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**PROPOSAL**

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| from:    | European Commission   |
| dated:   | 24 July 2009  |
| Subject: | Proposal for a Council Recommendation on measures to combat neurodegenerative diseases, in particular Alzheimer's, through joint programming of research activities |

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Delegations will find attached a proposal from the Commission, submitted under a covering letter from Mr Jordi AYET PUIGARNAU, Director, to Mr Javier SOLANA, Secretary-General/High Representative.

Encl.: COM(2009) 379 final



COMMISSION OF THE EUROPEAN COMMUNITIES

Brussels, 22.7.2009  
COM(2009) 379 final

2009/0113 (CNS)

Proposal for a

**COUNCIL RECOMMENDATION**

**on measures to combat neurodegenerative diseases, in particular Alzheimer's, through  
joint programming of research activities**

{SEC(2009) 1039}

## **EXPLANATORY MEMORANDUM**

### **EXECUTIVE SUMMARY**

The Commission is proposing more strategic cooperation among EU Member States (MS) in research and development (R&D) in view of addressing large societal challenges. One way to do so is a new 'Joint Programming' approach. Joint Programming (JP) involves MS engaging voluntarily on a variable-geometry basis in defining, developing and implementing strategic research agendas. Neurodegenerative diseases (ND), and in particular Alzheimer's disease (AD), have been proposed as a pilot project.

Around 7.3 million people are reckoned today to suffer from AD and related disorders in Europe, a figure that is expected to double by 2020. AD is expected to place a heavy and growing burden on health-care systems, including informal care and long-term care facilities, in Europe. In an ageing society, research on ND mobilises significant financial and human resources, both in the EU and at the level of the EU Framework Programme for research and technological development (RTD).

In spite of this, there is at present no effective treatment able to slow down or stop the deterioration of brain function. Early diagnosis is close to impossible, and because it often occurs too late, treatment to mitigate the effects of the illness remains limited. If we are to succeed in combating ND in general and AD in particular, a focused research effort addressing prevention, diagnosis and treatment is essential. Coordinating research in Europe would bring added value, better results and lead to more accurate diagnostic tools and more effective forms of treatment.

In September and December 2008, the Council adopted conclusions recommending that a common European initiative be launched in this field through a JP approach. It invited the Commission to submit a proposal for a Council Recommendation with a view to this pilot initiative being launched in 2009.

As a consequence, this Recommendation invites the MS to work towards a common vision of how research cooperation and coordination at European level can help us to understand, detect, prevent and combat ND, especially AD, and develop a Strategic Research Agenda (SRA) establishing medium to long-term research needs and objectives, including an implementation plan establishing priorities, milestones and timelines. This might include exchanging information on national programmes, research activities and health care systems; identifying areas which would benefit from coordination, joint calls or the pooling of resources; facilitating transdisciplinary and cross-sectoral mobility and training; and exploring the joint exploitation of research infrastructures and the networking of research centres.

The Recommendation also invites MS to cooperate with the Commission with a view to exploring possible Commission initiatives, using the facilities provided by the existing instruments, to assist MS in developing and implementing the common research agenda or to promote JP in this area.

#### **1. TOWARDS JOINT PROGRAMMING**

Until recently, the main tools for promoting cooperation in science and technology in Europe were transnational collaborative research projects and networks.

In 2008 the Commission proposed a new approach called Joint Programming for large-scale joint public research initiatives at European level<sup>1</sup>. JP grew out of the revised Lisbon strategy and is the process by which MS engage voluntarily and on a variable-geometry basis in defining, developing and implementing common SRA based on a common vision of how to address major societal challenges that no MS is capable of resolving alone.

In September 2008, the Council recognised the challenges posed by ND in the context of an ageing European population and the need to understand, detect, prevent and combat the basic mechanisms which trigger these diseases, particularly AD. The Council conclusions recommended that a European initiative be launched, bringing together MS, the Commission and other stakeholders with a view to reducing ND, particularly AD<sup>2</sup>.

In December 2008, the Council adopted conclusions recognising the necessity of a pilot JP initiative on ND, especially AD, and inviting the Commission to submit a proposal for a Council recommendation to prepare for this pilot initiative as soon as possible in 2009<sup>3</sup>.

