

Article

# Sport and Enhancement in the Age of Human Rights: Genetic Testing as a Case Study

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**Abstract:** The paper focuses on the ethical–legal implications of a specific area of scientific and technological progress for the recognition of sport as a human right, which is the field of genetic advances with regard to application of genetic testing for non-medical purposes, and in particular for talent identification (genetic talent identification). As with most biomedical innovations, this use of genetic tests has both constructive and more ethical–legal problematic implications. The attempt made by this paper is to highlight controversial implications of genetic talent identification tests for the recognition of sport as human right.

**Keywords:** bioethics; biolaw; genetic talent identification; fundamental rights; equality; right to freely construct one’s personality; human enhancement; genetic testing



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## 1. Introduction

Starting from the second half of the 20th century, sport has been internationally recognized as a human right.<sup>1</sup> This is a normative unprecedented recognition imparting a specific message to politics, sports organizations, institutions, and society in relation to values promoted by sport. Over time this acceptance has also shaped the European model of sport as emerging by formal normative statements by attributing an essential pedagogic, educational, cultural, and ethical mandate to sport. This mandate embodies progressive values of dignity and equality well expressed in principles and rights like the principle of equality and non-discrimination, the principle of self-determination, the right to freely construct one’s personality, and the right to health.

These principles and rights frame sport activities at all levels: from elite sport to sport for wellbeing. These activities are systematically organized between different, but interdependent, degrees of sports because in all sports those values underpinning the legal framework can and have to be applied consistently and virtuously if the promotion of human rights has to be of any utility and effectiveness. In fact, once sport is recognized as a human right, this normative condition places it within a framework of universal, interrelated, indivisible, and interdependent rights demanding formally and axiologically consistent implementation throughout the multifaceted universe of sports. For this to be achieved, almost all aspects, ranging from economic factors to scientific and technological ones, related to or involved in sport are required to be measured against possible violations of human rights, freedoms, and principles as just referred to. Factors and mechanisms that may be responsible for systemic inconsistency and deviations from the normative model are of a different kind (economic, social, cultural, political and so on). Among the currently crucial challenges for human rights in general and for sport as a human right in particular, scientific and technological advances are of utmost importance. The paper will therefore focus on the ethical–legal implications of a specific area of scientific and technological progress for the recognition of sport as a human right, which is the field of

<sup>1</sup> See for instance the 1978 UNESCO International Charter of Physical Education and Sport.

genetic advances with regard to administration of genetic testing for non-medical purposes, and in particular for talent identification (genetic talent identification, genetic TI). As with most biomedical innovations, this use of genetic tests has both constructive and more ethically–legally problematic implications. The attempt made by this paper is to highlight some controversial implications for the recognition of sport as a human right with specific reference to axiological inconsistencies emerging between the practice of sport and the model of sport depicted in formal provisions, in other words between *ideals and realities*.

## 2. Values and Functions of Sport in the 20th Century

In order to correctly address the topic of this paper, we need to first understand the normative narrative of sport in the 20th century. The link between sport, values, and political vision indeed becomes clearly evident in this age. It was a period of spectacular and rapid transformations, also defined as the *Age of Extremes*<sup>2</sup>, characterized by a radical change in the political–legal influence after World War II. This change deeply impacted the role of sport in promoting values in the European society as we will see in what follows.

But before turning to assess the profound discontinuity marking the ethical and political role of sport before and after World War II, let us highlight a further peculiarity featuring that *short century*. The 20th century was indeed a fundamental turning point for the history of science and for the intimate connection established between science and technology. As for sport, this period witnessed the origin of scientific research applied to sport and the rise of a phenomenon termed *medicalization of sport* [2,3] that anticipates the well-known concept of *medicalization of society* [4] studied in the USA from the 1960s.

In a nutshell, the 20th century was a crucial age both for marked efforts to impose opposite moral and political visions by means of sport and for the scientific-based approach adopted towards sports and athletes.

In what follows, these two distinct, albeit interrelated, aspects will be investigated.

