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Chapter XXX
Which Rights for Which Subjects?
Genetic Confidentiality and Privacy in the Post-Genomic Era

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ABSTRACT

The aim of the present chapter is to elucidate the paradoxical position of the individual legal subject in the context of human genetics. It first discusses the assumed individual "right to know" and "right not to know" about genetic susceptibilities, predispositions and risks when genetic tests exist, and assess the usual assumption according to which more information necessarily increases liberty and enhances autonomy. A second section is dedicated to the issues of confidentiality, intra-familial disclosure and familial management of genetic information. The idea is suggested that those issues challenge the fundamental liberal unit of the individual traditionally understood as a stable, unitary, embodied entity.

INTRODUCTION

Notwithstanding the fears and expectations unleashed by the hype surrounding the "genetic revolution" initiated in the early nineties with the Human Genome Project, the so-called "new human genetics" has not transformed nor provided definitive elucidation of what it is to be human but has undoubtedly shifted the locus of inquiry for characterising commonalities and variations among the human species. Focusing on "genes", the scrutiny has shifted from 'visible' superficial physiognomy and anatomy, from the layer of physical appearance and expressed behaviours, and from 'incalculable' social, economical and environmental contexts, to the 'invisible' but locatable and 'calculable' internal, molecular milieu.

What may the rights and duties of the individual subject be with regard to "his" newly accessible genetic information? Does the individual have a "right to know", a "right not to know", a "duty to know" or "liberty to know" about medically or otherwise meaningful features of his own genome? Given the shared nature of genetic information, how are those rights or liberties of the

subject to be weighed against competing claims by blood relatives interested in the same genetic information? Genetic information is the "locus" of intersection of a network of concurring and conflicting interests, and obfuscates the lawyers' predispositions to think in terms of dual relations of individual rights and correlative individual or collective duties.

A second section will be dedicated to the intra-familial conflicts of interests in genetic information, and to the ensuing challenges this imposes to medico-legal norms such as the health provider's duty of confidentiality. What are the possibilities and implications of acknowledging the existence of a collective 'genetic subject' transcending individual embodiment? The *subject* of genetic information and of genetic privacy (the *patient* entitled to care and confidentiality in the patient-doctor relationship) is not even easily identifiable in the genetic context. Enabling the prediction of disease or the assessment of disease-risk with varying degrees of certainty, genetic information is of course important to the tested person,[1] but may also be crucial to persons who share the same genetic inheritance and are virtually exposed to the same genetic risks. Those persons (blood relatives) may sometimes be recognized a legitimate and legally protected interest, however not usually raised up to the status of a right to force intra-familial disclosure, but requiring some procedural measures enhancing the patient's aptitudes to reflect upon the interests of those third parties and to act "morally" towards them. The moral or legal character of the obligations owned by the individual directly concerned regarding disclosure of genetic information to family members is a controversial issue. Indeed, isn't the subject of genetic information the whole 'genetic group' or genetically-related family? The dual doctor-patient relationship seems prone to explode into a complexified network of relationships extending to the whole "genetic family". The duties owed by one person *vis a vis* his relatives when aware of the presence of specific familial genetic ailments (Rhodes, 1998), or when asked to cooperate in a familial inquiry in order to establish the results of a genetic test required by one of the members of his family are to be assessed as well as the consequences of this potential collectivization of genetic rights for our representation of the liberal individual. Indeed, the extension of the medical doctor's duties towards members of the genetic group and the related issue of intra-familial disclosure of genetic information further challenge the exclusive control traditionally granted to the liberal individual over "his" personal information and biological material, and contradicts current discourses about individual self-ownership and empowerment.

THE "RIGHT TO KNOW" AND THE "RIGHT NOT TO KNOW"

A usual argument favouring the "duty to know" over the "right not to know" is that genetic risk information positively reinforce the 'genetically informed' and 'genetically empowered' individual's autonomy. The argument appears particularly compelling as a major ethical and legal imperative of neoliberal societies is the respect and, where necessary, enhancement of individual autonomy. Being aware of one's genetic risks, it is assumed, allows individuals to better adapt their lifestyle and diet, adopting a preventative attitude in order to keep healthy.[2] Yet, the relationship between genetic information and individual autonomy is much more complex than usually assumed.

What predictive genetic testing allows is the designation of patients in an anticipatory sense. Although in classical medical practice, the quasi contractual patient-doctor relationship arose because of observable symptoms, a genetic test may be offered to currently asymptomatic, healthy individuals. In the legal sphere, that shift is also resented as a disruption: what rights and obligations should the 'asymptomatic ills' be allocated by virtue of their status' as 'genetically at risk'?

Genetic testing is closer to the notion of *prognostic* than to the notion of *diagnostic*. Most of the time genetic testing doesn't reveal a currently existing health problem in a symptomatic individual but rather reveals, for asymptomatic, healthy persons, a mere probability or a particular susceptibility to develop some illnesses for which preventive or curative strategy are most often not, or not yet available. Notwithstanding the uncertainty characterising the genetic predictions,[3] what is new is the presentation of a clear genetic causal line (even if genetic make-up is merely exceptionally the exclusive and sufficient cause) going from an identified locus in the genome to the phenotypic manifestation of the disease. 'The chanciness and luck that accompany present-day risk assessment will be replaced by the clear mark of genetic susceptibility in one's very identity', Johnsen noted (Jonsen, 1996: 10). A new dimension that genetic information introduces in the individual takes the form of his inescapably anticipated 'future self' which the genetically informed individual can no longer ignore. The relationship existing between 'genetic self-knowledge' and autonomy or liberty deserves new assessment in light of that new 'genetic condition' of self-experiencing.

A seemingly universal intuition is that:

the better informed the individual is, the more capable he is of making decisions in line with his own basic wishes, since he is more likely to succeed in realizing his wishes if the beliefs he acts from are well-founded. This makes autonomy a matter of degree: generally, the more information relevant to a decision one has when making it, the more autonomous it is. From this point of view it seems difficult to defend a general right to ignorance. (Radetzki, 2003: 110)

Information about risks to oneself is usually considered enhancing individual liberty by allowing for better informed, and thus more rational, actions and choices. The perceived liberating virtues of information emancipating individuals from the constraints that uncertainty imposes on their freedom reinforce the impression that uncertainty adversely affects the autonomous character of acts and choices.

