

#### Selling your Organisation to the Public



#### **Dr Mary Baker MBE**

President, European Brain Council

President, European Federation of Neurological Associations

Patron, European Parkinson's Disease Association

### **EPDA Charter for People with Parkinson's Disease**

People With Parkinson's Disease Should Have the Right to: - Be referred to a doctor with a special interest

- Receive an accurate diagnosis Have access to support services
- Receive continuous care, and
  - ~ Take part in managing the illness

Declared this 11th day of April 1997

21st May, 1996

#### Dear Mary.

I am delighted to learn that it will be World Parkinson's Disease Day on 11th April next year. There can surely be no more perfect way of remembering James Parkinson's birthday.

Worldwide recognition of this cruel disease is so important and I am immensely encouraged by all your plans for this special day. I wish you every possible success in this excellent initiative.



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Mrs. Mary G. Baker, MBE

# Formed by the World Health Organisation 27 May 1997

### ... in support of the EPDA Charter and the World Parkinson's Disease Day



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From the Vatican, 25 October 1997

Dear Friends,

His Holiness Pope John Paul II has received the kind message which you sent to him and he has directed me to express his gratitude and to assure you of his prayers.

His Holiness invokes God's blessings upon your efforts on behalf of people suffering from Parkinson's disease.

Yours sincerely,



Ms. Mary G. Baker Professor Leshe Findley European Parkinson's Disease Association 22 Upper Woburn Place LONDON





THE PRIME MINISTER

Parkinson's Disease is one of the most serious and widespread of neurological disabilities, affecting about 120,000 people in the United Kingdom and millions in Europe and worldwide, often causing severe distress to patients and their families.

People with the condition will often require a wide range of support and treatment from different health and social services. This presents particular challenges to the NISA, and to health departments around the world, to ensure the effective and timely coordination of different agencies. In addition, there is a continuing need for research into the causes and treatment of Parkinsen's Disease.

The European Parkinson's Disease Association and in member national associations are in the foretroot of highlighting and promoting the international understanding of Parkinson's Disease and the need for effective services to enable patients to achieve the best quality of life possible. It also makes an invaluable contribution in encoraging vital research into the causes, treatment and ourse of Parkinson's Disease.

I am sure that World Parkinson's Disease Day will make a major contribution to achieving these aims.

April 1997











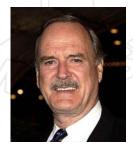














Oscar Gershanik Argentina



Aleksandar Janca [WHO Liaison] Australia



Francisco Cardoso Brazil



Wolfgang Oertel [MDS Liaison] Germany



Bhim Singhal India



Yoshikuni Mizuno Japan



Ashraf Kurdi Jordan



Alla Guekht Russia



Eduardo Tolosa Spain



Mary Baker [Chair] UK

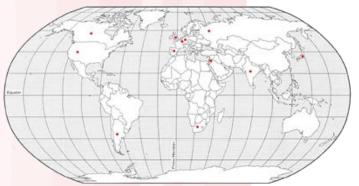


Leslie Findley UK



Matthew Menken USA







Lizzie Graham Working Group Coordinator UK



#### **Areas Targeted**

- Epidemiology
- Management of the illness
- Education programme
- Emotional and economic cost of the illness to families



Measure of lost health – (disability-adjusted life years)

