

WHO DOES THE EPDA REPRESENT?

The EPDA has member organisations in the following countries:

Austria, Belgium, Bulgaria, Croatia, Cyprus, the Czech Republic, Denmark, Estonia, the Faeroe Islands, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Lithuania, Luxembourg, Malta, the Netherlands, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovenia, Spain, Sweden, Switzerland, Turkey, Ukraine and the UK.



“Work with the EPDA to **change attitudes, speed diagnosis, reduce inequality and improve funding**”

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The EPDA is a charitable organisation registered in Bruxelles (Numéro de l'association: 87272000, No TVA ou no entreprise: 465299201) and governed by the Belgian law of 25 October 1919, modified by the Law of 6 December 1954.

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Who we are, what we do and why we need to work in partnership with the European Union to improve the lives of people with Parkinson's disease

“The EPDA’s **vision** is to enable **all** people with Parkinson’s in **Europe** to live a **full life** while **supporting** the search for a **cure**”

ABOUT THE EPDA

The EPDA is the only European umbrella organisation for Parkinson’s disease and represents 45 member organisations advocating for the rights and needs of more than 1.2 million people with Parkinson’s and their families. For more information, visit www.epda.eu.com.

WHAT DOES THE EPDA DO?

By working with its member organisations, who represent the needs of individual people with Parkinson’s and their families at a national level, the EPDA aims to:

- ensure equal and timely access to prompt diagnosis and good-quality Parkinson’s disease care across Europe by raising standards and reducing existing inequalities
- increase public awareness of Parkinson’s disease as a priority health challenge
- help reduce stigma and remove discrimination against people with Parkinson’s disease
- support the development of national Parkinson’s disease organisations throughout Europe.

OUR PARTNERS

Our partners (listed below) are companies and organisations of high standing and reputation, all of whom reinforce the

EPDA’s overall strategic direction and help support the integrity of the organisation. The EPDA has adopted the EMA Code of Practice, and partnership is established on the basis of shared interest, transparency, trust and mutual benefit.

EPDA partners: Abbott, Burson-Marsteller, European Commission (Seventh Framework Programme), GE Healthcare, GlaxoSmithKline, Lundbeck, Medtronic, Medtronic Foundation, Merck Serono, Merck & Co, Norgine, Orion Pharma, Teva and Weber Shandwick.

WHAT IS PARKINSON’S DISEASE?

Parkinson’s disease is a serious chronic neurodegenerative disease that has no cure. It affects all aspects of daily living and is the most common neurodegenerative disease after Alzheimer’s disease. The incidence of Parkinson’s disease is forecast to double by 2050 primarily as a result of the ageing population. Treatment and management is available for a number of aspects of the disease but is not yet accessible to all. Ongoing research has resulted in significant improvements but more is needed to delay, stop or even reverse the disease.

THE CAUSE OF PARKINSON’S DISEASE

Parkinson’s disease is caused by the destruction of nerve cells in the brain that produce the neurotransmitter dopamine. A similar destruction occurs naturally with ageing, but in Parkinson’s disease the process is much faster with certain specific nerve cells lost, leading to the typical major symptoms of tremor, stiffness of muscles and slowness of movement.

WHO GETS PARKINSON’S DISEASE?

Parkinson’s disease affects both men and women in almost equal numbers, and affects one in 100 people over the age of 60, which is the average age of onset. Young-onset Parkinson’s disease (onset at the age of 40 or younger) is estimated to occur in 5% to 10% of people with Parkinson’s disease. It shows no social, ethnic, economic or geographic boundaries.

SYMPTOMS

Parkinson’s disease is a complex disease and is often associated with movement problems, known as ‘motor symptoms’. These include tremor, rigidity, slowness of movement and postural instability. Non-motor symptoms – that

are not related to difficulty with movement – are increasingly being recognised as common and important components of the condition. They are highly varied and can occur at any stage, and include sleep disorders, depression, pain, fatigue, bladder disturbances, constipation and sexual dysfunction. The symptoms are different for each person and they can vary from day to day, hour to hour, even minute to minute.

TREATMENT

The process of making a Parkinson’s disease diagnosis can be difficult, and a poor differential diagnosis is a major problem in the management of the condition. Those diagnosed will most likely need medication for the rest of their lives, and continuous medication is one of the cornerstones of treatment – it is always individual and can vary greatly between people. After some time, the medication can cause disturbing side effects that often require medical treatment by a physician with a good knowledge of the condition.

COST TO SOCIETY

Parkinson’s disease represents a high and increasing economic and social burden. In 2006, the prevalence in Europe was estimated at 1.2 million people, with an annual cost of €11 billion. As the population’s life expectancy increases, this burden will continue to rise, especially in the late stages of the disease where the impact is at its greatest on the people with Parkinson’s, their families, carers and society as a whole.

WHAT IS THE EPDA ASKING THE EUROPEAN UNION TO DO?

- 1 To maintain and increase funding for research into Parkinson’s disease under the next framework programme.
- 2 Improve data collection across Europe as well as establish standards for the monitoring and reporting of Parkinson’s disease across EU member states.
- 3 To make provision for Parkinson’s disease organisations so their members have a voice when vital decisions are made about their healthcare.
- 4 To ensure EU policies on neurodegenerative diseases are fully integrated into current EU health initiatives.