TILBURG UNIVERSITY

Dutch protection against genetic discrimination in work environments

Adequate or non-existent?

K.J.F.A. de Koning

7/4/2012

Anr 253247

Inhoudsopgave

List of Abbreviations

CoE	Council of Europe
CNV	Christelijke Nederlandse Vakbeweging (*Dutch Christian Trade Union)*
CPD	Commissie Gelijke Behandeling (*Equal Treatment Committee)*
DCC	Dutch Civil Code (*Burgerlijk Wetboek*)
EC	European Community
ECHR	European Convention on Human Rights
ECJ	European Court of Justice of the European Union
ECtHR	European Court of Human Rights
ETC	Equal Treatment Committee (*Commissie Gelijke Behandeling*)
EU	European Union
FNV	Federatie Nederlandse Vakbeweging (*Dutch Trade Union Confederation*)
ICCPR	International Covenant on Civil and Political Rights
ILO	International Labor Organization
PDPA	Personal Data Protection Act (*Wet Bescherming Persoonsgegevens*)
TEC	Treaty establishing the European Community
TEU	Treaty on the European Union
TFEU	Treaty on the Functioning of the European Union
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organization
ZonMw	a Dutch organization for health research and development with the Ministry of Health, Welfare and Sports and the Dutch Organization for scientific research as its main clients.

Introduction

In a world with ever evolving technology concerning genetics it is important to have a system of hard and soft law that keeps up with it. Recent violations by the media of medical confidentiality and patient's privacy[1], requires a detailed research of hard and soft law to determine protection against genetic discrimination and of privacy. There is no current Dutch hard law that concerns the protection of genetic information specifically, so current Dutch hard law shows possible gaps in protection and might be in need of improvement or maybe even renewal. For example, take a look at Article 1 of the Dutch Constitution[2], which contains the prohibition of discrimination. When two private parties have a dispute that does not fall within the scope of the Equal Treatment Act[3] or other specific regulations, Article 1 of the Dutch Constitution offers protection. If genetic discrimination would be the subject in this dispute, Article 1 of the Constitution[4] might offer potential protection since genetic discrimination could fall within the residual category 'on any other grounds whatsoever[5]'.

According to Gevers[6] there has not been any discussion on whether to insert 'genetic information' as an additional legal ground into Article 1 of the Constitution. Insofar problems with genetic information exist they mainly focus on some areas of society. However, Gevers published his work in 2004 and much has changed since. In the following sections the definitions of genetic information, hard and soft law, and individual and familial discrimination will be clarified. After which, in Chapter 1 the protective value of national, European and, if needed, international hard law will be examined, concerning individual genetic discrimination. Secondly, in Chapter 2 an analysis will be made of national, European and/or international soft law concerning individual genetic discrimination. Chapter 3 will visit the protective value of national, European and/or international hard law concerning familial genetic discrimination. Fourthly, in Chapter 4 the protection of familial genetic discrimination will be examined based on national, European and/or international soft law. Finally, a concluding chapter will close with an answer to the question of this thesis: *"Does the existing system of Dutch hard and soft law protect against both individual and familial genetic discrimination in work environments, in a satisfactory manner?"*

[1] For example,the Eyeworks' program "24 uur tussen Leven en Dood"
[2] Dutch Constitution 1815 (*Grondwet)*(NL)
[3] Equal Treatment Act 1994 (*Algemene Wet Gelijke Behandeling*)(NL)
[4] Article 1 of the Dutch Constitution: *"All persons in the Netherlands shall be treated equally in equal circumstances. Discrimination on the grounds of religion, belief, political opinion, race or sex or on any other grounds whatsoever shall not be permitted."*
[5] JKM Gevers and AC Hendriks., *Bescherming tegen Genetische Discriminatie; een juridische analyse* (Stichting NJCM-Boekerij 40 2004) 94
[6] Gevers (n 5) 92-95

I. Genetic information

In its most basic (medical) definition, genetic information is information that can be found in genes. Genes are responsible for characteristics such as the color of eyes, the length of bodies or blood types. Genes are part of chromosomes, which are inherited from an individual's parent. With every copy of inherited chromosomes come certain pieces of genetic information. If a mutation of one of these copies of a gene results is malfunctioning, this mutation can result in a hereditary disease[7]. Gevers[8] defines genetic information as a combination of definitions. 'Information' is data concerning an individual, which can lead to direct or indirect identification of that individual and 'genetic' refers to genes. The definition on genetic information can be found by combining Gevers' definition on 'genetic information' with Callens' definition on 'personal information'. According to Callens, 'personal information' comprises all kinds of information that can identify or help to identify one individual[9]. A type of personal data is medical data, which includes personal data concerning the state of health, during past, present or future, physically and mentally, including all data that can be related to the state of health[10]. The combined definition of 'genetic information' would result in: data concerning an individual, which comprises all kinds of information that can identify or help identify one individual. The Council of Europe has offered a more refined definition of genetic information. In her definition 'genetic information' refers to all data, of whatever type, concerning the heritable characteristics of an individual or on the pattern of inheritance of such characteristics within a related group of individuals. It refers to all data on the carriage of any genetic information (genes) in an individual or genetic line relating to any aspect of health or disease, whether present as identifiable characteristics or not.[11]" This definition will be used in the further examination of the protection against individual and familial genetic discrimination. The Dutch legislator has not yet tried a definition of genetic information. However, both a recommendation by the Council for Health and Care to the Minister and State Secretary for Health, Welfare and Sport from 2008[12] and a research conducted by ZonMw, mentions the subject of genetic information. Though none of these documents exactly define genetic information, a couple of tentative characteristics are brought up. Genetic information includes data that can identify an individual[13] and data that reveals a predisposition to several diseases that usually are hereditary[14]. Genetic information can be detected through analysis of body materials[15] such as human tissue and cells. However,

[7] For more information: www.eurogentest.org
[8] Gevers (n 5) 5-6
[9] Stefaan Callens, *Goed Geregeld? Het gebruik van medische gegevens voor onderzoek* (MAKLU 1995) 74.
[10] Callens (n 9) 80-81
[11] Project Group on Data Protection, *Draft recommendation on the protection of medical data*, (Straatsburg 1993, CJ-PD (93)53) 18
[12] Raadgevend Comite voor Bio-ethiek, *Advies nr. 20 van 18 november 2002 betreffende predictieve genetische tests en HIV-tests in het kader van arbeidsverhoudingen,* http://www.ceg.nl/themas/bekijk/voorspellende-geneeskunde/adviezen (NL)
[13] Committee Genetics of ZonMw, *Toepassing van de genetica in de gezondheidszorg: Gevolgen van de ontwikkelingen voor de huidige wet- en regelgeving* (The Hague: ZonMw 2003) 91
[14] Gevers (n 5) 29
[15] Callens (n 9) 111

according to Gevers[16], herein lies another problem revolving genetic information next to its vague definition. The predictive value of genetic information is also problematic, since it is very limited and dependent on factors such as the type of gene mutation and exposure to external risks. This results in a very vague line between genetic and non-genetic information. For example, if sister A has breast cancer, sister B might also be at risk of carrying the gene for breast cancer, but she may also be free of that gene.

In summary, genetic information refers to all data, of whatever type[17], concerning the heritable characteristics of an individual or on the pattern of inheritance of such characteristics within a related group of individuals. It refers to all data on the carriage of any genetic information in an individual or genetic line relating to any aspect of health or disease, whether present as identifiable characteristics or not[18].It is not an understatement to say that genetic information concerns very sensitive data and should therefore be carefully protected.

II. Hard and Soft Law

Technology has kept developing and the question is whether Dutch law is still capable of protecting its subjects. In this research is important to find out if hard law and/or soft law can protect an individual's very sensitive genetic information.. The first definition in this section that needs clarification is hard law. After which, the definition of soft law will be given. According to Article 81 of the Dutch Constitution, hard law is law adopted by the Government and States-General, whereby the Government consists of the Queen and Ministers, Article 42 of the Dutch Constitution. In order to create hard law the bill needs to be published in the Book of Statutes[19]. Dutch hard law that is relevant to protection against discrimination are the Dutch Constitution, the Equal Treatment Act[20], Equal Treatment Act on Disability or Chronic illness[21], Equal Treatment Act on grounds of age in employment[22], Equal Opportunities Act[23], Medical Examinations Act[24] and the Personal Data Protection Act. The following grounds of discrimination can be found in Dutch hard law: race, gender, sexual orientation, transsexuality, political opinion, religion, belief, disability or chronic illness, marital status, age, nationality, working time and type of paid employment contract (permanent or temporary). Current legislation offers protection against certain parts of genetic discrimination. Discrimination on grounds of race, gender, disability or chronic illness are important grounds on which protection

[16] Gevers (n 5) 7
[17] For example: human DNA, RNA, chromosomes, proteins, or metabolites.
[18] Project Group on Data Protection, Draft recommendation on the protection of medical data, Straatsburg, 15-11-1993, CJ-PD (93)53, 18.
[19] Book of States (Staatsblad)(NL), <www.staatsblad.nl>
[20] Equal Treatment Act 1994 (*Algemene Wet Gelijke Behandeling*)(NL)
[21] Equal Treatment Act on Disability or Chronic Illness 2003 (*Wet gelijke behandeling op grond van handicap of chronische ziekte*)(NL)
[22] Equal Treatment Act on grounds of Age in Employment 2003 (*Wet gelijke behandeling op grond van leeftijd bij arbeid*)(NL)
[23] Equal Opportunities Act 1980 (*Wet gelijke behandeling van mannen en vrouwen*)(NL)
[24] Medical Examinations Act 1997 (*Wet op medische keuringen*)(NL)

can be provoked. These characteristics could be results from the information hidden in our genes. For example, blindness is a handicap, but could occur from an individual's genes or from an accident. The problem with genetic information is that it is not always obvious from the outside, and if it is visible to the eye, it might not always be because of a genetic deficiency. For example, recruiter A will not be able to see if candidate X has the Huntington's gene, though X's medical record might contain that information. This example shows that both anti-discrimination or equal treatment law are relevant with regard to the protection of genetic information, but also privacy protection law. In other words, the sensitive data concerning candidate X should be thoroughly protected against the prying eyes of recruiters.

Also, the second definition that needs clarification is soft law. Soft law consists of measures that are not legally binding, but are taken in good faith and have the possibility of someday evolving into hard law[25]. Soft law consists of measures such as consistent policies of insurance companies and labor unions and codes of conduct. These will be researched specifically in order to create a better understanding of where soft law protection can be found and lacks of protection exist. In order to examine if Dutch hard and soft law need improvement, with regard to genetic information, it should be compared to international and European hard and soft law[26].

III. Individual and familial discrimination in a work environment

Next to 'genetic information' and 'hard and soft law', another definition that needs clarification is 'discrimination'. Discrimination is making any kind of unlawful distinction, exclusion, limitation or preference[27]. With regard to this thesis, genetic discrimination can be best described as when an employer takes an adverse employment action based on an applicant's or employees' (asymptomatic) genetic predisposition to or probability of having a disease or medical condition[28]. Discrimination can occur in an individual and familial manner. Individual genetic discrimination is a distinction directed to one person. Some good examples of individual genetic discrimination are, firstly[29], the case in which an individual was genetically screened and learned that he was carrier of a single mutation for Gaucher's disease. His carrier status indicated that he might pass his mutation to his children, but not that he would develop Gaucher's disease himself. He revealed this information when applying for a job and was denied the job, because of this genetic mutation, even though it had no bearing on his present or future ability to perform a job. In a second case[30] a 53 year old man revealed at a job interview with an insurance company that

[25] For example, Modelregeling arts-patiënt 1998, <http://knmg.artsennet.nl/Publicaties/KNMGpublicatie/Modelregeling-artspatient-1998.htm>, clarified in Chapter 2.
[26] I am aware that since the Lisbon Treaty entered into force on the 1st of September 2009, there may be differences with directives, regulations, etcetera that are based on the articles of the former TEU. In case those differences change the way a piece of legislation should be interpreted I will explain those differences. However, this is not a research comparing the TEU and the TFEU and therefore I will not spend too much time on it.
[27] CC de Fey, Met *recht discriminatie bestrijden* (Boom Juridische uitgevers 2004) 19-20
[28] P Miller, 'Analyzing Genetic discrimination in the workplace' (US Department of Energy Human Genome Program) <www.ornl.gov/sci/techresources/Human_Genome/publicat/hgn/v12n1/09workplace.shtml>
[29] Department of Labor ea, 'Genetic information and the workplace' <www.genome.gov/10001732>
[30] <www.genome.gov/10001732>

he had hemochromatosis, but was asymptomatic. During the second interview, he was told that the company was interested in hiring him, but would not be able to offer him health insurance, because of his genetic condition. He agreed to this arrangement. During his third interview, the company representative told him that they would like to hire him, but were unable to do so, because of his genetic condition. A third example[31] is a case in which an employee's parent developed Huntington's disease, indicating that the employee had a 50 percent chance of inheriting the mutated gene that would cause her to develop the disease. She decided to be tested. A genetic counselor advised her to secure life and health insurance before testing, because a positive test result would not only mean that she would get the disease, but would probably prevent her from obtaining insurance as well. A co-worker, who overheard her making arrangements to be tested, reported the employee's conversations to their boss. Initially, the boss seemed empathic and offered to help. When the employee eventually shared the news that her test results indicated that she did carry the mutated gene, she was fired from her job. In the 8 month period prior to her termination, she had received three promotions and outstanding performance reviews. Frightened by their sister's experience, none of her siblings are willing to undergo genetic testing for fear of losing health insurance or jobs. Consequently, they most live with the uncertainty of not knowing whether they have inherited the genetic trait that leads to Huntington's disease.

Familial genetic discrimination can be defined as a distinction made as a result of one person's association with another person, who has an (asymptomatic) genetic predisposition to or probability of having a disease or medical condition. A good example of familial discrimination is the case of S. Coleman v Attridge Law[32] in this case Coleman was dismissed as an employee of Attridge Law on the ground of the disability of her child. She is the sole caretaker of her son who suffers from apneic attacks and congenital laryngomalacia and bronchomalacia. Articles 1 and 2 of the Council Directive 2000/78/EC of 27 November 2000[33] offer protection against discrimination on the basis of disability. The Grand Chamber decided that this protection was not limited to employees who are themselves disabled. If an employee is discriminated not based on his/her own disability, but for instance on the basis of the disability of his/her child for whom he/she is responsible, then the Directive[34] also offers protection. This case offers a great example of legislation focused on individual discrimination in a work environment, which also can be used for protection in case of familial discrimination. Familial genetic discrimination will be discussed, since even if there have not been cases on this subject, in an American interview[35] on confronting genetic disease this subject also come up. Fears of discrimination arose that even the knowledge that one is a caregiver of an ill family member could be held against one. Or the fear of discrimination against symptomatic individuals heightens the anxieties among their

[31] <www.genome.gov/10001732>
[32] Case C-303/06 *S. Coleman v Attridge Law* [2008] OJ
[33] Council Directive (EC) 78/2000 establishing a general framework for equal treatment in employment and occupation [2000] OJ 2000 L-303/16
[34] Council Directive (EC) 78/2000 (n 36)
[35] R Klitzman, 'Views of Discrimination among Individuals Confronting Genetic Disease' (Journal of Genetic Counseling 2010) vol 19 no 1 68-83

asymptomatic family members. In other words, the interviewees' feared that knowledge about a genetic disease could not only lead to them being discriminated, but also to discrimination of their (asymptomatic) family members. For example, one man was asked by his local TV-station to do an interview on his genetic disease. The man decided to wait until his son had moved, before he would give the interview, since he was afraid that the knowledge of his son's carrier status could lead to discrimination in employment.

Consequently, one of important questions of this thesis concerns the protection by hard and soft law, and if it only applies to individual genetic discrimination, or if it also protects against familial genetic discrimination.

1. Dutch and European hard law regarding the protection against individual genetic discrimination

Since non-discrimination norms exist at a number of levels, international, European, national and sub-national[36], it is important to examine protection against individual genetic discrimination on more than just the national level. In order to find actual protection[37] for a Dutch resident in case of individual genetic discrimination, which the individual may directly apply, it also is important to include European hard law. Therefore, the first section will start with national hard law. After which hard law will be researched on a European level in the second section and compared to Dutch hard law. Though not a lot of cases have emerged regarding discrimination on the grounds of individual genetic information, it is worthwhile to explore solutions or problems resulting from this case-law. The third Chapter will be devoted to a conclusion regarding the protective value of Dutch and European hard law concerning individual genetic information.

1.1 Dutch Hard Law

In this section national hard law will be researched on its protective worth in case of individual genetic discrimination. The applicable hard law can be divided in two categories. In the first subsection, the first category of law, which has the purpose to prohibit discrimination, will be examined. In the second subsection, the second category of law, which involves the way the privacy of sensitive information, such as genetic information, is protected, will be examined. This section on Dutch hard law will be concluded with an interim conclusion.

A. First type of law: prohibiting discrimination

First of all, as provided in the introduction, the definition of hard law: a product from the government and the States-General created under Article 81 and further of the Dutch Constitution[38]. Anti-discrimination law has two functions: a principled function and an instrumental function. The principled function of anti-discrimination law is protecting the equal treatment of persons and to indicate in what kind of situations exceptions on the rule of equal treatment are allowed. The instrumental function of anti-discrimination law is to protect persons against exclusion on account of specific personal characteristics[39]. As Bell[40] explains, non-discrimination law consists of anti-discrimination laws and equality laws. The difference between both laws is that the first contains a set of negative obligations, focusing on actions that for example employers must refrain from, as opposed to the second kind that imposes positive duties on employers to act in favor of equal opportunities[41]. The two generic pieces of anti-discrimination legislation are Article 1 of the Dutch Constitution and the Dutch Equal Treatment

[36] M Bell, *Anti-discrimination law and the European Union,* (Oxford University Press 2002) 146
[37] In other words: adequate protection for a Dutch resident.
[38] M Burkens, *Beginselen van de Democratische rechtsstaat: Inleiding tot de grondslagen van het Nederlandse staats- en bestuursrecht* (Kluwer 2006) 62
[39] Gevers (n 5) 18
[40] Bell (n 41) 146
[41] Bell (n 41) 148

Act. When confronted with discrimination, the aggrieved should start off with specific anti-discrimination law. If none of those specific laws are applicable the aggrieved should apply generic anti-discrimination law. The most important pieces of specific anti-discrimination legislation are the Dutch Civil Code[42], the Equal Treatment Act on Disability or Chronic Illness and the Medical Examinations Act. Those offer more specific protection against discrimination than Article 1 of the Dutch Constitution does. However the question remains if the anti-discrimination legislation offers adequate protection against discrimination on the grounds of genetic information. Therefore, the first law to examine will be Article 1 of the Dutch Constitution. Since it is the most prominent and important anti-discrimination article in Dutch hard law. Secondly, the Equal Treatment Act on disability and chronic illness will be examined for a more specific form of protection. After which the protection offered by the Equal Treatment Act will be clarified. Fourthly, the Dutch Civil Code will provide an insight in its protective value in case of an infringement on equal treatment. Finally, the examination of Dutch anti-discrimination law will be concluded with an examination of the Dutch Penal Code. A short interim conclusion will close this section.

First of all, as said above, the most important and prominent article involving an anti-discrimination statement from the Dutch legislator, is Article 1 of the Dutch Constitution. The Dutch Constitution starts with the declaration that "*all persons in the Netherlands shall be treated equally in equal circumstances. Discrimination on the grounds of religion, belief, political opinion, race or sex or on any other grounds whatsoever shall not be permitted",* Article 1. However grand this statement, a number of authors[43] question whether it also offers protection against discrimination on the grounds of genetic information discrimination. The first sentence of Article 1 of the Dutch Constitution is about the principle of equality: every person shall receive equal treatment when in equal circumstances. The second sentence of this Article formulates the prohibition of discrimination on certain specific grounds. These grounds originate from several pieces of European legislation[44]. Most relevant for this thesis research is the vague concept of 'any other grounds'. Whereas the first sentence of article 1 is exhaustive, the second sentence of the article contains a semi-exhaustive list of grounds on which protection against discrimination can be offered.

An exhaustive list of grounds means that only in by law explicitly mentioned situations a regulation is applicable. The opposite of such a list is a non-exhaustive one, often referred to as part of an open system. In case of such a list no grounds on which discrimination could occur are listed. For example, the first sentence containing the principle of equal treatment does not contain any grounds. However, in case of a semi-exhaustive list a combination of explicitly mentioned grounds and the possibility of additional grounds is created. The second sentence of Article 1 is a perfect example of such a semi-exhaustive list, since it sums up grounds such as

[42] Dutch Civil Code 1838 (*Burgerlijk Wetboek*) (NL)
[43] For example: Gevers (n 5)
[44]< www.art1.nl> (NL)

religion, belief, race, etcetera and it offers the possibility of adding other grounds with "any other grounds".