35% is Brain Disease

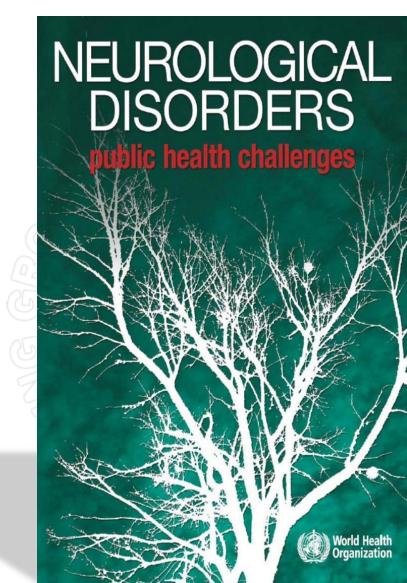
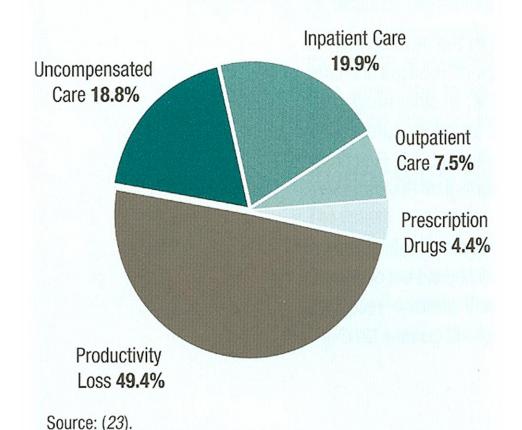


Figure 3.8.1 Cost distribution in Parkinson's disease



Neurological Disorders Public Health challenges WHO 2007

Countries

Canada

Italy

Japan

Spain

UK

USA

Involved

Physicians

**PWPD** 

Carers

1,900 people

203

1020

687

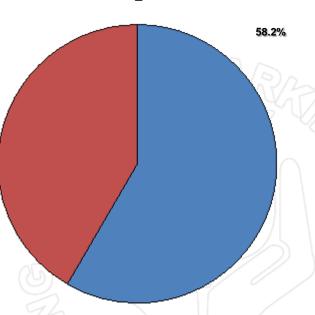


G.P.D.S



# 17.3%

#### **Depression**



Alliances: Patient associations, Healthcare professionals, Pharmaceutical industry, Academia





7<sup>th</sup> World PD International Symposium Mumbai, India - 7 December 2003



8<sup>th</sup> World PD Day Toronto, Canada - 21 April 2004



EPDA 5<sup>th</sup> Multidisciplinary Conference Lisbon, Portugal - 7 May 2004



5th International Symposium APPDA Conference Melbourne, Australia – 24 October 2005



10<sup>th</sup> World PD Day Cape Town, South Africa - 3 April 2006



12<sup>th</sup> World PD Day Cairo, Egypt – 10 April 2008



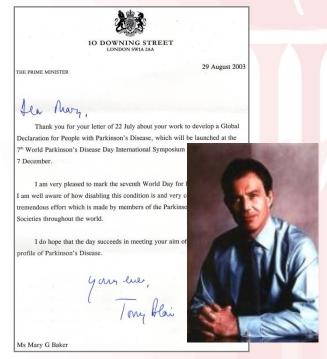
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X-Ray Chanding (1982)

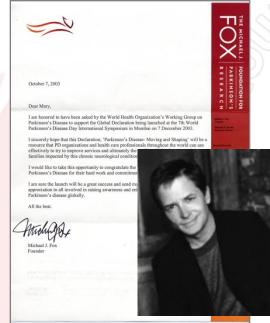
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RING OROLF ON PARKINGON'S PISEASE .

#### **Launch of Global Declaration**



**Letter of support** Tony Blair, UK Prime **Minister** 



Letter of support Michael J Fox

#### **Muhammad Ali signing** the Global Declaration



Janet Reno. first woman Attorney General of the United States of America

Mumbai, India - 7 December 2003









Toronto, Canada - 21 April 2004









### Formed by the World Health Organisation 27 May 1997

### EPDA 5th Multidisciplinary Conference Lisbon, Portugal - 7 May 2004



Peter Hoogendoorn, EPDA Vice President

Robin Elliott, Chief Executive of Parkinson Disease Foundation USA

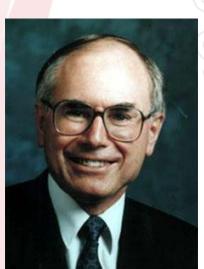


### **APDA 5th International Symposium** Melbourne, Australia - 4 October 2005











#### MESSAGE: WORLD CHARTER FOR PEOPLE WITH PARKINSON'S

I am pleased to provide this message of support for the World Charter for People with Parkinson's Disease.

