



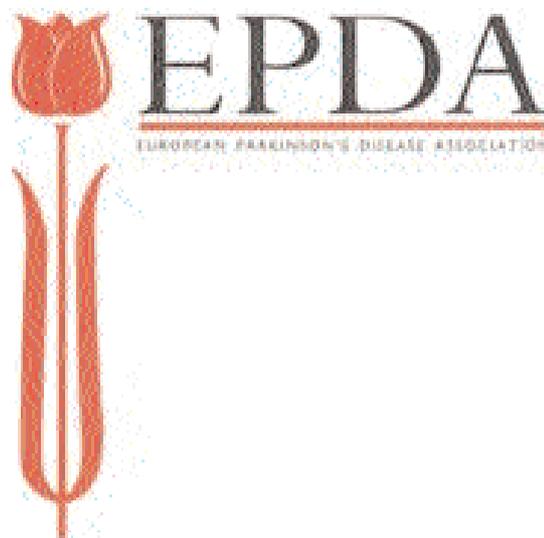
**EPDA**

EUROPEAN PARKINSON'S DISEASE ASSOCIATION

**2003**

*Annual*

*Report*



# EPDA 2003 ANNUAL REPORT

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# A new report for a new year



**The EPDA Board – full of experience, commitment and dedication**

We would like to welcome you to our first Annual Report. The EPDA, now into its twelfth year has never produced an annual report that, as a registered organisation, it should. We believe it is an attractive publication and it will be placed on the website to be freely accessed and printed off. It will also be used as a marketing tool to promote not only the work programme of the EPDA but at the same time enhance the public image of the organisation itself.

In May, Bruno Dupont, Board member, who resides in Brussels, decided to retire from the Board having worked with the EPDA in an advisory capacity for the European Commission for eight years. We would like to express our sincere thanks to him for his help behind the scenes during this time, especially for his knowledge and hard work during the EPDA registration process in Belgium in 1997/98.

The work programme reflects the further changes, building on the infrastructure that was put in to place at the beginning of our term of office in 2001. The continued appointment of the liaison/project manager has ensured that the EPDA has continued to grow, has become more efficient so that the membership receive information on a regular basis, which hopefully assists you with the work of your individual organisations and your membership. This appointment has also meant that the role of the Board is a strategic one enabling them to concentrate their efforts on providing operational guidance.

We hope that you will find the annual report a welcome addition to the EPDA publications and that it will demonstrate the important work that is being carried out in trying to enhance awareness and improve quality of life for people with Parkinson's and their families living throughout Europe.

The Board would like to thank the membership for all their support and interest in what we have tried to achieve throughout 2003. It has been a year of hard work and change, not only in structure but also in the Board.

We would like to express our sincere thanks and gratitude to Dr Irena Rektorova, Louise van der Valk and Raphael Medan for their dedication and commitment to the work programme of the EPDA. Irena has provided her support, expertise and interest since 1996,

became a Board member in 1998 and served as vice president since 2001. Louise was a founder member, initiator, and editor of the EPDA magazine until the summer of 2001 and since 1996 she has been secretary. Raphael joined the Board as Treasurer in 2001 but his continued, constant support has been evident since 1998. The EPDA owes a great debt to them all and we look forward to our continued working together.

While saying farewell to Irena, Louise and Raphael, Peter and I would like to welcome our newly elected Board Members for the next two years Mariella Graziano, Branko Smid, Gila Bronner, and Svend Andersen.

The Board has many talents and expertise ranging from experience as carers, living with Parkinson's, running their own PD organisations, physiotherapy, and sexual therapy. They also have great enthusiasm and commitment, and together with Lizzie Graham, liaison/project manager, will continue developing the strategic direction that the previous Board put in place during the last two years and provid-

## **“The Board has many talents, from expertise & enthusiasm to commitment”**

ing validated information and resources for people with Parkinson's and their families.

The EPDA has come a long way since our humble beginnings in 1992. We have initiated and developed many projects, both European and international, including 10 conferences (five multidisciplinary and five for the young onset Parkinsonians), but there is still much to do.

The new Board looks forward to continuing with this never-ending challenge throughout the next two years and not least in developing an ever-closer relationship with the World Health Organisation and the European Commission when there is changing legislation which will impact on the quality of life of people with Parkinson's and their families throughout Europe.

Finally, we would like to thank Stephen Pickard, legal advisor for his help and advice, despite having a very busy schedule; and Lizzie Graham, liaison/project manager, for the support and hard work that she has provided to us all and to the membership in general.

## EPDA in 2003: the Board's executive summary

With the continued growth of ICT and emails, it has been necessary for the Board to hold only three administration meetings in 18 months, since the General Assembly in June 2002. In addition, the lengths of these have been reduced to two days and are held at weekends when travel and accommodation is less expensive. Where possible they are held in the homes of Board Members in a further effort to save funds. The first was held in October 2002 in The Hague, the home of Peter Hoogendoorn, and the second in January in Brussels and the third in the UK at the home of Mary Baker. Every effort has been taken by the Board to find ways of reducing the cost of these meetings.

### Overview of activities

Our work continues to grow and to flourish and we are trying to provide valuable, validated information that will help improve the quality of life of those people throughout Europe, who live with this chronic neuro-

logical condition and those who care for them. You can read more about the projects on pages 6–7.

### Collaborative Proposal and Guidelines

The Board continues to try to raise funds to ensure that the work already begun will continue. We have therefore developed a document (visit [www.epda.eu.com](http://www.epda.eu.com)) which will be presented to companies, including the pharmaceutical and biotech industry, to encourage their support in becoming partners to the EPDA, its members, mission and objectives while at the same time raising the profile and credibility in a Europe that is increasingly concerned about the importance of health and the current state of healthcare provisions.

The EPDA will only partner with companies and organisations of high standing and reputation and all partnerships will be transparent to the EPDA and its membership, its key stakeholders, as well as to prospective partners and donors.

## Acknowledgements

The EPDA would like to thank the following people and companies for their support of the EPDA and its work programme throughout 2003. Without them it would not be possible to continue with our work programme.

