## FUNDACIÓ VÍCTOR GRÍFOLS i LUCAS

## Annual Report 2010

ANNUAL REPORT 2010

SUMMARY

## Annual Report 2010

## 01 Introduction

**02** The Foundation

- Objectives
- Board of Trustees

## 03 Activities

- Presentation of the book Ética en enfermería
- Seminar: Maleficence in prevention programmes
- Ethical question: Surrogate pregnancy
- Seminar: The ethics of scientific communication
- Lecture: "Individual healthy behaviour and healthy life styles. Advances in prevention and Chronic Care Management"
- 4th Josep Egozcue Lecture Cycle
- Course: The elderly sick patient

**04** Awards and Grants

- Bioethics Prizes
- Members of the Jury

- 12th Bioethics Research Prize
- 10th Journalism Prize
- 12th Research Grants
- Completed research projects

## 05 Publications

- Published titles
- Publishing partnerships

## **06** The Foundation online

- Website
- Bionethics
- RSS feeds
- YouTube channel

**07** Financial data

**08** Press review

**09** Diary of Events 2011



FUNDACIÓ VÍCTOR GRÍFOLS I LUCAS

01 ANNUAL REPORT 2010

This annual report describes the activities organized by the Foundation in 2010. The last year has seen a packed programme of debates and lectures on issues including not only those topics which are at the top of the bioethics agenda but also others which have tended to be ignored. The latter group includes the seminar on "Maleficence in prevention programmes" and the discussion day on "Surrogate pregnancy". The first of these is a public health issue, and as such raises extremely complex social, ethical and political questions. At the Foundation we have been keen to encourage reflection in this area, starting with the analysis and evaluation of breast cancer prevention programmes. We hope to stimulate ethical discussion of the justification, reasons and consequences for certain interventions in preventive medicine which are not always clearly beneficial for those at whom they are directed. The issue of surrogate pregnancy concerns an arrangement which is currently illegal in most countries but which is permitted in some. The globalized world in which we live makes it easier than ever to circumvent such local prohibitions by travelling to other countries, and this means that we need to be clear about whether such arrangements should indeed be illegal and what the ethical reasons for such a prohibition might be. The debate we organized addressed this concern.

A few years ago, the Foundation established a series of discussions and reflections on medical and scientific communication and the ethical problems it raises. These were welcomed both by health professionals and by journalists in new and traditional media grappling with the challenges posed by the new information technologies which have revolutionized the world of health communication. With the cooperation of the Scientific Communication Research Centre of the Pompeu Fabra University, we have decided to analyse and discuss the individual issues which affect the acquisition and transmission of



health culture in the internet era, to identify both the threats and the opportunities offered by these new technologies, and to provide a framework within which to evaluate them.

This year's Josep Egozcue lecture cycle was delivered by Dr. Mark Siegler, of the University of Chicago. Dr. Siegler's professional reputation and his record as a promoter of medical ethics drew a large audience, who enjoyed the opportunity of listening to his ideas and participating in a discussion about the problems in the doctor-patient relationship in a period when we are striving to move beyond the paternalistic and authoritarian template of the past. Another activity which reflects long-standing concerns of the Foundation was the course on "The elderly patient", organized in conjunction with the Menéndez Pelayo International University. This course addressed a range of issues and conflicts which arise when treating patients who are elderly and are often in a position of dependency, where the aim is to ensure that extending life expectancy is not achieved at the expense of quality of life.

One of the major ways in which the Foundation adds value to its activities is through its publishing programme. During 2010, the Foundation produced its twenty-fifth monograph, and also expanded its list of reports and ethical questions. The main demand for these publications is from those involved in teaching about bioethics in universities, high schools and other educational establishments.

Finally, we are committed to constantly updating our website so that the information it contains is easily accessible to all. We encourage website users to take an active interest in the contents, and send out publications to anyone who requests them. In 2010 we launched our YouTube channel, which provides highlights of the Foundation's events.



Recalling the ideas of Pedro Laín Entralgo, Dr. Mark Siegler argued in his lectures that the medical relationship should be one of friendship, adding that "this is the language of professionalism." It is our aim that the activities and discussions promoted by the Foundation, starting from an ethical perspective, represent among other things a commitment to professional excellence in the truest sense.



