Liam Aylward, MEP (Ireland) hosts a lunch debate on Alzheimer’s disease in the European Parliament.

EU Commissioner Androulla Vassiliou discusses European initiatives to address Alzheimer’s disease.

Aresenio Hueros Iglesias considers the consequences of recent austerity measures in Spain.

Maria Guzenina-Richardson, Finnish Minister of Health and Social Services, highlights the newly-launched Finnish Memory Programme.
Welcome
By Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe.

Prioritising Dementia

Debating dementia in the European Parliament
A summary of Alzheimer Europe’s 13th lunch debate, which was hosted by Liam Aylward, MEP (Ireland) and focused on how European health and research programmes are helping to address Alzheimer’s disease.

Alliance in action
An update on some of the European Alzheimer’s Alliance members’ work to raise the awareness of dementia.

Ethical issues linked to restrictions of freedom of people with dementia
Dianne Gove, Information Officer, Alzheimer Europe, highlights the main points from the first meeting of the working group on the ethical issues linked to restrictions of freedom of people with dementia.

Comparing national dementia strategies
Alzheimer Europe reports on the Public Affairs meeting which saw representatives from national Alzheimer associations come together to discuss dementia strategies around Europe.

PharmaCog project
The importance of monitoring the progression of memory impairment is presented by Dr. Giovanni Frisoni, senior researcher for the PharmaCog project.

Policy Watch

Addressing dementia in the EU
Androulla Vassiliou, European Commissioner for Education, Culture, Multilingualism and Youth, discusses the various ways in which European initiatives may help people with dementia and their carers.

National Memory Programme, Finland
A special report on the newly-launched National Memory Programme, including interviews with Maria Guzenina-Richardson, Finnish Minister of Health and Social Services and with Eila Okkonen, Executive Director, The Alzheimer Society of Finland. In addition, a carer lists what they expect and Sirpa Pietikäinen, MEP (Finland) talks about the Programme.

Austerity measures
The impact of austerity measures on people with dementia and their carers is discussed by Arsenio Hueros Iglesias, President of the Spanish Confederation of Associations of Families of People with Alzheimer’s disease (CEAFA) and by Annette Dumas, EU Public Affairs Officer, Alzheimer Europe.

A success story
Antigoni Diakou, President of the Cyprus Alzheimer Association, reports on the successful collaboration between the Association and the Ministry of Health during the work of the Multidisciplinary Committee dedicated to Alzheimer’s disease.

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40 Reaching out to the community

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XI Living with dementia in Austria

A carer from Austria relates his story about caring for his wife who lives with dementia.
Welcome to issue 12 of the Dementia in Europe magazine which is being launched during Alzheimer Europe’s 22nd Annual Conference in Vienna. This conference is entitled “Changing perceptions, practice and policy” and our special section highlights the situation in Austria, with contributions from Alois Stöger, Health Minister for Austria, MEPs Heinz Becker and Angelika Werthmann, as well as Antonia Croy, President of Alzheimer Austria and from a carer.

We provide updates on the work at European level to help people with dementia and their carers. Androulla Vassiliou, European Commissioner for Education, Culture, Multilingualism and Youth, explains how various European initiatives can be used to support work in the field of dementia. In June, Alzheimer Europe hosted its 13th lunch debate in the European Parliament which focused on how the European public health and research programmes will continue to address dementia in Europe.

Since 2007, Alzheimer Europe has developed a considerable body of work in the area of ethics. In this issue we provide an update on our work in 2012 dedicated to ethical issues linked to restrictions of freedom.

Also this year, Alzheimer Europe is continuing to host a series of public affairs meetings with its members and you will find a summary of the most recent public affairs meeting which compared national dementia strategies. Another focus is on our collaboration with European research programmes and we include a report from Dr. Giovanni Frisoni, explaining how PharmaCog may help people with memory problems.

If we are really going to make a difference to the daily lives of people with dementia and their carers, it is essential that national dementia strategies are put in place. Finland launched its National Memory Programme in May 2012 and we provide extensive coverage with contributions from Maria Guzenina-Richardson, Minister of Health and Social Services, Eila Okkonen, Executive Director of the Alzheimer Society of Finland, Sirpa Pietikäinen, MEP (Finland) and also from a carer living in Finland.

I am particularly grateful to Arsenio Hueros Iglesias, President of the Spanish Confederation of Associations of Families of People with Alzheimer’s disease (CEAFA), for his frank article on the impact that austerity measures in Spain and the work of CEAFA to try to put a national dementia policy in place. An overview of the consequences of austerity measures in Europe is provided by Annette Dumas, Public Affairs Officer, Alzheimer Europe.

Whatever the climate, national Alzheimer associations across Europe strive to improve the lives of people with dementia and their carers. We highlight the work of five associations: Cyprus reports on their successful collaboration with the government, Poland, Luxembourg and Ireland look back at 20, 25 and 30 years’ work respectively and Sweden describes how the organisation successfully reaches out to the community through a series of theme nights.

I hope you enjoy our magazine and look forward to meeting you during the conference.

Heike von Lützau-Hohlbein,
Chairperson, Alzheimer Europe
Debating dementia in the European Parliament
A summary of Alzheimer Europe’s 13th lunch debate, which was hosted by Liam Aylward, MEP (Ireland) and focused on how European health and research programmes are helping to address Alzheimer’s disease.

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An update on some of the European Alzheimer’s Alliance members’ work to raise the awareness of dementia.

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PharmaCog project
The importance of monitoring the progression of memory impairment is presented by Dr. Giovanni Frisoni, senior researcher for the PharmaCog project.
DEBATING DEMENTIA IN THE EUROPEAN PARLIAMENT

Alzheimer Europe organised a lunch debate in the European Parliament on 26 June 2012. The focus was on Alzheimer’s disease within the context of the new European public health and research programmes.

“Alzheimer’s disease is forecast to dramatically increase in the next decades and globally it is estimated that there will be 4.6 million new cases of dementia each year, with one new case every seven seconds.”

Liam Aylward

Mr Aylward said that the EU programmes do have the potential to make a big difference in the direction, treatment and lives of sufferers, carers and families and welcomed the presenters from the European Commission: Philippe Cupers, Head of Neurosciences Sector, Medical Research, DG Research and Innovation, and Jürgen Scheftlein, Policy Officer, Mental Health Unit, DG Health and Consumers.

Philippe Cupers also emphasised the importance that dementia has, affecting every family in Europe with a societal cost of EUR 72 billion which is expected to rise to EUR 144 billion in 2040 if no action is taken.

Mr Cupers showed that since 2007, Alzheimer’s disease has been an EU research priority with more than EUR 115 million being allocated to support research in this area. The Commission expects the final figure to be nearer to EUR 150 million by 2014. Whilst the supported research has been carried out in different areas, all share the aim of helping us to better understand the disease. Specific examples of projects include:

• “Memoload” (Neurobiological Mechanisms of Memory Loss in Alzheimer’s Disease).

Opening the meeting, Mr Aylward highlighted the tremendous challenge which Alzheimer’s disease presents: one person in every 20 over the age of 65 is affected by the disease, seven million people in Europe have Alzheimer’s disease or other forms of dementia with some 21 million people looking after people with dementia in Europe. It is forecast to dramatically increase in the next decades and globally it is estimated that there will be 4.6 million new cases of dementia each year, with one new case every seven seconds. The impact on health and social services is already huge and the need for timely and effective actions is paramount.
“LUPAS” (Luminescent polymers for in vivo imaging of amyloid signatures) which aims to develop novel agents and methods for diagnostic, prevention of protein aggregation and treatment of Alzheimer’s and prion diseases.

“PharmaCog” (Prediction of cognitive properties of new drug candidates for neurodegenerative disease in early clinical development). This project focuses on the bottlenecks in drug development. It aims to provide new methodologies to make the process more efficient and result in better information on the development of the disease.

“Chances” (Consortium on Health and Ageing: Network of Cohorts in Europe and the United States). This aims to produce evidence on ageing-related health characteristics and their social-economic implications.

In addition, the JPND (Joint Programming Initiative on Neurodegenerative disease, in particular Alzheimer’s disease) is an initiative driven by Member States and enabling them to coordinate their research in this area.

Future opportunities for research exist with the last call of FP7 and with Horizon 2020. The last calls for FP7, including for the “Health” theme, have been published on 10 July 2012. The health theme includes 5 specific topics for brain research, including the development of effective imaging tools for mental disorders where Alzheimer’s disease can be addressed.

After FP7, the next European research programme “Horizon 2020” (2014-2020) will be launched which has a substantial Commission-proposed budget of EUR 80 billion. There are three main pillars: Industrial leadership, excellent science and societal challenges. Mr Cupers explained that Alzheimer’s research falls in each pillar and in particular within the societal challenges under the “Health demographic change and well-being” which has been allocated around EUR 8.5 billion. He listed the priorities for health research as:

- Understanding the determinants of health, improving health promotion and disease prevention,
- Developing effective screening programmes and improving the assessment of disease susceptibility,
- Understanding the disease,
- Developing better preventive vaccines,
- Improving diagnosis,
- Using in-silico medicine for improving disease management and prediction and treating diseases,
- Transferring knowledge to clinical practice and scalable innovation actions,
- Better use of health data,
- Improving scientific tools and methods to support policy making and regulatory needs,
- Promoting integrated care and
- Optimising the efficiency and effectiveness of healthcare systems and reducing inequalities.

Mr Cupers showed that since 2007, Alzheimer’s disease has been an EU research priority with more than EUR 115 million being allocated to support research in this area.
Mr Cupers also highlighted the “Month of the Brain” initiative planned for May 2013. The aim of this is to raise awareness of the achievements which were carried out as part of FP7 as well as identify what future work should be done.

Jürgen Scheftlein presented other future work which includes Alzheimer’s disease. He highlighted the fact that currently there are only a few things which we can do to address this disease (investing in early diagnosis, improving quality of life, training carers and supporting family members). Whilst recognising these are all challenges in themselves, Mr Scheftlein highlighted the positive elements of the current environment:

- A high quality of commitment now exists. The French President gave his personal commitment to address this disease a few years ago, putting Alzheimer’s disease onto the policy agenda. This has had a long-lasting impact. Mr Scheftlein also noted that the lunch debate itself was well-attended, again showing a high quality of commitment.

- 2012 is the European Year of Active and Healthy Ageing.

- There exists stable cooperation between several European Commission bodies (DG Research, Education, Information and Society and Sanco) and this is not always the case.

- Industry is very active in the development of new drugs to delay the progression of Alzheimer’s disease and

- Alzheimer Europe is a strong NGO which can assist other actors.

Mr Scheftlein said that research includes the exchange of knowledge and best practice and that the latter is a key area which is being focused on. In 2009 the Commission adopted a more strategic approach with the introduction of Joint Actions and Joint Programming. Currently the Joint Action on dementia, ALCOVE (Alzheimer Cooperative Valuation in Europe) is at a half-way point and areas of work include data on prevalence and data on diagnosis. Another focus area in ALCOVE is to improve the rights of people with dementia.

In the meantime, discussions had started within Europe 2020 and the need to focus on innovation and active and healthy ageing. One outcome was the development of the European Innovation Partnership on Active and Healthy Ageing (EIP AHA) which has now taken off and resulted in a strategic implementation plan by the Commission. All stakeholders have been invited to join this partnership and to indicate what they can do themselves to promote active and healthy ageing to work towards the target of two healthy added years. Some 260 commitments have been made. Most partners involved are from the Netherlands and the UK and the most commitments concern diagnosis and cognitive decline. The actors involved in this initiative are diverse and it illustrates that the EIP AHA reaches a wide audience and not only the health sectors.

Mr Scheftlein explained that whilst there are a lot of similarities between “Health for Growth”, the next European health framework programme and “Horizon 2020”, there are also differences. In particular, he highlighted the financial difference between the two, with “Health for Growth” being a
much smaller programme. Therefore the Commission has decided that if it wants to make the best value from the “Health for Growth” programme, it needs to strengthen the focus on: 1. Innovative and sustainable health systems. 2. Increasing access to better and safe health care for citizens. 3. The prevention of disease and the promotion of good health, including active and healthy ageing (AHA). 4. The protection of citizens from cross border health threats. At the moment the Health for Growth programme is being considered by the European Parliament.

Delegates learned that there will be a significant shift with the next health programme. In future there will be less invitations for project activities and Joint Actions will be more common. Alzheimer’s disease will not remain on the health policy agenda as a priority in its own right, but as a challenge integrated into horizontal activities.

Activities which have emerged in the last two years are the AHA initiatives, the building of responsive sustainable health systems and activities on chronic disorders. Mr Scheftlein assured participants that there will still be a strong element of Alzheimer’s disease and that the results from the Joint Actions and research programmes will feed into the implementation of new initiatives.

Ms von Lützau-Hohlbein thanked everyone for their participation, in particular acknowledging the support of the Members of the European Alzheimer’s Alliance. She asked that the Council and European Commission be vigilant to the on-going discussions in the area of chronic diseases, neurodegenerative diseases and ageing. She also called for a good balance to be made between basic research and social and care research to help people with dementia and their carers.