### Patrons

In March, we notified you that we had invited several people to become patrons of the EPDA and were honoured and delighted to announce that the following people, who have provided support and encouragement to the EPDA throughout the years, had confirmed their acceptance of our invitation.

- Christoph Cardinal Schonborn, Archbishop of Vienna
- John Bowis, OBE, member of the European Parliament
- David Jones, CBE, chairman, Next plc
- John Walker, executive director, Ford Motor Company.

We are thankful that they will continue to support our important aims and objectives in the years to come.

We are continuing to approach other Europeans and have invited Dr Alois Mock, Austria and Professor Arvid Carlsson, Sweden, in the hope that they too would also be willing to serve as Patrons for the European Parkinson's community.

### Auditor: M J Read & Co

In January of this year, the Board took the decision to identify an auditor who could provide the same excellent professional services at a cheaper rate and who resided nearer to the EPDA office base.

Three companies were interviewed, all members of the Institute of Chartered Accountants in England and Wales, registered to carry out audit work, and regulated for a range of investment business activities and M J Read & Co was appointed to carry out the audit for the financial year 1 January – 31 December 2002 and reappointed at the 2003 General Assembly for a further year.

### Pharmaceutical Industry

The EPDA could not carry out its work programme without the constant and consistent support of the pharmaceutical industry.

They help in many ways: by providing advertising for the EPDA Focus, funding the preparation and development costs of publications including Medication Information Sheets, Patient Information Leaflets, Flexicard, EPNN Journal and more, and by providing funds to support projects and conference development.

We gratefully acknowledge the support of all the following companies who have worked so closely with the EPDA in partnership throughout 2003.



# The need for networking

How the working group on PD has been pro-actively engaged in building Parkinson's disease's profile to an all-time high



The fight's on: Boxing legend Mohammed Ali is just one of the high-profile names to back the PD Global Declaration

## Launch of the Global Declaration on Parkinson's Disease: 'Moving and Shaping'

The Working Group on Parkinson's Disease, formed by the World Health Organisation (WHO) in May 1997, launched the Global Declaration at the 7th World Parkinson's Day International Symposium in Mumbai, India on 6-7 December 2003.

Following the first World Parkinson's Disease Day on 11 April 1997 and the launch of the World Charter for People with Parkinson's disease, the Working Group on Parkinson's disease held its first meeting at the WHO offices in Geneva.

The group consisted of leading specialists in Parkinson's disease from Argentina, Austria, Canada, Germany, Russia, South Africa, Spain, UK, and USA and representatives from the EPDA. In subsequent years the group membership has increased to include Africa, India, Japan and Jordan, with annual meetings being held alongside World Parkinson's Disease Day celebrations in Spain, USA, Argentina, Japan and Russia.

The Group members reflect the WHO Regions: America, Europe, East Mediterranean, Africa, South East Asia, and Western Pacific. Their aim has been to develop a Global Parkinson's Disease Alliance and to work in partnership with the lay organisations in order to

transfer the 'Charter for people with Parkinson's disease' into a Global Declaration.

Parkinson's disease, which is globally distributed, affects all cultures and races, with the overall prevalence in the world being estimated to be 6.3 million with more than one in 10 people with Parkinson's being diagnosed before the age of 50 years of age.

Demographic changes mean that Parkinson's is set to become more and more common with the rise in the number of the elderly worldwide – the Netherlands estimate that for the period 2000–2020, the number of people diagnosed with Parkinson's will rise by 44.7%.

This increase is coming at the same time as a decrease in the availability of informal carers and the change in family and career structures.

Therefore, it is the time to urge Governments to provide effective and appropriate management strategies, which could improve the quality of life of those with Parkinson's and reduce the cost and impact on the global community.

The Working Group on Parkinson's Disease looks forward to the support of the global PD organisations in promoting this important event throughout their countries and regions.

It is planned to hold a further launch at the World PD Day celebrations being held in Canada in April 2004 followed by a further launch at the EPDA conference 'Working in Harmony – The Team Approach, in Lisbon, Portugal, in May 2004.



The Global Declaration: to encourage a change in attitude towards PD

# Projects

Outlines of the main developments the EPDA has been working on in 2003

## UK Community Pharmacy Medicines Support Pilot in PD

**M**edicines Partnership, a UK Department of Health initiative, is collaborating with the EPDA and a number of other organisations to develop a project to evaluate the effectiveness of an extended medicines support service to be provided to patients with PD by specially trained community pharmacists.

Given the many problems faced by PD patients with medicines, community pharmacists are ideally placed to provide local, expert assistance.

The pilot project will train 18 pharmacists to offer regular, structured consultations with PD patients and/or their carers in which they will identify and address patient issues and concerns regarding their medicines and condition, including how medicines work, side

effects and interactions and practical aids to medicine taking.

The service is planned to commence mid-2004. Sweden, has also expressed a sincere interest in this project and Lars Nillson of the NEPI Foundation attended the last meeting.

It is hoped that the pilot project will lay the groundwork, not only for a widespread service for patients with PD in the UK, but also for the establishment of 'pharmacists with a special interest' in a range of disease areas.

The Health Services Research Unit at the University of Oxford will carry out the evaluation of the service, and Medicines Partnership and Pfizer jointly fund the project. Further details are available at

[www.medicines-partnership.org/projects](http://www.medicines-partnership.org/projects)

## INFOpark



**T**his three-year study, funded by the European Commission, is a partnership between the

EPDA and Estonia, Finland, Germany, Greece, Portugal, Spain and the UK. It involves 231 people with PD (over 65 years of age), 224 Carers and 291 health care professionals working in 58 focus groups including medical doctors, nurses, psychologists, therapists (physios, OT's and speech), pharmacists, social workers and voluntary organisation staff.

Sources of information have included face-to-face interviews, written, audiovisual and PD Society support groups. It has been identified that successful information giving is as a result of this being given individually, step-by-step, according to disease severity, different information for patient and carers, emotional support and team management.

Barriers in information giving include: lack of communication skills, lack of professionals' time ; lack of interest of patients/carers; lack of general practitioner's knowledge; lack of patients' readiness to participate in decision making; poor communication between professionals.