Victòria Camps President



# The Foundation

FUNDACIÓ VÍCTOR GRÍFOLS I LUCAS



### Objectives

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 <u>Grifols</u>, a holding company dedicated to the hospital pharmaceutical sector, the Foundation is an independent body which dedicates resources to the investigation of the ethical problems which arise among the diverse range of people working in the health sector.

#### The Foundation's goals are as follows:

- To promote research in specific areas of bioethics by awarding grants and prizes.
- To organize lectures and seminars which raise awareness of and explore the ethical issues which are constantly raised by the life and medical sciences.
- To produce publications which disseminate the work of the Foundation.
- To be receptive to any activities which aim to explore the ethics of life.



The Foundation



#### **Board of Trustees**

The Board of Trustees of the Foundation has fourteen members, all of whom are recognized for their achievements in different areas of bioethics research and investigation. Their links with a wide range of disciplines including philosophy, medicine, teaching and law provide a multidisciplinary basis for the Foundation's activities.

President: Victòria Camps

Professor of Moral Philosophy at the Autonomous 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:

Francesc Abel

President of the Board of Trustees of the Borja Institute of Bioethics

#### Neal Ball

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

Ramon Bayés

Professor of Basic Psychology and Emeritus Professor at the Autonomous University of Barcelona

Montserrat Busquets

Lecturer at the School of Nursing at the University of Barcelona

Ignacio Calero

Lawyer with Osborne Clarke S.L.P.

#### Xavier Carné

Head of the Clinical Pharmacology Service of the Hospital Clinic of Barcelona

Tomás Dagá

Lawyer with Osborne Clarke S.L.P.

#### **The Foundation**



Vladimir de Semir

Lecturer and Director of the Scientific Communication Research Centre of the Pompeu Fabra University of Barcelona

Guillem López i Casasnovas Professor of Economics at the Pompeu Fabra University of Barcelona

Josep M<sup>a</sup> Lozano Lecturer at the ESADE Department of Social Sciences

Francesca Puigpelat Professor of Legal Philosophy at the Autonomous University of Barcelona



Board of Trustees



FUNDACIÓ VÍCTOR GRÍFOLS I LUCAS



Throughout 2010 the Foundation promoted a range of events and activities with the aim of generating debate and discussion of issues related to bioethics.

#### Presentation of the book Ética en enfermería

The first event of the year was the presentation of the book *Ética en enfermería* (*Nursing Ethics*). On the 9th of March the Foundation invited one of the authors of this handbook, Verena Tschudin, to present the Spanish edition of the book published by Triacastela. At the presentation, Tschudin delivered a lecture on "the importance of learning, teaching and practising ethics in nursing". The event was organized in cooperation with the Official College of Nursing of Barcelona (COIB), and was hosted by them.

The participants were:

- Mariona Creus, president of the COIB.
- Montserrat Busquets, nurse and member of the board of Trustees of the Víctor Grífols i Lucas Foundation.
- Maria Gasull, Member of the Professional Ethics Committee of the COIB.
- José Lázaro, director of the Medical Humanities list for Triacastela publishers.



Presentation of the book Ética en enfermería

#### Seminar: Maleficence in prevention programmes

In cooperation with the Institute for Health Studies (IES), on 20 April the Foundation organized a seminar with the title "Maleficence in prevention programmes". The discussion day analysed ethical issues relating to secondary breast cancer prevention programmes based on two-yearly breast scans of apparently healthy populations of women aged between 50 and 74 years.

The speakers were:

- Andreu Segura, Director of Public Health at the Institute for Health Studies.
- José Ramón Repullo, Head of the Department of Health Planning and Economics at the Carlos III Institute.
- Ricard Meneu, of the Health Services Research Institute Foundation in Valencia.
- Teresa Queiro, of the Agency for the Evaluation of Health Technologies of Galicia.
- Montserrat Casamitjana, President of the Catalan Society for Public Health.