Working through an informal working group set up under the French Presidency, MS started discussing how best to develop a pilot JP initiative on ND and AD. These discussions led to a Declaration of Intent in December 2008, agreed by ten MS and one country associated with the 7th Framework Programme (FP7).

The Declaration underlines these countries' willingness to take on the challenge, setting the basis for a shared vision in this field, outlining the research fields where Europe could add value, and describing a preliminary management structure. Following a presentation to the High Level Group on JP (GPC), representatives from 20 countries are currently involved in formulating the terms of reference for a management structure for this pilot initiative.

### **A case for Joint Programming**

During the French Presidency in 2008, ND and AD in particular, were identified by MS as an area where social demand is high and where a common initiative, using JP, would offer major added value compared with the current, fragmented efforts in the European Research Area.

There is a real and urgent need to pool and coordinate the efforts of European fundamental, clinical and social researchers in this field. Given that most research on ND is still at the pre-clinical phase, publicly funded research will be instrumental in any breakthrough in such areas as research on biomarkers, the development of new criteria and methods for prevention and diagnosis, and the testing of new therapeutics in large-scale clinical trials. These will increase Europe's chances of understanding, detecting, preventing and combating the basic mechanisms that trigger ND, and particularly AD, and of providing better care for people suffering from these diseases. In turn, this would mitigate the financial burden caused by having such a large population of sufferers.

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<sup>1</sup> COM(2008) 468.

<sup>2</sup> <http://register.consilium.europa.eu/pdf/en/08/st13/st13668.en08.pdf>

<sup>3</sup> <http://register.consilium.europa.eu/pdf/en/08/st16/st16775.en08.pdf>

## 2. COMBATING NEURODEGENERATIVE DISEASES, IN PARTICULAR ALZHEIMER'S

### **A major issue for public health in Europe**

ND are hereditary or sporadic conditions which are characterised by progressive nervous system dysfunction, often associated with atrophy of the affected central or peripheral nervous system structures. They are a heterogeneous group of age-associated, chronic illnesses of varying aetiologies.

AD is the most prevalent ND, accounting for around 50 -70% of all dementias, followed by Parkinson's disease<sup>4</sup>. In 2006, 7.3 million Europeans across the 27 Member States were suffering from dementias<sup>5</sup>. Alzheimer's is the fourth most common cause of burden of disease in high-income countries.

With the rise in life expectancy in Europe this number will increase dramatically, and current forecasts speak in terms of a doubling of the number of affected persons every twenty years in EU-27<sup>6</sup>.

Indeed, the population of Europe is ageing, with persons aged over 80 constituting the fastest growing cohort in most European countries. 70% of diagnosed AD patients are aged 75 and over. Dementia is therefore expected to be one of the main challenges for healthcare systems, including informal care and long-term care facilities, in the coming decades.

AD and related disorders are terminal conditions, but people can live and progressively deteriorate for 7–12 years after initial diagnosis. The disorder manifests with a progressive decline in multiple areas of function, including memory, reasoning, communication and the skills needed to carry out daily activities.

AD is a devastating disorder for the patients themselves. Also, a very heavy burden is placed on the shoulders of the patients' relatives. Family carers are often old and frail themselves, with high levels of depression and physical illness, and a diminished quality of life. As a consequence, AD is extremely costly for society as a whole: according to the Dementia in Europe Yearbook (2008), the total direct and informal care costs of AD and other dementias in 2005 amounted to €130 billion for EU-27, 56% of costs were for informal care<sup>7</sup>.

### **A substantial research effort is needed**

The causes of AD and related disorders are not well understood, but they all result in structural and chemical changes in the brain, leading to the death of brain tissue.

There is currently no treatment for AD which is able to slow or stop the deterioration of brain cells<sup>8</sup>. Available therapies are still very limited and mostly treat the symptoms rather than

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<sup>4</sup> M. Flint Beal, Anthony E. Lang, Albert C. Ludolph. Neurodegenerative diseases: neurobiology, pathogenesis and therapeutics, Cambridge University Press 2005.

<sup>5</sup> [http://ec.europa.eu/health/ph\\_information/dissemination/echi/docs/dementia2\\_en.pdf](http://ec.europa.eu/health/ph_information/dissemination/echi/docs/dementia2_en.pdf)

<sup>6</sup> Alzheimer's disease: Scientific, medical and societal implications, Synthesis and recommendations, INSERM, 2007.