Parkinson's disease can be a debilitating condition requiring appropriate understanding and management. Its chronic nature can incorporate unique challenges for patients, their carers and families.

Chronic diseases are a major focus of the Australian Government and State and Territory Governments. As an indicator of this, Health Ministers have commissioned an integrated chronic disease strategy which will be presented to them for adoption later this year. This strategy aims to improve the overall integration and continuity of care for people with chronic conditions by emphasising the importance of primary health care, health promotion and earl

The Australian Government supports research relevant to Parkinson's disease through its National Health and Medical Research Council. In 2005 the government will provide around \$2.9 million for research grants addressing

To raise awareness of Parkinson's disease, the Australian Government provides health information to the general public via the Health Insite web site. HealthInsite is a single entry point to quality information from leading health information providers, including peak health organisations, government agencies and educational and research institutions

John Howard Prime Minister of Australia [1996 – date]



### 10th World PD Day Cape Town, South Africa - 3 April 2006



### In support of the Global Declaration 2005 9th World PD Day Luxembourg - 11 April



Swiss federal president Samuel Schmid Bern, Switzerland



Jean-Claude Juncker the Prime Minister of Luxembourg

**HRH The Duchess** 

of Luxembourg

Rasheda Ali

#### In support of the Global Declaration 2005

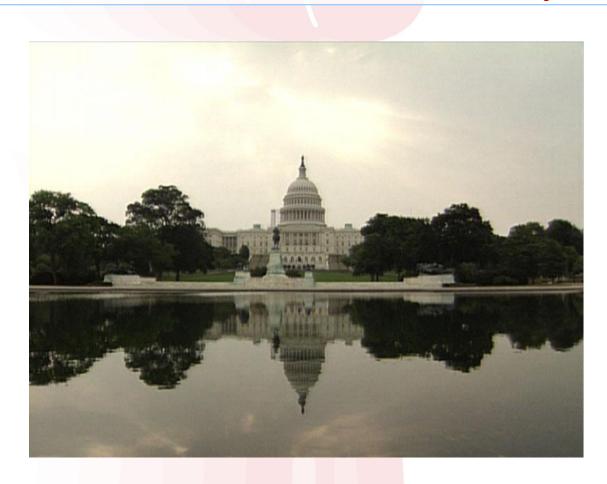


**Princess Alexandra of Denmark** 



Mary Harney
Minister for Health for Ireland

World Parkinson's Congress - Washington 22 – 26 February 2006



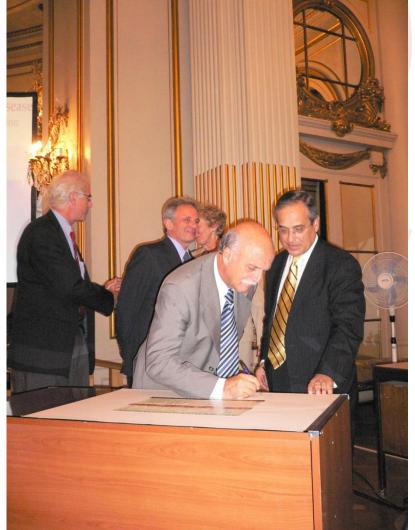


### Representatives from the following countries have supported the launch of the Global Declaration

- Argentina
- Australia
- Austria
- Belgium
- Bulgaria
- Cameroon
- Canada
- Cyprus
- Czech Republic
- Denmark
- Estonia
- Finland
- France
- Germany

- Hong Kong
- Iceland
- India
- Ireland
- Israel
- Italy
- Japan
- Jordan
- Korea
- Lithuania
- Luxembourg
- Malaysia
- Netherlands
- New Zealand

- Norway
- Poland
- Portugal
- Russia
- Serbia
- Singapore
- Slovenia
- South Africa
- Spain
- Sweden
- Switzerland
- Turkey
- Ukraine
- United Kingdom
- USA



### World PD Day 11 April 2007 Buenos Aires, Argentina







#### 10 April 2008 - Cairo, Egypt





 Coming together is a beginning

 Keeping together is progress

 Working together is success