



## Survival of the Fittest: The ‘Right to Enjoy the Benefit of Scientific Progress’ and Corresponding Bioethical Issues

Maeve Elizabeth Clayton

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Supervisor: Professor Helena Pereira de Melo

2<sup>nd</sup> Semester University: Universidade Nova de Lisboa

## **Abstract**

This thesis shall examine the “Right to enjoy the benefit of scientific progress and its applications” (REBSP) in relation to the contemporary bioethical issue of genetic screening/ testing. The research question that shall be posed is whether it is legally and ethically acceptable to use the benefits of scientific progress, specifically pre-implantation genetic diagnosis for the purposes of prevention leading to eradication of certain genetic diseases. Firstly the right itself and how it is enshrined in various international and regional documents shall be examined, followed by the discipline of bioethics and how recent advances in scientific and technological knowledge could have great implications for this field. Then it will look at practical applications of these benefits of scientific progress and their interplay with other human rights and fundamental freedoms. The recent decision of the European Court of Human Rights in the case of *Costa & Pavan v. Italy* will be discussed in relation to potential ramifications this ruling may have for future cases/ scenarios. The concept of human dignity underlies this thesis and is intrinsically interlinked with the REBSP, particularly when taken into consideration with the theories of eugenics. Eugenic fears are frequently invoked when speaking about genetic testing procedures however this thesis shall attempt to assuage those fears by presenting both sides of the argument relating to these contentious yet promising procedures. Some recommendations for the future will be given in order to avoid abusive practices and allow for this right to be fully realised and benefited from the world over.

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## **Introduction**

Charles Darwin was one of the first proponents of the term “Survival of the fittest”. He was referring to his theory of evolution based on natural selection which basically means that those with the more favourable genetic or natural endowments live longer and are more likely to propagate their species. This thesis shall attempt to answer the question of whether it is legally and ethically acceptable to use the benefits of scientific progress, specifically pre-implantation genetic diagnosis (PGD) for the purposes of prevention leading to eradication of certain genetic diseases, a kind of genetically enabled survival of the fittest.

It shall firstly examine the “Right to Enjoy the Benefit of Scientific Progress and its Applications” (REBSP) and the position of this right under international and regional laws. A great number of soft-law documents have been issued regarding this right but not a whole lot of binding hard law documents. This means that while the vast potentialities of this right have yet to be realised, there is still a great deal of flexibility and room for interpretation surrounding it. The REBSP is a right with huge scope and potential and this thesis shall examine only a few select issues pertaining to it.

Then it shall examine the discipline of bioethics and how it pertains to this right. Recent advances in scientific and technological knowledge could have great implications for this field, in particular issues such as genetic testing and genetic screening, with a particular focus on PGD. It will look at an application of these benefits of scientific progress in practice, in Cyprus which implemented a policy of carrier screening in a bid to eradicate a certain genetically transmitted disease. How the use of these benefits of scientific progress interacts with other human rights and fundamental freedoms shall also be examined here.

Then the case of *Costa & Pavan v. Italy* which recently came before the European Court of Human Rights shall be discussed in relation to the potential

implications this case could have for future rulings or scenarios. The fear of eugenics always underlies any kind of debate on the usage of genetic testing procedures and the final section shall try to frame those debates in a contemporary light in order to decipher if it is legally and ethically acceptable to use the benefits of scientific progress, specifically PGD with a view to the eradication of certain diseases. This thesis shall attempt to assuage those eugenic fears by presenting both sides of the argument relating to these contentious yet promising procedures. Some recommendations for the future will be given in order to avoid abusive practices and allow for this right to be fully realised and benefited from the world over.

# **Chapter 1: The Right to Enjoy the Benefit of Scientific Progress and its Applications**

## **1. International Law**

The notion of a “Right to Science”<sup>1</sup> first appears in International Law in the Universal Declaration of Human Rights (UDHR) which proclaims that “Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.”<sup>2</sup>

This right is further elaborated upon in the International Covenant on Economic, Social and Cultural Rights (ICESCR) which declares that, “The States Parties to the present Covenant recognize the right of everyone:

- a. To take part in cultural life;
- b. To enjoy the benefits of scientific progress and its applications.”<sup>3</sup>

It further stresses the obligation on States to take steps “necessary for the conservation, the development and the diffusion of science and culture”<sup>4</sup> as well as the need for States “to respect the freedom indispensable for scientific research and creative activity.”<sup>5</sup> It also encourages States to “recognize the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific and cultural fields.”<sup>6</sup>

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<sup>1</sup> The term “Right to Science” here is used interchangeably with the “Right to enjoy the benefits of scientific progress and its applications” as done by Ms. Farida Shaheed, United Nations Special Rapporteur in the field of cultural rights, in A/HRC/20/26, 14 May 2012, para.1.

<sup>2</sup> United Nations (UN), Universal Declaration of Human Rights, 10 December 1948, at <http://www.un.org/en/documents/udhr/index.shtml>, Article 27 (1), (consulted on 19 June 2013).

<sup>3</sup> UN, International Covenant on Economic, Social and Cultural Rights, 16 December 1966, at <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx>, Article 15 (1) (a) & (b), (consulted on 19 June 2013).

<sup>4</sup> Ibidem, Article 15 (2).

<sup>5</sup> Ibidem, Article 15 (3).

<sup>6</sup> Ibidem, Article 15 (4).

Whilst some may argue that Economic, Social and Cultural Rights do not carry the same weight as Civil and Political Rights in the global Human Rights sphere, this is not the view promulgated by the United Nations (UN) and as such there is no denying their normative content.<sup>7</sup> Nor is it possible to refute the ever increasing acceptance that the UDHR by means of customary law is a binding international agreement.<sup>8</sup>

## **2. Regional Law**

The advent of these State oriented obligations imposed by the UDHR and the ICESCR has resulted in the elaboration and inclusion of this “Right to Science” in the vast majority of the Human Rights treaties/ documents of the Regional Inter-State Organisations. It is clear that there is an obvious international trend towards the recognition of the importance of this right, which will only continue to grow over time thanks to the rapid advancements in science and technology today.

### **2.1 Americas**

The American Declaration of the Rights and Duties of Man which actually pre-dates the UDHR by 8 months states that, “Every person has the right to take part in the cultural life of the community... and to participate in the benefits that result from intellectual progress, especially scientific discoveries.”<sup>9</sup>

The Charter of the Organization of American States (OAS) speaks of the need to devote efforts to the “Protection of man's potential through the extension and

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<sup>7</sup> “Civil and political rights and economic, social and cultural rights are not fundamentally different from one another, either in law or in practice. All rights are indivisible and interdependent.” UN, Economic, Social and Cultural Rights Handbook for National Human Rights Institutions, 2005, at <http://www.ohchr.org/Documents/Publications/training12en.pdf>, p.3, (consulted on 19 June 2013).

<sup>8</sup> UN, Digital Record of the UDHR, February 2009, at <http://www.ohchr.org/EN/NEWSEVENTS/Pages/DigitalrecordoftheUDHR.aspx>, (consulted on 19 June 2013).

<sup>9</sup> OAS, American Declaration of the Rights and Duties of Man, April 1948, at <http://www.cidh.oas.org/Basicos/English/Basic2.american%20Declaration.htm>, Article XIII, (consulted on 19 June 2013).

application of modern medical science”<sup>10</sup> as well as requesting that “The Member States shall extend among themselves the benefits of science and technology by encouraging the exchange and utilization of scientific and technical knowledge in accordance with existing treaties and national laws”<sup>11</sup>

The American Convention on Human Rights or the “Pact of San Jose, Costa Rica”<sup>12</sup> says that “The States Parties undertake to adopt measures, both internally and through international cooperation, especially those of an economic and technical nature, with a view to achieving progressively, by legislation or other appropriate means, the full realization of the rights implicit in the economic, social, educational, scientific, and cultural standards set forth in the Charter of the Organization of American States as amended by the Protocol of Buenos Aires.”<sup>13</sup>

The Additional Protocol to this Convention, the “Protocol of San Salvador”<sup>14</sup> further states that “The States Parties to this Protocol recognize the right of everyone:

- a. To take part in the cultural and artistic life of the community;
- b. To enjoy the benefits of scientific and technological progress.”<sup>15</sup>

## **2.2 Africa and the Arab World**

The Charter of the African Union emphasises the need for scientific and technical co-operation between Member States in order to fulfil its purposes.<sup>16</sup>

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<sup>10</sup> OAS, Charter of the Organization of American States, 30 April 1948, at [http://www.oas.org/dil/treaties\\_A-41\\_Charter\\_of\\_the\\_Organization\\_of\\_American\\_States.pdf](http://www.oas.org/dil/treaties_A-41_Charter_of_the_Organization_of_American_States.pdf), Article 34 (i), (consulted 19 June 2013).

<sup>11</sup> Ibidem, Article 38.

<sup>12</sup> OAS, American Convention on Human Rights “Pact of San Jose, Costa Rica”, 22 November 1969, at [http://www.oas.org/dil/treaties\\_B-32\\_American\\_Convention\\_on\\_Human\\_Rights.htm](http://www.oas.org/dil/treaties_B-32_American_Convention_on_Human_Rights.htm), (consulted on 19 June 2013).

<sup>13</sup> Ibidem, Chapter 3, Article 26.

<sup>14</sup> OAS, Additional Protocol to the American Convention on Human Rights in the area of Economic, Social and Cultural rights "Protocol of San Salvador", 17 November 1988, at <http://www.oas.org/juridico/english/treaties/a-52.html>, (consulted on 19 June 2013).

<sup>15</sup> Ibidem, Article 14 (1) (a) & (b).

Whilst not included in the original 1994 version of the Arab Charter on Human Rights, the updated 2004 version of the charter also professes that “Every person shall have the right to take part in cultural life, and to enjoy the benefits of scientific progress and their applications.”<sup>17</sup>

### **2.3 South-East Asia**

The recently formulated ASEAN (Association of South-East Asian Nations) Human Rights Declaration also proclaims that “Every person has the right, individually or in association with others, to freely take part in cultural life, to enjoy the arts and the benefits of scientific progress and its application.”<sup>18</sup>

### **2.4 Europe**

The Charter of Fundamental Rights of the European Union (EU) in its preamble speaks of the necessity to “strengthen the protection of fundamental rights in the light of changes in society, social progress and scientific and technological developments by making those rights more visible in a Charter.” Thus it states that “The arts and scientific research shall be free of constraint. Academic freedom shall be respected.”<sup>19</sup>

In addition, the Council of Europe (COE)’s Oviedo Convention,<sup>20</sup> in its preamble, resolves to “take such measures as are necessary to safeguard human dignity and the fundamental rights and freedoms of the individual with regard to the application

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<sup>16</sup> Organization of African Unity (OAU), OAU Charter, 25 May 1963, at [http://www.au.int/en/sites/default/files/OAU\\_Charter\\_1963.pdf](http://www.au.int/en/sites/default/files/OAU_Charter_1963.pdf) charter, Article II (2) (e), (consulted on 19 June 2013).

<sup>17</sup> The League of Arab States, Arab Charter on Human Rights, 22 May 2004, at [http://www.acihl.org/res/Arab\\_Charter\\_on\\_Human\\_Rights\\_2004.pdf](http://www.acihl.org/res/Arab_Charter_on_Human_Rights_2004.pdf), Article 42 (1), (consulted on 19 June 2013).

<sup>18</sup> ASEAN, ASEAN Human Rights Declaration, 19 November 2012, at <http://www.asean.org/news/asean-statement-communiques/item/asean-human-rights-declaration> , Article 32, (consulted on 19 June 2013).

<sup>19</sup> 2000/C 364/01, 7 December 2000, Article 13.

<sup>20</sup> COE, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo Convention), 4 April 1997, at <http://conventions.coe.int/Treaty/en/Treaties/Html/164.htm>, (consulted on 19 June 2013).

of biology and medicine.” Following up on this, it states that “the interests and welfare of the human being shall prevail over the sole interest of society or science.”<sup>21</sup> It also adds that “Scientific research in the field of biology and medicine shall be carried out freely, subject to the provisions of this Convention and the other legal provisions ensuring the protection of the human being.”<sup>22</sup> The explanatory report for this Convention further elaborates on this and states that “Freedom of scientific research in the field of biology and medicine is justified not only by humanity's right to knowledge, but also by the considerable progress its results may bring in terms of the health and well-being of patients.”<sup>23</sup> However it clarifies that this “freedom is not absolute. In medical research it is limited by the fundamental rights of individuals,”<sup>24</sup> thus ensuring compliance with its own previously stated aim to safeguard human dignity and respect their rights and freedoms.

Thus it is clear in the mind of this author that an internationally recognised “right to science” does indeed exist, is of the utmost importance and should be both respected and protected whilst also having due regard to other fundamental rights and freedoms.

### **3. General Comments**

Whilst no General Comment (GC) has yet been issued on the Right to Enjoy the Benefits of Scientific Progress and its Applications (REBSP), two GC's have been issued by the Committee on Economic, Social and Cultural rights (CESCR) which bear some relevance to this right whilst not explicitly dealing with it. These are General Comment No. 14.( 2000) The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights)<sup>25</sup> and

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<sup>21</sup> Ibidem, Article 2.

<sup>22</sup> Ibidem, Article 15.

<sup>23</sup> COE, Explanatory Report to the Oviedo Convention, 17 December 1996, at <http://conventions.coe.int/Treaty/EN/Reports/Html/164.htm>, para. 95, (consulted on 19 June 2013).

<sup>24</sup> Ibidem, para. 96.

<sup>25</sup> E/C.12/2000/4, 11 August 2000.

General Comment No. 21 (2009) Right of everyone to take part in cultural life (article 15, para.1 (a), of the Covenant).<sup>26</sup>

The Committee has also issued General Comment No. 17 (2005) The right of everyone to benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he or she is the author (article 15, para.1 (c), of the Covenant).<sup>27</sup> This GC shall not be discussed here as it is not relevant to this thesis, however it is certainly interesting to note its existence as there are now GC's pertaining to both article 15 (a) and article 15 (c) of the Covenant, but not to article 15 (b), REBSP. This could perhaps be viewed as somewhat of a reluctance on the part of the Committee to issue a declaration on a potentially contentious and highly challenging issue, the scope and implications of which we almost certainly do not yet fully grasp.

### **3.1 General Comment No. 14 (2000) The Right to the Highest Attainable Standard of Health**

In this GC, the Economic and Social Council (ECOSOC), through the CESCR, referring to art. 12. 2 (c)<sup>28</sup> of the ICESCR posits that, “The control of diseases refers to States’ individual and joint efforts to, inter alia, make available relevant technologies, using and improving epidemiological surveillance and data collection on a disaggregated basis, the implementation or enhancement of immunization programmes and other strategies of infectious disease control.”<sup>29</sup>

This author then would contend that, considering the clear link between the REBSP and other rights such as the right to health, as elaborated upon by the Special Rapporteur in the field of cultural rights, Farida Shaheed, in her 2012 report<sup>30</sup>, discussed

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<sup>26</sup> E/C.12/GC/21, 21 December 2009.

<sup>27</sup> E/C.12/GC/17, 12 January 2006.

<sup>28</sup> “The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for... The prevention, treatment and control of epidemic, endemic, occupational and other diseases.”

<sup>29</sup> E/C.12/2000/4, 11 August 2000, para. 16.

<sup>30</sup> A/HRC/20/26, 14 May 2012.

in further detail below, that the reference to “other diseases” in art. 12. 2 (c) could here be interpreted to mean genetic diseases, whilst the reference to “relevant technologies” could refer to such technologies which have arisen as a result of scientific and technological advances, namely, in terms of relevance to this particular thesis, such genetic testing procedures as PGD. Whilst the Committee acknowledged that limitations to this right were permissible, in accordance with art. 4 of the Covenant, they also stated their wish to “emphasize that the Covenant’s limitation clause, article 4, is primarily intended to protect the rights of individuals rather than to permit the imposition of limitations by States.”<sup>31</sup>

Thus, it is this author’s belief that this provision could be read as implying an obligation on States to make available these types of technologies, wherever practicable, in accordance with the right to health due to the potential benefits arising from them to individuals within the State. This obligation could be further derived when viewed in conjunction with the other core obligations the Committee imposes on States parties which include obligations to take measures “To ensure reproductive, maternal (pre-natal as well as post-natal) and child health care”<sup>32</sup> and perhaps more importantly, “To take measures to prevent, treat and control epidemic and endemic diseases.”<sup>33</sup> Based off these provisions this author would then strongly contest that there is an obligation on States to provide for, or at the very least to undertake to make provisions for, certain healthcare procedures, which this author feels could be interpreted as including the procedure of PGD as a means of reproductive and pre-natal healthcare with a view also to preventing or controlling endemic diseases.

