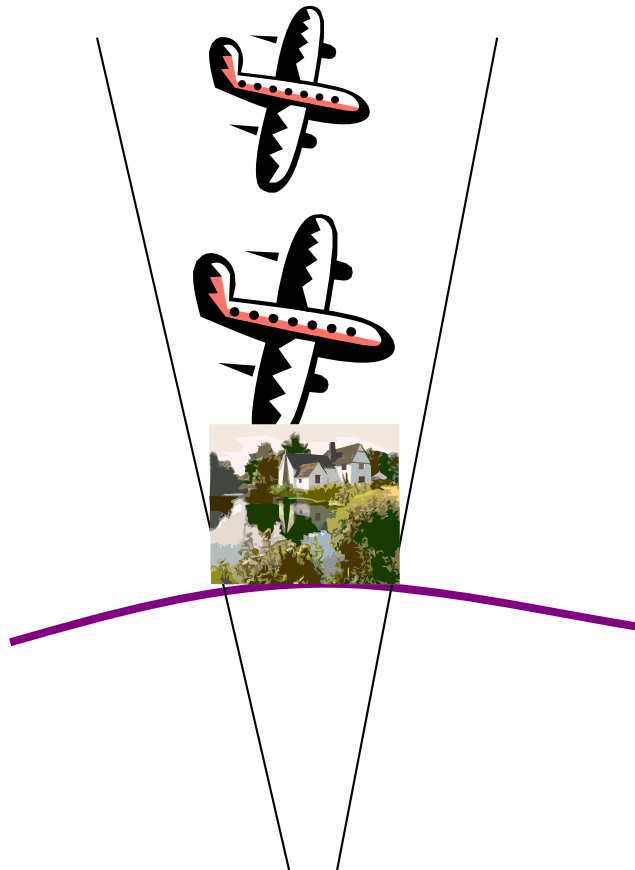


usto Melotti esposti nei giardini del Pac. Le opere al Carducci potrebbero essere precedenti alle

Scientific point of view v. legal-political point of view ?

A) (*Metaphor*) Property and the limit of the owner's **interest**

Cuius est solum, eius est usque ad caelum (ad sidera), et usque ad inferos



U.S. Supreme Court

UNITED STATES v. CAUSBY, 328 U.S. 256 (1946)

328 U.S. 256

UNITED STATES

v.

CAUSBY *et al.*

No. 630.

Argued May 1, 1946.

Decided May 27, 1946.

On 27 May 1946, the Supreme Court ruled on the case. It agreed with Causby that the use of his farmland was a taking in effect, and that Causby was entitled to his just compensation under the Fifth Amendment. Justice Douglas wrote the opinion for the majority, with Justice Black, joined by Justice Burton, dissenting.

Declaring the air "a public highway," Douglas rejected Causby's claim that his airspace had been taken from him. "To recognize such private claims to the airspace would clog these highways," Douglas opined, "seriously interfere with their control and development in the public interest, and transfer into private ownership that to which only the public has a just claim." However, he did concede "that if the landowner is to have full enjoyment of the land, he must have exclusive control of the immediate reaches of the enveloping atmosphere." Thus the low altitude overflights constituted an invasion of Causby's space "in the same category as invasions of the surface."

Scientific point of view v. legal-political point of view ?

A) Property and the limit of the landowner's **interest**

Cuius est solum, eius est usque ad caelum (ad sidera), et usque ad inferos

Italian Civil Code (1942), Article 840 :

The land property extends to the subsoil, and the landowner is permitted to excavate or build without causing damage to neighbours.

The landowner **is not entitled to oppose** to third party's works extending into the deep subsoil or the space above the land, unless he has a **specific interest**.

Art. 100 cpc

Art. 24 Cost

Nuremberg Doctors Trial and Code

“... [information on] the effects upon his **health** or **person** which may possibly come from his participation in the experiment”.

“The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury”.

In genetics

Person - Biological material - Information

Does it make any difference ?

Improper use of my personal information by a third party may produce injury !

- What is a personal information ?
- Any kind of personal information ?
- Even the smallest one I share with far relatives and... the *Common Ancestor* of all humans ?
- May we extend the individualistic pattern to all information related to my person, even the **smallest** or **remote** ?

Beyond the boundary of our bodies and beyond relevant information on health and other personal aspects...

How should interest be defined?

