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PROTECTION AGAINST GENETIC DISCRIMINATION AND THE BIOMEDICINE CONVENTION

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1. *Introduction*

Henriette Roscam Abbing was one of the first legal scholars to acknowledge the close relationship between health and human rights,¹ an issue that has inspired her—and others—until today.² Building on her national, European and international experience in the field of health law and health policy she has extensively written on the challenges which developments in the field of science and their application within and outside the health care sector can pose for human rights.³ At the same time, she has zealously and indefatigably alerted national, European and international policy makers, legislators, fellow scholars and the public at large to the detrimental health impacts resulting from (other) human rights violations. In this respect, she has always been particularly concerned about the adverse health impacts of violations of privacy rights (e.g. breaches of confidentiality, non-compliance with the principle of informed consent and other measures infringing on individual liberty)⁴ and discrimination on such irrelevant factors as (prospective) health status with respect to health care, employment and necessary insurances.⁵ Her approach was commonly future-oriented: what are the likely effects of the current developments in medical science

¹ H.D.C. Roscam Abbing, *International Organizations in Europe and the Right to Health Care* (Deventer, Kluwer, 1979).

² H.D.C. Roscam Abbing, 'Health, Rights of the Patient and Patient Participation', in: H.D.C. Roscam Abbing, K.F. Bopp (eds.), *Health, Ethics and Human Rights. The Council of Europe Meeting the Challenge* (Strasbourg, Council of Europe, 2005), pp. 141–164.

³ H.D.C. Roscam Abbing, 'Medische technologische vooruitgang, kans of vooruitgang voor het recht op de persoonlijke levenssfeer' (Henk Leenen lezing), 28 *Tijdschrift voor Gezondheidsrecht* 5-2004, 347–352.

⁴ H.D.C. Roscam Abbing, 'AIDS, Human Rights and the Legislator in the Netherlands', in: M. Breum, A.C. Hendriks (eds.), *AIDS and Human Rights. An International Perspective* (Copenhagen, Akademisk Forlag, 1988), pp. 96–104.

⁵ H.D.C. Roscam Abbing, 'Recht op gezondheidszorg: een beschouwing over grenzen

on the enjoyment of human rights? It should come as no surprise that the progress made in the field of predictive medicine, notable genetics, has been closely scrutinised by Roscam Abbing.⁶

From the above one could get the impression that Roscam Abbing was one-sidedly concerned about negative liberty,⁷ as reflected in rights that seek to guarantee individuals the right to live their own lives free from outside intrusion.⁸ This is everything but true. In her work she paid considerable attention to the obligations of the State to ensure that individuals can indeed make their own informed choices and decisions with respect to health care and other social goods and services.⁹ These duties coincide with positive liberty or, in the terminology of the European Court of Human Rights (ECtHR), positive State obligations which are known to extend to the field of health care.¹⁰ In addition to examining both negative and positive freedom rights, Roscam Abbing has stressed the importance of finding a fair and proper balance between (individual) liberty and (collective) solidarity, particularly with respect to access to scarce social goods and services, such as health care.¹¹ Here her underlying thesis has always been that individual liberty can not be at the expense of such precious principles as equality and solidarity.

Efforts to strike a fair balance between individual liberty and collective solidarity go back to the French Revolution. *Liberté, égalité, fraternité (ou la mort!)* was not just the slogan of the revolutionaries, but reflected the recognition of liberty-inspired civil and political rights and solidarity-based social

en grenzen aan het stellen van grenzen', in: J.K.M. Gevers, J.H. Hubben (eds.), *Grenzen aan de zorg: zorgen aan de grens* (Liber Amicorum voor prof. dr. H.J.J. Leenen) (Alphen aan den Rijn, Samsom H.D. Tjeenk Willink, 1990), pp. 84–97.

⁶ Special reference should be made here to the milestone report of the Health Council of the Netherlands, *Heredity: Science and Society; on the possibilities and limits of genetic testing and gene therapy* (The Hague, Health Council of the Netherlands, 1989; publication no. 89/31), a report that was prepared by a committee chaired by Roscam Abbing. In the 1990s she sought, once again, as advisor to the Minister of Health, attention for the impact of genetics inside and outside the health care sector, resulting in the policy paper 'The Application of Genetics in the Health Care Sector', submitted to Parliament on 5 December 2000 (*Kamerstukken II* 2000/01, 27 543, nr. 1–2).