### **3.2 General Comment No. 21 (2009) The Right of Everyone to Take Part in Cultural Life**

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<sup>31</sup> E/C.12/2000/4, 11 August 2000, para. 28.

<sup>32</sup> Ibidem, para 44 (a).

<sup>33</sup> Ibidem, para 44 (c).

The Committee reaffirms the strong link between this right and the REBSP in this GC.<sup>34</sup> It also states that “Given the interrelationship between the rights set out in article 15 of the Covenant... the full realization of the right of everyone to take part in cultural life also requires the adoption of steps necessary for the conservation, development and dissemination of science and culture.”<sup>35</sup> This GC also implicitly refers to the REBSP in more general terms by calling for non-discrimination in the fields of scientific education, research and diffusion as well as an effort at encouraging and enabling widespread participation in all areas of cultural life, which would include scientific areas.

As is evidenced from the above- mentioned GCs’ there is no clear effort made to expand on nor clarify the REBSP, merely allusions to what it could potentially entail, if we accept it as being intrinsically linked to the more specific Rights to Culture and Health, as endorsed by Special Rapporteur Shaheed in her Report. It is clear that there is a need for a more specific GC, focussing expressly on the REBSP in order to further clarify this right and set out exactly what obligations are expected of States and other international and regional actors and groups under it. This necessity for a specific GC in order to elaborate on the right is echoed in the report of the expert working group on the REBSP, the “Venice Statement” which we shall now discuss.

#### **4. Venice Statement**

The Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and its Applications<sup>36</sup> is a report which was published as a result of the third experts’ meeting on the REBSP held in Venice on 16-17 July 2009, organised jointly by the United Nations Educational, Scientific and Cultural Organisation (UNESCO) and the European Inter-University Centre for Human Rights and Democratisation (EIUC) in partnership with the Amsterdam Center for International Law and the Irish Centre for

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<sup>34</sup> E/C.12/GC/21, 21 December 2009, para. 2.

<sup>35</sup> Ibidem, para. 47.

<sup>36</sup> Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and its Applications, 16-17 July 2009, at <http://unesdoc.unesco.org/images/0018/001855/185558e.pdf>, (consulted on 20 June 2013).

Human Rights. The experts consisted of members of intergovernmental organisations (IGO's) and bodies, members of the CESCR, the UN Special Rapporteur on the Right to food and representatives both of UNESCO and non-governmental organisations (NGO's). The aim of the meeting was primarily to set-out and clarify the right's normative content and the corresponding relevant State Obligations.

The need for a GC from the CESCR was stressed during the drafting debate for the statement. The lack of clarity concerning the right's normative content and the corresponding obligations on States was also expressed as well as the need for greater international co-operation between both State and non-State actors in order to effectively implement and vindicate that right. The considerations of the experts were taken on board in the drafting of the text which was then adopted by consensus. The opinions expressed therein are those of the individual experts and are not necessarily reflective of any of the bodies which they represent.

The Statement purports to clarify the normative content of the right as well as State obligations arising from it. It is divided into a number of sections, as summarised below. Though not legally binding, the result is a solid starting ground from which to begin in terms of fully elucidating the right. The potential scope of the right is undeniably huge and this statement raises a number of key relevant issues for consideration as well as offering some excellent guidelines for its future elaboration. The Statement is divided into sections relating to the contemporary relevance of the right, conceptual challenges, the normative content, State obligations and the next steps to be taken.

Globalisation has had a huge impact on human rights, both positive and negative. It has led to inequalities and caused disparities between States concerning access to and the availability of certain goods and services. The increasing role played by non-state actors is also a concern here, as it is the responsibility of States to regulate their practices, at least within their jurisdiction and they need to be able to effectively balance the rights of all concerned parties.

## **4.1 Challenges<sup>37</sup>**

The benefits arising from science should be available to all without discrimination. It is necessary to clarify what exactly is meant by the different components of the right, how to resolve its potential conflicts with other rights and freedoms and how to balance the right equally among all actors. Freedom of inquiry and research are also important as well as the transfer of, availability and access to scientific knowledge. Most importantly, the report draws a distinction between “enjoyment as ‘participation’” and “enjoyment as actual ‘sharing.’ Participation in scientific progress is valuable in its own right... The right to share in scientific benefits should not be predicated on participation, particularly where there is a direct threat to fundamental rights, most notably the rights to life, health and food.”<sup>38</sup>

## **4.2 Normative Content**

The fundamental principles which should be considered, according to the Venice statement, when elaborating the normative content of this right are; that it is applicable to all fields of science and its applications, it must be consistent with fundamental human rights principles, in conformity with the principles of universality, indivisibility, interdependence and interrelatedness, an awareness of the fact that this right is inextricably linked to other rights, that it can be enjoyed individually and collectively, should be applied in accordance with the precautionary principle and that the implementation of the right requires close international cooperation.<sup>39</sup>

Bearing this in mind, it states that the normative content of the right should aim at creating an “enabling and participatory environment” where the development and diffusion of science and technology is possible in accordance with the freedoms of expression and opinion. This includes academic and scientific freedom. It should also

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<sup>37</sup> Ibidem, paras. 6-11.

<sup>38</sup> Ibidem, para. 11.

<sup>39</sup> Ibidem, para. 12.

allow for non-discriminatory access to the benefits arising from scientific progress and its applications as well as protection from the misuse or abuse of same.<sup>40</sup>

### **4.3 State Obligations**

The State Obligations which the Venice statement believes should apply are categorised under the universally recognised tripartite typology of obligations i.e. the duties to respect, protect and fulfil.

The duty to respect includes respect for freedoms necessary to carry out scientific research such as freedoms of thought and opinion, information and cross-border co-operation. It also refers to appropriate measures taken to ensure non-interference with the enjoyment of other rights and freedoms.<sup>41</sup>

The duty to protect means to implement measures, including legislative ones in order to prevent and prohibit the use of science and technologies by third parties which could be detrimental to other rights and freedoms as well as to take measures to protect those people subject to scientific research.<sup>42</sup>

The duty to fulfil thus includes the adoption of legal and policy frameworks as well as the establishment of institutions to promote the diffusion and development of science, consistent with other rights and freedoms. It also includes the promotion of access to the benefits of science in a non-discriminatory manner, monitoring its potential harmful effects and taking measures to strengthen international co-operation as well as providing opportunities for public engagement in decision making and implementing effective science curricula at all levels of the educational system.<sup>43</sup>

### **4.4 Next Steps**

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<sup>40</sup> Ibidem, para. 13.

<sup>41</sup> Ibidem, para. 14.

<sup>42</sup> Ibidem, para. 15.

<sup>43</sup> Ibidem, para. 16.

In order to fully and effectively raise awareness of and implement this right, the co-operation and participation of a number of different State, non- State and International actors are required. It calls on UNESCO particularly to take the lead in the promotion and elaboration of this right, especially with regards raising awareness of the complaints mechanism which exists under Ex 104/ Decision 3.3<sup>44</sup> to allow recourse for violations of the right.<sup>45</sup>

It also calls on other specialised agencies to do their part to promote and draw attention to this right, e.g. United Nations Children's Fund (UNICEF), The World Health Organization (WHO), The Office of the High Commissioner for Human Rights (OHCHR) in particular should devote resources towards clarifying this right and work in conjunction with ECOSOC, creating a link between this and other rights.<sup>46</sup>

They called upon the Human Rights Council (HRC) to consider appointing an independent expert on the matter and for existing special procedures to pay closer attention to the issue.<sup>47</sup> These particular requests can be seen as one of the successes of the Venice statement as the Council evidently took this on board. HRC resolution 10/23<sup>48</sup> allowed for the appointment of and established the mandate for a Special Rapporteur in the area of cultural rights. This resolution recognizes the right of everyone to take part in cultural life and to enjoy the benefits of scientific progress and its applications and it eventually resulted in the issuance of a report in 2012 on said right.

It calls on treaty bodies to monitor more closely references to this right in their treaties and particularly requests that the CESCR engage more effectively in dialogue

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<sup>44</sup> UNESCO, 104 EX/Decision 3.3, 10 July 1977, at <http://unesdoc.unesco.org/images/0002/000284/028409e.pdf#page=13>, p.12, (consulted on 20 June 2013.)

<sup>45</sup> Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and its Applications, 16-17 July 2009, at <http://unesdoc.unesco.org/images/0018/001855/185558e.pdf>, para. 18.

<sup>46</sup> Ibidem, paras. 19-20.

<sup>47</sup> Ibidem, para. 21.

<sup>48</sup> A/HRC/RES/10/23, 26 March 2009.

with States Parties about this right. It also again expresses the desire for a General Comment on the matter.<sup>49</sup>

It also calls on the regional Human Rights bodies to find a way of implementing the right.<sup>50</sup> It points out that States have a large role to play and should apply human rights based approaches in their science and technology fields. They should also promote international co-operation as well as taking measures to protect individuals from the potential harmful effects of science. States parties should report more on the right in their periodic reports and those who have not yet done so, should ratify the optional protocol to the ICESCR in order to allow for recourse to an effective complaints mechanism.<sup>51</sup>

The scientific community could use their expertise to help develop greater awareness of the right.<sup>52</sup> Civil society groups have a critical role to play regarding the implementation of this right through advocacy and aiding the victims of violations of this right by submitting reports to the relevant complaints mechanisms.<sup>53</sup>

Finally the increased importance of the role of the private sector is again noted here. It is not contrary to their aims and purpose to endorse this right and they should consider finding a way to contribute to it, such as by implementing relevant guidelines for the protection of relevant parties.<sup>54</sup>

As stated above, the potential scope of this right is undeniably huge and the guidelines set out in the Venice statement are but a mere starting platform for the international community to consider in their eventual full and effective elucidation of the right, concerning its normative content and the corresponding State obligations. This report was published 4 years ago, however not that much progress has been made in the field since then. No GC has been issued as of yet and many of the other suggestions

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<sup>49</sup> Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and its Applications, 16-17 July 2009, at <http://unesdoc.unesco.org/images/0018/001855/185558e.pdf>, para. 22.

<sup>50</sup> Ibidem, para 23.

<sup>51</sup> Ibidem, para. 24.

<sup>52</sup> Ibidem, para. 25.

<sup>53</sup> Ibidem, para. 26.

<sup>54</sup> Ibidem, para. 27.

made here have also it would seem been largely ignored by the individuals, groups or organisations they were directed towards. However the more recent 2012 Report of the Special Rapporteur in the field of cultural rights was certainly a positive and affirming step in the right direction and has brought renewed attention to this extremely important right once again.

## **5. Report of the Special Rapporteur**

The mandate of the Special Rapporteur in the field of cultural rights was renewed and updated for three more years by the HRC in 2012 in its Resolution 19/6.<sup>55</sup> The Special Rapporteur, Farida Shaheed accordingly issued a report on “The right to enjoy the benefits of scientific progress and its applications” in 2012.<sup>56</sup> In this report she elucidated observations and made recommendations concerning the right to enjoy the benefits of scientific progress. In this section this author will examine the report and highlight parts which are relevant to this thesis under 3 main thematic sections as discussed by Shaheed namely,

- (i) The relationship between this right and other human rights
- (ii) The scope, normative content and obligations on States
- (iii) Recommendations/ Areas for further consideration

### **5.1 Relationship with other human rights**

The Right to science and the right to culture are inherently inter-linked. They are grouped together in the same provisions, both of the UDHR and the ICESCR. In GC no. 21 as mentioned above, the committee refers also to “the interrelationship between the rights set out in article 15 of the Covenant.<sup>57</sup> Shaheed refers to the discussions leading

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<sup>55</sup> A/HRC/19/L.18, 15 March 2012.

<sup>56</sup> A/HRC/20/26, 14 May 2012.

<sup>57</sup> E/C.12/GC/21, 21 December 2009, para. 47.

to the Venice Statement as also establishing a bond between the rights to science and culture, where she says that it was “stressed that access to the benefits of scientific progress not only allowed improving one’s socio-economic situation but also gave the opportunity to take a meaningful part in the life of communities”<sup>58</sup> which is a fundamental part of cultural life.

She states that both rights relate to the “pursuit of knowledge and understanding and to human creativity in a constantly changing world.”<sup>59</sup> She reiterates this idea of the constantly changing world and pursuit of knowledge when she speaks of people’s “ability to aspire” towards a “better future that is not only desirable but attainable”<sup>60</sup> Clearly she is envisaging the enormous potential benefits which could be gleaned from the effective implementation and realisation of the right to science in the future. When considering that “aspirations embody people’s conceptions of elements deemed essential for a life with dignity”<sup>61</sup> and these aspirations are drawn from commonly shared culturally and societally permeating notions of what is desirable, combined with knowledge of what is and what could be attainable, then one could only reasonably come to the conclusion that this right to science is indeed inherently linked to the right to culture.

She also discusses the fact that considering the far-reaching effects of the right to science on the world at large, it is obvious that the right is linked with other fundamental rights and freedoms, namely the freedom of expression, the right of everyone to take part in the conduct of public affairs, the right of all peoples to self-determination and the right to development.<sup>62</sup> She discusses the importance of due consideration concerning what exactly is to be thought of as a “benefit” or “scientific progress” and the possible right to make informed decisions arising out of this.<sup>63</sup> She

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<sup>58</sup> A/HRC/20/26, 14 May 2012, para. 19.

<sup>59</sup> Ibidem, para. 17.

<sup>60</sup> Ibidem, para. 20.

<sup>61</sup> Ibidem.

<sup>62</sup> Ibidem, para. 21.

<sup>63</sup> Ibidem, para 22.

also mentions the obvious link between this right and others such as the right to water, housing, education and the right to health.<sup>64</sup>

## **5.2 Scope, normative content & obligations on States**

### **5.2.1 Scope**

As previously stated, the potential scope of this right is enormous. The Special Rapporteur encourages us to remember that the “benefits” of science encompass not only scientific results and outcomes but also the scientific process, its methodologies and tools.”<sup>65</sup>

### **5.2.2 Normative Content & State Obligations**

Considering this, it is required that the normative content of the right be able to encompass, in a non-discriminatory manner, equal access to the benefits of scientific progress for all as well as equal opportunities to contribute to the “scientific enterprise.” Freedom of research, inclusive participation in decision-making and an enabling environment fostering the “conservation, development and diffusion of science and technology”<sup>66</sup> are also requisites. These classifications seem largely to be echoes of those expressed in the Venice Statement.

The “right of access” to the benefits of science refers to “access to science as a whole”<sup>67</sup> that is to say, scientific knowledge, education, information, applications and technologies. “One core principle is that innovations essential for a life with dignity should be accessible to everyone, in particular marginalized populations”<sup>68</sup> This concept

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<sup>64</sup> Ibidem, para. 23.

<sup>65</sup> Ibidem, para. 24.

<sup>66</sup> Ibidem, para. 25.

<sup>67</sup> Ibidem, para. 26.

<sup>68</sup> Ibidem, para. 29.

of a “life with dignity” plays a key part in the debate over genetic testing. In order to facilitate this right of access, “States should ensure that the benefits of science are physically available and economically affordable on a non-discrimination basis.”<sup>69</sup>

Freedom of scientific research refers to political non-interference as well as freedom of inquiry and association for scientists, both domestically and internationally. Freedom of expression is important here too and “barriers to scientific research and opportunities for entering the science professions... must be overcome.”<sup>70</sup> This must be done in accordance with the principles of non-discrimination.

The participation of individuals and communities in decision-making is important in order to hear the views of all members of society, including the most vulnerable or most likely to be affected by the “negative consequences of scientific testing or applications.”<sup>71</sup>

The conservation, development and diffusion of scientific knowledge and technology are paramount to the full and effective realisation of the right. In all instances the onus is clearly on States to facilitate the fulfilment of each of these necessary requirements.

Limitations to this right are permissible in accordance with article 4 of the ICESCR and due regard must be given to all other rights and freedoms. The Special Rapporteur reiterates the importance of the precautionary principle here<sup>72</sup>, “in the absence of scientific consensus”<sup>73</sup> as previously mentioned in the Venice Statement, in order to avoid potentially harmful practices.

The Special Rapporteur also acknowledges the importance of other international declarations and guidelines in this domain, particularly in relation to the avoidance of harmful practices and speaks of the need to develop ethical codes more in line with

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<sup>69</sup> Ibidem, para.30.

<sup>70</sup> Ibidem, para. 42.

<sup>71</sup> Ibidem, para. 43.

<sup>72</sup> Ibidem, para. 50.

<sup>73</sup> Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and its Applications, 16-17 July 2009, at <http://unesdoc.unesco.org/images/0018/001855/185558e.pdf>, paras. 12 (f) and 16 (c).