Given the potentially devastating psychological, familial, social and economic impacts of adverse genetic test results though, respecting individual autonomy has been considered, both in Europe and in the United States, as implying the individual's right to know or not to know.

By autonomy, I mean the rights and liberties necessary to individuals in order for them to live a life characterized as (in part at least) self-determined, self-authored or self-created, following plans and ideals - a conception of the good - that they have chosen for themselves.[4]

In the context of human genetics, respect for personal autonomy amounts, for example, to the recognition of a right of an individual to know or not to know about their genetic disorder. But this is contested, given that allowing a right not to know would allow people to stand uninformed, whereas autonomy is sometimes presented as requiring all the available information which may be pertinent in order to choose one's way of living. Rosamond Rhodes, for example, held that:

if autonomy is the ground for my right to determine my own course, it cannot also be the ground for not determining my own course. If autonomy justifies my right to knowledge, it cannot also justify my refusing to be informed. (...) From a Kantian perspective, autonomy is the essence of what morality requires of me. The core content of my duty is self-determination. To say this in another way, I need to appreciate that my ethical obligation is to rule myself, that is, to be a just ruler over my own actions. As sovereign over myself I am obligated to make thoughtful and informed decisions without being swayed by irrational emotions, including my fear of knowing significant genetic facts about myself. (Rhodes, 1998b)

The relationship between information and autonomy is not as straightforward as it is usually conceived however, especially when the information involved increases the range of predictable events, as is the case for genetic information. A belief in the positive relationship existing between information and freedom has been criticized, both generally and in the genetic context. Isaiah Berlin, notably, draws attention to the fact that:

Knowledge, especially risk-knowledge, if it allows the individual to take some preventive actions or decisions for himself or for others, also potentially impacts negatively on other ranges of opportunities and experiences by which the unknowing individual would have been tempted. What knowledge gives with one hand, it may well take back with the other. The growth of knowledge increases the range of predictable events, and predictability - inductive or intuitive - despite all that has been said against this position, does not seem compatible with liberty of choice. (...) if, in other words, I claim to have the kind of knowledge about myself that I might have about others, then even though my sources may be better or my certainty greater, such self-knowledge, it seems to me, may or may not add to the sum total of my freedom. The question is empirical: and the answer depends on specific circumstances. From the fact that every gain in knowledge liberates me in some respect, it does not follow (...), that it will necessarily add to the total sum of freedom that I enjoy: it may, by taking with one hand more than it gives with the other, decrease it. (Berlin, 2000)

Whether in fact genetic information enhances autonomy and freedom is always provisional. The fact that, in many cases, predictive genetic information is not really specific nor sensitive enough (the identification of a predisposing gene in one individual doesn't mean that he will necessarily develop the disease; conversely, the absence of any known predisposing gene in an individual's make-up doesn't guarantee that he will never develop the illness and is considered 'medically useless and potentially psychologically harming' given that no preventive or curative strategies currently exist for the disease at issue), has made some scholars and professional groups advocate that tests for unpreventable diseases such as Alzheimer's disease should not be provided to patients, even at their request.[5] What is seldom taken into account, moreover, in discussions about the right/duty to know and the right not to know is the probable *pleiotropic* character of the genetic mutations detected through genetic testing. Whereas it may be perfectly sensible to wish to gain information about one's increased risk of developing a preventable disease, when the same mutation also indicates that one is at the pre-symptomatic stage of an incurable and unpreventable disease or that one is at increased risk of developing such a disease, the test is both clinically useful and potentially devastating. The APOEe4 genotyping testing is one of those pleiotropic tests: it provides information about the risk of both atherosclerosis (coronary artery disease) - a condition for which preventive measures such as cessation of smoking, low-fat diet, exercise, and avoidance of stress may decrease the risk - and an increased risk of developing Alzheimer's disease. Risk information about heart disease is medically useful as it allows early prevention. On the contrary, information about the risk of developing Alzheimer's disease does not allow the patient to do anything about it, and a positive result may produce net adverse consequences.[6]

However the strong current presumption existing in favor of *genetic transparency*, both to oneself and towards others, contributes to concealing the fundamental and subtle ambiguities existing between *information* and *truth* (particularly the *probabilistic truth* of genetic risks identified through genetic tests) on the one hand, and between *information* and *freedom* or *autonomy* on the other.

In fact rather than determinism, what is suggested by the availability of genetic services is

an *extension* of human agency and choice and a parallel decrease in the scope of luck and necessity. The use of new genetic diagnostic and prognostic tools does not initiate any so-called *genetic revolution*, they only intensify an existing tendency to shift the responsibility for ill-health away from environmental, social and economic factors to the individual. Despite the claim – which may be partially true - that genetic counselling is fundamentally non-directive and that decisions about genetic risks are always left to individual choices,[7] those choices become the precise medium through which a new form of governance is exercised, taking citizens' bodies as both vectors and targets of normalization.

[T]he transformed non-directive ethos is based on the transmission of expert knowledge to create autonomous actors who, through the medium of choice consent voluntarily to act responsibly.(...) In this practice a prominent social rationality emerges: to acquire knowledge about genetic risks and embark on preventive action comes to stand out as the right way of relating to oneself (taking personal responsibility for health), the family (saving lives of relatives) and society (maintaining a healthy population).[8]

The opposition often assumed to exist between choice and directiveness lacks operability when, instead of opposing directiveness in the name of respect for expressed individual choices, one acknowledges that individual choices, far from being given, natural and objective facts, result, as Foucault suggested, from the disciplines, that is, from the power immanent in the social field which makes up the individual. One may regret that an insistence on the positive impact of information on an individual's capacity to make decisions in line with his basic wishes be not accompanied by a critical assessment of the conditions under which those basic wishes are formed.

