


EMBRACE TOMORROW

Annual Report 2006





“We continue to support new and existing members to provide optimum care and rehabilitation”

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EPDA Annual Report 2006

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EPDA Board's Welcome

2006: an exciting year for members

In 2006, the EPDA continued to enhance its profile throughout Europe and other parts of the world, proving it to be an exciting and fulfilling year for the board and its membership.

Knowledge about the organisation, respect for its achievements and what it stands for continued to grow throughout the international community. This was aided and abetted by our website www.epda.eu.com, the educational resources we provide and the projects we continue to develop.

As you read through this annual report we hope you will continue to share the resources we offer with your members, colleagues and healthcare professionals in your individual countries.

Everything we produce is aimed at improving quality of life, and assisting people with Parkinson's, their families and healthcare professionals with achieving that aim.

We try to do this by listening to the needs of people with Parkinson's, their families and carers, by developing projects and resources based on those needs and encouraging a constructive dialogue between science and society. Some of our projects have come to fruition. Others have begun while others continue to develop, changing to meet the needs as they become apparent.

Partnership

The EPDA has a well-earned reputation for working in 'partnership' with international organisations, both patient and neurological, as well as the World Health Organisation, European Commission and the pharmaceutical industry.

Without these partnerships, we would not be in a position to provide the resources that we do. The pharmaceutical industry in particular provides us with much needed funding and resources.

Parkinson's specialists, too numerous to mention, help the EPDA provide validated information that enables people with Parkinson's and their families to make the right choices.

It was also the year that saw the retirement of Mary G Baker, MBE as president after seven terms of office. Baker, one of the EPDA founder members, retired in style at the General Assembly in Ljubljana, Slovenia in September.

During the last 14 years, Baker has seen the EPDA membership grow from nine to 38 organisations, and as she said "the EPDA has been the most exciting and enriching part of my work."

Baker continues to support the EPDA as Patron and retains her involvement with the European Federation of Neurological Associations and the European Brain Council, while continuing to lecture on a worldwide basis.

We also welcomed Rasheda Ali-Walsh as one of our patrons. As the daughter of Muhammed Ali, Rasheda has first-hand experience of living in a family affected by Parkinson's, and we look forward to working closely with her in the years to come.

New Members for the EPDA

In 2006, Delta Parkinson Egyesület, Hungary and Asociatia Antiparkinson, Romania, joined the EPDA family. We continue to try to support new and existing members to provide optimum care and rehabilitation.

We do hope that you enjoy reading about the many activities developed throughout the last year, and take the opportunity of sharing this with your members.

Finally, grateful thanks are extended to the hardworking administration team, which has grown this year. Chiu Man, our resourceful web expert, now works three days a week managing the website's continued expansion. Carolyn Loveless, who has worked with the EPDA on conference organisation since 1998, provides administrative support. Lizzie Graham, secretary-general, who – having worked with the EPDA since it was formed in 1992 – continues to demonstrate her enthusiasm and sense of humour.

EPDA Board's Welcome (cont)

The Board's executive summary

It has been a good year for the EPDA. We have enjoyed working together as a board and have formed a cohesive team, continuing to focus on developing important projects and resources that we believe will indeed 'make a difference'.

Involving European patients and their families in our work programme is an integral part of the EPDA ethos. We have therefore reviewed the business plan to ensure that our focus remains on track throughout the next few years.

Our mission statement has also been amended and reflects accurately what the EPDA stands for:

"To ease the lives of people with Parkinson's disease and their families and carers by promoting a constructive dialogue between science and society, and by encouraging and supporting the development of national PD organisations."



EPDA Ongoing Projects

UK community pharmacy medicines support pilot in PD

The Community Pharmacy Parkinson's Disease Pilot was launched in autumn 2004.

It offered patients structured consultations with community pharmacists based in the UK, to help patients gain a greater understanding of their condition and how to manage it effectively. The pilot, which ended in January 2006, provided community pharmacists the opportunity to work alongside other healthcare professionals in their locality to provide seamless care.

Questionnaires were completed by 145 patients, who attended focus groups and participated in random telephone interviews, with the pharmacists

conducting 336 consultations over 12 months. By discussing their condition with the community pharmacists, patients were able to gain a better understanding of their Parkinson's and the treatment used in its management without risk of confusion, results revealed. The pharmacists found their involvement to be satisfying and their input invaluable to many patients.

Further reading:

The Pharmaceutical Journal (Vol 278) 16 June 2007 and EPNN Journal (No.7) 2006 see <http://www.epda.eu.com/PDInfo/Publications/EPDA/epnnJournal/archive.asp>

European participation in life survey

In 2004, the EPDA began the study of European people with early onset Parkinson's.

The study – the most comprehensive of its kind – involved 18 European countries and almost 600 people with Parkinson's. Completed in 2005, the survey's aim was to explore the quality of life, psychological adjustment and service use/needs of people with Parkinson's diagnosed before 50 years of age.

Data was collected by a questionnaire translated into 15 languages. The response rate for this type of survey was exceptionally high, demonstrating the benefits of partnership between people with Parkinson's, patient organisations, the research team and the pharmaceutical industry.

Results were influenced by country and culture and more commonalities than differences were revealed. Significantly, 40% received no support from a consultant neurologist, despite the fact that treatment for young onset can be extremely complicated and requires specialist input.

