

# Perspectivas

en Derecho y Genoma Humano

Number 9, June 2007

Inter-University Chair BBVA Foundation-Provincial Government of Biscay in Law and the Human Genome. University of Deusto, University of the Basque Country

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This issue is also published in Basque and Spanish

Editorial

Opinion

The New Law on Biomedical Research (Law 14/2007 of 3 July) constitutes an important legal tool to ease the promotion of scientific research in some ambits in the forefront of the biomedical sector. On the other hand, it aims to guarantee that this research is done with the strictest respect of fundamental rights and the public freedoms of people and of certain legal goods that may be affected in research.

In fact and in reference to its aim, the LBR establishes an innovative normative framework in relation with genetic analysis for the research of certain diseases related with DNA, besides the diagnostic purposes of a health care nature; for the obtaining and use of human biological samples as "new" material to undertake these researches, likewise providing a specific regime for biobanks; research with gametes, embryos, fetuses and human embryonic stem cells obtained through diverse procedures of cell reprogramming (though prohibiting the creation of pre-embryos and embryos for research), among them that of the activation of oocytes through the technique of nuclear transfer (non-reproductive cloning); and other researches related with human health that involve invasive procedures for the subject of the research. At the same time, there has been an establishment of some mechanisms for the encouragement and promotion, planning, evaluation and co-ordination of biomedical research in order for it to be more efficient and qualified.

As a counterweight, the LBR proclaims that biomedical research shall be undertaken with full respect towards human dignity and identity and to the inherent rights of a person. There is no doubt that this new law, in accordance with these statements, strongly favours that the health, interest and welfare of the human being who participates in biomedical research prevails over the interest of society or science, thus following the stance of the Convention of the Council of Europe on Human Rights and Biomedicine of 1997. On the other hand, it establishes that all biomedical research shall require the previous evaluation by the corresponding committee.

During the immediate years to come, we shall be able to verify to what extent the Law on Biomedical Research has satisfied the expectations it has generated.

## Preimplantational Genetic Diagnosis (PGD)

The techniques of assisted human reproduction and predictive genetic diagnosis have been progressively opening the possibilities for the prevention of births of children carriers of pathologies that are transmitted by their ancestors and that they could suffer from their infancy, adolescence or even much later as an adult.

Specifically, the obtaining of embryos in vitro and its subsequent testing through preimplantation genetic diagnosis (PGD) would permit to screen possible chromosome anomalies or genetic alterations that the pre-embryos in vitro could have before being transferred to a woman and in this manner, these would be selected for genetic purposes and those that would have some anomaly would be discarded. That is, this diagnosis is undertaken with the intention to select pre-embryos for a healthy pregnancy and future child. However, we mustn't forget that at times, a spontaneous genetic mutation can occur that could give rise to an anomaly.

The problem raised here lies in determining up to what point is it ethical and legal to use PGD in order to screen diseases or even mere predispositions to a disease and based on that to decide its non-transfer to the woman of the analysed pre-embryos which have been detected to have them. Additionally, up to what point is it ethical and legally possible to use PGD to select embryos for therapeutic purposes for third parties or for perfective purposes.

In reference to the first of the uses of PGD, that is, when undertaken in order to **detect serious diseases of an early onset**, which seriously condition the future development of a person, has broad social acceptance, being

legally authorised in many countries such as Spain, Denmark, Norway or Sweden. Nonetheless, we mustn't forget that there are countries that reject the use of PGD for any purpose as they consider that it contravenes the right to the protection of the embryo and due to the risk of favouring eugenic trends, for example, in countries such as Germany, Austria, Switzerland and Italy.

A different stance is taken when the PGD is used to **detect other diseases of predisposition of late onset, multifactorial and of a variable phenotype expression** as well as the **predisposition to certain pathologies**, as for example, cancer. In these cases, there isn't a social consensus on its convenience as it raises ethical and legal issues of great relevance.

In this sense, the United Kingdom is the first country which has permitted these diagnoses for this purpose. In fact, the Human Fertilisation and Embryology Authority (HFEA) (Authority on Human and Embryo Fertilising) has authorised the use of PGD to detect a **predisposition** of hereditary colon cancer (Familial Adenomatous Polyposis Coli). This is a serious disease that generally develops when the child reaches adolescence and where the majority of the affected to this predisposition usually suffer rectal and colon cancer, and it is even normal to undergo surgery to have the colon extirpated.