⁷ I. Berlin, *Two Concepts of Liberty* (Oxford, Oxford University Press, 1958), p. 7.

⁸ Cf. according to the case law of the Strasbourg organs Article 8 ECHR secures to the individual a sphere within which he or she can freely pursue the development and fulfilment of his or her personality (see e.g. *Briggeman and Scheuten v. Germany*, Appl. no. 6959/75, Commission's report of 12 July 1977, Decisions and Reports 10, p. 115, § 55).

⁹ H.D.C. Roscam Abbing, *Beslisten door de patiënt* (Houten/Zaventem, Bohn Stafleu Van Loghum, 1994).

¹⁰ ECHR 4 January 2005 (dec.), *Pentiacova et al. v. Moldova*, EHRC 2005, 33, with a commentary by A.C. Hendriks.

¹¹ H.D.C. Roscam Abbing, 'Solidariteit en individuele gebondenheid: vrijheid in gebondenheid', *Preadviezen Zorg, schaarste en recht* (Utrecht, Vereniging voor gezondheidsrecht, 2002), pp. 1–35.

rights as equally important for the protection of human dignity, with equality often serving as a bridge (as well as an independent right).¹² Roscam Abbing can be seen as a contemporary French revolutionary trying to find a proper balance between these fundamental principles both inside and outside the health care sector.

Attempts to harmonise liberty, equality and solidarity can also be detected when studying the European Convention on Human Rights and Biomedicine (Biomedicine Convention).¹³ As with most other human rights instruments, the Convention does not merely bestow rights and freedoms on 'all human beings' (Article 1) and 'everyone' (Article 10), but also endeavours to uphold the principles of equality (Article 3)¹⁴ and non-discrimination (Article 11), and contains provisions granting additional protection to especially vulnerable groups, such as people unable to consent (Article 6), persons with a mental disorder (Article 7) and research subjects unable to consent (Article 17).

According to Article 11 of the Biomedicine Convention 'Any form of discrimination against a person on grounds of his or her genetic heritage is forbidden.' The meaning of this non-discrimination clause is not particularly clear. This is also a major reason why Roscam Abbing was disappointed about this provision, the other one being that Article 11 fails to provide proper protection against the discriminatory use of genetic information by insurance companies and employers.¹⁵ Since other health and human rights scholars have almost systematically neglected this provision, it remains uncertain to what extent Roscam Abbing's anxiety about the (lack of) safeguards offered by Article 11 of the Biomedicine Convention against genetic discrimination was well founded.

In this contribution I will assess the protection guaranteed by the Biomedicine Convention against genetic discrimination. This requires, first of all, providing clarity about the meaning of the terms 'discrimination' (section 2) and 'genetic discrimination' (section 3). In articulating the meaning of these concepts particular attention will be paid to the standards set by the European Convention on Human Rights (ECHR)¹⁶ and the jurisprudence of the ECtHR now that the Biomedicine Convention was meant to elab-

¹² Cf. *Vienna Declaration and Programme of Action—Final document of the World Conference on Human Rights* (Vienna, 14–25 June 1993), UN Doc. A/CONF.157/23.

¹³ Convention on Human Rights and Biomedicine, Oviedo, 4 April 1997, ETS 164.

¹⁴ Although this provision refers to 'equitable access to health care'.

¹⁵ H.D.C. Roscam Abbing, 'The Convention on Human Rights and Biomedicine. An Appraisal of the Council of Europe Convention', 5 *European Journal of Health Law* 4-1998, pp. 377–387 (383).

¹⁶ Convention for the protection of Human Rights and Fundamental Freedoms, Rome, 4 November 1950, ETS 5.

orate some of the principles enshrined in the ECHR and seeks to offer additional protection for the human person in the context of the development of biomedical sciences and their application.¹⁷ Subsequently, I will—building on the previous sections—examine the object and purpose of Article 11 of the Biomedicine Convention (section 4), followed by an appraisal (section 5) and, finally, I draw some conclusions (section 6).

