Ten years of the *Universal Declaration on Bioethics and Human Rights*

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**Abstract**

The Universal Declaration on Bioethics and Human Rights of UNESCO, on 2005, represents a radical change between the “classical bioethics”, devoid of a social and political view, and the “new bioethics” which inserts man into a global stage with their peers and other components of the biosphere. Ten years after its entry into force, the paper relates its history, as well as its social and political value of the Declaration, highlighting its more significant contributions and concluding with a vision of the future.

**Keywords:** Human Rights-Bioethics. Policy-Treaties. International acts-Social justice.

**Resumo**

Dez anos da *Declaração Universal sobre Bioética e Direitos Humanos*

A Declaração Universal sobre Bioética e direitos Humanos da Unesco, de 2005, significa um ponto de corte entre a “bioética clássica”, desprovida de uma visão social e política e a “nova bioética” que situa o homem em um cenário global com seus semelhantes e demais integrantes da biosfera. Após dez anos de sua vigência o artigo relata os antecedentes assim como o valor jurídico, político e social da Declaração, ressaltando seus aportes mais significativos e concluindo com uma visão de futuro.


**Resumen**

Diez años de la *Declaración Universal sobre Bioética y Derechos Humanos*

La Declaración Universal sobre Bioética y Derechos Humanos de la UNESCO de 2005 significó un punto de corte entre la “bioética clásica”, desprovista de una visión social y política, con la “nueva bioética” que ubica al hombre en un escenario global junto a sus semejantes y a los demás integrantes de la biosfera. A diez años de su vigencia el artículo relata sus antecedentes, así como el valor jurídico, político y social de la Declaración, subrayando sus aportes más significativos y concluyendo con una visión del futuro.

**Palabras-clave:** Derechos Humanos-Bioética. Políticas-Tratados. Actos internacionales-Justicia social.

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Declara não haver conflito de interesse.
The history of the Declaration

Ten years after the signing of the UNESCO Universal Declaration of Bioethics and Human Rights, an assessment has to be made of its importance, the fulfillment of goals pursued and its future projections. The Declaration was not an improvised text, the fruit of an idea launched in one of the many Unesco meetings, but on the contrary, arose from a long process of elaboration through many very enlightened debates.

Going back to its history, we would have to return to the 30th of March of 2001, the date on which the President of France launched the idea of developing a universal instrument devoted to bioethics within the United Nations Commission on Human Rights. Based on this idea, the International Bioethics Committee (IBC) of UNESCO commissioned the doctors Giovanni Berlinguer and Leonardo De Castro to report on the possibility of developing a universal instrument concerning bioethics.

Based on the prepared report, the IBC entered upon the task of its implementation, beginning in January 2004. Three phases took place in this process:

1. Consultations during the first months of 2004, with the Member States of Unesco, governmental and non-governmental organizations, as well as the IBC, on the cover page, objectives, structure and content of the future declaration;
2. Drafting of the text of the declaration by an editorial group of the IBC.
3. Completion of the text of the future declaration, in the setting of two meetings of governmental experts, extensive discussion within the IBC and finally the approval of the Declaration, which was unanimously ratified by the Member States of UNESCO.

As can be observed, the Declaration was carefully prepared and sufficiently debated within UNESCO. The unanimous vote is resounding proof of this. While it was never translated into a treaty, there is no denying the binding force that it has on the internal order of the States, as we present below. The texts, as Badía Martí affirms, mean the consolidation of bioethics in international relations beyond the scientific dimension, its full incorporation in the relations between States with their implications in the economic, political and social fields, entering fully into the international arena.

The author claims that the Declaration still has the indisputable merit of incorporating the subject of bioethics in the international legal order, in the hands of an issue so sensitive and universal in nature, such as human rights, which opens a new scope in this order which is not easily dealt with due to the diversity of interests at stake and the multidimensional character of the matter.

The indissoluble link between bioethics and human rights

Beginning with its title, continuing with the explanation of its history, this Declaration is to be understood in a manner consistent with domestic and international law in conformity with human rights law; the aims of this Declaration are to promote respect for human dignity and protect human rights, by ensuring respect for the life of humans beings, and fundamental freedoms, the intimate link between bioethics and human rights that it establishes is very clear.

