

**Report of the Research Division of
the European Court of Human Rights
on Bioethics and the case-law of the ECHR
(working document)**

SUMMARY

The term “bioethics” has been understood for the purposes of this report to encompass the protection of the human being (his/her human rights and in particular human dignity) in the context of the development of biomedical sciences. Specific issues which come under this term and are addressed in the report include reproductive rights (prenatal diagnosis and the right to a legal abortion), medically assisted procreation, assisted suicide, consent to medical treatment or examinations, ethical issues concerning HIV, retention of biological data by the authorities and the right to know one’s biological identity. These complex issues are increasingly being raised before the European Court of Human Rights, and we can perhaps expect more applications touching subjects such as gene therapy, stem cell research and cloning in the future. The cases cited raise important questions and often highly sensitive issues under Articles 2, 3, 5, 6 and most often Article 8 of the European Convention on Human Rights.

References to the Oviedo Convention on Human Rights and Biomedicine of 4 April 1997 (ETS no. 164), or the work of the Council of Europe in this area, have been found in a number of cases before the European Court of Human Rights.

TABLE OF CONTENTS

I. Examples of cases in which bioethical issues have been raised	1
A. Reproductive Rights	1
1° <i>Pre-natal diagnosis</i>	1
<i>Draon v. France [GC], no. 1513/03, judgment of 6 October 2005</i>	1
2° <i>Right to a legal abortion</i>	2
<i>D. v. Ireland, no. 26499/02, decision of 27 June 2006, application declared inadmissible</i>	2
<i>Tysic v. Poland, no. 5410/03, [4th Section], judgment of 20 March 2007</i>	4
<i>A, B, and C v. Ireland</i>	5
<i>Z v. Poland</i>	7
B. Medically assisted procreation.....	8
<i>Evans v. the United-Kingdom [GC], no. 6339/05, judgment of 10 April 2007</i>	8
<i>Dickson v. the United-Kingdom [GC], no. 44362/04, judgment of 4 December 2007</i>	10
<i>S.H and others v Austria,</i>	13
C. Assisted suicide.....	14
<i>Sanles v. Spain, no. 48335/99, ECHR 2000-XI, [4th Section], decision of 26 October 2000</i>	14
<i>Pretty v the United-Kingdom, no. 2346/02, ECHR 2002-III, [4th Section], judgment of 29 April 2002</i>	15
<i>Ernst G Haas v. Switzerland, application no. 31322/07, communicated to the parties on 20 October 2008</i>	16
<i>Ulrich Koch v Germany, application no. 497/09, communicated to the parties on 11 September 2009</i>	17
D. Consent to medical examination or treatment	18
1° <i>General issues of consent</i>	18
<i>Hoffmann v. Austria, judgment of 23 June 1993, Series A no. 255-C, n° 12875/87</i>	18
<i>Glass v. the United Kingdom, no. 61827/00, ECHR 2004-II, [4th section], judgment of 9 March 2004</i>	20
<i>Jalloh v. Germany [GC], no. 54810/00, judgment of 11 July 2006</i>	22
<i>Bogumil v. Portugal, no 35228/03, judgment of 7 October 2008, complaints under Articles 3 and 8 inadmissible</i>	25
2° <i>Consent to gynaecological examinations</i>	27
<i>Juhnke v. Turkey, no. 52515/99, 13 May 2008</i>	27
<i>Salmanođlu and Polattas v. Turkey, no. 15828/03, judgment of 17 March 2009- violation of Article 3</i>	29
3° <i>Consent to sterilization operation</i>	31
<i>V.C v. Slovakia, no. 18968/07, 16 June 2009, decision as to admissibility</i>	31
E. Ethical issues concerning HIV	31
1° <i>Threat of expulsion</i>	31
<i>Arcila Henao v. the Netherlands (dec.), no. 13669/03, decision of 24 June 2003</i>	31
<i>N. v. the United Kingdom [GC] Application no. 26565/05, 27 May 2008</i>	32
2° <i>Isolation</i>	34
<i>Enhorn v. Sweden, no. 56529/00, [2nd Section], ECHR 2005-I, judgment of 25 January 2005</i>	34
3° <i>Confidentiality</i>	36
<i>I. v. Finland, No. 20511/03, [4th Section], 17 July 2008</i>	36
<i>Armonien v. Lithuania, no. 36919/02 and Biriuk v. Lithuania, no. 23373/03, 25 November 2008 violations of Article 8 in both cases</i>	38
<i>Colak and Tsakiridis v. Germany, nos. 77144/01 and 35493/05, [5th Section], judgment of 5 March 2009</i>	41
4° <i>Preventive measures/Access to treatment</i>	43
<i>Shelly v. the United Kingdom</i>	43
<i>Aleksanyan v. Russia, no. 46468/06, [1st Section], judgement of 2 December 2008</i>	44
F. Retention of finger print, cellular samples and/or DNA by authorities	47
<i>Van der Velden v. the Netherlands no. 29514/05, 7 December 2006, inadmissible</i>	47
<i>S. and Marper v. the United Kingdom [GC] Applications nos. 30562/04 and 30566/044, 4 December 2008</i>	48
<i>W. v. the Netherlands, Application no. 20689/08, 20 January 2009</i>	49
G. The right to know one’s biological identity?	50
<i>Odivre v. France [GC], no. 42326/98, 13 February 2003</i>	50
<i>Jggi v. Switzerland, no. 58757/00, 3 July 2003, violation of Article 8</i>	51
<i>Phinikaridou v. Cyprus, Application no. 23890/02, 20 December 2007</i>	52
II Examples of cases where the Oviedo Convention on Human Rights and Biomedicine of 4 April 1997 or the work of the Council of Europe in this area have been cited.....	53
A. References to the Oviedo Convention on Human Rights and Biomedicine of 4 April 1997	53
- <i>Cyprus v. Turkey, no. 25781/94, 10 May 2001, (partly dissenting opinion of Judge Marcus- Helmond)</i> ;	53
- <i>Glass v. the United Kingdom, no. 61827/00, 9 March 2004,  58</i> ;	53
- <i>Vo. v. France, no. 53924/00, 8 July 2004,  35</i> ;	53
- <i>Evans v. the United Kingdom, no. 6339/05, [GC], 10 April 2007,  40</i> ;	53
- <i>Hlyla ZALP v. Turkey, no. 74300/01, inadmissibility decision of 11 October 2007, (Article 5 of the Oviedo Convention cited)</i> ;	53
- <i>Juhnke v. Turkey, no. 52515/99, 13 May 2008,  56</i> ;	53
- <i>V.C v. Slovakia, no. 18968/07, 16 June 2009, decision as to admissibility (Article 5 of the Oviedo Convention relied upon by the applicant before the Constitutional Court of Slovakia)</i>	54
B. References to the work of the Steering Committee on Bioethics of the Council of Europe.....	54
- <i>Wilkinson v. the United Kingdom</i>	54
- <i>S.H. and others v. Austria</i>	54

I. EXAMPLES OF CASES IN WHICH BIOETHICAL ISSUES HAVE BEEN RAISED

A. Reproductive Rights

1° Pre-natal diagnosis

Draon v. France [GC], no. 1513/03, judgment of 6 October 2005
Limitation of compensation claims in the Law of the 4th March 2002 for parents of children whose disabilities had not been detected before birth.

In the present case it is not disputed that there was an interference with the right to peaceful enjoyment of a “*possession*” within the meaning of Article 1 of Protocol No. 1 to the Convention. The parties accept that, regard being had to the position regarding liability which obtained under French law at the time of the enactment of the Law of 4 March 2002, and particularly to the settled case-law of the administrative courts, which had been established by the *Quarez* judgment mentioned above, the applicants had suffered prejudice caused directly by negligence on the part of AP-HP and had a claim in respect of which they could legitimately expect to obtain compensation for damage, including the special burdens arising from their child’s disability.

“82. In the present case, however, section 1 of the Law of 4 March 2002 abolished purely and simply, with retrospective effect, one of the essential heads of damage, relating to very large sums of money, in respect of which the parents of children whose disabilities had not been detected before birth, like the applicants, could have claimed compensation from the hospital held to be liable. The French legislature thereby deprived the applicants of an existing “asset” which they previously possessed, namely an established claim to recovery of damages which they could legitimately expect to be determined in accordance with the decided case-law of the highest courts of the land.

83. The Court cannot accept the Government’s argument that the principle of proportionality was respected, provision having been made for an appropriate amount of compensation, which would thus constitute a satisfactory alternative, to be paid to the applicants. It does not consider that what the applicants could receive by virtue of the Law of 4 March 2002 as the sole form of compensation for the special burdens arising from the disability of their child was, or is, capable of providing them with payment of an amount reasonably related to the value of their lost asset. The applicants are admittedly entitled to benefits under the system now in force, but the amount concerned is considerably less than the sum payable under the previous liability rules and is clearly inadequate, as the Government and the legislature themselves admit, since these benefits were extended recently by new provisions introduced for that purpose by the Law of 11 February 2005. Moreover, neither the sums to be paid to the applicants under that law nor the date of its entry into force for disabled children have been definitively fixed (see paragraphs 56 to 58 above). That situation leaves the applicants, even now, in considerable uncertainty, and in any

BIOETHICS AND THE CASE-LAW OF THE COURT

event prevents them from obtaining sufficient compensation for the damage they have already sustained since the birth of their child.

Thus, both the very limited nature of the existing compensation payable by way of national solidarity and the uncertainty surrounding the compensation which might result from application of the 2005 Act rule out the conclusion that this important head of damage may be regarded as having been reasonably compensated in the period since enactment of the Law of 4 March 2002.

84. As regards the compensation awarded to the applicants by the Paris Administrative Court to date, the Court notes that it covers non-pecuniary damage and disruption to the applicants' lives, but not the special burdens arising from the child's disability throughout his life. On this point, the Court is led to the inescapable conclusion that the amount of compensation awarded by the Paris Administrative Court was very much lower than the applicants could legitimately have expected and that, in any case, it cannot be considered to have been definitively secured, since the award was made in a first-instance judgment against which an appeal is pending. The compensation thus awarded to the applicants cannot therefore compensate for the claims now lost.

85. Lastly, the Court considers that the grounds relating to ethical considerations, equitable treatment and the proper organisation of the health service mentioned by the Conseil d'Etat in its opinion of 6 December 2002 and relied on by the Government could not, in the instant case, legitimise retrospective action whose result was to deprive the applicants, without sufficient compensation, of a substantial portion of the damages they had claimed, thus making them bear an individual and excessive burden.

Such a radical interference with the applicants' rights upset the fair balance to be maintained between the demands of the general interest on the one hand and protection of the right to peaceful enjoyment of possessions on the other.

86. In so far as it concerned proceedings pending on 7 March 2002, the date of its entry into force, section 1 of the Law of 4 March 2002 therefore breached Article 1 of Protocol No. 1 to the Convention¹."

2• Right to a legal abortion

D. v Ireland, no. 26499/02, decision of 27 June 2006, application declared inadmissible.

Lack of abortion services in Ireland in the case of lethal foetal abnormality

In late 2001 D., who already had two children, became pregnant with twins. In early 2002 an amniocentesis indicated that one foetus had died in the womb and that the second foetus had a chromosomal abnormality known as Trisomy 18 or Edward's Syndrome. A second amniocentesis confirmed those findings. D. was given to understand that Edward's

¹ See also: *Maurice v. France* [GC], no. 11810/03; judgement of 6 October 2005 - Similar case to the above.

BIOETHICS AND THE CASE-LAW OF THE COURT

Syndrome was fatal and that the median survival age for children with the syndrome was six days. She therefore decided that she could not carry the pregnancy to term.

D. went to the United Kingdom for an abortion. She did not seek legal advice as to her eligibility for an abortion in Ireland. At that time, the only recognised exception to the constitutional prohibition of abortion was “a real and substantial risk to the life of the mother” including one of suicide: this exception was established in the case *Attorney General v. X* (1992) where a 14-year-old pregnant girl who had been raped threatened to commit suicide if denied an abortion.

The abortion was performed in the United Kingdom. D could not remain in the United Kingdom thereafter and could not therefore take advantage of counselling on, amongst other things, the genetic implications for future pregnancies although she was given some statistical information about the recurrence of the abnormality. The applicant required some follow-up medical treatment in Ireland but she explained to the hospital and to her own family doctor that she had had a miscarriage.

The applicant complained about the lack of abortion services in Ireland in the case of lethal foetal abnormality a situation unnecessarily exacerbated by the Regulation of Information (Services outside the State for Termination of Pregnancies) Act 1995. Sections 5 and 8 of the 1995 Act limit what a doctor can tell a pregnant woman with a lethal foetal abnormality and prohibit that doctor from making proper arrangements, or a full referral, for a therapeutic abortion abroad. She also complained that she had been discriminated against as a pregnant woman or as a pregnant woman with a lethal foetal abnormality.

She relied on Articles 1 (obligation to respect human rights), 3 (prohibition of inhuman or degrading treatment), 8 (right to respect for private and family life), 10 (right to receive information), 13 (right to an effective remedy) and 14 (prohibition of discrimination) of the Convention.

The Court concluded that there was a constitutional remedy in principle available to the applicant, although some uncertainty attached to three relevant matters arising from the novelty of the substantive issue and the procedural imperatives of the applicant’s position - the chances of success, the limited time available to conclude the proceedings (the applicant had only six weeks left before the expiry of the 24-week period in which abortion was normally available in the UK) and the guarantees that her identity would be kept confidential.

However, the Court was of the view that, having regard to the potential and importance of the constitutional remedy in a common law system, especially concerning the issue in question, the applicant could reasonably have been expected to have taken certain preliminary steps. She should have obtained legal advice on those substantive and procedural uncertainties and issued a Plenary Summons allowing her to apply for an urgent, preliminary

BIOETHICS AND THE CASE-LAW OF THE COURT

and *in camera* hearing to obtain the High Court's response to her timing and publicity concerns. It was true that it was assumed that the applicant would continue during those steps an already advanced pregnancy. However, the Court was satisfied on the evidence that such preliminary steps could have been completed without disclosing the applicant's identity and in a matter of days and, further, that the evolution of those initial steps would have elucidated some of the uncertainties and allowed her to assess the effectiveness of the remedy in her situation as the days went by. In the absence of those preliminary steps, the Court was unable to dismiss as ineffective the constitutional remedy available in principle to the applicant.

The Court therefore concluded that the applicant did not comply with the requirement to exhaust domestic remedies as regards the availability of abortion in Ireland in the case of fatal foetal abnormality.

The Court further noted that the limitations of the 1995 Act, about which the applicant complained also under Articles 3, 8 and 10, concerned abortion services abroad and had no application to a lawful abortion in Ireland. Consequently, the applicant's failure to pursue domestic remedies as regards obtaining a lawful abortion in Ireland meant that her complaints about the 1995 Act, together with her associated complaints under Article 13 and 14, had also to be rejected on the grounds of a failure to exhaust domestic remedies.

Tysic v. Poland, no. 5410/03, [4th Section], judgment of 20 March 2007 Limitation on legal abortion and important detriment of the mother's health following the birth of her child

“65. (...) The failure of the State to make a legal abortion possible in circumstances which threatened the applicant's health, and to put in place the procedural mechanism necessary to allow her to have this right realised, meant that the applicant was forced to continue with a pregnancy for six months knowing that she would be nearly blind by the time she gave birth. The resultant anguish and distress and the subsequent devastating effect of the loss of her sight on her life and that of her family could not be overstated. She had been a young woman with a young family already grappling with poor sight and knowing that her pregnancy would ruin her remaining ability to see. As predicted by her doctor in April 2000, her sight has severely deteriorated, causing her immense personal hardship and psychological distress.

66. The Court reiterates its case-law on the notion of ill-treatment and the circumstances in which the responsibility of a Contracting State may be engaged, including under Article 3 of the Convention by reason of the failure to provide appropriate medical treatment (see, among other authorities, *Ilhan v. Turkey* [GC], no. 22277/93, § 87, ECHR 2000-VII, *mutatis mutandis*). In the circumstances of the instant case, the Court finds that the facts alleged do not disclose a breach of Article 3. The Court further considers that the applicant's complaints are more appropriately examined under Article 8 of the Convention.

...

BIOETHICS AND THE CASE-LAW OF THE COURT

77. As to the first limb of this complaint, the applicant argued that the very special facts of this case had given rise to a violation of Article 8. She had been seeking to have an abortion in the face of a risk to her health. The refusal to terminate the pregnancy had exposed her to a serious health risk and amounted to a violation of her right to respect for her private life.

...

112. The Court observes that the notion of “respect” is not clear-cut, especially as far as those positive obligations are concerned: having regard to the diversity of the practices followed and the situations obtaining in the Contracting States, the notion’s requirements will vary considerably from case to case. Nonetheless, for the assessment of positive obligations of the State it must be borne in mind that the rule of law, one of the fundamental principles of a democratic society, is inherent in all the Articles of the Convention (see *Iatridis v. Greece* [GC], no. 31107/96, § 58, ECHR 1999-II; *Carbonara and Ventura v. Italy*, no. 24638/94, § 63, ECHR 2000-VI; and *Capital Bank AD v. Bulgaria*, no. 49429/99, § 133, ECHR 2005-...). Compliance with requirements imposed by the rule of law presupposes that the rules of domestic law must provide a measure of legal protection against arbitrary interferences by public authorities with the rights safeguarded by the Convention (see *Malone v. the United Kingdom*, judgment of 2 August 1984, Series A no. 82, p. 32, § 67 and, more recently, *Hasan and Chaush v. Bulgaria* [GC], no. 30985/96, § 84, ECHR 2000-XI).

113. Finally, the Court reiterates that in the assessment of the present case it should be borne in mind that the Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective (see *Airey v. Ireland*, judgment of 9 October 1979, Series A no. 32, p. 12-13, § 24). Whilst Article 8 contains no explicit procedural requirements, it is important for the effective enjoyment of the rights guaranteed by this provision that the relevant decision-making process is fair and such as to afford due respect to the interests safeguarded by it. What has to be determined is whether, having regard to the particular circumstances of the case and notably the nature of the decisions to be taken, an individual has been involved in the decision-making process, seen as a whole, to a degree sufficient to provide her or him with the requisite protection of their interests (see, *mutatis mutandis*, *Hatton and Others v. the United Kingdom* [GC], no. 36022/97, § 99, ECHR 2003-VIII).”