2. *Discrimination*

The prohibition of discrimination is the counterpart of the principle of equality. It prohibits the adverse treatment of persons on grounds that are intimately related to human dignity. The latter concept underlies all human rights,¹⁸ including the rights protected by the Biomedicine Convention,¹⁹ and is also recognized as a general principle of law under Community law.²⁰

The connection between equality and human dignity reflects the idea that discrimination should be distinguished from arbitrary or otherwise unjustified forms of unequal treatment adversely affecting a person or group. The grounds protected by the principle of non-discrimination are therefore, by definition, rather exclusive, all having an immediate link with human dignity. Grounds protected by human rights instruments, such as the ECHR, include such personal criteria as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property and birth.²¹

Article 14 of the ECHR, which prohibits discrimination, contains a non-exhaustive list of covered grounds. This means that persons who feel that they have been discriminated against on a non-enumerated ground can also claim protection under Article 14. At the same time, it should be noted that Article 14 is not framed in general terms of equality before the law or equal protection under the law, but merely guarantees everyone within the jurisdiction of a State party to the ECHR the equal enjoyment

¹⁷ Explanatory Report to the Convention on Human Rights and Biomedicine, Strasbourg, Council of Europe, May 1997, Dir/Jur (97)5.

¹⁸ ECtHR 9 March 2004, *Glass v. UK*, NJ 2005, 14, EHRC 2004, 38, with a commentary by A.C. Hendriks and ECtHR 8 July 2004, *Vo v. France*, EHRC 2004, 86, with a commentary by A.C. Hendriks & J.A. Bomhoff, both being cases where the Court referred to the Biomedicine Convention.

¹⁹ Article 1 § 1.

²⁰ Court of Justice of the EC 14 October 2004, case C-36/02 (*Omega*), Jur. 2004, EHRC 2004, 103, with a commentary by J.H. Gerards, § 34.

²¹ Article 14 ECHR.

of the rights and freedoms protected by the Convention. Or, to phrase it differently, Article 14 does not contain an independent right to equality or non-discrimination, but has an accessory nature now that its meaning is confined to rights and freedoms set forth in the ECHR and the additional protocols thereto.

Through the adoption of Protocol XII to the ECHR, the meaning of the prohibition of non-discrimination under the ECHR has changed, now that it has obtained the status of an independent right.²² Accordingly, it is no longer necessary that a complaint falls within the ambit of a substantive Convention right before a plaintiff can invoke the right not to be discriminated against.²³ The list of explicitly mentioned grounds and the non-exhaustive nature thereof enshrined in this catalogue remained unchanged. As a result, Protocol XII offers more ample protection against discrimination, although—different from the Biomedicine Convention—no reference is made to genetic heritage or—as in the case of Article 21 of the Charter of Fundamental Rights of the European Union²⁴—to genetic features.

Discrimination commonly entails making a comparison. This also holds true with respect to the case law of the ECtHR. According to the initial jurisprudence of the Court the prohibition of discrimination was violated in the case of a detrimental distinction that had no objective and reasonable justification.²⁵ This presupposes similar situations,²⁶ analogous situations²⁷ or relevantly similar situations.²⁸ At a later stage the Court acknowledged that discrimination could also occur when States, without an objective and reasonable justification, fail to treat differently persons whose situations are

²² Protocol XII to the Convention for the protection of Human Rights and Fundamental Freedoms, Rome, 4 November 2000, *ETS* 177.

²³ Here it should be noted that the Court has interpreted Convention rights rather broadly. E.g. although the Convention does not proclaim a right to work, the Court has repeatedly held that discrimination with respect to employment contradicts Article 8 in conjunction with Article 14. ECtHR 27 July 2004, *Sidabras & Dziautas v. Lithuania*, *EHRC* 2004, 90, with a commentary by J.H. Gerards, and ECtHR 7 April 2005, *Rainys & Gasparavičius v. Lithuania*, Appl.nos. 70665/01 & 74345/01.

²⁴ Charter of Fundamental Rights of the European Union, Nice, 8 December 2000, *OJ* 2000, C 364/1.

²⁵ ECtHR 22 July 1968, *Case relating to certain aspects of the laws on the use of languages in education in Belgium*, Series A, n. 6, § 7.

²⁶ ECtHR 13 June 1979, *Marckx v. Belgium*, Series A, n. 31, *NJ* 1980, 462, with a commentary by E.A. Alkema, § 32 and ECtHR 28 October 1987, *Inze v. Austria*, Series A, n. 126, *NJ* 1989, 661, with a commentary by E.A. Alkema, *NJCM-Bulletin* 1988, p. 242, with a commentary by J. de Boer, § 41.

²⁷ ECtHR 28 November 1984, *Rasmussen v. Denmark*, Series A, n. 87, *NJ* 1986, 4, with a commentary by E.A. Alkema & E.A.A. Luijten, § 35.

