

MARCELO PALACIOS

**THE MISTREATED
TREATY**

Bioethics Convention
(Council of Europe 1989-1996)

Asturias made history in Bioethics

Marcelo Palacios

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**BIOETHICS
CONVENTION**

(Council of Europe 1989-1996)

**RESTITUTION
OF THIS TITLE**

BIOETHICS CONVENTION Council of Europe 1989-1996

Notes on the relevance of the Restitution of the title *Bioethics Convention*:

* That “**an injustice was committed by eliminating** the Title *Convention on Bioethics*” and that “**the word *Bioethics* would have been an excellent term to describe the Convention**”... **was made clear** (until today) from Maurice A. M. de Wachter's article *The European Convention on Bioethics*.

The Hasting Centre Report 27 no. 1 (1997): 13-23, pag. 22

* “The Drafting Committee or Working Group of the Bioethics Steering Committee, CDBI, observed that the term *bioethics*, although **it was widely used** in English-speaking countries and France “had a connotation pejorative in certain States,” and “noted **that the *Convention* was referred to as the *Bioethics Convention* and was likely to remain so; however,** ... recommended that the CDBI delete the short title (note: Bioethics Convention)”. **And the CDBI (06/4-7/1996) did it.** (CO-RED, 04/24/1996)

* OPINION **184** (1995) “1. **The Assembly has undertaken** a considerable amount of work **since 1976 with regard to the bioethical aspects** of human biotechnology and biomedicine. 2. This work, based on principles designed to **protect human dignity and the corresponding fundamental human rights relating to human biology and medicine**, led to **Recommendations 1100** (1989) and **1160** (1991) which contained proposals for the preparation of a comprehensive ***European Bioethics Convention*** intended as a legal instrument open to non-member states”.

** The Convention that we adopt today is **intended to be the common European standard in the area of bioethics.***

Declaration of the Secretary General Report of June 7, 1996

** 1. **The idea of a Bioethics Convention** is neither a political whim nor bureaucratic stubbornness. **It responds to a social need** and to the concerns of the public who feel misinformed, outside the circuits, and threatened by scientific discoveries at breakneck speed and who have difficulty assessing the consequences.*

*35. We are convinced that **the Bioethics Convention**, once adopted, **will constitute the third great pillar** of the Council of Europe together with the European Convention on Human Rights and the Social Charter.*

Doc. 7622 July 6, 1996 IV. Conclusions. Assembly Debate sept. 1996

** “**The origin of the change** in the title of the Convention is **not found** at the level of the Parliamentary Assembly, **but in the work of the Bioethics Steering Committee, which** in its plenary **session of June 4-7 (1996) decided to replace the reduced title Bioethics Convention** by the title “Convention on Human Rights and Biomedicine”, proposed by a delegation...”).*

Director of Human Rights, CdE, February 6, 2023. Letter to M Palacios

** Besides, the Council of Europe adopted in **1950** the *European Convention for the Protection of Human Rights and Fundamental Freedoms*, known as the *European Convention on Human Rights (ECHR)*. And in 1997 it adopted the *Convention for the protection of human rights in relation to applications of**

human biomedicine and biotechnology (+). Convention on human rights and biomedicine.

Aren't these too many repetitions that could have been avoided by maintaining the title *Bioethics Convention* instead of (+)?

* IF the term *Bioethics* already had international roots when it was discredited in 1996 by the CDBI, *Bioethics Steering Committee*, **is it not an incomprehensible contradiction** that this *Committee* continued to exist for years and gave way in 2012 to the DHBIO, *Bioethics Committee*, until 2022?

The Council of Europe maintained the CDBI (Bioethics Steering Committee) and in 2012 created the DH-BIO, *Bioethics Committee* that replaces the CDBI to interpret the Convention approved in 1997, and approves annual budgets for bioethical activities.

In addition to the above, **if it was assured** in 1996 by the CDBI that “**the title Bioethics Convention was the appropriate one and would last**”, as it happened, **why did it eliminate it?**

Are those responsible for the Council of Europe going to continue **to consent** to their anomaly of the current document of the Convention?

Isn't that also mistreatment of the Convention?

It is always time to rectify,
restoring the title *Bioethics Convention*.

Because the **title** *Bioethics Convention* was eliminated in 1996 in an inappropriate manner and for inappropriate reasons, and because **Bioethics** has taken international root in the whole world:

—There are numerous countries with *laws* or *regulations on bioethics*, starting with the *French bioethics' law of 1972*; and numerous countries with Departments related to bioethics, and International and Interregional Bioethics Committees; and more than fifty countries with National Commissions on Bioethics.

—In 1995 the Inter Parliamentary Union (IPU) adopted a Resolution *on Bioethics and Protection of Human Rights* (I was the speaker in the meeting of Madrid).

—In 2005 UNESCO adopted the *Universal Declaration on Bioethics and Human Rights*.

—19 October has been declared *World Bioethics Day* at the initiative of UNESCO.

and **the opinion** of the Council of Europe **on Bioethics** has radically changed since the damaging CDBI Report of June 1995 7, 1996, and **today** states:

“Bioethical issues concern us all, as patients, professionals, but also as members of a society facing new choices as a result of scientific progress”.

“The Convention on Human Rights and Biomedicine is the first international legally binding instrument in the field of bioethics”.

(WWW.CoE .INT General Directorate of Human Rights and Rule of Law of the Council of Europe www.coe.int/bioethics)

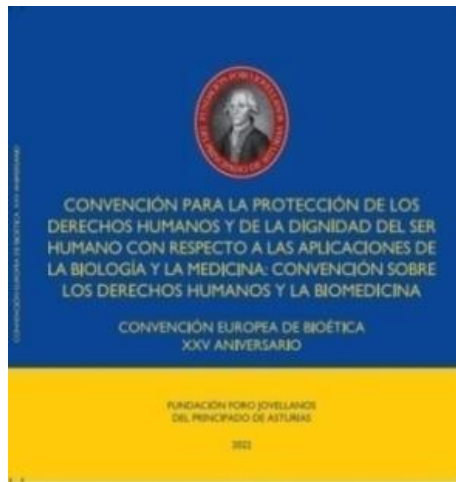
My special and heartfelt DEDICATION of this book to Ms. Leny Fisher and Mr. Daniel Tarschys, my political colleagues in the Parliamentary Assembly of the Council of Europe from 1986 to 1996.

Both, respectively as Chairwoman of the Parliamentary Assembly and Secretary General of the Council of Europe, recognized me in person in Gijón and Oviedo (Spain) on April 3 and 4, 1997 what was hindered and vetoed to me at home and that after nine years of dedication I could not bring to a conclusion in the Parliamentary Assembly, and to Asturias what it would lose if the opening to the signing of this transcendental *Convention* had been diverted to another country.

We owe them that eternally.

Thanks, dear friends.

The Foro Jovellanos Foundation of the Principality of Asturias



(Gijón, Spain) published in 2023 a book (with my verbal and documentary contributions) on the origins of the *Bioethics Convention* (1989-1996) and opening to the signature (with current title) in the Principality of Asturias (Spain) on April 4, 1997, for which I deeply thank its president Mr. Ignacio García-Arango Cien-

fuegos-Jovellanos and the director Mr. Orlando Moratinos Otero for their jovellanist enthusiasm and professional rigor. Book to which I refer, and from which I was authorized to take images and analogies from the text by the copyright owners.

My thanks to the mayoress of Gijón at the time, Ms. Ana González —and the municipal corporation—, who hosted the publication and presentation. And my gratitude also to my collaborator in the Secretariat of the Scientific Committee of the SIBI (International Society of Bioethics), Ms. Beatriz García Arviza, for her intense commitment to this entity and to bioethical issues, and for providing this book —with my guide— with the necessary documentation.

And to Mr. Baris Perin (+), Commission lawyer, from whom I received permanent support and advice.

Countless pages and meetings of deliberation and debate have been written and held about *Bioethics* and the elaboration of the *Bioethics Convention* while that Convention was being created until 1996 (and many more have been produced in the last quarter of a century since the current Convention was approved in Oviedo, Asturias, Spain, in 1997), of whose extensive contents and for its purpose this book, very abbreviated, collects what I consider essential of what is available.

The arguments in Chapters I and II, and especially Chapter III (Restitution of the title) and Epilogue are decisive to understand the main reason of this book: to demonstrate that **the title *Bioethics Convention* must be restored** to the current “Convention on Human Rights and Biomedicine” for reasons of justice and membership of the Council of Europe at the international level that corresponds to it in matters of Bioethics.

Gijon (Spain), 2024
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The images come from the media La Nueva España, El Comercio, El País, ABC and El Mundo, from the Foro Jovellanos Foundation of the Principality of Asturias, and from my files of the Council of Europe (in the International Society of Bioethics, SIBI). Help the text with Google Translate. Thanks to all of them.

BIOETHICS AND COUNCIL OF EUROPE

Bioethics and Ethics ARE NOT SUCH
because they are talked or writing about
them, or because they are taught, THEY
ARE because they are believed in, prac-
ticed and become a habit of our lives.

Modern *Bioethics* began with the American oncologist Van Rensselaer Potter, from his publications *Bioethics: science of survival* (1970, article) and *Bioethics: a bridge to the future* (1971, book).

Since then, as a CIVIL INSTRUMENT of a multi and interdisciplinary nature that “seeks to harmonize human dignity with the right of everyone to participate in and benefit from scientific knowlegment and medical progress, as well as combat the chronic scourges of misery, poverty and violence, the negative effects of climate change, environmental pollution and the degradation of nature, and to enjoy a protected environment and nature”, the Bioethics has gradually gained ascendancy, to the point that today we can speak of a “global cultural movement, an “existential philosophy”, the *Bioethical Culture* based on VALUES and BEHAVIORS at the service of humanity and protector of the biosphere, which, more or less established everywhere, is becoming an area of reflexion and positive proposal.

Considering Bioethics as *the universal call for knowledge aimed at the study and deliberation on the applications of science and technology from ethical perspectives, and at the formulation of applicable proposals for the required humanization of those, harmonizing their use with the utmost respect for the*

dignity of the human being and the protection and conservation of the Biosphere —whose essential pillars are truthful information, well-founded argumentation, pedagogy at different educational levels, public and specialized debate, anti-violence attitude and cooperation without territorial barriers—, *today it is evident that it has become a common area.*

From such assumptions, *Bioethics* is involved in the present scientific and technological reality —and in anticipation of the future— with a renewed and updated ethical disposition, without confessional or partisan influence, euphemisms or reservations, opposed to preestablished principles that are little or not at all receptive to modification, which incorporates and represents the accepted rational ethical elements, sufficient and indispensable to protect the dignity of every person and human society.

The 21st century was largely defined by *ethical responses* to bioscientific and technological uses, and to the chronic scourges of poverty, violences and climate changes which is why I considered it the *Century of Bioethics*. And along with the regulations in this regard (which will not be able to keep up with the accelerated pace of those advances and uses), *a pact of civility* is urgently needed for each specific historical period in which everyone, citizens, legitimate representatives, scientists, companies, etc., and for the different democratic channels of action and participation, we call for a *universal ethical consciousness that points to the rational application of science and its technologies*, in short, to the authentic “humanization of the sciences”. This requires above all, that “biosciences and their technologies must serve the well-being of humanity, the sustainable development of all countries, world peace, and the protection and conservation of the nature; which implies that developed countries must share

the benefits of biosciences and their technologies with the inhabitants of the least favoured areas of the planet and serve the well-being of each human being.

In a tight synthesis, the methodological structure of Bioethics is based on three elements: the description of the issue or problem to be treated, its ethical consideration, and, if necessary, its legal assessment. Regarding its conceptuality, Bioethics **is not** a veneer or a pretext, **neither it is** an intellectual entertainment, an area for personal brilliance, nor a scenario for personal or group economic interests; above all *Bioethics is a civil, social instrument* (or it is nothing), a vital conduct, an existential philosophy, a global cultural movement (*Bioethical Culture*) of VALUES and BEHAVIORS at the service of humanity and protector of human beings and the biosphere.

They are VALUES of Bioethics, those that respect human rights:

a) what concerns the right of people to: life, without which other rights would not be possible; dignity and rights emanating from them: freedom: of conscience, expression, information, religion, opinion, etc.; equality, equity; intimacy, personality development: personal security; psychophysical integrity, with a prohibition of torture and inhuman or degrading punishments or treatment.

b) the primacy of law, from legality and equality before justice to non-discrimination and social and economic rights (protection of health with adequate services, of consumers and users, of the environment, etc.), democracy, pluralism, etc.

c) the recognition of science and technology as heritage of humanity, and essentially social contributions of individuals to the human community.

d) the right of citizens to participate in scientific progress and benefit from it.

They are BEHAVIORS/attitude of Bioethics: dialogue/founded argument/deliberation; self-criticism/heterocriticism; responsibility; truth/objectivity; security/safety; freedom/autonomy; equity/equality; decision making/settlement; modesty/humility.

An essential conduct of Bioethics is self-criticism: “no one should try to teach another person what they do not know, or try to convince them of what they do not believe”. And also, humility, to be defined as “an enormous power and self-control of those who decide scientific and technical actions over others, even more so if they do not share them”.

In its long half century of existence, *Bioethical Culture* has:

—*externalized the Biosciences*, their actions are in the public domain, known and socially evaluated, increasingly participated, and they address the ethical and social aspects of their activities.

—*stimulated the Right* to keep pace with scientific technological implications, not with the delay that characterized it.

—*removed Philosophy* from its selective circuits, and has given it relevance in new fields of deliberation.

—*expanded its activity* beyond medicine and biology, and deals with food, water, hunger, poverty, nature, biodiversity, the environmental pollution, violences, etc.

—*encouraged and promoted debate*, especially the *public*, and *also* the *academic*, insisting on the importance of informed

and contrasted deliberation to base the opinion and the proposal.

—*guided* political, parliamentary, legal, educational, industrial, labour, etc. decisions.

—*progressively permeated* all world regions. There is discussion, debate, writing, committees, congresses, and all kinds of meetings are organized, legislation is passed, and we are now faced with an authentic international *Bioethical Culture*.

The COUNCIL OF EUROPE **was a pioneer** in the world in addressing issues of bioethical assessment, and played a continuous and decisive role in all of the above regarding the origin and future of Bioethics, basically in Europe and especially through *its Convention* recognized as *Bioethics*, despite the annulling of that title years ago.

In 1976, five years after the publication of the cited writings of prof. Potter the COUNCIL OF EUROPE began these activities in his Parliamentary Assembly with Resolution 613*

*The Assembly declared that it was "convinced that what the terminally ill want is, above all, to die in peace and dignity, with the support and company, if possible, of their family and friends.

and Recommendation 779** *on the rights of the sick and dying*,

** Assembly debate on January 28, 1976 (23rd session) (see Doc. 3699, report of the Committee on Social Affairs and Health). Text approved by the Assembly on January 29, 1976 (24. th session).

and continued the Assembly's work on bioethics items with Recommendation 818 *on the mentally ill* (1977); Recommendation 934 (1982) *relating to genetic engineering*; Resolution 812 (1983) *on acquired immunodeficiency syndrome (AIDS)*; Recommendation 1046 (1986) *on the use of human embryos and*

fetuses for diagnostic, therapeutic, scientific, industrial and commercial; Recommendation 1100 (1989), relating to the use of human embryos and fetuses in scientific research, which proposed the development of a Convention on Human Rights and Biomedicine; Recommendation 1116 (1989) on AIDS and human rights; Recommendation 1159 (1991) on harmonization of autopsy rules; Recommendation 1160 on the elaboration of a Bioethics Convention (1991), open to non-member states; Recommendation 1235 (1994) on psychiatry and human rights; Recommendation 1240 (1994) on the protection and patentability of material of human origin, which insists on soon approving the Bioethics Convention.

The COUNCIL OF EUROPE **was permanently and deeply involved in bioethical issues,**

a) creating, among others:

—in 1985 the CAHBI, *Ad hoc committee of experts on the progress of biomedical sciences* under the direct authority of the Committee of Ministers, with intergovernmental activities of the Council of Europe in the field of Bioethics.

—in 1986 the figure of Speaker “on the future of research in human embryology”,

—in 1990 the figure of General Speaker and representative of the Parliamentary Assembly on bioethics,

—in 1991 the Sub commission on Family, Health and Bioethics.

—in 1992 the CDBI or *Bioethics Steering Committee*, dependent on the Committee of Ministers and derived from the CAHBI,

(The members of CAHBI/CDBI were not parliamentarians, they were experts appointed by the governments of the countries that

constitute the Council of Europe, and its Secretary has been an official of the Council of Europe).

—in 2012 the DH-BIO, *Bioethics Committee* that replaces the CDBI to interpret the Convention approved in 1997, also with tasks on the protection of human rights in the field of Biomedicine, and dependent on the CDDH or Human Rights Steering Committee (1976),

The Bioethics Committee is assisted by a permanent secretariat, the Bioethics Unit, which reports to the General Directorate of Human Rights and Rule of Law of the Council of Europe.

—in 2022 the CDBIO, *Human Rights Steering Committee in the fields of Biomedicine and health*, derived from the DHBIO and dependent on the CDDH.

Under the authority of the Committee of Ministers, the tasks of the CDBIO are:

- carry out the work assigned to the Bioethics Committee by the Convention on the Protection of Human Rights and Dignity of the Human Being with Respect to Applications of Biology and Medicine. Convention on Human Rights and Biomedicine;

- carry out intergovernmental work on the protection of human rights in the fields of biomedicine, as well as health; particularly with regard to the issues raised by the Covid-19 pandemic and taking into account the lessons to be learned from the health crisis.

b) elaborating Opinions (Avis), Reports and Recommendations, and it is with mentioned Recommendation 1160 *on the elaboration of a Bioethics Convention* in 1991, when the Council of Europe acquired increasing prominence in Bioethics, several Commissions, mainly the Assembly (and the CDBI) produced documents related to the “Bioethics Convention. Convention on

the Protection of Human Rights and the Dignity of the Human Being with respect to the applications of Biology and Medicine”, with internal and external repercussions, at an international level that they consolidate;

and, c), organizing events on Bioethics, or participating in them, in its headquarters of Strasbourg or outside, national and international (even after the term “bioethics” was devalued and the title *Convention of Bioethics* was eliminated, unfoundedly and harmful for the Council of Europe).

His greatest work in this regard and “one of the most out-standing instruments of the Council of Europe” (Daniel Tarschys, Secretary General, February 3, 1995, in a letter to me) is the *Bioethics Convention*, which proposed and in development since 1987 and in force since December 1, 1999 —and unfortunately without that name— its considered among the five most important documents in human history, and “of equal significance to the Universal Declaration of Human Rights”, in the words of the Spanish Minister of Health Mr. Romay Beccaría during the opening for the signing of the Convention in Oviedo (Principality of Asturias, Spain), April 4, 1997.

PREAMBLE

In the years 1970-71 the term *Bioethics* emerged modernly, and SINCE 1989 UNTIL TODAY, especially in the Council of Europe, the name *Bioethics Convention* or *European Convention on Bioethics* and the document thus titled were in common, growing, relational and documentary use in the Parliamentary Assembly, Commissions, the Committee of Ministers of the Council of Europe, the CAHBI and CDBI, and circulated at the national and global level, in conferences, courses, masters, laws, Interparliamentary Union (IPU), UNESCO, Holy See, Committees and National and International Bioethics Societies, such as SIBI, etc.

(At the same time, in the United States of America Bioethics took an exceptional rise, and in other world regions it did so gradually).

The publications on *Bioethics* or on the *Bioethics Convention* are incessant, it is impossible to bring them all to this book or any other if not in library collections or by resorting to digital media, which I suggest to the reader. As there are countless courses, masters, magazines and other papers (whose contents do not always adjust to reality on the origin and the develop of the Bioethics Convention, with blatant and not at all ethical omissions or unfair attributions, I suppose due to ignorance or by reiterating interested information from third parties).

UNTIL TODAY, I insist, after more than a quarter of a century in which the title Convention of Bioethics was eliminated, which unequivocally indicates the impact and social vigor achieved by *Bioethics*, which took universal roots and bears constant fruits, and the *Bioethics Convention*, a title that won the battle against

misunderstanding, that persists through the years as a victory of public and specialized opinion and must be restored.

The Bioethics Convention **was called to be the first binding international instrument in the area of Bioethics and the third pillar** of the Council of Europe in the European construction, the integrative cause, together with the European Convention on Human Rights (1950) and the European Social Charter (1961). And with the *Bioethics Convention* the Council of Europe would “formally” join the cusp of world Bioethics.

But the CDBI (Bioethics Steering Committee) **frustrated** this characteristic and important approach, since, as we will break down later, he made a “mistreated Treaty” with it:

—**by exceeding its powers** by sending its report of June 7, 1996 to the Parliamentary Assembly having removed the title *Bioethics Convention*, **without having legislative or normative power to do it**;

—**by going against his own actions**, since he generated the doc. 7124 on the preparation of the *European Convention on Bioethics* (with my constant contributions as General Rapporteur of the Parliamentary Assembly for Bioethics, and those of the Committees on Health, Science and Technology and Subcommittee on Bioethics), he **presented it at a press conference** and **later eliminated it** (this are analysed in Chapters I and especially II).

—for shamelessly **adopting contradictory actions** that cause astonishment (see **List** of CDBI to the Committee of Ministers in Chapter II, **reviling** the term *bioethics* and **eliminating** the title *Bioethics Convention*, and in the same CDBI report of June 7, 1996, proposing the *promotion of bioethics*, requesting

*adequate resources in the Bioethics budgets, and iprepare the **third Bioethics Symposium** for six months later!)*

And all this nonsense occurred without the slightest subsequent self-criticism, the CDBI did not disappear, as was logical and decent for it to happen, they continued in their positions as officials.

*It was deeply regrettable that the Council of Europe, the institution that provided for a *Bioethics Convention*, **has been improperly deprived of that global recognition** by removing that title from the current Convention.*

However, it is confirmed with enormous satisfaction:

—that *Bioethics*, as a multidisciplinary scenario for deliberation and proposals, has been established in world societies; that legislation has been passed on Bioethics; that there are more than 50 National Bioethics Committees, parliamentary, governmental, etc.; that October 20 is celebrated as *World Bioethics Day* from 2022; that you can speak about an authentic *Bioethical Culture*.

—and that the *bioethical spirit* of the Council of Europe endures, and the current *Convention on Human Rights and Biomedicine* continues to be treated as the *Bioethics Convention* of the Council of Europe in national events (congresses, teaching, round tables, interviews, reports and other activities) and international settings.

Therefore, convinced that the elimination of the Bioethics Convention title was done ignoring the rise and momentum of Bioethics in the world, and overlapping the intervention of the Assembly without respecting its indispensable democratic role;

And appealing to the very important role played by the Council of Europe in Bioethics, and to the possibility of amending the

error made specially by its article 32 (or to article 38, section *g*) of the current Convention itself,

I addressed the Secretary General of the Council of Europe, and through it to other bodies of the institution (see Chapter III) demanding the RESTITUTION of the title *Convention of Bioethics*, with **an amendment from the Council of Europe itself** (article 32 of the current Convention) **and I reiterate it in this book**, believing it to be fair, given the anomalous ways in which it was eliminated, as is argued in this book, and taking into account the firm and undoubted international implementation of Bioethics in all world regions, in which the **bioethical trajectory** of the Council of Europe should be **formally recognized and respected** and **cannot be** diluted and much less **ignored**, in which we would all have a historical responsibility.

MY STAGE
IN THE COUNCIL OF EUROPE
(1986-1996)

My commitment to Bioethics is almost as old as it. And I have to admit that I am overcome with emotion when I attend meetings, listen to news or read publications that deal with the *Bioethics Convention*, a winning title despite the obstacles to which it was subjected.

The preparation of the Bioethics Convention was for me an unusual, intense and shared experience for years, reasons for which, even with that title annulled, my gratitude goes to all the people in the political and social spheres who contributed with their honest work to making it possible, has become a universal reality of undoubted importance and common utility, and is considered by relevant personalities among the five most important documents adopted so far.

When asking the General Secretariat of the Council of Europe for the restitution of the title *Bioethics Convention* it is not my intention to polemicize with the Council of Europe, an organization for which I have great respect and eternal gratitude. But precisely for this consideration and respect, **I believe that the Council of Europe should take the initiative** and present the corresponding amendment to recover that title *Bioethics Convention*.

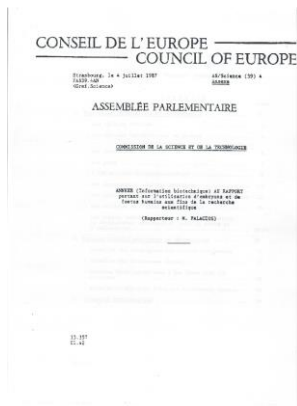
For my direct participation in the proposal and preparation of the *Bioethics Convention* (for me, and for many people from different fields, it will always be the *Bioethics Convention*) in the Council of Europe in April **1986** until my departure from that

international institution in May **1996**, it is inevitable that this book is presented in the first person. I will ensure that it has documentary verification and to avoid as much as possible the unpleasant aspects of the not easy path of elaboration of the Convention, and **I will insist on my convictions** at the cost of being repetitive, even in bold font, with objective evidence that demonstrates what it seeks: to restore the *Bioethics Convention* title, which was eliminated in an improper manner.

I attest to the important activity of the Council of Europe with full knowledge of the facts, since for ten years I was a member of the Spanish Delegation in the Parliamentary Assembly of the Council of Europe as a socialist deputy. At first I observed that matters related to science, biology or medicine were dispersed by Commissions that issued Opinions (Avis) and prolonged the deliberations for up to months, so I suggested unifying them and for this purpose the Family, Health and Bioethics Sub commission was created; and on the other hand, in the Commissions, health, biological, etc. topics were sometimes discussed or debated that had not been previously defined, and of which some parliamentarians had little or no knowledge; one of them was about the embryo, a very sensitive issue, so there was an opportunity in 1986 to exchanges by telephone and telegrams on definition, actions and deadlines in the *preembryo* of Franco Foschi (President of the Health Commission, former Italian Minister of Labor and Social Policy with Francesco Cossiga, 8th President of the Italian Republic, June 24, 1985- April 28, 1992) and I with Cardinal Elio Sgreccia, who since 1985 was director of the Centre for Bioethics and since 1992 director of the Institute of Bioethics created within the Faculty of Medicine of the Catholic University of the Sacro Cuore in Rome.

Months later, on 2/22/1987 in the Encyclical Instruction DONUM VITAE “on respect for nascent human life and the dignity of procreation” of the Sacred Congregation for the Doctrine of the Faith, Cardinal Joseph Ratzinger being Prefect, at the foot of page 2 the term *preembryo* appears: “The terms «zygote», «preembryo», «embryo» and «fetus» in the biological vocabulary can indicate successive stages in the development of the human being. This Instruction freely uses these terms, attributing them the same ethical meaning. With them it designates the fruit, visible or not, of human generation, from the first moment of its existence until birth. The reason for this use will be clarified in the text (cf. I, 1)” Coincidence?

Years 1986-87 In the Commission meetings I observed that some parliamentarians were unaware of the topics discussed, and to facilitate the understanding of that and other topics as much as possible I asked the Science and Technology



The brochure, 38 pages, was approved by the Commission and published by the Council of Europe on 4.7.1987 as an ANNEX and distributed very widely.

Commission to prepare **a booklet**, especially with drawings made by me, about gametes, fertilization of the egg and spermatozoid, the embryo and its development phases, natural and assisted reproduction, gens, gene therapy, cloning, and others.

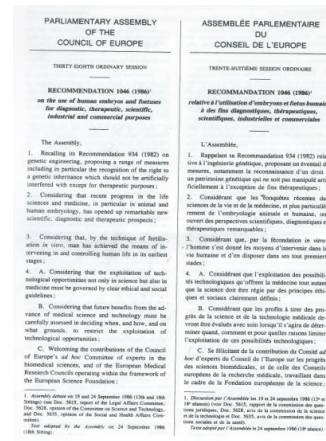
I presented 17 amendments to Report No. 5,615, in agreement with its rapporteur Mr. Haase, which would give rise to

Recommendation 1046 *regarding the use of human embryos and fetuses for diagnostic, therapeutic, industrial and commercial purposes* on 9/24/86; they had to be incorporated into an *opinion report* by the deputy Mr. Lluís M^a de Puig, since no report had yet been entrusted to me; 11 of them were approved, including those related to “undesirable deviations from techniques”, such as cloning.

