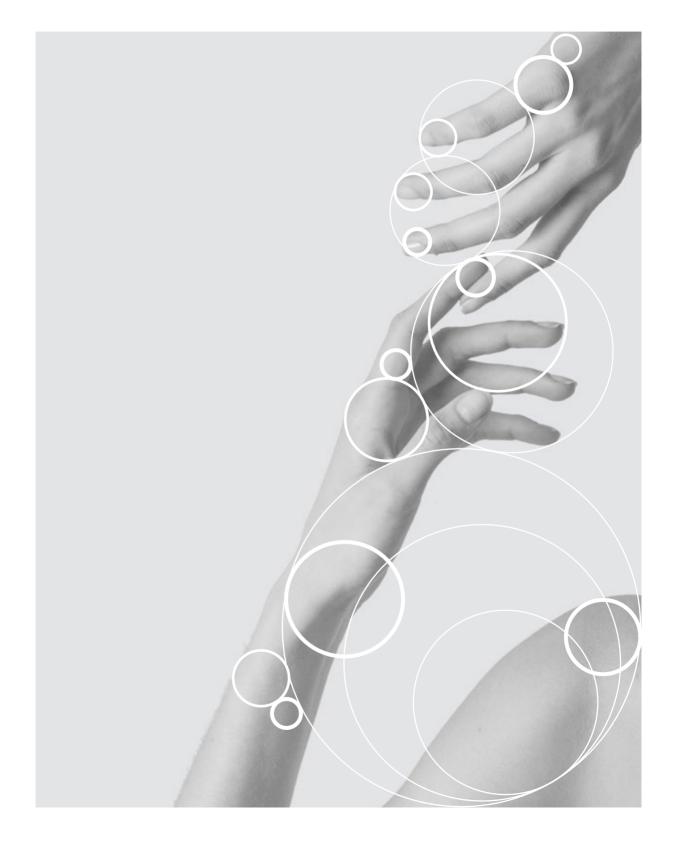


# Annual Report 2015





# Annual Report 2015



April 2016

Fundació Víctor Grífols i Lucas

Photography\_ Maximiliano Segura

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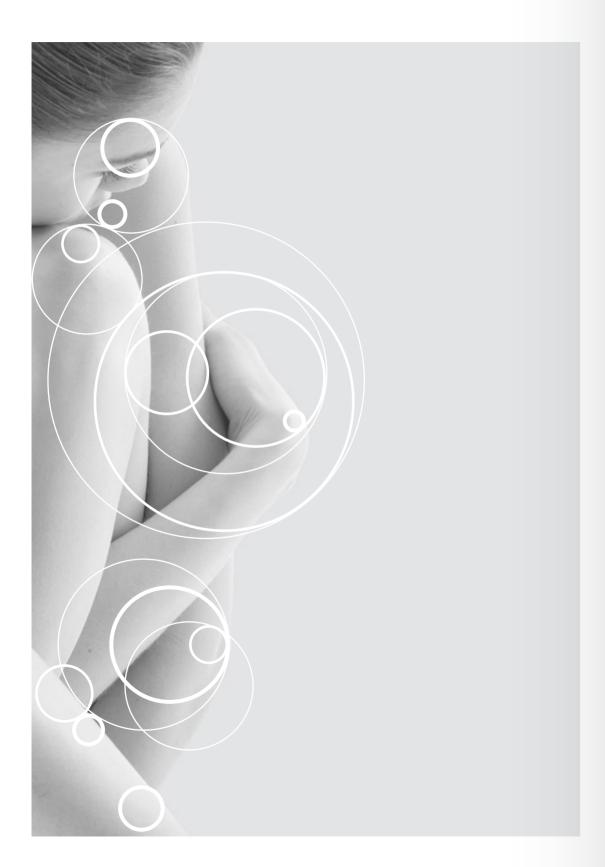
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# Introduction



During the course of 2015, the Foundation has continued to organize debates, deliver training, and support research in the field of bioethics, a discipline that touches on all those concerns that, in one way or another, affect human life and raise ethical questions. It is this need to combine scientific and technical progress with the fundamental values that should be the touchstone of any human activity, together with a sense of responsibility toward the most vulnerable and neglected groups and individuals in society, that drive the discourse of bioethics, and which the Foundation reflects through creative, innovative work designed to create new channels of debate and analysis.

The 7th Josep Egozcue Lectures, which this year were dedicated to the discussion of euthanasia and assisted suicide, play a central role in the work of the Foundation. Although this is one of the most widely studied and debated issues in bioethics, the Foundation felt that it would be of great interest to organize an event to hear about the experience of countries where the practice of helping people to die has been decriminalized for years. There was also an opportunity to discover the perspective of individuals who have been affected by the issue of euthanasia.

In the field of education, in addition to organizing courses at the request of institutions and centres, the Foundation has signed an agreement with the University of Vic to create the "Grifols Foundation Chair of Bioethics". The Chair will raise the profile of bioethics in the university sector, working across disciplinary boundaries as part of a commitment to social progress and achieving a nationwide presence through consultancy, teaching and research projects. This initiative, the first of its kind in Catalonia, will also give the Foundation a permanent presence in the higher education sector, enabling it to establish synergies with other Chairs at the UVIC-CCC such as Palliative Care, Intensive Care and Health, Social Services, and Health Management, all of which are part of the university's Centre for Health and Social Studies (CEES).

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The Foundation continues to support research of ethical issues relating to the life and health sciences. Three years ago, this programme was expanded to include senior high school students, with the aim of ensuring the inclusion of the ethical dimension in the projects that pupils submit at the end of their course. And the Foundation has also created an award to encourage proposals that seek to link ethics and science in secondary education, promoting analysis and debate in educational establishments throughout Spain. All of these initiatives spring from our conviction that ethics should not be treated as one discipline among many, but rather as a dimension of any area of study.

Finally, the Board of the Foundation is delighted to welcome a new trustee, Pere Ibern, an expert in health economics. After a long and productive stint of service to the Foundation, Guillem López Casasnovas and Ramón Bayés are leaving the Board of Trustees. We would like to take this opportunity to thank them for their support and for all the time they have dedicated to our activities.

#### Victòria Camps

President

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Victoria Camps, President of the Victor Grifols i Lucas Foundation.

# The Foundation



The aim of the Víctor Grífols i Lucas
Foundation is to promote the study and
development of bioethics within the world of
human health and the life sciences.

Established in 1998 under the auspices of Grifols, a business group dedicated to the hospital and pharmaceutical sector, the Foundation is an independent body that supports the promotion of bioethics, defined as ethics applied to biomedical activity and human health, with its main focus being the application of an ethical approach to relationships between organizations, companies and people involved in the health sector.

### The Foundation's objectives are:

- To promote research in specific areas of bioethics by awarding grants and prizes
- To organize lectures and seminars that raise awareness of and explore the ethical issues which are constantly posed by the life and medical sciences
- To produce publications that disseminate the work of the Foundation
- To cooperate with universities and educational establishments to conduct research and development into ethics in the pharmaceutical industry and in the human health sector in general, and to promote bioethics.

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# **VÍCTOR GRÍFOLS I LUCAS (1919–2015)**

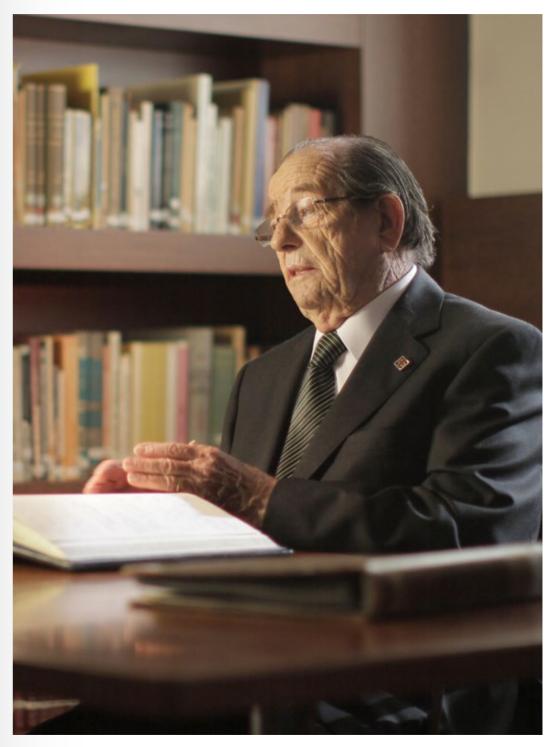
On the 1st of June, Víctor Grífols i Lucas, one of the founders of Grifols and the inspiration behind the Foundation that bears his name, sadly passed away.