²⁸ ECtHR 18 February 1991, *Fredin v. Sweden*, Series A, n. 192, § 60.

significantly different.²⁹ More recently, the Court seemed inclined to recognise that the prohibition of discrimination not only applies to direct discrimination, but also to indirect discrimination.³⁰ In addition, the Court has meanwhile also found that certain pejorative forms of treatment do as such violate the principles of equality and non-discrimination, independent of the treatment which a comparator receives.³¹ It follows that the Court, starting with a formal approach towards the principle of equality, nowadays interprets the prohibition of discrimination in a more substantive way, thus taking differences into account. The latter is important, now that people, due to their (predictive) health status, often do find themselves in a 'different situation' and are prone to forms of exclusion and the denial of unequal opportunities which others will never be confronted with (below, under section 5).

From the jurisprudence of the ECtHR it can also be seen that the Court has, referring to the fact that the Convention is a living instrument that must be interpreted in present-day conditions,³² frequently made use of the non-exhaustive character of the non-discrimination provision in the Convention to offer protection against discrimination on non-listed grounds, such as nationality,³³ being born within or outside marriage³⁴ and sexual orientation,³⁵ which are so intimately related to human dignity that adverse treatment on these grounds constitutes discrimination.

On the basis of the case law of the ECtHR it can be concluded that Article 14 of ECHR and Protocol XII to the ECHR prohibit the unjustified different treatment of persons who find themselves in equal situations as well as the unjustified equal treatment of persons who find themselves in different situations on grounds intimately related to human dignity. The

²⁹ ECtHR 6 April 2000, *Thlimmenos v. Greece* (GC), AB 2000, 386, with a commentary by L.F.M. Verhey, EHRC 2000, 45, with a commentary by J.H. Gerards, *NJCM-Bulletin* 2000, p. 1095, with a commentary by A.C. Hendriks & T. Loenen, RN 2000, 1245, with a commentary by R.A. Lawson, § 44.

³⁰ ECtHR 6 January 2005, *Hoogendijk v. the Netherlands* (dec.), EHRC 2005, 24, with a commentary by J.H. Gerards, *NJCM-Bulletin* 2005, with a commentary by A.C. Hendriks, USZ 2005, with a commentary by M. Driessen.

³¹ ECtHR 26 February 2004, *Nachova et al. v. Bulgaria*, *NJCM-Bulletin* 2004, p. 1153, with a commentary by D. Houtzager, EHRC 2004, 35, with a commentary by K. Henrard.

³² ECtHR 25 April 1978, *Tyrer v. the UK*, Series A, no. 26, § 31.

³³ ECtHR 16 September 1996, *Gaygusuz v. Austria*, RJD 1996-IV, No. 14, p. 1129, NJ 1998, 738, AB 1997, 179, with a commentary by F.J.L. Pennings, *NJCM-Bulletin* 1997, p. 461, with a commentary by C.A. Groenendijk, § 42.

³⁴ ECtHR 13 June 1979, *Marckx v. Belgium*, Series A, n. 31, NJ 1980, 462, with a commentary by E.A. Alkema.

³⁵ ECtHR 21 December 1999, *Salgueiro da Silva Mouta v. Portugal*, NJ 2001, 271, EHRC 2000, 16, with a commentary by J.H. Gerards, *NJCM-Bulletin* 2000, p. 880, with a commentary by C.J. Forder.

prohibition of non-discrimination also sets minimum standards to protect essential aspects of human dignity. Despite the accessory nature of Article 14, legal protection against discrimination extends to various areas which are essential for the development and fulfilment of an individual's personality. It was furthermore noticed that the Court nowadays applies the principle of non-discrimination in a non-formal, substantive way, an approach which allows individuals to challenge dominant standards and to demand measures to accommodate differences.

3. *Genetic Discrimination*

The term 'genetic discrimination' was coined to refer to unfair adverse treatment on the basis of a person's genetic constitution that has not (yet) led to expression. Although differentiation on the basis of hereditary factors has always taken place in human history, it was felt that progress in the field of human genetics enhanced the risk of (groups of) individuals being unjustifiably denied equal opportunities on the basis of inherited characteristics that are known or thought to be related with a predisposition to a genetic disease, a susceptibility to a genetic disorder or otherwise associated with genetically determined morbidity and mortality. There was (and is) particular concern about the use of genetic information as a tool to identify and exclude 'high risk' individuals from employment and private insurance, not only because of doubts about the legal and ethical acceptability and effectiveness,³⁶ but also now that it might undermine the legitimacy of genetic research.³⁷

However, what is precisely meant by 'genetic discrimination'? Upon closer scrutiny it becomes clear that this term is used in various ways. Taylor distinguishes three forms of genetic discrimination.³⁸ First, discrimination on the basis of genetic information derived from genetic data. Second, discrimination on the basis of genetic information not derived from genetic data, but on certain conditions that correspond with a particular genetic make-up. Third, discrimination on grounds of a particular characteristic that is disproportionately associated with a particular genetic variation.