Pending cases

A, B, and C v. Ireland (Application no. 25579/05) communicated to the parties on 7 May 2008, hearing before the Grand Chamber on 9 December 2009

The applicants are two female Irish nationals and one female Lithuanian national, resident in Ireland.

The first applicant was unmarried, unemployed and living in poverty at the time of the events in question. She became pregnant unintentionally and believing that her partner was infertile. She had four young children, all at that time in foster care as a result of problems the applicant had experienced as an alcoholic. During the year preceding her fifth pregnancy the applicant had remained sober and had been in constant contact with social workers

BIOETHICS AND THE CASE-LAW OF THE COURT

with a view to regaining custody of her children. She considered that a further child at this critical moment in her life would jeopardise the successful reunification of her existing family. She decided to travel to England to have an abortion. The United Kingdom National Health Service refused to carry out the operation at public expense and she had to borrow the money for treatment in a private clinic from a money lender. Her difficulty in raising the money delayed the abortion by three weeks. She had to travel to England alone, in secrecy and with no money to spare, without alerting the social workers and without missing a contact visit with her children. On her return to Ireland she experienced pain, nausea and bleeding for eight to nine weeks, but was afraid to seek medical advice because of the prohibition on abortion.

The second applicant was single when she became pregnant unintentionally. She had taken emergency contraception (the “morning-after pill”) the day after the unprotected intercourse, but she was advised by two different doctors that this had not only failed to prevent the pregnancy but also given rise to a substantial risk that it would be an ectopic pregnancy, where the foetus develops outside the uterus. The applicant was not prepared either to become a single parent or to run the risks associated with an ectopic pregnancy. She travelled to England for an abortion. On her return to Ireland she started passing blood clots and, since she was unsure whether or not this was normal and could not seek medical advice in Ireland, she returned to the clinic in England two weeks after the abortion for a check-up. The impossibility for her to have an abortion in Ireland made the procedure unnecessarily expensive, complicated and traumatic.

For three years the third applicant was treated with chemotherapy for cancer. Before commencing the treatment, she asked her doctor about the implications of her illness as regards her desire to have children and was advised that it was not possible to predict the effect of pregnancy on the cancer but, if she did become pregnant, it would be dangerous for the foetus if she underwent chemotherapy during the first trimester. The cancer went into remission and the applicant unintentionally became pregnant. She was unaware of this fact when she underwent a series of tests, contraindicated during pregnancy, to determine her current state of health. When she discovered she was pregnant she was unable to find a doctor willing to make a determination as to whether her life would be at risk if she continued to term or to give her clear advice as to how the foetus might have been affected by the tests she had undergone. Given the uncertainty about the risks involved, the applicant decided to have an abortion in the United Kingdom. Although her pregnancy was at a very early stage she could not have a medical abortion (where drugs are used to induce miscarriage) because she could not find a clinic which would provide this treatment to a non-resident because of the need for follow-up. Instead she had to wait for eight weeks until a surgical abortion was possible, which caused her

BIOETHICS AND THE CASE-LAW OF THE COURT

emotional distress and fear for her health. On returning to Ireland after the abortion, the applicant suffered the complications of an incomplete abortion, including prolonged bleeding and infection. The third applicant complained that the restriction on abortion, and the lack of clear legal guidelines regarding the circumstances in which a woman may have an abortion to save her life, infringed upon her right to life under Article 2 of the Convention.

All three applicants complained that the restriction on abortion stigmatised and humiliated them and risked damaging their health in breach of Article 3 of the Convention.

They further complained, under Article 8, that the national law on abortion was not sufficiently clear and precise, since the Constitutional term “unborn” was vague and since the criminal prohibition was open to different interpretations. The fact that it was open to women – provided they had sufficient resources – to travel outside Ireland to have an abortion defeated the aim of the restriction and the fact that abortion was available in Ireland only in very limited circumstances was disproportionate and excessive.

The restriction was, in addition, discriminatory in breach of Article 14 in that it had placed an excessive burden on them, as women, and particularly on the first applicant, a poor woman, who had found it more difficult to travel.

Finally, the applicants complained under Article 13 that the State had failed to provide them with an effective domestic remedy

Z v. Poland no. 46132/08, [4th Section] communicated to the parties on 19 June 2009.

Applicant’s daughter developed ulcerative colitis early during her pregnancy. The daughter was admitted to a number of hospitals before diagnosis of her condition. Certain examinations (including a second endoscopy and a colonoscopy) which would have made it possible to gather more information on the location and extent of the problem were not performed on the applicant’s daughter. One doctor refused to perform a full endoscopy stating “my conscience does not allow me”. The applicant’s daughter lost the foetus and then died herself two weeks later of septic shock caused by sepsis. Under section 39 of the Medical Profession Act, a doctor may refuse to carry out a medical service, invoking his or her objections on the ground of conscience.

Applicant complains, *inter alia*, under Article 2 that the State failed to adopt a legal framework that would have prevented the death of her daughter, specifically challenging the manner in which the law governing conscientious objection is regulated and overseen. She also submits, under Article 14 in conjunction with Articles 2, 3 and 8 that her daughter was discriminated against on the ground of her pregnancy.

B. Medically assisted procreation

Evans v. the United-Kingdom [GC], no. 6339/05, judgment of 10 April 2007
Impossibility for the applicant to have an IVF treatment due to the withdrawal of her ex-partner's consent to implant the embryos created jointly by them

“The margin of appreciation

81. In conclusion, therefore, since the use of IVF treatment gives rise to sensitive moral and ethical issues against a background of fast-moving medical and scientific developments, and since the questions raised by the case touch on areas where there is no clear common ground amongst the Member States, the Court considers that the margin of appreciation to be afforded to the respondent State must be a wide one (see X., Y. and Z, cited above, § 44).

82. The Grand Chamber, like the Chamber, considers that the above margin must in principle extend both to the State's decision whether or not to enact legislation governing the use of IVF treatment and, once having intervened, to the detailed rules it lays down in order to achieve a balance between the competing public and private interests.

Compliance with Article 8

83. It remains for the Court to determine whether, in the special circumstances of the case, the application of a law which permitted J effectively to withdraw or withhold his consent to the implantation in the applicant's uterus of the embryos created jointly by them struck a fair balance between the competing interests.

84. The fact that it is now technically possible to keep human embryos in frozen storage gives rise to an essential difference between IVF and fertilisation through sexual intercourse, namely the possibility of allowing a lapse of time, which may be substantial, to intervene between creation of the embryo and its implantation in the uterus. The Court considers that it is legitimate – and indeed desirable - for a State to set up a legal scheme which takes this possibility of delay into account. In the United Kingdom, the solution adopted in the 1990 Act was to permit storage of embryos for a maximum of five years. In 1996 this period was extended by secondary legislation to ten or more years where one of the gamete providers or the prospective mother is, or is likely to become, prematurely infertile, although storage can never continue after the woman being treated reaches the age of 55 (see paragraph 36 above).

85. These provisions are complemented by a requirement on the clinic providing the treatment to obtain a prior written consent from each gamete provider, specifying, inter alia, the type of treatment for which the embryo is to be used (Schedule 3, paragraph 2(1) to the 1990 Act), the maximum period of storage, and what is to be done with it in the event of the gamete provider's death or incapacity (Schedule 3, paragraph 2(2)). Moreover, paragraph 4 of Schedule 3 provides that “the terms of any consent under this Schedule may from time to time be varied, and the consent may be withdrawn, by notice given by the person who gave the consent to the person keeping the gametes or embryo ...” up until the point that the embryo has been “used” (that is, implanted in the uterus; see paragraph 37 above). Other States, with different religious, social and political cultures, have adopted different solutions to the

BIOETHICS AND THE CASE-LAW OF THE COURT

technical possibility of delay between fertilisation and implantation (see paragraphs 39-42 above). For the reasons set out above (paragraphs 77-82), the decision as to the principles and policies to be applied in this sensitive field must, primarily, be for each State to determine.

86. In this connection the Grand Chamber agrees with the Chamber that it is relevant that the 1990 Act was the culmination of an exceptionally detailed examination of the social, ethical and legal implications of developments in the field of human fertilisation and embryology, and the fruit of much reflection, consultation and debate (see, *mutatis mutandis*, *Hatton and others v. the United Kingdom* [GC], no. 36022/97, § 128, ECHR 2003-VIII).

87. The potential problems arising from scientific progress in storing human embryos were addressed as early as the Warnock Committee's Report of 1984, which recommended that a couple should be permitted to store embryos for their own future use for a maximum of ten years, after which time the right of use or disposal should pass to the storage authority. In the event that a couple failed to agree how the shared embryo should be used, the right to determine the use or disposal of the embryo should pass to the "storage authority". The subsequent Green Paper specifically asked interested members of the public what should happen where there was no agreement between a couple as to the use or disposal of an embryo, and the 1987 White Paper noted that those respondents who agreed that storage should be permitted were broadly in favour of the Committee's recommendations, but that some rejected the idea that the "storage authority" should be empowered to decide the embryo's fate in the event of conflict between the donors. The Government therefore proposed "that the law should be based on the clear principle that the donor's wishes are paramount during the period in which embryos or gametes may be stored; and that after the expiry of this period, they may only be used by the licence holder for other purposes if the donor's consent has been given to this". The White Paper also set out the detail of the proposals on consent, in a form which, after further consultation, was adopted by the legislature in Schedule 3 to the 1990 Act (see paragraphs 29-33 above).

88. That Schedule places a legal obligation on any clinic carrying out IVF treatment to explain the consent provisions to a person embarking on such treatment and to obtain his or her consent in writing (see paragraph 37 above). It is undisputed that this occurred in the present case, and that the applicant and J both signed the consent forms required by the law. While the pressing nature of the applicant's medical condition required her to make a decision quickly and under extreme stress, she knew, when consenting to have all her eggs fertilised with J's sperm, that these would be the last eggs available to her, that it would be some time before her cancer treatment was completed and any embryos could be implanted, and that, as a matter of law, J would be free to withdraw consent to implantation at any moment.

89. While the applicant criticised the national rules on consent for the fact that they could not be disapplied in any circumstances, the Court does not find that the absolute nature of the law is, in itself, necessarily inconsistent with Article 8 (see also the *Pretty* and *Odièvre* cases cited in paragraph 60 above). Respect for human dignity and free will, as well as a desire to ensure a fair balance between the parties to IVF treatment, underlay the legislature's decision to enact provisions permitting of no exception to ensure that every person donating gametes for the purpose of IVF treatment would know in advance that no use could be made of his or her genetic material without his or her continuing consent. In addition to the principle at stake, the absolute nature of the rule served to promote legal certainty and to avoid the problems

BIOETHICS AND THE CASE-LAW OF THE COURT

of arbitrariness and inconsistency inherent in weighing, on a case by case basis, what the Court of Appeal described as “entirely incommensurable” interests (see paragraphs 25-26 above). In the Court's view, these general interests pursued by the legislation are legitimate and consistent with Article 8.

90. As regards the balance struck between the conflicting Article 8 rights of the parties to the IVF treatment, the Grand Chamber, in common with every other court which has examined this case, has great sympathy for the applicant, who clearly desires a genetically related child above all else. However, given the above considerations, including the lack of any European consensus on this point (see paragraph 79 above), it does not consider that the applicant's right to respect for the decision to become a parent in the genetic sense should be accorded greater weight than J's right to respect for his decision not to have a genetically-related child with her.

91. The Court accepts that it would have been possible for Parliament to regulate the situation differently. However, as the Chamber observed, the central question under Article 8 is not whether different rules might have been adopted by the legislature, but whether, in striking the balance at the point at which it did, Parliament exceeded the margin of appreciation afforded to it under that Article.

92. The Grand Chamber considers that, given the lack of European consensus on this point, the fact that the domestic rules were clear and brought to the attention of the applicant and that they struck a fair balance between the competing interests, there has been no violation of Article 8 of the Convention.”

Dickson v. the United-Kingdom [GC], no. 44362/04, judgment of 4 December 2007

Refusal of domestic authorities to grant the prisoner's request for artificial insemination

“Applicability of Article 8

65. The restriction at issue in the present case concerned the refusal to the applicants of facilities for artificial insemination. The parties did not dispute the applicability of Article 8, although before the Grand Chamber the Government appeared to suggest that Article 8 might not apply in certain circumstances: where, for example, a prisoner's sentence was so long that there was no expectation of ever “taking part” in the life of any child conceived and Article 8 did not guarantee a right to procreate.

66. The Court considers that Article 8 is applicable to the applicants' complaints in that the refusal of artificial insemination facilities concerned their private and family lives which notions incorporate the right to respect for their decision to become genetic parents (the above-cited cases of *E.L.H. and P.B.H. v. the United Kingdom*, *Kalashnikov v. Russia* (dec.), no. 47095/99, ECHR 2001-XI; *Aliev v. Ukraine*, no. 41220/98, § 187-189, 29 April 2003; and *Evans v. the United Kingdom* [GC], no. 6339/05, § 71-72, 10 April 2007).

...

BIOETHICS AND THE CASE-LAW OF THE COURT

68. Accordingly, a person retains his or her Convention rights on imprisonment, so that any restriction on those rights must be justified in each individual case. This justification can flow, *inter alia*, from the necessary and inevitable consequences of imprisonment (§ 27 of the Chamber judgment) or (as accepted by the applicants before the Grand Chamber) from an adequate link between the restriction and the circumstances of the prisoner in question. However, it cannot be based solely on what would offend public opinion.

...

The conflicting individual and public interests

75. ... The Court, as the Chamber, reiterates that there is no place under the Convention system, where tolerance and broadmindedness are the acknowledged hallmarks of democratic society, for automatic forfeiture of rights by prisoners based purely on what might offend public opinion (Hirst, cited above § 70). However, the Court could accept, as did the Chamber, that the maintaining of public confidence in the penal system has a role to play in the development of penal policy. The Government also appeared to maintain that the restriction, of itself, contributed to the overall punitive objective of imprisonment. However, and while accepting that punishment remains one of the aims of imprisonment, the Court would also underline the evolution in European penal policy towards the increasing relative importance of the rehabilitative aim of imprisonment, particularly towards the end of a long prison sentence (see paragraphs 28-36 above).

76. ... The Court is prepared to accept as legitimate, for the purposes of the second paragraph of Article 8, that the authorities, when developing and applying the Policy, should concern themselves, as a matter of principle, with the welfare of any child: conception of a child was the very object of the exercise. Moreover, the State has a positive obligations to ensure the effective protection of children (*L.C.B. v. the United Kingdom*, judgment of 9 June 1998, Reports of Judgments and Decisions 1998-III, § 36; *Osman v. the United Kingdom*, judgment of 28 October 1998, Reports 1998-VIII, § 115-116; and *Z and Others v. the United Kingdom* [GC], no. 29392/95, § 73, ECHR 2001-V). However, that cannot go so far as to prevent parents who so wish from attempting to conceive a child in circumstances like those of the present case, especially as the second applicant was at liberty and could have taken care of any child conceived until such time as her husband was released.

...

Balancing the conflicting interests and the margin of appreciation

80. In the present case, the parties disputed the breadth of the margin of appreciation to be accorded to the authorities. The applicants suggested that the margin had no role to play since the Policy had never been subjected to parliamentary scrutiny and allowed for no real proportionality examination. The Government maintained that a wide margin of appreciation applied given the positive obligation context, since the Policy was not a blanket one and since there was no European consensus on the subject.

81. The Court notes, as to the European consensus argument, that the Chamber established that more than half of the Contracting States allow for conjugal visits for prisoners (subject to a variety of different restrictions), a measure which could be seen

BIOETHICS AND THE CASE-LAW OF THE COURT

as obviating the need for the authorities to provide additional facilities for artificial insemination. However, while the Court has expressed its approval for the evolution in several European countries towards conjugal visits, it has not yet interpreted the Convention as requiring Contracting States to make provision for such visits (see the above-cited *Aliev* judgment, at § 188). Accordingly, this is an area in which the Contracting States could enjoy a wide margin of appreciation in determining the steps to be taken to ensure compliance with the Convention with due regard to the needs and resources of the community and of individuals.

82. However, and even assuming that the judgment of the Court of Appeal in the *Mellor* case amounted to judicial consideration of the Policy under Article 8 (despite its pre-incorporation and judicial review context, see paragraphs 23-26 above), the Court considers that the Policy as structured effectively excluded any real weighing of the competing individual and public interests, and prevented the required assessment of the proportionality of a restriction, in any individual case.

In particular, and having regard to the judgment of Lord Phillips MR in the *Mellor* case and of Auld LJ in the present case, the Policy placed an inordinately high “exceptionality” burden on the applicants when requesting artificial insemination facilities (see paragraphs 13, 15-17 and 23-26 above). They had to demonstrate, in the first place, as a condition precedent to the application of the Policy, that the deprivation of artificial insemination facilities might prevent conception altogether (the “starting point”). Secondly, and of even greater significance, they had to go on to demonstrate that the circumstances of their case were “exceptional” within the meaning of the remaining criteria of the Policy (“the finishing point”). The Court considers that even if the applicants' Article 8 complaint was before the Secretary of State and the Court of Appeal, the Policy set the threshold so high against them from the outset that it did not allow a balancing of the competing individual and public interests and a proportionality test by the Secretary of State or by the domestic courts in their case, as required by the Convention (see, *mutatis mutandis*, *Smith and Grady*, cited above § 138).

83. In addition, there is no evidence that, when fixing the Policy the Secretary of State sought to weigh the relevant competing individual and public interests or assess the proportionality of the restriction. Further, since the Policy was not embodied in primary legislation, the various competing interests were never weighed, nor were issues of proportionality ever assessed, by Parliament (see the above-cited judgments in *Hirst*, § 79, and *Evans*, §§ 86-89). Indeed, the Policy was adopted, as noted in the judgment of the Court of Appeal in the *Mellor* case (see paragraph 23 above), prior to the incorporation of the Convention into domestic law.