### 2.1. Sport during Totalitarian Regimes in Europe: Functions and (Dis)Values

During the totalitarian regimes in Europe, sport became a means to export the political vision of the regime and the underpinning (dis)values abroad, and, at the same time, sport acted internally as a “glue” between the regime and the citizens. This was, for instance, the case of sports during fascism in Italy [2]. In order to disseminate its political message and its alleged grandeur, the fascist regime relied both on elite sport and sport activities like physical education. The former mirrored the ideas of fighting, war, and victory and became the emblem of the regime’s propaganda: elite athletes were the soldiers and messengers of sport. The latter served the two-fold goal of maintaining the health of the people and of creating moments and places of aggregation where political visions and ideas could be disseminated. In the fascist regime, the social, ethical, and pedagogical functions of sports<sup>3</sup> aimed at a proper regimentation of the sport movement [2]. It was possible to achieve this goal by exploiting a *minimal social function* [5] that characterizes sport, that is, its ability to create, strengthen, and maintain over time social and interpersonal relationships between active participants (athletes) and passive participants (spectators). This “minimal social function” is grounded in a motivational force towards aggregation mainly based on emotions than on rationality [5]. For this reason, the regime could exploit this peculiar aspect to fix its vision through sport as it could target all categories of the Italian population.

Formal provisions contributed to the success of this operation. As a matter of fact, the (un)ethical contents underpinning the fascist ideology were clearly stated in Article 2 of the 1928 Charter of Sport in which physical and moral enhancement of the *race*

<sup>2</sup> As clarified by Hobsbawm [1].

<sup>3</sup> The author has coined the term *minimal social function* [5]. This “minimal social function” is grounded in a motivational force towards aggregation, which in turn is the basis for different and sometimes opposite functions as this force is based on emotions and not on rational arguments. Sport can have opposing pedagogic, cultural, ethical and political functions because sports and values do not have to be linked (no necessary conjunction). Values are a contingent variable promoted by means of a constant, namely the “minimal social function”. This constitutive definitional element of sport allows its use to support very different models of civil and social coexistence.

were the main goal of the newly formed Italian National Olympic Committee (CONI). During fascism, sport allowed the pursuit of the “hygiene of the race”, the “health of the race”, and the “physical strengthening of the Italian race” [2]. To achieve these goals the “Byotipological Orthogenetic Institute” in Genoa was constituted in 1926 and directed by Nicola Pende. The purpose of this institution was to screen the health of the entire Italian population, including athletes. And, as a consequence, a systematic selection of athletes was carried out through a mandatory periodic clinical examination of physical fitness. The aim of the test was to achieve: “a classification [ . . . ] of biotypological and anthropometric parameters of athletes, and consequently a selection of those individuals best suited to competitive sport, in the name and on behalf of the regime”<sup>4</sup> [2]. This selection procedure was the forerunner of today’s genetic talent identification. And this confirms the continuity of the scientific approach applied to sport over time.

On the contrary, the marked discontinuities between the first and the second half of the 20th century concern the normative model of sport.

When the “age of rights” was affirmed after World War II, sport was committed to playing a crucial role in marking a profound discontinuity by imposing a fundamental change in the underlying ethical contents. However, this ethical and legal discontinuity, intended as a virtuous value-laden progress aiming at reaching higher standards of decency, risks being limited by questionable administration of genetic testing for talent identification in absence of a clear ethical framework and legal regulation. And this may reawaken distant, albeit always latent, conceptions of sport rooted in the first part of the 20th century.

We will discuss these aspects in the next subparagraphs.

## 2.2. Sport as a Human Right

After the defeat of totalitarian regimes, the new political–legal order at the international, European, and national levels was committed to freedom and equality in dignity and rights. In the new political–legal scenario, human rights were conceived as the foundation of the system and were the measure of legal equality following a universalistic vocation. This has not changed in the current formal legal framework where the narrative of human rights is the arrangement to limit power, not just economic or state power, but also technological power, and to expand individual freedoms and rights.

Following this perspective, individual identities or differences amongst individuals are equally protected and respected as they belong to the intimate, intangible, and unquestionable sphere of every Person [6]. Thus, equality as equal freedom of rights is the *equality of differences*, which represents the value or the dignity of the Person [6]. In other words, equality is the equal right of everybody to affirm and protect one’s own identity by virtue of the equal value associated with all differences that make the Person an individual different from others and each individual Person like everybody else [6].