The survey has important implications for service providers, demonstrating that although young onset Parkinson's symptoms are the same as those

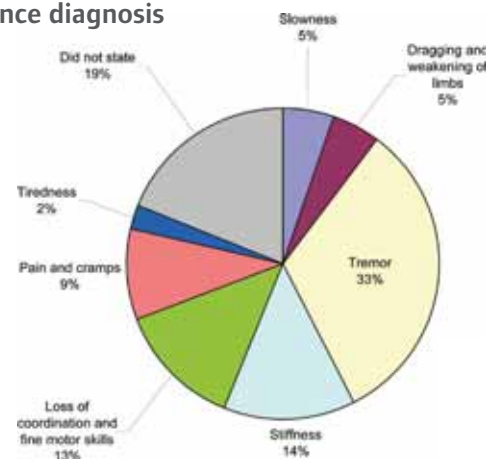
of older people, their needs are very different.

They are of working age, and are often still bringing up young families, with social relationships tending to be more greatly affected.

Further reading:

EPDA Plus 4 see <http://www.epda.eu.com/PDInfo/Publications/EPDA/epdaPlus/archive.asp>

Most frequently reported symptoms since diagnosis



EPDA Ongoing Projects (cont)

PDNS core competencies

Key goals

- To facilitate the uniform development of PDNS practice internationally
- To establish an international framework for guiding the development of comparable standards and core competencies in specialty-focused nursing practice

In support of the overall aim and key goals, the project seeks to accomplish the following objectives by December 2008:

- To undertake an international audit of the current state of PDNS practice
- To develop, disseminate and promote an international framework to guide the development of specialist nurse core competencies and standards, and provide a model from which competencies and standards could be developed in other specialty areas
- To develop, disseminate, promote and implement an international profile and framework of core competencies and standards for the PDNS within the continuum of generalist to advanced practice.

The PDNS role, first introduced in the United Kingdom in the early 1990s, was in response to a need by people with Parkinson's and their families. Over the past decade, increased recognition has been given to the role these nurses play in the care and management of this patient population.

In addition to improving access to services, it has been demonstrated that through their involvement and intervention hospital admissions, outpatient appointments and consultations have been reduced, and clinical outcomes and quality of life improved.

The current lack of available information on how PDNS practice is organised internationally makes it difficult to estimate the number of nurses practicing in this role. The need to establish standards and core competencies at national and regional levels has been driven by patient demand for the provision of an internationally consistent, quality service.

Development of PDNS standards and core competencies will serve clients and nurses nationally and regionally and by necessity, require the development of a specialist framework. This is currently the missing link between generalist entry level and advanced practice frameworks globally.

Fostering the uniform development of PDNS practice and promoting more consistent levels of care will contribute to improving the quality of Parkinson's services, this professional group's performance and influence the development of other specialised global nursing standards.

Against this backdrop, the time is right to establish an international profile and framework of PDNS core competencies and standards. The benefits in doing so are wide-reaching and include:

- improving the quality of services
- promoting professional accountability
- shaping curricula development
- advancing research
- increasing public awareness of the level of competence expected
- guiding human resource planning
- development of job descriptions and career pathways.

EPDA Ongoing Projects

Patients' Guide to Parkinson's and its treatment

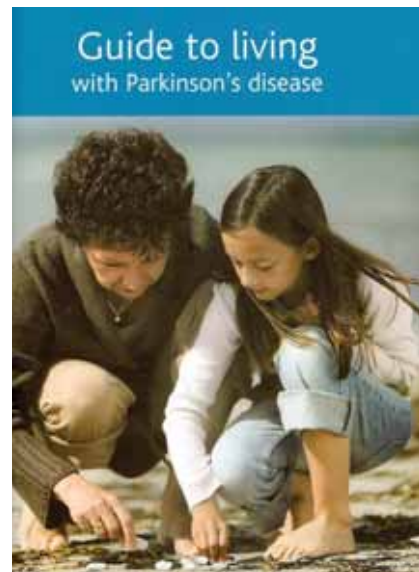
The patients' guide to Parkinson's and its treatment was completed this year.

It is designed to answer the most immediate questions of a person diagnosed by providing information on the disease itself, and the many aspects of treatment and management.

The provision of the guide and website www.epda.eu.com/patientGuide was made possible due to the partnership between H Lundbeck A/S, Teva Pharmaceuticals Industries and the EPDA, with expert advice, information and review comments provided by a European committee of members and associates.

Part of living with Parkinson's is keeping a full and active life, while maintaining good communication with others. With this in mind, the guide contains hints, tips and tools to help in daily communication with carers, family, friends and children, as well as with doctors and other members of the healthcare team.

These resources can be used every day alongside the other elements, such as the 'guide to healthy eating' for keeping a healthy balanced diet, the daily diary, and the medication record.



Patients' Decision Aid

Patients are more likely to fully benefit from medicines and achieve better health outcomes if they play an active role in making decisions about their care.

This requires greater discussion between professionals and patients about treatments, and a patient expectation that they will be involved in decision-making.

The doctor's advice will be an important tool in making those decisions, but it is not an easy task for them either.

Firstly, the symptoms of Parkinson's are different in everyone; secondly, they can vary within each person from day-to-day, hour-to-hour, even minute-to-minute; and thirdly, people's expectations of their own quality of life differ widely – things that are important to one person may not be so important to another.

For these reasons, the EPDA has begun the development of the Patients Decision Aid.

Throughout 2007 this will incorporate the involvement of the EPDA membership, healthcare professionals, and the pharmaceutical industry, to develop a guide that is drawn from the Parkinson's community's breadth of experience.

The Steering Group, formed in November, will produce a questionnaire to be circulated to European people with Parkinson's, carers and healthcare professionals around the world.

Their comments and suggestions will be used as the basis for the development of the Patients Decision Aid.

The EPDA acknowledges, with sincere thanks, a grant provided by Medtronic Foundation which has enabled the start of the Aid's development.