Human Rights standards, as well as the need for increased active State participation in the overseeing of activities undertaken both by the public and the private sector.<sup>74</sup>

### **5.2.3 Areas for further consideration**

Intellectual property rights and the interests of the holders therein should also be considered. But, the Special Rapporteur notes, “States must establish ‘minimum standards of protection’<sup>75</sup> in order to protect human rights norms and standards. The “equitable sharing of benefits and transfer of technologies”<sup>76</sup> should also be considered. For an interpretation of what exactly this entails for different categories of States the Special Rapporteur recommends looking to a number of different international and regional documents for guidance. The Special rapporteur notes that despite the increasing role of the private sector in the area of science, the States should not rely solely on them and instead should “ensure that private companies respect human rights,”<sup>77</sup> either through clear guidance or incentivising initiatives and strategies.

She makes a great number of further recommendations but here are summarised the most important, in relation to the topic of bioethics, which shall be discussed in greater detail in the following chapter. Firstly she recommends that States make sure that “innovations essential for a life with dignity reach everyone and identify the priority needs of marginalized populations.” She then calls upon States to respect the freedoms necessary for the promulgation of the right to science as well as carrying out their obligations to “respect, protect and fulfil.” Education, participation and promotion are all priority areas of work, as well as awareness raising, conservation, development and the diffusion of science. States need to prioritise their goals in accordance with their capabilities but all should respect human rights and ethical principles whilst avoiding causing any harm.<sup>78</sup>

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<sup>74</sup>A/HRC/20/26, 14 May 2012, paras. 50-55.

<sup>75</sup>Ibidem. para. 59.

<sup>76</sup>Ibidem. paras. 66- 69.

<sup>77</sup>Ibidem. para. 71.

<sup>78</sup>Ibidem. para. 74

She calls upon States to implement her recommendations and makes further recommendations including a call for the CESCR to elaborate a GC which could shed more light on this right for the sake of clarity. Increased co-operation and communication and a more inclusive participatory process between all relevant individuals and groups relative to this right would also be beneficial. She finally calls upon the HRC to request of the OHCHR to facilitate a process which assesses the impact of new scientific research on human rights, measures to deal with this and an appropriate monitoring system.<sup>79</sup>

Both the Venice Statement and the Report of the Special Rapporteur make a number of extremely interesting points concerning the REBSP. They set out some broad guidelines and definitive, yet not exhaustive avenues to take in terms of further elaboration of the right so that it may come to realise its full scope and power. It is indubitably a right which holds a great amount of potential and could in time prove to be of great benefit to all humankind though equally, if abused could prove disastrous. It is for all these reasons that a right such as this, with such far-reaching potentialities needs now more than ever to be fully recognised and understood by the International Community so as to allow for the full and effective implementation of the right in order both to benefit and to protect humanity and indeed the world at large.

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<sup>79</sup> Ibidem. para. 75.

## **Chapter 2: Bioethics**

### **1. Origin/ Definition**

“In the years following World War II, concerns about the ‘dehumanization’ of medicine arose in a variety of places... What is known today as "bioethics" thus began a decade and a half after the end of World War II as a loosely-defined movement to “humanize” medical education and practice.”<sup>80</sup> The term “Bioethics” is widely established to have been coined by Van Rensselaer Potter in 1971 in his book *Bioethics: Bridge to the future*. This was confirmed in an interview he undertook with Warren Thomas Reich in 1992.<sup>81</sup> Reich describes the discipline as having undergone a “bi-located birth,”<sup>82</sup> for at around the same time that Potter coined the term and was developing the discipline as he interpreted or envisaged it to be at the University of Wisconsin, another individual, André Hellegers at Georgetown University who was a key figure in the establishment of the Kennedy Institute of Ethics at Georgetown University, (the first institute dedicated specifically towards bioethical issues), was also working on the discipline as he understood it to mean.

“For Potter, a research oncologist, the word ‘bioethics’ had an environmental and evolutionary significance; whereas Hellegers the Dutch obstetrician/ foetal physiologist/ demographer... used the term more narrowly to apply to the ethics of medicine and biomedical research.”<sup>83</sup> “Potter’s bioethics language... was probably judged to be excessively biocentric and too untested, Georgetown’s more traditional and familiar language of ethical principles (such as justice and autonomy), natural law theory, the rules of utilitarian calculus, and the like were evidently found more congenial to the educational and policy-making purposes being pursued”<sup>84</sup> and as such Helleger’s and Georgetown’s more restrictive model of the bioethics discipline became the dominant

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<sup>80</sup> Pellegrino, 1999, p. 75.

<sup>81</sup> Reich, 1994, p. 322.

<sup>82</sup> Ibidem, p. 320.

<sup>83</sup> Ibidem.

<sup>84</sup> Reich, 1995, p. 22.

one. While Potter seemed to hope that bioethics would become a much more global, all-encompassing discipline, Helleger dreamed of the “importance bioethics would achieve as a new speciality combining medical and ethical knowledge.”<sup>85</sup> In reality, the discipline as it exists today and the scope of issues pertaining to it is probably much vaster than either man had ever envisaged possible. “Almost from the beginning, bioethics was an interdisciplinary enterprise. While ethics had been the near-exclusive domain of moral philosophers and religious thinkers, bioethics crossed the boundaries not only of medicine, nursing and the biomedical sciences, but of law, economics and public policy as well.”<sup>86</sup> It is a relatively new, fast-paced and ever growing discipline. Whilst a series of declarations have been issued pertaining to the field of bioethics there is still no internationally agreed and elaborated upon definition of the term.

The “Explanatory Memorandum on the Elaboration of the Preliminary Draft Declaration on Universal Norms of Bioethics”<sup>87</sup> (subsequently re-fashioned as the Universal Declaration on Bioethics and Human Rights) issued from the First Intergovernmental Meeting of Experts Aimed at Finalizing a Draft Declaration on Universal Norms on Bioethics, published a proposed version of a definition that was rejected on the grounds of being “too academic.” It had originally said that “bioethics is a systematic, pluralistic and interdisciplinary field of study involving the theoretical and practical moral issues raised by medicine and life sciences as applied to human beings and humanity’s relationship with the biosphere.”<sup>88</sup> However on foot of these concerns, the relevant article was changed and in the final version it reads “This Declaration addresses ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions.”<sup>89</sup>

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<sup>85</sup> Reich, 1994, p.324.

<sup>86</sup> Kuhse and Singer, 1998, pp. 3-11.

<sup>87</sup> UNESCO, Explanatory memorandum on the elaboration of the preliminary draft declaration on universal norms of bioethics, 21 February 2005, at <http://unesdoc.unesco.org/images/0013/001390/139024e.pdf>, (consulted on 27 June 2013).

<sup>88</sup> Ibidem, para. 17.

<sup>89</sup> UNESCO, Universal Declaration on Bioethics and Human Rights, 19 October 2005, at [http://portal.unesco.org/en/ev.php-URL\\_ID=31058&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html), Article 1(1), (consulted on 20 June 2013).

This is a big departure from the originally proposed definition, as it avoids actually qualifying what “bioethics” itself is, merely saying what it pertains to. It is also obvious based off the nature of the language employed that this is a far-reaching and highly ambitious document. The term “life sciences” applies to a whole plethora of issues<sup>90</sup> and accordingly its “associated technologies” even more. This is an extremely broad definition of the scope of the document but also the field of bioethics. Under the criteria set out therein, bioethics as a discipline is extremely large and encompassing of a huge range of issues.

“International bioethics originated in the trauma of the Holocaust, specifically, in the 1946-1947 Nuremberg "Doctors Trial" when a tribunal of three American judges convicted Nazi medical researchers of "crimes against humanity." In justifying their judgment, the Nuremberg Tribunal cited 10 principles for morally permissible research, which, they claimed, were based on "fundamental" principles that civilized societies "all agree" upon and accept as the foundations of their "moral, ethical, and legal" norms. Foremost among the principles was one stating that morally permissible human experiments require the informed voluntary consent of the subject.”<sup>91</sup> Multiple international declarations reaffirming and adding credence to these principles were formulated in subsequent decades.

It appears then that the discipline of bioethics was being conceptualised and formulated at the same time that the modern human rights system, centring around the International Bill of Rights, was also being created. The UN was established in the wake of the atrocities carried out during World War II, to ensure that the same horrific events could never occur again. The concept of “human dignity” is the focal point of the UDHR as evidenced in its article 1, “All human beings are born free and equal in dignity and in rights.” It would appear to this author that this concept of human dignity and respect for same was also at the core of the bioethics movement and had a

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<sup>90</sup> “Life sciences are the sciences concerned with the study of living organisms. They encompass a broad range of disciplines that include, amongst others, biology, biochemistry, microbiology, virology and zoology.” UNESCO, Explanatory memorandum on the elaboration of the preliminary draft declaration on universal norms of bioethics, 21 February 2005, at

<http://unesdoc.unesco.org/images/0013/001390/139024e.pdf>, para.19.

<sup>91</sup> Baker, 1998, p. 202.

resounding and presiding influence over the discipline that greatly shaped its development and permeates through to the present day.

## **2. Contemporary Bioethical issues for debate**

The field of bioethics is still relatively new and as such constantly evolving and adapting. As our knowledge of science and the world we live in grows, added to the rapid and on-going advancements in scientific and technological progress, it is evident that more and more issues related to this field are going to come up. It would be counter-productive to try and list, much less envision them all here, however a short compilation of some of the most interesting and relevant issues of the day will go some way towards highlighting the enormous vastness and potential scope of this discipline, as well as its occasionally controversial status as it pertains to human rights in general and more specifically towards the REBSP.

### **2.1 Examples of issues**

Daniel Callahan, one of the founding members of the “Hastings Center,” one of the first institutes dedicated to bioethics research and education said that when choosing the focus of the institute they had to prioritise and choose issues that they perceived would be of importance in the coming years. “Faced with an intimidating range of issues and a small staff, we felt it would be wise to select a few areas as a focus of our attention. We choose death and dying, genetics, reproductive biology and population issues, and behavior control.”<sup>92</sup> These issues are still at the forefront of bioethical considerations today, however due to the aforementioned advancements in technologies related to these issues, which could with ease be equated to “benefits of scientific progress,” the range and scope of issues to be considered has expanded greatly.

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<sup>92</sup> Callahan, 1999, p.60.

Some of the key issues for consideration within the field of bioethics today, in the opinion of the Council of Europe are; Cloning, Organ and Tissue Transplantation, Biomedical Research, Human Genetics, End of Life, Psychiatry and Human Rights, Human Embryo and Foetus. These are all extremely broad areas which cover many more sub-branches. Stem-cell research is another major area of focus, however arguably the broadest and one of the most controversial fields of the bioethics discipline is the area of Human Genetics.

The field of Human Genetics has undergone somewhat of a huge growth, both in scale and controversy as a result of advanced knowledge of the field due to on-going scientific and biomedical research, in particular as a result of the research and findings of the Human Genome Project.

### **3. Human Genome Project**

The Human Genome Project began formally in 1990, it was a “13-year effort coordinated by the U.S. Department of Energy and the National Institutes of Health. The project originally was planned to last 15 years, but rapid technological advances accelerated the completion date to 2003.” The main goals of the project were to “identify all the approximately 20,000-25,000 genes in human DNA, determine the sequences of the 3 billion chemical base pairs that make up human DNA, store this information in databases, improve tools for data analysis, transfer related technologies to the private sector, and address the ethical, legal, and social issues (ELSI) that may arise from the project.”<sup>93</sup> The Genome is the sum of the entire DNA in an organism; this includes all its genes. “A gene is the basic physical and functional unit of heredity.”<sup>94</sup> Your genes act as somewhat of an instruction manual for all the tissues in your body, they influence protein production which then influences DNA which in turn influences your cell make-up. A fault or mutation in a single gene could mean the difference

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<sup>93</sup> Human Genome Project Information, What is the Human Genome Project? at, [http://www.ornl.gov/sci/techresources/Human\\_Genome/project/about.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/project/about.shtml), (consulted on 29 June 2013).

<sup>94</sup> Genetics Home Reference, “What is a gene?” at <http://ghr.nlm.nih.gov/handbook/basics/gene>, (consulted on 29 June 2013).

between an individual's ability to lead a healthy lifestyle or the likelihood that they will suffer from or later contract a certain disease or disorder.

The Human Genome Project has led us to have a much greater understanding of the Genome than previously possible. "The Human Genome Project has already fuelled the discovery of more than 1,800 disease genes. As a result of the Human Genome Project, today's researchers can find a gene suspected of causing an inherited disease in a matter of days, rather than the years it took before the genome sequence was in hand. There are now more than 2,000 genetic tests for human conditions. These tests enable patients to learn their genetic risks for disease and also help healthcare professionals to diagnose disease."<sup>95</sup> It has revolutionised the field of genetic knowledge and it is now possible to pinpoint the location and status of several genes which could inform us of a person's risk of or susceptibility to certain genetic diseases or disorders. Analysis and compilation of the results of the project are still on-going and as time goes by, in line with the natural progression of scientific knowledge and advancements in technology, we will have a much greater understanding of the utility of and benefits to be derived from this knowledge.

"This knowledge will dramatically accelerate the development of new strategies for the diagnosis, prevention, and treatment of disease, not just for single-gene disorders but for the host of more common complex diseases (e.g., diabetes, heart disease, schizophrenia, and cancer) for which genetic differences may contribute to the risk of contracting the disease and the response to particular therapies."<sup>96</sup> The potential implications of this are enormous. One area where this knowledge is of particular importance is that of Genetic Testing.

"Whereas genetic testing was once sought almost exclusively by couples with a family history of early-onset disease, for the purpose of family planning, information about genetic status is increasingly sought by persons who wish to learn

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<sup>95</sup> National Institute of Health, Human Genome Project, at <http://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=45>, (consulted on 1 July 2013).

<sup>96</sup> Collins, 1999, p. 31.

about their own predisposition to adult-onset illness.”<sup>97</sup> Previously the main barrier to the individual wishing to undertake this kind of testing procedure is the cost. However, Eric D. Green, the director of the National Human Genome Research Institute at the National Institutes of Health in a recent interview stated that “We can sequence a human genome in a couple of days for well under \$10,000, probably around \$4,000 or \$5,000.”<sup>98</sup> Soon it is likely that this figure will decrease even more. “NIH is striving to cut the cost of sequencing an individual’s genome to \$1,000 or less. Having one’s complete genome sequence will make it easier to diagnose, manage and treat many diseases.”<sup>99</sup>

The possibilities for massive breakthroughs in biomedical science here are endless. Our understanding of the human genome and all its potentialities are advancing with great speed and humankind is likely to enjoy untold benefits from this hugely important scientific progress. “Now we sit at the dawn of the ‘Genomics Revolution’ and all humankind will reap the benefits as we transfer what we now know about the human genome into major breakthroughs including: new forms of ‘personalized medicine’ and genetics therapy better suited to solving the problems we all care so much about, such as cures for cancer, cardiovascular diseases, Alzheimer’s, HIV/AIDS and many more terrifying diseases.”<sup>100</sup> This type of personalised medicine is still a long way from being ready and available for popular use, however genetic testing technologies are a very current and well-utilised reality.

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<sup>97</sup> Ibidem.

<sup>98</sup> New York Times, Human Genome, Then and Now, 15 April 2013, at, <http://www.nytimes.com/2013/04/16/science/the-human-genome-project-then-and-now.html>, (consulted on 30 June 2013).

<sup>99</sup> National Institute of Health, Human Genome Project, at <http://report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=45>.

<sup>100</sup> Battelle, \$3.8B Investment in Human Genome Project Drove \$796B in Economic Impact Creating 310,000 Jobs and Launching the Genomic Revolution, 10 May 2011, at, [http://www.battelle.org/media/press-releases/\\$3.8b-investment-in-human-genome-project-drove-\\$796b-in-economic-impact-creating-310-000-jobs-and-launching-the-genomic-revolution](http://www.battelle.org/media/press-releases/$3.8b-investment-in-human-genome-project-drove-$796b-in-economic-impact-creating-310-000-jobs-and-launching-the-genomic-revolution), (consulted on 1 July 2013).

## **Chapter 3: Genetic Testing Procedures as a “Benefit of Scientific Progress”**

The Human Genome Project and resulting knowledge, which is constantly progressing and being updated, marks one of the biggest single advancements in scientific progress of recent decades. It has paved the way for many and varied new technologies each of which brings with them their own unique set of complications.