Víctor Grífols i Lucas, President and CEO of the Grifols group until 2001, was responsible for creating the Foundation in 1998. His professional career was always characterized by honesty, transparency and courage in addressing the ethical dilemmas that arise in relation to pharmaceutical products.

He gained his early experience when he assisted his father, an eminent haematologist and analyst, with the day to day tasks of a clinical testing laboratory. After completing his education in Chemical Sciences and Pharmacy, he took charge of Grifols, the company that had been founded in 1940, and was the firm's technical director until 1987. In this position, he demonstrated his commitment to continuous improvement, introducing good manufacturing practices, promoting research in the field of haematology, and inventing and patenting several devices and procedures. His work was not limited to the technical sphere, and he also established the basis for the company's international expansion.

From 1987 until 2001, Víctor Grífols was President and CEO of the Grifols group, setting an example with his professionalism and his firm commitment to ethics. He passed away in Barcelona on the 1st of June, 2015.

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Víctor Grífols i Lucas, the driving force behind the Foundation.

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#### **ABOUT US**

#### Board of Trustees

The members of the Board of Trustees of the Foundation have been recognized for their achievements in different areas of bioethics research and investigation. The Board has thirteen members, drawn from a wide range of disciplines including philosophy, medicine, teaching, research and the law, providing a multidisciplinary basis for the Foundation's activities. This year, we welcomed Pere Ibern as a new trustee, while Guillem López-Casasnovas and Ramón Bayés have resigned.

#### **PRESIDENT**

Victòria Camps

Professor of Moral Philosophy and Politics at the University of Barcelona

#### VICE-PRESIDENT

Marc Antoni Broggi

Surgeon and President of the Bioethics Committee of Catalonia

#### TREASURER

Manuel Canivell

Doctor and former Scientific Director of Grifols, S.A.

#### **MEMBERS**

Neal Ball

Founder and Honorary President of the American Refugee Committee and Member of the American Committee of UNICEF

Montserrat Busquets

Lecturer at the School of Nursing at the University of Barcelona

Ignacio Calero

Lawyer with Osborne Clarke, SLP

Xavier Carné

Head of the Clinical Pharmacology Service of the Hospital Clínic, Barcelona

Tomás Dagá

Lawyer with Osborne Clarke, SLP

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Rafael Dal-Ré

Director of Clinical Research at the UAM-CSIC Campus for International Excellence

Vladimir de Semir

Director of the Scientific Communication Research Centre at Pompeu Fabra University, Barcelona

Pere Ibern

Researcher at the Centre for Research into Health and the Economy at Pompeu Fabra University, Barcelona

Josep Maria Lozano

Lecturer at ESADE Department of Social Sciences

Francesca Puigpelat

Professor of Legal Philosophy at the Autonomous University of Barcelona



Entrance to the Foundation from Vendrell Street.

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Management Board

The Management Board is entrusted with the task of implementing the guidelines and projects approved by the Trustees, and of proposing other activities that reflect the interests of the Foundation. This year, the Foundation's team has been strengthened by the addition of Sílvia Perabá as secretarial and administrative manager.

Núria Terribas

**Director General** 

Maria Ferrer Project Coordinator

Sílvia Perabá

Secretarial and Administrative Manager

### Educational Advisory Board

The Foundation places particular emphasis on education, with the aim of promoting reflection, discussion and awareness of current ethical issues in this sphere. This year, it has promoted a number of educational initiatives aimed at health professionals, teachers and students. The Foundation has established a committee of experts to act as an advisory body on these projects:

Èlia Farré

Director of the Tandem Schools and Study Grants projects for Fundació Catalunya–La Pedrera

Salvador Garcia

**Executive Director of Ara newspaper** 

Josep Menéndez

Assistant Director of Fundació Jesuïtes Educació

Gregorio Luri

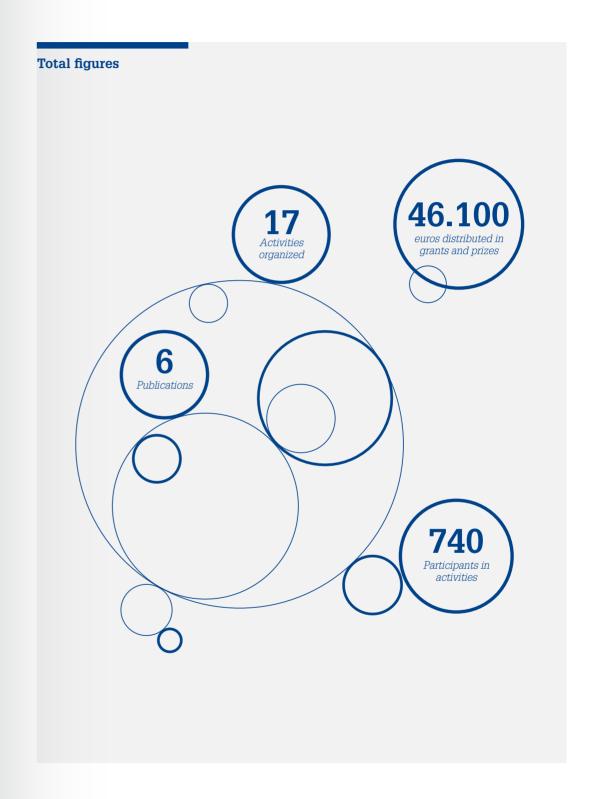
Ph.D. in Philosophy from the University of Barcelona and Bachelor in Education Science

Ferran Ruiz

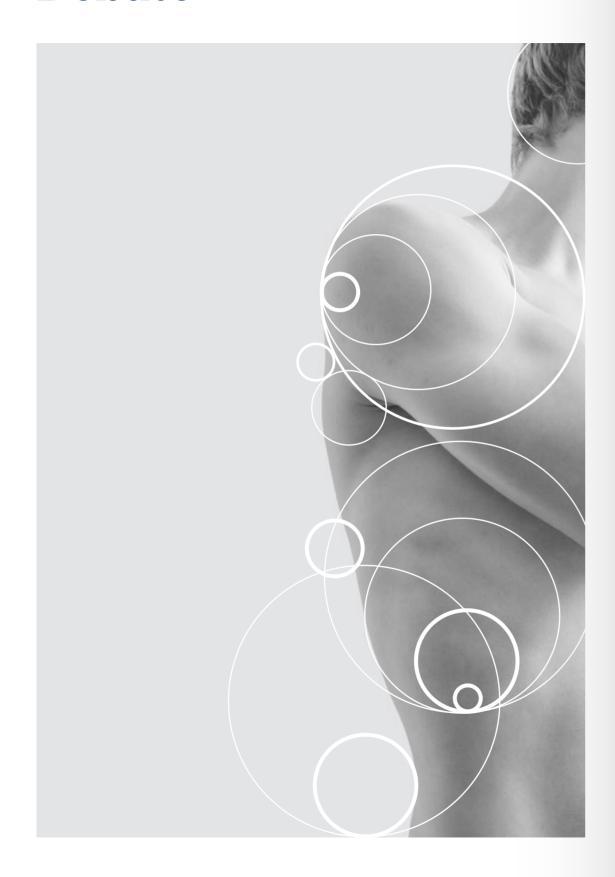
President of the Education Committee of Catalonia

Eva Salvà

Director General of Agrupació Escolar Catalana (Catalan Schools Association)



# **Debate**



The Foundation organizes workshops and expert seminars addressing a range of current issues, with the aim of deepening society's understanding of the ethical issues that underpin the life sciences.

