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JOINT STATEMENT ON DEMENTIA - 15 MAY 2017

The trio of Presidencies of the Council of the European Union 2016-2017, The Netherlands, Slovakia and Malta:

Taking into account

- that worldwide 47.5 million people live with dementia, of which 58% live in low and middle income countries; in the EU an estimated number of 6.4 million people live with dementia;
- that dementia is a major cause of disability and dependency among older people worldwide, having a significant impact not only on individuals but also on their carers, families, communities and societies; dementia accounts for 11.9% of the years lived with disability due to a noncommunicable disease; in light of the improved survival globally, this figure is expected to increase further;
- that dementia may develop at a relatively young age leading to unique challenges for the person with dementia, relatives and friends;
- that dementia leads to increased costs for governments, communities, families and individuals, and to loss in productivity for economies;

<u>Referring to</u>

- the council conclusions on supporting people living with dementia: improving care policies and practices, adopted by the EU Council of Health Ministers, under the Luxemburg Presidency, on December 7, 2015;
- the outcomes of conferences on dementia organised under the Netherlands' and Slovak Presidencies on May 9-10 and November 29, 2016 and the proceedings during the meetings of DG Sante's Governmental Expert Group on Dementia on November 28, 2016 en May 15-16, 2017, hosted by the Slovak and Maltese Presidencies;
- the activities of the World Health Organisation, resulting in the expected adoption of the Global Action Plan on Public Health Response to Dementia by the seventeenth World Health Assembly, on May 23-31, 2017, and the development of a Global Dementia Observatory;
- the human rights of people with dementia, as stipulated in the United Nations Convention on the Rights of People with Disabilities;

Wishing to emphasise the importance of:

- research into all aspects of dementia, including, but not limited to, finding a cure, prevention and improvement of care;
- providing good care for both patient and informal carer, referring to the key principles of good dementia care, attached to this statement;
- preserving the best possible quality of life for a person with dementia;
- the creation of dementia-inclusive communities;
- public awareness of dementia and its consequences, including risk and protective factors;
- patient advocacy by national and international Alzheimer organisations;
- Call upon the European Commission
- to promote and support the international cooperation in dementia research and improve the coordination of existing European research programmes, e.g. in the European Joint Programme on Neurodegenerative Diseases Research (JPND), Innovative Medicines Initiative, Horizon2020, Active and Assisted Living (AAL) programme and related research and innovation programmes;

- to promote and support the exchange and implementation of best practices in dementia care, diagnostics and prevention in, but not limited to, the EU Joint Action Act on Dementia and in the EU Governmental Expert Group on Dementia;
- to stimulate and promote the development of a society that supports and accepts people with dementia as worthy members of society;

Call upon our fellow EU-Member states

- to participate in, promote and support the international cooperation in dementia research, e.g. in the European Joint Programme on Neurodegenerative Diseases Research (JPND) and related research and innovation programmes;
- to work together in the exchange and implementation of best practices in dementia care, diagnostics and prevention in, but not limited to, the EU Joint Action Act on Dementia and in the EU Governmental Expert Group on Dementia;
- to support persons with dementia to have the best possible quality of life, to live a life with dignity and to participate in society, in accordance with their human rights;
- to stimulate and promote the development of a society that supports and accepts people with dementia as worthy members of society;
- to support patient advocacy by national and international Alzheimer organisations.

Mr Martin van Rijn State Secretary for Health, Welfare and Sport The Netherlands On behalf of Ms Andrea Kalavská State Secretary for Health Dr Boris Banovsky, Medical Director Ministry of Health Slovakia

Dr Justyne Caruana Parliamentary Secretary for Rights of Persons with Disabilities and Active Ageing Malta

ANNEX 1

Key Principles on Dementia Care

- 1. Dementia is a neurocognitive disorder
- 2. People with dementia are entitled to respect and dignity
- 3. People with dementia are worthy members of society
- 4. People with dementia are entitled to a correct and timely diagnosis
- 5. People with dementia and their relatives are entitled to appropriate treatment, care and support
- 6. Medical and care professionals have adequate knowledge of all aspects of dementia
- 7. Treatment of people with dementia is aimed at:
 - maintaining their independence in daily life
 - delaying progression of the disease
 - coping with co-morbidities
- 8. Care provides necessary assistance when a person with dementia loses functions due to the dementia, while conserving as much independence as possible
- 9. Support helps people with dementia and their relatives to:
 - cope with the disease
 - remain in control of their lives
 - maintain social activities
 - prepare for the effects of the progression of the disease, while using methods to prevent or delay symptoms of the disease
- 10. Public health raises awareness on and promotes ways contributing to the prevention of dementia.