### **1. Genetic Testing**

Genetic testing lacks a common and well defined meaning. The term is often used interchangeably with genetic screening, which is incorrect. The COE’s “Convention on Human Rights and Biomedicine additional protocol on genetic testing for health purposes”<sup>101</sup> states that “This Protocol applies to tests, which are carried out for health purposes, involving analysis of biological samples of human origin and aiming specifically to identify the genetic characteristics of a person which are inherited or acquired during early prenatal development.”<sup>102</sup> Thus it excludes from its definition, any kind of genetic testing carried out in vitro. In contrast to this however, UNESCO in its international declaration on human genetic data defines genetic testing as “A procedure to detect the presence or absence of, or change in, a particular gene or chromosome, including an indirect test for a gene product or other specific metabolite that is primarily indicative of a specific genetic change.”<sup>103</sup> This definition then is more inclusive as it would seem to encompass testing procedures done not only in vivo but also in vitro.

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<sup>101</sup> COE, Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes, 27 November 2008, at <http://conventions.coe.int/Treaty/en/Treaties/Html/203.htm>, (consulted on 20 June 2013).

<sup>102</sup> Ibidem, article 2 (1).

<sup>103</sup> UNESCO, International Declaration on Human Genetic Data, Article 2 (xii,) 16 October 2003, at [http://portal.unesco.org/en/ev.php-URL\\_ID=17720&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html), (consulted on 20 June 2013).

This lack of clarity in the definition of the term is problematic as it results in a lot of uncertainty surrounding its actual meaning, particularly considering the soft law status of UNESCO declarations. A study carried out on the definition of genetic testing in various international declarations, recommendations, reports, instruments etc. concluded that, despite the multiple different interpretations and definitions available, “most types of DNA testing, if related to a heritable disorder (germline mutations), performed in a medical context, either in affected persons and healthy relatives, embryos and foetuses, seem to be covered by all definitions.”<sup>104</sup> Thus, considering the findings of this report, for the purposes of this thesis we shall stick to the UNESCO definition due to the fact that it has been more recently issued than the COE definition is more globally influential and also seems to be the most inclusive of all the potential test procedures.

In a study carried out by the International Bioethics Committee (IBC)<sup>105</sup>, different reasons were given for why genetic material might be collected, by means of genetic testing, these included medical reasons, social reasons and research and development reasons. Research and development reasons are significant as they could lead to greater knowledge of certain genes and genetic diseases. Social reasons could lead to ethical concerns as they include both physical and psychological components. However those which are most relevant to us here, (in keeping with the REBSP and how best to ensure the enjoyment of that right), are medical reasons. This study gives a good overview of the different types of testing which could occur for medical reasons, these are; diagnostic testing which identifies the cause of a disease, pre-symptomatic testing which identifies in healthy individuals a gene for a late onset disease, predictive/susceptibility testing which tests for a genetic predisposition to a certain disease which may or may not occur, carrier testing which also relates to the testing of a healthy individual for the potential presence of a mutated gene which may or may not cause their offspring to be affected and prenatal testing which involves testing a foetus

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<sup>104</sup> Sequeiros et al, 2012, p.122.

<sup>105</sup> UNESCO IBC, Human Genetic Data: Preliminary Study by the IBC on its Collection, Processing, Storage and Use, 15 May 2002, at [http://portal.unesco.org/shs/en/files/2138/10563744931Rapfinal\\_gendata\\_en.pdf](http://portal.unesco.org/shs/en/files/2138/10563744931Rapfinal_gendata_en.pdf) (consulted on 1 July 2013).

to diagnose a disease or a potential for a future disease in that being.<sup>106</sup> Not specifically mentioned here is pre-implantation genetic diagnosis, though it would appear to this author that considering the UNESCO definition for genetic testing, this particular type of procedure would also certainly fall within the considerations of these outlined definitions of testing for medical reasons.

## **2. Genetic Screening**

Genetic screening on the other hand is defined as “Large-scale systematic genetic testing offered in a programme to a population or subsection thereof intended to detect genetic characteristics in asymptomatic people.”<sup>107</sup> This definition appears to be more universally accepted due to the uncontroversial or non-negotiable nature of its description, however the status of the procedure itself holds great scope for controversy. It is a procedure that has the potential to be carried out on a much larger scale, population-wide and “in contrast to genetic diagnosis, screening is not usually sought by the person tested, but rather it is initiated by the provider of the test, such as public health authorities.”<sup>108</sup>

Due to the vast potentialities for the use and abuse of these procedures, the COE has issued some strict guidelines concerning genetic screening, when and how it should be allowed. “A health screening programme involving the use of genetic tests may only be implemented if it has been approved by the competent body. This approval may only be given after independent evaluation of its ethical acceptability and fulfilment of the following specific conditions: the programme is recognised for its health relevance for the whole population or section of population concerned; the scientific validity and effectiveness of the programme have been established; appropriate preventive or treatment measures in respect of the disease or disorder which is the subject of the screening, are available to the persons concerned; appropriate measures are provided to

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<sup>106</sup> Ibidem pp 7- 8.

<sup>107</sup>, UNESCO, International Declaration on Human Genetic Data, 16 October 2003, at [http://portal.unesco.org/en/ev.php-URL\\_ID=17720&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html), article 2 (xiii).

<sup>108</sup> Madden 2011, p.301.

ensure equitable access to the programme; the programme provides measures to adequately inform the population or section of population concerned of the existence, purposes and means of accessing the screening programme as well as the voluntary nature of participation in it.”<sup>109</sup> It also explicitly states that mandatory, appropriate genetic counselling should be made available, “When a genetic test is envisaged, the person concerned shall be provided with prior appropriate information in particular on the purpose and the nature of the test, as well as the implications of its results.”<sup>110</sup> The UNESCO declaration reaffirms this by stating that “It is ethically imperative that when genetic testing that may have significant implications for a person’s health is being considered, genetic counselling should be made available in an appropriate manner. Genetic counselling should be non-directive, culturally adapted and consistent with the best interest of the person concerned.”<sup>111</sup> For the purposes of that declaration genetic counselling is defined as, “A procedure to explain the possible implications of the findings of genetic testing or screening, its advantages and risks and where applicable to assist the individual in the long-term handling of the consequences.”<sup>112</sup> (It should occur both before and after the testing takes place.)

By virtue of both of these definitions it is apparent that screening could refer either to genetic testing procedures carried out systematically on new-born babies to detect certain diseases early on in a bid to treat or prevent further complications, a common occurrence in many countries or also to testing done prenatally, on foetuses in utero. This second type of screening procedure is far more controversial as it opens up many more avenues for consideration. A recent study carried out in the Netherlands which considered the latter type of procedure focused their attentions on “the tension

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<sup>109</sup> COE, Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes, 27 November 2008, at <http://conventions.coe.int/Treaty/en/Treaties/Html/203.htm>, article 19.

<sup>110</sup> Ibidem, article 8 (1).

<sup>111</sup> UNESCO, International Declaration on Human Genetic Data, 16 October 2003, at [http://portal.unesco.org/en/ev.php-URL\\_ID=17720&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html), article 11.

<sup>112</sup> UNESCO, International Declaration on Human Genetic Data, 16 October 2003, at [http://portal.unesco.org/en/ev.php-URL\\_ID=17720&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html), article 2 (xiv).

between individual considerations versus collective ramifications regarding certain technologies.”<sup>113</sup>

### **3. Netherlands Debate on Genetic Screening**

This study showed that as early as the 1970’s and 80’s, when the amount and variety of testing procedures which would become available was starting to become apparent, there was debate in the public sphere over the lengths and limits of these types of procedures. A documentary TV series from 1987, evidently influenced by a fear of eugenics, questioned whether with the advent of genetic testing and counselling procedures and the general hypothesis that improved diagnostic testing mechanisms would lead to more abortions, as potentially detrimental health defects were detected, questioned then, “whether handicapped people would still be welcome in future society.”<sup>114</sup> This argument however, was countered by saying that while “reduction of the number of children born with a handicap may be an effect of genetic counselling, it is clearly not its aim.”<sup>115</sup> The idea of offering population wide pre-natal screening was widely debated but ultimately decided against as “there was consensus at the time that the instrument of population screening should be solely offered to improve public health if used for treatable disorders with an available early intervention. In short: no treatment, no screening.”<sup>116</sup>

In 1996 the Population Screening act came into being to prevent potentially deleterious screening procedures and with it entered a whole new range of issues to be considered. It was unclear what this act meant for the current practice of screening pregnant women over the age of 36 in order to detect the presence of Down syndrome in the foetus. However it was decided that as this procedure was not being requested by individual women but rather being offered to a specific group, by reason of their age, this was held to be screening but was allowed to continue as such as it had already been

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<sup>113</sup> van El et al, 2011, p.80.

<sup>114</sup> Ibidem, p. 81.

<sup>115</sup> Ibidem.

<sup>116</sup> Ibidem, p. 83.

common practice for a number of years.<sup>117</sup> The idea that “benefit must outweigh harm” was strongly promulgated here when deciding whether to then also screen women younger than 36 for the same disorder, “it was thought that the balance would be uneven while they would suffer from the psychological burden whereas their group risk was relatively small.”<sup>118</sup>

However an argument based on the principles of democracy then began to surface, should the Government or legislators be allowed to decide who can and should avail of screening procedures, or indeed of knowledge that these procedures exist? This paternalistic approach is not particularly in sync with contemporary views of what it means to live in a democratic society and indeed has vague echoes of an Orwellian nature, though perhaps not quite as extreme. The debate thus shifted by the early 2000’s to one of a more rights-based approach centring on views of personal autonomy. The Health Council tried to push for abandonment of the age-limit and for a variety of genetic screening tests to be made available to women who would have the freedom to choose whether or not to hear what these tests involved as well as whether or not to undergo them. “It was reiterated that it was not the aim to detect as many abnormalities as possible. Parents of children with Down syndrome should never be questioned as to why there had not been prenatal screening.”<sup>119</sup> This should have been enough to quell fears of a eugenic nature, nevertheless prenatal screening for Down syndrome is still not offered to women of all ages however, information about the procedure is. Women can then choose to undergo the procedure, should they so wish, at their own expense. The idea of “no treatment, no screening” has seemingly been replaced as women of all ages can now scan for e.g. Down syndrome should they so wish, however there is no treatment, in the form of cure for this disorder. In addition there is also a population wide screening offered now for a variety of other untreatable conditions.<sup>120</sup> This would seem to be somewhat contradictory in nature, considering the reasoning of the Dutch Government.

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<sup>117</sup> Ibidem.

<sup>118</sup> Ibidem pp 84-85.

<sup>119</sup> Ibidem, p.85.

<sup>120</sup> Ibidem pp 85- 86.

The advent of further advances in pre-natal screening procedures allowing for the detection of more and more diseases is particularly problematic when considered in the light of the growing commercialisation of genetic testing procedures. “If certain tests are not offered by the government, people may arrange to have testing in other, perhaps commercial, centres or hospitals in other countries, or via the internet.”<sup>121</sup> This then means that parents who have not undergone any genetic counselling can suddenly be burdened with the knowledge that their potential offspring is going to be afflicted with a disease or disorder of some type. This is an extremely worrying possibility as the psychological effects of this could be disastrous.

Focusing on the stated aim of the article to explore “the tension between individual considerations versus collective ramifications,” it became clear to the researchers involved here that “individual choices add up to a collective effect.”<sup>122</sup> As the idea of genetic testing becomes normalised, it is possible that these choices “may result in a ‘collective eugenics.’”<sup>123</sup> When many people choose to undergo testing with the intention of avoiding the coming into existence of a child born with a disability or handicap, it is then reasonably foreseeable that the previously articulated fears that those born with handicaps, disabilities or diseases which can be tested for and therefore potentially acted on (in countries which allow for abortion on demand or therapeutic abortion), would not be welcome in future society is of a very real and highly prudent nature. This is a highly complicated, controversial and as of yet theoretical scenario, though there is nothing to say it could not become a possibility in the future.

Advancing technologies lead to advancing complications, and nowhere is this more relevant than in the area of PGD.<sup>124</sup> This involves testing carried out on an embryo in vitro, to determine that potential future individuals likelihood of being born with a disease, predisposed to a certain disease or their risk of contracting a late onset disease.

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<sup>121</sup> Ibidem, p. 86.

<sup>122</sup> Ibidem, p.86.

<sup>123</sup> Ibidem.

<sup>124</sup> “Preimplantation genetic testing is a technique used to identify genetic defects in embryos created through in vitro fertilization (IVF) before pregnancy”. Medscape Reference, Drugs, Diseases & Procedures, Preimplantation Genetic Diagnosis, August 29 2011, at <http://emedicine.medscape.com/article/273415-overview>, (consulted on 24 April 2013.)

“Until recently, both human geneticists and bioethicists have (rightfully) stressed the importance of taking the *individual* (emphasis added) as a focal point when considering genetic testing.”<sup>125</sup> The concept of the “individual” however in most cases does not pertain to embryos in vitro. The European Court of Human Rights (ECtHR) in the case of *Evans v. the U.K.*<sup>126</sup> held that embryos did not for the purposes of the convention fulfil the characteristics of same and as such were not deemed to fall with the protection of the European Convention on Human Rights<sup>127</sup> (ECHR) article 2 Right to life. This then means that PGD and all the associated genetic testing procedures and possibilities that go hand in hand with it, simply fail to be considered in the laws of many States. This leaves the field open for huge potential for both use and abuse. This issue shall be discussed further in Chapter 4 in light of a recent decision of the ECtHR concerning this issue. All of this offers up new and unique avenues and challenges previously unimagined such as, for example the “Right not to know” and “The Right to an open future”. This right to an open future also becomes particularly relevant when speaking of genetic testing which is to be carried out on a child.

As previously mentioned, it is now quite commonplace in many countries around the world to routinely screen new-born infants in order to test for a wide variety of illnesses, diseases, disorders and other complications. This can be said to be relevant to the right to health<sup>128</sup> as well as to the REBSP. In Ireland for example, the country with the highest world-wide incidence of the degenerative disease cystic fibrosis, routine testing is done on all babies shortly after birth to see if they are affected.<sup>129</sup> In addition a number of other tests for other diseases are also performed. This practice is almost universally accepted as it is done to ensure an adequate and fair opportunity is afforded to the child in question to lead the best life possible with all due respect for

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<sup>125</sup>van El et al, 2011, p.87.

<sup>126</sup>Evans v. U.K, ECtHR, 2006.

<sup>127</sup> European Convention for the protection of Human Rights and Fundamental Freedoms (ECHR), 4 November 1950, at [http://www.echr.coe.int/Documents/Convention\\_ENG.pdf](http://www.echr.coe.int/Documents/Convention_ENG.pdf), (consulted on 10 July 2013).

<sup>128</sup> UN, Universal Declaration of Human Rights, 10 December 1948, at <http://www.un.org/en/documents/udhr/index.shtml>, Article 25 (1).

<sup>129</sup> Health Service Executive, Newborn Screening for Cystic Fibrosis (CF) <http://www.hse.ie/eng/about/Who/ONMSD/practicedevelopment/screeningcf/>, (consulted on 4 July 2013).

their right to health and other human rights. The types of diseases screened for in these scenarios are congenital (present at birth, not late-onset) and in many cases, where the disease is at least controllable if not treatable, the earlier it is detected the better. The possibility of genetic testing in these scenarios can offer huge benefits to the quality of life not just of the child but also of its family or care-givers.

#### **4. Right to an Open future**

This area becomes even more controversial and problematic when it involves genetic testing which is to be carried out on a child or a minor who is unable to consent. In situations where a parent of an underage minor is diagnosed with a late-onset hereditary disease, it is quite common for them to wish for their child to also be tested for the disease. This raises various legal and ethical issues, the conflicting right of the parents to respect for their private and family life<sup>130</sup> with regards to knowledge of the health status of their child and the right of the child to an “open future.”

The COE Oviedo Convention in article 6 (1) states that “an intervention may only be carried out on a person who does not have the capacity to consent, for his or her direct benefit.” This is further clarified in the additional protocol on genetic testing where it elaborates that, “Where, according to law, a minor does not have the capacity to consent, a genetic test on this person shall be deferred until attainment of such capacity unless that delay would be detrimental to his or her health or well-being.”<sup>131</sup> It furthermore clarifies this however by stating that, “Exceptionally, and by derogation from the provisions of Article 6, paragraph 1, of the Convention on Human Rights and Biomedicine and of Article 10 of this Protocol, the law may allow a genetic test to be carried out, for the benefit of family members, on a person who does not have the capacity to consent, if the following conditions are met:

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<sup>130</sup> (ECHR), 4 November 1950, at [http://www.echr.coe.int/Documents/Convention\\_ENG.pdf](http://www.echr.coe.int/Documents/Convention_ENG.pdf), Article 8.

<sup>131</sup> COE, Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes, 27 November 2008, at <http://conventions.coe.int/Treaty/en/Treaties/Html/203.htm>, article 10.