The neurosciences, euthanasia, the ethical challenges of disability and the transfer of scientific knowledge were just some of the issues tackled at these events during 2015.

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#### 03 DEBATE

# SEMINAR: "DISABILITY, NEW APPROACHES AND ETHICAL CHALLENGES IN THE LIGHT OF THE UN CONVENTION"

3 July 2015

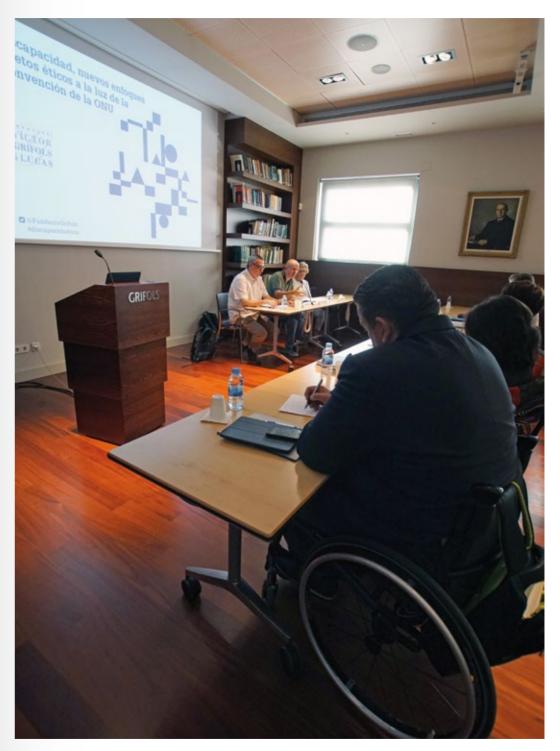
The United Nations Convention on the Rights of Persons with Disabilities has led to a paradigm shift in the disability care sector, and requires changes to Spanish legislation. The convention defines people with disabilities as the holders of rights, not as the recipients of treatment and of social protection. To analyze the potential impact of this convention, the Foundation brought together representatives from the fields of ethics, the legal system, the care services, the third sector, and disabled people themselves.

# SEMINAR: "ETHICS, HEALTH AND THE SQUANDERING OF KNOWLEDGE"

21 and 22 September 2015

The Víctor Grífols i Lucas Foundation and the Spanish Society for Public Health and Health Administration (SESPAS) organized the fifth meeting on ethics and public health with the participation of Menéndez y Pelayo International University (UIMP) at the School of Public Health of Menorca, with the participation of the European Public Health Association (EUPHA). The seminar took as its starting point the premise that there is often a failure to transfer research knowledge into clinical practice, far less to the general public. A number of experts analyzed and explored the ethical aspects that influence whether such knowledge is shared with its potential beneficiaries.

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Participants at seminar on "Disability, new approaches and ethical challenges in the light of the UN.

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PANEL DISCUSSION ON "ETHICS AND NEUROSCIENCE" AT THE FESTIVAL OF PHILOSOPHY "BARCELONA PENSA" (BARCELONA THINKS)

18 November 2015

The Foundation organized a panel discussion on "Ethics and neuroscience" as part of the Festival of Philosophy "Barcelona Pensa" (Barcelona Thinks), promoted by the University of Barcelona. The panel discussion addressed the ethical dilemmas that arise when we seek to identify and define moral behaviour, accessing and using information obtained from neurosurgery, and basing our treatment of patients on respect for their condition as moral subjects.

The panel members were:

Margarita Boladeras

Professor of Moral Philosophy and Politics at the University of Barcelona

Anna Estany

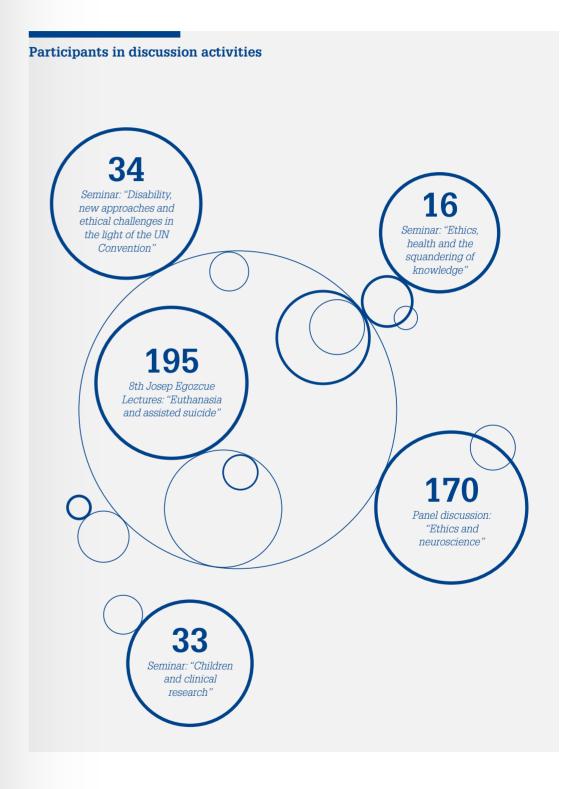
Professor of Philosophy of Science at the Autonomous University of Barcelona

Alberto Lledá

Neurologist and secretary of the Study Group on Cognition and Behaviour of the Catalan Neurology Society

Bernabé Robles

Head of the Neurology Service, Parc Sanitari Sant Joan de Déu



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#### 03 DEBATE

# 8TH JOSEP EGOZCUE LECTURES: EUTHANASIA AND ASSISTED SUICIDE

3 and 4 December 2015

This year's Josep Egozcue Lectures addressed the topic of euthanasia and assisted suicide, and were held at the Ateneo Barcelonés. The aim of this lecture cycle was to contribute to considered debate of this issue, analyzing it from ethical, legal and clinical perspectives. With the participation of international experts, it explored the models applied in countries such as Belgium, Switzerland and the Netherlands, where these practices are not criminalized. There was also an opportunity to hear from the perspective of institutions, individuals affected by these issues and those with direct experience of them.

The main speakers were:

Josep M<sup>a</sup> Esquirol Lecturer in Philosophy at the University of Barcelona

Aycke Smook President of Right to Die Europe

Jérôme Sobel President of Exit, Switzerland

Jacqueline Herremans Association pour le Droit de Mourir dans la Dignité

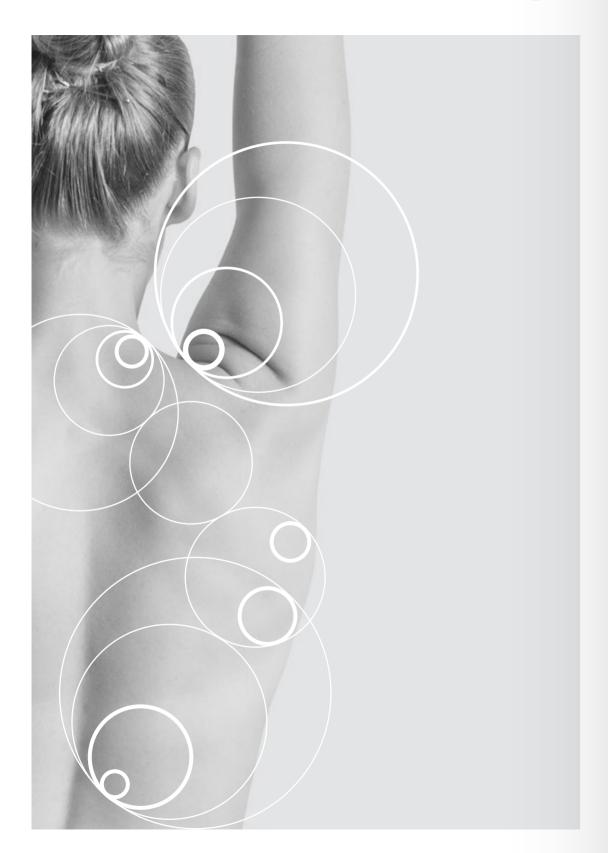
Carmen Tomás-Valiente Lecturer in Criminal Law at the University of Valencia

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Jérôme Sobel, Jacqueline Herremans and Aycke Smook at Josep Egozcue Lectures

# **Education and learning**



For several years, the Foundation has been expanding its offering in the spheres of education and learning, gradually diversifying the contents of its courses and workshops and reaching out to a wider public, which includes doctors, other health professionals, and high school teachers and students.