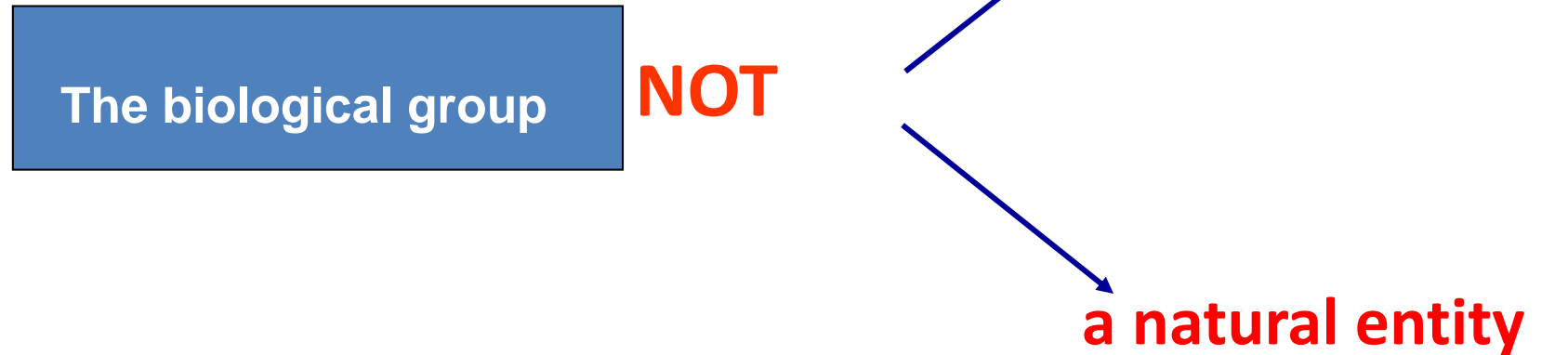
- according to the **kind of activity** (research or other...)
- according to the **genetic distance** ?
- according to the **time that has passed from** from the collection of a sample and its use and to the **kind of use** ?

Who is the **burden of proving his/her interest** up ?

Who is **entitled to oppose** to some kinds of use?

*May we say that at a certain **genetic distance** the existence of a right (and its related interest) has to **be demonstrated by who is claiming it?***

Legal point of view



The biological group

- A construction of legal theory
- in a specific historical situation and
- according to scientific knowledge of that moment

Scientific point of view v. legal-political point of view

Thus

The (*legal*) biological group is a *legal artifact*.

It is the result of how *biologically involved* people have exercised their own *individual rights* ?

B) The biological group as a legal artifact

“ **Thirdly**, follows the liberty of combination among individuals; freedom to unite, for any purpose not involving harm to others: the persons combining being supposed to be of full age, and not forced or deceived.”

J.S.Mill

Should privacy be abolished in genetics ?

YES, if privacy is biologically extended to any biological connection at any time

NO, if privacy is referred to **directly involved people** and, in a wider area, only to those who are able to demonstrate a **concrete interest**.

Grazie !

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Usi primari, usi secondari

Informazioni e materiali

(source Mariachiara Tallacchini)

- **Informazioni sanitarie personali (Personal Health Information, PHI)**

- Uso di informazioni sanitarie personali (PHI) a diretto beneficio di un individuo
- Uso di informazioni sanitarie personali che includono, ma non si limitano all'analisi, alla ricerca, alla misura di qualità e sicurezza, sanità pubblica, etc..

Biological Materials/ Human Tissues

- Materiali prelevati a diretto beneficio dell'individuo da cui sono prelevati
- Usi successivi o comunque diversi non a diretto beneficio del soggetto da cui sono prelevati

La **maniera solita** di definire la persona fisica:

la **persona fisica** è un **essere umano**

mentre

la persona giuridica non lo è.

Per il diritto

“La persona esiste soltanto in quanto *ha* doveri e diritti;
senza di questi essa non ha alcuna esistenza”.

Hans Kelsen,
General Theory of Law and State
1945

UOMO	PERSONA
concetto biologico e fisiologico	concetto della giurisprudenza
scienze naturali	analisi delle norme giuridiche
essere umano	persona fisica <i>giur.</i> (soggetto di doveri e diritti) personificazione di doveri e diritti