³⁶ K.T. Palmer et al., 'Quantifying the Advantages and Disadvantages of Pre-Placement Genetic Testing', 61 *Occup Environ Medicine* 2004, pp. 448–453.

³⁷ Cf. the proposed US Genetic Information Nondiscrimination Act. A Bill was passed by US Senate on 17 February 2005.

³⁸ M.J. Taylor, 'Problems of Practice and Principle if Centring Law Reform on the Concept of Genetic Discrimination', 11 *European Journal of Health Law* 4-2004, pp. 365–380.

Taylor adds that these forms of genetic discrimination are not mutually exclusive but can—and quite often do—reinforce each other.

Underlying these distinctions is uncertainty about the meaning of the adjective ‘genetic’ in combination with the noun discrimination. Does genetic refer to the human genome³⁹ or genetic status,⁴⁰ as a result of which genetic discrimination would also cover adverse treatment on such grounds as sex, race and (some forms of) disability? Or should the adjective genetic be interpreted in a more restrictive way, linking it to information obtained from genetically-based diagnostic and prognostic tests⁴¹ or, even more confined, connecting it with genetic information about an asymptomatic person?⁴²

Elsewhere I have argued—together with others—that the aim of prohibiting genetic discrimination is to protect individuals from being unjustifiably denied equal opportunities on the basis of (real or assumed) information about their genetic characteristics.⁴³ This goal-oriented approach seeks to ensure that a prohibition of genetic discrimination can adequately respond to problems that may (and sometimes already do) emerge as a result of progress in the field of genetics, and which are not already addressed by existing non-discrimination laws and rules. In this way, the introduction of a prohibition of genetic discrimination will complement the applicable non-discrimination standards and has, from a human rights perspective, added value.

Although there is as yet no universal consensus about the meaning of ‘genetic discrimination’ it seems logical to reserve this term for forms of unjustified adverse treatment on the basis of information about one’s genetic characteristics.⁴⁴

³⁹ P.R. Billings, et al., ‘Discrimination as a Consequence of Genetic Testing,’ 50 *American Journal of Human Genetics* 1992, pp. 476–482 (477).

⁴⁰ M.A. Rothstein, ‘Genetic Discrimination in Employment: Ethics, Policy and Comparative law’, in: Swiss Institute of Comparative Law (eds.), *Human Genetic Analysis and the Protection of Personality and Privacy* (Zurich, Schulthess, 1994), p. 129.

⁴¹ L. Gostin, ‘Genetic Discrimination: the Use of genetically based Diagnostic and Prognostic Tests by Employers and Insurers’, 17 *American Journal of Law and Medicine* 1991, pp. 109–144.

⁴² M.S. Yesley, ‘Protecting Genetic Difference’, 13 *Berkeley Technology Law Journal* 1998, pp. 653–672.

⁴³ A.C. Hendriks & J.K.M. Gevers, ‘Juridische bescherming tegen ongerechtvaardigd gebruik van genetische informatie buiten de gezondheidszorg’, 29 *NJCM-Bulletin* 8-2004, pp. 1114–1130 and J.K.M. Gevers, A.C. Hendriks et al., *Bescherming tegen genetische discriminatie. Een juridische analyse* (Leiden, Stichting NJCM-Boekerij, 2004).

⁴⁴ This description does not apply a value judgement with respect to the distinction made between genetic and non-genetic health information (also known under the name ‘genetic exceptionalism’), an issue that I will not further embark upon in this contribution. For an extensive analysis of the term genetic discrimination from a comparative perspective, see J.H. Gerards, A.W. Heringa & H.L. Janssen, *Genetic Discrimination and Genetic Privacy in a Comparative Perspective*, Antwerp: Intersentia 2005.