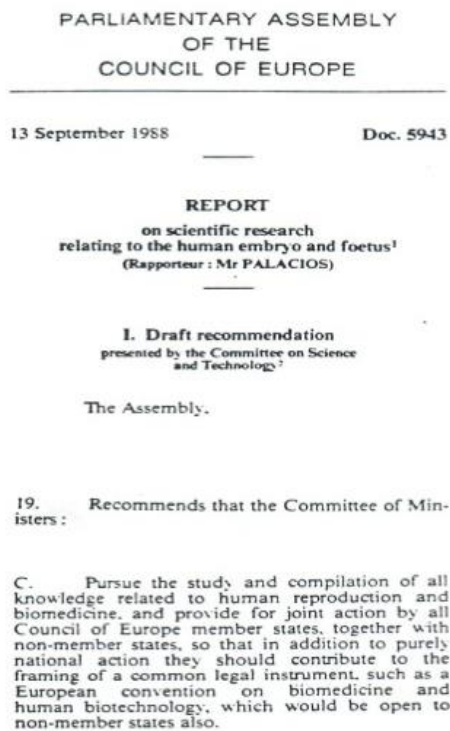
On December 29, 86 under the presidency of M. Pettersson the Commission of Science and Technology (by mandate of Directive 432) **named me** as Rapporteur *on the future of research in human embryology* (“for the information of members of the Assembly. Clerk of the Assembly. Log-book n° 38/72 Fcdb. cst”), in short, it commissioned me to prepare a Preliminary Project on scientific research on embryos and fetuses, which would give rise, over two years, to a series of Reports and the Bioethics Convention.

Years 1987-88 Towards the Bioethics Convention

On July 10, 1987, in the Science and Technology Commission **I presented** the AS/Science Report (39) 4, Part I *on research on human embryos and fetuses*, approved by the Commission on the 4th. May 1988, and published as **document No. 5943** by the Council of Europe on 9/13/88. In its section 19 C, the Committee of Ministers recommended to “continue the study and inventory of all knowledge related to human reproduction and biomedicine, and to encourage common action by the member states of



the Council of Europe and those that are not part of it, so that, transcending the purely national framework, they contribute to



the development of a common legal instrument, such as a *European Convention on biomedicine and human technology*, open to non-member States of the Organization”.

It was the first time that a proposal was made for a *global Convention* on the broad aspects of human biology and medicine that would cover all aspects related to those scattered and diversified subjects (and not only those related to genetics as indicated in Recommendation 934, or embryos, in Recommendation

1.046).

There the *Bioethics Convention* begins to be carved out.

In Opinion Report No. 5792 (of October 1, 1987) on the activities of the OECD in 1986 relating to scientific and technological policy, the French parliamentarian **Jean Pierre Fourré** stated: “In his Preliminary Draft Recommendation on the future of human embryology, our colleague and author, **M. Palacios**, calls for the elaboration of an *International Convention on biomedicine and human biotechnology*, a work that could undoubtedly be the object of cooperation between the OECD and the Council of Europe, as was the case in the recent past regarding data protection.

Also in her Report on the 1987 activities of the OECD (Doc. 5,947, of September 26, 1988), the German deputy **Leni Fischer** (who years later would be President of the Parliamentary Assembly and would attend the

solemn opening for the signing of the Convention in the Principality of Asturias) recalled that “in the draft recommendation on scientific research relating to the human embryo and fetus **No. 5,943 approved in May, the Science and Technology Commission requests the elaboration of an international Convention** on the human biomedicine and biotechnology that could be accessed by non-member states”, and reiterated the terms and cooperation raised in the previous year's Report by Deputy Mr. Fourré.

Some international media echo this activity in the Council of Europe.

EL PAÍS

The danger of embryo factories The Council of Europe has received a report commissioned to the doctor Marcelo Palacios

MALEN RUIZ DE ELVIRA Madrid 6 JUL 1987

“Los avances científicos en reproducción humana hacen urgente una regulación de la utilización del material embriológico humano y de los nuevos métodos de reproducción, diagnóstico y tratamiento. Marcelo Palacios, encargado por el Consejo de Europa de redactar **un informe sobre el esta-tuto biológico del embrión** -informe que ha sido entregado recientemente a esta institución-, cree que la ciencia no se puede parar y que es mejor regular que negar posibilidades que ya existen técnicamente”. SITUACIÓN EN ESPAÑA El trabajo encargado a Palacios, médico, diputado socialista desde 1982, desarrolla una recomendación del Consejo de Europa, con fecha de septiembre de 1986, sobre el uso de embriones humanos para diversos fines que ya incorporó 13 enmiendas de las 17 presentadas por los representantes españoles. El Consejo de Europa, que agrupa a 21 países, **ha tomado el liderazgo para dar pautas a los países miembros** sobre la armonización de sus textos legales relativos a las nuevas técnicas de reproducción. ([Translated: The Council of Europe, which brings together 21 countries, has taken the lead in giving guidelines to member countries on the harmonization of their legal texts related to new reproduction techniques](#)). El informe de Palacios será discutido en septiembre en la reunión del Consejo de Ciencia y Tecnología a celebrar en Copenhague y tiene varios puntos que se consideran conflictivos.....”

“Un cambio muy importante es la nueva división de las etapas del desarrollo humano a partir de la concepción. Se está imponiendo el término **preembrión**, que recoge la etapa que va desde los 0 a los 14 días..... “

Year 1989

My Report 5,943 (Science and Technology Commission) goes to the Parliamentary Assembly, where it is approved and gives rise to Recommendation 1,100 (1989) *regarding the use of human embryos and fetuses in scientific research*, which includes my idea aforementioned of the elaboration of a Convention on Biomedicine and Biotechnology. of a general ethical-legal nature, soon (1991) *Bioethics Convention*, and I was its speaker until May 1996; and I requested (1994) that, if it became a reality, it be opened for signature in the Principality of Asturias (Spain), as happened on April, 1997.

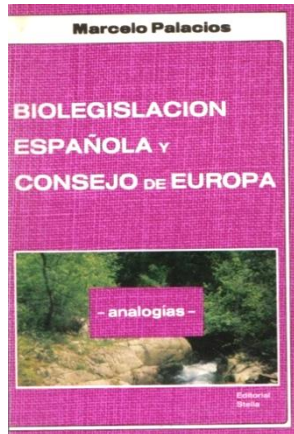
EL PAIS SCIENCE

The Council of Europe recommends prohibiting the creation of embryos for scientific purposes EFE Strasbourg 3 FEB 1989

“Yesterday the Parliamentary Assembly of the Council of Europe approved several recommendations based on a report by the Spanish deputy Marcelo Palacios to regulate the use of human embryos and fetuses in scientific research. These recommendations, which join others approved in 1986, constitute the only European action to date regarding new human procreation techniques.

The Palacios report is based on the idea that the intentional creation of human embryos or fetuses for purposes other than procreation **should be prohibited**”.....

BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



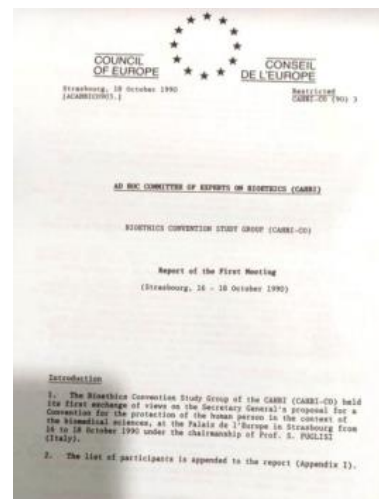
Book 231 pages Year 1989

Letter from the Secretary General of the Council of Europe, Mrs. Catherine Lalumière, thanking me for my book and the in-depth knowledge of the Council of Europe.



Year 1990

At the 17th Conference of European Ministers of Justice (Istanbul, June 5-7, 1990), the Secretary General of the Council of Europe, Ms. Katherine Lalumière, gave important support to this Convention. The ministers approved *Resolution No. 3*, in which they **supported a framework Convention**, and expressed their preference for a legal instrument open to non-member countries, which coincided with what had been requested since the end of 1986 in my outline of which It would be the preliminary draft of 10.7.87, and, later, in Recommendation 1.100 of 1989 cited above. In the fall of 1990, a CAHBI Group **was created** to examine the viability of the project for a Bioethics Convention, chaired by the Italian lawyer Salvatore Puglisi (whose untimely death had to be regretted), and on October 16-18, 1990, it put forward. This work was underway at its first



meeting, which I attended representing the Science and Technology Commission.

On 10/26/1990 I was appointed General Rapporteur for *bioethics representing the Parliamentary Assembly*, and from then until April 1996 I was part of the meetings of CAHBI (ad hoc Committee for Biomedicine or Bioethics), which later, in 1992, it would become the CDBI or Steering Committee for Bioethics (due to obligations as a deputy in the Congress of Deputies in Spain, I was not always able to attend those meetings), with which I maintained exchanges (sometimes confrontational or not easy), at that I contributed with numerous proposals and amendments in relation to the Convention and its protocols and the opinions of the Commission on Science and Technology and the Subcommittee on Family, Health and Bioethics (which was created at my proposal, and I chaired for five years, coinciding almost with the same stage).

Little by little the idea matured that the missing *pillar of the tripod of European construction*, together with the two already existing ones -the European Convention on Human Rights and the European Social Charter-, had to be an instrument of general and social interest and acceptance: a *Bioethics Convention* open to non-European countries. And so it was assumed, as has been said, with Bioethics supported by VALUES: human rights, with *dignity* and *life* as substantial references, and BEHAVIORS: *self and heterocriticism, objectivity, freedom, autonomy, responsibility, security, equity, humility* (objectively and in advance recognizing the power that their knowledge, its ascendancy over the receiving human collective and its possibilities of action, and how its actions can impact others; and on the other, the demystifying

prudence of that power, to ensure that freedom runs as humanized as possible, civic, participatory, empathetic, vindictive and protected by law) characteristic of Bioethics, and understood as an “area of deliberation and argued proposal, and in the 21st century Bioethics would be consolidated as an indispensable civil and coexistence instrument *for achieving the desirable and authentic humanization of sciences and technologies*, hence I largely considered it the *Century of Bioethics*; and must provide its ethical guidelines to overcome the “**Culture of violence**”, social injustice and intransigence that marked the 20th century to the “**Culture of dignity and respect**”, and to move towards achieving a rational capitulation of universal awareness about the correct use of science and technology and its use at the service of all humanity (*Bioethical Culture*).

As expressed in Recommendation 1160 *regarding the elaboration of a Bioethics Convention* unequivocally impregnated of that spirit, the Convention was focused and possible in areas of the Council of Europe linked to bioethics, to the **bioethical spirit** that was created, fundamentally parliamentary (the Commissions and the Parliamentary Assembly) or not, the CAHBI and the CDBI (the continuing task of the latter since its creation in 1992, was marred by tensions and with contradictions and excessive actions such as the report of 7/6/1996 in which the *Bioethics Convention* title was improperly annulled, as stated in the documents until May 1996, four months before its adoption by the Parliamentary Assembly). (In reality, this unjustified mutilation of the title of the Convention has little effect, **since in general it is held openly**, without reservations, **by the *Bioethics Convention***. In the media

during the opening for signature and in many other moments, Congresses, Conferences, naturally we talk about the *Bioethics Convention*).

La Nueva España

The signing of the Convention makes Asturias
in European capital of Bioethics

Oviedo, Spain April 3, 1997 Pablo ALVAREZ / Elena FDEZ.-PELLO

"This is a very important event, and not only for Spain, but for the 40 countries of the Council of Europe, since for the first time [we have achieved standards on bioethics](#) and biomedicine common to all." "This is how the German Leni Fischer, President of the Parliamentary Assembly of the Council, assessed yesterday afternoon the signing of the Convention on Human Rights and Biomedicine that will take place this afternoon in Oviedo, with the presence of the Minister of Health, José Manuel Romay Beccaría."

But what it is about is to formally recognize that title *Convention on Bioethics* and have the Convention officially named with it, as I have stated and reiterated before and here.

It was obvious that some contents of the Bioethics Convention, those not related to biology and medicine, would have to be addressed and established mainly by jurists. Throughout this time, the CAHBI and CDBI played their role, and I found collaboration and information and numerous supports, the closest ones from the Presidents of Commissions (Mrs. Morf, Mrs. Petterson, Lenzner, Bassinet, Roseta, Pini, Foschi, Güssembauer) and lawyers, Mr. Hartland and especially Mr. Baris Perin, lawyer of the Science

and Technology Commission, an invaluable collaborator to whom I became united by a friendship that did not need confirmation.

Year 1991

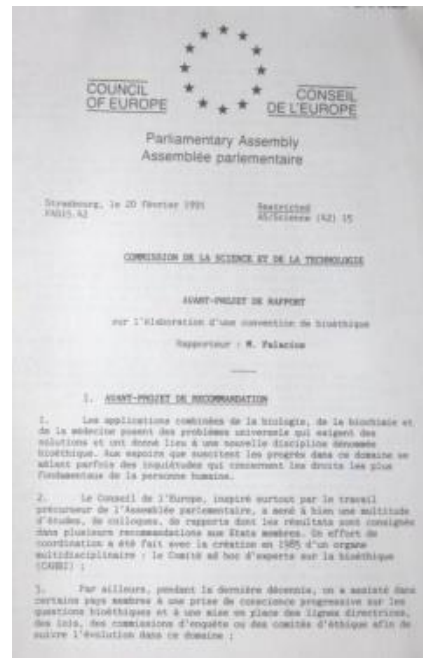
On March 14 to 16, 1991, the Science and Technology Commission of the Council of Europe met, at my proposal, in the Principality of Asturias (cities of Oviedo and Gijón). My first draft (doc. AS/ Science (42) 15, of 20.2.91), was discussed and would later be the Preliminary Draft AS/ Science (43), 4, of 13.5.91 *on the elaboration of a Convention of Bioethics*.

This last document was:

a) accepted by CAHBI (Strasbourg, April 24, 1991),

b) adopted unanimously at the next meeting of the Science and Technology Commission (Paris, May 27, 1991) as doc. No. 6,449.

c) definitively and unanimously approved in Helsinki (Finland) on June 28, 1991 by the Permanent Commission of the Council of Europe, on behalf of the Assembly, as Recommendation 1,160 *regarding the elaboration of a Bioethics Convention*.



BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



In it, in summary, it is recommended that the Committee of Ministers consider a **framework Convention**, with: 1), a general part, main text or Convention itself, which concerns respect for

human rights in relation to the applications of biology and medicine and its technologies, and, 2), a specific part, with five additional **protocols** on: organ donation and transplantation, medical research in humans (including the use of embryonic structures), genetic technology and studies on the human genome, use of genetic information in nonmedical media, and human artificial procreation; furthermore, authorize and encourage CAHBI to resort to all consultations that it deems useful in the preparation of the project, for example, representatives of the Third World, scientific organizations, and in particular, community institutions, as well as international organizations. Governmental and specialized nongovernmental; and also, submit the draft Convention to the Assembly with a formal opinion report, before its final adoption.

On April 23-24, **1991**, I have participated in the CAHBI meetings. Its Working Group proved incapable of carrying out the

Reminder, see below Council of Europe
The Secretary General

Strasbourg, February 3, 1995

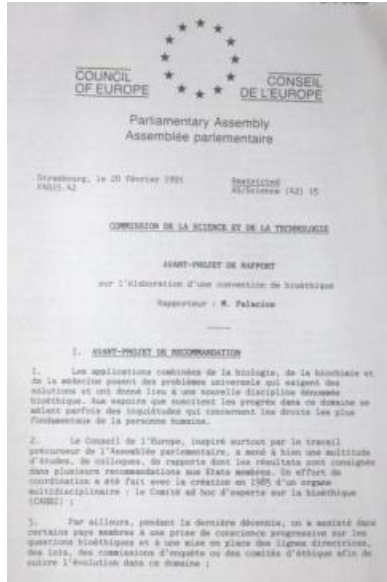
Mr. Marcelo Palacios Mr. President, dear friend,

Having finished the debate in the Parliamentary Assembly on the draft **Bioethics Convention**, I want to express my gratitude for **the considerable efforts that you have deployed in this matter**.

In the past, the Parliamentary Assembly had already adopted important texts on the matter, mainly **Recommendations 1,100 and 1,160**, of which **you were Rapporteur** on behalf of the Science and Technology Commission.

Throughout the preparation of the Bioethics Convention project, you have represented the Assembly in the Bioethics Steering Committee **and have been the Rapporteur of this project** on behalf of the Science and Technology Commission.

Daniel Tarschys



Convention, due to the obstacles and disagreements caused by the reservations of representatives of some countries, such as the United Kingdom, Norway, Cyprus and others, the CAHBI formally communicated this, and at the same time I informed the Science and Technology Commission (and others) about it. In order to overcome the blockage, **I was commissioned** by the Science and Technology Commission to continue the preparation of a Preliminary Draft **on the**

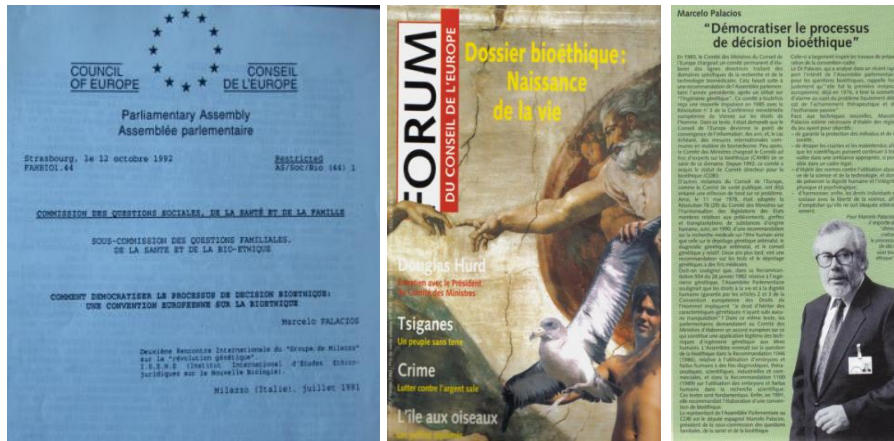
elaboration of a model of Bioethics Convention that could come to fruition, like the one that had been presented at the Asturias meeting by a month before, in March, in the preparation of which I received the invaluable logistical support of the Commission's lawyer Mr. Perin.

On June 2, **1991**, at the meeting held in Innsbruck (Austria), **I was appointed president of the Sub Commission on Health, Family and Bioethics**, a position I would hold until May 1996.

In July **1991**, the Second International Meeting of the Milazzo Group on “The Genetic Revolution” took place in Milazzo (Sicily, Italy).

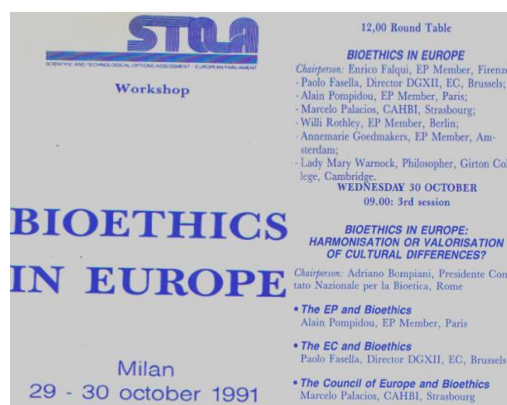
I represent the Commission and as rapporteur with the topic *Democratizing the Bioethics decision process*, which would be published by the Council of Europe on 10/12/92 (doc. AS/Soc/Bio (44) 1 in its Forum magazine.

BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



In September **1991**, the Committee of Ministers chaired by Vicent Tabone, by Resolution No. 3, entrusted the CAHBI (Ad Hoc Committee for Bioethics) "to prepare, in close cooperation with the Steering Committee for Human Rights (CDDH) and the European Committee of Health (CDSP) a framework Convention, open to non-member States, establishing common general standards for the protection of the human person in the field of biomedical sciences, and protocols to this Convention, relating, in a phase preliminary, to organ transplants and the use of substances of human origin".

In **October** 1991 I participated in the working sessions of **STOA** (Scientific technological advisory Group of the Committees in the Parliament of the European Union, created in 1987) in Milan, on *Bioethics in Europe and the Council of Europe*.



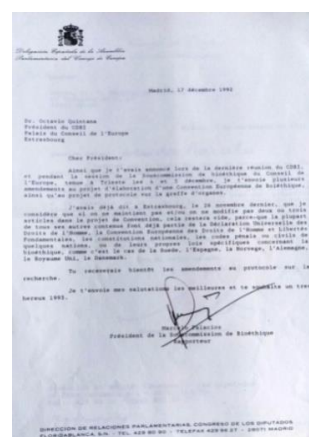
And from **1991** to **1994** I was a member of the European Union “Human Genome Analysis Programme” of the Commission of the European Communities, in the ESLA Working Group (ethical, social and legal aspects). And Co-author of the *Final Report*, from 1993.

Year 1992

In March 1992, at the direction of the Committee of Ministers, the CDBI (derived from the CAHBI) established a Working Group chaired by Dr. Michael Abrams (United Kingdom) to prepare a draft Convention of Bioethics.

In documents distributed during the CAHBI meeting of 26.11.92 on the *Convention on Bioethics* is declared that “the CAHBI reaffirm the *great principles and values that must guide all bioethics regulations*”.

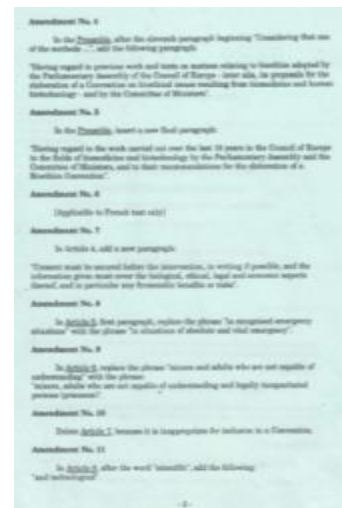
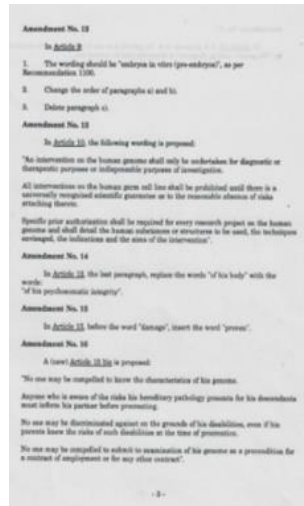
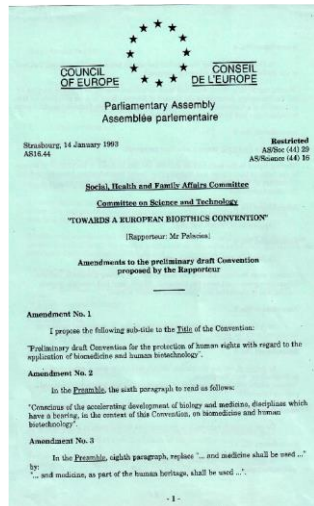
December **1992** I periodically submit amendments to the CDBI for the text of the Bioethics Convention, and I insisted (in this letter, for example, and also verbally) to the then President of the CDBI that **the Convention will be worthless if no additions and/or they modified some articles or content.**



BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS

Year 1993

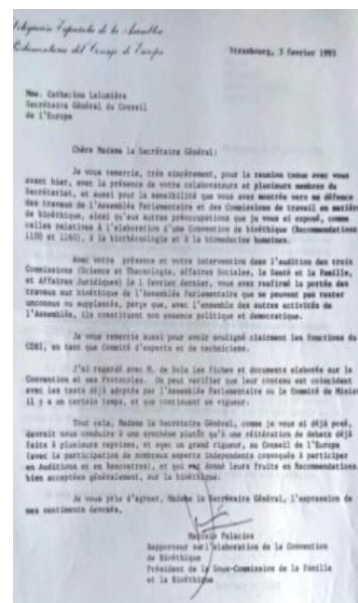
Some of my amendments (in Science and Technology, and Health Committees), including No. 1 with the subtitle, for the draft Convention:



January 30, 1993
Letter from the Secretary of the CDBI on my amendments included in the Draft Convention with "congratulations from the President of the CDBI working Group of the Convention, Mr. Thompson, for my valuable collaboration on the text"

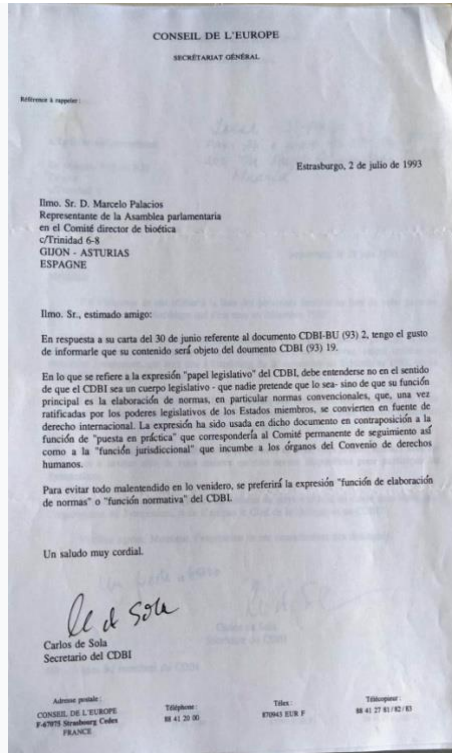
On 1.2, **1993**, for my constant demand for a scrupulous definition of the functions on the Convention, due to the occasional hoarding and deserving attitude of the CDBI —with my confrontations as General Rapporteur of the Parliamentary Assembly on Bioethics with its Secretary General, due to the pretensions, contradictions and tensions of the latter's secretariat—, some Commission Presidents intervene (sirs Gussembauer, Pini, Foschi, Pettersen) and on 1.2.93 a meeting takes place in the office of the Secretary General of the Council of Europe, Mrs. Lalumière, with her collaborators and members of the secretariat , in which he is very sensitive to the defense of the work of the Parliamentary Assembly of the Council of Europe on bioethics. For that same day in the afternoon, a HEARING had been called with the presence of the Presidents of the Committees on Science and

Technology, Social Affairs, Health and Family, and Legal Affairs, as well as the CDBI and the European Parliament and others, in which the Secretary General would reaffirm that the work on Bioethics of the Parliamentary Assembly cannot be forgotten or supplanted, clearly pointing out the advisory functions of the CDBI as a Committee of experts and technicians. To me he refers to the rise of Bioethics in the Assembly and the Council of Europe and its international prestige as a *deus ex machina*.



My letter dated February 3, 1993 thanking for the intervention of the Secretary General, Mrs. C. Lalumière at the HEARING.

BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



1993 The Secretary of the CDBI recognizes that **this Committee does not have legislative nor regulatory power**. But in its Report of June 7, 1996, CDBI **eliminated the title *Bioethics Convention***, without Amendments and debate in the Assembly.

COUNCIL OF EUROPE
GENERAL SECRETARIAT

Strasbourg, 2 July 1993

Ilmo. Mr. Marcelo Palacios
Representative of the Parliamentary Assembly on
the Bioethics Steering Committee
C/Trinidad, 6-8 GIJÓN-ASTURIAS SPAIN

Ilmo. Sir, Dear friend,
In reply to your letter of June 30 concerning
document CDBI-BU (93) 2. I am pleased to
inform you that its contents will be the sub-
ject of doc.. CDBI (93) 19.

As regards the expression "legislative role"
of the CDBI, **it should be understood NOT in the sense that the CDBI is a legislative body –which no one claims it to be– but that its main function is the elaboration of norms**, in particular conventional norms, **which, once ratified by the legislatures of the member States**, become a source of international law. The expression was used in that document as opposed to the "implementation" function of the Standing Monitoring Committee and the "adjudicatory function" of the human rights Convention bodies.

To avoid any misunderstanding in the future,
the term "standard-setting function" or "normative function" of the CDBI will be preferred.

With best regards

Carlos de Sola Secretary of CDBI

Postal address: COUNCIL OF EUROPE F-67075
Strasbourg-Cedex FRANCE

In correlative Reports (Expl. Memorandum) such as AS/ Science, **1994**, numbers 11, 19 and 20; and doc. 7.156 on the Bioethics Convention, as well as in the last of these Reports (nº 7,210, January 12, 1995, paragraph 18) *I proposed that the signing of the Bioethics Convention take place in the Principality of Asturias*, since the outline of the Convention had been presented

in the Science and Technology Commission for the first time” once in Asturias (Spain), maintaining the hope that the Parliamentary Assembly would approve this proposal”.



have been complex and difficult, but highly gratifying and extremely satisfactory and with great practical consequences for Europe and, indeed, the whole world.

15. Following our acceptance of these terms and their approval by the Committee of Ministers, they will be opened for signature by the member states of the Council of Europe and by any non-member states that wish to accede to them. That will mark the end of an extraordinary chapter, but also the beginning of an even more important chapter with the implementation of the principles set forth in those documents, leading to widespread harmonisation and standardisation of the laws of many countries in such sensitive fields and responding as far as possible to differences in national regulations.

16. In conclusion, although it is not usual to make such remarks in a report of this kind, I would like to take this opportunity to express my sincere gratitude for the confidence bestowed on me, the constant stimulation and support received and the able, but positive way in which disagreements have been expressed, although I am aware that the members of the Assembly, experts and others involved in this task have at no time sought such recognition, believing that in carrying out this work they are only doing their duty.

I should like to thank the Presidents of the Parliamentary Assembly (Mr. Jung, Røed and Martens) and the Secretaries General (Mr. Gode and Mrs. Lalumière), who have encouraged and followed our work and helped us continue to resolve particular difficulties, thereby enhancing and advancing the scope of the activities of the Assembly.