Associated with the recognition of equality is the recognition of the constitutional Person as having the right to freely construct one’s personality. The free construction of one’s personality is a key right of the post-war Universal Declaration of Human Rights (UDCHR), of European constitutions, and an essential element of the European Charter of Fundamental Rights. Article 22 of the UDCHR clearly states: “Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.” And this right is further underlined in Art. 29.<sup>5</sup>

This right is the expression of self-determination, which is, as Stefano Rodotà deftly illuminated, “identified with the life plan pursued by the person concerned [ . . . ] for it is governed by the uninterrupted exercise of sovereignty, enabling that free construction

<sup>4</sup> Translation by the author of this paper. Original sentence: “classificazione quanto più rigorosa possibile dei parametri biotipologici e antropometrici degli atleti, e della selezione quindi dei soggetti più adatti all’attività agonistica, in nome e per conto del regime”.

<sup>5</sup> Article 29, 1, UDCHR: (1) Everyone has duties to the community in which alone the free and full development of his personality is possible.

of personality which we find enshrined at the outset of our own constitution as well as in others" [7] (p. 11). The right to freely construct one's personality is granted to *all* human beings, and there are no exceptions for those who would like to pursue a sport career at the highest level.

As regards sport, its legal recognition as a human right implies that every Person, including elite athletes, has the possibility of freely developing her personality through the different activities that are labeled "sports", ranging from physical education, fitness to the highest level of sport performance (elite sport). This point is clearly expressed in Article 1, 1.1 of the 1978 UNESCO International Charter of Physical Education and Sport.

The right to freely construct one's personality is not a monad in the legal system. Rather, it is interrelated with other rights like the right to health, the right to respect for the dignity of the person, the right to non-discrimination, the right to equality, and so on.

Of course, the right to freely construct one's personality does not have an absolute value. On the contrary, it needs to be balanced and specified in each single case. Balancing has to be fair and cannot result in economic and market interests to constantly jeopardize individual rights, including athletes' rights. As previously said, human rights are non-disposable and universalistic, and because of these features they cannot suffer sector-related exemptions. Following this view, human rights are a structure designed to protect *all* individuals in *all* their activities, in which they express their personality, against the technological and economic hazards of unrestrained powers. These rights have substantial functions: they aim at meeting fundamental needs or interests of all individuals, but especially those in weak positions, protecting them against the market and the discretionary decisions made by interest groups in the very different fields in which they operate. No exemptions are made for sport. Sport as a human right is a constitutive determinant of this architecture and is protected from being organized according to a purely economic and market logic of profit and loss.

Despite this formal scenario, we must sadly note that today decisions on the destiny of elite athletes are mainly, if not exclusively, economically driven. Although economic interests in sport activities are of course relevant for self-evident reasons, they may become problematic whenever the value of the athlete as Person is exclusively measured against economic and market interests.

The basic definition of equality according to which equal cases have to be treated equally and different cases have to be treated differently is not to be understood as the possibility to provide discretionary exemptions for some categories of individuals like elite athletes. Rather, this basic meaning of equality is the first bulwark against any form of discriminatory practices implemented by any kind of power, including the power of sport organizations.

Equality cannot suffer exemptions unless we are ready to admit that, in elite sport, those who have economic power can use it at their discretion, even to violate individuals' fundamental rights. To accept this exemption implies to be fully ready to extend it to further areas of human activities where group interests aim to impose their programs and strategies, irrespective of the impacts for those who may be on that occasion in the weaker position. And this would occur despite the fact that such exemptions will ultimately dwarf the original intentionality of the human rights narrative.

To allow the aforementioned exemptions implies the acceptance of the axiological inconsistency it produces. In fact, when formal statements about human rights are contradicted by what occurs on the ground, as is often today the case for elite sport, the inconsistency is not just between theory and practice, between the model of sport and its implementation. Rather, it is subtler as it questions the values underpinning the recognition of sport as a human right. Some widespread practices in sport like doping or strict genetic TI (i.e., the sole tool used to identify talented athletes) contribute to widening the gap between formal declarations and regulations that frame the current formal model of sport and the values to be promoted through it and the way it is practiced and perceived in society. The ethical tension between a strict genetic TI and the right to freely construct

one's personality and the values associated with it is just one paradigmatic example of this inconsistency, as it will be discussed later in this paper.

Before turning to this analysis, let us stress a less evident, though relevant, outcome of the recognition of sport as a human right: this normative recognition covers an all-embracing idea of sport that normatively connects all sport activities (elite sport, amateur sport, physical education, and sport for fitness and wellness) by establishing an interdependent virtuous relationship as shown by Figure 1.<sup>6</sup>



**Figure 1.** The interrelation between sport activities under the recognition as a human right.

The qualification of sport as a human right represents therefore both the ultimate goal to be achieved and the principle that begins the whole pedagogic–educational process following a human rights approach. Put it simply, decisions taken in elite sport will have crucial implications for the way other sport activities are practiced and experienced. In this perspective, elite sport is an integral part of the pedagogic–educational and cultural process and at the same time the best expression of this process. What occurs at the level of high-performance sport influences attitudes and behaviors at the other levels, from amateur sport down to sport for fitness and wellness (emulative effect). Emulation concerns both sporting achievements as well as life-styles and behavioral patterns.