EPDA Ongoing Projects (cont)

Rewrite Tomorrow

Rewrite Tomorrow www.rewritetomorrow.eu.com is a new website being developed by the EPDA and supported by Medtronic Europe. It seeks to bridge the current patient information gap for Parkinson's management and was launched at the EPDA General Assembly in Ljubljana.

In 2007 the EPDA will try to pull together some of the abundant information that exists on Parkinson's management. This is a mammoth task and one that will take some time. To do this, we will be seeking our experts' support and help in gathering and reviewing important information. This information will enable people with Parkinson's and their families to manage their daily lives better and to enhance their level of independence.

Sections will include motor and non-motor Parkinson's symptoms, medication, surgical treatments and deep brain stimulation. It will focus on important issues such as skin and sweating; communication problems involving facial expressions, body language, speech, drooling etc.; and psychological problems including anxiety, apathy, memory and depression.

Patients' histories will also be added as the website progresses. The 'Therapies used to manage Parkinson's' section will focus on complementary therapy, occupational therapy and physiotherapy. All will provide explanations on what the therapies are, why they are important, how they can help and where to access further information and specialised organisations.

The physiotherapy section will also include videos and demonstrations of proven techniques to help people with Parkinson's cope with common daily problems such as getting up out of a chair or walking through a doorway.

Written in a user friendly style, it is hoped the website will become a valuable resource for people with Parkinson's and their families. It can also help healthcare professionals who are non Parkinson's specialists by providing tools at their fingertips, enabling them to better understand Parkinson's; how it affects people; and signposting to the various people and organisations that can help, particularly when symptoms become increasingly resistant to medication.

The screenshot shows the 'Rewrite Tomorrow' website. At the top left is the EPDA logo with the text 'EUROPEAN PARKINSON DISEASE ASSOCIATION'. Below it is the date 'Friday, July 27, 2007'. The navigation menu includes 'Home', 'Management of Parkinson's Disease', 'Deep Brain Stimulation [DBS]', 'Glossary', and 'Feedback'. The main heading reads 'Understanding Parkinson's disease (PD) will enable you to better manage your lives and improve its quality.' Below this are five circular icons representing: 'What is PD?', 'PD Symptoms', 'PD Medication', 'Therapies For PD', and 'Deep Brain Stimulation'. A text box contains the message: 'Enhancing knowledge on [Deep Brain Stimulation](#) and therefore clarifying the expectations of people with PD and their carers' expectations.' A quote from Muhammad Ali is displayed: 'Never lose faith & never stop living each day to the fullest extent possible. I wish all who find themselves part of this courageous battle much luck and I send them my gratitude and love.' The footer includes 'Copyright © 2007 EPDA. All rights reserved.' and 'About this site Terms Of Use'. A Medtronic logo is visible in the bottom right corner of the page content.

EPDA Ongoing Projects

EPDA website

The EPDA website www.epda.eu.com continued to expand and develop throughout 2006, evolving into one of the EPDA's greatest resources.

It is accessed on a daily basis by people with Parkinson's, family members, and healthcare professionals from around the globe. More information is being added, more requests are being received from organisations wishing to link with the EPDA, and more offers being received from a variety of organisations and professionals offering to share information and publications.

Information is printer friendly and can be easily

downloaded. One of the most important resources on the website is the medication and surgical information pages. These provide information on the different types of medication available for Parkinson's management. In each section, a general overview is provided, describing how these medications work.

This is followed by more specific drug information on the different marketed products available for each type, and in which countries they can be obtained. These are constantly being reviewed to ensure the information provided is as accurate as possible.

EPDA Publications

EPNN Journal

This publication provides news and features focussing on the management of people with Parkinson's from the healthcare perspective.

Each year the journal's focus changes. In 2006 it concentrated on international models of care. This series provided a fascinating insight into the differences and similarities that exist in managing Parkinson's worldwide.

It also reported on important Parkinson's Research,

including the PD Med trial – a large randomised assessment of the relative cost effectiveness of different classes of drugs for Parkinson's – and the PD Life Study, a national UK-based audit project in 15 UK centres, set up under the auspices of the UK Parkinson's Association and the EPDA.

In 2007, the EPNN focus will be on practical, educational topics to help the readers keep their practice up-to-date and ensure the best quality of life for their patients.



EPDA Publications (cont)

EPNN Journal

This publication, launched in April of this year, replaced the EPDA Focus that was discontinued in 2005 due to lack of funding.

The EPDA decided to change the focus of this publication, aiming to provide 'added value'. It reports predominantly on issues of European and international interest, and seeks to engage those working in the Parkinson's field.

Each issue contains up-to-date news, features, advertorials, interviews, research surveys and resources. The first issue highlighted the launch of the Global Declaration for Parkinson's in Africa, signed by Archbishop Tutu.

It also featured an interview with Dr Jonathan Brotchie, a British scientist based in Canada. He is researching the role of non-dopaminergic neuro transmitter systems, and aiming to develop new treatments for Parkinson's.

The second issue reported on the launch of ParC,

a new care centre with 'high quality care' for patients and their families in The Netherlands.

There was also an interview with Professor Eldad Melamed, one of the many doctors and neurologists leading the charge for finding a realistic and effective stem cell therapy for brain disorders.

The third acknowledged the 'End of an era for EPDA' with the retirement of Mary Baker, EPDA President for seven terms. It included an in-depth interview with about her 25-year-career in neurology.

Also in this issue, Professor Heiner Ellgring explains how strong communication and motivation is still vital for patients. Each issue contains a four-page pull-out reporting on EPDA news and its work programme and also project updates.

The centre pages are dedicated to EPDA member organisations, giving them the opportunity to share information about their excellent models of best practice, campaigns and resources.