Let us note here that the qualification of an individual's entitlements towards "his" genetic information as either "rights" or "liberties", though somewhat neglected in current scholarship, is of immense practical importance: if taken seriously, the theory of fundamental legal relations means, for example, that a "right" to know could potentially imply a correlative "duty" for the state to make genetic testing part of the health benefits packages for those willing to know about their genetic make-up, whereas a "liberty" (or privilege) to know merely implies that no restriction can be imposed to an individual willing to get tested for genotypic traits but not that he must be offered the test for free if he cannot pay for it.[9] In this line of reasoning, the growing ideas that individuals do have, if not a legal, at least a moral "duty to know" about their genetic predispositions, susceptibilities and risks, and to participate in genetic research[10] may appear incongruent in a situation where existing genetic tests are for the most part to be paid by the individuals themselves.

Another comment I would like to make here, is that the assessment of public policies about genetic rights and liberties needs to be made taking into account the somewhat contingent context of the current dominant mode of socio-economic and cultural interactions. More precisely, that those issues of individual rights towards genomic information appear so crucial today is inescapably related to the specific drives of neoliberal societies: "informational capitalism" and the "moralization of risks".

Informational capitalism has been described by various critical scholars. Perri 6 (6, 1998, p. 14-15) held that:

what is distinctive about informational capitalism is that personal information has become the basic fuel on which modern business and government run and (...) the systematic accumulation, warehousing, processing, analysis, targeting, matching, manipulation and use of personal information is producing new forms of government and business (...).

According to Julie Cohen (2001):

The use of personal information to sort and classify individuals is inextricably bound up with the fabric of our political economy (...). The conflation of information with certainty and projections with predictions is not confined to markets. The destruction of privacy is the necessary by-product of a particular set of beliefs about the predictive power of information that operate in both market and government spheres. Within this belief structure, nothing is random. Success in markets, politics, and policy-making can be predicted, and failure avoided, using the proper algorithms and the right inputs.

In Cohen's view, the use of even partial or incomplete personal information or isolated facts about individuals to predict risks and minimize uncertainties is described as 'the hallmark of the liberal state and its constituent economic and political markets.'

As for the "moralization" of risks, whereas the 'insurance society' had switched the focus from the subjective, moral notions of individual fault and responsibility to the objective notions of risk and solidarity, neo-liberal governance supposes a return from the 'insurance society' to the 'actuarial, post-Keynesian' society where '(...) acceptance of solidarity is (...) accompanied by a demand for control over personal behavior' (Rosanvallon, 1995). With the gradual substitution of selectivity to universality as a principle for the distribution of welfare benefits, *discourses of personal empowerment, activation and responsibility* induce individuals to assume personal responsibility for most adverse circumstances resulting from bad (brute) luck for which they would have expected some compensation from the collectivity in a traditional welfare-state (Handler, 2000; Handler, 2001). "Genetic risk" functions as a technology of the self, urging individuals to get the most information they can about their own genetic risk status, to act 'rationally and responsively' to promote their and their relatives' health upon receiving information, and to take personal responsibility – rather than transferring their risk in a collective pool and awaiting relief from social solidarity – for the adverse outcomes would they have failed to take advantage of the available predictive genetic information. To that extent, genetic testing may well become a privileged disciplinary tool of neoliberal governance, but does not necessarily increase the liberty and autonomy of individuals.

CONFIDENTIALITY, INTRA-FAMILIAL DISCLOSURE, AND FAMILIAL MANAGEMENT OF GENETIC INFORMATION: SELECTED ISSUES

Although the horizon of neo-liberal governance is the "responsibilisation and empowerment of individuals", or their emancipation from the old welfare institutions, at the fundamental level of philosophical anthropology, the genetic 'representational regime' induces fundamental perturbations in the liberal representations of the modernist sovereign subject on which, however, neo-liberal governance precisely relies. The liberal individual legal subject understood as a stable, unitary, embodied entity acknowledged as the fundamental unit of liberal societies does not match the 'subject' of genetic information, which transcends the boundaries of the individual both "over time", as has just been suggested, and "spatially", as intrafamilial conflicts of interests with regards to genetic information makes the very identity of the 'legal subject' and its equivalence with the unitary, embodied individual unsure in the genetic context.

The 'subject' of genetic information has even been identified as a transgenerational, collective, 'non-material genomic body' (Scully, 2005), an 'information structure' (Harraway, 1997),[11] that overflows the traditional limits of material embodiment characterizing the unitary vision of the subject as fundamental unit of liberal societies.

Both in space and in time - the 'subject', *contemplated from a genetic point-of-view* overflows the boundaries of the individual legal subject.[12] Taking inspiration from feminist scholarship it might be useful to consider whether and to what extent the 'self' deserving legal protection exceeds the spatially identifiable, physically bounded subject (Karpin, 2005). Disembodied biological and informational samples collected in biobanks 'create' informational identities (Franko Aas, 2006) 'parallel' to the body and independent from the narratives through which individuals construct and keep their biographical identity. The new identities, as information structures, allow new types of surveillance practices which, because they do not immediately target embodied identities, but merely the virtual identities composed in the dry language of electronic records, are not readily open to negotiation or contestation. Those issues will not be addressed in the present chapter, even though the questions raised by the superposition of virtual identity to the embodied identity gain ascendancy in science and technology studies given current developments in the field of information technologies with research projects in ambient intelligence and ubiquitous computing. It is enough for our present purpose to suggest that both the "genetic revolution" and the "information revolution" (involving profiling techniques, rfid tags, video surveillance, ambient intelligence etc.), despite their apparent heterogeneity, may in fact raise intersecting challenges.