Due to the nature of this disease, some clinics solicited the HFEA to authorise or grant a license in order to undertake PGD when they deemed that there was a significant risk to develop this disease. These clinics considered that the families with this disease had a fifty per cent probability of carrying this condition

to their offspring, for which they deemed that the PGD could detect the pre-embryos that would have the condition as carrier and which would not. Therefore, an embryonic selection would be undertaken and the families would be assisted in having healthy children. We must bear in mind that in order to undertake these diagnoses, we would have to take into account certain factors: the possibility to offer a current or future therapy to the detected anomaly, the speed of degeneration of progressive anomalies, the degree of suffering associated with the condition as carrier of said disease, the family circumstance of the persons seeking treatment, among others.

After reviewing the request and posing this case for an evaluation by the Committee which took a decision after reviewing all the medical, ethical and legal information of the matter at hand, the HFEA authorised the undertaking of PGD. Likewise, a demand was placed whereby all PGD had to be undertaken with a minimum of two revisions of the case by experts in this field.

Likewise, in the United Kingdom, there are examples of other diseases such as Beta-Thalassemia, cystic fibrosis, Duchenne muscular dystrophy, Huntington's disease or haemophilia which have been granted a licence to undertake PGD in order to determine the transfer of the analysed pre-embryos *in vitro*.

In Spain, the use of PGD is established by law. In fact, the now repealed Law 35/1988 of 22 November on Assisted Reproduction Techniques (art. 12) made possible the use of PGD on pre-embryos, alive or *in vitro*, when the purpose was to evaluate their viability or to detect hereditary diseases when the purpose was to either cure them, if possible, or to discard their transfer for procreation. Likewise, the First Final Disposition in this law beseeched the Government to establish a list of genetic or hereditary diseases that could be detected using prenatal diagnosis- in its broad sense: preimplantation and prenatal diagnosis-, for prevention or for therapy, and capable of being modified as the scientific knowledge would require so. Although this list was never drafted, in my opinion, the intent for its creation was similar to the stance taken in the United Kingdom, that is, the practice of PGD would be advisable depending of the type of predisposition to a disease or the type of anomaly that bears a risk of carrying.

We must highlight in relation with that list that the Provincial Government of Andalusia in 2005 approved the first regional regulation that recognised the right to PGD within the Public Health System of Andalusia to all people with residence in this territory that had a risk of carrying to their descendants any of the following diseases: Spinal Muscular Atrophy, Duchenne Muscular Dystrophy, Huntington's Disease, Cystic Fibrosis, Haemophilia A, Haemophilia B, other disease with heritage

linked to the Chromosome X, and Alport's Syndrome linked to the X chromosome. (Decree 156/2005).

On its part, the Law on Assisted Reproduction of 14/2006, currently in force, regulates the technique of PGD in a more thorough manner. In fact, its authorisation may be granted in two situations: a) for the detection of serious hereditary diseases, of early onset and not capable of postnatal healing treatment in accordance with the current scientific knowledge, in order to undertake a selection of pre-embryos that are not affected for their transfer; b) for the detection of other alteration that could compromise the viability of the embryos (art. 12.1).

Mention must also be made of Law 14/2007 on Biomedical Research, a regulation that will complement the law on assisted reproduction in the field of the selection of embryos through PGD, as some articles deal with genetic analysis. In the aforementioned law, when determining the suitability of genetic diagnosis, it states that these will be undertaken in order to identify whether a party is affected or whether they are carriers of a genetic variation that could predispose the development of a disease.

Therefore, according to Spanish regulation, the use of PGD *to detect serious diseases of early onset*, which seriously condition the future development of a person are legally authorised by law.

Regarding the use of PGD in order to determine the *predisposition* or the condition of being a carrier of the pre-embryo, the parents will decide whether to accept that the pre-embryo be transferred to the maternal uterus. This raises a new issue from an ethical-legal point of view. In fact, it is an ethical matter as we are rejecting a pre-embryo that could give rise to a healthy person that would never develop a disease. Likewise, it is a legal matter as Law 14/2006 does not make reference to that assumption, but does expressly allow, in article 12, the possibility of the selection of embryos for therapeutic purposes of third parties. This, in turn, could be interpreted in the following manner: that when there is permission for the broadest – selection of pre-embryos for therapeutic purposes for third parties- the, the narrowest is also permitted – selection of pre-embryos with a predisposition. In other words, the rejection of the use for implantation of embryos that could be healthy, and even without any type of predisposition but that would be incompatible with the person trying to be healed, is being allowed. Therefore, we can deduce that we would also be able to select and reject those pre-embryos that would have a mere predisposition to a disease. Personally, I consider that the undertaking of this selection would be positive always when it is justified due to the importance and

seriousness of the predisposition of the disease and with a previous report by a Commission and an express authorisation, on a case by case basis.