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The chair has been created with the aim of delivering specialist education

**GRÍFOLS FOUNDATION CHAIR OF BIOETHICS** 

On 20 April, the University of Vic—Central University of Catalonia (UVic—UCC) and the Víctor Grífols i Lucas Foundation signed an agreement to create the Grífols Foundation Chair of Bioethics.

The Chair will be held by Victòria Camps, and directed by Núria Terribas, respectively President and Director of the Víctor Grífols i Lucas Foundation. This is a pioneering initiative that establishes the first Chair of Bioethics in the Catalan university system, with a clear, social remit.

One of the first projects of the chair was to advice the University of Vic on the creation of a Research Ethics Committee at UVic–UCC, as an essential tool to enable researchers to validate all of the ethical aspects of their research projects. The chair will play an active role in this committee.

Activities

#### 12 May 2015

in bioethics

Nursing Discussion Day, organized by the Faculty of Health Sciences and Wellbeing and the Osona branch of the Official College of Nursing of Barcelona. Opening lecture by Núria Terribas, "Ethical values in the nursing profession."

#### 28 May 2015

UVic Health Meeting, talk by Núria Terribas, "The ethical conflicts that arise from digital health."

#### 19 October 2015

Presentation of UVic–UCC Code of Ethics, and public presentation of the Chair of Bioethics.



Jordi Montaña, Victòria Camps and Núria Terribas at the presentation of the Chair of Bioethics.

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#### **04 EDUCATION AND LEARNING**

#### TRAINING COURSES FOR PROFESSIONALS

Online course: "Introduction to bioethics in multidisciplinary clinical practice"

### Catalan Institute of Oncology (ICO) February 2015 15 hours

The Víctor Grífols i Lucas Foundation and the Catalan Institute of Oncology (ICO) organized the second edition of this online course, delivered via the e-oncology virtual platform. The course drew on a number of case studies to present a range of situations that students might encounter in their professional practice. Topics addressed included patients' rights, the clinical relationship, decision-making and the rational use of resources.

www.e-oncologia.org

Course: "Bioethics for health professionals"

### Quirón Dexeus 11 February to 4 March 2015 16 hours

This course was aimed at members of the Clinical Ethics Committee (CEC) of Quirón Dexeus University Hospital and had three objectives: to raise awareness of the importance of incorporating ethical reflection into professional practice; to offer tools to deal with situations where conflicts of values arise; and to train participants to solve case studies.

Course: "Bioethics: a new discipline or applied ethics?"

### Barcelona College of Doctors (COMB) 5 February to 5 March 2015 20 hours

The Foundation has formed a partnership with the study centre of the Barcelona Official College of Doctors to organize and sponsor two courses in bioethics. The first course to be delivered in 2015 consisted of 20 hours, with the aim of

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explaining the principles and procedures of bioethics in order to identify and address the ethical conflicts that may arise in professional practice.

Course: "Bioethics in care practice"

L'Anoia Health Consortium 18 to 26 March 2015 12 hours

The Foundation organized this course in partnership with l'Anoia Health Consortium to provide health and social service professionals with the knowledge and skills they need to identify and analyze the ethical questions that arise in professional practice.

Course: "Bioethics for health professionals"

### Barcelona Children's Hospital 22 April to 13 May 2015 16 hours

This training was provided for the members of the Clinical Ethics Committee (CEC) of the Barcelona Children's Hospital, with the aim of offering tools with which to tackle conflict situations, and to provide training in methodologies to resolve case studies, with a particular focus on the problems arising when caring for children and adults and their need for interaction with their families.

Course: "Introduction to basic contents of bioethics"

### Official College of Doctors of Barcelona 1 and 8 July 2015 8 hours

During the summer, the Foundation organized the second annual course on bioethics with the Official College of Doctors of Barcelona (COMB). The course addressed basic concepts and issues in bioethics, including the principles of universal ethics, the doctor—patient relationship, genetics and the end of life.



Marc Antoni Broggi and Núria Terribas at the course organized with CUIMPB.



Sergio Ramos delivered the bioethics course as part of the "Teachers and science" programme.

Course: "The right to know about one's biological origins: ethical and legal challenges"

# Menéndez y Pelayo International University Consortium, Barcelona

**19 November 2015** 

In partnership with the Menéndez y Pelayo International University Consortium, Barcelona (CUIMPB), the Foundation organized a course designed to analyze the legal, ethical and social aspects of the right to know about our biological origins, both in the case of people who have been adopted and in cases where people have been born as the result of assisted reproduction using donor gametes. The topic attracted not only professionals from the assisted reproduction sector but also those working in social services and dealing with adoption issues, together with professionals from other disciplines such as psychology and sociology.

### Bioethical training for nursing care auxiliaries

### Hospital Clínic, Barcelona 26 November 2015 5 hours

The Foundation contributed to the 3rd Oncohaematology training course for nursing care auxiliaries at the Hospital Clínic, with a session titled "Bioethical reflection: the analysis of conflicts in care practice."

#### TRAINING FOR THE EDUCATION SECTOR

Course: "Introduction to Bioethics"

# Catalan Schools Association 26 and 28 January 2015

This course was aimed at high school teachers in Catalonia and aimed to promote bioethical debate in the classroom. It provided an overview of bioethics, with special emphasis on its application in the medical context. It addressed topics such as the doctor—patient relationship, bioethics at the end of life, participation in clinical trials, ethics committees, and the use of health resources.

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#### **Education Fair**

#### 18 to 22 March 2015

The Foundation participated in the Barcelona Education Fair to help publicize its Prizes for Bioethics Research by senior high school students, and its Ethics and Science Award for educational establishments. In partnership with the Catalan Foundation for Research and Innovation (FCRI), the Foundation attended EspaiCiència, an event for institutions and universities with an active research profile.

#### 16th Exporecerca Jove

#### 26 to 28 March 2015

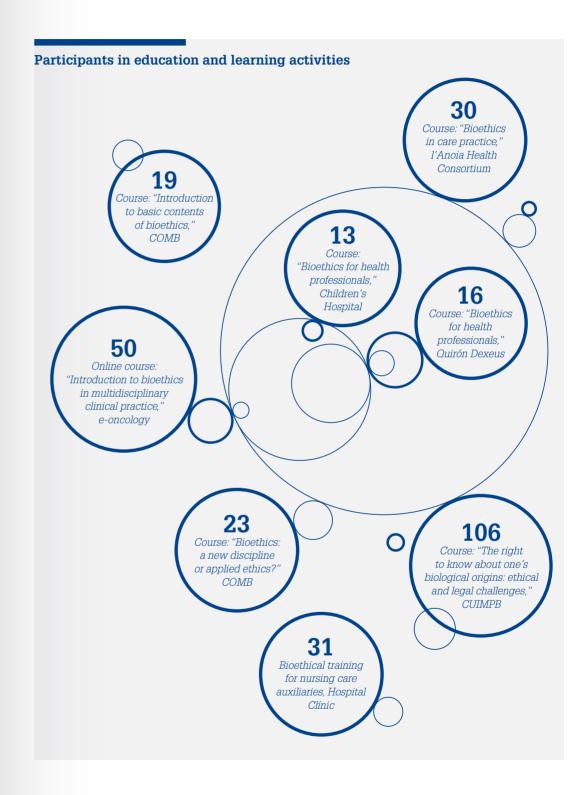
For the second year running, the Foundation has contributed to Exporecerca Jove 2015, organizing a workshop with the title "Is it ethical to design people à la carte?" The Foundation also organized a prize for research projects, presented as part of this event. This was won by Mireia Jaimot Pallejà of Arabell school, Lleida, for her work, "Umbilical cord blood stem cells: business or science?"

