



The Queen Sofía Foundation's Alzheimer's Disease Project

Alzheimer's Disease Research Unit

CIEN Foundation – Queen Sofía Foundation

Dr. P. Martínez Martín

Scientific Director

**Alzheimer's Disease Research Unit
CIEN Foundation – Queen Sofía Foundation**

Launch

- ❖ **Presentation of the Project – December 2002, El Pardo Palace**

H.M. King Juan Carlos and H.M. Queen Sofía

Minister of Health & Consumer Affairs

Minister of Labour & Social Affairs

Madrid Regional Authority

Madrid City Council

Board of Governors of the Queen Sofía Foundation

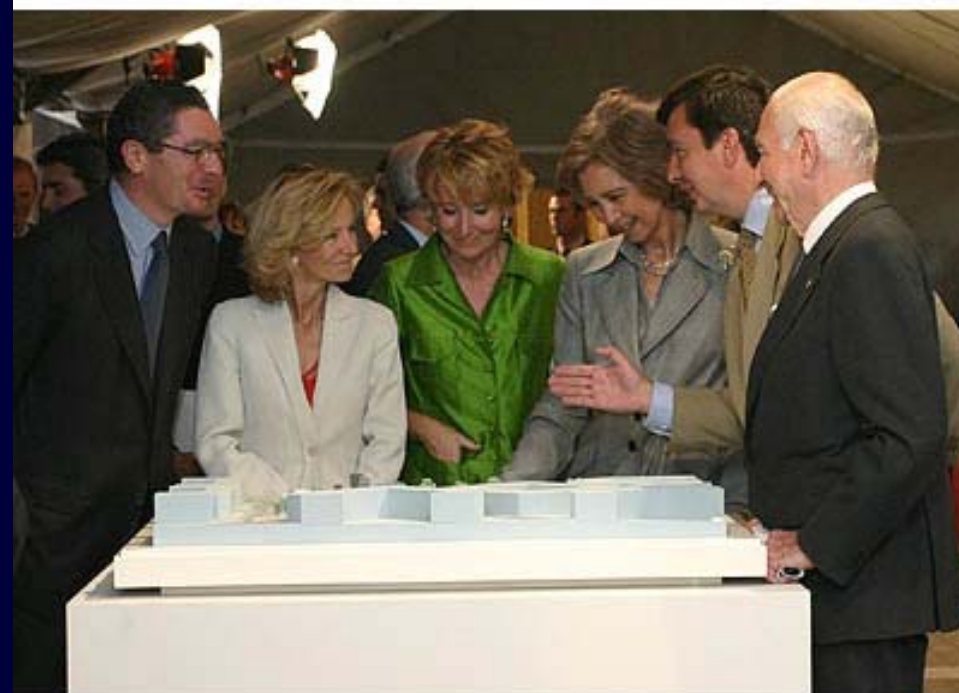
Political Representatives

Relevant representatives of society

Patient Associations

Scientific Bodies

- ❖ **Start of preparatory activities - January 2003**
- ❖ **Foundation stone laid – 4 October 2004**



Guiding principle

- ❖ **“A socio-healthcare approach that seeks to address the consequences of Alzheimer’s Disease for sufferers and their family circle” and for society as a whole.**
- ❖ **The basis of the above principle is “the need to fight the disease from a multidisciplinary stance, envisaging all the factors that influence it, while choosing to provide overall solutions to the problem”.**

Approach

- 1 - **Identification** of the problem posed by Alzheimer's Disease to sufferers, their family and friends, and society as a whole
- 2 - H.M. Queen Sofía's keen **sensitivity** to this problem
- 3 - **Decision** of the Queen Sofía Foundation, presided over by Her Majesty, to address the needs of the present situation
- 4 - **Convergence** of the desires and interests of all parties involved, i.e., Central, Regional and Local Government as well as society as a whole

Implementation of the Project

Site

Zone designated for town planning in the district known as the “Vallecas extension”, Madrid

Composition and layout

- * Long-term inpatient care facility**
- * Day-care centre**
- * Training and education facility**
- * Research unit**