Mr Aylward closed the debate, thanking the speakers for sharing their expertise and saying, “hopefully sufferers of Alzheimer’s disease and their families and carers’ problems will be put on a higher plane at European level.”
A snapshot of Alzheimer Europe’s 13th lunch debate in the European Parliament
ALLIANCE IN ACTION

Alzheimer Europe reports on some of the recent activities carried out by members of the European Alzheimer Alliance.

François Grossetête, MEP (France)
François Grossetête, MEP (France) and Chair of the European Alzheimer’s Alliance participated in the launch of the European Year for Active Ageing and Solidarity between Generations that took place in Paris. The event was an opportunity to present and give visibility of various projects carried out in the field of active ageing.

Ms Grossetête cautioned that the promotion of active ageing to enable EU citizens live independently for as long as possible and in good health should not make us to forget our fight against neurodegenerative diseases. She reminded the audience that, since the French EU presidency that propelled neurodegenerative diseases and Alzheimer’s disease in particular on the European agenda, the European Parliament adopted a series of texts calling upon the European Commission, the Member States and stakeholders to create synergies, share best practice and intensify their efforts to fight neurodegenerative diseases.

As an example, Ms Grossetête mentioned the Joint Programming of research in Neurodegenerative Diseases (JPND), the Innovative Medicines Initiative (IMI) public/private partnership and one of its projects on dementia research (PharmaCog).

The event was opened by Marie-Anne Montchamp, Secretary of State in charge of Solidarity and Social Cohesion, and Anne Houtman, Head of the EC Representation in Paris. Nora Berra, Secretary of State in charge of Health, Claude Greff, in charge of Family, and Paola Testori Coggi, Director General of the Directorate-General for Health and Consumers of the European Commission gave a speech at the close of the meeting.

Marina Yannakoudakis, MEP (UK)
Marina Yannakoudakis, MEP (UK), attended the last quarterly meeting of England’s Dementia Action Alliance (DAA) held on the 30th May in London. The DAA brings together over 120 organisations from across the not for profit, private and statutory sectors to radically improve the lives of people living with dementia. The Alliance takes a voluntary and organic approach to bringing change with each member committing to specific actions such as training staff and conducting research, and then holding each other to account on fulfilling them.

Members meet quarterly to exchange good practice and listen to keynote speakers. At this meeting, members listened to Senior Civil Servant David Behan and British celebrity Angela Rippon describe Prime Minister David Cameron’s Challenge on Dementia and how members could get involved. Ms Yannakoudakis received feedback from members and people living with dementia on the strengths of the Challenge and its possible implications for work at a European level.

The European Alzheimer’s Alliance was set up in the European Parliament in 2007. It is a non-exclusive, multinational and cross-party group which brings together Members of the European Parliament committed to support Alzheimer Europe and its members to make dementia a public health priority in Europe. Currently there are 66 members representing 22 EU countries. (www.alzheimer-europe.org/Policy-in-Practice/European-Alzheimers-Alliance)
Jan Killeen emphasised that often professionals lack confidence in their abilities to assess capacity, or there is a lack of clear guidelines.

Dianne Gove, Information Officer, Alzheimer Europe reports on the work of Alzheimer Europe’s working group on the ethical issues linked to restrictions of freedom.

The first meeting of the working group on the ethical issues linked to restrictions of freedom was held in Brussels on 14 to 15 June 2012. This was the first opportunity for the working group to discuss the scope of the project and to exchange views on the ethical issues linked to several key topics such as involuntary internment, the use of restraint and coercive measures, voting, making a will, having a relationship and driving. These were all issues which Alzheimer Europe had previously addressed but only in relation to their legal aspects. It was a small working group comprised of experts from eight different countries and with varied backgrounds such as law, medical ethics, theology, philosophy, medicine, psychology and care provision. Amongst the experts, there was one person with dementia, a carer and representatives from Alzheimer associations.

James McKillop (MBE) set the scene by asking members of the working group to consider which of a range of activities people with dementia should or should not be free to carry out and why. Throughout the meeting, he shared with the group his personal experience and reflections on various restrictions of freedom from the perspective of someone who has dementia. Maureen McKillop shared her experience as a carer who has been confronted with decisions about restrictions of freedom linked to James having dementia.

Some of the other members of the group then focused on a different issue related to the restriction of freedom and led the discussion about the relevant ethical issues. Chris Gastmans, for example, provided an overview of the ethical issues related to the expression of sexuality in nursing homes based on a review on that topic carried out in collaboration with Lieslot Mahieu. He suggested the need to look beyond the four ethical principles derived from the work of Beauchamp and Childress to a broader ethical consideration including principles related to care, dignity, vulnerability, singularity, historicity and relationality. He also highlighted the impact of age-related stereotypes on attitudes towards sexuality and older people with dementia.

Fabrice Gzil emphasized the close relationship between the deprivation of freedom and the deprivation of rights, reflected on broad, narrow and legal definitions of restraint and highlighted the relationship between personal liberties, civil rights and the law. He explained that restrictions of freedom tend to be based on criteria linked to the necessity to prevent harm to the person and/or others, proportionality (the appropriate level of response to the established need) and subsidiarity (the least restrictive method being used first). He also drew attention to possible conflict between the ethical principles of autonomy, beneficence and nonmaleficence, as well as to the importance of the principle of justice (equity, non-discrimination) regarding the use of restraint.

The grounds for compulsory detention were further developed by Jan Killeen based on her work with the Mental Welfare Commission for Scotland. The group reflected on a series of case studies involving decisions related to compulsory detention or measures to maintain the person in the community. This raised the issue of the need...
to consider carers, of difficulties balancing safety and respect for autonomy and private life and of concerns about liability rather than a person's best interests possibly influencing decisions for compulsory detention. It was suggested that there is perhaps a continuum with the need to respect autonomy and privacy at one end and the need to protect at the other end. Whilst it was agreed that measures should be taken to provide sufficient support to enable a person to maintain his/her freedom, the question which remained was “up to what point?” This highlighted the need to explore the concept of reasonable accommodation. This involves the duty to take reasonable measures to ensure to people with disabilities (i.e. including people with dementia) “the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms” (United Nations Convention on the Rights of Persons with Disabilities of 2006, article 2).

Jan emphasised that often professionals lack confidence in their abilities to assess capacity, or there is a lack of clear guidelines. Failing to make such assessments, she added, may actually limit the options open to the person and by waiting for a crisis, end up restricting their liberty more than necessary.

Speaking about voting and making a will, Maria do Rosário Zincke dos Reis drew attention to the legal practice in some countries of applying a classification of the degree of incapacity to a person with dementia and the implications of this. She questioned whether such practices, which affect the right to make a will and vote regardless of whether a person has the necessary capacity for those tasks, actually protect or promote self-determination. The relevance to this debate of Recommendation CM/Rec(2011)14 of the Committee of Ministers to member states on the participation of persons with disabilities in political and public life was highlighted.

Marianna Siapera reflected on how disclosure of the diagnosis of dementia respects the principle of autonomy by enabling people with dementia to make informed decisions about care, treatment and life in general. She drew attention to the impact of negative perceptions of dementia on practices related to disclosure and raised several issues linked to driving such as privacy and confidentiality, the safety of the person with dementia versus that of other people and the justification and means of testing driving capacity (i.e. do measures used have ecological validity?).

Antonio Burgueño Torijano provided a compelling argument for zero tolerance regarding the use of restraint.
Last but not least, Antonio Burgueño Torijano provided a compelling argument for zero tolerance regarding the use of restraint. He highlighted the possible physical and psychological adverse effects of physical and chemical restraint and provided scientific evidence in support of his argument. He also warned against paternalism, emphasized that accepting some degree of risk is an essential part of good care and suggested that the use of restraint was poor clinical practice.

The points raised during this meeting will now be further considered in the light of the ongoing literature search. A first draft of the final report will be presented and debated at the next meeting in October when the working group will also draft recommendations to accompany the description of the ethical issues identified. The working group will produce a report on the ethical issues related to restrictions of freedom which will be published at the end of 2012.

Alzheimer Europe’s 2012 Ethics Working group:

Ms Eleanor Edmonds, Legal Policy Officer, Alzheimer Society of Ireland (not at the meeting); Dr. Brenda Frederiks, Assistant Professor Health Law, VU medical centre, Amsterdam, Netherlands (not at the meeting); Prof. Chris Gastmans, Professor of Medical Ethics, Centre for Biomedical Ethics and Law, Faculty of Medicine, Catholic University of Leuven, Belgium; Ms Dianne Gove, Information Officer, Alzheimer Europe, Luxembourg; Dr. Fabrice Gzil, Fondation Médéric Alzheimer, Research Program Manager (France); Ms Jan Killeen, Policy Consultant, Alzheimer Scotland; Mr James McKillop MBE, Scottish Dementia Working Group (SDWG), Scotland, UK; Ms Maureen McKillop, Carer, Scotland, UK; Dr. Anna Maki-Petäjä-Leinonen, Finland; Dr. Marianna Siapera, Greece; Dr. Antonio Burgueño Torijano, Director of The National Program to Untie the Elderly and the Person with dementia in Spain; Ms Maria do Rosário Zincke dos Reis, Chairperson Alzheimer Portugal and Honorary Treasurer Alzheimer Europe Board.

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For over 50 years, Novartis has been a leader in neurology care. Our neuroscience products have touched the lives of millions of patients worldwide. In dementia care, we continually strive to translate scientific innovation into therapies and technologies that matter.

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COMPARING NATIONAL DEMENTIA STRATEGIES

We report on Alzheimer Europe’s third Public Affairs meeting on 26-27 June 2012 which was dedicated to a comparison of national dementia strategies and policies.

In June, members of Alzheimer Europe came together to discuss national dementia strategies and policies in the areas of early diagnosis, treatment and research. Discussions were lively and extremely thorough, resulting in a wealth of information being exchanged by representatives from all regions in Europe. These contributions will help to create national reports which will be published in the 2012 Dementia in Europe Yearbook. This is the first of two books on national dementia strategies around Europe.

The meeting revealed many differences between the various countries. The importance of harmonising the variations was highlighted during the meeting. For example, although some diagnostic criteria exist on a European level (European Federation of Neurological Societies) there is no consensus about which criteria should be used. Currently, practitioners vary how they apply such criteria, not only from country to country, but even from doctor to doctor. Further, the criteria will change as the concept of dementia develops. Unfortunately, the consequence of a lack of a commonly accepted and applied criteria results in information which cannot be fully utilised. Therefore valuable information is being lost which could be highly beneficial when addressing Alzheimer’s disease. In particular, policy makers are unable to fully appreciate the situation and take appropriate action.

Similar problems were highlighted and debated in the following areas:

- The role of general practitioners in the detection and diagnosis of Alzheimer’s disease,
- Care pathways from primary to secondary care,
- The reimbursement of treatments,
- GP training and support,
- The support of dementia research by national governments,
- The creation of information centres,
- Awareness campaigns and lobbying activities of national Alzheimer associations and
- The involvement of national organisations in the development and monitoring of dementia strategies.

The outcome of the frank discussions was extremely positive as they enabled members to identify best practices which will be included in the Yearbook as recommendations.

Public Affairs meeting attendees:

Dr. Giovanni Frisoni, senior researcher for the PharmaCog project writes about the importance of monitoring the progression of memory impairment.

If you had problems with your memory, you would be very worried. If you repeatedly forgot important events of your recent past, such as whom you had dinner with last Sunday or your niece’s wedding last month, you would be very, very concerned.

A study is currently underway in Europe, aiming to understand what happens in the brains of people who have started losing their memories and are missing bits and pieces of their autobiographical past. The project is called “PharmaCog” and is funded by the European Commission (Innovative Medicine Initiative funding scheme) and a number of pharmaceutical companies committed to develop effective and innovative drugs. The project has 29 partners (including Alzheimer Europe) coming from ten different EU Member States.

PharmaCog gives people with memory troubles the opportunity to check what may be going wrong in their brains. They undergo the most updated image collecting protocols on Magnetic Resonance, blood drawing for the study of blood biomarkers of Alzheimer’s disease, EEG for electrophysiological biomarkers, lumbar puncture to study the intimate chemistry of the brain and neuropsychological tests to track the progression of cognitive impairment.

Importantly, these exams are performed every six to 18 months, which allows scientists to monitor the rate of progression of the fundamental neurobiology of neurodegeneration and Alzheimer’s disease.

Physicians are often asked by caregivers of patients with Alzheimer’s disease: “Doctor, my relative is going from bad to worse, can we take another Magnetic Resonance scan to figure out what is happening in that brain?” As a rule, the answer is negative because routine Magnetic Resonance is less sensitive to change than neuropsychological tests or even clinical observation.

However, physicians taking part in PharmaCog can give a positive answer: their patients can undergo a range of very sensitive exams that capture a number of neurobiological phenomena representing disease progression.

PharmaCog is not only an advanced and exciting scientific initiative, but a spectacular opportunity for patients with memory problems. For more information about the project please see www.pharmacog.org.

Giovanni Frisoni is currently Deputy Scientific Director of the IRCCS (Scientific Institute for Research and Care) and Director of the LENITEM (Laboratory of Neuroimaging and Telemedicine) at the IRCCS-FFB as well as Imaging Section Editor of the journal of Neurobiology of Aging.