The Study so far concludes that:

- Between different countries there were more similarities than differences concerning information needs, sources, experiences and barriers in information giving
- From time of initial diagnosis, patients have ongoing needs for information
- Lack of knowledge and fear concerning the future gives a negative influence on quality of life
- The specific needs of carers require separate attention from healthcare professionals
- The information needs are individual and change during the course of the chronic illness
- Information should be given regularly, repeatedly, on individualised basis according to disease severity
- Team management of PD with inter-professional communication is the most effective approach
- Patients with chronic progressive diseases and their carers need education
- The standardised materials have to be available in understandable languages
- Professionals need easy access to a protocol advising on best care.
- Professionals need training in communication skills
- Well-informed patients and carers are empowered to contribute to decision making as full members of the multidisciplinary team.

## Questionnaire for younger people with PD – the Participation in Life survey

Many members will remember the energetic discussion at the 2002 and 2003 General Assemblies about the needs of younger people with Parkinson's – and the consensus that younger people with PD do have special needs that should be more systematically and thoroughly explored before ways of meeting them can be found.

Since the last General Assembly, the Board has considered how to progress this important research, which unfortunately got off to a bad start in 2001-02.

It agreed that the most effective approach would involve a mechanism for data collection that would be rapid and anonymous while not demanding excessive time and energy.

A survey was the most favoured method, and it was agreed the research team must be able to work collaboratively with service-



users at all stages of the design, implementation and conduct of the study. Service-users must also be prepared to share the findings in a way that would benefit participants and future service-users and could be used to influence policy.

## Economic impact of PD: A research survey in the UK

The paper Movement Disorders 2003 DOI 10.1002/mds.10507 is available via the Movement Disorder Website: [www.interscience.wiley.com/movementdisorders](http://www.interscience.wiley.com/movementdisorders)

The direct costs of care were evaluated prospectively in a sample of people with Parkinson's disease (PD) in the United Kingdom in 1998.

A random sample of people with PD was drawn from general practitioner practices within a representative sample of 36 regional health authorities – and the equivalent.

A total of 444 resource-use questionnaires

with useable data were returned (response rate 59%). The total mean annual cost of care per patient for all patients by age was £5,993 (9,554 euros, n = 432).

Hoehn and Yahr stage significantly ( $P < 0.001$ ) influenced expenditure by stage as follows: 0 = I, £2,971 (4,736 euros, n = 110); II, £3,065 (4,886 euros, n = 89); III, £6,183 (9,857 euros, n = 120) IV, £10,134 (16,155 euros, n = 87); V, £18,358 (29,265 euros, n = 17).

National Health Service costs accounted for approximately 38% and social services for 34% of the direct costs of care.

## PD Med



This project, funded by the NHS Health Technology Assessment programme, is a large, simple "real life" trial that aims to determine reliably

which classes of drugs provide the most effective control with the fewest side effects for both early and later Parkinson's disease.

The main outcome measure is patient-related quality of life.

### Progress

- 525 patients recruited into PD MED
- 402 in early disease
- 123 in later disease

### Literature support

A series of recent articles have called for more clinical trial evidence from studies – such as PD MED – comparing different classes of drugs. This trial has been specifically cited in Rogers et al's review of initial agonist treatment in the American Journal of Neurology (Feb 2003) as an important source of data to help guide future clinical practice.

The trial is being carried out in the UK with two international collaborators (the Czech Republic and Russia).

For further information visit [www.epda.eu.com](http://www.epda.eu.com) or contact PD Med Trial Office PD-Trials@bham.ac.uk.

# European developments

Here are some of the fine examples of how organisations are working together to drive best practice across Europe

## European Parkinson's Nurses Network



In the last two years, there have been many requests from Parkinson's disease nurses as well as people with Parkinson's throughout

Europe as to whether or not there was a possibility for a nurses organisation to be formed.

Such a network would have the opportunity of applying for research funding from the European Commission and would help with the many challenges that exist including inequity of service, availability of medication, which varies from country to country, and the lack of PD nurses in many European PD centres.

The aim of this European network is to work in partnership with other similar organisations such as PDNSA and the International

Nurses Group, for the benefit of people with Parkinson's and their families.

PD Nurses from throughout Europe were invited to become members of the European Nurses Steering Committee and they are:

Annette Bowron, Alison Forbes (PDNSA), Jane Merrills, Kirsten Turner (Chair) – from England.

Orna Moore – from Israel.

Martje Drent, Josje Hilgers, Gill McLean and Lidy Tinselboer – from the Netherlands.

Liz Morgan – from Wales.

Lizzie Graham, EPDA liaison/project manager has been asked to co-ordinate and administer this group during its development and separate sponsorship is being sought to fund the administration. The launch of the EPNN will take place at the EPDA's 5th multidisciplinary conference from 6–9 May 2004 in Lisbon, Portugal. The nurses will also hold a satellite symposium, followed by their first business meeting.

## European Brain Council (EBC)



President, Jes Olesen, neurologist and Mary Baker, vice president were instrumental in the foundation of the EBC in March 2002. It has a unique structure – bringing

together as it does, a host of European organisations with a specific interest in the brain.

Members include pan-European bodies representing neurologists and psychiatrists, as well as patient federations in those respective fields, neurosurgeons, basic neuroscientists, and relevant areas of industry and commerce.

## EBC's work programme for 2003

Strengthening the collaboration among all stakeholders across European organisations and with the EC is a major EBC drive in order to further develop brain research and brain disorders.

It also proposes a separate programme on "brain research" to be expanded within the forthcoming 7th Framework Programme.

The EBC will seek to be actively involved from the very beginning in influencing the content of the 7th Framework Programme.

This will involve gathering and scientifically analysing data on the cost and burden of brain disorders in Europe.

This project will provide, for the first time, a single document containing the costs of brain disorders in Europe in economic and social terms.

It also published a booklet "Brain connections" in collaboration with the European Dana Alliance for The Brain highlighting some important areas where advances in basic science promise new hope for patients with brain disorders.

## EBC: The Founding Members

Members include pan-European bodies representing neurologists and psychiatrists, as well as patient federations in those respective fields, neurosurgeons, basic neuroscientists, and relevant areas of industry and commerce.