Nevertheless, the question is whether such a possibility of adding grounds is enough for protection against individual genetic discrimination. Gerbranda[45] explains that though originating from international treaties, the listed grounds in Article 1 phrase 2 of the Dutch Constitution were created by society. Grounds deemed important by society found its way into the treaties and subsequently into the Dutch Constitution. If protection against individual genetic discrimination would be found necessary by society, this ground might also find its way into the Dutch Constitution. The purpose of the Dutch Constitution was to authorize and restrict the actions of the State and, most important, to impose obligations on the State to protect civilians. However, the Constitution also has horizontal effect and this can result in two situations. Firstly, in case of infringement of Article 1 of the Dutch Constitution, the claimant could seek legislation fitting to his or her circumstances. Secondly, Article 1 of the Dutch Constitution is directly applicable and does not need further elaboration[46].

Secondly, the Equal Treatment Act on Disability or Chronic Illness is hard law with two important activities. The first is prohibiting a distinction, be it direct or unjustified indirect, between persons on grounds of an actual or alleged disability / chronic illness. The distinction should, in order to be prohibited, not be necessary for protection of safety and health or a preference policy. The second activity of the Act is dictating the performance of effective adjustments when the need arises, unless this would be a disproportionate duty[47]. At first reading the Act seems to offer a rather welcome protection for those who suffer from a disability or a chronic illness. However, what kind of real protection does the Act really offer? In articles 1 to 8 the Act clarifies what kinds of distinctions are prohibited. Finally, in paragraph 5 the Act clarifies the actual protection. In summary, the articles on protection are not capable of providing litigants with actual instruments to attack the injustices they have suffered[48]. According to article 12 of the Act, the Equal Treatment Committee can investigate if a distinction has been or is being made. However, the judgment of the Committee is not binding and the defendant is not obligated to act on the judgment of the Committee. In 75% of the cases, judgments are acted upon by the defendant, but in 25% of the cases the defendant ignores the judgment which results in further frustration and possible hurt for the litigant. The litigant does have the option to take the ETC's judgment and bring the dispute before a judge. The judge has to mind the ETC's judgment in his/ her verdict and has to give a motivation when he/ she reaches a different judgment. Therefore, it cannot be said that the Equal Treatment Act on Disability or Chronic Illness offers a very adequate kind of protection.

---

[45] Tjetske Gerbranda ea, *Grondrechten Evaluatie-Onderzoek: Documentatierapport* (Stichting NJCM-Boekerij 1991) 1-315

[46] Gert-Jan Leenknegt, 'Het gelijkheidsbeginsel en de scheppingsorde: een staatsrechtelijke botsproef' (Ars Aequi 2005 vol 54 no 9) 659.

[47] PC Vas Nunes, 'Gelijke behandeling op grond van handicap en chronische ziekte in het arbeidsrecht' (Tijdschrift Arbeidsrechtpraktijk 2009)(NL) 23

[48] PJJ Zoontjens, *Handicap en Chronische ziekte* (Gelijke behandeling: Oordelen en commentaar 2010) 173

Thirdly, Dutch Equal Treatment Act is the generic law as opposed to the Equal Treatment Act on Disability or Chronic Illness. The Act protects against discrimination on the grounds of religious or philosophical beliefs, political opinions, racial origin, gender, nationality, sexual orientation and marital status. The Equal Treatment Act clarifies the open norm of Article 1 of the Dutch Constitution and explains in which situations equal treatment is required. Since the Act has an exhaustive list of grounds of discrimination, Article 1 of the Dutch Constitution should be invoked in the situation when another ground of discrimination, which is not protected by the Act, is at issue[49]. Therefore, it cannot be said that in case of individual genetic discrimination, the Act offers adequate protection. Not even a partial protection can be found in the Act, since genetic discrimination[50] happens when an employer takes an adverse employment action based on an applicant's or employees' (asymptomatic) genetic predisposition to or probability of having a disease or medical condition. Therefore, the grounds that could protect parts of genetic information, for example racial origin or gender, cannot offer adequate protection. In conclusion, the Equal Treatment Act does not offer adequate protection against individual genetic discrimination in a work environment.

Fourthly, the Dutch Civil Code offers examples of both the principled function of anti-discrimination law and of the instrumental function of anti-discrimination law. Firstly, articles 7:646 to 7:649 of the Dutch Civil Code indicate what equal treatment on the basis of gender should encompass in situations that involve labor and what rights employees have. However, the actual instrumental articles to enforce these rights are articles 6:162 and 7:611 of the Dutch Civil Code[51]. Whereby article 6:162 DCC is the most powerful of both articles, since art. 7:611 DCC only stipulates that both employer and employee should behave appropriate to what is expected of them in their functions. Article 6:162 DCC offers the possibility of tort when someone infringes the right of another person acts or fails to act contrary to his or her legal obligation or with what befits unwritten law in society.

Finally, though not really part of specific equal treatment legislation the Dutch Penal code also offers protection against discrimination. It has its own definition of discrimination, which can be found in Article 90quater. *´Discrimination or discriminating shall be defined as any form of distinction, any exclusion, restriction of preference, the purpose or effect of which is to nullify or infringe upon the recognition, enjoyment or exercise on an equal footing of human rights and fundamental freedoms in the political, economic, social or cultural fields or any other field of social life[52]'.* This definition constitutes both direct and indirect discrimination, because of the words "the purpose or effect". If discrimination occurs with purpose then the behavior is directly aimed. In the case of indirect discrimination, the behavior had a discriminating effect. Two different situations in which discrimination occurs are acknowledged by the Dutch Penal

[49] de Fey (n 30) 131-132
[50] Miller (n 23)
[51] Art.1, 'Verslag Anti-discriminatie- en diversiteitstraining Nederland', (www.art1.nl 2008) <http://ec.europa.eu/social/BlobServlet?docId=1644&langId=nl> 26
[52] CoE ECRI, 'The Netherlands: Legal measures to combat racism and intolerance in the member States of the Council of Europe' (<www.coe.int/t/dghl/monitoring/ecri/Legal_Research/National_legal_measures>, 'the Netherlands' 2006) 10

Code. Article 137g of the Penal Code concerns discrimination on account of race in the exercise of their office, profession or business. However, the second situation of discrimination could be interesting with regard to protection against discrimination on account of genetic information. Article 429quater of the Penal Code: '*any person who in the exercise of his office, profession or business discriminates against persons on account of their race, religion, convictions, sex or heterosexual or homosexual preference shall be liable to a term of detention not exceeding two months or a third-category fine.'* The second paragraph of this article is the most interesting, since it stretches the limits of the article to persons with a physical, psychological or intellectual disability whose human rights or fundamental freedoms are affected in the exercise of their office, profession or business. The Dutch legislator has created grounds for protection against direct and indirect discrimination by again using the words "purpose or effect". However, as seen with the Equal Treatment Act, the grounds of discrimination, which it protects, cannot offer protection against individual genetic discrimination. Discrimination based on a (asymptomatic) genetic predisposition to or probability of having a disease or medical condition cannot be protected by one of the above mentioned grounds. Also, the Department of Public Prosecutions decides if they want to instigate proceedings or not. The discriminated individual cannot know if he/she will actually be protected against future discrimination or not.

In conclusion, Dutch hard law, more specifically non-discrimination law, concerning individual genetic information, can be found in Article 1 of the Dutch Constitution, the Equal Treatment Act on Disability or Chronic Illness, the Equal Treatment Act, the Dutch Civil Code and the Dutch Penal Code. Article 1 of the Dutch Constitution has the possibility of providing protection on 'any other grounds', which could be the ground of individual genetic information. Also, according to the doctrine of horizontal effect, the Dutch Constitution can either be used directly during proceedings or needs further elaboration. The Equal Treatment Act on Disability or Chronic Illness can protect those cases in which the existing grounds 'disability' or 'chronic illness' cover parts of 'genetic discrimination'. However, the Act does not provide for adequate protection by itself. Furthermore, Article 6:162 of the Dutch Civil Code does not provide protection against discrimination, but can be used to claim damages resulting from discrimination. Finally, the Equal Treatment Act and the Dutch Penal Code cannot offer adequate protection against individual genetic discrimination, since both have an exhaustive list of grounds, which does not cover genetic discrimination[53].

B. Second type of law: protecting privacy

In order to get a good understanding of how a person's genetic information can be protected it is relevant to understand what privacy exactly is. This section will start with a short summary of what privacy is considered to be by the legislator. Close to follow will be two different approaches to protecting genetic information via the right to privacy. The first approach is to

[53] Genetic discrimination, in the work environment, occurs when an employer takes an adverse employment action based on applicant's or employee's (asymptomatic) genetic predisposition to or probability of having a disease or medical condition.

protect the way sensitive data, such as genetic information, is processed. The second approach is the protection of databases, in which the data is stored.

i. Definition of privacy

'Privacy' is a broad definition and is interpreted in Article 8 of the ECHR, Article 17 of the ICCPR and Article 10 of the Dutch Constitution. Firstly, the right to privacy can be seen as a right to be left alone, to exclude others from certain areas of a person's private life. According to Article 8 of the ECHR privacy expands to the private life, family or household life, a person's home and his/her correspondence. In the second paragraph of Article 8 the legislator created room for exclusions. It starts off with stating that no interference by a public authority is allowed when exercising the right to privacy. However, the article says that it is possible to interfere with a person's right to privacy: if it is necessary in a democratic society, because of reasons of national security, public security or the financial wellbeing of the state, the prevention of public disorder or legal offenses, the protection of the health or morals or the protection of the rights and freedoms of others. Article 17 of the ICCPR expands this right to respect of a person's privacy by stating that the interference cannot be arbitrary or unlawful. Also, the ICCPR expands the areas that are protected by the right to privacy by adding that a person's honor or reputation may not be affected. So the ICCPR not only says that a person has a right to protection against interference, but also a right to protection against degradation.

While the ECHR and the ICCPR, which will be discussed more thoroughly in the second section of this Chapter, focus mostly on the right to ward off interference, Article 10 of the Dutch Constitution focuses more on the rules that the law poses to protect a person's privacy. Gevers[54] sees in the second paragraph of Article 10 of the Dutch Constitution a duty to protect for the legislator. Another explanation, of the importance of Article 10 of the Dutch Constitution, is the realization of the legislator that the most important protection against interference is the protection of personal data. The third paragraph of Article 10 adds to this first statement of the importance of personal data, since it deals with the follow up after the processing of information. After being processed, the question remains who has a legal right to demand knowledge about that data.

ii. Protection of genetic information

This subsection will start with a comparison of the definitions of 'genetic information' and 'sensitive data. After which the Dutch hard law concerning the protection of sensitive data will be examined. A short interim conclusion will close this subsection.

First of all, in Dutch hard law, the legislator often uses the definition 'sensitive data'. Due to its sensitive nature, it could be argued that genetic information falls within that category. However, sensitive data consists, according to Article 16 Personal Data Protection Act and Article 8 of the Directive 95/46/EC, of data concerning racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, health and sex life. Genetic information refers to all data, of whatever type, concerning the heritable characteristics of an individual or on the

[54] Gevers (n 5) 32-34

pattern of inheritance of such characteristics within a related group of individuals. It refers to all data on the carriage of any genetic information (genes) in an individual or genetic line relating to any aspect of health or disease, whether present as identifiable characteristics or not."[55]. Therefore, genetic information can be seen as being part of sensitive data, but also as data going beyond the scope of sensitive data. For example, genetic information concerning health can be seen as part of sensitive data. However, the genetic predisposition to a disease, which has not had its effect on a person's health, does not fall within the category of sensitive data. The first conclusion concerning the protection of genetic information by means of using the protection of sensitive data, is that the protection is incomplete.

The Personal Data Protection Act, the Medical Examinations Act and the Act of Agreement on Medical Treatment, are important sources of protection for sensitive data[56].

The Personal Data Protection Act[57] serves to implement the EC Directive 95/46/ EC concerning personal data. The Directive was created in order to regulate the ongoing development of society and technology. It offers the individual legal safeguards concerning the collecting, recording, transmitting, and further use of personal data. The PDPA focusses especially on the regulation of the processing[58] of personal data[59]. The PDPA also has a number of articles, in the second paragraph of its second Chapter, which is entirely dedicated to 'sensitive personal data'. On this type of data a heavier regime of protection is placed and in some cases a complete ban of processing the sensitive date is issued.

The PDPA can be seen as very valuable in taking care of the standards of processing sensitive data. Also, Article 49 and 50 PDPA say that in case damages have been suffered by the individual, whose personal data has been compromised, he/she has a right to compensation. That right to compensation can be exercised by invoking Article 6:162 of the Dutch Civil Code. In conclusion, the protection of sensitive data does not entirely cover genetic information, but the part it covers, can be protected by use of the Articles 49 and 50 PDPA in conjunction with Article 6:162 of the Dutch Civil Code.

The Medical Examinations Act was created to protect the privacy and physical integrity of an examined person and to strengthen his/ her legal status. According to Ippel[60] there are two types of medical examinations. Firstly, there is 'genetic screening', which means an examination in advance to discover potential health risks of a prospective employee. This could result in a person, who was diagnosed with Parkinson, being refused as a military pilot. Secondly, there is 'genetic monitoring', which researches if working in a certain environment causes detrimental

---

[55] Project Group on Data Protection, *Draft recommendation on the protection of medical data* (Straatsburg 1993 CJ-PD (93)53) 18.

[56] Callens (n 9)

[57] Further mentioned as 'PDPA'.

[58] 'Processing': '*any operation or set of operations concerning personal data, in any case the collection, recording, organization, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or other form of posting, bringing together, piecing together, blocking, erasure or destruction of data'.*

[59] Callens (n 9)

[60] PC Ippel, 'Gegeven: De Genen; Morele en juridische aspecten van het gebruik van genetische gegevens'(<cbpweb.nl> 1996) 8

genetic effects to employees. So while genetic screening will be quicker linked to a case of genetic discrimination, there could be cases in which genetic monitoring might result in genetic discrimination. The purpose of genetic monitoring is to prevent or reduce the risk of a disease caused by genetic damage. Though genetic changes such as chromosomal changes are often associated with exposure to radiation, little is known about the about which changes are predictive of subsequent disease risk. However, since the relationship between those changes and their subsequent disease risk still needs research, the use of genetic monitoring results to make employment decisions are rarely justifiable[61]. Therefore, the focus of the examination on protection against individual genetic discrimination will be on genetic screening[62]. While providing protection of the privacy of an individual, the Act does not prohibit the discrimination of a prospective employee with certain unwanted genetic features as compared to a 'genetically clean'[63] prospective employee. In case of misuse of genetic information, the only protection that can be derived from the Act is an indirect form of protection. This protection consists of the prohibition of the collection of certain data, which renders the selection of employees based on certain types of data impossible. The advantage of this prohibition of collection of certain data is some form of protection against the misuse of genetic information. However, the disadvantage of the prohibition is the tension of the Act with the Equal Treatment Act on Disability or Chronic Illness, which urges employers to generate adjustments, when needed[64]. If that information cannot be collected, than no measures can be taken in order to generate adjustments. Also, the Act has a limited scope which consists of medical examinations when entering into employment or getting a private (pension) insurance[65]. Therefore, due to its limited scope and disadvantageous form of indirect protection, it could be concluded that the Medical Examinations Act, does not offer adequate protection against individual genetic discrimination[66].

The purpose of the Act of Agreement on Medical Treatment[67] was finding a good balance between the protection of individual privacy interests of patients and the public's interest of an unhindered scientific research. In order to perform a research the scientists have to get the patient's consent, which must be explicit and sufficiently specific. Before consenting, the patient must receive a minimum of information comprised of the nature, content and the purpose of the research, the importance of the research and the expected duration of the research. Particular aspects of the research such as the character (hereditary research) or the scope on which it is takes place (national or international), can expand the duty of informing the patient. There are two exceptions to the duty to inform, because the requirement of consent can substantially

[61] Department of Labor e.a, '*Genetic Information and the Workplace*', (<http://www.genome.gov/10001732> 1998)
[62] The relation between genetic monitoring and its effect on employment decisions might be an interesting subject for another research.
[63] 'Genetically clean': without certain unwanted or undesirable features.
[64] Gevers (n 5) 101.
[65] ibid 108.
[66] Article 5 of the Medical Treatment Act prohibits questions concerning hereditary diseases, unless the disease has manifested itself. However, this prohibition only applies in case of a medical examination needed to apply for or alter insurance. The prohibition does not apply in case of a medical examination needed for employment.
[67] Act of Agreement on Medical Treatment 1994 (*Wet op de geneeskundige behandelingsovereenkomst (WGBO))*

impede the possibility to research. Without research the possibility of improvements will lessen. The first exception, Article 458 of Book 7 of the Dutch Civil Code, occurs if asking for consent is reasonably impossible. The second exception occurs when asking for consent is a possibility, but considering the nature and purpose of the research, it cannot be reasonably asked of the researcher.[68] If however the exceptions are used to evade the patient's consent, then it will have consequences for the types of data that can be obtained[69]. A problem resulting from the patient's consent is that once it is given, the consent legitimizes any type of intended provision of data[70]. So the difficulty within the consent is that a patient does not and probably cannot know beforehand what kind of consequences his or her consent will have. Both article 11 (1) of the PDPA and the Code of Conduct for Health Research of Federation of Medical-Scientific Associations[71] offer a solution to this problem. However, according to Ploem[72] it is doubtful that the code of conduct is known to physicians and researchers and is applied during the entire process of research. Thereby, when the research is conducted internally, the Act of Agreement on Medical Treatment has no (explicit) preconditions, since it is not contrary to professional secret. Such a situation renders the Act of Agreement on Medical Treatment not applicable. Also, the Act of Agreement on Medical Treatment does not impose conditions on independent bodies[73]. The Code of Conduct has, in Article 2.12, an obligation to review the research of independent bodies. However the question remains if this obligation is carried out[74]. In conclusion, the Act of Agreement on the Medical Treatment does not offer adequate protection against individual genetic discrimination. The focus of the Act is clearly to offer guidelines to researchers and not to offer rights to patients. In summary, the protection of genetic information, in order to prevent individual genetic discrimination, can mainly be found in the PDPA. The PDPA offers only partial protection of genetic information, which amounts to protection of health and racial or ethnic origin. Although this protection is only partial, it can be invoked before a judge by use of Articles 49 and 50 PDPA in conjunction with Article 6:162 of the Dutch Civil Code.

iii. Risks or problems involving privacy protection

Firstly, the use of the right to privacy has the risk that the rightful owner experiences exclusion, because he/she decided to refuse consent to share personal information. The exclusion would, in such a case, result from suspicion: if a person does not want to share, he/she probably has

[68] MC Ploem, 'De regeling inzake het gebruik van patiëntengegevens voor wetenschappelijk onderzoek in de WGBO – Tijd voor herziening?' (Boom Juridische Uitgevers Tijdschriften 2006 issue 6) 401-403.
[69] For example, in case of the second exception only coded data can be provided.
[70] Ploem (n 80) 404.
[71] Code of Conduct for Health Research of Federation of Medical-Scientific Associations (*Gedragscode Gezondheidsonderzoek van de Federatie voor Medisch-Wetenschappelijke Verenigingen)* <www.cbpweb.nl/downloads_gedragscodes/gedr_FMWV.pdf>
[72] Ploem (n 80) 406-407
[73] The independent bodies do have a duty to report to the College of Data Protection (*College Bescherming Persoonsgegevens,* www.cbp.nl), unless Article 30 of the *Vrijstellingsbesluit Wbp* applies.
[74] Ploem (n 80) 407

something to hide[75]. Secondly, genetic information can manifest itself in external and internal differences from what is perceived as 'normal'. This can result in two types of situations, but involve the same problem[76]. In the first situation person A, the recruiter, is familiar with the genetic information of person X, the candidate, because of a previous acquaintance or because of hearsay. The privacy of the genetic information is invaded, because there was no way to prevent the knowledge about the medical condition of person X. The only way to 'protect' the privacy of person X would be to create a fictional situation, in which person A would need to feign ignorance about the genetic information of person X. However what if the second situation would take place: the genetic information of person X is clearly visible, because of the external manifestation of certain symptoms. It would again ask for a fictional situation in which person A should try to pretend not to notice the clearly visible information and not take it into consideration while making a decision about hiring or not. Situation 1 may be susceptible for protection, but in case of situation 2, data protection cannot provide adequate protection.

C. Interim conclusion

To summarize, the most effective protection based on Dutch hard law against discrimination on the grounds of individual genetic information can be found in one article: Article 6: 162 of the Dutch Civil Code. Dutch hard law offers two kinds of protection: protecting an individual against the discriminating act or protecting the individual against the possibility of the discriminating act. The first type of protection can be found in Article 6:162 DCC which can be invoked when a person suffers damages. It might be best to see this article as a means to an end. The Equal Treatment Act on Disability or Chronic Illness offers protection against discrimination on the basis of disability or chronic illness. So a part of genetic information is protected by this act. If it is infringed upon an individual can take their case to the Equal Treatment Committee who will issue a judgment that is not legally binding, but can serve as information that a Dutch judge has to bear in mind. In order to bring a case before a national court on the basis of the ETA on grounds of disability or chronic illness, to the use of Article 6:162 DCC is necessary. Next to the special anti-discrimination law, the Dutch Constitution offers in its first Article the possibility to see individual genetic information as a ground on which discrimination can occur. In other words, individual genetic information could be placed under 'any other grounds', which would result in protection against individual genetic discrimination.