Besides this superposition of a disembodied informational identity to the embodied self, the *subject* of genetic information and of genetic privacy, the *patient* entitled to genetic confidentiality is not even easily identifiable in the genetic context. Enabling the prediction of disease or the assessment of disease-risk with varying degrees of certainty,[13] genetic information is of course important to the tested person,[14] but may also be crucial to persons who share the same genetic inheritance and are virtually exposed to the same genetic risks, namely his or her **blood-relatives**. The nature of the duties owed by one person *vis a vis* his relatives when aware of the presence of specific familial genetic susceptibility, predisposition or genetic ailment that may increase disease risk, or when asked to participate in a familial inquiry in order allow detection of genetic risks on the request of other persons the family, are highly controversial.[15] (Knoppers, 1998; Knoppers, 1998a; De Sola, 1994; Abbing, 1995; Apel, 2001; Rhodes, 1998; Takala and Häyry, 2000).

Those persons (family members), "third parties" with regard to the doctor-patient relationship, may sometimes be recognized a legitimate and legally protected interest, however not usually raised up to the status of a right to force intra-familial disclosure, but requiring some procedural measures enhancing the patient's aptitudes to reflect upon the interests of those third parties and to exhibit some sense of responsibility towards them. The limited scope of the present chapter will not allow a full discussion of the full range of questions ensuing from possible conflicts of interests between the individual "tested" and interested "third parties" in the context of human genetics. Our ambition is merely to outline five major issues that challenge the traditional centrality of the individual legal subject in bioethics and biolaw.

Does a Child's Right to Know His/Her 'Genetic Identity' Trump His/Her Parent(s) Right to Genetic Confidentiality?

The questions raised by the new human genetics in this regard are not absolutely novel. The question that the European Court of Human Rights had to confront in *Odièvre v. France*,[16] for instance, involved a woman's claim to access confidential information concerning her birth (where her biological mother had decided to use the possibility of "anonymous delivery" offered by French law) and to obtain copies of any documents, public records or full birth certificates whereas her biological mother had requested that the birth

be kept secret and had waived her rights with regard to the child. The French law governing confidentiality at birth prevented the daughter (claimant) from obtaining information about her natural family. The Court held that the French Law did not constitute, in that case, a disproportionate interference with the claimant's right to privacy, but nevertheless acknowledged that the right to privacy (Article 8 of the European Convention on Human Rights) protects, among other interests, the right to personal development, and that matters relevant to personal development included details of a person's identity as a human being and the vital interest in obtaining information necessary to discover the truth concerning important aspects of one's personal identity.

In the United Kingdom, the Administrative Court faced a comparable case in *Rose v Secretary of State for Health and the HFEA*[17] involving the claim brought by two persons, one who had been conceived by artificial insemination in 1972 (before the Human Fertilisation and Embryology Act of 1990) and one born also from an artificial insemination procedure in 1996, both requesting disclosure of information about the respective donors. The Administrative Court held that Article 8 of the Human Rights Act of 1998 encompassed the right to respect of «genetic identity» entitling children born from in vitro fertilization procedures to receive information about their biological fathers.

It is far from certain however that a person's rights with regards to her «genetic identity» implies that she has a right to know about genetic test results relating to her blood relatives, nor that her right to know trumps the tested person's right to confidentiality and privacy.

Is There a 'Duty of Genetic Beneficence' Towards Family Members?

Genetic information, given its collective, inherited character, may challenge the classical duties of health practitioners: with regard to whom are they obliged to respect their obligations of confidentiality and beneficence? Moreover, one may wonder if the patient's *right to know* may imply that his family members are obliged to collaborate in the testing procedure by themselves undergoing diverse tests or by answering the many questions which arise in the context of the familial inquiry.

There are indeed other factors, specific to genetic information, which contribute to its *shared* character. For example, genetic knowledge about individuals may have to be supplemented by information obtained from relatives in order for such knowledge to be meaningful. This problem may be a partially temporary one, due to the fact that there is at present no direct test for the gene itself in many genetic conditions, and a marker or linkage test remains necessary. Linkage tests are now less frequently used, however even where a direct gene test is available, it remains important to confirm the mutation in at least one other affected family member. This is especially important where, as is the case of most genetic disorders, there is more than one form of genetic mutation that causes the disorder (Bell, 2001).Complex dilemmas relating to the familial disclosure of genetic information are worsened by practical difficulties. The dispersion and atomisation of families, which is one of the major specificities of our times, renders it impossible sometimes to carry out research on relevant blood-related persons, from which one would need to obtain information or to whom one would like to communicate certain information concerning their genetic risks. There is indeed something paradoxical in the attempts to reconstruct genetic families when, precisely, one increasingly witnesses the decomposition and recomposition of biological families several times by generation (Knoppers, 1998b).

How should the twofold opposition between the right to confidentiality and privacy of some and the right to the protection of health of others, and between the right to know of some and the

right of others to remain ignorant of their genetic make-up be resolved?

Is There a Professional 'Duty to Warn' Family Members of Genetic Risks?

The availability of genetic testing challenges one of the most classical ethical rules governing the patient-doctor relationship: the rule of confidentiality. Because genetic disease is transmitted only by way of procreation, information about genetic disease is unique in that there is a propensity (highly variable) for the condition to be shared by members of a family who are biologically related. The issue of how individual patients and their doctors should act in relation to the knowledge that the patient has a genetic condition - specifically, whether the patient and/or the doctor should or must inform relevant members of the patient's family - is a looming area of medico-legal controversy. There is a tension between the existing legal and professional obligation of the health care professional to keep confidential any medical or otherwise personal information discovered in the context of a medical examination or consultation and his competing *obligation* to prevent harm to others. In the genetic context, the confidentiality duties of the physician and the privacy rights of the *patient* may conflict with a perceived duty to prevent harm to others. In the landmark case *Tarasoff v. Regents of the University of California*,[18] the Supreme Court of California ruled that mental health professionals have a duty to provide adequate warning if a patient threatens the life of a third party during counseling sessions. The facts of the case were as follows. Prosenjit Poddar killed Tatiana Tarasoff. Two months earlier, he had confessed his intention to kill her to Dr Lawrence, a psychologist employed by the Cowell Memorial Hospital at the University of California at Berkeley. Tatiana's parents sued the Regents of the University of California on two grounds: the defendants' failure to warn the victim of the impending danger and their failure to bring about Poddar's confinement. The defendants argued in return that they owed no duty of reasonable care to Tatiana, who was not in any doctor-patient relationship with them. But the opinion of the Court was that:

the public policy favouring protection of the confidential character of patient-psychotherapist communications must yield to the extent to which disclosure is essential to avert danger to others. The protective privilege ends where the public peril begins. Our current crowded and computerized society compels the interdependence of its members. In this risk-infested society we can hardly tolerate the further exposure to danger that would result from a concealed knowledge of the therapist that his patient was lethal. If the exercise of reasonable care to protect the threatened victim requires the therapist to warn the endangered party or those who can reasonably be expected to notify him, we see no sufficient societal interest that would protect and justify concealment. The containment of such risks lies in the public interest.

