Dementia in Europe

Florence Lustman reviews the progress of the French Alzheimer Plan

Enda Connolly provides an update on the Joint Programming Initiative

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Alzheimer Europe has enjoyed a particularly busy few months! Our 21st Annual Conference in Poland in October attracted over 470 participants from 40 countries and we hope you enjoy reading about the various presentations in our dedicated conference section.

In December, Alzheimer Europe organised its 11th lunch debate in the European Parliament which was hosted by Frieda Brepoels, MEP (Belgium). It concentrated on the launch of the Value of Knowing survey in five languages (English, French, German, Polish and Spanish). The debate was important and useful in helping us to understand that there is an overwhelming willingness by the general public to confront Alzheimer’s disease and to get a diagnosis despite the fear of the condition.

Since the last issue of the magazine, Alzheimer Europe has published two reports: The 2011 Dementia in Europe Yearbook which focuses on the legal provisions relating to the restriction of the freedom of movement of people with dementia and the Ethics of Dementia Research, which provides a detailed discussion of some of the main ethical issues linked to carrying out dementia research in an ethical manner. I am grateful to all those who contributed to these comprehensive publications and am sure they will prove invaluable to all who work in the field of dementia.

We provide an update on current initiatives at European level. Commissioner Neelie Kroes, Vice-President of the European Commission, explains how the European Innovation Partnership of Active and Healthy ageing initiative can help people with dementia and their carers. Enda Connolly, Member of the Joint Programming Initiative on Neurodegenerative Diseases, talks with Alzheimer Europe about the progress of the Joint Programming Initiative. Also, we hear about the health agenda for the EU during the Danish Presidency from Astrid Krag, the Danish Minister for Health.

The situation for people with dementia and their carers in Denmark is considered by Ole Christensen MEP, (Denmark). An update on the status of the national dementia strategy in France is provided by Florence Lustman, Vice-Chair of the Foundation for the Scientific Coordination of the French Alzheimer Plan and in Luxembourg by Mars di Bartolomeo, Luxembourg Minister for Health.

With the economic crisis deepening drastic cuts are being made. At the same time, the need for support and services is increasing. Professor Magda Tsolaki from Greece and Maurice O’Connell from Ireland talk about how austerity packages are impacting people with dementia in their countries.

Our Dementia in the News section includes highlights of national Alzheimer’s associations’ celebrations of World Alzheimer’s Day as well as a moving article by carer Ramona Amairei from Romania.

When we started the Dementia in Europe magazine we were concerned about finding sufficient content. Now we are publishing our 10th issue and I think the variety and depth of articles are a clear indication that there is much to be debated and to be done to help people with dementia and their carers.

Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe
Prioritising dementia

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Jean Georges, Marina Yannakoudakis MEP (UK), Heike von Lützau-Hohlbein and Frieda Brepoels MEP (Belgium) at the 11th Alzheimer Europe lunch debate in the European Parliament

Fulvio Galeazzi discusses the European project “DECIDE”

Frédérique Ries, MEP (Belgium), hosts an event on Alzheimer’s disease
The “Value of Knowing” survey and report were presented in the European Parliament on 6 December 2011. Alzheimer Europe reports on the debate and the issues raised.

Frieda Brepoels, MEP (Belgium) and Vice-chair of the European Alzheimer’s Alliance, hosted Alzheimer Europe’s 11th lunch debate, “Public perceptions of Alzheimer’s disease and the value of diagnosis”. The survey was carried out by Alzheimer Europe in association with the Harvard School of Public Health in four European countries (France, Germany, Poland and Spain) and the US. The debate in the European Parliament was attended by nine MEPs and/or assistants, national policy makers, representatives from the European Commission, Alzheimer associations and pharmaceutical companies.

Opening the debate, Ms Brepoels reminded the audience that in Europe 7.3 million people have dementia and that this is estimated to increase significantly. She illustrated how EU policy makers are prioritising Alzheimer’s disease and said “It is indisputable that early diagnosis will help people with dementia and their carers to put in place measures that help them to deal with the disease in a better way.”

A summary of the findings was presented by Jean Georges, Executive Director, Alzheimer Europe. (Further details of the findings were reported in issue 9 of the Dementia in Europe magazine). During the debate some of the key issues discussed were:

- A willingness to see a doctor and to receive a diagnosis
- A high level of fear amongst the public of the disease, with Alzheimer’s disease being the 2nd most feared disease
- An overwhelming support for greater public investment in care and research
- A lack of understanding of later symptoms and the severity of the disease
- A misunderstanding of the efficacy of available treatment and the reliability of existing diagnostic tests.

Marina Yannakoudakis, MEP (UK) questioned why there was a delay of 32 months in the UK to receive a diagnosis of dementia from the first presentation of symptoms. Mr Georges explained that the structure of healthcare systems can have an impact on prolonging the time to diagnosis, especially if the primary care sector plays a gatekeeper role in which general practitioners need to refer suspected cases to a specialist for diagnosis and treatment. This UK approach contrasts with other countries, such as Germany, where general physicians can diagnose Alzheimer’s disease.
Nessa Childers, MEP (Ireland) asked whether symptoms may be missed during the primary care process and Mr Georges highlighted that another survey had revealed early symptoms such as forgetfulness and other minor symptoms are not always picked up on. Even when people presented symptoms such as behavioural issues it was found that a diagnosis was not given and therefore, Mr Georges said that a lot of awareness raising still needs to be done.

Ms Brepoels was interested to know why it was that only in Poland people were more frightened of heart disease than dementia. Alicja Sadowska, Chairperson of the Alzheimer’s Association in Poland, explained that a very successful campaign had been run on raising awareness about the consequences of heart disease and that now the government needs to develop a national Alzheimer’s plan which incorporates raising awareness and understanding of dementia and prescribes ways to support people with dementia and their carers.

As more investment in research was endorsed in the survey, Vittorio Prodi, MEP (Italy) suggested that the European Parliament use the Horizon 2020 initiative to secure this. Mr Georges concurred and suggested that the public health programme is also of key importance. He said, “From our point of view, the European Parliament and the European Alzheimer’s Alliance have been fantastic allies and we are counting on their continued support to ensure that Alzheimer’s disease and other forms of dementia are recognised as priorities in the new research and public health programmes.”

Frieda Brepoels concluded that “This survey clearly shows significant public interest in dementia and reinforces the commitment to support early diagnosis in Europe. It also highlights the importance of managing false expectations and this is precisely why it is important that realistic awareness raising is supported by the EU”. She closed the debate saying, “Since I joined the Alliance, important achievements have been made but it is also thanks to the work of Alzheimer Europe. However, a lot remains to be done and I can assure of my continued support as well as that of my colleagues here today.”

To a question about the development of a predictive test, Sigurd Sparr, Honorary Secretary of the Board of Alzheimer Europe, explained that there is currently no such test and highlighted the importance of ethical consideration for predictive tests in the absence of treatment and preventive measures.

Jean Georges: “from our point of view, the European Parliament and the European Alzheimer’s Alliance have been fantastic allies and we are counting on their continued support to ensure that Alzheimer’s disease and other forms of dementia are recognised as priorities in the new research and public health programmes.”
A snapshot of Alzheimer Europe’s 11th lunch debate
THE EUROPEAN ALZHEIMER’S ALLIANCE MEMBERS IN ACTION

There are 59 Members of the European Parliament who have joined the European Alzheimer’s Alliance. In this article, we highlight some of the ways in which Alliance members have raised awareness and understanding of the disease at European and national level. In addition, we bring news of awards recently given to Alliance members.

Françoise Grossetête, MEP (France) and Chairperson of the European Alzheimer’s Alliance
On the occasion of World Alzheimer’s Day (21 September 2011), Françoise Grossetête and Philippe Amouyel (Professor of Epidemiology at the University of Lille, France, and Chair of the Joint Programming of Neurodegenerative Disease (JPND)) jointly wrote an article for one of France’s most read newspapers, Le Monde: “Fight against Alzheimer’s disease: The European Union is on the front line”.

In their article, Ms Grossetête and Prof. Amouyel explain how the European Union, in conjunction with public and private actors, strives to stimulate research across the EU to improve the daily lives of the people with dementia and their carers.

They presented the European Alzheimer strategy from 2007 when France was in the driving seat to kick-start both European awareness about the challenges of dementia and the various initiatives: the (JPND) with a priority on Alzheimer’s disease, the European Joint Action ALCOVE (Alzheimer’s Cooperative Valuation in Europe) as well as the Innovation Medicines Initiative (IMI) which links up public and private research.

Also on World Alzheimer’s Day, Françoise Grossetête could participate in a meeting organised by the Parliament Magazine and Sanofi thanks to her assistant who delivered a speech on her behalf. In her own speech, Ms Grossetête considered the European steps forward in the fight against Alzheimer’s disease, the role of the European Parliament as well as the importance of the commitment of the European Alzheimer’s Alliance members. This meeting was hosted by another Alliance member, Frédérique Ries.

Frédérique Ries, MEP (Belgium)
On 21 September 2011, Frédérique Ries also marked World Alzheimer’s Day by hosting an event organised in Brussels by the Parliament Magazine and Sanofi: “Facing the future – Developing an EU strategy on Alzheimer’s”.

The speakers at this event gave an overview of the current research priorities (JPND, Sanofi),
the on-going European Joint Action (ALCOVE),
the European political priorities (European
Commission and Polish EU Presidency) and the
engagement of the patient organisations (including
Alzheimer Europe).

For Ms Ries, the fight against Alzheimer’s disease
is more than a medical issue: it is about improving
the quality of life of people with dementia and
their carers. It is essential to have coordinated
action at EU level. This will help Member States to
enact plans that support early diagnosis and
bridge the gaps between Member States. She added
that it was important to focus on a multidisci-
plinary approach, with better public/private
partnerships.

Ms Ries also said that she found the lack of
volunteers regrettable during the clinical trials
phase and hoped the revision of the clinical trials
Directive will address this issue.

The enquiry found that shifting resources away
from hospitals into community-based services
can improve the quality of life of the people with
dementia and bring savings to the health and
social care systems. This can cover early inter-
vention services, carer support services, mental
health liaison teams for older people and preven-
tion services.

The lunch-debate was well-attended, with
representatives from the European Commis-
sion, MEPs, Permanent Representations to the
EU, Belgian policy makers and social care
professionals, health professionals, Alzheimer’s
disease associations, NGOs and industry.

The event was moderated by John Bowis,
former MEP and former Member of the European
Alzheimer’s Alliance, now Ambassador to the
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Keith Taylor, MEP (UK)
Keith Taylor co-hosted
a lunch debate in the
European Parliament on
11 October 2011 alongside
Marina Yannakoudakis,
MEP (UK). The event
was organised by the
All-Party Parliamentary
Group on Dementia in the UK (APPG) and the
Alzheimer’s Society. The APPG and the Alzhei-
mer’s Society presented the findings of their 2011
inquiry “The £20 billion question: An inquiry
into improving lives through cost-effective
dementia services”. Mr Taylor welcomed the event
as a valuable opportunity to share best practice
and knowledge at EU level on this crucial issue.

Marina Yannakoudakis,
MEP (UK)
Ms Yannakoudakis was shadow rapporteur for
the European Conservatives and Reformists
(ECR) group for the European Parliament Resolu-
tion on a European initiative on Alzheimer’s
disease (2011). She reminded the audience about
the necessity to increase awareness about demen-
tia, the importance of early diagnosis and the need
to increase research in dementia.
On 21 October 2011, Ms Yannakoudakis organised a European information event at Europe House in London to discuss Alzheimer’s disease with Dr Simon Ridley, Head of Research at Alzheimer’s Research UK as guest speaker. The event focused on developing new treatments for Alzheimer’s disease and other forms of dementia.

Ms Yannakoudakis said that increasing awareness about the disease can help early diagnosis which in turn will lessen the effects of the disease while reducing healthcare costs. She added that best practices needed to be shared at EU level and research should be pooled to better use the resources. In spite of all efforts made, Ms Yannakoudakis called on the EU to dedicate more funding for dementia research.

Dr Ridley reminded the audience that dementia is not a normal part of ageing; it is caused by brain diseases which can be beaten with enough research.

Six MEPS join the European Alzheimer’s Alliance

Since the last issue of the Dementia in Europe magazine, the following six members of the European Parliament have joined the European Alzheimer’s Alliance: Richard Ashworth (UK), Heinz Becker (Austria), Ole Christensen (Denmark), Maria da Graça Carvalho (Portugal), Elżbieta Lukacijewska (Poland) and Jens Rohde (Denmark). The total number of MEPS in the Alliance now stands at 59, representing 21 Member States of the European Union and from the major political groups in the European Parliament.

European Alzheimer’s Alliance members receive MEP Award

At the 7th MEP Awards ceremony, European Alzheimer’s Alliance member Marisa Matias (Portugal) received the Health Award. This Award recognises Ms Matias’ engagement in health issues in the European Parliament. She was Rapporteur for the European Parliament Resolution on a European initiative on Alzheimer’s disease and other dementias (2011) and Co-Rapporteur for the European Parliament Resolution on the Joint Programming of research to combat neurodegenerative diseases, particularly Alzheimer’s disease (2009).

Other European Alzheimer’s Alliance members also received Awards: Mairead McGuinness (Ireland): Agriculture and Rural Affairs; Astrid Lulling (Luxembourg): Economic and Monetary Affairs; Claude Moraes (UK): Justice and Civil Liberties and Lambert van Nistelrooij (Netherlands): Regional Development.

The annual MEP Awards bring together members of the European parliament, EU stakeholders and industries and EU institutional staff to celebrate the work and highlight the outstanding achievements of MEPS over the last year. The event is organised by Dods and was hosted by Mr Maroš Šefčovič, European Commission Vice-President for inter-institutional relations and administration.
Prioritising Dementia

Legal provisions relating to the restriction of the freedom of movement of people with dementia

Alzheimer Europe reports on the legal provisions relating to the restriction of the freedom of movement of people with dementia throughout 27 EU countries as well as Iceland, Norway, Switzerland and Turkey.

People with dementia may face restrictions to their freedom of movement. The legal provisions which relate to such restrictions, in terms of (a) involuntary internment, (b) the use of coercive measures and (c) driving licences are the focus of the 2011 Dementia in Europe Yearbook published by Alzheimer Europe. The Yearbook is the result of a body of work by a number of dedicated lawyers and legal experts who checked, updated and in some cases wrote entire sections of the report. These contributions were coordinated by Dianne Gove, Information Officer of Alzheimer Europe. The publication of the 2011 Yearbook marks the end of three years’ work updating and expanding the original reports from 2000 as well as including new reports on the countries which have subsequently joined the European Union.

(a) Involuntary internment

Involuntary internment is the term used to describe the situation where a person is obliged by law to reside in some form of institution. Usually, the grounds for this restriction of liberty are that the person has a mental disorder and is considered a danger to him/herself or others. While this may sometimes be appropriate, national laws are often ill-suited to the needs of people with dementia. In some countries, laws regarding involuntary internment only apply to internment in a psychiatric institution. This is not the ideal place to provide appropriate care and support for people with dementia.

Many people with dementia who live in nursing homes and other residences did not consent to leaving their own homes and moving into such places. However, some countries (e.g. Denmark) have addressed this by prescribing in law how a person opposed to removal, or who lacks capacity to give informed consent, may be admitted to a specific facility. In Malta, a similar law allows for such a person to be admitted to hospital for observation. Sometimes the law allows for a patient to be cared for in the family environment (e.g. in Belgium and Luxembourg) although the initial period is short (up to 40 days) but it may be extended to a period of two years.

(b) Coercive measures

The term “coercive measures” denotes methods that are used to restrain a person which involve restraint, force or threat. Examples include bed rails, chair and bed belts, threatening behaviour or words, various electronic devices and the use of tranquilisers. Some coercive measures can be quite subtle, such as forcing people to wear sleeping attire – and can make people feel unable to leave the building. The use of coercive measures can sometimes be justified, e.g. to prevent a person from harming him/herself or others or to enable medical staff to administer necessary medication or treatment.