<sup>7</sup> Alzheimer Europe (2008) Dementia in Europe Yearbook 2008.

<sup>8</sup> 2009 Alzheimer's disease facts and figures, US Alzheimer's Association, [http://www.alz.org/national/documents/report\\_alzfactsfigures2009.pdf](http://www.alz.org/national/documents/report_alzfactsfigures2009.pdf)

being curative. Indeed, although our understanding of the mechanisms of the disease has greatly improved over the past few years, we are far from seeing the full picture, and there is no immediate prospect of finding therapies that might slow or halt the progression of the illness.

Furthermore, diagnosis is usually made at too late a stage to make best use of the treatments currently available. While some genetic, behavioural, cardiovascular, and nutritional risk factors have been observed, long-term prevention studies have yet to be conducted to see if the incidence of AD can be reduced. Furthermore, the possible link between environmental stressors and ND including AD has to be investigated in depth.

The main cause for concern, according to the available epidemiological data, is that AD remains under-diagnosed in the EU<sup>9</sup>. Currently only about one-third of people with the disease receive a formal diagnosis at any time in their illness. When diagnoses are made, it is often too late for sufferers to make choices. The battle against ND and AD in particular will therefore not be won until we mobilise the research effort, covering the whole spectrum from prevention and diagnosis to treatment. Priorities for future research should include: prevention; biomarkers, including genetic susceptibility; imaging technologies; early diagnostic methods using a multidisciplinary approach; standardisation of diagnostic criteria and diagnostic instruments; large databases that could be used for population studies; treatment strategies and clinical trials of new chemicals, biologicals, vaccines or novel technologies.

## **A field of growing priority for research funding in Europe**

### **Current action in the Member States**

AD and related disorders present a common challenge to all MS, as percentage figures for dementia prevalence are roughly similar from country to country. They also pose particular challenges to the way health care is provided nowadays. Often, the services offered are not adapted to current needs, and there is also a lack of capacity, continuity and knowledge.

Given the expected increase in ND, and particularly AD, for healthcare systems in Europe in the medium and long term, most European countries have started recognising the need for specific comprehensive strategies for tackling AD and related disorders. In many countries, AD is becoming one of the emerging research priorities.

Several countries have adopted or are in the process of adopting national plans. In 2008, France made ND, and AD in particular, a priority, and adopted a €1.6 billion national plan in this field<sup>10</sup>. England launched in 2008 a National Dementia Strategy, Lifelong Health and Well Being Initiative<sup>11</sup>, backed by £150 million over the first two years, as well as its 2008 Medical Research Council Strategic Review of Neurodegeneration<sup>12</sup> and, also in 2008, Scotland launched the Dementia as National Priority initiative<sup>13</sup>. Norway adopted the

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<sup>9</sup> Moise, P., Schwarzingen, M., Um M-Y (2004) Dementia Care in 9 OECD Countries: A comparative analysis, OECD Health Working Papers No 13, OECD, Paris.

<sup>10</sup> Alzheimer Plan 2008-2012, <http://www.plan-alzheimer.gouv.fr/>

<sup>11</sup> Living well with dementia: a National Dementia Strategy, UK Department of Health, 2008 [http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/DH\\_083355](http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/NationalDementiaStrategy/DH_083355)

<sup>12</sup> <http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC004898>

<sup>13</sup> <http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/DFMH/dementia>

Dementia National Plan 2015<sup>14</sup> with five main strategies for meeting future care challenges. Early diagnosis of ND including AD was defined in 2008 as one of the six priority areas of the German Federal Ministry of Education and Research (BMBF)<sup>15</sup>. In addition, a German Helmholtz Centre for Neurodegenerative Diseases (DZNE) has been established in Bonn with an annual budget of €50 million.

In Sweden, the Swedish Brain Power Network was launched in 2005 as a national collaborative effort between six founders in the sum of SEK 100 million over five years. It seeks to improve early diagnosis, treatment and care of patients affected by ND<sup>16</sup>. In Ireland, almost €100 million are being devoted to age-related disease and care research<sup>17</sup>.

The Netherlands<sup>18</sup> and Italy have funded large cohort studies in the field for years, establishing an important collection of research data. Italy has made Alzheimer's a research priority for its Ministry of Health<sup>19</sup>. Spain has established several consolidated national networks addressing biomedical research on ND and mental health<sup>20</sup>.