Next to anti-discrimination law, there is a second kind of law that aims at preventing discrimination: privacy law or data protection law. By ensuring the privacy of personal data, the possibility of other unauthorized persons to know about that data is prevented. The Dutch Personal Data Protection Act has implemented the rights resulting from Directive 95/46/EC[77], resulting in the possibility to sue the controller of the processing of your data for any event after

[75] Gevers (n 5) 35
[76] ibid 38-39
[77] Directive (EC) 46/1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data (Data Protection Directive) [1995] OJ L 281

which you suffer damages. According to article 49 and 50 PDPA a data subject that suffers from any event in which his/ her data is handled unlawful, can start a procedure based on tort, Article 6:162 DCC. However, in case of misuse of sensitive data, more specifically a part of a person's genetic information, by the (future) employer, the (future) employee cannot invoke the protection of the PDPA.

1.2 European Hard Law

This section will start a quick summary of the definition of European hard law. After which, in the first subsection, the two indicated types of law, of which protection against discrimination consists, will be examined. In the second subsection, law, that prohibits discrimination, will be addressed. Thereafter, law that protects the individual's privacy will be researched in the third subsection. After a short interim conclusion, the comparison of the protective value of hard law, on both the national and the European level, regarding individual genetic discrimination, will be made in the conclusion of this chapter.

A. Short definition of European hard law

Hard law on a European level consists of primary community law and secondary community law. Primary community law consists of Treaties, of which the Member States are the legal subjects. These treaties assign obligations to the Member States that individuals cannot invoke before a court. However, secondary community law consists of directives, regulations, (individual or collective) decisions, recommendations and opinions. Article 288 TFEU clarifies that regulations are binding in their entirety and are directly applicable. Directives are addressed to the Member States and are binding as to the result that should be achieved. However, directives are not directly applicable, but need to be implemented by the Member States[78]. A decision is also binding in its entirety, but shall only be binding to those who are addressed by it. These different forms of hard law are adopted by the European Union's institutions[79] in order to exercise the Union's competences. Hard law can be established by two kinds of legislative procedures: the ordinary legislative procedure, Article 289 (1) TFEU, and the special legislative procedure, Article 289 (2) TFEU. Which procedure should be used depends on the Article in the Treaty that authorizes the decision[80].

B. First type of law: prohibit discrimination

In this subsection European non-discrimination law will be researched. As mentioned in subsection 1.1, non-discrimination law consists of anti-discrimination law and equal treatment law. According to Bell the majority of Member States focuses on anti-discrimination laws, but that means there also is a minority that either focuses on equality laws or a mix of both laws. Since European hard law needs to represent a diversity of national legal traditions, both types of

[78] Paul P Craig ea, *EU Law: Text, Cases and Materials* (Oxford University Press 2008)
[79] See Article 13 TEU: '(..)The Union's institutions shall be: the European Parliament, the European Council, the Council, the European Commission, the Court of Justice of the European Union, the European Central Bank, the Court of Auditors (..)
[80] See www.europadecentraal.nl and search for 'Vaststelling wet- en regelgeving' (NL)

law will be important to research. The research in this subsection will start with anti-discrimination laws, such as the TFEU, the EU Charter of Fundamental Rights and the European Convention of Human Rights. Secondly, equal treatment law such as Article 26 ECHR and Directive 2000/78/EC will be examined. This subsection will be concluded with a short interim conclusion.

With regard to anti-discrimination the TFEU has Article 18 (former Article 12 TEC) and Article 19 (former Article 13 TEC). Article 18 TFEU deals with discrimination regarding nationality, whereas Article 19 TFEU functions as an extra safety net with specific dimensions. The additional protection against discrimination offered by Article 19 (1) TFEU consists of the grounds of sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation. The article has no 'any other grounds'-category, such as Article 1 of the Dutch Constitution, which limits its protective value against individual genetic discrimination. Genetic information does involve obvious genetic features, such as for example sex, racial or ethnic origin or age. However, the situations in which protection is needed, is when genetic information concerns a genetic predisposition to a disease. In such a case the ground of 'disability' could offer partial protection, if the predisposition would manifest itself. Indeed, if a case would take place, involving those grounds, Article 19 (1) TFEU might offer protection. However, a lot of genetic information is not all that obvious and needs a more specific ground to invoke protection against discrimination. Article 19(2) TFEU shows the dependence of the European Union on the competences it has been delegated by the Member States, which it cannot go beyond.. Another interpretation of Article 19(2) TFEU is, that when a Member State initiates protection on another ground than mentioned in Article 18 or 19 TFEU, and if the purpose of that action is in accordance with the objectives of paragraph 1 (Article 19 TFEU), which consists of the prohibition of discrimination on other grounds than nationality, then the European Union may adopt basic principles of Union incentive measures. This interpretation of Article 19(2) does not offer reliable protection against individual genetic discrimination, but an opening to improve protection could be imagined. Next to Articles 18 and 19, Article 153 (1) TFEU can also be seen as prohibiting discrimination, more specifically in the workplace, since it provides on matters such as 'improving the working environment', 'working conditions' and the 'integration of persons excluded from the labor market'. Discrimination in the workplace would appear to fall within all of these headings[81]. However, adequate protection is not offered in case of discrimination on the grounds of individual genetic information by for example an employer towards an employee. Article 230 TFEU and case law[82] provide that when three conditions have been met a Member State can be held liable. Firstly, the rule upon which infringement took place aims at conferring rights to individuals. Secondly, the infringement can be charged to the Member State and contains a sufficiently serious breach. Thirdly, there should be a causal link between the infringement and the damage. An employee cannot directly use Article 230 TFEU to hold the infringing employer liable. Arguably, an employee could hold a Member State liable for

[81] Bell (n 41) 130
[82] See www.europadecentraal.nl and search for 'Aansprakelijkheid van decentrale overheid' (NL)

not offering adequate protection against discrimination by the employer. However, this option does not offer adequate protection in a horizontal relationship, since an individual will not be willing to involve a Member State in a case that is between an employer and employee.

An improvement regarding protection against discrimination of the grounds of genetic information is Article 21 (1) EU Charter of Fundamental Rights. The Charter lists a number of grounds of discrimination which are prohibited: sex, race, color, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation. Most interesting with regard to this thesis is the ground of 'genetic features'. Gostin[83] defines genetic features, as features over which an individual has no control. These genetic features can be genetic traits, conditions or predispositions, of for example Huntington's disease, but also genetic determinants for blue eyes or black hair. However, the genetic features that have the most potential to become reasons for discrimination will be those that are traits, conditions or predispositions. Also, Gostin[84] says that, discrimination based on those genetic features, actual or perceived, can be as unjust as that based on race, gender or disability. Therefore, content-wise, the EU Charter of Fundamental Rights could potentially offer adequate protection against individual genetic discrimination. Even so, Article 51, the Charter only addresses the institutions and bodies of the European Union. Invoking the protection of Article 21(1) of the Charter, in a horizontal relationship such as, for example, that between employer and employee will not be possible.

Even though not all Member States of the European Union have signed or ratified the European Convention on Human Rights, they all are members of the Council of Europe[85]. Therefore, it is important to search the ECHR for protection against discrimination on the grounds of individual genetic information. The Netherlands has ratified the ECHR and it falls within the category European hard law, albeit not from European Union as a source. However, since the purpose of this research is to find out if a Dutch national is protected adequately, it is important to take a look at Article 14 ECHR. The Article is meant to protect the use of the rights and freedoms from the ECHR against discrimination on the grounds of: sex, race, color, language, religion, political or other opinion, national or social origin, associated with a national minority, property, birth or other status. In the case of Kiyutin v. Russia[86] the applicant, born in Uzbekistan, applied for a residence permit in Russia in order to live there with his Russian wife and daughter. For a residence permit a medical examination was needed during which procedure he tested positive for HIV. On account of those results his application was refused. Kiyutin took his case to the European Court of Human Rights and invoked Article 14 ECHR in combination with Article 8 ECHR. In other words, he argued that his health status fell under the ground 'or other status' in Article 14 ECHR and that the discrimination on this ground infringed his right to family life, Article 8 ECHR. In section 56 the Court agreed, since the list of Article 14 ECHR is

[83] L. Gostin, 'Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers' (1991)17 AM JL & MED. 112
[84] Gostin (n 99) 112
[85] See www.coe.int
[86] *Kiyutin v. Russia* no 2700/10 (ECHR, 10 March 2011)

not exhaustive, because of the words 'any grounds such as'. In earlier cases the words 'other status' were given a wide meaning and their interpretation has not been limited to characteristics which are personal in the sense that they are innate or inherent. The Court continued in section 57 that although Article 14 does not expressly list a health status or any medical condition among the protected grounds of discrimination, the Court has recently recognized that a physical disability and various health impairments fall within the scope of this provision.

This case is important with regard to the subject of individual genetic information, since Article 14 ECHR needs one of the other rights or freedoms from the ECHR to be effective; it cannot be invoked independent of any other article. However, the European Court of Human Rights explains in Kiyutin v. Russia[87] that 'other status' can protect medical conditions or a person's health status. Thereby the Court also indirectly says in section 56 that genetic information might belong to this ground. Since 'other status' is not limited to innate or inherent personal characteristics it could also protect genetic information. Even though Article 14 ECHR sounds promising especially in combination with Article 8 ECHR, the right to private and family life, there are some difficulties with this kind of protection against discrimination. The difficulties lie with the admissibility criteria of Article 34 and 35 ECHR. A case that has been brought before the European Court of Human Rights needs concern a violation of one of the ECHR-rights and the applicant needs to be the victim of this violation. The first difficulty is the requirement that the violating party needs to be one of the High Contracting Parties. In other words, in case an employee has been discriminated by an employer, he/ she cannot bring her case before the Court. In principle, the employee could take the High Contracting Party, responsible for not protecting against the possibility of discrimination, to Court. However, as argued earlier concerning the TFEU, no adequate protection can be found in a case concerning a horizontal relationship when the protection focuses on a vertical relationship.

In conclusion, the examined European hard law, that has the purpose to prohibit discrimination, does offer possibilities for protection. However, when not the content but its protective value in a horizontal relationship is examined, the European hard law is found lacking. As mentioned before law on non-discrimination can be found in the form of anti-discrimination law or law that focuses on equal treatment. First, the TFEU only offers protection in the sphere of equal treatment if it concerns the equality of man and woman. Secondly, Article 26 of the EU Charter on Fundamental Rights says that the European Union respects and recognizes the rights of persons with a disability. Since the article is placed within Chapter III – Equality, despite the vague wording of Article 26, it can be argued that it actually offers protection on the grounds of equality. However, the only way a part of genetic information can be protected by this article, is in the situation that a disability stems from an inherited disease or medical condition. The protective value of this article is vague and incomplete at best. Thirdly, the ECHR does not include equal treatment in its articles.

[87] Ibid (n 102)

The European Union has issued several Directives focusing on equal treatment. However, Directive 2000/78/EC[88] is the only directive that is of interest regarding the protection of genetic information. The purpose of the Directive is to combat discrimination on the grounds of religion or belief, disability, age or sexual orientations as regards employment and occupation, with a view to putting in effect in the Member States the principle of equal treatment. Article 2 of the Directive explains that the principle of equal treatment, in this Directive, means no direct or indirect discrimination on any of the grounds mentioned in Article 1 of the Directive. Article 8 of the Directive places minimum requirements on the Member States, but emphasizes that more protection is allowed and that if a higher level of protection already exists, then there is no need to lower that protection in order to implement the Directive. Thereby, Article 9 and 10 of the Directive explain that the protection offered by the Directive is applicable in horizontal relationships. Equal treatment-wise, the Directive offers an interesting amount of protection. However, in comparison to the above mentioned European anti-discrimination law, the Directive does not offer some kind of rest category in which genetic information could be placed. Just as the EU Charter on Human Rights, the only protection against discrimination on the grounds of genetic information that could be offered is discrimination on the ground of disability, if that disability stems from genetics. In other words, if the disability was inherited it could be said that at least a part of genetic information is protected by this Directive.

In summary, European hard law that has the object to prohibit discrimination, be it via anti-discrimination law or equal treatment law, does offer promising possibilities for protection. However, to say the protection is adequate in a horizontal relationship, such as that between employer and employee, is an overstatement.

C. Second type of law: protect privacy

Though the primary source of Community law, the TFEU, does not mention the subject of privacy, both the EU Charter on Fundamental Rights and the European Convention on Human Rights devotes an article to the subject. Firstly the Charter will be examined on protective value, after which the Convention will follow and this subsection will be finished with a research of Directive 95/46/EC.

Privacy is the subject of Article 7 and 8 of the EU Charter on Fundamental rights. Article 7 says the needed respect for private and family life, whereas Article 8 expounds on the protection of personal data. In the case that discrimination on the grounds of individual genetic information takes place, indeed the privacy of that person or rather the private life of that person has been invaded. However, the effective protection of the personal data concerning genetic information, in order to prevent the invasion of a person's private life, Article 8 is needed. Article 8 protects personal data in the sense that it lays down how the data can be processed and who has the right to access that data. First of all, in order to process personal data the consent of the data subject, the individual whose personal data is being processed, is needed. Secondly, the processing of the data needs to have specified purposes. Concerning the right to access those

[88] Council Directive (EC) 78/2000 establishing a general framework for equal treatment in employment and occupation [2000] OJ 303/16

data, the data subject has implicit right to access it and to have it rectified if necessary. According to Article 47 of the Charter, if the right to private life or protection of personal data has been infringed upon, this results in a right to an effective remedy. For example, if an employer suddenly holds personal information about his employee, then that employee has the right to an effective remedy. However, even if the employee has a right to an effective remedy, the addressees of the Charter, Article 51, are the institutions and bodies of the European Union. Therefore, an employee is not able to invoke this right within a horizontal relationship.

The European Convention on Human Rights has the same problem. Article 8 offers a right to respect for private and family life, which can be protected by invoking Article 14. However, Article 34 and 35 of the Charter, regarding admissibility, only mention a High Contracting Party as a possible violator of a person's rights. Directive 95/46/EC can be called promising in the light of privacy protection. The Directive aims at protecting the fundamental rights and freedoms of natural persons, and in particular their right to privacy with respect to the processing of personal data. Personal data, Article 2(a), concerns any kind of information relating to an identified or identifiable natural person. An identifiable person is one who can be identified, directly or indirectly, in particular by reference to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity. Individual genetic information is capable of identifying a person and would in this situation be placed under the physiological or physical factor. The Directive mainly expounds on the rules of when to consent and how to process data. However, most interesting are Articles 17, 22 and 23, since those explain what happens in case of data not being processed, but lost, altered, disclosed without authorization, if transmission of data over a network takes place or if any other kind of unlawful forms of processing take place. In case any of the in Article 17 mentioned actions take place, the data subject has a right to remedy for any breach or right guaranteed by the national law, that was adopted pursuant this Directive, applicable to the processing in question, Article 22. In any case, the controller of the data processing can be held liable, according to Article 23, unless the controller can prove he is not responsible for the event giving rise to the damage. The Directive is not directly applicable, but has been implemented into the Personal Data Protection Act.

D. Interim Conclusion

The protection offered by European hard law is different from the national hard law in the sense that European hard law addresses Member States and national hard law addresses its nationals. In order for European hard law to have direct effect, they have to be either implemented by the Member States into national law or are of the very nature to have direct effect. Regulations of the EU belong to the second kind of European hard law and automatically have direct effect. However, in this thesis only treaties and directives were found concerning protection against discrimination. Just as with national hard law, the protection offered by European hard law is either focused on prohibiting discrimination or on protecting privacy of personal data. The most promising European hard law, in the sense of possible protective value, is derived from the EU Charter on Fundamental Rights or from the EU Convention on Human Rights. Article 21(1) of

the EU Charter on Fundamental Rights has ‘genetic features’ as a possible discrimination ground. The presence of such a specific genetic information related term allows for hope that at least a very promising part of genetic information could be protected by the article. The EU Convention on Human Rights created a rest category by adding the words ‘or other status’ to the discrimination grounds. As the European Court for Human Rights ruled in the Kiyutin v. Russia-case ‘other status’ can concern for example someone’s medical or health status. In section 56 en 57 they allowed for a very broad definition of ‘other status’. So it would not be a very far cry from allowing genetic information, as part of a person’s medical status. The privacy-related articles from both the Charter as the Convention mainly focus on the right to a private life. However, Article 8 from the Charter offers better protection of a person’s privacy since it concerns the protection of personal data. The best protection is offered in the Privacy Directive (95/46/EC). Articles 17, 22 en 23 concern unlawful or unauthorized use/ actions with personal data and ways the data subject can sue for damages. The content of the articles has already been transposed to national hard law and already have effect.

1.3 Conclusion

In conclusion, does Dutch hard law, in comparison with European hard law, regarding individual genetic information offer adequate protection against discrimination? Dutch hard law does not allow for as much discretion as European hard law does. For example, the use of words such as ‘genetic features’ or ‘any grounds as such’ or ‘other status’ implies that the European legislature is more willing to allow for other discrimination grounds than the Dutch legislator. Probably the difference, concerning this willingness to be open to other interpretations, lies within the fact that the European legislator has to allow for a large diversity of national law traditions. However, on both levels, hard law is conservative on protection against individual genetic discrimination. The current grounds of discrimination are able to protect obvious parts of genetic information. Genetic information does have obvious features, such as gender, color or some forms of disability, but there are important gaps within this protection. The current protection on individual genetic discrimination is not yet adequate. First of all, there is no uniform definition of genetic information. Secondly, genetic information seems to be partially protected, but is mainly ignored, when compared to the current discrimination grounds. Thirdly, currently the only satisfying way, in which to prohibit discrimination, is by suing for damages, by means of Article 6:162 of the Dutch Civil Code. The other articles relating to discrimination or protection of personal data are either not applicable in a horizontal relationship, or need to rely on a tort action to invoke their right to protection. Therefore adequate protection against discrimination on the grounds of individual genetic information does not exist within Dutch or European hard law.

2. Dutch and Global soft law concerning the protection against individual genetic discrimination

In this Chapter the protection by soft law against individual genetic discrimination will be examined. The purpose of this research is concluding if the current Dutch system of hard and soft law offers adequate protection against genetic discrimination. Since the European legislature has not created a source of soft law with the possibility to protect (parts of) individual genetic information, international soft law will be examined. Firstly, this Chapter will start with a refreshment of the definition of soft law, after which national soft law will be examined. This section on national soft law will be divided in three subsections, namely: labor unions, companies and other sources. A short interim conclusion will end this section on Dutch soft law. Thirdly, international soft law is examined, will be divided in four subsections. In the first subsection the ILO's Code of Practice on Protection of Workers' Personal data will be examined, the second subsection will be dedicated to the Universal Declaration on the Human Genome and Human Rights, the third subsection will examine the International Declaration on Human Genetic Data and the fourth subsection will be dedicated to the Universal Declaration on Bioethics and Human Rights. This section on international law will be concluded with a short interim conclusion. The Chapter will be ended with a conclusion on the question if Dutch soft law offers, compared to international soft law, adequate protection against individual genetic discrimination.

2.1. Definition of 'Soft law'

Soft law consists of rules of personal conduct, secured in instruments that as such do not possess any legal binding, but nevertheless, can have certain (indirect) legal effects in practice. Dutch soft law can mainly be found in codes of conduct, company codes. European soft law could be found in the form of recommendations, notices, resolutions, conclusions, guidelines, declarations, programs, codes of practice etcetera. The common denominator of these European instruments is that they all are created by the European Communities' institutions and have not been attributed legally binding force.

2.2. Dutch Soft Law

In this section, soft law such as codes of conduct from labor unions and companies, and other sources will be explored. In this section, the examined codes of conduct will involve either anti-discrimination guidelines or guidelines regarding the processing of personal data. Since there are a lot of labor unions and companies that provide codes of conduct, the focus will lie with the largest and/or most well-known organizations. This section will be concluded with a short interim conclusion.

A. Labor Unions

In the Netherlands the two largest labor unions are the FNV and CNV[89]; therefore the codes of conduct or regulations of these unions will be researched, since the largest percentage of the work force will be covered by those codes of conduct.