However, these measures infringe on personal liberty, which is a fundamental human right. Consequently, their use must be closely monitored.
In the case of people with dementia – many of whom are older and frail – many forms of coercion are increasingly considered as abusive and should be avoided whenever possible. There is even evidence that the use of certain forms of restraint can increase the likelihood of falls or injury.

In the last ten years, various countries have begun to address this issue. In Austria, a new law came into force in 2005 which has two central objectives: The protection of residents in nursing homes or other institutions for handicapped persons against restrictions of free movement, as well as support for the staff in these institutions when faced with difficult decisions for or against such restrictive measures.

In the Czech Republic, the ombudsman has the power to check the well-being of people whose freedom has been restricted, irrespective of whether such restriction is the result of a legal ruling. The ombudsman may visit the place where the person is held to check on treatments received and whether fundamental rights are being respected.

A few countries have specific laws to protect vulnerable people against abuse/mistreatment, especially by those people responsible for their care. For example, the Portuguese criminal code provides protection for vulnerable people, including “someone who is especially weak because of his/her age, handicap or disease.” Another example can be found in Sweden, where social services professionals are legally bound to report abuse.

Legislative reform is ongoing in Finland which specifically addresses the deprivation of liberty in the care of people with mental disabilities and dementia. Its goal is also to strengthen the multidisciplinary cooperation and the availability and development of services to lessen the need to limit liberty and self-determination.

(c) Driving licenses

The withdrawal of one’s driving licence – or limitations on its use – is also perceived as a restriction of freedom of movement by many people with dementia. Losing the opportunity to drive often entails a gradual restriction of one’s activities and social contacts.

Restrictions related to driving differ widely across Europe. In some countries, everyone over a specified age must take a medical test to determine their fitness to drive (e.g. 65-70 years in Cyprus, 60 in the Czech Republic and 70 in Norway). In some countries (e.g. the Czech Republic), general practitioners are obliged to report people who may be unfit to drive. In Luxembourg, any person with a driving licence may be requested at any time to have a medical examination if there is a doubt concerning their capacity to drive.

The Yearbook contains an acknowledgement of all the experts who contributed and Alzheimer Europe would like to take this opportunity to thank them again. The 2011 Dementia in Europe Yearbook is available on the Alzheimer Europe website.
DECIDE: NEW TOOL POTENTIALLY OFFERS FASTER ACCESS FOR EARLIER DIAGNOSIS OF ALZHEIMER’S DISEASE

Fulvio Galeazzi, “DECIDE” project coordinator, speaks with Alzheimer Europe about the European project “DECIDE” and how it can help people with dementia and their carers.

Alzheimer Europe (AE): Mr Galeazzi, can you explain what the DECIDE project is and what its aims are?

Fulvio Galeazzi (FG): DECIDE (Diagnostic Enhancement of Confidence by an International Distributed Environment) is a European project within the Seventh Framework Programme (FP7). It began in September 2010 and is based on the pioneering neuGRID e-infrastructure, which is also an FP7 project. DECIDE aims to develop a European e-service dedicated to researchers and clinicians for the study and the early diagnosis of Alzheimer’s and other neurodegenerative diseases. It includes among its partners internationally renowned researchers on Alzheimer’s disease. The service will be based on a secure and unique infrastructure of powerful computing resources, high-speed networks and international databases that allows clinicians to quickly upload, analyse and compare medical imaging data and enabling informed diagnoses.

By making advanced, simple to use diagnostic tools available to clinicians across Europe, DECIDE enables support for the early diagnosis of Alzheimer’s disease, improving patient care and family planning.

AE: How will this e-service help clinicians in the early diagnosis of Alzheimer’s disease?

FG: Applications integrated in the DECIDE environment allow clinicians and researchers to perform the computer-aided extraction of diagnostic markers from patients’ data and medical images such as Positron Emission Tomography (PET), Magnetic Resonance Imaging (MRI), and Electroencephalography (EEG) scans, and explore a multimodal distributed reference database including 850 datasets from control subjects and 2,200 from neurological subjects. It is a huge amount of data to analyse and its elaboration will be possible because DECIDE brings together the power of research networks, distributed databases, powerful diagnostic algorithms and grid computing.

The diagnostic markers extracted will provide clinicians and researchers with quantitative measures of the statistical deviation with respect to the control database, allowing a more sensible and specific early detection of the disease.

AE: Can you explain how clinicians will be able to access the DECIDE service?

FG: It will be available by using a simple web browser. The clinicians, irrespective of location, will access the DECIDE portal through their web browser, upload the biomedical images of the patient and, by a simple click, let DECIDE securely handle the processing, protecting data confidentiality. Markers that have been associated with the onset of Alzheimer’s disease will be extracted.

AE: Which are the main benefits that DECIDE may potentially offer people with Alzheimer’s disease?
FG: The potential impact for clinical use and research of the proposed e-infrastructure will be on a large scale by enabling clinicians from hospitals with no access to sophisticated computational algorithms, resources, and large sets of reference databases (images, EEG recordings) to carry out analyses remotely and efficiently. This means that people with Alzheimer’s disease will benefit from a more appropriate inclusion in clinical trials, or advanced research therapies, given the better accuracy in early diagnosis.

AE: What have been the key achievements of the project to date?

FG: The distributed e-infrastructure is up and running, providing a testing environment for the new applications that offer very high service levels. We have also implemented a secure but very user-friendly Authentication and Authorisation Infrastructure (AAI), which allows users to be securely and easily authenticated in the grid environment.

A working pilot of the service, implementing the Statistical Parametric Modelling (SPM) and Electroencephalography (EEG) applications was deployed and was successful during initial tests. These applications will soon be available for real users’ validation. As of now, we have received expressions of interest from neurologists, imaging experts and other professionals working with people with Alzheimer’s disease in 13 European countries: All these people are interested in becoming part of the user panels that will test each application with real patient cases. Once their feedback is collected, we’ll be able to launch the service at a wider level and define protocols and rules for the training and qualification of experts enabled to use the service for clinical diagnostic purposes.

AE: Patient information is generally held under legal and ethical obligations of confidentiality. How is the issue of patient privacy in relation to data handling addressed in this project?

FG: Only referent trained medical personnel responsible for a given patient will manage medical data. All patient data will be anonymised from the beginning, so that the patient’s personal information can never be associated with his or her diagnostic exams. The physician will be solely responsible to keep the connection between the two, thus protecting the patient’s privacy. Furthermore, all data movement, as well as temporary data storage, will be protected by using strong cryptographic techniques.

AE: The DECIDE project is due to end in 2012. Do you envisage the work being carried forward?

FG: The project will strive to ensure the actual usability and exploitability of the service in real-life clinical settings.

The implementation of the DECIDE infrastructure and service should be regarded not only as a step towards streamlining and enhancing confidence in early diagnosis of neurodegenerative pathologies, but as a concept that can be successfully extended to other pathologies and communities, not only in the field of neurology. For instance, it could be extended to disciplines like cardiology and traumatology, where imaging techniques are heavily used, bringing the relevant communities the benefit of automated quantitative image analysis using complex algorithms.

Moreover, DECIDE is keen and open to extending its infrastructure and to enriching its application portfolio by involving other research communities. This will help to build a wider network of scientists and potentially boost the pace of each research programme by allowing scientific cooperation as well as data and information exchange, with the eventual goal of shortening the time needed to enter the daily clinical practice.

People affected by Alzheimer’s disease will benefit from a more appropriate inclusion in clinical trials, or advanced research therapies, given the better accuracy in early diagnosis.
THE ETHICS OF DEMENTIA RESEARCH

This month, Alzheimer Europe published its report, “The Ethics of Dementia Research”. We take a look at some of the main elements of the report.

The report, “The Ethics of Dementia Research” provides a detailed discussion of some of the main ethical issues linked to carrying out dementia research in an ethical manner. Funded by the European Commission, it was developed within the context of the European Dementia Ethics Network (EDEN) and as part of Alzheimer Europe’s 2011 workplan.

This is a thought-provoking piece of work which clearly lays out and discusses the ethical considerations surrounding each topic. Recommendations are provided aimed at encouraging researchers to consider the ethical issues in dementia research.

The introduction to the report provides a brief overview of research, research methods and ethical models. It defines dementia research as “any kind of research aimed at increasing the understanding of the disease biology and of disease prevention or improving the treatment, care, well-being and quality of life of people with dementia either directly or indirectly.” The scope of the report covered “ethical concerns which apply to the whole research process from the initial choice of a research topic right up to the publication of results and the provision of feedback to participants.”

The main body of the report focuses on eight areas:

1. Involving people with dementia: People with dementia are sometimes considered as incapable of participating in dementia research and this is challenged in the report. Discussions include consideration of the barriers to involvement, the need for a wide cross section of people to be involved (older people, ethnic minorities, people dying with dementia and at all stages of dementia and carers), as well as confidentiality issues.

2. Informed consent: With respect to medical treatment in the EU, medical practitioners have a legal obligation to obtain consent before treating a patient. This obligation also extends to research and this section looks at how information is provided, capacity (to understand information, the assessment of capacity), the timing and form of consent, factors which may influence informed consent, factors which may change after consent is given and the involvement of third parties in the context of research.

3. Protecting the wellbeing of people involved in dementia research: The ethical issues highlighted are dignity (with discussions on the different types of dignity and why it is important to a person’s dignity not to be excluded), integrity, respect, personhood, confidentiality, privacy, vulnerability and considerations of transparency and official recognition of researchers as well as deception. The report states “It is hoped that by being aware of these issues the participation of people with dementia may be carried out without undue stress, exploitation or danger.”

4. Risk, benefit, burden and paternalism: Discussions of risk often include discussions on burden and benefit too. This section considers the balance of personal risk and benefit to society, how one makes sense of risk, the perspective of
risk and benefit at the end of life, proportionality and paternalism.

5. Medical research: Whilst the other sections of the report cover both medical and social sciences research, this section addresses additional issues related specifically to medical research. The ethical issues surrounding clinical trials, epidemiological research, genetic research and end-of-life care are all considered with recommendations being given at the end of each topic.

6. End-of-life care: People with dementia may require end-of-life care due to the complications of the disease itself, but end-of-life care may also be applicable to people with dementia who reach the end of life but die from some other identifiable condition or who have a mix of mental and physical problems. Research into end-of-life care is insufficient yet it is needed to increase access to palliative care for people with dementia and to improve the quality of the care provided. Potential conflict between various views and interests and the generalisations which can be made about the value or quality of life of people with dementia in the advanced stages of the disease are discussed.

7. The donation of brain and other tissue: The importance and concerns of brain donation are introduced and the ethical issues discussed are consent to donation, timing of consent and psychological and emotional wellbeing.

8. Publication and dissemination of research: It is important to disseminate the findings of studies to ensure wide access, avoid duplication, expand on knowledge but also to respect and acknowledge participants. At the same time, it is important that such publication and/or dissemination is not subject to a conflict of interest (whether financial, academic or professional). Other issues which arise are the question of integrity, the publication of negative or inconclusive findings and ghost authorship.

Also included in the Report is a comprehensive glossary as well examples of:

- A consent form
- A participant information sheet
- Issues that researchers and committees might consider.

Discussions which took place during the development of the report were thorough, lively and insightful and reflect the vast depth and spectrum of knowledge provided by the working group on the ethics of dementia. Chaired by Dianne Gove of Alzheimer Europe, participants of the group were experts in the fields of bioethics, the development of medicines, old age psychiatry, psychology, geriatrics, neurology, social studies and end-of-life care. In addition, invaluable contributions were given by a person with dementia, two carers and two representatives from national Alzheimer associations.

**Working group:** Dianne Gove, Information Officer of Alzheimer Europe is the Chair of the working group which consists of representatives from Austria – Dr Thomas Frühwald, Chief Doctor of the Department of Acute Geriatry of the Hietzing Hospital, Vienna; Belgium – Prof. Dr Lieve Van den Block, senior founding member of the end-of-life care Research Group of the Ghent University and Vrije Universiteit Brussel, and professor of communication and education in Family Medicine at the Vrije Universiteit Brussel; France – Dr Fabrice Gzil, Head of Social Studies Department, Fondation Médéric Alzheimer in Paris; Italy – Dr Carlo Petrini, Head of the Bioethics Unit of National Institute, Rome and Prof. Sandro Sorbi, Professor of Neurology, Department of Neurological Science and Psychiatry at the University of Florence; Lithuania – Dr Rasa Ruseckiene, Consultant in adult and old age psychiatry and therapist; Sweden – Dr Peter Annas, Senior Research Scientist, PhD. and AstraZeneca’s representative in the PharmaCog project; UK (England) – Angela Clayton-Turner, volunteer, carer, member of the Alzheimer’s Society and lay member of her local Research Ethics Committee and UK (Scotland) – James McKillop (MBE), who lives with dementia and is a founding member of the Scottish Working Group on Dementia, and his wife, Maureen McKillop, carer.
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**Alzheimer Europe (AE):** Commissioner Kroes, the ageing of the EU population and the competitive decline of Europe are among the challenges that call for urgent action. Age is a risk factor to develop dementia, a disease that often leads to complete dependency of the person affected by the disease. How can the European Innovation Partnership on Active and Healthy Ageing address these challenges and provide practical solutions for people with dementia?

**Commissioner Neelie Kroes (NK):** Let me first acknowledge the importance of dealing with dementia in the context of developing policies for active and healthy ageing. The Innovation Partnership is likely to include actions that are specifically focused on Alzheimer's disease, but its scope is wider than that. The Steering group of the European Innovation Partnership (EIP) agreed on a set of five specific actions within three main areas: prevention, care and cure and independent living. Five actions are ready to be launched in 2012:

1) adherence programmes for various chronic diseases to support patients’ compliance to medical advice and treatment regimens through innovative tools;

2) innovative solutions to prevent falls and support early diagnosis for older people;

3) cooperation to help prevent functional decline and frailty (with a particular focus on malnutrition);

4) spread and promote successful innovative integrated care models for chronic diseases amongst older patients (such as through remote monitoring) and

5) improving the uptake of interoperable ICT independent living solutions through global standards to help older people stay independent, mobile and active for longer. Moreover, among some horizontal actions starting in 2012, networking and knowledge sharing on innovation for age-friendly buildings, cities and environments will be pursued.

We believe there is great potential in what this Partnership can achieve, precisely because it is a partnership. European institutions, national governments and a wide range of stakeholders in the innovation chain, including Alzheimer Europe, are actively involved with their suggestions, ideas and views, in an effort that concerns us all.

The work that we are all committed to do from now on is about translating this new common strategy into the concrete actions I mentioned earlier.
We must be able to support the different stages from long-term research to innovation in a coherent and consistent manner.

Even though it is not yet possible to provide a cure for this cognitive disease, innovation can lead to more effective prevention and allow earlier diagnosis. This means, for example, increasing the health literacy of the elderly, making them fully aware of the importance of preventive health measures, and promoting a healthy lifestyle, also through innovative ICT-enabled personal guidance systems and services. It also implies detecting the disease earlier, for example through unobtrusive long-term observation of changes in behavioural patterns, and starting immediate remedial actions.

At a later stage, when unfortunately the illness has already manifested itself, the quality of life of older people suffering from dementia and their carers can benefit from innovative solutions that prolong the patients’ active and independent living. ICT solutions for telemonitoring, telecare and social interaction enable the elderly to remain active and safe at home and to participate in the social life of their communities. This can significantly reduce the rate of unnecessary hospitalisation or institutionalisation. For example GPS tracking, activity reminders and remote safety monitoring, such as automatically turning off ovens and cookers, allow people with milder forms of dementia to stay at home rather than going into institutional settings. This increases quality of life for the older person, saves public resources and also improves the working conditions and quality of life of their carers.

AE: Informal carers of people with dementia play an important role in society. How can the partnership support these carers and how do the Commission’s different Directorates General (DGs) work together to provide innovative solutions for informal carers?

NK: We want to promote a patient-centred approach in healthcare; therefore strong communication and coordination among all the different actors involved in the care process, both for providers and users, are essential. This approach is based on integration between primary and secondary care and between health, social and community care, with a special focus on patient empowerment.

