



ANNUAL REPORT OF ACTIVITIES

2012

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COMPOSITION OF THE SPANISH BIOETHICS COMMITTEE (SBC)

Title VII of the Biomedical Research Act 14/2007 of 3 July (*Ley de Investigación Biomédica*) sets up the Spanish Bioethics Committee as *an independent, collegiate, consultative body, concerned with matters relating to the ethical and social implications of Biomedicine and Health Sciences* (Article 77).

MEMBERS (2008-2012)



Victoria Camps Cervera

Victoria Camps is a Doctor of Philosophy and Professor of Moral and Political Philosophy at the Autonomous University of Barcelona. She was an independent senator for the PSC/PSOE from 1993 to 1996, and acted as advisor to the Catalan Audiovisual Council from 2002 to 2008. She chairs the Víctor Grifols i Lucas Foundation (Barcelona), is a member of the Catalan Bioethics Committee, and has published a number of books on ethics, political philosophy, bioethics and education.

President



Carlos Alonso Bedate

He holds degrees in Philosophy from the University of Alcalá de Henares, and in Theology and Biology from the University of Granada, as well as a Master's Degree in Genetics from the University of California (USA). He is a doctor of Sciences and *ad honorem* Professor of Research at the Molecular Biology Centre of the Spanish Council for Scientific Research (Consejo Superior de Investigaciones Científicas - CSIC) at the Autonomous University of Madrid. Carlos Alonso has sat on numerous national and international bioethics committees.

Vice-president



Carmen Ayuso García

Carmen Ayuso holds a Doctorate in Law from the Autonomous University of Madrid, and is associate head of the Genetics Department and Sub-director of Research at the Jiménez Díaz Foundation (Madrid).



Jordi Camí Morell

A Doctor of Medicine and specialist in Clinical Pharmacology, Jordi Camí is currently Professor of Pharmacology at the Pompeu Fabra University (Barcelona), and Director-General of the Barcelona Biomedical Research Estate (Parque de Investigación Biomédica de Barcelona/PRBB) and the Pasqual Maragall Foundation. He is a member of the Health Advisory Board (Ministry of Health). Until 2005, he held the post of director of the Barcelona Municipal Medical Research Institute (Instituto Municipal de Investigación Médica/IMIM). In 2000, he was awarded the Narcís Monturiol Medal for scientific and technological merit.

María Casado González



María Casado is a Doctor of Law, and the Resident Professor of Legal, Moral and Political Philosophy at the University of Barcelona (UB). She is director of the UNESCO Chair of Bioethics at the University of Barcelona, director of the UB-PCB Bioethics and Law Observatory Research Centre, and coordinator of the Catalanian Regional Authority's Consolidated Bioethics, Law & Society Research Group, the Bioethics and Human Rights Thematic Network, and the Bioethics Joint Teaching Network. In addition, she holds the Narcís Monturiol Medal awarded by the Catalanian Regional Authority for contribution to scientific and technological progress, and is a member of the Board of Directors of the International Association of Bioethics, the Catalanian Bioethics Advisory Committee and the National DNA Committee.

Yolanda Gómez Sánchez



Yolanda Gómez is a Doctor of Law, a Professor of Constitutional Law at the National Distance Education University, a holder of the Jean Monnet Chair of the European Union, and an advisor to the European Agency of Fundamental Rights. Until 2008, she was a member of the UNESCO International Bioethics Committee. She is a specialist in fundamental rights, the author of numerous publications in the field of bio-law, and is the PhD- and specialisation-programme director in these same subjects.



César Loris Pablo

César Loris is a Doctor of Medicine and specialist in paediatrics. He is Chairman of the Aragonese Clinical Research Ethics Committee and Head of the Paediatric Nephrology Department at Zaragoza's Miguel Servet University Teaching Hospital.



José Antonio Martín Pallín

José Antonio Martín is a Supreme Court judge, a permanent member of the Canary Islands Institute of Studies, a member of both the International Secretariat of Jurists for Amnesty and Democracy in Paraguay and the Hispano-German Association of Jurists, and has undertaken a number of special missions on human rights on behalf of Amnesty International (Venezuela, Mexico, Peru). He was awarded the 1996 Jurist Prize by Madrid's Complutense University.



