“Activity has continued to increase; the EPDA’s reputation continues to flourish; and our work programme reflects that we continue to listen to the needs of our members”

Board’s welcome, page 4
EPDA Board’s Welcome

Flourishing times

The EPDA’s mission statement – 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 Parkinson’s organisations – reflects our work throughout 2008. Activity has continued to increase; the EPDA’s reputation continues to flourish; and our work programme reflects that we continue to listen to the needs of our members.

One way we met these needs is through the launch of our Awareness campaign – our most ambitious project to date. It was launched in August and has made a tremendous impact not only in Europe but other parts of the globe. The launch was the first part of a multi-phased campaign that the EPDA will be continuing with in the years to come. Another important project is Learning in Partnership (LiP), which is dedicated to listening to our members, finding ways that our members can help each other and to share their knowledge and expertise so all can benefit.

As always, to be effective means there has to be enough resources available to meet the demands of an ever-increasing work programme. As a result, this year we appointed a project manager on a consultancy basis who will work with us on developing the Awareness campaign and the LiP project.

Partnership

Partnership with the treatments industry continues to grow and develop. We value their active participation in the EPDA programme – without their unconditional support our projects would not have been possible. They also provide much needed annual core funding, without which the EPDA would be unable to function.

This year has been the best yet for working in partnership with our members, in particular the following projects: the online Parkinson’s Passport and PD Doc; Eastern European Roadshow, (held in Kracow, Poland, in September); the LiP project that began in 2007; the Awareness Campaign; and the Euroyapmeet in Croatia.

Our members’ enthusiasm to work together and to share experiences and expertise is benefitting all our organisations and we look forward to even closer involvement as we move forward into 2009.

The EPDA’s ongoing success means there is even more demand for successful promotion and marketing. We do have various vehicles that aid our visibility, including our websites and publications. Translation of our materials is vital but costly, and in 2009 we will look at how we can achieve translating materials so that more people can benefit around the globe.

Membership

In July we welcomed the Greek Epikouros – Kinisis (Movement) Parkinson’s Society as our 40th member. They have proved active and supportive, taking EPDA information via our Rewrite Tomorrow website and translating the content into Greek.

We also welcomed the German Parkinson-Hilfe Deutschland e.V. as our 41st member in September. We are delighted our membership is continuing to grow and look forward to working closely with our new colleagues in the years to come. Our members’ World PD Day celebrations continue to gather momentum. We thank you for your willingness to share with us your many varied activities.

At the 7th Euroyapmeet conference in Zagreb, Croatia, we tried a different format involving more workshops and delegate interaction. We listened to the delegates’ comments at our 2007 conference after they indicated it was time for a change to the normal format.

Of course, the increased activity would not be possible without the EPDA ‘engine’ – the dedicated team that deals with the traffic on a daily basis. It was necessary to increase the size of the team again this year to manage the increased demand, and we extend our sincere thanks to: Lizzie Graham, Secretary-General; Chiu Man, IT and Web Manager; Carolyn Loveless, Researcher and Co-ordinator; Lara Winchcombe, Logistics and Liaison; and Kate Browne, Project Manager.
Welcome by Stephen Pickard, EPDA President

I have supported the EPDA for several years, but in 2001 I became more closely involved when I was co-opted as Legal Adviser. During the last seven years I have witnessed the impact that the EPDA has made within Europe and other parts of the world. Its working programme, which has always been based on ‘partnership’ and listening to the needs of people with Parkinson’s and their families, is strengthening because of the changing requirements of society. For an organisation to be effective, it has to change internally as well as externally to meet the ever-changing needs of not only the membership but society as a whole.

With Europe expanding, the EPDA’s aspirations have to change if we are to respond to the increasing aging population. Some of this work has begun, and the EPDA aims to meet this challenge as the years progress.

The involvement of our membership in our work programme continues to be an integral part of the EPDA ethos and we look forward to working more closely with you in 2009.
EPDA Ongoing Projects

PDNS Core Competencies

The role of the PDNS is intrinsic to the promotion of dignity and empowerment for people living with Parkinson’s (PWPs). In 2006 international agencies such as the International Council of Nurses (ICN) and the World Health Organisation (WHO) Parkinson’s Disease Working Group joined together with the EPDA to undertake an international audit of the current state of PDNS practice; to facilitate the uniform development of the PDNS practice internationally; and to establish an international framework for guiding the development of comparable standards and core competencies in specialty-focused nursing practices.

This project is now nearing completion and will be launched in June 2009 when the PDNS Core Competencies Executive summary will be published.

To view the PDNS Literature Review carried out by PDNSs Janet Doherty (Australia) and Orna Moore (Israel), visit www.epda.eu.com/projects/PDNScoreCompetencies/literatureReview.asp.

An international audit of the current state of PDNS practices has also been carried out with the final report nearing completion. Go to www.epda.eu.com/projects/PDNScoreCompetencies/questionnaire/survey.asp.

