

Alzheimer Europe: The importance of awareness in dementia

Alzheimer's disease is a neurodegenerative condition that affects more and more people throughout the world each year. **Jean Georges** is the Executive Director of Alzheimer Europe, a non-profit organisation aimed at improving care and treatment of patients with the disease. *Research Features* recently spoke to him about the organisation's work and how awareness of Alzheimer's disease has changed throughout his 20 years at the organisation.

Alois Alzheimer identified the first case of Alzheimer's disease over 116 years ago in a patient called Auguste D. Since then, the disease has become more and more prevalent worldwide and is today recognised as the most common cause of dementia. According to the 2016 Alzheimer's Disease International report, the condition now affects 47 million people worldwide and that figure is set to treble by 2050.

In light of these growing numbers, Alzheimer Europe wants to make dementia a European public health priority. *Research Features* recently sat down with their Executive Director, Jean Georges to find out more about the organisation and discuss the way forward towards this goal.

Hi Jean! Could you tell us what your role is at Alzheimer Europe and what kind of responsibilities you have there?

I have been the Executive Director of Alzheimer Europe for the past 20 years and joined the organisation on 1 November 1996. My duties include overseeing the small, but truly dynamic team of Alzheimer Europe, supporting the board and managing the various projects of the organisation.

Could you tell us some more about Alzheimer Europe's background and the kind of work that is done there?

Alzheimer Europe was formed in 1990 and operates a common European platform through co-operation among our 39 members of national Alzheimer associations. Through our work we hope to answer a growing need in society, especially among the community of people affected by dementia. In 2012, we set up a European Working Group of People with Dementia (EWGPWD), comprised of people with different forms of dementia and of different ages and nationalities. The EWGPWD advises and participates, either as a group or as individual members, in all our activities and projects.

We are also a source of information on all aspects of dementia, through our yearbooks and the European Dementia Ethics Network (EDEN) which was established in 2009. The yearbooks focus on different issues linked to dementia, for example the legal rights and protection of people with dementia, social support, care pathways and dementia-friendly environments, and they provide a comparison of national systems allowing for the identification of existing good practices.

Supporting dementia research and campaigning for increased funding for dementia research at EU and national level continues to be one of the main priorities of Alzheimer Europe ”

In 2017, Alzheimer Europe will continue to develop EDEN and will look at the ethical implications of recognising dementia as a disability. In September 2016, Alzheimer Europe launched its Clinical Trial Watch (CTW), which provides accessible and up-to-date information on clinical trials that are investigating drugs for Alzheimer's disease and/or dementia. All our activities aim at making dementia a European priority; promoting a rights-based approach to dementia, supporting dementia research and strengthening the European dementia movement.

How big an influence has Alzheimer Europe had on the understanding of Alzheimer's disease since it was first established?

When I started working for Alzheimer Europe 20 years ago, there was little recognition that dementia constituted a public health challenge. Thanks to the campaigning of national Alzheimer associations and individual people with dementia and their carers this has now completely changed.

The number of countries recognising dementia as a priority and developing national dementia strategies or plans continues to grow. Currently there are such plans in Austria, Belgium, the Czech Republic, Denmark, Finland, France, Greece, Ireland, Italy, Luxembourg, Malta, the Netherlands, Norway, Slovenia and the United Kingdom (with separate plans for England, Northern Ireland, Scotland and Wales). This public recognition needs to go hand in hand with greater awareness campaigns, the promotion of timely diagnosis, the development of post-diagnostic support, the improvement of care services and increased funding of dementia research. ▶



A meeting of existing and new members of the European Working Group of People with Dementia, their carers, and Alzheimer Europe staff (October 2016, Copenhagen)

Alzheimer Europe is involved in several research projects across Europe. Could you tell us about the current projects you are involved in, and what you are hoping to achieve from them?

We are active in many European projects funded by the Innovative Medicines Initiative (IMI) and Horizon 2020, and are a partner in the European Commission's second Joint Action on Dementia, which follows on from ALCOVE, the first Joint Action on Dementia. The aim of the second Joint Action, launched in March 2016, is to provide practical guidance for policy makers when developing and implementing their national dementia plans, policies and strategies. It will focus on four key areas: diagnosis and post-diagnostic support; crisis and care coordination; residential care; dementia-friendly communities. To ensure that the voice of people with dementia in Europe is heard, in relation to research being conducted in these four areas, one of the things we have committed to do for our core funding is to ensure the involvement of the EWGPWD in the work of the Joint Action.