César Nombela Cano

César Nombela holds a degree in Pharmacy and Chemical Sciences as well as a doctorate from the University of Salamanca. He is Professor of Microbiology at the Pharmacy Faculty of Madrid's Complutense University, and has been Chairman of the Spanish Council for Scientific Research and the Scientific & Technological Research Ethics Advisory Committee of the Spanish Foundation for Science & Technology (Fundación Española para la Ciencia y la Tecnología/FECYT) at the Ministry of Education & Science. Currently, he is director of the Extraordinary Chair of Genomics and Proteomics, sponsored by the pharmaceutical company, Merck, Sharp & Dohme. Until 2003, he was a member of UNESCO's International Bioethics Committee.



Marcelo Palacios Alonso

Marcelo Palacios is a specialist both in General Surgery (recognized by Germany's Westphalian Chamber of Medicine and the Medical Education Council), and in Traumatology and Orthopaedics (Medical Education Council). He sat as a Member of Parliament from 1982 to 1996. Among his other posts, he chaired the Special Committee for the Study into *in Vitro* Fertilization & Human Artificial Insemination of the Lower House of Parliament and drafted the Committee's final report. Dr. Palacios has acted as Chairman of the Bioethics Committee of the Council of Europe and is the founder of the International Society of Bioethics (SIBI).



Carlos María Romeo Casabona

Carlos María Romeo is a Professor of Criminal Law and Director of the Inter-University Chair of Law and the Human Genome, at the University of Deusto and the University of the Basque Country. He holds doctorates in both law and medicine, is a member of the Committee for the Supervision and Monitoring of Human Cell and Tissue Donation & Use, the Bioethics Advisory Committee of the Basque Country (*Euskadi*), the Bioethics Steering Committee of the Council of Europe, the Ethics Committee of the Human Genome Organization, the European Research Area Board (ERAB) of the European Commission, and is Chairman of the Basque Country Clinical Research Ethics Committee. He has received six honorary doctorates.



Pablo Simón Lorda

Pablo Simón took his Doctorate in Medicine at the University of Santiago de Compostela and has specialised in Family and Community Medicine. He is currently a lecturer in bioethics at the Andalusian School of Public Health (Granada). He holds Master's Degrees in Bioethics from Madrid's Complutense University and in Health Service Administration and Management from the Pompeu i Fabra University (Gaspar Casal Foundation). In addition, he has a seat on the Andalusian Regional Ethics and Research Committee.

RENOVATION

Having expired the period of four years of term of office of said members and, therefore, concurring the cause of cessation thereof referred to in paragraph a) of Article 80.3 of Law 14/2007 it was proceeded to their cessation of service and to the appointment of new members of the Bioethics Committee of Spain as provided in Article 79 of the Act, by Order SSI/2890/2012 of 19 December. The new members of the Committee are:

- Proposed by the Autonomous Communities, as agreed by the Council of Interregional National Health System:
 - D. Nicolás Jouve de la Barreda
 - D. Vicente Bellver Capella
 - D. Federico Montalvo Jääskeläinen
 - D. Manuel de los Reyes López
 - D. Pablo Ignacio Fernández Muñiz

- D. Carlos Romeo Casabona
 - Proposed by the Ministry of Justice: D. Fidel Cadena Serrano.
 - Proposed by the Ministry of Industry, Energy and Tourism: D^a Natalia López Moratalla.
 - Proposed by the Ministry of Economy and Competitiveness: D. Carlos Alonso Bedate.
 - Proposed by the Ministry of Health, Social Services and Equality:
 - D^a M^a Teresa López López
 - D. José Miguel Serrano Ruiz-Calderón
- D. César Nombela Cano

ACTIVITIES UNDERTAKEN

~ MEETINGS:

PLENARY MEETINGS

During 2012 the following plenary meetings of the Spanish Bioethics Committee were held:

- 24th January 2012
- 20th March 2012
- 22th May 2012

MEETINGS OF THE STEERING COMMITTEE

During 2012 the Steering Committee held the following scheduled meetings:

- 17th April 2012
- 19th September 2012

MEETINGS WITH OTHER ETHICS COMMITTEES

1st October 2012

As agreed at the second meeting in Barcelona, the 3rd Meeting of the Portuguese National Ethics Committee for Life Sciences and the Spanish Bioethics Committee was held in the city of Lisbon.