84. The Policy may not amount to a blanket ban such as was at issue in the *Hirst* case since in principle any prisoner could apply and, as demonstrated by the statistics submitted by the Government, three couples did so successfully. Whatever the precise reason for the dearth of applications for such facilities and the refusal of the majority of the few requests maintained, the Court does not consider that the statistics provided by the Government undermine the above finding that the Policy did not permit the required proportionality assessment in an individual case. Neither was it persuasive to argue, as the Government did, that the starting point of exceptionality was reasonable since only a few persons would be affected, implying as it did the possibility of justifying the restriction of the applicants' Convention rights by the minimal number of persons adversely affected.

BIOETHICS AND THE CASE-LAW OF THE COURT

85. The Court therefore finds that the absence of such an assessment as regards a matter of significant importance for the applicants (see paragraph 72 above) must be seen as falling outside any acceptable margin of appreciation so that a fair balance was not struck between the competing public and private interests involved. There has, accordingly, been a violation of Article 8 of the Convention.”

Pending cases

S.H and others v Austria, (Applications nos. 57813/00), Decision as to admissibility 15 November 2007

Lawfulness of certain medically assisted procreation techniques

The claim is brought by two couples, S.H and D.H, and H.E-G and M.G. S.H. suffers from fallopian tube-related infertility and D.H. is also infertile. H. E.-G. suffers from gonadism which means that she does not produce ova and is completely infertile. M.G. can produce sperm fit for procreation.

On 4 May 1998 S. H and H. E.-G. filed a request with the Constitutional Court applying for a review of the constitutionality of section 3 §§ 1 and 2 of the Artificial Procreation Act. Under section 3 § 1 of the act, only ova and sperm from spouses or from those living in a relationship similar to marriage can be used for medically-assisted procreation. The only exception, under section 3 § 2, is that sperm from a third person can be used for artificial insemination when introducing sperm into the reproductive organs of a woman. In all other circumstances, and in particular for the purpose of in vitro fertilisation, the use of sperm by donors is prohibited.²

S.H. argued that the only means of conception open to her and her husband would be in vitro fertilisation using sperm from a donor. H. E.-G. submitted that she would have to resort to a medical technique known as heterologous embryotransfer, which would entail implanting into her uterus an embryo conceived with ova from a donor and sperm from M.G. They argued that the prohibition of those two heterologous artificial procreation techniques for in vitro fertilisation under the Artificial Procreation Act was a breach of their rights under Article 8 (right to respect for private and family life) of the European Convention on Human Rights. They also relied on Article 12 (right to found a family) of the Convention and on Article 7 of the Austrian Federal Constitution, which guarantees equal treatment.

On 14 October 1999 the Constitutional Court rejected the applicants’ case. They found that there was an interference with Article 8, but that it was justified on the ground that the aim was to avoid the forming of unusual personal relations such as a child having more than one biological mother (a

² As far as can be seen the same situation as in Austria exists under Swedish and Norwegian law and, although not easy to compare, under German law. Donation of sperm is prohibited in Italy, Lithuania, and Turkey, and ovum donation in a larger number of European countries, namely Croatia, Germany, Italy, Lithuania, Norway, Switzerland and Turkey.

BIOETHICS AND THE CASE-LAW OF THE COURT

genetic mother and one carrying the child) and to avoid the risk of exploitation of women.

The applicants complained about the prohibition of heterologous artificial procreation techniques for in vitro fertilisation, relying on Articles 8 and 14 (prohibition of discrimination).

C. Assisted suicide

Sanles v. Spain, no. 48335/99, ECHR 2000-XI, [4th Section], decision of 26 October 2000

Incompatibility *ratione personae* of an application concerning recognition of the right to dignified life or dignified death filed by a third person

“With regard to the substantive rights relied on by the applicant, the Court has previously held that, under Article 35 § 1 (former 26) of the Convention, the rules of admissibility must be applied with some degree of flexibility and without excessive formalism (see the *Cardot v. France* judgment of 19 March 1991, Series A no. 200, p. 18, § 34). Account also has to be taken of their object and purpose (see, for example, the *Worm v. Austria* judgment of 29 August 1997, Reports 1997-V, § 33) and of those of the Convention in general, which, in so far as it constitutes a treaty for the collective enforcement of human rights and fundamental freedoms, must be interpreted and applied so as to make its safeguards practical and effective (see, for example, the *Yaşa v. Turkey* judgment of 2 September 1998, Reports 1998-VI, § 64).

The Court reiterates that the system of individual petition provided under Article 34 of the Convention excludes applications by way of *actio popularis*. Complaints must therefore be brought by or on behalf of persons who claim to be victims of a violation of one or more of the provisions of the Convention. The concept of victim must, in theory, be interpreted autonomously and irrespective of domestic concepts such as those concerning an interest or capacity to act. In order for an applicant to be able to claim to be a victim of a violation of the Convention, they must be able to show that they have been directly affected by the impugned measure (see, for example, the *Open Door and Dublin Well Woman v. Ireland* judgment of 29 October 1992, Series A no. 246, § 44). However, victim status may exist even where there is no damage, such an issue being relevant under Article 41 of the Convention, for the purposes of which pecuniary or non-pecuniary damage flowing from the breach must be established (see, for example, the *Wassink v. the Netherlands* judgment of 27 September 1990, Series A no 185, § 38, and the *Ilhan v. Turkey* [GC] judgment, no. 22277/93, § 52).

...

The Court considers it important to point out from the outset that it is not required to rule on whether or not there is a right under the Convention to a dignified death or a dignified life. It notes that the action (*jurisdicción voluntaria*) brought by Mr Sampedro in the Spanish courts was for recognition of his right to have his general practitioner prescribe him the medication necessary to prevent the suffering, distress and anxiety caused by his condition without that act being considered under the criminal law to be assisting suicide or to be an offence of any kind whatsoever. Admittedly, the applicant may claim to have been very affected by the circumstances surrounding Mr Sampedro’s death despite the lack of close family ties. However, the Court considers that the rights claimed by the applicant under Article 2, 3, 5, 8, 9 and

BIOETHICS AND THE CASE-LAW OF THE COURT

14 of the Convention belong to the category of non-transferable rights. Consequently, the applicant cannot rely on those rights on behalf of Mr Sampedro in the context of his action in the domestic courts.

...

Referring to the decision given by the Constitutional Court in this case, the Court reiterates that the purpose of an amparo appeal is to protect individuals from actual and effective infringements of their fundamental rights. It is not a proper remedy for requesting and obtaining an abstract decision on claims concerning allegedly erroneous interpretations or incorrect applications of constitutional provisions, but only and exclusively claims intended to re-establish or protect fundamental rights where an actual and effective violation has been alleged. It cannot hold the Spanish authorities responsible for failure to comply with an alleged obligation to have a law passed decriminalising euthanasia. It notes, moreover, that Mr Sampedro ended his days when he wanted to and that the applicant cannot be substituted for Mr Sampedro in respect of his claims for recognition of his right to die in dignity, since such a right, supposing that it can be recognised in domestic law, is in any event of an eminently personal and non-transferable nature.

The Court concludes that the applicant cannot act on Mr Sampedro's behalf and claim to be a victim of Articles 2, 3, 5, 8, 9 and 14 of the Convention, as required by Article 34.

It follows that this part of the application is incompatible *ratione personae* with the provisions of the Convention for the purposes of Article 35 § 1 and must be rejected in accordance with Article 35 § 4.

...

For these reasons, the Court unanimously declares the application inadmissible.”

Pretty v the United-Kingdom, no. 2346/02, ECHR 2002-III, [4th Section],
judgment of 29 April 2002
Refusal to give undertaking no to prosecute husband for assisting wife to
commit suicide; euthanasia

“39. The consistent emphasis in all the cases before the Court has been the obligation of the State to protect life. The Court is not persuaded that “the right to life” guaranteed in Article 2 can be interpreted as involving a negative aspect. While, for example in the context of Article 11 of the Convention, the freedom of association has been found to involve not only a right to join an association but a corresponding right not to be forced to join an association, the Court observes that the notion of a freedom implies some measure of choice as to its exercise (see *Young, James and Webster v. the United Kingdom*, judgment of 13 August 1981, Series A no. 44, pp. 21-22, § 52, and *Sigurdur A. Sigurjónsson v. Iceland*, judgment of 30 June 1993, Series A no. 264, pp. 15-16, § 35). Article 2 of the Convention is phrased in different terms. It is unconcerned with issues to do with the quality of living or what a person chooses to do with his or her life. To the extent that these aspects are recognised as so fundamental to the human condition that they require protection from State interference, they may be reflected in the rights guaranteed by other Articles of the

BIOETHICS AND THE CASE-LAW OF THE COURT

Convention, or in other international human rights instruments. Article 2 cannot, without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die; nor can it create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life.

40. The Court accordingly finds that no right to die, whether at the hands of a third person or with the assistance of a public authority, can be derived from Article 2 of the Convention. It is confirmed in this view by the recent Recommendation 1418 (1999) of the Parliamentary Assembly of the Council of Europe (see paragraph 24 above).

...

52. ... The suffering which flows from naturally occurring illness, physical or mental, may be covered by Article 3, where it is, or risks being, exacerbated by treatment, whether flowing from conditions of detention, expulsion or other measures, for which the authorities can be held responsible (see *D. v. the United Kingdom and Keenan*, both cited above, and *Bensaid v. the United Kingdom*, no. 44599/98, ECHR 2000-I).

...

55. The Court cannot but be sympathetic to the applicant's apprehension that without the possibility of ending her life she faces the prospect of a distressing death. It is true that she is unable to commit suicide herself due to physical incapacity and that the state of law is such that her husband faces the risk of prosecution if he renders her assistance. Nonetheless, the positive obligation on the part of the State which is relied on in the present case would not involve the removal or mitigation of harm by, for instance, preventing any ill-treatment by public bodies or private individuals or providing improved conditions or care. It would require that the State sanction actions intended to terminate life, an obligation that cannot be derived from Article 3 of the Convention.

56. The Court therefore concludes that no positive obligation arises under Article 3 of the Convention to require the respondent State either to give an undertaking not to prosecute the applicant's husband if he assisted her to commit suicide or to provide a lawful opportunity for any other form of assisted suicide."

Pending cases

Ernst G Haas v. Switzerland, application no. 31322/07, communicated to the parties on 20 October 2008.

Le requérant souffre d'un grave trouble affectif bipolaire depuis une vingtaine d'années. Il commit deux tentatives de suicide et effectua plusieurs séjours dans une clinique psychiatrique. Le 1^{er} juillet 2004, il devint membre de « Dignitas », association de droit privé suisse dont le but est d'assurer à ses membres une vie et une mort respectant la dignité humaine. Elle propose en particulier une assistance au suicide. Ne considérant plus pouvoir vivre dans la dignité en raison de sa maladie difficile à traiter, le

BIOETHICS AND THE CASE-LAW OF THE COURT

requérant demanda à « Dignitas » de lui apporter de l'aide dans le cadre de son suicide. Afin d'obtenir la substance nécessaire, à savoir 15 grammes de natrium pentobarbital, soumise à prescription, le requérant s'adressa à différents médecins, en vain.

Le 8 juin 2005, le requérant s'adressa à différentes autorités afin d'obtenir l'autorisation de retirer ladite substance à la pharmacie sans ordonnance, par l'intermédiaire de l'association « Dignitas ».

L'Office fédéral de la justice rejeta la demande le 27 juin 2005, au motif qu'il n'était pas compétent.

Le 20 juillet 2005, l'Office fédéral de la santé publique débouta le requérant, au motif qu'il ne s'agissait pas d'un cas d'urgence dans lequel une substance soumise à prescription pouvait être obtenue sans prescription médicale, et que seul un médecin pouvait établir une ordonnance. Le 20 décembre 2005, le Département fédéral de l'intérieur déclara irrecevable un recours contre cette décision, après avoir constaté que l'Office fédéral de la santé publique n'était pas compétent en l'espèce.

Enfin, le 3 août 2005, la direction de la santé du canton de Zurich rejeta également la demande du requérant. Le requérant recourut auprès du Tribunal fédéral contre les décisions du Département fédéral de l'intérieur et du tribunal administratif cantonal de Zurich. Il invoqua notamment l'article 8 de la Convention et soutint que cette disposition garantissait le droit de décider de sa propre mort. Par arrêt du 3 novembre 2006, le Tribunal fédéral réunit les deux procédures et rejeta les recours.

Le 2 mai 2007, le requérant adressa un courrier à 170 médecins. Il demanda à chacun d'entre eux s'il accepterait de le recevoir dans le but d'établir une expertise psychiatrique le concernant, en vue d'une éventuelle ordonnance médicale de natrium pentobarbital. Aucun médecin ne répondit positivement à sa demande. Certains refusèrent par manque de temps et/ou des compétences nécessaires, ou pour des raisons éthiques. D'autres avancèrent que la maladie du requérant pouvait être traitée.

Invoquant l'article 8 de la Convention, le requérant se plaint des conditions requises pour l'obtention du natrium pentobarbital, à savoir une expertise psychiatrique approfondie et une ordonnance médicale. Ces conditions ne pouvant être remplies en l'espèce, le droit du requérant de décider du moment et de la manière de mourir ne serait pas respecté. Le requérant soutient que, dans les situations exceptionnelles comme en l'espèce, l'accès aux médicaments nécessaires au suicide devrait être garanti par l'État.

Ulrich Koch v Germany, application no. 497/09, communicated to the parties on 11 September 2009

Since 2002 the applicant's wife (B.K.) had been suffering from total sensorimotor quadriplegia after falling in front of her doorstep. She was almost completely paralysed and needed artificial ventilation and constant

BIOETHICS AND THE CASE-LAW OF THE COURT

care and assistance from nursing staff. She therefore wished to end what was, in her view, an undignified life by committing suicide with the assistance of the Swiss assisted-suicide organisation, Dignitas.

In November 2004 B.K. requested the Federal Institute for Drugs and Medical Devices (“the Federal Institute”) to grant her authorisation to obtain 15 grams of pentobarbital of sodium, the fatal dose of medication enabling her to commit suicide at her home in Braunschweig. On 16 December 2004 the Federal Institute refused to grant her that authorisation. On 14 January 2005 the applicant and his wife lodged an administrative appeal against that decision with the Federal Institute.

On 3 March 2005 the Federal Institute confirmed its earlier decision. On 12 March 2005 B.K. committed suicide in Switzerland, assisted by Dignitas. On 4 April 2005 the applicant lodged an action for a declaration that the aforementioned decisions of the Federal Institute had been unlawful and that it had thus had a duty to grant his wife the requested authorisation. On 21 February 2006 the Cologne Administrative Court declared the applicant’s action inadmissible. On 22 June 2007 the North-Rhine Westphalia Administrative Court of Appeal dismissed the applicant’s request for leave to appeal. On 4 November 2008 the Federal Constitutional Court declared a constitutional complaint lodged by the applicant inadmissible.

The applicant complains under Article 8 of the Convention that the Federal Institute’s refusal to grant his wife authorisation to obtain the lethal dose of medication infringed her right to respect for her private and family life, in particular her right to a dignified death. He also complains that the refusal infringed his own right to respect for private and family life as he was forced to travel to Switzerland to enable his wife to commit suicide. He further complains, under Article 13, that the German courts violated his right to an effective remedy when denying his right to challenge the Federal Institute’s refusal to grant his wife the requested authorisation.

D. Consent to medical examination or treatment

1• General issues of consent

Hoffmann v. Austria, judgment of 23 June 1993, Series A no. 255-C, n° 12875/87.

Attribution of custody of children in connection with religion (Jehovah’s Witnesses); refusal of blood transfusions

“28. The applicant complained that the Austrian Supreme Court had awarded parental rights over the children Martin and Sandra to their father in preference to herself, because she was a member of the religious community of Jehovah’s Witnesses; she claimed a violation of her rights under Article 8 (art. 8) of the Convention, both taken alone and read in conjunction with Article 14 (art. 14+8).

BIOETHICS AND THE CASE-LAW OF THE COURT

...

31. In the enjoyment of the rights and freedoms guaranteed by the Convention, Article 14 (art. 14) affords protection against different treatment, without an objective and reasonable justification, of persons in similar situations (see, amongst other authorities, the *Sunday Times v. the United Kingdom* (no. 2) judgment of 26 November 1991, Series A no. 217, p. 32, para. 58).

It must first be determined whether the applicant can claim to have undergone different treatment.

32. In awarding parental rights - claimed by both parties - to the mother in preference to the father, the Innsbruck District Court and Regional Court had to deal with the question whether the applicant was fit to bear responsibility for the children's care and upbringing. In so doing they took account of the practical consequences of the religious convictions of the Jehovah's Witnesses, including their rejection of holidays such as Christmas and Easter which are customarily celebrated by the majority of the Austrian population, their opposition to the administration of blood transfusions, and in general their position as a social minority living by its own distinctive rules.

...

33. This Court does not deny that, depending on the circumstances of the case, the factors relied on by the Austrian Supreme Court in support of its decision may in themselves be capable of tipping the scales in favour of one parent rather than the other. However, the Supreme Court also introduced a new element, namely the Federal Act on the Religious Education of Children (see paragraphs 15 and 23 above). This factor was clearly decisive for the Supreme Court.

The European Court therefore accepts that there has been a difference in treatment and that that difference was on the ground of religion; this conclusion is supported by the tone and phrasing of the Supreme Court's considerations regarding the practical consequences of the applicant's religion.

Such a difference in treatment is discriminatory in the absence of an "objective and reasonable justification", that is, if it is not justified by a "legitimate aim" and if there is no "reasonable relationship of proportionality between the means employed and the aim sought to be realised" (see, amongst other authorities, the *Darby v. Sweden* judgment of 23 October 1990, Series A no. 187, p. 12, para. 31).