The ICN Framework of Competencies for Nurse Specialists has been completed and published, see www.icn.ch/ICN_Nurse_Specialist.pdf.

Key goals of the Core Competencies:

• To facilitate the uniform development of PDNS practice internationally.

• To establish an international framework to develop comparable standards and core competencies in specialty focused nursing practice.

• 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 implement an international profile and framework of core competencies and standards for the PDNS within the continuum of generalist to advanced practice.

Parkinson’s Decision Aid (PDA)

The PDA is an educational tool to encourage communication and concordance, and has been developed with the assistance of the EPDA membership, healthcare professionals and the treatments industry. Work continues on this enormous project and it is anticipated it will be ready for launching at the EPDA annual conference and general assembly in 2009.

The importance of the PDA is reinforced by Tom Isaacs, EPDA Young Onset Board member, who says, “Choosing the best course through Parkinson’s in terms of both mental and physical health can be confusing. “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. 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.”

The PDA includes a short introductory leaflet that can be given to people with Parkinson’s via visits to their doctors and healthcare professionals, as well as at pharmacists.

It will serve as a gateway to the web-based tool kit that includes very user-friendly questions and answers on all disease stages of Parkinson’s – from diagnosis, early, middle (three to 10 years) and late, including end-of-life management. The tool kit will continue to evolve, continuing step by step through the journey of Parkinson’s, using the Global Declaration as the pathway.
Real Life Real PD

Launched at the 2007 EPDA General Assembly, this online survey focused on the realities of living with Parkinson’s both ‘day and night’, and was supported by GlaxoSmithKline. It was completed by nearly 3,000 people across 30 countries, and closed at the end of February. Results were shared with each of the participating organisations so they could build these into their World PD Day celebrations – where they would assist in the aim of raising awareness about what it is like to live with Parkinson’s on a daily basis.

The findings emphasised that Parkinson’s affects people’s ability to function properly during the day – in fact 24 hours a day – due to regular interrupted sleep patterns. Nearly three-quarters of the people surveyed experience difficulty getting to sleep, and of those 70% wake at least once during the night, and possibly more often.

Key findings:

• Over two-thirds of respondents did not feel in control of their symptoms during a 24-hour period, with more than half stating that their day had to be planned around taking medications.

• 78% of respondents felt Parkinson’s affected their ability to function during the day, with more than a third reporting difficulties with eating and drinking.

• Emotional problems as a result of Parkinson’s were frequently reported, with anxiety, frustration and worry among the most prevalent.

• 72% of respondents experience difficulty getting to sleep and 70% of these people wake at least once during the night as a result of Parkinson’s.

• The two areas that people with Parkinson’s most wanted to improve were their daily living activities and feelings of daytime tiredness.

Ten recommendations for change have been drawn directly from the issues raised by the survey and are intended to encourage people with Parkinson’s to communicate these aspects more effectively to ensure healthcare professionals consider their day-to-day challenges and requirements for treatment.

The 10 recommendations for change:

• Parkinson’s treatments should provide more reliable and predictable symptom control and be more easily integrated into the daily lives of patients.

• Healthcare professionals should be more aware of the non-motor symptoms of Parkinson’s.

• There should be better communication across the entire healthcare team in order to understand what matters to patients as individuals.

• Patients need to be encouraged to communicate more effectively their needs and expectations to healthcare professionals.

• Nurses should assume a greater role in helping patients explore their individual needs.

• There should be greater communication with patients’ families, partners and carers.

• Patients should be treated as individuals, not only when considering treatment regimens, but also when discussing their ideal lifestyle requirements and their expectations for living with Parkinson’s.

• Patient support groups and organisations should provide clear and accessible information for patients and their families.

• There should be a multidisciplinary approach to treating Parkinson’s with healthcare professionals closely integrated into patients’ treatment plans.

• The complex nature of Parkinson’s should be better communicated to those with Parkinson’s and society as a whole to ensure a greater understanding of the disease.
Learning in Partnership (LiP)

In 2007 the Swiss Parkinson’s Association invited a handful of EPDA member organisations to participate in a survey – this has since developed into the Learning in Partnership (LiP) project.

The survey’s aim was to compare the different services and products offered by each Parkinson’s organisation. This pilot study aimed to demonstrate the organisations’ experience with new and innovative services and products, and to identify new needs that may have to be met in the future. The survey results were presented at the Swiss Parkinson’s Association’s workshop, held alongside the 2007 General Assembly.

In July 2008 the Swiss Parkinson’s Association agreed that the EPDA provided a perfect forum for the developing LiP project – and to encourage member associations to work together.

What will LiP do?

**LiP exists** to encourage working together between associations to enable improved services for the benefit of people with Parkinson’s and their families.

**LiP will** support the people responsible for the leadership and development of the member associations by actively facilitating the inclusive exchange of know-how and experience for the benefit of the associations and the people they represent.