Undesirable behavior

The FNV and CNV[90] have created a regulation to prevent undesirable behavior which includes a code of conduct, a regulation concerning complaints and a regulation concerning counselors. The most interesting information can be found in the code of conduct, which is based on Articles 4, 5 and 9 (5) of the FNV or CNV Statutes. Both unions hold equality of all people in the highest regard and resists discrimination on the grounds of religion, belief, race, gender, sexual orientation, nationality, origin, marital status, health, handicap, age or any other improper ground[91]. Discrimination is undesirable behavior to the extent that it is untrue, offensive or derisive. In order to prevent such behavior the FNV or CNV conduct a preventative policy by sanctioning undesirable behavior[92]. The scope of the FNV code of conduct only goes as far as the work organization and within the organization, employees and members. The FNV or CNV work organization is responsible for the execution of the FNV- or CNV policy[93]. The code of conduct states that if an employee signals a form of undesirable behavior, such as discrimination, then he/ she should deal with that situation adequately, possibly with the help of a manager. The victim of discrimination has the option to either talk to a counselor or to issue a complaint. According to Article 5 of the Regulation on Complaints the conditions of a complaint are: the complaint needs to be in written form, signed, mention against which persons the complaint is issued and a description of the undesirable behavior. After issuing the complaint, it will be examined by the Research Committee, who will write a report on the matter, which will be sent to a number of parties and can have dire consequences for those that are addressed by the rapport.

So the FNV/ CNV have left a margin of space for protection against discrimination on the ground of individual genetic information, by using the words 'any other improper ground'. Thereby, it also offers protection against discrimination on the obvious forms of individual genetic information, by condemning discrimination on the grounds of health and handicap. The problem with protection against discrimination on the grounds of FNV/ CNV soft law is the scope of the Regulation on Undesirable Behavior. According to Article 1, Section 2, Subsection 3 of the Regulation on Complaints, a person can complain about the behavior of a member or employee of the union, insofar as the undesirable behavior concerns or results from activities or situations connected to the association or work relationship. The latter is a relatively vague

[89] See <http://www.mkbservicedesk.nl>
[90] The FNV and CNV created this Regulation on Undesirable Behavior together.
[91] FNV Bondgenoten, 'Regeling tot voorkoming van ongewenst gedrag'(<www.fnvbondgenoten.nl> 'Regeling tot voorkoming ongewenst gedrag') 2
[92] Sanctions mostly are seen as punishment for unwanted behavior, however, the purpose of sanctioning is to prevent unwanted behavior by threatening with some form of punishment.
[93] FNV Bondgenoten (n 107) 2

concept, because it is not really clear if these activities or purely the connection with the association or work relationship, also concern the application for employment. A work relationship is generally defined as the relationship between employer and employee. So to summarize, the FNV/ CNV offers protection to their members, employees and other persons that are affected by undesirable behavior. However, it is not clear if the FNV/ CNV offers protection during the application for employment. The FNV/ CNV offer possibilities for the protection of a part of individual genetic information by using the grounds health, handicap and any other improper grounds. Thereby, the actual value of the code of conduct is still vague, since the entire complaints procedure is processed internally and no actual sanctions are written down in the Regulation on Undesirable Behavior. However, case law has shown that it is possible to base a case on hard law, but use soft law as a reference tool[94] or a complaint based on soft law might result in an act of tort, Article 6:162 of the Dutch Civil Code[95]. In conclusion, in itself the FNV/CNV's codes of conduct do not offer adequate protection against individual genetic discrimination. However, it could be used as a reference tool in legal proceedings based on hard law.

Processing of personal data

As was the case with hard law, such is also the case with soft law: there are two kinds of ways to protect against discrimination against individual genetic information. First, there is the way in which the discriminating act is prevented or punished. Secondly, there is the way of privacy: the only way in which your sensitive data can be used for discrimination is when your sensitive data is inadequately protected. The FNV/ CNV also wrote a model for regulation on privacy, which is connected to and supplements the PDPA. However, in the light of protection against discrimination on the grounds of individual genetic information, the protection offered seems meager. The regulation does not speak of special or sensitive personal data and only offers safeguarding of legal rights, when those legal rights belong to people employed by or working for organization X. Thereby, the regulation on privacy is only a model for a code of conduct on processing personal data. So in conclusion, the Model for a Regulation or Code of Conduct on the processing of personal data cannot offer protection, only inspiration. Therefore, it can be concluded that the produced soft law by the labor unions cannot be seen as sources of adequate protection against discrimination on the grounds of individual genetic information.

B. Dutch companies

Soft law created by companies concerning protection against discrimination, can be derived codes of conduct, which are instruments used to implement rights and/ or freedoms created by

[94] Sector Kanton Rechtbank Arnhem, 05-06-2007, LJN BA7119, procedure concerned the severance of the employment agreement because of the employee's ancillary activities, which were in violation of the code of conduct and article 2.5 of the CAO Woondiensten. Sector Kanton Rechtbank Alkmaar, 06-05-2010, LJN BN1637, procedure concerned the severance of the employment agreement, in which the employer based his plea on norms of the company's code of conduct. The plea failed because of a discrepancy between the company's code of conduct and the company's policy. The employee acted according the code of conduct and therefore the court denied the employer's plea. (NL)

[95] de Fey (n 30) 116

the Dutch legislator. The creation of a code of conduct can be said to fall within the obligation of an employer to act as a good employer, Article 611 of Book 7 of the Dutch Civil Code. Law is created to offer rights and freedoms, that are applicable in numerous situations, but it often is not specific enough to be used under certain circumstances. Therefore, in order to align their company's policy with relevant law, employers create codes of conduct. The alignment is not only necessary to prevent unwanted behavior of infringements on privacy, but also has the positive effect of changing society's perception of that company.

Undesirable behavior

It can also be said that if both employers and employees are aware of a policy that prevents and/ or strictly prohibits discrimination, the unwanted behavior of discrimination will occur less often. This would be because he positive effects of a diminished number of discrimination cases create happier employees, whom are more productive[96]. The examined codes of conduct focus on the processing of data, since the FNV/CNV code of conduct is applicable in almost all branches.

Processing of personal data

The FNV argued in their Evaluation on the Personal Data Protection Act that the rules on the processing of personal data should be more extensive. Their main arguments focused on the lack of rules on work-specific privacy problems. Especially the protection and security of personal data concerning the health of employees is on an impressively low level. Also, the FNV argues that the use of personal data that is obtained by privacy-infringing means should be prohibited by the legislator[97]. Thereby, the act of acquiring and the content of personal data stored by third parties should be with the consent of the individual, from whom the data originates. The FNV also wants companies to hire or instate a complete impartial counselor in order to prevent situations in which the counselor both obtains personal information from an employee and needs to perform health tests commissioned by the employer. However, these arguments have as of yet not had a great influence on current existing codes of conduct. For example, the College of Data Protection wrote a brochure on how to write a code of conduct concerning the protection of personal data as meant in the PDPA. In order to create clarity for employees about the way in which the company wants the general standards of the PDPA to be executed, a company regulation or a code of conduct is needed. The differences between the two are the conditions of Article 25 PDPA.

For example, a company regulation consisting of rules on the control of e-mail,will, in principle, not be examined by the Committee on the Protection of Personal Data . However, codes of conduct relating to certain norms, originating from the PDPA, that cover an entire sector or branch of industry, will probably, because of its importance, Article 25 PDPA, be examined by that Committee[98]. Since the processing of personal data is a very sensitive

[96] See www.art1.nl, search 'Gedragscodes'.
[97] Catelene Passchier, 'Reactie van de FNV op de Evaluatie Wet bescherming persoonsgegevens' (home.fnv.nl/arbeid/2009/privacy/Reactie_FNV_op_evaluatie_Wbp.pdf 2010) 2-4
[98] College Bescherming Persoonsgegevens, 'Gedragscodes; Bescherming van persoonsgegevens door zelfregulering' (www.cpbweb.nl, 'Gedragscode') 4

endeavor, the creators of codes of conduct should be very aware of the consequences, of not being in accordance with the PDPA. Thereby, since a code of conduct is designed to fit an entire branch of industry, it has a great effect on company policy and behavior. If the right to privacy, in the case of a code of conduct concerning personal data, isn't protected adequately, it may have alarming consequences. Regarding the scope of the code of conduct, it should be noted that a branch of industry is defined either as a more or less homogeneous entity of companies, institutions or professionals that perform similar activities, and are confronted, as a result, with the same privacy issues or defined as companies and institutions that are part of a chain of activities wherein there is a certain hierarchy. Further, the entity responsible for the code of conduct draft should be representative in the sense that they have a notable amount of members[99].

In conclusion, corporate policies concern internal rules on behavior, and are created by the company in order to comply with hard law. These policies should result in a raised awareness in the work environment of the sensitivity of certain personal data and the importance to refrain from undesirable behavior. Considering the protection against individual genetic discrimination, corporate policies do not offer adequate protection. For example, in a situation where in an employee is discriminated by the employer, the employee cannot bring a case before court based on a violation of the corporate policy. Also, next to the limited applicability of the corporate policy, the current content of codes of conduct does not offer the possibility of protection of individual genetic information.

C. Other sources

Soft law can originate from a variety of sources. Next to labor unions or companies there are numerous councils and other institutions, which provide their thoughts on the interpretation of relevant hard law.

Processing of personal data

In 2003 the Social-Science Council[100] created a recommendation for a code of conduct on use of personal data in scientific research. This recommendation emphasized that there are not only rules on how to obtain data, but also on secondary data use. In practice it is often more interesting to use already obtained data than to acquire new data, since it saves costs, is already of quality and is often of a high quantity. In addition the Council also created a Code on good behavior, which focusses on data, whereupon medical confidentiality applies[101]. The purpose of these codes of conduct is not only to clarify how to put law into practice, but also to raise the norms for the entire branch. Thereby, by offering a way to review the purpose of the use of data, the code of conduct can prevent the exclusion of certain data from research. In other words, if every scientist is aware on how the law should be interpreted, it is a lot easier to know how

[99] CPB (n 114) 7
[100] Social-Science Council (*Sociaal-Wetenschappelijke Raad)* www.knaw.nl.
[101] Sociaal-Wetenschappelijke Raad, 'Gedragscode voor gebruik van persoonsgegevens in wetenschappelijk onderzoek' (KNAW 2003) 9

acquired and/ or stored data may be used, without infringing on a person's rights or freedoms. The code also clarified what kind of personal data should be seen as sensitive data: religion or belief, race, political opinion, health, sexual life, personal data concerning the membership of a labor union, criminal records or data about wrongful or offensive behavior concerning an imposed prohibition following that behavior. If a person's actions, both variables being within the scope of the code of conduct, are contrary to the code of conduct, the victim of this behavior can complain to the Committee of Appeals. The regulation on the Committee of Appeals is applicable in this situation.

D. Interim Conclusion

The intention of using Dutch soft law to close the gap between hard law and practice is commendable, since it clarifies how to interpret hard law and how to act when a situation of discrimination or a potential infringement on a person's privacy occurs. However, though codes of conduct offer necessary guidelines in a work environment, a problem exists with how to handle an infringement of those instruments. Indeed, it is possible to lodge a complaint before the Committee on Appeals, or to talk with a counselor. However, the probability of a case being built on soft law will be small. The difficulty with soft law lays within the fact that mostly the consequences for discrimination or infringement of privacy, when solved within the company, are too light or even unknown. However, it might be unnecessary to change this in a companies' policy, since a victimized employee can always turn to hard law, in order to sue for damages. Also, as said above, case-law exists where a case is built on hard law, but the norms of hard law are clarified by the use of soft law instruments, such as codes of conduct[102]. Therefore, Dutch soft law does not offer adequate protection against individual genetic discrimination, but may be a welcome addition to adequate protection.

2.3. Global Soft Law

In the European Union soft law has three different functions: to raise awareness, to anticipate future developments and to stimulate national policy initiatives[103]. However, when looking for European soft law concerning data protection or non-discrimination, all that can be found are recommendations or declarations on equal treatment of men and women, or on the subject of race. Therefore, it might be interesting to widen the scope of this research slightly, to allow for international soft law to which Dutch soft law could be compared. This comparison is necessary to see if the protection by Dutch soft law against individual genetic discrimination is adequate, or if it should be altered. In the first subsection the ILO's Code of Practice on Protection of

[102] Sector Kanton Rechtbank Arnhem, 05-06-2007, LJN BA7119, procedure concerned the severance of the employment agreement because of the employee's ancillary activities, which were in violation of the code of conduct and article 2.5 of the CAO Woondiensten. Sector Kanton Rechtbank Alkmaar, 06-05-2010, LJN BN1637, procedure concerned the severance of the employment agreement, in which the employer based his plea on norms of the company's code of conduct. The plea failed because of a discrepancy between the company's code of conduct and the company's policy. The employee acted according the code of conduct and therefore the court denied the employer's plea.(NL)

[103] http://www.europarl.europa.eu/workingpapers/libe/102/text1_en.htm

Workers' Personal Data will be examined. The Netherlands became a member of the International Labor Organization on the 28th of June 1919. Therefore, it is interesting to examine this international soft law instrument on protective value, since the Code of Practice is addressed to ILO's member states in the form of a recommendation. Secondly, in the second, third and fourth subsections three declarations from UNESCO, a specialized agency of the UN, are examined on protective value against individual genetic discrimination. On the 1st of January 1947 the Netherlands joined the United Nations Educational, Scientific and Cultural Organization. Therefore, the three declarations on bioethics will be examined on protective value in case of individual genetic discrimination. This section will be concluded with an interim conclusion on the protection of international soft law.

A. ILO's Code of Practice on Protection of Workers' Personal Data

The ILO's document is not a legally binding instrument, and though drafted in 1997, it should still inspire the level of protection against individual genetic discrimination. When the FNV, in the subsection on labor unions, spoke of a more extensive kind of protection which was needed in the Netherlands, a reference should have been to this soft law instrument[104]. The ILO code of practice makes recommendations on the development of data protection provisions which specifically address the use of workers' personal data. The most important recommendations made by the ILO concerns gaps that as of yet have not been addressed by other types of hard or soft law. Firstly, the term "worker" that should not only includes *'any current or former worker'*, but also any '*applicant for employment'*. Secondly, according to 5.5 of the code of practice, the processing of personal data should not have the effect of unlawfully discriminating in employment or occupation. Thirdly, when collecting personal data, it should, in principle, be obtained from the individual worker. However, if it is necessary to collect personal data from third parties, the employer should meet the following conditions. The employer should indicate the purposes of the processing, the sources and means the employer intends to use, as well as the type of data to be gathered, and the consequences, if any, of refusing consent (6.2). Also, the employer cannot collect personal data concerning a worker's sex life, political, religious or other beliefs, or criminal convictions. In 6.7, the ILO emphasizes that medical personal data should not be collected unless it is in conformity with national legislation, medical confidentiality and the general principles of occupational health and safety, and only as needed in three circumstances. The first circumstance being to determine whether the worker is fit for a particular employment, the second to fulfill the requirements of occupational health and safety, and the third to determine entitlement to, and to grant, social benefits. In 10.8 and 10.9 the ILO clarifies what information would be exactly given to the employer, in case of a medical examination. The employer would only receive conclusions, devoid of any information of a medical nature, that indicate fitness or the fulfillment of requirements, etc.

In comparison to Dutch soft law, concerning data protection, the ILO's code of practice pays a lot of attention to the importance of adequately protecting medical personal data. Not only

[104] FNV (n 107)

does the ILO describe what rules should apply when collecting medical data, it also adds rules on how to store it. According to 8.2, personal data covered by medical confidentiality should be stored only by personnel bound by rules on medical secrecy and should be maintained apart from all other personal data.

In summary, the ILO recommends to be very careful when processing medical data. Next to collecting and storing data, there is also the issue of communicating personal data. Apart from the usual prohibition of communicating personal data to third parties without the worker's explicit consent, the ILO stresses that this prohibition should also apply in the relationship between two employers or between different agencies of government. Thereby, the ILO also realizes that a large number of workers are recruited by employment agencies, 13.1. So the scope of data protection should also include these agencies in order to offer adequate data protection.

B. Universal Declaration on the Human Genome and Human Rights

This Declaration was adopted and acclaimed by UNESCO's General Conference on the 11th of November 1997 and endorsed by the UN General Assembly in 1998. As a member of the UN, the Netherlands have endorsed this Declaration; however, the Declaration has not been implemented in Dutch hard law. Therefore, the examination of the protective value of the Declaration is purely fictitious and the focus will be on its content. Considering the content, the Declaration was created as a result of research of the human genome and the resulting prospects, which could improve the health of individuals and humankind as a whole. However, it could also impact the rights to human dignity, freedom and human rights, as it could result in all forms of discrimination based on genetic characteristics. In Article 2, not only the right to human dignity is protected but the condition 'regardless of their genetic characteristics' is added, to ensure that individuals will not be reduced to their genetic characteristics. Next to this extended respect for human dignity, Article 6 contains the prohibition of discrimination based on genetic characteristics, which could have the (intended) effect of infringing human rights, fundamental freedoms and human dignity. The declaration not only has an anti-discrimination article, it also has an article on the protection of genetic data, which must always be held confidential in the conditions set by law, Article 7. In Articles 14-23, States are recommended to protect and promote the principles of this Declaration. In conclusion, the Declaration acknowledges the existence of genetic characteristics and data, and the impact they could have on the right to human dignity, fundamental freedoms and human rights. However, no definitions are given by UNESCO, which creates very open norms for the above mentioned subjects. The advantage of these open norms could be that the Dutch legislator could create its own definition. The disadvantage would be that the step to create such a definition will not be easy, and the definition could vary within different countries.

C. International Declaration on Human Genetic Data

The International Declaration on Human Genetic Data was acclaimed and adopted by UNESCO's General Conference on the 16th of October 2003. Except for being one of the members who acclaimed and adopted the Declaration, the Netherlands has not taken any steps

towards implementation of the Declarations' principles. The Declaration was created to ensure the protection of human dignity, human rights and fundamental freedoms regarding human genetic data. Due to its sensitive nature, its predictive use for genetic predispositions and its hereditary impact, human genetic data should be handled carefully and protected adequately. This Declaration, as opposed to the Universal Declaration on the Human Genome and Human Rights, does clarify important definitions. In Article 2 (i) the definition of human genetic data is given: 'information about heritable characteristics of individuals obtained by analysis of nucleic acids or by other scientific analysis'. Also, in Article 4, the special status of human genetic data is emphasized. Though the International Declaration provides definitions, where the Universal Declaration on the Human Genome and Human Rights refrains from those, similarities can be found. The first similarity with the Universal Declaration on the Human Genome and Human Rights, is the realization that a person should not be reduced to his/her genetic characteristics[105]. Another similarity can be found in Article 7, which says that every effort should be made to ensure that human genetic data should not be used for purposes that discriminate in a (intended) way to infringe on human rights, fundamental freedoms or human dignity. However, where the Universal Declaration on the Human Genome and Human Rights only says what actions States should take, the International Declaration says in Article 23 that States should implement the principles set out in the Declaration, in accordance with the international law of human rights. In conclusion, the International Declaration clarifies more definitions concerning human genetic data, while offering similar protection of human dignity, fundamental freedoms and human rights as the Universal Declaration on the Human Genome and Human Rights.

D. Universal Declaration on Bioethics and Human Rights

On 19th October 2005 the Universal Declaration on Bioethics and Human Rights was acclaimed and adopted by UNESCO's General Conference. As one of UNESCO's member states, the Netherlands has also adopted the Universal Declaration. Though no further steps towards implementation have been taken by the Netherlands, the content of the Universal Declaration is interesting when comparing Dutch soft law in order to determine the adequacy of the protection against individual genetic discrimination. The purpose of the Universal Declaration is to examine ethical issues raised by rapid advances in sciences and technological applications, while protecting the principle of human dignity and respecting human rights and fundamental freedoms. This Declaration both protect the privacy of persons and the confidentiality of their personal information, Article 9, as it protects individuals and groups from being discriminated, Article 11. However, this Declaration does not specifically mention human genetic data or any related definition, as the other two UNESCO Declarations did, which reduces its protective value in case of individual genetic discrimination. Even though the content is less protective, the scope of this Declaration is more extensive than the scopes of the other two Declarations. Next to addressing States, this Declaration also provides, Article 1(2), guidance to individuals, groups,

[105] Article 3 of the International Declaration on Human Genetic Data

etcetera. In conclusion, this Declaration offers less protection against individual genetic discrimination than the other two Declarations, but has a more extensive scope.

E. Interim Conclusion

In retrospect, it could be said that current 'new' soft law is the outdated instrument, since a document originating from 1997 goes past their protection with a much more extensive amount of protection. The ILO's Code of Practice on Workers' Personal Data is important, since it offers a good perspective on personal data protection in a work environment. As a supplement, the Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data, provide for a clear perspective on the importance of protection the privacy and confidentiality of human genetic data, and to protect against discrimination based on human genetic data. Additionally, the International Declaration provides for a definition on human genetic data and the important status of human genetic data. In conclusion, those three instruments combined created a clear perspective on the importance of protecting human genetic data in a work environment. Considering the scope of these soft law instruments, the Universal Declaration on Bioethics and Human Rights offer an improvement, as it not only addresses States, but also individuals, groups, communities, institutions and corporations, Article 1(2).