4. *Article 11 of the Biomedicine Convention*

As mentioned before, Article 11 of the Biomedicine Convention prohibits 'any form of discrimination against a person on grounds of his or her genetic heritage.' The reason to include this provision reflects 'concern that genetic testing, which can detect a genetic disease, predisposition or a susceptibility to a genetic disease, may become a means of selection and discrimination.'⁴⁵

From the Explanatory Report it becomes clear that the meaning of the prohibition of discrimination in Article 11 of the Biomedicine Convention should be understood with reference to the case law of the ECtHR with respect to Article 14 of the ECHR.⁴⁶ It follows that both provisions should be interpreted and applied identically.

Surprisingly, the Explanatory Report fails to elaborate on the meaning of 'genetic heritage'. In fact, the report merely stipulates that 'the fundamental principle established by Article 11 is that any form of discrimination against an individual on grounds of his or her genetic heritage is prohibited.'⁴⁷ A document prepared by the Secretariat of the Council of Europe's Steering Committee on Bioethics (CDBI), under the title 'Preparatory Work on the Convention', neither explains the meaning of 'genetic heritage' nor provides a rationale for embracing this term.⁴⁸ From this report, one gets the impression that the discussion in the preparatory phase above all focussed on clarifying the meaning of 'discrimination', instead of 'genetic (heritage)'.

It follows that Article 11 of the Biomedicine Convention, which prohibits discrimination on grounds of 'genetic heritage', should be interpreted in conformity with the general goals of the Biomedicine Convention, that is to say to complement the protection already offered by the ECHR geared towards human rights problems that may emerge as a result of advances in medicine and biology. Although one could argue that the term 'genetic heritage' lacks precision and is also otherwise inaccurate, it is abundantly clear that the intention has been to expand the scope of Article 14 of the ECHR to guarantee that individuals enjoy protection against unjustified adverse treatment on grounds of (information concerning) genetic characteristics that are not yet (explicitly) covered by Article 14 of the ECHR.

⁴⁵ Explanatory Report to the Convention on Human Rights and Biomedicine, Strasbourg, Council of Europe, May 1997, Dir/Jur (97)5, § 74

⁴⁶ *Ibidem*, § 76.

⁴⁷ *Ibidem*, § 75.

⁴⁸ CDBI, Preparatory Work on the Convention, Strasbourg, Council of Europe, June 2000, CDBI/INF (2000) 1, pp. 52–53.

5. *Appraisal*

If one accepts that developments in science and their application both within and outside the field of health care may have adverse effects on the equal opportunities of those with inherited characteristics that are known or thought to be related to a predisposition to a genetic disease, a susceptibility to a genetic disorder or otherwise associated with genetically determined morbidity and mortality, then the inclusion of Article 11 in the Biomedicine Convention should be welcomed. This holds particularly true now that Article 14 of the ECHR does not explicitly refer to (information concerning) genetic characteristics and the ECtHR has so far never addressed the issue of genetic discrimination. Against this background Article 11 of the Biomedicine Convention may reinforce legal protection against genetic discrimination. Still, one can question whether this provision offers sufficient protection against genetic discrimination. These doubts stem from (1) the complex (legal) nature of genetic discrimination, (2) the limited scope of the prohibition of discrimination under Article 14 of the ECHR and Protocol XII to the ECHR, and thus Article 11 of the Biomedicine Convention, and (3) the weak enforcement mechanism established under the Biomedicine Convention.

With respect to the nature of genetic discrimination, it should be recalled that genetic discrimination is different from most other forms of discrimination now that it refers to people who are being denied equal opportunities on the basis of an (assumed) future risk that has not (yet) expressed itself. In other words, at present they are not substantially different from their comparator but as a result of hereditary factors a difference may or will occur in the future. Due to the latter, and the uncertainty about the predictability of most genetic factors, genetic discrimination is as much an issue of genetic privacy as of non-discrimination law. The fight against genetic discrimination very much depends on safeguards against the unauthorised use and disclosure of privacy-related information. Offering adequate protection against unjustifiable adverse treatment on the basis of (information concerning) genetic characteristics therefore requires a concerted and comprehensive privacy/non-discrimination approach, to avoid the situation where the protection offered by one body of law can be undermined by weaknesses in the other body of law and vice versa. Although the Biomedicine Convention also protects the 'right to respect for private life in relation to information about his or her health' (Article 10), nothing in the text of the Convention and its Explanatory Report suggests that both provisions should be read in conjunction to tackle genetic discrimination.