Course: "Ethical dialogue and bioethical perspectives on science"

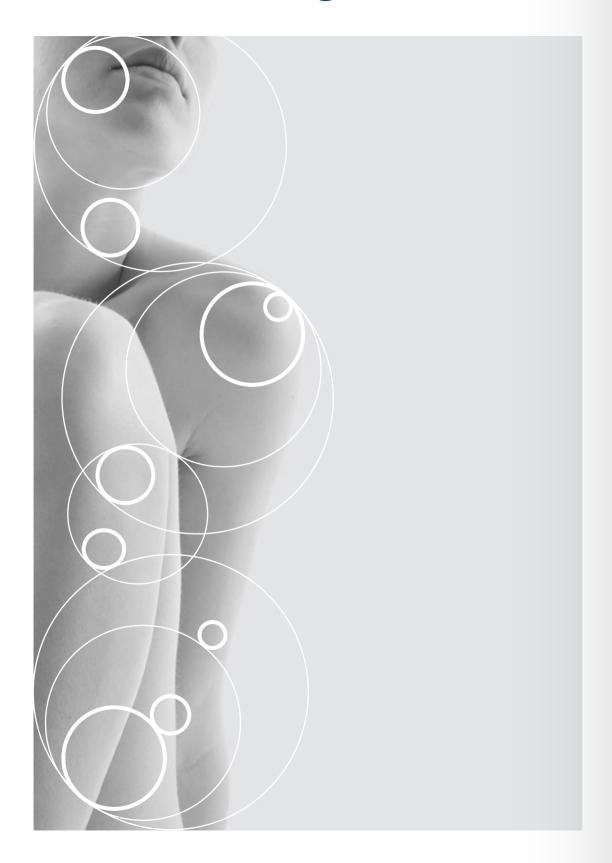
#### 4 and 6 November 2015

The 9th edition of the "Teachers and science" training programme for high school science teachers, organized by Fundació Catalunya—La Pedrera, once again received support from the Foundation, which organized a course. This year, the theme was dialogue between the sciences and the humanities, as part of the search for answers to the dilemmas raised by biomedical and technological progress, attempting to address them in the classroom in ways that are accessible to students.

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# **Awards and grants**



As part of its commitment to promoting the study and awareness of bioethics, in 2015 the Foundation awarded a journalism prize, six bioethics grants, three senior high school prizes and a prize for educational establishments.

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#### **BIOETHICS AWARD CEREMONY**

27 October 2015

The bioethics award ceremony was held at the Barcelona Athenaeum and included a homage to Víctor Grífols i Lucas, the driving force behind the Foundation, who sadly passed away this year. This tribute was followed by the lecture, "Living well and dying well," by Jesús Mosterín, Research Lecturer at the Institute of Philosophy at CSIC.

In his lecture, Mosterín argued for a vision of life and death in which our lives are a work of art that is created by us, from beginning to end: an end that can be timely and welcome if we learn how to face it with serenity and reason.

This was followed by the presentation of prizes. The winning entrants were chosen by a jury consisting of:

Salvador Alsius

Professor of Journalism at Pompeu Fabra University, Barcelona

Margarita Boladeras

Professor of Moral Philosophy and Politics at the University of Barcelona

Àngel Puvol

Director of the Department of Philosophy at the Autonomous University of Barcelona

Jordi Caïs

Professor of Sociology and Organization Analysis at the University of Barcelona

Màrius Morlans

Member of the Bioethics Committee of Catalonia

#### **RESEARCH GRANTS: 17TH EDITION**

The grants to support research projects, worth 5,000 euros each, were awarded to:

Loreto María García Moyano of the University of Zaragoza for: **«Constructing a tool to quantify professional commitment in nursing»**.

Lydia Feito Grande and Tomás Domingo Moratalla of the Complutense University in Madrid for: «Narrative bioethics: applying the model in the clinical and educational setting».

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Awards ceremony.

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#### **05 AWARDS AND GRANTS**

The team led by Maite Cruz Piqueras of the Andalucian School of Public Health for: «Non-vaccination as a meeting point: analyzing discourse to build bridges».

Elena Lauroba of the University of Barcelona for: «The legal protection of intersex people: reconsidering the (arbitrary?) assignation of gender from a legal perspective».

To Sonia Jimeno Ramírez of the University of Barcelona for: **«Biotechnological patents: at the limits of legality»**.

To Gemma Robleda and Josep E. Baños of Pompeu Fabra University, Barcelona for: **«Evaluating pain in adults without the capacity for communication. A bioethical analysis in hospitalization units for critical patients»**.

#### **COMPLETED RESEARCH GRANTS**

The reports and conclusions of the winning projects from last year were presented. Details of these projects can be consulted on the Foundation's website:

- **«The advance directives document in mental health»** by Sergio Ramos Pozón of the University of Barcelona.
- **«The epidemiology of resilience»** by Jordi Cabòs Teixidó of the University of Barcelona.
- **«Communication and apology after a medical error»** by the team led by Priscila Giraldo of the Hospital del Mar Medical Research Institute (IMIM).
- **«Study of empathy in primary care doctors and nurses in the Lleida Health Region and its relationship to clinical variables»** by the team led by Oriol Yuguero of the University of Lleida.
- «The concept of autonomy in the DSM 5: features and possible implications of its modification» by Omar García Zabaleta of the University of the Basque Country.
- **«Programme for shared decision-making in breast cancer with mastectomy. The woman's right to decide»** by Míriam de la Flor of Joan XXIII University Hospital.

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Teachers from IES Fontanelles collected the first Ethics and Science prize.

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#### **JOURNALISM PRIZE: 15TH EDITION**

The report **Patients waiting** (**«Pacients en espera»**) by the 30 minuts programme on TV3, broadcast on 1 June 2014, was awarded the Bioethics Journalism Prize, worth 3,000 euros.

# PRIZE FOR RESEARCH BY SENIOR HIGH SCHOOL STUDENTS: 3RD EDITION

The prizes for bioethics research by senior high school students were awarded to:

**First prize**, Marta Galisteo Garrido, Instituto Llavaneres, for: **«Modern** eugenics: should we intervene to improve human genetics?»

**Second prize**: Mariona Asensio and Júlia Marqués Espuga, Instituto Joaquima Pla i Farreras, Sant Cugat del Vallès, for: **«Intersexuality: the breakdown of a binary system»**.

**Third prize**: Mireia Jaimot Pallejà, Arabell school, Lleida, for: **«Umbilical** cord blood stem cells: business or science?»