Among the players in the care process, informal carers make an extraordinary contribution to the system, especially in the context of dementia and other chronic diseases. Informal carers also sustain a major share of the costs associated with the care of Alzheimer and other dementia diseases: 56% of the annual direct and indirect costs are borne by them.

Given the key role informal carers play, their views and expertise are essential to define the organisation and implement integrated care systems. The Partnership will make sure they can benefit from the different existing innovative solutions. For example, a husband or a spouse may get more personal freedom if their partner can be left at home with safety support, activity reminders, movement tracking and alarm systems. Relatives can also provide care from a distance by getting information about alarms, updating calendars and activities and communicating through simple video conferencing (e.g. TV based). We intend to provide them with adequate education and training programmes to raise awareness of the advantages of these solutions and help them develop the skills for an effective use. Informal carers, being so close to the everyday management of dementia patients, are also in the best position to assist in the development and validation of innovative solutions.
In line with the logic of the Partnership that involves a large variety of parties with different expertise, the European Commission does exactly the same in-house with close cooperation between DG Information Society and Media, DG Health and Consumers and DG Research and Innovation. Pooling competences in the relevant policy areas also ensures that horizontal issues, such as regulatory harmonisation and funding, are addressed by leveraging on a wide range of instruments. We are also working with DG Education and Culture and DG Employment and Social Affairs on ICT skills for informal carers to help improve the capabilities of carers to be able to benefit from innovative solutions. We have funded large-scale pilot projects validating the impact from innovative ICT solutions for the independent living of people with cognitive impairments, involving more than 12 regions, and we are in dialogue with DG Regional Policy to investigate the possible use of structural funds to promote the wider uptake of proven solutions.

**AE:** What mechanisms will be put in place to enable people with dementia to benefit from new and proven technology and live independently, as long as possible in a familiar environment, without creating further inequalities and disparities among and within countries?

**NK:** ICT solutions play a major role in supporting active and independent living of people with dementia and they can help in overcoming geographical barriers. For example, telecare and telemedicine solutions ensure that the elderly receive adequate treatment and medical advice, regardless of their location.

Older people can also benefit from tools and applications which stimulate their mental and physical functions, such as brain training and serious games, or enhance the assistance in their own environment (e.g. via reminders and safety monitoring), thus making them more independent.

Given the capacity of ICT solutions to increase efficiency of care, this will allow policy makers to offer more care with less resources, benefiting all regions of Europe. But I am very aware of the different social realities across Europe and part of innovation is also how to provide cost-effective ICT solutions which can also be used in remote or less developed regions. Here the Ambient Assisted Living Joint Research and Innovation Programme, funded jointly by 23 European Countries and the EU, can play a specific role in providing solutions which can be used all over Europe.

**AE:** What mechanisms will be put in place to motivate Member States to invest in research in new technologies and ICT devices?

**NK:** The Active and Healthy Ageing Innovation Partnership is not a new funding instrument. It will lever on existing or forthcoming European financial instruments: Health for Growth, Seventh Framework programme (FP7), Competitiveness and Innovation Framework Programme (CIP), European Structural Funds, and, after 2014, Horizon 2020 and the Connecting Europe Facility. These will have to be combined with resources mobilised by the actors interested in bringing forward some or all of the actions.

The scale of the challenges addressed for the current and next generations of Europeans means that authorities should consider the priorities identified by the Partnership when allocating funds for research, innovation and deployment.
The Partnership thus invites the Member States, together with the European Institutions, to facilitate the access of implementing bodies (including regions) to funding instruments and to seek synergies across different funding options, stimulate the use of innovative procurement (including pre-commercial procurement), develop incentive mechanisms at appropriate levels (public, private, third party payers, etc.) and explore venture capital support.

AE: How will DG Digital Agenda engage in supporting Member States, professionals and end-users in effectively benefitting from new ICT developments?

NK: There are several critical elements to reach this goal which are all an integral part of the Digital Agenda.

First we need to ensure that ICT solutions are developed in response to user needs. This is why user-driven research and innovation is a firm principle in our funding schemes.

Secondly, we must be able to support the different stages from long-term research to innovation in a coherent and consistent manner. We need to ensure that successful results of research and innovation will be put at the disposal of users in the forms of products and services available on the market. This is why we have established funding sources to support the whole innovation process, including the Seventh Framework programme (FP7) for longer term research, Ambient Assisted Living Joint Programme for translating research results into solutions and the Competitiveness and Innovation Programme to provide the evidence of socio-economic impact and the required enabling boundary conditions for take-up.

Thirdly, we must ensure that there is a favourable environment for bringing proven solutions into the real world. Here we have developed eHealth and ICT for Ageing Well action plans to look at regulatory and legal barriers, standardisation and developing new policies building on the capacity of ICT solutions, in cooperation with Member States and other stakeholders. In addition, we also have other actions to improve digital literacy and skills for all Europeans and to promote the availability of broadband as enabling conditions.

Finally the European Innovation Partnership on Active and Healthy Ageing aims to provide a strong common political vision of where and how to accelerate and scale up innovation across Europe, setting priorities, mobilise resources and working to remove barriers in cooperation with Member States and other stakeholders.

This is a very comprehensive agenda, which is now starting to show real results and mobilisation of resources towards the triple goal of improved quality of life for elderly people and their carers, sustainable care systems and the creation of new opportunities for jobs and growth.

AE: Commissioner, thank you for this interview. We look forward to future collaboration with you on this important topic.
EU PRESIDENCY: DENMARK

Astrid Krag, the Danish Minister for Health speaks about the health agenda for the EU Presidency, which is held by Denmark until the end of June 2012.

The main challenge of Europe is to adapt to an ageing population while keeping health care budgets under control.

Denmark has the Presidency of the Council of the EU from 1 January to 30 June 2012. We aim to target some of the major health challenges in Europe such as ageing, antimicrobial resistance and chronic diseases which affect millions of Europeans’ lives every day. These challenges not only constitute a problem for the individual, they are also driving our health care expenditures in Europe dangerously close to their limits.

During the Danish Presidency we want to turn the tables and start talking about opportunities instead of challenges. We want to create smart health and better lives for the individual European and for European growth in general. We want the European approach to be broad; we must address both the framework for innovation in the European industries and within the European health care sectors – private, public and in cooperation.

- Better treatment and care for patients
- Better working conditions for the employees in the health and welfare sectors
- Better use of resources and thereby the fiscal sustainability of the European healthcare and welfare sectors
- Growth and export of both products and systems.

Therefore Denmark will promote the strengthening of innovation within the welfare and healthcare technologies in Europe during its Presidency. We call this innovation agenda “Smart Health – Better Lives”.

Good examples of relevant European subjects on the matter are the cooperation on eHealth, health technology assessments and public-private partnerships.

Also, we must address the use of innovative technology in the health sector because new technology which is truly smart can not only improve patient care but also the working conditions for health care professionals and create sustainability and improved growth in the EU.

Prudent use of antimicrobials

All over the world resistance towards lifesaving antimicrobials is emerging. The increasing development of antimicrobial resistance (AMR) is a global threat to human and animal health. In the EU more
than 25,000 people die each year from infections caused by antibiotic-resistant bacteria.

The costs are considerable, not only in regards to human life, but also socioeconomically because of prolonged illnesses and increased hospitalisation rates, which in turn increase health care costs and reduce productivity.

The misuse, and especially overuse, of antibiotics have resulted in the development of AMR.

Because the rising level of resistance is caused by an increased use of antibiotics in humans and animals, we see a great opportunity to promote prudent use of antibiotics during our Presidency of the Council of the EU.

Among others, the Danish Presidency of the Council will work for an improved data collection and surveillance of antibiotic use and resistance for both animals and humans throughout the EU.

Also we aim to work for a reduction of the use of critically important antibiotics in humans and animals.

**Active and Healthy Ageing**

The Commission has designated 2012 as the year for “Active and Healthy Ageing and Solidarity between Generations” which includes aiming at an increase in life expectancy by two years by 2020. However, one of the consequences of a steadily ageing population is that European citizens live longer with one or more chronic diseases. Alzheimer’s disease is one of these important chronic diseases which we must be better at tackling.

During the Danish Presidency, we plan to focus on patient empowerment. Principles and actions to support the self-management capacity of the patient are important. The aim is to give people with chronic diseases the ability to live an active, independent and healthy life so they can actively take part in the surveillance and treatment of their disease.

The Danish national strategy for the control of chronic conditions has moved from a disease specific approach to a broad, generic strategy addressing the full group of chronic conditions. In my view, this should also be our approach at European level.

In this regard, important lessons have been learned from the example of diabetes and our experiences from the field of diabetes can be used in the fight against other chronic conditions.

In our view, the European reflection process is a good framework that can help bringing the work forward in a comprehensive and systematic way.

Denmark will work hard to reach solutions that can prepare all Europeans to handle future challenges of an ageing population and increasing health care expenditures. This is not the time to do business as usual but is the time to act so we can all be well prepared to deal with future challenges – and create new opportunities.

Alzheimer’s disease is one of these important chronic diseases which we must be better at tackling.
In April 2010, Alzheimer Europe talked about the aims of the Joint Programming Initiative on Neurodegenerative Diseases (JPND) with the Initiative's Chairperson, Professor Philippe Amouyel. In this issue, we catch up with Enda Connolly, Member of the JPND Executive Board and Chief Executive of the Irish Health Research Board to find out about the progress achieved.

Alzheimer Europe (AE): Mr Connolly, What are the major achievements of the JPND to date?

JPND has recently passed three major milestones on its journey towards effectively tackling the enormous challenges posed by neurodegenerative diseases. Firstly, a mapping exercise of the various national and European research activities in this field has been completed and is available as a searchable database on the JPND website (www.jpnd.eu). Secondly, we launched our European Research Strategy on February 7th, 2012, an initiative that will guide research activity and investments in the field of neurodegenerative diseases over the coming decades in Europe. Thirdly, JPND has proven that the concept of joint programming works. Funding calls for Centres of Excellence in Neurodegeneration (COEN) and harmonisation of the use of biomarkers have been initiated under the umbrella of JPND and transnational, collaborative projects to address these areas of need have already begun.

AE: What were the key findings of the mapping exercise and how does funding of dementia research compare to research in other disease areas, such as cancer?

Throughout 2011, JPND conducted a comprehensive mapping exercise of the National and European research landscape relevant to neurodegenerative diseases to give an objective view of the level and strength of research activity across Europe and to identify both gaps that can be addressed and opportunities for improved coordination and alignment, both at Europe-wide and national levels. The baseline information collected is now available to the wider community on the JPND website (www.neurodegenerationresearch.eu) with the aim that it will aid connectivity between research groups both within and beyond Europe and promote better use of resources and infrastructure.

The data was collected on national and Europe-wide programmes and initiatives, infrastructure such as research networks and population cohorts, and bioresources such as DNA collections, tissue banks, and animal models. This asset map will also assist decision making for the implementation of the JPND European research strategy and it is planned that this information will be suitably updated as the initiative progresses to ensure the information is current and to help monitor the impact of JPND.

A snapshot of research programmes or grants1 "live" as of 1st January 2011 positively identified nearly EUR 1,620 million of investment in research directly relevant to neurodegenerative diseases, with the majority of this investment (82%) in major programmes or grants.2 A breakdown of the total
and per year costs captured during the mapping exercise is presented in Table 1.

As might be expected in an area with so few available treatments, only 11.3% of research (12.8% annualised) is carried out in patients or a patient population (i.e. clinical research, as strictly defined here). While figures for investment by the industry sector are not available, commercial investment in research and development is critical for the development of drug or biologic-based therapies, diagnostics and devices, and assisted living technologies for neurodegenerative diseases. However, it is a concern that in recent years a number of major companies within the biopharmaceutical sector have either withdrawn or reduced their activity in neurodegeneration research due to the pressure of the economic downturn, coupled with a perceived lack of tractability of the research questions and a relatively high number of failures of new drugs during early stage clinical trials.

The mapping exercise has captured some of the key research infrastructures and technologies available in the academic sector in many European countries, which collectively provide a solid foundation for future research into neurodegenerative diseases. However, it is also apparent that numerous gaps are present compared to what is ideally needed, and that problems exist relating to resource quality and access which are currently limiting what can be achieved both individually and collectively.

Unfortunately, this exercise has not allowed us to make a direct assessment of how Europe-wide funding of research into neurodegenerative disease compares to that in other age-linked diseases such as cancer and cardiovascular disease. However, it is clear from other analyses that neurodegenerative and other brain diseases have not received the same level of support compared to the large investments in research made in these other areas. For example, while brain disorders collectively constitute around 35% of the total (direct) cost burden of all diseases in Europe, a far smaller proportion of the healthcare (~15%) and research budgets are allocated to this area. A 2010 report in the United Kingdom demonstrated that dementia costs the UK economy GBP 23 billion per year – more than cancer and heart disease combined. Despite this, UK government and charitable spending on dementia research is 12 times lower than on cancer research and 4 times lower than on heart disease research.

AE: JPND recently launched its European Research strategy. How was this strategy developed, and what are the key recommendations?

The development of a European research strategy has been central to the JPND initiative, in order to establish a platform for future EU-wide activity and a reference point for developing national and organisational strategic plans. The JPND Research Strategy provides a framework for future investment and addresses how the European research effort can most effectively be harnessed to improve prevention, diagnosis, treatment and patient care for these debilitating conditions. It has been delivered by the JPND Management Board (MB) based upon the recommendations and advice of the Scientific Advisory Board (SAB). The strategy was developed in an iterative manner reflecting the scientific recommendations identified by the SAB and, wherever possible, stakeholder priorities. In depth analysis was provided through a series of workshops involving the SAB and additional academic experts, and consideration of stakeholder priorities was obtained through a mixture of meetings and individual contacts with key groups including industry, organisations representing
people with neurodegenerative diseases and their carers, healthcare and social service professionals, healthcare providers and policy makers. This process provided a holistic view of the research landscape and a roadmap for future research activity, with key recommendations validated via a public consultation exercise, prior to consideration of feasibility and prioritisation by the SAB and MB.

A number of scientific priorities for future research have been identified in the JPND Research Strategy, as well as appropriate enabling activities to progress these scientific priorities. The scientific priorities have been broken down into five key thematic areas, which reflect the basic, clinical and healthcare/social research needs specific to neurodegenerative diseases.

1. **The origins of neurodegenerative diseases:** For example, investigating the causes of specific neurodegenerative diseases, the factors that determine people’s risk and resilience, and the triggering events leading to illness.

2. **Disease mechanisms and models:** We need a more complete understanding of the underlying disease mechanisms to drive the development of new diagnostic and therapeutic approaches.

3. **Disease definitions and diagnosis:** Currently standard clinical assessments fail to capture the presumed complexity of common neurodegenerative diseases, so one priority is to refine and update current diagnostic criteria.

4. **Treatments and prevention:** One area of focus will be procedures to improve the selection (or stratification) of subjects entering clinical trials, in order to give a greater chance of clinical efficacy for new treatments.

5. **Healthcare and social care:**

   One current gap is inefficient coordination between health and social care systems in individual countries, so one early task might be an evaluation of the equity of access to, and the effectiveness and cost-effectiveness of, pathways to diagnosis, treatment, care and support for neurodegenerative diseases across Europe.

Coupled to these scientific themes, the strategy identifies a number of cross-cutting enabling activities where activity is required, such as working in partnership with industry; building research capacity; providing supportive infrastructure and technology platforms; international partnership beyond Europe, as well as education and training.

The strategy was launched in Brussels on February 7th, 2012 and copies are available through the JPND website. The next stage, currently being planned, will see JPND develop a programme of research through large-scale initiatives that will deliver this European Research Strategy within the next ten years. JPND is already looking at how research funding agencies can support the priorities identified in the strategy, and is exploring ways to engage both national and international stakeholders in its implementation.

AE: When developing the strategic agenda, you carried out consultations with a wide group of stakeholders. How do you see the continued involvement of patient and carer organisations such as Alzheimer Europe in future JPND activities?