Finally, and as aforementioned, another reason for undertaking the selection of embryos through the use of PGD is for a *therapeutic purpose for a third party*. The clinical case consists in a petition for PGD to detect a hereditary disease, together with the determination of histocompatibility anti-genes (HLA), requested by a couple with a child with a disease- lets say, acute myeloblastic leukaemia- and who need a compatible donor, which would be his or her future sibling previously selected in the embryonic stage.

Law 45/2006, in force, allows this procedure always when there is an express authorisation by the corresponding health authority, which shall study it on a case by case basis and always when there previously is a favourable report by the National Assisted Human Reproduction Commission, which must evaluate the clinical therapeutic and social characteristics of each case (art. 12.2) In these events, the role of the National Organisation on Transplantation must be taken into account as the coordinating and counselling organisation to the Ministry of Health and Consumption in matters related to the donation and transplantation of organs and tissues (Additional Clause 3).

From an ethical point of view, this selection of embryos for therapeutic purposes for third parties would bring the problem of reification of human beings and their possible instrumentalisation.

Finally, we have available the possibility of using PGD for the purpose of attending the needs of the improvement of health, of individual capacities or with *perfective ends* (positive eugenics). Nonetheless, for the time being, the use of PGD for these ends is prohibited.

In sum, a broad concept of the reproductive freedom of the couples is fostered in practice. They will be able to decide, after suitable genetic counselling, whether they want a transfer of a pre-embryo though it only has a predisposition, whether they want to have a child with the intent that it can offer a therapy to a third or whether they prefer not to have children. Nonetheless, other important moral values are set against that reproductive freedom, such as the protection of the dignity of the embryo, the preservation of the genetic identity of future generations or discriminatory practices.

## News on the Inter-University Chair in Law and the Human Genome

### XIV Conference in Law and the Human Genome

The Inter-University Chair in Law and the Human Genome held during the 23 and 24 of April its traditional Conference in Law and the Human Genome that this year celebrates its 14th edition. The inaugural conference entitled "La bioética y temas científicos recientes de interés mediático", was addressed by Dr. Marcelo Palacios, President of the Scientific Committee of the International Society on Bioethics. The first session that followed it dealt with the issue on "assisted human reproduction", which was moderated by Susi Marcos Muñoz, of the University of the Basque Country. During this session, the following participated: Emilio Armaza Galdos, professor of Criminal Law of the Universidad San Agustín de Arequipa (Peru), who spoke on "las respuestas legales a la clonación reproductiva en iberoamérica"; Xavier O'Callaghan Muñoz, Magistrate of Civil Law of the Supreme Tribunal and Professor of Civil Law, whose topic was "El nuevo régimen legal español de la reproducción asistida"; and Javier Rey del Castillo, Secretary of the National Commission on Assisted Human Reproduction, who disserted on "diagnóstico preimplantatorio".

The second session was centred on "the ethical control of biomedical activity". Antonio Martínez, Technical Director of Progenika was responsible for moderating this session and had the collaboration of Nuria Terrizas y Sala, Director of the Instituto Borja de Bioética (Barcelona), who disserted on "el proceso de toma de decisiones por los órganos colegiados de Bioética"; Vicente Belver Capella, Professor of the Philosophy of Law, Morality and Politics of the Universidad de Valencia, who spoke on "Comité de Bioética de España: comparación con otros modelos"; and Gonzalo Trincado Ibáñez, Pharmaceutical Director of the Health Department of the Basque Government, who spoke on "los Comités de Ética en el País Vasco. Cuestiones prácticas relativas a su actividad".

The third session was entitled "Genetic counselling" and was moderated by Iñaki Gutiérrez Ibarluzea, of the Agencia Vasca de Evaluación de Nuevas Tecnologías Sanitarias. The participants were Fernando Fonseca Ferrándiz, Professor of Administrative Law of the Universidad Carlos III (Madrid), with the presentation "La implantación de nuevas prestaciones sanitarias"; Emilssen González de Cancino, Professor of Law of the Universidad Externado de Colombia, who spoke on "los derechos del paciente"; and Salvador Darío Bergel, Head of the UNESCO Chair in Bioethics of the Universidad de Buenos Aires, who disserted on "aspectos éticos del consejo genético".