Although State laws and administrative practices can amount to genetic discrimination, the call for protection against genetic discrimination notably

emerged in response to concern about discriminatory practices by employers and private insurers. This raises the question to what extent, if at all, the prohibition of discrimination as enshrined in Article 14 of the ECHR and Article 11 of the Biomedicine Convention requires States to outlaw discrimination in the private sector. Here it should be recalled that the Biomedicine Convention, just as other human rights treaties, above all seeks to regulate the relations between the State and individuals (vertical relations). Although conventions may also have an impact on horizontal relations, this is hardly ever their primary objective. This also holds true with respect to Protocol XII to the ECHR, where it is stipulated that 'No one shall be discriminated against by any *public* authority . . .' (Article 1 para. 2; italics added—AH). From the Explanatory Report to the Protocol it can be seen that 'Th[is] Article is not intended to impose a general positive obligation on the Parties to take measures to prevent or remedy all instances of discrimination in relations between private persons.'⁴⁹ Now that Article 11 of the Biomedicine Convention should be applied in the same way as Article 14 of the ECHR and, as can be assumed, Protocol XII to the ECHR, it follows that States are allowed to address genetic discrimination in the private sector but are not required to do so. This can have far-reaching consequences now that many States are in the process of privatising public services and social insurances. This would mean that, once privatised, there is no longer a duty to offer protection against (genetic) discrimination. With respect to the latter, it should be noticed that the Biomedicine Convention in fact only contains a duty to 'provide appropriate judicial protection' against the unjustifiable infringements—presumably by State agents—of rights and principles set forth in the Biomedicine Convention (Article 23) and to provide for 'appropriate sanctions to be applied in the event of infringement' of a Convention right (Article 25). The protection offered by the Biomedicine Convention is thus insufficient to adequately tackle genetic discrimination.

A third weakness of the Biomedicine Convention, also backslashing on the protection against discrimination, concerns its weak enforcement mechanism. The Convention does not foresee a right for individuals to petition the ECtHR or any other independent authoritative international body in case of an alleged violation of Article 11. The Convention merely foresees the possibility of 'advisory opinions' by the ECtHR (Article 29) and a monitoring role by the Secretary General of the Council of Europe, who is

⁴⁹ Explanatory Report to Protocol No. 12 to the Convention for the Protection of Human Rights and Fundamental Freedoms, Strasbourg, Council of Europe, [<http://conventions.coe.int/Treaty/EN/Reports/Html/177.htm>] § 25.

entitled to ask States parties to furnish a report on compliance with the Convention (Article 30).

6. *Conclusions*

Roscam Abbing was right to conclude that Article 11 of the Biomedicine Convention contains various flaws that weaken its potential to serve as a powerful legal basis to outlaw and eliminate genetic discrimination in the States parties to this convention. This does not make this provision redundant. Genetic discrimination is increasingly perceived as a threat to human rights, thus calling upon legislators and policy makers to take appropriate measures. In obliging States parties to forbid discrimination on grounds of genetic heritage, Article 11 of the Biomedicine Convention conveys an important message that can be used as a tool to discuss law and policy reform measures.

It was argued here that it is relatively easy to overcome the conceptual unclarity surrounding the term 'genetic heritage'. Now that Article 11 of the Biomedicine Convention seeks to complement the protection offered by Article 14 of the ECHR and Protocol XII to the ECHR it appears logical to interpret this term as meaning information about one's genetic characteristics.

Admittedly, Article 11 of the Biomedicine Convention, in its present form, offers as such an insufficient basis to adequately tackle (prospective) genetic discrimination, notably in those fields where legal protection is probably most needed. These weaknesses were attributed to the interrelationship between genetic privacy and genetic discrimination, which call for concerted action, the fact that human rights law, including the Biomedicine Convention, above all seeks to regulate the relations between the State and individuals whereas genetic discrimination is above all feared to threaten freedom, equality and solidarity in horizontal relations, and the weak enforcement mechanism established under the Biomedicine Convention.

The above shortcomings should not deter States from using Article 11 of the Biomedicine Convention as an incentive and vehicle to introduce the necessary legal and policy measures to prevent and prohibit genetic discrimination. This is not to deny that Roscam Abbing's visionary expertise will be particularly and sadly missed with respect to the formulation and design of measures like these. Her written work contains a goldmine of information and inspiration from which the coming generation of health and human rights lawyers can gratefully benefit, also with respect to issues as discussed in this contribution.