I should also like to thank all the following: the chairman of the Committee on Science and Technology (Mr. Petricone, Laurent, Baccant and Riera), of the Social, Health and Family Affairs Committee (Mr. Fouché and Pini) and Mrs. Harck, and those of the Sub-Committee on Family Affairs, Health and Biotechnology (Mr. Wozniak and Mrs. Maffei), of which I have been a member since my arrival at the Council of Europe. And all those who, in one way or another, but their assistance, which was sometimes understated but always valuable. My appointment as Chairman of the Sub-committee on Family Affairs, Health and Biotechnology and as General Rapporteur of the Parliamentary Assembly for Bioethics are honours for which I am deeply grateful and in my ongoing efforts to carry out these duties I hope I have fulfilled the hopes placed in me.

17. I wanted to acknowledge this crucial role played by the Council of Europe and I believe that my research will not be considered out of place and that my findings are in fact widely shared since, ultimately, the efforts of any one individual are likely to be shared without reasonable criticism and support from all those people, as is the Council of Europe, who ensure the success of the work, for the benefit of the general public.

18. Finally, in view of the fact that the preliminary draft of the Convention was first submitted to the Committee on Science and Technology in the Parliamentary Assembly in Spain, I suggest that the signing of the Convention take place there and I trust that the Parliamentary Assembly will adopt it.

As it was. Also from mid-1994 I addressed members of the Spanish Government, and received their support.

On March 18, **1994** I was invited to the Inauguration of the European Pharmacopoeia building (in Mainau) by the Secretary General of the Council of Europe Catherine Lalumière, together with Mr. Hugo Founder, Belgian Ambassador and then President by Delegation of the Committee of Ministers in the Council of Europe. It consisted of the placement of a commemorative PLAQUE, which included me in reference to Bioethics, several interventions and a visit to the facilities.

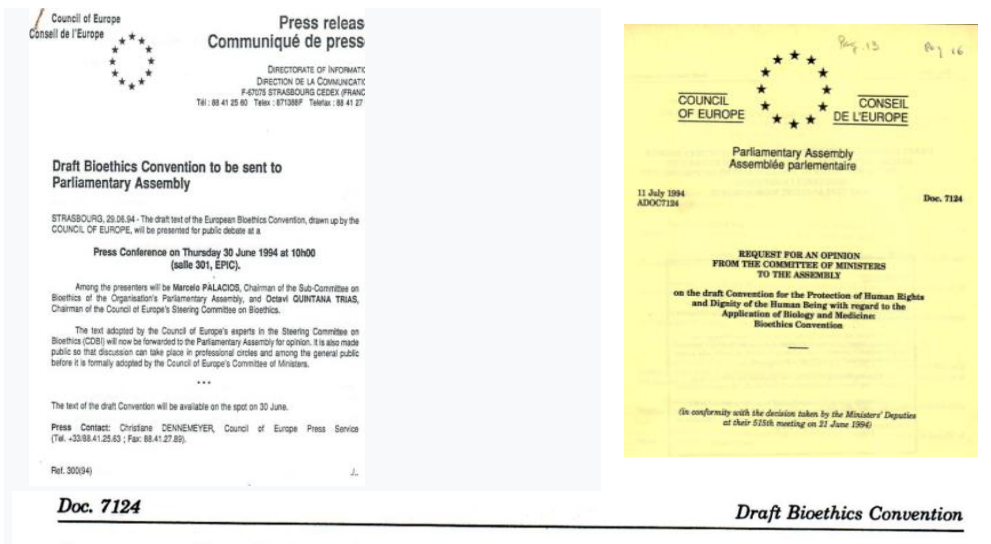
BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



In Recommendation 1240 *concerning the protection and patentability of products of human origin* (1994), the Assembly recommends to the Committee of Ministers: «i. Approve the text of the *Convention on Bioethics* as soon as possible, send it within the deadline to the Parliamentary Assembly for its opinion and **quickly open it for signature**, thus offering Europe as a reference the fundamental moral principles in the field of **bio-ethics**».

June 30, **1994** the then president of the CDBI calls a press conference on the *European Convention on Bioethics*, Doc 7124, to which I refuse because I consider the text immature and not having been consulted.

BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



19. The term "bioethics" was used in a supplementary title to give a succinct and convenient indication of the purpose of the text.

It should be remembered that the **title** of Document **7124** of the year **1994** of the CDBI is a synthesis of documents from the Science and Technology Commission (Speaker: Marcelo Palacios):

—Doc. 6449 and Recommendation 1160 (year 1991) *Elaboration of the Bioethics Convention*.

—Amendment No. 1 (year 1993). *Convention for the protection of human rights and the dignity of the human being with respect to the application of biology and medicine*.

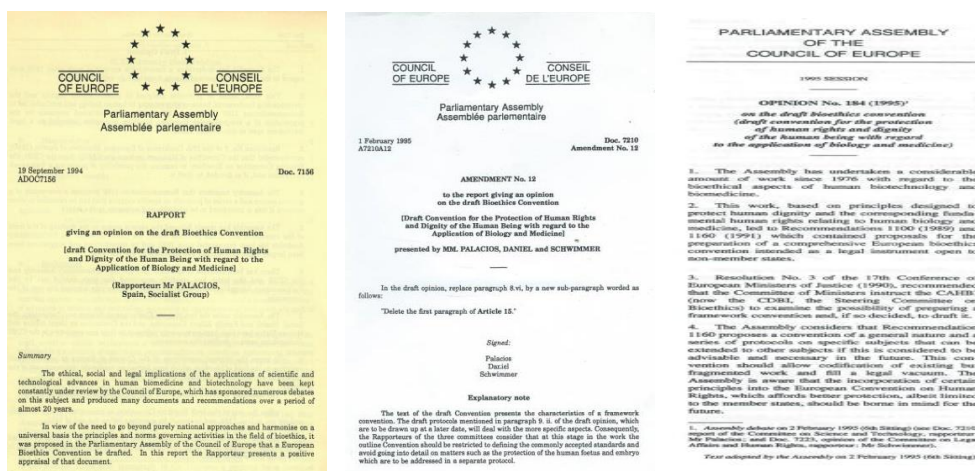
Year 1995

On February 2, 1995, [my Report No. 7210](#) (Science and Technology Commission) on the Draft *Bioethics Convention. Convention for the Protection of Human Rights and the Dignity of the Human Being with Respect to the Application of Biology and Medicine*, **was debated** in the Parliamentary Assembly, with certain amendments (11 were approved, among them the one

BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS

that I promoted jointly with deputies Daniel and Schwimmer, of withdrawal of section 1 of the article 15, on embryo research), and it is agreed to forward the document to the Committee of Ministers as Opinion 184 for an in-depth TEXT review.

(My note: remember that **Opinion 184** requests revision of the TEXT, not revision of the TITLE as CDBI did)



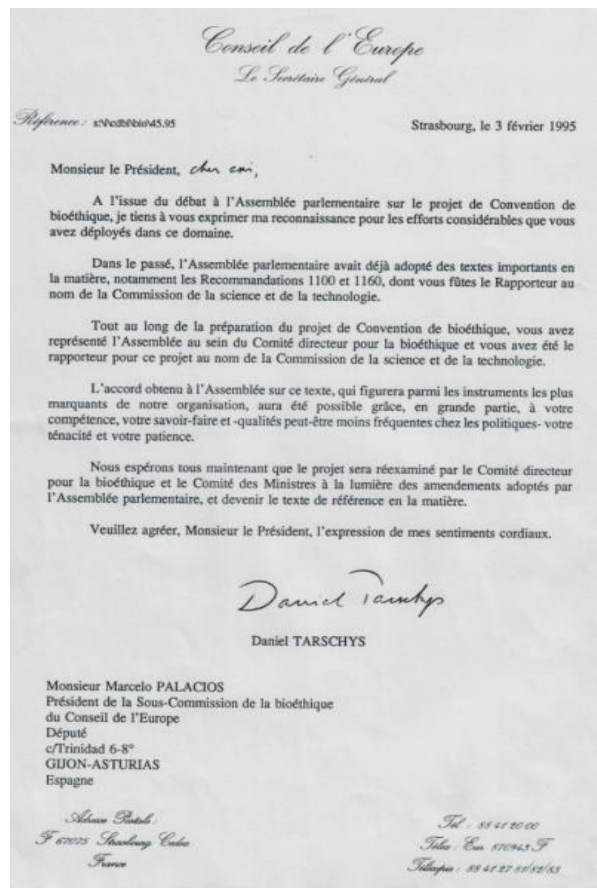
It was rumored that the *Bioethics Convention* would be rejected. And the opposite happened.

I have indelible memories of that day. The Italian Mr. Sartri, former minister, president of the European Christian Democrat group, as he walked the steps of the Chamber, gently put his hand on my shoulder, leaned towards me, smiled and said: "Let's vote in favour of your Convention, then we'll see how I defend this in Italy". We had never spoken before.

The debate aroused great interest, the chamber was packed, it culminated in prolonged applause lasting several minutes and I received a congratulation card from an usher from a senior legal official "stating that in many years he worked there he hadn't seen anything like that". I was also congratulated by the usher.

In my Report No. 7210 on the *Bioethics Convention* that was debated on 2.2.95, I expressed my gratitude to those who for so many years encouraged my work and gave me the invaluable trust of preparing the Report on the Bioethics Convention, granted me the Presidency of the Bioethics Subcommittee and appointed me General Representative for Bioethics of the Parliamentary Assembly and its spokesperson at international events, as well as numerous collaborators, and out of parliamentary courtesy even those who prosecuted her for reasons of their position.

The next day, February 3, I received a letter from Daniel Tarschys, the Secretary General of the Council of Europe, which always moves and makes me proud, about my commitment and effort to make a reality the *Bioethics Convention*.



Council of Europe
The Secretary General
Strasbourg, February 3, 1995

Mr. Marcelo Palacios

Mr. President, dear friend,

Having finished the debate in the Parliamentary Assembly on the draft **Bioethics Convention**, I want to express my gratitude for **the considerable efforts that you have deployed in this matter.**

In the past, the Parliamentary Assembly had already adopted important texts on the matter, mainly Recommendations 1,100 and 1,160, of which **you were Rapporteur** on behalf of the Science and Technology Commission.

Throughout the preparation of the Bioethics Convention project, **you have represented the Assembly** in the Bioethics Steering Committee **and have been the Rapporteur of this project** on behalf of the Science and Technology Commission.

The agreement reached in the Assembly on **this text**, which **will be among the most outstanding instruments of our organization, has been possible thanks**, in large part, to your competence, your know-how and –qualities that may be less common in politicians– your tenacity and patience.

In the meantime, we all hope that the project will be examined by the Bioethics Steering Committee and the Committee of Ministers **in light of the amendments approved by the Parliamentary Assembly** and become a reference text on the subject.

Accept Mr. President, the expression of my cordial feelings

Daniel Tarschys

1995 March-April

INTERPARLIAMENTARY UNION (IPU)

93rd Conference (Madrid)

1300 representatives from 135 countries

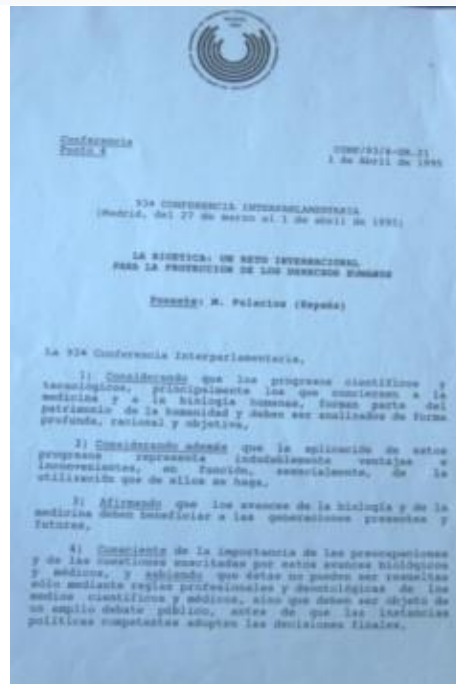
I was appointed member of the IPU only the week of the Conference, to defend the report I was asked to prepare:

—AUTHOR of the Spanish Report on Bioethics for the Conference.

—Appointed by the members of the Conference GENERAL SPEAKER on *Bioethics*, one of the two major topics on the agenda.

—CO-EDITOR and Speaker of the final report, approved by consensus, which contains much of the Spanish report guided by me, and which, extracting, would be adopted as Resolution *Bioethics*, an international challenge for the protection of human rights, to which, not without resistance from some non-European country, was incorporated, my amendment (point 7) "Proposes that after the Convention on Bioethics (Council of Europe)

has come into force, as many non-member States of the Council of Europe as possible avail themselves of the opportunity to accede to the Convention, thereby giving it a **universal character**"



BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



I highlight this IPU meeting (1995) because the member states of the Council of Europe and a hundred more participated in it, **valuing Bioethics very positively**, that they would not take into account CDBI representatives one year later (inform of 7 June 1996) **discrediting the term Bioethics** and **eliminating** the title *Bioethics Convention*.



El País Madrid April 2, 1995

93rd IPU Conference endorses Resolution on bioethics.

Parliamentarians from 135 countries approve banning human gene patents

Yesterday in Madrid, parliamentary representatives from 135 countries around the world approved a ban on patenting human genes.

Spain has played a leading role in the preparation of the [resolution on bioethics](#), approved yesterday for the plenary session of the 93rd Conference of the Interparliamentary Union (IPU). Defended by a Spaniard, the socialist deputy Marcelo Palacios, the document encourages all governments to prohibit all benefits obtained from the human body or parts thereof, "except exceptions provided for by law" as happens with the legal marketing of blood components.



April 5th, 1995 I inform the Secretary General of the Council of Europe of my participation as the speaker on Bioethics at the 93rd IPU Conference held in Madrid the days before, and the amendment presented supporting the *Bioethics Convention* and the accession to it when it is approved. At the same time, **I criticize the slowness of the CDBI**, with the concern that it will take

too many months (as it would otherwise) to return the Convention to the Committee of Ministers for its opening for signature.

Year 1996

Convention sur les Droits de l'Homme et la biomédecine

II. Exposé des motifs
par M. PLATTNER

I. Introduction

1. En l'espace de dix ans, il y aura eu à l'Assemblée parlementaire une dizaine de débats concernant les problèmes relatifs à la bioéthique. Deux d'entre eux ont été consacrés à l'utilisation d'embryons et de fœtus humains à des fins diagnostiques, thérapeutiques, scientifiques, industrielles et commerciales. Trois autres débats ont porté sur l'idée même d'une convention européenne ainsi que son contenu. Une liste exhaustive des textes adoptés par l'Assemblée et le Comité des Ministres concernant la bioéthique, ainsi que l'historique des travaux ont été présentés d'une manière détaillée dans des documents précédents, en particulier dans les rapports de la Commission de la science et de la technologie (Docs. 6449, 7156 et 7210). Il ne semble pas opportun de les répéter ici. M. Palacios, qui fut Rapporteur pendant de longues années, a eu l'honneur et le privilège de participer de près à cette aventure intellectuelle. Quant à moi, j'ai le grand plaisir de vous en présenter les fruits sous forme d'un

From 1987 to 1996, almost 10 years, some of my steps in the preparation of the **Bioethics Convention**.

Etapas de la elaboración de la Convención de Bioética 1987-1996

Informe As/Science, 6, de 17 de abril de 1996. MP: Lo defiendo el mes de mayo 1996

—On June 4 to 7, meeting from CDBI, where the term *bioethics* is downgraded, the title *Bioethics Convention* is removed and a *Bioethics Seminar* is organised for next December. ☹

I was not able to participate in that meeting of the CDBI on 4-7 June 1996 to try to prevent it with all my arguments, since I was no longer General Rapporteur of the Parliamentary Assembly, having recently ceased to be a member of the Spanish Delegation

BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS

to the Council of Europe and could not be formally summoned. If I had been able to attend, I would have been adamantly opposed with arguments to the annulling of the title *Bioethics Convention*, which is unjustified and harmful to the Council of Europe.

Official report

30th session September 1996

Avis 198

Doc. 7622 Mr. Plattner and
Convention

The title Bioethics Convention **is NOT amended OR debated, it has been previously eliminated by the CDBI**, as indicated in its Report of June 7, 1996 attached to Doc. 7622

A complete irregularity

PARLIAMENTARY ASSEMBLY OF THE COUNCIL OF EUROPE	
1996 ORDINARY SESSION	
OFFICIAL REPORT	
Thirtieth Sitting	
Thursday 26 September 1996 at 9.45 a.m.	
SUMMARY	
1. Adoption of the minutes 1063	Doc. 7664, rapporteur: Mr. Daniel; and the opinion of the Committee on Legal Affairs and Human Rights, Doc. 7654, rapporteur: Mr. Schymmer, 1063
2. Attendance register 1063	
3. Changes in the membership of committees 1063	
4. Opinion on the draft convention on human rights and biomedicine (joint debate on the report of the Committee on Science and Technology, Doc. 7622, rapporteur: Mr. Plattner; the opinion of the Social, Health and Family Affairs Committee, Doc. 7654, rapporteur: Mr. Schymmer)	5. Statement by Mr. Marc Forst Molot, Head of Government of the Principality of Andorra 1083
	6. Date, time and orders of the day of the next sitting 1088
	Appendix Attendance register 1089

Mrs Fischer, President of the Assembly, took the Chair at 9.45 a.m.

THE PRESIDENT. – The sitting is open.

1. Adoption of the minutes

THE PRESIDENT. – The minutes of proceedings of the previous two sittings have been distributed. If there are no objections I will take the minutes as agreed.

The minutes are adopted.

2. Attendance register

THE PRESIDENT. – The names of those Substitutes present at this sitting, of which notice has been given to the President, will be published with the list of Representatives appended to the minutes of proceedings and the official report of debates.

3. Changes in the membership of committees

THE PRESIDENT. – First we consider the proposed changes notified by the Georgian delegation in the membership of committees, which are set out in an un-numbered document which is available at the documents counter.

Are the proposed changes in the membership of the Assembly's committees agreed?...

They are agreed.

4. Opinion on the draft convention on human rights and biomedicine

Joint debate on the report of the Committee on Science and Technology, Doc. 7622, rapporteur: Mr. Plattner; the opinion of the Social, Health and Family Affairs Committee, Doc. 7654, rapporteur: Mr. Daniel; and the opinion of the Committee on Legal Affairs and Human Rights, Doc. 7654, rapporteur: Mr. Schymmer

THE PRESIDENT. – The first item of business this morning in the debate on the report giving an opinion on the draft convention on human rights and biomedicine presented by Mr. Plattner on behalf of the Committee on Science and Technology, Document 7622, with an opinion presented by Mr. Daniel on behalf of the Social, Health and Family Affairs Committee, Document 7654, and an opinion presented by Mr. Schymmer on behalf of the Committee on Legal Affairs and Human Rights, Document 7654.

The list of speakers closed at 6 p.m. yesterday. Thirty-four names are on the list, and fifteen amendments and one sub-amendment have been tabled.

In view of the time available, and the number of speakers on the list, I propose that speaking time in the debate be limited to five minutes.

It is proposed to conclude the general debate at noon today, when we hear the address of Mr. Forst Molot, Head of Government of the Principality of Andorra and to have the votes on the draft opinion and amendments at the sitting this afternoon.

1063

—On **September 26**, the Parliamentary Assembly of the Council of Europe discussed the Convention, **without amending, debate and vote** on the change of the title by eliminating the title *Bioethics Convention*.

Doc. 7622 Mr. Plattner Debate September 26, 1996 PACE

Appendix I

Comparative study of the initial and final texts of the draft Convention

Draft Convention transmitted to the Assembly on July 11, 1994	Amendments proposed for the Assembly on February 2, 1995 Opinion184	Draft Convention adopted by the CDBI on June 7, 1996 Incorporated into Doc. 7622
Title Draft Convention for the Protection of Human Rights and the Dignity of the Human Being with respect to The Application of Biology and Medicine. European Bioethics Convention	NONE No debate No vote	Title Draft Convention for the Protection of Human Rights and the Dignity of the Human Being with respect to the Application of Biology and Medicine. Convention on Human Rights and Biomedicine

—On November 19, 1996, the Committee of Ministers of the Council of Europe adopted the Convention.

—And on 12/19/96, a month later, the Committee of Ministers agreed to open it for signature in Asturias (Spain), as I had requested and at my request from the Spanish Government.

Year 1997

On **3/4/1997** Leni Fischer (President of the Parliamentary Assembly of the Council of Europe, APCE) and Daniel Tarschys (General Secretary) were the object of a Tribute at the Gijón City Hall, for the support I received as proponent and speaker (for 10 years) of what Leni Fischer lovingly called the “Asturias Conven-

BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS

tion on Bioethics” or otherwise, “Palacios Convention”, as the media recognized. This reminded me of the letter I received from the previous Secretary General Miguel A. Martínez.



Gijón (Spain) City Council 3.4.1997 Tribute to the President of the Parliamentary Assembly (Mrs. Fischer) and the Secretary General (Mr. Tarschys) of the Council of Europe. Interventions by Mr. Álvarez Arces, Mayor of the city, and the honorees. Public Assistant, Authorities, Parliamentarian.



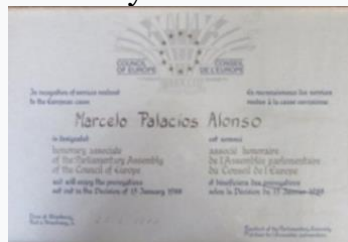
On **4/4/1997** the Convention **was opened for signature** in Oviedo (Principality of Asturias, Spain) with the participation of twenty-one States and with the assistance of Ms. Leni Fischer and Mr. Daniel Tarschys and other authorities.

In the morning Ms. President Fisher grant me the European Pro-merit Medal of the Council of Europe and the Diploma as Honorary Parliamentarian of said Institution, in the presence of members of the Science and Technology Commission, representatives of the Council of Europe and authorities of Asturias.

I simply stated that it was an honour and I only said thank you. He was surprised, we appreciated it in his gesture, and also those who asked me the reasons for my brief intervention. I did not wish to make any comments, the much-loved



title *Bioethics Convention* had disappeared in ways that I disapproved of, but the Convention was a fundamental achievement for the entire world, and I/we had been honoured with its opening for signature in my land.



And I decided for the future not to address the circumstances and actions that led the CDBI to annul the original title. **Until now.**

El Principado hace historia en la construcción europea

El asturiano Marcelo Palacios, promotor de la Convención de Bioética, recibió ayer el protagonismo en la firma de la normativa europea sobre bioética, redactada en buena parte gracias a su empeño personal. La presidenta de la asamblea del Consejo de Europa, Leni Fischer, le entregó el título de miembro honorario de este órgano. El presidente asturiano, Sergio Marqués, también reconoció que «no es casualidad ni azar que este convenio se firme aquí» y se refirió a su «principalísima» intervención en el texto.



Leni Fischer estrecha la mano de Marcelo Palacios tras entregarle el título. Sentado, en el centro, Sergio Marqués.

Grisolia: «No hay que tener miedo a la Ciencia»

Oviedo, E. F. P.

Desde primera hora de la mañana Santiago Grisolia, premio «Príncipe de Asturias» de Investigación Científica y Técnica, se paseaba por el hotel entre el resto de los invitados a la firma del convenio. El director del Instituto de Investigaciones Citológicas de Valencia y del proyecto «Genoma», que no faltó al homenaje de Marcelo Palacios, señaló que «estamos en medio de una revolución tecnológica y médica, y también social. Lo importante es mantener abierta la conversación». «No hay que tener miedo a la ciencia y ése es el objetivo de esta convención».

«Este convenio no sólo tiene que firmarlo Europa», afirmó Grisolia, y añadió: «Hemos escrito una carta a Su Santidad en la que le planteábamos la posibilidad de discutir allí, en una serie de reuniones, sobre el genoma, y están muy abiertos a ello».

El presidente del Consejo Superior de Investigaciones Científicas (CSIC), César Nombela, subrayó la relevancia de documentos como el ayer suscrito, dado que «a medida que avanza la biomedicina surge la preocupación de que se puedan violar límites de forma inaceptable».

Octavi Quintana, quien presidió durante tres años el Comité Director de Bioética del Consejo de Europa, señaló que el convenio refrenda y en ningún momento contradice la legislación existente en España.

El Consejo de Europa reconoce el papel decisivo de Palacios

The Council of Europe recognizes the decisive role of Palacios

Elena FERNÁNDEZ-PELLO
Marcelo Palacios, ex presidente de la comisión redactora del Convenio de Bioética, fue el protagonista del primero de los actos oficiales de la apretada programación del día, que para los embajadores y representantes de los países que firmaron la normativa europea comenzó a las 9,30 de la mañana. La presidenta de la asamblea parlamentaria del Consejo de Europa, la alemana Leni Fischer, entregó al médico gijonés la medalla y el diploma en reconocimiento a los méritos de Palacios, así como su nombramiento como miembro

Consejo de Europa.

Fischer bromeó sobre la conveniencia de hablar de «la Convención del señor Palacios o la Convención de la Asturias del señor Palacios». La presidenta de la asamblea felicitó a Marcelo Palacios «por su duro trabajo no sólo para poner en marcha la normativa, también en las discusiones».

Marcelo Palacios fue miembro de la asamblea parlamentaria del Consejo de Europa y de su Comisión de Bioética, que presidió durante cinco años. Dos meses antes de que concluyera la redacción del convenio, fruto

de las negociaciones, finalizó su mandato al frente de la comisión.

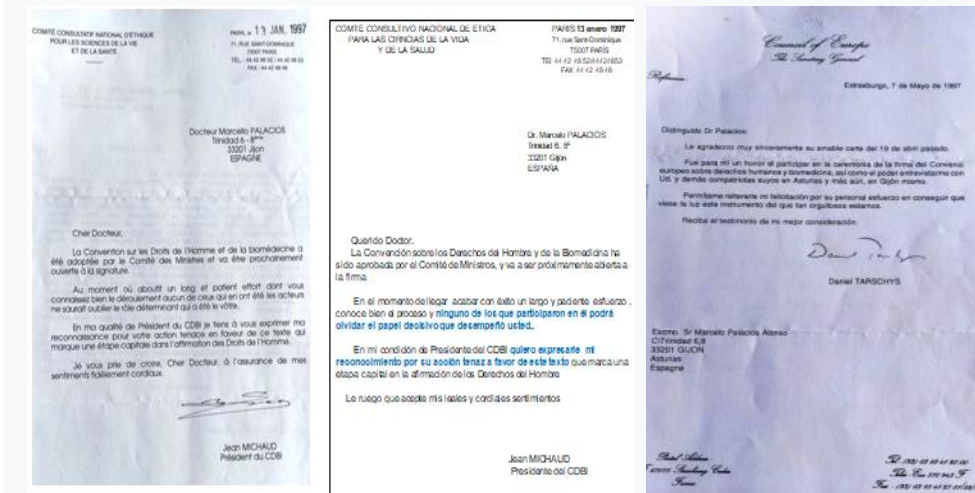
La imposición de la medalla, con la que la figura de Palacios recibió el lugar destacado en este evento histórico que durante las jornadas previas parecía haber perdido, se realizó al finalizar la presentación de la subcomisión de ciencia y tecnología en el hotel de la Reconquista de Oviedo y en ella estuvo presente el presidente del Principado, Sergio Marqués, que presidió el acto. Más tarde Palacios compartió mesa, durante el almuerzo, con Marqués y las personalidades más destacadas.

salón donde se celebraba el acto protocolario, Marcelo Palacios escuchó las palabras de reconocimiento que le dedicó el responsable del Ejecutivo regional. Marqués reconoció que «no es casualidad ni azar que este convenio se firme aquí, en Asturias». El presidente asturiano glosó brevemente la figura del promotor de la normativa europea sobre biomedicina, que, dijo, «participó de manera principalísima y eminente en su elaboración». Marqués despidió al médico asturiano con un efusivo: «Gracias, doctor Palacios, ¡bien hecho!».

BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



Leni Fischer (Chairwoman of Parliamentary Assembly): “Isn't this the Asturias Convention? Isn't Palacios the father of the Convention?”

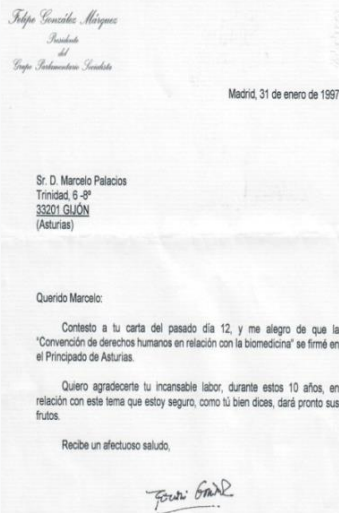


President of the CDBI, J. Michaud, January 1997 and Daniel Tarsysch, May 1997, congratulating me for my efforts over so many years to achieve the Convention

BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



A doctor who builds Europe



31.1.97 Congratulations from Felipe González to my letter

El PAIS

Oviedo, capital of bioethics

JAVIER CUARTAS Oviedo - 05 Apr1l 1997

"The choice of the Asturian capital as the venue for this event is due to a proposal by former Asturian socialist deputy and former parliamentarian of the Council of Europe Marcelo Palacios, promoter of this international Convention a decade ago. Palacios is also the author of the first draft of the document, whose proposal he formalized, in March 1991, during a working meeting of the Science and Technology Commission of the Council of Europe, held in the same Oviedo hotel that yesterday served as the setting for the event.