We certainly wish to continue and expand on the pre-existing direct engagement of JPND stakeholder communities – we see it as being essential to our overall success! Our patient stakeholder consultation in May of last year was a perfect example of how patient and carer priorities were...
Polish conference stresses the importance of solidarity with people with dementia

Highlights from the 21st Alzheimer Europe conference where more than 470 delegates from nearly 40 countries came together in Warsaw, Poland.

People with dementia speak out

Alzheimer Europe reports on the keynote speeches given by Archie Latta, Helga Rohra and Marek Romecki during the plenary session “The Value of Diagnosis”.

Feedback on the conference by people with dementia

People with dementia share their thoughts on the conference and Archie Latta reports back to the Scottish Dementia Working Group on his trip to Warsaw.

Climbing Seven Summits for Alzheimer’s disease

Mountaineer and carer Alan Arnette discusses his motivation for and success of his campaign to raise awareness and funds for the disease.
POLISH CONFERENCE STRESSES THE IMPORTANCE OF SOLIDARITY WITH PEOPLE WITH DEMENTIA

More than 470 delegates from nearly 40 countries came together in Warsaw, Poland, to participate in Alzheimer Europe’s 21st Annual Conference. This article reports on some of the conference highlights.

It was under the patronage of Mr Bronislaw Komorowski, the President of Poland and of the European Parliament that Alzheimer Europe’s 21st Conference, entitled “European Solidarity without Borders” took place in Warsaw from 6-8 October 2011. Participants represented a wide spectrum of backgrounds within the field of dementia (including people with dementia, their carers, and representatives of national Alzheimer associations, healthcare professionals, academics and researchers, as well as policy makers). The conference programme focused on how societies can show greater solidarity towards people with dementia and their carers. It also illustrated how Alzheimer organisations in all European countries have campaigned for greater inclusion and participation of people with dementia.

Alicja Sadowska, Chairperson of the Polish Alzheimer Association, opened the conference with a reminder of the very special relationship which exists between the term solidarity and Central and Eastern Europe. Delighted that so many people were supporting the conference, Ms Sadowska said that this would enable people with dementia to feel how solidarity can support them in their lives. The Chairperson of Alzheimer Europe, Heike von Lützau-Hohlbein, also spoke of the power that solidarity can have and illustrated significant achievements made within Europe in the last five years, giving examples of work being carried out collaboratively at European and national level. Speaking about the future she said, “I am convinced that in our society in 5 to 10 years’ time we can make significant progress towards addressing the needs of people with dementia and their carers.”

Sube Banerjee, Professor of Mental Health at King’s College, London, explained that Alzheimer’s disease is a great challenge for all societies. He said that even though our understanding has increased, it is also the case that two-thirds of people with dementia never receive a diagnosis. He illustrated how various sections of society can provide necessary information and support, identifying the help required by medical staff, health care professionals, society and at policy makers at national and EU level. In Poland, Mr Szczudlik stressed the importance of having a national dementia plan in place if people with dementia and their carers’ needs were to be addressed.

Much work is being done by researchers to target dementia before symptoms are apparent. Alexander Kurz from the Technische Universität München, Germany, explained that Alzheimer’s disease is a cascade of pathological events which gradually destroy large parts of the brain with the process...
taking some 30 years. However, even though these changes occur, it is not until the disease reaches the 21 to 25 year mark that people are no longer able to continue with activities of daily living. It is only at this stage that the term “dementia” is used and a diagnosis made. Currently, treatments are limited towards the end stage which is very late in the disease process. However, Prof. Kurz said that treatments are being developed which target upstream events in the pathological cascade. The protein amyloid beta (Aβ) has long been associated with Alzheimer’s disease and many of the treatments try to target it (for example, some new drugs enhance Aβ clearance, some try to block entry of Aβ into the brain, some try to prevent the aggregation of Aβ and some try to prevent the aggregation of tau.) There are also some treatments which aim to stop dementia from developing at all. Prof. Kurz concluded by saying, “I think that never before has so much money gone into the development of drugs and there are a number of promising candidates”.

It was the pre-clinical stage of dementia which Maria Barcikowska, Professor of Neurology at the Mossakowski Medical Research Centre, Poland, spoke of. Working for one of the few centres in Poland which carries out genetic tests for Alzheimer’s disease, Prof. Barcikowska believes that people need to know the truth about dementia even in the pre-clinical stage as it can help families to be aware and have more understanding of certain behaviour as well as enable them to prepare for the fact their life will become focused on caring. Prof. Barcikowska noted the important role of genetic counselling in this process. In families that are at risk of dementia she highlighted the particularly important role that prevention may have. People can be active in preventative measures and Prof. Barcikowska highlighted ways in which to keep cognitive reserve and connections functioning such as continuing education, being physically active, keeping a rich social life and controlling blood pressure.

“Psychosocial interventions”, said Prof. Myrra Vernooij-Dassen, Principal Investigator at the Nijmegen Centre for Evidence Based Practice, “are considered as effective, if not more effective, than pharmacological with the most effective being occupational therapy.” She explained that the intervention should “fit like a shoe”, enabling people to participate fully and make choices. Prof. Vernooij-Dassen said that when people get something it is a basic response to want to give something in return and she illustrated her point beautifully by sharing a video in which a person with dementia was caring for his partner. Psychosocial interventions can, she said, contribute to a better health status and reduction of costs in dementia care which in turn leads to a sustainability of quality care and health status. Prof. Vernooij-Dassen concluded by quoting a Chinese proverb, “We cannot prevent that birds of sorrow fly over, but we can prevent that they build nests in our hair.”

A particular highlight of the conference was the plenary session, “The Value of Diagnosis” in which three people who live with dementia (Archie Latta, Helga Rohra and Marek Romecki) spoke movingly about their own experience of diagnosis. Each told a different story, but all gave valuable insight into the effect of being given a diagnosis of dementia. An article has been dedicated to their presentations in this magazine (see p. VI).

In the same plenary, a medical perspective of diagnosis was given by Prof. Tadeusz Parnowski, Head of the 2nd Psychiatric Department at the Institute of Psychiatry and Neurology, Warsaw, who suggested that fundamentally we are getting better at diagnosing Alzheimer’s disease and other dementias. However, he also acknowledged that there still exists an inadequate basic knowledge of the importance of early diagnosis among GPs and other specialists as well as a lack of epidemiological data and social awareness. He emphasised the special and important relationship between the carer, patient and doctor, saying that, in addition to helping the patient, the doctor should also act as a supporter of, and to the carer.

Jean Georges, Executive Director of Alzheimer Europe, also focused on diagnosis when he presented the results of the “Value of Knowing” survey which Alzheimer Europe developed with the Harvard School of Public Health and carried out in France, Germany, Poland, Spain, and the USA. Mr Georges said that the survey indicated that people generally do have a good indication of what Alzheimer’s disease is and that the work of Alzheimer organisa-
tions has clearly paid off, even though some of the messages may need fine tuning. In particular he said that more work needs to be done on dismantling the barriers to diagnosis.

The final plenary was dedicated to policy. Ireland expects to have a national dementia strategy in place by 2013. Giving people with dementia a voice, early diagnosis, responding to what people with dementia need and the provision of services in an equitable way are all key elements highlighted by Maurice O’Connell, Chief Executive of the Alzheimer Society of Ireland.

The National Scottish Dementia Strategy was launched in 2010 and Geoff Huggins, Deputy Director for Health and Social Care Integration at the Scottish Government, emphasised just how much ground work had been done prior to the Strategy itself. Once the decision was taken to develop the Strategy, the element of trust and engagement was added by ensuring the development was done in a collaborative and inclusive way. However, he said, the strategy itself is not enough as you also need hands-on process management, improvement measures and the development of momentum. A particular objective was that continuity be achieved and that everyone would remain in post, including those at ministerial level.

In France, continuity has been a problem, said Florence Lustman, who is charged with overseeing the implementation of the French Alzheimer Plan. However, unlike other European countries there is continuity at the very top, in the form of the French President. Reflecting on the last three years Ms Lustman said, “The lessons I draw would be humility first and optimism second.” She reflected that since the Alzheimer Europe conference in Oslo (2008), when there was nearly no European involvement and no international involvement, it is clear that there has been real change. In France, after three and a half years most of the objectives of the national plan have been reached and France is now amongst the leading countries in the research of dementia.

“A dementia is not the problem, good quality dementia care is the solution.”

Sube Banerjee

Antoni Montserrat Moliner, Policy Officer at the Directorate of Public Health in the European Commission, also remarked that the change since 2007 has been significant. He said: “If I reflect, in 2007 the European Union was a desert in the field of Alzheimer’s disease and today I can say that some really concrete things have been done”. In 2008 an opportunity arose as the European Presidency (held by France) was extremely engaged and this, said Mr Montserrat Moliner, resulted in action being taken. Today there are 19 Member States working together under the ALCOVE project, 21 countries collaborating in the Joint Programming, the European Commission has been able to launch the PharmaCog project and soon 200,000 Europeans will take part in the European health examination survey which will provide better data.

In addition to the above plenary speakers, over 90 different presentations were offered during parallel session on topics including psychosocial interventions, residential and community care, policy initiatives, family carers, behavioural and psychological symptoms in dementia, the support of people with dementia and their carers, awareness campaigns and lobbying, the prevention of isolation and loneliness, effective communication, care evaluation, dementia strategies, end-of-life care, diagnosis and assessment, sexuality and relationships and legal systems and regulations.

A further four special symposia covered the following areas: (1) primary care and the management of dementia, (2) biomarkers for the diagnosis of Alzheimer’s disease, (3) a year-long campaign to raise awareness of Alzheimer’s disease and (4) research advances from the IMI PharmaCog project.

Alicja Sadowska thanked everyone for their participation and support through the conference. Heike von Lützau-Hohlbein closed the conference with the news that because of the economic crisis, some services for people with dementia in Greece are to close. She said “We must call on our politicians to protect these people because they are the ones who really need our solidarity.”
A snapshot of Alzheimer Europe’s 21st Annual Conference in Poland
PEOPLE WITH DEMENTIA SPEAK OUT

Alzheimer Europe reports on the plenary session, “The Value of Diagnosis” which was a highlight for many participants, with key note speeches by Archie Latta, Helga Rohra and Marek Romecki, all of whom live with dementia.

Archie Latta lives in Glasgow, Scotland and was given a diagnosis of Korsakoff’s syndrome around ten years ago.

Archie was an auto electrician who worked for more than 20 years in his father’s haulage business, both as a mechanic and heavy goods vehicle driver and latterly worked for Glasgow City Council. Around ten years ago, he found that he was unable to remember things such as where he parked the car when shopping, or he would take a vehicle to the wrong place for repair. He didn’t know what was going on but he knew “something was happening and did not like it.” The impact of receiving a diagnosis was, he said, huge. He had to give up his job and his class 1 heavy goods vehicle licence was taken away. Archie explained that he felt empty, alone and angry. He believed that had his doctor understood more about alcoholism that he could have helped more. However, on the positive side, Archie said that his attitude has changed and that he has become more responsible. He didn’t believe that he could live alone, but has found that he can. Whilst he plans for tomorrow, he said he lives for today. Archie summed up his new perspective on life leaving delegates with the reflection that, “the past is history, tomorrow a mystery and today is a gift.”

Helga Rohra was born in Romania and lives in Germany. Until 2006 she worked as an interpreter and speaks English, French, German, Hungarian, Romanian and Latin. Since receiving a diagnosis of dementia she has been an active advocate for the rights of people with dementia.

Helga explained that the first symptoms for her were that she began to forget vocabulary in other languages and also that she got lost and couldn’t find her apartment. When she initially went to her doctor, he told her that she had “burnout”. Six months passed but she did not improve, so she kept a diary of those things she could not do and how she felt. For example, money and time were problems for her. Helga also explained that she began to have hallucinations in which she could see herself in five or six films running around which made her feel frightened. Still the doctor told her to take more time. Depression then descended and Helga remembers that when Christmas arrived it was the hardest time in her life. She began to think she had a tumour. It never occurred to her that she might have

“The past is history, tomorrow a mystery and today is a gift.”
Archie Latta

“It is not the end but the beginning of a new life.”
Helga Rohra
dementia. She spoke with her son and together they went to a memory clinic where she was asked if she would like a diagnosis. Helga agreed as she said “I wanted to change my life accordingly. He gave me a diagnosis, from that moment my life changed.” As well as discussing medication with Helga, the doctor told her to go to the Alzheimer association and gave her a leaflet. Helga has become an advocate for people with dementia and she passionately believes that people with dementia have the right to the best treatment available. Helga also said that people with dementia have many resources and that we should all give a helping hand to ensure that people with dementia are integrated and involved. She concluded by saying that her message is that “it is not the end but the beginning of a new life.”

Marek Romecki is from Poland. He describes himself with these words “I do not work because some years ago I was diagnosed with Alzheimer’s disease. I am a pensioner and live in Bydgoszcz with my wife Janina. I have two sons, Carol and Kamil, and two grand-daughters, Mia and Nadia. I like jazz music, sport and painting. I like to draw too. I have a turtle. I like to participate in therapeutic sessions.”

The chairperson of the plenary session, Miroslawa Wojciechowska, thanked Marek for attending the conference and explained that he was the first Polish person with dementia to attend a national conference in Poland and speak about living with dementia. Marek explained that he wanted to participate in order to share the problems and experiences he has had with other people who live with dementia. He felt that it is most important to be healthy and happy and he said he gets pleasure from his family and friends visiting him. Marek said that in Poland there is a need for greater access to treatment and good medication. He explained that some of the medicines are costly and inaccessible. He asked that the state reimburse medication. Treatment, he said, would enable people with dementia to be more active and to meet other people, which would help to limit the progression of the disease. He also highlighted the problem of very long waiting lists in Poland and called for better access to specialist doctors in Poland. In order for people with dementia and carers to be able to help each other, Marek said that it was of the utmost importance to belong to associations.

How people with dementia work alongside Alzheimer Europe

The presentations made by Archie, Helga and Marek at the 2011 Alzheimer Europe conference form part of a larger aim of Alzheimer Europe to involve people with dementia in the work it carries out. Alzheimer Europe has long been committed to this aim: people with dementia have participated in Alzheimer Europe projects since the organisation began its work in 1996. Each annual Alzheimer Europe conference provides a platform for people with dementia to share their experiences and be heard. Since the launch of the Dementia in Europe magazine in 2008, articles by people with dementia and their carers have featured in nearly every issue and have also been included in the newsletter. To facilitate people with dementia attending Alzheimer Europe conferences, a bursary system was set up in 2009 which provides free registration for a number of people with dementia each year. In addition, Alzheimer Europe covers their travel and hotel costs. At the 2011 Annual General Meeting, the members of Alzheimer Europe took two additional significant decisions to promote the involvement of people with dementia: firstly, the organisation decided that a new European Working Group for people with dementia will be set up in 2012 in order to provide a forum for people with dementia to advise Alzheimer Europe. Secondly, the Chairperson of this working group will also be a member of the Alzheimer Europe Board with full voting rights. With these decisions, the organisation has taken an important step towards achieving its aim of involving people with dementia in its governance, leading Helga Rohra to call this an “historic moment.”
Feedback from people with dementia

“The event met and exceeded all our expectations. I found myself rushing from one presentation to another not wanting to miss anything. Without exception the presenters were excellent. I was delighted that you were able to give so much time to fellow people with dementia, all of whom did an excellent job in promoting our collective interests. Your [Alzheimer Europe's] proposal to set up a working group of people with dementia and to have the chair of that body automatically appointed to the AE Board, to me, is the dream of the last ten years come true.”

Peter Ashley  (UK)

“Many topics were interesting. I myself liked best Alan Arnette’s presentation and slides about climbing the summits of the highest mountains and fighting against the prejudice of dementia. He reached millions of people with his message! The scenery was not only marvellous but also showed the infinity of life despite living with diagnosis. Simply beautiful! I wish some of us affected could join him to take out the message.”