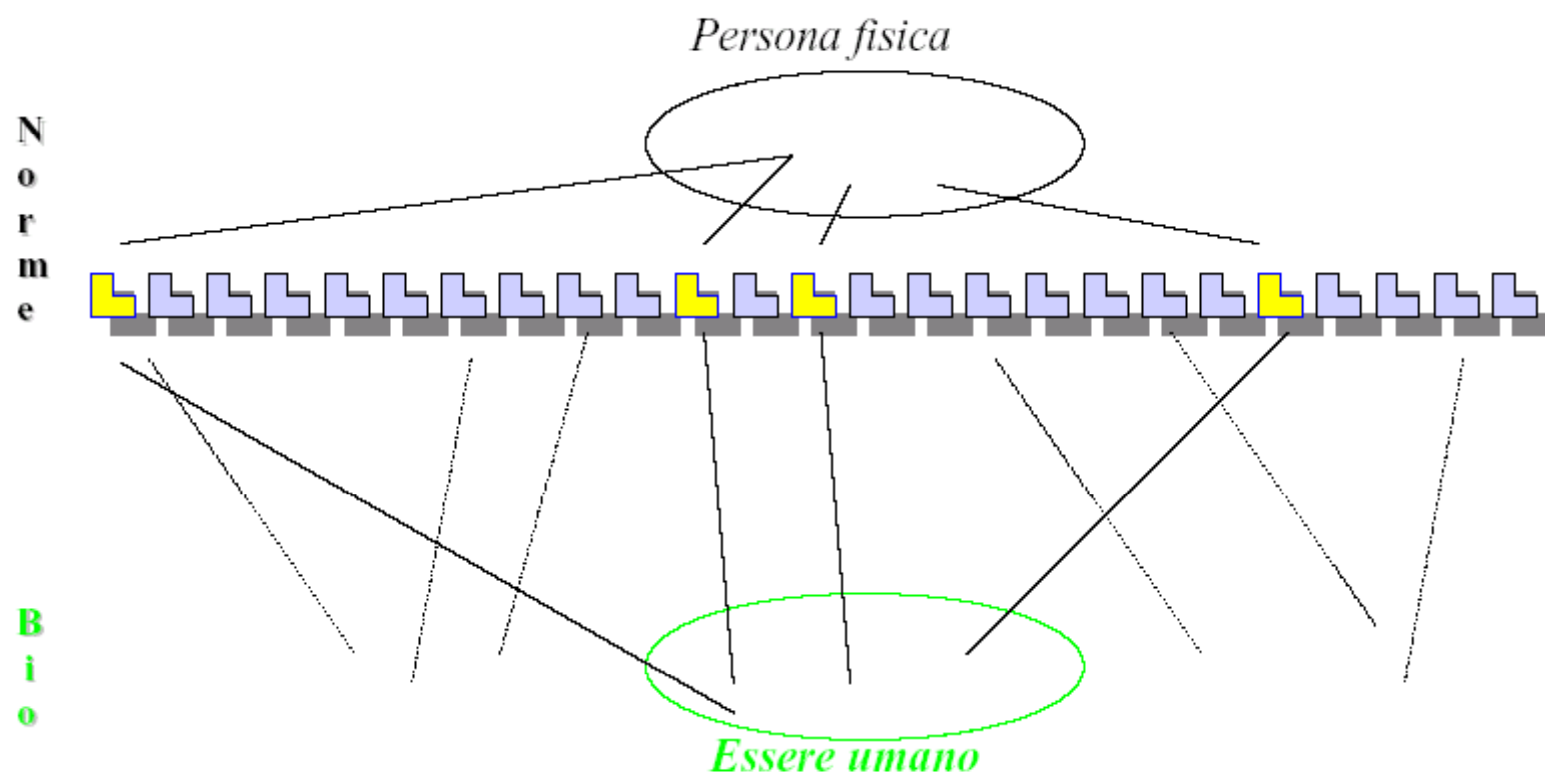
la persona fisica (giuridica/per il diritto) è la

personificazione di un complesso di norme giuridiche

le quali, ponendo i doveri ed i diritti che formano il contenuto della condotta di uno stesso essere umano ne regolano la condotta.

La PERSONIFICAZIONE di norme giuridiche

L'essere umano **non è** la persona fisica **ma è**, per così dire, soltanto la “**delimitazione**” di una persona fisica (per il diritto).



Dire che “la persona fisica **È** un essere umano” è inesatto.

**La persona fisica NON È UNA REALTÀ NATURALE
ma È UNA COSTRUZIONE del pensiero giuridico.**

a) On information and consent:

How to deal with the conflicts within the biological group?

Each member of a biological group shares, to some extent, its genetic dowry with the members of the same genetic line or collateral relatives.

- If everybody shares a part of its genetic dowry with the members of the same biological group can we still say that everybody has *his own* genetic dowry?

How do genetics affect *family ties* ?

What about people *able* to consent ?

The general rule of informed consent ?

Article 18 – Information relevant to family members

Where the results of a genetic test undertaken on a person can be relevant to the health of other family members, the person tested shall be informed.

Explanatory Report

Article 18 – Information relevant to family members

138. The results of certain genetic tests may be relevant for the health of other family members. The person concerned must have been informed of this before the test is carried out, in accordance with the provisions of Article 8 of this Protocol.

