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### **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 28<sup>th</sup> 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<sup>212</sup>. 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

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<sup>207</sup> R Barents ea, *Grondlijnen van Europees recht* (issue no 12 Kluwer 2006) 200

<sup>208</sup> Senden (n 199) 107

<sup>209</sup> Senden (n 199) 23

<sup>210</sup> *ibid*

<sup>211</sup> Senden (n 199) 24-25

<sup>212</sup> *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 11<sup>th</sup> 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*<sup>213</sup> 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 32<sup>nd</sup> General Conference, October 16<sup>th</sup> 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

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<sup>213</sup> 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

complaints 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 on 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 and 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<sup>214</sup> 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'<sup>215</sup>. 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

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<sup>214</sup> Equal Treatment Act on Disability or Chronic Illness 2003 (*Wet gelijke behandeling op grond van handicap of chronische ziekte*)(NL)

<sup>215</sup> 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<sup>216</sup>. 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<sup>217</sup>.

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’<sup>218</sup>. 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<sup>219</sup> 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*<sup>220</sup> 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

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<sup>216</sup> Project Group on Data Protection (n 66) 18

<sup>217</sup> Gevers (n 5) 101

<sup>218</sup> Other grounds are also mentioned in the Article, however, in the ground of ‘disability’ is most interesting in case of individual genetic discrimination.

<sup>219</sup> Gostin (n 99) 112: genetic features are features over which an individual has no control and can be genetic traits, conditions or predispositions.

<sup>220</sup> *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<sup>221</sup> 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<sup>222</sup>.

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

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<sup>221</sup> FNV (n 107) 2

<sup>222</sup> 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<sup>223</sup>. 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<sup>224</sup>. 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<sup>225</sup>.

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<sup>226</sup>, in which case the mother was discriminated because of her son’s disability. Her son’s disability consists of a

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<sup>223</sup> Article 1 of the International Declaration on Human Genetic Data

<sup>224</sup> Article 7 of the International Declaration on Human Genetic Data

<sup>225</sup> Article 1(2) of the Universal Declaration on Bioethics and Human Rights

<sup>226</sup> *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<sup>227</sup> 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<sup>228</sup> 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<sup>229</sup>. Also, Advocate General M Poiares Maduro<sup>230</sup> said in his conclusion on the Coleman case<sup>231</sup> 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

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<sup>227</sup> Smis (n 128)

<sup>228</sup> *ibid*

<sup>229</sup> Klitzman (n 38)

<sup>230</sup> See (n 181)

<sup>231</sup> *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<sup>232</sup> 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<sup>233</sup> 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.

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<sup>232</sup> FNV (n 107)

<sup>233</sup> 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.

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