In what follows the medical and non-medical uses of genetic testing will be examined in order to put genetic TI into context. After this examination, implications of some problematic aspects that will emerge with particular reference to non-medical uses will be discussed in relation to sport as a human right.<sup>7</sup>

### 3. Genetic Testing: Therapeutic v. Non-Therapeutic Applications

Genetic tests in sport can serve two different purposes: therapeutic/medical or non-therapeutic/non-medical aims.

As for the therapeutic uses, they are framed within the traditional physician–patient relationship and generally follow the same rules established for these techniques starting in the 1980s. These genetic tests are usually employed for preventative purposes.

Genetic testing for prevention is very widespread as it can detect gene mutations that predict possible future health problems. These predictive tests search for gene mutations responsible for development of future diseases or disorders if other environmental factors are present (gene–environment interplay). In sports, genetic testing for prevention may focus on diseases with high-risk potential for the life of athletes like gene testing for (inherited) heart diseases or may be employed for identifying gene mutations for far less

<sup>6</sup> This is the ideal pursued by the 1978 UNESCO International Charter of Physical Education and Sport. In article 3.3 the Charter states: “Even when it has spectacular features, competitive sport must always aim, in accordance with the Olympic ideal, to serve the purpose of educational sport, of which it represents the crowning epitome. It must in no way be influenced by profit-seeking commercial interests”.

<sup>7</sup> The paper does not discuss the humiliating practice of sex-testing female athletes. On-site genetic screening of female athletes was officially abandoned by the International Olympic Committee in 1999.

risky diseases like those affecting bones and tissues causing potential injuries to tendons and ligaments.

Genetic tests for medical purposes have long since been object of legal regulation starting in the 1980s in Western countries. Despite these tests still raise ethical–legal concerns around genetic discrimination, privacy, and consent in employment and in insurance, they are however far less controversial than genetic tests for non-medical purposes. One reason for this is that the therapeutic aim of these tests already represents a clear-cut distinction between ethically acceptable techniques and the still ethically controversial ones. Thus, the therapeutic aim is a relevant ethical justification for their administration. The access to these techniques for therapeutic purposes allows indeed the exercise of the rights to health and to self-determination. And a further reason is that genetic tests for therapeutic purposes have long since been the object of regulation at the international, regional, and national levels, a regulation generally compliant with protection of fundamental rights.

Thus, even when the use of this kind of tests is measured against the recognition of sport as a human right, it clearly emerges that major ethical problems related to their administration have already effectively been addressed, and that existing rules in this field have promptly reacted by extending existing or creating new rights like non-discrimination based on the genetic-make up, the right to know or not to know one’s information, the right to genetic counseling, and so on.

Beyond genetic testing for medical reasons, the DNA technique is being used in sport also for non-medical purposes in particularly to early identify talent. More precisely, “[g]enetic tests determine DNA variants (polymorphisms) that are directly or indirectly associated with the disposition for sports-related skills” [8] (p. 1493). In other words, genetic TI tests try to estimate the role of genetic luck in making an athlete a champion.<sup>8</sup> As they do not have a therapeutic purpose, but rather an enhancing one, they are still ethically and legally controversial. In fact, the general framework of the debate about genetic TI is the discussion about human enhancement. This inclusion has to be understood according to the following considerations: “human genetic enhancement means the use of genetic knowledge and technique to bring about improvements in the capacities of existing individuals or future generations. Human genetic enhancement might be accomplished most obviously by interventions that produce directed genetic change. But it might also be brought about through genetic screening and selection of individuals with “more desirable” genotypes.”<sup>9</sup>