- a: the purpose of the test is to allow the family member(s) concerned to obtain a preventive, diagnostic or therapeutic benefit that has been independently evaluated as important for their health, or to allow them to make an informed choice with respect to procreation;
- b: the benefit envisaged cannot be obtained without carrying out this test;
- c: the risk and burden of the intervention are minimal for the person who is undergoing the test;
- d: the expected benefit has been independently evaluated as substantially outweighing the risk for private life that may arise from the collection, processing or communication of the results of the test.”<sup>132</sup>

In summation, only in instances where the potential benefit to the minor of knowing his or her genetic make-up would outweigh the harmful ramifications of knowing, can this type of procedure be permissible. UNESCO echoes this position in its declaration on Human Genetic Data when it states that; “In diagnosis and health care, genetic screening and testing of minors and adults not able to consent will normally only be ethically acceptable when they have important implications for the health of the person and have regard to his or her best interest.”<sup>133</sup>

The right to an “open future” is a relatively new concept in the field of human rights and one which is particularly relevant to the area of genetic testing. This right was first discussed by Joel Feinberg in his essay “The Child’s right to an open future”<sup>134</sup> and was further elaborated on by the bioethicist Dina Davis, whose work has particular bearing on the right to an open future in the context of genetic considerations. Ms Davis would consider that “when faced with the ethical challenges of our new genetic capabilities” that “rather than conceptualising them as a conflict between autonomy and beneficence, we recast it as a conflict between parental autonomy and the child’s potential autonomy:

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<sup>132</sup> Ibidem, Article 13 (a) - (d).

<sup>133</sup> UNESCO, International Declaration on Human Genetic Data, 16 October 2003, at [http://portal.unesco.org/en/ev.php-URL\\_ID=17720&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html), article 8 (d), (consulted on 20 June 2013).

<sup>134</sup> Feinberg, 1980, p.124.

what Joel Feinberg has called “the child’s right to an open future.”<sup>135</sup> The implications of this are that should a parent choose to make a decision on behalf of their child which would then affect the child’s future irreparably, despite thinking that they are acting in the best interests of the child, in actual fact they are then removing all potential for the future autonomous decision making capacity of that child. This would then be a violation of that child’s right to an open future.

What then does this mean for the child whose parents wish to test him or her for a late onset disease, such as for example Huntington’s Disease?<sup>136</sup> As it is an autosomal dominant disorder, if one parent is affected by the disease there is a 50% chance that their offspring will be too. “Arguably, a mutation-positive HD test result can harm more than help a young child. Hence, for a parent to test a child may violate principles of beneficence and nonmaleficence—i.e., benefits to an individual should be maximized, and harms minimized.”<sup>137</sup> This principle of non-maleficence stems from the maxim “Primum non nocere” or, “first, do no harm” whose existence is believed to derive from the Hippocratic Oath, (an oath for physicians and medical personnel to abide by in their professional lives.) It is then generally advised against due to the fact that it is generally not of any benefit to the child to know, by virtue of the extremely negative psychological impact it can have on the child. Davis discusses these psychological implications and notes that individuals diagnosed with the disease are at higher risk of depression and social stigma, but also that those tested and found not to be suffering from the disease can also suffer. This “survivor’s guilt” can have equally deleterious effects.<sup>138</sup>

In fact the “Huntington’s Disease Society of America” themselves recommend against the testing of children before they reach the age of 18, “Minors should not

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<sup>135</sup> Davis, 1997, p. 562.

<sup>136</sup> Huntington disease (HD) is an incurable, adult-onset, autosomal dominant inherited disorder associated with cell loss within a specific subset of neurons in the basal ganglia and cortex. Characteristic features of HD include involuntary movements, dementia, and behavioural changes. HD is a relentlessly progressive disorder, leading to disability and death, usually from an intercurrent illness. The mean age at death in all major series ranges from 51-57 years. Huntington Disease, medscape reference, at <http://emedicine.medscape.com/article/1150165-overview#a0199>, (consulted on 5 July 2013).

<sup>137</sup> Klitzman, 2009, 662.

<sup>138</sup> Davis, 1997, pp. 576- 577.

undergo genetic testing unless there is a medically compelling reason, such as a clinical diagnosis or a strong suspicion of HD. In these unusual circumstances, testing should be preceded by a complete neurological and neuropsychological evaluation. Parental anxiety about a child's risk does not constitute a medically compelling reason for genetic testing.<sup>139</sup> In addition to this a number of regional ethics bodies have also advised against the practice as, results of such tests may have significant medical, psychological, and social implications, not only for the minor but also for other family members.<sup>140</sup>

A study carried out in the U.K. on pre-symptomatic testing for HD found that where knowledge of available testing procedures existed for at risk individuals, the "actual number of tests done on those at 50% risk was 2722, which represents around 18% of those eligible."<sup>141</sup> This extremely low uptake amongst consenting, informed adults is troubling when considering whether to test children for this, or other diseases. "If the vast majority of adults prefer not to know whether they will suffer from HD or not, how can we assume that a 3-year-old boy would benefit from such devastating information?"<sup>142</sup> To not allow them the opportunity to make the decision for themselves is a violation of their right to an open future and furthermore forcing them to then become aware of their future genetic heritage as a result, is also a violation of another right, the "right not to know."

## **5. Right not to know**

The right to an open future spills over into a similar right, the right not to know the information surrounding ones genetic make-up. This right is recognised in a number of international documents concerning genetic research and testing. "The right of each individual to decide whether or not to be informed of the results of genetic examination

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<sup>139</sup> Huntington's Disease Society of America, Genetic Testing for Huntington's Disease Revised HDSA Guidelines, February 2003, at <http://www.hdsa.org/images/content/1/1/11884.pdf>, (consulted on 6 July 2013).

<sup>140</sup> Ross et al, 2013, pp. 4-7.

<sup>141</sup> Harper et al, 2000, p. 570.

<sup>142</sup> Andorno, September 2009, p. 667.

and the resulting consequences should be respected.<sup>143</sup> “When human genetic data, human proteomic data or biological samples are collected for medical and scientific research purposes, the information provided at the time of consent should indicate that the person concerned has the right to decide whether or not to be informed of the results. This does not apply to research on data irretrievably unlinked to identifiable persons or to data that do not lead to individual findings concerning the persons who have participated in such a research. Where appropriate, the right not to be informed should be extended to identified relatives who may be affected by the results.”<sup>144</sup> The Oviedo Convention, in article 10 (2) states that “Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.” They then reaffirm this in the additional protocol on genetic testing, “1. Everyone has the right to respect for his or her private life, in particular to protection of his or her personal data derived from a genetic test. 2. Everyone undergoing a genetic test is entitled to know any information collected about his or her health derived from this test. The conclusions drawn from the test shall be accessible to the person concerned in a comprehensible form. 3. The wish of a person not to be informed shall be respected. 4. In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraphs 2 and 3 above in the interests of the person concerned.”<sup>145</sup>

However oftentimes the interests of family members are at play here too, knowledge of the existence of a genetically contracted illness could be beneficial or detrimental to them also. “Where one family member refuses to undergo testing, this may effectively block other member’s ability to discover their risk factor. The... difficulties that may arise here centre on the value of the right to know one’s genetic make-up and the right to refuse to be tested for genetic disorder. If the relative refuses to

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<sup>143</sup> UNESCO, Universal Declaration on the Human Genome and Human Rights, 11 November 1997, at [http://portal.unesco.org/en/ev.php-URL\\_ID=13177&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html), article 5 (c), (consulted on 20 June 2013).

<sup>144</sup> UNESCO, International Declaration on Human Genetic Data, 16 October 2003, at [http://portal.unesco.org/en/ev.php-URL\\_ID=17720&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html), article 10.

<sup>145</sup> COE, Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes, 27 November 2008, at <http://conventions.coe.int/Treaty/en/Treaties/Html/203.htm>, article 16.

be tested due to a wish not to be informed of his/her genetic risk, it may be possible to inform other relatives without informing the donor of the tissue, but this is not always appropriate.”<sup>146</sup> Madden envisages this as possibly occurring in the case of identical twins, as they are genetically the same, if one twin is found to be at risk for a certain disease, then so is the other. Even if he or she doesn’t wish to be informed/know, unfortunately it is inevitable.

There are many and varied reasons a person may wish not to know their genetic make-up. The psychological burden and associated complications may be too much to bear and as such it is probably preferable to carry on living in ignorance. Andorno would argue that the right not to know “lies on the respect for individual autonomy” but that “what is in the end protected is the psychological integrity of the person.”<sup>147</sup> He elaborated on this in a subsequent article where he stated that “This new right can be regarded as a legitimate expression of personal autonomy, although its ultimate foundation is people’s interest in not being psychologically harmed by such potentially devastating information about their health status.”<sup>148</sup> To him, it would be greatly unjust or even inhumane to inform a person of their potential or upcoming debilitating illness thus removing all hope from their lives for the future, especially in scenarios where there is no treatment available.

## **6. Reasons against genetic testing**

As outlined above, people may choose not to undergo genetic testing both for psychological reasons and the fear of being stigmatised within their community. But there are also other larger scale reasons that people may wish to avoid either undergoing, or promoting the procedure of genetic testing. These issues emerge in light of violations of human rights as a result of discrimination on the bases of genetics in terms of insurance or employment prospects.

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<sup>146</sup> Madden, 2011, p.305.

<sup>147</sup> Andorno, 2004, p. 437.

<sup>148</sup> Andorno, September 2009, p. 666.

Although UNESCO has proclaimed 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,”<sup>149</sup> there is still a very real threat of life or health insurance companies using genetic data they have obtained to discriminate against individuals in their insurance policies. Whilst the United States has passed legislation to outlaw this kind of discrimination there is still no concrete law on the area in Europe. This means that “Employers and insurance companies are using the results of genetic tests to discriminate based on perceptions of long-term health risks and possible future disabilities. Employers and insurance companies have an interest in utilising genetic testing as a powerful predictive tool, primarily for their financial advantage.”<sup>150</sup> This practice is both highly controversial and undesirable.

The Kantian philosophy of the categorical imperative, that is to say that the human being is to be seen as an end in itself, not simply as a means to an end, which heavily influences the field of bioethics, is surely completely disregarded here. “The most clear-cut cases of Kantian “respect” for humanity involve not using others in ways whose ends they cannot formally share-i.e., by not acting on them without their own consent.”<sup>151</sup> Thus to use a person’s genetic make-up against them can be said to be a violation of their rights, fundamental freedoms and their human dignity.

What we can extract from the controversial and conflicting status’ and views surrounding the issue, as outlined above and the debate in the Netherlands on the matter, is that there exists clear evidence of a need for a universal, uniform, internationally applicable interpretation of genetic testing procedures in order to

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<sup>149</sup> UNESCO, International Declaration on Human Genetic Data, 16 October 2003, at [http://portal.unesco.org/en/ev.php-URL\\_ID=17720&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html), article 7 (a).

<sup>150</sup> De Paor, Aisling, Genetic Discrimination by Employers and Insurance Companies- a Battlefield of Fundamental Human Rights? 1 December 2010, at <http://humanrights.ie/civil-liberties/genetic-discrimination-by-employers-and-insurance-companies-a-battlefield-of-fundamental-human-rights/>, (consulted on 6 July 2013).

<sup>151</sup> Shell, March 2008.

properly regulate the procedure and ensure correct adherence to international norms and standards regarding best practice and respect for human rights and to avoid abuses of same, in particular in the context of bioethical concerns. Clearly an international, legally binding document would be the best way to do this, however it unfortunately seems that we are still a long way from achieving the agreement and adoption of same. That being said however, there are a number of international declarations and protocols which offer some guidance in this area.

## **7. International Declarations/ Protocols**

Due to the rapid advancements in science, technology and awareness of the past few decades it became apparent that greater legal and ethical guidance was necessary in the domains of bioethics, biotechnology and associated areas in order to ensure for the respect and protection of human rights. In response to this need the international community, comprised of various different bodies and organisations issued a number of declarations which we can consider to be relevant to the procedures outlined above. Whilst they are merely “soft law” documents and as such have no legally binding status they can be considered as customarily desirable, an example of best practice and definitely an excellent potential starting point towards an International Convention which could consolidate all recommendations made therein and lead to the establishment of a binding and enforceable international law in this area.

### **7.1 Oviedo Convention**

The COE issued the “Convention on Human Rights and Biomedicine”<sup>152</sup> in 1997 in response to these rapid developments in science and technology with a view to establishing safeguards for the protection of human dignity. This convention sets out

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<sup>152</sup> COE, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo Convention), 4 April 1997.

some strict provisions concerning what is and what is not permissible in terms of biomedical research and practices on individuals. Two follow up protocols have also been issued which are relevant to the issue of genetic testing, though not specifically PGD, the protocol on biomedical research<sup>153</sup> and the protocol on genetic testing for health purposes.<sup>154</sup> This convention read in conjunction with these protocols gives us some excellent guidance on what is considered permissible and what is expected within Europe in terms of this kind of research and procedures.

### **7.1.1 Additional Protocol on Genetic Testing for Health Purposes**

The aim of this Protocol which complements the objectives set out in the Convention is to “protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the tests to which this Protocol applies in accordance with Article 2.”<sup>155</sup> “This Protocol does not apply:

- a to genetic tests carried out on the human embryo or foetus;
- b to genetic tests carried out for research purposes.”<sup>156</sup> So, as elaborated in the explanatory report for the protocol this means that “preimplantation (PGD) and prenatal genetic diagnosis (PND) are not covered” within the scope of the protocol nor are “tests on components of embryonic or foetal origin (such as DNA or cells) present in the mother’s blood to obtain information about the foetus or embryo.”<sup>157</sup>

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<sup>153</sup> COE, Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research , 25 January 2005, at <http://conventions.coe.int/Treaty/en/Treaties/Html/195.htm>, (consulted 10 July 2013).

<sup>154</sup> COE, Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes, 27 November 2008.

<sup>155</sup> Ibidem, article 1.

<sup>156</sup> Ibidem, article 2 (2).

<sup>157</sup> COE, Explanatory Report to the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes, 7 May 2008, at <http://conventions.coe.int/Treaty/EN/Reports/Html/203.htm>, para. 31, (consulted on 20 June 2013).

### **7.1.2 Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research**

This Protocol is concerned with defining and safeguarding “fundamental rights in the field of biomedical research, in particular of those participating in research.”<sup>158</sup> “This Protocol does not apply to research on embryos *in vitro*. It does apply to research on foetuses and embryos *in vivo*.<sup>159</sup> Thus it excludes from its scope PGD because as explained in the accompanying explanatory report “The CAHBI (Ad hoc Committee of experts on Bioethics) decided at its 15th meeting (24-27 March 1992, Madrid) to exclude the embryo from the draft Protocol on Medical Research. It was foreseen that this type of research would be addressed in another Protocol on the protection of the human embryo and foetus.”<sup>160</sup> No such additional protocol has as of yet been elaborated however.

There is however in existence a report by the working party on the protection of the human embryo and foetus, as part of the steering committee on bioethics (CDBI), entitled “The protection of the human embryo *in vitro*.<sup>161</sup> This report while not of any legally binding status, gives a good overview of the position of the embryo within Europe, particularly in relation to PGD. It stresses the need for “common approaches (to) be identified to ensure proper conditions for the application of procedures involving the creation and use of embryos *in vitro*.<sup>162</sup> It is clear that an additional protocol, as envisaged by the CAHBI over twenty years ago is still desirable today in a bid to cover this lacuna in the law.

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<sup>158</sup> COE, Explanatory report to the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research, 30 June 2004, at <http://conventions.coe.int/Treaty/EN/Reports/Html/195.htm>, para. 2, (consulted on 20 June 2013).

<sup>159</sup> COE, Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research , 25 January 2005, at <http://conventions.coe.int/Treaty/en/Treaties/Html/195.htm>, article 2 (2).

<sup>160</sup> COE, Explanatory report to the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research, 30 June 2004, para. 19.

<sup>161</sup> COE, Steering Committee on Bioethics (CDBI), The Protection of the Human Embryo *in vitro*, 19 June 2003.

<sup>162</sup> Ibidem, p.37.

## **7.2 UNESCO Declarations**

UNESCO has issued a number of declarations which are also extremely useful in outlining the expectations from and obligations on States and other relevant parties here in relation to the protection of human rights concerning bioethics and more specifically genetic considerations. Genetic testing and in particular PGD could have some far-reaching implications for human rights and human dignity, both positive and negative. The following declarations offer some excellent guidance on what kind of provisions should be implemented in order to ensure full respect for human rights and fundamental freedoms whilst also allowing the international community to benefit from these types of technologies and capabilities.