**The PharmaCog consortium consists of the following partners coming from 10 different EU Members States:**

1. Alzheimer Europe (Luxembourg),
2. AstraZeneca (United Kingdom),
3. Boehringer Ingelheim (Germany),
4. Centre National de la Recherche Scientifique (France),
5. Eli Lilly and Company (United Kingdom),
6. Exonhit Therapeutics (France),
7. F. Hoffmann-La Roche (Switzerland),
8. GlaxoSmithKline (United Kingdom),
9. H. Lundbeck (Denmark),
10. Innovative Concepts in Drug Development (France),
11. Innovative Health Diagnostics (France),
12. Institut d’Investigacions Miomèdiques August Pi i Sunyer (Spain),
13. Institut de Recherche Servier (France),
14. Institut National de la Santé et de la Recherche Médicale (France),
15. Istituto di Ricerche Farmacologiche "Mario Negri" (Italy),
16. Janssen Pharmaceutica (Belgium),
17. Merck (Germany),
18. Novartis Pharma (Switzerland),
19. Ordine Ospedaliero di San Giovanni di Dio Falebenefratelli (Italy),
20. Qualissima (France),
21. SAS Alzprotect (France),
22. UCB Pharma (Belgium),
23. Universidad de la Méditerranée, Aix-Marseille II (France),
24. Università degli Studi di Foggia (Italy),
25. Università degli Studi di Verona (Italy),
26. Universitat de Medizin Essen (Germany),
27. Université de la Méditerranée, Aix-Marseille II (France),
28. Université de Lille 2 (France),
29. Universität Leipzig (Germany),
30. Università di Roma La Sapienza (Italy),
31. Università degli Studi di Bari (Italy).

**“PharmaCog gives people with memory troubles the opportunity to check what may be going wrong in their brains.”**

Dr. Giovanni Fisoni
Antigoni Diakou, President of the Cyprus Alzheimer Association, talks about the Multidisciplinary Committee on Alzheimer’s disease.

Annette Dumas, Public Affairs Officer, Alzheimer Europe, considers the impact that austerity measures have on people with dementia.

Maria Guzenina-Richardson highlights the newly-launched Finnish Memory Programme.

Androulla Vassiliou, European Commissioner for Education, Culture, Multilingualism and Youth, discusses the various ways in which European initiatives may help people with dementia and their carers.

A special report on the newly-launched National Memory Programme, including interviews with Maria Guzenina-Richardson, Finnish Minister of Health and Social Services and with Eila Okkonen, Executive Director, The Alzheimer Society of Finland. In addition, a carer lists what they expect and Sirpa Pietikäinen, MEP (Finland) talks about the Programme.

The impact of austerity measures on people with dementia and their carers is discussed firstly by Arsenio Hueros Iglesias, President of the Spanish Confederation of Associations of Families of People with Alzheimer’s disease (CEAFA) and secondly by Annette Dumas, EU Public Affairs Officer, Alzheimer Europe.

Antigoni Diakou, President of the Cyprus Alzheimer Association, reports on the successful collaboration between the Association and the Ministry of Health during the work of the Multidisciplinary Committee dedicated to Alzheimer’s disease.

Alzheimer Europe highlights some of the recent policy developments.
Alzheimer Europe speaks with Androulla Vassiliou, European Commissioner for Education, Culture, Multilingualism and Youth about European initiatives which will help, amongst others, people with dementia and their carers.

“...I firmly believe that education in any form can improve health and well-being.” Commissioner Androulla Vassiliou

Learning also improves knowledge about healthy living and encourages healthy activities like physical exercise. Research indicates that people who take part in leisure activities and volunteering are healthier, happier and live longer.

The European Commission supports action to address these issues through “Alzheimer Cooperative Valuation in Europe” (ALCOVE), an initiative involving 19 countries which seeks to increase knowledge about dementia, which will lead to earlier diagnosis, as well as to improve care for sufferers, particularly those with behavioural disorders.

AE: How does DG Education and Culture support the European Commission’s European Innovation Partnership on Active and Healthy Ageing and its priorities related to the care of chronic diseases, independent living, malnutrition and age-friendly environments?

AV: Education and learning are recognised as an important part of healthy and active ageing strategies. The World Health Organization defines the availability of lifelong learning as a key factor for creating a social environment that enhances health. The European Union supports the learning needs of older people in various ways. Lifelong learning has been actively promoted by the EU in the past decade and highlights...
the benefits of a long-term and joined-up approach to education and training.

The Council’s resolution on a renewed European Agenda for Adult Learning adopted by Ministers last November is very clear on this point. We need well-developed learning provision for older people in order to promote active, autonomous and healthy ageing, and to use older people’s knowledge and experience for the benefit of society as a whole. The resolution calls for a strong commitment to promote adult learning as a means of fostering solidarity between different age groups – a message which has been widely echoed during this 2012 European Year of Active Ageing and Solidarity between Generations.

Learning later in life can also contribute to improving the sustainability and efficiency of healthcare systems, which is one of the objectives of the European Innovation Partnership on Active and Healthy Ageing. The majority of European family carers are aged 45-64 and are often caring for both their parents and their children. Despite the significant economic value of family caring and the fact that it is essential for those members of society in need of care and assistance, the level of attention focused on carers’ needs in policy and practice has until recently been low. However, our ageing population in Europe means that the issue is now much higher on the policy agenda and research suggests that learning is especially important for carers themselves in order to progress in their careers or return to work.

The Commission has received more than 260 commitments from stakeholders who want to support the European Innovation Partnership on Active and Healthy Ageing. The commitments include a range of measures, such as use of ICT and virtual reality tools, to stimulate intellectual activity among people with symptoms of dementia. Such interventions have shown their potential for slowing down the loss of cognitive functionality and the ability to live independently.

AE: How can DG Education and Culture support the Europe 2020 Strategy and, in particular, the “New Skills, New Jobs” flagship?

AV: The Europe 2020 strategy for growth and jobs is aimed at all age groups; the need to invest in lifelong education and training is fundamental for smart, sustainable and inclusive growth.

The aim of the European Commission’s agenda for new skills and jobs is primarily to help people develop their skills and to ensure that these skills match labour market needs. This is imperative, given the demographic situation in Europe, where every single one of us will need to remain active as long as we can. In this light, it is crucial that working experience and competences acquired outside the formal education system are fully recognised and that employers encourage more flexible working patterns. The European Qualification Framework and other tools for validation and recognition of competences have been developed to facilitate learning and working mobility. The European Commission supports specific ICT and entrepreneurship projects focusing on older people. The idea is to keep developing and using our skills so that we can contribute to the economy long after we have retired from work.

AE: “Erasmus for All”, your new programme for education, training and youth, seeks to improve the employability of young people. Can “Erasmus for All” provide solutions to the current shortage of healthcare workers and contribute to improvements in the care of people with dementia?

“Despite the significant economic value of family caring ... the level of attention focused on carers’ needs in policy and practice has until recently been low.” Commissioner Androulla Vassiliou
AV: You are right: Erasmus for All aims to improve the employability of young people by significantly increasing the availability of study and work opportunities abroad. This international experience allows them to develop their language abilities, as well as their communication, team-working and intercultural skills.

But Erasmus for All is not just about young people. The proposal includes an 80% increase in funding for adult learning, from EUR 60 million a year to EUR 110 million a year. This includes support for learning exchanges and cross-border projects covering all disciplines, including health care.

One of our objectives is to bridge the gap between education and the world of work, and to encourage young people to take up studies in fields where we can expect increased demand. The Commission has identified health services as one of the three areas with the biggest job potential for the future, together with the green economy and ICT. But it is clear that we must improve health workforce planning and forecasting to match the demand and supply of health professionals, while offering them better long-term job prospects. We also need to stimulate exchange on innovative and effective recruitment and retention strategies for healthcare workers.

AV: Cultural expression is deeply rooted in all of us and does not diminish over time, though we sometimes forget that age and diseases might become an obstacle to accessing or sharing culture. However, I believe that culture and art can be our allies in helping to remove or alleviate such obstacles, especially when it comes to elderly people, including those with dementia.

Projects focused on music and art therapy can apply for funding under the current Culture Programme provided they meet the selection criteria: for example, at least three organisations in three of the 37 European countries which participate in the programme must be involved. In principle, it will be the same under the future “Creative Europe” programme, provided the projects are in line with the overall aims of the programme.

Many of the projects we currently fund target the elderly and disadvantaged groups in general. For instance, we supported the “Discovering Theatrelands” project with the Polish Theatrum Gedanense Foundation and partners in the Czech Republic, Germany, Hungary and the United Kingdom. The project promotes culture as a tool for social change and offers interactive cultural activities for various social and age groups.

There is an enormous potential for projects to reach out to the elderly, in particular those affected by dementia. I am convinced that we can help raise awareness of the beneficial effects of culture on dementia sufferers and improve their quality of life.
NATIONAL MEMORY PROGRAMME, FINLAND

Ms Maria Guzenina-Richardson, Finnish Minister of Health and Social Services, talks with Alzheimer Europe about the National Memory Programme, which was launched in May 2012.

Alzheimer Europe (AE): Can you explain why Finland launched the Finnish National Memory Programme?

Maria Guzenina-Richardson (MGR): More than 13,000 people in Finland are diagnosed with dementia every year. Memory disorders do not only affect older people; estimates of the number of people among the working-age population who suffer from memory disorders vary between 5,000 and 7,000. Individuals suffering from progressive memory disorders need and rely heavily on social welfare and health care services; for example, three out of four clients receiving 24-hour care have cognitive decline. In order for us to be able to meet the increasing demand for services, we need action a) to promote brain health, b) to prevent memory disorders, c) to detect memory loss symptoms as early as possible and d) to develop a system that ensures that treatment, rehabilitation and support are provided systematically and at the right time and that allows monitoring and follow-up – in other words, an effective and seamless clinical pathway.

The National Memory Programme is Finland’s way of joining many other countries that are responding to the European Parliament’s written declaration on preventing memory disorders, especially Alzheimer’s disease, and on improving the quality of life of those suffering from memory disorders as well as their significant others.

AE: What do you see as the main priorities and challenges of the Programme, particularly in relation to dementia?

MGR: The objective of the National Memory Programme is to build a “memory-friendly” Finland on the basis of four pillars:

- Promoting brain health,
- Fostering a more open and positive attitude towards brain health, care and treatments as well as rehabilitation,
- Ensuring a good quality of life for those with memory disorder and their families through timely support, treatment, rehabilitation and services and
- Strengthening research and education.

“A ‘memory-friendly’ Finland is a society that takes the promotion of brain health and the early detection of memory loss symptoms seriously.” Maria Guzenina-Richardson

A “memory-friendly” Finland is a society that takes the promotion of brain health and the early detection of memory loss symptoms seriously. Anyone diagnosed with a memory disorder has access to appropriate treatment, care and rehabilitation. Patients can lead their lives with dignity, and they will not be left without support.
AE: How will the Programme be implemented and over what time period?

MGR: The programme ties in with the objectives of Finland’s social welfare and health policies and existing care guidelines and quality recommendations, and its implementation will be coordinated with on-going legislative initiatives and other programmes such as Finland’s National Development Programme for Social Welfare and Health Care. The time period is from this year up to 2020.

AE: What role do you see patient groups playing in implementing the Programme?

MGR: NGO’s representing persons with memory disorders play an important role in the implementation. There are proposals for actions and coordinators in the programme, for example:

- providing support and information about brain health promotion to the general public as well as

- providing people with memory disorders and their families with opportunities to engage in social activities, access to peer support and information to help them cope with daily routines and enjoy a richer life and are examples of the roles that the NGO’s could have. There are several other possibilities included in the programme.

AE: In Finland you have in place “Current Care guidelines for the treatment of memory disorders”. How can these guidelines help people with dementia and their carers?

MGR: The Current Care guidelines are evidence-based clinical practice guidelines. The guidelines are intended as a basis for treatment decisions, and can be used by physicians, healthcare professionals and citizens. The guidelines are available on the internet. When professionals use the guidelines, people with dementia are treated effectively. The best available evidence is used in diagnostics and care.

AE: Do you see a need for greater European collaboration on dementia?

MGR: Of course. The challenge is common and we must learn from each other and share the best practices. The Finnish Memory Programme has just been translated into English in order to facilitate collaboration.

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A carer for a person with dementia lists what they expect from the National Memory Plan

- To see a major change in attitudes. A person with dementia must be regarded as a full and equal member of the Finnish Society and be entitled to good quality of life.
- To see improved service and care of all people with dementia irrespective of whether they live at home, nursing home or hospital.
- To see an increase in the number of qualified memory nurses.
- To see that quality of service is being measured frequently.
- To see timely diagnosis.
- To see that when a person with dementia needs to move to a nursing home he or she can live there without the threat of having to move again when health deteriorates.
- The successful implementation of the plan is depending on the human and financial resources which have not yet been defined. This is an urgent matter.
Alzheimer Europe (AE): What role was played by the Alzheimer’s Society in the development of the National Memory Programme?