EPDA Acknowledgments

EPDA Patrons

The EPDA would like to sincerely thank the following people for their continued support and interest in our work programme throughout 2006:



Clockwise, from top left: Professor Arvid Carlsson, Nobel Laureate; Cardinal Christoph Schönborn, Archbishop of Vienna; David Jones, CBE; John Bowis, OBE, MBE; Rasheda Ali-Walsh; Mary G Baker, MBE; John Walker

Pharmaceutical Industry

Without the support of the pharmaceutical industry, the EPDA would not be in a position to provide the resources and level of information that it does.

They not only finance the organisation and its activities but also take an active part in developing projects that help to improve the lives of people with Parkinson's and their families.

We are ever grateful for their support not only with the core funding that finances the EPDA's day to day administration, but also for their keen interest in working with the EPDA and their membership in developing important projects and surveys, providing the necessary resources to do this.

We thank them for their support last year and look forward to working closely with them in 2007.

GE Healthcare



EPDA News

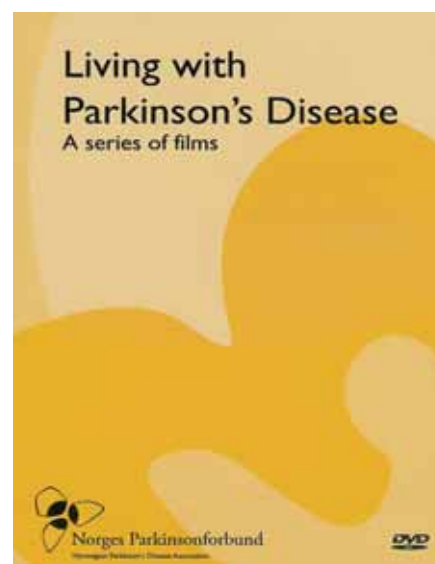
Norges Parkinsonforbund

Early in 2006, Norges Parkinsonforbund – the Norwegian Parkinson's Association – produced a series of five films to provide a realistic picture of some of the challenges Parkinson's creates.

The films, available on DVD, have proved to be extremely popular and offer helpful advice that can be used by people with Parkinson's and healthcare professionals alike.

Thanks to the support of Solvay Pharma, an English version was made available and is compatible with most players.

These DVDS are free of charge to people with Parkinson's and their families, with a small fee being payable to the EPDA for healthcare professionals.



Old Friends Remembered

This year the EPDA remembered with affection and thanks two people who had sadly died and who had supported the EPDA, its membership, and its goals.

Alf Ericsson, of Sweden, was the former chief executive of Neurologiskt Handikappades Riksförbundet (NHR).

"Alf provided invaluable help to the EPDA in its early days. He was a tremendously charismatic character and contributed much to the

development of the present-day EPDA," said Mary Baker. Roger Linster of Luxembourg, former Member of Parliament and Luxembourg's ambassador to the Western European Union, became a key figure in the development of the Parkinson Luxembourg (PL) a.s.b.l.

Roger, who had Parkinson's, provided invaluable assistance to the Working Group on Parkinson's when staging the World Parkinson's Day celebrations in Luxembourg in 2005, by his advice and connections.



Alf Ericsson (left) and
Roger Linster

EPDA News (cont)

Veterans Honoured

In May, Queen Beatrix of the Netherlands honoured Peter Hoogendoorn for his work with people with Parkinson's and their families.

The former EPDA vice president and retired vice president of the Parkinson Patiënten Vereniging, the Netherlands, was appointed Ridder (Knight) in the Order of Oranje Nassau (the royal house of the Netherlands).

In the summer, Jean Junker (diagnosed with Parkinson's at the age of 35), was appointed honorary president of Parkinson Luxembourg (PL) a.s.b.l.

Junker was a founding member of the Luxembourg Association, and with his encouragement the Luxembourg Association became a founder member of the EPDA in 1992.



Running For Parkinson's

In April, Terry Kavanagh who has had Parkinson's for 19 years, completed the 14th Flora London Marathon and raised £868 for the EPDA.

Despite relentless rain, Kavanagh joined almost 34,500 people, aged from 18 to 80 years from 50 nations, to complete the 26-mile (42km) course.

Kavanagh and his wife Jean have been familiar faces since 1996 at the EPDA conferences and general assemblies, and the EPDA is extremely grateful for their continued support and Kavanagh's energy!



EPDA Other Activities

The Hidden Side Of Parkinson's

Non-motor symptoms in Parkinson's are important and recognition is growing. This was the message delegates heard at the EPDA's sixth multidisciplinary conference, The Hidden Side of Parkinson's, in Ljubljana, Slovenia in September.

Speakers explained how factors such as depression, fatigue, pain and sexual dysfunction have been ignored for years because of the traditional emphasis on motor symptoms.

Neurologist David Vodusek from Slovenia, highlighted the prevalence of lower urinary tract (LUT) dysfunction, stating that "this problem significantly affects quality of life".

Maja Relja, Croatian neurologist, reported: "Age at diagnosis is a very important consideration in ensuring a patient's quality of life. Younger people may have more motor complications and their emotional well being can be greatly affected."

Speaking about the neuro-imaging technique, Irena Rektorová, a neurologist from the Czech Republic, said: "Achieving an accurate diagnosis is important for quality of life, and it also has a direct economic benefit by helping to exclude false positive diagnosis."

Lively and practical one-hour workshops were a particular feature of the conference, all being different in style and characterised by a relaxed, patient-centred approach, encouraging active participation. Mariella Graziano, physiotherapist focused on practical tips to help with movement.