**LiP will:**

- encourage associations to learn from each other
- develop exchange of information and expertise
- provide the opportunity to “learn in partnership” at the EPDA annual conferences
- facilitate communication between associations
- support the integration of the early-onset groups.
- focus on providing benefit to all associations irrespective of their size and structure.

Case study: PDNSs

Parkinson’s disease nurse specialists (PDNSs) had already been widely discussed in the 2007 workshop. A pilot study soon followed, carried out by a team from the University of St Gallen; it featured telephone interviews with associations to investigate their PDNS experiences. Some associations (Denmark, Norway, Sweden and the UK) had already successfully implemented PDNSs; others were still struggling with financial or organisational difficulties.

The study revealed there is no “one-size-fits-all” PDNS approach appropriate for every country, with different laws, modes of funding and relationships with health services. Nevertheless, using the results from the 2007 workshop and from the telephone interviews, the university team designed a programme for the first LiP workshop in Croatia in October with the aim of facilitating exchanges between member association representatives. They identified a typical process for the introduction of PDNS that was used as a basis for the group discussions.

The workshop conclusion was that the following questions need to be answered when developing a PDNS strategy:

1. What are the needs of Parkinson’s patients?
2. What is the PDNS function?
3. What can associations do to establish a PDNS?
4. Do our national institutions support the development of PDNSs?
5. What can we do to establish 10 PDNSs and what support do we need?
6. What support do we need to provide PDNSs?
7. How much money and/or volunteer work do we need to establish (a) one and (b) 10 PDNSs and what resources are needed to (c) provide specialised education courses?
8. Who is interested in establishing PDNSs and who has enough money to support the development?
Publication: EPDA Plus

An exciting magazine targeting international healthcare professionals.

EPDA Plus is published in the spring, summer and winter, and reports predominantly on issues of international interest and provides ‘added value’.

Publication: EPNN Journal

This publication provides news and features that focus on the management of people with Parkinson’s. It focuses on the healthcare perspective and aims to help the readers keep their practice up to date. It is published in the spring, summer and winter.
EPDA Resources (cont)

DVD: Coping Strategies

The EPDA has completed its first CD-ROM, following three years of collecting video footage at EPDA conferences and workshops. The disk – of people demonstrating their tips and tricks from countries that include Argentina, Ireland, Italy, Japan, Luxembourg, Slovenia and South Africa – was launched in Seville in May this year.

The simplicity and rawness of the footage captures spontaneous moments and authentic demonstrations by people with Parkinson’s of the various coping strategies that they have developed.

These solutions make daily living easier when the effectiveness of medication decreases and when symptoms re-emerge before it is time to take the next dose or medication (wearing off).

Online: Parkinson’s Passport

For this project we have used the expertise of European people with Parkinson’s and healthcare professionals. We welcome the help of the membership with translation into other languages.

We hope it will be especially relevant when people travel to other countries. It contains information on:

• Personal details
• Emergency contacts
• Medication details, name, dosage and timing
• Other medication taken regularly
• Doctors’ contact details
• Important information about Deep Brain Stimulation and electronic treatment such as Diathermy, ultrasound etc.

Visit www.epda.eu.com/pdfs/parkinsonsPassport/PDpassport_EN.pdf
Online: PD Doc

Available online the PD Doc is for the many and not just the few. It is accessible to anyone who has access to the internet and a printer, and is available in a choice of languages. The PD Doc can be easily completed and carried around either in a pocket, wallet or purse. If it becomes damaged or lost, just go online and print another. Visit www.epda.eu.com/projects/PDdoc for more information.

Online: www.rewritetomorrow.eu.com

www.rewritetomorrow.eu.com bridges the current patient information gap for Parkinson’s management. With the support of our ‘experts’, we are gathering and reviewing important information that will enable better management on a daily basis to enhance independence.

Written in a user-friendly style, we hope that Rewrite Tomorrow is proving to be a valuable resource for people with Parkinson’s, their families and healthcare professionals who are non-Parkinson’s specialists, providing them with ‘tools at their fingertips’.

Online: www.epda.eu.com

www.epda.eu.com is easily accessible and chronicles the EPDA’s activities and progress, its projects, conferences and publications. Not only do we promote the work of the EPDA but we also actively encourage information and resources from our membership and other organisations around the globe. We try to act as a gateway and signpost for people with Parkinson’s, their families and healthcare professionals.

Online factsheets: Medical and Surgical Information

These factsheets began in 2002 and have proved to be invaluable to many people with Parkinson’s and their family members around the world as well as healthcare professionals.

Throughout the years, a close partnership between the treatments industry and the EPDA has developed, and it is thanks to the industry that we are able to annually provide updated, accurate and validated information.

www.parkinsonsdecisionaid.eu.com/medInfo provides information on the different types of medication and surgical ‘products’ available for the management of Parkinson’s.