In Europe, Human Enhancement was first addressed at the institutional level in 2009 in the *Study on Human Enhancement* released by the Panel for the Future of Science and Technology (STOA) of the European Parliament. Enhancement practices are at the center of a heated debate between different philosophical–ethical currents: bioconservatives and transhumanists. These are two very nuanced philosophical perspectives, which I cannot discuss here in detail, because this would exceed the scope of this paper. Thus, I will just make a brief and general reference to them to highlight the basic implications of the two approaches to the law. Whereas bioconservatives hold that human nature is constant and immutable, and what should be allowed in terms of technological interventions on humans has to be derived by the intrinsic finality of nature, transhumanists instead consider human nature totally malleable by technological progress to any aim we consider legitimate. These two opposite positions have also different ideas about the role of the law in guiding technological advances. Bioconservatives promote a “strong” model of the law in which obligations, prohibitions, and sanctions play a key role in regulating scientific and technological progress, as they consider these arrangements useful to maintain the natural order of things. Transhumanists view the “self-regulating market” as the original state of nature

<sup>8</sup> It is still under scrutiny the actual role of genes in determining the success of elite sport performance. Attempts have been made for instance to link speed to the ACTN3 gene [9], however the sport gene has not been detected yet [10].

<sup>9</sup> This is clearly stated in the 2002 Staff Background Paper on Human Genetic Enhancement prepared by the President’s Council on Bioethics: <https://bioethicsarchive.georgetown.edu/pcbe/background/humangenetic.html>, last accessed on 18 January 2021.

and “government interference” as largely illegitimate and counterproductive. Between these two currents, the mid-position points at human rights as a valuable approach to discuss the multifaceted scenario of technical possibilities to intervene on human nature. In a nutshell, the human rights approach states that whereas scientific progress and technological applications have to be promoted to the wellness of human beings, they cannot remain ungoverned and need to be put on a formal and substantial “human rights footing”. In this view, the law is the adequate means to balance different positions, safeguarding the most vulnerable ones, preserving freedom and autonomy of individuals without disregarding the contribution of science in creating better conditions of life.

In the next paragraph, we will discuss the ethical challenges of the non-medical use of genetic testing for TI as this represents an interesting testing ground to explore whether the human rights approach is adequate to guiding scientific progress in elite sport.

#### 4. Genetic Tests for Genetic TI in Sport: Ethical Open Challenges

Genetic tests for TI are increasingly used in athlete selection based mainly upon the assumption that *the sports gene* can be traced and high performance can be predicted [8]. Genetic TI is achieved by means of genetic tests. These “determine DNA variants (polymorphisms) that are directly or indirectly associated with the disposition for sports-related skills” [8] (p. 1493).

This practice is at the center of a heated ethical–legal debate concerning in particular the role of law in governing technological progress. As already noted, transhumanist authors strongly support—some of them want to impose—the use of science and technology to achieve higher performance. Following such a perspective, the supply and demand rule will measure the success of these techniques as individuals are self-determined and can freely choose what is best for them. They promote a weak law that lets the market rules play the game. For transhumanists, market mechanisms and private institutions are usually preferable to governmental ones. Unlike transhumanists, bioconservatives base their arguments on the unnaturalness of genetic TI, on genetic luck as a gift that cannot be changed. Thus, in order to preserve the human nature, they opt for a strong intervention of the law based on prohibitions and sanctions.

A position in-between these two extremes demands balancing different interests as well as risks and benefits of scientific and technological advances. This approach—the human rights approach—is based on two basic assumptions: (1) the primacy of the human being over society and science is one fundamental value of the entire European legal system. The European Convention on Human Rights and Biomedicine (The Oviedo Convention) clearly states this supremacy over the sole interest of science and society in Article 2. This Article has inspired the process of balancing scientific progress with the rights of individuals or groups in further regulations directly concerning genetic testing at the international, regional as well as national levels; (2) promotion of scientific and technological innovation as it contributes to the well-being of humans. The corollary of these two assumptions is that promotion of and support in technological innovation ought to be governed by rules that protect all actors involved.

If we apply the human rights approach to the case study of genetic TI in sport, the abovementioned need for balancing different rights and interests becomes particularly evident. Whereas genetic TI can fruitfully impact the decision making process concerning the future of athletes, it does not follow that their future has be determined solely by the outcomes of the TI genetic test. In what follows, I will select the most relevant paradigmatic problems arising from genetic TI applied to sport through the lens of human rights. I will in particular examine the right to freely construct one’s personality, the right to self-determination, the right to health, and the right to equal treatment.

A first aspect to be highlighted is the following. If the use of genetic TI rests upon the discretion of economic actors and sport organizations, these powerful elites will choose strategies and programs that best meet their interests, which, needless to say, are mainly, if not exclusively, economic driven rather than altruistically oriented. They will insist on

utility of exclusively relying on genetic TI to select the future champion more rapidly than allowed by traditional talent identification techniques. To achieve their goals, they will be ready to overstate the outcomes of genetic testing in this field.