### **Current action at European Union level**

Research on ND, and particularly AD, has also benefited from growing attention at European level. In the 6th RTD Framework Programme (FP6) €136 million were allocated to 28 collaborative research projects in this area. Of this, €40 million specifically tackled a translational approach to the study of AD<sup>21</sup>.

FP6 has also provided a means of addressing fragmentation and coordination of national research activities on ND, including AD, through the ERA-NET projects ERA-AGE<sup>22</sup> and NEURON<sup>23</sup>. The latter, involving 12 MS, issued a first joint call for proposals in 2008. 12 projects are being supported, with funding of €10 million<sup>24</sup>.

Efforts in this area have been strengthened as part of the Health Theme within FP7 (2007-2013) with special reference to brain research and 'Optimising the delivery of health care to European citizens'. Currently, one-third of the available funds for brain research for 2008-2009 have been allocated to neurodegeneration research. 24 collaborative research projects in the sum of €94 million are being supported in this field, of which €24 million are for AD and related disorders. A further €8 million are dedicated to collaborative research focusing on various aspects of the organisation, provision and quality of long-term care of the elderly in Europe.

The White Paper 'Together for Health: A Strategic Approach for the EU 2008-2013'<sup>25</sup>, developing the EU Health Strategy, also identifies better understanding of ND, such as AD, as

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<sup>14</sup> <http://www.regjeringen.no/upload/HOD/Dokumenter%20KTA/DementiaPlan2015.pdf>

<sup>15</sup> <http://www.bmbf.de/en/10849.php>

<sup>16</sup> [http://www.swedishbrainpower.se/eng/about\\_us.htm](http://www.swedishbrainpower.se/eng/about_us.htm)

<sup>17</sup> <http://www.hrb.ie/>, <http://www.tcd.ie/Neuroscience>

<sup>18</sup> <http://www.minocw.nl/english/index.html>

<sup>19</sup> <http://www.ministerosalute.it>

<sup>20</sup> <http://www.isciii.es/htdocs/index.jsp>

<sup>21</sup> [ftp://ftp.cordis.europa.eu/pub/lifescihealth/docs/major\\_catalogue\\_complet.pdf](ftp://ftp.cordis.europa.eu/pub/lifescihealth/docs/major_catalogue_complet.pdf)

<sup>22</sup> <http://era-age.group.shef.ac.uk>

<sup>23</sup> <http://www.neuron-eranet.eu>

<sup>24</sup> [http://www.neuron-eranet.eu/\\_media/newsLetter\\_January09.pdf](http://www.neuron-eranet.eu/_media/newsLetter_January09.pdf)

<sup>25</sup> COM(2007) 630 - [http://ec.europa.eu/health/ph\\_overview/strategy/health\\_strategy\\_en.htm](http://ec.europa.eu/health/ph_overview/strategy/health_strategy_en.htm)

an important need to be addressed in the context of demographic ageing. EU action has been launched under the Public Health Programme (2003-2008) in the field of information on AD and related disorders.

The **EuroCoDe** (European Collaboration on Dementia)<sup>26</sup> Project (2006-2008), supported by the Public Health Programme (2003-2008) and coordinated by Alzheimer Europe, is aimed at: (i) devising new consensual prevalence rates for dementia; (ii) developing guidelines on diagnosis, treatment and non-pharmacological interventions; (iii) establishing prevention strategies; (iv) analysing the socio-economic costs of AD and making an inventory of social support systems.

As part of EuroCoDe, Alzheimer Europe has published the **Dementia in Europe Yearbooks** 2006, 2007, and 2008<sup>27</sup>, which provide a comprehensive overview of the present situation of AD and other dementias in the European Union.

The **European Pact on Mental Health and Well-Being**, adopted in 2008, focuses on four priority themes: prevention of suicide and depression, mental health in youth and education, mental health in workplace settings, and mental health in older people<sup>28</sup>.

The EU also supports the EADC (European Alzheimer's Disease Consortium)<sup>29</sup>, a network of **European centres of excellence** working in the field of AD. The centres increase basic scientific understanding of, and develop ways of preventing, slowing, or ameliorating the primary and secondary symptoms of AD by facilitating trans-European research.