The European Federation of Neurological Associations (EFNA) represents Europe-wide organisations for patients with neurological illnesses, such as the European Parkinson's Disease Association, Alzheimer Europe, European Dystonia Federation etc.

The Global Alliance for Mental Illness Advocacy Networks (GAMIAN-Europe) represents associations of psychiatric patients.

The European Federation of Neurological Societies (EFNS) represents national societies of neurologists throughout Europe and the European

College of Neuropsychopharmacology (ECNP) is a Europe-wide organisation of psychiatrists and pharmacologists and other basic scientists.

The European Association of Neurosurgical Societies (EANS) is a federation of national societies of neurosurgeons.

The EBC seeks to have industry representation but, in most cases, industry does not yet have sub-divisions dealing specifically with the brain at a European level.

Until that happens, the EBC accepts individual companies as representatives of their industry.

For example, AOK (Allgemeine Ortskrankenkasse), as the biggest German health insurance company – represented by AOK Schleswig-Holstein – is an EBC member and representative of the European insurance industry.

## European Federation of Neurological Associations (EFNA)



Mary Baker, President of the EPDA and EFNA has

together with her fellow Board

members, spent considerable time, working with the European Commission putting forward the patients' point of view in the big debate in the Parliament about direct consumer information.

EFNA's motto is "Partnership for Progress" and the association really does try to achieve its aims by this route, combining the strength and experience each of the member organisations has acquired in the work for its own particular medical condition.

EFNA draws together all that experience to unite in a common cause, providing the international medical community, politicians and other decision-makers with an active partner and source of authoritative information across a broad, but extremely important and distinctive area of medicine – brain disorders.

EFNA's projects, which try to reflect this breadth include:

- Working towards the elimination of stigma
- Participation in production of consensus guidelines and procedures
- Supporting the formation of a European Stroke Patients' Group
- "Parliamentary Partners in Brain Diseases"
- Creation and application of a European Media Pack
- Bridging the Treatment Gap
- Compliance in medicines

### Publications include:

- Common neurological symptoms & conditions – a guide for non-professionals.

### Partners:

- EFNA-affiliated associations
- European Federation of Neurological Societies (EFNS)
- World Federation of Neurology (WFN)
- World Health Organisation (WHO)

### Neurological and general Medical

#### Information:

- IntelliHealth
- Mayo Clinic
- MedicineNet
- MedLineplus
- NOAH – New York Online Access to Health

### Other general patients' and citizens' organisations:

- ADI – Alzheimer's Disease International
- APAI – Associazioni Patologie Autoimmuni Internazionale
- BEUC – European Consumer's Organisation
- ECAS – European Citizen Action Service
- EDF – European Disability Forum
- EMSP – European MS Platform
- EPPOSI – European Platform for Patients' Organisations, Science and Industry
- EURORDIS – European Organisation for Rare Diseases
- IAPO – International Alliance of Patients' Organisations
- PA – The Patients' Association

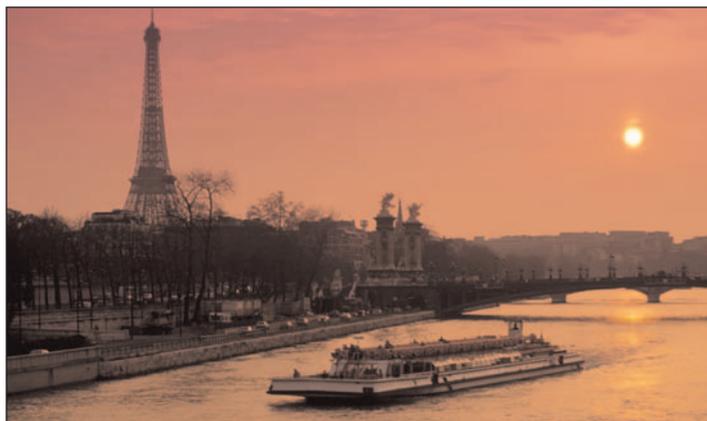
## Other EPDA activities in 2003/4

### General assembly unites old friends

The EPDA members and their friends from 23 European countries gathered together for the annual General Assembly weekend in the lovely city of Paris in November. It was a time to meet old friends and welcome new ones; to listen to many interesting presentations; to share news and join in discussions. It was also the time to say goodbye to elected Board members who had decided to retire from their positions of office and to welcome new members who will continue to develop and lead the EPDA work programme for the next two years.

Dr Irena Rektorova, Czech Republic provided the annual update on EPDA Projects and Prof Pille Taba, Estonia provided a fascinating and informative update on the Infopark project (see page EPDA projects page 6 – 7).

Annette Bowron, a senior Parkinson's disease nurse specialist at the North General Tyneside hospital in the UK and committee member of the European Parkinson's Nurses Network presented the results of a 12 month study (funded by Novartis and Orion Pharma) involving international PD specialists to promote better recognition by both the



The beautiful sights of Paris greeted delegates at last year's GA

patient and physician of the symptoms of wearing off.

A controlled survey was designed by the group to compare the sensitivity of a patient questionnaire versus clinical assessment. It was completed earlier this year and the data presented at the EFNS congress, Helsinki, and at the Parkinson's Study Group meeting, San Francisco, in October. For further information visit [www.epda.eu.com](http://www.epda.eu.com)

'Dilemmas concerning sexuality and intimacy in Parkinson's disease' was led by Gila Bronner, sexual therapist, Israel, who spoke about the importance of intimacy and touch, and of how it is not

given the attention it deserves in the management of Parkinson's. Also, sometimes, the symptoms of PD can affect this normal everyday activity – even kissing can be difficult because of dyskinesic movements.

She stressed that 'loving' is a pleasant activity for two people and if the expectation of one is not matched by the other, this can lead to disharmony and can erode a relationship. In 2004, the coming months, the EPDA will be working closely with Gila to find ways of increasing awareness and understanding of this very important quality of life issue.

### Parkinsonpoly sparks interest

One of the EPDA's latest initiatives is Parkinsonpoly – an interactive patient education resource that uses a board game analogy to engage patient interest and aid memorability.