Helga Rohra (Germany)

“It was useful for me. I heard interesting things from specialists and from patients too. One professor helped me to understand why it seems to me that Gingko does not help me like before. And it was interesting to speak with Archie Latta about his work with the Alzheimer organisation in Scotland. It was so exciting for me!”

Nina Baláčková  (Czech Republic)

“I came to Warsaw hoping and believing that perhaps a new drug had been invented to cure people like myself. But now I know there is no such drug. I also know it is a disease of the 21st century. I met a lot of other people with Alzheimer’s disease from all over Europe. And the lectures and talks were interesting although I cannot remember much now. They were much more useful to my wife so she was making notes.”

Jozef Podkowka (Poland)
First I would like to thank the group, for giving me the opportunity to go to Warsaw on your behalf to represent SDWG. I would also like to thank Jenny Douglas, Caroline Crawford, Janette Killeen, John Laurie and a special thanks to Teresa Straczynska who is originally from Poland. She acted as an interpreter for all of us. Without her I believe we would not have enjoyed the trip to the extent that we all did.

I believe that this trip challenged me. Personally, because of all the travelling, I was worn out when we got there. I now understand that this is part of this illness. The conference itself was an amazing experience which I believe challenged me. I have never spoken publicly to that many people in my life. I kept it very simple and tried to follow instructions which for me can be very difficult. My head keeps telling me to get it over and done with very quickly. However I know my head tells me lies. So I just took my time, and I believe it came off better than I expected. I thank Jenny for putting pauses in my script which also helped me to slow down.

I would also like to thank Teresa for taking us to a Polish restaurant which was very opulent and grand. I understand that it was one of the places that was not damaged in the war as the German officers used it as one of their headquarters.

I also found the conference itself an amazing experience. You are speaking to people who have the same illness. I believe that only someone who has this illness can fully understand the way that this illness affects you. I believe that is what inspires you to go on and not to give up as you are no longer alone.

On the lighter side I was still trying to do my John Travolta on the dance floor at the restaurant we were in, the music was inspiring me to go back to my youth and reminded me of when I used to go down to the Bobby Jones in Ayr. However I realise that was nearly 42 years ago and I was wondering why I was worn out after my boogieing. I now realise what people mean when they say that old age does not come alone.

So in closing I would recommend that if anyone of you has the opportunity to go to one of these conferences to grab it with both hands as I will again if the opportunity arises.

Thank you for listening.
CLIMBING SEVEN SUMMITS FOR ALZHEIMER’S DISEASE

At the Alzheimer Europe Conference in Warsaw, mountaineer Alan Arnette presented his integrated campaign to raise awareness of Alzheimer’s disease by climbing the highest mountain on each continent. Alzheimer Europe catches up with him to discuss his motivation and the success of his campaign.

Alzheimer Europe (AE): Alan, climbing seven of the highest mountains in the world for Alzheimer’s disease requires some incredible commitment. What was your personal motivation for this impressive journey?

My mother, Ida Arnette, passed away from Alzheimer’s after an eight year struggle. As I watched her go through the stages of memory loss, inability to care for herself, losing her identity and finally her life; I knew I had to do something. As a caregiver, I was very unprepared for this disease and knew little about it. Had I known then what I know now, I might have made some different choices along the journey. What I did learn was that the global population needs more education on the disease, more awareness and we also need improved treatments and, obviously, need to find a cure through increased funding for research.

AE: Your presentation was about an integrated campaign to raise awareness of and funds for Alzheimer’s disease. Could you elaborate on this for us?

I have been climbing big mountains for over 15 years and have a loyal following on my personal website where I chronicle my adventures. As I considered how I could make a meaningful impact for Alzheimer’s, I believed combining a global awareness campaign with a huge climbing goal would be effective.

With the support of the Alzheimer’s Immunotherapy Program (AIP) of Janssen Alzheimer Immunotherapy and Pfizer Inc. who funded my climbs, we launched a campaign using traditional and social media to raise awareness about the growing Alzheimer’s epidemic and the burden it places on people with the disease, their family caregivers and society. My efforts also focused on raising funds for the Alzheimer’s community. The campaign launch involved interviews with television and radio stations, magazine articles and an aggressive mixture of Facebook, Twitter and dedicated websites. This was all anchored by my personal website where I posted frequent dispatches directly from each climb complete with pictures, videos and audio posting from the summits. Three non-profit organizations (Alzheimer’s Association, Cure Alzheimer’s Fund and National Family Caregivers Association) leveraged their own communications tools, including Twitter, Facebook, blogs, newsletters and e-blasts to generate awareness about the campaign among their members.

AE: Your aim was to climb the highest mountain on each of the seven continents, yet you climbed...
eight mountains. Please help us with the geography here. Which mountains were part of your programme and what were your results?

Climbing is a strange sport! Geographical continent definition is somewhat arbitrary so when the seven summits were first climbed in the 1980’s they included a small hill in Australia (Kosciuszko at 2229m) which was challenged and replaced by a much higher and difficult one in Papua (Carstensz Pyramid at 4884m). Today both are included and I choose to climb them both to ensure completeness. I made it to the summit of seven of the eight with Denali in Alaska escaping me due to extreme weather conditions.

AE: You dedicated each summit to a specific cause or aspect of the disease. What were the dedications?

This was a special part of each climb where I made the dedication as a voice dispatch placed to my blog using a satellite phone. They were:

Vinson: Early onset individuals
Aconcagua: Caregivers
Everest: Moms with Alzheimer’s
Denali: Alzheimer’s Researchers
Elbrus: 5 Key Points to share with 5 friends
(frequency, financial impact, caregiver impact, symptoms and lack of a cure)

Kilimanjaro: World Alzheimer’s Month
Carstensz Pyramid: Dads with Alzheimer’s
Kosciuszko: The hope, need and urgency for caregivers, individuals and a cure

“I never came close to giving up because we cannot give up on caregiver support or finding improved treatments and a cure; full stop.”

AE: We imagine that each summit represents a different set of challenges to mountaineers. What were the most difficult situations you faced and did you ever come close to giving up?

I never came close to giving up because we cannot give up on caregiver support or finding improved treatments and a cure; full stop. However, there were certainly challenges such as eight days trapped in a tent at 5200m on Denali waiting out weather; an immobilizing ankle sprain on the descent from Kilimanjaro; labor strikes in Papua preventing flights; and wondering sometimes if I was making a difference.

With each challenge came strong support through the integrated campaign’s followers (comments, emails, calls) that gave me further motivation and encouragement to keep going.

AE: Thanks for your inspiration, Alan.

Thank you and for all you are doing to make a difference in Europe.
OUR MEMBERS ARE HELPING PEOPLE WITH DEMENTIA AND THEIR CARERS IN 29 COUNTRIES

Alzheimer Europe Members

- Austria – Vienna: Alzheimer Angehörige
- Belgium – Brussels: Ligue Nationale Alzheimer
- Bulgaria – Sofia: Alzheimer Bulgaria
- Bulgaria – Varna: Alzheimer Bulgaria
- Croatia – Zagreb: Alzheimer’s Disease Societies Croatia
- Cyprus – Larnaca: Pancyprian Alzheimer Association
- United Kingdom – London: Alzheimer’s Society
- United Kingdom – Edinburgh: Alzheimer Scotland
- Turkey – Istanbul: Alzheimer Vakıf
- Switzerland – Yverdon-les-Bains: Association Alzheimer Suisse
- Sweden – Stockholm: Demensförbundet
- Sweden – Lund: Alzheimerföreningen i Sverige
- Spain – Madrid: Fundación Alzheimer España
- Spain – Pamplona: C.E.A.F.A.
- Slovakia – Bratislava: Slovak Alzheimer Society
- Slovenia – Šentjur: Association “Forget me not”
- Romania – Bucharest: Societatea Alzheimer
- Portugal – Lisbon: APADIA
- Poland – Warsaw: Polish Alzheimer’s Association
- Netherlands – Bunnik: Alzheimer Nederland
- Norway – Oslo: Nacionalforeningen Demensforbundet
- Malta – Msida: Malta Dementia Society
- Cyprus – Larnaca: Pancyprian Alzheimer Association
- Czech Republic – Prague: Czech Alzheimer Society
- Denmark – Hellerup: Alzheimerforeningen
- Estonia – Tartu: Estonia Association of Alzheimer’s Disease
- Finland – Helsinki: Muistiliitto
- France – Paris: Association France Alzheimer
- Germany – Berlin: Deutsche Alzheimer Gesellschaft e.V.
- Greece – Thessaloniki: Greek Association of Alzheimer’s Disease and Related Disorders
- Ireland – Dublin: Alzheimer Society of Ireland
- Italy – Rome: Alzheimer Uniti Onlus
- Italy – Milan: Federazione Alzheimer Italia
- Jersey, St Helier: Jersey Alzheimer’s Association
- Luxembourg – Luxembourg: Association Luxembourg Alzheimer
clearly identified, taken on board by the JPND Scientific Advisory Board and translated into specific priorities within the JPND Research Strategy. We will continue to support key stakeholders such as patients and carers with appropriate information at relevant times through our website news updates in order to maximise both support for the JPND and the involvement of participating member states in the collaborative initiatives. We are currently planning a European-wide stakeholder engagement process, which will create an international stakeholder community to facilitate stakeholder engagement and address unmet needs. Patient and carer organisations such as Alzheimer Europe will play a vital role in this engagement process to facilitate cooperation, two-way communication, knowledge transfer, as well as consultation on JPND plans and initiatives.

AE: The JPND has now published its first call for projects with the aim of improving and harmonising the use of biomarkers in the area of neurodegenerative disorders. Why is there this focus on biomarkers?

It is widely perceived that one of the greatest unmet needs in the field of neurodegenerative disease research is the availability of sensitive and specific biomarkers for the diagnosis and the monitoring of progression of neurodegenerative disorders, which are sufficiently robust to be used in large trials run across multiple clinical centres. In recognition of this need, JPND launched a EUR 16 million transnational funding call for “European research projects for the optimisation of biomarkers and harmonisation of their use between clinical centres” with four projects,
containing participants from 20 different countries, being recommended for funding in December of 2011. We are very excited about these projects which are due to begin in the middle of 2012.

AE: Alzheimer Europe fully supports the JPND comprehensive and triple focus on cause, cure and care, especially as the latter aspect is often under-funded in research programmes. Are there any concrete plans to promote psychosocial research collaboration in Europe?

The answer is a resounding yes – there are several examples of JPND priorities within the broad theme of “Healthcare and social research” which have specific relevance to the psychosocial research field. The determination of cognitive decline in patients involves the observation of behavioural and psychological symptoms which are often under the influence of multiple biological, environmental, social, economic and other factors. JPND is recommending research into the complex interplay between these factors and also into the management of such symptoms in relation to addressing challenging behaviour and improving the quality of life in patients with neurodegenerative diseases. In addition, more research is required into the effects of interaction with family, carers, the environment and health and social care systems on a patient, which can be critical factors that impact on disability and quality of life. Other JPND priorities include an evaluation of approaches both to the better recognition of carer needs and preferences, and to the support of carers, particularly through carer-centred and carer-mediated interventions, and improved outcome measures that better reflect patient and carer perspectives.

AE: Mr Connolly, thanks for this update. We wish you and the Joint Programming Initiative all success.

We certainly wish to continue and expand on the pre-existing direct engagement of JPND stakeholder communities – we see it as being essential to our overall success!

<p>| Table 1: Total and per year costs captured during the JPND mapping exercise |</p>
<table>
<thead>
<tr>
<th>Number of projects</th>
<th>Full value (EUR millions)</th>
<th>%</th>
<th>Per year (EUR millions)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>2244</td>
<td>1,620</td>
<td>-</td>
<td>370</td>
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<tr>
<td>Major Investment¹</td>
<td>357</td>
<td>1,329</td>
<td>82</td>
<td>273</td>
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<tr>
<td>Smaller Projects</td>
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<td>291</td>
<td>18</td>
<td>97</td>
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<tr>
<td>By research category³</td>
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<tr>
<td>Basic</td>
<td>1538</td>
<td>1,261</td>
<td>84</td>
<td>301</td>
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<tr>
<td>Clinical</td>
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<td>183</td>
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<td>47</td>
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<tr>
<td>Health and social care</td>
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<td>76</td>
<td>4.7</td>
<td>22</td>
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<tr>
<td>By disease (Major)⁴</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s</td>
<td>192</td>
<td>346</td>
<td>26</td>
<td>86</td>
</tr>
<tr>
<td>Motor Neuron</td>
<td>18</td>
<td>37</td>
<td>2.8</td>
<td>8</td>
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<tr>
<td>Prion</td>
<td>28</td>
<td>57</td>
<td>4.3</td>
<td>14</td>
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<tr>
<td>Parkinson’s</td>
<td>80</td>
<td>171</td>
<td>12.9</td>
<td>39</td>
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<td>Huntington’s</td>
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<td>41</td>
<td>3.1</td>
<td>10</td>
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<td>SCA</td>
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<td>0.2</td>
<td>0.6</td>
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<td>SMA</td>
<td>4</td>
<td>9</td>
<td>0.7</td>
<td>2</td>
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<tr>
<td>ND in general</td>
<td>89</td>
<td>665</td>
<td>50</td>
<td>114</td>
</tr>
</tbody>
</table>

¹This figure excludes spend on training or career-development posts (PhDs, fellowships etc), and resources or infrastructure.
²Individual programmes or grants in excess of EUR 500,000 in the basic and clinical research domains or >EUR 200,000 in the health and social care domain.
³For the definitions of basic, clinical, and health and social care research used here, see the JPND Research Strategy on www.neurodegenerationresearch.eu
⁴Major investments only
FUTURE USE OF MRI IN EUROPE STILL THREATENED BY OPPOSITION IN EUROPEAN COUNCIL

The “Alliance for MRI” campaigns to ensure that new EU health and safety legislation will not adversely restrict the use of magnetic resonance imaging (MRI). In this article, Monika Hierath, Alliance for MRI Secretariat, European Society of Radiology, explains the importance of its work in light of current legislation.

The European Parliament and European Council are currently discussing a proposal to revise European Health and Safety legislation on workers exposure to electromagnetic fields. This revision will ensure that patients have access to magnetic resonance imaging (MRI), which uses electromagnetic fields and is an important diagnostic technology for a wide range of conditions, including Alzheimer’s disease.

The directive contains exposure limits for workers using applications generating electromagnetic fields such as power lines and welding tools. If adopted, the European Commission’s proposal would exempt MRI workers such as doctors and nurses from exposure limits that are inappropriate for MRI. MRI workers are already protected by specific safety standards for MRI scanners as well workers’ protection guidelines, which cover all MRI workers from doctors to cleaning and maintenance staff. The exemption would not impair the health and safety of MRI workers, but would allow continued patient access to this life-saving technology.

MRI is a safe, ionising radiation-free modality that is used for instance in brain surgery and in imaging vulnerable patients and children, where closer patient contact is required. It also helps to diagnose Alzheimer’s disease, by ruling out other possible causes for cognitive impairment, such as a brain tumour or blood clot. Recent research suggests that MRI could become a key diagnostic tool by revealing changes in the brain even before Alzheimer’s disease appears and researchers may then be able to determine which adults with mild cognitive impairment are more likely to develop Alzheimer’s disease.

Both the European Parliament and Council are currently discussing the Commission proposal. While MEPs from most political groups in the European Parliament support the exemption, a number of Member States in Council are opposing this exemption for various reasons, mainly because they do not wish to have an exemption for one particular sector. The MRI Alliance understands that a recent proposal was made in Council to give Member States the responsibility to grant an exemption instead of granting it at EU-level. This would create uneven workers’ protection rules across Europe with some Member States exempting all workers using electromagnetic fields and others not granting any exemptions, leaving a patchwork of patient access to MRI technology in Europe.
The current revision of the electromagnetic fields directive 2004/40/EC was brought about in 2007 when the Alliance for MRI – a coalition of patient groups (including Alzheimer Europe), scientists, the medical community and Members of the European Parliament (MEPs) – raised concerns about the problem. Although the original target for the directive was the uncontrolled exposure to EMF from welding tools, overhead power lines, and banks of computer terminals in confined spaces, it also included magnetic resonance imaging (MRI) technology.