At this meeting, the following topics were addressed:

- *Opinion On Blood and Tissue Banks of the Umbilical Cord and Placenta*: a document drawn up by both committees, and presented by Jorge Sequeiros and Maria do Céu Patrão Neves (CNECV) and Marcelo Palacios (CBE)
- *Benefits for patients in biomedical research*: a document drawn up by CBE and presented by Yolanda Gómez.
- *Opinion on a model of determination of funding the cost of medicines*: a document drawn up by CNECV and presented by Rosalvo Almeida, Ana Sofia Carvalho.
- *Opinion on Draft Bills No. 266/2012 and No. 323/2012 on Clinical Research and Clinical Trials*: a document drawn up by CNECV and presented by Ana Sofia Carvalho.

~ ATTENDANCE AT NATIONAL AND INTERNATIONAL EVENTS

9th NEC Forum held in Carthago, Tunisia, in September. The topics addressed were as follows:

- Islam and freedom.
- Biobanks.
- Ethics of care and control of infectious diseases.
- Ethics of transplantation of organs, tissues and cells.
- Generic discussion about emerging ethical challenges, regional activities and research ethics.

It was agreed that D. Carlos Alonso Bedate and D. Javier Arias would attend on behalf of the SBC.

IV Conference on Ethical Aspects of Biomedical Research, organized by the ISCIII Animal Research Ethics and Welfare Committee.

In this Conference the topic areas addressed were not confined to research but extended to health care and bioethics in general.

Insofar as the round tables were concerned, issues of maximum interest were chosen, whether in research, including the problem of the benefits for patients in biomedical research, the new regulations on biobanks, the role of the Research Ethics Committees, biomedical innovation and ethical aspects of the prioritization of health resources in an environment of "crisis".

As speakers, attended the conference Yolanda Gómez Sánchez, César Loris Pablo, and Carlos Alonso Bedate, as members of SBC, as well as Javier Arias Díaz in his capacity as Chair of the Animal Research Ethics and Welfare Committee.

DOCUMENTS APPROVED IN 2012



Opinion on Blood and Tissue Banks of the Umbilical Cord and Placenta

Joint Report of the Bioethics Committee of Spain and the Portuguese National Ethics Committee for Life Sciences

The document refers to the current situation of storage and donation of blood and tissue from the umbilical cord and placenta. There has been a great growth in this sector in the public and private sectors, but some patients still fail to find compatible donors, so the question arises also in terms of access to health and human rights. Several recommendations are made to promote the donation and regulate the collection and storage system of the tissues.

This report is the result of collaboration of Bioethics Committees of Spain and Portugal that jointly approved the text at the meeting held on October 1, 2012.

WORK IN PROGRESS

In 2012 the following topics were discussed:

- 1) Benefits for patients in biomedical research.
- 2) Bioethical aspects of death with dignity

DOCUMENTS PUBLISHED



Opinion of the Spanish Bioethics Committee as to the Organic Bill on Voluntary Interruption of Pregnancy

7 October 2009



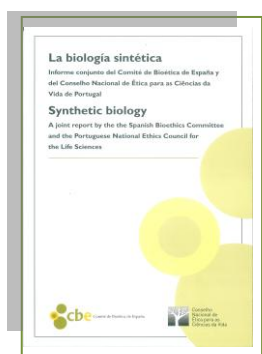
Recommendations for implementation of Good Scientific Practices in Spain

12 April 2010



Opinion of the Spanish Bioethics Committee on Conscientious Objection in Medical Care

13 October 2011



Synthetic biology

Joint Report of the Spanish Bioethics Committee and the Portuguese National Ethics Committee for Life Sciences

24 October 2011



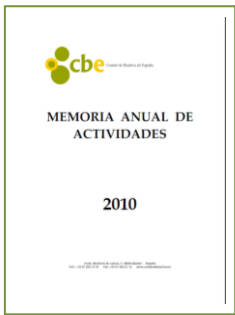
**Opinion on Blood and Tissue Banks of the Umbilical Cord
and Placenta**
**Joint Report of the Spanish Bioethics Committee and the
Portuguese National Ethics Committee for Life Sciences**

1 October 2012

ANNUAL REPORT



2009 Annual Report of Activities



2010 Annual Report of Activities



2011 Annual Report of Activities