### **7.2.1 The Universal Declaration on the Human Genome and Human rights<sup>163</sup>**

This declaration and its corresponding guidelines for implementation offers us some good advice concerning human dignity, the human genome and research on same as well as seeking to promote international co-operation and solidarity in this field.

### **7.2.2 International Declaration on Human Genetic Data<sup>164</sup>**

Whilst also ensuring respect for human dignity this declaration focuses more specifically on individual's genetic data and the legal and ethical rights and obligations concerning individuals, States and other actors related to this topical and complex issue.

### **7.2.3 Universal Declaration on Bioethics and Human Rights<sup>165</sup>**

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<sup>163</sup> UNESCO, Universal Declaration on the Human Genome and Human Rights, 11 November 1997, at [http://portal.unesco.org/en/ev.php-URL\\_ID=13177&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html).

<sup>164</sup> UNESCO, International Declaration on Human Genetic Data, 16 October 2003, at [http://portal.unesco.org/en/ev.php-URL\\_ID=17720&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html).

This declaration, aimed at States is arguably the most far-reaching and ambitious of the three declarations as it seeks to “provide a universal framework of principles and procedures to guide (them) in the formulation of their legislation, policies or other instruments in the field of bioethics.”<sup>166</sup> It also seeks to promote and respect human dignity as well as encourage greater international co-operation across all levels and recognise the importance of freedom of scientific research.

### 7.3 Other Relevant Declarations

The World Medical Association (WMA) Declaration of Helsinki<sup>167</sup> sets out the ethical principles which should govern research conducted on human beings. It is directed largely at medical practitioners but offers some good guidance to the international community at large as to what is and should be ethically permissible concerning research on human persons.

The UN General Assembly (GA) issued a declaration in 1975 entitled the “Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and for the Benefit of Mankind,”<sup>168</sup> this declaration states that “All States shall take effective measures, including legislative measures, to prevent and preclude the utilization of scientific and technological achievements to the detriment of human rights and fundamental freedoms and the dignity of the human person.”<sup>169</sup> The concept of human dignity is central to all bioethical concerns and considerations.

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<sup>165</sup> UNESCO, Universal Declaration on Bioethics and Human Rights, 19 October 2005, at [http://portal.unesco.org/en/ev.php-URL\\_ID=31058&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html), (consulted on 20 June 2013).

<sup>166</sup> Ibidem, article 2 (a).

<sup>167</sup> WMA Declaration of Helsinki- Ethical Principles for Medical Research Involving Human Subjects, June 1964, at [http://www.wma.net/en/30publications/10policies/b3/index.html.pdf?print-media-type&footer-right=\[page\]/\[toPage\]](http://www.wma.net/en/30publications/10policies/b3/index.html.pdf?print-media-type&footer-right=[page]/[toPage]), (consulted on 20 June 2013).

<sup>168</sup> GA Resolution 3384 (XXX), 10 November 1975.

<sup>169</sup> Ibidem, para. 8.

Lastly, the GA adopted the Convention on Biological Diversity<sup>170</sup> in 1992 in response to these on-going scientific and technological advancements. It is the opinion of this author that the General Assembly recognised the vast potentialities of the scientific domain and its potential implications in the field of science related to genetic issues and as such was attempting to enshrine some basic principles of protection in the mind of its Member States. In its preamble it states that it is “Aware of the general lack of information and knowledge regarding biological diversity and of the urgent need to develop scientific, technical and institutional capacities to provide the basic understanding upon which to plan and implement appropriate measures” and also that it is “Aware that conservation and sustainable use of biological diversity is of critical importance for meeting the food, health and other needs of the growing world population, for which purpose access to and sharing of both genetic resources and technologies are essential.” Having regard to the fact that this declaration was issued almost 40 years ago, it is somewhat of a massive shortcoming on the part of the international community that there still exists no more specific convention setting out what exactly this is and what it should entail.

## **8. Disease Eradication?**

We shall now look at a contemporary example of an available genetic screening technology in practice. As previously outlined, the potential benefits and outcomes which can stem from the utilisation of these types of technologies are vast. They can be used to detect potentially harmful diseases or disorders early on in an individual’s life with a view to preventing their occurrence, or perhaps just in order to allow for early medical intervention with a view to helping affected individuals lead a healthier or more fulfilled life, to the best of their individual capabilities. However, they can also be used prior to partaking in any reproductive endeavours, medically assisted or otherwise. We

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<sup>170</sup> UN GA, Convention on Biological Diversity, 5 June 1992, at <http://www.cbd.int/doc/legal/cbd-en.pdf>, (consulted on 20 June 2013).

shall now examine the case of a State that used population genetic “carrier screening”<sup>171</sup> measures to great effect. Whether or not these measures are legally and ethically acceptable and should be condoned or condemned will be discussed also.

### 8.1 The Case of Cyprus

A number of Mediterranean States report high levels of incidences of the blood disorder beta-thalassemia. It is particularly prevalent in Cyprus where an estimated 1 in 7 people are carriers. “Beta thalassemia syndromes are a group of hereditary disorders characterized by a genetic deficiency in the synthesis of beta-globin chains. In the homozygous state, beta thalassemia (ie, thalassemia major) causes severe, transfusion-dependent anaemia. In the heterozygous state, the beta thalassemia trait (ie, thalassemia minor) causes mild to moderate microcytic anaemia.”<sup>172</sup> People who suffer from this disease lead a greatly reduced lifespan, generally of around 30 years and are subject to on-going and painful treatment methods, mostly through the use of daily blood transfusions. “Painful, daily, life-long administration of an expensive life-saving medication was... the essential context in which several groups of Cypriots decided to create a mandated genetic screening program.”<sup>173</sup>

In 1973 the island of Cyprus began introducing genetic counselling and carrier screening for beta- thalassemia for pre-marital or pre-conceptional couples. This process became mandatory by the Government among Turkish Cypriots and quasi- mandatory by the Church among Greek Cypriots.<sup>174</sup> Cypriots wishing to marry had to undergo genetic counselling and screening to test for beta-thalassemia, they were then provided with the options available to them, one of course being, to choose not to carry on with the marriage considering the risks facing them. They were also provided with voluntary

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<sup>171</sup> “Carrier screening is defined as the detection of carrier status in persons who do not have an a priori increased risk for having a child with a certain disease,” at <http://www.medscape.com/viewarticle/741623>, (consulted on 6 July 2013).

<sup>172</sup> Emedicine, Beta thalassemia, at <http://emedicine.medscape.com/article/206490-overview#aw2aab6b2b4aa>, (consulted on 7 July 2013).

<sup>173</sup> Cowan, 2009, p. 98.

<sup>174</sup> Cousens et al, 2010, p. 1078.

pre-natal diagnosis and voluntary termination of affected pregnancies should they so choose. “In 1986, the Cypriot legislature...made abortion for foetal indications legal in the Republic, which means that today, women who cannot afford to go to a private clinic for an abortion, can have it done (if the results of CVS<sup>175</sup> are positive for thalassemia), at public expense.”<sup>176</sup> It would appear that these were very popular decisions as between 1974- 1979 the number of affected births decreased from 51 to 8 and then further still from 5 births between 1991- 2001, to an astonishing 0 between 2002 and 2007.<sup>177</sup> This was clearly an overwhelmingly effective endeavour as it essentially resulted in eradication of the disease within the space of a generation.

However it would seem to violate many existing bioethical norms and standards as outlined above. The majority of commentary on the practice states that the result is not eugenic, but is this really the case? “Eugenicists wanted to prevent people whom they deemed genetically unfit from reproducing; the Cypriot program is designed to do just the opposite, that is, it is designed to encourage carriers of disease-causing genes to have as many children as they want. Eugenicists, furthermore, wanted governments to sanction, pay for and require both genetic testing (such as it was in those days), and reproductive limitation; the Cypriot program requires only the testing, leaving the reproductive decisions entirely to parents.”<sup>178</sup> This is certainly an example of using the applications of scientific progress as a “benefit” to society, in this case utilising advanced genetic testing procedures in order to prevent the promulgation of a debilitating and undignified disease, however how far can practices such as this be allowed to go before they are considered eugenic? This shall be discussed more in the following chapter.

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<sup>175</sup> CVS= Chorionic villus sampling.

<sup>176</sup> Cowan, 2009, p. 101.

<sup>177</sup> Cousens et al, 2010, p. 1081.

<sup>178</sup> Cowan, 2009, p.101.

## **Chapter 4: Eugenics & The Case of Costa & Pavan v. Italy**

### **1. Cystic Fibrosis**

“With an incidence of 1 in 2500 live births, cystic fibrosis is the most common lethal genetic disease that affects Caucasian populations.”<sup>179</sup> It is particularly prevalent in many Member States of the European Union. The Republic of Ireland has the highest incidence of Cystic Fibrosis (CF) worldwide with approximately 1 in 19 people being carriers of the defective gene responsible for the disease.<sup>180</sup>

Cystic Fibrosis is a monogenic recessive disorder caused by a mutation on the cystic fibrosis trans-membrane conductance regulator (CFTR) gene. The gene is located on autosomal (non-sex determinative) chromosome 7. CFTR is a protein responsible for the transportation of “chloride (Cl-) ions across the membranes of cells in the lungs, liver, pancreas, digestive tract, reproductive tract, and skin.”<sup>181</sup> A defective CFTR gene leads to poor water and salt transportation between cells resulting in cystic fibrosis and associated complications.

As it is a recessive disorder, both parents need to be carriers of the mutated gene in order for it to be passed on to their child. Every time two parent carriers of the affected gene conceive there is a 1 in 4 chance that the gene will be passed on to their offspring.

CF “affects the respiratory, digestive and reproductive systems involving the production of abnormally thick mucus linings in the lungs and can lead to fatal lung infections.”<sup>182</sup>

People affected by CF have a variety of symptoms including;

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<sup>179</sup> Kumar, V. et al, 2010, p.465.

<sup>180</sup> Cystic Fibrosis Ireland, Carrier Testing for Cystic Fibrosis, at <http://www.cfireland.ie/index.php/carriertesting>, (consulted on 3 March 2013).

<sup>181</sup> Human Genome Project Information, CFTR: The Gene Associated with Cystic Fibrosis, at [http://www.ornl.gov/sci/techresources/Human\\_Genome/posters/chromosome/cftr.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/posters/chromosome/cftr.shtml), (consulted on 5 March 2013).

<sup>182</sup> WHO, Genes and human disease, at <http://www.who.int/genomics/public/geneticdiseases/en/index2.html>, (consulted on 3 March 2013).

- Poor digestion leading to malnutrition
- Low growth rate
- Wheezing, shortness of breath, phlegmy cough
- Frequent and Persistent Lung infections
- Sinus, Lung, Intestinal, Pancreatic and Liver disease
- Salty tasting skin
- Infertility in males
- Shortened life expectancy

### **1.1 Treatment:**

There is no available cure for CF. Afflicted persons must undergo a combined daily treatment regime of physiotherapy and medicines. These include antibiotics to fight and pre-emptively stave off infection, enzymes to help with food absorption and nebulisers to help clear the airways of mucus. Frequent and lengthy hospital stays are also necessary in the case of particularly bad infections.

Though there is great variation in the severity of CF amongst sufferers as well as an increased life expectancy today due to advancements in knowledge and awareness, it is still a progressive and degenerative disease and in all cases will lead to a premature death. In advanced stages of the disease sometimes lung transplantation becomes necessary in order to prolong and improve the quality of life.

Gene Therapy, an innovative and pioneering area of scientific research is currently being explored as a potentially beneficial method of treatment for persons affected by CF.<sup>183</sup>

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<sup>183</sup> University of Oxford, Largest gene therapy trial for cystic fibrosis begins, 16 March 2012, at [http://www.ox.ac.uk/media/news\\_stories/2012/120316.html](http://www.ox.ac.uk/media/news_stories/2012/120316.html), (Consulted on 13 March 2013).

## **1.2 Quality of Life:**

Due to their frequent infections and poor immune systems sufferers of cystic fibrosis spend lengthy periods of time in hospital. This naturally makes attending school and work more difficult which makes it more challenging for sufferers of cystic fibrosis to lead a so-called “normal life.” Also due to their ill-health and the large incidence of infertility in males with the disease, (“Infertility rates among males with cystic fibrosis (CF) approximate 97%”)<sup>184</sup> it is less likely that sufferers of CF will be able to conceive and bear a child. The on-going and largely self-managed treatment and management of the disease is also extremely time consuming and burdensome.

Though it is not possible to accurately predict the life expectancy of someone suffering from CF, in Ireland where there are approximately 1300 sufferers of the disease, “the predicted median age of survival for a person with CF is in the early and mid-30’s.”<sup>185</sup> Similar life expectancy predictions are reported from the U.S “In 2009, the median predicted age of survival was in the mid-30s.”<sup>186</sup> Whereas the U.K. sets the bar slightly higher, there “the median predicted survival for someone with CF currently stands at 41 years old.”<sup>187</sup>

It is obvious that significant advancements in medical science have led to vast improvements in life expectancy for people suffering from CF “In 1955, children with CF were not expected to live long enough to attend grade school.”<sup>188</sup> Now their life expectancy stands somewhere in the mid 30’s and though this number is likely to rise significantly as research progresses and more treatment options become available, the

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<sup>184</sup> National Center for Biotechnology Information, Male infertility in cystic fibrosis, July- August 2009, at <http://www.ncbi.nlm.nih.gov/pubmed/19771998>, (consulted on 13 March 2013).

<sup>185</sup> Cystic Fibrosis Ireland, What is Cystic Fibrosis? at <http://www.cfireland.ie/index.php/aboutcf>, (consulted on 3 March 2013).

<sup>186</sup> Cystic Fibrosis Foundation, What is the life expectancy for people who have CF (in the United States)? at <http://www.cff.org/AboutCF/Faqs/>, (consulted on 3 March 2013).

<sup>187</sup> Cystic Fibrosis Trust UK, What is the life expectancy of someone with cystic fibrosis? at <https://www.cysticfibrosis.org.uk/about-cf/frequently-asked-questions.aspx#na>, (consulted on 20 June 2013).

<sup>188</sup>Cystic Fibrosis Foundation, What is the life expectancy for people who have CF (in the United States)? at <http://www.cff.org/AboutCF/Faqs/>.

life expectancy of someone with CF is still on average more than 40 years lower than their non CF affected counterparts residing in the same countries.<sup>189</sup>

### **1.3 Diagnosis:**

Diagnosis of CF is generally done shortly after birth through the ‘sweat test’<sup>190</sup> method. In some countries, for example in Ireland which has a very high prevalence of the disease, routine testing is done on babies shortly after birth to determine whether or not they have the disease.<sup>191</sup> This is done via the ‘heel prick’ blood sample test and has proved successful in indicating incidences of the disease early on.

Less commonly, but in a procedure that is rapidly gaining ground, thanks to developments in scientific progress and increased public knowledge and awareness of genetic tests and their potential benefits and outcomes, the diagnosis of cystic fibrosis can be made via genetic testing. This can be performed either in utero, (pre-natal genetic testing) or in cases of individuals undergoing In Vitro Fertilisation (IVF), through PGD. These procedures allow the persons involved to make an informed decision regarding the pregnancy and what is in their own and the embryo or foetus’ best interests.

## **2. Costa & Pavan v. Italy**

PGD was the issue at the centre of the case of *Costa & Pavan v. Italy*<sup>192</sup> which recently came before the European Court of Human Rights (ECtHR).

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<sup>189</sup> United Nations Development Programme, 2013 Human Development Report, 14 March 2013, at [http://hdr.undp.org/en/media/HDR2013\\_EN\\_Statistics.pdf](http://hdr.undp.org/en/media/HDR2013_EN_Statistics.pdf), (consulted on 14 March 2013).

<sup>190</sup> Cystic Fibrosis Foundation, The Sweat Test, at <http://www.cff.org/AboutCF/Testing/SweatTest/>, (consulted on 3 March 2013).

<sup>191</sup> Health Service Executive Ireland, Heel Prick Test for newborns now screening for Cystic Fibrosis, 4 July 2011, at <http://www.hse.ie/eng/services/News/newsarchive/2011archive/july2011/heelpricktestnewbornscysticfibrosis.html>, (consulted on 13 March 2013).

<sup>192</sup> *Costa & Pavan v. Italy*, ECtHR, (2012).

## **2.1 Facts of the case:**

The applicants in this case are Rosetta Costa and Walter Pavan, a couple of Italian Nationality, living in Rome. They found out following the birth of their first child in 2006 (and her subsequent affliction) that they were both healthy carriers of the gene for Cystic Fibrosis. In 2010 they again fell pregnant but pre-natal testing showed that this foetus was also affected by Cystic fibrosis and they chose to terminate the pregnancy on medical grounds.