Occupational therapist Jelka Jansa explored solutions to help with daily living activities. Sex therapist Gila Bronner, from Israel, explored the

concept of sensuality. "Many people think that sexuality is only about sex," she explained. "But it is about much more; physical touch, emotional care and love, intimacy, friendship, sharing and being close for example."

An open-forum, led by EPDA vice president Susanna Lindvall, discussed the need for and the development of national Parkinson's associations, highlighting the changing role of European patient organisations in recent years.

Partnership and its benefits were reinforced by Aleksandar Janca, head of a Western Pacific World Health Organisation collaborating centre. He stressed the importance of increasing awareness of public health aspects of neurological disorders. The global declaration also played an important part, with Andrej Brucan, Slovenia's Minister of Health signing it, following a personal message of support from the Slovenia Prime Minister, Janez Jansa.

General assembly honours old and new:

This year saw the retirement of Mary Baker as president (see page 12), with Stephen Pickard being welcomed as the interim president for the next year.

It was also the time for acknowledging the commitment and dedication of Ingemar Bruto, EPDA founder and former vice president, Irena Rektorová, former vice-president, and Raphael Medan, former Treasurer for the EPDA in its formative years.

Chiu Man, EPDA IT manager, demonstrated the EPDA website and what it has to offer, as well as the newly developed Rewrite Tomorrow website.



EPDA Feature

Mary Baker Retires

After seven extremely busy terms of office, Mary Baker stepped down as EPDA president at a glittering gala evening in Ljubljana, Slovenia on 30 September.

Over 160 people joined with EPDA patrons John Bowis, OBE and John Walker to say a very special 'thank you' to Mary. Faces from the past included Ingemar Bruto, Sweden, founder EPDA member and former vice president and Raphael Medan, Israel, former treasurer,

Master of ceremonies Knut-Johan Onarheim, board member, led a series of acknowledgements, and Susanna Lindvall, EPDA vice president, presented Baker with gifts from around Europe. The biggest surprise of the evening for Mary and her husband Bob was the sight of their three sons and their wives, who had travelled especially to Slovenia to be with them.

With a career spanning 25 years, it is difficult to summarise the impact Mary has had in the world of neurology. It was at the Parkinson's Disease Society (UK) in the mid 1990's that her work in Europe and other parts of the world began to make an impact. "Partnership is the key ingredient," she claims. "Everything is possible if people work together." Reflecting on the development of the Parkinson's nurse specialist initiative, the EPDA Work Programme and partnership with the World Health Organisation, she says: "All of these developments were built on trust, mutual support and dialogue."

According to Mary, the EPDA has been the most exciting and enriching part of her work so far, with the association's "greatest achievement" being the growth from nine members in 1992 to 38 in 2006. "Added value is the main benefit of EPDA membership," she said.



Each organisation is very good at responding to their national needs, but what they cannot do is negotiate with Europe. "To do that, and to influence the EU Commission, there has to be a European organisation for them to have a voice and participate in the debate."

Mary's work goes on in the world of neurology. She will continue to support the EPDA as patron and retain her involvement with the European Federation of Neurological Associations and the European Brain Council, while continuing to lecture on a worldwide basis. Anyone who has met Mary will know that the word 'retirement' does not exist in her vocabulary.

EPDA Feature

Africa Supports Declaration

Archbishop Desmond Tutu signed the global declaration for people with Parkinson's in Africa at the tenth World Parkinson's Day celebrations, held in Cape Town on 3 April.

He was joined by British high commissioner the Rt. Hon Paul Boateng, former Miss South Africa Amy Kleinhans-Curd and other South African dignitaries.

The event was organised by the Working Group on Parkinson's, in proud association with Parkinson's South Africa Association (PASA),

It followed on from the initial launch in Mumbai, India in 2003, South East Asia, being the first of the WHO six regions. The second and third launches were quickly followed in the Americas and Europe in 2004, the Western Pacific in 2005 and then Africa in 2006.

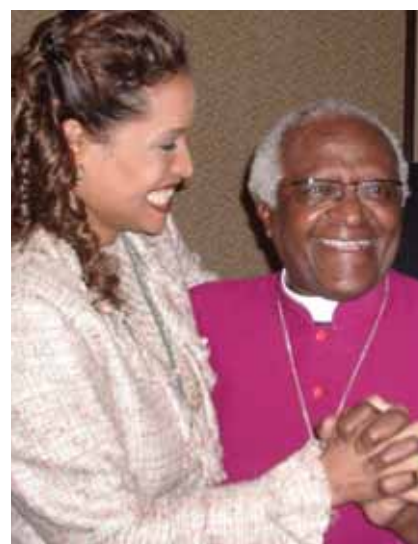
The final global declaration launch will be in the East Mediterranean region, with the location and date yet to be confirmed.

Over 200 delegates attended and listened to presentations by: Rasheda Ali-Walsh, (USA), EPDA patron; Mary Baker, MBE, chair (UK), Working Group for Parkinson's Disease; Jonathan Carr (South Africa), neurologist; K Ray Chaudhuri (UK), neurologist; Jennifer Fine (South Africa),

neurologist; Oscar Gershanik (Argentina), neurologist; Aleksandar Janca (Australia) professor of psychiatry and WHO Liaison; James Maphiri, (South Africa) a person with Parkinson's; Matthew Menken (USA), World Federation of Neurology; Bhim Singhal, (India), neurologist; and Johan Smuts (South Africa) neurologist.

Mariella Graziano, (Luxembourg) EPDA, led a physiotherapy workshop. Some of the exercises were filmed and are to be added to the Coping Strategies website which is currently being developed. A media event involving Archbishop Tutu, Paul Boateng, James Maphiri and Rasheda Ali-Walsh was also held in addition to the conference. Both events resulted in wide media coverage, raising the profile of Parkinson's throughout the nation.