In the Case of Genetic Testing, Should the Relevant Health Professional Inform a Patient's Relatives that They Could be Genetically at Risk Even in Cases where the Patient Does not Consent to Such Disclosure?

In another case - *Pate v.Threlkel*,[19] the Florida Supreme Court was asked by the plaintiff to recognise a genetic family as a legal unit. In that case, commenced in the early 1990's, Heidy Pate claimed that Dr. J. Threlkel, the physician of Pate's mother, Marianne New, was under the obligation to warn her mother that she suffered from a hereditary disease that placed her children (including the plaintiff) at risk of developing the same condition. At the time of the suit, the plaintiff had fallen ill and claimed that, had she been warned of her hereditary risk, her own condition would have been discovered earlier and might

have been curable. The court recognized a duty owed by the doctor to warn his patient's child as well as the patient herself, but also stated that 'To require the physician to seek out and warn members of the patient's family would often be difficult or impractical and would place too heavy a burden upon the physician. Thus we emphasise that in any circumstances in which the physician has a duty to warn of a genetically transferable disease, that duty will be satisfied by warning the patient.'

However, in *Safer v. Pack*,[20] the New-Jersey court went further and imposed a duty to directly warn the family members at risk. The facts were quite similar to the facts of *Pate v. Threlkel*: in 1990, Donna Safer was diagnosed with a hereditary form of colon cancer from which her father R. Batkin had died twenty-six years earlier. In 1992, Donna Safer brought a suit against Dr. G. Pack, her father's former physician, asserting that he had provided her with negligent medical care, although Dr. Pack had never treated Donna or acted as her physician in any way. Donna Safer argued that the physician was obliged to warn those at risk that his patient's condition was hereditary, so that they might have the benefits of early examination, monitoring, detection and treatment, and thus the opportunity to avoid the most baneful consequences of the condition. The *Safer* court, unlike the Florida Supreme Court in *Threlkel*, rejected a limited interpretation of the doctor's duty to warn (a duty to warn his patient, but not to directly warn members of that patient's family), and defined a broad duty to warn not only the patient, but also to directly warn those members of the patient's family at risk of falling ill with the hereditary disease at issue. Judge Kestin explained: 'Although an overly broad and general application of the physician's duty to warn might lead to confusion, conflict or unfairness in many types of circumstances, we are confident that the duty to warn of avertable risk from genetic causes, by definition a matter of familial concern, is sufficiently narrow to serve the interests of justice. Further, it is appropriate… that the duty be seen as owed not only to the patient himself but that it also extend beyond the interests of a patient to members of the immediate family of the patient who may be adversely affected by a breach of that duty'. Interestingly enough, the court had considered that there was *no essential difference* between 'the type of genetic threat at issue here and the menace of infection, contagion or threat of physical harm… The individual at risk is easily identified, and the substantial future harm may be averted or minimised by a timely and effective warning.'

The more far-reaching implications of that case are controversial. They were even rejected by the New Jersey legislature in 1996,[21] when a statute was passed for the purpose of protecting genetic privacy, which allows health care providers to warn relatives of those suffering from genetic disorders only if the patient has consented to such disclosure or after the patient has died.

In the *Schroeder v. Perkel* case, the New Jersey Supreme Court[22] had observed that the duties of physicians may extend beyond the interests of his patient, to members of that patient's immediate family who might be adversely affected by the physician's breach of duty. In that case, the court reasoned that the doctor's duty followed from the potential harm that might occur to the patient's parents in case they were conceive a second child, unaware that the second child might also suffer from cystic fibrosis.

In *Molloy v. Meyer*,[23] the Supreme Court of Minnesota held that 'A physician's duty regarding genetic testing and diagnosis extends beyond the patient to biological parents who foreseeably may be harmed by a breach of that duty.' The plaintiffs, Kimberly Molloy and her husband Robert Flomer, had a daughter with developmental retardation. Four years after their daughter's birth, K. Molloy consulted Dr. Diane Meier to determine whether her daughter's developmental retardation had a genetic cause. Dr. Meier ordered chromosomal testing of the child, including a test for fragile X

syndrome, a hereditary condition that causes a range of mental impairments. But the fragile X test was never performed, and the tests that were done revealed no genetic abnormality. After having been told by Dr. Reno Backus, another physician to whom K. Molloy referred her daughter, that the child was developmentally delayed with autistic tendencies of unknown origins, she asked about the risk of having another disabled child, as she intended to have a second child with her second husband, Glenn Molloy. Dr Backus told her that the chances of having a second child with the same impairments were extremely remote. Unfortunately, her second child also appeared to have the syndrome. Two years after the birth of her second child, K. Molloy took a genetic test that identified her as a carrier for fragile X. Her two children were also identified as having the fragile X syndrome. The Molloys sued Dr. Meier, Dr. Backus and another physician for their negligence in the care they owed to the first child and to themselves. They reproached the physicians that they negligently told them that the first child did not have the fragile X syndrome when in fact the child had never been tested for it.