The first element of the Parkinsonpoly patient initiative is a website which gives people with Parkinson's disease, their families and carers a concise, visual guide to structured information, advice and help, to reflect their changing information needs over time.

The website includes content from the new EPDA Parkinson's leaflet information series and these leaflets are further published under the Parkinsonpoly umbrella and can be downloaded from the Parkinsonpoly website as well as from the EPDA website. See [www.parkinsonpoly.com](http://www.parkinsonpoly.com)

### EPDA website gets makeover

The EPDA Website, [www.epda.eu.com](http://www.epda.eu.com), was designed in 1998, redesigned in 2002, and has now received another face-lift – thanks to the support of one of our patrons David Jones.

His son has redesigned the website so that it is more visually attractive and the information easier to find. Paula Proctor, at Sheffield University, has supported the EPDA since 1996 and has carried out this work for us in her free time despite having a very busy schedule.

But times change, and with her agreement, the site was rehomed from 15 September 2003. We would like to thank Paula for her hard work, time, friendship, and her interest in the work of the EPDA.

The production of the Medication Fact Sheets, Patient Information Leaflets and

Parkinsonpoly have been as a result of the collaboration between the EPDA and Novartis Pharma AG and Orion Pharma who provided an unrestricted educational grant for their development.

● In June 2003, these leaflets were produced in a series of six produced with the active participation of people with Parkinson's and carers throughout Europe, and were added to the website.

They contain information including treatment options, working together, talking about parkinson's, taking control, what is the latest science, and coping with Parkinson's.

The EPDA is enjoying its new website redesign



## 2004 to see fund raising ideas with Rotary International

At the General Assembly 2002 the EPDA discussed the possibility of collaborating with Rotary International on a project that would help the exchange of doctors in the field of Parkinson's disease.

Discussions have continued and it is anticipated that fund raising initiatives will be developed in 2004 to fund bursaries to help with the integration of these doctors within the community and society while living within the countries during their period of training.

Countries actively involved in this project are the UK, Belgium, and Italy.

## No meeting for Euroyapp&rs

Regrettably, the Federation Francaise des Groupements (FFGP), had to take the decision, due to financial reasons, to cancel the Euroyapp&rs conference which was due to be held the same weekend as the General Assembly. With the appointment of Svend Anderson to the Board with responsibility for young onset the needs of the younger people with Parkinson's will be a focal point in our work programme and we hope that a Euroyapp&rs conference will be held in the near future.

● The EPDA is trying to continually provide up-to-date and validated information, which will assist not only people with Parkinson's and their families but also the health professionals who care for them.

We are using the EPDA Website to do this so that this information reaches as many people as possible. During 2003, the Medication Fact Sheet has been developed.

This replaces the printed European Medication leaflet and contains not only information about the medication, where it is available and in which countries, but also provides graphics of the packaging.



The new EPDA Medication fact sheet

## 'Working in Harmony' encouraged by EPDA

The fifth EPDA multidisciplinary conference is being held in Lisbon, Portugal, from 6 – 9 May 2004 (see [www.epdaconferences.org](http://www.epdaconferences.org)).

It has been reviewed and approved for CME (Continuing Medical Education) by the European Federation of Neurological Societies.

It promises to uphold the EPDA Mission Statement 'to develop a dialogue between science and society' and to promote international understanding of Parkinson's, enabling people living with the chronic neurological condition and their families to draw on best caring practice by accessing the latest medical and surgical advice thereby enabling them to make informed choices to achieve the best quality of life possible.

Delegates, including health and social care professionals as well as people with Parkinson's and their carers, are expected. And there are dedicated satellites for PD nurses, physiotherapists, occupational therapists and Making Life Easier – a Multidisciplinary Approach, workshops, Meet the Expert sessions, and the final report on the European Commission-funded three year project, INFOpark (Information needs of People with PD and their

carers, and how professionals can help meet those needs).

Jan Herzog, a neurologist from Germany, and Rui Vaz, neurosurgeon, Portugal, are working together to lead a much needed session on Deep Brain Stimulation (DBS) – Some of your questions answered.

Many people with Parkinson's, their carers and healthcare professionals involved in their management want to know a lot more about DBS and they have many questions that need answering.

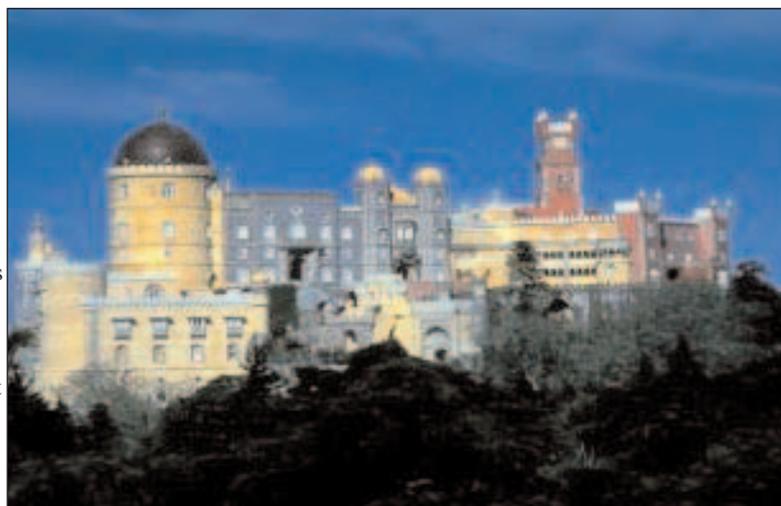
The EPDA wanted to provide an opportunity where people could listen to the facts about DBS and have the opportunity of not only listening but also asking many of their questions and this interactive session, has been designed to do

just that.

One of the highlights will be the launch in Europe of the Global Parkinson's Disease Declaration 'Moving and Shaping', following on from its highly successful launch in Mumbai in December 2003 (See page 5).

But overall the programme has been developed to allow debate and encourage the participation of those involved in the management of what is a most difficult and challenging illness.