As well as the above, the declaration has received the support and signatures of many from around the world including: Prime Ministers Tony Blair, UK; John Howard, Australia; Jean-Claude Juncker, Luxembourg. Celebrities: Muhammed Ali; Michael J Fox; and Yukta Mookhey, former Miss World; Princess Alexandre, Denmark; HRH The Duchess of Luxembourg; The Hon. Carolyn Bennett, minister of state (Public Health), Canada; Samuel Schmid, Swiss federal president ; John Bowis, OBE, MEP (EPDA patron); Mary Harney, minister for health for Ireland.



EPDA Feature

EPDA World Day

The EPDA members celebrated World Parkinson's Day in many ways, both large and small. After months of hard work, they all achieved great success.

Their aim to increase the profile of Parkinson's and raise awareness in their individual countries about the impact that Parkinson's has on daily living. Below are just a few of the many celebrations.

The EPDA thanks each and every one of the organisations for their continued commitment, enthusiasm and determination in continuing to celebrate this most important day. Many of the organisations are not fortunate in being able to employ any staff and the EPDA would like to add a special acknowledgement to those organisations for all that they achieve.

Belgium

Flemish Parkinson's Association "Vlaamse Parkinson Liga" celebrated the World Parkinson's Day on Sunday 23 April by holding a conference. The motto was "new and old", and five prominent speakers took part. The Belgian TV broadcast the event on the evening news.

Hungary

The Hungarian Parkinson Disease Society (MTPT) and the Delta Parkinson Association (DPE) celebrated on the 11 April by holding a conference. Their motto was "let me hold your hand so that you don't fall". The conference, attended by over 200 people, was preceded by a press conference.

Ireland

The Parkinson's Association of Ireland celebrated by extending World Parkinson's Day from the 12 April until 2 May. The reason for this was the launch of a Parkinson's information pack about medications wearing off and how best to delay its onset or ameliorate its effects. The pack included a wearing off card and pill chart.

By close of business on 11 April every Irish pharmacy had received a poster announcing the

packs' availability on 1 May. The Irish Times Health Supplement featured the campaign, resulting in pharmacists and people ringing the office to reserve packs.

Lithuania

Lithuanian Parkinson's Disease Society organized a gathering of patients and caregivers on the Hill Of Crosses, a unique place in the world and also a symbol of hope and faith in Lithuania.

Luxembourg

Parkinson Luxembourg celebrated with typical European flair by holding a conference in two languages (German and French), which was attended by over 165 people of different nationalities including French, Belgium, Portuguese, German and Luxembourgers.

Among the many presenters was Professor Heiner Ellgring from Würzburg, Germany, speaking about the psychosocial impact of Parkinson's disease.

Sweden

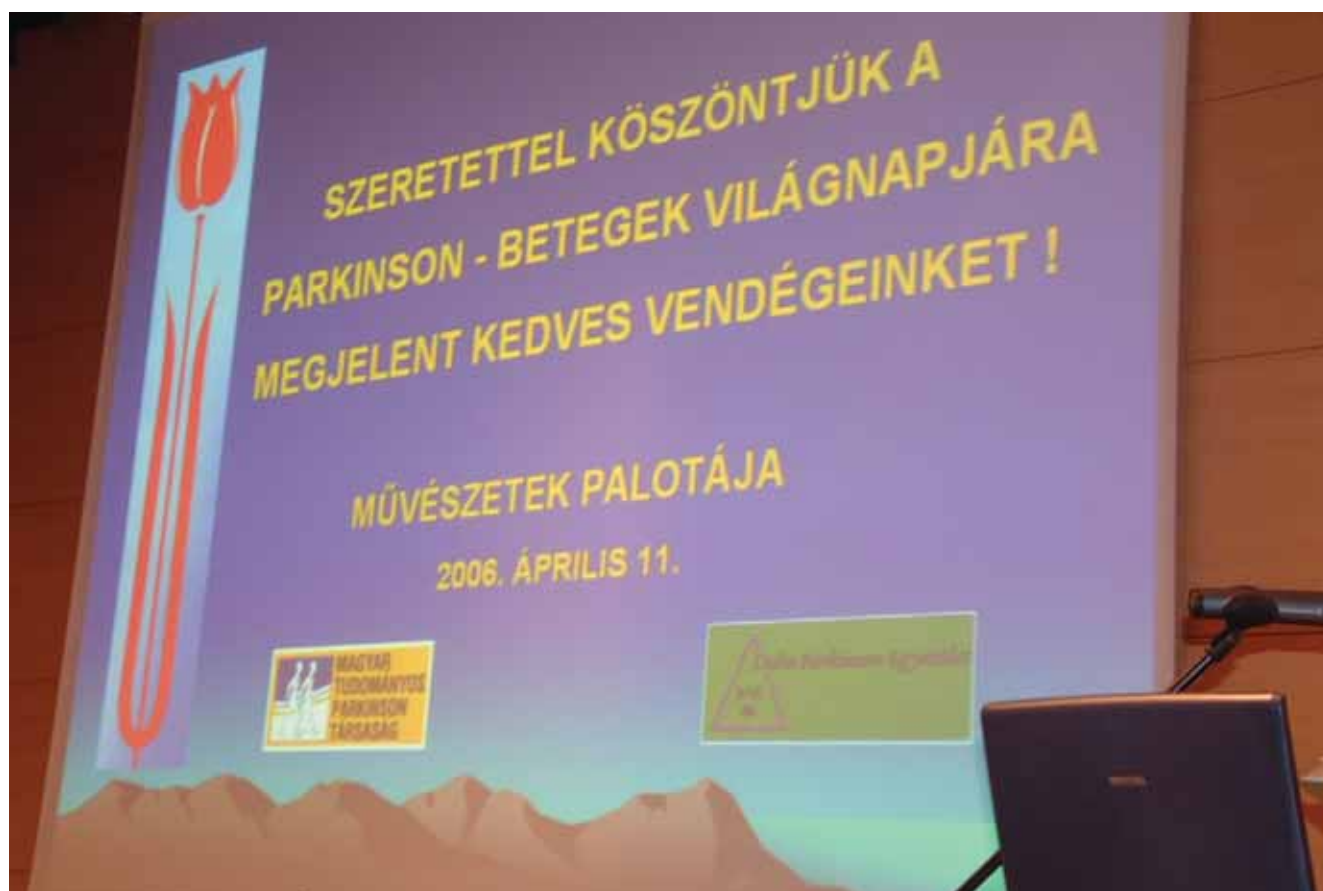
The Swedish Parkinson's Disease Association (SPA) and the Parkinson Foundation, Stockholm, held a scientific conference with many goodwill messages being received. These included one from Her Majesty Queen Silvia, patron of the Parkinson Foundation.