In addition to this governmental collaboration on dementia, we are also partners in a wide range of research projects. We want to ensure that this research addresses relevant issues, is conducted in an ethical manner and involves people with dementia in a meaningful way. It is also important that it promotes the interests and wellbeing of people with dementia across Europe by working towards timely diagnosis or detection, appropriate care and measures to promote independent living and social inclusion.

Why is advancing the debate on Alzheimer's disease so important and how does Alzheimer Europe go about facilitating this?

Until recently much of the focus has been on the later stages of Alzheimer's disease. It is now becoming increasingly recognised that with a timely diagnosis and adequate post-diagnostic support, it is possible to "live well with dementia". Alzheimer Europe works very closely with people who have been diagnosed with Alzheimer's disease and other dementias. The input of the EWGPWD into our work has been tremendous and thanks to their contributions we have been able to change perceptions of the disease.

We are also a lobbying organisation, promoting dementia awareness, care and research within the EU institutions. This includes the European Alzheimer's Alliance, a group of 128 MEPs in the European Parliament from all political parties and 27 member states aiming to make dementia a public health priority at a pan-European level. In addition, research into the stages preceding the dementia phase provides us with hope of identifying treatments which may delay or postpone the appearance of symptoms.

Is Alzheimer's disease sufficiently recognised within scientific research? Or do you think it should receive more funding and attention?

European-wide research continues to grow. Several European level initiatives worth mentioning are Horizon 2020, the Innovative Medicines Initiative (IMI) and the Joint Programme – Neurodegenerative Disease Research (JPND), all of which are actively



supporting key dementia research projects. This shows that the European Union (EU) has fully understood that dementia cannot be solved by one single country.

However, despite this growing recognition, dementia research is still underdeveloped, compared to research into other diseases. Supporting dementia research and campaigning for increased funding for dementia research at EU and national level, and for greater collaboration between European countries in the field of research

therefore continues to be one of the main priorities of Alzheimer Europe.

Although your name (Alzheimer Europe) has Europe in its title, do you collaborate with other countries internationally? Or are you a mainly European-focused institution?

All our members are from Europe (WHO region) and our main focus and work is within Europe, but we collaborate with Alzheimer's Disease International (ADI) for the recognition of dementia as a global priority, at G7, G20, OECD and WHO level.

Alzheimer Europe organises an annual conference which brings together all types of people who are affected by, and work within the field of, dementia. What kind of impact do these conferences have, especially in terms of the relationship between researchers and those living with dementia?

Our annual conferences attract people with varied backgrounds in dementia, including people with dementia and their carers, representatives of national Alzheimer

associations, healthcare professionals, academics and researchers, as well as policy makers. The conference offers participants the opportunity to inform themselves about new findings in the fields of research on, and treatment of, Alzheimer's disease. The 2017 conference will take place in Berlin, Germany, under the theme "Care today, cure tomorrow". The conference in 2016 was held in Copenhagen, Denmark and its theme was "Excellence in dementia research and care".

Alzheimer Europe has recently released its strategic plan, outlining the aims they hope to achieve by 2020. Could you tell us what some of your main objectives are?

Making dementia a European priority with people with dementia and their carers as full partners in policy development, research and service design is at the heart of our strategy. This includes developing closer ties with the Joint Programme – Neurodegenerative Disease Research (JPND) and the Innovative Medicines Initiative (IMI). We would like to see all European countries develop a comprehensive dementia strategy and the

Heike von Lützu-Hohlbein (former Chairperson, Alzheimer Europe) Birgitte Vølund, (Alzheimerforeningen, Denmark), Jean Georges (Alzheimer Europe), Sabine Jansen (Deutsche Alzheimer Gesellschaft Selbsthilfe Demenz, Germany), Iva Holmerová (Chairperson Alzheimer Europe) (October 2016, Copenhagen)

European Union should develop a European Action Plan, promoting a rights-based approach to dementia.

By 2020, Alzheimer Europe hopes to have expanded its membership to all countries of the European Union with a view to reaching all countries belonging to the European region of the World Health Organization.

Do you think we will ever find a cure for Alzheimer's disease?

Looking at the increased recognition of dementia as a public health and research priority, I am truly hopeful for the future. We need to continue research efforts in the hope of better treatment and eventually a cure or prevention for Alzheimer's disease. In the meantime, we need to provide concrete answers and care approaches to the people currently living with the disease and their carers.

"Care today, cure tomorrow" best captures the holistic approach necessary to dementia care and research which, as mentioned before, is the theme of this year's annual conference.

• To find out more information about Alzheimer Europe's upcoming conference, or to read more about their work, please visit their website at www.alzheimer-europe.org.



Executive Director, Jean Georges

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