Following the priorities set out in the EU Health Strategy and the Council conclusions on public health strategies to combat ND associated with ageing, and in particular AD, adopted in December 2008 by the Ministers of Health, a Commission Communication on a European Initiative on Alzheimer's Disease and other Dementias is scheduled to be adopted in July 2009. The Communication will state that these diseases constitute a priority for action in view of the ageing of the European population, and will take account of how the increase in these diseases might impact on the financial sustainability of health and social protection systems.

### **The benefits of better coordination**

Reducing the burden of ND, in particular AD, is a major societal challenge for Europe, as 16% of the population is aged 65 and older, a share which is expected to double in the next 25 years, should current European population trends continue and no prevention methods emerge.

Brain research is subject of a significant research effort both in the MS and at European level. In 2005, the total spending on brain research in Europe was some €4.1 billion. Of this, €855 million came from the public sector, with the EU Framework Programme contributing €94 million and €105 million specifically to research on ND.

However, the picture of support for ND research in Europe is complex, mostly due to the variety of financing systems, research policies and organisational structures across MS, and

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<sup>26</sup> [http://ec.europa.eu/health/ph\\_projects/2005/action1/action1\\_2005\\_10\\_en.htm](http://ec.europa.eu/health/ph_projects/2005/action1/action1_2005_10_en.htm)

<sup>27</sup> [http://ec.europa.eu/health/ph\\_information/reporting/docs/2008\\_dementiayearbook\\_en.pdf](http://ec.europa.eu/health/ph_information/reporting/docs/2008_dementiayearbook_en.pdf)

<sup>28</sup> [http://ec.europa.eu/health/ph\\_determinants/life\\_style/mental/docs/pact\\_en.pdf](http://ec.europa.eu/health/ph_determinants/life_style/mental/docs/pact_en.pdf)

<sup>29</sup> <http://eadc.alzheimer-europe.org/introduction.html>



the wide variation in spending on ND research by different organisations and countries. Coordination of national research efforts in this field at European level leaves much to be desired. Key elements accountable for this situation include:

- The barriers between disciplines and fields of research, and the compartmentalisation of research activities. The knowledge needed to advance our understanding of the problem and the potential solutions spans not only a broad and diverse range of disciplines and stakeholders, but also the various European countries.
- A major weakness is the lack of linkages between basic, clinical and public health, and social research, which means that only some of the existing or acquired basic knowledge feeds into current clinical practice and care organisation and delivery.
- The way these activities are run, mainly in a national context, reinforcing fragmentation and limiting the sharing of current best practices throughout the EU as regards diagnosis, treatment and prevention.

Thus, despite the high volume of financial resources, and the substantial range of initiatives on the part of individual MS, current efforts are not seeing the advantages of a coherent and coordinated approach.

Approaches at a macro level are the way to bridge the gaps in our understanding and action. A few examples include pinpointing best practice in the early diagnosis of AD and related disorders, and the use of existing interventions, which could best be achieved by sharing knowledge and efforts. Coordinated databases with genomic information, banks of samples and tissues will of course be essential to this drive.

Developing and validating new prevention methods and therapies, and assessing the effectiveness of current ones, will require large-scale clinical studies whose natural environment would be cross-border collaboration, given the very large number of patients of (more or less) different genetic backgrounds needed if meaningful results are to be obtained.

Similarly, the launching and integration of large-scale population cohorts, databases and registries will be needed if we are to fully understand the role and contribution of genetics, nutrition, behaviour and other risk factors in the development of these diseases, and the place for prevention strategies. Understanding European diversity related to these risk factors and putting it to use could help us gain a competitive edge when it comes to a better understanding of the disease.

Standardisation of diagnostic criteria and assessment tools throughout MS will be essential if best practices and optimal clinical care are to be delivered across Europe.

By enabling a critical mass of skills, knowledge and financial resources to be pooled, and by facilitating interdisciplinarity, joint action would get us closer to dealing with the medical and social challenges posed by these diseases.

A dedicated JP action in this politically and socially highly challenging area would capitalise on the existing structures and programmes, while avoiding unnecessary duplication of work, effort and resources, to the benefit of all European citizens. It would also help the EU to develop a coherent approach in international cooperation with third countries of a comparable demographic profile and facing the same issues, in particular those countries associated to

FP7, building on such initiatives as the European Alzheimer's Disease Neuroimaging Initiative supported by the US National Institute of Health<sup>30</sup>.