Addressees

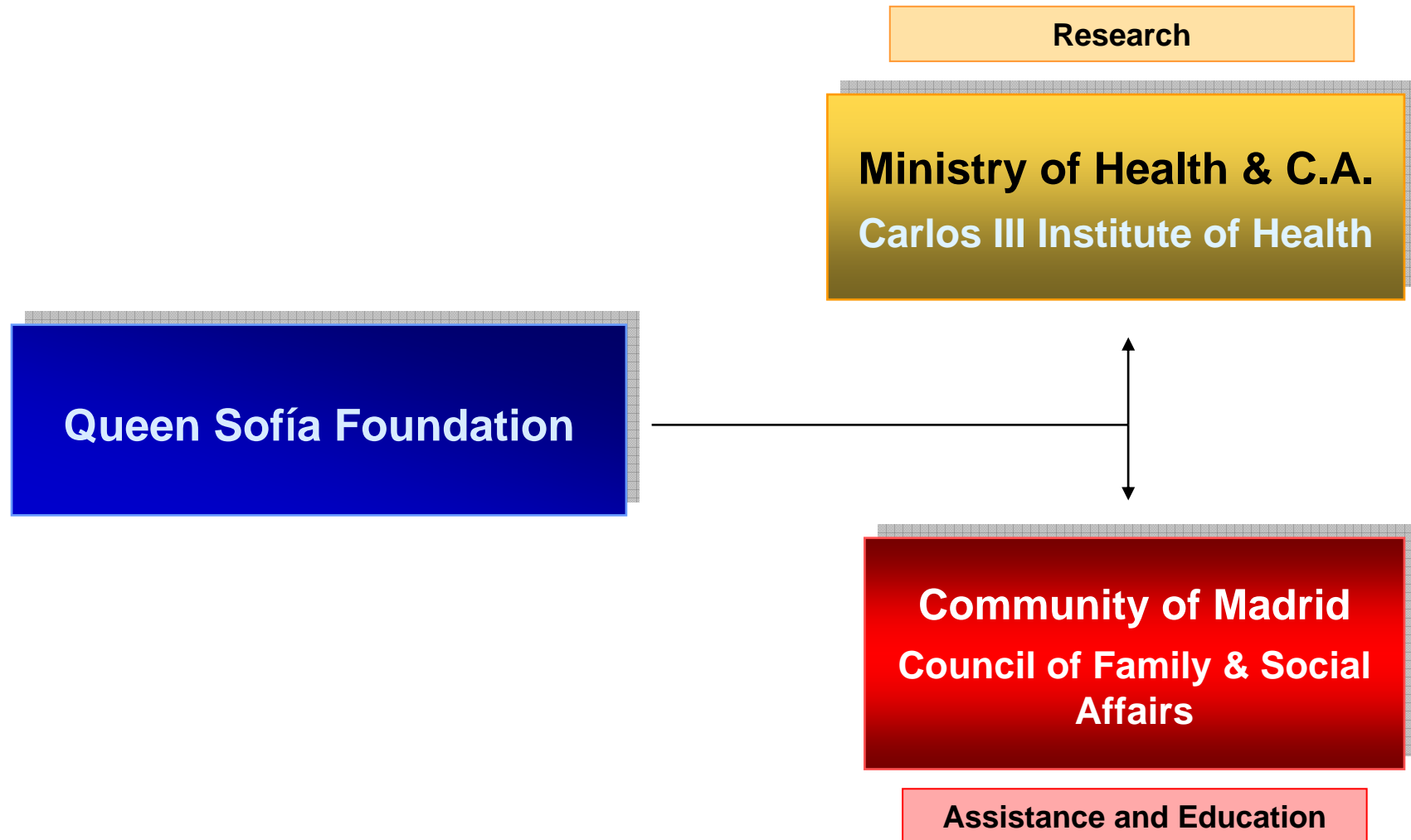
Queen Sofía Foundation

**Ministry of Health & C.A.
Carlos III Institute of Health**

**Community of Madrid
Council of Family & Social
Affairs**



Addressees



Alzheimer's Disease Research Unit CIEN Foundation - Queen Sofía Foundation



ISCIII Advisers for the Research Unit design

- **Prof. J. Ávila** – Severo Ochoa Molecular Biology Centre. CSIC - AUM
- **Prof. F. Bermejo Pareja** – 12 de Octubre Hospital
- **Dr. M. Calero Lara** – National Microbiology Centre, *ISCIII*
- **Dr. A. Rábano** – H. Alcorcón Foundation and Brain Bank
- **Dr. J. de Pedro Cuesta** – National Centre for Epidemiology, *ISCIII*
- **Dr. J. Álvarez Linera** - Rúber International Hospital, Madrid
- **Prof. A. Calcedo Barba** - Gregorio Marañón Hospital, Complutense University
- **Dr. T. del Ser Quijano** – Severo Ochoa Hospital → Neuropharma
- **Dr. D. Muñoz García** – Madrid Brain Bank → Toronto, Canada
- **D. Manuel Nevado Rey** - Head of Training. AFAL Alzheimer's Association