This pernicious attitude raises different problems. The first one concerns clinical validity and utility. These are two essential requisites of appropriateness of genetic testing as described in the *ACCE* (analytic validity, clinical validity, clinical utility, and ethical, legal and social implications) model of evaluation. The second problem is justification. Indeed, if there is no proven clinical validity and utility how can administration of these genetic tests to athletes be justified? Athletes, especially elite athletes, fall into the category of workers. As a consequence, they are protected by regulations on genetic testing as *all* workers are. Existing regulations on genetic testing for medical purposes exclude that genetic tests can be used to discriminate between workers. “The use of genetic information to make determinations about selection and employment could disproportionately interfere with an individual’s human right to be free from discrimination on the basis of their genetics” [11] (p. 2).

What could be the ethical–legal justification for genetic testing for non-medical purpose to breach this rule? Some could argue that sport has a special essence best preserved by means of autonomous rules and a distinct discipline. However, what is neglected following this argument is that the legal recognition of sport as a human right frames it within a set of rights, which cannot be affected by any power. This framework limits the “sphere of undecidable”, as Luigi Ferrajoli [6] terms it. In this sense, as already noted, *all* individuals are equally protected against any form of power, irrespective of the role or work they have in society. Following this understanding, athletes are no exception, and the protection of their lives has to be measured against the human rights framework [12] (p. 153). Moreover, unregulated use of genetic testing for non-medical purposes like TI does not only violate the principle of equality, but it also raises issues of autonomy and consent, of privacy and confidentiality, and of breaching the right to freely construct one’s personality. The problem of consent concerns the possibility for an athlete to refuse to take a genetic TI test, as is the case for all other individuals. The problem of privacy and confidentiality deals with protection of sensitive information and with the question whether the European General Data Protection Regulation 679/2018 (GDPR<sup>10</sup>) and other rules apply to sports and if not why?

As for the right to freely construct one’s personality, some very pernicious side effects deriving from the unregulated use and wild spread of genetic testing for non-medical purposes concern the view on human nature, and in particular on athletes. Firstly, in absence of clear scientific evidence about the correctness of the outcomes of genetic testing for TI, decisions to exclude athletes from or include them in a sports career seem fully arbitrary. This is indeed contrary to the exercise of equality in access to sport. Secondly, sponsors can exploit athletes and ambitious parents can exploit children based on an allegedly precociously detected ability. In so doing, the construction of the child’s personality would be quite fully conditioned and shaped by external factors and actors, thus violating the freedom and autonomy of choice, and the correlated right to develop such autonomy.

Moreover, when selection of athletes is almost exclusively based on genetic outcomes, this can pave the way for *genetic reductionism or essentialism*. This conception has negative psychological outcomes as it reduces what is human to what is genetically determined. Thus, when athletes are selected based on their genetic predisposition, they will feel the pressure of being champions, no matter what. As a consequence, selection based on genetic luck puts an enormous burden upon the (usually very young) individual to pursue her predefined destiny. She is destined to be a champion, and in case of failure, the athlete, especially in case she is a child or adolescent, can suffer from a *guilt phenomenon* with adverse psychological side effects.

The resurgence of a deterministic view on human nature has been at the center of the early regulation of genetic testing for medical purposes. At the international, European,

<sup>10</sup> European General Data Protection Regulation 679/2018.



and national levels there are provisions that clearly prohibit any reduction of human beings to genetic make-up. The paradigmatic provision on this point remains Art. 3 of the 2003 UNESCO *International Declaration on Human Genetic Data*: “each individual has a characteristic genetic make-up. Nevertheless, a person’s identity should not be reduced to genetic characteristics, since it involves complex educational, environmental and personal factors and emotional, social, spiritual and cultural bonds with others and implies a dimension of freedom”.

In light of the current regulation on genetic testing for medical purposes, the question is why should rules established to protect dignity and guarantee respect of *all* individuals suffer exemptions in case of athletes. Are autonomy of sport organizations and economic interests good reasons to reinforce the stigma of diversity<sup>11</sup> in direct contradiction to the commitment of sport to non-discrimination, including genetic discrimination?