Seminar: Maleficence in prevention programmes

### **Ethical question: Surrogate pregnancy**

On 22 April, the Foundation debated the ethical question "Surrogate pregnancy. Analysis of the current situation". The "ethical questions" series is an initiative of the Foundation designed to bring together a small group of experts to discuss an issue in bioethics and to generate ideas. In this case, the issue was one of the most controversial within the field of assisted production: that of surrogate pregnancy.

#### Coordinators:

- Francesca Puigpelat, Professor of Legal Philosophy, Co-director of Postgraduate Studies in Gender and Inequality at the Autonomous University of Barcelona and member of the Board of Trustees of the Víctor Grífols i Lucas Foundation and of the Bioethics Committee of Catalonia.
- Ventura Coroleu, Head of Reproductive Medicine Department at the Dexeus University Institute and President of the Spanish Fertility Society.



Ethical question: Surrogate pregnancy

#### Invited specialists:

- Itziar Alkorta, Senior Lecturer in Civil Law and Vice-Chancellor for Quality and Teaching Innovation at the University of the Basque Country.
- Montserrat Boada, Director of the Assisted Reproduction Laboratories at the Dexeus University Institute.
- Victoria Camps, President of the Víctor Grífols i Lucas Foundation.
- Diana Guerra, Clinical Psychologist with IVI Barcelona.
- Juan Ortiz, Lawyer and Legal Coordinator of NQ Abogados España.
- Carme Valls-Llobet, Endocrinologist and President of Catalunya Segle XXI Foundation.



#### Seminar: The ethics of scientific communication

In 2001 the Foundation organized its first debate on "The ethics of scientific communication". Nine years on, it was essential to revisit the subject in light of the far-reaching and rapid changes in the world of communication. With the support of the Scientific Communication Research Centre of the Pompeu Fabra University, the Foundation organized a discussion day chaired by Vladimir de Semir, director of the Communication Research Centre. The event consisted of two papers followed by four working groups which brought together health and medical professionals and students on the Master's Course in Scientific Communication at the Pompeu Fabra University.

Lecture:"Individual healthy behaviour and healthy life styles. Advances in prevention and Chronic Care Management"

For the second year in a row, the Foundation supported the Global Health Leadership Forum by sponsoring one of its sessions. This course is a health management seminar organized by the Barcelona Graduate School of Economics, the Centre for Research in Economics and Health (CRES) and the University of Berkeley.



Seminar: The ethics of scientific communication



Lecture: "Individual healthy behaviour and healthy life styles. Advances in prevention and Chronic Care Management"



This year the Foundation sponsored the paper titled "Individual healthy behaviour and healthy life styles. Advances in prevention and Chronic Care Management," given by Rafael Bengoa, Regional Health Minister for the Basque Country, and Ellen Nolte, director of Rand Europe. The lecture was open to professionals with an interest in public health and health management.

#### 4th Josep Egozcue Lecture Cycle

The Josep Egozcue Lectures are now well established as an annual event at which the Foundation invites international experts in bioethics to share their insights. This year the guest speaker on 19 and 20 October was Mark Siegler, Professor of Medicine and Director of the MacLean Center for Clinical Medical Ethics at the University of Chicago.

Mark Siegler's lectures addressed the following topics:

#### The three ages of medicine and the doctor-patient relationship.

Siegler identified the different eras of the doctor-patient relationship: the age of paternalism, the

Mark Siegler



4th Josep Egozcue Lecture Cycle



age of patient autonomy, and the age of bureaucracy. In all of these eras there has been an interaction between doctor and patient which has recently led to a model based on shared decisionmaking

#### Past and future contributions to the medical ethics of caring for patients.

In his lecture, Siegler noted how research, technological progress, and the changing nature of the doctor-patient relationship have awakened interest in ethics. Over the last fifty years, ethics has helped to improve the quality of the doctor-patient relationship.

#### Course: The elderly sick patient: fragility and autonomy

The final event of the year was the course "The elderly patient: fragility and autonomy," organized jointly by the Foundation and the Menéndez Pelayo International University Consortium – Ernest Lluch Center of Barcelona, and with the support of the Letamendi Forns Foundation. The course, which took place on 11 and 12 November, was directed by Marc Antoni Broggi, president of the Bioethics Committee of Catalonia and member of the board of trustees of the Víctor Grífols i Lucas Foundation. The course addressed the need to ensure that individuals, despite being elderly and physically dependent, should be able to participate as widely as possible in the decisions which affect them.