Eila Okkonen (EO): The Alzheimer Society of Finland was established in 1988 to provide help and assistance for people with Alzheimer’s disease and their caregivers. The society is a non-profit organisation and it is mainly funded by the Finnish Slot Machine Association. The Society consists of a national office with 3 local branches and 44 local associations across the country with more than 11,000 members altogether.

In the year 2010, the Alzheimer Society of Finland was one to demand a National Memory Strategy for Finland by collecting over 14,000 names for a petition. The collection of names was arranged many ways, for example via Internet, in the “Good Age Exhibition” and in many events in different parts of Finland. The Alzheimer Society of Finland has been active in demanding rights for people with memory-related diseases and their next of kin.

The Finnish Ministry of Social Affairs and Health started the development process for a National Memory Strategy in December 2010 by setting up a working group consisting of 18 professionals, including a representative from the Alzheimer Society of Finland. The Strategy went through a commentary round in November 2011 and we commented on the draft.

The National Memory Strategy was launched on 5 May 2012.

AE: What impact will the Memory Programme have and what challenges does the Alzheimer’s Society see?

EO: The Alzheimer Society of Finland is pleased to see the Memory Programme taking firm approach to brain health promotion and the prevention of memory-related diseases. Rehabilitation – in addition to good care – is also one of the four basic principles, and the right for self-determination is pinpointed as well. These are important aspects concerning the well-being and the quality of life of people with dementia.

The Society expects a strict policy for the implementation and monitoring of the Strategy, including definite time schedules and monitoring the organisations in charge.

A significant proportion of people with dementia remain undiagnosed, which leads to excessive use of social and health services and is extremely expensive to society. That is why public and occupational health care professionals have to recognise early memory problems and direct people to memory examinations when required. The aim is to diagnose memory-related diseases in order to start medical treatment, good care and rehabilitation as early as possible. The investment in the good expertise of social and health care professionals is needed.

Research and the competence of social and health care professionals is one of the four basic principles of the Strategy. Multidisciplinary and coordinated research is seen essential to combat the challenge that dementia builds on public health services and economy.
We have and need high-quality, versatile and nationwide research. Research on brain health, diagnostics and care services has already helped to develop new innovations, but we still need more on the psychosocial support and the possibilities of technology for the people with dementia. We also need to advance the research results being processed into action especially in the public health care services, so that practice is evidence-based.

Our greatest concern is that the action plan will give clear and concrete enough steps so that people with memory-related diseases and their next of kin will feel that not only can they get the help and support they need but that they are also included throughout the different stages of the disease.

We will continue our work to

- improve the quality of life for people with memory related diseases and their caregivers,
- promote the legal, economic and social rights of people suffering from dementia,
- develop the support system of people with memory-related diseases and their caregivers,
- influence the attitudes towards people with memory disturbances and
- influence the political decision making process.

Sirpa Pietikäinen, MEP (Finland) gives her response to the National Memory Programme for Finland

Fundamental rights of people with memory diseases still need strengthening

It is with great pleasure that I can say the National Memory Programme 2012-2020 now sees daylight and stands side to side with other European National Plans. The Finnish Memory programme has many positive things in it. Firstly, the importance and relevance of tackling memory diseases is enhanced, giving priority to early diagnosis and rehabilitative care.

Also, the programme underlines the fact that currently 75 per cent of people living permanently within institutionalised care are suffering from memory diseases. As a remedy for this, support for home care, the role of rehabilitation and custom-based care chain are prioritised in the programme.

As one of the thematic points, the National Memory Programme introduces the promotion of positive attitudes towards people with memory diseases. Change in attitudes is certainly needed. However, changing of attitudes doesn't reflect the more urgent need to safeguard the fundamental rights of people with memory diseases. This is not currently sufficiently done – a more rights based approach is needed in order to protect the rights of those who are not able to protect themselves. In relation to this, more powers should be given to the memory organisations to serve as proxies for the general interest of people with memory diseases as well as for the individual patients in decision-making situations concerning their own interest in care, housing and other fields of life.

What is also missing from the programme is the call for social innovations and society’s infrastructural adaption to the increasing amount of citizens with memory diseases. Also, I would have wanted to see some more concrete measures to be taken, such as a clear timetable and allocation of funding for the implementation of the programme and set staff sizing targets for memory disease professionals in the health care sector.
Addressing dementia in Austria
Alois Stöger, Austrian Health Minister, discusses how the challenge of dementia is being addressed on a national level.

The view from Austria
Austrian MEPs Heinz Becker and Angelika Werthmann talk about the situation in Austria for people with dementia and their carers.

Alzheimer’s disease is a reality in our society
Antonia Croy, President, Alzheimer Austria, reflects on the work of the association since it was launched in 1990.

Some thoughts on the work of Alzheimer Austria
Andreas Wrinker, Neurologist and Vice-President of Alzheimer Austria, together with DdR Michael Landau, Director of Caritas, diocese of Vienna, reflect on the work carried out by the association.

Living with dementia in Austria
A carer from Austria relates his story about caring for his wife who lives with dementia.
Alois Stöger, Health Minister for Austria, speaks with Alzheimer Europe about how the challenges of dementia are addressed in Austria, the impact of the economic crisis and the need for European collaboration.

Alzheimer Europe (AE): How is Austria dealing with the ageing of the population and the challenges of age-related diseases like dementia?

Alois Stöger (AS): Today our country has one of the highest life expectancies worldwide. According to the Austrian Statistical Office, life expectancy at birth for men is currently 78.1 years, and that for women 83.4 years. Women thus live on average approximately 5.3 years longer than men. Life expectancy of Austrians has considerably increased over the past few decades, by almost three years per decade.

A consequence of longer life expectancy is the growing significance of non-communicable diseases including dementia. In a similar way to other illnesses, treatment for age-related illnesses is covered by comprehensive social health insurance which is a major feature of the Austrian health care system.

Important factors to ensure quality and enjoyment of life for old people include the ability to take part in social life and the autonomy to live in one’s own home for as long as possible. For this reason, health promotion and prevention are important issues of the Austrian health policy.

AE: How does dementia impact people with dementia and their carers in Austria?

AS: Dementia is one of the major causes of disability and dependency among older people. It is also a tremendous burden for families and caregivers of people affected by dementia. The need for long-term care for people with dementia strains the health and social system and the budget. The contribution by informal carers cannot be appreciated enough.

AE: Are there any steps being taken in Austria towards a national dementia strategy?

AS: Within the scope of Austrian health policy, dementia in general and Alzheimer’s disease in particular are regarded as urgent and complex issues.

The Austrian Ministry of Health established the “Advisory Board for Geriatric Medicine” in 2007. It includes experts from the relevant fields who work on the complex topic of geriatrics. The task of this advisory board is to define age-specific and medical problems. Naturally, dementia is a central theme. Our goal is to develop suitable measures and to improve the general medical conditions.

In Austria there are many initiatives and projects aiming to find answers to the problems of dementia. One specific project deals with person-centred and gender-sensitive communication with women and men with dementia. This project highlights many empathic non-verbal ways of response and communication such as gestures, mimic and touch. Hopefully the recommendations will contribute to a new culture of adequate and respectful manners towards people affected by dementia.

AE: How is Austria addressing the economic crisis and the danger that health and social support may be adversely affected?

AS: The main principles of the Austrian health care system are solidarity, affordability and universality. Currently there are no implications of the economic crisis on our health care system.
In Austria, healthcare is based on a social insurance model that guarantees all inhabitants equitable access to high quality health services – irrespective of their age, sex, origin, social status or income.

The Austrian healthcare system is based on statutory social insurance. Access to services is regulated by law, the most important legislative basis being the General Social Insurance Act (ASVG). All insured people have a legal right to a large number of benefits.

AE: Do you believe it is necessary to collaborate on the issue of dementia at European level and, if so, in which areas?

AS: From an Austrian perspective I believe that on an EU-level networking and collaboration of all people concerned with problems of dementia care is strongly required. Sustained action and coordination is essential across multiple levels and with all stakeholders at international, national, regional and local levels.

“The contribution by informal carers cannot be appreciated enough.”

Alois Stöger

**ESTIMATED NUMBER OF PEOPLE WITH DEMENTIA IN AUSTRIA (2006)**

There were 126,296 people with dementia in Austria in 2006

N.B. Prevalence figures for 30-59 age group from EURODEM (Hofman et al) and for 60+ age group from EuroCoDe (Reynish et al).
THE VIEW FROM AUSTRIA

Alzheimer Europe interviews Austrian MEPs and members of the European Alzheimer’s Alliance, Heinz Becker and Angelika Werthmann about the challenges faced by people with dementia and their carers in Austria.

Heinz Becker, MEP (Austria)

Alzheimer Europe (AE): Mr. Becker, what are the key challenges that people with dementia and their carers face in Austria?

Heinz Becker (HB): Dementia patients have to cope with enormous changes in their lives. Simple everyday tasks, such as going to the supermarket become a challenge, due to the progressing memory loss and beloved persons suddenly seem to be strangers, which leaves the people with dementia with a feeling of loneliness and misunderstanding. The permanent deterioration of the disease and the fact that there is no hope for recovery pose new challenges every day of the patient’s and their carer’s lives. In addition to these problems, people suffering from dementia and their carers have to deal with a lack of support and insufficient information. They don’t know who to consult and where they can obtain help, which makes this difficult situation even more challenging. Furthermore carers are exposed to a permanent overload, as around 80 percent of all dementia patients are being taken care of at home. Studies show that carers are more likely to fall ill as a consequence of the permanent emotional and physical stress. As women account for the majority of the carers, this has a particular significance for them. Up to 47 percent of carers suffer from depression and the mortality risk is 60 percent higher compared to the rest of the population. Therefore it is important to take action and improve the support of the patients and their relatives.

AE: Governments across Europe are starting to pay more attention to the demographic changes in our societies and the resulting increase in the number of people with dementia in the future. Are there similar discussions in your country on a governmental or parliamentary level?

HB: The national report of dementia in Austria shows there are currently 100,000 people suffering from dementia, two thirds being female. Due to the rising life expectancy this number could almost be tripled in 2050 with every twelfth Austrian older than 60 being a dementia patient. This makes dementia one of our most important challenges in the future. In the Austrian Government Program 2008 - 2013 the health promotion and prevention of dementia is specifically mentioned as one of the main goals of the current government and various measures towards a better environment for dementia patients and their carers have already been taken. Nevertheless, there is still need for action as not all of the problems have yet been solved.

AE: Do you believe that Austria will follow the example of France, Norway, the Netherlands, Scotland and England and create a National Alzheimer’s Plan?

HB: At the moment there are no reports on plans to implement a National Alzheimer’s Plan in Austria. Therefore I am calling for a change in this matter. In order to deal with the increasing challenge of dementia we urgently need a specific plan, including a certain budget in order to provide strong support for people with dementia, to finance research in this area in order to provide the patients with a more effective treatment, to develop guidelines for the treatment of dementia, to offer regular check-ups for an early detection of the disease and the support of Active Healthy Ageing concepts in order to prevent or at least to achieve a decline in the number of people with dementia. We must not accept the fact that 100,000 people in Austria and approximately
9.95 million (World Alzheimer Report 2010) people in Europe are suffering from dementia and that this number is steadily increasing. I am urgently pressing for more specific measures, such as the creation of a National Alzheimer’s Plan.

AE: What do you believe the three policy priorities should be for Austrian policy makers to improve the lives of people with dementia and their carers in your country?

HB: First and foremost it is essential to provide more information on this serious disease for the dementia patients, their family members and carers in order to reduce the uncertainty which usually results from dementia. Therefore the implementation of one key contact person for all concerns and questions about dementia and its therapy could be an option. After the diagnosis of dementia the patients and their relatives are overwhelmed by the news and don’t know to whom they can refer to. A main contact could provide the people affected by the disease with information and help them navigate through the system and plan their care pathway.

Secondly the establishment of a “competence centre” has already been suggested by the Austrian national report of dementia, in which everyone included in the process of caring for a dementia patient, as for example carers from inside or outside of the family, doctors and social workers, work together. This “integrated care” could result in a better orientation for the people with dementia and facilitate the therapy.

Thirdly a strong focus must be put on the early detection and prevention of dementia, as therapy is especially important in the first stages of the disease. Even though there is no chance for recovery, the progression of the disease can be slowed down. I would also like to point out the importance of “Active Healthy Ageing in a Lifetime Perspective”, a subject on which I put a strong emphasis in my work as a member of the Committee for Employment and Social Affairs and to which I have recently hosted an expert’s roundtable in the European Parliament. “Active Healthy Ageing” should be centred around mental activity, physical activity and a balanced diet. These factors can decrease the risk of developing dementia and therefore it is essential that we start with preventive action at an early age.

AE: A last question on the need for a European response to the growing numbers of people with dementia. Would you support the development of a European Action Plan in this field and, if so, what should the priorities for such a collaboration be?

HB: As Dementia represents a challenge not only for specific countries, but for the entire European Union, a European Action Plan would be a necessary instrument to cope with the rising number of people with dementia. It is important to raise awareness of dementia in order to prevent the stigmatisation of dementia patients and the fear of dementia, for example by starting EU-wide information campaigns in which all stakeholders and member states’ authorities should be actively involved from now on.
Angelika Werthmann, MEP (Austria)

Alzheimer Europe (AE): Ms Werthmann, what are the key challenges that people with dementia and their carers face in Austria?