#### ETHICS AND SCIENCE PRIZE: 2ND EDITION

The members of the jury for the second edition of the ethics and science prizes, for educational establishments, were:

Ester Busquets

Professor of Bioethics at the University of Vic—Central University of Catalonia (UVic—UCC) and contributor to the Borja Institute of Bioethics (Ramon Llull University)

Eva Calvés

Director of the Young People and Science Programme of the Fundació Catalunya—La Pedrera

Jaume Funes

Psychologist, educator and journalist

Rosina Malagrida

Director of the unit for public participation in biomedical research of the IrsiCaixa AIDS Research Institute and coordinator of Xplore Health

Ferran Ruiz

President of the Education Committee of Catalonia

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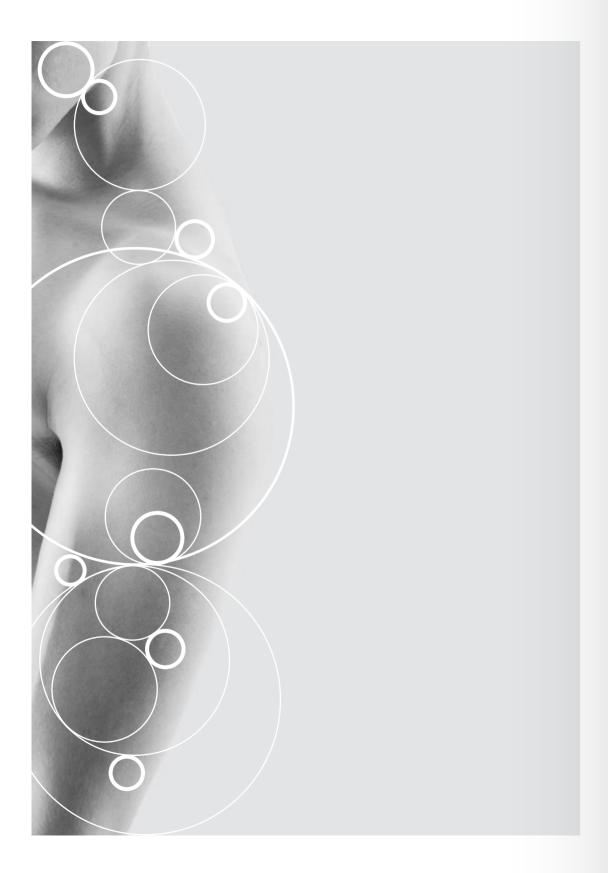
The awards were presented on 22 December at the Palau Macaya in Barcelona as part of an event that included the lecture "Values make you a winner" by Pep Marí, a psychologist who specializes in sporting performance. In his talk, he discussed strategies for transmitting values. Marí explained how values establish the rules of the game in all of our lives. Training in values can help us to take better decisions and to be winners, both in sport and in life. The lecture was followed by the award ceremony. The winners were:

First prize: **IES Fontanelles de Les Borges del Camp** for the project **«Hospital Role Play»**.

Second prize: **Instituto Juan Manuel Zafra in Barcelona** for the project **«Doing science to communicate about science»**.

Third prize: **Escola Sant Gervasi Cooperativa** for the project **«Blood and tissue donation: scientific ethics and social reality»**.

# **International**



As part of its strategy of raising its profile outside of Spain, the Foundation was involved in two international collaborations in 2015.

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#### **06 INTERNATIONAL**

# SEMINAR: "CHILDREN AND CLINICAL RESEARCH"

12 June 2015

The Foundation and the highly-regarded Nuffield Council on Bioethics have an existing partnership agreement, under which they organized a seminar on ethical aspects of research with children. The event, hosted by the Foundation in Barcelona, was attended by around forty health professionals and experts, drawn from the fields of paediatric research and bioethics, from both Spain and the United Kingdom. The purpose of this private seminar was to present the document "Children and clinical research: ethical issues," published by the Nuffield Council, and to generate debate on a number of topics, giving researchers from both countries a chance to share their perspectives.

As part of its partnership with the Nuffield Council, the Foundation published Spanish summaries of the report and also sponsored the translation into Spanish of a video about clinical research aimed at children (see publications and communication).

#### ANNUAL CONGRESS OF THE EACME

17 to 19 September 2015

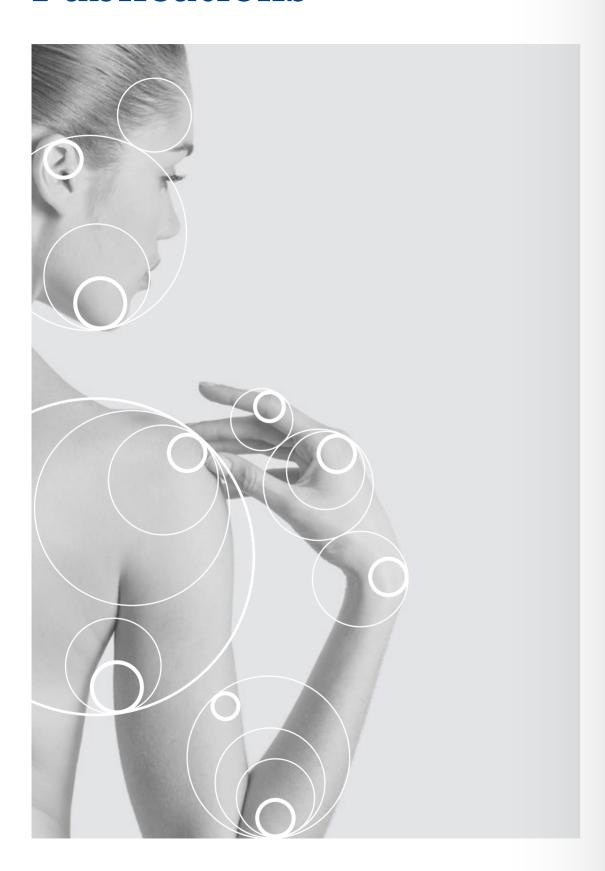
The Centre for Clinical Bioethics of the Mediterranean, Università degli Studi di Cagliari, Sardegna Ricerche and the European Association of Centres of Medical Ethics (EACME) organized the EACME Annual Conference on the theme: "Clinical ethics: past, present and future," in Cagliari, Italy. The Foundation gave a presentation with the title: "1964 to 2014: 50 years of the Helsinki Declaration – the ethical dilemmas of clinical research."

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Seminar organized with the Nuffield Council on Bioethics.

# **Publications**



### **MONOGRAPHS**



# Treinta años de técnicas de reproducción asistida

1984 saw the first birth in Spain as a result of in vitro fertilization. Thirty years on from this milestone, the Víctor Grífols i Lucas Foundation organized an event with the aim of providing an overview of the application of assisted reproduction techniques during the last three decades. This monograph includes the papers presented at the seminar.

Edited in Spanish.



# Ética y altruismo

What makes us generous? Putting a face to a person in need, a sense of connection to others, the feeling that we are doing the right thing, having a variety of different methods and incentives for donating... Peter Singer and other authors reflect on altruism in this monograph.

Edited in Spanish.

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#### **07 PUBLICATIONS**



# Determinantes personales y colectivos de los problemas de la salud

Our health depends on our strength of will, our lifestyle, risks, decisions and behaviour. But it also depends on our biology and on the environment in which we live. This monograph analyzes where responsibility for our health lies and how this affects health policy.

Edited in Spanish.

#### **REPORTS**



# La interacción públicoprivado en sanidad

We find ourselves in a situation where the need to rationalize health resources and increase the efficiency of the system has reopened a vigorous debate about the interaction between the public and private spheres. The articles contained in this publication are designed to offer a starting point to address the regeneration of the public health system, based on a recognition of the complexity of the current situation.

Bilingual edition (Catalan & Spanish).

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#### **PARTNERSHIPS**



# Children and clinical research

Between 2013 and 2015, a working group led by the Nuffield Council on Bioethics analyzed how to conduct clinical research with children in an ethically correct manner. The results were published in the report "Children and clinical research." The Foundation sponsored the translation into Spanish of summarized versions of the report.