#### The speakers were:

- Salvador Altimir, Coordinator of the Geriatrics and Gerontology Unit of the Germans Trias i Pujol University Hospital.
- Rogeli Armengol, psychiatrist and author of the book La felicidad y el dolor: una mirada ética.



Course: The elderly sick patient: fragility and autonomy

- Ramon Bayés, Professor of Basic Psychology at the Autonomous University of Barcelona (UAB).
- Josep Maria Bosch, Coordinator of the Communication and Health Programme of the Spanish Society for Family and Community Medicine (semFYC).
- Josep Maria Busquets, doctor with Programa d'Atenció Domiciliària i Equips de Suport (PADES).
- Victoria Camps, President of the Víctor Grífols i Lucas Foundation.
- Laura Coll, Doctor and Researcher at the Institute for Ageing at the Autonomous University of Barcelona (UAB).
- James Drane, Professor at Edinboro University, Pennsylvania.
- Pilar Gómez, Clinical psychologist and psychoanalyist.
- José Leal, Clinical psychologist and psychoanalyist.
- Clara Llubià, Doctor with the Anaesthesiology and Reanimation Service of the Germans Trias i Pujol University Hospital of Badalona.
- Mercè Pérez Salanova, head of the Psychosocial Area and Participation at the Autonomous University of Barcelona (UAB).



Course: The elderly sick patient: fragility and autonomy



- Josep Maria Busquets, *Programa d'Atenció Domiciliària i Equips de Suport* (PADES).
- Pilar Rodríguez, head of quality at ABD.
- Begoña Román, Professor of Moral Philosophy and Politics at the University of Barcelona.
- Jordi Trelis, Head of Palliative Care at the Catalan Institute for Oncology, at the Germans Trias i Pujol University Hospital.



# **Awards and Grants**

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## **Bioethics Prizes**

One of the objectives of the Víctor Grífols i Lucas Foundation is to promote research in bioethics. Each year the Foundation awards a research prize, a journalism prize, and four grants to support research in bioethics.

The awards ceremony for these was held on 19 October, under the auspices of the Egozcue Lectures. There were 11 submissions for the research prize, 29 for the research grants, and 9 for the journalism prize.

#### Members of the Jury

The winning entrants were chosen by a jury consisting of:

- Salvador Alsius, dean of Journalism Studies at the Pompeu Fabra University.
- Margarita Boladeras, Professor of Moral Philosophy and Politics at the University of Barcelona and chair of the jury.
- Jordi Caïs, Professor of Sociology and Organization Analysis at the University of Barcelona.
- Màrius Morlans, Member of the Ethics Committee of the Vall d'Hebron University Hospital.
- Francesca Puigpelat, Professor of Legal Philosophy at the Autonomous University of Barcelona.

#### **Awards and Grants**



#### 12th Bioethics Research Prize

The Prize for Research in Bioethics, worth 6000 euros, was awarded to **Josefina Goberna Tricas**, lecturer at the University School of Nursing at the University of Barcelona, for her work: <u>Women and procreation: ethics in the medical practice and the healthcare relationship during pregnancy and birth</u>.

Her study is a doctoral thesis which proposes an ethical reflection on the contemporary realities of health care during maternity. This care is delivered in a highly technological setting in which the care relationship itself is somewhat dehumanized.



Josefina Goberna Tricas



12th Bioethics Research Prize



### **10th Journalism Prize**

The documentary strand "30 minuts", broadcast by the Catalan TV channel **TV3**, won the Journalism Prize, now in its 10th year and worth 3000 euros, for the report <u>Decidir la mort (Choosing death)</u>, broadcast on 4 October 2009.

In recent years there have been successions of cases of euthanasia, assisted suicides, or requests for the withdrawal of treatments which keep people alive artificially. The "30 minuts" report considered the right to decide how and when to die, through the experiences of three people suffering from incurable, degenerative diseases.