## 5. Conclusive Remarks

In this paper I have argued that the recognition of sport as a human right has important and involved ethical–legal implications when genetic tests are administered to athletes, especially in case of tests for non-medical purposes like talent identification.

My point is that genetic TI can be used as a valuable additional resource in selecting athletes, but decisions of exclusion from or inclusion in sport career should not be exclusively based on the outcomes of this technique. On the contrary, genetic TI could be one of the tools, but never the sole one, along with traditional TI that sport organizations can use for athletes’ selection. Genetic tests in general should never be a means to arbitrary discriminate among athletes. Rather, they could serve to direct athletes towards the most suitable activities considering their biological structure and to tailor training regimes [13] given some constitutive factors and all things considered.

It is time that this topic is seriously tackled by European institutions in ad hoc regulation. It is time for European and national legislators to provide a regulation on genetic testing for non-medical purposes if we want to protect athletes from potential abuse. We need a regulation that specifically addresses administration of genetic tests for non-medical purposes in sport.

Switzerland is the first country where the existing regulation on genetic testing passed in 2004 has undergone a total revision. The new Federal Act will enter into effect in 2021.

The 2004 version, which is still in force, focused on genetic testing for medical purposes. The new Act tries to fill the knowledge gap of the previous Act, as the lack of an adequate regulation of genetic testing for commercial purposes is concerned. In this scenario, Chapter 3 of the new Act is dedicated to non-medical uses. After listing in Art. 31 the categories of genetic tests for non-medical purposes<sup>12</sup>, which include genetic testing aiming at detecting characteristics of personality worthy of specific protection among which there are genetic testing for TI, the following Article 32 instead focuses on information. It underlines that, in addition to information given to a person in case of genetic testing for medical purposes as provided in Article 6, in case of genetic testing for non-medical purposes the person should receive information concerning the laboratory performing the genetic analysis even in case of foreign companies and laboratories. Information is written and includes contact data of an expert who can answer questions and of the data controller. Incidental findings cannot be communicated to the person who undergoes genetic testing (Art. 33). Only health care professionals operating in the field where the test is required can prescribe genetic testing for non-medical purposes (Art. 34). For cytogenetic and molecular genetic testing concerning tests for non-medical purposes authorization is needed from the Federal Office

<sup>11</sup> As was the case when the story of Y chromosome genes in elite female athletes with the 46, XY disorder of sexual development, was first made public.

<sup>12</sup> Article 31 clarifies that these genetic tests include: tests concerning physiological characteristics whose knowledge could impact on lifestyles; personal characteristics like character, behavior, intelligence, preferences and talents; or characteristics concerning ethnical origin, etc.

of Public Health (Art. 35). In addition, there needs to be an appropriate standard of genetic counselling always provided.

Whereas the attempts of the revised Act to strictly link the use of non-health related tests to health care professionals in the field of genetics and to the basic requirement of a transparent information are valuable, the Act lacks specificity. In my opinion, the Act fails because it does not provide ad hoc rules for administration of genetic tests for TI in the field of sport.

At the European Union (EU) level, as other existing regulations will soon need to be revised because they are no longer up to date, this would be a good opportunity for EU to intervene with a harmonizing regulation. This regulation ought to include a special part concerning use of genetic testing in sport in line with protection of human rights as also required by the Council of Europe.

For this purpose, the EU legislator should take into account a long-term horizon with a greater risk of uncertainty. In these circumstances, flexible legal tools based on an anticipatory approach could be the adequate way of dealing with scientific uncertainty and a great number of possible risks. This kind of approach needs a strategic future vision, an understanding of where we want to go both in terms of the development of a technology but also at the societal level. Based on the existing human rights framework, the non-medical uses of genetic testing have a clear direction of travel for everyone to follow, including sport. And, as a consequence, at the second level of regulation, namely the one directly targeting athletes, sports clubs, physicians, and trainers, this anticipatory approach could be supported by implementing rules that directly aim at stimulating desirable behaviors through positive sanctions.<sup>13</sup> In fact, to award athletes, sports clubs, physicians, and trainers that make a sound ethical use of scientific and technological advances with some kind of subsidy would be an example of this sort of sanction. This legal tactic based on positive sanctions could contribute to maximizing the potential of sport for moral change, in particular for achieving higher moral standards of coexistence. Thus, making the circular virtuous relationship between different, but interdependent, degrees of sports, as referred to earlier, a reality.

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<sup>13</sup> We can transpose here the notion of “promotional function” of the law that was coined by Norberto Bobbio [14].