34. The aim pursued by the judgment of the Supreme Court was a legitimate one, namely the protection of the health and rights of the children; it must now be examined whether the second requirement was also satisfied.

...

36. ... Notwithstanding any possible arguments to the contrary, a distinction based essentially on a difference in religion alone is not acceptable.

BIOETHICS AND THE CASE-LAW OF THE COURT

The Court therefore cannot find that a reasonable relationship of proportionality existed between the means employed and the aim pursued; there has accordingly been a violation of Article 8 taken in conjunction with Article 14 (art. 14+8).”

Glass v. the United Kingdom, no. 61827/00, ECHR 2004-II, [4th section], judgment of 9 March 2004.

Unauthorised medical treatment of the applicants' severely mentally and psychologically disabled son, in the absence of a court's authorization.

“61. The applicants maintained that the decisions to administer diamorphine to the first applicant against the second applicant's wishes and to place a DNR notice in his notes without the second applicant's knowledge interfered with the first applicant's right to physical and moral integrity as well as with the second applicant's Article 8 rights. In their submission, the failure of the hospital authority to involve the domestic courts in the decision to intervene without the second applicant's consent resulted in a situation in which there was an interference with the first applicant's right which was not in accordance with the law.

...

70. The Court notes that the second applicant, as the mother of the first applicant – a severely handicapped child – acted as the latter's legal proxy. In that capacity, the second applicant had the authority to act on his behalf and to defend his interests, including in the area of medical treatment. The Government have observed that the second applicant had given doctors at St Mary's Hospital on the previous occasions on which he had been admitted authorisation to pursue particular courses of treatment (see paragraphs 15, 17 and 66 above). However, it is clear that, when confronted with the reality of the administration of diamorphine to the first applicant, the second applicant expressed her firm opposition to this form of treatment. These objections were overridden, including in the face of her continuing opposition. The Court considers that the decision to impose treatment on the first applicant in defiance of the second applicant's objections gave rise to an interference with the first applicant's right to respect for his private life, and in particular his right to physical integrity (on the latter point, see, *mutatis mutandis*, *X and Y v. the Netherlands*, judgment of 26 March 1985, Series A no. 91, p. 11, § 22; *Pretty v. the United Kingdom*, no. 2346/02, §§ 61 and 63, ECHR 2002-III; and *Y.F. v. Turkey*, no. 24209/94, § 33, 22 July 2003). It is to be noted that the Government have also laid emphasis on their view that the doctors were confronted with an emergency (which is disputed by the applicants) and had to act quickly in the best interests of the first applicant. However, that argument does not detract from the fact of interference. It is, rather, an argument which goes to the necessity of the interference and has to be addressed in that context.

...

77. As to the legitimacy of the aim pursued, the Court considers that the action taken by the hospital staff was intended, as a matter of clinical judgment, to serve the interests of the first applicant. It observes in this connection that it rejected in its partial decision on admissibility of 18 March 2003 any suggestion under Article 2 of the Convention that it was the doctors' intention unilaterally to hasten the first applicant's death, whether by administering diamorphine to him or by placing a DNR notice in his case notes.

BIOETHICS AND THE CASE-LAW OF THE COURT

78. Turning to the “necessity” of the interference in issue, the Court considers that the situation which arose at St Mary’s Hospital between 19 and 21 October 1998 cannot be isolated from the earlier discussions in late July and early September 1998 between members of the hospital staff and the second applicant about the first applicant’s condition and how it should be treated in the event of an emergency. The doctors at the hospital were obviously concerned about the second applicant’s reluctance to follow their advice, in particular their view that morphine might have to be administered to her son in order to relieve any distress which the first applicant might experience during a subsequent attack. It cannot be overlooked in this connection that Dr Walker recorded in his notes on 8 September 1998 that recourse to the courts might be needed in order to break the deadlock with the second applicant. Dr Hallet reached a similar conclusion following his meeting with the second applicant on 9 September (see paragraphs 12 and 17 above).

79. It has not been explained to the Court’s satisfaction why the Trust did not at that stage seek the intervention of the High Court. The doctors during this phase all shared a gloomy prognosis of the first applicant’s capacity to withstand further crises. They were left in no doubt that their proposed treatment would not meet with the agreement of the second applicant. Admittedly, the second applicant could have brought the matter before the High Court. However, in the circumstances it considers that the onus was on the Trust to take the initiative and to defuse the situation in anticipation of a further emergency.

80. The Court can accept that the doctors could not have predicted the level of confrontation and hostility which in fact arose following the first applicant’s readmission to the hospital on 18 October 1998. However, in so far as the Government have maintained that the serious nature of the first applicant’s condition involved the doctors in a race against time with the result that an application by the Trust to the High Court was an unrealistic option, it is nevertheless the case that the Trust’s failure to make a High Court application at an earlier stage contributed to this situation.

81. That being said, the Court is not persuaded that an emergency High Court application could not have been made by the Trust when it became clear that the second applicant was firmly opposed to the administration of diamorphine to the first applicant. However, the doctors and officials used the limited time available to them in order to try to impose their views on the second applicant. It observes in this connection that the Trust was able to secure the presence of a police officer to oversee the negotiations with the second applicant but, surprisingly, did not give consideration to making a High Court application even though “the best interests procedure can be involved at short notice” (see the decision of Mr Justice Scott Baker in the High Court proceedings at paragraph 38 above).

82. The Court would further observe that the facts do not bear out the Government’s contention that the second applicant had consented to the administration of diamorphine to the first applicant in the light of the previous discussions which she had had with the doctors. Quite apart from the fact that those talks had focused on the administration of morphine to the first applicant, it cannot be stated with certainty that any consent given was free, express and informed. In any event, the second applicant clearly withdrew her consent, and the doctors and the Trust should have respected her change of mind and should not have engaged in rather insensitive attempts to overcome her opposition.

BIOETHICS AND THE CASE-LAW OF THE COURT

83. The Court considers that, having regard to the circumstances of the case, the decision of the authorities to override the second applicant's objection to the proposed treatment in the absence of authorisation by a court resulted in a breach of Article 8 of the Convention. In view of that conclusion, it does not consider it necessary to examine separately the applicants' complaint regarding the inclusion of the DNR notice in the first applicant's case notes without the consent and knowledge of the second applicant. It would however observe, in line with its admissibility decision, that the notice was only directed against the application of vigorous cardiac massage and intensive respiratory support, and did not exclude the use of other techniques, such as the provision of oxygen, to keep the first applicant alive."

Jalloh v. Germany [GC], no. 54810/00, judgment of 11 July 2006 Forcible administration of emetics in order to obtain evidence of a drugs offence, use of this illegally obtained evidence at the trial

"Alleged violation of Article 3 of the Convention

68. Treatment has been held by the Court to be "inhuman" because, *inter alia*, it was premeditated, was applied for hours at a stretch and caused either actual bodily injury or intense physical and mental suffering (see *Labita v. Italy* [GC], no. 26772/95, § 120, ECHR 2000-IV). Treatment has been considered "degrading" when it was such as to arouse in its victims feelings of fear, anguish and inferiority capable of humiliating and debasing them and possibly breaking their physical or moral resistance (see *Hurtado v. Switzerland*, Commission's report of 8 July 1993, Series A no. 280, p. 14, § 67), or when it was such as to drive the victim to act against his will or conscience (see, for example, *Denmark, Norway, Sweden and the Netherlands v. Greece* ("the Greek case"), nos. 3321/67 *et al.*, Commission's report of 5 November 1969, Yearbook 12, p. 186; *Keenan v. the United Kingdom*, no. 27229/95, § 110, ECHR 2001-III). Furthermore, in considering whether treatment is "degrading" within the meaning of Article 3, one of the factors which the Court will take into account is the question whether its object was to humiliate and debase the person concerned, although the absence of any such purpose cannot conclusively rule out a finding of violation of Article 3 (see *Raninen v. Finland*, judgment of 16 December 1997, *Reports of Judgments and Decisions* 1997-VIII, pp. 2821-22, § 55; *Peers v. Greece*, no. 28524/95, §§ 68 and 74, ECHR 2001-III; *Price*, cited above, § 24). In order for a punishment or treatment associated with it to be "inhuman" or "degrading", the suffering or humiliation involved must in any event go beyond that inevitable element of suffering or humiliation connected with a given form of legitimate treatment or punishment (see *Labita*, cited above, § 120).

69. With respect to medical interventions to which a detained person is subjected against his or her will, Article 3 of the Convention imposes an obligation on the State to protect the physical well-being of persons deprived of their liberty, for example by providing them with the requisite medical assistance. The persons concerned nevertheless remain under the protection of Article 3, whose requirements permit of no derogation (*Mouisel*, cited above, § 40; *Gennadi Naoumenko*, cited above, § 112). A measure which is of therapeutic necessity from the point of view of established principles of medicine cannot in principle be regarded as inhuman and degrading (see, in particular, *Herczegfalvy v. Austria*, judgment of 24 September 1992, Series A no. 244, pp. 25-26, § 82; *Gennadi Naoumenko*, cited above, § 112). This can be said, for instance, about force-feeding that is aimed at saving the life of a particular detainee who consciously refuses to take food. The Court must nevertheless satisfy

BIOETHICS AND THE CASE-LAW OF THE COURT

itself that a medical necessity has been convincingly shown to exist and that procedural guarantees for the decision, for example to force-feed, exist and are complied with (*Nevmerzhtsky v. Ukraine*, no. 54825/00, § 94, 5 April 2005).

70. Even where it is not motivated by reasons of medical necessity, Articles 3 and 8 of the Convention do not as such prohibit recourse to a medical procedure in defiance of the will of a suspect in order to obtain from him evidence of his involvement in the commission of a criminal offence. Thus, the Convention institutions have found on several occasions that the taking of blood or saliva samples against a suspect's will in order to investigate an offence did not breach these Articles in the circumstances of the cases examined by them (see, *inter alia*, *X. v. the Netherlands*, no. 8239/78, Commission decision of 4 December 1978, Decisions and Reports (DR) 16, pp. 187-189; *Schmidt v. Germany* (dec.), no. 32352/02, 5 January 2006). This can be said, for instance, about force-feeding that is aimed at saving the life of a particular detainee who consciously refuses to take food. The Court must nevertheless satisfy itself that a medical necessity has been convincingly shown to exist and that procedural guarantees for the decision, for example to force-feed, exist and are complied with (*Nevmerzhtsky v. Ukraine*, no. 54825/00, § 94, 5 April 2005).

71. However, any recourse to a forcible medical intervention in order to obtain evidence of a crime must be convincingly justified on the facts of a particular case. This is especially true where the procedure is intended to retrieve from inside the individual's body real evidence of the very crime of which he is suspected. The particularly intrusive nature of such an act requires a strict scrutiny of all the surrounding circumstances. In this connection, due regard must be had to the seriousness of the offence at issue. The authorities must also demonstrate that they took into consideration alternative methods of recovering the evidence. Furthermore, the procedure must not entail any risk of lasting detriment to a suspect's health (see, *mutatis mutandis*, *Nevmerzhtsky*, cited above, §§ 94, 97; *Schmidt*, cited above).

72. Moreover, as with interventions carried out for therapeutic purposes, the manner in which a person is subjected to a forcible medical procedure in order to retrieve evidence from his body must not exceed the minimum level of severity prescribed by the Court's case-law on Article 3 of the Convention. In particular, account has to be taken of whether the person concerned experienced serious physical pain or suffering as a result of the forcible medical intervention (see *Peters v. the Netherlands*, no. 21132/93, Commission decision of 6 April 1994; *Schmidt*, cited above; *Nevmerzhtsky*, cited above, §§ 94, 97).

73. Another material consideration in such cases is whether the forcible medical procedure was ordered and administered by medical doctors and whether the person concerned was placed under constant medical supervision (see, for instance, *Ilijkov v. Bulgaria*, no. 33977/96, Commission decision of 20 October 1997).

74. A further relevant factor is whether the forcible medical intervention resulted in any aggravation of his or her state of health and had lasting consequences for his or her health (see *Ilijkov*, cited above, and, *mutatis mutandis*, *Krastanov v. Bulgaria*, no. 50222/99, § 53, 30 September 2004).

...

79. As to the manner in which the emetics were administered, the Court notes that, after refusing to take the emetics voluntarily, the applicant was pinned down by four

BIOETHICS AND THE CASE-LAW OF THE COURT

police officers, which shows that force verging on brutality was used against him. A tube was then fed through his nose into his stomach to overcome his physical and mental resistance. This must have caused him pain and anxiety. He was subjected to a further bodily intrusion against his will through the injection of another emetic. Account must also be taken of the applicant's mental suffering while he waited for the emetics to take effect. During this time he was restrained and kept under observation by police officers and a doctor. Being forced to regurgitate under these conditions must have been humiliating for him. The Court does not share the Government's view that waiting for the drugs to pass out of the body naturally would have been just as humiliating. Although it would have entailed some invasion of privacy because of the need for supervision, such a measure nevertheless involves a natural bodily function and so causes considerably less interference with a person's physical and mental integrity than forcible medical intervention (see, *mutatis mutandis*, *Peters*, cited above; *Schmidt*, cited above).

...

82. Having regard to all the circumstances of the case, the Court finds that the impugned measure attained the minimum level of severity required to bring it within the scope of Article 3. The authorities subjected the applicant to a grave interference with his physical and mental integrity against his will. They forced him to regurgitate, not for therapeutic reasons, but in order to retrieve evidence they could equally have obtained by less intrusive methods. The manner in which the impugned measure was carried out was liable to arouse in the applicant feelings of fear, anguish and inferiority that were capable of humiliating and debasing him. Furthermore, the procedure entailed risks to the applicant's health, not least because of the failure to obtain a proper anamnesis beforehand. Although this was not the intention, the measure was implemented in a way which caused the applicant both physical pain and mental suffering. He therefore has been subjected to inhuman and degrading treatment contrary to Article 3.

83. Accordingly, the Court concludes that there has been a violation of Article 3 of the Convention.

...

Alleged violation of Article 6 of the Convention

87. The applicant further considered that his right to a fair trial guaranteed by Article 6 of the Convention had been infringed by the use at his trial of the evidence obtained by the administration of the emetics. He claimed in particular that his right not to incriminate himself had been violated.

...

105. As noted above, the use of evidence obtained in violation of Article 3 in criminal proceedings raises serious issues as to the fairness of such proceedings. The Court has not found in the instant case that the applicant was subjected to torture. In its view, incriminating evidence – whether in the form of a confession or real evidence – obtained as a result of acts of violence or brutality or other forms of treatment which can be characterised as torture – should never be relied on as proof of the victim's guilt, irrespective of its probative value. Any other conclusion would only serve to legitimate indirectly the sort of morally reprehensible conduct which the

BIOETHICS AND THE CASE-LAW OF THE COURT

authors of Article 3 of the Convention sought to proscribe or, as it was so well put in the US Supreme Court's judgment in the *Rochin* case to "afford brutality the cloak of law". It notes in this connection that Article 15 of the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment provides that statements which are established to have been made as a result of torture shall not be used in evidence in proceedings against the victim of torture.

...

108. In these circumstances, the Court finds that the use in evidence of the drugs obtained by the forcible administration of emetics to the applicant rendered his trial as a whole unfair.

109. This finding is of itself a sufficient basis on which to conclude that the applicant was denied a fair trial in breach of Article 6. However, it considers it appropriate to address also the applicant's argument that the manner in which the evidence was obtained and the use made of it undermined his right not to incriminate himself."

Bogumil v. Portugal, no 35228/03, judgment of 7 October 2008, complaints under Articles 3 and 8 inadmissible

Alleged lack of consent to an operation following the ingestion of cocaine bags

« 69. S'agissant en particulier des interventions médicales auxquelles une personne détenue est soumise contre sa volonté, l'article 3 de la Convention impose à l'Etat une obligation de protéger l'intégrité physique des personnes privées de liberté, notamment par l'administration des soins médicaux requis. Les personnes concernées n'en demeurent pas moins protégées par l'article 3, dont les exigences ne souffrent aucune dérogation (*Mouisel*, arrêt précité, § 40, et *Gennadi Naoumenko*, arrêt précité, § 112). Une mesure dictée par une nécessité thérapeutique du point de vue des conceptions médicales établies ne saurait en principe passer pour inhumaine ou dégradante (voir, en particulier, *Herczegfalvy c. Autriche*, arrêt du 24 septembre 1992, série A n° 244, pp. 25-26, § 82, et *Gennadi Naoumenko*, arrêt précité, § 112). Il incombe pourtant à la Cour de s'assurer que la nécessité médicale a été démontrée de manière convaincante et que les garanties procédurales dont doit s'entourer la décision de procéder à une telle mesure existent et ont été respectées (*Jalloh c. Allemagne* [GC], n° 54810/00, § 69, CEDH 2006-IX).

70 Il faut en outre tenir compte des points de savoir si l'intervention médicale pratiquée sous la contrainte a causé à la personne concernée de vives douleurs ou souffrances physiques, si elle a été ordonnée et exécutée par des médecins, si la personne concernée a fait l'objet d'une surveillance médicale constante et, enfin, si ladite intervention a entraîné une aggravation de l'état de santé de l'intéressé ou a eu des conséquences durables pour sa santé (*Jalloh*, précité, §§ 72-74).

i. Sur le consentement

71. En l'espèce, la première question sur laquelle la Cour est tenue de se prononcer est de savoir si le requérant a consenti ou non à l'intervention médicale en cause. Si en

BIOETHICS AND THE CASE-LAW OF THE COURT

effet il y a eu consentement éclairé, comme l'allègue le Gouvernement, aucune question ne se pose sous l'angle de l'article 3 de la Convention.

(...)