In doing so, it did not try to seek a protective shield for bioethics – which it otherwise did not need – but rather emphasized in conveying to its recipients that bioethics provides for a concrete application of human rights in the field that is its own (the life, health and welfare of human beings) and this not only with regard to the progress of the technosciences, but also in a much more open field: that of the social and economic determinants of life and human health. Both constructions speak the same language and note a common objective in the final analysis: the defense of human dignity before the pitfalls of a world that advances precipitously, leaving out large masses of the population which remain trapped through their dramatic exclusion from the most diverse areas of life.

The 1948 Universal Declaration of Human Rights was not the fruit of an invention carried out
by a handful of enlightened people, which while the world was emerging from one of the most grueling catastrophes in history sought to protect human dignity, shielding it with a catalogue of elemental and essential principles for organizing a peaceful and lasting coexistence. It was much more than this: the awareness of this need could perhaps be the most relevant merit of the instrument voted in 1948.

We say that it was not an invention, as much as it limited itself to translating – perhaps masterfully – principles and demands already floating in collective consciousness. The Declaration of 1948 did not intend to constrict human rights into a closed catalogue and if there is anything that may be learned from it, it is the need to move forward in the search for new rights, in accord with the natural preoccupation of human beings with improving the conditions of their existence for their own enjoyment and to transmit to future generations a legacy superior to that received.

In its shadow – as the always remembered E. Rabossi described it - an extremely complex, very dynamic legal, political, ideological and moral phenomenon, of global scope and revolutionary consequences, has been developed. The phenomenon, Rabossi observes, is not anarchy, as it provides a macro scenario in which the interests at play are confronted, logic intersects and solutions (sometimes) are reached 
. As far as these rights are human, they represent needs, primary criteria, social, economic and cultural material without which the individual cannot develop his life with dignity 
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Several classifications have been developed over the years, which not only aimed to organize the material, but also intended to establish a hierarchical order of human rights, according to economic capabilities of fulfilling this. All these classifications, deep down, aim to explain or attest the null or diminished validity of economic and social rights, which are – coincidently – the ones most persistently violated. The reality is that all human rights have the same reason for existing and all must be applied and respected on an equal footing. Cataloging only contributes to weaken their practical application. Violation of these rights marks, precisely, a field of struggle, a demand that only ceases with their effective entering into force.

In this picture, proclaims the UNESCO Declaration proclaims, in essence, is a set of human rights that are systematically violated in the field of human life and health. It did so with regard to the reality of the moment at which it was signed, which did not imply that in the future, other rights could be incorporated according to the arising of new demands and the progressive character assigned to them. In short, the Declaration of 2005 is integrated with that of 1948 and other instruments that were generated at the international or regional level through the influence of social and political demands on the field of human rights. Among other rights mentioned:

- the right to respect for personal autonomy;
- the right to respect for personal integrity;
- the right to enjoyment of the highest attainable standard of health;
- the right to quality health care;
- the right of access to essential medicines;
- the right to adequate nutrition;
- the right of access to drinking water;
- the right to the meeting of basic needs (poverty reduction);
- the right to literacy;
- the right to enjoyment of the results of scientific research;
- the right to an unpolluted environment 
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“In establishing human rights among its principles,” Dora Porto points out, “the social dimension was recognized as intrinsic to bioethics” . Bioethics thus incorporated – preponderantly – human rights issues relating to the social and economic conditions of human life and health.

The legal, political and ethical value of the Declaration

It is known that under international law, a declaration does not have the same effectiveness as a treaty or convention. Based on this difference, it has been held that the contents of 2005 Declaration are not binding for the countries that signed it. Faced with this attitude from those who try to relegated the Declaration to a simple expression of good wishes signed by representatives of the States, Héctor Gros Espiell, an outstanding figure in international law and driving force of the three UNESCO Declarations on Bioethics, wonders: What does 'non binding' mean?, That which does not create links? And he answers: It can not be said that a Declaration adapted by the United Nations General Assembly does not create links. For Gros Espiell and for the majority of the doctrine it is a source of rights 
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argued that it was merely a moral text that would serve as an example for domestic law. That same day, the French delegate, René Cassin, one of the authors, said: on the contrary. In a masterful and premonitory speech, he said that the Declaration of 1948, as a projection and refinement of the United Nations Charter, had its own legal value and would come to be a source of rights.