The Spanish Government endorsed the request for the Principality of Asturias to host this event, and thus it was approved

unanimously on November 26 by the Committee of Ministers of the Council of Europe.

Yesterday afternoon's ceremony was attended by 40 ambassadors, the Ministers of Health of three of the signatory countries - among them, the Spanish Romay Beccaría-; a large delegation from the Council of Europe led by the president of the Assembly Leni Fischer; authorities of the Spanish Government and Parliament and the Principality of Asturias.

The Spanish biochemist Santiago Grisolia, Prince of Asturias Research Award winner and present at the event, expressed his satisfaction with the entry into force of this agreement: "Fundamentally what we have to do is respect the individual." "Science," he added, "should not be limited" in any way. Science is neither good nor bad: discover what exists. Another thing is technology because that scientific knowledge can be applied, in one way or



another. It is important to defend science and at the same time take into account the possible dilemmas that may arise. And this is the fundamental objective of this Convention".

Europe defines the limits of Biomedicine.

The European Deputy and Spanish doctor Marcelo Palacios achieved his old dream that the Convention on the Rights of Man and Biomedicine would be signed in Asturias.

La Voz de Asturias

25/9/97

Sociedad/Cultura

La Sociedad Internacional de Bioética se constituirá en Gijón a final de año

Marcelo Palacios afirma que participarán 25 personalidades de distintos países

CEFERINO VALLINA
Gijón

Asturias dará un paso más en la defensa de los derechos del hombre frente a los avances biomédicos. Además de la cátedra acordada por el Consejo de Europa y el Principado y la posible designación de Asturias como sede permanente de la bioética, el impulsor del Convenio de Oviedo, el asturiano, Marcelo Palacios, se guarda un as en la manga. A finales de año presentará en Gijón la Sociedad Internacional de Bioética que integrarán, en un primer momento, más de 25 personalidades de todo el mundo. Durante estos días, Palacios ultima el texto fundacional, la financiación y el acto por el que se constituirá esta sociedad.

El médico gijonés afirmó que **"contribuirá a convertir a Asturias como un lugar de referencia mundial"**. Personalidades del Derecho, la Medicina, Filosofía, Genética y la Iglesia de renombre internacional se reunirán dos veces al año en Gijón para profundizar en los meteóricos avances de ciencia y las repercusiones en el hombre.

Esta sociedad internacional, dispuesta a colaborar con el comité de Bioética del Consejo de Europa en aquello que requiera, se planteará como primer objetivo la elaboración de un texto de carácter europeo sobre bioética **"puesto que sólo hay trabajos sueltos y particulares"**. También confeccionará textos para un nivel de cursos preuniversitarios, y estudiará la concesión de dos becas a estudiantes.

El doctor gijonés aseguró que esta organización nacerá con gran ambición y entre sus planes también figura la publicación de una revista internacional. Además de constituir este foro de debate y análisis, Marcelo Palacios sigue





Marcelo Palacios y Santiago Grisolia. El impulsor del Convenio recibe el saludo del investigador español

The idea of the Bioethics Convention stimulates the creation in December 1997, at my proposal, of the **International Society of Bioethics, SIBI**, based in Gijón (Asturias, Spain), with a prestigious Scientific Committee with members from 18 countries.

See some SIBI activities on the SIBI website
www.sibi.org





Desde el año 2003

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SEDE de la SOCIEDAD INTERNACIONAL DE BIOÉTICA (SIBI)

SIBI HEADQUARTERS

With its **Bioethics Classroom**, the SIBI Scientific Committee has developed a

- Pedagogical Program with hundreds of Secondary School students,
- and organized
- 12 World Bioethics Conferences with the participation of 72 countries and 14 international institutions,
- Seminars,
- Annual Cycles of Conferences since 2002,
- Exhibitions, etc.,
- Teaching on Bioethics and on the Bioethics Convention of the Council of Europe.

(See summary of activities at the end of the book)

BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



In response to my request as President of the Scientific Committee of the SIBI to the Mayor of Gijón Ms. Paz Fernández Felgueroso, on November 10, 2009 the Governing Board of the Gijón City Council approved granting the “[street of Professor Potter, father of Bioethics](#)”, which is located in the Scientific-Technological Park of Gijón (Spain) and was inaugurated by his granddaughter [Lisa](#) on September 19, 2011, coinciding with the celebration of the VII World Congress of Bioethics.



Prof. Van Rensselaer Potter died on September 6, 2001. A good friend of the SIBI, in his *Final Message and Thank You*, he expressed:

“...For a long time 1970-1990 there was no one who recognized my name and wanted to be part of a mission. In the US there was an immediate explosion of the use of the word Bioethics by doctors who did not mention my name nor did they mention any of my four publications from 1970-1971. Unfortunately, his image of Bioethics delayed the emergence of what exists today.



....The next big event was in 2000, an invitation to speak at a World Congress in Gijón, Spain, coming from Dr. Marcelo Palacios, President and Founder of the International Society of Bioethics (SIBI). Again, not traveling, I offered a tape and the offer was accepted.... [The Gijón meeting was one of the most important events of my life](#), all captured on film with copies that were sent to me, with the medal and diploma of the 2000 SIBI Award.”

Representing my Committees and the Parliamentary Assembly of the Council of Europe, during years I took part and participated in various meetings related to bioethics, medicine and biology, in institutions, the Institute of Human Rights of Trieste (Italy) and before the Assembly of the IPU (Interparliamentary Union), Congresses, Conferences, institutes and Scientific and cultural associations in Malta, Greece, Norway, Ireland, Italy, Switzerland, Hungary, Sweden, Finland, Denmark, Iceland, Germany, United Kingdom, Brazil, Colombia, Venezuela, Cuba, Egypt, Canada, France, Spain, Portugal, Turkey, Belgium, Holland, etc., carrying with me and trying to improve it the wonderful and growing creature called Bioethics Convention.

¡Common sense and the force of reason prevail; **they constantly demand the *Bioethics Convention* since a quarter of a century ago this title was clumsily eliminated!**

CHAPTER I

The CDBI Report of June 7, 1996

Unfortunate consequences

The *Convention on Bioethics*, as said, could have been the third pillar of the Council of Europe in European construction, in the European integrative cause, together with the European Convention on Human Rights (1950) and the European Social Charter (1961). And with the *Bioethics Convention* the Council of Europe would become own right, “formally” part of the elite of world Bioethics.

But the Bioethics Steering Committee, **CDBI, prevented it:**

“Strasbourg, 17 July 1996 Restricted CM (96)103

COMMITTEE OF MINISTER For consideration at the 573rd Meeting of the Ministers Deputies (9-12 September 1996, A level, item 10.1).



“At its 11th meeting in Strasbourg (France) on June 4-7, 1996, the Bioethics Steering Committee (CDBI) of the Council of Europe, **presents the LIST of topics discussed and decisions taken:**

1. The CDBI met in Strasbourg from 4 to 7 June 1996, under the chairmanship of Ms. J. Kits Nieuwenkamp (Netherlands). The list of participants is in Appendix I. The agenda is in Appendix II.

2. In order to **finalize the Draft Convention on Bioethics** at the present meeting, in accordance with the instructions of the Alternate Ministers, the CDBI decided to hold three daily sessions (morning, afternoon and evening).

3. The CDBI considered the Draft Convention on Bioethics, as set out in the report of the final meeting of the CDBI-CO-RED (CDBI-CO-RED/RAP. II Appendix III), in light of the proposed amendments (see documents referred to in the agenda, Appendix II).

“In particular, **it decided to replace the abbreviated title “Convention on Bioethics” with “Convention on Human Rights and Biomedicine.”** The provisions adopted are detailed in Appendix III of this document. The detailed report of the meeting is reproduced in document CDBI/RAP 11.96.”

4. The Committee adopted the final draft of the Convention as shown in Appendix IV of this document, by 31 votes to 1 (Germany), with 2 abstentions (Belgium and Cyprus)

The explanations of the vote are in Appendix V of this Report

5. In accordance with the decision of the Committee of Ministers, the draft of the Convention **is sent to the Parliamentary Assembly for its final opinion”.**

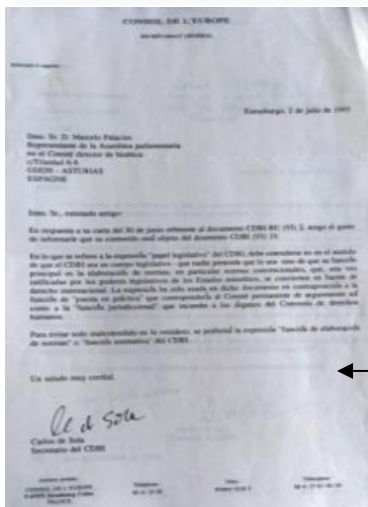
The CDBI sent its Report of June 7, 1996, without the title *Bioethics Convention*, to the Parliamentary Assembly added to and based on

Doc. 7622. It had dire consequences, which **must be considered** for the recovery of the title *Bioethics Convention*.

The first 5 paragraphs of the cited **List** are **here** commented.
(We will analyse **the very important rest** in CHAPTER II)

FIRST CONSIDERATION

The CDBI **seriously exceeded its powers by eliminating**, from an international document neither more nor less, the **title**, here *Bioethics Convention*, which it replaced with "Convention on Human Rights and Biomedicine"; and it did so **without having legislative, normative or regulatory power**, since by Opinion No. 184 (of February 2, 1995, Parliamentary Assembly, 6th Session), the Assembly recommends that the Committee of Ministers carefully **examine the TEXT** of the draft *Convention on Bioethics* (Reporter: Marcelo Palacios)



cios) transmitted to the Assembly and reproduced in the doc. 7124, and amend it as follows before opening it for signature: "...and later it repeats again that **only the TEXT** will be examined or revised, since "The Assembly also recommends to the Committee of Ministers: **transmit the final revised TEXT**, in a final report (Opinion), **to the Parliamentary Assembly**, unless the Committee of Ministers accepts the changes proposed by the Assem-

bly»

CDBI did not have legislative, normative or regulatory power, its General Secretary confirms to me this evidence in writing of July 2, 1993, when I reprimanded him with my letter of June 30 for powers that Committee did not have.

The Committee of Ministers decides to send to the CDBI Opinion 184 *on the preparation of the Bioethics Convention*, in which the Assembly requests -and I must insist

on this repeated- that ONLY THE TEXT be reviewed, **not to annul the TITLE.**

But in its Report of June 7, 1996, CDBI **eliminated the title *Bioethics Convention*, and did so with arguments that even cause embarrassment**, because, following the agreements of its Drafting Committee (CO-RED 04/24/1996):

1) The CDBI assured that the term “**bioethics**” had a *pejorative connotation* in certain States, German-speaking countries:

“The Drafting Committee of the CDBI observed that the term *bioethics*, although widely used in English-speaking countries and France, “had a pejorative connotation in certain States”, and “was noted that ***the Convention was referred to as the Bioethics Convention and was likely to remain so***”; however, the Working Group considered it preferable to maintain the Convention title for the protection of human rights and the dignity of the human being with respect to the Applications of Biology and Medicine. Accordingly, **it recommended that the CDBI delete the short title. And the CDBI deleted it.**

NOTES:

—That is, “the term bioethics was widely used in English speaking countries and in France, and the CDBI (its secretary was Spanish, and the former president of the Committee present there, too!)

omitted to refer to Spanish-speaking countries, where Spanish is the native language spoken by almost 500 million people, the fourth most spoken in the world (the second most spoken in the world after Mandarin Chinese) almost double that of French, and where *bioethics* is widespread, as well as knowledge of the *Bioethics Convention*.

—Besides, resorting to dictionaries, regarding the adjective *pejorative* we find: “Said of a word or a mode of expression. Which **indicates an unfavourable idea**”. And as synonyms *pejorative* is: “**derogatory, contemptuous, offensive.**” Without wishing to overload it, it seems negative enough to me that the CO-RED uses the term *bioethics* in its version of *an unfavourable idea* (with my disagreement), I leave the other synonyms to that Drafting Committee and the CDBI to which it belonged and advised.

—“*The Convention was referred to as the Bioethics Convention and was likely to remain so*”, and yet **it is annulled**.

Let's also see. At that time, the 36 member states of the Council of Europe were represented in the CDBI, and it **demonstrated against the term *bioethics* and eliminated the title *Bioethics Convention***. On the other hand, **135 countries of the IPU**, Interparliamentary Union, meeting in Madrid at its 73rd Conference in March-April 1995 where were all (36) countries of the Council of Europe, **approved by consensus** one of the two major topics on the agenda, the **Resolution *Bioethics, an international challenge for the protection of human rights***, of which I was co-editor and speaker.

In short, the **CDBI went against the world, dragged the Council of Europe with it and deprived it of the rank** on the global Bioethics stage that corresponds to it.

2) The CDBI further argued that "the term *bioethics* does **not adequately emphasize** the legal (as distinct from ethical) nature of the contents of the text".

NOTES: a), it is a unusual, blatant contradiction that the CDBI would allege that, **while in its Doc. 7124 on the elaboration of a European Bioethics Convention**, Explanatory memorandum, paragraph 19, 1994) **it assures** that "the term bioethics is used as a title supplementary **to give a succinct and convenient indication of the objectives** of the text; and b), if the CDBI **is contrary** to the term Bioethics and **if eliminates** the title *Bioethics Convention*, for ethical and objective reasons **the CDBI would have no reason to exist**, and should have disappeared immediately, since its emasculating attitude was incompatible with it, it can be called the "Steering Committee of anything" but not of Bioethics; and the National Committees on Bioethics of the countries that held this opinion and supported the withdrawal of the title Bioethics Convention, etc., had to be annulled.

But no, as we will see later (Chapter II, **List** of CDBI Report of June 7, 96, "paragraph 11 The Secretary General intended to encourage better coordination of activities in the **fields of bioethics** and health. And in **Listing** "paragraph 14... The CDBI.... He asked the Committee of Ministers for budgetary authorization of Article 2119 (**Bioethics**) of the General Budget for the proper organization of the **3rd Bioethics Symposium** from December 15 to 18, 1996 *on medically assisted procreation and protection of the human embryo*".

CDBI **disdain** the term *Bioethics*, **remove** the title *Bioethics Convention*, **still exists** and then **organize important Bioethics activities!** ¡Scandalous!

3) and the CDBI affirmed that *the title* (Bioethics Convention) *was relatively long*.

In Doc.7622 (July 16, 1996) supporting the CDBI report of June 7, 1996 on the Convention, III Revision of the provisions. Title and Preamble, section 10., it says “**As the current title is relatively long**, the terms Convention on the Rights of Man and Biomedicine have been added to serve in the future as the title of the Convention. **This new formulation seems acceptable** given that it is **more appropriate than the title Bioethics Convention** used until now.” ¿

NOTE. The CDBI **could have proposed to replace** the title “Convention for the Protection of Human Rights and the Dignity of the Human Being in Relation to the Applications of Biology and Medicine”, *which is the relatively long one*, **with** “Convention on Bioethics, but **did not do it**, and consequently we find that:

- * **the new title** “Convention on the Human Rights and Biomedicine” **is even longer than** the one it replaced “Bioethics Convention”

- * the **CDBI opted for** the current repetitive, redundant double title: “**Convention for the Protection of the Human Rights** and the Dignity of the **Human Being** in Relation to the Applications of **Biology** and **Medicine**. **Convention on the Human Rights** and **Biomedicine**, when **two similar titles were not appropriate to formulate the same thing**, one title or the other was enough.

Aren't there too many repetitions that could have been avoided by keeping the title Bioethics Convention instead of (+)?

¡And it does so in an institution, the Council of Europe, which has adopted a *European Convention for the Protection of Human Rights and Fundamental Freedoms*, known as the

European Convention on Human Rights (ECHR). November 4, 1950 (Rome), in force since 1953!

As for “it seems acceptable”, “it is more appropriate”, etc., supported by those and other value judgments, ignorance of Bioethics and ambiguities as assumptions of argument, the CDBI **destroyed** the title *Bioethics Convention*! Never better said “The mistreated Treaty”

In referred doc. 7622 support of the CDBI report of June 7, 1996 on the modified Convention in which the title *Bioethics Convention* is eliminated in III Review of the provisions, Title of the preamble, section 10., it says: “**The Assembly has not presented any amendment regarding that**”

NOTE: The Parliamentary Assembly limited itself to giving incidentally a document that arrived prepared, without amendments or debate or vote on *the Bioethics Convention* title. It was in the CDBI where this arrangement was previously arranged, violating the rules with total impunity! In that same doc. 7622, **in the comparative study presented by the CDBI** on its Convention proposal and that of doc. 7124, the title *Bioethics Convention* has been eliminated without any amendment and debate.

In **Opinion 198**, approved by the Assembly on September 26, 1996, it is established: “6. Therefore, the Assembly recommends to the Committee of Ministers: 6.11 adopt the draft amended Convention, without referring it again to the CDBI, and open it for signature before the end of the current year, **since a further delay could jeopardize the innovative nature of the TEXT as a model for the national legislator**”;

NOTE: **What endangered the innovative nature of the TEXT as a model for the national legislator was eliminating the title “Bioethics Convention”** With that **the damage had been done with impunity!** because the innovative character of the text and the third distinctive pillar of the Council of Europe was the BIOETHICS CONVENTION.

In the Parliamentary Assembly, and mainly in the Committees of Science and Technology and Health, and Bioethics Subcommittee, a spirit of *bioethical culture* had been forged with its values and conduct that permeated the areas of the Council of Europe and radiated abroad, where the *Bioethics Convention* in development was deliberated, debated in meetings, seminars and conferences for years since 1991.

This **third pillar** of the Council of Europe (along with the European Convention on Human Rights and the European Social Charter), **was not to be a mere Convention** with the reference: **a)**, to human rights, which were already dealt with in its cited European Convention on Human Rights; nor, **b)**, regarding the aspects of biomedicine, which are found in texts for this purpose, codes of ethics, etc. **The only authentic, innovative, symbolic character** should carry the bioethical spirit that **was** already part of the essence of the Council of Europe: the *Bioethics Convention*. **Without this title the Convention was denatured of bioethics, it will remain without bioethical identity in its ethical and legal aspects.**

In short, the Committee of Ministers adopted the definitive Convention without having been debated in the Assembly the elimination of the TITLE *Bioethics Convention*, it was adopted based on a previous decision of the CDBI. Of this fact, in case

there was the slightest doubt, which there is not, in the Summary of the doc. 7622 debated in the Assembly states: “The Assembly congratulates the work carried out by **the Bioethics Steering Committee for many years** which **came to fruition by approving on June 7 the draft Convention** on the Human Rights and Biomedicine.” (Same as Opinion **198.1**: “The adoption by the Bioethics Steering Committee (CDBI) on June 7 of a revised draft Convention is the culmination of **long years** of work”).

NOTES: We will see that in the intricacies of the elimination of the title Bioethics Convention, the Parliamentary Assembly was a passive and mocked actor.

As for **many years, long years**? It is an exaggeration or self-aggrandizement, since **the CDBI was created in 1992** and Report 7124 on the European Convention on Bioethics is from **1994**.

And **what was fruitful** of their labour **is nothing to be proud of**, since it was **destroying the *Bioethics Convention* title** and **harming** and **isolating the Council of Europe** from the international sphere of Bioethics!

SECOND CONSIDERATION

The CDBI clamorously **went against its own acts**:

—**Since 1992**, the CDBI has worked for a Bioethics Convention, **bioethics** being a topic-initiated years ago in its predecessor, the CAHBI, and within the framework of the Parliamentary Assembly. For example, in the documents circulated during the CDBI meeting of 26.11.1992, the document on the Bioethics Convention states that "the texts of the CAHBI reaffirm **the main**

principles and values that should guide all regulations on bioethics".



July 1994, October **1995**, March **1996**

Documents on the *Bioethics Convention*

—The **most incoherent thing** was that the CDBI itself:

a), generated Doc. 7124 *on the elaboration of the Convention on Bioethics*, with the constant contributions of the commissions of Science and Technology, Health and subcommittee on Bioethics through the General Rapporteur of the Parliamentary Assembly for Bioethics (myself), document n° 7124 that CDBI Chairman presented at a press conference in June 1994; and

b), from that own document it **deleted the title** *Convention on Bioethics* in its report of 7 June 1996.

—It is also **inconsequential** that, as already mentioned, in the Explanatory Memorandum to Doc. 7124 *Convention on Bioethics*, paragraph 19, it is stated: "The term *bioethics* **is used** as a supplementary title **to give a succinct and convenient indication of the objectives of the text**", while the report of 7 June of the CDBI on the Convention states that "**the term *bioethics* does not adequately emphasise the legal nature** (apart from ethics) of the contents of the text'. What are we left with?

—**No less incongruous** was the fact that the title "Convention on Bioethics" had been eliminated from the CDBI, the Secretary General stated in the Final Declaration (Report of

June 7, 1996): "**The Convention adopted today is destined to be the common European standard in the field of bioethics**". He adds: "There have been many who have worked to achieve this result. If some names are to be mentioned, special tribute should be paid to the Rapporteur of the Assembly, Mr. Marcelo Palacios, who was the origin of the proposal for a new Convention; the continued work...."

—and **curl** the curl of the contradictory and nonsensical is when in **IV Conclusions 35.** of doc. 7622, July 16, 1996, support of the Convention debated (**the title *Bioethics Convention*** was not debated) in the Parliamentary Assembly on September 26, 1996 with the clear imprint of the CDBI:

I Opinion of the project

"In 3. The draft text is in tune with the thinking behind the Assembly's proposals, although **it has not always respected the text of each of the amendments.**" (NOTE. Mean, the CDBI did and undid what it wanted, disregarding the Assembly!)

II Explanatory memorandum 1. Introduction

"1. In ten years, the Parliamentary Assembly has held a dozen debates on problems related to **bioethics**. Two of them were dedicated to the use of human embryos and fetuses for therapeutic, scientific, industrial and commercial diagnostic purposes...."

"3. The idea of a Bioethics Convention is neither a political whim nor bureaucratic stubbornness. It **responds to a social need** and to the concerns of the public that feels ill-informed, is threatened by scientific discoveries at breakneck speed and has difficulty assessing the consequences."

And in "IV. Conclusions

"34. We would like to pay tribute to all those who, through their contribution and criticisms —sometimes contradictory,

sometimes severe— have enriched the debate and defended the reputation and standards of the Council of Europe. In particular, we remember at this time with gratitude the great contribution of Marcelo Palacios, who was rapporteur and "guiding spirit" of the Assembly for so many years. We deeply regret that he has not been able to carry out this adventure in his role as "intellectual

And it ensures:

"35. We are convinced that THE CONVENTION ON BIOETHICS, **once adopted**, WILL CONSTITUTE THE THIRD MAJOR PILLAR **of the Council of Europe**, together with the European Convention on Human Rights and the Social Charter."

NOTE: How can this paragraph **35**, and the Declaration of the Secretary General of the CDBI: "the Convention approved today is intended to be the common **European standard in the area of bioethics**" **be affirmed**, and then delete the title *Convention on Bioethics*? What kind of nonsenses is all this?

—and it **is at least striking** that the CDBI has eliminated the title *Bioethics Convention*, when **Recommendation 1160** (1991) *on the elaboration of a Bioethics Convention* is included in the Preamble of the current Convention.

If everything was so recognized, and the Convention should be titled Bioethics, **why did the CDBI act like this?**

In short, it is objectified that the TITLE *Convention on Bioethics* WAS HANDLED FOR YEARS UNTIL in its Report of June 7, 1996 the CDBI **removed** the Title "Bioethics Convention". ("By 24 votes in favour, 8 against and no abstentions, the Committee decided to replace the abbreviated title "Bioethics Convention " with the title "Convention on Human Rights and Biomedicine, proposed **by a delegation**" (Inform CDBI 4-

07/06/1996). The sending of this document to the Assembly was a **serious mistake** (and it is not justified as the CDBI wanted to embellish this outrage!).

And even greater mistake was the approval of that unusual elimination of the title in the Parliamentary Assembly, by undemocratic means, without amending it, debating it and voting on it expressly on 26 September 1996 (30th and 31st Sessions), embodied in **Opinion 198**, which could have caused great discredit to the Council of Europe.

In that plenary, 3 Opinions were presented, one by Mr. Daniel, No. 7664, which cites the French Bioethics Law of 1994, and two by Mr. Schwimmer, No. 7622 and No. 7654, with 8 amendments outside the title of the *Bioethics Convention*. With these eight amendments, up to fifteen amendments and one sub-amendment were tabled, by Mr About, Mr Figel, Mr Kaspereit, Mr Haack and Mrs Terborg, none of which referred to the title "Bioethics Convention". They could not do so because the title Convention on Bioethics had disappeared, and the Convention mutilated in that title passed to the Committee of Ministers in this undemocratic way.

Those who eliminated this Title recognized "that **this designation of the Bioethics Convention would endure**" (CDBI report of June 4-7, 1996) as has happened to this day and will continue to happen, **but even so they decided to eliminate it.**

Two questions remain to be clarified:

1. Why did it **take the CDBI almost a year and a half** (2.2. 95-7.6.96) to comply with Opinion 184 that resulted from **my document 7210** on *the elaboration of a Bioethics Con-*

vention debated in the Parliamentary Assembly on February 2, 1995?

2. What **real interest** was there in removing the title *Convention on Bioethics*?

Did it have to do with the HEARING convened by the then Secretary General, Mrs. Catherine Lalumiere, in February 1, 1993, at the request of several Committee Chairman and myself, in which she made clear the relevance of the work on bioethical issues of the Parliamentary Assembly, which should not be undeserved, and the CDBI stick to its technical advisory role?

Did the winks of the Secretary of the CDBI influence the understanding of the Convention as an exclusively legal, not also a bioethical instrument, not knowing that the legal is (or can be) part of the bioethical? In the article (voice) “Convention on human rights and biomedicine (legal)” by Carlos de Sola Llera, which he signs as Head of the Health and Bioethics Service of the Council of Europe and as Secretary of the Bioethics Steering Committee, the CDBI, during the negotiation of the Convention, **the author does not cite the term *bioethics*** at any time except when naming his Editorial Group (CO-RED), **nor does he make the slightest reference to the bioethical history of the Convention in the Parliamentary Assembly** (see *ENCYCLOPEDIA of BIOLAW and BIOETHICS*, directed by Carlos María Romeo Casabona, Chair of Law and Human Genome. University of Deusto, year 2012).

Or does Doc. 7622 *Draft Convention on Human Rights and Biomedicine* give us the clue? “II. Explanatory memorandum 2. On the revised draft Convention 7. “We are aware of the difficulties of reconciling the different, and even contradictory, points of view of a wide range of countries with different cultures, histories and scientific traditions, especially now that **the membership**

of the CDBI has increased from twenty-seven states that in 1993 to thirty-nine in 1996 when Russia joined the committee. Furthermore, by its very nature, the topic required a multidisciplinary approach; hence the very varied composition of the Steering Committee. Dialogue was not always easy between ethicists, legal experts and members of the medical profession. Despite these arguments, the **Science and Technology Commission has regretted on numerous occasions the delay** in the completion of the project. Indeed, after the publication of the first draft and the two subsequent debates in the Assembly, the public's eyes were on the Council of Europe, and deadlock at this stage could have been considered a **political failure**.

NOTE: These justifications are not acceptable, **it seems that the CDBI** (that is, the Council of Europe), renounced its **bio-ethical experience and prestige and the Bioethics Convention** title with the entry of new countries, as if a **steam-roller** was taking it ahead, forgetting, for example, that the majority of those countries, 135, members of the Interparliamentary Union (IPU), a year before in Madrid had approved by consensus a *Resolution on Bioethics for protection of Human rights*.

That is, the 12 incoming states in three years **have abducted** the previous 27, turning them against the term *Bioethics* and the title *Bioethics Convention*, proof of this is that except one, all of them together voted in favour of withdrawing that title, see Report 7.6.96 “page 132 Final vote, by de CDBI on the draft Convention on Human Rights and Biomedicine in its entirety, the following **31 States** voted in favour of the Draft Convention: Albania, Austria, Republic Czech, Denmark, Estonia, Finland, France, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Luxemburg, Malta, Netherlands, Norway, Poland,

Portugal, Romania, San Marino, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, Ukraine and United Kingdom. Vote against: Germany; Abstentions: Belgium and Cyprus”

And **the main political failure was not the CDBI's delay** in finishing the Convention project, **the flagrant failure was removing** the *Bioethics Convention* title without democratic guarantees of debate in the Assembly.

It was stated that in the Final Report of the CDBI of June 4-7, 1996 the title *Bioethics Convention*, which had remained since 1991 in the various documents for this purpose of the Council of Europe, **was eliminated**.

It was equally manifest that the arguments (¿) of the CDBI and its Working Group on the rejection of the term "bioethics" and the title "Convention on Bioethics" were either value judgments or inconsistent and contradictory statements.

What was clear is that:

1) Recommendation 1160 (1991) *on the elaboration of a Bioethics Convention* **is included in the Preamble** to the current Convention. Just the one that was deleted.