76. Dans ces conditions, la Cour, faute d'éléments suffisants à cet effet, n'estime pas établi que le requérant ait donné son consentement à l'intervention en cause. Rien n'indique par ailleurs qu'il aurait refusé l'intervention chirurgicale et qu'il ait été forcé à la subir.

ii. Sur l'intervention médicale

77. S'agissant d'abord de la finalité de l'intervention médicale litigieuse, la Cour estime au vu des éléments de fait disponibles qu'elle a découlé d'une nécessité thérapeutique et non de la volonté de recueillir des éléments de preuve. En effet, nul ne conteste que le requérant risquait de mourir d'une intoxication. Par ailleurs celui-ci a été maintenu sous observation pendant quarante-huit heures : c'est seulement lorsqu'il est apparu que le fait d'attendre l'expulsion du sachet par les voies naturelles constituait un risque pour sa vie que le personnel médical – et non la police – a décidé de pratiquer l'intervention chirurgicale. Enfin, comme le souligne le Gouvernement, le sachet de drogue ingéré par le requérant n'était pas indispensable – et encore moins déterminant – aux fins des poursuites pénales : le requérant a été condamné sur la base de plusieurs autres éléments de preuve, notamment la drogue saisie lors de son interpellation à l'aéroport de Lisbonne (paragraphe 28 ci-dessus).

78. A propos des risques pour la santé que comportait l'opération en cause, le Gouvernement a souligné – et le requérant n'a pas contesté – qu'il s'agissait d'une intervention simple. La Cour constate par ailleurs qu'elle a eu lieu dans un hôpital civil et qu'elle a été pratiquée par un personnel médical compétent. Enfin, à aucun moment il n'a été nécessaire d'utiliser la force envers le requérant.

79. Pour ce qui est de la surveillance médicale, la Cour observe que si le requérant a été transféré le jour même de l'intervention de l'hôpital civil à l'hôpital pénitentiaire, ce qui peut susciter une certaine perplexité, il n'en demeure pas moins qu'il a bénéficié à l'hôpital pénitentiaire d'une surveillance constante et d'un suivi médical adéquat, ce jusqu'au 6 décembre 2002, date de son transfert vers un établissement pénitentiaire.

80. Quant aux effets de l'intervention sur la santé du requérant, la Cour prend note des affirmations de celui-ci sur ce point. Eu égard toutefois aux éléments du dossier, elle ne juge pas établi que les troubles dont l'intéressé dit souffrir depuis lors soient liés à l'opération en cause.

81. Compte tenu de l'ensemble des circonstances de l'espèce, qui présentent des différences considérables par rapport à celles de l'affaire *Jalloh* précitée – qui portait également sur l'extraction d'un sachet de stupéfiants hors de l'estomac de l'intéressé – , la Cour estime que l'intervention litigieuse n'a pas été de nature à constituer un traitement inhumain ou dégradant contraire à l'article 3 de la Convention.

82. Dès lors, il n'y a pas eu violation de cette disposition.

2. Sur la violation de l'article 8

BIOETHICS AND THE CASE-LAW OF THE COURT

(...)

a) **Légalité de l'ingérence**

(...)

88. La Cour est cependant prête à accepter, compte tenu des circonstances de l'espèce, que l'article 127 du décret-loi n° 265/79 du 1^{er} août 1979, lequel établit les règles d'exécution des mesures privatives de liberté, pouvait fournir une base légale suffisante à l'intervention en cause. Le requérant se trouvait en effet détenu et dans la nécessité de recevoir des soins afin d'éviter un risque grave pour sa vie ou sa santé. Enfin, le fait que l'intéressé se trouvait détenu, pour des raisons liées à son état de santé, dans un hôpital civil et non pas dans un établissement pénitentiaire, ne semble pas faire obstacle à l'applicabilité de cette disposition. L'ingérence dans les droits du requérant était donc « prévue par la loi ».

b) **Nécessité de l'ingérence**

89. Pour ce qui est du but de l'ingérence, la Cour admet que cette dernière visait, à tout le moins, la « protection de la santé ».

90. Quant à la proportionnalité de la mesure, la Cour estime, pour les raisons déjà exposées s'agissant de l'article 3, qu'un juste équilibre a été ménagé entre l'intérêt public consistant à protéger la santé et le droit du requérant à la protection de son intégrité physique et morale (paragraphe 77-82 ci-dessus).

91. Dès lors, il n'y a eu aucune violation de l'article 8 de la Convention.

2° *Consent to gynaecological examinations*

Juhnke v. Turkey, no. 52515/99, 13 May 2008

Gynaecological examination without applicant's free and informed consent – violation of Article 8

In October 1997 the applicant was arrested by Turkish soldiers on suspicion of membership of an illegal armed organisation, the PKK (Workers' Party of Kurdistan) and handed over to gendarmes stationed in Hakkari (Turkey). In September 1998 she was convicted as charged and sentenced to 15 years' imprisonment. She was released in December 2004 and deported to Germany.

The case concerned, in particular, the applicant's complaint that her detention was unlawful and that during that detention she was subjected to ill-treatment and a gynaecological examination against her will. She relied inter alia on Articles 3, Article 5 and Article 8.

The Court, finding that there was no evidence to substantiate the applicant's allegation that she had been subjected to ill-treatment, declared that part of her complaint inadmissible. The Court further found the applicant's allegation that she had been forced to have a gynaecological

BIOETHICS AND THE CASE-LAW OF THE COURT

examination to be unsubstantiated. It therefore held by five votes to two that there had been no violation of Article 3.

However, the Court did find that the applicant had resisted a gynaecological examination until persuaded to agree to it and that, given the vulnerability of a detainee in such circumstances, the applicant could not have been expected to indefinitely resist having such an examination. The Court decided to examine that issue from the point of view of Article 8. The Court found that there had been an interference with the applicant's private life in that the examination had been imposed on her without her free and informed consent. Indeed, it even considered that she might have been misled into believing that the examination had been compulsory. Nor had it been shown that that interference was "in accordance with the law". Moreover, the examination appeared to have been a discretionary measure taken by the authorities to safeguard those members of the security forces who had arrested and detained the applicant against a false accusation of sexual assault. That safeguard did not justify seeking to persuade a detainee to agree to such an intrusive and serious interference with her physical integrity, especially given that she had not complained of having been sexually assaulted. The interference had not therefore been "necessary in a democratic society" either. Accordingly, the Court held by five votes to two that there had been a violation of Article 8.

"81. The only aim invoked by the Government in carrying out gynaecological examinations on those in custody is to protect the security forces against false allegations of sexual assault. Even if this could in principle be regarded as a legitimate aim, the Court cannot find that the examination carried out in the present case was proportionate to such an aim. While, in a situation where a female detainee complains of a sexual assault and requests a gynaecological examination, the obligation of the authorities to carry out a thorough and effective investigation into the complaint would include the duty promptly to carry out the examination (see, for example, *Aydın v. Turkey*, judgment of 25 September 1997, *Reports* 1997-VI, § 107), a detainee may not be compelled or subjected to pressure to such an examination against her wishes. As noted above, the applicant in the present case made no complaint of sexual assault against those who detained her and did not request a gynaecological examination. No reason has been advanced to suggest that she was likely to do so. The Court finds that the protection of the gendarmes against false allegations is, in any event, not such as to justify overriding the refusal of a detainee to undergo such an intrusive and serious interference with her physical integrity or, as in the present case, seeking to persuade her to give up her express objection to such an examination.

82. In sum, the Court finds that the gynaecological examination which was imposed on the applicant without her free and informed consent has not been shown to have been "in accordance with the law" or to have been "necessary in a democratic society". There has accordingly been a violation of the applicant's rights under Article 8 of the Convention."

(N.B. see the partly dissenting opinion of Judge David Thór Björgvinsson joined by Judge Lech Garlicki: "*I believe that a gynaecological examination in such situations gives rise to feelings of inferiority and degradation and that,*

BIOETHICS AND THE CASE-LAW OF THE COURT

without any rationally acceptable justification, it will be understood by the subject as being aimed exclusively at debasing and humiliating her. I accordingly believe that the kind of treatment the applicant was subjected to in this situation was degrading and, as such, aroused feelings of fear, anguish and inferiority capable of humiliating and debasing her. Therefore I find that Article 3 of the Convention has been violated.”).

Salmanoğlu and Polattaş v. Turkey, no. 15828/03, judgment of 17 March 2009- violation of Article 3

Lack of consent to a gynaecological examination

The applicants, 16 and 19 years old at the time, were arrested in March 1999 in the context of a police operation against the PKK (the Workers' Party of Kurdistan). Both girls claim that, during their police custody, they were blindfolded and beaten. Nazime also alleges that she was sexually harassed and, forced to stand for a long time, was deprived of food, water and sleep. Fatma further alleges that she was raped by having a truncheon inserted into her anus.

The applicants were examined between 6 and 12 March 1999 during their police custody by three doctors who all noted that there was no sign of physical violence to their bodies. Both applicants also had a gynaecological examination (a “virginity test”) to establish whether they had recently had sexual intercourse; the examinations recorded that the girls were still virgins. On 6 April 1999 Fatma was also given a rectal examination; the doctor noted no sign of intercourse.

Following complaints made by the two applicants on 26 March and 1 June 1999, an investigation was launched by the prosecution authorities. The Hatay Assize Court subsequently decided that criminal proceedings should be brought against the police officers who had questioned the applicants during their police custody.

On 14 April 2000, during the first hearing of the case, the girls confirmed their allegations of ill-treatment. They also submitted that, when brought before the public prosecutor and judge on 12 March 1999 with a view to their being remanded in custody, they had not made statements about their ill-treatment as they were scared. In particular, they both contended that, during certain medical examinations and when they had made statements to the prosecution, the presence of police officers had intimidated them.

The accused police officers denied that they had ill-treated the girls; nor had they been present during their medical examinations or the taking down of their statements.

During the criminal proceedings the applicants had various further medical examinations. In particular, on 23 October 2000 experts from the Istanbul Faculty of Medicine diagnosed them both with post-traumatic stress disorder. Fatma was further declared as having a major depressive disorder. Those conclusions were based on the applicants' submissions about the physical, psychological and sexual assault they had endured one

BIOETHICS AND THE CASE-LAW OF THE COURT

and a half years previously. The applicants subsequently underwent psychotherapy. Further reports by the Forensic Medicine Institute of 5 March 2003 and 25 August 2004, on the whole, corroborated those conclusions.

Ultimately, following numerous requests for further medical reports and postponements of hearings, in April 2005 the domestic courts acquitted the police officers on the ground that there was insufficient evidence against them. Subsequently, in November 2006 that judgment was quashed; however, the criminal proceedings against the police officers were terminated as the prosecution had become time-barred.

In the meantime, in November 1999 the two girls were convicted of membership of an illegal organisation and of throwing Molotov cocktails. They were sentenced to terms of imprisonment amounting to more than 12 and 18 years, respectively.

Relying in particular on Article 3, the applicants alleged that they were subjected to ill-treatment while in police custody, notably sexual abuse and rape, and that the investigation into their allegations was inadequate. They also alleged that they were subjected to “virginity tests”, in breach of Article 14 (prohibition of discrimination).

Finding of a violation of Article 3 under the substantive limb (four votes to three) and unanimously under the procedural limb of Article 3.

“88. Lastly, the Court observes that the applicants were subjected to virginity tests at the start of their detention in police custody (see paragraphs 7 and 9 above). However, the Court notes that the Government have not shown that these examinations were based on and were in compliance with any statutory or other legal requirement. They just submitted that the examinations were carried out following the applicants' complaints of sexual violence and that the latter had consented to the tests. In the latter connection, no evidence of any written consent was submitted by the Government. In assessing the validity of the purported consent, the Court cannot overlook the fact that the first applicant was only sixteen years old at the material time. Nevertheless, even assuming that the applicants' consent was valid, the Court considers that there could be no medical or legal necessity justifying such an intrusive examination on that occasion as the applicants had yet not complained of sexual assault when the tests were conducted. The tests in themselves may therefore have constituted discriminatory and degrading treatment (see, *mutatis mutandis*, *Juhnke v. Turkey*, no. 52515/99, § 81, 13 May 2008).

89. Having regard to the above, the Court finds that the applicants' medical examinations between 6 and 12 March 1999, as well as the examination of 6 April 1999, fell short of the aforementioned CPT standards and the principles enunciated in the Istanbul Protocol. It concludes that in the present case the national authorities failed to ensure the effective functioning of the system of medical examinations of persons in police custody. Therefore, these examinations could not produce reliable evidence. Consequently, the Court attaches no weight to the findings of the reports of 6, 8, 9 and 12 March and 6 April 1999.”

3• Consent to sterilization operation

V.C v. Slovakia, no. 18968/07, 16 June 2009, decision as to admissibility
Sterilization of Roma woman during delivery of second child

The applicant is a Roma woman who was sterilised during the delivery of her second child via Caesarean section. Under Article 3 of the Convention the applicant complained that she had been subjected to inhuman and degrading treatment on account of her sterilisation without her full and informed consent, and that the authorities had failed to carry out a thorough, fair and effective investigation into the circumstances surrounding her sterilisation.

Under Article 8 of the Convention the applicant complained that her right to respect for her private and family life had been violated as a result of her sterilisation without her full and informed consent. Under Article 12 of the Convention the applicant complained that her right to found a family had been breached on account of her sterilisation without her full and informed consent. She also complained under Articles 13 and 14. Application declared admissible.

E. Ethical issues concerning HIV

1• Threat of expulsion

Arcila Henao v. the Netherlands (dec.), no. 13669/03, decision of 24 June 2003

Expulsion of an HIV-positive drug offender; adequate medical treatment

“According to established case-law aliens who are subject to expulsion cannot in principle claim any entitlement to remain in the territory of a Contracting State in order to continue to benefit from medical, social or other forms of assistance provided by the expelling State. However, in exceptional circumstances an implementation of a decision to remove an alien may, owing to compelling humanitarian considerations, result in a violation of Article 3 (see *D. v. the United Kingdom*, judgment of 2 May 1997, Reports of Judgments and Decisions 1997-III, p. 794, § 54). In that case the Court found that the applicant’s deportation to St. Kitts would violate Article 3, taking into account his medical condition. The Court noted that the applicant was in the advanced stages of AIDS. An abrupt withdrawal of the care facilities provided in the respondent State together with the predictable lack of adequate facilities as well as of any form of moral or social support in the receiving country would hasten the applicant’s death and subject him to acute mental and physical suffering. In view of those very exceptional circumstances, bearing in mind the critical stage which the applicant’s fatal illness had reached and given the compelling humanitarian considerations at stake, the implementation of the decision to remove him to St. Kitts would amount to inhuman treatment by the respondent State in violation of Article 3 (see *D. v. the United Kingdom*, cited above, pp. 793–794, §§ 51–54).

The Court has therefore examined whether there is a real risk that the applicant’s expulsion to Colombia would be contrary to the standards of Article 3 in view of his present medical condition. In so doing, the Court has assessed the risk in the light of

BIOETHICS AND THE CASE-LAW OF THE COURT

the material before it at the time of its consideration of the case, including the most recent information on the applicant's state of health (see *S.C.C. v. Sweden* (dec.), no. 46553/99, 15 February 2000, unreported).

The Court notes that the applicant stated on 16 August 2002 that he felt well and had worked, although he did suffer from certain side-effects of his medication. The Court further notes that, according to the most recent medical information available, the applicant's current condition is reasonable but may relapse if treatment is discontinued. The Court finally notes that the required treatment is in principle available in Colombia, where the applicant's father and six siblings reside.

In these circumstances the Court considers that, unlike the situation in the above-cited case of *D. v. the United Kingdom* or in the case of *B.B. v. France* (no. 39030/96, Commission's report of 9 March 1998, subsequently struck out by the Court by judgment of 7 September 1998, Reports 1998-VI, p. 2595), it does not appear that the applicant's illness has attained an advanced or terminal stage, or that he has no prospect of medical care or family support in his country of origin. The fact that the applicant's circumstances in Colombia would be less favourable than those he enjoys in the Netherlands cannot be regarded as decisive from the point of view of Article 3 of the Convention.

Although the Court accepts the seriousness of the applicant's medical condition, it does not find that the circumstances of his situation are of such an exceptional nature that his expulsion would amount to treatment proscribed by Article 3 of the Convention."

N. v. the United Kingdom [GC] Application no. 26565/05, 27 May 2008,
No violation of Article 3, not necessary to examine complaint under Article 8 (both held by fourteen votes to three)

The applicant, who is HIV positive, alleged that if she were returned to Uganda she would not have access to the medical treatment she required and that this would give rise to violations of Articles 3 and 8 of the Convention.

The Court resumed its case-law concerning expulsion cases where the applicant claimed to be at risk of suffering a violation of Article 3 on the grounds of ill-health, noting that it had not found such a violation since its judgment in *D v. the United Kingdom* (application no. 30240/96) on 21 April 1997, where "*very exceptional circumstances*" and "*compelling humanitarian considerations*" were at stake. In the *D.* case the applicant was critically ill and appeared to be close to death, could not be guaranteed any nursing or medical care in his country of origin and had no family there willing or able to care for him or provide him with even a basic level of food, shelter or social support.

The Court recalled that aliens who were subject to expulsion could not in principle claim any entitlement to remain in the territory of one of the States which had ratified the European Convention on Human Rights (a Contracting State) in order to continue to benefit from medical, social or other forms of assistance and services provided by the expelling State. The

BIOETHICS AND THE CASE-LAW OF THE COURT

fact that the applicant's circumstances, including her or his life expectancy, would be significantly reduced if s/he were to be removed from the Contracting State was not sufficient in itself to give rise to breach of Article 3. The decision to remove an alien who was suffering from a serious mental or physical illness to a country where the facilities for the treatment of that illness were inferior to those available in the Contracting State might raise an issue under Article 3, but only in a very exceptional case, where the humanitarian grounds against the removal were compelling, such as in the case D.

Although many of the rights it contained had implications of a social or economic nature, the Convention was essentially directed at the protection of civil and political rights. Furthermore, inherent in the whole of the Convention was a search for a fair balance between the demands of the general interest of the community and the requirements of the protection of the individual's fundamental rights. Advances in medical science, together with social and economic differences between countries, meant that the level of treatment available in the Contracting State and the country of origin might vary considerably. Article 3 did not place an obligation on the Contracting State to alleviate such disparities through the provision of free and unlimited health care to all aliens without a right to stay within its jurisdiction. A finding to the contrary would place too great a burden on the Contracting States.