The conference aimed to bring together researchers, healthcare professionals and people from trade and industry to hear about research and the latest therapies, while presenting clinical Parkinson's projects that deserve greater support. There was excellent media support with the event being repeatedly broadcast on Swedish television.

Turkey

Parkinson Hastalığı Derneği organised a conference attended by 120 patients who listened to presentations given by five Parkinson's experts. This excellent conference was followed by lunch for all by the Bosphorus.

EPDA Feature



EPDA Contacts

EPDA At A Glance



President (Retired)
Mary G Baker, MBE, UK

Mary, until her retirement in September, had served seven terms as President. A founder member of the EPDA and now a patron, her other roles include: president of EFNA, vice president of the European Brain Council and chair of the Working Group on Parkinson's Disease, formed by the World Health Organization.



Interim President
Stephen Pickard, Belgium

Stephen, an English solicitor working in Brussels, has been involved with the EPDA since 1993 and it's legal advisor since 2000. Stephen's father, Cyril Pickard, himself a Parkinsonian, was treasurer of the UK Parkinson's Disease Society in the 1980s.



Vice President
Susanna Lindvall, Sweden

Elected as vice president in 2005, Susanna was born in Romania and has lived in Sweden since 1962. She is vice president of the Swedish Parkinson's Disease Association, president of the Swedish Parkinson Foundation and board member of the Arvid Carlsson Foundation.



Treasurer
Branko Smid, Slovenia

Branko is serving his second term and has had Parkinson's since 1986. President of the Slovenian Parkinson's Society for the last 11 years, there have been many changes under his leadership. Membership has increased, offices have been set up and financial support from the Slovenian Government obtained.



Secretary
Mariella Graziano, Luxembourg

Born in Buenos Aires but living in Luxembourg since 1997, Mariella is serving her second term of office as secretary. A practicing physiotherapist, she is president of the Association of Physiotherapists in Parkinson's Disease Europe (APPDE) and works very closely with Parkinson Luxembourg (PL) a.s.b.l.

EPDA Contacts (cont)

EPDA At A Glance



Member

Knut-Johan Onarheim, Norway

Knut-Johan elected to the EPDA Board in 2005 was born in Norway and is a senior partner in a Norwegian law firm. Knut-Johan, whose father had Parkinson's, became a board member of the Norwegian Parkinson's Disease Association in 1997 and president in 2001.



Young Onset Representative

Tom Isaacs, UK

Diagnosed with Parkinson's at 27, Tom continues to fight the condition and raise funds and awareness. From April 2002 to April 2003, Tom walked 4,500 miles around the British coastline raising over £350,000. Charity Personality of the Year in 2005, Tom is co-founder of the Cure Parkinson's Trust.



Secretary-General

Lizzie Graham, UK

Lizzie, executive officer, has been involved with the EPDA since it was formed in 1992. In November 2001 she was appointed to manage the development of the organisation, its projects, conferences, promotion and fundraising. Previously, Lizzie worked for 11 years at the Parkinson's Disease Society (UK).



Web and IT Manager

Chiu Keung Man, UK

Chiu has worked with the EPDA in a freelance capacity since January 2004. In addition to web design and management, Chiu has a broad portfolio of skill sets and qualifications allowing him to take on many other EPDA projects including creative design, print and video media, systems analysis and database management.



Liaison

Carolyn Loveless, UK

Following a degree in French and Italian, Carolyn began organising pharmaceutical conferences. In 1997, she began working with the EPDA assisting with conference organisation and joined the EPDA team this year in a freelance capacity. A mother of two young children, she also enjoys teaching French one day a week.

EPDA Consolidated Income and Expenditure Account

(For the year ended 31 December 2006)