Later, in the Tehran Conference of 1968 and Vienna Conference of 1993, it was established that the Universal Declaration was obligatory for the entire international community. This materialized in doctrine which is particularly unanimous today on this matter and repeatedly sustained by the International Court of Justice. Concluding his observations, Gros Espiell expresses that the Universal Declaration has a binding character, not only morally and politically, but also binding as an eventual source of rights, from a legal point of view.

In this same line of thought, Maria Yolanda Gómez Sánchez, Professor of the National University of Distance Education (Universidad Nacional de Educación a Distancia - UNED) and former member of the IBC, considers that the Universal Declaration of UNESCO, adopted by the Member States of the United Nations, is an international legal document, from which commitments are derived, and also legal materials with respect to its content for all of the countries which have adopted it. In its construction, there is a distinction between the legal value of the Declaration and its internal legal effectiveness in each of the States which have signed it.

When the principles of international law define the concept of a ‘binding document’ for the States, she states, they are alluding to the internal legal sphere of each of the States subscribing to the international document, but not to the general legal value derived from its adoption by the States within a particular international organization. The legal value of the Declaration applies equally to all the States that signed it and with regard to the commitment of each state (which is subject to international law) to the international community.

Consequently, the author notes, the content of the Declaration will always be binding, in a general sense, for all of those States which have signed it, with regard to their international commitments. ‘Internal effectiveness’ alludes to the position of the Declaration in the internal legal systems of the States and their hierarchical relationship (supremacy of some rules over others). Although both the international value and the internal legal effectiveness would be essential elements of the Declaration, the second is a determining factor for the practical implementation of the Declaration in the internal systems of the various States, since it allows the defining of the legislative and executive goals of a given State, and in each particular case, the possible legal protection to be recognized in the Declaration.

The accepting of the “non-binding” thesis to the Declaration, would lead to the legal incongruity that the states can commit internationally to while not being bound by to the commitments undertaken. In this direction, Article 3 of the Vienna Convention on the right of the treaties to determine which international accords do not remain included within the scope of the same states:

The present Convention does not apply to international agreements concluded between States and other subjects of international law or between such other subjects of international law, or to international agreements not in written form, shall ‘not affect the legal force of such agreements’ 11. This is all the more reason why these principles should be applied to a written instrument signed by the States.

A compelling example of the legal status of an international Declaration in domestic law is offered in article 75, subsection 22 of Argentina’s Constitution, the second paragraph of which establishes that the American Declaration of the Rights and Duties of Man, and the Universal Declaration of Human Rights …have constitutional hierarchy, do not repeal any article of the First Part of this Constitution and are to be understood as complementing the rights and guarantees recognized herein.

In short, the Declaration on Bioethics and Human Rights, unanimously signed by the Member States of the United Nations and ratified by the General Assembly of one of its organs (UNESCO), has a tangible legal status in the internal order. While in our country it does not yet have constitutional status, its the corresponding legal value cannot be denied due to the sole fact of it being a Declaration, ratified by the States.

What has not been translated into a treaty does not impede recognition of the legal value of the Declaration, which was widely discussed for two years and passed by the unanimous vote of the signatories. What does not enable the demand of the obligations assumed by one or various states from the non-compliant, does not mean that, in their internal order, the signing of the Declaration amounts to assuming the obligations of the State to its citizens. Moreover, regardless of its legal status, the Declaration has an important ethical value in terms
of its effect on the current agenda, incorporating ethical issues whose importance cannot be ignored, as will be seen in the next development.

From a political point of view, the Declaration provides sufficient tools for those aspiring to a bioethics which is closer to the problems and dilemmas of everyday living for large masses of the global population.

The Contributions of the Declaration

Beyond the depths and heights of the debate that preceded the approved text, it is only fair to recognize the fundamental contribution made by Latin American bioethics, especially Brazilian, to the content of the Declaration. In this direction, it is worth mentioning the grand Congress of Bioethics in Brasília in 2002, which took place under the suggestive slogan “Bioethics, power and injustices”.

The Congress of 2002, as noted, “politicized” in actual practice the international bioethics agenda. The principles of autonomy, beneficence, non-maleficence and justice – despite being indispensable and central to bioethics – ceased to be the only theoretical and methodological tool available to researchers and scholars. The practical result has been gradually incorporated into the international epistemological context of bioethics. These contributions were translated into the “principles” of the Declaration. These principles not only constitute the axis along which the “new bioethics” travels, but – essentially – constitute guides to action.