Finally, the Court observed that, although the applicant's case concerned the expulsion of a person with an HIV and AIDS-related condition, the same principles had to apply to the expulsion of any person afflicted with any serious, naturally occurring physical or mental illness which might cause suffering, pain and reduced life expectancy and require specialised medical treatment which might not be so readily available in the applicant's country of origin or which might be available only at substantial cost.

Although the applicant applied for, and was refused, asylum in the United Kingdom, she did not complain before the Court that her removal to Uganda would put her at risk of deliberate, politically motivated, ill-treatment. Her claim under Article 3 was based solely on her serious medical condition and the lack of sufficient treatment available for it in her home country.

In 1998 the applicant was diagnosed as having two AIDS defining illnesses and a high level of immunosuppression. As a result of the medical treatment she had received in the United Kingdom her condition was now stable. She was fit to travel and would remain fit as long as she continued to receive the basic treatment she needed. The evidence before the national courts indicated, however, that if the applicant were to be deprived of her current medication her condition would rapidly deteriorate and she would suffer ill-health, discomfort, pain and death within a few years.

BIOETHICS AND THE CASE-LAW OF THE COURT

According to information collated by the World Health Organisation, antiretroviral medication was available in Uganda, although, through lack of resources, it was received by only half of those in need. The applicant claimed that she would be unable to afford the treatment and that it would not be available to her in the rural area from which she came. It appeared that she had family members in Uganda, although she claimed that they would not be willing or able to care for her if she were seriously ill.

The United Kingdom authorities had provided the applicant with medical and social assistance at public expense during the nine-year period it had taken for her asylum application and claims under Articles 3 and 8 of the Convention to be determined by the domestic courts and the European Court. However, that did not in itself entail a duty on the part of the United Kingdom to continue to provide for her.

Concluding that the applicant's case did not disclose "*very exceptional circumstances*", the Court found that the implementation of the decision to remove her to Uganda would not give rise to a violation of Article 3.

"50. The Court accepts that the quality of the applicant's life, and her life expectancy, would be affected if she were returned to Uganda. The applicant is not, however, at the present time critically ill. The rapidity of the deterioration which she would suffer and the extent to which she would be able to obtain access to medical treatment, support and care, including help from relatives, must involve a certain degree of speculation, particularly in view of the constantly evolving situation as regards the treatment of HIV and AIDS worldwide.

51. In the Court's view, the applicant's case cannot be distinguished from those cited in paragraphs 36-41 above. It does not disclose very exceptional circumstances, such as in *D. v. the United Kingdom* (cited above), and the implementation of the decision to remove the applicant to Uganda would not give rise to a violation of Article 3 of the Convention."

2• Isolation

Enhorn v. Sweden, no. 56529/00, [2nd Section], ECHR 2005-I, judgment of 25 January 2005

Compulsory isolation of a person infected with the HIV virus in order to prevent the spreading of this infectious disease.

"44. Taking the above principles into account, the Court finds that the essential criteria when assessing the "lawfulness" of the detention of a person "for the prevention of the spreading of infectious diseases" are whether the spreading of the infectious disease is dangerous to public health or safety, and whether detention of the person infected is the last resort in order to prevent the spreading of the disease, because less severe measures have been considered and found to be insufficient to safeguard the public interest. When these criteria are no longer fulfilled, the basis for the deprivation of liberty ceases to exist.

45. Turning to the instant case, it is undisputed that the first criterion was fulfilled, in that the HIV virus was and is dangerous to public health and safety.

BIOETHICS AND THE CASE-LAW OF THE COURT

46. It thus remains to be examined whether the applicant's detention could be said to be the last resort in order to prevent the spreading of the virus, because less severe measures had been considered and found to be insufficient to safeguard the public interest.

47. In a judgment of 16 February 1995, the County Administrative Court ordered that the applicant be kept in compulsory isolation for up to three months under section 38 of the 1988 Act. Thereafter, orders to prolong his deprivation of liberty were continuously issued every six months until 12 December 2001, when the County Administrative Court turned down the county medical officer's application for an extension of the detention order. Accordingly, the order to deprive the applicant of his liberty was in force for almost seven years.

Admittedly, since the applicant absconded several times, his actual deprivation of liberty lasted from 16 March 1995 until 25 April 1995, 11 June 1995 until 27 September 1995, 28 May 1996 until 6 November 1996, 16 November 1996 until 26 February 1997, and 26 February 1999 until 12 June 1999 – almost one and a half years altogether.

48. The Government submitted that a number of voluntary measures had been attempted in vain during the period between September 1994 and February 1995 to ensure that the applicant's behaviour would not contribute to the spread of the HIV infection. Also, they noted the particular circumstances of the case, notably as to the applicant's personality and behaviour, as described by various physicians and psychiatrists; his preference for teenage boys; the fact that he had transmitted the HIV virus to a young man; and the fact that he had absconded several times and refused to cooperate with the staff at the hospital. Thus, the Government found that the involuntary placement of the applicant in hospital had been proportionate to the purpose of the measure, namely to prevent him from spreading the infectious disease.

49. The Court notes that the Government have not provided any examples of less severe measures which might have been considered for the applicant in the period from 16 February 1995 until 12 December 2001, but were apparently found to be insufficient to safeguard the public interest.

50. It is undisputed that the applicant failed to comply with the instruction issued by the county medical officer on 1 September 1994, which stated that he should visit his consulting physician again and keep to appointments set up by the county medical officer. Although he kept to three appointments with the county medical officer in September 1994 and one in November 1994, and received two home visits by the latter, on five occasions during October and November 1994 the applicant failed to appear as summoned.

51. Another of the practical instructions issued by the county medical officer on 1 September 1994 was that, if the applicant was to have a physical examination, an operation, a vaccination or a blood test or was bleeding for any reason, he was obliged to tell the relevant medical staff about his infection. Also, he was to inform his dentist about his HIV infection. In April 1999, before the County Administrative Court, the county medical officer stated that during the last two years, while on the run, the applicant had sought medical treatment twice and that it had been established that both times he had said that he had the HIV virus, as opposed to the period when he had absconded between September 1995 and May 1996, during which the applicant had failed on three occasions to inform medical staff about his virus.

BIOETHICS AND THE CASE-LAW OF THE COURT

52. Yet another of the practical instructions issued by the county medical officer on 1 September 1994 required the applicant to abstain from consuming such an amount of alcohol that his judgment would thereby be impaired and others put at risk of being infected with HIV. However, there were no instructions to abstain from alcohol altogether or to undergo treatment against alcoholism. Nor did the domestic courts justify the deprivation of the applicant's liberty with reference to his being an "alcoholic" within the meaning of Article 5 § 1 (e) and the requirements deriving from that provision.

53. Moreover, although the county medical officer stated before the County Administrative Court in February 1995 that, in his opinion, it was necessary for the applicant to consult a psychiatrist in order to alter his behaviour, undergoing psychiatric treatment was not among the practical instructions issued by the county medical officer on 1 September 1994. Nor did the domestic courts during the proceedings justify the deprivation of the applicant's liberty with reference to his being of "unsound mind" within the meaning of Article 5 § 1 (e) and the requirements deriving from that provision.

54. The instructions issued on 1 September 1994 prohibited the applicant from having sexual intercourse without first having informed his partner about his HIV infection. Also, he was to use a condom. The Court notes in this connection that, despite his being at large for most of the period from 16 February 1995 until 12 December 2001, there is no evidence or indication that during that period the applicant transmitted the HIV virus to anybody, or that he had sexual intercourse without first informing his partner about his HIV infection, or that he did not use a condom, or that he had any sexual relations at all for that matter. It is true that the applicant infected the 19-year-old man with whom he had first had sexual contact in 1990. This was discovered in 1994, when the applicant himself became aware of his infection. However, there is no indication that the applicant transmitted the HIV virus to the young man as a result of intent or gross neglect, which in many of the Contracting States, including Sweden, would have been considered a criminal offence.

55. In these circumstances, the Court finds that the compulsory isolation of the applicant was not a last resort in order to prevent him from spreading the HIV virus because less severe measures had not been considered and found to be insufficient to safeguard the public interest. Moreover, the Court considers that by extending over a period of almost seven years the order for the applicant's compulsory isolation, with the result that he was placed involuntarily in a hospital for almost one and a half years in total, the authorities failed to strike a fair balance between the need to ensure that the HIV virus did not spread and the applicant's right to liberty.

56. There has accordingly been a violation of Article 5 § 1 of the Convention."

3• Confidentiality

I. v. Finland, No. 20511/03, [4th Section], 17 July 2008

Domestic authorities' failure to protect, at the relevant time, the applicant's patient records against unauthorised access. (HIV + Confidentiality)

BIOETHICS AND THE CASE-LAW OF THE COURT

“38. The protection of personal data, in particular medical data, is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life as guaranteed by Article 8 of the Convention. Respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the Convention. It is crucial not only to respect the sense of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general. The above considerations are especially valid as regards protection of the confidentiality of information about a person’s HIV infection, given the sensitive issues surrounding this disease. The domestic law must afford appropriate safeguards to prevent any such communication or disclosure of personal health data as may be inconsistent with the guarantees in Article 8 of the Convention (see *Z v. Finland*, judgment of 25 February 1997, Reports of Judgments and Decisions 1997-I, §§ 95-96).

39. The Court notes that at the beginning of the 1990s there were general provisions in Finnish legislation aiming at protecting sensitive personal data. The Court attaches particular relevance to the existence and scope of the Personal Files Act of 1987 (see paragraph 19 above). It notes that the data controller had to ensure under section 26 that personal data were appropriately secured against, among other things, unlawful access. The data controller also had to make sure that only the personnel treating a patient had access to his or her patient record.

40. Undoubtedly, the aim of the provisions was to secure personal data against the risk of unauthorised access. As noted in *Z v. Finland*, the need for sufficient guarantees is particularly important when processing highly intimate and sensitive data, as in the instant case, where, in addition, the applicant worked in the same hospital where she was treated. The strict application of the law would therefore have constituted a substantial safeguard for the applicant’s right secured by Article 8 of the Convention, making it possible, in particular, to police strictly access to an disclosure of health records.

41. However, the County Administrative Board found that, as regards the hospital in issue, the impugned health records system was such that it was not possible to retroactively clarify the use of patient records as it revealed only the five most recent consultations and that this information was deleted once the file had been returned to the archives. Therefore, the County Administrative Board could not determine whether information contained in the patient records of the applicant and her family had been given to or accessed by an unauthorised third person (see paragraph 10 above). This finding was later upheld by the Court of Appeal following the applicant’s civil action. The Court for its part would also note that it is not in dispute that at the material time the prevailing regime in the hospital allowed for the records to be read also by staff not directly involved in the applicant’s treatment.

42. It is to be observed that the hospital took ad hoc measures to protect the applicant against unauthorised disclosure of her sensitive health information by amending the patient register in summer 1992 so that only the treating personnel had access to her patient record and the applicant was registered in the system under a false name and social security number (see paragraph 7 above). However, these mechanisms came too late for the applicant.

43. The Court of Appeal found that the applicant’s testimony about the events, such as her colleagues’ hints and remarks beginning in 1992 about her HIV infection, was

BIOETHICS AND THE CASE-LAW OF THE COURT

reliable and credible. However, it did not find firm evidence that her patient record had been unlawfully consulted (see paragraph 15 above).

44. The Court notes that the applicant lost her civil action because she was unable to prove on the facts a causal connection between the deficiencies in the access security rules and the dissemination of information about her medical condition. However, to place such a burden of proof on the applicant is to overlook the acknowledged deficiencies in the hospital's record keeping at the material time. It is plain that had the hospital provided a greater control over access to health records by restricting access to health professionals directly involved in the applicant's treatment or by maintaining a log of all persons who had accessed the applicant's medical file, the applicant would have been placed in a less disadvantaged position before the domestic courts. For the Court, what is decisive is that the records system in place in the hospital was clearly not in accordance with the legal requirements contained in section 26 of the Personal Files Act, a fact that was not given due weight by the domestic courts.

45. The Government have not explained why the guarantees provided by the domestic law were not observed in the instant hospital. The Court notes that it was only in 1992, following the applicant's suspicions about an information leak, that only the treating clinic's personnel had access to her medical records. The Court also observes that it was only after the applicant's complaint to the County Administrative Board that a retrospective control of data access was established (see paragraph 11 above).

46. Consequently, the applicant's argument that her medical data were not adequately secured against unauthorised access at the material time must be upheld.

47. The Court notes that the mere fact that the domestic legislation provided the applicant with an opportunity to claim compensation for damages caused by an alleged unlawful disclosure of personal data was not sufficient to protect her private life. What is required in this connection is practical and effective protection to exclude any possibility of unauthorised access occurring in the first place. Such protection was not given here.

48. The Court cannot but conclude that at the relevant time the State failed in its positive obligation under Article 8 § 1 of the Convention to ensure respect for the applicant's private life.

49. There has therefore been a violation of Article 8 of the Convention."

Armonienė v. Lithuania, no. 36919/02 and *Biriuk v. Lithuania*, no. 23373/03, 25 November 2008 violations of Article 8 in both cases.

Failure to provide protection of privacy due to severe legislative limitations on judicial discretion in redressing the damage and therefore on deterring the recurrence of abuses of press freedom (HIV + Confidentiality)

The Court held by six votes to one, in both cases, that there had been a violation of Article 8 concerning the low ceiling imposed on damages awarded to them on account of a serious breach of their privacy by a national newspaper.

BIOETHICS AND THE CASE-LAW OF THE COURT

See *Armonienė v. Lithuania* judgment:

“40. More specifically, the Court has previously held that the protection of personal data, not least medical data, is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life as guaranteed by Article 8 of the Convention. Respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the Convention. The above considerations are especially valid as regards the protection of the confidentiality of a person’s HIV status (cf. Council of Europe materials, paragraphs 20-21 above). The disclosure of such data may dramatically affect his or her private and family life, as well as the individual’s social and employment situation, by exposing that person to opprobrium and the risk of ostracism (see *Z v. Finland*, judgment of 25 February 1997, *Reports* 1997-I, §§ 95-96).

41. It is in the light of the above considerations that the Court has now to examine whether the State has fulfilled its positive obligation to secure respect for the applicant’s right to respect for private and family life.

(b) Application of these general principles to the present case

42. The Court notes that the publication of the article about the state of health of the applicant’s husband, namely that he was HIV-positive, as well as the allegation that he was the father of two children by another woman who was also suffering from AIDS (see paragraph 6 above), were of a purely private nature and therefore fell within the protection of Article 8 (see, for example, *Dudgeon v. the United Kingdom*, cited above, § 41). The Court takes particular note of the fact that the family lived not in a city but in a village, which increased the impact of the publication on the possibility that the husband’s illness would be known by his neighbours and his immediate family, thereby causing public humiliation and exclusion from village social life. In this respect the Court sees no reason to depart from the conclusion of the national courts, which acknowledged that there had been interference with the family’s right to privacy.

43. The Court will next examine whether there existed a public interest justifying the publication of this kind of information about the applicant’s husband. However, the Court sees no such legitimate interest and agrees with the finding of the Vilnius City Third District Court, which held that making public information about the husband’s state of health, indicating his full name, surname and residence, did not correspond to any legitimate public interest (paragraph 8 above). In the Court’s view, the publication of the article in question, the sole purpose of which was apparently to satisfy the prurient curiosity of a particular readership, cannot be deemed to contribute to any debate of general interest to society (see, among many authorities, *Prisma Presse v. France* (dec.), nos. 66910/01 and 71612/01, 1 July 2003). Consequently, given that the balance lay in favour of the individual’s right to privacy, the State had an obligation to ensure that the husband was able effectively to enforce that right against the press.

44. Furthermore, the Court attaches particular significance to the fact that, according to the newspaper, the information about the husband’s illness had been confirmed by employees of the AIDS centre. It cannot be denied that publication of such information in the biggest national daily newspaper could have a negative impact on the willingness of others to take voluntary tests for HIV (cf. paragraph 21 above). In this context, it is of special importance that domestic law provides appropriate

BIOETHICS AND THE CASE-LAW OF THE COURT

safeguards to discourage any such disclosures and the further publication of personal data.

45. The Court takes into account that the national law at the material time did contain norms protecting the confidentiality of information about the state of health of a person. It has regard to the existence of the judicial guidelines to be followed if the right to privacy of a person has been breached (see paragraphs 12-19 above). The Court also notes that the domestic courts indeed awarded the husband compensation for non-pecuniary damage. However the principal issue is whether the award of LTL 10,000 was proportionate to the damage he sustained and whether the State, in adopting Article 54 § 1 of the Law on the Provision of Information to the Public, which limited the amount of such compensation payable by the mass media, fulfilled its positive obligation under Article 8 of the Convention.

46. The Court agrees with the Government that a State enjoys a certain margin of appreciation in deciding what “respect” for private life requires in particular circumstances (cf. *Stubbings and Others v. the United Kingdom*, 22 October 1996, §§ 62-63, *Reports* 1996-IV; *X and Y v. the Netherlands*, 26 March 1985, § 24, Series A no. 91). The Court also acknowledges that certain financial standards based on the economic situation of the State are to be taken into account when determining the measures required for the better implementation of the foregoing obligation. The Court likewise takes note of the fact that the Member States of the Council of Europe may regulate questions of compensation for non-pecuniary damage differently, as well as the fact that the imposition of financial limits is not in itself incompatible with a State’s positive obligation under Article 8 of the Convention. However, such limits must not be such as to deprive the individual of his or her privacy and thereby empty the right of its effective content.

47. The Court recognises that the imposition of heavy sanctions on press transgressions could have a chilling effect on the exercise of the essential guarantees of journalistic freedom of expression under Article 10 of the Convention (see, among many authorities, *Cumpănă and Mazăre v. Romania* [GC], no. 33348/96, §§ 113-114, ECHR 2004-XI). However, in a case of an outrageous abuse of press freedom, as in the present application, the Court finds that the severe legislative limitations on judicial discretion in redressing the damage suffered by the victim and sufficiently deterring the recurrence of such abuses, failed to provide the applicant with the protection that could have legitimately been expected under Article 8 of the Convention. This view is confirmed by the fact that the impugned ceiling on judicial awards of compensation contained in Article 54 § 1 of the Law on the Provision of Information to the Public was repealed by the new Civil Code soon after the events in the present case (see paragraph 33 above).