The fourth session on "genetic print in the judicial process" was moderated by Fernando Díez Ruiz, Director of the Agencia para la Promoción y Gestión de la Investigación de the Universidad de Deusto. The

following participated: Oscar García Fernández, President of the Grupo Español y Portugués de la Sociedad Internacional de Genética Forense, who disserted on "presupuestos científicos"; Benito de la Cruz Reverón Valenzuela, Professor of Procedural Law of the Universidad de La Laguna (Tenerife), with the conference "Las muestras de ADN en el proceso penal"; and Jaime Miguel Peris Riera, Professor of Criminal Law of the Universidad de Murcia, who spoke on "derechos fundamentales implicados y su tratamiento jurisprudencial".

### Professor Leire Escajedo San Epifanio has been awarded the 2006 Research Award of the International Society of Bioethics.

The work entitled "Towards a sustainable and healthy development of Biotechnology", submitted by Dr. Leire Escajedo San Epifanio (Professor of Constitutional Law at the UPV/EHU and Researcher of the Chair in Law and the Human Genome) was given the JGPA-SIBI award in the 2006 awards.

The work is a monograph that tackles the challenge to balance the advance of biotechnology with the defense of the health and the environment. Along these lines, special attention is placed on the efforts undertaken by the different States and International entities. The SIBI-JGPA award is organised by the prestigious International Society of Bioethics (SIBI) together with the underwriting of the Parliament of the Principality of Asturias. It has a 12.000 Euro monetary prize and includes the printing of the monograph both in Spanish and English. The Jury that in this present edition has evaluated the works and who has awarded the prize is composed by: Mr. Marcelo Palacios, President of the Science Committee of the SIBI, Mr. Jean Michaud (Magistrate and Counsellor of the Court of Appeals of France), Mr. Juan Ramón Lacadena (Professor and Director of the Department of Genetics of the Faculty of Biology at the Complutense University at Madrid) and Mr. Antonio Cueto (Secretary of the Science Committee of the SIBI).

The awards will be granted the 8 of February 2007 in the Palace of the Parliament of the Principality of Asturias in Oviedo.

### Current state of affairs of the research projects

A meeting was held by the members of the BIOTHET-ED European research Project in Sheffield, United Kingdom, June 6-8, where Dr. Iñigo de Miguel Beriain participated as a representative of the Chair. There was a broad discussion on matters related with the organisation of the Project and about the course which shall be held in Vilan (Lithuania) during the month of August, as well as the possibility that the Chair will undertake in the near future the training of foreign

researchers from those universities that participate in the Project.

Likewise, a meeting was held among all the participants in the European Project CHIMBRIDS, 20-24 April, in Frankfurt am Oder. Dr. Iñigo de Miguel Beriain assisted as a representative of the Chair. The purpose of the meeting was to finalise and discuss the reports on the proposed cases on chimeras and hybrids. As a result of this meeting, the Chair assumed responsibility for drafting two of the ten comparative reports and the responsibility of offering a critical vision of the final report that must be presented to the European Commission.

Dr. Aitziber Emaldi Cirión, as member of the European group EURECA, attended a meeting of this Project in Vilnius on February 25-28. This meeting had two distinct parts. The first was a discussion on various matters related to the Project: a) there was a choosing of those presentations that had greatest acceptance for its publishing in the final report of the project from among all the presentations made in the different workshops of the Project. b) Seeing how well the team had worked, some proposals were made to submit a new Project to the EU on matters related with the research on both stem cells as well as with human beings and animals, etc.

The second part of the meeting was a Seminar on biomedical research in which experts from several countries and different backgrounds posed the most common problems facing this field.

### OSAGENE Project

The Inter-University Chair participates in the OSAGENE Project, financed by the Ministry of Education and Science, which aims to develop tools for diagnostic purposes and for the analysis of the response to a treatment within the framework of individualised medicine. The project is directed by Progenika Biopharma S.A with the collaboration of 15 partners. The Chair is responsible for the study of the ethical, legal and economic aspects involved.