In each section we provide a general overview of how these medications work, followed by more specific information on each of the different marketed products for each medication type, and the countries they are available in.
EPDA Acknowledgements

EPDA Patrons

The EPDA would like to sincerely thank the following people for their continued support and interest in our work programme throughout 2008:

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

Treatment Industry

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

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

We are grateful for their support, not only with core funding – that finances the EPDA’s day-to-day administration – but also for their keen interest in working with the EPDA and our membership in developing important projects and surveys, and providing resources to do this. We thank them for their continued support throughout 2008 and look forward to working closely with them in 2009.
Other EPDA Activities

Euroyapmeet: moving in the right direction

Movement was the theme of the EPDA’s 7th Euroyapmeet, held in Zagreb, Croatia, in October. The programme focussed on how movement can help maintain quality of life by promoting a positive outlook.

The weekend included workshops featuring Tai Chi (pictured), the Alexander Technique and salsa dancing.

The plenary session was interactive, focusing on movement and rhythm. ‘Music as Medicine for Parkinson’s patients’ was presented by Norway’s Audun Myskja with the finale being ‘Multisensory Stimulation – rehabilitation and healthcare in sync with body and soul’, the RGRM (Ronnie Gardiner Rhythm & Music) method. Gardiner, and colleagues Magnus Liljeroos and Ole Moe, from Sweden, involved all the delegates and speakers in the RGRM Method that uses rhythm, music and movement to promote natural, harmonic patterns in the body and senses.

Eliane, a delegate from Luxembourg, said: “I was proud and happy to be at this great event and to meet a lot of young people with Parkinson’s. I’m always astonished to see the different faces of Parkinson’s, and at the same time overwhelmed by the simplicity and unity of everyone taking part, both doctors and the patients.”

An open forum ‘Parkinson’s: Beyond the pills – dispelling perceptions’ was led by Tom Isaacs and Branko Šmid, both diagnosed with Parkinson’s in their late twenties. They discussed the challenging issues facing the multidisciplinary team.

“This year, EPDA treasurer Branko Šmid and I were asked to mediate an open forum at the Euroyapmeet with the idea of letting us, the people with Parkinson’s, set the agenda and to ask challenging questions of the multidisciplinary team and industry,” said Tom. “We wanted to empower the audience and patient advocates to take a more proactive stance in the management of the disease as well as the search for a cure.”

He said Parkinson’s is not an AIDS or a cancer, yet these conditions have the upper hand on a global scale as their patients are more engaged in their own healthcare and research advances, and receive more respect from their medical community.

These qualities need to be delivered in Parkinson’s, he argued, with patients contributing focus, media attention and sources of funding.

“Sadly, we are falling way short of this cultural change,” he said. “Whose fault is this? I think people with Parkinson’s are still afraid to come out and communicate their condition. I believe it is far more selfish not to let people share in their experiences. Scientific progress ultimately thrives through emotional engagement. There is no unified purpose in the Parkinson’s community. We are disparate and unfocused. The key to changing this is communication, but with more emphasis on the ‘listening’ than the ‘telling’.”
Other EPDA Activities (cont)

Spotlight on sharing at GA

Sharing expertise and information between EPDA member organisations was the focus of the 2008 annual general assembly. Members from Belgium, Denmark, Hungary, Israel, Lithuania, the Netherlands, Portugal and Switzerland presented their annual activities, revealing resources they are producing that can be utilised by the other members.

The results of the 2007 members’ questionnaire outlining the association’s priorities – which included communication, raising awareness, funding research and education – were presented by EPDA vice-president Susanna Lindvall, and the delegates learned about the final results of the Real Life, Real PD survey launched in 2007. They also heard about the development of a ‘patient tool’, a direct result of the survey. All members were encouraged to support the Parkinson’s Decision Aid (PDA), a project that began in 2006 and is set be launched in 2009.

Meanwhile, attending the general assembly for the first time was Panayiotis Zikos from Greece, representing the EPDA’s 40th member, Epikouros – Kinisis (Movement) Branch.

On the road again

The second EPDA eastern European roadshow was held in Cracow, Poland, from 19-21 September. It represented a partnership between Luxembourg and Poland that aimed to exchange knowledge and good practice with each other.

The visiting team (pictured) included Luxembourg physiotherapist and EPDA Secretary Mariella Graziano and retired geriatrician and EPDA Board member Mahendra Gonsalkorale. Local speakers were led by Polish EPDA Medical Board Adviser Anna Krygowska, president of Kracow Parkinson’s Disease Association Andrzej Bialko, and Dr Pawel M. Socha, a Psychologist who has Parkinson’s.

As well as the conference and workshops, a round table discussion was held between the EPDA and representatives from the main Polish Parkinson’s associations. Facilitated by Mahendra Gonsalkorale, the aim was to encourage partnership between the 17 patient associations in Poland; to pool resources; and to retain some of their individual autonomy.