MRI is an essential diagnostic tool for Europe’s patients that has been used safely over past 25 years and has contributed to saving the lives of thousands of patients throughout Europe. If the limit values laid down in the Directive were applied to MRI, it would prohibit MRI-guided surgery, forbid nurses from remaining with patients during a scanning procedure, and thus deny Europe’s patients access to this much needed technology. Due to the efforts of the Alliance for MRI the original national implementation deadline of April 2008 was postponed by the European Commission until April 2012 in order to revise the Directive and to find a lasting solution for MRI.

This year will be crucial to ensure patient access to MRI as the European Parliament will have its plenary vote and the Council will have to give its opinion on the proposal. It is vital that decision-makers understand the importance of supporting the exemption for MRI in order to ensure the availability of MRI for the diagnosis and therapy of neurological disorders. Unavailability of this technology would mean that patients need to revert to other diagnostic technologies such as computed tomography using radiation, which is known to cause cancer.

The Alliance for MRI is in contact with MEPS and Member State representatives to highlight the importance of this issue to Alzheimer patients.

**Alliance for MRI**

The "Alliance for MRI" is a coalition of European Parliamentarians, patient groups, leading European scientists and the medical community, who together are seeking to avert the serious threat posed by EU health and safety legislation to the clinical and research use of Magnetic Resonance Imaging (MRI).

The Alliance for MRI was officially launched in March 2007 in response to the implementation of the EU Physical Agents 2004/40/EC (EMF) in April 2008. The Alliance was founded by the European Society of Radiology, the European Federation of Neurological Associations and Dr Swoboda MEP, Vice-Chairman of the Socialist Group in the European Parliament. Alzheimer Europe is a member of the Alliance for MRI.

More information at [www.alliance-for-mri.org](http://www.alliance-for-mri.org)

**The Alliance for MRI has the support of the following MEPS:**

János Áder (Hungary), Frieda Brepoels (Belgium), Derek Clark (UK), Alejandro Cercas (Spain), Jorgo Chatzimarkakis (Germany), Frank Engel (Luxembourg), Robert Goebbels (Luxembourg), Françoise Grossetête (France), Richard Howitt (UK), Stephen Hughes (UK), Ville Itälä (Finland), Anneli Jäätteenmäki (Finland), Philippe Juvin (France), Eija-Riitta Korhola (Finland), Peter Liese (Germany), Elizabeth Lynne (UK), Linda McAvan (UK), Miroslav Mikolášik (Slovakia), Elisabeth Morin-Chartier (France), Angelika Niebler (Germany), Siiri Oviir (Estonia), Pier Antonio Panzeri (Italy), Frédérique Ries (Belgium), Zuzana Roithová (Czech Republic), Horst Schnellhardt (Germany), Hannes Swoboda (Austria) (Founding member), Thomas Ulmer (Germany), Derek Vaughan (UK), Anja Weisgerber (Germany)
NATIONAL DEMENTIA PLANS: FRANCE

Florence Lustman, General Inspector of Finances and Vice Chair of the Foundation for the Scientific Coordination of the French Alzheimer Plan, talks with Alzheimer Europe about the progress achieved in implementing the Plan.

Alzheimer Europe (AE): Ms Lustman, the French Alzheimer Plan has now passed its mid-stage point and an evaluation on the implementation of the different recommendations has been carried out. One of the aims of the French Alzheimer Plan was to make an unprecedented research effort in order to improve our understanding of the disease and to identify better treatments for people with Alzheimer’s disease. How successful has this investment in research been?

Florence Lustman (FL): The research effort is already bearing fruit. It is coordinated by the “Alzheimer Plan Foundation”, a non-profitable private foundation, specifically created for this purpose. Directly funded with EUR 81 million from the plan, 125 research projects (basic, clinical, therapeutic, technology, humanities and social sciences) are in progress. 138 new researchers have been recruited. The instruments to structure research are being implemented:

- A database was set up in late 2009 and now contains data from more than 211,000 patients by 335 memory clinics (more than two-thirds of them);
- Practitioners have been trained in clinical epidemiology (620 in November 2011) and in the development of industrial methods;
- A group is dedicated to methodological support (especially for cohorts and social and human sciences);
- An expert centre for imaging has been created;
- A cohort of a general population follows up 6,000 people over 65 after 12 years; [http://www.three-city-study.com](http://www.three-city-study.com)
- A prospective cohort of more than 2,000 people with dementia, MEMENTO, is in progress in order to improve the knowledge on natural history of Alzheimer’s disease and related disorders from early signs (light cognitive deficits, isolated cognitive complaint) throughout the disease; the pilot phase has demonstrated its feasibility with 88 people with dementia included;
- A cohort of young people with dementia has already 176 patients;
- In genomics, a European Genomic-wide association study collected more than 20,000 samples including 6,000 cases of Alzheimer’s disease.

This last work allowed a major breakthrough in 2009: The discovery of two new genetic susceptibility factors for Alzheimer’s disease. Since then,
7 new factors have been published and an international Genome-Wide Association Study GWAS has been set in order to complete the mapping of genes that may be associated with the disease.

An international mobilisation of researchers has been initiated by the Foundation, during the French Presidency of the European Union, through a new European pilot Joint Programming of Neurodegenerative Disease research initiative which brings together 23 countries, and also through a French-Canadian collaborative action by the national French agency for research (ANR). Researchers came together during the ICAD (International Conference on Alzheimer’s Disease) which was held in Paris, from July 16th to 21st, 2011. Cooperation of the best researchers from all domains, from all countries and from both the academic and the private fields is the only way to accelerate significantly the discovery of solutions to fight efficiently these terrible diseases.

AE: The Plan also identified the quality of life of people with dementia and their carers as a priority and aimed, amongst other things, at improving early diagnosis, residential care, as well as respite and support for carers. What have been the achievements of the French Plan in this field?

FL: The general population study conducted at the start of the Plan showed that 91% of respondents would like their diagnosis to be announced to them if they had symptoms. With the help of the Plan, the French territory is covered so that patients can have easy access to a timely diagnosis. Since the Plan began in 2008, 65 hospital memory clinics have been set up, 202 have been reinforced and two research and resources memory clinics have been created in Limousin and Auvergne. Therefore, 444 hospital memory clinics are available with a total of 507 access points. Throughout France, access to a consultation by a specialist in hospital or in an ambulatory setting is quickly available nearby. In addition, the waiting time (measured in hospital memory clinics in October 2009) is reasonable: 51 days on average, 4 out of 5 giving an appointment in less than three months.

Practice guidelines for the diagnosis and support for people with dementia, the disclosure of diagnosis and the provision of support were published in November 2009 and December 2011. Recommendations for the provision of support at home after the diagnosis and the definition of the relationship between doctor and the MAIAs (homes for the autonomy and integration for people with Alzheimer’s disease) are being developed.

People with dementia who are younger than 60 years (8,000 of them being identified by the health insurance) are faced with specific problems of delayed diagnosis or even misdiagnosis, socio-professional impact or care. The Plan Alzheimer young patients centre (http://www.centre-alzheimer-jeunes.fr) established in February 2009 provides local medical and medico-social contact points throughout France to answer the specific questions asked by these patients. This centre has become the regional, national and international reference point among both the professionals and the public. Last year, over 2,400 young people with difficulties were referred to the centre: more than one third of them were diagnosed with Alzheimer’s disease or a related disease.

The new structures to ease the pathway for people with dementia are spread across France in order to tangibly improve the lives of people with dementia and their caregivers.

Seventeen “MAIAs” have been piloted. MAIAs offer the patients and their families a single entry...
Experiments have also shown that the benefit of MAIA is not limited to people with Alzheimer’s disease and in the territories covered by MAIA, the integration of available services has in fact benefited all the elderly who are dependent.

Even with Alzheimer’s disease, a person must have the choice to stay at home, in an environment he or she is familiar with. To facilitate home care, the Alzheimer’s Plan will provide, by the end of 2012, 500 multidisciplinary Alzheimer mobile teams, composed of professionals trained in rehabilitation, stimulation and support of patients and their families early on in the disease. These teams are a reality today with 140 Home Care Nursing Services.

Because they have to constantly care about the person with Alzheimer’s disease, the family caregivers are under persistent pressure. There are structures that allow them to rest for a few hours by providing therapeutic benefit to patients for one or more half-days. The creation of new day care places has gone on since the beginning of the Plan (about 1,000 places have been created each year). The decision to restructure the supply in order to improve its quality was taken in February 2010: Since then, the funding of day centres has been on condition that it complies to a standard of activity (minimum 6 people for a centre backed by a nursing home and minimum 10 people for an independent centre) and with implementation of a solution for patients’ transport. The centres also now have to complete every year an online report on their activity. At the end of 2010, over 10,000 places in 1,663 day centres were listed on the national territory: 61% of day care places met all the new requirements. We’re looking forward to the figures for 2011.

In order to expand supply to meet the various needs of people with dementia and caregivers, 11 support and respite platforms have been piloted. They bring together a variety of services such as day care but also home respite, overnight care, temporary shelter, foster care, holiday travel, cultural activities, physical or artistic workshops rehabilitation or sensory stimulation. 75 are currently selected and 75 more will be created in 2012. In addition, 18 projects of innovative respite measures (respite home, art therapy, vacation stays, night visits) have defined how to complete the offer of support and respite.

To help family caregivers, information about the symptoms of the disease is provided: Two days of training per year are offered to each caregiver. Between November 2009 and December 2010, France-Alzheimer has trained 2,600 family caregivers.

Giving these harmful drugs (neuroleptics) to people with dementia reflects poor management of behavioural disorders and constitutes the wrong answer to a real problem.
As a result of the conference organised by France during the French Presidency of the European Union in October 2008, the fight against Alzheimer’s disease has become a European priority.

To cope with crises that require hospitalisation, 56 cognitive-behavioural units have opened in order to avoid going through many hospital services that weaken these patients. The objective of the Plan is to have 120 such units by the end of 2012.

Sometimes, home support is no longer possible or even desirable considering the worsening of behavioural problems, and care in an institution is needed. The Alzheimer Plan aims to adapt institutions to provide better care for patients faced with such situations. By 2012, the goal is to have 1,800 appropriate care and occupational units (PASA) for 12 to 14 patients with moderate behavioural problems as well as 360 reinforced residential units (UHR) (5,000 resident beds) for patients with more severe problems. More than 500 PASA and 160 UHR are already operating or ready to operate.

The implementation of these solutions involves trained professionals. A new position, “gerontology care assistant (ASG)”, was created by the Plan in September 2010. The training textbook (4,000 copies of the first edition in February 2011) has already been reprinted. In addition, the Plan requires 2,000 more psychomotor and occupational therapists by the end of 2012. Besides the effect of new schools for training these therapists to open in 2012, almost 1,900 new entries in schools will have been generated by the end of 2012.

The deployment of all these new structures to facilitate the care pathway of the person with dementia will continue in 2012, specifically in order to change the lives of people with dementia and their caregivers. A map to locate the available structures is posted on the website www.plan-alzheimer.gouv.fr.

Thanks to the work of the French National Health Authority (HAS), we now have a first indicator of the quality of care: the prescription of neuroleptics. Giving these harmful drugs to people with dementia reflects poor management of behavioural disorders and constitutes the wrong answer to a real problem. In 2010, 15.5% of patients (against 16.9% in 2007) were sedated by this type of treatment. The goal is to reduce this ratio to 5%, by improving the quality of care and quality of life.

AE: Changing the image of dementia and mobilising society against this common cause were very innovative aims of the Alzheimer Plan. How have these aims been met?

FL: Alzheimer’s disease and related diseases have been stigmatised in France. This is why the Alzheimer Plan also aims to better inform the general public, to promote an ethical approach, and to give this policy a European context.

The summary of the surveys conducted by the INPES among general population, people with dementia, family caregivers, professional home caregivers shows the perceptions and opinions of different audiences. The general outlook towards the disease varies from commonplace to severity. Studies conducted with people with dementia themselves early in the disease showed a picture very different from the general perception: people with dementia are aware of their difficulties and their problems, rather satisfied with life in general and their management but feel sad and powerless towards their disease.

At the local level, after the regional conferences in 2009, the territory deployment began in 2010 through the work of regional health agencies, and using referents Alzheimer within them. In 2011 and 2012, this effort is increasing as structures created by the plan are put in place to meet...
the needs of people with dementia and their caregivers.

The testing of a helpline with a single phone number was implemented around 21 September, on World Alzheimer’s day with the effective cooperation of France-Alzheimer and Prémalliance and was a success. The generalisation of this device taking calls between 2 and 10 pm is in progress.

Concerning the ethical approach, a new configuration has been established and was officially launched on 10 December, 2010. The ethical centre of hospitals in Paris in collaboration with the ethical centre of hospitals in Marseille is in charge of the ethics on Alzheimer’s disease. The goal is to provide practical ethical responses for everyone – people with dementia, caregivers and professionals – on all subjects – from the representation of people with dementia to the use of new technologies.

As an example of how awareness of Alzheimer’s disease is reaching a larger audience, I would like to point out that last July the French magazine “l’Express” highlighted the French Alzheimer’s plan as one of the 111 reasons to be optimistic for France.

AE: Alzheimer Europe welcomed the commitment of the French Plan to make Alzheimer’s disease a European priority. How successful has European collaboration been so far?

FL: As a result of the conference organised by France during the French Presidency of the European Union in October 2008, the fight against Alzheimer’s disease has become a European priority. The European Union has adopted an initiative in July 2009 which set four objectives: early diagnosis, epidemiology, ethics and the exchange of good practices. The “ALCOVE” joint action led by France is underway. On a voluntary basis, it brings together 30 partners from 19 Member States and aims to create a platform of European experts to improve knowledge, practices and security for Alzheimer’s care in Europe, starting with the inappropriate use of neuroleptics as a first example.

In research, the fight against neurodegenerative diseases, particularly Alzheimer’s disease, has become a pilot issue for the European Joint Programming in Neurodegenerative Disease research. Under the French leadership, 23 countries now combine forces to defeat Alzheimer’s disease. A first call for proposals launched in May 2011 on the standardisation of biomarkers of cerebrospinal fluid has selected four projects and the European strategic research agenda has been defined.

AE: And a final question, Ms Lustman. Should there be a follow-up plan to the French Alzheimer Plan?

FL: The “Alzheimer Plan 2008-2012” has demonstrated strong political commitment both to people with dementia and their families. By the end of 2012 tremendous results should be seen on its three ambitions: to know the disease and find a cure, and before that, to change the way we look at this disease and to build a personalised pathway for each person with dementia, from diagnosis to care at home, and in institutions where appropriate. But everything will not be achieved. Some objectives have already been surpassed, but still a lot will remain to be done. This is why, for instance, the Alzheimer Plan Foundation will continue to operate and the generalisation of MAIAs has already been scheduled for 2011 to 2014.

AE: Many thanks for your time.
NATIONAL DEMENTIA PLANS: LUXEMBOURG

The development of a dementia plan is part of the Government Programme for the period of 2009-2014. Alzheimer Europe talks with the Luxembourg Minister of Health Mars di Bartolomeo about the progress in the development of such a strategy.

Alzheimer Europe (AE): Minister, the Government committed to the development of a dementia plan in Luxembourg. Why was dementia identified as a priority in the coalition agreement?

Mars di Bartolomeo (MDB): Societies across Europe are ageing. Even if in Luxembourg the 25-55 age group is larger than in other countries, we see a similar pattern in our country. Our statistics show the same increase in life expectancy over the past decades – which of course is a positive development. But as the proportion of older people in our population is increasing we have to be prepared to provide a good and high quality offer of services to our elderly population to enable them to fully participate in society.

This starts much before people become “old”. Contributing to healthy ageing is a key goal of our policy. We have to support mental health and well-being in our population. But we also need to establish quality care for dementia patients. Bringing all of this together in one strategy is the aim of the Luxembourg dementia plan.

We know that the prevalence of dementia will rise. But this is not only a medical or social care issue. Dementia concerns partners, relatives, and friends. It is a common challenge for our communities.