2) In June 1994 the CDBI presented at a press conference the *Convention on Bioethics*, Doc. 7124, and in the Explanatory Memorandum, paragraph 19. it stated: "The term 'bioethics' is used in the Supplementary **title to give a succinct and appropriate indication of the purposes of the text.**" A year later the CDBI removes that Title because "the term "bioethics" does not adequately emphasize the legal (apart from ethical) nature of the stipulations in the text". Yesterday one thing, today the opposite.

3) The Drafting Committee of the CDBI (CO-RED 24-26/04/1996) noted that "the term *bioethics*, although **widely used** in English-speaking countries and in France, *had a*

pejorative connotation in certain States, and it **recommended that the CDBI delete the abbreviated title "Bioethics Convention"**. And the CDBI did so.

NOTE. And in Spanish-speaking countries also, native language it is spoken for almost 500 million people, the 6.3 % of the world population,

4) The Declaration of the Secretary General in the Final Report of 7 June 1996 states that "the Convention adopted today is intended **to be the common European standard in the field of bioethics**". But the Title *Convention on Bioethics* was eliminated. It causes painful perplexity.

If, as stated in 1996 in the CDBI and its environment, "the title *Bioethics Convention* was widely used and it was likely that it would continue to do so", if "[the Convention approved today is destined to be the common European standard in the area of bioethics](#)", and if "we are convinced that the Convention on Bioethics, once adopted, It will constitute the third great pillar of the Council of Europe, together with the European Convention on Human Rights and the Social Charter", **arbitrarily removing the title *Bioethics Convention* was going against the Council of Europe itself**, the CDBI ignored the present and the future, dragged the Council of Europe against what was already accepted almost everywhere in the world, and deprived it of the international rank in Bioethics that it deserved (and deserves).

CHAPTER II

THIRD CONSIDERATION

As mentioned above, finished its 11th meeting in Strasbourg (France) on June 4-7, 1996, the Bioethics Steering Committee (CDBI) presented to the Committee of Ministers the **List of topics discussed and decisions taken**.

Demanding the RESTITUTION of the title *Convention of Bioethics*, in my correspondence with the Secretary General of the Council of Europe, the Director General of Human Rights, the President and the Vice President of the CDBIO (see Chapter III, Correspondence), I considered that the arguments referred to in paragraphs 1. to 5 of said **List** (Chapter I) **would be sufficient** to support my request presenting an amendment by the Council of Europe itself by the procedures established by Article 32 of the Convention”.

There was **no response**, or my proposal was **not considered, or** my hope was **not understood**.

In this situation **other arguments** —and honestly, I would have liked not to have to resort to them— **come to reinforce my request**, so that:

A) the following paragraphs —some of them of a "prosaic" nature, especially budgetary— are added to the cited paragraphs of the LIST of CDBI (adopting contradictory actions that cause astonishment: disqualifying the term *bioethics* and eliminating the title *Bioethics Convention*, and in the same report of June 7, 1996, proposing the *promotion of bioethics*, requesting resources appropriate in the *Bioethics budgets*, and **prepare the third Bioethics Symposium for six months later!**) due to their special importance for the argument:

“Paragraph 11. The Committee noted that the Secretary General intended to encourage **better coordination of activities in the bioethics and health fields.**

“Paragraphs 14. The CDBI.... requested the Committee of Minister to authorize the necessary adjustment within Article 2119 (**Bioethics**) of Head II of the General Budget **to ensure proper organisation of the bioethics Symposium from 15 to 18 December 1996** on medically assisted procreation and protection of the human embryo

NOTE. The CDBI says this and the opposite with total lightness. Among other "niceties" argued by its Drafting Committee and assumed by the CDBI to eliminate the title Bioethics Convention, it states that "the term *bioethics* does not adequately highlight the legal nature (different from ethics) of the content of the text", and now (**List** paragraph 11.) “encourage better coordination of activities in the **bioethics** and health fields”, and (**List** paragraph 14.) asks the “necessary adjustment within Article 2119 (**Bioethics**) of Head II of the General Budget”.

It is observed, with astonishment, that the term *Bioethics* is used by the CDBI for its purposes without the slightest shame, after considering it “inappropriate”, and having annulled the title *Bioethics Convention*.

And for greater fickleness the **List of topics discussed and decisions taken** presented to the Committee of Ministers at its 11th meeting in Strasbourg on June 4-7, 1996, the CDBI Inform continue this way: **“Decisions to be taken:**

“Deputies are invited to consider, with a view to their adoption, the following decisions of the project:

vi. The Deputies asked the Secretary General to make the necessary adjustment within the budgetary package to Article 2119 (Bioethics) of Head II of the General Budget to ensure proper organisation of the Symposium on Bioethics.

APENDIX II

4. Preparation of the **3rd. Symposium on Bioethics**”

NOTE. It is an inadmissible action that **at the same meeting** of June 4-7, 1996, the CDBI **disqualified the term *bioethics*** and **eliminated the title Bioethics Convention and organized a Symposium on Bioethics**, which would be held in December 1996 and for which **a better budget allocation was requested** for **bioethics** activities.

And, **B**), with the approval by the CDBI at the June 1996 meeting of the draft of the Convention on Human Rights and Biomedicine that is in force today, and **from then on** events occur that would seem incomprehensible, especially in an Institution like the Council of Europe, and that justify the

FOURTH CONSIDERATION

—After disqualifying the neologism *bioethics*, and eliminating the title *Bioethics Convention* in 1996, the CDBI or Bioethics Steering Committee, for coherence and ethics had to disappear, or be called something other than bioethical. But he did not do it, he continued as if nothing had happened, developing **bioethical activities** and receiving funding from the Bioethics item in the budgets of the Council of Europe.

—Until in 2012, by resolution of the Committee of Ministers, the CDBI was replaced by the DH-BIO or Bioethics Committee to interpret the Convention approved in 1997, with tasks also on the protection of human rights in the field of biomedicine, and dependent on the CDDH.

All of the above **seems incredible**, but it is true, unfortunate and regrettable, and the Council of Europe cannot tolerate such an unjust and incongruous situation any longer; even after the past years, it should take the necessary measures to restore the title Bioethics Convention.

Because luckily *the opinion* of the Council of Europe on *Bioethics* *has changed* in recent years and today states:

Bioethical issues concern us all, as patients, professionals, but also as members of a society facing new choices as a result of scientific progress

The Convention on Human Rights and Biomedicine is the first legally binding international instrument in the field of bioethics.

(Portal of the Council of Europe. General Directorate of Human Rights and Rule of Law; **or** www.coe.int/bioethics)

what I defended during years in the Commission on Science and Technology, the Subcommittee on Bioethics, and as Proponent of the Convention on Bioethics and General Speaker in the Parliamentary Assembly (caught in Report No. 7622 (Mr. Plattner) IV. Conclusions. Debate in the Assembly in September 1996 and did not considerate: “**35. We are convinced that the Bioethics Convention**, once adopted, it will constitute the third great pillar of the Council of Europe, together with the European Convention on Human Rights and the Social Charter”; and in the Declaration of the Secretary General of June 7, 1996: “The Convention that we adopt today is destined to be the common European standard in the area of bioethics”.

CHAPTER III

RESTITUTION AND UPDATE OF THE TITLE CONVENTION ON BIOETHICS

The Convention is not a set of rigid and invariable postulates, and by itself it proposes its updating when it is deemed appropriate.

Previous confirmations of Chapters I and above all II should be sufficient and conclusive arguments to RESTORE THE TITLE *Convention on Bioethics* that was removed by the CDBI in its report of June 7, 1996 and annulled to the debate in the Parliamentary Assembly on September 26, 1996.

I insist, it is not my intention to polemicize with the Council of Europe, an organization for which I have great respect and gratitude. But for this consideration and respect, **I believe that the Council of Europe should take the initiative (article 32 of the Convention)** and present the corresponding amendment to recover the title *Bioethics Convention*.

With the aim of contributing to restoring the lacklustre prestige of the Council of Europe as a pioneer of Bioethics in the world, as said in the Preamble, **I addressed the General Secretariat** of the Council of Europe, and through it to other instances of the institution (see Preamble and Chapter IV) **demanding the RESTITUTION** of the title *Bioethics Convention*, believing it to be fair, and taking into account the undoubted implementation of Bioethics in all world regions, in which **the trajectory of the Council of Europe cannot be diluted and much less ignored**, as I have asked and argued in this book.

1) Fundamentally because **since 1976** the Council of Europe was a **pioneer** in the ethical-legal approach to bioethical problems, and in the creation of structures and preparation of documents related to bioethical matters.

2) For the **anomalous actions**, circumstances and decisions that led to its elimination in the CDBI meetings of June 4 to 7, 1996 and in the session of the Parliamentary Assembly of September 26, 1996 (which I requested in writing to be carefully and objectively reviewed)

The CDBI **could issue a report** to a Document providing changes and send it to the Assembly for its democratic evaluation, **but it could not supplant the functions of the Parliamentary Assembly** by considering that Document or a modified part of it definitive (in this case the elimination of the title Bioethics Convention) without the required debate, as has happened in this case.

In a letter of February 6, 2023, in response to my letter of January 31, 2023 the General Director of Human Rights Mr. Giakoupopoulos writes to me: *“I would like to clarify that the origin of the change in the title of the Convention **is not to be found at the level of the Parliamentary Assembly but in the work of the Steering Committee on Bioethics** which was responsible for the development of the Convention... and **in its plenary session of June 4-7 decided to replace the reduced title Bioethics Convention with the title “Convention on Human Rights and Biomedicine”....***

NOTE: These words are defining. In case it was not, and with the arguments presented it was, any doubt was now cleared up: **the Parliamentary Assembly did not intervene in the**

elimination of the title *Bioethics Convention*, a Committee, the CDBI, had been in charge of doing so! The CDBI could issue a report providing modifications to a Document and send it to the Parliamentary Assembly for its democratic evaluation, but it could not supplant the functions of the Parliamentary Assembly by considering that modified Document or a part of it definitive (in this case the elimination of the title *Bioethics Convention*) without the required debate, but it did, as has happened in this case. Unheard!

The question is, what purpose is the Parliamentary Assembly then if it receives documents with the amendments decided by a committee (*ad hoc*, after all) and it gets them right and accepts them as good?

3) Because **Bioethical Culture** is a fact throughout the world, and to object to the terms “Bioethics” and “Bioethics Convention”, as was done years ago in the CDBI, would be to continue rowing against the current, **laughable, something which only harms the Council of Europe**, given the undoubted international implementation of Bioethics in all world regions.

It must remember that SINCE 1991 (Recommendation 1100 *on the elaboration of a Bioethics Convention*, as stated in the Preamble of the current Convention), **in all documents** of the Council of Europe **the title *Bioethics Convention* or European Convention on Bioethics was maintained, UNTIL 7 June 1996** the CDBI decided to remove it, for clearly irregular ways.

The CDBI Report of June 7, 1996 should have been limited to the TEXT of the Bioethics Convention; **it had no legitimacy to change its TITLE; nor could that legitimacy** lie solely in the incorporation of this CDBI report into the doc. 7622 of 7/16/96

discussed on September 26 in the Assembly; **legitimacy should have been unequivocally in amending and debating** this new Title “Convention on Human Rights and Biomedicine”, and whether it was appropriate to adopt it and eliminate the “Bioethics Convention”. But it was not done, supplanting the CDBI a power that only corresponded to the Parliamentary Assembly, invalidating what was approved regarding said Title over the years and misleading the Committee of Ministers.

What was argued by the CDBI Working Group and accepted by the CDBI in its Report of June 7, 1996 to eliminate the Title “Bioethics Convention” **was an accumulation of nonsense**. So, **I have to repeat it** as many times as necessary.

For the RESTITUTION of the title *Bioethics Convention*, the Council of Europe has mechanisms to do this, and I requested it. Two articles of the current Convention may be applicable:

A) The **Article 32**. *Amendments to the Convention*, which establishes:

“1. The tasks assigned to "the Committee" in the present article and in Article 29 shall be carried out by the Steering Committee on Bioethics (CDBI), **or by any other Committee** designated to do so by the Committee of Ministers.

5. Any proposal for an **amendment to this Convention** and any proposal for a Protocol or an amendment to a Protocol **submitted** by a Party, **by the Committee, or by the Committee of Ministers**, shall be communicated to the Secretary General of the Council of Europe, and he shall send it to the Member States of the Council of Europe, to the European Community, to the Signatories, to the Parties and to the States invited to sign this Convention in accordance with the provisions of Article 33 and to all

other States invited to accede to it, in accordance with the provisions of article 34”.

6 The Committee shall examine the proposal not earlier than two months after it has been forwarded by the Secretary General in accordance with paragraph 5. The Committee shall submit the text adopted by a two-thirds majority of the votes cast to the Committee of Ministers for approval. After its approval, this text shall be forwarded to the Parties for ratification, acceptance or approval.

In response of January 1, 2022 to my letter to Secretary General, the Director General of Human rights and Rule of law (Council of Europe) Mr. Christos Giakoumopoulos he clarifies that *“Any change in the title of a Convention after its adoption can only be made by means of an amendment to the instrument itself. This requires the adoption of a Modifying Protocol or, at least, the written or tacit acceptance of all Parties. **For the Convention on Human Rights and Biomedicine, article 32 on amendments explains the procedure** that can only be initiated by a Party, the responsible Committee or the Committee of Ministers.*

*“I hope that these elements provide **clarification** on the context and conditions under which a request to change the title of the Convention could be considered”.*

NOTE. He corroborates my arguments, and **that means that the Council of Europe has its own structures to present amendments** to the Convention (the aforementioned Committee —currently it would be the **CDBIO**—, which in my opinion would be the most practical and fastest) or the Committee of Ministers.

In short, the Council of Europe **now has the floor to present the corresponding amendment.**

Another possibility of amending the Convention according to itself is through the **Article 38. Notifications**: “The Secretary General shall notify the Member States of the Council of Europe, the European Communities, any Signatory, any Party and any other State that has been invited to access this Agreement, of: **g/ any other act, notification or communication related to this Convention**” NOTE. This Article 38. **g is imperative**. But it is more difficult to apply, as all the Member States enter the fray, etc.

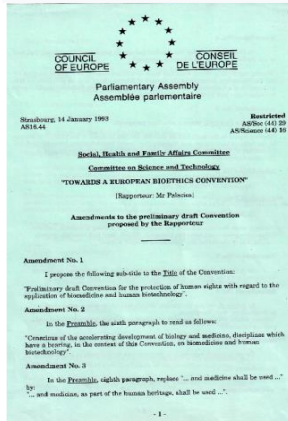
IT'S TIME TO RECTIFY

IT'S TIME TO PUT THIS ISSUE IN ORDER.

A quarter of a century has passed since the title *Bioethics Convention* was eliminated from the current Convention, more than enough time to confirm that *Bioethics* has taken root throughout the world, that we can speak of an authentic *Bioethical Culture* or of the *Century of Bioethics*, and that, therefore, the inappropriate reservations that at the time (7.6.1996 and 19.6.96) led to the rejection of both the term “bioethics” and the title “Bioethics Convention” have been shown to be unjustified.

Let us objectively recognize that the current double title is redundant: “Convention for the Protection of **Human Rights** and the Dignity of the Human Being with **respect** to the applications of **Biology** and **Medicine**. Convention on **Human Rights** and **Biomedicine**”.

Also, the first part is unnecessary, given that the **European Convention for the protection of Human Rights** of the Council of Europe already extends to part of these **respects**.



In January 1993, through my Commissions, I proposed an amendment with the current title *Convention for the Protection of Human Rights in Relation to the Applications of Human Biomedicine and Biotechnology*.

Today it would seem right to eliminate it, and reincorporate de title *Bioethics Convention* in its place.

It would **NOT be redundant NOR** would it be **unnecessarily long** if “Convention for the Protection of Human Rights and the Dignity of the Human Being with Respect to the Applications of Biology and Medicine” **is changed to** “Convention on Human Rights and Biomedicine.”

With this logical change, **the definitive title**, neither redundant nor long, and I agree, **would be:**

**Bioethics Convention.
Convention on Human Rights
and Biomedicine.
Council of Europe**

It should not be forgotten that a Treaty, Agreement or Convention is binding, its contents will be in the top of the legislative pyramid of the States Part.

Consequently, the incorporation of the title *Bioethics Convention* to the current Convention on Human Rights and Biomedicine would mean an international consolidation of term *Bioethics* in teaching, legislation or labour, thanks to the decisive historical commitment of the Council of Europe.

CORRESPONDENCE TO RESTORE
CORRESPONDENCE EXCHANGE

—December 20, **2022** by email and via WeTransfer to Ms. H.E. Ms. Marija Pejčinović Burić, Secretary General of the Council of Europe.

On that same date, an email was sent from the SIBI informing Mr. Antonio Gutiérrez Limones, President of the Spanish Delegation of the Parliamentary Assembly (with a copy to Ms. María Teresa Gómez-Bernardo, Secretary of the Spanish Delegation) about the sending of the letter and the documentation to the Secretary General of the Council of Europe. The President **did not respond**.

—December 21, **2022** Email is received confirming receipt of the letter and information addressed to the Secretary General of the Council of Europe.

—January 12, **2023** Letter is received from the Director General of Human Rights and Rule of Law of the Council of Europe, Mr. Christos Giakoumopoulos, in response to the initial letter addressed to the Secretary General.

—January 17, **2023** Response to Mr. Giakoumopoulos.

—January 26, **2023** Response from Mr. Giakoumopoulos

—January 31, **2023** Response from SIBI to the General Director.

—February 6, **2023** Response received from Mr. General Director

—February 13, **2023** Response from SIBI to Mr. General Director.

- March 24, **2023** another letter from SIBI to the General Director.
- May 3, **2023** Letter to the General Secretary Mrs. H.E. Ms. Marija Pejčinović Burić **No response**
- September 18, **2023** A letter is sent to the General Secretary **No response**
- September 18, 2023 A letter is sent to the President of the CDBIO Prof. Siobhan O'Sullivan and to Vice President Prof. Tomáš Doležal. **No response**
- September 27, **2024** Letter to the General Secretary Mr. H.E. Mr. Alain Berset.

* * *

SUBJECT: Communication (personal) requesting the RESTITUTION of the original Title of the (European) Convention on Bioethics by the current "Convention for the protection of human rights and the dignity of the human being with respect to the applications of biology and medicine. Convention on Rights Humans and Biomedicine".

Excellency Mrs. MARIJA PEJČINOVIĆ BURIĆ
Secretary General of the Council of Europe
Avenue de l'Europe F-67075
Strasbourg FRANCE Gijón (SPAIN), December 20th, **2022**

Excellency:
My name is Marcelo Palacios, I am a specialist doctor, President of the Scientific Committee of the International Society of Bioethics (SIBI), former deputy, former member of the Spanish Delegation to the Parliamentary Assembly of the Council of Europe (for 10 years, from April 1986 to May 1996) and proponent and rapporteur of the development of the Bioethics Convention (from 1988 to 1996). From 1990 to

1996 I was General Rapporteur for Bioethics representing the Parliamentary Assembly, and from 1991 to 1996 President of the Bioethics Subcommittee. In 1997 I was awarded the European Medal of Merit in recognition of my dedication to the Parliamentary Assembly of the Council of Europe, and the Honorary Association to the Parliamentary Assembly for services rendered to the European Cause.

I present to you, a (personal) REQUEST FOR RESTITUTION of the original Title of the Bioethics Convention to the current “Convention for the Protection of Human Rights and the Dignity of the Human Being in relation to the Applications of Biology and Medicine. Convention on human rights and biomedicine.

The recovery/restitution of the (European) Bioethics Convention Title is fair, as argued and shown in the documentation that I attach, due to the peculiar actions that took place at the meeting of June 4-7, 1996 of the CDBI (Bioethics Steering Committee) for the elimination of that Title in the Final Report, and, subsequently, in the session of the Parliamentary Assembly of September 26, 1996 in which said report was discussed in Doc.7622, and it was adopted with that Title eliminated, in my opinion without due parliamentary guarantees, facts that I ask you to review objectively.

We read on Wikipedia: “The objective of this agreement is to prevent the abuse of technological development with regard to biomedicine and to protect human dignity and human rights. It aims to serve as a base infrastructure for the **development of bioethics in Europe**, always maintaining respect for human dignity), and removing the Title Bioethics Convention went against the Council of Europe itself.

I remain at your disposal, with a cordial greeting
Marcelo Palacios

(An extensive argumentative report is attached, widely reproduced in this book, and largely exposed, to reduce repetitions, in my letter to the President (and Vice-president) of the CDBIO of September 2023)

11.1.2023

Response from

Mr. Christos Giakoumopoulos
Director General of Human Rights and
Rule of Law of the Council of Europe.

Dear Dr. Palacios

I wish to acknowledge receipt and to thank you for your letter of 20 December addressed to Ms Marija Pejcinovic Buric, Secretary General of the Council of Europe, requesting the “restitution of the original title of the (European) Convention on Bioethics to the current “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”.

Your responsibilities in the PACE for and during the development of the Convention were particularly important as was your engagement in this work and for the promotion of bioethics in Spain and in Europe in general.

As pointed out in the documents that you sent in support of your request, **the text** of the draft Convention **as well as its title** were the subject of important discussions involving the relevant bodies of the Council of Europe. The final decision and adoption of the Convention, as for any Council of Europe legal instrument, was taken by the Committee of Ministers, taking into account the different views expressed on the text, **including from the** PACE.

Any change to the title of a Convention after its adoption can only be done via an amendment to the instrument itself. This requires the adoption of an Amending Protocol or, at least, the written or tacit acceptance of all Parties. For the Convention on Human Rights and

Biomedicine, Article 32 on amendments explains the procedure which can only be initiated by a Party, the Committee in charge or the Committee of Ministers. Furthermore, since the protocols to the Convention on human rights and biomedicine take the title or an abbreviation of the title of the Convention in theirs, any change to the title of the Convention would require changing also the title of the additional Protocols (Note: Not necessarily, that would be applicable to the new Protocols, not to the existing ones)

When it comes to the term “European”, this would not be in line which has moved to name new conventions as “Council of Europe with recent CoE practice conventions”. (Note from me: The term “European” it was applied from the beginning by the CDBI, not by me, for example in Doc. 7124 *on the elaboration of a European Bioethics Convention*).

Finally, I wish to point out that recent changes have been made in this field of activities of the Council of Europe to emphasize the human rights dimension of the work, including in the title of the Committee, which is now Steering Committee for Human Rights in the Fields of Biomedicine and Health (CDBIO).

I hope that those elements will provide clarifications on the context and conditions under which a request to change the title of the Convention could be considered”.

NOTE from me: In that aspect it fully coincides with my writing. But without reference to the General Secretary, by his own decision or by the relevant Commission or the Ministerial committee, carrying out the initiative for an amendment.

My Response to Mr. Christos Giakoumopoulos
Director General
Gijón (Spain), 19 January 2023

Dear Mr. Giakoumopoulos

I thank you for your reply to my letter addressed to H.E. Ms. Marija Pejčinović Burić, Secretary General of the Council of Europe requesting the Restitution of the original title of the Convention on Bioethics to the current "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".

I agree with your explanations, with an important exception: you have not taken into account the decisive proven facts of my arguments, namely that the change of the title and the deletion of *Convention on Bioethics* in PACE seance of September 1996 was done without amendment, debate and vote, and subsequently the Committee of Ministers approved the *Avis* **198** on the Convention originated from an act without parliamentary and democratic legitimacy as for the title, which jeopardised the prestige of Council of Europe and PACE.

This **serious irregularity** is not just my personal opinion, **it is reliably proven** by the facts and corroborated in the documents I sent to Miss Secretary General, and I am not going to repeat here.

Although you say that "the Convention and its title have been the subject of important discussions in the relevant Council of Europe bodies" it did not guarantee the essential, because the correct decisions were not taken, and although it is uncomfortable for me to try on proving what is obvious, I feel the duty to insist. In short, Mr. Director General, **and that is what matters**, in the final acts (CDBI June, PACE September, 1996) for the approval of the Convention **a parliamentary error was made, that cannot objectively be denied**. And since there is no doubt that this ruling was committed, **the Council of Europe should be the first interested in correcting it**.

In a constructive mood I consider that there are, at least, two ways to restore the title Bioethics Convention:

1) **One way** is optional, depends on the **institutional and political will** of the Council of Europe and is determined in *Article 32, Amendments to the Convention* to which you refer, as I expected, since according to its *paragraphs 1 and 5* **the Council of Europe can do a proposal from amendment**, a Protocol or an amendment to a Protocol -through CDBI (which no longer exists and was replaced by CDBIO) or another Committee constituted for that purpose by the Committee of Ministers, or by the Committee of Ministers- to restore the Bioethics Convention title

2) The second way, let's say that it is mandatory, is established in the current Convention *Article 38. Notifications*:

“The Secretary General of the Council of Europe shall notify the member States of the Council, the European Community, any Signatory, any Party and any other State that has been invited to accede to this Convention, of: *g.* **any other act, notification or communication** related to this Convention”

Thus, the situation, and abounding in the last paragraph of your letter, I believe that the conditions exist to address the restitution of the *Bioethics Convention* title that I propose.

Therefore, I ASK the Secretary General, 1), to ensure that the provisions of Article 38 are **complied with**, as I asked, and the all Parties to the Convention be informed and can decide; and also, 2), to explore **the most appropriate of the options of article 32** previously mentioned to file an amendment, which would simplify and abbreviate the procedure if it is an initiative of the Council of Europe itself.

It's a matter of getting down to work. And **I suggest** that the final title be:

Bioethics Convention.
Convention on Human Rights and Biomedicine

My letter to

H.E. Ms. Marija Pejčinović Burić

Secretary General of the Council of Europe

2023 September

Your Excellency:

In May 2003 I wrote to you regarding my reasoned request for the RESTITUTION of the original title CONVENTION ON BIOETHICS to the existing Convention on Human Rights and Biomedicine. I have received no reply either as to the obligatory compliance required by my request under Article 38 (g) of the Convention, or as to the options for amendments under Article 32.

I remind you that it is at least your obligation as Secretary General to deal with my request under Article 38 g. of the Convention.

I hereby inform you that, as a following step on the same Item I am informing the President and Vice-President of the CDBIO of these circumstances and of my request for the RESTITUTION of the title CONVENTION ON BIOETHICS, as it is only fair and in order to place the Council of Europe on the high international level of Bioethics that it deserves and for which it has worked tirelessly.

Best regards,

Marcelo Palacios

Prof. Siobhan O'Sullivan

Chair of the Steering Committee for Human Rights

in the fields of Biomedicine and Health (CDBIO)

Council of Europe

Strasbourg FRANCE

Gijón (SPAIN) September **2023**

HE. Prof. O'Sullivan

My name is Marcelo Palacios, I am a physician with various

specialties, President of the Scientific Committee of the International Society of Bioethics (SIBI), former Member of Parliament, former member of the Spanish Delegation to the Parliamentary Assembly of the Council of Europe (for 10 years, from April 1986 to May 1996) and proposer and rapporteur for the elaboration of the Convention on Bioethics (from 1988 to 1996). From 1990 to 1996 I was General Rapporteur for Bioethics on behalf of the Parliamentary Assembly, and Chairman of the Subcommittee on Bioethics. In 1997 I was awarded the European Medal Pro Merit in recognition of my dedication to the Parliamentary Assembly of the Council of Europe, and the Honorary Association to the Parliamentary Assembly for services rendered to the European Cause.

I submit to you a **Request** for the restitution of the original title of the (European) Convention on Bioethics to the current "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".

The **recovery/restitution** of the Title "Convention (European) on Bioethics" is justified, as argued and shown in the attached documentation, by the peculiar actions that took place at the meeting of 4-7 June 1996 of the CDBI (Steering Committee on Bioethics) for the elimination of that Title in the Final Report, and subsequently at the session of the Parliamentary Assembly of 26 September 1996 in which that report was dealt with in Doc.7622, and adopted without the necessary parliamentary guarantees, facts that I ask you to review objectively.

In December 2022 I went to the H.E Ms. Secretary General of the Council of Europe, H.E. Ms. Marija Pejčinović Burić on the basis of articles 32 and 38 of the existing Convention for the Protection of Human Rights under the Application of Biomedicine, Convention on Human Rights and Biomedicine of the Council of Europe formally calling for the RESTITUTION of the original title BIOETHICS CONVENTION, eliminated in its day in an evidently illegal way.

After an epistolary exchange with General Director of Human Rights, Mr. Christos Giakoumopoulos has failed (the Secretary General) to show me documentarily that the elimination of the Bioethics Convention Title was done legally (and since May 2023 **I have no answer**).

On the contrary, as accredited in the minutes of the PARLIAMENTARY ASSEMBLY OF THE COUNCIL OF EUROPE 26 September 1996 REPORT *giving an opinion on the draft 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* (Doc.7622 Rapporteur: Mr Plattner, Switzerland, Socialist Group: 3. Examination of the provisions TITLE and Preamble. “**10. The Assembly did not put forward any amendments on this aspect**”

(This statement should already be enough to show that the TITLE *Convention on Bioethics* was removed without the approval of the Assembly and it has to be restored!)

