



History in the making?

The EPDA hopes its unprecedented ‘Chronic diseases in an ageing population – a spotlight on Parkinson’s disease’ debate in the European Parliament in November will prove to be a turning point in the lives of many people with Parkinson’s (PWP). The event brought together for the first time MEPs, European Commission officials, European patient organisation and treatment industry representatives, and PWPs. Attendees discovered (some for the first time) the tremendous challenges that face those living with Parkinson’s every single day *and* heard positive solutions that can be achieved if only the key disease stakeholders worked together – with the PWP at the centre of their own care. What follows are snapshots of what was said at the event and evidence of how the influential speakers share so many interests – above all the desire to rid Europe of the dangerously expensive and damaging neurological diseases that exist today. See page 1 for more details of the event.



John Bowis OBE: ex-MEP says we must listen to the true 'experts' – the PWP's

"We have a task ahead of us to ensure that neurodegenerative diseases – especially Parkinson's – are very much on the agenda in Europe. Doors are opening – 2014

will hopefully become the European Year of the Brain and it was recently announced that DG Research/the European Commission will have a month in 2013 in support of this initiative – but we have to ensure these doors are firmly pushed.

"We must not forget the true experts – the Brankos and the Jos [see page 20] – the people living with the disease. They are experts unmatched by any other knowledge, education or experience. PWP's live with the disease's side effects, pain and impact. When this expertise goes hand in hand with the professionals' skill, we can learn from them. When looking at Branko's transformation, one can see the miracles available. If only we could make them available to everyone. We have to raise our ambitions for people. It's a question of ensuring that PWP's lives are not only full but fulfilling – it's so important to all of us."



Linda McAvan: UK MEP knows first-hand the impact of Parkinson's

"Parkinson's is a big burden on our society. But I know very well that burden as I have a family member with Parkinson's and my mother died of a disease in the Parkinson's

family. I know exactly what it means. I want to make sure that the next generation will not suffer in the same way as people close to me have.

"It's a good time to talk about Parkinson's as 2012 is the official European Year of Active Ageing and Solidarity between Generations (EY2012). If we're lucky, most of us will live healthy and active lives as we get older, and there's no reason why PWP's can't do that as well with the right kind of treatment and the right kind of support. And that's what we've learned today – the importance of all European citizens having access to the same kind of support. It's been good to hear the European Commission's support of new research programmes and I hope to see a lot more investment in brain disorders as a result."



Paul Timmers: European Commission official supports EPDA Consensus Statement

"I was very impressed by this event, especially John's excellent moderation and Jo and Branko's courage. It was really instructive and has helped me a lot. I

have already twittered on the importance of *The European Parkinson's Disease Standards of Care Consensus Statement*.

"I wanted to stress that the Pilot European Innovation Partnership on Active and Healthy Ageing is not just about bringing money to the table. It's about actions and ensuring the cost of care is made more sustainable. We already have a whole list of people with ideas who are willing to contribute. But that's stage one. This willingness to commit, to invest and to share research has got to continue into action next year. It is an ambitious venture but the political will is there. The Commissioners expect to see results in the next few years."



Maria Iglesia-Gomez: European Commission official says 'let's all work together'

"Ageing is going to change our society as we know it. Health systems will become unsustainable if we don't do something. But we can't do what we need to do exclusively.

We need to involve all the actors – namely patients, healthcare professionals, carers, venture capitalists, the industry. We can't have a healthy economy without healthy people.

"The Pilot European Innovation Partnership is trying to encourage innovative research to develop tangible benefits for patients and citizens. For this to happen, we must make sure patients' needs are at the centre of what we do and we have to involve them; demonstrate to European health systems that there may be existing treatments/technological devices/organisational models elsewhere that can be less expensive but provide more efficient benefits; and promote companies and export their work outside of Europe. If such a holistic approach to healthy ageing is encouraged, it will lead to a triple win for all of us."