In a case decided in Italy by the *Garante per la protezione dei dati personali*, the *Garante* allowed a woman to access her father's genetic data despite the latter's refusal of consent. The woman's request was motivated by her wish to take a fully informed reproductive decision by assessing the risk of transmitting a genetic disease that affected her father. The justification provided for the decision consisted in the evaluation by the *Garante* that the woman's 'right to health' (health being defined by the *Guarante* as including 'psychological and physical well-being') trumped her father's right to privacy.[24]

Other cases are imaginable where a patient's right to privacy and confidentiality would conflict with the interests of members of his/her family with regard to information about their own risk status. One may imagine, for example, the following situation: a woman aware of her strong familial history of breast cancer decides to take a BRCA1 gene test. Although her mother never went for the test, her grandmother had tested positive for the BRCA 1 mutation. If the woman also tests positive for the mutation, it necessarily means her mother is also positive. Should the latter be warned of her increased risk? What if the tested woman does not want to disclose that information to her mother?

At the opposite end of the spectrum, the case may arise where a family member who does not want to know that he/she is at risk may be forced to know: a positive test for Huntington disease performed on an unborn child indicates that the parent with a familial history of Huntington disease will for sure develop the disease. Given the Predictive and prenatal testing are available for Huntington disease, but not all people at risk choose to have the test.[25]

Conflicts of interests may also arise when, for example, having conceived a child, a man with a family history of Huntington disease and thus at a 50 per cent risk of developing Huntington's disease himself later in life does not wish to be tested and prefers not to know whether he will actually develop the illness. If the woman asks for prenatal genetic diagnosis, a positive test will indicate, with certainty, that the father will have Huntington's disease. Should the *right not to know* of the prospective father trump the paramount interest of the mother to know whether the unborn child is affected or not? The current global legal attitude regarding decisions to undertake prenatal genetic diagnosis is to respect the will of the mother who is physically concerned by the test. She *is* the patient to whom medical doctors and genetic counsellors have a duty of care (Tassicker, 2003).

Yet, the American Society of Human Genetics has already suggested that genetic information may be viewed as a 'family possession rather than simply a personal one'. In a note explaining the suggestion, one even reads the suggestion of a family-health model that contemplates the

physician's patient as the entire family, where *family* is understood to refer to a genetic network rather than a social institution (American Society of Human Genetics, 1998).

The Royal College of Physicians of the United Kingdom similarly suggested in 1991 that:

because of the nature of genes, it may be argued that genetic information about any individual should not be regarded as personal to that individual, but as the common property of other people who may share those genes, and who need the information in order to find out their own genetic constitution. If so, an individual's prima facie right to confidentiality and privacy might be regarded as overridden by the rights of others to have access to information about them. (Royal College of Physicians Committees on Clinical Genetics and Ethical Issues in Medicine, 1991)

Even more radically, some scholars dismiss concerns about patient confidentiality by assuming the pre-eminence of the genetic family within which individual identity is subsumed by the identity of the whole. For example, R. Burnett writes that:

[T]here is no need to consider confidentiality in the genetic context because, arguably, confidentiality is not sacrificed. Confidentiality is not in danger because, even assuming that policies in favour of confidentiality outweigh a duty to warn, a duty of confidentiality is not violated in the situation involving the warning of genetic diseases. (...) Now, with the introduction of genetic mapping, (...) the patient/physician relationship has been reconfigured to reflect the individual's ties to his or her ancestors and descendants. (Burnett, 1999: 559)

According to this comment, the right to privacy is just not applicable to genetic information in genetic family contexts. At the heart of the ideological construction of the genetic family is the obliteration of privacy.

This appears odd especially to the extent that it would suggest that a person's right to genetic confidentiality could not be opposed to any blood-related person, be that person part of his or her "social family" or not. The European working party set up under Article 29 of the Directive 95/46/EC on data protection (the so-called Article 29 Data Protection Working Party), acknowledged, in its Working Document on Genetic Data of 17 March 2004,[26] that:

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 a 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 child birth, did not recognise her child and requested that her particulars should not be disclosed - this right being supported in certain legal systems. The anonymity granted to the latter entities raises a further issue, which is usually dealt with by providing that the personal data required for genetic testing be communicated exclusively to a physician without referring to the identity of the relevant individual.

One may fear that subsuming the individual's right to genetic confidentiality to the interests of the other members of the same "genetic group" would adversely impact on the trust and confidence that should prevail in any doctor-patient relationship, with consequences detrimental to both the individual's and public health.

Individual v. Familial Consent in Biobanking

According to regulations in force in most countries, notably in Europe and the United States, the

establishment of a biobank or a genetic database would require the previous consent of each individual involved. In Iceland however, individual consent has been presumed, each person being automatically included in the database unless she formally expresses her refusal. In *Ragnhildur Guömundsdóttir v. The State of Iceland*,[27] the Icelandic Supreme Court ruled that the Health Sector Database Act of 1998 does not comply with Iceland's constitutional privacy protections. The case involved the question whether a woman could refuse that health information about her deceased father be included in the Health Sector Database. The court ruled that Ms. Guömundsdóttir could not opt out of the database on behalf of her father, but that she could prevent the transfer of her father's medical records (especially those concerning her father's hereditary characteristics) because of the possibility to infer information about her from such records. Moreover, the Court found that removing or encrypting personal identifiers such as name and address is not sufficient to prevent the identification of individuals involved in the database, since they may still be identified by a combination of factors such as age, municipality, marital status, education and profession, and the specification of a particular profession. The mere encryption of *direct* personal identifiers, and the various forms of monitoring entrusted to public agencies or committees, the court ruled, are not enough to comply with the Icelandic constitution's protection of privacy. This, according to the Court, required a change in the Health Database Act of 1998 (Gertz, 2004a).

Although the above mentioned case appears quite isolate so far, the mushrooming of population biobanks makes it most probable that intra-familial disagreements relating to the inclusion of genetic material in biobanks will become problematic in the future. For the purpose that concerns us here, the case is interesting to the extent that it shows how human genetics disrupts the traditional views about the individual right to consent and withdraw consent to research participation and the extent to which the law is forced to acknowledge the fact that the 'subject' of genetic information exceeds the individual liberal unit of the traditional legal subject.

CONCLUSION

The aim of the present chapter was to elucidate the paradoxical position of the individual legal subject in the context of human genetics. In particular, it has observed the discrepancy existing between the neoliberal idea of the subject as a unified, embodied, bounded, autonomous self enclosed in the present, and the somewhat 'disciplined' and at the same time 'collectivized' subject that results from the complexification of that notion in the "post-genomic genetic era".