Article 8 – Information and genetic counselling

1 When a genetic test is envisaged, the person concerned shall be provided with prior appropriate information in particular on the purpose and the nature of the test, as well as the implications of its results.

2 For predictive genetic tests as referred to in Article 12 of the Convention on Human Rights and Biomedicine, appropriate genetic counselling shall also be available for the person concerned. [...]

The form and extent of this genetic counselling shall be defined according to the implications of the results of the test and their significance for the person or the members of his or her family [...].

140. For the communication of this information to the **family members**, appropriate provisions should be made, bearing in mind the rules on confidentiality and the protection of the private life of the various persons concerned (person on whom the test is performed and members of his or her **family**).

The choice of procedure(s) is left to the States. If the person tested is unable or unwilling to contact his or her **family members** directly he or she may be given appropriate material or letters to pass on to the family member(s). Consideration could be given to setting up a mediating body responsible for contacting **family members** of the person concerned if the latter has asked for them to be informed without him or herself being identifiable as the source of the information.

Another example, would be the possibility to provide for a decision by a competent body, following comparative assessment of the respective interests of the persons concerned, on whether or not the information in question must be communicated to **the members of the family**.

Two questions:

a) On information and consent:

- Are provisions on information an adequate safeguard ?
- If informed consent is the rule, informed refusal should be considered on an equal basis ?
- What are the consequences ?

b) Family members or biological group ?

Case law

- (i) the *Icelandic Supreme Court* decision (27 November 2003), who upheld the right of a woman to prohibit the transfer of the died father's information into the national database;
- (i) the decision of an *Italian Administrative Court* (Tribunale Amministrativo Regionale Veneto, 30 gennaio 2003) on the right of a woman to have access to her sister's medical data, which were collected in a hospital repository;
- (i) the decision issued by the *Garante per la protezione dei dati personali* (Italy, 1999);
- (ii) Tribunal of Milan, 2008, on a deceased person
- (iii) *Other cases*....

b) Family v. biological group

Council of Europe, Recommendation 1997(5). Point 58 of the *Memorandum*:

“The collection and processing of genetic data involves the storage of data concerning third parties.

*These **third parties** may be constituted by members of the data subject's genetic line or collateral relatives or members of his/her social family...*

b) Family v. biological group

*The drafters agreed to **accord an intermediate status** to members of the data subject's genetic line*

so as

*to distinguish them from third parties in the strict sense of the term and **to grant them a hybrid legal protection.***”

b) Family v. biological group

One of the fundamental features of genetic data consists both in its marking out an individual from others and the fact that this data – and more precisely: the characteristics to which it refers - is structurally shared by all the members of the same **biological group**.

ARTICLE 29 Data Protection Working Party Working
Document on Genetic Data (17 March 2004)

b) Family v. biological group

Given the highly sensitive nature of this issue, **a balance must be found** between a **data subject's right** not to disclose his or her genetic information and the potential serious **implications** the disclosure and use of such information could have **on the members of a biological family**.

ARTICLE 29 Data Protection Working Party Working
Document on Genetic Data (17 March 2004)

The problem

We have no definition of the concept of

- ✓ **intermediate status**
- ✓ **hybrid legal protection**
- ✓ **balance of rights .**

As a consequence

- **Legal criteria**, according to which such a hybrid or intermediate status should be **defined**
- and the way of **managing the conflicts** among third parties having an intermediate status

are dramatically *unclear*.

IN AMBITO INTERNAZIONALE

❖ Dichiarazione Universale sul Genoma Umano e i Diritti Umani, UNESCO (1997), Articolo 1: *The human genome underlies the **fundamental unity of all members of the human family** as well as the recognition of their inherent dignity and diversity. On a symbolic sense, it is the heritage of human family.*

❖ Statement on DNA Sampling: control and access (1998), HUGO Ethics Committee: *special considerations should be made for access by immediate relatives. Where there is a high risk of having a transmitting a serious disorder and prevention or treatment is available, **immediate relatives** should have access to store DNA (..)*

❖ Additional Protocol to the Convention on Human Rights and Biomedicine concerning Genetic Testing of Health Purpose (2008), Articolo 18 “Information relevant to family members”: *Where the results of a genetic test undertaken on a person can be relevant to the health of **other family members**, the person tested shall be informed.*

(Nel Report Esplicativo il “membro familiare” è indicato semplicemente come “*with whom the person concerned has a biological link*”)

Dal Preamble: Recalling that the human genome is shared by all human beings, thereby forming a mutual bond between them while slight variations contribute to the