2.4. Conclusion

This chapter examined whether Dutch and International soft law could offer adequate protection against individual genetic discrimination. In comparison, there really is one major, important, difference as Dutch soft law only offers a general kind of protection against discrimination and misuse of personal data, whereas the International soft law instruments provide for very specific protection. Thereby, discrimination grounds mentioned in Dutch soft law originate from Article 1 of the Dutch Constitution. However, while Article 1 of the Dutch Constitution offers an extra category, Dutch soft law only offers an exhaustive list of grounds, which has its effects on the adequate protection against individual genetic discrimination. The examined soft law instruments: ILO's Code of Practice on Workers' Personal Data, the Universal Declaration on the Human Genome and Human Rights, the International Declaration on Human Genetic Data and the Universal Declaration on Bioethics and Human Rights, do not include a list of grounds which it protects, but offers specific protection in a situation of individual genetic discrimination.

That being said, Dutch soft law offers a victimized employee the possibility of changing a situation by lodging a complaint, which can result in tort that can be brought before a civil judge[106], while international soft law only offers recommendations. In conclusion, Dutch soft law can be brought before a civil judge, if a violation of that soft law results in an act of tort, Article 6:162 of the Dutch Civil Code. However no adequate protection can be expected from Dutch individual genetic discrimination, since the grounds that are covered by Dutch soft law do not extent to genetic information. It may be recommendable to start implementing the principles of

[106] de Fey (n30) 116

the examined international soft law in Dutch soft or hard law. Either instrument would be improved on the level of protection against individual genetic discrimination.

3. Dutch and European hard law on familial genetic discrimination

In this chapter the protection of Dutch hard law will be compared with that of European hard law, concerning the subject of familial genetic discrimination. In the first section, a short refreshment of the definition of familial genetic discrimination will be given. Secondly, in the next section Dutch hard law will be examined on its protective value against familial genetic discrimination. After which, in the third section European hard law will be examined. This chapter will be concluded with a conclusion on the adequacy of the protection of Dutch hard law, when compared to European hard law, against familial genetic discrimination.

3.1. Definitions

In short, discrimination can occur in a direct and indirect fashion. Indirect discrimination occurs when a neutral act has (unforeseen) discriminating consequences[107]. Direct discrimination occurs when a person is directly affected by a discriminating act[108]. Direct discrimination can be divided in individual and familial discrimination. As seen in the introduction[109], individual genetic discrimination is a distinction directed to one person. As opposed to familial genetic discrimination, which is a distinction made as a result of a person's association with another person. For example, the situation in which a family member has a certain percentage of risk to disease X, which was revealed by the manifestation of disease X in another family member.

3.2. Dutch Hard law

In Chapter 1, an examination of Dutch hard law took place insofar as it offers protection against individual genetic discrimination. In the conclusion it was summarized that only parts of genetic information were protected. Of those grounds on which genetic information could be protected, were, obviously the open ground 'any other ground'[110], and secondly, the grounds of 'disability' and 'chronic illness'. Therefore, the first subsection will start with an examination of Article 1 of the Dutch Constitution, followed by an examination of the Equal Treatment Act on disability and chronic illness. After which, in the second subsection the other side of the protection problem, the protection of privacy, will be examined. This section on Dutch hard law concerning the protection against familial genetic discrimination will be concluded with a short interim conclusion.

A. Protection against discrimination or unequal treatment

Firstly, Article 1 of the Dutch Constitution[111] is the most important article against discrimination. A quick first interpretation of this article will be that it can only be used in situations of

[107] de Fey (n 30) 28
[108] de Fey (n 30) 27
[109] Section IV of the Introduction, p. 6
[110] Article 1 of the Dutch Constitution: all persons in the Netherlands shall be treated equally in equal circumstances. Discrimination on the grounds of religion, belief, political opinion, race or sex or any other grounds whatsoever shall not be permitted'.
[111] ibid

individual discrimination. However, in another interpretation, which considers the purpose of Article 1 of the Constitution, is that it first of all demands equal treatment of all citizens[112]. Within such an interpretation, the situation presented in the Coleman case[113], would result in the invocation of Article 1. In the Coleman case, Ms Coleman was treated unequally compared to her colleagues, because of her association with her son. Her son suffers from apneic attacks and congenital laryngomalacia and bronchomalacia. As the sole caretaker of her son, Ms Coleman suffered familial discrimination. The second sentence of Article 1 of the Constitution contains the grounds on which discrimination can take place. Ms. Coleman could place her case under the ground of 'or any other grounds'. However[114], in another interpretation of Article 1, Smis[115] explains that there is a difference between equal treatment, as written in the first phrase of Article 1, and discrimination, as mentioned in the second phrase of Article 1. Equal treatment covers all situations wherein a distinction is caused by none of the questionable criterions. In the reverse situation wherein one of the questionable grounds causes the distinction, discrimination can be invoked, since every questionable ground is prohibited from causing a distinction. The difficulty with grounds that are not clearly defined in the second phrase of Article 1 lies in areas where there is a broad margin of appreciation. In such a situation, the claimant needs to prove that there were no objective or reasonable grounds, that could justify the (assumed) distinction, and therefore the distinction is a discriminating act. However, this means that the distinction based on 'any other grounds' is not immediately recognized as a questionable criterion, such as the grounds of religion, belief or gender. A disadvantage of this interpretation, is the heavy burden of proof, which in case of a questionable ground, lies with the defendant, but, in case of another ground, lies with the claimant. A resulting drawback, regarding the protection against familial genetic discrimination, is the explanation of the author of the pejorative meaning of discrimination. The definition of discrimination is connected to 'personal group characteristics'. In other words, essential personal characteristics of a person that are congenital or part of the personality and or mental integrity. Such an interpretation of Article 1 would suggest that a person is only protected against individual genetic discrimination. A person that suffers from familial genetic discrimination would not be able to invoke the protection of Article 1.

In my opinion, the literal interpretation of Smis[116], should be combined with the purpose of Article 1. The purpose is to protect all who reside in the Netherlands from discrimination and make sure that none are treated unequally. In this interpretation, protection against familial genetic discrimination could also be invoked, since there is no need for a personal characteristic.

[112] Stefaan Smis, *Handboek Mensenrechten: De internationale bescherming van de rechten van de mens* (Intersentia Antwerpen-Cambridge 2011) 523
[113] Section IV of the Introduction, p. 6
[114] C Staal, *De vaststelling van de reikwijdte van de rechten van de mens* (Ars Aequi Libri Nijmegen 2005) 463-472
[115] Smis (n 128) 523
[116] Ibid

The fact that a distinction or a (assumed) discriminating act occurs should be enough to invoke Article 1 of the Dutch Constitution[117].

As mentioned in the introduction of this section, on Dutch hard law and its protection against familial genetic discrimination, the Equal Treatment Act on Disability or Chronic Illness[118] will also be examined. First of all, though the Equal Treatment Act on Disability or Chronic Illness does not clarify the definitions of 'disability' and 'chronic illness', there is case law which explains both subjects. In *Chacón Navas*[119] the ECJ clarified the definition 'disability' by stating that it is a physical, mental or psychological disorder that prevents the participation in professional society. The ECJ reflected that the legislator meant to create two different definitions that mainly differ in duration. In other words, a disability is in principle irreversible and a chronic illness is at least long-lasting[120]. Second of all, the scope of the protection offered by disability or chronic illness was discussed in the Coleman case[121], in which the European Court of Justice ruled that discrimination on the grounds of disability can occur if the claimant is not disabled, but a person with whom they are associated with is. This case[122] will be examined in more detail in section 3.2 of this chapter. In other words, the Coleman case[123] shows that if discrimination occurs on the grounds of being connected to a disabled person, that the Equal Treatment Act on disability and chronic illness is also applicable. Both definitions could fit properties of genetic information, if the disability or chronic illness is based on genetic characteristics. It has to be kept in mind that disabilities and chronic illness could result from genetic characteristics, but also from other factors. Though, insofar the disability or chronic illness is based on genetic characteristics, it is interesting to see if the Equal Treatment Act on Disability or Chronic Illness[124] also offers protection against familial genetic discrimination. The act has a very wide scope, since it does not have a specific group of persons which it addresses. In other words, parties other than the employer, fall within the scope of the act, if they are involved in the employment relationship. Also, the act is applicable when a person has or does not have a disability or chronic illness. For example, if a 'healthy' applicant is denied access to an interest group for people with a chronic illness, because he/ she does not have that chronic illness[125]. This results from the principle that the Equal Treatment Act on disability and chronic illness protects everybody. Its legislative history says that in order to invoke the protection of this act, the focus is not on having a disability or chronic illness, but being discriminated compared to

[117] On the 14th of June 2010 a legislative proposal was presented, proposing to include disability and hetero- or homosexual orientation in Article 1 of the Dutch Constitution. The proposal currently lies with the House of Representatives.
[118] Equal Treatment Act on Disability and Chronic Illness 2003 (*Wet gelijke behandeling op grond van handicap of chronische ziekte)*
[119] Case C-13/05, *Chacón Navas* [2006] ECJ
[120] *Kamerstukken II* 2001/02, 28169, nr. 3, p.24, zie o.a. CGB 2007-27 (NL)
[121] *Coleman* (n 35)
[122] ibid
[123] ibid
[124] Equal Treatment Act on Disability or Chronic Illness 2003 (n 134)
[125] KMC Stalenhoef, 'De WGBH/CZ en de spagaat van het sollicitatiegesprek' (ArbeidsRecht 2009-49, 01-11-2009)(NL) 2

a person who does or does not have that disability. In other words, the Equal Treatment Act on Disability and Chronic illness also protects against reverse discrimination[126]. Therefore, the question could be asked if it also would be possible to also include protection against distinction in a situation where in a person suffers from discrimination based on his/her association with a person that suffers from a disability or chronic illness, resulting from genetic characteristics

If an incompetence does not limit the applicant in his/her ability to perform his/her job, it is not necessary for the applicant to share information about his/ her disability or chronic illness. However, in case the incompetences are relevant in order to perform the job, or if the employee realizes or should realize that the incompetence disqualifies him for the job, then the applicant should inform the employer about his/ her disability or chronic illness[127]. Insofar the employer is aware of a disability or chronic illness, the Equal Treatment Act on disability and chronic illness restricts the consequences this knowledge may have. The causal connection between the (assumed) disability or chronic illness and the discriminating behavior, is very important in evaluating this question. Also, there is the question if the limitations of the applicant result from the (assumed) disability or chronic illness or from another source. If the applicant's limitations result from the (assumed) disability or chronic illness, the employer has the obligation to search for effective measures in order to take away or lessen these limitations. However, if an employer cannot take away or lessen the limitations by taking effective measures, the act does not obligate the employer to hire the applicant. For example, an employer cannot hire a blind person as a taxi driver. In other words, if the reason for the decision not to hire an employee (or keep an employee) is independent of that employees' disability or chronic illness, there is no case of discrimination[128]. Nevertheless, the unsuitability of an applicant or employee has no clear definition and should be judged per case. This is a weakness of the Equal Treatment Act on disability and chronic illness, since it offers little guidance for both employers as employees. In short, in case of familial genetic discrimination, the protection of the Act[129] could be invoked if the three conditions could be fulfilled. Firstly, there needs to be a disability or chronic illness, which in case of genetic discrimination results from genetic characteristics. Secondly, if the claimant is discriminated because of an association with a disabled person[130], the Act[131] also applies. Thirdly, sharing information about the association with a disabled person is only necessary if a resulting incompetence disqualifies him/ her for a specific job, or if the claimant realizes or should realize that the resulting incompetence disqualifies him for the job. As a clarification for 'resulting incompetence', an example, which was given in the Introduction[132], is a case in which an employee's parent developed Huntington's disease, indicating that the

[126] BHM Werken, 'Wet gelijke behandeling op grond van handicap of chronische ziekte: met vallen en opstaan vooruit'(SR 2008, 47 01-08-2008)(NL) 6
[127] Stalenhoef (n 141) 10
[128] ibid
[129] Equal Treatment Act on Disability or Chronic Illness 2003 *(Wet gelijke behandeling op grond van handicap of chronische ziekte)*
[130] *Coleman* (n 35)
[131] Equal Treatment Act on Disability or Chronic Illness 2003 (n 145)
[132] Section IV of the Introduction, p. 6

employee had a 50 percent chance of inheriting the mutated gene. Between the period of testing and getting the results about the employees' carrier status, a co-worker leaked this sensitive information to the employer. When the employer officially heard that the employee indeed was a carrier of the mutated gene, the employee was fired[133]. In this case the employee had no symptoms of a disease, but the fact that she was associated with a person who developed Huntington's disease, was enough to decide on dismissal.

Next to the content of the Act[134], it is also important to examine the burden of proof. The burden of proof lies with the employer, who has to prove that effective measures have been taken, to no avail, or that the rejection of the employee is not linked to the employees' disability or chronic illness. The proof of having taken effective measures cannot be based on a general research, but has to be proven by research whereby all specific circumstances have been taken into account. The employee only has to claim that there is a presumption of discrimination, and reasonably argue that there is a causal connection between the discriminating act and his/her (assumed) disability or chronic illness. As mentioned above the scope of the Equal Treatment Act on handicap and chronic illness is not limited to a person's (assumed) disability or chronic illness. In the Equal Treatment Committees'[135] judgment of 23 November 2006, the Committee mentioned that in certain circumstances it is possible for a person, who is not (assumed) disabled or suffering from a chronic illness, to invoke the protection of the Equal Treatment Act on handicap or chronic illness, in case of a function limitation of another person. In a more recent judgment[136], the ETC[137] followed the ECJ's Coleman-decision[138] and decided that if a disability or chronic illness is an underlying reason for the (assumed) discrimination, then that suffices the question of the presence of discrimination on the grounds of disability or chronic illness.

There are certain drawbacks to this system of protection against discrimination. In one of its judgments[139] the Committee on Equal Treatment decided that an employer was guilty of discriminating a disabled applicant. This decision was based on the absence of other arguments than the employer's argument that the response of the employee on a question regarding her disability gave reason for refusal. The Committee on Equal Treatment argued that even though a question may seem neutral, it may come across a disabled person as a discriminating question. The risk that an employer cannot disprove a supposition of discrimination, may give a disable person an unfair advantage. Though the level of protection against discrimination is commendable, it should not result in situations wherein the disabled person can use his disability as a means to acquire a job. The Committee of Equal Treatment agreed in its judgment of 27 February 2007[140] that another difficulty, with deciding on discrimination, is formed by the question if the suitability of an employee or the functioning of an employee is the issue. In

[133] Department of Labor ea (n 32)
[134] Equal Treatment Act on Disability or Chronic Illness 2003 (n 145)
[135] CGB 23-11-2006, judgment 2006-227 (NL)
[136] CGB 15-06-2011, judgment 2010-388 (NL)
[137] Equal Treatment Committee (*Commissie Gelijke Behandeling*)
[138] *Coleman* (n 35)
[139] CGB 23-10-2007, JUDGMENT 2007-184 (NL)
[140] CGB 27-02-2007, JUDGMENT 2007-24 (NL)

conclusion, the two drawbacks of the Equal Treatment Act on Disability or Chronic Illness, regarding the burden of proof, are, firstly, the ease with which a claimant could start a procedure, since the claimant only has to claim a presumption of discrimination and establish a causal connection, and, secondly, the description of what the presumed discriminating act consists of. In other words, the presumed discrimination could focus on the suitability of an employee, or the functioning of an employee.

In conclusion, the protection against familial genetic discrimination by Dutch hard law, focused on prohibiting discrimination, does not offer direct protection. After interpretation of Article 1 of the Dutch Constitution and the Equal Treatment Act on Disability or Chronic Illness, in the light of their legislative history, their purpose and relevant case law, it could be argued that they also protect against familial genetic discrimination. However, whereas Article 1 of the Dutch Constitution has the possibility of protection genetic information in its entirety, the Equal Treatment Act on Disability or Chronic Illness only protects genetic information, if that information is translated into either a disability or a chronic illness. In other words, only if the disability or the chronic illness results from a person's genetic characteristic can the Act[141] be invoked.

B. Infringement on the right to privacy

In this subsection the protection of Dutch hard law against the infringement of the right to privacy will be examined. Firstly, a restatement is given on the boundaries of the right to privacy of an employee. Secondly, the Personal Data Protection Act[142] will be examined, after which an examination of Article 6:162 of the Dutch Civil Code will follow. This subsection will be closed with a short interim conclusion.

Concerning the right to privacy of an employee, employers are not allowed to ask the applicant about any disability or chronic illness, and may only ask for medical tests if the job requires the applicant to fulfill special conditions[143]. However, the privacy of the applicant is not without boundaries, since it is expected of the applicant to inform the employer of his/her incompetence to perform a task[144]. If the applicant refuses to share relevant information, he/she acts contrary to the principles of reasonableness and fairness. Possible consequences to this behavior vary from forfeiture of the right to wages[145] to acute dismissal[146].

The situations in which a person will be confronted with an infringement on his right to privacy, because of information about a family member, will probably occur less often than infringements based on his own personal information. Difficulty with these kind of situations is that often the person who illegally or unlawfully obtains personal information, would not be certain if that kind of information would also concern a third party. For example, when

[141] Equal Treatment Act on Disability or Chronic Illness 2003 (n 145)
[142] Personal Data Protection Act 2000 (*Wet bescherming persoonsgegevens)*(NL)
[143] Medical Examinations Act 1997 (*Wet medische keuringen)(NL)* Articles 3-4
[144] Stalenhoef (n 141) 9
[145] Article 7:629 of the Dutch Civil Code
[146] Stalenhoef (n 141) 9

information is obtained about an employee's sister's Parkinson, would the correct consequences be derived from that information? Or would the employer immediately (incorrectly) assume that the first complaints signaling Parkinson will manifest any day now[147]? However, in the situation whereupon a person's right to privacy is infringed by the use of personal information of a family member[148], tort can be used to sue for damages. On the grounds of Article 16 of the Personal Data Protection Act[149] the processing[150] of sensitive personal data is prohibited[151]. When an employee invokes Article 6:162 of the Dutch Civil Code to start a tort on the grounds of infringement of his/her right to privacy, he/ she first needs to prove he/ she has a right to invoke the provisions of the Act. In other words, that he/she is a legal subject of the Personal Data Protection Act[152]. The explanatory memorandum to the Act[153] says that the definitions from Article 1 of the Act[154], might create the possibility to prove that a 'third' person can also invoke protection from the Act. The personal data, as referred to in subsection a, Article 1, contains information about a person, whose identity could be determined without disproportionate effort. The disproportionate effort depends on the nature of the data and the possibility of the responsible person to identify the data's subject. The concerned party, subsection f, Article 1, is the person whose right to privacy of his/her personal data is infringed upon. In the situation of genetic information, the concerned party could be any associated person[155]. According to the College on Personal Data Protection[156], in order to prove personal data are provided or processed three elements[157] need to be fulfilled. . Firstly, the substantive element concerns a person's information. Secondly, the element of purpose: when data is (assumed to be) used with the purpose to treat a person a certain way or to judge or influence his/ her status or behavior. The third and final is the element of result: the use of the personal data will probably influence the rights and interests of that person, in such a way that he/she will be treated differently. Thereby, in combination with articles 6 to 24, the unlawful or illegal use of that personal (sensitive) data could be proven. This could prove a sound basis for a tort act based on Article 6:162 of the Dutch Civil Code.

---

[147] For more information: www.parkinson-vereniging.nl (NL) or www.parkinson.org (EN).
[148] In this situation infringement on the right to privacy on the basis of association with a person is too vague a definition. The subject of this thesis is genetic information and association does not result in the prospect or the consequence of having a risk to a certain characteristic of that genetic information. Since genetic information about a non-family member should have no consequence to the genetic information of the employee or applicant, I will speak of relation instead of association.
[149] Article 16 of the Personal Data Protection Act 2000 (*Wet bescherming persoonsgegevens)*: '(..)processing of personal data concerning a person's religious or philosophical beliefs, race, political opinions, health, sexual life (…) personal data concerning the membership of a trade union is prohibited(..)
[150] Article 1 sub b of the Personal Data Protection Act 2000 (*Wet bescherming persoonsgegevens)*: '(..)processing of personal data: (...)collecting personal data(…); sub o 'collecting personal data: obtaining personal data
[151] Save for the exceptions in Articles 17-24 of the Personal Data Protection Act.
[152] Personal Data Protection Act 2000 (*Wet bescherming persoonsgegevens)*
[153] *Kamerstukken II* 25 892, nr. 3, p. 46-47 (NL)
[154] Personal Data Protection Act 2000 (*Wet bescherming persoonsgegevens)*
[155] Association caused by the hereditary nature of genetic characteristics
[156] Cbp, 'Richtsnoeren publicatie van persoonsgegevens op het internet' (www.cpbweb.nl 2007) 9
[157] Opinion 4/2007 on the concept of personal data van de Artikel 29-werkgroep (20-06-2007)(NL) 6

In summary, effectively the kind of protection offered by Dutch hard law against familial discrimination on the grounds of genetic information is meager at best. Firstly, Article 1 of the Dutch Constitution could offer protection against unequal treatment because of association and maybe even against familial discrimination, if the right interpretation is followed. Secondly, the Equal Treatment Act on Disability or Chronic Illness could be used when a person is unequally treated because of his/her association with a person, who is disabled or chronically ill[158]. However, this protection can only be found by interpretation and not as a direct result from the phrasing of Dutch hard law. Thirdly, also the Personal Data Protection Act depends on extensive interpretation. Therefore, Dutch hard law has the possibility to offer protection against familial genetic discrimination. However, more case law is needed on the subject as are more grounds which protect against discrimination, since only disability or chronic illness or medical information are protected. Also, the grounds of disability and chronic illness can only offer protection against familial genetic discrimination, if those grounds result from genetic characteristics instead of other factors.