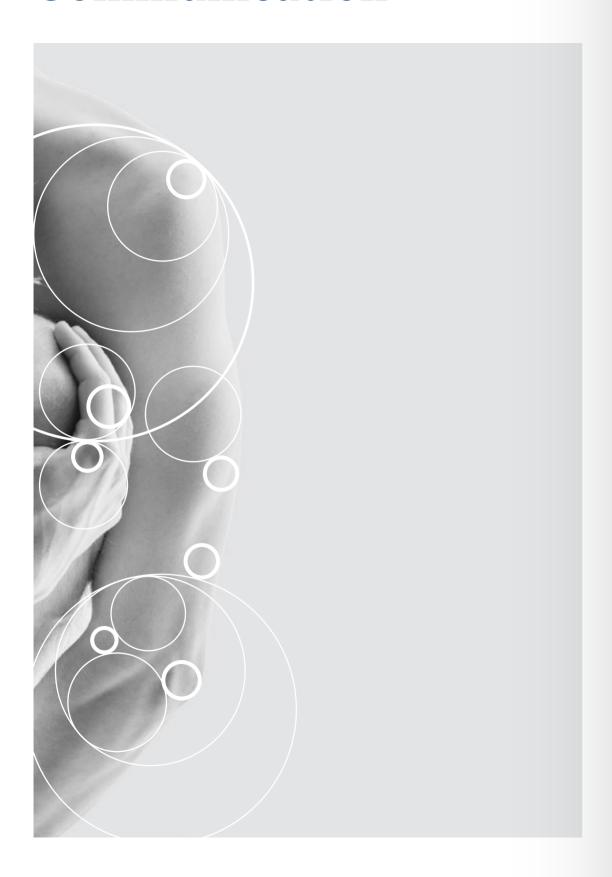
Edition for children and families:

Participación de los niños y jóvenes en la investigación clínica: cómo hacerlo correctamente

Edition for health professionals:

Los niños y la investigación clínica: aspectos éticos

# Communication



Throughout 2015 the Foundation continued to emphasize the importance of communication activities to disseminate and raise awareness of its initiatives in bioethics. The website has been redesigned, media relations continue to be strengthened, and the Foundation's presence on social networks has increased.

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#### **08 COMMUNICATION**

#### **PRESS**

The Foundation works closely with the media to inform people about the activities it organizes, the awards it presents, and the monographs and reports it publishes. During 2015, the Foundation issued 15 press releases. Six of these referred to the bioethics prizes and grants, and the ethics and science prize; four related to events, in particular the Josep Egozcue Lectures on euthanasia and assisted suicide; and three press releases contained information about publications.

#### WEBSITE AND NEWSLETTERS

In June 2015, the Foundation unveiled its new website sporting a fresh design that will make the site easier to navigate, and which offers improved content management. The information content has been restructured to reflect the Foundation's current activities. Plans for 2016 include improving usability in order to simplify the registration of users and the process of registering for activities.

This year, the website received an average of 1,900 visits per month, a slight decline compared to the previous year, as a result of the increasing diversification of communication channels. Many users currently find out about

The newsletters reach 4,700 users, an increase of 30% from the previous year.

the Foundation's activities through social networks or newsletters, and only visit the website when they need to register for activities or download publications. Together with the awards and grants, these are the sections that receive most visitors. Despite the lower number of visits to the website, there has been an increase in registered users.

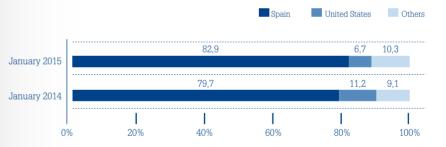
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#### **Total sessions / Monthly visits**

actualized 2014



#### Total pages visited



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#### **08\_COMMUNICATION**

#### **SOCIAL NETWORKS**

The Víctor Grífols i Lucas Foundation sustained its commitment to social networks, particularly Twitter and Facebook, during 2015. These digital tools enable the Foundation to reach more users, and to interact directly with people who are interested in its activities. The Foundation's Twitter account gained 440 followers during the year, an average of 36 new users each month. The Foundation's profile received an average of 905 visits per month, with a total of 19,700 impressions each month. The Foundation's followers on Twitter are interested in science and news, with 90% living in Spain, of whom 48% are male and 52% are female. On Facebook, 59% of the Foundation's followers are female and 40% are male, with 80% living in Spain, and the rest from other countries, including Argentina, Mexico and the United States.

f /fundaciogrifols

**■** @FundacioGrifols

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#### 08 COMMUNICATION

#### **VIDEOS**

This year, the Foundation has uploaded the following videos to YouTube: bioethics awards ceremony lecture Living well and dying well by Jesús Mosterín; lecture series by Christian Felber about The economics of the common good; and Francisco Ayala's lecture on The roots of morality. The three videos have been viewed a total of 1,790 times.

As part of its collaboration with the Nuffield Council on Bioethics, the Foundation sponsored the translation of the animated video "Children and clinical research," aimed at children. The film is told from the perspective of Mia, a character who goes through some of the questions and issues that might be raised when a young person is invited to take part in clinical research. The short film includes the main points of the report "Children and clinical research: ethical issues" published by the Nuffield Council.



La buena vida y la buena muerte



Investigación médica: La decisión adecuada para mí Video translated into Spanish:



Raíces de la moralidad



Health research: Making the right decision for me original version with Spanish subtitles



La economía del bien común

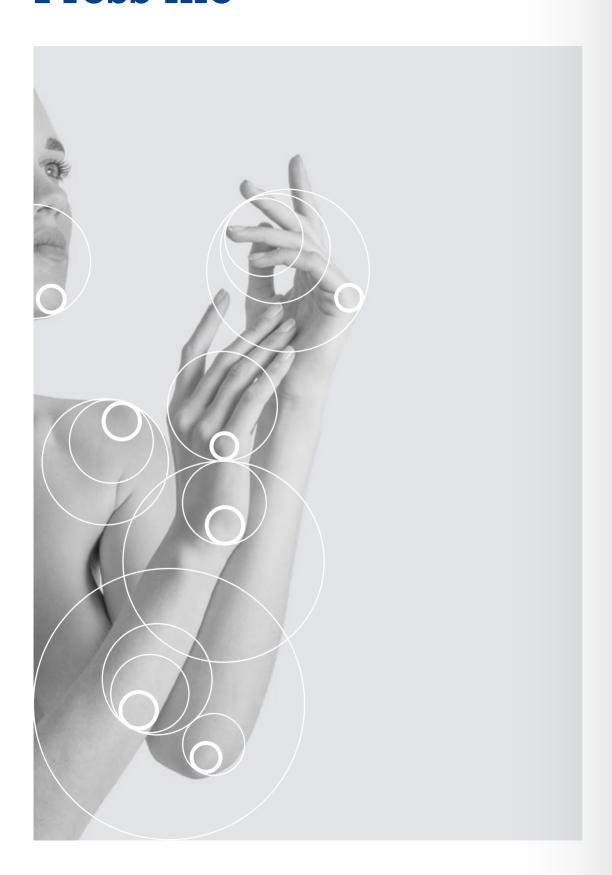
#### **CORPORATE MATERIALS**

This year the Foundation has produced a range of corporate materials, designed to raise the Foundation's profile and to promote its activities. These include programmes for specific events and the production of a general leaflet, while images for the awards and for other corporate information have also been updated. The new designs, based on geometric figures, maintain the Foundation's visual identity.