We did not start from scratch in taking up the task. In the 2009 Hospital Plan, six specialised units for elderly people were foreseen to provide qualified care and support for the special needs of these patients. Also, the need for cooperation with outpatient services is highlighted. We are involved in research with a programme on the prospective evaluation of neuropsychological and biological characteristics of mild cognitive impairment and of associated subclinical health problems. We are also launching fundamental research to validate a new therapeutic strategy to prevent neurodegeneration and subsequent impairments.

But in order to be successful, it is important that we commit to a common approach in prevention, diagnosis, adequate acute and long term care for the elderly population, creating supportive structures both for patients and relatives, and projects on research.

This is the idea behind the national plan on dementia – to be a tool to coordinate and link all relevant actions and activities towards the best care and support for people with dementia and their relatives.

AE: What have been the steps undertaken so far to develop a Luxembourg dementia plan?

MDB: In spring 2011, the Minister of Family and Integration and myself invited relevant partners from the social sector, health care institutions,
We have to develop knowledge about how best to offer older people an adequate place and role in our societies to respond to their expectations and needs.

medical and para-medical professionals, patient and family organisations, and local government representatives to participate in four working groups, covering:

- Supply chain: medical-nursing-social with particular interest in prevention and early diagnosis
- Supporting families and patients' rights
- Social stigmatisation.

These groups were asked to analyse the current situation and to develop proposals for further actions by the end of 2011. Up to now it seems realistic that all groups will have finished their report in January 2012.

The four final reports will then be summarised and presented to an expert group in spring 2012. The group consists of the working group chairs, representatives of the suppliers of long term care, representatives of Association Luxembourg Alzheimer and external experts, and is led by the Plan coordinator. It is foreseen that the expert group will develop a proposal for a national dementia plan to the two Ministers in April 2012.

AE: If you had to choose three key priorities to include in the dementia plan, what would they be?

MdB: Prevention would be very important. We need effective primary prevention approaches to promote healthy life styles, and secondary prevention in the form of a comprehensive program including weight control, smoking prevention, cognitive training, social activities, control of medication and if necessary adequate treatment of depression.

Second, diagnosis and especially early diagnosis should be improved and become easily accessible to all patients who wish to be examined. For me, a two step system where GP’s perform a first screening test in cases of suspected dementia which would be followed up by differential diagnosis, seems efficient and cost-effective. If we expand diagnostics we also need to ensure that patients and relatives have the possibility to contact an information and a coordination centre to obtain full information on health and psycho-social issues and to coordinate support following diagnosis of dementia and during the course of their disease.

Thirdly, treatment and nursing care should be improved. Treatment should follow international guidelines which would be adapted to the Luxembourg situation, and doctors – GPs and specialists – should be informed and advised to follow these guidelines. Better concepts in nursing care for patients with dementia should be developed to provide the best care and to avoid deterioration and complications in case of hospitalisation.

AE: As you know, Alzheimer Europe has been campaigning for greater European collaboration in the Alzheimer’s field. What would be your expectations from European collaboration and would you support the development of a European Dementia Strategy?

MdB: In the past a lot of work to understand dementia and to develop best practices in care and treatment has already been taken forward by different organisations, universities, associations, cities and authorities all over Europe – I think this needs to continue to learn more about inter-dependencies between dementia, Alzheimer’s disease, wellbeing in old age and healthy and active ageing.
We have to develop knowledge about how best to offer older people an adequate place and role in our societies to respond to their expectations and needs. Promoting well-being in older people is essential to strengthen and mobilise the mental capital which we need for a successful future.

In Europe, we need to implement ideas and concepts such as:

- Understanding dementia is linked to addressing the increasing problems we will face in mental health in general
- Acting early to diagnose dementia and to promote well-being is an important task of our health and social systems
- A shared European effort to better understand dementia conditions: improving epidemiological knowledge and coordination of research should be promoted
- Sharing best practices for care of people suffering dementia and last but not least
- Respecting the rights of people with dementia is essential.

Consequently Luxembourg is happy to participate as a partner in the joint action ALCOVE and supports this common effort to optimize the care of Alzheimer patients.

We also support work under the European Pact for mental health and well being and the mental health joint action now under preparation, as well as the European Partnership for Active and Healthy Ageing. Taken together, I am confident that this will give us a good set of instruments to better understand and start to address the dementia challenge.

AE: Thank you Minister for your time.
THE VIEW FROM DENMARK

Ole Christensen, MEP (Denmark) speaks about the key challenges that people with dementia and their carers face in Denmark.

It is estimated that 80,000 people have dementia in Denmark and that one in five Danes that reach the age of 85 years or more will be hit by some form of dementia. While the illness is severe enough for the person suffering from dementia, it also implies notable changes in the daily lives of family, friends and carers. In Denmark no less than 400,000 people are related to a person with dementia.

As demographic changes start to take place over the coming years, resulting in a larger segment of elderly people, prognoses indicate that people with dementia in Denmark will double within a period of 25 to 30 years.

These demographic changes are not unique for Denmark. A number of countries in Europe are experiencing a larger share of elderly people in their respective populations and governments are starting to pay more attention to the prospect of an increased number of people with dementia in the future.

This same prospect is also dawning on Danish politicians and during recent years the debate on dementia has increased in scope and depth.

However, despite this awareness, the general effort on behalf of dementia has, until recently at least, been rather less organised and of less quality than in other European countries, including the United Kingdom, France, Norway and Sweden where national action plans have been in place for a number of years.

Recognising this lack of a coordinated approach towards dementia, Denmark launched a four-year action plan for Dementia in 2010. The plan presents 14 specific recommendations which will strengthen and improve national efforts to deal with dementia. The recommendations include giving a timely and better diagnosis of dementia in all parts of the country.

The plan also includes recommendations for the different regions of Denmark to follow guidelines in order to create cross-sectional diagnostic procedures. Since dementia has been dubbed “the illness of relatives and close ones” it is also important that recommendations are made not only for the people directly suffering from dementia but also their informal caregivers.

I certainly find the plan a step in the right direction and it sends a clear signal that dementia is beginning to receive the recognition in the public and political debate that it deserves. However, it should merely be seen as a first step. As already mentioned the demographic changes that European societies will experience in coming years will present enormous challenges for politicians and requires continuing adjustments and updating of the current framework for dealing with dementia.

In light of these challenges, I am of the opinion that the policy priorities for Danish policy makers are threefold:

First of all, it is of utmost importance that policy makers focus on achieving the highest possible effect of our investments for the admittedly increasingly scarce resources available.

Already today, dementia accounts for DKK 7 to 8
We should make better use of patient-organisations and volunteers that can help relieve the efforts of family and friends.

billion in expenses for treatment and care. If one adds the indirect costs of dementia in the form of lost income for relatives and close ones the expenses are easily doubled. The growing amount of people with dementia will therefore result in an increased pressure on public finances of European societies in the near future.

In addition to the challenges of demography, most governments in the EU are currently tested by the economic and financial crisis which leads to a growing public budget deficit and resulting cuts in public outlays for certain health expenses.

Therefore we need to spend the money we have more smartly. The administrative burdens should be lessened and resources currently being used to bureaucratise treatment of dementia should undergo a reprioritisation.

Furthermore, in Denmark there is a widespread division of tasks in health care where the state, the regions and the municipalities all play important functions. This division of labour has a long history in Denmark and should not necessarily be changed. However, it does require that the different actors should communicate when completing their tasks so that we achieve effective coordination between the levels responsible for treating and caring of people with dementia.

However, a more effective use of resources should not be made by sacrificing the quality of the treatment and care. I recognise that there are limits to how efficient we can be for the resources available. Therefore, we should not demand too much of carers and medical staff who contribute massively by investing time and effort in the lives of others and thus face large enough challenges as it is.

This also leads me to my next policy priority for Danish policy makers. As already mentioned, carers of people with dementia are essential. In a world where there is not only an increasing number of people with dementia but also a decreasing number of younger people to look after the ill, a second priority should be to create improved day-care and relief facilities for people with dementia and their close ones. More specifically, we should make better use of patient-organisations and volunteers that can help relieve the efforts of family and friends.

Finally, I think it is important to raise public awareness of dementia. Public awareness campaigns could be initiated as has been the case for other illnesses affecting large segments of the public. These campaigns should inform people living with dementia about the initiatives undertaken, the research being conducted in the area and the possibilities of meeting other people confronted with the challenges that dementia poses. Since dementia is going to affect an increasing number of people in the future and thus increasingly become a societal challenge that we will have to solve in community, information campaigns should also have a broad focus informing the general public about dementia.

In addition to the responses on national level, I find it important that we develop a common European approach to dealing with dementia. Dementia is an illness that confronts most EU member states especially the ones experiencing aging populations. Therefore, I find it essential that we tackle the issue in cooperation.

I would therefore be very much in favour of a European Action Plan in line with the ones that are already in place for cancer, human immuno-deficiency virus (HIV) and heart diseases. Within such collaboration we should focus on achieving a better and coordinated effort to have the illness diagnosed as early as possible. In Denmark for example only a third of all people with dementia have been given a diagnosis.

It should also be a priority to improve the amount and quality of aid that is given to people with dementia and their close ones. These are the people most affected and most in need of aid and it is long overdue that we give them a helping hand by easing the daily challenges posed by the illness.
POLICY DEVELOPMENTS

Alzheimer Europe reports on recent policy developments which may impact people with dementia and their carers.


The Political Declaration of the High-Level Meeting of the General Assembly on the Prevention and Control of non-communicable diseases (NCD) was adopted on 20 September 2011. Paragraph 18 of the Declaration of the summit states that the Heads of States and Government and representatives of States and Governments “recognise that mental and neurological disorders, including Alzheimer’s disease, are an important cause of morbidity and contribute to the global non-communicable disease burden, for which there is a need to provide equitable access to effective programmes and health-care interventions.” Options for strengthening and facilitating multi-sectorial action for the prevention and control of NCDs through effective partnership are due to be submitted to the General Assembly at the end of 2012.

On 15 September 2011, the European Parliament adopted a resolution on European Union position and commitment in advance to the UN high-level meeting on the prevention and control of non-communicable diseases. The resolution notes that the implementation of national plans, associated with the more effective prevention, diagnosis and management of NCDs and risk factors, could significantly reduce the overall burden of NCDs and contribute to the sustainability of the national healthcare systems.

European Commission responds to questions on national dementia plans.

Written questions from Ms Elżbieta Łukacijewska, MEP (Poland), concerning national dementia plans were responded to by the European Commission on 7 November 2011. Ms Łukacijewska asked:

- What does the EU think of existing measures taken by the Member States to implement national plans to combat brain diseases and neurodegenerative diseases?
- How many Member States have introduced or are drawing up such plans?
- Will the EC publish a report detailing the most effective solutions, with a view to encouraging other countries to adopt such plans?

Mr Dalli, European Commissioner for Health and Consumer Policy said that the Commission will produce an implementation report on the progress made under the 2009 communication from the Commission to the Parliament and Council on a European initiative on Alzheimer’s disease.
Prioritising Dementia Policy Watch

disease and other dementias in 2013. He continued, “the main underlying activity in this context is the joint Action between the Commission and the Member States on Alzheimer Cooperative Valuation in Europe (ALCOVE). With regard to the question on detailing effective solutions, Mr Dalli said “the Commission does not dispose of detailed information on the drawing up of national plans to combat brain diseases and neurological diseases.”

UK government runs advertising campaign for early diagnosis of dementia.

The UK Department of Health ran a EUR 2.3 million advertising campaign aimed at improving early diagnosis of Alzheimer’s disease during November 2011. The campaign is a result of the DOH pilot studies, which suggested that it helps people to realise that early diagnosis of dementia can lead to better treatment and the slowing down of symptoms. The advertisements appeared on TV, radio and in print, telling the story of a forgetful man who is helped by his daughter and a doctor to find out that he has a degenerative brain condition.

Paul Burstow, UK Care Services Minister said, “People are afraid of dementia and rather than face the possibility of someone we love has the condition, we can wrongly put memory problems down to “senior” moments. But if we are worried, the sooner we discuss it and help the person seek support the better. We can’t cure dementia but we can help keep the person we love for longer.”

Northern Ireland publishes a new regional dementia strategy.

The Northern Ireland Ministry for Health, Social Services and Public Safety published a regional dementia strategy entitled, “Improving dementia services in Northern Ireland: a regional strategy” on 8 November 2011. The strategy makes recommendations aimed at improving the services and support arrangements currently available for people with dementia, their families and their carers. It also aims to reduce the risk or delay the onset of dementia. In addition, new legislation is being developed which addresses mental capacity and mental health.

Commission proposes EUR 80 billion investment in research and innovation.

On 30 November 2011, Máire Geoghegan-Quinn, Commissioner for Research, Innovation and Science, presented Horizon 2020, a package of measures to boost research, innovation and competitiveness in Europe. The package will bring together all EU research and innovation funding under a single programme. In addition, the current bureaucratic rules and procedures will be reduced, in order to attract more researchers and a broader range of businesses. Horizon 2020 will focus on three objectives:

- Support the EU’s position as a world leader in science, with a budget of EUR 25.6 billion. This includes a major increase in funding for the European Research Council.

- Secure industrial leadership in innovation (EUR 13.7 billion) in key technologies and support for SMEs.

- Address key concerns in areas including health, demographic change, food security, sustainable agriculture, marine research and clean energy.

The funding programmes will run from 2014-2020.
World Alzheimer’s Day
A snapshot of the celebrations of the 2011 World Alzheimer’s Day by national Alzheimer associations.

Members’ news
Alzheimer Europe reports on some of the recent activities carried by national Alzheimer associations in Denmark, France, Germany, Italy, Malta, Portugal and the UK.

Putting a face to commitment
A look at the recognition given to people who work in the field of dementia as well as new appointments in Alzheimer Europe member associations.

Austerity measures in Ireland and Greece
Maurice O’Connell, Chief Executive Officer of the Alzheimer Society of Ireland and Professor Magda Tsolaki, the President of the Panhellenic Federation of Alzheimer’s disease and related disorders consider the consequences for people with dementia and national associations of recent austerity measures put in place in their respective countries.

Dementia in society
Alzheimer Europe takes a look at how dementia is portrayed in the media.

Living with dementia in Romania
Ramona Amariei, from Romania, talks about her experience of caring for her mother, who has Alzheimer’s disease.
WORLD ALZHEIMER’S DAY 2011

On 21 September each year, people with dementia, their carers and Alzheimer associations from nearly 80 countries come together to raise awareness about the realities and effects of dementia on individuals, families and societies. Below are snapshots of World Alzheimer’s Day activities from the various European Alzheimer Associations.
MEMBERS’ NEWS

Alzheimer Europe reports on some of the recent activities carried out by national Alzheimer associations around Europe.

**Denmark:** Alzheimer Denmark co-authored (with Pfizer Denmark) a study on the costs of informal care for people with dementia which was published on 18 November 2011. The report concludes that informal care delivered by family and friends is significant and that the value of informal care constitutes an important part of the societal cost of dementia in Denmark.

**France:** A project on early onset dementia carried out by France Alzheimer found that mental anguish – including depression – often follows diagnosis, as families try to find ways to cope. Published in December 2011, the conclusion was that improvements are needed in the doctor-patient relationship, particularly in the way diagnoses are presented and discussed.

**Germany:** In a letter dated 21 October 2011, Alzheimer Germany asked Chancellor Merkel to enact a national dementia plan. The association proposed a national strategy that provides a coordinated approach to improve the lives of people with dementia and their families. Heike von Lützau-Hohlbein, Chairperson of the German Alzheimer Society and Chairperson of Alzheimer Europe, wrote that an ever-growing older population is likely to increase dementia cases from the present 1.2 million to 2.6 million cases in 2050.

**Italy:** Alzheimer Uniti Onlus took part in a conference aiming to create a regional Alzheimer’s disease plan for the Lazio region of Rome on 10 November 2011. If the regional plan becomes a reality, Lazio will be on the second Italian region (of 20) to implement a regional dementia plan.