10th Journalism Prize



## **12th Research Grants**

The grants to support research projects, worth 5000 euros each, were awarded to:

The team led by Joan Canimas of the *Campus Amau d'Escala Foundation* for the work: <u>Guidelines</u> for de facto guardians of individuals with Alzheimer's disease who are invited to participate in clinical research projects.

The team led by Sara Fidel Kinori of the Psychiatry and Mental Health Research Group of the Vall d'Hebron University Hospital for the work: *Protection of confidentiality in computerized medical records: hospital mental health department patients*.

Montserrat Guillaumet of the Sant Pau University School of Nursing for the work: <u>The experience</u> of being cared for in hospital. The perspective of non-EU economic immigrants.

The team led by José Luís Villanueva for the multi-centre study in five hospitals in Madrid: <u>Mechani-</u> <u>cal ventilation, percutaneous gastrostomy and decision-making in patients with ALS: survey</u> <u>of opinions of patients, relatives and doctors</u>.



11th Research Grants



## **Completed research projects**

The authors of the projects which received grants last year presented their reports and conclusions in October. Details of projects can be consulted on the website:

Social work with families: the responsibility of social workers in the self-determination of the most vulnerable groups by the team led by Josefa Fernández Barrera of the Department of Social Work and Social Services in the Faculty of Education of the University of Barcelona.

Research protocol: listening to the voices of children. Ethical aspects of the process of informing hospitalized minors by Ana Lucía Noreña Peña and Elena Ferrer of the Department of Nursing of the University Hospital of San Juan in Alicante.

<u>Positive eugenics and its impact on sporting practice</u> by José Luís Pérez Triviño of the Department of Legal Philosophy at the Pompeu Fabra University of Barcelona.

<u>Portal on advance directives across the world</u> by the team led by Maria Isabel Tamayo Velázquez of the Andalucian School of Public Health for the work.



# Publications

FUNDACIÓ VÍCTOR GRÍFOLS I LUCAS

#### **Publishing programme**

The Foundation produces three collections of publications – Monographs, Reports and Ethical Questions – in which it publishes documents and papers from the activities it organizes. All the publications are offered free of charge to users, with the aim of helping disseminate an understanding of bioethics. These can be downloaded as PDF files via the website, or ordered in printed form.

During 2011 the Foundation expanded its collection, with five new monographs, two ethical questions and the translation of six publications.

#### **Bioethics monographs**

#### Ethics in care services for people with severe mental disability

This publication is designed to provide a starting point for the drafting of a shared code of good practice for centres and services caring for people with severe mental disability. This monograph includes the opinions and concerns of experts in ethics and care professionals, and addresses some of the ethical dilemmas which arise when caring for these patients. Published in Spanish, Catalan and English.

Ethics in care services for people with severe mental disability



## 05 ANNUAL REPORT 2010

#### **Publications**

#### Consent by representation

It is compulsory to obtain a signed informed consent document prior to any medical treatment. The document and the information which support it raise several ethical dilemmas. When the patient loses the capacity to decide freely, the situation is complicated by the fact that consent must be given by a relative or representative of the patient. This monograph considers how this situation should be approached from both a medical and a legal perspective. Published in Spanish and English.

#### Ethics and Clinical Research

The third annual Josep Egozcue lecture cycle was delivered by Ruth Macklin. Ruth Macklin, professor of Ethics at the Department of Epidemiology at the Albert Einstein College of Medicine in New York, addressed the issue of ethics and clinical research. This monograph contains her three lectures: the ethics of research, ethics in multinational research, and grey areas in research. Published in Spanish and English.

#### Maleficence in prevention programmes

Public health initiatives have a positive impact on the population as a whole, but many individuals derive no direct benefit from them and may even be exposed to risks as a result. This monograph contains the contributions of health and legal specialists who analyse the information provided by public health programmes, with special emphasis on breast cancer prevention programmes. Published in Spanish and English.



Ethics and Clinical Research Ruth Macklin







#### **Publications**



#### Ethics: the essence of scientific and medical communication

In 2001 the Foundation organized a debate on the ethics of scientific communication, which formed the basis for a publication. Nine years on, it was essential to revisit this issue to consider the impact of the generalization of access to knowledge on scientific and medical communication. This monograph includes the working document from the seminar, together with the contributions of the participants. Published in Spanish and English.