In order to conceive a child free from Cystic Fibrosis they wished to partake in PGD while undergoing IVF. However proceedings of this nature are prohibited under Italian Law.<sup>193</sup> They brought their case to the European Court of Human Rights (ECtHR) claiming that the Italian law in this area, prohibiting outright the procedure of PGD and prohibiting IVF except in circumstances where the couple had been medically certified as sterile or infertile, or where the male is suffering from a sexually transmitted disease (STD) was a violation of their Convention Rights under Article 8 (The Right to Respect for Private and Family Life) and Article 14 (Prohibition of Discrimination.) They also brought an action under Article 41 (Just Satisfaction.)

## **2.2 Article 8:**

### **2.2.1 Italian State:**

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<sup>193</sup> Law 40/2004 which limits IVF treatment to cases of sterility or infertility.

Ministerial Decree no. 31369, 11 April 2008, which reverses Decree no. 15165, 21 July 2004 by stating that the reference to “observation” as a finality regarding embryos created in vitro should be eliminated, it also allows for access to IVF by males suffering from STD’s.

The Judgment of the Regional Administrative Court of Latium no. 398, 21 January 2008 also rejected the 2004 decree.

However, in a one off decision, no. 1274/09, 13 January 2010, the Court in Salerne, allowed for the first time for two parent carriers of Muscular Atrophy to undergo PGD, recalling the 2008 decree which stated that embryos created in vitro are not merely limited to observational ends. It stated that as far as it was concerned, in this situation PGD could only be considered as a technique to find out the health status of the embryo and as such it would be unreasonable to allow for potential abortion of the foetus but not to allow for PGD of the embryo to ascertain whether it was suffering from muscular atrophy or not.

The principle arguments put forward by the Italian State were that the applicants were trying to invoke a “Right to have a healthy child” which is not protected under the Convention and as such the case should not have been admissible *ratione materiae*.

However, should it be deemed admissible anyway, they argued that the measure in question, namely the prohibition of PGD was prescribed by law, pursuing a legitimate aim and necessary in a democratic society. They said that they were considering the best interests of the health both of the child and of the mother as well as protecting the dignity and freedom of the medical profession whilst avoiding Eugenic Practices. They also invoked their State Margin of Appreciation here, stating the lack of a European Consensus<sup>194</sup> on this moral, ethical and socially contentious issue.<sup>195</sup>

### **2.2.2 The Applicants:**

The applicants were contesting that the right to become or not to become a parent, in the genetic sense, fell under Article 8, as set out in the case of *Evans v. The U.K.*<sup>196</sup> They argued that the State should not interfere in any way with that right and that they should in fact put in place measures in order to allow for the full and free realisation of that right.<sup>197</sup>

### **2.2.3 Reasoning of the Court:**

The Court first examined the alleged Article 8 violation having decided that the case was not manifestly ill-founded and as such was admissible.

The Court rejected the Italian State’s argument that the Applicants were attempting to exercise a “Right to a healthy child,” rather, they held that they were merely trying to be

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<sup>194</sup> It should be noted here that despite this “Lack of consensus,” of the 32 European States whose legislation the Court examined, only two other States, Austria and Switzerland also expressly prohibited PGD.

<sup>195</sup> *Costa & Pavan v. Italy*, ECtHR, 2012, paras. 44 – 47.

<sup>196</sup> *Evans v. The United Kingdom*, ECtHR, (2007).

<sup>197</sup> *Costa & Pavan v. Italy*, ECtHR, 2012, paras. 48 – 49.

allowed access to a PGD procedure, as PGD itself would not rule out any and all other health risks to the potential foetus or child.

They then proceeded to look at whether this interference was prescribed by law and pursuing a legitimate aim. While IVF treatment was available solely to infertile or sterile individuals or those where the male was affected by an STD, PGD was prohibited to everyone. The Court thus held that it was prescribed by law and could indeed potentially hold a legitimate aim in the protection of morals and personal liberties.<sup>198</sup>

With regards to the question of whether it was necessary in a democratic society, the Court found the Italian Law in the area to be both incoherent and lacking proportionality. The only recourse available to the applicants in this case, should they wish to bear a child free from Cystic Fibrosis seemed to be to conceive naturally, undergo pre-natal testing and then abort the foetus were it shown to be affected. It seemed illogical to them that this was permissible whilst PGD which, it could be argued is a much less invasive and emotionally charged procedure for the parents, was not.

The Court rejected the notion that disallowing for PGD in conjunction with IVF but allowing for this kind of therapeutic abortion was protecting the health of both the mother and potential child. They also stated that the Italian Government had failed to show how allowing for abortion but not for PGD could possibly be construed as a way to curtail eugenic practices.<sup>199</sup>

The Court thus felt it was clear that this was a disproportionate interference by the Italian State into the private and family life of the applicants and as such was a violation of their Article 8 Convention Right.

### **2.3 Article 14:**

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<sup>198</sup> Ibidem, paras. 58 – 59.

<sup>199</sup> Ibidem, paras. 58 – 71.

Concerning the alleged breach of article 14, the Court found that as PGD was not available to any category of persons there was no discrimination made against the applicants as they were treated no differently from anyone else, namely males suffering from STD's, and as such the complaint here was manifestly ill-founded.

#### **2.4 Article 41:**

Concerning 'Just Satisfaction' the Court ordered the Italian State to pay the recipients €2 500 in Court expenses and €15 000 in non-pecuniary damages.

#### **2.5 Summary:**

The Court found that there had been a violation of the Applicant's Article 8 Convention Rights. They found no violation of their Rights under Article 14. The Court ordered the Italian State to pay the applicants €17 500 as outlined above. As this was a Chamber decision the Italian State had a period of 3 months to appeal the decision to the Grand Chamber for their consideration.

On the 11th February 2013 this decision was held to be definitive in virtue of Articles 44 & 2 of the Convention.

The judgment in this case is interesting for multiple reasons, it finds that there is no European consensus on the procedure of PGD which is quite likely due to the fact there is no real European, or for that matter internationally agreed upon declaration setting out what it is, but this then highlights what a pioneering and useful procedure it could potentially be. As embryos are not considered to fall under the protection of the Right to life as envisaged in the ECHR, this is of extreme importance for those living in States with restrictive or non-existent abortion laws as it means that they are not in any way lawfully restricted from using this procedure in order to prevent their potential future child from being born suffering from some particular illnesses. However the problem here lies with how far that can go. While the amount of flexibility surrounding

the procedure is potentially beneficial in terms of avoiding inflicting any unnecessary pain and suffering on a human being, what does it mean for other characteristics that can be discovered via genetic testing?

### **3. Eugenics**

It is well-known that the Nazi Regime in Germany, beginning in 1933 and finishing after the end of the Second World War, was heavily engaged in abusive practices, deemed eugenic, such as racial sterilisation and racial extermination via the systematic, prolonged and wide-scale killings of millions of people. Jews, Gypsies, homosexuals and the mentally impaired, among with many other groups of individuals were targeted based on their characteristics, genetic or otherwise. This was done in order to fulfil Hitler's plans for what he envisaged as a master race, comprised only of Aryan people who satisfied certain, desirable physical and mental requirements.

The word eugenics is derived from the Greek “eu” meaning “well” and “genes” meaning “born.” Thus it literally translates as well-born. However the word “eugenics” itself was coined by Sir Francis Galton in his 1883 book, “Inquiries into Human Faculty and its Development.”<sup>200</sup> He defined it as the “science of improving inherited stock, not only by judicious matings, but by all the influences which give more suitable strains a better chance.” This was so in order to “give the more suitable races...a better chance of prevailing steadily over the less suitable.” We can also define it as “the use of science applied to the qualitative and quantitative improvement of the human genome.”<sup>201</sup> Simply put, it is the science of ensuring that the “better” sections of society or those with better genetic attributes would prevail over the weaker or less desirable ones.

While everyone is aware of the atrocities of the Nazi era and their abuse of eugenic policies, it is perhaps less well-known that it was also a very popular theory in the United States throughout the beginning of the 20<sup>th</sup> century. Many U.S. States

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<sup>200</sup> Galton, 1883.

<sup>201</sup> Galton & Galton 1998, p. 99.

implemented eugenic measures such as forced sterilisations and restrictive immigration policies. “30 states adopted eugenic sterilization laws, which together accounted for the forced sterilization of approximately 60,000 Americans. In addition to targeting U.S. citizens, the eugenics movement was also one basis of the ethnic bias that led to the passage of the Immigration Act of 1924, which severely limited the number of southern and eastern Europeans who could enter the U.S. each year and almost completely barred all immigrants from Asia.”<sup>202</sup> In fact the work of these United States eugenicists was highly influential on Hitler when he was formulating and conceptualising his own vision of it and applying it to the society in which he resided and ruled over. He even makes mention to these highly restrictive immigration policies in his book *Mein Kampf*, as he says, “At present there exists one State which manifests at least some modest attempts that show a better appreciation of how things ought to be done in this matter. It is not, however, in our model German Republic but in the U.S.A. that efforts are made to conform at least partly to the counsels of common sense. By refusing immigrants to enter there if they are in a bad state of health, and by excluding certain races from the right to become naturalized as citizens, they have begun to introduce principles similar to those on which we wish to ground the People’s State.”<sup>203</sup>

### **3.1 Survival of the fittest: Social Darwinism**

Galton based his eugenics theory heavily on the work of Charles Darwin as set out originally in his book, “The Origin of Species.” Though not originally coined by him, Charles Darwin brought the term “Survival of the Fittest” into popular parlance in the fifth edition (1869) of his 1859 book. The original full title of the book, “On the Origin of Species by Means of Natural Selection, or the Preservation of Favoured Races in the Struggle for Life,” which was used until the sixth edition in 1872 is perhaps more indicative of the potentially eugenic components expressed in it. Darwin’s use of the term was to become synonymous with his idea of “natural selection.” What Darwin

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<sup>202</sup> Norrgard, Karen, Human Testing, the Eugenics Movement, and IRBs, 2008, at <http://www.nature.com/scitable/topicpage/human-testing-the-eugenics-movement-and-irbs-724>, (consulted on 7 July 2013).

<sup>203</sup> Hitler, 1939, p.341.

meant by natural selection, his now essentially universally accepted evolutionary theory, was the “preservation of favourable variations and the rejection of injurious variations.”<sup>204</sup>

Although Darwin was not speaking here specifically about humans and the human race, but rather the biosphere and its inhabitants as a whole, his original conceptualisation of the term survival of the fittest has been appropriated and distorted by many of those in the school of “Social Darwinism” to have some eugenic connotations. Social Darwinists, of whom Galton is generally accepted as being one, heavily influenced the eugenic practices of the late 19th and early 20<sup>th</sup> century. O’ Mathúna would say that one of the fundamental principles at the core of the contemporary human rights system that is, the “belief in the inherent dignity of all humans was rejected by social Darwinists.”<sup>205</sup>

There is a fine line which can be drawn between the idea of good “eugenics” and bad “eugenics” Which of the two is acceptable, if indeed either, is highly subjective and open to much critique and controversy. Human dignity is the main issue at stake when considering eugenic practices or the possibility of same. We shall now look at some contemporary and controversial issues which we must contemplate in light of the past, when we are considering the use of certain genetic testing procedures in order to achieve certain aims or goals.

#### **4. The Eugenic Debate**

Considering the ethical and legal dilemmas posed in Chapter 3 surrounding the limits of genetic technologies as well as the reasoning employed in the case of *Costa & Pavan v. Italy*, it is important to now reflect on the reasons for these limitations and constraints. Cystic Fibrosis is a horrible and extremely undesirable disease. It would be difficult to argue that anyone would ever voluntarily choose to either suffer from the condition or give birth to someone suffering from the condition,

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<sup>204</sup> Darwin, 1859, p.40

<sup>205</sup> O’ Mathúna, 2006, p.1.

where that condition could be avoided through the use of ethically accepted genetic testing procedures. While this line of reasoning may vex those of the pro-life movement who believe that life begins at the point of conception, it is important to remember to consider it in terms of legal and ethical considerations of when life begins according to European law, which while there is no consensus on the issue, does not include pre-implantation embryos. Also, any comparison between the utilisation of PGD to avoid the otherwise unnecessary infliction of a disease on future child that could otherwise avoid it and eugenic fears/ arguments needs to be carefully considered. “Any attempt to draw connections between the Nazi Holocaust and contemporary bioethical debate must be done carefully.”<sup>206</sup>

The fear of “Eugenics” is always at the fore of any ethical debate surrounding the field of genetic testing. There are of course, historically significant reasons for this but it is necessary in order to give due respect to and to fully vindicate the REBSP to consider things now, in the present day, as they are contemporarily applicable rather than in the light of any historical fears and doubts. The REBSP is, as previously mentioned a right with great potential and scope, it can certainly be utilised to great advantage, but also has the potential for abusive and detrimental usage. It is likely no one would argue against the non-implantation on foot of PGD, of an embryo likely to suffer greatly and lead a drastically shortened life-time but what about the choice of non-implantation of an embryo for other reasons? By virtue of its sex for example, or even, something less apparent?

Attitudes towards what exactly constitutes human dignity underwent quite a lot of upheaval throughout the last century. German thinkers from the beginning of the last century, Binding and Hoche proclaimed that “There was a time, now considered barbaric, in which eliminating those who were born unfit for life, or who later became so, was taken for granted. Then came the phase, continuing into the present, in which, finally, preserving every existence, no matter how worthless, stood as the highest moral value.”<sup>207</sup> It was once considered that the best way to respect human dignity was to end

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<sup>206</sup> Ibidem, p. 3.

<sup>207</sup> In Issues in Law and Medicine. Volume 8. Leipzip: Verlag von Felix Meiner; 1992:231-265.

some lives which were deemed not worth living. However bizarre these views may seem to us now considering modern conceptions of human dignity and our belief in the inherent worth of all human beings, early eugenicists and the Nazi's frequently genuinely believed that what they were doing was best for the human race and for the respect of human dignity.

Then in the post-World War 2 era, as a result of the Nuremberg trials and the new conceptualisation of human rights, which was largely centred on ensuring that which had happened during World War 2, could never happen again, the concept of human dignity shifted towards respect for the inherent worth of every human being. This is the view held by most throughout the world today and the reason why bioethical concerns can sometimes be so controversial and fraught with difficulties. For the purposes of the European Charter of Fundamental Rights, "The dignity of the human person is not only a fundamental right in itself but constitutes the real basis of fundamental rights."<sup>208</sup> It underpins all other rights and is of the utmost importance, particularly when considering that the Charter also expressly states that "In the fields of medicine and biology, the following must be respected in particular... the prohibition of eugenic practices."<sup>209</sup>

As previously explained, genetic testing, specifically here PGD, can offer untold opportunities for society at large to prevent or indeed even eradicate certain debilitating and undesirable diseases, however considering the events of the not too distant past people are afraid of allowing these technologies to become commonplace. As our knowledge of human genetic make-up grows and more and more genes are discovered, more and more possibilities of what to test for can be envisaged.

#### **4.1 PGD: Eugenics or Benefit?**

What if for example, we start discovering genes for other traits that may sometimes be characterised as "undesirable" by certain segments of certain societies?

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<sup>208</sup> 2007/C 303/02, 14 December 2007, p.1.

<sup>209</sup> 2000/C 364/01, 18 December 2000, article 3 (2).

What then if, for example a gene for homosexuality is discovered? Or a gene for colour-blindness, are they also reasons not to implant an embryo? Some, prominent bioethicists would say yes, they are. James Watson, one of the co-discoverers of the structure of DNA and establishing member of the Human Genome Project, stirred controversy a few years ago “by saying that if a gene for homosexuality were discovered, a woman should be free to abort a foetus that carried it. When his remark provoked an uproar, he replied that he was not singling out gays but asserting a principle: women should be free to abort foetuses for any reason of genetic preference—for example, if the child would be dyslexic, or lacking musical talent, or too short to play basketball.”<sup>210</sup> Sandel poses the question “If it is morally troubling to contemplate abortion to avoid a gay child or a dyslexic one, doesn’t this suggest that something is wrong with acting on any eugenic preference, even when no state coercion is involved?”<sup>211</sup> As PGD involves the selecting of any embryo based off the characteristics deemed most desirable by the prospective parents, one could argue that this is indeed a eugenic practice, however a key distinction to make here is that PGD is carried out on embryos in vitro, embryos are not considered as human beings for the purposes of the ECHR, thus testing carried out on them and actions undertaken as result of those tests cannot reasonably be equated to any of the eugenic practices carried out by the Nazis on non-consenting individuals.