It was agreed to implement the constitution of The Krakow Declaration and form the “Forum Parkinson Polska”, with a Presidency rotating every three years. Member associations will retain their autonomy with the Forum acting as a co-ordinating Body.

When asked what Mariella and Mahendra felt about the outcome of the weekend, they replied, “We feel that we more than met our objectives and are especially proud to have helped with the process of making the Forum a reality. By meeting key people in the Polish Parkinson’s organisations, combined with open and honest discussions, we feel that we have further enhanced the EPDA’s reputation and paved the way for greater involvement with Poland, ultimately resulting in benefiting the people who really matter, those with Parkinson’s and their carers.”
Awareness Campaign: ‘Parkinson’s is visible – make it livable’

The EPDA has embarked on one of its most ambitious projects yet – to raise awareness throughout Europe about what Parkinson’s is and why it is important to manage it effectively.

Raising global awareness about Parkinson’s is a major focus for the EPDA, especially as it represents nearly 200,000 people impacted by Parkinson’s throughout Europe alone.

Its mission statement, “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 Parkinson’s organisations”, reinforces this campaign’s importance.

“I have been connected to Parkinson’s for many years, both personally and professionally,” says EPDA vice-president Susanna Lindvall. “It is now time to make people understand that Parkinson’s is a chronic disease; that anyone can get it; it can and should be treated at all stages of the disease; and the cost to society is less if treated properly than not to treat it at all.”

The campaign has four main objectives: to highlight the challenges experienced by people with Parkinson’s; to raise awareness – especially its consequences for daily living; to influence decision makers; and to raise funds for resources, management and research projects.

What is the target audience?

According to the World Health Organisation’s report, Neurological Disorders – Public Health Challenges, the social and economic burden of Parkinson’s is high – and is increasing – and efforts need to be made to increase public and professional awareness; minimise stigma and eradicate discrimination; strengthen neurological care within health systems; and define priorities for research.

Scientists need more funding for research into the cause of the disease, neuroprotection, cell replacement and gene therapy. Healthcare professionals need to encourage a partnership with their patients so that communication can be improved, leading to concordance.

People with Parkinson’s and their families need to be involved and understand their choices; they need to have the confidence to engage in a good partnership with their doctors so that improved management of the disease can be achieved.

At the same time, the public needs to better understand what Parkinson’s is and how it affects every aspect of daily living. “Many neurological organisations and the pharmaceutical industry have supported our efforts,” says Lindvall. “Without them, we could not have embarked on such an ambitious ongoing campaign.”

Future plans

There is less cost to society when Parkinson’s is treated early and properly so influencing the European decision makers is one of the priorities. Throughout Europe there exist inflexible pricing and reimbursement schemes, doctor appointment time limitations, and concerns over the availability and access to medication.

“Parkinson’s is a costly disease and places a huge burden on society as a whole,” says EPDA president Stephen Pickard. “One of our main thrusts is to develop a lobbying tool for our members, one that is translated into their national languages.”

By using this and the Awareness Kit (see box), they and the EPDA can lobby their national governments. It is a top-down, bottom-up approach. “We need governments to realise that taking action to reduce this burden – by ensuring people receive the best care and treatment available – makes the most economic and social sense,” says Stephen.

This campaign has been supported by many external organisations, including the European Federation of Neurological Societies and World Federation of Neurology, and also the treatments industry - GlaxoSmithKline, Medtronic Foundation, Merck Serono and Solvay Pharmaceuticals.
Media Launch in Madrid

The EPDA launched its pan-European ‘awareness’ campaign and kit ‘Still life with Parkinson’s: Parkinson’s is visible – make it liveable’ in Madrid, Spain, on 25 August – alongside the EFNS congress.

“Parkinson’s is a costly disease and places a huge burden on carers and society as a whole,” says Stephen Pickard. An estimated 1.2 million Europeans have Parkinson’s – and the figure is set to rise.

Dr Fabrizio Stocchi (pictured below), member of the EPDA’s medical advisory board, called on the pharmaceutical companies to develop new medicines to slow the progression of the illness and to develop treatments with fewer side effects. “We need new drug therapies that can slow down the progression of Parkinson’s, therapies that are more effective at treating cognitive impairment,” he said.

He also urged the European Union (EU) to overhaul regulatory procedures for existing drugs, saying “there is a crucial need for better treatments with fewer side effects and simpler methods to administer drugs as some patients have to take their medications five, six or even seven times a day.” Stocchi told reporters that over the past 20 years there has been a considerable improvement in Parkinson’s treatments but pharmaceutical companies still must spend more on research.

Results of the media reach:

- 35 pieces of coverage to 16 September, including five national daily newspapers
- Total circulation reach: more than 5.5 million
- Regions: Austria, France, Ireland, Italy, Luxembourg, Poland, Romania, Spain, Sweden and the UK

For further information visit: www.parkinsonsawareness.eu.com
The EPDA Awareness Kit

The EPDA’s comprehensive awareness kit (some of which is pictured below) has been developed to raise the profile of Parkinson’s and to enhance the impact that this chronic neurological condition has on people’s quality of life.