—the Acts of the Parliamentary Assembly of September 26, 1996, and with the Convention and the **Comparative study** attached to it for debate at that session, it is evident that NO amendment was presented and therefore the elimination of the title CONVENTION OF BIOETHICS was NOT discussed, and with this change caused by an illegality, at the initiative of the CDBI in its report of June 5-7, 1996 was presented to the Committee of Ministers.

It demonstrates, it should be beyond any doubt, that the elimination of the title *Bioethics Convention* was not done in compliance with the obligatory procedures and consequently that *Bioethics Convention* title must be restored by the mechanisms that the Convention itself establishes in its articles 32 or 38, as I will continue to claim and I hope that the Council of Europe will attend. Only then will this unfair (illegal) situation be clarified and corrected.

The fact is very serious. Huge damage has been done to the Council of Europe (world pioneer since 1976 in the biomedical problem related to bioethics), depriving it of a *Bioethics Convention*, especially when

bioethics has taken root in the whole world. For example:

- There are numerous countries with *laws or regulations on bioethics*, starting with the *French bioethics' law of 1972*,

- There are numerous countries with departments related to bioethics.

- There are International and Interregional Bioethics Committees

- In 1995 the Inter Parliamentary Union (IPU) adopted a *Resolution on Bioethics and Protection of Human Rights* (I was the speaker in the meeting of Madrid)

- In 2005 UNESCO adopted the *Universal Declaration on Bioethics and Human Rights*

- There are more than fifty countries with National Commissions on Bioethics.

- 19 October has been declared World Bioethics Day at the initiative of UNESCO

And that the erroneous decisions without regulatory safeguards required taken in 1996 eliminating the title *Bioethics Convention* have inexplicably deprived the Council of Europe of the leadership of European and even global Bioethics.

This Convention was conceived as a bioethical-legal instrument and third pillar of the Council of Europe in the European cause, and to remove the title *Bioethics Convention* was against this spirit of the Council of Europe itself.

In numerous forums, congresses, seminars, etc., on talk about Bioethics and the Bioethics Convention in its different applications,

The Council of Europe is an indispensable Institution in the defence of Human Rights and its Commissioner for Human Rights ensures that anyone can demand respect for those Rights.

Therefore I ASK the President of CDBIO, without the need to resort to other instances, including legal, 1), to ensure that the provisions of Article 38 are complied with, as I asked, and the General Secretariat will choose to submit my notification/petition to all Parties to the Convention referred to in this article to reinstate the title *Bioethics*

Convention, and can decide; and also, 2), to explore **the most appropriate of the options of article 32** previously mentioned to file an amendment, which would simplify and abbreviate the procedure if it is an initiative of the Council of Europe itself.

You yourself are Director General of Bioethics at the Irish Department of Health, and responsible for the development of policy councils and legislative instruments on bioethics issues. And you will have understanding for my request on the Council of Europe *Convention* restitution.

I remain at your disposal, with cordial greetings
Marcelo Palacios

Prof. Tomáš Doležal
Vice-Chair of the CDBIO (Steering Committee for Human Rights
in the fields of Biomedicine and Health)

HE. Prof. Doležal:

I am sending you a copy of the documentation sent to the Prof. O'Sullivan. President of the CDBIO of the Council of Europe

You yourself are Head of the Department of Civil Law and Head of the Research Unit for Medical Law and Bioethics at the Institute of State and Law, Academy of Sciences of the Czech Republic. And I am sure you also will have understanding for my request on the RESTITUTION of the Title *Bioethics Convention*.

With cordial greetings,
Marcelo Palacios

Excellency Mr. ALAIN BERSET
Secretary General of the Council of Europe
Avenue de l'Europe F-67075
Strasbourg FRANCE Gijón (SPAIN), September 27, 2024

Mr. Secretary General:

Firstly, congratulating you on your appointment to such a responsible position and waiting that your positive efforts and wishes will be fulfilled for the benefit of society in general and the Council of Europe

My name is Marcelo Palacios, I am a physician specialist, President 1997-2023 (now Honour President) of the Scientific Committee of the International Society of Bioethics (SIBI), former Member in the Spanish Parliament (Socialist Party) and of the Spanish Delegation to the Parliamentary Assembly of the Council of Europe (for 10 years, from April 1986 to May 1996) and proposer and rapporteur for the elaboration of the Convention on Bioethics (from 1988 to 1996). From 1990 to 1996 I was General Rapporteur for Bioethics on behalf of the Parliamentary Assembly, and Chairman of the Subcommittee on Bioethics. In 1997 I was awarded the European Medal Pro Merit in recognition of my dedication to the Parliamentary Assembly of the Council of Europe, and the Honorary Association to the Parliamentary Assembly for services rendered to the European Cause.

I submit to you a **Request** for the restitution of the original title “Convention on Bioethics”, title at the time improperly annulled, to the current "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".

That “**an injustice** was committed by eliminating the Title Convention on Bioethics” and that “the word **Bioethics** would have been an **excellent term to describe the Convention**”... was made clear (and until today on countless occasions) from Maurice A. M. de Wachter's article *The European Convention on*

Bioethics (The Hasting Centre Report 27 no. 1 [\(1997\)](#): 13-23, pag.22)

When asking the General Secretariat for the restitution of the title *Bioethics Convention* it is not my intention to polemicize with the Council of Europe, an organization for which I have great respect and eternal gratitude. But precisely for this consideration and respect, I believe that the Council of Europe should take the initiative and present the corresponding amendment to recover that title Bioethics Convention.

The **recovery/restitution** of the Title *Bioethics Convention* or *Convention on Bioethics* is justified, as argued in the letters of correspondence I maintained since December 2022 with the preceding General Secretary Ms. Marija Pejčinović Burić (with response through Mr. Christos Giakoumopoulos, Director General of Human Rights and Rule of Law) and also with Prof. Siobhan O'Sullivan and Prof. Tomáš Doležal, President and Vice-President of the CDBIO, Human Rights Committee in the field of Biomedicine and Health) in both cases without response, concerning to the elimination of that title *Bioethics Convention* in the Final Report at the meeting of 4-7 June 1996 of the CDBI (Steering Committee on Bioethics), and subsequently at the session of the Parliamentary Assembly of 26 September 1996, in which that report was dealt with in Doc.7622, and adopted without the necessary parliamentary guarantees, since the elimination of **that title was not proposed or debated**, facts that I ask to review objectively. (To avoid repetitions, please, I refer you to the dossier of the aforementioned correspondence)

In December 2022 I wrote to the former Secretary General Ms. Pejčinović Burić, requesting the reinstatement of the title *Convention on Bioethics* on the grounds that it had been inappropriately removed from the existing Convention on Human Rights and Biomedicine. and in letters of 11.1.2023 and 6.2.2023, the Director General of Human Rights and Rule of Law, Mr. Giakoumopoulos informed me about what was already known: "Any

change in the title of a Convention after its adoption can only be made **by means of an amendment** to the instrument itself... For the Convention on Human Rights and Biomedicine, **article 32** on amendments explains the procedure, which can only be initiated by **a Party, the responsible Committee or the Committee of Ministers**. I hope that these elements provide clarification on the context and conditions under which a request to change the title of the Convention could be considered.” And he also assured: “The **origin of the change in the title** of the Convention is NOT found at the level of the Parliamentary Assembly but in the work of the Bioethics Steering Committee, which in its plenary session of June 4-7 decided to replace the reduced title “Bioethics Convention with the title “Convention on human rights and Biomedicine, proposed by a delegation...” (Note: bold font is mine)

In its Report of June 7, 1996 (final meeting of the CDBI-CO-RED (CDBI-CO-RED/RAP.II Appendix III) the CDBI accepted, among others, that "the term **bioethics** had a *pejorative connotation* in certain States, “The Drafting Committee or Working Group of the Bioethics Steering Committee, CDBI, observed that the term *bioethics*, although **it was widely used** in English-speaking countries and France “had a connotation pejorative in certain States, the German-speaking countries”, and that " does not adequately emphasize the legal nature (apart from ethics) of the contents of the text", and, furthermore “noted **that the Convention was referred to as the *Bioethics Convention* and was likely to remain so; however.....recommended that the CDBI delete the short title (note: Bioethics Convention)”. **And the CDBI did it** iSomething unprecedented, without being debated in the Parliamentary Assembly, when the CDBI had no normative, legislative or regulatory capacity!**

I was not able to participate in that meeting of the CDBI on 4-7 June 1996 to try to prevent it with all my arguments, since I

was no longer General Rapporteur of the Parliamentary Assembly, having recently ceased to be a member of the Spanish Delegation to the Council of Europe and could not be formally summoned. If I had been able to attend, I would have been adamantly opposed with arguments to the annulling of the title Bioethics Convention, which is unjustified and harmful to the Council of Europe on the world stage of Bioethics.

Luckily, it is time to rectify on the part of the Council of Europe, recognizing the term *Bioethics* and restoring the title *Bioethics Convention*:

Because the term *Bioethics* has taken international root in the whole world, and because the **title** *Bioethics Convention*, eliminated in an inappropriate manner and for inappropriate reasons, it is commonly used to refer to the current Convention on Human Rights and Biomedicine:

1)

—There are numerous countries with *laws or regulations on bioethics*, starting with the *French bioethics' law of 1972*, subsequently modified; and numerous countries with Departments related to bioethics, and International and Interregional Bioethics Committees; and more than fifty countries with National Commissions on Bioethics.

—In 1995 the Inter Parliamentary Union (IPU) adopted a Resolution *on Bioethics and Protection of Human Rights* (I was the speaker in the meeting of Madrid).

—In 2005 UNESCO adopted the *Universal Declaration on Bioethics and Human Rights*.

—19 October has been declared *World Bioethics Day* at the initiative of UNESCO.

2) And because **the** assessment of *Bioethics* **in** the Council of Europe has radically changed since the damaging CDBI Report of June 7, 1996. Today, in this Organization it is stated that:

Bioethical issues concern us all, as patients, professionals, but also as members of a society that faces new options as a result of scientific progress.

The Convention on Human Rights and Biomedicine is the first legally binding international instrument in the field of bioethics.

(WWW.COE.INT Portal of the Council of Europe. General Directorate of Law Human Rights and Rule of Law; or www.coe.int/bioethics)

It is comforting to know, even though it has taken so long, that contrary to the serious errors made by the CDBI in its Report of June 7, 1996 (discrediting the term *Bioethics* and eliminating the title *Bioethics Convention*), the Council of Europe advocates the bioethical idea defended for years in the Science and Technology Commission, the Bioethics Subcommittee, and myself as Proponent of the Bioethics Convention and as General Rapporteur on Bioethics, reflected in Mr. Plattner's Report, *socialist, Suisse*, No. 7622 (follower in the Science and Technology Commission of my report No. 7210 on the preparation of the Bioethics Convention, adopted by the Parliamentary Assembly on 2 February 1995): **IV. Conclusions.** Debate in the Assembly in September 1996: "1. **The idea of a Bioethics Convention is neither a political whim nor bureaucratic stubbornness.** It responds to a **social need** and to the concerns of the public who feel misinformed, outside the circuits, and threatened by scientific discoveries at breakneck speed and who have difficulty assessing the consequences". "34. We would like to pay tribute to all those who, through their contribution and criticisms –sometimes contradictory, sometimes severe– have **enriched the debate and defended the reputation and standards of the Council of Europe.** In particular, we remember at this time with gratitude the great contribution of Marcelo Palacios, who was rapporteur and "guiding spirit" of the Assembly for so many years. We deeply regret that he has not been able to carry out this adventure in his

role as "intellectual" 35. **We are convinced that the Bioethics Convention, once adopted, will constitute the third great pillar** of the Council of Europe to get her with the European Convention on Human Rights and the Social Charter." He adds: "There have been many who have worked to achieve this result. If some names are to be mentioned, special tribute should be paid to the Rapporteur of the Assembly, Mr. Marcelo Palacios, who was the origin of the proposal for a new Convention; the continued work...."

But let me say that the statement "the first instrument legally binding international law in the field of bioethics" does not apply beyond being a NON-binding Declaration of intent, an **unilateral manifestation of will**, since neither in the title nor in any article of the current Convention mentions the term *bioethics*, therefore that claim is inappropriate to give the current Convention a binding international bioethical character, something that would only be legitimized and would be normative by incorporating the title *Bioethics Convention* to the current document, denatured of bioethical identity.

Consequently, the incorporation of the title Bioethics Convention to the current Convention on Human Rights and Biomedicine would mean an international consolidation of term Bioethics in teaching, legislation or labour, thanks to the historical commitment of the Council of Europe.

A quarter of a century has passed since the title Bioethics Convention was eliminated from the current Convention, more than enough time to confirm that Bioethics has taken root throughout the world, that we can speak of an authentic **Bioethical Culture** or of the **Century of Bioethics**, and that, therefore, the inappropriate reservations that at the time (7.6.1996 and 19.6.96) led to the rejection of both the term "bioethics" and the title "Bioethics Convention" have been shown to be unjustified.

Let it be said with all consideration to the General Secretariat and authorities of the Council of Europe that "removing the title *Bioethics Convention*, and continuing to maintain that situation

over the years was and is mistreatment of that document, and goes against the Council of Europe itself.”

That may already be close, the general circumstances are given for this, **it depends on you**, believing it to be fair, and taking into account the undoubted implementation of Bioethics in all world regions, in which the trajectory of the Council of Europe cannot be diluted and much less ignored, fundamentally because since 1976 **the Council of Europe was a pioneer** in the ethical-legal approach to bioethical problems, and in the creation of structures and preparation of documents related to bioethical matters..

It is to be hoped that the Council of Europe will not continue to consent to this, and will implement (article 32 facilitates this) **the restitution of the title *Bioethics Convention*** in the current document of the Convention, as suggested here:

BIOETHICS CONVENTION
CONVENTION ON HUMAN RIGHTS AND BIOMEDICIN
(Council of Europe)

and also, on **sibi.org, the website of the** International Society of Bioethics, in its English version “The Mistreated Treaty. Bioethics Convention (Council of Europe 1989-1996)”, as well as in the recently published book, in Spanish, “Convención de Bioética. El Tratado maltratado.” (Edit. Círculo Rojo, España)

I remain at your disposal.

Kind regards,

Marcelo Palacios
*Honorary President of the Scientific Committee
International Society of Bioethics (SIBI)*

CHAPTER IV

DOCUMENTS

ets Treaty No. 164 of the Council of Europe

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

Preamble

The member States of the Council of Europe, the other States and the European Community, signatories hereto,

Bearing in mind the Universal Declaration of Human Rights proclaimed by the General Assembly of the United Nations on 10 December 1948;

Bearing in mind the Convention for the Protection of Human Rights and Fundamental Freedoms of 4 November 1950;

Bearing in mind the European Social Charter of 18 October 1961;

Bearing in mind the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights of 16 December 1966;

Bearing in mind the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data of 28 January 1981;

Bearing also in mind the Convention on the Rights of the Child of 20 November 1989;

Considering that the aim of the Council of Europe is the achievement of a greater unity between its members and that one of the methods by which that aim is to be pursued is the maintenance and further realization of human rights and fundamental freedoms;

Conscious of the accelerating developments in biology and medicine;

Convinced of the need to respect the human being both as an individual and as a member of the human species and recognizing the importance of ensuring the dignity of the human being;

Conscious that the misuse of biology and medicine may lead to acts endangering human dignity;

Affirming that progress in biology and medicine should be used for the benefit of present and future generations;

Stressing the need for international cooperation so that all huma-

nity may enjoy the benefits of biology and medicine;

Recognizing the importance of promoting a public debate on the questions posed by the application of biology and medicine and the responses to be given thereto;

Wishing to remind all members of society of their rights and responsibilities;

Taking account of the work of the Parliamentary Assembly in this field, including Recommendation 1160 (1991) on the preparation of a convention on bioethics;

Resolving 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 of biology and medicine,

Have agreed as follows:

Chapter I General provisions

Article 1 *Purpose and object*

Parties to this Convention shall 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 application of biology and medicine.

Each Party shall take in its internal law the necessary measures to give effect to the provisions of this Convention.

Article 2 *Primacy of the human being*

The interests and welfare of the human being shall prevail over the sole interest of society or science.

Article 3 *Equitable access to health care*

Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.

Article 4 *Professional standards*

Any intervention in the health field, including research, must be carried out in accordance with relevant professional obligations and standards.

Chapter II Consent

Article 5 *General rule*

An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and

risks. The person concerned may freely withdraw consent at any time.

Article 6 *Protection of persons not able to consent*

1 Subject to Articles 17 and 20 below, an intervention may only be carried out on a person who does not have the capacity to consent, for his or her direct benefit.

2 Where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorization of his or her representative or an authority or a person or body provided for by law. The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity.

3 Where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disease or for similar reasons, the intervention may only be carried out with the authorization of his or her representative or an authority or a person or body provided for by law. The individual concerned shall as far as possible, take part in the authorization procedure.

4 The representative, the authority, the person or the body mentioned in paragraphs 2 and 3 above shall be given, under the same conditions, the information referred to in Article 5. 5 The authorization referred to in paragraphs 2 and 3 above may be withdrawn at any time in the best interests of the person concerned.

Article 7 *Protection of persons who have a mental disorder*

Subject to protective conditions prescribed by law, including supervisory, control and appeal procedures, a person who has a mental disorder of a serious nature may be subjected, without his or her consent, to an intervention aimed at treating his or her mental disorder only where, without such treatment, serious harm is likely to result to his or her health.

Article 8 *Emergency situation*

When because of an emergency situation the appropriate consent cannot be obtained, any medically necessary intervention may be carried out immediately for the benefit of the health of the individual concerned.

Article 9 *Previously expressed wishes*

The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.

Chapter III Private life and right to information

Article 10 *Private life and right to information*

1 Everyone has the right to respect for private life in relation to information about his or her health.

2 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.

3 In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraph 2 in the interests of the patient.

Chapter IV Human genome

Article 11 *Non-discrimination*

Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.

Article 12 *Predictive genetic tests*

Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling.

Article 13 *Interventions on the human genome*

An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.

Article 14 *Non-selection of sex*

The use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided.

Chapter V Scientific research

Article 15 *General rule*

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.

Article 16 *Protection of persons undergoing research*

Research on a person may only be undertaken if all the following conditions are met:

- i there is no alternative of comparable effectiveness to research on

humans;

ii the risks which may be incurred by that person are not disproportionate to the potential benefits of the research;

iii the research project has been approved by the competent body after independent examination of its scientific merit, including assessment of the importance of the aim of the research, and multidisciplinary review of its ethical acceptability;

iv the persons undergoing research have been informed of their rights and the safeguards prescribed by law for their protection;

v the necessary consent as provided for under Article 5 has been given expressly, specifically and is documented. Such consent may be freely withdrawn at any time

Article 17 *Protection of persons not able to consent to research*

1 Research on a person without the capacity to consent as stipulated in Article 5 may be undertaken only if all the following conditions are met:

i the conditions laid down in Article 16, sub-paragraphs i to iv, are fulfilled;

ii the results of the research have the potential to produce real and direct benefit to his or her health;

iii research of comparable effectiveness cannot be carried out on individuals capable of giving consent;

iv the necessary authorization provided for under Article 6 has been given specifically and in writing;

v the person concerned does not object.

2 Exceptionally and under the protective conditions prescribed by law, where the research has not the potential to produce results of direct benefit to the health of the person concerned, such research may be authorized subject to the conditions laid down in paragraph 1, sub-paragraphs i, iii, iv and v above, and to the following additional conditions:

i the research has the aim of contributing, through significant improvement in the scientific understanding of the individual's condition, disease or disorder, to the ultimate attainment of results capable of conferring benefit to the person concerned or to other persons in the same age category or afflicted with the same disease or disorder or having the same condition;

ii the research entails only minimal risk and minimal burden for the

individual concerned.

Article 18 *Research on embryos in vitro*

1 Where the law allows research on embryos in vitro, it shall ensure adequate protection of the embryo.

2 The creation of human embryos for research purposes is prohibited.

Chapter VI

**Organ and tissue removal from living donors
for transplantation purposes**

Article 19 *General rule*

1 Removal of organs or tissue from a living person for transplantation purposes may be carried out solely for the therapeutic benefit of the recipient and where there is no suitable organ or tissue available from a deceased person and no other alternative therapeutic method of comparable effectiveness.

2 The necessary consent as provided for under Article 5 must have been given expressly and specifically either in written form or before an official body.

Article 20 *Protection of persons not able to consent to organ removal*

1 No organ or tissue removal may be carried out on a person who does not have the capacity to consent under Article 5.

2 Exceptionally and under the protective conditions prescribed by law, the removal of regenerative tissue from a person who does not have the capacity to consent may be authorized provided the following conditions are met:

i there is no compatible donor available who has the capacity to consent;

ii the recipient is a brother or sister of the donor; iii the donation must have the potential to be life-saving for the recipient;

iv the authorization provided for under paragraphs 2 and 3 of Article 6 has been given specifically and in writing, in accordance with the law and with the approval of the competent body;

v the potential donor concerned does not object.

Chapter VII
Prohibition of financial gain
And disposal of a part of the human body

Article 21 *Prohibition of financial gain*

The human body and its parts shall not, as such, give rise to financial gain.

Article 22 *Disposal of a removed part of the human body*

When in the course of an intervention any part of a human body is removed, it may be stored and used for a purpose other than that for which it was removed, only if this is done in conformity with appropriate information and consent procedures.

Chapter VIII
Infringements of the provisions
of the Convention

Article 23 *Infringement of the rights or principles*

The Parties shall provide appropriate judicial protection to prevent or to put a stop to an unlawful infringement of the rights and principles set forth in this Convention at short notice.

Article 24 *Compensation for undue damage*

The person who has suffered undue damage resulting from an intervention is entitled to fair compensation according to the conditions and procedures prescribed by law.

Article 25 *Sanctions*

Parties shall provide for appropriate sanctions to be applied in the event of infringement of the provisions contained in this Convention.

Chapter IX Relation between this Convention
and other provisions

Article 26 *Restrictions on the exercise of the rights*

1 No restrictions shall be placed on the exercise of the rights and protective provisions contained in this Convention other than such as are prescribed by law and are necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others.

2 The restrictions contemplated in the preceding paragraph may not be placed on Articles 11, 13, 14, 16, 17, 19, 20 and 21.

Article 27 *Wider protection*

None of the provisions of this Convention shall be interpreted as limiting or otherwise affecting the possibility for a Party to grant a

wider measure of protection with regard to the application of biology and medicine than is stipulated in this Convention.

Chapter X Public debate

Article 28 *Public debate*

Parties to this Convention shall see to it that the fundamental questions raised by the developments of biology and medicine are the subject of appropriate public discussion in the light, in particular, of relevant medical, social, economic, ethical and legal implications, and that their possible application is made the subject of appropriate consultation.

Chapter XI

Interpretation and follow-up of the Convention

Article 29 *Interpretation of the Convention*

The European Court of Human Rights may give, without direct reference to any specific proceedings pending in a court, advisory opinions on legal questions concerning the interpretation of the present Convention at the request of:

- the Government of a Party, after having informed the other Parties;
- the Committee set up by Article 32, with membership restricted to the Representatives of the Parties to this Convention, by a decision adopted by a two-thirds majority of votes cast.

Article 30 *Reports on the application of the Convention*

On receipt of a request from the Secretary General of the Council of Europe any Party shall furnish an explanation of the manner in which its internal law ensures the effective implementation of any of the provisions of the Convention.

Chapter XII Protocols

Article 31 *Protocols*

Protocols may be concluded in pursuance of Article 32, with a view to developing, in specific fields, the principles contained in this Convention.

The Protocols shall be open for signature by Signatories of the Convention. They shall be subject to ratification, acceptance or approval. A Signatory may not ratify, accept or approve Protocols without previously or simultaneously ratifying accepting or approving the Convention.

Chapter XIII

Amendments to the Convention

Article 32 *Amendments to the Convention*

1 The tasks assigned to "the Committee" in the present article and in Article 29 shall be carried out by the Steering Committee on Bioethics (CDBI), or by any other committee designated to do so by the Committee of Ministers.

2 Without prejudice to the specific provisions of Article 29, each member State of the Council of Europe, as well as each Party to the present Convention which is not a member of the Council of Europe, may be represented and have one vote in the Committee when the Committee carries out the tasks assigned to it by the present Convention.

3 Any State referred to in Article 33 or invited to accede to the Convention in accordance with the provisions of Article 34 which is not Party to this Convention may be represented on the Committee by an observer. If the European Community is not a Party it may be represented on the Committee by an observer.

4 In order to monitor scientific developments, the present Convention shall be examined within the Committee no later than five years from its entry into force and thereafter at such intervals as the Committee may determine.

5 Any proposal for an amendment to this Convention, and any proposal for a Protocol or for an amendment to a Protocol, presented by a Party, the Committee or the Committee of Ministers shall be communicated to the Secretary General of the Council of Europe and forwarded by him to the member States of the Council of Europe, to the European Community, to any Signatory, to any Party, to any State invited to sign this Convention in accordance with the provisions of Article 33 and to any State invited to accede to it in accordance with the provisions of Article 34.

6 The Committee shall examine the proposal not earlier than two months after it has been forwarded by the Secretary General in accordance with paragraph 5. The Committee shall submit the text adopted by a two-thirds majority of the votes cast to the Committee of Ministers for approval. After its approval, this text shall be forwarded to the Parties for ratification, acceptance or approval.

7 Any amendment shall enter into force, in respect of those Parties

which have accepted it, on the first day of the month following the expiration of a period of one month after the date on which five Parties, including at least four member States of the Council of Europe, have informed the Secretary General that they have accepted it. In respect of any Party which subsequently accepts it, the amendment shall enter into force on the first day of the month following the expiration of a period of one month after the date on which that Party has informed the Secretary General of its acceptance.

Chapter XIV Final clauses

Article 33 *Signature, ratification and entry into force*

1 This Convention shall be open for signature by the member States of the Council of Europe, the non-member States which have participated in its elaboration and by the European Community.

2 This Convention is subject to ratification, acceptance or approval. Instruments of ratification, acceptance or approval shall be deposited with the Secretary General of the Council of Europe.

3 This Convention shall enter into force on the first day of the month following the expiration of a period of three months after the date on which five States, including at least four member States of the Council of Europe, have expressed their consent to be bound by the Convention in accordance with the provisions of paragraph 2 of the present article.

4 In respect of any Signatory which subsequently expresses its consent to be bound by it, the Convention shall enter into force on the first day of the month following the expiration of a period of three months after the date of the deposit of its instrument of ratification, acceptance or approval.

Article 34 *Non-member States*

1 After the entry into force of this Convention, the Committee of Ministers of the Council of Europe may, after consultation of the Parties, invite any non-member State of the Council of Europe to accede to this Convention by a decision taken by the majority provided for in Article 20, paragraph d, of the Statute of the Council of Europe, and by the unanimous vote of the representatives of the Contracting States entitled to sit on the Committee of Ministers.

2 In respect of any acceding State, the Convention shall enter into force on the first day of the month following the expiration of a period of three months after the date of deposit of the instrument of accession with the Secretary General of the Council of Europe.

Article 35 *Territories*

1 Any Signatory may, at the time of signature or when depositing its instrument of ratification, acceptance or approval, specify the territory or territories to which this Convention shall apply. Any other State may formulate the same declaration when depositing its instrument of accession.

2 Any Party may, at any later date, by a declaration addressed to the Secretary General of the Council of Europe, extend the application of this Convention to any other territory specified in the declaration and for whose international relations it is responsible or on whose behalf it is authorized to give undertakings. In respect of such territory the Convention shall enter into force on the first day of the month following the expiration of a period of three months after the date of receipt of such declaration by the Secretary General.

3 Any declaration made under the two preceding paragraphs may, in respect of any territory specified in such declaration, be withdrawn by a notification addressed to the Secretary General. The withdrawal shall become effective on the first day of the month following the expiration of a period of three months after the date of receipt of such notification by the Secretary General.

Article 36 *Reservations*

1 Any State and the European Community may, when signing this Convention or when depositing the instrument of ratification, acceptance, approval or accession, make a reservation in respect of any particular provision of the Convention to the extent that any law then in force in its territory is not in conformity with the provision. Reservations of a general character shall not be permitted under this article.

2 Any reservation made under this article shall contain a brief statement of the relevant law.

3 Any Party which extends the application of this Convention to a territory mentioned in the declaration referred to in Article 35, paragraph 2, may, in respect of the territory concerned, make a reservation in accordance with the provisions of the preceding paragraphs.

4 Any Party which has made the reservation mentioned in this article may withdraw it by means of a declaration addressed to the Secretary General of the Council of Europe. The withdrawal shall become effective on the first day of the month following the expiration of a period of one month after the date of its receipt by the Secretary General.

Article 37 *Denunciation*

1 Any Party may at any time denounce this Convention by means of a notification addressed to the Secretary General of the Council of Europe.

2 Such denunciation shall become effective on the first day of the month following the expiration of a period of three months after the date of receipt of the notification by the Secretary General.