The first complexification that has been suggested results from the "risk anticipation" that predictive genetic testing imposes to the subject. Because genetic testing allows the identification of patients in an anticipatory sense, a dimension of otherness that genetic information introduces in the "self" takes the form of an inescapably anticipated 'future self' which the genetically informed individual can no longer ignore. Focusing on the debates occurring regarding the individual's right to know and right not to know, the first section has been the occasion to criticize presupposition that information about one's genetic risks increases one's liberty and/or autonomy.

Another disruption that genetics imposes on the notion of the unified self as fundamental liberal unit results from the "collective nature" of genetic information as the "patient/genetic data subject", in the post-genomic era, tends to become a "collective entity". Issues of confidentiality, intra-familial disclosure and familial management of genetic information, discussed in the second section, illustrate the disruptions undergone by the notion of the traditional legal subject in this regard.

Some authors, like Dolgin (2000), worry that the emerging notion of the genetic group, and the shift in the locus of privacy and identity from the autonomous individual to the genetic group threatens long-standing Western values that depend upon the ideological centrality of autonomous individuality.[28] Dolgin also warns that:

The genetic family insists only on one thing - the recognition of biological information. In that, it upsets a society and a legal order committed to the position that autonomous choice can sustain a moral frame within which family life is distinguished from life in other social domains (...) At the edges of a broad commitment to freedom, and thus choice, the law faces the medicalized family, and begins to elaborate its variant: the genetic family. At least in the first instance, this family serves neither individualism nor choice. It reflects the amorality of DNA through which it is delimited, and to which it can be reduced. Unlike the notion of biogenic substance as traditionally defined, DNA is indifferent to the content of family life. This construct of family differs from others in abandoning even the repentance that contemporary families should be modeled on nostalgic images of traditional families within which, it is presumed, enduring love and absolute loyalty were assured. (Dolgin, 2000)

Others (Karpin, 2005; Sommerville and English, 1999) insist that genetic challenges to the individualist conceptions of the subject provides the beneficial opportunity to deconstruct the liberal myth of the self-sufficient, autonomous individual and to acknowledge the inherent interdependency of human beings. Anyway, debates about genetic confidentiality, genetic privacy, and intra-familial management of genetic information provide a fresh opportunity to reassess our political and cultural conceptions of what it means to be a "subject" in the circumstances of our times.

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KEY TERMS

Confidentiality: A duty held by professionals towards their clients and patients whereby they are committed to keep secret anything they learn in the course of the context of their professional relation with their client or patient.

Genetic Risk: Revealed and quantified by assessment of family history and/or by genetic testing, a genetic risk may, in exceptional cases, indicate with certainty that the individual will develop a specific disease but at unknown time, or,

most of the time, merely indicate that the individual may be particularly predisposed or susceptible to develop a specific disease if exposed to specific chemicals, aliments, or lifestyle.

Informational Capitalism: A contemporary political, economic and cultural tendency to perceive personal information as a basic resource (just as energy), an essential input to the management of public and private enterprises, as the most reliable element on which to build safety enhancement and efficiency strategies, and as a commodity, exchangeable on the "information market".

Legal Subject: Classically, the legal subject as central unit of liberalism, is perceived as a unified, fix embodied entity. Post-modern and post-conventional scholars have challenged that unitary vision of the subject. The "genetic paradigm" further questions the adequacy of the liberal vision of the subject for the law.

Privacy: As fundamental human rights, encompasses both the right for the individual to control some aspects of his personality he projects on the world, and a right to freely develop his personality without excessive interference by the State or by others in matters that are of his exclusive concern.

Right Not to Know: Used in the context of genetic testing, an individual's right not to know refers to the right an individual who has undergone a genetic test to refuse information about the full or partial test results.

Right to Know: Used in the context of genetic testing, an individual's right to know refers to the right an individual who has undergone a genetic test to know the full test results if he so wishes. The right to know does not necessarily implies the right for a person to benefit from genetic testing for free nor his right to learn about the result of a genetic test performed on a member of his family, be that person genetically related.

ENDNOTES

1 The judicial relationship between that person and the genetic information *produced* by the tests are usually qualified as individual *rights*.

2 The important financial support provided by the European Commission to research consortia such as the Public Health Genomics European Network (PHGEN) preparing all relevant actors for the future integration of genomic insights in general public health policy amplifies the general level of expectation that indeed genetic information will become central in managing individual and public health.

3 Depending on the patterns of inheritance of the genetic diseases studied - whether the illness is monogenic or not, whether it is monofactorial or not -- the degree of certainty and accurateness of the conclusions driven by genetic information regarding the future outburst of an illness or as to the probability of transmission of that illness to the offspring will vary substantially. The matter will be developed further later.

4 See Onora O'Neil (O'Neill, 2002), recalling the wide variety of notions that have been associated to the concept of autonomy by scholars such as Gerald Dworkin's (Dworkin, 1988), listing liberty (positive or negative), dignity, integrity, individuality, independence, responsibility and self-knowledge, self-assertion, critical reflection, freedom from obligation, absence of external causation, and knowledge of one's own interest as concepts that have been equated to the concept of autonomy, or as Ruth Faiden and Thomas Beauchamps (Faden, 1986) according to whome autonomy may also be defined as privacy, voluntariness, self-mastery, choosing freely, choosing one's own moral position and accepting responsibility for one's choices.

5 A correlation has been detected, for example, between APOE4 genotype and a greater probability of developing Alzheimer's disease, but this is only one of the factors of the illness.

6 See Wachbroit (1998). For more information about ApoE genotyping, see http://www.labtestsonline.org/understanding/analytes/apoe/test.html.

7 The World Medical Association, in its Declaration on the Human Genome Project explicitly mentioned that 'One should respect the will of persons screened and their right to decide about participation and about the use of the information obtained.' (World Health Organization, 2005) Similarly, the Council for International Organizations of Medical Sciences, in its 1991 Declaration of Inuyama, held that 'voluntarism should be the guiding principle in the provision of genetic services'.