This is how they were understood by the cultivators of bioethics in their meetings and would serve to move the future agenda. From these principles we take those that in our judgment are the most original contributions:

a) Health Promotion

The Declaration refers to various health-related rights: the right to the highest level of health, the right to quality health care, the right of access to medicines, all of these regardless of economic and social health conditions. In its introduction, it stresses that health does not solely depend on the progress of scientific and technological research, but also on psychosocial and cultural factors.

Berlinguer, the illustrious bioethicist and Italian sanitarian, tells us of a society in which the possible does not oblige to medicine the sad duty of engaging itself in reparative activity, which is late and generally useless on the damages caused outside its field of action. Both primary prevention and health promotion jointly propose preventing disease and improving the psychophysical conditions of the individual. These types of prevention tend to mobilize the preventive capacity that is the fruit of decisions made in other areas, the spread of education, the humanization of work, the improvement of housing and urban living and the spirit of coexistence and solidarity between citizens.

As outlined, all medicine has health as a goal, but only prevention has as its intrinsic character and specific aim the equality of every citizen in the field of health. Article 14 of the Declaration begins by affirming that health promotion and social development for their people is a central purpose of governments, shared by all sectors of society. The right to quality health care translates into care that guarantees the adequate selection of an indication in accordance with evidence or at least with some scientific support that shows its usefulness; an adequate assessment of risks and possible harms it can cause, a human care that respects the rights of the patient and that complies with the criteria of justice.

The rights of access to health services and medicines are essential components of the right to health. When health suffers, the most basic of rights that can be exercised is that of access to health services; access in adequate time and with the required quality according to the type of care. The existence of people who cannot count on the possibility of such access, constitutes an offense to the human species. Parallel to the right to health care is that of access to medicines. The World Health Organization (WHO) periodically draws up a list of so-called essential medicines. Beyond this, the provision of medicines is imperative, without major distinctions – which should be a primary benefit from the State.

The power to heal — returning us to Berlinguer — has become a direct, legitimate and explicit function of money, and due to this there is affirmed in practice, and sometimes in the laws, the right to medical care and health proportional to wealth. These situations, which unfortunately even today many countries display, should be definitively overcome and the Declaration points to this in its Article 14.

Primary prevention and health promotion are often outside the bioethics agenda. The issue of health — it has been noted — is rarely present in bioethical debates. These increasingly favor extreme situations like “artificial” births, organ transplants, the survival conditions of terminal patients, neglecting the fact that health and disease are for all a universal field...
of experience, of reflection and also of moral choices. Health is commonly denied ennoblement as an object of ethics and in the best cases it is attributed only the value (which for some is considered philosophically irrelevant and intellectually plebian) of a social issue 19.

b) Poverty, malnutrition and illiteracy

For the first time, a universal document on bioethics places the focus of attention on these themes which were commonly considered beyond its mandate. Poverty is still the main cause of illness and is a factor which is beyond immediate control. Material poverty (as well as cultural) as well as necessitating insalubrious labor activities, which bring little satisfaction, causes the action of all disease-specific factors, hindering the adoption of preventative measures, and making healing more difficult 20.

Around poverty – as we pointed out on another occasion – a perverse circle is formed, which leads to malnutrition, environmental degradation, marginalization, social disintegration, crime, poverty, illiteracy, and the loss of self-esteem; a circle which makes leaving difficult for those who enter it, since they tend to reproduce these conditions in their descendants 21.

The 1995 World Summit on Social Development, in Copenhagen, had stated that the lack of income and productive resources to guarantee sustainable livelihoods generated hunger and malnutrition, ill-health, lack of access or limited access to education and other basic services, increased morbidity and mortality caused by diseases, discrimination and social exclusion 22. Closely linked to poverty is malnutrition, which in the first years of life, produces devastating effects. The right to food – specified as safe, healthy and adequate food – presents as the most specific field of global citizenship. Through adequate and safe food, not only the body is nourished, but also the dignity of the person 23.