### The Chair in Law and the Human Genome participates in a course in the Spanish Senate

The Chair has participated in the course entitled "Biomedicina: ámbitos científico, ético y social", organised by the Instituto Roche for Integral Health Solutions which was given in the Spanish Senate on the 5th and 13th of February 2007. Carlos Romeo coordinated the module entitled "Investigación con Muestras Biológicas: relevancia de los biobancos", in which he addressed the Health Committee of the Spanish Senate on those matters most relevant to research with biological samples, both from a scientific as well as legal point of view.

## Publications of the Inter-University Chair

**Publications of the Inter-University Chair**  
**Revista de Derecho y Genoma Humano/Law and the Human Genome Review.** Has published issue no. 26, January-June 2007, with the following content: *Bioética y temas científicos de interés mediático* (Marcelo Palacios); *Los límites del deber de sigilo del médico en las situaciones de riesgo. Especial referencia al ámbito de la genética* (María del Carmen Gómez Rivero); *El delito de manipulación genética con fines de clonar seres humanos. Una contribución al estudio jurídico-dogmático del nuevo artículo 324 del Código penal peruano (Parte II)* (David Rosario Mendiguri Peralta); *Debate on patentability of biotechnological studies in Turkey* (Tekin Memis); *Política legislativa penal y extrapenal en relación con la biotecnología humana* (Carlos María Romeo Casabona); *Shared genetic data and the rights of involved people* (Valentina Sellaroli/Francesco Cucca/Amadeo Santosuosso); *La denegación de práctica de prueba biológica y la vulneración del derecho a la tutela judicial efectiva en la jurisprudencia constitucional* (Ana Isabel Herrán Ortiz); *Biotecnología y sociedad en el nuevo siglo* (M<sup>o</sup> Rosario H. Sánchez Morales).

**Pilar Nicolás Jiménez, La protección jurídica de los datos genéticos de carácter personal, Cátedra Interuniversitaria de Derecho y Genoma Humano-Comares, Bilbao-Granada, 2006**

The obtaining and use of personal genetic data is everyday more frequent in the biomedical ambit, both

for scientific research as well as for clinical diagnosis. The concern over the legal implications of these practices is a constant that goes along with the most important projects in this matter. This publication systematizes the set of rights involved in the handling of genetic data, setting out the conflicts that may arise in this process and proposing solutions to such. The respect of the primacy of the human being, while at the same time conciliating this principle with other interests, are the axis on which the content of this work turns.

**Sergio Romeo Malanda, Intervenciones genéticas sobre el ser humano y Derecho penal. Consideraciones político criminales y consecuencias dogmáticas, Cátedra Interuniversitaria de Derecho y Genoma Humano-Comares, Bilbao-Granada, 2006**

This work makes a detailed study of the existing fundaments for the criminalisation of genetic interventions, establishing some clear guidelines on the most adequate manner for the incrimination of such behaviours. The author deals with the analysis on the existing legislation, mainly criminal, in relation to genetic interventions, to verify whether the Spanish legislator has acted correctly or not. In case of the latter, making the opportune *lege ferenda* considerations.

**Leire Escajedo San Epifanio, El Medio ambiente en la crisis del Estado Social: su protección penal simbólica, Comares, Granada, 2006**

The Social State has been described as a model of the State which has the vocation to transform society and within this context, the use of the *ius puniendi* in environmental matters has been interpreted as a symbol that recognises the growing importance of the environment; a symbol that the criminal system is modernizing to attend to new social needs and is also a symbol that shows that the concept of delinquency is becoming more democratic.

This way of understanding has made Environmental Criminal Law a cornerstone in the modernisation of Criminal Law and has fostered its expansion, but the experience of more than 20 years of being in effect has demonstrated a negative over dimension of its symbolism. From numerous forums there is a claim that in matters truly of the task of protecting the environment, the measures undertaken have had an efficacy more symbolic or political than legal.

This book pays attention to this claim and deals in depth with the reach of such in relation to both political-criminal matters as well as criminological and dogmatic matters on the criminal protection that is currently being provided to the environment.