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# Press file



Es crea en col·laboració amb la Fundació Grífols i la dirigirà Núria Terribas

# Victòria Camps dirigirà la nova Càtedra de Bioètica de la UVic





**El 9 Nou** 20 February 2015

# **Diario Médico** 21 April 2015

# Victoria Camps, titular de la nueva Cátedra de Bioética de UVic-UCC



# La UVic i la Fundació Grífols creen la càtedra de Bioètica

**El 9 Nou** 27 April 2015

# La bioètica és cosa de nens



Press file

### Acceptació i dignitat davant la mort

14 October 2015

Ara 8 November 2015

# IESÚS MOSTERÍN "NO REFLEXIONEM SOBRE LA MORT SI TOT VA BÉ"



VICTOR
GRIFOLS

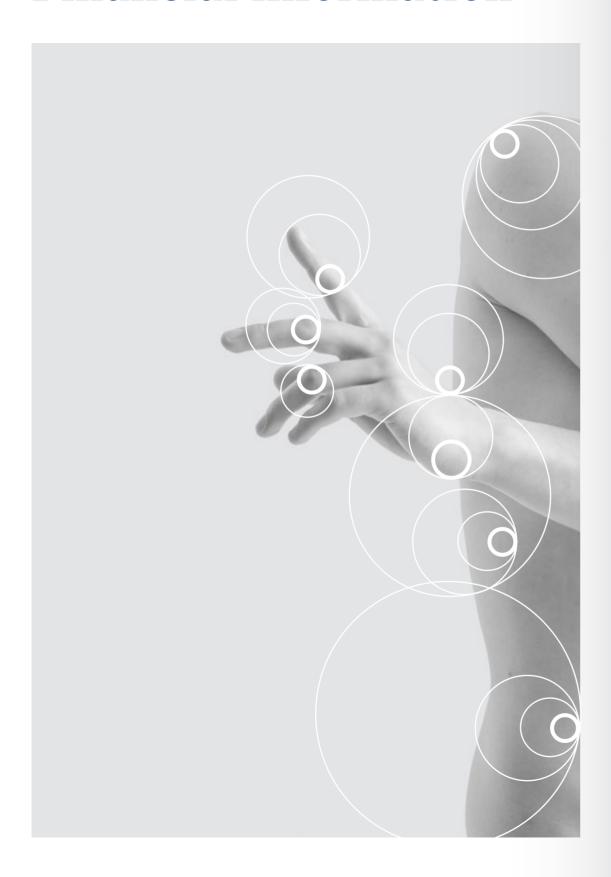
| El quámico y farmacéstico catalán heredó junto a su hermano José
Antonio el que hoy es el conglomenado empresarial Gelfols, del que hue
uno de sus antifices al traspasar las fivontenas españolas en la década de los 60 del siglo-

#### Desde la ética personal

El Mundo 20 June 2015



# **Financial information**



The financial figures for 2015 can be consulted in the balance sheet and the profit and loss account.

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### **BALANCE SHEET**

December 31th 2014 and 2015

|   | _       |         |
|---|---------|---------|
| Assets  | 2015    | 2014    |
| Non-current assets  |         |         |
| Tangible assets   | 925     | 925     |
| Working Capital   |         |         |
| Other Debtors   | 112     | 5.309   |
| Treasury  |         |         |
| Cash  | 143     | 311     |
| Banks and credits institutions, current accounts and sight deposits | 145.791 | 136.725 |
| Total Working Capital   | 146.046 | 142.344 |
| Total Assets  | 146.971 | 143.269 |
| <br>Liabilities   | 2015    | 2014    |
| Equity  |         |         |
| Endowment fund  | 12.020  | 12.020  |
| Surplus from previous periods                                       | 33.914  | 33.026  |
| Surplus for the period  | 6.915   | 888     |
| Total Equity  | 52.849  | 45.934  |
| Short-term Creditors  |         |         |
| Short-term Creditors  |         | 0       |
| Total Short-term Creditors  |         | 0       |
| Suppliers and Other Creditors                                       |         |         |
| Debts for the purchase or provision of services                     | 68.688  | 70.294  |
| Public bodies   | 18.746  | 17.203  |
| Total Suppliers and Other Creditors                                 | 87.434  | 87.497  |
| Others Liabilities Personal Current                                 | 6.688   | 9.839   |
| Total short-term Creditors  | 94.122  | 97.366  |
| Total Liabilities   | 146.971 | 143.269 |

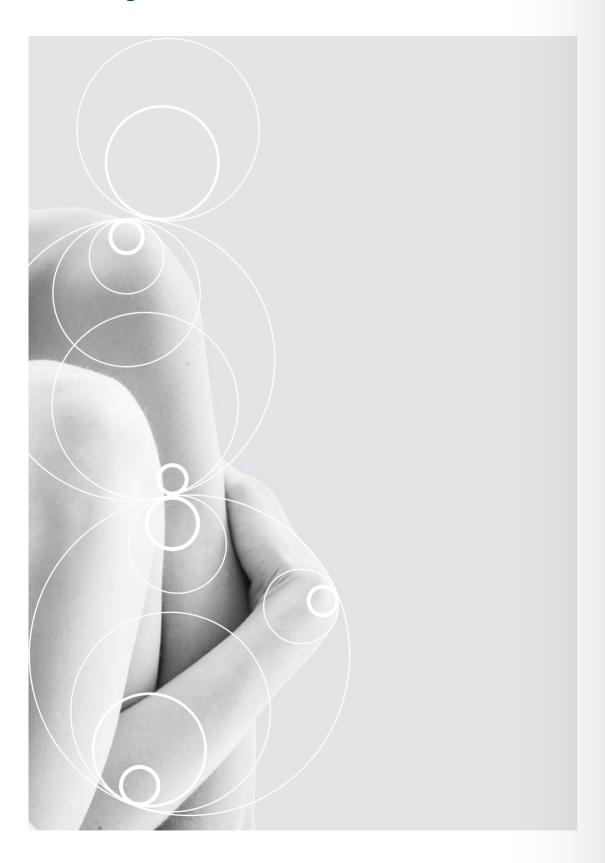
## PROFIT AND LOSS ACCOUNT

December 31th 2014 and 2015 (In euros)

| Expenses                             | 2015    | 2014    |
|--------------------------------------|---------|---------|
|                                      |         |         |
| Cash grants and other expenses       | 43.742  | 69.720  |
| Other expenses                       |         |         |
| External services                    | 156.526 | 251.059 |
| Taxes                                | 267     | 282     |
| Total expenses                       | 374.671 | 458.509 |
| Operating profit                     | 6.915   | 1.491   |
| Profit from ordinary activities      | 6.915   | 1.491   |
| Positive surplus for period (profit) | 6.915   | 1.491   |

| Income  | 2015    | 2014    |
|---|---------|---------|
| Foundation's income from activities                 |         |         |
| Income from promotions, sponsors and joint projects | 375.921 | 460.000 |
| Provision of Services                               | 5.665   | 0       |
| Total operating income                              | 381.586 | 460.000 |
| Operating losses                                    | -       | -       |
| Losses from ordinary activities                     | -       | -       |
| Negative surplus for period (loss)                  | -       | -       |

# **Diary of events**



The diary of events includes the activities scheduled for 2016. It is provisional, with some activities and dates still pending confirmation.

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## **January**

#### 20 January

Course on the advance directive document. Quirón Dexeus

# **February**

#### 16 February

Presentation of report: "Public private interaction in health care"

#### 4 February to 3 March

COMB Course: "Bioethics: A new discipline or applied ethics?"

### March

### 1 March to 1 May

Bioethics Course, in partnership with the Catalan Institute for Oncology

#### 9 to 13 March

Education Fair

#### 17 to 19 March

Exporecerca. Workshop: "The right to know one's biological origins"

#### 31 March

Panel discussion on neuroscience (CCCB)

# **April**

#### 4 April

Lecture: "The augmented brain," Jean-Pierre Changeux, neuroscientist (CCCB)

#### 7 April

Lecture: "Living forever," Aubrey de Grey. (CCCB)

# May

#### 19 May

Lecture on the ethical aspects of the right to know one's biological origins (Barcelona)

Discussion seminar: "Genetic counselling"

## **June**

#### 14 June

Managing genetic data for research (UVIC workshop)

#### 27 and 28 June

COMB course: Introduction to bioethics

# July

Barcelona International Youth Science Challenge: Session on Ethics and Science as part of the international meeting of young researchers, Fundació Catalunya— La Pedrera, Barcelona.

SESPAS public health seminar, Barcelona

# September

#### 8 to 10 September

EACME "30 years of European bioethics"

# **October**

Seminar "The human condition in the age of biotechnology" (Grupo Aporia)

Awards ceremony

### **November**

#### 15 November

Josep Egozcue Lectures "Brain death and persistent vegetative state: clinical and ethical challenges"

#### 17 to 18 November

ICREA talk "Personhood and the locked-in syndrome"

Festival of Philosophy "Barcelona Pensa" (Barcelona Thinks)

### **December**

Ethics and Science Awards Ceremony



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