3.3. European Hard law

This section will start with the 2000/78/EC Directive, the Employment Equality Directive, after which the ECHR, the EU Charter on fundamental rights and the 95/46/EC Directive will be researched on protection value. These sources of European hard law will be discussed since these sources proved to be most promising regarding the protection of genetic information.

A. Protection against discrimination or unequal treatment

The Dutch Equal Treatment Act on disability and chronic illness is the implementation of the 2000/78/EC Directive. A notable difference, however, between the Dutch Act and the EC Directive is the Dutch addition of 'chronic illness'. The EC Directive only prohibits discrimination on the grounds of disability[159]. Even though the grounds of protection are more limited than the Dutch implementation of the Directive, the Directive also has promise with regard to familial discrimination. In its first article the Directive starts off with its purpose: the challenging of discrimination with the goal to apply the principle of equal treatment. The kinds of discrimination that are challenged by the Directive are of both a direct and an indirect nature. Direct discrimination is a measure with direct discriminating nature/ result[160]. Indirect discrimination is a neutral measure that would have discriminating results[161]. In Article 2 the EC legislator says "*when one person is treated less favorably than another is, has been or would be treated in a comparable situation"*, there is direct discrimination[162]. Though most protection focuses on individual discrimination, in this Directive there clearly is a margin left for protection against familial discrimination. Another argument that the Directive also covers familial discrimination is the fact that the EU legislature has the obligation to act in accordance with the

[158] *Coleman* (n 35)
[159] Article 1 of the 2000/78/EC Directive
[160] de Fey(n 30) 28
[161] de Fey (no 30) 27
[162] Indirect discrimination will not be examined in this thesis.

principles of Community law[163]. One of these principles is the principle of equality. Therefore, it would not be just to say that the Directives confine protection to individuals, who have the covered characteristics themselves, but also to individuals who experience disadvantages based on their association with person who suffer from certain characteristics.
For example, in the Coleman-case[164] the claimant was employed as a legal secretary at a law firm in 2001. In 2002 she gave birth to a son who suffers from apnea and congenital laryngomalacia and bronchomalacia. His condition demands specialized and special care, which is mainly provided by his mother. On the 4th of March 2005 the claimant voluntarily left her employment. However, on the 30th of August 2005 the claimant posed that it was an implicit dismissal, since she was treated in a less favorable fashion by the employer than other employees, which left her no other choice than resignation. The claimant has asked the ECJ prejudicial questions, which can be summarized to the question: does the European Directive concerning the discrimination on the grounds of disability and chronic illness, also relate to employees who do not have a disability themselves, but are treated in a less favorable manner than other employees, because of their association with a person with a disability. The ECJ answered that the Directive has the objective to combat all forms of discrimination on the grounds of disability with regards to labor and employment. Though the Directive contains a lot of articles focused primarily on disabled persons, this should not lead to the conclusion that the principle of equal treatment enshrined in this Directive is restrictive. The Advocate General reaches the same conclusion via a different path of argumentation. Advocate General Poiares Maduro wrote in his conclusion on the *Coleman*-case that it should not be forgotten that the Directive upon is based on Article 13 EC. Article 13 EC declares that the European Community will not condone discrimination and values the principle of equal treatment highly. Poiares Maduro reminds that the principle of equal treatment is based on the value of human dignity and personal autonomy. If human dignity is about all persons having the same value, than the grounds upon which a person differs from another person should be ignored. Also, if because of a disability or chronic illness a person would be denied access to fundamental activities, this would infringe upon their personal autonomy. Thereby, fundamental activities such as employment and labor are not only a way to make a living, but also an important way to achieve personal growth and reaching a person's full potential[165]. Also, indirectly, another way to affect a person with a specific characteristic is by affecting third persons with whom he/she has a close relationship. This more subtle way of discriminating transforms the person with a specific characteristic from a victim of discrimination, to a means to discriminate, which not only affects the third person, but also affects the human dignity of the first person. The Directive has the obligation, delegated by non-discrimination law, to treat people in a manner which is comparable to the manner in which others are treated[166]. The Advocate General concludes that the purpose of 2000/78/EC is to

[163] L Waddington, 'Protection for Family and Friends: Addressing Discrimination by Association' (European Anti-Discrimination Law Review Issue no. 5 2007) 18
[164] *Coleman* (n 35)
[165] Case C-303/06, Conclusion A-G M. Poiares Maduro, §10-11.
[166] Conclusion A-G (n 181) §17

combat injustice both in the form of individual and familial discrimination[167]. In case of individual discrimination the illegal behavior that should be prohibited. Familial discrimination shares the same material aspects: in both cases the hostility against them results in being treated less favorable than other persons. Therefore, if a person is discriminated because of a disability, it is not necessary, protection-wise, that the disability is his/ hers. Considering this example of familial discrimination, the purpose of the Employment Equality Directive[168] and the wording of the definitions in Article 1 and 2, it would seem right to interpret that the Directive also applies in situations of familial discrimination.

However, Waddington argues that there currently is no legal authority to confirm this standpoint[169]. "The wording of the Directives is certainly open to this interpretation, but it is not unambiguous and clear in this respect: and there are no judgments of the ECJ, interpreting the provisions of the Directive in this light, or even addressing the issue". Even so the European Parliament resolution of 20 May 2008 on progress made in equal opportunities and non-discrimination in the EU, makes in interesting statement in section 37 on, for example, discrimination by association. The European Parliament believes "that any new proposed directive designed to combat discrimination as referred to in Article 13 of the EC Treaty will have to prohibit *all forms of discrimination*[170], in all areas already covered by Directives 2000/43/EC and 2000/78/EC". Discrimination by association is written down as one of the forms of discrimination. Also, the European Parliament states that the Directives "should make clear that there is no hierarchy between the different forms of discrimination and that they must all be combated in equally strong measure". This still does not allow for a legal standpoint by an authority, but it shows promise for the future.

Another legal entity that shows promises for the future is the European Court on Human Rights. As seen in Chapter 1, Article 14 of the ECHR[171] had the possibility of protecting genetic information based on the ground of 'other status'. However, the needed conjunction with Articles 34 and 35 ECHR, concerning admissibility conditions was problematic, as was the condition that only ECHR specific rights were protected by the Article. The second condition is clarified inthe 'Handbook on European Non-Discrimination Law', created by the Council of Europe. Herein the Council of Europe explains that when Article 14 ECHR[172] is invoked, the ECtHR adopts a wide interpretation of the scope of ECHR rights. Firstly, the ECtHR has made clear that it may examine claims under Article 14 if taken in conjunction with a substantive right, even if there has been no violation of the substantive right itself. Secondly, it has held that the

[167] This is my own interpretation of the Advocate General's opinion.
[168] Council Directive (EC) 78/2000 establishing a general framework for equal treatment in employment and occupation [2000] OJ 2000 L-303/16
[169] Waddington (n 179) 19
[170] Italicized by myself
[171] Article 14 of the European Convention on Human Rights: 'The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, color, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status'.
[172] European Convention on Human Rights 1950

scope of the ECHR extends beyond the actual letter of the rights guaranteed. It will be sufficient if the facts of the case broadly relate to issues that are protected under the ECHR[173]. In light of this interpretation, it might not be too farfetched to interpret Article 8[174] and its right to privacy, as also concerning the infringement of a person's right to privacy when the personal data of another person, with whom he is associated, is violated. Even though this interpretation sounds promising, the problem with the ECHR is the admissibility in court. Article 34 of the ECHR explains that one of the High Contracting Parties should be the violator and Article 35 reminds that firstly, a claimant should exhaust all domestic remedies. Therefore, in employer versus employee-situations the ECHR does not really offer protection against familial discrimination, but it does seem promising in the relation the Netherlands versus person X.

In conclusion, European hard law that has the purpose to prohibit discrimination does not offer actual adequate protection against familial genetic discrimination. The 2000/78/EC Directive only offers protection in case of a disability, which in summary only protects insofar the disability results from genetic characteristics. However, the Coleman case[175] extends the scope of protection against discrimination based on disability to situations of familial discrimination. Therefore, in theory, the offered protection is small, but could be adequate. Also, in the European Parliament resolution[176] the European Parliament indicated the wish to extend the scope of prohibition of all forms of discrimination, which would create the possibility of future directives on genetic discrimination. Another legal entity that could be promising in the future is ECtHR[177], which interpreted the scope of Article 14 ECHR as being more extensive.

B. Infringement on the right to privacy

This subsection will consider the protection of European hard law in case of infringement on the right to privacy. Since the 95/46/EC Directive is the only relevant European hard law concerning the protection of privacy, this Directive will be discussed first. Secondly, a short interim conclusion will conclude this section.

The 95/46/EC Directive is more restrictive in wording than the Dutch Personal Data Protection Act is. In its definition of personal data the EU legislator says that "*an identifiable person is one who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity"*. In other words, no familial protection exists when personal data which concerns another person, infringes upon the claimant's right to privacy. There is no complaint the claimant can make with regard to personal data that may also concern him, if the entirety of that data specifically concerns another person.

---

[173] CoE, 'Handbook on European Non-Discrimination Law' (Luxembourg, Imprimerie Centrale 2010) 61
[174] Article 8 of the European Convention on Human Rights: '(1) Everyone has the right to respect for his private and family life(..)'
[175] *Coleman* (n 35)
[176] European Parliament Resolution (2008) on progress made in equal opportunities and non-discrimination in the EU [2009] OJ C 279 E/05
[177] European Court for Human Rights

In summary, the Coleman case teaches that in a case where discrimination of a person, who is associated with a disabled person, is the subject, the discriminating act to which he/she was exposed should be compared to the treatment of a person who would not have such a relationship. However, the question is if the ECJ[178], in its judgment on the scope of Directive 2000/78/EC in the Coleman-case, has restricted the scope solely to caretakers or if the extended scope also covers other areas[179]. Another note by the authors is that the Netherlands have already written down the enforceable rights, created by the Coleman-case, in the Work and Care Act[180]. However, whereas the Coleman-case may also promise protection in other situations than that of caretaker, the Dutch Work and Care Act focuses on pregnancy, child-birth, adoption and foster care and does not offer the same width of scope. Though all discussed sources of European hard law seem to be open to familial discrimination, if interpreted correctly, there has not, as of yet, been made a standpoint by a legal authority. This therefore does not offer much protection for familial discrimination on the recognized ground, let alone a ground such as genetic discrimination. It may be concluded that though some characteristics of genetic information could be protected in the future against familial discrimination, the entire ground of genetic information is still not adequately protected. With regard to the protection of the right to privacy, the European hard law does not offer much leeway.

3.4. Comparison/ Conclusion

In comparison, Dutch and European hard law, concerning the protection against familial discrimination, shows roughly the same amount of protection. Both types of hard law show that their sources are open to a wider interpretation, however no legal authority has taken a standpoint. Again, the only characteristic of genetic information that is marginally protected is disability or chronic illness. This would in conclusion mean that also in the situation of familial discrimination, both sources of hard law do not offer any protection against genetic discrimination in its entirety. The Dutch Equal Treatment Act on disability and chronic illness and Article 1 of the Dutch Constitution, both show a lot of room for improvement for familial discrimination. However, for the time being, the protection of genetic information should be sought by using the existing grounds, such as disability and chronic illness. With regard to the 'new' European Parliament Resolution of 20 May 2008, hope exists that, in the future, Directives will also provide protection against familial discrimination. This hope exists because of the obligation of the EU legislature to promote the principle of equality and therefore the obligation to combat discrimination. With regard to EU hard law, concerning the ground of 'genetic information', no protection should be expected any time soon. The best hope would in this case be to try and bring a case of familial genetic discrimination under one of the existing grounds.

[178] European Court of Justice of the European Union
[179] G Heerma van Voss ea, 'Kroniek van het Sociaal Recht' (NJB 2008, 1734 03-10-2008)(NL) 3
[180] Wet Arbeid en Zorg 2001

4. Dutch and Global Soft law on the protection against familial genetic discrimination

In this chapter the protection offered by soft law in case of familial genetic discrimination will be examined. First of all, a short restatement of the definition of soft law and familial genetic discrimination will be given. Secondly, the Dutch soft law from different sources will be examined for protective power. Those sources are derived from labor unions, companies and a variation of other sources. Thirdly, the European and international soft law instruments will be examined. This chapter will be concluded with the answer to the question: does Dutch soft law offer adequate protection against familial genetic discrimination?

4.1. Definitions

Firstly, in a definition given by Luijendijk[181], soft law consists of rules of personal conduct, secured in instruments that as such do not possess any legal binding, but nevertheless, can have certain (indirect) legal effects in practice. Soft law is created on the basis of a derived authority to regulate or with the cooperation of a public body. The reason for companies to adopt codes of conduct is the growing recognition that a company's reputation does affect its bottom-line. Such codes fall within the realm of soft law, lacking the hard law status of mandatory national legislation or international treaty law[182]. The advantages of soft law are firstly, that it is capable of rapid adaption and adaption of rules and secondly, therefore much more flexible than hard law. The disadvantages, apart from the ones mentioned above, result firstly from its flexible nature in the sense that the principle of legal certainty is not safeguarded. The lack of a legally binding force is an important factor, but a second important condition is the willingness of States to be bound by soft law[183]. Hard law is created on the basis of consent of States to be bound. However, soft law does not always have such democratic legitimacy.

Secondly, genetic discrimination is discrimination based on a person's (asymptomatic) genetic predisposition to or probability of having a disease or medical condition[184]. Thirdly, familial genetic discrimination can be defined as discrimination based on an association with a person who has a (asymptomatic) genetic predisposition to or probability of having a disease or medical condition. The discriminating nature of behavior can be found by comparing the (perceived) discriminating act with a situation in which the associated person would not be associated.

[181] H Luijendijk ea, 'De gelaagde doorwerking van Europese Administratieve Soft Law in de nationale rechtsorde' (< http://www.nver.nl/documents/Preadvies2011_NVER_Luijendijk_Senden.pdf> 2011)(NL)
[182] JJ Kirton ea, *Hard Choices, Soft Law: Voluntary Standards in Global Trade, Environment and Social Governance* (Ashgate Publishing Ltd. 2004) 189
[183] L Senden, *Soft Law in European Community law* (Hart Publishing, Oxford and Portland Oregon 2004) 26-27
[184] Miller (n 31)

4.2. Dutch Soft law

Soft law in the Netherlands mostly can be found in the form of codes of conduct. Self-regulation that would fall within the category of soft law is the type of regulation that is permitted by the government. When the government offers a margin of appreciation to organizations in order to contribute to reaching government goals, the resulting product is an instrument of soft law. This type of self-regulation could also be called legally conditioned self-regulation. In other words, the government creates the constraints and the fulfillment of those constraints is created by the organizations[185]. An example[186] of the effectiveness of self-regulation is the Model Regulation doctor-patient[187] of 1998. In 1983 the State secretary of public health requested a few health care organizations to reach agreements on the rights and obligations concerning a treatment relationship. The creation of the Model Regulation doctor-patient of 1998 was the result. After the entering into force of the Model Regulation a lot of provisions found their way into the Medical Treatment Act[188]. The only way in which rules of self-regulation could eventually become law, is by acknowledgment from the judiciary. This acknowledgment can only be achieved when the court detects a void in hard law that can be filled by rules of self-regulation. However, the rules of self-regulation need to be in accordance with the system of law. More specific, the rules of self-regulation need to fit within the current legal dogmatisms and not be contrary to previous case-law and legislation. Also, the rules need to agree with the general legal policy and legal culture[189]. The effectiveness of soft law can be found in for example, a case before the District Court, which involved a procedure concerning the severance of the employment agreement. In the procedure, the employer based his plea on norms of the company's code of conduct. The plea failed because of a discrepancy between the company's code of conduct and the company's policy. However, the fact that the employee had acted according the code of conduct resulted in the court denying the employer's plea. Therefore, soft law and self-regulation could have positive results for protection, but need the extra support of hard law to be of use in legal proceedings.

A. Labor Unions

As seen in Chapter 2, the FNV and CNV, two of the largest labor unions in the Netherlands, have created a Regulation on Undesirable Behavior, because of the lack of protection of private life offered by Directive 95/46/EC. Especially, the lack of protection of privacy in the sphere of labor stands out, according to the labor unions[190]. In the Regulation both labor unions declared to take directed measures within the union and the work organization, in order to prevent and, if needed, combat discrimination, sexual harassment, aggression and/or violence.

---

[185] H Weyers ea, *Zelfregulering* (Reed Business Information 2004) 2-8
[186] Weyers (n 201) 148
[187] Modelregeling arts-patiënt 1998 (http://knmg.artsennet.nl/Publicaties/KNMGpublicatie/Modelregeling-artspatient-1998.htm)
[188] Act of Agreement on Medical Treatment 1994 (*Wet op de geneeskundige behandelingsovereenkomst (WGBO)*)
[189] Weyers (n 201) 15-16
[190] FNV (n 107)

Undesirable behavior

According to the Regulation[191], 'undesirable behavior' is behavior that can be perceived as (sexual) harassment, aggressive, threatening, (verbally) offensive, bullying or undesirable in any other way, by the person to whom the behavior is directed and/or to the person who is confronted with it. Both labor unions will not tolerate this kind of behavior and the offending person is at risk of being sanctioned. Individual discrimination is protected by the words 'to whom the behavior is directed', and the words 'to the person who is confronted with it' offer the possibility for protection against familial discrimination. 'Confronted', in this definition, could suggest that the discrimination is not directed at a person's own characteristics, but that person is affected by the discrimination with almost the same impact. In other words, the reason why person A is affected by the discrimination is not because of his own disability, health or any other grounds, but because of his direct association with person B, who is disabled. The grounds that are recognized by the labor unions on which undesirable behavior can occur are: religion, belief, race, gender, sexual preference, nationality, ethnicity, marital status, health, disability, age, and place within the organization or on any other improper ground. Therefore, familial genetic discrimination is protected insofar the 'genetic' part of the discrimination involves one of the other mentioned grounds. If the invocation of one of those grounds does not offer satisfaction, the offended party could also try to invoke an appeal 'on any other improper ground'. Therefore, the regulation does offer protection in a situation of familial discrimination, since the regulation[192] could apply to any person who is confronted with discrimination, be it directed at him based on his personal characteristics, or directed at him based on characteristics of a person with whom that person is associated. The grounds on which protection, against familial genetic discrimination, could be based would be 'health', 'disability' or 'any other improper ground'. 'Health' and 'disability' can only offer protection against familial genetic discrimination, insofar they either concern genetic information or result from genetic characteristics.

When an act of (perceived) undesirable behavior occurs, the offended party has the right to bring a complaint before the Committee of Complaints. This committee will write a report and the advice given in this report could have dire consequences for the defendant. When the gravity of the complaint and/or other relevant circumstances warrant necessary, temporary measures, the committee can recommend those measures in a preliminary report to the board of FNV or CNV and/or the managing director.

In conclusion, when an employee, being a member of the FNV or CNV, is confronted with undesirable behavior of a discriminative nature, on grounds of handicap, health or 'any other ground', he/she can file a complaint before the Committee of Complaints, which could result in serious consequences for the defendant. Those serious consequences could be the severance of the employment agreement, or a procedure before court, with the employer as claimant and the employee as defendant. There have been cases wherein the employer decided to sever the employment agreement on the grounds of violation of the company's code of

[191] ibid
[192] FNV (n 107)

conduct[193]. The legal basis of such a procedure would be formed by hard law, but the norms upon which the employer would refer to were based in soft law[194]. Therefore, a code of conduct cannot be the legal basis of a legal procedure, due to its soft law status. Even so, the code of conduct can be used to give substance to a procedure.