Article 38 *Notifications*

The Secretary General of the Council of Europe shall notify the member States of the Council, the European Community, any Signatory, any Party and any other State which has been invited to accede to this Convention of:

- a** any signature;
- b** the deposit of any instrument of ratification, acceptance, approval or accession;
- c** any date of entry into force of this Convention in accordance with Articles 33 or 34;
- d** any amendment or Protocol adopted in accordance with Article 32, and the date on which such an amendment or Protocol enters into force;
- e** any declaration made under the provisions of Article 35;
- f** any reservation and withdrawal of reservation made in pursuance of the provisions of Article 36;
- g** any other act, notification or communication relating to this Convention.

In witness whereof the undersigned, being duly authorized thereto, have signed this Convention. Done at Oviedo (Asturias), this 4th day of April 1997, in English and French, both texts being equally authentic, in a single copy which shall be deposited in the archives of the Council of Europe. The Secretary General of the Council of Europe shall transmit certified copies to each member State of the Council of Europe, to the European Community, to the non-member States which have participated in the elaboration of this Convention, and to any State invited to accede to this Convention.

ADDITIONAL PROTOCOLS and OPINIONS
TO THE CONVENTION

The Council of Europe approved four additional protocols:

—The Additional Protocol on the *prohibition of cloning human beings* (Paris, January 7, 1998, in force since March 1, 2001),

—The Additional Protocol on the *Transplantation of Organs and Tissues of Human Origin* (Strasbourg, January 24, 2002, effective May 1, 2006),

—The Additional Protocol *on Biomedical Research* (Strasbourg, June 30, 2004, signed January 25, 2005, entered into force on January 1, 2007)

—The Additional Protocol *concerning genetic testing with medical fines* (Strasbourg, September 27, 2008, in force since July 1, 2018).

The Additional Protocol on the Protection of Human Rights and Dignity of Persons with Mental Disorders Regarding Involuntary Admission and Treatment was challenged, it is pending

OPINIÓN 184 (1995)

Author(s): Parliamentary Assembly

Origin Assembly debate on 2 February 1995 (6th Sitting) (see Doc. 7210, report of the Committee on Science and Technology, rapporteur: Mr Palacios; and Doc. 7223, opinion of the Committee on Legal Affairs and Human Rights, rapporteur: Mr. Schwimmer). Text adopted by the Assembly on 2 February 1995 (6th Sitting).

1. The Assembly has undertaken a considerable amount of work since 1976 with regard to the bioethical aspects of human biotechnology and biomedicine.

2. This work, based on principles designed to protect human dignity and the corresponding fundamental human rights relating to human biology and medicine, led to Recommendations 1100 (1989) and 1160 (1991) which contained proposals for the preparation of a comprehensive European Bioethics Convention intended as a legal instrument open to non-member states.

3. Resolution No. 3 of the 17th Conference of European Ministers of Justice (1990), recommended that the Committee of Ministers instruct the CAHBI (now the CDBI, the Steering Committee on Bioethics) to examine the possibility of preparing a framework convention and, if so decided, to draft it.

4. The Assembly considers that Recommendation 1160 proposes a convention of a general nature and a series of protocols on specific subjects that can be extended to other subjects if this is considered to be advisable and necessary in the future. This convention should allow codification of existing but fragmented work and fill a legal vacuum. The Assembly is aware that the incorporation of certain principles into the European Convention on Human Rights, which affords better protection, albeit limited to the member states, should be borne in mind for the future.

5. The Assembly has closely followed the various stages in the drafting of the texts of the convention and of the protocols within the CDBI, **in which the Parliamentary Assembly has been represented since 1990, and its contributions and suggestions have been largely taken into account and incorporated into the texts.**

6. There has been excellent co-operation between the Parliamentary Assembly and the CDBI and the latter has carefully considered **the work carried out by the Parliamentary Assembly over the last twenty years, which largely inspired the text of the draft convention.**

7. The Assembly notes the fact that the Committee on Science and Technology, the Social, Health and Family Affairs Committee, and the Committee on Legal Affairs and Human Rights **have been kept permanently informed by their representative in the CDBI during**

these years of drafting the Convention.

8. The Assembly therefore recommends that the Committee of Ministers **review thoroughly the TEXT of the draft Bioethics Convention** as transmitted to the Assembly and set out in Doc. 7124, **and amend it as indicated below** before opening it for signature:

8.1 At the end of Article 1, add the following new sentence: "They shall introduce the substantial provisions of this convention into their national legislation."

8.2 In Article 4, add a new paragraph to read as follows: "Services offered to the public involving the use of the biomedical services and techniques shall be subject, in the interest of the protection of the persons concerned, to control of their quality."

8.3 Amend Article 5, paragraph 1, to read as follows: "No intervention may be carried out in the health field without the informed, free, express and specific consent of the person undergoing it."

8.4 Replace Article 6 by the following text: "Interventions may be carried out on persons who have no legal capacity of giving consent and those who, though legally capable of giving consent, have a reduced capacity of understanding, only for their direct benefit and with the consent of their legal representative or an authority or an individual authorised or designated under his national law. A legally incapacitated person may not undergo medical research unless it is expected to produce a direct and significant benefit to his health. Any refusal by the incapacitated person must always be respected. At national level a body (an independent multidisciplinary ethical committee) should be set up to oversee any intervention involving mentally handicapped persons. For the purposes of this Convention, "incapable persons" shall mean: persons who have a reduced capacity for discernment; persons whose ability to enjoy rights and be bound by obligations is limited, whether due to age or mental illness; people who have a de facto disability."

8.5 In Article 7, at the end of paragraph 2, add the following words: "and also the free and informed consent of the parent(s) or legal guardian(s) is necessary".

8.6 In Article 7, at the end of paragraph 3, add the following words: "and no intervention may be undertaken without their consent."

8.7 In Article 13 the words: "only if this is done in conformity with appropriate information and consent procedures" are to be clarified.

8.8 Delete the first paragraph of Article 15.

8.9 In Article 15, paragraph 2, delete the word "solely".

8.10 Replace Article 16 with the following text: "An intervention on the human genome may only be undertaken for preventive, therapeutic or diagnostic purposes without any intervention in the human germ cell line."

8.11 At the end of Article 18, add the following words: "and in accordance with the national legislation about data protection."

8.12 In Article 20, delete "according to the conditions and procedure prescribed by law".

8.13 In Article 26, paragraph 2 (and elsewhere), replace "European Community" by "European Union"

8.14 In Chapter V, add a new article worded as follows: "For the purpose of observing the application of the convention on the territory of the Contracting Parties and of interpreting the text of the convention, a monitoring body in connection with the European Court of Human Rights is hereby set up".

8.15 In Article 28, paragraph 1, delete "and by the unanimous vote of the representatives of the Contracting States entitled to sit on the Committee of Ministers".

8.16 In Article 30, at the end of the first paragraph, add: "No reservations may be made in respect of Articles 15 and 16."

9. The Assembly also recommends that the Committee of Ministers:

9.1 transmit the final revised text for a definitive opinion to the Parliamentary Assembly except in the event of the Committee of Ministers accepting the changes proposed by the Assembly;

9.2 invite member states and non-member states (according to the procedure provided for in Articles 27 and 28 of the draft convention) to sign and ratify the reviewed and amended convention and to implement it as soon as possible;

9.3 invite the CDBI to continue with the preparation of the four draft

protocols concerning medical research, organ transplantation, protection of the human embryo and foetus, as well as genetics, in the light of the opinion of the Parliamentary Assembly;

9.4 transmit for opinion to the Parliamentary Assembly each draft protocol as soon as it is finalized.

OPINION 198 (1996)

Author(s): Parliamentary Assembly

Origin: Assembly debate on 26 September 1996 (30th and 31st Sittings) (see Doc. 7622, report of the Committee on Science and Technology, rapporteur: Mr. Plattner; Doc. 7664, opinion of the Social, Health and Family Affairs Committee, rapporteur: Mr. Daniel; and Doc. 7654, opinion of the Committee on Legal Affairs and Human Rights, rapporteur: Mr. Schwimmer). Text adopted by the Assembly on 26 September 1996 (30th and 31st Sittings).

1. The adoption on 7 June 1996 by the Steering Committee on Bioethics (CDBI) of a revised draft convention marked the culmination of many long years of work. In this connection, the Assembly draws particular attention to its Recommendations 934 (1982) on genetic engineering, 1046 (1986) and 1100 (1989) on the use of human embryos and fetuses, and 1160 (1991) on the preparation of a convention on bioethics, as well as its Opinion No. 184 (1995) on the first draft convention in which it recommended that the Committee of Ministers "review thoroughly" the draft text.

2. The new draft convention is more complete and better structured as a whole. The order in which its provisions are placed and the links between them are more logical than in the initial draft. The text has been more carefully worded, and the addition of new articles, for example, on organ transplantation, constitutes an improvement. On some points, such as the protection of embryos, the articles have been kept brief and are intended merely to provide the basis for future protocols.

3. The draft text is in tune with the thinking behind the Assembly's

proposals, although the exact wording of the individual amendments has not always been followed. A series of newly drafted provisions provides a satisfactory response to one of the Assembly's main concerns, namely the question of "consent" and, in particular, the protection of persons unable to give consent. At the same time, a further guarantee is enshrined in a new provision, based on the Assembly's amendments, concerning the role to be played by the European Court of Human Rights in interpreting the convention.

4. The Assembly believes that the new draft convention is a coherent and balanced text. It represents the maximum degree of European consensus that can be achieved at present. Once it has been adopted, the convention will serve as a universal benchmark and will encourage many states to comply with and go beyond the standards it lays down.

5. As with all texts based on compromise, it could, however, be improved in some areas. In the view of the Assembly, the draft convention provides no clear guidance on the question of the communication of results of genetic tests to third parties. This problem, which is likely to assume considerable social and economic importance in the years ahead, cannot be left unmentioned.

6. The Assembly therefore recommends that the Committee of Ministers:

6.1 amend Article 1 (Purpose and object) of the draft convention by inserting a second sentence as follows: "The Parties to this convention shall take all legislative and administrative actions necessary to give effect to and carry out the provisions of this convention within their own territories.";

6.2 modify Article 2 (Primacy of the human being) of the draft convention as follows: "The interests and welfare of the human being shall prevail over the sole interest of society or science.";

6.3 amend Article 4 (Professional standards) of the draft convention by inserting a second sentence as follows: "But persons working in the field of health and biomedical research shall have the right to exercise conscientious objection to any such interventions.";

6.4 amend Article 12 (Predictive genetic tests) of the draft convention by adding the following two new paragraphs: "2. The communication of results of genetic testing outside the health field may be allowed only in accordance with the provisions of Article 26, paragraph 1, of this convention and in accordance with national legislation on data protection. 3. Even where the person concerned has consented or is bound by contract, the results of predictive genetic tests shall be used strictly in accordance with paragraphs 1 and 2 above.";

6.5 amend Article 14 (Non-selection of sex) of the draft convention to read as follows: "The use of techniques of medically assisted procreation shall not be permitted for the purpose of choosing a future child's sex.";

6.6 amplify Article 16.iii (Protection of persons undergoing research) of the draft convention as follows: "The research project has been approved by the independent multidisciplinary competent body after independent examination of its scientific merit, including the importance of the aim of the research, and ethical acceptability.";

6.7 amend Article 17, paragraph 1.ii, of the draft convention to read: "the results of the research have the potential to produce real and direct benefit to his or her health.";

6.8 amend Article 18 (Research on embryos in vitro) of the draft convention as follows:

- research on embryos in vitro shall be permitted only in the interests of their development. It may, nevertheless, relate to the diagnosis of the most serious diseases;

- the creation of human embryos for research purposes is prohibited;

6.9 amend Article 20, paragraph 2.iv, of the draft convention, to read: "The authorization provided for under paragraphs 2 and 3 of Article 6 has been given specifically and in writing, in accordance with the law and with the approval of the judicial authorities responsible for the protection of children.";

6.10 amend Article 32, paragraph 6 (Amendments to the convention), of the draft convention by amplifying it as follows: "The committee

shall examine the proposal not earlier than two months after it has been forwarded by the Secretary General in accordance with paragraph 5. The committee shall submit the text adopted by a two-thirds majority of the votes cast to the Committee of Ministers for approval. The Committee of Ministers shall transmit the adopted text, before approval, to the Parliamentary Assembly for opinion. After its approval, this text shall be forwarded to the Parties for ratification, acceptance or approval.";

6.11 adopt the amended draft convention without referring it back to the CDBI and open it for signature before the end of this year, as any further delay could jeopardize the innovative nature of the text as a model for national legislators;

6.12 establish a timetable for the preparation of the draft protocols on organ transplantation, medical research and the protection of embryos, instruct the CDBI also to prepare a protocol on genetics, and transmit each draft protocol to the Assembly for opinion as soon as it has been finalized.

IPU (Inter-parliamentary Union)
Bioethics and its implications worldwide
for human rights protection
Resolution adopted by consensus by the 93rd Inter-
Parliamentary Conference (Madrid, 1 April 1995)

The 93rd Interparliamentary Conference,

Considering that scientific and technological progress, particularly in the fields of human medicine and biology, is part of the heritage of mankind and must be analysed thoroughly, rationally and objectively,

Also considering that the application of this progress undeniably has advantages and disadvantages, depending primarily on how it is used,

Affirming that progress in biology and medicine should be used for the benefit of present and future generations,

Mindful of the importance of the questions and concerns raised by these biological and medical advances, and **aware** that they cannot be resolved solely by the professional and ethical rules of scientists and the medical profession but should also be subject to a broad and open public debate before final decisions are taken by the responsible political bodies,

Considering that general information plays a decisive role because it enables citizens to express enlightened views on scientific and technological progress,

Also considering that bioethics must provide a means of reconciling freedom of research with protection of individuals and humanity, both of which are paramount,

Recalling that bioethics derives from the Universal Declaration of Human Rights and the international agreements and conventions on the protection of human rights, as well as the Code of Nuremberg, the World Medical Association's Helsinki Declaration and the Manila Declaration of the Council for International Organizations for Medical Sciences,

Stressing that such bioethical issues are the focus of the work of several international institutions,

Considering therefore the need to promote the following universal principles and rights, while ensuring respect for cultural, social and religious values:

- the inviolability of the human body and the intangibility of the genetic heritage of the human species;
- the unavailability of the person, which prohibits the human body or its parts, including human genes and their sequences, from being the object of trade or subject to a right of ownership;
- the anonymity of donor and beneficiary in donations of organs or human products, subject to exceptions provided for in national laws;

- the obligation to secure the free and informed consent of persons on whom biomedical experiments are practised and the establishment of rules to protect vulnerable groups, more particularly in developing countries, and vulnerable persons, especially children, incapacitated persons, persons deprived of their freedom and patients in emergency situations;

- the regulation of cases where study and research may be conducted on embryos, particularly those produced by procedures of medically assisted procreation, and the resulting applications, in order to preclude selective eugenics, including on the basis of gender;

- the right to share in the benefits of scientific progress and its applications, without any form of discrimination;

- the right of all persons, in particular children, to be protected against all forms of trade or exploitation;

1. *Stresses* the urgent need to:

- develop an international corpus of common principles which respect diversity of culture, belief, spiritual values and historical heritage;

- prohibit all financial gain from the human body or parts thereof, subject to exceptions provided for by law;

- ban the patenting of human genes;

- provide for genuine health security at the international level;

- ensure equitable sharing of the knowledge and advances resulting from scientific research and new medical practices, in particular with regard to the developing countries, so as to correct imbalances in this field between them and the developed countries;

- allow the use of personal information in the medical sector and in legal proceedings only as provided for by law;

2. *Calls on* governments and parliaments to provide their citizens with exact information on issues relating to bioethics, particularly in the fields of human biology and medicine, and **encourages** an ongoing debate on these issues;

3. *Recommends* that bioethics be taught at all levels of education;

4. *Urges States* to set up national ethics committees to monitor protection and respect for the dignity, freedom, identity and integrity of the individual in biomedical research, in co-operation with UNESCO's International Bioethics Committee, if they so wish;

5. *Calls on* national parliaments to define a legal framework within which ethical rules may be established to govern biomedical and biological research and its implications for individuals;

6. *Urges* parliaments and governments in developing countries where cultural, social and economic conditions are favourable to genetic research to monitor and control the way in which such research is conducted, and to bear in mind that local knowledge could be exploited by non-local corporations;

7. *Proposes* that, **after the Bioethics** Convention (Council of Europe) has come into force, as many non-members' States of the Council of Europe as possible avail themselves of the opportunity to accede to the Convention, thereby giving it a universal character;

8. *Recommends* that **governments promote genuine international cooperation in bioethics**, to be monitored and evaluated within the Interparliamentary Union, in co-operation with the competent intergovernmental and international organizations.

UNESCO

Universal Declaration on Bioethics and Human Rights

The Declaration was unanimously approved by 191 countries at the 33rd Session of the General Conference of UNESCO (Paris, October 19, 2005)

The General Conference:

Conscious of the unique capacity of human beings to reflect upon their own existence and on their environment, to perceive injustice, to avoid danger, to assume responsibility, to seek cooperation and to exhibit the moral sense that gives expression to ethical principles,

Reflecting on the rapid developments in science and technology, which increasingly affect our understanding of life and life itself,

resulting in a strong demand for a global response to the ethical implications of such developments,

Recognizing that ethical issues raised by the rapid advances in science and their technological applications should be examined with due respect to the dignity of the human person and universal respect for, and observance of human rights and fundamental freedoms,

Resolving that it is necessary and timely for the international community to state universal principles that will provide a foundation for humanity's response to the ever-increasing dilemmas and controversies that science and technology present for human-kind and for the environment,

Recalling the Universal Declaration of Human Rights of 10 December 1948, the Universal Declaration on the Human Genome and Human Rights adopted by the General Conference of UNESCO on 11 November 1997 and the International Declaration on Human Genetic Data adopted by the General Conference of UNESCO on 16 October 2003,

Noting the United Nations International Covenant on Economic, Social and Cultural Rights and the International Covenant on Civil and Political Rights of 16 December 1966, the United Nations International Convention on the Elimination of All Forms of Racial Discrimination of 21 December 1965, the United Nations Convention on the Elimination of All Forms of Discrimination against Women of 18 December 1979, the United Nations Convention on the Rights of the Child of 20 November 1989, the United Nations Convention on Biological Diversity of 5 June 1992, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities adopted by the General Assembly of the United Nations in 1993, the UNESCO Recommendation on the Status of Scientific Researchers of 20 November 1974, the UNESCO Declaration on Race and Racial Prejudice of 27 November 1978, the UNESCO Declaration on the Responsibilities of the Present Generations Towards Future Generations of 12 November 1997, the UNESCO Universal Declaration on Cultural Diversity of 2 November 2001, the ILO Convention 169 concerning Indigenous and Tribal Peoples in Independent Countries of 27 June 1989, the International Treaty on Plant Genetic Resources for Food and Agriculture which was adopted by the FAO Conference on 3 November 2001 and entered into force on 29 June 2004, the Agreement on Trade-Related Aspects of Intellectual

Property Rights (TRIPS) The General Conference, Universal Declaration on Bioethics and Human Rights* annexed to the Marrakech Agreement establishing the World Trade Organization, which entered into force on 1 January 1995, the Doha Declaration on the TRIPS Agreement and Public Health of 14 November 2001 and other relevant international instruments adopted by the United Nations and the specialized agencies of the United Nations system, in particular the Food and Agriculture Organization of the United Nations (FAO) and the World Health Organization (WHO),

Also noting international and regional instruments in **the field of bioethics**, including the 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 of the Council of Europe**, which was adopted in 1997 and entered into force in 1999, together with its Additional Protocols, as well as national legislation and the international and regional codes of conduct and guidelines and other texts in the field of bioethics, such as the Declaration of Helsinki of the World Medical Association on Ethical Principles for Medical Research Involving Human Subjects, adopted in 1964 and amended in 1975, 1983, 1989, 1996 and 2000 and the International Ethical Guidelines for Biomedical Research Involving Human Subjects of the Council for International Organizations of Medical Sciences, adopted in 1982 and amended in 1993 and 2002,

Recognizing that this Declaration is to be understood in a manner consistent with domestic and international law in conformity with human rights law,

Recalling the Constitution of UNESCO adopted on 16 November 1945,

Considering UNESCO's role in identifying universal principles based on shared ethical values to guide scientific and technological development and social transformation in order to identify emerging challenges in science and technology taking into account the responsibility of the present generations towards future generations, and that questions of bioethics, which necessarily have an international dimension, should be treated as a whole, drawing on the principles already stated in the Universal Declaration on the Human Genome and Human Rights and the International Declaration on Human Genetic Data

and taking account not only of the current scientific context but also of future developments,

Aware that human beings are an integral part of the biosphere, with an important role in protecting one another and other forms of life, in particular animals,

Recognizing that, based on the freedom of science and research, scientific and technological developments have been, and can be, of great benefit to humankind in increasing, inter alia, life expectancy and improving the quality of life, and emphasizing that such developments should always seek to promote the welfare of individuals, families, groups or communities and humankind as a whole in the recognition of the dignity of the human person and universal respect for, and observance of, human rights and fundamental freedoms,

Recognizing that health does not depend solely on scientific and technological research developments but also on psychosocial and cultural factors,

Also recognizing that decisions regarding ethical issues in medicine, life sciences and associated technologies may have an impact on individuals, families, groups or communities and humankind as a whole,

Bearing in mind that cultural diversity, as a source of exchange, innovation and creativity, is necessary to humankind and, in this sense, is the common heritage of humanity, but emphasizing that it may not be invoked at the expense of human rights and fundamental freedoms,

Also bearing in mind that a person's identity includes biological, psychological, social, cultural and spiritual dimensions,

Recognizing that unethical scientific and technological conduct has had a particular impact on indigenous and local communities,

Convinced that moral sensitivity and ethical reflection should be an integral part of the process of scientific and technological developments and that bioethics should play a predominant role in the choices that need to be made concerning issues arising from such developments,

Considering the desirability of developing new approaches to social responsibility to ensure that progress in science and technology contributes to justice, equity and to the interest of humanity,

Recognizing that an important way to evaluate social realities and achieve equity is to pay attention to the position of women,

Stressing the need to reinforce international cooperation in the field of bioethics, taking into account, in particular, the special needs of developing countries, indigenous communities and vulnerable populations,

Considering that all human beings, without distinction, should benefit from the same high ethical standards in medicine and life science research,

Proclaims the principles that follow *and adopts* the present Declaration:

General provisions

Article 1 *Scope*

1. 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.

2. This Declaration is addressed to States. As appropriate and relevant, it also provides guidance to decisions or practices of individuals, groups, communities, institutions and corporations, public and private.

Article 2 *Aims*

The aims of this Declaration are:

(a) to provide a universal framework of principles and procedures to guide States in the formulation of their legislation, policies or other instruments in the field of bioethics;

(b) to guide the actions of individuals, groups, communities, institutions and corporations, public and private;

(c) to promote respect for human dignity and protect human rights, by ensuring respect for the life of human beings, and fundamental freedoms, consistent with international human rights law;

(d) to recognize the importance of freedom of scientific research and the benefits derived from scientific and technological developments, while stressing the need for such research and developments to occur within the framework of ethical principles set out in this Declaration and to respect human dignity, human rights and fundamental freedoms;

(e) to foster multidisciplinary and pluralistic dialogue about bioethical issues between all stakeholders and within society as a whole;

(f) to promote equitable access to medical, scientific and technological developments as well as the greatest possible flow and the rapid

sharing of knowledge concerning those developments and the sharing of benefits, with particular attention to the needs of developing countries;

(g) to safeguard and promote the interests of the present and future generations;

(h) to underline the importance of biodiversity and its conservation as a common concern of humankind. Principles Within the scope of this Declaration, in decisions or practices taken or carried out by those to whom it is addressed, the following principles are to be respected.

Article 3 *Human dignity and human rights*

1. Human dignity, human rights and fundamental freedoms are to be fully respected.

2. The interests and welfare of the individual should have priority over the sole interest of science or society.

Article 4 *Benefit and harm*

In applying and advancing scientific knowledge, medical practice and associated technologies, direct and indirect benefits to patients, research participants and other affected individuals should be maximized and any possible harm to such individuals should be minimized.

Article 5 *Autonomy and individual responsibility*

The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests.

Article 6 *Consent*

1. Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free and informed consent of the person concerned, based on adequate information. The consent should, where appropriate, be express and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice.

2. Scientific research should only be carried out with the prior, free, express and informed consent of the person concerned. The information should be adequate, provided in a comprehensible form and should include modalities for withdrawal of consent. Consent may be withdrawn by the person concerned at any time and for any reason without any disadvantage or prejudice. Exceptions to this principle should be made only in accordance with ethical and legal standards

adopted by States, consistent with the principles and provisions set out in this Declaration, in particular in Article 27, and international human rights law. 3. In appropriate cases of research carried out on a group of persons or a community, additional agreement of the legal representatives of the group or community concerned may be sought. In no case should a collective community agreement or the consent of a community leader or other authority substitute for an individual's informed consent.

Article 7 *Persons without the capacity to consent*

In accordance with domestic law, special protection is to be given to persons who do not have the capacity to consent:

(a) authorization for research and medical practice should be obtained in accordance with the best interest of the person concerned and in accordance with domestic law. However, the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent;

(b) research should only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law, and if there is no research alternative of comparable effectiveness with research participants able to consent. Research which does not have potential direct health benefit should only be undertaken by way of exception, with the utmost restraint, exposing the person only to a minimal risk and minimal burden and, if the research is expected to contribute to the health benefit of other persons in the same category, subject to the conditions prescribed by law and compatible with the protection of the individual's human rights. Refusal of such persons to take part in research should be respected.

Article 8 *Respect for human vulnerability and personal integrity*

In applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.

Article 9 *Privacy and confidentiality*

The privacy of the persons concerned and the confidentiality of their personal information should be respected. To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to, consistent with international law, in particular international human rights law.

Article 10 *Equality, justice and equity*

The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably.

Article 11 *Non-discrimination and non-stigmatization*

No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.

Article 12 *Respect for cultural diversity and pluralism*

The importance of cultural diversity and pluralism should be given due regard. However, such considerations are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms, nor upon the principles set out in this Declaration, nor to limit their scope.

Article 13 *Solidarity and cooperation*

Solidarity among human beings and international cooperation towards that end are to be encouraged.

Article 14 *Social responsibility and health*

1. The promotion of health and social development for their people is a central purpose of governments that all sectors of society share.

2. Taking into account that the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition, progress in science and technology should advance:

(a) access to quality health care and essential medicines, especially for the health of women and children, because health is essential to life itself and must be considered to be a social and human good;

(b) access to adequate nutrition and water;

(c) improvement of living conditions and the environment;

(d) elimination of the marginalization and the exclusion of persons on the basis of any grounds;

(e) reduction of poverty and illiteracy.

Article 15 *Sharing of benefits*

1. Benefits resulting from any scientific research and its applications should be shared with society as a whole and within the international community, in particular with developing countries. In giving effect to this principle, benefits may take any of the following forms:

(a) special and sustainable assistance to, and acknowledgement of, the persons and groups that have taken part in the research;

(b) access to quality health care;

- (c) provision of new diagnostic and therapeutic modalities or products stemming from research;
- (d) support for health services;
- (e) access to scientific and technological knowledge;
- (f) capacity-building facilities for research purposes;
- (g) other forms of benefit consistent with the principles set out in this Declaration.

2. Benefits should not constitute improper inducements to participate in research.

Article 16 *Protecting future generations*

The impact of life sciences on future generations, including on their genetic constitution, should be given due regard.

Article 17 *Protection of the environment, the biosphere and biodiversity*

Due regard is to be given to the interconnection between human beings and other forms of life, to the importance of appropriate access and utilization of biological and genetic resources, to respect for traditional knowledge and to the role of human beings in the protection of the environment, the biosphere and biodiversity. Application of the principles

Article 18 *Decision-making and addressing bioethical issues*

1. Professionalism, honesty, integrity and transparency in decision-making should be promoted, in particular declarations of all conflicts of interest and appropriate sharing of knowledge. Every endeavour should be made to use the best available scientific knowledge and methodology in addressing and periodically reviewing bioethical issues.

2. Persons and professionals concerned and society as a whole should be engaged in dialogue on a regular basis.

3. Opportunities for informed pluralistic public debate, seeking the expression of all relevant opinions, should be promoted.

Article 19 *Ethics committees*

Independent, multidisciplinary and pluralist ethics committees should be established, promoted and supported at the appropriate level in order to:

- (a) assess the relevant ethical, legal, scientific and social issues related to research projects involving human beings;

- (b) provide advice on ethical problems in clinical settings;

(c) assess scientific and technological developments, formulate recommendations and contribute to the preparation of guidelines on issues within the scope of this Declaration;

(d) foster debate, education and public awareness of, and engagement in, bioethics.

Article 20 *Risk assessment and management*

Appropriate assessment and adequate management of risk related to medicine, life sciences and associated technologies should be promoted.

Article 21 *Transnational practices*

1. States, public and private institutions, and professionals associated with transnational activities should endeavour to ensure that any activity within the scope of this Declaration, undertaken, funded or otherwise pursued in whole or in part in different States, is consistent with the principles set out in this Declaration.