## Activities of the members of the Inter-University Chair

**Carlos María Romeo Casabona** has participated as a speaker in several courses and congresses, among which the following should be highlighted: Curso sobre "Biodiritto" (Università Degli Studi di Trento, 7-17 May); *Technology and Culture: Genetics and its Ethical and Social Implications in Asia and Europe*, organised by the European Alliance for Asian Studies and the Asian-European Foundation, (Bangkok, Thailand, 17-18 March), with the presentation entitled "International legal trends on research with embryonic stem cells"; *Human Dignity: sociological, ethical and bioethical aspects* (Rabat, 26-27 June), with the report entitled "Uses and abuses of the Human Dignity principle in relation with Biolaw"; *Biomedicina: ámbitos científico, ético y social*, organised by the Spanish Senate (Madrid, 5 March), with the presentation "Panorama en el derecho español sobre los datos genéticos, muestras biológicas y biobancos. Especial referencia al Proyecto de Ley de Investigación Biomédica"; *XIX Congreso Universitario Alumnos de Derecho Penal*, organised by the Universidad de Salamanca (Salamanca, 28-30 March), with the presentation "El Derecho penal frente a los avances de la medicina"; In the Congress on "Protección de datos personales e investigación biomédica: el desafío del equilibrio. Experiencias en Estados plurinacionales y federales: Canadá, España y Suiza", organised by the Agencia Catalana de Protección de Datos (Barcelona, 25 April), with the report "La protección de datos de carácter personal en relación con la obtención de muestras biológicas de origen humano con fines de investigación biomédica; In the doctorate course and diploma of advanced studies "Problemas actuales del derecho penal y de la criminología" organised by the Universidad Pablo de Olavide and the Universidad de Sevilla (Seville, 26 February), with the conference entitled "Modernas biotecnologías en Derecho penal"; *II Encuentro Moral, Ciencia y Sociedad en la Europa del Siglo XXI. Interdependencia: El bienestar como requisito de la dignidad* (San Sebastian, 15 March), with the report "El marco jurídico-constitucional de la dignidad humana y su proyección sobre los sujetos vulnerables; *3rd Meeting of the European Association of Global Bioethics (EAGB)* (Bilbao, 4-5 May), with the presentation "El debate jurídico en Europa sobre la investigación con células troncales embrionarias"; In the Post-graduate course "Derecho penal Económico: cuestiones de parte general y especial", organised by the Toledo Faculty of Legal and Business Sciences of the Universidad de Castilla La Mancha (Toledo, 22 January), with the presentations entitled "Investigación biomédica y Derecho Penal" and "Cuestiones sobre el dolo";

**Aitziber Emaldi Cirión** has addressed the following conferences: "Principios generales en la investigación biomédica", Nuevas políticas legislativas en España en relación con la investigación biomédica Organizado por la Cátedra Interuniversitaria de Derecho y Genoma Humano (Bilbao, Noviembre 2006). "Research with biological samples", Workshop European Project on Delimiting the Research Concept and Research Activities, (Lithuania, February, 2007).

"Personal Rights over an individual biological samples while they are in a biobank to research". European Association of Global Bioethics (EAGB) Workshop on "Investigación con células troncales: promesas y dificultades", (Bilbao, May, 2007) "Bioética y Biotecnología", Advance Diploma on Bioethics granted by the Escuela Nacional de Sanidad, (Madrid, March 2007). "Las instrucciones previas: concepto y formalización" and "El marco normativo de la investigación biomédica en España", V Congreso Mundial de Bioética (Gijón, May 2007). "Principios generales y garantías para la protección de los derechos de las personas implicadas en la investigación Biomédica" Seminar of continuing education. Nuevas perspectivas de investigación con material biológico humano: el Proyecto de Ley de Investigación Biomédica organizado por el Comité Ético de Investigación Clínica de Euskadi. (Bilbao, June 2007).

She has also attended the Conference on "Derecho y Genoma Humano", organised by the Inter-University Chair in Law and the Human Genome (Bilbao, 2007); V Congreso Mundial de Bioética (Gijón, 2007); Course on the Drafting of an On-line Learning Guide, organised by the Universidad de Deusto (March, 2007).

She has recently joined as researcher in the OSAGENE Project "Biotecnología aplicada al desarrollo de nuevas herramientas diagnósticas y pronósticas de enfermedades complejas", whose main co-ordinator is Progenika (April 2007)