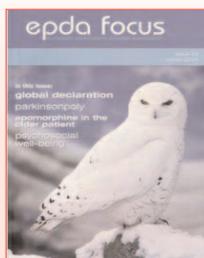
**The conference promises to uphold the EPDA Mission Statement 'to develop a dialogue between science and society'**



Lisbon will come alive in May with the EPDA multidisciplinary conference

# EPDA PUBLICATIONS

## EPDA Focus



### WHAT IS IT?

Focus is a way of sharing best practice and tips on how to manage Parkinson's and improving quality of life. We continue to seek funding for the Focus. Some very kind people have sent donations and together with some advertising funds, we have been able to continue with the publication

### HOW FREQUENT IS IT?

Quarterly

### HOW DO I GET IT?

Contact Lizzie Graham

## European Parkinson's Nurses Network (EPNN) Journal



### WHAT IS IT?

A new publication will be launched in Lisbon in May at the EPNN Satellite, running alongside the 'Working in Harmony – The Team Approach' conference. It is a vehicle for networking with international PDNS individuals and groups to exchange and promote higher standards of care

### HOW FREQUENT?

Quarterly

### HOW DO I GET IT?

Contact Lizzie Graham

## EPDA Newsletter



### WHAT IS IT?

The Newsletter is to be redesigned and will be used as a marketing tool to promote not only the work programme of the EPDA but at the same time enhance the public image of the organisation itself. We hope that you will take some of the news and reproduce this in your own magazines and newsletters

### HOW FREQUENT?

Quarterly

### HOW DO I GET IT?

See EPDA website

## Flexicard



### WHAT IS IT?

In the summer of 1995 a Flexicard was produced and funded by Hoffmann-La Roche which stated 'I have Parkinson's disease. Please allow me time. In case of an emergency contact...' Once again, thanks to Hoffman-La Roche, these cards have been reproduced but this time in eight languages. These cards are available, free of charge

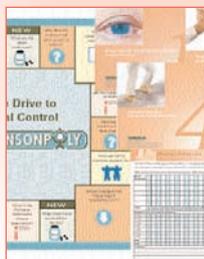
### HOW FREQUENT?

Always available

### HOW DO I GET IT?

Contact Lizzie Graham

## Patient Information Leaflets



### WHAT IS IT?

The Patient Information Leaflet series on the EPDA website has also been published and produced with the help of people with Parkinson's from throughout Europe. With the support of Novartis and Orion Pharma, these leaflets have been translated into other languages e.g. Bulgarian, Italian, Icelandic to name but a few

### HOW FREQUENT?

Always available

### HOW DO I GET IT?

Contact Lizzie Graham

# The European Parkinson's Disease Association business plan: What it is and what it will do

## Mission statement:

To develop a dialogue between science and society

## Objective:

To promote international understanding of Parkinson's disease, enabling people living with Parkinson's and their families to draw on best caring practice worldwide, to access the latest medical and surgical advice and thus make informed choices to achieve the best quality of life possible

The ethos of the Association is to manifest a "partnership for progress", bringing together dedicated organisations representing the interests of people living with Parkinson's disease together with their professional counterparts in medical, scientific, commercial, industrial and pharmacological spheres.

The specific focus of the association is on promoting a wider understanding of how Parkinson's disease impacts on the lives of patients, their fami-

lies and carers, as a means to mobilising actions for removal of barriers to their fullest possible social and economic participation.

The EPDA seeks to make a significant impact on the enormous costs of the current failure to:

- Provide the maximum opportunity for those with Parkinson's disease and their carers to make a significant contribution to their community
- Alleviate the social and economic burden on a decreasing number of carers and on society in general

## Emerging strategies and implementation

### Key indicators

The successful implementation of strategy is crucial to the EPDA developing credibility as an added value body supporting and complementing the efforts of its constituent organisations.

Key indicators for early actions that are potentially affordable, are:

- Have universal application to the EPDA
- Influence understanding and communication of the realities for those with PD
- Distribute existing "best-practice" knowledge and guidelines to all patient groups within the EPDA
- Establish a database of facts, figures and demographics which will support the "business case" for further actions
- Already in progress with one or more of the EPDA constituents who are prepared to take the lead in progressing further.

### Projects

Projects, which have been identified for possible early adoption, from which a selection will be made, include the following:

- Working with pharmacists to improve compliance
- Working with the media to improve their understanding and more positive reporting on Parkinson's disease
- Developing educational programmes within the sphere of Parkinson's disease, with the patient as educator
- Counteracting discrimination and misunderstanding of Parkinson's disease.

This list will be varied and added to through the ongoing consultation processes with constituent organisations.

### Newly elected Board members

Mary Baker	President	United Kingdom
Peter Hoogendoorn	Vice president	Netherlands
Mariella Graziano	Secretary	Luxembourg
Branko Smid	Treasurer	Slovenia
Gila Bronner	Member	Israel
Svend Anderson	Young onset	Denmark

### Retired Board members

November 2003

Irena Rektorova	Vice president	Czech Republic
Raphael Medan	Treasurer	Israel
Louise van der Valk	Secretary	The Netherlands