Angelika Werthmann (AW): Currently, there are 120,000 patients with dementia in Austria, two-thirds of them are women and many of them suffer with Alzheimer’s disease. 80% of these people stay at home for many years and receive care and assistance by their close family. There is a lack of day-care services, of long-stay centres and, in addition to this, home-based care needs to be further developed. Another problem is that neither the patients nor their carers receive any recognition for the situation they are in. In some cases there is no recognition from family and friends, and in other cases, family and friends belong to the carers and do not receive any recognition either.

There are only six day-care centres in the country (all of which are run by Alzheimer’s Associations under the 3rd European Support Framework) and there are no homes specifically for Alzheimer’s patients. There is no national action plan to fight dementia.

As the life expectancy of the Austrian population increases, the number of people with dementia will increase to 270,000 by 2050, which actually means that it will almost triple. By 2050 it is expected that every twelfth Austrian over 60 will have the dementia.

Dementia will also impact on work-life – the relationship between employment and people with dementia will change rapidly; according to the “First Austrian Dementia Report” it is expected that in 2020 every 32nd person of working-age will have dementia and in 2050 this will increase to be every 15th.

AE: Governments across Europe are starting to pay more attention to the demographic changes in our societies and the resulting increase in the number of people with dementia in the future. Are there similar discussions in your country on a governmental or parliamentary level?

AS: The Commission’s proposal for Horizon 2020 identifies the ‘health, demographic change and well-being’ challenge which is likely to provide opportunities for research on Alzheimer’s disease. No action specifically addresses Alzheimer’s disease in the Competitiveness and Innovation Framework Programme or in the Connecting Europe Facility (2014-2020).

Neither the Austrian government nor the Austrian Parliament pays much attention to the growing problem of dementia in Austria.

So far, FP7 support for research on Alzheimer’s disease has been received in 20 Member States. Variation in the participation depends on several factors such as national interest and investment in this area, existence of expertise and dedicated infrastructure which may influence scientists’ interest in a specific subject. Several measures are foreseen under Horizon 2020 to widen participation across Europe.

AE: Do you believe that Austria will follow the example of France, Norway, the Netherlands, Scotland and England and create a National Alzheimer’s Plan?

“There is an urgent need to get dementia on the public and political agenda in Austria.”
Angelika Werthmann
AS: Yes, there is an urgent need to get dementia on the public and political agenda in Austria. Austria should certainly follow the examples of France, Norway, the Netherlands, Scotland and England. I hope that it will not take too long for Austria to take that path.

AE: What do you believe the three policy priorities should be for Austrian policy makers to improve the lives of people with dementia and their carers in your country?

AS: At EU-level, support for research on neurodegenerative diseases was a priority in the 7th Framework Programme for Research and Technological Development (FP7, 2007-2013) with about EUR 320 million dedicated to this area, including some EUR 115 million on Alzheimer’s disease. Research is essential to combat the fact that the more the population of Europe is ageing, the more European citizens will have to face Alzheimer’s disease.

Research on Alzheimer’s disease could be supported by cohesion policy. Austria, as well as other Member States, is responsible for the selection of projects under national or regional programmes, which may best contribute to the objectives of this policy, ensuring respect of applicable rules and keeping a record of these projects. The Commission’s responsibility is to ensure compliance with the EU legislation.

The three policy priorities for Austrian policy makers should be:

1. To boost cooperation and alliances between local health authorities and NGOs,
2. Raising awareness and to fight stigma, and last but not least,
3. To improve access to diagnosis, treatment and quality of live for patients as well as for their carers.

AE: A last question on the need for a European response to the growing numbers of people with dementia. Would you support the development of a European Action Plan in this field and, if so, what should the priorities for such collaboration be?

AS: A European Action Plan in this field would definitely allow the mutual exchange of knowledge and factual experience on the practical issues for people with dementia as well as for their carers. One would assume that it could be also beneficial to the Member States’ budget, especially regarding national health costs. Such exchange could also be beneficial between specially trained nurses and carers.

It should always be taken into consideration that the exchange of knowledge and European-wide research activities and their findings benefit patients. The patients must be in the focus of our attention.

“The patients must be in the focus of our attention.”
Angelika Werthmann
ALZHEIMER’S DISEASE IS A REALITY IN OUR SOCIETY

Antonia Croy, President, Alzheimer Austria, talks about the work of the association since it was launched in 1990.

Already today there are 100,000 people living with Alzheimer’s in Austria. This number will increase by 2050 up to 300,000, nearly three times as many as today.

It will increase because people are getting older and age is the biggest risk factor for getting Alzheimer’s disease. People with dementia and their families should not be forgotten as the health system is updated and reformed. In particular, we should remember that it is largely family members who care for people with dementia, often under very difficult and strained circumstances.

20-25 years ago self-help groups were being set up all over the world and in 1990 the association “Alzheimer Angehörige Austria” was founded as a direct partner for people with dementia and their relatives. The organisation’s mission continues to be to give advice and support for family carers. We accompany the families during the long period of the illness and now have 1,500 members. The first President was Lisl Pammer and I took on this role in 2000.

Families are confronted with different problems. We try to find individual solutions through detailed consultations, the provision of information and through our own experience. The work of a carer is vast. Financial and time management issues as well as social isolation can be additional burdens to them. Our services include: counselling, information on medical, social, legal, financial and ethical issues, the exchange and sharing of experiences, advanced training, training courses for relatives, focus groups for family carers and people with dementia and the monthly meetings at the Alzheimer Café. Our first café opened in 2002 and is a starting point for people affected by the disease to meet other people, make new social contacts, learn to understand the problems of being confronted with the disease and exchange thoughts and experience with other people in a similar situation. The idea of the Alzheimer’s Café was taken from sister organisations in Holland and Belgium and has become a huge success. The family carers appreciate the support of the group, the information, the meetings, the exchange of experience and get a better understanding of the disease and its impact on their daily life.

Because of the long-lasting support and companionship of the relatives and carers, some people with dementia can often stay longer in their familiar surroundings. Many people with Alzheimer’s disease require support around the clock and would rather be cared for at home than in a foreign environment. The majority of this type of care is provided by informal carers and as such informal carers are the biggest and most valuable care service in the country. They save the State an enormous financial burden. If they are to continue, we need to support them more effectively and they should have the respect they deserve.

Within the past 20 years, the association was always an important partner in the health system. The aim was to bring the actual needs of people involved with the disease to discussions, presentations, training for experts and expert talks at ministerial level. We are working closely with doctors, psychologists, therapists, ambulatory care and care personnel. The care of people with dementia is of great significance, not only for the carers but also for the whole of society.

Alzheimer Austria considers it very important
that measures are taken to increase the quality of life for people with dementia and their carers by broadening the possibilities of support, improving the education and training of doctors and professional carers in the area of dementia. In line with an increasing number of European countries, we would also like to see Austria develop a national dementia plan.

Apart from attending or organising many conferences for many years the association has also been involved in events like World Alzheimer’s Day. This is organised by Caritas Vienna in cooperation with Alzheimer Austria at the Viennese Stephansplatz. There is also the yearly Alzheimer’s day in the Viennese city hall.

Within Austria there are around 40-50 counselling and interacting groups for relatives who take care of people with dementia. An example is the group “M.A.S Alzheimerhilfe Bad Ischl” since 1997), which offers the following:

- Dementia Service in Upper Austria,
- Vacation offers for persons with dementia and their relatives and
- M.A.S Alzheimer Academy for training as an M.A.S trainer.

In 2012 we changed our name from “Alzheimer Angehörige Austria” to “Alzheimer Austria”. The new name should show that we provide support not only for relatives, but also for people with dementia and that we are ready for the challenges in the future. Through intensified media coverage we have raised awareness of the disease and now people with dementia in an early stage are more likely to get in contact with the association to seek help and to have the opportunity to talk with other people affected by the disease.

Since 1993 Alzheimer Austria is a member of “Alzheimer Europe” and “Alzheimer’s Disease International” and benefits from the knowledge, support and exchange of experience between these organisations.

“The care of people with dementia is of great significance, not only for the carers but also for the whole of society.”

Antonia Croy

Since 1993 Alzheimer Austria is a member of “Alzheimer Europe” and “Alzheimer’s Disease International” and benefits from the knowledge, support and exchange of experience between these organisations.

The work of our association has been recognised, being awarded a prize for humanity by the Vienna Commune and I was honoured to be awarded the Alois Alzheimer prize for my work in 2006.

We have achieved a lot over the last 20 years, but in reality our work has only just begun.
SOME THOUGHTS ON THE WORK OF ALZHEIMER AUSTRIA

Andreas Wrinker, Neurologist and Vice-President of Alzheimer Austria, talks of the challenges ahead for the association

People with dementia place a great deal of value on medical research, social care and the fact that social structures are in place. These will also be important in the future for the economy and the sustainability of our health system. There has been some progress in the practical aspects of caring. In addition, training programmes for carers as well as the use of non-pharmaceutical therapies are considered as having very positive effects on the quality of life, the duration of the illness and being able to keep people at home. Nevertheless, the situation of people with dementia and carers remains unsatisfactory. We recently hosted an information and advice day and it was disappointing to hear that people think doctors do not take the problem seriously enough.

Michael Landau, Director of Caritas, diocese of Vienna, highlights the important role the association carries out

Alzheimer’s disease is not curable and despite having made huge progress in research not a lot has been achieved. In this context Alzheimer Austria has an essential role and mission. Improving the life situation of people with dementia and their carers is a common societal need and one which everyone shares a responsibility in achieving. Since 2003 the Association has worked alongside Caritas for the care day held in September. They carry out various activities in the centre of the city. It is right that the theme of Alzheimer’s disease and dementia is brought to the fore in this way, in the centre of the city, just as it is also belongs to the centre of society. Voluntary work is a gift to society, a gift to us all. For this reason, politicians should support self-help groups such as Alzheimer Austria in the future, especially with financial support. I congratulate Alzheimer Austria on playing its important role. People with dementia and their carers should be encouraged that they are not forgotten by everyone. I would like to express my appreciation to the voluntary workers and to wish them strength and motivation as well as God’s blessing for their future work.
LIVING WITH DEMENTIA IN AUSTRIA

A carer from Austria relates his story about caring for his wife who lives with dementia.

On that day, 12 years ago after I consulted a psychiatrist and stepped out from the corridor onto the street my world had completely changed: so unbelievable, so painful, so fundamental. I was now sure that my wife, Heidi, had Alzheimer’s disease, having received an official diagnosis.

Until then we had filled our lives with a lot of work and, happily, also leisure activities such as sport and culture. We shared all this with our friends, in good health and harmony. We were looking forward to our retirement.

From now on, I had to arrange our life in a completely new way, as I knew that my wife would lose her independence step by step and she would turn back into a toddler. I had decided that as long as I could, I would walk every step with her and take good care of her.

The different stages of the disease pass, and although you learn to anticipate them they are still very painful when they arrive: the time when there is no love, the aggressiveness, the slammed doors, the mean words, the denial, the accusations, her wandering off and the fearful time while searching for her, when I had lost her. The loss of orientation, reading, writing and language, the first time it was difficult for her to eat on her own, the first epileptic seizure, a hard week in hospital, the incontinence, the insecurity of walking and the falls, the nearly complete loss of mobility and the first wheelchair.

Through this, the association of Alzheimer’s relatives in Vienna has given me so much support, advice and help to be able to deal with all aspects of the disease and related situations. It was not always very easy to cope but I became very strong and I know I will be able to cope with what lies ahead of me.

After bringing my wife Heidi to bed every night, I tell her that tomorrow for sure will be a lovely day. And as strange as it might sound, I strongly believe it.
DEMENTIA AND AUSTERITY MEASURES IN SPAIN

Arsenio Hueros Iglesias, President of the Spanish Confederation of Associations of Families of People with Alzheimer’s (CEAFA), explains how austerity measures are having an impact on people with dementia and their carers in Spain.

In a global context dominated by the economic crisis, countries are forced to adopt austerity measures to enable them to meet the challenges the crisis generates. Spain is no exception. For several years we have been witnessing a kind of theatrical performance of macro-economics where budget adjustments are the main characters. However, the reality of this is that all spheres of our society are being adversely affected.

Recently, the Government of Spain approved the State Budget 2012, which contains significant cuts in the main policies that affect directly or indirectly people with Alzheimer’s disease and their family caregivers. For example, the funding allocation for Health has been reduced by 6.8%, whereas that for Social Policy has decreased by 15.7%. In addition, the budgets assigned to the Law of Dependency have been depleted by 13.7%, and finally, the budget for R & D has been cut by 25% in comparison to last year.

It is clear that these cuts are having a negative impact not only on CEAFA and its 300 member associations, but also and especially on those affected by Alzheimer’s disease.

This situation forces us to reflect on the decision-making and action taken, particularly in relation to the consequences they lead to. In Spain, 3.5 million people are affected by Alzheimer’s disease: 800,000 of them suffer directly from the disease and the rest are family caregivers. This situation represents a serious social and health challenge for the government, especially as the number of people with dementia will increase, creating a tide of enormous magnitude. Therefore, necessary, timely and adjusted measures are essential if we are to address this challenge.