#### The management of medical errors

As part of its objective of creating a bilingual collection of publications, the Foundation is retrospectively translating those titles which are only available in Spanish. In 2010, *La gestión de los errores médicos* (originally produced in 2002), was published in English as *The management of medical errors*. This text analyses the ethical conflicts posed by the management of medical errors from both a legal and a medical perspective, and includes contributions from a number of experts in this area. Ethics: the essence of scientific and medical communication



The management of medical errors



#### **Publications**



#### **Ethical questions**

#### Sexuality and the emotions: can they be taught?

This publication is the result of dialogue between a group of education experts with an interest in sexual and emotional education. It is designed to offer a set of ideas, opinions and considerations on this subject to those responsible for educating children and adolescents. Published in Spanish, Catalan and English.

#### Surrogate pregnancy: an analysis of the current situation

Surrogate pregnancy is prohibited in most countries. Its illegality in Spain has resulted in some couples travelling abroad to enter into surrogacy agreements. This publication analyses this practice, sometimes referred to as "wombs for hire", to evaluate whether legislative reform would be desirable and, if so, what form this should take. Published in Spanish, Catalan and English.

Sexuality and the emotions: can they be taught?



Surrogate pregnancy: an analysis of the current situation



#### **Publishing partnerships**

The Foundation has cooperated with the Bioethics Committee of Catalonia to publish the bilingual edition of the manual *Recomendaciones a los profesionales sanitarios para la atención a los enfermos al final de la vida* (Recommendations for health professionals caring for patients at the end of their lives). This document is designed to help health professionals caring for patients who are close to death, whatever their discipline or specialist area.

The handbook is designed not as a theoretical treatise or a technical protocol, but as a practical document to help understand the values involved in caring for those who are dying. Among other issues it considers basic clinical decisions, addresses a range of care settings, and clarifies confusions regarding certain ethical and legal concepts. The book has been published in Spanish and Catalan and is distributed by the Bioethics Committee of Catalonia. It can be downloaded as a PDF document from the Foundation's website.





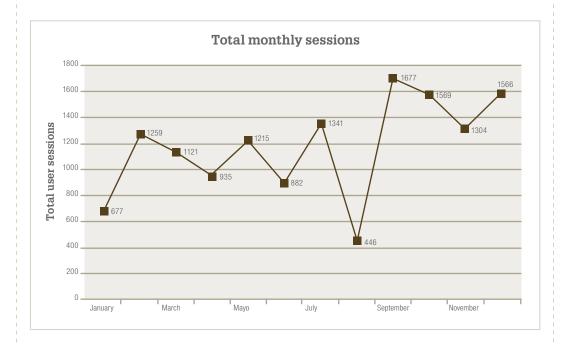
## **The Foundation online**

FUNDACIÓ VÍCTOR GRÍFOLS I LUCAS



#### Website

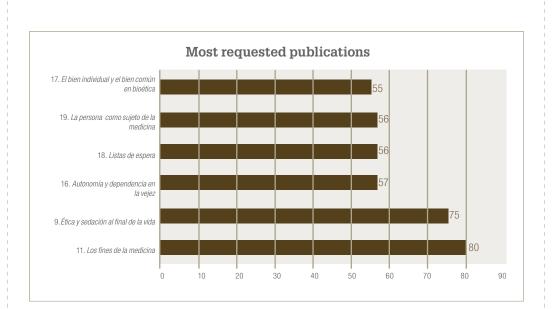
A year after being launched, the new website has become established as the main channel for communication with the Foundation's users. It currently receives an average of 1200 visits per month. The most frequently viewed sections are the activities, the bulletin and publications. This year, the Foundation handled 980 requests for printed publications through its website.





The Foundation online





In addition to requesting printed copies, the website also allows users to download PDF versions of publications. The most frequently downloaded monograph this year was *Consentimiento por representación* with 125 downloads.