Research Unit - Definition

The Alzheimer's Disease Research Unit will act as a national focal point for research into Alzheimer's Disease under the governing principles of co-ordination, integration, universality and multidisciplinary action.

Research Unit

Queen Sofía Foundation

**Ministry of Health & C.A.
Carlos III Institute of Health**

CIEN Foundation

**CIBER for
Neurodegenerative diseases**

←
**Administrative
Management**

←
Scientific Activity

Functions

- ❖ **Promoting, implementing and following up research projects**
- ❖ **Reference centre for research into Alzheimer's Disease & R.D.**
- ❖ **Stimulating the generation of hypotheses**
- ❖ **Identifying new or neglected areas of interest**
- ❖ **Furnishing knowledge to the interface with other processes**
- ❖ **Promoting research by training researchers**
- ❖ **Disseminating results and spreading knowledge**
- ❖ **Co-ordination with other centres at home and abroad**
- ❖ **Setting-up co-operation agreements with other institutions**



Alzheimer's Disease Research Unit

CIEN Foundation - Queen Sofía Foundation

MANAGEMENT AND ADMINISTRATIVE ORGANS

- ❖ **Executive Board**
- ❖ **Scientific Director**
- ❖ **General Manager**
- ❖ **Scientific Committee**
- ❖ **Research Ethics Committee**

Alzheimer's Disease Research Unit

CIEN Foundation - Queen Sofía Foundation

MANAGEMENT AND ADMINISTRATIVE ORGANS

❖ **Executive Board** →

Director General of the Carlos III Institute
Scientific Director of the CIEN Foundation
Scientific Director of the AD Research Unit
Representative of the Queen Sofía Foundation
General Manager of the CIEN Foundation

Alzheimer's Disease Research Unit

CIEN Foundation - Queen Sofía Foundation

MANAGEMENT AND ADMINISTRATIVE ORGANS

❖ **Executive Board**

❖ **Scientific Director →**

**Appointed by the Board of Governors
of the CIEN Foundation**



Alzheimer's Disease Research Unit

CIEN Foundation - Queen Sofía Foundation

MANAGEMENT AND ADMINISTRATIVE ORGANS

- ❖ **Executive Board**
- ❖ **Scientific Director**
- ❖ **General Manager** → **General Manager of the CIEN Foundation**

Alzheimer's Disease Research Unit

CIEN Foundation - Queen Sofía Foundation

MANAGEMENT AND ADMINISTRATIVE ORGANS

- ❖ **Executive Board**
- ❖ **Scientific Director**
- ❖ **General Manager**
- ❖ **Scientific Committee →**

Scientific Director of the AD Research Unit
1 scientist appointed by the:
Queen Sofía Foundation
Carlos III Institute of Public Health
AD Research Unit researchers
CIEN Foundation
NHS Interterritorial Council
Self-help Associations

Alzheimer's Disease Research Unit

CIEN Foundation - Queen Sofía Foundation

MANAGEMENT AND ADMINISTRATIVE ORGANS

- ❖ **Executive Board**
- ❖ **Scientific Director**
- ❖ **General Manager**
- ❖ **Scientific Committee**
- ❖ **Research Ethics Committee →**

Scientific Director of the AD Research Unit

1 Clinical pharmacologist

2 Researchers

2 Experts in bioethics

1 Member of the healthcare staff

1 Representative of the Associations



Alzheimer's Disease Research Unit

CIEN Foundation - Queen Sofía Foundation

Research programmes

- **Focused on dementia (preference: Alzheimer's Disease)**
- **Based on priorities set by the Scientific Committee**
- **In force for 5-year periods**
- **Short-, medium-and long-term activities**
- **Flexible and open to innovation**