This exercise of reflection will not be easy. The factors that will determine the decisions to be made are not absolute and can have a negative or positive effect: Decisions which appear to improve the situation can also negatively impact other areas. Striking a balance has never been easy and we understand the challenges in finding the best path.

However, the facts speak for themselves and we fear the consequences of recent events. Often, perhaps too often, we justify the reasons for decisions yet questions remain overwhelming, leaving us to try and clarify why:

- Decisions are being forced by the current crisis which may not be the best. It is first necessary to prioritise if we are to address the situation properly.
• Are people with dementia and their carers “easy targets” making it easy for the government to make budgetary cuts in this area.

• There are some groups who are seemingly untouched by the economic crisis? The burden must be distributed fairly, by all.

• Decision makers focus only on the political implications, forgetting the damage caused by reforms, cuts or adjustments on the most needy and dependent, sick people, pensioners, children, etc.

• Politicians do not look at what these families suffer. Why is it that the work of the associations is not taken more into account? After all, associations discharge the State from its obligations to provide quality service and at a much lower cost.

• People with dementia, their carers and Alzheimer associations are impacted so adversely by current decisions when other options are available to the government to solve this crisis.

There are many doubts, especially when one looks around and sees astronomical salaries, perks, luxury, wasteful spending and abuse that are visible to all. Their very existence offends those with basic needs of life which increase daily.

Our associations, the Associations of Families of People with Alzheimer’s, are suffering. Some are being doomed, if they do not disappear altogether, to restrict their programmes and reduce their activities. The problem is that behind these associations are real people who are losing the only possibilities they have to not only maintain their already poor quality of life but also maintain the support which helps them to mitigate the hardship that grips them.

CEAFA with their federations and associations has, for over twenty years, been trying to help those affected 800,000 families. We want to continue fighting for recognition and awareness. It is essential that our partnerships with volunteers and professionals remain operational in a relevant and effective framework to ensure a good quality of life for people affected by dementia.

There are 300 associations that are currently trying to maintain and continue activities, serving nearly 100,000 people. These associations rely on the work of 3,700 volunteers and 3,400 working professionals. The question in the current crisis is not necessarily one of more money, but how to make sure the money available is invested well. Everyone needs to understand that adequate investment today will ensure future sustainability. We should also understand the void that would exist without the enormous high quality of health and social care offered by these organisations.

In addition, Alzheimer’s disease is a global disease and some neighbouring countries have raised the priority of this disease by articulating specific measures which have been translated into national plans. These measures are aimed not only at the health and social care provisions and the promotion of research, but also towards the rationalisation and optimisation of investments. In addition, the World Health Organization calls for decisive action now, otherwise the impact of this disease will become the biggest crisis to face any health care system.

Spain currently does not have a specific plan but CEAFA is working to enact a State Policy on Alzheimer’s disease; obviously this will not be released in the short-term. In the meantime, it is necessary that all people living with disease receive the care they need to ensure a good quality of life.

In this context, the news of the freeze on the implementation of the Law of the Dependency is like a jug of cold water and will also have a perverse effect. Being able to integrate people with Alzheimer’s disease in its early stages into the system and enforcing the individual right that the law itself
recognises will help support people with dementia. It has been clearly demonstrated that early specialised care helps to slow the progression of the disease and therefore delays the need for access to care or more expensive resources later on.

In addition, I am convinced that easier access to the system for dependents in the early stages of the disease need not represent an added burden to the State or the autonomous regions. This is because, fortunately, in Spain a dense capillary network of highly specialised centres and the associations of Families of People with Alzheimer’s disease exist, as mentioned above. These are incorporated into the resource portfolio of SAAD (system of autonomy and attention for dependence) and are able to respond to the challenges of a decreased quality of life and also to optimise resources.

For all these reasons, I would like to send the message that is important to reconsider the idea of simply cutting budgets and propose that all possibilities are fully explored so that available resources can be used in an effective and optimal way, resulting in further progress in developing the welfare state to meet the needs of our society.
AUSTERITY MEASURES AND EUROPEAN ACTION

Annette Dumas, EU Public Affairs Officer, Alzheimer Europe, considers the implications which the economic crisis has on people with dementia, their carers and Alzheimer Associations throughout Europe.

The impact of the crisis on people with dementia, their carers and the activities of the Alzheimer Associations has been featured in Alzheimer Europe’s Dementia in Europe Magazines. Members from Greece, Ireland, Portugal and Spain have expressed their concerns about the consequences that drastic measures taken by national policy makers to respond to the crisis impose on them all.

The picture is bleak: growth in health spending is grinding to a halt. 2012 OECD health data show that growth in health spending started slowing or falling in 2010 in almost all OECD countries and preliminary figures suggest little or no growth in 2011 for some countries. Over the years, the reductions in public spending in the EU Member States were inter-alia cuts in wages or fees paid to professionals, cuts in the number of health workers, lower public reimbursement of health services, investment plans being put on hold as well as more out-of-pocket payments for prescribed medicines.

The financial and economic crisis is putting at risk the European social model based on solidarity, fair redistribution of resources and social cohesion. It is exacerbating inequalities between the citizens and the Member States: some parts of the population, such as people with a low income, increasingly have to make choices on how they spend their money. Very often these people will save on medical costs, thus postponing medical appointments and the purchase of medicines. They will also save on food and heating, again putting their health at further risk.

In this context, national and European policy makers have to strike a fine balance between the sustainability of the health and social services, the economic imperatives engendered by the crisis, the increasing health and social needs of an ageing population and the support Alzheimer associations need to continue their engagement.

The intergenerational solidarity challenge will compel policy makers to find a balanced system that will unite those who contribute to society and the oldest part of the population or the population in need. People should have access to the care they need rather than the care they can afford. Shared responsibility over the healthcare system is likely to be a way forward.

Health as a pre-condition for economic growth is the leading thread of the next European Public Health programme, “Health for Growth”, for the period 2014-2020. The Council Conclusions of June 2011 “Towards modern, responsive and sustainable health systems” stated that “investments in health should be acknowledged as a contributor to economic growth”. In various public speeches, European Commissioner for Health and Consumer Policy, John Dalli, has recognised that health is a long-term investment,
that people’s health is a key asset for the economy as a whole and that cutting back on healthcare delivery is a false economy. However, it is absolutely essential to remember that some parts of the population cannot contribute to the system due to irreversible health problems. This is particularly the case for dementia, a debilitating and unpreventable chronic disease that leads to complete dependency of the person affected.

The crisis seriously calls into question the strength of Europe’s economies and the necessity to adjust to the specific needs of an ageing society. Another priority of the Health for Growth Programme is to contribute to innovative and sustainable health systems. Common tools and mechanisms will need to be developed to address the human and financial shortages of resources and facilitate the up-take of innovation in healthcare.

Another European initiative, the “European Innovation Partnership on Active and Healthy Ageing” is a stakeholder-driven approach that will support innovation across health and care sectors. The Partnership has identified some priority areas on which to focus such as early diagnosis, prevention and treatment of diseases and independent living. A key feature of this initiative is that actors at local, regional, national and European level will work hand in hand to find innovative, user-centred, efficient and sustainable solutions to the needs of an ageing population.

To reflect the increase in life expectancy of the citizens and their ability to contribute to the economy, the European Commission “Country Specific Recommendations” and “Pension Adequacy Report” will guide the Member States in finding innovative solutions in the labour market. The labour force will need to be adjusted to the new needs of an ageing population: the number of people employed in the healthcare systems is expected to double within the next decade. The EU 2020 Strategy “New Skills, New Jobs” flagship can provide innovative solutions to this trend.

The very impact of the crisis on the people with dementia, their informal carers and the services rendered by the Alzheimer Associations is a major concern. In Europe, over 7.3 million people suffer from dementia and an estimated 21 million informal carers are directly impacted by the disease. These numbers are predicted to increase dramatically over the next decades. Dementia comes with a high financial cost too: EUR 21,000/patient/year (56% being for informal care).

Alzheimer Associations play an important economic and social role at national level: they run services for people with dementia, support the informal carers (training and respite care) and offer training. They are key partners, inspiring and supporting the national policy makers to find innovative solutions that will go beyond emergency measures and ensure that people with dementia and their carers can still have access to the care and support they need.

Although the constraints of our times are high, the national and European policy makers have the duty to embrace the challenges that are accompanying the crisis. It is essential that people with dementia, their carers and Alzheimer Associations benefit from innovative, timely and sustainable decisions.

“Alzheimer Associations are key partners, inspiring and supporting the national policy makers to find innovative solutions.”
Annette Dumas
Lilly salutes Alzheimer Europe.

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Together we make a difference.
Antigoni Diakou, President of the Cyprus Alzheimer Association, speaks about the successful cooperation between the Association and the Cypriot Ministry of Health in the fight against Alzheimer's disease.

The Cyprus Alzheimer Association was established in 1996 with the main aims of:

- Raising awareness of Alzheimer’s disease among the public,
- Safeguarding the rights of patients and their families with respect to pharmaceutical aid, subsidies and legislation,
- Offering social and psychological support to the patients and their families,
- Encouraging the development of medical or non-medical interventions for the benefit of patients and their families,
- Promoting research related to Alzheimer issues and
- Supporting the creation of establishments to attend to the needs of the patients and their families (short and long-term care centres and clinics).

In order to accomplish the above aims, the Association has organised many activities, including workshops, conferences, TV and radio broadcasts and campaigns in the context of the World Alzheimer's Day. Moreover, the Association has urged relatives and carers of people with Alzheimer’s disease to step forward and share their experiences with the public in an effort to wipe out the stigma associated with the disease.

Many of these activities have been carried out in cooperation with the Multidisciplinary Committee of the Ministry of Health which deals exclusively with Alzheimer issues. Back in 2000, representatives of the Cyprus Alzheimer Association requested the Minister of Health to form a Multidisciplinary Committee which would provide solutions to the problems faced by people with Alzheimer’s disease and their families. The former Minister of Health, Mr Frixos Savvides responded enthusiastically and established this Committee which currently consists of 13 public and non-public organisations including the elected President of the Cyprus Alzheimer Association. The Multidisciplinary Committee is headed by the Director of the Mental Health Services of the Ministry of Health, currently Dr. Yiannis Kalakoutas.

Since 2001, the Cyprus Alzheimer Association has been working closely and systematically with the other members of the Multidisciplinary Committee to achieve targets that are jointly set. This collaboration has resulted in many positive outcomes, for example:

- On an annual basis, the medication is provided free of charge from state hospitals and the others are provided through co-payment,
"A lot remains to be done, yet the joint efforts and commitment of all stakeholders allows us to be optimistic about successfully confronting the fight against Alzheimer’s disease."

Antigoni Diakou

- Training on Alzheimer issues has been offered to doctors and nurses,
- Conferences have been held by the Association with contributions of members from the Multidisciplinary Committee (e.g. Middle Eastern Conference 2009, held under the auspices of the Minister of Health),
- Printed material about Alzheimer’s disease has been produced and distributed freely to the public,
- Awareness campaigns for World Alzheimer Day have been held,
- TV shows and radio broadcasts about the disease have been aired and media articles published,
- The creation and support of two Daycare Centers and
- A draft national Strategic Alzheimer’s disease plan has been developed.

Back in 2008, the Association undertook the initiative to campaign for the creation of the Cyprus Strategic Plan against Alzheimer’s disease. The former Minister of Health, Dr. Christos Patsalides, responded positively and assigned this task to the Multidisciplinary Committee. This Committee is now ready to present the Cyprus Strategic Plan to the current Minister of Health, Dr. Stavros Malas.

The Cyprus Alzheimer Association, with the support of the Multidisciplinary Committee, has recently focused on the fight of stigma that surrounds dementia. We work hard to combat stigmatisation, negative stereotyping, ignorance and indifference and we jointly appear in the media to offer advocacy for this vulnerable group. Within this context, on the occasion of World Alzheimer’s Day in September last year, the Association presented the art exhibition of Nicholas Panayi (son of a person with Alzheimer’s disease) entitled ‘Mother Memory’. His work expressed the feelings, experiences and conceptualisation of the disease and was a therapeutic process for the artist as well as an enlightening and highly informative exhibit to the public. The exhibition was held under the auspices of the Minister of Health, Dr. Stavros Malas.

Engaging the public in an artistic concept is indeed an exciting prospect. It is a friendly way to raise awareness of both children and adults and to mobilise them to combat the stigma associated with the disease. For the 2012 World Alzheimer’s Day, the Association will rely on music as a tool for raising social awareness; a musical titled “Dimentia” will be held in Paris in October 2012 during the EU Presidency of Cyprus and will follow in November in Nicosia, Cyprus.

Both the Association and the Multidisciplinary Committee believe that well-prepared campaigns can change social values, make paradigm shifts and transform perceptions in relation to Alzheimer’s disease. The members of the Multidisciplinary Committee meet every two months in order to review the progress made in relation to the set goals and determine the additional actions that need to be taken. A lot remains to be done, yet the joint efforts and commitment of all stakeholders allows us to be optimistic about successfully confronting the fight against Alzheimer’s disease.