# EPDA 2003 FINANCIAL REPORT

## CONSOLIDATED INCOME AND EXPENDITURE ACCOUNT – FOR THE YEAR ENDING 31 DECEMBER 2003

	2003			2002		
	EPDA £	PDI £	TOTAL £	EPDA £	PDI £	TOTAL £
<b>INCOME</b>						
Members fees	10,285	0	10,285	7,910	0	7,910
Contributions	58,462	0	58,462	73,846	0	73,846
Working Group donations	46,408	0	46,408	0	0	0
EPNN donations	6,750	0	6,750	0	0	0
Goods sold and commission received	0	0	0	50	0	50
Advertising revenue	0	11,100	11,100	0	900	900
	121,905	11,100	133,005	81,806	900	82,706
<b>OTHER INCOME</b>						
Gains on foreign exchange	595	0	595	464	0	464
Deposit account interest	224	39	263	139	0	139
	122,724	11,139	133,863	82,409	900	83,309
<b>EXPENDITURE</b>						
Printing postage and stationery	765	586	1,351	358	0	358
Euralia	0	0	0	0	0	0
Meetings – AB, GA etc	11,308	0	11,308	16,699	0	16,699
Officers expenses	3,506	0	3,506	8,930	0	8,930
Website	640	0	640	640	0	640
Purchases	0	0	0	0	0	0
Gifts and donations	0	0	0	1,650	143	1,793
Honorarium	0	0	0	0	0	0
Magazine costs	0	17,285	17,285	0	11,792	11,792
Consultancy and overhead costs	33,600	0	33,600	40,671	0	40,671
Travel expenses	452	120	572	4,970	0	4,970
Transfer to P D I Ltd	50,800	(50,800)	0	27,855	(27,855)	0
Working Group costs	20,983	0	20,983	0	0	0
EPNN expenses	2,883	0	2,883	0	0	0
Conference costs	0	0	0	0	12,931	12,931
10th Anniversary Conference	0	(775)	(775)	23,718	31,290	55,008
Grants repaid	0	0	0	8,408	0	8,408
Pharmacy Through Europe costs	5,000	0	5,000	0	0	0
Conference promotion	0	1,970	1,970	0	624	624
Companies House fees	0	15	15	0	29	29
Membership fees	301	0	301	0	0	0
Accountancy	0	2,350	2,350	0	1,800	1,800
Depreciation	0	92	92	0	92	92
Bank charges and interest	265	112	377	269	53	322
	130,503	(29,045)	101,458	134,168	30,899	165,067
<b>NET SURPLUS/(DEFICIT)</b>	<b>(7,779)</b>	<b>40,184</b>	<b>32,405</b>	<b>(51,759)</b>	<b>(29,999)</b>	<b>(81,758)</b>

# EPDA 2003 FINANCIAL REPORT

## CONSOLIDATED BALANCE SHEET – FOR THE YEAR ENDING 31 DECEMBER 2003

	2003			2002		
	EPDA	PDI	TOTAL	EPDA	PDI	TOTAL
	£	£	£	£	£	£
<b>INCOME</b>						
Fixed assets:						
Tangible assets	1	92	93	1	184	185
<b>CURRENT ASSETS</b>						
Stocks	0	0	0	0	0	0
Debtors	19,033	1,014	20,047	762	4,602	5,364
Cash at bank	98,747	10,610	109,357	39,174	6,042	45,216
	117,780	11,624	129,404	39,936	10,644	50,580
<b>CREDITORS: AMOUNTS FALLING DUE</b>						
<b>WITHIN ONE YEAR</b>						
Creditors and accruals	99,293	1,850	101,143	13,670	41,146	54,816
<b>NET ASSETS</b>	<b>18,488</b>	<b>9,866</b>	<b>28,354</b>	<b>26,267</b>	<b>(30,318)</b>	<b>(4,051)</b>
<b>RESERVES</b>						
Balance brought forward	26,267	(30,318)	(4,051)	78,026	(319)	77,707
(Deficit)/surplus for year	(7,779)	40,184	32,405	(51,759)	(29,999)	(81,758)
Balance carried forward	18,488	9,866	28,354	26,267	(30,318)	(4,051)

### Basis of audit opinion

We conducted our audit in accordance with Auditing Standards issued by the Auditing Practices Board. An audit includes examination, on a test basis, of evidence relevant to the amounts and disclosures in the financial statements. It also includes an assessment of the significant estimates and judgements made by the Administration Board in the preparation of the financial statements, and of whether the accounting policies are appropriate to the Association's circumstances, consistently applied and adequately disclosed.

We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial statements are free from material misstatement, whether caused by fraud or other irregularity or error. In forming our opinion, we also evaluated the overall adequacy of the presentation of information in the financial statements.

### Opinion

In our opinion the financial statements give a true and fair view of the state of the association's affairs as at 31 December 2003 and of its deficit for the year then ended and have been properly prepared in accordance with the association's constitution.

### M J Read & Co

1 Cobden Road  
Sevenoaks  
Kent  
TN13 3UB

# EPDA MEMBER ORGANISATIONS

Austria		Parkinson Selbsthilfe Osterreich
Belgium		Association Parkinson Belge
Belgium		Viaamse Vereniging Parkinson
Belgium		Association Parkinson (Fraiture-en-Condroz)
Bulgaria		Fondazia Parkinsonism
Czech Republic		Parkinson's Disease Society
Cyprus		Parkinson's Disease Association
Denmark		Dansk Parkinson Forening
Estonia		Estonian Parkinson's Society
Faeroe Islands		Parkinsonfelagid
Finland		Suomen Parkinson-Litto Ry
France		Federation des Groupements de Parkinsoniens
Germany		Forderverein Parkinson e.V
Iceland		Parkinson Association in Iceland
Ireland		Parkinson's Association of Ireland
Israel		Parkinson Group
Italy		Azione Parkinson
Italy		Parkinson Italia
Lithuania		Lithuanian Parkinson's Society
Luxembourg		Association Luxembourgeoise de la Maladie de Parkinson
Netherlands		Parkinson Patienten Vereniging
Norway		Norges Parkinsonforbund
Poland		Kracow Parkinson's Disease Association
Poland		Stow, Choroby Parkinsona
Portugal		Associacao Portuguesa de Doentes de Parkinson's
Russia		The Regional Non-profit organisation for the Advancement of Parkinsonien Patients
Slovenia		Parkinson's Disease Society of Slovenia
Spain		Federacion Espanola Parkinson
Sweden		The Swedish Association of Neurologically Disabled
Sweden		The Swedish Parkinson's Disease Association
Switzerland		Schweizerische Parkinsonvereinigung
Turkey		Parkinson's Disease Society
Ukraine		The Association for Parkinsonian Disabled
United Kingdom		Parkinson's Disease Society of the United Kingdom
Yugoslavia		Serbian Association against Parkinson's Disease