Frieda Brepoels: Belgian MEP from Flanders hails 'excellent' event

"I'm so happy to see so many colleagues here. What an excellent event this has been. We've heard interesting discussions and I have learned a great deal through the exchange of truths, of ideas and best practices across the member states. I was so moved to hear the testimonies of Branko and Jo, it was very interesting for all of us. They will help us on our road here in the European Parliament.

"We've also learned that Parkinson's impacts European Union healthcare budgets to such an extent that raising awareness and investing in early diagnosis and appropriate treatment would be hugely beneficial – not only for the patient but for authorities too. Such actions would improve PWP's quality of life, independence, mobility and their contribution to society. I will do my best to support this course, and to fight the stigma and discrimination that PWP's face. Let's stay in touch so we can work with the experts – the PWP's themselves – the professionals and the patient organisations. There's a lot of work to do."



Branko Šmid: Slovenian PWP demonstrates the right treatment at the right time

“As you all saw, when I’m off, I really suffer. I get extreme tremor and all the other things that come with Parkinson’s. I prefer to be in a good condition so I am happy to be back

now. It’s all about getting the right medication at the right time – that’s what’s important for PWPs.

“In my country, you have to go through all the stages of Parkinson’s to get what I have got. It’s a long process. I have now had my Duodopa® pump for three years and I’m one of about 30 people in Slovenia lucky enough to have one. Some have had deep brain stimulation, others have had the APO-go® pump. I was fortunate to be able to choose. So it’s a good service in Slovenia these days but the queues are so, so long. I pray that things are never as bad as they once were. But it costs the insurance company about €4,000 a month to give me what I need so there’s always that worry hanging over our heads.”



Jo Collinge: UK PWP reveals the hidden impact of living with Parkinson’s

“It took five years to convince my GP that there was something wrong with me. That’s unacceptable. As a result of certain drugs

I’ve taken in recent years I’m more of an impulsive character now. This led to a car crash recently, which I was extremely lucky to survive.

“It’s only now that I can see just how tremendous an impact the incident has had on my family – and especially on my relationship with my husband. But it’s made me re-evaluate my life and take my disease seriously. I do recognise it is a debilitating illness and its impact is huge. And I recognise that I have a responsibility to myself and my family. I also acknowledge that I need to make my life more fulfilled. I’ve chosen to look on the positive side of my life with Parkinson’s.”

Bastiaan Bloem: Dutch neurologist showcases the power of a good-quality model of care

“I’m going to say it just the way it is. The situation today is terrible for PWPs. If patients are lucky they’ll find an expert in Parkinson’s. Most don’t and get no access to good-quality care. The problem is that the disease is so complex; you can’t leave PWPs in the care of an average general neurologist. But there are too few specialists around and patients can’t find the ones that exist. There’s a lack of expertise, a lack of transparency, and a lack of collaboration.

“But as complex and horrible as Parkinson’s is, I want to underscore that with the right treatment at the right time, PWPs can lead a full life and ably participate in society.

“If healthcare systems develop programmes that involve a few experts who are visible and who collaborate – as opposed to a number of generalists hidden from view – then the quality of care goes up. A good example of this is ParkinsonNet in the Netherlands. It’s not a dream, it exists today. We select a few people who we train thoroughly in Parkinson’s and get them to collaborate with other specialists. We then make these ‘experts’ visible through the web and patients can choose



from this ‘yellow pages’ of specialists. The results speak for themselves. Hip fractures have gone down throughout the country by 50% since ParkinsonNet’s launch in 2004 and Parkinson’s costs have reduced by €20m – not by working harder but by working more intelligently.

“Healthcare systems will explode and become unmanageable in the next few years unless we move towards patient-centred care and specialised networks. We must invest in this kind of high-quality research and no longer see healthcare as a threat to our finances. Instead, we should

see it as a fast-growing economy that we can develop into a European export.

“At the same time, policymakers should be looking across Europe for other evidence-based models of good-quality care. ParkinsonNet is just one that can be easily adapted in other countries. So why don’t we? I see a role for the European Commission in facilitating this. If we only invested in people who are interested in the wider, holistic healthcare objective then it would only require a small investment to make significant savings. If this were to happen, we could see huge positive developments for PWPs.”

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