As laid out in the case of *Costa & Pavan v. Italy*, PGD can in fact be considered to be a highly beneficial practice as it allows for the selection of an embryo free from disease and does not involve any invasive pre-natal testing, potentially resulting in abortion. As the court found that it was absurd to allow for abortion, (which is illegal in some Member States of the COE), but not to allow for PGD which was only expressly prohibited or regulated in a select few States, we can reasonably come to the preliminary conclusion that PGD is in fact an excellent method of using scientific progress and its applications for the benefit of human beings. If it were possible to use this type of procedure on a wide scale to eradicate certain genetic diseases as happened in Cyprus with the use of carrier screening, can this be ethically allowed? Rather than in Cyprus where carrier-screening has the apparent effect that it discourages some from

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<sup>210</sup> Sandel, 2004, p. 7.

<sup>211</sup> Ibidem.

marrying or having children or potentially encourages, however passively, them to abort foetuses affected with a certain disease, PGD would allow for greater freedom of choice, to marry and to choose whether or not to have children which would respect more the ECHR Article 8 right to private and family life.

In an interview conducted with two prominent U.S. bioethicists, Arthur Caplan and Robert P. George, Caplan makes the distinction between modern day genetic modification or enhancement techniques and the eugenics practiced by the Nazis. As he says, he believes there is “some role for what (he will) concede as eugenics- if you want to take eugenics as just trying to improve the overall hereditary health of the public.”<sup>212</sup> He notes that some in the disability community might then suggest that his goal was to get rid of the disability to which he would concede that yes it is, however not by getting rid of the disabled. That is the key distinction here between the Nazi practices and the use of new genetic procedures to improve the health and life quality of today’s world citizens. This view seems to be shared by Harris when he states that there is “no moral difference between attempts to cure dysfunction and attempts to enhance function where the enhancement protects life or health.”<sup>213</sup>

The main argument stemming from those in the disabled community seems to be that had their parents had access to prenatal screening and a legal abortion, they might never have been born.<sup>214</sup> While this may be true of pre-natal screening and controversial by reason of the fact that it does seem to be getting rid of the disabled rather than the disability, the same cannot be said of PGD which would seem to be serving to get rid of the disability rather than the disabled. Surely this is a desirable outcome? As Heller says, when debating the use of human dignity as a concept in order to constrain genetic research, that while we cannot appeal to the dignity of a person who may not have existed anyway, “we can appeal, to the dignity of those persons, living or future, *who will be affected by our choice to bring or not to bring potential... persons into*

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<sup>212</sup> Girgis, Democratic Bioethics and Eugenic, 15 April 2011, at <http://www.thepublicdiscourse.com/2011/04/3156s/>, (consulted on 10 July 2013).

<sup>213</sup> Harris, 1999, p. 168.

<sup>214</sup> Kaplan, 1993, p.130.

existence.”<sup>215</sup> From this then we can preliminarily conclude that we have a responsibility not to bring into existence a child suffering from a certain disease or disability.

The notion of “disability” is largely socially constructed and those in the Deaf community, who view themselves not as having a disability but rather as a linguistic minority or a culture<sup>216</sup> would disagree with this notion of “improving the overall hereditary health” of the population. Deaf couples frequently wish to have a child who is also deaf,<sup>217</sup> if this is possible through using PGD in order to select an embryo which is certain to be deaf also, should this be permissible? By virtue of being born deaf, though certainly able to still live a very fulfilling and happy life, the opportunities afforded to this child will be more limited than those of a hearing child. As Davis puts it, “A decision made before a child is born that confines her forever to a narrow group of people and a limited choice of careers, so violates the child’s right to an open future that no genetic counsellor should acquiesce to it.”<sup>218</sup> Thus, it would seem that the act of deliberately choosing an embryo which is either already affected by or certain in the future to be affected by, a disease or disability should not be ethically permissible, however how far should this be allowed to go?

Savulescu believes we have a moral obligation to improve our children, he says, “medicine has changed evolution- we can now select individuals who experience less pain and disease. The next stage of human evolution will be rational evolution, where we select children who not only have the greatest chance of surviving, reproducing and being free of disease, but who have the greatest opportunities to have the best lives in their likely environment.”<sup>219</sup> Many parents already try to do this by manipulating external factors in order to improve their child’s prospects or development, as Agar puts it they “are already free to improve intelligence and physical prowess by modifying environmental factors such as schooling or diet.”<sup>220</sup> This can be accomplished through

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<sup>215</sup> Heller, 2004, p. 123.

<sup>216</sup> Darby, 2013, pp. 2-3

<sup>217</sup> Ibidem.

<sup>218</sup> Davis, 1997, p. 575.

<sup>219</sup> Savulescu, 2009, p. 427.

<sup>220</sup> Agar, 1999, p. 172.

any number of means, by providing them with extra after-school tuition or merely by improving the food they eat. Is genetic manipulation then the logical next step?

Though Savulescu concedes that deafness is “not that bad,” and also states that “couples who select disabled rather than abled embryos or foetuses should be allowed to make those choices, even though (he believes) they are having a child with worse life prospects.”<sup>221</sup> He views deafness as a disability and thus it seems that morally he cannot reconcile the idea of deliberately inflicting a disability on your children with his version of giving them the best life available to them.

But what does this mean for testing that provides the potential for less definitive or potentially developed diseases. Through the use of PGD it is possible to test for the BRCA gene mutations which exponentially raise someone’s risk of developing certain types of cancer throughout their lifetime. The highly acclaimed Hollywood actress Angelina Jolie brought the BRCA-1 gene mutation into popular parlance earlier this year when she wrote an editorial in the New York Times about her discovery, as a result of genetic testing, that she carried a defective BRCA-1 gene which meant that her risk of developing breast cancer was 87% and ovarian cancer 50%.<sup>222</sup> Knowing her family history and the fact that the same disease claimed the life of her mother, she opted to undergo a preventative double mastectomy in order to reduce her chances of developing the disease in the future. However this form of procedure is costly and the expense potentially prohibitive to many women not in Jolie’s privileged position. The chances of these women being able to undertake such preventative measures is markedly smaller and as a result the likelihood of them developing and then succumbing to the disease is much higher.

Cancer is a terrible and highly prolific disease, “each year globally, 12.7 million people learn they have cancer, and 7.6 million people die from the disease.”<sup>223</sup> Few

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<sup>221</sup> University of Oxford, Is it Wrong to Deliberately Select Embryos which will have Disabilities?, Savulescu, 12 March 2008, at <http://blog.practicaletics.ox.ac.uk/2008/03/is-it-wrong-to-deliberately-select-embryos-which-will-have-disabilities/>, (consulted on 8 July 2013).

<sup>222</sup> New York Times, Jolie, Angelina, My Medical Choice, 14 May 2013, at [http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html?\\_r=0](http://www.nytimes.com/2013/05/14/opinion/my-medical-choice.html?_r=0), (consulted on 8 July 2013).

<sup>223</sup> Centers for Disease Control and Prevention, World Cancer Day, at <http://www.cdc.gov/features/worldcancerday/>, (consulted on 8 July 2013).

families in the world escape the advent of cancer in one or more family member's lives. The effect of this is draining emotionally, physically and financially. It would appear logical then that were a couple to undergo IVF and select which embryos they wish to implant that those embryos which carry the BRCA gene mutation would almost certainly not be implanted. Indeed one New- York based fertility clinic even advertises on their website that "we are able to determine which embryos carry the abnormal BRCA gene. Only BRCA-free embryos will be transferred into your womb, therefore practically guaranteeing that you will not transmit this treacherous gene to your children! The more patients with the BRCA gene are aware of PGD the less and less women and men will have that gene in generations to come."<sup>224</sup> This clinic, for example does not even seem to offer the option to implant that embryo, so assured is it that people would choose not to do so.

But what if this embryo, if implanted and matured into personhood was indeed the next Angelina Jolie, Oscar-winning actress and internationally known humanitarian activist (not to mention, mother, partner, daughter, sister etc.), if the BRCA gene mutation is thought to be such an unwanted extra burden in an individual's or a family's life, (at least in the minds of this fertility clinic) deemed worthy of attempted eradication via the non-implantation of affected embryos, this could potentially create a worrying precedent. As, if a defective BCRA gene, which under no reasonable conception could be deemed either as a disease or a disability in and of itself, (it is a mere increased likelihood of development of a disease,) is considered a reason not to implant, it is clear that other genetic characteristics of similar or even less stature too, can be. Were it possible to implement this idea of eradication of the BRCA gene mutation it would be neither a way of getting rid of the disability, nor of the disabled, furthermore even if it were possible to eradicate it, this would not accomplish anything terribly impressive as it is but one small part of a much greater picture. Cancer can be caused by any number of factors, genetic and environmental, thus to not implant an embryo on the basis that it may or may not develop cancer is perhaps a bridge too far.

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<sup>224</sup> North Shore LIJ, The Center for Human Reproduction, at <http://www.northshorelijvfc.com/wordpress/?tag=preimplantation-genetic-diagnosis>, (consulted on 8 July 2013).

This could be a slippery slope leading into potentially abusive eugenic activities. It is possible that had the parents of Ms Jolie undergone PGD in order to conceive their child, she would never have been born at all, a more favourable embryo with less chance of developing a possibly fatal illness being preferred. Of course we can never know this for certain but the potential scenarios which could arise are chilling. It is for this reason that it is necessary for stricter guidelines and codes of ethics to be developed with a view to establishing some kind of internationally binding laws in the area. Although some regulations have been set on EU Member States through a directive of the European Parliament and the Council of the EU concerning quality, control and management of human cells and tissues<sup>225</sup>, in a European study carried out on the usage of PGD within Europe, a number of respondents from the Member States of the EU were critical of these regulations, suggesting instead that a more patient- centric approach, as opposed to one too focused on State obligations was preferable.<sup>226</sup> It was suggested that it was the potential parents who should make the determination as they were best suited to deciding the specificities concerning PGD.

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<sup>225</sup> 2004/23/EC, 31 March 2004.

<sup>226</sup> European Commission, Joint Research Centre Institute for Prospective Technological Studies, Preimplantation Genetic Diagnosis in Europe, 2007, pp. 80-81, at <ftp://ftp.jrc.es/pub/EURdoc/eur22764en.pdf>, (consulted on 11 July 2013).

## **Conclusion:**

### **1. Elaborate on the REBSP**

#### **1.1 General Comment**

It is clear that the REBSP is an internationally recognised right, enshrined in many international and regional documents. While attempts have been made to elaborate on its scope and normative content, through the report of the Special Rapporteur on the right as well as the work involved in the drafting and elaboration of the Venice statement, no official, internationally binding document has yet been issued to give us greater guidance here. This right has enormous potential, it could be used to great advantage in order to benefit, protect and vastly improve the lives of people all over the world. However in order for it to realise its full potential it needs to be elaborated upon and clarified so that States and all other relevant stakeholders understand what obligations are imposed on them. For this to occur, it is necessary that a General Comment be issued by the CESCR in order to fully respect and vindicate this right. Awareness raising and increased education and knowledge concerning the right, as desired both by the experts involved in the drafting of the Venice Statement and the Special Rapporteur in her report are also crucial factors in ensuring the proper respect for and fulfilment of this right which has such huge potential for the benefit of humankind.

#### **1.2 Optional Protocol to ICESCR<sup>227</sup>**

Another way to ensure correct respect for, protection and fulfilment of the REBSP is to encourage States who have not yet done so to sign and then ratify this

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<sup>227</sup> A/RES/63/117, 10 December 2008.

protocol so as to allow recourse to an effective complaints mechanism for violations of this right. Of course, for people to be aware that their rights have been violated they need to be aware of their existence in the first place, which is why the elaboration of a GC to set out its scope and normative content is so important in the first place, followed by education and awareness raising concerning this right

The enormous potential of this right both for use and misuse is so great that it cannot be ignored for much longer. However, considering some of the mistakes of the past, concerning certain practices, as outlined above, it is necessary to proceed with caution when considering how to expand on this right and associated beneficial applications and technologies arising out of it.

## **2. Past mistakes to future potential**

Advancements in technology and science of the past century have led to previously unimaginable possibilities becoming a reality. The improvements in genetic testing and screening capabilities, clearly a direct example of a “benefit of scientific progress” mean that a whole new avenue of human rights linked considerations have opened up. Concern for the abuse of these new technologies is apparent, while there is good reason to be fearful about the possible misuse of certain of these technologies, should proper regulations be in place, those fears would be unfounded. The widespread usage of genetic testing procedures, as a practical application of the “benefits of scientific progress” as a way of realising the REBSP, has vast potential to be of huge benefit to the human race.

The aim of this thesis was to decipher whether it is legally and ethically acceptable to use genetic testing procedures, specifically in this instance PGD, as a means to eradicate certain harmful genetic diseases. And this author would contend that yes, it does seem to be ethically and legally acceptable to do so, in the case of PGD. PGD can be used as a benefit of scientific progress as a way to eradicate disease but needs to be carefully regulated in order to avoid misuse from occurring.

One of the key problems of the Nazi era and its eugenic policies is that they were State-mandated, there was no room for individual autonomy nor the concept of consent. The issue of informed consent to medical treatment or in medical research became of huge importance in the aftermath of the Second World War and the Nuremberg trials. The modern discipline of bioethics was borne as a result of the atrocities carried out during the Nazi regime, with its blatant disregard for the dignity and inherent worth of every individual. As stated previously, bioethics addresses ethical issues related to medicine, life sciences and associated technologies as applied to human beings, taking into account their social, legal and environmental dimensions. As such the “human being” and all their rights and freedoms, including human dignity is of key importance here.

Thus, concerning PGD, the choice needs to largely remain that of the parents, whether or not to implant an embryo on foot of information they obtain in order to fully respect their rights and freedoms, although of course, there should be certain restrictions to this, in line with democratic principles. As people fear a return to the eugenic policies of old, some kind of binding international declaration on the matter would be useful in order to clarify how and for what purpose this can be used. The case of *Costa & Pavan v. Italy* highlighted the lack of consensus on the procedure of PGD in Europe and stated how bizarre and contradictory the Italian law in the area was, for when you consider that abortion of a foetus affected by a disease was permissible, why then would PGD on an embryo (not an individual for the purposes of the ECHR) be disallowed?

Of course the vast majority of people do not wish to see a return to the eugenic policies of old nor the advent of a Gattaca<sup>228</sup>-like society where people are genetically engineered to have the best traits available to them and those who have not been genetically engineered or who possess less desirable traits are discriminated against. Thus, it is important to balance multiple conflicting rights, such as the right of the parents to respect for their private and family life, with the potential child’s right to an open future. Though this is a complex area to legislate for as it is difficult to know

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<sup>228</sup> Gattaca, 1997, Directed by Andrew Niccol, A Science Fiction Film set in the not too distant future where genetic modification of people is considered the norm and those unlucky enough not to be genetically engineered suffer from huge disadvantage and discrimination.

where to draw the line in terms of what reason is a good enough reason not to implant an embryo, this author would suggest that perhaps respect for parental autonomy, balanced with due respect for the rights of the potential child, in line with democratic principles, is the best course of action to take for now, at least until further knowledge becomes available. Though, it would be suggested that any genetic variant, not considered to be indicative of a disease or a disability, or the strong possibility of a severe disease or disability which may manifest itself later on, is not a viable reason.

The case of Cyprus is a good indication of how a genetically caused disease which can have devastating consequences can be essentially eradicated without technically violating any human rights, as it leaves the decision to reproduce entirely up to the parents, based off the information afforded to them, thus respecting parental autonomy. However, the Cyprus example could still lead to cases of abortion of affected foetuses, which at the very least, for those in the pro-life movement, echoes more of the eugenics of old, which aimed to exterminate all those deemed unfit for life, than does PGD. As PGD is carried out on embryos in vitro, there is absolutely no violation of the (non-existent) right to life of the embryo.

This author would thus contend that PGD is the best example of an application of scientific progress working in a beneficial way for the human race. We already try to give our children or potential children the best shot possible at life through the manipulation of external, environmental factors, so this author would contend it is not much of a stretch to try and alter their genetic patterns in order to do the same, specifically, however for the purposes of the avoidance of disability or disease, not for any other enhancing measure. Though it will probably never be possible to completely allay fears of a eugenic nature, better education for individuals concerning the REBSP and the potential technologies arising out of it are a good place to start. Then, some kind of internationally binding guidelines on the use of PGD would be desirable in order to make sure its vast potential can be realised and that abuse of same can be avoided. As Madden posits, “law has traditionally been reactive rather than proactive”<sup>229</sup> but perhaps it is finally time for the international community to step up and recognise the vast

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<sup>229</sup> Madden, 2011, p.294.

potentialities of this right through the technologies which arise as a result of it, to be proactive and ensure that people can reap the full benefits of this right in all its many forms, for the benefit of humanity whilst still maintaining respect for human dignity and other fundamental rights and freedoms.

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