48. In the light of the foregoing considerations, the Court rejects the Government’s preliminary objection as to the applicant’s victim status and concludes that the State failed to secure the applicant’s right to respect for her family’s private life.

There has therefore been a violation of Article 8 of the Convention.”

BIOETHICS AND THE CASE-LAW OF THE COURT

Colak and Tsakiridis v. Germany, nos. 77144/01 and 35493/05, [5th Section], judgment of 5 March 2009

Failure to inform applicant about companion's infection with HIV – no violation of Articles 3, 8 or 6 § 1.

Relying on Articles 2, 6 § 1 and 8 of the European Convention on Human Rights, the applicant complained that she had been denied a fair trial in proceedings she had brought against her doctor for failing to inform her that her companion was suffering from AIDS and that the domestic courts had refused to award her compensation for not knowing that she was HIV-positive. The Court considered that the domestic courts had had sufficient regard to her right to life and physical integrity; it further found that their assessment of the facts had not been arbitrary and that the principle of equality of arms had been complied with. Consequently, the Court held, unanimously, that there had been no violation of Article 2 of the Convention and no violation of Article 6 § 1. It further held, by six votes to one, that there had been no violation of Article 8

“29. An event, however, which does not result in death may only in exceptional circumstances disclose a violation of Article 2 of the Convention (see *Acar and Others v. Turkey*, nos. 36088/97 and 38417/97, § 77, 24 May 2005; *Makaratzis v. Greece* [GC], no. 50385/99, § 51, ECHR 2004-XI; and *Tzekov v. Bulgaria*, no. 45500/99, § 40, 23 February 2006). Those may be found in a lethal disease. Having regard to the particular circumstances of the present case, the Court starts on the assumption that the present case raises an issue as to the applicant's right to life.

30. Having regard to the specific sphere of medical negligence, the Court reiterates that the positive obligations under Article 2 may be satisfied if the legal system affords victims a remedy in the civil courts, either alone or in conjunction with a remedy in the criminal courts, enabling any liability of the physicians concerned to be established and any appropriate civil redress, such as an order for damages, to be obtained (see *Calvelli and Ciglio*, cited above, § 51).

31. The Court observes at the outset that the applicant does not contest that the Government pursues a general policy of informing both the public and the medical profession with an aim of preventing new infections with HIV. The Court further observes that domestic law provides the possibility of bringing an action for damages before the civil courts under sections 823 and 847 of the Civil Code and, notably in section 34 of the Criminal Code, provides a general legal framework for resolving the conflict of interests between a physician's duty of confidence owed towards one patient and another patient's right to physical integrity. Having regard to the complexity of the subject matter, the Court accepts that it was not possible for the legislator to issue stricter rules on the solution of all conceivable conflicts of interests even before they arose. The Court further notes that section 172 of the German Code of Criminal Procedure provides the aggrieved party with the possibility of lodging a request for a court decision against the discontinuation of criminal proceedings. As established by the Court in its decision on admissibility in the present case, the applicant did not, however, exhaust domestic remedies in this respect.

BIOETHICS AND THE CASE-LAW OF THE COURT

32. The Court concludes that the German legal system provides for legal remedies which, in general, meet the requirements of Article 2 as they afford parties injured through medical negligence both criminal and civil compensation proceedings.

33. The Court further notes that, under the pertinent domestic law, a patient requesting damages from a physician for medical malpractice generally carries the burden of proof for the requisite causal connection between the physician's negligence and the damage to his or her health. According to the established domestic case-law, only a "gross error in treatment" would lead to a reversal of the burden of proof to the physician. Such gross error is generally assumed if the physician clearly breaches well-established medical rules (see paragraph 20, above). In the instant case the Frankfurt Court of Appeal, in its judgment on the applicant's compensation claims, expressly acknowledged that the defendant physician had violated his professional duties towards the applicant by failing to inform her about her companion's infection. That court considered, however, that this behaviour could not be qualified as a "gross error in treatment", as the physician had not disregarded medical standards in a blindfold way, but had merely overestimated his duty of confidence while balancing the conflicting interests. It followed that it was not possible to apply a less strict rule on the burden of proof in the instant case. Accordingly, it was up to the applicant to prove that she contracted the virus after January 1993, when the physician himself was informed about her companion's HIV status. Relying on expert opinion, the Court of Appeal considered that it could not be excluded that the applicant had contracted the virus before January 1993, when the physician himself learned about the companion's infection.

34. The Court notes that at the time the Frankfurt Court of Appeal rendered the instant judgment in 1999, no established domestic case-law existed as to whether a family physician was obliged to disclose a patient's HIV status to the patient's partner even against the patient's express will. The Court further observes that the three judges deciding on the case in the first-instance court, unlike the Court of Appeal judges, did not consider that the physician had been obliged to disclose her partner's status to the applicant. Under these circumstances, it does not appear contrary to the spirit of Article 2 of the Convention if the Court of Appeal, while fully acknowledging that the physician acted in breach of his professional duties, did not consider that the latter committed a "gross error in treatment" which would have led to a reversal of the burden of proof. This does not exclude the possibility that a higher standard would have to be applied to a physician's diligence in cases which might arise after the Frankfurt Court of Appeal's judgment given in the instant case, which clarified the physician's professional duties in these specific circumstances, had been published.

35. Having regard to the above considerations, the Court considers that the German courts, and in particular the Frankfurt Court of Appeal, had sufficient regard to the applicant's right to life and physical integrity. It follows that the domestic courts did not fail to interpret and apply the provisions of domestic law relating to the applicant's compensation claims in the spirit of the Convention.

36. Accordingly, the domestic authorities did not fail to comply with their positive obligations owed towards the applicant under Article 2 of the Convention. For the same reasons, the Court considers that there has not been a violation of the applicant's rights under Article 8 of the Convention."

4• Preventive measures/Access to treatment

Shelly v. the United Kingdom, Application no. 23800/06, inadmissible
Lack of needle exchange programmes in prisons.

The applicant, a prisoner, instructed solicitors as he was concerned that the provision of tablets instead of needle exchange programmes in prisons failed sufficiently to address the risks caused by the sharing of infected needles. Such risks were not confined to drugs users but also other prisoners or prison staff who could be accidentally infected

The applicant complained under Article 2 of the Convention that the authorities were failing to take preventive steps in respect of a known real and immediate risk to life through the spread of viruses in prison. The authorities had also failed in their positive obligation under Article 3 to adequately secure his health and well-being and under Article 8 to protect his safety from bodily threats from others or from the transmission of disease. He relied *inter alia* on the reports of the European Committee for the Prevention of Torture which state that prisoners are entitled to health care of the same standard as that available to those in the community.

The applicant also contended that there had been a breach of Article 14 on the basis that prisoners in England and Wales, as a group, were treated without proper justification, less favourably than people in the community.

“To date the Court’s case-law has been limited to holding that the acts and omissions of the authorities in the field of health care policy may in certain circumstances engage their responsibility under the positive limb of Article 2. This has so far imposed systemic and structural obligations, such as to make regulations compelling hospitals, whether public or private, to adopt appropriate measures for the protection of their patients’ lives, and to provide for an effective independent judicial system to be set up so that the cause of death of patients in the care of the medical profession, whether in the public or the private sector, can be determined and those responsible made accountable (*Calvelli and Ciglio v. Italy* [GC], no. 32967/96, § 49, ECHR 2002-I; *Byrzykowski v. Poland*, no. 11562/05, § 104, 27 June 2006; *Silih v. Slovenia*, no. 71463/01, § 117, 28 June 2007).

So far as preventive health is concerned, there is no authority that places any obligation under Article 8 on a Contracting State to pursue any particular preventive health policy. The case-law discloses that complaints have been more commonly brought against preventive measures taken by States to safeguard general health (such as the obligation to use safety helmets, pedestrian crossings or subways, and compulsory seatbelts e.g. 8707/79, (Dec.) 13.12.79 DR 18 p. 255 (contrast cases where the complaint was about the requirement to undergo medical treatment such as vaccinations: e.g. 7154/75, (Dec.) July 12, 1978, 14 D.R. 31). While it is not excluded that a positive obligation might arise to eradicate or prevent the spread of a particular disease or infection, the Court is not persuaded that any potential threat to health that fell short of the standards of Articles 2 or 3 would necessarily impose a duty on the State to take specific preventive steps. Matters of health care policy, in particular as regards general preventive measures, are in principle within the margin of appreciation of the domestic authorities who are best placed to assess priorities, use of resources and social needs (*mutatis mutandis*, *Osman v. the United Kingdom*, judgment of 28 October 1998, Reports of Judgments and Decisions 1998-VIII, § 116.

BIOETHICS AND THE CASE-LAW OF THE COURT

Giving due leeway to decisions about resources and priorities and to a legitimate policy to try to reduce drug use in prisons, and taking account of the fact that some preventive steps have been taken (disinfecting tablets) and that the authorities are monitoring developments in needle exchange programmes elsewhere, the Court concludes that the respondent Government have not failed to respect the applicant's private life.

It follows that this part of the application must be rejected as being manifestly ill-founded pursuant to Article 35 §§ 3 and 4 of the Convention."

"The Court finds that the difference in treatment falls within the margin of appreciation and considers that it may be regarded, at the current time, as being proportionate and supported by objective and reasonable justification. This part of the application must also be rejected as manifestly ill-founded pursuant to Article 35 §§ 3 and 4 of the Convention."

Aleksanyan v. Russia, no. 46468/06, [1st Section], judgement of 2 December 2008
Access to anti-retroviral medicine and specialized medicine in prison – violation of Article 3.

145. The Court recalls that the HAART treatment was prescribed to the applicant for the first time in November 2006. The doctors concluded that the applicant could be kept in the remand prison provided that he received proper treatment and underwent regular monitoring of his health in a specialised medical institution. However, the applicant's medical file does not contain any clear indication that the HAART treatment was administered in the first half of 2007.

146. The Court further notes that it was not until 10 July 2007 that the applicant signed a written statement accepting the HAART treatment. As transpires from the parties' submissions, such a statement was a pre-requisite for commencement of the HAART treatment. There is no information indicating that the applicant refused any treatment before June 2007. The Court concludes that the HAART treatment was not proposed to the applicant between November 2006, when it was recommended, and June 2007.

147. As to the following period, the Court notes that the applicant's medical file and official reports produced by the Government attested that on several occasions the applicant refused "an examination", "injections", and "treatment" (the first such entry in the medical file is dated 15 June 2007). However, those documents did not specify what kind of treatment was offered to the applicant and what examinations he was supposed to undergo. The Court reiterates that the authorities of the penitentiary institution should have kept a record of the applicant's state of health and the treatment he underwent while in detention (see *Khudobin v. Russia*, no. 59696/00, § 83, ECHR 2006-... (extracts)). Logically, such a medical record should contain sufficient information specifying what kind of treatment the patient was prescribed, what treatment he actually received, who and when administered it, how the applicant's state of health was monitored, etc (see the 3rd General Report of the CPT, quoted in the "Relevant International Instruments" part above). If the applicant's medical file is not specific enough in these respects (as in the case at hand), the Court may make inferences. Furthermore, the Court observes that in September 2007 the

BIOETHICS AND THE CASE-LAW OF THE COURT

investigator recommended that the prison authorities ensure a medical examination of the applicant and the administration of the HAART treatment to him. In the circumstances the Court concludes that, in all probability, the applicant did not receive the HAART treatment from the prison pharmacy.

148. That finding, however, is not decisive. First of all, the Court does not consider that in the circumstances the authorities were under an unqualified obligation to administer the HAART treatment to the applicant free of charge. The Court is aware of the fact that modern anti-retroviral drugs remain very expensive (see, *mutatis mutandis*, the cases of *Karara v. Finland*, no. 40900/98, Commission decision of 29 May 1998; see also *S.C.C. v. Sweden* (dec.), no. 46553/99, 15 February 2000; and *Arcila Henao v. The Netherlands* (dec.), no. 13669/03, 24 June 2003). The Court refers to its findings in the recent case of *N. v. the United Kingdom* ([GC], no. 26565/05, § 44, 27 May 2008), where it recognised that “advances in medical science, together with social and economic differences between countries, entail that the level of treatment available in the Contracting State and the country of origin may vary considerably”. That case concerned the provision of free health care to an alien suffering from Aids. In the Court’s opinion, broadly the same principle applies in the area of provision of health care to detained nationals: the Contracting States are bound to provide all medical care that their resources might permit.

149. Secondly, as follows from the applicant’s medical file, he did not depend on the pharmacy’s stock and could receive necessary medication from his relatives. The applicant did not allege that procuring those medicines imposed an excessive financial burden on him or on his relatives (cf. *Mirilashvili v. Russia*, (dec.), no. 6293/04, 10 July 2007, and *Hummatov v. Azerbaijan*, nos. 9852/03 and 13413/04, 29 November 2007). In such circumstances the Court is prepared to accept that the absence of the anti-retroviral drugs in the prison pharmacy was not, as such, contrary to Article 3 of the Convention.

150. The Court notes, however, that the applicant’s complaint concerns not so much access to the necessary drugs as the authorities’ refusal to place him in a specialised clinic. The Court accepts that *complex medicinal treatment often requires constant supervision by specialist doctors, and taking drugs without such supervision may cause more harm than good. As follows from the official reports produced by the Government, the applicant insisted on his placement in a specialised hospital in order to undergo the HAART treatment. Therefore, the next question to be answered is whether that was a legitimate claim, or, as the Government suggested, a mere pretence.*

151. The Court wishes to recall certain facts which, in its opinion, are crucial for understanding the applicant’s situation. From the Government’s submissions it follows that the prison hospital was equipped and staffed to treat a broad range of illnesses, in particular those prevalent in the Russian prison system, such as tuberculosis. However, it is clear that the prison hospital did not have a department specialised in the treatment of Aids. The Court notes that one of the doctors in the prison hospital had undergone training in HIV diagnostics. However, there is no evidence that that training included anti-retroviral therapy. Furthermore, there is no information that the HAART therapy has ever been administered within the prison hospital, and that the medical staff working there had the necessary experience and practical skills for administering it.

BIOETHICS AND THE CASE-LAW OF THE COURT

152. The Court notes that, among other departments, the prison hospital had a department for infectious diseases, where the applicant was placed in October 2007. According to Decree no. 170 of the Ministry of Health (see the “Relevant Domestic Law” part above), if there was no specialised clinic available, a patient suffering from Aids could be placed in an infectious diseases hospital. The text of the Decree shows that even in domestic terms an infectious diseases hospital is not regarded as a “specialised clinic” for the treatment of Aids: it is a substitute where no specialised clinic is available.

153. The Court further notes that on 23 October 2007 the applicant was examined in the Moscow AIDS Centre which, indisputably, was a “specialised clinic”. The doctors concluded that the applicant should undergo further in-patient examination and treatment in that Centre. On 26 October 2007 the applicant was admitted to the prison hospital. Five days later the investigator in charge of the applicant’s case decided that the applicant’s diseases could not be treated in the conditions of the remand prison and asked the court to release the applicant on bail. However, ten days later the investigator changed his mind and refused the application for release on bail. The applicant’s medical file does not contain any evidence that between 31 October and 9 November 2007 the applicant underwent any new medical examination which would rebut the conclusions of the earlier report. If there is any explanation for the sudden change in the investigator’s position, it does not pertain to the medical needs of the applicant.

154. It is true that in the following weeks the applicant refused examination by the prison doctors. The Court admits that in certain circumstances the refusal to undergo examination or treatment may suggest that the applicant’s state of health is not as critical as he claims (see *Gelfmann v. France*, cited above, § 56). However, in the circumstances of the present case the applicant’s attitude was understandable. Notwithstanding a serious deterioration in the applicant’s health, and despite the specialist doctors’ clear recommendation that he should be transferred to an outside specialised clinic, he remained in the prison hospital. Furthermore, the prison doctors attested that the applicant was fit to support the continuing detention and could participate in the criminal proceedings (see the court’s ruling of 15 November 2007), despite the fact that (a) the most recent medical examination had reached the opposite conclusion, and (b) since then the applicant had not undergone any new comprehensive examination, for whatever reason.

155. On 21 December 2007 the Court, having examined the evidence before it, decided to obtain more information about the applicant’s state of health. It indicated, under Rule 39 of the Rules of Court, that the Government and the applicant should form a bi-partisan medical commission which would answer a number of questions, formulated by the Court. The Government replied that the creation of such commissions would be contrary to the domestic legislation. However, they did not refer to any law which would prevent the examination of a patient by a mixed medical commission, to include doctors of his choice. The Court further observes that the applicant’s health was examined on several occasions by mixed commissions made up of doctors from various clinics. In any event, *the State* “*should not deny the possibility to receive medical assistance from other sources, such as the detainee’s family doctor or other qualified doctors*” (see *Sarban v. Moldova*, no. 3456/05, § 82, 4 October 2005). In the circumstances the Court considers that the Government’s refusal to form a mixed medical commission was arbitrary. The Court will therefore draw adverse inferences from the State’s refusal to implement the interim measure.

BIOETHICS AND THE CASE-LAW OF THE COURT

156. To sum up, the Court concludes that as from the end of October 2007, at the very least, the applicant's medical condition required his transfer to a hospital specialised in the treatment of Aids. The prison hospital was not an appropriate institution for these purposes.

157. Finally, the Court observes that it does not detect any serious practical obstacles for the immediate transfer of the applicant to a specialised medical institution. Thus, the Moscow AIDS Centre (a clinic which would most probably have been the applicant's destination in the event of his transfer from the prison hospital) was located in the same city, and it was prepared to accept the applicant for in-patient treatment. It appears that the applicant was able to assume most of the expenses related to the treatment. Furthermore, in view of the applicant's state of health and his previous conduct, the Court considers that the security risks he might have presented at that time, if any, were negligible compared to the health risks he faced (see *Mouisel v. France*, no. 67263/01, §§ 47, ECHR 2002-IX). In any event, the security arrangements made by the prison authorities in Hospital no. 60 did not appear very complicated.

