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I am delighted to have been invited to write the foreword for this issue of *European Neurological Review*, especially in the 20th anniversary year of the European Parkinson's Disease Association (EPDA). Twenty years ago, the concept of a united Europe was very much at the forefront of people's minds and this continues to be the case today – the desire to help shape a better world through partnership and progress. During that time, the 'voice' of the patient has grown louder. They are very much considered to be at the centre of healthcare – a huge shift since 1992 and the EPDA has played its part in this change of focus.

Since it was formed, the EPDA has continued to ask and to listen to people with Parkinson's, their families and their carers about the impact Parkinson's has on their daily lives. This approach has led to evidence collection from across Europe – so needed if change is ever to be effected. It began in 1997 with the Participation in Life survey (across 14 countries) asking people with Parkinson's about their 'hidden' symptoms such as sleep, constipation, pain and anxiety and closely followed by the Global Parkinson's Disease survey in 1998 (across four continents) revealing evidence that drug management was only a small part of the bigger picture. Instead we had proof that these 'hidden symptoms' – not considered as important at that time as motor symptoms – caused greater distress. This wealth of evidence led to the launch in 2003 of the Global Declaration for Parkinson's Disease which urged governments around the world to make Parkinson's a priority health challenge.

In 2008, the EPDA realised that for this 'voice' to grow louder a European awareness campaign was needed to enable the EPDA member organisations to raise awareness and outreach at a national level. 'Life with Parkinson's' is an awareness raising campaign that aims to highlight the lack of understanding and knowledge concerning Parkinson's that exists throughout Europe today. The first part focused on highlighting the importance of early diagnosis as well as advanced disease management. The second part – which began in 2010 – focused on the disease's non-motor symptoms. The EPDA will be launching the third and final part of this campaign in 2012 which will address the necessity of an accurate diagnosis and the importance of the right treatment for the right person at the right time.

In 2010, the EPDA Move for Change campaign began – a three-year, three-part pan-European on-line survey (translated into 24 languages) that asks people with Parkinson's whether their lives have improved since the launch of the Charter for people with Parkinson's in 1997. The results from Part I have been published in the *European Journal of Neurology* and the Part 2 data is being prepared for a further submission to a peer-reviewed journal in 2012.

All this evidence – and much more – led to the development in 2011 of the first European Parkinson's Disease Standards of Care Consensus Statement. This Consensus Statement defines what the optimal management of Parkinson's should be and utilises the evidence from the Move for Change campaign that records how people with Parkinson's are actually being managed. This Consensus Statement has been launched in the European Parliament (November 2011), resulting in the development of the Parkinson's Disease MEP Network (over 50 MEPs) on the 11 April, 2012.

Today, there are more than one million people living in Europe with Parkinson's disease and this number is set to double by 2030. The Parkinson's community continues to be at the heart of what the EPDA is – this has not changed in the last 20 years. To celebrate this sense of community and to raise their voices even louder, the EPDA will be holding the first ever European Unity Walk in Amsterdam in September – alongside the EPDA's celebratory conference. If you would like to show your solidarity for what EPDA is striving for – equality and optimisation of Parkinson's treatment across Europe – come along and let your 'voice' be one of many (www.epda.eu.com). ■



20 YEARS IMPROVING LIVES FOR PEOPLE WITH PARKINSON'S AND THEIR FAMILIES

There are more than 1.2 million people living with Parkinson's disease in Europe.

Since 1992, the EPDA has worked with 45 national Parkinson's organisations across Europe to campaign for the right treatment at the right time. Early, effective intervention reduces the long-term financial impact of Parkinson's on society – and improves lives.

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The voice for Parkinson's in Europe