Processing of personal data

As seen in Chapter 2 the processing of personal data, more especially genetic data is not specifically protected. Though the purpose[195], of the FNV's model on rules on privacy, is only to be an aid to Works Councils or employers, the protection offered for processing data does seem adequate[196]. In Article 7 it is said that personal data should not be collected from third parties without unambiguous consent of the concerned party. Also the processing of the data should be in accordance with the PDPA[197] and be proper and careful. The data may only be processed according to purposes which are agreed upon. The data should not exceed the boundaries of the purposes, in other words, the data should be sufficient, and relevant without being excessive. The article finishes with a reference to Articles 16 to 23 of the PDPA when the data concerns special personal data. The model also refers to a complaint procedure, which could be invoked by the concerned party, and the authorization of the College on Data Protection [198] to monitor compliance, Article 22 of the FNV's model on rules on privacy. The problem with the FNV's model is that it does not offer protection in case of familial genetic discrimination. As seen in Chapter 2, the protection of personal data in case of individual genetic discrimination was inadequate. In case of familial genetic discrimination it is non-existent. In conclusion, the only way in which a concerned party could invoke the protection of a code of conduct, based on this model, would be if the personal data concern that party. However, if the personal data concerned a person with whom the employee was associated, meaning there is a familial relationship, there is no possibility of filing a complaint. The employee does not have any means in which to act upon a violation of personal data of a person with whom he/she is associated. When such a situation would occur and result in discrimination, soft law, concerning undesirable behavior, could offer a solution against familial genetic discrimination.

---

[193] Sector Kanton Rechtbank Arnhem, 05-06-2007, LJN BA7119, procedure concerned the severance of the employment agreement because of the employee's ancillary activities, which were in violation of the code of conduct and article 2.5 of the CAO Woondiensten. Sector Kanton Rechtbank Alkmaar, 06-05-2010, LJN BN1637, procedure concerned the severance of the employment agreement, in which the employer based his plea on norms of the company's code of conduct. The plea failed because of a discrepancy between the company's code of conduct and the company's policy. The employee acted according the code of conduct and therefore the court denied the employer's plea.(NL)

[194] ibid

[195] FNV, 'Model Privacyreglement' (http://home.fnv.nl/02werkgeld/arbo/wetgeving/privacy/Model%20Privacyreglement/model_privacyreglement1.htm)

[196] It is to be understood that not the FNV's model is seen as a source of protection, but the codes of conduct based or resulting from the model.

[197] Personal Data Protection Act 2000 (*Wet Bescherming Persoonsgegevens)*

[198] College Bescherming Persoonsgegevens.

B. Dutch companies

The codes of conduct that are promoted in the previous section will have effect within companies. Therefore, their content will not be repeated in this section. However, the alternative ways in which companies can be held responsible for violations of soft law will be examined in this section. First of all, the 'checks and balances system', which results from a corporate code[199], will be discussed and both the internal as external effect will examined[200]. The internal checks and balances system is in effect between management and the employees. The system is created in order to make both parties act critically in order to prevent undesirable behavior and promote communication. The intended result is less complaints and a better work environment. The external checks and balances system concerns the relationship of the organization with the community. This system should result in careful behavior of the organization in order to keep a good reputation within the community. The end result for the company would not have a direct result such as fines or other kinds of punishment decided by a Committee of Complaints. This is because of organizations cannot legally be held responsible on grounds of their corporate code.

However, an exception could be made if the code of conduct focuses on concrete standards and rules. If such is the case, third parties will expect compliance with that code of conduct[201].If the code of conduct is more of a mission-statement or code of targets, the violation of such a code would come down to the failure to keep the companies' good intentions. The failure to keep good intentions is not a ground on which a company could be held liable.

A third way in which non-compliance with the corporate code could be punished would be by using the principles of reasonableness and fairness, and the procedure to redress[202], in order to challenge the policy of the board if they do not act in a society responsible way. In other words, act in breach of their corporate code of conduct.[203] This could result in a legal procedure before court. In conclusion, there are not much soft law possibilities, created by companies, by which means familial genetic discrimination could be protected in legal proceedings. Nevertheless, next to legal proceedings, there is also the possibility of using alternative forms of dispute resolution. For example, mediation could be an interesting possibility, in a soft law conflict, since it considers both individual interests as rights[204].

C. Other sources

The Recommendation on personal data in scientific research, created by the Social-Science Council[205], should be mentioned as interesting source for protection. However, as was the case in the first subsection with the code of conduct on the processing of data, the definition of 'concerned party' again forms a problem. In case of familial genetic discrimination, the person

[199] A corporate code can be seen as an instrument with internal and external effect and can consist of corporate norms and values, ambitions, responsibilities, and etc.
[200] Weyers (n 201) 23-26
[201] ibid
[202] Article 6:162 of the Dutch Civil Code.
[203] Weyers (n 201) 26
[204] Roger Blanpain, *Labour Markets, Industrial Relations and Human Resources Management; From Recession to Recovery*, (Wolters Kluwer 2012) 135-148
[205] Sociaal-Wetenschappelijke Raad, see www.knaw.nl.

that is associated with the genetically challenged person is not offered the same protection. In short, the other sources concerning protection of personal data do not offer protection against familial genetic discrimination.

D. Interim conclusion

In conclusion, when familial genetic discrimination is the case, soft law provided by labor unions can be of assistance during a hard law procedure. Codes of conduct can provide the substance of the procedure, while the basis of the legal procedure is derived from hard law. However, this only goes for codes of conduct on undesirable behavior. The applicability of the code of conduct depends on the interpretation of the definition 'confronted'. On the other hand, codes of conduct focusing on the processing of personal data do not consider violation of privacy, resulting from association with a person, who has a (asymptomatic) genetic predisposition to or probability of having a disease or medical condition, as within their scope. The discussed forms of soft law from companies and other sources do not by itself offer adequate ways in which familial genetic discrimination or genetic privacy could be prevented or protected. However, soft law can, in the form of, for example, codes of conduct, be used as a reference tool in procedures to clarify hard law norms.

4.3. Global Soft Law

This section will firstly start with a brief restatement of the definition of soft law. As seen in Chapter 2, there is no relevant European soft law to be found. However, in order to find an answer to the question if national soft law can offer adequate protection against familial genetic discrimination, a source of higher soft law needs to be examined to offer a good perspective. Therefore, four relevant global soft law instruments will be examined. The first being the ILO's code of practice on worker's personal data will be examined, which is relevant since the Netherlands have been a member state of the International Labor Organizations since the 28th of June 1919. Secondly, the Universal Declaration on the Human Genome and Human Rights will be researched, followed by a section on the International Declaration on Human Genetic Data. Fourthly, the Universal Declaration on Bioethics and Human Rights will be examined. The UNESCO Declarations are relevant, since the Netherlands joined UNESCO as a member state on the 1st of January 1947. This section will be closed with a short interim conclusion.

A. Definition

European law can be found in three different sources. The primary sources of European law are the treaties: the Treaty on the European Union and the Treaty on the Founding of the European Union. The secondary sources of European law are the legal instruments mentioned in Article 288 TFEU that are legally binding: the regulation, directive and decision. The tertiary sources of European law have not been attributed binding force, in other words these are soft law instruments [206]. According to Article 288 TFEU, those soft law instruments consist of recommendations and opinions. Decisions sui generis can also be seen as non-legal binding

[206] Senden (n 199) 55-56

instruments; however, the decisions only have internal effect and will therefore not be researched for protective value.[207]. The function of these soft law instruments is not to create legal consequences, but to be of use for the decision-making within the European Union. Though Article 288 TFEU only provides for two forms of European soft law, numerous Treaty provisions leave a scope for the institutions to create other forms of soft law instruments[208]. Examples of these other instruments of European soft law are: recommendations, notices, resolutions, conclusions, guidelines, declarations, programs, codes of practice etcetera. The common denominator of these instruments is that they all are created by the European Communities' institutions and have not been attributed legally binding force. The use of soft law instruments is not new in European Community law, but their proposed use as an alternative to legislation is new[209]. Senden[210] explains that everyday Community practice suggests that there indeed is a preference to use soft law instead of hard law. A decrease in the number of legislative acts can be found as opposed to an increase in the number of soft law acts. Another way in which the popularity of soft law as an alternative can be noted, are by looking into the content of action programs and like documents, which are setting out policy aims in various areas of Community law. The increased popularity can also be found in terms of more case law of the Court throwing light on the nature and legal status of (certain) soft law instruments in European Community law. Most interestingly, it has become clear that 'no legally binding force' does not automatically mean that soft law has no legal effect at all [211] .

B. ILO's code of practice on worker's personal data

The ILO's code of practice on worker's personal data has no binding force and has the purpose to provide guidance and be used as an aid in the development of legislation, regulations, collective agreements, work rules, policies and practical measures. The Netherlands has been a member of the International Labor Organization since 28th of June 1919 and therefore this soft law instrument is relevant to this discussion. The ILO's code offers a lot of potential protection in case of individual genetic discrimination. In case of familial genetic discrimination the code as one giant obstacle: it concerns a worker's personal data. In the ILO's words, 'any information related to an identified or identifiable worker'. The intention of ILO's definition on personal data could be explained in a broad or in a restrictive sense. If the definition could be explained in its broadest sense 'related' would also apply in such a situation as the Coleman-case[212]. In other words, if 'related' would be interchangeable with 'associated with'. However, the ILO's definition also includes 'an identified or identifiable worker', which would suggest that the ILO explains 'related' in a restrictive sense. Also, the ILO mentions that personal data should mainly

[207] R Barents ea, *Grondlijnen van Europees recht* (issue no 12 Kluwer 2006) 200
[208] Senden (n 199) 107
[209] Senden (n 199) 23
[210] ibid
[211] Senden (n 199) 24-25
[212] *Coleman* (n 35)

be obtained from the concerned party. In other words, the ILO's code of practice on worker's personal data cannot be of any use in case of familial genetic discrimination.

C. Universal Declaration on the Human Genome and Human Rights

On the 11th of November 1997 UNESCO's General Conference acclaimed and adopted the Universal Declaration on the Human Genome and Human Rights. In 1998 the UN's General Assembly endorsed the Declaration. However, the Netherlands have not taken additional steps in implementing the principles of the Declaration. The Declaration was created as a result of research of the human genome and the resulting prospects, which could improve the health of individuals and humankind as a whole, but could also have a negative impact on human dignity, fundamental freedoms and human rights. In Article 2, sub a, everyone's right to respect for their dignity and for their rights regardless of their ***genetic characteristics***[213] was said. In sub b, UNESCO expounds that dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity. That declaration does not only state the importance of respect for human dignity, but also the importance of non-discrimination. Furthermore, Article 6 says "no one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity". The words 'everyone's right to respect for their dignity and for their rights regardless of their genetic characteristics' and 'no one shall be subjected to discrimination', provide a broad margin of interpretation. Both sentences suggest that the Universal Declaration on the Human Genome and Human Rights would also offer protection against familial genetic discrimination. Interestingly, UNESCO already started in 1997 with protecting genetic characteristics. However, in every piece of legislation, national and European, or national soft law instrument, only certain genetic characteristics are mentioned. Instead of adopting the term genetic characteristics, states apparently needed a narrower definition as a ground on which they could offer protection. Though impressively early with defending genetic characteristics, UNESCO's declaration also has the weaknesses that are inherent to soft law. In conclusion, the declaration is a great source for inspiration for protection against familial genetic discrimination, but not a soft law instrument that offers an adequate kind of protection.

D. International Declaration on Human Genetic Data

The International Declaration on Human Genetic Data was acclaimed and adopted by the UNESCO during its 32nd General Conference, October 16th 2003. The Netherlands has not taken additional steps to implement the principles of the Declaration. According to the preamble, the declaration was created to address concerns in a rapidly developing field in which many people feared that human genetic data would be used for purposes contrary to human rights and freedoms. UNESCO recognized "that genetic information is part of the overall spectrum of medical data and that the information content of any medical data, including genetic data and

[213] Bold and italicized accent were applied by me.

proteomic data, is highly contextual and dependent on the particular circumstances". Therefore protection of human genetic data is very important. UNESCO also recognizes that human genetic data has a special status, since they can be "predictive of genetic predispositions concerning individuals and that the power of predictability can be stronger than assessed at the time of deriving the data". Also, UNESCO realized that this human genetic data could have a "significant impact on the family, including offspring, extending over generations and in some instances on the whole group". UNESCO's main conclusion in its International Declaration on Human Genetic Data was that because of the highly sensitive status of human genetic data, they should be handled with the utmost care and sensitivity. Thereby the interests and welfare of the individual should have priority over the rights and interests of society and research. The scope of the declaration encompasses the collection, processing, use and storage of human genetic data. Article 2 clarifies a few definitions concerning genetic data. Firstly, human genetic data is 'information about heritable characteristics of individuals obtained by analysis of nucleic acids or by other scientific analysis'. Secondly, the scope of the declaration considers three forms in which human genetic data can be found. There is data linked to an identifiable person, which concerns information such as a name, birth date or address. Also, there is the type of data unlinked to an identifiable person, which means the information is unlinked from its source by use of code. Finally, there is the form of data that is irretrievably unlinked from an identifiable person. This concerns information that cannot be linked to its source because of a destruction of the link between the data and its source. Most interestingly, the International Declaration contains a non-discrimination and non-stigmatization article. In Article 7 it is said that 'every effort should be made to ensure that human genetic data and human proteomic data are not used for purposes that discriminate in a way that is intended to infringe, or has the effect of infringing human rights, fundamental freedoms or human dignity of an individual or for purposes that lead to the stigmatization of an individual, a family, a group or communities'. The wording of this Article would suggest that human genetic data should also be prevented from being used as a means to familial genetic discrimination. Thereby, the declaration also has an article concerning privacy and confidentiality. In Article 14 the General Conference created a duty for the states to endeavor to protect the privacy of its citizens. In sub b of that article, it is said that human genetic data should not be disclosed or made accessible to third parties in particular: employers, insurance companies, educational institutions and the family. In short, protection against familial genetic discrimination should be possible by the declaration, since it recognized the scope of importance human genetic data has. In other words, it recognizes that human genetic data can affect multiple persons at the same time. Also, States should take responsibility in preventing that sensitive information becoming a source for discrimination or a cause for violating a person's privacy.

Next to States, the declaration recognizes in Article 15 that persons and entities responsible for processing human genetic data should also take necessary measures to prevent harm or hurt. They need to exercise rigor, caution, honesty and integrity. The great weakness of the International Declaration lies within the fact that it does not offer any procedure in which

complains could be brought before a committee or violations of the declaration could be brought before a judge. The declaration only gives the recommendation to States to consider establishing a framework for monitoring and management of human genetic data. Next to that recommendation, UNESCO affirms that the International Bioethics Committee (IBC) and the Intergovernmental Bioethics Committee (IBGC) will oversee the promotion and implementation of the declaration (Article 25).

In conclusion, again UNESCO offers great inspiration for States, but no adequate way for citizens to protect their privacy or protect themselves from being discriminated.

E. Universal Declaration on Bioethics and Human Rights

The Universal Declaration on Bioethics and Human Rights was acclaimed and adopted by UNESCO during the General Conference in October 2003 in order to create universal standards in the field of bioethics. The Netherlands has not taken additional steps in order to implement the principles of the Declaration. The most important concerns, of the Declaration, are for human dignity and human rights and freedoms. UNESCO's choice to use an instrument of a declaratory nature can be explained, at least initially, by being best suited to a constantly changing context and would enable the broadest possible consensus to be reached among Member States. The focus of this declaration lies with the protection of sensitive data. In its preamble UNESCO says that it recognizes *"that decisions regarding ethical issues in medicine, life sciences and associated technologies may have an impact on individuals, families, groups or communities and humankind as a whole"*. Next to this consideration, UNESCO says "*that all human beings, without distinction, should benefit from the same high ethical standards in medicine and life science research"*. This suggests that if every person should benefit from the same high ethical standards, that in a very broad interpretation of the declaration, persons associated should also be protected. In Article 9, UNESCO explains that when the privacy of persons is concerned confidentiality of their personal information should be respected. This should happen to the greatest extent possible, and such information should not be used or disclosed for purposes other than those for which it was collected or consented to. Next to this privacy-related article, the declaration also has a non-discrimination article. In Article 11 it says that no individual or groups should be discriminated against or stigmatized or any grounds, in violation of human dignity, human rights and fundamental freedoms. The interpretation of this declaration could either be in the broadest or the most restrictive sense. In comparison with the Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data, this declaration does not mention genetic data or genetic characteristics. The potential protection of this declaration is therefore much less dependable than that of the other two declarations. Though it shares the weakness of being soft law and of being addressed to States, this declaration has, in Article 1 section 2, extended its applicability to being able to provide guidance to decisions or practices of individuals, groups, communities, institutions and corporations, public and private.

In conclusion the declaration's content may be less dedicated to genetic characteristics or

genetic data than the other two declarations; its application is interestingly bigger than that of the other two.

F. Interim Conclusion

The global soft law instruments do not offer adequate protection against familial genetic discrimination. Firstly, the ILO's Code of Practice on Worker's Personal Data does not allow for interpretation on its scope in order to protect against familial discrimination. Secondly, UNESCO's declarations are interesting sources of inspiration concerning familial genetic discrimination. The only weakness the declarations have is being soft law instruments and therefore lacking legally binding force. In conclusion, the global soft law instruments cannot be said to provide adequate protection in case of familial genetic discrimination.

4.4. Conclusion/ Comparison

In this chapter the question: "does national soft law offer adequate protection against familial genetic discrimination?" was examined. The sources of national soft law mainly offer protection against undesirable behavior. The question remains if for example the codes of conduct also provide adequate protection against familial genetic discrimination. Whereas UNESCO's declarations are much more clear on the 'genetic' part of the discrimination, both sources of soft law, national and international, offer a broad margin of interpretation on the 'familial' scope. In national soft law, for example, the FNV's code of conduct on undesirable behavior created room for interpretation by using the word 'confronted' next to the possibility of being directly the target of discrimination. This left the possibility of being protected in case of familial discrimination wide open to interpretation. UNESCO's declarations acknowledge the fact that genetic information affects more than one person at the same time. Therefore, if the room for interpretation would allow it, protection in case of familial genetic information would also be a possibility. However, insofar the question if national soft law offers adequate protection against familial genetic discrimination, the answer is no. Both sources of soft law could be used in a procedure as a supplement to hard law, but their adequacy insofar protective value depends on the interpretation by the court. In conclusion, national nor global soft law does not offer adequate protection against familial genetic discrimination or any kind of familial discrimination for that matter.

5. Conclusion

Due to rapid changes in technology, which affects various areas of a person's private life, it is important to know that a person's rights and freedoms are protected adequately. In this thesis the rights to the protection of very sensitive information were highlighted. The research subject was the adequacy of protection offered by Dutch hard and soft law, compared against European and global hard and soft law, against individual and familial genetic discrimination. The suppositions concerning this subject were, firstly, that only a part of genetic information was protected. Secondly, it was presumed that the current protection would only concern individual genetic discrimination. Thirdly, the protection from soft law would not concern the subject of genetic information and would therefore not be able to offer protection.

Chapter 1: Hard law protecting against individual genetic discrimination

In this chapter the protection against individual genetic discrimination, from both Dutch as European sources, was discussed. Both sources provided hard law that could be divided in two categories: the first category being about prohibiting discrimination and the second category being protection of privacy. In the first category, Article 1 of the Dutch Constitution was the most interesting anti-discrimination article, since it offered protection on the ground 'or any other grounds'. The advantages of this article were firstly, that it could accommodate the ground 'genetic information', and secondly, the direct applicability of the article in court, which results from the principle of horizontal effect. A disadvantage of the Article is that it depends on the judge if 'genetic information' could be shelved as 'any other ground'. Another source of interesting Dutch hard law is the Equal Treatment Act on Disability or Chronic Illness. The advantage of this Act is that it offers protection against disability or chronic illness, which can be related to a part of genetic information. However, an immediate disadvantage is that the grounds of 'disability' or 'chronic illness' can only be used insofar the result from genetic characteristics. Also, the Act[214] says that the Equal Treatment Committee can investigate (alleged) distinctions. However, the judgments of the ETC are not legally binding. Therefore, Article 6:162 of the DCC is needed, since it offers the possibility of tort.

In the second category, there was no source of hard law that could entirely protect genetic information. As important sources of protecting sensitive data, the Personal Data Protection Act, the Medical Examinations Act and the Act of Agreement on Medical Treatment were found. Sensitive data consists of data concerning 'racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, health and sex life' [215]. However, genetic information refers to all data, of whatever type, concerning the heritable characteristics of an individual, or on the pattern of inheritance of such characteristics within a related group of individuals. It refers to all data on the carriage of any genetic information in an individual or

[214] Equal Treatment Act on Disability or Chronic Illness 2003 (*Wet gelijke behandeling op grond van handicap of chronische ziekte*)(NL)
[215] Article 16 of the Personal Data Protection Act

genetic line relating to any aspect of health or disease, whether present as identifiable characteristics or not[216]. Advantage of the protection, by the three above mentioned Acts, are that insofar genetic information coincides with the ground of 'sensitive data', all types of processing that data is protected. So can Article 49 and 50 PDPA in conjunction with Article 6:162 DCC protect sensitive data by using tort. Disadvantages of the protection are, firstly, that genetic data would only be partially protected by the ground 'health'. This partial protection would only exist in case genetic characteristics had its effect on a person's health. However, in case of asymptomatic genetic characteristics, the ground 'health' could not be used. A second disadvantage is that by prohibiting the processing of sensitive data, a conflict with the Equal Treatment Act on Disability or Chronic Illness could occur, which urges the employer to undertake adjustments[217].