# MAB AND ASSOCIATE MEMBERS

MEMBER

ORGANISATIONS

## Medical Advisory Board

Prof. Werner Poewe, Austria	Mindaugas Socas, Lithuania
Dr Chris Van der Linden, Belgium	Dr Bucchler Pit, Luxembourg
Prof. P J Delwaide, Belgium	Dr M Horstink, Netherlands
Dr Jean-Emile Vanderheyden, Belgium	Dr R S Holmsen, Norway
Prof. Wenzeslav Bossnev, Bulgaria	Dr Anna Krygowska-Wajs, Poland
Prof. P J Delwaide, Belgium	Dr Jakub Sienkiewicz, Poland
Dr Marios Pantzaris, Cyprus	Dr A Castro Caldas, Portugal
Dr Jan Roth, Czech Republic	Prof. Natalia Federova, Russia
Dr Erik Dupont, Denmark	Prof. Alla Guekht, Russia (Ass Member)
Prof. Pille Taba, Estonia	Dr Dan Pirtosek, Slovenia
Dr Heikki Teravainen, Finland	Prof. Eduardo Tolosa, Spain
Prof. Herve Allain, France	Prof. Olle Lindvall, Sweden
Dr Ferenc Fornadi, Germany	Dr Bo Johnels, Sweden
Dr S Sveinbjornsdottir, Iceland	Dr M Sturzenegger, Switzerland
Dr Michael Hutchinson, Ireland	Dr Prof Sibel Ozemekci, Turkey
Dr Nir Giladi, Israel	Dr Irina Karaban, Ukraine
Prof. Tommaso Caraceni, Italy	Prof. Leslie Findley, UK
Prof. Alberto Albanese, Italy	Prof. Nadia Sternic, Yugoslavia

## Associate members

**Association of Physiotherapists in Parkinson's Disease EUROPE (APPDE)**



APPDE

**Atlantic-Euro-Mediterranean Academy of Medical Sciences**

**Division of Movement Disorders of the Russian Society of Neurologists**

**European Federation of Neurological Societies (EFNS)**



EFNA

**European Federation of Neurological Associations (EFNA)**

**Long-term Medical Conditions Alliance (LMCA)**

**Movement Disorder Society (MDS)**



National Tremor Foundation

**National Tremor Foundation, UK**

# The European Parkinson's Disease Association: Here's a glance at the people behind it and what it is they do...

## EPDA Administration Board



**President:**  
**Mary Baker,**  
**United Kingdom**

*Mary is serving her sixth term in office as president. She is also president of the European Federation of Neurological Associations and vice president of the European Brain Council.*



**Vice president:**  
**Peter Hoogendoorn,**  
**Netherlands**

*Peter became actively involved in the Dutch Patients Association (PPV) in the early 90s, initially as a member of the Publicity Working group. In 1998 he was elected a member of the Board and has been Chair of PPV since 2000.*



**Secretary:**  
**Mariella Graziano,**  
**Luxembourg**

*Mariella was born in Buenos Aires, Argentina, and emigrated to Great Britain in the 80s, where she graduated as a physiotherapist. She is currently the president of the Association of Physiotherapists in Parkinson's Disease Europe (APPDE).*



**Treasurer:**  
**Branko Smid,**  
**Slovenia**

*Branko was born in Kranj, Slovenija, in 1956. In 1996 he became president of the Slovenian PD Society. Under his guidance, membership has increased from 30 to almost 400 people. Branko has had PD since 1986.*



**Member:**  
**Gila Bronner,**  
**Israel**

*Gila is a sex therapist and sexual health counsellor, active in the promotion of sexual health since 1973. Her professional experience includes treatment of men and women with sexual dysfunction. Her international activities include training of physicians, nurses and social workers.*



**Young onset:**  
**Svend Andersen,**  
**Denmark**

*Svend, has had Parkinson's disease for 13 years and worked as a clinical psychologist full time from May 1978 until August 1996 and since then he has worked part-time. He has also written and published, "Health is between your ears" about living a good life with a chronic disease.*



**Liaison/  
Projects:**  
**Lizzie Graham,**  
**United Kingdom**

*has worked with the EPDA since it was formed in June 1992, in a voluntary capacity until November 2001, when she was appointed on a consultancy basis to organise, administer and co-ordinate the EPDA calendar of events. She has two sons.*



**Legal advisor:**  
**Stephen Pickard,**  
**Belgium**

*Stephen Pickard is an English solicitor working in the Brussels office of a large Spanish law firm, Garrigues. Stephen's father, Cyril Pickard, himself a Parkinsonian, was treasurer of the UK Parkinson's Disease Society in the 1980's. His role is voluntary.*

### EPDA CONTACT DETAILS

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[www.epda.eu.com](http://www.epda.eu.com)  
[www.epdaconferences.org](http://www.epdaconferences.org)  
[www.parkinsonpaty.com](http://www.parkinsonpaty.com)

### EPDA PATRONS

Christoph Cardinal Schonborn  
John Bowis, OBE, MEP  
David Jones, CBE  
John Walker

## EPDA Presentations/Meetings in 2003

January	European Parliament, meeting with MEPs, Brussels	Mary Baker (MB)
February	EPDA Best Practice meeting with pharmaceutical/biotech industry, London	MB/Lizzie Graham (LG)
February	EPDA Pharmacy Project meeting, London	MB/LG
March	Drug Information Association Meeting, Rome	MB
April	World PD Day, Moscow	MB/LG
April	Working Group on PD meeting, Moscow	MB/LG
April	World PD Day, Belgium	MB
May	Novartis Foundation, Basle	MB
May	Amersham Health meeting, Seville	MB
May	EBC Meeting, Nice	MB
May	Novartis Foundation meeting, Colmar	MB
June	Biotech Industry Meeting, Washington	MB
June	Launch of EBC meeting, Brussels	MB
July	APPDE Conference, Southampton	MB
July	Medtronic meeting, Lausanne	MB/LG
July	EPDA Pharmacy Project meeting, London	MB/LG
August	Amersham Health meeting, Amsterdam	MB
September	EFNS Congress, Helsinki	MB/LG
September	EFNA General Assembly meeting, Brussels	MB/Peter Hoogendoorn (PH)
September	Neuroscience meeting in European Parliament, Brussels	MB
September	Atlantic Euro Med Academy of Med Sciences, Bulgaria	MB
October	WHO meeting, Geneva	MB
October	First BMJ Patients Advisory Committee meeting, London	MB/LG
November	Relationship between Industry and Patient Associations, Coventry	MB
December	WPDD International symposium & launch of Global Declaration for PD, Mumbai	MB/LG
December	4th Annual Accelerating Clinical Trials, Geneva	PH