2. When research is undertaken or otherwise pursued in one or more States (the host State(s)) and funded by a source in another State, such research should be the object of an appropriate level of ethical review in the host State(s) and the State in which the funder is located. This review should be based on ethical and legal standards that are consistent with the principles set out in this Declaration.

3. Transnational health research should be responsive to the needs of host countries, and the importance of research contributing to the alleviation of urgent global health problems should be recognized.

4. When negotiating a research agreement, terms for collaboration and agreement on the benefits of research should be established with equal participation by those party to the negotiation.

5. States should take appropriate measures, both at the national and international levels, to combat bioterrorism and illicit traffic in organs, tissues, samples, genetic resources and genetic-related materials.

Promotion of the Declaration

Article 22 *Role of States*

1. States should take all appropriate measures, whether of a legislative, administrative or other character, to give effect to the principles set out in this Declaration in accordance with international human rights law. Such measures should be supported by action in the spheres of education, training and public information.

2. States should encourage the establishment of independent, multi-disciplinary and pluralist ethics committees, as set out in Article 19.

Article 23 *Bioethics education, training and information*

1. In order to promote the principles, set out in this Declaration and to achieve a better understanding of the ethical implications of scientific and technological developments, in particular for young people, States should endeavour to foster bioethics education and training at all levels as well as to encourage information and know-ledge dissemination programmes about bioethics.

2. States should encourage the participation of international and regional intergovernmental organizations and international, regional and national non-governmental organizations in this endeavour.

Article 24 *International cooperation*

1. States should foster international dissemination of scientific information and encourage the free flow and sharing of scientific and technological knowledge.

2. Within the framework of international cooperation, States should promote cultural and scientific cooperation and enter into bilateral and multilateral agreements enabling developing countries to build up their capacity to participate in generating and sharing scientific knowledge, the related know-how and the benefits thereof.

3. States should respect and promote solidarity between and among States, as well as individuals, families, groups and communities, with special regard for those rendered vulnerable by disease or disability or other personal, societal or environmental conditions and those with the most limited resources.

Article 25 *Follow-up action by UNESCO*

1. UNESCO shall promote and disseminate the principles set out in this Declaration. In doing so, UNESCO should seek the help and assistance of the Intergovernmental Bioethics Committee (IGBC) and the International Bioethics Committee (IBC).

2. UNESCO shall reaffirm its commitment to dealing with bioethics and to promoting collaboration between IGBC and IBC.

Article 26 *Interrelation and complementarity of the principles*

This Declaration is to be understood as a whole and the principles are to be understood as complementary and interrelated. Each principle is to be considered in the context of the other principles, as appropriate and relevant in the circumstances.

Article 27 *Limitations on the application of the principles*

If the application of the principles of this Declaration is to be limited, it should be by law, including laws in the interests of public safety, for the investigation, detection and prosecution of criminal offences, for the protection of public health or for the protection of the rights and freedoms of others. Any such law needs to be consistent with international human rights law.

Article 28 *Denial of acts contrary to human rights, fundamental freedoms and human dignity*

Nothing in this Declaration may be interpreted as implying for any State, group or person any claim to engage in any activity or to perform any act contrary to human rights, fundamental freedoms and human dignity

CHAPTER V INSTITUTIONS

To facilitate the understanding of the text of this book, a description of the Council of Europe, its structures and its principals' functions is made, and a reference to other institutions.

(DATA taken in part from the website of the Council of Europe and others)

THE COUNCIL OF EUROPE

The Council of Europe "is an international institution intended to promote the configuration of a common political and legal space on the continent, based on the values of democracy, human rights and the rule of law, using the cooperation of States. of Europe.

It was established by the *Treaty of London* on May 5, 1949, signed at Saint James's Palace, it is the oldest of the organizations that pursue the ideals of European integration, and it is also the only one integrates all European States within it, with the salvation of Belarus, Kazakhstan, Vatican City and Russia; excluded because their political regimes are incompatible with the principles that underpin membership of the Council. The Holy See and five non-European states have observer status: Canada, Israel, Japan, the United States and Mexico. The legal regime of the Council of Europe is governed in accordance with its *Statute*, approved by the founding Treaty of London in 1949.

The Treaty that constitutes the Statute of the Council of Europe was, initialized by ten states: Belgium, France, Luxembourg, the Netherlands and the United Kingdom, to which They join Ireland, Italy, Denmark, Norway and Sweden. Between 1949 and 1970 they joined the Council of Europe. Greece, Iceland, Turkey, Germany, Austria, Cyprus, Switzerland and Malta (in that order), In 1961, the Cultural Cooperation Council was formed, in which countries not members of the Council of Europe participated from the beginning, such as Finland, which would join the Council of Europe 28 years later.

In 1964 the European Pharmacopoeia was created; and in 1967, the European Youth Centre.

The **Council of Europe** consists of 46 member countries, with some 800 million citizens and is the most relevant political and legal forum in the European integration process.

It has **two official languages**: English and French, with three other complementary languages: German, Italian and Russian. Spain and Greece, for their part, cover the use of their respective languages, which are thus effectively equated to the three complementary languages.

In order to achieve its objectives and properly deploy its powers, the Council of Europe consists of various **internal bodies**:

—**The Parliamentary Assembly** brings together 306 parliamentarians from the 46 member states, and another 306 substitutes elected by the parliaments of the member states. The number of representatives depends on demographics (between 2 and 18). They meet every year (Ordinary Session) not exceeding one month in duration.

*Has a Presidency. The President/in of the Assembly will be elected if he/she is nominated in writing by ten or more representatives or substitutes at least forty-eight hours before the opening of the session or partial session. If there is only one candidate for the Assembly, the candidate will be declared elected without the need for a vote. When there are several candidates, the President/in will be elected by secret ballot.

*Elects the Secretary General, the Commissioner for Human Rights and the judges of the European Court of Human Rights;

*Provides a democratic forum for debate and carries out election observation missions;

*Its Commissions play an important role in examining current issues,

—**The Committee of Ministers**, the executive body of the Council of Europe, is made up of the foreign ministers of each member state or their permanent diplomatic representatives in Strasbourg; determines the Organization's policy and approves its budget and program of

activities. The 46 member states represented by their own foreign ministers or by their accredited ambassadors. The chairmanship of this committee alternates every six months and follows the state's English alphabetical order.

—**The General Secretariat**, elected by the Parliamentary Assembly for a five-year mandate at the head of the Organization, is responsible for strategic planning, guiding the program of activities and the budget of the Council of Europe; directs and represents the Organization, whose functions are carried out in a coordinated manner integrated within its own institutional mechanics, through which the will of the organization is formed, articulated and applied.

The Council of Europe **has been equipped with other autonomous institutional instruments**, the most prominent of these international organizations linked to the organization, due to the political and legal significance of its work, is the European Court of Human Rights.

—**The European Court of Human Rights**. Created by the European Convention on Human Rights of 1950 (Rome Convention), it is composed of a number of Judges equal to that of the High Contracting Parties (currently 46), for a period of 9 years, not re-electable. The full Court elects a president for a period of three years, re-electable.

—**The Commissioner for Human Rights**. He is elected by the Parliamentary Assembly for a non-renewable term of 6 years. It is responsible for promoting education and awareness regarding human rights.

It can send recommendations to member states and reports to the Committee of Ministers and the Parliamentary Assembly.

—**The Congress of Local and Regional Powers**. Created in 1994. It represents local and regional authorities within the Council of Europe. It is divided into two chambers: one for local powers and another for the regions. They have 306 regular members and as many

substitutes who represent the more than 200,000 regional and local authorities of the member states. They meet once a year in Strasbourg.”

The Council of Europe adopted two pillars of European construction:

—**The European Convention on Human Rights** (ECHR) or European Convention for the Protection of Human Rights and Fundamental Freedoms, November 4, 1950 (Rome), in force since 1953

—**The European Social Charter**, in Turin on October 18, 1961, with additional protocol of 1988, revised in 1996 and in force since July 1, 1999.”

The **third pillar** for the construction of the European cause was thought to be the **Bioethics Convention**.

THE EUROPEAN UNION (EU)

It is a legal political community with a special organizational regime, to facilitate and accommodate the integration and joint governance of the States and Nations of Europe. It was created on November 1, 1993, with the entry into force of the Maastricht Treaty.

The EU it is currently made up of 27 European states.

They belong to the European Union:

- the European Parliament,
- the European Council (Not to be confused with the Council of Europe)
- the Council of the European Union (Not to be confused with the Council of Europe)
- the European Commission,
- the Court of Justice of the European Union,
- the European Central Bank,
- the European Court of Auditors,
- the European Economic and Social Committee,
- the European Committee of the Regions,

—the European Investment Bank.

—THE EUROPEAN PARLIAMENT. It has three basic powers: legislative, budgetary and control

—THE EUROPEAN COUNCIL. It is an institution of the European Union made up of the heads of State or Government of the Member States, the President of the European Commission and the person designated as its President, which defines the general political direction and priorities.

—THE COUNCIL OF THE EUROPEAN UNION. It is another institution of the European Union that brings together the ministers of the Governments of each country, depending on the subject they are going to discuss, to deliberate, debate, modify and approve legislative measures and coordinate policies.

. **NOTE:** The **European Council** and the **Council of the European Union** have similar names to the **Council of Europe** that are often confusing, but **they are very different institutions**.

THE INTERPARLIAMENTARY UNION (IPU)

The Interparliamentary Union (IPU), founded on June 30, 1889 at the initiative of the Englishman William Randal Cremer and the Frenchman Frédéric Passy, is considered the pioneering “international political organization of parliaments”, the only one that represents the legislative branch of governments worldwide, currently with 178 affiliated national parliaments and 12 associated regional parliamentary assemblies.

The IPU is not an intergovernmental Organization but an institution for promoting cooperation between parliaments among themselves, and **its fundamental purpose is to achieve peace, cooperation between peoples and the consolidation of representative institutions through political dialogue**. Today, the IPU is the

main parliamentary interlocutor of the United Nations and brings the voice of parliaments to the decision-making processes of the United Nations, regularly presenting its resolutions to the General Assembly, making statements, participating in debates and organizing meetings. parliamentary discussions on key issues on the UN agenda. In recognition of this important role, in 2002 the United Nations granted it permanent observer status. The IPU shares the objectives of the United Nations, supports its efforts and works in close cooperation with it.

UNESCO

United Nations Educational, Scientific and Cultural Organization

UNESCO (United Nations Educational, Scientific and Cultural Organization) was created in London in 1945 and came into force in 1946. It is the organization dedicated to achieving the establishment of peace through international cooperation. in the fields of education, science, culture and communication and information.

Following the outbreak of two world wars in less than thirty years, UNESCO was founded with a clear vision: to achieve lasting peace, given that economic and political agreements between States were insufficient to achieve it. It was necessary to unite the peoples of the world and strengthen the intellectual and moral solidarity of humanity through mutual understanding and dialogue between different cultures.

To achieve this objective, UNESCO has promoted a series of pioneering programs throughout its history.

UNESCO has mobilized philosophers, scientists, artists and intellectuals from all nations to denounce and combat racist

theories and carry out innovative projects that have transformed our world, for example:

- The Universal Copyright Convention (1952)
- The Program on Man and the Biosphere (1971)
- The Convention on the Protection of the World Cultural and Natural Heritage (1972)
- The Convention for the Safeguarding of Intangible Cultural Heritage (2003)
- The Universal Declaration on Bioethics and Human Rights (2005)

UNESCO has led to the creation of several international scientific research institutions, such as CERN (1952) and the SESAME centre (2017), as well as the launch of a global tsunami warning system. It has also brought together specialists and researchers to publish the history of the five continents and the first General History of Africa.

The literacy campaigns carried out by the Organization have helped boost the development of several nations, such as Italy, the Republic of Korea and Afghanistan.

UNESCO has not only established universal principles on the ethics of science and the genome in defence of human rights, but has dedicated itself to protecting the most admirable achievements of humanity, saving the temples of ancient Egypt from flooding, preserving the treasures cultural heritage of Venice or Angkor and rebuilding the Old Bridge of Mostar collapsed by the war, etc.

EPILOGUE

In this book, and on many other occasions, I have mentioned the *Bioethics Convention* -which never came to be by that name, but rather as Treaty No. 164 of the Council of Europe-, as *The mistreated Treaty*.

—The **most obvious mistreatment was the elimination of the title *Bioethics Convention*** —which had been maintained during the years 1991 to 1996 of its elaboration in the Council of Europe from the current Convention.

*Maurice A. M. de Wachter. *The European Convention on Bioethics*. Published By: The Hasting Centre Report 27 no. 1 (1997): 13-23, page 22" 4. ...**the word "Bioethics" would have been an excellent term to describe the Convention..**“ “But the bioethical reflection of recent years and the **great development of this discipline**, as shown by **its penetration in the media**, **lead us to affirm that a certain injustice has been committed by not including the name Bioethics in the title or subtitle of the Convention**”.

—The **mistreatment is implicitly recognized in countless publications and dissertations** stating that with the elimination of the title *Bioethics Convention* an injustice was committed, which is equivalent to saying: a), that from an ethical point of view it was an undeserved act, abusive, unreasonable, inappropriate; and b), from a legal point of view it was illicit, improper.

—In my speech on May 19, 2022 in the Spanish Congress of Deputies, at the commemorative event “25 years of biomedical legislation in Spain”, organized jointly by the Bioethics Committee of Spain and the Chair of Law and Human Genome of the University of the Basque Country, in front of a large national group of representatives of law, medicine, philosophy, the two Chambers, etc. I made a general reproach, highlighting that unfortunately in the years since its entry into force the essential

meaning of the Convention had not been understood: to constitute the third pillar of the European cause, and I encouraged those present to request the Council of Europe to restore the title Bioethics Convention

—Something that I repeated again as inaugural speaker at the Congress of the National Association of Research Ethics Committees (ANCEI) on May 25, **2023** in Gijón (Principality of Asturias, Spain), in which I once again invited the participants to ask the Council of Europe to restore the title *Bioethics Convention*.

—On September 30, **2023** I receive a video from the University of Barcelona about a master's degree on the 20th anniversary of the Convention in which the moderator and other participants mention the *Bioethics Convention* or *European Bioethics Convention*.

And so on endlessly.

In its Report of June 7, 1996 (final meeting of the CDBI-CO-RED) the CDBI accepted, among others, that "the term bioethics had a *pejorative connotation* in certain States, "and that "the term bioethics does not adequately emphasize the legal nature (apart from ethics) of the contents of the text." And also, the CDBI **decided to eliminate the title *Bioethics Convention***.

Let it be repeated: "removing the title Bioethics Convention, and continuing to maintain that situation over the years was and is mistreatment of that document, and goes against the Council of Europe itself." **Once more: "Without this title the Convention was denatured of bioethics, it will remain without bioethical identity in its ethical and legal aspects".**

Luckily, **the assessment of Bioethics in the Council of Europe has changed radically.** So, for example, in

WWW.COE.INT Portal of the Council of Europe. General Directorate of Law, Human Rights and Rule of Law; or www.coe.int/bioethics is confirmed:

Bioethical issues concern us all, as patients, professionals, but also as members of a society that faces new options as a result of scientific progress.

The Convention on Human Rights and Biomedicine is the first legally binding international instrument in the field of bioethics.

But let me say that the statement “the first instrument legally binding international law in the field of bioethics” does not apply beyond being a non-binding Declaration of intent, an unilateral manifestation of will, since neither in the title nor in any article of the current Convention mentions the term *bioethics*, therefore that claim is completely inappropriate to give the current Convention a binding international bioethical character (for example, in the legal, educational or labour spheres), something that would only be legitimized and would be normative by incorporating the title *Bioethics Convention* to the current document, denatured of bioethical identity.

In Report No. 7622IV. Conclusions. Debate in the Assembly in September 1996 and not considered: “**35.** We are convinced that *the Bioethics Convention, once adopted, will constitute the third great pillar of the Council of Europe*, together with the European Convention on Human Rights and the Social Charter.” That was always my goal and that of many.

As I already said, **the circumstances currently exist** so that it can be carried out. It is hopeful that the General Secretariat and other responsible authorities of the Council of Europe **initiate the restoration** of the title *Bioethics Convention* to the current Convention denatured of bioethical identity, if possible, as suggested here:

BIOETHICS CONVENTION
CONVENTION ON HUMAN RIGHTS
AND BIOMEDICINE
Council of Europe

That may already be close, it depends on you.

Bioethics Classroom of the SIBI Scientific Committee (summary of activities)

Presentación pública de la SIBI en el Teatro Jovellanos diciembre 1997



Presentación de la SIBI en el Teatro Jovellanos de Gijón 1997



Presentación del Comité Científico 10-12-97

De izquierda a derecha: D^a Paula Martinho da Silva (Portugal), D. Jesús A. Fernández (España), D. Maurice Dooley (Irlanda, Santa Sede), D. Juan Ramón Lacadena (España), D. José Elizalde (UE, Bruselas), D. José Egózcue (España), D. Julio Rodríguez (Rector, España), D. Vicente Álvarez Areces (Alcalde de Gijón), D. Santiago Dexeus (España), D^a Margarita Salas (España), D. Marcelo Palacios (España), D^a Agni Vliavianos (Grecia), D. Amos Shapira (Israel), D. Carlos Romeo (España), D. Erwin Bernat (Austria), D^a Encarna Roca (España), D. Alain Pompidou (Francia), D. Ferenc Oberfrank (Hungría). Ausentes, por imponderables: D. Santiago Grisolia (España), D. Erwin Deutsch (Alemania), D. Jean Michaud (Francia), D. Carlos de Sola (Consejo de Europa) y D. Guido Gerin (Italia)



Presentación de la SIBI en el Teatro Jovellanos en diciembre de 1997 (De izquierda a derecha: D. Vicente Álvarez Areces (Alcalde de Gijón), D. Julio Rodríguez (Rector de la Universidad) y D. Marcelo Palacios (Fundador de la SIBI))



El Profesor Santiago Dexeus impartió la Conferencia de presentación



BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



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Comité de Bioética de España en la SIBI 2009

El **Comité de Bioética de España**, del que fue miembro el Presidente del Comité Científico de la SIBI Marcelo Palacios, y a su propuesta, se reunió en la sede de la SIBI, en Gijón, el **1 de junio de 2009**. Terminada la reunión, tuvo un encuentro con representantes de diversos Comités de Ética hospitalarios de Asturias (en el centro y abajo).

- Los temas previstos por el Comité para abordar en 2009 fueron:
- Objeción de conciencia en general en temas sanitarios.
 - Códigos de buenas prácticas clínica y de investigación
 - Protección de datos. Biometría.
 - Beneficios de los pacientes derivados de la investigación clínica.
 - Patentabilidad y derechos del paciente (Ponente: Marcelo Palacios)
 - Placebos
 - Investigación en práctica quirúrgica y consentimiento informado.
 - Quimeras e híbridos en la investigación.
 - Bancos de cordón umbilical (Ponente: Marcelo Palacios)
 - Legislación eutanasia y aborto (Sugerencia de Marcelo Palacios)



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El filósofo
abrió ayer el
ciclo anual de
charlas en la
Sociedad de



LNE Viernes 26
de febrero de
2010 Gijón

La actual crisis
económica «no
traerá cambios
en la sociedad»,
sostiene Bueno



SIBI
Ciclo
Anual
de
Conferencias
2011
Colegio de
Abogados de

Xavier O'Callaghan (Madrid)
Ciclo Anual de Conferencias 2008
Colegio de Abogados de ijón



Paz de Andrés
(Oviedo)



Ciclo Anual de Conferencias
SIBI 2010
Hospital de Jove

BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS

SIBI CICLO ANUAL DE CONFERENCIAS 2006



SIBI Ciclo Anual de Conferencias 2014



REAL INSTITUTO DE JOVELLANOS GIJÓN
EXPOSICIÓN XVII ANIVERSARIO DE LA SIBI
(Sociedad Internacional de Bioética)
Días 2 a 13 de marzo de 2015



BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



Alumnos y profesores de Mar de Niebla X Congreso Mundial de Bioética 2018



Instituto Fernández Vallín



Exposición y Conferencias SIBI



BIOETHICS CONVENTION (Council of Europe 1989-1996) MARCELO PALACIOS



I Congreso Mundial Extraordinario de la SIBI V Congreso Brasileño de Bioética
SAO PAULO (Brasil)



K. Annan
Secretario General de la ONU

BIOÉTICA II CONGRESO MUNDIAL DE BIOÉTICA
WORLD CONFERENCE ON BIOETHICS
GIJÓN (ESPAÑA) 30 septiembre - 4 octubre 2002

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"XV Aniversario SIBI" 2013

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EXTENDED INFORMATION

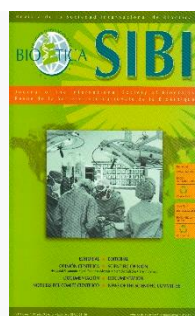
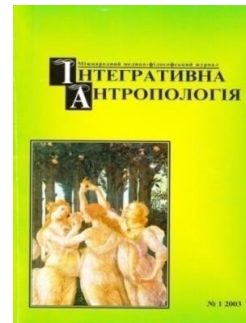
**Medical assistance to people who are carriers of
symptomatic and asymptomatic coronaviruses.**

PETITION TO THE WHO AND THE MINISTRY

**GLOBAL COMMITMENT ON THE RATIONAL
(RESPONSIBLE)
USE OF BIOTECHNOLOGIES IN MEDICINE
AND THE ENVIRONMENT**

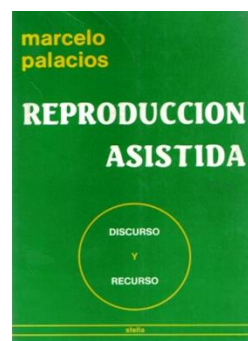
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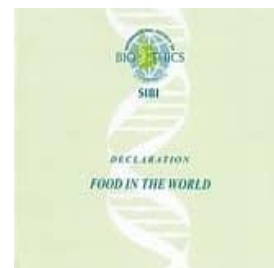
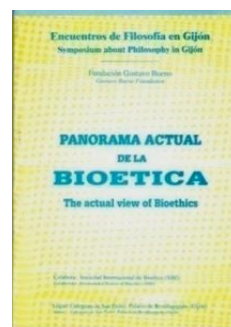
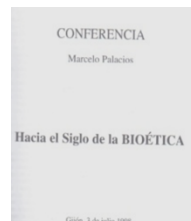
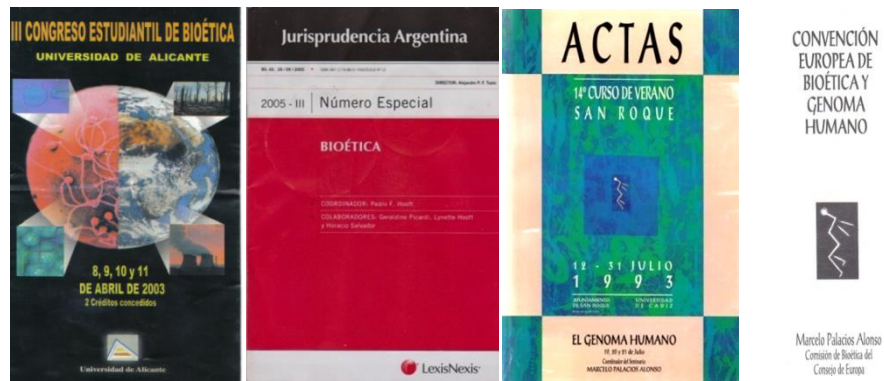


Revista SIBI
Sociedad Interdisciplinaria de Bioética y Bioética

Revista SIBI nº 4



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(España)



Marcelo Palacios (España)
Presidente Honor 1.1.2023



Desde su creación en 1997 también fueron miembros del Comité Científico:



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(España) +



Guido Gerin
(Italia) +



Héctor Gros
(Uruguay) +



Luis M. Roldán
(España)



A. Cueto
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Agni Vavianos
(Grecia) +



Georges Kutukdjian
(Libano)



Daniel Piedra
(Cuba) +



Santiago Dexeus
(España) +

Marcelo PALACIOS

Personal Information

Spain (21/08/1934) *Socialiste* Deputy Congreso de los Diputados
C/ Floridablanca s/n 28071 Madrid Tel: (34.91) 429 77 65

COUNCIL OF EUROPE

Assembly Member: from 21/04/1986 to 29/06/1990 and from 22/04/1991 to 24/06/1996 Ten years

Working language: English, French (Spanish, German)

–MEMBER of the Health and of the Science and Technology Commissions 1986-1996

–PRESIDENT of the Bioethics Sub Commission 1991-96

–GENERAL SPEAKER ON BIOETHICS of the Parliamentary Assembly from 1990 to 1996, and REPRESENTATIVE in the CAHBI, the CDBI (Bioethics Steering Committee) and others.

–Coparticipant in the final drafting of Recommendation 1,046, on "use of human embryos and fetuses for diagnostic, therapeutic, industrial and commercial purposes", adopted by the Parliamentary Assembly on September 24, 1986.

–AUTHOR AND SPEAKER:

* From the 1986 and 1990 Reports on the preparation of an International Convention on Biotechnology and Biomedicine (later Bioethics Convention), in accordance with human rights. I formally proposed it in Asturias (March, 1991) before the Science and Technology Commission of the Council of Europe, which met in the Principality with representatives from 17 countries. I also proposed, in 1994, that the Convention be opened for signature in Asturias, which occurred on April 4, 1997 (21 countries signed).

* Of the Report on "scientific research on human embryos and fetuses" (Doc. 5943), which would give rise to Recommendation 1,100 on the same subject, adopted by the Parliamentary Assembly on 3/2/89.

* From a Report on clinical autopsies (approved, 1993)

–**1995** March-April INTERPARLIAMENTARY UNION (IPU) 93rd Conference (Madrid). **Co-editor** and **Speaker** of the final report **Resolution: Bioethics, and its implications worldwide for human rights protection.** approved by consensus, which contains much of the Spanish report guided by me.

–AUTHOR AND SPEAKER:

* Of the Proposition on the health of seafarers.

* From the Proposition on individual, social and economic aspects of climacteric health care (1994).

*From the Proposition on human genetic patents (approved 1994)

–REPRESENTATIVE of the Council of Europe in:

* International Conference: Drugs (**Paris**, 1987).

* European meeting (audition) on Performances with human pre-embryos (**Paris**, 1989). Interventions on my Report regarding the matter.

*Ottawa Parliamentary and Scientific Conference (**Canada**, June 1990) Intervention on Atmospheric Pollution and the Ozone Layer.

*Meeting at the XII International Meeting of the Milazzo Group (**Italy**, July 1991) on “The genetic revolution”, with the presentation How to democratize the bioethical decision process: A European Convention on Bioethics

*Meeting on the health and environmental effects of the radiation released in the Chernobyl accident (**Budapest**, November 1991). Intervention on genetic damage, malformations, termination of pregnancy and cancer.

*Meeting of the Scientific-Technical Advisory Office (STOA) of the European Union. Intervention on the Bioethics Convention (**Paris**, 1993)

*Two meetings of the French National Committee for Life and Health Sciences (**Paris**, 1993 and 1994). Interventions on the Activities of the Council of Europe and on Spanish bio laws.

*European Symposium on "Genetic Engineering and Ethics" (**Strasbourg**, 1994). Closing intervention.

CONGRESS OF DEPUTIES

*Voluntary termination of pregnancy law 1985

*General Health Law 1986

*Special Commission Report on techniques of assisted human reproduction TRA (Chairman) 1986

*Law on the use of human embryos and fetuses 1988

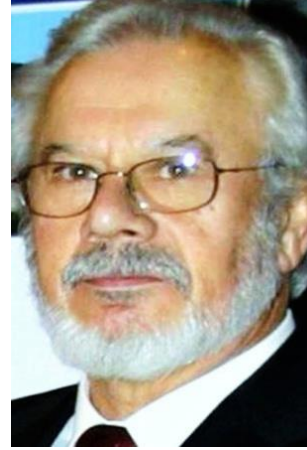
*Health Law 1990

*Law on genetically manipulated microorganisms 1994

*Penal Code Law 1995

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The “Convention for the protection of human rights and the dignity of the human being in relation to the applications of biology and medicine. Convention on Human Rights and Biomedicine”, considered among the five most important documents in the history of humanity, is usually known as the *Bioethics Convention*, a title it maintained from 1989 to 1996, years of its elaboration in the Council of Europe, and that it was removed in an inappropriate manner so that it would have to be reviewed and corrected, as considered in this book, in which they are shown the initiatives addressed to the General Secretary of the Council of Europe requesting the restitution of the cancelled title *Bioethics Convention* through an amendment of the Council of Europe itself.



(WWW.COE.INT Council of Europe Portal Directorate General Human Rights and Rule of Law or www.coe.int/bioethics):

Bioethical issues concern us all, as patients, professionals, but also, as members of a society facing new choices as a result of scientific progress.

The Convention on Human Rights and Biomedicine it is the first international legally binding instrument in the field of bioethics

But that statement it does not go beyond being a Declaration of intents. Only by incorporating the title *Convention on Bioethics* will be given bioethical binding identity to the current Convention denatured of it and without bioethical identity.