In case of European hard law, the most interesting sources of the first category on the protection against individual genetic discrimination, were Article 19 TFEU, Article 21 EU Charter of Fundamental Rights and Article 14 ECHR. The advantage of Article 19 TFEU was that it could offer protection on the ground of 'disability'[218]. The disadvantages are that it only offers protection insofar the disability results from genetic characteristics, and also, that the TFEU does not have direct effect. Whereas Article 21 EU Charter of Fundamental Rights suffers from the same disadvantage of not being directly applicable, it has a very interesting advantage. Article 21 EU Charter of Fundamental Rights protects on the ground of 'genetic features'. In theory, if the interpretation by Gostin[219] is used, there could be an actual ground of protection against individual genetic discrimination. Also, another interesting article is Article 14 ECHR, which has the advantage of having the ground 'or other status'. In Kiyutin v. Russia[220] the ECtHR said that 'other status' can protect medical conditions or a person's health status. 'Other status' is not limited to innate or inherent personal characteristics and genetic information involves innate or inherent personal characteristics. Therefore, by extending the scope of 'other status', it can be concluded that genetic information would be protected by 'other status'. A disadvantage, however, are the admissibility criteria of Article 34 and 35 ECHR, which preclude the use of Article 14 ECHR in horizontal relationships.

The second category of European hard law, also suffers from the problem of not being applicable in a horizontal relationship. Article 7 and 8 of the EU Charter on Fundamental Rights could offer protection against invasion of privacy or personal life and does not offer limitations which exclude the protection of genetic information. However, Article 51 of the Charter only addresses the institutions and bodies of the European Union. Secondly, Article 8 of the ECHR offers a right to respect for private and family life and could be protected in conjunction with

[216] Project Group on Data Protection (n 66) 18
[217] Gevers (n 5) 101
[218] Other grounds are also mentioned in the Article, however, in the ground of 'disability' is most interesting in case of individual genetic discrimination.
[219] Gostin (n 99) 112: genetic features are features over which an individual has no control and can be genetic traits, conditions or predispositions.
[220] *Kiyutin v Russia* (n 102) section 56

Article 14 ECHR. However, the admissibility criteria of Articles 34 and 35 ECHR prevent actual protection in a horizontal relationship.

In summary, only Dutch hard law offers protection against individual genetic discrimination. A direct source of protection, if the interpretation by the judge would be positive, would be Article 1 of the Dutch Constitution with its 'or any other ground'. However, if the discrimination is focused on a disability, chronic illness or health, there is also some form of protection. Nevertheless, in order to use those grounds they need to result from genetic information/ genetic characteristics.

Chapter 2: Soft law protecting against individual genetic discrimination

In this chapter the protection that could be found in soft law on the subject of individual genetic discrimination was discussed. Firstly, the codes of conduct produced by labor unions were considered. The protection found in the FNV's Regulation on Undesirable Behavior[221] was most interesting, since it could protect against individual genetic discrimination by use of the ground 'any other improper ground', 'health' or 'handicap'. The first ground being the most interesting, since the latter grounds need to result from genetic information/ genetic characteristics. The disadvantage of this protection is, apart from it not being legally binding, that it only offers protection to members, employees and other persons when in a work relationship. Therefore, it does not offer protection during the application for employment. An advantage offered by case law is that codes of conduct could be used as a reference tool in legal proceedings[222].

Considering corporate policies, the protection consists of internal rules on behavior which are created by the employer in order to comply with hard law. Even though corporate policies are supposed to raise awareness in the work environment, the lack of sanctioning leaves those policies without a back bone. However the question is if soft law needs sanctioning, since a claimant often has the chance to use hard law in case of discrimination. The conclusion was given that though Dutch soft law does not offer adequate protection, it could however be seen as a welcome, more detailed, addition to Dutch hard law.

The most interesting sources of protection against individual genetic discrimination can be found in global soft law. The first inspiration can be found in the ILO's Code of Practice on the Protection of Workers' Personal Data. Firstly, the Code extends the scope of the term 'worker', by including any applicant for employment. Secondly, it says that the processing of personal data should not have the effect of unlawfully discriminating in employment or occupation. These first two statements achieved that the Code has a more focused scope on protection of personal data in a work environment than any other source of soft or hard law. Also, as a third statement, the ILO emphasized that medical data should only be collected under special circumstances and with specific purpose. Fourthly, the ILO has also realized that a large number of workers is recruited by employment agencies and therefore the scope of data protection should also include those agencies. Even though the Code is not specifically aimed at

[221] FNV (n 107) 2
[222] See (n 110)

the protection of genetic information, it would be very beneficial if its principles would be implemented in current Dutch hard and soft law.

Another interesting source of global soft law is the Universal Declaration on the Human Genome and Human Rights. This Declaration acknowledges the existence of genetic characteristics and data, and the impact they could have on the right to human dignity, fundamental freedoms and human rights. The disadvantage of the Declaration is that there are no definitions given, which leaves for very open norms. However, these very open norms could be defined by the Dutch legislator. The International Declaration on Human Genetic Data does clarify some important definitions. The most important definition being that of human genetic data which refers to 'information about heritable characteristics of individuals obtained by analysis of nucleic acids or by other scientific analysis'. The International Declaration on Human Genetic Data shares the view of the Universal Declaration on the Human Genome and Human Rights that it is important that no person is reduced to his/her genetic characteristics[223]. Another shared view is the statement that human genetic data should not be used for purposes that discriminate in a (intended) way to infringe on human rights, fundamental freedoms or human dignity[224]. Whereas the ILO's Code specified the scope of protection of personal data, the Universal Declaration on Bioethics and Human Rights' most important statement is that not only States are addressed by the Declaration, but also guidance is provided by the Declaration to individuals, groups, etcetera[225].

In conclusion, the Dutch legislator should implement the principles given by the discussed global soft law, since it would provide for a much more efficient and extensive system of protection against individual genetic discrimination.

Chapter 3: Hard law protecting against familial genetic discrimination

In this chapter the protection against familial genetic discrimination is discussed. The focus of this chapter was to specify if the hard law, that was found capable of protecting against individual genetic discrimination, could also protect in case of familial genetic discrimination. Familial genetic discrimination refers to a distinction made as a result of a person's association with another person, who has a (asymptomatic) genetic predisposition to or probability of having a disease or medical condition. The presumption against familial genetic discrimination was that it would not occur very often and that expanding the grounds of discrimination to allow for familial variants thereof would result in misuse of those grounds. This misuse could occur since it is relatively easy to accuse an employer of discrimination, since only the existence of, for example, a disability, and a causal connection between that disability and the discriminating act, is needed, as is a description of the discriminating act.

Arguments in favor of this position are supported by the Coleman case[226], in which case the mother was discriminated because of her son's disability. Her son's disability consists of a

[223] Article 1 of the International Declaration on Human Genetic Data
[224] Article 7 of the International Declaration on Human Genetic Data
[225] Article 1(2) of the Universal Declaration on Bioethics and Human Rights
[226] *Coleman* (n 35)

symptomatic genetic disease, which would point this case to familial genetic discrimination. However, the ECJ decided that Ms Coleman could also be protected by the European Directive on the grounds of disability or chronic illness. Also, in the European Parliament Resolution of 20 May 2008 on progress made in equal opportunities and non-discrimination in the EU, the European Parliament expressed the wish to protect against discrimination in all forms. One of those forms is familial discrimination. When this view is adopted in future directives, the scope of the current grounds, on which protection could be invoked, would be broadened immensely.

However, protection against familial genetic discrimination can be found. The Dutch hard law that by itself already could, given the right interpretation, protect against familial genetic discrimination would be Article 1 of the Dutch Constitution. In Chapter 3, Smis[227] interpreted the 'any other grounds' of Article 1 of the Dutch Constitution as a criterion that could not be immediately recognized as a questionable criterion. The disadvantage of this interpretation was that the burden of proof would lay with the claimant. However, Smis[228] also said that the definition of discrimination is connected to 'personal group characteristics'. When this definition refers to essential personal characteristics of a person that are congenital, the 'group' would refer to a family. In this interpretation, familial genetic discrimination would also be protected by Article 1 of the Dutch Constitution.

Also, the Equal Treatment Act on Disability or Chronic Illness could also protect if the disability or the chronic illness would result from a person's genetic characteristics. As could the Personal Data Protection Act, if the 'concerned party' would also envelop a person associated with a person, who has a (asymptomatic) genetic predisposition to or probability of having a disease or medical condition. The same conclusion can be drawn for their European counterparts.

However, counterarguments are that though there have not yet been cases in the Netherlands on the subject of familial genetic discrimination, the possibility does exist. In an American interview fears were expressed by persons of a symptomatic genetic disease, that their family members would be discriminated in employment[229]. Also, Advocate General M Poiares Maduro[230] said in his conclusion on the Coleman case[231] that another way to affect a person with a specific characteristic would be by affecting third persons with whom he/she has a close relationship. This would transform the person with the specific characteristic from a victim of discrimination to a means to discriminate. In other words, also the Advocate General acknowledges that there is a possibility that the association with a person could result in discrimination.

In conclusion, the Dutch legislator should be very careful if she decides to follow the European Parliaments' Resolution to offer protection against other forms of discrimination, mainly discrimination by association. The Dutch hard law is open to broader interpretation, but caution must be held concerning misuse of extra protection. It should be kept in mind that even

[227] Smis (n 128)
[228] ibid
[229] Klitzman (n 38)
[230] See (n 181)
[231] *Coleman* (n 35)

though there is no current case law on the subject of familial genetic discrimination, this does not mean that it will stay that way forever.

Chapter 4: Soft law protecting against familial genetic discrimination

The most important statements, that could be derived from Dutch soft law instruments, concerning the protection against familial genetic discrimination, came from codes of conduct on undesirable behavior. Firstly, codes of conduct could be used as a reference tool in procedures to clarify hard law norms and are therefore interesting to discuss. Secondly, the FNV/ CNV's Regulation on Undesirable Behavior[232] was interpreted as also allowing for protection against familial genetic discrimination. However, this was under the condition that 'confronted' would suggest that the discriminating act was not directed at a person's own characteristics, but that person is affected by the discrimination with almost the same impact. The second condition for familial genetic discrimination was that it could only be protected on the grounds of 'health' or 'disability', which would need to result from genetic information/ genetic characteristics. Also, the scope of the Regulation is not as broad as the ILO's Code of Practice on Protection of Worker's Personal Data, since it does not protect applicants of employment.

Next to the use as a reference tool in procedures, it is also important to realize that there are other forms of alternative dispute resolution. Blanpain[233] introduced mediation as a befitting form of alternative dispute resolution in case of an infringement on soft law, since it does not solely focus on rights, but also on individual interests.

Considering global soft law on familial genetic discrimination, the problem with the ILO's Code of Practice on Protection of Workers' Personal Data is that it does not allow for an interpretation that suggests familial genetic discrimination. However the Universal Declaration on the Human Genome and Human Rights does have the possibility to offer protection against familial genetic discrimination. In Article 2, sub a, it says 'everyone's right to respect for their dignity and for their rights regardless of their genetic characteristics', and again in Article 6 'no one shall be subjected to discrimination', the Declaration provides for a broad margin of interpretation. Both sentences would suggest that the Universal Declaration on the Human Genome and Human Rights would also offer protection against familial genetic discrimination.

The International Declaration on Human Genetic Data also provides for a broad margin of interpretation. In Article 7 it said that 'every effort should be made to ensure that human genetic data and human proteomic data are not used for purposes that discriminate in a way that is intended to infringe, or has the effect of infringing human rights, fundamental freedoms or human dignity of an individual or for purposes that lead to the stigmatization of an individual, a family, a group or communities'. The wording of this Article would suggest that human genetic data should also be prevented from being used as a means to familial genetic discrimination. Therefore, the International Declaration on Human Genetic Data could potentially also protect against familial genetic discrimination.

[232] FNV (n 107)
[233] Blanpain (n 220)

The Universal Declaration on Bioethics and Human Rights does not have any articles that would suggest protection against familial genetic discrimination. However, in its preamble UNESCO says "*that all human beings, without distinction, should benefit from the same high ethical standards in medicine and life science research"*. This suggests that if every person should benefit from the same high ethical standards, that in a very broad interpretation of the declaration, persons associated should also be protected.

In conclusion, if inspiration about the protection against familial genetic discrimination is needed, it should be sought in global soft law. Dutch soft law concerning familial genetic discrimination does not make such allowances for broad interpretation.

Conclusion

The protection offered by Dutch hard and soft law, compared to European hard law and global soft law, against genetic discrimination is not adequate, but neither is it non-existent. Protection can be found in various sources of hard law, as summarized above, however in order to find it, interpretation is needed. There is no current Dutch or European hard law that offers protection against genetic discrimination. At the moment the protection needs to be found by interpreting 'open' grounds of discrimination, such as the one in Article 1 of the Dutch Constitution, or by trying to piece the genetic information together so that it fits existing grounds of discrimination, such as 'health', 'disability' or 'chronic illness'. In this thesis it was found that often European hard law or global soft law offer inspiration in order to protect against genetic discrimination. However, the criteria of admissibility are often problematic or the binding force of the source for protection is not legally binding. Concerning familial genetic discrimination it should be concluded that there is often room for interpretation that could allow for its protection. Though there currently is no known case law on the subject, it should not be concluded that this will always be the case. As was done in America after the entering into force of the Genetic Information Discrimination Act of 2008, it might be recommendable to start interviews or research on the subject of genetic discrimination. Considering the limited time frame it was not possible to conduct such an interview or research extensively for this thesis. However, the fact that there are no cases concerning genetic discrimination might also result from the fact that there still is a taboo on discussing genetic diseases or the fact that there is no adequate protection against discrimination based on (asymptomatic) genetic predispositions to or probability of having a disease or medical condition.

Bibliography

Art.1, 'Verslag Anti-discriminatie- en diversiteitstraining Nederland', (www.art1.nl 2008) <http://ec.europa.eu/social/BlobServlet?docId=1644&langId=nl>

Barents R and Brinkhorst LJ, *Grondlijnen van Europees recht* (issue no 12 Kluwer 2006)

Bell M, *Anti-discrimination law and the European Union* (Oxford University Press 2002)

Blanpain R, *Labour Markets, Industrial Relations and Human Resources Management; From Recession to Recovery*, (Wolters Kluwer 2012)

Burkens M, *Beginselen van de Democratische rechtsstaat: Inleiding tot de grondslagen van het Nederlandse staats- en bestuursrecht* (Kluwer 2006)(NL)

Callens S, *Goed Geregeld? Het gebruik van medische gegevens voor onderzoek* (MAKLU 1995)(NL)

CoE, 'Handbook on European Non-Discrimination Law' (Luxembourg, Imprimerie Centrale 2010)

CoE ECRI, 'The Netherlands: Legal measures to combat racism and intolerance in the member States of the Council of Europe' (<www.coe.int/t/dghl/monitoring/ecri/Legal_Research/National_legal_measures>, 'the Netherlands' 2006)

College Bescherming Persoonsgegevens, 'Gedragscodes; Bescherming van persoonsgegevens door zelfregulering' (www.cpbweb.nl, 'Gedragscode')(NL)

College Bescherming Persoonsgegevens, 'Richtsnoeren publicatie van persoonsgegevens op het internet' (www.cpbweb.nl 2007)(NL)

Committee Genetics of ZonMw, *Toepassing van de genetica in de gezondheidszorg: Gevolgen van de ontwikkelingen voor de huidige wet- en regelgeving* (The Hague: ZonMw 2003)(NL)

Craig PP and De Búrca G, *EU Law: Text, Cases and Materials* (Oxford University Press 2008)

Department of Labor e.a, '*Genetic Information and the Workplace*', (<http://www.genome.gov/10001732> 1998)

Fey CC de, Kellermann A and Niewboer JW, *Met recht discriminatie bestrijden* (Boom Juridische Uitgevers 2004)(NL)

FNV Bondgenoten, 'Regeling tot voorkoming van ongewenst gedrag'(<www.fnvbondgenoten.nl> 'Regeling tot voorkoming ongewenst gedrag')

Gerbranda T and Kroes M, *Grondrechten Evaluatie-Onderzoek: Documentatierapport* (Stichting NJCM-Boekerij 1991)(NL)

Gevers J.K.M. and Hendriks A.C., *Bescherming tegen genetische discriminatie; een juridische analyse* (Stichting NJCM-Boekerij 40 2004)(NL)

Gostin L, 'Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers' (1991)17 AM JL & MED. 112.

Heerma van Voss G and Slooten J van, 'Kroniek van het Sociaal Recht*'* (NJB 2008, 1734 03-10-2008)(NL)

Ippel PC, 'Gegeven: De Genen; Morele en juridische aspecten van het gebruik van genetische gegevens'(<cbpweb.nl> 1996)(NL)

Kirton JJ and Trebilcock MJ, *Hard Choices, Soft Law: Voluntary Standards in Global Trade, Environment and Social Governance* (Ashgate Publishing Ltd. 2004)

Leenknegt G-L, 'Het gelijkheidsbeginsel en de scheppingsorde: een staatsrechtelijke botsproef' (Ars Aequi 2005 vol 54 no 9)(NL)

Luijendijk H and Senden L, 'De gelaagde doorwerking van Europese Administratieve Soft Law in de nationale rechtsorde' (<http://www.nver.nl/documents/Preadvies2011_NVER_Luijendijk_Senden.pdf> 2011)(NL)

Passchier C, 'Reactie van de FNV op de Evaluatie Wet bescherming persoonsgegevens' (home.fnv.nl/arbeid/2009/privacy/Reactie_FNV_op_evaluatie_Wbp.pdf 2010)(NL)

Ploem MC, 'De regeling inzake het gebruik van patiëntengegevens voor wetenschappelijk onderzoek in de WGBO – Tijd voor herziening?' (Boom Juridische Uitgevers Tijdschriften 2006 issue 6)(NL)

Project Group on Data Protection, *Draft recommendation on the protection of medical data*, (Straatsburg 1993, CJ-PD (93)53)

Raadgevend Comite voor Bio-ethiek, *Advies nr. 20 van 18 november 2002 betreffende predictieve genetische tests en HIV-tests in het kader van arbeidsverhoudingen,* http://www.ceg.nl/themas/bekijk/voorspellende-geneeskunde/adviezen (NL)

Senden L, *Soft Law in European Community law* (Hart Publishing, Oxford and Portland Oregon 2004)

Smis S, *Handboek Mensenrechten: De internationale bescherming van de rechten van de mens* (Intersentia Antwerpen-Cambridge 2011)(NL)

Sociaal-Wetenschappelijke Raad, ‘Gedragscode voor gebruik van persoonsgegevens in wetenschappelijk onderzoek’ (KNAW 2003)(NL)

Staal C, *De vaststelling van de reikwijdte van de rechten van de mens* (Ars Aequi Libri Nijmegen 2005)(NL)

Stalenhoef KMC, ‘De WGBH/CZ en de spagaat van het sollicitatiegesprek’ (ArbeidsRecht 2009-49, 01-11-2009)(NL)

Vas Nunes PC, ‘Gelijke behandeling op grond van handicap en chronische ziekte in het arbeidsrecht’ (Tijdschrift Arbeidsrechtpraktijk 2009)(NL)

Waddington L, ‘Protection for Family and Friends: Addressing Discrimination by Association’ (European Anti-Discrimination Law Review Issue no. 5 2007)

Werken BHM, ‘Wet gelijke behandeling op grond van handicap of chronische ziekte: met vallen en opstaan vooruit’ (SR 2008, 47 01-08-2008)(NL)

Weyers H and Stamhuis J, *Zelfregulering* (Reed Business Information 2004)

Zoontjens PJJ, *Handicap en Chronische ziekte* (Gelijke behandeling: Oordelen en commentaar 2010)(NL)

List of cases

European Court of Human Rights

Kiyutin v. Russia no 2700/10 (ECHR, 10 March 2011)

European Court of Justice of the European Union

Case C-303/06 *S. Coleman v Attridge Law* [2008] OJ

Case C-13/05, *Chacón Navas* [2006] ECJ

District Court

Sector Kanton Rechtbank Alkmaar, 06-05-2010, LJN BN1637(NL)

Sector Kanton Rechtbank Arnhem, 05-06-2007, LJN BA7119(NL)

Equal Treatment Committee

CGB 15-06-2011, judgment 2010-388 (NL)

CGB 23-10-2007, judgment 2007-184 (NL)

CGB 27-02-2007, judgment 2007-24 (NL)

CGB 23-11-2006, judgment 2006-227 (NL)