



**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**

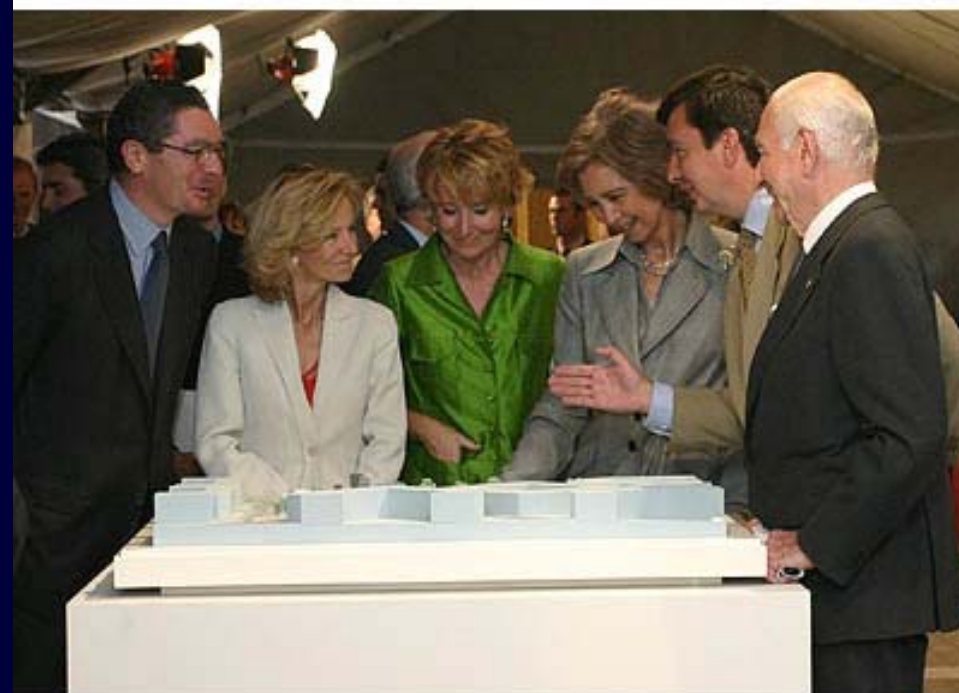
**Political Representatives**

**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

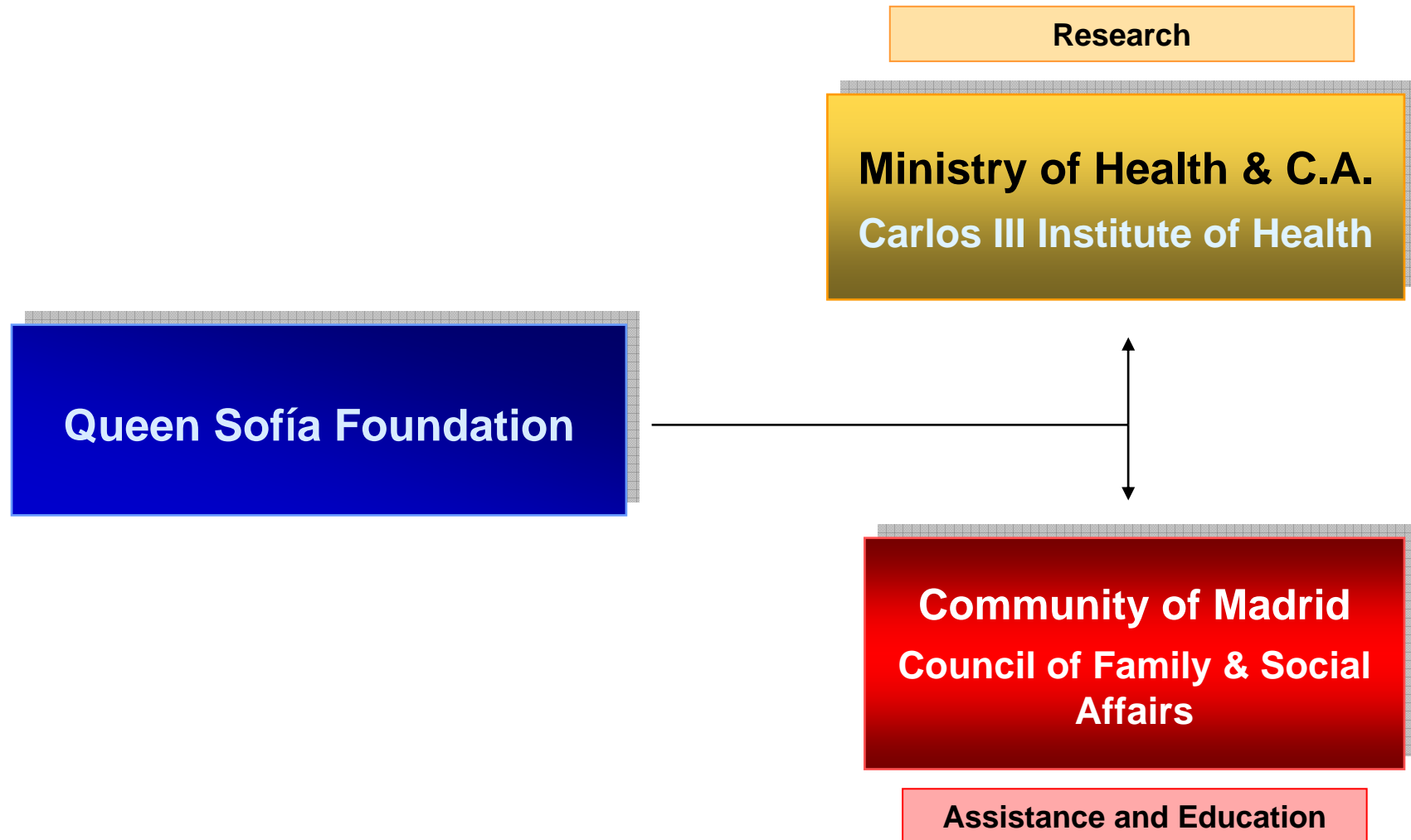
**Queen Sofía Foundation**

**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

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

# Alzheimer's Disease Research Unit

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- ❖ **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**

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- ❖ **Executive Board**
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- ❖ **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 –  $\beta$ -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”**

**20<sup>th</sup> September, 2006**

**Ministry of Health and Consumer Affairs**

### **III Course “Updating in dementia” – Continuous Medical Education**

**19<sup>th</sup> – 22<sup>nd</sup> September, 2006**

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

**Carlos III Institute of Health**



**OFFICIAL OPENING CEREMONY**  
**21 September 2006**