Fifteen years ago, the illustrious Brazilian geneticist and bioethicist Eliane Azevêdo published a fascinating essay titled “O direito de vir-a-ser após o nascimento” (The right to exist after birth) 24, which stresses the need for adequate nutrition in the first years of life. Malnutrition of children, she noted, slows cell division, DNA synthesis and the total number of cells in the brain, up to the point of interfering with the process of myelination, recalling that in a 1998 UNICEF document 25 it was recognized that malnutrition impairs intellect, productivity and the potential not only of the person, but of the whole society. Azevedo adds that the absence of the minimum conditions of food and shelter, required by the human body, functions as a nullifier of genetic potentialities, driving people to an early death, preceded by a sub-biological life. Denying the essential minimum to anyone is to usurp the most sacred of the essential rights, that is, the right to full development of the biological and mental potentialities that it brings 24.

Years later, Stefano Rodotá, a prominent Italian lawyer and bioethicist – perhaps without having read Azevedo – returned to the issue in similar terms. The right to exist, he expressed, entails surpassing the zero degree of existence, that is, freeing oneself from a biological reductionism which guarantees a minimum subsistence. In the already lengthy discussion that accompanies the recognition and rejection of this difficult right, we often find an overlap, a confusion between survival and existence. This is due to the fact that this discussion is born in the field of poverty that accompanies several of its overt manifestations through time and in varying cultural contexts, dramatically linked to terrible conditions 26.

Since 2001, G. Keyeux reminds us, more than 100 million children were born with severe birth defects and genetic disorders 27. The impact is particularly serious in low and middle income countries where 94% of births occur in those conditions. Undoubtedly – to be specific - genetic disorders are socially determined; 90% of these children are born in poor households, with degraded living conditions, to parents with low levels of education in the context of systems that provide minimal health packages for the poor and most vulnerable. Birth defects and genetic diseases, the author emphasizes, are not so much diseases of genes as of poverty.

Experience gained over the last 50 years in high income countries shows that mortality and disability caused by birth defects could be reduced by up to 70% in low income countries, if measures were implemented which are relatively simple and low cost, but highly effective, which would encompass from education to prevention, from prenatal diagnostic and pre-conception services to early access to the institutes mentioned 27.

I allowed myself to transcribe these three contributions from illustrious contemporary thinkers, in order to show the effects of poverty and under-nourishment on human life and development. In light of these realities, it is easy to conclude that bioethics needed to include economic and social
determinants of health in its analysis and in its programs. Otherwise, the placid contemplation of the damages, caused by poverty, undernourishment, social exclusion, lack of clean drinking water, without warning of their consequences to the health and lives of men, simply means diverting the path of thought.

Without the pretext of applying an aseptic bioethics, which limits itself to borderline problems, excluded from its reach are central themes of urgent importance. The inclusion of social and economic determinants of health and life can be described as an gateway from bioethics to politics, which is nothing bad. The defense of an apolitical bioethics is a political position that is objectively contributes in favor of the reconciliation of interests within the existing social status quo, as Sotolongo says 28.

The Declaration of 2005, with all the edits that had to be accepted for there to be consensus, constituted – without doubt – a strong step towards the integration of economic and social determinants of human life and health. In this sense, Article 14 plays a central role in the achievement of such ends.

c) Protection of future generations

UNESCO had already shown its concern in a specific declaration on the rights of future generations 29. Now the Declaration of 2005, by reiterating this concern, points in particular to effects that could engender the application of advances in scientific research to the genetic makeup of the individuals who will succeed us.

This is not a minor issue: when Man has managed to penetrate into the innermost secrets of heredity, when he has managed to modify genetic capital through techniques such as recombinant DNA – used today in fields other than human, such as agriculture – concern is born about what limits can be imposed when applying it to the human species.

The human genome is by nature evolving, as recognized by Article 3 of the UNESCO Declaration on the Human Genome; but this variability born of natural evolution of species cannot authorize a “directed variation”, since in this case future generations will not be conditioned by natural processes, but the intentional participation of Man would come to play a role. This is obviously dangerous as there are no parameters to determine the limits of such interventions, which could lead to alteration of certain characteristics in future generations.

Science and technology, the adventures of human thought, do not recognize limits and if they are hypothetically fixed, can easily be vulnerable. The destiny of the human being is a distinct thing that imperatively demands respect, beyond and despite the projections of the biotechnical sciences, in the conception of Fermin Roland Schramm 30. Today the possibility of altering genetic information to enable transmission of hereditary diseases may be debated. This is a topic on which different criteria have been outlined, which must be duly respected and debated.