8 See Koch (2005) See also Lupton (1993: 433): '[R]isk discourse as it is currently used in public health draws upon the fin de millennium mood of the late 20th century, which targets the body as a site of toxicity, contamination, and catastrophe, subject to and needful of a high degree of surveillance and control. No longer is the body a temple to be worshipped as the house of : it has become a commodified and regulated object that must be strictly monitored by its owner to prevent lapses in health-threatening behaviours as identified by risk discourse', and (Novas, 2000, p 507) : '[G]enetic forms of thought have become intertwined within ethical problematizations of how to conduct one's life, formulate objectives and plan for the future in relation to genetic risk. In these life strategies, genetic forms of personhood make productive alliances and combinations with forms of selfhood that construct the subject as autonomous, prudent, responsible and self-actualising.'

9 For a clear analysis of jural opposites (Right/No-Right; Privilege/Duty; Power/Disability; Immunity/Liability) and jural correlatives (Right/Duty; Privilege/No-Right; Power/Liability; Immunity/Disability), see the foundational work of Wesley N. Hohfeld (1923).

10 The principle of « solidarity », as endorsed by the HUGO in its recent Statement of Pharmacogenomics (PGx): Solidarity, Equity and Governance (*Genomics, Society and Policy*, 2007, Vol.3, No. 1, pp. 44-47), relies on the assumption that « because of shared vulerabilities, people have common interests and moral responsibilities to each other. Willingness to share information and to participate in research is a praiseworthy contribution to society" yet is complemented by a principle of "equity" according to which "to reduce health inequalities between different populations, and to work towards equal access to care is an important prerequisite for implementing genomic knowledge for the benefit of society."

11 'Most fundamentally,(…) the human genome projects produce entities of a different ontological kind than flesh-and-blood organisms (…) or any other sort of "normal" organic being (...) the human genome projects produce ontologically specific things called databases as objects of knowledge and practice. The human to be represented, then, has a particular kind of totality, or species being, as well as a specific kind of individuality. At whatever level of individuality or collectivity, from a single gene region extracted from one sample through the whole species genome, this human is itself an informational structure.' (Harraway: 1997, p. 247)

12 'Genetic technologies, even as they seem to promise the perfectly delimited and controlled human body, break down and disrupt other boundaries. In learning how to control body boundaries, geneticists inevitably

shift them, producing anxiety, horror, and disgust. Modernist definitions of the body, based on boundaries of self and other, human and animal, organism and machine (and the context of nature and culture) are disrupted by a blueprint that allows unprecedented interactions, swapping over, interference, and convergence of the subject. This is genetics at its mot threatening, at least to a self-conception based on stable boundaries.' (O'Connell, 2005, p. 225)

13 Even though the current practice does not allow, in most cases, to determine the time of occurrence of *late onset* illness.

14 The judicial relationship between that person and the genetic information *produced* by the tests are usually qualified as individual *rights*.

15 Rhodes, R (1998b). Genetic Links, familiy ties and social bounds: Rights and responsibilities in the face of genetic knowledge. *Journal of Medicine and Philosophy*, 23(1): 10-30.

16 *Odièvre v. France*, 42326/98 (2003) ECHR 86 (13 February 2003).

17 *Rose v Secretary of State for Health and the HFEA* [2002] EWHC 1593

18 *Tarasoff v. Regents of the University of California*, 17 Cal. 3d 425, 551 P.2d334, 131 Cal. Reptr. 14 (1976). See Riccardi (1996).

19 *Pate v.Threlkel*, 661 So.2d 278 (Fla. 1995).

20 *Safer v. Estate of Pack*, 677 A.2d 1188 (1996)

21 Genetic privacy Act, NJ, Stat. Ann & 17B:30.

22 *Schroeder v. Perkel*, 87 N.J. 53 at 69-70 (1981).

23 *Molloy v. Meyer*, 679 N.W.2d 711, 719. Molloy v. Meier, 2004 Minn. Lexis 268 (May 20, 2004). See Offit (2004)

24 Garante's Bulletin (Cittadini e Società dell Informazione 1999, No.8, 13-15), cited in Article 29 Data Protection Working Party, Working Document on Genetic Data, 17 March 2004, 12178/03/EN, WP 91 (The Working Party was set up under Article 29 of Directive 95/46/EC as an independent European advisory body on data protection and privacy.): 'In linea de principio deve osservarsi che la conoscenza, prima del coceptimento o durante la gravidanza, del rischio probabilistico di insorgenza di patologie, anche di tipo genetico, sulla persona che si intende concepire o sul nascituro puo certamente contrubuire a migliorare le condizioni di benessere psico-fisico della gestante, nel quadro di une piena tutela della salute come diritto fondamentale dell'individuo ex art.32 Cost. L'accesso ai dati sanitari del padre della richiedente appare giustificato dall'esigenza di tutelare il benessere psico-fisico della stessa e tale interesse puo, nella circostanza in esame, comportare un ragionevole sacrificio del diritto alla riservatezza dell interessato.'

25 It has even been found that most people at risk for Huntington's disease choose not to be tested (Binedell, 1998).

26 12178/03/EN WP 91.

27 Icelandic Supreme Court, No. 151/2003, 27 November 2003.

28 Dolgin is also concerned that 'The genetic family insists only on one thing - the recognition of biological information. In that, it upsets a society and a legal order committed to the position that autonomous choice can sustain a moral frame within which family life is distinguished from life in other social domains (…) At the edges of a broad commitment to freedom, and thus choice, the law faces the medicalized family, and begins to elaborate its variant: the genetic family. At least in the first instance, this family serves neither individualism nor choice. It reflects the amorality of DNA through which it is delimited, and to which it can be reduced. Unlike the notion of biogenic substance as traditionally defined, DNA is indifferent

to the content of family life. This construct of family differs from others in abandoning even the repentance that contemporary families should be modelled on nostalgic images of traditional families within which, it is presumed, enduring love and absolute loyalty were assured.' (Dolgin, 2000).