The Recommendation also invites MS to cooperate with the Commission with a view to exploring possible Commission initiatives to assist MS in developing and implementing the common research agenda.

The Commission may take any other initiatives to promote JP in this area, such as providing "ad-hoc" and complementary measures to support such a pilot JP initiative. These measures could include the support to the management structure and the establishment of the SRA, the provision of data and information and analysis on the state of art in this field in MS and at European level and annual reporting on the progress of this initiative. Commission may also look into possible forms of consultation and cooperation on this subject with scientifically advanced groupings at international level.

### 3. LEGAL ELEMENTS OF THE PROPOSAL

#### **Summary of the proposed action**

The proposal invites the MS to adopt a common approach at European level through JP in research on ND, in particular AD.

JP will require the interested MS to work together to define a common vision of research needs and opportunities in this field and, on this basis, develop a SRA establishing priorities, milestones and timelines, including an implementation plan outlining the actions, instruments and resources needed to implement the SRA and realise the joint vision. For these purposes, a management structure has to be set up, and MS are asked to define its mandate. The proposal also invites MS to cooperate with the Commission with a view to exploring possible Commission initiatives to assist MS in developing and implementing the SRA. The Commission may take any other initiatives to promote JP in this area.

#### **Legal basis**

Article 165 EC Treaty provides the legal basis.

#### **Subsidiarity principle**

The proposal complies with the subsidiarity principle as its objectives cannot be sufficiently achieved at MS level and can therefore, by reason of the scale and effects of the objectives, be better achieved at Community level. The added value of addressing such a research issue in the framework of a common European effort, through JP, resides mainly in the fact that joint action would allow the pooling of a critical mass of skills, knowledge and financial resources, combining mutually complementary expertise more easily and avoiding wasteful duplication of efforts. Action at Community level would counter the current fragmentation and disparities, and ensure better use of increasingly scarce resources while maintaining full leadership of the process by the MS. Accordingly, a set of recommendations at Community level will offer for addressing such societal challenges in a more efficient and coordinated way.

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<sup>30</sup> [http://www.adni-info.org/index.php?option=com\\_frontpage&Itemid=1](http://www.adni-info.org/index.php?option=com_frontpage&Itemid=1)

### **Proportionality principle**

The proposal complies with the proportionality principle because rather than replacing, it complements and streamlines current action in MS on fighting ND, including AD. It leaves it up to the MS to decide how to put the recommendations into practice.

On the other hand, the magnitude of the challenge that European nations have to face, and their demographic trends, together demand so much more in the way of means and resources that selected joint action will be the only possible way to deliver the results needed to preserve social security systems and protect the well-being of large cross-sections of the population.

### **Choice of instrument**

Council Recommendation.

#### **4. BUDGETARY IMPLICATIONS OF THE PROPOSAL**

This proposal has no implications for the Community budget.

Proposal for a

**COUNCIL RECOMMENDATION**

**on measures to combat neurodegenerative diseases, in particular Alzheimer's, through joint programming of research activities**

THE COUNCIL OF THE EUROPEAN UNION,

Having regard to the Treaty establishing the European Community, and in particular Article 165 thereof,

Having regard to the proposal from the Commission<sup>31</sup>,

Having regard to the opinion of the European Parliament<sup>32</sup>

Having regard to the opinion of the European Economic and Social Committee<sup>33</sup>,

Having regard to the opinion of the Committee of the Regions<sup>34</sup>,

Whereas:

- (1) Article 152 of the Treaty provides that Community action, which shall complement national policies, shall be directed towards improving public health, preventing human illness and diseases, and obviating sources of danger to human health.
- (2) The number of people suffering from Alzheimer's disease and related disorders in Europe is estimated to be 7.3 million. There is currently no effective treatment for Alzheimer's disease able to slow or stop the progression of the illness and available therapies remain very limited. Alzheimer's accounts for around 50 -70% of all dementia cases, representing one of the main causes of disabilities of the elderly.
- (3) Those figures are expected to rise drastically by 2020, due to the increased life expectancy and a decreasing ratio of working to retired populations. This will lead to a greater burden on patients, their families and caregivers and pose substantial challenges ahead for Member States' healthcare systems in terms of costs and organisation.