The Multidisciplinary Committee on Dementia

The basic target of the Committee is the improvement and better coordination in the provision of care for the people with the disease as well as their families.

The Committee comprises representatives from the public and private sectors:

- The Ministry of Health (Mental Health Services, Medical and Public Health Services, Pharmaceutical Services, Nursing Services, Physiotherapy Department), the Cyprus Alzheimer Association, the Cyprus Medical Association, the Cyprus Psychiatric Association, The Cyprus Neurological Society, the Cyprus Institute of Neurology and Genetics, the Ministry of Works and Social Insurance – Department of Social Welfare, the Cyprus University of Technology – Nursing School, Chief Visiting Health Officer.
POLICY NEWS

Alzheimer Europe highlights some of the recent policy developments.

Launch of the European Joint Action on Patient Registries
On 12-13 June 2012, the European Commission and representatives of 11 EU Member States gathered in Brussels to launch the Joint Action (JA) on Patient Registries. The aim of this JA is to support Member States in developing comparable and coherent patient registries in important fields such as chronic diseases, rare diseases and medical technology.

Council presents conclusions on responding to demographic challenges
On 21 June, the Employment, Social Policy, Health and Consumer Affairs Council meeting adopted conclusions to respond to demographic challenges. For elderly people, the Council inter alia invites the European Commission and the Member States to promote the growth of the “silver economy” and independent living in view of its positive impact on the demand for goods and services.

Cyprus takes over EU Presidency
Cyprus started its six-month Presidency of the Council of the European Union on 1 July 2012. The Presidency motto is “Towards a Better Europe”. During its term, Cyprus will work towards a better, more relevant Europe for its citizens, meaning a more efficient and sustainable Europe, contributing to a better performing and growth economy. The Presidency health priorities will focus on serious cross border health threats and healthy ageing in relation to the European Health Strategy 2008-2013.

European Parliament Committee discusses report on the prevention of age-related diseases of women
The Committee on Women’s Rights and Gender Equality discussed its own-initiative draft report on the prevention of age-related diseases of women on 12 July 2012. The Rapporteur is European Parliament Vice-President, Roberta Angelilli (EPP, Italy). The report states that in spite of women’s greater longevity, the incidence of debilitating diseases is much higher in their case than among men of the same age. The same applies to the progressive onset of disabilities caused by episodes of mental confusion and dementia (such as Alzheimer’s disease), the incidence of which soars with advancing years.

France: French President Hollande announces plan to address dependency
On 13 July, President Hollande announced a consultation on the theme of dependency will be launched in France in autumn this year. This will be followed by a five year plan to deal with dependency, exclusion and poverty.

Portugal: Living will law approved
The living will law was unanimously approved by the Portuguese Parliament on 1 June 2012. This law will regulate the rights of citizens on the provision of health care in the event of incapacity and also includes the creation of a national registry.

UK: Report shows large variations in time to dementia diagnosis
A report, “Unlocking Diagnosis: The key to improving the lives of people with dementia”, published in July 2012 in the UK by the All-Party Parliamentary Group on Dementia (APPG) shows that people with dementia are facing considerable variations (a few weeks up to over a year) in the time it takes to receive a diagnosis. The APPG called for an improvement of services with more investment, compulsory accreditation and better accountability.
Wouldn’t it be great if Pete could find the way home?

Pete has Alzheimer’s disease. This condition not only has a profound effect on sufferers, it can also increase the burden on their families and carers. Sufferers can become increasingly vague and confused about everyday matters, which may be dangerous and upsetting for them. Late or incorrect diagnosis can exacerbate the situation. We want Pete and millions of patients like him to lead as normal a life as possible.

As well as Alzheimer’s disease, there are many other conditions with unmet medical needs: it is Janssen’s mission to develop innovative treatments for serious illnesses such as HIV/AIDS, schizophrenia, hepatitis C, tuberculosis, psoriasis, arthritis, multiple myeloma, cancer and diabetes. We make extraordinary efforts so that patients around the world can lead a better life.

Extraordinary efforts for a normal life.

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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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**Spotlight on Luxembourg, Poland and Ireland**

A reflection of the work of three national Alzheimer associations which celebrate their anniversaries this year is provided by Alicja Sadowska, Chair, Alzheimer Poland, (20 years), Alain Tapp, Public Relations Manager, Alzheimer Luxembourg Association (25 years) and by Niamh Sheeran, Head of Fundraising and Communications, The Alzheimer Society of Ireland (30 years).

**Reaching out to the community**

Kristina Westerlund, Communications and Office Manager of the Swedish association, Alzheimerföreningen, speaks about the association’s campaign to raise awareness and understanding of the disease.

**Members’ news**

A selection of news highlights from national Alzheimer associations around Europe.

**Dementia in society**

A brief look at some of the news and publications on dementia in the media.
SPOTLIGHT ON LUXEMBOURG, POLAND AND IRELAND

Alzheimer Luxembourg Association celebrates its 25th anniversary this year. Alain Tapp, Public Relations Manager, reflects on how the Association has grown since it was launched in 1987.

The Alzheimer Luxembourg Association (ALA) was launched in 1987 by just two people: Paul Diderich and Jeannot Krecké. Both were carers of people with dementia and both wanted to put in place a structure whereby people with dementia and other carers could find support. With support from the government, the first service to be opened was a helpline which operated during office hours. We were able to extend this service to become a 24-hour help line in 1994. It was clear that carers needed support as well as practical tips to care for their loved ones and in 1997 ALA set up its first training courses for carers of people with dementia.

In 1989 the first day care centre for people for dementia opened (in Howald), initially for just six people. Soon after (1992) our second day care centre opened (in Dommeldange) and by this time the Association could offer day care for up to 22 people in total. In 1999 there was uncertainty regarding the work plan of the Association as government funding was stopped due to the Luxembourg care insurance coming into force. It took a while to adapt to the new funding structure but we found ourselves able to open four more day care centres (Esch, Berchem, Dahl and Rumelange). In 2011 we opened a new home in Dudelange to replace Berchem. To facilitate people attending these centres, we started a transport system which is funded partly by the long-term health insurance and partly by the client.

It was with great pride that the Association was able to open its first nursing home, caring specifically for people with dementia in 2007. The home enables 116 people with dementia to be cared for. It also has a special unit with a common area together with eight adapted private bedrooms for people with dementia in the end stage of the disease. This is a unique centre in Luxembourg which aims to offer people with dementia the best possible palliative care with dignity. Today we have a waiting list of 300 for the nursing home and it is essential for us to open two more homes if we are to meet this demand.

2008 saw the launch of our Alzheimer cafes enabling people with dementia and their carers to come together in an informal setting and have a chat. These run twice a month with between 10 and 15 attendees at each meeting.

The Association also acts as an information point and houses over 700 books, CDs and films on dementia in French, German, Luxembourgish and English.

During our 25th year, the Association is expanding its work plan by running a series of conferences aimed to further help carers and people with dementia. Courses are offered on topics such as the importance of biographical information for people with dementia, humour in the provision of care, nutrition and the importance of validating the personal experience of a person with dementia. We have been able to offer these by teaming up with RBS training institute, which specialises in courses and training days for old-age and geriatric professionals.

In addition, we have extended our World Alzheimer’s Day memory walk in recognition of the Association’s anniversary and during August and

“By far the biggest challenge which the Association will face is how to meet the growing need for nursing home places in the current economic climate.”

Alain Tapp
A message from Jeannot Krecké, former Minister for the Economy and Foreign Trade for Luxembourg and founding member of the Luxembourg Alzheimer Association:

After the pioneer times, when every activity was covered by board members on a voluntary basis, the Luxembourg Alzheimer Association now has a strong and good basis for the people working there with the infrastructures in place.

The person with dementia and his family are being focused on in a very sophisticated way, assuring a very high standard of quality of care and support.

Some of the founding members, who were once family members of people affected by Alzheimer’s disease, are still on the Board of Directors, making sure that the basic spirit and commitment is still applied.

A carer’s perspective

Living with dementia is a challenge for the families and you need support. The Alzheimer Association offers a professional support for those suffering from the disease and their families and we are thankful that this exists. It hurts every day, to accept that our father doesn’t live at home any more. However, what is most important is his well-being, and we know that now he is in good hands. We thank the Alzheimer Association for their daily support for all people being in affected by this disease.

September we ran a TV campaign on raising awareness of the disease.

ALA has grown considerably since its early years both in terms of the work it carries out and in the number of people it supports. Founding member, Jeannot Krecké, remains involved with the work of the Association, as a Board Member of the Foundation.

All of our services enable people with dementia and their carers to live better with this disease. If I were to choose highlights from the work we have carried out over the 25 years they would be the training for carers, the helpline together with the day care centres and nursing homes. By far the biggest challenge which the Association will face is how to meet the growing need for nursing home places in the current economic climate.
This year, Alzheimer Poland celebrates its 20th anniversary. Polskie Stowarzyszenie Pomocy Osobom z Chorobą Alzheimera was founded in July 1992 by a group of 23 people, including family carers, doctors and psychologists. The association was established after the radical social and economic changes brought about by the political transformation of 1989 in Eastern Europe. This inspired and supported colleagues throughout Poland to set up new organisations.

Amongst the founders were Ms Mirka Wojciechowska, Prof. Maria Barcikowska, Prof. Tadeusz Parnowski and Dr. Tomasz Gabryelewicz. Remarkably, all are still active members and are still working in the field of dementia: they represent the association in the Polish Alzheimer’s Coalition, which has developed the Polish Alzheimer’s Plan.

Today, the association has grown to 35 local organisations in big and small towns all over the country. The Polish Alzheimer’s Association is the national coordinator of the Polish Alzheimer’s movement which provides active support to people with dementia, their families and caregivers. There are currently some 250,000 people with Alzheimer’s disease in Poland.

During its lifetime, the association has provided help, psychological support, information and education to thousands of people. This includes the vital role of raising public awareness of Alzheimer’s disease and educating citizens to understand and embrace the needs of people with dementia. We are particularly proud of our record of raising awareness of the disease and this was a priority of ours early on. Indeed we organised our first awareness week as long ago as 1993. Along the way, the volunteers and professionals working with the Association have gained invaluable experience and knowledge on how to support people more effectively. One of the key events for the association is its Annual Conference which facilitates discussions on common priorities and ways in which to overcome problems. However, by far the most important and satisfying role of the association has been to offer support to people with dementia and their carers.

The association has also played an important European role as one of the founder members of Alzheimer Europe. Dr. Gabryelewicz, co-founder and former Chair of the Polish association, was a delegate at the very first meeting in 1990 that led to the formation of Alzheimer Europe. He also served as a member of the Alzheimer Europe Board from 1994 to 2000. I too have been closely involved with Alzheimer Europe and have been on the Board since 2004.

Currently, the main focus of the Polish association is to convince politicians that the implementation of the Polish National Alzheimer’s Plan is vital and necessary. This task is probably the hardest of all. However, we believe that one day we’ll succeed, provided that we have the moral and financial support of the government.
Niamh Sheeran, Head of Fundraising and Communications, The Alzheimer Society of Ireland, looks back at the Society’s work over the last 30 years.

This year, The Alzheimer Society of Ireland celebrates its 30th Anniversary. The organisation has come a long way since it began in 1982 when a small group of family carers joined forces and realised that information and support for people living with dementia in Ireland was non-existent. They set about making remarkable changes around dementia care in Ireland. Thirty years on, The Alzheimer Society of Ireland is the leading national provider of dementia specific care, support and information.

In 1982, the only statistics available indicated there were 480 cases of Alzheimer’s disease in Ireland. Within a year of lobbying for better statistical reporting, these figures had been revised upwards to 850 cases. Current statistics indicate there are 41,700 people with dementia in Ireland and this figure is expected to reach 147,000 by 2041 due to people living longer.

The early aim of The Alzheimer Society of Ireland was to offer information, understanding and support to those caring for a loved one with Alzheimer’s disease. The wider aim was to increase awareness and understanding of dementia. Public information meetings were held around the country with the support of the medical community. These meetings inspired the establishment of many of the branch networks which are an integral part of The Alzheimer Society of Ireland today. These branches, led by volunteers, operate throughout the country providing information and support at a local level to people affected by Alzheimer’s disease and dementia.

Today, The Alzheimer Society of Ireland’s network includes over 120 dementia specific services throughout the country including day care centres, home care services, carer support groups, social clubs, two respite centres and the Alzheimer National Helpline Service. Services such as these are vital for carers and for people with dementia.

A “Family Carer Training” programme has also been rolled out across country over the past two years. The response to these meetings has been very positive and has raised awareness around caring for loved ones with dementia, and carers themselves.

From the beginning, The Alzheimer Society has tried to exert pressure on the Government to take more responsibility for the care of people with dementia and carers. This continues to be the case today with a Public Affairs team in national office focused on lobbying the Government for the implementation of a National Dementia Strategy.

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The goal of creating a dementia friendly society is still in progress but we are a lot closer thanks to the efforts of many people over the last thirty years.