The website is also used to administer registrations for lectures and other public events organized by the Foundation.

www.fundaciogrifols.org

# Bionethics

Since the launch of the Foundation's new website, the number of visits to Bionethics, the Foundation's specialized bioethics search engine has risen to 2660 per month. This increase has also been aided by the option of incorporating the search engine into users' websites.

www.bionethics.com

# **RSS feeds**

In 2010 the Foundation included the RSS service which allows users to receive updates from the Foundation automatically, without the need to visit the website. Users can subscribe to news, publications and activity updates by entering the Foundation's RSS address in their browser or feed reader, and then consulting updates for their chosen sections.







# YouTube channel

The Foundation has created a YouTube channel to offer users the chance to view videos of its key events. The first videos offered on the channel were of the Josep Egozcue lectures, held on 19 and 20 October. The videos contain excerpts from the opening address given by Mark Siegler, director of the MacLean Center for Clinical Ethics of the University of Chicago, and of the bioethics awards ceremony. http://www.youtube.com/user/fundaciogrifols





# **Financial data**

FUNDACIÓ VÍCTOR GRÍFOLS I LUCAS



# **Balance Sheet**

31 December 2010 and 2009 (In euros)

Assets	2010	2009
Working Capital		
Other Debtors		
Sundry debtors	0	0
Treasury		
Cash	16	46
Banks and credit institutions, current accounts and sight deposits	84,328	93,538
Total Working Capital	84,344	93,584
Total Assets	84,344	93,584

Liabilities	2010	2009
Equity		
Endowment fund	12,020	12,020
Surplus from previous periods	9,174	8,822
Surplus for the period	355	352
Total Equity	21,549	21,194
Short-term Creditors		
Creditor beneficiaries	29,516	23,267
	29,516	23,267
Suppliers and Other Creditors		
Debts for the purchase or provision of services	31,030	47,368
Public bodies	2,249	1,754
	33,279	49,122
Total Short-term Creditors	62,794	72,390
Total Liabilities	84,344	93,584



# **Profit and Loss Account**

31 December 2010 and 2009 (In euros)

Expenses	2010	2009
Staff Expenses	0	0
Cash grants and other expenses	29,000	29,000
Other expenses		
External services	220,387	221,431
Taxes	258	217
Total expenses	249,645	250,648
Operating profit	355	352
Profit from ordinary activities	355	352
Positive surplus for period (profit)	355	352

Income	2010	2009
Foundation's income from activities		
Income from promotions, sponsors and joint projects	250,000	251,000
Total operating income	250,000	251,000
Operating losses		
Losses from ordinary activities		
Negative surplus for period (loss)		



# **Press review**

FUNDACIÓ VÍCTOR GRÍFOLS I LUCAS



### **DIARIO MEDICO**

LOS PROBLEMAS MÁS COMUNES SON LA PRIVACIDAD Y LA INTIMIDAD

# Expertos en bioética proponen un código ante la discapacidad intelectual grave

C.F. Barcelona Expertos en bioética y profesionales de servicios vinculados recogen en el último cialmente positiva); autode- la persona discapacitada). informe de la colección Cua- terminación (los afectados demos de la Fundación Víctor Grifols y Lucas varias propuestas para la elaboración de un código de buenas prácticas en la atención a las a través de gestos, parpadeo personas con discapacidad o vocalización); personalizaintelectual grave.

Según recogen en el trabajo, son múltiples los proenfrentan los profesionales responsables de la atención a este tipo de pacientes y requieren el apoyo de guías específicas y de comités de ética asistencial como los que hospitales de agudos. Los problemas éticos a los

que los profesionales se enfrentan más a menudo tienen que ver con la privaciejemplo, prefieren aisla- en ocasiones dudas éticas al-

ne una pérdida de posibilidad de interacción potenra promover su elección se les debe ofrecer opciones y saber interpretar sus deseos ción (la atención en centros con muchas personas con discapacidad intelectual grablemas éticos a los que se ve tiende a despersonalizarse); normalización (¿los niños con discapacidades intelectuales con grave plurideficiencia tienen que ser atendidos dentro del marco de la enseñanza normalizase están extendiendo por los da o la educación especial o necesitan centros de atención de día específicos y diferenciados?), y sobre las familias (los afectados tienen generalmente una situación dad y la intimidad de esas jurídica de incapacidad total personas (los autistas, por o permanente y eso genera

miento aunque eso les supo- rededor de la participación de la familia, como representante de los intereses de

Los autores también desexpresan muy poco pero pa- tacan aspectos de asistencia sanitaria y aseguran: "Habría que incluir la formación específica en discapacidad intelectual en el curriculum médico ya que actualmente, en general y por la experiencia, la atención que reciben estas personas no es la misma que recibimos la mayoría de nosotros. Nos toca también como profesionales exigir y asegurar la asistencia sanitaria de calidad para nuestros usuarios".