What should deserve general revulsion is the eventual intent to alter genetic information to incorporate in the offspring certain features of “enhancement” according to the criteria to be determined by those who practice them. Here the prohibition on affecting the rights of future generations plays a strong part.

There are difficult reasons for opposing transhumanist positions, – as Per Puigdomenech teaches – but one of these is to protect the generations that follow us from the problems caused by inequality between individuals that will occur under these conditions. If some day we achieve precise control over the genome modification process on the germ line, this may be one of the most important factors that should be taken into account when making decisions about the use of these technologies 31.

d) Protection of the environment, biosphere and biodiversity

“Classic” bioethics – so to speak – is characterized by accentuated anthropocentrism. It was only interested in man, and where possible, isolated from his habitat and society. In the UNESCO Declaration of 2005, as R. Junges points out 32 – environmental protection appears to be a human right, but this anthropocentric perspective is corrected by the sustainability of the biosphere and biodiversity. In other words, the environment is only preserved when there is a complex vision which comprises the environment as an integral system of interdependence (biosphere) and for this system to be in homeostatic equilibrium, there needs to be biodiversity, which enables these interrelationships. Only this systemic vision of the environment illustrates to organize social coexistence, and around its own ecosystemic vision of health, is a basis for understanding health as a human right and the environment as a basic component in the field of health 32.

The inclusion of this principle, in the midst of an extremely concerning situation, generated by the consequences of irrational exploitation of...
the planet, marks the road ahead. In this process, this principle is interconnected with that referring to the rights of future generations. We noted, on a previous occasion, that discourse about future generations involves a broader direction than the defense of Man in the future. In advocating, as the center of the debate, the defense of the quality of life of the generations to come, there is an implicit tendency to improve the living conditions of all present or future living beings.

Final Considerations

The UNESCO Declaration of 2005 took an important step. We have tried to demonstrate that far from being a simple “declaration”, a simple intellectual essay formulated by state representatives to justify the reasons for their meeting, it is a legal and political instrument which creates obligations in the States and correlative rights for their inhabitants.

The extinguishment of pockets of extreme poverty, access to drinking water, food compatible with development, access to health services and to essential medicines, and an environment neither polluted nor polluting, constitute not only the duties of the signatory States, but also, in parallel, the rights of their inhabitants. The Declaration has the merit of showing these defects, but makes it incumbent on the citizens, in the broadest and most comprehensive sense of the word, to demand and fight for such goals.

If a task is imposed on the basis of the Declaration, it is to deepen the analysis of problems linked to public health and social medicine. Thus, the Declaration constitutes a great battle flag that has the virtue of exposing an issue that for many years was absent from the debates. It is the duty of all who approach a field as fecund as it is fascinating, that of bioethics, to work towards spreading the underlying principles of the Declaration and at the same time to participate in actions which are aimed at expanding them.

To celebrate the 20th anniversary of the UNESCO Bioethics Program, several authors have created a book entitled, Why a Global Bioethics? Among the contributions, H. Ten Have, Director of the Division of Ethics of Science and Technology at UNESCO, wrote a brief essay titled, “Bioethics needs bayonets” noting the need to intensify actions to make effective the principles issued in the Declaration. Here it is worth reaffirming the efforts for bioethics to be conducted within a broad social and cultural movement, directed to defending life and promoting health.

Social movements have demonstrated their effectiveness beyond the existence or nonexistence of legal norms. An unquestionable example given was the social reaction, not only internal but also extended to the international arenas in the case of medicines to combat AIDS, which brought the South African government to ignore treaties aimed at enabling its inhabitants to have access to essential medicines; an example later followed by Brazil under the Lula da Silva administration, which eventually led to moderating the Doha Agreement (REF) with regard to industrial property.

I consider that the conditions have been met to proceed with the signing of an international treaty on bioethics. The principles of the Declaration have been studied, in depth, and discussed in innumerable international forums, its doctrine has been extended considerably in the directions noted here, and the lack of adequate response to many of the problems which the Declaration articulates, make necessary a stronger commitment in the international order, without prejudice to the intensification of efforts to achieve the proposed objectives in the internal order.

References

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