**Malta:** The Malta Dementia Society together with the Malta Pharmaceutical Student Association (MPSA) organised an awareness campaign on dementia in 19 October 2011, during the Mental World Health Day. The aims of this campaign were to raise awareness among lecturers, staff and university students about dementia and to enable the public to learn about the work of the Malta Dementia Society. Information leaflets, journals and books were distributed and carers were encouraged to join the Society.

**Portugal:** Alzheimer Portugal and AFALcontigo (an association from Spain) organised the annual pan-liberian conference on Alzheimer’s disease in Portugal on 21-22 October 2011. Nearly 300 delegates from both countries attended. The main topics were clinical issues and research, psychological interventions and quality of life, legal rights, guardianship and advance directives. Delegates learned about the new provisions of living wills which were recently approved by the Portuguese parliament.

**UK:** The Alzheimer’s Society produced the report “Short changed: Protecting people with dementia from financial abuse” in December 2011. The Society reports that people with dementia are cheated out of at least GBP 100 million. The purpose of the report is to “gather new evidence about the issues that people with dementia and carers face when managing their money. It also explores what they consider to be financial abuse. The aim of the report is to raise awareness among the public, and those working with people with dementia, about the issues raised by money management and financial abuse in the context of dementia.”
UK (Scotland): Alzheimer Scotland has initiated a programme to help people talk about death. “Essential Conversations: Talking about death and dementia” by Alzheimer Scotland, is managed by the National Carer Organisations and funded by the Scottish Government. Made in partnership with Artlink, it consists of a website (www.essentialconversations.org.uk) and DVD about dying, which aim to “help encourage professionals to instigate and manage these sorts of discussions”. Contributions are made by staff and carers involved with Alzheimer Scotland. It was launched on 9 January 2012. In addition, Alzheimer Scotland has written the information sheet entitled “Loss and bereavement in people with dementia. Helping people with dementia come to terms with the death of someone close to them.” The sheet provides practical tips and advice on telling the person, funeral arrangements and strategies for coping with “awkward” questions.

PUTTING A FACE TO COMMITMENT

Angela Clayton-Turner
Carer and Alzheimer Society’s volunteer, Angela Clayton-Turner, was awarded a William Brooks award on 2 November at Buckingham Palace. The award is given in recognition of Angela’s “outstanding contribution to Alzheimer’s Society and dedicated volunteering for people with dementia and their carers.” Amongst her many volunteer activities, Ms Clayton-Turner sits on the Society’s nominations committee and is also part of the Alzheimer Europe working group on the ethics of dementia research.

Marie-Odile Desana
On 12 October 2011, the French President, Nicolas Sarkozy, bestowed the highest decoration in France, the “Chevalier de la Légion d’Honneur” upon Marie-Odile Desana, the President of France Alzheimer. This distinction recognises Mrs Desana’s long-standing associative engagement at regional and national level. Accepting the award, Mrs Desana said: “This award recognises the engagement of the previous presidents and that of the local associations. Not only is this the recognition of the volunteers’ daily and tremendous work, it also encourages us to mobilise even further. I would also like to share this award with all the families affected by this disease”.

John Laurie
Alzheimer Scotland appointed John Laurie as the new Convener (Chairperson) of the association on 4 November 2011. He replaces Ms Noni Cobban. A former engineer and manager in the construction industry, Mr Laurie retired in order to become a full-time carer for his wife Avril, who has vascular dementia. Mr Laurie joined the Council of Alzheimer Scotland in 2004 and has since served on the Executive and Staffing Committees.

Patrick Maugard
Patrick Maugard was appointed Vice-President of France Alzheimer on 1 October 2011. Mr Maugard has been an active member of the French association for many years, but had voluntarily taken a back seat due to health reasons. He has now recovered and is very pleased to take on new responsibilities within France Alzheimer. Mr Maugard is also a Board member of Alzheimer Europe.
Dementia in the News

Austerity Measures

In an attempt to address the economic crisis in Europe, austerity measures have been put in place in many countries. This article looks at some of the consequences such measures can have on people with dementia and their carers in Ireland and Greece.

Ireland:

Maurice O’Connell, Chief Executive Officer of the Alzheimer Society of Ireland talks about the effects of austerity measures on people living with dementia in Ireland.

In the immediate aftermath of the recent 2012 Budget, The Alzheimer Society of Ireland – along with many health service and advocacy providers – is assessing the cumulative impact of another austerity budget on our organisation.

As part of the obligations under the EU/ECB/IMF financial package the Government has made financial “adjustments” of EUR 3.8bn for next year divided between EUR 2.2bn in revenue cuts and EUR 1.6bn in tax increases. Specifically, in Healthcare, the Government is proposing to cut EUR 462m in funding through reducing the price of drugs, staff cost (and numbers), improving the collection of private income in public hospitals and securing 2% efficiencies in disability and children’s services.

As with most things, the devil is in the detail, and at the time of writing the exact means of delivering these savings remain sketchy, at best. What we do know is that even against this backdrop of stinging austerity (where political choices are severely limited) an additional EUR 35m is being provided for new mental health services and EUR 15m to provide free GP care for people on the Long Term Illness Scheme.

Over the past number of years we have worked tirelessly to reflect the new financial reality by adjusting our salaries downwards, greater use of volunteers and sadly, but inevitably, some redundancies. It has been far from easy but we have been, and continue, to play our part.

As to be expected, with a significantly high ageing demographic in our population, we have noticed a vast increase and demand for our services. At any one time we have over 1,400 people on a waiting list and as Ireland’s leading dementia care and provider specialist, we continue to develop support for people in the community through day care and training to meet this growing demand. In addition we have taken the decision to branch into the private home care market in response to a growing demand from our client base.

The Society is actively growing its Branch network with plans to expand substantially during 2012. An evaluation of existing Branches conducted in April 2011, demonstrated that those services supported by a local branch are better supported in terms of fundraising and community awareness. Ultimately, the Management of The Alzheimer Society recognises that the implementation of best practice models of care, including growth and support of services is more effective when the local community are offered ownership.

“Whilst we struggle to maintain our services – and at a national level regain our economic sovereignty – our challenges can no longer be viewed in isolation as part of the EU periphery.” Maurice O’Connell
Our primary challenge is to ensure that funding sources are maintained and that dementia specific policies are designed and implemented against the backdrop of the proposed abolition of the Health Service Executive and moves towards developing a universal, single tier system.

In that context, we have increased our engagement with key officials, advisers and politicians to ensure that the Programme for Government commitment to develop a Dementia Strategy by 2013 (to be implemented over the subsequent five years) is delivered, and that sufficient funds are allocated to ensure that it meets and anticipates the needs of those with dementia.

Over 40 members of the Oireachtas have signed a pledge to become “Political Friends of dementia” and we are actively exploring establishing an informal cross party group using the successful European Parliament model.

Additionally, collaborative campaigning and alliance building with groups such as Older and Bolder, Active Retirement, Third Age and Amnesty, on a range of shared policy platforms (such as Mental Capacity) is proving an increasingly effective component of our overall public affairs approach.

These efforts have undoubtedly helped to push the dementia issue up the political agenda but much work remains to be done.

Whilst we struggle to maintain our services -and at a national level regain our economic sovereignty- our challenges can no longer be viewed in isolation as part of the EU periphery.

As Irish people and Europeans, we are active stakeholders and participants in ensuring that the wider European debt crisis is effectively tackled.

This will no doubt require flexibility, imagination and vision from all of the participants. Only then can we truly embrace the future with certainty and optimism.

**Greece:**

Professor Magda Tsolaki, the President of the Panhellenic Federation of Alzheimer’s Disease and Related Disorders, talks about the impact austerity measures are having in Greece.

The Austerity measures taken in Greece during the past months have put an enormous pressure on the mental health services provided in the country. Greece’s mental health professionals’ association highlighted that funding for community-based mental health programs had been cut down almost in half since the crisis started in late 2009.

Of course these measures have also affected our organisation. In more detail, there has been a cut of our budget (by the Greek Ministry of Health and Social Solidarity) by almost 25%. In other words, we were asked to run our day care services with EUR 350,000 less for the year 2011, which in turn has caused many problems in our day to day functioning. For example, Alzheimer Hellas was not able to pay the rent of the two Day Care Centers for quite a few months, which, potentially could have caused many problems with the owner of the buildings. In addition, during the last year our payroll has been delayed from 1 to 3 months. Furthermore, for the year 2012 there is no official update regarding the budget that will be allocated by the Ministry of Health to our Association. Therefore all the Alzheimer Associations throughout the country are worried about the funding in the next year. In the case that Ministry continues to severely cut the funding of our services, all the Alzheimer’s associations will face economic problems that may even result in shutting down.

“In the case that Ministry continues to severely cut the funding of our services, all the Alzheimer’s associations will face economic problems that may even result in shutting down.”

Prof. Madga Tsolaki
Restoring the Tradition of European Medical Innovation

Over the past 200 years European scientists have been at the forefront of medical progress. Today, that proud tradition is under pressure from policies that devalue the role of innovation.

Innovation takes many forms: from the ground-breaking treatments and cures that emerge from our laboratories, to new solutions for today’s and tomorrow’s major health challenges. An ageing population, access to the best treatments and the availability of credible health information are issues of concern for both policy makers and society as a whole.

We believe that partnerships between governments, public institutions and the research-based pharmaceutical industry are essential to meet public demand for medical excellence, while revitalizing Europe's spirit of innovation and competitive position in the global marketplace.

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Why ... Us? I'm still asking myself even if there has been already four years from the first signs of the
disease and three years since my mother was diagnosed with Alzheimer dementia.

This happened when she retired, perhaps in that moment, I think, when she felt alone, far away from her
social life, from her clients, from the dynamic part of her life. I have to say that for my mother her job was
very important, so important that when she stopped going to work she felt isolated from the outside world.

In a way, my mother was forced to retire because she worked as a hairdresser in a hair salon which closed. She
refused to get hired in another hair salon and she accepted the idea of retirement at the beginning, but afterwards
she reconsidered and changed her mind, but it was too late, her request of retirement had already been accepted.

In that moment I felt her to be both disappointed and affected. She felt like it was the end. However I would
have tried to convince her that she's got all the time in the world to walk, to read, to go shopping, to cook different
specialities ... but it was useless. I realised that all these activities I enjoyed, my mum disliked.

She was saying to me that she had no money to buy everything she wanted and I realised that this issue
concerning “money” started to become an obsession for her and very soon she refused to touch it. She was saying
to my dad that she couldn’t remember clearly what had happened two or three days ago, but we didn’t pay any
attention and we supposed she was tired.

In all this period, my mum started to be more and more absent in conversations, to avoid telephone conversa-
tions, to refuse to go out alone and what really shocked me was her look that showed no feeling, neither angry,
nor love. She looked empty, she was sad all the time and there was no smile on her face.

She was asking me how to cut the bread or if it’s good how she chops the onions and the carrots. At the
beginning, I thought she didn’t want to concentrate enough to do her habitual activities and I was nagging her
sometimes. Then, reading more about this disease, I realised that even if she wanted so, she couldn’t do that.
And I learnt that I had to show her every time how to cut the bread or to chop the onion and every time
I had to encourage her as she was like a child and trying to make my tears stop.

I kept asking myself and, if it was possible, to get some answer: How could that be possible? She taught me
how to cut the bread, to chop the onion and now.....? But in time, unfortunately, all this became normal.

This disease changed her completely and also our lives, mine and my father’s. My dad had to give up to his job
to take care of her. We had to learn how to treat her in her different states. She has moments when she behaves
normally and she remembers what she has to do and also moments when she is completely lost and she needs help.
There are moments when she starts crying as a child and even if we ask her what is going on, she can’t
answer and we feel useless. But we go on with our fight of keeping her knowledge and memories alive in
order to be with us as long as possible.

We are afraid of the moment when she won’t recognise us and we will be completely useless in her life. We feel
really sad because instead of talking to me and my dad, she lies in bed watching the ceiling having the same empty look.

We live day by day, enjoying her small successes, being sad when she forgets something, smiling when she
acts like a child. But, the most important is that we still feel her huge love she has for us and this remained
untouchable by the disease.

And even we learnt to live like this and enjoy our life, I’m still asking myself why... us?

LIVING WITH DEMENTIA IN ROMANIA

As a caregiver, I felt as I wanted to write down my thoughts and my
feelings concerning this cruel experience we are living. By the way, my name is Ramona
Amariei, I am 28 years old and I’m from Bucharest, Romania.
DEMENTIA IN SOCIETY

A brief look at news items on dementia within the media

L’Oréal heiress Liliane Bettencourt is placed under guardianship.
A French judge ruled on 10 October 2011 that l’Oréal heiress Liliane Bettencourt, will become a legal dependant of her daughter and grandsons. The ruling came after medical experts concluded that the cosmetics billionaire has “mixed dementia” and “moderately severe” Alzheimer’s disease.

“Tommy on Tour” Dementia campaigner reaches the Scottish Parliament.
During 2011, Thomas Whitelaw walked through Scotland’s towns and cities, collecting letters from fellow carers of people with dementia. Starting in January 2011, he spoke with thousands of carers and collected letters and e-mails from all over Scotland. Mr Whitelaw also maintained a blog and made a film about his campaign. On 10 November 2011, “Tommy on Tour” reached a successful conclusion when he delivered all correspondence to Nicola Sturgeon, Deputy First Minister, at the Scottish Parliament.

Singer David Cassidy talks about family’s struggle with dementia.
American singer, songwriter and actor David Cassidy has released a YouTube video in which he speaks about his family’s struggle with dementia. The video was produced by the Alzheimer’s Research and Prevention Foundation and released on 9 November 2011.

Alzheimer Australia launches free iPhone application.
Alzheimer Australia and the Bupa Health Foundation have launched a free iPhone application called BrainyApp, in order to raise awareness of the risk factors for Alzheimer’s disease and other types of dementia.

Film about the life of Margaret Thatcher released.
The “Iron Lady” is a film about the life of former British Prime Minister, Margaret Thatcher, who is portrayed by actress Meryl Streep. The film shows Mrs Thatcher as an elderly woman living with dementia who has flashbacks to various personal and professional moments throughout her life. Ms Streep has received recognition for her interpretation of living with dementia. A review of the film in the Telegraph stated:

“The way Streep captures this is outstandingly accurate. Anyone who has cared for someone with Alzheimer’s, for example, will recognise the waxing and waning confusion; the way in which sufferers appear to slip into another world, their loss of a sense of time, the way they look at you utterly perplexed in stark contrast to rare moments of startling clarity and insight – all the things that make this disease so cruel and tragic. The film is faultless in its depiction of dementia.”

The ethical issue of the right to privacy has been highlighted by this film with some arguing that by showing Mrs Thatcher with dementia results in her right to privacy being violated.
MEMBERS OF THE EUROPEAN PARLIAMENT UNITE FOR THE DEMENTIA CAUSE

Antonescu Elena Oana (Romania, EPP)
Ashworth Richard (United Kingdom, ECR)
Audy Jean-Pierre (France, EPP)
Aylward Liam (Ireland, ALDE)
Becker Helnz (Austria, EPP)
Blinkewicute Vilija (Lithuania, S&D)
Brepoels Frieda (Belgium, Greens-EFA)
Cabnoch Milan (Czech Republic, ECR)
Carvalho Maria da Grazia (Portugal, EPP)

Childers Nessa (Ireland, S&D)
Chountis Nikolaos (Greece, GUE-NGL)
Christensen Ole (Denmark, S&D)
Coelho Carlos (Portugal, EPP)
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Engel Frank (Luxembourg, EPP)
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Jaakonsaari Liisa (Finland, S&D)
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Koppa Maria Eleni (Greece, S&D)
Kratsa-Tsagaropoulou Rodi (Greece, EPP)
Lukáciová Elžbieta (Poland, EPP)
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Lynne Liz (UK, ALDE)
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Schaldemose Christel (Denmark, S&D)

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Staes Alojz (Belgium, Greens-EFA)
Tola Patrizia (Italy, S&D)
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Vaughan Derek (United Kingdom, S&D)
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