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<sup>31</sup> OJ C, p

<sup>32</sup> OJ C, p

<sup>33</sup> Optional consultation, OJ C, p

<sup>34</sup> Optional consultation, OJ C, p

- (4) Member States have therefore recognised the need to adopt specific national plans and strategies for Alzheimer's disease and related disorders in order to alleviate the burden on society in general and on healthcare systems.
- (5) However, there is also a growing awareness that the impact of neurodegenerative diseases on the population in Europe is of such a magnitude that no Member State is capable of resolving it alone. Member States would therefore benefit from coordinating their actions to develop a stronger, better coordinated and more effective response at the European level.
- (6) On 2 December 2008, the Competitiveness Council recognised neurodegenerative diseases as an area where Joint Programming would provide a major added value to the current, fragmented efforts of Member States in the field of research. It therefore adopted conclusions recognising the need to launch a pilot Joint Programming initiative on combating those diseases, in particular Alzheimer's disease, and inviting the Commission to submit a proposal for a Council Recommendation.
- (7) Joint Programming in research on neurodegenerative diseases would encourage the pooling of skills, knowledge and resources, with a view to advancing research on the prevention, diagnosis and treatment and to alleviating the burden of neurodegenerative diseases on patients and society.
- (8) In order to ensure the efficiency of the joint efforts of Member States in fighting neurodegenerative diseases, Member States should develop a strategic research agenda based on a common approach as regards the prevention, diagnosis and treatment of neurodegenerative diseases.
- (9) With a view to ensuring effective management of the different common actions to be taken, Member States should set up a common management structure mandated to establish common conditions, rules and procedures for cooperation and coordination and to monitor the implementation of the strategic research agenda.
- (10) In order to achieve the goals set by this Recommendation, Member States should cooperate with the Commission in exploring possible Commission initiatives to assist Member States in developing and implementing the strategic research agenda.
- (11) The Commission should act as a facilitator by adopting complementary measures to support the implementation of this pilot Joint Programming initiative and should report regularly to the Council on the progress of this initiative. Furthermore, the Commission should further explore how best to contribute to the strategic research agenda and to its implementation plan via Community funding instruments, in synergy and complementary to the instruments and actions of the Member States and other stakeholders.

HEREBY INVITES THE MEMBER STATES TO:

- 1. Develop a common vision on how cooperation and coordination in the field of research at the European level can improve prevention, diagnosis and treatment of neurodegenerative diseases, in particular Alzheimer's.
- 2. Develop a strategic research agenda establishing medium to long term research needs and objectives in the area of neurodegenerative diseases, in particular Alzheimer's.

The strategic research agenda should contain an implementation plan establishing priorities and timelines and specifying the actions, instruments and resources required for its implementation.

2.1. The following actions should be undertaken as part of the implementation plan:

- (a) identify and exchange information on relevant national programmes and research activities;
- (b) reinforce joint foresight and technology assessment capacities at the level of basic, medical, health and social services research;
- (c) identify areas or research activities that would benefit from coordination or joint calls for proposals or pooling of resources in areas such as the development of new prevention and treatment strategies, new imaging technologies and biomarkers;
- (d) exchange information resources and best practices in areas such as the comparison of healthcare systems, including long term care and informal care settings;
- (e) share, where appropriate, existing research infrastructures or develop new ones in areas such as coordinated registries, biobanks for blood samples and tissues or the development of animal models for the study of these diseases;
- (f) network centres dedicated to research on neurodegenerative diseases in areas such as clinical trials, standardisation of diagnostic criteria and diagnostic instruments.

3. Set up a common management structure in the field of neurodegenerative diseases, in particular Alzheimer's disease, mandated to establish common conditions, rules and procedures for cooperation and coordination and to monitor the implementation of the strategic research agenda.

4. Cooperate with the Commission with a view to exploring possible Commission initiatives to assist Member States in developing and implementing the common research agenda.

HEREBY INVITES THE COMMISSION TO:

- 1. Provide ad-hoc and complementary measures to support the pilot Joint Programming initiative. Those measures should include support to the management structure and the establishment of the strategic research agenda, the provision of data, information and analysis on the state of the art in this field in Member States and at European level.
- 2. Explore how best to contribute with complementary measures to the strategic research agenda and to its implementation plan via Community funding instruments.
- 3. Look into possible forms of consultation and cooperation on this subject with scientifically-advanced groupings at international level.

Done at Brussels, [...]

*For the Council*  
*The President*