	2006			2005		
	EPDA	PDI	TOTAL	EPDA	PDI	TOTAL
	(£)	(£)	(£)	(£)	(£)	(£)
Income						
Members fees	12,680	-	12,680	10,781	-	10,781
Contributions	203,924	12,629	216,553	232,497	-	232,497
Conference/General assembly	52,867	-	52,867	43,231	-	43,231
EPNN donations	25,852	-	25,852	4,758	-	4,758
TOTAL	295,323	12,629	307,952	291,267	-	291,267
Other income						
Gains on foreign exchange	-	-	-	-	-	-
Deposit account interest	2,699	74	2,773	2,612	65	2,677
TOTAL	298,022	12,703	310,725	293,879	65	293,944
Expenditure						
Printing postage and stationery	835	-	835	821	635	1,456
Meetings etc	15,026	-	15,026	6,104	-	6,104
Officers expenses	2,923	-	2,923	2,716	-	2,716
Web site	1,000	-	1,000	2,152	-	2,152
Magazine costs	250	22,362	22,612	1,420	-	1,420
Fund raising and publicity	67,102	85	67,187	43,926	-	43,926
Travel expenses	717	-	717	3,504	113	3,617
Transfer to P D I Ltd	12,733	(12,733)	-	7,500	(7,500)	-
Living with PD DVD	15,790	-	15,790	-	-	-
Conference costs	56,891	-	56,891	55,350	60	55,410
Conference promotion	-	-	-	-	60	60
Project expenditure	76,053	-	76,053	113,303	-	113,303
Companies House fees	-	30	30	-	14	14
Membership fees	140	-	140	-	-	-
Accountancy	-	3,200	3,200	-	2,150	2,150
Depreciation	-	340	340	-	340	340
Loss on foreign exchange	1,307	-	1,307	388	-	388
Bank charges and interest	564	77	641	820	58	878
TOTAL	251,331	13,361	264,692	238,004	(4,070)	233,934
NET SURPLUS/(DEFICIT)	46,691	(658)	46,033	55,875	4,135	60,010

EPDA Consolidated Balance Sheet

(For the year ended 31 December 2006)

	EPDA	2006 PDI	TOTAL	EPDA	2005 PDI	TOTAL
	(£)	(£)	(£)	(£)	(£)	(£)
Fixed assets						
Tangible assets	1	681	682	1	1,022	1,023
Current assets						
Stocks	-	-	-	-	-	-
Debtors	40,112	4,558	44,670	7,461	6,533	13,994
Cash at bank	140,461	8,501	148,962	115,958	3,254	119,212
TOTAL	180,573	13,059	193,632	123,419	9,787	133,206
Creditors: amounts falling due within one year						
Creditors and accruals	16,784	7,450	24,234	6,321	3,861	10,182
Net assets	163,790	6,290	170,080	117,099	6,948	124,047
Reserves						
Balance brought forward	117,099	6,948	124,047	61,224	2,813	64,037
Surplus/(deficit) for year	46,691	(658)	46,033	55,875	4,135	60,010
Balance carried forward	163,790	6,290	170,080	117,099	6,948	124,047

Basis of audit opinion

We conducted our audit in accordance with International Standards on Auditing (UK and Ireland) 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.

We have undertaken the audit in accordance with the requirements of APB Ethical Standards including APB Ethical Standard - Provisions Available for Small Entities, in the circumstances set out in note 7 to 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 2006 and of its surplus 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

Date: 5 July 2007

EPDA Members



Parkinson Selbsthilfe Österreich-Dachverband

Association Parkinson's Rue Champs des Louettes

Vlaamse Parkinson Liga vzw

Fondazia Parkinsonism

HUBPP Croatian Parkinson's Disease and Movement Disorders Association

Cyprus Parkinson's Disease Association

Czech Parkinson's Disease Society

Dansk Parkinsonforening

Tartu Parkinson's Disease Society

Parkinsonfelagið

Suomen Parkinson-liitto ry

La Fédération Française des Groupements de Parkinsoniens

Delta Parkinson Egyesület

Parkinsonsamtökin a Íslandi

Parkinson's Association of Ireland

Israel Parkinson Association

Azione Parkinson (Lazio)

Parkinson Italia "Confederazione Associazioni Italiane Parkinson e Parkinsonism"

EPDA Members (cont)



Lithuanian Parkinson's Disease Society

Parkinson Luxembourg (PL) a.s.b.l

Parkinson Patiënten Vereniging

Norges Parkinsonforbund

Fundacja "DyD z ChorobD Parkinsona"

Kracow

Stow. Choroby Parkinsona

Stowarzyszenie Osób Niepełnosprawnych AKSON

Associação Portuguesa de Doentes de Parkinson

Asociatia Antiparkinson

The Regional Non-Profit Organisation for the
Advancement of Parkinsonian Patients

Serbian Association Against Parkinson's Disease

Društvo TREPETLIKA

Federación Española de Parkinson

Parkinson Förbundet

Neurologiskt Handikappades Riksförbund

Parkinson Schweiz

Parkinson HastalıĐı DerneĐi

Ukrainian Parkinson Disease Society

Parkinson's Disease Society

EPDA Advisory Board



Dr Dieter Volc



Dr Timothy Lynch



Prof Alain Maertens



Dr Nir Giladi



Prof Wenzeslav Bossnev



Prof Tommasco Caraceni



Prof Zdravko Lackovic



Dr Mindaugas Socas



Ass. Prof Jan Roth



Dr Alexandre Bisdorff



Ass. Prof Pille taba



Dr Bastiaan Bloem



Dr Kirsti Martikainen



Dr Sascha Mitrovic



Dr. András Fazekas



Dr Jakub Sienkiewicz

EPDA Advisory Board (cont)



Dr Helena Coelho



Prof Dr Matthias Sturzenegger



Dr Zvezdan Pirtosek



Prof. Dr. Hülya Apaydin



Prof Eduardo Tolosa



Dr Iryna Karaban



Dr Bo Johnels



Prof Leslie Findley

EPDA Associate Members

Association of Physiotherapists in Parkinson's Disease Europe (APPDE)

Atlantic Euro Mediterranean Academy of Medical Science


Division of Movement Disorders of the Russian Society of Neurologists

European Federation of Neurological Associations (EFNA)

European Federation of Neurological Societies (EFNS)

The Movement Disorder Society (MDS)

The National Tremor Foundation (NTF)



European Parkinson's Disease Association

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