The booklet ‘Still life with Parkinson’s’ contains very open, personal stories told by people with Parkinson’s in various countries, with their reflections on the challenges that the disease poses in everyday life. Facts linked to the stories explain different symptoms and how they affect people with Parkinson’s and their families.

It also provides detailed information on what it is like to live with Parkinson’s; the medical treatments needed to live a relatively normal life; incidence and prevalence of Parkinson’s throughout Europe; indications and contraindications for advanced therapies; the cost of treatment and care; and different aspects of treatment, side effects and comorbidities.

To emphasise the difficulties faced, the kit also includes a DVD featuring two people with Parkinson’s demonstrating the impact that two normal daily activities can have upon not only people with Parkinson’s, but also people in general.
Widening perspectives

www.epda.eu.com

epda plus  promoting international understanding and awareness  supporting national parkinson’s organisations
promoting informed choices  parkinson’s awareness  providing access to best practices  quality of life issues
europameet conferences  encouraging interaction between scientific and patient communities  epda charter
managing your pd  promoting a constructive dialogue between science and society  patient information
professional information  european participation in life survey  global declaration on parkinson’s disease
real life real pd survey  parkinson’s decision aid  pdns core competencies  medical and surgical information
epnn journal  world pd day  supporting research initiatives  patient guide to living with parkinson’s disease
patient guide to healthy eating  infopark  coping strategies  multidisciplinary conferences  flexicard

www.rewriteTomorrow.eu.com

EPDA
EUROPEAN PARKINSON’S DISEASE ASSOCIATION
EPDA Contacts

EPDA At A Glance

President
Stephen Pickard, Belgium

Stephen, an English solicitor working in Brussels, has been involved with the EPDA since 1993 and its legal adviser since 2001. His father, Cyril, 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 board member of the Swedish Parkinson’s Disease Association and president of the Swedish Parkinson Foundation.

Treasurer
Branko Šmid, Slovenia

Branko is serving his third term and has had Parkinson’s since 1986. Under his presidency of the Slovenian PD Society (for 11 years until his retirement in 2007), membership increased, offices were set up and financial support was obtained from the government.

Secretary
Mariella Graziano, Luxembourg

Born in Buenos Aires but living in Luxembourg since 1997, Mariella is serving her fourth term of office as secretary. A practicing physiotherapist, she is president of the Association of Physiotherapists in Parkinson’s Disease Europe (APPDE).

Member
Knut-Johan Onarheim, Norway

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

Member
Mahendra Gonsalkorale, UK

Mahendra, a retired geriatrician, was elected to the EPDA Board in 2007. Since 1989 he has been an active member of the UK PDS serving in numerous capacities and was a Board member for four years until September 2007.
EPDA Contacts (cont)

EPDA At A Glance

**Young Onset Representative**  
Tom Isaacs, UK

Diagnosed with Parkinson’s at 27, Tom has raised Parkinson’s funds and awareness. Tom has walked 4,500 miles around the British coastline raising more than £350,000. Charity Personality of the Year in 2005, Tom is co-founder of the UK 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 to raise funding.

**Web and IT Manager**  
Chiu Keung Man, UK

Chiu has worked with the EPDA in a freelance capacity since 2004. In addition to web design and management, Chiu has a broad portfolio of skill sets and qualifications allowing him to work with the EPDA on creative design, video media and systems analysis.

**Researcher and co-ordinator**  
Carolyn Loveless, UK

Following a degree in French and Italian, Carolyn began organising pharmaceutical conferences. In 2006, she began working with the EPDA in a freelance capacity assisting with conference organisation, research and project co-ordination.

**Liaison and logistics**  
Lara Winchcombe, UK

Lara, a manager of an independent travel agency for 18 years, is experienced in dealing with the general public and event management. Lara joined the EPDA in 2007 in a freelance capacity, utilising these skills in her liaison and logistics role.

**Project Manager**  
Kate Browne, UK

Kate is a freelance consultant working with the EPDA as project manager on the awareness campaign and Learning in Partnership (LiP). Kate has worked within the treatments industry for a number of years, as well as with the EPDA.
EPDA Consolidated Income and Expenditure Account

(For the year ended 31 December 2008)