E incluso van más allá: "En nuestros servicios y entidades hay a menudo una falta de conocimiento por parte de los profesionales, transversalmente hablando, de cuáles son los valores y la misión de la organización de la que forman parte".

Diario Médico, 7 May 2010





Diario Médico, 22 October 2010





<u>La Vanguardia, 24 November 2010</u>



# **Diary of Events 2011**

FUNDACIÓ VÍCTOR GRÍFOLS I LUCAS

#### January

ANNUAL REPORT 2010

#### 27 January

Meeting of the Board of Trustees of the Foundation.

#### March

#### 23 March

Presentation of document *Sexuality and the emotions: can they be taught?* 

#### April

# **11-12 April** Course: Economic crisis and the right to good health.

May

#### 16 May

Seminar: e-patients, web 2.0 and empowerment.

#### 31 May

Closing date for submission of entries for prizes and grants 2011.

#### June

**15 June** Selection of Prizes and Grants Jury 2011.

# July

**From 17 to 23 July** Session on health management at the Global Health Leadership Forum.

#### September

22-23 SeptemberCourse: Ethics and public health.27 SeptemberMeeting of the Board of Trustees of the Foundation.

#### **October**

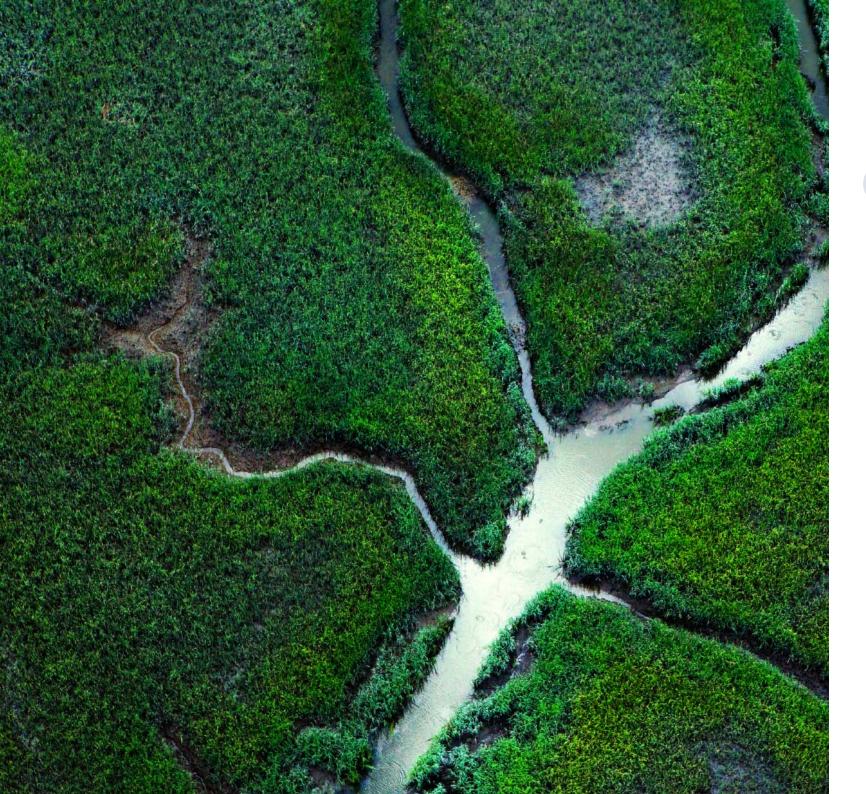
Foundation Award Ceremony. 5th Josep Egozcue Lectures.

**10 November**s and Grants Jury 2011.Seminar: Ethical values in healthcare professionals.

### December

**November** 

**1-2 December** Course: Cultural diversity and healthcare.





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