For more information visit www.alzheimer.ie

“From the beginning, The Alzheimer Society has tried to exert pressure on the Government to take more responsibility for the care of people with dementia and carers.”
Niamh Sheeran
Kristina Westerlund, Communications and Office Manager of the Swedish association “Alzheimer-föreningen”, speaks with Alzheimer Europe about the theme nights the association provides to raise awareness and increase understanding of Alzheimer’s disease and other cognitive disorders.

Alzheimer Europe (AE): Why did you decide to run the theme nights and who attends them?

Kristina Westerlund (KW): We started our theme nights in 1999 to be able to spread knowledge and understanding about Alzheimer’s disease and other cognitive disorders. By collaborating with the top researchers, clinicians and department heads of memory clinics in the country, we hoped to provide current and high quality information.

The attendees are of a wide variety; we have people with dementia and other cognitive disorders, relatives, doctors, nurses and other health care professionals, politicians and others concerned with health care in the community. Depending on the size of the town and the premises, usually 200 to 800 people will attend. In a year we will reach in total roughly 10,000 individuals.

AE: How often do you have a theme night, how are they structured and what sort of information is exchanged?

KW: We offer about 30 lectures every year all over Sweden, from Luleå in the north to Ystad in the South. We try to use communal spaces such as libraries, cinemas and even churches, to allow easy access for the people in the community that we want to reach. We travel around the country about three times per month. The next scheduled talks will start in September. The specific programme is designed together with the speakers.

Each of our theme nights will last for about two hours and we always start at 6 pm. There is a moderator and three speakers. For example, we recently had one of our theme nights in Malmö. Krister Westerlund from the Association was the moderator. Professor Lennart Minthon spoke about clinical research and Associate Professor Elisabet Londos enlightened us about dementia with Lewy bodies and Parkinson’s disease dementia. Dr. Sebastian Palmqvist talked about the use of simple cognitive tests.

We always emphasise the importance of early diagnosis and of medical treatment. Each speaker has 30 minutes for his/her presentation and then we have a break for socialising and sharing experiences, as well as offering books and films for sale which concern dementia.

We collaborate with the Swedish Alzheimer Foundation as well as the four pharmaceutical companies providing dementia medication. Each person who comes to the talk will receive a goodie bag of information regarding the clinical features and treatments. This has been very much appreciated.

All our speakers attend our theme nights in their spare time and without charge. We recruit...
them from all over the country e.g. from Stockholm, Gothenburg and Malmö. We either pay for their transport or, more often, we give them a lift in our car to save costs. It is not unusual that we drive between 600-700 km for each theme night and, consequently, we do not return home until well after midnight. Another consequence is that it proves difficult to provide dinner for our speakers as few restaurants remain open so late. However, our speakers are understanding and happy to have a snack from a petrol station. We think they are amazing to be so kind in supporting us in these circumstances and are even more amazed that they often call us to ask if they might be invited to the evenings.

We also try to involve speakers who are culturally important. For example, we have several well-known Swedish actors and artists who also participate in our theme nights to support our organisation and to attract a broader audience. The theme nights are funded completely by the above-mentioned collaborators, and conducted within the Swedish guidelines and regulations of partnership between non-profit organisation and the pharmaceutical industry.

**AE: Have you received feedback on these evenings?**

**KW:** We get excellent feedback from the audience, which recruits further members to our Association. The theme nights have become more and more popular over the years, we always have a full house and more towns all over the country are contacting us.

**AE: The association has been running the theme nights for 13 years. What do you feel has been achieved over this period and what, if any, are the challenges which still need to be addressed?**

**KW:** Our main goal, which we think is being achieved by these theme nights, is that we spread knowledge about these complex brain disorders and why it is important to find the patients early, treat them and give them appropriate support throughout their disease.

What still needs to be achieved? Three things: information, information and more information. We want to further the general understanding of the dementia disorders and ensure that the general public understands that dementia is not only a disease of the old, but it is also present in a younger, working population. There needs to be greater awareness that treatment is available, so that people with these problems will seek help. Still, in Sweden six out of ten people with Alzheimer’s disease do not receive any medical treatment.

To allow this, it is important to further engage and involve politicians, company leaders and other influential people within our community. We need their support to continue our mission to raise the awareness of the early signs of the disease and where to go for help.

“There needs to be greater awareness that treatment is available, so that people with these problems will seek help.”

Kristina Westerlund

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**Elisabet Londos**

**Sebastian Palmqvist**
MEMBERS’ NEWS

Alzheimer Europe highlights some of the recent work carried out by national Alzheimer associations.

**Greece: Greek youth theatre plays for people with dementia**

Alzheimer Hellas and the Neapolis youth theatre team jointly organised a theatrical play that was performed on 28 June 2012. The play, “Servant of two masters” by Carlo Goldoni, was attended by almost 200 people, including people with dementia, caregivers, professionals and members of the association.

**Italy: Alzheimer Uniti Italy carries out literary readings for people with dementia**

On 18 June, Alzheimer Uniti’s Day Centre was involved in a literary project, reading passages aloud from the novel “Ragazzi di vita” (“Boys of Life”) by Pier Paolo Pasolini. The Day Centre is situated in the part of Rome where Pasolini lived and worked and groups of people with mild dementia from the Day Centre met regularly to listen to the book being read aloud. Meanwhile, photographs of the neighbourhood were projected on a screen, showing where events from the novel took place. These readings led to discussion among the participants, thus stimulating autobiographical memory and language.

**Ireland: Alzheimer Ireland prepares input for national dementia plan**

During June and July 2012, The Alzheimer Society of Ireland participated in a national consultation on the draft Irish National Dementia Strategy. The Society held a number of focus groups with staff and families living with dementia. The process has enabled those involved with disease to influence the future lives of people with dementia and their carers.

**Slovenia: Slovenia organises first Alzheimer Café**

The Slovenian Alzheimer Society organised its first Alzheimer Café on 24 July in a nursing home in Ljubljana. It was very well attended, featuring a presentation from Dr. Štefanija Lukič-Zlobec, head of the Slovenian Alzheimer Society, was very pleased with the result and said that she is looking forward to the next meeting of the Alzheimer Café, in cooperation with the Medical Chamber of Slovenia.

**Spain: Fundación Alzheimer Española signs agreement to develop assistive technologies**

On 4 June, Fundación Alzheimer Española signed a research agreement with CeDInt (Centro de Domótica Integral) of the Polytechnic University of Madrid for the development of assistive technologies for people with dementia. The aim of the agreement is to make these technologies more accessible for carers of people with dementia through the development of simple and practical solutions which are reasonably priced. The organisations will jointly identify the actual needs of people with dementia and their carers, develop experimentations in real life settings and create a counselling service providing individual advice on specific solutions for specific situations.

**Switzerland: Swiss petition draws 50,000 signatures for Alzheimer’s disease**

The Swiss Alzheimer Association announced on 1 June that it has collected over 50,000 signatures for its online petition: the “Alzheimer Priority Manifesto” is a call for support for the growing
number of people with Alzheimer’s disease who live at home. The petition urges authorities to provide the necessary resources for these people to remain in their homes for as long as they wish.

UK (Jersey): Jersey launches new Counselling and Family Support Service

The Jersey Alzheimer’s Association launched new Counselling and Family Support Service on 30 June. Family Support helps to support families or individuals going through a difficult time; this can be with or without the person with dementia being present. Relatives and carers may find it easier to cope with an individual’s behaviour if they understand what is happening and why a person is behaving in a particular way. These services will be provided free of charge by the Jersey Alzheimer’s Association. Jo Cummins, Manager of the Jersey Alzheimer’s Association, said: “We have developed these services because it is of great importance that people with dementia and their families are able to share their thoughts and concerns with someone confidentially, who is trained to listen and who has experience and understanding of the issues of living with dementia.”

UK (Scotland): Alzheimer Scotland wins Charity Award

On 14 June, Alzheimer Scotland won the 2012 Charity of the Year Award at the Scottish Council for Voluntary Organisations (SCVO) award ceremony. The organisation was recognised for making major progress in tackling the difficulties arising from Scotland’s ageing population, particularly dramatic increases in the number of Scots living with dementia. Henry Simmons, Chief Executive of Alzheimer Scotland, said, “I would like to say how delighted we are to win this prestigious award. We have only been able to achieve such strong progress thanks to the thousands of people who support us, the dedication and hard work of all our staff and volunteers and to the positive and supportive partnerships with key policy makers at all levels.”

In memoriam

We regret to announce the passing of Hendrik “Henk” Willem ter Haar on 19 July at the age of 89. Dr ter Haar founded Alzheimer Nederland in 1984 and was a founding member of Alzheimer Europe. He also served as ADI’s Conference Chairman in 1991.

Dr ter Haar was a delegate at the very first meeting in Leuven (1990) that led to the formation of Alzheimer Europe. He was a member of the Board from 1990 to 1996, serving as Honorary Treasurer (1991-94) and was the second Chairperson of Alzheimer Europe (1994-96).

During his tenure, he continually lobbied the European Institutions: he accomplished the adoption of a report on Alzheimer’s disease by the European Parliament and also the establishment of an Alzheimer’s budget line.
At Lundbeck we are dedicated to **overcome the challenges** of Alzheimer’s disease. It is our goal to improve the **quality of life** for people living with the disease and for those who care for them.

Find out more on www.lundbeck.com
DEMENTIA IN SOCIETY

A brief look at some of the news and publications on dementia in the media.

European Reminiscence Network launches new website
On 30 June 2012, the European Reminiscence Network launched a new website for its project "Remembering Together: Reminiscence Training for people with dementia and their family carers". This project involves partners in ten EU countries. The main emphasis over the two years of the project has been to develop creative reminiscence work involving different participatory art forms with people with dementia and their family carers.

Yitzhak Shamir, 1915-2012
Mr Yitzhak Shamir, former Prime Minister of Israel, passed away on 30 June in Tel Aviv at the age of 96. He had lived in a nursing home since 2004 due to poor health, including Alzheimer’s disease. Mr Shamir was Israel’s Prime Minister in 1983-84 and again from 1986-92. He is survived by two children and five grandchildren.

Arts-based education benefits people with dementia
An education project based on painting has shown considerable benefits for people with moderate or advanced dementia. The research, which was led by Kathleen Downi and published on 24 July 2012, was implemented at a care home in Toronto, Canada and engaged ten participants in painting classes that met once a week for one hour over a ten-week period.

Young musician donates profits from memorial song to dementia research
On 6 August 2012, Rupert Brooke, a professional singer and songwriter, released a song in memory of his grandmother, who passed away with Alzheimer’s disease. “Always” is available globally for download from Rupert’s official charity website and all profits will be donated to Alzheimer’s Research UK.

Gabriel García Márquez, can no longer write due to dementia
The Nobel prize winning author Gabriel García Márquez has dementia and is no longer able to write. Mr. Márquez has been fighting lymphatic cancer since 1995; it is thought that cancer treatment has accelerated his mental decline. The announcement was made by his brother Jaime on 9 July 2012. The 85-year-old Colombian writer won the Nobel prize in Literature in 1982. He is best known for novels such as One Hundred Years of Solitude (1967), Chronicle of a Death Foretold (1981) and Love in the Time of Cholera (1985). His last novel, Memoirs of My Melancholy Whores, was published in 2004.

Online petition calls for support of U.S. dementia plan
The American Health Assistance Foundation (AHAF) launched the “Stop Alzheimer’s Petition” online on 31 August 2012. This calls on the President and Congress to dedicate all resources necessary to fulfil the commitment of the new American national plan to address Alzheimer’s disease.

New guide helps elderly drivers with dementia
The San Antonio Alzheimer’s Association (Texas, USA) launched a new programme called Dementia...
and Driving on 21 June 2012. This online tool is designed to help families deal with discussing driving restrictions with elderly family members with dementia. The programme includes four short video scenarios of families having this type of conversation.

**Results published concerning medication and people with dementia**

**Ireland:** A report, “Medication use in patients with dementia at the end of life” found considerable uncertainty and variation in the medicines doctors say they would prescribe for people with dementia at the end of life when presented with clinical scenarios. Published by the Centre for Ageing Research & Development in Ireland (CARDI) on 6 July 2012, it shows that GPs and hospital physicians indicate they would continue with dementia medications and statins and actively prescribe antibiotics when there is limited evidence of benefits to patients with dementia at end of life.

**Switzerland:** Findings published on 10 June 2012 from a survey commissioned by the Swiss Alzheimer Society and Swiss Society for Old Age Psychiatry, suggest that staff shortages result in more than two thirds of Swiss care home residents with dementia are daily consumers of psychotropic and anti-depressant drugs.

**UK:** On 17 July 2012, the National Health Service (NHS) reported that the number of prescriptions of antipsychotic drugs for people with dementia have fallen by half in the last three years. This follows various campaigns for a reduction in the use of antipsychotic drugs for people with dementia in the UK.
MEMBERS OF THE EUROPEAN PARLIAMENT UNITE FOR THE DEMENTIA CAUSE

You can make a difference.
Join the European Alzheimer’s Alliance today by contacting Alzheimer Europe at
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23rd Alzheimer Europe Conference
Living well in a dementia-friendly society
Valletta, Malta, 10-12 October 2013
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www.alzheimer-europe.org/conferences