<table>
<thead>
<tr>
<th></th>
<th>EPDA (£)</th>
<th>PDI (£)</th>
<th>TOTAL (£)</th>
<th>EPDA (£)</th>
<th>PDI (£)</th>
<th>TOTAL (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Members fees</td>
<td>17,304</td>
<td>-</td>
<td>17,304</td>
<td>13,090</td>
<td>-</td>
<td>13,090</td>
</tr>
<tr>
<td>Contributions and sponsorship</td>
<td>578,448</td>
<td>15,689</td>
<td>594,137</td>
<td>278,092</td>
<td>12,628</td>
<td>290,720</td>
</tr>
<tr>
<td>Conference/General assembly</td>
<td>74,931</td>
<td>-</td>
<td>74,931</td>
<td>62,317</td>
<td>-</td>
<td>62,317</td>
</tr>
<tr>
<td>EPNN donations</td>
<td>19,500</td>
<td>-</td>
<td>19,500</td>
<td>33,260</td>
<td>-</td>
<td>33,260</td>
</tr>
<tr>
<td>Sales of Tulip pins, DVD's etc</td>
<td>7,775</td>
<td>-</td>
<td>7,775</td>
<td>14,090</td>
<td>-</td>
<td>14,090</td>
</tr>
<tr>
<td>TOTAL</td>
<td>697,958</td>
<td>15,689</td>
<td>713,647</td>
<td>400,849</td>
<td>12,628</td>
<td>413,477</td>
</tr>
<tr>
<td>Other income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gains on foreign exchange</td>
<td>14,740</td>
<td>-</td>
<td>14,740</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Deposit account interest</td>
<td>10,022</td>
<td>260</td>
<td>10,282</td>
<td>2,609</td>
<td>372</td>
<td>2,981</td>
</tr>
<tr>
<td>TOTAL</td>
<td>722,720</td>
<td>15,949</td>
<td>738,669</td>
<td>403,458</td>
<td>13,000</td>
<td>416,458</td>
</tr>
<tr>
<td>Expenditure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Printing postage and stationery</td>
<td>1,464</td>
<td>-</td>
<td>1,464</td>
<td>395</td>
<td>-</td>
<td>395</td>
</tr>
<tr>
<td>Meetings and officers expenses</td>
<td>27,807</td>
<td>-</td>
<td>27,807</td>
<td>19,480</td>
<td>-</td>
<td>19,718</td>
</tr>
<tr>
<td>Magazine costs</td>
<td>2,737</td>
<td>19,543</td>
<td>22,280</td>
<td>1,835</td>
<td>21,684</td>
<td>23,519</td>
</tr>
<tr>
<td>Fund raising and publicity</td>
<td>113,403</td>
<td>-</td>
<td>113,403</td>
<td>90,736</td>
<td>-</td>
<td>90,736</td>
</tr>
<tr>
<td>Travel expenses</td>
<td>1,277</td>
<td>-</td>
<td>1,277</td>
<td>905</td>
<td>-</td>
<td>905</td>
</tr>
<tr>
<td>Transfer to P D I Ltd</td>
<td>8,235</td>
<td>(8,235)</td>
<td>-</td>
<td>15,040</td>
<td>(15,040)</td>
<td>-</td>
</tr>
<tr>
<td>Conference costs</td>
<td>75,428</td>
<td>-</td>
<td>75,428</td>
<td>72,548</td>
<td>-</td>
<td>72,548</td>
</tr>
<tr>
<td>Real life real PD costs</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1,600</td>
<td>-</td>
<td>1,600</td>
</tr>
<tr>
<td>Trade mark</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2,214</td>
<td>-</td>
<td>2,214</td>
</tr>
<tr>
<td>Advertising</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>85</td>
<td>-</td>
<td>85</td>
</tr>
<tr>
<td>Project expenditure</td>
<td>248,151</td>
<td>-</td>
<td>248,151</td>
<td>103,503</td>
<td>-</td>
<td>103,503</td>
</tr>
<tr>
<td>Companies House fees</td>
<td>-</td>
<td>15</td>
<td>15</td>
<td>-</td>
<td>29</td>
<td>29</td>
</tr>
<tr>
<td>Accountancy</td>
<td>-</td>
<td>3,615</td>
<td>3,615</td>
<td>1,650</td>
<td>3,400</td>
<td>5,050</td>
</tr>
<tr>
<td>Insurance</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>928</td>
<td>-</td>
<td>928</td>
</tr>
<tr>
<td>Depreciation</td>
<td>-</td>
<td>340</td>
<td>340</td>
<td>-</td>
<td>340</td>
<td>340</td>
</tr>
<tr>
<td>Loss on foreign exchange</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>541</td>
<td>-</td>
<td>541</td>
</tr>
<tr>
<td>Bank charges and interest</td>
<td>639</td>
<td>89</td>
<td>728</td>
<td>1,093</td>
<td>77</td>
<td>1,170</td>
</tr>
<tr>
<td>Taxation</td>
<td>-</td>
<td>54</td>
<td>54</td>
<td>-</td>
<td>73</td>
<td>73</td>
</tr>
<tr>
<td>TOTAL</td>
<td>479,141</td>
<td>15,421</td>
<td>494,562</td>
<td>312,553</td>
<td>10,801</td>
<td>323,354</td>
</tr>
<tr>
<td>NET SURPLUS/(DEFICIT)</td>
<td>243,579</td>
<td>528</td>
<td>244,107</td>
<td>90,905</td>
<td>2,199</td>
<td>93,177</td>
</tr>
</tbody>
</table>
## EPDA Consolidated Balance Sheet