158. In the final analysis, the Court considers that the national authorities failed to take sufficient care of the applicant's health to ensure that he did not suffer treatment contrary to Article 3 of the Convention, at least until his transfer to an external haematological hospital on 8 February 2008. This undermined his dignity and entailed particularly acute hardship, causing suffering beyond that inevitably associated with a prison sentence and the illnesses he suffered from, which amounted to inhuman and degrading treatment. There has therefore been a violation of Article 3 of the Convention."

F. Retention of finger print, cellular samples and/or DNA by authorities

Van der Velden v. the Netherlands no. 29514/05, 7 December 2006, inadmissible

Retention of cellular material from applicant following conviction

In view of the applicant's extortion conviction, and pursuant to section 8 in conjunction with section 2 § 1 of the DNA Testing (Convicted Persons) Act the public prosecutor, on 8 March 2005, ordered that cellular material be taken from the applicant – who was at that time detained in a penitentiary institution in Dordrecht – in order for his DNA-profile to be determined. A mouth swab was taken from the applicant on 23 March 2005. The applicant lodged an objection against the decision to have his DNA profile determined and processed, i.e. entered into the national DNA database. He submitted that his DNA profile had never played any role in the investigation of the offences of which he had been convicted. The Roermond Regional Court dismissed the objection on 21 April 2005. No appeal lay against this decision.

The applicant complained under Article 7 of the Convention that the order given by the public prosecutor, the taking of a sample of cellular material and the storage of the DNA profile derived therefrom in the DNA

BIOETHICS AND THE CASE-LAW OF THE COURT

database amounted to an extra penalty which it had not been possible to impose at the time he committed the offences of which he was convicted.

He further complained that the impugned measure infringed Article 8 of the Convention, in that it constituted an unjustified interference with his right to respect for his private life. Finally, the applicant argued that he had been the victim of discrimination as prohibited by Article 14 of the Convention.

The Court found the Article 7 complaint incompatible *ratione materiae*. As concerned Article 8, the Court departed from the Commission's case-law which had found that retention of DNA did not amount to an interference,

“... the Court nevertheless considers that, given the use to which cellular material in particular could conceivably be put in the future, the systematic retention of that material goes beyond the scope of neutral identifying features such as fingerprints, and is sufficiently intrusive to constitute an interference with the right to respect for private life set out in Article 8 § 1 of the Convention.”

The Court is satisfied that the impugned measure was “in accordance with the law”. The Court further has no difficulty in accepting that the compilation and retention of a DNA profile served the legitimate aims of the prevention of crime and the protection of the rights and freedoms of others. “The Court does not consider it unreasonable for the obligation to undergo DNA testing to be imposed on all persons who have been convicted of offences of a certain seriousness.”

“Finally, the Court is of the view that the measures can be said to be “necessary in a democratic society”. In this context it notes in the first place that there can be no doubt about the substantial contribution which DNA records have made to law enforcement in recent years. Secondly, it is to be noted that while the interference at issue was relatively slight, the applicant may also reap a certain benefit from the inclusion of his DNA profile in the national database in that he may thereby be rapidly eliminated from the list of persons suspected of crimes in the investigation of which material containing DNA has been found.

It follows that this complaint is manifestly ill-founded and must be rejected in accordance with Article 35 §§ 3 and 4 of the Convention.”

S. and Marper v. the United Kingdom [GC] Applications nos. 30562/04 and 30566/044, 4 December 2008

Blanket and indiscriminate retention of fingerprints, cellular samples and DNA profiles following acquittal.

The case concerned the retention by the authorities of the applicants' fingerprints, cellular samples and DNA profiles after criminal proceedings against them were terminated by an acquittal and were discontinued respectively. On 19 January 2001 S. was arrested and charged with attempted robbery. He was aged eleven at the time. His fingerprints and DNA samples were taken. He was acquitted on 14 June 2001. Mr Marper was arrested on 13 March 2001 and charged with harassment of his partner. His fingerprints and DNA samples were taken. On 14 June 2001 the case was formally discontinued as he and his partner had become reconciled.

BIOETHICS AND THE CASE-LAW OF THE COURT

Once the proceedings had been terminated, both applicants unsuccessfully requested that their fingerprints, DNA samples and profiles be destroyed. The information had been stored on the basis of a law authorising its retention without limit of time.

The applicants complained under Articles 8 and 14 of the Convention about the retention by the authorities of their fingerprints, cellular samples and DNA profiles after their acquittal or discharge.

The Court found that the blanket and indiscriminate nature of the powers of retention of the fingerprints, cellular samples and DNA profiles of persons suspected but not convicted of offences, as applied in the case of the present applicants, failed to strike a fair balance between the competing public and private interests, and that the respondent State had overstepped any acceptable margin of appreciation in this regard. Accordingly, the retention in question constituted a disproportionate interference with the applicants' right to respect for private life and could not be regarded as necessary in a democratic society. The Court concluded unanimously that there had been a violation of Article 8 in this case.

W. v. the Netherlands, Application no. 20689/08, 20 January 2009

Retention of cellular material following conviction of criminal offence

On 15 February 2007 the Juvenile Judge for criminal cases of the Maastricht Regional Court found the applicant guilty of causing bodily harm. The applicant was sentenced to a suspended term of juvenile detention, a community service order of 30 hours and a training order of 20 hours.

In view of the applicant's conviction, and pursuant to article 2 paragraph 1 of the DNA Testing (Convicted Persons) Act ("the Act"), the public prosecutor, on 7 June 2007, ordered that cellular material be taken from the applicant in order for his DNA profile to be determined. A mouth swab was taken from the applicant on 18 July 2007.

On 31 July 2007 the applicant, pursuant to article 7 of the Act, lodged an objection against the decision to have his DNA profile determined and processed, i.e. entered into a national DNA database. He submitted that, in accordance with Article 8 of the Convention and Article 40 of the Convention on the Rights of the Child of 20 November 1989, the personal interests of a minor should be balanced against the general interests of society when it was being considered whether to apply the Act to that minor, and within that balancing exercise the interests of the minor should be the primary consideration pursuant to Article 3 of the Convention on the Rights of the Child. The applicant submitted that regard should be had to the age of the convicted person at the time of the commission of the crime, the seriousness of the offence, the circumstances under which the offence had been committed, the risk of the convicted person reoffending and other personal circumstances of the convicted person. On 2 November 2007 the

Maastricht Regional Court, having heard the public prosecutor and counsel for the applicant in camera, dismissed the applicant's objection.

Declaring the application inadmissible, the Court found that, contrary to the S. and Marper case, the present case deals with the issue of storing and retaining DNA records of persons who have been convicted of a criminal offence. Furthermore the Court considers that, pursuant to the provisions of the DNA Testing (Convicted Persons) Act, DNA material can only be taken from persons convicted of an offence of a certain gravity, and that the DNA records can only be retained for a prescribed period of time that is dependent on the length of the statutory maximum sentence that can be imposed for the offence that has been committed. The Court is therefore satisfied that the provisions of the Act contain appropriate safeguards against blanket and indiscriminate retention of DNA records.

Considering, moreover, that the DNA material is stored anonymously and encoded, and that the applicant will only be confronted with his stored DNA record if he has previously committed another criminal offence or commits one in the future, the Court sees no reason to diverge from its findings in Van der Velden on account of the mere fact that the applicant is a minor.

G. The right to know one's biological identity?

Odièvre v. France [GC], no. 42326/98, 13 February 2003

Rules governing confidentiality on birth prevented applicant from obtaining information about her natural family *no violation Article 8 (ten votes to seven)*

« 24. La requérante se plaint de ne pouvoir obtenir la communication d'éléments identifiants sur sa famille naturelle et de l'impossibilité qui en résulte pour elle de connaître son histoire personnelle.

29. La Cour rappelle à cet égard que « l'article 8 protège un droit à l'identité et à l'épanouissement personnel et celui de nouer et de développer des relations avec ses semblables et le monde extérieur. (...) La sauvegarde de la stabilité mentale est à cet égard un préalable inéluctable à la jouissance effective du droit au respect de la vie privée » (arrêt *Bensaid c. Royaume-Uni*, n° 44599/98, § 47, CEDH 2001-I). A cet épanouissement contribuent l'établissement des détails de son identité d'être humain et l'intérêt vital, protégé par la Convention, à obtenir des informations nécessaires à la découverte de la vérité concernant un aspect important de son identité personnelle, par exemple l'identité de ses géniteurs (*Mikulić c. Croatie*, n° 53176/99, §§ 54 et 64, CEDH 2002-I). La naissance, et singulièrement les circonstances de celle-ci, relève de la vie privée de l'enfant, puis de l'adulte, garantie par l'article 8 de la Convention qui trouve ainsi à s'appliquer en l'espèce.

(...)

48. En l'espèce, la Cour observe que la requérante a eu accès à des informations non identifiantes sur sa mère et sa famille biologique lui permettant d'établir quelques racines de son histoire dans le respect de la préservation des intérêts des tiers.

BIOETHICS AND THE CASE-LAW OF THE COURT

49. Par ailleurs, le système mis en place par la France récemment, s'il conserve le principe de l'admission de l'accouchement sous X, renforce la possibilité de lever le secret de l'identité qui existait au demeurant à tout moment avant l'adoption de la loi du 22 janvier 2002. La nouvelle loi facilitera la recherche des origines biologiques grâce à la mise en place d'un Conseil national pour l'accès aux origines personnelles, organe indépendant, composé de magistrats, de représentants d'associations concernées par l'objet de la loi et de professionnels ayant une bonne connaissance pratique des enjeux de la question. D'application immédiate, elle peut désormais permettre à la requérante de solliciter la réversibilité du secret de l'identité de sa mère sous réserve de l'accord de celle-ci de manière à assurer équitablement la conciliation entre la protection de cette dernière et la demande légitime de l'intéressée, et il n'est même pas exclu, encore que cela soit peu probable, que, grâce au nouveau conseil institué par le législateur, la requérante puisse obtenir ce qu'elle recherche.

La législation française tente ainsi d'atteindre un équilibre et une proportionnalité suffisante entre les intérêts en cause. La Cour observe à cet égard que les Etats doivent pouvoir choisir les moyens qu'ils estiment les plus adaptés au but de la conciliation ainsi recherchée. Au total, la Cour estime que la France n'a pas excédé la marge d'appréciation qui doit lui être reconnue en raison du caractère complexe et délicat de la question que soulève le secret des origines au regard du droit de chacun à son histoire, du choix des parents biologiques, du lien familial existant et des parents adoptifs.

Partant, il n'y a pas eu violation de l'article 8 de la Convention. »

Jaggi v. Switzerland, no. 58757/00, 3 July 2003, violation of Article 8 Refusal of authorities to analyse DNA of alleged father (deceased)

Le requérant se plaint de ne pas avoir pu faire effectuer une analyse ADN sur une personne défunte dans le but de déterminer s'il s'agissait de son père biologique. Il allègue avoir subi une violation de ses droits découlant de l'article 8 de la Convention.

« 34. La Cour constate qu'en l'espèce, les autorités suisses ont refusé d'autoriser une expertise ADN qui aurait permis au requérant d'avoir la certitude que A.H., son père présumé, était véritablement son géniteur. Ce refus affecte le requérant dans sa vie privée.

(...)

36. La Cour rappelle que le choix des mesures propres à garantir l'observation de l'article 8 de la Convention dans les rapports interindividuels relève en principe de la marge d'appréciation des Etats contractants. Il existe à cet égard différentes manières d'assurer le respect de la vie privée et la nature de l'obligation de l'Etat dépend de l'aspect de la vie privée qui se trouve en cause (Odièvre précité, § 46).

37. Or, l'ampleur de cette marge d'appréciation de l'Etat dépend non seulement du ou des droits concernés mais également, pour chaque droit, de la nature même de ce qui est en cause. La Cour considère que le droit à l'identité, dont relève le droit de connaître son ascendance, fait partie intégrante de la notion de vie privée. Dans pareil cas, un examen d'autant plus approfondi s'impose pour peser les intérêts en présence.

BIOETHICS AND THE CASE-LAW OF THE COURT

38. La Cour considère que les personnes essayant d'établir leur ascendance ont un intérêt vital, protégé par la Convention, à obtenir les informations qui leur sont indispensables pour découvrir la vérité sur un aspect important de leur identité personnelle. En même temps, il faut garder à l'esprit que la nécessité de protéger les tiers peut exclure la possibilité de contraindre ceux-ci à se soumettre à quelque analyse médicale que ce soit, notamment à des tests ADN (voir Mikulić précité, § 64). La Cour doit rechercher si, dans le cas d'espèce, un juste équilibre a été ménagé dans la pondération des intérêts concurrents.

39. Dans la mise en balance des intérêts en cause, il convient de considérer, d'un côté, le droit du requérant à connaître son ascendance et, de l'autre, le droit des tiers à l'intangibilité du corps du défunt, le droit au respect des morts ainsi que l'intérêt public à la protection de la sécurité juridique.

(...)

44. Il apparaît que, compte tenu des circonstances de l'espèce et de l'intérêt prépondérant qui est en jeu pour le requérant, les autorités suisses n'ont pas garanti à l'intéressé le respect de sa vie privée auquel il a droit en vertu de la Convention.

Il s'ensuit qu'il y a eu violation de l'article 8 de la Convention. »

Phinikaridou v. Cyprus, Application no. 23890/02, 20 December 2007 Proceedings instituted for judicial recognition of paternity held to be time-barred under the applicable law.

"44. In this connection the Court notes that the applicant, a child born out of wedlock, sought by means of judicial proceedings to determine her legal relationship with the person she claimed was her father, through the establishment of the biological truth.

45. The Court reiterates that birth, and in particular the circumstances in which a child is born, forms part of a child's, and subsequently the adult's, private life guaranteed by Article 8 of the Convention (see *Odièvre v. France* [GC], no. 42326/98, § 29, ECHR 2003-III). Respect for private life requires that everyone should be able to establish details of their identity as individual human beings and that an individual's entitlement to such information is of importance because of its formative implications for his or her personality (see, for example, *Mikulić v. Croatia*, no. 53176/99, §§ 53-54, ECHR 2002-I, and *Gaskin v. the United Kingdom*, judgment of 7 July 1989, Series A no. 160, p. 16, §§ 36-37, 39). This includes obtaining information necessary to discover the truth concerning important aspects of one's personal identity, such as the identity of one's parents (see *Jäggi v. Switzerland*, no. 58757/00, § 25, ECHR 2006-...; *Odièvre*, § 29; and *Mikulić*, §§ 54 and 64; both cited above).

46. Accordingly, the facts of the case fall within the ambit of Article 8 of the Convention.

(...)

65. Hence, even having regard to the margin of appreciation left to the State, the Court considers that the application of a rigid time-limit for the exercise of paternity

BIOETHICS AND THE CASE-LAW OF THE COURT

proceedings, regardless of the circumstances of an individual case and, in particular, the knowledge of the facts concerning paternity, impairs the very essence of the right to respect for one's private life under Article 8 of the Convention.

66. In view of the above, and in particular having regard to the absolute nature of the limitation period, the Court considers that a fair balance has not been struck between the different interests involved and, therefore, that the interference with the applicant's right to respect for her private life was not proportionate to the legitimate aims pursued.

67. Accordingly, the Court finds that there has been a violation of Article 8. »

II EXAMPLES OF CASES WHERE THE OVIEDO CONVENTION ON HUMAN RIGHTS AND BIOMEDICINE OF 4 APRIL 1997 OR THE WORK OF THE COUNCIL OF EUROPE IN THIS AREA HAVE BEEN CITED

A. References to the Oviedo Convention on Human Rights and Biomedicine of 4 April 1997

- *Cyprus v. Turkey*, no. 25781/94, 10 May 2001, (partly dissenting opinion of Judge Marcus-Helmond);³
- *Glass v. the United Kingdom*, no. 61827/00, 9 March 2004, § 58;
- *Vo. v. France*, no. 53924/00, 8 July 2004, § 35;
- *Evans v. the United Kingdom*, no. 6339/05, [GC], 10 April 2007, § 40;
- *Hülya ÖZALP v. Turkey*, no. 74300/01, inadmissibility decision of 11 October 2007, (Article 5 of the Oviedo Convention cited);
- *Juhnke v. Turkey*, no. 52515/99, 13 May 2008, § 56;

³ “With the rapid evolution of biomedical techniques, new threats to human dignity may arise. The Convention on Human Rights and Biomedicine, signed at Oviedo in 1997, seeks to cover some of those dangers. However, to date only a limited number of States have signed it. Moreover, this Convention only affords the European Court of Human Rights consultative jurisdiction. In order this “fourth generation of human rights” to be taken into account so that human dignity is protected against possible abuse by scientific progress, the Court could issue a reminder that under Article 2 of the European Convention on Human Rights the States undertook to protect everyone's right to life by law.

The right to life may of course be interpreted in many different ways, but it undoubtedly includes freedom to seek to enjoy the best physically available medical treatment.”

BIOETHICS AND THE CASE-LAW OF THE COURT

- *V.C v. Slovakia*, no. 18968/07, 16 June 2009, decision as to admissibility (Article 5 of the Oviedo Convention relied upon by the applicant before the Constitutional Court of Slovakia).

B. References to the work of the Steering Committee on Bioethics of the Council of Europe

- *Wilkinson v. the United Kingdom*, no. 14659/02, inadmissibility decision of 8 February 2006 (reference to the publication of a consultation paper on the protection of the human rights and human dignity of people suffering from mental disorder).
- *S.H. and others v. Austria*, no. 57813/00, decision as to admissibility of 5 November 2007 (reference to the replies by the member States of the Council of Europe to the Steering Committee on Bioethics' "*Questionnaire on Access to Medically-assisted Procreation*" (Council of Europe, 2005)).