Alzheimer's Disease Research Unit

CIEN Foundation - Queen Sofía Foundation

High-priority research lines 2006 - 2010

- ★ **Early diagnosis of AD – MRI, Biomarkers**
- ★ **Molecular and cell biology in AD – β -amyloid peptide, *tau***
- ★ **Ageing and risk factors for AD**
- ★ **Traslational research in AD**
- ★ **Assignment of resources and quality of care for AD patients**

First call for project application – December 2006

Alzheimer's Disease Research Unit

CIEN Foundation - Queen Sofía Foundation

Basic areas

- **Clinical research - Neurology**
Psychiatry
Neuropsychology
Geriatrics
- **Epidemiology**
- **Socio-healthcare research**
- **Neurobiology**
- **Neurophysiology**
- **Neuroimaging**
- **Neuropathology**

Equipment and resources

- **Clinical research** – Examination rooms
Gait/ Mov. Disord. research facility *
Concealed observation room
- **Epidemiology** – Telephone-survey room
- **Socio-healthcare research** – Videoconference and interview room
- **Neurobiology** – Cell biology laboratory, Cell culture
- **Neurophysiology** – Video-EEG room *
- **Neuroimaging** – MRI 3.0 T
- **Neuropathology** • – Autopsy, brain dissection and storage rooms
- **Biologic samples** • – Processing and storage

• Connected to CIBER biobanks

* Only when active research projects in these areas exist

Multidisciplinary Clinical Unit

- **Shared with the Madrid Regional Authority**
- **Basic co-ordinated multidisciplinary research team**
 - Neurologist + Psychiatrist + Neuropsychologist +**
 - Geriatrician + Physiotherapist + Sociologist**
- **Goal – Information from patients at the facility**
 - Demographic and historical data**
 - Clinical status at admission**
 - Comorbidity**
 - Neuropsychological status**
 - Added impairments**
 - Characterisation of complications**
 - Prognostic factors**
 - Disability: determinants, measures**
 - Palliative care**
 - Death-related aspects**
 - Caregivers and environment**
 - Socio-healthcare and econometric data**

Main research platforms

- **Neuroimage**
- **Neuropathology**
- **Cell biology**
- **Clinical database**
- **Scientific e-Library**

Multidisciplinary support unit

Agreements in course with other institutions

- **Mount Sinai School of Medicine, NY, USA**
- **University of Washington & VA Puget Sound HCS, Seattle, WA, USA**
- **University of Milan and University of Catania, Italy**
- **Institution Federative de Recherche en Neurosciences, INSERM, France**
- **Institute for Neurociences of Castilla and León, Salamanca, Spain**
- **Centre for Research in Alzheimer Disease, Murcia, Spain**
- **Hospital Ruber Internacional, Madrid, Spain**
- **Matia Foundation, San Sebastián, Spain**
- **ASGER, Barcelona, Spain**
- **Institute for Economy and Geography, CSIC, Madrid, Spain**



Alzheimer's Disease Research Unit

CIEN Foundation - Queen Sofía Foundation

Other projected activities

- **Training aids in Alzheimer's Disease and Dementia research**
- **Annual Symposium on advances in Alzheimer's Disease and Dementia**
- **Queen Sofía International Alzheimer's Disease Conference**
- **Brainstorming meetings**
- **Seminar: "From research to practice" (practical applications)**
- **Meet the researchers (general public)**
- **Seminar: "Research on dementia and society" (mass media)**
- **Queen Sofía Foundation Alzheimer's Disease Research Prize**
- **Publications targeted at the public and professionals**
- **Alzheimer's Disease Research Unit website with news and information**



MINISTERIO
DE SANIDAD
Y CONSUMO



Instituto
de Salud
Carlos III



cién
Fundación Centro Investigación
Enfermedades Neurodegenerativas

Alzheimer's Disease Research Unit

CIEN Foundation - Queen Sofía Foundation

III International Symposium “Advances in Alzheimer’s Disease”

20th September, 2006

Ministry of Health and Consumer Affairs

III Course “Updating in dementia” – Continuous Medical Education

19th – 22nd September, 2006

University of Milan and Catania – Unit of Neuroepidemiology, N.C.E.

Carlos III Institute of Health



OFFICIAL OPENING CEREMONY
21 September 2006