(For the year ended 31 December 2008)

<table>
<thead>
<tr>
<th></th>
<th>EPDA 2008 (£)</th>
<th>PDI 2008 (£)</th>
<th>TOTAL 2008 (£)</th>
<th>EPDA 2007 (£)</th>
<th>PDI 2007 (£)</th>
<th>TOTAL 2007 (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fixed assets</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tangible assets</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>341</td>
<td>342</td>
</tr>
<tr>
<td><strong>Current assets</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stocks</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Debtors</td>
<td>18,866</td>
<td>265</td>
<td>19,131</td>
<td>3,486</td>
<td>4,565</td>
<td>8,051</td>
</tr>
<tr>
<td>Cash at bank</td>
<td>482,542</td>
<td>25,989</td>
<td>508,531</td>
<td>308,933</td>
<td>6,956</td>
<td>315,889</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>501,408</td>
<td>26,254</td>
<td>527,662</td>
<td>312,419</td>
<td>11,521</td>
<td>323,940</td>
</tr>
<tr>
<td><strong>Creditors: amounts falling due within one year</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Creditors and accruals</td>
<td>3,135</td>
<td>17,238</td>
<td>20,373</td>
<td>57,725</td>
<td>3,373</td>
<td>61,098</td>
</tr>
<tr>
<td><strong>Net assets</strong></td>
<td>498,274</td>
<td>9,017</td>
<td>507,291</td>
<td>254,695</td>
<td>8,489</td>
<td>263,184</td>
</tr>
<tr>
<td><strong>Reserves</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Balance brought forward</td>
<td>254,695</td>
<td>8,489</td>
<td>263,184</td>
<td>163,790</td>
<td>6,290</td>
<td>170,080</td>
</tr>
<tr>
<td>Surplus/(deficit) for year</td>
<td>243,579</td>
<td>528</td>
<td>244,107</td>
<td>90,905</td>
<td>2,199</td>
<td>93,104</td>
</tr>
<tr>
<td>Balance carried forward</td>
<td>498,274</td>
<td>9,017</td>
<td>507,291</td>
<td>254,695</td>
<td>8,489</td>
<td>263,184</td>
</tr>
</tbody>
</table>

### 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 charity’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, in accordance with the United Kingdom Generally Accepted Accounting Practice applicable to Smaller Entities, of the state of the charity’s affairs as at 31 December 2008 and of its incoming resources and application of resources, including its income and expenditure for the year then ended;
- the financial statements have been properly prepared in accordance with the Associations constitution; and the information given in the Report of the Administration Board is consistent with the financial statements.

**M J Read & Co:** Chartered Accountants, Registered Auditors, 1 Cobden Road, Sevenoaks, Kent, TN13 3UB, UK.

**Date:** 23 June 2009
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
Parkinsonfelagíø
Suomen Parkinson-liitto ry
La Fédération Française des Groupements de Parkinsoniens
Georgian International Charitable Union of Parkinson’s Disease Patients
Parkinson-Hilfe Deutschland e.V.
Epikouros – Kinisis (Movement) Branch
Delta Parkinson Egyesület
Parkinsonsamtökinn a Islandi
Parkinson’s Association of Ireland
Israel Parkinson Association
Azione Parkinson (Lazio)
Parkinson Italia “Confederazione Associazioni Italiane Parkinson e Parkinsonism”
Lithuanian Parkinson’s Disease Society
Parkinson Luxembourg (PL) a.s.b.l
EPDA Members (cont)

Parkinson Patiënten Vereniging
Norges Parkinsonforbund
ParkinsonPolskaFundacja “Zyc z Choroba Parkinsona”
Kracow

Stow. Choroby Parkinsona
Stowarzyszenie Osób Niepelnosprawnych 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 Hastalıgi Dernegi
Ukrainian Parkinson Disease Society
Parkinson’s Disease Society
EPDA Advisory Board

Dr Dieter Volc

Dr Panayiotis Zikos

Dr Chris Van der Linden

Dr András Fazekas

Prof Wenzeslav Bossnev

Prof Alberto Albanese

Prof Zdravko Lackovic

Dr Mindaugas Socas

Ass. Prof Jan Roth

Dr Alexandre Bisdorff

Ass. Prof Pille Taba

Dr Bastiaan Bloem

Prof. Heikki Teräväinen

Dr Arnulf Hestnes

Dr Georg Ebersbach

Dr Anna Krygowska-Wajs
EPDA Advisory Board (cont)

Dr Joaquim Ferreira

Dr Zvezdan Pirtošek

Prof Eduardo Tolosa

Prof Per Odin

Prof Dr Matthias Sturzenegger

Prof Dr Hülya Apaydin

Prof Vladyslav V Bezrukov

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)