**Pilar Nicolás Jiménez** has addressed the following conferences: "Implicaciones legales de la utilización de muestras biológicas en la investigación biomédica", *Curso de Doctorado, Especialización y Formación Continua: Avances en Neuro-oncología*, Hospital de Cruces, Bilbao, February 24, 2007; "Panorama de Derecho Comparado sobre los datos genéticos, muestras biológicas y biobancos", in the Course entitled *Biomedicina: ámbitos científico, ético y social*, organised by the Instituto Roche for Integral Health Solutions, Spanish Senate, Madrid, 13 March 2007; "Aspectos legales de los análisis genéticos y el consentimiento informado en cáncer hereditario" in the course: "Cáncer familiar y consejo genético: De las bases moleculares al manejo clínico", organised by the Instituto Roche for Integral Health Solutions, Salamanca, 20 April, 2007. Additionally, she attended the expert's meeting on "Sample and Data use and Protection in Biobanking in Europe: Legal Issues", 29 March, 2007, organised by the Instituto de Estudios sobre Prospectiva Tecnológica (European Commission, DG-JRC). Likewise, she is part of the Group of Experts in Public Health and Genetics that met for the first time on 12 January, 2007, in Barcelona, sponsored by the Instituto de Estudios sobre Prospectiva Tecnológica (European Commission, DG-JRC). This group of experts actively collaborates with the Public Health Genomics European Network (PHGEN), a Project financed by the European Commission. Finally she has published the work entitled "Concepto de dato genético y dato de salud", en *Estudios de protección de los datos de carácter personal en el ámbito de la salud*,

Santiago Ripoll (Ed.), Jordi Bacaria (coord.), Agencia Catalana de Protección de Datos, Marcial Pons, Barcelona, Madrid, 2006.

**Leire Escajedo San Epifanio** has participated as a Professor in the Summer Course "Bioética, encuentro con la ciencia y los valores", held at the University of Oviedo (Oviedo, 9-13 July), with the presentation "El Genoma Humano y sus implicaciones ético-jurídicas". Additionally, she has spoken on "Aspectos jurídico-legales acerca de la investigación con células troncales humanas: nuevas legislaciones y garantías jurídicas de la investigación", in the *I Jornadas sobre la Investigación con células troncales: Aspectos científicos, éticos y jurídicos*, University of Seville (23 March); and attended the V Congreso Mundial de Bioética (Gijón, 21-26 May), where she spoke on the following: "Comités de Bioética en los Estados democráticos de Derecho: problemas de legitimación y ubicación institucional", and "Comunidades autónomas y regulación jurídica de los registros de instrucciones previas". Furthermore, she has published a work entitled "Segurança dos alimentos transgénicos e proteçao constitucional dos direitos dos consumidores", in Carlos M. Romeo Casabona and Maria de Fátima Freire de Sá (coords), *Desafios Juridicos da Biotecnologia*, 2007.

**Iñigo de Miguel Beriain** has attended the II Encuentro Moral, Ciencia y Sociedad en la Europa del Siglo XXI, entitled "Interdependencias: El bienestar como requisito de la dignidad", held in San Sebastian, 15-16 March, 2007. Furthermore, he has addressed the following conferences: "Una nueva pieza en el puzzle bioético: el ovonúcleo", in the XV Semana de Ética y Filosofía Política, held in Madrid 27-29 March, 2007; "El Proyecto de Ley 121/000104 de Investigación Biomédica: luz verde a la "clonación terapéutica", in the XXI Jornadas de la Sociedad Española de Filosofía Jurídica y Política, held in Alcalá de Henares, Madrid, 28-30 March, 2007; "La clonación y el embrión", presented in the Global Bioethics Meeting, held in Bilbao, 3-6 May 2007. Likewise, he has taught in the Higher Diploma Course on Bioethics and has published the following articles: "A Biotecnología é uma ameaça para o direito?", in Romeo Casabona, C. M. / Freire de Sá, M. F., *Desafios Juridicos da Biotecnologia*, 2007; "Por una concepción normativa de la solidaridad humana", en *biTARTE*, Year 14, nº 41; "La nueva organización de los Comités de Ética en España: una visión crítica", in *JANO*, Nº 1.653, 25-31 May 2007.

**Sergio Romeo Malanda** has participated in *The Eighth Asian Bioethics Conference: Biotechnology, Culture, and Human Values in Asia and Beyond*, held in Bangkok, 19-23 March 2007, where he addressed a conference entitled "Confidentiality and Genetic Data: Ethical and Legal Rights and Duties. A European Perspective". Likewise, he attended the *V Congreso Mundial de Bioética*, which took place in Gijón, 21-25 May 2007, where he spoke on "Límites y controles a la utilización de muestras biológicas con fines de investigación en el proyecto de Ley de Investigación Biomédica".

## Inter-University Chair in Law and Human Genome

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